

Submission:

Family and Community Development Committee

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Inquiry into social inclusion for people with disability



**Communication Rights
Australia**

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Introduction

Communication Rights Australia is a human rights information and advocacy organisation, which works in partnership with people who have communication difficulties. People request our service when they experience discrimination and isolation/exclusion. Services are designed to break down barriers and remove discrimination through:

- Individual and systemic advocacy, advice and referral when the system has broken down;
- Information on human rights, entitlements, and the right to communicate;
- Community education and outreach – how to ensure the protection of communication rights.

We represent a range of people on a continuum from severe speech and communication difficulties, such as Autism Spectrum Disorder, acquired brain injury, illness (such as Motor Neurone Disease, stroke, mental health, physical and sensory impairment, intellectual disability), through to children whose capacity to communicate impacts on correctly and consistently sending their message (such as Apraxia). People approach us when their ability to communicate their message is impacting on their ability to access their human rights.

Communication Rights uses the UN Convention on the Rights of People with Disabilities, Victorian Charter of Human Rights and Responsibilities Act, disability discrimination legislation and government policies to ensure people can enjoy their rights. Our activities promote change and facilitate inclusion into community activities.

The Disability Discrimination Legal Service (DDLS) is a community legal centre that specialises in disability discrimination legal matters. DDLS provides free legal advice in several areas including information, referral, advice, casework assistance, community legal education, and policy and law reform. The long term goals of the DDLS include the elimination of discrimination on the basis of disability, equal treatment before the law for people with a disability, and to generally promote equality for those with a disability.

EXECUTIVE SUMMARY

Over the last two decades in Victoria and Australia, numerous research studies and reports have been published that set out the barriers to social inclusion for people with disabilities. These reports have covered areas including the following:

- education and early childhood facility access for children and young people with disabilities;
- the status of carers;
- violence against children and adults with disabilities in government schools, government funded community residential units and institutions;
- the socio-economic state of people with disabilities in Australia;
- the inability of state and federal discrimination legislation to adequately protect the rights of people with disabilities.

The above list is not an exhaustive one. If one conducts research on the diversity of reports over the last 40 years produced on barriers to inclusion for people with disabilities, one will find repetition of the same issues. Why? Many of the identified issues preventing people with disabilities from being equal and active members of the community are well recorded but remain unaddressed.

While different governments have been enthusiastic in their commissioning of inquiries into the issues set out above, this enthusiasm does not extend to actually addressing the barriers which are well articulated by different individuals and organisations.

As a result, the same barriers are raised decade after decade.

It is insufficient to discuss these barriers repeatedly. The answer is not in the establishment of disability committees. The answer is not in the writing of action plans where the goals are so broadly articulated that little action of substance is required to evaluate them as being met at the end of the relevant period.

Those working in the sector, and people with disabilities themselves, are well within their rights to wonder why it is that the most active addressing of the barriers to social inclusion, is constant discussion, rather than action.

Until the conflict of interest that government has in competently addressing the barriers to social inclusion for people with disabilities is articulated and addressed, we expect little of substance to progress the matter.

The largest service provider to people with disabilities in Victoria is the State of Victoria, being the Department of Education and Early Childhood Development, and

the Department of Human Services and their contractors. This needs to be openly recognised and dialogue needs to take place as to how the State can be both service provider, and controlling and policing the quality of these services.

*'One of the most telling and challenging statistics is that Australia ranks 21st out of 29 OECD countries in employment participation rates for those with a disability. In addition, around 45% of those with a disability in Australia are living either near or below the poverty line. These facts alone show us that we need to change.'*¹

Given the multitude of reports, feedback and advice provided to government over the years on the barriers facing people with disabilities, how could the above be the case in 2011?

Until people with disabilities and those that stand with them can see that there is a body genuinely interested in improving their quality of life, a body that does not have conflicting concerns such as budget control, liability and the politicisation of issues, the answer as to why countless reports over the decades remain unaddressed will be clear. The government needs to look backward before it looks forward, and come to an understanding as to why the overall outcomes for people with disabilities have not changed.

¹ *Disability Expectations Investing in a Better Life a stronger Australia 2011* Price Waterhouse Cooper

3.1 What needs to happen to ensure that people’s individual disability and experience are accounted for in efforts to increase their social inclusion?

The State of Victoria should revisit and act upon previous reports outlining the barriers to social inclusion for people with disability. Government providers of services to people with disabilities in education and human services have policies and procedures that address these issues but are not followed.

An example is that the Department of Education and Early Childhood Development commit to meeting the individual needs of children with disabilities. As to whether this actually occurs, statutory authorities such as the Victorian Equal Opportunity and Human Rights Commission and Victorian Auditor General's Office (if the State is not inclined to listen to students with disabilities and their parents directly) make it clear that it does not.²

3.2 How should ‘social inclusion’ for Victorians with a disability be defined?

‘Inclusion’ for an individual is the opportunity for them to fully participate in the social and economic life of their community as valued and respected members. People with disabilities bring to the community their own diverse skills, knowledge, experience and expertise contributing to the richness of the Australian community.

Social Inclusion is the end product, resulting from a process of:

- Ensuring people have equal access to the benefits and services enjoyed by other members of the community in order that they are not excluded.
- Supporting people in accessing resources and developing capacity building skills so they may remain connected to the community in difficult times. People’s opportunities are developed through their experiences of family and community.
- Ensuring individuals can identify their needs, give feedback on their environment, and influence and take charge of their futures. This includes influencing decision makers on how services should be designed and provided to them.

Having an agreed-upon definition of the term "social inclusion" is one of the least important issues for the State to spend time on.

3.3 What is the difference between the concepts of ‘social inclusion’ and ‘participation’ in the context of people with a disability?

These are philosophical questions that are of little importance.

² Victorian Auditor General Office Report 2012 “Programs for Students with Special Learning Needs”
"Held Back-the Experiences of students with disabilities in Victorian schools" 2012 Victorian Equal Opportunity and Human Rights Commission

3.4 What does social inclusion for Victorians with a disability look like now?

We refer to our Executive Summary.

People with disabilities have little access to quality education, family, the legal system, employment and quality of life. Some of the many but more recent relevant reports include:

- *'Disability Expectations Investing in a Better Life a stronger Australia'* 2011 Price Waterhouse Cooper
- Victorian Auditor General Office Report 2012 "*Programs for Students with Special Learning Needs*"
- "*Held Back-the Experiences of students with disabilities in Victorian schools*" 2012 Victorian Equal Opportunity and Human Rights Commission
- "*Desperate Measures-the Relinquishment of Children with Disability into State Care in Victoria*" 2012 Victorian Equal Opportunity and Human Rights Commission
- "*Equal before the Law*" Australian Human Rights Commission 2014

4.2 In what ways do Victorians with a disability participate in the economic, social and civil dimensions of society?

We refer to 3.4.

4.3 What do you see as the emerging issues for Victorians with a disability over the next 20 years and how might these things influence their social inclusion?

An emerging issue is ageing parents who to date have responsibility for the care of their adult children with disabilities.

4.4 How effective have awareness campaigns been in improving social inclusion for people with a disability in Victoria?

Ineffective. See 3.4.

4.5 How can social inclusion and the participation of people in the community be effectively measured?

The collection and analysis of data against current reports. An example is the unavailability of quality education for children with disabilities. The Victorian Auditor General Office states:

'Since 2006, DEECD has distributed more than \$2.6 billion to schools through the PSD. However, DEECD does not have the information it needs to determine whether PSD funding is being used efficiently and effectively. Concerns raised about this by VAGO in 2007 still have not been adequately addressed and instead of having five years worth of high-quality data about

*the program, the department still knows very little about its impact on the educational outcomes of supported students.*³

A body is required to be responsible for actioning reports and measuring change through data.

4.6 What tools can be used to determine if there have been improvements or changes in the levels of social inclusion for people with a disability over time?

See above.

5.1 To what extent have the inclusion and participation of Victorians with a disability been advanced following the introduction of the Disability Act 2006 (Vic)?

An important step forward have been the recent guidelines relating to restrictive practices adopted by the Department of Human Services.

5.2 What impact has the Disability Act 2006 (Vic) had on the social inclusion of people with a disability with respect to Victorian government services?

Little. See 3.4.

6.1 How effective are services and initiatives designed to enhance the social inclusion of Victorians with a disability?

See 3.4.

ROLE OF GOVERNMENTS AND COLLABORATION

7.1 What needs to happen in the implementation of the National Disability Insurance Scheme to improve the social inclusion of Victorians with a disability into the future?

The NDIS is simply a vehicle and resource structure. Social inclusion needs to be guided by domestic and international human rights legislation.

7.2 What should be the role of governments and the community sector in increasing social inclusion for Victorians with a disability?

As they are the major provider of disability services through education, accommodation and general service provision, government has the primary responsibility for acting on the reports mentioned in 3.4

³⁴ *Programs for Students with Special Learning Needs* 2012 p viii

CASE STUDIES

The following case scenarios are drawn from the consumer rights/advocacy work of Communication Rights Australia. Each case represents the interaction between someone with a disability and the exclusion experienced by that person which caused them to approach for our service. In each case we have addressed the following questions:

1. Case Study - the facts of the case, the role of Communication Rights Australia and the outcome.
2. What the case reveals - what systemic issues and gaps in the service system are evident.
3. What needs to happen to ensure that an individual's experiences are accounted for in efforts increase their social inclusion?

1a) Case Study:

A man with autism and little speech [”John”] had lived for many years in a group home run by the Department of Human Services. A new resident was moved into the home and began physically and verbally assaulting John. This continued on a regular basis over many months. The assaults were witnessed by both house staff and members of John's family. Documented assaults against John included:

- Being struck in the face with no provocation
- Being choked, resulting in unconsciousness for 4-5 minutes
- Assaults with household objects
- Attempted assaults with a hammer and pieces of broken dinner plates
- Regular threats, shouting and other verbal abuse

Despite John's family making repeated requests to the Department of Human Services for the other resident to be removed, this did not occur. Instead the pattern of violent assault continued, and the man was placed on anti-anxiety medication by the GP to help him endure what was occurring. The family became increasingly concerned about emotional and neurological damage to John due to the violent abuse.

Once engaged, Communication Rights Australia obtained case-note records which confirmed the above abuse. Communication Rights provided 'court advocacy' to support John's mother to obtain an interim Intervention Order on his' behalf. This

order was difficult to obtain. The magistrate was reluctant to grant it and it was only made for a 5m radius which did adequately protect the victim. However the additional pressure resulted in the relocation of the other resident to accommodation with appropriate mental health support.

1b) What this case reveals about exclusion

A different standard is applied to violence and abuse against a person with a disability compared with other members of the community. There was evidence of social exclusion of the individual by both the human service workers and magistrate in their reluctance to use the rights and protection mechanisms other members of the community are accorded.

1. The Department of Human Services permitted a situation of documented ongoing client-to client violence to continue for eight months. Incident reports were not completed for the majority of incidents.

The incident reporting system introduced by the Department of Human Services in 2012 provides for incident reporting in the following two scenarios:

Category 1

All assaults of or by a client that led to serious injury and hospitalisation as an 'inpatient'.

- *Assaults involving a weapon regardless of injury.*
- *All assaults or alleged assaults of a client by a staff member or volunteer carer regardless of injury*

Category 2 Assault of or by a client that:

- *results in medical attention being sought or required for the victim, and/or*
- *presentation at a hospital emergency department and/or*
- *threatens health, safety or wellbeing.*
- *threatened assault of or by a client that has potential to cause harm.*

Note all staff/carer to client assault must be reported as Category 1.

(Source: Critical client incident management summary guide and categorisation table: 2011, page 17)

It is expected that senior staff will use their professional judgement in considering the sensitivity and appropriate grading of incidents being reported.

(Source: Clinical Client Management Instructions 2011, How to Choose Incident Type and Category, P 20)

These categories provide no mandated reporting for client-to-client violence that does not involve a weapon or require medical attention. Although the Department's intention may have been to eliminate low-level violence from the reporting system (such as occasional shoving between clients), actual practice demonstrates that

regular punching, scratching and other physical assault of residents is also not being reported.

The definition of a Category 2 assault as including that which “threatens health, safety or wellbeing” leaves too much discretion for reporting up to the individual carer who has witnessed the assault.

Carers are often casual employees with minimal training. Faced with competing demands for their time and attention it is evident that carers will avoid completing incident reports unless mandated to do so.

Over the six month period in which the abuse occurred, the police were generally not contacted by the Department. On the few occasions when police allegedly were contacted, they did not investigate. This meant that when court advocacy was required, the police were unable to provide evidence or recommendations to strengthen the application.

Without the service of a disability advocacy organisation such as Communication Rights Australia, the victim would still be suffering regular physical and emotional violence. Communication Rights Australia is funded for one full time advocate for the State of Victoria.

Despite the Magistrate’s Court’s regular practice of issuing interim intervention orders in domestic violence cases, the magistrate indicated a reluctance to issue an interim intervention order because it related to a resident residing in a Department-run house.

1c) Areas for reform indicated to address inclusion

1. The Department of Human Services (and all other equivalent state and federal departments) must ensure that client-to-client violence becomes a mandatory reportable incident in all cases.
2. Reported incidents must be responded to by the Department (and funded service provider if applicable)
3. Case-notes and Incident reports must be made available to affected clients, their families and advocates upon request. ‘Privacy’ must not be used to block access to information when a client is suspected of being a victim of abuse
4. Ongoing client to client violence must result in the relocation of offenders to appropriate alternative accommodation.
5. The police must be contacted by the Department of Human Services and funded service provider if applicable in cases of physical violence and in cases of ongoing, significant verbal abuse and threats.

6. Police must investigate reports of abuse in group homes on the same basis as if the alleged offences occurred elsewhere.
7. Clients and their families must be provided with information on disability advocacy services
8. Disability advocacy must receive funding commensurate with the level of need.
9. Clients and their families should be provided with information on legal options available
10. Courts should be educated in the importance of applying consistent standards to violent behaviour irrespective of whether that behaviour occurs in the community, in the family home or in a disability group home or other setting for persons with disabilities

2a) Case Study

After completing school a young woman tried to access a community day program to have social interaction with other young people. The young woman who has multiple health issues was in the receipt of a DHS funding package to participate in a day program including the sufficient allocation for a one on one staff funding. The young woman was excluded by a number of services due to her high medical support needs. The day programs were not willing to make reasonable adjustments to ensure the inclusion of the young woman.

The same young woman had been a regular patient at the Royal Children's Hospital but was denied access to the Intensive Care Unit during a critical medical intervention due to her turning 18. The young woman had not been transitioned to any other hospital despite her medical conditions being complex. During this crisis situation she was transferred to an adult hospital where a family member was required to be present 24/7 due to the lack of handover procedures. During that time an incident occurred where incorrect medication was going to be administered which was later identified by the doctor as potentially fatal.

The lack of equitable access to health services and a day program for this young woman has been devastating, both for her family and herself. The decision made by both the hospital and day program resulted both in her exclusion from meaningful social interaction on a daily basis, and a denial of responsive health care. Neither the adult nor children's hospitals were prepared to make the reasonable adjustment for the young woman's medical needs to be met in an emergency.

2b) What this case reveals about exclusion

The lack of preparedness of both hospitals and day programs to work to get the best result for the young woman would not have been tolerated by any other member of

the community. There is evidence of a double standard, or discrimination, when dealing with people with disabilities. Providing the support and transition required to remain connected to the community was not a priority of either service. The overlapping factors impacting on this young woman, being medical condition, age, and care excluded her from being included in a responsive health service as well as a day program.

2c) Areas for reform indicated to address inclusion

Both the hospital system and day programs need to make a commitment to counteract social exclusion of all people through their work practices – those from lower economic groups, homeless and people with disabilities by providing the best possible response and opportunities to all on an equal basis.

Factors that contribute to social exclusion include the systems/providers blocking opportunities for individuals to participate and lead fulfilling lives. The operations of the medical system and day programs need to be designed and delivered with a view to challenge the prevailing belief systems held concerning disadvantaged persons, including the need to work towards providing full access to all people.

Governments have a role within this process to ensure they provide the specialist resources and training to key community services to:

- ensure there is some acknowledgement of problem areas;
- understanding the factors impacting on access;
- committing to bring change; and
- capacity building to take the necessary action.

Strong leadership needs to occur from government but also each and every member of the community, including those who are excluded to challenge the barriers that are the causes of exclusion.

3a) Case Study

A young adult [“Sue”] living at home due to complex disability and cognitive impairment demonstrated unpredictable and sometimes violent behaviours. These behaviours had exacerbated since her placement at a day service had been terminated a year earlier. Since that time her family had been caring for her for 24 hours a day, seven days a week with no funding or carer support. This had resulted in:

- Her mother having to resign from her job
- Her father’s employment becoming sporadic and in jeopardy due to phone calls and meetings concerning his daughter
- Extreme emotional stress for family members

- Mental health concerns and medication for parents
- Financial stress and potential loss of the family home
- Neglect of younger siblings
- No respite in two years for Sue's parents
- Ongoing pressure on parents to relinquish care despite their deeply held commitment to Sue

A further key issue was that the previous day centre continued to receive Sue's funding in her absence for 18 months, and failed to communicate the exact circumstances surrounding her exit from that service.

3b) What this case reveals about exclusion

This case reveals the tentative and fragile state many families with children who have multi-disabilities experience when the system is not responsive to their needs. The impact is not only on the individual, leading to exclusion from the community and the benefits of funding, but also the isolation of family members.

When Communication Rights became involved, there had been no investigation as to why the placement had broken down or why there was a change in behaviour of the young person. It was assumed it was the problem of the individual, rather than the result of an event that may have occurred at Sue's day placement which made her terrified to be near the centre. It is all too easy to ignore the isolation of individuals and families in the midst of under-resourced services and economic pressures.

3c) What needs to be reformed for social inclusion?

Despite having an individualised package, the advantages of this did not move with the individual. The parents did not have the knowledge or expertise to transfer the funding over from the service. Families who do not know the system are vulnerable to being exploited.

The role of an external monitor (advocate) within this situation allowed for the negotiation of a reimbursement of funds from the 18 months Sue was not in attendance at the community program. Equally, Department of Human Service cut backs and a hands-off approach leave families to identify the information they need to know to bring the changes required. However as they are often providing the caring responsibilities directly, they become too exhausted to take action.

Investigations by the Advocate revealed a detailed report from the previous service provider concerning potential traumatic incidents witnessed by Sue. This understanding allowed the family to establish a workable model whereby Sue now receives support from carers at home. This has enabled her parents to finally begin

leaving Sue at the house with someone else for small periods of time, and so attend important meetings or enjoy brief respite. This has strengthened the parents' ability to cope and inclusion back into the community.

Case Work Conclusions

For Victorians with disabilities to enjoy social inclusion there needs to be a series of responses from all levels - community and Government. This will require a commitment to investing in people for long-term gain. The Victorian community, including our political leaders, must be willing to invest in the future of a diverse community as it does not just happen.

1. Governments need to ensure all individuals have the resources/ supports required to access the community as valued members. This includes providing funding packages to the level that reduces their disadvantage. In addition services within the community need to delivery and promote equal access for all. It will require the allocation of resources, education sessions and marketing around this concept.
2. Equitable access to early intervention, education and employment will assist people to develop the skills to connect with the community. Governments need to invest in people who are disadvantaged by demanding all government departments, including educational institutions, provide equity of access to the benefits of education. There has been a long history of evidence showing that the existing education system is not prepared to make the adjustments required to include children with disabilities. If a child cannot get an education there is little hope for them to move onto employment. As a result, their connection with the general community is broken.
3. People with disabilities need to have a greater say in the design of the community at all levels of government. Australia has only one parliamentary representative in South Australia who has taken her concern for community inclusion to the next level by putting the issues of people with disabilities to voters. While people do not have equal access to education and employment they are locked out of being a true voice of influence in planning and directing social inclusion within the community. People with disabilities need both the rights and responsibilities to form a future for inclusion.

True policy development should be built on a platform of inclusion for all using an approach of long-term investment in the people, and eradication of barriers. It is only then that we will have a Victorian community that is healthy, prosperous and sustainable for all.