

**SUBMISSION TO THE VICTORIAN STATE INQUIRY INTO ABUSE IN
DISABILITY SERVICES STAGE 2 October 30th 2015**

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INTRODUCTION

Please accept this in response to the Interim Report to the Inquiry into Abuse in Disability Services 2015. I have read the Victorian Ombudsman report, June 2015, plus the submissions to this inquiry. My submission is based on experiences that include the training of disability support workers; employment within disability services; employment in accommodation services; the study of advocacy; and being the parent and family to a young woman who uses disability services. Appendix 1 is a brief bio.

I am concerned with the focus of the report to advise the NDIA. There is a need to move forward and learn from the current experiences of the violence, abuse, sexual abuse, neglect and exploitation of people using disability services. However, this takes away from the need to help people who have been abused; are being abused; have had no recourse; disclosing, or not, the abuse and suffering experienced under the current system. Both inquiries, including the Ombudsman Report, have been unable to identify the current incidence of violence and sexual abuse against people receiving disability services. Both reports do not identify individuals who have failed to report or respond. The submissions to this inquiry from individuals using disability services, and parents, are distressing and need to be addressed, they have a right to resolution. It must be noted submissions from individuals disclosing abuse wish their names to be withheld. They, and others, have a right to disclose and tell their stories to a community that will listen, learn and respond; one that will not abuse and vilify them; one they have a right to trust. It would seem a broader level of investigation needs to be undertaken.

There is a trend in the current rhetoric that the NDIA will bring welcome change to the lived experience of disability, families depending upon it with a sense of optimism and trust, a great victory has been won. Perhaps a reason for a low number of submissions; people believing things will change regardless of this inquiry. I am reserved and wonder about 'the new'; or 'innovation'; or 'real change'. The NDIA is an insurance scheme and a system for the allocation of individualised funds. In its development the NDIA have recruited people from DHS and disability service organisations in senior roles. The submission from St Laurence Services highlights the infancy of NDIA; the urgent need to address the current crisis; and to institute measures and safeguards for people now. The safeguards need to meet the needs of individuals receiving services under all current arrangements and, in the future, when arrangements change. The safeguards need to be in place across the community, reinforcing and supporting current legislation and human rights.

Disability service providers are conducting sessions advertised as 'information sessions about the NDIS'. I have attended. They are sessions in which major providers are marketing their services. The services are 'same old, same old', being 'rolled out', but with advertising to attract and convince that directing your funds to them is best. When I asked about the self-management of funds and the direct employment of support workers, there was a lack of information. It was given no

time, but stating the current NDIA statistics indicated only 1% of participants were doing so. 'It's not an easy thing to take on', I was told. The rhetoric around the NDIA changing the landscape will only happen if recipients are the managers of their funds; are given accurate information; and have the power to demand a high standard of service delivery or go elsewhere. Some may need considerable support to gain this power. Others will find it manageable, with minimal overheads, costs and time, bringing a greater value for the dollar.

The World Health Organisation advises the community needs to mainstream services with the lived experience of disability on the same continuum as other health and support needs identified by the community. Disability Service Providers need to change significantly to survive if such change will happen. I observe providers not wanting to shift from their positions of empire building, claiming caps on costs listed in the NDIA are too low. They have large, expensive, hierarchical, management structures considered sustainable. The desire to maintain the status quo may pose significant resistance to any 'new landscape'.

The Interim report and the Ombudsman explore in detail the lack of complaints process and the failure in reporting of violence and abuse of people receiving services from disability service providers. Both reports highlight the complexity of the system that has failed people. Both reports highlight, irrespective of significant safeguarding mechanisms in place many individuals have failed to meet a level of competency required to make the system work. There is an exclusions list that prevents support workers who have been implicated in violence toward residents from working in accommodation services. This example of zero tolerance must extend to all those who abuse, fail to report, or take action against acts of violence, abuse, sexual abuse, neglect and exploitation of people engaged with the services. Again, it would appear a broader level of investigation is needed.

Culture

Considerable importance has been placed on 'change in culture' as a part of the prevention of violence. We come from a community in which there are many messages about living with disability.

The message embedded in genetic testing; abortion of an abnormal foetus; the tragedy expressed when a baby is born with a medical condition, suffers an injury or accident; conversations about withdrawing, or not providing, lifesaving interventions, have an implicit message to some members of the community; 'yours is a life not worth living', a tragedy. If it's your child then the expressed attitudes can range from pity at the perceived tragedy, beliefs that parents need to grieve over having such a child, terms such as vegetable, not a vegetable, special, retarded, are frequently used today; there are often inferences of blame attached; infrequently a celebration of birth and often a withdrawal of real family relationships offered to the child. In our recent past, babies and children might be placed in institutions. More recently respite, early intervention (EI), and 'disability services' are offered to families. Friends and families believing they are not able to offer play dates, babysitting, sleep overs, etc., believing there are services with 'expertise' willing and waiting to provide; expressions such as 'you can't expect me to' or 'you need respite', are common. The baby/child and family often adopt a lifestyle that is imposed on them. One in which their child is not permitted the normal life cycle with opportunities and relationships.

This lack of opportunity and exclusion from community can retard the development of the family and prevents them from engaging in the life cycle most family's experience. Most importantly the experience of disability impacts on the child/young person/adult with the lack of real opportunity and inclusion from the start.

“Respite”

It takes a village to raise a child but for many the village turns its back. ‘Respite’ is offered to the families of babies identified with a diagnosis. One dictionary defined it as ‘a break from something unendurable’, a clear early message to the families, but most importantly to the child. Respite involves leaving one’s baby or child with a stranger, being told by the Council, or organisations, they employ trained and experienced staff, parents can ‘have a break’ they say. This is what is offered – time away from one’s child/baby, just as parents before me were told institutions were the best place for their sons or daughters. The focus is on the parents, relieving the perceived burden of the baby or child. This is often stated by the providers of such services. Organisations and workers are vulnerable to making negative judgements about families and children.

Children are forced to become accustomed to strangers; often a series of them; in positions of power over them; providing personal care often with a lack of privacy to the routines. This continues well beyond the years of which most children are expected to develop a sense of independence, privacy, ownership of body and protective behaviours. Resistance can be seen as noncompliance or behaviours of concern, punishment or restraint to enable completion of the personal care task, may occur routinely. Children learn to accept this ‘role of adult, stranger’ expecting compliance with all aspects of their care and behaviour. The service is driven by notions of ‘duty of care’; a diligent worker seen as one who can satisfactorily complete or impose routines of cleanliness, or be very protective, limiting what they may see as ‘risky’ situations. This can be in sharp contrast to the child care environment in which early learning is driven by a balance a duty of care and dignity of risk, in the company of other children.

“Early Intervention”

In addition, families and the baby or child are provided with early intervention services (EI). There is a lot of emphasis placed on the importance of early intervention, therapists investing their careers in it; the rhetoric supporting the necessity for all children to have access to it; and all parents to embrace it. EI may be a therapist, or 4, visiting the home; parent and child attending appointments with a therapist, or 4; parent and child may attend programs with other families of children with a diagnosis, up to the start of school.

EI staff can be employed by DHS; the disability service providers; private therapists who generally claim experience in the organisations plus mainstream services to children and families. EI can be the first introduction to the culture of disability service organisations. Some of the therapists having been there for decades.

EI is marked by therapists providing information about what is best practice; expect all to participate, parents sent home with tasks to do with their child. Parents can

adopt a language that EI is about 'fixing' their son or daughter and it is 'the parents duty' with 'cure' being possible for some. A lot of judgements are made about children and the families; a lot of advice is given by those who appear to know best, or we are told they know best. There can attitudes expressed in statements such as 'parents need to be educated', and 'we need to show them what to do', generated by therapists and picked up by support workers, and others, in the program. At times there are views expressed the parent may be to blame for the child's perceived difficulties; the parents not doing as they are advised or not trying hard enough; in denial; at a particular stage of grieving; mental health etc. Therapists and the support staff are vulnerable to using such labels and making such judgements. There is often a lack of interest or value, placed on the skills or experience the parent and child brings. Principles of family centred practice and person centred practice not necessarily well understood or implemented.

Depending upon the location, you can be expected to travel some distance if you want to be a part of it. EI is driven by the medical diagnosis and its consequent model of treatment, management and grouping according to impairment. A further message is sent to family and most importantly the child. Significant development of the child is often equated to the good practice of therapists and committed parents. Slower reaching of milestones associated with 'lack of commitment' or diligence. Goals are usually around speech, standing and walking. When goals are not reached there are strong messages of failure and 'not fixed' to the child.

Therapists are in positions of power. Therapist's assessments, views and reports often drive access to funding for families and individuals, for aids, equipment, supports etc. Suppliers unwilling to conduct assessments, provide quotes or supply, unless a therapist is present. Therapists write reports; the family may or not see. There is little opportunity to provide feedback in regard to the performance, skills and experience of therapists, often an assumption that anyone of the discipline is up to the job.

There can be rhetoric around particular EI practices and particular therapists causing parents to feel they urgently need to have them for their children. Waiting lists and exclusions can bring a greater sense of urgency. EI programs can become elitist with staff resistant to new ideas and change, some programs demanding high fees. Parents can feel a sense of purpose; they are making a difference to their child's life and future. This can happen in the absence of evidence based research. Parents and children can feel a sense of support and belonging in EI. Parents like to meet up with other parents. During EI parents are introduced to the idea their children be grouped together.

Notions of a 'hierarchy of impairment' can start in EI marked by conversations or statements from many engaged in the service, 'this child is high functioning', 'not as BAD as others', 'low functioning', 'very able', 'very disabled'. A hierarchy of impairment is being constructed and reinforced with children, and associated medical conditions and impairments, placed according to a level of social acceptability. This continues over the life cycle. The hierarchy can be imposed by the attitudes of community; can be from within the group; parents and those with the lived experience. EI therapists often have strong views about school settings and can influence the choices made by parents. Messages of belonging and exclusion are evident within EI groups.

Is there adequate evidence based research to support the expectations of EI programs? This is a good question to ask when you spend hours engaged in it. There needs to be more rigor in establishing evidence based research to support the child and their family's efforts in EI. Parents can be exploited by charlatans or those with egos of grandeur. Most importantly children can spend a lot of time whilst adults engaged in 'fixing' routines that might make no difference at all.

This is the beginning, the baby, the child, the parents being treated differently to a child or baby without a diagnosis. Some children being treated with increased negative messages according to the hierarchy established in the group. Significant negative themes are reinforced to Parents and most importantly the child. EI can reinforce themes of:

- The medical model of Diagnosis, Treatment and Management dominating
- Therapists considered the expert
- Therapists and staff vulnerable to making negative judgements about parents and child
- Therapists/EI have significant influence in families access to services/funds
- Medical terms and other tags used to describe children
- The term 'early intervention' is negative and labelling
- Separation from extended family and community
- Exclusion
- Segregation
- Grouping according to impairment
- Notions of a 'hierarchy of impairment' introduced and reinforced
- Messages to parents that others know best
- Parents disempowered in the way services are managed and delivered
- Often having to travel out of one's local community

Community efforts to provide well supported kindergarten and child care placements must be available to all. The focus on the early years to be driven by the themes of equal access to their community, enriching opportunities and learning skills.

“Compulsory Education – Primary and Secondary School”

Embracing themes that can be embedded in EI, 'respite' plus feelings of community exclusion can lead to choosing schools that are 'Special', 'Special Developmental Schools' or 'Specialist Schools'. Mainstream schools with the 'Program for Students with a Disability, PSD' ; considered possible for those further up the hierarchy, or 'perhaps just for a day or two'. It is my understanding, according to Department of Education' statistics, there is an increase in the numbers of children in school, but the percentage of children going to 'special' schools has remained unchanged over the decades. The 'special' schools continue the themes listed, these drive new themes and poor practice.

- A lack of curriculum driven education and assessment
- A lack of knowledge around student management and well being
- Staff are vulnerable to making negative judgements about students and family

- Continued use of medical terms or other tags for students
- Current media reports indicating the persistent use of restraint and seclusion in special developmental schools and others
- Low expectations of students, teachers and staff
- Acceptance of up to 4 hours of bus travel per day to school locations
- EXCLUSION FROM LOCAL COMMUNITY
- Planned, group excursions ‘into the community’
- Missed opportunities to identify and be engaged as a member of one’s local community
- A lack of parent and family inclusion and engagement

The experience of disability can mean these negative themes, or violations, continue through the life cycle.

The interim report from this committee has not identified the cultural beliefs and attitudes that enable services and schools to maintain these practices. I believe the practices are violations as were those which institutionalised babies, children and adults.

The evidence based research is overwhelming that students do best in their local, mainstream schools. OVERWHELMING, and has been for decades. Mainstream schools offer equity of educational opportunity and inclusion in local community. Sadly mainstream schools are often influenced by current attitudes and maintain themes listed above as ‘special settings’ do. The opportunities for real inclusion being undermined by the reinforcing of negative themes. This can be seen in student and parent decisions to leave the mainstream school for a ‘special setting’ and make a choice that is not supported by evidence based research. The decision driven by ‘protective attitudes’ toward the students, believing the ‘special’ settings offering a safer environment. Practices based on notions of a hierarchy of impairment are also present in ‘special’ settings with some students being bullied, excluded, isolated, and marginalised by other students and staff. Whilst other students deemed high on the hierarchy have their positions reinforced.

“Adult Day Services”

There is a well-worn path to adult day services for those who have had to embrace the above themes through EI and ‘special’ schools. There are established pathways for students from Special Schools to Certificate 1 Work Education (TAFE), based at TAFE. Students from Special Developmental Schools appear to attend local Adult Day Services as a matter of course.

The themes continue:

- Day services and TAFE programs follow school hours and school holidays, with minor variation.
- The TAFE program is for school leavers and the Day services provide for ages 18 plus, participants can be in Day services well into their twilight years
- Grouping according to impairment persists
- Grouping according to age is a more recent trend
- Travel time often expressed as further ‘respite’ to ‘carers’
- Activities conducted by support staff, hit or miss, in terms of appropriate skills

- Qualification or training of staff can be varied
- Staff are vulnerable to making negative judgements of individual and family
- Language used at home, used in service, hit or miss
- Often English language competence in workers, lacking
- Notions of Community inclusion often paying lip service at best
- Lots of sitting around
- Education, hit or miss

Language

The use of particular words and expressions are part of our culture. Changing language can be a driving force in bringing about cultural change. The submission from Women with Disability Victoria (WDV) placed emphasis on this.

Women with Disability Victoria (WDV) challenged the term ‘vulnerable’ (and other terms), challenged the culture in which language continues to disempower, although the committee mentioned this view it was dismissed quickly as WDV did not provide an alternative. The term ‘vulnerable’ persisted over the course of the report and submissions, this is persuasive in itself; leading the readers to accept this term should be used. I was disappointed the view of WDV was not explored and considered further, as part of the strategy to prevent violence. Examining the use of appropriate terms as an opportunity to examine cultural attitudes. The advice from WDV, was at the core; how to change persistent negative attitudes. In addition, essential to cultural change and the prevention of violence, is to listen and engage with voices of the lived experience. It is important as a community we stand beside and stand behind.

The report refers to ‘the profoundly disabled’, ‘profound intellectual disability’, ‘totally reliant on others’, ‘people who cannot speak or communicate for themselves’, the report talks about ‘the vulnerable’ and having a special check for working with ‘vulnerable people’.

I would like to support WDV in the ongoing challenge to the language and the cultural beliefs we continue to express about the experience of disability. There are many users of disability services who have little or no speech. We have all learned from early studies in communication that 85% of communication is nonverbal. Therefore individuals have a great capacity to communicate without words. Referring to people as ‘nonverbal’, assuming low intelligence, little communication and decision making on their behalf is part of the culture that needs to change (addressed in the submission from Communication Rights Victoria)?

Recently I attended a presentation in regard to the welcomed changes in legislation to victim’s rights, in South Australia. The audience was told of the need to support witnesses with intellectual disability as credible witnesses. Historically intellectual disability has been viewed as children have been; vulnerable with credibility as a witness questioned. An example was given of young woman of 24 years of age; she was described as having the mind of a 12 year old. There seemed to be an acceptance of this way of speaking about the woman and confusion when I raised it as inappropriate and supported notions of intellectual disability and child. Not long ago the Age reported a woman saying, although her daughter was 50 (or so) she had a mind of a two year old. I felt compassion for the woman. She had lived apart from

her daughter, never having had the opportunity to learn this was wrong. As a community there is still an acceptance of this drivel. It's a violation.

The 'profoundly disabled' is also a term that is not helpful. It doesn't tell us anything about the person. An understanding and respect for a person's communication, Assisted and Augmented Communication (AAC) and an appreciation that we have different ways of communicating, some requiring significant support through a close relationship; must be part of the cultural change needed to prevent violence.

My daughter has suffered all kinds of tags and terms used to describe her – I see it as a violation, e.g. severely disabled, profoundly disabled, medical diagnoses X3, nonverbal, vulnerable, at risk, like many an exhaustive list, often depending upon the age, education or profession of the name caller, often the increased level of education and age, bringing a greater use of the tags. What I have observed is those who use these terms will be anxious in her company, may ignore her and at best wave or provide a simple greeting, sometimes in a louder than necessary voice and/or likened to a greeting you may have for a child. Little engagement follows.

My daughter is nearly 21, she communicates by going to the right for yes and the left for no, it can be unclear or the answer might be somewhere in between, on occasion she will use her device and can point if supported, you need to spend time with her or you will not understand and value her communication. She uses a wheelchair and needs support to move and transfer her position. She eats and drinks a wide range of softened food and slightly thickened liquid, with assistance. People greet her differently if they know what she can do, engagement and relationships can follow. She reacts strongly to language and responses that do not see her as a person, sneers, and withdraws often demanding to leave the room. I think she sees it as a violation. She is right of course.

There is a plethora of tags and terms used across disability services which are disrespectful and indicative of a lack of value of the person. Accommodation services are often described by support workers and their management in a way that denotes the differences in resident. 'Incontinent House', 'Dual Disability', 'Behaviour House', 'Medical House' and 'Political House'. The political house was interpreted by support workers as 'the residents who have parents and family who have gone to the Minister and/or media with their complaints and have been given improved conditions'; with warnings to workers 'there are parents from hell'. 'Non-verbals', 'wheelchairs', 'absconders', 'downsy's', 'ID's', 'high needs', 'nappy wearers', 'mind of a child or baby' are all terms I have heard support workers, managers and trainers use, when referring to people. Similarly more endearing terms such as 'my children', 'special' and 'munchkins'. Such name calling needs to be taken as seriously as the use of racist terms. As a community we have moved away from using terms such as 'cripples' and 'retards' it would be pleasing to stop using tags at all. Often workers in disability services can be told they are 'special people', 'remarkable', 'wonderful' for doing what they do. The messages are embedded. My daughter has endured being pointed at, with children and adults exclaiming 'what's wrong with her' or 'what happened to her'. I am sometimes referred to as an angel or very special. Recently, we were pursued by a very enthusiastic god botherer at a shopping centre wanting to pray for her. Little has changed over her 21 years. Reminiscent of the UK disability service provider of the past called 'Yee Poor wee things'. There is considerable

ignorance around the causes of medical conditions and people are often curious or misinformed. At one of my daughters schools one of the aids told me my daughters problems were a result of me being too old when I had her and that I ate too many chips.

Those employed in disability service organisations come from wide range of cultural and language backgrounds and reflect the diversity of the Australian population. Cultures vary in terms of how they might interpret the incidence of impairment and medical conditions. Beliefs can include that it is a punishment for having erred in this life or a previous life; it can be seen as misfortune and to be avoided. Conversely there are beliefs that some impairment signifies being an angel or having particular powers. Such beliefs are embedded and difficult to shift, they can lead to attitudes and behaviours which place a lower value on some lives, conversely elevating others. Competence in English and the ability to talk through, reflect and adopt a reflexive approach to one's attitude to supporting people is essential. There needs to be much greater an emphasis placed on normalising our language.

Responses to the Questions set by the Parliamentary Committee

1. Experience of Disclosing or Reporting Abuse.

I am reporting the experiences I have had in complaining and reporting violations of my daughter's rights. There is a culture of silence expected in regard to the discrimination and violations of rights that occur within the community and disability service organisations. The messages are clear. You receive a degree of acceptance if you are silent, if not, you are greeted with disdain and an adversarial system begins. This is the environment in which disclosures of abuse are made.

1 Complaint to Equal Opportunity Commission re Victorian Arts Centre

When my daughter was about 7 years of age we attended a performance for children at Hamer Hall. There were parents with children sitting in the front, on the ground and in the aisles, we joined them. An usher approached, I was told that I had to leave my daughter in her wheelchair, at the door, against the wall, the rest of us (2 adults + 3 children) were directed to seats in the audience perhaps 8 metres away from my daughter. She was expected to stay there alone, people coming in and out in front of her view. I refused, complained, they were placing her at risk and discriminating against her etc., they insisted on the back wall. I lodged a complaint with EOC with support from a lawyer from Disability Discrimination Legal Service.

The mediation was well managed. The Arts Centre came with 3 representatives, one a director and two managers. The two managers attempted to justify the actions of the Arts Centre, debate ensued. The director, articulate and conciliatory, apologised, agreed that a young girl should not have been treated in this way. He interjected a number of times with the same message and then indicated he was taking over saying nothing justified how she was treated. He assured us the reparations would be made within 6 months, my complaint would assist him securing funding. He thanked me. After 6 months they contacted me saying they were on the way, enclosed pictures. After 12 months we were invited to see the new seating arrangements for people who used wheelchairs. I had agreed prior, with lawyer, he would request the Arts Centre

make their website more accessible as a part of the reparation, they agreed. The lawyer had received complaints in the past from others. A great result, quick and painless, they agreed the process and result did not need to be confidential.

What struck me about the process of this complaint?

- The lawyer was well versed in anti-discrimination law.
- His service had received a number of complaints against the Arts Centre over time - the Arts Centre had a 5 year action plan in place.
- He decided although there was an action plan my daughters complaint could challenge it
- He took the opportunity to include reparation in response to other complaints he was privy to
- The director of the Art Centre was intelligent, thoughtful, fair minded and turned a complaint into an opportunity for his organisation. I think he was also keen to do the right thing- was clear about what that was - he had vision
- He was happy to allow the outcome to be public appreciating it could be a learning opportunity for all
- This was the ideal response

II Complaints to Local Council re Respite Services

My daughter was a challenge for me, after a traumatic birth she had a range of difficulties. In my mother's group a number of us were having difficulties around our babies feeding and sleeping. The other mothers were referred to Mother/Baby bonding programs. A referral was made to the Council for me to have respite services. I was told I could not use the hours to pursue work; I had to engage in some kind of hobby or interest and leave my baby with a stranger. They suggested tennis or macramé; I wanted to work.

Although my first and only, I was well educated and had a career working with youth in residential services. When I was presented with experienced respite workers I quickly determined whether this was accurate or not. The first young woman lasted a few months, I was told she was fantastic, their best. The woman disclosed a back injury which made lifting babies difficult but working in aged care no longer possible, nor did her job description include any domestic work, she had gone to a reiki healing workshop and would care for my baby, she had no experience with babies. After what seemed like a lot of crying time from my baby and TV watching from the respite worker I complained. I was told they had no one else available, I agreed to wait.

My experience of respite services from two local councils over a period of 12 or so years, was a series of women, mostly older, who usually working in aged care, they often had low levels of education and often spoke about my child in terms I did not like. Or such like'. The women would initiate these conversations with me in front of my child. I found they often had few skills to work with children; the TV would be central and hit or miss in terms of what home duties might be taken on. The service was often unreliable with mistakes made with bookings; there were rules around having any direct communication with workers which might enable clarity, or being informed if someone was running late. Some workers were unhappy with working alone with my child, involved the union, and insisted on uniforms and badges, my child branded if out of the home with them. Two of the workers had personal

disagreements and one played a recording to me of the other making physical threats against her.

I terminated both councils in their offer of 'respite'. The service made our lives more difficult. We did not like the attitudes or a culture coming into our home imposing their view upon us. We did not like leaving our baby/child with strangers. They were unreliable. Notwithstanding there were 2 women over the years who we thought were appropriate and skilled, most importantly our daughter really liked them. I was rarely asked for feedback by the service. I would ring and express concerns about support workers – their language when referring to my daughter or others they provided a service to; their skills or lack of interest in child friendly activities; at times a lack of will or avoidance to provide what was necessary; or giving too much information about their own personal lives. When I gave feedback and complained I was given a strong message I needed to be grateful and the worker was appreciated by others. There was never any ongoing discussion about my complaints and the women were simply rostered on with other families, swopped around. Naturally parents discussed experiences with different opinions about what constituted a good worker. We would discuss the ones to avoid, generally workers who had displayed dishonesty or a lack of engagement or valuing of our sons and daughters. We knew the ones to look out for. In addition, one learned that if you expressed enthusiasm and preference for a worker this could go against you, the provider suspecting dependence or over involvement. Invitations to birthday parties considered a sign of 'over involvement'. There was a reluctance to complain directly to Council, fearing the service will be taken from them. Themes emerged.

- Minimal standards of skills and education of support workers
- Often a lack of will to disclose any work history of support workers
- Message to families - be grateful
- Little or no opportunity for real feedback
- Reluctance to complain
- Complaints considered personality differences or poor compatibility
- Relationships set by Council
- Focus on respite to parents and not the child's interest or activity
- Workers then believing that pursuing their own interests was acceptable

The process is disempowering; the quality of care more often than not substandard; everyone knows it; but you need to be quiet about it or you will get less; families are subjected to this for years before their son or daughter might get to an adult service. There is an acceptance that develops with parents, marked by statements such as 'it's only a few hours' or 'I guess TV is not the worst thing' or 'the child will learn there are all sorts'. The baby, child, young person grows up with this notion that being left with strangers is normal. Time spent can be largely in front of the TV. They too must learn to be grateful and not to complain, complaining might lead to getting less, and they are alone with the adult support worker and dependent upon their good will. The power relationships are being set. The child is getting the messages loud and clear. This is the environment in which families and individuals make complaints or report abuse. There are residential respite services. I would not send my daughter there. I believe they are unsafe places.

There are early warning signs, those who are close, pick up. My daughter always grimaced, unusually, when a particular woman would enter the house, she would call out to me if I left the house or was angry with me on my return. I found the woman tiring and inappropriate in her conversation, often speaking angrily about her life stories when I asked 'how are you'. I explained to Council that I did not wish to have the woman's services anymore; I don't think they really understood or whether they believed my daughter was able to communicate her feelings. I heard later from another parent she thought the woman had stolen from her but couldn't prove it, another parent stated she had been told the woman had hit a child. Concerns and feelings about people need to be listened to, they can be about compatibility but they can also be early signs the worker is not coping or poses risk. Demonstrating a lack of valuing and respect, a lack of interest in who the person is and what they want, can lead to an environment in which those feelings of worker toward individual can escalate into something more sinister – anger, resentment, the worker developing a sense of enjoyment in the power.

What struck me about the process of these complaints?

- The booking person listened and acknowledged the complaint
- They were seen as personality differences
- Support workers would be swopped around
- A lack of process, interest or understanding

III Complaint to Early Intervention (EI) re access

There was an EI program I wanted my daughter to attend although it was up to a one hour drive from home. There was a multi-disciplinary team. I was keen to use the services of the speech therapy and some of the physical therapy. The physical therapy followed a set regime, part of that was to bind the children to frames, in standing positions, if they were unable to weight bear. I was not comfortable with that and it was contrary to a home based physical therapy we were pursuing. I asked for an exception to be made for my daughter, just in the rigid standing. I was told this was not possible. I asked if we could just have the speech therapy services. I was told this was not possible. Either I followed the regime they set or my daughter could not attend. We did not attend.

What struck me about the process of this complaint.

- One of the therapists took the complaint and responded to it
- Nothing put in writing
- No recourse or process
- Authoritarian

IV Complaints to Community Based Respite program and Disability Services Commission (DSC)

My daughter attended a 'respite program' each Saturday, once a month, on a Saturday for 4 hours, from age 6. The organising group were granted funds and ran the group autonomously for 10 years with little involvement from the very supportive centre manager. The group was planned for children who needed individual support; lived

locally; were often excluded from mainstream activities; and were compatible. The group was diverse yet exclusively children with a disability. I don't think there was one complaint over 10 years from the group of 8, or so, young people and their parents. Communication was direct, there were always the same staff with only occasional fill ins. Although I would have preferred an inclusive setting the women offered a lot of different activities and sometimes went to events. When the centre manager changed, however, so did the group. The staff felt unsupported, resigned, the new staff were recruited in an ad hoc way and there was no consideration given to compatibility of the group. Children were often yelling, running around, throwing things, leaving my daughter feeling unsafe. Parents and staff complained, nothing changed, most of us left.

Sometime later I was contacted by the Community Centre re the respite program, there was a new Co coordinator who wanted to revive the group and was contacting all families. We met, he was keen, responsive and he delivered. The group started up again, he divided the group up which seemed to make my daughter feel safe and had some good staff. A few months later he resigned acknowledging difficulties with the management. A new co coordinator started, she was also employed as an aid at the local special development school. She decided that the Saturday social group would be better off held at the school setting and moved it. I complained, to the Co-coordinator and manager. They told me the group would be located at the school and my daughter could attend or not. My daughter attended for a short while, there were problems, again I complained to co-coordinator and management. I was told there would be no change. I lodged a complaint with the Disability Services Commission DSC with a range of concerns.

- The group was intended to be a week end, community based activity
- The school was deserted on a Saturday
- The children were confined, all doors and gates were secured
- I was unable to get anyone to hear when I arrived at the gate and I could not enter
- The accessible toilet was a distance from the activity area creating problems with my daughter getting to a toilet and/or supervision
- The mix of children was poorly considered
- One young boy would grab the attendant control to my daughter's wheelchair with no understanding of the damage he could do to her
- The co-coordinator and manager referred to the group as 'wheelchairs' and 'absconders'.
- They believed outings were too risky and that the setting needed to be secure
- My daughter had never been locked up in a secure setting before

The DSC consulted with the manager of the centre then contacted me. I was told the centre manager was very keen to please and was trying to do his best to please parents. He suggested I had not tried hard enough to consult with them, said he sounded like a good guy. After this call my daughter was excluded from the program. Parents telling me I should have been grateful and should not have complained. I had upset the Co-coordinator.

I let the DSC know my daughter had been excluded; other parents seemed to know about my complaint although I had not informed them. The DSC pursued the complaint to conciliation. Conciliation was planned around the times that were convenient for the Co-coordinator and Manager, I fitted in, that appeared to be the expectation. I found the process lacked professional skills in conciliation; at times the communication was too familiar with attempts to be charming. After some hours there was little gained. There were some telephone calls from the DSC after this, during evenings, at dinner time, I was informed the Co-coordinator and Manager were being given 'awareness training'. My daughter was invited back to the program, she attended some events. The Saturday program alternated between the Special Developmental School and the Community Centre. My daughter was not happy with the events so did not continue. It is my understanding that when the co-coordinator resigned the group no longer met at the SDS.

What struck me about the process of this complaint?

- DSC had a very clear allegiance to service provider
- DSC did not see my daughter being confined as a reason for complaint
- DSC did not see the language used to describe participants as reason for complaint
- DSC saw my daughters exclusion from the program as a reason for complaint
- DSC did not see the initial confinement of my daughter or the language, as early indicators of a service that was struggling, therefore posing potential risks to participants
- If the initial complaint had been responded to differently, more seriously, then the behaviour of the service may not have escalated to excluding my daughter from the program and vilifying me
- DSC lacked professional skills in conciliation
- DSC did not provide advice, direction, leadership or vision
- I complained to the Commissioner about the experience
- Neither the co-coordinator or manager demonstrated an understanding their behaviour was not acceptable
- I think they learned parents could be difficult and not grateful enough

V Complaint to Equal Opportunity Commission re Council Youth Group

The local council ran a youth program for young people with a disability. When my daughter applied they said she wasn't suitable. Too disabled was the term used. I complained to management and went to a local council meeting, no change. I lodged a complaint with the Equal Opportunity Commission. The mediation is confidential. Council accepted my daughter into the youth group.

What struck me about the process of this complaint?

- Council lacked a process to consider my complaint
- Council did not see their actions were discrimination, they appeared genuinely surprised

VI Complaint to Council re Youth Group

My daughter attended events and enjoyed some however I was aware she became reluctant to go.

- There were a number of older women (55+) who supported the program, unlike any other youth program, one would kiss and hug my daughter regularly
- the woman told me one of the participants, a young man of 27 yoa (my daughter 14 at the time) kissed my daughter. 'What's in a kiss, your daughter smiled', she said. I said I thought this was not appropriate
- It was usual practice for the Council to include this wide age range, I had expressed dissatisfaction about this
- My partner was an hour late one evening to pick her up, the woman had stayed back with my daughter till he arrived. I was grateful so did not complain about the kissing
- I knew the participant and his mother. He lived in adult accommodation services, I knew there were concerns about him kissing young girls at shopping centres, and complaints had been made.

At one of the activities I saw my daughter cringe in response to the woman kissing and hugging her, the woman did not seem to be aware. I told her I observed my daughter trying to pull away and suggested it was not appropriate. The woman agreed saying she had got use to this from working in a day service; they hugged and kissed all the clients. 'Who else is going to', she said. I assured her my daughter received significant hugs and kisses at home or by those close to her. When I returned to pick my daughter the woman fled, crying, others saying she was very upset by me. They told me I should be grateful she had agreed to work and they had difficulty filling the support role. By the Monday morning we were all on the telephone to Council management. I was told by the management that other children might really like this physical contact. I complained about the 27 yo guy who kissed her. There was no response. I got the message that I had nothing to complain about. The fact my daughter cringed was not considered her communicating dissatisfaction, and it was unreported by the worker. I did not contact the Council further and my daughter stopped attending.

What struck me about the process of the complaint.

- Lack of interest or considered not serious
- Acceptance of the behaviour
- Lack of interest in follow up
- Withdrawal from the group seemed appropriate response
- Council did not see a reason for them to change
- The initial exclusion/discrimination toward my daughter was a warning sign the service were struggling

VII Complaint to Disability Services Commission (DSC) re Activity Group run by Parent Group

A parent group organised a social group for young people. My daughter was keen; after 2 disorganised events in which we turned up but found were cancelled; we were told my daughter was too 'high needs' for the group. They developed a selection criteria which stated applicants had to be 'independent when in the community'. I complained bitterly but was told they would not change. I was told they would be running a group for 'high needs' shortly. Some years later, about 2 I think, I was contacted and told there was group my daughter could join, she was about 16/17 years of age. It was planned to be in a Specialist School – across town (45 min travel), on a Saturday afternoon, for other 'high needs' age 12 upwards, they would be playing wheelchair travel and accessible toilets available. I complained and made suggestions, advised on the location of accessible toilets within the community. The Specialist School was made up of a number of buildings; all would be empty save the small group of perhaps 6. The building would be locked. It was set down in the street and well away from residential or other buildings. I believed the setting posed a risk, I believed my child should not be locked up on a Saturday in an empty specialist school. My daughter should not be segregated, isolated, confined and grouped according to impairment.

- I put my complaints in writing to the committee. I was told by the Staff (some being parents of young people in the original social group, the 'independent' group they called them); some of the young people in that group, and other parents all thought this was exactly what 'high needs' children needed.
- I lodged a complaint with the DSC. Without informing me they contacted the parent group about my complaint. The DSC let me know they could not get involved as the group were not a registered disability service provider. They were using philanthropic funds for the activity. They said the parent group were very happy to hear from me.
- A member of staff contacted me saying the group was going ahead, as planned at the Specialist School.
- I contacted the philanthropic groups who funded the activity to ask them if they set any standards about how the group is delivered. No, they said. My daughter did not attend.

What struck me about the process of this complaint.

- DSC and parent group believed segregation, isolation, confinement and grouping according to impairment is acceptable for children and young people they call 'high needs'.
- DSC should have consulted me before contacting the group if they were aware they could not conciliate
- Contact by DSC did not change the organisations behaviour
- The hierarchy of impairment is evident with parents and their sons and daughters
- Perception of being higher on the hierarchy can lead to assumed position and power over others

- I have a different view of discrimination to the DSC and those delivering services to my daughter

VIII Complaint to Yooralla and the Disability Services Commission (DSC) re delivery of therapy services in school

My daughter attended a mainstream school in which Yooralla provided therapy services. The school requested the visiting Physiotherapist and Speech Therapist include my daughter for services. It was our routine that on a Friday I would take my daughter to DEAL Communications for individual communication support with a special education teacher. I told the Yooralla therapist. As a result Yooralla would not deliver services to my daughter as they did not approve of DEAL Communications. I complained to Yooralla therapy services manager. I asked if we could just access the Physiotherapist and not the Speech therapist if they had a conflict. I was told no. I lodged a complaint with the DSC. They contacted Yooralla about the complaint and were told the same story. Yooralla stated they did not use DHS funds in the therapy delivery so they could manage how they wished. DSC said they could not do anything. My daughter did not receive Yooralla services.

IX Complaint re Agency delivery of support staff

About 2 years ago I had a surgical procedure and was told not to lift or strain for 6 weeks. My partner works full time and my daughter was going to school, we needed assistance. The hospital social worker made an application for 'respite funds' specifically for this purpose. Carers Vic said I needed to go through a particular agency. We made contact and were told it might take a few days to organise support workers. We asked for 2 hours help in the mornings, it was school holidays at the time. There was no assessment and minimal information given over the telephone. I asked if the agency could register and employ 2 support workers who worked with my daughter, both agreed to register with the agency. The two support workers sent their CV's in and were told they were not suitable. The agency required a Certificate 111 in Aged Care (or Disability I think). One support worker had a Certificate 1V in Disability, Dip Ed in teaching and a Degree in social science. The second had a Certificate 1V in Disability and Certificate V1 Advanced Diploma in Disability.

We used the agency for 2 weeks, they sent 7 different women, some with experience in using a hoist others said they did not feel comfortable in using it. We never had the same person long enough to train them in our daughter's routines and supports. We were never able to leave them alone. One of the 7 was a person we would comfortably employ and most importantly our daughter really liked her. The workers were often late, up to 1.5 hours, sometimes no call, they would tell us they rang the office but we would not get told. After 2 weeks of this we stopped the service and my partner took a month off work.

When I had recovered and things were back to normal, I contacted the agency to give feedback about how it was for us. I think the young woman I spoke to started crying, she said she had planned the roster and had worked really hard at it, I spoke to another woman who decided the support workers lacked training – 'a training issue' she summed up confidently. I asked to speak to Manager of the service, I was keen to

give my feedback, and they said they would leave a message for them. I tried a couple of times, never got through. I never received a call back.

X Complaint to Council and Yooralla re Council based Activity

My daughter attended a music group for 2 hours once a week run by the local council. It was advertised for people in the area with disability and mental health, parents and carers, and started in February. My daughter had finished school but her ISP had not come through – it came in June. I attended the group as my daughters support person, she was not happy about me going but I had been unable to employ and pay a support worker.

One of Yooralla's Day Services also attended. There were up to 9 participants with 2 support workers.

- All participants had similar support needs to my daughter, perhaps the same diagnosis, I don't know. They arrived in a vehicle referred to by the support workers as a 'truck'. They were often late, filed in from the back entrance, sometimes leaving people at the door whilst they ran and got another.
- In the middle of the 2 hours the facilitators called a break and provided tea, coffee and biscuits. My daughter would usually want something so I provided meal assistance whilst having a coffee myself. The other participants all required meal assistance, they were not offered anything. One young woman complained quite loudly indicating she had food with her she wanted. One of the support workers scolded her saying, 'this is our break time, you know how you like to have yours, and well this is ours'.
- There were occasions when participants required the toilet
- There were occasions when a number of the participants did not want to be there
- The toilets were upstairs, one outside. None of the 10 participants could access any of the toilets
- I complained to council over the course of a couple of weeks, via email. Each reply seemed to include another person; we were going up the ladder. They were unwilling to change the location although most of their other centres had the accessible toilets all participants required. There were a range of reasons. They were very keen to invigorate the area this centre was in.
- The facilitators were supportive of me complaining. They did not like the location but feared losing funding and their jobs if they asked for a change
- The Yooralla staff were not interested in the toilet issue
- After the refusal I stated I would take it further unless I was assured that no person had to sit in their own urine or faeces during the next group.
- The group was post poned and some weeks later moved to a centre with accessible toilets
- I complained about the lack of support to the participants from Yooralla, Council said they were meeting with Yooralla and would let them know of my concerns, nothing changed
- I contacted Yooralla through their website where you lodge complaints and compliments. I explained my complaint but did not identify the activity or the day service. I was contacted by Yooralla asking for the information as they wanted to follow up

- I gave the details. In return I received a letter from the Yooralla centre manager, she had never attended the program, defended the staff and stated the participants had all communicated in their support plans they did not want tea, coffee or a biscuit at break time.
- My daughter hated going
- When she had an ISP and could go with a support worker, she returned
- Her support worker reported the same dynamics and that my daughter did not want to be there. She stopped going.

XI Complaint to major Hospital and the Health Services Commission

Last year my daughter was admitted to Hospital. She was put on the Neuro ward, by day 2 she was sharing a room with 3 adult men. I am use to the expectation of having to stay in hospital with my daughter 24/7, sleeping on a chair beside her. Sometime after midnight, I found it difficult to sleep so sat in the hallway outside her door reading. 20 minutes later I hear her call out; the nurses were in their room having snacks and did not hear her. I went in to find one of the male patients standing over her with his hands on the rails of her bed. I pushed the nurse's button twice and told him to go away. By the time the nurses arrived he had moved away from the bed and was at the curtain that divided them. The nurse asked me who called. I explained I had found this man standing over my daughter, hands on rails. Her immediate response was 'nothing would have happened he is a nice man'. They guided the man back to bed and left. I spent time with my daughter and felt comfortable she was ok. A doctor arrived an hour later saying she came to check on my daughter, she was asleep, the doctor looked at her and said she thought she looked fine. They would not transfer anyone to another room, I remained on guard.

That night I tried to talk with the nurses again about what had happened. They claimed nothing happened; the man was at the curtain. I wrote a complaint, next day demanded a meeting with head nurse, a room not with men. My daughter was transferred. They interviewed the man with an interpreter, assured me he was horrified that I thought he might have hurt her. The ward said they would try not to place my daughter in a room with men next time, if possible. I spoke with Patient Liaison who thought I got a 'good result'. I spoke with Health Services Commission who thought I got a 'good result'. I gave up, exhausted, never to go back.

I spoke to my daughter's neurologist she thought I needed to stay over as the Neuro ward could have patients who could be quite unpredictable putting my daughter at risk.

XII Complaint to Equal Opportunity Commission and VCAT re lack of support services at Primary School (Department of Education)

- The complaint was not resolved through mediation
- I took the complaints to VCAT
- The Department of Education won and I was considered unreliable witness and treated as vexatious
- After the hearing, I was instructed by the lawyers to D of E (Minter Ellison) to sign a document saying I would not criticise the Department of Education or

they would take me to court to claim costs. They tried to force my partner to sign, he refused.

- It demonstrated the lengths organisations will go to protect their reputation with the legal profession happy to go to any lengths making lots of money out of it.
- I would think Minter Ellison earned thousands
- When we applied for enrolment the local secondary school vice principal stated ‘we don’t want people like you in our school’, she said she knew about my case
- My daughter attended a mainstream secondary school across town. We drove her there and picked her up for 6 years, an hour each way in traffic.
- In one of the meetings with the school the regional disability officer attended, I hoped he would be supportive. When I was expressing some concerns about my daughters school experience the officer put his finger to his lips making a shushing sound to me, ‘remember’ he said.

2. Human Rights and Safeguards

How can the rights provided under the Charter of Human Rights in Victoria be maintained for people accessing disability services in the transition to the NDIS once it has been fully rolled out?

There is a lack of evidence to show that safe guards will be in place under the NDIS or that disability services will operate any differently. In fact, there is some evidence to suggest otherwise in terms of the concern around the capping of unit cost for support work and other. The parliamentary committee needs to respond without making assumptions the future will be different under the NDIS.

The broader community and whole of government needs to be ensuring that mainstream services are developing capacity to respond to the experience of disability and include all.

DHS, and the organisations they fund, must be instructed to develop other models of support and housing. Encouraging and supporting individuals and their families to go beyond the current system. The solution for my daughter is to be engaged as little as possible with disability services and to be engaged as much as possible in her local community and or mainstream education, recreation, housing and interests. Well supported in a way that meets her needs. There is safety in the community.

- We directly employed a young woman for 10 years as a support worker for our daughter. She is now a family friend – we visit.
- Another for a year, moved onto other work, now a family friend.
- Another left after 7 months, wanting something more structured, it wasn’t working for us either.
- Another support worker has been involved for over 12 months, 4 days a week. We talk about everything, swap ideas, what works, what doesn’t.
- We develop relationships with the support workers and ensure our daughter is happy with her relationship with them.
- We have never had complaints about them, any concerns well discussed.

There must be a willingness and a clear vision as to what constitutes having ‘an ordinary life’; an agreement that every person has a right to it, with no ‘yes buts’, an acknowledgement the conditions in which many people live within disability services, are sometimes at best, just an existence or survival.

Supported Housing needs to engage with progressive and innovative models driven by residents, service users, their families and the broader community. The model of a Community Residential Unit (CRU) is only one of a whole suite of options that could be developed. The CRU’s are often purpose built driven by notions of ease of supervision by support workers offering ‘fish bowls’ with little personal space and an expectation people live as a group, during most of their day time hours. A recent article in the Age newspaper written by the Public Advocate endeavoured to convince the reader the CRU’s are like families. This is unhelpful and misguided. For many the CRU operates as a prison marked by segregation, confinement and little personal space.

A model of supported housing provided under Mental Health is the Haven. The Haven provides supported housing for 14 tenants – there is a foundation that includes parents, community members and mental health professionals. (Allan and Isobel Fels being 2 of the founding members). Some of the members of the foundation volunteer at the Haven. There is a committee of parents and carers who support the Haven. All family members are welcome; an essential ingredient to the model, with their views and contribution valued. There is a tenants group and Prahran Mission are contracted to provide staff support 24/7. After four years the tenant group is stable, happy and state they feel safe. I have attached a document – The Haven South Yarra Tenant Experience. It provides an outline but most importantly a rigor in ensuring the tenants experience is at the for front. Including the Haven model is not to suggest there be a ‘roll out’ of such, but rather to highlight the result of families, those with the lived experience, service providers and the broader community working together, developing housing that best suits the current tenants. It is not without tensions. The tensions evidence that voices are listened to; conversations and debates well accepted; with outcomes that have engaged with others to ensure tenants’ rights and wellbeing are primary.

Footscray Community Arts Centre Art Life program is funded through DHS as a day program. What makes it safe with participants engaged and productive?

- The centre is open to the public with a café well supported by the community throughout the day
- It is a desired, very ‘hip’ destination
- The centre has classes alongside the Art Life Program that are well attended by the community – all ages
- The centre has an art gallery open to the public, there are many visitors throughout the day
- There are opportunities to engage in mainstream centre activity
- The classes are conducted by professionals in their fields of dance, art, music and animation
- The arts based skills pursued by participants are valued

- Performance and exhibitions are mainstreamed and showcased to the community including international opportunities
- The classes have a combination of peer support and individual support if needed
- Support workers are recruited according to the needs of the individual with an attitude and passion for the arts consistent with the centre

The delivery of services need to planned and delivered with approaches that are embedded in the fabric of the community.

3. Independent Oversight Body

During the interim period of transition to the NDIS from 2016 to 2020, should the Victorian Government:

Create a new body under the legislation?

The community have been under the allusion the Disability Services Commission (DSCS) and the Office of the Public Advocate (OPA) were there to provide oversight. The Ombudsman's Report suggesting that Victoria has a robust system.

Is the issue that we have the system but people have not performed accordingly? If this is the determination of the Parliamentary Inquiry then a restructure of both offices with new appointments, plus a strengthening and clarification of their authority, would seem appropriate.

If a single oversight body were established in Victoria what Governance, accountability ad oversight arrangements would need to be established to ensure it is accountable in safeguarding people who access disability services?

If this is the determination of the Inquiry then it would be confusing for all if the DSC and OPA maintained their roles.

A single oversight body needs to exist for all complaints, violations, reports of abuse from all disability service providers, This process needs to include reporting matters to the police, for the courts and treated in a manner that any person in the community has a right to. The process needs to be transparent, conciliatory based on a decision making process with clear outcomes. The body needs to have the power to remove an organisations registration as a registered disability service provider and advise on the dismissal of individuals.

Complaints raised can be indicators or early signs of a service that is vulnerable and 'at risk' of more serious issues. A number of complaints from the one service identify a culture. It is important these are addressed before more serious incidents and or violations occur. A report of abuse or a violation of one's rights may have a history of complaints lodged prior to disclosures or reports of a more sinister nature. It's important that the oversight body have all the information about a service provider.

4. Disability Advocacy Services

What would be the most appropriate approach to the administration of funding disability and advocacy services, bearing in mind there are both state and Federal funding streams?

The Ombudsman's report advises that advocacy services be completely independent of disability services and safe guarding bodies. With this, there needs to be a much broader conversation about advocacy, one that engages with the broader community. The Framework for Disability Advocacy Services and current review are not adequate to develop the service people need. The current system is ad hoc, difficult to access, and lacking in professional practice. It's based on this notion of a 'Disability environment' or 'sector' or 'system', inward looking. Advocacy services need to speak to a wider range of individuals and lifestyles than it currently does.

Anyone can call themselves a 'Disability Advocate'. Lots of groups say they are engaged in doing 'Systemic Advocacy', 'train others to advocate' and are 'the voice'. Currently, we know more about what doesn't work than about what does work. There is a lack of agreement about what constitutes advocacy, who should be doing it and who gets it right.

Service providers need to have mechanisms in place to ensure they are able to listen and respond. Service providers need to have a process in place that is rigorous and valued by their organisation, a value of whistle blowing and the raising of concerns and complaints, a willingness to listen to those who use the service and those who support them. There needs to be real transparency and honesty in place not cover up and deny at all cost.

Community legal centres and the Human Rights and Equal Opportunity Commission are obvious services from which to develop advocacy. There needs to be access to a broad range of qualified legal advocates and lawyers. Some individuals need opportunities, encouragement and significant support in communication to enable access. I think this is a different kind of advocacy. It requires people who are skilled in communication, particularly AAC, who have a significant relationship with the person over a longer period of time.

5. Prevention, Screening and Accreditation

Should the Victorian Government develop a state-wide prevention and risk management strategy for the Victorian disability workforce from 2016-2019?

A combined version of an exclusion scheme and a working with vulnerable persons check?

Should a disability worker registration scheme be established, similar to the Australian Health Practitioner Regulation Agency (AHPRA)?

If so, should this be a national agency?

Should an independent body be established to overseas service standards, accreditation and registration?

If so, should this be a national agency?

It is my understanding from the submissions, and other reports, there is a problem in the workforce with a lack of support workers; and often a lack of people applying who have the desired attitude or skills set. Actions that might make it more difficult to enter the field, or in some way provide disincentives, would be counterproductive. The pay for a support worker is commensurate with Coles and Cold Call Centres. Notwithstanding action needs to be taken to ensure people receive the services they need in safe environments, by well-intentioned and trained support workers. Workforce development needs to happen urgently, but rather than bringing in a single qualification as mandatory requirement I would like to see a broad and flexible approach to entry level requirements.

A registering body or national agency is a good place to start. This would include a range of entry level requirements to meet registration. I don't know the Australian Health Practitioner Regulation Agency but the website looks user friendly. The registering body would have a process by which support workers could be de registered by employers, until matters are resolved, Fair Work Australia could assist in resolving those matters. I would prefer this process, to the exclusion list currently in place for DHS accommodation services.

I support WDV in their advice against the use of the term 'vulnerable'. It is disempowering, also, who is making the decision that one person is more or less vulnerable than another, this is fraught.

I would like to suggest the name 'Working with Adult Check' and that all support workers who register with this body, have the check.

A registering body would be a fabulous work force development that also supports individuals and families to directly employ. Sourcing and ensuring the credentials of support workers is one of the biggest challengers to individual as employer.

The registering body could also provide 'Working with Adult' checks for other service providers eg. Cleaners, gardeners, cook, etc. Increased work opportunities as an incentive to register.

6. Professional Development

Should minimum qualifications be introduced for all disability workers?

If so, what should be the minimum qualification?

Should this be a national requirement?

Should there be compulsory requirements for professional development for disability workers?

If so, what care components of ongoing professional development would be required?

There has been a community investment in the training of support workers for many years. The competency based packages have developed with significant advice from industry, the claim in the rhetoric being that training is industry driven.

The provision of training is just as vulnerable as any other bureaucracy driven service in its failure to meet expectations. The Certificate 1V in Disability as minimum requirement for support workers is not a new proposal yet still unattainable. Moreover, it is a simplistic response that will not address current problems.

- Competency based training packages meet minimal standards of competency
- Competency based training packages are driven by assessment
- Currently, the Certificate 1V is entry level training for DHS only
- DHS can engage agency staff who do not have the Certificate 1V or other
- There are a range of organisations TAFE and Registered Training Organisations that deliver – although the rhetoric is about regulation and quality, the reality is significant differences in standards
- Support workers may present with a Certificate 1V in Disability that required them to attend for 12 months at a TAFE with a placement in one or two programs – others may have achieved the Certificate on line with minimal contact with a teacher and little or no placement.
- The trainers may be very different in the ‘standards of the delivery of support services’ they believe in and great differences in what constitutes a picture of ‘inclusion’.
- There is a preference by training organisations to recruit trainers from disability service providers believing the experience is a necessary background
- Trainers can teach poor attitudes towards support and the experience of disability, albeit unwittingly.
- Poor language and attitude can be taught reinforcing a negative culture across services
- Underpinning the notion of Certificate 1V in Disability as a minimum standard of disability support workers is that training is aimed at a ‘service industry’
- The training maintains a community attitude and practice of segregation, exclusion and grouping according to impairment.
- The Certificate 1V Disability continues a notion that disability is a primary experience to a person in contrast to the training of workers in Aged Care, Child Care and Youth Work that relate to the stage of the life cycle of the people who are going to receive services from them

As a community we do not know enough about what constitutes best training for support workers. Research into the area is required and needs to engage with the broader community.

The World Health Organisation promotes the notion of ‘mainstreaming services’ that is ensuring services are able to respond to all people in the community.

A training response to this could be that the training in Aged Care, Child Care and Youth Work include responding to the experience of disability in the people who require these services. The entry level for Aged Care is a Certificate 111; Child Care is a Certificate 111 and Youth Work, a Certificate 1V.

A vision for disability support services could look quite different, a shift away from seeing disability as the primary consideration:

- children who require support services would employ a child care worker
- older people who require support services would employ an aged care worker
- young people who require support services would employ a youth worker
- a shift away from training an army of disability support workers, based on notions of disability as primary to one's identity, to one in which we are all included
- a shift to principals of Universal Design and Access

HACSU and Disability Service Organisations are industry driven and provide advice that might make services appear more streamlined, trained and compliant, perhaps a more manageable looking workforce.

We need to be constantly mindful that we need to be moving to supports that are driven by the individuals, not facility or centre based. A significant community shift needs to occur. This will not appear as streamlined; it might look messy, and requires creativity in planning.

I have the current brochure from a TAFE college advertising their Certificate 1V in Disability. It is **part time over 1 year and includes mixed delivery** (I assume this to mean some is on line). The career opportunities once you have achieved this Certificate 1V are listed – (copied from the brochure)

Worker in non-gov residential services
Disability development support officer
Integration aide/education support
Support worker in employment services
Home carer
Attendant carer
Community outreach worker
Support worker in day and adult services
Individualised support worker
Advocate

It is unrealistic that a part time, one year, Certificate 1V could lead to being competent in all these areas. For example the competencies taught do not include any that target the education/ curriculum needs of a student. Supporting a student in a school setting with their learning is a very different role to supporting a person in a residential setting. There is a Certificate 111 in Education Support that endeavours to target the needs of aids who want to work in an Educational Environment. Students from this group are also encouraged to consider the pathway to teaching. There may be a division of labour with the NDIA although they are not funding school support

officers; there is a view that students with support requirements beyond those provided in the classroom may be funded through NDIA. The management of such a division may pose difficulties.

The brochure further announces that much of the delivery is being facilitated by Vice President of a disability service organisation. I like the principles of this organisation but it doesn't make them good educators.

Including specific training about the diversity of people's support needs across Child Care, Aged Care and Youth Work, is not new, there are competencies that can and are included in the packages. There needs further development of these competencies and a commitment to ensure a high quality delivery. Industry would need to plan the delivery of their services, and recruitment, to meet this range of support workers. HACSU need to plan services that support them.

Current residential services may benefit from engaging with other training models for their support workers. They could also benefit from adopting a division of labour and duties that might employ those other than support workers, need have expertise in other areas of residential/home life, bringing a diversity of people and skills into the home.

- Cleaners might be recruited to do the bulk of the cleaning duties undertaken by support staff.
- A Cook could be employed to undertake the meal preparation and planning currently undertaken by support staff
- Personal Care Attendants to provide personal care duties only
- Gardener could be recruited to maintain the garden
- Reducing the number or hours a support worker might be employed

Arguments against such a vision might include:

- It can take from the natural opportunities in the home to learn independent living skills
- It can take opportunities for support workers and residents to practice the 'Active Support Model of Behaviour'
- It can take opportunities for support workers to ensure sensory experiences that naturally occur in some of these routine tasks

These would be valid concerns, as all 3 opportunities are essential and intrinsic to home life.

- Most support workers in DHS are given training in active support and it is well included in all training I suspect. Many workers report not putting this into practice claiming it takes time they do not have and feel unsure whether the residents are valuing the opportunities.
- Some residents have a great capacity to be involved and complete jobs in the home, others need considerable support to complete, from the workers
- Individualised planning ensuring residents are involved and have the opportunities that would benefit them most
- Professions other than support workers have a capacity to learn 'active support' and be mindful of what can be a great sensory experience – it's not rocket science and this sharing of experience is something we all do – we may

not name it and we may not be aware, increasing this interaction can be encouraged so that any person in the home is naturally supporting these opportunities.

- Peer support models lead to development of skills.

The mandatory requirement of a Certificate 1V in Disability is not a solution, particularly in context of significant social change.

The Certificate 111 in Disability could be considered entry level training with a WIDE RANGE of EQUIVALENTS that will facilitate entry to employment as support workers. There could be an acceptance of child care workers, youth workers and aged care workers to support people at different stages of the life cycle – a qualification in their field plus an intensive induction, placement and probation period to register as a support worker. Training providers and organisations could be engaged with the student from induction to registration. Registration brings the person in at Level 1 Support Worker.

Some years ago consumer feedback identified many who expressed high levels of satisfaction with support workers who were young, students working part time. Attracting students on a career path, and also providing opportunities for career paths, is important to developing a diverse and skilled workforce. The lack of support workers making a career of the job increasing once there is an improved work place.

Completion of 1st year university in social sciences, psychology, social work, speech therapy, physiotherapy, occupational therapy, nursing, law, recreation or related; could also be considered entry level with students having a pathway in at the intensive induction, followed by placement and probation.

All students should come with a First Aid Certificate and a Criminal Record Check. After the probation period students must apply for a 'Working with Adults Check' to apply for registration.

The Certificate 1V in Disability could provide additional training and professional development. Competencies grouped to provide skill sets to train in specific supports. This should be mandatory professional development when working with particular people. Eg:

- Personal care, movement and transferring position
- Active support
- Supporting AAC
- Supporting safe and healthy lifestyles
- Planned Support
- Supporting Recreation
- Supervising and supporting other workers

A worker could complete Certificate 1V in Disability and then becomes a Level 2 Support worker, able to supervise a Level 1 and probationary Support Worker.

The Certificate 111 in Disability and Certificate IV in Disability could have established pathways to all previously mentioned professional qualifications plus pathways to Community Service Management. Trainers could be qualified in the

professional occupations mentioned plus the Certificate IV in workplace training and assessment (as a minimum teaching qualification).

Inductions, placements and probations of support workers should be possible within individual's residential or family home if the user or family member have a Certificate IV in workplace training and assessment or equivalent. Training providers engaged with the students' progress until the worker is registered.

7. Workforce Culture

What does the Victorian Government need to do to support a disability workforce culture that does not tolerate abuse, neglect or exploitation?

What do Victorian disability service providers need to do to promote and achieve a workforce culture that does not tolerate abuse, neglect or exploitation?

I found this a really important question yet any attempt to answer it was simplistic. All of the issues covered by the questions set by the Parliamentary Inquiry need to be addressed to bring about significant change of the workforce culture.

I include a couple of case studies that briefly show some support worker experiences:

Jim and Ammon

Jim was a student who part way through the course got a part time job with DHS as a casual support worker. Jim was new to the field and was half way through the course. Jim was offered a job to provide individual support (one on one was the DHS term) to a man living in one of their Community Residential Units (CRU). Ammon was reported as being violent toward other residents and staff, the man had not been charged for any of the assaults, staff considered him dangerous. Jim was asked to take Ammon out of the house for 3-5 hours each shift he worked, to give everyone else a break. Jim was told Ammon liked to be driven around and visiting the airport sometimes amused him.

During a class we discussed physical contact with residents, what was considered appropriate and what was not. Students talked about their own levels of comfort and what is appropriate for them in their own relationships. I talked about what they might see happen in disability services. Generally the class agreed that physical contact with residents was to be respectful and appropriate, with most students preferring the boundaries they would have with work mates. Jim disagreed he talked about his work with Ammon. He said that Ammon met all staff at the door as they came onto their shifts. Ammon demanded a hug from each person. Jim was told by staff that everyone hugged Ammon and that if you didn't; Ammon would give you a hard time all shift. The staff impressed on Jim the need to hug the residents, it was important because no one else hugged them they said. Jim learned to hug Ammon. Jim took Ammon out for drives, going to the airport and visiting a park he thought had few people around. He thought Ammon might put others at risk.

Each class I checked in with Jim, about the hugging and the driving round. After a couple of weeks Jim admitted the hugs were becoming squeezes and he was very

uncomfortable with it, and in fact always was. He had been convinced by the staff at the house that hugging Ammon was best practice; Jim assumed they were more experienced and he was new to the field. Jim felt worried about his safety, firstly because the hugs were getting a bit rough and secondly, what would Ammon do to him if he didn't hug. There were suggestions from the class to Hi 5 instead. We then asked for a bit more information about Ammon; we learned he was 36 years of age. Jim decided that shaking hands was the most appropriate greeting for a man of this age.

Jim reported back to the class. Jim had insisted on shaking Ammon's hand when he next met him by gently guiding his hand before Ammon positioned himself for a hug. Jim stated that Ammon really enjoyed the hand shake and this became the norm. Interestingly, Jim then started doing more things with Ammon, finding out what interested him, supporting him to access places in the community. Jim discovered that Ammon could control his behaviour pretty well if he was interested in what they were doing. With Ammon's improvement the 'one to one' finished and Jim was offered shifts in the house. Jim stated he tried to influence the other staff's behaviour – replacing the hugs with a hand shake, planning so that Ammon could be more active with the things he enjoyed, increasing opportunities for Ammon to get out and about. Jim said no one would change. He thought the house was an unsafe place for residents and staff. Jim resigned from the position. Jim completed his studies, a high performing student. He went on to study social work.

Marianne and Louise

Marianne is an experienced worker she has been working for DHS as a casual worker for 10 years, she was a student in my class when she started, and we maintained contact. She liked to stay with one or two houses so she could develop relationships with residents. Sometimes she filled a line – DHS term for filling a vacancy short term. Marianne was an exceptional worker, intuitive, taught herself about AAC and liked the challenge of working with clients considered difficult. Marianne was asked to work in another house in which one of the female residents was being reported as difficult to support. Louise was an older woman, well used to DHS services, she would tease staff, refuse to cooperate with them and place many demands upon them. Marianne spent time with Louise and very quickly found her interesting and easy to support. She found a wicked sense of humour behind a lot of her behaviour toward staff. Some of the other staff became angry toward Marianne calling her names like, 'a soft touch', 'softy', 'she's got rings around you', 'martyr'. Marianne felt confident in her approach and continued. Staff complained about her, they were advised to try and learn from her, they became angrier toward Marianne and started excluding her, not talking to her and claiming she was making a range of mistakes. Marianne resigned from the position.

Janine

Janine was a student in the advanced diploma in management, working as a house supervisor. Janine was loud in class, always knowing best, claimed she was one of DHS's 'hot supervisors' who would be used as a 'trouble shooter', that is going into houses with residents who were considered difficult to control. Janine was often talking over other students and would become angry if someone's opinion differed to hers. Janine demonstrated a lack of respect to students who were not house supervisors and generally toward the teaching staff. Janine's assessment tasks were

often of poor quality and I did not pass her. Janine continued to work as a house supervisor and other students found themselves doing shifts in her house. The reports were that Janine bullied residents and staff, she yelled, she physically stood over people, she punished residents by not allowing them to have food, outings or things they might have wanted. I received reports from students about some of Janine's famous lines 'it's my way or the highway', 'my house, my rules', 'do you want in or out', 'it's up to me whether you stay here or not', they could be directed to residents and staff. Two students who worked in her house left without complaining, they feared it would impact on getting work in other houses. Sometime later Janine returned to complete her advanced diploma, another Trainer passed her. This Trainer was under qualified for the role, had worked in a disability service provider and I believed had a poor attitude toward residents, marked by low expectations and the use of poor terminology when talking about previous work. She thought Janine was fine, very assertive.

CRU visit

I visited a CRU to conduct an assessment on a student. The meeting was with the house supervisor, the student and me. I would plan my visits when the residents were not home so as I did not intrude on their time. This day all the residents were home expectantly and waiting to go out waiting for the supervision session to finish. I offered many times to postpone but the house supervisor was insistent she would not be available. During the meeting one of the residents - an elderly man in his 60's quietly entered the room and took a biscuit from the table. The house supervisor had put them out for the 3 of us. As the man approached the house supervisor grabbed the plate and said 'no'. The man asked for a biscuit saying the pantry was locked. The woman said that he could have a biscuit if he said please; he did so and got a biscuit. What do you say next she asked? He said nothing. Thank you she said and the man repeated thank you. I ended the visit saying I was not comfortable with residents waiting on me nor that they had to ask for a biscuit. The house supervisor was shocked saying that they had to learn manners. The student did not say anything. Outside we talked he said he was uncomfortable with the treatment of the residents but this was the norm.

Visit to a Day Service

I visited a student on placement at a day service. The support worker supervising the student had no qualifications, he once worked in retail. He told us that the building was riddled with asbestos and each month there was an inspection to meet occupancy requirements. He proceeded to tell us that the participants were all "nonverbal" and did not want any speech therapy or communication aids. They had tried. Most of the participants were using wheelchairs, young adults not long having left school. They spent much of their time in one room at the centre or in a van. I returned to my workplace complaining saying that we should not have students there. One of the teachers reported what I had said to the Manager of the day service. The manager contacted me stating I had no right to speak about her service, they offered a full program and everyone was happy there. She said the asbestos was not a problem.

The relationships of power need to change in the way in which services are delivered. Currently with Individual Support Packages and under the NDIA, families can elect to be the employer of support workers and can employ extended family members. This is fantastic. Support needs to be provided so that anyone who wants this kind of

autonomy and independence from disability services can be supported to manage it... For individuals and families who do not want the role then every effort should be made to ensure they are engaged in the process of employing the support worker/s of their choice eg involved in recruitment, able to view CV's, involved in performance appraisals, provide the worker with 'home rules' in conjunction with rules set by the disability service provider. Families and individuals should be able to communicate directly with their support staff about times etc. Consistency in the workers, using as few different people as possible, living locally, not wearing uniforms and obvious brands are also important to the in home provision of services. The advantages are not just about service of choice it's about the change in the power dynamics which can make the environment a safer one.

There needs to be very deliberate action taken to develop strategies that change the power relationships within the CRU's. There are a plethora of strategies that could be implemented.

8. Complaints Handling

If the Victorian Government introduces an independent oversight body, should it have responsibility for handling general complaints about disability service providers, as the disability Services Commissioner currently does?

If there is a new independent oversight body with responsibility for complaints handling and responding to serious incidents, should it have the power to conduct own-motion investigations?

Should these powers relate to both complaints and the investigation of allegations of abuse and neglect?

I think I answered this in my response to question 3. I emphasise my view that all complaints, serious incident reports and reports of abuse need to go to the one body. All incidents that are ordinarily a police matter should proceed to the police and the courts.

9. Guidelines for Responding to Abuse

If an independent oversight body is established in Victoria, should that body have responsibility for developing a standard set of guidelines for responding to allegations of abuse and neglect in disability services?

Setting out guidelines is a minimal response. There needs to be significant change in the management of services.

10. Visiting Schemes

Although the Community Visiting Program has failed in many ways I like the notion of engaging the community into the life of the Community Residential Units CRU's.

The Haven have a foundation and members of the community are involved, not in a policing capacity but in supportive role, volunteering and engaging with Tenants. It's a much more positive approach. At the same time they are people who can observe and reflect provide another view of life at the Haven.

I think it has to be organised, I don't think the Visiting scheme serves a purpose with the Office of the Public Advocate. Community visitors should be members of the local community engaged to enrich the life of the people living in the CRU. If they do have concerns then the Inspector would be the person to report to.

I think there is a role for Inspectors, attached to the body that handles complaints, serious incident reports and reports of abuse.

11. Mandatory Reporting

Should the Victorian Government introduce mandatory reporting of serious or critical incident to a new independent, oversight body?

If so:

What individuals and organizations should be mandated to make such reports?

What current functions of the Department of Health and Human Services regarding the management of critical incidents should be transferred to the new body?

And should the department retain any functions t critical incident management?

I am not sure about mandatory reporting. It does serve as a message that such behaviour is taken seriously. Every member of the community needs to feel they should act in response to injustice. I am not convinced that such mandating is really effective.

12. Oversight of Restrictive Practices

I believe the current 'oversight of restrictive practices' through the Office of the Senior Practitioner is not a suitable response to the development of good practice in the provision of support services. The state government's response to insist schools report incidents of restraint and seclusion of students with disability, to this same office, is a knee jerk reaction and inadequate as a response.

This office should be engaged in developing strategies to change the current power relationships – Innovation and Social Change.

Appendix 1

Jenny Harrison *BSc, Grad Dip Psych, MPAA*

Past Employment

- 12 years as a trainer (TAFE) of Support Workers for Disability Services – Certificate 111, Certificate 1V, Diploma, Advanced Diploma – in Disability and Management. Welfare Diploma and Youth Work, some Aged Care.
- 3 years employed by Yooralla as a Case Manager
- 10 years employed as a youth worker in residential services for young people with intellectual, mental health or juvenile justice issues. This included 3 years as house supervisor of long term accommodation for young people with intellectual disability.
- 3 years employed in institution for young women

Education

- Master's in Public Advocacy and Action – a master's program delivered by Victoria University in consultation with Amnesty International, Oxfam and Greenpeace. My interest area and thesis focused on leadership, advocacy and the lived experience of disability.
- Post Graduate Diploma in Behavioural Health Care (4th year Psych)
- Bachelor in Behavioural Sciences

Past Voluntary Committee Memberships

- Cerebral Palsy Support Network
- Disability Advocacy Network – Western Region
- STAR
- Local Council Disability Advisory Committee
- United Voices for People with Disability Inc.

Current memberships

- Member of local Labor Party Branch -Interest in Inclusive Labor

Family and engagement with the lived experience of disability.

- My daughter, now nearly 21, has been a user of disability services since she was a baby. My daughter lives in the family home with us; I work alongside and support her today.