



Children and adolescents with developmental disabilities

The GP's role

BACKGROUND General practitioners play a central role in the health care for families of children with disabilities, but may feel inadequately trained or resourced for this role.

OBJECTIVE This article highlights the important issues arising for children and their families as the child grows – from birth through to adolescence and adulthood. It also provides some key resources for the GP, patient and their family during this transition.

DISCUSSION Families need GPs to provide primary and preventive health care, and referral to and coordination of other health care services. The families of children with disabilities are no different. They need their GP to provide care to all family members and to work as a part of a health care team for children with complex needs relating to developmental disabilities.

Developmental abnormalities are present in 3.9% of babies.¹ Many of these defects involve impairments in neurological function leading to intellectual, physical, social or sensory disabilities. Other children experience hypoxic, traumatic, infective or toxic injuries to their developing brain that lead to developmental disabilities. Each of these children has parents and siblings, aunts and uncles, grandparents and cousins who are also affected by the child's developmental disability – every general practitioner has a significant proportion of their patient population involved with disability in some way. The Australian Institute of Health and Welfare² estimates there are nearly 500 000 people with intellectual disability in Australia, therefore each general practice population of approximately 1000 patients would expect to have 20–30 patients with intellectual disabilities. Developmental disability affects many lives and an understanding of the relevant issues in medical care will therefore have far reaching effects.

In the beginning

Significant disability or functional impairment in a child may be identified soon after birth (as in the case of a child with Down syndrome) or in the first months or years of life (frequently the case in children with cerebral palsy and intellectual disability or autism respectively).

Parents often raise their concerns first with their GP.



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A note about language

The language we use both reflects our own attitudes and influences those of others. Using inappropriate language can be seen as demeaning and offensive by people with disabilities and their families. People with disabilities are people first; their disability is a part of them, but is certainly not all of who they are. In the same way that someone with epilepsy is not only 'an epileptic' (as if that sums up all they are in one word) – a person with a disability is not 'a disabled person', 'a spastic' or 'a Downs'. Rather, someone may have a disability, or have Down syndrome. Part of building positive relationships with our patients is using appropriate expressions to and about them.

Unless the disability is obvious, there may be a temptation to reassure parents; great care must be taken not to inappropriately reassure as this can undermine parents' confidence in themselves, trust in the doctor and lead to delays in diagnosis and intervention. Parents' concerns need to be seriously addressed and, if there is any doubt, formal developmental assessment and/or consultation with a paediatrician are required. The use of efficient screening tools such as The Parent Evaluation of Developmental Status (PEDS) is a sensitive and specific way of deciding the next step in assessment³ (see Resources).

Assessment can be a prolonged process and the family will need their GP's support through that time. Regular appointments or follow up phone calls are usually appreciated. The Specialist Children's Services team at the regional office of the Victorian Department of Human Services (or equivalent in other states) can provide services to the family while a definitive diagnosis is still being established.

Making an aetiological diagnosis is important both to parents and for the appropriate medical management of the child. Knowing the cause of the disability may:

- give information about when and why the disability occurred – important information for the person with the disability themselves and their family
- offer accurate information concerning recurrence risk for the person concerned and/or their family
- provide specific information relevant to medical care (eg. increased risk of thyroid dysfunction, depression and dementia in people with Down syndrome), and
- enable families to locate specific information about the condition and to find support groups.

When a diagnosis is made, parents experience a grief

reaction with feelings of denial, anger and deep sadness. Shame, guilt, blame, isolation and feelings of inadequacy and confusion can also occur. The GP can provide support and referral to appropriate services (eg. support groups, counselling) to help parents through this time.

The grief experienced by parents is lifelong. At first there will be acute pain and many tears. Slowly, the acute pain changes into what has been referred to as 'chronic sorrow'.⁴ Grief may resurface at particular times and be expressed in a variety of ways including anger and sadness. Diagnoses of additional health issues, transition to new services, birthdays, the birth of other children, and the insensitive remarks of others are some of the many triggers that may lead to a resurfacing of grief. Understanding the long term nature of this grief – and its possible triggers – will help GPs provide appropriate support.

The childhood years

The child with disabilities will need the same things all children need – family, fun, friends and medical care. Sometimes there is so much focus on the disabilities, that parents feel professionals see their child only as a compilation of defects and impairments. The key to good relationships and building self esteem in the child and parent alike is focussing on strengths and abilities, while being mindful of the difficulties the people concerned are facing. Primary health care for a child with complex medical needs requires:

- learning about the disability and known associated medical conditions
- partnership between the child, parents, GP, paediatrician and other specialists
- good communication – written and oral – between all those involved
- knowledge of, or where to find out about, community support structures such as specialist children's early intervention services team, disability services, Centrelink benefits, local council services, support and advocacy services (*Figure 1*).

Off to school

Parents may ask the GP or paediatrician which school is the 'right' one for their child. This is a personal family decision but the doctor can help by:

- emphasising that it is the parents' right to choose – the child can go to a mainstream school whatever their level of disability, or to a segregated special school. Support structures for students with disabilities and impairments are available in both

- encouraging the parents to consider the decision from the point of view of both the child and the family⁶, and
- supporting the family's decision by providing the required letters outlining the child's areas of difficulty and need for support.

And through adolescence

Adolescents with disabilities experience most of the same issues as their age peers.

Physical maturation

Adolescence is a time of rapid and dramatic physical development. Many adolescents take some time to become comfortable with their new strength, body size and shape, and this is also the case in adolescents with disabilities. Angry outbursts can become much more problematic for carers when the young person is bigger than they are, and so physically based behaviour management strategies need to be replaced with more long term solutions well before puberty.

Case history – Michael

My child Michael has epilepsy. His seizures are not well controlled and we have tried many different medications and combinations to improve control over the years. He also has an intellectual disability, no speech and cannot understand why he has to take his anticonvulsants every day. Over the years we have used logic, encouragement, bribery, threats and force – all in an effort to improve 'compliance'. It exhausts us all. Michael's strong aversion to oral medication arising from these battles pollutes his attitude to other medications and it's so important that my GP listens to me and works through the options available if Michael requires treatment ... antibiotics for instance. It's no good just prescribing the drug the GP uses for other kids and telling me it tastes nice and won't be a problem – giving Michael medication is a major trauma for the whole family and we need the significance of adding another medication to our day acknowledged.

*Mary, Michael's mother
(names have been changed)*

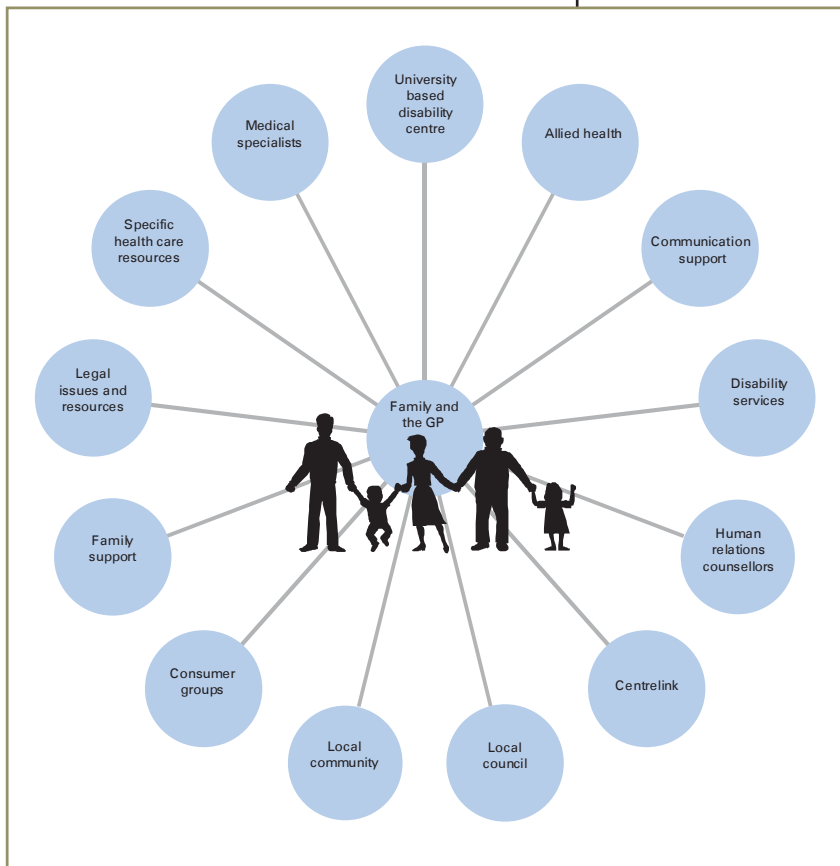


Figure 1. The health care team

Menarche occurs in most girls with disabilities at the same time as their age peers. For most, specific information and support will enable her to manage menstrual hygiene independently. For more information see the Centre for Developmental Disability Health Victoria (CDDHV) Menstrual Management booklets (see *Resources*).

Behavioural difficulties

Behaviours that are acceptable in the child often become less so as he/she grows to adult size and shape. It is important that parents and health professionals help the child learn early what is acceptable in specific situations. It is also important to understand the behaviour – sometimes the child's only way to express themselves – may be communicating illness, pain, distress, fear, confusion or may be a manifestation of a psychiatric disorder⁸ (see *Resources*).

Relationship and sexual issues

Sexual feelings and desires play an important part in the lives of all adolescents, and helping people with disabilities understand these feelings while learning to manage

them in an appropriate way is an important component of care. Young people learn about relationships, sexuality and appropriate behaviour through their peers, the media, reading, school and their parents. Young people with intellectual disabilities take longer to learn new information and require more repetition and practice, but their life circumstances often mean they have limited access to the sources of information important to their peers. They may need specific teaching and support in these areas (see *Resources*).

Desire for independence

The step into the adult world is a leap into independence for most young people. For many with disabilities however, opportunities for independence may be limited. This can lead to sadness, anger and frustration in the young person and their parents. Parents and service providers can help by maximising a sense of growing autonomy and control in life by providing every opportunity for the young adult to make choices and influence the direction their life takes. This may be the time for professionals to consider seeing the young person on their own (not always with a family member) so that direct communication and negotiation can occur. This also reinforces the young person’s need and capacity to take responsibility (commensurate with their abilities) for their own health and medical care.

Peer relationships

Peer relationships provide opportunities to learn, communicate, share, give, and control impulses and behaviours. Young people with disabilities may need assistance in finding and maintaining friendships, but this is an important step in building both identity and resilience (see *Resources*).

Transition to adult services

The needs of a young adult with a disability are the same as other young people: an income, accommodation, friends, opportunities for further learning, community participation, recreation, transport, and hopes for the future. Sometimes these needs are met through generic community services, and sometimes through specifically targeted programs and agencies.

On leaving school, there is a range of education, employment, vocational and day programs available to young people with disabilities depending on their interests and support needs. Further information can be obtained from disability services in each state and territory (see *Resources*).

When the young person turns 16 years of age, Centrelink requires that they (or someone on their behalf) negotiate the paperwork required for the Carer’s Allowance (adult) and the Disability Support Pension. These are important benefits, but the amount of paperwork can use up both emotional and time reserves for all concerned. The GP may be asked to assist in this process by confirming in writing that the young person still has their developmental disability!

During these latter teenage years the young person also moves from paediatric care to generic adult medical services. There is no adult equivalent to the paediatrician in the care of adults with developmental disabilities, and so primary care and coordination of specialist services is the province of the GP. If all has gone well, with good communication flow and collaborative decision making in a shared care arrangement during childhood, leaving paediatric services should occur smoothly.⁷ Unfortunately however, this is often not the case. General practitioners may feel poorly trained and inadequately resourced to care for those with multiple or complex medical issues⁸ and few specialised disability medical services are available. The CDDHV (and equivalent centres in other states) provide GPs with resources, telephone advice and secondary and tertiary consultancy services (see *Resources*). Many people with disabilities need the assistance of carers. *Table 1* provides strategies for the GP working with carers of patients with developmental disabilities.

The GP and paediatrician can contribute to a positive and successful transition from paediatric to adult services by:

- discussing the process with the young person and the family from mid-teenage years and giving specific information about how the ongoing care will be provided and by whom

Table 1. Working with carers

- Always talk to the patient directly and include him/her as much as possible – don’t just talk to the carers
- Use the available expertise. Family members have considerable acquired knowledge and experience – use it!
- Parents have lifelong grief related issues that may resurface at times of stressful life events or transitions
- Don’t assume knowledge. Paid carers will have expertise in disability, but not specifically in medical matters
- People with disabilities often have multiple carers involved in their lives so ensure important medical information about management and follow up is clearly written down to ensure accurate interpretation and implementation

- increasing the involvement of the young person in medical decision making and care (commensurate with their ability) through the childhood years
- encouraging the celebration of transitions in other areas of life (eg. leaving school)
- writing a transition plan that includes all the health services the young person will need on leaving adult services (addressing medical, psychological and social issues)
- maintaining good communication between the GP, paediatrician, other health professionals, and the family throughout the childhood years
- provision by paediatric specialists of a comprehensive summary of the child's medical issues and treatment and likely ongoing health care needs to the adult health care providers, particularly the GP. It is generally helpful to also provide a copy to the family, and
- understanding the uncertainty, sadness and fear some young people and families may feel at leaving familiar paediatric providers, and providing support and perhaps a gradual transition to adult providers in some cases.

Successful transition is a process, not an event – and requires a partnership between the young person, the family, the GP, and paediatric and adult health care providers.^{7,9,10}

A Personal Health Record can be a valuable tool in the efficient and effective communication and transfer of care between health professionals working with patients with complex health needs. Templates for this can be downloaded from the CDDHV website (see *Resources*).

Case history

I had developed a close relationship with our paediatrician and neurologist over 18 turbulent and emotional years – it was hard to say goodbye. My GP has been really supportive in talking through issues arising in Michael's teenage years with me. I don't have all the answers and I don't expect him to have them either, but making decisions about Michael's care can be a lonely and overwhelming responsibility at times and it's good to share that with someone who understands the medical side of things. I feel we can work together to find solutions to the issues that will inevitably arise for Michael in his adult years.

Mary, Michael's mother

Conclusion

The care of people with developmental disabilities is the province of all GPs. Although barriers exist to providing good primary care, the pleasures and satisfaction gained from working in partnership with the young people concerned, their families, carers and other health care providers can be most rewarding. Many resources and services are available to support health providers and some key examples are listed below.

Summary of important points

- Making an aetiological diagnosis is important both to parents and for the appropriate medical management of the child.
- Physically based behaviour management strategies need to be replaced with more long term solutions well before puberty.
- It is important to understand that unacceptable behaviour may be communicating illness, pain, distress, fear, confusion, or may be a manifestation of a psychiatric disorder.

Resources

The Centre for Developmental Disability Health Victoria

- Publications
 - Menstrual Management booklets for GPs and carers
 - Facts sheets: About developmental disabilities
 - Hospital care for people with a disability
 - Information and template for Personal Health Records
- Telephone advice
- Secondary and tertiary consultation service (Victoria): cddh.med.monash.edu.au.

Other states

Queensland: www.sph.uq.edu.au/QCIDD

New South Wales: www.cdds.med.usyd.edu.au.

Specific health care resources

- Lennox N, Diggins J, eds. Management guidelines: people with developmental and intellectual disabilities. Melbourne: Therapeutic Guidelines Ltd, 1999. (www.tg.com.au)
- Centre for Genetics Education: provides current genetics information to individuals, family members and health professionals (www.genetics.com.au/)
- Online Mendelian Inheritance in Man: information on genetic conditions (www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=omim)
- Parent Evaluation of Developmental Status (PEDS) (www.pedstest.com).

Human relations counselling

For advice, information and resources regarding human relations and sexuality issues:

- Centre for Developmental Disability Health: human relations counsellors (www.cddh.med.monash.edu.au)

- Family Planning Australia (www.fpa.net.au)
- Department of Human Services (Victoria) or equivalent in other states (www.disability.vic.gov.au/).

Allied health professionals

Many people with disabilities benefit from intervention provided by speech pathologists, physiotherapists, orthotists, occupational therapists, continence nurses, dieticians, audiologists, optometrists and other allied health professionals. Some may be accessed through community health centres or disability specific organisations such as (in Victoria) Scope or Yooralla.

Communication support

Children with communication impairments need every opportunity to establish the best communication system they can using the abilities they have. Specialised speech pathologists can provide assessments and interventions. Organisations such as Scope (Victoria) (www.scopevictoria.org.au), Novita (SA) (www.novita.org.au), or the Crippled Children's Association (SA) have particular expertise in this area.

Family support groups

- ParentLine: www.parentline.vic.gov.au
- Centre for Adolescent Health: www.rch.org.au/cah/.

Specialist agencies

- The Australian Association for Families of Children with Disability, the National Network for family support: www.aacd.org.au/aafcd/indexb.htm
- The Victorian Association for Children with a Disability offers a range of information and advocacy services, presentations and publications for parents and siblings of children and young people with disabilities including 'Through the maze: a guide to services and benefits for families of children with a disability' (www.acd.org.au).

Diagnosis specific support groups

The Royal Children's Hospital (Melbourne) keeps an up-to-date list of disability specific support groups at their Child Health Information Centre, accessed via: www.rch.org.au/chic/support/index.cfm?doc_id=988.

The internet is also a valuable resource for disability specific support groups such as Autism: www.autismaus.com.au and Down Syndrome of Victoria: www.dsav.asn.au/.

Commonwealth government disability services

- Carelink Centres are a single access point for up-to-date contact, availability and eligibility information on community aged care, disability and support services in each area. Phone 1800 052 222 (www.commcarelink.health.gov.au).

Carer respite centres

Commonwealth carer respite centres coordinate access to respite services in your local area. Toll free: 1800 059 059 (www.health.gov.au/acc/carers/respcent.htm).

Centrelink

Financial assistance: www.centrelink.gov.au.

State government

In Victoria these provide a range of services for people with disabilities and their families including:

- Specialist children's/early intervention services for preschool children
- Case management
- Respite, recreation, in home support and accommodation services
- Futures for Young Adults program for school leavers
- Aids and equipment programs
- Specialist services including behaviour intervention support teams and family intervention support services: www.disability.vic.gov.au/. Similar services exist in other states and territories and further information about these can be accessed through 'Links': www.disability.vic.gov.au/.

Local government

Local government provides a range of services including home help, respite, and recreational services. For information about local government services in your area contact health and aged services at your local council.

Legal issues

For more information about the rights of people with disabilities and the legal responsibilities inherent in their care:

- Office of The Public Advocate (Victoria) (www.publicadvocate.vic.gov.au)
- Guardianship List of the Victorian Civil and Administrative Tribunal (www.vcat.vic.gov.au).

Conflict of interest: none declared.

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