# St Paul's Court

# An evaluation of a supported living unit for people with dementia


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# 1. Introduction

## The Unit

St Paul's Court is a purpose built supported living unit for people with dementia which enables older persons who require housing support with care to live in the community. St Paul's Court opened in March 2004.

The unit has been designed for:

- People who have dementia.
- People who meet the NI Housing Executive's complex needs criteria.
- People who currently have a care package in place which is delivered by South Eastern Area Trust personnel.

The aim of the unit is to provide a place where people continue to have independence whilst having their support and care needs met. The environment can be adapted to the physical and social well-being of the residents and offers individual tailor-made care and support, depending on assessed needs. The development was originally planned to provide a home for life and was designed for people with mild to moderate dementia and people with complex needs.

Praxis Care staff are available twenty four hours per day to provide advice, guidance, support and care at a level appropriate to the individual's needs. Each person has a staff key worker who is committed to assisting the older person to fulfill the aims outlined in his/her support plan.

St Paul's Court is staffed by one Manager, three Senior Project Workers and fourteen Project Workers. Six of the Project Workers work part time.

St Paul's Court has two phases.

Phase One: Fifteen two bedroom bungalows set in a safe and secure environment, each with a small back garden, looking out onto a "courtyard type street" with a separate resource centre. Phase One was opened in March 2004.

Phase Two: A separate block of eight ground floor apartments built around a large open plan room or atrium. Phase Two was opened in February 2009.

## Aims

The evaluation is a case study of St Paul's Phase Two which is the separate block of eight ground floor apartments.

Phase Two is occupied by three males and five females with a mean age of seventy four years. Two of the tenants moved from St Paul's Phase One, two tenants came from their own homes and the remaining four came from Nursing Homes.

There have been no leavers during the period of the evaluation.

The evaluation was completed over a twelve month period between March 2009 and March 2010.

In order to assess the efficacy of this part of the unit, the evaluation uses the Joseph Rowntree Foundation's (JRF) "Six Keys to a Good Life" as a framework for data collection (Bowers et al 2009). The Keys were developed with the objective of promoting "voice, choice and control for older people with high support needs" (Bowers et al 2009 p. 29). The Keys are therefore an appropriate framework against which to measure St Paul's work when it is borne in mind that the unit exists to provide holistic care and support which recognises that the Service Users's dignity and individuality is recognised and valued (St Paul's Aims and Objectives Internal Document [no date]).

JRF's Six Keys to a Good Life are:

1) Meaningful relationships.

2) Meaningful Daily and Community Life.

3) Personalised Support and Care.

4) Personal Identity and Self Esteem.

5) Home and Personal Surroundings.

6) Personal Authority and Control.

## Methods

Written consent was obtained from three of the eight Service Users who were willing to participate in interviews. Data on the remaining five Service Users was collected using a range of unobrusive measures (methods two – six).

In the interests of anonymity, Service Users' names have been replaced by the prefix "SU" which is followed by a number. This label is used consistently throughout the text. SU_Five therefore refers to the same person where ever it occurs in the text which follows. Similar notations were adopted for the Staff (Staff_<Number>) and Service Users' relatives (SURep<number>).

Six methods were used to collect the data.

These methods include:

1. **Completion of social web.**

Interviews were conducted with three (38%) Service Users in Phase Two who consented to be interviewed by the researcher. The interviews were designed in order to find out about relationships between the SUs and family, friends and staff. This information was obtained by collecting data using an adapted Inclusion Web (Hacking and Bates 2008). This is a circle divided into segments where each segment represents the type of person who the Service User may encounter. The segments are Neighbourhood, Education, Volunteering, Arts and Culture, Faith and Meaning, Family, Sports/Exercise and Services.

The data was obtained by interviewing Service Users and staff at three monthly intervals over a twelve month period in order to discover who each Service User had met prior to interview. Each person encountered by the Service User was then allotted to one of the eight segments where the segments represent different parts of a person's social network. An encounter with a person from a particular category was represented by shading in the appropriate segment.

## 2. Administration of the Bristol Activities of Daily Living Scale

The Bristol Activities of Daily Living Scale (BADLS Bucks and Ashworth el al 1996) is a carer rated assessment of a person's ability to perform twenty activities of daily living designed specifically for assessing clients with dementia. The rater is asked to select one of five statements for each activity. Scores may lie in the range 0 – 60 with higher scores identifying clients who need more assistance. Calculating a sub-score for five items dealing with orientation and communication gives some indication of the degree of cognitive impairment. Scores for this sub-score lie in the range 0 – 15 with higher scores identifying clients who are more disorientated. BADLS was selected because it is sensitive to changes in clients with dementia and correlates well with tests like the Mini Mental State Examination (Bucks and Ashworth p. 113). Moreover, collecting data on a person's ability to perform the activities of daily living is important because these capabilities may not decline at the same rate as a person's cognitive state.

## 3. Observation by the researcher of a range of ad-hoc and pre-arranged activities within the unit.

Two ad-hoc and two pre-arranged activities were observed by the researcher. The ad-hoc sessions occurred where Service Users unexpectedly sat down together in the large public space of St Paul's Phase Two. The pre-arranged activities included a Video Night and observation of Reminiscence work. Video Night is a pre-arranged activity where Service Users meet on a regular basis to watch a film and to talk about it. Reminiscence work may use a series of "cues" (objects which may be associated with a particular point in time) in a group setting to encourage Service Users to reflect upon the past and present in their own words. Observational techniques were used in order to study social interactions between tenants, staff and relatives.

## 4. Interviews with staff.

Interviews were conducted with eleven (61%) St Paul's staff. (All staff were invited to take part in the interviews). A semi-structured interview schedule was used in order to obtain data pertinent to the evaluation. Each interview was recorded digitally by the researcher and transcribed. Themes were identified by looking for comparable themes across each transcript.

5. **A postal survey to the Service Users' relatives.**

The survey was administered to relatives of the eight Service Users in St Paul's Phase Two. Four (50%) of the eight relatives returned the survey. The survey was administered in 2009/10 and was designed to collect the opinions of people who were in a position to help Praxis Care to deliver better services.

6. **An analysis of the Critical Incident and Incident data received by the Praxis Care Research Department from St Paul's Court.**

Critical Incidents (CI) and Incidents (I) are completed on a monthly basis with a copy of CIs and/or Is being sent to the Praxis Care Research Department for collation.

Methods one and two were repeated at three monthly intervals.

# 2. Meaningful Relationships

This chapter examines the degree to which:

- service users have maintained existing relationships.
- developed new relationships within and outside of the unit.

The maintenance of existing relationships and their extension where possible is an important area to explore because dementia is increasingly understood as the result of a series of interactions between "neurological impairment, life history, health status, social environment, personality and malignant social psychology" where malignant social psychology refers to methods of interaction which can depersonalise the person with dementia (Kitwood quoted in Davies and Nolan 2008).

Investigating the existence (or otherwise) of meaningful relationships therefore is of the utmost importance in a situation where changes to the social environment (which includes a person's relationships) can negatively impact upon their experience of the illness.

## Key Findings

- Eight Service Users (100%) maintained contacts with external services, family members and with people who were involved in a range of arts and cultural activities.
- Relationships have been established and maintained between Service Users and between staff and Service Users.
- Observation of a number of voluntary activities shows that participating Service Users were always included in sessions.
- Where an activity was pre-arranged and structured, the data shows that a staff member was the facilitator of the session with more interactions than any other person involved in the activity.
- High levels of participation by Service Users in voluntary activities was *not* related to increasing cognitive impairment in the sessions observed.

## Method

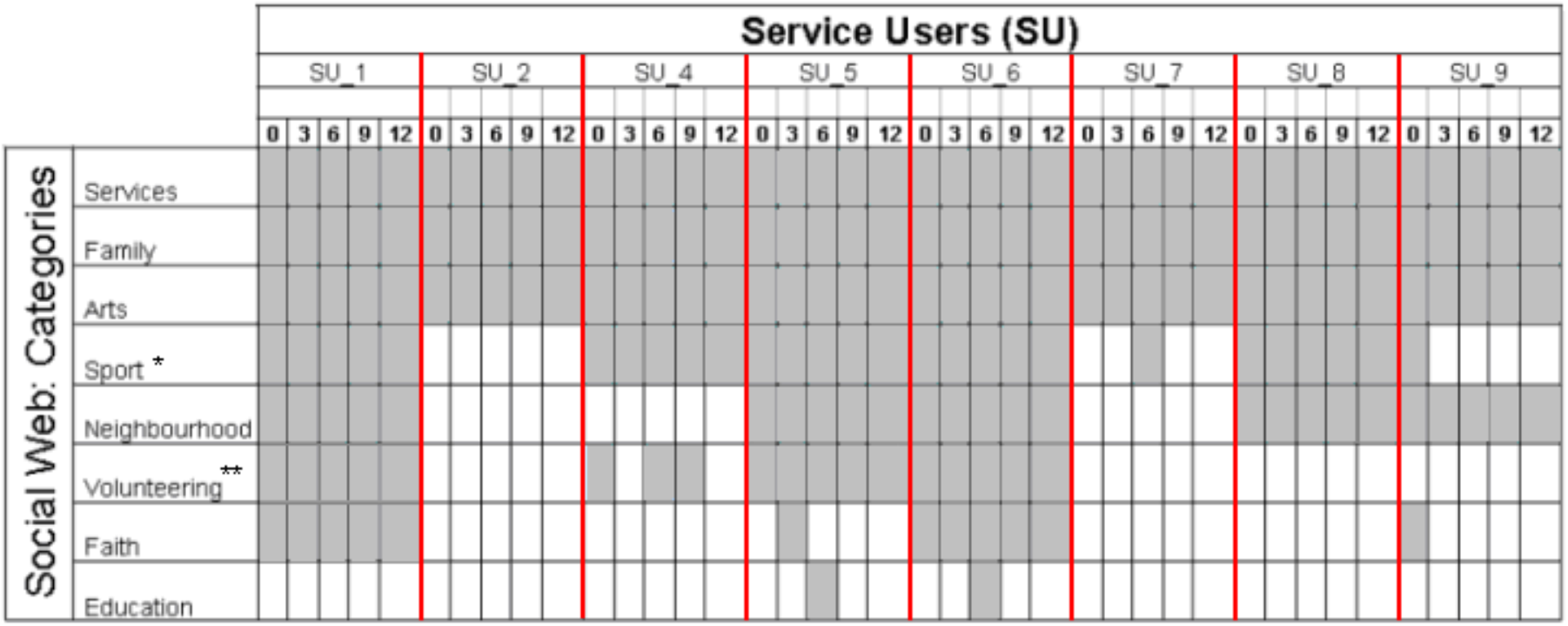
"Relationship" information was obtained by

- collecting data using an adapted Inclusion Web (Hacking and Bates [2008])
- observation of a range of activities in which staff and Service Users participated
- collecting data from Service Users' relatives.

### Inclusion Web

The data was obtained by interviewing Service Users and staff every three months over a twelve month period in order to discover who each Service User had met prior to interview. Each person encountered was then allotted to one of eight categories where the categories represent different parts of a person's social network. The categories are Neighbourhood, Education, Volunteering, Arts and Culture, Faith and Meaning, Family, Sports/Exercise and Services.

Table One represents the results for eight Service Users at the five time points where a shaded block shows that a service user has interacted with at least one person from a domain. The shaded box in the extreme upper left corner of the table therefore shows that SU_One has interacted with at least one person from the "Neighbourhood" domain at time point '0'. Conversely, an unshaded box shows that the client did not interact with a person from a particular domain.




* includes physical activity

** within the unit

*Table One: Service Users' Relationships by Category*

## Inclusion Web: Results

### Services

- The Service domain shows that all eight Service Users retained contact with a range of health and social care professionals from 0 – 12 months.

### Family

- The Family domain shows that all eight Service Users have maintained contacts with the family from 0 – 12 months.

    - Service Users also report that their family members visited the home and in some cases visited their relatives and/or went on outings with them.

*"My family are here regular..I would go up to my daughter. She picks me up and brings me back" (SU_Six).*

### Arts

- The Arts Domain shows that all eight Service Users interacted with people during arts and cultural activities where "Arts" activities include activities arranged by St Paul's and activities facilitated by external bodies. Within St Paul's, activities include Lunch Clubs, Reminiscence Therapy, Pampering sessions, Video Nights. External to St Paul's, one Service User attends photography classes whilst others visit the library, play pool and table tennis and another Service User attends football. There have also been ad hoc visits by the Rotary Club and trainers from the Workers' Educational Association (WEA).

One Service User also *expanded* her social network by meeting people on holidays and *maintaining* these contacts.

With reference to a holiday, the Service User describes the experience as follows:

*"Dancing, they got you up on the floor, they got you up on the stage, we met people, went shopping…." (SU_ Six).*

*"Everyone gets out at least once or twice a week.." (Staff_Six).*

### Sport/Physical Activity

- Five of the eight Service Users took part in some form of physical activity/exercise from admission and continued with this activity throughout the data collection period.

## Neighbourhood

- Five of the eight Service Users have maintained contact with neighbours from 0 – 12 months.

*"when my daughter takes me up to see, I would go round the houses…" (SU_Six).*

## **Volunteering** (within the unit)

- Three of eight Service Users maintained a willingness to volunteer from admission to twelve months where volunteering takes the form of helping more dependent service users to do things around the unit.

*" if we are busy doing something, she (another service user) will show them to the toilet or something…. (Staff_Seven).*

And in relation to a second Service User, another staff member says:

*"she would wash dishes after supper club – she always has to wash but she would dry. And now she does participate in tidying up…." (Staff_Six).*

## Faith

- Four of the eight Service Users maintained contacts with a person or people from whom they derived spiritual comfort.

Faith in the context of this section is not restricted to Christian activities but may include contacts with people who talk about wider spiritual concerns. Although faith and spirituality are by their nature difficult concepts to measure, it is a need which has to be addressed when Service Users talk about how they would like to practise their faith. Moreover, Shamy (1997) describes how religious rituals can be adapted so that they remain spiritually uplifting for the person with dementia.

*"The pastor's wife said to give St Paul's their number and they (St Paul's) have to contact them. They couldn't come in because they would feel that they are pushing" (SU_Six).*

## Education

- Two of the eight Service Users had learnt new skills.
    - One of the two attended photography classes.
    - The second Service User began to learn new crocheting skills.

**Recommendations**

**Staff should:**

- continue activities which help to maintain existing skills and which provided opportunities for Service Users to develop new interests.
- explore the viability of having each Service User assessed by an Occupational Therapist/Physiotherapist.
- develop a programme of "seasonal" activities which change as the seasons change so that the programme of activities is varied.
- explore the viability of offering low impact exercises like swimming.
- establish contact with a chaplaincy service where Service Users ask for their spiritual needs to be recognised.
- Investigate the possibility of organising festivals which are spiritual without necessarily being denominational.

## Observation

Four sessions were observed in which staff and Service Users interacted with each other.

Two of the observed activities had not been pre-arranged and two had been set up in order to meet a specific need.

### The Significance of Informal, Impromptu Activities

These activities involved meeting on an impromptu basis and developed into sessions where staff and Service Users conversed with each other.

Observational data was collected in order to:

- detect the existence of meaningful relationships.

Where an activity occurs spontaneously and interaction occurs during that activity, it is assumed that interaction points to the existence of meaningful relationships because people will not meet voluntarily unless they have things in common. This is known as the "Principle of Homophily" (Lin [2001])

- ascertain whether Service Users are included in activities.

### The Significance of Formal, Pre-arranged Activities

The activities were

- a Reminiscence Therapy session which was facilitated by a staff member
- a Video Night again facilitated by a staff member.

#### Reminiscence Therapy Sessions

Two rounds of Reminiscence Therapy were provided during the evaluation period with each round consisting of ten sessions. Each session was led by a staff-facilitator with sessions focusing on a specific theme which provided the topic for discussion.

Reality Orientation (RO) tries to orientate the Service User to time, place and person and generally takes place within a group context. Reality Orientation may employ props to either re-orientate the client or to reminisce about the past. RO may use Reality Orientation Boards which present basic information about the day, time, weather and season.

#### Video Nights

Video Nights occur as part of St Paul's regular programme of activities and involve clients and staff watching a film together which they have previously agreed to view.

## Methods

### Data Collection

The data was collected by defining an interaction as a conversation between staff and/or service users or the use of non verbal communication. (Attention was given to instances of non verbal communication because of Hubbard et al's (2002) work which has shown how people with dementia and increasing levels of cognitive impairment used non verbal communication to initiate interaction). The researcher therefore observed staff and Service Users' interactions and recorded only one instance of interaction between pairs of individuals within the network before using techniques from Social Network Analysis to tease out the nature of relationships within the network (de Nooy et al 2005). The techniques include a) drawing social network diagrams and b) superimposing the data onto a network grid or matrix.

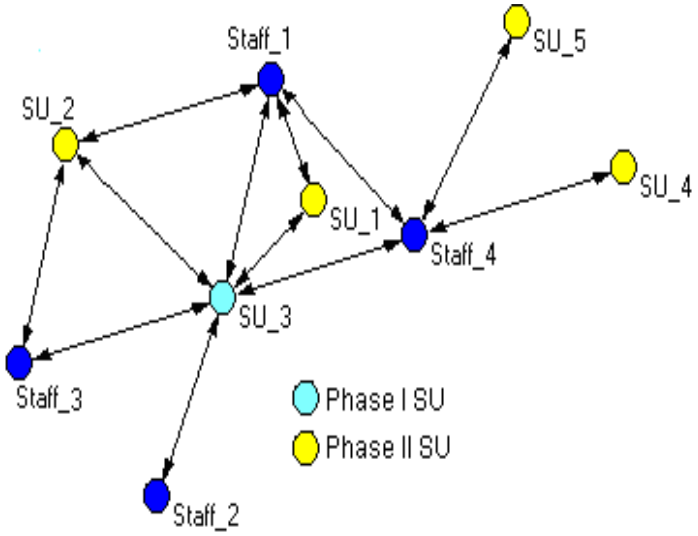
### Social Network Diagrams

The social network diagram is a representation of a social network in which individuals are shown as circles and relationships between individuals are represented by lines or "ties" between the circles. Specifically, circles represent either staff or Service Users and lines represent the relation "interacts with". Lines may therefore have single or double headed arrows where the former shows that the relationship is one way and the latter shows that an interaction is being

reciprocated. Circles are also colour coded by membership type and labelled in order to identify the presence of the same individual

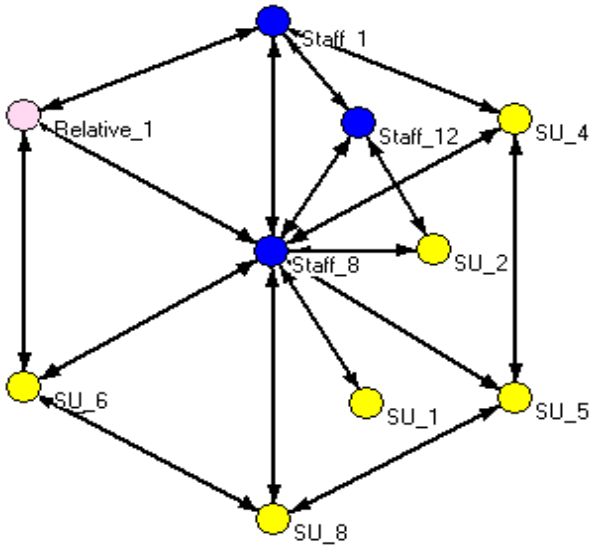
across different activities. Service User Three (SU_Three) therefore attends Activity One (Figure One) and can be identified as a Service User because their circle is shaded in yellow. Moreover, Service User Three interacts with Staff Members 1 - 4 and Service Users One and Two who reciprocate the interaction.

The researcher drew four network diagrams of the interactions between staff, Service Users and relatives for two informal activities and for the reminiscence therapy and video night sessions.




- <u>All</u> individuals interacted with <u>at least one</u> other individual;
- <u>All</u> ties were <u>reciprocated</u> – there were no individuals who were in the vicinity who were not engaging with the members of the group;
- Staff had more interactions with SUs than with each other.

Figure One: Network Diagram of Informal Activity One




- All individuals interacted with at least one other individual;
- Staff member eight acted as the facilitator of the session and therefore interacted with every participant.

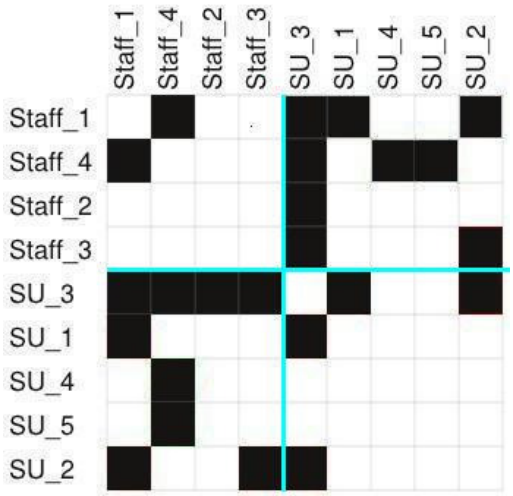
*Figure Two: Network Diagram of Reminiscence Therapy Session*

## Matrix

The matrix is a representation of the social network diagram which is used to detect relationships between individuals within the network. The matrix is divided into a series of cells where each cell represents an individual. The block in the upper left hand corner of the matrix in Figure Three represents staff member one (Staff_One). Cells which contain a black block therefore show that an interaction has taken place whilst a blank cell denotes its absence. By moving across the top row of Figure Three, one observes that staff member one interacts with staff member four and Service Users one, two and three. Because the rows and columns of the matrix represent the same individuals, the diagonal from top left to bottom right is always blank because our model assumes that individuals do not interact with themselves.

The network grid may be re-arranged in order to detect who interacts with whom on a range of variables i.e. role within Phase II, cognitive state, gender etc.

The matrices in Figures Three and Four were re-arranged in order to assess the extent of interaction between staff and clients.




- staff tend to interact with Service Users rather than with other staff members as seen in the clustering of black blocks on the top right diagonal in Figure Three

Figure Three: Matrix Diagram of Informal Activity One

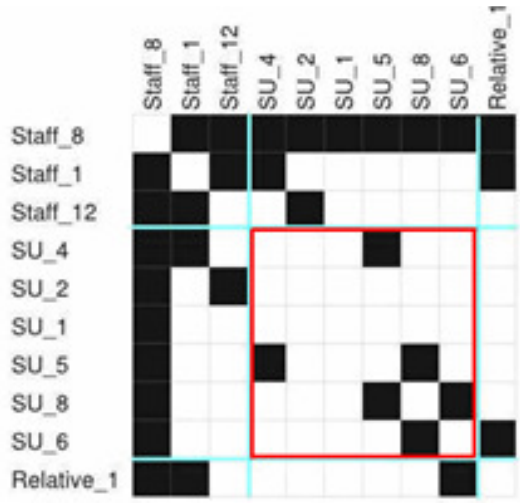


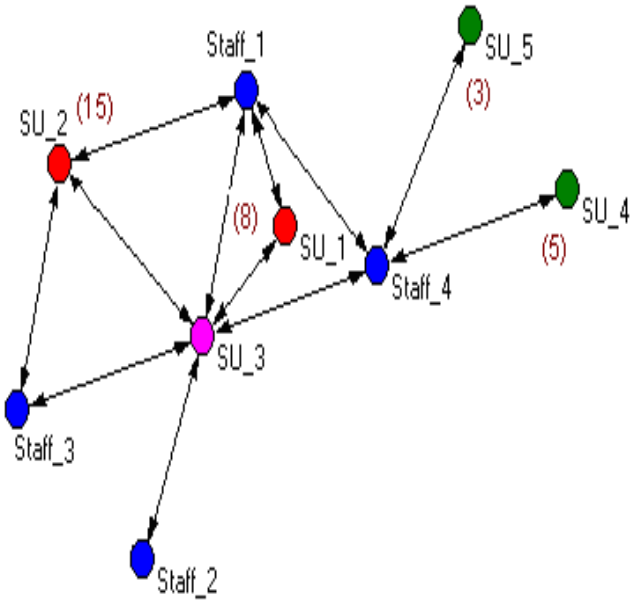

*Figure Four: Matrix Diagram of Reminiscence Therapy Session*

- Staff Member Eight interacts with all staff, Service Users and relatives as seen in the first row of the complete matrix.
- SUs don't tend to interact with each other but, where they do, interactions are reciprocated as seen in the distribution of blocks in the section enclosed by a red perimeter

The observational data therefore shows the complete absence of staff demarcation between staff and Service Users in so far as participation in activities is concerned. Although interaction between Service Users and staff is not uniform with some Service Users interacting more than others, this can be explained by the fact that staff were very aware and respectful of clients' right *not* to participate if they didn't want to.

## SU/Staff Interaction and Level of SU Orientation/Disorientation

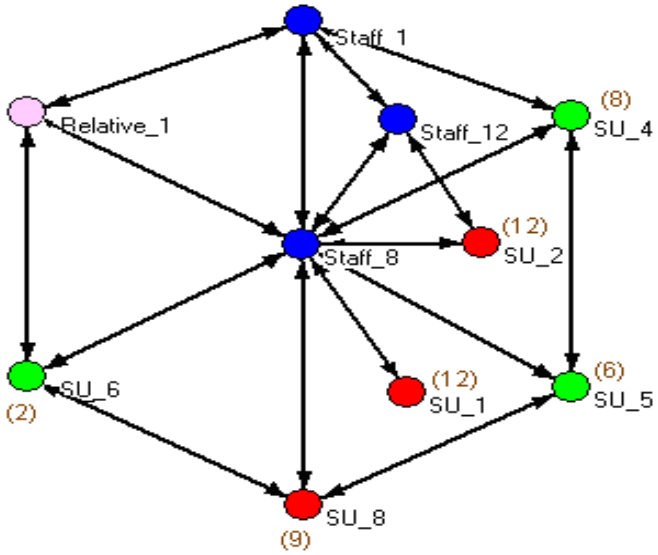
- Service Users were fully integrated into activities irrespective of their cognitive level.




- Figures Five and Six show that SUs with high Bristol Activities of Daily Living (BADLS)[1] orientation scores had *at least* as many interactions as those service users who were classified as 'disorientated'.

- This is a significant finding and differs markedly from the finding of Kuhn and Fulton el al (2004) who show that low participation in staff led activities is related to high levels of cognitive impairment – a phenomenon known as the "inverse care law".

*Figure Five: Network Diagram of Informal Activity One with Mean BADLS Orientation Score of 7.6*




Sus with BADLS orientation score showing a greater degree of disorientation

Sus with BADS orientation score showing a lesser degree of disorientation

SU from Phase I: no BADLS data available

(no): individual BADLS orientation scores

Figure Six: Network Diagram of Reminiscence Therapy Session with Mean BADLS Orientation Score of 8.1

[1] The BADLS orientation score is the sum of Service Users' scores on five questions relating to orientation to time, place, ability to communicate, to participate in hobbies and to use transport with higher scores representing greater degrees of disorientation.

## Recommendations

## Staff should:

- continue to encourage Service Users to participate in organised and ad-hoc activities.
- think about the number of people who can participate in a session.
    - beyond a certain size, the number of interactions which a person can have is limited (de Nooy et al 2005 p. 63).
- consider whether activities are appropriate to SUs with middle to late dementia.
- consider whether one-to-one work may be needed.
- decide whether an assessment of any communication problems and/or dyspraxias may have to be undertaken before a Service User can be matched to appropriate activities (Brooker 2008).

### Making New Friendships

Three of the four Service User Representatives said that their relatives had made friends with other SUs in the unit.

*"Made friends with other residents - much to our amazement as she always has difficulty making friends" (SURep_One).*

*"She is very friendly and makes friends easily and she enjoys the company" (SURep_Two).*

*"Our relative gets on well with the other residents having tea with them at least once a week and lunch at the lunch club. He has developed very good friendships with most of the staff" (SURep_Four).*

# 3. Meaningful Daily and Community Life

This chapter examines:

- the *breadth* and *appropriateness* of social/recreational activities offered in St Paul's Phase Two.

## Key Findings

- Four (100%) Service User representatives who completed the Service Users' Representative Survey 2009 felt that the range and quality of services was either good or above average.
- One Service User representative felt that Agency staff demonstrated a lack of commitment although there is no additional data from other relatives or other sources to corroborate this impression.

## Method

The data was collected by administering a survey to Service Users' relatives and by taking account of the interview testimony of both St Paul's Phase Two staff and clients.

### Views from Service User Representatives

A Service User (SU) Representative Questionnaire was administered to eight family members in October 2009.

Four SU representatives (SURep) replied representing a response rate of 50%.

4 (100%) respondents thought that the range of services was either excellent or good.

*"By being in St Paul's, our relative can attend a local Day Centre where he is engaging his hobbies" (SURep_Four).*

4 (100%) respondents thought that the quality of services was either excellent or above average.

*"St Paul's are giving my mother every opportunity to develop" (SURep_Three).*

3 (75%) report that social/recreational needs were fully met with one respondent reporting that social and recreational needs were partly met.

*"Overall, we are happy with the care and facilities at St Paul's" (SURep_One).*

One respondent also felt that the use of Agency Staff should be discouraged because of a perceived lack of commitment.

*"No Agency staff please – not the same commitment….She is very happy and content with the employees of St Paul's. Agency staff can be a challenge in some cases" (SURep_Three).*

The perception of the frequent use of Agency staff was also corroborated by the staff members.

*"The agency staff have been there really from the beginning. There is the odd one. It is hard for the staff trying to show somebody new the ropes and you are trying to do your work as well." (Staff_Seven)*

A second staff informant also refers to the desire to do Life History work with the Service Users but feels constrained by the lack of time. This informant doesn't refer specifically to the use of Agency staff but the implication is that the absence of permanent staff makes it difficult to perform "best practice" activities.

*"I would love to do the life story work. That's an example where I think the clients would benefit because I would love to say, right, I have the time…" (Staff_Two)*

## Staff and Service User Views

The impression that St Paul's Phase Two offer a wide range of services which are appropriate to the needs of Service Users is confirmed by staff and SUs who reported in a series of informal interviews how St Paul's Phase Two provides a range of structured activities, the opportunity for service users to maintain their connection with non Praxis Care Day Centres and the chance to participate in impromptu activities whenever the Service User wants.

*"Oh, we sit and have a yarn…. sometimes you play like you know bingo… I go on trips" (SU_Eight).*

*"We play skittles. When we go in, we have a cup of tea. And then we have our dinner. And then we have another cup of tea and then a game of bingo.." (SU_Six).*

*"We are having music night. The Rotary Club are coming in. We are having a Choir and Music night. Then, oh I think St Patrick's High School are coming in – so actually there is a lot going on" (Staff_Two).*

"There are two who go down to the Day Centre – there is one gentleman who just goes on the Monday. There is one gentleman who goes Monday to Friday, another gentleman, he goes, is it Monday, Tuesday, Thursday and Friday. Mainly, pampering them, do nails and their hair, make up, take them out" (Staff_Six).

In terms of the programme of pre-arranged activities, other examples include Reminiscence Therapy with a Workers' Educational Association employee leading each session, video nights, lunch clubs and pampering sessions.

Staff are also responsive to the particular interests of the Service Users and are willing to adapt existing programmes or initiate activities for individual interests on the basis of client feedback.

*"we are going to make out a form and we are going to ask the project work staff to go around all the different tenants and ask what they would like to do on a one to one basis" (Staff_Two).*

One Service User also said that he "would like to do a photography class" (SU_Four) and was given the opportunity to pursue his interest.

*"so, I'll go in and sit down and talk about cameras. And I'll say "That's a brilliant photo you took. Do you have to think about the light?" And he'll talk me through it and I do find that that one on one time his confidence in his own ability grows." (Staff_Three)*

One staff respondent did however refer to those Service Users' who used non Praxis Care Day Centres without being sure what the clients do at these facilities.

*"I have asked the Day Centre would they send me up a programme that they do and I'm still waiting but basically what they do is, they go down and they go in the mornings about eleven, have a cup of tea like and they do different activities like paint and crafts and things like that. Then they stop for lunch, then in the afternoon they would do different activities" (Staff_Three)*

## Recommendations

## Staff should:

- nominate an "activities coordinator" to be responsible for the management and implementation of activities and review the frequency and appropriateness of activities on a regular basis.
- continue with a programme of reminiscence therapy.
- practise informal reminiscence when working with Service Users.
- re-start life history work for appropriate Service Users.
- produce memory wallets for SUs which contain pictures and sentences about the their past (Bourgeois 1992).
- use appropriately trained and vetted volunteers to run reminiscence therapy sessions and to do life history work where staff are unable to perform these activities.
- request a programme from external facilities in order to confirm what they are offering and to assess how St Paul's can offer activities which are complementary.
- reduce the frequency with which Agency staff are used or ensure that the same personnel are used in order to guarantee continuity of care.

# 4. Personalised Support and Care

This chapter examines the degree to which St Paul's Phase Two staff:

- deliver personalised care

## Key Findings

- Staff interviewees demonstrated a commitment to the delivery of care which avoids inflexible routines and is focused on the needs of the client.
- There was a tension between caring for the client and assisting them to maintain their independence. This tension may be explained by the wide cognitive capabilities of Service Users within the unit.
- Staff were confident of the unit's ability to care for the Service Users where the unit can access external care packages or Praxis employees with a variety of skill sets.
- Challenging behaviours were dealt with on a case-by-case rather than generic basis.
- There were six Medication Errors between April 2009 and March 2010.

## Method

The data was collected by conducting interviews with eleven staff members and by examining the Critical Incident data.

### Routines

An inflexible, task orientated routine is noticeably absent with staff being acutely aware of the need to fit in with clients' established routines.

*"Most of them would be up early. There is a gentleman who would lie on during the weekend. You would go in to give him his medication and breakfast and he wouldn't get up until may be two in the afternoon" (Staff_Seven).*

*"I would usually see if they fancy something for their breakfast – make them whatever they fancy at that time" (Staff_Three).*

One respondent was aware of the need to encourage and maintain Service User independence whilst being conscious that relatives can have the perception that the support worker *does* things for a client rather than *assists* them with an activity.

*"There are certain family members of residents who, with all the best intentions, want their brother, sister, mother, father cared for" (Staff_Three).*

There may therefore be a tension between providing supported assistance for a Service User in keeping with the objectives of the unit and attempting to meet the expectations of relatives who may perceive "support", "social care" and "nursing care" to be labels for an equivalent level of assistance.

A number of staff also seemed to be unclear about the precise purpose of the unit.

*"I'm still trying to grasp what the scheme is actually about…. Because I thought it was to be mild to moderate but I have heard people saying that this is for oh moderately to severe…." (Staff_Two).*

*"I think the Trust thinks this is residential rather than supported living" (Staff_Six).*

*"I'm not sure of my role" (Staff_Seven).*

## The Challenge of Increasing Cognitive Impairment

There was a consensus among staff respondents that Service Users could present challenges for the staff where cognitive impairments become more acute although the majority view was that Service Users would be able to remain in situ in St Paul's provided that the right care package was in place. One respondent felt that the skill mix of staff could be improved by the employment of staff with a wider skill mix.

*"I think the care packages from external staff work extremely well" (Staff_Three).*

*"I just feel a broader skill set wouldn't be a bad thing. But I suppose on the flip side, we have to think that it is community living and people don't have a nurse in their own home in the community" (Staff_Two).*

The lack of clarity among staff about their roles is interesting in view of the fact that a unit which supports Service Users would look very different to a unit which takes an extremely proactive approach towards people with dementia offering programmes which deliberately attempt to influence the course of cognitive decline. Examples of interventionist strategies of this type include cognitive training which involves the practice of standardized tasks in order to target a particular area of cognition, cognitive stimulation which involves service users participating in activities and cognitive rehabilitation which aims to maintain cognitive functions (Oyebode and Clare 2008).

Staff were also aware of the need to avoid generic interpretations of challenging behaviour and to interpret behaviours on a *case-by-case* basis.

*"So I think as a staff team, we do try our best to understand where the service user is coming from. We don't say, she's aggressive, get her a diazepam" (Staff_Two).*

Staff respondents felt that their ability to deal with behaviour on a case-by-case basis could be consolidated by offering specialised, practical courses which honed in on a particular aspect of caring for the person with dementia.

*"I think something like cognitive skills. How you could help improve or maintain things like that. So are there actual specific strategies that we could be doing as a staff team that we are may be not aware of" (Staff_Two).*

*"There is a course on person-centred dementia. And the dementia unit in Belfast has organised that – the research centre. I think there would be great learning in that and I could take that back to the*
*scheme so I think things like that would be good because they are specifically focused on dementia" (Staff_Two).*

Staff also recognised that cognitive deficits may not necessarily be matched by deficits in other areas and that Service Users may be able to continue to wash, clean and perform other activities of daily living under supervision.

This mismatch between cognitive deficits and functional abilities like cleaning, washing etc can be shown by cross-referencing staff perceptions of SUs' ability to self care with the Bristol Activity of Daily Living Scale (BADLS) orientation scores which were taken at the point nearest to the interview date.

BADLS scores may range from 0 – 15 with 0 denoting orientation and 15 denoting disorientation.

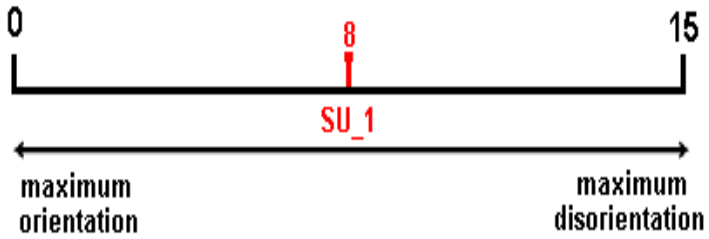



Figure 7: BADLS Score of 8 for SU_1 (Mean Score: 7.5)

*"She cleans. She is a big part of the scheme. She hoovers, she mops the floors."*

*Staff 6 referring to SU 1*

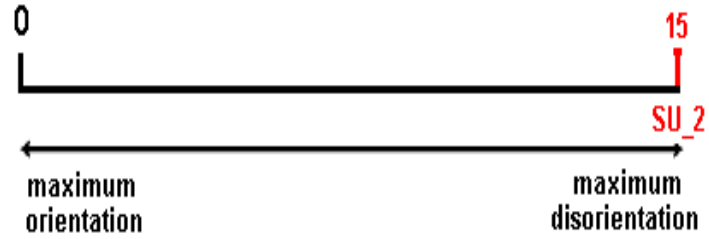



Figure 8: BADLS Score of 15 for SU_2 (Mean Score: 7.5)

*"Dancing – SU_Two loves dancing. If you put old music on, it's amazing how she sings away."*

Staff 11 referring to SU 2

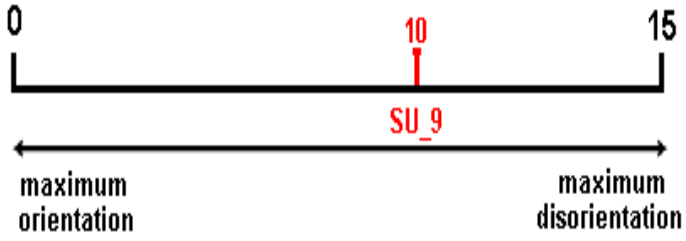



Figure 9: BADLS Score of 10 for SU_9 (Mean Score: 7.5)

*"..comes to Lunch Club and now, they go out to all the activities. You know, the likes of the trips to Newcastle, Donaghadee and the potteries…."*

Staff Six referring to SU 9

What is significant is that staff report that Service Users can do things whereas the quantitative BADLS data would suggest a lack of functionality *if analysed in isolation* from the other evidence.

**Medication Errors**

- there were 6 Medication Errors for the period accounting for 40% of all Critical Incidents and Incidents between April 2009 and March 2010.

- 5 (83%) of the 6 Medication Errors occurred in the second half of the period between September 2009 and March 2010.

However,

- the qualitative data shows that corrective action was taken following each error.

- of ten thousand one hundred and forty medicines administered to Service Users in both phases, six errors were made in St Paul's Phase II and one error was made in Phase I which represents an error rate of 0.07%.

## Recommendations

## Staff should:

- ensure that relatives understand the purpose of supported living.

- ensure that they understand their role.

- try to upskill by attending specialist in house or external courses. Such courses could include the:

    - identification of those behaviours which are associated with particular types of dementia.

    - communicating with Service Users who no longer use language.

- disseminate any learning from training sessions to colleagues who couldn't attend the session.

- be aware that if quantitative assessment tools – MMSE, 6CIT etc – are used to assess functional capability, that there is a possibility that these tools may *over-estimate* client deficits.

- access workshops which provide ADL skills training so that they can promote independence in personal care e.g. workshops using the Pool Activity Level instrument (Pool 2002)

# 5. Personal Identity and Self Esteem

This chapter examines how staff have taken steps to promote the *personal identity* of the Service Users.

## Key Findings

Staff try to respect the personal identity of their clients by:

- actively listening to their requests.
- by using systematic tools like ABC Charts to study behaviour.
- by creating a space in which Service Users can pursue their own interests and explore new pastimes.

## Method

The data was collected by interviewing staff.

### Contextualising Behaviour

Sabat and Harre (1992) distinguish between the self which is constructed by the person and selves which are constructed by others. In a situation where staff assume that they know about a Service User's background and about his or her personality, there may be a tendency to give superficial explanations of behaviour rather than to think carefully about why some clients behave as they do.

However, the qualitative data shows how staff try to understand their clients by learning about their history before admission to the unit because of the belief that a person's past life may provide a clue to their current behaviour.

One notable example of the attempt to contextualise behaviour occurred where staff tried to understand how a particular client's behaviour could be linked to the association in the client's mind between a staff member and a person from the client's past.

*"Let me just give you an example if I can. Client "X" was not aggressive but was more resistant to one of the workers so we were trying to work out why this could be."*
*(Staff Member Two)*

### Systematic Observation

A second staff member also describes how staff try to place client behaviour in context by using Antecedant Behaviour Consequence Charts (Thompson 2006).

*"And once that kind of ABC work has started with that lady, the staff were then recording what the trigger behaviour was, what they did, so that they have got a record in her file of how they dealt with that." (Staff_Eight)*

Staff may abandon the attempt to get to know their clients because of the assumption that staff/client interactions are too difficult. (Bowie and Mountain). However, Innes and Capstick (2008) provide advice on how to interact with clients who have a variety of communication problems. The relevance of their research is that it *is* possible to communicate with clients with cognitive deficits and that one can therefore avoid labelling by listening carefully to what a client says.

Indeed staff members did describe how they or others had used active listening skills in order to understand what their clients wanted.

*"Absolutely, and I mean the other day we went over and SU_Four and I had a really good chat. May be some of it wasn't coherent but she was telling me about her job and she was laughing and joking about it" (Staff_Two).*

## Practising Hobbies and Acquiring New Interests

The evidence from Chapter Two also shows how St Paul's provides a space in which Service Users can continue to pursue their established interests or develop new ones.

- SU_Five attends photography classes which he began to attend after moving to St Paul's.
- SU_Six has taken up knitting again after abandoning the activity prior to admission to St Paul's.
- SU_Eight attends football matches with a friend.

# 6. Home and Personal Surroundings

This chapter examines:

- the degree to which the Phase II building meets the needs of the service users.

## Key Findings

Of the Service User representatives who completed the Service User Representative Survey:

- all respondents felt that the Service Users' accommodation, the communal spaces and the external buildings were either above average or excellent.
- the Phase II atrium is insufficiently used.
- staff interviewees felt that the clients would benefit from having an external, safe space.

## Method

The data was collected by:

- interviewing staff;
- examining the quantitative and qualitative data for the Service User Representative Survey;
- analysing the number of falls within the unit.

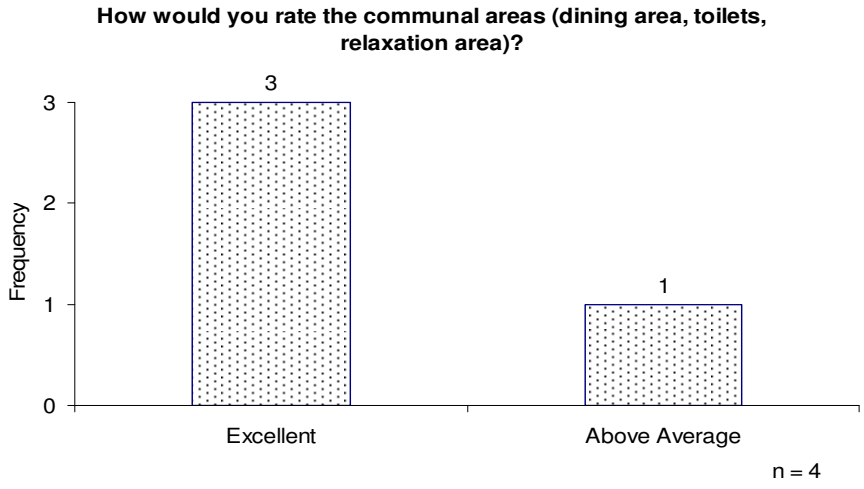



*Figure Ten: Relatives' View of St Paul's Communal Facilities*

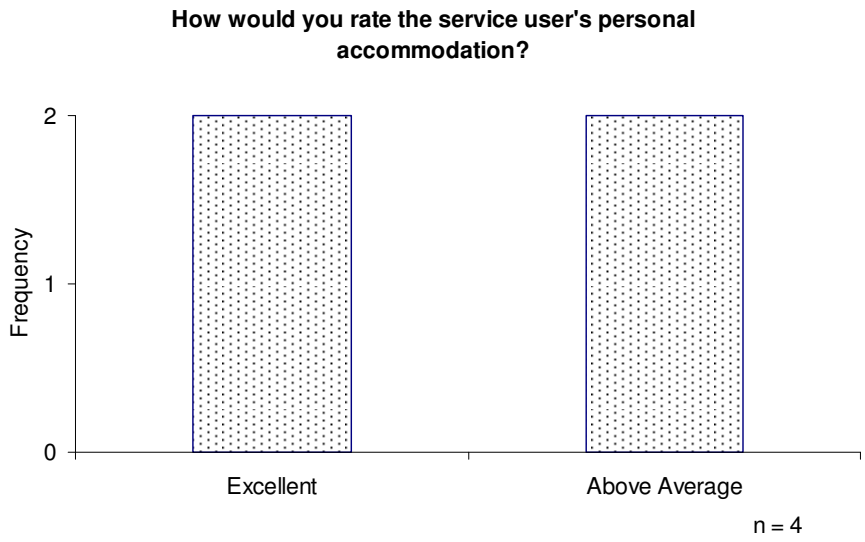



*Figure Eleven: Relatives' View of Personal Accommodation*

## General Design

Two staff members suggest that the decision to arrange the apartments around an Atrium may confuse some Service Users – a not unreasonable view because of the fact that there are few physical cues which clients can use to orientate themselves within the unit. Moreover, because it is not possible to look outside when positioned in the atrium due to the windows being positioned in the roof space, clients may find it difficult to use external physical cues to re-orientate themselves.

*"I think may be more windows outside as opposed to up there (interviewee points to the ceiling) (Staff_Eight).*

*"I would have designed it..so that the apartments were may be in the centre..and the seating area was on the outside" (Staff_Nine).*

## The Atrium

Three of the four staff who expressed an opinion about the Atrium or large public space felt that it is either too large or is not sufficiently used. One could argue that St Paul's Phase II does not meet some of the features of good design because of the absence of a variety of rooms which meet a variety of functions (Marshall 2008 p. 180).

*"but there is one communal sitting room and I know that there is thought behind that but there is something I don't like about the fact that when you come out of your room you just sit in the communal room or you sit in your room" (Staff _Three).*

*"I think separate rooms. I think that there is a lot of wasted space in that common room - it could be utilised so much better. And having may be a room that is devoted to reminiscence stuff you know. I watched some programme on another unit that had the old stuff dotted about on the walls. I think that space is wasted." (Staff_Eight).*

*“It’s not getting used to its full potential. But then again, they were thinking of having like Day Care and then when the previous manager was here, when it was all getting set up, she wanted dividers so*
*that it was all different wee areas. But we could not get them and then we had no time” (Staff_Fourteen).*

In contrast, one staff member felt that the existence of the Atrium gave Service Users the option to socialise or to retain their privacy by staying in their apartments.

*"I think there is something nice about the communal space. What I like about it is. You have your own flat. If you don’t want to come out, you don’t have to. With the communal area you can take as much or as little of it as you want" (Staff Two).*

### Phase II Facilities

One staff member thought that the wide corridors were an example of a positive design choice.

*"There is a lot of things about Phase II that I can see, dementia research has been taken in – wide corridors and things like that” (Staff_Two).*

### Bathrooms

Each of the apartments has ensuite facilities so that the Service Users do not have to walk down the corridor to the bathroom. There is also an assisted bathroom but two staff members report that it isn’t fully used because of the absence of a hoist.

*"The bathroom can’t be used because there are no aids there and the tenants have voiced their opinion. They would love a bath. These tenants don’t like showers" (Staff_One).*

*“We need a hoist for the assisted bathroom” (Staff_Ten).*

### IT Equipment

Moving between the Phases in order to do paper work seems also to be necessary but could be lessened if a computer was available in Phase II.

*“We need a computer over there, we need a photocopier over there, we need a filing system." (Staff_Two)*

## Exterior

The majority of staff interviewees who expressed an opinion felt that a secure, safe, external space needed to be developed.

*"The only place they make use of is the space where the tables are in the summer time although I feel out the back, it could be made nice and private. That enclosure, because it's padlocked, that could be made into a permanent seating area" (Staff_Nine).*

*"Something else would be an outdoor area that needs made safe and then we need to look at say raised beds or something so that people can do a bit of gardening" (Staff_Ten).*

*"It would be lovely, it would be fantastic. We could get potted plants. They would love that. And it's not very fair sitting them out there with people coming and going in the car park. What privacy is that for the tenants" (Staff_Eleven).*

*"I think a bit more space on the outside. Having a whole big open area and having may be the common room a bit smaller." (Staff_Fourteen)*

A safe external space may also be useful by helping to defuse aggressive behaviour.

*"And that's when a client gets really angry, she wants out that door so nothing will satisfy her. If she had an open courtyard, if she could walk out and be secure…." (Staff_Eleven).*

## Working between the two Phases

There was no consensus among the staff in relation to the advantages and disadvantages of working across both Phases. One staff member reported that it was difficult making the transition between Phases after spending sustained periods of time in the other phase.

*"Sometimes when you come back, so much has changed. You do a week over there and a week over here. So you come in and have to start all over again" (Staff_Eleven).*

A second staff member also felt both Phases should operate as separate schemes but did not elaborate any further.

*"I think, it would've been better just as one Phase. I know it still is one scheme but you can't deny that there are two Phases; it is very hard. I think we would be better having two different sets of staff (Staff_Fourteen).*

Working between two Phases can also impact negatively on the Service Users because of the lack of continuity of care with one staff member putting this down to the way in which shifts are allocated.

*"It depends on the way the task sheet is and where you are. Now one of the ladies down there, she is quite aware. We would have had a routine, we would have gone into her at night and I was in there the other night and she said, 'I haven't seen you for ages. You see people here and then they disappear" (Staff_Nine).*

Conversely, a fourth staff member felt that working between both schemes meant that the job is more stimulating than it would otherwise be.

*"I think it's a good thing because – even Phase I and Phase II can be deceptive because they are so close and for instance, I know today that two of the tenants from Phase I are in Phase II for the afternoon. So it is a good atmosphere and it allows the staff a change of scenery and keeps you on your toes and I think very much, and more importantly, it allows the service users to give their head peace of the staff" (Staff_Three).*

**Falls**

- there was one Fall between April 2009 and March 2010.
- the qualitative data shows that the fall did not involve an admission to hospital, no injury was sustained and a review of the incident was held within a week of its occurrence.
- the fall occurred at the start of the observation period and did not occur again during the rest of the study.

Although falling may not necessarily be associated with a client's cognitive state (Parsons 2008), one may surmise that the near absence of falls at St Paul's points to the existence of assessment procedures which effectively manage those who may be at risk. The low incidence of falls at the time of writing does not however preclude the possibility that they may increase in the future. However, exercise programmes have been shown to reduce falls in community settings (Sherrington, Whitney et al 2008) and may be a useful precautionary measure which St Paul's staff could introduce.

## Recommendations

## Staff should:

- use an assessment tool like EVOLVE (Torrington et al 2008) in order to:
    - determine whether an established building meets the needs of people with dementia.
    - design buildings which meet the needs of people with dementia before they are built.
- partition the Atrium by function so that the clients have the opportunity to use the "TV Room" or the "Games Room".
- establish an Alzheimer's Café which would meet on a monthly basis for the "purpose of emotional support, education and social interaction" (Anon 2010).
- encourage the wider community to use the Atrium in order to increase the frequency with which it is used without compromising the unit's obligation to protect vulnerable adults.
- take steps to ensure that the communal bathroom is appropriately equipped.
- take steps to ensure that Phase II has a computer and photocopier so that the "Nurses' Station" can be used.
- identify a suitable space within the grounds which could be used as a garden.
- investigate whether it is viable for Phase II clients to help Phase I Service Users who have a garden.
- introduce a balance training programme at an early stage in the dementia pathway for each SU before the propensity to fall increases.

# 7. Personal Authority and Control

This chapter examines the degree to which:

- Service Users are consulted about changes which may affect their lives.
- Service Users initiate change.

## Key Findings

The Service Users can:

- personalise their apartments.
- suggest changes to the daily routine.
- suggest changes to the programme of activities.
- challenge staffs' current understanding of their capabilities.
- avail of the support of relatives who often advocate on their behalf.

### Methods

The data was collected by:

- interviewing Service Users.
- Interviewing staff.
- diagramming the distribution of a selection of possessions in SUs' apartments.

## Staff Views and Choice

There is ample evidence both from staff and Service User interviews that the latter have some control over how they live.

*"I think so. I think that there is quite a good respect for the importance of personal choice Yea I do, I think that service users have a vast say in what they eat, what they wear, whether they go out"*
*(Staff_Three).*

*Most of them would be up early. There is a gentleman who would lie on during the weekend. You would go in to give him his medication and breakfast and he wouldn't get up until may be two in the afternoon." (Staff_Six).*

Staff also take account of Service Users' view of activities and will amend the programme of activities where responses show that there is a need which has not been met.

*"I know that "staff member A" had gone round and asked everybody what kind of things they would be interested in..I think things like the nails, the pampering, the beauty was brought in as a result of that research. So I think the staff here are very proactive" (Staff_Eight).*

Service User Eight also notes that one can participate in an activity by simply asking that it is provided.

*Interviewer: "And do you go anywhere else outside of St Paul's?"*

*Respondent: "No – I go on trips."*

*Interviewer: "And would you like to?"*

*Respondent: "Oh aye, but it's only a matter of saying you know."*

## Choice and Safety

Staff were also willing to take account of an SU's wish to maximise his or her personal freedom.

*"Well, I think the premise is that there is a lady here who has mild dementia and she did want to go out on her own and a review was called and it was decided that, it was put to the lady; "no sorry, you can't go out of here by yourself" which she accepted" (Staff_Eight).*

Although the interview data shows that the Service User wasn't able to become more independent on this occasion, the scheme does have mechanisms in place to consider what the SU would like to do. It is not clear however whether a Service User's wish to do things independently can be reconciled with the staff's responsibility to keep SUs safe.

**Personalising Apartments**

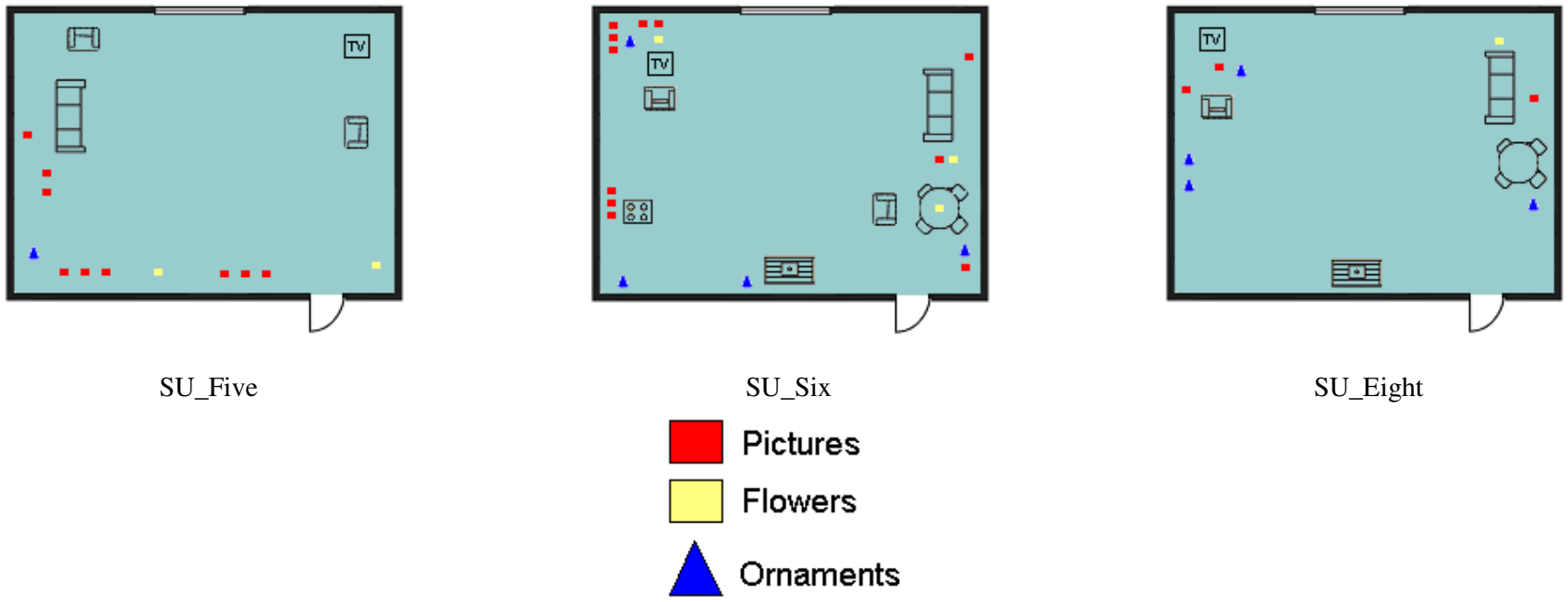



*Figure Twelve  Distribution of a selection of personal items in service user apartments*

Figure Twelve shows how three Service Users have personalised their  apartments using pictures, flowers and ornaments. The difference in the distribution of personal effects between the three diagrams shows that a) the SUs have made these personal spaces their own and b) that the culture of the unit is such that this is actively encouraged.

## Recommendations

## Staff should:

- encourage Service Users to be vocal about their concerns using techniques which are appropriate to the person's cognitive state. Group interviews and individual interviews may be used in the early stages of cognitive decline (Bamford 1998, Sperlinger and McAuslane 1993)

- acquire "careful listening" skills which will be useful for canvassing the views of Service Users with more severe cognitive deficits.

- act on the views of users which may already be available through Views from You.

# 8. Conclusion

### Meaningful Relationships

- All eight Service Users maintained contacts with their family members. This is important because of the negative impact which a diagnosis of dementia often has on the family circle.

- The Service Users' relatives referred to the positive impact which the placement of their loved one had had on their own lives outside of the unit with a number observing that they had been able to consolidate or re-establish other relationships.

- All Service Users who participated in activities were fully integrated into each session. There was therefore no relationship between being cognitively impaired and the level of participation in activities. This is a significant finding which contradicts the view that people with significant impairments receive low levels of input by the staff.

### Meaningful Daily and Community Life

- The unit offers a range of activities which are appropriate to the interests of the Service Users and steps are being put in place to review the activities programme at regular intervals.

- Service Users' relatives report that the range and quality of services was at least good although one relative was concerned about the use of Agency Staff.

- Agency Staff form an important part of the work force with their continued use perhaps having cost implications for St Paul's and practice implications for Service Users.

### Personalised Support and Care

- The interview data shows that staff were clearly committed to the delivery of personalised care with staff moving away from the use of task-orientated, non-SU focused routines.

- The Incident data shows that the number of falls was low and that a pattern of recurrent falls was absent.

- Service Users maintained some ability to look after themselves irrespective of their level of cognitive impairment. This is an important finding which shows that SUs can maintain a degree of independence beyond normal levels of cognitive functioning.

- Staff report that Service Users are functionally more capable than the quantitative BADLS data would suggest *if analyzed in isolation* from the other evidence.

- Staff were unclear about the purpose of the unit which is an interesting finding in view of the fact that the support provided by staff may be different in units which provide supported care, social care and nursing care.

### Personal Identity and Self Esteem

- St Paul's provides a space in which SUs can pursue their own interests and pastimes.

- Staff try to protect the individuality of the SUs by using methods like ABC Charts to systematically study behaviour which may not be immediately explicable.

## Home and Personal Surroundings

- 4 (100%) relatives of the Service Users felt that their loved ones' personal accommodation was excellent.

- The public space or Atrium was not used effectively or regularly.

- Use of an assessment tool like EVOLVE may identify potential building designs or existing structures which are suitable for people with dementia.

## Personal Authority and Control

- Service Users are consulted about changes which may affect their lives.

- Service users initiate change in certain circumstances.

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# Appendices

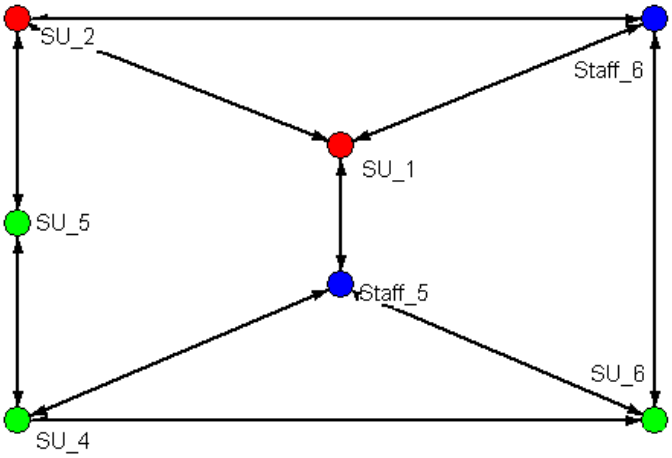



Figure Thirteen: Network Diagram of Informal Activity Two

- All individuals interacted with at least one other individual;
- All ties were reciprocated – there were no individuals who were in the vicinity who were not engaging with the members of the group;

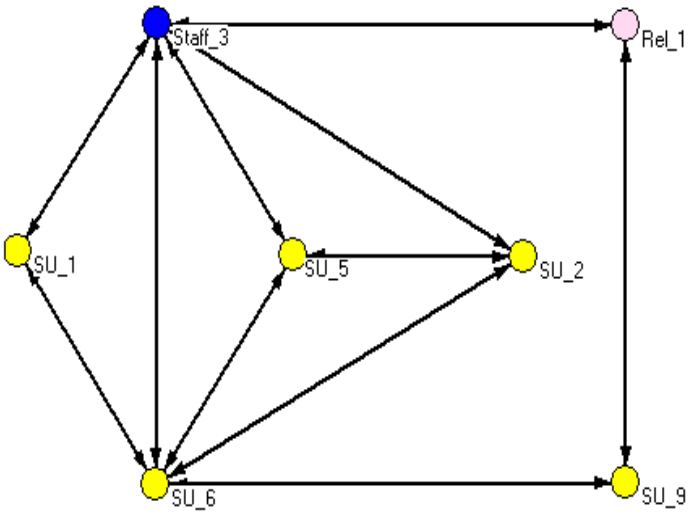



Figure Fourteen: Network Diagram of Video Night

- All individuals interacted with at least one other individual;
- All ties were reciprocated – there were no individuals who were in the vicinity who were not engaging with the members of the group;

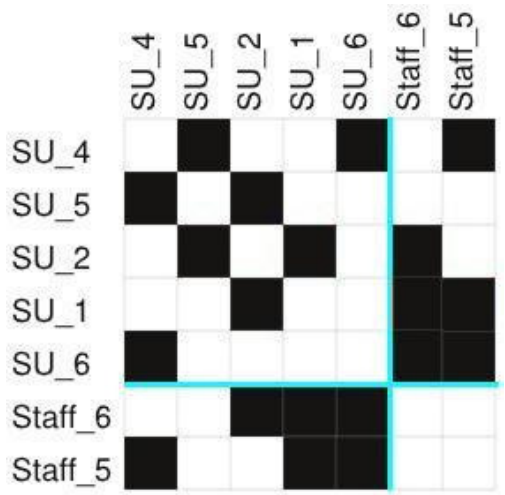



Figure Fifteen: Matrix Diagram of Informal Activity Two

The matrix for Figure Fifteen shows that:

- staff interactions are directed exclusively towards the service users in Informal Activity Two.

    a. Observe the complete absence of blocks on the bottom right diagonal in Figure Fifteen.

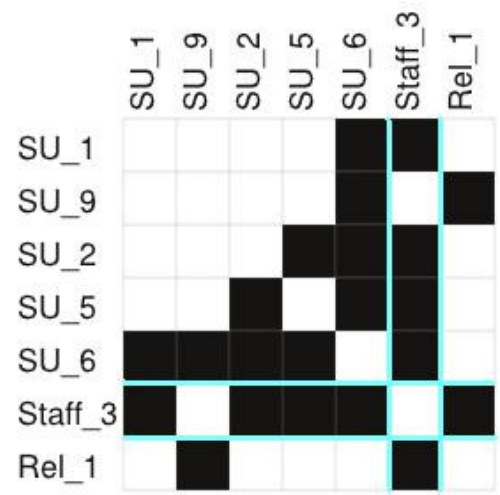
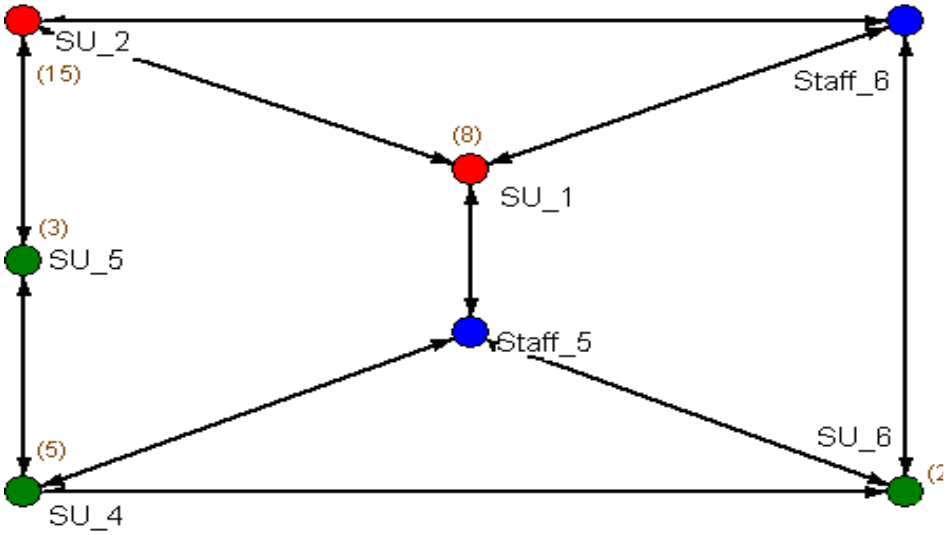



Figure Sixteen: Matrix Diagram of Video Night

The matrix for Figure Sixteen shows that:

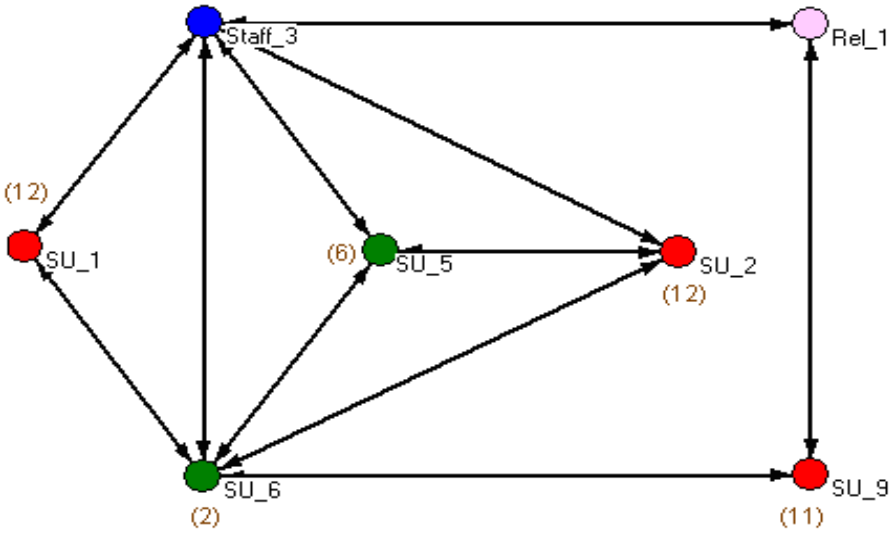
- Staff Member Three interacts with four of the five service users and with one relative.

    a. Refer to the second row from the base of the complete matrix.




- Figures Seventeen and Eighteen show that SUs with high Bristol Activities of Daily Living (BADLS)[2] orientation scores had *at least* as many interactions as their peers with lower scores

Figure Seventeen: Network Diagram of Informal Activity Two with mean BADLS score of 6.6




SUs with BADLS orientation score showing a greater degree of disorientation.

SUs with BADLS orientation score showing a lesser degree of disorientation.

(no) Individual BADLS orientation scores.

Figure Eighteen: Network Diagram of Video Night with Mean BADLS score of 8.6

[2] The BADLS orientation score is the sum of service users' scores on five questions relating to orientation to time, place, ability to communicate, to participate in hobbies and to use transport with higher scores representing greater degrees of disorientation.