Home Visits: A Reflection on Family Contact in a Specialist Forensic Intellectual Disability Service

Journal:	*Advances in Mental Health and Intellectual Disabilities*
Manuscript ID:	AMHID-02-2015-0010.R1
Manuscript Type:	Research Paper
Keywords:	LEARNING DISABILITY, FORENSIC, FAMILY CONTACT, SOCIAL SUPPORT, SOCIAL WORK, SECURE

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Abstract

Purpose: There is little published literature about the number of home visits provided to patients within forensic intellectual disability services, and there is no published data on variables that affect home visits. There is a need for a baseline audit that can formulate standards for future practice.

Design/methodology/approach: This paper describes the home visit programme within a forensic intellectual disability service, and a baseline audit of the programme. The audit measured the number of home visits, any factors that adversely affect home visits, and the extent of family contact. We propose audit standards for evaluation of good practice in this area.

Findings: The audit involved 63 patients over a one year period. 81% of patients had some form of family contact and 54% of patients at least one home visit. 19% of patients had no contact with their family due to a variety of reasons. There were no significant differences in the number of home visits between men and women, patients on civil vs. criminal sections, or those treated “within area” or “out of area”. Patients in rehabilitation wards had significantly more visits than those in low or medium secure.

Originality/value: Conventional wisdom is that reduced family contact is the direct result of patients being placed “out of area”. The results of this audit suggest that, at least in this group, the reasons may be much more nuanced and that the current definition of “out of area” has to be improved to incorporate the actual distance between the patient’s *current* family home and the service. Audit standards have been proposed to monitor family contact and home visits. Future work should focus on the relationship between family contact and treatment outcomes.

Key words

1. Learning disability
2. Family
3. Social work
4. Forensic
5. Secure
6. Assessment and Treatment

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Introduction

The events at Winterbourne View and the subsequent investigation reports placed inpatient hospital care for people with an intellectual disability in the spotlight (BBC One, 2011). What emerged was a critical review of inpatient placements for people with intellectual disabilities, with the practice of placing patients “out of area” highlighted as a particular concern. The term “out of area” is used when a person with mental health / social care needs is using medium-long term treatment / rehabilitation services away from their home area (Royal College of Psychiatrists, 2011). “Out of area” placements are typically used when demand for beds outstrips capacity or where specialist services are not available locally (Department of Health, 2012). The Department of Health (2012) review highlighted a widespread failure to design, commission and provide services which give people the support they need close to home.

The negative impact of placing people in settings away from their families has been highlighted by many authors. Walsh *et al.* (2001, p. 294) reports that “arguably, institutionalization – living for years in a large, remote institution such as a hospital ward – militates against any sort of family life”. McMillan (2006, p. 5) states that “patients' relationships with their families and friends can be jeopardised”, and the Department of Health (2012, p. 20) expresses that “sending people out of area into hospital or large residential settings can cause real harm to individuals by weakening relationships with family and friends and taking them away from familiar places and community…which could “increase the likelihood of challenging behaviour”. Indeed, social support has been identified as a major protective factor in preventing mental health problems and quality of life (Lippold and Burns, 2009). Working with families has been identified as important in helping prevent relapse of mental illness, which in turn reduces risk (Richards et al., 2009). For people with intellectual disabilities, especially those with complex needs, families are usually the main source of love, care and support. The Department of Health (2009) note that; “families continue to offer a lifetime of involvement, support and advocacy”. Families have been described as the most enduring support network throughout the life course of adults with intellectual disabilities (Seltzer & Krauss, 1994), as people with intellectual disabilities are likely to name fewer people as members of their social networks, and rather, to name professional workers or family friends as their own friends (Walsh et al., 2001).

Most of this work suggests that family contact indicates a positive outcome, and a predictor of quality of life for adults with intellectual disabilities (Walsh *et al.,* 2001). However, this may not always be the case. There is a limited amount of literature that has qualitatively examined the family relationship experiences of inpatients with intellectual disabilities. Chinn *et al.* (2011, p. 50) reported that four of their 17 patients with intellectual disabilities in out of area placements experienced painful relationships with family, and histories of conflict and abuse. One of the problems with research studies investigating family contact (e.g. Bonell *et al., 2011*) is that they tend to only recruit participants and their relatives who are actively in touch, which does not represent the experience of those who are not in contact. Chinn et al (2011, p. 50), reported that “many” participants mentioned missing family intensely, and “most” said they would like to be closer to family. Beadle-Brown *et al.* (2006) reported that the majority of people with intellectual disabilities placed “out of area” said that they wanted more contact with their families.

Inpatient intellectual disability services have been criticised for failing to support visits between patients and their families. Relatives have raised concerns regarding the length of travel time and the costs of visiting relatives (Walsh *et al.,* 2001). Elderly or disabled family members were particularly affected (Bonell *et al.,* 2011; Chinn *et al.,* 2011). Walsh *et al.* (2001) reported that family contact declined the further the distance from their relative's placement, but surprisingly, the relatives of residents in campus settings reported a higher total number of contacts with their family members, than those in community housing.

At present, only one study has investigated family contact of patients with intellectual disabilities within inpatient services. Chaplin *et al.* (2010) investigated the frequency of visits from family and friends, and other types of contact, such as telephone and letters between 27 within area, and 28 out of area patients with a variety of needs. Significant differences were revealed for average visits per month from family and friends, with 75% of within area patients receiving a visit more than once a month, as compared to 20% of the out of area group. However, contact through telephone and letters from family and friends was much more common for those placed out of area. A minority of patients in both groups had no visits from family, and this was slightly higher for within area patients, at 12.5%, and 6.7% of out of area patients.

There is little published literature about initiatives within forensic intellectual disability services that aim to support family contact. This paper describes "The Home Visit Programme", whereby the service proactively offers and facilitates patients the opportunity to visit home. This project was therefore designed as a baseline audit of the home visit programme and aimed to:

1. Measure the number of home visits patients had
2. Measure the extent of other forms of family contact
3. Examine factors that adversely affected home visits or family contact
4. Propose audit standards for future evaluation of good practice in this area.

Method

Participants and Setting

The study took place within a forensic intellectual disability service in the East of England. The service consists of medium secure, low secure and rehabilitation wards- i.e., category 1, 4 and 5 beds in the classification used by the Royal College of Psychiatrists' Faculty of Psychiatry of Intellectual Disability (2013) and the Count me in Census (Health and Social Care Information Centre, 2015). All patients admitted to the service are detained under the Mental Health Act 1983 for England and Wales, with the majority being under part 3 of the Act (so called criminal sections, see Table 1). There were 63 patients within the service at the time of the audit, and all of these were included.

The Home Visit Programme

Led by the social work department, and actively supported by the multidisciplinary team, the service has proactively offered patients the opportunity to visit home for a number of years. Home visits are defined as "contact with person(s) deemed as family by the patient outside of the service". Home visits aim to support the patients and their families to maintain their links. They are usually to the family home, or to another location within the patient's home area. All financial commitments for the home visits are met by the service. Home visit dates are often set either at the beginning of the year for currently admitted patients, or on admission for those recently admitted to the service. Anecdotally, it has been noted that setting dates in advance has a number of benefits. Pre-arranged home visits give patients something to look forward to, and in some circumstances work towards. Further, setting dates well in advance facilitates the maximum time to make practical arrangements, such as contacting patients' family, agreeing a location, risk assessments, and organising vehicles and staffing. Alternatively, some patients prefer to make an individual request when they wish to have home visits, rather than following the advance booking system. This enables empowerment and involvement in setting dates and also allows them to choose important personal anniversary dates such as birthdays and the Christmas period.

There are currently no published audit standards on the number of home visits for patients within forensic intellectual disability services. This service aims to provide patients with at least four home visits each year, and therefore this was adopted as a preliminary measure to evaluate.

Procedure

Routinely recorded data on home visits for a one year period (2011-2012) was retrospectively analysed. This included the number of successful home visits that occurred over the year, and any factors felt to affect this qualitatively for each patient.

In order to further explore factors affecting home visits, between group comparisons were carried out on the variables detailed in Table 1.

In addition to the current administrative definition of "out of area" based on the commissioning area, this audit calculated the mileage between the service and the current address of the patients' family home using Google Maps. The rationale for this is described later in this paper.

Information on family contact, e.g. whether the patient was in touch with their family and whether the patient was visited at the service by their family, was also audited.

Table 1: Variables measured

Gender
Level of security Medium, low, or rehab (category 1, 4 or 5 beds) (Royal College of Psychiatrists' Faculty of Psychiatry of Intellectual Disability, 2013).
Section Sections 35–38, 47, 48, and CPIA(5) of the Mental Health Act, where the detention order is made either by a court or by the Ministry of Justice were designated as criminal sections. All others were classified as civil sections.
Commissioning area status – "within area" or "out of area "Within area" patients were those from the funding authority local to the services. "Out of area" patients included patients from all other regions.

Analysis

Between group comparisons were used to examine whether there were any differences in the number of home visits between the groups described in Table 1. Non-parametric tests were used as the data violated the assumptions for parametric tests. The Mann Whitney *U* test was used for all variables, excepting level of security, where the Kruskal-Wallis and post hoc tests were employed.

Results

Home Visits

Over the course of the year, 111 home visits were carried out. This was an average of 1.8 home visits per patient. Table 2 provides a breakdown of the number of patients and the number of home visits achieved. Twenty patients (32%) had one to three visits, and 14 patients (22%) had more than four visits. Therefore 54% of patients had at least one visit over the year while 46% had no home visits.

Table 2: Number of Home Visits

***n* Home visits**	**n Patients**	**(%)**
0	29	(46)
1 - 3	20	(32)
> 4	14	(22)

The records of the 29 patients who did not receive a home visit was sought to further investigate the factors affecting their lack of visits.

Lack of family contact – Twelve of the patients who had no home visits did not have any contact with their families in the first place. Three of these had no immediate family. Other reasons included the family having issues with their relative's offence, particularly in the case of child sex offences, a past history of abuse within the family setting or other causes for a negative relationship.

Forensic – Forensic reasons affected 12 patients. Of these, two did not have Ministry of Justice permission to leave the service. Four had either not yet obtained Section 17 leave, or had lost leave due to behavioural and risk issues. Two patients were subject to Sexual Offences Prevention Orders (SOPOs), a civil preventative order restricting the activities of those convicted of a sexual offence that prevented them from visiting their home areas. Four patients were in contact with their family, but could not visit due to their risks presented to children resident in the family home.

Distance - Two patients were unable to visit home purely due to the distances involved.

Mental health – Three patients were unable to visit home due to their mental health presentation. These patients often had trips planned which were cancelled due to mental health deterioration around the time of the home visit.

Table 3 describes the between groups analyses. There were no differences in home visits between men and women. There was a significant difference between patients within different levels of security and the number of home visits, with post hoc tests highlighting that the difference was between medium and rehab wards (.03), and low and rehab (.008) wards, with patients within rehab wards having significantly more home visits than those in higher levels of security. There were no differences between patients under a civil or criminal section. There were no significant differences in the number of home visits between patients treated “within area” or “out of area”.

Table 3: Between group comparisons

Variable measured		*n* Patients	*n* Home visits	Mean per patient	Statistical test
Gender	***Male***	40	76	1.9	*U* = 442.5, P = .79
	Female	23	35	1.5	
Level of Security	***MSU***	20	28	1.4	$\chi 2(2)$ = 7.8, **P = .02***
	LSU	29	37	1.3	
	Rehab	14	46	3.3	
Commissioning area status	***Within Area***	28	33	1.2	*U* = 442.5, P = .49
	Out of Area	35	78	2.1	
Section	***Civil***	25	50	2	*U* = 459.5, P = .82
	Criminal	28	61	2.2	

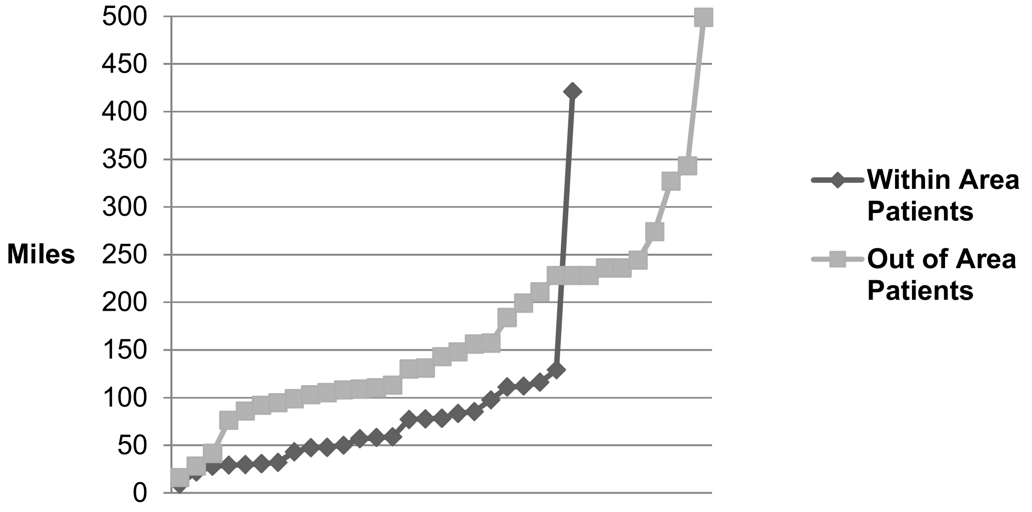
Mileage data

Traditionally, studies examining whether the patient is “out of area” or not are based on the address of the commissioning authority which in turn, is based on the last known address where the patient was resident. This approach is clearly problematic for a patient group that often have a history of repeated placement breakdowns, different addresses and family mobility. Hence this audit, in addition to the “out of area” status based on the address of the commissioning authority, also calculated the mileage from the service to the patients’ *current* family home address.

Figure 1 displays this information for both “within area” and “out of area” patients. To produce this graph, mileages were sorted in ascending order for each group, with each shape on the graph representing how many miles each patient is from home.

On average, “out of area” patients were 164 miles away from home, with a range of 16-499 miles, while “within area” patients were 90.6 miles away from home, with a range of 9-421 miles. As is clear from the ranges, a number of “out of area” patients were closer to their families’ current home than patients within area and vice versa.

Figure 1: Mileage distances from service to family home, “within area” and “out of area” patients



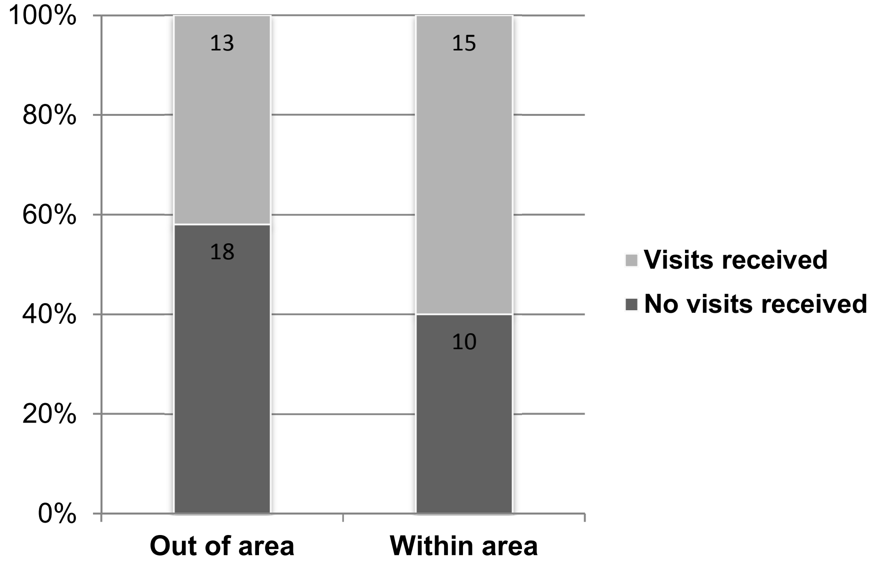
Family Contact

The audit, while focusing primarily on the assessment of the home visit programme, also covered family contact with the patient in service. Of the 63 patients, twelve (19%) were not in any contact with any member of their family. The majority of patients (n = 51, 81%) maintained some degree of contact with their relatives, whether this was by letter, telephone, visits to home, or family visits to the service. Data regarding the relatives patients were in touch with was available for 41 patients. 37 (59%) were in contact with immediate family (i.e. parents, siblings, grandparents). Three of these were not in any contact with father due to allegations of abuse, and one of these patients had a strained relationship with her mother due to her remaining with her father despite these allegations. Two were in contact with siblings only due to parental abuse. Two of the 37 had very recently initiated contact with their families after estrangement. Four (6%) were in contact with extended family only, such as uncles. All four of these patients' parents had passed away.

Family Visitors to Service

Of the 63 patients, 28 (44%) were visited by their family at the service during the year covered by the study, whereas 28 (44%) did not receive any visits. Data was missing for seven patients. There was no statistically significant difference between out of area and within area patients in receiving family visitors to service (Figure 2).

Figure 2: Proportion of patients who receive visits from their family to the service, "within area" and "out of area" patients



Discussion

This paper is a baseline audit that described the "home visit" programme used within a forensic intellectual disability service, which measured the number of home visits, the extent of other forms of family contact and the factors that adversely affected it.

Methodological drawbacks include the study being conducted within a single service, which limits the generalizability of the findings, and the reliance on routinely collected retrospective data. This limited the ability to focus on the multi-modal methods of contact utilised by patients and their families, such as telephone, video-calls, and letters. On the other hand, and despite the widespread acknowledgement regarding the importance of family contact to people with intellectual disabilities and their families, this is the first attempt to investigate family contact among patients within an inpatient forensic intellectual disability setting using quantitative data and propose audit standards for the future.

The home visit programme is highly popular with patients, their families and staff. For staff, planning and facilitating home visits with patients and their families is a positive interaction. Home visits also have a number of indirect benefits, such as observing the patients behaviour away from the service, in a community setting.

Factors Limiting Home Visits and Family Contact

The study found that roughly 81% of patients maintained some degree of contact with their relatives, whether this was by letter, telephone, visits to home, or family visits to the service. However, 19% of patients had no contact with their family in the first place due to a variety of reasons- some had no living family and others had been ostracised from their families due to their criminal offences, particularly those who had sexually offended against children. Difficulty in coming to terms with a relative's offence has been highlighted by previous research (Hubert *et al.,* 2007; Bonell *et al.,* 2011). Haar-Pomp (2015) also highlighted that among a group of 36 male personality disordered forensic psychiatric patients, family members were the most likely victims of the patients' offences. In the case of others, this was due to safeguarding concerns stemming from past physical and / or sexual abuse. Alexander *et al.* (2011) reported that as many as 50% of patients within forensic intellectual disability settings have experienced abuse. Furthermore, this has often contributed to the development of challenging behaviours. Murphy *et al* (2007) explored the experiences of 18 people with intellectual disabilities who had allegedly been abused. Compared to the three months prior to the abusive incident, there was a negative impact on adaptive behaviour and an increase in challenging behaviour. Sequiera *et al.* (2003) studied 54 adults with intellectual disability who had experienced sexual abuse and 54 adults with intellectual disability without such a history. Victims of sexual abuse were found to have higher rates of mental illness, behavioural disturbance and PTSD, with the severity of the effects was related to the severity of abuse.

There were no significant differences between genders, neither did the type of Mental Health Act section (i.e. civil or criminal) appear to impact the number of home visits. However results highlighted that the frequency of home visits increased as the level of security went down, with the lowest level of home visits experienced by patients in medium and low secure wards, and highest within rehabilitation wards. This is an intuitive finding, which supports the notion of risk decreasing as the patient positively progresses through levels of therapeutic security. It could also reflect that as risk and challenging behaviour decreases, family relationships improve.

Home Visit Equivalents

A substantial minority (19%) of patients in this study had no contact with their family. Other similar services are also likely to have the same proportion of patients in this position. Although not described in this paper, patients not able to have a home visit, are offered a ‘home visit equivalent’ by this service. This is to ensure that patients who are not in contact with their family also have a day out of the service that has been planned for them. Where possible and appropriate, these trips have a ‘home’ element. For example, if both parents of a patient are deceased, they may be taken to visit their graves.

“Out of area” Definitions and Anomalies

The negative impact of “out of area” placement on relationships with family and friends has been highlighted recently (DH, 2012). We therefore investigated the number of home visits between patients “out of area”, compared to those “within area”. There were no statistically significant differences between these two groups; in fact the “out of area” group had slightly more home visits than those within area. This finding was counterintuitive and needs careful consideration.

One reason for this could be the very definition of “out of area”. As mentioned earlier, traditional definitions of “out of area” is based on the address of the commissioning authority which in turn, is based on the last known address where the patient was resident. Within the patient group in forensic intellectual disability services, this is problematic because they have suffered repeated placement breakdowns, been moved from place to place and in many cases the address where they last resided before admission to service has little to do with the address of the family home. In addition, the families themselves may have chosen to move after the patient’s admission to service. Hence a reliance on the address of the commissioning authority to decide the “out of area” question is clearly inadequate. In this audit therefore, we chose to calculate the mileage from the service to the patients’ *current* family home address. This approach highlighted some nuances regarding the “out of area” and “within area” labels. As noted, some “within area” patients were further away from their families than their “out of area” counterparts. This is partly due to the large geographical scale of the East of England region. If a patient was deemed “out of area” because the family lived just over the border of the neighbouring commissioning authority, they could still be closer to the service than a “within area” patient who lived at the opposite end of the same commissioning authority.

The term ‘home area’ refers to a persons’ “ordinary residence”, or the place they grew up, essentially the geographical location that person considers home. When defining ordinary residence, Department of Health (2013) guidance refers to case law, Shah vs. London, Borough of Barnet (1983) where Lord Scarman stated that: “Ordinarily resident refers to a man’s abode in a particular place or country which he has adopted voluntarily for settled purposes as part of the regular order of his life for the time being, whether of short or long duration” (DH, 2012). The term ‘resident’ in the Mental Health Act 1983 is not the same as “ordinarily resident” and therefore the definition above does not apply (DH, 2013). Therefore by definition to be ‘out of area’ a person is being treated elsewhere than the last place they lived prior to being detained under the Mental Health Act. It cannot be assumed, that because a patient is “out of area” for their commissioning body, they are also “out of area” their family and social links. Other authors have highlighted this phenomena (Bartlett *et al,.* 2014).

It is therefore important that apart from the recording whether a patient is “out of area” or not based on the commissioning authority, the actual distance from the service to the family’s current address is also recorded. The latter should be sought carefully from the records, because there can be a tendency to calculate these distances based on the last address in the file or the one of the commissioning authority.

Proposed Audit Standards

It is widely accepted that patients who experience positive family support are likely to experience a better quality of life. The results of this study highlight that the issue of family contact within forensic intellectual populations is a highly complex issue, one that goes beyond the dichotomies of “within area” and “out of area”. Therefore, the following audit standards are proposed as a result of this baseline audit:

1. On admission to a secure service, information on a patient’s family and wider social relationships should be sought from a variety of sources- the patient, family members, past reports and previous care teams.
2. If the patient is in contact, or seeking to re-establish contact with their family, personalised care plans should be developed to facilitate this.
3. The actual distance between the service and the family’s *current* home address should be recorded.
4. The number of home visits should be recorded on a 6 and 12 monthly basis.
5. There should be at least four home visits per year for those who are eligible. 100% of those eligible or suitable should have received home visits. Reasons why a patient is not eligible or suitable for home visits should be recorded.
6. “Home Visit Equivalents” should be offered to all patients who do not have, or do not wish to have family contact.
7. All family contact (telephone calls, video calls, letters, visits to the service) should be recorded.

Future research is recommended which prospectively measures the level of contact between patients and their families, the perceived supportiveness of these relationships, and the impact of family support on quality of life, and treatment outcomes. Secure services should continue to innovatively assess ways to support family contact, and ways in which to involve families in the care of their relative, including the provision of family therapy (Absalom *et al.,* 2010; Davies *et al.,* 2014).

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