Regulations and codes of practice in relation to Part 3 of the Act, on Assessment, and Part 4 of the Act, on Meeting Needs, including care and support planning and direct payments

1. Introduction

1.1. Headway – the brain injury association is pleased to have the opportunity to respond to the Welsh Government's consultation on how the Social Services and Well-being (Wales) Act 2014 will be implemented through Regulations and Codes of Practice. We are responding to the relevant consultations through a letter, rather than the formal response form, as this will better enable us to share our views on the proposals.

1.2. As outlined below, brain injury can have a broad range of impacts on survivors and their families. These cover behavioural, physical, emotional and cognitive functioning, and the problems faced by people with a brain injury are often complex and multifaceted. It is therefore vital that they are supported to have timely access to specialist rehabilitation and support services so that they are enabled to live as full and independent lives as they can.

1.3. Our response to this consultation consequently focuses on the impacts of brain injury, and the intervention points at which we urge the Welsh Government to consider the needs of brain injury survivors within the Social Services and Well-being (Wales) Act Codes of Practice and any further guidance.

1.1.1. Headway – the brain injury association

1.1.2 Headway is a UK-wide charity that works to improve life after brain injury, providing frontline services to help people to rebuild their lives. We provide information, support and services to survivors of brain injury and their families and carers, including a national nurse-led helpline and an emergency fund for those in crisis. We also undertake research, policy and campaigning work to help people better understand the impact of brain injury, to raise awareness of its impact, and reduce its prevalence. Locally, Headway has a network of more than 120 groups and branches, providing services such as rehabilitation therapies, advice and advocacy, occupational projects and peer support.

1.1.3. In Wales, Headway currently has one group in Cardiff and ten branches which together cover 16 counties. From its base at the Rookwood Hospital, Headway Cardiff provides a variety of services, from carer support through to social rehabilitation programmes, delivered by staff and volunteers. Branches, which are led by volunteers, provide a range of services and information, such as group social activities and carer support.[1]

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[1] For more information on Headway and the services it provides in Wales, please see the contact details and the end of this submission.

1.1.4. With such experience and expertise, Headway is well-placed to contribute to this consultation on the implementation of the new Act.

1.2. The impact of brain injury

1.2.1. Brain injury can impact a person in a range of different ways, and can affect them for the rest of their life (Williams, 2012:12). It can lead to physical issues, such as headaches, pain, and immobility, and emotional problems, including depression, anger and anxiety. Brain injury can also cause behavioural issues, such as a lack of control regarding impulses, and cognitive symptoms, like memory problems, forgetfulness and issues with concentration. It can therefore result in multifaceted problems which require a range of distinct – yet integrated – rehabilitative therapies to help a person recover as best they can, and to enable them to live as full a life as possible. In turn, effective intervention can additionally decrease the need for long-term support measures.

1.2.2. In addition to those listed above, cognitive and physical effects of brain injury can also impact on a survivor’s ability to communicate effectively. A study exploring the impact of severe traumatic brain injury in young men with their mothers found that 55 percent of these brain injury survivors had memory problems, 43 percent had expressive language issues, and 15 percent had problems understanding language (Kinsella, Packer and Olver, 1991: 242). Further research found that those with severe traumatic brain injury can struggle with conversations. Here, it is reported that individuals may speak a lot yet with little meaningful content; a little with impoverished language, or; with confusion over content (Sim, P., Power, E. and Togher, L., 2013: 718).

1.2.3. Yet such issues are not confined to severe brain injury. Another study found that both those with a mild or a moderate brain injury had problems in forming and / or expressing descriptive information (Tucker, F. M., and Hanlon, R. E., 1998: 790). Such repercussions can impact on the ability of people with brain injuries to participate fully and clearly in interactions with others.

1.2.4. Unfortunately there is no cure for brain injury, however rehabilitation can help people to understand and manage its effects. If referred to specialists, such as neuropsychologists, speech and language therapists, and neurological physiotherapists, at the earliest opportunity, survivors can learn compensation strategies to help them manage their symptoms. In addition to increasing their well-being, this can also be preventative in guarding against additional future injuries. The cumulative effects of repeated head injuries can be significant; every new injury to the brain can make it more susceptible to increasingly severe damage in the future.

1.2.5. It is against this background of research and information that Headway has developed its response to the consultation in connection to assessments and meeting needs. Having considered the Codes of Practice, we believe there are several key areas that the Welsh Government should factor brain injury within when finalising the Code and implementing it. These include: training for social care professionals about how to communicate with brain injury survivors; the value of input from carers and medical professionals in assessments, and; having the best long-term interests of brain injury survivors, and others with care needs, at the heart of the revised system.

2. Social care professionals working with those being assessed must be aware of how brain injuries can impact of an individual's language, behaviour, and communication abilities

2.1. We feel it is vital that the language used to communicate with those being assessed is clear, simple and straightforward, and we are pleased that the Code states that using appropriate language and communication methods is a principle of care and support planning. This is vital as, following brain injury, some individuals may struggle with speech, comprehension, and retention of information.

2.2. We urgently call on the Welsh Government to ensure that social care professionals are aware and appropriately trained as to how to identify the often hidden effects of brain injury, modify their communication and language, and to appreciate how particular conditions will impact on how they need to deliver information. Such training should include information on brain injury and its possible effects so that assessors can approach individuals with confidence. In addition, this would also help social care professionals to understand how people with brain injuries may respond to them; for example, those with brain injuries may struggle to be succinct, provide appropriate information, and they may use impoverished language, and in turn the assessor may need to use sensitive encouragement to clarify circumstances and needs.

2.3. We believe that such training would fit with the Code's statement that '*local authorities* ***must*** *enable practitioners to provide an assessment process that reflects the extent of the care and support needs being presented such that the depth and detail of the assessment and care and support planning process is appropriate to the individual's needs.*' (Code of Practice on the exercise of social services functions in relation to part 3 (Assessing the needs of individuals) of the Social Services and Well-being (Wales) Act 2014, pp 8-9). It additionally fits with the statement that, '*... all practitioners undertaking assessments* ***must*** *be suitably skilled, trained and qualified in undertaking assessments*' (ibid, p. 15).

2.4. Headway believes it would be additionally helpful if this clear approach to language was consistent across the social care system. For example, we feel that the term 'personal well-being outcomes' – which is a key part of the assessment – is a rather ambiguous term which is unlikely to be widely understood without context and explanation. Clearer terms throughout the system would be likely to benefit all; not just those being assessed, but also social care professionals required to meet with and / or assess the needs of individuals such as brain injury survivors.

3. Assessments must include input from those with detailed knowledge of the individual and their prognosis

3.1. We are pleased that the Code of Practice outlines other individuals that the authority should involve in assessments where possible and appropriate. Headway particularly welcomes the inclusions of '*any person whom the person... asks the local authority to involve*', and '*other practitioners / professionals with expertise in the circumstances or needs of the person concerned*' (Ibid, p. 11).

3.2. As detailed above, brain injury is complex and can lead to a range of symptoms that require support. Given that it is a condition which is often not visible (although some of its impacts may be, for example, if it affects behaviour or motor control), it may be more challenging for social care professionals to make an accurate assessment without guidance. In addition, some individuals may struggle to communicate the issues they face as a result of their injury, while others may suffer from a lack of self-awareness or insight. As such, involving further parties who can add clarity the issues faced and highlight where help is needed would be of great benefit in ensuring that an assessment is appropriate.

3.3. Family members, carers, and / or medical professionals, like neuropsychologists, could be incredibly helpful here in enabling the social care professional in both understanding a brain injury survivor's prognosis and how this impacts on their daily living. Headway urges, therefore, that such people are routinely considered when setting up an assessment with an individual with a brain injury, as this will help to ensure that any care and support that stems from it will meet the needs of the person being assessed to the best possible extent.

4. The aim of the revised care system must be to improve the lives and opportunities of those with disability and their carers

4.1. Headway believes there are many aspects of the care system detailed in the Code of Practice which should – if enacted appropriately – help to accommodate the needs of people with brain injuries. It is imperative that people in genuine need get the support and care that they need, and that resources are used effectively.

4.2. We would like an assurance, however, that cost-saving is not the primary reason behind these changes. Part 4 of the Code states that, '*The adoption of this process will mean that fewer people will require care and support intervention through the planning and delivery of a care and support plan by a local authority*' (Code of Practice on the exercise of social services functions in relation to part 4 (Meeting needs) of the Social Services and Well-being (Wales) Act 2014, p 9). We are concerned about the emphasis here. Headway believes that reducing numbers should not be an aim; giving those with needs the best possible support solutions should be.

Further information

For more information on any of the content of this consultation submission, please contact Holly Towell, Policy and Campaigns Manager, at campaigns.manager@headway.org.uk or on 020 8640 8413.

References

Kinsella, G., Packer, S., and Olver, J. (1991) *Maternal reporting of behaviour following very severe blunt head injury*, Journal of Neurology, Neurosurgery, and Psychiatry Vol. 54 pp. 422-426

Sim, P., Power, E. and Togher, L., (2013) *Describing conversations between individuals with traumatic brain injury (TBI) and communication partners following communication partner training: Using exchange structure analysis*, Brain Injury, Vol. 27, Ed. 6, pp/ 717-742

Tucker, F. M., and Hanlon, R. (1998) Effects of mild traumatic brain injury on narrative discourse production, Brain Injury, Vol. 12, Ed. 9, pp. 783-92

Williams, H., (2012) *Repairing shattered lives: Brain injury and its implications for criminal justice*