Health and Social Care Committee HSC(4)-07-12 paper 6 Cynulliad

Cenedlaethol Cymru

National Assembly for **Wales** 



Y Pwyllgor Deisebau Petitions Committee

Mark Drakeford AM Chair, Health and Social Care Committee National Assembly for Wales Cardiff Bay Cardiff CF99 1NA

Bae Caerdydd / Cardiff Bay Caerdydd / Cardiff CF99 1NA

Our ref: P-03-295

February 2012

Dear Halk

Petition: Kyle Beere - Paediatric Neuro Rehabilitation Services

The following petition is currently open for consideration by the Petitions Committee.

'We, the undersigned, call upon the National Assembly for Wales to urge the Welsh Government to recognise and deliver services for the rehabilitation of brain injured children. There is currently no facility in Wales to provide this vital service. Despite there being a purpose built children's hospital being built in Cardiff, there is still no provision included in its design.'

The Committee would like to draw your attention to the issue raised in the petition, and would ask you to consider including the subject of neuro-rehabilitation services in Wales in your forward work programme. I attach correspondence from the Welsh Health Specialised Services Committee, Headway, and the petitioner for your information.

Thank you for your consideration of this issue.

Yours sincerely.

William Powell AM

**Chair, Petitions Committee** 

Encs: Correspondence from WHSSC; Headway; petitioner.

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Ffôn / Tel: 029 2089 8393

E-bost / Email: William.powell@wales.gov.uk

Croesewir gohebiaeth yn y Gymraeg a'r Saesneg / We welcome correspondence in both English and Welsh



Your ref/eich cyf: P-03-295 Our ref/ein cyf: ML/NJ/CR- KB Date/dyddiad: 12<sup>th</sup> December 2011

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William Powell AM Chair, Petitions Committee National Assembly for Wales Petitions Committee Cardiff Bay Cardiff CF99 1NA

Dear Mr Powell

# RE: P-03-295 Kyle Beere – Paediatric Neuro Rehabilitation Services

Thank you for your letter dated 23<sup>rd</sup> November 2011, requesting the number of children requiring admission to Tadworth over the last 10 years.

I can confirm that since the 1<sup>st</sup> of February 2002 to date, 8 children have required admission to The Children's Trust, Tadworth.

I hope this answers your request. If I can be of further assistance, please do not hesitate to contact me.

Yours sincerely

Dr Cerilan Rogers

**Director of Specialised & Tertiary Services** 

Welsh Health Specialised Services Committee Unit 3a

Caerphilly Business Park

Caerphilly CF83 3ED Pwyllgor Gwasanaethau Iechyd Arbenigol Cymru

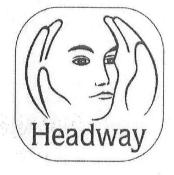
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Chair/Cadeirydd: Professor Mike Harmer

Director of Specialised and Tertiary Services/Cyfarwyddwr Gwasanaethau Arbenigol a Thrydyddol: Dr Cerilan Rogers



10<sup>th</sup> January 2012

William Powell AM
Chair, Petitions Committee
National Assembly for Wales
Cardiff Bay
Cardiff
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**Headway Cardiff** 

Dear William Powell,

Headway Cardiff is a registered charity that provides support and services to adults affected by acquired brain injury (ABI), their families and carers throughout south east Wales.

The survivors we assist are adults, but many sustained their injury during childhood and have experienced paediatric neuro-services first hand.

Firstly it is important to acknowledge the lack of accurate statistics relating to ABI due to a combination of shortfalls in the coding system and in the case of minor brain injury, non-identification or mis-diagnosis.

It is also important to not wholly focus on those who are classified as having a severe brain injury. Those with a moderate or even a mild classification have complex, life-long difficulties, that impact on their ability to live an independent life.

Beyond the acute setting, it is vital that children receive a period of specialist neurological intervention. Appropriate, timely specialist intervention can greatly improve the level to which individuals recover and the speed in which this happens.

As the input of the family is crucial at this stage and throughout recovery, this service needs to be as accessible to the family as possible and offer as flexible and as personalised a programme as possible.

Following this intensive period of rehabilitation, a long term community based specialist multi-disciplinary team should be available until the child reaches adulthood and then in theory, there is a seamless transition to specialist adult services.

Headway Cardiff
Rookwood Hospital, Llandaff, Cardiff CF5 2YN
Tel: 029 2057 7707 E.mail address: info@headwaycardiff.org



A Company Limited by Guarantee Registered in Wales No. 3331865 Registered Charity No. 1063221 Registered address: 5th Floor, Hodge House, 114 - 116 St Mary Street, Cardiff, CF10 1DY Patron: Mr Jonathan Davies M.B.E.

Affiliated to Headway - the brain injury association. A Registered Charity

It is in the area of community services that the biggest gap appears in adult specialist neuro- services and it is vital that this area is considered in the development of any paediatric service.

Community services in Wales have not kept pace with acute services and the piecemeal nature of services has left many survivors feeling isolated and unsupported leading to crisis and family breakdown. Many of the gains they make in the immediate aftermath are lost due to the lack of ongoing therapy and support.

For those children whose impairments are severe enough to warrant a placement in a specialist educational establishment, ongoing treatment such as Occupational Therapy, Speech and Language Therapy and Physiotherapy is available.

What then happens to those with moderate and mild difficulties, who frequently go undiagnosed, unrecognized or whose difficulties are attributed to behavioral problems?

Who then supports them as the child reaches each new stage of development? Who then provides the individual with ongoing rehabilitation and strategies? Who supports the family in ensuring the child's educational needs are recognized and they are statemented correctly?

Headway Cardiff wholeheartedly endorses the Petition to the Welsh Government to recognize the need for and to deliver specialist services for the rehabilitation of brain injured children within Wales.

Yours sincerely

Julie Smith

General Manager

### Correspondence from the Petitioner 11 January 2012

Dear sirs

I apologise for the delay in replying, but I have been waiting on information from Aneurin Bevan and Hywel Dda Health boards, that have failed to comply with the freedom of information act.

In the last 5 years there have been a total of 529 paediatric patients (between Abertawe Bro Morgannwg University, Betsi Cadwaladr University, Cardiff & Vale University and Cwm Taf Health Boards) that could have benefited from a paediatric neuro-rehabilitation centre in Wales. Powys Teaching Health Board do not have any paediatric services which, although is concerning in itself, does not have any impact on this petition.

Yours faithfully

Katherine Simmons

## Further correspondence from the Petitioner 30 January 2012

#### Dear sirs

We have now heard from Aneurin Bevan Health Board and they have had admitted 345 paediatric patients with acquired brain injury in the last five years. This takes the overall total to 874. We have still not heard from Hywel Dda.

In response to WHSCC's correspondence, there may have only been 8 children referred to Tadworth but is this due to cost or need? It seems 8 patients out of a possible 874 does seem disproportionate which would bear out the comments made by Headway.

#### Regards

Chris Wools For and on behalf of Kyle and the trust.

