

Supporting Document for Carer Submission

I am the mother of a 21 year old young man with diagnoses of Autism, Tourette's syndrome, Schizophrenia, and as I point out in carer support groups, the straw that broke the camel's back has been his choice to become a vegetarian (of all things!) at the age of 15. When I mention this to families they laugh, because we have an understanding between us as mental health carers of the sheer volume of work we undertake on behalf of our family members and that in fact cooking two meals is out of the question. Our family is resilient. We have a strong sense of humour to get through the challenges and they are many. I am a single parent, and have my teenage daughter living with me. My son lives in temporary accommodation at a mental health Community Care Unit (CCU). I share care of him, as he returns home three days a week.

I work within the mental health system. I am a mental health trained social worker, and I work in NDIS advocacy for mental health family and friends (carers). My work within community health, carer services, disability services and the mental health system spans 15 years.

Early history

My family experience of the mental health system began at age 20 (1997) when as a young married woman with a child on the way (my son), my then husband began experiencing strange ideations. I can now reflect that in truth it began while dating, but I didn't really see what was happening. These were auditory hallucinations and paranoid beliefs and he developed positive symptoms around these. We separated as a consequence of family violence (behaviours of concern) linked to his mental health. We received no health service support at the time but did ask our community, largely church groups we were involved with, for advice and support. In the main the advice cast him as a selfish person and no one recognised the distress we were under as a young couple dealing with his needs with a brand new baby. I am ashamed to say I avoided the stigma of divorce by substantiating that his illness was significant and others were compassionate to my situation. I didn't know to assist him to seek health care and this is a great disappointment and regret I hold.

I took my son to visit his father at [REDACTED] Hospital when he was 2 years old. It was a chaotic place, and scary to be there. No nurses ever explained his circumstances and I knew nothing of the diagnosis. I was concerned about whether it was an appropriate setting for my son to visit but I believed in the importance of family relationships and supporting these, no matter the difficult circumstances. In retrospect, having some knowledge of the diagnosis and circumstances would have better allowed me to ensure my son was safe in visiting his father over weekends, or supporting if this was required when his father was in the community. As the primary parent for my son, I wasn't informed to know whether my son would be safe on visits with his dad and certainly the only support to his father at the time came from the paternal grandparents.

For a few years we had semi-normal experiences of my son having weekend visits with his father, until he was about the age of 4. There were a few instances of police calling because my son's father had told him to run with him, away from police, at the train station. I don't recall the reason why he told my son to run; I do recall that he encouraged him to cross train tracks far from any safety crossings by jumping down one platform and up onto another. There were more than a few times we collected my son from the police station.

Forensic Services

Several years later, my son's grandparents took him to see his father at [REDACTED] Hospital. Many times he would visit and his father would not see him as he was not in a suitable frame of mind. Perhaps naively I thought it

was just another mental health hospital ward. The significance of the facility was not something I understood until a double homicide occurred there in 2009. At that point I had not visited there myself. The grandparents were never truly transparent about where my son visited his father and no-one sought my consent for my son to have visitation within a forensic institution under the age of 10, or put safety plans in place around this. The name of the place didn't mean anything until heard on the news, and I researched on the internet. I reacted with anger and fear, and very distressed at the lack of information provided to me to seek my consent. I now view this as a gross failure of the system placing our son in unnecessary risk of harm and trauma. I would have possibly encouraged visitation and recognised his rights; I might also have sought him further support than I did. I had no idea what my son might be experiencing. I met with the nursing staff and met with my ex-husband at his unit in 2010 and had some further information of the circumstances of his incarceration provided around that time. I allowed continued contact.

I advocated for child-sensitive approaches to be available within [REDACTED] in 2010-11 as I found that when my son visited (age 10-13) he was exposed to nude posters of women in his father's room, and left unsupervised with his father. I had no knowledge of other people in the unit with my ex-husband, and I imagine the environment has worsened since that time. It frightens me to think of children there now, without considerable supports and safety practices in place. I am not familiar with the current state of child focused practices there.

I have respect for the difficult work of staff at the hospital and recognise with great sadness and disappointment that possibly my ex-husband received better care and consistency of support in that setting than might have been available in the community, at that time. My ex-husband was treated with ECT while in [REDACTED], and has suffered significant cognitive decline. He was in forensic care for 9 years and now lives in a Melbourne supported independent living unit. I would not suggest his treatment was optimal, only less chaotic and irregular than in the outside world.

I feel, based on my knowledge of the crime, that justice was not meted out – the law was used excessively against my ex-husband in his case, in my view. I am concerned by the way community stigma leads to weighting of sentencing.

Family Inclusive Practice

A good experience from our family experience of the forensic environment included that a kind social worker arranged for day leave for my ex-husband to be present at our son's 16th birthday party and accompanied him there. That was an important experience for both he and my son, and a very sad experience personally. This rare sense of family in our fragmented lives, so intertwined with health and justice systems, is little understood in my own family or friendship circle, let alone the broader community. It is rare to have an opportunity to discuss such experiences or put them in a context.

I did link to organisations such as VACRO and Shine for Kids to support my family. VACRO offered family therapy free of charge and provided me support to reframe our family experience helpfully in a strength-based way. I am grateful we had a year or more of this support and can see it built our resilience and self-compassion. Soon afterward, vital funding to provide this service to vulnerable families was cut. I also had Gestalt therapy through this service. I credit this free weekly support for over a year as having transformed my experience of myself and my life at the time, and my value as a human being, in such a way that I was able to return to university and improve my life. I have repaid this in my work in the sector and have reflected on the opportunity of timing where rental costs and government payments somehow aligned enough to survive on 3 days' work a week. I am not sure families now, 10-12 years on, are so fortunate.

Intergenerational trauma – carers as care recipients also needing support

Because of my ex-husband's illness I was left alone in my own caring role for our son who also had Autism and emerging mental health needs. That early adulthood trauma of marriage and mental health issues shaped my future relationships, and I struggled in forming healthy relationships. I believe my own trauma as an adoptee has been poorly supported and also contributed to this.

I have been part of the group requiring the services so frequently described as the 'missing middle' although I have no formal diagnosis; possibly complex trauma. On many occasions my concern for my own health, and for my son, was dismissed. The impact of early life trauma for myself, or for him, was little recognised.

Carer Peer work – training and support needs for carers

Mental Health Carer Network (now Tandem) invited me on to the Victorian Forensic Mental Health Advisory Committee around 2012 but as interested as I was, it wasn't possible to maintain involvement at this level as a single parent at the time beyond one or two meetings. I value this experience because I was less schooled in the mental health system then. I remember how overwhelmed I felt with the 'official' health department people, and the tokenism afforded to my involvement. It gave me insight into how alienating processes of government can be for the ordinary person. Bureaucratic terminology of models of care, professional roles, and organisational structures confused me. I now feel more equipped representing others with a view to making complex systems simple to understand for people in distress. Ideally though, a plain language approach would reduce alienation of families in need of health care and support.

Early childhood – co-occurring disability and mental health

My son's own disability specific needs have been significant to manage including advocacy required for a diagnosis (age 7 – in spite of seeking help when he was 2 years old and ongoing from that time) and he was never provided adequate support in schooling, or in early intervention due to the service constraints of that time. Our family has faced a battleground with education and health systems and I am now quite hardened and exhausted from the journey.

A brief timeline of events – my son's mental health journey:

- Born 1997. Ordinary birth – no complications but the cord was around his neck. [This seems to interest psychiatrists more than getting to know who he is now, at times, and this is tiring as a family to recount details as far back and as anecdotal as this, as though our lives are a research study.] Sought diagnosis when he was 3 years old for Autism, was told he was 'just a bit serious' and provided a brochure for social skills for myself, as though I was the issue. I now see that I was dismissed in my efforts to find support for him even though I'd had long experience with many children in my family, babysitting in my community as a teenager and so on, and had a sense of 'normal' child development. Now that my son is an adult I feel that questions asked of me by mental health services link to ideas of a mother's responsibility in her child's eventual mental health issues. There is a lack of compassion in the persistent questioning of our whole family history in this way that targets families in mental health unnecessarily and disproportionately to the processes of relationship building and assessment typical within physical health care.

2004

- Diagnosis age seven. Autism with co-occurring anxiety impacting schooling including self-harm, hitting out at other children and frequently harming his sister from age 7-13 (approx.) and worsening with age, as his sensory needs and learning support needs were not well met. From a young age biting or scratching his own hands, avoiding eating sugar, touching dirty objects, constant hand washing, and difficulty with motor skills or self-care skills (bathroom / eating with cutlery) with age-appropriate skill. Could not read until Grade 3 (age 8) but then read texts for a 13 year old with high skill immediately.
- Beyond Autism specific challenges (which are not the focus of this account) my son suffered bullying across school life, and I withdrew him from environments and tried to find places that were a better fit. His IQ too high for specialist education settings, his social skills putting him at risk, I was frequently called to the school, and frequently met with disdain or suspicion by school teachers and school administration. I lost jobs, we almost became homeless multiple times, as a consequence of his absconding, behaviours, anxiety and school refusal, which amounted to months, sometimes 6+ months at a time.
- In the absence of mental health support for children I sought support through organisations focused on child welfare and parenting skills. I located the problem within myself, as many parents do while trying to understand what might be going wrong. I attended Signposts to develop goals for him as a child with

disability, to reduce behaviours. I developed my emotional literacy through the Emotion Coaching program at McKillop. I learned the 'postcode lottery' and moved our family home, to find suitable services. Many of these services were useful but an increase in support to our family may have improved outcomes for my son and reduced the sense of blame and guilt I held as a mother.

- I listed our family with an OT at a community health service. A year later and we weren't seen. No-one explained the purpose of such allied health supports so I didn't really understand why they might be useful. I had followed up monthly but a new worker was hired and changed the waitlist order. Early intervention supports were not as freely available then as they may be now.

2009

- Once I worked at [REDACTED] I sought an OT appointment as a favour from a new colleague, to review my son's anxiety / handwriting skills. Her single session assessment and supportive referral to [REDACTED] Outpatients clinic (our region) led to a good episode of support to build sensory awareness, a sensory profile, reduce anxiety, and find strategies for my son to manage the school environment.
- This assisted greatly for about 6 months however my son's needs and home based behaviours were worsening. After absconding after school the school principal called Child Protection rather than inviting me in for a discussion of the difficulties we were having (and which were longstanding). The school supported with Ardoch Foundation support – coffee and chats. While well meaning, this felt tokenistic and I was encouraged to consider anti-depressants myself. This reveals a pattern across my son's life of services identifying the acute stress I was under, and rather than addressing the gap or referring or suggesting appropriate services, pathologising me as a mother for the experience we were having. I presented as coping 'well enough' meaning I didn't wear track pants and spoke well, and so our family slid under the radar as being near breadline and going under. I had never, at this point, received or heard of respite.

2011

- I sought support from McKillop Family Services (disability services) and the Great Breaks program and Sibs (sibling) program were a lifeline. I connected with and worked for Carers Victoria, also a lifeline. Flexible respite included a massage for me, acknowledgement of my role and the significance of our challenges, an activity to reduce stress for my daughter (dancing – not education related but building her self-esteem) and respite workers through HACC for my son. Finally someone was listening to our situation.
- After much advocacy I received support for behaviours of concern – received a DHHS Disability Services Case Manager, BIST team support (CBT was unhelpful) and was then referred to Affirming Families at Melbourne City Mission. The worker was down to earth, with life experience coupled with superior academic expertise in Autism and mental health. To this day, we have maintained a connection with this worker and she remains a valued and trusted person in the care team.
- I self-referred our family to CAMHS [REDACTED] for behaviours related to self-harm and harm to others. Thus began the rounds of registrars changing every 4-6 months, explaining our family situation over and over again that continues to this day, nearly a decade later. The boundaries changed and we were moved to [REDACTED] CAMHS.
- We used [REDACTED] to smooth education-related issues including the lack of awareness of anxiety in Autism which led to my son leaving school at lunchtime daily. The school never notified me that he left. I learned that he hid under the table in year 7 in French class, and instead of an alternative education approach he was playing cards each week with the Chaplain.
- We (myself and health services) were resolving issues such as behaviours linked to getting out of the house, getting to school, travel training, staying at school, anger and self-harm after school, going to bed at the wrong time of day and waking at 3am, and harm to himself and others. I was also working three days a week and trying to parent my daughter.
- At one point, in exhaustion, I thought I had a heart attack and called emergency respite. They couldn't attend quickly enough. I called family to come from across town – luckily I had that option but they were rarely involved as supports. I was taken to hospital and had a CT scan. When it was found this was possibly a

panic attack or absolute mental breakdown, I was sent home without any plan for how the strain might be reduced. However it did help me to advocate more strongly with disability services and we accessed \$10k per year toward respite funding (CYP respite package) to supplement my role and the supportive, skilled worker at Baptcare was a lifeline at this time.

2012

- We took a family holiday to Queensland. My son pulled a knife on me, a terrifying situation for both of us. He was acutely distressed and in retrospect was presenting unusual symptoms. He was in year 8 and before long totally school refusing. My son was in bed for 6 months with anxiety, punching brick walls with his fist to the point of needing emergency department and stitches, breaking windows and hitting himself with wooden spoons and stabbing himself with sticks. I was left to problem solve education and health options largely alone – no warm handovers or connected up services. His school had a patronising, shaming approach that excluded not just my son but our whole family. This school was considered a leading and ground-breaking public school in the inner south region. I had tried to seek aides, or reasonable adjustments, from when he was in Year 7 but there was no action.
- Police involvement became more common. In the middle of the night my son would run off. If we tried to have a respite break away, invariably we found ourselves at the local hospital, or with police involvement as he ran off or threw furniture across the room. I was concerned that my son was seriously distressed and I couldn't find the type of support and consistent interest to reduce harm to him, and my daughter's needs were severely ignored at this point. Her school started asking her questions, and she became mistrustful of institutions as she sensed they did not understand and were trying to understand the family picture without directly asking me as her parent.
- While working for [REDACTED] I asked the staff in the mental health services area supporting mental health carers if I might be able to seek support there. I was told that my circumstances fit the 'disability' aspect of the service, even though they only anecdotally knew I was a mother of a child with Autism and hadn't sought further information, including of the family involvement with forensic services. I didn't push that as the staff member I spoke to was in management while I was in a less senior role. I couldn't understand why being involved in CAMHS meant less than adult service involvement or why support would be less to families of younger children with mental health needs. When my son did have early psychosis in 2013-14, these supports were no longer available. The services that existed then are now decimated. Families are currently fending for themselves.

2013-14

- My son's disordered thoughts were increasing, and he was frequently urinating outside.
- I realised that my home situation reflected what I'd studied in youth mental health first aid. My son was wandering around the house in figure-eight movements, slept on the couch for the week, and wasn't eating. I recognised these as indicators that he was trying to communicate something. He seemed very unwell. He fell short of saying what was wrong even though he hovered nearby.
- Concerned, I asked directly if he was okay and he slowly shared disordered thoughts he'd had that pointed to auditory and visual hallucinations. I was on alert for this due to the family history and when I called paramedics they were concerned to find he had a plan to suicide and a location in mind.
- He went to [REDACTED] Hospital and was admitted in the middle of the night. I went too, to settle him in. He was 15. I asked of the nurse, the process from here – was there a time I should call or come by in the morning, what happens now. The response was devoid of emotion, and I didn't even receive a brochure about the service. No one asked about his disability specific needs, or what may make him comfortable or about his routines. The service did not recognise that as a mother I too felt the pain of his illness and distress. It was terrifying leaving a child with additional needs in that environment without a knowledge of medical process, routines or available support. I was not linked to a carer consultant and learned of these services years later.

- I was not contacted to discuss his care even though I did meet with my son to take him on walks on leave outside the hospital. The process was alienating of my role as a mother and invalidating of the significant advocacy I'd undertaken over many years to support him. He returned home a week later.
- Upon discharge the clinician said that 'your son is a lovely boy' and provided a brochure for Orygen. Limited practical advice was provided, and no handover to the next service. In order to get into Orygen I stayed on the phone with an intake worker for an hour, explaining that the symptoms were indeed mental health and not Autism, and requesting diplomatically that a first appointment for an assessment be arranged so they could see for themselves. I'm not sure a less forthright parent would pass the gauntlet. They did indeed arrange the appointment and then found that yes, he had significant auditory and visual hallucinations and beliefs which sat outside the usual realm.
- We moved region as I had a new job in 2014, some distance away. Upon transfer to ██████ CYMHS they immediately implemented the very recent recommendations of medication from ██████. This was reassuring. We started our time in the region with police looking for my son overnight, including with a police helicopter after he lost his way home from school.
- Police involvement across ages 12-19 would stand at an average of 3-5 occasions a year, increasing in significance as he aged. I remember when he was 16, Police attending in full combat gear, six of them in the living room, and by that stage my son was in the shower and much calmer. I wanted to ask them to move to another space so they didn't frighten him when he got out of the shower. I recognised their need for caution but felt it wasn't balanced with a child-focused lens. I felt I couldn't ask as they were the authority. It was very difficult. I remember still the look on his face as he stepped into the lounge, the fear and shame, and I think now about how such experiences have shaped his self-image over many years.
- My son was in a specialist Autism school which better met his needs, and for a time things felt a little less shaky, or at the least, as though people were listening to difficulties while within CYMHS. I recognise though that CYMHS provided my son a consultant and myself a social worker, and so in a way it wasn't family centred practice but a way of treating him, while managing me. His Risperidone barely touched the sides. An in home outreach session would have picked up on that easily, but only one such session ever occurred and it was before he was in an acute state.

2015-16

- By early 2015, my son's ability to focus in class was diminishing and the school commented that he had not produced work at all. He had always required significant prompting, but the situation was escalating. He spent his days half naked in the backyard, urinated outside as a preference to the bathroom, made a tea of pine needles and refused to eat ordinary food, wouldn't shower, was sunburnt from hours of meditating outside, and spoke in 'tongues'. He also began to drink his urine. I was encouraging CYMHS with a change of therapeutic approach but they increased the dose. Retrospectively it seems they viewed it as Autism with a touch of psychosis until it reached a point where the psychosis was unmistakable but for whatever reason, they would not name it fully. I believe this was grossly unfair for my son as it denied him reasonable treatment options and in fact the approach to treatment did not comply with the ██████ guidelines for early psychosis. I learned about these some three years later. It has been very sad to see his skills and abilities diminish through extended psychoses that might have been met with greater compassion and urgency at that early point.
- There were other family difficulties at the time so it was a difficult period for a range of reasons. My son was transferred to ██████ – very unhelpful, not attending to his level of need and risk profile - and the wheels absolutely fell off after we relocated to the East. He had a first episode of full blown psychosis, in the midst of which a now former partner called my son a 'retard' such is the health literacy of our community, and in his manic state my son would not stop dancing all night and sweating. The CATT team were called and monitored closely for a few days on a daily basis.
- Subsequent to this he was placed in hospital at ██████ Hospital. I felt so bad about this; the adult ward was terrifying but having him supported even if inadequately also allowed me to escape a dreadful relationship and relocate with urgency.

- In short, my son's teen years were an escalating period of mental health issues leading to family isolation and ill health for all of us, trauma for all of us, financial and social disadvantage, stigma and undoing the good work we had developed to overcome barriers earlier in our family with the forensic system. Alongside this I was trying to study and reduce financial risks as a single parent. I tried, and failed, in a new and unhealthy relationship while juggling significant caring responsibilities that left me more vulnerable in a way. Support was incredibly limited to keep us safe, healthy and connected with each other as a family, and with the broader world.
- Once in the adult system at 18, my son's frustration with me as his mother (with whom he located all the cause of his troubles) led to a misread of the situation by the [REDACTED] clinic. They cut me out of early communication post-discharge, even insofar as not speaking to me by phone, or speaking to my son to answer a question instead of me when I asked 'when would the next appointment likely be' (i.e. 'am I needed to assist with transport / etc.'). I had no idea why they would be so rude, and indicated to them that MIND had just released a document regarding working with carers and families. I also shared my concern that they were modelling to an 18 year old young man that this is the respect his mother should be treated with when I was to go home with him - a 6'2" child (with Autism / atypical development) with angry and physical tendencies. I recognised the difference of the approach of the adult space but didn't expect a response so unsupportive. I was truly shocked and provided no information about the safety plan post discharge, or any information to inform next steps. Recently (July 2019) I asked my son why he didn't want me to know things at that time and he said "I just didn't think it was important when they asked me." It would be helpful for family inclusive practices to be the norm unless explicitly requested by a person with mental health issues. While my son was in a period of psychosis and distress, it may have been difficult for him to have any awareness that not having me involved in his care may be detrimental to the safety of his sister and me.
- During this period of begging regularly for the psychiatric triage to take our family circumstances seriously, my son was largely without any meaningful occupation in his life, walking in circles around a tree in the yard, howling at the moon and in broad daylight, causing concern to my elderly neighbours who, notwithstanding, were incredibly patient and kind. He was scary to be in the company of, he would snap at a whim, tensions were high in our home and my daughter frequently slept in my bed in fear. I was afraid to come home at night – home felt like an unsafe and horrible place.

2016-2019

- As recently as within the last fortnight (2019) my son admitted that during this period of 2016-17 he had homicidal ideation – which he wanted to kill me. I had no idea, no means to protect myself, and was not aware that I needed to be on watch. For the period 2016-17 we frequently had knives around the house, and my daughter and I dealt with and supported some of the most extreme ideations, catatonia, mannerisms and behaviours. We dealt with four times the usual household workload, lived in unhygienic and unsatisfactory conditions, and were ever alert to risk. I was lucky to have a police officer and a mental health nurse as a neighbour – sheer luck. Without the support of my immediate community I am not sure I'd be alive today.
- I was also responsible for monitoring what happened when he was out of my care, for example in public on transport, or at the home of other family members. I was not able to prevent him from inappropriately and forcibly kissing a woman who was a friend of extended family. This was unfortunately behaviour encouraged by family members who saw it as a game to interact with him in ways that increased risk to this girl. The lack of broader community awareness of mental health and risks associated frequently led to tensions in my conversations with extended family who minimised my risk management as overstepping, when I had a level of awareness from daily contact with my son. Some of the interactions of this period have irreparably damaged relationships with my extended family and to some extent my relationship with my parents who defended and were involved with extended family at this time.
- Upon insisting that DHHS step in, we had short term, limited case management that was supportive but was time limited. I had to discuss poor service provision by a disability service with the Disability Services Commissioner. The situation was worsening. In early 2017 I refused to take Patrick home from hospital.

- My daughter, now 17 and my son, now 21, both describe those years as a 'blur'. I discuss it sometimes to try to unpack the order or sequencing of events but we are truly so traumatised by the system that we find it hard to remember which episode, which hospital visit, which set of police came, which occasion he donkey kicked me in the stomach, that led to a refusal to take him home.
- As a mother and particularly as an adoptee, it was excruciating to advise DHHS and clinical services in 2016 that I could no longer care for my son, pleading in absolute tears for support to multiple people. I said I relinquished him in order to reduce risk to him, to my daughter, and to myself. There was no wrap around support, grief and loss support, recognition that systems pushed us all beyond a healthy point of family functioning. This in spite of being reasonably articulate, able to represent our circumstances, and having attempted to locate supports over many, many years. I know many other carers from multicultural backgrounds who are discriminated against to a further degree than even the dreadful experience I've had within this system.
- In 2016, post-discharge, my son was taken into PARC, then into inpatient services for months, then PARC, then home, and around in circles. I lost my job, faced reputational damage consequent to this, faced stigma and lost friendships, and our experience over 2016-18 included living on the carer pension and barely surviving with the costs of my son living half an hour away and supporting his life as well.
- I have not had the fortitude or time to prepare, to also include accounts of challenges within the inpatient ward for my son across 2016-7, although they are many. He had multiple inpatient stays, for months on end. I have provided an email as an appendix, outlining one such experience which resulted in a meeting of all heads of department at ██████████ Hospital. I believe that the hospital did then make efforts toward further adapted approaches to service delivery where co-occurring mental health issues and intellectual disability or Autism are concerned. I do not wish to shame or point out particular services as we have lived in various regions and have found difficulties consistent across all regions, and indeed in my work I also recognise this to be the case; that quality facilities, staffing resources, attitudinal change, family inclusive practice training, and dual disability / behavioural assessment specialisations (among others) are areas to address.
- Upon my son's acceptance into a CCU their approach to his early 'assessment' breached human rights standards in waiting for him to fall before catching him – isolating him in a unit on his own, not feeding him, waiting for him to communicate his needs when he needed prompting and much greater support. Having worked in disability accommodation services I found the approach severely lacking and frightful and added to my guilt, acute anxiety and distress. My insight and concerns as a professional and a mother were not adequately taken into account. Over the last few years I would bring groceries, clean, and called the OPA regarding rats in the house, pantry moths because of housemates' issues. So many issues and assumptions have taken a long time to reach a point of better understanding. The NDIS funding has relieved some of this direct strain but it is replaced with huge levels of administration.
- Wrong assessments of my son's capacity escalated into risks with no clear process around who is responsible for oversight of those risks – his travel on trains while in psychosis, urinating in public, blowing his nose on the general public while at the shops. Every time a new registrar begins, we start again. I have forever been explaining who my son is and I am tired of doing so.
- My son has now overstayed the typical period in a CCU and yet CCU staff have not told me what I can count on in relation to their role in finding alternative accommodation. I have directly asked them. This work is left to me. They have kindly said there is no rush for him to move on, but this does not resolve the longer term problem.

NDIS

- The NDIS process was made much easier with the support of case managers listing evidence of my son's needs. I am aware that across the system, this support to access the NDIS is left to chance and relates to the degree and quality of 'evidence' available to support the claim. It was suggested that we received a good package of care in our first NDIS package in 2018, but I have still been responsible for putting this care in place, for turning the resources into supports and individuals hired to assist him, to an unreasonable and unsustainable degree.

The review we requested (because of the lack of accommodation outlined in the package) took 6 months before being seen in a further 'internal review' assessment, and then a further 6 months before any minor changes to the NDIS package – yet again, not including accommodation. It falls to families to plead, beg, wrangle and leverage connections rather than for reasonable supports to be made available because of the shortage of appropriate accommodation options for this group.

It is a matter of urgency and putting at risk many lives, that the mental health system does not yet understand Autism with proper disability case management. The NDIS failure to understand models and individual needs within mental health is equally a challenge for families such as ours. My son now lives in sub-standard CCU accommodation, with 50 year old men, in a medical model, and I have been fighting first DHHS, and now the NDIS, for three years for a long term housing solution for him. There is no clear resolution and it is putting all of us in extreme strain to navigate without the expertise and adequate assistance in the system. I have engaged MP's about this however with Minister Josh Frydenberg as my federal representative, I have no support to resolve NDIS related issues.

Trauma and the support needs of families in their own right

I have included as an appendix one example of the kinds of experiences our family has encountered within the mental health system. It contains a full account of multiple barriers to access and inadequate service received in the mental health system, including experiences of myself and my son.

I am not sure I will fully recover from the hardened way I approach life having had such a lack of compassion and kindness during this horrific period across 2015-2018, and the extended stress over many years prior and since. My children and I have experienced discrimination, judgement, and bias due to Autism and mental health issues, and disrespect and exclusion disproportionate to the community experience afforded other interest groups. My son and daughter also have a distrust of government and health systems as a consequence of our experience of trauma within these settings.

Family services support within major mental health service providers were a supportive but underfunded support during this time of great stress. I found support groups a lifeline at first and then depressing and distressing and full of people with their own trauma bouncing off each other after a time. I eventually worked in this space but feel no current model is the ideal. Models exist to assess the needs of carers such as the Carer Star but they are infrequently utilised.

I am not able to access the carer allowance as I do not provide 'personal care' every single day. What I do provide is on-tap phone based emotional support to my son. I provide him prompting and direct other workers to know what to do daily, like a project manager and I use technology to do this remotely. I am expected to support a care team of 12+ people, which I liken to running a small business in the background of my life. I navigate services and suggest options, I advocate endlessly, I don't really sleep. I live in acute stress and worry about and research my son's housing prospects in the absence of proper support for this to take place elsewhere.

As a mother in the mental health system I am, to an extent that is unrealistic and unreasonable, the holder of the gaps of the system.

When my son visits home I am proud that he has survived and that he is on his recovery journey. I am grateful for thoughtful and experienced clinicians, and medications that have assisted to bring him to greater stability in mental health to some degree. I want to enjoy these periods of better health while he has these, and to be a mother, like any other mother – not an on-call informal support, or a carer, as I am expected to be.

We did have two excellent case managers at the CCU, and currently have a supportive person even if they have a slightly different approach. However, the whole team does not include me in an adequate way as an expert in my son's life or as an equal to the team - even though in my case I'm a trained social worker. I have worked hard to advocate a successful NDIS package for him but have had ZERO support coordination because there are no people available with the requisite skills for complexity left. I cannot find one. I am working a full time job, and a full time home life, and the demands of the caring role are unsustainable.

Risks, future considerations, and final points

I would like to have pizza on Friday night with my kids and spend quality time with them. I would like to recoup some years of memories and reframe our experience now that additional support through NDIS is available. But to do this requires that I am not still looking for my son's housing needs to be resolved, that his workers have skills and that they are available across the week. I am forever called upon as educator, recruiter of NDIS staff, administrator, manager and advocate.

The current mental health system leaves my son bored and restless, with a low expectation of his life. To create a good structured life conducive to Autism and co-occurring Schizophrenia and Tourette's gross motor tics requires more investment of time than I have available. He is forever in situations of stigma and risk when left isolated for periods of time.

Consequent to boredom, behaviours of concern are again escalating such that my son is, for example, urinating in public places. I am fearful that in spite of all my advocacy, my vigilance, my knowledge of health and bureaucratic systems, my son may unwittingly become involved with the justice system in some kind of indecent exposure situation. I am fearful that, like my son's father, this kind of intervention is the only way he might receive stable and consistent mental health support. Professionals in the mental health system are at times openly dismissive of the expertise, concerns and trauma of mental health families when we could assist them as partners in care.

I am grateful for recommendations of specialists such as the Victorian Dual Disability Service. I would like to highlight that I proactively asked for this support in 2016, and had I not known of it, I believe it may not have been suggested to me. I also wish to highlight that there is no funded support in the current mental health system to break down such recommendations into useful practical steps. It falls to families to work proactively with services to interpret guidelines, translate these into actions, and hold staff accountable to a set of goals. This work is not only sophisticated, it is intensive and time consuming and in order to be sustainable, requires some locus of responsibility with the people who daily work with people with mental health issues.

There are a lack of systems and processes to provide a true system of health support with dignity rather than a series of ad-hoc services one must scramble to uncover for ourselves. Our family account demonstrates the dual disability family experience. There is a need for increased access to specialised behavioural assessment skills in psychiatry and clinical service models. The different support needs across the life span could be better acknowledged and addressed – particularly at points of life transition.

I cannot concurrently work, sustain parenting another child, and be called up by professionals daily, weekly even, about matters that should be contained within a clear set of processes just because I have expertise. I have the same 24 hours in each day, as any other person. I want to be involved but in ways that allow an age-appropriate approach and that respect my need to fulfil other roles across my life. My daughter, in particular, has sacrificed much as a sibling/ young carer in this situation. Our family is very cut off from extended family and friendships in managing this life.

I have had 20 years of caring for my son in the disability and mental health systems. I refuse to become a homeless older woman as a consequence of poor policy of successive governments. I must work: **the 1950's dream / myth of the neighbourhood of women available to stay home and care for every family member for free must be sincerely scrutinised for the exploitation that it is.** Yes, some men are in caring roles and contribute greatly, but this is an undeniably gendered issue.

I greatly appreciate the opportunity to share our family story. I hope that it may shed light on some of the themes of family challenges; overwork, risks to carer health and wellbeing, lack of connected up services, lack of rights for carers to outline limits to their role in ways acceptable to them, and the intergenerational trauma of a system failing to address increasing need.

Sincerely,

[REDACTED]

Further context to attached email (see appendix):

Following this episode within [REDACTED] [REDACTED] health declined further. In a subsequent inpatient stay he had a forcible PRN administration in seclusion which he still describes as a triggering event three years later. It occurred a day after I meekly asked his keyworker / nurse if she was aware of the OT report written up in his previous admission as it may assist with recommendations for his sensory needs. She ignored my suggestion and the following day a very typical Autism physical behaviour Patrick has for self-soothing, which is to hit his own arm, was seen as a high risk situation and wrongly handled.

DHHS provided a short term case manager toward late 2016. Just as we were starting to bring together a team approach in disability and mental health oversight with all care team members in a communication loop, we were transferred from this good support to a DHHS 'long term team' intimating that he would be supported to apply for the DSR housing register. This never took place, the absence of which application has meant no end of trouble in the NDIS to substantiate a right for transfer of accommodation into NDIS Specialist Disability Accommodation.

DHHS effectively disappeared from the scene once the frequency and length of his hospital inpatient stays gave them the political opportunity to state that the primary difficulty was Schizophrenia, not Autism. This has been a political football since about 2014, and my NDIS Review of a Reviewable Decision in August 2018 was not heard until January 2019, with a new plan not written until June 2019, and this plan does not include SIL / SDA. It is not mentioned, not even in the subtext, however I am asked to work with a Specialist Support Coordinator (I can't find one) to AGAIN address housing needs with them rather than have funding named in the NDIS plan. Clinical Mental Health services are playing no significant role in advocacy or administration of this, outside of the possibility of a letter of support in coming months.

The states and territories and the Commonwealth would do well to resolve the impasse of mental health as a priority group for housing and I am hopeful that the joint Productivity Commission results and that this Royal Commission will provide not just hope and promises, but much needed resources to this space.

Appendix

From: [REDACTED]
Sent: Thursday, 11 August 2016 11:04 PM
To: [REDACTED]
Subject: Formal complaint - mental health services, [REDACTED]

To whom it may concern,

Re: Admission / Mental Health Services experience

Complaint from: [REDACTED] – parent of [REDACTED]

Address: [REDACTED]

Phone: [REDACTED]

I am writing to provide a formal account of my concerns about gaps in organisational process, in recent exposure to [REDACTED] mental health systems in support of my son [REDACTED] who has a primary diagnosis of Autism and recent diagnosis of Schizophrenia. My son's name is [REDACTED], aged 18 years, who was admitted with a first significant episode of psychosis. DOB [REDACTED].

This complaint has been slightly delayed due to continuing challenges accessing appropriate community supports, including incredibly limited support around discharge planning to ensure my son's safety upon his return home next week. In all, my son has been in hospital ([REDACTED] Inpatient, Ground Floor) 3 months, followed by a further 28 day stay in [REDACTED]. He also previously had a PARC stay in April 2016, and CATT team support variously between each inpatient episode.

The points of your organisation that we have interfaced with:

- [REDACTED] Mental Health team
- [REDACTED] / CATT team
- Mental Health Inpatient ward ([REDACTED])
- [REDACTED] PARC

I would summarise the key challenges as: communication challenges at initial triage / intake, lack of consultation with family in cognisance of [REDACTED] interdependence with family at age 18, lack of understanding of how to respond to disability specific need at various points of interaction, including ZERO discharge planning to support him within the community upon exit from hospital and limited discharge planning / awareness of his disability specific needs upon exit from PARC.

Some instances of our interactions:

- Dismissive attitude at an initial triage point, upon calling distressed by my son's decline. The Mental Health Triage nurse advised me that I 'must have some resources, you've been doing this for over 10 years'. Inadequate triage around risk, direct questions to determine disability vs. mental health need, and assumptions made that the concern was Autism alone and not mental health. Patronising and condescending tone requiring significant advocacy to get past to real listening of the core health issues. This was not only distressing, but also created a barrier to accessing service.
- An inability for staff ([REDACTED], acute inpatient) to recognise and be resourced to support disability specific needs appropriately within the mental health space. This lack of resources evidenced by lack of prompting my son appropriately to support self-care, showering, and at times he would wear the same clothes 5-6 days in a row. While I acknowledge the chaotic presentation of certain individuals I can distinguish that this related to a lack of appropriate prompting to assist him to meet his own self-care needs, due to a lack of appropriate staffing ratio. His disability specific needs were entirely missed within this space and it fell to the quality of his relationship with particular nursing staff to manage this. They did their very best, however there was a lack of coordinated approach to his support. As I couldn't go in his room, I couldn't provide additional support which was very distressing.

- Theft of personal items – a weighted blanket worth \$200+ and a phone. A person with disability requires additional assistance to manage personal items in a chaotic space. Without family support to go into a bedroom, tidy, take things home, this is next to impossible.
- Misreading of behavioural cues, such as tics (Tourettes) which, in spite of information provided by myself (██████████ mother) to confirm they were longstanding, and lifelong, were medicated without consent by medical staff out of a concern they may be a grimace with a medical basis. ██████████ has had tics since early childhood and the particular tic described was known and familiar.
- Emphasis on accommodation options rather than on overall wellness from the Community case manager (██████████) in a prior PARC stay (April 2016) which was prompted by ██████████ comments that he wanted to leave home. (these may be deemed typical ‘teen wants’ rather than something to action as a matter of health priority). These notes entered into the CRM system resulted in a disrespectful and inappropriate discussion of housing for ██████████ in the first family meeting with the clinician in the inpatient unit without consideration of his age, his interdependence with family and the purpose of his hospital stay, which was to assist him to manage psychosis and alter medication to improve his wellness.
- In several instances I experienced workers excluding me from case meetings, or having a ‘blind spot’ around including family / carers. They would then claim, ‘oh it wasn’t a case meeting, we all just needed to discuss what he was doing this week’. Yet the room was filled with carers, clinicians, case managers, etc. (PARC) At times they were dismissive toward me, wouldn’t provide accurate information over the phone about his wellbeing, and I would discover he had scratched his arms in distress only upon arrival to the ward. (inpatient ward)
- A lack of youth focussed support, or skills from staff to approach youth early psychosis sensitively and in a plain-language approach for ██████████ to understand, given his additional disability needs. A lack of basic ‘mental health 101’ to disclose the diagnosis sensitively to ██████████ with his family present. I believe he was told without me there. If we went to hospital and learned the diagnosis was of a physical nature, it wouldn’t ‘accidentally’ be shared, or be shared in a letter from a secondary consult team (VDDS). This has been our experience.
- ██████████ was discharged from hospital by being told he could ‘go now’ – he walked mid-afternoon unaided. He felt rushed, ‘influenced to go’ and didn’t have money or anyone to support him. My understanding is that this represents gross absence of procedure on a number of levels, including not adhering to PARC’s requirement that he arrive with his clothes and resources for food / money etc. I would be happy to speak further about this specific incident as there were a number of breakdowns. ██████████ walked to PARC, alone, with a book and his medication, up ██████████. He didn’t even have a tram fare. This alone is worthy of an in depth investigation. I believe some undertaking has been done, and I would be interested to have a meeting to discuss this specific situation.

I have encountered so much in the last 4 months that has been painful, dismissive, a barrier to quality service, disregarding my own personal journey of grief and loss and coming to terms with ██████████ journey as a mother, and in watching him be shunted around and supported by 2 clinicians and 2 registrars within his first 3 scary weeks in adult inpatient service, that my sense is that a complete process overview is required where supporting people with additional disability specific needs is concerned, within the ██████████ mental health space. I have experienced a shaming and excluding process which did not, in the main, involve me as a participant in my son’s medical care. My expertise in supporting him with Autism since diagnosis at age 7 was dismissed, as was any of our previous experiences with youth mental health services, ██████████ history of having a father with paranoid Schizophrenia (and my experience of this and trauma surrounding this). The hospital could do much to adopt a trauma lens and to consider ways to adopt a youth focussed frame even within the adult space, where young

people under 25 present. Excuses within PARC at times included ‘the systems just don’t work well together’. I think it is important to explore whether attitudinal barriers exist, as much as professional development barriers.

I am presenting this information in a fairly curt way because at this point, I am battling to save my job at the same time as trying to ensure the best care for my son, as a consequence of the degree of stress I have been placed under in interfacing with multiple systems to support [REDACTED]. I am also the person my son is most likely to act out toward, as a consequence of his frustrations and ill health. Our whole family encounters this illness with him, and our life options and capacities are limited as a consequence of an ongoing advocacy battle to ensure dignity and choice are in place for him.

What would be helpful:

- The triage experience where risk was dismissed and I hung up in tears, unsupported, which resulted in CATT team and also Police at my door. Due to the lack of listening of the staff member, it resulted in an escalation of the situation at home. Listening, validating, calming the circumstance are important skills to ensure a person feels safe to outline the mental health symptoms they are observing to ensure safety for all. Assuming the symptoms are part of a broader Autism picture is dismissive and potentially puts an individual and their family at risk.
- [REDACTED] was admitted to the acute inpatient unit within 7 days. At the time of dropping him off it would have felt supportive to have a brochure, some guidance about what might happen in the morning when he wakes in the strange environment, or some sense of the hours of day I was welcome to visit. It was a very painful experience to leave a young person (my child) in such a place.
- An initial meeting with a worker to ‘induct’ me as a family member visiting for the first time. I felt very out of my depth, but would act in a happy way so as not to upset my son. I really had no idea what was going on.
- Where possible, clear plans for discharge giving notice to a family member 48 hours in advance. If this is not possible, advising the discharge process so that a family member collecting someone understands that discharge may happen at any time, and to clarify emergency contacts in the event they are not available. In my case, a phone message was left at 4:30pm Monday afternoon by the registrar inviting me to call if I had any questions. I didn’t get the message. I had called at 9:30 am that day, asked directly whether [REDACTED] was likely to be discharged, with a negative response. I also called at 8pm to speak to [REDACTED]. I wasn’t advised that he would be discharged when I called on either occasion. While this is human error and not intentional, it links to processes being insufficient where dual diagnosis is a component of the presentation. A nurse called at 10am on Tuesday, the day of discharge, but I was in a day long plenary at a conference unable to check my phone. I found out about [REDACTED] moving to PARC by visiting the inpatient unit, finding him gone. If I wasn’t available to take him, an emergency contact should have been called. I expressly requested that I be the person to take him, and this was not honoured.
- Within PARC, the emphasis is so much on person-centred approaches that family are excluded from the conversation at times. Where dual disability presents, this presents a risk of gaps in the scaffolding provided for participation in daily activities and life skills. Inviting family to list areas of skill and areas of need where disability exists would be more acknowledging of their role, in an intake process. This is done loosely, but recognition of disability-specific need is misread as ‘lack of motivation’ in this space. Where the support is offered, a person will and can participate. Professional development from Autism / behavioural specialists to convey ways that people with neurodiversity may present and require support could assist with knowledge gaps.
- Discharge planning for dual disability includes thinking about the sustainability of home but at a pace family are ready to discuss, in order to be respectful. It is a very Western construct that ‘everyone leaves home at 18’ – young people today may stay home until age 25+. The only impetus to move a young person

with dual disability out of home, in my view, is if home is not sustainable, due to behaviours, or if the community can't offer supports at an appropriate level and these are more readily offered at the moment within a CCU (a construct which, in itself, limits choice). Timing, pace, style of this discussion is very important for it to be supportive and not forced. It is very painful to think about sending one's child away, when ones entire existence has been wrapped up in their care for 15+ years. Policies and procedures could better consider this and consider how to bring clinical knowledge and knowledge of the system to a family 'where they are at'. Greater knowledge of family systems, soft skills would reduce trauma for all concerned.

I wish for this information to be used constructively to support systemic development within the hospital. I would appreciate a meeting with the managers of the inpatient unit, with an apology and explanation for the way in which my son's discharge planning was handled and his transfer to PARC. It is sheer luck that he did not end up in harm's way.

I look forward to your response. I may be contacted for further comment or to glean dates / details as required.

Kind regards,

[REDACTED]

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