



## ORIGINAL ARTICLE

## Engagement of undergraduate medical students of paediatrics in special schools for children with disabilities

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**Aims:** Over 200 000 Australian children suffer significant disability. How should medical students be prepared for this challenge? Community engagement has become fundamental to education, but there is little experience with engagement of undergraduates with children with disabilities. This paper reviews such experience in Western Sydney.

**Methods:** Since 2011, UWS paediatric students have been rotated through local special schools for 2 weeks each term. In 2013, feedback was solicited in a questionnaire from the 129 students involved that year with 109 being returned. It had been solicited from school staff and parents in formal and informal communication from the beginning.

**Results:** Fourteen per cent of students reported no prior exposure to disabled children: 55% only chance, 24% regular and 7% extensive. Thirty-seven per cent reported greatly increased understanding: 39% moderately, 15% somewhat, 7% a little and 2% not. Forty-three per cent declared understanding of impact on family greatly increased: 40% moderately, 11% somewhat, 5% a little and 1% not. Twenty-seven per cent declared greatly increased knowledge of services, 43% moderately, 25% somewhat, 4% a little and 1% none. Fifteen per cent declared greatly increased preparation for caring, 44% moderately, 30% somewhat, 6% a little and 5% none. Thirty-six per cent declared greatly increased understanding of role of schools, 30% moderately, 20% somewhat, 10% a little, and 2% none and 2% cannot recall. School staff and parents reported very favourably. Problems involved professionalism in students and some fatigue in parents.

**Conclusion:** The engagement has been successful. Professionalism has been emphasised, and rotations have been designed to prevent fatigue.

**Key words:** community engagement; medical students; paediatric disabilities.

### What is already known on this topic

- 1 Children with disabilities comprise the 'new morbidity' in paediatrics.
- 2 Community engagement is now fundamental to medical education.
- 3 This engagement has involved students and adults.

### What this paper adds

- 1 Paediatric students at UWS have been rotating through special schools for 2 weeks of their 9-week placement.
- 2 Their understanding of disabilities and the role of schools and allied health has increased.
- 3 School staff and parents have praised the programme, but there have been problems with student professionalism and parent fatigue.

Of the more than four million children in Australia in 2009, nearly 300 000 are considered to have a disability, with 'limitation of core activity' in over 200 000.<sup>1</sup> Care of such children is now a feature of paediatrics in Australia as the earlier scourges of infection and under-nutrition have receded with vaccinations, antibiotics and greater wealth, and neonatal disease has been transformed by technology. Better individual care has led to 'increased survivorship' of children with disabilities, and this 'new morbidity', together with 'socioeconomic' and other

broader issues, would be described, at the turn of the last century, as comprising the 'millennial morbidity'<sup>2</sup> of the future, at least in developed countries. This change in emphasis meant care for many children moved from disease-specific entities addressed in sub-specialist clinics to issues of general health and well-being in which 'special needs' are addressed by a team of people for a child within its family and its community.<sup>3</sup> Together with prevention and advocacy, this provision of special and general needs is the basis of 'community paediatrics' which involves paediatricians and general practitioners alike.

The question facing medical educationalists is how can undergraduates be prepared for these new challenges? And, at what stage of their training should they be exposed to children with disabilities? Research confirms undergraduates benefit from non-clinical community placement in their pre-clinical years.<sup>4</sup> Students have reported more confidence in communication,

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increased empathy, and better understanding and appreciation of the challenges and contributions by allied staff. However, in Australia, most community engagement of students has been with adults receiving care from major non-government organisations and general practices.

To how much emotional challenge should an undergraduate be exposed? A report from New Zealand declared students benefited from engagement with adults receiving palliative care, but the literature does not reveal experience of undergraduates participating in the care of seriously disabled children.

In NSW, special schools are designed for children with moderate to severe intellectual disabilities often associated with autism, physical and sensory disabilities and compounded by emotional disturbance. After discussion, some special schools near our campuses in Western Sydney accepted our invitation to become partners in the training of medical students, and we began to rotate our fourth year students through them for 2 weeks of each 9-week paediatric term which occur four times a year. We intended students would learn of the effect of the disability on the child and the family, and of the care provided by teachers and allied staff and that this experience would 'align them with patient and community perspectives on illness and receiving healthcare provision'.<sup>5</sup> This report summarises our experience since we began the programme in 2011. It contains feedback from students, teachers and parents, and reveals the mechanism of achievement and some of the problems we have faced.

The aim of this study is to review the community-based block rotation of fourth year undergraduate students of paediatrics in special schools for disabled children.

## Methods

Schools for children with disabilities in the suburbs around the two campuses of the University of Western Sydney were visited to discuss the possibility of student emplacement, and invitations to join us in the educational programme were extended. Our goals were explained: we wanted the students to participate in the schooling programme, not merely to observe but to participate as much as possible in the 'hands-on' business of education and allied health.

Explanatory letters were circulated to all parents, and at least one 'parents and friends' meeting was addressed. Parents' permission was sought for students to participate in the school programme, and parents were also invited to share their experience with the students. Primarily, we wanted the students to learn of the impact of the disability on the child and its family. Only secondarily did we want the students to be absorbed by the actual diagnosis.

Student performance would be monitored by the teachers, and any concerns would be relayed to us by the principal or delegate. Performance would also be assessed by a 'school report' of 2000 words which would be based on an interview with a child's parent and include the effect of the disability on the child and the family, a review of literature, and a personal reflection. As introduction to advocacy, students were invited to comment on how the broader 'system' of care for children with disabilities might be improved. The reports were assessed for

form, content and evidence of engagement by a community paediatrician, and the best was awarded an annual prize in community paediatrics.

In preparation for their engagement, students received lectures on common disabilities and were warned of the emotional challenges they might expect. School staff were already experienced in the challenges faced by trainee teachers, and a strong, easy means of communication was established between leading people in the schools and the department of paediatrics so that any of our students with 'special needs' could be helped.

The effect on the students was assessed by a questionnaire in their fifth year of study, after months of time for reflection. Answers to specific questions were graded on Likert scales, and particular comments were invited.

Feedback was received from the schools after each rotation and whenever particular needs arose. It was solicited in written and verbal form and involved specific questions on the success or otherwise of the project as well as general invitations for comments. One formal meeting was held with delegates from all the schools and paediatric staff in which successes and problems were discussed.

Feedback from parents was received informally and after specific invitation through a general letter.

The questionnaire submitted to the students was approved by the University of Western Sydney Human Ethics Committee.

## Results

Seven schools were invited to be partners and none refused. They included three private and four government organisations. Two students were placed in each school for 2 weeks in each of the four semesters.

## Students

Questions submitted to the students and their answers are as follows. One hundred twenty-nine questionnaires were distributed with answers received from 109.

- Had you any previous contact with children with developmental disabilities?  
Fourteen per cent reported no prior exposure to disabled children. Fifty-five per cent reported chance or occasional encounters with unknown children with developmental disabilities (for example in public areas), 24% reported regular encounters and 7% extensive contact.
- What effect did the engagement have on your understanding of the effects of disabilities in children?  
Thirty-seven per cent of students replied their understanding was greatly increased, 39% moderately increased, 15% somewhat increased, 7% a little increased and 2% not at all. Several students specifically commented that this experience helped them identify and communicate with children with disabilities and to realise the importance of the schools in their care.
- What effect did the engagement have on your understanding of the impact of child disabilities on the family?  
Forty-three per cent of students reported their understanding to be greatly increased, 40% moderately increased, 11% somewhat increased, 5% a little increased and 1% not at all.

One of the most common comments related to the surprise of students about the magnitude of effect on the families, particularly the emotional burden.

- 4 What effect did the engagement have on your knowledge about services for children with disabilities and their families? Twenty-seven per cent of students reported greatly increased knowledge, 43% moderately increased, 25% somewhat increased, 4% a little increased and 1% not at all. A common spontaneous comment related to increased awareness of services: their variety, their specificity and their effect.
- 5 What effect do you think the engagement had on your readiness and preparedness to care for such children? Fifteen per cent of students reported greatly increased readiness and preparation, 44% moderately increased, 30% somewhat increased, 6% a little and 5% not at all.
- 6 What effect did the engagement have on your understanding of the work of the schools? Thirty-six per cent of students reported attendance had greatly increased their understanding, 30% moderately increased, 20% somewhat increased, 10% a little increased, 2% no increase and 2% cannot recall.

The only criticism contained in comments was about the length of the engagement; 17% of students declared 1 week would have been sufficient. These students would have preferred more time in other facets of the term, including A/E, children's wards and special care nurseries: the more clinical pursuits.

Of 1 year of 129 students, the professionalism of two was considered unsatisfactory, and they were obliged to repeat the engagement later in the year. Conversely, 37 (28.6%) received almost full marks (95–100%) for their written school report.

### School staff

From the beginning, school staff had been involved in regular unstructured communications which included visits by our staff to the schools, our attendances at end of year performances, phone calls and emails.

Ten teachers provided written, unstructured feedback. Nine declared it to be highly successful. Seven declared they had had no general problems: three thought 2 weeks was too short to get to know the student well. The teachers were very satisfied with the engagement. They found it to be a very worthwhile experience. Many students impressed them very favourably.

Specific problems related to individual performances by several of the 362 students who passed through the schools in the 3 years and involved 'professionalism' including arriving late and the use of mobile phones in class. In line with general obligations for attendance in the paediatric department, failure to attend 80% of the days without an appropriate excuse meant that two students repeated the school engagement. Some students were noted to be more 'interested' than others, but fortunately, there were no problems in relationships between students and children.

### Parents

Ten parents provided written feedback. Eight declared the programme to be highly successful giving it scores of 5/5; two gave scores of 4/5. A most common comment was they hoped the

students learnt disability not only affects the child, but the whole family, and that children can be very content and happy despite their disabilities. Over the 3 years, many parents declared informally that it will be very good to have doctors who understand the whole system. Parents have been enthusiastic, but in one school, in the recent term, some parents expressed weariness at having being interviewed by students in each of the four terms of each year since the beginning of the project.

## Discussion

The programme has been successful, thanks to the staff at the schools that welcomed the idea from the beginning and continue to embrace each new batch of students. Staff remain committed to training doctors who understand more of the problems of disabilities. It could be concluded they had felt neglected by the medical profession and were toiling in isolation. A common question at the initiation of the programme was 'why has it taken so long?'

Parents asked the same question, often expressing disappointment that the profession did not seem to really understand. Some doctors understood the diagnosis, but many did not seem to understand the long-term challenges and the services that existed to help. We have not yet attempted to quantify this disappointment but it does suggest the need for a better approach to education about the 'millennial morbidities' of paediatrics.

This privilege of enthusiasm was recognised by the department of paediatrics which has done its best to preserve and nurture the relationship. Special sessions of medical updates have been provided to staff, the department administrator has visited schools, events have been attended, and there has been close personal communication on the phone with regard to any problems. Certificates of partnership have been awarded, and adjunct associations of the leading teachers with the university are in process.

Nevertheless, we feel we could be doing more. Perhaps, mutual benefit could involve more regular 'updates' for the teaching staff and more involvement with parent groups. With regard to the 'weariness' expressed by some parents, we intend to invite other schools to join in partnership so that rest periods can be assured.

Perhaps more could be done for the students if medical staff could visit the schools during each rotation to provide the students with better understanding of the medical issues. This would move the engagement from a self-directed to an instructed experience which would please some students but would need extra staff. The occasional complaint that 2 weeks consumes too much 'clinical' time is countered by the fact that lectures and presentations on other aspects of child health are included in those weeks. And, if students would like to experience more general paediatrics, they are welcome in the hospital after hours. We were encouraged, however, by the high quality of the school reports which seemed to reflect their involvement with the project.

A special advantage from regular visits by medical staff would be the opportunity to get to know the students and to encourage them to share the emotional impact of the engagement. One visit emphasised the importance of this communication. One of

us was invited to a special discussion with a school counsellor who was concerned about one of our students who appeared to be doing poorly, appearing withdrawn and uninterested.

On arrival, the counsellor was busy so this student from the Middle East who was unaware of the counsellor's concerns was invited to coffee where he began to share his thoughts. How horrified he was by the disabilities. How sad for the parents. How much he appreciated the friendliness of the children with Down syndrome whom, he had concluded, were really not beyond his capacity to care for as a father. He was frightened by a child with autism: a beautiful child who had come up to look at him but then stared and stared, giving the impression he could see into the student's soul and was preparing to spring and bite. How inspired he was by the staff, and the work of the school. He concluded you could judge the value of a society by the way it cared for its disabled, and this country was doing very well. The school counsellor was later astonished.

As this is an early report from an unusual educational collaboration, our research will continue in order to improve the experience for all participants and to monitor longer-term results. In particular, we are keen to improve our contribution to the schools.

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