OPINION

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“Developmental Disability Medicine: Isn’t it time for its inclusion into the paramedic curriculum?”

Interview with Dr Jane Tracy on 27th April 2006, followed by responses from Andrew McDonell and Melinda Service

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Dr Jane Tracy is a general practitioner who has been with the Centre for Developmental Disability Health (CDDH) Victoria since its inception in 1998. Prior to the Centre's formation she worked in the Monash Developmental Disability Unit and the Developmental Disability Clinic and Spina Bifida Clinics at Monash Medical Centre. She has an adult son with developmental disabilities and so has both a professional and personal understanding of and commitment to the field. Dr Tracy is Educational Director of the Centre and has worked with her colleagues to develop an undergraduate curriculum in Developmental Disability Medicine and teaching resources for both undergraduate and postgraduate students. During her time at the Centre she has completed a postgraduate degree in higher education to enhance her teaching knowledge and skills. In 2005 Dr Tracy and her colleague Dr Mary Burbidge produced the Centre's new teaching resource, Healthcare Scenarios in Developmental Disability Medicine. More recently, Jane was selected by Monash University as one of only 10 staff members representing the University in the national selection process for the Carrick Awards for Australian University Teaching under the category ‘Citations for Outstanding Contributions to Student Learning.’

BW: Morning Jane, and thanks for the opportunity to interview you. So, can you tell us a little bit about your role for the Centre for Developmental Disability Health Victoria please?

JT: *Thank you for this opportunity, Brett. Our Centre was established in the late 90s, through an amalgamation of two Developmental Disability Units, one at Monash University and one at the University of Melbourne. These units had been established in the early 90s, and the Centre for Developmental Disability Health was the result of their amalgamation in 1998. The goal of our Centre is to improve the health and healthcare of*

adults with developmental disability in our state, through the support of the generic health services. The work we do falls into four main categories. There's the education component, research projects, clinical work and there's an important role for advocacy as well.

In relation to our clinical work, we focus on supporting medical practitioners, usually general practitioners and psychiatrists, in the care of their patients with developmental disabilities. We are a small centre and not able to see everybody in the state - and neither would it be appropriate to do so. It's much better that people have their healthcare delivered locally by local medical practitioners, but unfortunately many doctors feel that they have been inadequately trained and are inadequately resourced, to care for their patients with developmental disability. We encourage doctors to ring us and discuss their clinical dilemmas, to email and write to us, to visit our web site and look for resources that might be of use to them. We will also see patients for assessment. We might see that patient once or three or four times and then send them back to the referring doctor with an extensive report and management recommendations. We don't offer long-term care.

We also produce a number of resources that GPs find useful in caring for their patients. We have written, with other experts in Developmental Disability Medicine throughout Australia, a text book on the medical care of people with developmental disability throughout the age range, from paediatric to adult services. That book, "Management Guidelines: Developmental Disability" is published by the Therapeutic Guidelines Ltd. It's a locally written and relevant text that is both affordable and concisely written. Another recently produced resource is a CD ROM called "Health Scenarios in Developmental Disability Medicine" and perhaps we'll talk a little more about that later. We have a Personal Health Record, a patient-held record, available from our web site as well as booklets on menstrual management for doctors and carers of women with intellectual disability. So we have a range of resources to support medical practitioners in their care of people with developmental disabilities that are available through our Centre and our web site.

Our Centre is also involved in a range of research projects, focussing on the health and healthcare of people with disabilities. We have an interest in both mental health and physical health, and the presentation of psychiatric and medical illness. Many of our patients are not able to speak and so they present with a behaviour disturbance or a change in behaviour. Teasing out what's caused that change in behaviour presents many of the clinical challenges we face. Some of our research projects focus on looking at the ways we can better diagnose, for instance, depression and dementia in people with intellectual disabilities.

My passion, and my main role at the Centre, is teaching. We now teach in both Victorian medical schools, and in fact now teach every medical student graduating in the state. Most of my time is spent developing teaching packages for undergraduate medical students and in implementing and delivering those packages to the students. I love this work and find it both immensely challenging and satisfying

BW: Thank you. So, why is there a need for a Centre such as yours?

JT: *Well, the Centre was established because there was an awareness of the health needs of this population in our community. Adults with disabilities often have very bad outcomes on a whole range of parameters. Their life expectancy is less than the general population, some 20 years less in fact, and they are more than 50 times more likely to die before the age of 50. These poor health outcomes relate to a whole range of factors. Certainly there are underlying risk factors that are part of the disability itself that increase morbidity and mortality, but there are other important factors too, including unrecognised or untreated or under-treated medical conditions that are not managed appropriately. That, in turn, comes from a whole lot of reasons that relate to both health providers and the carers/support workers with whom people are living. Carers may not have been trained or equipped to identify the presentations of significant medical conditions and illness as well as they might. So, hearing and visual impairments for instance, may go undetected, epilepsy may be unrecognised or under-treated. One of the conditions that we see that is often unrecognised is gastro-oesophageal reflux disease, which can present as behaviour disturbance, anaemia, and sleep disturbance or in many other ways. Dental disease and nutritional disorders, and indeed constipation are much more common in this group. These are all common problems that are easily treated, but are often unrecognised or inadequately managed.*

Side effects of medications may produce symptoms that our patients may suffer from and not be able to tell us about. We have to be quite creative and resourceful in our questioning of why somebody might be behaving in a particular way at a particular time. For instance, if somebody is reluctant to get out of bed in the morning it might be seen as just a "behaviour disturbance" but they may actually have ischaemic heart disease, be suffering angina when they move around and are frightened of that pain and so are reluctant to get up - or they may have a painful plantar wart or injury to their foot. They may refuse to come to the table at meal times, and again that may be looked on as a "problem behaviour" but it might be that eating hurts them. They may have dental disease or reflux disease. An individual may push or shove somebody in their vicinity and be labelled as having "aggressive behaviour". They may, however, be depressed and not want to engage in their normal activities and what has been labelled as "aggressive behaviour" is the only way they have of expressing their desire to be left alone.

Many doctors feel inadequately trained and resourced to tease these issues out and care for people with developmental disabilities. They may lack confidence in working with this group of patients but people with disabilities have the same range of medical problems as the rest of us. Doctors may just need the confidence to apply the knowledge they have to the care of people with developmental disabilities. People with disabilities also suffer the effects of the negative attitudes that exist in the community towards disability. Unfortunately doctors and other health professionals are not immune from those and sometimes people are not offered the standard of healthcare to which they are entitled because of those negative attitudes.

So I guess our Centre is needed to support medical practitioners and other healthcare providers. We want to model and reinforce appropriate attitudes and underline the value of people with disabilities, and the ways in which they contribute to their communities. We want to support medical service providers in ensuring that they get a high standard of medical care so that their health and well-being is cared for in exactly the same way we want our own health and well being cared for. We support medical practitioners in a range of ways, through medical assessments of referred patients and through phone consultations. We encourage doctors to ring us and discuss their clinical dilemmas and have found this to be an efficient way of using our time as well as it being much more convenient for patients and carers to receive care locally. Our Centre's contribution to the undergraduate curriculum has been valuable in enabling medical students to acquire the attitudes, skills and knowledge required to provide high quality care to people with disabilities. In acquiring these specific attributes, students are also learning important lessons that have much wider application, such as understanding the role and value of a multidisciplinary healthcare team and the fundamental importance of tailoring our communication strategies to the patient with whom we are working. Learning to communicate effectively with people with disabilities and their families and carers facilitates the acquisition of a flexibility and a depth of understanding that applies to many other patients with physical and/or cognitive impairments associated with communication difficulties.

BW: Do you teach in any other programs, such as paramedics or other allied health disciplines?

JT: *We would love to teach in the courses that you nominate, because as I said before, the healthcare of people with disabilities is an inter-disciplinary, multi-disciplinary endeavour. People often need input from a range of professionals in order to have their healthcare adequately assessed and managed. So, we would love to teach in different courses, but it's always a matter of resources isn't it Brett! We can only stretch ourselves so far, and we are, as I say, quite a small unit and haven't been able to do as much teaching in allied health courses as we would like. We are however looking at other ways of contributing to those courses through the development of teaching resources. The resources I mentioned before, particularly the CD ROM "Healthcare Scenarios in Developmental Disability Medicine" are appropriate for students of other health professions. We are also working with the Faculty of Medicine, Nursing and Health Sciences at Monash University to develop some on-line learning modules, which would be useful for both medical and students of other healthcare disciplines. These modules would enable us to share the resources that this Centre has to offer, in terms of our staff, our experience and expertise and our patients, many of whom have expressed a desire to contribute to teaching in this field.*

BW: What other specific challenges face healthcare workers when dealing with patients with disabilities? What are some of the strategies to assist in this process?

JT: *Well, the challenges faced by health professionals caring for people with a developmental disability could relate to the person with the disability themselves, the health professional and/or the system within which they are working. The patients may have a cognitive or communication difficulty that affects their ability to understand the significance of the symptoms they're experiencing, or to tell family members or support workers about those symptoms, or to cope with aspects of the examination and investigations required, or to participate in management. So there may be factors relating to the patient that make it particularly challenging to provide healthcare in some situations. But there may also be compounding factors relating to the health professionals themselves. Their understanding of disability, their attitudes towards people with disability, and their own levels of knowledge and skill may all influence the standard of care provided. And then there are some particular legal issues, those involving informed consent and the right to privacy and confidentiality for instance, that have particular relevance to our patient group.*

There are also situational and systemic factors that impact on care. People with a disability may have more difficulty accessing health related information for instance. Much of the information that we acquire comes from the media, particularly the written word, from our exploration of the sources available to us and from peers. People with a disability may not have the same access to accurate information from peers. They may have low levels of literacy, and/or have difficulty reading because of a vision impairment. So there are a range of reasons that people with a disability may not have the same foundation of health understanding and knowledge as their peers without disability.

They may have difficulty physically accessing health services. The absence of appropriately designed and situated steps and stairs, rails and toilet facilities may all reduce access. Even an unfriendly or unhelpful attitude of reception staff or waiting rooms that are cramped and can make life that bit more difficult with somebody with a disability who finds those conditions stressful.

People with disabilities often have difficulty with transport and arranging timely and appropriate transport to an appropriate health service can be a real challenge. They may face social and financial disadvantage, and many on pensions are not able to pay for private healthcare and other ways of facilitating access to high quality care. There are also constraints relating to the funding of health service provision, particularly in relation to the time required to care for somebody with a disability. A patient with a communication, physical or cognitive impairment may require a much longer consultation than someone presenting with a similar condition but without the co-existing disability. If the health professional's time is not funded accordingly, that can be a disincentive to taking a thorough approach to assessment and management.

We were talking earlier about the particular challenges in an emergency care situation and I guess many of the challenges that I've referred to apply in that situation as well, perhaps even more dramatically so. Somebody who has trouble expressing their symptoms, or saying what they're feeling or experiencing may demonstrate their distress,

pain, or fear through a change in their behaviour. They may be less co-operative, less compliant with your suggestions or even aggressive when they're in a distressed and fearful state. We are, after all, all likely to be frightened in situations that we don't understand, where we feel powerless, and where we are surrounded by unfamiliar environments and people. The situation of a medical emergency may combine all these things. If someone has an intellectual disability they may have more difficulty understanding what's going on, and they, like all of us, will be calmer if they understand something of what is going on, what is to happen next and if they can have familiar things and people around them. If they are being transported to hospital, for instance, they may feel less frightened if someone they know travels with them.

So my suggestion would be always talk to the person with the disability directly first, even if they have severe cognitive and communication difficulties. Speak to them, look at them directly, make them feel and understand that they are the primary patient and that your focus is on them, and information that you might get from support people is supplementary. Your focus must remain on them and not on their carer. Explain what's going to happen clearly and in simple language, without jargon. Sometimes people talk to adults with a disability, as if they're children. They are not children they have 20, 40, 60 years of life experience and so are not like a child at all. They may, however, have difficulty understanding abstract concepts so the language you use has to be straight forward and clear and simple. Information should be delivered in small chunks, with a pause, a bit of processing time, in between so that they can catch up with the concepts that you are trying to convey.

It's very important and very useful to listen to the expertise of people who know the patient. Family members may have had a lifetime of valuable experience learning the most effective ways to gain co-operation, or how to best calm them when they are distressed. This information is invaluable - and such a time saver! Again and again we hear stories in which the expertise of the parent or sibling has not been valued and the whole exercise has been much more time-consuming and traumatic for all concerned than it need have been if that expertise had been listened to from the beginning. While saying that the family members, and indeed support staff who have worked with somebody for a long time, have invaluable knowledge of that person, it is also important to remember that those people may not have any medical background. Disability support workers, direct care staff, are not medically trained and therefore it is important not to assume a knowledge of medication or symptoms or medical conditions when working with them.

Encourage the person with the disability, if they're going to hospital for instance, to bring a comforting item on that journey. The person supporting them would be able to identify something appropriate. Such an item is likely to be precious to the person concerned and it is very important that all healthcare staff are aware of its importance and do all they can to ensure it doesn't get lost. Also encourage familiar people, family members or support workers, to accompany the patient to hospital and to stay with them wherever possible.

If the patient has a communication impairment it is crucial to ask if they have a communication aid or device of some kind and ensure that it goes with them to, and stays with them in, hospital. Imagine how frustrating it would be for you if you have an effective communication aid but it got left behind at home when you were taken to hospital - the very time when you will need all your communication ability to communicate with the healthcare staff. You would be anxious to communicate effectively with those providing your medical care, to let them know what you were experiencing, and to ask questions about what it meant and what was going to happen. How dreadful it would be to be deprived of the means of doing so!

So, does that give you some ideas or some strategies that might be useful?

BW: It sounds great. I understand you received funding to create a multi-media CD ROM. Can you tell us more about this?

JT: *Yes, the genesis of this CD was actually in our teaching program. One of the sessions we run for fourth year medical students at Monash focuses on communicating effectively with someone with a developmental disability. In this session we employ tutors with disabilities to work with students, so students can hear the perspective of, and learn from, people who live with these communication difficulties in their daily life. This session is very positively evaluated by the students and it's been clear that people with disabilities are potent teachers. Student attitudes are powerfully influenced through meeting people with disabilities in a context where they are able to demonstrate their competence and power to make choices and contribute to their communities. Medical settings, however, tend to reinforce the association between disability, illness and dependence. We wanted to find a way of providing students, and indeed postgraduates, with an opportunity to 'meet' people with disabilities in a positive context, and through those people to learn more about this discipline of Developmental Disability Medicine.*

In 2003, we received funding from the Melbourne-Monash Collaborative Funding Grants in Educational Technology and made a CD ROM entitled "Healthcare Scenarios in Developmental Disability Medicine". This teaching resource has two main components. There are four video scenarios, each with a different person with a disability, through which students learn a little about that person's life, go through a medical consultation with that person, and have key learning objectives identified and addressed by working through a learning pathway. Each contains a self-assessment exercise at the end of the pathway.

A knowledge base provides extensive background information to the four video scenarios. There are five areas covered and all are illustrated with both still images and video clips. The first is an Overview Of Developmental Disability covering some of the fundamental concepts and terminology of Developmental Disability Medicine. The second knowledge base is General Issues In Healthcare and cover some of the barriers to healthcare and strategies for reducing those barriers. Common medical problems, issues in preventive healthcare, and specific areas in men and women's health are also addressed. The third area is Communication, and strategies for communicating effectively with someone with

a developmental disability are canvassed. This section is extensively illustrated with images of communication aids and equipment. The fourth area is Mental Health And Illness With People With Intellectual Disability. The fifth area is Issues For Families And Carers for people with developmental disability. Apart from the video scenarios and the Knowledge Bases, there are a list of resources and a glossary of terms. The product is quite large, over 200 screens of information, so it is quite comprehensive.

We have used this teaching resource in our own teaching of medical students and found it very effective, and I know it has also been taken up by disability support workers. I think one of the really important aspects of effective teamwork across disciplines is understanding each other's perspective. Doctors and support workers are often working together with the person with the disability, and perhaps their family, to optimise the health outcomes for that person. If support workers and doctors can understand each other's perspective, they can work together more effectively. Healthcare Scenarios in Developmental Disability Medicine seems to have a role in contributing to this mutual understanding.

BW: It is a great student resource, having got a copy myself and seen it in use several times. Do you think there is enough emphasis placed on disability care and management in healthcare education, and if not, is this a curricula issue or simply because it's not seen as important as other areas?

JT: Well, I have to admit its reputation is not that of the sexiest area in medicine! I think however it is a really challenging, stimulating and rewarding area to work in, and I hope that in our teaching we convey some of our enthusiasm and passion for the area to our students. We've been very fortunate over the last seven or so years, that both the University of Melbourne and Monash University have reviewed their medical undergraduate curriculum. That has provided opportunities for us to contribute to medical training in a way that was not possible in the past. We now teach on a number of occasions through their course, all medical students graduating in Victoria. Yes, of course we would like more teaching time, and would like to be able to provide students across both universities with an equal amount of teaching in areas we feel are important. But having said that, we are very appreciative of the opportunity in recent years to contribute substantially to medical undergraduate training.

Our students express a sense of relief really when they understand what developmental disabilities are about. It's not scary; it's not shrouded in mystery. Once they can understand what the terminology means, understand what developmental disability is, and the implications for health and healthcare then they feel more confident and better equipped to work with people with developmental disabilities in their own practice. I see this written again and again in the evaluation forms that I get from the students. I am also reminded of the importance of the work that we do when I receive phone calls from GPs wanting to discuss a clinical dilemmas they have with a patient with a developmental disability. I am then made very aware of the lack of training most GPs have received, and the lack of confidence that many feel in working with people with developmental disabilities.

In the past there hasn't been enough importance placed on the education of medical, and other healthcare, students in this area. Now there is certainly more emphasis and yes, I think there should be more still because, as I said before, not only are they learning specific skills to better equip them to work with people with developmental disabilities, but they're learning such valuable generic skills too. Through focusing on the care of people with a disability they gain understanding and skills applicable to many other groups in the community, who encounter barriers to healthcare related to physical, cognitive or communication difficulties.

BW: Jane, thanks for your time.

JT: *You're most welcome Brett, thanks for the opportunity.*

Response by Andrew McDonell - Acting Assistant Manager - Clinical and Education Services, Rural Ambulance Victoria

This interview is extremely timely as health professionals examine their curriculum and clinical practice. Disabilities are overtly examined in the core curriculum of many health professionals such as nursing, midwifery, medicine and paramedicine. This is probably due to barriers put up by the curriculum developers and practitioners not viewing people with disabilities as important and part of main stream health care. "It is somewhere over there!"

Of course misunderstandings about caring for people with physical, psychological and learning difficulties develop the barriers that are seen in the provision of health care to this group of people. Our own prejudices as health professionals are often reflected in the way we interact with people with disabilities and also in the way we reject applicants that prevent them from become members of the health care disciplines.

This is particularly evident in paramedicine where recruitment, particularly through the medical examination, is used to prevent people with any form of disability from entering the practice. I am not saying that people with certain disabilities can do all types of health employment, in some instances people with disability can't, however people with disabilities are not even given the opportunity to enter courses or occupations and thus be given the chance to demonstrate their abilities and skills.

It becomes evident that all health professions need curriculum and ongoing education that develops an understanding of how to work with people with disabilities. It is extremely clear that learning to work with people with disabilities develops core course competencies such as communication, listening, tolerance and cultural understanding. While curriculum writers may argue that there is not enough time to include everything in a course or continuing education program, there are many innovative ways to incorporate

content and specialities into core curriculum. Broadening and presenting actual life experience is often better received than chronic didactic philosophies that have been delivered over the years and continue to be delivered.

Health professions lack understanding of many other aspects of working with people with disabilities particularly the carers. Often carers who are parents or children of people with disabilities are not considered. Health professions may on many occasions brush aside the view, opinions and vital observations of carers. This lack of understanding of the worth of carers is degrading and reflects the poor understanding of the community at large.

It is essential that caring for people with disabilities and their carers is included in all core curricula of all health disciplines. I commend the interviewer and interviewee on publishing their thoughts and views.

Response by Dr Jane Tracy

I entirely agree with Andrew McDonell. It is very important to ensure curriculum components addressing issues in the health and healthcare of people with disabilities are included in the undergraduate courses of all healthcare disciplines. Andrew McDonell identifies core competencies in communication, tolerance, cultural understanding and working with carers as all being areas of practice that are focused upon through considering the needs, and working with, people with disabilities. Attitudes, skills and knowledge developed in relation to this patient group both informs and enhances our management of their often complex healthcare needs and improves and enriches our ability to care of all our patients.

Response from Melinda Service Undergraduate Course Coordinator, School of Public Health, Queensland University of Technology

As I read this interview I was reminded of the curriculum designers' dilemma of what knowledge to include, which pedagogy will achieve the outcomes or what assessment will be authentic.

I think Jane discusses a couple of points that offer the most potential for changing graduate outcomes. One is the concept of interdisciplinary health care teams. Jane states that "...the healthcare of people with disabilities is an inter-disciplinary, multidisciplinary endeavour. People often need input from a range of professionals in order to have their health care assessed and managed." I think all of us in health care know this to be true yet we have been very slow to respond in the tertiary education

sector. Many of the current health care workforce have been educated in the 'silo' model of specific discipline programs (medicine, speech pathology, podiatry, psychology etc) consisting of even more specific discipline units/subjects (anatomy, pathology, biomechanics, physiology etc). Such curricula models in no way reflect how we are now saying healthcare should be delivered in the community.

It is pleasing to note that some of the medicine and allied health curricula are now designed around 'topics' or 'problems' rather than the traditional disciplines. Others have students from a variety of programs undertaking the same core units. However, when Jane is able to state that she teaches the medical, paramedic, speech pathology, and psychology etc students in the one room and they are discussing the prepared scenarios as an interdisciplinary team then we will know that we may make a real difference to health outcomes.

Another interesting teaching strategy mentioned by Jane with a focus on communication, was the inclusion *"of tutors with disabilities to work with students, so students can hear the perspective of and learn from, people who live with these communication difficulties in their daily life."* I think this has the potential to be one of the most powerful strategies that could be used to affect the attitudes of health students. It is well acknowledged that knowledge alone does not change behaviour and hence clinical knowledge of disabilities will not always change the attitudes of health care workers to people with disabilities. By providing students with an opportunity to have their understandings and perhaps attitudes challenged by those with disabilities should have the potential to achieve affective outcomes.

I think all professional educators are challenged by the tension between what has been traditionally included in the curriculum and what 'society' thinks should be in the curriculum. Just as there is pressure placed on the school curriculum to include the 3R's as well as topics such as driver education, parenting, alcohol, and STD's, the pressure on the health curriculum to be inclusive of all knowledge from the traditional to the latest in medical research is immense.

I commend Jane on the development of the CD teaching resource but more importantly on the interdisciplinary approach and the inclusion of tutors with disabilities as I think these have the most potential to change attitudes and health outcomes.

Response from Dr Jane Tracy

I certainly share Melinda's dream of undergraduates in a range of health disciplines learning together. Just as our patients have multifaceted issues, so our response to them requires a broad based, holistic approach informed by different perspectives and skills. Being educated together provides wonderful opportunities to learn from, as well as with, each other and to develop an understanding of how we can complement each other's

skills and build a more comprehensive, inclusive and sensitive foundation for patient care.

In a similar vein, students can learn a great deal from people who have personal life experience of particular issues. Students have both valued and enjoyed the sessions with tutors who have developmental disabilities. Their evaluations reflect their new understandings and demonstrate that they have learned broadly applicable lessons, as well as specific skills in relation to patients with disabilities. These points are illustrated in the following student comments...

“this is the first time I have been aware of the spectrum of communication differences and how I have to tailor my communication to best fit the patient” and

“the session created awareness that everyone has the same feelings, emotions...with or without a disability. Feel more open and comfortable (used to feel scared). Thanks!”