An accidental career

In the Psychiatry of people with an intellectual Disability by Bruce Chenoweth

(With apologies to Helen Beange for stealing her title)

Beginnings

Some as young as fourteen, they were marched out of their cells or the exercise yard, and into the bare office that served as my consulting room at the Worrimi Youth Detention Centre.

In my job with Adolescent Mental Health Services, I had always enjoyed my contact with 'goofy' mono-syllabic inarticulate adolescent boys. They would sit, cap on backwards, looking at their big, often-smelly feet, and grunting 'dunno' at every conversational overture. That is, until some quip would have them cracking up and we would be off and away.

These boys were different. Many of these offenders had obviously low or even of borderline intelligence, some illiterate, and obviously disadvantaged in so many ways.

Most of these kids were very likeable.

One young red headed boy, all of fourteen, and small of stature, was quite a legend around Waratah. He had stolen perhaps some tens of Holden Commodores over a two-year period.

He would 'case' a target, always an older model, easily 'hot-wired,' wait until the lights of the house had been extinguished. He would then break in, 'hot-wire' the car and would be off down the freeway to Sydney where he would part with the car for a few hundred dollars. This money would be subsequently blown on drugs, so two weeks later, he would do it all again.

He was too short to see over the car dashboard so always took a cushion with him to achieve adequate elevation.

He was none too bright, was funny, was illiterate and a reject from several schools. He touched my heart.

Then, I received an unexpected phone call from Mark Porter, Programme Director at the large Stockton Residential Facility.

Previously, this was a large asylum-type institution for the mentally ill. It is now a group of buildings in a pleasant seaside setting noted for the century- old Norfolk pine trees and a very fine cricket pitch.

It then housed about 800 residents, all with moderate to severe intellectual disability, who could not, because of the complexity of their behaviours and physical co-morbidities, be placed in the community following the Richmond devolution of the 1980's.

Mark wanted a Psychiatrist to come regularly to review the state of the residents, many of whom were being given heroic doses of traditional anti-psychotic medications.

I was very underwhelmed by his request. I knew nothing of disability, nothing of the causations, and less of the syndromes or genetics underpinning many of the presenting behaviours.

However, I did agree to a visit. Walking through the units, I was not really prepared for the high degree of disability and dysmorphia that I encountered. Nor did I really want to take on what appeared to be this Herculean task with the promise of little in the way of a positive outcome for any of those 'poor souls.'

Around the perimeter road, we came upon a unit with about twenty wheelchairs lined up in the afternoon sun. 'What is that unit?' I asked Mark.

'Oh, sadly, that is the cerebral palsy unit' he said. 'We don't know just how much some of those guys understand what is going on, despite not being able to communicate'

'See that little guy on the end with the cap on?' he said.

"Walking through the units, I was not really prepared for the high degree of disability and dysmorphia that I encountered"

‘I can understand him mostly and I make a point of coming by fairly often’

‘He needed some dental work done. I knew that he would not cooperate so I did a deal.’

‘If he got his teeth fixed, I would get him a ride in a police car!’ (He had a fascination with police cars, Mark explained.)

His teeth were duly attended to and Mark found himself fronting the burley sergeant down at the Stockton police station…when there was one.

‘Whadaya want,’ the sergeant asked.
Mark explained his mission’
‘Yeah, she’ll be right!’ said the sergeant.

On the appointed day, it was not a police car that turned up, but a paddy-wagon.

The little guy was hoisted up into the passenger seat, Mark needed to climb ignominiously into the back of the wagon and so they set off down Fullerton St. toward the Stockton village

The little guy was quite delighted….for a while. He soon becoming quite agitated and vocal.

‘What’s he want?’ yelled the sergeant through the small trapdoor behind his head.

Mark had no idea. ‘He wants to put your hat on’ he yelled back.

‘Right-o’ and it was done.

This scene was repeated several times. First it was the flashing lights, then all bells and whistles, siren and all, to the absolute delight of the little guy.

At that stage, I was hooked! How could I not throw in my hat as well? I agreed to be part of that world and have remained so ever since.

That was in 1991.

The Task

I was a complete novice but I knew a few things.

Firstly, the high levels of traditional antipsychotics being used had to be reduced. Novel antipsychotics had recently arrived with fewer side effects and at lower doses.

However, the task of withdrawing the thioridazine and chlorpromazine had to be achieved very slowly to obviate discontinuation side-effects. These residents had been on these drugs for many decades and had semi-permanent neural receptor changes which would take months to years to reverse if at all.

Most of the residents had survived the dark days of harsh institutional living, had experienced loss of family, and sometimes been abused within the system. Some had been in an institution since being deposited at the Watt St Hospital as infants and had known no other life.

That old system had changed and continued to change over the decades. Gone were the old large wards, replaced by discrete residential units within those large buildings.

Residents began to participate in community day programmes. Psychology, OT, Speech Therapy, Activity Centres, Foster Grandparents, all contributed to a much-improved 'quality of life' for the residents. There was a 24-hr medical presence with CMOs who would accompany me on my rounds and discuss each referral in some depth.

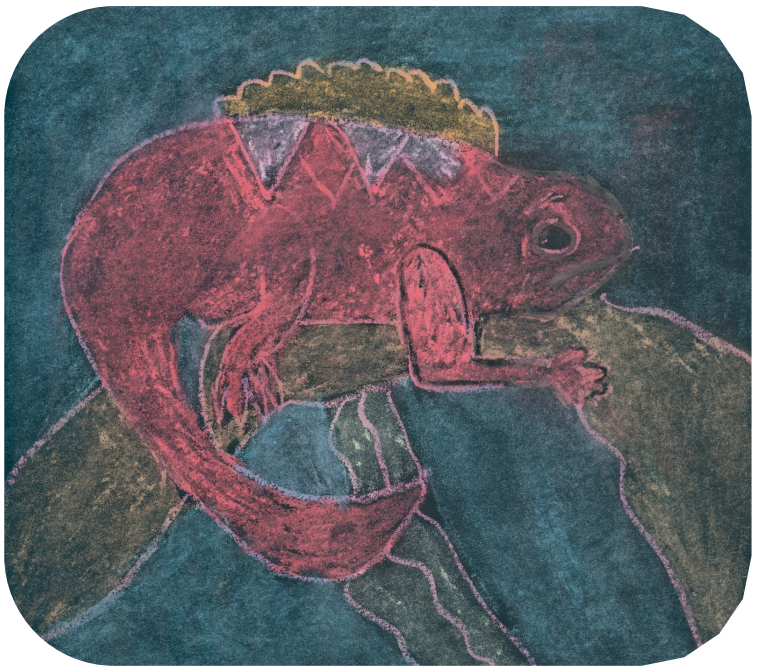
Newer and much more stringent training of staff and procedural governance had been in place for a decade, a process that was progressing rapidly.

I had no interest in having residents brought down to the centre clinic preferring to see them in their own units, in their own milieu, getting to know the staff and wanting to experience for myself the quality of the prevailing relationships.

The gardens and grounds, the old pine trees, the cricket pitch, the soft light in autumn across Fern Bay, lent a sense of peace and 'contagious calm' that could at times, be all pervasive.

However, the old stigma of the institutional model still hung over the centre, more an ideological remnant than an actuality.

I am not sure whether it has been the opportunity to devolve all costs of a high-functioning disability service to the Commonwealth, or the ideological objection to 'institutionalisation' or both, but the imminent closure of the large residential facilities is inevitably resulting in the profound loss of amenity and quality of life for those going out into the community. There can really be no justification for uprooting these residents to place them in group homes with limited resources, poorly trained staff, less specialist medical and allied health support and with uncertain funding models.



However, I digress!

I then heard about a small group of Psychiatrists proposing to meet in Sydney to discuss ID Mental Health.

With some trepidation, I drove down from Newcastle, expecting the meeting to be along the familiar lines of competing high profile egos; i.e. Those of big-shots from academia and Macquarie St.

Indeed, present were some very high-profile people including Profs Bruce Tonge from Monash, Stewart Einfeld, then from UNSW, David Dossetor from Westmead, Michael Fairley from Prince of Wales Hospital, and Peter Wurth who was establishing himself as the go-to person in Northern Sydney and regional NSW.

Feeling completely out of my depth, I was reassured by Bruce or Stewart, (I can't remember which), saying after a pause, 'Well, I guess that we are all here because none of us knows just what the hell we are doing!'

What a relief! Here was a group that I could belong to! We still meet regularly some 28 years later.

It happened by stealth

More and more referrals came to see me of those with Intellectual disability. I saw them in my private practice mostly. Sometimes, I saw the clients in their transport van in the street, or the hotel carpark next door if transfers into the office were too difficult.

For many years. I bulk-billed them all until it was clear that I was going backwards financially and that the Medicare rebates were not going to rise anytime soon.

I was propelled by sense of outrage that the mental health facilities actively denied access to those with an intellectual disability. Maybe, I had an inflated notion of myself as a 'caped crusader' offering an alternative mental health service to that population.

Since the devolution of disability services away from health services, we had as now, generations of Psychiatrists with no training in, nor experience in intellectual disability, nor in autism.

Fly-in, Fly-out

I began to offer a regional consultation service to regional and rural centres, beginning with Coffs Harbour, Port Macquarie, and then to Armidale, and Inverell.

Peter Wurth was already doing this extension work mainly in southern NSW. I inherited Inverell from him after he had overseen the closure of Ireby Lodge, a large residential complex in the centre of town.

Every couple of months, my long-suffering Office Manager and I would board a fairly decrepit Beech Aerostar at the Rutherford Airfield and set off for Port Macquarie.

The clinics were always interesting and appreciated. However, I could not discount the fact that it was the journey itself rather than the arriving, that held much challenge.

On one occasion, the landing gear refused to retract, and on another, the pilot had forgotten to turn on his transponder, which located us in relation to other traffic. In zero visibility, we had a narrow miss with an approaching QantasLink Dash 8 on a reciprocal course before he realised and switched on the offending instrument!

Clinics in other centres were accessed on regular passenger services with hire car added when necessary.

An Accidental career Part II

Sydney 2004

It was mentioned in mid 2004 at a Psychiatrists meeting in Sydney, that a position might be available at the Developmental Assessment Service (DAS) at St George Hospital. The previous incumbent, Helen Moloney was on leave and my memory is that Michael Fairley was covering for her. From the earliest days of that service, there had been a Psychiatrist at that clinic offering management of the many mental health comorbidities associated with Intellectual Disability. Helen Moloney was that pioneer, building a Psychiatric service from 'cradle to the grave'.

> "We also had a strong commitment to capacity-building in these communities "

Not only did DAS do initial assessments on children but over the years had expanded to provide a full range of specialist services to children, adolescents and finally to adults with ID.

Robert Leitner was the director there, a man of great vision and tireless energy who was able, in my time there, to expand the service to include several regional clinics as well as other outreach clinics to schools and to other ADHC-run facilities (the NSW Department of Aging, Disability and Home Care.

My appointment there firstly as a part-time, and then as full-time permanent Senior Staff Developmental Psychiatrist was the first such appointment in NSW.

He was responsible for generating the 'Metro-Regional Intellectual Disability (MRID) service with clinics in Goulburn, Shell Harbour, Wollongong and even included outreach to my old clinics at the Stockton, and Kanangra large residential facilities, and which also allowed me to continue clinics in Armidale and Inverell.

Whilst the clinical emphasis was on children and adolescents with ID, adults became a large proportion of our patient load. We also had a strong commitment to capacity- building in these communities and took the opportunity to provide educational talks and presentations to the local GPs and allied health as well as to the local disability support workers.

At one stage in 2014, we had five Psychiatrists working there, all part-time permanent staff including myself as a full-timer

> “Training younger Psychiatrists from the Neuropsychiatric stream has been a consistent privilege ”

Our Disability clinic in Kogarah was staffed by many other specialist disciplines including Paediatrics, Neurology, Gastroenterology, Endocrinology, Geneticists, Sleep Physicians and others. There were Psychologists, OTs and Speech Pathologists at hand.

It was indeed a very comprehensive service to children, adolescents and adults and a great privilege to be part of that.

During my time at DAS, I was able to contribute in a small way to the generation of policy and planning through the ACI, (and hence the Ministry of Health,) sat on Complex Case Review panels for ADHC, was coopted on to the NSW Ombudsman’s expert panel on Abuse in Care, was able to present at conferences, publish, participate in research projects, and lecture to colleagues and other stake holders in the disability field.

Training younger Psychiatrists from the Neuropsychiatric stream has been a consistent privilege throughout the last 10 years.

I have also valued greatly my association with the UNSW Dept of Developmental Disability and Neuropsychiatry.

Why bother?

The field has an intellectual fascination encompassing every aspect of what I had learned and then some.

The rapidly expanding hard scientific domains of Neuropsychiatry, Genetics, Neuropsychopharmacology, and others, were grafted on to my previous experience as a Psychotherapist; i.e. in Attachment Theory, Family Therapy, and Developmental trajectories. All could be potentially brought together in one complex presentation of one complex patient.

Next, the human factor.

It has been such a privilege to meet people who, to quote Michael Fairley, are the most ‘noble’ of people. The parents and carers selflessly give of their lives to love and to care for those incapable of the usual or expected reciprocity and who demand so much of them.

Finally, unlike some other areas of Psychiatry, there is authenticity and a relative absence of subterfuge or duplicity. What you see is what you get!

A note from Dr David Dossetor

Bruce Chenoweth wrote this article at the time of his retirement from his career as a psychiatrist. He is a much loved and respected doctor and colleague, who had an interesting and eminent career. He qualified in medicine at Monash University, trained in psychiatry in UK, was in charge of Psychiatry Services at Royal Brisbane Hospital for a few years, before moving to Newcastle in 1985 working with adolescents and adults, where this account starts. He has a rich training background from psychotherapy, attachment theory, family therapy, drug and alcohol and neuropsychiatry. He has contributed widely in training and education and published broadly. He has been a key figure in the development of psychiatry of intellectual disability in NSW, collaborating across agencies, and contributing to expert panels for example the NSW Ombudsman Panel on abuse in care.

Further Reading

Chenoweth, B. (2013). The words we use. *Australian and New Zealand Journal of Family Therapy.* Volume 19, Issue 3.

Chenoweth, B. (2017) Accessed march 2020. Making it easier for staff to speak up. Youtube video. https://www.youtube.com/watch?v=7uoM16kevPU

Chenoweth, B. (Accessed March 2020). Online Video. Intellectual Disability and mental health https://www.aci.health.nsw.gov.au/resources/intellectual-disability/intellectual_disability_training/id-training-videos

Debono, D., Wille, J., Skalicky, D., Johnson, J., Leitner, R. and Chenoweth, B. (2015). Case 8: Improving Care for people with Intellectual Disability. The Story of Andy (Australia) in, Johnson, J., Haskell, H. and Barach, P. (Eds). *Case Studies in Patient Safety*. Page 101.

Leitner RP, Chenoweth B, O'Connor L, Wille J, Funke A, Lenroot R. (2014). Metro-Regional Intellectual Disability Network (MRID.net) A Statewide Collaborative Multidisciplinary Care Model. *International Journal of Integrated Care*. Volume 14, Issue 9. DOI: http://doi.org/10.5334/ijic.1927

Roth, J; Wills, A; Chapman, J; Riess, C; Stark, A and Chenoweth, B. Beyond narrative. *Australian and New Zealand Journal of Family Therapy*, Vol. 18, No. 4, 1997. Pp 222-5.

Trollor, J. and Chenoweth, B. (2017) Accessed march 2020. Deciding if, and what to prescribe. Youtube video. https://www.youtube.com/watch?v=-Jhr1ny3yPg