

Settled in the Community: An Evaluation of Five Years of
Community Living for Residents Relocated from Kew Residential
Services, 1999-2005.

February 2006

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INTRODUCTION

Kew Residential Services (KRS), formerly known as Kew Cottages, is the oldest and largest institution for people with intellectual disabilities in Australia. Since the 1960s resident numbers have declined slowly from a high of 950 to approximately 250 at the beginning of 2006. The Kew Residential Services Community Relocation Project was instigated in 1997 by the then Kennett Government and was responsible for moving 58 residents into small group homes (houses) managed by non government organisations, between July 1999 and April 2000. A research team from the LaTrobe University School of Social Work and Social Policy were contracted to undertake an evaluation of the relocation project.

The study used quantitative and qualitative data collection strategies to examine the process of relocation and quality of life changes that occurred during their first year of community living for 27 residents (Bigby, Frederico, Cooper, 2004, see also, Bigby, 2005). The report concluded that most residents appeared happier, they all lived in a better environment, were more likely to be treated as an individual or part of small group and many had made initial steps towards increased self worth. It found however, that residents were much like guests in their houses and visitors to the community; they were not strongly embedded in their local communities and had not expanded their individual networks or repertoire of skills and interests (see appendix 2 for executive summary). The report suggested that rather than being disappointing the findings reflected the enormity of both the task at hand and the expectations for change associated with the relocation. The findings were similar to other relocation studies and issues raised by research on community living. In particular the variability of residents' outcomes and the increased community presence but lack of personal relationships and community connections (Felce et al., 1998; Ericsson & Mansell, 1996).

This present report documents a follow up study of the relocated residents after 5 years of living in the community. The aims of this study were to examine:

- residents quality of life after 5 years in the community,
- the nature of changes that have occurred during the 5 years in particular

- whether support to residents becomes more individualised,
- the extent to which residents built connections into their communities,
- the role of family members and other outsiders in ensuring responsive accommodation support and
- organisational responses to aging of residents.
- factors in the organisation of community living that support residents' participation and inclusion and those that create obstacles.

CHANGING CONTEXT

Significant policy changes occurred in Victoria in the five years since the residents were first relocated to the community in 1999. The Bracks government that came to power in 2000 emphasised community development designed to combat social exclusion and create greater community cohesion (Victorian Government 2005, A Fairer Victoria). This thrust is also reflected in the State Disability plan released in 2002 with the vision that:

By 2012, Victoria will be a stronger and more inclusive community - a place where diversity is embraced and celebrated, and where everyone has the same opportunities to participate in the life of the community, and the same responsibilities towards society as all other citizens of Victoria. (DHS, 2002)

The plan's focus is broader than disability services, regarding it as a whole of government responsibility to create inclusive communities for people with disabilities. The plan's three major aims are to: reorient disability supports to be more responsive to individual needs; to strengthen communities so that people with a disability have the same opportunities to participate in the social, economic, cultural, political and spiritual life of the community and to take the lead in improving the accessibility and responsiveness of public services. Strategies have included for example, creation of positions in local government designed to create access for people with disabilities, directing new funds into more individualised packages of support options, redevelopment of disability standards and development of a Learning and Development strategy to address workforce recruitment, retention and training issues. A key initiative is the total closure of KRS by 2007. The relationship between

government and the non government sector has also been recast as partnership rather simply as purchaser and provider.

It is possible that the residents in this study may have benefited from some of the new initiatives aimed at community capacity building that have occurred during the last 5 years. Although new funds have been directed at individualized community support rather than provision of new shared supported accommodation services, significantly the closure of KRS has led to the establishment of over 90 new group homes for people with intellectual disabilities. This has provided the impetus for improving support provided to residents. For example, new strategies such as active support and employment of area based integration support staff have been piloted to foster participation of residents in daily life of their homes and the community. However, both government and non government disability services still operate in a context where demand outstrips supply, substantial waiting lists still exist for accommodation and other support services and priority of access is based on urgency of need. The period has also seen a consolidation of the shift away from provision of specialist services by diagnostic grouping towards a more generic focus on disability mediated by individual needs.

METHODOLOGY

Participants

The 27 original participants in the study were randomly selected from 58 residents with intellectual disability to be relocated from KRS to houses in the community during 1999-2000. The participants moved to 9 houses, all initially with five residents and managed by non government organizations. As three residents have died during the 5 years of the study, the full data set now only included 24 residents. All residents had been labeled as having an intellectual disability, and their institutional files indicated that 15 had moderate level of intellectual impairment, six severe or profound with no data available for three residents. Six residents had a mobility impairment, seventeen had identified health problems and six a psychiatric diagnosis. At the conclusion of the study, the average age of participants was 51.5 years (SD 7.6 years, range 39 to 68 years). The average time they had lived in a large institution was 38 years with a range of 10-54 years.

Data Collection

Four waves of data were collected, the first whilst residents were living in the institution and the second third and fourth, one, three and five years after their move to the community. At each wave a structured interview, that lasted approximately two hours was conducted with a staff member who knew each resident well. The schedule consisted of a range of open-ended questions, standardised outcome measures and global rating scales about the following domains, living situation, general health and well-being, personal development, community integration and interpersonal relationships. Measures included the “Physical Environment Scale” (Rotegard et al., 1983), 17 items from the “Behaviour Development Scale” (Conroy et al., 1982), and the 1990 version of the “Quality of Life Questionnaire (Schalock, Keith & Hoffman, 1990). Staff rated the resident’s use of local community services, facilities and resources using the basic dimensions of frequency of activity and the location of activity. Questions were asked about the resident’s formal and informal network including the relationship of each identified person to the resident, frequency, place and nature of contact. Informal social contacts were categorised into friends with and without intellectual disability, and co resident or not and relatives. These questions allowed a social network analysis to be conducted for each resident based on the technique suggested by Tracy and Whittaker (1990). In addition to the questionnaire each resident’s individual relocation plan, program plans, and general service plan were collected and examined. Difficulties in collecting individual program plans meant incomplete sets were collected at time 3 and 4.

A family telephone survey was conducted after 1, 3 and 5 years with 18 family members, of whom 15 were the same person at all three times. Family members were 9 parents, (4 mothers, 5 fathers) and 9 siblings, (6 sisters and 3 brothers). The survey had a mixture of open and closed questions and sought information including family satisfaction with the move to the community, opinions of the resident’s current lifestyle, attitudes towards deinstitutionalisation, and patterns of family contact and interaction with the resident.

A telephone survey of staff from the day program attended by each resident was conducted after 1, 3 and 5 years. The interview schedule sought information about: views on the relocation process and outcomes and the nature and hours of the

day program attended by the resident. Twenty-three staff participated in the survey at time 2 and 24 at time 4.

A series of in-depth qualitative case studies were undertaken with a purposive sample of 11 residents drawn from the three levels of support into which they were classified. These residents lived in 4 houses and each participant was visited at least twice whilst still living in the institution and then at 4 monthly intervals for the first 12 months, and then again after three years in the community for the following 2 years again at 4 monthly intervals. During these visits the researchers were participant observers, they interacted with the residents and staff, observed aspects of the physical and social environment and sought information from staff about the workings of the house. A checklist of elements to be observed was compiled both as a guide to observing the visits and to writing field notes. This included items such as: personal appearance, resident use of space, social interactions with staff and other residents, community participation/integration, personal autonomy/decision making and social network.

Interviews were also conducted with program and senior residential managers (administrators) in each of the 5 organisations that managed the 9 houses where the participants in the study resided, at Times 2 and 4. Due to staff changes only one of the original managers was interviewed at time 4 however. Interviews at time 3 were also conducted with the community visitor for the 6 of the 11 houses that had a regular visitor. Planned interviews with case managers were not conducted, as no residents were identified to have had a case manager at either time 3 or 4.

The quantitative data were analysed using descriptive and inferential statistics using SPSS for Windows. Qualitative data was analysed thematically using NVivo textual analysis software.

Limitations

A major limitation of the study was absence of information directly from residents about their lives and the reliance on residential staff for much of this information. Due to communication difficulties, there are significant challenges in tapping the views of residents. Some data, such as that about family relationships could be triangulated with similar data reported by families through the phone survey. It was evident from this process and an examination of the data across the 5 years that some staff were poorly informed about the resident's families. For example, in several

instances family members who were reported dead at one interview were reported as alive in the following one. No triangulation mechanism was available in regard to other data such as friendships, domestic or community involvement and it was data on staff perceptions of these matters rather than the residents own views that were collected. Staff knew very little about the nature of day programs attended by residents, particularly their friendships at these programs. Thus data more accurately reflect friendships between residents and people outside their day program than the full spectrum of relationships. However, a strength of this study was the longitudinal focus and the use of multiple outcome measures, supplemented by in-depth qualitative case studies.

Structure of the Report

The first part of the report uses quality of life domains as an organizing framework to consider findings about aspects of residents' quality of life after 5 years and the changes that have occurred over this time. Qualitative data, primarily derived from the intensive case studies, complements the statistics and also illustrates these findings and the variability found among residents. Findings from interviews with administrators and the surveys of family members and day program staff and their views on quality of life are incorporated into the relevant sections. Major themes that arise from the findings are set out in the discussion section. Throughout the report, excerpts from field notes, or direct quotes from staff are used to illustrate points in addition to vignettes of individual residents and houses. To ensure confidentiality all names and other identifying characteristics have been changed.

FINDINGS

Community Access

The simple quantitative measure of community access used was the number of times residents had gone out of their house in the previous 7 days. As shown in table 1, by year 5 residents were going out a mean of 8.37 times a week. For most people these outings included attending a day program on weekdays. However, three residents either did not go out to a day program or only went on a part time basis. The range included one resident who had moved to a nursing home who did not go out at all and another had gone out 12 times. As Table 1 shows, there was a statistically significant linear trend for the relationship between time and the number of times

clients accessed the community in the past week, $F(1, 18) = 13.95$, $p < 0.05$, the more time that passed the more often the clients accessed the community in the past week. The proportion of the variance that is attributed to the linear effect (partial η^2) is 0.44. The quadratic trend, $F(1,18) = 6.26$, $p < 0.05$ (partial $\eta^2 = 0.26$) and the cubic trend, $F(1,18) = 6.54$, $p < 0.05$ (partial $\eta^2 = 0.27$) were also statistically significant, indicating evidence of a non-linear trend over time.

Table 1. Means and Standard Deviations for Number of Times Residents Accessed Community in Past Week

Number of times accessed community in past week (n=19)	<u>M</u>	<u>SD</u>
Time 1	4.74	2.28
Time 2	8.47	3.03
Time 3	6.89	2.23
Time 4	8.37	3.55

Few participants went out during the week in the evenings and many had settled into a routine of going out to the day program 5 days a week with outings at weekends. This was a routine fairly similar to that at KRS, although then far fewer residents had attended a full time day program. Table 2, overpage, summarises the activities undertaken or places visited when residents left home

As Table 2 indicates after 5 years the most common type of activity had become the more traditional “outing” to a place of interest. For residents in five of the nine houses their main form of activity was weekend bus trips with other members of the household. Fewer people went shopping than at the end of the first year and more people were using disability specific activity or interest groups. This may be a reflection of the growth of specialist disability activities organised by local government and other organisations as a result of initiatives such as metro access or Access for all Abilities. Residents were going to a wider range of community activities and places, than at the end of year 1 and these now included church and local shops.

Table 2. Activities Undertaken or Places Visited When Out of Home for Residents in the Community

Type of Place or Activity	No of people visited/participated in last 7 days.			
	Time 2. n = 22	%	Time 4. n = 24	%
Day Placement	22	100%	23	96%
Shopping	9	41%	7	29%
Walking in local park or neighbourhood	7	32%	6	25%
Bus Trip to historic location or picnic	7	32%	12	50%
Attend doctor or other medical appointment	3	14%	2	8%
Disability specific group based hobby, such as boot scooting, bowling, basketball.	4	18%	8	33%
Eating out, lunch or dinner	6	27%	9	38%
Attend a show or movie	5	23%	3	13%
Weekend stay with family	2	9%	-	-
Visit to another community residential unit	3	14%	1	4%
Other, eg attend gym, bushwalking club, corner shop, church	2	9%	4	17%

Although most people still went out in household groups, many but not all also went out alone or in smaller groups, although for some more individualised outings did not occur every week. In several houses smaller group outings were the norm as mobility issues made it very difficult to take all residents out together. The family of at least one man in the study paid for additional staff time privately to give his son extra individual support. This enabled his son to swim regularly at a local pool and reduced demands made on regular staff thereby increasing overall staff support available to the residents. Most residents used some form of commercial or community facilities such as hairdressers, community health centres, shopping centres, bowling centres, cafes and cinemas. In the seven days about which data was collected at year 5 for example:

Jo had gone to her day program 5 days, gone for a walk in the local park, to a disco for people with disabilities, to the supermarket and had lunch in a café with other house residents.

Bill had gone to a supported employment program 5 days. He had gone bowling one evening and also on Saturday morning with several other house residents. By year 5 the residents had joined a bowling league at the local centre and were competing against other groups of people with disabilities. Bill had participated in an indoor cricket club and a basket ball club for people with disabilities on two evenings, on both occasions with one other man from his house. He had walked to church with one other resident and gone out for dinner with co residents.

Very few residents participated in community clubs or organisations that were not specifically for people with disabilities. Two men regularly attended a church, although their experiences of inclusion were quite different.

Between the first and third year Bill began to attend church. There was a church in the next block from the house, and at the initiative of the house supervisor all the residents started to attend. One resident was often away for weekends with his family, and another decided he was not interested and preferred to stay at home, so Bill and Dave started to go on their own and over time without staff support. The supervisor told staff to always remind the men to sit at the back but this had led to them sitting at the very back of the church quite removed from the rest of the congregation until the supervisor realised what had happened when she looked several months later. Bill is a very keen singer but was excluded from the church choir. Neither men have made any social connections or participated in any other activities at the church.

During the third year in the community, the new house supervisor, who had connections to a church in the next suburb, supported Mike to attend a service regularly. He also started to attend a group that shared a meal before the

service and a monthly youth group at the church. Mike gets a lift home from this group and sometimes attends other church based activities such as a dinner dance or outings. He has also been invited to a member's house for a party but was only able to stay a short while as the toilet was not accessible.

The experiences for residents in houses 8 and 11 in the intensive sample stood out as being more individualised and involving participation as well as presence in the community. From the time they moved residents in these two houses had gone out in the evenings and during the first few years a range of different activities and support arrangements had been tried. Over time fewer activities were likely to include all residents as each man began to pursue his own interests and required less staff support. This was only achieved by maximising flexibility in staffing, constant juggling and some compromises. For example,

For the first few years in the house although only Bill participated in cricket and basketball all the men had to go with him, as there was only one staff member on duty and no one could be left alone at home. By halfway through year 3 flexibility in staffing achieved by the new house supervisor meant he was able to go alone or with one other resident accompanied by a staff member. By the end of year 4 however, the frequency of individual activities was becoming a contentious issues in the house as it was impossible to have two staff on duty every night. The situation improved when it was agreed that two men were able to stay alone in the house. Attempts to arrange a lift for Bill to cricket with a man from another house had not worked out and possibilities for Bill to go alone in a taxi were being explored. Meanwhile although Bill wanted to attend activities more often at this time it was only possible to go to cricket every other week. On an evening visit during year 4, the men had a hurried tea, as Dave was going to his regular bowling night with a mixed ability team, Bill and Mark were going to indoor cricket, Tom was going by taxi to drama and Ned was going on public transport to football training.

The experience of residents in another house contrasted sharply.

During the first year in the community the supervisor had arranged for a local hairdresser to visit the house so she could regularly do all the women's hair. Appointments at the community health centre and the GP were also

made for the women as a group. By the third year, Joy, Maureen and Sheila each went individually with a staff member to visit a local hairdresser regularly and often go for walks in a local park either alone or with each other. They also visit allied health professional such as a podiatrist or medical practitioners individually. The women are not involved in shopping for the household, and during one observation visit a staff member left to go shopping alone, commenting that to take any of the women would “take too long, be too difficult, and they would not understand”. The women usually go out to eat one day over the weekend and for a trip in the bus. The entry into the house of a new resident who does not like going out has had some impact and her refusal at times means that no one goes out. Their absence of external activities is not due to lack of staff resources, during one observation visit a long term staff member commented, “ that the supervisor pushed staff to do more and overtime was available but it was too hard and too depressing to do any more”

Residents in several houses had friendly relationships with at least one neighbour, or regularly used a local park or milk bar. Overwhelmingly, however, residents did not know people in their local area and did not belong to locality based organisations.

The results from the community integration/social belonging subscale of the quality of life measure are shown in Table 3. The scores on this scale can range from 1 to 30 and reflect the relatively little connection residents had with their local area, with neighbours and their low involvement with civic and recreational organisations.

Table 3. Means and Standard Deviations for Community Integration/ Social Belonging Scores.

Community Integration Scores (n=20)	<u>M</u>	<u>SD</u>
Time 1	17.82	3.03
Time 2	21.12	3.01
Time 3	17.52	5.23
Time 4	15.59	4.89

The results show an initial increase in community integration after a year in the community followed by a gradual decline in later years, such that the score after 5

years in the community was lower than the original score in the institution. This may reflect a loss of contact with friends and acquaintance from the institution as well as other factors including high health needs of some residents that reduced recreational outings over time. There was a statistically significant linear trend for the relationship between time and community integration scores, $F(1, 19) = 7.04$, $p < 0.05$, the more time that passed the lower the community integration score. The proportion of the variance that is attributed to the linear effect (partial η^2) is 0.27. The quadratic trend, $F(1, 19) = 48.77$, $p < 0.05$ ($\eta^2 = 0.72$) and the cubic trend, $F(1, 19) = 13.02$, $p < 0.05$ ($\eta^2 = 0.41$) were also statistically significant, indicating a non-linear change over time. The trend in this scale was also reflected in the descriptive and statistical data about resident's social relationships.

Staff Support for Community Engagement

When residents went out individually staff were able to describe the activities in which residents participated but could seldom talk about what residents actually did and how they interacted with others in the course of the activity or outing. For example, one house supervisor was not aware of what occurred at a social group for people with disabilities attended by one of the residents and was not aware of the age group of people who attended this group. On several occasions the researchers accompanied residents to activities and observed their interactions. On such occasions it was clear that further analysis of the situation and support might foster greater inclusion for the resident. The field notes record several examples:

The group have been going bowling on Saturday mornings for a long time. The supervisor is unclear what actually happens when they go out and has only been with them once. Initially I met the men at the bowling alley, 4 of them were there with a new member of staff who has only been employed for 6 months, she said this was the first time she had been and she didn't know what she was doing really. She was sitting at the back of the lanes, ignoring the men, each of the whom had their own lane and were just bowling, not against each other, not really interacting with each other. The staff person was not supporting or commenting on what they did, The were at the end of the bowling alley, well away from everyone else. It seemed they were isolated, not interacting with other people or each other.

I went to the bowling alley to watch Dave. Before he went out the worker gave him \$20 and told him to remember to get a receipt. Dave plays in a team with 3 other men who are all much younger, although there are some older men in other teams. Dave appears at ease and they remind him when it is his turn and tell him not to go when it isn't ready. There is a ritual of touching hands when they have cleared all the pins but no one does this to Dave and he does not do it to the others. There is little interaction, and Dave doesn't seem to watch the others or congratulate them, they always clap when he gets a strike but little else. The organizer knew Dave and said hello. On several occasions Dave tried to attract the attention of people in other lanes attention without any luck. He seems to enjoy being there and though not fully part of the rituals seems accepted. The worker picks him up at 8.30. The Bowling Alley is on the bus route which stops at the end of his street.

Organisational Perspectives on Inclusion

From the administrators' perspective organisations have been challenged to support community inclusion of residents. Their views were well summed up by one administrator who said, "This group from KRS were so ill prepared for community involvement that it is such a difficult process and any progress must be viewed from a very low beginning but there has been some progress in accessing the community". Their view reinforces the importance of measuring individual outcomes rather than more benchmarks, as what may appear as small gains may in fact represent significant steps.

Broader organisational policies recognise the importance of community inclusion, although in most organisations responsibility to engage with the community and facilitate inclusion for the residents rested solely with house staff with little direction or concrete support from the wider organisation. Administrators saw community inclusion broadly as any activity that furthered the residents' experience in the community including outings or contact with neighbours and measured success in these terms. Achievement of stable staffing within a house was seen by one organisation as a prerequisite for planning community inclusion.

Social Networks

Contact with Family Members after Five Years

Most residents (22, 92%) had a family member alive and 75% (18) of all residents were in touch with a relative at least once a year. As table 4 shows however, only 50% (12) residents had more than annual contact with a family member.

Table 4. Frequency of Resident Contact with Family Members After Five Years.

Frequency of contact	Number of residents	
	n = 24	%
No contact	6	25
At least 12 monthly	18	75
At least 6 monthly	12	50
At least 3 monthly	10	42
At least monthly	8	33
More than monthly	5	21

Most commonly residents were in touch with parents, siblings, and members of their sibling's family. Nine residents had contact with parents and siblings, six only with siblings, and three only with parents. Two (8%) residents did not have a sibling of whom one had no family contact. The four residents who had a sibling with an intellectual disability living in shared supported accommodation or the institution had not had any contact with this sibling in the previous 12 months.

The number of family members with whom residents had annual contact ranged from 0-4 with a mean of 1.38. As table 5 shows, when contact was more frequent it was with fewer family members.

Table 5. Mean Number of Family Members in Contact and Frequency of Contact

Frequency of contact	Mean number of family in contact			
	M	SD	Min	Max
12 monthly	1.38	1.10	0	4
6 monthly	0.88	1.08	0	4
3 monthly	0.75	1.07	0	4
Monthly	0.62	1.06	0	4
More than monthly	0.62	1.06	0	4

Contact with Friends

Most residents identified a staff member with whom they had particular relationships and twelve residents (50%) were reported to have no friends other than staff. Twelve residents had friendships with co-residents, and for all residents the mean number of friends was 1.38 (SD 1.56). Six residents (25%) had friendships with people who lived outside their house, the mean number of such friends being .54. Two of these residents had known each other at the institution but moved to different community houses maintained a friendship through regular visits to each others households. However, such visits always involved all the members of each household. Three (13%) residents had a friend who was person without an intellectual disability. These people included a long term advocate who visited the person monthly at their day program, members of a church community he attended weekly, and a previous worker. Only two people had contact with a friend from their day program out of the program's hours. No residents identified an intimate friend and only one a close friend.

Informal Network Size

The size of each resident's informal network was calculated on the basis of the number of people with whom they had at least 12 monthly contact, who lived outside of their household and did not know them in a paid capacity. As table 6 shows informal networks ranged in size from 0-6 people with an average of 1.92 people. The age of residents was negatively correlated with size of both family and informal although not to the degree of statistical significance.

Table 6 Average size of informal network

	M	SD	Min	Max
Number in network	1.92	1.47	0	6

Four types of informal networks were identified: “non existent”, “special occasion family”, “engaged family” and “friendship based”. Four (16%) residents had a non existent network, with no contact with either family or friends beyond their home. Six (25%) residents had a special occasion family network. They did not have

contact with any friends outside their house and their main contact with family was through visits or phone calls on special occasions such as birthdays, Christmas or organized house events such as a Cup Day party. Nine (38%) residents had engaged family networks, with a family member who played a similar role to that of key informal network member described by Bigby (1997a) and undertook instrumental tasks, being in regular contact and providing both affective and social support. The most active key person was a father who visited his son's house at least twice a week, and actively assisted the household with various tasks as well as both providing support and monitoring the formal support provided to his son. For residents with this type of network a family member was involved in their day to day lives, and actively monitored their wellbeing and the support provided to them. Some of these residents regularly stayed overnight with family members or spent a holiday once a year with them. Two residents were supported by staff to visit and stay overnight with an elderly parent who was no longer able to visit. Five residents (21%) had friendship based networks, they had minimal contact with family but regular contact with friends outside their home.

Examples of Network Types

Non Existent Network

Pat does have some siblings and her father was contacted in 1998 by the family reunification project. She was matched to a citizen advocate as part of the relocation process. The advocate visited her during the first year in the community taking her out for walks and coffee. However, between the first and third years the advocate stopped coming and she was not replaced. Pat's mother died in April and a sister rang the house to check Pat's details but has not been in contact since that time, making it clear she did not want to be involved in Pat's life.

Non Existent Network

Both Wendy's parents are dead but she has 4 siblings who live in country Victoria. They were contacted by staff in regard to the relocation but have not been in touch since she moved into the community. She was had a close relationship with another residents with whom she shared a house, however he died during the third year of the study. Her sister participated in the phone

interviews at the end of the first year and said that she didn't really know Wendy and she was too shy to ring staff as they wouldn't know who she was and she wouldn't know what to ask.

Special Occasion Social Network.

Both Maureen's parents are dead and her sister and a niece were put in contact with her as part of the family reunification project in 1998. Before she left KRS and during the first year she had monthly contact with a citizen advocate but she had lost contact with her by the end of the first year. Her sister and niece have continued to visit Maureen, at home, once a year on her birthday.

Engaged Family Network

Josh has an engaged but very small family network. His mother is a widow in her 80s and lives on a farm about 2 hours drive from his home. He has no siblings but is known to several of his mother's friends. When he was living at Kew his mother rang every week and visited every couple of months. Josh went to stay with her for at least two weeks every year. His mother phones the house every week and talks to Josh and staff. In the first couple of years he stayed with his mother sometimes at weekends but this no longer happens as his mother is unable to manage the physical support that he requires Staff have offered to organise a carer to stay but she is not comfortable with this idea. Since his mother is no longer happy driving staff have taken Josh to visit his mother once or twice a month. This may increase now that he is only going to a day program part time.

Friendship Based Network

May has two brothers and a sister. Her mother lives in the country with one of her sisters and is now aged over 100. She last visited May in 1998 and her father died in about 2000. One of her brothers visited the new house before she moved from Kew. Since the move family members are in touch but not more than once a year and her sister's last visit to the house was 2 years ago. A citizen advocate is in touch with May about every three months and takes her out. She has a friend from her day program with whom she goes to a

program at a local neighborhood house, and every now and again an ex staff member takes her out for a meal.

Changes to Informal Networks 5 Years After Relocation to the Community.

The nature of resident's networks varied over the period since their relocation from the institution. From the time residents were living at the institution to five years after relocation, the size of the family network of nine (38%) residents increased, it decreased for further nine (38%) and remained the same for six (25%) residents. The proportion of residents with neither parent alive increased from 26% to 38%. However, at interview four, Chi-square tests found no statistically significant association between contact with family in the previous 12 months and having a parent alive $\chi^2(1)=0.06, p>0.05$.

There was a downward trend in the number of residents in contact with family members as the proportion in at least annual contact dropped from 85% (20) to 75% (18) over the 5 year period. However, a Cochran's Q test showed that there is no difference in these proportions, $\chi^2(3)=1.32, p>0.05$. As Table 7 shows, a slight decrease occurred over time in the mean number of family in contact annually. The highest average was at interview 2, and the lowest average was at interview four. A Friedman's Test¹ for related samples showed that there was a statistically significant difference in the mean number of family in contact according to the time of interview, $\chi^2(3)=11.24, <0.05$. Wilcoxon² tests showed that the average number of family in contact at interview 2 was higher than at interview 4, $z=-2.39, p<0.05$ but there was no difference between the averages for interview 1, $z=-1.59, p>0.05$ and three, $z=-1.54, p>0.05$.

¹ A Friedman's Test is the non-parametric equivalent of a repeated measures ANOVA.

² Wilcoxon Tests are the non-parametric equivalent of a paired t-test, they're used to determine where differences in the means occurs as the Friedman's test has no built in contrasts in SPSS.

Table 7. Mean Number of Family in Contact in the Last 12 Months at Each Interview.

	M	SD	Min	Max
Interview 1 (Living in institution) (n=24)	1.75	1.29	0	4
Interview 2 (1 year living in community) (n=24)	1.88	1.39	0	5
Interview 3 (3 years living in community) (n=24)	1.67	1.37	0	5
Interview 4 (5 years living in community) (n=24)	1.38	1.10	0	4

Tables 8-9 show that similar trends were found for the mean number of family in contact with residents 6 monthly and 3 monthly.

Table 8 Mean Number of Family in Contact 6-Monthly at Each Interview.

	M	SD	Min	Max
Interview 1 (n=24)	1.00	1.18	0	4
Interview 2 (n=24)	1.25	1.29	0	5
Interview 3 (n=24)	1.08	1.32	0	5
Interview 4 (n=24)	0.88	1.08	0	4

Table 9 Mean Number of Family in Contact 3-Monthly at Each Interview.

	M	SD	Min	Max
Interview 1 (n=24)	0.79	0.93	0	3
Interview 2 (n=24)	1.25	1.29	0	5
Interview 3 (n=24)	0.92	1.35	0	5
Interview 4 (n=24)	0.75	1.07	0	4

Although a similar trend is found for monthly contact as shown in Table 10, no statistically significant difference was found in the mean number of family in monthly contact at the different interview times.

Table 10 Mean Number of Family in Contact Monthly at Each Interview.

	M	SD	Min	Max
Interview 1 (n=27)	0.50	0.83	0	3
Interview 2 (n=27)	0.88	1.30	0	5
Interview 3 (n=25)	0.67	1.27	0	5
Interview 4 (n=24)	0.62	1.06	0	4

Six families reestablished contact with their family member at the institution prior to their relocation as part of a family reunification project. There was no statistical association between families having been part of this program and still being in touch with their relative five years after relocation. Of the six families, two had ceased contact, three were still in touch and one had dropped but then re-established contact.

The average number of co-resident friends identified was higher at interview one when residents were living in the institution than at the following interviews when residents lived in the community. Table 11 shows the average number of non co-resident friends identified at each interview which were highest at one year post relocation and then decreased at three and five years. A Freidman’s Test did not show any significant difference in the average number at each interview, $\chi^2(3) = 6.55$, $p < 0.05$.

Table 11. Average Number of Non-resident Friends Identified at Each Interview.

	M	SD	Min	Max
Interview 1 (n=24)	0.63	0.58	0	2
Interview 2 (n=24)	1.08	1.77	0	7
Interview 3 (n=24)	0.71	1.16	0	5
Interview 4 (n=24)	0.54	1.10	0	4

Hidden in these figures is the drop from 4 to 2 in the number of residents who had a non resident friend without intellectual disability who played some sort of advocacy role in their life. Table 12 shows the proportion of residents who had a close friend decreased over time and a Cochran’s Q test showed a statistically significant difference in the proportion who identified a close friend as a function of interview

time, $\chi^2(3) = 17.46$, $p < 0.05$. A significant decrease in the number of residents who had an intimate friend also occurred over time.

Table 12. Residents With a Close or Intimate Friend

	Interview 1	Interview 2	Interview 3	Interview 4.
Residents with close friend	11	3	6	1
Residents with intimate friend	6	2	3	0

As Table 13 shows the average size of residents' informal networks increased at interview two, but then decreased at interviews three and four. A Friedman's Test did not reveal a statistically significant difference between the means, $\chi^2(3) = 6.30$, $p > 0.05$.

Table 13 Average Size of Informal Network at Each Interview.

	M	SD	Min	Max
Interview 1 (n=24)	1.83	1.27	0	4
Interview 2 (n=24)	2.71	1.81	0	7
Interview 3 (n=24)	2.38	1.95	0	7
Interview 4 (n=24)	1.92	1.47	0	6

Reasons for Changed or Low Levels of Family Contact.

The phone survey of 18 family members found various reasons for changes in family contact. In several instances changes in its nature was associated with their changed family circumstances. For example, phone calls replaced visits when parental health declined or a family member moved from the city to country or interstate. Five family members referred to the difficulties of staying in touch caused by the structure of the services, including, their lack of knowledge of the daily life of the resident, frequent changes in staff that meant relationships were not built and staff did not know who they were when they did phone. The low frequency that staff were able to support residents to visit their family member was also mentioned as an issue. Five

relatives referred to obstacles that stemmed from their own characteristics, such as other demands on their time and ill health and four referred to obstacles related to the characteristics of their relative such as aggressive behavior or their inability to acknowledge them.

Attention to Networks

Job descriptions of staff in houses that related to the aims of supporting residents to maintain contact with family and friends and build new relationships were not reflected in resident's individual program plans. Eighteen (75%) of such plans examined after residents had been in the community for 3 years, did not have specific goals or strategies about contact with family or friends, and only 4 had clearly articulated strategies. Recommendations made by the relocation team specifically about family contact for three residents were not implemented, which led in one case to a resident losing contact with a sibling. Only 2 recommendations made for 5 residents about continuing contact with particular friends were fully implemented.

Family Perspectives

After the first year in the community 100% of family members made positive comments about the impact of the move on residents' quality of life. Thirteen family members were extremely pleased and 5 quite pleased with the quality of life outcome of the move for residents. Despite this however, as shown on table 14, half of family members also made negative comments about the impact of the move, most commonly about inconsistency in staffing. Family members tended to use Kew as a comparison, pointing to reasons for being pleased with the outcome as due to the resident "being settled" having their "needs taken care of" having less difficult behaviour and involved in more activities. Most family members were not frequent visitors to the house nor did they have a good sense of its day to day running. Only one family member had regular involvement, in doing some, maintenance, the garden and generally helping out.

Table 14. Comments made by Family Members on Outcomes for Residents

Comments	Family Members			
	Time 1		Time 4	
	n =18	%	n = 18	%
<u>Total respondents indicating positive change</u>	18	100%	18	100%
<u>Nature of positive comments about changes</u>				
Improved health, skills and well-being	10	56%	9	50%
Resident happier	-		4	22%
Improved environment	16	89%	6	33%
Improved quality of care	11	61%	4	22%
More staff or greater consistency	4	22%	-	
Improved staff quality of attitudes	8	44%	3	17%
More chance for social interactions	3	17%	5	28%
<u>Total Respondents suggesting negative change.</u>	8	44%	9	50%
<u>Nature of negative comments about changes</u>				
Loss of friendships	-		2	11%
Poorer standards of hygiene, clothing, grooming	-		-	
Reduced access to specialist services reduced	3	17%	-	
Unhealthy weight gain	2	11%	-	
Effects of lack of history and information	3	17%	-	
More restrictive environment	5	28%	1	6%
Failure to be aware of individual needs	1	6%	-	
Increased transport costs and poor reliability	-		-	
Impact of inconsistency of staff	-		5	28%
House mix of residents compatibility, disadvantage			1	6%

Table 15, overpage, summarises family members responses to the closed questions that asked them to rate aspects of the relocation.

Table 15. Summary of Relatives' Views on Aspects of the Relocation

	Time Unchanged	Time 4	Time 1 Very much better	Time 4	Time 1 Somewhat better	Time 4
Relatives knowledge of programs and activities	7	5	6	9	4	3
Quality of support services	7	6	6	3	3	7
Overall satisfaction with living situation	1	-	11	10	4	6
Satisfaction with location of residence	1	1	10	8	4	7
Relatives general happiness	4	1	9	9	3	6
Relationship with resident	9	11	4	-	3	6
Relatives involvement with staff and residence	6	6	7	7	4	4
Relatives general happiness i.e. informant	3	2	13	7	1	8

Organisational Perspectives on Family Involvement

All organisations had policies of including families in the lives of residents and in organisational governance. Few family members were on Boards although all had processes whereby contact could be made with senior management by family members or residents express ideas or concerns. Administrators expressed some concerns about family involvements, one saw the dangers of parents trying to take over day to day management, whilst another raised the issue of resident privacy and stressed that family members can only be involved in the IPP process for their relative rather than be involved in the house as a whole. One administrator had instituted a more formal complaints process to try and change the nature of family involvement.

Several administrators felt that residents in the relocation houses had less contact with family than residents in other houses. It was suggested however that some houses had been proactive in tracing family members and an occasion was

described where all the residents of one house travelled to a country town so that one resident could meet previously unknown relatives. However, one administrator commented that linking residents to lost family members did not appear to have brought about enduring contacts. Administrators said family members were encouraged to phone regularly, visit the house, attend functions or take residents out and where possible to be included in IPPs. Only one organisation had taken any initiative to more formally support family involvement, in this case through the introduction of a Family and Parent handbook.

Quantitative Findings on Choice, Skills and Adaptive Behavior Development

The quantitative findings indicate that over the 5 year period houses in the community continued to provide a more homelike environment than residents had experienced at Kew and potentially more opportunities to exercise skills. Table 16 shows there was a statistically significant linear trend for the relationship between time and staff ratings of residence, $F(1, 19) = 9.29, p < 0.05$, the more time that passed the higher the staff ratings of residence. The proportion of the variance that is attributed to the linear effect (partial η^2) is 0.33. The data also has a statistically significant quadratic trend, $F(1, 19) = 11.19, p < 0.05$ (partial $\eta^2 = 0.37$), indicating evidence of a non-linear change over time.

Table 16. Means and Standard Deviations for Staff Ratings of Residence.

Staff Ratings of Residence (n=20)	<u>M</u>	<u>SD</u>
Time 1	3.34	1.17
Time 2	4.42	0.61
Time 3	4.43	0.58
Time 4	4.26	0.50

Similarly as shown in Table 17 there was a statistically significant effect of time for interviewer ratings of residence, $F(1, 16) = 12.68, p < 0.05$. The proportion of the variance that is attributed to the effect of time (partial η^2) is 0.44.

Table 17. Means and Standard Deviations for Interviewer Ratings of Residence T1 and T4.

Interviewer Ratings of Residence (n=17)	<u>M</u>	<u>SD</u>
Time 1	2.11	1.15
Time 4	3.13	0.67

As Table 18 shows the positive changes to the physical environment that made it more homelike and potentially less restrictive were reflected in significant changes over the period of the study in the number of skills residents were unable to perform due to the lack of opportunity . There was a statistically significant linear trend for the relationship between time and number of skills unable to be performed due to lack of opportunity, $F(1, 19) = 12.88, p < 0.05$, the more time that passed the lower the number of skills unable to be performed due to lack of opportunity. The proportion of the variance that is attributed to the linear effect (partial η^2) is 0.40.

Table 18. Means and Standard Deviations for Changes in Number of Skills Unable to be Performed Due to Lack of Opportunity

Changes in number of skills unable to be performed due to lack of opportunity (n=20)	<u>M</u>	<u>SD</u>
Time 1	20.70	20.83
Time 2	13.10	13.05
Time 3	8.55	13.20
Time 4	4.15	5.98

The preceding three measures essentially reflect the nature of the physical environment and potential opportunities it offers. However, the development and exercise of residents' skills are more likely to be associated with the degree of environmental press i.e. demands made of residents and the actual opportunities and support offered. This will reflect the complex interplay of the physical environment with social and organizational factors that together make up the social milieu of each house. Statistical findings indicative of the impact of the social milieu were not

consistent. Measures of independent living skills and competence indicated that no statistically significant change had occurred for residents over the period of the study. As Table 19 shows there was no evidence of an effect of time for the changes in independent living skills, $F(3, 63) = 0.75, p > 0.05$. Table 20 showed a more negative picture for the effect of time on competence scores, $F(3, 48) = 20.78, p < 0.05$ demonstrating a statistically significant linear trend for the relationship between time and competence scores, $F(1, 16) = 34.96, p < 0.05$, the more time that passed the lower the competence score. The proportion of the variance that is attributed to the linear effect (partial η^2) is 0.69. There was also a significant cubic trend, $F(1, 16) = 19.70$ (partial $\eta^2 = 0.55$), indicating a non-linear decrease in competence over time.

Table 19 Means and Standard Deviations for Changes in Total Independent Living Skills.

Changes in Total Independent Living Skills (n=22)	<u>M</u>	<u>SD</u>
Time 1	42.41	33.58
Time 2	36.91	32.13
Time 3	35.68	28.64
Time 4	37.91	30.13

Table 20. Means and Standard Deviations for Competence Scores.

Competence Scores (n=17)	<u>M</u>	<u>SD</u>
Time 1	20.82	4.94
Time 2	21.66	4.70
Time 3	13.07	3.54
Time 4	14.46	3.89

Measures of maladaptive or challenging behaviour, as shown in Table 21 showed no statistically significant effect of time $F(1.6, 35.7) = 1.88, p > 0.05$, nor did the scores for satisfaction $F(3, 48) = 1.52, p > 0.05$, shown in Table 20.

Table 21. Means and Standard Deviations for the Challenging Behaviour Measure.

Challenging Behaviour Measure (n=24)	<u>M</u>	<u>SD</u>
Time 1	1.23	0.21
Time 2	1.24	0.23
Time 3	1.25	0.20
Time 4	1.36	0.42

Table 22. Means and Standard Deviations for Satisfaction Scores.

Satisfaction Scores (n=17)	<u>M</u>	<u>SD</u>
Time 1	22.97	2.86
Time 2	22.08	2.98
Time 3	23.37	5.36
Time 4	21.35	3.48

As Table 23 shows measures of choice, however, also an indicator of the social milieu showed a significant positive effect of time for the choice measure, $F(3, 63) = 3.28, p < 0.05$. Furthermore, there was a statistically significant linear trend for the relationship between time and choice, $F(1, 21) = 6.82, p < 0.05$, the more time that passed the higher the choice measure. The proportion of the variance that is attributed to the linear effect (partial η^2) is 0.25.

Table 23. Means and Standard Deviations for the Choice Measure by Time.

<i>Choice Measure</i> (n=22)	<u>M</u>	<u>SD</u>
Time 1	1.94	0.51
Time 2	1.99	0.39
Time 3	2.06	0.54
Time 4	2.17	0.47

As Table 24 shows, the related dimension of empowerment scores was related to time, $F(2.0, 37.3) = 5.66, p < 0.05$, although the standard deviations in this score were much higher than for choice. There was a statistically significant linear trend for the relationship between time and empowerment scores, $F(1, 19) = 5.06, p < 0.05$, the more time that passed the lower the empowerment score. The proportion of the

variance that is attributed to the linear effect (partial η^2) is 0.21. There was also a significant quadratic trend, $F(1, 19) = 7.18, p < 0.05$ (partial $\eta^2 = 0.27$).

Table 24. Means and Standard Deviations for Empowerment Scores.

Empowerment Scores (n=20)	<u>M</u>	<u>SD</u>
Time 1	17.92	1.84
Time 2	18.53	3.25
Time 3	18.26	4.35
Time 4	15.54	4.01

Qualitative Indicators of Choice and Individual Engagement

The qualitative data suggested wide variation in the degree of choice, individual engagement and participation in matters of everyday life. Differences were evident on these dimensions both between individual residents but also between house groupings of residents suggesting the importance of opportunity and individual capacity. Increased choice was identified for all residents, either from direct observation by researchers or from the perspective of staff or family members. Similar to other studies change was most marked for people with less severe intellectual impairment. For example,

During the first year in the community the house supervisor talked about Bill as being “still very reluctant to make any choices”. The field notes recorded that “the supervisor said that he knows he doesn't like Broccoli but he is unwilling to say he doesn't want any, but she continues to give it to him to help him express his choices. He is reluctant to ask for things such as a coffee but will respond when asked. He is reluctant to initiate going to bed but will follow encouragement. The researcher observed “all the men sat at the table and were given similar size servings already put on plates with no questions as to how much people wanted”.

In contrast during a visit at year 5 the field notes recorded, “Dinner was rice and stir fry, which is a Tuesday night “special “as time is limited for everyone due to the activities. The residents served themselves from a large

bowl and sat together at the table. It was noted that Bill finished quickly and seemed to take a role of ensuring that others were getting organized, looking for bags and such.

In another house, during the visit after 8 months in the community, the field notes recorded, "Alison said that now the clients are showing preference for particular workers and the plans have been written to take this into account. Overall she felt there had been no change in any of the residents. During a visit after four years the field notes recorded, "Joy sat on the swing. Almost immediately Pat came outside and also sat on the swinging seat. Margaret said that until recently Pat would have never come outside on her own initiative".

And in another house the field notes recorded, "When the house was first established the supervisor devised a menu that was used every week. Then after 6 months "the supervisor began to sit with men and devise a menu on a weekly basis. At year 4 the field notes recorded, "When the staff member asked what they wanted for lunch, Mike replied, what have you got, and she ran through a whole range of things. Mike had a hamburger, as did Josh, two other residents had a pie and another had pasta".

For people with complex communication needs the expression of choice is often difficult which may be exacerbated by inconsistency in the way staff interpret signs and gestures. For example Dan does not talk and lives in a house where there has been considerable change of staff.

As soon as he is home from day placement he will take the staff member by the hand and lead him/her to the kitchen and take a cup from the cupboard. When he is given a drink he will set at the table. If he wants food he will take staffs' hand and go to the fridge; he will take them to the sensory room to get them to turn on the lights. If he is tired he will go and get his doona. He ate his lunch happily, made the sign for good for me and asked for a drink. When he finished the drink he got up and went into the kitchen but threw it on to the bench near the jug. Basil explained that this is his way of

showing that it is empty and he would like another. Other staff regard it as aggressive and have all found it difficult to alter this behaviour.

The diversity of resident activity in a house is a good indication of the degree to which residents exercise individual choice about the way they spend their time. Significant change in respect of this was observed in two houses.

In the first year the field notes recorded, “ as I walked in three of the residents were in the lounge watching TV, or rather the TV was on but they did not appear engaged with it. They were however all still there in the same place an hour and a half later when I came out of the office.

In the same house after three and a half years the field notes recorded, “The TV in the main lounge was on again, but no one was watching it. When I arrived at 12.0 Josh was in the front room watching TV, Keith had just had a bath and was in the living room and Patsy was making him a coffee. Dave was in the lounge and it looked as if Mike had just got up. Ernie was in his pyjamas in the bedroom.

After 4 years the field notes recorded, “It seemed that every one was going to different places, they were going to take Josh to see his mother and then Mike and Keith were going out for lunch, Ernie was going to see his girlfriend at Kew and Jack's family were coming over.

And in another house 4 months after the move the field notes recorded, “Tom spends a lot of time in his room watching a small TV .While I was there, the staff member and 3 other residents watched a video in the living room. Tom stayed in his room animatedly watching the cricket. He made a lot of comments and grimaces. However he leaves the door open and from there has a good view of the living room. Bill watched the video but was talking with himself and flicking his finger against his eye and head.

After four years the notes record, “Tom opened the door and let me in and disappeared back into his bedroom, Rob was in his chair in the lounge watching TV, Bill was in his bedroom watching football. Dave was outside

with Tim planting flowers, they had just mowed the lawn. Tim had bought some plants from home to put in the garden, he said they had run out of petrol for the lawn mower, He said that Rob had come out to help as well for the first time.

In some houses however, the patterns of daily activity observed remained very similar during the course of the study, with all residents doing much the same. For example,

After eight months the field notes observed, “after drinking their coffee they all went back to sitting on chairs. After three years, ‘the rearrangement of the furniture gave a sense of more interaction. It was noticeable however that residents sat on the same chair or couch they had sat on previously even though the position of the furniture had changed”

After three years and eight months, “ When I arrived the residents were sitting in their chairs and the television was on with no one watching it. After 4 years, “all the residents were sitting in their usual places with the exception of [new house member] The television was on but no one other than staff looked at it.” And after four years and eight months, “the four residents (Sheila, Maureen, Carmel, Joy) were all sitting in their set positions on the two sofas and chairs. Apart from Joy they were sitting upright and formally as if they were at the movies. However they were not taking any notice of the TV program, and still sit in the same fashion if the TV is turned off.

In some house opportunities presented for the exercise of choice changed little for little for some residents.

The field notes after a visit to Unit 1 whilst the residents were living at KRS recorded “staff just put their plates in front of them and removed the plates” After eight months in the house the supervisor said, “staff are unable to tell residents likes and dislikes regarding food. Sometimes Pat refuses to eat some particular food - but the next time it is served she wants to eat it” and the field notes recorded that, “ coffee was ready for everyone when they arrived home. They sat at the table to drink –decaf coffee- milk – one sugar. Alison said they had been told by KRS that was how they had it.

The residents all had plain sweet biscuits, which staff brought to the table in a jar and they could take their own. After 3 years and eight months the field notes recorded that, “ each resident had one cup of coffee which they drank quickly and then had a few biscuits each. Marg put the biscuits on a plate in the middle of the table. No one took a biscuit until Marg handed them to each individual. Marg commented that residents do not know how to share a communal plate”. During the visit after 4 years it was noted, “Margaret brought a jug of cordial and a container of biscuits. She handed each one a biscuit taking time to select the biscuit. Margaret asked Carmel if she wanted another biscuit. With encouragement Carmel got out of her seat and went around to Margaret and took a biscuit from her. She immediately went back to her seat”.

Communication

There continued to be little attention to the use of communication aids in the houses, with staff members often indicating that they understood resident’s speech or could interpret their gestures and other forms of communication. The absence of devices such as individual chat books made it difficult for any visitor to communicate about recent interests or activities with residents who did not have good verbal skills. The development of digital camera technology during the period of the study did mean the photos of activities such as holidays were more available in some houses although these were seldom presented in an organised manner that could support independent communication with a visitor. One resident, whose file notes record at least half a dozen communication assessments with accompanying recommendations for assisted communication devices, had solved the issue himself using everyday junk mail.

In the last two years Tom who has very limited speech discovered the utility of sales brochures that appear in letter boxes. By the end of the study he was effectively using such brochures to make and communicate choices about clothes he wanted or new pieces of furniture he desired for his room”.

In another house, although the resident had a communication board, during the period of the study its use was extremely variable, and it was difficult to determine whether this was due to his wish to control communication or inconsistency on the

part of staff. At the last visit however, the new house supervisor was utilising new technology of digital camera to aid communication with this resident.

Margaret(a community advocate) is the only one who uses the spelling board with Gerry. He spelt out that he would only spell with her not with staff. Basil said this means they can't use the Board. Basil said Gerry also has a communication book which he is trying to get him to use but thinks Gerry does not want to use the spell book because he has staffs attention for longer if they are trying to work out what he wants. has initiated Gerry buying a digital camera and Basil has put the photos on the screen. All residents have liked to see themselves on the screen. Basil has used this to communicate with Gerry. He put a photo of a cup of tea and asked Gerry if he wanted the tea, Gerry nodded yes. Then he put a phot of Gerry having a peg feed and said they would have to do this first. Gerry put his head down but also nodded and then Basil put the photo of the tea cup on again and said then we will have tea and Gerry brightened up.

Participation in Domestic Activities

For eleven of the twenty-four respondents participating in domestic chores was mentioned as part of their daily routine in the two days preceding the data collection. Most commonly, involvement in preparation of their packed lunch and taking plates to the kitchen were mentioned. From the case studies it was apparent that most residents were only involved in a minimal range of the domestic tasks. With one exception, resident's participation was not a systematic part of household organisation and support for participation varied over time as well as with different staff within a particular time frame. Such inconsistency appears to be particularly challenging for people with more severe intellectual impairment. For example,

The notes field notes recorded that "She clears the placemats after dinner often without prompting and takes them to the washing machine. She sometimes clears the table and takes the plates to the kitchen. If she sees someone else has finished their meal she will sometimes take their plate to the kitchen. With prompting she undresses herself at night and takes her clothes to the laundry. Maureen and Carmel can still get upset with agency people. They respond well to instruction. Margaret said that when other staff do not follow this routine it confuses the residents. When I was there,

Margaret called Maureen to take glasses outside Maureen did so and put the glasses on the table. Maureen also took the glasses back inside when asked to. Janet [staff member who is deaf] could not hear Margaret asked Maureen to bring the glasses in and tried to stop her following Margaret inside. Maureen was puzzled but still kept trying to do what she had been asked”.

One house stood out as fostering a growing sense of responsibility as well as participation in the household for residents. It was notable that most residents in this house had moderate intellectual impairment and some had been participating in domestic tasks prior to leaving KRS.

The relocation report written whilst Bill lived at Kew stated, “Bill has opportunities on a daily basis to participate in domestic duties and is an active, willing participant. Bill is able to make tea, coffee and light snacks. He can use a washing machine with verbal prompts and can use a dishwasher, wash, dry and put away dishes. Bill can also vacuum, his makes his bed and keeps his room tidy. Bill occasionally requires verbal prompts to complete tasks, and requires staff assistance and support to use a toaster, electric kettle and a stove”.

After four months in the community the field note observed, “The men placed their plates in the dishwasher but the staff person tidied up, washed the plastic place mats and set the dishwasher on.

After 9 months it was observed, “Tom cooked the sausages in an electric saucepan while the staff member grilled the rest and prepared the rest of the dinner. The staff member took over cleaning up. I suggested Rob help me empty the dish washer but the staff member said “I do it in the evenings because there are so many things to do and you have to do it properly. Its not so important in the mornings so they help then”

At the end of year 1 the house supervisor reflected. “ Bill regularly hoovers parts of the house in the morning. With other residents he serves himself cereal in the morning and will help to put things in the dishwasher and

clear away. He is not involved in regular food preparation. He makes his bed regularly, he will put his clothes in the washing machine. He goes shopping with the rest of the household on Saturdays”

A field note after 3 years in the community reads, “Tom came home from Bowls and cooked the sausages with no prompting and dished up whilst Dave buttered the bread, they all ate outside. They made themselves coffee and Tom made one for Eillie. The men seem much more in control of their house and taking the initiative in cooking. The supervisor said that “the men are all getting their own breakfasts, with almost no assistance and Tom is reminding about medication. It appears that when other less experienced staff are on they get the men’s breakfast for them.

At 3 years and nine months, the field notes reported, “The men all have tasks in the morning and are doing much more cooking for themselves. Although as I sat the supervisor did all the preparation for tea. Tom mops all the house everyday, Bill vacuums, Rob empties the bins, and Dave clean the toilet”.

After four year the field notes observed, “The supervisor was cooking the meal, but left the potatoes for Dave to mash and left him to serve. The men then each got their plate from the bench. The supervisor left the washing up completely to the men, the dish washer is broken, but Ned washed and Dave wiped and Bill put away, Tom avoided doing anything as it took him much longer to eat and then he said he had a sore knee and went off to have a bath. Even Rob put the mats away and the salt and pepper, There was no staff supervision or assistance. Tim is trying to reinforce that the men do more things for themselves. For example they are now being held more accountable for their cleaning, so that in the past if they had not done it properly staff would do it when they were not around, now they are helped to do it again or do it properly the first time.

In another house, which had experienced considerable staff change involvement in tasks was more variable over time, and continued to be hampered by design of the kitchen that could not accommodate wheel chairs.

The field notes from the visit to the resident whilst he was living at Kew observed, "Mike recited to me the various tasks that he did in the wing when he returns home from his day program, he made his bed, had a shower, brushed his teeth, and often "sat around doing nothing"

After 4 months the house supervisor said, "All members of the household have jobs. Mike cleans the sinks and sometimes helps with other jobs. After 9 months she said, "in the morning they do their little jobs. Mike cleans the sinks and will dust the skirting boards. Apart from this there are no routines for residents to help with any of the cooking and other domestic chores. Staff do it mostly or at weekends they will help make a cake or something, but the time is a factor".

After three years the field notes observed, "the staff appear to do all the household tasks, whilst I was there, one staff member folded up all the towels while the residents just sat. The staff got the lunch ready, served it and cleared up. Ernie made the coffee and the staff took it in. Staff do the shopping. Mike no longer does the sinks and he does some cooking during the week and no longer at weekends. He cooks a meal once a week and always cooks meat loaf, he puts his clothes away and takes his clothes to the laundry. The supervisor could not think of any other jobs that he does. She said that he mucks in when they have a big clean up".

After 3 years and six months the acting supervisor said, "Although all the men have chores, (Patsy had to look these up in the book), it is only Dave that really does any and he tidies and takes the papers and rubbish out. The men are not prompted to do chores and it is up to them. Ernie likes doing chores and if you told him to do the cupboards he would be very willing to do them" After four years and four months, it was observed, that, "No one got up to help or even lay the table or even go into the kitchen to get their

food, the staff member did the whole process. Dave is the only resident who does much to help in the house, he does the dishwasher stacking, empties the bins and looks after the recycling, now and again he vacuums, sets the table. Mike does not do anything in the house really other than take his clothes into the laundry and tidy his bedroom. Josh and Ernie both get their own bibs for food, but don't do much else. There used to be cooking programs but they don't do that any more.

Obstacles to Choice.

Expressed choices, although understood were not always be respected. A range of organisational imperatives, many connected to risk or value judgements, accounted for this and interfered with choice being exercised by residents. The ability of staff to place restrictions on choice also illustrated the often unacknowledged degree of control staff exercised over the day to day lives of residents. In Robbie's case for example, even though his expressed need was understood there had been different responses over time. Field notes recorded during one visit,

“Dan has his dinner about an hour before the other residents, as he likes to have it as soon as he comes home and will not wait. Before Basil was at the house he had to wait but Basil says if he enjoys it then he should be able to have his food when he wants it. He can still sit with the others if company is important. At a visit a few months later however the situation seems to have changed again and the notes recorded, “Dinner was slightly earlier that night than usual, as Dan was hungry and wanted to eat. I wondered why they didn't give him some fruit (like a banana) to eat before dinner, to keep him happy (he seemed quite hungry) and so that the others didn't have to eat early just because of him. I mentioned a banana to Rachel, but she said that they don't like to feed them too much just before dinner. Toni wasn't very hungry and didn't want to eat.”

Risk and safety, though under different guises was a factor that was observed as consistency limiting choice and opportunities. Group living often meant that residents other than the one primarily considered at risk were effected by decisions to restrict choice or ensure safety.

The field notes recorded that, Maureen does some tasks but staff feel strongly that it is not safe or practical to have residents in the kitchen. If she [Joy] can get into the kitchen she tries to make coffee, or eat raw potatoes and onions. Due to concern about Joy the staff pressed to have a gate to prevent his access to the kitchen in the open plan siting /large bench kitchen area. This has been an area of considerable debate with the community visitors and the gate has been up and down and now up, but modified to make it lower to prevent Joy but not other residents. Joy wandered around the kitchen as the kitchen gate was not locked, however she started opening the dish washer and was told to leave the kitchen and the kitchen barrier was locked”.

After five years the field notes recorded that, “Pat and Joy had changed rooms so that Joy would be closer to the staff room as she gets up at night. Both Alison and later Guin said the women had not minded although Pat kept wandering back into her own room for about a week. I had been previously told how much Pat liked her room”

A field note for another house noted that, “Neither Mike or the others are allowed to go to wheelchair tennis any more as they people who run it do not have first aid certificates”

And in another it was noted that, “ Amy is doing a nutrition course (4 sessions run by the organisation) and they have decided the men are putting on too much weight and that they should eat less in the evening”.

In another house it was noted that,” Toni [who usually stayed at home one day a week for a rest] has not been able to stay home as Hilary needed to be doing things for Gerry and Hilary thinks this may have effected her”.

A particularly recurring theme was in relation to expressed choices about food and drink particularly coffee. These appear to be the things about which residents are mostly likely able to express choice, yet consistently appeared to be subject to

restrictions imposed without clear rationale. Little evidence was found of creative approaches to managing the perceived issues drinking too much coffee or overeating posed.

The field notes recorded, "After we had coffee Daphne went into the kitchen and indicated she wanted a cup of coffee by lifting up the jar. The reliving staff member asked what she was doing. The manager said she was indicating she wanted a cup of coffee but as she had just had one to take the jar and not give her one".

In another house, the notes recorded, "I was offered coffee and asked for a glass of water. Joy kept trying to take my glass. She accepted when I diverted her and would go to the kitchen then back to my glass. I eventually asked if she was thirsty and Katie then took her to the kitchen and made her some coffee. Joy drank the coffee quickly and Katie commented she was really thirsty.

At a later visit it was noted, "When Margaret went to the kitchen Joy followed her. Margaret made herself a cup of coffee and Joy wanted one also. When Margaret gave Joy water to drink she did not want it. Joy is not allowed coke because of the caffeine and only can have decaffeinated coffee She eats and drinks very quickly Marg makes Joy's coffee quite hot as this stops her gulping it too quickly. I thought Joy seemed to be in some minor pain when she first gulped her coffee, but the temperature did not seem to stop her gulping it.

And in another house it was noted, "She likes coffee - but staff have to put some restriction on how many cups she can have. They tend to do this by giving her coffee when he asks but smaller amounts. On my very first visit Joan said that Paula was addicted to coffee also, but they do not give the residents coffee there. Joan said they all lived on tea and coffee at Kew, because it was all they had to drink, but that it's not a suitable drink for them. Coffee is banned, but tea has been permitted. The rule is that they

first have to eat their dinner, then have a fruit smoothy, and after that they are allowed a cup of tea. She often hovers round the kitchen waiting for a drink of tea”.

Coffee is an important currency for the expression of choice and means of control by staff of residents. The offering and making coffee is also an important symbol of the residents growing confidence and ownership of their home.

As a later section explores more thoroughly the apparent increased flexibility in the use of funds and staff time, meant that in later years staff talked less about the restrictions of group living than after the first. However, still apparent were restrictions on choice that stemmed from organisational imperatives and staff convenience.

The field notes recorded, that, “She [staff member] sat near Joy and touched her to keep her awake a few times. She also stood Joy up so she would go for a wander around the house to keep her awake. Marg said she was on night duty and did not want Joy to be awake half the night. Eventually Marg gave up and let Joy snooze. Joy only slept for a short time and then woke”.

The extent of staff control was mostly clearly demonstrated by changes in house supervisors which often led to an observable “regime” change in a house which entailed the speedy implementation of new routines and approaches reflecting the ideas of the new supervisor.

House 11 was particularly susceptible to such changes over the 5 years as it experienced 7 supervisors. One indicator in this house of different approaches as the way supervisors regarded residents and terms used to refer to them. The first supervisor saw the residents as “guy’s and herself as a defacto mother, (organising for another staff member to buy card on mothers day from residents to her). After a substantial interim period the second supervisor regarded residents as “bachelors”, and the next adopted the term “clients”. There was a dramatic change in attention to cleanliness and house décor between the first two supervisors. The first had decorated the house with pretty trimmings, such as place mats, ornaments, and flowers, and kept it spotless. Whilst the second paid such little attention to such things that placemats and table cloths were no longer used and the house began to look

grimy and neglected. The only long term staff member in the house reflected on the changes that occurred in routines and focus of the house with different supervisors, particularly those imposed by the second, “each manager wanted to change things, which has been confusing” She explained that for example, George had lots of firm ideas about more input into activities such as cooking. But the house became run down, the men tired and poorly cared for physically. Dinner would often be as late as 9pm because it would take too long if the men were expected to help. They used to go boot scooting but this was stopped by George, and she was not sure why. George had been clear they should only have one activity a week as he thought they were doing too much. George had stopped Mike going to the social club, on the basis the men were going out too much, and they needed to go things on their own rather than in groups. After George left, Mike had said he wanted to start going to the social group at Mill Park on Thursday again. She said there seemed to be a problem between doing too many activities and not enough. George thought they were doing too much and Patsy now feels they are not doing enough. When George left they had also restarted the "dining out program" they all go out together on Saturday nights, to the place of choice.

Behavioural and Health Changes

All residents in the intensive case studies demonstrated positive changes to their skills and/or behaviour. For many this was evident by their increased participation in domestic tasks or individual activities in the community which are illustrated in the preceding sections. Contrary to the quantitative measures the data indicated a reduction in identified challenging behaviour for some residents during the course of the study. For example, the field notes recorded that,

Tom no longer tore clothes or took other men’s clothing, behaviour which KRS staff had noted required locks on bedroom cupboards and laundry door.

Bill’s stereotypical behaviours reduced and he became much more sociable. After 5 years in the community he was no longer taking medication prescribed for the “mania” had been diagnosed with at Kew

Sally no longer smeared faces, stopped wetting the bed at night, no longer had pica which means she can go outside, no longer routinely threw ornaments placed in her bedroom. Sally now eats with a knife and fork and takes longer to eat her food, which was initially viewed by staff as negative but later explained by them as Sally no longer having to worry that someone will eat her food.

Change, however, was not always in a positive direction.

After 3 years the field notes recorded that, “Marg has noticed a change in Maureen's behaviour over time. She thinks she is often more agitated. Her sleeping patterns are worse. On average Maureen gets up 4-5 times a night. She bangs doors closed, goes to the toilet and makes a lot of noise. She will go back to bed herself. Staff have to hide the toilet paper as Maureen eats it. She thinks Maureen self abusive behaviour has increased. She will hit herself on the arm quite hard so there are bruises. She bangs her ankles on the bars in the bathroom and has bruises due to this. She has been doing this for about a year.

During the 5 years change did not always follow a straightforward pattern of improvement for all residents. Several residents experienced noticeable negative changes after several years in the community, and some experienced quite marked “good time” and “bad times”, often associated with physical and mental health issues. As well as illustrating these periods in resident’s lives the field notes illustrate the challenges that confront staff in understanding behavioural changes and obtaining health care.

Whilst at Kew the relocation report noted that, “Dan has a history of pinching, scratching and tends to target female staff (can grab on the breast). This behaviour occurs approximately once a week and is not considered to be of high severity”.

After five months in the house the field notes record that, “it still isn't easy, Dan’s behaviour has deteriorated since leaving Kew and he has lost the ability to go to the toilet on his own.

After 4 years the field notes recorded that, “staff (and father) said Dan's behaviour has improved out of sight. Things seem to be going well at day placement - more good time than bad. He has one to one worker 3 days a week. He seems happy when he wakes up. He no longer pinches staff. He will go and sit in the sensory room and seems happier. He was very sick over Christmas - with a virus and his behaviour and his eating deteriorated, He would only eat smoothies. However now Dan is well. He has got back into his routines.

After four years and 4 months the field notes recorded that, “Basil is concerned about Dan's unpredictable behaviour and he is to see the psychiatrist who has seen the other residents”. And after 5 years, that, “ Dan's behaviour does not appear to have triggers that can be identified. He has very good and very bad days. Early in 2004 Dan's behaviour was of significant concern at the house and at the day program. Behaviour management strategies were ineffectual at times and it was difficult to identify triggers for his aggressive agitated outbursts. He targeted particular staff without warning and developed a pattern of hurting Toni, who does not respond to being hurt. His father started to become very concerned after Dan was hospitalised due to him being "beaten up" at his day program. Towards the end of 2004 his father agreed to a trial of medication (anti-psychotic) for Dan. Initially Dan became lethargic, obsessed with food, put on weight and wanted to over sleep. With adjustments to the medication these symptoms have decreased. He does not use the sensory room as frequently as previously, preferring to sit at the dining room table, watching staff, especially when they are in the kitchen. His behaviour is still unpredictable, including pinching and scratching, but he is not pacing in an agitated manner. Hilary expressed that he was often reacting to imagined threats and fighting of what he feared was attacks. Dan's eyesight has deteriorated (glaucoma) and it is difficult to access how much of his aggressive behaviour is due to distorted vision. He is very anxious walking on uneven ground or in unfamiliar areas, he will feel

secure with Vic as he familiar with him and he is securely holds his arm and walks very close to him.

In another house the field notes recorded after 3.8 years that, “Joy’s sleeping patterns have deteriorated. She tends to be awake at night and wants to sleep during the day. Due to her sleeping pattern Joy is now on mild sleeping tablets. Marg said Joy has a lot of energy and wants to keep wandering. In addition to change in sleeping Joy had cataracts removed 6 months ago. Staff had noticed she was bumping into things. Now Joy walks much better. Joy's seizures have increased - now once every 2 weeks - previously once a year. She was taken off her medication when she first arrived at the house. She has not been put back on but has an appointment with a psychiatrist. After 4 year it was noted that, “Joy’s epilepsy and sleeping patterns have improved. She was taken to the Centre for Developmental Disability Health (CDDH). She is on medication and seems better. There have been no seizures”. But after 4.8 years the situation had changed and the notes recorded that, “Joy sat on the dining room chair all the time I was at the house. She did not take any notice of me, she is usually more active, taking my hand and wanting me - or a staff member to get her coffee. She is now on medication for agitation as well as epilepsy. She has had her epilepsy medication increased - but although it stopped the seizures for a while they are now back and she is not sleeping any better. Joy gets up during the night. She has major mood swings. She will run up and down the corridor, screaming out, running into the other resident’s rooms and is almost impossible to quiet. For example, last night she got up at 1.30am and did not go to bed until 4.30am. She was given a second sleeping pill at 3.45 . She was sleepy when she was got up in the morning going off to day placement. They are also waiting to get her some behavioural management but have to check out first her behaviour is not physically caused. They have been told she is manic depressive.

In regard to another resident, the relocation reports from KRS indicated that Gerry had a history of depression, becoming agitated and thrashing in

his wheelchair when he got frustrated in being unable to communicate his needs. After 3 and half years in the community the field notes said, "Hilary thinks Gerry's behaviour has improved immensely and he is now takes responsibility for his own actions. e.g. she will tell him he has to stop thrashing about in his chair because if he falls out and she is alone she cannot put him back and he will have to lie on the floor. She says he seems to respond to this and then she is able to care for him. At 4 years it was noted, Gerry was relaxed and Basil feels he is the best he has been for some time. He is keen to take fluids orally and is not becoming distressed with this as often as before. His rash is better also, a doctor found that he is allergic to urine and the new medication seems to be helping. There is a new young local doctor who is giving all residents lots of time and is keen to solve all problems. A great deal of the peg feeding issues have been managed. He has put on weight. His formula has changed which also seems better. A key change for Gerry was getting his wheelchair adjusted so he can sit straight up. Previously the chair seemed to make his slump forward - this led to the strap of the chair knock his stent. Now when he sits up his head is also up instead of hanging down so he can't see people. I did notice that Gerry did look at me more directly. He has been on both anti-depressants and Valium for about 3 months and was not shaking and agitated and has clearly put on weight.

After 5 years, "Gerry has been on anti-depressants medication for more than 12 months and combined with him finishing his day program at the end of 2004 has resulted in a marked change in emotion in Gerry. Hilary is his key worker and she says she no longer "despairs for him" and his sense of humour has returned. Hilary describes periods when Gerry was so depressed and angry that he would hurt anyone around him and attempt to inflict harm on himself. He persistently fought those attempting to feed him, until the site of his feeding tube became ulcerated and infected.

In another house, the field notes from the 3 year visit observe, "a staff member starting his shift wanted to talk with Hilary about how dreadful Toni's behaviour has been the previous night. Biting, hitting, throwing

herself about refusing to cooperate. Hilary told me she wonders if Toni has had a stroke as a few weeks ago she was unsteady on her feet for a couple of days. An appointment has been made with a neurologist. Toni has also has an ear infection and she has been constantly scratching at her ear and does not want to let anyone near her. Staff also wondered if she was menopausal. The notes of the visit at four years and four months, “Toni was on the sofa watching TV. She was much more settled than on my previous visit. She is finally going to have the ear surgery as the heart tests have been done and they have a different doctor who has actually set a date. It has been such a difficult process with lots of tests and delays. Toni is on lots of medication as she now has antibiotics as well as the anti psychotics. She is otherwise quite healthy and ok if allowed her space.

After the visit at 5 years the field notes observe, “Toni has lost 14kg in the last ten months and has deteriorated physically and emotionally over this time. Hilary is most concerned about her health, it took many months for the specialist to agree to surgery for her seriously inflamed inner ear. The surgery for one ear was effective and there are plans for surgery for the second ear in the near future.

A comprehensive evaluation of each resident’s health was not undertaken but the survey asked staff to rate the status of each resident’s health. As table 24 illustrates the health of a number of residents declined during the 5 years and although those on psychiatric medication initially declined the number subsequently rose. From the data in this study it is impossible to reach any conclusions as to the causes for the decline in some residents health and whether this could have been averted.

Table 25. Staff Rating of Residents’ Health

<i>Time</i>	<i>Good</i>	<i>Fair</i>	<i>Poor</i>	<i>Psychiatric medication</i>
Kew	21	3	-	6
2 years	23	1	-	2
5 years	17	4	3	7

As the forgoing case examples have illustrated physical and mental health conditions have a significant impact on residents' wellbeing. Staff encountered difficulties in getting timely diagnosis and treatment, which prolonged the discomfort and disruption health problems posed for residents and households. Comments about the poor management of health issues were made by community visitors in regard to half of the 6 houses. Several houses took steps to change GPs when they considered the service offered was poor. Various residents spent time in hospital, and although the hospitals differed the experiences seemed much the same. Consistently, heavy demands were placed on house staff to remain with the resident in hospital and it was expected that they rather than hospital personnel would take responsibility for managing the residents' personal care and rehabilitation. For example, the field notes record that,

Staff reported that Pat fell at day placement and initially did not appear to be hurt but when she arrived home could not get out of the van. Pat did not give any indication that she was in pain. No grimacing, or crying.

She needed a pin in her hip, it was not immobilised. She was In Box Hill hospital 4-5 days. Nursing staff found her care difficult and expected house staff to shower her in the hospital. They rang house to say they did not know what to do. Pat cannot dance much now because her movement is restricted. The pins in her hip have fused and she has limited mobility. No further operation is planned. A short time ago Pat was walking very slowly bent over and holding her hip. Alison has arranged for a medical appointment but Pat now seems OK. This has happened twice. Pat does not receive any physio for her hip as it was not recommended.

Maureen was in Box Hill hospital for three days and had an abscess removed. Alison and Guin both said she was fine in hospital provided staff stayed with her. At night she still got up and took off her pjs and got back into bed. This is what she does at home. Guin said that she took Maureen to the emergency dept and waited for 5 hours until Maureen was admitted.

Basil takes Toni for appointments and has found such lack of care for example, he will make times explaining that she gets agitated if kept waiting

but will still have to wait for hours and then she will be uncooperative. He will also explain that she does not like her personal space to be invaded but the nurse will then lean over her to reassure her and get scratched as Toni will be frightened. Basil had to be with her at all times (even sleeping on the floor in intensive care) or the hospital staff refused to have her. Hilary claims that the hospital staff showed prejudice and ignorance and would not attend to her needs. This difficulty in relation to Toni, as well with Dan, has been at a public Hospital.

Many residents made use of podiatry and dental services offered by Community Health Centres and local GPs. The absence of reference in the 4 case study houses to preventative screening such as pap smears, mammograms, sight and hearing tests was however noticeable. House 5 stood out in relation to the consistent emphasis they placed on daily exercise and a low fat diet. However, all residents in houses 11 and 8 were doing either regular exercises or sport. Despite this Mike put on considerable weight during the 5 year period as house staff struggled to consistently maintain a low fat diet rather than rely on high fat convenience foods. By the end of 5 years however a quarter of all residents were overweight.

The number of residents using antipsychotic medication had increased after 5 years, it had ceased for one resident but commenced for two others. Staff voiced concerns about anti psychotic medication and the quality of psychiatric care. For example the field notes record that,

Hilary was rather defensive when discussing the medication for each of the residents and admitted that at times Toni, Gerry and Dan have all been over medicated, but claims that all this has been adjusted and Dr T monitors their medication regularly. However, in discussion, it appears that the doctor relies on staff accounts of behaviour and likely interpretations. On one occasion Hilary mentioned as an example of Dr T being helpful, that he consulted with the residents briefly when they were in the bus.

Planning For Individuals

The qualitative data from the four case study houses, suggests that difficulties are experienced in following through actions plans both for individual residents and for the house in general. Many examples were found of initiatives that had not been sustained over time, as well as inconsistencies in the way staff understood or

interacted with residents. There was little sense in these houses that a planned, consistent and individualised approach was being taken to supporting each residents' needs based on a shared understanding of their preferences and needs. Most pronounced was the disconnection between what occurred for residents during the day and after hours and at weekends. In the phone survey of day program staff 8 respondents (33%) referred to difficulties in working with house staff to coordinate the needs of residents. Examples were found however of good partnerships between the two types of programs and in the last year one house had began an initiative to make a regular phone call to the day program of each resident once a fortnight. Little evidence was found that knowledge about residents, particularly about friendships, was shared between staff in different programs. This was captured by the comment of one supervisor who said, when asked about a resident's friends at the day program, "I wouldn't have a clue".

Several house supervisors talked about their frustrations in being unable to follow through ideas for the house.

The field notes record, "I asked if anyone ever sat in the front room. Guin said they did not. She also said they had plans to make the room once again into a second sitting room with a TV. She added with a laugh they frequently had plans for this room but never did anything".

In another house the field notes after four months recorded, "the supervisor said, "everything takes so long" and after 6 months the notes stated, "she described her frustration and inability to set up and follow through any training and organise external activities or programs for residents " just getting through everyday and feeling that you have given each of them a bit of time, and everybody is happy, as to achieving anything else....doesn't happen"

In another house the field notes record, "Tim admits that he started 12 months ago with lots of ideas and high intentions. However in practice progress has been slow and frustrating. Just daily living has proved so time consuming that implementing any change has been slow. He feels he has been quite creative with rostering - but there is a limit to what they can

cover and this restricts the activities that resident can undertake. The "juggle" of providing adequate staff coverage to cater for the range of needs for the residents is regarded by Tim as exhausting. Later, on the phone Tim repeated that there is so much he would like to be working on to help the residents be more independent, but he is continually frustrated by lack of money and therefore staff. He is still to achieve most of what he has talked about.

Changes of staff, conflicting or multiple demands mean that initiatives can be lost over time and with them opportunities for residents. An example is the computer, with a voice recognition program that was given to one of the houses during the transition.

After four months it was observed, "one person had a computer via Deal with voice recognition and they had not yet hooked it up to the internet and the table was too high for him to comfortably use it". After 3 years 1 month it was noted, "Josh has not used the computer, although I was told he had good skills, the modem is not powerful enough to download email. Apparently he is saving up for a modem and a staff member has expertise in computers is going to assist". After 3 years 11 months, "the supervisor said, Josh could probably operate the computer and use it to make choice and communicate, there used to be a computer in the front room, when they first moved, but no one used it and she doesn't think it ever worked. She checked with Ben who says it doesn't boot and he is going to have a go at fixing it".

In another house a supervisor instigated a communication strategy that involved many tiny pictures and signs on the bedroom wall of a resident. Very soon after he left however all the signs had been removed. In another it took the supervisor 12 months to open a passbook account for each resident at a bank, however these were never consistently used and later lost to be replaced by a key card account for each man.

Evidence from the data on resident's social networks indicated that staff knowledge about resident's family constellation and relationships was very variable, with some staff having almost no knowledge about resident's backgrounds and in

some instances had quite incorrect information. For example, the elderly mother of one resident lives in Queensland very close to where the residents went on holiday, but none of the staff members were aware of this until they returned home, which meant a lost opportunity for the resident to visit his mother.

Individual programs plans are a mechanism that can potentially assist in identifying individual goals and taking action to meet them. However, the survey data collected from all houses suggests their utility is limited; as such plans are not prepared in a timely manner and rarely used to inform support provided by staff support or resident activities. A more detailed but similar story of delay and failure to use plans as a guide to everyday support was found in all the case study houses. This was particularly highlighted when new supervisors were observed to make plans for the house and residents with no reference to previous individual plans or the available background information about residents. The field notes recorded,

After 4 months, “the supervisor said, staff are currently working on IPPs which will address individual programs and activities to a greater extent than has been possible until now. After 3 years and 10 months, “IPPs are currently being redone over the next couple of months”. Cate has now been employed since Wednesday (three days ago) as team leader, she has not worked in the house before and does not know the men or the routines. She did not know where the IPPs were or what was in them. She managed to find Mike's but could not locate Josh's at all. She was unaware of relocation files and has little sense of the men's history. She talked about all the new things they were going to do, wean away from the TAFE program, use more community facilities, go out more individually, do more skills development. She has reorganized the roster so that there will be an additional "activity shift" staff person on at the weekends, which will allow people to go out individually rather than in groups. She has also organized for two staff to be on during the day on Tuesday and Friday when Keith and Josh are home so they can do individual programs and don't have to go around together.

After four years 6 months, “the acting supervisor a long term staff member said, aims for the next three months are to achieve greater independence for the men so they don't work, live and play with each other all the time. Each

manager wanted to change things, which has been confusing. She is tired of new people coming in and doing things to draw attention to themselves, but have no idea of how hard the work is. Some of the IPPs have now been completed [these are the one referred to at the 3 year 10 month visit]. Mike's was done in July August, present were his father Dot and Patsy, Josh's will be today, his mother will not come but she has written something, the area manager Susan will also come. Ernie has his last week and his mother and sister came. Apparently the IPPs are too long, approx 16 pages, and were based on work done by George, some parts were not appropriate, and the area manager is working on them at the moment to cut them down.

After 5 years, "Collected the IPPs that are dated August but have been with the area manager since that time and Josh's has only just been returned to the house. The new house supervisor has not seen it before today. She said "it was basically meaningless" and anyway IPPs are going to be scrapped and the new person centred planning is going to replace them.

And in another house, "He [supervisor] has a lot of good ideas re making things more flexible, trying new thing for the men, giving more control and independence. He has found the relocation files but has not read them, is unaware of much of their history. After 4 years 2 months (Sept), the IPPs that were due in May have not yet been completed, Tim said he had difficulty organizing all the others to be at the meetings, this was mainly the day program staff. He said he was inclined just to get on and do them and to get those who couldn't come to write a report. After 4 years and 6 months, today the staff are going to do a yearly plan for the house, IPPs still have not been done, from previously, Tim says the whole format of IPPs are changing so they are not doing them, instead now they have permanent staff each will have a resident and be their key worker and do a monthly one page report of the various areas of their life.

In another house, after 8 months,” the plans are not finalised as the staff are to have training on how to do IPPs. However Alison gave me the current plans. They are certainly more 'useable 'than previous plans with specific behaviours expect of staff to assist clients. In drawing up the IPPs staff sat in another room and formally asked each resident to sit in on their planning”. After 4 years, “the day program staff are coming to the house for a meeting re Maureen. Margaret is pleased as she believes IPPs should be followed at Day placement as well as the CRC. The IPPs have not been done as they are going to be changed. Staff have been meeting with an expert in this area who thinks IPPs should focus upon how life will be for the residents. After 4 years 8 months, IPPs have not been done again. Still working out an organisation approach to IPPs. A few weeks later, they are just finishing the process of IPPs and this year both Guin and Marg have been involved not just Alison as previously. They have met with the day program manager Enda and found that helpful and are talking of co-ordinating more. There was discussion of the different expectations and behaviour in the house and at the day program. For example Maureen and Pat do cooking each Thursday but are not encouraged to be involved in the kitchen at the house. The community visitor commented that, “medical problems not attended to, IPPS not done, other paperwork not good”

The organisational policy and practices about IPPs described by the administrators differed from what the field notes recorded as occurring on the ground. All administrators said IPPS were completed annually and reviewed either as required or every 6 months. They all said that where possible clients are actively involved in the development of the plan and in one organisation attempts were made to engage non verbal residents by using pictures and other communication aids. In most organisations house staff were responsible for coordinating the completion and review of IPPs, although for one organisation a senior manager was also involved in these processes. Administrators differed in their views about the value of IPPs. Some felt the concept was good but the value had been lost in the formal processes and suggested that staff saw the completion of the IPPs as an administrative requirement that did not benefit residents. It was also noted that DHS have not provided training which has impacted on quality and utility. However one organisation saw the process

of drawing up an IPP as important and suggested that it was used to guide day to day planning for the residents.

A formal review of the operation of houses by the senior manager of one organisation identified very similar issues to those found in the fieldwork, finding approximately 1/3 of IPPs to be out of date, some to be poorly written and a perception of them being an administrative requirement rather than a meaningful plan for supporting individual residents. The review had recommended the organisation introduce a Person Centred Planning process together with training and monitoring of individual plans.

The absence of IPPs or their inaccessibility means that new staff are given little guidance in how to work with residents, although after 5 years one house supervisor was beginning to take steps to address this issue.

Molly said she has begun to get on with Toni by having pillow fights and Toni does smile at her. I asked how she knew how to approach the residents. Molly said she had suggested to staff they should agree on one approach to residents as she thinks the different staff responses may confuse clients. I did get the impression that staff do 'what they think is best', but there is not overall approach and Molly had not seen the IPPs. After 4 years Basil has done up a contingency file on each client. In this he records the core activities for each client, information of medication, behaviour, likes and dislikes. He said this makes it easy for staff to refer to then if they need more information they can go to the larger file. .

It was not generally clear how, in the absence of IPPs staff communicated or learned about each resident.

As Margaret said staff communicated through case notes I asked her if I could read them. The notes which covered about the past three weeks were all focused upon activity at night i.e. who was or was not sleeping and whether the residents were eating. There was a separate file for each resident. There was nothing about IPP's. As some of the staff never meet I don't know how they do share what the residents are doing behaviourally other than through their staff meetings.

In several houses there were very clear differences of opinion about the abilities of residents and what occurs for residents, reflecting the lack of individualised planning and communication between staff. For example the field notes report:

Alison's assessment of the women's abilities was lower than that of Guin and her assessment of the community activities was higher than Guin's. Alison assured me that the women go out frequently on a one to one basis with staff. However Guin later told me that they do not go out with staff unless to an appointment - medical, hairdresser. She said Maureen gets too agitated when shopping and sits down a lot. Again about the community activities Alison told me they go out as a group frequently. She pointed to the day program list on the wall - but that was last year's list! Guin said they cannot go out very much - often now because the staff member has been up all night with Joy the staff member does not feel alert enough to go out. Occasionally on Friday night they go to a restaurant up the road and the women are always well behaved. Guin also mentioned picnics at Williamston but that seemed to be last year or earlier this year.

In another house, at 4 years 8 months, Basil seemed to see the residents in a more positive light than Hilary. Listening to him the residents sounded much more capable. However Hilary has told me Basil does not really know the clients! When asked about TV watching Vic said Joy does appear to notice different programs such as days of our Lives and Home and Away. Hilary disagreed saying that although she sits there she doesn't really notice if it is on or not. Joy did appear to react when Vic then switched the TV off - but it may have been the noise - as it did happen to be quite loud opera! She appeared to be laughing, which Basil said was a response to the audience noises and she especially enjoys the programs with audiences and comedies.

Key workers

Appointment of a key worker for each resident was adopted by at least two houses as a way of ensuring an individual focus on each resident, although staff had different ideas about the role of key workers. This mechanism requires staff who are

able to build up a picture of a resident over time and follow through on initiatives which can be made difficult by staff turn over or a limited number of permanent staff. The field notes indicate the complexities of implementing a key worker system effectively.

All men have key workers but as these are full timers and there are only two the job is not spread across many people.

After 4 years, the residents have key workers and their role is to make appointments for residents and buy their clothes. I asked how the key workers program was going. Alison thought it was working well with key workers making appointment for residents and e.g. buying clothes for them. There was not a lot of recognition re key workers role in the continued development of residents. After 4 years and 8 months, I asked about key workers and was told that each resident had a key worker. However Alison said they had not had a staff meeting for some time and had not discussed key workers and it was probably about time they changed. Guin who came in on this conversation said she thought it may be better not to change - because it meant when you take the resident to the doctor etc you don't know the history - even though she acknowledges that all staff should know these things.

Day Programs

The Views of Day Program Staff

After the first year in the community 75% of day program staff made positive comments about the impact of the move on residents' quality of life. Most of the day program staff considered the move to have been an unqualified success (13), whilst 5 considered there had been improvement on some domains of quality of life but decline in others, and 3 considered their quality of life had declined. As table 26 shows, after five years in the community the proportion of day program staff making positive comments about changes for resident had increased to 83% and the number of negative comments about the impact of the move had declined considerably. By this time the majority of positive comments were about improved, health, skills and wellbeing, whilst negative comments were in relation to continued challenging or

aggressive behaviour by residents (2). The bulk of negatives comments were about inconsistency of residential staff, the impact of this on residents and the working in partnership between day program and residential staff. In contrast however 7 day program staff referred to positive working relationships with residential staff. Most day program staff expressed the view that their programs would continue to change and adapt in line with residents changing needs as they got older.

Table 26. Comments made by Day Program Staff

Comments	<i>Day Program staff</i>			
	Time 2. n = 24	%	Time 4 n= 23	%
<u>Total respondents indicating positive change</u>	18	75%	19	83%
<u>Nature of positive comments about changes</u>				
Improved health, skills and well-being	4	17%	17	74%
Resident happier	12	50%	1	4%
Improved environment	6	25%	1	4%
Improved quality of care	6	25%	-	-
More staff or greater consistency	-	-	1	4%
Improved staff quality of attitudes	2	18%	2	8%
More chance for social interactions	-	-	-	-
<u>Total Respondents suggesting negative change.</u>	8	33%	8	35 %
<u>Nature of negative comments about changes</u>				
Loss of friendships	3	13%	-	-
Poorer standards of hygiene, clothing, grooming	7	30%	-	-
Reduced access to specialist services reduced	2	8%	-	-
Unhealthy weight gain	4	17%	-	-
Effects of lack of history and information	-	-	-	-
More restrictive environment	-	-	-	-
Failure to be aware of individual needs	-	-	3	13%
Increased transport costs and poor reliability	3	13%	-	-
<u>Impact of inconsistency of staff</u>	-	-	8	35%

Daily attendance at day programs was a core component of the relocation design. Structurally funding had been split, with day programs funding directly by DHS, and organisations that managed houses being funded on the basis that residents would be out for most of the day every weekday. One administrator noted the imperatives this created, saying, ‘there is no policy that residents have to attend day programs but an assumption that they will as there is no funding for day staffing or alternative programs’. The general feeling of administrators was that this expectation,

that all residents attend a day program 9- 5 for most days of the year excluding holidays was not appropriate for all the residents and is increasingly becoming a problem as residents' age.

Some administrators thought that the separation of day funding and tying it to formal day programs has discouraged organisations from being innovative in planning residents' activities as it had artificially separated resident's lives into two. It was clear from the interviews with day program staff that the working relationships between the two organisations involved in resident's lives varied. Administrators suggested that the main form of communication was via communication books, and that a staff member usually the house supervisor has day to day responsibility for liaising with the day program. The organisations' perception of the importance of the communication is illustrated by at least one organisation having a more senior manager visit the relevant day programs about 4 times a year, and the expectation that house staff will involve more senior managers if issues arise. Administrators said it was not infrequent for there to be tensions with day programs and one referred to this as a 'Mexican standoff'. One organisation had established a formal process for reviewing the organisations relationship with the day program.

Understanding and Responding to Residents Getting Older

All administrators identified that aging of residents and deteriorating health would be major issues to be confronted in the future. The original DHS funding specified the age range of residents to be from 18 years of age to 65 years of age but it is noted that a number of residents are already over 65 year of age. Administrators envisaged greater reliance on age related community services and the identification of community activities to take the place of day programs for aged clients. They felt that DHS had no clear plans how to manage the issue of resident aging other than on individual basis.

The original funding that required that all residents attend day programs has been slowly altering over the 5 years as changes have been made on the basis of changes to the support needs of individual residents. All administrators said their organisations had policies about the management of the aging of residents but their execution had to be on a one by one basis as this was the only way to negotiate funding increases with DHS to take account of higher levels of supervision and increased health needs. In addition they suggested that staff required training in aged

care for staff. One administrator noted that they had 20 staff with qualifications in aged care. Administrators suggested too that day programs needed to re-design their programs to accommodate the aging population and that this was already being done in some day programs.

The majority of organisations wanted to provide life long care to the residents at least until they required nursing home care and a couple of organisations would like to provide this type of care as well. Administrators stressed that decisions regarding whether the aged resident remained at the house also needed to consider quality of life and the needs of the other residents of the house. Organisations differed in their approach to planning for nursing home care for the residents. All highlighted that this was the responsibility of DHS and they did not expect to be involved in selecting the nursing home care. No administrators thought their organisation should have on going formal responsibility or contact with the resident once they moved but the majority stated that staff and/or residents may keep in touch on an informal basis. The responses from the organisations were influenced by the wider operations of the organisation, hence those who already had facilities for the aged were more positive about the possibility of life long care for residents.

End of Life

Three residents died during the course of the study, one suddenly in her sleep, one in a nursing home after a long period of dementia, and the third after 3 weeks in hospital from ovarian cancer that had not be diagnosed previously. The very different circumstances mean it is difficult to find common threads from these experiences other than in the period following the death. However, the commitment to residents and flexibility in the use of time was very evident in regard to the two residents who were in out of home care prior to their death. The field notes record,

Mary stayed at the hospital. The House staff made sure she was never alone.

In discussion with DHS the recommendation was to place him in a nursing home 12 months prior to his death due to his increasing medical needs. Staff and supervisor and management disagreed and worked to support him to stay at the house. All staff “rallied to help” and it appears this helped of form a strong bond with residents and staff. Supervisor and staff would

have preferred Adrian to remain at the house to enable him to die at home although he was not aware of his surroundings over the last weeks. All residents were aware of his failing health and staff had to often cover extra hours so outings would not be cancelled. His move [to nursing home] was discussed and all residents visited him.

In all cases other residents in the house and staff attended the person's funeral and in two houses debriefing for staff and counselling for residents was provided by the organisation. Residents' continued to be remembered in two of the houses by photos and in one case a plaque. However there did not appear to be a systematised response to dealing with grief and loss. For example, when a longer term staff member who had been very close to a resident, died in one house, the resident had to fund his own sessions with a grief counsellor. The house supervisor who was absent at the time felt the support provided had not been well organised.

The death of one Rex really upset Bill who was very attached to him. Bill went through an intense grief period. The residents went to the funeral but a tree was planted in his memory which appeared to confuse Bill. Ellie said Bill responded by regressing to using fuck all the time and pacing and repeating words. She found a grief counsellor to gain advice from which she says was a much for her benefit to work out how to deal with Bill than for her directly. He had to pay the \$100 for a psychologist to brief the house supervisor and another staff member on how to deal with this process. In the end, she threatened him with removal of rights to watch TV to get him to stop the repititious swearing.

In the three houses where a resident died they were replaced through the DHS Vacancy Management process within about 6 months with no input from residents. Two of the administrators felt that DHS were more willing to listen to their views about filling the vacancy than in the past, and had tried to ensure an appropriate fit between the new and existing house residents. One administrator felt this change had come about because they had been able to demonstrate the consequences of not matching residents. However, another administrator felt that DHS did not listen to the advice from the house staff and had inappropriately rung about the vacancy before the funeral of a deceased resident had been held.

The field notes only recorded detailed data on the process of filling the vacancy for one house, in the case of which considerable unease was expressed about the compatibility of the new residents.

The field notes for the house observed, “ the residents have different colour schemes in their rooms but not many possessions, apart from the” new girl” who came from home. This is the staff’s description as she is considerably younger than the other residents and markedly different in behaviour. She does have some speech and is responsive to staff which does not apply to the other residents according to Guin. Guin cannot understand why Debbie was placed at the house. She is 21 years old at least about 25 years younger than the others. She had some language when she came into the house - but being with residents who are non verbal she has lost this language”.

Adjustments to Older Residents

The indepth case studies of the houses suggested that staff held quite stereotypical view of aging and had little understanding of the likely issues that may arise. Residents in their 50s and early 60s were clearly perceived as old, tiring much more easily and needing to slow down and the common response was to suggest reduced hours of attendance at day programs, rather than attention to health monitoring or lifestyle. For example, one supervisor said;

” Josh gets tired, I mean he is 58... getting up early in the morning and coming home in the afternoon is too much for him.....fitness and exercise are not as important for the two older men in the house as it is for the younger ones...

Advocating for retirement from the day program another supervisor said, after all he is in his 60s and going to TAFE”.

It was noticeable that responses to aging of residents were not individualised and failed to acknowledge variation in the aging process or in individual preferences. For example, the field notes record the inconsistency between the stereotypical view of aging and the preferences of the individual resident.

The house supervisor says that Tom is starting to forget things and they may think about starting to ease back on his involvement in the day program next week. His health is excellent and he has no flare up of gout in the last 3 months. He also talked about Dave slowing down, getting worn out, "he is 54 and getting tired more easily". He falls asleep and used to want to go out now just wants to stay at home. At the same time as talking about reducing his hours of work he said the Dave loved work and didn't want to retire or ease back. He also mows lawns for other houses and Tim indicated this would reduce too. His health is fine and he has regular check ups but Tim says he is looking older and more worn out.

One of the case study houses had negotiated for two residents both aged over 60 to reduce their attendance at their day program, initially by two days a week and then by the end of the study by three days a week. The need for reduced attendance had been identified by the house supervisor who negotiated with the organisations' area manager. However, this reduction was not part of a broader individualised retirement planning process for these residents nor was their use of time at home planned in any systematic way.

Field notes at 3 years and one month record, "Josh and Keith have been encouraged to retire and are only attending the TAFE program 3 days a week. On one day Keith spend time with Hilary and Josh goes out with Patsy and does what he choses, it is left to them to decide on the day rather than making it too structured. I asked what Josh and Keith had done the last Friday and Patsy said they were home and was told both just stayed at home.

Field notes at 3 years 6 months record, "The supervisor said, the two days a week at home is working for Keith and Josh. Yesterday, they had gone for a hair cut, to the office, and had fish and chips out with one staff member. Patsy is no longer the staff person who works these days with the men. And its seems the person will now rotate. She said they just like to go for coffee, Josh likes to watch the TV, Keith is however more keen to do things and doesn't like sitting around all day.

At four years and four months the notes record, the new supervisor has negotiated that Josh only go for 2 days instead of 3 and TAFE will fund an extra day at home, the area supervisor is going to find a case manager so the issue of retirement and funding for this can be dealt with. She said that Josh wants to go into "full time retirement". When I asked what this meant she said he will be able to do more things at home, and is very optimistic what is possible for home to do. However she was very vague as to where the funding support might come from and who might be responsible for organising activities. Josh will maintain his swimming, and start seeing his mother more, she wants him to come up to her farm more often and they will look into other program. Later she also said that he was very interested in going to the cricket. We discussed how Keith and Josh made choices and what the processes might be; very simply she said staff spoke to them. She is not clear about the funding for retirement or how the funding system operates, but thinks it will be paid direct to the client and might be managed by state trustees, however the area manager is following all this up.

Both the men referred to in the field notes have very little verbal communication and do not use any communication aids, yet no mechanisms had been put in place to assist them in exploring ideas for their new leisure time. The house also appeared to be focussed on relying on its own staff and resources and had not considered contacting one of the day centres or brokerage programs in the region that are experienced in programs for older people with intellectual disabilities.

Neither house supervisors nor staff were clear with whom or even with which organisation responsibility for planning and funding around retirement lay. One supervisor told the researchers that DHS had guidelines in place for retirement of resident at the age of 45 years.

Staff appeared to have little knowledge of health related issues associated with aging such as sensory decline, and no mention was made by any staff of the need for sight or hearing tests for older residents. During the first three years a resident in one house was diagnosed with Alzheimer's by the psychiatrist at CDDHV, but this did not seem to be accompanied by any long term planning by the house staff or the organisation. The supervisor said, she was "taking every day as it comes with this "day by day" and does not want to think about long term planning". This house

experienced an almost complete turn over of staff after three years and it was not at all clear that the incoming house supervisor was aware of the resident’s diagnosis or if his condition was being regularly monitored.

Staffing Turnover and Flexibility.

Interviews with administrators suggested that in most of the houses there had been considerable staff turnover, which in one house had been so high that the organisation had been criticised by DHS. The organisation felt that the cause of the high turnover was the high support needs of residents in this house. One house had had the same house manager for the entire period of the study, apart from the first three months. However, she had left by the time the organisational interviews were conducted after 5.5 years. This house also had one of the most stable group of staff. In another two houses 2 of the staff had been constant over the 5 year period of the study. In contrast in one house by year 5, no staff member had been in the house for longer than 12 months. As Table 27 summarises the supervisor and staff changes in the four case study houses.

Interviews with the administrators referred to the difficulties recruiting and retaining staff and the continuing situation whereby staff can gain higher overall wages if they work as casuals, and some staff choose to retain this mode of employment. Some staff also hold permanent positions in one organisation and take on casual work elsewhere.

Table 27 Summary of Staff Turnover in Case study Houses

	No of supervisors	Staff members from house establishment still employed	Longest serving staff member by year 5
House 9	2	No	2.5 years
House 8	4	No	2x 4 years
House 4	2	Yes at least 2	2x 5 years
House 11	7	No	4.5 years

All four case study house demonstrated considerable flexibility in staffing to deal with changes that occurred for residents such as ill health and reduced attendance at day programs, or to facilitate more individualised activities by residents. Staff commented on their ability to draw on additional hours from the management

organisation or to rework rosters to suit the needs of residents. At least in the case study houses pressure on staff resources did not appear to be as pressing an issue by the end of five years as it had been at the end of the first year in the community. For example, the field notes recorded in one house.

A resident had refused to shower and been told if he did not he would not go out with the other men. This threat had been carried through and supervisor had been able to get permission to employ a casual staff member to stay with him.

In another house the field notes indicated, “ The house will open at 7.30 instead of 7.0, this means the sleep over staff person is on duty from this time and they start to get the men up. The residents do not have to be at TAFE until 10.30 now so the staff have more time to do the jobs and also they are not driving them. It seemed that lately a lot of tasks have been left undone or for the next shift.

And in another house, “the house supervisor Joan said that they receive a lot of support at the house, in terms of being able to have a third staff member on at all times when they requested it. Normally there are two staff on at one time and three for mornings and evenings. Margaret felt the funding for the house was OK. Initially the organisation put on an extra person from their own funds but this is now funded. Hilary has found it more difficult since Gerry is home all day as she says she gets no time to do administrative work. She has been told she can employ more staff but finds that is not helpful as she either can't get the staff or they only come when there is no need for extra staff. However she was planning to have someone in on Monday for four hours so she can do admin work.

In another house the supervisor said that, she had recently got funding which will allow each man to go out on his own to an activity during the week rather than the whole house having to go together

Perspectives from Organisational Administrators

During the five year period senior staff in several organisations, including at the CEO level had changed, and one organisation had changed its name to more clearly reflecting its orientation to person centred support and choice. Other organisational changes had been: the adoption by one organisation of the model of one supervisor for each house; expansion of the number of community houses managed by the organisation with the closure of a large campus facility; organisational restructure that meant the creation of two separate administrative regions.

The interviews with administrators of organisations at time 2 focused on the relocation process. As the previous report documented there was a high degree of dissatisfaction with the process of relocation and its impact on the residents. However after 5 years, the process of relocation was no longer perceived to be a major issue for administrators, most had not been involved and the views of others had mellowed. Several however were concerned about the huge impact of the relocation on residents. One administrator said:

The residents were not prepared for the world. They were so isolated in such a huge community and with the move life became so limited to 4 others and rotating staff who come and go.

Another reflected "it was so sad for residents as it was like a nightmare initially not knowing what to expect and residents were thrown into such total change".

All organisations seemed to have 'moved on' from the relocation process, with study houses having been absorbed into the wider organisation, even those that did not have a history of working with people with intellectual disability prior to the Kew project. This suggests the relocation process was not seen as important, which is not an uncommon experience for institutions, where connections are not made through the life course of the organisation which fails to build connectedness for the individual residents. For the residents of this study the relatively sudden change from KRS to their new house was a major event with the potential to be life changing - but it is now history.

Funding and Relationship with DHS

By time 4 after 5 years, in contrast to Time 2, most administrators reported a relatively high degree of satisfaction with the link between the organisation and DHS. One administrator was concerned that these houses were funded at a lower level of funding than other houses managed by the organisation. Paradoxically, he thought that the lower funding had forced the staff to be more innovative in this house. Another administrator commented that the nature of the original funding and service agreement had restricted the structural changes that had been possible. The original funding model that all residents attend a day program on a full time basis had changed gradually over the 5 year period remained the same but each organisation has renegotiated funding to take account of the changing needs of particular residents. For example, one organisation now had block funding for day programs as the individual needs of the residents made the initial arrangement unworkable. All organisations were clear that DHS rather than individual residents should bear the cost of any additional support required. However, there were differences between organisations in regard to who bore the costs of specialist services, such as purchase of household equipment or one to one support.

Holidays

All organisations regarded holidays for residents as a preferable option and considered the choice of destination should lie with each resident. It was suggested where the resident's capacity to exercise choice was limited, others such as staff, family, day program and advocates should be involved in the decision, which should also taken account of cost. One organisation used IPPs as a forum for planning holidays. The common practice across all organisations was that residents should pay their own costs of holidays as well as the travel and accommodation costs of accompanying staff whilst the organisation will pay staff salaries. Generally, the preferred model was for residents to go on individual holidays with specialist organisations or family members rather than as a group from the CRU.

There was some acknowledgment that it is possible for staff to influence the resident and to select a destination preferred by staff but this is really against policy. Holidays were generally perceived as positive for residents; one administrator also thought they may be unsettling. The actual practice regarding holidayshad varied across houses in the study; to the extent that one group of residents had been away on

holiday at least once a year, while residents in another house had not been on holiday at all since their move.

Staffing

In most organisations the level of reporting from the CEO to the house was between 3 to 6 positions, with the majority being between 5-6. The staffing of each house comprised permanent part and full time direct care staff, and either a house supervisor or house manager, sometime known as a team leader. In a majority of organisations the house manager was responsible for more than one house, and reported to a coordinator or area manager, who in turn reported to a General Manager or the CEO. These reporting arrangements suggest that whilst direct care is not managed directly at a senior level it is not too distant from senior management.

Staff qualifications

Staff continued to hold a diversity of qualifications. Managerial staff generally held tertiary qualifications in disciplines such as psychology, disability studies, teaching, management and social work, whilst the frequent qualification held by house managers and direct care staff was Certificate 4 in Disability. The number of staff with this qualification or studying towards it had increased since Time 2.

All organisations found recruitment of qualified house staff difficult. One strategy was to recruit casuals and support their training; another was to recruit students from speech, physiotherapy and disability studies for part time work to complement the pool of casual staff. This approach is influenced by the view that skills in direct care work may be gained from other qualifications and experience. One organisation had a policy that in order to become permanent casual staff had to commence study for Certificate 4.

Casual staff still have a major role in the provision of direct care. Some organisations factor the use of casuals into their staffing structure and attempt to use the same people as casuals whilst others utilise casual staff as replacement for staff holidays or illness and for special care if required. One organisation had sought to diminish reliance on casual staff, reducing their use from 35% to 12 % across the program. As a consequence one of the houses only uses one casual a week.

Organisations had different policies regarding the use of volunteers in the houses. These included no use of volunteers, use of volunteers as a way of increasing

community knowledge of the field, and initial stages of developing the use of volunteers to increase community inclusion. The fieldwork did not find any evidence of the use of volunteers in houses.

Staff Shifts

Changes had occurred in the shift structures in several houses due to residents remaining at home some days and at least one house now had active night staff rather than sleep over provisions due to changes in the support needs of residents. Staff rosters were designed to ensure an adequate number of staff available at times of high demand for physical personal care.

A typical shift arrangement is:

- Sleep over staff awake at 6.30 – 7.00 to assist residents to shower shave and co-ordinate transport
- Permanent staff member works from 8.00 -10.00 and returns at 2.30pm to cover for any appointments
- Second staff member works from 3.30 to 8.30pm.
- Peak times are from 4.00 – 8.00/9.00pm as this covers mealtime assisting residents in evening activities. The second peak time is morning from 7.00 – 8.00am. There is always two staff on at these times.
- There is a variable spread of staffing across the other times during the week, depending on the resident's needs and activities.

Administrators reported the focus was on engaging clients in household activities rather than doing things for them, but felt the shift arrangements left little staff time to engage the residents in personal development. House supervisions are generally allocated 12 hours for administration which includes staff supervision but not time is allocated to other house staff to for supervision or writing up of notes. Such activities must occur during 'down time' from personal care activities, but whilst residents are at home, and as such reduced time available for engagement with residents.

Recruitment

Staff recruitment continues to preoccupy administrators, who are forced to devoted considerable energy to this task. Various methods have been tried over the

period of the study by different organisations, including, running general information sessions for interested applicants and from those that attend short listing for interview, using primarily word of mouth targeting university students and poaching from other organisations. Most however, rely on advertisements in the print media. Although all organisations prefer to appoint staff with qualifications, all expected to appoint some staff without, although this would not normally be at the supervisor level. The standard qualification is Certificate 4, although at least one administrator was very critical of this training and preferred to seek staff with other qualifications, such as music. Minimal desirable staff characteristics were seen to include: general intelligence and awareness of disability, basic literacy skills, good thought processes, compatibility with existing staff, personality, an understanding of team work and holding appropriate values.

The objectives of a typical direct care job description at one organisation included; contributing to the mission of the organisation; a high level of service provision which encourages empowerment of residents and includes the role of key worker; acting in a professional manner, an understanding of the industry and the organisations policies and procedures, working effectively in operations including meeting timelines, business planning to achieve key objectives for the service, involvement in quality assurance. The knowledge and skills requirements stressed knowledge of the disability industry and knowledge of the values of the organisation and included written and verbal communication, IT, personal care and teamwork.

Staff development

Provision for staff development is still very limited. For example, one organisation provides 4.5 hours of training for each staff member a year. In some organisations staff are expected to fund their own training such as First Aid or Certificate 4, but may be reimbursed for expenses after completion. DHS funds staff development, at the rate of approximately 1.3% of the organisation's program funding, and most organisations top up this amount. Staff training programs have remained static in several organisations, and all tend to focus on occupational health and safety issues. New directions adopted during the course of the study by some organisations have included, input on community work and community inclusion and linking Certificate 4 in Disability with Certificate 3 in Aging. The administrators

recognised a greater need for training about community and individual development, but felt it would take some time before this could be achieved.

Staff Supervision

All organisations provide supervision for staff at direct care and supervisory level. Each organisation has a senior staff member who is responsible for the quality of supervision. For direct care staff supervision occurs either fortnightly or monthly and ongoing monitoring occurs on a day to day basis. Staff appraisals happen yearly for permanent staff based on performance against their job description, through demonstrated knowledge and feedback from key people and/or observation. Performance indicators include liaison with families, engaging in community based options and function as a key worker. At least one organisation requires supervision sessions to be documented and reviews this documentation. Although some administrators suggested that the demands of day to day work can mean that supervision does not always occur, they all felt good structures were in place to support and monitor good quality work.

All organisations use the DHS procedures for reporting critical incidents which are classified as being level 1, 2 or 3. Critical incidents can vary from issues about dangerous behaviour by residents, kitchen fires or resident death. At least one organisation has provided specific training for staff on managing and reporting critical incidences following the issue being raised with them by DHS.

Internal Organisational Evaluations

One organisation had undertaken a formal evaluation of the operation of its houses during the course of the study. This had taken the form of the general manager visiting houses, observing and spending time alone with the residents. Issues identified had included; incompatible client groupings, lack of 1:1 staff support for residents, sense of control by senior management, too much paperwork, difficulties with computer technology, the décor and fabric of the house and a sense of being over managed. Residents had reported liking staff but found some 'bossy'. As well as identifying issues about IPPs referred to in an earlier section the report had concluded that other issues that needed to be addressed were increasing awareness of resident's rights, promotion of informal relations, engagement in domestic and recreational

activities. Another organisation had undertaken a quality assurance exercise that found a decrease in the number of incidents over the last 12 months.

The future

Over the long term administrators foresaw few major changes for these houses. Most would like to see a greater degree of individualised planning for residents and funding that reflects their needs for individualised support to participate in activities, greater involvement by residents in decisions about their own lives, inclusion in the community, capacity to treat residents as individuals rather than a group, and a shift away from the expectation that all residents attend full time day programs. At least one administrator was sceptical however about the possibilities of community inclusion for this group of residents in view of their long history of institutionalisation. As discussed earlier all administrators highlighted aging of clients and their deteriorating health as the major issue to be faced in the future.

DISCUSSION

Variability

As the findings indicate, the residents in this study were not a homogenous group. Although they were all labeled as having intellectual disability, their cognitive and communicative capacities were very different as well as their physical and mental health. For example in one house all the residents were mobile, independent in self care tasks and communicated verbally or used sign and pictorial representation. In contrast in another house none of the women communicated verbally and all required significant support with personal care and tasks of every day living.

Similarly residents each had their own unique personal history and constellation of family relationships. There is no simple benchmark of a “good” outcome for such a diverse group of residents as the manifestations of notions such as community inclusion and domestic participation differed for each resident. This study has sought to capture the changes that occurred for individuals and detail what their life is like in the community. A major finding was considerable variation in the magnitude of change and life in the community both among individual residents and between house groups of residents. Overarching this variability however, all participants continued to be perceived by family and day program staff as living in a more pleasant environment and having a better quality of life in the community than

they had done at Kew. They all had a greater community presence and were all considered to have developed as individuals and to exercise more choice and initiative. However, the changes residents had experienced and the nature of skill development, individual autonomy, participation and inclusion in the community and at home, and their relationships with family and friends differed considerably. Variability was also found in the operations and milieu of the 9 houses in the study, particularly in the staff turnover, management structures and expectations of residents by staff.

Appendix 1 has a brief vignette of each house in the study that gives a picture of variability between houses and of people's lives in the community. Drawing on this detailed data, Table 28, over page summaries the characteristics of each house on a number of key dimensions. As this table indicates, house 8 is the only house where

Table 26. Characteristics of the Houses and Residents

	Staffing	Family Ties	House Visitors	Domestic Involvement	Community Inclusion	Community Presence	Resident Health Status	Support Needs Rated by DHS	Age range
House 1	Unstable	No family ties	Only CV	Limited	No connections to community organisations	Mainly group outings	Residents with psychiatric diagnosis, and sensory problems	Low	48-54
House 2	Stable	All residents have family ties	Regular family & CV	Limited	No connections to organisations	Individual and group, use of local facilities	All residents health associated problems	Low	41-53
House 3	Unstable	Variable family ties	Regular family	None	No connections to organisations	Mainly group outings	Residents with health associated problems	High	40-54
House 5	Stable	Variable family ties	Only CV	Some involvement	No connection to organisations, one resident goes out with friend from day program.	Individual and small group outings	Strong focus on health and fitness. One resident health problems and psychiatric diagnosis	Medium	45-58
House 10	Stable	Variable family ties	Regular family, no CV	Unknown	Strong relationship with men from another ex KRS house	Group outings to local facilities	Residents have a range of major and minor health problems	Low	39-59
House 8	Stable	Only one resident with strong family ties	No CV, regular visitors	Significant involvement and responsibility	Connections to church and disability specific organisations, Strong connection with men from another house,	Individual and group outings	One resident with poor health	Low	36-53
House 11	Unstable	Most residents strong family ties	Irregular family, no CV	Variable	Connections to church and disability specific organisations	Individual and some group outings	Some resident have mobility problems, none with significant health problems.	Medium	42-63
House 9	Unstable	Several residents with strong family ties	Frequent family	Limited	Not connected to community organisations.	Individual and small groups, use of local facilities	Some residents with significant health problems and psychiatric diagnosis	High	36-45
House 4	Stable	No family ties	Only CV	Limited	No connection to community organisations.	Individual and small group outings, use of local facilities.	Some residents with health problems and psychiatric diagnosis	Medium	49-68

residents have significant involvement in domestic tasks and some connections to community based organizations. There is however, no discernable pattern in the characteristics of this house and its residents that might account for the relative success experienced by this house in fostering the inclusion of residents. Houses 8 and 11 stood out on the dimension of community inclusion and connections between residents and community based organizations, yet it is also difficult to pin point the dimensions shared by these house, other than no residents having major health and psychiatric problems and having few regular visitors to the house. These findings reinforce existing understandings that a complex interplay of factors foster domestic and community participation rather than single dimensions such as staff stability, low resident support needs or strong family ties.

The findings suggest that a range of issues confront organizations and house staff in trying to support a high quality of life for residents and implement visions of community inclusion. These cluster around: the capacity to know and respond to residents as individuals consistently over time; interpreting the meaning and operationalising inclusion for people with more severe disabilities; harnessing the potential of family to be engaged in resident's lives, monitor the quality of care and undertake advocacy; developing strategies that support choice and the exercise of rights; accessing quality health care and adapting to change as well as aging.

Knowing and Responding to Individual Consistently over Time

The findings suggest that the support residents receive from staff is inconsistent, disjointed and often ad hoc. The nature of support is liable to change not only over time but from shift to shift and day to day. The nature of support is seldom underpinned or guided by any type of person centred plan. IPPs even when they exist, do not inform the day to day work of staff with residents. Whilst they are a large number of dedicated and skilled staff many staff have only a superficial understanding of the background of residents with whom they work, many are not aware of their family relationships, past or present friendships, or acquaintances they meet and activities they undertake during the day at formal programs. For residents, particularly the increasing number without ties to family, this means that no one knows them well. Staff turnover and the use of casuals are not the only reason for this lack of knowledge and inconsistency of support. Even among relatively stable staff groupings, there was little evidence of a shared understanding or consistent approach

to providing support. Subtle changes of approach occur every day with every staff member, and more visible regime changes occur over time. The appointment of new supervisors inevitably means a new set of expectations are imposed on residents as to how they will lead their lives and the culture in their house. New ideas and changes to the way of doing things are not necessarily problematic. What is of concern is that changes are primarily driven by supervisors and staff based on their ideas about how things should be rather than being explicitly grounded in plans or responses to resident's expressed needs or informed by knowledge about residents' derived from the range of sources who know them well. Poorly planned and inconsistent support impacts on residents' quality of life, among the identified consequences in this study were loss of contact with family or friends, lost opportunities to develop skills and participation in household tasks, denial or reduction of choice. Inconsistent expectations and responses to particular behaviours, expression of choice, carrying out daily chores, mean that residents continually adapt to different expectations and ways of doing things rather than pursuing their own agenda's for learning and their own interests.

Existing tools designed to support consistency of support and knowledge about residents, GSPs, IPPs, relocation reports are clearly not working well in the study houses. It is difficult to pin point why this might be so. The administrator's views were that staff perceived such plans as administrative requirements seemingly unrelated to resident outcomes. House staff certainly accorded little importance to plans, a view that was reinforced structurally, as no staff time was explicitly allocated to all staff for reading resident's histories, discussing residents with significant others, observing day programs, preparation, formulation, monitoring or review of either individual or house wide plans. It seemed that in most organisations responsibility for knowing residents and planning support about both the short and long term matters resided exclusively within the house, primarily the house supervisor. There was little sense of collective direction or responsibility for these tasks among house staff and it was only in circumstances of an exceptional or crisis nature that more senior staff were involved in thinking about issues for residents or decision making. When supervisors changed a vacuum was created and it seemed the processes of individual and house planing had to start afresh. New supervisors came into the house seemingly cold without a blueprint to orientate them to each resident or to the culture of the house. The limited understandings of why existing planning mechanisms don't work

in these houses, suggest it is due to failure by staff to recognise the value, the failure of the importance to be reinforced through structural arrangements and the absence of any monitoring. A draw back to existing forms of planning too is their failure to set the individual resident in context of the house milieu of which they are part.

The research literature documents the success of individualised program plans and person centred planning in attaining outcomes for people with intellectual disability, and suggest the difficulties more often lie in systematic implementation than design (see Cambridge & Carnaby, 2005; Emerson et al, 2005). In Victoria, initiatives are occurring in this terrain, person centred planning and principles for a support and choice approach have been developed by DHS. Perhaps the application of these need to be trialled and evaluated with residents in houses such as those in the study. Whatever approach is used, it seems that greater importance to provision of consistent client centred support must be accorded by organisations structures, through the allocation of time, monitoring of what is occurring, and by regular and skilled support to help staff reflection on what is happening for residents and the house - what is not happening, why and what could happen. One such model is that of periodic service review currently used by organisations such as Golden City Services in Bendigo (LaVigna, Willis, Shaull, Abedi, & Sweizer, 1994). There are dangers in simply adopting a new method of planning without attention to the structures necessary to make it meaningful. Renaming the approach to individual planning (for example Person Centred Planning) or adopting a new program to address one part of the issue, such as day to day engagement (for example Active Support) alone will not address this issue. What is required is not only a new method of planning but a more rigorous approach and structural changes that will facilitate provision of person centred and consistent support.

One of the striking features about group houses for people with intellectual disabilities is the vast range of expectations of what will be achieved “in house” and the consequent breadth of roles to be played by staff and skill set required. Almost sole responsibility lies with house staff to: provide day to day personal care, monitor health, administer finances, manage the household, assess, formulate and implement short and long term plans around issues such as skill development, pursuit of interests, community inclusion, domestic participation, and longer term issues such as retirement, provide support and nurture relationships between residents and families, support residents to exercise choice and protect their human rights. House staff are

expected to be domestics, attendant carers, case managers, social workers, advocates, community developers, caterers and housekeepers, roles that are complex and at times contradictory. As this study indicates, where demands on staff time exceed resources and tensions exist between different roles, staff attention is most likely to be held by those tasks that are most immediately obvious if left undone and will pose most risk in the short term – attendant care, catering, household management. These are the tasks that dominated the use of staff time, those that “keep things going” that took priority over those without visible or quantifiable outcomes, such as individual relationship building. The question is then how can importance and time be accorded to the longer term more developmental tasks. Perhaps it is worth thinking about an alternative model, where fewer expectations and less resources are placed within in each house and more placed externally to support and resource or even to complement the roles performed by house staff.

Elements of a key worker model were being adopted by several houses by the end of the five years, although none had developed this fully. A model such as this has the potential to ensure each resident is known well by at least one staff member. Adapting this model to accommodate the frequent staff changes that occur in some houses, and to ensure shared rather than diffused responsibility for residents is a challenge that could be explored by through piloting different models and evaluating implementation and outcomes.

Attention too must be given to the processes by which new staff and house supervisors take up their positions within houses to avoid pre-emptive changes. Strategies such as a defined period of orientation to the residents and house for new supervisors, an enforced period of observation and getting to know the residents, their families and day programs, an embargo on change, convening of whole house planning meeting prior to any changes might be trialled..

Complexity of Inclusion

There is no doubt that the community presence of residents had increased. After five years in the community most of the residents went out into the community more often and were more likely to go out in smaller groups or individually than when they lived at Kew, and indeed after the first year of community living. Most residents used commercial facilities such as shopping centers and cinemas, and community based services such as GPs and community health centers. Most however

had not built new relationships either with people with or without intellectual disabilities or become involved in community organisations. A small minority were regular participants in disability specific community activities such as basketball, bowling and indoor cricket but such participation had rarely led to the development of friendships and shared activities or informal contact outside the particular organisation. As with the most other domains of residents' life responsibility for community inclusion rested primarily with house staff, although it was notable that one organisation provided regular information to house staff about activities in their local area.

In the four case study houses it was the relatively more able residents, those with fewer health problems, better communication skills and less cognitive impairment who were more individually involved in community based activities. This reflects previous research that more able people are likely to receive higher levels of staff support (Felce et al., 1998).

The trend in all the houses of reverting back to the group based outings into the community, that had been common practice in the institution was particularly evident in one of the case study houses where residents had very poor communication skills. Staff had did not have a clear vision of what community inclusion might mean for these residents or how they could be supported to forge new relationships, a view which was summed up by one staff member person who said, "it is too hard and depressing as none of the residents initiate any activity ". This suggests the stories of community inclusion for people with more severe impairments are not being told, that resources may need to be developed that provide such examples, that staff require training, consultation and support to first visualise community inclusion for this group, and then, more specifically, the strategies that might be involved in its achievement. .

However, greater attention must also be paid to the pursuit of community inclusion for all residents. The case study data suggests that staff focus on "getting there" be it a particular venue or activity, but once residents have arrived, staff see their job as done. Staff are often unaware of what happens next from the resident's perspective, as they are left unsupported to take on the complex tasks of reading and adjusting to the expectations and rituals of the particular social context. This approach fails to acknowledge the nature of cognitive impairment and the difficulties that many people with intellectual disability have with learning social skills, observing and

complying with the implicit rules of social interaction. Research suggests that supporting community inclusion is more than just getting someone there, it is a complex proposition, that may require intensive and sometimes long term support from staff. If community presence is to be moved towards inclusion and new social relationships it is vital that greater consultation is available to staff as to the steps involved. The DHS Eastern region has adopted a consultative model to promote community inclusion in respect of the residents newly relocated as part of the KRS closure. In this model an external “adviser” assists staff to plan and monitor resident inclusion. Anecdotal evidence suggests this model has been successful in promoting a fuller understanding of inclusion among staff and demonstrating possibilities with residents. A useful strategy may be useful to pilot and evaluate this and other of models, such as community building programs (see Bigby, 2003) to assess which is most efficient in complementing the existing skills and resources of house staff in this endeavor. What is clear is that the meaning of community inclusion for people with higher levels of cognitive impairment is not fully embraced by all house staff and it is not being achieved with the current structure and resources available to the houses in this study.

Harnessing the Potential of Family to be Engaged in Resident’s Lives and Undertake Advocacy and Monitoring

Although a relatively large sample of residents this was a small study, which made it difficult undertake tests of statistical significance. Few statistically significant differences in the size or composition of residents’ informal networks were found over the 5 year period. Despite this several key trends clearly occurred over the five years as this group of middle-aged residents got older; 1) an increasingly sizeable minority had no family members and nobody other than co resident friends in their informal network; 2) a minority had a key informal person in their network; 3) the frequency and nature of contact with family members reduced and changed; 4) friendships with non co resident friends or people without intellectual disabilities decreased; 5) the initial increase in informal network size and family contact was not sustained and only a very small proportion formed new friendships with people in the community.

The study identifies some of the adaptations that occur in the nature of family contact to accommodate age related changes. These should inform staff practices where residents and their families are ageing. For example, parents being no longer able to drive or retiring interstate or to the country, can lead to greater reliance on telephone contact, fewer opportunities to actively monitor the operations of the house and less informal channels to keep up to date with their relatives activities. Such changes challenge staff to be more proactive in facilitating face to face family contact and in finding mechanisms to retain the engagement of family members in the life of residents and the house.

The lack of association between the death of parents and loss of family contact together with the high proportion of residents who had contact with both parents and siblings suggests that in many families siblings not only replace parents when they die, as the primary family contact, but also that they have ongoing relationships with their brother or sister with intellectual disability prior to the death of parents. This emphasizes that when support for family relationships is considered by house staff or case managers, the focus should be broader than simply parents. The absence of other more distant family members in resident networks, suggests that people without siblings are particularly vulnerable to the loss of family contact as they age.

Comparison between the social networks of older people who had lived most of their lives with parents in the community and those in the present study, the majority of whom had lived most of their lives in institutions suggests the basis for strong later life family relationships lies in a long term proximal relationship. For example, Bigby (2000) found older people with intellectual disability who had stayed at home with their parents until at least the age of 40 years but who were now living in similar group houses in Victoria, had an average of 7 family members in 6 monthly contact which is a stark comparison to the average of .88 in the present study.

The broad findings that a majority of residents have neither friends without intellectual disability nor family members who know them well are not unique to this study (see Robertson, 2001 et al.; McConkey, 2005), although previous studies have not noted the steady decline over time found in this study. In relation to formal support, staff have been found to have little knowledge about resident's day time friendships (Emerson & McVilly, 2005) but their knowledge of family constellation has not been addressed.

The impact of deficient informal networks and of being “known well by no one” may be amplified as people with intellectual disabilities age. Ageing will mean people are likely to encounter chronic health problems, as well as be forced to confront key life decisions, about issues such as retirement, health care, support needs or place of residence. Victorian research has shown that some older residents in disability services are vulnerable to placement in aged care accommodation, sometimes against the wishes of family members, and often considered to be inappropriate by them. (Bigby, 1997b). There can be little doubt of the heightened vulnerability to hasty, inappropriate or demand management type decisions based on poorly articulated rationales faced by aging residents who do not have an active informal network member. Such vulnerability may be compounded by the absence of staff who know them well. In the context of current disability policy these findings further highlight issues raised by Mansell & Beadle-Brown (2004) as to the viability of implementing for residents, such as this group, models of person centered planning that have as their foundation the input and commitment of a circle of supporters informal or otherwise who know the person with intellectual disability well.

Despite broader policy aims, the organisation of community based residential services in this study gave little focused attention to the development of informal relationships, indeed, family members encountered obstacles to maintaining contact that stemmed from systemic factors in these houses. The findings also suggest the success of reunification programs is equivocal and raise doubts about the value of staff time spend on tracing lost relatives. The issue appears to be what happens next, and family comments about the difficulty of keeping in contact with a family member who is not well known to them are an indication of the flaws in such programs. One of the reasons may lie with the expectations that staff have of family members and their relationships with their relative and the house. Family members who were in touch with their relative were primarily visitors to the house, who either came for special occasions organized by the house such as a Christmas or Cup Day BBQ, to visit their relative for a short period or to take their relative out. These arrangements, particularly visits do not acknowledge the difficulties some family members may face in “visiting” a person they care about but with whom they had difficulty communicating and share few common experiences, and in the case of newly found relatives, a person whom they hardly know. Shared activities and regular proximity are essential ingredients for building and maintaining relationships which suggests

that one strategy to retain connections with family members of residents is to find roles for them within house, that may sit more comfortably than simply that of visitor, - perhaps, gardener, sewer, consultant on things such as, décor, computers, photography. In this study very few family members were members were actively involved in house and it was not clear whether this was an active choice made by them or staff or whether such possibilities had not been explored or were too threatening to the position of staff. One of the administrators appeared to be using notions of resident privacy to reach the conclusion that family members should not be actively involved in houses. Such concerns may however be more imagined than real and can be overcome by discussion and negotiation with all residents and their families.

As table 28 shows less than half the houses had regular visitors, and some did not even have a regular visit from a community visitor. However, there was no discernable pattern of differences between these to indicate the influence of external visitors on the functioning of a house, and this element appears to be one of many that together affect the quality of support. It was clear however from the interviews with the community visitors that their role is pivotal in monitoring the quality of support provided in houses and following up on issues identified. Of concern therefore is the number houses without a regular community visitor.

The study suggests the necessity of active strategies to nurture and build informal networks, to enable the spectrum of network functions to be fulfilled for each resident. In a similar vein to issues discussed in relation to supporting community inclusion, an approach may be the creation of dedicated function, a skilled worker, to work across a cluster residents, that will allow at least one worker in the formal system to know residents well, map family constellations and tackle creatively the continuing engagement of families in the lives of residents, as well as develop individual strategies for the development of friendships or advocacy relationships.

This study echoes the now familiar finding from the UK and US that physical presence in the community does not equate with new social relationships and suggests the impact may be greater, as people with intellectual disabilities embark on the aging process, as the risks of not having any informal advocate to manage relationships with the formal services system will potentially increase, and they face difficulties engaging the emerging system of person centred planning system.

Supporting Choice and Upholding Residents Rights

Given that a majority of residents had poor verbal and written communication skills and could not read, the absence of alternative forms of communication was striking. In the case study houses there was almost no evidence of attempts to communicate key information such as menus, activity timetables, staff on duty, or support choices about such things as holiday destinations, TV programs, activities, food, or retirement in a form that might be understood by residents. Staff were invariably unable to elucidate how they supported residents to make such choices, and usually reported they had talked with residents. As well as issues of choice the lack of attention to communication also meant there were few channels available for information about activities and events that had occurred during the day to be conveyed to house staff or indeed families, which added to the fragmentation of resident's lives between programs.

There was also an absence of mechanisms by which residents either individually or as group could express their views about what occurred in the house and changes they would like to see. In only one house was any reference made to a formal resident's meeting where views could be aired, and only one or two residents were involved in an external self advocacy group. Neither were there formal mechanisms whereby interested or involved family members could be consulted about the operation or future directions of the household. Holidays highlight the issues that stem from the lack of communication aids and consultative mechanisms. Decisions about holidays are complex and should involve considerable thought to the opportunity costs involved. Few rationales for the different choices made about this issue between houses were found. Policies about the utility of holidays differed between organisations and practices differed between houses, and decisions on whether holidays occurred and destinations appeared to be more driven by staff preferences rather than being responsive to residents expressed or assessed needs. Staff and organisations must be challenged to demonstrate processes by which they support residents to make choices and explicitly develop the capacity of residents to not only make choices but voice their perspective on the way houses operate. Retirement from day programs is another key decision increasingly made by staff for residents about little education or consideration of options was evident. Decisions such as this did not appear to be made within the more formal context of a GSP or IPP

and thus seemed to be made without involvement of key others in the person's life, or with the possibility of external review by the IDRPs.

Considerable developments have occurred in these areas over the past 5 years, in Victoria which it is important for the organisations managing these houses to make optimum use of. For example the development of the Communication Resource Centre funded by DHS and auspiced by Scope with the mandate to support and resource community based organisations and services about communication issues and more recently a renewed attention to self advocacy that has led to the development of a Self Advocacy Resource Centre.

Access to Health Services

The data on the health status of residents that showed an increased number of residents with poor health and taking psychiatric medication was based on staff report and not independent medical assessment. It should be treated with caution as being no more than indicative. The qualitative data suggested that house staff were taking a proactive role in health related issues, by for example, changing GPs when dissatisfied with the care provided, liaising and advocating for residents in regard to hospital based services. The apparent absence of regular sensory or health screening tests, such as mammograms, sight and hearing, warrants further investigation and perhaps the development of more formal and prescriptive standards in this area. Certainly the impact of undiagnosed and untreated health conditions on resident's quality of life was evident in the study.

One of the emerging issues is the interface between the hospitals and disability services. The findings suggest that considerable advocacy is required to ensure hospital and out patient care is responsive to the needs of people with intellectual disability and takes into account the information provided by house staff about particular needs of residents. The data also suggests that hospitals do not readily adapt the type of in patient care to the needs of people with intellectual disability, and expect house staff to supplement the care provided whilst residents are hospitalised. Whilst usually met by house staff such expectations place significant strain on resources and it is debateable whether they are warranted. The current policy embedded in the Victorian State Plan for People with Disabilities clearly articulates the aim of increasing access by people with disabilities to community facilities and services, which must be seen as including the health system. The interface between

the two systems and the degree of responsiveness and reasonable adjustment that can be expected from the health system is an area where policy and program initiatives are required at the level of State Government. Developments in this area have occurred both overseas and in other States, and include, development of protocols between hospitals and disability services about the adaptations required and shared costs between the two sectors, establishment of hospital disability liaison positions, and employment of nurse practitioners within the disability to provide consult and specialist support in regard to health care for residents.

Adapting to Aging

Aging was identified by administrators as a major issue to confront organisations in the future, and evidence was found of current adaptations in the nature of support to residents who were aging. Similar to other research, staff generally held quite stereotypical views of aging that did not reflect its diversity of aging or differentiate between third and fourth age issues (see Bigby et al., 2004b). Such attitudes hold potential dangers of aged related discrimination especially in relation to opportunities for development and choices presented. Residents' retirement or semi retirement from formal day programs had not been accompanied any formalised individual planning or education about aging and retirement. The additional time at home for resident was being managed solely by house staff on what appeared to be a very ad hoc basis and was in danger of simply being seen as additional administrative or errand time for staff.

The findings from this study suggest it is important that neither the non government organisations that manage the houses or DHS, the funding body have undertaken significant program or policy development in regard to adapting to the needs of aging residents. At the central level protocols have been developed between Aged Care Assessment Teams and DHS disability services in regard to people with lifelong disabilities but no policies are in place in regard to issues such as retirement and aging in place which means there are few known parameters or expectations, and each organisation must negotiate on a case by case issues which not only leads to uncertainty but also variability across the system. Retirement from day programs can potentially mean that one organisation is solely responsible for all the support provided to residents which reinforces the need for an adequate system of person centred planning that can be monitored and the importance of outsiders such as

Community Visitors or Family members to monitor what is occurring. The findings from this study are mirrored in a recent study undertaken for the National Disability Administrators about Aging in Place that explores the interplay of factors that support or obstruct aging in place in shared supported accommodation (see Fyffe, Bigby, McCubbery, 2005). One of the findings from that study is the tendency for staff and organisations to confound issues of aging with the host of other change that occur as adults get older and progress through middle age, which suggest it may often just be adaptation to changed health or support needs that confront organisations, something they are experienced in rather adaptation to age related change in which they are less experienced.

Organisational Summary

Organisations had moved on from the initial relocation process and the houses are now embedded in the greater organisation. However the impact of the relocation design is still observed. Some of the areas which have been affected by relocation include the ongoing problematic matching of residents in some houses, the requirement (supported by the funding model) for day program attendance and the design of 5 residents per house. The relocation process and design of the program does not appear to have supported individual designed programs for residents who live together by night and for the majority attend the same day program by day. The impact of the institutional lives of the residents' increases the difficulty of engaging them in the community thus this has only been successful for a minority of residents.

Moreover the lack of forward planning for the already aging population who were relocated was a major weakness of the relocation model. There still does not appear to be planning at policy level for this situation. Staffing still remains a problem for all organisations with qualified staff difficult to recruit. However all organisations felt that this situation had improved to a degree. The focus of the daily activities of the residents is still personal care and there appears to be minimal time in some houses for engagement of the residents to improve their communication and ability to engage in the community. If staff are not qualified even with the support of the organisation they are likely to rely on their own intuition and personal views as to what might work to improve communication. Although on one hand it is good to have this creativity on the other it is not respectful of residents to have a continual trial and error approach to facilitate their engagement.

Conclusions

This study had found that the move from institutional to community living has improved the quality of life for the 24 residents in this study in various ways. After 5 years in the community the residents live in a much smaller more pleasant home environments that afford them greater privacy and more opportunities to participate in the domestic chores of everyday life. They have a much greater community presence, and are considered to have developed as individuals, to exercise more choice and initiative. Their chances of being regarded as an individual are greater and most go out, at least some of the time, individually or in small groups. Some of those with less severe intellectual impairment and without major physical or mental health problems have also become active participants in their households and have become members of both disability specific and mainstream community based organizations. Such opportunities were not afforded to these residents whilst they lived at KRS.

Tracing the development of community inclusion and participation for the residents over 5 years has demonstrated that it is a slow, uneven and variable process. It is dependant on a complex interplay of factors that revolve around residents' characteristics, the nature and availability of support and organizational structures, as well as the broader external context. Progress towards policy visions of inclusion for the ex residents of institutions are clearly tempered by resources available and the relative priority afforded by Government to different groups of people with disabilities and other marginalized groups. Tensions are also found between the implementation strategies for achieving inclusion, the micro level where immediate impact can be identified and the macro level that have less visible and more generalized perhaps longer term outcomes. Visions of community inclusion must compete with, and may be compromised by other more pressing goals. Whilst waiting lists and unmet demand exist, for example, they will shape decisions about vacancy management, and create situations where resident compatibility and quality of life are balanced with the urgent more basic needs of those outside the system for accommodation.

Life for the ex residents of KRS is clearly better than it was, but the question of whether it is good enough must be seen in the context of competing priorities and relative progress. This report has highlighted some of the issues that staff and

organizations grapple with in supporting community living and suggested possible strategies by which these might be considered.

- Developing the organizational capacity to know and respond to residents as individuals consistently over time;
- Interpreting the meaning and operationalising inclusion for people with more severe disabilities;
- Harnessing the potential of family to be engaged in resident's lives, monitor the quality of care and undertake advocacy;
- Developing strategies that support choice and the exercise of rights;
- Accessing quality health care and adapting to change as well as aging.

The research suggests an important task is the clearer articulation of what community inclusion may look like for people with more severe intellectual impairment. Many staff who work with this group currently do not have a clear vision of what they are striving for and the sense is beginning to develop that inclusion is something that occurs for "others" who are more able or have better communication skills. Despite wide and long term acknowledgment of the industrial issues pertinent to the non government sector, the difficulties in the recruitment and retention of qualified house staff continue to exist along with turnover of both supervisor and direct care staff. These issues are a reality and must be factored into the organization of community living. Suggested then, is the restructuring of support for residents living in community house, with a greater emphasis at both organizational and house level on consistent implementation of person centered plans as the guide to all staff action and provision of greater access for house staff to supervision, specialist support and consultation in carrying out or sharing their multiplicity of functions. Action is also needed at the level of State government to development of systematic policy and programs responses to the issues of aging and changing resident support needs, due to any reason, and partnerships with all levels of the health sector.

Community inclusion for people with intellectual disabilities may never be good enough until such significant societal changes renders concepts such as inclusion and exclusion redundant. In the interim, research continues around the world that contributes to understanding and improving the implementation of strategies to improve quality of life outcome for people with disabilities. The first

steps of moving out community presence and being regarded as an individual rather than a member of a group have begun for the ex institutional resident in this study.

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APPENDIX 1 HOUSE VIGNETTES

House 1.

Four of the five women living in house 1 were in the study. One woman died, quite unexpectedly in her sleep in December 2004. The women were rated as having low support needs, all had a moderate level of intellectual disability, one woman had a psychiatric diagnosis and two had sensory impairments. By the end of the study, the three residents in the study were aged between 48-54 years. They all continued to attend separate full time day programs. Day program staff all thought there had been marked improvement in their wellbeing and that aggressive or agitated behavior had reduced. The community visitor was initially concerned however about the poor management of the women's health needs and one women's continued agitated state. Significantly staff from the three different day programs as well as the community visitor were concerned about the quality and consistency of support the women received at home. The house had difficulty recruiting and retaining qualified staff and heavy reliance was placed on the use of casual staff who were not acquainted with the women. For example, the house had 5 supervisors during the first three years. Staff were perceived as poorly prepared and concerned simply to "keep the place running". At the end of three years, the house was perceived as chaotic with staff having no substantial knowledge of the women and at times relying on negative stereotypical images. For instance, the researcher was told by a staff member about one women, that "all you need to know about her is she is schzio and dangerous". Researchers as well as family members had difficulty making contact as the phone was rarely answered. The staffing situation made it difficult for family members to stay in touch. An elderly parent of one resident remarked that they didn't ring any more as it was too difficult as the staff were always different and they didn't know who they were. Another elderly parent said they knew neither the staff nor the other residents. None of the three women had contact with a family member more than once a year and none went out

with family or friends. One woman continued to see an elderly advocate who visited her at the day program once a month. The women did not go out in the evenings nor did they attend any regular community based activities. They generally went out together at the weekends to shopping centers or other outings. One woman regularly walked alone to the local milk bar. The women are involved in packing their own lunches, helping to set the table and food preparation. The individual program plans for the women were unable to be located and were not used as a guide to support.

Staff turnover had been a major issue although it appeared to have stabilized by year 5, at which time both the community visitor and day program informants were more positive about the house. The residents in this house had no strong connections to family, friends or to community organisations other than their day program. No outsiders other than the community visitors had regular involvement in the house.

House 2.

All of the residents in this house were in the study, three women and two men. One of the men died in April 2002 as a result of Alzheimer's disease. He was cared for at the house until a few weeks before his death. Staff had been determined to keep him at home until absolutely necessary for him to move which entailed significant personal and organizational flexibility and commitment to the resident. By the end of the study the remaining residents were aged between 41 and 53 years. Similar to house one the support needs of the residents were rated as low. All had a moderate level of intellectual disability and problems associated with their health. The turn over of staff in this house has been minimal with the house manager remaining constant over the 5 year period. House staff and family members were very positive about the impact the move to the community has had on the well being of residents, changes to confidence, increased assertiveness, greater independence and reduced unpredictable behavior were mentioned. Concerns raised by the community visitor about weight problems, dental and health care for several residents, were addressed. The residents do not

normally go out on weekday evenings but sometimes walk in the local park. They go out together or individually with staff at weekends. Regular outings include, shopping, walking in the local park, a disco run for people with disabilities, and local café's. Several residents had been on holiday with family members and the residents have at least one holiday together in rural Victoria. A good working relationship exists between the day program and house staff with regular communication between the two, especially in relation to two residents who do not get along well together. Families were positive about the staff and the support provided to residents. One father however was concerned that information had not been shared with him about the dismissal of a staff member. All residents have strong regular relationships with either their parents or siblings. Two residents stay overnight with family members on a regular basis, whilst the other two are in phone contact with relatives who live in the country. One of these residents is supported to visit his very elderly mother in the country regularly. The atmosphere of the house is relaxed and happy; residents are involved in assisting with domestic chores such as packing lunches, tidying and washing up. Several residents can independently make coffee for visitors. Two residents have home based hobbies - painting and puzzles. This house had experienced stability of staff; residents had strong family connections which involve at least fortnightly visits to the house by some family members. Residents did not have strong ties to any community based organisations but regularly used the local facilities such as the park and shopping centre.

House 3.

Only one of the residents in this house of 5 woman participated in the study. The residents were aged between 40-54 and the woman in the study was aged 52 years. All the residents were considered to have high support needs. The woman in the study has various health problems and her weight problem has increased over the 5 year period. She takes anti psychotic medication primarily it seems as a behavior management strategy. Day program staff and family members thought there had been steady improvement in her well being marked by a reduction in aggressive

behavior and increased participation and enjoyment in a number of activities at the day program. They thought that she required routine and certainty and had initially changed day program as the first had been unsuitable for her. She does not go out in the evenings during the week and spends much of her time at home just sitting or watching staff. She is not involved in domestic tasks or any particular hobbies or activities at home. She does not like to walk or exercise. Residents and staff have a friendly relationship with the neighbors next door although have experienced very negative attitudes from residents in a block of flats opposite. The residents generally go out as a group at the weekends; sometimes they visit another of the houses managed by the same organisation or just go out for drive. There is little scope for individual support although residents can purchase one to one support from their own resources. Some occupational therapy students were involved in the house and began to develop a sensory room, to which residents have contributed the costs of materials. She has strong relationship with several of her siblings which has strengthened since her move to the house. Her sister remarked that she was now much more part of their family than she had been. Her siblings visit the house at least fortnightly and regularly take her out. The house has experienced considerable turn over of staff and the women's sister remarked that some very capable staff have come and gone. She thought the quality of care was generally good but was concerned about the lack of continuity that resulted from staff changes. At times she has been very involved in the house but different managers have held different expectations about this.

House 5.

Three of the five women in this house were participants in the study. They were considered to require a medium level of support and by the end of the study were aged between 45-58 years. They had severe or profound intellectual disability and one woman has health problems as well as a psychiatric diagnosis. One of the participants moved to a nursing home after about 4 years in the house. She was diagnosed with dementia and considered to require more individual support than the organisation was

able to provide. It was not a smooth transition as the first nursing home withdrew the placement after several weeks and she returned to the house until another was found. She has no contact with family and staff members remain in regular contact with her. Day program staff and family members remarked on the improvements that had occurred for the other women particularly in relation to their health, weight loss and confidence. A father remarked that his daughter was brighter, more settled and less frightened than she had been at Kew. The house experienced some initial instability of staff but after a change of house supervisor at about 18 months staffing has been more stable, although significant use is made of casual staff. The house has a strong focus on health and fitness. All the residents exercise either using a treadmill or by walking outside every day and are supported to adhere to a strict low fat diet. Apart from daily exercise the women have few activities at home, apart from watching the television or drawing. They help with packing lunches and some domestic tasks. They generally do not go out in the evenings during the week. They go out either as one or several smaller group on the weekends to places such as the beach, cinema or shopping. They occasionally use public transport. Flexibility of staffing and funding have been an issue in this house and it has been difficult for residents to stay at home during the day if they are unwell, staff feel they have insufficient time for administrative tasks and equipment such as food processor has been purchased for the house from residents own funds. The community visitor has suggested investigation of a communication aids such as a compic board for one resident but the supervisor felt this was inappropriate. Contact between residents and family is variable, two of the women have little contact with family and though the father of the third women remains in regular contact since his move interstate but this means he does not visit as often as in the past. He would like his daughter to be supported to spend holiday time with him. One woman who has very limited contact with her family goes out every three months with an advocate and occasionally with a friend from her day program.

House 10

Three of the five men in this were in the study. Residents were aged between 39-59 and considered to have low support needs. They all have a moderate intellectual disability and health problems. One man requires dialysis three times a week. Both family and day program staff commented on the positive changes that have occurred for the three men, mentioning in particular improved health and communication. Although one man continues to behave aggressively and at times be unpredictable his family considered he had settled well and was much better off in the house than he had been at Kew. The family of this man was impressed with the support and care he received from staff at the house. The men do not go out in the evenings and go out together at the weekends to activities such as bowling, the cinema or shopping. Several of the men in this house have strong relationships with men from Kew who moved to another house. The two groups of men visit each other on a regular basis and one year went on a joint holiday to Queensland. Two of the three men do not have contact with family members whilst the third has regular contact with his three brothers, one of whom visits the house regularly. There is no community visitor for this house and there is little data on the extent to which the men are involved in the domestic tasks of the house or the degree of staff turnover.

House. 8.

Two of the five men in this house were in the study and it was one of the intensive case studies. These men moved twice, as they lived for the first year in a temporary house in the same neighborhood whilst their new home was built. Their support needs were considered to be low and they had moderate intellectual disability. One man had health related problems and the other was on psychiatric medication at the time of the move. At the end of 5 years, the men in the house were aged between 36- 53 years. The health of both had improved over this time, and one was no longer on anti psychotic medication. Both men were more assertive and more able to make choices about activities. The men each had at least one evening activity outside the house in which they participated every week as an individual rather than part of the house group. These activities were however

primarily those organized for groups of people with disabilities such as indoor cricket, basketball, drama and a bowling league. The men also did some activities together as a house group such as bowling on Saturday morning and visiting residents in another house whom they knew from when they lived at Kew. One man attended the local church with another resident but had been refused membership of the choir. Neither have good verbal communication skills and one man has increasingly made use of advertising brochures to communicate his desires. One man is very keen on football and follows a particular team but lack of staff interest in football and availability of volunteers have meant no one has been available to support him to attend matches. Both men are responsible for cleaning and organizing their own room and clothes and share in other domestic tasks such as food preparation, and clearing away. One man is very proud of his own room and spends a lot of time organizing and tidying his clothes, the other has taken over the second sitting room which he uses to listen to music. The residents are increasingly able to clean up after a meal without support from staff. Neither men have close ties to family or see family members on a regular basis. The house has no regular visitors other than the group of men who also previously lived at Kew. There is no community visitor. Every year the men have gone on holiday, either as a house group or in smaller groups. Last year the two men in the study went fishing in Tasmania. The house has had two supervisors over the past 5 years but experienced difficulty retaining staff in the first three years. By the end of the study the longest serving staff member had been at the house for two and a half years.

House 11

This was a case study house in which two of the five male residents were in the study. The residents in the house were aged between 42 and 63 and considered to require a medium level of support. They all had difficulty with mobility. The two men in the study had a moderate intellectual disability and both used wheelchairs. Neither had significant health problems but one had gained a substantial amount of weight since the move from Kew and attempts to control his weight through a low fat diet had not been followed

through. Day program staff remarked that the physical capacity of both men had reduced since the move but social skills had improved. One man retained a strong relationship with his elderly mother and was supported to visit her on a regular basis while the other saw various family members irregularly. All residents had some contact with family members who were sometimes invited to BBQ's at the house. The nature of residents social activities had changed during the five years and the men no longer went out as much as a group to as many social activities. By the end of the study they were all going out alone to different activities. The younger of the two men in the study continued to enjoy the arts and crafts day program he attended and also went out regularly in the evening to various social activities. Some of these were organized activities for people with disabilities such as a disco and a social club. He also attended a social group at the local church and had been invited to various other activities by members of this group. The other man, who was now in his 60s had reduced attendance at his day program and stayed at home with another resident three days a week. He did not go out in the evenings, but on one of his days at home had begun to attend an individual swimming class at a local pool. The rest of his time at home was often spent accompanying a staff member on various jobs that had to be done or sometimes going out for coffee or shopping. The men's participation in domestic tasks is variable and though they would be very able the design of the kitchen makes participation in food preparation difficult and generally the men are observers who are served food rather than participants in these tasks. This house has experienced considerable staff changes, and had house supervisors with very different ideas about how the house should be run. As a consequence the men have experienced significant changes in expectations and domestic arrangements. Staff as well as residents had resented and felt negatively affected by these changes. In all there have been 7 supervisors over the 5 years, the longest one had stayed was 2 and half years and the shortest a few weeks. At the close of the study one staff member had been there for 4 and half years but was about to leave as she had continually be overlooked for the job of house supervisor.

House 9

This was a case study house in which three of the five residents, one woman and two men, were in the study. Residents were aged between 36 and 45 and considered to have high support needs. All three had health problems and at the time of moving one man had a psychiatric diagnosis. The three residents continued to experience poor health over the 5 year period which led to substantial variability in their wellbeing. One man's behavior regressed considerably and remained often aggressive and unpredictable which eventually led to a psychiatric diagnosis and medication. Another man's depression became worse but with increased medication his condition was beginning to improve. The women resident in the study experienced major problems related to an ear infection which took many months to be diagnosed and treated. The house experienced considerable instability in staffing, particularly during the first year such that by its end none of the original staff remained. During the 5 years there were 4 house supervisors, 3 by the end of the third year. Despite this however, there were two long term staff members, although one still employed casually who had been at the house for 4 of the 5 years. Tensions were evident between one of these long term staff members and the new house supervisor. Family members were concerned about the disruption and inconsistency of support caused by staff changes and the high use of casuals. The house appeared prone to disruption of routines and inconsistency of response which led to unsettled behavior and difficulty of communication among residents whose health and emotional needs required skilled communicators, consistency and technical expertise. For example, it was clear that communicative behavior by one resident was interpreted quite differently by various staff. The family of one man was very concerned about the compatibility of residents feelings the needs of his son were overshadowed by other residents. Nevertheless family members felt the household was beneficial for residents and provided a calmer and more secure atmosphere than Kew had done. One man experienced considerable difficulty with his day program which was unable to manage his health care needs and by the end of the study an individual day program had been negotiated for him.

However, this was still in the early stages of development and appeared fairly ad hoc and unresponsive to his particular needs. The residents go out individually with staff or in small groups. One family purchases additional one to one support for several hours a week which provides this resident with more opportunities for walks in the community and use of the local swimming pool. Other residents tend to have one or two outings normally at weekends. One of the men in the study and another resident not in the study have very strong ties with a parent who each visit the house at least weekly but often more regularly for periods of time. Another resident has erratic and sometimes conflictual ties with his family who also visit regularly and also he has a long term relationship with a community advocate. The women in the study however had no meaningful family relationships. The house always has a sense of being busy as residents embark on outings with family members or support workers. They are however only minimally engaged in domestic tasks. A sensory room was developed with the support of a family member although its use had declined since it was first in operation.

House 4.

This was a case study house in which four of the five women residents participated in the study. One of the women died after a short period of hospitalization, 18 months after the move. The remaining residents were aged 49-68 by the end of the study. The residents were considered to require a medium level of support. They had severe and profound intellectual disability, no verbal communication skills, health problems and one woman had a psychiatric diagnosis. The resident who died was replaced by a young woman many years younger than the other residents, who had previously lived with her parents. None of the women have any contact with family members and as a consequence there are few visitors to the house. Day program staff had a good relationship with house staff but thought more support could be given to the women to be actively involved in activities or domestic tasks. The women spend much of their time at home sitting and each has their own favorite spot. They interact little with each

other or staff. However, in small ways all women had become more able to express choice, initiate activity or follow directions during the period of the study. For example one woman was able to indicate she wanted a bath, whilst another was now able to dress herself when prompted. Each was involved in some way in domestic activity such as helping to pack their lunch or putting their clothes in the washing machine. Generally the women were considered to be settled in the house, although one continued to experience mood swings, and two have experienced periods of disrupted sleep patterns and night waking and wandering. The staff in this have been stable with the house supervisor and at least one other staff member being constant for the entire 5 year period. However, the manager and one long term staff member clearly had very different opinions of what was possible for the residents. The staff member expressed the view that staff were demoralized and worn out as they found it difficult to work with women with whom they were unable to interact verbally. The residents had not gone on holiday during the period. Each went individually to the hair dresser and podiatrist. They did not generally go out during the week other than to day programs and went out as a group at weekends to lunch or tourist attractions.

Appendix 2

Not Just a Residential Move But Creating a Better Lifestyle for People with Intellectual Disabilities: Report of the Evaluation of Kew Residential Services Community Relocation Project 1999

Executive Summary

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Executive Summary

In June 1997, 58 new community based accommodation places were allocated to residents of Kew Residential Services. At that time Kew had a population of 581 people with intellectual disability who lived in nineteen units on the site. All residents and their families were invited to put in an expressions of interest to move to the community, 221 were received. A team from LaTrobe University School of Social Work was contracted to undertake an evaluation of the relocation process and the outcomes of relocating to the community for the residents.

Previous relocation studies show that people with intellectual disability are generally satisfied with community living and do not wish to return to institutions, but most fall short of demonstrating long term significant improvements across a range of subjective and objective quality of life measures. Significant variability of outcomes is found and relocated residents are more likely to be present in the community than included as part of it. Little attention has been paid to the variables associated with community living although these are beginning to be teased out by UK researchers who suggest that the micro organisation of resources may be as important as the quantum.

Design of Evaluation

This evaluation used multiple methods of data collection before the move and a year later to seek information on processes and outcomes. A sample of 27 residents was selected at random. Phone and face-to-face interviews, observations and questionnaires were used to collect data from the residents themselves, family members, and day and residential staff. Key domains used to consider outcomes were; living situation, general health, personal development, community integration, interpersonal relationships, friendships and family contact. Interviews and focus groups were also conducted with the management of non-government organisations and Kew as well as the relocation team. In addition more intensive case studies were undertaken in respect of 11 residents in 4 community based accommodation services. The first residents in the study moved out in July 1999 and the last in April 2000. The last wave of data collection occurred in November 2001. In this report the location and identifying characteristics of community based houses, units at Kew Residential Services and individual residents are not revealed.

Relocation Processes and Organisation of Community Living

In line with the then government's policy of purchasing rather than providing services, provision of the new accommodation services were subject to public tender and delivered by funded non-government services. The model adopted was that of a 5 bedroom community residential unit. The most challenging part of the relocation process was to avoid the suggestion of transmission of business from the institution to the community that would have meant industrial conditions and wage rate of Kew staff had to be replicated in new community residential units. This meant that Kew direct care staff were kept at arms length from the process and all resident assessments and collation of information was handled by case managers attached to the relocation team.

Overall the relocation was well planned, thorough and respectful of the rights of the clients and their families. As it was implemented it inevitably began to diversify as three different regions were involved in tendering and negotiation of contracts with non-government organisations. It diversified further still as the six separate successful organisations began to establish staff and management infrastructures to manage eleven different houses.

Lack of staff resources was the overarching theme pinpointed by house staff, who saw this factor as obstructing the achievement of greater individualisation, developmental progress and community inclusion for residents. Most commonly the problem of sheer lack of numbers on the ground were identified, but also, difficulties in recruiting and retention due to lower wage rates in the non-government sector, and low levels of training, experience and expertise in supporting people with intellectual disability to live in the community were evident. Despite job position aims that reflected visions for a more inclusive life these were overshadowed by the specified tasks that were more reflective of the immediacy of ensuring daily care and safety needs were met.

A related issue was the appropriateness for all residents of the five-bedroom community residential service model adopted. The model gave rise to concerns about the best ways to group residents and their compatibility. Such problems will always arise when residents are fitted into models rather than individualised lifestyle planning taking precedence and the construction of models or options around individuals. The policy context of the relocation emphasised the contractual nature of the relationship

between DHS and the non-government organisations that managed the community houses. This approach failed to engage the organisations as planning partners or to utilise their expertise in implementing community living options for people with intellectual disabilities.

Each organisation managed and structured its use of resources in different ways. One of the major issues identified as a shortcoming of the relocation process, poor transfer of information. This stemmed not only from the embargo on direct contact between house staff and Kew direct care staff but also from the manner in which the information provided was utilised by organisations and communicated to staff. The challenges of this later task were compounded by the relatively high turnover of staff and use of casuals.

Resident Outcomes

The ages of the 27 residents in the sample ranged from 35 to 65 years, with a mean age of 47.5 years. They had lived in Kew from between eight to 64 years, and many had spent much of their childhood and all their adulthood living at Kew. The majority (17) were recorded as having a moderate level of disability, whilst seven had a severe or profound level. Twenty residents had health issues, six had some form of psychiatric diagnosis and six had a mobility impairment

Many but not all residents were judged by others to be happier living in the community than at Kew. Indicators of this were increased self esteem, greater personal confidence, and changed demeanour. The fabric of residents' everyday environment was clearly of much higher quality than that experienced whilst living at Kew and residents had more personal space and privacy available to them. For most residents a sense of being treated as one of a group rather than an individual was still a strong factor impacting on their lives. However, they were part of smaller groups than they had been at Kew. Residents' choices, autonomy and activities were often limited by their membership of a household group. It was clear that the available resources and the manner in which they were structured meant that staff were only able to do "just the basics." Staff attention was focused on ensuring resident safety and provision of adequate care from day to day. This was reflected in the lack of significant changes in residents' adaptive behaviour a year after the move. Daily routines were organised around the necessity of getting things done. The forethought and planning required to engage residents in every day tasks was lacking as was the

additional time required to engage residents in such tasks. Residents were treated more like guests who helped out rather than participants in a communal household.

Despite the improved fabric of the resident's living environments, they presented few challenges to residents and were seldom adapted to accommodate their special needs. This was most evident by the failure to adapt kitchen designs to the needs of people in wheelchairs. The majority of residents attended day programs, which provided a central focus to their weekdays and in many ways shaped their lives. The loss of case management from Kew by the end of the first 12 months of community living meant that neither the day or residential program staff had the mandate to take a whole of life planning approach to each resident. As a result residents' lives were fragmented by program types (accommodation and day), with little evidence of cross sector communication, collaboration or planning around individuals.

The community presence of the residents increased significantly with their relocation to the community. Their use of community facilities and their level of activity in the community increased. But few participated in any community based organisations or established new friendships or acquaintances in their local geographic or communities of interest. Residents were still "visitors" to the community, "observers" rather than participants who had connections into their community. Related to this were the restricted nature of residents' informal networks and their continuing fragility. Very few had any friends or advocates who were not family or paid workers.

Ways Forward

Active engagement and individualising structures

More attention must be focused on the engagement of every resident as an individual rather than a member of a group and furthering the broad aims of inclusion and participation. Research suggests that such aims are not achieved just by the provision of staff or use of intuition but require detailed and careful planning.

Further exploration of the strategies suggested by the active support model and consideration of its adoption in community houses may be one mechanism for achieving more individualised attention for residents and extending their engagement. An overarching recommendation is that attention must be paid not only to the need for

adequate resources to attain quality of life outcomes for residents but also to the way in which existing and any new resources are structured.

Supporting staff and other issues

The workforce issues in the disability accommodation support sector are well documented and this report illustrates the problems that emanate from low rates of pay, poorly qualified staff and the difficulties of recruiting and retaining staff. Many of these are being addressed at a systemic level by DHS. One important issue not given a great deal of prominence however, is the absence of reflective supervision.

Lifestyle support rather than day programs

Exploration should occur of alternatives to the current model of funding day and accommodation support separately and requiring residents to attend full time day programs. Residents should have the choice to remain in their home and be safe, and use their home as the base from which to embark on a range of daytime activities. Such choice is essential for all age groups, but the aging of residents is likely to become a catalyst in the need to rethink the central role of day programs in people's lives.

Whole person planning

The absence of continuing case management and thus someone with responsibility for overseeing what is happening across all aspects of the person's life with the ability to take preventative action should be addressed. It is suggested that all residents have a case manager. At a minimum the case manager will be aware of the person's general service plan, regularly monitor the range of services provided to them and conduct preplanned reviews.

Focusing on strengths and compensating for limitations.

Whilst a focus on what people can do, their strengths and interests is critical, attention must also be paid to adapting the environment to optimize people's capacities and compensating for their limitations. In this regard modes of resident communication and more extensive exploration of augmented communication should be undertaken and the physical design of houses and interior aides and décor could be used more effectively to compensate for residents' limitations.

A proactive approach to health issues

It is suggested that in future relocations from institution to community resources should be allocated to a thorough medical and psychiatric review and screening for all residents and reports of such reviews form the basis for “handover” reports to community based health practitioners. In addition effort must be made to compile a medical history for each resident from the diverse sources available. Informed and interested practitioners exist, but their numbers are few and knowledge of their whereabouts is fragmented. In future the task of collection and sharing of information about good practitioners should be undertaken by the relocation team in consultation with relevant stakeholders and this information shared with new community house staff. The provision of support and consultancy about communication with and treatment of people with intellectual disability be made available to interested new medical or allied health practitioners for a period of time. Perhaps also the engagement of a nurse practitioner as a resource/consultant to support a cluster of houses over the longer term. Such a role would liaise with mainstream medical services, resource and support house staff in ensuring preventative health checks are conducted, symptoms are identified and optimal health care is received by residents.

Communicating information and preparing for relocation

Liaison and discussion between institutional and community based staff is regarded as a critical factor in communicating information about residents and their support needs. The importance of comprehensive assessments and the compilation of key information into one central report are reflected in our findings. One missing aspect is the existence of a “life book” and it is suggested that such a record be compiled with each resident and their family using both written and graphical forms of communication. This will provide residents with a medium for life review to assist in the psychological challenges associated with aging, and ensure important events, relationships and markers in their lives are not left behind, or lost with the passing of their parents. Attention must also be paid to the dissemination of information to direct care staff, which is an ongoing process as staff change.

It may be useful to consider a slower more structured process to preparing residents for the move. It is suggested that staff get to know residents prior to the move and that residents have at least several opportunities to visit completed new

houses and meet staff who will support them in that in that setting. In addition return visits to the institution should be facilitated for residents who indicate they would like this.

More extensive work should be undertaken to map the resources and understand the community into which residents will move. Attention must be devoted to these task prior to the move and time must be allowed for ongoing scanning of the community for changes and investigation of resources specific to particular residents' interests.

Ensuring values and policies are translated into practice.

The importance of starting from the expressed and assessed needs of each individual and listening to the views of those in their informal network, and building individualised supports around the person is a fundamental principal in current policy directions. To achieve this it critical that future relocation projects have flexible parameters and do not attempt to fit all residents into one or even several models. Rather the process must be open to the evolution of a diversity of options reflecting the diverse wishes and needs of institutional residents. It is important however, to recognize the tensions and competing demands that will be at play in any relocation project, such as resource constraints, political and policy imperatives, industrial issues and time factors. A recognition of these factors will help ensure that where compromises are made about resident choices and outcomes they are apparent and considered rather than unforeseen or accidental. A danger is that once the processes begin, the day to day matters swamp the broader picture. It may be useful to put in place a mechanism to enable participants caught up on the processes to take time out to critically reflect on the process or to have a position with the sole responsibility to examine whether decisions both large and small reflect the espoused policy principles that should be at the forefront of the process.

Conclusions

Residents were more like guests in their houses- visitors to the community; they were not strongly embedded in their local communities and had not expanded their individual networks or repertoire of skills and interest. But some appeared happier, they all lived in better environments, were more likely to be treated as an individual or part of small group and many had made initial steps towards increased

self worth. These findings are not disappointing rather they reflect the enormity of both the task at hand and the expectations for change associated with the relocation. Perhaps too much was expected from the move, community based house staff and the organisations for whom they work. Broader more systemic changes to community attitudes, staffing and funding models, training and supervision need to occur in tandem with resident relocation to the community. The findings also reflect those of other relocation studies, and the issues raised by research on community living. In particular the variability of outcomes for residents, and the increased community presence but lack of personal relationships and community connection and participation for people with intellectual disabilities (Felce et al., 1998; Mansell & Ericsson, 1996).

The planned follow up study of residents over a 5 year period provides the opportunity to see whether continued changes occur to improve the quality of residents lives, particularly if supports do become more individualised and residents build up connections into their communities. It will also enable further examination of the role of ‘outsiders’ in ensuring responsive accommodation support, and how the organisation of community living responds to the aging of some residents.

Policy makers, government departments and service providers are grappling with these issues across Australia and in other Western countries. It is important that in Victoria DHS remains abreast of developments elsewhere and provides opportunities for critical reflection on its progress towards achievement of the goals of optimal health, choice, inclusion, participation and empowerment for people with intellectual disabilities.