



'To belong, I need to be missed'

Disability and inclusion in faith communities

Multifaith
Disability Project



A collaborative research project to investigate the experiences of people with disabilities and faith leaders, from Buddhist, Christian, Jewish and Muslim perspectives

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SYNOD OF VICTORIA AND TASMANIA



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Executive Summary

Background

Victoria has historically incorporated many changes to its social fabric, resulting in a multi-cultural and cosmopolitan society. This rich diversity of cultures, beliefs and relationships is highly valued, and is something which the state can be very proud of. The Victorian state government has policy frameworks and strategies which emphasise social inclusion.

Victoria also has an excellent culture of ecumenical and interfaith dialogue, as evidenced by a range of bodies which encourage dialogue and cooperation on a range of matters. Such bodies play a significant role in promoting harmony and social inclusion.

It is within this faith and social/cultural context that the current research, focussed on people with disabilities within faith communities, is situated. This research is very timely. In terms of community endeavours and advocacy for the inclusion of people with disabilities, it could be contended that faith communities are the 'final frontier'.

Approximately one in five Australians identify as a person with a disability; this is projected to be one in four by 2051 (Australian Bureau of Statistics, 2004). Across the spectrum of disability, this includes people with mental health issues, and people with physical, intellectual, sensory, cognitive or neurological impairments.

Even in a contemporary secular society, such as Victoria, faith is an important aspect of many people's lives, and the reason many individuals and families participate in faith and religious activities, or identify with a faith community. Within Victoria numerically, the prominent faiths are Christianity (64%), Buddhism (2.1%), Muslim (1.7%), Hinduism (.7%) and Judaism (.5%) Many of those who say they have no religion nevertheless describe themselves as religious, engage in spiritual practices such as prayer, or profess a belief in God or a spiritual entity (Bouma, 2006).

This research project has its genesis in a growing awareness of the rights of people with disabilities, from all faith perspectives, to have their aspirations taken seriously in regards to participation in worship and social activities within their faith communities.

Whilst the findings of this research project draw from a small sample of individuals with disability, and faith leadership, it nevertheless points to the importance of faith and spirituality, and the social connections they provide for some people with disabilities. Given the projected population growth in Victoria over the next 20 to 30 years, including people who acquire disability because of age-related issues, it is surmised that the numbers of people with disabilities who seek to be involved with faith communities will grow. The findings of this research suggest certain interventions are required in the immediate to short-term timeframe, with an opportunity to strongly enhance social inclusion within the Victorian community.

Purpose of research

The purpose of the research was to investigate the experiences of people with a disability in Victoria in relation to inclusion within the major faith communities: namely Buddhist, Christian, Islam and Judaism. Using interviews and focus group discussions, it compared and contrasted their stories of inclusion and exclusion with the experiences of their faith leaders. The research also sought to understand reasons for low participation levels in faith communities by people with disabilities.

13 individual interviews with people with a range of disabilities were conducted from each of the four faith communities, five leaders representing each of these faith communities were interviewed and 84 people participated in two forums, one conducted in a rural/regional setting. A number of the interviewees, both people with disabilities and faith leaders, were filmed for the purposes of developing a DVD of the research.

Human rights context

The United Nations *Convention on the Rights of People with Disabilities* was adopted by the federal government in 2008 and is concerned about the difficult conditions faced by persons with disabilities who are subject to multiple or aggravated forms of discrimination on the basis of race, colour, sex, language, *religion*, political or other opinion, national, ethnic, indigenous or social origin, property, birth, age or other status.

Within Australia the *Disability Discrimination Act 1992* (DDA), makes it unlawful to discriminate against people on the basis that they have or might have a disability.

Victorian legislation in relation to people with disabilities is underpinned by the *Equal Opportunity Act 1995*, the *Disability Act 2006* and the *Charter of Human Rights and Responsibilities Act 2006*, each affirming the full participation of people with disabilities in all dimensions of community life.

The Victorian State Disability Plan, developed for the period 2002-2012 affirmed a number of Guiding Principles: the values of Equality, Dignity and Self-Determination (Choice), Diversity, and Non-Discrimination.

The Principle of Equality recognises that “*people with a disability are citizens who have the right to be respected and the right to have equal opportunities to participate in the social, economic, cultural, political and **spiritual** life of society. As citizens, people with a disability also have equal responsibilities towards Victorian society and should be supported to exercise these*”.

Findings and Learnings

Review of the information obtained from the combined total of 18 interviewees, revealed four broad clusters of responses:

These were:

- Understandings, perceptions and experiences of inclusion;

- Obstacles and suggested strategies to increase participation;
- People's interpretations of their disability and the teachings/beliefs of their religion/faith community; and
- Role of leadership as a catalyst to promote positive change.

These four clusters were used to summarise the interview findings from people with disabilities, and also faith leaders.

(i) Understandings, perceptions and experiences of inclusion

People referred to 'inclusion' meaning different things. For some people the issue of physical access was the first thing mentioned, as this is the means by which they can access a place of worship via public transport, or park their car and enter a building without obstacles, and once inside be able to move around unimpeded and use a range of facilities without difficulty or embarrassment. There is also the need for suitable equipment and technology for people with sensory impairments, along with consideration given to adaptations of the presentation and style of worship.

These are all issues that require serious attention, and are the material precursors for an inclusion spoken of by others in which they have a sense of belonging or 'being at home', of being embraced and accepted. These factors are interlinked, and if people do not experience a sense of belonging, of welcome, the physical adaptations are in vain. This is not to suggest though that issues of physical access should not be addressed by all faith communities. Many people with disabilities speak of social isolation and loneliness, and so the importance of addressing all of these factors is essential.

Interviewees spoke positively of changes that had been made to the built environment, and what a difference this had made to both the person with a disability and the wider community of faith, resulting in significant relationships being formed. Whilst physical changes were applauded, others spoke less favourably about attitudes and diminished expectations of their role and contributions. These responses made the people concerned feel less included and placed in situations where they variously had to defend, explain or advocate for themselves. Whilst this was sometimes seen as necessary in terms of educating and informing others, it could also be a very tiring and demoralising experience.

Religious leaders universally spoke of the imperative for increased inclusion, underpinned by a range of values: human rights, mercy, justice, kindness and compassion, which all derive from sacred texts and teachings.

(ii) Obstacles to participation, and suggested strategies to increase participation

The three broad areas of obstacles described by people fell into **attitudinal**, **structural** and **personal** circumstances.

A major concern of people with disabilities is being patronised, victims of charitable intent, and having assumptions made about their personhood or capabilities. Whilst this is also confronted on a daily basis within a number of life situations, the fact that it was mentioned by some interviewees suggests that faith communities also have a propensity for such communication. There was an implied hope by people with disabilities that faith communities might be a haven or sanctuary devoid of such attitudes. This research suggests it is incumbent upon faith communities to closely examine such communications.

A major stumbling block is the built environment which is so often cited as being disabling for people with disabilities. The most important response cited is for faith communities to listen to the needs of people with disabilities; to those within their own community, and also learn about the needs of people who may visit or wish to join in the future. Disability action plans, developed by many community organisations as well as government and statutory bodies, provide a thorough examination of systems and structures, and develop a timeline for implementation of changes to alleviate any discriminatory practises.

The importance of staff in the community services sector to facilitate social inclusion was also raised: this workforce could play a significant role as bridge-builders, by encouraging and linking people with disabilities in residential care with faith communities.

Cultural background and language are significant factors for many people with disabilities. Protectiveness of the family member with a disability means that that child or adult may rarely, if ever, participate in faith activities.

Responses from faith leaders acknowledged the difficulties people are experiencing and that there is a need for significant improvement, although reticence and ignorance will be encountered. This presents an opportunity to develop awareness and education materials: consultation with people with disabilities is fundamental to such developments. There was also recognition of the good things that are happening, including initiatives to improve the built environment. There is also an opportunity to share ideas, strategies and resources.

(iii) People's interpretations of their disability and the teachings/beliefs of their religion/faith community

The comments received in relation to understanding the relationship between sacred texts and disability were most interesting, as they appear to define how someone views their world of being labelled with a disability, or treated differently.

There was a range of interpretations and beliefs about existential questions, what could be done in the 'here-and-now', and interpretations of the written texts. Such interpretations may be gained by personal reflections and life experience, or interpretations received from esteemed teachers and scholars within a particular faith.

Faith leaders spoke of particular interpretations and understandings, and reference was also made to universal themes and values that weave through many faiths, such as justice, hospitality and compassion. As people with disabilities seek to be more actively involved, bringing their perspectives and experiences of disability and spirituality into dialogue with communities of faith, this will create a new opportunity for dialogue with leadership.

(iv) Role of leadership to encourage positive change

The need for proactive and supportive leadership was clearly expressed. A number of ideas were proposed, all with merit. The initiatives to date to reduce discrimination and increase access and belonging for people with disabilities were applauded, and these need to be promoted and discussed amongst faith communities, who can then each determine their best course of action.

One of the interviewees with a disability had been a serving member of the decision-making Council of their congregation. People with disabilities have so often been considered passive recipients of other people's decisions, without having the opportunity, or expectations, that they may also bring leadership qualities to a faith community. Indeed, the findings from this research suggest that all religious communities need to develop an awareness that recognises people with disabilities as the 'experts' of their needs, and that leadership roles of all descriptions need to be more proactively pursued.

There also is an opportunity for public statements in writings and sermons and teachings that portray people with disabilities in a positive light, and encourage support and friendship networks to continue evolving.

An important skill is to listen for the ways that a particular tradition or faith describes, facilitates and guides the transition from 'stranger' to 'member'. To be a member is to belong, in both name and experience.

Leaders also recognised the need to foster and identify champions from within their own faith community to advocate and motivate others.

Conclusion

The 18 people interviewed provided honest and telling accounts: variously of satisfaction, disappointment, frustration and joy. This research has highlighted a number of positive initiatives undertaken by faith communities to address the needs of people with disabilities. It has also revealed that much more needs to change in order for people with disabilities to take their rightful place within faith communities as equals in all senses of the word.

Commitment to such change needs to come from a range of sources. Cooperative partnerships and collaboration need to be fostered within faith communities, in which the voices, stories and aspirations of people with disabilities are taken seriously. There is also an opportunity to develop collaboration more fully between faith communities and a range of community 'bridge-builders' who are in relationship with people with disabilities.

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Introduction

Victoria has historically incorporated many changes to its social fabric, resulting in a multi-cultural and cosmopolitan society. This rich diversity of cultures, beliefs and relationships is highly valued, and is something which the state can be very proud of.

Victoria also has an excellent culture of ecumenical and interfaith dialogue, as evidenced by bodies such as the Victorian Council of Churches (VCC), Faith Communities Council Inc, Jewish-Christian-Muslim Association (JCMA) and most recently, the establishment of the Multi-Faith Advisory Group to advise the government via the Victorian Multi-Cultural Commission (VMC). Such bodies play a significant role in promoting harmony and social inclusion.

It is within this faith and social/cultural context that the current research, focussed on people with disabilities within faith communities, is situated.

Approximately one in five Australians identify as a person with a disability; this is projected to be one in four by 2051 (Australian Bureau of Statistics, 2004). Across the spectrum of disability, this includes people with mental health issues, and people with physical, intellectual, sensory, cognitive or neurological impairments.

68% of Australians believe in God and/or a universal spirit (The Age/Nielsen poll 2009). Such a high rate of belief is not reflected by participation in faith communities. Anecdotally, and acknowledging the absence of any evidence about participation rates, these figures suggest many people with disabilities may have chosen not to participate in faith communities. It is also surmised that people with disabilities 'missing out' on belonging to a faith community will increase in the future with projections of population in Victoria reaching 7.395 million by 2036, an increase from 2006 of 1.267 million (*Victoria in Future* 2008).

Spirituality and Disability

Even in a contemporary secular society, such as Victoria, faith is an important aspect of many people's lives, and the reason many individuals and families participate in faith and religious activities, or identify with a faith community. Within Victoria numerically, the prominent faiths are Christianity (64%), Buddhism (2.1%), Muslim (1.7%), Hinduism (.7%) and Judaism (.5%) Many of those who say they have no religion nevertheless describe themselves as religious, engage in spiritual practices such as prayer, or profess a belief in God or a spiritual entity (Bouma, 2006).

For some people, the spiritual dimension of injury and disability has been described as a 'grand project and everyday task' of coming to terms with finite losses and limitations as well as the infinite possibilities for a meaningful life, and for a relationship with the world and a higher power (Fitzgerald, 1997).

For some people, living with disability may be an opportunity for spiritual growth and meaning-making - a catalyst for profound individual transformation and re-connection with the sacred as a central organising value in life (Pargament, 1998).

Conversely, for some people the onset or ongoing experience of disability may be a catalyst for profound spiritual distress or discontent, and provoke various forms of spiritual struggle (Fitchett & Murphy, 2004; Saylor, 1991). This may include questioning of spiritual beliefs or one's relationship with God or deity, a deep crisis of faith, disillusionment with a previously supportive faith community, or disinterest in previous religious activities (Cressey and Winbolt-Lewis, 2000).

Either way, the relationship of spirituality and disability is an important one, and some people with disabilities seek involvement within a faith community to explore themes described above. Others have experienced a problematic relationship with faith communities and positive associations have not developed.

Background

This research project has its genesis in a growing awareness of the rights of people with disabilities, from all faith perspectives, to have their aspirations taken seriously in regards to participation in worship and social activities. During the period 1996 to 2004 within Australia and New Zealand a series of conferences to explore issues of disability and spirituality were held. In 2001, as part of that movement, Victoria hosted its first international multi-faith gathering of people interested in matters of disability and spirituality. Called 'Exclusion and Embrace', this conference gave rise to a number of new resources, networks and impetus for dialogue and responses regarding inclusion.

One outcome was the submission by the Uniting Church Synod of Victoria and Tasmania to the Human Rights and Equal Opportunity Commission, of its 2000-3 disability action plan (DAP), the first such to be submitted by a religious organisation in Australia.

A disability action plan is a useful tool for organisations to plan and implement changes that remove barriers to access for people with a disability. The implementation of a DAP also contributes to an organisation's obligations under the *Disability Discrimination Act 1992*, the *Charter of Human Rights and Responsibilities Act 2006*, as well as supporting the principles of the United Nations *Convention on the Rights of Persons with Disabilities*.

In 2005, with financial support from the Department of Human Services, through a State Disability Plan Innovation Grant, a number of forums throughout Victoria were conducted, and a report entitled: 'Inclusion of People with Disabilities in Faith Communities' was completed. This was a joint project initiated by the Uniting Church and supported by the Victorian Council of Churches, the Heads of Churches and the Leaders of Other Faith Communities.

Predominantly, the forums were attended by service providers and adherents of Christian congregations. The major recommendation was that a Disability and Spirituality Resource Unit be established to support and encourage people's choice to participate in a faith setting.

The rationale for this was that the Unit would play a crucial role in assisting community service organisations, faith communities and people with disabilities to

integrate awareness of spirituality into person-centred planning and service provision.

Other Victorian developments in recent years have witnessed:

- In 2008 Inclusion Melbourne, began conducting workshops funded by the Victorian Multicultural Commission, to support inclusion of people with an intellectual disability within the City of Port Phillip into a range of community settings, including synagogues
- Jewish Inclusion Network, formed in 2009, is a non-profit volunteer organisation, supporting full and effective accessibility, participation and inclusion of Jewish people with a disability in our community
- In 2009 Luke 14 was launched. Developed by Christian Blind Mission, it has developed some audio-visual resources aimed at encouraging Christian communities to be more responsive to the inclusion of people with disabilities
- Increased awareness within a range of faith communities to improve the built environment
- As a contribution to this momentum, in 2009 the Uniting Church, with financial support from the Office for Disability, Department of Community Planning and Development, commenced this multi-faith disability inclusion research project.

The lives of people with disabilities are shaped by many factors, including culture, ethnicity, socio-economic status, language and faith. Yet little research has been done on these intersections. It is believed that very little research with a multi-faith focus has been undertaken internationally; it is hoped that this Australian research will contribute to that knowledge base, and also to increased participation of people with disabilities in faith communities.

One of the inherent difficulties when undertaking such research with a multi-faith focus is to define terms such as 'spirituality', 'beliefs', 'faith' and 'religion'. Researchers, theorists and practitioners define such terms in a variety of ways. Spirituality and faith are sometimes contrasted with religion; the latter being reserved for organised faith communities with systematic beliefs and practices, whilst the former are applied more broadly to describe personal experience or beliefs. Rather than polarising such definitions, the terms spirituality and faith, when used in this research project, embrace both religious and personal expressions.

Purpose of the Project

- To investigate the faith lives of people with disabilities from the major faith traditions in the Victorian community: namely Buddhist, Christian, Islam and Judaism. Using interviews and focus group discussions, it will seek to gather information about the faith lives of people with disabilities, comparing and contrasting their stories with the experiences of faith leaders in those traditions.
- The research and sharing of narratives of inclusion and exclusion in faith communities will lead to recognition of the shared humanity, value and rights of people with disabilities to be full participants in their respective faith communities. This project will provide a valuable opportunity for discussion of the obstacles to participation, and the necessity of their removal.
- The Project will produce a written report, providing a platform for the stories of people with disabilities and their faith communities to be shared with the wider community, to maximise the potential to be heard and engaged with. The project will also explore multi-media options to engage participants and communicate the findings

Key aims of the Project

- To listen to the stories of inclusion and exclusion of people with disabilities, in relation to their faith tradition.
- To also listen to the stories of inclusion and exclusion from the leaders of those faith traditions, in order to examine and understand reasons why people with disabilities have not been fully involved, and to address reasons for exclusion.
- To document and communicate these stories as widely as possible through the Victorian community.
- To establish an ongoing means of dialogue beyond the life of the Project, in order to further the goal of inclusion of people with disabilities within faith communities of Victoria.

(Stated Project Purpose and Aims in Terms of Reference Appendix 1)

Rights and Legal Context

The United Nations *Convention on the Rights of People with Disabilities* was adopted by the federal government in 2008. Within the Preamble of the Convention,

- (a) *recalls* the principles proclaimed in the charter of the United Nations which recognises the inherent dignity and worth and the equal and inalienable rights of all members of the human family as the foundation of freedom, justice and peace in the world,
- (b) *reaffirms* the universality, indivisibility, interdependence and interrelatedness of all human rights and fundamental freedoms and the need for persons with disabilities to be guaranteed their full enjoyment without discrimination, and
- (c) *is concerned* about the difficult conditions faced by persons with disabilities who are subject to multiple or aggravated forms of discrimination on the basis of race, colour, sex, language, **religion**, political or other opinion, national, ethnic, indigenous or social origin, property, birth, age or other status.

Within Australia the *Disability Discrimination Act 1992*, (DDA) makes it unlawful to discriminate against people on the basis that they have or might have a disability. It is also unlawful to discriminate against a person on the basis that one of their associates (partner, carer, friend, or family member), has or may have a disability. This applies to any activity in our society, from the provision of goods and services to the provision of facilities.

Victorian legislation in relation to people with disabilities is underpinned by the *Equal Opportunity Act 1995*, the *Disability Act 2006* and the *Charter of Human Rights and Responsibilities Act 2006*, each affirming the full participation of people with disabilities in all dimensions of community life.

In response to this legislation and community expectations, the Victorian State Disability Plan, developed for the period 2002-2012 affirmed a number of Guiding Principles: the values of Equality, Dignity and Self-Determination (Choice), Diversity, Non-Discrimination.

The Principle of Equality recognises that “*people with a disability are citizens who have the right to be respected and the right to have equal opportunities to participate in the social, economic, cultural, political and **spiritual** life of society. As citizens, people with a disability also have equal responsibilities towards Victorian society and should be supported to exercise these*”.

Of the goals listed in the plan to attain the vision of social inclusion, Goal 2, Building Inclusive Communities, has particular relevance to this research project:

Building Inclusive Communities means strengthening communities so that people with a disability have the same opportunities as all other citizens of Victoria to participate in the life of the community—socially, economically, culturally, politically and **spiritually**".

Social inclusion

The following comments provide a brief overview of government policy and responses by some faith-based communities to the concept of social inclusion.

Both the federal and Victorian state governments have adopted policy frameworks and strategies which emphasise social inclusion. Social policy researchers have taken into consideration traditional measurements of poverty and disadvantage (such as income deprivation), as well as focussing on social capital, cohesion and wellbeing as broad measures of participation and community resilience.

The 2009 report, *A Stronger Fairer Australia. Reducing Social Disadvantage and Increasing National Prosperity*, says:

'Social inclusion is about all Australians working together. It's helping individuals to develop their skills and abilities. It's supporting local communities to respond with confidence to new pressures and problems. The impact of mental illness or disability on life outcomes can be severe. As well as the practical challenges presented by disability and mental illness, many people also encounter misunderstanding and systematic discrimination. These factors can affect social, community and economic participation'.

Some community service agencies, associated with faith-based outreach, have also developed and adopted context-specific social inclusion policies. Broadly speaking, a socially inclusive approach emphasises the importance of each individual having choice about, and control over, how they live their life. By working to build people's capabilities and material resources, it aims to ensure that all people can participate in community and social life ('Social Inclusion and Belonging', Wesley Mission Victoria, 2009).

Faith communities play a significant role in the social fabric of Victoria, as faith and adherence to a particular set of beliefs and practices attract people from a diversity of backgrounds to worship and socialise together. Written policies such as Wesley Mission's are usually the exception within faith communities; 'social inclusion' is a term not necessarily familiar to many faith communities, who respond rather to sacred teachings in terms of welcoming people. People with disabilities who are involved in faith communities, participate either autonomously, or with a range of supports as needed: family, the faith community, or community service agencies.

This research contributes to the promotion and encouragement of faith communities to develop more proactive responses, thereby enriching the faith and social fabric of all Victorians.

Research Methodology

Management and Reference Committees

In consultation with the Office for Disability, Department of Planning and Community Development (DPCD) it was decided to establish two groups to support the development of the project. For purposes of governance, a Project Management Group met on a number of occasions, with membership including managerial staff from both the Office for Disability, DPCD and Uniting Church Synod of Victoria and Tasmania. The purpose of the group was to oversee the implementation of the project and to make decisions pertaining to project progress, delivery of project outcomes and funding.

The second was a Reference Group which comprised a diversity of people, including people with disabilities from the four faith communities. People with disabilities from the Christian, Jewish and Muslim faith communities were represented and Buddhist representation was provided by a faith leader. Members included the carer of a child with a disability, and a Commissioner of the Victorian Multicultural Commission. The group was chaired by the General Secretary of the Victorian Council of Churches; this Council has close links with the Faith Communities Council Inc which represents multi-faith leadership in Victoria. Representation was also provided by the Office for Disability, DPCD along with the researcher employed by the Uniting Church.

The Reference Group's role was to provide guidance, feedback and mentoring to the researcher, in addition to linking people with disabilities and carers from their faith communities with the Project. This ensured the Project was accountable, focussed and attuned to the sensitivities, both religious and cultural, of those communities.

Members of the Group were encouraged to participate as sources of advice and information to the Project, and assist in informing their communities and networks about the Project.

Minutes of meetings were recorded and circulated, with meetings held bi-monthly for the duration of the one-year project. Meetings were held at an accessible central city location, and some costs incurred by members for their attendance were reimbursed.

Research considerations and parameters

In writing of research involving vulnerable people, Liamputtong refers to 'people with disabilities as being amongst a number of social groups who are often hard to reach; they are the silent, the hidden, the deviant, the tabooed, the marginalised and hence invisible populations in society. The reasons for their invisibility are many and may include their marginality, lack of opportunity to voice their concerns, fear of their identity being disrespected, stigma attached to their social conditions, heavy responsibilities and scepticism about being involved in research' (Liamputtong, 2007).

In consultation with members of the Management Group, some broad parameters for the design of the data collection tools and process were established.

- Since the research aimed to explore the personal experiences of people with a disability, a qualitative methodology was deemed most appropriate – in other words, participants were encouraged to provide feedback ‘in their own words’
- For purposes of consistency the same list of questions (Appendix 2) was sent in advance to participants. Where feedback was received that the questions may pose difficulties for the interviewee, a modified version was used and digression from the set questions was also used when deemed appropriate
- Leaders representing each of the four faith communities were interviewed, with a distinct, but related, set of questions (Appendix 3), to learn about their experiences of people with disabilities participating in faith activities. Some of their responses have been incorporated in the development of a DVD to supplement the written project report, as were those of three people with disabilities
- The written report was based on between three to five 1:1 interviews with people with a disability from each of the four faith communities. At least one leader from each faith community was also interviewed, and focus groups were used to inform the report. Focus group discussions were held at forums held in Melbourne and Sale, as described below.

Project Phases and Components

The research project, over a twelve month period, engaged a part-time researcher, and had three distinct phases, as follows:

- (i) The promotion and organisation of a forum, at an accessible location within central Melbourne. This was a significant event in that it provided a platform for the ‘launch’ and public engagement with the research. Professor John Swinton, School of Divinity, History and Philosophy, University of Aberdeen, Scotland was the keynote presenter. In addition to his keynote address, a variety of faith perspectives were presented by people with disabilities, and small group discussions held.

Two topics of discussion were considered by the groups, namely:

What are the most important factors to be addressed by your faith tradition to ensure increased participation of people with disabilities? and,

What is the role of leadership in such faith communities, and how might people with disabilities and faith leadership come together to ensure positive change?

62 people participated in the forum. Based on self-recorded information the distribution of people according to faith and disability was (i) 32 did not name a faith affiliation, whilst 23 were Christian, 6 were Jewish and 1 was Buddhist, and (ii) 12 identified as a person with a disability.

- (ii) Conducting of the 1:1 interviews with people with disabilities, and with representatives of leadership from the four faith communities. A forum was also held at Sale, Gippsland, to learn about rural/regional perspectives. The same questions considered at the Melbourne forum were also discussed in small groups. At that forum, (i) all self-reported faith affiliations were Christian, and (ii) 4 people with intellectual disabilities participated.

Also, whilst the primary focus of this research was on the accounts of people with disabilities, and with faith leadership, two additional interviews were held; one with the Director of Action on Disability within Ethnic Communities (ADEC), and the other with a carer of a person with a disability. These interviews provided valuable supplementary information and insights.

13 individual interviews with people with disabilities were conducted from each of the four faith communities (an additional Christian interview), 5 leaders representing each faith community were interviewed (an additional Jewish interview), and 84 people participated in the two forums. A number of the interviewees, both people with disabilities and faith leaders, were filmed whilst responding to the respective questions.

The purpose of the 1:1 interviews was to learn from people with a disability in relation to inclusion: people with mental health issues, and people with physical, intellectual, sensory, cognitive or neurological impairments, as below:

Buddhist	Christian	Jewish	Islamic
Intellectual disability(1)	physical disability (4)	Intellectual disability (1)	Physical disability (2)
Physical disability (1)		Mental health (1)	Hearing impairment (1)
Mental health (1)		Speech impairment (1)	

Interviews were held at the location of the interviewee’s choice; it included either their home, the work environment of the researcher, or a community service agency setting.

For interview purposes, a considerable amount of time was spent locating people with disabilities, as an introduction was often via a third person, with trust and cooperation needing to be fostered. To interview Vicdeaf Muslim clients, arrangements for an Auslan interpreter also needed to be put in place.

- (iii) Collation of the information from interviews and forums for the purposes of a final report. An Easy English version of the report’s Executive Summary was also produced. This phase also included the editing and final production of a DVD. The content of the DVD incorporated some of the

people with disabilities and faith leaders who were filmed during the interview phase.

Methodology Critique

This multi-faith research project, using individual interviews and focused on this particular topic, is the first known of its kind within Australia. It had originally been anticipated that up to 60 individual interviews would be held. Within the constraints of available time and resources, this needed to be renegotiated. Working through family and professional 'third party' persons, meant that many lines of inquiry, bore no fruit. Such processes also required the 'third party' to be convinced of the merits of such research before further contact could be progressed.

Numbers of interviews in any future such research may be enhanced by researchers from within each faith community being appointed and trained to interview people with disabilities from within their own community.

It is possible there was a perception of bias or uncertainty about being involved, given the researcher is an ordained minister in a particular faith community. That is difficult to know for certain.

The researcher being male may have limited conversations with many women from culturally and linguistically diverse (CALD) communities.

Findings and Learnings

Review of the information obtained from the combined total of 18 interviewees, people with disabilities and faith leaders, revealed four broad clusters of responses:

These are:

- (i) Understandings, perceptions and experiences of inclusion;
- (ii) Obstacles and suggested strategies to increase participation;
- (iii) People's interpretations of their disability and the particular teachings/beliefs of that religion/faith community; and
- (iv) Role of leadership as a catalyst to promote positive change.

These four clusters are used to summarise the interview findings from firstly, people with disabilities, and then faith leaders. The information gathered from the two forums, and two additional interviews, will be referred to in the Discussion section of this report. In the case of the forums, the comments gathered from the groups was not attributed to a particular person, and therefore such additional supplementary information, whilst very important, needs to be viewed in a general sense.

People with disabilities

(i) Understandings, perceptions and experiences of inclusion

Responses in this cluster varied from definitions of the concept 'inclusion', accessibility to physical spaces, and faith practices of the individual's community.

A Buddhist perspective offered was that whilst use of the term 'disability' may be a helpful label in certain circumstances, there was a preferred use of 'wounded soul/woundedness' because all of humanity is wounded in some way, and these terms are an inclusive way of speaking about our own selves and the wider community. 'Woundedness' then applies to faith communities where stigma (meaning, wound) is to be found.

In Victoria, owing to cultural variations, Buddhist faith communities broadly follow either Tibetan (western followers) or Theravadin teachings (Indo-Chinese followers who are first and second generation). In terms of physical access and sense of welcome, whilst temples are rarely well designed for physical access needs, one interviewee, who uses crutches because of multiple sclerosis observed: 'I was doing a course and within two minutes people hovered to take me to the toilet and offered refreshments. That never happens when I go to a western temple. They're afraid you might ask for more than they can provide. I'm not being down on people, but usually it is the older people from village backgrounds who rally around. Mind you, the temple I now attend is a very important community of faith and social life for me – where I have a number of friends'.

The issue of physical access was also specifically raised by all Christian interviewees. Their statements of inclusion included 'heart of the gospel', 'Church must be inclusive', and 'It is hospitality. It is who the people are, or it should be.' One person said it is very good and important that people with disabilities should be able to go to church if they wanted to. This person also spoke positively of the efforts her church has gone to on account of her husband's disability. 'They care very well for him and his needs: lifting in and out of the bus and a wheelchair is available for him when he gets there. They have also installed a ramp, and he gets to read the Bible once a month'.

Others however spoke of difficulty.

In talking about inclusion, two ordained people spoke of their experiences of exclusion including: 'patronising attitudes which have a detrimental affect on self esteem and self-confidence', reduced expectations in regards to performance of their role: 'the sanctuary was inaccessible, so a parishioner said I might consider going around the back of the church and come in that way', and reference to inflexible structures: 'With each remission, I was working against the demands of the church structure to be fit and active' and 'the irony for women with disabilities is that it can be a double exclusion as we are also vulnerable to a patriarchal system'.

Some respondents across the faith spectrum focussed on the importance of their faith, and its practices, although they may not be regular attendees at worship. 'Keeping the faith' seemed to be integral to their sense of inclusion, and included meditation, prayers, and observing sacred events on their religious calendar. Examples were as follows:

- Sending their children to an Islamic school
- Observance during the month of Ramadan, practising the values of Islam and praying five times daily
- Weekly observance in the family home of the Sabbath (Shabbat), and High Holidays (Hanukkah and Passover)
- Personal meditation rather than regular attendance at a temple.

The above examples of inclusion are summarised by one of the interviewees in these words:

'When you are born/created to a religion, this defines who you are, or is the foundation of who you are'.

(ii) Obstacles to participation, and suggested strategies to increase participation

Many reasons were cited as obstacles and points of resistance to participation in religious communities. Some creative solutions and suggestions were also offered that people believed would contribute to enhanced opportunities for people with disabilities to more fully participate.

The difficulties described were grouped into attitudinal, structural, and personal circumstances.

In relation to attitudes, in addition to patronising remarks, one person with a disability referred to an early life experience in which a priest visited the family after the mother's death. No attention was paid to this person's grief and sadness, which made them feel they did not belong: 'Priests are much better today about that, but it would have made a huge difference if I had at least been said hello to'. Mention was made by a person with a disability who has a worship leadership role, of people with an intellectual disability and the possibility of loud or 'inappropriate' noise during a service. Mention was made that many people find such behaviour problematic in a worship context.

Comment was made of sometimes not being welcomed in the same manner as all other people are – there was perception of discomfort and awkwardness on the part of people who are not familiar with disability matters.

One person raised the issue of healing of people with disabilities, both personally and in relation to other people with disabilities. Reference was made to some contexts where people with disabilities are offered prayer for healing, to be restored to a 'perfect' body. Such attempts were not welcomed.

Reference was also made to issues of power and patriarchy within the Church: 'As the first woman priest in my Archdiocese, I was aware of some of the same issues and questions in terms of my gender. 'What to do with you? Which gave me a taste of exclusion. With the onset of my disability, and with each remission, then weakness, I was working against the demands of the Church structure to be fit and active'.

Physical access was mentioned by a number of people across the religious spectrum as being problematic. Practical issues were also raised, such as: 'What if it's raining or I have to park too far away? Bathroom? Seating? I don't want to sit at the front and walk past all these people. But my fears could be allayed if I could talk to people in advance'.

For Deaf people to be more fully involved, the cost and availability of interpreters is a very big concern. One person spoke of a desire to undertake the hajj to Mecca, but would need to pay for costs of an interpreter, in addition to personal travel costs. Mention was also made of the need for an interpreter to assist with further understandings of Islam. Isolation for Deaf people is also an issue, both within established community groups of Deaf people because of so many different beliefs, and also, when Auslan is a person's first language it is difficult to communicate with others within a religious community.

Within families also, miscommunications can occur because of language differences, putting at risk the 'Keeping the faith' examples mentioned previously: 'I read at home and try to learn from the book (Koran), and would like to be more involved. It's very hard – it's not in English and my first language is Auslan'. Mention was made of the need for hearing loops to be installed in buildings, and that hearing aid technology needs to be compatible with the loops. The need for Easy English and large print versions of printed material for worship and notices was raised.

Within rural/regional communities mention was made of the lack of diversity in congregations. The 'village mentality' means it is harder for new people with

disabilities to break-in and feel welcomed. Mention was also made of ageing country people tending to be stoic, and so disability issues were not always brought to the attention of the community in order to be attended to.

An additional structural issue raised by two interviewees concerned the link between disability service providers and faith communities. The importance of supported residential settings working to support people's individual aspirations was highlighted in the instance of one person who is supported by the residential staff to attend annual religious festivals and weekly Shabbat with their family.

Personal and cultural issues were also raised. Protectiveness of the family member with a disability may mean that that child or adult rarely, if ever, participates in religious activities. An example of this was mentioned as follows: 'It is very difficult for ethnic people with disabilities to attend church, as the family as a whole needs support which is often not there. They feel they are being looked at a great deal, and the family gets upset by this and don't bother going anymore'. One comment by a Christian interviewee also touched on people sometimes 'blaming God for who or what they are', and 'may believe in God but don't want to go to church because it is all too hard'. Support of an informal nature was also mentioned as being crucial: 'Simply put, it only works if you have an informal network. If I didn't I would not go – if I don't know of someone going then I just won't go'.

Some examples of inclusion mentioned were:

- Jewish Care organises for its residents with disabilities, to attend High Holiday events at local synagogues on a rotating basis, and the Caulfield Town Hall where there is a lift provided. Within the Jewish community services sector there is discussion about encouragement of regular participation within synagogues. A lift has also been installed in a synagogue to support the elderly women who sit upstairs. This is also of assistance for people with disabilities
- Extra assistance provided at the mosque such as seating for someone with a disability, and ramps for people with disabilities who visit Mecca
- People offering to assist and carry someone up steps in order to be in the temple for teachings
- An adaptation of the text to enable a man with an intellectual disability to read the Bible to the congregation.

Some suggested strategies for improvement were as follows:

- Most local places of worship, across the religious spectrum, have websites and this is an excellent place to promote accessibility and welcome to people with disabilities
- Printed and electronic material to invite people to make contact and discuss their particular needs
- Use of You-Tube to promote positive teachings
- One person initiated the idea of disability action plans being developed, both state-wide and locally – including guidelines and checklists for accessibility

- Examine the structure of worship services to be more inclusive of people with disabilities (e.g. shorter in length/sensory engagement/less 'wordy'/valued roles of involvement including leadership)
- Missing ingredient is person-to-person – same response whether you have a disability or not, such as: 'Hi, how are you going? Where are you from? Need a drink or any assistance?'
- Personal responsibility and motivation: 'When you have a disability you have to make a decision to include yourself – got to invite yourself to the party – need to develop your courage muscle!'

(iii) People's interpretations of their disability and the teachings/beliefs of their religion/faith community

Comments received were as follows:

- 'Buddhism teaches the notion of this life being a journey and we are not confined to one life only – there are many incarnations which may not be human. There are many lessons to be learned and debts we incur to be paid. Disability is understood to be karmic (not random), and the value of the disability is that it teaches you things and helps to pay the karmic debt'
- 'I have a saying: everyone has an innate sense of self-worth – not just disability or ability-wise'
- 'Torah does not speak of disability, but Moses had a speech impediment'
- 'Being in the wheelchair makes my faith even stronger. Means I get to interact with a lot of different people and places – I have to be strong. People are patronising but it is their problem. When they see the hijab and ignore me (eg train or bus drivers) it is their problem. When there are steps I can always find alternatives. There are many nice and good people who help out if needs be. The most important thing for me to learn is to be patient – it is one of the values of Islam and if I accept there will be rewards in heaven'
- 'Hearing children hear about their own faith and information becomes ingrained. With a deaf child they are told what to do but there are no further teachings about its meanings'
- 'When we read other faiths it helps our own faiths'
- 'A sense that we are all created as clay – all are broken – not whole – and to be moulded into what God wants us to be'.

(iv) Role of leadership to encourage positive change

Across the religious spectrum of those interviewed, there was unanimity about the importance of proactive leadership to encourage increased inclusion and acceptance. The following excerpts and ideas illustrate this:

- 'The leadership can provide guidance and teachings regarding a response of acceptance and compassion which are the important principles of everyday life and which apply in all religions and faiths'
- 'An article could be written in Jewish News'
- People with disabilities need to be in leadership roles within the community's decision-making processes eg Board/Council membership
- Encourage leadership of faith groups in Victoria to address this issue: Victorian Council of Churches, Council of Imams, Rabbinical Council of Victoria, Teachers and Committees of Buddhist temples
- Positive statements, teachings and sermons to be developed and encouraged via the above leadership structures
- 'A survey of needs would be good to be undertaken'
- 'Need to support the children of parents with disabilities, and also provide opportunities for support of siblings'
- 'If a Muslim signer was available, they could lead a group at the mosque with a small separate space for women and extra teachings'
- 'Need to promote disability awareness – younger priests seem open to this. The Church needs new 'blood' and education'
- Mention was made of other sectors in society developing awareness and disability action plans (eg Victoria Police and others), and could also be encouraged amongst Churches.

Leadership

The responses from faith leaders, grouped within the same four clusters as above, are as follows:

(i) Understandings, perceptions and experiences of inclusion

The following selected comments are a reflection of views from across the religious spectrum:

- 'Inclusion is the heart of the matter. It is the move beyond tolerance, and any group that is not part of our life means we are all diminished'
- 'Inclusion is a very important thing as it is a human rights issue, and means a wider community outreach and embrace, and people also becoming more confident to demand what they need'
- 'It means people in wheelchairs and the deaf and blind are all participating – it is an unrecognised need'
- 'It is the opposite of exclusion and how things should be in the everyday course'

- ‘Some highly religious families still hide away their disabled children’.

(ii) Obstacles to participation, and suggested strategies to increase participation

In response to this area of inquiry, all faith leaders spoke of the need to make the physical environment more accessible. Getting into a building or facility might be one thing, but then there is the issue of accessing toilets and meeting places. One person spoke of ‘not knowing what our disabled community needs’. Mention was also made of the need to find ways to more effectively involve people with disabilities in different aspects of a religious community’s activities and practices.

Some suggestions and recommendations made by faith leaders included the following:

- ‘The physical barriers should not be any drama to fix. To make a statement, I could consider boycotting places that are not accessible when asked to speak’
- ‘Our organisation could adopt a Statement of Principles of Inclusion and encourage member churches to consider and adopt’
- ‘To hear the voices of people with disabilities would not be a great jump – it’s a similar issue to the marginalisation of refugees’
- ‘There are many examples of great work. We don’t have to start from zero; we can copy the good work of others’
- ‘Establish networks where people can interact, ask questions and be educated regarding disability and inclusion’
- ‘Mosques vary greatly across Melbourne in terms of access. If we develop a checklist when building or upgrading, that becomes a reminder. We also need contact people to assist’
- ‘Someone at the temple to take care of people with disabilities’
- ‘It has not really been on our agenda till now, but we are going to set up a working group to reach a lot more people’
- ‘There is ignorance and reticence about the unknown. We need to take steps to make this the norm, and work with the hesitations and expectations of different people’
- ‘There are some great stories of rabbis being flexible to enable successful bar and bat mitzvahs for people with disabilities’.

(iii) People’s interpretations of their disability and the teachings/beliefs of their religion/faith community

The following quotations from faith leaders across the four religious communities provide some insights into how beliefs and values influence responses:

- 'The place and symbol of the pulpit is powerful. If it's up 6 steps that signals it's a 'no-go' zone for people with disabilities'
- 'How we address the text is most important – what questions we take to it and what questions arise for us'
- 'The two huge underlying principles are mercy and justice. And these apply across all faiths'
- 'Disability is not an obstacle to leadership. A blind imam here in Melbourne reads the Koran using Braille which empowers him to still connect and teach'
- 'The core Jewish belief of an 'unblemished soul' has been very sustaining for many people'
- 'It is an emerging area. There are surprising intersections, and the Buddhist idea is that your mind and attitude are most important'
- 'Biblically and theologically there is no differentiation between classes of people – everyone has rights and purpose. Jewish law says there is no basis to discriminate at any level. In our responsibility to share and give we are 'not to place a stumbling block before a blind person'.

(iv) Role of leadership to encourage positive change

The following quotations are clear directions for the future. Leadership is critical in providing the impetus for education, policy development and increased awareness of the issues confronting people with disabilities:

- 'Need to honestly face the truths and meet together around the table with all concerned'
- 'Schools of faith communities are where it is best to focus on change for the next generation'
- 'The Rabbinical Council is where policy may be affected as most synagogues are affiliated. The Jewish Community Council of Victoria has a Social Justice Committee where disability statements and policy could be developed with all affiliate bodies'
- 'We need dialogue, and to find out from people with disabilities what their needs are. We also need our federation to establish a working group to improve the situation'
- 'Leadership has an important role to play; develop programs and to follow through with human-to-human contact. Build capacity and think outside the box to empower others. It's important we go through the steps of education and understanding regarding people who may behave differently'
- 'University and scholarly studies need to be utilised'
- 'Disability action plan kits are a good idea, but without champions and building relationships it won't be as effective. It takes time but has more advantages'.

Discussion

This research is very timely within Victoria. In terms of community endeavours and support of social inclusion, it is contended that religious communities are the 'final frontier'. It is interesting that social research rarely analyses and explores the value and importance of such expression in the lives of people with disabilities. Two suggested reasons for this are: historically and generally within religious communities, people with disabilities have been recipients of others' largesse, with assumptions made about their interest or capacity to articulate the importance of needs or faith understandings. Secondly, whilst religious freedom and expression are enshrined in Victorian legal statutes, within a predominantly secular society, religion and faith are perceived as the private domain of individuals and less recognised as integral in the matrix of some people's lives.

Whilst the findings of this research project draw from a small sample of individuals with disability, and faith leadership, it nevertheless points to the importance of faith and spirituality and the social connections they provide for some people with disabilities. Given the projected population growth in Victoria over the next 20 to 30 years, including people who acquire disability because of age-related issues, it is surmised that the numbers of people with disabilities who seek to be involved with faith communities will grow. The findings of this research suggest certain interventions are required in the immediate to short-term timeframe, with an opportunity to strongly enhance social inclusion within the Victorian community.

Discussion of the findings will follow the same four clusters used in the Findings and Learnings section of the report.

(i) Understandings, perceptions and experiences of inclusion

People referred to 'inclusion' meaning different things. For some people the issue of physical access was the first thing mentioned, as this is the means by which they can access a place of worship via public transport, or park their car and enter a building without obstacles, and once inside be able to move around unimpeded and use a range of facilities without difficulty or embarrassment. There is also the need for suitable equipment and technology for people with sensory impairments, along with consideration given to adaptations of the presentation and style of worship.

These are all issues that require serious attention, and are the material precursors for an inclusion spoken of by others in which they have a sense of belonging or 'being at home', of being embraced and accepted. These factors are interlinked, and if people do not experience a sense of belonging, of welcome, the physical adaptations are in vain. This is not to suggest though that issues of physical access should not be addressed by all faith communities. Many people with disabilities speak of social isolation and loneliness, and so the importance of addressing all of these factors is paramount.

Interviewees spoke positively of changes that had been made to the built environment, and what a difference this had made to both the person with a

disability and the wider community of faith, resulting in significant relationships being formed. Whilst physical changes were applauded, others spoke less favourably about attitudes and diminished expectations of their role and contributions. These responses made the people concerned feel less included and placed in situations where they variously had to defend, explain or advocate for themselves. Whilst this was sometimes seen as necessary in terms of educating and informing others, it could also be a very tiring and demoralising experience.

The issue of being within a religious context that was experienced as patriarchal was mentioned by two interviewees. The effect spoken of was that there was less appreciation of their distinctive gifts and roles, and an inability to be involved in some of the decision-making processes.

Seven of the interviewees spoke of being occasional or non-attendees at a place of worship. However, personal faith was an integral part of their lives in spite of infrequent attendance at a congregation or gathering of like-minded people, and they felt spiritually connected and 'included' by adherence to particular prayers and rituals at appointed times and seasons. This research did not probe personal reasons for non-attendance, beyond the interview questions, but these interesting comments give rise to speculation about the link between private observance and public involvement.

Religious leaders universally spoke of the imperative for increased inclusion, underpinned by a range of values: human rights, mercy, justice, kindness and compassion, which all derive from sacred texts and teachings. The issue of shame was raised by one leader in regards to people with disabilities not participating. This is a challenging area for careful consideration and response, as it touches on people's understandings at personal, cultural and spiritual levels.

(ii) Obstacles to participation, and suggested strategies to increase participation

The three broad areas of obstacles described by people fell into attitudinal, structural and personal circumstances. Some excellent suggestions were made to address these, and the following is a synthesis of the expressed concerns and suggestions for improvements.

Attitudinal

A major concern of people with disabilities is being patronised, victims of charitable intent, and having assumptions made about their personhood or capabilities. Whilst this is also confronted on a daily basis within a number of life situations, the fact that it was mentioned by some interviewees suggests that religious communities also have a propensity for such communication. There was an implied hope by people with disabilities that religious communities might be a haven or sanctuary devoid of such attitudes. This research suggests it is incumbent upon religious communities to closely examine such communications.

One respondent, from within the Christian community, spoke of their concern about people assuming healing was needed. Black (1996) in discussing *cure* and *healing*, suggests faith communities need to consider the following:

‘Too often a healing service (with an emphasis on *cure*) for persons who are blind or deaf or paralysed implies that these persons are not acceptable as they are.

It says that there is something ‘sinful’ or ‘evil’ about their condition of existence, and only physical ‘wholeness’ is welcomed in the sphere of the holy. On the other hand, healing services that focus on the healing of broken relationships and the isolation some experience from the community and important people in their lives can be very important. Services that build people’s self esteem and inner strength to handle the problems they face can be truly *healing*.

This approach, as well as providing an alternative interpretation to the healing stories in the Christian gospels, reinforces a more positive approach in that any feelings of guilt and shame are not exacerbated when cure does not occur, and also shifts the community to think about healing in a whole new light. This approach shifts the focus and emphasis from being ‘medicalised’ and individual, to one that is social and communal.

Structural

A major stumbling block is the built environment which is so often cited as being disabling for people with disabilities. A range of factors have been previously mentioned, and rather than exhaustively describe here a range of considerations, the most important response religious communities can initiate is to listen to the needs of people with disabilities; to those within their own community, and also learn about the needs of people who may visit or wish to join in the future. Accessibility checklists and audits have been developed by government departments and community organisations, including some religious communities, and could readily provide a check-list of what is currently in place, as well as a priority list for future actions.

Disability action plans, developed by many community organisations as well as government and statutory bodies, provide a thorough examination of systems and structures, and develop a timeline for implementation of changes to alleviate any discriminatory practises. The state government has developed templates for such plans, and religious communities could develop plans specific to their circumstances. It is worth noting that religious communities are not exempt from the *Disability Discrimination Act 1992* (DDA), which makes it unlawful to discriminate against people on the basis that they have or might have a disability.

The issue of the importance of human services support staff to facilitate social inclusion is underscored by the following: ‘The hidden value of the community services workforce is their role in building social capital through the personal interaction and support they provide to people needing assistance. For disadvantaged or marginalised people, the value of social interaction with community service workers is perhaps even more great – for instance in a recent survey of people with mental illness using services almost 90% of respondents considered social relationships to be ‘important’ or ‘very important’ in helping to

manage the effects of mental illness and maintain mental health (*Building Social Inclusion in Australia*, 2008).

This workforce could play a significant role as bridge-builders, by encouraging and linking people with disabilities in residential care with religious communities. To enable this, an example was cited of a person being supported to attend annual religious festivals and weekly Shabbat. Additional material gathered from the two forums during this research also supported such partnerships.

Comments received included:

- ‘Needs to be more contact with services and people who work with people with disabilities who attend worship – learn about the person, find out about the services and if they can help’; and
- ‘Is there a connection between disability service providers and faith communities? So faith groups don’t have to do it on their own, are there resources already available so we can start making connections?’

Development of spirituality and faith information in curriculum material for people working in this industry would be a significant advance, given the emphasis on individualised planning and support of people with disabilities.

Personal

Cultural background and language are significant factors for many people with disabilities. There is a need to navigate multiple identities. A recent report commissioned by the National Ethnic Disability Alliance entitled *Cultural and Linguistic Inclusion? Literature Review on Social Inclusion, Cohesion and Culture* (2009), explored the definitions and measures of social exclusion, social inclusion and social cohesion. In a follow up report, *This is my Home – Belonging, Disability and Diversity* (2009), 32 people from Non-English Speaking Backgrounds NESB (some of whom were parents of children with a disability) described the challenge of the dual identities of living with disability, and being a person from a Culturally and Linguistically Diverse Background (CALD). People said that having a voice and being treated with respect and dignity was a key component of belonging. This included being afforded the same rights as all people to having a job, being able to undertake meaningful activities, being connected to friends and family and making a contribution to society. The role of religion, faith and spirituality was an important social connector for people. One of the five key findings of that report was that future measures of inclusion need to adequately value the role of faith in building inclusion and connectivity for many Australians.

Two other key findings from *This is my Home*, and relevant to many of the interviewees in the multi-faith disability inclusion project under consideration were that:

- *Family and friends are important gateways to social participation and belonging. Friendship networks in particular are worthy of further investigation as an enabler of social inclusion; and*

- *Creating more positive interactions between support agencies and customers can have the benefit of a stronger sense of belonging and connection for people who face social exclusion.*

For people with disabilities, family and friends play an integral role in faith activities. Also emerging is the powerful role that support agencies play in legitimising people's expressed faith preferences, and supporting them in activating person-centred plans and advocacy when seeking community involvement.

Responses from faith leaders acknowledged the difficulties people are experiencing and that there is a need for significant improvement, although reticence and ignorance will be encountered. This presents an opportunity to develop awareness and education materials: consultation with people with disabilities is fundamental to such developments. There was also recognition of the good things that are happening and there is an opportunity to share ideas, strategies and resources.

(iii) People's interpretations of their disability and the teachings/beliefs of their religion/faith community

The comments received in relation to understandings of sacred texts and disability were most interesting, as they appear to define how someone views their world of being labelled with a disability, or treated differently, and how to best adapt to changed circumstances with an acquired disability.

There is a range of interpretations and beliefs about the existential questions of why things are as they are, what is to be done in the 'here-and-now', and interpretations of the written texts. Such interpretations may be gained by personal reflections and life experience, or interpretations received from esteemed teachers and scholars within a particular faith community.

Over the past three decades, especially but not exclusively within Christian and Jewish circles, there has been an increasing international interest, as evidenced by literature and scholarship and dialogue, in the interpretation of sacred texts. Increasing numbers of people with disabilities are writing treatises and engaging in dialogue which critiques inherited faith teachings and interpretations. There is a desire to understand the meaning of certain stories and statements, in both the context of the time they were written, and their application and relevance in contemporary times. Questions such as:

- *What are the particular understandings about faith and people with disabilities? Is this important and if so why? What is helpful and what is not for people with disabilities?*

Religious leaders spoke of particular interpretations and understandings, and reference was also made to universal themes and values that weave through many faiths, such as justice, hospitality and compassion. As people with disabilities seek to be more actively involved, bringing their perspectives and

experiences of disability and spirituality into dialogue with communities of faith, there are some anticipated challenges for leadership, including:

- *How will those voices be legitimated and encouraged? Will there be an openness to hear perspectives that wish to engage with, and possibly challenge, inherited assumptions and practices? Will there be an openness to invite people with disabilities to discussions of doctrine and faith and policy, where decisions are made?*

(iv) Role of leadership to encourage positive change

The need for proactive and supportive leadership is clearly expressed. A number of ideas were proposed, all with merit. The initiatives to date to reduce discrimination and increase access and belonging for people with disabilities are to be applauded, and these need to be promoted and discussed amongst religious communities, who can then each determine their best course of action. It is interesting that during the course of this research, one leader said the issue ‘had just never come to our attention – our disabled people have not raised the matter before now’, and another said ‘we need to develop policy to begin to tackle this’. The winds of a sea-change are blowing, and there is an opportunity for all faith communities to continue working towards improvements.

One of the interviewees with a disability had been a serving member of the decision-making Council of their congregation. People with disabilities have so often been considered passive recipients of other people’s decisions, without having the opportunity, or expectations, that they may also bring leadership qualities to a faith community. Indeed, the findings from this research suggest that all faith communities need to develop an awareness that recognises people with disabilities as the ‘experts’ of their needs, and that leadership roles of all descriptions need to be more proactively pursued.

There also is an opportunity for public statements in writings and sermons and teachings that portray people with disabilities in a positive light, and encourage support and friendship networks to continue evolving. This may also be in the form of disability awareness materials which are readily available.

One significant arena which could play an important part in shaping future responses is the awareness and information that existing leadership and future leaders receive during their formation and studies. Specific modules for clergy-in-training have been developed by the Elizabeth M. Boggs Centre on Developmental Disabilities in New Jersey, USA, and have been very successful in this regard. Some courses now also include curriculum material focussing on the contributions and needs of people with disabilities.

One of the concerns expressed during the research was: ‘We want to do more, but how do we begin?’ This call and desire to express hospitality, ‘hospitality to the stranger’, is an historical tradition at the core of Christian, Jewish and Muslim traditions (Palmer, 1986). An important skill is to listen for the ways that a particular religion or faith community describes, facilitates and guides the transition

from 'stranger' to 'member'. To be a member is to belong, in both name and experience.

Once this listening commences, and the desire for action is agreed upon, some resources are available to begin the practical responses.

Leadership plays an integral role in encouraging such listening, and this was acknowledged by those leaders who were interviewed. The need for cooperative approaches was emphasised, and the need for leadership to take personal interest and involvement as well as initiating structural change. The place of schools as a formative place to educate a future generation, in addition to work within faith communities, was also raised and holds considerable potential. Disability action plans were affirmed as a means of initiating change, but the optimal way of introducing them is to engage with selected people to influence change. Leaders also recognised the need to foster and identify champions from within their own religious community to advocate and motivate others.

Rural/Regional considerations

Many rural areas face disadvantages – most notably environmental issues such as drought or economic decline which contribute to the loss of livelihoods and population numbers. In a report commissioned by the Australian Services Union, (*Building Social Inclusion in Australia, 2008*) a recent study of local government areas found the fastest decreasing populations across the country from 1998-2003 were all located in rural regions. These factors result in a lower population base to recruit workers, a lower skills base as people in these areas tend to have lower levels of relevant education and higher unemployment, and greater turnover of staff who frequently relocate for alternative employment. Most community services report that workforce shortages in rural, regional and remote areas are a particular problem while the increased need for services to address social problems grows.

As pointed out by a Mission Australia study, change in rural and remote areas presents increased burdens for community services: 'Declining levels of government human services provision are occurring in some rural communities at the same time as demand is growing. This trend can have a serious impact on demand for non government organisations' services' (*Building Social Inclusion in Australia, 2008*).

Whilst the research of this project has not been able to gather a wide spectrum of rural/regional views, the above report points to possibly diminished opportunities and support for some people with disabilities who may depend on staff assistance in accessing religious activities.

Conclusion

This research project has sought to learn from people with disabilities about their experiences of inclusion and exclusion within four major faith communities of Victoria: Christian, Buddhist, Jewish and Muslim. This has also been compared and contrasted with the perceptions and experiences of designated faith leaders from within those communities.

The 18 people interviewed have provided honest and telling accounts: variously of satisfaction, disappointment, frustration and joy. Whilst some people were content

with things as they are, the interviewees also revealed a desire for change. A change that sees increased participation of people with disabilities in religious communities, and dialogue that openly addresses the perceived and real obstacles. A change that includes attention to basic human rights and positive benefits of inclusion for all concerned.

Given future growth predictions in Victoria and the need for increased social connectedness to alleviate social alienation and associated issues, it is timely and crucial that this generation seizes the opportunity to put structures and approaches in place to welcome many more people with disabilities in the future.

There is also a need for greater emphasis and recognition of the importance of faith in the lives of people with disabilities from within the agencies and funded community services support sector.

In addition to family and friends being supporters and advocates, employees in the community service sector play an important role in encouraging and supporting moves towards social inclusion within faith communities.

Inclusive societies are strong societies and this project seeks to build on that, and complement existing Victorian and Australian social inclusion policies. For people with disabilities who wish to be more strongly connected within religious communities, much work needs to be done into the next generation and beyond.

This research has highlighted a number of positive initiatives undertaken by religious communities to address the needs of people with disabilities. It has also revealed that much more needs to change in order for people with disabilities to take their rightful place within religious communities as equals in all senses of the word.

Commitment to such change needs to come from a range of sources. Cooperative partnerships and collaboration need to be fostered within religious communities, in which the voices, stories and aspirations of people with disabilities are taken seriously. There is also an opportunity to develop collaboration more fully between religious communities and a range of community 'bridge-builders' who are in relationship with people with disabilities.

And the final word from the *Shut Out Report*:

'Disability is characterised by desire for positive change and striving for emancipation and flourishing. It is seen every day amongst people living with disability. It is active hope. **We desire a place within the community.** This place is not just somewhere to lay down our heads, but a place which brings comfort and support with daily living, friendship, meaningful work, exciting recreation, spiritual renewal, relationships in which we can be ourselves freely with others. And out of this great things may flourish'.

Recommendations

It is recommended that the current Multi-faith Disability Inclusion Reference Group establish a mechanism for continued dialogue and development of strategies for inclusion, good practice examples and exchange of ideas, experiences and successes across the Victorian multi-faith spectrum. An outcome of this would be that all faith communities in Victoria work towards developing disability action plans, ensuring that people with disabilities are the foremost advisers and informers within such developments.

Within the State Disability Plan there is recognition that people have equal opportunities to participate in the spiritual life of society. It is recommended that the Office for Disability convene a Forum with the Department of Human Services, Victorian Multicultural Commission, Victorian Council of Churches and Faith Communities Council to consider mechanisms of collaboration, in order to support people with disabilities from different contexts, including residential care to access faith communities of their choice.

Further research and interviews with a wider base of faith representation is needed. It is recommended that faith communities and government seek resources to enhance social inclusion for people with disabilities within faith communities

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APPENDIX 1

Multi-faith Disability Inclusion Project Terms of Reference

Purpose Statement

The Multi-faith Disability Inclusion project will investigate the faith lives of people with disabilities from the major faith traditions in the Victorian community: namely Buddhist, Christian, Islam and Judaism. Using interview and focus group discussions, it will seek to gather information about the faith lives of people with disabilities, comparing and contrasting their stories with the experiences of faith leaders in those traditions.

The research and sharing narratives of inclusion and exclusion in faith communities will lead to recognition of the shared humanity, value and rights of people with disabilities to be full participants in their respective faith communities. This project will provide a valuable opportunity for discussion of the obstacles to participation, and the necessity of their removal.

The Project will produce a written report, providing a platform for the stories of people with disabilities and their faith communities to be shared with the wider community, to maximise the potential to be heard and engaged with. The project will also explore multi-media options to engage participants and communicate the findings.

Key aims of the Multi-faith Disability Inclusion Project

To listen to the stories of inclusion and exclusion of people with disabilities, in relation to their faith tradition.

To also listen to the stories of inclusion and exclusion from the leaders of those faith traditions, in order to examine and understand reasons why people with disabilities have not been fully involved, and to address reasons for exclusion.

To document and communicate these stories as widely as possible through the Victorian community.

To establish an ongoing means of dialogue beyond the life of the Project, in order to further the goal of inclusion of people with disabilities within faith communities of Victoria.

Reference Group

This group will be comprised of a diversity of people, representing people with a range of disabilities from these four traditions. Representation will also be provided by the Office for Disability, the Project Manager from the Uniting Church. It is also hoped that leaders of those faith traditions will be represented on the Reference Group.

The group will provide guidance, feedback and mentoring to the Project Manager, in addition to linking people with disabilities and carers from their faith tradition with the Project. This will ensure the Project is accountable, focussed and attuned to the sensitivities, both religious and cultural, of these traditions.

The Group will be chaired by a member of the Reference Group, other than the Office for Disability representative or the Project Manager. Members of the Group will be encouraged to participate as sources of advice and information to the Project, and assist in informing their communities and networks about the Project. The implementation of the Project will be the responsibility of the Project Manager.

Minutes of meetings will be recorded and circulated within a week of each meeting.

Meetings will be held bi-monthly for the duration of the one-year project.

Each meeting should be preceded by a pre-agenda as required by the Chair, one week before the group's scheduled meeting.

It is hoped that members of the Reference Group would attend each meeting. If circumstances mean that this not possible, members need to inform the Project Manager prior to the meeting.

Support for members of the Reference Group will be provided as needed, so that members can get to and take part in meetings e.g. interpreters including Auslan and community language interpreters, hearing induction loops, accessible venues, reimbursement of travel costs and personal assistance costs as appropriate.

Use of language/communication

Respect for each other's faith belief is paramount.

Members of the Reference Group should try to use easy to understand language.

Papers will be provided in easy to understand versions for people with an intellectual disability and in accessible formats as required for people with sensory impairments.

Sensitive information may be shared on occasions, and requests for privacy or confidentiality must be respected.

For further information, please contact the Project Manager, Andy Calder on 92515489, 0417562556 or andy.calder@victas.uca.org.au

APPENDIX 2

Multi-faith Disability Inclusion Project Interview questions for people with disabilities

A brief synopsis of your background

What is your own faith interests/involvement?

In what way do you identify with disability inclusion?

What do you understand by the word inclusion?

What motivates you about increased inclusion?

What are the obstacles to greater participation in your faith community for people with disabilities?

Have you experienced exclusion yourself and in what ways?

What are the most important factors to be addressed by your faith community to ensure increased participation of people with disabilities?

Can you relate any positive stories about being included? If so, how did that come about?

Some conversation about your faith and disability. In what way(s) does your faith speak of disability, and have you been influenced by that?

What is the role of leadership in your faith community? How might people with disabilities and faith leadership come together to ensure positive change?

APPENDIX 3

Multi-faith Disability Inclusion Project Questions for faith leaders

A brief statement about your current faith role/involvement

What do you understand by the word inclusion – especially as it relates to participation in your faith communities?

What motivates you about increased inclusion for people with disabilities?

What are the obstacles to participation in your faith tradition for people with disabilities?

Have you experienced exclusion yourself and in what ways?

Were you able to make any changes? If so, how?

What are the most important factors to be addressed by your faith community to ensure increased participation of people with disabilities?

Can you relate any positive stories about being included? If so, how did that come about?

How might leadership in your faith community encourage increased involvement?

Do your sacred texts provide guidance or insights that would encourage increased inclusion in the life of worship and social activities?

Do you know of any scholars in your tradition who study and/or write about faith and disability issues?

How might people with disabilities and faith leadership come together to ensure positive change?



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