

Carers Consultation, response to the pre-legislation questionnaire from Aberlour child care trust, informed by the views of carers who use our services

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Prepared by Alex Cole-Hamilton, Head of Policy

Introduction

As Scotland's Largest, solely Scottish Children's charity, we warmly welcome the intent by Scottish Government to legislate for greater support for Scotland's carers. Our society is dependent on the largely unpaid devotion of tens of thousands of people who provide care and support to vulnerable people. As such we welcome moves by the Scottish Government to further recognise the contribution of these individuals, through providing greater and more consistent support through legislation.

Working in over 40 locations across Scotland, we offer a diverse portfolio of services to vulnerable children and families facing adversity or a range of vulnerabilities. As such there are three specific groups of carers that we work with in this regard:

1: Parent carers of children with profound and complex physical and learning disabilities: We have both short break respite and long term residential care services for families affected by disability.

2: Siblings of children with profound disabilities who provide caring support in the home: Many of the siblings of children with disabilities with whom we work have to grow up far earlier, and take on more responsibilities in the home than their peers. We have designed special packages of support for these siblings that recognise the very special role they play.

3: Children affected by parental substance use who provide a caring role for siblings or parents themselves: We run Scotland's only residential rehabilitation unit for families affected by parental substance use where children come to live with mothers while they manage their dependency. We work in a holistic way to build resilience and attachment in the children we work with.

Preparatory work:

To inform Aberlour's response to 'the Carers Consultation' we conducted 2 focus groups of parents in the first category, that is those who are caring for profoundly disabled children. Our answers to the consultation questions are, as such, predominantly focussed on the needs of this group in particular. We have however made reference to the needs of young carers with whom we work where it is relevant to do so.

1: Should we change the name from "carer's assessment" to "Carer's Support Plan"?

This question triggered an interesting response in the parents we spoke to. Most didn't even know what a carer's assessment was in the first place. Indicating that they had never been offered one or if one had been undertaken it had not been done so in a sufficiently formal way to have registered. This underscores the inconsistent nature under which carers assessments are currently undertaken and those who were aware of it said there had never been a great deal done to promote one to them.

Nevertheless, following discussion, those parents present felt that the shift in name was positive as it suggested a presumption that support would follow once an assessment was undertaken.

2: Should we change the rules so that all carers can have a Carer's Support Plan?

There was universal support for this. General dissatisfaction was expressed by all carers at the level of support that had been offered to them and this was also their view of a general lack of information.

One parent carer whose daughter has severe and complex disabilities revealed that it had been 2.5 years before they realised that as a family they were entitled to any kind of financial assistance, such as the DLA or the carers allowance and then only after a chance conversation with another parent.

3: Should the person being cared for have to qualify for local authority support to get a carer's assessment?

Parents felt that particularly when there was an absence of a diagnosis for their child, as is often the case in the early years of a condition, then there was potential for carers not to qualify solely for this reason when there was nevertheless a real need for support.

4: Should we change the rules so that carers can ask for a Carer's Support Plan or be offered one by the local authority?

There was a consistent view among the parents that we asked that a carers support plan should be offered to all people identified as a carer. Most parents cited anywhere between 2-4 years for an accurate diagnosis to be offered to their child and that in that time they had been largely unable to access any kind of support. A view was expressed that the likely hood of a parent needing to take on profound care needs of a disabled child would likely be evident from birth regardless of diagnosis. As such support should be offered from this early stage.

5 Should we change the rules so that the Carer's Support Plan doesn't say anything about a carer's ability to give care?

The parents we spoke to felt that assessment of ability to care should remain within the carers support plan as they suggested it should be the key thing that such a plan should exist to support. Consistently the most important thing to the families we work with express to us is their desire to stay together as a family and have as normal and sustainable existence as possible. As such a shift in a carer's ability to care should be met with a commensurate shift in support available to them.

6 Should local authorities have to tell carers how long they'll have to wait to get a Carer's Support Plan? Should the local authority have to give reasons if carers have to wait longer?

The parents we spoke to all agreed that better communication as to how long things might take was important to them in terms of both planning and managing expectations. Several cited examples of feeling 'left in limbo' while they waited to hear back from various departments or bodies in their care journey.

7: How important do you think it is that service users and carers should get the same support if they move to a new area?

Parents not only thought that it was essential for the same care package to be available to them should they move to another area, but that care packages should be consistent within the same local authority. They cited an example where some families were entitled to 4 weeks respite in one unit while families attached to another were offered 5 within the same authority.

8: Should the Government and local authorities work together to make this happen?

Families agreed that all statutory partners should work together, and that such a duty should not just be confined to Government and Local Authorities but should include Health Boards as well.

9: Should we make it a rule that local authorities have to have information and advice services for carers and young carers?

Lack of useful information at the right time was a key problem for the parents we spoke to. Many cited word-of-mouth from peers as the most effective source of communication that they had received in terms of the support they were entitled to. The majority of parents suggested that they had received little or no information from the local authorities other than direct responses to questions asked of them.

10: Do you think local authorities should have to show plans to the Government?

There was a general agreement that this was a good thing given what can only be described as a healthy scepticism among parents who believed that without such a duty, authorities would be unlikely to adequately deliver on their duty to provide timely and appropriate information to carers.

11: Should we make a rule saying that local authorities have to give support to carers and young carers who qualify?

There was universal support for this suggestion. The parents agreed that if people were identified as carers there should be a basic level of entitlement to support. Discussion ensued around how this support might vary between different kinds of carer, i.e. a sibling providing a level of care and support might benefit from access to a peer group of other siblings, while parent carers might require support with arranging care or other respite and childcare considerations.

12: Should we keep the rules as they are now, and let local authorities decide if they will give support?

N/A

13: Should we make a rule that local authorities have to give short breaks to carers?

“Is this a trick Question?! Short breaks represent the difference between sanity and insanity to me, they let me spend time with my other daughter and do other things I wouldn’t get a chance to do when I’m caring for my son, like having a bath.”

This was the immediate response of one of our carers, it was a sentiment shared by all of the others some of whom pointed out that without a duty on Authorities to provide short breaks, they may find themselves having to spend considerably more to deal with crises and family breakdown.

14: Should we change the rules so that the Carer’s Support Plan helps deal with different stages of care?

There was broad agreement that carer’s support plans need to change and adapt to the very fluid and dynamic nature of the care needs that they continue to meet. For instance, one parent explained that their support needs will vary greatly from what they are now if and when their daughter’s condition deteriorates to the point where they are preparing for the end of her life.

There was a view that carers support plans should be reviewed on a regular basis and that if things were to change dramatically then under circumstances, the carer could trigger a review themselves. At the same time, parents expressed a desire that reviews not become overly burdensome or too regular given the number of other meetings they are required to attend.

15: Should the new rules let young carers have a Carer’s Support Plan if they are going to become adult carers?

There was some discomfort at the use of the term ‘young carer’. Even though this is the role that siblings certainly fill, there was a reluctance to have them badged in this way.

Parents pointed out that they should have an individual carer support plan any way and that this should be reviewed to recognise periods in the lives of young people when they are likely to be under additional levels of stress, such as when they should be sitting life-qualifying exams.

16: Should carers be involved in planning support for the people they care for and support for themselves?

The response to this was quite emphatic with Carers explaining that they know their child best and as such are far better placed to support planning arrangements.

17: Should carers’ organisations be involved in planning support for carers and the people they care for?

There was a mixed response to this. Parents wanted to know what kind of involvement carers’ organisations would have in the planning of support. They were content if this was confined to sign posting, advocacy and provision of services, but expressed a desire to be known personally to the carer’s organisation.

18: Should we change the rules so that carers are involved in planning care?

For the reasons described above, all of our parents said yes to this.

19 Should we change the rules so that young carers are involved in planning care?

The response to this was more nuanced with a view that siblings who provide a caring role should be asked their opinion within the planning process.

20: What do you think about young carers being involved in planning support for the people they care for and for themselves?

Again, it was felt that young carers should be invited to have involvement, with their opinions being meaningfully considered, but that recognition of issues like their mental health and pressures of life, such as exams, be considered in this regard.

21: Should we make a rule that all these organisations must work together with carers to make plans? Should these plans be looked at and updated every three years?

There was universal agreement to this suggestion as there is a view held amongst parent carers that NHS boards and councils aren't always aware of what each other is doing. An example was offered of where a family had been told by social work that they could not receive respite without the provision of a sling to facilitate moving a handling in respite provision. It fell to the health board to provide this. Due to a miscommunication the health board did not provide one and the family went without respite until Aberlour sourced and paid for one. Concern was expressed that if these bodies could not communicate around primary care then it could not be assumed that they would work together around planning without a duty to do so.

22: Should we make it a rule to have a range of services available for carers and young carers?

Again there was confusion as to whether this was a serious question with all parents expressing emphatic support. One father suggested that as well as provision of such services there should be extra capacity to ensure there was always a 'crisis space' to cater for situations of urgency.

23: Should it be a rule that doctors (GPs) have to find out who is a carer and put them on a list of Carers?

It was felt that GPs were best placed to identify carers and put them on a central data base of carers. Parents felt that young carers (siblings) should also be identified in this regard. It was also expressed that doctors should receive in work training to assure their compliance with this.

24 Should we make a rule that Health Boards share ideas on how to raise awareness about carers in doctor's surgeries?

This was seen as just one much needed way of increasing awareness of support available to carers.

25 Should the Government ask Health Boards to make sure that doctors (GPs) are keeping their list of Carers up to date?

This suggestion was supported by all parents.

26 Which local authority do you think should do the Carer's Support Plan?

Opinion was divided on this as some parents felt support would be needed closer to the person being cared for or to that carer's home.

27: Which local authority should pay for the carer's support?

Again, opinion was divided.

28: Should the Government and local authorities come up with guidelines for this?

The parents felt this was necessary, given the uncertainty they had had amongst themselves.

Case study- Caring for a child with severe autism: In the words of an Aberlour service user:

Life is exceedingly challenging living with autism. I have two children who are both on the autistic spectrum. B has Asperger's syndrome and is aged 15 and J, aged 11, has severe autism and is pretty much non-verbal. They both present additional parenting challenges and although I no longer have a paid salary, my job is extremely demanding and it takes up all of my time caring for my family.

We have a respite service for our 11 year old which provides us with an overnight stay away from us one night every 6 weeks during term time. We are appreciative of having this as it means we can spend some time with our son B, which is a rare occurrence. We cannot take J to most leisure opportunities so our leisure time out with the home tends to centre around a couple of quiet walks and riding the escalator in our local shopping centre!

I have always struggled to have my son J go to a respite provision. When we requested it, we were at breaking point as a family. Our son never slept, shrieked all the time, was extremely hyperactive and slapped us up to 400 times an hour. I dreaded him coming home from school at night. He would run past me without acknowledgement to get to his beloved videos, the only thing which seemed to give him some peace. He would spend the evening enthralled in them and I think some other autistic parents thought I was lucky that I had a child that would watch TV. It was absolutely devastating. His main interaction with us was aggressive and it was not right that TV was his main focus in life. He had no form of communication other than hitting (but of course we couldn't always tell what he was trying to convey to us) and using PECS symbols to pass us a few basic pictures to request e.g. food items. Life was extremely stressful and I had little hope for his future. I felt tortured. I have struggled with sleeping since B's autism diagnosis at age 4.

J slept with his dad or myself every night for about 9 years (now sleeps in his own bed most of the time) during which he spent most of the night running round the room, slapping us and shrieking. I have developed health problems which I have yet to find the time to address. My son now often can sleep in his own bed although recently he has struggled getting to sleep (stomach issues) and his dad has been taking him into bed with him if he is not asleep after 12 o'clock. I cannot remember the last time his dad and I slept in the same bed.

About a year and a half ago we started doing Applied Behavioural Analysis therapy in our home with J. This is a science which involves data keeping and basically uses motivation to teach. Our son has responded amazingly well to this. He can now use 60 sign language signs, has a few speech words and quite a lot of speech approximations, has better fine and gross motor skills, can dress himself, can cope with doctors and dental examinations, can eat a broad diet, is basically toilet trained during the day, has good eye contact and seeks interaction, can follow more instructions and has improved compliance, has gone from doing toddler insert boards to 35 piece jigsaws himself, he has a desire to learn and before he would not have seen the Benefit, he has a significantly reduced hitting problem and has less pain caused by his stomach issues. He is also more importantly much happier.

We were also told by our ABA consultant that our son had Apraxia issues which meant he lacked the motor planning to know how to produce the correct speech sounds. We also do speech and language therapy work with him under guidance from our ABA consultant. This involves e.g. oral motor exercises and Talk Tools e.g. bubble blowing and mouth props to exercise the jaw and to get rounding shape to produce certain sounds. Our son also needs taught for each sound how much he needs to open his mouth, what shape he has to produce with his mouth, whether sounds are voiced or voiceless and what he needs to do with his tongue to produce speech sounds. We use tactile cues to build up single sounds then work on basic blends of word approximations. These exercises are producing speech sounds, approximations and some individual words and the words we work on are the ones we have assessed as being most reinforcing e.g. certain foods that we keep as treats and only use for teaching. It is devastating that so many children would benefit from this and have the ability to speak but are given pictures to communicate. There also seems to be a huge lack of knowledge amongst public sector Speech and Language therapists.

We also started doing a biomedical intervention with J a year and a half ago. Autism is often regarded, not as a disease but as a genetic condition which cannot be altered. My research suggests that this is not the case for a majority of children. NHS offer nothing to our kids but most of them have significantly compromised immune systems, gut pain issues and bowel problems, and when urine, blood tests etc. are performed their markers are significantly abnormal. If a child had cancer and doctors did nothing there would be an outcry but because autism is not fully understood they address nothing. Biomedical doctors treat the test results using e.g. supplementation and diet and try to balance the gut flora and heal the gut and digestive system which improves immunity and reduces vulnerability to other disease. Often hitting and aggression occur as these children live in pain. Our son can often have 6 diarrhoea accidents a day as his digestive system does not function as it should. If pain issues can be addressed then aggression should reduce and when gut healing occurs a child's development and functioning should improve. We have had to put our son on an extremely strict diet and have to cook basically everything from scratch. He is hugely intolerant of many foods and often when he does not sleep we can relate this to a mouthful of food he should not have had access to. We also have to ensure our son's environment is as toxin free as possible e.g. filter water tap, pure cleaning products etc. ABA and biomedical interventions have significantly improved our son's ability and desire to function although we have a long way to go. Without going down this route I do not even know if we would have been able to still have J living with us.

Since running an ABA and biomedical programme our life is stressful in a different way. We do not get funding to assist with our home programme which runs for about 15 hours a week while families in England can request funding to home school their child or send their child to an ABA school. In America, ABA is the standard intervention offered by insurance to families whose children are diagnosed as being autistic and early intervention is hugely beneficial. In Scotland nobody seems to know what ABA is and we have to travel to visit our consultant in Wales who manages our programme or her staff have to visit us. It is expensive to run a home biomedical and ABA programme. My partner works long hours and all our money beyond our basic living costs goes into J's care and we are extremely financially stretched. Running the programme also involves a lot of work. We no longer have any social life. I find it stressful now to spend time going out for a coffee as it takes me away from getting on with my son's programme. I spend hours every week doing paperwork, setting targets, reading, doing reports, planning teaching and resources, cooking for J's diet, feeding him and administering the 4 pages of daily supplements he is on, dealing with diarrhoea accidents or trying to manage constipation issues, as well as teaching. Stopping running this programme is not an option as we would have no hope for J's future and we know he would live a life of physical and mental pain, as would his family.

It is amazing to see what our child can do with the right support and disappointing how little understanding there seems to be about autism in Scotland. There also seems to be little intervention planning. Children like J will cost a fortune to look after long term but given help when they are younger, costs could be significantly reduced. I believe if my son had had the help he is now getting as a youngster, he would be functioning in mainstream school. Also, the longer gut and digestive system issues go unaddressed the more damage is done, the longer the healing process and the more chance a child has of further disease or epilepsy.

As a carer, I do not really want my son away from us for respite. I do not think it is solving anything. I want to be supported to aid my son's development so that I can cope with him at home. Although respite provides us with a night where we know we are not going to be up all night dealing with J, it is still stressful having a vulnerable child staying away from you. I would rather address why my child is unable to sleep and surely this is the best option for everyone.

I find there is a huge lack of affiliation between education and health. They are very separate in approach and it seems nobody seems to consider the affect that a child living in physical pain would therefore be less able to function well at school and may have aggression issues as an expression of this pain which would then impact on his work.

I also find it bizarre that Social Services may be able to provide families with money for "respite" e.g. a carer coming into the family home to spend time "babysitting" a child however this money is not allowed to be used for educational purposes e.g. employ someone to teach your child during this time which also provides respite for a family.

As a carer, what would help me most would be to be supported to allow my son to reach his potential. I would love my son to attend an ABA school, not feel that I am responsible for his development and I would like to be supported to run a home programme so that respite time for his family meant teaching rather than babysitting time for J. The costs of special school for a childlike J are significant and I would like to be able to train people up to deliver a home programme which would be cheaper than his school costs. We have an individual education plan produced after testing I do with him so we know what we need to work on. I would also like for NHS to acknowledge that although autism treatments are still somewhat misunderstood that tests usually indicate e.g. heavy metal poisoning from the environment etc. which impact on our children's bodies but which can be treated and reduce immune system distress. Most autistic children have huge problems with bowel issues too, all of which can be treated rather than put down to them having autism.