

## International research

# Mental health service provision for adults with intellectual disability: sources of referrals, clinical characteristics and pathways to care

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### ABSTRACT

There is a certain amount of ambiguity and confusion over the provision of mental health services for people with intellectual disabilities (ID) referred by both primary care services (primary care (PC)/social services (SS)) and secondary care services (generic mental health services (GMHS)). Psychosocial and clinical characteristics of new referrals ( $n = 791$ ) were compared with regard to their source of referral. GMHS referrals were more likely to have schizophrenia spectrum disorder, personality disorder and mild ID and were more likely to be hospital inpatients and to have an

Asian ethnic origin. PC/SS referrals were more likely to live in supported housing and require further involvement from the specialist service. These findings suggest that services are operating at two different levels, i.e. secondary and tertiary, depending upon particular service-user characteristics. Implications for the accessibility of different services and care pathways of adults with ID and mental health problems are discussed.

**Keywords:** care pathway, intellectual disability, mental health services, source of referral

### Introduction

Evidence has suggested that adults with intellectual disabilities (ID) are at an increased risk of developing mental health problems.<sup>1</sup> It has been estimated that as many as 50% may have a significant psychiatric problem, with a considerable proportion contacting mental health services at some point in their life.<sup>2</sup> In the past, psychiatrists have typically conducted the mental healthcare of this population on the wards of

long-stay NHS hospitals for people with ID. However, following de-institutionalisation and the shift towards community life, there has been no real consensus as to who should now provide these services.<sup>3,4</sup> While there has been an obvious attempt by the government to integrate mental health provision for people with ID with generic (mainstream) mental health services,<sup>5</sup> there are still many who

believe that specialist mental health teams should provide specific care for this highly vulnerable group.<sup>4</sup>

To approach this important issue, there has been recent research into the care pathways and outcomes for adults with ID and mental health problems. In one study, Xenitidis *et al* compared the service outcomes of a specialist mental health unit in south-east London to mainstream mental health units in the area.<sup>6</sup> They found the specialist unit to be an effective alternative to the generic units on several different outcome measures such as psychopathology, global functioning, behavioural impairment and severity of mental illness.<sup>6</sup>

As well as investigating the effectiveness of services, it is also necessary to identify which people are referred to different services, for what reason, and by whom. Raitasuo *et al* examined the demographic, medical and psychosocial characteristics of new referrals to a special psychiatric unit for adults with ID.<sup>7</sup> They found the typical referral to this unit to be young, male, with a mild ID. Typical referrals would also have had a previous psychiatric diagnosis, and would have been referred because of their affective symptoms and/or disruptive behaviour. Their finding that psychiatric inpatients are most likely to have a mild level of ID has been prominent throughout the research on this population.<sup>8–10</sup> Driessen *et al* identified further characteristics associated with the psychiatric referral of those with ID such as older age, higher levels of functioning and living alone.<sup>11</sup>

From this previous research, we have a good idea of the individual characteristics that predict referral to mental health services, as well as the typical reasons for this referral. Often overlooked, however, are the care pathways of these referrals (i.e. which services are accessed prior to referral). Since people with ID are rarely able to initiate the referral process themselves, their care pathway is highly dependent upon those around them (such as relatives, general practitioners (GPs), social workers, friends etc). Source of referral (SoR) may be associated with particular clinical characteristics, and therefore might also be an important factor in predicting the type of service that people with ID are likely to receive.

While recent studies have explored SoR in mental health services for children with ID,<sup>12,13</sup> there is no known research of this kind within the adult population. Picton and Karki found that among children with ID, those with mild ID were the most likely to be diagnosed with a mental disorder and to have been referred by a GP, whereas those with severe ID were the most likely to have been referred by a consultant paediatrician.<sup>13</sup>

The current study explores the profiles of those referred to a mental health service for adults with ID that accepts referrals from both primary care services (i.e. primary care (PC)/social services (SS))

and secondary care services (i.e. generic mental health services (GMHS)). Clinical and sociodemographic comparisons are then carried out between those referred from each source. We predicted that GMHS referrals would have more severe psychiatric disorders (such as schizophrenia) than those referred from primary care services, because severe disorders are the most likely to have required urgent hospital attention during acute episodes. On the basis of previous evidence,<sup>7,10</sup> we also expected to find a higher proportion of GMHS referrals with mild ID. Finally, due to the different natures of the referral services, we expected to discover variations in sociodemographic data, for example more PC/SS referrals living in supported housing, and more GMHS referrals being hospital inpatients.

## Methods

### Participants

We studied new referrals (791) to a mental health service for people with intellectual disabilities (MH-ID) in south-east London between 1983 and 2003. Participants were between the ages of 16 and 86 years (mean = 33.5, standard deviation (SD) = 13.5), of whom 61% were male and 39% were female. All participants fulfilled the eligibility criteria for intellectual disability of having an IQ below 70 and significant social impairment based on ICD-10 clinical criteria. Participants were grouped by their source of referral (SoR), depending on whether they had been referred from primary care services (i.e. PC/SS), or secondary care services (i.e. GMHS).

### Assessment

Data were collected on a specially designed form, to gather both clinical and socio-demographic information.<sup>14</sup> Clinical diagnoses were made by a psychiatrist following clinical interviews with key informants and the patients as part of delivering a clinical service. Two experienced psychiatrists agreed further on the diagnosis by using ICD-10 clinical criteria. Historical details of early social and communication problems were obtained from past medical records. The degree of intellectual disability was coded on ICD-10 criteria into mild (F70), moderate (F71) or severe (F72–73), and the presence of autistic spectrum disorders by a diagnosis of pervasive developmental disorder (F84). Psychiatric diagnosis was coded to the following major ICD-10 categories: schizophrenia spectrum disorder (F20–27), personality

disorder (F60–69), anxiety (F40–48), depressive disorder (F32–39), adjustment reaction (F43), and dementia (F00–03).

## Analysis

Using the statistical package SPSS 12.0.1 for Windows, chi-square ( $\chi^2$ ) tests were carried out to examine possible variations in sociodemographic details, clinical diagnoses, and the action management decisions made for referrals from each source. A binary logistic regression was then performed to control for the contribution of potentially confounding demographic variables. The model used a stepwise forward method, with SoR as the dependent variable. In line with this method, the variables were added successively, according to their magnitude of correlation with the dependent variable, and then were successively removed until the predictive ability of the regression model, as indexed by the model chi-square ( $\chi^2$ ), was not significantly improved.

## Results

Table 1 shows the sociodemographic details of participants from each source of referral. Preliminary analysis revealed that there were no statistically significant changes in the referral pathways over the 20 years of data collection ( $P > 0.10$ ). The total number of participants in each group is shown according to their sex, age, ethnicity, and place of residence.

Statistical comparisons of the SoR groups revealed significant differences in sex ( $\chi^2 = 6.46$ , degrees of freedom (df) = 1,  $P = 0.01$ ), ethnicity ( $\chi^2 = 7.06$ , df = 2,  $P = 0.03$ ) and place of residence ( $\chi^2 = 69.74$ , df = 4,  $P < 0.001$ ). The significant effect in sex was due to there being a higher proportion of female referrals from PC/SS (42.9%) than from GMHS (33.8%). No significant differences were found in the ages of participants in each group.

Further analysis of the ethnicity data showed that people referred from GMHS were more likely to be

**Table 1** Sociodemographic data: the number and percentage of participants in each SoR group by different sociodemographic measures

	Source of referral	
	Primary care/social services <i>n</i> (%)	Generic mental health services <i>n</i> (%)
<b>Gender*</b>		
Male	281 (57.1)	198 (66.2)
Female	211 (42.9)	101 (33.8)
<b>Age group (years)</b>		
<24	152 (30.9)	111 (37.1)
25–34	123 (25.0)	84 (28.1)
35–44	105 (21.3)	55 (18.4)
45–54	65 (13.2)	28 (9.4)
55+	47 (9.6)	21 (7.0)
<b>Ethnicity*</b>		
White*	391 (79.5)	218 (72.9)
Black	71 (14.4)	48 (16.1)
Other non-white*	30 (6.1)	33 (11.0)
<b>Place of residence*</b>		
Family home*	216 (43.9)	155 (51.8)
Hospital inpatient*	12 (2.4)	40 (13.4)
Independent	50 (10.2)	44 (14.7)
Supported housing*	213 (43.3)	59 (19.7)
Other	1 (0.2)	1 (0.3)

\* Significant  $P$  value ( $\chi^2$  tests)

from the 'other-non-white' (predominantly Asian) ethnic group (11.0%) than those referred from PC/SS (6.1%) ( $\chi^2 = 6.19$ ,  $df = 1$ ,  $P = 0.01$ ), and that people referred from PC/SS were more likely to be 'white' (79.5%) than those referred from GMHS (72.9%) ( $\chi^2 = 4.52$ ,  $df = 1$ ,  $P = 0.03$ ).

Further analysis of the 'place of residence' data revealed a number of significant effects. Firstly, participants referred from GMHS were more likely to be living in their family home (51.8%) than those referred from PC/SS (43.9%) ( $\chi^2 = 4.70$ ,  $df = 1$ ,  $P < 0.03$ ), and were more likely to be hospital in-patients (13.4%) than those referred from PC/SS (2.4%) ( $\chi^2 = 36.23$ ,  $df = 1$ ,  $P < 0.001$ ). PC/SS referrals were more likely to be living in supported housing (43.3%) than GMHS referrals (19.7%) ( $\chi^2 = 45.76$ ,  $df = 1$ ,  $P < 0.001$ ), and while there was a trend towards more GMHS referrals living independently (14.7%) compared to PC/SS referrals (10.2%), this did not quite reach statistical significance ( $\chi^2 = 3.68$ ,  $df = 1$ ,  $P = 0.06$ ).

Table 2 shows the clinical characteristics of participants in each SoR group. The number of participants is given according to their degree of ID, the presence of autistic spectrum disorders, and their psychiatric diagnosis.

A significant difference was found between the groups in level of ID ( $\chi^2 = 29.20$ ,  $df = 1$ ,  $P < 0.001$ ),

with GMHS referrals being more likely to have a mild ID (75.9%) than PC/SS referrals (56.9%). There was also a significant difference in psychiatric diagnosis between the groups ( $\chi^2 = 37.21$ ,  $df = 7$ ,  $P < 0.001$ ), but not in the diagnosis of autistic spectrum disorder.

Participants referred from GMHS were more likely to have a diagnosis of schizophrenia spectrum disorder (25.4%) than those referred from PC/SS (13.6%) ( $\chi^2 = 17.49$ ,  $df = 1$ ,  $P < 0.001$ ), and were more likely to have a diagnosis of personality disorder (11.4%) than those referred from PC/SS (4.7%) ( $\chi^2 = 12.47$ ,  $df = 1$ ,  $P < 0.001$ ). PC/SS referrals were more likely to have no diagnosable psychiatric disorder (50.4%) than those referred from GMHS (38.8%) ( $\chi^2 = 10.09$ ,  $df = 1$ ,  $P = 0.001$ ), and higher rates of dementia (4.5%) than GMHS referrals (1.7%) ( $\chi^2 = 4.42$ ,  $df = 1$ ,  $P = 0.04$ ).

Table 3 shows the clinical action management decisions that were made for participants in each SoR group. The number of people is given according to the perceived need for further involvement from the mental health service for people with ID, admission to an adult psychiatric unit, or referral to adult mainstream psychiatric outpatients.

There were found to be significant differences between the groups in all three of the clinical action management decisions made: people referred from GMHS were more likely to require admission to an

**Table 2** Clinical data: the number and percentage of participants in each SoR group by different clinical measures

	Source of referral	
	Primary care/social services <i>n</i> (%)	Primary care/social services <i>n</i> (%)
<b>Degree of intellectual disability*</b>		
Mild	280 (56.9)	227 (75.9)
Moderate/severe	212 (43.1)	72 (24.1)
<b>Autistic spectrum disorder</b>		
No	393 (79.9)	246 (82.3)
Yes	99 (20.1)	53 (17.7)
<b>Psychiatric diagnosis*</b>		
No diagnosis*	248 (50.4)	116 (38.8)
Schizophrenia spectrum disorder*	67 (13.6)	76 (25.4)
Personality disorder*	23 (4.7)	34 (11.4)
Anxiety disorder	36 (7.3)	20 (6.7)
Depressive disorder	48 (9.8)	25 (8.4)
Adjustment disorder	32 (6.5)	14 (4.7)
Dementia*	22 (4.5)	5 (1.7)
Others	16 (3.3)	9 (3.0)

\* Significant *P* value ( $\chi^2$  tests)

**Table 3** Management action data: the number and percentage of participants in each SoR group by different management action decisions

	Source of referral	
	Primary care/social services <i>n</i> (%)	Primary care/social services <i>n</i> (%)
<b>Further involvement from MH-ID service*</b>		
No	130 (26.4)	107 (35.8)
Yes	362 (73.6)	192 (64.2)
<b>Admission to adult psychiatric unit*</b>		
No	449 (91.3)	258 (86.3)
Yes	43 (8.7)	41 (13.7)
<b>Referral to adult psychiatric outpatients*</b>		
No	466 (94.7)	268 (90.0)
Yes	26 (5.3)	30 (10.0)

\* Significant *P* value ( $\chi^2$  tests)

adult psychiatric unit (13.7%) than those referred from PC/SS (8.7%) ( $\chi^2 = 4.85$ , *df* = 1, *P* = 0.03), and were more likely to need further input from adult mainstream psychiatric outpatients (10.0%) than those referred from PC/SS (5.3%) ( $\chi^2 = 6.38$ , *df* = 1, *P* = 0.01), whereas people referred from PC/SS were more likely to require further involvement from the mental health service for people with ID (73.6%) than those referred from GMHS (64.2%) ( $\chi^2 = 7.77$ , *df* = 1, *P* = 0.005).

Table 4 summarises the logistic regression model, which uses SoR ('GMHS' versus 'PC/SS') as the dependent variable. The variables that showed significant effects in the previous  $\chi^2$  tests were entered in the equation as binary covariates. This model was

significant ( $\chi^2 = 135.803$ , *df* = 7, *P* < 0.001,  $-2 \log$  likelihood = 913.186), accounting for about 22% of the variance (Nagelkerke  $R^2$ ). Having controlled for all other variables, significant effects remained in seven of the variables. While supported housing residence and further involvement from the service had negative associations with referral from GMHS, all the other variables were associated positively. Both schizophrenia spectrum and personality disorders were more than twice as likely to be found in GMHS referrals as in PC/SS referrals, but the highest odds ratio was for being a hospital inpatient, which was 4.9 times more likely among GMHS referrals than PC/SS referrals.

**Table 4** Regression model predicting referral from 'GMHS' versus 'PC/SS'

	Odds ratio	95% confidence interval	<i>P</i>
Supported housing	0.39	0.27–0.55	<0.001
Hospital inpatient	4.89	2.41–9.93	<0.001
Mild ID level	1.96	1.36–2.83	<0.001
Schizophrenia spectrum disorder	2.09	1.38–3.15	<0.001
Personality disorder	2.67	1.44–4.95	<0.005
Further involvement with MH-ID service	0.58	0.41–0.81	<0.005
Other non-white ethnic group	1.76	1.01–3.06	<0.05

## Discussion

### Clinical findings

The main clinical findings of this study are that GMHS (secondary care service) referrals were more likely to receive diagnoses of schizophrenia spectrum disorder and personality disorder, and were more likely to have a mild ID than PC/SS (primary care service) referrals. This suggests that the MH-ID service is operating at two different levels, depending on its service-user characteristics: a secondary level for people with more severe ID, and a tertiary level for people with more severe mental disorders (i.e. schizophrenia spectrum and personality disorders). The double role of the specialist MH-ID service seems similar to some specialist mental health services (e.g. child and adolescent, old age), but different from others (e.g. home treatment teams, mothers and babies, eating disorders etc) that operate at a tertiary level. It also appears that both levels of operation in the specialist MH-ID service are determined by particular service-user characteristics. There clearly remains a number of accessibility issues for certain people with ID, despite the government's attempts to integrate their mental health provision with GMHS.<sup>5</sup>

The finding that people with severe mental illnesses are the most likely to have come from GMHS was predicted because of the urgent psychiatric attention required for more severe disorders. In the acute stages of schizophrenia, for example, an individual is likely to show drastic changes in behaviour with 'positive' symptoms such as hallucinations, delusions, and strange thinking; i.e. the kind of behaviour likely to prompt an emergency admission to hospital. The same might be said about the complex, often very challenging display of behaviours accompanying personality disorder. It is also possible that these severe disorders might overshadow the usual symptoms of ID until after an admission to GMHS has been made. However, disorders such as anxiety and depression, which are not so debilitating, may not generate the same sense of urgency in finding treatment. This might explain why there were no such differences between referral groups in these 'less severe' diagnoses.

The other clinical finding that people with mild ID are more likely to have accessed GMHS than people with moderate/severe ID was also predicted because of similar findings in previous research.<sup>7,10,15</sup> In a US study, Reiss *et al* suggest that such effects may be explained by 'diagnostic overshadowing' in the assessment of people with ID.<sup>15</sup> They claim that ID decreases the diagnostic importance of abnormal behaviour, and that this is most likely to influence

the assessment of adults with severe ID. 'Diagnostic overshadowing' in ID assessment has also been identified more recently among clinicians in the UK.<sup>16</sup> This may contribute to the under-representation of adults with severe ID being admitted for psychiatric assessment in GMHS. Another explanation may simply be that GMHS are not prepared to accept people with severe ID onto their wards because of inadequate staff training, or lack of confidence and expertise. Further, the ongoing concern of 'bed-blocking' in GMHS hospitals may come into consideration when planning care for those with severe ID.

### Sociodemographic findings

The sociodemographic comparisons showed that GMHS referrals were more likely to be of an 'other non-White' ethnic origin (predominantly Asian in our sample), and to be hospital inpatients, while PC/SS referrals were more likely to live in supported housing. The differences in place of residence are to be expected because of the very nature of referral services. However, the finding that GMHS referrals were more likely to be of an 'other non-white' (mainly Asian) ethnic origin is more intriguing, and may be due to ethnic differences that have been found in the psychiatric diagnoses of adults with ID.<sup>10,16,17</sup> Chaplin *et al* found functional psychosis to be more common among Asian people with ID than controls,<sup>16</sup> and Maitland *et al* noticed that a predominantly Asian ID group were more likely than both a black and a white group to be diagnosed with schizophrenia.<sup>17</sup> It may be that an increased incidence of severe mental illness in Asian populations can account for the disproportionate number of 'other non-white' GMHS referrals in this sample.

### Management decision findings

Regarding the clinical management decisions made, PC/SS referrals were more likely than GMHS referrals to require further involvement from the mental health service for people with ID. A consideration of the alternative action management decisions (i.e. admission to adult psychiatric unit, or referral to adult psychiatric outpatients) makes it easier to interpret this finding. Since PC/SS referrals were more likely to have severe ID and less likely to have severe mental disorders, it is doubtful that many would require, or benefit from a move into the mainstream psychiatric services. Instead, it might be preferable for them to be cared for by the specialist MH-ID service, where staff is better trained to deal

with severe ID. Conversely, the mental health needs of many of those with mild ID could be met, in line with the government policy, within mainstream mental health services.

## Conclusion

Having identified some of the characteristics that determine the care pathway of adults with ID and mental health problems, we are in a better position to find ways of implementing government policy.<sup>5</sup> If the specialist mental health service for ID is to be brought in line with other specialist mental health services by operating at a tertiary level, there has to be far better access into GMHS for adults with moderate/severe ID. For this to happen, GMHS have to make their services more suitable for people with moderate/severe ID, maybe by providing staff with more specialised training, advice and support for specialist mental health services. Also, clinicians must be more aware of the dangers of 'diagnostic overshadowing' by making sure that mental health problems are not overlooked, and that people with moderate/severe ID have access to GMHS when necessary.

A possible limitation to the current study is that there was no knowledge of care pathways prior to the immediate SoR, and it may be that someone was referred to a number of different services before their referral to the specialist service. Future research might therefore gather complete referral histories, providing a better picture of access pathways to services. More studies of this kind may help to end the ambiguity and confusion by highlighting the development required to provide an explicit care pathway for this highly vulnerable population. Another potential limitation is that the present sample was drawn from an inner-London area, and therefore, the findings might not be entirely representative of non-urban areas or services outside the UK. Consequently, similar future studies in non-urban areas as well as in other countries would be both informative and methodologically desirable. With people with ID living in the community, and the increasing emphasis on their integration and social exclusion, the present study is of particular relevance to primary care and GPs (who may or may not be aware of the various interface issues in psychiatry of learning disability) as it draws particular attention to complex issues on the relationship between client characteristics, clinical decision management and pathways to care for this particularly vulnerable population.

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#### CONFLICTS OF INTEREST

None.

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