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Citation: McManus, S., Ali, A., Bebbington, P. E., Brugha, T., Cooper, C., Rai, D., Saunders, C., Strydom, A. & Hassiotis, A. (2018). Inequalities in Health and Service Use among People with Borderline Intellectual Impairment. London, UK: NatCen.

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November 2018

Inequalities in health and service use among people with borderline intellectual impairment

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McManus S, Ali A, Bebbington P, Brugha T, Cooper C, Rai D, Saunders C, Strydom A, Hassiotis A. (2018) *Inequalities in health and service use among people with borderline intellectual impairment*. NatCen: London.

Main and summary reports available: www.natcen.ac.uk/borderline-intellectual-impairment

This report is independent research commissioned and funded by the Department of Health and Social Care (DHSC). The views expressed in this publication are those of the author(s) and not necessarily those of the DHSC.

Cover illustration: 'City' by Alexander Andreev.

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Executive summary

The Department of Health and Social Care (DHSC) commissioned the National Centre for Social Research, University College London, and Leicester University to undertake analysis of Adult Psychiatric Morbidity Survey (APMS) data to profile the circumstances of people with borderline intellectual impairment. APMS is one of the most authoritative and comprehensive national household surveys to assess both intellectual functioning and mental health in adults. This report quantifies the extent to which people with borderline intellectual impairment face inequalities in health and use of services compared with the rest of the population, and seeks to improve awareness of these inequalities.

Borderline intellectual impairment is common, affecting about one adult in ten in England. The term is used here to refer to people with good verbal skills and living in private households, but who may experience cognitive impairments not evident without a detailed assessment. The findings in this report are consistent with previous research: people with borderline intellectual impairment are a disadvantaged group who are not well understood despite their relatively high levels of need for care. APMS data show that adults in this population face high mental health morbidity, poorer general health, and many limitations in their daily lives.

Their level of use of mental health treatment and services does not appear to be commensurate with their higher level of need. This indicates that they are underserved compared with the rest of the population. This may be due to a lack of professional awareness of their needs, to services not adapting enough to meet those needs, or to difficulties the individual faces in seeking treatment and support.

Existing advice from the General Medical Council, Public Health England and the National Institute for Health and Care Excellence about delivering reasonable adjustments and tailored healthcare for people with an intellectual impairment, along with focused training, signposting of support, and the promotion of self-help interventions, can all play a role in improving health outcomes.

Adults with borderline intellectual impairment constitute key users of primary and secondary health care, and employment, education and welfare support. Improving awareness of the needs and circumstances of this group should form part of wider plans to reduce inequalities in health and service use in England.

This report presents a profile of people with borderline intellectual impairment who are living in private households and who have the cognitive and verbal ability to participate in a general household survey. It could not cover people with intellectual impairment who live in residential settings or who lack the cognitive or verbal skills to participate in a general survey of this kind.

1 Introduction

1.1 Borderline intellectual impairment

Intellectual impairment or disability is a lifelong condition with difficulties in adaptive behaviour and cognitive functioning evident since childhood. Intellectual disability, also called learning disability in the UK, has been defined as an IQ below 70 combined with functional limitations. The focus of this report is mostly on people above this threshold, who may have borderline intellectual impairment. It is accepted that testing for intellectual impairment is subject to error due to variations in cultural norms or constructs. For example, measures that assess IQ may lead to fewer people identified as having an intellectual impairment than measures that identify people based on limitations in adaptive functioning. A range of intellectual developmental disorders are associated with early onset and cognitive and adaptive limitations, and abilities and skills may differ between individuals at the same IQ level (Bertelli et al. 2018).

The Adult Psychiatric Morbidity Survey (APMS) included a range of measures relevant to intellectual impairment. These include an assessment of verbal IQ (the National Adult Reading Test) and questions about: self-perceived presence of a ‘difficulty learning or an intellectual impairment’, needing assistance with activities of daily living, and highest educational qualifications achieved. These different measures are considered in Chapter 2 of this report.

Chapters 3 to 6 present analysis based on verbal IQ using six groups of banded IQ score, ranging from 70–79 to 120–129 (Ali et al. 2006). Discussion focuses on those in the 70-79 group - who we refer to in the text variably as intellectually impaired or with borderline intellectual impairment. Given that the lowest V-IQ score that can be reliably derived using the NART is 70, it is likely that this group of people in the survey sample includes some who would score below 70 if their IQ had been assessed fully. It is also important to note that everyone in the sample had the cognitive and verbal skills required to participate in a long survey interview (see 1.4).

While an upper threshold of 84 has been used elsewhere to indicate borderline intellectual impairment, it is often used in combination with evidence of functional adaptive limitations. Our more conservative threshold did not take account of whether someone reported that they had intellectual impairment or if they faced functional limitations. While information about needing assistance with activities of daily living was not used to identify people with possible borderline intellectual impairment, it was used to demonstrate the extent and nature of such limitations in this group.

Similar approaches have been used in other country-wide population surveys and are important sources of comparative data that allow prediction of need and hence service planning (Hughes-McCormack et al., 2017).

1.2 Report aims and scope

This report examines how people's health, wellbeing and service use varies with their level of intellectual ability, focusing on those with borderline intellectual impairment.

Chapter 2 examines the prevalence of borderline intellectual impairment in the population, and its demographic profile, using the different indicators available in the survey.

Chapters 3 to 5 examine rates of mental health, physical health and disability, and self-harm and suicidal thoughts and behaviours among people who are intellectually impaired.

Chapter 6 describes use of mental health treatment and services in England by intellectual ability level.

Chapter 7 summarises conclusions and proposes recommendations for further action.

1.3 Data used in this report

Every seven years since 1993, the Department of Health and Social Care (DHSC) has funded the high quality, national Adult Psychiatric Morbidity Survey (APMS) to monitor the mental health and wellbeing of people in England. Further analysis of APMS data can be used to describe the circumstances of particular groups of people and to profile the wider inequalities they face (such as whether they are more likely to have particular physical health conditions or unmet needs for treatment and services compared with the rest of the adult population). This report focuses on data from the most recent survey in the series (APMS 2014), as well as trends drawing on APMS 2000 and 2007.

1.4 Survey sample and population coverage

This report presents a profile of people with borderline intellectual impairment who are living in private households and who have the cognitive and verbal ability to participate in a general household survey. It does not include people with intellectual impairment who live in residential settings or who lack the cognitive or verbal skills to participate in a general survey of this kind.

APMS uses a stratified, random probability sample of the general population aged 16 and over living in private households in England. An interviewer was present throughout the interview to support participants. The questionnaire was mostly administered face to face, and the self-completion part of the interview was read out by the interviewer when a participant had difficulties with literacy or eyesight. However, people unable to understand the types of questions used on a general population survey or who were unable to communicate verbally would not have been able to take part. People living in a group residential or institutional setting were not included in this survey of people living in private households. Quite different research approaches would be required to include those with more severe levels of intellectual impairment. However, it is important to note that the people identified on a survey like this potentially represent the majority of people with intellectual impairment, as well as the majority of those often missed by services, some falling just below the threshold for eligibility but still experiencing pronounced disadvantages and inequalities.

The National Adult Reading Test (NART; Nelson and Willison 1991) is the main measure used in this report to identify people with intellectual impairment. It is described more fully in Section 2.1. Being based on reading ability and pronunciation, it is only valid when used with people for whom English is their first language. People whose first language was not English are therefore not included in most of the analyses in this report.

1.5 Data access and approval

Permission to use APMS data was granted by the Data Access Request Service, NHS Digital. The dataset was downloaded from the UK Data Service archive under Special License agreement. Ethical review of this secondary analysis was provided by NatCen's internal ethical review committee.

1.6 Data analysis and significance testing

Data management and descriptive analyses were carried out in SPSS v21 using survey weights (to adjust for non-response) and accounting for complex survey design. Statistical significance testing was also carried out in SPSS. Testing focused on whether presence of intellectual impairment varied by the factor being examined, and whether or not this association interacted with sex (that is, whether the pattern of association was similar or different for men and women). Results of significance testing are given as a footnote to each table. Each variable was tested for statistical significance in two ways. The first test indicated whether the variable of interest had a significant overall trend across the six groups of V-IQ score (70-79; 80-89; 90-99; 100-109; 110-119; 120-129). The results of this test are given at the foot of each table. The second test compared those with a V-IQ score of 70-79, with those with a score of 80 or more. The two tests tended to produce a similar result; any differences in results are highlighted in the text. Only associations that have been established as statistically significant are highlighted in the text. In tables, data are redacted for categories with fewer than 40 participants. Base sizes are provided on all tables, and these are unweighted.

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2 Measuring intellectual impairment

Summary

Intellectual impairment can be tested for on surveys in different ways. This chapter considers some of the different options available using APMS 2014 data. The approach used affects the prevalence estimate and the profile of people identified with borderline intellectual impairment.

1. Use predicted verbal IQ based on the National Adult Reading Test (NART)

About one adult in ten (10%) in the English household population had a predicted verbal IQ of less than eighty, and about one in five (20%) scored less than ninety. A verbal IQ below eighty was more common in men (12%) than women (8%). It was also more common in the youngest age groups, as well as in those aged 75 or more.

2. Ask survey participants if they have a 'difficulty learning or an intellectual impairment'

In the general population, about one adult in twenty (4%) self-identified with a 'difficulty learning or an intellectual impairment'. This was more common in men (6%) than women (2%); and in younger people (7% of 16-24 year olds) than older people (1% of those aged 75 or more).

3. Combine lack of educational qualification with either: self-reported impairment or low V-IQ

A binary variable was constructed where intellectual impairment was defined as having no educational qualification above GCSE/O level, but only if the person also either self-identified with intellectual impairment or had a predicted verbal IQ of less than 85. Because verbal IQ was being used in combination with other criteria, the higher (and more widely used) threshold was applied. Using this approach, 11% of adults were identified with intellectual impairment. Rates were higher in men (13%) than women (9%), and in younger people (13% of 16-24 year olds) as well as the oldest (15% of those aged 75 or more).

The first approach – a predicted verbal IQ of less than 80 derived from the NART – is used throughout this report to indicate someone with intellectual impairment (Chapters 3 to 6). This approach was selected as it is based on a validated dimensional measure that allows variation across the population as a whole to be explored, and also because it is less affected by changes in wider educational and diagnostic practices. The group identified in this survey population should be considered as borderline intellectually impaired.

2.1 Assessments of intellectual impairment

APMS 2014 included an assessment of intellectual impairment, questions about self-perceived presence of intellectual impairment, and questions about achievement of educational qualifications.

National Adult Reading Test (NART) is the primary measure of intellectual impairment used in this report (Nelson and Willison 1991). An algorithm can be applied to the scored NART data to generate a reliable prediction of verbal IQ (V-IQ) in people whose first language is English. The NART is largely unaffected by the presence of mental illness and neurological disorders (Crawford et al. 1987, 1988; O’Carroll et al. 1992). The developers of the NART have investigated whether use of reading ability introduces a social class bias to identification of intellectual impairment, and found that this was not the case.¹ It comprises a list of 50 words and is scored by counting the number of errors made in reading out the words.

The lowest V-IQ score that can be identified using the NART is 70, and it cannot be used to reliably identify an IQ score of less than 70. Participants with a V-IQ score of below 80 were grouped together for this analysis and could be considered to be of borderline intellectual functioning. The dimensional nature of the measure means that both a sufficient number of people with the greatest need can be identified in the sample for robust analysis, and that comparisons can be made with others across the population. The NART was used in APMS 2000, 2007 and 2014.

Self-identified with a ‘difficulty learning or an intellectual disability’ in the most recent APMS (2014) participants were asked *‘Do you have a difficulty learning or an intellectual disability?’* Those responding affirmatively were followed up with questions about what the condition is, how severe the difficulty is, and how often it limits the amount or kind of activities that they could do.

A combined variable was produced drawing on the information provided by participants about whether they believe that they have a learning or intellectual impairment, their predicted V-IQ score, and their highest level of educational qualification achieved. This produced an alternative binary measure: a positive case was assigned where an intellectual impairment was reported or the predicted V-IQ was less 85, combined with not having any educational qualifications above GCSE/O level. Because V-IQ was used in combination with other criteria, the higher (and more widely used) threshold of below 85 was applied. This builds on an approach developed elsewhere (Hassiotis et al. 2017).

2.2 Prevalence and trends

National Adult Reading Test (NART): About one adult in ten (10%) in the English household population has a predicted V-IQ (based on the NART) of less than 80. There are indications this rate may have increased among 16-64 year olds over time (it was 6% in 2000 and 9% in 2007). A V-IQ of less than eighty was more common in men (12%) than women (8%). There was also a significant association with age, with rates highest in the youngest group (13% of 16-24 year olds) and the oldest group (12% of those aged 75 or more). Rates were lowest among those aged 45 to 74 (8%). The high rate among older people may reflect cognitive decline later in life, although the NART has been found to be a measure of premorbid IQ and so in theory having dementia or age-related deterioration should not affect the score. (Tables 2.1 and 2.2)

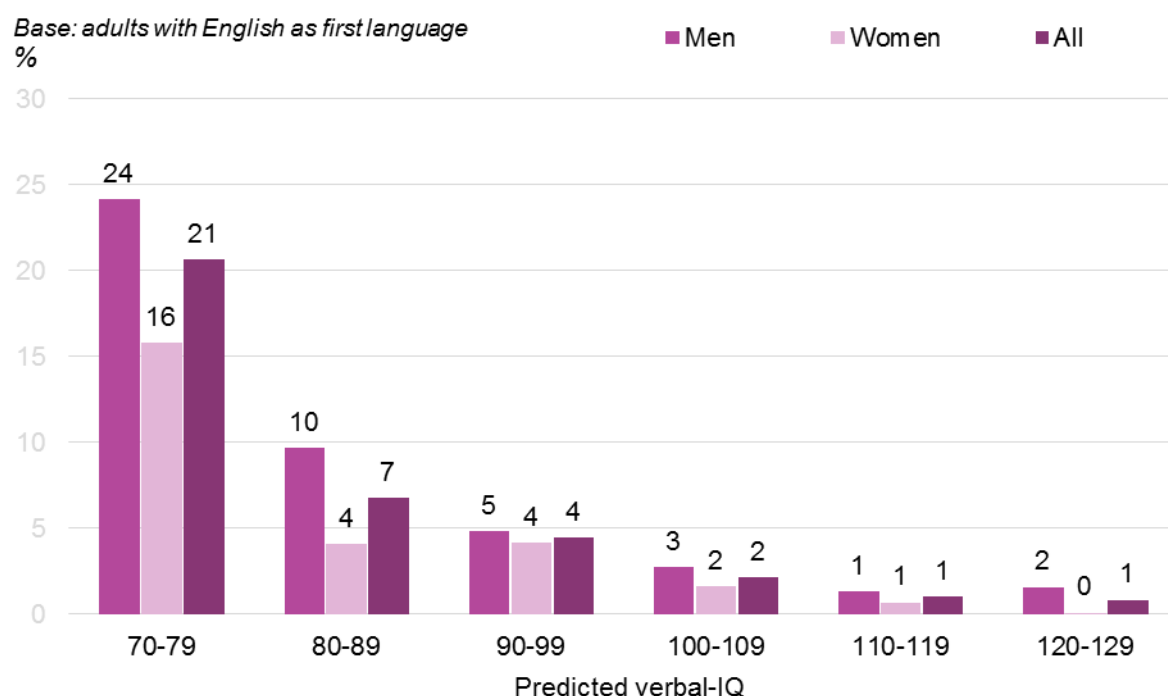
¹ See page 7:

http://www.academia.edu/2515150/National_Adult_Reading_Test_NART_test_manual_Part_1

Self-identified with a ‘difficulty learning or an intellectual disability’: About one person in twenty (4%) in this household sample responded affirmatively when directly asked whether they had a ‘difficulty learning or an intellectual impairment’. Again, this was more common in men (6%) than women (3%); and among younger people (7% of 16-24 year olds) than older people (1% of those aged 75 or more). Among those reporting ‘a difficulty learning or intellectual impairment’, about half (46%) described it as mild, a third (37%) said it was moderate, and a fifth (17%) said severe. (Tables 2.3 and 2.4)

Self-identifying with ‘difficulty learning or an intellectual impairment’ had a strong linear association with predicted verbal IQ score. A fifth (21%) of those with a V-IQ less than 80 reported that they had an intellectual impairment, compared with 7% of those with a score between 80 and 89, and 1 or 2% of those scoring over 100. Those in the higher IQ groups are likely to be reporting dyslexia or other similar learning difficulties. (Table 2.5; Figure 2.1)

Figure 2.1: Self-identified ‘difficulty learning or an intellectual impairment’, by predicted verbal IQ and sex



Combined variable: Using the combined intellectual impairment measure (described in Section 2.1), one adult in nine (11%) was identified with an intellectual impairment. Rates were higher in men (13%) than women (9%), and in younger people (13% of 16-24 year olds) and older people (15% of those aged 75 or more). It should be noted when interpreting this association with age that younger people may still be in education and therefore are likely to obtain further educational qualifications in the future. People in the population aged in their seventies and older tend to have fewer educational qualifications; compulsory education until age 16 was not introduced in England until 1972. Furthermore, changes in diagnostic practice and cultural narrative may mean that younger people are more likely to be assessed for possible intellectual impairment. (Table 2.6)

2.3 Discussion

There are many ways in which people with possible borderline intellectual impairment can be identified in general household surveys. All the measures available on APMS suggest that borderline intellectual impairment may be relatively common in the English household population. Between about one adult in nine and one adult in twenty may be affected. These rates relate to people living in households in England and who have sufficient functional ability to complete a long social survey, they vary with the thresholds used and it should be noted that quite conservative thresholds have been applied here.

In the rest of the report, the focus is on a measure based only on predicted verbal IQ (also referred to as V-IQ). Verbal IQ does not cover other aspects of IQ measurement such as performance IQ, although V-IQ has been found to strongly predict full scale IQ. A drawback of this indicator is that those for whom English was not their first language are excluded. However, V-IQ was ultimately preferred because:

- It is a validated measure
- It produces a dimensional score allowing variation across the population as a whole to be explored
- It is relatively resistant to the impact of wider societal changes in educational opportunities and diagnostic practices.

Throughout this report a predicted V-IQ score of less than 80 is used interchangeably with the terms ‘intellectually impaired’, which in this household population is more akin to borderline intellectual impairment. While we do not exclude those with an IQ score below 70, we expect there were relatively few in this survey sample given the cognitive demands involved in participating.

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Table 2.1 Predicted verbal IQ score, by age and sex*Adults whose first language is English*

2014

Verbal IQ ^a	Age							All
	16-24	25-34	35-44	45-54	55-64	65-74	75+	
	%	%	%	%	%	%	%	%
Men								
70 ^b	4	5	3	6	4	3	7	4
71-79	11	11	8	5	7	8	4	8
80-89	13	11	10	9	9	9	10	10
90-99	33	21	21	12	12	16	14	18
100-109	22	23	21	21	20	15	17	20
110-119	14	23	25	31	30	27	25	25
120-129	3	7	11	16	19	22	22	14
Women								
70	1	2	3	1	1	2	6	2
71-79	12	6	6	5	4	5	7	6
80-89	13	16	10	9	9	8	10	11
90-99	33	28	21	19	16	16	19	22
100-109	18	20	23	24	18	22	19	21
110-119	19	20	27	25	31	27	22	24
120-129	4	8	10	16	20	19	18	14
All adults								
70	2	4	3	3	3	2	6	3
71-79 ^c	11	8	7	5	5	6	6	7
80-89	13	13	10	9	9	9	10	10
90-99	33	24	21	16	14	16	17	20
100-109	20	22	22	23	19	19	18	21
110-119	17	21	26	28	30	27	23	25
120-129	4	8	11	16	19	20	19	14
Bases^d								
Men	220	296	391	467	514	520	406	2814
Women	270	569	587	751	645	626	615	4063
All	490	865	978	1218	1159	1146	1021	6877

^a This is predicted verbal IQ score based on the NART results. The assessment process for the NART is described in Chapter 2.

^b The NART cannot be used to predict V-IQ scores below 70; it is likely that this group includes people who would score less than 70 using a fuller assessment.

^c The proportion of people with a predicted verbal IQ score below 80 varied with age ($p=0.005$) and sex ($p<0.001$). There was no significant interaction.

^d All bases in this report are present unweighted, unless stated otherwise. Note that a valid predicted V-IQ cannot be generated for people for whom English was not their first language. All tables showing V-IQ are based on people reporting that English was their first language.

Table 2.2 Predicted verbal IQ score in 16-64 year olds, by age, year and sex*16-64 year olds, with English as first language**2000, 2007, 2014*

Verbal IQ ^a	16-34 year olds			35-64 year olds			All (16-64)		
	2000	2007	2014	2000	2007	2014	2000	2007	2014
	%	%	%	%	%	%	%	%	%
Men									
70-79^b	11	16	15	6	8	11	8	11	12
95% CI:	(9,13)^c	(13,20)	(12,19)	(5,7)	(7,9)	(9,13)	(7,9)	(10,13)	(11,14)
80-89	18	15	12	13	11	9	15	12	10
90-99	28	28	27	19	17	15	22	21	19
100-109	23	16	22	24	19	21	24	18	21
110-119	16	21	19	28	29	29	24	26	25
120-129	3	4	5	11	17	15	8	12	11
Women									
70-79	8	9	10	4	5	7	5	7	8
95% CI:	(7,10)	(7,12)	(8,13)	(3,5)	(4,6)	(6,8)	(5,6)	(6,8)	(7,9)
80-89	19	19	15	12	9	9	14	12	11
90-99	31	28	30	22	19	19	25	23	23
100-109	25	19	19	26	23	22	26	21	21
110-119	15	19	19	27	29	27	23	25	24
120-129	2	6	6	9	15	15	7	12	12
All adults									
70-79	9	13	13	5	7	9	6	9	10
95% CI:	(8,11)	(11,15)	(11,15)	(5,6)	(6,7)	(8,10)	(6,7)	(8,10)	(9,11)
80-89	19	17	13	12	10	9	14	12	11
90-99	30	28	28	20	18	17	24	22	21
100-109	24	18	21	25	21	21	25	20	21
110-119	16	20	19	27	29	28	23	25	25
120-129	3	5	6	10	16	15	8	12	12
Bases^d									
<i>Men</i>	<i>1016</i>	<i>599</i>	<i>516</i>	<i>2070</i>	<i>1559</i>	<i>1372</i>	<i>3086</i>	<i>2158</i>	<i>1888</i>
<i>Women</i>	<i>1295</i>	<i>823</i>	<i>839</i>	<i>2470</i>	<i>2011</i>	<i>1983</i>	<i>3765</i>	<i>2834</i>	<i>2822</i>
<i>All</i>	<i>2311</i>	<i>1422</i>	<i>1355</i>	<i>4540</i>	<i>3570</i>	<i>3355</i>	<i>6851</i>	<i>4992</i>	<i>4710</i>

^a The assessment process for the NART is described in Chapter 2.^b The NART cannot be used to predict V-IQ scores below 70; it is likely that this group includes people who would score less than 70 using a fuller assessment.^b Figures in brackets indicate 95% confidence intervals.^c The 2000 analysis excludes those participants living in Scotland and Wales, which were in scope in that survey. 2007 and 2014 were England only.

Table 2.3 Self-identified 'difficulty learning or intellectual impairment', by age and sex

All adults

2014

Learning disability reported	Age							All
	16-24	25-34	35-44	45-54	55-64	65-74	75+	
	%	%	%	%	%	%	%	%
Men								
Present	8	9	5	6	5	3	2	6
Women								
Present	7	4	4	2	2	1	1	3
All adults								
Present ^a	7	6	4	4	3	2	1	4
Bases								
Men	249	355	467	489	541	537	418	3056
Women	311	680	712	805	685	651	644	4488
All	560	1035	1179	1294	1226	1188	1062	7544

^a Presence of self-reported 'difficulty learning or intellectual disability' varied with age ($p < 0.001$).

Table 2.4 Severity of self-identified difficulty learning or intellectual impairment, by age and sex

Adults reporting 'a difficulty learning or an intellectual impairment'

2014

Severity of intellectual impairment ^a	Age			All
	16-34	35-54	55+	
	%	%	%	%
Men				
Mild	51	45	39	47
Moderate	30	44	33	35
Severe	19	11	28	18
Women				
Mild	46	42	^b	46
Moderate	44	30	^b	39
Severe	10	27	^b	15
All adults^c				
Mild	49	44	43	46
Moderate	36	40	35	37
Severe	15	16	21	17
Bases				
Men	48	52	51	151
Women	54	41	31	126
All	102	93	82	277

^a Relates to self-reported level of severity among adults reporting that they have 'a difficulty learning or an intellectual impairment'.

^b Base below 40, and so results not shown.

^c No statistically significant association between severity of intellectual impairment and age or sex, among adults reporting an impairment.

Table 2.5 Self-identified difficulty learning or intellectual impairment, by predicted verbal IQ and sex

Adults whose first language is English

2014

Learning or intellectual impairment reported	Verbal IQ score						All
	70-79 ^a	80-89	90-99	100-109	110-119	120-129	
	%	%	%	%	%	%	%
Men							
Present	24	10	5	3	1	2	6
Women							
Present	16	4	4	2	1	0	3
All adults							
Present ^b	21	7	4	2	1	1	5
<i>Bases</i>							
<i>Men</i>	328	270	475	557	733	449	2812
<i>Women</i>	342	432	840	860	997	592	4063
<i>All</i>	670	702	1315	1417	1730	1041	6875

^a The NART cannot be used to predict V-IQ scores below 70; it is likely that this group includes people who would score less than 70 using a fuller assessment.

^b The presence of a self-reported learning disability varied by both predicted verbal IQ score ($p < 0.001$) and sex ($p < 0.001$). There was no significant interaction.

Table 2.6 Combined indicator based on self-identified impairment, predicted verbal IQ and highest educational qualification, by age and sex

Adults whose first language is English

2014

Combined indicator present ^a	Age							All
	16-24	25-34	35-44	45-54	55-64	65-74	75+	
	%	%	%	%	%	%	%	%
Men								
Present	15	14	10	12	12	14	15	13
Women								
Present	11	9	8	8	8	10	14	9
All adults								
Present ^b	13	11	9	10	10	12	15	11
<i>Bases</i>								
<i>Men</i>	249	355	468	489	541	538	418	3058
<i>Women</i>	311	680	712	805	685	651	644	4488
<i>All</i>	560	1035	1180	1294	1226	1189	1062	7546

^a Combination of either a) predicted verbal IQ of less than 85 and highest educational qualification is GCSE/O level or below, or b) self-identified with 'a difficulty learning or intellectual impairment' and highest educational qualification is GCSE/O level or below. The higher (and more widely used) V-IQ threshold of below 85 is used for this indicator as it is combined with other criteria.

^b The presence of intellectual impairment (defined as above) varied by both age ($p < 0.001$) and sex ($p < 0.001$).

3 Comorbidity with mental health

Summary

People with intellectual impairment were more likely than the rest of the population to have a mental disorder. This increased risk was evident for the majority of different types of mental disorders assessed, but not for alcohol dependence.

A quarter of people (24%) with a V-IQ of less than eighty had a common mental disorder (CMD) such as anxiety disorder or depression, compared with 17% of the adult population as a whole.

Rates of severe mental illnesses, such as psychotic disorder and bipolar disorder, were about twice as high in people with intellectual impairment as in the wider population.

Patterns of association between intellectual impairment and mental health were similar for men and women (that is, there were no statistically significant interactions). However two disorders stood out as being particularly prominent in men or in women with intellectual impairment.

Women with intellectual impairment were about three times more likely to test positive for PTSD (15%) than women in the population as a whole (5%).

Men with intellectual impairment were about five times more likely to test positive for problem gambling (5%) than men in the population as a whole (1%).

3.1 Background

There is a consistent body of research showing that mental disorders, as well as symptoms of mental disorder, are more common across the lifespan in people with intellectual impairment. IQ is associated with the prevalence of several mental disorders and may be part of a common pathway in the aetiology of several disorders and conditions, such as autism and psychotic disorders, which are currently thought to have an inter-related developmental underpinning (Owen, 2012).

Hughes-McCormack et al. (2018) found a seven-fold increase in mental disorders in those self-reporting an intellectual disability; Hassiotis et al. (2017) found hallucinations and delusions to be more common in adults with borderline intellectual functioning using data from the APMS 2007; Hassiotis et al. (2008) showed that adults with borderline intellectual functioning had increased rates of neurotic disorders, substance misuse and personality disorders. Rai et al. (2013) examined problem gambling in adults, and reported two-fold adjusted odds with each standard deviation drop in verbal IQ.

The APMS series has facilitated the investigation of prevalence and trends of a range of mental disorders in people with intellectual impairment and comparisons with the population without

intellectual impairment. This information is pivotal for the development of services and identification of need.

3.2 Definitions and methods

A range of different types of mental disorder were assessed in the APMS. These are listed in the table below, along with references for the assessment or testing tool used. Some of the conditions were tested for (which tends to result in a high prevalence), and others were assessed using diagnostic criteria (assumed to be more robust). The reference period also varied: common mental disorders were assessed as present in the past week, while probable psychotic disorder related to presence in the past year. Further details are provided below.

Summary of mental disorders covered and their assessment			
Mental disorder	Diagnostic status	Assessment tool used	Reference period
Common mental disorders			
Generalised anxiety disorder (GAD)	Present to diagnostic criteria	CIS-R (Lewis <i>et al.</i> 1992)	Past week
Obsessive and compulsive disorder (OCD)	Present to diagnostic criteria	CIS-R	Past week
Depressive episode	Present to diagnostic criteria	CIS-R	Past week
Panic disorder	Present to diagnostic criteria	CIS-R	Past week
Phobia	Present to diagnostic criteria	CIS-R	Past week
CMD not otherwise specified (NOS)	Present to diagnostic criteria	CIS-R	Past week
Other mental disorders and conditions			
Attention-deficit/ hyperactivity disorder (ADHD)	Test positive	Adult Self-Report Scale-v1.1 (ASRS) (WHO, 2003)	Past six months
Autism	Present to diagnostic criteria	ADOS and AQ20	Lifetime
Bipolar disorder	Test positive	Mood Disorder Questionnaire (Hirschfield <i>et al.</i> 2000)	Lifetime
Eating disorder	Test positive	SCOFF (Morgan <i>et al.</i> 1999)	Past year
Personality disorder	Test positive	SAPAS (Moran <i>et al.</i> 2003)	Lifetime
Posttraumatic stress disorder (PTSD)	Test positive	PTSD Check List- civilian (PCL-C) (Blanchard <i>et al.</i> 1996)	Past week
Problem gambling	Test positive	Based on DSM	Past year
Psychotic disorder	Present to diagnostic criteria	SCAN (WHO, 1999)	Past year
Substance dependence disorders			
Alcohol use disorders	Test positive	AUDIT (Saunders <i>et al.</i> 1993);	Past six

		SADQ-C (Stockwell <i>et al.</i> 1994)	months
Drug dependence	Test positive	Based on Diagnostic Interview Schedule (Malgady <i>et al.</i> 1992)	Past year

Common mental disorders (CMDs)

CMDs cause marked emotional distress and interfere with daily function, although they do not usually have major sustained effects on insight or cognition. CMDs comprise different types of depression and anxiety. Symptoms of depressive episodes include low mood and a loss of interest and enjoyment in ordinary things and experiences. They impair emotional and physical wellbeing and behaviour. OCD is characterised by a combination of obsessive thoughts and compulsive behaviours. Obsessions are defined as recurrent and persistent thoughts, impulses or images that are experienced as intrusive and inappropriate, are resisted, and cause marked anxiety or distress. Compulsions are repetitive, purposeful and ritualistic behaviours or mental acts, performed in response to obsessive intrusion and to a set of rigidly prescribed rules (NICE 2006).

Specific CMDs and symptoms of CMD were assessed using the Clinical Interview Schedule – Revised (CIS-R). The CIS-R is an interviewer administered structured interview schedule covering the presence of non-psychotic symptoms in the week prior to interview. It can be used to provide prevalence estimates for six types of anxiety disorder and depression. Anxiety disorders include generalised anxiety disorder (GAD), panic disorder, phobias, and obsessive compulsive disorder (OCD). A further category of CMD not otherwise specified (CMD-NOS) is identified by the CIS-R. This identifies people with significant level of symptoms but not meeting the specific diagnostic criteria for the other disorders. Symptoms of depression and anxiety frequently co-exist, with the result that many people meet criteria for more than one CMD (Lewis *et al.* 1992).

Other mental disorders and substance dependences:

Attention-deficit/hyperactivity disorder (ADHD) is a complex neurodevelopmental disorder which starts in childhood and often persists into adulthood. Adult ADHD is often unrecognised or misdiagnosed by professionals. It is associated with significant impairment and adverse outcomes, including premature mortality. The survey included the six-item Adult ADHD Self-Report Scale (ASRS) testing tool for adult ADHD. The test assesses ADHD characteristics of inattention, hyperactivity and impulsivity during the six months prior to interview. A score of 4 or more constituted a positive test for ADHD.

Autism spectrum disorder (hence forth referred to as Autism) is a developmental disorder characterised by impaired social interaction and communication, severely restricted interests, and highly repetitive behaviours (Brugha 2016). In the phase one APMS interview, autism was tested for using the Autism Quotient (AQ-20). In the phase two interview, detailed assessments were carried out by clinically trained interviewers using the previously population validated (Brugha *et al.* 2012) Autism Diagnostic Observation Schedule (ADOS, module 4) with a subset of participants with an AQ test score of 4 or more. The results were weighted to generate a prevalence estimate for the population as a whole. The recommended threshold of a score of 10 or more on the phase two ADOS assessment was used to identify autism.

Bipolar disorder is a common, lifelong, mental health condition characterised by recurring episodes of depression and mania. The 15-item Mood Disorder Questionnaire is a positive test requiring endorsement of at least seven lifetime manic/hypomanic symptoms, as well as several co-occurring symptoms, together with moderate or serious functional impairment. A positive test indicated the likely presence of bipolar disorder and that fuller assessment would be warranted.

Eating disorders include a variety of types of disordered eating and range greatly in severity. The SCOFF testing tool for eating disorders was administered as part of the self-completion section of the interview. Endorsement of two or more items represented a positive test for eating disorder. This threshold indicates that clinical assessment for eating disorder is warranted.

Personality disorders are longstanding, ingrained distortions of personality that interfere with the ability to make and sustain relationships. Personality disorder is characterised by core interpersonal dysfunction and the presence of a range of adaptive and maladaptive traits. A general personality disorder test (the SAPAS) was included in APMS 2014 to test adults of all ages for 'any personality disorder' (PD).

Posttraumatic stress disorder (PTSD) Some individuals who experience trauma go on to develop PTSD. PTSD is a severe and disabling condition, characterised by flashbacks, nightmares, avoidance, numbing and hypervigilance. Participants completed the 17-item PTSD Checklist – Civilian (PCL-C) in the self-completion part of the interview. Those with a score of 50 or more and meeting Diagnostic Statistical Manual (DSM) criteria for PTSD were identified as testing positive for PTSD. A positive test did not mean that a disorder was necessarily present, only that there were sufficient symptoms to warrant further investigation.

Problem gambling is gambling to a degree that compromises, disrupts or damages family relationships, personal wellbeing and functioning, or recreational pursuits. The problem gambling test used on APMS 2007 is based on the DSM-IV criteria. The DSM-IV criteria endorsed were summed to generate a score. Those who had not gambled in the past year were given a score of zero. A score of three or more was used to identify 'problem gambling'.

Psychotic disorders produce disturbances in thinking and perception that are severe enough to distort perception of reality. The main types are schizophrenia and affective psychosis. Participants were identified with 'probable psychotic disorder in the past year' if they completed a phase two SCAN (Schedule for Clinical Assessment in Neuropsychiatry) interview and it was positive, or, if they did not complete a SCAN interview, met two of the psychosis testing criteria, such as currently taking antipsychotic medication or hearing voices.

Alcohol dependence - the Alcohol Use Disorders Identification Test (AUDIT) (Saunders et al. 1993) takes the year before the interview as a reference period, consists of 10 items and covers: alcohol consumption (frequency of drinking, typical quantity, frequency of heavy drinking); alcohol-related harm (feeling of guilt or remorse after drinking, blackouts, alcohol-related injury, other concern about alcohol consumption); and symptoms of alcohol

dependence (impaired control over drinking, increased salience of drinking, morning drinking). An AUDIT score of 16 or more was used to indicate signs of potential alcohol dependence.

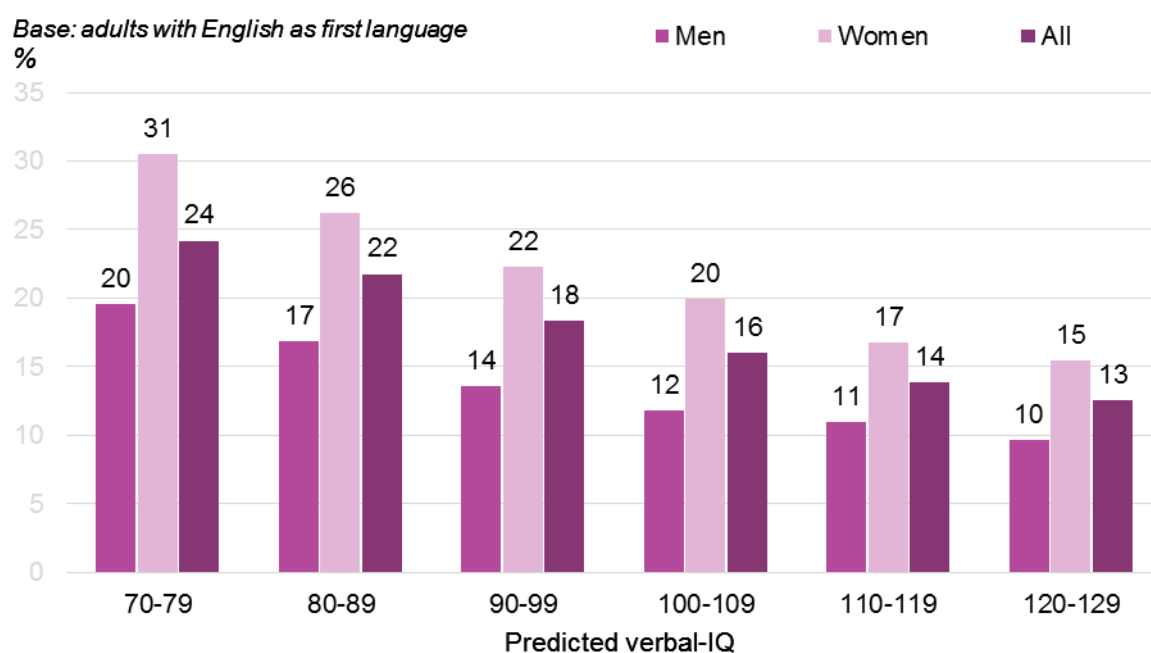
Drug dependence People who reported usage of particular drugs were asked about signs of dependence on that drug. The signs, or markers, asked about were: daily use for 2 weeks or more; having a sense of need or dependence; inability to abstain; increased tolerance, and withdrawal symptoms. Presence of at least one sign was used to indicate possible signs of drug dependence.

3.3 Comorbidity with mental health disorders

Most types of mental disorder assessed or tested for on APMS were found to be more common in people with intellectual impairment than in those without. There were no significant interactions with sex, which means that the pattern of association between intellectual impairment and mental disorder was generally similar for men and women. (Tables 3.1, 3.2 and 3.3)

A quarter (24%) of people with intellectual impairment (as indicated by a V-IQ of less than 80) had a CMD such as anxiety or depression, compared with 17% of the population as a whole. There was a linear association between V-IQ and CMD, with increases in V-IQ associated with reduced likelihood of CMD. All subtypes of CMD were higher in people with intellectual impairment than in people without, except for generalised anxiety disorder and phobias, where differences did not reach statistical significance. As in the population as a whole, CMD rates were higher in women with intellectual impairment (31%) than in their male counterparts (20%). (Table 3.1, Figure 3.1)

Figure 3.1: Common mental disorder, by predicted verbal IQ and sex



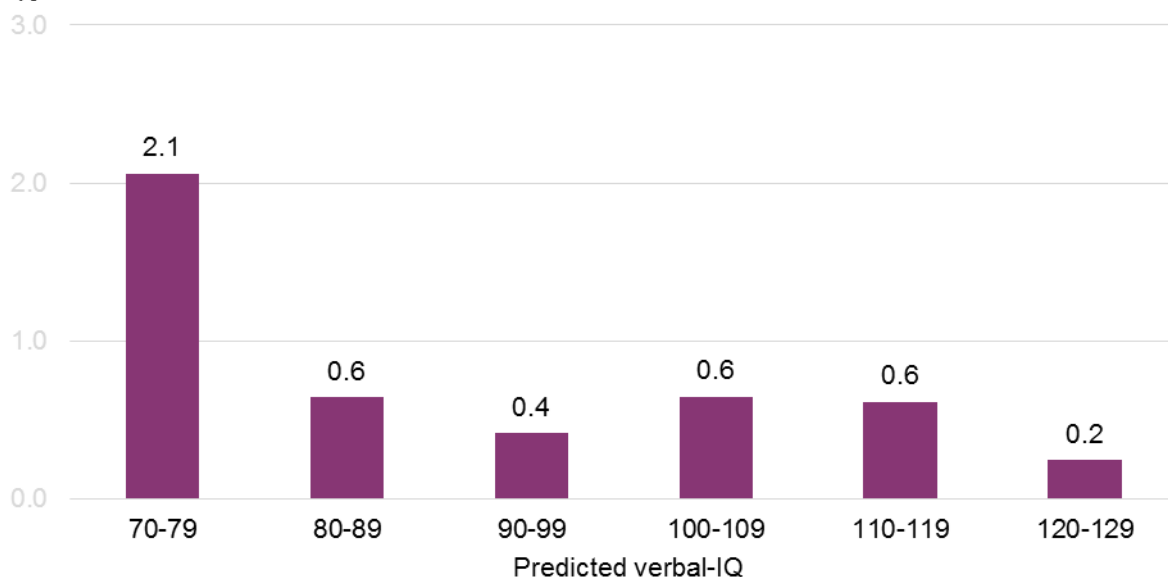
Similar patterns were observed for the other types of mental disorders and conditions included on the survey.

Among people with impairment, 4% tested positive for **bipolar disorder** and 2% for **probable psychotic disorders**, compared with 2% and 1% in the wider population respectively. (Figure 3.2)

Figure 3.2: Probable psychosis, by predicted verbal IQ

Base: adults with English as first language

%

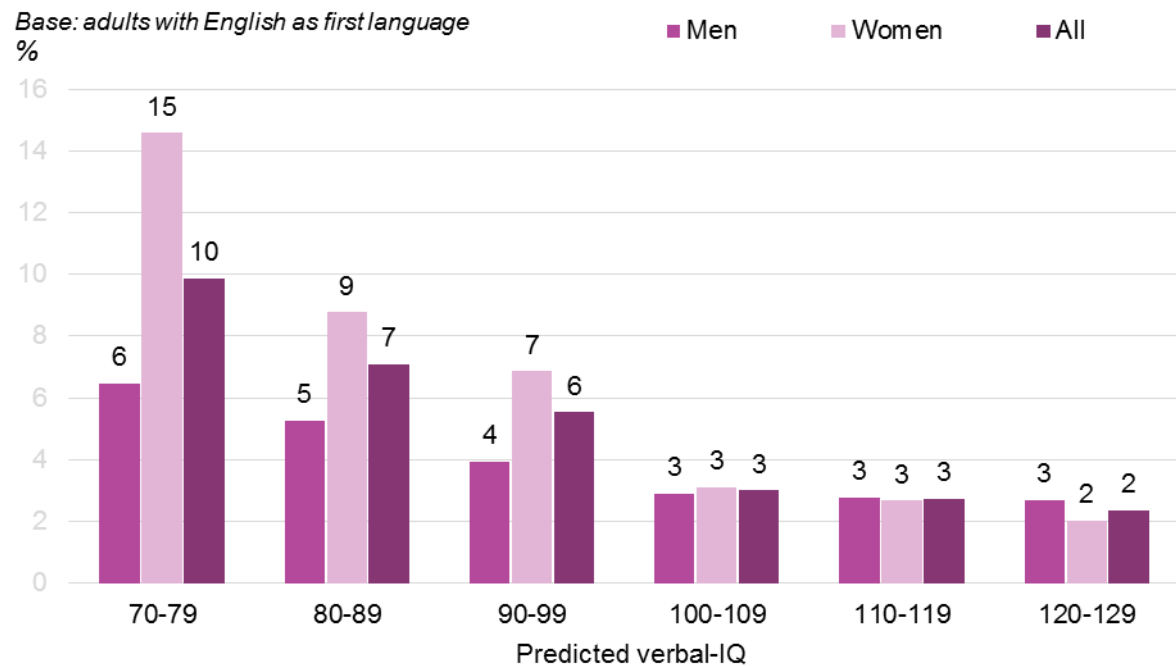


A positive test for **eating disorder** was present in 7% of those with intellectual impairment and 6% of the population as whole (a difference significant at $p=0.006$).

A quarter (23%) of people with intellectual impairment tested positive for a **personality disorder** (23% of both men and women), compared with 14% of the population as whole (13% of men, 14% of women).

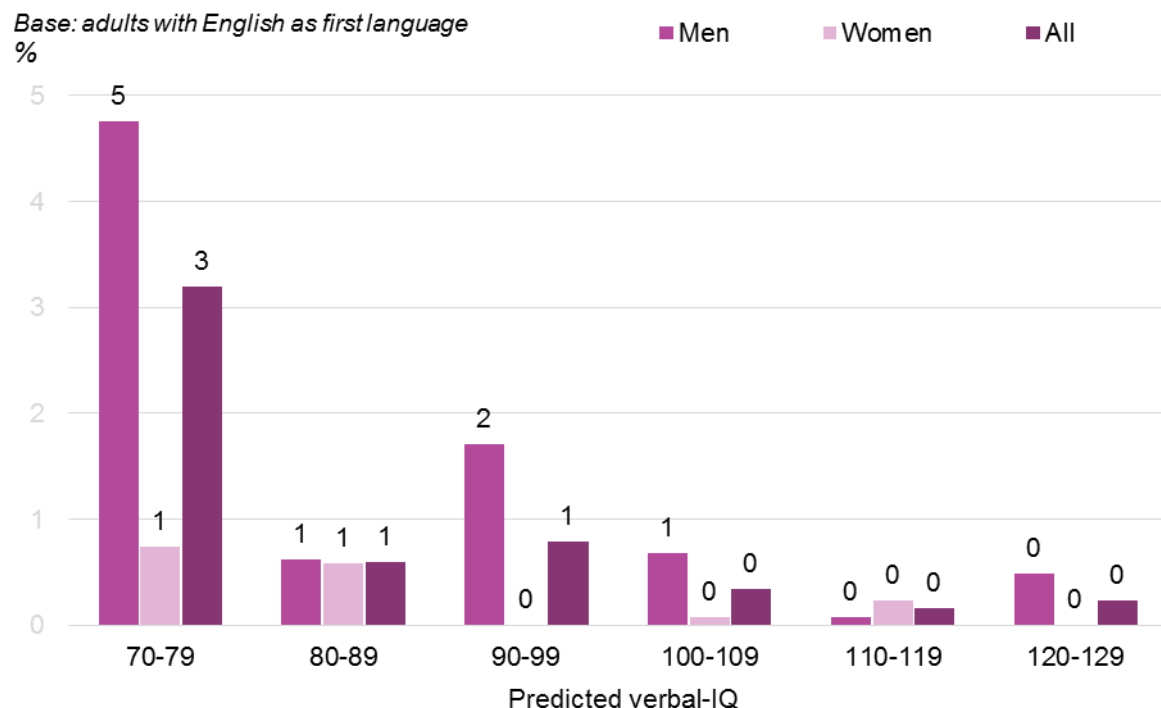
One in ten (10%) people with intellectual impairment tested positive for **post-traumatic stress disorder** (PTSD) (6% of men and 15% of women), compared with 4% of the population as whole (4% of men, 5% of women). (Figure 3.3)

Figure 3.3: PTSD test positive, by predicted verbal IQ and sex



3% of people with intellectual impairment tested positive for **problem gambling** (5% of men and 1% of women), compared with 1% of the population as a whole (1% of men and 0% of women). (Figure 3.4)

Figure 3.4: Problem gambling test positive, by predicted verbal IQ and sex



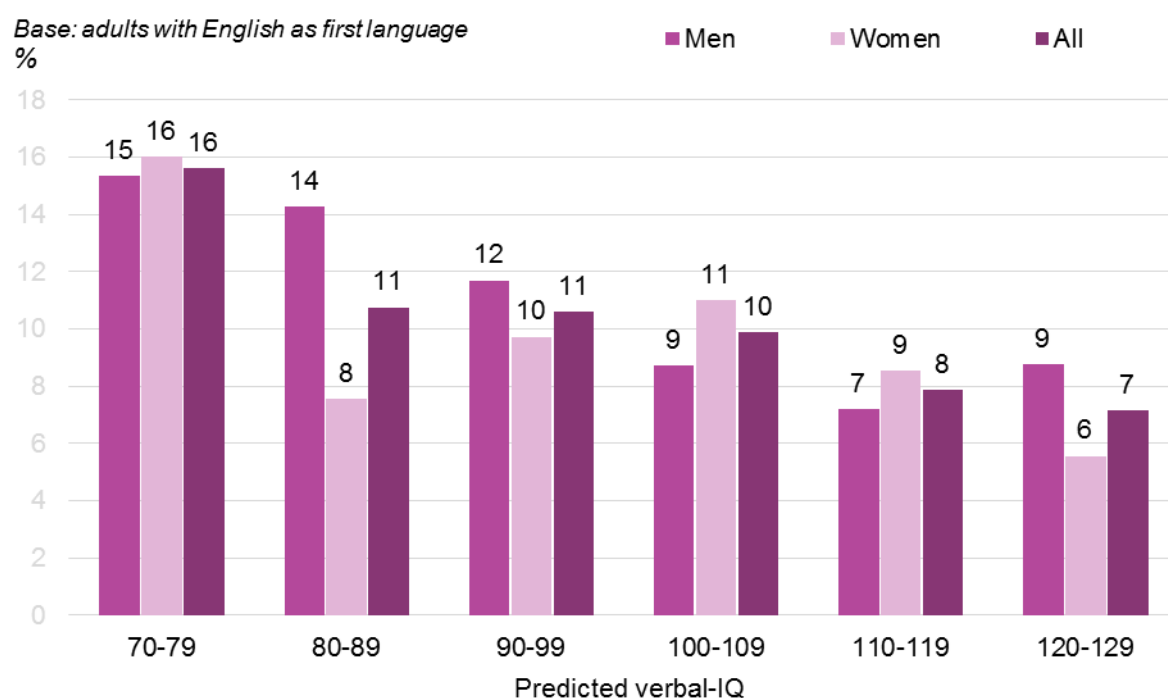
Alcohol dependence was not associated with intellectual impairment. This contrasted with signs of **drug dependence**: 5% of people with intellectual impairment reported signs of

dependence on drugs (7% of men, 2% of women), compared with 3% of the population as whole (4% men, 2% women).

Comorbidities were also identified between intellectual impairment and neurodevelopmental disorders.

Among people with intellectual impairment, 15% tested positive for **ADHD** (15% of men and 16% of women), compared with 10% in the population as a whole (10% of men and 9% of women). There was a broadly linear association, with increasing V-IQ linked with decreasing likelihood of ADHD. (Figure 3.5)

Figure 3.5: ADHD test positive, by predicted verbal IQ and sex



About 2% of people with intellectual impairment were identified with **autism** (3% of men and 0% of women), compared with 1% of the population as a whole (1% of men and 0% of women). There was a significant trend of association across the V-IQ range, but a test comparing those with a score of 70-79 with a combined group of those with a score of 80 or more did not reach significance.

3.4 Discussion

As expected, people with intellectual impairment were found to be more likely than the rest of the population to have a mental disorder. This increased risk was evident for the majority of different disorders assessed, although not for alcohol dependence. A quarter of people (24%) with intellectual impairment tested positive for a common mental disorder such as anxiety disorder or depression, compared with 17% of the adult population as a whole. This pattern was also identified by Rajput et al. (2011). Rates of severe mental illnesses, such as psychotic disorder and bipolar disorder, were about twice as high in people with intellectual impairment

than in the wider population. It is known that chronic mental illnesses like psychosis can lead to cognitive decline so part of this may be reverse causality.

Patterns of association between intellectual impairment and mental health were similar for men and women (that is, there were no statistically significant interactions). However two disorders stood out as perhaps having particular salience for men or for women with intellectual impairment.

Women with intellectual impairment were about three times more likely to test positive for PTSD (15%) than women in the population as a whole (5%). Studies of PTSD prevalence in people with intellectual impairment are scarce and the reported rates vary widely (Cooper et al. 2007). Therefore, this is a very important finding that also indicates that women with intellectual impairment may be more vulnerable than their male peers and women of average intelligence.

Men with intellectual impairment were about five times more likely to test positive for problem gambling (5%) than men in the population as whole (1%). Kalinowski (2007) explored problem and pathological gambling in 79 consecutive clinic attenders with intellectual impairment in Las Vegas, USA. They reported that 6.3% (n=5) met DSM-IV-TR criteria for problem gambling and 2.5% (n=2) for pathological gambling. The authors argue that the pervasive availability of opportunities and the setting enticed individuals with impaired cognitive abilities to engage in gambling. Such exposure has become commonplace with the advent of smartphone applications, online gambling sites and high street betting shops. Mental illness may also play a role in precipitating or maintaining problem gambling, including psychosis, severe depression or anxiety disorders. Such individuals should be prioritised when developing treatment programmes, at assessment of mental illness and also in advertising campaigns, the slogans of which may be misinterpreted by those with intellectual impairment.

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Tables

Table 3.1	Common mental disorders, by predicted verbal IQ and sex
Table 3.2	Other mental disorders, by predicted verbal IQ and sex
Table 3.3	Sift positive for problem gambling or eating disorder, by predicted verbal IQ and sex (APMS 2007)

Table 3.1 Common mental disorders, by predicted verbal IQ and sex*Adults whose first language is English*

2014

Mental health conditions ^b	Predicted verbal IQ ^a						All
	70-79 ⁱ	80-89	90-99	100-109	110-119	120-129	
	%	%	%	%	%	%	%
Men							
Any CMD	20	17	14	12	11	10	13
Generalised anxiety disorder	6	7	6	4	5	3	5
Depressive episode	5	2	3	3	2	3	3
Phobias	3	2	2	2	1	1	2
Obsessive compulsive disorder	1	2	1	2	0	0	1
Panic disorder	1	0	0	0	0	0	0
CMD NOS	9	8	6	6	4	4	6
Women							
Any CMD	31	26	22	20	17	15	21
Generalised anxiety disorder	9	9	7	7	5	7	7
Depressive episode	7	7	4	3	2	2	4
Phobias	7	6	3	2	2	2	3
Obsessive compulsive disorder	3	3	1	1	1	0	2
Panic disorder	0	1	1	1	1	1	1
CMD NOS	16	11	11	8	8	6	10
All adults							
Any CMD ^b	24	22	18	16	14	13	17
Generalised anxiety disorder ^c	8	8	7	6	5	5	6
Depressive episode ^d	6	5	3	3	2	2	3
Phobias ^e	5	4	3	2	1	1	2
Obsessive compulsive disorder ^f	2	3	1	2	1	0	1
Panic disorder ^g	0	1	0	1	1	1	1
CMD NOS ^h	12	10	8	7	6	5	8
Bases							
Men	329	270	475	557	734	449	2814
Women	342	432	840	860	997	592	4063
All	671	702	1315	1417	1731	1041	6877

^a Predicted verbal IQ was based on the National Adult Reading Test. The NART cannot be used to predict V-IQ scores below 70; it is likely that this group includes people who would score less than 70 using a fuller assessment.

^b Any CMD varied by both predicted verbal IQ ($p<0.001$) and sex ($p<0.001$).

^c Generalised anxiety disorder did not vary by predicted verbal IQ, but did vary by sex ($p=0.014$).

^d Depressive episodes varied by predicted verbal IQ ($p<0.001$) (but not sex).

^e Phobias varied by both predicted verbal IQ ($p<0.001$) and sex ($p<0.003$).

^f Obsessive compulsive disorder (OCD) varied by both predicted verbal IQ ($p<0.001$) and sex ($p<0.001$).

However, when significance testing was carried out using a binary V-IQ score indicator, the association with OCD no longer reached statistical significance.

^g Panic disorder did not vary by predicted verbal IQ or sex.

^h CMD not otherwise specified varied by both predicted verbal IQ ($p<0.001$) and sex ($p<0.001$).

Table 3.2 Other mental disorders, by predicted verbal IQ and sex*Adults whose first language is English*

2014

Mental health conditions ^b	Predicted verbal IQ ^a						All
	70-79	80-89	90-99	100-109	110-119	120-129	
	%	%	%	%	%	%	%
Men							
PTSD test positive	6	5	4	3	3	3	4
Probable psychotic disorder	1	0	0	1	1	0	1
Autism	3	1	1	0	1	2	1
Personality disorder (SAPAS)	23	12	13	12	12	10	13
ADHD test positive	15	14	12	9	7	9	10
Bipolar disorder test	5	1	3	2	1	2	2
Alcohol: AUDIT score 16+	7	6	3	4	5	5	5
Drug dependence signs	7	7	5	3	2	2	4
Women							
PTSD test positive	15	9	7	3	3	2	5
Probable psychotic disorder	3	1	1	0	1	0	1
Autism	0	0	0	0	0	0	0
Personality disorder (SAPAS)	23	19	19	12	10	7	14
ADHD test positive	16	8	10	11	9	6	9
Bipolar disorder test	4	2	2	2	2	0	2
Alcohol: AUDIT score 16+	2	2	3	2	2	1	2
Drug dependence signs	2	6	2	2	1	1	2
All adults							
PTSD test positive ^c	10	7	6	3	3	2	4
Probable psychotic disorder ^d	2	1	0	1	1	0	1
Autism ^e	2	0	0	0	1	1	1
Personality disorder (SAPAS) ^f	23	15	16	12	11	9	14
ADHD test positive ^g	16	11	11	10	8	7	10
Bipolar disorder test ^h	4	1	2	2	2	1	2
Alcohol: AUDIT score 16+ ⁱ	5	4	3	3	3	3	3
Drug dependence signs ^j	5	6	3	3	2	2	3
Bases							
<i>Men</i>	284	253	457	531	703	435	2877
<i>Women</i>	292	403	795	816	960	558	4184
<i>All</i>	576	656	1252	1347	1663	993	7061

^a See Chapter 2 for description of how predicted verbal IQ was derived from the NART.^b Mental health conditions tested for or assessed on APMS 2014.^c Positive PTSD test varied with both predicted verbal IQ ($p < 0.001$) and sex ($p < 0.007$).^d Probably psychotic disorder varied with predicted verbal IQ ($p < 0.048$).^e Autism varied with predicted verbal IQ ($p < 0.001$) in terms of a trend across the six V-IQ groups.

However, when significance testing was carried out using a binary V-IQ score indicator, the association with autism no longer reached statistical significance

^f Personality disorder varied with predicted verbal IQ ($p < 0.001$).^g ADHD varied with predicted verbal IQ ($p < 0.001$)^h Bipolar disorder varied with predicted verbal IQ ($p < 0.011$).ⁱ Positive alcohol dependence tests varied with sex ($p < 0.001$) but not predicted verbal IQ ($p = 0.442$).^j Signs of drug dependence varied with both verbal IQ ($p < 0.001$) and sex ($p < 0.001$).

Table 3.3 Test positive for eating disorder or problem gambling, by predicted verbal IQ and sex

Adults whose first language is English

2007

Mental health conditions ^b	Predicted verbal IQ ^a						All
	70-79	80-89	90-99	100-109	110-119	120-129	
	%	%	%	%	%	%	%
Men							
Eating disorder test	5	4	3	4	3	2	4
Problem gambling	5	1	2	1	0	0	1
Women							
Eating disorder test	9	14	9	9	8	6	9
Problem gambling	1	1	0	0	0	0	0
All adults							
Eating disorder test ^c	7	9	7	7	6	4	6
Problem gambling ^d	3	1	1	0	0	0	1
<i>Bases - eating disorder</i>							
<i>Men</i>	307	335	571	541	765	427	2946
<i>Women</i>	267	466	835	814	1002	524	3908
<i>All</i>	574	801	1406	1355	1767	951	6854
<i>Bases - problem gambling</i>							
<i>Men</i>	301	314	546	513	728	397	2799
<i>Women</i>	249	428	790	755	932	502	3656
<i>All</i>	550	742	1336	1268	1660	899	6455

^a Predicted verbal IQ was based on the National Adult Reading Test.

^b Mental health conditions tested for on APMS 2007, but not APMS 2014.

^c Testing positive for an eating disorder (SCOFF score 2+) varied by predicted verbal IQ ($p=0.006$) and sex ($p<0.001$).

^d Testing positive for problem gambling varied by predicted verbal IQ ($p<0.001$) and sex ($p<0.001$).

4 Comorbidity with physical health problems, sensory impairment and disability

Summary

People with intellectual impairment were more likely to experience a wide range of different aspects of poor physical health and functioning. They were more likely to:

- Rate their general health as poor
- Need help with activities of daily living
- Be limited in day to day activities due to sensory impairments.

Among people needing assistance with activities of daily living, those with intellectual impairment were somewhat more likely to receive assistance. This, however, is probably explained entirely by their overall level of greater need.

4.1 Background

People with intellectual impairment are likely to suffer multiple morbidity (Cooper et al. 2015) and general ill-health, physical disability, and mental ill-health in this group are closely associated (Deb et al. 2001; Hughes-McCormack et al. 2017). People with intellectual impairment are more likely to die from preventable causes (Heslop et al. 2014), and frequently report difficulties accessing health services (Ali et al. 2013).

4.2 Definitions and methods

Physical health, disability and functional impairments were assessed using a range of different measures:

General health People were asked to rate their general health on a five point scale, from excellent to poor.

Chronic physical health conditions APMS participants were presented with a list of 22 physical conditions (or categories of physical illness) and were asked which they had ever had; which they had had in the past year; whether the condition had been diagnosed by a health professional; and if they received any medication or other treatment for it. It should be noted that self-report data on diagnosed conditions are subject to participants being aware of and recalling that a diagnosis has been made, which could lead to under-identification. The extent of under (or indeed, over-) reporting could have varied by V-IQ. Five chronic physical health conditions were combined to form the derived variable analysed in this chapter: asthma, cancer, diabetes, epilepsy, and high blood pressure.

Disability: Activities of Daily Living (ADL) A number of different activities of daily living (ADL) were asked about. These are the activities that people need to perform on a daily basis to live independently. The survey included both basic ADLs (fundamental self-care tasks such as washing, dressing, toileting, and mobility) and instrumental ADLs (which enable someone to live independently in the community, like cleaning the home, managing money, preparing meals, shopping and taking prescribed medicines). Because some types of ADLs may be more likely to be problematic for people with intellectual impairment than others, each ADL is analysed separately:

- Personal care such as dressing
- Getting out and about or using transport
- Medical care such as taking medicines or pills, having injections or changes of dressing
- Household activities like preparing meals, shopping, laundry, and household
- Practical activities such as gardening, decorating, or doing household repairs
- Dealing with paperwork such as writing letters, sending cards or filing forms
- Managing money, such as budgeting for food or paying bills

Everyone reporting difficulty with at least one ADL was asked whether they received any required assistance.

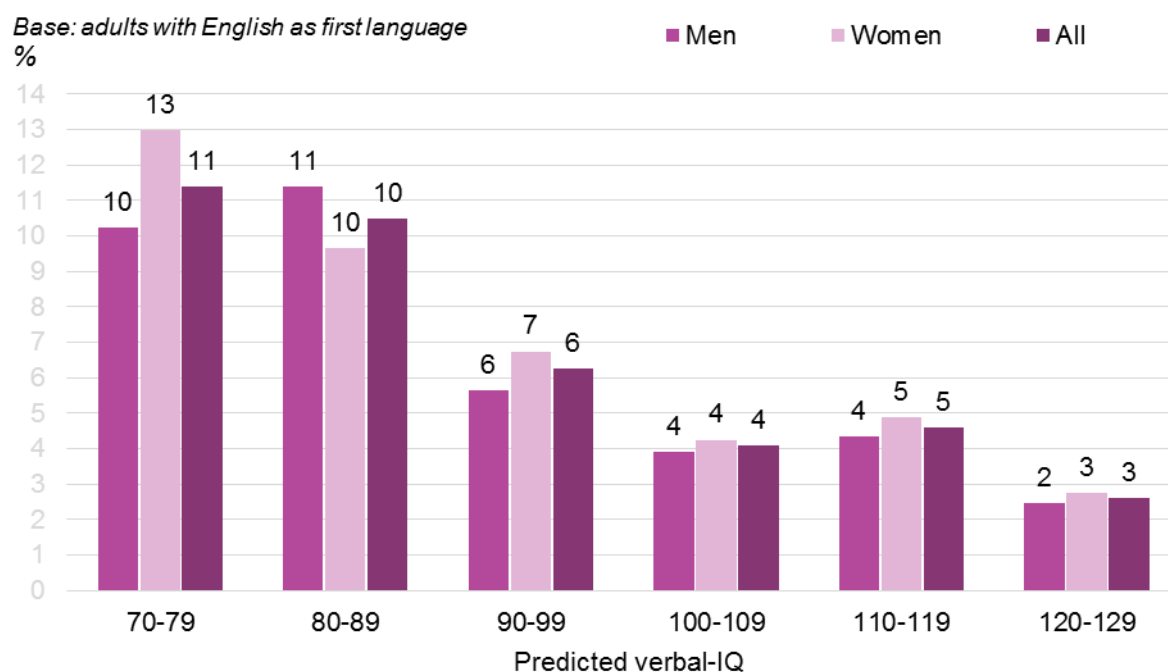
Sensory impairment Questions were asked of all participants about sight loss (ability to read newsprint at arms' length or to recognise someone across the road, with glasses if used) and about hearing loss (including whether or not hearing aids are used). Where sensory impairments were reported, level of impact on daily life was asked. Sensory impairments were examined using derived variables relating to the extent to which activities are limited.

4.3 Comorbidity with health

One in nine (11%) people with intellectual impairment described their **general health** as 'poor' (13% of women, 10% of men) compared with 6% of people in the population as whole (6% of both men and women). (Table 4.1; Figure 4.1)

A third (33%) of people with intellectual impairment report presence of at least one of five **chronic health conditions** - asthma, cancer, diabetes, epilepsy, and high blood pressure – in the past 12 months. This was slightly higher than the rate for the population as a whole (29%) when the statistical significance test examined a trend across the six V-IQ score groups. However, when people with a V-IQ score of 70-79 were just compared with those with a score of 80 or more, the difference no longer reached statistical significance ($p=0.054$). (Table 4.2)

Figure 4.1: Self-reports general health as 'poor', by predicted verbal IQ and sex



4.4 Comorbidity with disability

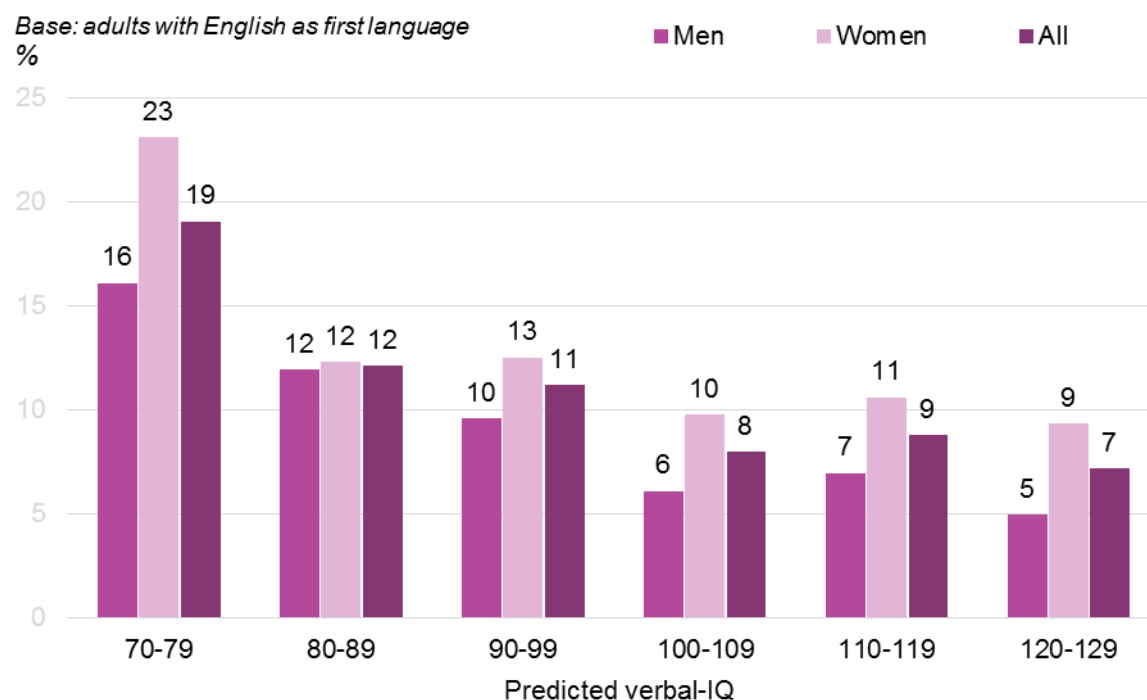
People with an intellectual impairment were more likely than the population as a whole to report difficulties with each of the seven types of activity of daily level asked about. 12% of people with an intellectual impairment report having at least some difficulty with **personal care** such as dressing, compared with 7% of the population as a whole. (Table 4.3; Figure 4.2)

Figure 4.2: Difficulty with personal care, by predicted verbal IQ and sex



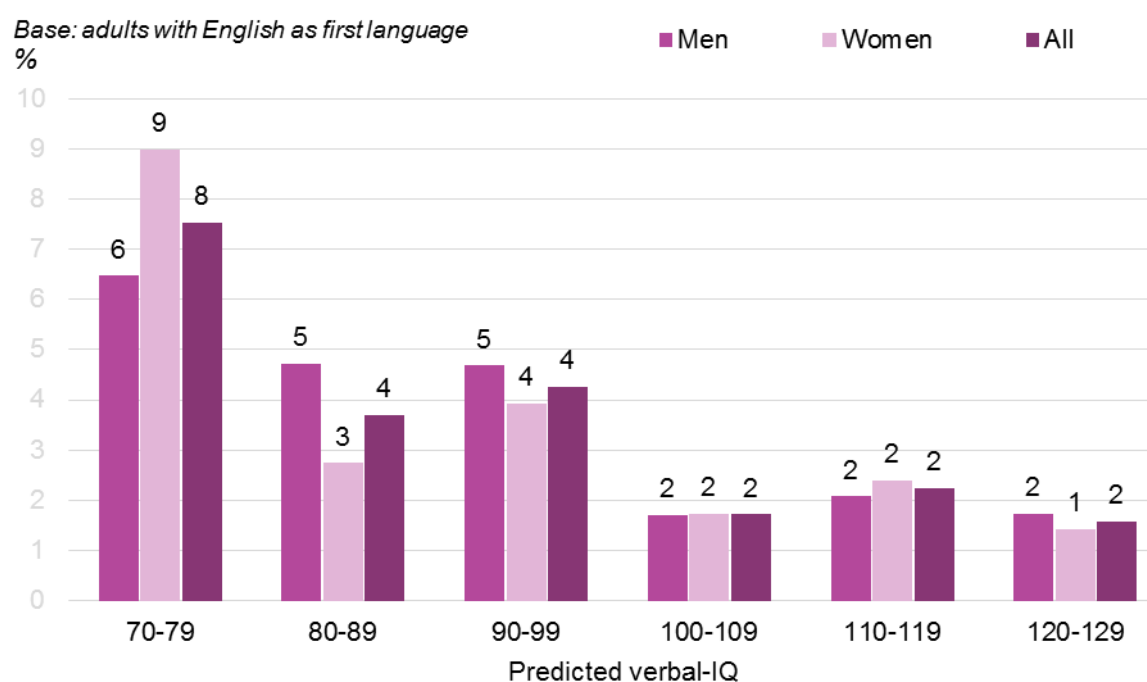
19% of people with an intellectual impairment reported having at least some difficulty with **getting out and about** or using transport, compared with 10% of the population as a whole. (Table 4.4; Figure 4.2)

Figure 4.2: Difficulty getting out and about, by predicted verbal IQ and sex



8% of people with an intellectual impairment reported having at least some difficulty with **medical care** such as taking medicines or pills, having injections or changes of dressing, compared with 3% of the population as a whole. (Table 4.5; Figure 4.3)

Figure 4.3: Difficulty with medical care, by predicted verbal IQ and sex

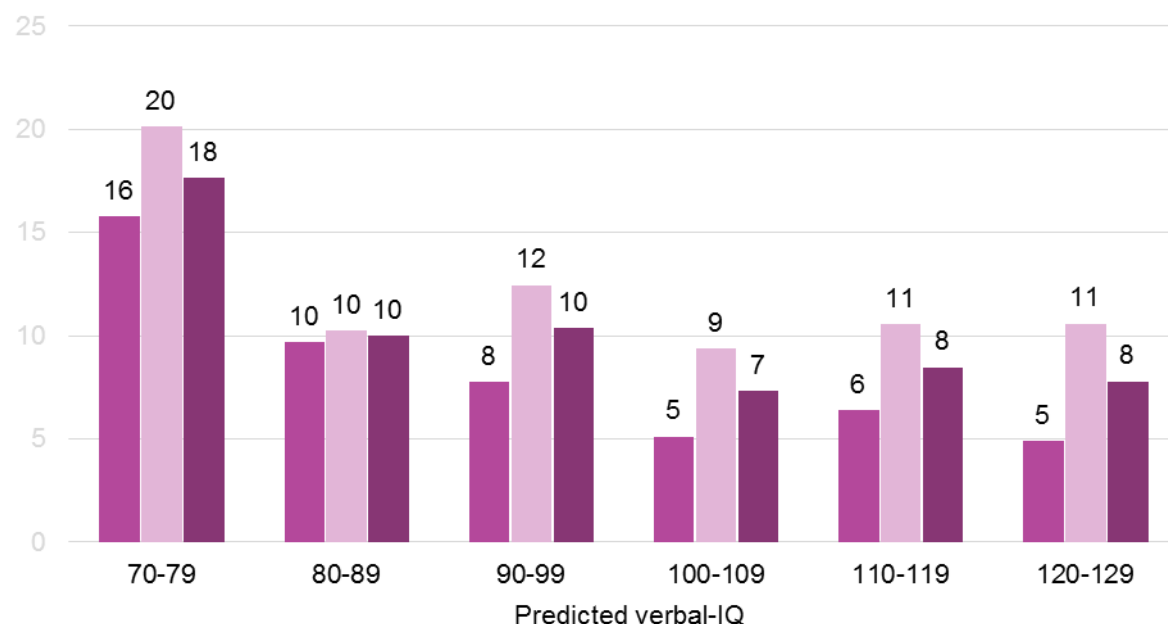


18% of people with an intellectual impairment reported having at least some difficulty with **household activities** like preparing meals, shopping, laundry, and household, compared with 10% of the population as a whole. (Table 4.6; Figure 4.4)

Figure 4.4: Difficulty with household activities, by predicted verbal IQ and sex

Base: adults with English as first language
%

Men Women All

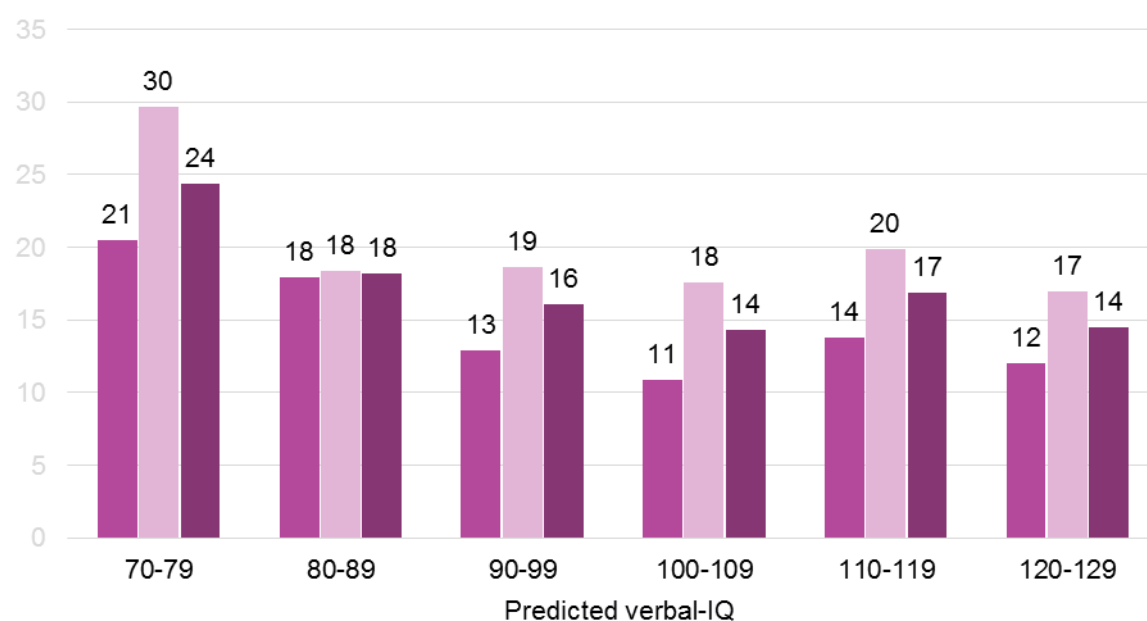


24% of people with an intellectual impairment reported having at least some difficulty with **practical activities** such as gardening, decorating, or doing household repairs, compared with 17% of the population as a whole. (Table 4.7; Figure 4.5)

Figure 4.5: Difficulty with practical activities, by predicted verbal IQ and sex

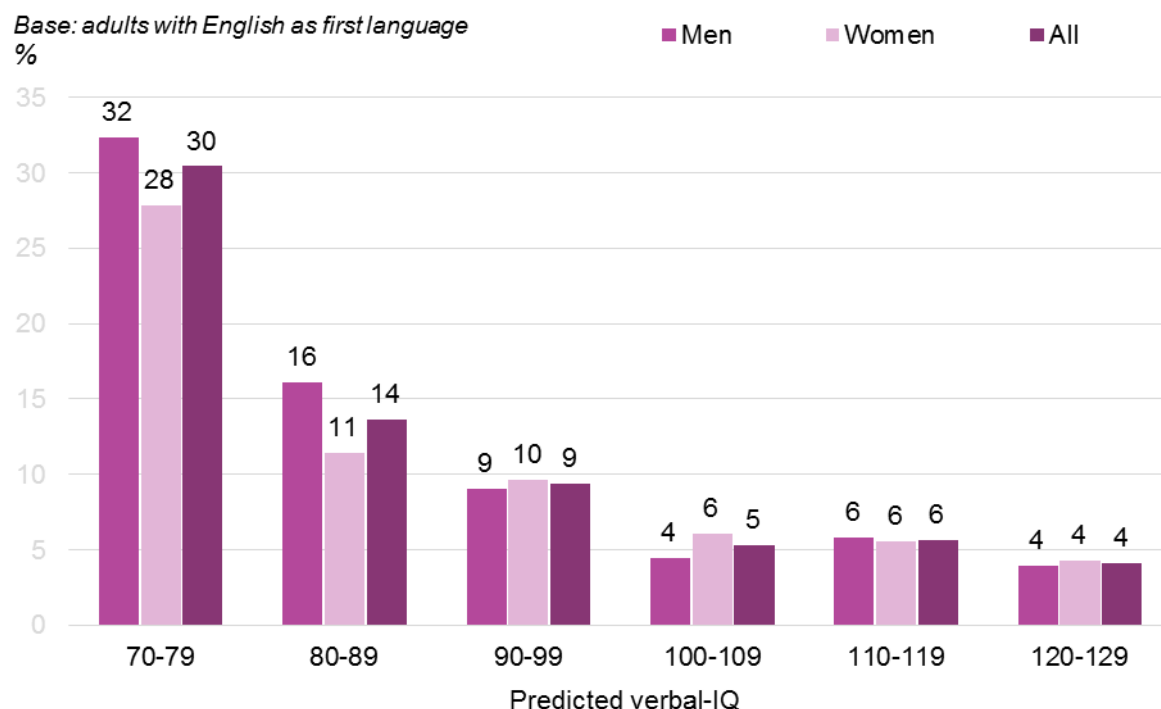
Base: adults with English as first language
%

Men Women All



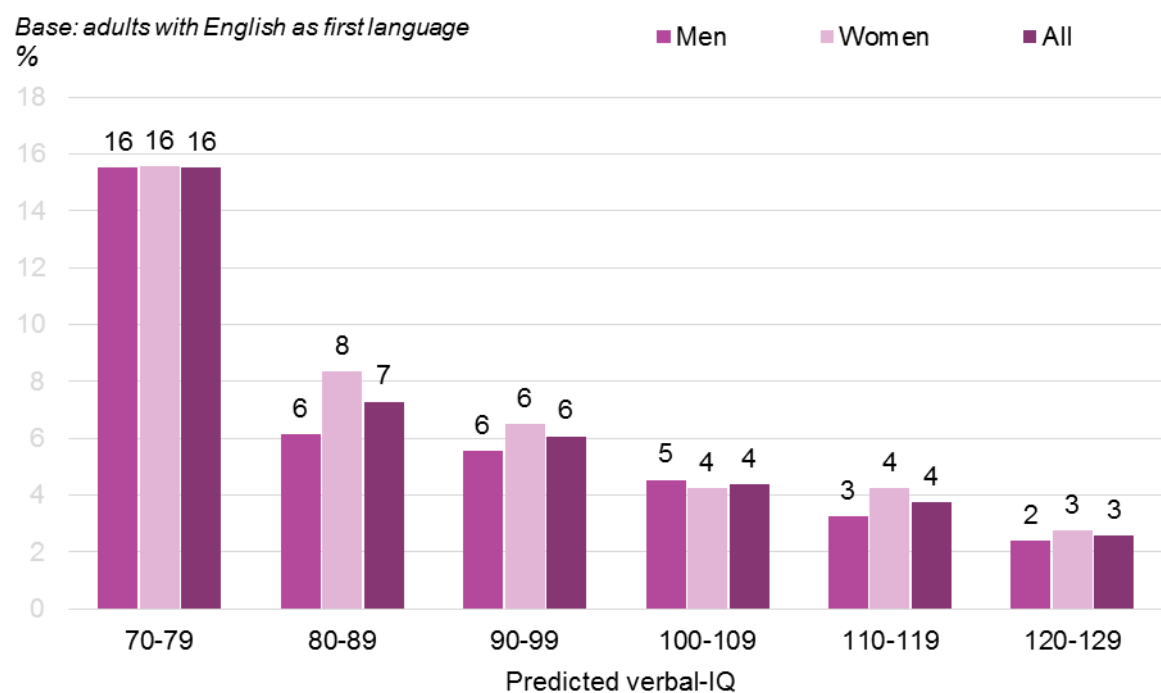
30% of people with an intellectual impairment reported having at least some difficulty dealing with **paperwork** such as writing letters, sending cards or filing forms, compared with 9% of the population as a whole. (Table 4.8; Figure 4.6)

Figure 4.6: Difficulty with paperwork, by predicted verbal IQ and sex



16% of people with an intellectual impairment reported having at least some difficulty **managing money**, such as budgeting for food or paying bills, compared with 6% of the population as a whole. (Table 4.9; Figure 4.7)

Figure 4.7: Difficulty managing money, by predicted verbal IQ and sex



The activities for which the gap was most pronounced between those with an intellectual impairment and the rest of the population related to administrative tasks like dealing with paperwork and managing money; and arranging medical care. For these, people with intellectual impairment were about three times more likely than the rest of the population to need assistance.

Among those who reported that they had difficulty with at least one activity, three quarters (77%) of people with intellectual impairment reported that they got assistance for these activities, compared with two thirds of the population as a whole (67%). While the rate for people with intellectual impairment was significantly higher, it is likely explained by their greater overall need, as those with intellectual impairment were likely to have had a higher overall number of difficulties. (Table 4.10)

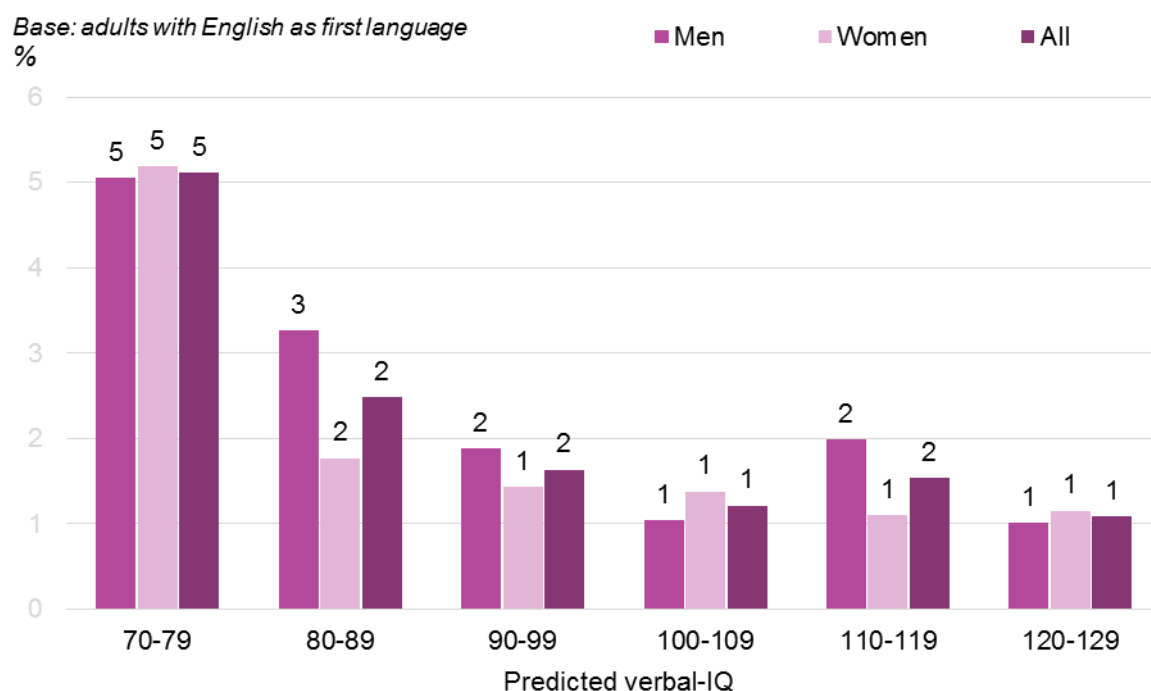
4.5 Comorbidity with sensory impairment

Intellectual impairment was also associated with limiting sensory impairments.

People with intellectual impairment were twice as likely as the population as a whole to report that **sight loss** limited the activities that they could do (18%, compared with 8%). 5% of people with intellectual impairment reported that their day-to-day activities were ‘always or often’ limited by sight loss. (Table 4.11; Figure 4.8)

People with intellectual impairment were slightly, but significantly, more likely to report that **hearing loss** limited the activities that they could do (9%, compared with 7% of the population as a whole). (Table 4.12)

Figure 4.7: Activities always or often limited by sight loss, by predicted verbal IQ and sex



4.6 Discussion

People with intellectual impairment were more likely to experience a wide range of different aspects of poor physical health, disability, and sensory impairment. Education has been shown to improve health in those in the lower range of cognitive ability (Auld and Sidhu, 2006). We have found that dealing with medicines and healthcare also presented particular problems for people with intellectual impairment. Other research has indicated that annual health checks help with health promotion and the identification of new pathology (Buszewicz et al, 2014). Therefore, targeted support to improve access to health checks and health promotion could well improve physical health in this group. In the light of self-reported challenges in activities of daily living, signposting and care management maybe essential in improving self-agency and efficiency in addition to overall assistance due to the long term condition.

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Table 4.1 General health, by predicted verbal IQ and sex*Adults whose first language is English*

2014

Health in general	Predicted verbal IQ ^a						All
	70-79 ^d	80-89	90-99	100-109	110-119	120-129	
	%	%	%	%	%	%	%
Men							
Excellent	16	15	21	23	25	25	22
Very good	26	33	36	37	33	33	34
Good	28	28	25	23	26	24	25
Fair	19	12	13	12	12	15	13
Poor	10	11	6	4	4	2	6
Women							
Excellent	16	15	22	22	21	22	20
Very good	23	30	31	36	39	40	35
Good	30	28	26	27	24	23	26
Fair	18	17	14	11	11	12	13
Poor	13	10	7	4	5	3	6
All adults							
Excellent	16	15	21	22	23	24	21
Very good	25	31	34	37	36	37	34
Good ^b	29	28	25	25	25	24	26
Fair	19	15	14	12	11	13	13
Poor ^c	11	10	6	4	5	3	6
Bases							
Men	329	270	475	557	734	449	2814
Women	342	432	840	860	997	592	4063
All	671	702	1315	1417	1731	1041	6877

^a The assessment process for predicting verbal IQ using the NART is described in Chapter 2. The NART cannot be used to predict V-IQ scores below 70; it is likely that this group includes people who would score less than 70 using a fuller assessment.

^b The proportion of people reporting good, very good or excellent health varied with predicted verbal IQ ($p < 0.001$) (but not sex).

^c The proportion of people reporting poor health varied with predicted verbal IQ ($p < 0.001$).

Table 4.2 Chronic physical health conditions (asthma, diabetes, CVD, epilepsy, high blood pressure), by predicted verbal IQ and sex

Adults whose first language is English

2014

Any chronic disease in last 12 months	Predicted verbal IQ ^a						All
	70-79	80-89	90-99	100-109	110-119	120-129	
	%	%	%	%	%	%	%
Men							
Present	32	34	24	24	30	33	29
Women							
Present	34	34	28	28	29	28	29
All adults							
Present ^b	33	34	26	26	29	31	29
<i>Bases</i>							
Men	329	270	475	557	733	449	2813
Women	341	431	839	858	997	591	4057
All	670	701	1314	1415	1730	1040	6870

^a The assessment process for predicting verbal IQ using the NART is described in Chapter 2.

^b The proportion reporting a chronic disease in the last 12 months varied with predicted verbal IQ ($p < 0.001$), but not by sex. However, when significance testing was carried out using a binary V-IQ score indicator, the association with presence of chronic physical health conditions no longer reached statistical significance.

Table 4.3 Difficulties with personal care such as dressing, bathing, washing or using the toilet, by predicted verbal IQ and sex

Adults whose first language is English

2014

Difficulties with personal care	Predicted verbal IQ ^a						All
	70-79	80-89	90-99	100-109	110-119	120-129	
	%	%	%	%	%	%	%
Men							
No difficulty at all	90	91	94	96	95	96	94
Some difficulty	8	8	4	3	3	3	4
A lot of difficulty	2	1	2	1	1	1	1
Women							
No difficulty at all	84	95	92	94	94	94	93
Some difficulty	12	4	6	4	4	5	5
A lot of difficulty	4	1	2	2	2	1	2
All adults							
No difficulty at all	88	93	93	95	95	95	94
Some difficulty	9	6	5	4	4	4	5
A lot of difficulty ^b	3	1	2	1	1	1	2
<i>Bases</i>							
Men	329	270	475	557	734	449	2814
Women	342	432	840	860	997	592	4063
All	671	702	1315	1417	1731	1041	6877

^a The assessment process for predicting verbal IQ using the NART is described in Chapter 2.

^b The proportion reporting at least some difficulty with personal care varied with both predicted IQ ($p < 0.001$) and sex ($p < 0.007$).

Table 4.4 Difficulties with getting out and about or using transport, by predicted verbal IQ and sex

Adults whose first language is English

2014

Difficulties with getting out and about or using transport	Predicted verbal IQ ^a						All
	70-79	80-89	90-99	100-109	110-119	120-129	
	%	%	%	%	%	%	%
Men							
No difficulty at all	84	88	90	94	93	95	91
Some difficulty	10	7	6	4	5	4	6
A lot of difficulty	6	5	4	2	2	1	3
Women							
No difficulty at all	77	88	87	90	89	91	88
Some difficulty	12	8	7	7	6	6	7
A lot of difficulty	11	4	5	2	4	4	5
All adults							
No difficulty at all	81	88	89	92	91	93	90
Some difficulty	11	8	7	6	6	5	6
A lot of difficulty ^b	8	4	5	2	3	2	4
Bases							
Men	329	270	475	557	734	449	2814
Women	342	432	840	860	997	592	4063
All	671	702	1315	1417	1731	1041	6877

^a The assessment process for predicting verbal IQ using the NART is described in Chapter 2.

^b The proportion reporting at least some difficulty getting out and about or using transport varied by both predicted verbal IQ ($p < 0.001$) and sex ($p < 0.001$).

Table 4.5 Difficulties with medical care such as taking medicines or pills, having injections or changes of dressing, by predicted verbal IQ and sex

Adults whose first language is English

2014

Difficulties with medical care	Predicted verbal IQ ^a						All
	70-79	80-89	90-99	100-109	110-119	120-129	
	%	%	%	%	%	%	%
Men							
No difficulty at all	94	95	95	98	98	98	97
Some difficulty	5	2	4	1	2	1	2
A lot of difficulty	2	2	1	0	0	0	1
Women							
No difficulty at all	91	97	96	98	98	99	97
Some difficulty	6	2	3	1	1	1	2
A lot of difficulty	3	1	1	0	1	0	1
All adults							
No difficulty at all	92	96	96	98	98	98	97
Some difficulty	5	2	3	1	2	1	2
A lot of difficulty ^b	2	1	1	0	1	0	1
Bases							
Men	329	270	475	557	734	449	2814
Women	342	432	840	860	997	592	4063
All	671	702	1315	1417	1731	1041	6877

^a The assessment process for predicting verbal IQ using the NART is described in Chapter 2.

^b The proportion reporting at least some difficulty with medical care varied with predicted verbal IQ ($p < 0.001$) but not by sex.

Table 4.6 Difficulties with household activities like preparing meals, shopping, laundry and housework, by predicted verbal IQ and sex

Adults whose first language is English

2014

Difficulties with household activities	Predicted verbal IQ ^a						All
	70-79	80-89	90-99	100-109	110-119	120-129	
	%	%	%	%	%	%	%
Men							
No difficulty at all	84	90	92	95	94	95	92
Some difficulty	10	6	5	4	5	4	5
A lot of difficulty	6	3	3	1	2	1	2
Women							
No difficulty at all	80	90	88	91	89	89	88
Some difficulty	12	6	9	7	8	7	8
A lot of difficulty	8	4	3	2	3	4	4
All adults							
No difficulty at all	82	90	90	93	92	92	90
Some difficulty	11	6	7	6	6	6	7
A lot of difficulty ^b	7	4	3	2	2	2	3
Bases							
Men	329	270	475	557	734	449	2814
Women	342	432	840	860	997	592	4063
All	671	702	1315	1417	1731	1041	6877

^a The assessment process for predicting verbal IQ using the NART is described in Chapter 2.

^b The proportion reporting a least some difficulty with household activities varied by both verbal IQ ($p < 0.001$) and sex ($p < 0.001$).

Table 4.7 Difficulties with practical activities such as gardening, decorating, or doing household repairs, by predicted verbal IQ and sex

Adults whose first language is English

2014

Difficulties with practical activities	Predicted verbal IQ ^a						All
	70-79	80-89	90-99	100-109	110-119	120-129	
	%	%	%	%	%	%	%
Men							
No difficulty at all	79	82	87	89	86	88	86
Some difficulty	8	11	8	7	9	8	8
A lot of difficulty	12	7	5	4	5	4	6
Women							
No difficulty at all	70	82	81	82	80	83	81
Some difficulty	10	9	9	10	12	7	10
A lot of difficulty	20	10	10	8	8	10	10
All adults							
No difficulty at all	76	82	84	86	83	86	83
Some difficulty	9	10	8	8	10	8	9
A lot of difficulty ^b	15	8	8	6	6	7	8
Bases							
Men	329	270	475	557	733	449	2813
Women	342	432	838	860	997	592	4061
All	671	702	1313	1417	1730	1041	6874

^a The assessment process for predicting verbal IQ using the NART is described in Chapter 2.

^b The proportion reporting at least some difficulty with practical activities varied with both predicted verbal IQ ($p < 0.001$) and sex ($p < 0.001$).

Table 4.8 Difficulties dealing with paperwork such as writing letters, sending cards or filling forms, by predicted verbal IQ and sex

Adults whose first language is English

2014

Difficulties dealing with paperwork	Predicted verbal IQ ^a						All
	70-79	80-89	90-99	100-109	110-119	120-129	
	%	%	%	%	%	%	%
Men							
No difficulty at all	68	84	91	96	94	96	90
Some difficulty	18	12	6	3	5	2	7
A lot of difficulty	15	4	3	2	1	2	4
Women							
No difficulty at all	72	89	90	94	94	96	91
Some difficulty	15	9	7	5	4	3	6
A lot of difficulty	13	3	3	2	2	1	3
All adults							
No difficulty at all	70	86	91	95	94	96	90
Some difficulty	16	10	7	4	4	2	6
A lot of difficulty ^b	14	3	3	2	2	2	3
Bases							
Men	328	270	475	557	734	449	2813
Women	342	432	840	860	997	592	4063
All	670	702	1315	1417	1731	1041	6876

^a The assessment process for predicting verbal IQ using the NART is described in Chapter 2.

^b The proportion reporting difficulties with paperwork varied by predicted verbal IQ ($p < 0.001$), but not by sex.

Table 4.9 Difficulties managing money, such as budgeting for food or paying bills, by predicted verbal IQ and sex

Adults whose first language is English

2014

Difficulties managing money	Predicted verbal IQ ^a						All
	70-79	80-89	90-99	100-109	110-119	120-129	
	%	%	%	%	%	%	%
Men							
No difficulty at all	84	94	94	95	97	98	94
Some difficulty	10	3	4	3	2	2	4
A lot of difficulty	5	3	2	2	1	1	2
Women							
No difficulty at all	84	92	94	96	96	97	94
Some difficulty	11	6	5	4	3	2	4
A lot of difficulty	5	2	2	1	1	1	2
All adults							
No difficulty at all	84	93	94	96	96	97	94
Some difficulty	10	5	4	3	3	2	4
A lot of difficulty ^b	5	3	2	1	1	1	2
Bases							
Men	329	270	475	557	734	449	2814
Women	342	432	840	860	997	592	4063
All	671	702	1315	1417	1731	1041	6877

^a The assessment process for predicting verbal IQ using the NART is described in Chapter 2.

^b The proportion reporting difficulties managing money varied with predicted verbal IQ ($p < 0.001$), but not by sex.

Table 4.10 Whether get assistance with activities of daily living if assistance is needed, by predicted verbal IQ and sex

Adults whose first language is English and reporting needing assistance with 1+ activity

2014

Gets assistance	Predicted verbal IQ ^a						All
	70-79	80-89	90-99	100-109	110-119	120-129	
	%	%	%	%	%	%	%
Men							
Yes	77	65	55	55	53	53	61
Women							
Yes	77	73	67	72	67	80	71
All adults							
Yes ^b	77	69	62	65	61	68	67
Bases							
Men	154	97	128	109	152	74	714
Women	161	132	260	213	250	122	1138
All	315	229	388	322	402	196	1852

^a The assessment process for predicting verbal IQ using the NART is described in Chapter 2.

^b The proportion of people who reported difficulties with activities of daily living and said that they needed assistance varied by both predicted verbal IQ ($p < 0.001$) and sex ($p < 0.001$).

Table 4.11 How often difficulty seeing limits the amount or kind of activities that you can do, by predicted verbal IQ and sex

Adults whose first language is English

2014

How often limited by sight loss	Predicted verbal IQ ^a						All
	70-79	80-89	90-99	100-109	110-119	120-129	
	%	%	%	%	%	%	%
Men							
Always/often	5	3	2	1	2	1	2
Rarely/sometimes	10	6	3	4	6	7	6
Never	85	91	95	95	92	92	92
Women							
Always/often	5	2	1	1	1	1	2
Rarely/sometimes	11	6	7	5	5	5	6
Never	84	92	92	93	94	94	92
All adults							
Always/often ^b	5	2	2	1	2	1	2
Rarely/sometimes ^c	11	6	5	5	5	6	6
Never ^d	84	91	93	94	93	93	92
Bases							
Men	329	270	474	557	734	449	2813
Women	341	432	840	860	997	592	4062
All	670	702	1314	1417	1731	1041	6875

^a The assessment process for predicting verbal IQ using the NART is described in Chapter 2.

^b The proportion reporting that difficulty seeing always or often limited the amount or kind of activities that they can do varied with predicted verbal IQ ($p < 0.001$).

^c The proportion reporting that difficulty seeing rarely or sometimes limited the amount or kind of activities that they can do varied with predicted verbal IQ ($p < 0.001$).

^d The proportion reporting that difficulty seeing never limited the amount or kind of activities that they can do varied with predicted verbal IQ ($p < 0.001$).

Table 4.12 How often difficulty hearing limits the amount or kind of activities that you can do, by predicted verbal IQ and sex

Adults whose first language is English

2014

How often limited by hearing difficulties	Predicted verbal IQ ^a						All
	70-79	80-89	90-99	100-109	110-119	120-129	
	%	%	%	%	%	%	%
Men							
Always/often	2	1	1	1	1	1	1
Rarely/sometimes	7	7	5	5	8	7	6
Never	91	92	94	94	92	92	93
Women							
Always/often	2	1			1	1	1
Rarely/sometimes	7	4	6	6	4	4	5
Never	91	95	94	93	94	95	94
All adults							
Always/often ^b	2	1	1	1	1	1	1
Rarely/sometimes	7	5	5	6	6	6	6
Never	91	94	94	94	93	93	93
Bases							
Men	329	270	475	557	734	449	2814
Women	342	432	840	860	996	592	4062
All	671	702	1315	1417	1730	1041	6876

^a The assessment process for predicting verbal IQ using the NART is described in Chapter 2.

^b The proportion reporting that difficulty hearing always or often limited the amount or kind of activities that they can do varied with predicted verbal IQ ($p < 0.001$).

5 Suicidal ideation, attempts and self-harm

Summary

While people with and without intellectual impairment were equally likely to think about suicide, those with intellectual impairment were more likely to make a suicide attempt. People with intellectual impairment were also at greater risk of non-suicidal self-harm.

5.1 Background

There is limited literature examining suicidality in people with intellectual impairment. Previous work using the APMS data suggests that people with borderline intellectual functioning are more likely to self-harm without intent to taking their own life (Hassiotis et al. 2011, Lunsby et al. 2012). A Canadian study found that people with intellectual impairment who self-harm, including people with comorbid autism, are younger and likely to have experienced a crisis, thus leading them to attend emergency services (Paquette-Smith et al. 2014). Being female and having had a history of self-harm also increased the odds of further attempts.

5.2 Definitions and methods

The fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (APA 2013) includes two types of self-harming behaviour as conditions for further study: non-suicidal self-injury (NSSI) and suicidal behaviour disorder (SBD). While intentionality can be difficult to establish (Kapur et al. 2013), this is broadly the approach that has also been adopted in the APMS series, with a separate focus on thinking about suicide; making a suicide attempt with the intention of taking one's own life; and harming oneself without the intent to die.

Face to face questions - Participants were asked in the face-to-face section of the interview a number of questions about suicidal thoughts, suicide attempts, and self-harm without suicidal intent. These questions form part of the revised Clinical Interview Schedule (CIS-R). For the purposes of the analysis in this chapter, suicidal thoughts, attempts and self-harm were assessed using the following questions:

- Have you ever thought of taking your life, even though you would not actually do it?
- Have you ever made an attempt to take your life, by taking an overdose of tablets or in some other way?
- Have you ever deliberately harmed yourself in any way but not with the intention of killing yourself?

A positive response to each was followed up with a question on whether this last occurred in the past week, the past year, or longer ago.

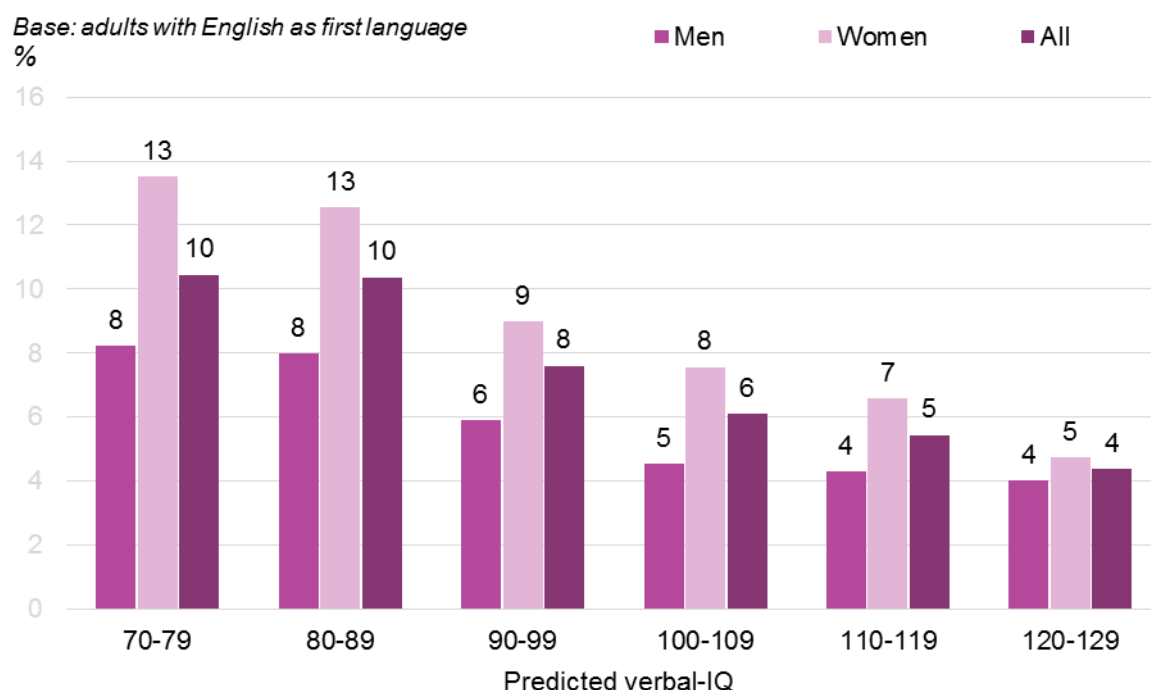
Self-completion questions - While questions about suicidal thoughts, attempts and self-harm were asked face to face, it was recognised that some participants might choose not to report them if asked face to face. For this reason, some questions were also asked of all participants a second time, later in the interview, using laptop self-completion.

Combined variables - The analyses of suicidal thoughts, attempts and self-harm in this chapter draw on derived variables that combine positive responses in the face to face interview with positive responses in the self-completion section, as we believe this approach to be the most accurate. Generally, reporting in the self-completion was higher than reporting face to face, but not all participants did the self-completion.

5.3 Suicidal ideation, attempts, and self-harm

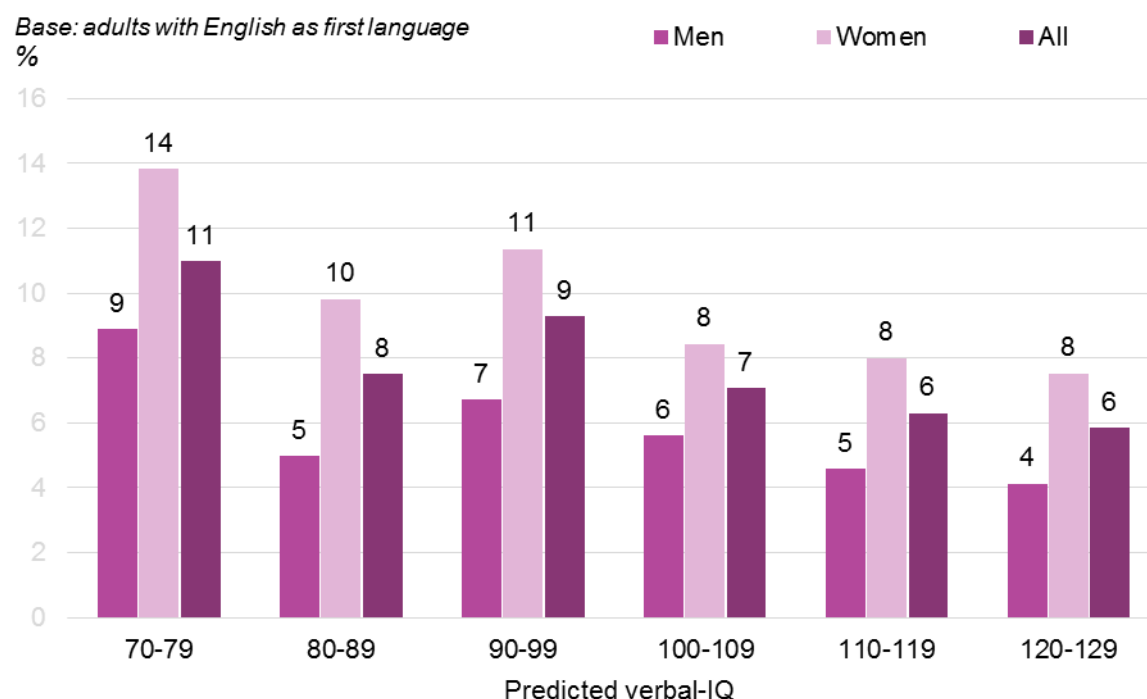
Around a fifth of people have had **suicidal thoughts**, and this rate did not vary significantly by V-IQ score (Table 5.1). The other indicators examined, however, did vary by V-IQ. One in ten (10%) adults with intellectual impairment had made a **suicide attempt** at some point in their life (8% of men, 13% of women), compared with 7% in the population as whole (5% of men, 8% of women). (Table 5.2; Figure 5.1)

Figure 5.1: Suicide attempt ever, by predicted verbal IQ and sex



Similarly, one in nine (11%) adults with intellectual impairment had **self-harmed** at some point in their life (9% of men, 14% of women), compared with 8% of the population as a whole (6% of men, 9% of women). (Table 5.3; Figure 5.2)

Figure 5.2: Self-harm ever, by predicted verbal IQ and sex



5.4 Discussion

While people were equally likely to have suicidal thoughts, irrespective of their level of intellectual functioning, those with intellectual impairment appear to be at greater risk of making a suicide attempt or of self-harming. Lack of appropriate instruments to elicit such behaviours at interview and lack of reasonable adjustments by emergency services may compound the problem. Meltzer et al. (2012) found that having a disability increased the risk of suicidal attempt four-fold. Specific difficulties that might precipitate distress and hence an attempt were managing paperwork and financial matters. It is, therefore, essential that researchers and policy makers are aware of this group whilst devising population level suicide prevention strategies as well as approaches targeting high risk groups such as those with cognitive limitations (Pitman and Caine 2012).

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Tables

- Table 5.1 Ever had suicidal thoughts, by predicted verbal IQ and sex
 Table 5.2 Ever made a suicide attempt, by predicted verbal IQ and sex
 Table 5.3 Ever self-harmed (without suicidal intent), by predicted verbal IQ and sex

Table 5.1 Ever had suicidal thoughts, by predicted verbal IQ and sex

<i>Adults whose first language is English</i>							2014
Ever had suicidal thoughts	Predicted verbal IQ ^a						All
	70-79	80-89	90-99	100-109	110-119	120-129	
	%	%	%	%	%	%	%
Men							
Yes	18	23	17	21	17	21	19
Women							
Yes	28	25	24	21	21	21	23
All adults							
Yes ^b	22	24	21	21	19	21	21
<i>Bases</i>							
Men	329	270	474	557	734	449	2813
Women	342	432	839	859	997	591	4060
All	671	702	1313	1416	1731	1040	6873

^a The assessment process for predicting verbal IQ using the NART is described in Chapter 2. The NART cannot be used to predict V-IQ scores below 70; it is likely that this group includes people who would score less than 70 using a fuller assessment.

^b The proportion of people reporting suicidal thoughts did not vary with predicted verbal IQ, but did vary by sex (p=0.002).

Table 5.2 Ever made a suicide attempt, by predicted verbal IQ and sex*Adults whose first language is English*

2014

Ever made an attempt to take own life	Predicted verbal IQ ^a						All
	70-79	80-89	90-99	100-109	110-119	120-129	
	%	%	%	%	%	%	%
Men							
Yes	8	8	6	5	4	4	5
Women							
Yes	13	13	9	8	7	5	8
All adults							
Yes ^b	10	10	8	6	5	4	7
<i>Bases</i>							
Men	328	270	475	557	734	449	2813
Women	342	432	840	860	997	592	4063
All	670	702	1315	1417	1731	1041	6876

^a The assessment process for predicting verbal IQ using the NART is described in Chapter 2.^b The proportion who reported ever making a suicide attempt varied by both predicted verbal IQ ($p<0.001$) and sex ($p<0.001$).**Table 5.3 Ever self-harmed (without suicidal intent), by predicted verbal IQ and sex***Adults whose first language is English*

2014

Ever self-harmed	Predicted verbal IQ ^a						All
	70-79	80-89	90-99	100-109	110-119	120-129	
	%	%	%	%	%	%	%
Men							
Yes	9	5	7	6	5	4	6
Women							
Yes	14	10	11	8	8	8	9
All adults							
Yes ^b	11	8	9	7	6	6	8
<i>Bases</i>							
Men	328	270	475	557	734	449	2813
Women	341	432	840	860	997	592	4062
All	669	702	1315	1417	1731	1041	6875

^a The assessment process for predicting verbal IQ using the NART is described in Chapter 2.^b The proportion who reported ever self-harming varied by both predicted verbal IQ ($p=0.002$) and sex ($p<0.001$).

6 Treatment, service use and unmet need

Summary

The majority (83%) of people with intellectual impairment were not in receipt of any mental health related treatment, despite the high rates of mental health conditions in this group.

They were slightly more likely to be prescribed psychotropic medication (16%) than the population as a whole (12%), but had similar rates of use of psychological therapies.

A small proportion (3%) reported that they had requested, but not been given, a particular mental health treatment.

6.1 Background

People with intellectual impairment are likely to have higher health needs but use fewer services including those for disease prevention. The use of generic mental health services and of primary care is variable within and between countries (Salvador-Carulla and Symonds 2016). Whilst it is recognised that the lifelong costs for caring for adults with intellectual impairment are high, the planning and availability of (mental) health services has not taken into consideration evidence of comorbidity, increasing life expectancy and patterns of disease in this population (Cooper et al. 2018, Dunn et al. 2018).

6.2 Definitions and methods

In this chapter reported use of psychotropic medication and psychological therapy around the time of the interview are examined, as well as the extent of use of health care services for a mental health reason (GP, inpatient and outpatient health care) and day and community service use. It should be noted that the rates presented here are based on participant self-reports, not health records.

Psychotropic medications: a show card listing psychotropic medications was shown to participants. People were asked to show interviewers the packaging for each medication reported, so that the interviewer could check it was correctly coded. See the Glossary in the main survey report for the full list of the medications asked about.

Psychological therapies: current use of psychological therapies was established by asking: 'Are you currently having any counselling or therapy listed on this card for a mental, nervous or emotional problem?'

Health service use for a mental health reason: health service use for a mental health reason was recorded if participants reported any of the following:

- Having spoken with their GP about being anxious or depressed, or about a mental, nervous or emotional problem, in the past two weeks or past year
- Being an inpatient for a mental, nervous or emotional reason in the past quarter
- Being an outpatient or day patient for a mental, nervous or emotional reason in the past quarter.

Community and day care service use: participants were asked about use of community and day-care services in the past year.

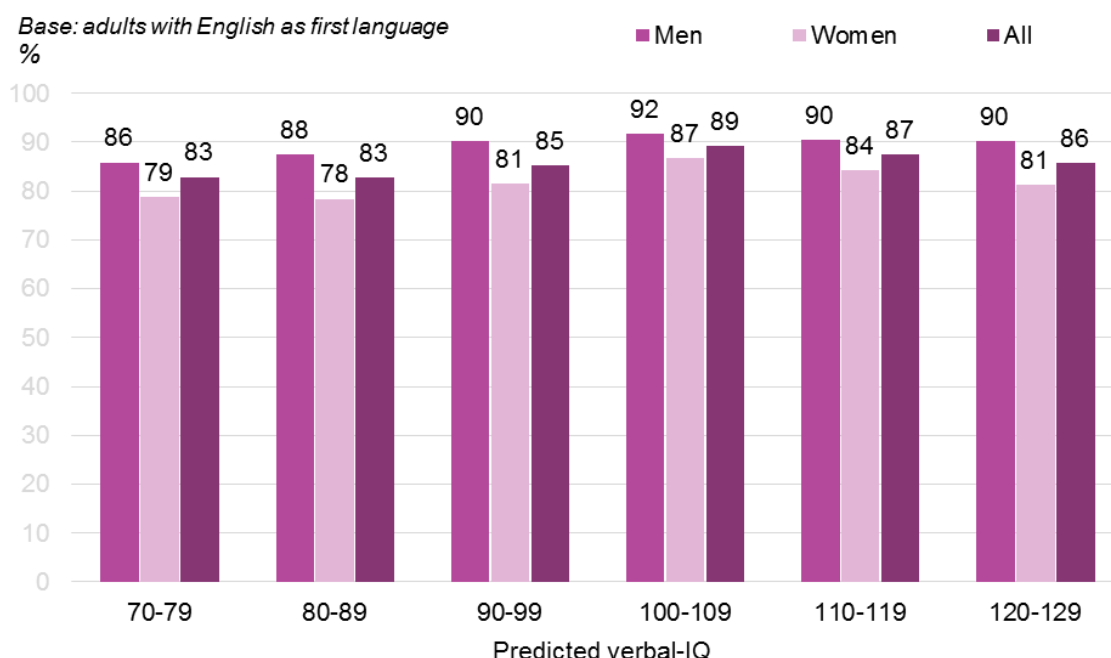
Measuring unmet treatment requests: in APMS 2014, participants were asked a new question about requesting, but not receiving, treatment: ‘In the past 12 months, have you asked for any type of counselling or mental health related medication, but not received it?’

6.3 Treatment, service use and unmet need

Given the higher levels of mental disorder in people with intellectual impairment, it is noteworthy that levels of mental health treatment and service use in this group were either similar to the rest of the population or only slightly higher.

At the time of the interview, 83% of people with an intellectual impairment were **not receiving any mental health treatment** (86% of men, 79% of women). The rate in the population as a whole was similar (86%: 90% of men, 83% of women). (Table 6.1; Figure 6.1)

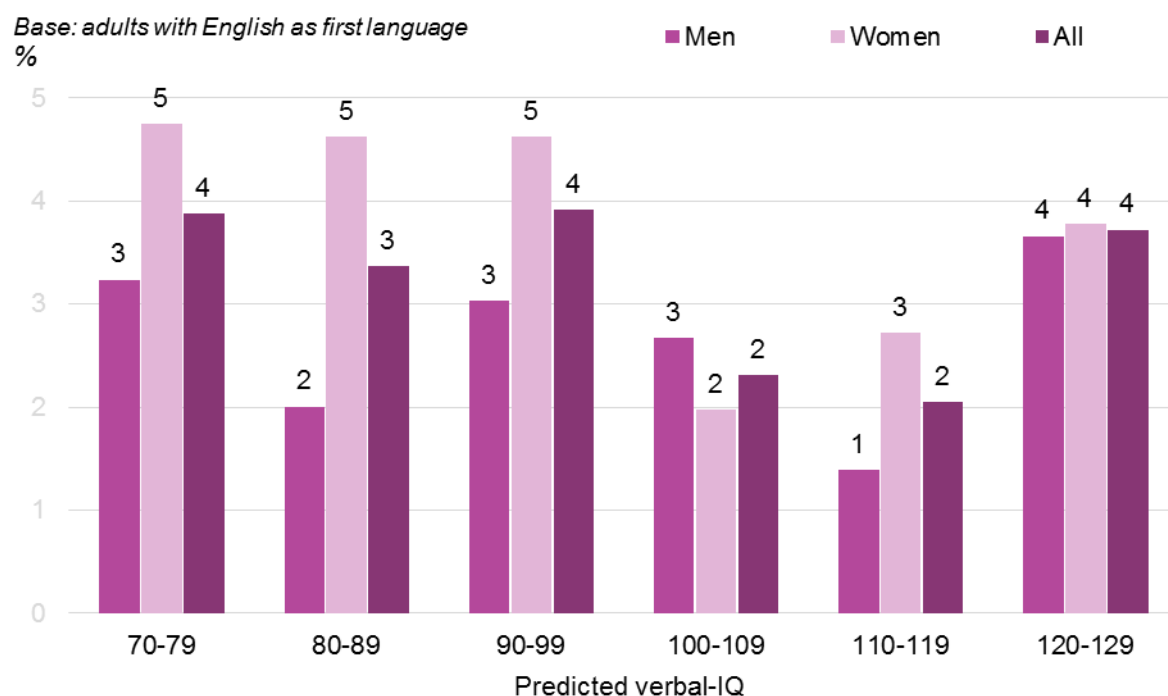
Figure 6.1: Receiving no mental health treatment, by predicted verbal IQ and sex



16% of people with an intellectual impairment were in receipt of **psychotropic medication** at the time of the interview (13% of men, 19% of women), this was somewhat higher than the proportion in the population as a whole (12%: 9% of men, 15% of women). (Table 6.2)

4% of people with an intellectual impairment were in receipt of **counselling or psychological therapy** (3% of men, 5% of women). This was very similar to the rate for the population as a whole (3%: 3% of men, 4% of women). (Table 6.3; Figure 6.2)

Figure 6.2: In receipt of psychological therapy, by predicted verbal IQ and sex



18% of people with an intellectual impairment were in receipt of **health care in the past year for a mental health related reason** (23% of men, 14% of women), compared with 13% in the population as a whole (13%: 10% of men, 16% of women). (Table 6.4)

11% of people with an intellectual impairment were in receipt of **community and day care services used in the past year** at the time of the interview (11% of both men and women). This was slightly higher than the rate for the population as a whole (8%: 7% of men, 9% of women). (Table 6.5)

Overall, 3% of people with an intellectual impairment had **requested specific mental health treatment in the past year** but had not received it (3% of men, 2% of women). This was similar to the rate for the population as a whole (2%: 1% of men, 2% of women). (Table 6.6)

6.4 Discussion

The level and type of support that people with intellectual impairment receive does not appear to be appropriate to their level of need. Hassiotis et al. (2008), examined service use by adults with intellectual impairment using data from APMS 2000. They found that while people with intellectual impairment attended emergency services more often than the rest of the population, they were less likely to access talking therapies such as CBT, and received more psychotropic medications. Taken together these results suggest that people with intellectual impairment may have both unrecognised and unmet needs and may require a different type of response than is currently available in routine care.

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Table 6.1 Currently receiving mental health treatment, by predicted verbal IQ and sex

Adults whose first language is English

2014

Receiving any medication, counselling, or therapy	Predicted verbal IQ ^a						All
	70-79	80-89	90-99	100-109	110-119	120-129	
	%	%	%	%	%	%	%
Men							
No treatment	86	88	90	92	90	90	90
Medication only	11	10	7	6	8	6	8
Counselling only	1	-	1	1	-	2	1
Both medication and counselling	2	2	2	1	1	2	2
Women							
No treatment	79	78	81	87	84	81	83
Medication only	17	17	14	11	13	15	14
Counselling only	2	2	3	1	2	2	2
Both medication and counselling	3	3	2	1	1	1	2
All adults							
No treatment	83	83	85	89	87	86	86
Medication only ^b	13	14	11	8	11	11	11
Counselling only ^c	2	1	2	1	1	2	1
Both medication and counselling	2	2	2	1	1	2	2
Bases							
<i>Men</i>	327	270	475	557	734	449	2812
<i>Women</i>	341	432	840	859	997	591	4060
<i>All</i>	668	702	1315	1416	1731	1040	6872

^a The assessment process for predicting verbal IQ using the NART is described in Chapter 2. The NART cannot be used to predict V-IQ scores below 70; it is likely that this group includes people who would score less than 70 using a fuller assessment.

^b The proportion of people receiving medication only varied by both verbal IQ ($p=0.002$) and sex ($p<0.001$).

^c The proportion of people receiving counselling only varied by sex ($p<0.005$).

Table 6.2 Receiving any psychotropic medication, by predicted verbal IQ and sex*Adults whose first language is English*

2014

Receiving any psychotropic medication ^b	Predicted verbal IQ ^a						All
	70-79	80-89	90-99	100-109	110-119	120-129	
	%	%	%	%	%	%	%
Men							
Yes	13	12	9	7	9	8	9
Women							
Yes	19	20	16	12	14	16	15
All adults							
Yes ^c	16	16	13	10	12	12	12
<i>Bases</i>							
Men	327	270	475	557	734	449	2812
Women	341	432	840	859	997	591	4060
All	668	702	1315	1416	1731	1040	6872

^a The assessment process for predicting verbal IQ using the NART is described in Chapter 2.^b Includes antipsychotic, antidepressant, ADHD, hypnotic, anxiolytic, bipolar medication.^c Receipt of psychotropic medication varied by both predicted verbal IQ ($p < 0.001$) and sex ($p < 0.001$).**Table 6.3 Having any counselling or therapy, by predicted verbal IQ and sex***Adults whose first language is English*

2014

Having any counselling or therapy	Predicted verbal IQ ^a						All
	70-79	80-89	90-99	100-109	110-119	120-129	
	%	%	%	%	%	%	%
Men							
Yes	3	2	3	3	1	4	3
Women							
Yes	5	5	5	2	3	4	4
All adults^b							
Yes	4	3	4	2	2	4	3
<i>Bases</i>							
Men	329	270	475	556	734	449	2813
Women	342	432	840	860	997	592	4063
All	671	702	1315	1416	1731	1041	6876

^a The assessment process for predicting verbal IQ using the NART is described in Chapter 2.^b Receipt of counselling or psychologically therapy did not vary by predicted verbal IQ or sex.

Table 6.4 Received any health care for mental health or emotional reason in past year, by predicted verbal IQ and sex

Adults whose first language is English

2014

Received any health care in last year for mental health or emotional reason	Predicted verbal IQ ^a						All
	70-79	80-89	90-99	100-109	110-119	120-129	
	%	%	%	%	%	%	%
Men							
Yes	14	13	11	8	9	7	10
Women							
Yes	23	18	18	16	15	13	16
All adults							
Yes ^b	18	15	15	12	12	10	13
<i>Bases</i>							
Men	328	270	475	556	734	449	2812
Women	342	430	840	859	996	592	4059
All	670	700	1315	1415	1730	1041	6871

^a The assessment process for predicting verbal IQ using the NART is described in Chapter 2.

^b The proportion who had received any health care in last year for a mental health or emotional reason varied by both predicted verbal IQ ($p < 0.001$) and sex ($p < 0.001$).

Table 6.5 Community and day care services used in past year, by predicted verbal IQ and sex

Adults whose first language is English

2014

Community and day care services used in past year	Predicted verbal IQ ^a						All
	70-79	80-89	90-99	100-109	110-119	120-129	
	%	%	%	%	%	%	%
Men							
Yes	11	9	7	8	6	6	7
Women							
Yes	11	10	10	7	8	7	9
All adults							
Yes ^b	11	9	9	8	7	6	8
<i>Bases</i>							
Men	329	270	475	557	733	449	2813
Women	342	432	840	860	997	592	4063
All	671	702	1315	1417	1730	1041	6876

^a The assessment process for predicting verbal IQ using the NART is described in Chapter 2.

^b The proportion of people using community or day care services varied by predicted verbal IQ ($p < 0.001$), but not sex.

Table 6.6 Waiting for or refused requested treatment in the past year, by predicted verbal IQ and sex

Adults whose first language is English

2014

Waiting for or refused specific treatment in past 12 months	Predicted verbal IQ ^a						All
	70-79	80-89	90-99	100-109	110-119	120-129	
	%	%	%	%	%	%	%
Men							
Yes	2	1	1	1	1	-	1
Women							
Yes	3	2	2	2	1	3	2
All adults							
Yes ^b	3	2	2	2	1	2	2
<i>Bases</i>							
Men	329	270	475	557	734	449	2814
Women	342	432	840	860	997	592	4061
All	671	702	1315	1417	1731	1041	6875

^a The assessment process for predicting verbal IQ using the NART is described in Chapter 2.

^b The proportion of people waiting for or refused treatment did not vary by predicted verbal IQ, but did vary sex (p=0.004).

7 Conclusions and implications for practice

The survey data reported on here, from the latest Adult Psychiatric Morbidity Survey, show that adults with borderline intellectual impairment (including people with different degrees of cognitive limitations and adaptive difficulties) have higher rates of mental health morbidity and face many other disadvantages and limitations in their daily lives.

Their use of mental health treatment and services does not appear to be commensurate with their higher levels of need. This may be due to a lack of professional awareness of their needs, to services not adapting enough to meet those needs, or to difficulties the individual faces in seeking treatment and support.

Rigidly enforced service eligibility criteria can lead to reluctance among service providers to accept these individuals, often resulting in multiple referrals and a lack of support or appropriate service provision. Difficulties in securing appropriate education and employment and in building relationships and social networks may further impair their mental health, as these factors are all central to health outcomes (Emerson 2018).

The findings reported here are consistent with previous research showing that those with cognitive limitations are an under recognised but disadvantaged group who are not well understood despite their high levels of care need. These results should be used to raise awareness of the persistence of disadvantages for this population, and prompt joined up action from multiple agencies involved in health, social care, and disability (Reppermund 2017).

Older adults with intellectual impairment and severe mental illness may present a particular challenge for service providers, as their intellectual impairment could be attributed to the chronicity of the mental disorder and information about the history of their conditions may be lacking. Prompt and informed assessments and decisions about the delivery of care are essential. Where intellectual impairment has been identified, reasonable adjustments can provide a framework within which to facilitate access to therapies and social care, and to ensure that patient opinions are valued and their rights are protected. Health services should recognise the pattern of psychiatric morbidity relevant to people with intellectual impairment.

Specialist models of care specific to this group have been established in other countries (Nouwens et al 2016) and could provide examples of good practice that could be transferable to NHS settings.

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