Perspectives on ‘Supported Living’ from people with intellectual disability

Professor Christine Bigby
Dr Emma Bould

Living with Disability Research Centre
c.bigby@latrobe.edu.au
Background - Supported Living

- Dissatisfaction with the inflexibility / variability of group home models
- Growth of ‘supported living’
  - semi independent living US
  - ‘personalised residential supports’ Australia (Cocks & Boaden, 2011)
- 1-3 people, separation housing & support, drop in support or 24 hour (Kinsella, 1993).
- Little evidence re outcomes, support arrangements or communities
- Better outcomes
  - choice, frequency and range of community activities,
  - more cost effective (Stancliffe, 1997, Stancliffe & Keene, 2000; Howe et al., 1998, Emerson et al., 2001, Perry et al., 2012)
- Poorer outcomes
  - exploitation, scheduled activities, health, money management (Felce et al., 2008; Perry et al., 2012; Emerson et al., 2001)
- Few differences – except choice and control (Stainton et al., 2011)
- Implementation issues – organising support – formal and informal
Aims and Method

- First phase of a study to identify the elements that contribute to successful (and unsuccessful) outcomes for ‘supported living’ for people with intellectual disability.

Aim

- understand the diversity of housing and support arrangements
- perspectives of people living in supported living
- identify key issue to inform survey development

Method

- Focus groups – recruited via service provider networks, advert NDS newsletter, letter to ex group home residents
- Questions - view about current living situation – how does it compare to previous arrangements, type of housing – type of support
- 7 groups, 34 people – clusters around particular service provider or regional self advocacy group
- Recorded – transcribed
- Thematic analysis – descriptive statistics
## Focus Group Participants

<table>
<thead>
<tr>
<th>Location</th>
<th>Participants</th>
<th>Male</th>
<th>Female</th>
<th>Average Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Regional 1 – South East</td>
<td>5</td>
<td>2</td>
<td>3</td>
<td>48</td>
</tr>
<tr>
<td>Regional 2 - South East</td>
<td>3</td>
<td>1</td>
<td>2</td>
<td>44</td>
</tr>
<tr>
<td>Inner West Melb</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>55</td>
</tr>
<tr>
<td>Northern – Melb</td>
<td>6</td>
<td>5</td>
<td>1</td>
<td>41</td>
</tr>
<tr>
<td>Inner South- Melb</td>
<td>4</td>
<td>2</td>
<td>2</td>
<td>45</td>
</tr>
<tr>
<td>Regional – North East</td>
<td>8</td>
<td>3</td>
<td>5</td>
<td>38</td>
</tr>
<tr>
<td>Outer South</td>
<td>5</td>
<td>2</td>
<td>3</td>
<td>43</td>
</tr>
<tr>
<td>Total</td>
<td>34</td>
<td>17</td>
<td>17</td>
<td>42 years</td>
</tr>
</tbody>
</table>
Findings - Housing and Living Situation

<table>
<thead>
<tr>
<th>Focus Group</th>
<th>FG1</th>
<th>FG2</th>
<th>FG3</th>
<th>FG4</th>
<th>FG5</th>
<th>FG6</th>
<th>FG7</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Housing</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Own home</td>
<td>1</td>
<td>2</td>
<td></td>
<td></td>
<td>2</td>
<td>5</td>
<td>16%</td>
<td></td>
</tr>
<tr>
<td>• Private rental</td>
<td>2</td>
<td>1</td>
<td></td>
<td></td>
<td>1</td>
<td>4</td>
<td>12%</td>
<td></td>
</tr>
<tr>
<td>• Social housing / housing commission</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>6</td>
<td>2</td>
<td>13</td>
<td>37%</td>
<td></td>
</tr>
<tr>
<td>• Service owned / social housing cluster</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Living situation</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Alone</td>
<td>2</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>3</td>
<td>4</td>
<td>15</td>
<td>44%</td>
</tr>
<tr>
<td>• Partner</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>3</td>
<td>1</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>• Co tenant</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>4</td>
<td>4</td>
<td>13</td>
<td>37%</td>
<td></td>
</tr>
<tr>
<td>• Other family</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>3%</td>
</tr>
</tbody>
</table>

- Most people lived in social housing 38%
- Cluster developments 36% - self contained units in a block
- Most people lived alone or with unrelated co-tenant
- Most had previously lived at home
Most people had block funded drop in support - delivered by an agency

Some had both block and individually funded support

Some people also had full or part time day service

Some were part of a Key Ring network

Parents and State Trustee manage most people’s finances

Role of Centrelink – Centrepay in bill paying
Support – diverse separate sources

- Formal and informal support - different focus - home help, maintenance, financial, household, employment, day support
- Not necessarily clear re source or limits

Sense of security - perception help available when need it

- Everyone had a ‘go to person’ to troubleshoot difficulties.
- Sense of open ended availability rather than finite

I’ve got family around Victoria, they always help me with everything I want. If I do get some problems I just call mum or dad or I could call Donna and Hatty [workers] to discuss things [FG6].

I do a lot of cooking… I cook a big meal and then put a portion of that into different containers and then freeze them but I do my own clothes shopping, shoe shopping can be a hassle but my mum helps with that and I guess that’s mainly it but if I need help with something it’s either mum or Susie or Roger might help out, Roger usually does the maintenance around the unit [FG9]
Better than before …
Freedom to do your own thing - ‘can do what you want’

Very different from living with family or in a group home – ‘no one can order me around’

I’ve enjoyed it more than anything….. even living with my mum cause my mum was always telling me to do this, do that, you can’t do this, you can’t wear that, you can’t do this, telling me what I can do and what I can’t do and things like that, she was always bossing me about [FG2] home with parents

I live on my own now and I like it, it’s better. Freedom, there’s no people dictating to me and telling me what to do, I like it better, I don’t want anyone dictating to me. That’s what I like about life. I can come and go as I please...you can live and do what you like. See if I want to do something at my place I can...[FG3] group home

Making up your own mind ‘you don’t have to ask’

You can do what you want, please yourself what you do, be home when you want, you don’t have to answer to anyone, you please yourself where you want to go, if you want to go to Melbourne for the day you don’t have to ask anyone, if you want to bring someone else, you don’t have to ask [FG1]

I think ........is a really fantastic opportunity to be independent and to have a really relaxed and safe …[I like] being able to go for walks, do your own thing [FG9]
Enjoying independence – doing things for yourself

I’m pretty good doing everything for myself, I’m pretty independent and get to work and go to Melbourne, do my own shopping, go to the bank on my own, the Trustees put the money in the bank [FG1]

I do the shopping myself, I used to have someone from the council help me then I said I don’t want anymore cause I didn’t like your arrangements [FG1]

I’m independent and I do everything … Well I do my own shopping, I just do things [FG3]

It’s better because…I can pay my bills, have people over for coffee or you know go out with people. Do your own thing, you know, do your own thing as you need it. [FG4]

I live by myself, there’s so many things I can do [FG5]
Socially connected – diverse weak and strong ties

Family – parents, siblings, nephews, nieces,

my oldest nephew is 21 next year and my godson was 20 last year and my nieces and nephews are 18 in October so I see them quite often, they pop round and put stuff together [FG4]

My brother coming to do some work for me, my sister asked him [FG3]

I ring my brother once a week, I ring my sister Wandin North once a week, and my other sister I talk to her every day [FG4]

Friends

I’m good friends with all my work colleagues…They treat me as equal…Sometimes my friends who also works at Safeway comes and visit and my other friends he works for the Shire, he came and visits.[Do they have disabilities?]. Yeah…My boyfriend, he’s just fun to hang around with and he really cheers me up when I’m having a down day. [FG1]

Partners

Belinda and I got married in May last year and we both enjoy our work. I’m at Chess, she’s up at the union and we enjoy living independently and want to keep doing that…We enjoy being on our own and doing our own thing. We might have workers come in from time to time but we’re okay with that [FG4].
Recognised in the locality

I say good morning when I go to work, say hello… a bloke said g’day to me the other day, I don’t know his name [FG1]

I know everybody around me and it’s only a court [cul de sac] so there’s no problems however if I go away someone is always there to watch my house and keep an eye on the place and I’ve got a lot of friends around the area that always keep an eye on me. [FG2]

I talk to the people next door. [FG3]

I might talk to a couple of people throughout the day, on the phone, but I know a lot of people but they’re not necessarily friends but acquaintances [FG4]

Connections to locality – use of community facilities, - gym, bowls, social clubs, pubs, church

I prefer to go out and see people, I don’t like hanging around the house all the time, I like to be out and go for a walk or have a drink’. [FG1]

At church…well they are like friends to me, they’re really nice and we had a morning tea and really lovely people, really nice. [FG3]
Structured regular engagement in purposeful activities

Mix across the week on part time basis

Work - Volunteering - Day centres - Self advocacy and Social Groups

Two days a week at the copy lounge…I’ve got my Salvation Army stuff Thursday, bowling Friday and three times a week I do my own self. [FG6]

As a casual worker and kitchen hand and cleaner. I’m with the women’s group on a Tuesday night if I’m not working. And also I’m involved with our Sunday group…I help a couple of others also on disability so that’s about four or five that I help apart from myself on disability as well. [FG1]

I work two days a week at the op shop…I go to mosaic classes two times a fortnight. [FG 5]

Unstructured interests and socialising

I’ve got a lot of interests like on the days I don’t work, I might go out for walks or do something, do appointments and other things, cook meals, practice my didgeridoo, do stuff on the computer, do lots of other things. [FG9]

I go out to the local café or go and see a live band or something like that, one of the pubs here or something like that. [FG 6]
Enthusiasm for supported living not deterred by difficulties

Restricted opportunities

- **Low income**
  
  Very tight so we don’t go out, we don’t really do anything, we have to stay home and what little money we do have has to be spent on food cause…yeah money is very tight…As for clothes shopping everything I wore I bought them years ago and I just have to keep on wearing the same clothes. [FG9]

- **Control of finances by others**
  
  I used to have a card but mum took it away from me and said I can’t do it anymore cause I buy mostly rubbish for myself. Yeah, I want my bank card back. [FG5]

  Do you know how much I get a week, every Tuesday. $130 that’s spending money and food money, it’s $130 every Tuesday, that’s my spending money too, that’s all they are giving me. [FG1]

- **Difficulties with state trustee**
  
  No different person every time. See it might not be the one person, if I ring up Tuesday there might not be that person be on the phone, might be someone different. It’s hard to get your administrator. [FG1]

  (there is a) contact person at Trustees…but now see there’s another number and I can’t get them, I get (support worker) to ring them..because I can’t get them, I can’t ring them up, it’s a different, hard number to. [FG3]
Fears about safety

I just don’t like going out too late, no not places but just going out, if I’m going up the street, if I have to go, if I wanted to see her, she says come up in the night and I said no, I don’t know who is hanging about, you don’t know who is hanging about. [FG3]

I’m not supposed to go out at night it doesn’t feel safe. Even going in a taxi, I will not do that at night. [FG1]

It’s dangerous going out at nights. [FG9]

Unpredictability of supporters - little control over who and when or behaviour

They help us with the menus, cleaning, cooking, shopping, any appointments and we just lost a really good support worker…there’s a bit up and down at the moment, we don’t know who is coming and who is not like so it’s been really unsettling… Really they need to ring the day before [tell us] who is going to be on and who’s not working…I don’t think this organisation is not really good enough because we need to know, my housemate and I need to know who is coming. [FG1]

But I just don’t want this carer…She did something that she, which I didn’t like, and I had bruises from it and she digged her nails in really hard and I had bruises. [FG1]

Many people had been abused by carers in the past
Negotiating troublesome people

Sales people

Oh I feel sometimes nervous…They are trying to sell things, I just say no we don’t want that, no…and then we get these telephone calls…like they want to sell things, If they do that we have a little whistle now, blow the whistle at them. [FG3A]

I had somebody come to the door trying to change the electricity company and I made a fib saying I don’t live here, I’m just minding the house. My carer came up with that. [FG1]

Neighbours

They have too much drunken parties. I’m here and here’s another house. I can hear this woman yelling at her kids. [FG1]

I don’t like them, he stole one of the bins of mine and I said you stole one of the bins, you want to put it back into unit one, she said no, she said that’s my bin. [FG3]

Well there’s a mixture of good and bad neighbours at the flats, bad ones…they stomp on people’s ceilings and keep them awake all night…One time I went up there and spoke to him about it, and he threatened to punch me in the face. And then the next day I was watching football…came downstairs, to my front doorstep and abused me on my front doorstep. [FG4]
- Co-tenants

Living by myself, no it wasn’t hard but I managed by myself, but sharing with another person is so hard. It’s harder… it’s not fair for me but I’m going around doing every job in the house. [FG3A]

I prefer living on my own but I don’t mind sharing, it depends on who I’m actually sharing with because if you’re only sharing, you got to make sure that the other person pays their share of the bills otherwise it is not worth sharing. [FG6]

Access to technology

Most people use phone, iPad or computer and the internet – few access at home

I got one [computer] at mum and dad’s…I have one, I don’t have the internet. Yeah, I learnt a bit more [using the internet] when I went to self advocacy group…We got Skype now, we can look up Skype…Yeah we’ve got it at self advocacy group…we can look up, we can get in contact with people on the computer. [FG1]

No I haven’t got the internet at home, I think it costs about $100. [FG2]

We used to have a computer but we used to deal with Dodo and each time we were using it, they’ll still charge you though, even though it was turned off and we thought that wasn’t right so we had it off altogether. [FG4]
Loneliness – not for want of trying

I look at telly but I’m sick of being by myself in the night, I’d like to go out for a change, like dancing or singing. [FG3]

I’ve got a step brother but he doesn’t want to see me…make me feel awful because he doesn’t really speak to me, he thinks he is better than me…I just feel I want to be wanted. Want people to like me and want to be needed in the world, I just don’t want to be with people and friends that don’t like me, that’s all. I don’t ask for much. [FG3]

I don’t have many friends much because I try to make friends but I used to go to this church at Northside Christian Church…but I had to stop going there because they wouldn’t accept me, like coming to their church, I wasn’t allowed to sit there.. I was advised not to go back there. I tried everything to go up and say hello to them and get mixed up with them and they just don’t want to know me I don’t have anyone that doesn’t have got disabilities at all…but I try to make friends. [FG4]

[So your friends are really the people you live with here and your mother?].And if I didn’t live here wouldn’t have anyone…[Have you tried to find some friends?] Yeah but really disappointing, it’s somewhat disappointing but anyway. [FG5]
Discrimination

- **Rental market**
  
The girl’s parents helped get the house. Went through three real estate agents and they never gave us a house, they knocked us back then they bought this house that we live in now [FG1].

- **Community attitudes**
  
  I do work at Safeways, we don’t mix outside of working hours…No they’ve got a rule you don’t mix after hours with workmates. [FG1]
Discussion and next steps

- Perceived control - similar to other studies
- Unlike other studies, do have regular scheduled activities
- Reliance of ‘go to person’ – probably unfunded support
- Key role families and agencies – structuring engagement – organising support

Highlights issues need further attention

- Money control - low income
- Access to technology
- Is safety net support real?
- Support to make social connections counter discrimination
- Confidence to complain re support

Next steps – finalising survey – interviewing key worker and person in depth about these issues – comparing to matched sample living in group homes – 6 in depth case studies