Centre for Disability Health
Adelaide, South Australia

Reducing the gap with the GAP Program at CDH

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Where it all began

• Set up to assist de-institutionalised clients (adults) from Strathmont to access generic health services.
• Requested to see children & young people because Service Coordinators (DSA), Disability Coordinators (Education), parents & carers were struggling to find services & support for the challenging behaviours.
Location

• Excellent location, occupies whole 2\textsuperscript{nd} (top) floor:
  – Carpeted, reduces noise level.
  – Longer & staggered appointments mean next client not kept waiting with too many people, & not rushed.
  – Large consulting rooms, now with couches and sensory items.
  – Slow lift, a ‘runner’ can take off, but not being chased its not much fun, don’t tend to repeat it. Slow lift is good, we could beat it down the stairs if we had to.
  – Nothing fazes staff, who all have a positive attitude.
Foyer of CDH
Finding appropriate referral options

• I had no difficulty identifying the issues.
• Many had regular paediatricians (in some cases psychiatrists also).
• Paediatricians addressed the physical medical aspects, and tried to manage the challenging behaviours with medication alone.
Finding appropriate referral options

• The challenging behaviours were generally considered part of the disability, not realising they were often due to secondary anxiety.

• Generic mental health services struggled when the client also had ID.

• I felt for families when I could identify the problems, but not appropriate services.
My Knight in Shining Armour

• Dr Jenny Curran, a child psychiatrist with extensive experience working with children & young people with ID, joined the CDH team.

• Discussing appropriate services to refer our young clients to, it was obvious there was little to nothing available, with long waiting lists.
The GAP clinic evolved

The Team, mostly part-time:

GP: Me (being part of a team is rewarding & offers learning opportunities)

Child Psychiatrists & specialists in ID:
  Dr Jenny Curran
  Dr Mohammed Usman

RN Mental Health: Kerry Rye

Support staff: CDH receptionists
The GAP clinic

- Eligibility: 8-20 year olds with ID, & an emotional or behavioural problem not successfully managed by generic health services.
- Integrated developmental disability/mental health framework.
- Functionally oriented, integrated & neuro-relationally informed.
- Family-centred approach.
Change of protocol

- Since writing the abstract, increasing referrals for Jenny & Mohammed means the wait for a psychiatric appointment is longer.
- I see the person referred with family/carer, often with staff from a number of services involved.
- When the young person objects to the parent giving information, or detailed discussion in front of the person can be counter-productive, I arrange a 2nd appointment to see just the parent/service providers.
My role as the GP

• Engage the young person as much as possible, to reduce the risk of them refusing to return.

• This starts when I call the person’s name in the waiting area. I can usually find something to comment on positively – hair cut/colour, clothes (pink jacket, handbag, footwear).

• Once in the room I give the young person permission to explore all the different objects, predominantly sensory (this avoids the parent telling the person not to touch, leading to confrontation).

• The next slides show some interesting items sourced by Kerry Rye, RN. Surprisingly little has been broken.
The consulting room
Consulting room
Meant for feet..but
More sensory items
My multiple roles as the GP

• Because many are presenting with anxiety, I minimise physical contact at the first visit.
• Some accept height, weight & blood pressure being done with electronic sphygmo (some with wrist sphygmo only). Most enjoy being allowed to press the button to turn the machine on & off.
• I go through medical history, and ask questions about symptoms with potential to cause pain.
A case study

- Sam is 9 years old, and has autism, non-verbal.
- Special School teachers wearing leather armguards because he scratched, pinched, bit.
- Paediatrician increased risperidone, worse.
- I treated previously undiagnosed gastro-oesophageal reflux, which was causing him pain.
- Sam’s family were thrilled to be able to take him safely out into the community again.
Causes of distress

In my experience, the 3 main (unrecognised) causes of distress in people with ID are GOR, pain & constipation, all very common in people with ID. When I show parents the list of non-verbal indicators of pain, they realise that their person with ID has in fact been experiencing pain. Many people, including some professionals, consider constipation to be a minor issue, but it causes pain and incontinence. Toilet training is not possible until this is corrected.
Tools

- DBC-Developmental Behavioural Checklists
  - Parent
  - Teacher/carer

When the anxiety scale is high it visually helps the parent/carer to understand that their young person has a treatable condition in addition to permanent disability.

DSM-5 for Autism Spectrum Disorder, where I feel the behavioural difficulties have inappropriately been ascribed to ID. The positive diagnosis has resulted in better outcomes for the person & family.
Parent support-communication

• Parent/s need information, often not understanding autism, or what might trigger a meltdown (many comment they know I have a daughter with autism, which makes them feel comfortable opening up to me).

• Lack of ability to communicate results in frustration, leading to meltdowns, but many parents do not understand about non-verbal communication.

• They forbid signing & PECS, fearing it will prevent the person learning to talk.

• Some parents use sentences when their person with ID barely copes with single words.
Parent support-communication

- For others with ID, expressive language might appear quite good, but the person may not have an equivalent level of understanding.
- Frustratingly for parents, school staff do not recognise the person with IDs severely delayed communication skills, and inability to understand consequences.
- They think that suspension & cancellation of taxi transport will help the student ‘see the error of his/her ways’, and behave better. Outcome: student prefers being home!
- The parent ends up being punished for something the person with ID is not able to developmentally achieve.
Resources for parent support

- Resources such as the Autism SA Resource Centre, services for children with specific disabilities, equipment for school-age children from the Special Education Resource Unit.
- Companion Card, Disability Parking Permit, DSP.
- Parent supports such as MyTime, support groups for specific disabilities, Inclusive Sport, other activities which might be possible depending on the needs & difficulties of their child.
- Simple ways of including & supporting siblings.
Referral options as a GP

Depending on the presenting issues:

• Chronic Disease Management: 5 sessions of allied health annually. Medicare funded, but patient may incur gap.

• Mental Health Care Plan: 10 sessions annually with psychologist/mental health professional, funded by Medicare, may incur gap, try to choose bulk billing ones.

• Disability SA – Intensive Family Intervention, respite hours, respite out of home.
Other referral options

- Referral to the Special Needs dentist.
- Specialist referral eg gynaecologist re menstrual management in some instances.
- Facilitate work with Disability Coordinators in educational settings, for them to support teachers not understanding that challenging behaviour is often due to unrecognised anxiety.
Case Study

• Keith, 11 year old boy with ID banned from special school taxi run for life.
• Father a single parent of 3 children, 2 with ID.
• Father doesn’t drive, Disability SA temporarily getting Keith to school.
• Keith was very severely physically & sexually abused by his mother’s then partner age 6 years.
• On the day Keith was banned, it was a new taxi driver. Keith apparently assaulted him, and damaged the taxi.
Keith continued

• Keith has now been seen by Mohammed, who diagnosed anxiety & probable PTSD (I went with Keith, his father & DSA staff, as Keith was nervous about seeing a strange male).

• Treating the anxiety is probably the easier part, the school staff need awareness-raising to not ban a student without making attempts to look at underlying causes (same for many schools). They also need to accept that suspension is the beginning of management, not the solution, and consider causes of behaviours.
Keith continued

• When Keith’s anxiety is reduced by the medication, it will be time to explore what happened in the taxi on that day (he is verbal).

• Keith is still extremely fearful of the perpetrator, which makes me wonder whether the new taxi driver reminded Keith of the perpetrator, or made Keith feel very anxious.

• The CDH process could be likened to peeling an onion, gradually peeling back the layers to reduce the tears.
Reward

• The best reward (apart from getting paid, perhaps) is to see parents who have come in initially looking very anxious and worn out, eventually coming back looking more relaxed, and feeling they have a future with their son or daughter.

• This secondarily impacts positively on the young person with ID, who also seems more relaxed & responsive.

• However, this does not happen overnight, it can be a slow process for some.
Conclusion
Although we are a small unit, with careful teamwork we are able to help individuals with ID & their families, some more than others.
We also have an educative role, helping DSA Service Coordinators, Education Disability Coordinators, special school staff and parents understand the meaning of behaviours, to work out how to manage them effectively.
Jenny & Mohammed also communicate with treating/referring GPs, paediatricians, and occasionally other psychiatrists, which has an educative role.