

Name of Organisation: Hunter Brain Injury Respite Options Inc (HBIRO)
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Signatory's Position: Co-Ordinator
Authorized By: The HBIRO Committee of Management

HBIRO is a disability service providing flexible respite options to children and adults with an acquired brain injury (ABI) who reside with a Carer and who live in the Hunter Region.

Flexible respite options include:

- Community respite - Consumers receive 1:1 support to engage in activities of their choice within the community with a Community Service Worker (CSW).
- In-House Respite – Consumers can stay for short periods in our respite house for a holiday. Up to 4 Consumers can stay at any one time.
- Camps for adults and children
- Monthly Group activities

The service is funded by the Department of Ageing Disability & Home Care (DAD&HC). A small amount of funding was received in year 2000 for children with ABI.

The issue which has reached crisis point for many of our families is the need for flexible accommodation options.

Service Statistics for families in need of supported accommodation

Fifty two (52) percent of families accessing respite through HBIRO are in need of some form of supported accommodation for their loved one.

Of the families in this percentile the age brackets of carers is as follows:

- Twenty five (25) percent of Carers are in the 70-80 year age bracket and the support needs for Carers in this age bracket are immense. Carers continue to provide this care despite increasing difficulties and are more at risk of continual periods of hospitalization, which destabilizes their accommodation and the family situation even further. The likelihood of increasing homelessness could be predicted given the combination of ageing parents and consequent family breakdown.
- Forty nine (49) percent of Carers are in the 50-60 year age bracket
- Twenty six (26) percent of Carers are in the younger age bracket of 20 – 40 years often with young children in their care.

HBIRO continues to assist families in such need by providing maximum community and In-House respite, however this is masking the real need for supported accommodation and prevents the other families within the service from receiving the amount of respite support they too require.

People who have an ABI have disabilities which will be permanent but will not affect the person's life expectancy. Respite support will always be required and therefore no places become available for people who have been recently injured.

As the service continues to grow and our resources are stretched to maximum capacity a waiting list has needed to be established.

Carers have expressed their real concerns of what will happen to their loved one when they are no longer able to care for them. Carers talk of their son / daughter constantly asking them what will happen if they (the Carer) die or cannot take care of them. This is a real fear for both Carers and Consumers.

Most Carers have voiced that they want supported accommodation, where their loved one would be cared for in an appropriate dwelling with trained ABI workers. The Carers would then be able to provide much of the respite by visiting, and taking them on outings through the week, but have a more normal life with the rest of the family.

Another preferred option is for flexible accommodation packages where additional supports could be placed within the home to enable Carers to continue caring for their loved one within the family unit.

Please find following case studies of three individuals who have allowed their stories to be shared with you.

Case Studies

John

John is a 43 year old man who sustained a severe head injury when he was 21 years of age as the result of a football injury in 1983. Before the injury John was a great advocate for the local Shoal Bay community and was named sports man of the year. Since the injury John has been cared for by his parents, Pattie and Kevin in the family home which was purpose built to accommodate John's needs. As a result of the injury John has significant physical disabilities and is totally reliant on 24 hour care requiring showering, dressing, feeding, bowel and bladder care and oral care. John has severe communication problems and uses a board and pointing stick with which to spell words. John requires assistance to hold his elbow whenever he uses the board which has contributed to Pattie's on-going neck problems.

Support has been provided by various services in the community however Pattie and Kevin are now in their late seventies and with their own health problems (at times requiring hospitalization) find it increasingly difficult to continue to care for John on a daily basis.

Kevin, Pattie and John desire a supported accommodation option where a transitional period can be provided. A transitional period would enable John to

stay in the accommodation on weekends to assist John, the family and support staff with a smooth and successful transition to permanent accommodation.

Lesley

Lesley is a 44 year old woman who in 1997 experienced a stroke resulting in significant physical and communication difficulties. Lesley is cared for by her husband Allan who left his job to perform this full time caring role. They have 2 adolescent children who reside in the home.

Lesley is unable to weight bare and requires assistance with showering, dressing, feeding, bowel and bladder care. With limited communication, Lesley will use facial expressions; pointing and simple yes no answers to communicate. Lesley experiences depression and often appears despondent and sad. Other services provide assistance such as home and respite care, however the strain on Allan and the family is telling with supported accommodation being the long term option required to maintain the family unit.

Brian

Brian is a 51 year old male who sustained an acquired a brain injury as the result of a motor bike accident in 1971. Brian requires considerable support and lives with his mother Marie who is a widow in her mid 80's. Difficulties Brian experiences include on going leg pain, limited insight, limited concentration, impulsivity and verbosity. Brian has difficulty managing his verbal communication and will speak inappropriately to strangers. There have been occasions when the police have been called and Brian has been escorted off public transport due to inappropriate verbal out burst. This prohibits Brian from accessing the community on his own.

Marie is concerned as to what will happen to Brian when she is unable to care for him.

It is critical that flexible supported accommodation options be made available for this disability group.

Should you require any further information please do not hesitate to contact me.
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Yours faithfully

Kathy Battle
Co-Ordinator