

**Credwch
mewn plant
Believe in
children**



**Barnardo's
Cymru**

Response from Barnardo's Cymru to:

**Legislation Committee Number 5
Consultation on the *Proposed Carers
Strategies (Wales) Measure***

Submitted by:

**Tim Ruscoe, Development Officer
Menna Thomas, Development Officer**

**Barnardo's Cymru South West Wales Office
1st Floor
4a Queen Street
Neath
SA11 1DL**

**Email: menna.thomas@barnardos.org.uk
tim.ruscoe@barnardos.org.uk**

Tel: 01639 620945

A. INTRODUCTION

- Barnardo's Cymru has been working with children, young people and families in Wales for over 100 years and is one of the largest children's charities working in the country. We currently run 41 diverse services across Wales, working in partnership with 18 of the 22 local authorities, supporting over 8,000 children, young people and families in the last year.
- Barnardo's Cymru services in Wales include: care leavers and youth homelessness projects, young carers schemes, specialist fostering and adoption schemes, family centres and family support, parenting support, community development projects, short breaks and inclusive services for disabled children and young people, assessment and treatment for young people who exhibit sexually harmful or concerning behaviour and specialist services for children and young people at risk of, or abused through, child sexual exploitation.
- Every Barnardo's Cymru service is different but each believes that every child and young person deserves the best start in life, no matter who they are, what they have done or what they have been through. We use the knowledge gained from our direct work with children to campaign for better childcare policy and to champion the rights of every child. We believe that with the right help, committed support and a little belief, even the most vulnerable children can turn their lives around.

B. BARNARDO'S CYMRU SERVICES FOR CARERS AND YOUNG CARERS.

- Barnardo's Cymru currently provides young carers services in five Local Authorities. Our first, the Carmarthenshire project, was established in September 1995. The fifth, Newport, was established in April 2009. Throughout this period we have continued to campaign for not only the rights of young carers as children but also the need to address their needs as carers equitably with any other unpaid carer.
- In addition to young carer services we provide services such as our family links services in Cardiff, the Vale and Blaenau Gwent that have a focus on families with disabled children; consequently we have frequent contact with and provide support to many parent and grand parent carers.

C. BARNARDO'S CYMRU POSITION ON YOUNG CARERS AND THE MEASURE.

Barnardo's Cymru is particularly concerned with the needs of:

- Young Carers aged up to 18.
- Young adult carers 18 to 25.
- Parents, Grand Parents or others taking the parental responsibility for disabled children as defined in Part 3 of the Children's Act 1989.

Although the committee's terms of reference do not specifically include the issue of young carers we feel we must take the opportunity to set out our position on this.

Barnardo's Cymru finds itself in a position where we disagree with the recommendations of the Carers Strategy Advisory Panel and consequently with the Minister's statement in introducing the proposed measure to the Assembly in regards of young carers.

When considering young carer issues there is a call to rightly look at young carers as children first. However, they remain carers, and require their needs as carers to be addressed in the same way as any other carer. They must appear in any developing carers service and information strategies in order for these needs to be properly and consistently addressed through coordinated responses.

It is our experience that attempts to address young carer issues solely through using the Common Assessment Framework alone is unhelpful. Seeking to eliminate the need for children to provide any care at all will lead to many families continuing to hide from social services believing the need to rely on children as carers will label them as bad and less able parents.

The situation that currently prevails, largely fails to provide adequate services for young carers. The lack of appropriate carer assessment for young carers and an insufficient response to the needs of the family as a whole, can also be exacerbated by the competition between budget holders that currently exists. The right to a carers assessment for young carers legislated for in the Carers (Services and Recognition) Act 1995 was a hard earned progressive development.

The ideal situation is one where young carer's needs, as a carer, are properly assessed and the care need, the families' needs and the carers' needs, are properly resourced and supported in a coordinated fashion, with no dispute between service providers and budget holders. As a result children who are carers could then access their rights as children and enjoy their rights to play and leisure, education and the opportunities for gaining wider experience. They would also be enabled to choose the levels of appropriate care they could provide.

An assessment of the child's needs through the Common Assessment Framework may form a portion of the holistic approach and identify needs not to be addressed through a carer's assessment. If additional Welsh legislation is brought forward under the matters referred to as vulnerable children, this could muddy the waters and position a cohort of carers in competition for resources earmarked for groups seen as more vulnerable and at risk.

In our view it will not be helpful to young carers or their families to see their care role as a burden and inappropriately label them as vulnerable as a consequence of wanting to care, provide support and demonstrate love for their families.

"Many young carers report that caring gives them feelings of maturity, and a sense of closeness to both their parents and family; they also value their responsibilities and consider them to be a source of practical life skills."

“Young carers are often happy to perform their role and can see it simply as providing support to the family, rather than something more onerous or distinct.” (SCIE briefing February 2005 “The Health and Well-being of Young Carers)

As the proposed measure does not explicitly call for information and service strategies to be provided equally for young carers, giving full regard to their role and position as carers, it will be significantly devalued and could result in considerable and unnecessary demand on legislative time to redress.

D. RESPONSE TO CONSULTATION QUESTIONS

1. Is there a need for legislation (by means of an Assembly Measure) to be made to introduce a new requirement on the NHS and Local Authorities in Wales (“the relevant authorities”) to work in partnership to prepare, publish and implement a joint strategy in relation to carers and if so why? If not, what alternatives do you propose?

Having outlined our position on young carers earlier, Barnardo’s Cymru welcomes the measure. We believe that there is a need for Welsh legislation as previous UK legislation has failed to fully address the needs of carers and has not been fully applicable to the NHS in Wales.

We think that placing the lead on the NHS is interesting as most of what exists, and has proved insufficient, has placed the lead responsibility on Local Authorities. It will also be interesting when a single large authority will be attempting to lead the development of strategies in partnership with a number of different Local Authorities and may increase the likelihood that young carers in particular can be better identified and gain access to an assessment of their need.

Whilst welcoming the measure in principle and understanding that the intention of the measure is not to exclude young carers, our concerns remain that the call for redress for young carers is through the development of a new measure in the matters developed through the vulnerable children LCO. This in our experience will be unnecessary if this proposed measure is strengthened.

As the committee is aware, there currently exists a raft of legislation that was developed and implemented to address the very issues that this proposed measure is also aiming to address. This being the case, does the need for new legislation highlight the issues of implementation with regard to accountability and scrutiny.

We expect that having a Wales specific piece of legislation, together with the implications of the recent restructuring of the NHS, could create a greater opportunity for effective scrutiny and accounting for this aspect of service to carers.

We very much welcome the inclusion of carers themselves in the creation of carer’s strategies, as we view this as being likely to produce;

- A more meaningful and workable strategy.
- A situation where young carers are more able to realise their rights as laid out in the UNCRC, and endorsed by the Welsh Assembly Government.
- A more focussed and efficient use of resources, in times of ever increasing resource constraint.

In relation to the groups that we represent we would like to see the explicit inclusion of the LEA's as key partners in the production of the strategy, due to the central role of education in the lives of children and young people.

Research shows that having a caring role can, depending on the nature of the relatives illness, lead to school absenteeism, which may have a detrimental effect on the educational attainment of the young carer;

"..children may be afraid to leave parents, especially when they have a history of self-harm or suicide (Aldridge and Becker 2003). Some physical illnesses are marked by periods of exacerbation and remission and during acute phases children stay at home to 'be there' in case they are needed. This can lead to low educational attainment if regular and persistent" (Dearden and Becker 2002)

Absenteeism can lead to lower educational attainment, both of which will be recorded on the young carers school record, and has implications for their future work prospects;

Dearden and Becker also highlight the influence that the experience of being in a caring role at a young age can have on employment choice. This is partly due to the role they have occupied, or possibly a result of not having gained sufficient qualifications to enter their career of choice, and therefore being forced into low-paid caring roles in the labour market. They conclude by describing the value of an assessment of the young carer's educational needs; *"Assessment of young carers is central in both determining the level of educational disadvantage and also its potential impact. Assessment issues parallel debates around defining carers by the quantity of support that they offer, i.e. should it have to be 'regular and significant' for them to receive support? We would argue that while quantity is important, outcomes/effects are equally important and young carers should not miss out on assessment and support because the care they provide is considered to be low. These young carers can still remain at risk of negative outcomes that may be severe."* (Dearden and Becker 2002)

Young carers may also experience increased levels of anxiety and reduced levels of concentration, and may be vulnerable to bullying.

Education is compulsory from age five to sixteen and there is a duty on parents and carers to ensure that their children go to school, indeed failing to do this can lead to prosecution. There is also a duty on education authorities to make provision for children to receive an education, and special circumstances must be taken into consideration in relation to a number of

groups. The right to education “is one of the rights enshrined in UK law, but also within the UNCRC. It is also one of the rights that some young carers are denied”.(Dearden and Becker 2002)

The roles of the LEA and school are equally important in the support provision for parent and grand parent carers as it is for young carers. There are some very good examples of schools working in partnership with the parents and grand parents of disabled pupils.

For the above reasons we think that the LEA’s should be included in the preparation of strategies from the start, and that to bring them on board later would be detrimental to the coherence of any approach to develop a strategy which addresses the needs of families where there is a caring responsibility.

2. Are the sections of the proposed Measure appropriate in terms of reforming legislation relating to the provision of information and advice to carers? If not, how does the proposed Measure need to change?

In considering this question, consultees may wish to consider, in particular, the nature of the provisions in the proposed Measure that:

(a) The definition of appropriate advice and information as defined in the Measure (Section 3);

Timely and appropriate information is critical in enabling carers to access assessment and sufficient support for their needs. An appropriate information delivery strategy will require breadth in its approach and should ensure full accessibility from the outset.

The Carers (Equal Opportunities) Act 2004 places a legal duty on Local Authorities to inform carers including young carers of their right to a carers’ assessment. It also stipulates that consideration should be given within the assessment process of the carer’s employment.

“Hidden Lives: Unidentified young carers in the UK” (Barnardo’s 2006) flagged up that young carers had spent on average four years providing care before they received any support. Had appropriate information been made available in a timely fashion to these carers they would have come to light far sooner. The right to information not only forms a specific article of the UNCRC but is also a basic tenet of the Universal Declaration of Human Rights.

The definition in the measure is open enough to allow further definition if necessary. However from experience of documents written in this way without greater clarity of what might be seen as appropriate, sufficient scrutiny and accountability could be difficult to achieve.

(b) Local authorities must ensure that in deciding what services to provide to or for a carer or the person cared for, they consult the

carer. Also authorities are required to ensure that they consult carers before they make decisions of a more general nature about service provision to or for carers and the persons cared for. (Sections 2 (1) (b) & (c));

As previously mentioned, services are more likely to be both an effective and efficient use of resources with the full involvement of carers in the assessment of their and the cared for's needs. This has long been thought of as best practice but as yet is not a universal experience.

Any local strategy should ensure that frontline workers are sensitive to the needs of the family as a whole and are skilled enabling their participation. The degree of the success of this venture is directly related to the understanding and buy-in of senior management and the levels of support frontline workers receive.

Working in partnership in this way implies consultation as part of a longer term relationship which incorporates continuous review and evaluation of need. It must not be understood as a one off event.

This level of involvement, care and concern for the family by workers, needs to be consistent and continued, with frequent reviews and adjustments particularly when talking about young and parent carers where needs are more likely to evolve and change frequently and sometimes rapidly.

The need and potential benefit of consultation and active involvement in these decisions is consistent with the WAG National Children and Young Peoples Participation Standards for Wales. This standard can be applied as best practice for any age as a basic human right entitlement.

(c) Welsh Ministers with the power to make regulations about the following:

- i. the services in respect of which the duty to prepare a strategy applies;**
 - ii. the matters to be dealt with in the strategy;**
 - iii. how and when the strategy is to be published;**
 - iv. keeping the strategy under review (including setting a period after which the strategy must be reviewed or replaced);**
 - v. the consultation which must be undertaken before or during the preparation, implementation or review of the strategy;**
 - vi. arrangements to monitor and evaluate the implementation of the strategy;**
- (Section 5 (2) (a)-(f));**

(d) Welsh Ministers would be able, for each strategy, to designate an NHS organisation as the lead authority for the purposes of co-ordinating and overseeing the preparation and publication of the strategy and any subsequent review.(Section 5 (3)); and

(e) The proposed Measure would also place a duty upon the lead authority, or, where there is no designated lead, the responsible authorities acting together, to submit the strategy to Welsh Ministers. Welsh Ministers would then be required to inform the responsible authorities that they are satisfied with the draft strategy, or if they were not satisfied, give the responsible authorities such directions as considered necessary for ensuring that the strategy complies with their requirements. (Section 6);

In response to (c), (d) and (e).

Barnardo's Cymru would welcome additional instruction as to;

- A named senior post within the LHB accountable for the development of a strategy.
- Named senior management lead posts from organisations listed in section 2 (3) accountable to the LHB lead.
- Required content within strategies such as
 - The provision of local systems of scrutiny and carers' place in that process.
 - The provision of service coordination within each local authority area.
 - The consistent provision of a carers' assessment for all carers.
 - The need for regular review.
 - A requirement for carers' access to advocacy.
 - A strategy for identifying carers.

3. How will the proposed Measure change what organisations do currently and what impact will such changes have, if any?

To reiterate, the inclusion of the NHS as a lead agency should increase the possibility of early identification of carers and create opportunities for a more comprehensive approach to addressing their needs as the carers and the cared for will be thought about and planned for together. If appropriately facilitated, the opportunity for carers to be involved in the creation of carers' strategies, and their own care plans, will make for more relevant and efficient use of resources and better outcomes for families.

4. What are the potential barriers to implementing the provisions of the proposed Measure (if any) and does the proposed Measure take account of them?

- Educational institutions are a key point of contact for the identification of young carers and also as providers of support. The measure as it stands runs the risk of not tying in the LEA's sufficiently to the strategies and thus could undermine the potential of the strategies to be as effective as they need to be. We have earlier identified the benefit to parent and grand parent carers of LEA involvement.

- Current work cultures and practice are also potential barriers. Demarcation of roles, limited information sharing and protection of resources are examples.
- The need for a clear designated leads in the establishment of a strategy.

5. What are the financial implications of the proposed Measure for organisations, if any? In answering this question you may wish to consider Part 2 of the Explanatory Memorandum (the Regulatory Impact Assessment), which estimates the costs and benefits of implementation of the proposed Measure.

There will inevitably be resource considerations for organisations tasked with strengthening the provision of support for carers of all ages to enhance the experiences of carers and their families. This could include the upfront resource and cost implications of; the adaptation of frontline assessments in the NHS; the additional drawing together of information and the creation of additional signposting and care pathway provision across authorities and agencies.

However any consideration of increased resource demand should be considered in conjunction with two additional factors. Firstly, that unpaid care in Wales, as reported in the Western Mail article “Young carers more likely to suffer from mental ill-health” (page 14 Friday the 26th February 2010), provide the equivalent of over £5 billion of provision and secondly inadequate support for these carers increases the likely hood of carers needing care. Consequently adequate and early support is likely to reduce demand on future health budgets and promote the economic activity of carers.

6. Are there any other comments you wish to make about specific sections of the proposed Measure?

Subordinate Legislation

7. What are your views on powers in section 8 for Welsh Ministers to make subordinate legislation?

We believe there needs to be sufficient scope for Welsh Ministers to bring forward adaptation, amendment and supplementary provision.

8. Question 2(c) above sets out the powers to make regulations (subordinate legislation) that the Proposed Measure would give to the Welsh Ministers. It is proposed that all of these powers would be exercised by the 'negative resolution procedure'¹.

¹ This procedure allows Ministers to make subordinate legislation without the approval of the Assembly, although the Assembly can subsequently vote to annul the legislation concerned. Alternatively the 'affirmative resolution procedure' can be used to ensure that subordinate legislation cannot come into force until the Assembly has voted to approve it. Ffon / Tel: 029 2089 8147 Ffacs / Fax: 029 2089

**8021 Minicom: 029 2082 3280 E-bost / E-mail:
legislationoffice@wales.gsi.gov.uk**

Has the appropriate balance been struck between the provisions in the Measure and the power delegated to Welsh Ministers, to set out the detail of the requirements to be placed on the relevant authorities in Wales through subordinate legislation? Is the use of the negative procedure appropriate in each case or are any of the powers sufficiently significant for the affirmative procedure to apply?

Barnardo's Cymru believes that the measure as proposed may proceed subject to the negative procedure. However we prefer it to progress through the affirmative procedure. If some or all of the changes we hope for are made, we believe that the measure would require the application of the affirmative procedure.

Conclusion.

We would like to conclude with a reiteration of our recommendations argued throughout this response. However, we would first like to highlight another question that has exercised us while considering this paper.

We have struggled with a particular issue that may seem inflammatory and reactionary, none the less, it is one we would welcome consideration by this and other committees.

We started to consider the implications of Article 5 of the UNCRC and Article 23 of the United Nations Convention on the Rights of Persons with Disabilities, particularly in relation to parents with impairments.

Article 5 of the UNCRC

States Parties shall respect the responsibilities, rights and duties of parents or, where applicable, the members of the extended family or community as provided for by local custom, legal guardians or other persons legally responsible for the child, to provide, in a manner consistent with the evolving capacities of the child, appropriate direction and guidance in the exercise by the child of the rights recognized in the present Convention.

Article 23 of the UNCRPWD excluding parts 3-5

Respect for home and family

1. States Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others, so as to ensure that:

(a) The right of all persons with disabilities who are of marriageable age to marry and to found a family on the basis of free and full consent of the intending spouses is recognized;

(b) The rights of persons with disabilities to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education are recognised, and the means necessary to enable them to exercise these rights;

(c) Persons with disabilities, including children, shall retain their fertility on an equal basis with others.

2. States Parties shall ensure the rights and responsibilities of persons with disabilities, with regard to guardianship, wardship, trusteeship, adoption of children, or similar institutions where these concepts exist in national legislation; in all cases the interests of the children shall be paramount. States Parties shall render appropriate assistance to persons with disabilities in the performance of their child-rearing responsibilities.

As we considered the articles above we further questioned the validity of the call for young carers to be supported through additional Vulnerable Children's legislation, as in the case of a parent with impairment we believe it may become a rights and equalities issue, one where discrimination may become institutional through the passing of the measure in its current form.

We further questioned the proposed measure in this regard as if a parent with an impairment chooses, as is their right, to "found a family" will any children they have be at greater risk of being considered a vulnerable child simply because of having a disabled parent. If support through a referral as a vulnerable child is the recourse to support does this suggest that a parent with impairment is consequently presumed impaired as a parent?

Recommendations.

1. That the measure refers to carers of any age.
2. That the measure includes specific requirements of implementation.
3. That the measure includes specific requirements of local scrutiny.
4. That the measure includes specific requirements for named posts within LHBs and Local Authorities.
5. That consideration is given to expanding Section 2(3) to include the LEAs.
6. That the measure recognises the need for the provision of advocacy.
7. That the development of a strategy includes the needs of carers after the care need has ended.

Tim Ruscoe and Menna Thomas
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