

Submission to Productivity Commission's inquiry into the Social and Economic benefits of improving mental health.

4th April 2019

EXECUTIVE SUMMARY

Context

Thank you to whoever initiated this inquiry.

With the scope going well beyond the mental health system itself, it is very welcomed.

Thank you also for the opportunity to contribute.

This submission is provided from a Carer's perspective.

One of our children (22yo) took their life 2 years ago as a direct result of their struggles with poor mental health (Borderline Personality Disorder, BPD). It is a sad and difficult story of;

- potentially lost opportunities to diagnose and intervene earlier;
- the social impact arising from the combination of their poor mental health and the fragmented mental health and related social support systems;
- as well as the direct and indirect cost of dealing with her issues, and
- the missed economic opportunities of her not being able to grow into a contributing member of society.

Finally, it is also an outline of what we see could potentially be done to improve things.

High level summary of our experiences

Probably the best summary we can give around our experiences is how we've described our journey to others - in that;

- a) We always appeared to be one step behind in the diagnosis of our daughter's condition;
- b) We then seemed to be a further step behind in the treatment, and finally,
- c) A further step behind in the case management – because we as parents ended up being the primary case managers and we knew the least about the system (being on our first journey through it).

High level needs for improvement

What we saw was the need for a few things, but fundamentally centred around integrated, collaborative, adaptive and openminded models of treatment.

- **Integrated** in the sense that each professional should take into account the person's entire environmental circumstances (accommodation and transport status, financial / income position, work / training / occupation status, history, diet, emotional support and relationship status etc), as well as their mental presentation, and ensure that something is being done about any areas of deficiency (ie. not holding the view that it is outside the scope of their professional responsibility);
- **Collaborative** in the sense that all service providers supporting, assisting, guiding the person should be actively and efficiently communicating and working in unison, with proactive centralised case management from an early stage;
- **Adaptive** in the sense that 'treatment' should be fully tailored to the person's stage of progression of their mental illness and their progression through the treatment

'program'. That is, no one should be "too ill" to treat. Treatment should adapt to their needs, not them have to adapt to or be suited to the treatment 'program'; and

- **Openminded.** In the sense that, although past family trauma can be a precursor to complex mental health issues, in just as many cases, it is not. Don't immediately assume the parents or carers are the prime or significant cause of the problems. Start with an inquiring mind and make adequate enquiries before judgements. Otherwise diagnosis and treatment can be delayed with very adverse consequences.

Some specific concepts for improvement

- **Earlier and more effective case management** (*by Allied Health staff rather than GPs*)
- **Earlier diagnosis and more Integrated and Collaborative treatment**
(*Staging of mental health diagnoses*)
(*More effective school programs*)
(*Less silos and more Team work*)
- **Acceptance of Advocacy and Carer involvement** (*when Impaired decision making is evident*).
- **More Adaptive treatment**
(*More outreach, outpatient and community support, via Headspace or other services*)
(*less siloing of specific treatment programs*)
- **Creation of Therapeutic communities** (*combined accommodation, therapy and education*)
- **More Medicare sessions / better use of EPC's & NDIS** (*codes for case management etc*)

Broader scope of enquiry

We would also like to suggest that the scope of the Productivity Commission's inquiries be extended to considering:

- a) The effectiveness and efficiency of **Private Health funding** of current mental health activities, and the potential to extend Private Health funding for more outpatient care and ensure there is a seamless transition from Medicare funded services to Privately funded services, and
- b) The potential for **large employers** (eg. Coles, Woolworths etc) to actively engage in making available real world 'work' programs for mental health sufferers (to help rebuild confidence and financial independence), perhaps independently of or in tighter collaboration with disability employment service providers.

Later sections elaborate on all the above and give specific examples where available.

(Unfortunately – due to time limitations, the comments contained in here do not take into account any changes announced in the 2019 Federal Budget)

(and apologies for the hand drawn diagrams)

Thank you again for the opportunity to submit our thoughts and we hope this helps improve the social and economic outcomes for Australians with Mental Health issues.

DETAILED COMMENTS

The following sections cover:

1. Emotional and social cost
2. Lost economic opportunity
3. Comment on the inquiry
4. General experiences / background
 - a) School education years
 - b) GP's
 - c) Mental Health (therapist) system
 - d) Social services support
 - e) DBT course
 - f) Gap year, Tertiary education, Centrelink and employment support
 - g) Accommodation
 - h) Friendships and social connections
 - i) Money management
 - j) Volunteering
 - k) Hospital ED's
 - l) Police
 - m) Diet & exercise
 - n) Other diagnoses (depression, ADHD-I etc)
 - o) NDIS
5. General comments and recommendations
 - a) Earlier and more effective case management
 - b) Earlier diagnosis and more Integrated and Collaborative treatment
 - c) Acceptance of Advocacy and Carer involvement
 - d) More Adaptive Treatment programs
 - e) Therapeutic communities
 - f) More Medicare sessions / Better use of EPC's & NDIS

Appendices

- A - Poem from my wife
- B – Summary of family background
- C - Characteristics of BPD (chart)
- D – Functionality vs Age history (chart)
- E - Summary of extracts from School reports
- F – Orygen & Dr Chanen's Clinical Staging model & Team Treatment approach
- G – Spectrum of Consent and Capacity (need for Advocacy)
- H – Concepts for Adaptive treatment programs

1. Emotional and social cost

Let us first paint a picture of how we are coping as a family.

Quite simply – it's tough, as you could imagine. A real kaleidoscope of mixed emotions.

- There is a strong sense of sadness in that our daughter is no longer here, and most importantly, not able to grow into the person she had the potential to be and to live the life we had imagined for her ... (see the Appendix A for a poem my wife wrote for her funeral)
- You need to be on your 'A' game to maintain your own positive mental health while dealing with the fallout. That in itself can have flow-on social and economic consequences for ourselves. (awkwardness with people you haven't seen for a while asking how your daughter is doing ...; needing to limit workload to not over stress yourself, and to ensure we have time to adequately connect and interact as a family ..., etc). I guess you could say we seem to be dealing with it ok compared to others.
- We may have had an advantage in one sense in that we had 3 full years of dealing with our child wanting to take her life, and know full well her reasons for doing so. (relationship breakdown, exacerbated and amplified by the significant emotional dysregulation features of BPD). We had to intervene probably 5 or 6 times when she was considering taking her life. For us, there is not that sense of not knowing what was going on and what was troubling her. That must be a deep unknown that many parents and carers have when they lose someone to suicide.
- In another sense, there is a feeling of relief that she is no longer severely tormented by her mental health condition. She weighed up the outlook of a long challenge of continuing to try to get better (after already being through 7 years of seeing mental health professionals and trying treatment, since age 15, with little to no traction), against the other option (We commented to people at the time of her funeral, that the feeling of grief we all have at the moment, is the feeling she had every day for 3 years because of her BPD. That seemed to help put her mental state into context for everyone and give some understand to her pain.)
- There is also a sense of frustration that we were not able to do more in a generally unknown, opaque, fragmented and sometimes resistive mental health system. (we have also since commented to others caring for someone with a complex mental health issue that you probably need to do much more than you think you are going to have to, so best to start early).
- But there is also a sense of hope and consideration for others, trying to ensure they don't have to go through the same circumstances as us, by sharing our story and endeavouring to support the early diagnosis and more effective treatment of complex mental health conditions like borderline personality disorder. We know there are many good people out there trying to do good things and that progress is being made.

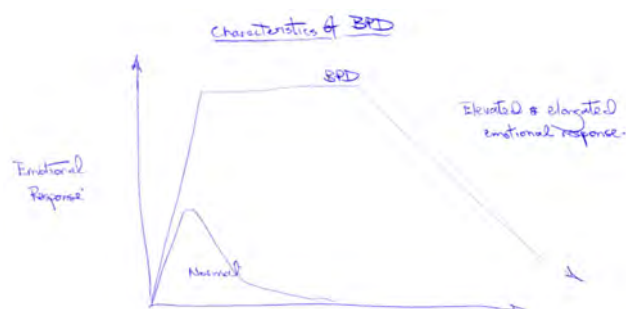
(please note, that our daughter was also transgender. She only began identifying as female around the age of 18, so much of the earlier material on her life refers to her as male. She was quite resolved in her situation as transgender and it did not seem to contribute significantly to her mental health condition once she was on hormone therapy)

2. Lost economic opportunity

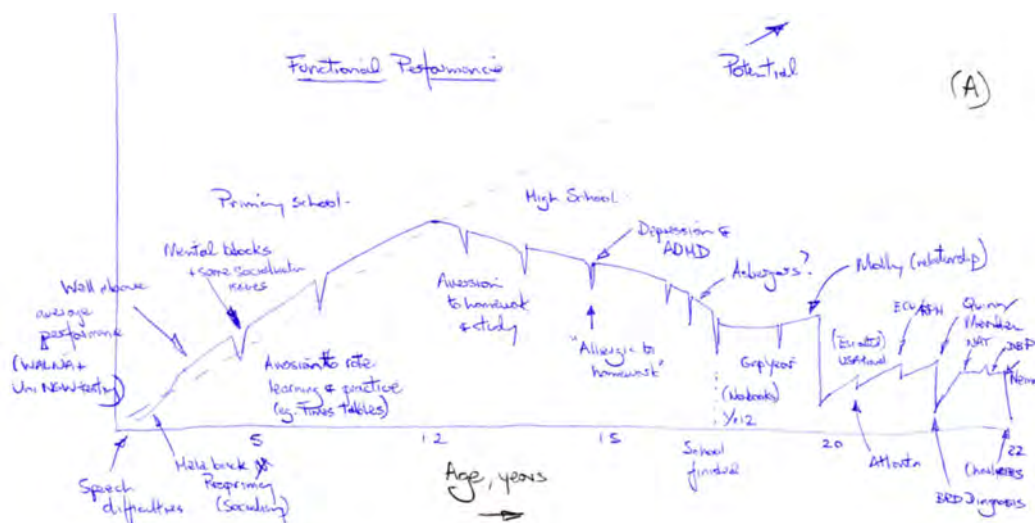
Let us also paint a picture of the lost economic opportunity.

Our daughter was intellectually bright (across Science, Maths and English). (See Appendix B for a short summary of our family background and below for some notes on her Education Years). That's not just parents talking. She had an inquiring mind and an innate aptitude to learn things (as identified in school reports and national testing – again, see below). She was also creative. A very competent writer, developing stories well beyond her years. Based on the performance of our other children and our daughter's early performance, we would have expected an ATAR in the high 90's.

However, BPD gradually eroded and stole her functionality and capability as she progressed through adolescence, high school and onto tertiary study. To the point where she was barely functioning on a daily basis by the time she was 22. (see below and **Appendix C** for a simple chart showing how BPD manifests itself by way of overloaded and elongated emotions).



And see below (and **Appendix D**), for an attempt to record our daughter's level of functionality vs potential as she grew



In short – she should have been able grow into a positively contributing member of society, not just in an economic sense – but in a creative and intellectual sense, rather than having an outlook of significant welfare and health system dependence.

3. Comment on the inquiry siloed nature of the industry

We very much appreciate the scope of the Productivity Commission's inquiry, as for some time we have been frustrated by the siloed nature of the mental health industry and the apparent divide between different professions and the fact that there is no overarching professional body for all.

The fact that it has taken the Commission to initiate such a wide ranging inquiry is itself an indication of the problems within the industry. As much as each segment would cite it is 'customer', 'client', 'patient', 'outcome' or even 'person' focussed, the fact that it has taken an outside body to initiate such a broad inquiry suggests that each stream of the industry is in fact not actually focussed on the person suffering mental illness, and in fact constrained by the limits of their own profession, institution or department.

4. General experiences / background:

This is a quick summary of some of our direct experiences in the complex world of mental health:

a) School education years

- Looking in hindsight, there appeared to be many early signs of BPD evident at school. The lack of adequate programs and awareness (both with us as parents and within the education system) potentially delayed diagnosis and subsequently effective treatment.
- Even though primary and high school reports & notes clearly identify these signs on an annual basis, no longitudinal pattern was looked for, identified, or flags raised of potentially prevalent or escalating mental issues. (See **Appendix E** for a summary of extracts from school reports showing a longitudinal pattern of good academic performance, punctuated by bouts of poor emotional and social performance – particularly in the high school years).
- Some more general examples we saw were:
 - 'Dropping her lip' and stepping out of situations at home and school (in the same situation where others were emotionally fine)
 - Mental blocks at school (inability to problem solve when things got tough)
 - Social problems at school
 - Saying inappropriate (insensitive) things to Friends.
 - Feeling 'bullied' when probably not (eg. in the same situation where others were fine)
 - Getting frustrated and punching 'bullies'
 - Didn't like rote (practice) learning (Times table, virtually anything involving repetition. Even sport like tennis))
 - Learning was very easy in the primary school early years. Very intuitive. Top 1 – 2% of Science & English in WA based on National tests))
 - But, ... became 'allergic' to homework in high school (her words) when topics became more complex and reading and practice was required.
 - Would state that we were 'always' on about homework, when we took quite a light touch approach. (we have 2 other children to compare to and corroborate) (In hindsight, the BPD seemingly made our daughter overly 'sensitive' to the issue)
 - Setting high standards for themselves, and couldn't push through if not achieving them
 - Didn't get much enjoyment from things. Tried a lot of activities. Searching for engagement and joy.
- Even when engagement with psychologists began at 15yo, no school performance information was reviewed, nor patterns considered or identified. We feel this, and a general lack of awareness of conditions like BPD in the community and educators, potentially delayed the diagnosis (along with the fact that the current DSM significantly limits the diagnosis prior to the age of 18 – although some Doctors, psychiatrists and

psychologists are attempting to change this currently. See later references to Dr Andrew Chanen and the Orygen Clinic). The reality is that, no-one ever looked at our daughter's educational experience from a diagnostic perspective, nor since her passing, from a research perspective to help improve the identification of children at risk.

- o On a positive note, circumstances appear to have improved in some schools. In recent discussions with our daughter's old Primary school, their approach seems very forward thinking (with higher levels of awareness of various mental health conditions, earlier interventions, mindfulness training and active case management by the school therapist). They were even aware of BPD as a diagnosis and how it could manifest itself in the symptoms being shown by our daughter at the time.
- o But - they acknowledged the approach they take is ahead of many schools. More could be done. (We asked if we could talk with someone higher up in the WA Education department so we could positively refer to some programs in use but have yet to hear back)

b) GP's

- o Our experience with GPs was Ok. They appeared to be well meaning but not proactive.
- o Our daughter saw 3 GPs over the years of her mental health issues. One in our home town and two in Perth while living there. One in Perth close to where she lived, the other more centrally located when she began to seek hormone therapy for her transgender. (The change over from one to another in itself poses problems.)
- o Our understand was always that the GPs were intended to be the central coordinating point in the health system via Mental Health Plans. (ie. the case manager)
- o Unfortunately, although capable and well meaning, GP's are generally:
 - time limited,
 - not funded for some critical activities (like communications),
 - seemingly not well connected with allied and related health professionals, and
 - appear to use outdated communication practices. (We likened the communications to the use of 'carrier pigeons' & 'Chinese whispers').
- o Also – there is seemingly too much deference to other professionals' 'judgement' and insufficient rigorous discussion, debate or communication with others over a person's situation. (the feeling you get is that things seem to just get 'thrown over the fence' to the next professional.). Whilst the others are typically specialists in their fields, there should be scope on both sides for clarifying communication.
- o In reality, GP's are typically not in a position to provide the type of case management required for incipient and escalating complex mental health issues, due to their time & funding limitations. (see later suggestions)

c) Mental health (Psychologist / therapist) system

- o In general, all the psychologist we had contact with appeared well meaning.
- o However, we found a significant lack of coordination and communication between GP's, psychologists and psychiatrists. (As noted above, things seemed to just get 'thrown over the fence' to the next professional rather than using a modern day collaborative / team communication approach and the many electronic collaboration tools available (like Slack) to compliment emails and written referrals)
- o Each profession seemed to operate with its own rules and norms and as such, was not really 'person' or 'client' focussed.
- o Also, seemingly significantly different approaches were taken by individual psychologists and getting the right fit with them takes time and is challenging (which makes it very hard when you are new to the system as a patient or carer)

- o Due to a range of circumstances (eg. availability, fit, location), our daughter had 5 psychologists over her 7 'mental health' years. We now know that continuity of care with a single (effective) therapist is a major determinant of effective recovery.
- o Reluctance by therapists to outline treatment paths and expectations to family / carers (see notes below on Advocacy)
- o No or limited scope for case management meetings (seemingly treated as therapy meetings instead) (see notes below on Case Management)
- o Reluctance by therapists to engage with social support services
- o Parents held at 'arms length', typically for the first 12 months, even though we were the primary carers and effectively the care coordinators
- o No detailed family history taken from parties other than the 'patient'.
No personal or family trauma was evident in our daughter's circumstance (other than items later exacerbated by the BPD). Probably quite the opposite. Our daughter was often not a good historian (as noted by one of the psychologists), and due to the emotional amplification of BPD, often had a distorted view of actual circumstances, but was given greater credence than our observations as parents – until the psychologist began to trust us. The only party who looked to take a detailed family history was an Occupational Therapist we sought out at one stage but decided not to go with as there was limited funding available for the service.
- o This all again seemed to contribute to a delayed diagnosis of BPD.
(We were not even aware BPD existed as a condition until the last 18 months of our daughter's life. We knew about depression, bipolar, psychosis, ADHD etc, but not BPD).
When identified – our daughter and we said – yes – that makes sense. There was no stigma at all and it gave hope)
- o There was also limited potential for a 'handover' between professionals when the opportunity came up for a more intense, publicly funded program for our daughter once the BPD was provisionally diagnosed. (Due to emotional impacts of her BPD our daughter didn't want to go through the 'trauma' of recanting her story to a new therapist – and we as parents were shut out from enquiring deeply about the program to help her in her decision making. In hindsight – this was probably a missed opportunity.)
- o Also, there was no or limited guidance on external support required to assist with & support therapy. No real interest in accommodation status, financial / income position, work / training / occupation status. Some interest in emotional support and relationship status.
- o Short (1hr) therapy sessions also seemed to inhibit progress. (see note below on longer Social Service 'Outreach' type programs)

d) Social Services support

- o Our daughter had access to a social 'Outreach' program in her later years when she moved to Perth to study. This was as a result of a referral from ourselves on the recommendation of one of our other daughters (an Occupational Therapist). That is – it was not part of a Mental Health plan recommended by a GP or psychologist.
- o In this program, social and peer workers would engage with our daughter in the community (ie. not in an office or therapy room setting) for 1-3hrs at a time, assisting in functional activities (like appointments, Centrelink, exercise, goal setting etc)
- o The fundamentals were good but the effectiveness was quite hit and miss depending on the skill and approach of the support worker. (First worker was fantastic but she left after 18 months to join Headspace. 2 follow workers were far less effective. And, virtually like starting from scratch, rebuilding the relationship. Not good with BPD. Even

though we provided the initial referral, we were also shut out during the transition from one worker to another one time due to some miscommunication)

- o The workers and management generally had a strong desire to engage with other professionals and advocate for and assist our daughter in decision making, but were often held at 'arms length' by other clinicians.
- o The longer session lengths seemed to engage effectively with our daughter. We found that in the depth of our her BPD, you needed 2-3hrs with her, sometimes a couple of time a week, to move from a non-functional depressed state, to a semi functional state with sufficient momentum until the next juncture or 'crisis'. A single 1hr therapy session with a psychologist once a week, fortnight or month was not sufficient to get traction nor change. (we didn't know this until too late)

e) DBT course (in-patient)

- o In her last year, our daughter undertook a dialectical behaviour treatment course as a day inpatient in a private clinic. This was a 10 week course, supposed to be the gold star treatment for people with BPD. (see Appendix E, 1 for a schematic of the typical process of the program)
- o Overall, it felt like a sausage machine for our daughter, more focussed on the mechanics of the 'program' than the 'person'. Some examples are:
 - Her medium term external psychologist was not invited to be part of the treatment team and had limited communication with the program overall. (the referral had to go all the way back to a GP, onto a psychiatrist in the clinic)
 - The referring psychiatrist did not actively follow progress in DBT treatment program (was more focussed on supporting the Transgender aspects)
 - Initially no psychologist was available for one on one support in the first few weeks (a key requirement of the program)
 - DBT requires practice at home, but our daughter had problems here (as noted in the 'school education years' above, our daughter had a long standing problem with 'practice' type study or learning (probably caused by the BPD) so this was always going to be a problem)
 - Limited assistance during the program, in particular no 'Outreach' services to help practice and problem solve in the field, nor coordination with existing social services to utilise them to help practice or problem solve in the field
 - Daughter eventually told she was 'too sick' (mentally) for the course.
 - No alternative or diversion or support program was offered,
 - But – She achieved a 'pass' certificate from the course (and they presumably got paid for it from the Health insurer funding it) – although she didn't really complete the course and the learnings didn't stick.
- o We have subsequently met with the Clinic involved and provided our feedback, which was seemingly well received. They felt they could potentially implement some of our suggestions such as 'Outreach' and 'offline' interventions, but will be interesting to see if they have. (see Appendix E, 2 for a schematic of our suggested enhanced DBT program)
- o Overall, the DBT course seemed to be a major waste of Private Health fund \$'s. We have endeavoured to meet with the health fund to provide our feedback on the program, but unfortunately have yet to be able to do so. However – we do understand the Private Health insurers are limited in how much they can intervene or query the effectiveness of specific programs like this due to accusations of 'Managed health'. There must be room for improvement here and should potentially be investigated as part of the scope of the Productivity Commissions investigations.

- o We have also subsequently become aware of a DBT program being run in the US and now being introduced in Perth, WA, which already incorporates most of our suggestions (we believe), which is a great move. (we also understand that these may in fact be fundamental part of running a successful DBT program.) (Hopeful the trial in Perth is successful and can be rolled out more)

(Ref. WA Primary Health Alliance, and Dr Alex Miller and Dr Kelly Graling of CBC – Cognitive Behaviour Consultants, NY. <https://www.cbc-psychology.com/>)

f) Gap Year, Tertiary education, Centrelink and employment support

- o Due to taking a gap year (18 months in fact), our daughter was able to get Youth Allowance to help financially support her in her studies. This was of great assistance, given that she needed to move to Perth to study (Computer Game Design and Programming).
- o The gap year was also good at giving her some work experience (working at Coles on cash registers), some life structure outside of school and some \$'s (of which she save quite a lot for travel, Perth and a computer).
- o Unfortunately, when she went to Perth she was not able to get traction in her chosen university course. (the BPD got in the way, but we didn't know that at the time. An earlier diagnosis would have assisted with providing more guidance on how to succeed at this), and she soon had her first presentation at a hospital emergency department.
- o Because the courses she wanted to do were not run on a dual semester basis, she often had to wait 6 months to get back to starting again or trying something similar.
- o Fortunately, both the university and Centrelink proved to be reasonably flexible and accommodating in navigating a way through things.
- o She eventually dropped trying at Uni and started a more hands on course at TAFE which had more structure (classroom style) to the study days. This was quite effective until about mid way through a semester, when the BPD caused her to get overly concerned about one aspect of the course that she was struggling in, which then cascaded to her losing confidence in it overall. (Even at that stage – we still had to typically drive her to TAFE on the first day of each week to get things off to a good start and momentum for the week ...)
- o When the ability to study faded out, Centrelink sent her down the Employment services path. We were supportive and saw that having structure and purpose in her life, like some work, would be good. But at this stage (in the last month or so of her life) simply things such as creating a basic CV, attending an appointment, filling in forms – where major tasks and significant barriers to progress.
- o A program specifically designed to help navigate people with complex mental health needs is vital.
- o Overall, we saw how easily it would have been for our daughter to have become long term dependent on welfare. (when she originally had so much promise). (Even though there was a lot being done to support her, it was too little too late)

g) Accommodation

- o Our daughter lived at home with us in the country through her school years – but wanted to further her studies, so, like our other children, moved to Perth for her last 3yrs, for tertiary study.
- o She initially lived in Student accommodation on campus at one of the Universities. This was ok – but settling in with 4 other housemates was difficult, and after living in 3 shared flats in the accommodation, she ended up being in a flat there on her own for ~3 months (which gave her good space) until it was required by other people. The accommodation effectively asked her to leave because they couldn't adequately house

her anymore. (this is an example of where the BPD again got in the way, and we still didn't fully know that at the time. An earlier diagnosis would have assisted with providing more guidance on how to work through this.)

- o The social services group was of limited assistance here. Mainly focused on finding short term crisis accommodation, which wasn't really the issue, although they did help with looking at a new form of supported accommodation, FOYER Oxford (in Perth) (<http://www.foyeroxford.org.au/>).
- o This was a great looking program of combined accommodation with support to focus on Study (particularly at an adjacent TAFE). Unfortunately, our daughter wasn't functional enough to get through the interview process. When she went to go to the interview (which she was meant to attend alone to demonstrate independence) after filling in an on-line application (with help and encouragement), she couldn't find a parking spot near the centre (on a Saturday morning in a busy shopping area) – so turned around, went home and lost faith. (This was the only service of its type in Perth, and unfortunately, the adjacent TAFE did not run the courses she was interested in).
- o Over her 3 years in Perth, one of us typically visited weekly to assist with cleaning, shopping, getting to class, Centrelink, Drs or psych appointments, general mood lifting and problem solving etc, and our other daughters provided 'respite' & 'crisis' accommodation when required. (While we had no qualms about doing this because it was for our daughter, we estimated at one point that our economic cost of doing so through lost income and time was approx. \$30k pa.)
- o For her last year – she lived in a shared flat with another transgender girl (fortunately Perth's rental market was reasonably open at that time and they were able to get the flat even though both were on Centrelink support). We had to help find the flat, move them in and also maintain weekly visits to support daily living.
- o Overall, we saw how easily she would have slipped into homelessness without our support. Due to the BPD, the challenge of dealing with these issues on her own was overwhelming and she would just avoid them.

h) Friendships and social connections

- o This was always a troublesome area, as our daughter's emerging BPD got in the way of establishing and maintaining good relations with her friends.
- o She lost most of her school friends as her interests changed and BPD got more severe.
- o Due to her limited scope of interests (specific on-line games and art) and sexuality (transgender), her friendship group became quite limited, and in fact largely limited to on-line interactions with a small group of transgender gamers around the globe, her flat mate and a very small local social network (2 or so others)
- o The Social support group and ourselves did what we could, but as you can imagine, it ultimately it was up to our daughter to engage and manage things. (She did often call on our help to assist, and to help draft communications etc when problems arose.)
- o It's obviously difficult for 3rd parties to assist in this area, but even simple things like Internet access, smart phone and computer availability were problem areas. (for a long while at home – our internet was severely limited because we lived out of town and could not get ADSL or NBN, and had to rely on mobile internet. At the time this was very expensive (\$500 per month) and a constant source of friction or drain on her / our \$'s. (access to better internet was one of the advantages of moving to Perth, as was access to a broader transgender community).
- o She would often not look after her devices so they would get broken, lost, damaged or so – which because of the BPD cause a lot of angst and barriers to getting them fixed or replaced.

i) Money management

- o She was generally good with money – but, on a couple of occasions when feeling very down or suicidal, she gave her remaining money away to people she felt more deserving (\$500 to \$1,000)
- o This would then cause problems when the situation passed.

j) Volunteering

- o During gaps in her study, we endeavoured to get our daughter to do some volunteering to help with social engagement and purpose.
- o Simple barriers in the training process and inconsistency of volunteering roles limited the effectiveness of this. (the BPD again got in the way, but we didn't know that at the time. An earlier diagnosis would have assisted with providing more guidance on how to succeed at this.)

k) Hospital ED's

- o Our daughter presented to ED's 4 times. Twice by way of friends / flat mates taking her. Twice as a result of the police being called to undertake 'mental health' checks (with a view to taking her into care).
- o She was generally compliant with going each time (all through this, all she wanted to do was get better).
- o The experiences at the ED's were mixed. Often quite disconnected from other care she was getting, until we caused the hospital team to join the dots (ie. contact her external service providers).
- o Usually busy places so it took some time to be seen. She was admitted once for 2 days in a general ward for observation (in a country town she had travelled to to consider / attempt suicide), and once overnight in a city ED. After the last overnight stay – she was provided with a 'hospital in the home' psych support team for a few days – but only after we caused the medical team to contact her psychologist when they were preparing to discharge her without support. (4 days before she took her life)
- o The main observation is that contact with a patient's existing mental health support should be a first port of call, not an afterthought or forced action.

(we did in the end have her booked in to go into an Inpatient clinic for a while – but she didn't make it)

l) Police

- o We have nothing but praise for the WA Police and how they conducted themselves the two times they did 'mental health' checks on our daughter and took her to a hospital for care. We called once, and her main psychologist called the second / last time when he couldn't contact us.
- o In the most significant case (when we called), they had to track our daughter down as she went missing out in the WA Wheatbelt. She was only just coming out as a transgender person and they treated her with great respect, using female pronouns and no stigma.
- o Whatever training they had had was very effective. We made a point of thanking them.

m) Diet, exercise etc

- o Diet was ok, but possibly too high in carbs and low in fruit and fibre in later years. There was likely to have been a gut health problem (as constipation was a problem), but there was no medical treatment investigated or prescribed for that other than suppositories.

- Alcohol was not a significant problem. Nor drugs (but you could see how either could become so. Limited budget was the restraining factor)
- Reasonable amounts of sport were played when younger but somewhat reluctantly. Exercise was pretty non-existent in the later years. Early Social Services support focussed on this but it fell by the way side. In hindsight – that was also probably a by-product of BPD because some of the exercise involved repetitious training (like Tennis), which didn't agree with our daughter at the time. (she didn't have the skills to manage her emotions when she couldn't play like she wanted to and the Social workers were not aware of the BPD). No active involvement or interest in this space from the GP's or psychologists.

n) Other diagnoses (Depression & ADHD-I, Aspergers etc)

- On the way to being diagnosed with BPD, our daughter had a diagnosis of ADHD (inattentive), combined with depression and was medicated for both (15 to 18 yo). And was subsequently reviewed for Aspergers.
- In hindsight, BPD was perhaps the underlying cause. Not diagnosed until 20 yo.
- She was also possibly addicted to on line gaming (probably as a relief from the BPD). We raised the possibility of this with Clinicians along the way – but were told that was not a recognised disorder. (it is now, we believe)
- We also asked if any of the treatment regimes or principles associated with PTSD may be relevant, as it seemed her BPD may have caused her to experience PTSD equivalent Trauma and symptoms from the relationship breakdown (all she wanted to do every day was to get back to the relationship – or more probably, the positive feeling she had while she was in the relationship). The answer was from the psychiatrist at the time was – she has not suffered a Trauma – why would PTSD be relevant?

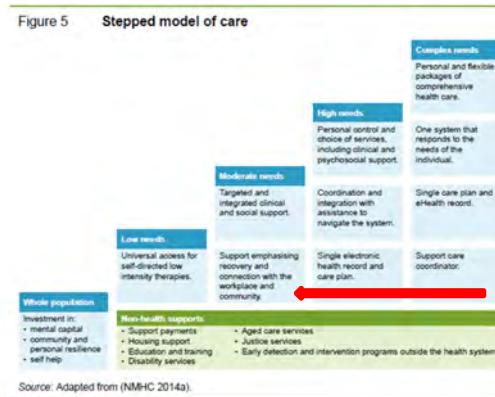
o) NDIS

- We understand that the NDIS can now fund support services for Psychosocial disabilities, which sounds fantastic.
- This was not available when we and our daughter were navigating the system, and would appear to have the potential to both better fund and direct much of the care required of people with complex mental health needs.
- More awareness needs to be made of it.

5. Some specific concepts for improvement

a) *Earlier and more effective Case Management (by Allied Health staff rather than GPs)*

At the moment, active case management only appears to be recommended for complex mental health conditions (ref. figure 5 in Issues Paper).



Due to the complexity of both the mental health system and the myriad of environmental factors that can affect mental health (such as accommodation status, financial / income position, work / training / occupation status, history, access to transport, emotional support, diet, and relationship status etc), and the fact that delayed diagnosis and treatment can cause complex mental health issues to grow faster than the application of treatment;

- case management should be one of the first ports of call.

GP's tend to be allocated the primary case management role in the current system. Unfortunately, this does not seem to work in circumstances where mental health needs are complex, or have the potential to grow into more complex situations. The challenge is that it can be difficult to determine which situations will grow, so it probably best to act earlier rather than later. GP's do not have the time and are not funded to undertake an effective case management role, which in most cases should have an element of Outreach (ie. in the community or home approach) and does not need a GP level of experience.

- Case management could be conducted by an allied health practitioner.
(such as an OT, practice nurse, mental health nurse or social worker, depending on availability and capability, and potentially funded initially under an EPC (Enhanced Primary Care) plan or NDIS) (Breast Cancer nurses are an example of the use professional case management and education in other health streams)

The level of case management would depend on the capability of the person themselves, the capability of their family carers, the complexity of their condition, the complexity of their environmental conditions etc. This would need to be ascertained during an initially diagnostic / educational process between the GP, the case manager, the patient and the carers. (eg. In simple circumstances, the Family carer may be able to do the majority of the case management themselves, with simple guidance from an allied health practitioner)

The objective being that the person is being proactively informed of (educated) and connected with appropriate support at all stages of their condition.

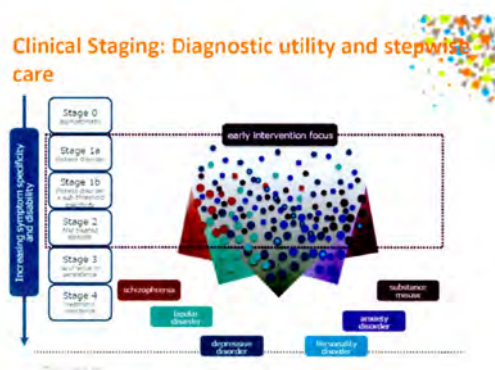
- Appropriate Medicare, Private Health or NDIS funding should be provided to ensure clinicians are funded to have the time to engage in this manner. Economic and social benefits should flow from faster or more effective recovery or management

b) **Earlier diagnosis and more Integrated and Collaborative treatment**
(Staging of mental health diagnoses) (More effective school programs)
(Less silos and more Teamwork)

There are a number of parts to this:

- One being prepared and armed to diagnose earlier.
- The second being able to intervene or treat more effectively earlier,
- The third being to have a 'whole of person' treatment regime.

Dr Andrew Chanen of Orygen (<https://www.orygen.org.au/>) has proposed a model of Staged mental health diagnoses, similar to how Cancers are diagnosed as Stage 1, 2 etc.
(See Appendix F1)

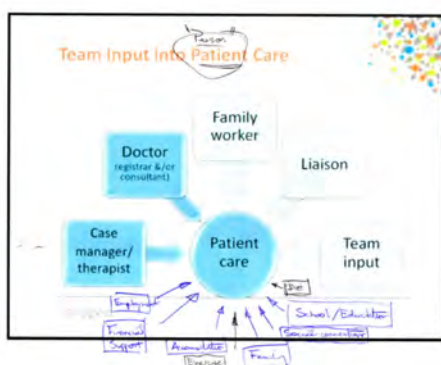


Under this model – even early signs of mental illness are treated as though they could grow into something more significant, such that treatment is designed to get ahead of the curve and avoid getting to 'treatment resistant' Level 4 conditions.

Our daughter's school reports (male at the time), show clear signs of someone having bouts of emotional distress or distraction that should have been a flag to earlier intervention. Her naturally good academic performance probably prevented her from being identified as being 'at risk'.

- We fully support such an approach and terminology.
- Stage 1 diagnosis could (should) begin in Schools.

Dr Chanen's model also includes a Team approach to treatment. **(See Appendix F2)**. We see this as being essential, as too many silos (more like chasms) exist currently.



We also see the potential to take the team approach beyond the basics, and ensure that each aspect of the 'person's' life is being assessed, addressed, treated etc, and that the team take responsibility for both individual elements as well as the persons 'whole situation' (including accommodation and transport status, financial / income position, work / training / occupation status, history, diet, emotional support and relationship status etc)

- This would require a major change in thinking, training and practice for GPs, Psychologists, Psychiatrists and other clinicians operating away from a combined clinic.
- Whole of person Mental Health plans, with active case management and team involvement of all clinicians should be mandatory and Medicare or NDIS funded.

(to date – the best style of thinking we have seen in this space is that of the Occupational Therapy (OT) profession. Their focus is on achieving health and well-being through occupation (ie. through the person doing things, particularly the things they want to do), thorough a 'whole of person', 'whole of circumstance' approach. They would seem to be in a position to play a very strong role in professionally case managing mental health needs)

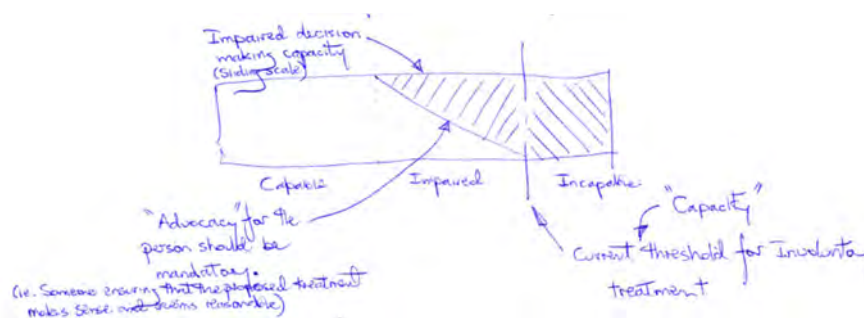
c) **Acceptance of Advocacy and Carer involvement** (when Impaired decision making is evident)

Doctors, Psychiatrists, and to some extent Psychologists, in traditional health models have played a very 'paternalistic' role. Being a combined advisor, educator, treatment decision maker, and treatment provider for people. (a 'Doctor knows best' approach, as such).

- In a modern society – the key roles should be educator, advisor and treatment provider, with decision making coming from the patient themselves, or with assistance of an advocate if the person has impaired decision making, so Consent can be properly given.

This is an important concept when considering Mental Health, particularly the role of Carers. Under most Mental Health Acts, a person is considered to have mental Capacity and can give Consent up to a point where a Dr decides they don't have it (at which point they can be involuntarily treated if required).

- In reality, Capacity should be looked at as a spectrum with some distinct break points.



(See Appendix G – Spectrum of Consent and Capacity)

People with Mental Health issues will typically have some level of 'Impaired' decision making capacity well before being considered as not having Capacity. The Impaired capacity may be permanent, temporary or circumstantial and will definitely come in different degrees.

- In order for Consent to be given, anyone with Impaired decision making (ie with a Mental Health issue), should have an Advocate (independent of the Dr, Psychiatrist or Psychologist treating them) acting for them, to 'assist' them in their decision making.

That does not mean making the decision for them. But does mean being in the room at some stage listening and discussing the treatment options with the Dr, Psychiatrist or Psychologist so the Advocate can ensure the 'patient' understands and can make a more independent and informed decision. This is an important and often misunderstood role that Carers play.

- It also means that Drs, Psychiatrists and Psychologists must seek out and engage with an appropriate Advocate for a person with a Mental Health issue, once it is acknowledged an issue may or does exist, and be prepared to have a 'peer' level type discussion.
- Typically, an appropriate / trusted Carer would fulfil this Advocacy role.
- In circumstances where the Carer is part of the problem, the Case Manager do it.
- This may require changes to Mental Health acts, or could more simply become part of the code of practice for appropriate clinicians such as Drs, Psychiatrists or Psychologists.

Confidentiality is likely to be raised as an issue by clinicians, but in most cases (except where the Carer is part of the problem, in which case a Case Manager should be filling the

Advocacy role), it would seem that a greater good would be achieved by sharing the problem or at least so much of it, such that Advocates can be effectively included in and support the both the decision making and treatment processes.

- This would help put the role of a Carer (who is a key part of the treatment Team and regime) in a more central and appropriate role for the effective operation of the regime.

(again – appropriate Medicare, Private Health or NDIS funding should be provided to ensure clinicians are funded to have the time to engage. While it may require more time up front, economic and social benefits should flow from faster or more effective recovery)

d) **More adaptive treatment programs**

(More outreach, outpatient and community support)

(less siloing of specific treatment programs)

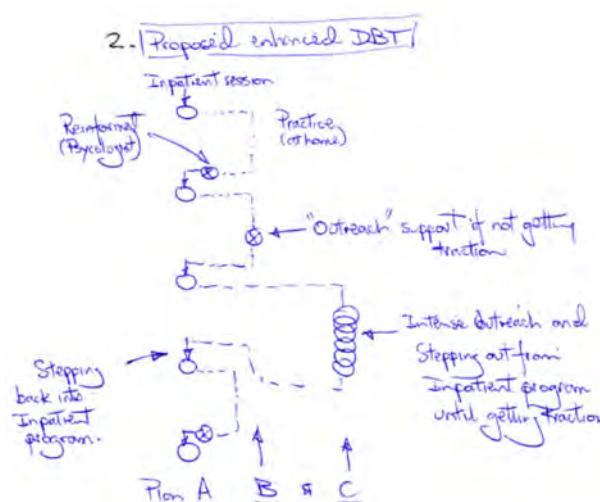
From our experience with our daughter's DBT program, it was relatively rigid, non-flexible (ie. no Adaptive), and in her case, potentially poorly executed, not Integrated with her other needs, nor Collaborative with other practitioners. Effectively a trifecta of failure.

- One of the things we observed is that treatment programs often seem rather introspective and focussed more on the program itself and the academic theory behind it, than the solving a particular 'person's' problem,

and – in the private health space – a potential money making opportunity with little focus on actual individual outcomes. That may be harsh but we have seen much of this first hand.

The language used in the therapy industry is also a barrier. There is a lot of specific training and jargon that becomes the norm in any professional industry (which is fine in a research, teaching or in-house environment), but in the real (patient) world, use of terms such as Schema, Dialectical, Cognitive can be a barrier to good engagement and understanding with the patient (and their Carers & Advocates).

- The answer would appear to be to ensure there is sufficient training and application of a broad range of psychological, (pharmacological) and social tools that can be 'Adapted' to help solve a particularly person's mental health issues.
- An example of an Adaptive DBT program could be as shown in **Appendix H2**.



- In this, if a person is not getting traction in a mainstream program, a basic Outreach add-on is applied (Plan B), and if that is not working, the person is broken out into a more intensive Outreach and clinical 'holding pattern' until a particular skill or so is mastered or set of external circumstances solved (Plan C), then reintroduced to the mainstream program. No one should fall through the cracks or be deemed 'too ill' too treat.

(As an analogy, I have worked for 20+yrs as a business consultant, getting deeply involved in both the hard and soft issues of businesses & organisations – and am now particularly involved with multi-generational family businesses. I typically have to go into very diverse industries, businesses and family situations; understand and decipher complex systems, break them down into simple communicable and adjustable components (on both the business and family front); then use my broad set of skills, tools, models to customise a solution of change & development, sometimes having to research, develop or adapt a tool, story or analogy from somewhere else to suit the particular circumstance.

I deliberately do this, rather than apply a standard pre-set program or solution, as I recognise that every situation, whilst there may be some common characteristics, is different, and the language, the tools, models and pace I use, needs to be tailored to the situation. I also actively built bridges between myself and other practitioners (such as Lawyers, Accountants, Financial Advisors etc) to ensure advice and support is not siloed.)

- I didn't get that feeling with most of the mental health system.
- Medicare and private health insurance may not be currently set up to support the above (although NDIS may be), but in many cases – professional training, approaches and practices appear to be the more significant part of the problem. (ie. more could potentially be done within the current systems)

e) *Therapeutic communities* (combined accommodation, therapy and education etc)

For people with more complex mental health needs – their mental health treatment is not just more complex – it usually means that their entire life circumstances are more complex.

One way of dealing with that may be the concept of a Therapeutic Community, which would be the combination of 3 existing concepts:

- Integrated Clinics (with collaborative Clinicians and programs) (like Orygen, Headspace)
- Active 'Outreach' programs (operating from the clinic)
- Combined with supported accommodation (like Foyer Oxford), adjacent to an education facility or major work area
- (and possibly even co located with Centrelink and an employment service offices)

That is – a one stop shop, that can adapt its services to suit the needs of a person with complex mental health needs, while providing them support in all the daily living items that can get in the way of getting better.

A facility such as this would ideally be collocated at:

- each University and major TAFE, and / or
- adjacent to major work areas (for those transitioning into employment), and
- adjacent to existing centres of therapeutic excellence (for example, suburbs where most private practitioners have their rooms so they can be easily accessed)

The economies of scale and social and economic benefits flowing from this should be positive.

f) More Medicare sessions / Better use of EPC's and NDIS

- As noted in the sections above - GP's, Psychologists and Psychiatrists should be provided with Medicare codes to undertake case management meetings, more extensive communications with other professionals, and patient 'decision making' meetings (with their Advocates).
- Further funding, or possibly just more awareness of existing funding channels, should be made available for treatment of complex mental health conditions – potentially through the more extensive use of Medicare EPCs or the NDIS (psychosocial disability channel)

Eg. We believe that treating someone with Borderline personality disorder could required ~160hrs of clinician time, either in a group setting, part group setting or a 'one on one' basis. This is significantly more than currently available under Medicare funded programs (eg. 10 session).

However, without such treatment (to help fund a 'slow and thorough' approach, rather than trying to apply a series of independent 'patches') – people are likely to slide into a 'treatment resistant' phase before sufficient traction is gained with them. Becoming welfare dependent for a very extended period of time, or opting out ... increasing the overall social and economic cost.

Thank you again for the opportunity to submit our thoughts and we hope this helps improve the social and economic outcomes for Australians with Mental Health issues.

----- End -----

APPENDIX A

Jill's poem (for our daughter's funeral)

'I wonder....'

I wonder if you knew how many times I thought of you?
While driving alone in my car, I've sat and cried.
I'm sorry I couldn't save you.

I wonder about the times we had together and the times that could have been.
Are you happy now and free?

I wonder if there was a clue?
The last time we kissed good bye, you held me just that little bit longer to you

I wonder what it is you can see?
I would like to believe in heaven, but I'm not sure you would agree.

I wonder how many know what it's like to lose a child?
I thought I knew.
But I was wrong, I had no idea ... until I lost you.

I wonder ... as I keep myself busy with the things to do.
But every time I pause, I think of you.

I wonder ... if you knew how much I loved you.

APPENDIX B

Family circumstance

We are upper-mid income family, living in reasonably comfortable circumstances in a coastal rural location in WA. Both parents have professional backgrounds (Nursing and Business Consulting), working in reasonably flexible roles that provided time to provide care, guidance and support to our daughter in the early mental health years. That became more difficult when she moved to the city to try tertiary education, but a reasonable level of weekly support was still able to be maintained.

We have two other daughters who now also work in professional /creative roles.

A reasonably normal / capable family you could say.

APPENDIX C – Characteristics of BPD (chart)

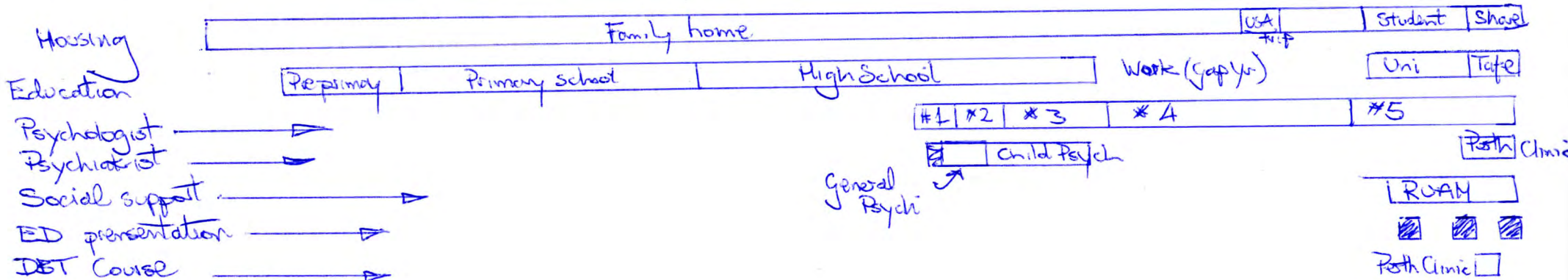
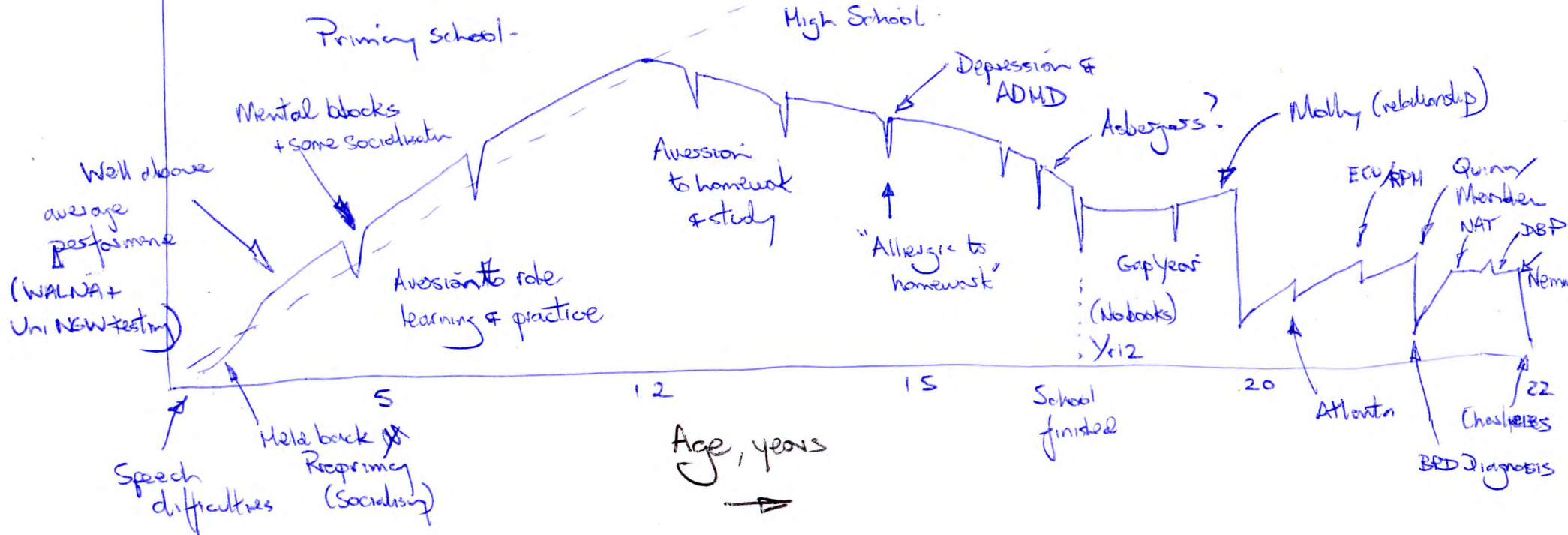
Characteristics of BPD



APPENDIX D – Functionality vs Age history (chart)

Functional Performance

Potential



APPENDIX E - Summary of extracts from School reports

Summary of school report comments

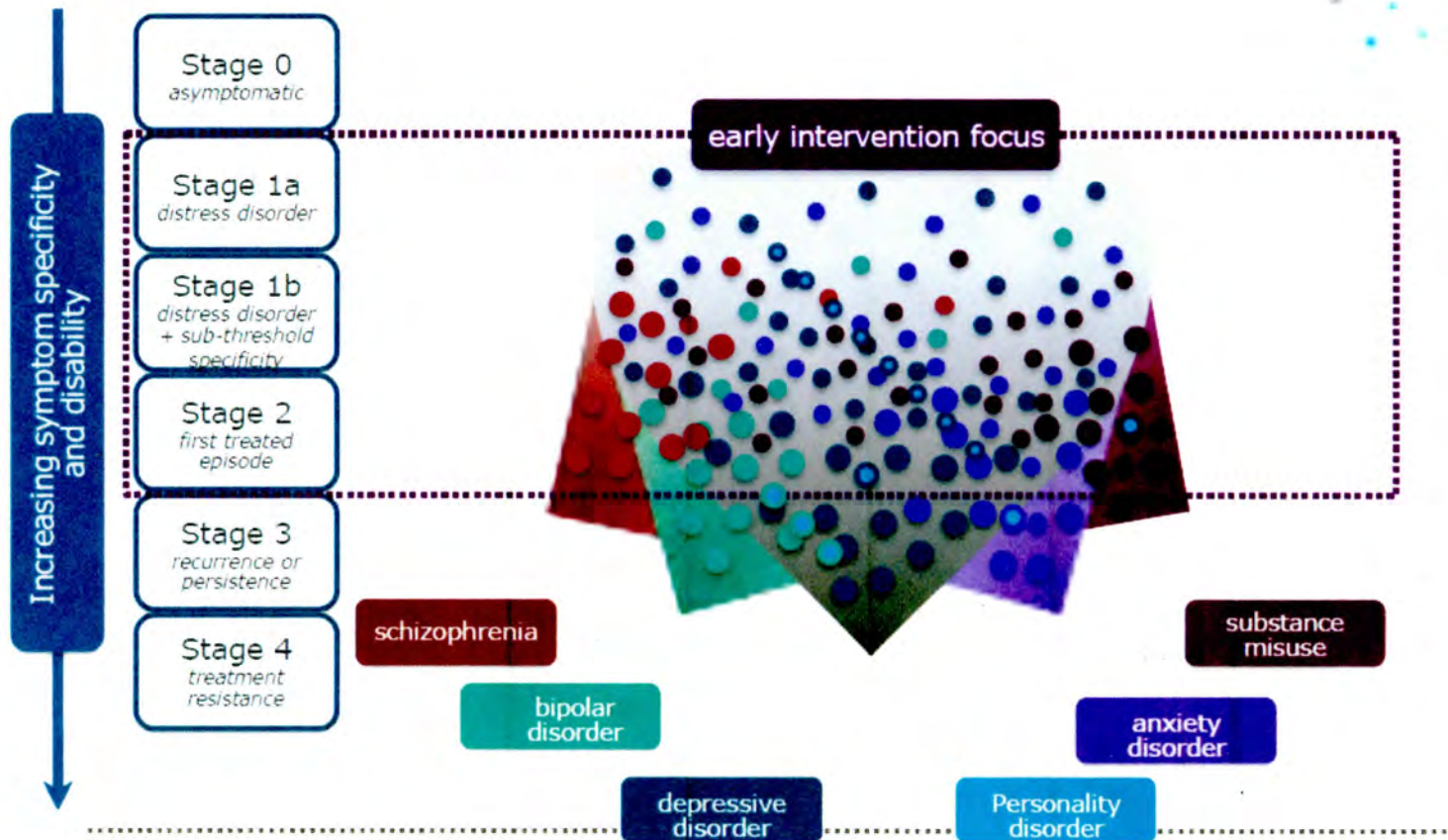
Yr 1 2001 Sem 2	XXXX is a friendly student who makes valuable contributions to group and class discussions. However, he is easily distracted and needs reminders to stay on task and complete his work. (Maths) XXXX displays an excellent level of ability and understanding ... (Prepared for lessons, Begins work quickly, Completes work): Usually
Yr 2 2003 Sem 2	A great year's work XXXX. You are a <u>very</u> capable student. Just try very hard to always finish your set work. XXXX has the ability to do <u>very</u> well with his studies. (writing) XXXX has some wonderful ideas. He just needs to stay focussed to make sure the writing is complete. (maths) Not all work completed and not because he doesn't understand. (Science) XXXX is extremely interested in the world around him
Yr 3 2003 Sem 2	XXXX is a unique individual who has demonstrated high order thinking skills ... However, XXXX is not always keen when it comes to staying on task when completing written activities. ... he is an ideas man and he loves a challenge. (Organises self and materials) 2 out of 5
Yr 4 2004 Sem 2	XXXX has had a mixed year with his acceptance of classroom procedures and the opinions of others. ... and encourage XXXX to continue to look for ways to resolve issues whilst considering the points of view of others. Academic progress has been of a high standard. (Organises self and materials) 2 out of 5
Yr 5 2005 Sem 2	(Overall) XXXX has had an excellent year academically and is working at a very high standard across all learning areas. His (low) WALNA scores do not in any way reflect his ability as a writer. What they possibly do reflect, when considered in conjunction with XXXX' proven ability for writing, is that XXXX has, on occasion, not found ways to progress past barriers when he has encountered them. One of XXXX' biggest challenges this year has been to attempt to focus when he feels bogged down by the plethora of ideas that often occur to him. XXXX has a wonderful attitude toward learning. We have had many long discussions over the year and I have enjoyed these because XXXX genuinely listens and considers. I think he will be very successful. (Other) He does not always respond well to the ideas of others and would benefit from being more flexible when working in group situations.

Yr 6 2006 Sem 1	(Overall) XXXX is a very capable boy. He has an excellent understanding in all learning areas. He has difficulty however with his ability to organise himself and with his listening skills. He appears to be so ‘busy’ in thought that he misses what he has to do and becomes easily frustrated and confused. XXXX is highly motivated in his desire to discover more. (English) XXXX is an excellent reader who displays a high level of understanding both literally and inferentially. He is an avid reader ... he is an outstanding writer XXXX does take a great deal of time determining how to approach a task and this often causes him frustration. He is often quite unsure as to what is required of him and has to have instructions repeated. (Maths) XXXX is a very talented mathematician. Although he has achieved very pleasing results overall, at times he does not appear to be making full use of his capabilities. He seems to be distracted and has difficulty remaining on task. During test situations he can give up too easily and again becomes frustrated. This attitude concerns me.
Yr 6 2006 Sem 2	XXXX is a very clever boy and he has an amazing ability to think laterally. He has continued to have some difficulty organising his ideas in ‘workable output’ but this has become less of a problem with him this semester. XXXX is becoming more tolerant of others and more accepting of criticism. Sometimes he gets a little too excited and carried away ...
Yr 7 2007 Sem 1	His approach has been very commendable ... XXXX does at times sway to either side of the emotional spectrum... from over excited to overly anxious. This does need to be monitored so XXXX knows how to react appropriately he regularly puts his head down and gives up instead of seeking help or persisting... XXXX is a talented student who should continue to do well ...
Yr 7 2007 Sem 2	(overall) I believe XXXX is a far more capable student than he is currently demonstrating. ... very erratic with his homework. ... does not enthusiastically tackle challenges. ... extremely talented student ... He is a pupil of considerable potential ...
Yr 8 2008 Sem 2	(overall) ... it is obvious from the comments of his teachers that he has the potential to do much better. ... needs to work on becoming more organised and prepared for lessons. XXXX is a very capable young man but he will not reach his academic potential until he learns to remain fully focussed during every lesson ...

Yr 9 2009 Sem 1	(Overall) There is a common theme running through many of the comments in this report which suggests he is capable of achieving a higher standard. XXXX needs to ...stay more focused .. avoid being distracted ... and to be prepared to ask for help ... needs to learn to remain focused in class and to prepare and plan thoroughly before attempting work. ... would encourage him to seek the help and advice of his teachers ... (English) ... is a pleasant and imaginative student who sometimes get carried away. I have been particularly impressed with his enthusiasm for creative writing tasks. ... but he is also easily distracted and has a tendency to waste time in class. ...can be erratic in his approach. (Science) XXXX is a very intellectual and analytical young man who has done very well in this subject. His downfall is that he can become distracted very easily and can become angry when asked to return to his studies. (Phys ed) Has forgotten his sports clothes on a few occasions. (Art) ... he is easily distracted and has not always use the time well ...
Yr 10 2010 Sem 1	(Overall) .. Report is a mixed bag. ... indicates that he needs to adopt a more diligent approach to his work .. XXXX could do well to concentrate on using his Home Study diary effectively ... and organising his time ... (English) Chis appears to have the potential to write well and succeed in English. Whether he translates his potential into achievements will depend upon his application and attitude. (Science) .. this would suggest that XXXX did not cope with the examination.. XXXX needs to really push himself ... (S&E) he finds analytical writing difficult.... He will need to work on the structure of his essays ... His essays were a disaster.
Yr 10 2010 Sem 2	(Overall) Inconsistent attitude...All assigned work must be completed and submitted on time. (English) Has capacity to write well but finds it difficult to get started with assignments. ... XXXX has found it difficult to organise his thoughts in a timely and succinct manner ... does not work well under time constraints and succumbs to anxiety rather than organising his supportive material in a systematic fashion. ... this is not an accurate reflection of his actual ability. Would encourage XXXX to avail himself of the support networks available in the school to assist him perform to his potential in future. (Maths) setting out can be messy and sparse. (Science) ... unfortunately did not complete one of the assignments. Well placed to succeed in upper school courses. (S&E) ...appeared to enjoy ... but had difficulty expressing his opinion encouraged to ask questions reluctant to write at length. Essay sections of exam was very poorly attempted. (Photography) .. struggled at times with his organisation and time management (RAPS) endeavour to be more organised and keep all work for each subject together in his file next year.

APPENDIX F – Dr Andrew Chanen’s Clinical Staging model & Team Treatment approach

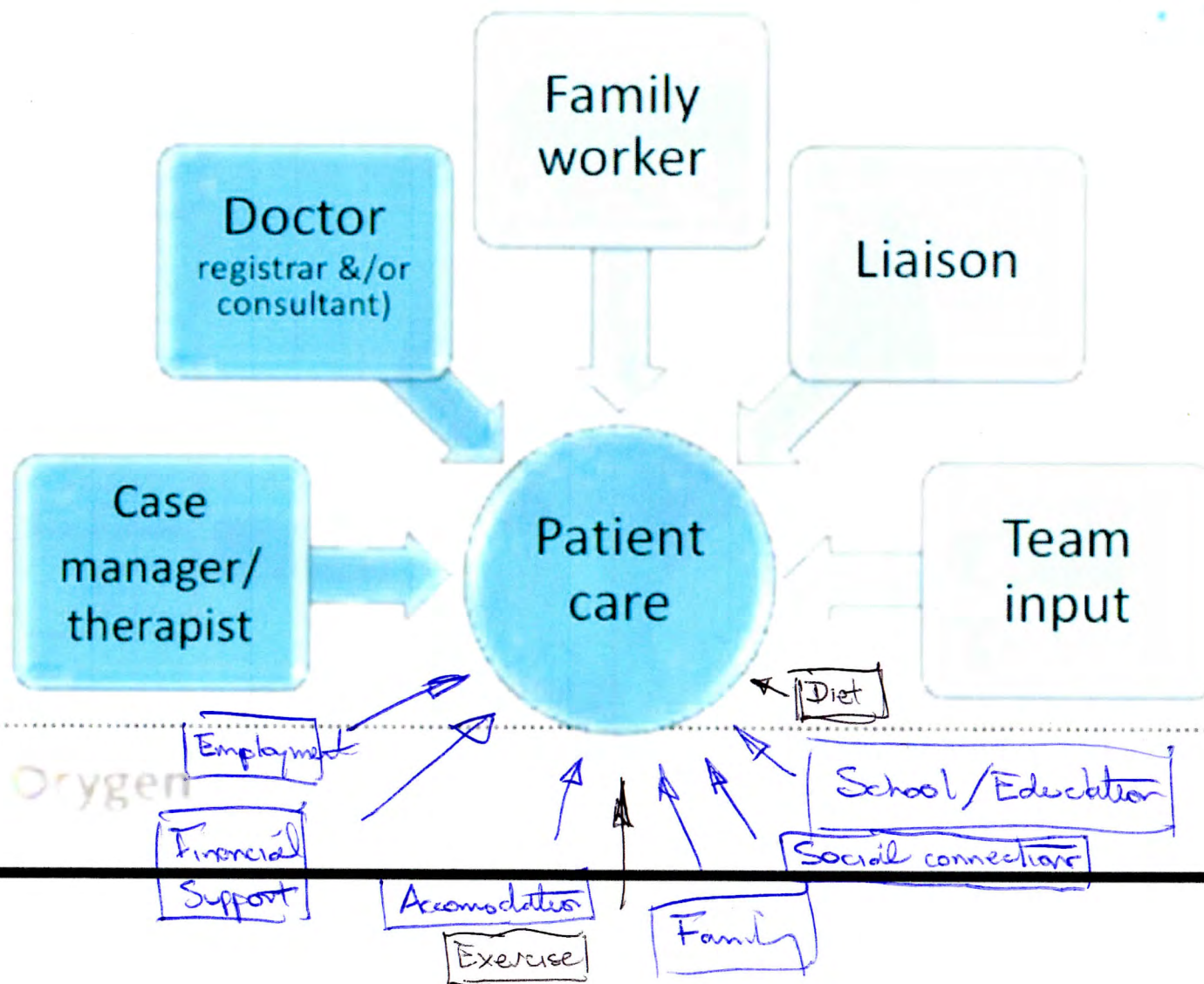
Clinical Staging: Diagnostic utility and stepwise care



Orygen

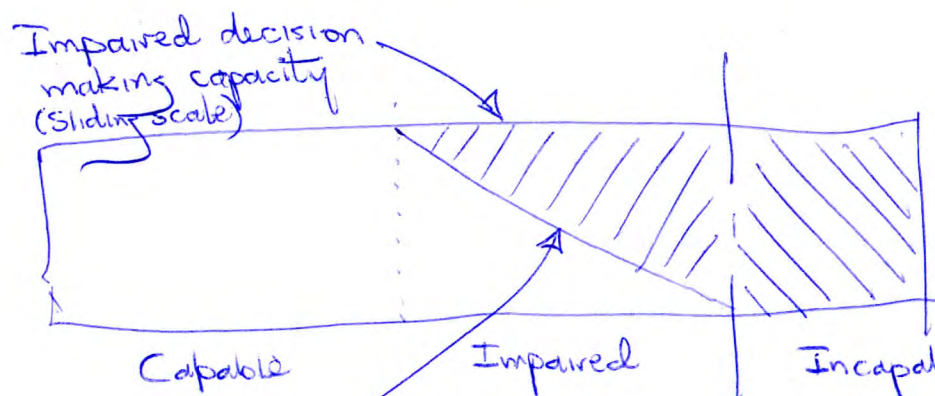
Dr Chander
Orygen Youth Mental Health

Team Input Into Patient Care



APPENDIX G – Spectrum of Consent and Capacity (need for Advocacy)

Concept for a spectrum of Consent & Capacity (Advocacy)



"Advocacy" for the person should be mandatory.

(ie. Someone ensuring that the proposed treatment makes sense and seems reasonable)

"Capacity"
Current threshold for Involuntary treatment

1. "Capacity" currently is a binary ~~capacity~~ state
2. In reality, there is a sliding scale of capacity prior to not having 'Capacity' when someone has a mental illness
3. GP's, Psychologists & Psychiatrist should engage with an "Advocate" on the person's behalf acting

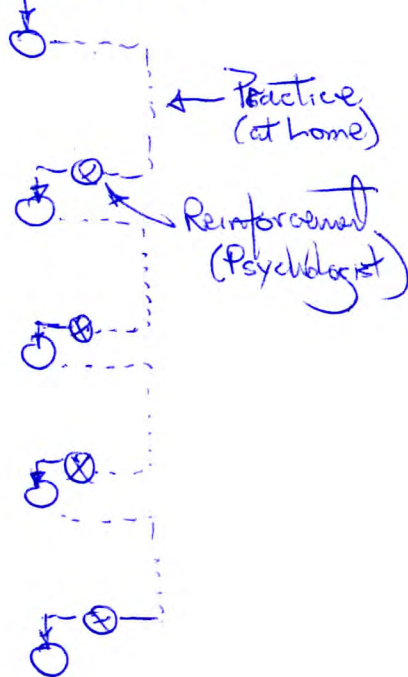
APPENDIX H - Concepts for Adaptive treatment programs (like DBT)

Appendix -

Concepts for alternatives to rigid treatment programs (Adaptive)

1. Classic DBT

Inpatient session



2. Proposed enhanced DBT

Inpatient session

