

Julie Wotherspoon  
Primary and Community Care Directorate Community Care Division  
Room 2.E.R  
St. Andrew's House  
Regent Road  
Edinburgh EH1 3DG  
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Dear Ms Wotherspoon

### **Consultation on Respite Care Guidance**

NCH Scotland's projects work with some of the most vulnerable and difficult to reach children, families and young people in Scotland. The provision of respite care is a significant issue for many of NCH Scotland's service users and their families, particularly the young carers, looked after and accommodated children, and the children and young people with disabilities, we work with. Our respite care provision includes residential services that allow service users and their families to enjoy short breaks. We also offer disadvantaged children opportunities to enjoy a wide range of social and leisure activities, which might otherwise be difficult to access.

NCH Scotland welcomes the opportunity to respond to the consultation on the Respite Care Guidance ("the Guidance"). Our response addresses certain general issues around respite care provision, as well as some of the specific questions raised by the consultation document. NCH Scotland's response draws upon our experience of providing respite care at a number of projects including, for example, the North Lanarkshire Young Carers' Project, the Silverton Short Breaks Project in South Lanarkshire and the Tayavalla Family Support Project in Falkirk. For ease of reference we have used the same headings as the Guidance.

**In summary the key issues NCH Scotland wishes to raise are:**

- **Respite care makes an important contribution to the lives of many of NCH Scotland's service users and their families, including young carers;**
- **NCH Scotland welcomes the Scottish Government's commitment to update the Guidance;**
- **NCH Scotland is concerned that the lack of ring fenced funding for children with disabilities, for looked after and accommodated children, and for young carers, could have an adverse impact upon the lives of some of the most vulnerable people in our society;**
- **We believe that the impact of the Guidance, and the capacity of local service planners to improve respite care, will depend upon the availability of resources;**
- **NCH Scotland is concerned that there is little respite care provision for people with profound difficulties;**
- **We consider that the respite care needs of young carers must be given greater consideration; and**

- **NCH Scotland believes that more should be done to support young people with disabilities who reach the transitional phase, and have to leave a respite service**

### **General**

NCH Scotland believes that unpaid carers make a significant contribution to the provision of care in Scotland, and that there is a real need to ensure carers, and/or those requiring care, are able to access suitable and affordable respite care. NCH Scotland, therefore, welcomes the Scottish Government's commitment to improve the planning and provision of respite care. We believe, however, that the impact of the Guidance, and the capacity of local service planners to improve respite care planning and provision, will depend upon the availability of resources.

In this respect, a major concern for NCH Scotland is that, in the absence of ring fenced monies for respite care, there is a serious risk that such provision will be inconsistent and uneven across Scotland, despite the introduction of the Guidance. Another concern is the lack of provision for people with profound difficulties, and how this will be addressed under the new funding arrangements. Against this background, NCH Scotland considers it vital that the Single Outcome Agreements between the Scottish Government and local authorities ensure a consistent approach is taken across Scotland to the funding of respite care. Failure to do so, could have an adverse impact upon the lives of some of the most vulnerable children and young people and their families in our society. We, therefore, consider it essential that each Single Outcome Agreement should be accompanied by clear targets and outcomes which local authorities must meet for the planning and provision of respite care.

Some of the issues around resourcing are highlighted by the limited funding currently available for "breaks using self-directed support". NCH Scotland is aware that many local authorities do not promote direct payments on the basis that they lack sufficient resources to fund such payments. We also consider that, if the direct payment market is to be effective, rates of pay should be introduced which will encourage the development of a highly skilled, dedicated workforce. This is essential if the direct payment market is to deliver sustainable, high quality services for some of the most vulnerable people in our communities. These factors underline the need to clarify the level of resources local authorities will be expected to make available under the new Single Outcome Agreements for breaks using direct payments, and to assist those with the most profound difficulties.

With specific reference to the funding of short breaks for disabled children and their families, it would be helpful if the Scottish Government could clarify local Health Boards' responsibility to fund (or part fund) these short break services, given that at least 30% of the user group will have substantial health needs. It would also be useful if the government could confirm if it will fund the anticipated improvements from the £34m allocated to Scotland as part of the extra £340m announced by the UK Government to improve services, including the provision of short breaks, for disabled children and their families.

### **Evidence of value of respite and purpose of respite**

#### ***Paragraph 5***

NCH Scotland believes the provision of respite care to both carers, and to those in need of care, is vital, a fact acknowledged by carers themselves in the Guidance. This is echoed by the following feedback NCH Scotland has received from service users and their families about the value and importance of our respite care:

## **Comments from children and young people**

*"I had a great weekend with all the other young people", Emma, Blantyre*

*"I enjoyed meeting new people", Rebecca, Hamilton*

*"I like it here 'cause we play games and spending my money", Stephen, East Kilbride*

*"I like the friends I have met and the staff because they help me", Emma, East Kilbride*

## **Comments from parents/guardians**

*"It makes all the difference in the world. We have never had this kind of respite before, it means we can relax at home, something we have not been able to do before all the family is able to sleep uninterrupted, we can spend quality time with our other children, we can have a night out without any worries, most importantly we can give our child into your care knowing that he is both happy and safe and we can do that with confidence. I don't think I can put into words how important this service is to our family". Parent, Lanark*

*"Words cannot even begin to tell you how our child staying with you has helped, it been great and we can spend time with our other child. My husband and I can go out for dinner or to the pictures. It is also giving our child confidence with other adults and beginning to help him start becoming more independent from us. Thank you for being there to help families like us, it really helps us to grow closer in ways we find hard to put into words". Parent, East Kilbride*

These comments underline the need to ensure that sufficient resourcing is made available to fund respite care, and to increase the number of paid care staff to meet the support needs of those requiring care, as well as of their unpaid carers.

NCH Scotland notes that Paragraph 5 also highlights the significant contribution respite care makes to help people develop independence. We believe that the Guidance should emphasise the particular problems faced by children and young people with a disability. NCH Scotland is aware, for example, that when young people with disabilities reach the transitional phase, and have to leave a respite service, the alternative often does not meet their needs in terms of age or gender related provision, and/or the staff's ability to care for them. NCH Scotland, therefore, considers that the Guidance should highlight the importance of ensuring that respite care is available, especially in the case of children with disabilities, during the key transition from childhood to adulthood. This is another area where NCH Scotland believes it essential that there should be clear targets and outcomes to assist local authorities meet their obligations under the proposed Single Outcome Agreements.

Furthermore, we take the view that Paragraph 5 should be extended to include a specific reference to the impact which their caring role can have upon young carers, and to the effective contribution respite care can make to their lives. Many young carers are, for example, frequently disturbed at night, which can impact on their motivation and learning at school. Respite care offers these young people an opportunity to get a full night's sleep on a regular basis, which can help them to improve their educational attainment.

It also offers them ordinary family life experiences such as, for example, having a friend for tea or to sleep over, which some young carers can be denied due to the needs of a disabled sibling. Respite care can also encourage young carers to develop their independence, and to move away from their caring situation. As part of this process, however, the Guidance should clearly state that young carers must be consulted on the level of care they wish, and feel able, to provide.

### **Paragraph 6**

NCH Scotland supports the following statement in the Guidance: *“Respite was found to be most effective in providing a break for carers when they were confident in the arrangements and did not need to worry about the person with care needs”*. In this respect, NCH Scotland is aware that foster carers, for example, are sometimes unable or unwilling to take short breaks during busy holiday periods where there is uncertainty about the available arrangements for alternative care. These arrangements should both allow the foster carer to enjoy a break from their care situation, and also minimise the risk of any disruptive impact upon the child or children in their care. The risk of disruption is greatest where the care arrangements put in place, or the temporary carer providing the alternative care, for the young person vary with each short break taken by the foster carer. NCH Scotland considers that, to avoid such disruption, the Guidance should state that each child affected by their carer’s short break should, where possible, receive care from the same alternative carer. The need for such an approach is underlined by the feedback we have received from parents, which confirms that being able to trust staff in residential short break services, is crucial.

To increase carers’ confidence in the arrangements put in place for respite care for children and young people with a disability, sufficient staffing levels are required to ensure children have opportunities to access community based leisure and play activities when away from home and this requires further investment. Partnerships with health services also need to be embedded to ensure staff are trained and supported to competently meet complex health needs which are associated with children with multiple and complex impairments.

## **Policy Context**

### **Paragraph 9**

NCH Scotland notes the commitment to shift “the balance of care towards preventative support and enabling self care”. We support this commitment, but would welcome clarification of the level of resources available to facilitate the proposed shift. It would also be useful to confirm what steps, if any, will be taken by the Scottish Government to ensure that local authorities adopt a consistent approach to changing the balance of care towards preventative support to promote self care.

## **Strategic Planning**

### **Paragraphs 11 – 12**

NCH Scotland believes, from our experience of providing services to support children, young people and their families affected by disability, that promoting collaborative working between agencies to maximise the effectiveness of respite care should be a key consideration in strategic planning. We, therefore, welcome the emphasis on joint and collaborative working in the Guidance.

NCH Scotland believes that collaborative work with social work, health, education and other voluntary organisations is essential to ensure a multi-disciplinary team is in place to respond to the diverse needs of young people and their families affected by disability. We take the view that it is only when all agencies work together that we can begin to ensure positive, long term outcomes for disabled children and their families. NCH Scotland's projects have found this joint and collaborative approach to be effective in helping families to support a young person with additional support needs, particularly if these needs are complex and enduring. A great deal of family support work is, however, required in these circumstances, which is reflected in all of the short break services within NCH with the development of outreach teams, intensive family support teams and out of school teams. Silverton Short breaks in partnership with South Lanarkshire Social Work Department have provided intensive support to a number of individual families since the Project opened in 2005. Rather than only looking at the young person's needs out of the family context, much of the work involves the whole family within their homes and in their local community.

We consider that, as part of the strategic planning process, local authorities should map the population of disabled children in the local authority area, and plan effectively to meet their needs. This, however, would require work on the eligibility criteria for different tiers of services and for these to be transparent.

***Paragraph 13***

We welcome the clear commitment in the Guidance that the needs of the child should be at "the centre of service delivery".

**Types of respite**

***Paragraph 25***

NCH Scotland further welcomes the statement that service users and carers should have "greater choice and flexibility to determine, how, where and when their services are provided". We believe, however, that additional resources will be required to develop and provide the services necessary to deliver such services on a more consistent basis.

**Information**

***Paragraph 28***

Parents frequently cite the lack of information about services as a barrier to accessing respite care, an issue which is magnified if you are from a BME community. Against this background, we welcome the emphasis in the Guidance on the need to provide easy access to information. NCH Scotland considers that, to improve access to information, local authorities should be required to publish information, and to share and distribute it, on a regular basis.

**Access to Services/Eligibility**

***Paragraph 35***

We note that Paragraph 35 states partnerships should "publish clear eligibility criteria for support based on the outcome of assessments", and that such support should be available to those most at risk. NCH Scotland believes that the eligibility criteria should be amended to ensure that the assessment process takes account of both the child's need and parental capacity.

## **Monitoring, Quality Assurance and Regulation**

### ***Paragraph 38***

NCH Scotland considers that as part of the monitoring, quality assurance and regulatory framework bespoke guidance and an inspection framework should be introduced to cover residential short break services for children and young people.

### **Annex A – Indicators of Good Practice**

NCH Scotland considers that the following indicators of good practice should be added to the Guidance:

- The respite care provision maximises the opportunities for young carers to access clubs, interests and activities groups, holiday breaks and peer support groups; and
- The respite care provision is based on collaborative working between different agencies in order to maximise the effectiveness of the respite care available

### **Annex B – Personalised Respite – Examples of Good Practice**

#### **Breaks for Young Carers**

We believe that increasing the level of available respite care is essential to increase the social inclusion of young carers. NCH Scotland's North Lanarkshire Young Carers' Project offers a wide range of services to support young carers. Our services have been developed, in consultation with the young carers themselves, to meet the latter's specific needs, including improving their health and emotional wellbeing, through the provision of respite care. The wide range of respite care services and support offered by the project are outlined in the case study at Annex 1 of our response.

#### **Respite care to support children, young people and their families affected by disability**

NCH Scotland's Tayavalla project provides respite care and support for around 35 families of disabled children in the Falkirk, Stirling and Clackmannanshire area. Earlier this year it won a Scottish Care Accolade award for its ground breaking work in helping children with complex needs and communication difficulties become more involved in decisions about how they are treated and cared for. The wide range of respite care services and support provided by the project are outlined in the case study at Annex 2 of our response.

### **Annex C – Respite Needs of Specific Groups**

#### **Short breaks for children, young people and their families affected by disability**

The Guidance should highlight the benefits of residential short break services which can offer an effective and efficient model for supporting children and young people and their families affected by disability. Such breaks can afford positive experiences by enabling families and carers to have a complete break from their caring role. They also support parent's needs and aspirations to work, which can help break the poverty cycle experienced by many families with a disabled child. Residential environments are also rich in opportunities to support the learning and development of each individual affected by a disability. This includes promoting methods of interaction and communication, encouraging independence, and increasing access to social and leisure experiences, all through the direct experience of a safe and supported environment and a skilled workforce.

NCH Scotland's Lisallana Project in Ayrshire, Ordinary Homes Project Glasgow, Renfrew Family Support Project, the Silverton Short Breaks Project in Hamilton and the Tayavalla Family Project in Falkirk all offer respite care for children and young people and their families affected by disability, including residential short breaks. These services promote active working links between NCH Scotland staff and practitioners in education, health and social work/social care services. At each project the parents and families of the disabled child receive a service, and practical support, which is centred around the needs of both the child and their family. The services can also, through the development of meaningful supportive relationships between the children and support staff, be influential in creating opportunities for the children's and young people's views and voices to be heard. By doing so, our services can facilitate real choices in the support children and young people receive, and in future decision making within any review process. All aspects of the work undertaken within NCH Scotland's residential short break services reflect the outcomes identified in *Getting it Right for Every Child*.

### **Maximising positive outcomes for Young Carers**

The impact of their caring role upon young carers, and the respite care needs of these vulnerable and often difficult to reach young people, must be given greater consideration by agencies providing respite care. Agencies providing respite care should also maximise the opportunities for young carers to access clubs, interests and activities groups, holiday breaks and peer support groups. This will help young carers to develop their independence, to move away from their caring situation, and to promote their social inclusion. As part of this process, however, NCH Scotland believes it is important that the Guidance states that young carers should be consulted on the level of care they wish, and feel able, to provide.

Please do not hesitate to contact either myself, or Frances Tran, NCH Scotland's Assistant Director, on 0141-550-9010 if you require more information, or would like to discuss any of the issues we have raised further.

Yours sincerely



Andrew S. Girvan  
Director of Children's Services  
NCH Scotland

## Annex 1

### **Case Study: NCH Scotland's North Lanarkshire Young Carers' Project**

Amy became a young carer at the age of 8 when her mother was diagnosed with MS. This progressive illness eventually meant that Amy's mother could no longer deal with day to day household tasks and soon became housebound and unable to walk, her vision deteriorated and she became completely incontinent and required almost round the clock care. As Amy lived alone with her mother she assumed the role of primary carer and her life quickly changed from that of a young, care free child, to having the worry of her mum's deteriorating illness, and the responsibility of caring for both herself and her mother.

Over the years Amy's caring role grew and she found herself responsible for finances, shopping, cooking, washing and ironing as well as collecting and administering medication, toileting and bathing and providing huge amounts of emotional support to her mother. Amy also liaised with NHS staff, and was shown how to lift and handle her mother appropriately. Obviously, being a young carer can have a huge impact on different areas of your life. Amy felt she lost her confidence and felt different and isolated from her peers; she began to struggle with school work when she went into secondary education as she had to take lots of time off and was regularly late due to her caring role. The school was unsympathetic to Amy's caring role and the Head Teacher requested that she keep her absences to 1 per year for caring!! Amy eventually suffered from exhaustion, trying to keep up with school homework and assignments along with a demanding caring role – even though there were other supports that helped with Mum during the day. Amy was lucky enough to be told about our project by a teacher who did understand her situation and support services were quickly offered to help both her and her mum.

What supports did NCH North Lanarkshire Young Carers Project Provide?:

- Advocacy – securing services and adaptations for the home via social work department;
- Talking to school in order to establish additional support for Amy as her school work had suffered dramatically and all confidence in even attending school had gone;
- Individual Work – Regular time out for Amy with a key worker providing opportunity to talk about her caring role and discuss her mum's illness and her own fears;
- Group Work – Focussed programmes with other young carers – giving Amy the opportunity to establish friendships and discuss her situation with other young people who understood her role;
- Residential Respite – Weekends away to have fun, time out and be like any other young person. (with support established in the home). Amy was also able to access activities and outings which helped her to relax and have some fun; and
- Young Carers' Youth Forum – Amy's involvement in this group helped her to focus on her aspirations for the future and seek further education.

Amy cared for her mum until she passed away and the Young Carers Project supported Amy through this extremely difficult time. Amy says that she would never have managed to cope without the support of the project and with this support Amy's grades improved at school and she was gradually able to build her life up again. Amy now lives with her grandmother, is coping well and is now a Part Time Group Worker with the NCH North Lanarkshire Young Cares Project.

## **Annex 2**

### **Case Study: NCH Scotland's Tayavalla Family Project Falkirk**

Emma McLeod is one of those who has benefited from the support and services provided by NCH Scotland's Tayavalla Project. Emma has a diagnosis of autism and epilepsy and, as a result, her behaviour can be difficult at times. The Falkirk based Tayavalla service has provided a range of support for Emma and her family, which has made a huge difference to them all. "Emma loves her time at Tayavalla," says her mum Linda. "On a morning when she knows she is going there she is jumping up and down with excitement. They have been incredibly supportive to us as a family."

Recently, Emma had to go into hospital to have two teeth extracted under general anaesthetic. It would be an anxious time for any child, but it was made easier by the preparations made at Tayavalla. The project's communication worker put together a box of toys and other equipment that could be found in hospital. Playing with these helped introduce Emma to some of the things she would experience in hospital. "It was still a scary experience but not as bad as it would have been without this," said Emma's mum Linda. Similar work has helped Emma, now aged 15, to make the transition to a new school earlier in August 2007. "The staff at Tayavalla know Emma inside out," says Linda "She also gets to mix with other children when she is there and she really benefits from the experience. If it wasn't for Tayavalla, I don't know what we would do – they have been absolutely wonderful for our whole family."

Tayavalla also provides Emma's family with short respite breaks which allow Linda and her husband Donnie to recharge their batteries and to spend more time with their other daughter. Families can cope better at home when they can rely on their child getting first class care in a small, home-like centre with trained staff that they trust.