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Mental Health Services for People with Learning Disabilities and Other Related Disorders in Supported Living in Iceland

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Foreword and acknowledgement

The subsequent research is a part of preparations for the establishment of a new mental health team under the Health Care Centre of the capital area. The role of the team is to care for people with intellectual disabilities and related disorders and who need more specialised mental health services than general health services. The aim of the survey was to obtain information about this subgroup, number of individuals, age and gender distribution, disability and diseases, use of psychotropic drugs, what mental health services the group receives, who provides it, and what the need for these services is.

This study thesis is a part of a requirement of the MSc degree in Clinical Psychology at the University of Reykjavík. The work was done under the supervision of Þorlákur Karlsson, an associate Professor in Psychology at Reykjavik University and Halldór Kristinn Júlíusson, a psychologist specialising in individuals with disabilities.

I want to thank everyone that supported me through my years of studying psychology, first my BSc degree and now my MSc degree. I want to thank Þorlákur Karlsson for his guidance in methodology and statistical analysis and Halldór Kristinn Júlíusson for his support throughout this project. I especially want to thank my family. My mother, for her never-ending positivity and optimism, my father, for always encouraging me to reach my goals and believing in my ability to do so, and my sister, for her invaluable friendship. Last but not least, I want to thank my brother, Atli. He has taught me tolerance, patience, and equity. Without him I most likely would not have gained interest in psychology or working with individuals with intellectual disabilities, and I dedicate this work to him.

Abstract

In the recent years it has been acknowledged that individuals with a learning disability (LD) are likely to display emotional troubles similar to people without an LD and studies show that people with a learning disability (PWLD) may be at an increased risk for developing a mental illness. In some countries psychologists and psychiatrists specialise in mental health problems of PWLD but this is not the case in all countries and general psychiatrists and other professionals may care for PWLD with mental disorders without having special knowledge of their problems. The lack of professionals trained to treat PWLD with mental health problems contributes to limited access to mental health services and low quality of care. For the current study, two hypotheses were tested: 1) PWLD living in Iceland do not receive adequate mental health care and 2) a large proportion of PWLD with supported living in Iceland use psychotropic medication. A questionnaire was sent to managers of all supported living services for PWLD in an attempt to explore the use, need and accessibility of mental health services within the group. Among the responses for 562 PWLD, 37.2% were diagnosed with a mental disorder, 66.0% did not have access to mental health services, and 58.2% were on psychotropic medication.

Keywords: Learning disability, Intellectual disability, mental health, mental health services

Mental Health Services for People with Learning Disabilities and Other Related Disorders in Supported Living in Iceland

World Health Organization (2018) describes mental health as a state of well-being where own abilities are realised, the normal stresses of life are coped with, and people are productively working and contributing to the community. They also state that it is important to not merely promote mental health but also address the needs of individuals with mental disorders. As reported in 2018 by the Global Burden of Disease (GBD), mental illness burden both sexes, all age groups and affect nearly 20 million people worldwide. The most common mental disorders are anxiety and depression.

Intellectual disability, commonly known as a learning disability (LD), is a disorder that starts during the developmental period and involves both intellectual and adaptive functioning deficits in conceptual, social, and practical domains (American Psychiatric Association, 2013). Many individuals with an LD also experience difficulties in emotional, cognitive, and behavioural regulation (Brown, 2017). The reported frequency of LD varies but most studies report rates between 1.0% and 2.5% (Gillberg & Soderstrom, 2003).

Borthwick-Duffy (1994) reported that many professionals believed for a long time that people with a learning disability (PWLD) were incapable of developing a mental illness. According to her, another view of the matter was that PWLD were vulnerable to mental disorders but their emotional troubles were of another quality and usually of a biological origin. However, in recent years it has been acknowledged that PWLD are likely to display emotional troubles similar to people without an LD. Over the years it has often been stated that PWLD may be at an increased risk for developing a mental illness (Buckles et al., 2013; Moss et al., 1997; Pyles et al., 1997) because they are more sensitive to psychosocial stress and, therefore, more prone to developing a mental illness (Deb et al., 2001). Cooper and associates (2007) reported that the prevalence among PWLD in unknown. They said there is

a large inconsistency in prevalence rates for mental disorders among PWLD and that the rates can range from 7 to 97%. They explain that this can for example be due to the diagnostic criteria used, biased sampling, using only screening tools or small cohorts. They reported findings from a large-scale population-based study where 35.2% of the people had a mental disorder. This is similar to findings reported by Morgan and colleagues (2018), as they found that 31.7% of PWLD had a mental disorder. Trollor and associates (2016) stated that even though the prevalence of mental disorders among PWLD is high, mental illness often goes undetected. They claim this can be due to communication difficulties, atypical presentations, coordinating multidisciplinary care, and the scarcity of professionals specialising in LD and mental health.

According to van Minnen and colleagues (1997), the most common form of treatment for PWLD with a mental disorder has been hospitalization but other treatment alternatives have been developed in the recent years. There are many reasons for this development. For example, admittance to a hospital can disrupt people's social life and can cause other emotional problems associated with disability such as inflexibility, reduced ability to adapt socially, and decreased capability to tolerate stress. It is also possible that changes in behaviour obtained in hospitalization might not generalise to the person's home environment. Furthermore, there are often long waiting lists for hospital treatment. Another common form of treatment is psychotropic medication and the use of psychotropic drugs prescribed to PWLD is concerning (Branford et al., 2018; Pyles et al., 1997; Sheehan et al., 2015; Trollor et al., 2016), in particular the use of psychotropic drugs prescribed for challenging behaviours (Brylewski & Duggan, 2001; Molyneux et al., 1999; Sheehan et al., 2015; Tsiouris, 2010). In the general population, the use of psychotropic drugs is 15.8% in the United States according to the National Center for Health Statistics (Terlizzi & Zablotsky, 2020) and almost 20% in Iceland (Tómasson et al., 2007). According to information obtained from The Health

Improvement Network (THIN) in the United Kingdom, among 32,306 individuals with an LD, 49% had a record of prescription of psychotropic drugs (Sheehan et al., 2015) and from a large scale study on 4,069 adults in New York, 59% received one or more psychotropic medication (Tsiouris, 2010).

Bouras and Jacobson (2002) reported that there is an international recognition of the need to respond more adequately to the mental health of this population. They stated that psychologists and psychiatrists are specialising in the mental health problems of PWLD in some parts of the world, such as in the United Kingdom. Yet, this is not the case in many countries, and according to the authors, general psychiatrists and other professionals may care for PWLD and mental disorders without having special knowledge of their problems.

Beasley and associates (2018) claim that the lack of professionals trained to treat PWLD with mental health problems contributes to limited access to mental health services and low quality of care and when there are not many outpatient options, the local hospital's emergency department might get overused. According to them, the use of the emergency department for psychiatric care is problematic because treatment in that setting can lead to the use of sedating medications, restraint, and seclusion. It can also be challenging to identify the appropriate service care subsequent to care from the emergency department due to the lack of inpatient psychiatric units equipped to meet the complex needs of PWLD. They say this can lead to stress, frustration, and disillusionment with the medical system among caregivers, providers, and PWLD. Fernandes and colleagues (2020) reported that another consequence of ineffective mental health care is the reliance on inpatient hospitalization services to manage an individual's mental health needs. They analysed visits by PWLD to an emergency department over 10 week period. The most common reasons for the visits were aggression, suicidality, and self-harm. Approximately one in three individuals were admitted to an inpatient unit and admitted individuals were more likely to have restraints used. Beasley

and colleagues claim that inpatient care involves restrictiveness, added expense, and should be considered a last resort. Furthermore, research has shown that the use of restraint and seclusion can have adverse physical and psychological effects on both patients and staff (O'Donoghue et al., 2020). Fernandes and colleagues concluded that many of the participants were inadequately supported and in need of stronger connections to community-based resources.

Whittle and associates (2018) stated that even though rates for mental illness among PWLD is substantially higher than within the general population, many do not seek appropriate assistance. According to them, the uptake of mental health services among PWLD does not match the prevalence rates of mental disorders. For example, Einfeld and Tonge (1996) reported that 47% of participants with a mental disorder had not sought any assistance and only 9% had sought assistance from mental health professionals that specialised in LD. They reported that barriers to access are widely cited as the primary reason that prevents this group from seeking mental health services. Whittle and associates identified four of the most common barriers in a systematic review from 2018. First was availability, which refers to whether there is an adequate supply of mental health services available to the population. Examples of this is insufficient number of service providers and both physical and logistical issues such as travel, distance, and location. Second was utilisation. People may be able to access the service but unable to utilise it due to personal, financial, or organisational barriers. An example of organisational barriers was presented in an article by Chinn and Abraham (2016) where they wrote about a service newly established in England and the ability for PWLD to access it. The service, Improving Access to Psychological Therapies (IAPT), was established to address mental health problems among the English population and is delivered by regional mental health teams. For efficacy, and the most value for money, the implementation of the IAPT services emphasises well-defined criteria for

eligibility and measurable and homogeneously operationalised process and outcome variables. PWLD often do not meet these criteria which consequently excludes them from the service. Third is equity, which mainly concerns fairness and social justice in relation to access to health care. For example, the severity of a person's intellectual disability may impact equity of access to services. Fourth is relevance and effectiveness which concerns the provision of the right service at the right time for the best outcome and the quality of the services available. Whittle and colleagues reported that one of the most significant obstacles in receiving adequate treatment was clinical knowledge. Insufficient clinical knowledge not only results in a lack of service but seriously impacts the quality of services available. Many mental health care professionals and primary care practitioners view themselves as being inadequately resourced and trained to meet the complex needs of PWLD and were unable to offer PWLD the service they need. Almost all of the literature reviewed by Whittle and colleagues noted that one of the most substantial hindrance in receiving effective mental health treatment was the misidentification of mental disorders. This is especially apparent in an issue called diagnostic overshadowing which refers to the misattribution of symptoms where all symptoms are considered to be a part of the LD rather than identified as related to mental health. This is whether it is a symptom of mental disorder, physical comfort, or emotional unrest.

It is evident that the need for mental health services for PWLD is extensive given the high prevalence of mental disorders among this group. Even though there has been substantial development in mental health services for PWLD over the years many do not receive adequate mental health service. This study attempts to explore mental health, and the use, need and accessibility of mental health services among PWLD living in residential services in Iceland. Two hypothesis were presented. 1) PWLD in supported living in Iceland

do not receive adequate mental health and 2) a large proportion of PWLD use psychotropic medication.

Method

Participants

Participants were all individuals with a learning disability (LD) at the age of 18 or older who were residents in supported living services in Iceland, a total of 583 out of 688. Response rate was 84.3%. After excluding individuals without an LD or autism the total was 562. The gender ratio was 40.9% females ($N = 231$) and 58.6% males ($N = 331$). The age of the residents ranged from 18 to 70 years old or older and the average age was 45.1 years ($SD = 15.6$). The supervisor in each living service answered the questionnaire on behalf of each resident. The supervisor answered the questions at their workplace and there was no compensation given for participation. No identifying information was gathered. An application was submitted to The National Bioethics Committee who concluded that the study was not a scientific study in the health sector and that their approval was unnecessary.

Measures

All questions were constructed by a newly formed team within the health care services dedicated to the mental health of individuals with an LD. First section of the questionnaire contained questions about general information like age, gender, and residency (see Appendix A). Second section was about current mental health services and contained for example questions whether the resident had ever been admitted to a psychiatric ward or had been diagnosed with a mental disorder and by whom the resident had been diagnosed. Third section dealt with mental health services in general and contained for example questions regarding whether the resident had access to mental health services, what kind of a mental health specialist they had access to, if they had received mental health care in the last 12 months, and if the resident was on any psychotropic medication. In the fourth and last section the respondent was asked to evaluate the need for mental health service for the resident.

Procedure

The study was performed throughout January to March 2021. The research team met in December 2020 to discuss what needed to be included in the questionnaire and to design the questions. The director of the psychiatric ward at the National University Hospital of Iceland was informed of the prospective survey and asked if they had anything they wanted to contribute. They had nothing to add to the questionnaire but were enthusiastic about a collaboration. The National Association of Intellectual Disabilities and their subsidiary associations like the Autism Association and Átak, Association of People with Developmental Disabilities were also informed and asked to consult on the project, which they accepted. In cooperation with social services in each district department, an e-mail was sent to the supervisor of every supported living services in Iceland. The e-mail contained information about the newly formed mental health team and the study in question (see Appendix B). The supervisor was asked to answer the questions on behalf of their service resident to the best of their knowledge. The consent of their residents did not need to be obtained. An e-mail was sent twice to all administrators, reminding them to answer the questionnaire if they had not done so already.

Data analysis

Open ended questions and semi-open ended questions were coded afterwards. An example of an open ended question concerned medication (Appendix A), first respondents were asked if the resident was on any kind of psychotropic medication then they were asked "If yes, what psychotropic medication does the resident use?" An example of semi-open ended questions are questions about mental health services. The question "Does the resident have access to a specialist in mental health services?" with the answer options of a number of specialists in the mental health services and then the answer option of "If other, who?".

Descriptive measures were mostly used in addition to crosstabulation and Chi-square test to examine association between the variables and if the association was statistically significant.

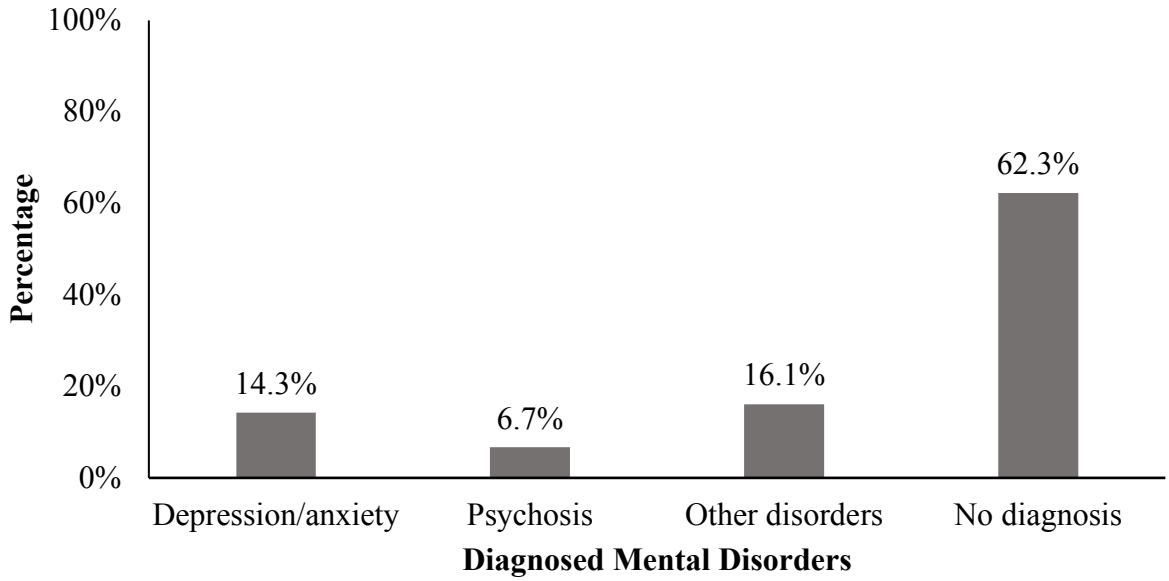
Results

Diagnosed Mental Disorders

Of the residents, 37.2% were diagnosed with a mental disorder. Figure 1 displays the types of diagnoses. The most common disorders diagnosed were depression and anxiety (14.3%) and second most common disorder was psychosis or psychotic disorder (6.7%). Only half of those diagnosed with a mental disorder, or 49.0%, had access to mental health services and only 44.8% had received mental health care in the last 12 months. There was no statistically significant association between residency, gender, or age on one hand and being diagnosed with a mental disorder on the other.

Figure 1

Proportion of Diagnosed Mental Disorders

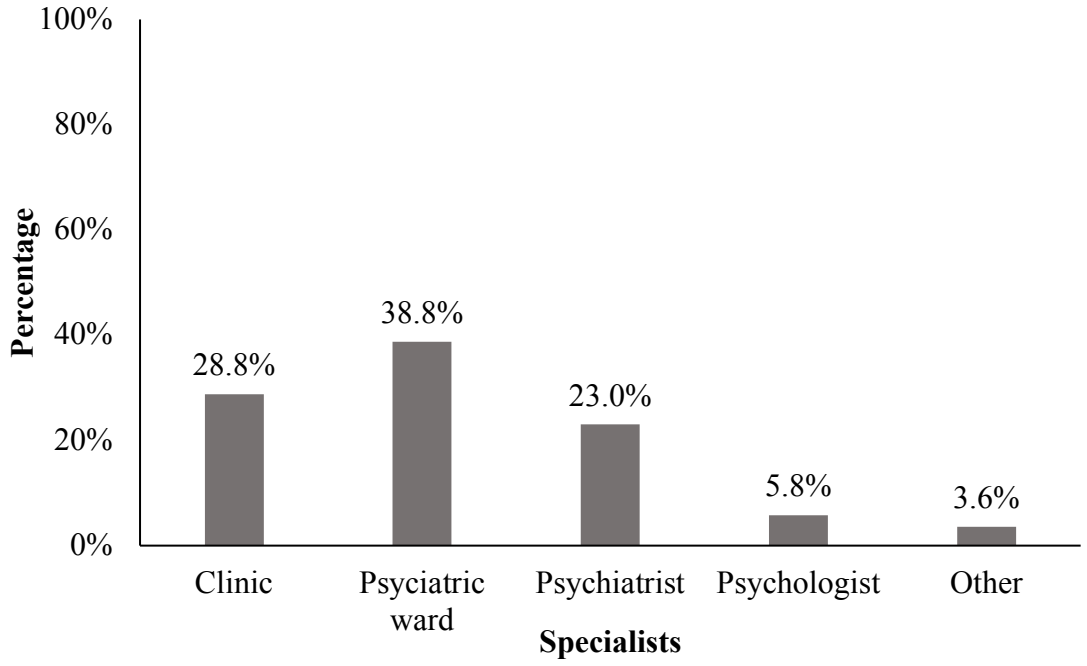


The majority of those diagnosed with a mental disorder, or 61.8%, were diagnosed by a psychiatrist or at a psychiatric ward, 28.8% by the health care clinic, and 5.8% by a psychologist (Figure 2). In total, 17.5% had been admitted to a psychiatric ward sometime in

their life and of those, 23.4% had not been diagnosed with a mental disorder (numbers not presented in figure). Of those who had been admitted to a psychiatric ward, 91.2% were on psychotropic medication daily and of those who were on psychotropic medication, 30.2% had been admitted to the psychiatric ward. There was a statistically significant association between admittance to the psychiatric ward and the use of psychotropic medication, χ^2 (*2*) = 68.3, $p < .001$. Of those who had a history of an admittance to the psychiatric ward, 73.7% displayed challenging behaviour daily. The association between admittance to the psychiatric ward and challenging behaviour was statistically significant, χ^2 (*4*) = 39.2, $p < .001$.

Figure 2

Proportion of Individuals Diagnosed by Mental Health Specialists



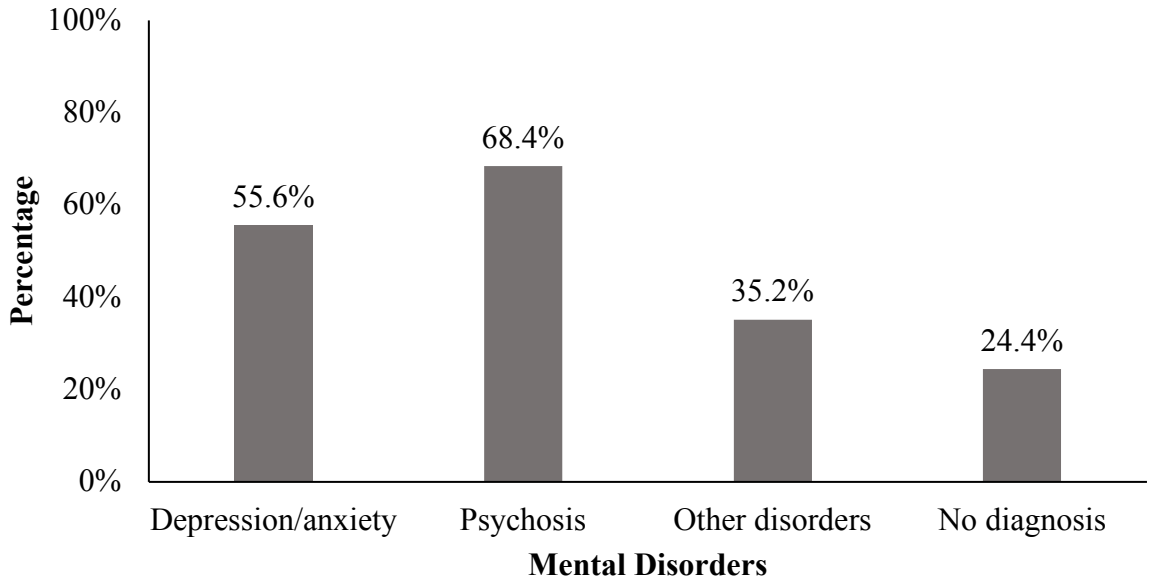
Access to Mental Health Services

A large proportion, or 66.0%, did not have access to mental health services. Of the residents in need of mental health care, 41.6% were without access to it. Of those who had been diagnosed with a mental disorder, 28.7% did not have access to mental health service. Figure 3 shows the diagnosis and proportion of residents who had access to mental health

service. Only 55.6% of those diagnosed with depression or anxiety had access to mental health services and 68.4% of those diagnosed with psychosis or psychotic disorder had access to mental health services.

Figure 3

Proportion of Those Who Had Access to Mental Health Services by Mental Disorder



Access to mental health service did not differ between residency, gender, or age. Only 24.9% had received any mental health care in the last 12 months. The use of health care in the last 12 months was not different between residency or gender, there was, however, a statistically significant association between age and receiving mental health care in the last 12 months, χ^2 (*5*) = 18.4, *p* = .002. Types of mental health care specialists and proportion of those with access to each of them, is presented in table 1, as well as proportion of individuals who received care from these specialists in the last 12 months. Most of those who had access to mental health services, or 43.9%, received it from their health clinic, others from the psychiatric ward (15.2%) or a psychiatrist in private practise (21.5%). Only 2.5% had seen a psychologist in the last 12 months and 2.8% had access to one.

Table 1

Proportion of those with access to each mental health care specialist and those who received care in the last 12 months

	Mental Health Services			Mental Health Services in the last 12 months		
Type of service	*n*	%	% of total	*n*	%	% of total
Clinic	98	43.9	17.4	62	36.0	11.0
Psychiatric ward	34	15.2	6.0	34	19.8	6.0
Psychiatrist	48	21.5	8.5	43	25.0	7.6
Psychologist	16	7.2	2.8	14	8.1	2.5
Social worker	4	1.8	0.7	3	1.7	0.5

Note. % = Percentage of those residents that had access to mental health service; % of total = Percentage of total residents.

Adequate Mental Health Care

Only 30.8% of the responding supervisors answered that the resident received adequate mental health care (Figure 4). Of those diagnosed with a mental disorder, only 26.3% answered the residents received adequate mental health care (numbers not presented in figure). Types of mental health services the respondent believed the resident needed is displayed in figure 5. There were 41.7% that said the resident needed comprehensive monitoring and service from a specialised mental health team and better access to mental health services in general, 35.7% said the resident needed a psychiatrist, mostly to re-evaluate medication dosages, and 18.0% said the resident needed care from a psychologist. The question was semi-open ended, examples of answers were “Better access for disabled people to the service in general”, “General access to mental health services”, “the resident needs psychological help, due to great anxiety and social anxiety”, “He urgently needs the services of a psychiatrist to re-evaluate medication dosages”, “No doubt the clinical physician is doing his best, but since the person in question is on three different types of psychotropic drugs, I

think it is important to re-evaluate medication prescription", "He was denied service due to his disability", and "We have repeatedly been told that there is no solution for the group struggling with multiple problems, mental disorders and disabilities".

Figure 4

Proportion of Those who Received Adequate Mental Health

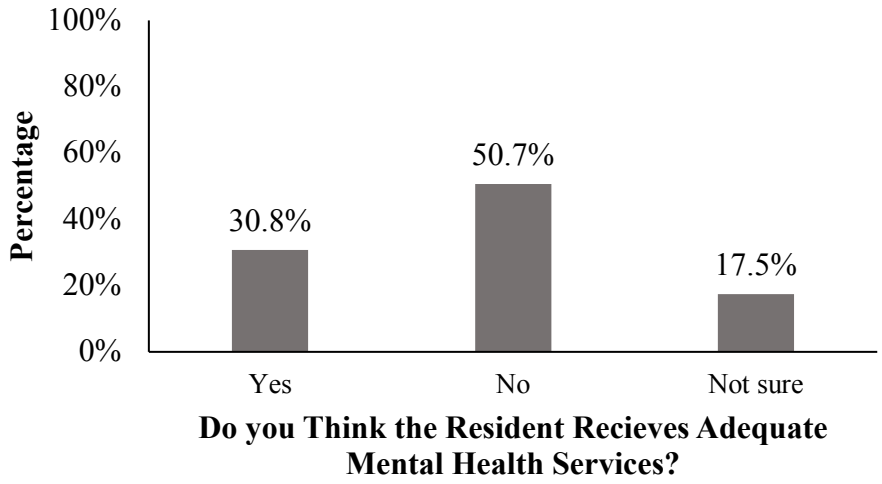
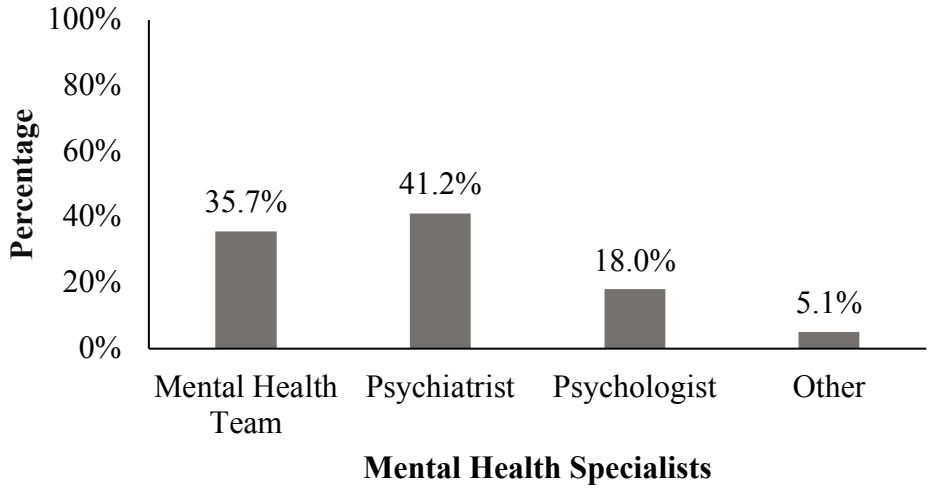


Figure 5

Proportion of Those in Need for Each Mental Health Specialist



Receiving adequate mental health did not differ between residency, gender, or age. Of those who answered that the resident did not receive adequate mental health care, 61.3% residents, were using psychotropic medication daily. The association between receiving

adequate mental health care, as answered by the supervisors, and use of psychotropic medication was statistically significant, χ^2 (*4*) = 47.9, $p < .001$.

Psychotropic Medication

The majority of residents, or 58.2% were on psychotropic medications daily, even though only 48.3% of those had not used any kind of mental health services in the last 12 months. Only 14.0% of those on psychotropic medication had access to a psychiatrist. Of those on psychotropic medications daily, 44.7% had not been diagnosed with a mental disorder. The use of psychotropic medication did not differ between residency, gender, or age. Table 2 shows the kind of psychotropic medication residents were taking and what mental disorders they were diagnosed with. Of those with no diagnosis, 22.7% were on antidepressants and 24.4% were on antipsychotics. There was a statistically significant association between being diagnosed with a mental disorder on one hand and antidepressants and antipsychotics on the other, but use of anxiolytics and hypnotics did not differ between diagnoses.

Table 2

Proportion of Residents on Each Type of Psychotropic Medication and Their Diagnosis.

	Antidepressants	Anxiolytics	Antipsychotics	Hypnotics
No diagnoses	22.7%	5.1%	24.4%	1.4%
Depression/anxiety	65.4%	8.6%	42.0%	3.7%
Psychosis	34.2%	7.9%	73.7%	2.6%
Other diagnoses	42.9%	11.0%	64.8%	6.6%
p	< .001	.201	< .001	.049

Note. The p-value is based on the Chi-square test of independence.

Challenging Behaviour

Almost half of the residents, or 48.7%, displayed challenging behaviour daily, and 15.6% displayed challenging behaviour weekly. Of those who displayed challenging

behaviour daily, 28.9% had been admitted to the psychiatric ward. Of those with behaviour difficulties on a daily bases, 76.4% were taking psychotropic medications daily. Table 3 shows what type of psychotropic medication those who displayed challenging behaviours daily were taking on a daily basis. The residents were mostly taking antidepressants (41.8%) and antipsychotics (51.3%). The association between usage of psychotropics and challenging behaviour was significant, χ^2 (8) = 101.4, $p < .001$.

Table 3

Challenging Behaviour on a Daily Basis and Use of Psychotropic Medication

Psychotropic medication	*n*	%	*p*
Antidepressants	115	41.8	< .001
Anxiolytics	28	10.2	.23
Antipsychotics	141	51.3	< .001
Hypnotics	14	5.1	.11
No medication	62	27.3	< .001

Note. The p-value is based on the Chi-square test of independence.

Discussion

The primary purpose of this study was to examine mental health among individuals with a learning disability (LD) in supported living in Iceland and what kind of mental health services they used and had access to. Two hypotheses were presented. First, people with a learning disability (PWLD) living under these conditions in Iceland do not receive adequate mental health care. Second, a large proportion of PWLD use psychotropic medication. Results showed that PWLD, as reported by supervisors of residential services, were not receiving sufficient mental health care since less than a third, or 30.8%, of the respondents answered that the residents were receiving adequate mental health care. Additionally, of those diagnosed with a mental disorder, only 26.3%, answered that the resident received adequate mental health care. When asked about access to mental health services, the majority

of the residents, or 66.0%, did not report access to mental health services. Close to three out of five of the residents, or 58.2%, used psychotropic medication. Of those, almost half, or 44.7%, had not been diagnosed with a mental disorder. Respondents expressed great need not only for better access to mental health services for their clients, but that the mental health professionals would be specialised in mental illness and LD. Moreover, respondents expressed the need for a comprehensive mental health team that would offer psychological services as well as a re-evaluation of the psychotropic medication prescribed as many voiced concerns over their resident being on unsuitable medication or dosages. The reason for inaccessible mental health services and inadequate care could largely be due to insufficient education and training on how to care for the mental health of PWLD. When mental health specialists are unqualified to treat PWLD they might deny them service. The specialists could also accept to treat them without having the qualification and inadvertently provide incorrect or poor treatment care. Same goes for medication prescription, unqualified physicians and psychiatrists could, unintentionally, be giving wrong medication prescriptions or dosages. Another possible reason so many PWLD use psychotropics is that there are not many treatment options available for those who display challenging behaviour so they might get prescribed psychotropic medication in an attempt to reduce the behaviour.

The results were in compliance with previous studies. Whittle and associates (2018) reported that the rates for mental disorders among PWLD did not match the use of mental health services. Einfeld and Tonge (1996) reported that only half of the children with a mental disorder had sought assistance. Results of the current study indicate that only 49.0% of those diagnosed with mental disorders had access to mental health services and only 44.8% had received mental health services within the last 12 months. Previous research has also shown concerning usage of psychotropic medication among PWLD (Branford et al., 2018; Pyles et al., 1997; Sheehan et al., 2015; Trollor et al., 2016). In comparison, less than

20% of the participants in a study assessing the use of psychotropic medication of the general public in Iceland reported by Tomasson and associates in 2007, used psychotropic medication for some time in the preceding 12 months compared to 58.2% in the current study.

The foremost strength of the study is that this is the first survey that tries to bring light to the mental health services for PWLD in Iceland. Other strengths are that all individuals with an LD in Iceland and are in supported living services were included in the study and there was a high response rate, which provided information on the situation in all regions in Iceland. Another advantage is that the study was carried out in cooperation with those connected to the matter like the psychiatric ward at the National University Hospital of Iceland and The National Association of Intellectual Disabilities and their subsidiary associations. It was important that those who the matter concerned, would be involved in constructing the questionnaire in order to include every important material. Limitations are that the information was gathered indirectly and the respondents to the questionnaire were supervisors of the living services, not the residents, and the supervisors might not know everything about the resident. No standardised questionnaires were used to measure mental health or to assess satisfaction with the mental health services so comparing resaults to other countries could be challenging. Additionally, answers to some questions were subjective evaluation based on the supervisors experience of each resident and not measurable data from the mental health institutions. Another limitation is that all residents were in supported living services and there are individuals with an LD that either live on their own or have not yet been provided with a residency in supported living. Even though those who are residents in supported living in Iceland represent a larger part of all PWLD in Iceland, those who are not in residential services could have other experiences.

Not much is known about the mental health and mental health services for PWLD, and there is much to examine yet. Potential further research includes studying a sample that

comprises all PWLD in Iceland, not only those in supported living services. It would also be beneficial to examine how general specialists in mental health services rate their ability to treat the mental health of PWLD. It would also be interesting to study their view on offering treatment to these individuals despite viewing themselves as being inadequately resourced and trained. Other potential research issues include examining the real prevalence of mental disorders among the group by using screening tests and diagnostic interviews.

This research covers an extremely important topic. The mental wellbeing among PWLD has for a long time been neglected and access to mental health services for these individuals has been limited. General practitioners, psychiatrists, and psychologist in Iceland have not been receiving the training and education needed to meet the complex needs of PWLD so even though these individuals have access to a mental health professional, it is unlikely that said professional is specialised in LD. Consequently, PWLD may receive insufficient care. It has also been discussed within the disability service that PWLD have been denied service due to their disability and there were quite a few respondents that claimed that their resident had been denied service. This is possibly because mental health professionals are unsure of what service to provide and how to provide it. An example of ways to improve the mental health services for PWLD is to form comprehensive interdisciplinary mental health teams that consists of varied professional that specialise in the mental health of PWLD. Another way is to increase education and training among general mental health professionals so they can provide PWLD with adequate mental health care.

Results of the current study strengthen the concerns that PWLD have not been receiving the mental health care they need. It is evident that access to specialists with appropriate resources and training within the mental health sector needs to be improved. Hopefully, this study will help raise awareness of the insufficient and limited mental health

services PWLD are receiving and contribute to the development of a better mental health care system for PWLD in Iceland.

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Appendix A

Questionnaire sent to respondents

1. Merkið við viðkomandi svæði þar sem þjónustan fer fram:

- ☐ Akranes
- ☐ Akureyri
- ☐ Bergrisinn
- ☐ Borgarbyggð
- ☐ Byggðasamlag Vestfjarða
- ☐ Dalvík/Fjallabyggð
- ☐ Fjarðabyggð/Múlaþing
- ☐ Garðabær
- ☐ Grindavík
- ☐ Hafnarfjörður
- ☐ Hornafjörður
- ☐ Hvalfjarðarsveit
- ☐ Kópavogur
- ☐ Mosfellsbær
- ☐ Norðurþing
- ☐ Reykjanesbær
- ☐ Reykjavík
- ☐ Seltjarnarnesbær
- ☐ Skagafjörður
- ☐ Skálatún
- ☐ Sólheimar
- ☐ Snæfellsnes
- ☐ Styrktarfélagið Ás
- ☐ Suðurnesjabær
- ☐ Vestmannaeyjar

2. Kyn

- ☐ Karl
- ☐ Kona
- ☐ Annað

3. Aldur

- ☐ 18-30
- ☐ 51-60
- ☐ 31-40
- ☐ 61-70
- ☐ 41-50
- ☐ 71 eða eldri

4. Hvernig fatlanir er íbúi með?

- ☐ Þroskahömlun
- ☐ Fjölfötlun
- ☐ Skynfötlun
- ☐ Hreyfihömlun
- ☐ Einhverfa
- ☐ Ef aðrar, hverjar?

5. Er einstaklingurinn með ICD-10 greiningu, ef svo hverja?

6. Hvaða fötlun hefur mest áhrif á lífsgæði?

- Engin fötlun hefur mest áhrif
- Þroskahömlun
- Fjölfötlun
- Skynfötlun
- Hreyfihömlun
- Einhverfa
- Ef önnur, hver?

7. Á íbúinn sögu um innlögn á geðdeild?

- Já
- Nei
- Upplýsingar vantar

8. Er íbúinn með alvarlegan líkamlegan sjúkdóm (sykursýki, flokaveiki, hjartagalla o.s.f.v.)?

- Já
- Nei
- Upplýsingar vantar

9. Ef já, hvaða sjúkdóm hefur íbúinn?

10. Truflar hegðun daglegt líf íbúans?

- Daglega
- Vikulega
- Mánaðarlega
- Sjaldnar en mánaðarlega
- Aldrei

11. Er íbúinn með geðgreiningu?

- Nei, er ekki með geðgreiningu
- Er greind/ur með þunglyndi/kvíða
- Er greind/ur með geðklofa/geðrof
- Upplýsingar vantar
- Ef önnur greining, hver?

12. Ef já, - hver framkvæmdi greiningu?

- Heilsugæslustöð
- Geðdeild LSH
- Geðlæknir á stofu
- Sálfræðingur á stofu
- Geðhjúkrunarfræðingur
- Félagsráðgjafi
- Ef annar, hver?

13. Hefur einstaklingur aðgang að sérfræðingi í geðheilsuþjónustu?

- Hefur ekki haft aðgang að geðheilsuþjónustu
- Heilsugæslustöð
- Geðdeild LSH
- Geðlækni á stofu
- Sálfræðing á stofu
- Geðhjúkrunarfræðing
- Félagsráðgjafar
- Ef öðrum, hverjum?

14. Hefur íbúinn á síðustu 12 mánuðum notið geðheilsuþjónustu frá:

- Íbúinn hefur ekki notið geðheilsuþjónustu
- Heilsugæslustöð
- Geðdeild LSH
- Geðlækni á stofu
- Sálfræðingi á stofu
- Geðhjúkrunarfræðing
- Félagsráðgjafa
- Ef öðrum, hverjum?

15. Notar íbúinn geðlyf?

- Nei
- Já notar geðlyf daglega
- Já notar geðlyf eftir þörfum

16. Ef já, telur þú geðlyfjanotkun vera:

- Of litla
- Hæfilega
- Of mikla
- Er ekki viss

17. Ef já, hvaða geðlyf notar íbúinn?

18. Notar íbúinn lyf vegna flogaveiki?

- Já og er með flogaveiki
- Já og er ekki með flogaveiki
- Nei

19. Telur þú að íbúinn fái nægilega geðheilsuþjónustu?

- Já
- Nei
- Ekki viss

20. Ef nei, hvaða þjónustu telur þú vanta?

21. Mat forstöðumanns/starfsmanns er að íbúinn þarfnist geðheilsuþjónustu frá:

- Þarfnast ekki geðheilsuþjónustu
- Heilsugæslustöð
- Geðdeild LSH
- Geðlækni
- Sálfræðingi
- Geðhjúkrunarfræðing
- Félagsráðgjafa
- Ef öðrum, hverjum?

22. Ef nei, telur þú að það myndi gagnast íbúanum að hafa aðgang að sérfræðingi í geðheilsuþjónustu?

- Já
- Kannski
- Nei
- Er ekki viss

23. Af hverju/af hverju ekki?

24. Annað sem þér finnst mikilvægt að komi fram:

Appendix B

Letter sent to respondents containing information about the newly formed mental health team and the study in question.

HEILSUGÆSLA
HÖFUÐBORGARSVÆÐISINS

Til félagsmálastjóra og stjórnenda fötlunarþjónustu Reykjavík 3. febrúar 2021

Varðandi geðheilsukönnun meðal fólks með þroskahömlun og skyldar raskanir

Könnun er gerð sem undirbúningur að starfi nýs geðheilsuteymis og er markmið hennar af fá yfirsýn yfir þörf og framkvæmd geðheilsuþjónustu sem fatlaðir íbúar í stoðþjónustu eru að fá. Jafnframt að afla upplýsinga um dreifingu hópsins og fjölda á landsvísu.

Könnunin er nú í fullum gangi og gengur öflun svara almennt vel. Góð þátttaka skiptir alla máli. Við leggjum áherslu á að fá góða svörun til að fá glögga mynd af stöðunni og þannig lagt sem áreiðanlegastan grundvöll að starfi nýja teymisins. Góð þátttaka skiptir þjónustuaðila ekki síður máli til að undirbúningur þjónustunnar verði í samræmi við þarfir íbúa. Niðurstöðum könnunarinnar verða síðan gerð skil í skýrslu þar sem ykkur, þjónustuveitendum, gefst kostur á meta niðurstöður í heimahéraði við stöðuna á landsvísu.

Kannanir af þessu tagi eru vandmeðfarnar þar sem viðkvæmra upplýsinga er aflað. Meðfylgjandi er kynningarbréf sem sent var öllum þeim sem tilnefndir voru sem upplýsingagjafar. Þar kemur fram hvernig staðið er að könnuninni, hverjir standa að henni og hvernig taka á þátt í henni. Vel hefur gengið að svara fyrirspurnum og leiðbeina um þátttöku.

Nú er komið að því að ljúka upplýsingaöflun og óskum við samvinnu ykkar við að ná sem mestri svörun. Á næstu dögum munum við senda fyrirspurnir til þeirra sem við söknum enn svara frá. Við, sem aðstandendur könnunarinnar, biðjum ykkur um að ítreka mikilvægi þátttöku við stjórnendur ykkar svo árangur okkar af könnuninni nýtist okkur öllum sem best.

Með þakklæti fyrir góða samvinnu,

Bjargey Una Hinriksdóttir
Bjargey Una Hinriksdóttir,
MA í fötlunarfræði, þroskaþjálfi,
teymisstjóri

Halldór Kr. Júlíusson
Halldór Kr. Júlíusson,
Ph.D., sálfræðingur,
ábyrgðarmaður könnunar