

Long Term Care Needs Following Acquired Brain Injury and Social Care Services in the UK

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With thanks to colleagues

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The territory

- ▶ Post-hospital discharge, some people in the UK affected by ABI access mainstream and/or specialist services, some access few/no services. (*Holloway 2014*)
- ▶ Community reintegration and improved quality of life will relate to a number of factors
- ▶ Intensity of service use varies, the range of services possibly encountered is broad

And the bad news....

- ▶ Significant use of non-specialist services
- ▶ Prison, homelessness, drug services, mental health, suicidality, unemployment services etc
- ▶ (Shiroma 2012, Oddy 2012, Corrigan 2012, Fleminger 2008, Simpson 2007 and Friedland 2014)

Aims

- ▶ To identify what services are being used by people affected by brain injury and their families
- ▶ To ascertain respondents/participants views of the effectiveness of services

Method and participants:

- ▶ **Stage 1: Online questionnaire**
- ▶ Multiple choice, Likert Scale, comments box and rating scale
- ▶ 99 Participants (19 survivors, 26 family members, 31 ABI specialist professionals and 23 generic community service professionals)

- ▶ **Stage 2: Face to face interviews**
- ▶ 14 individuals interviewed (2 survivors, 5 family members, 4 ABI specialist professionals and 3 generic community service professionals)

- ▶ **Stage 3: Thematic analysis of results**

Results:

- ▶ Most commonly encountered services General Practitioner, General Hospital and Social Services.
- ▶ Participants ranked a top 3 and bottom 3 of the services they had encountered
- ▶ Highest ranked service provided by Solicitors, General Practitioners and General Hospital Services
- ▶ Lowest ranked service (*by far*) Social Services but General Practitioner, Hospital and Mental Health services also poorly rated
- ▶ *(Holloway 2017, Flynn 2016, Norman 2016, Mantell 2010, George & Gilbert 2018)*

5 Themes (from Q's and interviews)

► Knowledge and Understanding of ABI

“GP listened to me rather than thinking he knew all the answers!”

“Where do you want to start? There is a terrible lack of underpinning knowledge amongst non-specialist professionals - insight and executive impairments are virtually always missed.”

► Access to and Quality of Services

“Follow up care and support after discharge from acute care is very poor, often non-existent”

“There is not a specialist service operating in our area and therefore these clients are missing out on specialist rehab”.

► Impact of ABI

“life’s changed completely um because I’ve got now like a...toddler that’s never going to grow up”

“You go through horrendous times with it. I’ve actually felt quite suicidal at times. And I don’t think people know that I really have.”

► Safeguarding

“Professionals taking what the person with an ABI says at face value, even when I have explained lack of insight and self awareness... Commissioners arguing that residential carers...are appropriate for a person with significant cognitive difficulty, when in fact they need consistency and support from people who can understand their needs and can direct them when their frontal lobes fail to”

► Hidden Disability

“if you met him now you wouldn’t think there was a problem...this is where the so called professionals have kind of not...seen what was there, I’ve seen it urm, my friends have seen it, my family have seen it”

“My clients have invisible disabilities and these are not responded to by social workers in particular. The response by social services is embarrassingly bad and is killing people with an ABI.”

Conclusion

- ▶ Individuals with an ABI encounter a wide range of services
- ▶ Specialist services/community services are frequently absent
- ▶ Lack of training of non-specialist staff exacerbates difficulties experienced by individuals with an ABI, their family members and the specialist staff who work with them (*ongoing work to address this*)

Thank you for your time and patience

▶ Any questions?

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