Brain Injury SA.

Response to the Review of:

National Disability Advocacy Program Discussion Paper

www.braininjurysa.org.au

Executive Summary

Brain Injury SA is the peak body in South Australia representing people with an Acquired Brain Injury (ABI), their families, carers and service providers.

We empower and support people living with an ABI, and we deliver specialist services and programs to see them achieve their very best.

We strive every day to improve the services we offer to people living with ABI, and to ensure that these services have the greatest impact possible to improving their lives.

Our ultimate goal is to see that ABI will never be a barrier.

We are proud to deliver advocacy services to a broad section of the community living with ABI, across the different facets of individual advocacy, family advocacy, self-advocacy and systemic advocacy across South Australia.

Our extensive, hands-on experience has provided us with the very best knowledge in understanding the needs of people living with disability, and the advocacy services that will most benefit them.

We believe it is vital that, for people with disability, advocacy services are made available by a broad spectrum of agencies across each state, ideally from organisations that provide services beyond advocacy.

Advocacy services must be accessible to all people living with disability, regardless of their geographic location or personal situation. It must be timely, fair, transparent, and must ensure that systematic issues of advocacy are escalated and addressed.

We welcome the opportunity to provide our input into this important review.

1. Models of Advocacy

1.1 How do people with disability, their families and carers benefit when agencies are funded to provide only one or two models of support?

1.2 What are the drawbacks?

Brain Injury SA's view is that agencies that provide only one or two models of advocacy support are not able to adequately provide for each situation. By its very nature, this limiting model will restrict the support that an agency is able to provide for each case.

A Case Study Example: A male client with a traumatic brain injury seeks assistance. He has a wife and two children. He presents complex issues with regard to his children's education, Centrelink benefits, and he has financial issues around a legal compensation matter. In addition, his wife needs support to address grief and loss as a result of her husband's traumatic brain injury. Marital breakdown is occurring and behaviours and relationships within the household are not as they used to be.

This family would be best served by family advocacy, and our client and his wife may each need individual advocacy, which is typical of support provided to people with traumatic brain injury. These are complex but regular issues that we work with. One advocacy model for this client would not be adequate, and this is one of many examples that Brain Injury SA can provide based on the enormity of complexities our clients regularly encounter.

In New Zealand various forms of advocacy provided by health and disability agencies include self-advocacy, best interest advocacy, peer advocacy, crisis advocacy and statutory[1]. In the United States some providers promote parent advocacy, self-advocacy, professional advocacy and legislative advocacy[2]. In Britain individual advocacy includes case advocacy, self-advocacy, peer advocacy and paid independent advocacy[3]*.* Whichever way individual advocacy is described, the agencies that provide advocacy services implement many different models of advocacy for each client.

While all advocacy could be termed either individual or systemic, it is clear that many different approaches are available and used across the world, including throughout Australian advocacy agencies. At Brain Injury SA, we provide individual advocacy, self-advocacy and family advocacy and refer to lawyers for legal advocacy and support of our clients. Individual advocacy is the term that succinctly describes all forms of advocacy, other than systemic advocacy, and can include many different models of advocacy described in a multitude of ways.

People with disability, their families and carers are well supported by having choice and control over the types of advocacy agencies available to them within each state. Offering differing models and combinations of advocacy increases the choice for people with disability, their families and carers and also assists to enhance outcomes

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[1] *Models of Advocacy,* Health & Disability Advocacy, Nga Kaitautoko, 2016, Found at: http://advocacy.hdc.org.nz/resources/models-of-advocacy

[2] *What is Advocacy?* Learning Disabilities Association of America, 2016, Found at: https://ldaamerica.org/advocacy/what-is-advocacy/

[3] *Types of Advocacy,* British Institute of Learning Disabilities, 2016, Found at: http://www.bild.org.uk/about-bild/advocacy/advocacy-types/

available to them. We must maintain the right for people with disability to have choice in the services they access and from where and how they access them.

Brain Injury SA believes that having one overarching advocacy service across the state would reduce transparency needed for people with disability, their families and carers. It is crucial that clients retain choice and control, and we understand this is a crucial aspect of the NDIA and, rightly, is a focus for disability services into the future. Having one or two models would restrict opportunity to enhance the lives of those in need by not presenting the universal advocacy available to them. We need to continue to reach out to users of advocacy with the various models currently in place. Although funding is always an issue in terms of the capacity to extend services, this would further restrict potential client outcomes.

1.3 *How do we value and support the various models of advocacy while ensuring equitable access to individualised, fit-for-purpose advocacy, regardless of location?*

In South Australia, the current models of advocacy provide holistic and equitable service and support to clients, further enhancing the value and front-line model to allow access and equity to improve the lives of those that need it the most.

Advocacy is, however, inherently difficult in remote communities, such as APY lands, mostly driven by the lack of support services available in those areas, including housing, health and medical services. However, this could be enhanced by developing further opportunities for community to service these remote areas through further targeted advocacy initiatives and funding, which would also assist to escalate further systemic issues to further assist and enhance community outcomes desperately needed.

It is therefore vital that the capacity of agencies to provide regional and remote services is increased and that the tyranny of distance and cultural requirements are also met. Many agencies, including Brain Injury SA, have well established and effective connections with remote and rural communities, which could be further built on with added resources.

Many of the geographic difficulties can be supported with increased funding to services where a community connection exists and services are provided. Adequate funding models can increase access to remote communities – funding needs to accurately reflect the cost of increased attendance, the tyranny of distance between these remote communities including the travel and staff number requirements. Consideration should be given to supporting members connected to that community to further enhance access and equity (local employment initiatives) and further strengthen the relationships with community staff and existing advocate agencies.

Brain Injury SA has established relationships with culturally appropriate agencies including Aboriginal Sobriety Group, NPY Women’s Council, Aboriginal Legal Rights Movement and the Turkindi Network in SA, which facilitates networking relationships between all agencies providing services within SA Aboriginal communities. We see great importance in agencies increasing their networks and facilitating working relationships with referring agencies.

2. Improving access to advocacy supports

2.1 How do we improve access for:

- *People with disability from Aboriginal and Torres Strait Islander communities and their families?*

Brain Injury SA works collaboratively with Aboriginal and Torres Strait Islander agencies that support rural and remote communities. Advocacy agencies simply cannot deliver holistic and appropriate services to Aboriginal and Torres Strait Islander communities without high levels of support from key elders, members of their communities and/or existing support services.

Whilst some of the Aboriginal and Torres Strait Islander population can be transient, and should be able to access services and supports in a transient manner, an agency providing services from one location can be restrictive. For some cases, having an advocate in one community will provide support to transient populations, but we believe that also having access to an advocate remotely who uses supports such as the Aboriginal Transitional Housing and Support Service (ATHOS[4]) would further support transient populations and enhance outcomes.

Community engagement and consultation is integral to the needs of Aboriginal and Torres Strait Islander communities. Supporting existing Advocate organisations to strengthen relationships with remote communities and enable community to better understand the advocacy services available will only benefit individuals with disability. Advocacy agencies need to be encouraged and appropriately funded to provide these services through effective networking and collaborative working relationship within these remote communities.

- *People with disability from culturally and linguistically diverse communities*

Brain Injury SA sees community engagement and building effective relationships as crucial to the delivery of advocacy services to people with disability from culturally and linguistically diverse communities.

Agencies must be encouraged to develop relationships and be appropriately funded so that they can do so. Funding must be directly linked to providing services to the culturally and linguistically diverse communities – particularly those locations that have large representations. Funding for supports such as interpreters will markedly improve service delivery to these community groups.

Brain Injury SA engages with culturally and linguistically diverse communities through organisations including the Migrant Resource Centre, Migrant Women's Support Services and Australian Red Cross and we believe that engagement with these and other relevant organisations is crucial to delivering services to these groups.

It is important to understand the challenges facing people with disability from culturally and linguistically diverse communities, that include:

- Language barriers – use interpreters where available, including family and community support.

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[4] *ATHOS - https://www.sa.gov.au/topics/housing/emergency-shelter-and-homelessness/homelessness-services-providers/homelessness-service-providers/aboriginal-transitional-housing-and-support-service-athos-adelaide*

- Rapidly increasing numbers of new cultural groups arriving.
- Limited understanding of services, leading to a limited uptake.
- Are services culturally relevant? The culturally and linguistically diverse communities must be aware that an agency is culturally relevant and how does the agency inform the community?
- Cultural reluctance to acknowledge a disability, which may differ among different cultural groups.
- The need for and lack of translated information.
- Use of professional interpreters are essential but at times are not used.
- There are limited services in regional centres.
- There is a limited understanding of self-advocacy for carers.

- *People with disability in rural, regional and remote locations?*

Many disability service providers and agencies already operate within this type of model, despite the geographical barriers and challenges remote and rural locations can present.

There is no question that service provision would be most effective with advocacy services staffed within each remote or rural location, but that is not always cost effective. It can also present challenges when recruiting suitable staff.

Creating partnerships with agencies that have regional representations would be one effective approach. Agencies would work with Department of Social Services and other government departments to help facilitate this process and be able to access funding that would allow this process to occur.

- *People who are very socially isolated including those with communication difficulties and those in institutional care?*

Brain Injury SA worked extensively on the Disability Justice Plan[5] in South Australia, alongside the Attorney-General's Department, South Australian Police, and the Courts Administration Authority. Brain Injury SA have also worked collaboratively with the Department of Correctional Services in South Australia, and have many clients who are incarcerated, and transitioning from prison to community and back. We provide ongoing support for clients within the court system, however feel that further rigor in service delivery to people within institutional care is required. Brain Injury SA believes that more can be done to support clients with disability to enhance their wellbeing inside and outside of the current care arrangements.

Brain Injury SA believe that building on relationships that currently exist between advocacy agencies with other organisations including SAPOL, Department for Correctional Services and Courts Administration Authority, is an important aspect in ensuring people in socially isolated situations receive the best services.

Brain Injury SA is in a unique position to support these clients. Brain Injury Australia estimated that as many as 60% or 17,900 out of 29,700 incarcerated offenders had

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[5] *Disability Justice Plan,* Attorney Generals Department South Australia, Found at: http://www.agd.sa.gov.au/initiatives/disability-justice-plan

acquired brain injury[6]. This is a staggering percentage and instances of brain injury continues to grow in the community as a result of falls, strokes, car accidents and assaults[7] as well as sporting accidents[8].

2.2 What are the strategies or models that have worked? What are the strategies that do not work?

Brain Injury SA have recently implemented the roll out of the External Merits Review Support Component of the NDIS in both regional and remote SA and the Barkly region of Northern Territory.

This process has involved extensive engagement with the community within the region as well as the external services that provide intermittent or outreach services to the area.

Some of the issues that have been identified in providing support service models in such a remote location include:

- Due to the transient nature of potential participants for the NDIS in the Barkly region, many are ineligible due to the residency requirement of the trial site. It is not unusual for people to move or stay with other family in other locations such as Alice Springs, Mount Isa or Borroloola for very extended periods only to return to Tennant Creek at some stage in the future. Perhaps more consideration could be given to the eligibility criteria if one is able to demonstrate strong ties to the region.
- Participants in the Barkly feel there is a strong indication supported by many providers that the planning process would be more efficient and possibly provide better outcomes if participants have access to an independent support person who they know and have a relationship with to support them throughout the process. Many Barkly residents struggle with engagement with bureaucratic processes and having a support person able to explain in language what is happening will likely deliver far more cost effective and appropriate support plans.

3. Improving the advocacy evidence-base and coordination on systemic issues.

3.1 What mechanisms could be used to ensure information on systemic issues gets to the right people and organisations?

A 2011 report into Advocacy for protected (legislated) groups in Britain found that

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[6] Rushworth, N., *Out of Sight, Out of Mind:* People with an Acquired Brain Injury and the Criminal Justice System, Brain Injury Australia, July 2011, http://www.braininjuryaustralia.org.au/docs/CJSpolicypaperFINAL.pdf

[7] Helps, Yvonne; Henley, Geoff; and Harrison, James*; Falls, transport accidents and assault top causes of traumatic brain injury;* Australian Institute of Health and Welfare, 2004-2005, *Media Release: http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=6442458806*

[8] Finch, Caroline; Clapperton, Angela; and McCrory, Paul; *Increasing incidence of hospitalisation for sport-related concussion in Victoria Australia*, The Medical Journal of Australia, 2012, Found at: https://www.mja.com.au/journal/2013/198/8/increasing-incidence-hospitalisation-sport-related-concussion-victoria-australia

advocacy agencies working collaboratively on systemic issues produced significant benefits including (but not limited to):

- a single point of access for service users
- reduced duplication
- sharing resources
- more systemic assessment of need and referral procedures, and
- a shared approach to quality and standards[9].

All agencies that provide advocacy services will work with clients who have various complex matters and those agencies need to be able to understand the systemic issues to enable them to escalate these issues to the right organisations – whether it is for information and learnings or to seek further support.

Brain Injury SA strongly believes that all agencies that provide advocacy services should have the processes in place, as well as the right, to escalate systemic issues. It is extremely important that this process not be compromised through restriction of agencies with respect to funding allocations due to the nature and complexity of client issues which vary from client to client.

Mechanisms to enhance systemic advocacy could include performance at state and national government levels through engaging activities that actively address and report on systemic advocacy matters. All advocacy organisations should have the capacity to commit to activities and further collaborations, to enhance relationships with other advocacy agencies. It is also important to bring advocate agencies into key consultation processes for any reform agenda or policy issues that are being addressed throughout the state. Disability Advocates must be afforded the opportunity to be part of the disability conversation to ensure that any systemic matters are being made broadly aware and dealt with through effective consultation, relationship building to support informed decision making.

3.2 *How can we help disability advocacy organisations work with a wide range of other organisations with similar aims, such as:*

- *Disabled people's organisations (DPOs)*
- *The Australian Human Rights Commission*
- *Ombudsman organisations*
- *Aged care advocacy organisations*
- *State disability advocacy organisations*
- *Peak bodies*

Information sharing is an imperative part of effective advocacy. Brain Injury SA's view is that information sharing empowers everyone and only serves to benefit the client, the community, and other agencies that learn through sharing.

Brain Injury SA is in a unique position to share information about our knowledge of the justice system and skill with working with clients within that system. In addition, our

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[9] *Equality and Human Rights Research Report 67,* Equality and Human Rights Commission, UK, 2010 https://www.equalityhumanrights.com/en/publication-download/research-report-67-advocacy-social-care-groups-protected-under-equality

participation and involvement in the Disability Justice Plan[10] advisory group. Brain Injury SA's involvement in the DJP advisory group sees us provide expert advice in regard to training that will assist investigative interviewers when working with people that have communication difficulties. This is a successful mechanism to address systemic issues and we believe this approach should be consistent across all government agencies. We see information such as this as vital learnings to be shared across advocacy and other relevant agencies, such as those listed above.

Consideration should be given to how systemic advocacy funding is allocated to ensure that experience and expertise is appropriately used. Some systemic advocacy may benefit from expert panels from agencies, others may best benefit from expertise of an individual from an advocacy agency. Flexibility needs to be retained in funding models so that expertise can be resourced in the most effective manner, according to the systemic issue.

Brain Injury SA suggests that there may be advantages from holding quarterly systemic advocacy meetings, where all agencies and organisations come together to discuss topical issues and areas of concern. Consideration should be given to the agencies most experienced to manage the systemic issue and allocate funding accordingly.

We believe that a database accessible by all advocacy and relevant government organisations to record their systemic advocacy issue could help to efficiently share information. Thought would need to be given to how smaller organisations would manage this issue, and funding would need to be allocated appropriately. It could be an effective way of sharing areas of systemic advocacy, while ensuring that data on systemic issues is efficiently captured.

We also suggest giving consideration to holding advocacy open days, perhaps held yearly in each state, which would see all relevant organisations come together to build their relationship with and learn from each other.

4. The interface with the NDIS and addressing conflicts of interest

4.1 What steps or organisational structures should be put in place to ensure conflicts of interest do not arise or are minimised?

At Brain Injury SA, we understand that government and advocacy agency environments are ever-changing and to that end, we believe that strategies required to avoid conflicts of interest need to be flexible, transparent and effective. Some of the organisational strategies we would like to see given consideration include:

- Strong governance approach to complaints, whistleblowers protection and accountability frameworks.
- Adequate policies and procedures around the declaration of conflicts of interest.
- Development of a conflict of interest register.
- Adequate complaints procedures.
- Skilled staff and management mix.
- Board or relevant governing body that ensures compliance and a strong

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[10] *Above at 5*

governance approach.
- Agencies continue to be accountable to clients and reportable to the funding bodies.
- Steps should be included in organisational audits to quality check the mechanisms of accountability and ensure that each advocacy agency has a conflict of interest register. There must be an audit process in place to address conflicts of interest.

4.2 How do we avoid gaps between supports provided by the NDIS and advocacy funded by the NDAP?

Brain Injury SA believes that advocacy that is funded by both NDIS and DSS will enable a broader approach to advocacy support, while enabling people with a disability to retain their own choice and control. It will also have a positive effect on frontline service delivery and enhance the outcomes for each case.

Self-advocacy training and awareness is essential to enabling people with a disability to live fulfilling lives, and Brain Injury SA believes such training should be funded through the NDIS, with funding for other advocacy services to be supported as required.

4.3 What policies and strategies do we need to protect the rights of people with disability?

As a service provider and advocacy agency, Brain Injury SA is in the unique position to accurately report on how an integrated approach works effectively for people with a disability. And, in our view, an integrated approach is vital to providing effective advocacy services.

Many organisations, that are not funded advocacy agents, provide a level of advocacy as a part of their role working with people with a disability. It is inherent in what they do. These include disability service providers, allied health professionals and other disability support workers. Many individuals support their clients to self-advocate as well as work to source advocacy agencies where issues become complex or perhaps outside of their skills or role. In many situations, this holistic support works effectively and clients enjoy a positive outcome. As a service provider and advocacy agency, Brain Injury SA has seen many examples of these positive outcomes through an integrated approach.

The ABI community anecdotally reports low levels of trust, as well as issues around building relationships and fear of new things, preferring consistency in service provision. We have found, through the provision of advocacy services, that the brain injury community, their family and carers feel comfortable and fully supported when they have the ability to access advocacy as well as services – all in an environment they trust and have an existing relationship with.

Brain Injury SA strongly believes that by not enabling an agency to be both a service provider and an advocate, with an integrated approach, it could significantly compromise a successful outcome for people living with disability.

5. Understanding and improving access to justice

5.1 What forms of legal review and representation do people with disability need most?

Brain Injury SA highly commends the incredible work undertaken in South Australia with the Disability Justice Plan[11] – it is a hugely positive step forward in supporting people with disability access justice. We are proud to be a significant part of this plan, and proud to be actively involved in the DJP advisory group. We are called on to provide expert advice with regard to our brain injury community, including the provision of information for the development of training for justice staff and advice on communication difficulties and interview strategies. This work undertaken by the State Government has enabled the establishment of a benchmark for other agencies to be guided by for any future reviews.

5.2 What barriers prevent people with disability from accessing justice?

Brain Injury SA works daily with clients with ABI who have significant experience in the justice system. It is particularly vital that review and representation of people living with a disability, are better represented through the justice system.

One particular case study involves a person with a disability who lives with complex and traumatic brain injury as a result of a serious assault caused by a family member. The offending family member was released without interventions in place to protect the victim (family member) – the perpetrator (family member) arrived at the victim's home the day he was released. The response from the official agency was to advise that the victim (with disability) should have completed a Victim Registration Form, placing the blame on a victim who has no capacity to read, write, walk and has very limited expressive language. The victim was unable to complete the form and as advocates we were not involved of the situation at that time of the incident (therefore unable to support the client until a later date, when issues became more complex). Safety was of significant concern due to systemic failures to provide minimum support and care to people/victims of crime who have a disability. Barriers as basic as this still need to be resolved so that this same issue is never repeated. Whilst we provide a high level of systemic advocacy in raising this issue, aswell as individual advocacy (only after the events), justice still need to inform, train and develop its staff to be well informed about people with disability to better protect and support them.

While a lot of energy and effort has been provided to this client to ensure overarching advocacy support, in an attempt to improve the situation, the reality is that if appropriate supports and processes to protect people with disability, particularly those that receive their disability as a result of crime were in place, the victim's safety would not have been compromised.

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[11] *Above at 5*

5.3 *What models of legal advocacy are most effective?*

Our view is that the most effective models of legal advocacy are those where people with disability, through their advocacy agencies, are able to access a pool of legal services. Legal Services that have high levels of understanding of both the legal system and the needs of people with disability would be complimentary for all parties and support greater outcomes for people with disability. This approach ensures that clients have access to services that understand disability and the complexities of the justice system and how they impact people with disability.

Brain Injury SA has had excellent experiences using a pool of legal services that have a higher than usual level of knowledge of cognitive disability.

There are also many administrative and civil matters that require advocacy support, and should be considered in this review, our experience and involvement includes matters as follows:

- Centrelink appeals
- NDIA appeals
- Civil litigation
- debt collections
- public trustee matters
- guardianship and administrative orders
- legal matters to support third party applications
- rehabilitation, health and medical issues
- child protection matters and family law as a result of a client's injuries
- compensation matters including WorkCover and motor vehicle accidents.

The impact of funding cuts to Community Legal Services has impacted the ability to access free legal support, compromising the existing complex situations people with disability experience.

Consideration should be given to the following issues that can impact people with disability in the justice and legal systems:

- Trust issues that prevent clients from attending police stations and court rooms.
- People from wider community organisations do not necessarily understand the impact of cognitive disability and request forms to be filled out or meetings be attended where clients are unable to do so.
- Restricted access generally, such as inability to attend court due to not understanding how to use a parking meter, or access to courts not being disability appropriate.
- Community Legal Services that have legal representatives as well as a high level of understanding of supports needed for people with disability, in particular people with cognitive or intellectual disability, is severely lacking.
- Legal services and justice agencies lack the understanding or knowledge to link people with disability back with advocacy agencies or services – doing so can assist with interaction with the justice system to make the process easier and more effective for the client.

In his paper "Access to Justice for Persons with Disabilities: An Emerging Strategy", David Larson (*2014*) rightly talks about how access to justice can be improved through the training of advocates[12].

David refers to the need to train advocates to better support people in the justice system in different ways rather than continuously attempting to change laws and regulations to be relevant to the ever-growing range of circumstances to protect people with disability.

Linking advocates to law schools, police training, teachers and education facilities and other social service providers would enable information and knowledge to be shared throughout the population, and provide access to justice in all forms for people with disability.

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[12] Larson, David; *Access to Justice for Persons with Disabilities: An Emerging Strategy;* Laws Journal, 05/2014; Volume 3; Issue 2; p 220-238