

# The General Practice Care of People With Intellectual Disability: Barriers and Solutions

N. G. Lennox<sup>1</sup>, J. N. Diggins<sup>1</sup> and A. M. Ugoni<sup>2</sup>

<sup>1</sup> Developmental Disability Unit, Department of Public Health and Community Medicine, The University of Melbourne, Carlton, Victoria, Australia

<sup>2</sup> Epidemiology and Biostatistics, Department of Public Health and Community Medicine, The University of Melbourne, Carlton, Victoria, Australia

## Abstract

A questionnaire exploring general practitioners' (GPs) perceptions of the barriers and solutions to providing health care to people with intellectual disability was sent to 912 randomly selected GPs throughout Australia. A response rate of 58% was obtained. Results indicated that numerous barriers compromise the quality of health care able to be provided to people with intellectual disability. Communication difficulties with patients and other health professionals, and problems in obtaining patient histories stood out as the two most significant barriers. A range of other barriers were identified, including GPs' lack of training and experience, patients' poor compliance with management plans, consultation time constraints, difficulties in problem determination, examination difficulties, poor continuity of care, and GPs' inadequate knowledge of the services and resources available. General practitioners also suggested numerous solutions to these barriers, and emphasized the need for increased opportunities for education and training in intellectual disability. The GPs showed an overwhelming willingness to be involved in further education. Other major solutions included increasing consultation duration or frequency, proactively involving families and carers in patients' ongoing health care, and increasing remuneration.

**Keywords:** general practice; health care; barriers; solutions; general practitioners

## Introduction

The primary health care of people with intellectual disability has been squarely placed in the hands of general practitioners (GPs) since the global shift from institutional to community-based care. However, studies which assessed the care of people with intellectual disability who access community-based GPs have identified significant shortcomings (Beange 1986; Howells 1986; Ziring 1987; Beange & Bauman 1990; Wilson & Haire 1990; Beange et al. 1995). These studies demonstrate that people with intellectual disability suffer from an excessive number of unrecognized or poorly managed medical conditions. Similarly, many authors suggest there is a lack of adequate health screening and preventative care in this population (Being: 1986; Parmenter 1988; Barker & Howells 1990; Minihan & Dean 1990; Wilson & Haire 1990; Beange et al. 1995; Kerr et al. 1996b).

Many barriers to the provision of health care have been identified or commented upon. Some commonly mentioned barriers are: communication difficulties between the doctor and patient (Howells 1986; Barker & Howells 1990; Beange & Bauman 1990; Cumella et al. 1991; Minihan et al. 1993; Beange et al. 1995; Beange 1996); communication difficulties between health professionals (Cumella et al. 1992; Lennox & Chaplin 1995; Lennox & Chaplin 1996); difficulties with accessing the health care system (Crocker & Yankauer 1987; Cumella et al. 1992; Beange 1996); poor remuneration (Garrard 1982; Crocker & Yankauer 1987; Crocker 1988; Beange & Bauman 1990; Minihan & Dean 1990; Minihan et al. 1993; Beange 1996), and the difficulties that short consultations times have on history taking (Beange 1996).

Negative attitudes held by the medical professions may also influence the quality of health care provision (Garrard 1982; Murdoch 1984; Barker & Howells 1990; Minihan et al. 1993) and GPs have been shown to have a limited view of their roles and responsibilities as health care providers for people with intellectual disability (Ineichen & Russell 1987; Kerr et al. 1996a).

To surmount these barriers, a range of strategies have been recommended. These suggestions include the need to provide adequate time and remuneration for consultations (Garrard 1982; Yankauer 1986; Beange & Bauman 1990; Wilson & Haire 1990; Beange 1996) and ensure better liaison with other professionals or agencies (Cumella et al. 1992; Lennox & Chaplin 1995; Lennox & Chaplin 1996). The development of better information systems, such as registers of patients with intellectual disabilities (Cumella et al. 1992; Kerr et al. 1996a), resource and specialist referral guides (Crocker & Yankauer 1987; Ineichen & Russell 1987; Minihan et al. 1993) and easier access to an accurate medical history (Beange 1996; Burbidge 1996), has been suggested. The obvious need for providing more preventative health care (Beange 1986, 1996; Crocker & Yankauer 1987; Parmenter 1988; Beange & Bauman 1990), better health promotion (Beange et al. 1995; Beange 1996; Kerr et al. 1996b), appropriate screening by GPs (Barker & Howells 1990) or nurses (Wilson & Haire 1990), and providing regular health

reviews/examinations (Beange 1986; Beange & Bauman 1990; Cumella et al. 1992; Beange et al. 1991) has been put forward. Finally, many authors have called for an increase in medical education and training (Yankauer 1986; Crocker & Yankauer 1987; Parmenter 1988; Beange & Bauman 1990; Cumella et al. 1992; Beange et al. 1995), and the development of a medical specialty in intellectual disability (Crocker & Yankauer 1987). Despite considerable discussion about the barriers to health care and their potential solutions, opinions of the actual providers of primary health care, the GPs, have been substantially ignored.

In Australia, as in the UK, the GP is the main primary health care provider and gate keeper to specialist services, and as such, is central to the provision of health care for people with intellectual disability. Therefore, it is essential to understand the perceptions of GPs concerning the provision of this health care. By drawing upon these perceptions, the barriers to health care may be addressed and potential solutions can be put into effect.

To better understand GPs' perspectives of the barriers and solutions to providing high-quality health care to people with intellectual disability, a random sample of GPs throughout Australia was surveyed.

## Method

Following focus group and individual interviews with practising GPs on the health care of people with intellectual disability, a questionnaire was developed. This was piloted and revised on two occasions using different practising GPs. The final questionnaire consisted of 24 items, with a six-point Likert response format which ranged from 'agree strongly' to 'disagree strongly'. Included in the questionnaire package were questions covering the respondents' demographic details, work environment and patient population, levels of training in intellectual disability, willingness to participate in further training and education, and levels of personal experience with people with intellectual disability. In addition, GPs were asked to list the three most significant barriers to providing health care for people with intellectual disability, and ways in which these barriers could be overcome or minimized.

The sample was derived from a national data base provided through the Australian universal health care system, called Medicare. The Medicare system identifies all full time and part time medical practitioners who are acknowledged and registered as GPs. One thousand randomly selected GPs were contacted by telephone with a courtesy call 2 weeks prior to sending out the questionnaire. Eighty-eight GPs were then excluded from the sample because they were found to be retired, deceased, specialist practitioners or uncontactable by mail. Two weeks after the questionnaire package was sent, non-respondents received a reminder card. A second copy of the questionnaire was mailed to non-respondents at 3 weeks, which was further augmented with a reminder telephone call to the remaining non-respondents 4 weeks after the questionnaire was originally posted.

## Results

A response rate of 58% was obtained (526 out of 912 returned), after excluding 88 retired, deceased, specialist or uncontactable GPs from the sample of 1000. Sixty-eight per cent of respondents were male and 32% were female. The mean age of the respondents was 46.3 years (SD  $\pm$  10.6 years). The mean length of time that the respondents had been in general practice was 17.4 years (SD  $\pm$  9.8 years). The mean number of working hours per week was 42 (SD  $\pm$  16.8 h).

The respondents' demographic characteristics, such as gender, Fellowship of the Royal Australian College of GPs (FRACGP), and type and location of practice closely matched available national data, and can be seen in Table 1.

### Training

Sixty-five per cent of respondents had received some form of undergraduate training, either through a visit to an institution (50%) lectures/seminars (40%), and/or contact on the wards (25%). Ten per cent of respondents reported receiving postgraduate training. This included knowing someone with an intellectual disability; gaining specific experience in places of work, and more formalized postgraduate courses or continuing medical education programmes.

**TABLE 1. Comparison of respondent demographics to national figures of general practitioners (GPs)**

Demographics	Percentage of respondents	Percentage from national data
Female GPs	32	29*
GPs in solo practice	26	27†
Practice located in a capital city	61	68*
FRACGP	23	21

\*Commonwealth Department of Health and Family Services (1996)

†Royal Australian College of General Practitioners (1996); Australian Institute of Health and Welfare (1995)

#### *Personal experience of people with intellectual disability*

Sixty-nine per cent of respondents stated that they had known or did know someone with intellectual disability outside their practice work. Out of all the respondents, 6% had an immediate family member, 16% had a relative, 10% had a close friend, 12% had a neighbour and 39% had an acquaintance with an intellectual disability. Six per cent indicated some other form of relationship with a person with an intellectual disability.

#### *Consultation length*

The GPs were asked the average amount of time they spend with patients with intellectual disability. The mean response was 19.5 minutes (range 5-60 minutes), compared to an average of 13.5 minutes (range 5-60 minutes) spent with non-disabled patients.

#### *Number of patients seen with intellectual disability*

In the 6 months prior to completing the questionnaire, GPs saw an average of nine people with intellectual disability (range 0-720), with 60% seeing between none and five, and 27% seeing between six and 10 people. The average number of patients (with and without intellectual disability) seen in one week was 134.6 or 3500 in 6 months. According to a publication entitled *Australia's Health 1996* (Australian Institute of Health and Welfare 1996), the average patient consults her/his GP 2.7 times in 6 months. Using these figures, the estimated proportion of GPs' patients who also have intellectual disability was calculated as being 0.7%.

#### *Residential location of patients*

General practitioners indicated on the questionnaire the residential location of their patients with intellectual disability seen over the last 6 months. The average proportion of patients living in these different residential locations were calculated, indicating that, on average, 52% of a GP's patients lived in the family home, 20% in supportive accommodation of one to six people, 7%, in supportive accommodation of more than six people, 8% in a large institution and 134 lived independently.

#### *Barriers and solutions*

The central findings from the questionnaire on the barriers and solutions to providing health care to people with intellectual disability can be seen in Table 2. Scores on the questionnaire were marked on a six-point Likert scale, with responses ranging from 'agree strongly' to 'disagree strongly'. Results are presented using the percentages of people marking any of the 'agree' or 'disagree' responses.

One of the most commonly agreed upon barriers to health care was communication difficulties (85% agreed). Eighty per cent also agreed that poor communication between the GP and other health professionals often limited the health care provided to people with intellectual disability. Another prominent factor was the problem of gaining the complete history of patients with intellectual disability (89% indicated it is not easy to gain the complete history). More generally, 80% of GPs agreed that it is harder to provide good-quality health care to people with intellectual disability than to non-disabled patients, and 93% agreed that they would be able to provide better health care if they undertook further education and training.

#### *Barriers mentioned in open-ended questions*

An indication of the main barriers and solutions to providing health care to people with intellectual disability were obtained by analysing 10% of the sample's responses (52 GPs' responses) to the open-ended questions. Five barriers stood out, with communication difficulties and history taking difficulties being clearly the most prominent.

#### **Five main barriers**

Communication difficulties included difficulties in understanding and obtaining information from the patient, and conversely, problems associated with patients' poor comprehension. Problems with history taking involved broad descriptions that patients' histories were often unclear and that this affected the quality of health care provided. About one third of these comments directly related history taking difficulties to residential staff. These included the lack of documentation by some residential facilities, staff not knowing the patient's history because of high staff turnover, and staff having a poor understanding of a patient's symptoms, especially the more severe the disability.

Lack of compliance with the GP's management plan was the third most frequently mentioned barrier, and included difficulties in reaching agreements with the patient or carer, difficulties in obtaining patient loyalty and cooperation, practical barriers such as a lack of money to buy scripts, and poor follow-up of patients over time.

A lack of knowledge of conditions or illnesses common in people with intellectual disability, and lastly, consultation time constraints which affect history taking and examinations were also commonly mentioned.

#### *Other barriers*

In addition to these five main barriers, numerous others were mentioned. These included a lack of communication and assistance from other health providers and the general exclusion from working as a team, difficulties accessing the system or hospitals, insufficient funding, and services not being geared to people with intellectual disability (under the Medicare billing system, GPs are paid less per unit time the longer the consultation becomes).

**TABLE 2. General practitioners' views on the health care provision for people with intellectual disability**

Themes and questions	Percentage agreement	Percentage disagreement
<b>Assessment factors</b>		
<i>History taking</i>		
It is usually easy to gain the complete history of a patient who has intellectual disability	11	89
Difficulties in obtaining a history significantly affect the quality of health care I am able to provide for people with intellectual disability	78	22
Residential care staff are usually able to provide me with a good history about people with intellectual disability	78	21
<i>Determining problem severity</i>		
I am often uncertain of patients' baseline health and behaviour when the patient has intellectual disability	76	24
It is often difficult to know how seriously to take a complaint when the patient has intellectual disability	70	30
<i>Consultation time</i>		
I find that consultation time restrictions limit the quality of care I provide to people with intellectual disability	74	26
It is often too time consuming to thoroughly examine patients with intellectual disability	55	45
<i>Examination</i>		
It is often difficult to examine a person with intellectual disability	77	23
<i>Communication</i>		
I find that communication difficulties are often barriers to high-quality health care with patients with Intellectual disability	85	15
Poor communication between general practitioners and other health professionals often limits the health care provided to people with intellectual disability	80	20
<i>Management factors</i>		
	68	32
<i>Compliance</i>		
I often find my management plan for people with intellectual disability is not being followed		
<i>Continuity of care</i>		
I have good continuity of care with patients with intellectual disability	76	23
It is easier to establish ongoing doctor patient relationships with non-disabled patients than with patients with intellectual disability	66	34
<b>Systemic factors</b>		
<i>Responsibility</i>		
General practitioners are the primary health professionals responsible for the medical care of adults with intellectual disability	88	12
General practitioners: are the primary health professionals responsible for the medical care of children with intellectual disability	70	30
<i>Remuneration</i>		
I would be more willing to see people with intellectual disability if I was provided with greater remuneration	52	48
<b>General practitioner competence</b>		
<i>Experience and confidence</i>		
I feel I lack experience when dealing with patients with intellectual disability	66	34
I know little about the resources available for people with intellectual disability	68	32
I feel confidence when treating people with intellectual disability	62	38
<i>Training</i>		
I am adequately trained in intellectual disability	24	76
I would be able to provide better health care for people with intellectual disability if I undertook further education and training in this area	93	7
<i>Other</i>		
Personally, I would prefer not to treat people with intellectual disability	15	85
I find it harder to provide good quality health care to patients with intellectual disability than non-disabled patients	80	20

A number of GPs mentioned having poor continuity of care with patients, particularly as a result of carers seeking out the help of numerous doctors. Other GPs mentioned difficulties in problem determination, such as confusing presentations of symptoms, or giving due significance to unusual or exaggerated symptoms. Services were criticized for being uncoordinated and fragmented over many professions. The GPs also indicated their ignorance of services and the difficulties in finding up-to-date information about services or resources. Examination difficulties were mentioned, especially with behaviourally disturbed patients. Patient fear, and reluctance to be examined and to comply with instructions in the examination was also an issue. Other barriers included difficulties in case management, a lack of back-up resources or specialty clinics for GPs to consult or refer to, and the issue of patients not seeking help for themselves or not seeking help early enough.

### Solutions to barriers

#### *Training and education*

Further training and experience in intellectual disability were frequently mentioned in the open question responses as a solution to many of the barriers spoken about. In response to a Yes/No question, 93% of GPs also stated that they would be prepared to receive further education. The proportions of GPs prepared to attend or make use of a variety of educational methods are shown in Table 3.

### Solutions mentioned in open-ended questions

#### *Training and education*

Further opportunities for undergraduate and postgraduate training and education was one of the most frequently mentioned solutions. This solution was given particular emphasis in relation to communications difficulties, history taking difficulties with the patient and/or carer, and difficulties in problem determination.

**TABLE 3. Proportion of general practitioners prepared to receive types of further education**

Type of education	Percentage of respondents willing to receive further education
Seminar on intellectual disability	53
A lunchtime/evening meeting	56
Local resource guide	59
Journal articles	42
Synopsis of the literature or short handbook (re: health care of people with intellectual disability in the community)	69
Other	5

#### *Increasing consultation times*

Increasing consultation times or the frequency of visits to the GP were mentioned in relation to communication, history taking and examination difficulties, as well as problems with patient compliance and dealing with a patient's fear or anxiety.

#### *Involving the family or carers into the patient's health care*

Another commonly mentioned solution was including family or carers in the consultation and then the management of the patient. Participation in the consultation was related to helping communication and history taking problems, as well as difficulties in determining problem severity and compliance in following the GP's management plan.

#### *Other solutions*

General practitioners also mentioned the need for better documentation to take place at residential facilities, and the importance of having the same staff member who knows the patient well to attend each consultation. Improving rapport with the patient was seen as important, and went hand in hand with trying to establish continuity of care with both the patient and the family/carer. Providing written instructions and regular follow-ups were suggested as solutions to compliance problems, and improving habits of communication and feedback between health professionals were also deemed necessary.

Finally, increasing remuneration in response to spending more time in consultations was mentioned. Better information available about resources for people with intellectual disability, proactive communication, and liaisons between the GP and allied health professionals and support services, and an attitude change to accept GP's central role in each patient's ongoing care were also issues mentioned by a smaller proportion of GPs.

### Discussion

The central aim of the present study was to gain a perspective of the range of barriers that GPs experience in the

provision of health care for people with intellectual disability. The opinions of the 'usual' GP were specifically sought out. A moderate response rate, and possible bias to GPs with a greater personal interest or experience in intellectual disability may have slightly skewed results. However, matching respondents' demographics to national figures suggest that this sample is quite representative of the typical Australian GP.

The GPs who responded to our questionnaire saw an average of only nine patients with intellectual disability in the 6 months prior to completing the questionnaire. This suggests that intellectual disability is a very minor part of most GP's work. Therefore, the typical GP is likely to be extremely inexperienced in this area of health care, which makes the results of this questionnaire even more compelling. In an area of health care known so to be so inadequate, the results identify the wide array of difficulties that GPs face when dealing with patients with intellectual disability. At every stage of health care provision, GPs have indicated that there are many barriers to providing this care and that the quality of care is subsequently compromised in most cases. However, the results show the willingness of GPs to help remedy the situation, and the GPs in this study have suggested many constructive methods of dealing with and reducing these barriers.

By far the most significant barrier to the health care provision for people with intellectual disability was found to be communication difficulties. Communication difficulties are almost always concomitant with intellectual disability. They provide an intrinsic and persistent barrier to the provision of health care. The processes of assessment, diagnosis and management in general practice are all highly dependent on the communication of information, and therefore, every stage of health care provision will be affected.

First, communication difficulties hinder the process of history taking. A process which Robin Fraser notes in his book, entitled *Clinical Method. A General Practice Approach* (Fraser 1990), as 'the key to the consultation'. Only 11% of the GPs agreed that it is usually easy to gain a complete history of patients with intellectual disability, while over three-quarters felt that difficulties in obtaining a history significantly affected the quality of care provided.

Although 78% of GPs felt residential care staff provided a good history, it was often mentioned as a barrier in the open-ended question. It is crucial that staff come to consultations prepared, and are able to provide GPs with concise, accurate and relevant information. General practitioners could facilitate this process by providing feedback to families and carers about what information is most useful. In turn, carers can educate the GP about the nature of specific disabilities, or various resources and services available for people with intellectual disability.

General practitioners should be prepared to respond positively to receiving such information. In these ways, problems with history taking may be significantly diminished.

Communication is also important in determining a person's baseline health and behaviour, or understanding how seriously to take a complaint. Typical patterns of behaviour, and response to discomfort or illness in the general population are usually familiar to GPs. However, people with intellectual disability may not follow the usual response patterns and their behaviour is often difficult to interpret. In fact, 76% of respondents agreed that they are often uncertain of a person's baseline health and behaviour. This would almost certainly affect their ability to confidently assess the person's condition. Furthermore, examinations and investigations are usually carried out to explore the nature and severity of a complaint. However, GPs have indicated that examinations are often difficult and that thorough examinations are also compromised by time restrictions. This further limits the GP's ability to successfully carry out the initial assessment of a patient. These difficulties may be alleviated by making double bookings for all patients with intellectual disability. General practitioners and service providers must specify that a person who is very familiar with the patient should also attend the consultation. This would improve the history taking process and facilitate communicating with and examining the patient. Patients and carers should also be encouraged to contact the same GP on every visit.

If a management plan can be arrived at, it needs to be understood and implemented to be effective. However, the majority of GPs felt their management plans were not being followed, and problems with compliance were commonly raised in the open-ended questions. These difficulties may again be explained by communication difficulties or misunderstandings between the GP, the patient and/or the carer. Alternatively, management plans may not be carried out because of conflicts of interest or belief between the GP and the individual, the family or carers or other health professionals. Sometimes people may have firm beliefs about the cause of a problem or the necessary manner in which the issue is addressed. The GP's intervention may not fit with another person's expectations or beliefs, and may result in the management plan not being followed or the patient changing GP. A change in GP may then only serve to dislocate the primary health care, disempower the GP, and reinforce the primacy of the care giver and not the person with intellectual disability.

Compliance to the management plan may be improved by extending consultation times or by increasing the frequency of consultations, in order to augment communication. Such strategies as providing written instructions, including carer/family members in the consultation, and open discussion of the proposed plan and any difficulties with this plan, may also be of benefit. Improved communication between health professionals may also ensure that the management plans are coordinated and maintained through all aspects of health care an individual receives.

Continuity of care is the cornerstone to the provision of high-quality care in general practice. Long-term relationships are often established between the GP and a patient, allowing care to be provided in the context of a detailed knowledge of the patient and her/his life. Although the GPs in this study identified a greater difficulty in establishing an ongoing relationship with patients with intellectual disability than

those who are not, over three-quarters of the GPs considered that they had a good continuity of care with their patients with intellectual disability. This means that, although faced with greater difficulties in establishing continuity of care, GPs believe they are still able to achieve this. However, it is surprising that, despite the good continuity of care, GPs are still often uncertain of patients' baseline health and behaviour, which suggests that a variety of barriers are contributing to this problem. It is important that GPs, carers and individuals with intellectual disability recognize the potential problems caused by not maintaining good continuity of care. People with intellectual disability, families and carers can ensure regular visits to the same GP and include this GP in the global health care management of the patient. Continuing efforts should be made by all parties to overcome these difficulties, and ensure that the highest quality of health care is delivered and received

Eighty-six per cent of the GPs felt that they were the primary health professionals responsible for adults with intellectual disability. This result is similar to UK and USA studies (Minihan et al. 1993; Kerr et al. 1996a); however, only 70% of GPs felt similarly with regard to children. This disparity between adults and children may reflect GPs' feelings of being marginalized from the role of primary health care provider by the paediatrician in childhood. Even with adults, GPs may feel excluded by specialist health professionals. General practitioners may also be responding to the anti-medical attitude sometimes held by staff who care for people with intellectual disability, as has been reported by trainee psychiatrists and psychiatrists (Lennox & Chaplin 1995, 1996). General practitioners may also be unaware of the need for ongoing, consistent and proactive health maintenance throughout the life of people with intellectual disability. Improved training and education may help GPs better recognize their role and address all of a patient's needs. Providing or improving support services for the GPs, such as disability nurse practitioners, resource guides, medical specialists in developmental disability medicine and lists of other medical specialists with an interest in the area, may also help GPs carry out their role as primary carer.

As only 0.7% of GPs' practice populations were identified as intellectually disabled, GPs would be expected to feel inexperienced in this area. Indeed, two-thirds of respondents in this study agreed that they felt inexperienced, but perhaps surprisingly, a similar number felt confident when treating people with intellectual disability. Given the poor standard of care in this population and the documented impediments to provision of this care, why are so many confident? Perhaps this confidence is driven by a lack of awareness of health care issues which are commonly overlooked or mismanaged. This may be compounded by patients' difficulties in communicating when a problem exists. However, it should also be acknowledged that the underlying biological and medical principles of medical care are substantially universal across all people. This may explain GPs' confidence, despite a lack of experience. Nevertheless, a call for equipping GPs with a greater range of experience in the area seems necessary. An obvious solution lies in further undergraduate, postgraduate and continuing medical education.

Only one-quarter of GPs felt adequately trained in intellectual disability and the little training GPs had received often involved a visit to a large institution where they may have simply been 'exposed' to people with high support needs. Such an experience is certain to reinforce negative stereotypes of people with intellectual disability, and is unlikely to stimulate student interest in this area. It is also unlikely to provide GPs with hands-on experience in history taking, assessment, examination and management. These are all necessary skills to be able to appropriately deal with patients coming to a GP's practice, and may not be generalizable from training with non-disabled patients. Only 10% of GPs had received any postgraduate training and this often related to a personal experience outside the clinical setting. Although potentially enlightening, these personal experiences would not necessarily enhance GPs' medical knowledge or skills as practitioners.

As much as the training of medical students appears inadequate, it is encouraging to find that 93% of GPs indicated they would be prepared to receive further education. The same percentage also agreed that they would be able to provide better health care as a result of this education, and further training and experience was frequently listed as a solution in the open-ended questions. The Minihan et al. (1993) survey of primary community physicians in the USA found that physicians were more interested in a resource list of specialists in the area than more formalized education. This tendency to shy from didactic education was reflected in the present study. There was substantial interest in a synopsis of the literature or short handbook (69%), and a local resource guide (59%), while the more traditional seminars, lunch time meetings and journal articles received more muted interest.

These findings suggest that GPs want more support and guidance in their care of people with intellectual disability. Although traditional teaching of knowledge and skills is still vital, user-friendly information to facilitate GPs may be more appropriate. The use of simple continuing education packages such as the *RACGP Check Program* on intellectual disability could also be developed and possibly combined with practice interventions to reinforce positive changes in practice behaviour. Practice interventions could include: medical audits; structured comprehensive health screening, and ongoing practice assessment activities. Other educational material could take the form of a handbook, with concise and rapidly accessible information about health problems in people with intellectual disability.

General practitioners have clearly identified the need for more support from within the medical profession. However, in Australia, physicians with a specialized knowledge of adults with intellectual disability are rare, despite the large number of people with intellectual disability, families/carers, GPs, neurologists, paediatricians and psychiatrists who are often desperate for support and assistance. There is a need for an increase in the quality

and number of clinicians who are experienced in the care of people with intellectual disability, and who can provide support to the primary care providers of people with intellectual disability.

One response to the increased needs and complexities of the health care of people with intellectual disability would be to increase remuneration. Curiously, there was a wide range of views by the GPs in this study to the statement that they would be more willing to see people with intellectual disability if provided with greater remuneration. Some practitioners may have been insulted that a link between money and caring for patients with intellectual disability was made, while others may have considered this an appropriate and sensible inducement. Given the difficulties involved with providing health care to people with intellectual disability, increasing remuneration seems a realistic and valid solution.

The impediments to high-quality health care are substantial and may result in frustration to the providers of this care; however, only 15% of GPs agreed that they would personally prefer not to treat people with intellectual disability. In fact, 43% of the GPs strongly disagreed to the proposition. However, it is clear that there still exists the need to make GPs' role more rewarding and attractive.

In this study, we directly linked the quality of care to; general communication difficulties; poor communication between health professionals; difficulties in obtaining a history; and consultation time restrictions. The GPs have clearly indicated that quality of care has been compromised, and furthermore, 81% considered that it was harder to provide good-quality health care to patients with intellectual disability than non-disabled patients. It seems evident that there are significant problems in providing adequate health care for people with intellectual disability in Australia, and undoubtedly, the world. These problems desperately need to be addressed. This article outlines a few immediate and practical methods of improving this current situation. However, long-term goals also need to be set and addressed from within the health care system. Health targets specific to people with intellectual disability, such as maintaining yearly thyroid testing in people with Down's syndrome, can be established. These targets could be monitored and renewed over time. Historically, it has been made too easy for communities, professionals and governments to ignore the poor health of people with intellectual disability. By setting targets and testing outcomes, an ongoing system of review will drive the agenda for improving the health care.

In conclusion, the barriers to health care for people with intellectual disability are substantial and demand immediate attention. However, these barriers are not insurmountable. The task is to move forward with this knowledge by developing and implementing strategies at all levels, monitoring their effectiveness, and finally, ensuring that people with intellectual disability receive an improved quality of health care and a better standard of life.

## References

- Australian Institute of Health and Welfare (1996) *Australia's Health 1966*. Australian Institute of Health and Welfare, Canberra.
- Australian Institute of Health and Welfare (1995) *Medical Labour Force 1992-93*. National Health Labour Force Bulletin Number 3, July, Canberra.
- Barker M, & Howells G (1990) *The Medical Needs of Adults: Primary Care for People with a Mental Handicap*. Occasional Paper 47. Royal College of General Practitioners, London.
- Beange H. (1986) The medical model revisited. *Australian and New Zealand Journal of Developmental Disabilities*, 12, 3-7.
- Beange H. & Bauman A. (1990) Caring for the developmentally disabled in the community. *Australian Family Physician* 19, 1558-63.
- Beange H., McElduff A. & Baker W. (1995) Medical disorders of adults with mental retardation: a population study. *American Journal of Mental Retardation* 99, 595-604.
- Beange H. P. (1996) Caring for a vulnerable population. *Medical Journal of Australia* 164, 159-60.
- Burbidge M. (1996) Patient-held medical records for people with an intellectual disability. In: *10th World Congress of the International Association for the Scientific Study of Intellectual Disability*, Helsinki, IASSID, p. 227.
- Commonwealth Department of Health and Family Services (1996) *General Practice in Australia: 1996*. General Practice Branch, Commonwealth Department of Health and Family Services, Canberra,
- Crocker A.C., (1988) Medical care for adults with developmental disabilities. *Journal of the American Medical Association* 260, 1455.
- Crocker A. C. & Yankauer, A. (1987) Basic issues. *Mental Retardation* 25, 227-32.
- Cumella S., Corbett, J., Clarke D. & Smith B. (1992) Primary health care for people with a learning disability, *Mental Handicap* 20, 123-5.
- Fraser R. C. (1992) *Clinical Method: A General Practice Approach*, 2nd edn. Butterworth-Heinemann, Oxford.
- Garrard S. D. (1982) Health services for mentally retarded people in community residences; problems and questions. *Australian Journal of Public Health* 72, 1226-8.
- Howells G. (1986) Are the medical needs of mentally handicapped adults being met? *Journal of the Royal College of General Practitioners* 36, 449-53.
- Ineichen B. & Russell O. (1987) Mental handicap: the general practitioner's contribution to community care. *Update* 15 September, 507-14.
- Kerr M, Dunstan F. & Thapar A. (1997a) Attitudes of general practitioners to people with a learning disability. *British Journal of General Practice* 46, 92-4.

- Kerr M. P., Richards D. & Glover G. (1997) Primary care for people with a learning disability: a group practice survey. *Journal of Applied Research in Intellectual Disability* 9, 347-52.
- Lennox N. & Chaplin R. (1985) The psychiatric care of people with intellectual disabilities: the perceptions of trainee psychiatrists and psychiatric medical officers. *The Australian and New Zealand Journal of Psychiatry* 9, 632-7.
- Lennox N. & Chaplin R. (1996) The psychiatric care of people with intellectual disabilities: the perceptions of consultant psychiatrists in Victoria. *The Australian and New Zealand Journal of Psychiatry* 30, 774-80.
- Minihan P. M. & Dean D. H. (1990) Meeting the needs for health services of people with mental retardation living in the community. *American Journal of Public Health* 80, 1043-8.
- Minihao P. M., Dean D. H. & Lyons C. M. (1993) Managing the care of patients with mental retardation: a survey of physicians. *Mental Retardation* 31, 239-46.
- Murdoch J. C. (1984) Experience of the mothers of Down's syndrome and spina bifida children on going home from hospital in Scotland 1971-1981. *Journal of Mental Deficiency Research* 28, 123-7.
- Parmenter T. R. (1988) An analysis of Australian mental health services for people with mental retardation. *Australian and New Zealand Journal of Developmental Disabilities* 14, 9-13.
- Royal Australian College of General Practitioners (1996) *Annual Report 1996*, Royal Australian College of General Practitioners, Forrest Lodge.
- Thomas A P., Bax M. C. O. & Smyth D, P. L. (1988) The provision of support services for young adults with physical and mental handicaps *Mental Handicap* 16, 92-6.
- Wilson D. N. & Haire A. (1990) Health care screening for people with mental handicap living in the community. *British Medical Journal* 301, 1379-81.
- Yankauer A. (1986) Community health services for mentally retarded adults. *American Journal of Public Health* 76, 1187-9.
- Ziring P. R. (1987) A program that works. *Mental Retardation* 25, 207-10.