

Submission S137

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Family and Community Development Committee

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Family and Community Development
Committee

INQUIRY INTO SERVICES FOR PEOPLE WITH
AUTISM SPECTRUM DISORDER

Submission from VALID and the Behaviours of
Concern Peer Action Group

April 2016

Introduction

This submission has been prepared by VALID in partnership with the Behaviours of Concern (BOC) Peer Action Group. The Behaviour of Concern Peer Action Group comprises parents of adult children with intellectual disability and Autism Spectrum Disorder (ASD) who present with challenging behaviours. VALID has facilitated the development of the Behaviours of Concern Peer Action Group through funding provided by the NDIS Peer Support Program.

The BOC Peer Action Group supports parents and adult carers of people aged 18 and over who have an intellectual disability, ASD and behaviours of concern and may have a history of seclusion, physical and chemical restraint, injury and trauma.

The Group aims to provide a safe and confidential opportunity for parents and carers to tell their stories, share accurate information and learn about the National Disability Insurance Scheme (NDIS).

VALID is Victoria's peak advocacy organisation for adults with intellectual disability who are in receipt of or eligible for State-funded disability services. It provides a state-wide individual advocacy service funded by the Office for Disability (DHHS). Through our individual advocacy work VALID has extensive experience in supporting people with intellectual disability and ASD who have developed behaviours of concern often as a result of various forms of abuse and neglect, including financial, sexual, physical and emotional.

The Behaviours of Concern Peer Action Group represent a cohort of families, amongst many, that VALID has worked with over a number of years who experience a range of complex challenges as they struggle to care for their adult children with disabilities.

In this submission, parents report a litany of failure in relation to responses from a range of services. This includes initial assessment, early intervention, school, disability support, community and other related services – essentially services across the life span.

The sense of isolation and despair felt by people with intellectual disability and ASD presenting with behaviours of concern is often acute. So, too, for their families. As one parent put it, 'there is no support for a better life for my son other than what I can provide as his mother'. Their experience of the system that is supposed to provide support is that it is broken and unable to respond to both the demand and the complexity of challenges posed by their son or daughter.

Parents report finding themselves in desperate and often dangerous situations, on their own and with no one who to turn to for help. The sense of moving from crisis to crisis also promotes a lack of trust and faith in the capacity of DHHS and other government department staff to provide assistance. This leads to a break down in relationships with departmental staff and other professionals who would normally be expected to provide assistance, advice and ongoing support options.

Parents also report being bumped from service to service as they try to find a place for their children to fit in. They feel that services are at a loss as to what to do next and are ill equipped to respond effectively to needs and demands.

Many of the issues raised in this submission are endemic to a system that is both crisis-driven and crisis-producing. In many ways, advocacy groups like VALID are left trying to bandage a system that is badly broken.

Submission Overview

Part One –The Parent Experience

Captures the experiences of families trying to care for their children with ASD and behaviours of concern in the context of a support system that for them is fundamentally inadequate.

Part Two – Building and Strengthening Support

Draws on the experience and knowledge of families to discuss a number of strategies for building and strengthening the system of support available to people with ASD who have behaviours of concern.

Part Three - Recommendations

Proposes the following recommendations:

1. Develop Best Practice
2. Support Self Management
3. Ensure Effective Coordination
4. Develop Peer Support
5. Build Community Capacity

Part One – The Parent Experience

Diagnosis and Assessment

“We now believe the poor and delayed diagnosis led to the dramas at home. L would attack his brothers and sisters. His father became the punching bag. We had no support at this stage; we were doing it on our own.”

A key issue for parents is getting access to specialist support that could provide them with an accurate and informed diagnosis and assessment of their child's condition. Where an accurate diagnosis of ASD was made, services were sometimes able to be mobilised which provided families with a plan and a framework for supporting the development and education of their child. Other families struggled on for years trying to come to terms with escalating levels of behaviours of concern with little or no explanation for their child's distress. In one case it took 15 years for a family to get an accurate diagnosis of their son's ASD.

Information Services - Understanding ASD and Behaviours of Concern

“Is there any other group of families so poorly supported by lack of staff expertise?”

Families are confounded by a lack of expertise and knowledge about ASD and Behaviours of concern both within the specialist disability support system and within mainstream organisations and services. Many reported that it was unclear where to go to get access to accurate and helpful information about ASD and behaviours of concern. The paucity of information promotes confusion and distress and a sense that no one really understands their needs or is available to help with their child's development.

Early Years

“Families want to learn more about behaviour management strategies - they want to be advised, assisted, encouraged and supported. We need to be able to identify, show and feel hope. When our children lash out they are communicating something to us. We need to ask ourselves, what is the function and meaning of that behaviour?”

“At 2 years of age T began displaying behaviours of concern – he screamed for 20 hours a day. To protect other family members I ‘slept’ with T in a room on our own for those 20 hours”.

“A lot of children start primary school without a diagnosis of autism spectrum disorder, and that leaves not only them at a disadvantage, but also the families who are caring for them and trying to provide them with the best possible start.”

The experience of support for many during the early years of their child's life was one of confusion and distress as their son or daughter began to display behaviours that they found troubling and could not account for. Getting access to support was described as bit of a lottery – as one family said 'it was more by good luck than good management that we found anyone who could help us'. This was especially the case for families who had not had previous experience or access to the service system.

Many families though, who had been able to access early intervention services, generally reported high levels of satisfaction with the support they received.

Schooling

Primary Years

"It all starts at School"

"T had no social experiences and friends as a child – there was no invitation to a birthday party all of his time at primary school. So, we would invite children to our home..... but no one would come. Despite this he made it to grade 6 and graduated."

Special School

"On one particular occasion I came to collect S from school and he was in a locked, small, dark room, lying on the floor in his jacket, his face flushed and red. This was the last day S ever spent at the school. He refused to go back (by way of tantrums). He was 17 years old. We were told that he had no other option but to stay at home until he reached the age of 18 and was able to access the Futures for Young Adults Program. As a result I had no other option but to cease employment to care for him on a full time basis".

"Our son attended an SDS which was supposed to specialise in supporting children with behaviours of concern. The school's response to his behaviours was to lock him in a cage where he was left alone everyday for hours on end. He now just has to think about school and he has a meltdown."

Secondary School

"Secondary school was a whole new ball game. We were told don't bring him here. He won't last a week. In his first week at school he was badly beaten up. To this day we still don't know what happened. There was no explanation for the incident."

"N was finally accepted at a local community school where he thrived. The keys to his success were the way the school played to his strengths – they engaged in dialogue with us. And the small classes and male teachers were good for N. But unfortunately there was nowhere to go after that."

As the quotes from families testify, the experience of schooling can be a very traumatic one. Schools can be a very hostile place for children who are perceived as 'challenging'. The inability for teachers both in mainstream and specialist settings to support and provide education programs that enable children with ASD and behaviours of concern to grow, develop and feel a part of the school community, only serves to escalate behaviours and further marginalise and isolate these vulnerable and lonely children. The experience of school can mark people for life – in this case the system marks children with ASD and behaviours of concern for exclusion and sets them on a career of rejection from most aspects of community life. Ineffective supports and commitment to some sort of developmental plan in the school system exacerbates behaviours which further stigmatise children and their families.

For many children this meant that no school in their area would take them – in some cases this resulted in families, usually mothers resorting to home schooling of their child.

In this context, teachers are not seen to be equipped with the skills, resources and awareness to be able to educate children with ASD and behaviours of concern. From the outset these children and their families are failed by a lack of staff expertise, in this case teacher expertise which would effectively support their educational goals and development and inclusion in the school community.

Post School Options

"Each one of our sons arrives at the adult system traumatised by his schooling."

"During J's last year at school, we approached 14 day programs - no one would take him."

"But we can't find staff that are prepared to work with your son".

The pattern is often set in school for a life of exclusion from friends, the workplace, sport and recreation options and other community activities. Services post school are also for the most part poorly equipped to respond to this group of people. In 2009, the **Shut Out Report** characterised the service system as broken - underfunded, under resourced, crisis driven and struggling to meet extremely high levels of unmet need. The support system was also seen as prescriptive, focussed on a one size fits all approach, offering little choice and control and very inflexible.

Organisation and system needs came first – client needs a distant second. For this group of people, who require consistency of support, predictability, and routine, this type of disability support system is diabolical.

Community Inclusion

“On one occasion E was went to his local swimming pool with his carer. He enjoys swimming immensely and in this environment is quite social and happy. He waves to people, smiles and says “how are you?” Whilst in the pool a father and his teenage daughter were also in close proximity to E. E waved and smiled at them. The father’s response to his daughter was “People like him should not be allowed in public places, come on, let’s go to another pool.”

R loves basketball. We lived close by to a local stadium which ran an underage competition and one of the parents noticed R and got him involved helping with refereeing the under-age competition. He loved it and was a real part of the competition. Unfortunately that parent moved on and it all fell apart.”

“D played at the local cricket club from the age of 12. He wasn’t a great cricketer but the coach made sure he got his 4 overs; he made sure he got a fair go.”

In many instances hope and possibility for a meaningful life for families is dependent on the capacity of community organisations to find a place for their sons and daughters. One Mum emphasised her constant surprise at the ‘kindness of strangers’ – people associated with sport, recreation or arts programs who were able to include her son in their club activities and promote his acceptance and connection with others who shared his interests.

This was a bit of a rollercoaster ride for families – periods of acceptance followed by their child’s ‘meltdown’ at some point and then exclusion from the community environment. Community inclusion in this context is very fragile and dependent on ‘champions’ in organisations who are prepared to advocate and work to engage people with ASD and behaviours of concern in their club or association environment. There needs to be a much more rigorous and informed approach to working with and engaging communities to ensure sustainability of peoples inclusion in community activities. This should include an emphasis on building community capacity which incorporates community education and awareness raising strategies and support staff who have the skills and knowledge to successfully engage and partner with mainstream community organisations.

Transition Support Services

“There needs to be more focus on the transition from school to post school options – either day programs or individualised support. This is where it fell down for me with B. We only had a one hour meeting to assist with the transition from school to day program before he left his school. This was despite it being well documented that B does not transition well from one activity to another. We had emphasised to the school the need for transition planning and how to do it successfully and that this needs to be taken into account before we go anywhere. However, it just did not happen with the school.”

Families reported feeling most vulnerable at key times of transition – early years to primary school; primary school to secondary school; secondary school to post school options; family home to out of home accommodation. These transition points presented families with high levels of uncertainty and stress. Sensitivity to the families needs during these times is critical.

Impact on Families

“It’s a whole new ball game when you have a child with ASD. You can quickly become very isolated and it’s a huge financial burden. We went from 2 incomes to 1 income and when my husband and I split up.....NO INCOME. “

“We had no funding; I had no family support; and I wasn’t working.”

“We couldn’t go anywhere; we couldn’t bring friends home. We didn’t know what was wrong. We didn’t know where to turn. We had no idea of how we were adjusting our lives to D.

“Don’t raise your voice. Don’t laugh. We didn’t know what to expect next – He would launch at us for what seemed like no reason.”

“You’ve gotta collapse before you get respite.”

“Parents feel overwhelmed and often have to wait so long when in crisis.”

“Basically our family does not exist to the outside world. We are extremely isolated with no contact beyond our front door. There is no extended family and friends. It’s too dangerous. No holidays. No meals together. Our other siblings can’t have friends over for fear of violent behaviours. We experience a lack of sleep and the basic needs of family members being able to shower, toilet, eat, prepare meals, etc are compromised due to our focus on A’s needs. The financial impact has been huge – including a loss of one income and a sale of our house to meet A’s needs. We have no break. If A does get out, my time is spent cleaning faeces, blood, sheets, walls, floors etc. Our movements are constantly restricted throughout the house so as not to upset A. All of this has resulted in mental health issues with other family members, - anxiety, depression, suicidal thoughts and even attempted suicide (siblings)”.

As is evidenced from the quotes above the stress on families is acute. Family carers, mothers, fathers brothers and sisters are often subjected to abuse from their family member with a disability. They are witness to their child's intense frustration and suffering and are at a loss as to what to do about it. The distress for parents in these situations is often extreme. They describe feeling isolated with no sense of hope for the future. Parents also describe feeling confused and conflicted. They want to be able to care for their son or daughter but are ‘falling apart’ under the pressure and the lack of support they are offered from a range of ‘experts’.

Behaviour Intervention and Support Team (BIST)

"What Response? You ring to get support which is refused because you are not desperate enough. And when you finally get support you are only allocated 3 sessions. But really what can they find out in 3 sessions?"

"BIST (Behaviour Intervention Support Team) is the only tool in the Department's armoury but is it what we actually need? We need practitioners with serious skills who go on the journey with us and can follow through on recommended behaviour intervention strategies and not just respond when we are in crisis."

"His Mum called the police and then had to watch her son capsicum sprayed, wrestled to the ground and handcuffed. Needless to say it was very traumatising for everyone involved."

"The disability support system has no experience in dealing with our guys, so they just call the cops."

BIST is commonly described by parents as a profoundly inadequate response to people with ASD and behaviours of concern. It is seen as too prescriptive, crisis driven, reactive and not grounded in the real life experiences of families.

Housing

"The first 12 months when J moved from the family home was more than we could ask for. But the change of staff and the constant turnover of casual staff through the house rang his bells. He is also one of 3 people with ASD in the house and they don't get on. He is now virtually a prisoner in his bedroom in the house. He has all his meals in his bedroom and has taken to climbing out of his bedroom window to exit the house so he has doesn't have to connect with the others."

"It would cost much less in the long run if people were housed in environments that understand and can respond to their sensory loads."

Severe underfunding by governments and under investment in appropriate housing creates a context where many people with ASD and behaviours of concern are forced to live in group accommodation with other residents who may not be compatible. In many instances, people are unable to enjoy being at home because they are in constant fear of being hurt or abused by others. This is a form of systemic abuse that would not be acceptable for any other citizen and causes great anxiety and guilt for families and carers.

Accessing the Health System

“The Royal Children’s Hospital was our only link to medical services besides our GP. Just prior to S turning 18 we had our 6 monthly visit. S was quite agitated by the need to wait for the appointment and the noise of the waiting room. By the time we entered the paediatrician’s room he became uncontrollable and a Code Grey alarm was called for. S was quickly surrounded by security and health staff and sedated. He was then escorted to Emergency, given more sedation and observed. At the end of the day we were given 4 sedation tablets and sent home. Due to S’s age that was the last time we were allowed to access RCH and no referral to adult services or transition process was ever organised. We were on our own.”

“To get even basic medical attention like a visit to the GP or the Dentist we have to call 000. J had pain in his teeth. We rang the ambulance. The ambulance came. They assessed the situation and told us to call the police. J was finally sedated and then put into ambulance and taken to the dentist.”

“The traditional response is just to ignore these health issues because both the health and disability support systems don’t know how to respond.”

“Every time my daughter went to hospital I had to stay with her and sleep overnight.”

“One Mum I know, who had breast cancer at the time, went everyday and sat with her son in hospital so he would not have to be restrained.”

The trauma associated with trying to access basic health care, that we would normally take for granted, is extremely disturbing. There is a range of complicated factors in play here. Poor support and behaviour management strategies have escalated behaviours of concern which in turn impact on the capacity of the health system to provide treatment. There is also a lack of awareness of the needs of people with disabilities in the health system which results in a reluctance to provide treatment that is appropriate and responsive to the additional needs brought to the health system context.

Trauma Support - Dealing with impact of trauma

“Raped, beaten and neglected. The support system has failed to provide a safe environment for our son and for us.”

“Our son moved into a group home. He was confined in a small room where he had no mattress. Staff used a bed slat to keep him under control. L would shred his clothes. Staff would shove his food under the door and push it into the room with the bed slat. It took 3 to 1 staff ratios just to deliver his meal.”

The impact of poor support and treatment, neglect and abuse of people with behaviours of concern has resulted in a range of traumas which scar people for life and reduce their capacity to engage with family, friends and community. Staff and services that are not able to provide effective support founded on solid clinical and evidence based practice resort to a range of ad hoc measures to deal with behaviours of concern.

There is a strong sense of betrayal that the system that is supposed to provide support and care has been so inadequate and bereft of solutions. The guilt that this invokes in parents, who have invested in agencies who they believe will deliver positive outcomes for their children, is acute. Parents see their children suffering intensely, effectively punished by the system that is supposed to support them. This results in unresolved trauma which paralyses people's development, exacerbating their behaviours and further isolating them within an already vulnerable family's limited capacity to care and to cope.

The NDIS – Access to Accurate and Accessible Information

While there is reason to be optimistic about the potential of the NDIS to address the needs of people with ASD who exhibit behaviours of concern, there are many issues that are yet to be resolved and clarified. For a start, information about the NDIS has been to this point confusing and complex. This contributes to people's natural fears about what may or may not happen under the NDIS. In relation to the group we are focusing this submission on, given the depth of trauma many have already experienced, it is critical they are provided with reassurance their sons and daughters will not be disadvantaged under the NDIS, and will indeed be better supported. Without a proactive effort to inform and support such families, and to effectively work through their legitimate issues – e.g. the need for a higher intensity and complex care unit cost that will allow skilled staff to be recruited and retained - many will continue to be traumatised by often inaccurate and alarmist commentary.

Access to accurate information and support is a critical foundation for navigating the system to ensure an effective response to families and children's needs.

This should also include access to system navigation information; clinically based research information and knowledge in accessible and easy to understand language; and access to people who have a lived experience of caring for someone with ASD and behaviours of concern and are willing to share that knowledge with others.

Part Two – Building and Strengthening Support

Consistency and Quality of Support

“We are dealing with low skilled workers who are not clinically informed and who operate in a culture of vested interest. The system has failed our son – the poverty of his support environment, which exacerbates his behaviours of concern, results in an over reliance on chemical restraints.”

“A has been deprived of continuity of education. Support staff have not been interested in following through on his education at all.”

In relation to people with ASD and behaviours of concern, the Developmental Principle has long been regarded as fundamental. It implies that people are always capable of learning through new experiences, regardless of the severity of a person's cognitive impairment, their ASD or their behaviours of concern. Support workers should therefore be skilled in facilitating such opportunities. Unfortunately, it appears that staff training has been systematically eroded over time, with little or no training and professional development in such basic techniques as task analysis, developmental programming, positive behaviour support and social role valorisation. These methods can be powerful tools for enhancing the capacity of people with ASD to participate in the community and develop meaningful lives. Without skilled staff to support them to effectively access community - both physically and socially - many people with an ASD and behaviours of concern will continue to be - as they are often currently being - failed.

While skills may vary, there are also values and principles which are common across all disabilities, and which are reflected through the UNCRPD, the NDIS Act and the Victorian Disability Act. E.g. the values of self determination, inclusion and respect, and the principles of person-centred thinking, self directed planning and empowerment. Such values and principles are responsible for shaping the culture of disability organisations. Training and orientation for support workers should, at an absolute minimum, emphasise such values and principles. Staff who do not share and commit to such values and principles have no place in the disability sector.

VALID believes there needs to be a thorough review of the training requirements of staff working with people with ASD and behaviours of concern, in order to ensure people are supported to achieve quality outcomes. The more skilled the workforce, the greater the outcomes will be; without skilled workers, many people with an intellectual disability and autism will not achieve greater independence or community participation, and their support needs will remain unnecessarily higher and therefore more expensive.

A Planned and Coordinated Response

“We now have monthly Care Team Meetings with workers from DHHS; and a range of mental health services. These meetings are driven by D’s needs and aspirations. He is the facilitator of the community/case coordination meetings which are held at our home. The meetings are known as Team D meetings where D is the Captain.”

“The NDIS has got it right with its focus on encouraging people to tap into their informal and community based networks. But it’s got it wrong if it thinks the other systems will naturally pull their weight.”

People with ASD and behaviours of concern have needs which span across a range of contexts – disability (accommodation, day service options), health, education, recreation, sport etc. VALID believes that effective planning and case management needs to bring together people and resources from across these contexts to ensure a coordinated response to many of the issues and challenges described above.

VALID would also like to emphasise that this is a policy issue and that whole of government responses need to be developed which mandate cooperation, planning and resource sharing across a range of government programs to ensure an effective response to the needs of these families.

This is also why it is imperative that the transition to the NDIS does not also mean a divesting of State responsibility for the needs of its most vulnerable citizens. While NDIS might streamline the provision of disability support, people with intellectual disability and ASD will still walk down Victorian streets, use Victoria’s health and public transport systems, come into contact with Victoria’s Police and Justice system, etc. It remains the Victorian Government’s job to ensure they are safe, free, respected and equal citizens of Victoria.

A commitment to strengths based approaches - Identifying and building on central life interests

“We met a renowned local Melbourne writer who agreed to mentor C. This writer was C’s saviour. C had always been a good reader and writer right throughout his schooling. The writer listened to C and valued his opinion. He made C feel good about himself. C has since published a book of poems which we launched at La Mama. At the book launch all of the key people involved in C’s life came along, including his local cricket club. He read his poem ‘The idiocy of a cricketer’, which was very moving for the club members. It was great for C to celebrate his time with the club. In reality they too had saved this life. They told us on the night that they always ask after C. It’s nice for C to be missed. “

“J lived at home until he was 21. When his behaviours became increasingly challenging J moved to a CRU with 4 other young men. Prior to the move J had a history of accessing the community independently – he loved walking. Unfortunately whilst out on his walks, J developed a range of behaviours which put him at risk, resulting in a range of negative community responses.

With his move into the CRU (community residential unit) there was a strong focus on stopping his walking – which was now seen en as ‘absconding’. John was locked in the CRU from which he was able to ‘abscond’ regularly, resulting in over 300 missing person reports and of course police involvement. During this time J experienced every type of constraint to stop him leaving the house. The family worked with the police and the Department of Human Services to develop protocols to enable a positive response to J accessing the community independently. However, rather than send someone to support J’s walking and community access the Department’s response was to lock him up based on a duty of care. He eventually spent 2 years in a forensic facility here he responded to the treatment he had received with a range of self harming behaviours. He was then moved into another facility where he was left with no program and no funding. As far as we were concerned his walking was not a danger, and with better support and a more imaginative response, J’s access to the community may have been managed successfully. No support worker with adequate skills was allocated to work with or even accompany J on his walks and his engagement with the community to offer training which would have enabled him to succeed. “

“J is a young man who has fought for his freedom.”

Families report that the support system is prescriptive, highly inflexible and lacking in imaginative and creative responses that draw and build on people’s strengths. Unfortunately disability support providers are often extremely poor at identifying these interests and strengths and organising responses that enable people to pursue their interests and aspirations.

VALID believes a commitment to person centred planning that builds on people’s strengths and interests is critical to successful engagement of people with behaviours of concern. All of the families we spoke to were able to clearly identify their children’s key life interests – writing, cricket, swimming, Men’s Shed activities, basketball, art, gardening, and walking were some of the things mentioned. Central life interests have the potential to provide a foundation for mobilising support and life planning that connects people to things they love to do and to share those activities with others who also love those pursuits. They are a rich source of engagement and meaning for people that have the potential to de-escalate behaviours of concern, promote family cohesion and build connections with the community.

Engaging Communities

“We live in constant fear of a meltdown when our son is in public. There needs to be an investment in community engagement and education so that if he does have a meltdown there is some understanding of the situation.”

“H now has his own Facebook site which we help him to manage. He has over 500 friends who are all invested in his life. H loves to walk and Facebook has become a great way for his friends to support his walking and at the same time monitor his safety. His friends will often post H’s movements on Facebook to which we can respond. Facebook has been a great way to develop a dialogue with the community about H’s behaviours. Inevitably there are sometimes negative comments posted which inspires a defence from H’s friends. We have been able to respond to these debates with explanations about H and what he is doing. Used in this way, Facebook has become a great community education tool for H and others who have ASD.”

“When we took over self management of H’s funds we enabled him to move to a new home – a place in Diamond Creek where he has always wanted to live surrounded by trees and bird life. It is a large property with plenty of garden space. One of the former community support staff approached us about the idea of running a community working bee on the property with the aim of helping the community to know and understand who H is. Over 100 people turned up to the working bee which was very moving for everyone involved. The house is now completely transformed. One lady who turned up at the working bee now visits every Monday to help develop a community garden. Because of his previous traumas H struggles to trust people but things are slowly changing.....He is now starting to talk and engage with people albeit through the safety of his now open bedroom window.”

There needs to be a much stronger investment in community capacity building initiatives which enable community organisations to support and include people with ASD and behaviours of concern. These initiatives include community education and awareness raising strategies, staff training in community development practice; and use of community planning and building strategies which guide organisations and enable them to adjust their environments to better meet the needs of people with ASD.

There are some strong examples of mainstream community organisations that have made a commitment to developing programs that are inclusive of people with ASD. These include the City of Banyule’s Sensory Friendly Events, and Arts Access Victoria’s and Arts Centre Melbourne’s Relaxed Performances. Relaxed Performances modify the audience and participation experience to enable people with disabilities to participate and engage at a level where they feel comfortable - people can talk, move around and exit and enter throughout the performance.

So far Arts Access Victoria and the Arts Centre have worked with Circus Oz and the Victorian State Opera to develop these audience experiences.

Banyule's sensory friendly events include film screenings in partnership with Hoyts; and festivals and other Christmas celebration events in partnership with local libraries and the Cities of Whittlesea and Nillumbik.

The leadership shown here by councils and other key Victorian arts organisations is important to recognise. It shows a commitment to adjusting environments that are potentially disabling for people with ASD and developing initiatives that are safe, supportive and affirming.

Interests that are embedded in community activities and programs are an important resource for these families and their children – they provide a sense of hope and possibility for the future. They are able to imagine a life lived in community, not apart from it.

Unconstrained by professional solutions, the investment in the voluntary resources provided by communities can often lead to highly imaginative, creative and previously unforeseen opportunities for people with ASD and their families.

Drawing on models of research and best practice

There are a number of models of best practice which need to be drawn on to inform a more sophisticated response to people with ASD and behaviours of concern. The Victorian Government needs to invest in the development of best practice in relation to people with ASD and behaviours of concern. A Behaviours of Concern Task group should be established by the Victorian Government to inform, guide and oversee the exploration and trial of various models in order to drive better practice.

Investing in Peer Support

“Thank you for tonight. I was blown away by what I heard. For the very first time since Autism entered our lives I was in a room with people who lived my life and that of my family. I don't even know if what I said was relevant as the entire night felt so surreal. If you would like to include me into the mix, I would greatly appreciate the opportunity to try and bring about the many changes for our family members that are needed. If there is anything I can do to assist, please let me know.”

“Unless you live with this, no one believes you.”

The power of peer support and connecting with others who have a lived experience of caring for someone with ASD and behaviours of concern was emphasised by the families we interviewed. There needs to be further investment in peer support initiatives which help people to share information and gain collective strength from sharing experiences and knowledge.

Carers are also a vital source of knowledge and information for support staff and other health, education and disability professionals.

There is a strong feeling amongst carers that they are not listened to or respected which leads to deep feelings of anger and frustration at the system that is supposed to provide them with support, reassurance and hope.

Peer support helps families to navigate this emotional landscape and to build knowledge and technical skills which enable them to support their children's development.

Supporting self management

"If we give you the funding, can you run it?"

"A team of professionals cannot deal with our sons and daughters but you are expected to do it on your own."

"They give the family the minimum because they know the family won't walk away."

"It felt like DHHS was getting out cheaply when we chose to self manage because they didn't have to fund the admin costs they would normally have provided if we were a service provider with overheads and on-costs."

"Prior to us opting for self management, the organisation supporting V was receiving \$400,000 per annum. When we agreed to look at direct payment the contract was signed over in a matter of weeks.....however we only received \$190,000 – less than half of what the organisation received."

A number of families associated with the Behaviours of Concern Peer Action Group have opted for self management of their sons or daughters individual support packages given their negative experience with the traditional support system. Whilst this has led to higher levels of satisfaction and a sense of control, it is not without its difficulties including:

- Inadequate funding of management and administrative infrastructure to support sustainability and quality outcomes
- Inadequate resourcing of staff development and supervision including access to practice coaching
- Issues associated with recruitment and retention of support staff

Part Three - Recommendations

1. Develop Best Practice

Over the years, VALID has attempted to move the disability system to explore and develop models which report success with this group in other settings, often overseas. We have been frequently frustrated by the lack of commitment to discovering best practice, and to work from a strong evidence base. We have often felt hope that a Minister or a Government has seen the light and will be prepared to invest in the research or industry development required, only to lose all momentum when the next election has come along. This is not the way to run an effective support system, and it's a lousy way to treat families experiencing extraordinary stress. The Victorian Government – in partnership with the NDIA -needs to invest in the development of best practice in relation to people with ASD and behaviours of concern. This should include development of a Behaviours of Concern Task Group to inform, guide and oversee the exploration and trial of various models in order to drive better practice. Some of the models to be explored should include:

- The role of the Practice Coach, which in our experience plays a critical part is developing and ensuring best practice is actually used and not just talked about.
- The use of the Mandt system, which appears to have achieved highly successful outcomes by recognising the effect of past trauma on people with ASD who are now exhibiting behaviours of concern as an expression of their post traumatic stress, often suffered in the course of their schooling..
- The critical importance of strong Multi-Disciplinary Team approaches, which include the family and person with disability, in ensuring all the disparate professionals are working to the same expertly developed and person centred plan

2. Support Self Management

A Framework needs to be developed to support families who elect to self manage their adult child's funds. This should ensure adequate funding that facilitates access to management and administration infrastructure; staff development and supervision; access to practice coaching and hands on behaviour intervention strategies.

3. Ensure Effective Coordination

Effective individualised planning, case management and support coordination needs to bring together people and resources across a range of contexts to ensure a coordinated and multi disciplinary response to supporting people with ASD and behaviours of concern. This should include:

- Development of multi-disciplinary teams which incorporate and are funded to implement the knowledge and expertise of behaviour specialists
- A whole of government approach which promotes resource sharing and a common understanding of how best to support people with ASD and behaviours of concern in key life areas – school, work, accommodation, health, sport and recreation contexts.
- A coordinated approach to transition planning which uses development programming and person centred practices to inform a range of life goals associated education, health, housing, vocational and recreation aspirations.

4. Develop Peer Support

There needs to be support for and validation of peer support initiatives which help families and their children with ASD and behaviours of concern to share information and knowledge and guide better practice. Parents are a vital source of knowledge and information for support staff and other health, education and disability professionals.

5. Build Community Capacity

Notwithstanding the important role the NDIA might play in improving the disability support system, the Victorian Government has a critical and ongoing role in building an inclusive society for all Victorians. It therefore needs to invest in initiatives which enable community organisations to support and include people with ASD and behaviours of concern. These initiatives include:

- Identification of barriers to participation in community life across a range of contexts (school, medical, work, sport, recreation, arts and culture, accommodation) and development of strategies for their mitigation;
- Community education and awareness raising strategies – including public campaigns and marketing which identify best practice in community inclusion;
- Staff training in community development practice; and
- Engaging Local Government and other key local stakeholders in community planning and capacity building strategies which guide mainstream organisations and enable adjust of environments to better meet the needs of people with ASD.

Conclusion

Thank you to the Victorian Parliament Committee for the opportunity to tell the stories of the parents represented in this submission, and to hopefully give voice to their profound sense of abandonment. One aspect of their stories has not been well captured, however, and that is the sense of their absolute commitment to their sons and daughters, and their seemingly boundless capacity to realise their rights. These families remain ever-willing to cooperate and collaborate and consult and co-design, in hope that those with the power to do something about the situation might eventually heed their advice. The parents represented through the Behaviours of Concern Peer Action Group would very much welcome the opportunity to present their case in person.