Learning how to care for people with intellectual disabilities

Dr Stephen Trumble MBBS MD FRACGP, CEO General Practice Education Australia Ltd

Here's a surprising statement. People with intellectual disabilities live in the community and attend general practitioners like any other member of our society. This simple statement has not always been true, however; throughout most of the 20th century, many children with disabilities were admitted to large institutions and remained segregated there until they died, sometimes seventy or eighty years later. Medical care tended to be provided behind the walls of these institutions leading to an isolation of knowledge and skills that prevented their acquisition by community-based doctors.

The acceptance of people with intellectual disabilities back into mainstream communities has done much to normalise their lives, but it has also demonstrated that community-based medical services are largely underprepared to meet the health needs of this group. Most GPs have only a small number of patients with intellectual disabilities in their practices, but the burden of disease borne by these patients, and the barriers to quality health care they confront, make them an important group.

The health care of people who have intellectual disabilities is one of the most challenging and rewarding areas of general practice. And it is indeed an area that is truly the domain of the general practitioner, depending as it does on the flexibility, broad knowledge and comprehensive approach that characterises our discipline. Expertise in all five key domains of general practice (as defined by the Royal Australian College of General Practitioners[1]) is required if high quality and effective care is to be provided to this patient group. These domains are:

- communication skills and the doctor-patient relationship;
- applied professional knowledge and skills;
- population health and the context of general practice;
- professional and ethical role;
- organisational and legal dimensions.

General practitioners function within these domains in every consultation with every patient. The extent to which each domain is explored within a consultation depends on the patient's presentation and the issues they bring. People with developmental disabilities are no different to other people presenting to a general practitioner; they bring a variety of health needs that need addressing and they will present them in a variety of different ways to the GP. In seeking to meet these needs, the GP will call upon the full range of his or her competence within the domains of their profession, often venturing further into the reaches of a particular domain than usual.

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It is concerning, therefore, that GPs are usually poorly prepared to provide health care to people with intellectual disabilities because of a dearth of education and training opportunities. Intellectual disability is sometimes consigned to the outer reaches of psychiatry and little attention is paid to the physical or social factors underlying many presentations to general practitioners.

The Section for the Psychiatry of Mental Handicap (now 'Learning Disability') of the Royal College of Psychiatrists published a one-page statement on undergraduate training in mental handicap in 1986[2] that recommended a minimum of 12–15 hours of curriculum time as a core. Not surprisingly, it was suggested that the overall responsibility for teaching and coordination should rest with university departments of psychiatry. The recommended core curriculum consisted of:

- epidemiology, classification, aetiology, prevention, clinical features and associated disorders of mental handicap;
- social and family aspects;
- assessment and management of the individual;

- concepts of care and service systems – where to get or refer for help;
- major ethical problems.

Holt and Huntley in 1973 surveyed 105 practising doctors in the United Kingdom and found that 32% had received less than one day's training in intellectual disability, with 18% having received none at all.[3] The following year Oster undertook a similar survey in Scandinavia, with colleagues asking similar questions in New Zealand, Australia and California.[4] His findings again showed that few hours were devoted to teaching in this area. As both Pilkington and, later, Hollins found in the UK: although teaching time had increased significantly, it was often squandered on educationally less-appropriate activities such as didactic lectures and unstructured visits to residential institutions.[5,6] These visits were more likely to engender feelings of horror and pity amongst students, rather than positive attitudes which can result from well-designed courses.[7–10]

Willer, Ross and Intagliata[11] surveyed all American medical schools in 1978, of which half responded. Their curricula on intellectual disability were assessed and graded as either ideal, acceptable or unacceptable. Almost 75% of the responding 64 medical schools had curricula on intellectual disability that were unacceptable. Closer to home, and to the present date, an unpublished survey conducted in 1996 by Associate Professor Nicholas Lennox of the University of Queensland found that most Australian medical schools offered less than ideal teaching in intellectual disability. The creation of academic appointments in some university departments of general practice has been an important step towards addressing these deficiencies but there is still not enough academic activity in this area.

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Opportunities for postgraduate education and training in intellectual disability are even less available and less frequently taken up than at the undergraduate level. Specialist training courses in intellectual disability have been mooted since the 1950s but have failed to attract substantial interest from funders and participants alike. These specialist training courses have also struggled to find a natural home. In the United Kingdom, the discipline of psychiatry has led the way with the creation of 'learning disability' as a recognised subspecialty headed by a network of academic Chairs across the country. In other countries, paediatricians have embraced the needs of intellectually disabled children but find, appropriately, that they must withdraw their services as the child becomes an adult. Finding a suitably skilled and similarly interested adult physician to take over their care is not a simple matter.

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Not that the creation of an adult specialty in 'disability medicine' would solve the problems of providing health care for people with intellectual disabilities; the vast majority of this care must remain in the province of the GP, with the specialist being consulted in the usual manner to support and enhance the GP's level of care.

Having worked between 1991 and 1997 as a GP whose practice was almost entirely composed of adults with intellectual disabilities, I frequently found a lack of suitable specialists with whom I could consult on the care of the 866 disabled patients registered with my clinic. An audit of my records shows that 32% of these patients had epilepsy (compared to a community prevalence of 0.5%) and, as indicated by almost half requiring more than one antiepileptic medication to control their seizures, their epilepsy was often severe and complicated. Seven patients required five drugs to partially control their seizures. An effective management team centred on the GP and neurologist, and incorporating the patient, family and other carers, was essential but often difficult to create.

Psychiatry in people with intellectual disability is another area where the GP needs good support from appropriately trained and attitudinally aligned consultants. Psychiatric symptomatology is frequently overshadowed or complicated by the effects of a patient's disability, and the teasing apart of behaviours to detect, diagnose and manage any underlying mental illness can be a complex matter.

Patients with intellectual disabilities have more in common with other patients than in difference, however, and the generic skills of both GP and specialist provide a suitable basis from which to provide high quality care to this group. Enhancement of these generic skills with some focussed learning in key areas such as neurology, psychiatry and the behavioural aspects of disability make the provision of this care far more satisfying for patient and doctor alike.

Communication (both verbal and non-verbal) should occur directly between the GP and the patient, regardless of an intervening disability. Family members or other carers who might accompany the disabled patient to a consultation can be an invalu-

able source of information about the patient's health, but they are not the focus of the consultation. Even patients with severe intellectual disabilities benefit from direct interaction with their GP, rather than having all communication routed through an accompanying person.

Equally important as adequate knowledge and good consultation skills, however, is the need for the GP to approach patients who have intellectual disabilities with the same professional values, respect and clinical rigor as we offer any other patient. Preventive health and health promotion activities need to be undertaken with the same frequency and diligence using the same indications and guidelines. Physical examinations and special investigations need to be carried out in the same way as with the general population. And families need to be involved in the health of the patient to the same appropriate extent.

The GP who treats his or her patients with knowledge, skill, holistic care and thoroughness while recognising their dignity and right to self-determination is a good GP. People with intellectual disabilities need good GPs, as do we all.

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