

a day in the life of a Developmental Paediatrician



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It is not uncommon that I am told by other people who work with children with developmental/intellectual disabilities that they would not want my job, as much of my work involves provision of developmental paediatric input to a multidisciplinary diagnostic and assessment service. I suspect this is related to the parents' expression to other workers of their distress and grief at finding out that their child has a life long intellectual disability. A personal story told by a mother of a teenage boy with autism and intellectual disability, who, over the years, had been quite violent, reinforced for me the impact of the period of diagnosis. Despite her personal experiences of physical injury and damage to her home, it was recollections about the period of diagnosis that were of lasting impact for her. Undoubtedly it is crucial for parents to be fully informed about their child's disability, and expectations for the future, yet how we do this may not always be as helpful for families as we might wish for their adaptation to the diagnosis.

There are few paediatricians who work exclusively in a diagnosis and assessment team for children suspected to have developmental disability, as I do. I have been able to develop my practice in developmental disability, seeing school age children with complex problems and leading a team that can see adults as well. I have listened to many stories told by families

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from varied cultures, heard of the struggles to obtain services, and the challenges for the whole family of the long term impact of disability. My professional connections have extended beyond the community child health network in which I was trained, to include many doctors, advocates and other professionals in the world of intellectual disability. My paediatric training has equipped me pretty well for provision of a holistic service that recognises that the needs of the family are central to the child's quality of life, as well as the importance of consideration of social, economic and general health determinants of outcomes for children with disability.

Undoubtedly, paediatricians have an important role in many health related needs of children with a disability. Recent surveys have confirmed this. Families often need a key medical contact who can understand the range of complex health, educational and social issues that can arise, and they tend to look to their paediatrician for advice and management.

From a scientific perspective, few areas of medicine approach research into intellectual disability for degree of interest. The potential benefits to understanding normal cognitive development must be enormous if we can understand the causes of intellectual disability and autism. From an advocacy perspective, the needs of people with an intellectual disability have long been under recognised and neglected. People with an intellectual disability are vulnerable and often experience the compounding impact of poverty. We should be encouraged by recent federal and state achievements (eg the possibility of a disability insurance scheme to provide better and ongoing services, a strategic framework in NSW for health services), the increased political action at elections, and increasing public awareness

(eg Four Corners recent programme). From a professional perspective, working closely with colleagues from other disciplines, eg education, case work, provides me with much reward, and substantially reduces the frustration we often feel about "other" services and the gaps that often exist between services.

Despite this group of children and young people clearly being vulnerable and at risk, how often are they identified as such? Australia has ratified the United Nations Convention on the Rights of Persons with Disabilities (2008), and the optional protocol (2009). Article 25 Health would seem to have many important implications for us as health service providers. Do children with a disability receive "those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons" (<http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>)? Are our services structured to positively contribute to the welfare of the child with a disability and their family, or do they add to the stress and frustration experienced by parents, and perhaps at times, allow clinical problems to develop, due to lack of services for detection, diagnosis and management, until they further impair functioning? Do we have the appropriate training and expertise within our health systems to meet the needs of children and young people with disabilities? How many of us are aware of our national obligations under this Convention?

Working with children with developmental or intellectual disability is often challenging, and some times frustrating, but it is mostly rewarding. The role of the paediatrician, is but one of many professionals involved, yet, often it is an important role in contributing to improved health and quality of life outcomes. ●

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