a note from David Dossetor...



How much should we worry about the Mental Health Needs of Children and Adolescents with or without Intellectual Disability?

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The planned closure of Anglicare's Kingsdene Independent Residential School for adolescents with intellectual disability made me wonder about how much we should be worrying about children and adolescents with intellectual disability in the context of our understanding of the mental wellbeing of those without intellectual disability. Kingsdene is the only residential school in NSW, and possibly Australia, that caters for young people with severe intellectual disability and complex behavioural, developmental and psychiatric problems. In these times, why should the spectrum of services appear to be deteriorating? Does the great media reaction suggest that this closure represents a sentinel event of the wider public/private service system? Knowing some of these families personally leads me to have some direct experience of what remarkable, committed and loving families these are and I have some understanding of the extraordinary hardship and adversity they cope with. The failure of funding for these special needs not only has major risk of breakdown of some families but also risks more serious adverse events.

How much concern should our community show

about the mental health of children and adolescents (Stanley *et al*, 2005)? The 50% growth in the number of children in care between 2002 and 2007 concerns me (Wood Inquiry, 2008). The recent significant increase of young people in juvenile detention centres concerns me. The number of children and adolescents that are homeless concerns me (36,000 teenagers on any night in Australia) (National Youth Commission, 2008). The level of welfare for homeless 12 year olds, often in refuge accommodation (so long as they are not violent) concerns me.

I witness these changes from the nature of clinical presentations over time. Particularly as the level of disturbance with risk to self and others of young people presenting to our emergency department is getting worse, more frequent and presenting younger. Does this mean the children and adolescents are becoming more disturbed over time? Are our families and community becoming less able to help them grow up? Epidemiologists may argue that things aren't changing, or that we are medicalising problems or that our standards of child protection are becoming more sensitive or that these aren't psychiatric problems. Maybe kids are growing up guicker. Those that I talk to in community work, education, health or mental health all say things are changing and getting worse whether you look over thirty years or the last five or ten years.

The reasons and the changes are complex. The economic growth and productivity of the last 20 years may mean higher expectations for everybody, but why should or could the emotional

wellbeing of this group be worse off? Amongst some of the multiple factors associated with national prosperity that may influence child development and wellbeing I shall mention four. First is the dramatic decline in the average amount of time parents spend with children by 20 hours less per week, over the last generation, largely related to both parents working (and the dramatic increase in "screentime"). Second is the decline of the extended family and of social capital networks in our community and increase of social isolation for many families. Third, measures of quality of family relationships show an increase in the emotional intensity in relationships associated with urbanisation and industrialisation. These measures of "expressed emotion" show a rise in the frequency of criticalness, hostility of, or emotional over involvement with children or other next of kin. These qualities of emotional communication affect the emotional development of children and others with mental wellbeing problems. Finally and possibly the strongest evidence is the influence of and changes in financial relative inequity which is shown to be a powerful driver of a whole range of factors. The World Bank has shown that across the western world, the percentage of a population that earn less than 50% of the median wage is closely correlated with community rates of psychiatric disorder, which is mainly depression and disruptive/criminal behaviour (Emerson, 2004). The recent analysis by Wilkinson and Pickett (2009) amplifies the implications of inequity. Even across the different states of the USA, they argue that the extent of financial and social inequity (the top 20% versus the bottom 20%) is causally related to a host of health as well as mental health factors, including infections, obesity, heart disease, substance abuse, depression, violence and even murder. Rates for these indices for the whole population are about 5 times



greater between the most unequal countries and the least unequal countries. In fact, even the top 20% are less healthy in more unequal communities. Australia may not be as severely affected by inequity as the USA but is this an inevitable consequence of the last decade of globalisation and corporate success?

What about children with intellectual disability? These children and families are affected by the same pressures yet they also suffer an extra risk factor of biological difference or disadvantage. It is found that rates of psychiatric disturbance are three to four times higher in these young people (Einfeld and Tonge, 1996). We also know that the risk of psychiatric disorder is related to the number of adversities that a child and family are exposed to but this rate goes up exponentially with the increase in the number of adverse factors. Emerson (2004) has shown that intellectual disability also exposes you to higher rates of adversity partly through greater social disadvantage. Accordingly, it does not surprise me that the demand for disability services, respite services and health and mental health services is growing for young people with intellectual disability. The frequency with which I encounter distressed parents who are preoccupied with thoughts of murder and suicide makes me concerned that as a community we aren't doing enough.

With the economic growth we should get better in the way we do things. People are better educated, have more access to knowledge through the internet and other media, and indeed there are advances in health and mental health sciences. Special education and training of parenting skills is the intervention found to have the biggest impact in the mental health of children and adolescents with intellectual disability

(Diggle *et al*, 2003). School culture has a big influence on social, emotional and psychiatric wellbeing, and schools can be a centre for community connection and even mental health promotion (Hendren *et al*, 1994). Behavioural, psychological and medical interventions also have growing scientific evidence of their value. For me the measure of a civilisation is how we deal with our most disadvantaged, disabled and disturbed. Young people with intellectual disability and other neurodevelopmental disadvantage are a special needs group that necessitate priority.

The Children's Hospital at Westmead School Link Initiative has the potential to be a part of finding ways of doing things smarter for the mental wellbeing of children and adolescents with intellectual disability, by using a collaborative approach in: promotion, prevention and early intervention, increasing workforce education, and improving pathways to care. The worth of this project will depend on partnership with others who share our concern. Ultimately our collaboration is with the young people with intellectual disability and their families. I don't think the average member of our community knows or understands how difficult it can be to care for, support and love a child or adolescent with intellectual disability particularly in the context of the additional challenge of associated emotional or behavioural problems. This level of community stigma and alienation really concerns me.

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Operation art project...



Operation Art is a project that encourages students from Kindergarten to Year 10 in all NSW schools to create artworks for children in hospital. It is an important state-wide visual arts exhibition that focuses on creating a positive environment to aid the healing and recovery process of young patients.

Operation Art is a way of involving young people in the special work of The Children's Hospital at Westmead – a total healing environment where design, decoration, facilities, gardens and art combine with the best possible medical care to help comfort and heal young patients.

For more information on getting your SSP involved in Operation Art for 2010, Join our email list! Email us at

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