



Audit Pilot Project

CAUS (Communication Rights Australia)

ABN: 25120 926 829

Mind the Gap

The Human rights Lived Experience of People
with Little or No Speech

2008

From the Participants ...

'The whole issue of human rights is incredibly important and perhaps for AAC users there are many stories people don't know about because they either can't tell you or don't have time to tell you.'

'It is difficult to think I have rights when I need people to do my care for me'

'At supermarkets, shops and banks, no one communicates so you can't communicate back'

'When I'm with a carer, they speak to them, not me'

'Everyone has the right to dignity and respect, and the right to be involved in the planning process for services and programs'

'On public transport, you get the feeling they are not listening, and not trained to listen to your speech'

'Because I've got poor speech they assume I'm unintelligent'

'I am frustrated because only one carer likes to take us away or on outings ...'

'I've been waiting two years for physio ...'

'I am passionate for life and enjoy what I can do to make a contribution'

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CAUS would like to take this opportunity to thank all who have participated in the development of this project. In the initial stages funding was received from the Victorian Department of Human Services, and in the later stage of audit development a grant was received from Helen McPherson Smith Trust. Much of the work has been sustained by CAUS in its desire to implement an evidence based tool to measure human rights experiences of people who have communication or speech difficulties against that of the general public. Development of the project has been plagued by lack of resources and time hence the process has been elongated. Despite this CAUS has remained unswerving and committed to the outcomes.

Internal supporters involved in the processes included:

- Deborah Halsey
- Kim Marks
- Eden Parris
- Oleg Bydanov
- Joanna Janikowski
- June Dalley
- CAUS Directors
- CAUS members who participated in the training program and pilot questionnaire.

External supporters include:

- Claire Thorn
- Marigo Raftopoulos
- Lee Ann Basser
- Marianne Diamond
- Penny Jordan
- Bronwen Jones
- Andrea McQueen
- Annie Millar
- Kylie McCabe

Project management remained the responsibility of the CAUS CEO. On behalf of the members and Directors of CAUS we wish to thank you.

Jan Ashford
CEO

EXECUTIVE SUMMARY AND RECOMMENDATIONS

This report and the project it describes have developed out of a concern that there is a significant disparity between current policy, rhetoric and legislation concerning human rights and social inclusion, and the actual lived experience of people with little or no speech within Victoria.

Since 2003 CAUS has been implementing a human rights model into our service. Between 2004-2006 CAUS staff examined the United National Conventions and more recently the Victorian Charter of Human Rights and Responsibilities to ascertain how these instruments could provide leverage to bring long-term change to people's lives. A study scholarship was awarded in 2006 to research audit tools operating in counties where Human Rights legislation existed. In 2007 CAUS developed an Education Kit and training program which was trialled with 30 people. People's feedback provided CAUS with a final document which is now available in both written and CD format. In 2008 CAUS continued the implementation by conducting a self-assessment audit tool, a survey, seeking to ascertain people's lived experience of human rights. The audit tool is designed to measure information gathered against standards provided by international human rights law. The survey questions were based on reported advocacy complaints and aligned against both the UN Convention and Victorian Charter.

The report begins with general background about CAUS and our members, and then provides a brief summary of recent policy and legislation concerning human rights and social inclusion. The report contains reflection on the methodology used to date, and an analysis of data collected. The results of the survey highlight human rights infringements across a broad spectrum of areas, impacting upon the ability of individuals to be free and active members of our society.

Finally, some recommendations are developed. As this is a preliminary report, recommendations have been divided into two groupings. External recommendations are directed towards policy makers and other bodies, while internal recommendations are developed with regard to the future development of this project.

The findings emphasis having the ability to communicate ones needs is essential for an individual to be able to exercise their rights. Without a means to communicate the person's ability to have relationships with key people in their lives are impacted upon. The project provided some insight

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into how this plays out as different groups in the community come into contact with the person.

Feelings of inequality in comparison to other members of the community is experienced, along with a belief that respondents felt that they were not treated the same as other members of the community hence felt that they did not experience human rights as others.

To further the development of the project an internal review will be completed with thoughts to the final stages of a comprehensive data base, standards, and data reporting system.

RECOMMENDATIONS (EXTERNAL)

It is recommended that:

- 1. CAUS to push the 'Right to Communicate' across the sector so people can protect their rights.**
- 2. CAUS to promote the results of this and future audits to increase awareness of Human Rights and the extent of infringements across a broad spectrum of areas.**
- 3. CAUS to further refine advocacy policy and procedure to reflect human rights model and include a human rights infringement assessment within introductory interviews.**
- 4. CAUS to further develop and promote their Communication Support Workers Program as a means of independent and unbiased communication assistance.**
- 5. Access to speech therapy services to be increased ensures people have adequate opportunity to develop an independent means of communication.**
- 6. Increased financial resources to be made available through the Aids and Equipment Program for communication aids to ensure individuals have the ability to exercise their rights.**
- 7. The wider disability services community to continue and further develop community education programs, targeting a broad sphere of community, to strengthen community understanding and responsiveness to people with communication and speech impairments.**

- 8. The Department of Human Services to integrate Human Rights information and education programs to management and also to direct support staff.**
- 9. CAUS to seek funds to work with Regional Divisions of General Practitioners to develop tools to support people with communication and speech difficulties when communicating with their own doctors and also to promote the needs of this group to doctors.**
- 10. Victorian Police to develop tools to support the Human Rights needs of people with communication and speech difficulties when communicating with the police and also to promote the needs of this group within the wider police force.**
- 11. CAUS and the wider disability advocacy community to actively promote the needs of people with disabilities to local political members and encourage the presentation of information in accessible formats.**
- 12. The Department of Human Services and Department of Education, Employment and Workplace Relations to dedicate resources to improve educational and employment opportunities for people with communication and speech impairments.**

RECOMMENDATIONS (INTERNAL)

With respect to this project, it is recommended that:

- 13. CAUS to re-examine the construction of the audit so that:**
 - + The preamble is in plain English.**
 - + The survey language is simplified.**
 - + Questions are re-written to avoid ambiguity;**
 - + Repetitive questions to be identified and eliminated when using the questionnaire in its entirety.**
 - + Answer options to be edited using 'Rarely' instead of 'Hardly'.**
 - + Answer options provide for 'Yes/No' responses where applicable.**

- 14. Trial the audit with a larger sample group that reflects the spectrum of the CAUS community from a skills perspective.**
- 15. Trial the audit with a sample group from the general community so that some understanding of benchmarking can be established.**
- 16. Facilitators provide participants with an Answer Chart for easy pointing where appropriate.**
- 17. The recommended time be changed to at least an hour (and providing notice that this estimation may increase if conversation arises from the survey).**
- 18. CAUS consider making the audit shorter.**
- 19. CAUS provide facilitators and participants with a clearer mechanism for follow up of advocacy issues identified through questionnaire.**
- 20. That participant selection criteria be refined so that the sample group includes people with significantly varying degrees of rights consciousness**

1. INTRODUCTION

1.1 People with little or no speech

It is worth noting that people who experience communication or speech difficulties are also referred to within documentation as people with complex communication needs and people who have little or no speech.

CAUS (Communication Rights Australia) represents the interests of people with communication or speech difficulties. It is funded by the Victorian Department of Human Services to provide advocacy, information and community education to people with communication or speech difficulties who are residents of Victoria. CAUS also receives federal funding that supports its national network of members on key issues.

Communication or speech difficulties can take many forms and have many causes. They may be associated with stroke, cerebral palsy, multiple sclerosis, acquired brain damage, autism, intellectual impairment and many other disabilities. More recently CAUS has been working with families of children with language disorders. The National Dissemination Centre for Children with Disabilities (NICHCY), describe language disorders as 'an impairment in the ability to understand and/or use words in context, both verbally and nonverbally'¹. Some characteristics of language disorders include the improper use of words and their meanings, the inability to express ideas, as well as inappropriate grammatical patterns and reduced vocabulary'. A study of Early Language in Victoria found that by the age of 4 there may be 8 -10% of children with a language disorder². This disorder is quite frequently hidden as there are no outward signs of a disability.

The exact number of people with communication or speech difficulties is hard to assess, as speech or communication difficulties are frequently cited secondary to other disabilities. For example, an individual with movement and mobility difficulties may be considered to have 'restriction in physical activities, as their primary disability. However, that individual may also experience communication or speech difficulties which greatly impact upon their activities and lifestyle.

The Commonwealth State Disability Agreement (1999)³ estimated that 66% of people with a disability have difficulties with communication. It is estimated that 1 in 500 people in the general population have complex

¹ Available internet: <http://www.nichcy.org/>

² Child Language Consortium, 'Early Language in Victoria Study. Available internet: <http://www.rch.org.au/emplibrary/speech/IALPBrisbane2004.pdf>

³ Available Internet: <http://www.aihw.gov.au/publications/index.cfm/title/6080>

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communication needs (Perry, Reilly, Bloomberg & Johnson 2002)⁴. However regardless of how many individuals with communication or speech difficulties are counted, there can be no doubt that they form an isolated and fragmented group within the community⁵; a large number of them with high support needs, segregated and dependent on others. This poor inclusion in the community is linked to feelings of alienation and powerlessness, a sense of not belonging to the broader community and of not having much control over one's destiny (Compton & Galway, 1989)⁶.

1.2 Human Rights Audits

An audit tool obtains information about human rights, their application and effectiveness. They are designed to gather information to measure against benchmarks or standards and in this case those provided by international human rights law. Australia is obliged under each of the international treaties to report periodically to the United Nations about the implementation and realisation of rights for their citizens.

Both the discussion paper and scoping paper commissioned by CAUS recommends that we undertake a human rights audit by using a self assessment tool. It is suggested that this type of audit tool can have a two-fold effect; a means of measuring outcomes as well as an avenue to provide human rights education to participant.

CAUS through its pilot program obtained straightforward information from people through the means of the audit/survey concerning their lived experience of human rights. The audit will then be adapted to better capture the information required to measure against benchmarks/standards developed under the international conventions.

4 Perry, A., Reilly, S., Bloomberg, K., and Johnson, H., (2002) Needs Analysis for People with a Disability who have Complex Communication Needs, DHS, Victoria

5 Perry, A., Reilly, S., Bloomberg, K., and Johnson, H., (2002) Needs Analysis for People with a Disability who have Complex Communication Needs, DHS, Victoria

6 Compton, B. & Galway, B.:(1989) Social Work Processes, Wadsworth Inc. USA.

1.2 Impact on the Individual

Research on the impact of communication or speech difficulties is limited yet Speech Pathology Australia has identified that people do experience feelings of grief, anger, frustration and embarrassment.

People with communication or speech difficulties are sometimes unaware of their own level of communication difficulty and thus rely on others to adapt considerably to ensure the message is received successfully. This process relies on the receiver being prepared to use strategies to support the communication process. If these strategies are not available, or are unknown then it is likely that communication will breakdown. Hence people with communication or speech difficulties experience challenges when talking to friends, relatives, doctors, and the general community.

It can have an immediate effect on the way people interact with each other and their relationships. It is assumed people are least affected when they are at home as families are open to adapting their communication patterns. While at work or out in the community people face greater barriers as the general public may choose not to participate in interactions.

In more structured environments such as schools or work, communication is a critical skill for learning, reading, writing and thinking. The impact of barriers within these situations leads to poor literacy skills and low academic achievement. Spelling problems are common, as are poor planning and problem solving abilities. Individuals find it difficult to express their ideas or have limited opportunities to join debates, ask questions, or contribute towards discussion hence feeling of anger, frustrations may result in behavior problems or the individual withdrawal.

Further many people with communication or speech difficulties are not in open employment as result of the barriers they face in earlier in their life. They may face discrimination when applying for employment or are overlooked for promotion.

Reactions of other people to those who have a communication or speech difficulty are varied. Individuals report that they are often ignored, or disregarded, their opinions are not asked for, and their needs remain unmet. People report low self esteem which impacts on their ability or desire to participate in what is happening around them.

1.3 Legislation and Policy

Recent developments have signaled a positive shift on the part of government towards a greater embrace of human rights and social inclusion. There are several key developments with relevance to the human rights of people with little or no speech.

1.3.1 The Victorian Charter of Human Rights and Responsibilities

The Charter of Human Rights and Responsibilities is an Act of Parliament which sets out rights, freedoms and responsibilities for all Victorians. The Charter focuses on civil and political rights. It places obligations upon the Government, public servants, local councils, Victorian police and funded service providers to act in a way that is consistent with the human rights protected under the Charter.

While a breach of the charter will not of itself give rise to a legal cause of action, new laws are required to be compatible with the Charter and the Charter allows a person to raise a human rights argument in a court or tribunal in an existing case.

The key rights protected by the Charter include:

- Freedom of movement, expression, assembly and association;
- Right to liberty and security;
- Rights for children in the criminal process;
- A fair hearing;
- Rights in criminal proceedings;
- Right not to be tried or punished more than once;
- Retrospective criminal laws;
- Freedom of thought, conscience, religion and belief;
- Property rights;
- Freedom from forced work;
- Right to life;
- Protection of families and children;
- Cultural rights, including recognition that human rights have a special importance for the Aboriginal people of Victoria;
- Equal recognition before the law;
- Entitlement to participate in public life (including voting);
- Protection from torture and cruel, inhuman or degrading treatment, medical or scientific experimentation or treatment without consent;
- Protection of privacy and reputation; and
- Humane treatment when deprived of liberty.

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As CAUS' advocacy work has demonstrated, people with a disability may often have their rights limited. While the Charter recognises that human rights are not always absolute, it provides that people's rights may be limited only to an extent that may be justified in a free and democratic society.

Overall, the Charter has the potential to enhance the freedom, respect, equality and dignity of Victorians with little or no speech. In describing the Charter, the Victorian Equal Opportunity and Human Rights Commission states that:

This formal recognition of our human rights protects people from injustice and allows everyone to participate in and contribute to society.⁷

1.3.2 Social Inclusion Policy

In recent years social inclusion has been a recurring theme of government policy. The current federal government has established a Social Inclusion Unit in the Department of Prime Minister and Cabinet. The recently appointed Minister for Social Inclusion has stated that 'to be socially included is to be able ... to play a full role in Australian life, in economic, social, psychological and political terms.'⁸

At a State Level, the Department of Human Services cites the following definition of a socially inclusive society:

A socially inclusive society is defined as one where all people feel valued, their differences are respected, and their basic needs are met so they can live in dignity. Social exclusion is the process of being

⁷ Available internet:

<http://www.humanrightscommission.vic.gov.au/human%20rights/the%20victorian%20charter%20of%20human%20rights%20and%20responsibilities/>

⁸ The Hon Julia Gillard MP, 'A Social Inclusion Agenda', 13 April 2008, available internet:

[http://209.85.173.104/search?q=cache:vm2cXoOfCIEJ:eherald.alp.org.au/articles/0407/natp13-01.php+social+inclusion+definition&hl=en&ct=clnk&cd=2&gl=au\).](http://209.85.173.104/search?q=cache:vm2cXoOfCIEJ:eherald.alp.org.au/articles/0407/natp13-01.php+social+inclusion+definition&hl=en&ct=clnk&cd=2&gl=au).)

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shut out from the social, economic, political and cultural systems which contribute to the integration of a person into the community.⁹

A Fairer Victoria 2008 developed by the existing Victorian Government makes a commitment of a 'fair and inclusive state with opportunities for all'¹⁰. The document provides a long-term commitment to reducing inequality and disadvantage. Further it acknowledges that a social inclusion approach, is one that 'understands that inequality and disadvantage can result not only from inadequate income, but inadequate opportunities to participate in what most Victorians take for granted'

State disability policy documents also place great emphasis on the theme of social inclusion. The *Victorian State Disability Plan* places a priority on the goal of 'Pursuing Individual Lifestyles' (Goal 1) and 'Building Inclusive Communities' (Building Inclusive Communities). Furthermore, the *Victorian Standards for Disability Services* seek to implement these policy statements for the sector. For example, Standard 5 states that 'Each client is supported and encouraged to participate and be involved in the life of the community'.

There is a clear nexus between the policy aim of social inclusion and the protection of individual rights, particularly when rights guaranteed under the Victorian Charter include freedom of movement and the entitlement to participate in public life.

1.3.3 UN Convention on the Rights of Persons with Disabilities

At an international level there has also been significant movement towards greater protection of the rights of people with disabilities. A key development is the *Convention on the Rights of Persons with Disabilities*. The convention was adopted by the United Nations in 2006 and opened for signature on 30 March 2007. There were 82 signatories to the Convention, the highest number of signatories in the history of a UN Convention on its opening day. The Convention details explicit rights for persons with disabilities and reaffirms that all persons with disabilities have human rights and fundamental freedoms. It qualifies how all categories of rights apply to persons with disabilities.¹¹ This Convention was signed on 30 March 2007 by

⁹ Cappo (2002), quoted in VicHealth Research Summary 2 - Social inclusion as a determinant of mental health & wellbeing (January 2005). Available internet:
<http://www.health.vic.gov.au/agedcare/maintaining/countusin/inclusion.htm>

¹⁰ Internet Access:
<http://www.dpcd.vic.gov.au/Web14/dvc/dvcmain.nsf/allDocs/RWPBA66A032F874AC59CA2572D00026A891?OpenDocument>

¹¹ United Nations Enable <http://www.un.org/esa/socdev/enable/conventioninfo.htm>

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Australia. On July 18th, 2008 the Australian Parliament ratified the UN Convention on the Rights of Persons with Disabilities.

The Convention includes specific rights concerning people with communication or speech difficulties. It defines 'Communication' as including augmentative and alternative modes (AAC), and also provides for rights to receive information and to express oneself in these modes. It commits State parties to facilitating the full and equal participation of AAC users in education and as members of the community. The Convention commits State parties to employing teachers who are trained in these methods (Articles 2, 21,24).

According to the UN, the Convention is of historic importance:

The Convention marks a "paradigm shift" in attitudes and approaches to persons with disabilities. It takes to a new height the movement from viewing persons with disabilities as "objects" of charity, medical treatment and social protection towards viewing persons with disabilities as "subjects" with rights, who are capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members of society.¹²

1.4 Rationale for Audit/Survey

As evident from the above discussion, there is much movement in terms of policy and legislation at a state, federal and international level in terms of increased protection for the rights of persons with a disability. In particular there is a strong emphasis on the value of social inclusion.

However there remains a significant question as to whether such policies have had any meaningful impact at the level of the every day, lived experiences of Victorians with communication or speech difficulties.

For a number of years, CAUS has been re-shaping its service in order to more closely monitor and respond to human rights infringements. Since 2003 CAUS has implemented a conscious human rights-based approach. This has involved the following steps for the organization:

1. Review and reflective analysis of CAUS advocacy processes, statistics, and recurring rights infringements.

¹² <http://www.un.org/disabilities/default.asp?navid=12&pid=150>.

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2. CAUS commissioned in 2005 a general 'Scoping' paper to ascertain the issues to consider when developing an Audit Tool. The document was completed by The Centre of Citizenship and Human Rights at Deakin University.
3. Late 2005 a 'Discussion Paper on Human Rights Audit Tool' was commissioned from La Trobe University's Legal Department, which incorporated information from the Deakin review, our own input and international conventions.
4. Late 2006 an Ethel Temby overseas study tour was awarded to research the development of a benchmarking process for identifying human rights infringements. It became clear that although disability advocacy groups may have been operating in countries with Human Rights legislation, they were not necessarily using a human rights framework.
5. In 2007 CAUS developed a human rights training program for people with little or no speech. This comprised of the document *A Human Rights Education Plan for Australians*, available in print and in audio format, and the conducting of 10 two day training sessions on human rights. These sessions were conducted in the community for small groups of people with little or no speech.
6. In 2008 CAUS staff members and contracted speech therapists conducted a preliminary Human Rights survey, using a human rights tool based on our research to date. This report analyses the information obtained through this process and develops some preliminary findings.

The final stages of the project are yet to be developed.

7. A stand alone human rights survey to be integrated as part of the CAUS 'Individual Advocacy Intake' process.
8. Development of a human rights data base to register infringements, barriers and actions reported through advocacy.
9. Development of a CAUS reporting system that is linked to key local, national and international bodies. The document will provide data for reporting to the UN and evidence base for future systemic advocacy. Further through the promotion and use of this system the Government will have an increased understanding of human rights infringement of people with a disability.

2. METHODOLOGY

2.1 Aims

The aims of this project were to assess the human rights lived experience of Victorians with little or no speech by:

- Researching the human rights of our target group as conferred by international covenants and domestic legislation;
- Developing a Human Rights Tool based on this research;
- Gathering information on the human rights lived experience of sample group;
- Identifying areas of access and barriers to access;
- Developing external and internal recommendations.

The long-term objective of the project is to establish an ongoing mechanism to measure the lived experience of human rights of people with communication or speech difficulties against that of other members of the of the community.

2.2 Sample

Sample Group included nine males and eight females with speech impairment, identified by CAUS or through contracted speech therapists. The age range of participants was broad, with seven individuals aged 26-35, four individuals aged 36-45, three individuals aged 46-55, and three aged over 55. All participants lived in the Melbourne metropolitan area.

Participants in Sample Group communicated in a range of ways, from using speech (with or without a communication assistant) or through augmentative and alternative modes. Communication books were used in addition to electronic aids such as LightWriters. All participants in this group were born in Australia.

2.3 Survey Procedure

Sample Group:

Facilitators were utilised to assist in the completion of surveys and included two CAUS staff, three contracted speech therapists and a group facilitator from a Day Service Program. All facilitators utilised their existing networks of people with communication or speech difficulties within Melbourne to identify potential participants.

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Once a potential participant was identified by the facilitator, the nature of the project was explained to them and their consent sought. If consent was given then at the commencement of the survey an introductory preamble was read or summarised by the facilitator. This preamble consisted of a basic summary of human rights, and a brief description of the questionnaire and its purpose (see Appendix 1).

The only exceptions to this procedure were two participants who completed the survey online. Of those participants, one completed the survey unaided while one received some facilitation support from a family member.

Survey Structure:

The questionnaire began with the collection of some basic demographic and general information. The body of the questionnaire was divided into several sections in order to collect information around specific groups of rights:

- Part 1: The Right to Communicate
- Part 2: Dignity
- Part 3: Civil Rights
- Part 4: Taking Part in Public Affairs
- Part 5: Social Participation
- Part 6: Economic Wellbeing

Each section began with a brief introductory paragraph which explained to the participant the nature of the right or rights in question.

2.4 Reflections on Methodology

CAUS asked questionnaire facilitators to provide written reflections on the methodology of the project. The reflections received include the following:

2.4.1 Strengths of Methodology:

One facilitator noted that the questionnaire asked questions which everyone should have the opportunity to discuss, and which are so big in their scope that people who use AAC may never be asked them, and certainly not in a comprehensive way.

Another facilitator observed that the methodology's strength was that it made the very broad issue of human rights tangible for people by asking

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real-life questions, and that the process itself had an educational benefit for both participant and facilitator.

Two facilitators noted that participants were very pleased to have had the chance to talk about these issues. One facilitator observed how a participant became increasingly focused and interested in the survey as it progressed. As a result this participant shared their views concerning matters such as politics and religion, and seemed pleased to have had the chance to do so.

Two facilitators described conducting the survey as an interesting experience, with one describing it as an invaluable personal and professional experience.

2.4.2 Methodology Issues Identified:

1. Sample Size:

As this is a pilot project, the number of participants in each group was not large. This needs to be considered when interpreting group responses. Data is reflective of the perceptions and experiences of individuals who agreed to participate in the project.

2. Use of Language and Complexity:

Participants were approached and selected for inclusion in the survey where facilitators perceived they met required adequate receptive language skills to comprehend the more abstract questions on the questionnaire. One facilitator noted that any survey of this nature should seek to include those with cognitive deficits (developmental or acquired) but that the methodology of this survey excluded those people, as many of the questions were abstract and worded in complex language. This point about the questionnaire's complexity was reinforced by another facilitator who commented that 'the survey was extremely long and complex and would preclude people with limited attention span or IQ being able to participate'. Another facilitator found that the preambles to each section problematic and needed to be translated into plain English.

3. Ambiguous Wording:

Facilitators noted that some questions caused confusion. One facilitator noted that the questions about voting in Part 4 caused confusion, but that this may reflect the participants' lack of involvement in public life. Two

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facilitators identified question 10 in Part 2 as being particularly ambiguous. This question consisted of the statement: 'I feel listened to when I have a concern with...' and lists several parties. The confusion it caused was described in the following terms by a facilitator: 'Was it when you had concerns about family, friends, doctors etc or whether these groups listened to you when you had concerns?'

One facilitator noted further ambiguities including the occasional presence of two very similar and perhaps identical questions, and the use of language that was unfamiliar to the participants (i.e. 'sexuality activities') which might lead to confusion. It should be noted that this facilitator provided highly detailed feedback which should be considered when revising the questionnaire.

4. Imprecise answer options:

Participants recorded their answers by placing a tick on a five point scale from 'Always' through to 'Never'. However one facilitator made the point that grammatically, the 'Hardly' option would more accurately be expressed as 'Rarely'. It is not known whether this caused confusion in participants but the suggestion appears correct.

A more problematic issue was the presence of the sliding scale of answer options in questions which clearly required a 'Yes' or 'No' answer. For example, questions 11 to 14 in Part 3 which concern being a victim of a crime and contacting the police. The presence of a sliding scale of answers for Yes/No questions was confusing for participants and facilitators. In general facilitators used 'always and never' to indicate these choices.

5. Communication Chart

One facilitator commented that, given the physical disability of a number of participants, it would have been much easier to conduct the questionnaire if a communication chart could have been provided whereby participants could have pointed to or otherwise indicated their choice of the five answer options. The facilitator created a sample chart and provided it to CAUS.

6. Length of Survey

Both facilitators and participants commented on the length of the questionnaire. While it could be expected that conducting a survey of this nature with people often using AAC would take time, the suggestion in the preamble that the survey 'should take no longer than 30 minutes' was highly misleading. For participants in the Sample, even when the survey was

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conducted with people not using AAC, the survey still extended to one hour. When the survey had been booked in conjunction with another appointment (i.e. an advocacy meeting), this created time constraints and may have meant some answers were rushed. Another facilitator commented that the two participants interviewed 'found the survey very long and repetitive'. A further facilitator found that when participants were given more open-ended time to both answer questions and engage in conversation concerning their answers, that survey time ranged from two to four hours per survey. One participant commented 'that CAUS of all people should be expected to know that AAC users could take up to 20 times longer than speech users to answer these questions' (facilitator's indirect quotation).

Regarding the issue of survey time and conversation arising, one facilitator noted:

It was not clear exactly how much respondents should be asked to elaborate on their answers, but this seemed especially important for questions which highlighted problem areas – and often these required lengthy and time consuming explanations. To do anything else would have been to compound their feeling that people who use speech often don't take the time to listen to what AAC users have to say.

7. No follow up for issues raised

The question of participants elaborating on answers relates to another potential issue raised by the survey. This is the question of whether conducting human rights awareness campaigns in general can create a higher awareness of problems and rights infringements in an individual's life, without offering them the means for this to be followed up or addressed. This was an issue raised by CAUS' CEO and also by one of the facilitators, who noted that:

There were ... questions with the potential to raise major issues – either psychological or to do with quality of care. I have an ethical concern about raising these issues with people unless there is a mechanism for following them up.

Certainly CAUS offers a rights-advocacy service that could be used for following up a small number of referrals. However due to sub-contracting facilitators the services offered by CAUS may have been obscured. A related issue is whether any larger scale project with a much greater sample size would lead to an amount of referrals beyond CAUS' service capacity. However it could be argued that such a process would provide data on un-

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met advocacy needs in the community which could be used to put upward pressure on funding bodies to increase advocacy services.

8. Bias towards rights-conscious participants

One facilitator noted that the self-selection process may mean the survey results will be biased towards participants who are already well aware of their rights and have personalities to go out and get them met. A CAUS facilitator also noted that participants may have been asked to do the survey based on their perceived interest in the topic. However this may not have had a great effect as there were a number of participants in the survey who had little or no consciousness of their rights. A suitable recommendation for a future survey may be to provide a mechanism so that the sample group includes a broad cross section of people with little or no speech in terms of their rights consciousness.

9. Bias of participants

A related issue noted by at least two facilitators was whether certain rights-conscious participants in Sample Group were accurately recording their experiences. This was particularly the case with individuals who had a long history of successful 'self-advocacy'. One facilitator noted that both participants interviewed had strong self esteem and strong views, and wondered whether that self-esteem 'may have been linked to their opinion of how they interact in the community so there may have been some denial about how able they were communicating in a range of situations'.

A similar reflection was provided by another facilitator who noted that two strong self-advocates tended to tick the 'always' box for almost all answers related to their access of rights, and the 'never' box related to their denial of rights. Again, such answers may be accurate or may be a reflection of a degree of denial (or perhaps their rightful pride in their achievements). However it would be merely speculative to form a definitive view on this question, especially given the small sample size.

3. DATA ANALYSIS / DISCUSSION

Seventeen people who have little or no speech agreed to participate in the pilot questionnaire.

Part 1: Right to Communicate:

For people with communication and speech difficulties being able to communicate is essential, however they also must have confidence that the people they are communicating will listen to what they are saying and respond in a satisfactory manner. While 89% of the participants in this study believed they had a way to communicate their needs to others, there were still 11% that believed that they could only sometimes communicate.

On exploring opportunities to communicate needs to particular groups within the community the respondents reported that 76% could always/most of the time with family and friends and the same number were able to communicate at school or work. Participants also reported less intimidation from family and friends and also school/work with 71% in both situations reporting feelings of intimidation only sometimes or never. Another essential aspect of communication is receiving information in a way that enables people to make a decision. Again, family and friends are rated well, providing information always or most of the time in 76% of cases. Here, school/work is slightly lower, with 68%. It was the belief of participants that in these environments people had fixed ideas on how or if a person communicates.

Although only 47% of participants reported being able to communicate independently in supermarkets, shops and banks, this was a location where people experienced the least intimidation, with 82% reporting never or only sometimes feeling intimidated. Participants also always or most of the time received adequate information for decision making in these areas in 76% of cases. One person responded 'no one communicates so you can't communicate back' when considering how they communicate in shops and banks.

It was identified that only 59% felt they could communicate with their service provider independently, and the same percentage reported receiving adequate information to make decisions. 59% of participants also reported that they felt intimidated when communicating with their service provider. 76% reported that they believed that their beliefs were respected by their

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staff. People reported that there is a lot of 'passing the buck' when dealing with service providers'.

Although 71% of participants reported they never or only sometimes felt intimidated when communicating with their doctor, only 41% reported being able to independently communicate with their doctor and only 59% felt they received information in a way that enable them to make a decision. 12% also reported they were forced to undergo medical procedures without their consent.

Within their everyday life experience, 70% were satisfied with most of the responses they received to their communication, although 50% raised concerns about people's attitudes towards them. 18% of the respondents reported that they were forced to do things against their belief and 35% identified that they only sometimes or hardly ever have a say over how they ran their lives. In relation to specific life choices, 29% reported that they were unable to participate in the religion of their choice and 18% were unable to participate in culturally appropriate activities. When discussing their sexuality only 59% believed they were able to express their sexuality; only 53% were able to engage in sexual activities if they wanted; and only 58% were able to express their sexual preference. While discussing their sexuality, one respondent reported 'I wish' while another stated 'with difficulty, if people were not nosey'. The ability to express their sexuality and engage in sexual activity may often be reliant upon the support of staff or family. It has been long reported that people with disabilities are considered 'asexual' their sexual desires not taken into consideration by supports, both professional and family, while planning for life and service.

It was reported that when a carer is present most people communicate with them rather than the individual. Participants reported they feel they have to put up with things instead of making a complaint. Respondents reported that with public transport people are not trained to listen and it becomes clear they are not listening.

Part 2: Dignity

The participants in this study reported significantly low levels of dignity in comparison to the perceived experiences of the rest of the community. Only 47% felt they were treated the same as other members in the community while 35% felt they did not have equal rights with others in the community. One respondent commented that 'people cannot forget that I have a disability'. 29% of respondents felt their privacy was not respected by others around them. Only 53% felt they could make decision on their life

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without interference while one respondent stated 'sometimes it is in my best interest to get interference'.

Of the respondents 88% felt they were treated with respect by professional with whom they work yet this dropped to 76% of professionals showing respect when providing a service to the participant. 76% stated that staff treated them with respect, although a lower number of respondents, 71%, felt their support staff treated them the same as others. Fewer still, 65%, felt that service providers listen to them when they had a concern. The same number reported that concerns were listened to at work and only 59% felt their concerns were listened to by their doctor. In contrast, 88% felt that they were listened to by their friends and family

Only 35% of the respondents had reported a crime to the police. From this only 50% felt that they were listened to and appropriate action was taken.

In discussing these situations further, one respondent explained that his sister is not made to feel welcome by staff at his home but the family is concerned to raise it with the service provider for fear of repercussions. Respondents also explained that there is lack of privacy with the doctor while other respondents complained about the lack of time for them to explain what is going also the presence of parents restricts our communication.

Part 3: Access to Civil Rights

Rights were seen as important to 88% of the respondents and the same number felt they received information on their rights in a way they could understand. Despite this, only 71% believed they had enough information to exercise their rights and had the ability to exercise their rights the same as other members of the community. Over two thirds felt they had someone to help them with legal issues and make contact with the police. Half of the participants felt comfortable responding to the police when they contacted them, but only one third felt comfortable contacting the police when needed. Only 24% reported that they had been a victim of crime. Respondents reported that they had never had to exercise their legal rights but they do not know how much power DHS actually has, while others reported they were happy with police responses yet felt the police needed more education.

As well as legal rights another important part of civil rights is being actively included within the community. A total of 35% of participants responded that they felt they couldn't be active in the community.

Part 4: Take part in public life

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One of the most essential activities of public life is voting in political elections. When asked about their voting habits 82% voted in Federal elections, 76% in State elections and only 65% in Local Government elections. 94% reported that they had the opportunity to vote, had information on how to vote and where to vote, although only 82% reported that the information on voting was clear. 82% reported they required assistance to vote, however only 76% have someone to help them vote. Only 50% of respondents know their local representative and less than one third had met their local representative.

Two thirds can access government services when required but less than 50% believed these services responds well to them. Just over half of the respondents believed local councils are responsive to their needs. 41% believed they have a say in the policies and procedures developed by their services provider and less than two thirds believed they had a choice of service provider. One respondent reported that 'it took support workers 6 times to ring DHS, starting in June, to arrange a meeting for November'.

Two thirds of the respondents felt safe in their community and in their home.

Part 5: Social Participation

82% of the respondents reported that they have a say on their social activities, however only 76% reported that they had the opportunity to participate in any aspect of the community life that interested them and worse yet, only 59% could access the community at any time they would like. Lower still, only 53% felt they were able to interact and socialise with a range of people within the community. 82% of respondents were able to participate in culturally appropriate activities. A respondent reported that he was frustrated because only 1 carer likes to take him out on outing as others are not available.

In relation to access to particular services, 76% reported that they access to health services as required, but only 41% reported that they access to therapy as required. 76% reported that they had the supports required to access education opportunities, but only 53% had the information on education opportunities. Over 50% did not have access to information on employment.

Some of the factors that are likely to impact on the ability of individuals to participate include that only 65% of respondents had the opportunity to use their support to achieve community access and 59% reported they received adequate information on how to get involved in community life. Only 65%

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had access to transport to access the community and just over 50% of respondents reported being able to access most buildings they wanted to.

53% respondents reported that they have a choice where they live and 47% had a choice with whom they lived. 71% reported that they have a say when support is provided.

82% reported to know how to make a complaint and felt they were listened to when a complaint was made. 76% believed they had someone to assist if they were not listened to after a complaint. Just over 50% felt they were politically active to the level they want.

Part 6 Economic well-being

Of the respondents, 53% had access to education and employment opportunities that suits their needs. 76% had the supports required to access education. 59% reported that they were happy with their employment status and 71% reported enough income to meet their needs. Just over 50% reported that they had enough income to meet the cost incurred as a result of their disability.

Over 94% reported their basic needs of food were met, 82% reported their housing and health care needs were met, while 64% reported their educational needs were met.

Discussion

Under the Victorian Charter of Human Rights and Responsibilities it is stated:

- Every person has the right to enjoy his or her human rights without discrimination.
- Every person has the right to freedom of expression which includes the freedom to seek, receive and impart information and ideas of all kinds, whether within or outside Victoria.

Every individual is entitled to claim his or her human rights and to demand that they be protected, respected and fulfilled. People are not asking for any special treatment only what their entitlement is as members of the community.

Having the ability to communicate ones needs is essential for an individual to be able to exercise their rights. Within this study 11% of the respondents reported that they only sometimes had a way to communicate their needs. This raises a significant barrier for the respondents who may wish to

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exercise their rights. The Right to Communicate should be fundamental to all.

The facilitators reported that the people selected to participate in the survey was considered an empowered group within the speech impaired community with a number having a history of self-advocacy. It is a concern when this group reports such high levels of dislocation from their rights. Priority should be given to those individuals who have either little understanding of their rights or how to claim or defend them as it leaves the person open to violation of all types.

Further it could be claimed that that by not providing a means to communicate is an infringement of rights. Unfortunately the questionnaire did not provide an understanding to the barriers to people accessing a means to communication but it should be a priority that all people where ever possible should be offered this right and be provided with adequate resources to achieve this.

Without a means to communicate the person's ability to have relationships with key people in their lives are impacted upon. The pilot project provided some insight into how this plays out as different groups in the community come into contact with the person. There seems to be an overdependence on family and friends to provide information to help respondents make decisions. Although there are a significant number of individuals who are not even able to effectively communicate with these people who are the closest to them. A suitable system needs to be developed to ensure that where individuals require support to communicate and make decisions regarding their lives, they can be receive the necessary assistance to do so in an independent and unbiased manner.

Communicating in the community is limited with only half of respondents being able to interact and socialise with a range of people. However this is the area with the lowest experienced intimidation and the greatest level of accessible information. Individuals report also show that they do not feel that they are communicated with any less than other members of the community. The limited communication may only become problematic if there a serious situation or emergency arises where communication becomes essential. There also appears to an indentified gap between receiving the information and the capacity to act upon this knowledge. There were significant reports of individuals feeling they could not access the community as they wished, due to limited opportunity, information, support and physical access. This creates serious situations where individuals were unable to actively participate in community life. Through increased community

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awareness and education, the ability of people with communication and speech difficulties to interact with the broader community will increase.

The accessibility of information drops away when dealing with service providers. It is anticipated that the new Disability Services Act, that has strong emphasis on providing information in accessible formats, will address many of these concerns. However over half of individuals reported feelings of intimidation and the same number believed that the services were not responsive to their needs the reports that service providers do not treat them with equal respect and do not listen to their concerns. This indicates that it will require more than just accessible information for individuals to exercise their rights; individuals need to feel confident that their providers will listen to their concerns and respond to them in a respectful manner. Through a process of cultural change within disability services, that is already underway, the attitudes and practices of providers will have an increased focus on the rights of service recipients.

When communicating with their doctors, the respondents reported lower levels of intimidation, however also reported low levels of being able to communicate and having information presented in an accessible manner. This may be a primary cause for 12% of respondents reported having undergone medical procedures without their consent. The Disability Services Act will not apply to doctors, or to schools and employers who were also reported to not be providing information in appropriate modes, and there appears to be limited opportunity for improved informed decision making and communication in these situations. An individual's inability to communicate with a doctor their concerns can potentially have long term impacts upon their health. This needs to be addressed through a two pronged approach, one providing additional training and information to medical practitioners and health professionals and also through making additional supports available to support people with communication and speech difficulties to have the time and support to communicate.

Rights were seen as important in a large majority of the participants, however that there was only two thirds had enough information or someone to assist them exercise their rights. There had been limited opportunities for the participants in the study to exercise their legal rights and the results from questions on police interaction cannot be used to draw significant conclusions due to the small number of participants that had the experience of reporting a crime to the police. However the low confidence in communicating with police is of great concern. The majority of participants stated that they knew how to make a complaint and two thirds believed they could access support if their complaint was not heard. However as these participants were often identified through an advocacy service, these reports

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may not be representative of the broader of people with communication and speech difficulties. Individuals need to have greater awareness of their rights and how to exercise them and at the same time bodies that may be involved in supporting individuals exercise their rights, such as the police, need to have a greater awareness of the needs of people with communication and speech difficulties.

Access to justice is a critical component of the enjoyment of human rights. People who feel wronged or mistreated in some way must be able to turn to the systems that are established to protect people. If the system fails to accommodate a person's communication needs it is clearly a denial of access to justice and potentially a basis for discrimination claim.

Almost all participants had the opportunity to vote, however reports that voting information was not clear for all and that the required supports were not available show that the right of individuals participate in elections is being impinged upon. There has been significant accessibility improvement within voting processes; however information relating to voting and political information still requires development. It is important to note that people have the right to assistance in the exercise of their voting rights.

Although the majority reported that their basic needs were met, only just over 50% reported they had adequate income to meet costs incurred as a result of their disability. Participants' responses to questions relating to education and employment indicate that the right to economic well being may be limited. Barely half had access to education and employment opportunities that met their needs or had information on such opportunities. This results in limited opportunity to improve economic wellbeing. People need to not only have increased access to information but also to support and resources to support the achievement of education and employment goals.

Throughout the survey participants identified feelings of inequality with other community members. Half of participants felt that they were not treated the same as other members of the community and 35% felt that they did not have equal rights with others. Of serious concern is that almost one fifth of respondents report being forced to do things against their belief and over one third of the respondents consistently reported throughout the survey that they did not have a say in their lives. No one question was responded to within the survey that did not indicate a breach of human rights on some level. This study, although brief, reflects human rights infringements across a broad spectrum of areas impacting upon people with communication and speech impairments.

4. RECOMMENDATIONS (EXTERNAL)

It is recommended that:

- 1. CAUS to push the 'Right to Communicate' across the sector so people can protect their rights.**
- 2. CAUS to promote the results of this and future audits to increase awareness of the extent of Human Rights infringements across a broad spectrum of areas.**
- 3. CAUS to further refine advocacy policy and procedure to reflect human rights model and include a human rights infringement assessment within introductory interviews.**
- 4. CAUS to further develop and promote their Communication Support Workers Program as a means of independent and unbiased communication assistance.**
- 5. Accesses to speech therapy services to be increased ensure people have adequate opportunity to develop an independent means of communication.**
- 6. Increased financial resources to be made available through the Aids and Equipment Program for communication aids to ensure individuals have the ability to exercise their rights.**
- 7. The wider disability services community to continue and further develop community education programs, targeting a broad sphere of community, to strengthen community understanding and responsiveness to people with communication and speech impairments.**
- 8. The Department of Human Services to integrate Human Rights information and education programs to management and also to direct support staff.**
- 9. CAUS to seek funds to work with Regional Divisions of General Practitioners to develop tools to support people with communication and speech difficulties when communicating with their own doctors and also to promote the needs of this group to doctors.**
- 10. Victorian Police to develop tools to support the Human Rights needs of people with communication and speech difficulties when communicating with the police and also to promote the needs of this group within the wider police force.**

- 11. CAUS and the wider disability advocacy community to actively promote the needs of people with disabilities to local political members and encourage the presentation of information in accessible formats.**
- 12. The Department of Human Services and Department of Education, Employment and Workplace Relations to dedicate resources to improve educational and employment opportunities for people with communication and speech impairments.**

RECOMMENDATIONS (INTERNAL)

With respect to this project, it is recommended that:

- 13. CAUS to re-examine the construction of the audit so that:
 - + The preamble is in plain English.**
 - + The survey language is simplified.**
 - + Questions are re-written to avoid ambiguity;**
 - + Repetitive questions to be identified and eliminated when using the questionnaire in its entirety.**
 - + Answer options to be edited using 'Rarely' instead of 'Hardly'.**
 - + Answer options provide for 'Yes/No' responses where applicable.****
- 14. Trial the audit with a larger sample group that reflects the spectrum of the CAUS community from a skills perspective.**
- 15. Trial the audit with a sample group from the general community so that some understanding of benchmarking can be established.**
- 16. Facilitators provide participants with an Answer Chart for easy pointing where appropriate.**
- 17. The recommended time be changed to at least an hour (and providing notice that this estimation may increase if conversation arises from the survey).**
- 18. CAUS consider making the survey shorter.**

- 19. CAUS provide facilitators and participants with a clearer mechanism for follow up of advocacy issues identified through questionnaire.**
- 20. That participant selection criteria be refined so that the sample group includes people with significantly varying degrees of rights consciousness**

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Victorian Charter of Human Rights and Responsibilities 2006: Victorian Government

United Nations Convention on the on the Rights of Persons with Disabilities

Internal Documents

CAUS commissioned the following reports to support the development of a human rights audit tool

Basser, L.A.: (2005) Discussion Paper on Developing a Human Rights Monitoring Tool

Bydanov, O: (2008) Strengthening Advocacy, CAUS

Connolly, J: (2005) *Scoping Paper- Developing a Human Rights Tool, Centre for Citizenship and Human Rights - Deakin University*

Appendix 1: Preamble

General Information:

Human rights are the basic rights that belong to all of us just because we are human beings. They have been recognised around the world as the basic standards required for governments, societies and communities to operate in a respectful and peaceful manner.

Human rights are the foundation for freedom, justice, peace and respect, and are an essential part of any democratic and inclusive society that respects the rule of law, human dignity and equality.

Everyone has the same human rights: men, women, and children, rich and poor, and all nationalities and faiths. Human rights are about recognising and respecting the dignity of other people.

Other obligations under the Victorian Charter of Human Rights and Responsibilities are that both Governments and Public Authorities must take human rights into account when developing policies and they must abide by the intent of the legislation.

Questionnaire:

CAUS is collecting information on the human rights lived experience of people with little or no speech. We wish to collect this information to gain some understanding on where our community sit in regard to their experience against other members of the community.

The questionnaire should take no longer than 30 minutes. You may choose not to answer any questions. At times the interviewer may ask for a more detailed response. Again you may choose to opt out of a response.

All responses are confidential and there will be no identifiable information collected on the questionnaire. We do need to collect some demographic information and these are compulsory questions.

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Appendix 2: Results.

Part 1: The Right to Communicate:

Part 1 - Questions	Always/Most of time	Sometimes Hardly/Never
Do you have a way to communicate your needs?	89%	11%
Are you able to independently communicate your needs to		
• Family and Friends	76%	24%
• Doctor	41%	59%
• Supermarket/Shops/banks	47%	53%
• School/work	76	24
• Service Provider	59	41
Are you satisfied with most responses	71	29
Are you concerned about people' attitude towards you	50	50
Do you feel intimidated when you attempt to communicate your needs?		
• Family and Friends	29	71
• Doctor	29	71
• Supermarket/Shops/banks	18	82
• School/work	29	71
• Service Provider	59	41
Do you receive information in a way that enables you to make a decision?		
• Family and Friends	76	24

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• Doctor	59	41
• Supermarket/Shops/banks	76	24
• School/work	68	32
• Service Provider	59	41
Sometimes I am forced to do things against my belief	18	82
I feel I have a say in how I run my life	65	35
Sometimes I am forced to undergo medical procedures without consent	12	88
I feel my beliefs are respected by my staff	76	24
I am able to participate in my cultural appropriate activities	82	18
I am able to participate in the religion of my choice	71	29
I am able to express my sexuality	59	41
I am able to engage in sexual activities if I want	53	47
I am able to express my sexual preference	58	42
I am able to have a say in the running of my day to day life	71	29

Part 2: Treated with Dignity

Part 2 - Questions	Always/Most of time	Sometimes Hardly/Never
Professionals with whom I work treat me with respect	88	12
I am respected by professionals who provide me with a service	76	24
I feel I am treated the same as others in the community	47	53

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I feel I have equal rights with others in the community	65	35
My support staff treat me with respect	76	24
I feel my support staff treat me as they treat others	71	29
I feel I can make decisions on my life without interference	53	47
My privacy is respected by people around me	71	29
I feel listened to when I have a concern with		
• Family and Friends	88	22
• Doctor	59	41
• School/work	65	35
• Service Provider	65	35
I had the opportunity to report a crime to the police –	35	
I felt I was listened to by the police	50	
I felt appropriate action was taken by the police	50	

3. Access to Civil Rights

Part 3 - Questions	Always/Most of time	Sometimes Hardly/Never
Rights are important to me	88	22
I feel I receive information about my rights in a way that I can understand	88	22
I feel I have enough information to exercise my legal rights	71	29
I have access to someone who can help with legal issues	76	24
I feel I have information on my rights as a community	76	24

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member		
I feel I exercise my rights the same as other members of the community	71	29
I feel comfortable dealing with the police when they contact me	53	47
I feel comfortable contacting the police when I need to	65	35
I have someone to help me when I need to have police contact	76	24
I am able to be active in the community	65	35
I have been a victim of a crime	24	76
Do you receive information in a way that enables you to make a decision from		
• Family and Friends	76	24
• Doctor	59	41
• Supermarket/Shops/banks	76	24
• School/work	71	29
• Service Provider	65	35

Part 4: Take part in public life

Part 4 - Questions	Always/Most of time	Sometimes Hardly/Never
I have the opportunity to vote	94	6
I received information on how to vote	94	6
I received information on where to vote	94	6
The information I receive about voting is clear to me	82	18
I need someone to help me to vote	82	18

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I have access to someone to help me to vote	76	24
I have met my local elected representatives	29	71
I do not know my local elected representative	47	53
I vote in local elections	65	35
I vote in state elections	76	24
I vote in federal elections	82	18
I can access government services when I require to	76	24
I find government services such as Centrelink, DHS responds well when I access them	47	53
I feel my local council is responsive to my needs	53	47
I have a say in the policies and procedures that develop my services	41	59
I have a choice to change my service provider	65	35
I feel safe within my community	71	29
I feel safe within my home	71	29

Part 5: Social Participation

Part 5 - Questions	Always/Most of time	Sometimes Hardly/Never
I have the opportunity to participate in any aspect of community life that interest me	76	24
I receive information on how to be involved in community life	59	41
I have access to information on education opportunities that suit my needs	53	47

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I have the support required to access education opportunities	76	24
I have access to information on employment opportunities that suit my needs	47	53
I have the opportunity to use my support to achieve community access	65	75
I can access most building I want to	53	47
I can access the community at any time I would like	59	41
I have access to the transport I need to access the community	65	35
I have a say on my social activities	82	18
I have a say when support is provided to me	71	29
I have access to health services when required	76	24
I have access to therapy services when required	41	59
I have a choice where I live	53	47
I have a choice with whom I live	47	53
I know how to make a complaint if I am not happy with service I receive	82	18
I am listened to when I make a complaint	82	18
I have access to people to help me when I am not listened to	76	24
I am able to be politically active in any way I want to	59	41
I am able to interact and socialise with a range of people within the community	53	47
I am able to participate in my cultural appropriate activities.	82	18

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Part 6: Economic well-being

Part 6 - Questions	Always/Most of time	Sometimes Hardly/Never
I have access to education opportunities that suit my needs	53	47
I have the support required to access educational opportunities	76	24
I have access to employment opportunities that suit my needs	53	47
I am happy with my employment status	59	41
I have enough income to meet my basic needs	71	29
I have enough income to meet the costs incurred as result of my disability	53	47
My basic needs are met in the areas of		
• Food	94	6
• Housing	82	18
• Health Care	82	18
• Education	64	36