

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

## Organisation Name

Different Journeys

## Name

Ms Melinda Spencer

## What are your suggestions to improve the Victorian community's understanding of mental illness and reduce stigma and discrimination?

"Background: Aspect Australia reported from 2018, 1 in every 70 people had Autism. There are approximately 55,000 diagnosed Autistic Victorians yet many more remain undiagnosed who urgently require support. Within this cohort between 50-70% have a diagnosed mental health condition. The statistics are alarming - many are attending mental health services without any support or guidance to manage both conditions (mental health and Autism) by the professionals working with them. Many often finding themselves labelled with another condition. Orygen have stated in literature that An audit of clinicians knowledge and confidence showed that the care of individuals with ASD and psychiatric co-morbidly was experienced as challenging. Clinicians reported low confidence in providing interventions and perceived less progress in episodes of care.

The Mental Health Complaints Commissioner advised We do not usually take complaints from people with a diagnosis of Autism Spectrum Disorder, as we consider complaints about publicly funded mental health services in Victoria. It is important to note that not every Autistic individual has an Intellectual Disability as many of the community think. Suggestions: Work with the Autistic community all levels and all of those with experiences; Understanding across the whole community that Autism does not mean the person is intellectually disabled. Some people are, some people are not. We need more tangible awareness and congruent understanding by all mental health professionals (all including workers) within the mental health space with regards to Autism Spectrum Disorder - how it presents, manages and best practice strategies; A best practice strategy needs to be developed but flexible enough to realise that each individual is different and needs to be treated as such; PHN's and Peak bodies need to provide access and bona fide support for all Autistic individuals; Services to be inclusive of the families and carers of the Autistic individuals and expand their services to the family and carers too; Change is often slow and over a lengthy period of time but support must be ongoing; We need a reduction in the stigma by all people including Government related to Autism (which is a hidden disability). NB: How can we expect to change people's perceptions, understanding, bias, judgements and stigma when the Mental Health Complaints Commissioner has not? "

## 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?

"Whilst there are some services that state they have Autism services; this is limited or there are restraints. For example, St Vincent's Dual Disability team focus on assessment and provide consultation for Autism and Intellectual Disability; Orygen report that they provide services specifically for the Autistic community, however, this is not the case as they are attached to the Western Child & Adolescent Mental Health Service. They do provide community seminars regarding Autism; however, these too are located within Melbourne's north west which is not accessible to all. The Royal Children's Hospital also have a Dual disability clinic, however, as reported by the Victorian Auditor General, DHHS and the Child & Youth Mental Health Services

across Victoria were unaware of this clinic. Furthermore, they only provide face to face services, so if the Autistic individual is house bound or struggling with crowds, it is an unattainable service. We want services to be trained in Autism and Mental Health across all of Victoria; we would like them to wear a badge or something similar to identify as a Autism friendly provider; we would like more services including training accessible to the Autistic community individuals, families and carers across all of Victoria (not just one site); we would like all organisations including government to have tangible and congruent Mental Health training for the Autistic community; we would like barriers to accessibility and continuous servicing removed. Whilst there may be limited evidence of therapies and treatments working well within the autism and mental health space (particularly if they have never received any early interventions with therapies), there is research to show that therapy needs to be consistent and ongoing in order to prevent escalation of mental health conditions. Time can often be a factor especially for the community and government systems as they have time constraints put on them, this Autistic community requires time. If this consistent and ongoing approach is not used, the end results include school refusal, unemployment, exclusion from society as a whole, deterioration of mental health - these are examples of what Different Journeys are currently seeing. The Australian Bureau of Statistics (ABS) report that the current unemployment rate for the autistic community is 6 times greater than any other disability. Almost half of those diagnosed with autism need assistance with communication. Obviously, this is a big issue affecting mental health. On the flip side the ABS state 40% of all autistic people are actually employed within the workforce (not all full time). We would like to see more research and data readily available to the whole community regarding Autism, Mental Health and Suicide. We would also like to see further research and implementations of successful early intervention and ongoing therapies. We would like to see a successful recovery model for Autism. Autism is not an illness, as such many of our cohort will not go to hospital to seek treatment for their mental ill health because they don't see themselves as sick. Many of our society's peer support for mental health are located at hospitals or via drug and alcohol organisations which will often preclude our community from participating. We want mental health peer workers specifically trained in Autism and accessible through a variety of avenues including grassroot communities. Parents have been turned away by health professionals when their Autistic child/teen or adult has attempted suicide. Only those who still have strength to fight will take matters further. We don't want families turned away. Phone and Skype services are not readily advertised for our community, and whilst they can work for some Autistic individual, it does not suit all. Therefore, many will not use these services. More needs to be done to communicate these services and tailor accessibility to the individual. Unfortunately, many providers either believe they are already doing a great job, or too focused on their own expectations or kpi's to understand the significance of the issues at hand. We would like to see the person-centred approach rather than kpi's utilised to determine when a person is exited from services. We would like to see providers get ongoing training, support and their performance regarding Autism assessed in order to best suit the needs of the Autistic community individuals, families and carers. We asked our community and the feedback was 100% aligning the same themes: Knowledge of Autism and Mental Health. Acceptance; Honesty from clinician, even if they don't know. Better communication. Understand my autism is part of me (identity). Not being exited from services. Not being given another psychiatric diagnosis, even if relates to the autism. Understanding change is hard and sensory overload. Understanding school refusal behaviour. Limited understanding of female presentation of autism by clinicians. Limited understanding of masking (for girls and boys) We would like the above incorporated into any Autism and Mental Health plan as this is what the community has indicated of their experiences to date. What we need is greater peer support and social connections within our community to reduce the isolation.

One small example has been created out of this need - Different Journey's Peer Support Events in Melbourne's outer east. It was created by parents (all volunteers) as a way to fill a need. The events are attended by over 250 people each month at two events. We believe there is a need for more peer events similar to Different Journeys across Victoria. I think they are an excellent idea and can be a great opportunity for those with an ASD to meet each other, not only to create friendships but also to discuss common issues and also create strategies that can be shared by the participants. From my clinical experience, sometimes the practical suggestions by people with Asperger's syndrome to help each other can be better than those in the text books, and sometimes even better than those provided by specialists in ASD. The group can also be an advocacy group to help the understanding and services for those with an ASD. Tony Attwood - Clinical Psychologist, World Leading Expert on ASD "

### **What is already working well and what can be done better to prevent suicide?**

"It is sad to report that obviously within this Autistic space there is not much, because: In 2016 a longitudinal population study in Sweden concluded that suicide is the leading cause of premature death in autistic people, on average dying 12 years earlier than those without autism. Premature mortality in autism spectrum disorder. T Hirvikoski et al. British Journal of psychiatry 2016; Approximately 70% of autistic adults are at risk of suicide because of masking/camouflaging of autism, unmet support needs and non-suicidal self-injury predicted suicidality. Risk markers for suicidality in autistic adults. Sarah Cassidy et al. Molecular Autism 2018; To quote Dr Cassidy from Coventry University (supervisor of 2014-17 research), "This is a shocking wake-up call for society, when a significant section of the population feel that they don't belong in the world. As a society, we urgently must do more to value neurodiversity. This could ultimately save lives." We would like to see less lives lost as these are unnecessary deaths. In 2013 the World Health Organisation created a report which detailed the need for more urgent support regarding the mental health of the Autistic community over their lifetime individuals, families and carers. We would like to see Victoria take on the recommendations of the World Health Organisation regarding Autism and Mental Health. As the Australian Bureau of Statistics have confirmed that they do not ask, research or review through the survey of disability, ageing and carers, about information regarding Autistic mental health nor suicide data; we would like to see this included in the Survey of Disability and Ageing. We would like to see the Peak Mental Health bodies work with the Autistic community individuals, families and carers in a variety of ways including training, research, lived experience panels, etc. across all of Victoria and across all of the Autism Spectrum. "

### **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.**

"As per our survey that was mentioned previously, there are a number of issues that can contribute to a person's mental health. The biggest for the Autistic community is barriers. Barriers include: Many try to fit in and/or try to mask their Autism/Mental Health and will not necessarily seek the service they require. We would like to see more training so these issues can be clearly identified and minimised by professionals including health, medical, teachers, etc. Many Autistic individuals do not engage with sport for a variety of reasons and require exercise built into their lifestyle. Groups sports are not recommended. We want to see funding for these programs with an Occupational Therapist employed for these programs. Service access Health/Medical. There is always a debate whether the Autism and Mental Health are disability or medical. The NDIS

often tell parents Mental Health is medical and therefore they are not funded by the NDIS and the Community Mental Health service will not assist the person as they are in receipt of NDIS. The provider does not understand that the individual has not been funded for psychosocial disability. We would like to see better consultation between services, education and alternative services provided (give me a solution). Service access NDIS. There is a barrier within the NDIA & LAC staff with regards to Autism as a whole then when you add psychosocial disabilities, the staff as reported by parents are somewhat confused and ill equipped to understand the needs of the individual. NDIS require training from lived experiences as well as professionals. Service access Autism and Mental Health. Many health professionals do not understand the intertwined relationship of Autism and Mental ill health. Many of our community have been exited from services because the provider did not know what to do; given multiple mental health diagnosis. For example, a diagnosis of Oppositional Defiant Disorder simply because the individual refused to speak with the provider, even though it was a new provider and rapport required a lot of time. Many have been told by mental health professionals (even after their multi-disciplinary assessment where a diagnosis of Autism was identified) they don't really have Autism. This is insulting to the individual, their family and their assessment team as they did have Autism, the provider was focusing only on the mental health issue. We would like to see organisations do a congruent skills audit, training including those who have lived experiences and implement best practices. If another diagnosis is recommended it should go through a multi-staged panel. Service access many children (as young as 8), teens and adults are attempting to take their own life. Many will not be provided with inpatient assistance nor specialised services for Autism. This leaves many families who are not professionals to be on 24-hour suicide watch. Provide support to the service but more importantly to the families who have been advised to be on suicide watch, including providing counselling to these families. The World Health Organisation (WHO) has stated Mental illness can be more common for autistic people than the general population. The mental health of Autism is often overlooked. Please implement the recommendations of the WHO. "

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

"Autism is a concern but apparently it is not a focus these are the words of many peak bodies and government departments. This is one of the drivers as to why we are experiencing poorer mental health outcomes. These bodies and departments need to action Autism training built into all facets as a priority. A diagnosis of autism is a significant barrier as many clinicians don't understand the connection and best practice to support this cohort including being aware that their improvement progress is much slower than that of their neurotypical counterparts because it has been much quicker to spike. For example, it has been reported that once a professional is aware the individual is Autistic, they immediately speak slower, assuming the persons has a lower intellect than themselves. Training is required but also consultation with the Autistic community and how to work with the individual. It should be noted every Autistic individual has very different needs to the other. As such a one size fits all approach which may work with neurotypical will not work with the Autistic community. People (not ASD) can generally: understand change; time and sequence of change; and can step back and look at the situation. Likewise with social issues most can read a social environment and still understand own & others emotional needs almost immediately or will have the ability to check. This differs with ASD, they do not necessarily understand the change (or the reason behind it); they require consistency (including very gentle limit settings - others don't need to be); their reaction is much faster, bigger, intensive, uncontrollable (also known as a meltdown) (1-100 in seconds) and don't have the ability to think

clearly during these moments. ASD will sit at the higher escalated point for a lot longer (she indicated with her hand how high the person sits) and will take time before they can come down from this escalation and can think clearly. The person will need to feel safe before they can come down from the escalation. The person must be given time to be able to do this but people try to reason with during this period of time but it won't work because they are (for lack of a better word) in "flight, flight, freeze" moment. oASD cannot have a one solution fits all approach compared to others, it has to be individual and one step at a time. What we would like to see is more people not only trained in this information but working successfully with our community regarding the above. For example, a consistent and ongoing approach means more time, assist the individual based on their needs in a manner suited to them. This should be performance managed. Dr Ruth Vine has spoken about young people and the increase in mental ill health (generally not ASD specific) she spoke about the sense of entitlement, the "right now" attitude, immediacy then spoke about how isolation is a major issue in young people and went on to say for ASD isolation is also a major issue, much bigger than general population. We would like to see more opportunities for our community to be engaged to reduce isolation and increase good mental health. "

### **What are the needs of family members and carers and what can be done better to support them?**

"Family members and carers are often a forgotten group. They are the ones best supporting the person, but do not have the support or strategies to know how to do it. Provide the family with the strategies, training and qualifications. The family members and carers require assistance themselves as many are often isolated, suffering injury, trauma and mental ill health themselves. Many are unable to work or work casual or part time as such many should be given an opportunity to get the support they need in all barriers and aspects of life. The ripple effect is significant affecting so many other elements of their life - employment, relationships, financial stability, friendships. There is evidence for ASD Mothers that have similar stress to combat soldiers with PTSD returning from a war. Recognise that the role of these families is tough and often have to fight for the right of their families including government departments to get the same access, opportunities as others. Many are dismissed or mistreated. Families live with Autism and Mental ill health throughout their lifetime and are indeed exposed to it 24/7 compared to professionals who may see them once a week or fortnight (as per NDIS funding) and are not only the experts but have no debriefing facilities, no professionals reflected systems in place nor do they have an Employee Assistance Program. A service should be created and specialised for these families talking to someone about diabetes is every different to speaking to someone who is Autistic and attempted to take their life. The WHO considers the families and carers of Autistic individuals are just as vulnerable and have similar issues regarding mental health systems as the individual themselves has. Take on the WHO recommendations Families and Carers do not get paid for caring. Many are in receipt if income support trying to make ends meet, many will never accrue superannuation due to their caring responsibilities. Create opportunities for the families and carers. Families and Carers are often thinking about the future or what happens when I'm sick, hospitalised or even die. Work with these families to create a program or model to assist Autistic individuals. The NDIS does not factor in many of these issues for the person or even know how to address such a thing. Results tend to happen after the individual or family member has died. "

### **What can be done to attract, retain and better support the mental health workforce, including peer support workers?**

"The wider community including health professionals need to treat Autism and Mental Health as specialised not too complex; Provide free or subsidised training especially to grassroots communities; Link mental health professionals with Autistic community to learn and embrace Autism. This can be achieved through setting up partnerships with professionals and peer support programs. Funding will also need to be provided for this to occur. The State Autism coordinator needs to be made accessible for all; The Mental Health Commissioner and Mental Health Peak Bodies need to embrace Autism, learn more about Autism and Mental Health. EAP ongoing for staff and their families not just a few sessions a year; Mandatory training on vicarious trauma and burnout; Introduce mandatory flexible working arrangements (including satellite); Introduce mandatory work/life family balance measures; Health Insurance benefits or at least heavily discounted; Create better remuneration packages; Encourage Autism friendly events, environments, etc. Allow lived experience to enter the field and if required provide training relevant to the specialised area (match the experience to the speciality); Compulsory Mental Health First Aid training including for specialised areas; Financial Incentives, free training will always attract people but the difficulty is retaining and this can only be done for those who have an interest vested or otherwise. Many people with lived experience tend to be people with an interest but are often not considered because they do not have the qualifications but are Qualified by Experience, so we should be encouraging these people to enter this employment. Build network of support where you offer genuine connections, lived experience, etc. Just like the McGrath Foundation has nurses for breast cancer, Autistic community requires mental health professionals in the same manner. Autism has 6 degrees of separation within the community there is someone who has a family member, friend, acquaintance, school friend, colleague with a diagnosis. Why not utilise these people to help attract the workforce too? "

**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?**

"We have provided the statistics of the Autism community, so the Victorian community needs to embrace the Autism community. A long time ago people thought people with wheelchairs were not capable of much look how far the community has come. This came about as a result of promotion, advocacy, opportunities and a change in attitude by the community. Look at the basic barriers education, employment, housing, health services and work on these because if our basic needs are not met, you cannot focus on anything else. The mental health system plays a massive part in this as there is constant crossover, consultation, etc. Encourage Autism conversations, learnings and solutions. Education is a big factor with regards to this question and multi-faceted. The community requires education of Autism to understand many if given a chance can be socially and economically participating. Health professionals need education in Autism and how Mental Health and co-morbidities are intertwined and work with the person to become a socially and economically participant of society. All education institutions require education in order how to successfully work with an Autistic individual so they are not sitting in a corner learning nothing. The education extends to families and carers too. Many have been told their young person is not capable by professionals over the years, so they too do not see the Autistic individual as capable of social or economic participation. Education extends to teaching Autistic community how to be a social and economic participant of society in a manner that suits them not to lecture them but show them the way. The Autistic community want a chance to be involved socially and economically but also to support the wider community on how to work with Autism and Mental Health. Offering opportunities to increase the feelings of connectedness with the communities in places that they feel supported, understood and can find their tribe. Many people with mental ill

health including Autistic individuals are given volunteer work but it is not converted to employment. Let's provide as a community employment opportunity. This should be extended to families and carers too. Likewise, with TAFE many cannot afford the cost of courses, so why aren't we providing free TAFE or apprenticeship/traineeships with incentives for both employer and employee for these communities. The Job Fund is not enough money as an incentive. Why aren't we employing and embracing lived experience within the mental health sector from the hospitals to community agencies, from the Office of Chief Psychiatry to grassroots communities. These people are experts and have a lot to contribute in a specialised area that requires the support. There is currently a campaign called Do one thing for Autism, why not promote this and do something now to support Autistic communities. "

**Thinking about what Victoria's mental health system should ideally look like, tell us what areas and reform ideas you would like the Royal Commission to prioritise for change?**

"Many providers believe they are doing a good job because they are meeting their KPI's or not exploring complaint opportunities. Recently in the Victorian Auditor General report, many organisations reported they provide a number of services, service a number of people, etc. but there was little transparency about the quality of the services. A best practice or standard needs to be developed to monitor the quality of the services, preferably an external source. If a person tells a worker they are not happy and lodges a complaint they are referred elsewhere and the complainant will not lodge the complaint to a different person as they were already dismissed. Complaints need to be taken and lodged at first contact. Likewise, all complaints should be acknowledged and addressed and should not be addressed 7+ days, but more immediate. If services cannot be provided, provide tangible alternative services. This also means do not tell a person that you do not know what to do to support them and exit them. You should be finding an alternative service which is free or of same value as to what is being charged. If the service is making families do the work train them, provide evidence of the training received. Listen to the individual, families and carers- all are experts in that person's mental ill health, do not dismiss them which happens a lot. Take the information with all seriousness and don't argue with them. DHHS and all mental health services need to be aware of all services within Victoria. Services need to be accessible to all, including all hidden disabilities just because a person cannot see the disability doesn't mean it does not exist. We would like to see families and carers fully supported. We require specialisation in Autism this is a great opportunity as there is very little in this area. We would like to see a complete mental health system that provides a complete circle person/family/carer centred approach. From training to working with an Autism focus. Another option is to create or a specialised branch that is must be used when working with the Autistic community to ensure everything is being done (autism specialised/focus) for the individual, family and carer. Review and implement new training and best practice methods for emergency workers including paramedics and police with regards to Autism and Mental Health. Work congruently with peer support groups (in partnership) as these groups are providing (many without training and support) the gap needs. PHN's, DHHS, Peak Bodies, Communities, Individuals and the community as a whole need to learn from, and work together incorporating all facets and dismissing the term too complex or too hard. Train and hire urgently required specialists and specialised staff now all have a focus or are involved with an aspect of Autism and Mental Health. There are 6-12 month waiting lists for specialised support. For example, there are not enough Occupational Therapists who are Autism specific with a focus on Mental Health as well. There are not enough behaviour support specialists to complete behaviour support plans. Aspect has a minimum 9-month waitlist. No one has considered a plan or options for families in the interim. Start working on a model or plan now, as the waitlists are only increasing not decreasing. There

are no available psychiatrists who specialise in Autism and Mental Health nor are psychiatrists covered under NDIS. Many psychiatrists have closed their books or have exceptionally long wait lists. Please reduce the wait times within the Mental Health Sector for our cohort. "

### **What can be done now to prepare for changes to Victorias mental health system and support improvements to last?**

"The State Autism co-ordinator can start to make contact with Autism groups, Autism specialised services/providers and ascertain needs and wants; Encourage, speak and consult with Autistic individuals, families, carers, grassroots organisations not just Peak bodies or large organisations to find out how they would like to be treated within a mental health system; Speak with people who have lodged complaints and find out why the system didn't work. Take those learnings and develop plans always consulting with the people it affects the most. Start dealing with complaints at first contact; Educate all government departments on Autism and mental health. These departments can then commence an inclusive plan which welcomes and acknowledges the Autistic community individuals, families and carers. Don't dismiss me - this could be a plan, policy or campaign that would mean everyone with Autism is not dismissed or ignored or considered too hard. There would be a service, solution, etc. Research can commence now and long-term plans implemented as a result, however it needs to be a living document with continuous improvements made. Start consulting with mental peer workers who offers supports to the Autistic community. Not focusing on intellectual disability or drugs and alcohol. Are there any formal or informal. Evaluate the training delivered regarding mental health and Autism including peer work is there any. What is the quality of it? Is it meaningful? Have the Autistic community been consulted? Is it targeted for a specific group of Autistic people? Does it include families, carers, organisations? We need to implement strategies in how to communicate effectively with the Autistic community and we don't mean speaking slowly to an Autistic individual. We mean to communicate in a way that is suitable to that individual, family, carer, organisation and that it is effective and respectful; this includes not becoming upset, angry or irate when nothing changes it may be the communication strategy was not successful or consistent or time is needed. Start working with Autistic peer support workers, groups, etc. to gain insights into issues, concerns, what works and how the mental health system can work with these organisations.

Everyone needs to find their tribe, other people who speak the same language and just "" get"" each other. For young people living with ASD attending the Different Journey's Dinner offers the opportunity to meet other members of their tribe. People who will and do accept those who see the world differently, who think and respond differently without having to explain why. Along with this is the opportunity to hang out just like other young people, at least once a month. Parents, who have often been criticised for their child's uniqueness, find a safe place where they can relax knowing they are in the company of others living the ASD journey. A place where their children's achievements are celebrated and understood. A place of resource information through friendship. Self-esteem, confidence and happiness are born from self-acceptance, something all people crave- Different Journeys Dinners facilitate this it's that simple. Heartfelt thanks to the Different Journey Dinner facilitators for offering a positive experience in the lives of young people living with ASD and their families.

### **Is there anything else you would like to share with the Royal Commission?**

"Please hear us and act now; Autism and Mental Health should be a focus not just a concern. We do not want the statistics to read the Autistic community have a 100% anxiety and depression burden of disease or worse the suicide risk increase to 70% as opposed to 50% higher



than the rest of the community. The Autistic community individuals, families and carers want to live normal lives and participate in society and contribute both socially and economically. It should be noted if all the right supports are in place (consistent, ongoing and over time) then we give this community potential to be included which will improve the cost to the economy and create opportunities for them to be contributing members of society. In the past decade governments have invested in important early intervention initiatives for children with an autism spectrum disorder. As these children reach adolescence and move toward adulthood, they're now equipped to find their place in society, but they need support to do this. There's plenty of well-researched evidence that people with ASD have a higher rate of mental illness than the rest of the population, which can lead to more costs and higher support needs over a lifetime. The philosophy behind the NDIS attempts to address some of this, with a more long-term view. The NDIS may enable teens and young adults to access structured activities and build specific skills, but where Different Journeys differs is that it allows these people to just be teens and young adults for an evening - making friends, socialising, learning to get along, and developing a sense of identity and resilience without it feeling like therapy. Denise In my role as a Clinical Psychologist at The ASD Clinic I have worked closely with teenagers and adults living with Autism Spectrum Disorder for many years. Different Journeys social groups offers teens and young adults with ASD an opportunity to connect with like-minded individuals, to feel included in the community and to know they are not alone and supports are available. Parents also have the opportunity to share their stories with others who understand and are supported without judgement and discover new tips and ideas that other parents found helpful along the way. These social outings help teens and young adults develop important life skills, which they can transfer to other situations in the community. Events like these empower families within the ASD community to connect with and support one another and extend their social networks. [REDACTED]