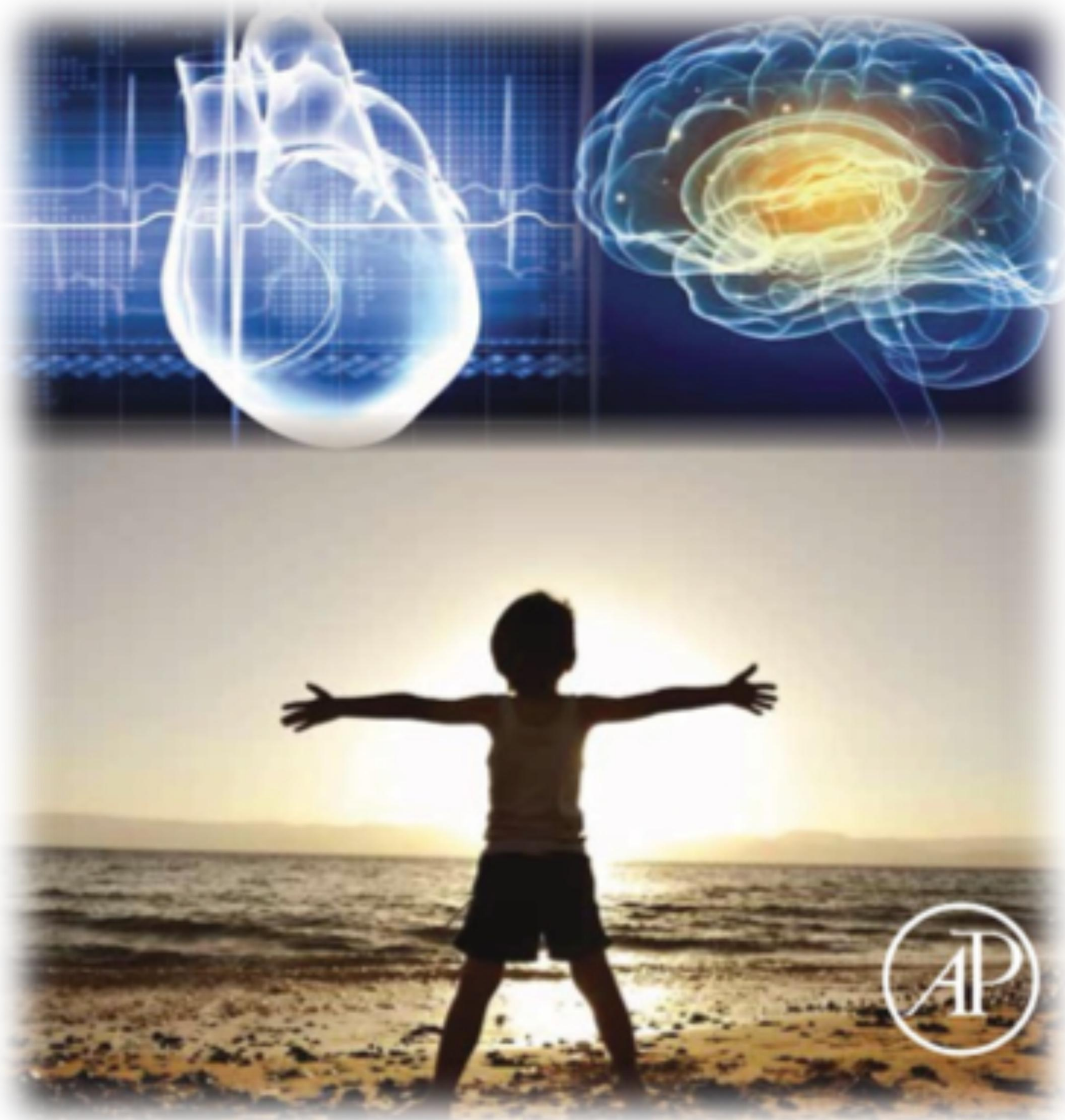


Translating knowledge into action – Family focused interventions improve outcomes for children with chronic illness and disability

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Predictors of Outcome in Childhood Chronic Illness

- We charted elevated rates of adverse psychological, social and educational outcomes in children with chronic illness and disability.
- These persist into adulthood with personal, social and economic costs.
- Our longitudinal work first examined risk and protective factors.
- Severity of disease NOT a reliable or greatest predictor.
- Family factors – parental worry, parenting, mental health, meaning making, family functioning and attachment relationships greater predictors of outcome.
- In turn, impact on families NOT reliably related to the severity of the illness / disability but by the above pre-existing family characteristics AND transactions with healthcare and education providers.
- This knowledge points towards family-focused and community interventions.
- We continue to develop and trial such programmes, with findings to date outlined below.



Family Focused Intervention Trials - Outcomes

Population Design	Outcomes	References
Infants with severe congenital heart disease - Controlled trial - 6 months – 7 years	<ul style="list-style-type: none">•Improved neurodevelopment (Bayleys) mental development index (not psychomotor) (6 months)•Reduced maternal worry and anxiety (6 months)•Greater rates of breastfeeding and easier transition to solids (6 months)•Behavioural adjustment better in children (7 years)	McCusker et al (2009) McCusker et al. (2013)
School Age Children with severe congenital heart disease - RCT - 1 year – 20 years	<ul style="list-style-type: none">•Improved parental mental health, worry, family functioning (1 year)•Fewer ED and unplanned medical consultations (1 year)•Fewer days missed in first year of school (1 year)•Better neuropsychological outcomes (20 years)•Parenting narratives across time less trauma infused and more active coping strategies evident	McCusker et al. (2012) Phillips et al. (2024) McCusker et al. (2024)
Children and Teenagers with Acquired Brain Injury - Large cohort pilot study - No control group - 6 months	<ul style="list-style-type: none">•Positive outcomes in relation to child behavioural adjustment, interpersonal competencies and family related quality of life	McCusker et al. (2024)
Children with hard to control epilepsy - Feasibility pilot study - No control group - Post intervention	<ul style="list-style-type: none">•Promising outcomes in terms of child behavioural adjustment and family functioning	McCusker et al. (2025)

SCAN FOR MORE INFO



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