

'How Families Live...' : the views and experiences of parent-carers who provide family placements to intellectual disability nursing students"

MCCLIMENS, Alex <<http://orcid.org/0000-0003-2859-910X>>, FINLAYSON, Janet and DARBYSHIRE, Chris

Available from Sheffield Hallam University Research Archive (SHURA) at:

<http://shura.shu.ac.uk/12891/>

This document is the author deposited version. You are advised to consult the publisher's version if you wish to cite from it.

Published version

MCCLIMENS, Alex, FINLAYSON, Janet and DARBYSHIRE, Chris (2016). 'How Families Live...' : the views and experiences of parent-carers who provide family placements to intellectual disability nursing students". *Journal of Intellectual Disabilities*. (In Press)

Repository use policy

Copyright © and Moral Rights for the papers on this site are retained by the individual authors and/or other copyright owners. Users may download and/or print one copy of any article(s) in SHURA to facilitate their private study or for non-commercial research. You may not engage in further distribution of the material or use it for any profit-making activities or any commercial gain.

ABSTRACT

AIM: The aim of this research was to learn about the value of family placements, as experiential learning opportunities, from the perspectives and experiences of parent-carers who provide them to nurse students via a Scottish university Family Placement Scheme.

METHOD: Qualitative interviews were conducted with seven (50%) parent-carers who provided at least one family placement over two academic years (2012/2013 and 2013/2014). Broadly descriptive data was analysed, organised into themes and subject to content analysis: parents' descriptions of their caring role; their perceived value of family placements; and their views and experiences of carer participation in nurse education, and intellectual disability nursing.

RESULTS: Family placements were perceived to be mutually beneficial to nurse students and families of children and adults with an intellectual disability, and provide for example, opportunity to develop communication. Detailed description of the daily and wider aspects of caring was provided, offering insight into the actual practical learning experiences of nurse students on these placements.

CONCLUSION: This hub and spoke model of learning provides unique opportunity for nurse students to learn what it is really like for families to care for a relative with an intellectual disability at home, and to develop their practice skills for working in partnership with family carers.

INTRODUCTION

Students on courses of study leading to professional nurse registration are required to spend up to 50% of their time within practice gaining direct experience with the client group they have chosen as the focus for their future work (Nursing and Midwifery Council (NMC), 2005). Traditionally the placement experience has been characterised by an emphasis on allocating students to service settings where they can be directed in their learning by suitably qualified staff. This meets the requirement as laid out by the NMC (2010a) that students should be able 'to learn with, and from, other health and social care professions' (2010:75).

More recently the placement learning experience has been expanded to include what has come to be known as the 'hub and spoke' model (Marlow et al 2008). In brief, this arrangement places the student in a location designated as the 'hub' which is where they will receive the bulk of their formal and regulatory input from an appropriately qualified practitioner. This area will have sufficient learning opportunities to meet the outcomes expected for that part of their training. There will also be one or more 'spoke' placements, physically remote from the hub, which the student will attend on a pre-planned basis in order to gain more experience of other client groups, to learn other related skills or to observe relevant procedures not routinely available at the hub. By operating across two or more areas the student will then become aware of the realities of inter-professional working. This model demands flexibility from placement providers and students but is reported on favourably by several commentators (Dean, 2010; Millar, 2014; Roxburgh, 2014).

For students intending to work with people with intellectual disability this model of learning opens up many possibilities. According to Emerson and Hatton (2008) it is the sub group of individuals with more profound disability and impairment who are likely to be looked after in specialist accommodation while the majority of individuals with intellectual disability live with their parents (Chadwick et al, 2013). It is this demographic fact that prompted us to consider utilising families as a potential practice learning experience. We have reported on this elsewhere, with a focus on how students on dedicated intellectual disability qualifying programmes of study experienced the family placement (Finlayson and Darbyshire, 2015). But in what follows we explore the family placement from the perspective of the parent/carers.

The locus for the care of individuals categorised as living with intellectual disability has been closely connected to those professionals equipped to deliver that care since both groups were first conceptualised (Mitchell, 2004). From the initial inception of the profession in the early years of the twentieth century, this meant in effect that much of that care took place within segregated settings (Allen, 2014). This period of institutionalisation reached a peak in the 1950s and 60s (Borsay, 2005). Since then, there has been a move towards a more individual response to disability (DH, 2001; DH, 2009). When coupled with reaction to more recent events where poor care has been exposed (Mencap, 2007; Department of Health (DH), 2008; Heslop et al, 2014) the need for contemporary intellectual disability professionals to work alongside individuals and families, to secure fairer access to health services, seems clear.

Emerson et al (2014) highlight the difficulty in obtaining precise numbers when attempting to calculate sub-sections of the intellectual disability population (2014:45-57). But we can

extrapolate from what is known to suggest that most children and young people with intellectual disability live in the family home, while there are a substantial number of adults with intellectual disability who also remain at home with surviving parents. This much was confirmed by other studies (Cairns et al, 2013; Chadwick et al, 2013) and by our own experiences of setting up the family placement scheme.

Dyson (1996) worked with families with a child with intellectual disability and from this she warned that 'the paucity of research warrants further study of the family' (1996:285). The exposure our students receive on the family placement scheme should make them more sensitive to this deficit in knowledge. We anticipate that their future practice will therefore shape both care delivery and research. Taggart et al (2012) offer a clue about the reasons behind this apparent lack of research when they note that family dynamics play a part here. They say 'Limited research has been undertaken on this topic because until recently, people with intellectual disability usually pre deceased their parents (2012: 217). Their study on the support needs of older carers identified a mainly female population who exhibited similar problems and concerns to the ones our own participants discussed. Chadwick et al (2012) also looked at the support needs of families. Here a main finding was that the families who took part in the study felt they didn't get enough help from statutory services. They spoke of having to fight to secure assistance and some even felt reluctant about making an fuss for fear of the service being withdrawn (2012:125). Walker and Ward (2013) extend this line of enquiry when they argue for more research around the family due to demographic factors, which means that there is now and will soon be even more need to accommodate the demands that ageing of carers and cared for will place on health and social care services. More recently Ryan et al (2014) conducted a literature review which examined family life

with an ageing individual with intellectual disability. This domestic situation leads to what the authors call a 'mutually dependent relationship' (2014: 217).

It is apparent then from the literature that there is value in making the family a focus for enquiry. By developing the family as a short practice placement experience for our students we may be able to forestall some of the problems that are being reported as our students take the lessons they learn into their future practice. The involvement of families also recognises the value users of services can bring to teaching, learning and research (Bigby et al, 2014; Northway, et al 2015).

AIMS AND OBJECTIVES

Our current project then aimed to uncover the views and experiences of the families who agreed to offer support to a student nurse within the family setting. This support could range from speaking to students within the university setting to inviting a student to spend some time as a guest of the family where they could begin to gain some understanding of the lived experience of caring for child who has an intellectual disability. Family carers were keen to contribute to the education of future professionals and also wanted them to know 'what life was really like' for them. Within this our objectives were to check on the scheme's suitability as a vehicle by which to offer placement experience to our students, and to confirm that the families hosting the placement were comfortable in that specific role and also more generally as being part of the educational process.

Methodologically a 'placement' whereby an individual (in this case a nursing student from an intellectual disability course) is located with a host family might appear, prima facie, to be an opportunity for an anthropological study (Bassett, 2013) or even an ethno-methodological approach (Kell, 2014). Here though our data generation and analysis occurred after the event and so resembles a modified ethnography. This 'practice-near research' model is defined thus - 'Practice-near inquiry might be defined as the use of experience-near methods for practice-based or practice relevant research. Such methods include ethnography, some forms of in-depth qualitative interviewing and observation, and the use of images and other sensory data in research' Froggett and Briggs (2012:3)

This description feels very close to the experience we wanted to gain access to - that which occurred when the students were working in the family home. As such we felt it appropriate to our own circumstances and to those of the families we interviewed.

PROCESS, PARTICIPANTS AND PROCEDURE

We secured ethical approval for the study via the School of Health and Life Sciences Research Ethics Committee, [insert university name].

The family placement scheme is run as part of a 'Hub and Spoke' model (see above) within the nursing programme. As part of the spoke practice learning opportunity students may spend some time with a family and thus become part of the Family Placement Scheme. The length of time spent with the family varies between the needs of the family and needs of the student but may range from a one day visit to up to 5 days over a 6 week period. The student

meets with the family well in advance to plan a mutually agreeable timetable of when it is appropriate for the student to visit the family home. Depending on the family this may be in the morning to help with getting the child ready or later in the day to be available to help with family outings. Some families are happy for the student to attend the full day from 9.00 – 5.00 but this very much dependent on the local circumstances. Students are encouraged to be sensitive to the needs of the family when planning their attendance.

Fourteen parents provided family placements to second-year nurse students over two academic years (2012/13 and 2013/14). All parents were invited to take part in individual qualitative interviews by a researcher within three months of the first placement they provided being completed (some parents provided more than one placement, one in each academic year). Seven (50%) of the parents chose to take part in the interviews. The interviews were conducted in the parents' homes by the researcher on dates and times which were mutually convenient. The interviews were recorded on a digital recorder, and then transcribed. All identifiable information (e.g. the names of participants, their children, and student nurses) was changed during transcription, thus pseudonyms were used for all participants who took part.

Transcribed qualitative interview data were subject to content analysis (Joffe & Yardley, 2004) and then arranged according to the following four themes (Braun & Clark, 2006):

1. Parents' description of their caring role.
2. Parents' perceived value of the family placement to the nurse student, themselves as a carer, and to their child with a learning disability.

3. Parents' views and experiences of the role of carers in nurse education.
4. Parents' views and experiences of learning disability nursing.

As this was a broadly descriptive study, these themes were derived from the interview schedule as specific areas of enquiry. A copy of the interview schedule is directly available via the authors. Subsequent themes which emerged from these interviews were: worry, depression and isolation; holiday/leisure time and things not going to plan; giving up and returning to work after becoming a parent of a child with learning disability; the impact of adverse life events on family support; parents' having someone to talk to; having new/extra company in the house for child with intellectual disability; placements offering nurse students a different experience/perspective; and parents' love and affection for their children with an intellectual disability. Analysis was first conducted separately by two authors (JF and CD), independently of each other, with the final emergent themes agreed upon after they were scrutinised by the other (AMC).

FINDINGS

Parent Characteristics

The characteristics of the seven parents who took part in the qualitative interviews are presented in table 1. All of the parents were mothers, white/native to Scotland and with an average age of 49 years. Five of the mothers cared for a child with intellectual disability (aged 16 years or under), whilst two cared for an adult with intellectual disability (who were 24 years and 26 years of age).

*****Insert table 1 about here*****

Here we present the findings from the study, in order of the four main themes as they were elicited in response to the interview guide.

Parent-Carer Role

When compiling our interview guide we wanted parents to describe their caring role before we enquired about the potential value of the family placement scheme, to get a sense of what the nurse students would gain exposure to through these placements. All seven parents described their daily demands and routines of caring, and related issues, which echo some of the issues we found in the literature (Green, 2007):

In the morning I get [my daughter] up sharp. [My daughter] gets showered at night time... We get hoisted up in the morning, breakfast, the school bus comes, [my daughter] goes to school... during the night I've got to turn [my daughter] ...so I don't get a full night's sleep. I have to get up four, five times during the night to turn her...so maybe I'll catch a wee hour [sleep] on the settee after the school bus comes' (Joan).

'In a typical morning when we're getting ready for school, [my son] takes an hour and a quarter to an hour and a half, all him in the morning to get ready. And that's not [my husband or I] having a shower or breakfast or anything. It's just when you look at it like that, when you're doing that in the morning, and it's kind of similar in the evening...when you add it all up, if it wasn't for school, we'd probably spend 5 or 6 hours just changing, dressing, washing, feeding' (Susan).

'Your life is consumed with appointments, with telephone calls' (Emma).

In addition to these descriptions, three parents described their worries and/or their feelings of depression or isolation:

'There are mornings where I can't get up, for a while, off the couch, because I've sent [my son] to school and I'm maybe reflecting or worrying. And when he's not well for quite a long period, that feeling in me can go on, and that's when my family starts to say, my mum will always say, are you sure you're not depressed?...I've referred myself to a place called [name of counselling service]' (Kelly).

'[My daughter] can't cope with...going to soft play...she can't cope with...going to the park, things like that, although she's got a lot better...So that was really isolating for me' (Emma).

Four parents also talked about their holidays/leisure time and things not always going to plan:

'Holidays and stuff...we've never held back...I drove down to [place name] last year. We went camping...I can take my son anywhere...You can't have a hundred per cent plan, because every single holiday we've had [my son] has had a seizure. Excitement gets him as well. Every birthday, every Christmas, and every single holiday...he has a seizure. So you can't actually plan things are going to work but you have to plan because you have to be normal' (Kelly).

'You think you're going on holiday to get a wee rest, but you don't because, see, everything's to be done for [my daughter]. If she decides she's not getting off the [cruise] ship, you're stuck on the ship' (Karen).

Two parents described giving up but then being able to return to work, and one further parent talked about having a part-time job out with the family home, which she sees as ‘[her] time’ (Karen):

‘It’s been really hard for me because I had to give up [work] ...[My son] was only six weeks old when [my daughter] was diagnosed [with Rhett syndrome] ...It’s been a huge, huge change...I’m actually...training to be a nursery teacher [now], so you can see how things have come on for us’ (Emma).

Three parents also talked about the impact of adverse life events (e.g. death of a close relative) on their family support:

‘...my dad passed away six months after [my husband] and I split up. It was very sudden...He was the main person helping me get [my daughter] off the bus when I was working, and sitting with her...I gave up my work’ (Joan).

‘[My eldest daughter] ...passed away. She was only forty as well...I just assumed my [eldest] daughter was the one who was going to take care of her because she always did say that, and now unfortunately that’s not going to happen...We need a break. [My husband] has retired. I think he feels everything’s been taken away from him. And all that happening with my eldest daughter... His whole life has changed’ (Karen).

Value of Family Placements

It is against this backdrop that we can situate the responses to our questions on the value of the family placement. We asked the participants about how they felt the placement worked for them, for their child, and for the student.

Susan, Karen and Kelly all spoke of the benefit they derived from having someone to talk to.

It was Kelly who emphasised this when she said:

I got a lot out of it because I was feeling quite alone at the time...There was a lot of chatting, which is good. I really enjoyed having [the nurse student] here, in the home...So it was good for me' (Kelly).

Likewise Karen also appreciated the benefits of having another person to talk to. She told us:

'I felt easy with [the nurse student]...she was easy to talk to. It wasn't awkward. I needed to talk to her, plenty of chat' (Karen).

In terms of the value of the family placements for their children with an intellectual disability, having someone new in the house, and having 'extra company' (Susan), was mentioned by three parents:

'I think [my daughter] enjoyed her company...Well, she enjoys company, so another person in the house was quite nice for her' (Mary).

Two of the parents also mentioned the appropriateness of the particular nurse student for their child with intellectual disability, both in terms of gender and being of a similar age and so being more likely to have shared interests:

'I had specifically asked for a male, because I thought that would help with [my son's] self-awareness, confidence and all that. [My son] really liked showing off and having a man in the house' (Kelly).

'Yes, [my daughter and the nurse student] went to see [famous pop star in concert]' (Karen).

Four of the seven parents felt that the different experience/perspective family placements offered was the most valuable learning outcome for nurse students. Emma for example, suggested that for the student *'...it's brilliant to get a whole different perspective of how families live'*. Emma also appreciated that this could work for her benefit too. She told us *'I think the experience really, really helped me, to let me know that not everybody sees [my daughter] the way I see her... sometimes as a parent you only see what difficulties and challenges are for the child'*

Karen felt that family placements help students to appreciate the demands of caring: *'Maybe seeing the stress families are under'*. A further two parents felt that family placements provide informal opportunity for nurse students to ask questions about their parent carer role:

'[The nurse student] was asking me quite a lot of questions. I felt that because she was with me one-to-one she was able to ask more' (Fran).

It was apparent too that the contribution of the students could have practical as well as emotional and psychological benefit. Joan described a situation where the knowledge of available services the student brought with her led to a real improvement in her circumstances.

'[The student] actually found out a lot of information about a wee swimming club, and different things, so they are bringing in information...I didn't have this and I didn't have that,

and [the student] said, you should [contact] your community occupational therapist...I got in touch [with Occupational Therapy] and I got a tracking hoist in...a new up and down bed...and...a new toilet seat. If [the nurse student] hadn't pointed that out...I would have carried on the way I was carrying on...' (Joan).

Carer Involvement in Nurse Education

We then talked about how the participants saw their own involvement in student nurse education. All seven parents said they thought it was important for colleges and universities to involve or include family carers of people with intellectual disability in intellectual disability nurse education. Three of the parents had participated in student training (other than their participation in the Family Placement Scheme) before. They described their experiences as being both nerve-wracking but enjoyable:

'It was fab...I was petrified...I am not a hot shot with a university degree. I don't speak the way university people speak, but I just hope [nurse students] take me as a mum, as a carer of a person with a disability. So if I can help that way I [do], it's not a problem' (Joan).

Some saw it more as an opportunity to share their experience of caring for their child by turning their insights into potential knowledge. Susan spoke of her time spent with students on a child nursing degree programme:

'One [of the times] was giving a presentation, and the other was just talking to a small tutorial group about what it's like to be a parent-carer...It was personal. It's challenging because it's been a really difficult time the last few years, but I feel that's kind of the silver lining, if I can pass on something to other professionals that will give them insight, and

therefore be better at their jobs, then it's kind of worthwhile...something positive coming out of it' (Susan).

In terms of increasing their involvement in intellectual disability nurse education in the future, four parents liked the idea of open days at the university, for parents, their children with intellectual disabilities, and nurse students to meet up and share their experiences and information:

'I really like the idea of open days. [It] would be brilliant to go on an open day. And it would be a meeting point for other parents, other children' (Kelly).

'...It's really important; maybe as an introduction before [family placements] start, to make sure the nurse and the mother or father, the family are comfortable' (Emma).

Of the four parents who had no previous experience of being involved in student education, three said they would be happy to become more involved in the future, to share their experiences. Karen however, said *'I'm not ready to talk about things or anything like that'*.

Parents' Views and Experiences of Intellectual Disability Nursing

Our final question asked the participants to reflect on their views and experiences of intellectual disability nursing. Perhaps surprisingly four of the parents had no prior experience of a nurse being involved in the care/support of their child. There are local reasons for this. Children with intellectual disability in this geographical region of Scotland are much more likely to receive health care/support via paediatric services, rather than community-

based intellectual disability health care teams. In Fran's case, a second, condition-specific factor was involved :

'I hadn't heard of them before. [Family support organisation who helped organise the family placement] said to me learning and disability nursing...The epilepsy nurse is at [paediatric hospital] and we just go and see her' (Fran).

Parents' Love and Affection

Throughout the interviews all parents described their love for their children with an intellectual disability, and the affection between them:

'...it is stressful. But at the same time I wouldn't be without her. I couldn't be without her. I really couldn't' (Karen).

'There's a lot of hard work. There's a lot of good fun...Last night she came back from a party and she was full of kisses and cuddles so, as I say, she's kind of full of happy nonsense most of the time which is fun' (Mary).

DISCUSSION

The main reason for conducting this study was to learn about parent-carer involvement in intellectual disability nursing education. This was realised principally through their involvement in the family placement scheme. From this our participants were able to share their experiences as carers with nurse students. The interviews we conducted with parent-carers of children with intellectual disability provide us with insight into the actual experiences nurse students were learning about whilst on family placement; from detailed descriptions of the daily demands of caring, to gaining understanding of the wider aspects of

family holidays and the impact of adverse life events on family support. And in the detail provided we find echoes of the divergence that characterises practice in intellectual disability settings. The reciprocal nature of family placements was also demonstrated, in that nurse students appeared to benefit from opportunity to ask questions on a one-to-one, informal basis, whereas parents also seemed to benefit from having someone to talk to about their caring role, gaining positive experience of seeing their child from someone else's perspective, and nurse student's knowledge of available services leading to improvement in care. Towards the end of the last century the idea of promoting a shared research agenda in this field was given impetus by commentators such as Zarb (1992), Charlton (1998), Kiernan (1999) and Rodgers, (1999). Since then user and carer involvement in research, education and practice fields has become standard (Bigby et al, 2014). For the present study this means that what might have once appeared as challenging or radical is now more readily acceptable, both in the academy and in practice and, as we hope we have demonstrated here, in the family home.

The parents valued the opportunity for nurse students to learn from their experience about what it is really like to care for a child with intellectual disability at home, and from the parents' perspectives, this was viewed as the most valuable learning outcome for nurse students on family placements. All parents felt that it was important for universities and colleges to involve family carers in nurse education. The majority (6 parents) spoke positively about they themselves being involved in nurse education more formally (e.g. seminars or open days at university), as well as providing family placements. One parent however, did not wish to be more involved on a formal basis due to *'[not being] ready to talk about things'*. This serves as an important reminder that caring for a relative or loved one at home is a highly personal experience, and that we must demonstrate sensitivity and respectfulness at all times. There are lessons here for both practice education and research.

The final theme to emerge from these interviews centres around the very positive aspects of caring, that were apparent in the interviews. We felt this was particularly important to emphasise as caring for a child with a disability can often be portrayed as a burden. In their literature review Ali et al (2012) looked at the concept of stigma and how this was shared by family members who endured the social isolation ascribed to their children by proxy. Elsewhere Irazabal et al (2012) calculated that any 'disability in participation in society and personal care are the main areas that contribute to higher family burden' (2012:801). These descriptions of stigma and burden would certainly include the families in our study. But they showed resilience in their attitude to caring, in that family holidays do not always go to plan they think it's important to go on holiday anyway, and having to give up work due to caring but returning to or commencing work later on. All seven parents demonstrated love and affection for their children throughout the interviews, and this too, is important learning for nurse students. There is some evidence that the only negative connotations associated with caring for a child with a disability are being recognised and challenged, whereby Blacher and Baker (2007) prefer the term impact to burden. Linguistics aside we felt it very important that the students were able to experience this positive sense of love and affection and parent/carer resilience for themselves, and also to report on it here.

All of the parents who took part in this study had recently provided family placements to intellectual disability nursing students, yet of the seven parents who also completed interviews, four have no experience of an intellectual disability nurse being involved in the care/support of their child with intellectual disability; thus were not able to comment on their experiences of intellectual nursing in practice. The placements themselves brought added

value as the parents liked making a contribution to the professional development of these nurse students, and appreciated the students' interest and/or enjoyment in their child with intellectual disability.

As mentioned earlier, these interviews build on our understanding of the value of family placements from both the parents' perspectives and the nurse students' (Finlayson and Darbyshire, 2015), and once again the reciprocal nature and benefit of family placements are emphasised. Both the parents in this study, and the nurse students in our earlier study who participated in the placements these parents provided (Finlayson and Darbyshire, 2025), stressed realising the daily demands of caring on family life, and the development of communication skills with family carers as main learning outcomes for nurse students; indeed in this present study, opportunity to talk about caring with each other is evidenced as having value.

Implications for Practice

Health and social care professionals in training/education must spend around 50% of their time 'on placement' in order to meet the criteria as laid out by regulatory bodies (NMC and HCPC). For those who want to work with people with intellectual disability the location and design of placement learning opportunities has changed. Today nurse education, in this field certainly, is guided more by principles of inclusion so that a partnership approach is favoured and this is reflected and supported by policy (Hodge, 2006; Martin, 2008). In addition the Nursing and Midwifery Council states, in point 15 of their guidance document for student

nurses, that they should 'Work in partnership with people, their families and carers' (NMC, 2010b:13).

The benefits here are that from a purely educational perspective the standpoint epistemology that the service user/patient brings to the situation can only ever reduce the theory/practice gap (Cooper and Spencer-Dawe, 2006). In intellectual disability settings the long-established principle of inclusion means that the learner (in our situation the student nurse) can be placed in direct contact with the source of knowledge via the family placement. The arrangement needs to be regulated by the faculty but the unmitigated experience of working in such close proximity can only ever be achieved in situ. And from a purely practical perspective, the placement ought to be defined by its target audience - people with intellectual disability and their families. We feel that the feedback from the participants in which they identify sharing and offering their own unique perspective as key to the success of the venture fully vindicates the use of the placement.

Strengths and Limitations

The strength of this study lies in the modified ethnographic approach. The 'practice-near research' gave us intimate access to the lives of the participants. This approach is favoured because by 'Positioning research close to practice creates opportunities for a greater complexity of experience to be understood by practitioners, across a wide number of fields. These fields range from considering the impact of structural disadvantage facing service users and their families, through to capturing inner world, emotional experiences which impact upon people's lives' (Hingley-Jones, 2009: 413/414). By allowing the parents/carers to

describe in their own words the daily trials of caring we were better able to then move on to elicit information about their views and experiences of the family placement scheme. Here we adopted a sympathetic stance via the interview schedule and so were able to ask open-ended questions which prompted a detailed account of experiences of caring and how this played out in practice when students became involved in the household.

A limitation is that only seven, or fifty per cent of the parent-carers who provided family placements during the assessment period, chose to take part; thus findings are not representative of all parent-carers who participated in the scheme. Nor are we able to extend any claim that what we found here might be replicated elsewhere. More work needs to be done, to involve parent-carers in research as well as increasing their participation in family placements and nurse education.

All seven participants were mothers (female). Five of the seven had a male partner, but their partners did not contribute to the interview, so the voices of male family carers/fathers were not heard. In addition, five were mothers of children with an intellectual disability, and as such, had limited or no experience of intellectual disability nursing in the care of their child. Future practice and research should include more family carers of adults with an intellectual disability, who receive care and support from intellectual disability nurses.

CONCLUSIONS

The role of the nurse delivering care to people with intellectual disability has evolved considerably over the past 40 years from operating within a mainly institutional system to one

of community support within the least restrictive environment (Clapham, 2014). The hub and spoke model of training develops this further and allows opportunity to work more closely with family carers of people with intellectual disability, to enhance learning; and there will always be families who need varying degrees of assistance to care for a child with intellectual disability. We believe this small scale example demonstrates that by aligning the educational needs of nurse students with the domestic arrangements of families who care for a child with intellectual disability, it is possible to provide a harmonious setting that is of mutual benefit to all parties.

REFERENCES

Ali, A. Hassiotis, A. Strydom, A. King, M. (2012) Self stigma in people with intellectual disabilities and courtesy stigma in family carers: A systematic review. *Research in developmental disabilities*, 33(6), 2122-2140.

Allen, P. (2014) in Jukes, M (ed). *Learning Disability Nursing Practice*. Andrews UK Limited

Bassett, A. M. (2013). *Cultural issues in pre-registered mental health student nurses' clinical placements: an anthropologically informed critical incident study* (Doctoral dissertation, Nottingham Trent University).

Bigby, C. Frawley, P. Ramcharan, P. (2014). Conceptualizing inclusive research with people with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 27(1), 3-12.

Blacher, J. Baker, B. L. (2007) Positive impact of intellectual disability on families. *American Journal on Mental Retardation*, 112(5), 330-348.

Bollard, M. Lahiff, J. Parkes, N. (2012) Involving people with learning disabilities in nurse education: towards an inclusive approach. *Nurse Education Today*, 32(2), 173-177.

Borsay, A. (2005) *Disability and social policy in Britain since 1750: a history of exclusion*. Basingstoke: Palgrave Macmillan.

Braun V, Clarke V (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101

Cairns, D. Tolson, D. Brown, J. Darbyshire, C. (2013). The need for future alternatives: An investigation of the experiences and future of older parents caring for offspring with learning disabilities over a prolonged period of time. *British Journal of Learning Disabilities*, 41(1), 73-82

Chadwick, D. D. Mannan, H. Garcia Iriarte, E. McConkey, R. O'Brien, P. Finlay, F. Harrington, G. (2013) Family voices: life for family carers of people with intellectual disabilities in Ireland. *Journal of Applied Research in Intellectual Disabilities*, 26(2) 119-132

Charlton, J. I. (1998). *Nothing about us without us: Disability oppression and empowerment*. University of California Press

Clapham, A. (2014) The future of learning disabilities nursing in the UK. *Nursing Standard*, 28(44) 44-51.

Cooper, H . Spencer-Dawe, E. (2006) Involving service users in inter-professional education narrowing the gap between theory and practice *Journal of Interprofessional Care*, 20 (6) 603–617

Dean, E. (2010) Pressure on universities to find more community placements *Nursing Standard* vol 24 no 52 12-13

Dyson, L. L. (1996) The experiences of families of children with learning disabilities: Parental stress, family functioning, and sibling self-concept. *Journal of learning disabilities*, 29(3), 280-286

Emerson, E. Hatton, C. (2008) CEDR Research Report 2008 (1): People with Learning Disabilities in England.

Emerson, E. Robertson, J. Baines, S. Hatton, C. (2014). The self-rated health of British adults with intellectual disability. *Research in developmental disabilities*, 35(3), 591-596.

Finlayson, J. Darbyshire, C. (2015) What students, carers and children can learn from family placements *Learning Disability Practice*, 18(4), 19-26

Froggett, L. Briggs, S. (2012). Practice-near and practice-distant methods in human services research. *Journal of Research Practice*, 8(2), 9.

Green, S. E. (2007) “We’re tired, not sad”: Benefits and burdens of mothering a child with a disability. *Social Science & Medicine*, 64(1), 150-163

Heslop, P. Blair, P. S.Fleming, P. Hoghton, M. Marriott, A. Russ, L. (2014). The Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study. *The Lancet*, 383(9920), 889-895

Hingley-Jones, H. (2009). Developing practice-near social work research to explore the emotional worlds of severely learning disabled adolescents in 'transition' and their families. *Journal of Social Work Practice*, 23(4), 413-428.

Hodge, S. (2006) Participation, Discourse and Power: a case study in service user involvement *Critical Social Policy* 25 (2) 164-179

Irazábal, M., Marsà, F. García, M. Gutiérrez-Recacha, P. Martorell, A. Salvador-Carulla, L. Ochoa, S. (2012). Family burden related to clinical and functional variables of people with intellectual disability with and without a mental disorder. *Research in developmental disabilities*, 33(3), 796-803

Joffe H, Yardley L. (2004) Content and thematic analysis. In: D Marks, Yardley L, eds. *Research methods for clinical and health psychology*. London: Sage Publications

Kell, C. (2014). Placement education pedagogy as social participation: what are students really learning?. *Physiotherapy Research International*, 19(1), 44-54.

Kiernan, C. (1999). Participation in research by people with learning disability: origins and issues. *British Journal of Learning Disabilities*, 27(2), 43-47.

Marlow A, Spratt C, Reilly A. (2008) Collaborative action learning: a professional model for education in nursing *Nurse Education in Practice* 8, 3, 184-189.

Martin, G. P. (2008) 'Ordinary people only': knowledge, representativeness, and the publics of public participation in healthcare. *Sociology of health & illness*, 30(1), 35-54.

Millar, L. (2014) Use of Hub and Spoke model in nursing students' practice learning. *Nursing Standard* 28 49 37-42

Mitchell, D. (2004) Learning disability nursing. *British Journal of Learning Disabilities* 32: 115-118

Northway, R. Howarth, J. Evans, L. (2015). Participatory research, people with intellectual disabilities and ethical approval: making reasonable adjustments to enable participation. *Journal of clinical nursing*, 24(3-4) 573-581.

Nursing and Midwifery Council (2005) *Standards of Proficiency for Pre- Registration Nurse Education*. London: NMC

Nursing and Midwifery Council (2010a) *Standards for pre-registration nursing education*. London: NMC

Nursing and Midwifery Council (2010b) Guidance on professional conduct for nursing and midwifery students London: NMC

Rodgers, J. (1999) Trying to get it right: undertaking research involving people with learning difficulties *Disability & Society*, 14(4), 421-433.

Roxburgh, M. Conlon, M. Banks, D. (2012) Evaluating Hub and Spoke models of practice learning in Scotland, UK: a multiple case study approach. *Nurse Education Today* 32 (7) 782–789

Roxburgh, M. (2014). Undergraduate student nurses' perceptions of two practice learning models: A focus group study. *Nurse education today*, 34(1), 40-46

Ryan, A. Taggart, L. Truesdale-Kennedy, M. Slevin, E. (2014). Issues in caregiving for older people with intellectual disabilities and their ageing family carers: a review and commentary. *International journal of older people nursing*, 9(3) 217-226.

Taggart, L. Truesdale-Kennedy, M. Ryan, A McConkey, R. (2012). Examining the support needs of ageing family carers in developing future plans for a relative with an intellectual disability. *Journal of Intellectual Disabilities*, 16(3), 217-234.

Walker, C. Ward, C. (2013). Growing older together: ageing and people with learning disabilities and their family carers. *Tizard Learning Disability Review*, 18(3), 112-119.

White, K. H. King, E. (2015). Hub and spoke model for nursing student placements in the UK: *Nursing children and young people*, 27(2), 24-29

Zarb, G. (1992) On the road to Damascus: first steps towards changing the relations of disability research production. *Disability, Handicap & Society*, 7(2), 125-138