Intellectual disability and autism in adults influence psychological treatments for mental health comorbidities

Rachel Mills, Rajan Nathan, Paul Soper, Felix Michelet, Alex G. Stewart and Sujeet Jaydeokar

Abstract

Purpose – The purpose of the study was to examine whether there were differences in the provision of non-pharmacological interventions based on the level of intellectual disability and the presence or absence of autism. Mental health conditions are often underdiagnosed in adults with intellectual disability and do not always receive psychological interventions as recommended by the National Institute for Health and Care Excellent guidelines. To realise the national UK programme's aim of stopping the overuse of medications in people with intellectual disability, it is important that these individuals have access to appropriate non-pharmacological interventions. The authors examined the relationship between an individual's level of intellectual disability and the presence or absence of autism with access to relevant non-pharmacological interventions from specialist community intellectual disability services.

Design/methodology/approach - A cross-sectional study of adults accessing four specialist intellectual disability services in North West England in 2019.

Findings - There was a high prevalence of mental health comorbidity, even higher for autistic adults. However, a relatively small percentage of the study population was receiving psychological interventions. The most frequent non-pharmacological intervention was a positive behaviour support plan, irrespective of comorbid mental illnesses.

Research limitations/implications - Not having access to psychological interventions for the treatment of mental illness could result in poor health outcomes and increasing health inequalities. The study highlights the need for developing psychological interventions, particularly for those with moderate to severe intellectual disability and for those with associated autism.

Originality/value - This large sample study examined the relationship between intellectual disability level and the presence of autism with accessing psychological interventions.

Keywords Learning disability, PBS, STOMP, Mental illness, Cognitive behavioural therapy, Anxiety management

Paper type Research paper

Introduction

Mental health conditions in individuals with intellectual disability are often overlooked and underdiagnosed (Mental Health Foundation, 2016). Explanations include problems applying standard assessment approaches and falsely attributing the clinical problems to the intellectual disability rather than recognising possible comorbid mental health diagnoses (Reiss et al., 1982). In addition, people with an intellectual disability have a higher prevalence of concurrent mental health diagnoses than the general population (Cooper et al., 2007); consequently, potentially diagnosable conditions are being left untreated (Mental Health Foundation, 2016), with increased barriers to accessing healthcare and specialist services (RCPsych, 2020). Overall, such individuals are more likely to have poor physical health, a (Information about the authors can be found at the end of this article.)

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Ethical information. The study was approved through the Trust's research ethics approval process. Data was extracted and anonymised from the standard electronic patient record system used in routine clinical care. According to the Health Research Authority algorithm (see http:// www.hra-decisiontools.org.uk/ research/), this study was not defined as research, and therefore, did not require submission to the Integrated Research Application System (a single system for applying for the permissions and approvals for health and social care/community care research in the UK).

greater risk of having comorbidities relating to physical and mental health conditions and a greater risk of premature death (LeDeR, 2020).

The UK position has gradually improved over the past few decades with mental health comorbidities better understood and diagnosed in this population. However, treatment options are still not consistently delivered in line with national guidance (National Institute for Health and Care Excellence, 2016), with responses varying across geographical areas (RCPsych, 2019). Factors influencing this variation include local health service commissioning arrangements, availability of services and the severity of the patients' intellectual disability.

For most individuals with an intellectual disability, mental health services are provided by specialist community intellectual disability teams; however, for those with a mild intellectual disability, the Equality Act 2010 (UK Parliament, 2020) and the Green Light Tool kit (National Development for Inclusion, 2017) advise that services should be provided by mainstream services rather than specialist intellectual disability services. Pathways and standards are developed and reviewed for those with a more significant degree of intellectual disability and comorbid health difficulties to ensure a more standardised approach to assessment, treatment and care (NICE, 2016).

There are a number of UK programmes that aim to improve mental health and mental health services for people with intellectual disability [Transforming Care Agenda (NHS England, 2012); Building the Right Support (NHS England, 2015); Stopping Over Medication of People [STOMP] (NHS England, 2016)]. These programmes contribute to the assessment, diagnosis and treatment of those with an intellectual disability, with the emphasis being placed on alternatives to pharmacological interventions, such as positive behaviour support plans and/or psychological interventions, where appropriate to do so (Banks and Bush, 2016). Evidence suggests that many of the psychological treatments available for those with intellectual disability concentrate mainly on those with mild intellectual disability. For those in the moderate to severe range of intellectual disability the focus is on behaviour management strategies (Vereenooghe and Langdon, 2013). At the same time, an increasing degree of intellectual disability correlates with the increasing presence of mental health disorders (Corbett, 1979; Lund, 1985; Cooper, 2007).

Our clinical experience also suggests that the effectiveness of such non-pharmacological interventions for comorbid mental health problems differs depending on the severity of the intellectual disability. Furthermore, around 35,000 adults with intellectual disability are prescribed various psychotropic medications (NHS England, 2016) for which there may be limited valid clinical justification.

A national benchmarking exercise in 2019 considered the performance of intellectual disability services, outlining key areas of clinical and service practice. However, this did not examine mental health comorbidities and the necessary multi-disciplinary resources to meet those needs (NHS England and NHS Improvement, 2021).

There is limited research examining the impact of the severity of intellectual disability on the treatment options for comorbid mental health problems in people with intellectual disability. Accordingly, we examined the mental health needs of, and provision of non-pharmacological treatment options for, adults with intellectual disability accessing specialist community intellectual disability services. We wanted to understand the characteristics of this population and examine whether there were differences in the provision of non-pharmacological interventions based on the level of intellectual disability and based on presence or absence of autism.

Methods

Study design

This was a cross-sectional study using primary and secondary data looking at individuals attending specialist community intellectual disability services in 2019 in the UK. The selected study design allowed data collection and analysis at a single point in time. Data was analysed from all individuals recorded as receiving a service from the identified specialist services in 2019.

Participants

The study was conducted in a large UK-based national health service provider of community and hospital-based mental health services in the North West of England. Four community intellectual disability services deliver specialist care to individuals with intellectual disability across a population of approximately 1.5 million. These multidisciplinary services have an open referral system that allows anyone (professional or member of the public) to refer an individual with an intellectual disability to these services. Services offer a range of multi-disciplinary specialist interventions and support to meet their health needs.

The study population included individuals aged 18 years and over who accessed specialist community intellectual disability services from January to December 2019. The data was extracted from the trust's electronic case-record system and anonymised.

Procedure

Data was extracted from the electronic records by Information Analysts and authors within the organisation. Key demographics and essential information relating to diagnosis, treatment and level of intellectual disability were determined as crucial to the study so was extracted alongside the demographics.

Data analysis

Indices of deprivation (IMD) deciles were sourced from the patient's postcode from https:// imd-by-postcode.opendatacommunities.org/imd/2019.

Data variables for the study included: for baseline characteristics, gender, age, ethnicity and IMD; for clinical characteristics, level of intellectual disability, presence or absence of autism and mental health comorbidities, including the type of mental health comorbidities based on the International Classification of Diseases – 10th edition (WHO, 1993). The presence or absence of autism, along with the severity of intellectual disability, was identified through diagnostic section of the electronic records, along with recorded International Classification of Diseases-10 codes. Diagnosis and codes are recorded onto the electronic system by clinicians for accuracy. Data variables also included non-pharmacological interventions defined as being on a care programme approach, having a positive behaviour support plan, having psychological intervention or having any other multi-disciplinary interventions (See Appendix). Extracted data was imported to Excel and StataSE statistical software for analysis (Stata Statistical Software: release 17. College Station, Texas, StatCVorp LLC). We examined the relationships between both autism and the degree of intellectual disability (as a dichotomous variable, combining moderate/severe/profound intellectual disability with mild intellectual disability separately) with mental health comorbidities and with non-pharmacological mental health treatment options (psychological treatment offered: therapies - cognitive behavioural, relaxation, dialectical behaviour, cognitive analytic, family and systemic); being on care programme approach (a process to assess, plan, review and co-ordinate care and treatment for individuals with mental health conditions and complex needs); having a positive behaviour support plan, by relative risk and adjusted relative risk. The p-values < 0.01 were regarded as significant.

Results

Characteristics of adults with intellectual disability attending specialist community intellectual disability services

There were 1,392 people with an intellectual disability seen in 2019, with slightly more men (56%) than women (44%); most were white British (94%), and about a quarter (27%) had an additional diagnosis of autism alongside their intellectual disability (Table 1). The lower four IMD deciles had higher representation in the study population. Mental health comorbidities were present in 54% (n = 752) with mood (affective) disorder being most prevalent (15%), followed by anxiety and associated disorders (13%), and 9% had schizophrenia or other non-mood psychotic disorders (Table 2). However, only 11% were receiving psychological intervention of any kind. With regards to other interventions, 21% had a positive behaviour support plan, 14% were on a care programme approach, but only 2% had not had any multi-disciplinary input apart from psychiatry (Table 1).

Impact of level of intellectual disability on mental health comorbidities and access to treatments

In relation to the level of intellectual disability, men were more likely than women to have moderate to severe intellectual disability (Table 2). However, mental health comorbidities, namely, schizophrenia and other non-mood psychotic disorders, mood (affective) disorders and anxiety disorders were more common in those with mild intellectual disability (Table 2). There was no difference in psychological interventions based on the level of intellectual disability; however, those with a moderate and severe learning disability were more likely to be on the care programme approach or have a positive behaviour support plan (Table 1). Having a diagnosis of schizophrenia and other non-mood psychotic disorders, or of mood (affective) disorder or that of anxiety disorder resulted in less multi-disciplinary input in those with moderate to severe intellectual disability (Table 3).

Impact of presence of autism on mental health comorbidities and access to treatments

Men were 1.5 times more likely than women to have autism in addition to intellectual disability. Mental health comorbidities were almost seven times more prevalent in autistic

Table 1 Demographics of	people	with ir	itellectual di	sabilit	y in 2	019						
Demographic	Total	%	Moderate/ Severe ID	%	RR	95% CL	р	ID with autism	%	RR	95% CL	р
Male	776	(56)	493	(64)	1.1	1.0–1.2	0.0041	243	(31)	1.5	1.3–1.8	< 0.0001
Female	616	(44)	344	(56)				128	(21)			
White British	1308	(94)	784	(60)	0.9	0.8–1.1	0.341	346	(26)	1.7	1.1–2.8	0.0164
Non-white British	84	(06)	36	(43)				17	(20)			
Psychological intervention	159	(11)	81	(51)	1.1	1.0–1.2	0.2182	58	(36)	1.4	1.2–1.8	0.0017
No psychological intervention	1233	(89)	474	(38)				313	(25)			
CPA	193	(14)	107	(55)	1.4	1.3–1.6	< 0.0001	87	(45)	1.9	1.6–2.3	< 0.0001
No CPA	1199	(86)	448	(37)				284	(24)			
PBS	292	(21)	101	(35)	1.3	1.2-1.5	< 0.0001	141	(48)	2.3	2.0-2.7	< 0.0001
No PBS	1100	(79)	454	(41)				230	(21)			
MDT yes	1361	(98)	539	(40)	1.1	0.8-1.6	0.4886	361	(27)	0.9	0.5-1.5	0.663
No MDT	30	(2)	16	(53)				9	(30)			
IMD 2019 Decile 1-2	681	(49)	372	(55)	0.9	0.8-0.96	0.0065	159	(23)	1.1	0.9-1.5	0.3798
IMD 2019 Decile 9-10	243	(17)	156	(64)				50	(21)			

Notes: CL = lower confidence interval; CPA = care programme approach; IMD = Index of Multiple Deprivation; MDT = multi-disciplinary team; p = level of statistical significance; PBS = positive behaviour support; RR = relative risk. p-Values in italic are significant at 0.01 level

I able 2 Miental nealth comorbidities of persons with intellectual disability in 2019	omorbic	alties or	persol	IIN SU	n Intellectu	al disa	DIIITY IN Z	8 0									
Comorbidities	Tota/	ID mod/ sev	%	RR	Д	aRR	95% LCI	aRR 95% LCI 95% UCL	d	ID with autism	%	RR	Ф	aRR	95% LCI 95% UCL	95% UCL	d
Overall comorbidity effect Mental health comorbidity	752	391	(52)	0.7	<0.0001					330	(44)	6.9	< 0.0001				
present No comorbidity	640	446	(70)							4	(9)						
Presence of ICD10 diagnoses	ses																
F00-F09	22	88	(67)	_	0.2627					0	(4)	0.1	0.003				
None	1335	799	(09)							369	(28)						
F10-F19	23	0	(6)	0.1	0.004					2	6)	0.3	0.0948				
None	1369	835	(61)							369	(27)						
F20-F29	127	33	(31)	0.5	< 0.0001	0.5	0.4	9.0	< 0.0001	22	(17)	0.4	< 0.0001	0.7	0.5	1.0	0.07
None	1265	798	(63)							349	(58)						
F30-F39	211	96	(46)	0.7	< 0.0001	0.7	9.0	0.8	< 0.0001	54	(56)	1.0	0.7071				
None	1181	741	(63)							317	(27)						
F40-F49	186	88	(47)	0.8	0.0007	0.8	0.7	6.0	0.001	81	(44)	-	< 0.0001	2.0	1.7	2.5	< 0.0001
None	1206	749	(62)							290	(24)						
F50-F59	7	4	(22)	0.95	0.876					4	(22)	2.2	0.02				
None	1385	833	(09)							367	(27)						
F60-F69	39	0	0							7	(4)	0.7	0.2411				
None	1353	837	(62)							364	(28)						
F90-F99	91	46	(51)	0.8	0.0817					46	6)	2.0	< 0.0001	2.2	1.8	2.8	< 0.0001
None	1301	791	(61)							325	(27)						

Notes: ICD10 comorbidities: F00-F09 = organic mental disorders; F10-F19 = disorders due to psychoactive substance misuse; F20-F29 = schizophrenia and non-mood psychotic F80-F89 = psychological development disorders, including autism. ID mod/sev = intellectual difficulty moderate or severe; LCL = lower confidence interval; p = level of statistical significance; RR = relative risk; UCL = upper confidence interval. p-Values in italic are significant at 0.01 level conditions; F30-F39 = mood disorders; F40-F49 = anxiety disorders; F50-F59 = adult-onset behavioural disorders; F60-F69 = personality disorders; F90-F99 = behavioural disorders starting in childhood and adolescence. The following comorbidities were not included in the table because they duplicate information: F70-F70 =intellectual disorders;

Notes: aRR = adjusted relative risk; ICD10 = International Coding of Disease v10; ID mod/sev = moderate or severe intellectual disability; LCL = lower confidence interval; p = level of statistical significance; RR = relative risk; UCL = upper confidence interval. p-Values in italic are significant at 0.01 level

adults with intellectual disability compared to intellectual disability alone (Table 2). They were more likely to have behavioural disorders starting in childhood and adolescence (51%), followed by anxiety disorders (44%).

When it came to non-pharmacological interventions (Table 1), autistic adults with intellectual disability were more likely to have a psychological intervention, be on care programme approach and have a positive behaviour support plan. However, in relation to individual comorbidities, those with anxiety disorders or behavioural disorders starting in childhood were more likely to have these interventions (Table 3).

Discussion

We assessed the relationship between characteristics of adults with an intellectual disability attending specialist community intellectual disability services and types of non-pharmacological interventions. There were four key findings.

Firstly, there was high prevalence of mental health comorbidities in the study population. Community intellectual disability services are specialist services set up to meet the mental health needs of adults with intellectual disability. They are also set up to support meeting the physical health needs of this population through direct interventions (e.g. dysphagia care, postural care) and through health facilitation to improve access to generic health services. This is reflected in the prevalence rate. In addition, autistic adults with intellectual disability and adults with mild intellectual disability were more likely to have mental health comorbidities. Anxiety disorders and behavioural disorders with onset in childhood and adolescence were more prevalent in autistic adults with intellectual disability, whereas schizophrenia and other non-mood psychotic disorders, mood (affective) disorders and anxiety disorders were more prevalent in those with mild intellectual disabilities. These findings were in line with the literature (Reid et al., 2011) and showed that the study cohort was not unusual.

Secondly, although there was a high prevalence of mental health comorbidities in the study population, a relatively small percentage were receiving the direct psychological intervention (cognitive behaviour therapy, relaxation, dialectical behaviour therapy, cognitive analytical therapy, family therapy or systemic therapy). Considering the high prevalence of anxiety and mood disorders in the study population, access to psychological treatments did not reflect likely adherence to national institute for health and care excellence (NICE) guidelines (NICE, 2016) for the treatment of these conditions. It is possible that this was due to the limited availability of resources to offer the full range of psychological interventions. It is also possible that some were not considered suitable for specific one-toone psychological intervention, either due to the level of intellectual disability or the presence of autism. Another explanation is that the focus for non-pharmacological intervention might be more on developing formulations and positive behaviour support plans. In recent years, there has been an added focus on providing positive behaviour support to manage behaviours that challenge (Gore et al., 2013).

Thirdly, the commonest non-pharmacological intervention was a positive behaviour support plan. This was used more for autistic adults with intellectual disability than those with intellectual disability alone. Despite the higher prevalence of mental health comorbidities in autistic adults with intellectual disability, they were more likely to get a positive behaviour support plan as an intervention than a psychological intervention. Again, this was not keeping in with NICE guidelines for the management of mental health comorbidities (NICE, 2016). Autistic adults with intellectual disability present with a range of mental health difficulties, needing a range of psychological interventions. At the same time, autistic adults are not likely to benefit from behaviour management strategies alone, aimed at behaviours that challenge, when the underlying issue could be due to mental illness.

Fourthly, autistic adults with intellectual disability and adults with moderate to severe learning disability were more likely to be on the care programme approach. The care programme approach, with an allocated care coordinator and associated care plan, allows services to manage risks better due to an individual's mental health needs. Considering the high level of mental health comorbidity in autistic adults with intellectual disability, higher use of the care programme approach was expected. At the same time, it is interesting that the care programme approach was more likely to be used in those with moderate to severe intellectual disability than those with mild intellectual disability. Because our data suggested a higher prevalence of mental health comorbidity in those with mild intellectual disability, it is possible that those with mild intellectual disability get a diagnosis of mental illness (and appropriate treatments, including medications) and, in many cases, do not reach the threshold for care programme approach. On the other hand, those with moderate to severe intellectual disability are more likely to present with a complex clinical picture, including behaviours that challenge, thus, needing a care programme approach.

There are three clinical implications and recommendations arising from the study findings.

Firstly, adults with an intellectual disability did not get enough access to psychological interventions based on NICE guidelines, despite the high comorbidity of mental health conditions. This means that pharmacological treatments continue to remain the mainstay of managing mental health conditions in this population. It also means that in the absence of recommended psychological interventions, adults with intellectual disability are likely to need a higher dosage of psychotropic medications and for a longer duration. This could result in further worsening of life expectancy and increasing health inequalities for this group. Although there is a clear national drive to stop the overuse of medications in adults with intellectual disability, strategies have often focused on using positive behaviour support plans to manage behaviours that challenge. Along with these strategies, services should also focus on treating mental health conditions with psychological interventions.

Secondly, autistic adults with intellectual disability were at significantly higher risk of mental health comorbidities and yet the focus of non-pharmacological intervention was positive behaviour support plans. Considering the heterogenous nature of autism and the additional complexity that intellectual disability and mental health comorbidities bring, it is somewhat simplistic to attempt to meet the needs of this population using positive behaviour support plans alone. There are a number of models that try to understand the needs of autistic people e.g. strengths and needs frameworks using thinking pattern profiles (Tollerfield et al., 2021). There is a need for developing therapeutic interventions based on such models.

Thirdly, the literature indicates that there is limited evidence for the effectiveness of psychological interventions based on the NICE guidelines in adults with intellectual disability. Most of the available evidence focussed on those with mild intellectual disability. Many of these treatments were adapted from generic mental health services and were not specifically developed for treating adults with intellectual disability. Moreover, it is possible that the adaptations needed for those with intellectual disability could be different from those for autistic adults with intellectual disability. Considering the heterogeneous nature of the study population, it is possible that this cohort could benefit from multi-modal therapy. There is some emerging evidence for the use of multi-modal therapy (Antochi et al., 2003), and this needs further exploration and research. Due to the presentation of the target population, there are, however, potential barriers relating to engagement in psychosocial or psychological therapies via a multi-modal therapy approach. There are also probable issues relating to the consent to treatment due to cognitive limitations. An additional recommendation would be to ensure and establish a more robust, thorough understanding of presentation and associated diagnosis (inclusive of Mental Health comorbidities) through initial assessment when entering the service. Due to the risk and implications of diagnostic overshadowing, ensuring more accurate identification of potential associated disorders and implications would allow for a better understanding of need. This would then permit for better service evaluation and need, inclusive of the potential adaptation of traditional therapy offers recommended by NICE or the development of alternative offers to meet the needs of the population.

There are several strengths of this study. The study cohort included a large number of adults with intellectual disability from four different service areas with data on a wide variety of variables giving enough power for multifactorial statistical analysis. In addition, the study used a robust level for statistical significance. The conduct and reporting of the study were in accordance with STROBE guidelines (2007).

There were, however, some limitations. We used routinely collected data that was extracted from the electronic patient record system. The quality of the data was affected by potential variations in data input by clinical staff; this made it difficult to make associations between mental health comorbidities and the types of intervention provided. We were not able to examine specific interventions provided by wider multi-disciplinary team members, including nursing, speech and language therapists, physiotherapists and occupational therapists. Although there was a significant amount of multi-disciplinary input provided to this cohort, we were not able to assess whether this was towards meeting the mental health needs of the population or towards supporting those with physical health issues. As previously highlighted, individuals with a mild intellectual disability largely access mainstream mental health services rather than specialist Intellectual Disability Services, which will be inclusive of psychological or non-pharmacological treatment options recommended by NICE. One of the limitations of this study is data from that particular population was not analysed to examine the relationship between mild intellectual disability and the uptake, engagement or outcome of alternative interventions to medication in the organisations mainstream mental health services. This could be further investigated to understand the need of this population, engagement and success of treatment options.

Conclusion

We demonstrated a high prevalence of mental health comorbidities in adults with an intellectual disability within the identified study population. Nevertheless, a relatively small percentage of the study population received the recommended psychological interventions as outlined in NICE guidelines. Positive behaviour support was the most common intervention irrespective of the high prevalence of mental illness comorbidities. Addressing this will help towards improving health outcomes and reducing health inequalities.

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Appendix

M, F, Transgender, Other, Missing	
	Electronic patient record (EPR)
Age in years, Missing	EPR: total age 18+
White, Asian, Black, Mixed, other, missing	EPR
IMD number based on postcode	EPR
Mild/Moderate, Severe/Profound, missing	EPR
Yes/No/Missing	EPR
	Clinic letters
	Care plan
F00-F09	EPR
	Clinic letters
	Care plan
Yes/No/Missing	EPR
	Clinic letters
	Care plan
Yes/No/Missing	EPR
	Clinic letters Care plan
	White, Asian, Black, Mixed, other, missing IMD number based on postcode Mild/Moderate, Severe/Profound, missing Yes/No/Missing Yes/No/Missing Yes/No/Missing Yes/No/Missing Yes/No/Missing

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