



The 10 year celebration of the CHW School-Link and the Journal of the Mental Health for Children and Adolescents with Intellectual and Developmental Disabilities.

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Introduction: The 10-year celebration of the CHW School-Link and the Journal of Mental Health (MH) for Children and Adolescents (C&A) with Intellectual and Developmental Disabilities (IDD) provides an opportunity for looking back and reflection. This article contains both a brief account of our history and achievements, and also some conjectures on the conceptual, scientific and service changes that have occurred over the last 10 years.

The people and first steps: In 2009 NSW Mental Health Drug and Alcohol Office funded CHW School-Link for mental health liaison with the schools that cater for children and adolescents with intellectual and developmental disabilities (IDD). Like the other Local Health District School-Link projects funded 10 years earlier, its aim was to support schools with the Prevention, Promotion and Early Intervention (PPEI) of mental health, training, and pathways to care. I want to first acknowledge the real leadership, energy and initiative provided by Jodie Caruana as School-Link Coordinator, and Hebah Saleh as Editor for the Journal and Project Officer who have stayed the course, despite 5 children between them! Alison Fettell, Helen Goltzoff, Terry Sarten and Kim Eisler also need acknowledgement who were the wonderful locums that maintained momentum during those maternity leaves.

The team started with a needs analysis entitled **'Leading the Way in Mental Health and Intellectual Disability' (2009)** with a survey of the 58 school counsellors who provided services to the Schools for Special Purposes that cater for children with ID. This found staff felt an absence of training in the Intellectual Disa-

bility Mental Health (IDMH), the prevention programs **that mainstream education used didn't work in this** population, and there were no clear pathways to care for the mental health needs of these young people and paediatricians were likely to be the only accessible service. It was remarkable to find in 2009 what appeared **to be 'a green field site' in the understanding of mental health of children and adolescents with intellectual and developmental disabilities in NSW!** What we did have was a unique partnership between Health/Mental Health, NSW Department of Education and The Department of Aging Disability and Home Care (ADHC), and more specifically the Statewide Behaviour Intervention Service (SBIS), led by Lesley Whatson.

The establishment of Developmental Psychiatry Clinic and Partnership: This high-level partnership had grown on the back of the monthly joint consultation inter-agency tertiary Developmental Psychiatry Clinic (DPC) which had been running since 2000 when Lesley Whatson brought the SBIS in to partner the DPC. This clinic derived from a once a month clinic that I took over in 1991, that ADHC funded to provide psychiatric support to the developmental paediatricians employed by ADHC and run originally at Grosvenor Hospital and subsequently with the Inner West Disability Service. When the funding available through ADHC for these sessions ceased, I continued to provide the service to the paediatricians, which were now held at CHW, Lesley and her team joined, with the view that the cases in this clinic should be seen as priority cases to ADHC. This act was a game-changer that led to strong collaboration between Health and ADHC going forwards. The clinic sometimes had upward of 20 people bringing information and experience to the consultation. We would have the patient and their family, their disability service provider and respite staff and representation from the school which might include the principal, teacher(s) and school counsellor. Our interagency tertiary team had paediatrics, psychology, speech therapy, occupational therapy, family therapy, cross cultur-

“This article contains both a brief account of our history and achievements”

al, pharmacy, special education and psychiatry skills. The cultural issues became a regular aspect of the clinic's work, because of the number of cases from immigrant families, who have additional difficulty in accessing appropriate services. These clinics developed a reputation for problem solving difficult cases. Indeed, collaboration is necessary for complex cases as no one agency has access to all the professional disciplines. In 2014, this partnership between health, disability and education was subject to an independent review by The Centre of Disability Studies under **Professor Patricia O'Brien (2014)**. The report found that the partnership provided best quality standards of patient-centred care, in keeping with the National Standards for Disability Services (2013) and it represented a world best practice for community-based care and support for the most complex cases, on minimal funding. It was seen as a beacon of hope, and several families reported that without this level of support they could not have gone on caring for their child or children with disability. The main recommendation was for expansion of the service and more funding support.

The development of specialised eclectic IDMH for children and adolescents.

Back in 1987, NSW disability services were transferred from health to welfare. Although the expertise of the medical assessment teams went with them, they were then handed back to health in 2013. In 1990 the Training Resource Unit (TRU), the tertiary disability resource for ADHC developed an applied behaviour analysis (ABA) service, based on the principle that all behaviour in those with intellectual disability could be explained by external antecedents and consequences, ie. **'the black box principle', and you didn't need to know anything about a state of mind.** The then head of the TRU reported to a special interest group of psychiatrists that she saw no role for psychiatrists for people with intellectual disability. There is no doubt that in early development, behaviourism is important, but a narrow interpretation can exclude the relevance of consciousness and inter-subjectivity. This philosophical or prejudicial standpoint is mirrored by the mental health clinician who said **"if he can't talk, he can't have a mental health problem!"** There is no dispute that the strongest evidence-base for intervention in emotional behavioural disturbance in children with intellectual disability is behavioural. This is illustrated by the epidemiological intervention of Stepping Stones Parent Training, which is cost effective, and illustrates improved mental wellbeing in parent and child and improved attachment behaviours (Einfeld *et al*, 2018). I conceptualise behavioural intervention as a non-verbal communication. This is to say, improved behaviours also improves how you feel, the feedback you receive, and improves what you think of the people that matter. However, recent research also emphasises the



limitations of ABA and emphasises co-design with participation of the client in the process (Hastings *et al*, 2018).

I must acknowledge that subsequently ADHC and SBIS, the successor to the TRU, not only took a primary concern for the challenges of emotional and behavioural disturbance but spent a good 10 years building collaboration with mental health services, developing the MOU between Health and ADHC (2010).

I feel that in recognising the contribution of the individual with autism, we also need to take account of our understanding of the sequential development of the mind as propounded in the developmental psychology and psychiatry model that we have written about (Dossetor 2015).

I reflect on the developments of developmental psychiatry in the context of my career and on the rate of change in ideas and service models. When I arrived in Sydney in 1991, the Department of Psychological Medicine had been dominated by the psycho-analytic model of child psychiatry and the problems of the department led to an external review by '3 wise men' of Ad-



ler, Carmichael and Werry, reporting on the lack of empirical and research approaches, the poverty of training and the lack of service to the children's hospital and of those with severe psychiatric disorder. Under **Ken Nunn's leadership, appointed as the new head of department**, there was a renewal to a modern, empirically-orientated, multi-modal, bio-psycho-social model with an interest in child neuro-psychiatry. This included an assumption that children and adolescents with intellectual disability should have equity of access to the service, something that is still lacking in many CAMHS services. Under his leadership the Department of Psychological Medicine prospered, nested in the tertiary/quaternary paediatric hospital for NSW, developing tertiary services in consultation liaison and medically unexplained symptoms, eating disorders, developing the CAPTOS (Child and Adolescent Psychiatric Telemedicine Outreach Service) to all of regional NSW in 1999 and an inpatient service in 2004. I continued to keep my specialist interest in children with intellectual disability and autism, and in 2004 I received funding for the first clinical psychologist to work in the mental health of children and adolescents with ID in NSW.

Dr Michelle Wong, who as a clinical psychology intern **did her PhD on 'Vicarious Hopefulness' (i.e. the hope you have for your child)** and was very experienced in ABA, was appointed. I determined that as we were such a small resource that half her time be designated to research to have a wider impact. She developed Emotions-Based Social Skills Training (EBSST) for autism and, with numerous important partners including Belinda Ratcliffe, we now have published the manuals with on-line training with the Australia Council for Education Research. The Westmead Feelings Program 1 (formerly EBSST) is for primary school aged children

who are verbal but not literate and program 2 for those who are literate (www.acer.org/au/westmead-feelings-program).

Westmead Feelings Program for adolescents with mild intellectual disability will be next, courtesy of our research fellow Anita Gardner and funding from a private hospital donor. There is 15 years of research demonstrating improvements in emotional literacy with the large effect sizes and improved mental health, in partnership with the NSW Department of Education, Aspect and other community clinicians. This research is central to establishing the developmental nature of autism and of emotional skills, and emotional regulation which contributes to mental wellbeing.

The developmental psychiatry curriculum and framework: In 2004-5 in partnership with ADHC we provided 2-day workshops around the state in the assessment and treatment of emotional and behavioural disturbance in autism, but this service was subsequently provided nationally by Aspect with federal funding. In 2006-9 our partnership was funded by both NSW Mental Health and ADHC which funded Donna White to **manage the 'Training Curriculum Project' to develop an evidence-based 2-day interdisciplinary curriculum for the mental health of children and adolescents with intellectual disability.** This was based on a literature review, a stakeholder survey, a review of training requests, but also based on clinical multidisciplinary expertise of what works. The curriculum included:

1. The scientific foundations for the bio-developmental-psycho-socio-cultural multi-causal framework.
2. Family adaptation and the burden of care.
3. Multidisciplinary interventions that promote de-

velopment.

4. Interventions that promote MH including formulation, medication and safety planning.
5. Models of service and collaboration.

Over 600 clinicians were trained with subsequent evidence of impact on practice. This project led to the publication of the textbook: *Mental Health of Children and Adolescents with Intellectual and Developmental Disabilities: A framework for professional practice* (Dossetor, White & Watson 2011). This in turn has led into this School-Link Journal for the Mental Health of Children and Adolescents with Intellectual and Developmental Disabilities which has been led by Hebah Saleh with an interagency editorial board (which now includes Barbara Lewis from Carers NSW) for 10 years and 24 editions. The journal provides a continuation of the same philosophy of providing an up-to-date evidence-based interdisciplinary journal on what you need to know about the changing world of this area of professionalism. It is a free downloadable electronic journal available through www.schoollink.chw.edu.au and has a readership of 2000 across NSW and around the world.

One of the limitations of working with a minority population is the lack of academia and funding for research. The professionals who work in this area also feel their minority status but share a self-belief that we can help. In between the critical difference between **‘the evidence of absence’ of effect and ‘the absence of evidence’ (where there has been no research funding to test the hypothesis)** is most of developmental psychiatry. There is a huge amount of important evidence, but much of it is based on cases studies, clinical cohorts, professional consensus and control studies. Further within these populations there is such diversity. Yet science is regularly working on a single mechanism model, looking for the single cause or a single cure, for example in autism.

Clinically, I feel the important work is describing and defining the developmental nature of autism and the co-existence of their multiple psychiatric disorders. Children follow the same developmental sequence seen in normal early childhood of skills in emotional literacy and theory of mind – this is paralleled in autism but delayed. This model explains why they have trouble understanding others but does enable us to have a framework for understanding the way they think and feel.

Child Psychiatry has tended to be anthropomorphic, and only slowly are we understanding the differences of childhood awareness from adults, and progressively demonstrating this sequence of social and emotional

“Only slowly are we understanding the differences of childhood awareness from adults”

development scientifically through our autism research.

The development of psychiatry and mental health is the art and science of progressively refining our knowing of others, and particularly how to understand those that fail to integrate socially, or in other words suffer a mental disorder. When everyone puts high priority on their own conscious world, why is mental wellbeing considered a low health and scientific priority? Pinker describes civilisation as the awareness of human consciousness of the world of 7 billion separate internal worlds (Pinker, 2017). At least quality of life is now an area of academic study and is found not purely related to affluence and gross national product (Cummins, 2012). **Martin Seligman’s studies of flourishing in European countries**, show that only between 7 and 33% of people feel they flourish, and are heavily influenced by the social reality and politics of equity (2011). Flourishment of course includes not just belonging but having something to contribute to others. It is fundamental to being human that we are connected and engaged with others. Robert Cummins described disorders of quality of life as the nearest thing to psychiatric disorders (2012).

Changing models of disability service provision: In the UK in 1980s a dominant view was the psychotherapeutic notion that having a child with a disability is a state of perpetual grief in the parent for the anticipated perfect child. Psychotherapy may be an interesting educational theory, but it is not helpful for many, especially with such real hardship. Evidence shows that caring for a child with intellectual disability involves care (predominantly by a mother) an average of 7 hours a day and 7 days a week. The level of emotional and behavioural disturbance has more effect on the wellbeing of parents and family than the level of disability. In the 1990s in the UK, the model of service provision was moving from psychiatric specialists in intellectual **disability providing care ‘from cradle to grave’ to having child psychiatrists** include young people with intellectual disability in their practice. I was amongst the first child psychiatrists to be trained in intellectual disability and so my MD research thesis aimed to bring child psychiatry methodology to the homes of 92 families who had a teenager with intellectual disability with

4-hour interviews.

In this 4-year study, I learned that these families truly love these disabled young people but also how isolated and little understood these families are. Many felt so indispensable to these young people that 20% said they would rather have their child die than to go into an institution! These were complex children and families, but my research, including a 7 year follow up study, gave me a special understanding of these teenagers/young adults and their families. It was at this time the Minister for health (in the UK) declared that no child should be raised in a hospital, and huge amounts of welfare funding was made available to re-house 25 severely disturbed young disabled people that I struggled to manage as they were moved from the intellectual disability hospital to community based residential units. Importantly, it must be realised that this was at approximately 3 times the cost! The lesson is that a humane standard of care does not come cheap. Mainstream child psychiatry really had no therapies that could help the level of emotional and behaviour disturbance of these challenging teenagers, and in tackling this disturbance and distress my mentor Dr

“Relying on symptom counting with questionnaires misses the most important information about relationships”

Agnes Hauck taught me that “any doctor worth his salt had to be prepared to prescribe”. Conversely, providing realistic hope is necessary to be therapeutic. However in the context of the severity and chronicity of disturbance, even small improvements made a big impact on the young people with intellectual disability and their families. Medication therefore had a potential for creating miracles in situations of chronic, irremediable adversity and disturbance.

Accordingly, my first dictum is that it is possible for any **child and their family to have a ‘good enough’ quality of life** (there is no such thing as perfection) and we should be aiming for that. The principles of what creates a quality of life for the general population also applies to those with intellectual and other disabilities.

Innovations in Skilled Practical Respite: One of my MD research findings was that family wellbeing and a positive relationship with the teenager with intellectual disability was correlated with practical help and support (rather than emotional support) from friends or rela-

tives (Dossetor & Nicol, 1990/91). Often this help was only once or twice a week and only for an hour or two. This importance of practical support from a friend or relative was explored in an ADHC funded NGO project that Leslie Watson and I were involved in. This project did enable and legitimise a family to register a relative or friend to receive funding for supplying respite. It also aimed to provide support to the family and respite carer by providing Stepping Stones Parent Training. Although I think the principals were good, the NGO were unable to fulfil the commitment to deliver the parent training, and not many friends or relatives came forward. It did however establish the legitimacy of funding a friend or relative to provide respite, thereby enhancing the natural supportive relationships.

We were also involved in another NGO project of residential respite care, on the basis that the family were prepared to learn specific behavioural skills learned from the respite unit, enhanced by Stepping Stones Parent Training. The clients found this project popular and effective, but funding was not continued. The burden of care is the main handicap for parents and families, and I find that too many parents with a child with IDD are highly stressed. The lack of support from others also contributes to them feeling indispensable and exclusively responsible. Inadequate support and help from our community leads to a heightened risk of parental murder suicide ideation. Is there any evidence that support funding from the NDIS has shifted this?

Scientific Methods and Relationships in Mental

Health: I impress on my medical trainees that the clinical process to psychiatric assessment has reliability and validity and relying on symptom counting with questionnaires misses the most important information about relationships. The methodology for evaluating the quality of relationships is derived from the Rutter Marriage Semi-structured Interview, which in turn led to the importance of high expressed emotion of the next of kin on the psychiatric wellbeing of the person with a psychiatric disorder (Leff & Vaughn, 1985). Humans, even 3-year-olds, have an absolute capacity to deceive their nearest and dearest. A fundamental question of every assessment is whether you have a reliable basis of knowing the child and family. When you provide them with the formulation, does it ring true to them in language that they understand, does it help them understand the predicament of their child and their family, and will they listen to and act on your advice? As a result, do you have a therapeutic engagement and a common understanding of the problem(s).

Study of the Psyche or soul, psychiatry, is therefore about the objectification of the state of mind of the presenting patient, or the description of phenomenolo-

gy. Despite the capacity of someone to deceive another and the issues of reliability of eliciting subjective phenomena, it is inherent to our social nature that we give objective validity to mental states. Not surprisingly there is greater difficulty reliably recognising the nature of the conscious world of children and people with intellectual disability. This does not mean they do not have a conscious world, but making a best judgement of what they experience is a special skill and a growth area of research enquiry. Professor Graeme Watts in his PhD (2010) described that the development of theory of mind skills at 2.5-3 years is historically described as when the spirit enters a child. They then appreciate that others have this skill of consciousness **of others' and a recognition of social belonging as a human.** The Westmead Feelings Program of emotional literacy education arose out of the question of what do you need to teach a child with autism, after they have had what ABA can contribute? In this framework, someone with autism has a social understanding of a 2 year-old or less, and for someone with Aspergers it is less than 4.5 years. It is also recognised that they progress in their emotional literacy over time, especially with specific education and support.

Elaborating the developmental model: I have long propounded the general laws of development and those **of delayed development (Dossetor, 2011): 'Where there is life there is development in a systematic sequence' (Werner). 'Development involves orderliness, sequentiality, and apparent lawfulness of the transition taking place from the birth or conception of an organism to the attainment of maturity' (Zigler, 1963).** It progresses from relative globality & lack of differentiation to increasing differentiation, articulation and hierarchic integration. Both individual and context differentiate, leading to a development-transactional approach. If development is delayed it still progresses in a predictable sequence, despite a diversity of identifiable causes of delay. If development is delayed, it is likely to be unevenly delayed across the different domains of development. If one area is delayed, then there is an increased likelihood of another area being delayed. Behaviour and emotional connection is best explained in the context of the level of development. Development is due to the increasing mathematical complexity of neuronal connectivity rather than neuroanatomical differences. Since I first made this observation, brains scans that picture connectivity of neuronal networks have developed, and atypical connectivity is described in autism (Ray et al, 2014). Importantly, parents and indeed the child themselves understand such developmental descriptions and this allows parents to modify their parenting to help a child with intellectual disability or autism. Developmental theory implies possible benefit from a whole range of development enhancing

interventions to help someone with developmental problems. This can be sensory/motor development, behavioural learning, speech or emotional literacy and indeed education as potential means to enhance skills and wellbeing. Such approaches are similar to positive **psychology or 'the recovery model' of psychiatry** which complements the illness model or the scientific model which aims to simplify disorder and identify single causal mechanisms. The recovery model or developmental model is individualised but assumes a multi-causal model of delay and disorder in context.

As Dr Ken Nunn recently articulated, all of human perception is through their body, and therefore the developing consciousness arises through awareness of the body in touch and pain and perceptual location, movement and rhythm, sound modulation and sight. These are also early sources of reciprocal engagement through touch and cuddles/massage, engagement in coordinated movement, which can be enhanced with music and dance, and gaze. Describing different domains of developmental stages is the best measure of ability before a child has a capacity to use their intellectual and conceptual skills which are then measured by psychometric tests. This developmental metric applies to all children, whether with or without developmental delay. Indeed, one can argue that this developmental progress is a measure of the influence of reciprocity which includes the nature of the emotional

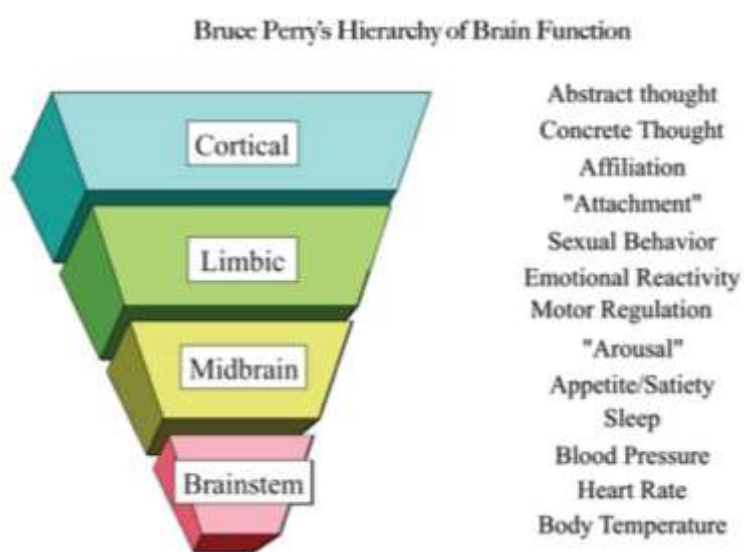


and stimulating environment on the developing child. Similarly, we need to ensure that therapy is developmentally appropriate for children with IDD.

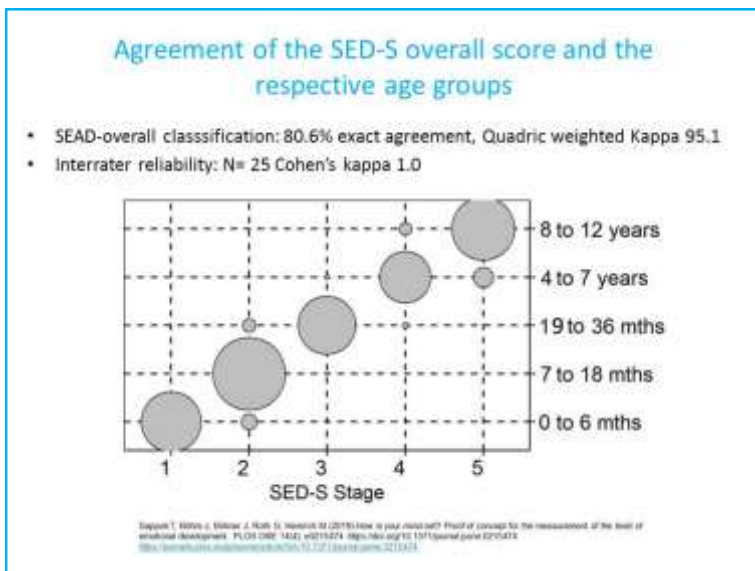
Nicolette Soler, our team Occupational Therapist, is demonstrating in her PhD how sensory therapeutic input, in terms of a modified Alert Program, has dramatic benefit to Tourette Disorder (Soler et al, 2019). What she has also found is that an abnormal sensory perceptual profile is not specifically related to Tourette but is associated to the number of co-occurring neurodevelopmental disorders (Soler et al, 2019). She is now working on improving the measurement of sensory profiling. Does the alert program work through increased sensory/motor awareness or self-control, or greater sensory/motor reciprocity?

Daniel Siegel working with traumatised children has described a similar neurodevelopmental sequence of the brain and mind, equating developmental awareness of: 1. arousal, 2. sensation/movement, 3. emotions and then 4. higher skills or executive functions to 1. brain stem (reptilian brain), 2. midbrain/cerebellum (rodent brain), 3. limbic system (mammalian brain) and 4. frontal lobes (human brain) respectively (Siegal & Szalavitz, 2017). Each level has to integrate with the lower level, and trauma at an early age can lead to **'stuckness' in an earlier component of reciprocal functioning**. He too therefore advocates for the therapeutic benefits of touch and massage, movement, rhythm and music, all to enable engagement in emotional awareness and attachment because of the consequent impact on affect and higher human functioning.

Figure 1 Neurosequential Model



Understanding these early types of reciprocal engagement are important for developing attachment in normally developing infants, but provides potential innovative therapies for developmental disorders which



need empirical study.

Anton Dosen and colleagues from Belgium have demonstrated a similar emotional development model now available in the English literature as illustrated in figure 2 which uses a similar neuro-anatomical functional sequence. Using the Scale of emotional development (Vandeveldt et al, 2014), they have demonstrated this sequence of emotional development correlates highly with age in normally developing children and with the level of intellectual disability in adults. This scale assesses 10 dimensions of skill: dealing with his/her own body; interaction with a caregiver; experience of self; object permanency; anxiety; interaction with peers; handling of material objects; verbal communication; affect differentiation; and aggression regulation and grades them on 5 levels. Further, Sappock and colleagues (2013) have demonstrated that adults of average age of 36 years with Autism and ID have a lower average emotional age of 1.5-3 years, than those with just intellectual disability whose average emotional age was 3-7 years. The emotional age was also predictive of emotional and behavioural disturbance.

Discrepancies between the level of ID and ED

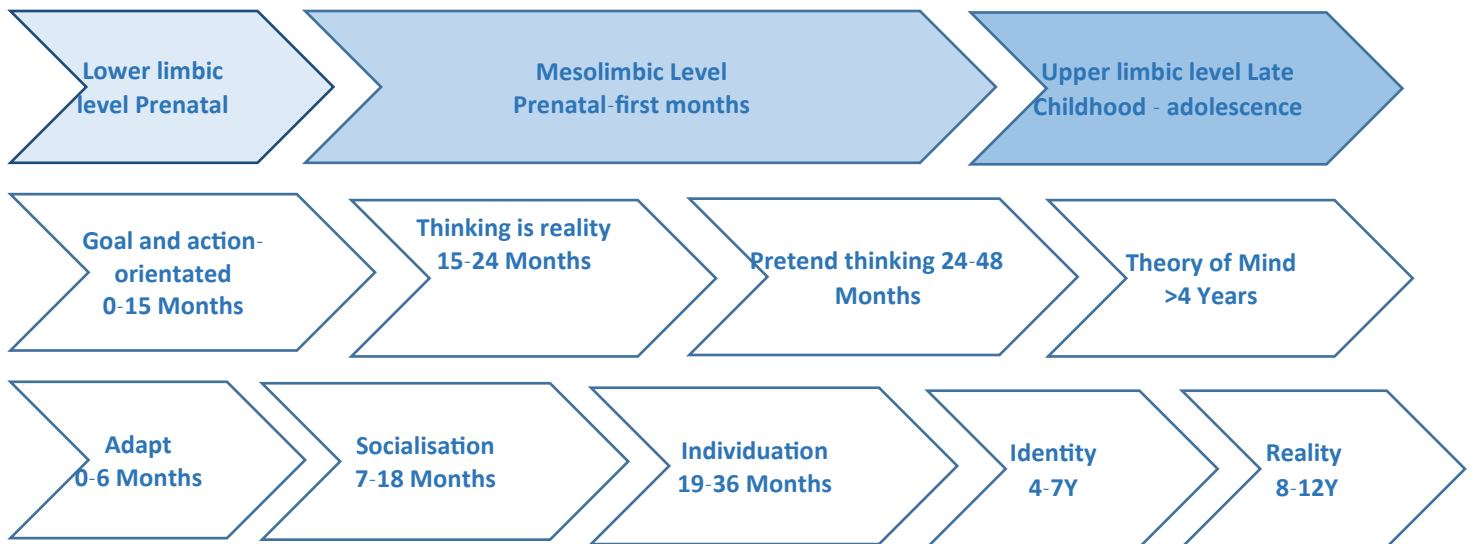
As expected, the level of ID and ED are highly correlated: $r = -0.6$, $p \leq 0.01$
 BUT: the level of ID and ED differed in every second person!

		Level of ED n (%)				
		SED-1	SED-2	SED-3	SED-4	SED-5
Severity of ID	Mild	1 (3)	2 (5)	1 (3)	20 (52)	14 (37)
	Moderate	1 (1)	5 (5)	21 (20)	61 (58)	17 (16)
	Severe	3 (3)	24 (25)	44 (45)	23 (24)	3 (3)
	Profound	4 (18)	4 (18)	13 (59)	1 (5)	0 (0)

N = 262, mean age 38 years, 54% male

Bolin, Grönbak and Sappock. (2018). Emotional development, aggression regulation and challenging behaviour in individuals with intellectual disability. *Frontiers in Neurology/Psychiatry*.

Development of Brain Networks, Cognitive and Emotional Functioning



The establishment of this emotional developmental model of understanding is certainly helpful clinically and therapeutically. Our autism research is also progressively establishing evidence on emotional and social sequence. It may also inform our future autism intervention research for those with moderate intellectual disability examining these earlier processes and skills of reciprocity in the future.

Insell and others have criticised the limitations of the scientific validity of DSM-5 and proposed the novel Research Domain of Criteria model of psychiatry (Insell, 2013). Although individual scientific discoveries can make stepwise contributions to our understanding of the brain and mental health, I do not see it replacing the phenomenological approaches to understanding others. Further, I feel that any empirical epidemiological mental health study for neurodevelopmental disorders and children will need to include a methodology for multidimensional developmental staging as well (Wing, 1981). In effect, in biology we cannot understand the mechanisms of the brain without also conceptualising the mind. In the same way the mathematics of flight is necessary to understand how the wings of birds fly.

10 milestones of the last 10 years of CHW School-Link:

1. School Clinics: We trialled interagency complex case discussions with Schools for Specific Purposes (SSPs) of Western Sydney LHD but this could not be sustained. However, we have continued to support school clinics at SSPs as an initiative and we support **Dr Gillian Brooks' school clinic at Kurrambee SSP**. We also ran a one-year research school clinic at Aspect

Vern Barnett School for autism, which identified how specialist school-based multidisciplinary clinics identify and treat needs not identified by community treatment-as-usual (Singhal et al, 2018).

2. In partnership with ADHC we supported the development of the first specialist parenting skills in SSPs using the Stepping Stones Parenting Program, which demonstrated dramatic effectiveness (Ray et al, 2019). We have subsequently been a partner to the MySay study to make an epidemiological and cost-effective difference to emotion and behavioural disturbance in children with intellectual disability and autism (Einfeld et al, 2018).

3. Workshops on understanding, preventing and intervening in the mental health problems of children and adolescents with intellectual disability and autism have continued and been well attended, although the demand has declined from a peak of 20 workshops a year. Since the introduction of the NDIS, there appears to be a decline in interest in interdisciplinary education on the mental health needs of young people with intellectual disability and autism.

4. We have supported mental health prevention, promotion and early intervention in intellectual disability, partly through watching and promoting those interventions that have an evidence-based literature, which you can find a list of in our promotional leaflet, available on the School-Link website. The collaboration with NSW Department of Education to provide emotion-based social skills training (Westmead Feelings Program) in a controlled study to 350 children across the state through the training of 64 school-counsellors, was a huge achievement and success (Ratcliffe et al, 2014 & 5). This study demonstrated large effect sizes



and improved mental health of high functioning primary school aged children with mild ID and Autism. We have since had a successful implementation study to all 8 NSW Aspect Schools for Autism. Westmead Feelings Program I was published with the Australian Council of Educational Research, with associated **'online' training in 2017, and WFP II in 2018, making these available to the English-speaking world (www.acer.org/au/westmead-feelings-program).**

5. There have been numerous Conference presentations both national and international. I recall IASSID in Rome in 2011 and Melbourne in 2015 where in partnership with SBIS we presented and subsequently reviewed the validity of our curriculum framework and explored whether there were new or better educational curricula for the mental health of C&A with ID.

6. **"Meet Jessica" an animation and mental health awareness training workshop** was developed in 2016 in partnership with NSW Department of Education and SBIS and which reached over 1000 clinicians and teachers across NSW with a train-the-trainer workshop and promoted approaches to reasonable adjustment to support the special needs of C&A with IDD (<http://www.schoollink.chw.edu.au/workshop-resources/>).

7. Webinars in IDMH have been developed in partnership with The Benevolent Society and education's Network Specialist Facilitator and hosted on the School-Link website, with more to follow. Current titles include:

- Curiosity, collaboration and action: Understanding & Responding to Behaviour in the Classroom;
- Cool, Calm, Collected & Connected in the Class-

room: Supporting Students with Self-Regulation;

- The Mental Health of Young People with Intellectual Disability: What you need to know and what you can do.

8. WellSEQ is a project to translate a mental wellbeing specialised questionnaire in easy to read English with a sound track and illustrations on an iPad for young people with mild and moderate intellectual disability from Swedish to English, and re-validate for free to air usage. This has the potential to become the Strengths and Difficulties Questionnaire (SDQ) equivalent for those with ID.

9. Several awards have been received by School-Link and the Westmead Feelings Program including: The Mental Health Matters Award for Cross Sector Collaboration in 2012; in 2014, Emotions-based Social Skills Training in Schools Project won the Cross-Sector Collaboration Award; and in 2014, CAPTOS won the same **award**. In 2016, **'Jessica' our mental health awareness animation and training** received the quality and **innovation award from the Sydney Children's Hospital Network** in 2016 and was the highly commended Mental Health Matters award for collaboration. In 2016, I was awarded the SCHN Collaborative Leader of the Year. In 2019, Westmead Feelings Program **received the Aspect "Professional Advancement Award"**.

10. Over the 10 years we have moved from a newsletter to a journal, the only one that focuses on mental health for C&A with ID. Over time I suspect we will gradually move from an interagency edited educational, best practice and informative journal towards more peer reviewed research. We try to encourage external

submissions. Kids art from SCHN makes it so attractive. There have been some key contributions to the Journal of Mental Health for Children and Adolescents with Intellectual and Developmental Disabilities including:

- Innovative treatments and advances, including Positive Behaviour Support, safety planning, trauma informed care
- Allied health therapies, play therapy, music therapy, pet therapy
- Reviews of prevention promotion and early intervention, including Mind Matters, Westmead Feelings Program, Stepping Stones Parenting in SSPs
- Behavioural phenotypes, psychiatric disorders, Autism, diagnosis, formulation, and prescribing guidelines
- Service Development, School Clinics and understanding families
- The Medicine Cabinet: a different medication each edition
- Planning, policy, funding and the politics of IDMH
- Conference Reviews
- Interviews with experts
- Book reviews

Future Opportunities and Threats:

Enhancement: Our service has received some additional funding to be recognised and provide a statewide second opinion and problem-solving service.

Until now it has been an initiative of the Children's Hospital at Westmead, built on recognised need and the opportunities that arose, providing and sharing tertiary expertise, teaching and clinical research. This enhancement will also build on the telepsychiatry outreach service of the CAPTOS service. It should ensure the future of Specialist Developmental Psychiatry in NSW.

The shifting sands of collaboration and the NDIS: The arrival of the NDIS has clearly been an important reform helping many. Some patients have benefitted from additional care support and the greater availability of funding for therapy. However, there have been problems in accessing reliable and good quality assessments for support and therapy. Many young people are accessing multiple therapies without a system to show evidence of benefit. Others are failing to find clinicians or support workers with the abilities to help, **partly because they don't live in a large urban centre** and partly because their problems are challenging and complex. The funding to enable collaboration and joint meetings is hard to get in complex cases. Perhaps the establishment of NDIS research funding will help evaluate therapy but also test out newer attractive therapies, such as a range of pet therapies. There are other significant problems. Health/Mental

Health NDIS representatives or champions are concerned about other problems such as access to dysphagia or oxygen support, or residential care for those with chronically disabling psychosis or personality disorder. Currently it seems there are problems accessing services for complex emotional and behavioural problems for which there needs to be access to the **'complex support needs pathway'**. There may be a focus on recording restrictive practice which may be a proxy for recording major incidents, but little access to quality multidisciplinary positive behaviour support, or reactive management plans for severe aggression or recurrent self-injurious behaviour. There is a need for a mechanism for urgent disability response, and a decline of the availability of emergency residential respite.

It saddens me that The Benevolent Society who took over the staff and tertiary service provision of SBIS of ADHC have disbanded this service. Although they are contributing to some training webinars, we have lost their interagency leadership role and academic leadership with the journal and research, and also the clinical collaboration for the Developmental Psychiatry Clinic. Funding problems are the explanation given. Evidently as a federal insurance system, the NDIS does not have any mechanisms to collaborate with state-based Mental Health Services as was negotiated and established over a 10-year period of relationship building to create the MOU between ADHC and Health/Mental Health. There is increasing pressure for health therefore to provide accommodation of last resort when troubled young people with intellectual disability arrive in emergency departments with a breakdown of disability funded care with acute and chronic disturbance or mental disorder, and there is a lack of a mechanism to bring higher level skills to residential services. **A warning is provided by the recent British Children's Commissioner report on the number of children spending excessive time in psychiatric wards (Longfield, 2019).**

There is a lack of agreement on what is restrictive practice and what are the implications between NDIS and Mental Health. When a guardianship tribunal declared that any psychotropic medication is a restrictive practice, this representative for disability services **evidently didn't consider the need or human rights of** someone with disability to receive mental health treatment.

Over the years of collaboration with ADHC, the main role of restrictive practice guidelines in the cases I see is to enable restrictive limit setting to be therapeutic, in the best interests of the child and in the context of best practice and effective treatments. It is critical that different agencies work together to support parents

and other carers to have reactive management approaches, and systems of ensuring safety (Whatson et al, 2011). Establishing parental authority is often the key to improving complex challenging behaviour (Dossetor, 2016).

Some in the NDIS, with experience of the best that the state-run disability services did particularly for complex emotional and behavioural disturbance, remain hopeful that some of these problems can be improved. The new Director of Planning of the new Complex Support Needs Branch, of Service Delivery and Performance of the NDIS remains optimistic that skilled professionals in different agencies can work together for those of greatest need. My message of hope that I give patients **is don't give up as the NDIS is legally obliged to provide sufficient and reasonable support, which includes provision to enable safety.**

Over the last 10 years there is increasing awareness of the significance of emotional, behavioural and mental disorders in people with intellectual disability. They certainly need access to specialist health and mental health services. Sometimes they need brief diagnostic admissions (including medical assessment made possible under anaesthetic), but I think long term care and support should be managed in the community. While major/psychotic mental illnesses need access to assessment and early treatment in a mental health setting, it is not appropriate and is contrary to the Mental Health Act to be admitted to a psychiatric service in the absence of such mental illness. This area of work needs priority access to disability services and expertise. Much of the reputation and influence of the Developmental Psychiatry Team and CHW School-Link has come from the power of collaborative approaches and the associated richness of ideas. We shall continue to work toward re-establishing similar rich and productive relationships of interagency collaboration, tertiary expertise and academic excellence in the context of the NDIS for these complex cases.

Research Partners and Promise: Clinical research has been central to advancing the mental health and well-being of young people with ID on limited amounts of funding. CHW School-Link has had a range of external academic partners for example with Julian Trollor, the first established chair of IDMH, and the University of NSW Department of Developmental Disability Neuropsychiatry, Susan Hayes and the University of Sydney, Belinda Ratcliffe and the University of Western Sydney, and the Agency of Clinical Innovation Disability Network. The appointment of Adam Guastella as the Michael Crouch Chair in Child and Youth Mental Health at the Children's Hospital at Westmead and Brain and

Mind Institute, opens new avenues of 'large data' approaches to exploring neurodevelopmental disorders with a consortium proposal to centralise information on 2000 new neurodevelopmental cases a year. This consortium proposes a national research enquiry, looking at genetics, immunology, drug studies, parenting, and community integration. My hope is that some of the strengths of the models that we use will be incorporated, and that government funding will support such a world leading innovation.

The next 10 years: CHW School-Link has established important roles in advocacy, leadership, education, training, research and clinical services, with contributions in awareness raising, prevention promotion and early intervention and tertiary collaborative clinical services for young people with IDD. The CHW School-Link 10-year anniversary has been a chance to celebrate its contribution to building collaborative interdisciplinary, interagency developmental psychiatry that did create that beacon of hope for the most troubled families. If people appreciate what can be done with such collaboration of expertise, I hope it will again. School-Link for children and adolescents with intellectual and developmental disabilities is an organisation of significant influence in NSW but has a presence nationally and internationally and I wish them and all their partners to have a continued growth, success and influence in the next 10 years.

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