

Title : Longitudinal study of behaviour and emotional problems in young people with intellectual disabilities	
Institution	Monash University, Centre for Developmental Psychiatry & Psychology
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Outline of Research	<p>This longitudinal study consists of a number of groups of young people with intellectual disability, including autism. The study has been running for 14 years and has collected four waves of data to date. Critical questions include:</p> <p>What happens to the behaviour problems of these young people in early adulthood? Do the young people “grow out” of them? Can factors identified in childhood predict those who will be disturbed in adolescence and young adulthood? What is the impact of the major social changes they are experiencing at this time, namely the loss of school structure, the attempts at vocational life, varying forms of independent living, and the maturation of sexual drive, and exposure to drugs and alcohol?</p>
Findings to date	<p>Behavioural and emotional disturbance is highly persistent from 4 years to 24 years, though there is a general trend for this to decline somewhat. Genetic cause of intellectual disability has a major impact on levels of psychopathology. Individuals with Prader-Willi syndrome have the highest and those with Down syndrome the lowest levels. Those with Prader-Willi syndrome have high levels of psychosis, approximately 6 times those in the epidemiological group with intellectual disability due to other causes. Individuals with Williams syndrome maintained high levels of anxiety disorder throughout the study period. Adolescents with autism and mild intellectual disability had high levels of depression. Family factors were also found to be associated with psychopathology. GHQ scores of parents and family dysfunction were correlated with levels of psychopathology in the children, with causal effects</p>

	<p>appearing to operate in both directions.</p> <p>Other key results:</p> <p>The cause of the mental retardation was identified in 53% of the sample. The cause remains undiagnosed in 47%, but these are likely to have a genetic aetiology with a significant proportion of the undiagnosed males having an abnormality of a gene on the X chromosome. Serious mental health problems in mental retardation occur in over 40% of children and adolescents with mental retardation and once established, these mental health problems persist or worsen till age 20 in 82% of those affected.</p> <p>“Disruptive” behaviours, although declining, persist as severe, whereas social relating difficulties increase over time. “Self- absorbed” behaviours, “anxiety”, and emotional and behavioural disturbance in those with autism are persistent.</p> <p>Psychosocial and family factors (such as unresolved parental grief, parental depression, family adversity) also contribute substantially. These findings have informed the development of intervention studies for disruptive behaviours, anxiety and autism.</p> <p>Early intervention programmes for young children with autism, anxiety, and disruptive behaviours have demonstrated improvements in child psychopathology and family functioning, including parental mental health and stress.</p>
<p>Expected start and finish dates</p>	<p>Starting date: January 1995 - ongoing</p>