2019 Submission - Royal Commission into Victoria's Mental Health System

SUB: 0002.0030.0278

Name
Anonymous

What are your suggestions to improve the Victorian communitys understanding of mental illness and reduce stigma and discrimination?
N/A

What is already working well and what can be done better to prevent mental illness and to support people to get early treatment and support?
N/A

What is already working well and what can be done better to prevent suicide?
N/A

What makes it hard for people to experience good mental health and what can be done to improve this? This may include how people find, access and experience mental health treatment and support and how services link with each other.
In my submission I have focused on adults with ASD Level 1. Refer to my submission for recommendations towards overcoming the barriers and helping this group achieve good mental health In this area most adults with ASD level 1 are undiagnosed though they constitute the largest proportion of people with autism.   Because most ASD adults are undiagnosed there is no adequate information to identify adequate service levels for the condition. The number of mental health professionals particularly psychiatrist and psychologists with the skills to assess to diagnose adults with the condition is extremely low. Assessment in the few private clinics is seen as very expensive. There are no publicly funded services for adult ASD diagnosis and assessment or support services to help manage the condition. Generally mental health professionals have no understanding of ASD. Hence they do not make appropriate referrals for assessment or make appropriate allowances for the nature of the condition in their patients' mental or physical health

What are the drivers behind some communities in Victoria experiencing poorer mental health outcomes and what needs to be done to address this?
N/A

What are the needs of family members and carers and what can be done better to support them?
Autistic adults with autistic kids need to be aware of their ASD status. This is the start to improved spouse and family relationship as well as increased understanding of their autistic offspring. They need a substantial increase in diagnostic and assessment services so that appropriate supports can be provided for their parenting/caring tasks as well support with vulnerable spouse relationships.   The ongoing role of many parents as carers for adult ASD offspring needs to be acknowledged From our perspective many of our mental health issues would be reduced if our

daughter received the supports with daily functioning that she needs to function as an independent employed women with generally positive sense of well being. Other carer support needs relate to having more than 10 Medicare subsidised counselling sessions under mental health plans. Burnout in carers leads to disproportionate mental health responses such as with anxiety. Support with coping is a constant issue

What can be done to attract, retain and better support the mental health workforce, including peer support workers?
N/A

What are the opportunities in the Victorian community for people living with mental illness to improve their social and economic participation, and what needs to be done to realise these opportunities?
N/A

Thinking about what Victorias mental health system should ideally look like, tell us what areas and reform ideas you would like the Royal Commission to prioritise for change?
My submission outlines recommendations for change in relation to adults with ASD and urgent needs to expand services for this group

What can be done now to prepare for changes to Victorias mental health system and support improvements to last?
"Develop a mental wellness framework for Victoria's mental health system. This include expectations about the level of services Victorians can expect and the universal rights of individuals to achieve their potential and have as good a life as is possible but a philosophical shift towards increasing opportunities for individuals to maximise their rights to respect and dignity If the values framework is sound enough and comprehensive enough it should help sustain adequate policy and services into the future. The style of the NDA framework for recognising individual rights to resources so they can be part of and contribute as members of the community rather than as bottom feeders on government funds, suggests a possible approach to a framework for mental health. As with establishing the NDA I see the biggest barrier to a continuing adequate mental health system is in the change needed in government funding thinking so that improved mental health in the community is seen as contributing to improved economic and social outcomes. Prevention and support reduce the long term costs of chronic mental illness and personal dysfunction as well as improving general mental well being. "

Is there anything else you would like to share with the Royal Commission?
As a family we appreciate the opportunity given by the Victorian Government to share our concerns and priorities about mental health issues which we experience every day at some level.

Submission to Victorian Royal Commission into Mental Health

Autho[redacted]. *Editors and Contributors*: [redacted],
[redacted]; [redacted] (Hons), Masters IT

Our mid thirties daughter has been involved in preparing this sumbission and is also happy with publication of the material with any names redacted.

A note from the Autistic Daughter

I have asked my Dad to prepare this submission on my behalf. I am currently working 4 days a week and have very limited personal resources to write my own submission. I have read and edited Dad's work and support what he has said. It is important to hear Autistic voices, so I believe my voice should also be heard in this submission. My father is also Autistic although we have not had a formal diagnosis due to his age (73) and the expense.

Although Dad has chosen to focus on the challenges of my Autism which plays into the "Autism as Tragedy" narrative common to many parents of Autistic children, I would also like to point out that my Autism also gives me the skills which I use daily to be brilliant and very fast at my job. My manager is often impressed that I operate at a much higher level than he would expect for a junior. It is hard for me to remember this praise in the middle of a meltdown when I am so upset and angry about my ability to cope with life and my lack of access to adequate support that I never want to leave the house again. I'm working on it!

Focus on Adults with ASD Level 1

The focus for this submission is on adults with autism particularly those with Autism Spectrum Disorder Level l under the DSM 5. The body of the text below provides a case example to give substance to the sorts of difficulties experience by the ASD Level 1 desriptor 'Requires Support'. Social media and other documentation provide many examples of similar impacts on daily functioning.

The submission includes two additional attachments which document related issues related to autism in our family. These are:

- **What's it like to parent an autistic girl?**
- **What are your experiences with being married to someone who is on the autism spectrum?**

Key Assertions

Key assertions behind the submission which may not have been conclusively supported are:

- Providing adequate and supports for adults with ASD Level 1 (requires support) would have a major impact on positive mental health outcomes for many Victorians;
- Autism in adults, particularly women, is substantially undiagnosed;
- It is strongly probable that hundreds of thousands of Australians have undiagnosed ASD, Level 1 and that the vast majority of those with ASD would qualify for Level 1 assessment;
- Level 1 ASD diagnosis recipients are classified as 'Requires Support' Many of these lead fairly dysfunctional lives and require significant support to enjoy better mental health outcomes;
- Autism is frequently a family affair causing challenges for parents/carers but also major issues for Aspie and non Aspie spouses as well as their offspring;
- There are no publicly funded adult autism assessment and support services in Victoria;
- There are several private private clinics where most adult referrals arise when parents seek a diagnosis after their child is diagnosed with autism;
- Mental health professionals and general practitioners have virtually no understanding of Level 1 ASD this leads to few referrals for assessment even if the services were available;

- There are very few mental health professionals with the skills to assess and diagnose ASD in adults. This skill is developed actually working with ASD people. Neurotypicals are mostly on a different wave length without this;
- ASD is not a disease, it is a permanent neurological condition. It means impairment some areas of daily functioning;
- ASD is a functional (sometimes hidden) disability impacting significantly on capacity for daily functioning;
- ASD is frequently associated with mental health comorbidities such as anxiety and depression in addition to other neurological conditions like ADHD and learning disorders.
- Any program proposals being developed need broad consultation with autism and service provider stakeholders. People with autism provide the best guide for services they need.

Key Recommendations

These are included here rather than then at the end as they are reflected the key assertions above.

- Further explore the numbers of adult Victorians with ASD level 1 with sufficient detail to establish potential diagnosis and support needs. The Autism CRC may be an appropriate agency for this.
- Develop a program for the ongoing development of a comprehensive adult autism diagnosis and support system in Victoria, developing resources in both the public and private sector. Such services to be regionally accessible.
- Establish at least one publicly funded adult ASD diagnosis and support service as an interim step towards a comprehensive system.
- Explore and develop training/education options for a work force of mental health professionals with the specialised skills for diagnosing and assessment of adult ASD. (This could include schools of psychiatry and University Schools of Psychology.) New services could be used as a resource in training new assessment and diagnosis professionals.

- Work with mental health stake holders and ASD educators to develop a program to educate all mental health professionals and General Practitioners about adult ASD level 1 particularly in women, to a level that they can make appropriate referrals for assessment. This will also enhance their capacity to take account of autism needs in dealing with health and mental health issues, and improve mental health outcomes for autistic people
- Develop a specific strategic policy within DHHS concerning the goals and implementation of assessment, diagnosis and support services for adults with ASDE level 1 with particularly focus on the needs of women with the condition. This policy to reflect the high level of difficulty with daily functioning needs of adults with ASD. This needs to draw on and supplement the Victorian Autism Plan currently being finalised.

The nature of ASD Level 1 Support Needs

It was only last year at age 34 that our daughter was diagnosed with Autism Spectrum Disorder (ASD) Level 1.

Under the DSM 5 diagnostic criteria, Level 3 applies to those ‘requiring very substantial support’, Level 2 – ‘requiring substantial support’ and Level 1 – ‘requiring support’.

The very large majority of Autistics are assessed as Level 1. Limited research has been done on the incidence of ASD in adult Australians however, with more thorough assessment of school children, the incidence in this population is shown as 1 in 36 or 2.8%. NDIS recipients in 2015 were around 43,500 with 80% of these aged under 25. The very large majority of NDIS clients are at Level 2 or 3. In the 2015 census 164,000 Australians (1 in 150) were identified as Autistic, suggesting the large majority of those had been diagnosed at ASD Level 1. https://www.aihw.gov.au/reports/disability/autism-in-australia/contents/autism

As a neurological and predominantly genetic condition Autism is lifelong and provides benefits as well as challenges. It is not unreasonable in the absence of other adult data that the 2.8% figure can be extrapolated into the adult community.

It is well recognised in social media and the literature that ASD is largely undiagnosed in Australian adults. Most adults currently seeking ASD assessment do this after their children are diagnosed. The dearth of understanding of Autism among health professionals such as GPs and even Psychiatrists means few adult referrals for assessment, masking the extent of ASD and mental health difficulties in the community.

Underdiagnosis of ASD is particularly relevant for women as it has only been realised in recent years that their presentation is often significantly different to men as they mask or camouflage their social difficulties using learned social responses to avoid appearing different. This is of course very tiring reducing energy to manage other aspects of their lives.

Our Daughter's Situation

I will explain what our daughter's daily life is like to identify what 'requiring support' under Level 1 ASD means for our daughter.

For our daughter, ASD is a major disability affecting all areas of her life. It is a constant struggle for her to cope with aspects of daily living whether at home, at work or with social activities. Although she receives some meaningful supports from a psychiatrist (with medication) and from a psychologist (with helping her understand her condition and learn how to manage it – a slow incremental process), she also needs other supports related to employment and managing daily activities of living. This includes support with making decisions about her routines, strategies to maintain focus so she can organise to get herself to work on time, as well as help with household tasks like decluttering and cleaning.

Her physical, mental and emotional resources are significantly limited. For her to have a reasonable life, maintaining employment and living independently some of the pressures of daily life need to be reduced.

Barriers to Her Mental Health

Our daughter has considerable strengths and abilities. In the following section I mainly want to focus on the barriers to her being able to improve her mental health.

Putting aside her diagnosed mental health conditions of depression and anxiety which are to some extent managed by medication but are an integral part of her other difficulties, she has several key difficulties particularly related to difficulties coping with the functions of daily living.

There is some good research showing this is common in those having ASD, with daily functioning levels well below relative IQ levels. Although the study focused on children, when applied to adult related functions of daily living, the study is informative about the coping skills of adults with ASD. https://www.spectrumnews.org/news/large-study-supports-discarding-term-high-functioning-autism/?utm_source=Copy+of+Spectrum+News+%28Daily+Report%29&utm_campaign=e8af07e948-EMAIL_CAMPAIGN_2019_07_02_05_52&utm_medium=email&utm_term=0_5d6f652fd5-e8af07e948-168673977

For our daughter specific difficulties include:

- Difficulty setting her own limits in daily life. Applies at work if clear directions and expectations are not available adding to anxiety and uncertainty; applies at home with difficulty in things like routines for getting out of bed and getting to work.
- Hypersensitivity to stimulating environments limiting the time she can cope with these. She wears noise cancelling headphones on the train or in pubs with friends; at parties. Without the headphones she would be unable to catch public transport and couldn't work. She can't cope with the noise of a vacuum cleaner so cannot clean her home. Overstimulation is a major drain on her daily energy resources.

- Masking or camouflaging of discomfort in social situations and using learned responses to avoid being perceived as awkward or weird – another high-level demand on energy resources and a pattern that is common in Autistic females;
- Constant tiredness because of difficulty getting to sleep and establishing good sleep patterns, often accompanied by difficulty in winding down after the stimulation of the day's activities.
- Difficulty starting tasks, difficulty stopping them. It is harder to leave work when involved in a project; hard to stop a pleasurable activity; harder to get out of bed.
- The challenges of having a balanced life can be overwhelming. She has difficulty with the decision making process to achieve this. The big picture is impossible to separate from the immediate demands of the moment;
- Because of executive function deficits a task like tidying her room is overwhelming as it requires step by step decisions about what to do next. She does not have this skill. Her mother has always provided external help with such tasks ('requires support') By contrast if a task is in sequential steps like knitting a garment or computer programming, this is not an issue.
- Difficulty with emotional regulation. This exacerbates negativity, vulnerability and feeling overwhelmed, leading to very low self-esteem and self-confidence;
- Melt downs. These may involve uncontrolled crying, angry outbursts, panic attacks, and dissociation. Melt downs are usually related to emotional and physical exhaustion or stress levels becoming too high.
- Her mother describes times when our daughter digs herself into a hole, where she is in a state of inertia; unmotivated; and extremely negative ('I don't care anymore!') including in relation to her job. That's when her mother must try to help her dig herself out.

These difficulties give an indication of areas life where she 'Requires Support' under ASD Level 1.

Employment

Having done further study in IT in 2017 and 2018, our daughter applied for graduate positions with IT firms. She was offered positions with three different companies. She faced the frequent dilemma of whether to disclose her ASD status. Her difficulties in making a choice led to a period of intense anxiety but finally she opted for the company that was aware of her ASD status, had provided an Autism appropriate assessment process, and had engaged her Autism employment agency to support her transition into their work force.

Her ASD support needs related to requiring an under-stimulating work environment, not being given clear directions and expectations, being isolated and not connected to work colleagues, and not being involved in meaningful work. She required support to ensure from he manager and colleagues so she could function in the work environment and be valued for her strengths and skills.

She has now been with a firm for seven months. In terms of what she has faced she has shown remarkable resilience to stumble her way through, but with lots of support from us, helped by our own understanding of large organisations and her particular support needs.

For most of her seven months she was given no clear direction and no projects other than a couple of contrived tasks. She was told she should do online learning but given no idea of what skills she should develop. Most of her colleagues were working at other sites so there was no problem with an overstimulating environment (no one to talk to). Her social needs were largely unmet, as those in the office took months to engage with her. She was the one expected to engage with other staff.

Her manager does not really understand what she needs by way of structure and support. The firm engaged an Autism employment agency. She was given some emotional support by the employment agency; however the consultant was unable to give adequate practical support or to change her manager’s behaviour. It can be noted that employment agencies like this cannot access Government funding except through the NDIS and most Level 1 ASD adults cannot access the NDIS. She has had to self-advocate and train her manager about the nature of her skills and support needs.

We, the parents are her main support which, at times, strains our spouse relationship. She continues to experience high anxiety about what failure to become established in this job would have on her future employability. This is a critical issue for her mental health. (Carers also despair frequently.) She has needed help to dig herself out of many holes since she started this job. We have received weekly teary phone calls where she decides to quit, and we must talk her out of it. These calls involve tears, anger and frustration as to why she is not adequately supported in this job. If she did quit, it is likely that she would not find another job and would spiral into a depression which may last months or years. This has been the outcome when she has been rejected from other jobs in the past.

Over the last months or so she has been able to contribute effectively and usefully in some small projects largely using resources she has managed to identify and obtain for herself. She has finally become involved in a project which she helped the firm obtain though only for one day a week. She has been told to take the role of consultant for this project! Ironically her manager says she performs well above her weight (she is a level 1 Analyst) and in view of her performance her manager cannot understand why she sees herself negatively. (The hidden disability conundrum.)

Consequence of Not Having an ASD Diagnosis

The part of my submission headed W*hat 's it Like to Parent an Autistic Girl?* focused on the destructive consequences of not having a diagnosis of ASD. Our daughter's worst mental health issues started in the final year of the combined science engineering course she started after high school.

She started on an Industry Placement which was expected to continue for the whole year either as an internship or a part time job. Things started to go awry in the latter parts of the first six months.

She has reflected on this experience and what her mental health may have been like if she had had her ASD diagnosis at the time. It speaks to the high importance of adult diagnosis of ASD level 1 as the basis of providing appropriate and adequate support.

> 'Initially I enjoyed the work but eventually I became burnt out. I continued to turn up to work but didn't do anything. At this time my psychiatrist misdiagnosed Bipolar Disorder and put me on Valpro which made me like a zombie. No one was able to take account

of the overstimulation, masking, organisational difficulties and the exhaustion these caused in a full-time job nor the difficulties I was having with public transport.

The result was that the Industry Placement was terminated and I was not able to get the job I had hoped for. I was devastated. This was the start of 13 years of severe mental health issues with which I am still struggling even though the reasons have become clearer since my ASD diagnosis in 2018.

I am angry and frustrated at all I have suffered because of not being diagnosed with ASD and damage done by inappropriate psychiatric diagnoses.

My life would have been a lot different if my ASD issues had been able to be managed, like the energy demands of overstimulation and social masking, organising to deal with public transport, help with the extra anxiety of changing from studying to working in my Industry Placement.'

What’s it like to parent an autistic girl?

[redacted], Social Worker and Aspie

Rewarding, challenging, exhausting, vexing

INFANCY
I still remember the loud screams when she had her first post birth bath, not happy with subtle change in temperature. That was the start to rearing a very sensitive colicky baby who was otherwise easy to love but leaving my wife exhausted particularly for the first two years.
This wasn't helped by my own undiagnosed ASD particularly my mind blindness about what my wife was going through and the resultant inadequate support.

EARLY CHILDHOOD
Though a bit slow at walking she was a bright little thing, learned quickly, was very interested in what was going on, a delight to her parents.

There were of course the ‘why can't you control your child?’ stares when she had a meltdown in the supermarket. Sufficient for my wife to pass the shopping role over to me.
Our daughter needed very consistent routines to keep her on an even keel.
In preschool and playgroups she fitted in fairly well.

PRIMARY SCHOOL
At primary school age she was highly interested in things that appealed to us such as wildlife, birds, flowers, bush camping and music. She learned about these things easily.
Being interested in nature she once carried a sheep skull back to camp. Then Mum discovered it was home to a red back spider. At another time she was quite interested in standing with her Mum observing a venomous red bellied black snake reclining in the sun.

At school literacy and numeracy were advanced for her age. We knew how bright she was. But were quite confused when in year 3 she was placed into a remedial class. This was confusing in view of what we knew about her. In year 5 she was psych tested which showed she was very at a gifted level on some measures but low on others. We now know that this typical of IQ scores for those with ASD Level 1. This also means on their have own IQ tests have limited value for assessing cognitive strengths.

At the time a friend of ours observed that in class our daughter would just be getting organised for a task when others had finished. If she had to cut items from a magazine for a project she would get distracted reading the articles and not complete the task. We also found out she was somewhat isolated and bullied at school which at the time we attributed to her advanced levels of interests not shared by her peers rather than relationship difficulties (presumed giftedness).

By Year 4 we noticed she wasn't invited to birthday parties. She had one close friend until her dependence got too much for the other girl. At this stage we started at the [redacted] Child and Adolescent Mental Health Service and continued as a family for several years. In the eighties and nineties with low awareness of female autism her only relevant diagnosis was for executive dysfunction (when 16) and learning disorder. Until very recently health professionals who knew her still did not agree to the possibility that she had ASD.

We also benefited from spouse counselling to help with managing our daughter, the stress involved, and our strained relationship linked to this stress and my undiagnosed autism.
The usual farcical possible psychiatric diagnosis, such as checking for ADHD (by trying medication), conduct disorders, oppositional behaviour disorder and bipolar disorder led nowhere. During high school years she was pretty depressed at times and sometimes had suicidal thoughts. We now know that failure to diagnose Level 1 autism particularly in girls was because knowledge of female autism was almost non existent till very recently even in publicly funded specialist child and adolescent mental health clinics with now regularly assess for autism.

HIGH SCHOOL
We were advised that selecting a high school where her individual needs would be recognised was critical. We settled on a small private girls school with a niche market for bright students. Our daughter functioned well academically. But she would only learn something if she was interested. She spent a lot of class time with her head on her desk for many subjects including history which she didn't want to learn. She was forced to sit the history exam and passed comfortably. Meltdowns in the car when picked up after school were fairly common.

We needed to maintain a strong advocacy role with the school as her particular needs were easily forgotten. Adolescent female peer intrigues were lost on her and she had limited friendships.
Singing and orchestra membership were important. She was confident enough as a performer to perform vocal solos. She still loves performing.

Having to pay high level private school fees to get educational needs met added significant financial stress for a family on medium income.

UNIVERSITY
She completed year 12 university entrance exams with very high scores and gained one of 8 Vice Chancellor scholarships to a Melbourne university. She enrolled in combined engineering and science degrees.

She did well up until the final years when she developed significant mental heath issues on an industry placement, her first exposure to a work environment with sensory overload and organisational planning demands, both areas of major difficulty. With only one final major research project to go she couldn’t complete her course or face going back to that university given the many panic attacks she was experiencing, the trauma and severity of her symptoms and the lack of support available.

This is how she describes this time:

> ‘Initially I enjoyed the work but eventually I became burnt out. I continued to turn up to work but didn’t do anything. At this time my psychiatrist misdiagnosed Bipolar Disorder and put me on Valpro which made me like a zombie. No one was able to take account of the

> overstimulation, masking, organisational difficulties and the exhaustion these caused in a full-time job nor the difficulties I was having with public transport.
>
> The result was that the Industry Placement was terminated and I was not able to get the job I had hoped for. I was devastated. This was the start of 13 years of severe mental health issues with which I am still struggling even though the reasons have become clearer since my ASD diagnosis in 2018.
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> I am angry and frustrated at all I have suffered because of not being diagnosed with ASD and damage done by inappropriate psychiatric diagnoses.
>
> My life would have been a lot different if my ASD issues had been able to be managed, like the energy demands of overstimulation and social masking, organising to deal with public transport, help with the extra anxiety of changing from studying to working in my Industry Placement.'

This started a continuing cycle of ups and downs based on complete lack of confidence, lack of energy, low self esteem, panic attacks, depression. This has been extremely stressful for us as well as we experience high levels of anxiety when she bottoms out especially as she can become suicidal. This has been a major contributor to our own mental health issues resulting in chronic anxiety disorders and burnout. Our daughter's mental health issues have been continuous from her early twenties. She is now in her mid thirties.

As parents we want our daughter to become independent, employable and have a good life. When her potential future is threatened by her immediate issues this causes enormous stress and anxiety both for her and for us due to our concern about what she is going through as well as for the future.

There is also the challenge of motivating her to get going again when her functioning drops below par while encouraging independence when her mental state and executive functioning difficulties make seeing the bigger picture and finding a way up and out of the morass of despondency appear to her to be almost impossible. We are always vexed about whether our interventions will maintain her dependency particularly because of her limits with executive functions. How do we maintain balance in our parenting role to help her become independent while sharing her roller coaster ride of despair For many years to the present this has been a continuing source of stress for us. As the primary carer and intervenor my wife in particular has needed major counselling support just maintain focus and to cope. Depression and inertia have caused our daughter to think about suicide at times so this is always on our mind while supporting our daughter.

Eventually, with a lot of intense support in developing structure inn her life, after several years our daughter progressed sufficiently to go back to another uni and completed an honours degree in science. Part of the ongoing challenge for her was completing course work when high anxiety was dealt with by procrastination, and writing essays was challenging because of her problems in synthesising the parts to get to the big picture. Our demanding support/carer role in helping her keep going, continued with this course as it did the year after she graduated and tried to get graduate positions. Supporting her in completing her honours thesis is another story.

Having completed this degree she sought employment in graduate positions. Although she was successful in getting through the assessment phase through to Partner interview she received no job offers. She other employment I this period and had a couple of short term contracts.

After major disappointment at not being being able to continue with jobs she was selected for (mainly through poor performance because of sensory overload and other autism issues), she decided to take some time out to improve her employment prospects by enrolling in a Masters in IT.

Her first year results were phenomenal and she networked effectively during the year, was selected for an internship and was able to negotiate a thesis project with a large IT firm. She was efficient at completing a demanding work load.

Unfortunately her internship didn't lead to entry into the firm's graduate program which she was desperate to achieve. This major letdown created another crisis. Her mother had suspected that her failure to get jobs was related to ASD whilst being unable to convince professsionals of this. She researched ASD and this supported her view.

Given her high capabilities our daughter has for some time questioned why she wasn't getting jobs. “What’s wrong with me?” This and he mother’s persistence has led to her finally getting assessment for Aspergers. Her history is finally beginning to make sense.

What are your experiences with being married to someone who is on the autism spectrum?

[redacted], Aspie, Social Worker (Written early 2018)

I will answer this on behalf of my wife who is the non Aspie spouse in our family. She said she would like to reply but at this stage doesn't have the energy as a result of burnout from living with an Aspie husband and our Aspie daughter. She has contributed and read this.

My wife had to contend with the Aspie double whammy, Aspie Spouse and Aspie daughter. For 34 years she has had the additional challenge of raising our Aspergers daughter. With no diagnosis until recently, our parenting role has been very challenging. The challenges multiplied in our daughter’s early twenties with major mental health problems developing. This involve in addition to depressive and anxiety disorder this involved our daughter frequently regressing to debilitating couch potato status and not being able to find any way out without a lot of help, and with her negative feelings restricting her at every turn.

Largely because of my wife’s support our daughter has moved from a state of intense inertiaand despair to graduating with honours in her science degree on her second attempt at completing a uni degree. Nevertheless, once she graduated, despite an impressive academic transcript, demonstrated people skills and an overtly friendly personality she has been unable to get work despite many successful graduate positions through to partner interview stage success. AAlthough either This may be due to some autistic presentations she hasn't been able to camouflage. We are hoping her diagnosis will help her sort this out. Even now we still live with the combined challenges of getting her remotivated after she zeroes down and can’t see a way out, and the constant anxiety about whether she will end up getting a good job and utilising her outstanding abilities – the prerequisite to having a good life.

The Double Whammy

For years my wife has been saying that she has been the carer for two disabled family members. Only after my ASD diagnosis could I accept and understand what she meant, though for a long time we jokingly referred to ourselves as a dysfunctional family. Without having an ASD diagnosis to explain it, her counsellors have for some time encouraged my wife to recognise that I am the way I am. This includes my lack of understanding of her thoughts and feelings and my poor organisational skills (like the time we were putting the car on a train for a holiday, I took too long and then had to do some repacking as there was no room in the car for my wife. We missed the train and instead had to drive to our destination In South Australia.

From birth our daughter was hypersensitive and colicky for a couple of years. My wife had to manage with poor support from me as I didn't know what she was going through. My intense interests didn't take account of family needs.

Our relationship has been tense for years, though it has improved since my wife retired and we have been able to enjoy a lot of travelling. It is of course even better now I have a diagnosis. Conflict caused chronic anxiety for both of us. Her anxiety was partly about how to deal with her confusing partner and a challenging daughter. Obviously she persisted, and very recently I have been able tell her she is an incredibly resilient women. For years we have been half jokingly saying we are a dysfunctional family.

My wife felt she was dealing with conflict all the time in communicating with me, for example if she needed me to do something she felt on tenterhooks as to how I might respond.
We both became burnt out some years ago, but particularly my wife. While still working in a stessful job she had to survive me and regularly take on the emotionally exhausting task of helping our daughter manage her extreme repeated ups and downs. Aspie husbands are not so good at this, especially with a daughter with similar traits.

While I have recovered somewhat my wife is still burnt out. This shows up with poor motivation to do almost anything and being constantly over anxious. She copes with this via intense involvement with her photobook projects (lots of trip photos) to help take her mind off her worries.

However my wife has managed very well with a an extended part of her life journey. In achieving this she has identified some key elements for surviving:

- Maintaining supportive friends and strong outside interest groups;
- Maintaining support from professional counsellors;
- Changing house keeping standards to what is achievable and thus enabling personal time;
- Setting personal limits on what to contribute to house keeping;
- Learning to state her position on something but not continue to argue it. This stopped circular conversations;
- Learning not to expect help with household projects but instead involve other people or pay someone;
- Only giving requests for one task at a time;
- Not taking the way I responded personally, which she found pretty hard when comments were directed at her;
- Ensuring she got good sleep.

The latter approaches were developed through work with counsellors.