2017

Understanding the experiences of people with Acquired Brain Injury and their interactions with outside services

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Appendices

Appendix A: Survey information sheet and consent form

Long term care following Acquired Brain Injury: Understanding the gaps in support and service provision

What is the study about?

The research aims to better understand the interactions between people with Acquired Brain Injuries (ABI) and outside services, for example social workers. Surveys will be used to look at the type of experiences those individual with ABI, their families and staff members have undergone with these services, and the degree to which they believe these services have an understanding of their difficulties. In addition staff from outside organisations will be asked to take part in surveys and interviews to identify the difficulties they experience when supporting clients with ABI. Ultimately this information will be used to develop a new form of support to bridge the gap in communication between services and those with ABI.

What will be expected of me as a participant?

You will be asked to take part in an online survey. These will be asking questions about your experiences, or your family member's experiences, with a number of services that will be listed. If you are a professional working within the organisations, you will be asked to answer questions about the difficulties you feel you face when supporting clients with ABI.

What are the risks and benefits?

There are no physical risks associated with this research.

The interview and questionnaires will be asking you to talk about your experiences and feelings in relation to a sensitive topic, however, and so involves the risk of psychological distress.

Little research has been conducted into the interactions between those with Acquired Brain Injury and outside services that are involved with them. We hope that this research will identify any issues which are significant to people in this position, and that this may be used to improve services in the future.

Will it be confidential?

All information given within the interviews and questionnaires will be confidential. Consent forms for the interview study will be kept separately to the data collected, and the data itself will be anonymised. All hard data will be kept in locked cupboards and electronic data in password protected computers. That data will be kept for ten years in line with University policy.

Will it be anonymous?

All questionnaires will be anonymous. The data collected from this survey will be used to further understanding of the experiences of those with ABI and outside services. However, no names will be used when disseminating the research findings.

Will it affect my relationship with the University?

Taking part in this study, or choosing to withdraw at any stage will not affect your relationship with the University in any way.

Can I withdraw?

You have the right to withdraw at any point before or during the questionnaire. If you wish to withdraw this data after you have finished the questionnaire you are free to do so, through informing the interviewing researcher, or contacting the Principal Investigator (named above) on the number below.

How will I notify my intention to withdraw?

Please contact the principal investigator Dr Alyson Norman by phone (01752 584844) or via email (alyson.norman@plymouth.ac.uk).

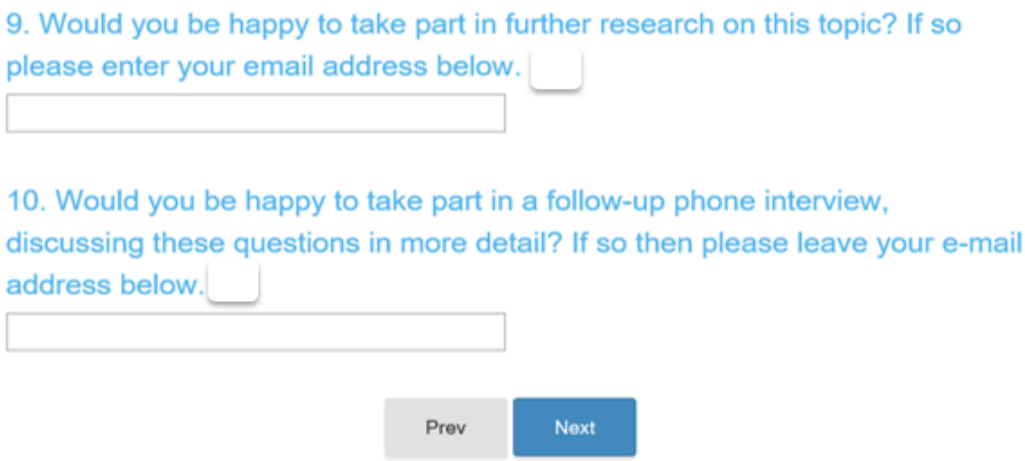
How can I get further information if I so wish?

More information about this study can be sought from the principal investigator. A report of the findings of this study will be available to all participants on completion of the study. The researcher will ensure this is sent to you via email

Are you happy to continue with this survey?

○ Yes ○ No

Appendix B: Online consent to interview



Appendix C: Informed consent sheet

PLYMOUTH UNIVERSITY
FACULTY OF HEALTH AND HUMAN SCIENCES

RESEARCH INFORMATION SHEET FOR PARTICIPANTS

Name of Principal Investigator:

Dr Alyson Norman

Title of Research:

What are the experiences that people with Traumatic Brain Injuries have with outside services? A Qualitative and Quantitative analysis, involving family and staff members.

What is the study about?

The research aims to better understand the interactions between people with Traumatic Brain Injuries (TBI) and outside services, such as probation and social workers. Surveys and interviews will be used to look at the type of experiences that families and staff members have undergone with these services, and the degree to which they believe these services have an understanding of their difficulties.

What will be expected of me as a participant?

You will be asked to take part in an online survey, which will be asking questions with regards to your experiences with a number of services that will be listed. This is designed to explore your own opinion on these matters, so there are no right or wrong answers within this survey.

Or/and you will also be asked to take part in a semi-structured interview, with questions relating to your experience, as someone close to a person with TBI, on how understanding these services have been towards them. The interview is designed to allow you to talk about your own feelings and thoughts around this, and there are also no right or wrong responses.

With your permission, the interview will be recorded as an audio recording.

What are the risks and benefits?

There are no physical risks associated with this research. The interview will be asking you to talk about your experiences and feelings in relation to a sensitive topic, however, it may involve the risk of psychological distress.

Little research has been conducted into the interactions between those with Traumatic Brain Injury and outside services that are involved with them. We hope that this research will identify any

issues which are significant to people in this position, and that this may be useful to inform those outside services of any potential additions to be made, if required.

Will it be confidential?

All information given within the interviews will be confidential. Consent forms will be kept separately to the data collected, and the data itself will be anonymised. All hard data will be kept in locked cupboards and electronic databases in password protected computers. That data will be kept for ten years in line with University policy.

Will it be anonymous?

All transcripts and surveys will be anonymous. The data collected from this study will be used to further understanding the experiences of those with TBI and outside services. However, no names will be used when disseminating the research findings.

Will it affect my relationship with these outside services?

Taking part in this study, or choosing to withdraw at any stage, will not affect your relationship with any outside services mentioned in any way.

Can I withdraw?

You have the right to withdraw at any point before or during the interview and the survey. In addition, any data we collect – survey information, audio recordings and transcription of these recordings – will be used only with your permission. If you wish to withdraw this data after the interview or survey you are free to do so, through informing the interviewing researcher, or contacting the Principal Investigator Dr Alyson Norman on the number below.

How will I notify my intention to withdraw?

Please contact the principal investigator Dr Alyson Norman by phone (01752 584844) or via email (alyson.norman@plymouth.ac.uk).

How can I get further information if I so wish?

More information about this study can be sought from the principal investigator. A report of the findings of this study will be available to all participants on completion of the study. The researcher will ensure this is sent to you via email or postal address. Please state how you would like to receive this information.

If you are dissatisfied with the way the research is conducted, please contact the principal investigator in the first instance: 01753 584844. If you feel the problem has not been resolved please contact the secretary to the Faculty of Health and Human Sciences Ethics Committee: Ms Sarah Jones 01752585339.

Appendix D: Consent form

PLYMOUTH UNIVERSITY
FACULTY OF HEALTH AND HUMAN SCIENCES
CONSENT TO PARTICIPATE IN PSYCHOLOGY RESEARCH PROJECT

_____

Name of Principal Investigator:
Dr Alyson Norman

_____

Title of Research:
What are the experiences that people with Traumatic Brain Injuries have with outside services? A Qualitative and Quantitative analysis, involving family and staff members.

_____

Brief statement of purpose of work:
The research seeks to improve understanding of the interaction between people with Traumatic Brain Injury (TBI) and outside services working with them, through analysis of interviews and surveys with family and staff members involved with people with TBI.

_____

The objectives of this research have been explained to me.
I understand that I am free to withdraw from the research at any stage, and ask for my data to be destroyed if I wish.
I understand that my anonymity is guaranteed, unless I expressly state otherwise.
I understand that the Principal Investigator of this work will have attempted, as far as possible, to avoid any risks
Under these circumstances, I agree to participate in the research.

Name: …….

Signature: .....…….. Date: .....

Appendix E: Interview schedule and script

Interview script and schedule

The research aims to better understand the interactions between people with Acquired Brain Injuries (ABI) and outside services.

This information will be used to develop a new form of support to bridge the gap in communication between services and those with ABI.

The interview will take approximately 30minutes to an hour and with your permission will be audio recorded. Is it ok for me to record this conversation? All conversations are confidential and all transcripts and recordings will be anonymised.

You have the right to withdraw at any point before or during the interview. If you wish to withdraw this data after the interview or questionnaire you are free to do so, by informing myself, or contacting Dr Alyson Norman the Principal Investigator by the number on the information sheet.

Do you have any questions about the process before we start?

Schedule:

Aftermath of ABI (impact)

1. **Could you give me a brief history of your work with brain injured patients/experience of someone with brain injury?**
    a. *Prompt: type of brain injury (traumatic, tumour, stroke), symptoms (physical, cognitive, social).*
2. **Could you describe what happens once a diagnosis is given?**
    a. *Prompt**:** explaining what happens next/ are you told what the whole process will be like?*
3. **How do you perceive the effects of brain injury?**
    a. *Prompt: psychosocial effects: anger, depression, difficulty with relationships, substance abuse, motivation. Physical effects. Cognitive effects: decision making, attention, memory.*
4. **How were these effects explained to you**? / How did you explain the possible effects?
    a. *Prompt: warned at the start or along the way? Leaflets / websites / key worker assigned?*
5. **What is your relationship like with the patients/professionals**?
    a. *Prompt: Front line services, health professionals*
6. **What parts of you experience with treatment worked well?**
    a. *Prompt: communication, services offered, treatment*
7. **What would you have liked more during the process of treatment?**

Family relationship

8. **What effect has this had on the family or close friends?**
    a. *Prompt: any groups for families to understand more?*

Life changes after brain injury

9. **What are the major differences after the injury?**
    a. *Prompt: employment/education, maintaining relationships, family dynamics*
10. **What do you think about the other services/ therapy sessions available?**
    a. *Prompt: what type? How long? Independent or group based? More than one option given? Are most people interested in part-taking in services available?*
11. **How did you benefit from therapy/services?**
12. **If you could, what would you add to the care after discharge?**
13. **How was the person with brain injury prepared for discharge?**
    a. *Prompt: social services LT or ST? Contacting employers*
14. **What sort of difficulties have you witnessed of those with brain injury?**
    a. *Prompt: Crime, substance abuse, housing*
15. **What other organisations were involved with the care?**
    a. *Probation services, social services, financial advisers, disability employment advisers, job centre, housing officers, learning support advisers, home care services, solicitors,*

GP, drug rehabilitation, mental health services, occupational health general hospital services.

b. *Negatives and positives.*

16. **How do you think long term community support can be improves after Brain injury?**
    a. *Prompt: communication, signposting/ referrals to services*

End

Thank you so much for taking the time to talk to me about your experience.
Summarise main points
Is there anything else you wish to add to this?
Do you have any questions for me?
Thanks again for taking part. Once the research is finished, we will make sure you receive information about the research findings.

Appendix F: Debrief sheet

PLYMOUTH UNIVERSITY
FACULTY OF HEALTH AND HUMAN SCIENCES

RESEARCH INFORMATION SHEET FOR PARTICIPANTS: INTERVIEW DEBRIEF

Name of Principal Investigator:

Dr Alyson Norman

Title of Research:

What are the experiences that people with Traumatic Brain Injuries have with outside services? A Qualitative and Quantitative analysis, involving family and staff members.

Thank you for taking part in this interview. Do you have any further comments, or any questions about the interview or the research as a whole?

If you have any concerns about the interview procedure which you do not wish to raise with me directly, please contact Dr Norman, the Principal Investigator, by email: Alyson.norman@plymouth.ac.uk, or at the number given below (01752 584844).

Likewise, if at a later time you have any further questions, or wish to withdraw your consent for your data to be used in this research, please contact Dr Norman. I would like to remind you that you can withdraw your data at any point up until it is submitted as part of the research report at the end of April 2017.

Please find below a list of contact details for agencies which may be helpful to you, should you suffer any distress in relation to the matters we have discussed in interview.

Thank you again for agreeing to take part in this study, and for your time today.

Headway UK Tel: 01159240200
Fax:01159584446
Email: enquiries@headway.org.uk
Helpline: 08088002244 or helpline@headway.org.uk

If you are dissatisfied with the way the research is conducted, please contact the principal investigator Dr Alyson Norman in the first instance: 01752 584844. If you feel the problem has not been resolved please contact the secretary to the Faculty of Science and Technology Human Ethics Committee:
Ms Sarah Jones 01752 584503.

Appendix G: Section of interview 7's analysis table

Emerging themes	Original transcript	Exploratory comments
	1.I: ok great. Ok. So please can you give me a brief history of your work with brain injured patients?	
Major issue of ABI is vulnerability	2.P: so, I'm a police officer, and urm, I, joined the police seven years ago and started of as a, response, urm, PC, which involves going out, and urm, dealing with, people, or 999 calls coming from members of the public. So urm, I guess like my first involvement was initially, dealing with, with with with calls that they make to the police, and very often or sometimes, people with urm, brain, injuries, are vulnerable within the community and they may call the police. So I guess in that stage it's initially as a response officer… urm and then, when I when I consequently been promoted, urm, I'm now, I'm now an inspector within the police, I sort of oversee urm, err, a district in in (area) so the whole of, (area), and urm I manage a police response throughout the shift, so I now, sort of manage the response if you like, for the brain injuries they may call us and a number of other people who call us during the shifts.	Perception of vulnerability of those with Brain Injuries
	3.I: ok, and under what circumstance would they normally call you?	Contact with police is mainly to do with aftereffects of brain injuries, e.g. cognitive difficulties
Vulnerability of ABI makes them at high risk of being exploited	4.P: well it could be hugely varied, but in all honesty its urm… it's very rarely in relation to an actual brain injury that they will call, that may be a a contributing factor, to why they're calling us, so for example it could be that someone with a brain injury, is potentially, urm vulnerable because perhaps they're being exploited by the wider community, in some circumstances, or… in other circumstances, they could become vulnerable for an inability to correctly dress themselves. Urrm, or it could be a fact of you know a call for concern of the public, so it's quite a wide variety really and, usually if you have, if you have a call, involving some form of vulnerability and it involves a brain injury, I think, I think the difficulty…perhaps police say is having that information readily accessible, that someone has a brain injury	Those with ABI are at high risk of being exploited Vulnerable Police contact also in relation to daily issues BI face
High vulnerability		Vulnerability is a major issue
Difficulty in identifying ABI initially		Difficulty of interaction with BI is knowing they have it initially
		Difficulty in identifying they have ABI
	5.I: right	

Questioning responsibility officers have for those with ABI

6.P: and also being able to identify it, at the first point of contact, as possibly a factor behind the reason why we're called there. I'd say that's the problem, that we, we face as policemen

7.I: hmm, and with some of the situations that you face, how would you guys normally respond to that?

8.P: well… I guess initially, the thing with urm, with sort of like brain injury, unless it's not presenting as this life threatening, at at that stage, you know a lot of people live, live with brain injuries and in (inaudible) so if it's not presented as life and life threatening then actually the action of police would take at the scene would be quite minimal, urm, that's why you look to get partner agencies involved to… manage the situation more effectively either through referral or depending on the person, children social care or adult social care or mental health or their GP, you would make that , initial, referral, if you wasn't happy or comfortable with what was going on, but then that links back into having the awareness that something is going on in the first place.

9.I: right

10.P: because people may not always disclose that they have you know some form of brain injury and then it links back into hospital training issues, or information sharing issue, about making sure that that police responder, has the information available to him because… understanding the, the the context and the demands and environment by what they say, for example last night I erm I was duty in (area) and I managed a large amount of calls and the majority of the calls were around… welfare and suicidal people and missing people, and I probably suggest that the data is delicate, you know a certain proportion of these will have some form of brain injury, urm and, having some sort of natural response police don't have that information so it will be down to them to sort of diagnose it, or not diagnose it to identify it at the scene if you know what I mean, so the information we use is police computers and PNC and, I think it's about, having the ability to interface those, those, those systems so we have all the knowledge we need to do the right thing at the right time if that makes sense.

11.I: yeah it does

12.P: hmm

Not job of officers unless life threatening
They cannot do much
Responsibility lies with other services

Major issue in identifying ABI for appropriate response

Knowledge of right services to contact
"depending on the person" – Individuality of differences in BI acknowledged

Difficulty in understanding ABI when unidentified – lack of knowledge

Inability to identify that they have a brain injury is a major issue
They are not equipped to respond appropriately if information is not passed on

Poor communication between service about individuals with ABI

Poor communication between different services makes it difficult for him to do his job and have the understanding in the first place

Major issue in identifying ABI for appropriate response
Lack of knowledge

High vulnerability among those with ABI.
Self-diagnosing/identifying as a result of little information being passed on

Yellow- Vulnerable
Green- Exploited/taken advantaged of
Blue- lack of knowledge (information not there)
Pink- Issues in identifying ABI
Red- difficulty in understanding behaviour when little information is shared
Dark blue- services not fulfilling their role
Teal- other services system is set up to fail
Dark green- lack of understanding from services
Grey – no official training regarding ABI

Understands what the issue is and has solution so that they have the knowledge to respond appropriately.
Shows that there is a lack of knowledge

Appendix H: Example of interview 7's cluster of themes table

Emergent themes

Interview 7
Major issue of ABI is vulnerability
Vulnerability of ABI makes them at high risk of being exploited
High vulnerability
Difficulty in identifying ABI initially
Questioning responsibility officers have for those with ABI
Major issue in identifying ABI for appropriate response
Difficulty in understanding ABI when unidentified – lack of knowledge
Poor communication between service about individuals with ABI
Major issue in identifying ABI for appropriate response
Lack of knowledge
Services need to be proactive
Services not fulfilling their role
System of other services are failing those with ABI when dealing with them
Vulnerability of ABI
Lack of understanding of other services about ABI needs
System of other services are failing those with ABI when dealing with them
Officers are overworked
Services need to build stronger relationships to understand ABI difficulties
Lack of training
Lack of training to cater for nonthreatening urgent demands
Lack of training for invisibility of ABI
Issue of invisibility leads to lack of understanding
Only equipped for visible urgent needs
System need to flag up ABI before officer interact with individual
Lack of broad understanding about effects of ABI
Vulnerability of ABI makes them at high risk of being exploited
Vulnerability leads to direct and indirect involvement in criminal behaviour
Being exploited due to vulnerability
Family members involvement can be beneficial
Invisibility of ABI makes interaction difficult
Family members involvement can be beneficial
Provide important history of person with ABI
Importance of record keeping for future interactions
Lack of training
Lack of knowledge (information) due to poor communication

Super-ordinate themes after clustering of emergent themes

Consequences of ABI
Vulnerability of ABI makes them at high risk of being exploited (x7)
Vulnerability leads to direct and indirect involvement in criminal behaviour
Vulnerability issues of ABI are not addressed by other services

Invisibility of ABI
Difficulty in identifying ABI initially
Major issue in identifying ABI for appropriate response
Difficulty in understanding ABI when unidentified – lack of knowledge
Issue of invisibility leads to lack of understanding
Only equipped for visible urgent needs
Invisibility of ABI makes interaction difficult
Importance of record keeping for future interactions
Issue of identifying ABI (x2)

Relationship between different services
Poor communication between services about individuals with ABI
System need to flag up ABI before officer interact with individual
Lack of knowledge (information) due to poor communication
Questioning responsibility officers have for those with ABI (x2)

Relationships between services and users
Services need to build stronger relationships to understand ABI difficulties
System of other services does not allow enough interaction
Lack of strong enough relationship between service providers and users

Failing system of outside services
Services need to be proactive
Services not fulfilling their role
System of other services are failing those with ABI when dealing with them
Other services are not fulfilling their role
Services are not involved enough
A lot of negative experience regarding other services
System of other services does not allow enough interaction
System of other services is failing those with ABI
Services are complacent

Difficulty in communicating important information
Boundaries in information sharing
Family member's involvement can be beneficial
Officers are overworked
Other services are not fulfilling their role
Vulnerability issues of ABI are not addressed by other services
Services are not involved enough
A lot of negative experience regarding other services
System of other services does not allow enough interaction
System of other services is failing those with ABI
Questioning responsibility officers have for those with ABI
Lack of training
Issue of identifying ABI
Questioning responsibility officers have for those with ABI
Lack of strong enough relationship between service providers and users
Services are complacent
Services are not proactive enough
Services lack understanding of needs and issues of ABI

Services are not proactive enough
Services lack understanding of needs and issues of ABI

Knowledge and understanding of ABI
Lack of knowledge
Lack of understanding of other services about ABI needs
System need to flag up ABI before officer interact with individual
Lack of knowledge (information) due to poor communication
Other services are not fulfilling their role
Services are not involved enough
Services lack understanding of needs and issues of ABI

External pressures of services
Officers are overworked (x2)
Questioning responsibility officers have for those with ABI (x2)

Lack of training in services
Lack of training (x3)
Lack of training to cater for nonthreatening urgent demands
Lack of training for invisibility of ABI
Issue of identifying ABI

Involvement of family members
Family members involvement can be beneficial (x2)
Family members involvement can be beneficial - Provide important history of person with ABI

Communication between services
Lack of knowledge (information) due to poor communication
Difficulty in communicating important information

Appendix I: Transcript extract from text citation

Master theme	Additional extracts
Hidden disability	*Int 8 p.142 "I was told not to talk about it, and, urm, they said they didn't want to hear about it, that, the workmen's compensation said that I was healed and that I had no disability, so I had no right to claim an accommodation, and not to speak about it… and I would cry at work, I was still really really emotionally unreliable, and not getting any support from services and I was written off by people that I used to manage, they were writing me up, it was really hard it was"* *Int 5 p.294 "he would get easily upset urrm and when he got upset he would just walk out of school, he still continued to have the headaches so he was unwell at home quite a lot he couldn't have possibly gone to school with the headache. Cause he often had sickness and nausea with them so his attendance urm was poor anyway but*

	I think what happened with the head injury he seemed to lose quite a lot of his confidence and self-esteem,"
Knowledge and understanding	*<u>Information provision</u>* *Int 3 p.64 " I don't think the signpost are good enough for for people that have gone through that you know hospital discharges, they you know they give them the urm the social worker puts in a package of care that's required, also and then they are sent on the way with no sort of real follow up with what about these services, can this be done ,"* *Int 1 p.125 "Urm other services that they haven't unless we've approached them we haven't really been pointed in the direction of anything, my mum is like a mad scientist looking up on the uhh she's a googler it does my head in urm looking up on google, oh what about them and this and that and there's this oxygen biometric oxygen chamber thing how about this and she's looking only with rose tinted glasses and the benefits and"* *Int 7 p.14 & 16 "having the awareness that something is going on in the first place." - "people may not disclose that they have you know some form of brain injury and then it links back into hospital training issues, or information sharing issue, about making sure that that police responder, has the information available to him because understanding the, the the context and the demands."* *<u>Empathy</u>* Int 4, p.206 he seened my husband, he urm urrm said to me, they said that, whilst my husband was getting dressed in the end he said it's about time you stopped wasting our time and got on with the rest of your life, and I have since found out that's is one of his favourite sayings because he had said it to at least one other person,
Impact of ABI	*<u>Cognitive & behavioural and psychological & social effects</u>* *Int 6 p.139,so quite often urm the the urm the rehabilitation service providers sort of always cautioned and, were very quick to say like oh you won't be able to do this or do that and didn't really strictly know what I could do in time and what could transpire. I got told by my occupation therapist that I would never work again, I would never go upstairs again and things like that and that's a lot I dealt with on a daily basis. So I think that urm service providers, rehabilitation service providers are really very quick to sort of tell you what you can't do and don't… understand the, potential that the brain can adapt and grow in time* *<u>Grieving old identity</u>* *Int 3 p.175 "in terms of family dynamics a sense of loss when er you know when the main bread winner that's experienced the injury and and you know about keeping the house going and all the other things, yeah it it is huge ramification for relationships"*
Access to services	*<u>Medical care</u>* *p.49 "obviously medical wise they have better understanding and insight in brain injuries than perhaps urrm urrrm the social workers have"* *<u>Specialist care</u>* *Int 2 p.186 "the third one we looked at it through the house manager said they had a vacancy in the nursing floor, but the actual home that manager of the whole context said no we've only got a vacancy in the dementia unit".* *<u>Interdisciplinary</u>* *Int 5 ,p: 334 well I know, my daughter tries to reach out to the social worker I don't really talk to anyone cause it's a waste of time* *Int 5, p.372 and that I, I just feel now, it's gonna be a real struggle to get him to an engage if anything, because what he his perception of what is happening through all this process, is no one really cares, and no one wants to help him, they are just want to shunt him around"* *<u>Staff and organisation issues</u>* *Int 2 p.64 he said she was an ideal candidate for his brain injury unit at (place) but I got staff problems I got a waiting list as long as that and we are in the middle of a move to a new hospital at (name of hospital) in (name of place).*

	In3 p.65 I don't know if the services are particularly there either because of reduction in funding and things like that *Int 7, p.84 they don't have the will, or it is a cultural thing that they're, they're set out to manage, people through… through meetings where the people aren't actually in the meetings, so it's like a professionals meeting, which I think is ridiculous, urm or they don't actually go to the address, and they don't actually leave their offices, they… by never actually being there and understanding this person challenges in the in the address and speaking with them, I don't think you can ever properly deal with them so.* *<u>Inconsistency</u>* *Int 5 p.76 "I think they had three different social workers, because of the case load moves around, and there hasn't been on consistent person at all"* *p.116 "his perception so why should he bother to engage with anyone, cause they'll just see him a couple times and then they'll you know we've got to close the case and move on." "cause the one person he did engage well with could only work with him for six weeks"*