The psychiatric care of people with intellectual disabilities: the perceptions of consultant psychiatrists in Victoria

Nicholas Lennox, Robert Chaplin

Objective: This study was undertaken to establish the perceptions of psychiatrists regarding the care of people with intellectual disabilities.
Method: A 28-item self-administered questionnaire was developed, piloted and sent on two occasions to 467 psychiatrists who receive the newsletter of the Victorian branch of the Royal Australian and New Zealand College of Psychiatrists. The questionnaire incorporated a Likert scale to document the opinions of the respondents.
Results: A response rate of 51.1 % was achieved. The respondents indicated that, in their opinion, people with intellectual disabilities receive a poor standard of care in the inpatient and community setting. To improve this situation, the following strategies were recommended: the development of improved liaison between services; improved training for all personnel who provide services to people with intellectual disabilities; the development of greater resources; and support for professionals working in the area. The study also indicates that there is a core group of very interested psychiatrists who are currently practising and that people with intellectual disabilities are accessing private psychiatric services. In addition, the results suggest that diagnostic overshadowing is not a major barrier to psychiatric assessment, and that disorders which were presumed to be commonly overlooked by doctors (such as depression) are in fact frequently being diagnosed.
Conclusions: Despite some positive findings, the majority of psychiatrists who responded held major concerns about the situation of people with intellectual disabilities. To improve the care provided to these people, it is recommended that these concerns are addressed by the psychiatric profession and responsible government departments in conjunction with university departments of psychiatry.

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Developmental Disability Unit, Department of Public Health and Community Medicine, University of Melbourne, Carlton, Victoria, Australia

Nicholas Lennox MBBS, BMedSc, FRACGP, Head

St Georges Hospital, London, United Kingdom

Robert Chaplin MBChB, MRCPsych, Consultant Psychiatrist

In Australia, the psychiatric care of people with intellectual disabilities who have a psychiatric disorder (i.e. people with a dual disability) has been an area of considerable concern to psychiatrists and researchers [1–6], governments [7] and a Royal Commission [8]. In December 1995, we reported the

findings of a survey which examined the perceptions of trainee psychiatrists and psychiatric medical officers [9]. This survey indicated that junior medical staff had major concerns regarding the care of people with dual disabilities. To gain a more comprehensive understanding of the situation, the same survey was undertaken involving psychiatrists throughout Victoria. This survey helps to determine the clinical experience of psychiatrists and their views regarding the quality of care provided to people with intellectual disabilities in Victoria.

Method

A 28-item self-administered questionnaire was developed by the investigators. It was pretested on eight psychiatrists and psychiatric trainees, and then revised following an analysis of their comments.

The questionnaire was divided into five sections. The first section requested information about patients with intellectual disabilities who had been reviewed by the respondents, including the number of patients assessed, the setting in which the patients were most often assessed, and the types of diagnosis which were commonly made. In section II, the respondents were asked to state their opinions regarding the management of people who have both intellectual disabilities and mental disorders (i.e. people with dual disabilities). Eighteen statements of opinion where presented to the respondents and their responses were recorded on a six-point Likert-like scale with responses ranging from 'very much agree' to 'very much disagree'. In section III, the respondents were asked to recommend strategies for improving psychiatric and community services for people with intellectual disabilities. This section allowed the respondents to elaborate on the opinions expressed in section II, and to introduce other issues which they deemed to be relevant to the issue of service provision for people with intellectual disabilities.

The final two sections requested demographic information about the respondents. The respondents were also asked to state whether they had a special interest in the psychiatry of intellectual disability.

On two occasions the questionnaires were mailed out (accompanying a monthly newsletter) to the 467 subjects. Subjects were Fellows of the Royal Australian and New Zealand College of Psychiatrists (RANZCP) and were residents in Victoria. It is of note that the Health Insurance Commission (a government organisation which funds, at least in part, the cost of all consultations by registered medical practitioners in Australia) stated that 444 psychiatrists had their major practice location in Victoria, indicating that some subjects in our sample population were either retired, on extended periods of leave or working on a very part-time basis.

The data from the questionnaires were entered on a computer database. The SAS computer statistical program was used to analyse the data and to express the results as percentages.

Results

Two hundred and twenty-seven of the questionnaires were completed and returned, resulting in a response rate of 48.6%. If the number of psychiatrists provided by the Health Insurance Commission (HIC) is utilised (in which 444 psychiatrists were reported to be involved in significant clinical practice at the time of the questionnaire being delivered), the response rate may be adjusted to 51.1%.

The majority of the respondents were male (78%) and 50% had graduated from medical school since 1971. Seventy-four percent of the respondents (205) indicated that they had managed patients with intellectual disability in the last 6 months. The majority (59%) of respondents indicated that they had a small case load (1–5); 14% of respondents managed 6 to 15 patients and 4% of respondents managed over 15 patients.

Fifty-four percent of respondents stated that the majority of their consultations with people with intellectual disabilities took place in the public setting: for 21% of respondents, most consultations occurred in the public inpatient setting, while for the other 33%, most consultations occurred in public outpatient clinics. The other 46% of respondents stated that the majority of their consultations with people with intellectual disabilities took place in the private setting: for 43% of respondents, most consultations occurred in a private outpatient setting, while for 3%, most consultations occurred in a private inpatient setting.

The respondents were asked to rank the three most common diagnoses which they had assigned to their patients with intellectual disabilities (Table 1). The high ranking of behaviour disorders and schizophrenia was expected. However, the relatively high ranking of neurotic and depressive disorders indicates these disorders are not being largely overlooked

Table 1. Ranking of descriptive diagnostic groupings (n=162)

Descriptive diagnostic groupings	Most common		Second most common		Third most common	
	n	%	n	%	n	%
Behaviour disorder	62	38	29	18	19	12
Schizophrenia	40	25	28	17	26	16
Neurotic or adjustment disorder	19	12	36	22	15	9
Unipolar depression	12	7	10	6	13	8
Other	10	6	3	2	13	8
Organic	9	6	17	11	19	12
Personality disorder	7	4	16	10	19	12
Bipolar affective disorder	5	3	14	9	9	6

in people with intellectual disabilities, as was once believed.

The subjects were required to respond to 18 statements regarding the management of people who have both intellectual disabilities and psychiatric disorders (dual disabilities). These responses are presented in Table 2. Eighty-five percent of psychiatrists who responded to the questionnaire supported the proposition that people with dual disabilities received a relatively poor standard of care. The majority of the respondents agreed strongly or very strongly with this proposition.

With regard to the issue of inpatient admission, over 70% of respondents believed that the acute admission ward was not adequately suited to the needs of people with dual disabilities. It was also felt that people with dual disabilities were exploited by other patients during inpatient admission, and that they stayed too long in psychiatric beds. Almost 90% of the respondents considered that a higher standard of care would be provided by specialised units, and that these units should be available. Indeed, most respondents agreed that a subspecialised group in psychiatry should be responsible for the treatment of people with dual disabilities.

Most of the respondents also believed that inadequate community resources led to the over-prescription of antipsychotic drugs, and that referral and liaison with intellectual disability services was not easy.

Over 75% of respondents agreed they had not received sufficient training in the general or behavioural management of people with dual disabilities. In addition, there was almost universal support for the proposal that psychiatric registrars (trainee psychiatrists) should have the opportunity to train in dual disability.

Thirty-nine per cent of the respondents agreed that they personally would prefer not to treat people with dual disabilities.

In section III, 71% of respondents made written comments on how psychiatric and community services for people with intellectual disabilities could be improved.

The most commonly identified themes were as follows: the current level of training of all professionals who provided care for people with dual disabilities was inadequate; there was a need to reduce the 'anti-psychiatry attitude' of the non-psychiatric staff; there was a need to increase liaison between psychiatric and intellectual disability services; a specialised service should be developed for people with dual disabilities; and sufficient funding should be made available to attract professionals to the area and to improve resources for people with dual disabilities.

The respondents stated that many of the problems could be addressed if all staff working in the field received training relating to the psychiatry of intellectual disability. More specifically, it was emphasised that residential care staff and intellectual disability services staff needed training in (i) the identification and management of psychiatric disorders, and (ii) the use of medications in people with dual disabilities. Many respondents also expressed the need to improve training for psychiatrists in the area of assessment, diagnosis and treatment of people with dual disabilities. Noting the inadequate liaison between psychiatric and intellectual disability staff, psychiatrists believed that training would allow

Table 2. The management of people with dual diagnosis: responses to statements

Statements	Agree (%)						Disagree (%)					
	Very much		Moderately		A little		A little		Moderately		Very much	
	n	%	n	%	n	%	n	%	n	%	n	%
Training												
Psychiatrists receive sufficient training to manage people with dual disabilities (n = 192).	5	3	16	8	22	12	31	16	74	39	44	23
Psychiatrists receive sufficient training in behavioural management of people with dual disabilities (n = 193).	4	2	11	6	19	10	38	20	77	40	44	23
The psychiatry of dual disability should be offered as a training option for all psychiatric registrars (n = 193).	72	37	57	30	51	26	4	2	7	4	2	1
Standard of psychiatric care												
People with dual disabilities are exploited by other patients during inpatient admission (n = 186).	16	9	54	29	70	38	32	17	13	7	1	1
The acute admission ward is adequately suited to the needs of people with dual disabilities (n = 186).	2	1	18	9	20	10	29	15	80	42	43	22
People with dual disability receive a relatively poor standard of psychiatric care (n = 191).	41	22	66	35	56	29	14	7	9	5	5	3
Specialised units and subspecialisation												
If available, psychiatric care should be provided in units which specialise in the care of people with dual disabilities (n = 193).	76	39	73	38	20	10	14	7	7	4	3	2
Specialised psychiatric units for people with dual disabilities would provide a higher standard of care (n = 193).	60	31	74	38	39	20	10	5	7	4	3	2
A subspecialty of psychiatry should be responsible for the treatment of people with dual disabilities (n = 192).	38	20	52	27	58	30	23	12	16	8	5	3
Inpatient and community care												
People with dual disabilities commonly stay too long in psychiatric beds (n = 178).	27	15	46	26	59	33	31	17	12	7	3	2
It is easy to refer and liaise with intellectual disability services (n = 186).	1	1	11	6	20	11	34	18	56	30	64	34
Inadequacy of community support services often make the prescription of antipsychotic drugs necessary (n = 193).	33	17	48	25	55	29	27	14	18	9	12	6
Antipsychotic drugs are over-used in the control of aggressive behaviour (n = 187).	19	10	47	25	59	32	31	17	23	12	8	4
Rehabilitation beds in psychiatric hospitals should be available for their management (n = 189).	25	13	67	35	39	21	15	8	26	14	17	9
Attitudes/judgements of respondents												
Personally I would prefer not to treat people with dual disabilities (n = 188).	17	9	21	11	35	19	45	24	45	24	25	13
There is seldom the need to investigate psychiatric symptoms in the more severely intellectually disabled (n = 192).	2	1	7	4	3	2	33	17	64	33	83	43
Individual supportive psychotherapy is a useful treatment (n = 192).	31	16	51	27	77	40	14	7	13	7	6	3
Psychiatric treatment of these people is usually symptomatic, rather than based on diagnostic classification (n = 191).	13	7	56	29	63	33	34	18	20	11	5	3

improved communication between, and understanding of, each others' services and disciplines.

A number of senior psychiatrists noted a deterioration of psychiatric services for people with dual disabilities over the time of their professional life. They attributed this deterioration to a shift towards a philosophy of 'normalisation', and to the demedicalisation of the field.

Considerable anger was expressed concerning the treatment of psychiatrists who had previously worked with people with dual disabilities. Many respondents perceived that there is an 'antimedical', and in particular 'antipsychiatric', attitude shown by some service providers. An example of this perception is provided in the following statement made by one respondent: 'they (the current service providers) have "thrown the baby out with the bath water" with their antimedical approach and alienated the medical practitioners they and their clients need'.

There was significant concern expressed regarding the quality of care of people with dual disabilities. Many psychiatrists felt pessimistic about the chances of improving the situation without major changes in the attitude of the community, the structure of the current system, and the professionals involved.

There was a call to improve the support for family-based carers and residential care staff. Respondents believed that the morale and motivation of the residential care staff was low, and that there was a need to reduce the high staff turnover in the residences. In addition, there was support for a greater number of community residential units, higher staff–client ratios, a greater range of residential options for people with dual disabilities, and an increase in the vocational or recreational activities offered.

Respondents strongly advocated the development of specialised units for the psychiatry of intellectual disability. It was envisaged that such units would become centres of excellence and provide training opportunities, support the generic services, and undertake research. The establishment of subspecialisation within psychiatry was supported; however, some respondents were concerned that full-time work in such an area may be too draining for the psychiatric personnel involved.

Twenty-eight per cent of the respondents were interested in further training in the psychiatry of intellectual disability. In addition, 22 psychiatrists (10% of respondents) reported that they had developed a special interest in the management of people with intellectual disabilities and mental disorders.

Discussion

The psychiatrists who responded to this study agreed that people with intellectual disabilities received a generally poor standard of care. The inpatient environment was considered unsuitable, and people with intellectual disabilities were felt to be at risk of exploitation by other patients. These concerns also applied to the community setting, with a perception that antipsychotic drugs were over-prescribed for behavioural control, perhaps as a result of inadequate staff numbers and training. In addition, nearly all respondents indicated that they had experienced major difficulties in liaison with intellectual disability services. These concerns are alarming, but perhaps not surprising, given the similar views expressed by their junior colleagues [9]. It is apparent that psychiatrists are faced with caring for a group of people whom they believe, despite presumably their best efforts, they are not able to deliver a satisfactory standard of care. This situation is a recipe for exasperation, exhaustion and eventually disinterest.

In fact, more psychiatrists (39%) agreed that they would prefer not to treat people with intellectual disabilities than their junior colleagues (30%). However, 61% of psychiatrists rejected the proposition and, indeed, 37% of the psychiatrists disagreed either moderately or very much with the proposition. What is more disturbing is that when the subgroup of psychiatrists who managed five or more people with intellectual disabilities in the last 6 months were isolated, 19% of this group agreed that they really did not want to treat people with intellectual disabilities.

However, some positive conclusions are suggested by these results. First, psychiatrists generally supported the proposal that intellectual disability should be available as an option to psychiatric trainees. The proposal that community services staff should receive education about mental disorders was also endorsed. Second, with regard to the disorders commonly diagnosed in people with dual disabilities, it was encouraging to see that neurotic and depressive disorders, which can be overlooked, were frequently encountered by some psychiatrists. It must be noted, however, that any discussion of psychiatric diagnoses in people with intellectual disability must take into account the difficulties associated with making a reliable and valid diagnosis. This is especially true among people with moderate or more severe disabilities [10]. Third, the respondents universally support-

ed the investigation of psychiatric symptoms in the severely disabled. This suggests that consultants are not falling into the trap of diagnostic overshadowing [11] as suggested by Parmenter [6]. Finally, within the psychiatric profession there is evidently a core of consultants (10 % of respondents) who have a special interest in the care of people with intellectual disabilities. The responses of this group indicated a clear interest in trying to improve the care provided to people with dual disabilities.

Although there are some positive aspects to these results, they are still cause for considerable concern. There is clearly a need for the professionals, families and other service providers who work with people with intellectual disabilities, in addition to government department/s, academic institutions and the psychiatric profession, to address the concerns documented in this paper.

The government department/s responsible need to encourage better liaison, training, resources and support for the professionals who provide services to people with intellectual disabilities. The two groups, psychiatric services and intellectual disability services (IDS), desperately need to be better integrated. In addition, active steps are required to diminish the mutual antagonism felt by psychiatrists and IDS staff. The considerable contributions which can be made by the psychiatric profession have to be drawn back to the care of people with intellectual disabilities. In Victoria, where government and university departments have worked together, some of the problems highlighted by these surveys can start to be addressed.

This, however, is not a one way street because in spite of the major concerns of individual psychiatrists there are only pockets of interest throughout Australia. In Sydney, a dual disability interest group has met on a regular basis for a number of years and a similar group has recently started meeting in Melbourne. Both the University of Melbourne and Monash University Developmental Disability Units have a psychiatrist who has major focus on adults with dual disabilities. For the first time in Australia the University of Melbourne has a psychiatric training position in dual disability which has been operating for the last 2 years. The RANZCP supported this study and the recent FRANZCP Fellowship examinations have included questions on the psychiatry of intellectual disability. The College, however, has yet to develop policies or specific initiatives to address the concerns of its members and trainees.

Furthermore, research funds to investigate the diagnosis, management and service provision aspects of dual disability have not been readily available. Only one major project has received significant funding through the National Health and Medical Research Council (NH&MRC). The NH&MRC could facilitate this by classifying dual disability as a research priority or special initiatives area.

The results of these two papers demonstrate an urgent need for the government, RANZCP and academic departments to actively cooperate and address what can only be described as an appalling situation. To shrink from these responsibilities could only be seen as perpetuating the neglect of one of the most vulnerable groups in Australia.

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