Making life good in the community: The story so far

Interim report

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Study by La Trobe University and RMIT

March 2007
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Foreword

The redevelopment of Kew Residential Services (KRS) is enabling over 460 people to move from a large institution to community based settings. More than 360 have already moved to houses across Victoria. The remaining residents will be moving to 20 new houses in a new neighbourhood on the KRS site.

The redevelopment was informed by a body of research both in Victoria and overseas that considered how best to support people with an intellectual disability. This research demonstrated that people with disabilities have a better quality of life in small supported accommodation settings in the community than they do in large institutions.

However we know from research and our experience that the move alone does not ensure that residents experience a ‘good life’ in comparison with lives led by others in the community. It is part of the process.

Research is being conducted by La Trobe University to assist us in determining what factors are most important in ensuring an improved quality of life for residents. This report marks the midpoint of this research project, called ‘Making life good in the community’.

The major component is an action research study involving the researchers spending time in a selected group of houses looking at how we support people to lead good and fulfilling lives in the community after they leave KRS. In addition, research questions have been formulated to study key themes at greater depth that arise out of the research in the houses, including what are referred to as ‘upstream’ issues that relate to policies and practices beyond the individual houses.

The change has been profound for residents and their families. Most residents had lived at KRS since childhood and become used to the pattern of life there. The prospect of moving was daunting for many concerned. Detailed consultation and planning took place to determine where, and with whom, each person would live and to ensure the necessary supports were put in place. This involved the residents, their relatives, advocates and others who knew them well.
I acknowledge the commitment of staff during this challenging period. Most staff had spent most of their working life at KRS and many had worked in the same unit for over ten years. Since the Redevelopment began, they have already adapted to the many major changes in establishing new services with new teams in new homes in different communities. They are now facing a further transition from roles that at KRS had mainly consisted of personal care tasks, to new roles that focus on supporting people to have a good ordinary life in their community.

This research project is guided by a very active and committed steering committee comprising self advocates, family members, staff from advocacy organisations, senior Department of Human Services’ staff from three regions, and the Disability Services Division.

This report contains valuable insights, lessons and pointers to how we can improve the lifestyles of the residents that we support. Positive developments have occurred in the houses since the individual reports were written but we have a significant way to go.

Lifestyle gains for many of the residents have already been significant and the response by family members very positive. Many more gains can and need to be made. The findings in this report provide guidance and a challenge for us all to keep up the momentum to continually improve the quality of our services.

This is a very important piece of research. It has implications for all staff working in disability accommodation services. It will contribute to work being undertaken by the Quality and Sector Development Branch and inform some of the broader policy work of the Disability Services Division.

I commend this report for your careful consideration.

John Leatherland
Regional Director
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Department of Human Services
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The research team receive support and encouragement from members of an enthusiastic steering committee.
Chapter 1: Introduction

By Tim Clement

Commissioned research typically produces a single, end-of-study report for wider dissemination. *Making Life Good in the Community* is not, however, a typical project. *The Story So Far* is a collection of project papers that are being widely circulated whilst the research is still underway.

As the project’s title suggests, the research is concerned with discovering ways of supporting people with intellectual disabilities to lead the best possible lives. This is consistent with the Victorian Government’s vision for all people with disabilities — that they have the same opportunities to participate in the life of the community as any other citizen (State Government of Victoria, 2002).

In the early years of institutional closure many people believed that changing people’s living environment from institutions to small homes would be enough to ensure that other outcomes, such as increased social networks, participation in domestic tasks and community organisations would follow. We have known for some years that this is not the case. Even though the lives of many people with intellectual disabilities have improved over recent decades, once we begin to compare their quality of life with the lives led by non-disabled people, it is clear there is still a long way to go.

Although *Making Life Good in the Community* is focused on the lives of former residents of Kew Residential Services, the project has relevance for any supported accommodation setting. Much of the work to date has highlighted the support given to people with intellectual disabilities in key areas: the interactions between staff and residents; the styles of support that residents receive to participate in meaningful activities inside and outside the home; and the skills and knowledge of support staff to promote community inclusion.

These papers do not provide a list of explicit recommendations about how to improve the lives of people with intellectual disabilities after they move to the community. Achieving the aspirations of the Victorian State Disability Plan 2002-2012 (State Government of Victoria, 2002) requires the implementation of hard-won lessons from a more ‘experimental’ approach. It requires more than simply ticking all the boxes in a checklist or following a series of steps in a ‘magic recipe’. Although people’s lives share similarities, there is enough substantial variation to know that the same approach will not work for everyone.
One of the principles underpinning this research is to find ways in which people can learn valuable lessons through reflecting on their own practice. What is it possible to learn from how we are providing support now? The papers in Chapters 2 to 4 contain descriptions of life in three houses, which are based on our experiences of working and observing in those settings. We wrote these papers so that the staff teams in those houses could use the descriptions to discuss their current practice as a way of improving the lives of the residents they are supporting. What we have found is that when read by staff, self-advocates and family members who are unrelated to these particular houses, the descriptions bring to the surface issues that have immediate relevance for their own lives.

A major reason for making the papers available to a wider audience is the hope that they can be used in a practical way. As you read the papers you will no doubt have a view about the lives of the residents in those houses, the practices of the staff supporting them, and the employing organisation. We suggest that you read the papers with a view to asking whether there are any issues or lessons that are relevant for your work in supporting people with intellectual disabilities.

You can read each chapter as an individual or as one of a group of people who want to have a discussion at a formal meeting or training event. We think that the papers can be used in any number of useful ways. Even without a list of recommendations, merely reading a description may suggest particular kinds of actions that you can take to improve the lives of people with intellectual disabilities. This is true whether you are an individual support worker working ‘at the coalface’ or a manager who no longer does, or perhaps never did, any ‘hands-on’ work. Reading the papers may help to inform you about areas of activity that your organisation should expand, change or discontinue.

As an individual support worker you can take a personal decision to test out supporting people in a different way, which may lead to improvements in your practice. As a manager you can focus on what the organisational response should be to develop the knowledge, skills and commitment of front-line workers that will enable them to meet the stated organisational goals.

One of the key ideas that is reflected in our writing about the three houses is that staff practice is influenced by the organisation in which they work. Chapter 5 distils our experiences in those three houses and asks a number of questions that need to be addressed by more senior figures within the organisation. We borrowed the term ‘upstream issues’ to suggest that some of what we uncovered in the houses will need a more systemic focus.
Chapter 1: Introduction

The papers in *The story so far* are presented in the order in which they were written. A close reading reveals ways in which both our thinking about key issues, and the way in which we are investigating the project, is evolving. Undertaking research rarely, if at all, follows a series of sequential straightforward tasks. Chapter 5 additionally makes a case for amending the original research proposal so that we can focus part of our work in the coming year on answering some of our own questions.

The papers are reproduced here without the polished re-editing that would accompany a final report. This is deliberate. Firstly it means that we can disseminate them more quickly. Secondly, it means that each chapter can be read as a stand-alone report. A disadvantage is that there is some repetition between the papers that would have been addressed by a thorough re-writing.

The style of writing, especially in Chapters 2 to 4 may be different from research reports that you have read before. This is because the papers use a lot of original data, which can have a few rough edges, but also because they are written in the first person.

If you read the chapters in the order in which they are given, you will find a progressive tightening and focusing of ideas. Chapter 6 is an interim report that provides a synthesis of some of our findings from the earlier papers. This chapter moves beyond the descriptive nature of the earlier writing, to include analysis and interpretation at a greater level of abstraction. Given that this is our interim report we also indicate some issues that remain to be explored and suggest what data we may need to collect. A further reason for not providing a series of recommendations at this stage is that we are still analysing the data that we have collected and have yet to draw any solid conclusions.

Much of our early writing aims to open up debate about how best to support people with intellectual disabilities, not close it off. Ultimately we hope to be able to disseminate more concise positive lessons about what worked in improving the quality of life for the residents in the focal houses. Our ongoing work with the staff teams at the three houses suggests that our initial descriptions are already inaccurate and that people’s lives are moving forward. We hope that this series of papers can be used to create some forward momentum in other settings where people with intellectual disabilities live.

*August 14th 2006*
Chapter 2: 96 High Street: Description, analysis, and interpretation

By Tim Clement

2.1 Introduction

The scope of this paper touches on some of the key questions outlined by the Department of Human Services in the original tender document (Victorian Department of Human Services, 2004). In particular it focuses on the interactions and styles of support between staff and residents at one house, the support that residents receive to participate in meaningful activities inside and outside the home, and the skills and knowledge of support staff to promote community inclusion, an aspiration of the Victorian Disability State Plan 2002-2012.

2.2 Aims

The first aim of this paper is to provide a ‘partial’ description of the interactions between the people who live and work at 96 High Street, a home for three men and three women who are in their early forties to mid sixties. The description derives from fieldnotes written during 36 hours of participant observation on nine different days over a three-month period. At the end of this period of participant observation the men and women had been living in their new home for six months.

The description is ‘partial’ in that it does not reflect everything that is happening in the house. All descriptions are incomplete (Spradley, 1980), but it is not in this sense that I am using the term ‘partial description’. As we began the research we identified a number of what we have called ‘upstream issues’. This means formal and informal policies, procedures, decisions and protocols which have been determined at higher levels within the Department of Human Services that seemed to be having an impact on practice within the house. I have chosen to

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1 The paper is written in a personal style, which I think is congruent with qualitative research. In the text I use both ‘I’ and ‘we’. The ‘we’ acknowledges that I am part of a larger research team, which includes my colleagues Chris Bigby and Kelley Johnson.

2 Names and places have been changed to provide a degree of anonymity.

3 The fieldnotes comprised more than 20,000 words in total. The original fieldwork plan was curtailed following discussions with the house supervisor as he had identified a number of practice issues that he wanted to explore. We were at a stage where we thought there were enough lessons to be learned from what we had observed. A downside of this quicker than anticipated move to the action research element, was that we had not made formal contact with the one family member who had expressed an interested in participating in the research.

4 It is worth noting that what we are doing here is a rhetorical ‘trick’. All parts of the organisation are linked, and what happens at one level has an impact elsewhere. Separating out issues in this way serves the purpose of the papers we are writing.
report in this paper those areas of practice that the staff group can work on immediately. I have not drawn out a series of prescriptions for people to follow. At the moment this is consistent with our commitment to helping the organisation learn through reflection on its own practice. However, even describing an event may suggest particular kinds of actions that can be taken (Eden and Huxham, 1996). Those issues that need consideration at a different organisational level have been kept separate as far as is possible, and will be written about in a different paper.

In writing this paper the goal is to give as much detail as seems sensible, which will give readers a sense of the general pattern of observed support to the residents. Such description serves as a written record of how things were at the house during the period of observation, before embarking on the first cycle of action research.

A second aim of the paper is to give readers an idea as to how we went about getting the information for this paper and how it came to be written. These are methodological issues.

Some of the fieldnote extracts that are included in this paper were given to the staff team at a half-day meeting as a means of engaging them in the action research cycle. By giving those descriptions to the staff team we were able to create a dialogue about how things were in the house, so that staff could reflect upon their observed practice. This is consistent with action research methodology, where people reflect on their practice in order to change it in light of what they have learnt. In giving permission for this paper to be made available to other audiences the house staff will allow us to create a similar dialogue in different areas of the organisation.

Giving the extracts to the staff in this way also served to validate our analysis and interpretation of the data (Creswell, 1998). We had analysed the fieldnotes prior to the half-day meeting, but not shared any of our ideas with the staff group. Analysis allows us to reduce our fieldnotes into organised ideas and patterns. The half-day meeting allowed the staff group to explore the fieldnotes in a relatively safe environment and share their interpretations of the raw data (that is, the fieldnotes). In this meeting we were also able to share some of our ideas.

A third aim is to begin to make links between our fieldnotes and the academic literature, including research from similar settings and more theoretical work.

5 Methodology is a research term that is concerned with how we do research.
2.3 The setting

Before moving to 96 High Street in 2005 the six residents had lived at Kew Residential Services for most of their lives. The house has been set up to provide the residents with an extensive support intensity, which is characterised by long-term daily involvement of paid staff in the home environment (Luckasson et al, 2002)\(^6\). A member of staff sleeps over from 22.00 until 07.00. When the residents are not at day programs there are usually two staff in the house (see Figure 1)\(^7\).

The residents attend six different day programs. Three residents attend full-time. The others attend three, four, and four-and-a-half days respectively and are supported at home when they are not at the day programs.

The house was purpose built from one of a number of basic designs and being newly built, decorated, and furnished provides an improved material environment in contrast to Kew Residential Services. (See end note 1). Although some of the residents in this house had finally acquired their own bedroom before leaving Kew, this was not the case for all of them. The physical space at their new homes is informally divided along gender lines (See end note 2) with the three men being in bedrooms at one end of the house and the three women at the other. There are also, in practice, separate men’s and women’s bathrooms and toilets. Improving people’s physical environment is a positive outcome of closing Kew Residential Services. Another hoped-for outcome is high resident participation in

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\(^6\) The American Association on Mental Retardation (AAMR) distinguish between four support intensities: Intermittent, Limited, Extensive, and Pervasive.

\(^7\) DDSO stands for Disability Development and Support Officer, of which there are various grades.
everyday activities. The research literature tells us that a better living environment is not a sufficient condition for greater involvement in activities. Research has shown that the key to involvement in activities by people with intellectual disabilities is what support staff do in relation to them (Felce, 1998).

2.4 Interactions and styles of support in the house

The extracts from our fieldnotes are examples of patterns of behaviours that we noticed in the house. Each example is therefore part of a much larger data-set that represents how things are in the house at different times of the day and on different days. Unless something is done to change these patterns of behaviour we might predict that the same patterns of behaviour will remain in the future.

This is not to say that what is recorded in this paper is the only way that people behave. We have examples of staff trying to support the residents in different ways and of the residents behaving differently. However, we propose that the extracts illustrate the dominant patterns of behaviours within the house.

2.5 Staff as the principal actors

There is evidence to suggest that staff have the dominant role in the house, and this has consequences for the social relationships in the house. For example, the staff who had ‘slept over’ had got up and organised the breakfast:

‘Six bowls were laid out on the kitchen counter. Some had Weetbix in and others a mixed cereal. A plastic container had a tinned fruit salad in it. Mugs were laid out on the counter. By the toaster were peanut butter, vegemite, and marmalade.

Andrew [staff member] told me that the others would be woken up at seven o’clock. At two minutes to seven he asked if I would go and knock on Simon’s door. I did, said, ‘Good morning’, told him the time and left him to his own devices. He came to the dining area in his blue striped pyjamas. Then I went to Brian’s room. He appeared to be asleep. I tapped him on the side, as Andrew had suggested, as he uses hearing aids. He got up and came to the dining area in his pyjamas. Sarah was sitting up in her bed with the door open. She put on a dressing gown and came to the dining area.

Andrew spooned the fruit salad over the cereal. Andrew called people up to the counter to “choose” a bowl. The first three people could choose between Weetbix/fruit and the cereal/fruit combination. After three bowls of one type of cereal had gone there was no choice.
Julie [staff member] arrived just after seven o’clock. She shouted ‘hello’ to everyone and went to Aphrodite’s bedroom. Aphrodite appeared in a dressing gown, gaping open, carrying her wet bed linen, which she placed in the laundry. She then came and sat down at the table. Just as Simon had put a spoonful of cereal in his mouth Andrew asked him to come and be weighed. He apologised for interrupting his meal.

Andrew made everyone coffee in a big plastic jug. He poured it out at the counter and gave people the mugs. Brian’s drink had been thickened. Andrew gave out the medication. Some people got their medication in their hand; Alberto’s tablets were put on his spoon. People took their cereal dishes back to the kitchen. Julie was standing by the toaster. She spread butter on the toast and people were given the option of the three spreads. Julie made an effort to get people to apply the spreads. Then Julie cut the toast in half and people took their toast back to the table. Rose only got one slice. Aphrodite was asked to point to the preferred spread from her place at the dining table’ (F/HS/02/12/05).8

One way of doing analysis is to compare what you are looking at with a standard (Wolcott, 1994). Two related benchmarks are The Principle of Dignity and Self-Determination (Choice)9 (State Government of Victoria, 2002) and Disability Standard 3: Decision Making and Choice10 (Department Of Human Services, Victoria, 2002). Concepts like these are often hard to define and apply, which often means that they are poorly defined and understood11. However, it is evident that in the above example staff have determined the parameters of resident participation by how the event has been set up, the choices available are limited, and staff have the most active roles, taking the lead in waking people, offering choices, serving food

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8 The fieldnotes are given a code to identify where and when they were recorded.

9 The Principle of Dignity and Self-Determination (Choice) is about respecting and valuing the knowledge, abilities and experiences that people with a disability possess, supporting them to make choices about their lives, and enabling each person to live the life they want to live (State Government of Victoria, 2002).

10 This standard is expressed in the following way, ‘Each client has the opportunity to participate as fully as possible in making decisions about the events and activities of his or her daily life in relation to the services he or she receives’ (Department of Human Services, 2002, p.7).

11 It would seem to me that the way in which this principle and standard are written add to the confusion. Dignity and self-determination are hard terms to operationalise. They would appear to be two principles not one. Presumably ‘choice’ has been written in parentheses to give a plain English version of the principle or part of the principle (self-determination). However self-determination and choice are not the same thing. Likewise what is the relationship between decision-making and choice?
and drink, weighing people and administering medication. The residents are by no means entirely passive. They make choices, they take dishes to the kitchen\(^{12}\).

2.6 The hotel model

A term that seems to have common currency in Disability Accommodation Services is the 'Hotel or Motel Model'. Although it is rarely defined by practitioners, the metaphor is used to evoke an image of what services should not be like. In a hotel, you expect the staff to wait on you, as in this example:

‘Morning tea is served at 10.30. A cloth has been put on the table in the back yard. Cathy [staff member] has made the drinks and a snack. The residents go outside and sit around the table. Cathy serves people their drinks. There are two individual tea pots. The milk has been put in the pot. There is a plastic jug of coffee. People are given little bowls and Cathy serves crackers with a topping. She serves them with barbeque tongs. Some people dip them in their drinks. Rose drinks and eats quickly and leaves the table. Brian stacks up the bowls. Simon wants to take a plate with some mugs on it into the kitchen. Cathy tells him that she thinks it will be too heavy’ (F/HS/05/11/05).

It is easy to see why an outsider reading about or observing this event might consider it a good example of the Hotel Model in operation. There are times when the staff do wait on the residents, do their laundry, and clean the house. Although the idea has some resonance, it is too simplistic, for staff do not always act like hotel staff and residents do not always act like guests, as can be seen from reading other field note extracts.

2.7 Parent – child interactions

In the following extract we can see again the major roles played by staff and the minor ones played by residents.

‘Kylie [staff member] starts to prepare tea at about six o’clock. She gets the cutlery out of the draw and puts it on the worktop and asks Aphrodite to lay the table. Aphrodite does this, and fetches glasses from the cupboard. Alberto comes in and moves the knives and forks further apart. Brian’s place is laid with a parfait spoon.

\(^{12}\) It is very easy to think of or portray people with intellectual disabilities as passive. Folkestad (2002) reminds us to treat all members in a particular setting as contributing actors.
Kylie carves the corned beef that she had cooked earlier in the day and puts it on the plates that she has put out on the work surface. She gets a large bowl of salad from the fridge and puts portions on the plate.

On the table are a jug of water and a large bottle of orange juice. Julie [staff member] encourages people to choose between the two. Aphrodite gestures to Alberto to pass the orange juice. He does not.

Kylie comes around and offers more salad. Julie fetches the tomato sauce and gives it to Brian. "The meat may be a bit dry for you”, she says. Simon, another resident, puts some sauce on his remaining food.

The dessert was put in bowls on the kitchen counter by staff. Watermelon and another fruit for everyone except for Brian who was given a banana in a bowl. Most people took their plate to the kitchen and picked up their dessert. Brian gestured to a bowl that someone else was eating, but I was the only one who noticed’ (F/HS/09/11/05).

Although staff are taking the lead, we can see again that people are participating in tasks, although they are on the margins of the task. A resident laid the table. People took their dishes to the kitchen. In thinking about the residents’ participation here I was reminded of my own experiences as a child and later a teenager living in my family home.

Adults with intellectual disabilities often find themselves in the role of eternal children (Wolfensberger, 1975). If someone is cast in the role of child, then it is no surprise to find that the staff sometimes take on the role of adult or parent. There was no doubt that in my family home my mother ruled the kitchen. She did the main tasks, remained in control of what was happening, but expected us to 'chip-in' or 'help-out'. In the house the staff keep things going, and the residents chip-in by laying the table, clearing their dishes, emptying the bin, or hanging out the washing. Often this seems to be asked as a favour to the staff member, rather than an expectation or responsibility. This is very different to seeing the resident as the person doing and owning the task, with the staff member there to give whatever support the person might need to complete the task.

‘At just after seven o’clock Simon came down the corridor from his bedroom, and Julie and Brenda [staff members] said “Hello”. Julie asked him if he would go and get the milk from the fridge and put it on the worktop, which he did’ (F/HS/08/12/05).
Interactions such as these can be very seductive. We can deceive ourselves that because people are making choices, are engaging in tasks, that this is the choice, involvement, engagement, participation or any other term that appears in Department of Human Services’ aspirational documents. What I have tried to show is that this is a false impression and that what is happening at the moment is the illusion of choice, the illusion of participation, which falls short of the aspirations of the Victorian State Disability Plan13.

Another example illustrates the restricted nature of choice in the house.

‘Julie [staff member] gets supper ready. She offers people a choice of tea, coffee, or Milo. People seem to make a genuine choice from the three options. A packet of biscuits is put on the table. Brian’s drink is thickened and put on the table in the measuring jug. He pours it into his mug. Alberto had tea, with the milk in the teapot. Aphrodite gestures to Alberto to pass the biscuits. Aphrodite takes two. Later she is told by Julie that she has had enough. When Julie is not watching she takes some more. People take their crockery to the kitchen when they have finished. Julie wipes down the chairs’ (F/HS/09/11/05).

The residents are offered a choice of drinks, which were determined by the staff member. Obviously, there are other drinks that people might like, but there are other choices to be made, such as who makes the drink, what time people have it, and where they drink it.

2.8 Choice: a dilemma

The residents also make choices that should create uncertainty for the staff in how to respond. Such situations are dilemmas and need to be discussed and resolved.

‘Andrew [staff member] has started to sweep and mop the kitchen. All the chairs are moved away onto the carpeted area. He asks Alberto if he wants to mop the floor. Alberto shakes his head, so Andrew does the job.

There are a number of vegetables growing in pots in the garden. They are visible through the window. They are beginning to brown. I ask Rose, Sarah and Brian in turn if they want to water them. No one wants to’ (F/HS/25/11/05).

13 Another possible interpretation here is that what we are witnessing is a step along the way to greater or full participation, involvement, or engagement. But there is enough evidence already to suggest that some staff think that what they are doing is the end goal. As I have already suggested, unless action is taken to change these patterns of behaviour they are likely to remain.
How should the staff at the house respond when people choose not to be involved in such activities? One response may be to renegotiate the task, so that the person chooses when they do it. But can residents choose absolutely? Can they opt out of activities that they don’t like doing?

2.9 Ownership

In our own lives we may not like doing a whole heap of tasks, but still end up doing them anyway. A useful concept here is that of ownership. I have already suggested that it appears that the staff have the dominant role in the house, that is, the control over the day-to-day running of the house and the direction of the house is owned by them. The residents seem to have this perception too.

I was working in the house one morning.

‘After the bus had gone I started to quiz Frank [staff member] about the morning routine, how the jobs were decided, and what would happen now.

He said that he was going to make himself a coffee. He said I could make myself a drink. I asked Simon, who was staying at home, if he wanted a tea or coffee. He did not answer, so I asked again. He said that he’d just had breakfast. Then he said that he would have to ask Frank’ (F/HS/08/12/05).

On another occasion I was at a Christmas party in the house, and had brought a box of chocolates with me, which I had put in the kitchen.

‘Later in the evening I asked Simon whether he could pass me the box of chocolates that I had bought. He looked at them and shook his head. I got up from my seat and told him. “I brought them, so I think I can open them”. I offered him one and then asked if he wanted to pass them around. He offered them to one person and then put them down’ (F/HS/14/12/05).

Ownership has a number of meanings (OED online, 1989)\textsuperscript{14}. If Alberto felt that it was his responsibility to mop the floor and was in control of when the floor was mopped, perhaps he would have done it. If Simon felt that the house belonged to him, then perhaps he would have said he wanted a drink or opened the chocolates. If Rose, Sarah or Brian felt that the vegetables

\textsuperscript{14} Some meanings that seem relevant here are: The state of being or feeling responsible for solving a problem; to have or hold as one’s own; to have control over or direction of a person or thing; to be or feel responsible for considering or solving a problem, issue, or task.
were theirs, perhaps they would have felt responsible for watering them, or feeling responsible for how they were going to get watered\(^\text{15}\).

**2.10 Activity and inactivity**

The fact that staff take the lead in the house has a number of consequences for the residents. The major consequence is that they spend a large proportion of time in their own home disengaged.

‘After morning tea I sit back on the settee again between Sarah and Rose. The horse racing is on the TV. No one is particularly watching it. Aphrodite is sitting in an arm chair that is not facing the television. She shuts her eyes. Sarah who is sitting on the couch spends much of the time trying to look at what is happening behind her in the kitchen and dining area. After a while Simon comes and sits down next to Brian. They do watch the TV for a little while, but Simon too shuts his eyes. The soundtrack for the horseracing competes with the sound of Dancing Queen coming from the other lounge, where Alberto is watching his ABBA DVD. Rose sings along to Dancing Queen. At some stage during the morning she appeared to tell one of the residents off for touching the table cloth, “Don’t touch that, it’s not yours”’ (F/HS/05/11/05).

‘Simon and Brian were sitting on one settee, Sarah on another. Aphrodite was in the toilet. Rose was in her bedroom, walking on her exercise machine. The TV was on in the lounge, and later Alberto’s Abba DVD was playing in the middle lounge at the same time’ (F/HS/09/11/05).

‘After tea Julie and Kylie [staff members] did most of the jobs. Loading the dishwasher, washing down the chairs and tables, sweeping the floor. Julie supported Alberto to mop the kitchen and dining area floor. Julie rinsed the mop and gave it to Alberto. There was always a nod to ask people to do things, such as putting the orange juice back in the fridge. At supper time Brian was asked to put the biscuits back in the cupboard’ (F/HS/09/11/05).

The purpose of the time spent in the house as a participant observer was not to get detailed quantitative data about the residents’ levels of engagement. We

\[^{15}\text{There are obviously other possible interpretations here. However, questions such as, How can we support people to feel responsible for what happens in their house? or How can we support people to feel that the house is their home? are likely to move the culture in the desired direction.}\]
know from the research that staff who work in community services may typically do little to facilitate resident participation so that even in homelike environments there are low levels of engagement (Emerson and Hatton, 1996).

If we think of our own lives at home, a significant amount of time is taken up with domestic activities, cooking, washing up, tidying, cleaning, decorating, washing and ironing clothes, and gardening. If staff have the lead role in completing these activities, and residents do not have other activities to fill their time, then their time in their home is likely to be characterised by disengagement and boredom. At the moment there are few organised activities in the house other than domestic ones, and staff do the bulk of these.

In the house there is one resident who seems to do more activities than the other residents.

‘Simon is vacuuming the hallway. Alberto is standing is the middle lounge. Brian, Aphrodite, and Rose are sitting on the settees in the other lounge. Sarah comes out of the toilet and sits down. The TV is on’ (F/HS/05/11/05).

Felce and Perry (1995) make the point that those people who are most able are likely to receive more attention and support than those who need it most. Simon is the most articulate of the six residents, has more adaptive skills than most of the others, and a greater willingness to do jobs around the house.

It is important to clarify what the aims of participation, involvement and engagement are for people with more profound and severe cognitive impairments, since their ability to engage in many tasks independently is very limited. For people with severe and profound impairments the role of staff is to make opportunities for residents to engage in activities and give them the support necessary to participate in them (Felce, 1998). For many people independence may be an unrealistic goal, whereas participation is always possible.

2.11 Activities outside the house

Goal number two in the State Disability Plan is Building Inclusive Communities\(^{16}\) (State Government of Victoria, 2002) and the fifth Disability Standard is

\(^{16}\) This goal is explained in the following way: To strengthen the Victorian community so that it is more welcoming and accessible, so that people with a disability can fully and equally participate in the life of the Victorian community. Building inclusive communities means strengthening communities so that people with a disability have the same opportunities as all other citizens of Victoria to participate in the life of the community – socially, economically, culturally, politically and spiritually (State Government of Victoria, 2002, p.9).
Participation and Integration (Department of Human Services, Victoria, 2002), where “Each client is supported and encouraged to participate and be involved in the life of the community” (p.7).

As part of the orientation to their work in the house the staff group received two training sessions to support this goal and standard. The first was during the transition training on social inclusion and then a one-day workshop Developing Community Connections at a Local Level (Scope (Vic) Ltd., 2005) was held after the house had been open for three months. (See end note 3)

Although the end goals of these initiatives are hard to achieve, there would also seem to be some uncertainty as to what the end goals of these initiatives are. The distinction made by O’Brien (1987) between Community Presence and Community Participation is helpful in directing staff to two facets of an inclusive community and is a useful analytic framework that allows us to see what type of activities the staff group are supporting outside the house.

Community Presence refers to the sharing of ordinary places, rather than the use of segregated facilities. O’Brien (1987) argued that people should be supported to increase the number and variety of ordinary places that a person knows and can access. In addition, many disabled people usually have small social networks, which are typically made up of other clients, staff, and immediate family members. The aim of Community Participation is to expand these networks to include non-disabled people, so that they experience being part of a growing network of personal relationships that includes close friends.

It would appear that at the house, the focus has been on increasing the number and variety of ordinary places that the residents know and access, such as shops, cafés, and parks. In relation to this the staff place a strong emphasis on making sure that the residents are dressed in a manner that is valued by other people in the community when they go out\textsuperscript{17}. It is probably fair to say that the residents have greater community presence since moving to their new home. The extract that follows, of a trip on a train, is a good example of this. The residents are using an ordinary service and for some it has increased their type of experiences.

‘Cathy [staff member] drives us [the six residents and myself] to Horsham station. Rather than park in the “disabled parking” spot because it is in the sun, she elects to park in other bays. She tells me that she is not very good at parking and then proceeds to park at an

\textsuperscript{17} This is consistent with guidance given in the Direct Care Staff Handbook (DHS, 2002).
angle across two bays. She gets out of the bus. I ask Simon if he will get out and open the rear door for us as it is locked. He gets out, but then Cathy tells him to get back in. Simon tells her that I asked him to open the door. She moves the car to the "disabled parking" spot. When we get out I apologise to Simon for getting him into trouble. "I thought we were parked" I say.

We walk the short distance to the platform. Cathy gives people the money, which she takes from an envelope, so they can buy their own ticket. She does not seem to know which buttons to press on the machine. I help her out. We want a two-hour, concession ticket, for Zone 3. Cathy and I travel with Companion Cards. Alberto throws his ticket on the floor. I pick it up. Cathy is collecting the tickets. I support one of the residents to validate the ticket. Cathy sees this and helps the others.

Our journey will take us to the first outbound train’s destination. This will either be to Reigate or Epsom. Cathy has been telling me during the day how much people have enjoyed going on the train before. Simon had not been on a train before she had taken him a little while back. "They are so happy. You’ll see for yourself". Cathy tells me that she really likes it when people are happy. She says that she never has any trouble with people because she is always organising an activity, which was true at Kew too.

The next train is for Reigate in ten minutes. In the shelter Alberto picks up a chip that Brian has removed from under the bench and he eats it.

When the train is approaching Cathy stands with her back to the rails on the yellow safety line. Her arms are slightly outstretched as if to say "Thou shall not pass". Cathy gives physical assistance to everyone on and off the train. There is a small gap between train and platform at Horsham and larger one at Reigate, but for some people the assistance did not seem necessary.

People sit down in three different seating areas. I sit opposite Rose who sings Little Red Corvette when the train pulls out. Cathy asks her to be quiet but tells me to notice how different she is now. A little while ago she was moaning about having to change her t-shirt, complaining about her back, and now is singing. She tells Simon that
this is better than having to carry the shopping bags with Frank [staff member], who has gone food shopping on his own.

We arrive in Reigate and get out. We sit inside by the ticket booth and Cathy gives people a snack bag of “Shapes” and a drink. We will be getting back on the same train that leaves in 17 minutes. Some boys ride their bicycles through the station and Cathy tells me that they should not do that and could knock over one of the residents.

On the return journey Rose grabs the arm of a woman who walks by her on the train and says, “Have a good time on your holiday”. The woman keeps on walking and Cathy turns around to tell the stranger that she touched her because she is so excited.

Cathy asks me whether we should let them stay on until Brighton. “Let’s get off at Horsham” I say. We do. On the way back to the bus Cathy sees a public bus which goes to Fulham. “We’ll go on that next time” she says’ (F/HS/05/11/05).

An emphasis only on creating community presence, although essential in itself, is unlikely to achieve the goal of building inclusive communities; it will require staff to supplement this aspect of their work with supporting community participation.

Some energy has also been made to develop links with staff and residents in other Department of Human Services’ supported accommodation in the area, particularly other staff and residents who have relocated from Kew Residential Services. Sometimes this has been driven by pragmatic concerns, such as sharing a bus ride to a day program. In other instances it has been concerned with maintaining contact between residents and staff who used to know each other at Kew. Although these links may be important they are also unlikely to further the goal of building inclusive communities. A visit to another Community Residential Unit is neither community presence nor community participation. These can be described as bonding relationships, that is relationships between people who have things in common, such as a shared Kew history, being Department of Human Services employees, being service-users and having the label of intellectual disability. Moving beyond the service culture for people with intellectual disabilities will rely on bridging relationships, that is making links between people who do not seemingly have things in common (Putnam, Feldstein, and Cohen, 2004).

It is worth making the point that there is nothing wrong with people with disabilities having friends and mixing with other people with disabilities. Indeed,
the growth of self-advocacy organisations is seen as a progressive development. There have been some harsh critiques of interpretations of normalisation theory that viewed relationships with other people with disabilities as the problem and those with non-disabled people as the solution (see Szivos, 1992 for example).

2.12 Final words

It is always hard to anticipate how a piece of writing like this will be received. My aim has been to record how things appeared to me at 96 High Street as a means to assisting the development of better practices there. There was enough passionate discussion at the half-day meeting to suggest that some staff are not content with the current state of affairs.

In one sense, what is recorded in this paper is already out of date. The document merely formalises some ideas that were discussed at the half-day meeting with the staff group. Things have begun to change at the house as a result of that meeting.

The paper is another tool that the staff group can use as a learning aid.

February 21st 2006
Chapter 3: 64 Penny Lane: A description

by Tim Clement\textsuperscript{18}

3.1 Introduction

This paper addresses some of the key questions outlined by the Department of Human Services in the original tender document for this project (Department of Human Services, 2004). In particular it describes the interactions and styles of support between staff and residents at one house and the support that residents receive to participate in meaningful activities inside and outside the home.

3.2 Aims

The first part of this paper provides a description of the interactions between the people who live and work at 64 Penny Lane, a home for five middle-aged men with intellectual disabilities. The description derives from fieldnotes written during 46 hours of participant observation on nine different days over a four-month period. At the end of this period the men had been living in their new home for five months\textsuperscript{19}. The fieldnotes are supplemented with quotations taken from semi-structured interviews with five of the staff who work in the house\textsuperscript{20}.

The first part of the paper is intentionally descriptive, where the goal is to give as much detail as possible, which will give readers a sense of the general pattern of observed support to the residents. For the staff at the house, this paper is their first sighting of the fieldnotes.

Such description serves as a written record of how things were at the house during the period of observation, before we embarked on the first cycle of action research. It is also hoped that the inclusion of extensive fieldnotes will allow the staff group to engage in critical reflection on their observed practices. This is consistent with action research methodology, where people reflect on their practice so that they might change it in light of what they have learnt.

The first part of this paper does not, therefore, contain a series of prescriptions for people to follow, although describing an event may suggest particular kinds of actions that can be taken (Eden and Huxham, 1996). Giving this paper to the

\textsuperscript{18} The paper is written in a personal style, which I think is congruent with qualitative research. In the text I use both ‘I’ and ‘we’. The ‘we’ acknowledges that I am part of a larger research team, which includes my colleagues Chris Bigby and Kelley Johnson.

\textsuperscript{19} The fieldnotes and interviews comprised more than 58,000 words in total.

\textsuperscript{20} Four interviews were also held with five relatives of the five men. No extracts from those interviews are presented in this paper.
staff team in this format is consistent with our commitment to helping the organisation learn through reflection on its own practice.

The second part of the paper moves beyond description, to include some analysis and interpretation. This is because the latter focus, Activities outside the house, was a topic that we discussed with the staff group at a specially arranged half-day meeting. The half-day meeting allowed the staff group to explore their practice in a relatively safe environment and for the researchers to share some of their ideas about how people were being supported, that is, the meeting was a forum for reflection on current practice, which included analysis and interpretation. The meeting also allowed the staff to validate or invalidate our analysis and interpretation of the data (Creswell, 1998), which we had done independently prior to the half-day meeting.

3.3 The setting

Before moving to 64 Penny Lane in 2005 the five residents had lived at Kew Residential Services for most of their lives. The house has been set up to provide the residents with an extensive support intensity, which is characterised by long-term daily involvement of paid staff in the home environment (Luckasson et al., 2002). There is an active night staff at the house. When the residents are not at day programs there are usually two staff in the house (see Figure 1).

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21 The American Association on Mental Retardation (AAMR) distinguish between four support intensities: Intermittent, Limited, Extensive, and Pervasive.
The residents attend four different day programs. Two of the men attend a day program five days a week. The other three are supported at home when they are not at the day programs.

The house was purpose built from one of a number of a basic designs (see end note 1) and being newly built, decorated, and furnished, provides an improved material environment in contrast to Kew Residential Services.

64 Penny Lane is at one end of a residential street in a neighbourhood that is multipurpose (Wolfensberger and Thomas, 1983). The west side of High Street, which joins Penny Lane is heavily industrialised. The road is busy, and used by a large number of trucks. Many of the industrial units are related to the selling and repair of cars. There are two cafés on the road, which serve the workers on the industrial estate. There is no bus route that goes down past the intersection of Penny Lane and High Street. The nearest bus stops are 10 to 20 minutes away by foot. Without the use of their vehicle the house is not within easy access of a variety of relevant community resources, such as shops, churches, libraries and theatres. The nearest facilities are squash courts with a small gym and a public walk along Arthur’s creek.
3.4 Interactions and styles of support in the house: A day in the life

The fieldnotes that appear below, which were written over a number of days, have been ordered so as to provide a chronological outline of a day.

During the weekday, the morning begins for two day staff at seven o’clock. The roster allows for a 20 minute overlap with the outgoing night staff.

‘I arrived in Penny Lane at 6.45 am, 15 minutes before the shift begins. Simon and Martin [staff] are due to come in at seven o’clock. Martin has not been at work for two days, and Simon has not been at work for three as he had taken an extra “sub” day. April [active night staff] answered the door.

Joseph and Franco were up and both had had a shower. I said “hello”. Joseph gestured to me that he had had a shower. Franco was wearing trousers that were four or five inches above his ankles. I read the communication book that was open on a filing cabinet in the office. There was a message about who had had their bowels open. I asked April how the men had been, and at first she did not understand, then she said, “The boys had been fine” (F/PL/191005).

It is common practice for some of the men to have a shower before the day staff arrive. John, the other active night staff, explains that this is a way in which the staff help one another, which has additional benefits.

‘I think here you do a bit in the morning to help [the day staff], and they appreciate it, because they’re coming in and they’ve only just got up. Everybody does their bit in the morning, especially when the five are going to programs. If they’re getting up at six it’s not you turfing them out of bed. As the guys get up, because they do a lot of things themselves, you’re not rushed, you can do three showers. It means that they can take their time with breakfast and the guys can just sit down. It’s like me coming on at night. You may have only been up for a couple of hours when you come in. They do things at night and the place is tidy, the dishwasher will be empty and things like that. People will just pitch in. I think at Kew sometimes the night staff and day staff were separated’ (I/JZ/141205).

22 At the weekend one staff will come in at 07.00 and a second at 08.00 as people do not need to be supported to get ready for day programs.

23 It is worth noting that I sometimes appear in the fieldnotes as I move between different roles. The classic model of the ethnographic researcher distinguishes between four roles, complete participant, participant-as-observer, observer-as-participant, and complete observer (Hammersley and Atkinson, 1995). For example, sometimes I was merely trying to watch what was going on in the house but on other occasions I was involved in supporting the men in the house.

24 Fieldnotes and interviews are given a code to identify what type of data they are, and where and when the data was obtained.
The five men in the house have virtually no spoken language, but have found other ways of making some of their wants known.

‘Dan appeared in the corridor, wearing un-matching pyjamas. He grabbed me by the arm and led me to the bathroom, opened the bathroom cabinet and reached for the top shelf. When I tried to get him to wait Dan started to take off his pyjama top. I went and asked April for guidance. Dan was led back to the living area and sat down at the dining table. On our way back to the bathroom she noticed Franco sitting on the toilet with the door wide open. She pulled it shut, so that it was open at about six inches.

Martin arrived just before seven o’clock. April told him that she was leaving at seven. Simon arrived at about 07.10’ (F/PL/191005).

On this particular morning the three of us began the shift with no detailed knowledge of how things had been the previous evening. On another occasion the time is spent in social conversation and thinking about the day ahead, not what has gone before.

‘I ring the door bell at 06.55 and April answers the door. Joseph and Franco have had a shower and are sitting on the same settee. Franco is lying curled up with his head on the arm. Dan grabs my arm and leads me to the shower. I try to explain to him that I would like him to wait. I go back and sit in the lounge and talk to April. Simon arrives a couple of minutes later. Shelagh [staff] arrives at 07.10. Simon tells us that the bus has to go in for a service today. No alternative arrangements have been put in place to get the residents to their day programs. Only Wally usually stays at home for the entire day on Wednesday as his mother visits in the afternoon. Milan goes to the day program for the afternoon only. Simon decides that Franco will go to the day program and Joseph and Dan will stay at home. There is some talk between us about yesterday’s Melbourne Cup. April won nearly $300.00 on Makybe Diva. Shelagh makes herself a hot drink and a slice of toast. Simon supports Dan to have a shower. April leaves at 07.20’ (F/PL/021105).

All of the men need support to get washed and dressed.

‘Wally came out of his bedroom. His bed was wet. He said “piss the bed” a number of times, which he repeated throughout the morning, even after he had had a shower and his bed had been stripped and re-made.

There was a lot of activity at this time. Martin and Simon did not seem to communicate very much, but just seemed to know that there were a series
of tasks that needed to be done. Milan appeared from his bedroom, grabbed me and took me to the bathroom. My understanding at this point was that people would have breakfast first and then have a shower, even though Dan had indicated that he was ready for the shower. I tried to explain this order of things to Milan, but he took off his pyjama top, then his bottoms and sat on the bench. I went and told Simon what had happened and he went to help Milan shower. Wally, who was naked as his pyjamas had been damp with urine, had to wait because Milan had taken possession of the bathroom. Martin [the staff member] was sorting out breakfast’ (F/PL/191005).

The routine was very similar on a day when four of the five residents were going to stay at home.

‘Shelagh and Simon go about doing things. Wally and Milan are helped to shower and dress. Shelagh strips the beds that are wet with urine and puts them in the laundry area. Dirty clothes are put in the laundry area’ (F/PL/021105).

The routine appears to run more by habitual action than any concrete planning between the permanent staff, as Shelagh explained25:

‘If I come in the morning I know to shower the guys, pack their bags, give them breakfast, get them ready and neat and tidy, get them off to the programs and come back, clean the house. There is a routine in the morning that you need to get through before you do anything else. There’s not really a cemented routine. We’re pretty easy going. It depends what shift really. For example, one morning I might come in and I’ll be working with Simon and we might give breakfast before we shower the guys. On another morning I might come in and I’ll be working with Linda and we’ll shower the guys before we give breakfast. It’s pretty easy going. We just go with the flow. If the guys seem hungry and are all sitting at the table and they want their breakfast, you know what I mean? We work with each other’ (I/SX/091105).

One of the staff will begin to serve breakfast whilst the other staff member supports the remaining residents to get washed and dressed.

‘Martin was serving the men breakfast. There was no attempt made to offer people a choice of cereal. Martin prepared something with hot milk and put it in front of people. Dan ate his breakfast before his shower. Simon told me

25 Mezirow (1991) identifies habitual action as non-reflective.
that Dan likes to have a shower before breakfast because if he does not have a shower then he will rush or sometimes leave his breakfast so that he can have a shave and shower. Franco pushed his breakfast away. Simon appeared and told Martin that he does not like his cereal with warm milk’ (F/PL/191005).

Linda identified a need for greater consistency in certain areas:

‘As a team we need to be consistent with the residents. For example, with Dan I know that he can pack himself off to dress in pyjamas but he has a habit of putting dirty socks and underwear in the drawer. If we could teach a skill, we need to assist him proactively. If it happens on one day and not the next it goes astray. That’s the same for Franco and his mealtime etiquette. The issues with residents are more important [than domestic routines]. It’s this consistency thing where all staff try and keep it so that it happens the same. It doesn’t have to happen exactly the same, just to have that little bit of consistency where it happens nearly the same every day’ (I/LW/102605).

Some of the issues relating to Franco’s behaviour at mealtimes were explained to me one day.

‘Simon says that Franco will regurgitate his food after breakfast. He likes Franco to have very hot coffee as this slows down his drinking.

Dan was given a drink of coffee. I’m not sure that he drank it, but the cup was empty. It was positioned on the table to the side of the cork place-mat and Franco was near. My suspicion was that Franco drank Dan’s drink’ (F/PL/191005).

Giving people their food at mealtimes was a practice that I witnessed on a number of occasions.

‘Breakfast is “served” to people. People are given cereal. People are given a drink. People are given toast. Plates, mugs, and mats are taken away. The cork place mats are very shoddy. Some are curled up at the edge; another has a piece broken off at the corner. Shelagh loads the dish washer. She wipes the kitchen surface down. Dirty laundry is put in the machine. Shelagh remakes Wally’s bed.

Simon sits down with Wally and feeds him the cereal with a spoon. He says that he is doing this because Wally has not been eating his food. Franco pushes his cereal away. Simon stands by him and feeds him with a spoon.
He tells Franco to sit firmly. After being given three or four mouthfuls
Franco finishes the cereal by himself. Franco picks up Milan’s drink and I
intervene to stop him drinking it. Joseph is sitting at the end of the table.
His drink is on the mat in front of him. Shelagh comes over and asks him to
lift his drink up so she can take the mat away. She asks him again. She lifts
the drink up and takes the mat away herself’ (F/PL/021105).

The above descriptions of breakfast have some similarities and some differences
with the house supervisor’s aspirations for the house:

‘I’ve tried to introduce a laid back, relaxed atmosphere. At Kew it was
always hyper and rush, rush, rush. I take it from first thing in the morning,
the ability to sleep in and take your time. When it’s breakfast it’s not cereal,
toast and a cup of tea on the table all in one go. I like the fellas to have
their cereal, and then they have their toast, and then they have their cup of
tea. From the word go it’s just relax. It’s hard to put it in words. Every task
or activity, it’s just a matter of calming down and relaxing and taking our
time and that’s important for us to do that. To show that as well, rather
than rush around, yelling at the boys to get moving, but just to relax. I’ll
probably yell a bit about getting them to relax’ (I/SD/021105).

After breakfast, those who are going to the day programs are driven by a
member of staff.

‘We leave for the day programs at 08.45. Franco, Dan and Joseph are going
to the day centre this morning. They are helped to pick up their knapsacks,
which have their lunches in. These have been made by the night staff. Wally
comes along for the ride. Before we leave Simon gets Franco out of the bus,
and takes him inside the house. When they come outside again Franco
rushes to get in the bus, trying to squeeze past the seat, which needs to be
tipped forward, and then past Wally. In his hurry, Franco hits his head on
the doorway.

Dan sits in the front seat. I sit in the back next to Joseph. It takes us 20
minutes to drive to the first day program. Simon sees someone that he
recognises. After he has taken the men in, he talks to the acquaintance for
a while.

At 09.15 we arrive at Franco’s day program. Franco gets out of the bus and
his trousers and the seat are soaked in urine. Simon says, “I’m going to be
a little bit longer” and goes with Franco into the building. I suggest to Wally
that he moves into the bench seat in front to avoid the urine. He does. He
says, “piss the bed” a number of times. He makes an “eeee” sound a lot, and pulls his hand to his face. I don’t know what it means.

Simon comes out of the building 15 minutes later. He asks whether I want to stay in the front seat, but I stay with Wally in the back. We arrive back at the home at 09.45, a 60 minute round trip’ (F/PL/191005).

Once the bus has returned to the house there are domestic jobs to do. On this particular morning a number of the men were in the house. If no residents are home the jobs will still be done by the staff members.

‘It was time to do some housework. Clean the bathrooms and toilets and mop the kitchen/dining area and bedrooms. I offered to do the kitchen/dining area and bedrooms. I offered the broom to Milan, who was sitting in the lounge. He got up from his chair and went and stood in the corner of the room.

Joseph had pushed all the chairs to the side wall. Wally had taken himself to the middle lounge. Dan had come in from the garden. He seemed agitated, grinding his teeth and vocalizing. Joseph started to vacuum the carpet. Susan [staff] cleaned the toilets and bathrooms. I offered Milan the mop, but he walked away from me. He did this three times.

So, I mopped the kitchen and then went to Franco’s bedroom. When I came to Joseph’s bedroom I went to see if I could get him to mop his bedroom. He was sitting down on a chair, vacuuming the space in front of him. I gestured to him. I turned the vacuum off and had to pull him to his feet to show him what I wanted him to do. He took the mop and cleaned a third of his floor, and then did a bit outside of the bathrooms and front door’ (F/PL/041205).

There is a strong emphasis on keeping the house clean, which may or may not involve the residents. Keeping the house tidy was a goal that the staff group had set for themselves during the transition training (F/PL/210705). The house supervisor explains:

‘We need to make the home itself homely, clean and tidy, because the fellas haven’t got the capability of doing that or in one case Milan doesn’t want to be involved. We need to make sure that that’s done. That’s an expectation they have on us as well.

Franco’s actually really good. One of the things we’ve been able to find out with Franco is that he enjoys one-on-one and he will help if he can get that
one-on-one. He’ll do a lot of things. He’ll do a lot of tasks. He’ll help with the washing, we were getting there the other day about him pegging on. Milan just won’t do anything’ (I/SD/021105).

The supervisor has tried to encourage resident participation in household activities, and this has been taken on-board by some of the staff group.

‘Simon wants you to get them to do a little bit. I’ve seen Simon when he’s cooking. He’ll get the guys up and get them to do a little bit. I don’t know whether that happened so much at Kew. With a smaller group, you can do that. At Kew when you had eight residents, it doesn’t sound that much more, but it makes a big difference. You can do more. Like when we’ve gone shopping, they’ll carry the shopping in and Dan will put things in the fridge for you, just trying to get them to do a little bit more’ (I/JZ/141205).

However, resident participation as a principle has not been picked up by all staff and residents and when residents appear to choose not to be involved in household activities this creates a practice dilemma for staff.

‘As we arrive back in the bus Simon tells me that there are the chores to be done — laundry, cleaning the bathrooms and toilets, and mopping the floors. It seems that Martin has done most of this already whilst we were on the bus-run. Milan is sitting on the floor of the lounge, with his back against the window. His right leg is vertical and his right arm is resting on the bottom of his right foot. It is suggested that I could put the laundry away. Simon takes me to the laundry room where piles of clothes are neatly arranged. Simon picks up some items to show me the name tags. I am determined not to do this by myself, so I ask if Milan and Wally can put away their own laundry. He is happy for me to have a go. I lead Milan to the laundry and give him his pile of clothes, about three items. He walks off in the wrong direction from his bedroom, so I lead him to his bedroom. I support him in putting the items away. I do the same with Wally. Both seem content enough to be involved. I leave the other men’s laundry. My view is that this can be an activity that they could be involved in later. I see Martin put the laundry away later that morning.

I ask whether Wally’s bed needs making and whether he can help. Again, I am encouraged to give it a go. I am shown the linen cupboard. I am introduced to the “kylie”, which soaks up urine. Again Wally assists in the making of the bed without any complaint’ (F/PL/191005).
The fact that resident participation has not been incorporated into staff practice as a matter of routine, and the staff group feel pressure to complete other tasks, means that the residents are sometimes unoccupied and disengaged.

‘I had asked earlier what the plan for the morning would be, as Wally and Milan were at home. I got the impression that there may be a trip outside somewhere. This never happens. Wally is asleep on a chair in the middle lounge. Simon comes out of the office and rubs Wally’s leg and turns the radio on. Wally’s preferred choice of music is classical, he tells me, an influence of his mother. He says that Wally is comfortable in any area of the house. He will sit or sleep in any area of the house and go into other people’s bedrooms. This is not the case for all the other men. Simon spent most of the morning in the office. He apologised when it was time for me to go, saying that when he has been off for a few days there are usually a number of things that he needs to address’ (F/PL/191005).

In the absence of staff prompting people to engage in activities, some of the men find things to do for themselves.

‘At 09.30 Dan appeared with a basketball. He paused in the lounge, and looked around for someone to say that he could go out to the backyard. Linda [staff] told him that he could go. A little later Dan was jumping up and down in the backyard and grinding his teeth. It was very windy outside. He did not seem interested in shooting baskets. He seemed to want to get to the shed, so I opened the security gate and he walked over to the shed and touched the padlock. He did exactly the same about ten minutes later, so I fetched the key and opened the shed. There were some paint cans and some tiles in the shed. Dan peered inside and then shut the door’ (F/PL/041205).

Like many people’s lives, days are structured around set times for food and drink. Mid-morning is time for ‘morning coffee’.

‘At 10.45 Martin announces to the men that it is time for a drink. He has got them a glass of orange. He takes it into the backyard and puts it on the table. Milan goes outside but Wally does not. Outside a radio is playing, which is tuned in to a non-English speaking radio station. Martin fetches Wally, who drinks all but an inch of his orange juice’ (F/PL/191005).

This will be followed some time later by lunch, which tends to be less substantial than the evening meal. Time spent in the house may be broken if a trip is organised. This may be to supermarkets, cafes and restaurants, leisure pursuits,
or visits to other ‘Community Residential Units’ (F/PL/030206). Suffice to note here that the house supervisor sees such activities as important. He stated that, ‘Our role and responsibility is to ensure that the fellas are given every opportunity to experience what community life is all about, like you and I’ (I/SD/021105).

In general, the residents in the house have a significant amount of contact with family members, some more than others. One man receives a visit from his mother twice a week.

‘Mrs. Smith puts a towelling bib around Wally. She refers to herself as “Mummy” when she talks to her son. She sits at the table whilst he eats a sandwich. For most of the afternoon Wally and his mother are shut in his bedroom, where Wally sits on his bean bag. They listen to music’ (F/PL/021105).

In the absence of any trips out, the afternoon continues in a similar vein to the morning.

‘Joseph picks up a t-shirt of his that is on the back of the settee. Some laundry has been sorted out. Linda fetches a huge amount of laundry from outside and dumps it on the coffee table. ‘There’s a big pile for you to sort’, she says.

I try to get Milan to help me fold a doona cover. I give him two corners to hold. I go to pick up the other end, but he drops his end. I try twice more with the same outcome’ (F/PL/021105).

This can mean that there is little to occupy the residents.

‘There was very little interaction with Milan for the 50 minutes that I had been in the house. When I was sitting on the settee he reached out to grab my hand, which he raised to rub his head. I saw him do this gesture a few times during the day. Linda put some water in a blue plastic mug and put it on the dining table and told him it was there. Martin reminded him that it was there a little while later. Later, he stood up and waited in the toilet doorway. He was told to go to the toilet. Someone said, ‘He feels like he needs permission’. Wally is slumped over on a settee in the lounge. The TV is showing a children’s program’ (F/PL/261005).

The residents who are at day programs need to be picked up by the house staff.

‘Martin was nominated to do the ‘bus-run’, picking up four men from three different day programs. At 14.20 Martin told me it was time to go. In the bus Martin filled in details of the journey in a file. This has to be done on
every trip. It is part of the lease agreement and helps identify staff for speeding and parking fines... We got back to the house at just before 16.00, so the round trip had taken about 90 minutes. Simon and Linda joked with us that they were beginning to get worried and were going to send out a search party.

A ‘snack’ had been prepared for the men. Everyone sat at the dining table and they were given a plastic bowl with lollies, crisps, and cheese balls in. Dan pushed his bowl away, and he was offered a cereal bar. He took one bite of it and put it down on the table. Wally picked it up and put it in his bowl. Simon had stated that he was going to make ‘the boys’ a coffee. Linda gave one person an orange drink, which was then given to everyone’ (F/PL/101005).

Although there are a couple of tasks that might be done in the period before tea, it would be an exaggeration to suggest they are formal practices. Tea has to be cooked, which is usually served around six o’clock. There may be a few household jobs to finish. Franco may go for a walk. Other residents may amuse themselves.

‘I went into the garden, where Dan was playing with a ball and the basketball net. He would bounce the ball two or three times and then shoot. More often than not he would find the basket. I would have a go and throw the ball to him, which he would catch. After we had played basketball for about 5 minutes he hurled the ball over the rear garden fence into the garden next door. The fence is high, perhaps ten feet. He made an expansive gesture which seemed to indicate that we or I should go and get the ball’26 (F/PL/101005).

The idea that the residents can do what they want to in this period may reflect the attempt to instil a laid back, relaxed atmosphere in the house.

‘No effort was being made to engage the residents, so I went to see what they were up to. Franco grabbed me by the arm and took me into his bedroom. He opened the wardrobe door. We stood and I talk about his clothing. He started banging gently, rhythmically, on the wardrobe door. Joseph was in the corridor. He was making various gestures to me which seemed to indicate the various rooms. He rubbed his hair outside the

26 There are a number of interpretations here. One, that he had had enough playing and it was a way of signalling the end. Two, that it gets a reaction from a staff member. Thirdly, he gets to go out of the house and walk around to the neighbours.
bathroom. Later he went and had a look at a cupboard in the kitchen’
(F/PL/101005).

The staff take the lead in preparing the evening meal.

‘Michelle [staff] is in the kitchen preparing the tea. She is cutting up some
vegetables that she places in a roasting tin. They are to go with the
lasagne, which is a ready-made meal.

Richard [casual staff] had put the placemats on the table. He told me that
Milan had come and pushed them off, so he had collected them in a pile.

Franco was up near his bedroom. There were wet footprints on his bedroom
floor. Richard went and got Michelle and they confirmed that he had been
incontinent. Michelle pulled on some rubber gloves and together they
supported him in the shower.

With the tea nearly cooked I saw this as an opportunity to engage people in
laying the table. I managed to get Milan to put out the place mats. We did
this together, as he seemed reluctant to walk all the way around the table.
He would not put out the cutlery. I asked Michelle whether anyone had
special cutlery, and was told ‘No’. I could not persuade Milan to get the
cutlery. I tried with Joseph. First I asked him and then I gathered the knives
and forks and took them to him in the middle lounge, where he was sitting.
He made no effort to move, or respond to my promptings, so I left him and
put the cutlery out myself. As it turned out Joseph was not happy with a
knife and fork that he had been given and got up to fetch a spoon’
(F/PL/261005).

The house opened with a number of staff vacancies, which were not filled during
the period of participant observation. This meant that the house was making use
of casual employees. As with other meals, this evening meal is served to the
residents by the staff, both of whom were new to the house and the residents.

‘Michelle with a little bit of help from Richard served up the food. This was
put on the mats in front of people. The vegetables were chunky and the
lasagne was in a big slab. Milan seemed to be struggling to eat it so I cut up
his food and then did the same for Franco. I sat at the table with my back to
the kitchen where Richard and Michelle were. Richard and Michelle would
come and deliver a drink in a plastic mug. They would take something
away. If people were finished I prompted them to take their plate to the
kitchen, which they all did. Franco finished quickly and got up and walked
around. He patrolled the table. He used his hand to take some food from
Joseph’s plate. Later he took Joseph’s drink. His behaviour was ‘hawklike’, looking for an opportunity to take food or drink. When I saw this happening I said ‘No, that’s Joseph’s food’. Joseph is the slowest eater, which probably makes him more vulnerable to having his food taken’ (F/PL/261005).

Even with good procedures in place it is hard for casual staff to support the residents to the degree of consistency advocated by one of the staff in the earlier quotation. Linda talks about her own experiences of getting to know the residents.

‘I remember in the beginning I found the transition [from Kew] a little bit difficult with a different group of residents to work with. I found with the residents in the beginning that a lot of things were trial and error. For example, with their choices for breakfast, for drinks, what the guys like to eat, what they didn’t. With Franco at meal times with his regurgitating. Franco likes that one-on-one attention. He obviously needs a staff to sit with him at mealtimes to slow him down because he eats his meals very fast. It was trial and error. We learnt that the best time to give him his drink and reduce his regurgitation was to give it half an hour before meals or half and hour after meals and that would work. Little things like that were trial and error’ (I/LW/261005).

Unless the learning is passed on to everyone that works in the house, the same errors can be repeated endlessly.

‘Wally does not want to eat his food. Michelle makes him a vegemite sandwich and puts it in front of him. He eats half the sandwich.

Michelle and Richard are giving the medication out. This is put on a dessert spoon and then put in people’s mouth. Richard attempts to give Wally his tablets, but they end up on the floor. Michelle asks whether Wally knocked them with his arm. Richard says ‘Yes’. They are picked up from the floor and given. Soon after Wally slumps and is taken to lie down in his bedroom.

Michelle gives Franco Wally’s lasagne, which he eats’ (F/PL/261005).

It was not anticipated that moving to a new home would change resident behaviours that had been entrenched by the routines that they had experienced at Kew for so long. Getting changed for bed after tea was one such routine for some people.

‘After tea, just after seven o’clock Dan appears in blue checked pyjamas and “ugg-style” slippers. Richard turns on the TV. He had told me about the plane that landed at Tullamarine on a burst tyre. He thinks that I would be
interested in seeing it. There is a manual in the house that has mapped out an evening schedule for the days of the week. All the evening activities are listed as TV/music’ (F/PL/261005).

Looking to change some of these ‘fixed’ behaviours has been a conscious strategy for one of the night staff.

‘John, the night staff arrives at 07.45. John’s strategy to keep people out of bed is to delay supper as long as is reasonable, because he says that some people will go to bed immediately afterwards’ (F/PL/261005).

‘A couple of them you give them a drink and it’s as if they think that’s supper and they go to bed, especially Dan. What I’ve found, especially on the warmer days is that I would give them a drink of cordial, but it won’t be at supper, [which is] about nine thirty. I have to say to them, I’ll give you a drink, go and play basketball or whatever’ (I/JZ/141205).

I go to see what Franco is up to. As I approach he comes towards me and grabs both my arms by the wrist. He leads me into the shower. He leads me into his bedroom. We go back in the corridor. He holds me by one hand and circles around me. He leads me down the corridor by the other end of the house. Richard leaves at eight o’clock. He is coming back the following morning.

I look for Milan. He is in his bedroom. He is sitting naked on his bed. John says that if you leave him he will put on his pyjamas. Later he appears in pyjamas and a dressing gown. Milan is short, less that five foot. The sleeves on the dressing gown come beyond his arms’ (F/PL/261005).

It was during an evening shift that I witnessed the most concerted effort to get the residents to participate in a domestic activity.

‘Joseph, Dan, and Milan are going to day programs tomorrow. John has to support them to make their lunches. There is an array of things on the kitchen worktop. Brown bread, peanut butter, vegemite, individual cheese slices, cream cheese, a processed meat, two boxes of fruit type bars, butter. The three men, John, Michelle and I are crowded around the kitchen counter. Wally is in bed and Franco in another part of the house. John supports each person, one at a time, to make their lunch. Joseph actively chooses peanut butter and pushes away the processed meat that John holds out for him. Joseph puts a spatula in the peanut butter and puts it on the bread. John finishes spreading the peanut butter for him. He puts the cheese on the bread. John cuts the bread in half and wraps the sandwiches
in cling film, and places it in the lunch bag, with a drink box, yoghurt, and a fruit bar. John held up the two boxes and Joseph pointed to one box. The same process is repeated for Dan and Milan. Dan is directed to the fruit bar that would be easier to eat, as he has no teeth. When Milan is given the cheese slice to put on the bread he puts it in his mouth. ‘I knew that was going to happen’ laughs John. Franco appears in the kitchen and watches what people are doing.

The men put their lunch boxes in the fridge and then put away the food with support’ (F/PL/261005).

However, even participation in this task is not standard practice. John explains:

‘I think with me, at night I’ll forget sometimes. I do try to get them to make lunches, but sometimes I’ll sit down with them and we’ll have a coffee or a Milo and then I’ll forget about the lunches and it’s really too late. I’ll go ahead and make the drinks. I’ll forget. It’s getting out of those habits where you do more things for them. The guys I worked with at Kew, it was a lot easier to do it yourself because they’d make a mess. It’s just getting out of that routine. These guys are capable of doing a lot of things. It’s just getting into that mentality...’ (I/JZ/141205).

The final formal meal of the day is supper.

‘Supper is served around nine o’clock. Dan has been waiting at the dining table for some time. Franco takes my arm and places it on top of the biscuit container that is on the kitchen worktop. A packet of chocolate mint biscuits are on top of the container. Franco unscrews the top from the orange squash and starts to pour it. It needs diluting.

John makes Milo and offers the biscuit container around. Dan is the only one that is allowed another biscuit. Wally is encouraged to come out of his bedroom. He appears in underwear and a pyjama top, but only stays for a minute before returning to his bedroom.

Dan takes himself off to his bedroom immediately he has finished.

John explains that other people need to be ‘toileted’. Joseph is put on the toilet for about 15 minutes.

Michelle is in the office writing in the communication book. She should leave at half-past-nine, but leaves at ten-to-ten. I leave at ten o’clock. Everyone is in bed or on a toilet’ (F/PL/261005).
A decision was taken not to observe what happened on the active night shift. However, both night staff were interviewed.

### 3.5 Activities outside the house

As part of the research process a half-day meeting was held with seven staff members at the end of the period of participant observation. Four family members were invited to participate in this day, but none did. At the request of the house supervisor the focus of the meeting was ‘community activities’.

This section moves beyond the earlier descriptive style and makes links between our fieldnotes and research findings from similar settings and theoretical work. This is because the meeting was used to discuss how things were in the house, so that staff could reflect upon their observed practice in order to change it (that is, action research). This section puts down in writing the analysis and interpretations that came out of the meeting.

The house supervisors topic of ‘community activities’ is related to goal number two in the State Disability Plan, *Building Inclusive Communities*\(^27\) (State Government of Victoria, 2002) and the fifth Disability Standard, *Participation and Integration* (Department of Human Services, 2002), where ‘Each client is supported and encouraged to participate and be involved in the life of the community’ (p.7).

Getting involved in community activities is something that the house supervisor has encouraged and personally enjoys supporting:

> ‘We took Dan, Joseph and Milan to Fasta Pasta, which is quite simple for most of us. However they have never been, or once or twice have been to restaurants. It was about them handing over the money and picking their ice cream and seeing the grin of excitement of Dan when he paid over his money and wandered back. He just had a grin from ear-to-ear, although he had no understanding or knowledge of what the money was all about. All he was concerned about was his cup of ice-cream he had in front of him, and he really enjoyed that. [It’s about] taking the boys out into the community

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\(^27\) This goal is explained in the following way: To strengthen the Victorian community so that it is more welcoming and accessible, so that people with a disability can fully and equally participate in the life of the Victorian community. Building inclusive communities means strengthening communities so that people with a disability have the same opportunities as all other citizens of Victoria to participate in the life of the community – socially, economically, culturally, politically and spiritually (State Government of Victoria, 2002).
so that they can have a walk around and not feel intimidated, not feel isolated’ (I/SD/021105).

As part of the orientation to their work in the house the staff group received two training sessions to support this goal and standard. The first during the transition training on social inclusion and a one-day workshop Developing Community Connections at a Local Level (Scope (Vic) Ltd., 2005) after the house had been open for three months.

At the half-day meeting the staff group described the pattern of ‘community activities’ that they had supported in the first six months. Table 1 groups these activities into rough clusters.

| Table 1: Activities outside the house as community presence (F/PL/030206) |
|---------------------------------|---------------------------------|-----------------|-----------------|
| **Bus trips**                   | **Walking from the house**      | **Community services** | **Shopping**    |
| The beach at Ocean Grove        | Walks around the block          | GP               | Safeway          |
| The airport                     | Arthur’s creek                   | Dentist          | K-Mart – clothes shopping |
| Phillip Island                  |                                 | Hairdresser       | Shoe shopping    |
| Healesville                     |                                 | People have also been on the tram | Christmas shopping |
| City (Federation Square)        |                                 |                  | Clothes shopping |
| Walking                         |                                 |                  |                  |
| Cinema                          |                                 |                  |                  |
| Dining out (Cafés, McDonalds, takeaway, Fasta Pasta, Smorgy’s) |                  |                  |                  |
| Barbeques                       |                                 |                  |                  |
| Christmas lights                 |                                 |                  |                  |
| Community Residential Services (CRS) Christmas party |                  |                  |                  |
| DHS office                       |                                 |                  |                  |
| Visits to other CRUs and residents and friends |                  |                  |                  |
|                                 |                                 |                  |                  |

Although the end goals of building inclusive communities, participation, integration, social inclusion or developing community connections are related to one another, they are not all the same. It would seem to us that people were not making distinctions between these terms, but tended to see them as
Chapter 3: 64 Penny Lane

interchangeable and to refer to the types of activities they were supporting and wished to do more of.

The distinction made by O’Brien (1987) between Community Presence and Community Participation is helpful in directing staff to two facets of an inclusive community and is a useful analytic framework that allows us to see what type of activities the staff group are supporting outside the house.

Community Presence refers to the sharing of ordinary places, rather than the use of segregated facilities. O’Brien (1987) argued that people should be supported to increase the number and variety of ordinary places that a person knows and can access. In addition, many disabled people usually have small social networks, which are typically made up of other clients, staff, and immediate family members. The aim of Community Participation is to expand these networks to include non-disabled people, so that they experience being part of a growing network of personal relationships that includes close friends.

It would appear that at 64 Penny Lane the focus has been on increasing the number and variety of ordinary places that the residents know and access. It is probably fair to say that the residents have greater community presence since moving to their new home. The extract that follows, of an outing to a nearby shopping mall, is a good example of how the staff have increased the residents’ presence in the community. The residents are using ordinary services and for some it has increased their type of experiences.

‘We are going out. It is a hot day. The top temperature is forecast to be 31 degrees. Simon changes some of the men’s clothes. Milan is wearing blue shorts, a blue and green diadora t-shirt, white Nike pumps and white socks. Wally is wearing a pastel green short sleeved shirt, putty-coloured shorts, blue and white trainers and socks. Dan has a Slazenger t-shirt which has cranberry, black, and white stripes, blue jeans and brown boots with three Velcro fasteners’ (F/PL/021105).

The house supervisor places a strong emphasis on making sure that the residents are dressed in a manner that is valued by other people in the community when they go out.

‘The presentation of the residents flows on to everything we do. There are times where you can be a little bit relaxed, once the fellas are active in the community. Whether at the day program or going out to have a coffee

28 This is consistent with guidance given in the Direct Care Staff Handbook (Department of Human Services, 2002).
around the corner it’s all about their presentation and about their grooming. I think that’s important to us as carers because that says if we take a little bit of extra time and care about the individual’s grooming we care about them. That’s been one of the things that I’ve been focused on. We still haven’t got it right but we’re getting there. I think it’s important to make sure that we do that because when an individual goes into the community and they’re not well dressed they could be standing next to somebody who looks just the same as them but because they have a disability that’s honed in on very quickly. This is my view and people look at them and say, ‘Look how shabby they are’. That’s how I look at things, we have to be quite conservative about how our residents dress’ (I/SD/021105).

‘Shelagh carries some money for the men — $5.00 each. The seven of us set out from the house at about 11.30. Shelagh walks in front holding Milan’s hand. Simon suggests that I go in the middle as he is walking with Dan, who is the slowest. Wally walks by himself. Joseph wants to hold my hand. I let him do this some of the way, but as I have seen him walk around the block on his own earlier I know that he can walk on his own.

We turn left into High Street. At the pace we are walking it would be at least 30 minutes to the bus stop. After ten minutes Simon decides we will catch the tram, which will take us to the Woodhouse shopping centre. It is very hot in the full sun. None of us have any sun cream on or sunglasses. No one has a hat. We cross the busy High Street. This takes quite a while to do as there is no pedestrian crossing. The road up to the tram stop is steep. Twice on the journey Milan sits down on the pavement.

After another ten minutes we near the tram stop. We miss a tram by a minute, which means that we have ten minutes to wait for the next one. There is a shelter that we can sit in. The tram is busy when it arrives. We do not need to purchase tickets. A man gets up for the residents and goes to the other end of the tram. Simon sits with three of the men. Milan sits next to a man who greets him and opposite two other people. Shelagh stands up. When someone moves Shelagh sits opposite Milan and the man and woman talk to her.

When we get to the shopping centre we are taken to a café/juice bar. The four men are seated around a table and Simon and Shelagh go to the counter. They come back with four identical drinks (orange-based drink) and doughnuts. I go and order my drink.
The seating area is quite tight, so Shelagh sits at a different table. Joseph clutches his trousers in the groin area. I confirm with Shelagh that this is his sign for wanting to go to the toilet. I take him to the toilet. We end up in the parent and child/disabled toilet.

Linda, who is working later that afternoon, passes the table where we are sitting and talks to Shelagh. Shelagh goes and buys herself a sandwich.

Simon and Milan go into the supermarket and come out with the trolley containing half-a-dozen plastic bags, containing mainly milk and bread. People are given a bag to carry. Milan refuses.

We go into K-Mart. Wally and later Dan take it in turn to push the trolley. The seven of us head off to the men’s shoe department. Simon wants to buy Dan some shoes. After trying on some shoes we head off to the clothes. A number of items are put in the trolley, but I have no idea who they are for. They are mainly t-shirts and shorts. The four men are not closely involved in any decisions about what to buy. Joseph gestures at all the clothes as we pass them in the aisle. Caps are placed on Dan’s head. Shelagh and Simon debate whether a Holden or Jim Beam logo is preferable. Neither of these caps is eventually chosen. Hats are placed on Milan’s head, but he takes them off and pulls a face. He does not like wearing hats. Wally wanders off several times and people raise their voice to get him to come back.

In the queue at the checkout Simon pays for the items in the trolley. Wally has wandered out of the store and is making his way onto the pavement. I hurry to him as he wanders out into the car park’ (F/PL/021105).

In an interview that I subsequently conducted with Simon, he commented on some of the interactions that he’d had during the outing, which indicate some of the attitudes of the general public that the staff encounter:

'It was interesting today that one of our senior citizens was next to Shelagh and when she got up and went into the shop she said something like, “You’re wonderful” and “God love you” or something like that. When I was at the check-out going through the young girl said, “It must be a rewarding job”. You don’t often get that. On the tram, as we were getting in, Joseph balanced himself and put his arm on another fella. I was quite surprised. The fella would have been in his mid-fifties. He got up for Joseph and I said, “Thanks”. There was enough room to sit down. “No, no, no, I’ll go down the other end” he said. So he got as far away from them as possible. He was
right down the other end of the tram. Those sorts of things you experience’ (I/SD/021105).

Simon has decided that we are all going to get taxis back to the house as Wally’s mother is arriving at about 13.00. She has been given her own key to get into the house. We wait by two bench chairs for the taxis to come. The men are sitting on the chair, next to an older man and woman’ (F/PL/021105).

Drawing out the differences between the different end goals of some of the social inclusion buzz-words is an important task. An emphasis on creating community presence alone is unlikely to achieve the goal of building inclusive communities; it will require staff to supplement this aspect of their work with supporting community participation.

3.6 Final words

It is always hard to anticipate how a piece of writing like this will be received. My aim has been to record how things appeared to me at 64 Penny Lane as a means to assisting the development of better practices there. The paper is one tool that the staff group can use as a learning aid.

March 6th 2006
Chapter 4: 16 Temple Court: A description

By Kelley Johnson

4.1 Introduction

This paper addresses some of the key questions outlined by the Department of Human Services in the original tender document for this project (Victorian Department of Human Services, 2004). It provides a description of the house and the people who live and work there and focuses on observations which I made of life both at the house and to a lesser extent, at two day programs which were attended by four of the men. The address of the house and the names of people living and working there have been changed to protect people’s identity.

4.2 Aims and structure

The paper is available for staff at the house to use as a basis for discussion of practice and it is also designed to raise some issues which go beyond a particular house to more structural issues. The latter is taken up in more detail in a paper, Making Life Good in the Community: The case for moving upstream.

The paper begins with a description of the home in which five men with intellectual disabilities live. It then provides a description of the lives of the men living in the house taken from fieldnotes over a six-week period. The fieldnotes were all written within 48 hours of the participant observation on nine different days. The time spent in the house at each visit varied from two hours to twelve. A partial night shift was completed (from 7.15 pm to 2.00 am). During the participant observation I visited the house on different days in order to have contact with a range of staff and be present at different times in the day.

The staff team at 16 Temple Court made the following points about the description:

‘The overall tone of the paper was critical rather than accentuating the positive features of the life in the house’. One staff member wrote, ‘Every word spoken by the staff was repeated in the document without any true regarding as to the manner that words were actually meant for, e.g. “even in jest”. It therefore appeared that it was deliberately intended that these words should be taken out of context in a negative sense. It also appeared that every positive word or action was not documented giving an overall negative impression of the house. It is not usual practice to wheel the residents away from the television if they are thought to be watching it. The staff make a judgement about whether residents are watching the television, how loud the volume should be, whether a person wants to go to bed, or undertake another activity, etc. The report does not accurately reflect the degree of consideration shown by the staff team in this matter. The residents are supported to go out from the house as much as is possible. The sentence that states, “...it was also clear that these men spent a lot of time at home” suggests that the residents spend more time at home than they actually do.’

As with the other papers in this series, this one is written largely in first person. It draws on fieldnotes which I took in a period of observation at Temple Court between late January and mid March 2006. The paper also draws on fieldnotes taken by Tim Clement both before I began work at Temple Court and after I left Australia to take up an overseas position.

Chapter 5 of this report.
three occasions I spent a whole shift at the house. On two days I accompanied the men to day programs and returned home with them at the end of the day. All staff in the house had access to the fieldnotes that were written when they were on a shift which they shared with me. Staff who were not present on a particular day did not have access to the fieldnotes. The fieldnotes and a written paper on which this one is based were used as background and points for reflection at a half day workshop with the staff.

The paper is divided into two parts. The first provides a description of life in the house for the five men based on fieldnotes. The second part provides an account of some of the experiences the men had outside their home.

Using participant observation is a rich way of recording observations. Observation without participation can lead to judgements by the researcher ‘about the work’ without really understanding some of the underlying experiences and issues which practice may raise. By becoming involved in the life of the house, I became much more aware of the pressures and issues that arose both for the men living there and the staff working with them. This paper at times reflects these experiences. The paper is not meant to be judgemental of staff and people living at the house. Rather it should be seen as a way of understanding some of the complex issues and culture that develop in a particular house where both the men living there and the staff have formed unique ways of interacting. It is not possible in fieldnotes to capture an entire experience. However over time detailed fieldnotes can provide rich accounts which reveal themes and consistencies as well as changes in the situation.

4.3 The setting

Before moving to 16 Temple Court in 2005 the five men who now live there had spent most of their lives at Kew Residential Services. Health issues are an important theme in the work of the house. Four of the men use wheelchairs although two of them can walk very short distances with support. Three of the men are subject to epileptic seizures. These can be severe for two of them and one has frequent milder ones. One of the other men in the house has Parkinson’s disease and also suffers from asthma. There is an active night staff member on duty at the house.

Four of the men attend two different day programs on a part-time basis. Plans were made for the fifth man to also attend a day program but illness prevented this from happening. The men range in age from 37 to 74 with most of them
being in their fifties. When the residents are not at day programs there are usually two and sometimes three staff in the house.

16 Temple Court is set in a quiet residential street. It is a substantial brick house that has been newly built.

‘Like many of the houses [built as community residential units] it stands out from its neighbours because of its size, the large van parked in the drive way and the raw newness of the front garden. The instant turf which was planted has now died back (to the frustration of some of the staff members in the house) and the shrubs are still very small. Temple Court is a pleasant winding street lined with well-established houses. The house has been open for about four months’ (Fieldnotes, 23 January).

(See end note 4)

The street is some distance from main roads and there are no shops, community facilities or churches within walking distance of the house. In fact I drove for some time in search of a place where staff could meet for a workshop. There is a neighbourhood house within a ten minute drive of the house in one direction and suburban shopping centres about the same distance away in the other. Across the road and down from Temple Court a little way is a small park with some children’s play equipment. It is quite run down and though it could provide a central place for neighbours to meet or for the men to sit, at the moment it is not particularly pleasant. The streets around the house are quite hilly making it difficult to push wheelchairs or to go for a walk of any distance.

There has been little contact with the neighbours, although several called in when the house had an afternoon tea. On one side of the house is a plumber who seems to work partly from home. This means that his trucks are often parked in the narrow street making it difficult for staff to back the large bus in and out of the driveway. No one has felt able to raise this issue with the neighbours. Two staff commented that the neighbours do not speak to them at all.

‘Penny and Ray said there was no contact with the neighbours. There seems to be a plumber next door working partly from home by the banging noises. Ray said one of the neighbours had said hello. Penny said one had ignored her greeting. Both said they thought that the neighbours believed their house values would go down because the men were living in the neighbourhood’ (Fieldnotes, 23 January).

When I commenced working at the house, it had been open for four and a half months. It has now been open for almost eight months.
4.4 Interactions and styles of support in the house: A day in the life

This section of the paper draws heavily on my fieldnotes but also uses interpretation of them to provide an account of some of the day’s routines and activities for each of the men. I have tried to focus on what happened for each man as their needs and their activities were quite different during the day.

Beginning the day:

I arrived for my first field visit at seven in the morning which is when the day staff begin a shift.

‘None of the men in the house were up and I gradually met them as they came in for breakfast. Penny and Ray were sitting at the table with Trevor (night staff) having a cup of coffee. Penny remembered me from my previous visit. I was offered a cup of coffee and sat with them for twenty minutes until Trevor left. It was good to have been in the house before and good to know at least one person on the staff. I think it would have been harder to have arrived without knowing anyone’ (Fieldnotes, 23 January).

It must be quite difficult for casual staff coming into a new house, particularly if they are only filling in an emergency role. I was conscious of not knowing the staff, all of whom knew each other, nor the men living in the house. But more than this I was unfamiliar with the house culture and routines. It took time to learn these.

During the week there is considerable pressure on the day staff to organise showers, dressing and breakfast before the bus leaves for the day programs at 8.45. When the men are going to day programs their lunches are prepared the night before by the night staff. This makes the mornings easier but means that the men are not involved in any way in the lunch preparation. A decision had been made that two of the men would shower in the mornings and the others at night to make the mornings a little easier.

Mathew in particular takes a long time to shower as he is a large man with only limited movement.

‘It was then Mathew’s turn. Mathew was on the commode in the toilet and was showered in the bathroom on the commode. He is a big man and quite heavy but was easier to shower than Michael. He really seemed to enjoy the shower, particularly having a good head massage with the helmet off. We talked about the helmet and Elizabeth said staff thought he had to wear it. But she knew that he hated it. She said she always gives him a very good
head massage in the mornings. After his shower we dried Mathew still sitting down. We had forgotten to shave him and it did prove difficult to do this after the shower. We did the best we could. Mathew was dressed as far as possible sitting down. Elizabeth then wheeled him to a rail and he stood with his hands on it as she pulled up his underpants, and shorts over the nappy. Putting on shoes and socks was quite difficult as Mathew is not able to help. He seemed really relaxed and enjoyed the fuss and our struggle with the socks and shoes. He gave us broad smiles and seemed very alert compared with later in the day. Elizabeth was getting worried about time. Again she chose Mathew’s clothes and rejected one T-shirt in favour of another. I noticed later at the day program that David was wearing Shane’s shorts which were very loose on him.

Elizabeth said there wasn’t time to allow Mathew to walk down to breakfast so she wheeled him down in the wheelchair.

Mathew seemed happier and more relaxed in the shower than I had seen him elsewhere at the house. He can walk for short distances but needs support to do so. The main opportunity he seems to have for a walk during the day is from the shower to the kitchen. Often because of time, he uses the wheelchair, as in this instance. Mathew wears a helmet which is put on immediately after his shower. Staff are anxious that if he has a seizure he may injure himself. There are different views about the need for the helmet and Mathew seems to be relieved and more relaxed when he is not wearing it’ (Fieldnotes, 23 February).

Michael too takes a long time to shower as he is not very mobile.

Shane who is young and active gets up quite early and comes into the living area to wait for his breakfast. He is always thirsty or wanting a drink. This is a concern to staff as they are afraid that he will drink hot liquids. He is barred from the kitchen of the house although he clearly wants to be there. The electric jug is always emptied and put away after use in the kitchen and Shane does not know how to open the refrigerator. He is, however, very persistent in seeking a drink.

‘Shane was the first up and came into the living area. He was very restless and walked around the living area, he was seeking a drink. He sat down and immediately began pulling at his shirt. The string he always plays with was missing and there was a search for it. Penny found it in the laundry. It was attached to his T-shirt and he immediately began to play with it. He was clearly very concerned about having a drink. It seems to be both an
obsession and a desperate need. He watches everything that looks like it might be leading to a drink, people in the kitchen, anything that looks like it might hold liquid is of keen interest. Penny went to wake the other men and Elizabeth and I were together in the living area. Shane walked into the kitchen heading for the breakfast dishes and the sink. Elizabeth tried to stop him as he was walking past the dining room table and he pushed her out of the way walking determinedly into the kitchen. She caught at his T-shirt and tried to stop him. I stood in front of the dishes and Elizabeth, unable to stop Shane’s movement, called for Penny. She came and took him by the arm and told him to sit down. He went with her immediately back into the living area and sat on the couch’ (Fieldnotes, 26 January 2006).

David often has his shower at night, and is woken, as is Michael a little later. Charles, because he does not go to day programs, has a little longer in bed although all the men breakfast together.

Breakfast can be a time consuming activity. All of the plates of cereal are organised by the staff member not involved in supporting the men in the showers. The bowls are placed in front of the men on the table. The tablecloth is usually removed for meals. All of the men wear bibs for breakfast although David always takes his off immediately. Mathew needs support to eat, his head in its helmet tips forward and staff feed him with a little difficulty. Michael takes a very long time to have breakfast. He is given a spoonful and holds it for a long time before being ready for the next. Staff commented that this is in part because he has problems with swallowing.

David is blind and requires some help with meals but he can eat his toast alone if it is placed in his hand.

‘Meena said that David could once feed himself but had for some years refused to do it. He simply puts his hand behind his back if asked. She said people lost skills very quickly if they didn’t use them. As usual David ate neatly. He had been very vocal this morning with lots of humming noises and twisting of his head as he waited for breakfast. Meena gave him some bread and jam and he ate that himself’ (Fieldnotes, 26 January).

Shane eats very quickly and staff try to slow him by feeding him. If he eats alone then much of the food falls off the spoon onto his bib or clothes. Both Tim and I have wondered if a more suitable bowl and spoon could be provided for him to make it easier to scoop his food from the plate.
Charles is able to eat and drink independently and usually sits at the head of the table.

After breakfast the men are wheeled in their chairs in front of the TV which is usually on (sometimes without sound). Mathew sits in a big chair, usually curled in a ball with his knees under his chin and his T-shirt pulled down over them. His head rests on his knees. The other men do not seem to be engaged in watching the TV. Shane sits on the couch or wanders around the living area playing endlessly with the cord attached to his jacket.

At this time lunches are packed into bags and changes of clothing are included for those men who are going to day programs. When they do not go, the time is used to clean the house and to clear up after breakfast.

**Going to the day programs**

When four of the men are going to day programs, getting there is both time consuming and complex. Three men are lined up in their wheelchairs at the front door. The house van is quite large and all staff talked about the difficulties of ‘parking it’, particularly in the city, ‘backing it out of the drive’ particularly when the neighbours are parked opposite, and ‘filling it with petrol’ which is often left to Ray, the one man on regular day duty in the house. The wheelchairs are lifted on to the van by a lift and then locked into place. Staff at the house are now skilled at this but it takes time. Shane gets on to the bus alone and sits in one of the chairs in the back. Usually only one staff member takes the men to the day program. On my first day at Temple Court two men went to the day programs.

‘Shane and David sat in the back of the van in wheelchairs. It was not possible to sit with them as there were no chairs so I sat in the front with Ray. The drive to the first day program took about 10-15 minutes and we got there just after 9 o’clock. Penny and Ray commented that the people at the day centre did not seem to like working with Shane as he was very active and liked moving around a lot. He had two changes of clothes with him and Ray said that if he didn’t like what was happening he peed. Shane got out of the bus with no seeming reluctance and went into the day program. He disappeared down the passage with a staff member whom we had met on the way in. I had said that I would like to visit the day program with him and was introduced to Mark who said that would be fine. We decided I would come on the 7th of February. He said that they were doing some ceramics and were hoping that Shane would like this. Talking with Ray in the van he said that staff in the house did not know what happened in the
day program. There were no opportunities to visit with the men’ (Fieldnotes, 23 January).

This lack of connection between the day programs and the house became a strong theme during the field work, in part because I later spent two days at the different programs. Two staff commented that it would be good to know what happened during the day and similar remarks were made by the day program staff who said it was frustrating not to know if the things the men were doing at the day programs were carried over into their lives at home. There were no regular communications between the two groups of staff and each time we dropped someone off there was a sense of rush and busyness as the day program staff began the day.

Shane attends a different day program to David, Michael and Mathew. He is usually dropped off first and then the van continues to the second day program which is about a further fifteen minute drive. It takes about an hour to drop people at the day programs and return to the house. They have now begun to organise a network with other houses so that people are picked up and taken to the day program by staff at one house, while staff at another house do an alternate trip. Staff tended to see these trips as making it difficult to do things during the day with the other men. The van needs to leave to pick the men up by about two o’clock in the afternoon. However there is at least a four-hour period in the morning and into the early afternoon where other activities are possible.

**Back at the house**

The period of time after breakfast and when the men have gone to day programs is when housework and washing are done. The washing is a constant process with several loads a day being washed, hung out and retrieved. Organising lunches for the men not going to day programs is then commenced and sometimes preparations for dinner are made. While these activities are underway the men are generally sitting in the living area in front of the TV.

‘I left the program and Elizabeth and I returned home. Meena had tidied up and we had a cup of coffee together while they read the notes I had made last week. Both thought they were accurate. Meena and I talked about the toileting issues. They did not suggest any other possible actions that we might undertake.

After this I suggested that Michael and I go outside for a little. Meena said she thought we should take Mathew and Michael out to lunch as she needed to do some shopping. Michael and I went out into the garden and looked at
the plants. Elizabeth joined us and told us the names of some of the plants and their characteristics. Meena came out too and we looked at some of the trees that are self-seeding. I showed Michael the lavender. He watches everything that goes on around him but makes no active movement in the world. There were one or two ripe tomatoes on some bushes. Two were no good but one was perfect. Elizabeth picked it, showed it to Michael and put it on his knee to take inside’ (Fieldnotes, 31 January).

On one occasion Elizabeth and I went for a walk with Shane and Michael to the small park further down Temple Court. However there was little use made by the men and the staff of the surrounding neighbourhood on a regular basis. Sometimes one staff member and one of the men sat outside on the patio and this was often used for lunches where staff and residents sat together with staff eating their lunches after the men had finished.

‘Shane and David were at day programs and Mathew, David and Charles were sitting outside on the patio with Penny and Simon. Simon works on the night shift but does one day shift to make up hours. I sat down and Maria joined us. There was some discussion about Charles and his health. He hadn’t eaten much lunch but had enjoyed a large doughnut earlier in the day. He looks very frail and Maria commented that he had lost nine kilos since his illness. Staff all agreed that he was settling back home well’ (Fieldnotes, February 9th).

Although the men were physically present at the table the conversation between staff went on around them. Sometimes a comment was made directly to one of them, particularly Charles. Sometimes there was a physical interaction, a head massage for Mathew, a gentle touch on Michael’s hand or a mock boxing match with Charles.

There were difficulties which I encountered in going out spontaneously. Going for a walk with Michael in the wheelchair was tiring in the heat of summer and was restricted to a walk through residential streets. My first day at the house Michael and I went out.

‘Michael and I went for a walk around the block. As we went I talked a little about the flowers and showed him the agapanthus. He looked around at the houses and the street and after the first few minutes stopped chewing his fingers. It was warm and although the wheelchair was easy to push I got quite hot. Half way round I realised that I did not have a mobile phone or the phone number for the house. Anxiety about Michael having a possible
seizure led me to speed up the walk. Although the area we walked in was quite flat a lot of the streets are hilly. It would be difficult to push a wheelchair round these streets.

Ray said that he sometimes takes Shane to a nearby park but I didn't see it on our walk. By the time I got back I was quite tired and Michael seemed a little sleepy too. As we rejoined the others on the veranda his eyes started to droop. Penny wheeled him into the house for a sleep. I said goodbye to him. Mathew also went for a rest’ (Fieldnotes, 23 January).

These fieldnotes reveal both how difficult it could be to physically go out without the van but also how quickly the anxieties about the men’s health had been transmitted to me.

There was no choice in the meals offered to the men and lunch was eaten either in the dining area or on the patio. Penny commented that the men really liked pumpkin soup and she provided this on several occasions while I was at the house. By early afternoon there was usually a very homely smell of the evening meal being cooked. Penny, when on duty, was usually the cook and clearly enjoyed this part of the job. She said that the meals had to be cooked for a long time because they needed to be soft so that the men could eat them. She felt this made it more difficult to go out in the afternoons.

After lunch, as stated in the fieldnotes, some of the men had a rest. Michael often was awake during the night and sometimes became tired. It is difficult to know whether the men actually slept but they did spend some time (sometimes an hour or two) in bed.

After the day programs

When the men returned from the day programs they usually went to the toilet, had a drink and then sat in front of the TV until dinner. Sometimes they sat outside on the patio with a staff member. Mealtimes dominated the life of the house, in part because it took a long time for everyone to eat. Staff also used the time before dinner to talk together and make arrangements for the rest of the day.

Shane was often restless at this time and wandered around the house. A staff member would follow him if he went out of the living area although there seemed to be nothing that he did in the rest of the house that might cause anxiety. On one occasion Maria discussed Shane’s behaviour on the afternoon before:
‘I talked a little about Shane’s day at day program. Maria said after I left he had gone outside and stripped off and “done a dirty thing” near the window of the house. She was concerned that the neighbours might see. Although there are high fences around the garden she said that she had seen a neighbour on a nearby roof a few weeks ago and they might see in by accident. I asked what she had done and she said she had sent Shane to his room as that is where he should do things like that. I said that Shane may not understand the connection here.’

(Fieldnotes, February 9th).

**Dinner**

Dinner happens early at Temple Court. It is finished by the time the night staff arrive; it takes quite a time as the men need support with eating and perhaps it is also early to break the long afternoon. It may also be that the men (and the staff) are used to early eating. Eating a little later however might make it easier to do things in the afternoons.

‘By twenty to six dinner was ready. Penny served it in bowls and the men came to the table. I supported Shane to eat his dinner which he did very quickly. I made a mistake by putting David’s bowl in front of Mathew. Ray started to give him his dinner and Penny quickly said that he couldn’t eat un-vitamised food. Ray commented that he had given him an ice cream sweet the day before and he had managed it. But because of the way he held his head down it was risky and the food might go into his lungs. David and Mathew’s bowls were exchanged. I supported David to eat his dinner. He eats delicately but ate all of the food on his plate. He hums and so I sing along with him. He also turns his head repeatedly and waves his hand in circles. I totally forgot to give Shane his drink which I felt badly about because he craves it so much. Ray gave him this and I gave David his. He manages a cup very well and so does Shane. But we still provide support.’

(Fieldnotes, January 30th).

**Evening at Temple Court**

After dinner there is a tidy-up and sometimes more washing is hung out or brought in. The men are wheeled in front of the TV again for a little while. The night staff member arrives at between 7.30 and 7.45 and there is a handover time. The night shift staff prepare supper of biscuits and a drink.

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32 On two other occasions Tim and I observed Shane masturbating in the house. On both occasions he was left for some time before being sent to his room.
‘At about quarter to nine Simon made supper for everyone. He put three biscuits on plates and made milky tea. Shane went over to the kitchen and watched the preparation with great interest. Meena asked me to put the electric kettle away in the cupboard under the sink in case he grabbed it. Michael had jellied Milo which Meena supported him to eat. It took him a long time and Meena said he was very slow today. She sat patiently on the arm of the chair holding the Milo and a spoon while Michael looked around him then gradually let the drink slide down. He opened his mouth when ready for the next spoonful. Mathew had emerged from the bathroom for his supper. Charles ate all the biscuits and Meena said he seemed very hungry. He drank all of the Sustagen quietly by himself. Shane ate the biscuits and then gulped his tea. When Charles's tea was left on the table for one minute he grabbed that too and drank it. I moved to save it but he is very fast. David refused to eat or drink anything, vocalising and holding his head in his hands. At this point David, Shane and Charles were sitting at the table’ (Fieldnotes, February 22).

On the night that I shared the shift, the men sat for a time in front of the TV after supper. There seems to be an acceptance by staff that they do not watch it as they are often ‘wheeled away’ in the middle of a program. However they still sit facing it as if there is an expectation that they are watching.

‘As I sat with Shane the other men gradually went to bed. It did not take Simon long to do this. The program which had been on the TV was not finished as they were wheeled away and I wondered whether any of them had been watching it and what it meant to be taken away before it ended’ (Fieldnotes, February 22nd).

The night shift is quiet the night I spent at the house. After the men go to bed, Simon works on the communication book and checks the men every half hour. He is anxious about doing this as each time he goes into Charles’ room he wakes. He expressed his concern about this issue in a staff meeting earlier in the month.

‘Simon said he was concerned that he had to make an hourly check on the men who were subject to seizures and this was okay with Michael who was a heavy sleeper. However Charles was a light sleeper and each time Simon checked him Charles jerked awake. He had tried leaving the door a little open but Charles still woke. He wondered if a baby alert system could be used so that if there was a change in breathing he would know without having to disturb Charles. Meena did not think this would work as Charles would still have to be checked every hour. She also thought that the device
did not record just breathing but only noises like someone getting out of bed or being distressed. Simon said he had used it for his children and you could hear them breathing. Meena said maybe he could bring in the machine and they could try it out. Simon said he no longer had it as his children were now older. No one else could think of a way around this. There was also a discussion that such an intercom if used for one person should then be used for others and it would become very expensive. Maria suggested a window in the door.

Penny said she had been anxious the other day when she went into Charles's room and he was lying there very still with his eyes open. She was afraid he was dead’ (Fieldnotes, February 9th).

Charles was present throughout this discussion. There was no resolution of the issue about disturbing the men during the night and on the night I was with Simon he remained concerned about it.

Night shift brought out the anxieties about the men’s health very clearly. This was an issue which emerged in many different contexts throughout my time at the house. Both night shift staff expressed anxiety about managing health crises when they were alone at night. Trevor had experienced a difficult situation when Charles became very ill. Simon and I discussed the issues around health during the hours we spent together after the men had gone to bed.

‘We talked about night shift. He said it was quite stressful and not many staff wanted to do it. If someone had a seizure he would wait for a minute or so and if it seemed to be getting worse, would call the ambulance and the on-call person within the Department. The on-call person could not offer assistance but reported to the cluster manager the next day that he had phoned in. He said that when the ambulance came to see Michael during a seizure they had wanted him to go in the ambulance with him to the hospital. He told them this was impossible as he couldn’t leave the four other men. He was happy to answer any questions they had but couldn’t leave the house. He told them that Michael had been admitted before and that his records were at the hospital. If Michael had a seizure during the day a member of staff went with him in the ambulance. I wondered what this meant to Michael if he came around with complete strangers in a new place. He said that if Michael was okay after being admitted at night then he would come home in the ambulance the next day’ (Fieldnotes, 9th February).
Breaks in routine

This account provides a view of one day, although a composite one, at Temple Court. Not all days were the same and as the next section shows there were outings into the wider community. However it was also clear that these men spent a lot of time at home. There was a great deal of care on the part of the staff towards them. Much of this was expressed in anxieties about their health. Charles was away when I first arrived. He had been seriously ill and returned some weeks later. Some staff were very concerned about his health and his return to the house and there were numerous discussions about this.

There were also concerns that Mathew might hurt himself leading to the vigilance of staff about him constantly wearing a helmet. Only one staff member removed it saying that he thought Mathew must be very hot with it on.

There were other breaks in the day. Shane had a birthday while I was at the house. We did not know about it until his sister rang on the morning. Staff bought a cake and treats for Shane. His sister arrived and spent the afternoon with him and with the other men. However there were few other visitors. Shane’s father sometimes visited the house although I never met him. The other men had very few visits or none from family members.

The supervisor of the house wanted the men to be more involved in its activities but it was clear on the half-day workshop that staff were unsure about how to go about doing this. On my last visit to the house after the workshop there was more involvement by them in household activities. Michael and Charles came out in their wheelchairs while we hung out the washing, and Charles went shopping with a staff member to the supermarket.

While I was at the house Shane’s sister said that he had liked music when he was a child and had played on the family piano. She wanted to buy him a keyboard. A week later a keyboard was purchased by staff members and was placed on the coffee table. It was a pink plastic one which would normally be used by children. It sat on the coffee table for some weeks. Staff members commented that Shane did not seem to be interested in it though Charles liked it. However there seemed to be little opportunity made for staff to spend time with Shane and the keyboard. The last notes made by Tim in late March indicated that the keyboard was no longer in the living area.

33 Dates of birthdays are included in people’s files. These were kept on a high shelf in the cupboard in the kitchen. They did not seem to be used regularly by staff in the house.
Activities outside the house

Four of the men spent at least part of their time at day programs and I spent two days visiting each one. It is not possible in this paper to write a detailed account of my observations but this should be the subject of a further discussion paper. In this section I want to describe some of the excursions that the men were involved in outside the house and staff views about these and to raise some key issues only that arose from the visits to the day programs.

Out and about in the community

During my visits to Temple Court there were reports of a number of different excursions into the community and I was part of a visit to a large shopping mall.

Ray reported that everyone in the house had gone to the park one Sunday for a walk. It was difficult with four wheelchairs and with Shane needing support. This seemed to be one of the problems in going out. It was difficult to organise for everyone to go together. Staff were worried that if they took one or two people others would be left at home. Ray commented that they were isolated from other people at the park.

There was an effort to go to fireworks for Australia Day which required reorganising the night shift so that there were enough staff. Unfortunately they arrived to find that the fireworks were cancelled with little notice.

‘Ray and I talked a little about the difficulties of making community links. Everyone had gone to the fireworks on Australia Day. There was supposed to be a concert and then the fireworks. Arrangements had been made for changes to staff rosters so that all the men could go. However when they arrived they discovered (with hundreds of other people) that the event had been cancelled. Ray thought it was really bad that the cancellation had not been publicised. It was a disappointment to take the men and then to have to come home as well as requiring a lot of work.

He talked about the weekend and how he had taken Shane for a drive on Sunday because he was a bit frustrated. They got out and went for a walk to see the railway trucks at a siding on the way. In the afternoon all the men had gone to a local park and shopping. Ray thought that they had really enjoyed the outing especially Michael who looked at everything. He said that other people “scuttled” out of the way when they saw the men in wheelchairs. It made life easier but he thought it was sad and different to New Zealand. He said that he wondered what kind of teaching was going on
in schools and also thought that people needed to realise that this could happen to their children as well’ (Fieldnotes, January 30th).

One day while I was at the house it was decided that we would go to a local shopping centre for lunch though Meena was concerned that she might not be able to find food that was of a vitamised consistency for Mathew and Michael.

‘With a little back seat driving from Meena we set off down Main Rd. It took about ten minutes to get to a large shopping centre where we had to find two adjacent vacant places for the van because of its size. Meena commented that the size of the van prevented them from coming to this shopping centre at weekends as there were no appropriate car parking spaces. The disabled car parking space is only a car length so is of no use. I pushed Michael through the car park over a road and up the ramp into the shopping centre. It was much harder to push Mathew who is a large man in a large chair. But even pushing Michael's chair up the ramp was a bit of an effort. Inside the shopping centre Meena said “lunch first” so we wandered through and searched for something that the men could eat. She could find nothing in the little cafés and food shops so went to the supermarket where she bought yoghurt and chocolate mousse.

Walking through the shopping centre pushing Michael’s chair was an interesting experience. Mathew still had on his helmet and sat slumped in his chair. He held a bib on his knees. Michael sat twisted in the chair a little. There were quite a few families and I noticed that parents tended to move their children closer to them as they approached us. I couldn’t decide if this was to do with not interfering with the wheelchair or some move to “protect” their children. No one spoke to us. We found a table and moved chairs so that the men could sit at the table. It took some time for Meena to return with the food. Elizabeth had a wander around and then I did the same. Originally we were all going to have lunch together but Elizabeth and Meena had brought their lunches and so decided only to have a coffee. I began to support Michael who slowly ate the yoghurt. I think the taste was a shock to him at first. He looked surprised and uncertain and then I wasn’t sure if he actually liked it. I tried another mouthful and he ate it. Eating is very slow with Michael and I find that I can’t judge it right. I sometimes am slow or too fast. I am also aware that sometimes I feel very impatient. Michael apparently cannot swallow properly and so the food has to slip down.
Meena went to do the shopping and Elizabeth and I walked around the shopping centre. Elizabeth (and later Meena) said how much they enjoyed the work. To be able to go out and have lunch and walk around was much better than being in an office. I bought some pasta and sauce for dinner and talked with Michael about what I was doing. Elizabeth looked at some clothes. Meena had taken Mathew's helmet off over lunch and he looked much more comfortable’ (Fieldnotes January 31st).

The difficulties of going out with more than one person in a wheelchair became apparent from this excursion and I also became aware of the isolation in which we moved. We were in the community but not part of it. Perceived community attitudes were a source of concern to the staff which was expressed repeatedly as shown in the fieldnote of the discussion with Ray. Staff did not feel it was their job to educate the community but did think that something ‘needed to be done’. Again the concerns about health and safety were paramount in this excursion and issues about food and being able to sit and have lunch dominated our visit to the shopping mall.

There was no real discussion among the staff about ways of linking the men into more community based activities. Ray talked about the possibility of joining church groups but doubts about this were expressed by other staff on the basis of the possibility of ‘inappropriate’ behaviour or family attitudes. I was left with a sense that taking this kind of step was too difficult. The supervisor commented that it was important to go slowly so that staff would own the changes.

4.5 The day programs

I visited two day programs with the men. Shane went to one, Michael, David and Mathew to the other. No one in the house seemed to know why they attended the different programs except that they thought that they had been going to the same ones in Kew Residential Services. (See end note 5). In this section I want to briefly describe some of the learnings that had relevance to the house from this experience.

I spent one day with Shane. We arrived at about 9.15 in the morning and left the day program at about 4 pm. Shane knew his way around the centre very well and in the morning went straight to the kitchen where he was given a drink. On the morning that I attended the day program Shane was involved in a cooking class. He spent almost two hours in the kitchen at the day program and sat with the other people in the group to watch and to participate a little in the cooking.
'Maple syrup was added to the pancakes when cooked and they were offered to each person. Vernon asked me to help with the cooking. Shane got up and went round the table and stood beside me. I took his hand and helped him to flip the pancakes. He doesn’t like being touched but was able to do this and did not seem to find it distressing. He enjoyed eating the pancakes and seemed to enjoy being part of the program. Evidence for this I guess is his attention and his continued presence in the room. When bored he simply leaves’ (Fieldnotes, February 7th).

This experience was quite different to his life at home where he was strictly kept out of the kitchen because of fears that he would hurt himself. Not all of his experiences at the day program that day were as interesting. The class for the afternoon was cancelled and we spent three hours wandering aimlessly around the centre. Shane searched for, and found, coffee cups with the dregs, spent time in one room repeatedly which had music playing and found favourite places where he made sounds by tapping on the walls. There was little else to do.

At the second day program I attended with Michael, David and Mathew. I spent the morning with Michael and David at the library. We had to go some distance to the library as there were eight people with five wheelchairs and nearer libraries were not large enough. Having arrived at the library we went to a central area where we sat alone as a group. Staff chose books from the shelves to read aloud. I found this task difficult as David is blind and neither he nor Michael seem to respond actively to spoken language. I was told that David liked science fiction and comedy. In the end I chose some poetry with a view that the rhymes and rhythm might prove interesting. It was not possible to borrow books from the library as the day program staff said that they were not returned on time or were returned in a damaged condition. The journey in the bus to the library took some twenty minutes leaving approximately an hour for the actual library.

In the afternoon the men attended a physiotherapy session.

‘The physiotherapist arrived. He was an older man who told me he was semi-retired but did this work and some other programs with people with disabilities. There were about 10 people in the class. He moved from one person to another. He suggested lying Michael on a sloping mat partly on his side. A staff member then gently stretched his legs and arms, opening them a little. He explained that he did this very gently so that Michael was not hurt and that he became more relaxed. Michael seemed to be enjoying the stretch and movement. Mathew was standing on his feet with a staff member holding his arm and supporting him. He began to walk around the
room. I had only seen him walk down the passage at the house but at the
day program he did three circuits of the large room and the kitchen. By the
end of the third circuit he was clearly tired. The physiotherapist commented
that it was very good for him to walk but that it needed to be not too
exhausting for him as he was a big man and not very fit. He said that if
Mathew did find it uncomfortable he would not be willing to do it next time.
He said that walks outside were good providing they were not too long.

I sat in front of Mathew and he was alert and smiling in a way that I have
not seen before. He was in a recliner chair which enabled him to put his
head back and look around. The physiotherapist said that he needed to sit
in different positions. There was a tendency to leave people in their
wheelchairs because it was easier and Mathew, he said, tended to hunch
over, to make himself small and unnoticed. The recliner enabled him to be
more stretched out and to see things more easily. There really was a
transformation. His helmet was removed. The physiotherapist said that he
did not need it— that if he had a seizure in the recliner he could not hurt
himself. He added, “Everyone here might have a seizure but they are not all
wearing helmets.” Mathew was a different person, a real sense of an
individual. He was looking around. He looked at me and smiled. The physio
wondered if he was pleased that I was present here as well as at the house.
He also thought he enjoyed the attention. I took off Mathew’s socks and
shoes and massaged his feet. He relaxed, and seemed to enjoy it although
there were clearly some sensitive parts of his feet that I learned to avoid. At
the end of the physio session Mathew was back in his chair with his helmet
on. Staff at the day program said they had taken it off but had been
criticised strongly by the house staff, so now he wore it all the time. By the
time we were back at Temple Court he was hunched over in the wheelchair
again.

David, whom I have only seen walk from his chair to the table, did two
circuits of the large room and the kitchen using his walker with a staff
member with him. He then sat again on the mat. Chris suggested I give him
a gentle neck massage. I did this for a while and then he indicated clearly
that he didn’t want any more, pushing my hand away and turning his head’
(Fieldnotes, February 23rd).

There were differences in the way these men were perceived by the
physiotherapist and by some of the staff at the house. Yet there were no
opportunities made to share these experiences. Nor were there opportunities for
staff to share their knowledge of the men. This failure meant that changes that might have been possible for Mathew at home were not taken up because staff simply did not know what he was doing at the day program.

4.6 Conclusion

This paper should be read in conjunction with a discussion paper prepared for a half-day workshop with the staff at Temple Court\(^3\). The latter paper identified three key issues which seemed to underpin much of the interaction in the house. The first of these was the health of the men. Anxieties about seizures, and about Charles’ fragility were key themes throughout the sessions. They were subjects of staff discussions and also shaped their practices. Isolation was the second theme which emerged. These men spend a great deal of their time at home. They have little contact with their relatives and do not have advocates or friends. Finding ways in which they can be included more in the activities of the house would seem to be one way to begin the process of involving them more in their community. However it was also clear that staff needed to think of ways that this could happen and for this to be legitimised both within the house and outside it. One staff member commented that the only time they heard from senior management was when there was trouble. There was a sense in which staff seemed to need support from outside in order to undertake activities which they saw as ‘risky’, for example allowing Shane to be in the kitchen. The third theme was communication. None of the men in the house used verbal language although they were sometimes able to indicate when they did or did not like something. The staff had difficulty in finding ways in which communication could be increased. (See end note 6). The lack of verbal feedback in some instances meant that staff assumed that the men did not understand and so they were discussed in their presence.

The process of people becoming included in the community is a slow one and it is not easy. The staff at Temple Court were committed and concerned about the men with whom they worked. However they did need more support in order to adopt a more inclusive approach to working with the men inside and outside the house. In part this support needs to address the anxieties that they have about the men’s health in a realistic fashion.

April 19\(^{th}\) 2006

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\(^3\) This discussion paper is not included in this series of papers.
Chapter 5: The case for moving upstream

By Tim Clement, Chris Bigby, and Kelley Johnson

A person walking alongside a river sees someone drowning. This person jumps in, pulls the victim out, and begins artificial respiration. While this is going on, another person calls for help; the rescuer jumps into the water again and pulls the new victim out. This process repeats itself several times until the rescuer gets up and walks away from the scene. A bystander approaches and asks in surprise where he is going, to which the rescuer replies “I’m going upstream to find out who’s pushing all these people in and see if I can stop it!”

(Egan and Cowan, 1979, pp 3-4)

5.1 Focus of the paper

Our previous papers were written primarily for the staff groups in the houses where we were working. We chose to write about areas of practice that we thought they could work on relatively easily. We hoped that in acting like a mirror and highlighting specific practices, an individual support worker could take a personal decision to test out supporting people in a different way. The original way in which this research project was conceptualised envisaged the bulk of our work being at this more individual level, working with small groups of staff in 10 houses. There are obviously a number of things that an individual worker can do to improve his or her practice. However, an overly individualistic way of thinking about the practice of direct care staff may lead an organisation to focus mainly on the direct service rather than other areas of the organisation that impact on service delivery.

In writing those papers we acknowledged that the Department’s employees are part of a large system and used the term ‘upstream issues’ to suggest that some of the issues that we uncovered in the houses arise from the organisation in which they work. It may not be sensible to put all of our energies into trying to make things better in the houses if the system that is the origin of staff difficulties remains unchanged.

Egan and Cowan (1979) distinguished between upstream and downstream approaches to responding to human needs. The distinction draws our attention to casualties of the system. We need to look at the behaviour of staff in the context of the employing organisation. By focusing on the Department’s broader organisational context, we are moving upstream, focusing on what the
organisation can do to develop the knowledge, skills and commitment of front-line workers and highlighting ways in which openly stated organisational goals are undermined by competing values and practices. We see this as being consistent with a model which suggests that service structures and processes mediate service outcomes (Felce et al, 1998). One function of this paper is therefore to make a case for amending the original research proposal, by cutting back on the number of houses that we work in and substituting action research initiatives upstream, at different levels within the hierarchy.

As in our previous writing we are content to flag issues in this paper and not suggest solutions, although certain actions may follow from what we have written. This is for two reasons. Firstly it is consistent with the methodological approach that we have used from the outset, where our commitment is to help the organisation learn through reflection on its own practices. Secondly, since we are suggesting that the issues are systemic, further inquiries need to be made beyond the sphere of our relatively narrow investigations to date.

Our work in the houses remains a vital component of the Making Life Good in the Community project. Indeed, the content of this paper arose out of our experiences in three houses, and ongoing work in houses will highlight additional systemic issues. However, we have not been overly surprised by the practices that we have witnessed. Our preliminary findings from three houses mirror those from quantitative research studies. Residents are given limited assistance to participate in running the houses they live in. Staff undertake many of the household activities themselves. Efforts to support clients outside of the house are geared towards a parallel presence in the community but not ‘social inclusion’. The importance of our qualitative research is that we are beginning to gain some insights into the dynamics that maintain this pattern of service provision in a way that is not possible from quantitative studies.

5.2 The Department of Human Services as an organisation

Management theorists have tried to classify organisations as certain types, which reflect different beliefs about the way work should be organised, how authority should be exercised, and people rewarded and controlled. It is worth stating that the Department of Human Services has many qualities of a bureaucratic organisation even though this is hardly an original insight. Recognising this does inform us about the broad organisational culture, and allow our work to be

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35 We acknowledge that interactions between people and organisations go both ways. Organisations affect employees, employees affect them.
enlightened by the wealth of organisational literature on the workings of bureaucracies.

Handy (1993) preferred the term *role culture* to bureaucracy, as bureaucracy is often used negatively, thereby ignoring any positive qualities of this type of organisation. In general, bureaucracies aspire to work by logic and rationality. They are coordinated by a narrow band of senior managers, where separate functions do their jobs according to the rules and procedures that prescribe clear roles for employees. These rules and procedures are the major methods of influencing people.

**Managing by values**

Values are important to welfare organisations. Emerson, Hastings and McGill (1994) suggested that it is so generally accepted that values underpin welfare services and influence everyday practice that this claim is rarely discussed anymore. The Victorian Department of Human Services publishes a number of value-based statements that relate to desired goals or outcomes for service-users and modes of conduct for employees. Four important documents are *Growing Victoria Together* (State Government of Victoria, 2001), the *Victorian State Disability Plan 2002-2012* (State Government of Victoria, 2002), the *Disability Standards* (in Department Of Human Services, 2002) and *Our Values* (Department of Human Services, n.d.).

One way of doing analysis is to compare what you are looking at with a standard (Wolcott, 1994). These four documents contain such 'standards' and point to the direction in which disability services ought to be moving. They therefore reflect a number of assumptions about the type of lifestyle a person with disability could be leading. This is important for the *Making Life Good* project, because the values, principles, and goals outlined in these documents are benchmarks against which judgments are being made.

**Role cultures and values: Qualifying remarks**

It is also worth making two points about the impact of value statements and rules and procedures on the practice of front-line staff, two methods that organisations use to influence work behaviour.

It is proposed that a tight set of shared values provides the framework in which people can work within the service. Senior managers attempt to influence work culture through the codification of values, promoting interactions and close ties amongst employees, the recruitment and socialisation of new employees, and monitoring how they are received and put into practice. Peters and Waterman
(1982) suggested that an organisation can be controlled through its culture, by people living and believing in the values of the organisation. There is a vast literature on how researchers, consultants and organisations have tried to use the concept of organisational culture to build a strong culture in order to improve an organisation’s performance and productivity (Martin, 2002).

The concepts that appear in these value statements are often ambiguous, conflictual and hard to apply, which often means that they are poorly defined and understood. People at the front-line are often left to work out their own versions of concepts like choice, participation, and inclusive communities, which may have little resemblance to the intentions of official versions. Even though people in an organisation may use the same phrase, they may not refer to identical situations or have the same meanings (Pålshaugen, 2001).

Likewise, it should not be assumed that rules and procedures automatically give management greater control of front-line practice, which often takes place between individual workers and ‘silent’ clients in unobserved settings where performance is hard to measure (Evans and Harris, 2004). In such circumstances front-line workers have a significant amount of autonomy to interpret and apply rules and procedures. Even in a highly bureaucratic organisation, where roles are tightly structured by rules and procedures individuals may develop a style of working that runs counter to what is required. Change may be hard in such circumstances.

The report necessarily covers a lot of ground and addresses issues that people will judge as being easier or harder to change. A systems approach means that we have to understand what we have observed in the houses as emerging from the properties of an interrelated organisation. Although it may be tempting and ultimately pragmatic to divide these issues into areas that are easier or harder to tackle, a systems approach assumes that ‘valid knowledge and meaningful understanding comes from building up whole pictures of phenomena, not by breaking them into parts’ (Flood, 2001, p.133).

5.3 Accommodation

Community Residential Units

There are large numbers of community residential units (CRUs - or ‘community houses’ as they are referred to in some communications about the Kew Residential Services Redevelopment) in Victoria. It seems pertinent to ask what impact service design might have on practice.
Our thinking about the types of services we provide for people with disabilities changes over time and continues to evolve. McGill (2005) outlines the development of services in the UK, which is broadly consistent with the general trend in Australia (Figure 1). *(See end note 7)*

**Figure 1. The development of services over time.**
Adapted from McGill (2005).

| Hospitals | 25-place locally based hospital units | Staffed houses | Planning services around the person where the individual controls how they are to live. |

A priority action in the Disability Services Divisional Plan (Department of Human Services, 2005b) is to broaden ‘the introduction of the Individualised Planning and Support approach’ (p.3). In CRUs staff strive to ‘tailor’ the service to the individual in an environment that is still congregate, despite the much smaller size. The Department of Human Services additionally funds residents to attend larger congregate day services. As Felce et al point out (1998) where this is the case individuals are often made to fit the model of the small group home rather than providing services on the basis of an individual’s needs and wants. The challenge is how best to individualise support in CRU settings where a number of people live together.

**Workplace or home (See end note 14)**

The very name, Community Residential Unit, promotes the idea that people are living in a service rather than a home. The fact that people come to work in these houses makes them unusual ‘homes’, yet the espoused goal is for CRUs to be homes first and workplaces second. There are various practices that support or undermine this aspiration.

Wolfensberger (1975) argues that the design of services reflects and reinforces attitudes and role perceptions. This shapes what people within those services can see and do. The Kew Residential Services redevelopment is using a set of basic house designs, a strategy that has been employed in other institutional redevelopments (see Fyffe and McCubbery, 2002, for example). There is no doubt that the new houses represent a much improved material environment and the hope is that the houses will give residents greater opportunities to participate in
the running of the house and build a life in the community, yet there are also forces that could limit this.

*Uniformity in design*

As we have moved from house to house we found ourselves in a different suburb, but in an environment that was architecturally very similar, (see end note 8) which was decorated in a similar style, and furnished in a similar way, with some rooms laid out in a similar manner36. Given that there is a significant movement of residents and staff between the houses, either to work in other houses or visit friends and acquaintances, we would suggest that this similarity is another strong cue to Department of Human Services employees (and possibly residents) that this is a service first and a home second.

*Community resources*

The areas where services are sited have important consequences for how people with intellectual disabilities are seen and the type of skills that they can develop (Wolfensberger and Thomas, 1983). One specific consideration should be the availability of community resources, such as shopping options, public services, spiritual centres, and recreational facilities. Available community resources promote social inclusion and allow people to develop skills in using them. Easy access to these resources is essential for the residents as they do not drive, and are therefore dependent on other people to drive them or support them to use public transport. The Department’s policy states that, ‘Public transport should be used whenever possible to transport clients’ (Health and Community Services, 2005).

Our brief has not been to thoroughly evaluate the neighbourhoods in which the houses have been built, but we have noted that some houses are in places where there is not easy access to public transport and other community resources. In such circumstances the residents are dependent on being driven to facilities that are some distance from where they live. It is recognised however, that the vast majority of the new houses are in locations that are in ‘middle distance’ suburbs of Melbourne or in country towns, not in the outer Melbourne suburbs, and none are in the new outer suburbs where community infrastructure may lag behind construction. *(See end note 10).*

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36 We are aware that in some houses a degree of choice was offered to the residents about paint colours and some furnishings. The choices were restricted to prescribed options. *(See end note 9)*


Chapter 5: The case for moving upstream

Staff facilities

There are other aspects of institutional thinking that seem not only to have transferred to the houses but have been built into the structure of the house through formal rules and procedures. In institutions ‘nursing stations’ were formal centres of power and control that are really little different to the offices that are in the houses. Institutions had separate amenities to separate ‘staff’ from ‘patients’ (O’Brien, 2005).

In new CRUs, there is a sleepover room/office, staff toilet and shower. This is a requirement of the HACSU ‘Parent’ Award, and is restated below in the agreement regarding the redevelopment of Kew Residential Services. (See end note 11)

‘Each house built in the Receiving Services shall have exclusive toilet, shower and hand basin facilities for the exclusive use of the employees in each CRU’ (Department of Human Services and Health Services Union of Australia, 2002, p.10).

Our experience is that the office looks like the most ‘lived-in’ room in the houses and the staff bathrooms typically seem more homelike with hand-towels, air-fresheners, and soap available, which is often not the case in the residents’ facilities. If separate amenities are formally endorsed by official policy, then it is no surprise that informal practices also develop that make unnecessary distinctions between residents and staff, such as staff mugs, plates, and cupboards.

5.4 Transport

Buses

The new houses have been well resourced with an expensive bus, which can accommodate all the residents and the supporting staff. In 47 out of a total of 93 houses being established as a result of KRS closing, there will be people who currently use wheelchairs so accessible transportation is necessary, but this is not the case in all houses. If we are right in suggesting that the design of services shapes what people do, then it may be the case that having a large bus makes it more likely that everyone in a house will go out together. This may be desirable on occasions, but as a common practice is inconsistent with the Victorian State Disability Plan’s strategy of reorienting disability supports to provide more individualised planning and support. In the houses where we have been working

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37 Receiving services mean, ‘the services to which employees will be transferred as a result of the redevelopment’ (Department of Human Services and Health Services Union of Australia, 2002, p.2)

‘Making life good in the community: the story so far’
large group trips that involve all or most of the residents is still a dominant type of outing.

At worst we are aware of groups of houses recreating outings that have all the similarities of the large coach trips that were a feature of Kew Residential Services. However, instead of one large coach, a number of buses from different houses will arrange to meet up at a particular venue, depositing twenty or so residents and eight staff at the same location.

It has also been suggested to us that staff who are not confident about driving the buses will select or rule out a venue for an activity by considering the ease of parking. Having a large bus is but one solution to people’s transport needs.

**Transport plans**

The houses open with a ‘transport plan’ designed to get people to day programs. *(See end note 12).* These are the notes from one particular journey:

> 'We left the driveway at 08.15. Simon sat in the front with Arun [staff member and driver], the rest of us sat in the back. The bus can seat 12 people. Arun brings in CDs to play in the bus. He often brings in music from the 70s and 80s. He tells me that Cathy, "The songbird" knows all the words. However, today it was a CD of Christmas songs ("Frosty the Snowman", "Rudolph the red nosed reindeer"), which was turned up very loud. After 25 minutes we arrived at the first centre in Balwyn, where Arthur and Gabriel got off. The bus has to rendezvous with a program bus that takes Cathy to a centre in Templestowe. However we missed the connection and had to drive to the day program. It was nine o’clock when we got there. Then to Zoe’s program in Surrey Hills at 09.20 and finally to let off Simon and Heather at 09.30, one hour and fifteen minutes after we left. We were back at the house for 09.45’ *(F/ZX/021205)*

This may be an example where the staff do not think that they can change an existing plan. It did strike us that two residents had to sit on the bus for 75 minutes when their program is 15 minutes away from the house. This was of course exacerbated by missing a connecting bus. It is also in a house where the two morning staff state that there is pressure to support six people to shower, dress and have breakfast in 60 minutes. If only four people had to be out of the house just after eight o’clock this would relieve the pressure. All the residents would benefit from better support to shower and dress and two residents would spend less time on the bus. It would however mean more driving for the staff.

*38 The names of people have been changed in all fieldnote extracts.*
5.5 Equipping the houses

Unintended consequences

Some of the things we observed appeared to be unintended consequences of the organisation’s formal practices. Proehl (2001) makes the point that some departments within an organisation act as if they are autonomous and fail to fully consider how other areas will be affected by a change. In certain instances an action or policy that was intended to have a particular outcome has resulted in unintended outcomes that are usually negative. Although some unintended consequences will be unforeseen we suggest that some could have been anticipated. In particular we have observed the consequences of ‘upstream’ purchasing decisions which impact on practices in the houses and outcomes for clients – in this case, similar basic furnishings and equipment in the houses we studied. (See end note 13).

Mops and buckets

With the type of flooring in the houses and a zealous commitment to cleanliness, we have witnessed a lot of mopping in the houses. The mop buckets that have been provided in the houses look to be top-of-the-range, possibly for commercial use, with an emphasis on ‘Occupational Health and Safety’. (See end note 14). To be able to operate the mop and bucket successfully on your own you have to have ‘normal’ motor skills, which may be impaired in some people with intellectual disabilities. You have to be able to use both feet at the same time. One foot goes on a stabilising plate on one side of the bucket and the other foot is used to press down a foot lever that operates a mangle-type arrangement in the bucket through which you pull the mop. Whereas some service-users might be able to mop the bathroom or their bedroom on their own with a different type of mop and bucket, the degree of coordination that is required means that with this equipment it will always be a job that requires the support of someone else.

Telephones

There has been a tendency for telephone equipment to get more complicated and smaller. The equipment that we have seen in the houses has both these qualities. An unintended consequence of this is that some residents are excluded from either making a call on their own, or the degree to which they are able to participate has narrowed. We know people with intellectual disabilities who can make a telephone call independently or can press the numbers if they are read out to them, or use a speed dial. Again the smaller equipment makes the likelihood of pressing two numbers simultaneously much more likely if your
dexterity is poor or limited. Some telephones require additional steps to begin and end calls rather than merely picking up a telephone and dialling a number and then replacing it when you have finished.

**Laundry**

Sometimes the solution may be more complicated than merely buying the right equipment in the first place. Some practices may be a result of an interaction between the knowledge and skills that the workers have in a house, how staff norms for completing a task have evolved, the equipment that has been put in the houses, and the messages that staff have heard from upstream sources. One example is how we have seen the laundry done.

There are many ways to organise how laundry is done in a household. What follows is based on a set of beliefs about how this task should be organised, which other people may dispute. As much as is possible, the adults in the house should be responsible for the care of their own laundry. This means washing and drying their clothes separately and then putting them away, whether this is independently or with support.

The houses are large-ish households, with perhaps a heavier than usual daily load of laundry to attend to. The washing-machines and tumble driers in the house seem to have been purchased with size and durability in mind.

What we have seen in practice is staff taking the lead in doing the laundry. Typically this means collecting all the dirty laundry that needs to be done on any particular day and aggregating it. It would be relatively easy for staff to change this behaviour and support people to wash their laundry individually. However, the practice is, in part, driven by the size of the washers and dryers. Why would you do two half-loads when you can do one? Again, people could make the decision that doing a number of partial loads is more desirable. The practice has also evolved and been sustained by the messages that people have heard about the need to conserve residents’ money. Half-empty machines use more electricity, more soap and conditioner than full ones.

A key message that was passed on by trainers during the transition training was that ‘money is tight’ and that staff need to keep a close eye on the house’s budget (F/ZX/210705). At one session, a worker used her own experience of working in the houses to reinforce this point. ‘We have to hang up the washing, not use the dryer, not like my son who puts in one item’ (F/ZX/041005).

39 The larger houses have six residents with additional staff members. Some houses have a number of residents who can be incontinent during the night and day.
Sometimes what seems to be more efficient and effective may produce poorer outcomes for service-users, notwithstanding that the outcome may conserve their limited financial resources.

5.6 Formal practices

Financial controls

The Client Expenditure Record System (CERS) is a good example of how rules and procedures have had a significant impact on how people do their job, particularly because it is backed up by robust monitoring mechanisms. However the system also has some negative consequences for the residents. As well as learning about the formal rules and procedures during the transition training, staff also learnt about the trainer’s understanding of why the policy had been developed and what this meant for practice. Most of the stories that were told by the trainers were of employees doing things wrong and getting caught. Organisational stories contain morals for the listeners (Martin, 2002). In this particular training session there seemed to be an implicit view that staff are not to be trusted and must therefore be monitored.

‘People are told about the financial systems and the different forms. The Record of Individual Client Expenditure; Requisition for funds; Client assets register; and Special purchases.

They were told that they would receive a six-monthly audit now they were in the community.

One house had gone on holiday recently and a receipt had been submitted for videos. The auditors had phoned the video store to see what videos had been hired. They were deemed not to be “politically correct”. The staff involved were “counselling”.

The trainer showed the staff a laminated picture, which had a person beating off a large dog with a stick. In the trees a policeman is watching. The auditors were likened to the dog. If the regular monitoring system detected errors, then it was suggested a whole team of people would come to the house to do more thorough and wider searches.

People were reminded that written records were legal documents, which could end up in a court of law. The trainer told a story of some notes where a staff member had written that a client had been a “complete bastard”. The client subsequently died and the court tried to prove that this person had been neglected, which had resulted in his death.
Staff who leave the premises with money that has not been recorded could be charged with "theft, fraud, misappropriation of funds, and one other charge". The trainer referred to an employee at Kew Residential Services who had siphoned off money for about two and a half years. People were familiar with the story. The system was said to be so tight now that people would be caught after one month, and the amount of money people could take would be negligible. "Not worth losing your job for".

A story was told of a staff member who reported a bank card as being stolen, who was subsequently caught on video at Crown Casino withdrawing money from an automatic teller machine.

There is a disposal policy, for throwing away clients’ items. The trainer gave examples of staff behaviour. A staff member says that a CD player got broken by the person’s challenging behaviour and that he threw it away. The bin got emptied. The implication of the story is that the CD player is at the staff’s home.

A staff member deliberately purchases shoes that are a little large and then buys them off the resident for $20.00.

One of the parents gives you $50.00 to buy something for her son. She’s a bit dotty. Next week she says it was $100.00. You’re not guilty as it is her word against yours, but you are under suspicion.

People are told to use electronic transactions where possible’ (F/ZX/210705).

The motives for CERS policy and procedures may be well intentioned to protect the funds of people with intellectual disabilities and the tax payer. Yet the implementation of these rules and procedures has consequences for the residents. When staff are given debit cards and urged to use electronic cards in a climate of distrust and suspicion, where every cent spent needs documenting, then the opportunities for residents to handle money are decreased. When staff remain in control of the process because the cards are issued to them, then service-users are denied opportunities to have money in their hands, learn about the function and value of money, hand over money and receive change, engage with shop assistants, and be seen as a contributing members of society.

40 These stories also reminded us of the maxim that extreme or hard cases make bad law. An extreme incident happens and the bureaucracy responds by putting in systems to make sure that it does not happen again.
If the ‘bottom-line’ is seen as paramount it can interfere with other Departmental goals. Building certain types of relationships in the community requires opportunities to access and participate in recurring activities (Lakin et al, 2005). Some staff recognised this and argued for residents being given money to purchase take-away food or bread and milk on a daily basis from the local Milk Bar. If giving people cash is not encouraged and, as other staff argued, buying bread and milk in bulk from a supermarket is seen as being better use of money, then certain outcomes for the residents are again closed off.

**Eating in the house**

We have written elsewhere about our observations of mealtimes at houses. We suggested that staff have the most active roles, determining the limits of resident participation, the choices that are available, and taking the lead in serving food and drink. It is interesting to consider how much the relevant formal rules and procedures, and the way in which they are communicated and understood, shapes mealtimes. Observed practices reflect this small part of the policy.

‘Staff are responsible for bringing or purchasing their own meals when on duty, though when staff share a meal at the unit or house, a contribution to the housekeeping expenses must be made’ (Health and Community Services, 2005)

This was the key message that was communicated to staff during the CERS component of the transition training:

‘People are told that they have to bring their own food in. Staff are expected to make a contribution for any food that they eat and to the telephone bill. The trainer says, “A Community Visitor may come in and see you eating something and accuse you of eating the clients’ food.” People get a receipt for any money they contribute. People were urged to eat food out of containers that they had bought from home, as this would signpost that this was food that the staff had brought in rather than being the residents’ food’ (F/ZX/210705).

At one house the policy was followed exactly, whilst at another no one had ever asked to eat a meal with the residents so no one was sure of what to do.

‘I ask Kjell how much I need to pay to eat the evening meal. He takes me to the office. There is a form that I need to sign to identify which meal I am eating and how much I have paid. He gives me a key to unlock the safe on top of the filing cabinet and I put $3.00 in a jar marked “staff contributions”. There are about five or six entries on the sheet before my
name. Kjell tells me that staff contribute $2.00 a fortnight for tea and coffee. As I don’t come in that often he tells me that he will shout me a cuppa. He has brought in his own tea bags and occasionally brings in milk’ (F/ZX/261005).

Typical staff behaviour was to do just as they had been instructed and interpreted the policy. People brought their own food in and ate it at a separate time from the residents. This left them free to serve the meals and support people with feeding if this was necessary.

Just as was the case with the laundry, there are many ways that mealtimes in houses can be organised. As has been suggested the general approach in the houses is for the residents to sit down at the same time to the same meal. In practice the policy has led to the separation of mealtimes for staff and residents. If mealtimes are organised along ‘traditional family lines’ then another alternative is for staff and residents to sit down together to eat of the same meal. This reframes the meal as an event that everyone participates in. It allows staff to model table manners. It offers the potential to utilise a genuine social occasion to talk generally, or more specifically, about how people are, how their day has been, what they want to do that evening or the next day, or in the future. The policy seems to allow for this. ‘If staff are directed by their supervisor to share household meals with clients, the Department will reimburse the clients’ housekeeping expenses’. (Health and Community Services, 2005). Has any supervisor directed all staff to sit down at every meal time with the purpose of creating that social climate?

**Information**

In a report on an earlier process that led to 60 people leaving KRS in 1999-2000, Bigby et al (2004) commented on the manner in which written information about clients was made available in the houses. The authors suggested that there were problems with organisational arrangements for using information. Various possibilities existed:

- Information was in the houses but was inaccessible and unused because of its style and format.
- Information may be inadequately disseminated to house staff.
- Information and knowledge sought by house staff did not exist.

*(See end note 15)*
These possibilities apply equally to the Department’s policies, rules, and procedures as they do to information about the clients.

The way that information is disseminated often requires reasonable literacy skills on the part of direct care staff. Increasingly employees are being asked to make use of information technology.

Even in the three houses that we have worked in we have come across a significant number of direct care staff who struggle with literacy in English and are computer-wary. In some cases people’s situation may be compounded by having a first language that is not English. Over the last decade there has been some innovative and imaginative work done on making information accessible to people with intellectual disabilities. There is some useful work to be done on making organisational information accessible and useful to front-line workers.

5.7 Organising client support

Rosters

As a general principle the way that the support is organised in the houses should be client-centred. The Department broadly recognises this by suggesting four different staffing formats that ‘cater for the support needs of Kew Residential Services residents’ (Department of Human Services and Health Services Union of Australia, 2002, p.10). The greater the support needs of the residents, the more hours each format allows. However, we would suggest that the more specific rosters that we have looked at are more accurately described as staff-centred.

Consider this bargaining at the transition training, which had little if any reference to the support needs of the residents. (See end note 16)

‘Mary returns to discuss the roster that is a revision of the version that they looked at in the morning. She states that it is only provisional and will have to be agreed with the Union and staffing services. Susan does not like this version of the roster as she thinks she has too many 10 pm finishes. She suggests that the men may be in bed by 8.30 pm in which case there will be no need to work that late. "Would something like 8.30 suit you?" she is asked. “Yes” she replies. Barry is not happy with the one day shift he has to work as the active night staff. He would like to do another night. The woman implies that the Union are keen on this one day shift, although she is not married to it herself. Maureen is much happier with the new roster as she no longer would have had to work seven days in a row. Mary had not been happy with this as it is not good for staff health. It is a health and
There do seem to be a number of hours in the houses that are not used effectively or efficiently. In part, this may be a consequence of the large proportion of full-time Kew Residential Services employees that have to be redeployed to the new houses. Consequently there are times during the day when there seem to be surplus staff in relation to the number of service-users in the house. These hours could be used productively for supervision or planning, for example, but are often not. The tendency is for front-line staff to find concrete tasks to fill their time, such as sorting out the laundry or cleaning a bathroom. Consequently these tasks have been done when people return from their day programs and clean clothes have magically appeared in their wardrobes.

Rosters can be inflexible, which means that activities may have to fit into the staff schedule, rather than support being provided when people need it.

‘Two women had come to the Christmas party from another house. The supervisor was disappointed with the “attitude” of the staff at the house. He had sent an invitation, which was not immediately replied to. It was lost. Then he was told that the staff member who would support the women to the party was finishing at eight o’clock in the evening. She would have to leave the party at 7.30 to get back to the house for her finish time. In the end the women were supported to arrive late, eat their food, and were then taken home immediately afterwards so the staff could go home at the end of her rostered shift’ (F/ZX/141205).

Neither does the design of the rosters we have looked at allow a house supervisor to spend an equal amount of time with all members of the staff team, which seems a prerequisite for being an effective manager, if house supervisors are to direct, coach, and support all front-line staff.

**House meetings**

A scheduled house meeting once a month is a good addition to the roster. However, in the houses where we have been working, the meetings appear to have been scheduled without reference to the support needs of the residents or organisational considerations. The meetings are all scheduled on the third Wednesday of the roster. It so happens that some of the residents do not attend day programs on these days. Unless the residents are invited to be an integral part of these meetings, which is not current practice, they may be left unoccupied for the duration of these meetings. There are days of the week in two of the three
houses in the project where all the residents attend day programs. If residents are not to be integral to such meetings, then adjusting the roster so that the meetings are held on days when residents are not at home would appear to make more sense.

In the three houses in which we have worked, the part-time staff are not scheduled to attend the house meeting. At one house this means that one third of the staff group are not included at the key forum for information sharing, problem solving, or decision making. This appears to have sent a message to some part-time staff that they are not as important as full-time staff. We would suggest that if you want to instil loyalty and commitment to the organisation then all employees should treated in the way that you aspire to treat full-time permanent employees. Peters (1995) makes this point about workers on temporary contracts, to which we might add casual employees.

In addition, should the team or cluster manager want to attend these meetings regularly, in the different houses they manage, it is impossible as they fall at the same time on the same day.

There is an agreement to conduct a roster review in each new house three months after it has opened and a process for changing the roster at other times (Department of Human Services and Health Services Union of Australia, 2002). It is hoped that the Department will monitor the outcomes of these reviews and roster changes.

**A stable workforce**

Part-time positions have been vacant in some of the houses since they opened, which means that casual staff are frequently used. The goal of providing people with intellectual disabilities with a **stable**, skilled workforce is integral to providing quality services (Lakin et al, 2005). Handy (1993) makes the point that role cultures succeed when they can operate in a stable environment. At a micro-level the recruitment challenges that the Department faces, and the use of casual staff, adds to the instability in the houses. Instability is exacerbated by people’s conditions of service, which can see people on leave for months at a time.

There are other practices, which cause even greater instability to the support provided. In one house two staff have had their redeployment from Kew Residential Services delayed. **(See end note 17)**. This has created an environment where service improvements are being delayed until a stable staff team is in place, because people who have been temporarily redeployed are not viewed as being fully committed to the house. In addition the practice of taking
people out of the houses to ‘act up’ in other positions for significant periods creates instability. In one house there were three acting supervisors in a month and two full-time staff ‘acting up’ in other areas of the service. Not only does this seem to create a leadership vacuum in the house, but a management one too. It was not surprising that the staff working in this house reported a decline in the quality of service they felt they were providing.

The practice of moving staff at team manager level has also been apparent. The team manager who oversaw the opening of the new houses has been moved on and the process of developing a relationship with the supervisor and the staff team, and getting to know the clients has begun again.

5.8 Training

Training: An introduction

(See end note 18)

Amongst other things employees need working knowledge and skills to accomplish their roles and promote the development of the service-users (Egan and Cowan, 1979) and to this end the Department spends a lot of time, effort, and money on staff training.

The opening of each house was preceded by a two week block of training, known as ‘transition training’, which is a form of orientation. Whilst we were waiting for consent to work in the houses we were fortunate enough to be allowed to attend some sessions, which we considered so valuable that we continued this practice even after we received consent to work in the houses. So far, we have participated in thirteen days of training. Attending the training as a researcher was not part of the original research proposal, nor was it our intention to attend the training in a researcher’s role. (See end note 19)

Our aim here is to use specific illustrations to make some broad comments about training, which Goldstein and Ford (2002) define as the systematic acquisition of skills, rules, concepts, or attitudes that result in improved performance.

In order to make some general points about training it is necessary to make it clear that effective training is a difficult and complex task. A lot of training falls short when measured against best practice models. Figure 2 gives a simple training cycle and Figure 3 a more complex instructional system.
Training needs analysis, costs, evaluation, training inputs and methods

The degree to which organisations take notice of the guidance given in the training literature is often the result of a cost-benefit analysis. To undertake a thorough training needs analysis takes time and money. This is often not done, even though training that is ill-directed and inadequately focused does not serve the purposes of the trainers, the learner, or the organisation (Boydell and Leary, 2002).
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1996). In many organisations an end of training evaluation sheet is often the sole form of evaluation even though our definition of training suggests that we are looking for a change in practice\(^ {41}\). It is harder and more costly to complete an impact evaluation to discover whether there has been a change in the practices of direct care staff or improved outcomes for service-users.

Many of the people who delivered sessions on the transition training were not trainers but Department of Human Services employees who were asked to present a session. *(See end note 20).* Careful planning is necessary to make sure that trainers avoid any ‘hidden curriculum’ entering the training process (Horwath and Morrison, 1999). Earlier, we have suggested that an implicit message of CERS training was that staff are not to be trusted and must therefore be monitored and an explicit message was that staff should use electronic transactions where possible. Trainers should realise that training inputs are everything that a trainer does to facilitate group learning. *(See end note 21)*

There was an acknowledgement from the organisers of the transition training that direct care staff found working nine-to-five for two weeks in a training context hard. An important consideration in the design of training is the selection of training methods, which are sensibly placed in the training program. The trainer from the Communication Resource Centre used a variety of learning methods to deliver the training, which appealed to different learning styles *(F/ZX/130905)*\(^ {42}\). However, there were some days when participants were passive for extensive periods. Training which positions people as empty vessels that need to be filled with knowledge is not likely to be successful. This was recognised by some training facilitators who made comments like, ‘You must be brain-dead’ *(F/ZX/031005)*. Many people who work in direct care may view their previous learning experiences negatively, which act as personal learning blocks in a training environment. Horwath and Morrison (1999) argue that unless blocks to learning are addressed at an organisational and an individual level, it is unlikely that trainees will engage in functional learning.

\(^{41}\) One study reported that 90 per cent of surveyed organisations used an end of training evaluation sheet as the sole form of evaluation (cited in Horwath and Morrison, 1999).

\(^{42}\) It must be stated that this session was weak on designing in any learning transfer or post-training learning support. *(See end note 22)* Rather than be given the MAKATON booklet or CD the staff group were advised to buy it. Cost $25.00. Our observations at this house would suggest that very little of the training has transferred to the work setting, even though the training was well-received and one staff member commented, ‘This is very important, I think’ *(F/ZX/130905)*.
**Generic or tailored programs**

Often it is cheaper for an organisation to deliver or commission a standardised training program that is repeated again and again. Sometimes this may be appropriate. The Fire and Emergency Evacuation Training would be a good example of this. On other occasions we would argue that there should be greater consideration about the participants and/or the specific service-users that direct care staff are supporting. We saw some good examples of this on the transition training. The Diet and Nutrition training was grounded in a good understanding of the residents in a particular house. We saw some instances when a general program, which is not grounded in the experiences of the staff group or the characteristics of the residents, impacted on the training effectiveness. The Community Connections training suffers from this dynamic with some staff groups, even though some exercises seemed to have been specifically designed to aid the transfer of this introductory training to the job. *(See end note 23)*

We propose that abstract ideas are harder to apply when the staff are working with people with more profound and multiple impairments and the examples that are given by trainers relate to people with mild or moderate intellectual disabilities or other impairments. People with profound and multiple impairments are often talked about in ways that single them out as being a special population for whom many ideas do not apply. The training therefore may appear irrelevant, unless the trainers use examples which resonate with people’s experiences and they are helped to apply the more ‘theoretical’ ideas to their work settings. In some circumstances trainers would benefit from information about staff participants and the service-users that they support. In this way trainers can consider what they need to do to overcome or prevent learner blockages.

**Training priorities**

The training that people receive is usually determined by mandatory requirements, which have to be repeated to keep people competent. Fire training and First Aid are two examples. Which training topics are on the repeat cycle seems somehow significant, in that this probably sends a signal about what is important. Using the above examples, keeping people safe is a message that is prioritised, whilst training on active support or person centred planning is perceived as secondary. Both are equally important.

**Evaluating staff performance in the work environment**

The ongoing nature of our research has afforded us a privileged position from which to comment on the impact of some of the training on the practices we
observed in the houses. For instance, in one house we participated in the Community Connections training, subsequently observed people’s practices over a two-and-a-half month period, and finally explored the staff groups understanding of ‘social inclusion’ at a half-day meeting.

In the half-day meetings with all the houses social inclusion was discussed. We have written elsewhere that staff typically understand social inclusion as meaning Community Presence and put their efforts in supporting residents to increase the number and variety of ordinary places that they know and can access to the exclusion of Community Participation (O’Brien, 1987). Staff must continue to support community presence. However, if they do not also understand that their role is to expand clients’ networks so that they experience being part of a growing network of personal relationships then we might conclude that a learning objective (knowledge) and a learning outcome (application of that knowledge into job behaviour) have not been met.

**Transition training, ownership and the hotel model**

The broad aims of the transition training were multi-purpose. The most explicit aim was to equip staff with the knowledge and skills to carry out their role in the houses within the constraints of a two-week program. Another aim was to create a space that marked the separation from Kew Residential Services. We also picked-up on a further aim, which was articulated as ‘giving staff ownership of the house’.

In a previous paper it was suggested that in a particular house it appeared that the staff had the dominant role, a perception that was also shared by the residents. We suggested that the concept of ownership was useful in articulating that the control over the day-to-day running of the house and the direction of the house was owned by staff. We are not suggesting that this was the desired outcome of promoting staff ownership of the house. Rather, we suggest that the intention was something to do with recognising that particular staff groups work in specific houses and they have responsibility for their practices in that setting. Yet we would suggest that some dynamics that we observed once the residents had moved into the houses were put in place or reinforced by certain aspects of the transition training. Would there have been a different outcome if an explicit aim of the transition training was to give residents ownership of the house?

People are rightly concerned about ensuring that the residents make a smooth and successful move to the new house. The view of one manager that we talked to is that, ‘99.9 per cent of residents have settled in well and that many lessons
have been learned from each opening’ (F/ZX/030705). Yet, an important aspect of the action research process is to question the expertise that is embodied within current knowledge (Winter and Munn-Giddings, 2001). Current practice suggests that the Department believes that residents should be able to move into a pristine new home, a way that is totally alien to the majority of the population. This may be desirable for some people with intellectual disabilities, but not all people with intellectual disabilities. Consider these observations from the transition training. No residents were present on this day.

'Some staff had carried out a large shop the night before. Most of the food had been put in the cupboards. Beverley was emptying packets of spices and herbs into Tupperware containers and putting labels on them. Cornflakes were emptied from the box into an airtight container.

As they are sorting out the cupboards Charles says, “These are staff cups”. The china mugs are put on the top shelf.

Purple and green towels are drying on chairs in the sunshine. Each resident has a particular colour. Steve tells me that Kjell asked the men to pick a colour. This is thought to be less institutional. At Kew all items were named.

There is a lot of laundry going on. All the new bed linen is being washed. Steve holds up a small towel and someone says, “That’s a staff towel”.

Selected staff had been given a meal that they were to cook that morning. The meals were to be made and frozen for the following week when the residents have moved in. Carly told me that this was because the following week would be busy and it would make things easier if meals were prepared.

Staff are going out tomorrow to buy pictures for the walls’ (F/ZX/030705).

We wondered why all this activity was being done without resident involvement. (See end note 24). Although we have commented that the motel or hotel model does not accurately capture the fullness of what is going on in the houses, there does seem to be an element of it here. Setting up a new house in this way is likely to be a once in a life-time experience for the residents. We remember our first homes as exciting times. Although there are examples of residents being involved in some minor decisions about their new home, for example choosing the colour of their towels, they are marginal to the process. Why should residents not be involved in the spending of this money? Why should the residents not be involved in the first shop for the house, of choosing where food, crockery, and linen should be stored? Why should clients not share the excitement of choosing
and opening new packets of untouched kitchen equipment? Why should residents not launder the new bed linen? Why should residents not go out and choose the new pictures for their bedrooms and the living areas? Do people really need to move into a pristine house? When you move house does it matter if you end up eating an hour later than you are used to or if you go out to pick up a take-away?

The staff were given the responsibility for making ‘minor’ decisions such as which cupboards the drinking glasses were to be stored, whereas we feel that their role should have been to support the residents to make such a decision and carry it out. Unintentionally ownership of the house is promoted for the staff and not the residents and staff are encouraged to carry out tasks in a way that is incongruent with their espoused role. An opportunity has been lost and the wrong thinking has been endorsed.

5.9 Management and leadership

The role of the house supervisors

There is a strong belief that the position and role of the house supervisor is crucial to obtaining desired outcomes for Disability Accommodation Services’ (DAS) clients. There is evidence to suggest that the greatest influence on how a person actually behaves in an organisation is the ‘leadership’ of the person’s immediate supervisor (Georgiades and Phillimore, 1975).

Implicit in what we have already written is that supervisors, as managers, should live and believe in the values of the organisation, promote them amongst the staff he or she manages, and monitor how they are put into practice. Supervisors should help direct care staff to understand policy, rules and procedures in a way that is consistent with a client’s best interests and give feedback to his or her manager when they operate in the opposite way. Supervisors are not helped if the Department communicates ambiguous or conflictual messages about its own policies.

We have pointed out that their job is made harder if the roster is constructed in such a way that the supervisor spends a disproportionate amount of time with certain staff, and part-time staff cannot come to house meetings. Their job is made harder if the links between what they do and the organisational values and directions is not clear. Their job is made harder if they or other members of the staff group are removed from a house for significant periods of time, or vacant positions are unfilled for lengthy periods.

We are aware that there are plans to develop and provide ‘leadership training’ for house supervisors in the near future. This may be a good example of people in
the same organisation using the same term but having different understandings of what is required. The term ‘leadership’ is sometimes used to make a clear distinction from ‘management’, but the terms may also be used interchangeably. We would suggest that the supervisors who we have worked with would benefit from practising the knowledge and skills identified as being necessary for first-line managers (see Ford and Hargreaves, 1991, for example), such as being able to run a meeting efficiently and effectively, making best use of formal planned supervision meetings, managing poor performance, or being able to resolve conflicts between direct care staff. There may indeed be many supervisors who would benefit from leadership training, but whose needs can only be determined by a valid training needs analysis that considers the organisational context, the knowledge, skills, and abilities necessary to perform in the supervisor’s role, and an analysis of the people in those positions (Goldstein and Ford, 2002).

5.10 Conclusion

In this paper we have tried to show that issues should be understood in the context of an interrelated whole, and that the trajectory of the research could be amended so that we can explore some issues in a way that embraces this thinking.

An alternative is to stick to the original proposal and focus on individual and group learning and simply identify through our reports the systemic nature of what we are learning and leave it to the Department to address these issues in a systemic way.

Much of our early writing aims to open up debate, not close it off. We hope that this paper will challenge readers to think about the ideas that are contained within it so that they begin to develop a view about each issue and the relative importance of each one to the Department’s goals.

Possible areas for research

It is much easier to list areas that are worthy of research than it is to write answerable research questions. We hope that reading this paper will be a catalyst for readers to suggest future research areas. Here are a few ‘rough’ questions that we came up with in writing this paper.

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43 This is not the place to critique the literature on management and leadership. The writing on leadership often takes on a magical tone with pithy sayings like ‘The manager does things right; the leader does the right thing’. In the context of the supervisor’s role, Drucker’s (1989) conceptualisation of management seems useful. He writes that, ‘The fundamental task of management [is] to make people capable of joint performance through common goals, common values, the right structure, and the training and development they need to perform and respond to change’ (p.214).
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- What is the impact on direct care staff of Department of Human Services’ practices that are incongruent with espoused values?
- How can vague policy objectives be clarified for direct care staff?
- How can we provide as much individualised care as possible in a setting that is based on group living?
- How can we make this Community Residential Unit as homelike as possible?
- How can we provide and maintain a stable workforce in the houses?
- How can each roster in each house be made as client-centred as possible?
- What impact does a specific policy, rule or procedures have on practice?
- How can people who design and commission services be supported to consider the impact that their designs have on the attitudes and roles of the people who work in them?
- How can supported accommodation services be sited in environments that maximise the availability of community resources that promote social inclusion and client skill development?
- What impact do different types of transport have in relation to community access?
- How can transport to and from day programs be arranged so that clients spend the least amount of time in transit?
- Are rules and procedures that endorse separate staff amenities really necessary?
- How can information be made accessible and useful to front-line staff?
- How can the equipment and furniture that is purchased be best tailored to the abilities of the residents?
- How can the organisation’s financial controls be designed to give the residents maximum control of money and keep it safe at the same time?
- How can training best serve the purposes of learners and the organisation?
- What is the role of the house supervisor?
- How can people in the role of the house supervisor best be supported and developed?

April 26th 2006
Chapter 6: The story so far: An interim report

By Tim Clement, Chris Bigby and Kelley Johnson

6.1 Introduction

This report draws on our earlier papers about three houses in the *Making Life Good in the Community* project (Clement, 2006a, 2006b; Johnson, 2006) and should be read as an interim report that provides a synthesis of some of our findings to date. The earlier papers focused on the interactions and styles of support between staff and residents at the houses; the support that residents received to participate in meaningful activities inside and outside the home; and the skills and knowledge of support staff to promote community inclusion. These were some of the key questions outlined by the Department of Human Services in the original tender document (2004).

The primary audiences for our earlier writing were the staff groups who worked in the houses. The papers were written in a descriptive style and contained our experiences as participant observers, which were embedded in the accounts. As Johnson (2006) argued, being participant observers allowed us to gain insights about the pressures and issues that arose for the people living in the houses and the staff supporting them.

In those papers we suggested that describing events may suggest particular kinds of actions that can be taken, but held back from drawing out a series of prescriptions for people to follow, hoping that the people could learn through their own reflections.

We acknowledged that the descriptions of the houses in our papers were partial, in that it was impossible to describe everything that was happening in a particular house. Although some individual staff members have been uncomfortable with the perceived tone of our analysis, when taken as a whole the staff groups agreed that our descriptions were accurate. We are confident therefore that our accounts have some validity.

This report also draws on ideas within a fourth paper, colloquially known as the ‘upstream’ paper, which broadened the context of our writing by locating the houses in the wider organisational environment (Clement, Bigby, and Johnson, 2006a). This paper emphasised the systemic nature of some issues, and suggested that further inquiries needed to be made beyond the sphere of our relatively narrow investigations to date. In that paper we made our case for
amending the original research proposal so that we could facilitate the investigation of some of these systemic issues.

This report moves beyond description, to include analysis and interpretation. If readers want more evidence than space allows here, they should refer back to the original papers. Our findings are linked to the literature, in particular three variables that have been shown to be associated with variations in outcomes for service-users living in community-based residential services:

- Characteristics of the service-users;
- Characteristics of the design of services; and
- Differences in staff performance (Mansell, 2005).

Given that this is an interim report we also indicate some issues that remain to be explored and suggest what data we may need to collect. The tone is therefore more evaluative than the earlier papers and contains a greater level of abstraction, which is necessary if we are to communicate some generalities that will be useful to staff groups working in other houses. At the same time we must acknowledge the issues that develop in a particular house have some unique characteristics that arise from the interactions of the people living and working there.

6.2 The context

The redevelopment of Kew Residential Services aims to move the residents into 93 new houses across metropolitan Melbourne and regional Victoria (Department of Human Services, n.d.).

Although much supported accommodation uses ‘ordinary’ housing, the Kew Residential Services redevelopment has utilised a number of house designs that were purpose built. (See end note 25) Whether supported accommodation uses ‘ordinary’ housing or purpose built homes, the aspiration remains the same, to promote ‘ordinary patterns of living’ for the people who live in them (Felce and Perry, 1995).

Previous research has shown that it is possible for people with intellectual disabilities to have a good quality of life in smaller, more homely environments (Mansell, 2005). However, there are variations in the quality of community-based services, and variations may be as extreme within the same service model as
they are between service models (Hatton, Emerson, Robertson, Henderson, and Cooper, 1995).44

Houses were initially selected for the research using a range of criteria, where the overall aim was to include diversity rather than similarity. For example, houses were chosen in rural Victoria and metropolitan Melbourne; within different regions within Melbourne; with same and mixed gender residents; where there were variations in family contact; where known friends were living together; and with differing levels of support needs. In essence the research brief was to work with whatever was happening in the particular houses, to identify the good things that were occurring in those houses, practices that could be improved, and to disseminate any benefits for the entire organisation.

6.3 Data

We began our work in the houses in-line with our proposals in the tender document. Bigby and Johnson (2004) wrote,

‘In our view there is a real need to examine closely the day-to-day culture that develops in a house and to explore how this may impact on the lives of people living and working there’ (p.7).

In order to examine this day-to-day culture it was proposed that,

‘The first three months will involve intensive participant observation in each house. This time will be used to observe the culture in each house, get to know the staff, residents and families and become involved in day to day activities. Detailed fieldnotes will be kept of each participant observation session” (p.14).

Our earlier papers were written representations of particular aspects of the house cultures (Alvesson and Sköldberg, 2002; Van Maanen, 1988). Table 1 gives some broad information about our contact with the houses and the data we collected there.

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44 In the future, given that the Kew Residential Services residents are fundamentally moving into similar houses, with slight variations in staffing levels and building design, the Department is well-placed to investigate the differences between high and poor quality services, which may shed some light on the factors that account for such within-model variation. As high and poor quality services emerge over time, this makes it a different research project to Making Life Good in the Community, which can only be done in the future or by considering longer established houses that are not part of the current redevelopment.
Table 1. Data information for the three houses

<table>
<thead>
<tr>
<th>Domain</th>
<th>64 Penny Lane</th>
<th>96 High Street</th>
<th>16 Temple Court</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hours of participant observation</td>
<td>46</td>
<td>36</td>
<td>59</td>
</tr>
<tr>
<td>No. of days on which data was collected</td>
<td>9</td>
<td>9</td>
<td>11</td>
</tr>
<tr>
<td>No. of interviews</td>
<td>9</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Data set (Number of words)</td>
<td>58,000</td>
<td>20,000</td>
<td>29,000</td>
</tr>
<tr>
<td>Time from first contact to half-day meeting</td>
<td>198 days</td>
<td>110 days</td>
<td>167 days</td>
</tr>
<tr>
<td>Period of participant observation in each house from first contact</td>
<td>137 days</td>
<td>104 days</td>
<td>163 days</td>
</tr>
<tr>
<td>Period of participant observation from first shift in the house (excluding training)</td>
<td>55 days</td>
<td>68 days</td>
<td>30 days</td>
</tr>
<tr>
<td>Number of months that the house had been open at the end of the period of participant observation</td>
<td>5 months</td>
<td>8 months</td>
<td>5 months</td>
</tr>
</tbody>
</table>

At the end of the period of participant observation a half-day meeting was held with each staff team as a means of engaging them in the action research cycle. By giving the data that we had collected back to the staff team we were able to create a dialogue about how things were in the house, so that staff could reflect upon their observed practice and as precursor to identifying practices for change.

6.4 The service-users and the settings in which they live

Table 2 gives some information about the three houses, which we named as 96 High Street, 64 Penny Lane, and 16 Temple Court. The table does not reflect the uniqueness of the 16 residents and the differing levels of support that they require. However, the summary information appears as it was made available to us and reflects the criteria that were used for the initial selection of houses for the research as outlined earlier.
The three houses were set up to provide the residents with the long-term daily involvement of paid staff in the home environment, which Luckasson et al (2002) label an extensive support intensity. Two houses (64 Penny Lane and 16 Temple Court) have active night staff, whilst staff sleep-over in the third house.

In part, the variation in client outcomes that is reported in the research literature reflects the individual characteristics of people with intellectual disabilities. People with higher support needs experience poorer outcomes than people who are more independent (Mansell, 2005). In this regard the information in the ‘Support needs’ column is inadequate in clearly differentiating between the characteristics of individual residents.

Many definitions of intellectual disability have differentiated between degrees of impairment, which are measured on objective tests (Luckasson et al, 2002). It was never our intention to subject the residents in the houses to diagnostic testing. On the basis of our observations there are differences in the support needs of the residents in the three houses, with the residents at 16 Temple Court having the highest and those at 96 High Street the lowest.

In a small number of words it is hard to present people as rounded human beings. Blatt (1987) reminds us that, ‘Some stories enhance life; others degrade

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45 Documents that we have examined are given a number and a date when they were produced. In this case the document is number 17, but is not dated (nd).
it. So we must be careful about the stories we tell, about the ways we define ourselves and other people’ (quoted in O'Brien and Mount, 1991, p.1). The two descriptions that follow are adapted from written information that was made available to staff at ‘resident familiarisation sessions’ during the transition training. They present a limited view of two men, being drawn from two of a wider range of information and planning documents but illustrate the varying support needs of the residents, which may be of help to readers.

‘Christos (57, a resident at 16 Temple Court) has severe intellectual disability, epilepsy, and spastic quadriplegia. He is a thin man who weighs 31kg. He needs full staff assistance to wash, dress, undress and attend to his personal grooming. Christos is showered and dressed on a shower trolley. A hoist is recommended for all transfers. Christos uses incontinence pads both day and night. He sleeps in an electric bed with cot sides and uses a v-shaped pillow to maintain an upright sleeping position. Christos uses a manual wheelchair and is unable to manoeuvre himself without staff assistance. He has limited protective behaviour and no “stranger danger” awareness. He would be vulnerable if exposed to aggression as he would not vocalise if injured. Christos is non-verbal and has limited means of communicating his needs. He reacts to touch, looks at people momentarily, and begins to show anticipation. His meals are vitamised and his drinks are thickened due to having aspiration pneumonia two years ago. He has a history of reflux oesophagitis, dysphagia, gastric ulcer and chronic constipation. Christos is a very slow eater. He enjoys eating all types of food, particularly chocolate, pureed fruit, and custard. Christos likes monthly visits from his mother, bus trips, spas, back rubs, massage and listening to soft music’ (D/19/nd).

‘Paul (51, a resident at 96 High Street) is verbal and is able to effectively communicate his needs. He can initiate and maintain a conversation and likes to converse with staff. He has good receptive communication skills. He is able to follow two-step instructions. Paul likes to be offered a choice rather than be directed. When he decides not to participate in activities it is extremely difficult to get him to change his mind. He likes playing tennis, watching SBS and the ABC on television in his room. He likes going out in the evenings with staff to dinner or to the movies. Paul suffers from epilepsy, having one seizure a month, lasting two to three minutes. He recovers well after his seizures. Paul does not have contact with his family’ (D/18/nd).
Given that the level of impairment is an important variable between the residents, we should acknowledge that this is a significant difference between the three houses and may be a contributing factor in the lifestyles that we described in our earlier papers. It is also the case that people with severe and profound intellectual impairments are more likely to have additional impairments and higher health needs.

Providing high quality services to people with profound intellectual disabilities, who may have additional impairments and complex health needs is certainly a challenge, but it is not impossible. There is a view that people with severe and profound intellectual impairments are a ‘special population’, which is implied in statements like, ‘That may be okay for their son and daughter, but not mine’ or ‘That may be okay for people with mild intellectual disabilities, but not the people I work with’. There is some evidence in our findings that some staff members are articulating like-minded thoughts. The degree of impairment therefore seems to us to be an important variable in relation to the aims of these houses. It appears to us that staff find it much harder to think through the relevance of espoused values, formal policy, rules and procedures when supporting people with severe and profound intellectual impairments, who may also have other impairments and complex health needs.

6.5 Client lifestyle and outcomes

We agree with the sentiments in the Department’s own literature that the redevelopment of Kew Residential Services provides people with intellectual disabilities with the possibility of better lives.

‘With its outmoded buildings and over-crowding, the conditions at Kew Residential Services make it difficult to deliver the quality of care and standards of privacy and dignity that people with disabilities and their families are entitled to expect’ (Department of Human Services, n.d.).

The purpose-built houses have instantly provided the residents with an improved material environment. Supporting residents to enjoy an all-round improved quality of life will take longer. It should be remembered that when we started our observations the three houses had been open for only six, four and three months.

We thought that a comment made in the steering committee for the research was telling, that the descriptions of the houses could be read more positively if they were understood as being a step on a longer journey towards the type of lifestyle envisioned for people with disabilities in the Victorian State Disability Plan (State Government of Victoria, 2002). However, it is not inevitable that residents’ quality
of life will continue to improve, or if it does that it will be sustained over time. Indeed, there is plenty of research evidence that shows services decay over time (Emerson and Hatton, 1994).

Our preliminary findings from three houses mirror those from quantitative research studies, which suggest that the opportunities that exist for residents to enjoy a good lifestyle in small housing are not being fully exploited. The importance of our ethnographic work is that we are beginning to gain some insights into the dynamics that maintain this pattern of service provision or shift it in a positive direction in a way that is not possible from quantitative studies.

If we were to summarise what we have observed in the first three houses so far, we could probably do no better than use words from Emerson and Hatton’s (1994) review of 71 published research studies examining the effects of the move from institutional to community care on people with intellectual disabilities. They suggested that from the available evidence:

‘Users of community based residential services: are relatively poor; develop few new skills once they have settled in the community; have few, if any, opportunities for choice over such life defining decisions as who to live with and who to be supported by; have few opportunities to exercise choice over everyday routine matters; have few relationships with non-disabled people, other than care staff who are paid to be with them; have little real presence in their communities; spend much of their day waiting for activities to happen and receive little active support from staff’ (p.43).

Contrasting what we have observed with findings from larger studies is useful for a number of reasons, as it suggests that the issues that staff are facing in a single house are not unique. This may help staff working in those houses to overcome any individualised feelings of reproach. It should also caution senior managers from thinking in an over individualistic way and direct them to systemic solutions. It may also stop non-participants distancing themselves from findings that arise from single ‘cases’ where a common response is to say, ‘Well, it may be like that in that house, but it’s not like it where I work’. Locating this research in the aggregated findings from similar settings suggests that manifestations of all or some of the issues that we have identified are likely to be found in many of the houses under the Disability Accommodation Services’ umbrella.

To date the quality of life of the residents in the three houses we have observed falls short of the high ideals which the Department’s values, principles, standards, and goals point towards, as described in the earlier chapters. The aspiration for
the action research element is to provide the houses with some forward momentum.

6.6 Values

We have been clear in our writing that the benchmark against which we have been testing our observations are the Department’s own values, principles, standards, and goals (Department of Human Services, 2002; State Government of Victoria, 2001, 2002).

It is perhaps disappointing for some people to read that what we have observed has fallen short of the Department’s own benchmarks. Yet the standards that the Department sets are exacting. The Victorian State Disability Plan, for example, ‘reaffirms the rights that people with a disability have to live and participate in the community on an equal footing with other citizens of Victoria’ (p.1).

In his reflections on deinstitutionalisation Tøssebro (2005) writes that in moving to community-based residential settings the lives of people with intellectual disabilities are better only in some regards, and suggests that in others their lives remain the same as they were in institutions. Despite all the progress that has been made by health and social care agencies in the past decades, Dowson (1997) suggests that once we begin to compare the quality of life of people with intellectual disabilities with the lives led by non-disabled people, we still fail miserably. The challenge remains for us to support people with intellectual disabilities to make their lives as good as they can be.

Qualitative research in general and action research in particular emphasize a continuous examination of the assumptions that are operating in the research arena. In our writing we do our best to clarify any assumptions we hold about how support should be organised. Although people may share some common ground, they will also have different values, knowledge, and experience. Articulating assumptions allows a space for discussion about different ways of supporting people with intellectual disabilities. Yet lack of consensus about what these concepts mean can result in lengthy arguments, anger, despair, resentment, and de-motivation (Hudson, 1995).

We have made the point that many of the concepts embedded in the Department’s documents are hard to define and apply, which often means that they are poorly understood and implemented by front-line staff. This may go some way to explaining why we have observed examples of interpersonal conflict between employees who seemed to have different attitudes, expectations, and motives about how to go about their jobs. We have also experienced this...
firsthand when working with the respective staff groups, when our own views have clashed with some Departmental employees. Bridging the gap between these views is a significant challenge in planning and taking action in this project. This gap seems to be more apparent when scrutinising the lives of people with profound intellectual impairments.

It may be difficult for those staff and family members who hold the view that people with profound intellectual disabilities are a ‘special population’ to see that they are able to participate in ways that other people with disabilities can. If this is the case it may be fruitful to investigate the assumptions that staff and family members hold about residents in the houses and the interplay between these assumptions and the Department’s espoused values.

Not only does this mean looking at ways of making the Department’s espoused values ‘practical guides for action’ for people supporting residents with profound intellectual disabilities, but also to critically examine the premises that underpin the espoused values and ask whether they are the ‘right’ values.

As well as struggling to see the relevance of these values and policies, staff may vary in how central they are to their own belief systems. Front-line workers take day-to-day decisions about what is important on any particular shift. Not surprisingly physiological and safety needs are routinely privileged over practices that would encourage self-determination, individual lifestyles, or building inclusive communities. Values are organised hierarchically in terms of importance (Rokeach, 1968). Some of the interpersonal conflict we have witnessed and experienced may be because different research participants order their values differently. Probably everyone agrees that it is important to make sure people have enough food to eat, but there is less of a consensus about the extent that residents should be involved in the purchasing and preparation of their food.

We ask that readers of this paper check out their own assumptions against what is written, so that areas of agreement and disagreement can surface in the discussions that follow. This seems to be paramount in building a consensus that can be clearly articulated within Disability Accommodation Services.

It is worth making two final related points about such benchmarks.

Firstly, they are aspirational and serve as guides for both individual employees and the organisation. Our findings suggest that some practices that we have observed do not reflect the Department’s espoused values. It is therefore important to reflect on the Department’s benchmarks themselves in terms of their feasibility and generalisability. It is difficult not to agree with them in principle or
conceptually. However, putting these benchmarks into practice requires careful consideration of the context in which people are living their lives, the needs of particular individuals and the skills and knowledge of the people around them.

Secondly, a function of these benchmarks is to create dissatisfaction with the status quo, so that employees strive to meet these high standards (Proehl, 2001). It may also be the case that if standards are perceived as being unrealistic they may have a very different impact.

6.7 Staff performance

Mansell (2005) writes that, ‘The way staff provide support to the people they serve has been singled out as a key determinant of outcome’ (p.25). In this section we comment on the support residents receive in the houses to participate in activities inside and outside of their homes.

**Inside the homes**

We have been struck by the good qualities of the staff we have encountered. They seem to us to be committed to the residents and express a great deal of care towards them. However, we did observe events and issues which we thought needed attention.

At 96 High Street we claimed that staff were the principal actors and discussed this dynamic using the concepts of the hotel model; parent – child interactions; and ownership (Clement, 2006b). Having the dominant, more active roles meant that staff had the lead in the day-to-day running of the house and the residents had minor roles. This dynamic was also evident in our observations at the other houses.

This impacted on the parameters of resident participation, how activities were set up, the choices that were made available, and on occasions staff relieving the residents of all or partial responsibility for household tasks. A major consequence of this, which we witnessed in all three homes, is that the residents could spend substantial periods in their own home disengaged.

Given the extensive support that the residents require in all three houses, there were times when the residents received significant support from staff. This was centred on tasks associated with ‘care’, such as getting up in the morning, showering, dressing, feeding, and attending to health needs. Other research studies have found that outside these personal care tasks much of the staff attention given to residents is in the form of communication rather than enabling people to participate in an activity (Felce and Perry, 1995). From our observations
there is some evidence that people are interpreting participation in a very narrow, passive sense. At 16 Temple Court, for example, moving residents so that they can watch staff carrying out tasks in the kitchen staff seems to have been suggested as an end goal.

In Chapter 2 we stated that moving Kew Residential Services residents into their new homes is predicated on the belief that services should aspire to promote patterns of ordinary living for all people with intellectual disabilities. This is because the extent to which people spend their time engaged in social, personal, leisure, and household activities is understood to be a significant feature of their quality of life (Felce and Perry, 1995). It has become clear from our discussions with the staff groups that some employees do not see these tasks as straightforward, achievable, or a high priority for the residents they are working with.

Staff experience the first part of the morning at 96 High Street and 16 Temple Court as pressured. There is a short period of time in which people have to be supported to get up, washed and dressed, have breakfast and get on the bus to go to the day program. Although one may understand if staff take short-cuts at this time, although not condone it, the same behaviours can also be seen at other times of the day, when there are less apparent pressures.

**Supporting residents to participate in activities**

Jones et al (2001) state that if people with intellectual disabilities with limited independent skills are to participate in activities, three factors must be present:

- An available activity
- Available staff support and
- Matching the level of assistance given by support staff to that which is required to participate successfully.

The fact that staff sometimes complete all or part of some domestic activities with no or little resident participation impacts directly on two of the three factors. Firstly, activities like cooking, cleaning, and laundry are removed from the available list of opportunities in which residents can participate. The houses were not so ‘activity-rich’ that they could afford to reduce the number of available activities. Secondly, the staff member has effectively made him or herself unavailable to support a resident in another activity.
Felce and Perry (1995) argue that the driving force for the engagement in these activities is, ‘the desire to take responsibility for the conduct of one’s own daily life and to learn and be supported to do domestic chores such as cooking and cleaning’ (p.800). This argument, rooted in the principle of self-determination, has been repeatedly made by articulate self-advocates (see Attrill, n.d., for some views from residents living in CRUs in Victoria). Indeed, we observed at 96 High Street that the most articulate resident, with the most adaptive skills, seemed to do more activities than the other residents and was more willing to do jobs around the house. It is typically the case that residents with the relevant adaptive skills are given or make their own opportunities to be involved in domestic activities, whilst staff do the same tasks for people with more profound and severe impairments (Felce et al, 1998) In such circumstances people who are most able are likely to receive more attention and support than those who need it most.

Yet the point is well-made by the same authors that the claim that people want to take responsibility for the conduct of their own daily lives has to be accepted by the staff working with people with severe and profound intellectual impairments and applied in their everyday practice. All of the residents at 16 Temple Court would fall into these categories, as would some of the residents at the other two houses.

All of the residents moved into the houses with a recently updated communication assessment, but there was little in our observations to suggest that staff were using the information proactively. Most of the residents in the three houses have difficulties in both understanding and using language and other symbolic forms of communication. In such circumstances many decisions about the opportunities offered to people and the way in which they are supported are effectively made by staff (Jones et al, 2001). When this is the case it seems essential to unpack the assumptions about one’s practice, to explore who is doing what to whom and why.

We would lean towards the assumptions underpinning active support. Jones et al (2001) explain that, ‘Active support tends towards the assumption that people would prefer to be occupied than not and to undertake the same range of activities as other people, unless they have given a contrary indication’ (p.356, our emphasis).

The social relationships that we described specifically at 96 High Street, where staff were the principal actors, had also effectively been made by staff, but based on very different assumptions. The particular research methodology we are using
in this project means that we are beginning to uncover people’s beliefs about their work and the assumptions they hold about people with intellectual disabilities. We might infer that such practices are more in tune with ‘caring’, ‘looking after’, and ‘efficiency’.

The principle that residents should learn and be supported to do domestic chores should be constant across all houses, but what should vary between houses and between people is the third factor given above, matching the level of assistance given by employees so that residents can participate successfully. The resident is seen as the person doing and owning the task, and staff are expected to give whatever support the person might need to complete it.

It is possible that a common sense understanding of ‘independence’ is a barrier to this way of working, especially if there is a tendency to think in binary opposites. The particular conceptualisation of independence that still has a strong hold on services for people with intellectual disabilities is the ability to look after oneself without the help of others. Our observations and discussions with staff suggest that this understanding of independence is held by a significant number of staff in the three houses. Thus, people are either independent or they are not. It is self-evident to the staff working with the men at 16 Temple Court that this concept has virtually no application.

A more useful conceptualisation of independence in such a setting developed from within the disability movement, and relates to the choice and control people are able to exercise over their lives whether or not they need assistance to do so. The actions of other people, especially personal assistants, can bring about independence (Swain, French, and Cameron, 2003). As with the argument about engaging in domestic activities, this argument too has to be accepted and applied by front-line staff.

It is important to clarify what the aims of participation, involvement and engagement are for people with more profound and severe intellectual impairments, since their ability to engage in many tasks without the help of others is limited. For people with severe and profound impairments the role of staff is to make opportunities possible for residents to engage in activities and give them the support necessary simply to participate in them (Felce, 1998). For many people doing things without the help of others may be an unrealistic goal, whereas participation is always possible. Given the importance attached to

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46 ‘Independence is not necessarily about what you can do for yourself, but rather what others can do for you, in ways that you want it done’ (Ryan and Holman, 1998, quoted in Swain et al, 2003, p.79).
participation we would ask how this task could be accentuated in the role of front-line staff.

The final part of the above quotation from Jones et al (2001) is problematic. How should we respond when residents appear to indicate that they would prefer not to be occupied and not to undertake the same range of activities as other people? We described instances when the behaviour of some residents was interpreted to mean that they did not want to participate in an activity that was offered to them and highlighted this as a practice dilemma, which can only be resolved through discussion and testing out in practice.

One strategy may be to expand the choice and control that is available to each resident. A response may be to renegotiate the task, so that the person chooses when they do it and the support they get to do it. LaVigna (2005) suggests that the right to choose is not absolute, particularly when choices are made primarily to avoid participating in activities. He argues that in such circumstances people may end up having a poor quality of life. These are discussions that need to be held (if possible) with the particular residents and within the supporting staff team and family members where relevant.

Implicit within this discussion are two different ways of working with people with intellectual disabilities, which are related to the level of impairment. Some residents may be able to take more control of their lives and make choices. For those staff working with people with profound impairments they have to accept the arguments laid out here and find ways of incorporating them into their practices.

**Community inclusion**

An early hope of deinstitutionalisation was that people with intellectual disabilities would become included in the mainstream of life, rather than live segregated lives. This hope has yet to be widely accomplished (Felce et al, 1998). For a number of reasons our research to date has had a strong focus on community inclusion. The original tender posed questions around the support that residents received to participate in meaningful activities outside the home, and about the skills and knowledge of support staff to promote community inclusion (Department of Human Services, 2004). The Department has articulated its commitment to building inclusive communities (State Government of Victoria, 2002), an aim and aspiration shared by the research team. We participated in specific training on developing community connections that was arranged for the staff teams during their transition training and on a subsequent course three
months after a house opened. We joined in community activities during our periods of participant observation in the houses. We met with the Community Inclusion Officer in the Eastern Metropolitan Region, and our work has become increasingly intertwined with hers as she has begun her interventions in the three houses. Staff practices to support community inclusion were discussed with all three staff groups at separate half-day meetings.

In the time that the houses have been open a similar pattern of activities has emerged in each of them. The focus has been on increasing the number and variety of ordinary places that the residents know and access, such as shops, cafés, and parks. The tendency has been to take out groups of residents to activities and places. It is probably fair to say that the residents have greater community presence since moving to their new homes. In contrast to their lives at Kew Residential Services these people probably go out in smaller groups, more frequently, and experience a greater variety of activities than they did in the past.

Given the specific training that the staff groups had received we were surprised by their focus on community presence and narrow understanding of the goals of community inclusion. The abundance of terms that are available to discuss the end goals of building inclusive communities seems to confuse rather than clarify. They do not have the same meanings, but people tended to see them as interchangeable. In our discussions with the staff groups and in our writing we have used O’Brien’s (1987) distinction between Community Presence and Community Participation to draw attention to these different facets of building community47. In general staff expressed an understanding of community inclusion solely in terms of community presence and their efforts to date have supported this outcome. Our attempt to persuade people to supplement this aspect of their work with supporting community participation has met some resistance. An emphasis on creating community presence in the form that we have observed is unlikely to achieve the goal of building inclusive communities outlined in the Victorian State Disability Plan (State Government of Victoria, 2002) with its emphasis on equal social, economic, cultural, political and spiritual opportunities.

O’Brien (1987) makes the point that the service accomplishments are interactive. It is therefore possible that community presence could lead to community

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47 ‘Community Presence’ refers to the sharing of ordinary places, rather than the use of segregated facilities. O’Brien (1987) argued that people should be supported to increase the number and variety of ordinary places that a person knows and can access. In addition, many disabled people usually have small social networks, which are typically made up of other clients, staff, and immediate family members. The aim of ‘Community Participation’ is to expand these networks to include non-disabled people, so that they experience being part of a growing network of personal relationships that includes close friends.
participation. Only by taking a closer look at the types of activities that we have called community presence can you make a judgement about whether they will lead to a growing network of personal relationships that includes close friends (that is, community participation). Trips to the beach or cinema, shopping at the supermarket, or buying clothes in the company of service-based supports are unlikely to result in the formation of close friendships.

We should not underestimate the scale of the task facing the staff at the houses. People with more profound impairments tend to have the most limited social lives (Felce et al, 1998). As one might infer from the description of Christos in Section 6.4 (above), health issues are a prime consideration for the staff group at 16 Temple Court. Three of the men are subject to epileptic seizures, which can be severe for two of them whilst the third has frequent milder ones. One of the other men in the house has Parkinson’s disease and also suffers from asthma. Four of the men use wheelchairs although two of them can walk very short distances with support. The house supervisor spoke clearly about her priorities:

‘We do the best we can, one step at a time. First and foremost in the house the priority is client care. Recreation and other things come along. Client care is our priority. If there is spare time you can go for involvement. People should be fit, clean, and comfortable. The other things come after that’ (F/TG/280206).

Three other aspects of building social connections are worth mentioning: contact with family members, neighbours, and other Department of Human Services’ employees and service-users.

Of these three domains, probably the most energy has been put into developing links with staff and residents in other Departmental supported accommodation, particularly with other staff and residents who have relocated from Kew Residential Services. Sometimes this has been driven by pragmatic concerns, such as sharing a bus ride to a day program. In other instances it has focused on maintaining contact between residents and staff who used to know each other at Kew. It does seem to be the case that some staff have a strong need to maintain links with other staff members. We described these links as bonding relationships, that is relationships between people who have things in common, such as a shared Kew history, being Department of Human Services employees, being service-users and having the label of intellectual disability (Putnam, Feldstein, and Cohen, 2004). Although such links may be important to individuals or may serve a functional purpose, unless they are supplemented by other types of relationships then residents are likely to remain within the ‘service culture’.
Many of the ex-Kew staff whom we have talked to speak about their time at Kew passionately.

‘I remember in the beginning I found the transition [to the new house] a little bit difficult. Maybe isolation is too big a word to use, you come to work and that was it, the people who came in for the day, they’re the people that you would see. Compared to Kew you would see a number of people throughout the day. I know a lot of people put Kew Cottages down and I get very insulted when they do that. I never looked at Kew as a disgusting place, as a bad place. I looked at it as a place where I went to work and I was very privileged and fortunate to have met a lot of residents and a lot of people. I spent half of my life there. Although there were some bad things that happened I think there were more good things than bad. When Kew Cottages was at its best I used to love going to work. It was a very social thing. There was a harmony, there was solidarity. You could have 47 residents in a unit and we worked very hard. Although you could be bathing 16 people, the lifting you had to do with your arms, I can’t express it properly...when there’s hardship there’s a team spirit and solidarity. It’s very hard to explain but you’re together and you support one another. Through hardship and struggles you form very close bonds. When there was party time everyone came. I don’t know what that is. I don’t know if it’s a particular group of people. I don’t know if it was an era or a time, but when I left I cried, I felt very emotional. That’s how I remember that, good times’ (I/LW/261005).

Given such intensity of feeling it should not be a surprise that energy has been put into making links with staff and residents in other houses.

Another bonding relationship is the contacts that people have with their family. Although the amount of contact that residents have with family members is variable, staff generally expressed views that supporting, maintaining, and increasing the amount of contact with family members is desirable. We observed some good examples of supporting family contact through telephone calls, facilitating visits, and invitations to organised functions. In fact Paul, who was said to have no contact with his family at Kew Residential Services (see Section 6.4), has had visits from his sister at 96 High Street.

Building inclusive communities will rely on bridging relationships, that is making links between people who do not seemingly have things in common (Putnam et al, 2004). In two of the three houses so far studied, we were made aware of proactive strategies to initiate contact with new neighbours, although the general...
view is that this has not been very successful. *(See end note 26)* We plan to work closely with the Community Inclusion Officer at 64 Penny Lane in the next phase of the research.

**Day programs**

All but one of the 16 residents attend day programs on a full or part-time basis. Only at 16 Temple Court have we observed residents at their day programs. Concern about a lack of connection between the day programs and the houses was strongly articulated at two of the houses, but was an issue at all three, with few opportunities made to visit the respective settings or communicate effectively between the staff groups. Some residents carried diaries between settings as a means of passing on information.

Our visits to day programs allowed the researcher’s observations to be shared with the staff teams, which was especially useful when a person’s experiences were quite different to life at home. The lack of connection means that possible changes that might be taken up either in the home or day programs were not because staff do not know what is going on in any detail at each setting. This would be a fruitful area for future research, but will not be a significant feature of the *Making Life Good in the Community* project because of resource constraints.

### 6.8 The design of services

Variation in outcomes for service users reflects the design of services (Mansell, 2005). Amongst other variables, researchers have investigated the impact of architectural design; décor and equipping of buildings, group size, staffing, and location (Felce and Perry, 1995).

**Physical buildings and equipment**

We wrote at length in our earlier report about the physical character of the buildings (Clement et al, 2006a). The houses provide a good physical and material environment for the residents, with the typical range of rooms, such as kitchen, laundry, and own bedroom. Providing such an environment, equipped with the normal range of domestic equipment provides the necessary context in which to promote typical patterns of living. Yet our findings have reinforced the messages from the research literature that the use of small size houses with good material standards is not sufficient to promote these typical lifestyles48.

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48 We have been playing around with the idea that the newly built and furnished houses have contributed to the inertia that we have experienced in the houses. The buildings, furniture, and buses are highly visible cultural artefacts, which staff understand to have cost about one million dollars per setting. The spoken message that we have put forward is that residents’ lives are not as good as they could be. This does not match the subliminal message reflected by the quality of the houses, which
We also made the point that although the Department aspires for these houses to be people’s homes first and workplaces second, there are some factors that may work against this, such as the similarity in design, décor, and equipment, and the provision of separate staff amenities. This is because the design of services reflects and reinforces attitudes and role perceptions and this shapes what people within those services can see and do (Wolfensberger, 1975). In addition, the longstanding practice of commonly referring to the buildings as Community Residential Units (CRUs) does not reinforce the desired message that these are people’s homes.

Given that the buildings, furnishings and equipment were brand new it was not surprising that there was a strong emphasis on keeping the houses clean. Staff were proud of the new houses and were looking after them in a way that one often does with new belongings, trying to maintain them ‘as good as new’. Unfortunately, we observed this did not always involve the residents. Privileging cleanliness may have the unintended consequence of maintaining the feel of a ‘display home’ rather than giving the houses a homely appearance. We acknowledge that it takes time to turn a house into a home, especially when the residents have few personal belongings.

In their review of the implementation of the ‘All Wales Strategy’ Felce et al (1998) suggested that when services come under pressure they can all too easily adopt formulaic, standard approaches. We noted that supplying the houses with identical equipment was sometimes done at the expense of tailoring equipment to the needs and skills of individual residents.

For example, to be able to operate the supplied mops and buckets successfully on your own you have to have ‘normal’ motor skills, which may be impaired in some people with intellectual disabilities. Whereas some service-users might be able to mop the bathroom or their bedroom on their own with a different type of mop and bucket, the degree of coordination that is required means that with the supplied equipment it will always be a job the requires the support of someone else.

The new houses have been provided with mini-buses, which can accommodate all the residents and the supporting staff. This may encourage large group trips, which were a dominant type of outing. It has also been suggested to us that staff seem to suggest the opposite (see Proehl, 2001).

49 This is a good example of how different people rank order their values differently. For some staff keeping the house clean was more important than engaging residents in an activity.
who are not confident about driving the buses will select or rule out activities by considering the ease of driving and parking.

**Location**

The areas where services are sited have important consequences for how people with intellectual disabilities are seen and the type of skills that they can develop (Wolfensberger and Thomas, 1983). We were not given a brief to thoroughly evaluate the neighbourhoods in which the houses have been built, but during our time at the houses we looked out for the availability of community resources, such as shopping options, public services, spiritual centres, and recreational facilities.

The three houses are all sited in quiet residential streets. The immediate neighbourhood surrounding 16 Temple Court is primarily residential, whereas 64 Penny Lane and 96 High Street are sited in multipurpose neighbourhoods.

Unfortunately other than its residential character the immediate neighbourhood for 64 Penny Lane is industrial, close to a busy road, which is used by a large number of trucks. 96 High Street has some public services, spiritual centres, and recreational facilities close by. As four of the residents at 16 Temple Court use wheelchairs, they are more reliant on their mini-bus than residents of the other houses. However, in general the location of the houses means that the residents are dependent on being driven to shopping facilities, cafés, and restaurants that are some distance from where they live. This has implications for social inclusion within the local neighbourhood.

**Group size**

Six people live at 96 High Street, and five residents live in each of the other two houses. Although group size provides an initial advantage in providing high quality services, they are no guarantee of quality services (Felce, 1998).

In any congregate setting there is always a tension between meeting the needs of the individuals and considering group interests. Mansell et al (1994) point out that in a group setting an entirely individualised approach is inadequate and leads to the group dimension being neglected. In this regard we would suggest that each staff group needs to do some thinking to clarify how staff should work when there is a tension between individual and group needs.

There were a number of examples in the ‘upstream’ paper where our thinking was at odds with the practices we observed. Two examples we used were how laundry was done and how mealtimes (especially lunch and dinner) were organised. We
acknowledged that there are many ways to undertake these tasks. We proposed that we would organise laundry along individual lines, whereas the group dimension was privileged in the houses, and we would extend the boundaries of the group to include staff at mealtimes.

This is because we believe that as much as is possible the adults in the house should be responsible for the care of their own laundry, whether this is done independently or with support. Where possible staff and residents could sit down together to eat the same meal, which frames it as a genuine social occasion and allows staff to model table manners, and give support from a more natural position, rather than ‘waiting’ on people (see Schwier and Stewart, 2005). This may not always be possible where people require a lot of physical assistance to eat.

**Staffing**

In the upstream paper we commented extensively on the staff rosters. We suggested that they were staff-centred; worked inflexibly; and contained a number of hours that were not used effectively. In addition supervisors’ hours were not well allocated to manage the entire staff team; house meetings were scheduled when residents were home from day programs, from which part-time staff were excluded; and there were some systemic practices that created more instability in the staff group than might be necessary.

Having said that, in comparison to Kew Residential Services the staff—client ratios are better at the houses, which former Kew staff have commented on positively. However, the relationship between staffing levels and quality of life is not straightforward. It is not the case that increased staffing produces more support directed towards the residents (Felce and Perry, 1995). Staff may often spend more time doing organisational or domestic duties independently of residents.

64 Penny Lane and 16 Temple Court opened with a number of staff vacancies, which are still not filled. This meant that the houses were making use of casual employees. Although we observed some excellent casual employees, a stable, skilled workforce is integral to providing quality services (Lakin et al, 2005). Our own experiences as new people in the houses reinforced how hard it can be for casual staff to provide good support to the residents, even with good procedures in place.
Beyond building design, size, location and number of staff

The single service attributes discussed above are usually referred to as necessary but not sufficient aspects of quality services. There are other organisational attributes that services ‘design’, such as policies and procedures. Systems for planning, supporting, and monitoring resident activity are associated with positive outcomes (Emerson and Hatton, 1994).

In their reflections on the implementation of the ‘All Wales Strategy’ Felce et al (1998) pointed out that people seemed to hold the belief that if we changed the housing environment to small homes then this was sufficient for other outcomes to follow. They proposed that we need to structure the delivery of support in a way that the evidence suggests is associated with positive outcomes in order to take advantage of the inherent opportunities that are found in smaller houses.

Training

In the upstream paper we commented on the time, effort, and money that the Department spends on staff training in order to give employees the knowledge and skills to accomplish their roles. We acknowledged that effective training is a difficult and complex task, and suggested that some of the sessions that we observed fell short when measured against best practice models. We thought that some of the messages that we heard being transmitted at some of the observed training sessions were ‘off-message’, by which we mean they were not in accordance with the intended Departmental position. The strongest example of this was unintentionally promoting ownership of the house for the staff rather than the residents during the transition training. (See end note 27) We thought that some generic training was missing the mark because it was not sufficiently grounded in the experiences of the staff group or the characteristics of the residents they supported. We thought that the Department probably had little idea as to whether training had effected changes in the practices of direct care staff or improved outcomes for service-users. We were able to track the impact of the Community Connections training in particular. Although we thought the communication training was effectively delivered on the day, the failure to plan any learning transfer or post-training learning support (a ‘train-and-hope’ approach), will have contributed to the circumstances that we described in the three houses where the information available to staff in the residents’ communication assessments is not being used effectively. (See end note 28)

Staff training is consistently identified as a key factor in supporting the outcomes desired for service-users. Mansell (2005) suggested that most of the training
received by front-line employees covers minimum statutory requirements and basic introductory material, which suggests that the training front-line employees receive is not sufficient to instil the skills, rules, concepts, or attitudes that result in the required performance (see Goldstein and Ford, 2002).

The patterns of interactions that we have described between staff and residents in the three houses suggests that overall there is not a critical mass of staff in each house who have the knowledge, skills, abilities or orientations to promote high levels of participation inside the house or facilitate community participation outside of it. ‘Active support’ training, which the Department has subscribed to, is said to be an essential component of high quality services (Felce et al, 1998), as it gives practical training for staff about how to interact with people with intellectual disabilities in a way that provides effective support. This has been shown to have a significant impact on the level of assistance received by people with more severe intellectual disabilities and on their engagement in activities (Jones et al, 2001). The Department has commissioned separate research regarding the implementation of active support.

It is worth making the distinction between practices which may be a direct result of receiving formal active support training and practices that mirror active support — as a Disability Development and Support Officer it is possible to support residents with severe intellectual disabilities in a way that promotes high levels of participation without having had active support training. This may be because people ‘instinctively’ bring a person-centred approach to their role or they may have been socialised into that role by a supervisor or other influential work colleagues. It would be an error to assume that high levels of participation can only happen in a particular house when active support training has occurred, given the logistics of providing this training to every single staff team. The Department needs to find other ways to promote what we might term ‘active support approaches’ as a separate strategy.

As we have loosely agreed with the staff team at 16 Temple Court that improving the level of resident participation inside the house should be the focus in the next phase of research there, we have proposed that the active support training should be offered to this staff group.

**Working methods and the organisation of staff resources**

A key element of implementing active support is establishing clearly defined organisational procedures. In the three houses we found no formal systems for planning resident activities in consistent operation or formal systems for how staff
would allocate their time on a specific shift. We described routines running by habitual action rather than concrete planning, where formal hand-over time was not utilised, where planning was more likely to be done on an improvised basis, perhaps during a coffee break, or staff accepted tasks tacitly, because they were seen to be the better cook, or were the only driver, for example.

This is not to say that residents’ lives in the houses were not highly structured. Indeed, most people’s lives are organised along routines, by which we mean a more or less unvarying sequence of actions. Often we take routines for granted rather than spending time thinking about how they came about or what their function is. Two of the three house papers were organised in such a way that they outlined a ‘typical’ day in the life of the houses (Clement, 2006a; Johnson, 2006). During the weekdays people were woken up, helped to shower and dress, ate their breakfast, and then were driven to day programs. The house was cleaned. Dirty laundry was washed. Any residents who remained at home had ‘morning coffee’, then lunch, and may have had a trip out before people were picked up from day programs. On return people had a snack, relaxed whilst tea was cooked, which they ate, relaxed some more before having supper and going to bed.

By labelling such routines as habitual action, we were suggesting that there seemed to be little conscious understanding as to why routines were organised that way. This can be useful as it frees up our minds to do other things, but it can also become problematic. It is when life becomes regular, mechanical and unvarying that ‘routine’ is used in a pejorative sense.

Some residents’ learnt evening routines were seen as an issue in two houses, where residents would get changed for bed after tea or immediately go to bed after supper or a drink that they perceived as supper. We wrote how one of the night staff at 96 High Street had employed conscious strategies to change these ‘fixed’ behaviours.

Process and premise reflection asks us to think about how we are performing and judging certain activities (Mezirow, 1991). For example, making a judgement — that leaving the residents to ‘occupy’ themselves whilst a staff member cooks tea is poor practice — requires us to ask ourselves whether we could have misinterpreted our observations. At 64 Penny Lane, for example, the supervisor has tried to instil a relaxed atmosphere in the house. Could it be that leaving the residents to occupy themselves is part of this relaxed atmosphere? Are the concepts of poor and good practice satisfactory for understanding and judging
what we have observed? We would suggest that questioning the way that things are done in the houses and the assumptions underpinning the processes are always useful exercises.

Let us be clear that we are not criticising routines per se. Many people like structure, and people can learn through routines. Indeed highly structured routines in the form of teaching programs have been the cornerstone of helping people with intellectual disabilities to learn new skills. We have also made the point that friendships are more likely to be made when people participate in recurring activities where social interaction is high (Lakin et al, 2005).

Although the basic rhythm of each day was highly structured, there were little or no formal facilitative structures around the key moments. It should be apparent from reading the descriptions of life in the houses that, as for most people, the basic structure of the day for residents is provided by times for food and drink. At 16 Temple Court in particular meal times dominated the life of the house, which seemed to be related to the long time it took for meals to be prepared and eaten. Active support systems would provide a way of planning resident involvement around mealtimes and allocate staff members to work with a resident or residents while meals were being prepared.

The principle of clear definitions should extend to every domain, such as organisational procedures, operational policies, job descriptions, operational goals, and well-defined outcomes. There may be a paradox in operation here. In the upstream paper we wrote that the Department of Human Services has many qualities of a bureaucratic organisation, where rules and procedures abound. We have not invested heavily in document analysis to judge whether rules and procedures are clearly defined. We have come across instances where concepts appear not to be clearly understood, such as choice, participation, and inclusive communities. We also suggested that in the houses front-line workers have a significant amount of autonomy to interpret and apply rules and procedures, and so individuals may develop a style of working that runs counter to what the Department requires.

In a high-quality service you would expect to see variety in staff practices, but based upon a person-centred approach to the design and delivery of services. Routledge and Sanderson (2001) use the term *person-centred* to refer to ‘activities which are based upon what is important to a person from their own perspective and which contribute to their full inclusion in society’ (p.11). If implemented thoroughly this ought to result in consistent high-quality outcomes for all service-users. We observed great variety in the way that staff went about
their job, which seemed to be based on individual interpretations of their role. For example, whether residents participated in activities seemed to reflect the working styles of individual employees at particular points in time, rather than a formal organisational practice and expectation of front-line workers. In such circumstances outcomes for service-users fluctuate wildly, where a service-user’s quality of life is a consequence of a support lottery, which is overly dependent upon the individual styles of the supporting staff.

**House supervisors**

In the upstream paper we highlighted the importance of the house supervisors in effectively managing these houses if desired outcomes for DAS service-users are to be obtained. This is because when front-line staff are required to do their job in a certain way, it is front-line supervisors that are the organisation’s opinion leaders, who influence the attitudes and behaviour of the people they manage (Larkin and Larkin, 1996). Emerson and Hatton (1994) identified having trained and experienced managers as a key factor in enabling the desired outcomes to be obtained. We would make the point that the performance of house supervisors will not only reflect the characteristics of the people in those posts, but also the design of the service.

Thus, we claimed that supervisors must have the knowledge and skills to promote the values of the organisation amongst the staff he or she manages, and monitor how they are put into practice. They should also help direct care staff to understand policy, rules and procedures in a way that is consistent with a client’s best interests. We suggested that their job is made harder if the roster is constructed in such a way that the supervisor spends a disproportionate amount of rostered time with certain staff, and part-time staff cannot come to house meetings. An analysis of the roster at 96 High Street indicates that the supervisor spends 71 per cent of his rostered hours in the company of one staff member, but only between 13 and 17.5 per cent of his hours with the other four.\(^{51}\) (See end note 29)

Our findings to date are suggesting that supervisors in the three houses are not always fulfilling an effective leadership or management role. In fact it is unclear to us at this time whether leadership or management is the key ingredient\(^{52}\). Proehl (2001) writes that,

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51 The numbers do not add up to 100 per cent as there are times when more than two staff are at work.

52 We made the point in the ‘upstream’ paper that these papers are not the place to critique the literature on management and leadership. We thought that in the the context of the supervisor’s role,
‘Although it is helpful to distinguish between the roles of leaders and managers, it is less helpful to suggest that leaders are more valuable in the change management process. It could be argued that the reason many change initiatives are never fully implemented is a lack of management’ (p.105).

It would seem to us that leaders within the Department have already defined what the future should look like. This is the function of documents like the State Disability Plan (State Government of Victoria, 2002). It is the job of front-line managers (supervisors) and middle managers (such as cluster managers) to make it happen. Part of our rationale for suggesting an amendment to the original research proposal was to allocate increased research time to better explore the role of the supervisor.

It may be the case that some staff in the houses do not clearly understand the implications of what is stated in their job descriptions, or do not have the technical competencies to do the job properly. Organisations typically operate a number of systems that managers use to address such issues, such as supervision and appraisal systems. One framework for thinking about formal supervision suggests that meetings should maintain a balance between three domains (Figure 1).

Although we have reported some excellent examples of residents being included

Drucker’s (1989) conceptualisation of management seems useful. He writes that, ‘the fundamental task of management [is] to make people capable of joint performance through common goals, common values, the right structure, and the training and development they need to perform and respond to change’ (p.214).
in household activities, such as people taking dirty clothes to the laundry, laying and clearing the dining table, pegging out laundry, and making sandwiches, we have suggested that overall the level of participation in domestic activities could be increased. Whether residents participated in activities seemed to reflect the working styles of individual employees at particular points in time, rather than a formal organisational practice and expectation of front-line workers, even though the purpose of the Disability Development and Support Officer is described in the following way:

‘This role involves assisting people with a disability with their daily activities, by facilitating the development and enhancement of independent living and other skills. Disability workers develop and implement programs aimed at achieving an individual’s goals and aspirations and enhancing the individual’s participation in the community’ (Victorian Department of Human Services, 2005a, p.1).

Our observations to date have not looked at formal supervision content and process issues for front-line staff, but we have highlighted the low levels of formal supervision and critical reflection by the direct support staff in the houses. Critical reflection should be encouraged in formal supervision meetings and house meetings. Emerson and Hatton (1994) identified the implementation of clearly defined and appropriate procedures for staff supervision as an evidence-based structural and procedural characteristic that is associated with positive outcomes.

It should be apparent that if used correctly that the normative and formative functions of supervision allow supervisors to discuss front-line workers job descriptions and specify the expected standards and identify learning needs. We acknowledge the resources that the Department has allocated to ‘active support’ training, which suggest a desire to incorporate this style of working into employees’ practice as a matter of routine.

The supervisors with whom we worked are different in their skills and strengths. However, we have suggested that they would benefit from support and training in practising the knowledge and skills identified as being necessary for first-line managers, such as being able to run good meetings, make best use of formal planned supervision meetings, manage poor performance, and resolve conflicts between direct care staff. Such support needs to identify the strengths and skills held by a particular supervisor and the areas in which they feel they need further support.
With regard to how staff interact with residents we have observed a permissive style of management where front-line workers are often left to their own initiative as to how to interpret concepts like choice and participation and put them into practice. This is one reason why we have observed such variability in employee practices. The relatively private nature of work in the houses, which often takes place between individual workers and ‘silent’ clients in unobserved settings, contributes to this.

The fact that staff in the houses have a great deal of autonomy creates a situation with similar problems to those which Handy (1993) calls autonomous work groups, where groups set norms and goals that are not congruent with those of the organisation. The serving of morning coffee at 96 High Street, which we used to illustrate the hotel model in action, would be an extreme example. The function of management in this instance is not to let people decide on their own what is appropriate but to support people to move in the direction that managers have discussed and agreed in staff teams (Mansell et al, 1994).

**Information systems**

Emerson and Hatton (1994) highlight the importance of effective information systems, an area that we have not thoroughly investigated to date. We are aware that supervisors and front-line staff are required to maintain a significant number of written records. If there is any truth in the adage that ‘what gets measured gets done’ then Emerson and Hatton’s questions are useful guides when considering the data that the Department collects from the houses:

- Does the data measure the outcomes experiences by service-users?
- Does the data measure the outcomes experienced by informal carers and paid staff?
- Does the data measure the implementation of procedures and processes that are linked to achieving positives outcomes?

### 6.9 Methodological reflections

As part of the research process, the core researchers have spent a number of meetings reflecting on the underlying assumptions that are related to the research methods we are applying in this project and how these are being played out in practice. We do this in an effort to make transparent some of the issues that are related to our participation, involvement, and interests in the research.
and reflect on some of the issues that we encounter in implementing the research design. Of particular note has been a tension between the ethnographic and action research approaches, with the former possibly hindering the latter, as the staff have to shift from a more passive participant role to a more active co-researcher role (Clement, Bigby, and Johnson, 2006b).

We initiated the research with an empowering conceptualisation of action research where staff, family members and residents could become researchers, shifting the practices in the houses in a direction that would be negotiated between these different stakeholders (Hart and Bond, 1995). For a number of reasons we have ended up with a very different dynamic. What has emerged is organisational action research, where our role is more akin to a research consultant, pushing the staff groups to accept the organisation’s agenda. The house staff are the people who are going to have to make interventions and we feel they have not totally bought into the project and probably still see themselves as respondents or participants. As relatively powerless outsiders we have little influence on what happens in the houses, as persuasion is about the only method of influence we have at our disposal. Given that external researchers inevitably withdraw from a setting, the ultimate responsibility for taking on the development or resolution of the issues identified through this project rests with the Department’s managers.

We have not been as successful as we would have liked in involving either the residents or the family members in the research to date. The level of impairment of most of the residents precludes comprehensive active involvement on their part, although they could be present and therefore part of some processes. This would challenge the informal norms that we have observed in the three houses. Six family members indicated a desire to have an active role in the research and to date we have interviewed four of them. Unfortunately, those four people were unable to attend the half-day meeting with the staff group.

During our periods of participant observation we have been made most welcome in the houses by the staff and residents. We have been able to join in activities, watch what was going on, and talk to people about life in the houses. The shift from an ethnographic to action research methodology has highlighted the houses as sites of competing demands, where the action research element of Making Life Good in the Community is but one initiative that requires staff time and energy. If the supervisor’s job is understood as having three overlapping areas, keeping things going, putting things right, and doing new things, then the project falls squarely into the final category. In having to compete with other Departmental
initiatives the tendency is for the project to be marginalised when other requests carry more ‘official’ weight. Our shift from ethnographic to action research has happened at the same time as the Community Inclusion Officer has begun her initiatives in the houses. Where possible our strategy has been to try and integrate the different initiatives into the project.

We made adjustments to the way that we implemented the research at 16 Temple Court on the basis of our reflections, and intend to make further changes at one of the next two houses that join the project. In addition, the instigation of half-day meetings with the three staff groups provided a much needed reflective space, where we saw that staff could reflect upon their observed practice if given the right circumstances.

6.10 Conclusions and the next steps

We started off by saying that our earlier papers were written in a descriptive style. If we relate our work to date to the action research cycle, we might argue that our observations have been the basis of diagnosis and a spur for planning (Figure 2).

![Figure 2. The action research cycle (in Coghlan & Brannick, 2001).](image)

Of the numerous issues that could have been tackled, the following were tentatively identified in the three houses (Bigby, Clement, and Johnson, 2006).
96 High Street

The research team will work with staff, house supervisor, and area manager on the concept of key workers; addressing questions such as: What is the role of a key worker? How can this role be incorporated into the work of direct care staff? What is the role of the house supervisor in supporting key workers? How can the key worker concept be incorporated into the operations of the house to support increased choice and participation for residents?

The research team will resource the exploration of the concept of a key worker, and support the line manager of this house to develop, implement and reflect on a model of key working. It is envisaged that over time the learning from this work will inform the way this concept is used in other houses. In parallel with this work we will also monitor and support initiatives already undertaken in this house around exploring increased opportunities for resident choice.

64 Penny Lane

As a departmental resource, in the form of the Community Inclusion Officer was already available to this house, it has been negotiated that the research team will work alongside that worker around community inclusion for the residents. The primary aim is to understand more about how practices that primarily support community presence can be shifted to an individualised approach that builds relationships with community members for residents. One advantage of the work in this house will be the opportunity for cooperative research with the Department of Human Services Community Inclusion Officer and to work with that person in reflecting on their practice.

16 Temple Court

In many ways the resident composition of this house brings to light some of the most difficult issues that confront staff in firstly accepting and secondly putting into practice ideas of inclusion and participation. Given the identified area for intervention was so close to ‘active support’, we hope to prioritise active support training for this house. Should formal training be unavailable then we could look for other alternative ways of promoting high levels of participation.

We think it is evident from our first three papers that the level of what is being achieved in the houses still falls short of the standards to which the Department aspires. The remaining stage in the action research cycle, taking action, will hopefully be able to demonstrate an increased potential of the three houses and produce generalizable lessons for other houses.
Our work in the remaining two houses will begin in the second half of 2006.

**Upstream issues**

In *The case for moving upstream* (Clement et al, 2006a) we argued for amending the original research proposal, cutting back on the work in individual houses and substituting action research initiatives that addressed linked research questions that were related to the wider organisation. The key argument was that many of the issues that we had identified so far were better understood through a ‘systemic’ approach. The ‘upstream’ paper identified a number of possible areas for research that were discussed with members of the steering committee and invited Department of Human Services employees at a specially convened workshop. The overarching aim of the workshop was to identify and prioritise research areas for the second half of the project’s life.

A success of the workshop was that participants confirmed that the issues raised in the upstream paper had resonance with their own work experiences and were important. Participants were able to begin to map-out a broader understanding of each research area and suggest priorities. Further discussions with the Department identified four broad research areas:

- The house supervisor’s position
- Individualised support in group settings
- Translating (aspects of) the Victorian State Disability Plan for support staff
- Homeliness.

At the time of writing the immediate task is to turn these broad areas into focused researchable questions. Given that the project has passed the half-way mark our research approach in the coming year will move away from the more *loosely structured* and *emergent* approach that gave rise to our first series of papers towards discrete projects that have a tighter focus.

Our aspirations in regard to these issues are twofold: firstly to build on the first year’s work which has already revealed ‘things’ about these issues and secondly to add-in a ‘systemic’ focus, which will shed light on the organisation’s impact on service delivery.

*August 8th 2006*
Appendix 1: Steering Committee – March 2007

Mr John Leatherland: Chair
Regional Director, Eastern Metropolitan Region,
Department of Human Services

Ms Alma Adams: Manager, Kew Residential Services Redevelopment

Mr Anthony Brown: Family member
Mrs Nancy Brown: Family member
Mr Peter Downie: Family member
Ms Heather Forsyth: Self-advocate

Mr Mark Feigan: Manager, Policy and Education, Office of the Public Advocate

Mr John Gray: Manager, Disability Accommodation Services, Southern
Metropolitan Region, Department of Human Services

Ms Kathryn Lamb: Director, Quality and Service Development, Disability
Services, Department of Human Services

Ms Christine Owen: Manager, Disability Services, Eastern Metropolitan
Region, Department of Human Services

Ms Kerrie Soraghan: Executive officer, Steering Committee

Mr Kevin Stone: Executive Officer, VALID (Victorian Advocacy League for
Individuals with a Disability)

Ms Silvia Warren: Coordinator - Lifestyle Approaches
Disability Accommodation Services
Eastern Metropolitan Region
Department of Human Services

Ms Dorothy Wee: Manager, Disability Services, North and West
Metropolitan Region, Department of Human Services

Ex-officio members

Dr Christine Bigby: Associate Professor
School of Social Work and Social Policy
La Trobe University

Dr Tim Clement: Research Fellow
School of Social Work & Social Policy
La Trobe University

Mr Alan Robertson: Researcher (formerly self-advocate)

The contribution of former members of the Steering Committee since the
beginning of the research in 2005 is also gratefully acknowledged.
Appendix 2: End notes

The following end notes include contextual information, provided by the Department of Human Services.

**End note 1**

The house was purpose built from one of a number of designs that were developed taking account of broad disability standards, additional exacting standards determined by the Disability Services Division of the Victorian Department of Human Services, and modified to accommodate any particular needs of the people who would live there.

**End note 2**

Bedrooms were not formally allocated based on gender. The following factors were determinant:

- Residents with high medical needs were allocated the bedroom closest to the staff ‘sleepover’ room.
- Residents requiring highest support to evacuate were allocated rooms closest to the exits.
- Where residents were able to choose their bedroom, either during house construction or afterwards, they were given their choice unless the first two factors precluded this.
- If residents could not choose, and their family members requested a particular room on their behalf, they were given their choice, unless the first two factors precluded this.

**End note 3**

Resources have been provided to each region to support community participation and social inclusion.

**End note 4**

The house was purpose built from one of a number of designs that were developed taking account of broad disability standards, additional exacting standards determined by the Disability Services Division of the Victorian Department of Human Services, and modified to accommodate any particular needs of the people who would live there. Typically there are a range of different house designs and sizes in any suburban Melbourne street. This house is larger than the houses around it, but the exterior colours and materials were chosen so that it would blend stylistically with neighbouring houses.

**End note 5**

Planning appropriate day activities for residents leaving Kew Residential Services was a significant task. After moving to their new home, many residents continued to attend the same day program which they had previously attended when they lived at KRS, if this was the best choice based on their needs and preferences. There were other instances where a new program was required, as a result of the resident’s choice, or distance, or the fact that they had not previously had day activities. When this occurred, the new program was identified based on information about what the resident liked doing, and where these activities were offered.
Appendix 2: End notes

End note 6

Staff moving from KRS received training during their orientation to their new role from therapists from the Communication Resource Centre (CRC). An individual communication dictionary for each person was developed during transition and given to the house staff who later had discussions with case managers about the use of these, and guidelines were given to each supervisor about their review.

End note 7

Although the general trend in Victoria has been broadly consistent with the development of services in the United Kingdom and elsewhere, there are some significant differences.

‘Locally based hospital units’ have not been a transitional feature in Victoria, nor has the ‘private for profit’ sector been asked to deliver residential support services to ex-residents of Victorian institutions as a consequence of their redevelopment or closure.

Large scale redeployments of staff from the institutions to become support workers to residents in their new homes in the community have been a feature in Victoria. As the State of Victoria is of comparable size to England and Wales, staff are required to make very significant changes in their lives during these processes.

(Note: KRS residents have moved to areas across the State chosen after balancing their and/or their families’ and advocates’ preferences with their needs and compatibilities with co-residents.)

End note 8

73 houses have been established across Victoria at date, with the last 20 planned to be established by the end of 2007. All but one is purpose built. Each is based on one of a number of floor plans and designs that were developed taking account of broad disability standards and additional exacting standards determined by the Disability Services Division of the Department of Human Services, State of Victoria, and modified to accommodate any special needs of the individuals from KRS who would move there.

Typically in Melbourne suburbs, there is a range of different house designs and sizes in any one street. The houses built for the ex-KRS residents are typically, but not always, larger than the surrounding houses. The exteriors are designed to blend stylistically with neighbouring houses.

End note 9

During the planning for the KRS Redevelopment, choice was offered to the residents for whom it was believed meaningful, and to those families who wished to be involved, regarding colour schemes and some furnishings. The choices of paint and carpet colours were restricted to prescribed options.

End note 10

The houses are located in the types of suburbs where most Victorians live. Greater Melbourne covers an area roughly equivalent to that of greater Los Angeles.
**End note 11**

‘HACSU’ is the Health and Community Services Union of Australia – also known as the Health and Services Union Australia (HSUA) No 2 branch.

In new houses, there is a sleepover room/office, staff toilet and shower. This is a requirement of the HSUA ‘Parent’ Award, and, as such, is applicable to all CRUs operated by Department of Human Services, not just those set up as a result of the closure of KRS.

**End note 12**

Planning is undertaken on an individual, not group, basis. Consequently, residents of any particular house commonly attend different day programs. This is positive in terms of broadening each individual’s networks and their community participation, but has some negatives in terms of the transport logistics.

**End note 13**

Furniture purchase for the houses is bound by the State of Victoria’s rules governing the expenditure of public monies. Within these constraints, each resident had the opportunity to choose furniture and linen for their bedroom, paintings etc, and many did so. Where they did not, some families chose make these choices on their relative’s behalf, although most did not. In addition to the basic furniture and equipment, other ‘one-off’ items were purchased on behalf of individual residents as required. These included bikes, exercise equipment, personal audio-visual equipment, mobile phones and adapted physiotherapeutic equipment.

**End note 14**

The houses are residents’ homes and as they are staffed, they are also workplaces. For this reason, the Department of Human Services needs to have very detailed processes in place to ensure compliance with the legislative requirements governing the health and safety of its employees, clients and members of the public. (Reference: Occupational Health and Safety Act 2004, Act No: 107/2004)

**End note 15**

Findings of this earlier report were addressed during the KRS Redevelopment - information about clients was presented and discussed with each house supervisor and house staff in a range of formats.

**End note 16**

Staff are redeployed from KRS to the new services. This requires them to change their working patterns very significantly.

At KRS, staff had worked very predicable and rigid shifts: day staff on a roster of two days on, two days off starting approximately 7.00 am and finishing approximately 8.00 pm; night staff — starting approximately 8.00pm and finishing approximately 7.00 am, again two nights on, two nights off. Night staff typically had no experience of what happened during the day and day staff little idea of what happened at night. The shifts at the institution were designed to deliver basic care and hygiene in a congregate environment, and mostly did not allow for extra support at weekends to support clients do ordinary weekend
activities, nor for night staff to have some hours at other times. The different roster formats in the houses reflect the range of support needs of the residents and are a significant improvement in terms of client centred-ness compared to the situation at KRS. The redevelopment of KRS has required staff to be redeployed across the state of Victoria and the new rosters (and locations) require them to change their working hours and patterns significantly. Many staff had worked at KRS for years in the ‘two days on, two days off’ roster pattern and had arranged their lives, and matters such as childcare and other family commitments, on that basis. In this context, some balance needed to be struck between an ‘ideal’ roster and one which considered, to an extent, staff needs. There are industrially agreed mechanisms for reviewing and changing rosters.

End note 17

The establishment of the new houses (with their higher staff ratios) together with the training schedule for staff has required a small number of staff having their redeployment delayed for a period to ensure adequate staffing at KRS for periods during its downsizing. Typically, staff whose redeployment is to be delayed are chosen from among those for whom that is also a personally attractive option.

End note 18

The opening of each house was preceded by a two-week block of training, known as ‘transition training’ - a form of orientation. The aims of this orientation were:

- to familiarise staff with the needs of the residents they would be supporting (one component of a broader strategy in this regard),
- to engender in staff a sense of personal responsibility and ownership of their work,
- to orient staff to the practices and procedures operating in the regions which are new to them,
- to begin the process of team building for the staff redeployed to each house, and:
- to introduce concepts of community connectedness.

The transition training was designed to represent a ‘clean break’ for staff from their old roster and mark the transition to the new format in the house.

Theory and practice sessions and the venues for training were scheduled to provide stimulus and variety and the training styles aimed to build rapport between trainers and trainees.

End note 19

650 days ‘transition training’ have been conducted at date which is in addition to ongoing mandatory training and traineeships. The transition training was designed following interviews with over 80 per cent of the KRS staff over a lengthy period.

End note 20

The people who delivered sessions during the staff transition/orientation were knowledge experts in the topic including Department of Human Services staff such as managers in Disability Accommodation Services, Client Expenditure Recording Services (CERS) and personnel staff, physiotherapists and dieticians, trainers from TAFE and other registered training organisations, and other
specialists such as therapists from the Communication Resource Centre. As well, case managers delivered sessions to staff relating to each individual resident’s needs and plans, which they followed up with documentation in a range of formats.

**End note 21**

The approach taken to CERS was deliberate in the context of KRS staff (with the exception of supervisors) not having experience of managing client funds and there being a robust audit framework and processes in place to protect clients from fraud. Trainers believed staff needed to be very clear about their responsibilities.

**End note 22**

Case managers followed up very specifically in relation to individual client requirements, and their personal communication dictionaries.

**End note 23**

The ‘community connections training’ in the two week period prior to house opening was designed to be only an introduction to the concept.

**End note 24**

The support that residents had during the period leading up to their move included the following.

Residents were supported to visit the site of their new home as it was being progressively constructed, unless this was perceived as being potentially stressful or not meaningful for particular individuals. As well, most residents visited the finished house before, during and after the furniture was delivered. Bedrooms were chosen or allocated as described in **End note 2**. Furniture, pictures and personal possessions for their rooms as well as linen and other items were bought as described in **End note 9**. Those who could do so, unpacked their own belongings when they moved.

**End note 25**

73 houses have been established across Victoria at date, with the last 20 planned to be established by the end of 2007. Of these all but one is purpose built. Each is based on one of a number of floor plans and designs that were developed taking account of broad disability standards and additional exacting standards determined by the Disability Services Division of the Victorian Department of Human Services and modified to accommodate any special needs of individuals from KRS who would move there.

Typically, in Melbourne suburbs, there is a range of different house designs and sizes in any one street. The houses built for the ex-KRS residents are typically, but not always, larger than the surrounding houses. The exteriors are designed to blend stylistically with neighbouring houses.

**End note 26**

In approximately 30 per cent of the houses opened at date, neighbours have visited for special occasions, but in only a relatively few is this contact ongoing and primarily with the residents, rather than the staff.
**End note 27**

Many staff at KRS had typically perceived accountability as being held only by the unit manager, and that their role involved operating in a routine determined by the unit manager and under his or her direct ‘hands on’ supervision. A key objective of the transition training was to engender in staff a sense of personal responsibility and ownership of their work. As the training was not a focus for the research, the trainers did not observe the range of sessions and activities aimed to ensure staff in the houses opened to date were all familiar with the people they would be supporting.

**End note 28**

The training was delivered by therapists from the Communication Resource Centre (CRC). As well case managers delivered sessions to staff relating to each individual resident’s needs and plans which they followed up with documentation in a range of formats including that documented by the CRC.

**End note 29**

In designing the rosters it was considered a priority that supervisors should have some shared roster time with all their staff, but the percentage of this time is not equally distributed.

The parameters of the design of the staff rosters for supporting people living in community houses established during the KRS redevelopment, and the rules that apply to changing these are outlined in section 13 of the ‘HACSU Department of Human Services (Intellectual Disability Services Victoria) Kew Residential Services Redevelopment Agreement 2002’. (See below).

Although the actual rosters that apply to any house have to comply with these formats and principles, there is significant individual variation within the formats in terms of the number of support hours rostered and other matters.

13.1.1 The parties agree to conduct a review of the roster in each new accommodation service three months after its commencement. The review will be initiated in a timely manner by the employer through the SSWP. The review will be done jointly with the HACSU and local regional management and access to employees meetings will be provided to HACSU so that full participation of employees will be possible.

13.2.1 The following roster principles will apply.

Services will commence in each of the new community houses utilising one of the following staffing formats. These formats have been developed to cater for the support needs of KRS residents and in response to management and HACSU consultations with employees in recognition of the current staffing profile at KRS which has a high proportion of full time employees. They have also been developed with the clear understanding and expectation that the employees will provide developmental support to residents, as well as assist them to access a range of community activities and services. The determination as to which of the four formats is the commencing roster for any particular service, will be made on the basis of the needs of the residents to be accommodated there.
1-Frail/Aged /High Medical needs: minimum of 5 Full time positions

2-Sleepover — High Support: 4 x Full time positions

3-Sleepover – Medium Support: 3 x Full time positions

4-Active Night – Medium/High Support: 5 x Full time positions

- All direct care full time shifts attract commuted allowance. Note their roster will entail working two weekends in four.

- Part-time positions will not be covered by all of these principles in order to maximise their ability to pick up as many hours as possible. Notwithstanding, part-time employees will be treated fairly in respect to adopting rosters and all of the normal policy and practices will apply to those employees as does currently. Part-time employees in the Receiving Services will have preferential access to full time work during periods of leave of full time employees in those services.

- Split shifts will be avoided.

- Rosters will maximise the numbers of days off between blocks of shifts.

- The maximum number of consecutive working shifts in a row is 5 days (unless otherwise agreed).

- Rosters will be posted at least two weeks in advance.

- Consistent with roster change provisions of the parent award, formal consultation processes will be adopted if the region wishes to alter any CRU roster.

- Those eligible employees employed in Kew Day Programs who currently work a five day week Monday to Friday may or may not, at their discretion, opt to move onto a rotating roster.

- Two weekends off duty over the relevant roster cycle will be provided;

- Split weekends will be avoided, except in the Frail Aged High Medical Needs format roster pattern;

- Rostered days off will be attached to weekends off or two consecutive weekdays off.

- Formalised mechanisms by which, within established parameters, full and part time employees may have a greater input into roster design to meet their preferred roster format at the workplace level shall be implemented.

- For the purpose of these principles, any shift that finishes the day after it commences, including a sleepover shift, shall be deemed to be the one shift.

- The practice of backfilling the entire shift where client needs dictate, as is currently the case at KRS, will be continued in the Receiving Services for twelve months after the service establishment, after which time this
practice will be reviewed with the prime consideration being client contact and need.

13.3 Roster change
For as long as KRS exists₆ the following procedures shall be observed when the employer intends to alter roster arrangements in any of the Receiving Services affecting persons who are eligible to be members of HACSU, whether those persons are members or not. This includes the review outlined in clause 13.1.1:

13.3.1 Any proposed alterations to rosters, which are of an operational kind, shall be discussed between local management and local representatives of HACSU. before implementation and in sufficient time to allow proper negotiations to occur both with HACSU representatives and the members concerned.

13.3.2 Alterations which go to the character of the roster, such as the alteration of two on two off system, or the number of days worked in a 28 day period, for example, should be the subject of consultation with HACSU on a centralised basis. Sufficient time should be given to allow that consultation to occur at a convenient time and to permit consultation with the employees concerned to ensure that whatever is agreed is implemented in a smooth and harmonious manner.

13.3.3 In the event that no agreement is reached after consultation in accordance with sub-clauses 13.3.1 and 13.3.2 has taken place, new or altered rosters may be posted by management to come into operation no less than 14 days after the date of posting.

13.3.4 HACSU shall, if it objects to the new or altered rosters, notify the employer and the Commission within seven days of the posting, or such earlier date prior to the posting, of its objections and that it requires the Commission to convene an urgent hearing.

13.3.5 On receipt of HACSU objection, the commencement date of the new or altered rosters will be postponed to a date 28 days (scheduled date) after the date of posting of the new or altered rosters.

13.3.6 During a hearing convened under sub-clause 13.3.5 HACSU may, without limiting other rights it may have, request the Commission to make an order that the posted roster not come into operation on its scheduled date, and seek any variations to the posted roster as it considers desirable.

13.3.7 Unless such an order is made by the Commission the posted roster shall come into effect on its scheduled date in accordance with sub-clause 13.3.5 and work shall be performed according to its terms.

13.3.8 Whilst the process above is being followed work shall continue normally.

13.3.9 Should any of the Receiving Service rosters be inadvertently altered without regard to this clause then, on discovery of the error, those rosters will, if practicable, immediately, or if not practicable, then at the commencement of the next roster, revert back to the initial rosters agreed by the SSWP or subsequent rosters agreed between KRS HACSU and the relevant Region.

13.3.10 Should HACSU believe that the process outlined in this clause has not been duly followed then it may bring this to the attention of the Executive Director, Disability Services with the Department.
Executive Director, Disability Services will then oversee the resolution of the issue.

* i.e. for the duration of the total period of the service redevelopment leading to its closure – 6-7 years
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