

**The Living History Project: Exploring the Lived Experiences of Living with Disability
1981–2002**

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Abstract

The International Year of Disabled Persons (IYDP) was held in 1981. IYDP emphasised full participation in society and equality for people with disability. The 21st anniversary of IYDP in 2002 raised questions about what change had been achieved in this period. Despite significant policy and legislative changes in this period, little data has been available to understand the direct experience of living with disability. The Living History Project explored the lived experiences of 22 people with disability and 17 parents of people with disability in Victoria during the period 1981–2002. The research participants identified a range of complex changes that they had experienced. Most of these were not simple 'before-and-after' differences, but were cyclic and fragmented. They often represented policy or technological developments impeded by lack of resources. A number of enduring themes were also apparent in the stories. These included continuing social and economic marginalisation, uncertainty and fear about future wellbeing, and feelings of powerlessness. Parents identified themes of scrutiny and loss of privacy, uncertainty and fear about their children's future, powerlessness, and experiences of emotional, mental and physical exhaustion. On the positive side, participants also commented on increased feelings of belonging and support in the varied communities with which they identified. Overall, the findings point to significant problems with, and barriers to, translating changes in the policy environment into integrated 'changes on the ground'. Most importantly the study highlights the need to listen to people with disabilities and their families to better understand the varied impacts of, and their desires for, change in their everyday lives.

Keywords

Disability, history, change, policy, lived experience

Introduction

The International Year of Disabled Persons (IYDP) was held in 1981. The year promised to bring about full participation in society and equality for people with disability. Actions were undertaken at the international, national, state and local level. In the Australian context, the Commonwealth Government placed an emphasis on IYDP 'activities likely to be of significant value to disabled persons and whose effects were expected to last beyond the Year itself' (Department of Social Security 1983, p. 74). In the state of Victoria, the participation of people

with disability in the process of planning and organising of IYDP, combined with strong government backing, resulted in the development of a strong agenda for lasting and ongoing societal change. Yet what changes have occurred and how have they been experienced? The 21st anniversary of IYDP in 2002 raised important questions about what change was achieved in the period 1981–2002. This paper reports the findings of an exploratory study – The Living History Project — which explored the lived experiences of 22 people with disability and 17 parents of people with disability from 1981–2002 in the State of Victoria, Australia.

The change agenda: The promise of IYDP

At the time of IYDP in 1981, the status of most people with disability was one of medical management and social restrictions. Disability was still largely understood within a medical model, and doctors and health professionals were seen as wielding an enormous amount of power over the lives of people with disability and their families. Many people with disability spent most of their time in segregated, institutional environments separated from mainstream society. Supported community-based accommodation and in-home attendant care schemes were still in their early or pilot stages, and segregated special schools and sheltered workshops were the norm. Most people with disability were living very restricted lives that were lacking in choices and often highly controlled by professionals and disability organisations.

During IYDP, themes of rights, independence and informed choices for people with disability emerged to challenge the dominance of paternalistic and charitable approaches to people with disability. Activists with disability lobbied hard to have their voices heard and their interests represented on the organising committee for IYDP in Victoria. Their influence focused IYDP on societal issues, resulting in a social agenda for change designed to bring about change in societal structures, legislative and policy reform, the reorganisation of the disability sector, and improvements in community attitudes and awareness of disability.

The focus on seeing disability issues as social issues generated the expectation that systematic societal change would address access issues, promote equal opportunity, and remove the social, economic, and attitudinal barriers which prevented people with disability from participating in the life of the community (Victorian State Committee on IYDP 1982, p. 35). In Victoria, an agenda for societal change emerged around issues of accommodation, income security and employment, representation and advocacy, rights legislation, access and mobility, recreation, prevention, community education and public involvement, and mental illness awareness. Overall, one of the key contributions of IYDP was that it painted a picture of the kind of society in which people with disability would live as equals, and identified the key societal changes that would be necessary for this to become a reality.

Despite the strong expectations that IYDP generated, no comprehensive analysis of social changes in the post-IYDP period has been undertaken. Most research that has occurred has tended to focus on 'before-and-after' changes relating to one or two key issues rather than on the broader significance of societal, cultural and personal changes in the lives of people living with disability. Commentary specifically on IYDP has been restricted to a small number of papers by disability activists, policy-makers, academics, and parents. Moreover, what has been written about the impact of IYDP present a mixed picture of change.

Some commentators consider IYDP to have been successful because of the impetus it provided for subsequent changes in formal government policy (Camilleri 1998; Correll 1998; Duncan 2002). These commentators argue that IYDP put disability issues onto government agendas, raised awareness of issues of 'medicalisation' of disability, and publicised the detrimental consequences of segregation, institutionalisation and isolation of people with disability. In place of charity, paternalism and fear, the public messages of IYDP about disability were ones of participation and inclusion (Camilleri 1998). Others commentators emphasise the importance of IYDP for consciousness-raising among people with disability and within the general community (Acton cited in Dietl 1981, p. 11; Cooper 1999; Newell 1999; Ozdowski 2002). Newell (1999), for example, writes that:

"Perhaps, most importantly, [IYDP] 1981 helped us recognise that we were people first, people who shared some common identity around our historical and political oppression. We constructed what emerged to be a rights movement, some of which utilised the rhetoric of individual rights" (Newell 1999, pp. 9-10).

In stark contrast, however, other commentators critically call into question the depth of the social changes that have occurred (Hall 2000). Ball (2001), for instance, maintains that the bulk of the changes achieved in the period since IYDP have been tokenistic:

"Okay, we've scored a few disabled toilets, kerb cut-outs now adorn most footpaths in the CBD and wheelchair-friendly taxis are becoming more common. But community attitudes have gone nowhere fast ... It seems to me that our token 'year' has left us with nothing but the token acceptance of a hostile world" (Ball 2001, p. 14).

While it is clear that there have been some enormous policy and legislative shifts and gains in the period 1981–2002, such as the large-scale closure of institutions and the rise of community-based living, the significance of these changes in the lives of people with disability and their families are far from clear-cut. Indeed, it is uncertain if these changes have been widespread or experienced as emancipatory as they were envisaged in 1981. We cannot assume that external, top-down policy changes have simple and equivocal impacts on the lives of people with disability and their families; they are not simply passive objects whose lives can be externally manipulated (Kendrick 2001, pp. 2-3). On the contrary, they actively partake in the creation of their lives' significance. Consequently, an understanding of lived

stories of change is needed to better understand both the impact and significance of IYDP for people with disability and their families, and to inform any plans for future change.

The Living History Project: Telling stories, sharing experiences, being heard

Twenty per cent, or one in five, Australians have direct experience of living with disability, and many more experience disability indirectly through the experiences of family and friends (Fairclough 2002). Yet, little is known of the personal experience of living with disability or parenting a child with disability in the now 24 years since the International Year of Disabled Persons (1981). Indeed, most research has not given people with disability and parents of people with disability the opportunity to tell their stories of their lived experiences.¹ A number of reasons have been suggested for the lack of research into the lived realities of people with disability and parents of people with disability. These include the rejection of knowledge derived from the lived experience of living with disability within conventional research and policy making (Newell 1999, p. 10; Cocks 2001; Grimes 2001, p. 5) and the overwhelming influence of 'experts' in the decision-making roles in the lives of people with disabilities and their families (O'Brien and Mount 1989, pp. 1-7). In this context, their 'untold stories become invisible stories' (Fairclough 2002), and our understanding remains restricted to the 'official' story told by professionals, policy-makers and other experts.

There are a number of reasons why it is important to understand past experiences from the perspectives of those who lived in the period since IYDP. Firstly, an appreciation of personal perspectives and experiences enriches recorded history and the lived present (Dillon and Holburn 2003, p. 130). There are few existing historical accounts of the experiences of people with disability (Bredberg 1999). Moreover, because many people with disability and their families may often be isolated from one another, they may not know the past of others with disability, or that others have similar circumstances and share their experiences. In this context, the documentation and telling of an accessible story about the complexity of lived experiences represents a significant contribution to the emancipation of people with disability and parents of people with disability, and to disability history in Victoria (Bredberg 1999; Fairclough 2002). The Living History Project provided such an opportunity for people with disability and parents of people with disability to tell their stories, share their experiences and, most important, be heard.

¹ There are a number of notable exceptions, including Bowman and Virtue 1993; Clear and Horsfall 1997; Cooper 1999; Clear 2000; Gray 2002. While local and international studies of the perceptions of people with disability are becoming more common, most explore single issues or are atemporal (e.g., Clear and Horsfall 1997; Leicester and Lovell 1997; Thomas 1997; Temby 1998; Davis 2000; Lupton and Seymour 2000; Tighe 2001). See also published personal accounts during this period, such as those published in the Association for Children with a Disability Noticeboard, 2000–2002; Ball 2001; Navtratil 2001. A recent study of carers in Australia found some (3 per cent) carers want 'more recognition and chances to tell their story' (Briggs and Fisher 2000, p. 41).

Secondly, an appreciation of past struggles, changes and enduring problems are a necessary basis for planning and lobbying for further change. As Cooper argued, 'We should never forget our past history and remember it with horror and be proud at our survival and at the changes we have made' (Cooper 2000, p. 131). Understanding history from the perspective of those who have lived it is an important way of facilitating future change, as we learn from what has happened in the past and do not find ourselves 'reinventing the wheel' (Sozomenou et al. n.d., p. 2).

Methodology

The overall aim of the Living History Project was to gain a deeper understanding of the lived experiences of people with disability and parents of people with disability in the post-IYDP environment. The study sought to be participatory and democratic in nature, and it provided participants with the opportunity to speak for themselves about their own lives throughout the period 1981–2002. The focus was on exploring and identifying changes they had experienced in their lives *from their own perspectives*.

An unstructured life history interview approach was devised to support participants to 'tell their story' and explore their experiences of change. This interview approach was chosen as the most inclusive and effective process after a number of alternative approaches were piloted.² The reason this method was successful is possibly because '... telling stories about past events seems to be a universal human activity ... and used throughout the life course by people of all social backgrounds in a wide array of settings' (Riessman 1993, p. 3). It allowed participants to talk freely about their lived experiences in the period 1981–2002, including the good and bad, the old and new, and the changing and enduring themes of their lives. It also allowed them to identify and define changes from their perspectives.

The use of the unstructured interview process for gathering data meant that themes emerged from the data itself and they were not predetermined by research questions. Participants' stories were rich in detail, but this process did limit the extent to which the same themes and issues could be consistently explored with all participants. Changes identified by participants were diverse. Most changes identified by participants drew comment from only a small number of participants. However, the enduring and recurring themes identified by participants were remarkably consistent across the sample.

A total of 22 people with disability and 17 parents of children or adults with disability living in one rural and one metropolitan regional area participated in individual and focus group

² Several methods (such as semi-structured and unstructured, open-ended, and closed-ended questioning) were tested in pilot interviews conducted with nine volunteer people with disability and parents. Specific questioning around IYDP themes was trialled in the pilot interviews but failed to elicit responses. Pilot participants expressed considerable uncertainty about how these IYDP themes related to their own lives.

interviews. Participants were recruited using a purposeful, snowball sampling approach. Participants were drawn from one rural area and one metropolitan area in Victoria. In drawing participants from these two areas, the project sought to gain some understanding of the similarities and differences between rural and urban participants' lives throughout the period since IYDP to 2002. The sample method did not seek to be statistically representative of people with disability or parents of people with disability. The nature of the disabilities experienced by people with disability or the children of parent participants included physical, intellectual, sensory and multiple disabilities. Some participants were born or were parenting before IYDP in 1981, while the rest became adults or parents in the post-IYDP years.

The interview process yielded varied, yet detailed, discussions of disability issues. The interview data was then analysed using grounded, interpretive analysis. As an interpretive study, the findings of this project have been drawn from analysis of the interview data collected. This entailed each transcript being read repeatedly in order to identify the presence of key themes and assumptions, and recurring issues, phrases and words. Meaningful clusters of topics and themes relating to change and enduring issues were identified in the data, rather than being imposed by preset coding categories.

Findings: Complexity, continuity and stalled revolutions

The stories that participants told offer unique insights into the changes and enduring difficulties they have experienced, from their perspective. A broad range of different types of changes were identified in relation to the following four areas:

- 1) Social changes
- 2) Changes in support systems
- 3) Lifestyle changes
- 4) Changes in personal lives.

Interestingly, and contrary to the way changes are usually evaluated in the disability sector, most changes were not experienced in participants' lives as simple and compartmentalised 'before-and-after' changes. Rather, change was lived as complex, often stilted, fragmented and uneven. Moreover, even positive changes were experienced against a broader background of ongoing themes, and often considerable difficulties. The majority of the enduring and recurring themes in participants' lived experiences were negative. Due to the word limit I will briefly describe and explain the main trends through the use of limited illustrative data.³

³ The more detailed report of the *Living History Project* is available in various formats at <<http://www.scope.vic.org.au>>.

Social changes

Both people with disability and parents described a number of changes in society that had impacted on their lives. These included participants' experiences and perceptions of changes in the built environment, transport, technology, information and communication, and community attitudes. People with disability spoke about how new technologies and changes in the built environment had given them better access and greater choice, increased their privacy and independence, and provided opportunities for companionship by facilitating access to social and work sites. The following examples give the flavour of their positive experiences:

"The newer buildings have come a long way because they do provide access"
(Helena, pre-IYDP person with disability, rural).

"The biggest change since 1981 for deaf people and speech disabled people too has been the transmission of the written word. Prior to 1981, telephone typewriters, TTY, were just coming in, but there were no relay services. Today with TTY we can communicate with non-TTY users ... [Prior to TTY] deaf people were reliant on other people to make medical and dental and social appointments, and so on. And deaf people had no way of contacting emergency services either. So deaf people were very dependent on other people to arrange their lives for them ... But in 1995, the National Relay Service was established and has grown since then ... So deaf and speech disabled people now have the communication at their fingertips. And email and fax machines have been a great help too since a lot of people don't know about the relay service. I [often] ask people to fax me and I call them back [through TTY], and so telecommunications is now much more readily available to disabled people" (Sue, pre-IYDP person with disability, urban).

"Getting out there on the train, more accessible transport, visiting friends ... Life seems a bit faster ... I got confident going into the city, finding out where to go to find out information" (Chris, pre-IYDP person with disability, urban).

"[With email] I can read my own mail. I can read it myself and I don't have to ask somebody else to read. It's instant. When I go and sit there, I can read it. I don't have to wait for somebody else ... So it's private, you know ... It's the privacy thing and that I can do it in my own time, that's really important to me ..." (Shelley, pre-IYDP person with disability, urban).

A small number of parents also noted general improvements in physical and built access, such as "more public places are ramped and accessible" (Tamara, post-IYDP parent, rural).

Yet, a number of participants noted how their own or others' access to transport and technologies was often inconsistent or undermined. Parents, for example, noted that changes to make buildings accessible were not consistent:

"[My child] can't go to ... [one building] because it's not accessible ... They're looking at getting a portable ramp here, there's no reason why the others can't get one too. I mean those buildings should just have a ramp somewhere. You shouldn't have to try and get in at the back ... There's always this thing about the 'whingeing wheelies'... But you need 'whingeing wheelies' to get things moving" (Karyn, post-IYDP parent, rural).

People with disability also described negative changes and lack of changes primarily in the areas of access, transport, work, and opportunities for friendships with other people with disability. Taxi and public transport use were identified for particular attention. Taxis were often unreliable or late, even though as one participant pointed out: "We can't be late just because we have a disability" (Ian, post-IYDP person with disability). Moreover, they compared unfavourably with accessible taxis in other parts of Australia:

"There's something good about Queensland. You can ring half an hour before to get a taxi and they'll be there five minutes early ... If I feel like doing something, I can just do it" (Chris, pre-IYDP person with disability, urban).

The automation of public transport and lack of staffing of train stations was also identified as a retrograde step that threatened to erode the ease and simplicity with which people with disability used public transport.

Kerbs, footpaths and overhanging trees were identified as persistent problems that undermine access, while new problems were identified that have arisen as a result of lack of maintenance. Participants spoke about how their physical access was compromised by ongoing problems and few or no changes in the condition of kerbs and footpaths in their local areas:

"Most footpaths still have a long way to go ... getting up and down gutters is hard in a chair" (Helena, pre-IYDP person with disability, rural).

"My pet thing is kerbs, cobblestones, footpaths, and I know they are being changed but around [this area] cobblestones are a problem. Literally a pain in the neck because I drive a chair with chin controlIt took about 30 years to get this street's footpath done with many letters from me ... It was done in 1998" (Chris, pre-IYDP person with disability, urban).

Several participants also identified how the advantages of new technologies, as well as accessible private vehicles, were restricted and undermined by economic barriers to people with disability gaining access to them:

“There’s a lot of technology that’s available for disabled people now. But while some of it is covered under the ... PADP, there are some devices that are not ... [Much is] beyond the [financial] reach of the very people for whom the devices were designed as these people tend to be on low incomes ... Some way needs to be found to make devices to the disabled ... to be in reach for the people whom it was designed, bearing in mind that most of them are on low incomes” (Sue, pre-IYDP person with disability, urban).

Overall, even the most positive changes at the level of policy or technology development were undermined because of fragmented implementation or lack of money or grants to purchase equipment.

Support services

A number of people with disability and parents spoke about the changes in the range of support services that they received, including some comments about the positive improvements in the availability of services, improvements in specific programs, good personnel, better aids and equipment, and peer friendships and support networks. Participants’ experiences and perceptions of changes in formal support systems, included changes in programs, service approaches, professional practices, encounters with medical professionals, and aids and equipment. However, persistent problems were identified in some support services due to staff not listening and responding to the concerns of people with disability. This was particularly the case with the medical profession. One participant spoke of her predominantly poor experiences with doctors, especially their failure to listen to her description of her health problems:

“Doctors have been really, really good or quacks. Because they’ve talked down to me, not to me, and they think that because you have a disability you don’t have a brain. And they think they know you better than you know yourself” (Helena, pre-IYDP person with disability, rural).

Another told of a recent experience where a doctor failed to take seriously her request to communicate with her in writing. This resulted in her feeling distressed and dissatisfied:

“After about three days I was very upset because [the doctor] didn’t respond to my request to write things down, so I didn’t know what treatment was being proposed ... I was really upset” (Sue, pre-IYDP person with disability, urban).

Older parents mentioned improvements in the services and supports available, while younger parents focused on the benefits of specific programs:

“He’s a Futures kid, and it’s the first time where there’s been a government program that is tailored to need. Everything else when it goes directly to the institution doesn’t mean that you have to first consider the client. Here you have to first consider the client ... You know, if you give it to the institution and they say ‘Well come along and we’ll plan it for you’, the institution is controlling it ... but with the Futures I can say what our needs are ... The fact that you can mix it, which you could never do when the money went to these institutions, that has been the most responsive policy implemented. We had never, ever been able to get that much flexibility in a respite policy. It’s nice to have it there ... So I really appreciate the Futures, and I am worried that it might be watered down and changed because the concept is brilliant. I think the fact that there is a Futures program is a most significant change in the twenty years” (Mandy, post-IYDP parent, rural).

Yet, even such positive changes were not experienced as permanent in the lives of parents of children with disabilities, as the many examples given of funding cutbacks and changing eligibility criteria illustrated:

“I think at that stage, until she was six, she was eligible for a speech therapist through DHS. I think it started off at once per week and then, like all funding, diminished” (Claire, post-IYDP parent, urban).

Innovations in disability programs were undermined by funding cuts or the expectation that the program would not last. For some parents, this has resulted in resignation to the view that programs would fail, be withdrawn, or be undermined:

“It’s just everything we’ve implemented in the past has fallen away because it hasn’t been supported properly and ... just every time I get excited and I think it’s all going to change and he’s going to have that, and then you just get disappointed because it doesn’t. And it’s almost like I can’t even rise to the occasion any more. I’m sort of excited [about the new management plan] but I’m excited in a reserved way” (Diana, post-IYDP parent, rural).

Some parents also described problems with communication as a continual problem they encountered with services and support systems. Some spoke of particularly frustrating or upsetting instances of poor, unclear, rude, or delayed communication with government departments, disability services, schools and other agencies:

“...recently my [child’s] pension changed from a child’s disability allowance to an adult’s disability pension, and I now receive a carer’s allowance. There was a muck-up during the change and we were apparently overpaid. They wrote to me saying that during such and such period, for the purposes of Human Services, my [child] was not in my care. I was happy to pay the amount, but I objected to the wording. Where was

she during that time? I would have preferred that they say that they made an error. Those sort of things get up my nose” (Tamara, post-IYDP parent, rural).

Parents described negative changes and ongoing problems in disability programs, especially funding cuts and the lack of follow-up support. Some parents faced ongoing problems with education, particularly the tendency of schools to want to exclude children with disability. A similarly important, but negatively experienced, change was continual staff turnover. Both people with disability and parents commented that they experienced this change negatively:

“I’ve been working hard with my man from Human Services who is now leaving today ... He just rang to tell me and I’m bitterly disappointed” (Annie, post-IYDP parent, urban).

“The ... problem we have is holding physiotherapists up here, and I think that that’s a country problem ... with physios they change or there’s none available or whatever, so you don’t get the same person for long, and possibly the occupational therapist is in the same boat” (Debbie, pre-IYDP parent, rural).

The result of such frequent changes was a climate of uncertainty and an expectation of negative changes in the future. In response to such uncertainties, parents stressed the importance of finding ways to work with organisations, and noted accompanying changes in the working styles of some professionals and support workers. A number of parents spoke about changes that stemmed from the actions of individuals, such as the working styles of individual professionals and support workers. Several parents and people with disability also described strategies they used to actively become agents of cultural or policy change by changing their own behaviour in a particular setting, by reacting more assertively with professionals, by taking an advocate with them to confronting meetings, or by working with others to lobby for systemic change:

“Perhaps if you’re going to see either the school or a doctor or someone that puts you out of your comfort zone, that you write this stuff down before you go, [or] you take someone with you” (Tamara, post-IYDP parent, rural).

“Get to know your people in community services, even though they sometimes move on in their job ... Learn to work with them, not against them ... I’ve learnt over the years from someone who said, ‘They’re more frightened of you than you realise’. So that gives you, ... they’re frightened of your power” (Debbie, pre-IYDP parent, rural).

While change should not depend wholly on the actions of people with disability and parents of people with disability, the actions of participants in this study point to their power to exercise by initiating big and small changes in their lives, and actively resisting others.

Lifestyle changes

Participants recounted changes in their living, working and studying arrangements, including changes they initiated, such as returning to study. Becoming a student was particularly important for one participant with a disability who had been excluded from education as a young girl.

A number of people with disability described deinstitutionalisation experiences, such as moving from a hostel or a sheltered workshop to community-based or mainstream accommodation and employment. Yet these participants did not describe how they experienced such changes. Their comments suggest these changes were things that happened to them from 'outside' or 'above', rather than the result of their own active involvement. Further work is needed in this area to draw out the specific meanings of such changes for people with disability.

Several people with disabilities living with their parents expressed considerable concern about the future and where they would live when it came time for them to move. One participant expressed clear ideas about where he did not want to live in the future: "I don't want to end up with someone who is 65 with a walking stick" (Brendan, pre-IYDP person with disability, urban). There were, however, indications that some change was starting to happen for these participants. One of the participants with disability who remained living in the family home experienced changes in accommodation. She described how she had recently begun to receive in-home attendant care support after several years of waiting.

"Two years ago I got in home support."

Interviewer: How did you get that?

"Well, I've been on the waiting list for a couple of years ... My parents said, "No, we don't need it. Others need it more than we do." ... [But] slowly we got a hoist in ..."
(Chris, pre-IYDP person with disability, urban).

Some parents acknowledged that they were reluctant to accept outside support within their home:

"I don't give up ... even to get the basic services like carers to come in and help shower and things like that, I did it for years, and then eventually I got a helper for one hour; somebody to come in for a morning ..." (Annie, post-IYDP parent, urban).

Most parents who took part in this study had opted to have their child live at home with them. Only a small number of parents had experienced their adult child moving out of the family home into supported community-based accommodation. Most spoke of their adult child's move as a positive change, and were relieved at being able to see them move and settle into comfortable new homes. This was particularly important for two parents who experienced ill

health or ageing. Their sense of relief at finding suitable accommodation, often after many years of caring and waiting for accommodation, was plain:

“At least [my adult child] is happy. I’ve been able to see her happy, and so if I disappear that’s all in place, and she hasn’t got that chronic grieving [of] one minute mum’s there and the next minute she’s not” (Debbie, pre-IYDP parent, rural).

“I can die now” (Jane, pre-IYDP parent, rural).

However, many of the parents who had resisted pressure to place their children in institutions when they were young, were now very concerned about the lack of community-based accommodation places, as they did not expect their other children to care for their sibling with disability. Hopes for accommodation were undermined by an enduring lack of change in the level of unmet need for appropriate accommodation for people with disability:

“I really know that eventually we won’t be able to look after [our son]. We’ll be too old. I’d obviously like to see [him] in a residential house with other people that suited him, and he suited them ... That’s what I’d ultimately like to see happen, but I know it’s not an easy thing. I mean I’ve spoken to a few parents who I’ve seen lately and they’ve had their name on the list for years and years” (Emily, pre-IYDP parent, urban).

“[Accommodation] hasn’t changed. It’s been an ongoing thing for so many years.”

Interviewer: So, [recounting earlier comments made during the interview] you’ve really lobbied and you’ve had your name down for years? And there’s nothing positive?

“No. Because I’m not on my deathbed, which you have to be for there to be anywhere; no not necessarily, but you have to be in pretty dire straits, the family situation has to be really untenable” (Hilary, pre-IYDP parent, rural).

These parents were becoming older, and they and their child with disability faced an uncertain future because of the lack of change in this area. Lack of change in relation to community-based accommodation had a similar impact on those parents of adult children with disability still living in the family home. These parents felt that they had no options and were increasingly frustrated and anxious about the future. Both younger and older parents said they did not want their other children to be responsible for the care of their child with disability.

Personal lives and achievements

Participants’ experiences and perceptions of good and bad changes in their personal lives included changes in relationships, friendships, achievements and health. People with disability spoke of the importance of their individual achievements in sport, relationships and study and how these had changed their lives. One participant described study as a turning point in her life:

"I just wanted to go back and study full-time which I found pretty exhausting as a single parent and doing house-cleaning jobs as well. But at the same time it was a turning point in my life. So I was really fortunate to have a ... lecturer who understood where I was at and put me into [university] as a mature age student" (Angela, post-IYDP person with disability, urban).

Other participants were pursuing new opportunities by studying in the TAFE system and at neighbourhood houses. A number of these participants, who had not studied before, were studying towards vocational qualifications. Some also hoped to undertake further study in the future.

Several participants spoke of making new friends and meeting family. One participant described how moving into a hostel allowed her to meet other people with disability and lessen the isolation she had experienced when living in a boarding house:

"I moved into [hostel] and that was beautiful there. I used to love it ... I was more happier and people were more friendly to me. I think I was absolutely spoilt when I moved there. You know I've never been more happier ..."

Interviewer: What was it about it that you liked?

"I just liked it because I had more people to talk to, and where I didn't have friends when I moved to [previous accommodation]. I just didn't have people to talk to" (Samantha, pre-IYDP person with disability, urban).

Another participant described being reunited with his family after being placed in care as a child:

"[I'd never met my parents because] they didn't like [disability]. Out of the blue when I was 15, my 20 year old ... [sibling visited and] told of my family. It blew my mind. I was reunited with my mum till [her] death ... Mum came to see me."

Interviewer: Do you still see your ... [sibling]?

"Tomorrow" (Ian, post-IYDP person with disability, urban).

Non-disabled peers were also identified as important for social support, especially to one participant who had previously led a very sheltered institutional life:

"They got me out of my shell. They told me how to experience life. They showed me things I never knew. They'd take you to restaurants ... They were gentlemen. They'd pull out chairs; they'd hold doors. It was a whole new life. They supported me with counselling ... They taught me stuff, simple stuff, like how to fill out forms or to coordinate clothes ... Just all those sort of little things that your parents are there to teach you, but mine weren't" (Helena, pre-IYDP person with disability, rural).

Several participants reflected on their experiences of meeting their peers with disability during the period 1981–2002. They described sharing their experiences with disabled peers as a way of gaining access to practical information, motivation and insight.

These findings of the importance of relationships and other achievements are consistent with recent research that has emphasised the importance of the connectedness of individuals, and that relationships and friendships are vital for developing and maintaining well-being and mental and physical health (VicHealth 1998, p. 10). Having a social network enables people to 'feel cared for, loved, esteemed and valued' (VicHealth 1998, p. 10).

Several parents of younger children said new social and recreations programs and funding had increased their children's opportunities to meet their peers, with and without disabilities:

"He's having a ball, he's having a huge time. I mean that's good. Before we actually targeted some of this stuff, you know, he was just sitting at home not doing much at all, and I thought, 'Oh, this is not a good place for him to be' ... he needs to be with his peers. I don't want him walking down and hanging out in the street because I'm a bit overprotective about that, but there's got to be a happy medium and I'm trying to find it for him, and he's got to find it too. Like, you know, I want him to become independent of me ..." (Karyn, post-IYDP parent, rural).

Yet, one parent also noted that her child was becoming more isolated from and by her peers as she matures:

"I've noticed a real change in the culture of adolescents as my daughter has gone to secondary school. She's become socially isolated, and I've just insisted that the school set up a buddy system twice a week so that she's not totally isolated at lunchtimes. We need programs to address this isolation. My [child's] okay, but she has a lower social understanding, that's why we need to teach our community, and the community in general, to look after its own members. We need to educate them that all differences belong as much as everyone else" (Clare, post-IYDP parent, urban).

Quite a few parents similarly indicated that they had lost friends after the birth of their child with disability, or that they found it difficult to find time for friends while meeting their new parenting priorities:

"It's weeded out a lot of friends. Whether that's good or bad, probably more good than bad" (Pam, post-IYDP parent, urban).

"Most of my friends have been great, but I think it happens when you have kids anyway, your life tends to revolve around the kids. I mean mine certainly did. It was an intense four years of full-on war, and now I've got my life back a bit. I still do a lot of work with the support group, that takes a lot of time ... Trying to juggle and balance

things, and you don't always get it right, but at least you're trying. Friends, most of them are supportive, but they certainly don't come out and say, 'Oh, I'll have [your child] this weekend'. That doesn't happen" (Karyn, post-IYDP parent, rural).

However, some parents mentioned that making friends with other parents of children with disability had been a positive change in their lives. Some had joined or started parent-to-parent peer support groups or networks. Parent-to-parent peer friendship and networks were identified as having a number of benefits. These included:

- reducing isolation
- sharing emotions and the experience of parenting a child with disability
- providing understanding and support when other close friends do not
- sharing information and knowledge
- working together, lobbying, and actively seeking to make the disability sector accountable
- fostering feelings of hope about the future.

A number of parents also indicated that their personal relationships with spouses and their children had changed during the past two decades. It is unclear how parents regarded these changes, because the majority chose not to talk about them in detail or reflect on them.

Changes in the personal lives of people with disability and parents were inextricably linked to disability, support systems and societal changes. Indeed, it is in the personal lives of participants where enduring and recurring themes were played out.

Enduring and recurring themes

A range of positive and negative enduring themes were identified by people with disability and parents. For both groups, however, there were more negative than positive themes identified:

- *Exposure, scrutiny and loss of privacy* — participants' experiences and perceptions of being exposed to scrutiny and judgement by professionals, and the lack of privacy experienced by clients of support systems
- *Exclusion* — participants' examples of the various ways in which they felt they were excluded, marginalised and socially restricted on a recurring or intermittent basis
- *Uncertainty and fear* — participants' uncertainties and fears, particularly about lack of accommodation, changes in diagnosis, and deteriorations in their own or family member's health
- *Power* — participants' experiences and perceptions of exercising power, and their feelings of being empowered or being powerless⁴

⁴ Popular notions often conceptualise power as a 'thing' that some people and institutions possess and exert at will to control others. This understanding of power was at the heart of the accounts shared by many participants in this study, and remains present in some theories of disability (e.g. Oliver 1990). However, it is important to acknowledge the difference

- *Fighting* — parents' experiences of fighting, and the effects on them and their families
- *Exhaustion* — parents' experiences of the mental and physical exhaustion of ongoing caring, including lack of appropriate respite and parental responsibility
- *Emotional turmoil, pain and guilt* — the difficulties parents experienced in their relationships with their spouses and children
- *Recognition, belonging and participation* — participants' experiences of feeling part of a 'community', including feeling safe, knowing people, liking where they live, and belonging to different types of 'communities'.

People with disability gave examples of enduring and recurring negative themes in their lives. These included their social and economic exclusion and marginalisation, their uncertainty and fear associated with changes in their or their friends' and family's health and well-being, being bullied and feeling powerless. Several participants in this study spoke of times when they had felt socially excluded, including "... times when I might be left out of a social situation and I have to initiate conversation rather than someone coming up to me" (Sue, pre-IYDP person with disability, urban).

Parents also identified enduring themes, including exposure, scrutiny and loss of privacy in the support system, the exclusion of their child, uncertainty and fear about the future because of an inability to plan, feeling powerless and continually having to fight on behalf of their child, emotional turmoil and guilt, and feeling mentally and physically exhausted from parenting a child with disability. One participant had experienced successive instances where she had felt exposed during meetings, such as when professionals had delivered new diagnoses and assessments to her. The following examples provide an insight into her lived experiences:

"We were called down to a meeting, which I shall never, ever forget. I don't even know who was there ... I don't know, I keep thinking that there were ten people there, and I don't remember ... We were told by this Doctor ... that ... [our son] had ... [diagnosis], and that he needed to attend a school for the physically handicapped and we had to look at other schools. And that was the first time anyone told us he had ... [this new diagnosis], and I was in this state. I don't know what else happened at the meeting, and I don't know what else was said" (Mandy, post-IYDP parent, rural).

between popular notions of power and contemporary social theory. In the latter, the complex and subtle workings of power are emphasised, and power is not seen as a 'thing' that can be simply possessed. For example, contemporary conceptualisations influenced by the work of Michel Foucault focus on how power is exercised, and how people are made subject to its exercise through discourses, knowledges and practices (Quibell 2004, pp. 74-8). Sharing such conceptualisations of power with people with disability and their families may be beneficial, as they may come to see that power is not just an intolerable repressive force exercised upon them, but something that they can resist and also exercise: '[T]here is always the potential that powers may be exercised and also resisted in multiple ways' (Quibell 2004, p. 74).

“We were called in ... two days before Mike’s sixth birthday. And that was when the first paediatrician, who was attached to ... [the physical disability service], told us that Mike would never speak, we would never have a conversation with him because he would never physically be able to speak. And we went from that meeting to a group meeting, with the OT, physio, speech therapist, paediatrician, social worker, [and] they discussed this. In the course of the meeting, I don’t remember it ...” (Mandy, post-IYDP parent, rural).

Most parents shared a common fear of the future when they would be unable, through illness, ageing or death, to be central figures in their children’s lives.

“I’m scared for the future, very scared of it. These last twenty years have gone by so quickly and I haven’t achieved what I set out to achieve. My goals have not been reached. I fear if my daughter had to go into a centre-based situation, I don’t trust a lot of people to look after my daughter as I would like her looked after. I mean only this last week, and it’s not the first time ... I don’t know if it was a young person, was left all night in their wheelchair because the carers didn’t turn up to put them to bed. Now I’ve heard of that before. Can you imagine being in your urine, faeces or whatever all night sitting there waiting for somebody to come? People won’t speak up, that’s why I’m a bit more outspoken. But I’m not doing anything. I’m wasting my energy...” (Annie, post-IYDP parent, urban).

The negative enduring themes in the lives of people with disability and parents were substantial and illustrate the high personal costs of the limitations of current policy, legislation and support services.

Discussion

Much is taken for granted about what has changed in the lives of people with disability, their families and friends since the International Year of Disabled Persons in 1981. By listening to them explore their personal experiences and perceptions of change, we are better able to understand what changes they have experienced and what these have meant to them. This project has provided an intimate insight into the lived experiences of 22 people with disability and 17 parents of adults or children with disability during the past 21 years. It has highlighted areas of their lives where they have experienced positive change, areas where they have experienced negative change, and areas characterised by enduring and recurring problems. The study has revealed a number of important aspects of changes and enduring and recurring themes in participants’ lives in the period 1981–2002.

Overall, the Living History Project revealed the complexity and uncertainty of changes in the lives of people with disability and parents of people with disability, and the complicated and tenuous relations between social policy agendas and lived experience. While most of the

participants were able to identify some changes in their lives in the period 1981–2002, the complex and diverse nature of the changes they experienced defies attempts to simplify them. Perhaps surprisingly, many participants did not mention key legislative and policy changes that have occurred in the State of Victoria. There are a number of possible reasons why this was the case. First, most participants only commented on changes that they had actually experienced. Second, it appears that some participants did not view the ‘personal difficulties’ that they experienced as ‘public issues’ shared with other people with disability (Mills 1970). Consequently, they did not identify with the terms in which disability issues were constructed as public issues in the IYDP and subsequent policy and legislation.

This important finding has several possible interpretations and implications, depending upon the social theory drawn upon to interpret its significance. Those drawing on theories of oppression would see participants’ failure to identify ‘personal issues as political issues’ as stemming from their ideological oppression (Oliver 1990, pp. 43-54, 1996; Barnes 1996) and ‘lack of consciousness to decode their situations’ (Hatton 2001, p. 273). In this interpretation, consciousness-raising education may be seen as needed so that people with disability and parents of people with disability can see the ideological devices through which they are oppressed. However, recent works on the lived experiences of people with disability (Pinder 1993; Boswell 2001; Shakespeare and Watson 2000) argue that dominant policy and activist discourses have obscured and silenced the dissenting voices of people with disabilities and their families, in similar ways as early feminist activists and theorists accounts failed to acknowledge important issues in the everyday daily lives of women. Boswell (2001), for example, argues that:

“those who resist ableism, like advocates fighting other “isms”, often call feminist movements to task, and argue that these movements *sometimes perpetuate the dominant discourses they seek to dislodge*, by themselves *closing out the “others”*” (Boswell 2001, p. 47; emphasis added).

In this second interpretation, the participant-led research methods utilized in this study have given voice to the fact that participants do not live their lives in the terms set down by the activist and policy agendas that stemmed from IYDP. Consequently, it is not surprising that many of the changes that participants considered important in their lives throughout the period 1981 to 2002 were not directly related to changes in legislation, policy or disability-specific practice. Overall, while the findings of this study point to the significant problems and barriers to achieving fundamental and integrated changes across the disability sector, they also highlight the uneasy relationship between policy, everyday life, activism and social theory.

In summary, people with disability and parents interviewed in this study felt that there had been some positive changes in access, but pointed to a number of examples where poor

access remained unchanged. The problems they encountered with older buildings provide further evidence to support the view that access to businesses is 'lagging far behind what we now expect of public buildings' (Housing Resource and Support Service 2001, p. 4). Their past experiences of lack of change and enduring barriers point to the likelihood that poor access will remain a reality for these participants in the foreseeable future, unless action is taken to remedy it. The fact that no participants indicated that they had used the legal means available under the *Disability Discrimination Act 1992* to remedy barriers to access indicates the need for work in this area. Further systematic and individual action and research on positive access changes and enduring access problems are required.

For most participants, change is not something that happens — it is an ongoing struggle. The mostly negative enduring and recurring themes in the lives of participants indicate the entrenched nature of many of the problems they confront. While policy at all levels of government now formally recognises people with disability as citizens, participants in this study gave examples of the many ways in which they were excluded, discriminated against, and isolated. People with disability identified numerous ways in which they were marginalised, such as not having enough money or resources, the attitudes of others, discrimination, access barriers, and no support or attendant care staff. Parents identified similar problems encountered by themselves and their children with disability. They identified ways in which disability systems negatively intruded into their lives, and the emotional, physical and financial impact of caring. Even 21 years after the International Year of Disabled Persons, these multiple sources and experiences of exclusion, powerlessness, exposure, fighting and exhaustion persist, and continue to undermine formal policy commitments to the equality and citizenship of people with disability and exile people with disabilities and their families to marginal positions within society.

The findings of this study, therefore, represent a challenge to the rhetoric of politicians, activists and policy-makers. The lived experience of disability was still, for most of the participants in this study, a difficult one. Participants easily identified specific problems that they faced in day-to-day life, along with possible solutions. While some participants had actively found solutions, we can not expect them to do so. If we listen to people with disability and those closest to them, then we may come closer to fostering continuing and constructive changes, both in society, communities and in the lives of people with disability and parents of children with disability.

Again, participants' experiences and perceptions of change are a powerful reminder of the complex interplay between individual, social, cultural, systematic and planned changes. Fragmented and uneven changes, together with enduring and recurring problems, point to the significant ongoing problems and barriers to achieving fundamental and integrated changes for people with disability and their parents. The findings of this study illustrate not only the

wide gulf between our hopes and expectations for change, but also the lived reality of the problems that many people with disability and parents continue to confront in their everyday lives. This in turn highlights areas in need of further work in the future. All levels of 'community', including government, service providers, welfare, advocacy, lobby and disability rights groups, need to listen to people with disability and their families as they continue to work towards further change in this area. In this sense, we need to remember the words of IYDP in 1981:

"1981 ... laid the foundation for real change in the status of disabled people in society. What is now required is a concerted effort to build on those foundations lest the whole of our endeavours become just a dim memory of what might have been" (Victorian IYDP Committee Report 1982, p. 35).

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