Family carers’ experience of the need for admission of their relative with a learning disability to an Assessment and Treatment Unit – a qualitative exploratory study

Dr Neil James
Unit for Development in Intellectual Disability (UDID)
University of South Wales
ASID Conference 5-7 November 2014
Aims

◦ To explore family carers’ perceptions of how their views and opinions were received by professionals during their relative’s stay in an assessment and treatment unit.

◦ To obtain the views of professionals in relation to what they consider to be the barriers and facilitators to addressing some of the experiences discussed by carers.

Neil James, UDID, University of South Wales, UK
Stage 1 – Interviews with carers

- 6 family carers
  - 3 mothers
  - 3 fathers
    - Mike and Sally; Owen and Sue; John; Ann

- 5 Semi-structured interviews
  - 4 individual
    - Ann; John, Mike; Sally
  - 1 with a couple
    - Owen and Sue

- 4 relatives
  - 2 x formal admission
  - 2 x informal admission
  - 3 first admissions

- Admission involved 3 Specialist Assessment and Treatment Units from Wales

Neil James, UDID, University of South Wales, UK
What is IPA

“…. aims to explore, in detail, how individuals themselves conceptualize the issues they face and how they arrive at and account for, the decisions they make. IPA is phenomenological in that it is concerned with an individual’s personal perception or account of an event or state as opposed to attempting an objective record of the event or state itself. However, IPA recognises that access to this phenomenological space is dependent on the researcher’s own conceptions which are required to make sense of that other personal world through a process of interpretative activity.”

(Smith, Michie et al. 2002, p.133)
Data Analysis

- Iterative
- Rigorous and systematic – subjective and reflexive
- Critiquing and constructing meanings
- Guidelines
  - Step 1 – reading and re-reading
  - Step 2 – initial noting
    - Descriptive, linguistic and conceptual comments
  - Step 3 – developing emergent themes
  - Step 4 – searching for connections across themes
  - Step 5 – moving to the next case
  - Step 6 – looking for patterns across cases

(Smith et al. 2009)

Neil James, UDID, University of South Wales, UK
Five Major Themes

- **Role of carer as impacting on self**
  - A disempowered self; A devalued self; Self as marginalised; A subjugated self; A compliant self; Self evaluating; A compromising self

- **Self as impacting on the role of carer**
  - Need for influence; Need to hold on; Need for certainty; Tentative self; Concern for view of self

- **Preserving a sense of self**
  - Self as different to others; Self as expert; Internal validation; External validation; Attribution of responsibility; Justification of self

- **Self as vulnerable**
  - A distressed self; Losing control of self; An insecure self; A protective self; A grieving self; A conflicted self

- **Valuing support for self**
  - Being listened to; An accessible point of contact; Honesty; Attentiveness to needs of relative

Neil James, UDID, University of South Wales, UK
Role of carer as impacting on self

- **A disempowered self**
  - Owen: “The one thing that we didn’t appreciate with her being sectioned is actually um, I don’t think they paid quite as much attention to what we were saying, during the whole process from then.”
  - Sally: “… you always felt like you were waiting, you had to have permission.”

- **A devalued self**
  - Sally: “… they don’t always take on board what you have to say because you’re just a mother, and I felt that throughout my life actually … they don’t always take on board what you’re saying do they because they do think that you are emotionally, it’s coming from some emotion rather than logic, …”
Role of carer as impacting on self

- **Self as marginalised**
  - John: “Well, like I say when we finally went to that one meeting, like I say they were all there. And er there was, but they had a discussion before we were there you see what I mean. … Coz Dr [Surname] was ready to sign my son out.”

- **A subjugated self**
  - Owen: “It just, it felt like the two of us who are reasonably au fait with the situation that’s going on, the two of us were completely ignored because he had his own agenda, he knew how he wanted what he wanted to do, and he just carried on regardless.”

- **A compliant self**
  - Ann: “...Well I don’t really know if they were taking it on board because I’ve got no proof, other than, the improvement in (name of relative), …. but then I was not, I tried not to be critical either. I tried not to say ‘look I don’t like being waiting left outside’ I just said okay I’ll abide by the rules. You know I wasn’t trying to be obstructive in any way.”
Role of carer as impacting on self

- **Self evaluating**
  - Ann: “… very protective, extremely protective I would say … I deal with all his finances. ... I have high standards and I expect high standards and I won’t tolerate anything lower than high standards so, I suppose I’m a little bit of a control freak in that sense.”

- **A compromising self**
  - Sue: “I think they were all um because he’s like the king of the castle there really and he sort of um, he is the big man in terms of the assessment and treatment unit, they had to do whatever he um suggested they had to do.”
Self as impacting on the role of carer

- **Need for influence**
  - John: “Terrible. You shouldn’t have to ring them up and say look err can you tell us what’s happening with my son err about the assessment, nothing.”

- **Need to hold on**
  - Sally: “And you know essentially we wanted somewhere near to us, we wanted her to live somewhere closer, …”

- **Need for certainty**
  - Sue: “… I think they accepted what we said.”

- **Tentative self**
  - Ann: “And I think they were, they were better than me in fostering his independence (Int: right). Things like if he decided to strip off they’d send him back to his room and make him dress himself. Whereas, I probably would have dressed him, you know.”

Neil James, UDID, University of South Wales, UK
Self as impacting on the role of carer

- **Concern for view of self**
  - Owen: “I don’t think we’re viewed as difficult, well we’re not, I think difficult, I don’t think we’re viewed as difficult but they know they’ve got to actually work quite hard when they are with us.”
  - Ann: “The supported living sounded fantastic, because it meant that one he was close to me, um because we have a lot of involvement with (name of relative) care believe it or not,…”

Neil James, UDID, University of South Wales, UK
Preserving a sense of self

- **Self as different to others**
  - Mike: “… we’re not critical difficult people to work with (laughs) as I know some parents can be, … ”
  - Sue: “… I mean we are not typical parents where we dropped her off and just enjoyed the 3 months there.”

- **Self as expert**
  - Sally: “… but you know we’ve been with like you know I’ve always cared for (name of relative), …”

- **Internal validation**
  - Sue: “Because we know what we want, we want what’s best for (name of relative) but we also ask an awful lot of questions. We’re intelligent people, we read up on things and we ask them about the things we read up on.”
Preserving a sense of self

- **External validation**
  - Owen: “And we we just left that meeting thinking that chap has have said to us what we’ve been saying for 2 years, um ... but from somebody’s whose got the knowledge and the background. So we left that meeting feeling very good.”

- **Attribution of responsibility**
  - Sally: “But because he was a consultant, and I know I work in a hospital, consultants still have the last say, even when you have a, a team of very professional people …”

- **Justification of self**
  - John: “He could get up say 1 o’clock in the morning and be up then right through the day, and the following day. That’s the sort of life we was leading with him ... You can’t, you couldn’t leave him alone in the, in the room on his own, you had to be with him at all times.”
Self as vulnerable

- **A distressed self**
  - John: “Well I broke down, broke down, I cried. I’m still not, I got to have counselling myself. I went to see someone and er, their going to send now for me to er go for 1 to 1 counselling.”

- **Losing control of self**
  - Mike: “I’m not I’m not a sparky person but I could feel my bloody hackles going up and I said well what you have to understand is you’re not the expert on (names relative) this is the expert on (names relative) and it would be useful if you did actually listen to her.”

- **An insecure self**
  - Sue: “… we contacted them every single day to, first thing every morning to find out what kind of a night she’d had, um how she’d been and um, …”

Neil James, UDID, University of South Wales, UK
Self as vulnerable

- **A protective self**
  - Ann: “… because they classed it as a hospital admission, whether you know. I suppose, that’s how I perceived it and my way of coping in my mind of what was going on as well I think.”
  - John: “Well I, to be honest with you I never went there to visit him, coz I would have been, I’d fetch him straight back home. So, the wife had to go, that’s the, the wife had to do the hard bits.”

- **A grieving self**
  - John: “It’s worse than losing someone when they pass away.”
  - Sue: “Um, and um, you know obviously it was probably, I would say the most single most difficult thing in the whole of our life I would say (looks at Owen) would you?”

- **A conflicted self**
  - John: “…well he’s going to be thoroughly have a check over you know. So we was happy but sad like you know. That’s the sort of thing, that’s the way I felt anyway.”

Neil James, UDID, University of South Wales, UK
Valuing support for self

- **Being listened to**
  - Sue: “…they dropped (name of relative) off and then came straight back to the house and sat down and had a cup of tea with us and talked to us. So I mean they were absolutely super.”

- **An accessible point of contact**
  - Sally: “…and um if I needed to talk to them you know I just, either phone by phone …”
  - Mike: “…we could pick up the phone and we, we could speak to whoever and that, …”

- **Honesty**
  - Ann: “…they told me everything that they could tell me, they’d been observing him…”
  - Owen: “Um, now the new psychiatrist has explained all that sort of stuff with us …”

- **Attentiveness to needs of relative**
  - Sally: “…there’s going to be ups and downs with a you know person like (name of relative), but overall I felt there um, looking after her was absolutely er fantastic.”

Neil James, UDID, University of South Wales, UK
Stage 2 – Interviews with professionals

- 9 professionals
  - 4 individual interviews
  - Focus group with 5 participants
    - 2 x community nurses
    - 1 x psychologist
    - 1 x psychiatrist
    - 5 x nurses A&T

- Descriptive thematic analysis process
  - 3 major themes
    - Resources
    - Inclusion
    - Respect

Neil James, UDID, University of South Wales, UK
Resources

• The unit
  ◦ A frightening environment; The needs of other service users; The physical environment; Privacy; Geographical location

• Time
  ◦ ‘To sit and talk’; Limited

• Community Services
  ◦ Need for better services; Psychological support; Limited post admission facilities

• Funding
  ◦ Frustrating; Disparity in what is available and what is affordable; Having to ‘fight’; Funding contribution negotiations

Neil James, UDID, University of South Wales, UK
Inclusion

- The admission
  - Can be distressing and disempowering; Need to work in partnership; Involve in decision making; Impact of formal processes/procedures; A planned admission?; A co-ordinator; Focus can be on person being admitted

- Information provision
  - Keeping up to date/making contact; Need to be open and honest with information; Issues of confidentiality; Information leaflets – caveat?

Neil James, UDID, University of South Wales, UK
Inclusion

• Involving
  ◦ Actively seeking views; Person centred approach; Fear in dealing with carers; A hierarchy to decision making

• Meetings
  ◦ Language use; Checking understanding; A time slot on agenda – caveat?; Timing / flexibility; IMHA (Independent Mental Health Advocate); Invited into a full room; Taking on responsibility for passing on information

Neil James, UDID, University of South Wales, UK
Respect

- **Understanding**
  - Being sensitive; Guilt and grief; Try and better understand responses

- **Openness and honesty**
  - Consider carer views; Respect and acknowledge disagreements; Reliability and consistency

- **Reassurance**
  - Contacting the unit and visiting; About relative; Empathizing and acknowledgement; Challenges to professionals – lack of own knowledge / uncertainty about future care

- **Attitude**
  - Previous experience future expectations; Don’t dismiss/diminish; Carers as experts; Inconsistencies; Separation of responsibilities; Formal evaluation of service

Neil James, UDID, University of South Wales, UK
Recommendations/conclusion

- Services and professionals need to be aware of increased needs for support, both psychologically and informatively, that carers require when their relative’s well-being deteriorates and there is a need for admission to an Assessment and Treatment Unit.
- There is a need to consider how the processes and procedures for admission can alienate carers rather than promote their involvement and support them during this difficult experience.
- Carers need to be given information about their rights and the rights of their relative in relation to the admission process and status.
- Regular contact needs to be facilitated so that carers are kept informed and reassured about their relative’s care and well-being during admission.
- Relationships should be developed that are based on the principles of openness, honesty and trust.
- Carers should continue to be kept actively involved and empowered in respect of the decisions relating to their relative’s care.
- The identification of a key worker in respect of support generally and during admission.
- Professionals should communicate their own practice remit in relation to policy, legislation, accountability, professional codes, organisational boundaries and resource availability.
- Professionals need to develop their knowledge and understanding of each individual carer.
- Professionals need to reflect on how their attitude, actions and engagement with carers can influence the way in which carers identify with themselves.
- Transparency in the decision-making process.

Neil James, UDID, University of South Wales, UK
Contact details

Neil James
Unit for Development in Intellectual Disability
Faculty of Life Sciences and Education
Cyfadran Iechyd, Addysg, Seicoleg a Chwaraeon
University of South Wales
Pontypridd
Rhondda Cynon Taff, CF37 4DB
http://udid.research.southwales.ac.uk/

E-mail: neil.james@southwales.ac.uk