



Developed at
the request of the
Department of Health

The Brain Injury Needs Indicator BINI

A tool to assist with identifying the deficits of people who have a suspected or diagnosed acquired brain injury and who may require adult social care and support.

Name of individual:

Name of assessor:

Date:

A light blue silhouette of a human head in profile, facing right, positioned to the right of the form fields.

Name of support network:

Relationship to individual:

Email address:

Telephone number:

Postal address:

A light orange icon of two hands, one slightly behind the other, positioned to the right of the form fields.

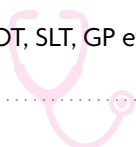
Name of health professional:

Job title (OT, SLT, GP etc.)

Email address:

Telephone number:

Postal address:

A light pink icon of a stethoscope, positioned to the right of the form fields.

This tool will also help to signpost the next steps to take; this may range from offering guidance and information to arranging specialist support services, including rehabilitation.

The BINI is consistent with elements of the Care Act 2014 Guidance¹. It is also documented in the 'Skills for Care' assessment and eligibility workbook on the Care Act².



You can learn more about the BINI and effects of brain injury in FAQs or at www.birt.co.uk/bini or email bini@thetdgroup.org

How does the BINI work?

The BINI is intended to be used by a social care assessor in conjunction with the local authority's own general needs assessment³ as it does not provide a whole assessment on need, carers' needs, eligibility or funding for care packages. For example, whilst the BINI might indicate that an individual has had a good recovery from brain injury, all other care and support needs may point to the individual requiring care and support.

The BINI uses a calculation to determine the risk to the individual caused by the brain injury. It identifies the likelihood that an injury was sustained, what the level of recovery is (i.e. physical, emotional and behavioural) and the level of an individual's insight.



*High level of risk is likely to indicate high level of need

An **individual** 🧠 with cognitive impairment such as that resulting from a brain injury may not have the ability to deliver the range and depth of information required during an assessment of need. That is why the BINI is not just a tool involving the individual; it requires clarifying information from the individual's **support network** 🤝 as well as evidence from medical records or input from a **health professional** 🩺 who has been involved in the case. This is called triangulation.



Learn more about an individual's support network and health professionals in FAQs or at www.birt.co.uk/bini

Instructions for the assessor

The BINI comprises four detailed sections, each working to identify the deficits of the brain injury to the individual by using our calculation. Each person tasked with answering the questions (the individual, the support network and health professional) should answer the questions to the fullest extent.

Section 1: Brain injury history

Section 2: Brain injury recovery

Section 3: Insight level

Section 4: FAQs + next steps

A brain injury may have involved a blow to the head, a stroke, or a non-degenerative brain disease. Your communication throughout the assessment must be **clear** and **easy to understand**, and your conversation spoken at an **unhurried pace**, as brain injury can affect speed of processing. If this individual's condition fluctuates you can halt the process and re-start over a period of time.

Section 1: Brain injury history

Please tick the appropriate response

? **Handy Hint:** The questions are written in the first person as if communicating with the individual only. 'You' should be substituted for 'they' for the second and third parts of the questionnaire.

 Individual	 Support network	 Health Professional
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1. Have you [?] ever had a serious blow to the head?	<input type="checkbox"/> YES <input type="checkbox"/> NO	<input type="checkbox"/> YES <input type="checkbox"/> NO	<input type="checkbox"/> YES <input type="checkbox"/> NO
--	--	--	--

.....

If yes, when?

.....

2. Have you had any other blows to your head?	<input type="checkbox"/> YES <input type="checkbox"/> NO	<input type="checkbox"/> YES <input type="checkbox"/> NO	<input type="checkbox"/> YES <input type="checkbox"/> NO
--	--	--	--

.....

Give details

.....

3. Have you had an illness affecting your brain?	<input type="checkbox"/> YES <input type="checkbox"/> NO	<input type="checkbox"/> YES <input type="checkbox"/> NO	<input type="checkbox"/> YES <input type="checkbox"/> NO
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.....

Give details

.....

4. Did you require medical treatment for your injury or illness?	<input type="checkbox"/> YES <input type="checkbox"/> NO	<input type="checkbox"/> YES <input type="checkbox"/> NO	<input type="checkbox"/> YES <input type="checkbox"/> NO
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.....

Give details

.....

Section 2: Brain injury recovery

The assessor will note that some of the questions are adapted from the Glasgow Outcome Scale Extended (GOS-E)⁴ and loosely relate to outcomes of the Care Act eligibility criteria. However, the level of need from a care and support perspective should be determined after all the information and evidence has been gathered from all assessments undertaken. Section 2 contains a dual scoring system whereby the assessor uses the triangles to shade in any obvious discrepancies in answers given (i.e. the support network or the health professional or both disagrees with the individual) and also uses low, moderate or good recovery to establish what level the individual's recovery is currently at. For each question the respondent should select the box that best describes the answer by placing a tick in the appropriate 'yes' or 'no' box.





TOP TIPS

- If the respondents don't understand the question, use the 'Handy hint' to give them a clearer idea of what is being asked.
- If your time is short, when the individual is answering the questions, a separate copy can be sent to the health professional and/or support network and answers can be amalgamated later.
- The responses in this section should be gathered separately. For example, the individual should answer all questions, then the questions should be completed by the support network and finally the health professional. This is to avoid bias or duplication of answers. Sometimes masking the answers of the previous respondent helps also.

1a. Is the assistance of another person in the home essential everyday for some activities of daily living for the individual?






Handy hint: For a 'no' answer the individual should be able to look after themselves. The Individual should be able to look after themselves at home for a **24 hour period** if necessary (for example if a spouse or carer has to leave the house). Looking after themselves should include the ability to plan for and carry out both daily living activities as well as handling potentially minor domestic crises (e.g. a smashed glass, a stranger comes to the door). The individual should be able to carry out all of these activities without needing prompting or reminding.

Respondent	 Individual	 Support Network	 Health Professional	 ASSESSOR shade in the triangle if there is discrepancy in answers given
Yes				
No				





1b. Does the individual need frequent help or someone to be around at home most of the time?



Handy hint: 'Most of the time' in this question is defined as an **eight hour period**. For example if the individual was left alone by a spouse or carer for this amount of time, would the respondent feel confident in the individual not receiving help, care or support during this period?





Respondent	 Individual	 Support Network	 Health Professional	Score
(the individual needs frequent help) Yes				LR
(the individual does not need frequent help) No				

1c. Was assistance at home essential before the injury?





Respondent	 Individual	 Support Network	 Health Professional	 ASSESSOR shade in the triangle if there is discrepancy in answers given
Yes				
No				

2a. Is the individual able to shop without assistance?

? *Handy hint:* Being able to shop without assistance includes being able to plan what to buy, take care of money themselves and behave appropriately in public. You could ask the individual to describe a trip to the shops, including what they plan to buy for their evening meal, where they will get the money to buy the food.




Respondent	 Individual	 Support Network	 Health Professional	Score	 ASSESSOR shade in the triangle if there is discrepancy in answers given
Yes					
No				LR	

2b. Was the individual able to shop without assistance before the injury?

Respondent	 Individual	 Support Network	 Health Professional	 ASSESSOR shade in the triangle if there is discrepancy in answers given
Yes				
No				

3a. Is the individual able to travel locally without assistance?

? *Handy hint:* Travelling locally may involve driving or using public transport to get around. If using a taxi, could they arrange the journey and instruct the driver on where to go?


Respondent	 Individual	 Support Network	 Health Professional	Score
Yes				
No				LR

3b. Was the individual able to travel locally without assistance before the injury?

Respondent	 Individual	 Support Network	 Health Professional	 ASSESSOR shade in the triangle if there is discrepancy in answers given
Yes				
No				

4a. Are they currently able to work (or look after others at home) to their previous capacity?




? *Handy hint:* this question is designed to identify if the individual with brain injury can take on responsibilities either in the workplace or at home. For example if a person was a homemaker prior to the brain injury, are they still able to carry out this responsibility? Or if they had a paid or voluntary position have they been able to go back to this position?

Respondent	 Individual	 Support Network	 Health Professional	 ASSESSOR shade in the triangle if there is discrepancy in answers given
go to Q5a Yes				
go to Q4b No				

→ If the respondent answers 'yes' go to question 5a. If the respondent answers 'no' go to question 4b.

4b. How restricted is the individual?

? *Handy hint:* This question is connected to 4a. Could they have reduced work capacity because of the mental or physical effort it takes to complete a full day of work? If this is the case, tick the 'reduced work capacity' box. If they are only able to work in a voluntary position or they are not able to work at all, tick the other box.





Respondent	 Individual	 Support Network	 Health Professional	Score
Reduced work capacity				MR
Able to work in a voluntary capacity or in a non-competitive job, or currently unable to work				MR

4c. Was the individual either working or seeking employment before the injury (Yes), Or they were doing neither (No)?

Respondent	 Individual	 Support Network	 Health Professional	 ASSESSOR shade in the triangle if there is discrepancy in answers given
Yes				
No				




5a. Is the individual able to resume regular social and leisure activities outside the home?

? *Handy hint:* The individual does not need to have resumed all of their previous leisure activities, however if they have not continued them because of a physical or mental change or they have lost interest or motivation in resuming leisure activities this should be answered as 'no.'





Respondent	 Individual	 Support Network	 Health Professional	 ASSESSOR shade in the triangle if there is discrepancy in answers given
go to Q6a Yes				
go to Q5b No				

→ If the respondent answers 'yes' go to question 6a. If the respondent answers 'no' go to question 5b.

5b. What is the extent of the individual's restrictions on their social and leisure activities?



Respondent	 Individual	 Support Network	 Health Professional	Score
Participate a bit less				GR
Participate much less				MR
Unable to participate				MR

5c. Did the individual engage in regular social and leisure activities outside the home before the injury?

Respondent	 Individual	 Support Network	 Health Professional	 ASSESSOR shade in the triangle if there is discrepancy in answers given
Yes				
No				




6a. Have there been any psychological problems which have resulted in ongoing family disruption or disruption to friendships?

? *Handy hint:* the respondent might not understand what 'psychological problems' may mean. Instead you could ask how the person feels since the brain injury? Has anyone commented that they 'have changed'? Do they think they now have a quick temper, become irritable easily, are anxious or insensitive to others? To learn more about post-injury personality changes see in FAQs.

Respondent	 Individual	 Support Network	 Health Professional	 ASSESSOR shade in the triangle if there is discrepancy in answers given
go to Q6b Yes				
go to Q7a No				


→ If the respondent answers 'yes' go to question 6b. If the respondent answers 'no' go to question 7a.

6b. What has been the extent of the disruption or strain?

Respondent	 Individual	 Support Network	 Health Professional	Score
Occasional (less than once a week)				GR
Frequent (once a week or more, 'it's tolerable')				MR
Constant (daily and intolerable)				MR




6c. Were there problems with family or friends before injury?

? *Handy hint: All relationships can be impacted negatively from time to time. However, if the respondent thinks that these have become markedly worse since the injury, the answer should be "no".*

Respondent	 Individual	 Support Network	 Health Professional	Score
Yes				
No				




7a. Are there any other current problems relating to the injury which affect the individual's daily life?

? *Handy hint: Brain injury can have an effect on lots of different parts of the body. Does the respondent think there has been headaches, dizziness, tiredness, sensitivity to noise or light, general slowness, memory or concentration problems since the injury? If one or many of these are identified please answer "yes".*

Respondent	 Individual	 Support Network	 Health Professional	Score
Yes				
No				GR

7b. Were similar problems present before the injury?

? *Handy hint: If there were some problems before the injury, but these have become markedly worse since injury, then answer "no".*

Respondent	 Individual	 Support Network	 Health Professional	 <p>ASSESSOR shade in the triangle if there is discrepancy in answers given</p>
Yes				
No				

Scoring Section 2 of the BINI

The results of the GOS-E can indicate Low Recovery (LR), Moderate Recovery (MD) or Good Recovery (GR). **Low Recovery is the lowest (poorest) outcome that can be scored in section 2 whereas Good Recovery is the best outcome.**

To determine the score: regardless of who has answered the question, if a tick lies on the same row/level as a box with LR, MR or GR, take the lowest outcome (for example, two ticks of GR and one tick of MR, you would use the MR score) and use this as the total score for this question.

The **overall** rating is based on the lowest outcome category indicated, across all respondents. This means you always use the **lowest** outcome as the score. Below are three examples to help you:

- The assessor has counted up 3 GR's, 3 MR's and on 1 LR. The Total Score for section two is **LOW RECOVERY**
- The assessor has counted up 6 GR's and 1 MR. The Total score is **MODERATE RECOVERY**
- The assessor has counted up 6 LR's and 1 MR. The Total score is **LOW RECOVERY**

Please mark which outcome level best applies to your client.

Outcome of the brain injury	Description	Overall rating for your client
Low Recovery (LR)	Fully independent before the brain injury, but there are clear difficulties identified in daily living which will have a detrimental affect on the individual's ability to live independently. This result would suggest the individual has a severe disability resulting from a brain injury.	
Moderate Recovery (MR)	The individual is likely to have had no prior problems or prior problems which have become markedly worse since the brain injury. For example the individual always had a short temper, but is now having difficulty sustaining a social life because of this. The result would suggest that the individual has a moderate disability resulting from a brain injury.	
Good Recovery (GR)	This result indicates that the individual has recovered well or sustained no serious deficits as a result of brain injury. It could be that injury still caused mild changes or that the individual is suffering from the psychological effects of a brain injury. For example a violent fight or serious traffic accident that has had serious repercussions for the individual or others involved	



Have any of the triangles been shaded in? This does not count towards the score but gives a good visual indication to the assessor that there are a number of discrepancies between answers given by the individual when compared with those of their support network and health care professional.

- Yes, there is at least one discrepancy between the individual and the other two answers**
- No, there are no discrepancies**

If this is the case and the GOS-E recovery rating indicates a Low or Moderate Recovery, continue to Section 3: insight level.

Section 3: Insight level

This section uses the awareness questionnaire to indicate if the individual has insight into the impact of their brain injury⁵. Therefore in this instance the assessor needs to consider who knows the individual the best and ask them to complete the BINI. This could be the original appointees from the support or health network, including a social worker who has worked with the individual prior to the brain injury.

Please rate from one to five the following questions from the Awareness Questionnaire according to the scale below. Place the scores in the relevant box.

- Much worse** **A little worse** **About the same** **A little better** **Much better**



Individual



Support Network

1. How good is your ability to live independently now as compared to before your injury?		
2. How good is your ability to manage your money now as compared to before your injury?		
3. How well do you get along with people now as compared to before your injury?		
4. How well can you do on tests that measure thinking and memory skills now as compared to before your injury?		
5. How well can you do the things you want to do in life now as compared to before your injury?		
6. How well are you able to see now as compared to before your injury?		
7. How well can you hear now as compared to before your injury?		
8. How well can you move your arms and legs now as compared to before your injury?		
9. How good is your coordination now as compared to before your injury?		
10. How good are you at keeping up with the time and date and where you are now as compared to before your injury?		
11. How well can you concentrate now as compared to before your injury?		
12. How well can you express your thoughts to others now as compared to before your injury?		
13. How good is your memory for recent events now as compared to before your injury?		
14. How good are you at planning things now as compared to before your injury?		
15. How well organised are you now as compared to before your injury?		
16. How well can you keep your feelings in control now as compared to before your injury?		
17. How well adjusted emotionally are you now as compared to before your injury?		
TOTAL		

Scoring Section 3 of the BINI

1. For each respondent, please add the scores from Section 3 and fill in the 'TOTAL' cells below.
2. Subtract the support network's total score from the individual's total score.



3. If the final total is:

- **0-20**, there is **no lack of insight or mild lack of insight** – indicative of low risk of vulnerability and/or self-neglect
- **20-29**, there is **moderate lack of insight** – indicative of a significant risk of vulnerability and self-neglect
- **29 or more**, there is **severe lack of insight**, which is indicative of high risk of vulnerability and self-neglect

Conclusion

BINI scores

Section 1: Brain injury history

Was a brain injury identified by at least two people? Yes No

Details:

Section 2: Brain injury recovery

- Low Recovery
 Moderate Recovery
 Good Recovery

Section 3: Insight level

- Severe lack of insight
 Moderate lack of insight
 Mild lack of insight



Risk determination

Use the matrix below to generate what **level of risk** the individual may have by ticking the appropriate box.

Section 2 \ Section 3	LOW RECOVERY	MODERATE RECOVERY	GOOD RECOVERY
NO or MILD LACK OF INSIGHT	MEDIUM/HIGH RISK <input type="checkbox"/>	MEDIUM RISK <input type="checkbox"/>	LOW/NO RISK <input type="checkbox"/>
MODERATE LACK OF INSIGHT	HIGH RISK <input type="checkbox"/>	MEDIUM RISK <input type="checkbox"/>	LOW/MEDIUM RISK <input type="checkbox"/>
SEVERE LACK OF INSIGHT	HIGH RISK <input type="checkbox"/>	HIGH RISK <input type="checkbox"/>	N/A <input type="checkbox"/>

Level of risk is a strong indicator of the needs of the individual.

Section 4: FAQs + next steps

You should now have a greater understanding of the needs the individual has, including their recovery process so far and the level of understanding they have into their abilities post-brain injury. The BINI and any other assessments the individual has undertaken should allow you to develop an integrated care and support package with brain-injury specific interventions. The BINI will also help you to evidence to other parties the extent of the individual's brain injury.

The common effects of brain injury can affect an individual's ability to be independent in or outside the home, and to participate in social roles and activities that are meaningful to them and their wellbeing. This may affect their work, leisure, religious or family life.

If the individual has scored high or moderate risk in the BINI this does not fully relate to the eligibility of the Care Act. However level of risk can help identify level of need. It should also be clear whether they have needs resulting from the brain injury and these should be addressed in the next steps you take.

Some people recover relatively well from brain injury and are able to return to their previous level of function. They may have some difficulties that can be circumvented by making small adaptations or ensuring that the skills they have are retained in order to prevent a further deterioration or requiring more support.

Below is some guidance of what you might do to provide support to someone with a brain injury who has been determined to have a level of need by the BINI.

High Risk

A person with scores that indicate a high level of risk could be in danger of self-neglect or vulnerability. The person may need to receive specialist care and support, and may not to be able to return to a 'normal' life, as they or their family lived it before brain injury.

Your next steps: They almost certainly have had a poor recovery from brain injury and have little or no insight into their abilities post-brain injury. This will impact on most parts of their daily living and it may be that they have difficulty in communicating what their true needs are. You should strongly consider that this individual will need brain injury rehabilitation. Rehabilitation is crucial to improving individuals with brain injury needs and should focus equally on proven brain injury rehabilitation methods and improving the wellbeing. To find out if this is the correct path, a specialist assessment from a brain injury provider will determine if this will help – these assessments are usually free of charge.

The assessment will help determine what strategies may be suitable for this person and how to meet their needs and reduce risk.

The assessor, the individual's GP or the relevant clinical commissioning group should be able to refer them for assessment. These next steps should be conducted in a multi-faceted way so that all parties are kept informed of developments as the individual may require support for an extended period.

Moderate Risk

A person with scores that indicate moderate risk is likely to have difficulties that affect their ability to work and/or to participate in social and leisure activities. Their difficulties are also likely to affect their relationships. These activities and relationships are important to them and a negative change could impact the individual's wellbeing, as well as that of those who are close to them. It is best if those who provide support to the individual have knowledge and experience of working with people with brain injury.

It is possible they will need to re-learn certain skills or have aids and adaptations in place, these are often required if an individual is not able to fully re-learn a lost skill or ability. They may also benefit from engaging with local support groups and from receiving information materials designed for people with a brain injury. Preventative and social support services at this point are crucial if the local authority does not want the individual to regress to a high need.

Your next steps: The local authority should have existing relationships with the local NHS community brain injury team. Accessible information about local support groups and general guidance for individuals with a brain injury should be made available as per Care Act guidance. Local area coordination to avoid isolation may also be of help to the individual.

Low or no Risk

Scores within the low need range indicate that the person has recovered reasonably well from their brain injury and has probably been able to return to their previous level of function with no or minimal adaptations. The risk of self-neglect and vulnerability is low. These individuals may still benefit from receiving information about accessing preventative services to help them maintain or improve their quality of life. Remember just because there is low or no need indicated from the brain injury there might be other issues or circumstances that need to be investigated if the individual is still showing signs of requiring adult social care and support.

Endnotes

¹ Care Act 2014 Guidance; www.gov.uk and search for 'Care Act Guidance'

² Skills for Care, Assessment and Eligibility workbook; www.skillsforcare.org.uk

³ Care Act 2014 Guidance, Assessment and Eligibility, Chapter 6

⁴ Glasgow Outcome Scale Extended. Wilson, J. L., Pettigrew, L. E., & Teasdale, G. M. (1998). Structured interviews for the Glasgow Outcome Scale and the extended Glasgow Outcome Scale: guidelines for their use. *Journal of Neurotrauma*, 15(8), 573-585.

⁵ Sherer, M., Bergloff, P., Boake, C., High Jr, W., & Levin, E. (1998). The Awareness Questionnaire: Factor structure and internal consistency. *Brain Injury*, 12(1), 63-68.

⁶ Care Act 2014 Guidance, Independent Advocacy, Chapter 7

Useful contacts

Assessment and rehabilitation

- **BIRT** is one of the largest providers of brain injury rehabilitation in the UK, and offers a range of services from England, Scotland and Wales. www.birt.co.uk
- **The Independent Neurorehabilitation Providers Alliance** www.in-pa.org.uk
- **United Kingdom Acquired Brain Injury Forum (UKABIF)** www.ukabif.org.uk
- **Neurological Alliance** www.neural.org.uk

Information and support

- **Headway** – the brain injury association www.headway.org.uk
- **The Stroke Association** www.stroke.org.uk
- **The Encephalitis Society** www.encephalitis.info

Frequently asked questions (FAQs)

Can anyone use the BINI to assess the needs of an individual with a brain injury?

The BINI should be used by social care assessor. It does not and should not seek to take the place of specialist brain injury social workers. It is a tool to evidence and procure a better definition of need of the individual. The assessor should have a good knowledge and experience of working with people who have a brain injury as the BINI requires an ability to spot the complex signs or deficits of brain injury that those such as social workers or occupational therapists rely on daily. The BINI can be used as evidence for funding but is not a calculator of care packages.

What is meant by the individual's support network?

The BINI follows the Care Act guidance on 'supporting the person's involvement in the assessment.' This means that, in all cases, the local authority must also involve any other person requested by the individual.

This could be a family member, friend or a support worker. If this is the case, any of these persons could be deemed to be part of the individual's support network.

It is important that whoever is appointed to help complete the BINI is regarded as a valuable and informative person who can provide the information needed. If the assessor has concerns then they must follow safeguarding procedure as stated in the Care Act.

If the individual asks for a paid worker to be present during the assessment to **act as an assessor** this is not allowed. However, the guidance is clear that the individual can ask for anyone they wish to be in the assessment and subsequent care planning processes, and this can include paid members of staff.

What if the individual does not want to appoint someone in their support network to answer the BINI questionnaire?

If the individual **does not** agree that a member of their support network may take part in the assessment and does not display a need for support to be fully involved, the assessor must rely on the medical records, or input from the health professional as well as that of the individual.

What if the assessor determines that the individual needs support to be fully involved in the assessment process?

If the individual does not request to involve a member of their support network in the assessment, but **does** need support to be fully involved, the appointed independent advocate could be consulted with.

In all cases that involve an individual with a suspected or identified brain injury, we strongly recommend that the independent advocate has specialist training and experience in advocating for individuals with a brain injury.

There is a case study for the 'advocacy' duties laid out in the Care Act 2014 guidance.⁶ 'Stephen' requires an independent advocate to help facilitate his involvement in the assessment process. The advocate has specialist brain injury training.

What about advocates appointed under the Mental Capacity Act?

If the individual requires an Independent Advocate or Independent Mental Capacity Advocate (IMCA), then they should be present during the BINI process as per guidance. Many of the individuals who qualify for independent advocacy will also qualify for advocacy under the Mental Capacity Act 2005.

What is meant by using medical records or seeking input from an associated health professional?

Any health professional who is providing, or has provided, care for the individual after their brain injury can have vital knowledge of how the individual sustained their injury, what parts of the brain were damaged, and the individual's behaviour, cognitive and emotional difficulties thus far such as changes in mood or personality. This information could come from a wide variety of sources including a GP, Registered General, District or Mental Health Nurse, a Clinical Psychologist, Occupational or Speech and Language Therapist, or similar.

What is lack of insight?

One of the major symptoms of a brain injury is an individual's lack of insight or self-awareness into their abilities or actions post-injury. This is usually associated with frontal lobe damage. Lack of insight is normally coupled with retained intellect and ability to converse well and some understanding from the individual that they are not the person they used to be. Therefore, 'lack of insight' can lead to misinterpretation of the social care needs and to increased vulnerability and risk for that individual.

Brain Injury Rehabilitation Trust (BIRT) cover 'lack of insight' in an online information video available on the BIRT website - www.birt.co.uk/bini

How does lack of insight relate to a social care assessment?

In an assessment or structured conversation, the individual is likely to seem able to understand the questions asked if they are based on factual understanding (e.g. Can you make yourself a sandwich for lunch? "Yes, I can.") However, probe further and many people are likely to fail to appreciate and sequence the actions needed to undertake a given task (i.e. locating the bread, lunch items and eating at the appropriate time).

Some individuals will have a good understanding of the physical nature of their injuries but little or no understanding of their cognitive defects. For example, a stroke survivor with left-side paralysis may be able to state that they suffered a stroke that affects their ability to move their arm but not comment on any other changes. Individuals may also overstate or understate their abilities based on their understanding of their brain injury.

A main focus of the BINI is to give the assessor the tools to interpret lack of insight so they have a clearer idea of the true needs of an individual. This includes the 'triangulation' method of triple-checking (through the individual's support network and health team) what an individual's true abilities are after the injury as well as using clinically evidenced outcome and self-awareness measurement tools.

What about lack of insight and social situations?

In a social situation many individuals are unaware of the effect their words and actions may have on others and so do not see the need to regulate, monitor or control their behaviour. This can be very distressing for family and friends. If the individual does understand they have changed because of their brain injury, it is not atypical to blame difficult social situations on external factors.

Lack of insight can lead to problems for the family if the individual with a brain injury insists on trying to do things that they are now unable to do and which could prove potentially dangerous. Examples include driving, going into town without support or taking medication.

How can brain injury have an impact on family life?

Coping when a family member has suffered an acquired brain injury is one of the most difficult challenges that a family can

face. Families are often the source of long term support and direct assistance to the injured person and this experience may be isolating.

With a stronger focus on the wellbeing of the carer within the Care Act, there is now a requirement that the needs assessment and care planning process focus on the needs of the carer and/or family as well.

Is there anything that can increase insight in an individual with brain injury?

Lack of insight varies in each individual and as time passes post-injury. It is possible to improve insight over time. This can be done through specialist brain injury rehabilitation. Some people may never fully regain their awareness of self and others. This is likely to impact on their ability to read social and professional situations, and lead to displaying poor interpersonal and social skills during their lifetime.

What about lack of insight and lack of mental capacity?

It is important that the assessor understands that lack of insight and lack of mental capacity are two separate issues, and that an individual can lack both insight and mental capacity, lack just insight or mental capacity or retain both insight and mental capacity after brain injury. As the Care Act guidance now has regulations around independent advocacy as well as 'mental capacity advocacy,' it will not be unusual that the an individual with a brain injury is assessed as not being able to be fully involved in the assessment without support. It is the local authority's decision to determine if that is because of lack of insight or capacity.

What are the common effects of brain injury?

As the brain is involved in all physical, mental and cognitive processes, injury to the brain, either through trauma or illness can have a very wide range of effects. These vary from person to person, depending on the exact nature and severity of the injury.

BIRT have produced a short video that describes the effects of brain injury in more detail, but it is important to remember these effects can manifest, physically, emotionally, cognitively behaviourally and in terms of motivation.

Online information video: www.birt.co.uk/bini

How does the BINI identify deficits of Brain injury?

The BINI uses the Glasgow Outcome Scale Extended and the Awareness Questionnaire, which were specifically designed to assess outcome and insight following a brain injury. Several national and international studies have shown that they are reliable and valid measures of outcome and self-awareness following acquired brain injury. In addition, they are well recognised and widely used by professionals working with people who have sustained a brain injury. The BINI uses the scores obtained in these two measures to give an indication of an individual's brain injury related deficits.

Glossary

Acquired Brain Injury (ABI): covers all types of brain injury, both acquired and traumatic. ABI can happen at any time of a person's life. It can be caused by stroke (including brain haemorrhage and ischemia, or restriction in blood supply), poisoning, brain tumour, substance abuse, hypoxia (deprivation of oxygen) and encephalitis (due to viral or bacterial infection) as well as traumatic force to the head.

Advocacy: a process of supporting or enabling people to communicate or reach their goal.

Assessment/Assessor: an individual employed or contracted through a local authority to determine care and support needs for people who require care and support. Social workers and Occupational Therapists are the professionals most likely to assess individuals with a suspected or evidenced brain injury.

BIRT: the Brain Injury Rehabilitation Trust provides specialist neurobehavioural rehabilitation to adults with an acquired brain injury at any point in their post-injury journey. BIRT offers a continuum of care from acute to community services. The Brain Injury Rehabilitation Trust is part of the Disabilities Trust.

Disinhibition: decrease or loss of social and functional restraints. For example, displaying abnormal increase in sexual needs, inability to behave typically in social and work situations.

Dysexecutive Syndrome: a loss of executive function (ability). It can affect communication, problem-solving and judgement, insight and initiation skills.

Enablement/Reablement: a way of helping a person to become more independent by gaining the ability to move around and do everyday tasks for themselves. A person may be offered an enablement service if they have lost some daily living skills because of poor health, disability or a hospital stay. These services are usually offered short-term.

Fluctuating needs: care and support needs that change over time, or that vary from day to day or hour to hour. The Care Act says that local authorities should ask, as part of a person's assessment, how their needs vary, and should look at the person over a long enough period of time to get a complete picture of their needs. If the individual has fluctuating needs, an assessor may want to complete the BINI over two or three meetings with the individual.

Head injury: an injury to scalp, or skull. A brain injury can be caused by a head injury, but not all head injuries result in brain injury.

Holistic Care: Care and support that treats the person as a whole and considers all their needs at the same time - physical, psychological, social and spiritual.

Impairment: partial or complete loss of a physical, mental or cognitive ability. For example, through stroke it is common to have decreased movement in one side of the body.

Mild Traumatic Brain Injury (mTBI): also referred to as concussion – is a traumatic brain injury that results in loss of consciousness and/or confusion and disorientation. mTBI can result in cognitive, emotional and physical symptoms, which can spontaneously resolve with time, but may require treatment in some cases.

Neurobehavioural Rehabilitation: BIRT uses a clinical approach called neurobehavioural rehabilitation. This combines the best evidence-based, scientific methods of training and changing behaviour with an understanding of the exact nature of brain injury and a philosophy of community based rehabilitation.

Outcome: the level of functional ability/disability observable after an injury or illness

Participation: a person's ability to engage in meaningful social roles.

Safeguarding: the process of ensuring that adults at risk are not being abused, neglected or exploited, and ensuring that people who are deemed 'unsuitable' do not work with them.

Social functioning: how easily and successfully an individual can react in social situations, for example, initiating conversation or using public facilities.

Traumatic Brain Injury: an outside force that causes damage to the brain, such as a road traffic accident (motor or pedestrian), violent assaults, sports related injuries or military combat injuries.

Wellbeing: phrase used to capture the idea of looking holistically at a person's needs rather than focusing on the illness or disability. There is no hierarchy in the areas of wellbeing listed in the Care Act – all are equally important. There is also no single definition of wellbeing, as how this is interpreted will depend on the individual, their circumstances and their priorities.

Assessor notes

If you require any additional advice or support, email bini@thedtgroup.org

The Brain Injury Rehabilitation Trust (BIRT)

The Brain Injury Rehabilitation Trust provides a continuum of care for people with acquired brain injury, from post-acute hospital based rehabilitation, assessment and rehabilitation, through continuing rehabilitation and supported housing and home support. Through our range of specialist services, we aim

to enable people to function more independently in the wider community and develop their lives in ways they choose.

For more information about our work please contact:
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The Brain Injury Rehabilitation Trust is the brain injury division of The Disabilities Trust and the means by which it provides its brain injury services.

Founded in 1979, The Disabilities Trust is now established as one of the UK's leading charities, offering imaginative, progressive services to people with autism, brain injury, physical disability and learning disability.

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 The Disabilities Trust

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