

Housing and Support for People with Disability conference – Sydney, 31 May 2007: conference report

By Joy Connor (Senior Policy Officer, Shelter NSW), 30 June 2007

Shelter NSW and **Multicultural Disability Advocacy Association of NSW** held a conference on Housing and Support for People with Disability on May 31. This conference brought together state and local government organisations, community housing associations, housing developers, housing providers, people with a disability, advocates, carers, support services and researchers. Interest in the topic was overwhelming, with more than 150 participants attending.¹

The conference received major sponsorship from the Department of Housing, the Department of Ageing, Disability and Home Care, and the City of Sydney Council.

The conference was chaired by Andrew Buchanan, Chair of the NSW Disability Council.

Paul Vevers, Deputy Director General, Department of Housing, opened the conference with an overview of the changes that had taken place in housing people with disability and outlined the initiatives the Department of Housing was currently undertaking.

What's happening and what works

Simone Finch from the Australian Housing and Urban Research Institute argued that efficient and fair service provision is hindered in Australia by the lack of a national framework for coordinated and flexible delivery. Trudy Van Dam and Belinda Epstein Frisch from Family Advocacy NSW presented research evidence showing that smaller groupings of housing for people with disability produce superior quality outcomes with marginal affects on costs. Despite research to the contrary, a reactive punitive approach to people with challenging behaviours continues to be the dominant approach.

The importance of public housing was the central message from three people with experience of disability who were interviewed by Helena O'Connell from the NSW Council of Intellectual Disability. For James Condren the security of a Department of Housing flat had made a huge difference in his life. Things became even better when he was able to transfer from Wollongong to be nearer his friends and support system in Sydney. For George Aboud his Housing Department house was appreciated by himself and his family, however distance from accessible transport and the lack of understanding from staff was a frustration. Judy Singer said the day she was granted the security of a Department of Housing flat was one of the best days of her life. However as a carer, problems caused by Centrelink and Welfare to Work now affect her ability to cope financially.

¹ For a profile of participants see page 3.

New models for providing housing and support

Chris Glennen from Supported Housing Ltd Victoria reported his visit to British community housing organisations providing support for people with disability. The British model depends on borrowings and private sector investment for 50% of its funding. Borrowings are possible as British housing associations have title to their houses and can support borrowings with rental and other subsidies for people with disability. Chris reported that the people with disability he visited had secure housing, individualised support and night-time back-up through electronic alarms which led to higher quality of life.

Joseph Connellan from Supported Housing Victoria outlined the Singleton model of shared equity and presented several new building projects which his organisation is currently developing. They ranged from single units surrounding a courtyard to single units incorporated into a design which from the street appears to be a large mansion.

Views from housing providers

The need for flexible long-term support, adequate funding, and tax incentives to private investors were the themes which emerged from the housing provider's panel. Derek Yule from the Churches Community Housing noted that for people with disability need not just well designed housing, but effective long-term flexible support to accommodate their needs over time. Sandra Mc Gee from the Real Estate Institute pointed out that there is not enough rental properties suitable for people with disability and those that are suitable are just too expensive for people on low fixed incomes. She called for government tax incentives to encourage investment in housing for people with disability and realistic rental subsidies so that people with disability could afford to live in the private rental market. Graham Wolfe from the Housing Industry Association said that the building industry could deliver more housing which was adaptable and suitable for people with disability and to help people aging in place. However he noted that clients were often not thinking of their future needs when they gave builders and architects their briefs and builders needed more information on the needs of people with different types of disability not just those in wheel chairs.

Coordinating housing and support

Eddie Bartlett from the Planned Individual Networks described the way his organisation assists people with disability and their families and networks to get together and work out long-term plans for ongoing support systems. Case studies which illustrated how this facilitation had assisted several families were particularly inspiring.

Workshops

The afternoon involved 6 workshops on key areas of concern and the questions, 'what do we want' and 'how are we going to get there?' The workshops generated new and creative ideas and a sense that change was possible. A recurrent theme was the chronic lack of resources for housing and support services and the unrealistic assumption by governments that coordinating existing resources was enough. Participants stressed that additional investment from the state and federal governments was essential for any improvements in either co-ordination or supply. The enormous strain on families of the rationing of accommodation and support was another concern. Participants noted that support often only arrived with a crisis and the unravelling of the family.

Figure 1: Profile of participants, by sector

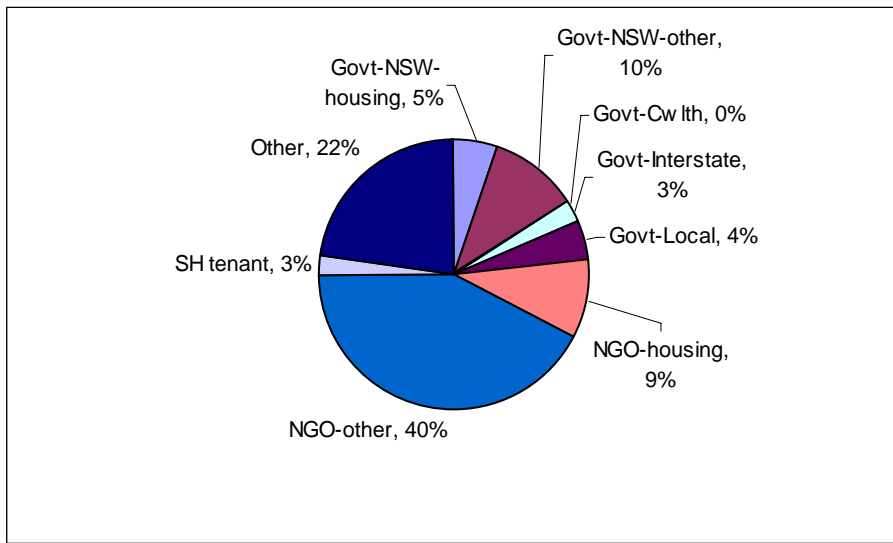
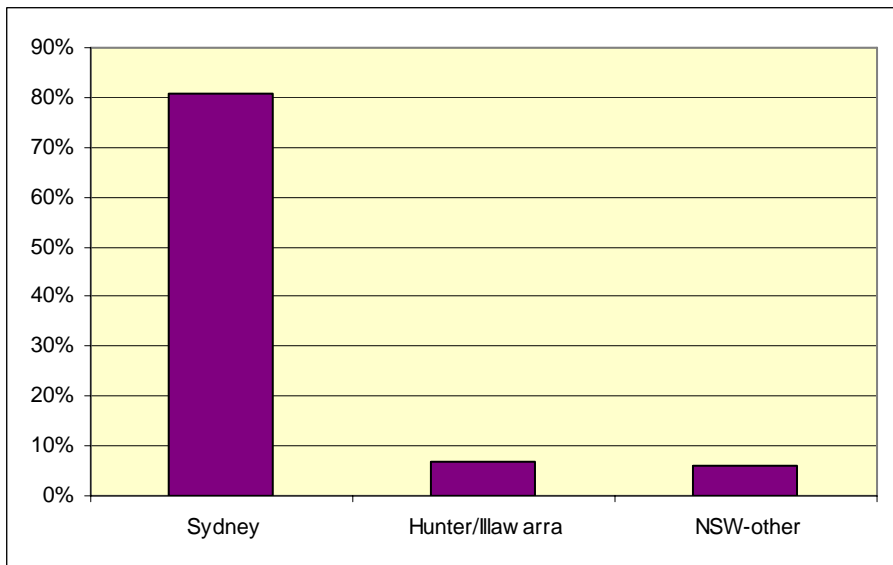


Figure 2: Profile of participants, by location



Overview of the workshops

By Joy Connor and Nick Warren

Below is a summary of the deliberations of the workshops of this conference.

The participants of the conference divided into small groups to work on particular issues of importance to people with a disability. The workshops covered areas including physical design of housing, new directions for service, coordinating housing and support, issues for families, issues for Indigenous people and issues for the multi-cultural community.

On the **physical design of housing**, the workshop identified the need to consider all types of disability in design, not just mobility issues, and to integrate good design for people with disabilities into all building design. The group felt that standards of 'visitability' as used in Britain were a good place to start and that design needed to be able to be modified as people's life cycle and needs change.

To achieve these things the group identified the need for a nationally consistent approach to universally adaptable design. The group also thought that publicity for architects and builders who can do this work would be a good reference point for developers and service development. In addition, there is still a clear need for greater lobbying on the diverse needs of people with disability and a need to reach groups that are involved in building but not traditionally engaged with the community sector such as developers and the real estate industry.

The workshop on **new directions in service** identified principles that should be applied to assess any new proposals for models of service delivery. They suggest that any new model needs to be evidence-based, accommodate an individual's strengths, needs, aspirations and changing circumstances and give people the right to choose who they live with and the right to an advocate to support them in making informed decisions. New models need to deliver secure, affordable, safe and well-located housing near services and the person's existing networks. People with disability and their families need significant influence over the details of what support is provided in a service system with well trained and monitored staff, accountable to clients and their services. Services should be accredited by a recognized quality assurance system. Finally new models need to ensure all levels of social security and other assistance work together, be available to all families who need it and have the capacity to increase the supply of housing.

The checklist generated by this group could be further refined against the UN Declaration of Rights for People with Disability and could form the basis for 'A Housing Charter for People with Disability'. The workshop group recommends lobbying the Premier, the Ministers for Housing, the Minister for Disability Aging and Home Care and local members to support the check-list and idea of a Charter of Housing Rights.

On **co-ordinating housing and support** the workshop called for an end to the chronic shortage of resources and the myth that all we need is better coordination. The group called for the empowerment of people with a disability in making decisions about their living and support arrangements and a greater access to advocacy services.

While better coordination of services and communication between providers was seen as an important step, so was an increase in the information available to people with disabilities and their families. The group felt there was a particular need for employers of carers to understand the costs and responsibilities they carry and for homelessness services to be more responsive to the needs of people with disabilities.

This group identified the need for much more lobbying and campaigning on these issues – especially for the general public and for the real estate and development industries. They also identified development of information resources as a high priority for people with disability and their families and carers. When it comes to developing new services or service arrangements, the group wants client-focussed services that are locally responsive but well coordinated with existing resources.

The workshop on **families** highlighted the extreme anxiety, stress and hardship that the families of people with a disability experience. There needs to be a better co-ordinated, simpler and more flexible system of early intervention to reduce crisis and more realistic expectations of what families can manage through partnerships between families and services. The group supported whole-of-life planning as envisaged by programs such as Planned Individual Networks (PIN). The group also thought there was a need for more co-operative and self-help models – where parents contribute capital and management – and more support networks for families with similar needs and interests.

The group recommended we lobby for funding of programs offering long term planning, more options and diversity and better coordination – the Planned Individual Networks (PIN) model was recommended as a good place to start. We also need to explore the possibility of partnerships between Community Housing organisations and families over co-operative self help models. The development of a central register of people's interests on the Internet could enable families to network more easily.

The workshop on **Aboriginal issues** felt that the consideration of historical events is vital to understanding the current situation: the 1967 referendum and 1975 Anti-Discrimination Act and the move from missions and camps to urban housing has affected indigenous people with disability. The reasons for disability are often different in Aboriginal communities. Poor health, malnutrition and poisoning from agricultural chemicals are all contributing factors. Now there is major push to 'mainstream' Indigenous services (e.g. loss of CHIP), which marginalizes Aboriginal communities and makes Aboriginal people compete with all others for services. The group identified a number of aims to improve the situation of indigenous people with a disability.

First we need good statistical information. Currently this is distorted because everything is classified as a health issue as this is where the health dollars are. We also need Aboriginal communities to re-think attitudes to disability and challenge the cultural resistance to acknowledging disability. In responding to the needs of indigenous communities we need State and Federal initiatives that treat Aboriginal families as a single unit and support keeping multi-generational families together. We also need Property relationships that match Aboriginal community values of collective and multi-generational living and custodianship of the land.

In achieving these aims we need to lobby for the development of better measures of Aboriginal disability and encourage the re-thinking of attitudes to disabilities in Aboriginal communities through community education campaigns. In the future, planning of new or extended services should be done in close consultation with Aboriginal elders and community leaders. The workshop highlighted one example of universal housing design that was developed in consultation with Aboriginal communities – the Red fern Aboriginal Housing Company Pemulwuy project – and asked that interested people and groups lobby all state ministers, members and Premier to support the project as a model for housing which works for indigenous people with disability.

The group looking at **multicultural issues** identified a simpler system and more accessible information about where to go and how to get help as important. The group also felt that greater efforts at empowering families from culturally and linguistically diverse backgrounds were needed for them to successfully negotiate the Australian system. There are also extra anxieties for these families and they need to be sure that group homes and other supported accommodation are safe and respectful of culture, religion and language.

Notes from the workshops

Below is a summary of the deliberations of each of workshop.

Workshop 1. Physical design of housing

Facilitator: Catherine Bridge

The group noted that in some places geographical barriers do not support accessible housing (e.g. flood areas have houses with lots of steps).

What do we want?	How will we get there?
People with disabilities to be able to be able to visit their friends, be part of the community and participate in the activities they wish to.	Lobby for laws similar to the UK, where new homes must be visitable by someone with a disability. Lobby for public support and funding for a unified federal approach on visitable building standards.
Building of well -designed accessible housing that is planned with the needs of people with disabilities in mind.	Lobby for universal adaptable planning standards for housing. (e.g. double lintels over doors.) Provide examples of well-built buildings and their plans through an on-line national repository of accessible housing and housing design samples. Accredit architects and builders who are able to do this kind of work and make then known, Encourage bulk builders to provide accessible options in their designs.
People with disability and their families are able to plan for housing or modifications to existing housing which works for them	Encourage the architects assn and building training facilities to provide training on the needs of people with disability Work for the development of a basic information kit on planning and design for people with disability
People with <i>all types</i> of disability catered for in housing and public places.	Education campaign on the design needs of people with all types of disability. Lobby for public buildings, which meet the needs of all types of disabilities. People with disabilities and their advocates to act as consultants during the planning and building process for public buildings.
To be able to modify housing as people's needs change over time (homeowners included) so people can stay in their own homes if they so choose.	Lobby for state and federal funding for ongoing home modifications as people's needs change over time. Information about how to get these funds and how to complete modifications needs to be readily available. Access and publicise information on successful overseas models e.g. multilevel, combined tenancies Encourage financial institutions to make reverse mortgages available for this purpose.

Workshop number 2. New directions for providing housing for people with disability

Facilitator: Joy Connor

What do we want?	How do we get there?
<p><i>We want any model for providing housing and support for people with disabilities to:</i></p> <ol style="list-style-type: none"> 1. Be based on evidence which demonstrates that it can assist in building a good life 2. Have the capacity to accommodate an individual's strengths, needs and aspirations. 3. Give people the right to choose who they live with in consultation with family and advocates. 4. Give people the right to an advocate to support them in making informed decisions. 5. Provide people with the option to move so that different life stages and aspirations can be catered for. 6. Be affordable, 7. Be located near services and the persons existing networks 8. Have secure tenure. 9. Be safe 10. be visitable by people dependent on wheel chairs 11. maintained to a high standard. 12. well trained and monitored staff, accountable to clients and their services. (Service agreement and contracts are needed) 13. Give the person with the disability and their family significant influence over the what, when, where and by whom support is provided. 14. Be accredited by a recognized system (Accreditation of all providers of housing for people with disabilities is needed) 15. Ensure all levels of social security work together 16. Be available to all families who need it 17. Have the capacity to increase the supply of housing 	<ol style="list-style-type: none"> 1. The checklist needs to be refined against the UN declaration of Rights for People With Disability. 2. The checklist needs to be presented by people with disability and their advocates to the Premier, the Ministers for Housing, the Minister for Disability Aging and Home Care, local members. The checklist also needs to be publicized as Conference news item by different organisations attending The Conference 3. The Checklist could form the basis for 'A Housing Charter for People with Disability'

Workshop 3. Coordinating housing and support
Facilitator: Christine Regan

What do we want?	How do we get there?
An end to chronic shortage of resources for housing and the myth that all we need is better co-ordination	Bring the problems to public attention and demand more resources
People with disability can direct decisions about their housing and support (and other aspects of their lives)	Demand that person with disability is at the centre of the conversation regarding their housing and support needs. Services need to fit the person rather than trying to fit the person into the service. Clients presenting with complicated needs that can't be met via a single stream need extra assistance.
We want locally based accommodation and support so that people can live where they are known and where their existing local networks can be part of the support they receive.	<ul style="list-style-type: none"> • Lobby for policy at state and federal levels to support local solutions • Encourage good relationships between people with disability and the local community, including neighbours and local services. • Start local projects with HACC and housing providers. • Audit the housing and support available in local and regional communities
We want people with a disability to get all the help they can from the many people who care about them.	Work to introduce the Planned Individual Networks (PIN) system in NSW
We want information about the range of support services in local and regional areas available to everyone i.e. people with disability, agencies, the housing industry, families, others	<ul style="list-style-type: none"> • Develop a map of local support services • Promote the use of the Care link number • Promote the use of HS Net when effectively operational • Provide community education especially of people and organisations outside the direct service system • Connect with other players in housing e.g. real estate agents
We want better communication between all agencies including government and non-government support organisations housing providers and the real estate sector.	<ul style="list-style-type: none"> • Local networks need to connect the community sector with all the agencies, housing providers and real estate agents. • Training on issues faced by people with disability needs to be available to the housing industry.
We want advocacy services to be available for people with disability	Tenancy advocacy and advice works well Buyer advocacy and advice works well.
We want employers of carers to understand the heavy costs and responsibilities they carry. Medical appointments, illness etc may prevent carers getting to work or shorten their working day.	Lobby for employment practices that are responsive to worker's caring responsibilities

Coordination must respect the confidentiality of the individual person with disability We do not want the risk of stigma and improper disclosure of personal information	Lobby for legislation and policies which protect privacy
We want clarity about what partnerships between agencies will actually deliver	Agencies need to understand their limitations and those of other agencies and be clear what they can do and when they can do it.
We want homelessness agencies to be more responsive to the needs of people with disabilities who are homeless.	Work with homeless organisations to include the people with disabilities
What will this coordination look like? Does it mean an office in each local or regional area? Will this coordination be enshrined in ACCORDS.	ACCORDS, including the housing accord and the human services accord: Need a point of responsibility for monitoring Need a leader Clarity surrounding public reporting Involvement of all parties affected by the accords especially the Non-government sector

Workshop4. Families.
Facilitator: Mary Perkins

What do we want?	How do we get there?
The current expectation of families is far too high. We need realistic expectations of what families can manage through partnerships between families and services.	Work to develop a model of partnership between families and services
We need a less complex more flexible better coordinated system which provides early intervention to reduce crisis. Crisis is costly of time, relationships, energy and resources.	Lobby for government funding for policies which provide a better system long term planning, more options, diversity and better coordination
Funding needs to take account of the diversity of individual; rather they are means of encouraging providers to provide appropriate services to their tenants in a way that is sensitive to individual and family need. Those without family support need particular assistance. Organisations need adequate block funding to co-ordinate services.	
An entitlement to suitable accommodation with long term security, a range of options during a persons lifetime.	

We want a way to navigate whole of life planning for housing and support for people with disability. It is especially important to plan where a person can go to live when a parent / carer dies	Look to projects such as Planned Individual Networks (PIN) for long -term co-operative planning models
We want to be able to contribute to housing stability through cooperative / self help type models – parents contributing capital and management.	Explore the possibility of partnerships between Community Housing organisations and families over the development of co-operative self help models.
We need greater support networks between families and the ability to connect with families with similar needs and interests	Develop a central register of people's interests on the Internet to enable families to network

Workshop 5. Indigenous Issues

Facilitators: Lester Bostock and Col James

The workshop felt that the consideration of historical aspect is vital to understanding current situation: Post '67 referendum and '75 Anti-Discrimination Act and the move from missions and camps to urban housing has affected indigenous people with disability. Now there is major push to 'mainstream' Indigenous services (e.g. loss of CHIP), which marginalizes Aboriginal communities and makes Aboriginal people to compete with all others for services.

The reasons for disability are often different in Aboriginal communities. Poor health, malnutrition and poisoning from agricultural chemicals are all contributing factors.

What do we want?	How do we get there?
Good statistical information. Currently this is distorted because everything is classified as a health issue as this is where the health dollars are.	Lobby for the development of better measures of Aboriginal disability
Aboriginal communities to re-think our attitudes to disability and challenge the cultural resistance to acknowledging disability. There is still the negative perception of disability as a curse.	Encourage the re-thinking of attitudes to disabilities in Aboriginal Communities through community education campaigns.
Wide spread awareness of the role of agricultural poisons in creating disability.	
State and Federal initiatives that treat Aboriginal families as a single unit and support keeping multi-generational families together including design for disability access in consultation with elders and community leaders.	

Property relationships that match Aboriginal community values of collective and multi-generational living and custodial responsibilities for the land.	Advocate for a sense of home ownership without the housing becoming a commodity. Advocate for development of a model similar to community title, in consultation with Aboriginal elders and community leaders.
Red fern Aboriginal Housing Company Pemulwuy project model of universal housing implemented in Redfern and elsewhere.	Lobby all state ministers, members and Premier to support the Redfern Aboriginal Housing Company Pemulwuy project as a model for housing which works for indigenous people with disability

Workshop 6. Multicultural issues
Facilitator: Barbel Winter

What do we want?	How do we get there?
A simpler system and information about where to go and how to get help.	Just do it
People from NESB need a planned solution to accommodation and support services before a crisis develops	For effective planning, the system needs to be geared to long- term local engagement with people
A supported accommodation system that enables people to live near family and community and stay connected.	Work on local solutions for local people
People from NESB with disability and their families need to be involved in making decisions and choices	Services need to adopt an empowerment model and build trusting long term relationships with the family and person with a disability
We don't want conflict between the interests of the person with disability and the family	Services and housing providers need to tell the person and the family clearly who the consumer is
Families need to be sure that group homes and other supported accommodation are safe and respectful of culture, religion and language	Lobby for staff training on cross-cultural understanding and respect. Work for local based organisations that put values into practice and build trust and ownership with families

Program

Shelter NSW and Multicultural Disability Advocacy Association of NSW

Housing and Support for People with Disability Conference

Good news stories and new directions

Rydges World Square, Sydney, 31 May 2007

Time	Chairperson	Speaker
8.50 - 9.00		<ul style="list-style-type: none">The Swish Dudes Barber shop Quartet begin singing to gather the crowd
9.00 - 9.15	Andrew Buchanan ABC/member of the Disability Council Board	<ul style="list-style-type: none">Acknowledgement of Traditional OwnersWelcome from Mary Perkins and Barbel WinterThe Swish Dudes sing one number
9.15 - 9.30	Andrew Buchanan	<ul style="list-style-type: none">Paul Vevers, Deputy Director General NSW Department of Housing opens the conference
9.30 - 10.20	Andrew Buchanan	<p>Session 1</p> <p>What's happening and what works: Bringing the stories together</p> <p>a. Perspectives on recent research on housing and support for people with disability</p> <p>Simone Finch: Assistant Director - Research, within AHURI Ltd, Melbourne Housing is a verb: the research AHURI has conducted regarding people with disabilities and their experience of housing - (20 minutes)</p> <p>Trudy Van Dam and Belinda Epstein Frisch: Presenting the Evidence: Accommodation and Support for People with a Disability - (20 minutes)</p> <p>Questions/Discussion – (10 minutes)</p>
10.20 -10.40		<p>Morning tea - (20 minutes)</p>

10.40 - 11.10 Andrew Buchanan

Session 1 (cont.)

What's happening and what works: Bringing the stories together

Panel 1 – Interviewer Helena O'Connell, NSW Council of intellectual Disability

- b. interviews with 3 people living with a disability or caring for people with a disability, about their housing history, what has worked and not worked for them - (30 minutes)
 1. James Condren - Issues for people with intellectual disability (10 minutes)
 2. George Ayoub - Issues for people with physical disability (10 minutes)
 3. Judy Singer - Issues for people with Augsberger syndrome and mental health issues and their carers (10 minutes)

11.10 - 11.55 Andrew Buchanan

Session 2

Housing Models, New Directions: Overseas and in Australia

Chris Glennen: Community Housing Associations providing housing and support for people with a disability: the British experience - (20 minutes)

Joseph Connellan: The Singleton Model –the mixture of bricks, mortar and support - (15minutes)

Questions/Discussion – 10 minutes

11.55 - 12.35 Andrew Buchanan

Session 3

Views from housing providers

Panel 2:

- **Derek Yule**, Churches Community Housing- Issues for community housing associations who provide housing for people with disability - (10 minutes)
- **Sandra McGee**, Real Estate Institute of NSW-Issues for the Real Estate Industry - (10 minutes)
- **Graham Wolfe**, Housing Industry Association -Issues for the building industry around housing for people with disability - (10 minutes)

Questions/Discussion - 10 minutes

12.35 - 1.30

Lunch – (55 minutes)

1.30 - 1.55	Andrew Buchanan	Session 4
		Co-ordinating Housing and Support
		Eddie Bartnick: Planned Family Networks - New Ideas for People with Disabilities and their carers, the Planned Individual Networks (PIN) model - (15 minutes)
		Questions/Discussion - 10 minutes
1.55 - 2.15		Coffee Break – (20 minutes)
2.15 - 3.30	Andrew Buchanan	Session 5
		What do we want? How can we get there? <i>Concurrent workshops exploring major areas of concern.</i>
		Each workshop will involve advocates, researchers and consumers - (1 hour & 15 minutes)
	Chairperson Cate Bridge Home Modification Clearing House Project Scribe	Workshop 1: Physical design of housing:
		<ul style="list-style-type: none"> • What do we want the physical design of housing to deliver for each of the groups affected by disability? • What issues are important for carers and privacy? • What actions need to be taken now?
	Chairperson Joy Connor Shelter Scribe Nadia Ballantine-Jones	Workshop 2: New Directions for providing housing for people with disability
		<ul style="list-style-type: none"> • The workshop will develop a checklist of the key criteria that any new way of providing housing for people with disability should meet
	Chairperson Christine Reagan NCOSS Scribe	Workshop 3: Co-ordinating housing and support
		<ul style="list-style-type: none"> • What happens when co-ordination works well ? • What actions need to be taken now to get there ?
	Chairperson Mary Perkins Shelter Scribe	Workshop 4: Families
		<ul style="list-style-type: none"> • What is it reasonable to expect from the families of those with disability? • How can we ensure that people supported by their families don't miss out? • How do we plan for the future? • What actions need to be taken now?

Chairperson
Lester Bostock
Chairperson Aboriginal
Disability Network
Scribe
Nick Warren and Jenny
Thompson

Workshop 5: Indigenous issues

- What are the major issues for indigenous people affected by disability?
- What issues are important for housing design?
- What actions need to be taken now?

Chairpersons
Barbel Winter and
Maureen Kingshott
Multicultural Disability
Advocacy Association\
Scribe

Workshop 6: Multicultural issues

- How can people from NESB with disability and their families be involved in planning and making decisions about supported accommodation?
- How can supported accommodation services put cultural competence principles and ideas into practice in planning and service delivery?
- How would a culturally competent supported accommodation service and the system surrounding it be different from how they are now? e.g. in-home accommodation support programs such as attendant care and flexible brokerage; group homes; the Disability Housing and Support Initiative; keyring support
- To deliver a culturally competent supported accommodation service, what skills and knowledge do planners, policy makers, managers and direct service staff need?
- What actions need to be taken now?

3.30 – 3.50

Afternoon tea (20 minutes)

3.50 - 4.50

Andrew Buchanan

Plenary: What do we want? How can we get there?

Bringing together the findings from the workshops –
(1 hour)

4.50 - 5.00

Wrap up and feedback