Title: Psychotropic medication use in adults with intellectual disability in Queensland, Australia, from 1999 to 2015: a cohort study

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Abstract

Background Longitudinal data on medication use in adults with intellectual disability (ID) are scarce. We describe the longitudinal use of and factors associated with psychotropic medication prescribing in adults with ID living in the Australian community.

Methods Longitudinal data were obtained from adults with ID in the community in Queensland, Australia, between 1999 and 2015. Participant characteristics and medication use information were extracted from baseline questionnaires and health check booklets. Logistic regression was used to investigate the associations between participant characteristics and psychotropic medication use, commencement, or cessation.

Results Longitudinal data were available for 138 participants on 697 reviews. The proportion of participants prescribed psychotropic medications increased from 43 to 54% between 1999 and 2015. The rates of commencement and cessation of psychotropic medications between consecutive time periods ranged from 9 to 18, and 7 to 15%, respectively. Challenging behaviour was associated with psychotropic medication use (adjusted odds ratio = 4.1; 95% confidence interval: 2.1-7.9). Presence of challenging behaviour, either consistent or newly identified, was positively associated with ongoing use or commencement of psychotropic medications.

Conclusions Psychotropic medications are commonly prescribed to adults with ID. Challenging behaviour is positively associated with ongoing use and commencement.

Keywords intellectual disability, psychotropics, antipsychotics, challenging behaviour, problem behaviour, cohort study

Background

Psychiatric illness and challenging behaviour are common among adults with intellectual disability (ID) (Sheehan et al. 2015). Precipitants of challenging behaviour include biological and psycho-social factors (Hastings et al. 2013). Psychotropic medication use is a common response to challenging behaviour (Sheehan et al. 2017). However, this intervention is questionable due to adverse effects (e.g. extrapyramidal symptoms, metabolic syndrome) and a lack of high quality evidence for efficacy (Sheehan *et al.* 2017; Matson and Mahan 2010). There are justified concerns that adverse effects outweigh effectiveness when psychotropic medications are used to manage challenging behaviours.

Several guidelines exist to control the use of psychotropic medications among people with ID. The Australian Intellectually Disabled Persons Services Act includes mandatory requirements for psychotropic medication use for behaviour management (McGillivray and McCabe 2004). The United Kingdom National Institute for Health and Care Excellence Guideline provides recommendations for the use of antipsychotic medications for challenging behaviour (National Collaborating Centre for Mental Health 2015). The National Health Service in England introduced a policy aiming for therapeutic alliances between people with ID, support staff, families, and professionals to promote medication review and the use of alternative management strategies (National Health Services England 2018).

There is a lack of data on temporal trends for psychotropic medications in people with ID. The proportions of adults with ID prescribed psychotropic medications range between 11 and 90% (Robertson et al. 2000; Doan et al. 2013; Tsiouris et al. 2013; Schützwahl et al. 2016; O'Dwyer et al. 2017; Bowring et al. 2017; Perry et al. 2018). The different prevalences reported may be due to different sample populations with varying rates of psychiatric illness and challenging behaviour, and to methodological differences including variation in diagnostic definitions. It is difficult to determine whether use is increasing or decreasing through time. This study aimed to investigate psychotropic medication use, commencement and cessation, and associated factors, in adults with ID.

Methods

Study design, settings, and participants

This cohort study was conducted in Queensland, Australia from August 1999 to December 2015. Participants were adults (≥ 18 years of age) with ID living in 24-hour supported accommodation with Endeavour Foundation (EF) - Queensland's major service provider to adults with ID. Adults were originally enrolled as part of a cluster randomised controlled trial (RCT) of the Comprehensive Health Assessment Programme (CHAP). The RCT was performed between 1999 and 2001, and found the CHAP substantially increased disease prevention activities (Lennox et al. 2007). From 2004, the CHAP was incorporated into regular review for EF clients, and was performed up to annually at the discretion of carers. After each health check, the CHAP booklet was retained by the EF. In 2016,

participants from the original RCT were contacted to seek permission to access the CHAP booklets completed in the previous 15 years. Ethical approval was granted by the University of Queensland Human Research Ethics Committee (approval number 2014000795).

Data sources

The CHAP is a two-part booklet. Part One is carer and person completed and includes health history and medications. Part Two is for general practitioners (GPs) to review Part One and conduct a health assessment.

Participants completed their CHAP booklets with their usual GPs. Then the CHAP booklets were returned to the EF for storage. The EF staff scanned and sent the electronic copies to our research team who completed data extraction and coding. Data extracted from the CHAP booklets were combined with data from the carer questionnaires at baseline. Concordance between CHAP booklets and carer questionnaires was tested by comparing the records within the intervention group for the original RCT.

Outcome data

Medications were coded using the Anatomical Therapeutic Chemical (ATC) classification system (WHOC - ATC/DDD Index 2018). For adults who had more than one ATC code but did not have indications recorded, ATC codes were assigned to the most relevant health condition through reviewing the CHAP booklets. Complementary medications, which are not ATC coded, include vitamins, minerals, amino acids, fish oil, and herbal products (Doan et al. 2013). Psychotropic medications were defined as medical agents for the nervous system, excluding analgesics and antiepileptics (de Bildt et al. 2006). They included antipsychotics, antidepressants, anxiolytics, psychostimulants, hypnotics/sedatives, anti-Parkinsonian medications, and opioid antagonists (de Bildt et al. 2006). Medication classification was performed by M.S. with guidance from D.H. and T.D.

To examine stability in prescribing over time, we defined four time periods (1999-2001, 2002-2006, 2007-2011, and 2012-2015). If one or more CHAP reviews within a study time period recorded any psychotropic medication, the participant was classified as taking the medication in that time period. Psychotropic medication commencement was defined when at least one psychotropic medication was recorded in a review but no psychotropic medication had been recorded in the preceding review. Cessation was defined conversely. Commencement and cessation were defined from each participant's second review onwards.

Participant characteristics

Demographic (gender, age) and medical variables (level of ID, Down syndrome, epilepsy, and psychiatric illness), treating GP, and challenging behaviour were recorded. Age groups were 18-34, 35-49, and ≥ 50 years. Levels of ID were Mild, Moderate, Severe, and Profound, using levels in the International Classification of Diseases, 10th Revision (World Health Organization 1992). Down syndrome, epilepsy, challenging behaviour, and

psychiatric illness were recorded as present or absent. Psychiatric illness was categorised using the Diagnostic Criteria for Psychiatric Disorders for Use with Adults with Learning Disabilities/Mental Retardation (Royal College of Psychiatrists 2001). Psychiatric illness was assumed to be chronic due to the complex comorbidities, and chronic and recurrent nature of most symptoms (Table A1 in Appendix 1). Challenging behaviour was defined as “behaviour of such intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy or behaviour which is likely to limit seriously or deny access to and use of community facilities” (Emerson 2001). We assessed challenging behaviour by reviewing the CHAP booklets against a checklist. This checklist extracted all forms of behaviours listed in the Behaviour Problems Inventory for Individuals with Intellectual Disabilities – Short Form, the Aberrant Behaviour Checklist, and the Checklist of Challenging Behaviour (Appendix 2) (Rojahn et al. 2012a; Rojahn et al. 2012b; Aman and Singh 1986; Harris et al. 1994). An individual was considered to have challenging behaviour if at least one of these behaviours was reported. Due to the strong relationship between challenging behaviour and context in Emerson’s definition, we considered that behaviours reported by staff and listed as described above to be intense, frequent, and durable enough to be considered challenging. GP switching was defined when a participant consulted different GPs between consecutive reviews and was thus defined from each participant’s second review onwards.

Data analysis

Contingency tables were used to determine changes in the prevalence of psychotropic medications in successive time periods. To investigate the association between participant characteristics and psychotropic medication use, data from all reviews were included in mixed effects logistic regression models. Individual participant was included as a random effect to account for the non-independence of observations from the same person. The same logistic regression models were used to investigate the association between participant characteristics and change in psychotropic medication use. Multivariable analyses included gender, age, Down syndrome, epilepsy, and challenging behaviour as covariables. Variables other than gender, level of ID, Down syndrome, epilepsy, and psychiatric illness were treated as time-varying. Logistic regression was used to investigate the association between change in challenging behaviour and change in psychotropic medication use. Analysis was performed using Stata statistical software (v15, Stata Corp, TX, USA).

Results

Of the 453 RCT participants recruited in 1999, 138 (30%) agreed to participate in this follow-up cohort study in 2016. There were 697 reviews completed in total, with 138, 93, 111, and 92 participants reviewed in the periods 1999-2001, 2002-2006, 2007-2011, and 2012-2015, respectively (Table A2 in Appendix 1). The median (interquartile range) number of reviews completed per person was 5 (4-6) (Figure A1 in Appendix 1). Individuals who re-

participated in the cohort study were similar to non-participants in terms of gender, age, health service use, and presence of Down syndrome, but those with mild ID and absence of epilepsy were less like to participate (Table A3 in Appendix 1). Twenty-eight percent of the participants had Down syndrome and 17% had challenging behaviours (Table 1). Among the 39 adults diagnosed with psychiatric illness, 15 adults had psychiatric comorbidities; 8 adults were diagnosed with psychosis, or comorbid depression and autism (Table A1 in Appendix 1).

At baseline, 65% were using medications (Table 2). This increased to 90% by 2012-2015. Most frequently used were nervous system medications, with 44 and 86% of the participants using these medications in 1999-2001 and 2012-2015. At baseline, in 2002-2006, 2007-2011, and 2012-2015, respectively, 43, 51, 53, and 54% of the participants were prescribed psychotropic medications. Antipsychotics (22-28%) and antidepressants (17-36%) were the most frequently used psychotropic medications. Alimentary tract and metabolism drugs, dermatologicals, respiratory, and cardiovascular system drugs were used by 67, 33, 29, and 22% of the participants reviewed in 2012-2015. Psychotropic medications were commenced in 18, 14, and 9% of the participants between consecutive periods of 1999-2001 to 2002-2006, 2002-2006 to 2007-2011, and 2007-2011 to 2012-2015 (Table 3). Medications were ceased in 15, 7, and 7%, respectively.

Challenging behaviour (adjusted odds ratio = 4.1; 95% confidence interval: 2.1-7.9) and psychiatric illness (11.6; 3.4-40.0) were positively associated with use of psychotropic medications (Table 4). Challenging behaviour (2.2; 1.3-3.9) and psychiatric illness (2.3; 1.2-4.4) were positively associated with change in psychotropic medication use (Table 5). Presence of challenging behaviour, either consistent or newly identified, was positively associated with ongoing use or commencement of psychotropic medications (Table A4 in Appendix 1).

Discussion

More than half (54%) of the reviewed study participants were prescribed psychotropic medications in the period 2012 to 2015. Challenging behaviour was positively associated. Commencement and cessation of psychotropic medications were most frequent between the first (1999-2001) and second (2002-2006) study time periods. Challenging behaviour was positively associated with psychotropic medication commencement.

Consistent with previous research, psychotropic medication use was common. Challenging behaviour was associated in our study (Sheehan et al. 2015). Inappropriate use of psychotropic medications for challenging behaviours has been reported (Tsiouris et al. 2013). Although we could not assess appropriateness of prescribing, psychotropic medications were prescribed without diagnosis of psychiatric illness in 35% of 138 participants and antipsychotics were prescribed without diagnosis of psychosis in 16% participants.

Challenging behaviour was associated with psychotropic medication commencement. Infrequency of commencement may reflect caution due to the lack of evidence for use in challenging behaviour, of practice guidelines, and of knowledge among professionals (Sheehan et al. 2017). Cessation of psychotropic medications was also infrequent. Doctors may be unwilling to cease psychotropic medication due to concerns about adverse effects associated with cessation (Sheehan and Hassiotis 2017; de Kuijper and Hoekstra 2017). The lack of evidence-based cessation strategies and of effective alternative interventions may also contribute. In addition, families, carers, and individuals may resist medication change.

Psychological and behavioural approaches (e.g. positive behaviour support, applied behaviour analysis) should be used before medication is considered (Grey and Hastings 2005; McGill et al. 2018). Interventional studies are required to allow better understanding of the risk-benefit ratio of psychotropic use and of cessation strategies (McNamara et al. 2017). Guidelines on psychotropic prescribing for challenging behaviour should be tested, updated and produced (Public Health England 2019). Studies of the use of psychotropic medications in population groups with common comorbidities of ID (e.g. epilepsy, autism) and aetiologies (e.g. Down syndrome) are also important.

A strength of this cohort study is the collection of health and medication information on up to 10 occasions per person over a 16-year period. The study adds to the relatively scarce information on temporal changes in psychotropic medication use among adults with ID. Additionally, our study is the first to investigate commencement and cessation of psychotropic medications through time. Participants were generally representative of people with ID living in supported accommodation, although people with mild ID and absence of epilepsy were less likely to participate. Otherwise, non-participation in ID research is more likely to be related to characteristics of the carer than the person with disability (Ware et al. 2017), which suggests the results may have good generalisability. However, some study limitations exist. We categorised medications according to the ATC system, which groups medications based on their main therapeutic use (WHOCC - ATC/DDD Index 2018). However, medications can have more than one indication, and the indication may be unknown. Nevertheless, the ATC system has been widely used for pharmacoepidemiology research (Chen et al. 2012). For 546 (22%) listed medications, there were two or more possible ATC codes, and the appropriate code was selected by reviewing the health conditions in CHAP booklets. In our study, the frequency of reviews varied among individuals, leading to difference in the number of participants reviewed in the four time periods. CHAP reviews were organised at the discretion of paid carers and thus were not researcher scheduled. While reasons for review are beyond the scope of this study, variation in review frequency may be attributable to factors such as health status, carer attitudes, and convenience. Our study did not use a validated instrument for measuring challenging behaviours. Instead, challenging behaviour was determined based on an exhaustive checklist and support staff reports. We acknowledge that support staff had discretion to determine which behaviours were of sufficient intensity, frequency, and durability to qualify as challenging. Psychiatric illness was assumed to be chronic. Our study provided a broad overview of medication use based on class rather than individual drugs, and did not consider changes in drug, dosage, and periods off medication.

Conclusions

Psychotropic medications are commonly prescribed in adults with ID. Challenging behaviour is positively associated with the ongoing use and commencement of these medications. High quality research is needed to aid appropriate and safe prescribing and cessation of psychotropic medications.

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Table 1. Participant characteristics at baseline (N_{participant}=138)

	Participant	
	N	%
Total	138	100.0
Gender		
Male	72	52.2
Female	66	47.8
Age (years)		
18-34	57	41.6
35-49	71	51.8
≥50	9	6.6
Level of intellectual disability		
Mild	35	27.1
Moderate	60	46.5
Severe	34	26.4
Down syndrome	39	28.3
Epilepsy	43	31.2
Challenging behaviour	23	16.7
Psychiatric illness		
Yes	39	29.3
No	94	70.7

Missing items: age, n=1; level of intellectual disability, n=9; psychiatric illness, n=5

Table 2. Prevalence of medication use among participants (N_{participant}=138)

	Time Period			
	1999-2001 n (%)	2002-2006 n (%)	2007-2011 n (%)	2012-2015 n (%)
Number of participants	138 (100.0)	93 (100.0)	111 (100.0)	92 (100.0)
Number of participants taking medications	90 (65.2)	82 (88.2)	107 (96.4)	83 (90.2)
Medication class				
Nervous system	61 (44.2)	60 (64.5)	94 (84.7)	79 (85.9)
Analgesics	9 (6.5)	26 (28.0)	73 (65.8)	73 (79.4)
Antiepileptics	31 (22.5)	22 (23.7)	32 (28.8)	24 (26.1)
Psychotropic medications	39 (43.3)	42 (51.2)	57 (53.3)	45 (54.2)
Antiparkinson	3 (3.3)	0 (0.0)	0 (0.0)	0 (0.0)
Antipsychotics	24 (26.7)	19 (23.2)	24 (22.4)	23 (27.7)
Anxiolytics	4 (4.4)	7 (8.5)	11 (10.3)	7 (8.4)
Hypnotics and sedatives	3 (3.3)	1 (1.2)	1 (0.9)	1 (1.2)
Antidepressants	15 (16.7)	23 (28.1)	35 (32.7)	30 (36.1)
Anti-dementia (galantamine)	0 (0.0)	0 (0.0)	1 (0.9)	0 (0.0)
Alimentary tract and metabolism	21 (15.2)	31 (33.3)	73 (65.8)	62 (67.4)
Genito urinary system and sex hormones	14 (10.1)	23 (24.7)	27 (24.3)	14 (15.2)
Cardiovascular system	6 (4.4)	15 (16.1)	19 (17.1)	20 (21.7)
Dermatologicals	2 (1.5)	8 (8.6)	33 (29.7)	30 (32.6)
Respiratory system	0 (0.0)	11 (11.8)	28 (25.2)	27 (29.4)
Systemic hormonal preparations, sex hormones and insulins	8 (5.8)	7 (7.5)	11 (9.9)	15 (16.3)
Musculo-skeletal system	7 (5.1)	8 (8.6)	17 (15.3)	12 (13.0)
Complementary medicatons	11 (8.0)	8 (8.6)	12 (10.8)	11 (12.0)
Blood and blood forming organs	1 (0.7)	6 (6.5)	13 (11.7)	11 (12.0)
Sensory organs	1 (0.7)	5 (5.4)	6 (5.4)	11 (12.0)
Anti-infectives for systemic use	4 (2.9)	7 (7.5)	6 (5.4)	6 (6.5)
Antineoplastic and immunomodulating agents	1 (0.7)	1 (1.1)	5 (4.5)	3 (3.3)

Table 3. Psychotropic medication use by time period (N_{participant}=138)

Psychotropic medication (Yes/No)		Time Period							
		1999-2001		2002-2006		2007-2011		2012-2015	
		Yes	No	Yes	No	Yes	No	Yes	No
1999-2001	Yes	39		24	6	29	5	17	6
	No		99	18	45	28	49	28	41
2002-2006	Yes			42		37	3	18	6
	No				51	7	40	11	20
2007-2011	Yes					57		30	4
	No						54	5	31
2012-2015	Yes							45	
	No								47

Bold font signifies the number of participants commencing or ceasing psychotropic medications between consecutive time periods.

Table 4. The association between participant characteristics and psychotropic medication use (N_{review}=697)

Participant characteristic	Participant N	Review N	Psychotropic medication n (%)	Unadjusted OR (95% CI)	Adjusted OR (95% CI)
Total	138	697	281 (40.3)		
Gender					
Female	66	319	125 (39.2)	1.0	1.0
Male	72	378	156 (41.3)	1.2 (0.4-4.1)	1.4 (0.5-4.4)
Level of intellectual disability [^]					
Mild	35	196	92 (46.9)	1.0	1.0
Moderate	60	289	83 (28.7)	0.3 (0.1-1.1)	0.3 (0.1-1.1)
Severe	34	153	79 (51.6)	1.4 (0.3-7.0)	1.1 (0.2-5.6)
Age ^{^^}					
18-34	57	98	39 (39.8)	0.4 (0.2-0.8)*	0.5 (0.2-1.0)
35-49	127	348	135 (38.8)	1.0	1.0
≥50	70	241	107 (44.4)	2.0 (1.0-4.4)	1.5 (0.7-3.1)
Down syndrome					
No	99	491	217 (44.2)	1.0	1.0
Yes	39	206	64 (31.1)	0.3 (0.1-1.0)	0.3 (0.1-1.3)
Epilepsy					
No	95	478	176 (36.8)	1.0	1.0
Yes	43	219	105 (48.0)	2.0 (0.6-7.1)	1.5 (0.4-5.0)
Challenging behaviour					
No	126	439	124 (28.3)	1.0	1.0
Yes	90	258	157 (60.9)	4.8 (2.6-9.1)***	4.1 (2.1-7.9)***
Psychiatric illness [#]					
No	94	484	156 (32.2)	1.0	1.0
Yes	39	198	118 (59.6)	12.0 (3.4-42.6)***	11.6 (3.4-40.0)***
General practitioner switching ^{##}					
No	120	372	159 (42.7)	1.0	1.0
Yes	109	187	83 (44.4)	1.1 (0.5-2.2)	1.1 (0.5-2.3)

CHAP: Comprehensive Health Assessment Programme; OR: odds ratio; AOR: adjusted odds ratio; CI: confidence interval

[^] Missing data for 9 participants and 59 reviews; ^{^^} Missing data for 1 participant and 10 reviews; [#] Missing data for 5 participants and 15 reviews; ^{##} 559 Reviews for “General practitioner switching” as first review for each participant excluded.

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$

Table 5. The association between participant characteristics, and change in psychotropic medication use (n_{review}=559)

Participant characteristic	Participant N	Review n	Commencement or Cessation ^{##} n (%)	Unadjusted OR (95% CI)	Adjusted OR (95% CI)
Total	138	559	90 (16.1)		
Gender					
Female	66	253	44 (17.4)	1.0	1.0
Male	72	306	46 (15.0)	0.8 (0.4-1.5)	0.8 (0.4-1.4)
Level of intellectual disability [^]					
Mild	35	161	23 (14.3)	1.0	1.0
Moderate	60	229	34 (14.9)	1.0 (0.4-2.2)	1.1 (0.5-2.3)
Severe	34	119	22 (18.5)	1.4 (0.6-3.3)	1.3 (0.6-3.2)
Age ^{^^}					
18-34	21	41	13 (31.7)	3.3 (1.3-8.2)*	3.0 (1.2-7.4)*
35-49	93	277	39 (14.1)	1.0	1.0
≥50	70	232	38 (16.4)	1.2 (0.6-2.2)	1.3 (0.7-2.4)
Down syndrome					
No	99	392	73 (18.6)	1.0	1.0
Yes	39	167	17 (10.2)	0.4 (0.2-0.9)*	0.6 (0.3-1.2)
Epilepsy					
No	95	383	50 (13.1)	1.0	1.0
Yes	43	176	40 (22.7)	2.2 (1.1-4.1)*	1.7 (0.9-3.1)
Challenging behaviour					
No	100	324	36 (11.1)	1.0	1.0
Yes	86	235	54 (23.0)	2.4 (1.4-4.2)**	2.2 (1.3-3.9)**
Psychiatric illness [#]					
No	94	390	50 (12.8)	1.0	1.0
Yes	39	159	38 (23.9)	2.6 (1.3-5.1)**	2.3 (1.2-4.4)*
General practitioner switching ^{##}					
No	120	372	53 (14.3)	1.0	1.0
Yes	109	187	37 (19.8)	1.5 (0.9-2.6)	1.5 (0.9-2.5)

CHAP: Comprehensive Health Assessment Programme; OR: odds ratio; AOR: adjusted odds ratio; CI: confidence interval

[^] Missing data for 9 participants and 59 reviews; ^{^^} Missing data for 1 participant and 10 reviews; [#] Missing data for 5 participants and 15 reviews; ^{##} 559 Reviews for “Commencement or Cessation” and “General practitioner switching” as first review for each participant excluded.
^{*} $p<0.05$; ^{**} $p<0.01$; ^{***} $p<0.001$

List of Appendixes

- **Appendix 1**

Table A1. Psychiatric diagnoses ($n_{\text{psychiatric illness}} = 39$)

Table A2. Participants reviewed by time period ($N_{\text{participant}} = 138$)

Table A3. Baseline characteristics of participants and non-participants for the cohort study.

Table A4. The association between changes in challenging behaviour and changes in the use of psychotropic medications ($n_{\text{review}} = 559$)

Figure A1. Review frequency for 138 participants between 1999-2015 ($N_{\text{review}}=697$)

- **Appendix 2**

Supplemental details regarding identification of challenging behaviour

Appendix 1

Table A1. Psychiatric diagnoses (n_{psychiatric illness} = 39)

	n (%)
Psychosis, or comorbid depression and autism	8 (20.5)
Depression, or comorbid anxiety, obsessive-compulsive disorder, and bipolar affective disorder	20 (51.3)
Anxiety, or comorbid depression	12 (30.8)
Bipolar affective disorder, or comorbid depression and autism	7 (17.9)

Number of adults in each diagnosis have overlaps due to comorbidities.

Table A2. Participants reviewed by time period (N_{participant} = 138)

Review (Yes/No)		Time Period							
		1999-2001		2002-2006		2007-2011		2012-2015	
		Yes	No	Yes	No	Yes	No	Yes	No
1999-2001	Yes	138		93	45	111	27	92	46
	No		0	0	0	0	0	0	0
2002-2006	Yes			93		87	6	55	38
	No				45	24	21	37	8
2007-2011	Yes					111		70	41
	No						27	22	5
2012-2015	Yes							92	
	No								46

Fifty four participants were reviewed at least once in each of the four time periods.

Table A3. Baseline characteristics of participants and non-participants for the cohort study.

Characteristics of adults with intellectual disability	Cohort participants	Non- participants	P Value
Total	138 (100.0)	315 (100.0)	
Male gender; n (%)	72 (52.2)	181 (57.5)	0.297
Age (years); mean (Stephenson <i>et al.</i>)	37 [21-56]	39 [19-73]	0.070
Down syndrome; n (%)	39 (28.3)	76 (24.1)	0.352
Level of intellectual disability; n (%)			0.000*
Mild intellectual disability	35 (27.1)	134 (47.7)	
Moderate intellectual disability	60 (46.5)	75 (26.7)	
Severe/profound intellectual disability	34 (26.4)	72 (25.6)	
Clinical records of adults with intellectual disability (from general practitioner notes)			
Epilepsy history (any); n (%)	43 (31.2)	34 (10.8)	0.000*
Health service use - number of consultation in year prior to RCT; mean (Stephenson <i>et al.</i>)	4 [0-20]	5 [0-34]	0.212

Missing items: Age, n (cohort participants) = 1; level of intellectual disability, n (cohort participants) = 9, n (non-participant) = 34

* $p < 0.05$

Table A4. The association between changes in challenging behaviour and changes in the use of psychotropic medications (n_{review} = 559)

	Review n	Remain not used n (%)	Continue to be used n (%)	Psychotropic medication				
				Odds ratio (95%CI)	Used now, but not used in previous CHAP n (%)	Odds ratio (95%CI)	Not used now, but used in previous CHAP n (%)	Odds ratio (95%CI)
Total	559	284 (50.8)	184 (32.9)		58 (10.4)		33 (5.9)	
Challenging behaviour								
Remains not identified	286	198 (69.2)	58 (20.3)	1.0	19 (6.6)	1.0	11 (3.9)	1.0
Remains identified	153	41 (26.8)	78 (51.0)	6.5 (4.0-10.5)	20 (13.1)	5.1 (2.5-10.3)	14 (9.1)	0.9 (0.4-2.2)
Identified in current but not previous CHAP	82	30 (36.6)	32 (39.0)	3.6 (2.1-6.5)	16 (19.5)	5.6 (2.6-11.9)	4 (4.9)	0.7 (0.2-2.1)
Not identified in current but identified in previous CHAP	38	15 (39.5)	16 (42.1)	3.6 (1.7-7.7)	3 (7.9)	2.1 (0.6-7.4)	4 (10.5)	1.3 (0.4-4.5)

Figure A1. Review frequency for 138 participants between 1999-2015 ($N_{\text{review}}=697$)

Appendix 2

Supplemental details regarding identification of challenging behaviours

We evaluated challenging behaviour by scanning a checklist developed by our research team. This checklist extracts all forms of challenging behaviours listed in the Behaviour Problems Inventory for Individuals with Intellectual Disabilities – Short Form (BPI-S), the Aberrant Behaviour Checklist (ABC, second edition), and the Checklist of Challenging Behaviour (CCB).

An individual was considered to have challenging behaviour if any of the following behaviours was reported: pinching people; biting people; scratching people; hitting out at people; grabbing, squeezing, pushing or pulling people; kicking people; head-butting people; pulling people's hair; choking or throttling people; using objects as weapons against people; throwing things at people; tearing other people's clothes; making unwanted sexual contact; picking scabs, head banging; inserting objects into nose, ears, anus; eye poking/gouging; biting or scratching self; damaging clothes, furniture or other objects; smashing windows; slamming doors; shouting and swearing at people; making loud noises (banging, screeching, screaming); threatening to hurt others (verbally or non-verbally); taking food or drink from others; eating inappropriate things (rubbish, faeces, dangerous objects); bizarre body postures; displaying ritualistic or repetitive behaviour (closing/opening doors, rearranging furniture, hoarding rubbish); engaging in stereotyped behaviour (body rocking, finger tapping, hand waving); manipulating (twirling, spinning) objects; showing withdrawn behaviour (difficult to reach or contact); spitting at people; deliberately soiling, wetting or vomiting; smearing or flicking faeces (or anal probing); exposing body inappropriately (stripping or masturbating in public); refusing to do things; absconding or trying to abscond from facility; causing night time disturbance.