



a note from David Dossetor...



Appreciating the more important things of life: Professor Trevor Parmenter's Festschrift

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Epistemology is the study of "why we are the way we are". This is the motif that Vivien Riches hung on her wall while she was Trevor's PhD Student, one of his earliest from some 30 years ago. A questioning of the theory and origin of knowledge is a measure of most significant academics. A festschrift is a book or academic meeting honouring a respected person, as was presented to honour Trevor Parmenter on 14/8/10 on his retirement as the Foundation Professor of Developmental Disability at the Centre for Disability Studies, Sydney Medical School, at University of Sydney, and indeed the first such professor in Australia. Trevor, who was born to a country life, started his teaching career in a single teacher school in regional Australia. 1970-73 he was a principal at Rowland Hassall School, Parramatta for those with learning difficulties, where he inspired both students and teachers alike in appreciating that you can't measure someone by their IQ, as he valued all other traits of human valour. He first became a university academic in 1972 first as a Lecturer at Kuringai College of Advanced Education and then at Macquarie University where he became a Senior Lecturer in 1980, associate professor in 1988 and Professorial Fellow in 1990. He took up the Director of the Centre Disability Studies in 1997 and has certainly has been at the

head of the development of academia in intellectual disability studies in Australia. He was Editor-in-Chief of the *Australia and New Zealand Journal of Developmental Disabilities*, now known as the *Journal of Intellectual & Developmental Disabilities*. He was on the executive of the International Association for the Scientific Study of Intellectual Disability (IASSID) for 13 years and served as its president. This gave him an international network of colleagues for mutual influence.

The focus of the day was concepts of intelligence and concepts of intellectual disability. The development of the intelligence test in the 1900s has led to an excessive reliance on the result of a simple test to identify certain people. It is one thing to identify the need for additional support, services or funding for which identification can be helpful, but such identification can also lead to a loss of status, access to certain environments, such as employment, or entitlement to choice in society. The threat of doing harm has led to changes in the definition of intellectual disability over time, to include "having problems of independent functioning in at least two areas" in DSM-IV (Diagnostic and Statistical Manual of Diseases) (1994) at a time that no such reliable measure had been developed. The next (Vth) version of DSM is moving away from the measurement of intelligence to a measure of "need for support", with further problems of reliability and validity of measures. Undoubtedly these concepts are mathematically correlated, but also make important and meaningful distinctions.

Professor Roy Brown, Trevor's visiting international friend and peer from Calgary, Canada, previously of Adelaide, described how much our concepts of intelligence have changed. 20 years ago we believed that brain cells couldn't reproduce or adapt, and aging was a constant decline and loss of neuronal activity from birth. This is no longer

a valid belief, with the discovery of ways of retraining brain activities and promoting repair and regeneration of neuronal activity. Roy argued that we are too preoccupied with science, which approaches understanding from the top down, with an assumption of knowing which deconstructs function, as opposed to the study of biology, which looks at natural function and adaptability and thereby teaches us about potential and change in different environments.

Further, intelligence is not a fixed human attribute but is an interaction of genetic faults and a lack of appropriate environment. Every decade the population becomes more intelligent as based on standardised testing (an average improvement of 34 points since 1950). The resilience model of understanding humans described by Alan and Anne Clarke (2003) is a combination of biological resources and social support. For example one additional attribute such as motivation can change IQ testing by 20 points! Accordingly we may be better to talk of competencies rather than a measure of generic potential, as implicitly measured by IQ.

Trevor helped set up the international working group on Quality of Life in IASSID in 1996. In an article he describes quality of life as: beliefs, goals, aspirations, knowledge of self and of how the world works. Nowhere is IQ mentioned. One can see how much of quality of life is dependent on an environment that gives choice. Social inclusion also provides stimulation and maximises choice. Accordingly intellectual ability is dependent on cognitive, social and quality of life components. Intellectual ability is therefore dominated by environmental factors, but also has major influences on that same environment. That is to say the broader qualities of ability have



a large impact in shaping the environment that you are faced with. Roy Brown quoted “if I hadn’t believed it I wouldn’t have seen it” to illustrate how important our concepts of the human predicament in influencing how we perceive our fellows. In this context, Normalisation is freedom and capacity to be yourself amongst others and therefore applicable to anyone. Indeed intelligence is more to do with awareness of self and consciousness. The core of a quality of life is a person understanding themselves. One may conclude that self concept is more important than intelligence.

In the debate for greater achievement in schools, driven by the competition to im-

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prove intelligence and materialism, we are at risk of creating a segregated group of elites who lack an understanding of the connection to others. In this age of the human genome, in the near future, these segregated elite may soon be derived from designer babies with genetically selected qualities. Such a spectre risks losing the natural variance we have as human beings which is our genetic resource for the future. This means that we all carry qualities of importance, it is just that we may not value them all. Conversely with rising complexity in our society, we may be increasing the number of people who cannot function in socially normed or accepted ways, thereby increasing the numbers who are intellectually disabled. I suspect this is a factor of not coping that is driving the rising numbers of emotional and behavioural disturbance in schools.

At a subsequent meeting Roy talked about his research with the Family Quality of Life Scale and the growth of international comparisons of quality of life in families with a member with intellectual disability. The dimensions are: health of the family, financial well-being, family relationships, support from other people, support from disability related services, spiritual and cultural beliefs, careers and preparing for careers, leisure and enjoyment of life, and community and civil involvement. This measure can draw comparisons between families with a member with intellectual disability to those without. There is plenty of research showing that in the current context these families are highly disadvantaged across most of these domains. International differences can be drawn according to cultural, policy and service differences for people with and intellec-

tual disability. Of additional concern is the difference between families with a child with autism compared with one with a child with intellectual disability. The quality of life for the former was worse in terms of lack of support from services (including a lack of respite), a lack of support from other people such as neighbours and community, and a lack of leisure and community involvement. Autism has a greater influence on poorer financial well-being and family relations, but this is related to the lack of services and community support above. This research provides epidemiological evidence that Autism remains an inadequately recognised and supported disability in our country, even more than intellectual disability!

Graeme Watts, retired Professor at the University of Sydney and current PhD student, talked on intellectual disability and spiritual development. As president of IAS-SID, Trevor had helped establish the Special Interest Research Group on intellectual disability and ethics. Within IASSID there is also a group with a special interest in spirituality and intellectual disability. Spirituality is to do with the dimension of growth in life that leads to finding meaning, transcendence, and recognition of the sacred. It has been suggested that intellectual disability in children impairs spiritual growth and church leaders have at times made mistakes in making prejudicial assumptions about people with an intellectual disability, limiting their social recognition and status as humans. It is clear that many with an intellectual disability have significant spirituality. Spirituality involves a developmental process which is aided by communication through symbols, and the influence of close personal relationships. Graeme drew analogy from Piaget’s developmental stages that all humans follow, and to Winnicott’s theory of object relations, from which one’s sense of otherness derives from close relationships but becomes the ‘transitional space’, with that sense of connected with otherness which is explored through symbols. For those in whom it is hard to see much spiritual awareness, there is still the underlying extraordinary pattern of developmental processes that have a capacity to lead to such awareness. Hans Reinders, Professor of Ethics at the Free University in Amsterdam, who attended by video conference, suggested such patterns can be seen as indicative of a divine intelligence. Indeed, it is often said that you can access the spirit by clearing the mind of intellectual struggle, and experience life like a child. Intelligence can be seen as finding your place in the world, in the way a baby finds the nipple that feeds him or her. In contrast Wolfensberger warned: we must take heed against investing technology with God like

capacity.

In another of Trevor’s articles: “Intellectual disability: quo vadis?” he addressed issues of ethics: stating that in an ethical community all are valued. Professor Stewart Einfield’s quote in the analysis of Australian mental health services for people with intellectual disability was “this is science in the service of those in need”.

Sam Arnold, analytical psychologist with Centre for Disability Studies, and a current PhD student, reviewed the reliability and validity of the psychometric testing of intelligence. Intellectual disability is diagnosed by a score on a test outside of 2 standard deviations from its mean. This necessarily means that measures around or below 70 will be unreliable, as it is at the extreme of its variance. Yet in the last century this measure was used to recommend individuals with an IQ below 70 for institutionalisation and/ or sterilisation. In some cohorts 80% of immigrants failed on this measure (failing to consider language and cultural issues). He summarised the issue IQ with Einstein’s observation: “Only two things are infinite, the universe and human stupidity, and I am not sure of the first!” More recently the generic potential of IQ took a further loss of conceptual and mathematical validity in 1999, when Howard Gardner described and validated multiple intelligences. Those he included were: linguistic, logical-mathematical, musical, spatial, bodily kinesthetic, naturalist, interpersonal and intrapersonal. This has spawned a new approach to education. Trevor anticipated this broadening of concepts in the 70s by describing capacities for ‘information processing’, as distinct from intelligence, one of the themes of his PhD thesis.

Professor Patricia O’Brien has succeeded to Trevor’s Chair at the Centre for Disability Studies. She developed the National Institute for Intellectual Disability at Trinity College in Dublin, where young people previously identified as intellectually disabled completed a university degree, completing 10 modules of learning which empowered them to fully participate as citizens and community leaders.

In the eyes of God, the differences between people are so minimal that we can but see ourselves as equal. The challenge of humanity and humanism is to find connectivity with others despite wars, poverty or disability. The day gave cause to acknowledge the conceptual, scientific and human limitations we are subject to. Such an acknowledgement and value system also unifies us as people and professionals in the challenge to help our fellows in the hardships they face. The breadth of this festschrift certainly honoured the man. ●