Mencap Cymru Response to the Health, Social Care and Sport Committee Consultation on The Impact of the Social Services and Wellbeing Act (Wales) 2014 on Carers

September 2018

1. About Us

Mencap Cymru is the voice of learning disability in Wales. Our vision is a world where people with a learning disability are valued equally, listened to and included. We want everyone to have the opportunity to achieve the things they want out of life. Everything we do is about making sure people with a learning disability are valued equally, listened to and included.

We welcome the opportunity to submit evidence to the Health, Social Care and Sport Committee Consultation on the impact of the Social Services and Wellbeing Act (Wales) 2014 on carers.

This response has been informed by speaking directly to carers across Wales through focus groups, seeking their views and experience. It has also been informed by our Wales' Independent Support and Empowerment (WISE) project, an advice and support service we offer across Wales, from the data we collect and the case work that we undertake.

2. Key Recommendations

1. Welsh Government should run a national awareness programme to promote the rights of carers.
2. Local Authorities should increase its work with third sector organisations to raise the awareness of the information, advice and assistance available to carers across Wales.
3. Local Authorities should publish if, and how, they are using 'What Matters Conversations' during Carers Needs Assessment.
4. Local authority staff awareness of the Social Services and Wellbeing Act (Wales) 2014 is often poor. Therefore, more needs to be done to inform social workers and social work teams of the Act, and their obligations to carers.
5. There should be a standard sheet of information that social workers provide that directs people towards other sources of information. The social worker should be required to work through this sheet, ensuring that the carer knows that they can refer back to the checklist of topics to request further information. This will ensure consistency of experience for all carers.
6. Social Workers should provide surgery like sessions. They would either talk around a specific theme, or provide the opportunity for groups of careers to come and ask the questions they need an answer to.
7. Whilst the Act represents a progressive attempt to change the general environment surrounding [ ] Carers' experiences are still either negative, or perceived as being negative. There needs to be significant cultural/institutional change in practice to change both the actual experience, and perceived experience, of carers so that the intentions of the Act become a reality.
8. To fully improve the wellbeing of carers the Government needs to address what will happen to the Cared for Person when the Carer is no longer alive to provide care, with particular focus on housing and support.
9. There is a need for clear and accessible information and guidance around direct payments. The information also needs to be readable and relatable. There is a

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3. Detailed Response

Assessments of Needs

3.1 Access to a Carers Needs Assessment

The right to a Carers Needs Assessment remains a key element of the Act. Carers have a right to an assessment in their own right, and local authorities have a clear duty to promote this right. Whilst the Act states that carers in Wales have equivalent legal rights to support as those that they care for. However, from what we have seen, carers are not routinely being offered assessment.

Access to a Carers Needs Assessment is varied – some carers confirmed they had received an assessment and knew who to contact for support; others commented that they were not aware that they were entitled to a Carer Needs Assessment. Moreover, some carers with significant caring responsibilities stated that they had to chase for an assessment, or had been refused an assessment. This is not acceptable.

The lack of knowledge around where to find out further information suggests that Carer's Needs Assessments need to be promoted more widely, both to carers and Social Workers, so that people are aware of their rights and what extra support they can expect from the assessment. Immediate action needs to be taken. A national awareness programme should be launched to promote the rights of carers.

Some carers we spoke to stated that they were unaware they were entitled to an assessment, others stated that they were denied an assessment. For example:

"I heard that others were getting them, I asked but was told I wasn't entitled, I'm not entirely sure why".

"I've asked to have my needs re-assessed and the person I care for re-assessed but they won't."

"I didn't know that I could have an assessment."

Others highlighted the need to fight for a Carers Needs Assessment:

"It's basically if you don't ask, and keep asking, then you won't get."

"It comes down to how good your social worker is. We had a trainee social worker and she was fantastic, she went through it all with us explaining what I could access and helping us access it, but the one before was awful everything was no. She was so good that she helped others families where the social worker they had was rubbish. It shouldn't be in the hands of an individual, the luck of if we get a good one."

3.2 Issues with the Process

Of those that we spoke to who had received a Carers Needs Assessment a strong theme emerged, that the assessment was a negative or difficult experience. A number of carers reported feeling that the assessment was being used to judge their ability to care, rather than what support they need. Many stated that they felt judged and intimidated by the process, often feeling unable to be honest about their needs out of fear. The process is seen as inherently negative by many carers and as such it colours their engagement with the assessment. Therefore, we feel that a cultural change is needed. There needs to be more consideration around the assessment process itself, and a movement towards proactively offering support.

The statements put forward by some of the carers we spoke to highlights the urgent need to modify the culture and language used in assessments.

"It is just all so negative, so demeaning."

"Sometimes you lie because the truth hurts. You always have to say what you can't do or they can't do, to get the support you need. You come away feeling dreadful, it really hurts. You feel like you are insulting them **[the person they care for]*****, doing them a disservice, like they are a burden, what about all the good they can do? Or you feel like you are a terrible parent failing them, it's not fair."***

"I feel judged, the tone is always so negative, I feel like a can't be honest because if I am then maybe they will decide I'm not capable of caring for my son and he will be removed. I'd rather struggle than see him go into a home".

"Sometimes I just feel ashamed or embarrassed, like I am failing as a parent, so I lie. I say something isn't an issue, I don't want people looking down on my daughter, I don't want to focus on what she can't do. I'm proud of her, I want others to be too. They don't realise how difficult it is to be honest. It's the whole approach, it's so negative and cold, it needs to change".

3.3 Use of 'What Matters Conversations'

There is ambiguity around how 'What Matters Conversations' are being used. We are aware that some local authorities are utilising pre-assessment 'What Matters' conversations and/or 'What Matters' documents. Whilst other local authorities are using a 'What Matters' conversation as the formal assessment. We are aware that in Anglesey those wishing to refer a client to the Social Services are being asked to complete a 'What Matters' referral form, which asks for information around what support an individual can access from the community. This is inappropriate.

Our concern regarding 'What Matters Conversations' is twofold. Firstly, each local authority is utilising 'What Matters' conversations in a different format, we feel that this is creating confusion for carers. Secondly, we are concerned with how some Local Authorities are using 'What Matters Conversations'. In theory 'What Matters Conversations' could be greatly beneficial to the carer, we can see that they can be used a create a 'person centred approach' where care is tailored around the person's wants and wishes. However, we fear that these are being used inappropriately and, in some cases, used to justify a reduction in support.

We feel that whilst the Act encourages fair assessments, councils may be using them inappropriately, especially if carers do not know the legal basis of the conversations or assessment they are having. We fear that some local authorities assess carers in terms of the support they could receive, considering personal circumstances of the family and extended family, and makes a claim of what support they think is available from the family.

Therefore, we ask for clarity on how 'What Matters Conversations are being used across Wales. Local authorities should publish whether, and how, they are using 'What Matters Conversations' during Carers Needs Assessment.

Provision of Information and Advice

3.4 Poor Dissemination

Providing information and advice to carers is a core component of the Act. However, information and advice is not being effectively disseminated to carers. A proactive and focused approach to disseminating information and advice is urgently needed. The carers that we spoke to stated that local authorities were not a source of information and advice. Instead they view charities and word of mouth as their main source of information and advice. For example:

"Getting information is a matter of luck, whether you get a decent social worker, or you know a family that have a good social worker, or a family that have experience of something you are looking for information on".

"Sometimes it's hard for people to communicate what they want or what support they need because they don't know what types of support they can receive"

Many carers do not know about their rights and entitlements. When a carer phones the WISE Helpline with a concern, they will have little (if any) awareness of their entitlements as a carer. We support nearly 1,000 via our helpline each year. Carers are often unaware that they are entitled to a Carers Assessment. This should not be the case.

A key theme that emerged amongst the carers that we spoke to was frustration around accessing information. Many reported that accessing information required considerable time and energy. For instance:

"We just don't know what support or help is available, nobody has told us, and where do we look? I don't know where to start, it's a puzzle".

"I know that information is out there if you look hard enough for it. But the reality is that I don't have time to look for it. And if I do find something it is often completely illegible to me, I don't know what it really means, it's as if it is another language".

"Everything is just by chance or luck. The luck of speaking to someone or coming across something, then the luck of speaking to the right person who wants to help".

"There is a feeling of being passed from pillar to post, it's so demoralising knowing that you don't matter, so much so that it's easier not to try."

When we asked carers how they would like to see information disseminated, three key themes emerged.

First, a number stated that they prefer to get information and advice from the third sector. From those that stated this, it was felt that when information was disseminated by the third sector it was more accessible and felt "less daunting, like I could ask what something means and not get judged".

Therefore, as the third sector is often the preferred source of information, we feel that local authorities should increase their work with third sector organisations to disseminate information and advice to carers across Wales.

Second, a number of carers commented on how local authorities and social workers were often unreachable or impenetrable. For instance:

"Social services office is not accessible on the phone or physically, you can't get into the office".

"Council receptionists act as a barrier, they either just won't let you see someone, or they ask you why you are here and what you want, there is no privacy… I feel like they are doing this on purpose to dissuade people. It's either shame or not getting the help, sometimes not getting the help is the easier option"

"As an individual parent access to care managers is so difficult, but if you say that you are a support worker then you will get access. I phone for my son and can't get through, nobody speaks to me, I phone as a support worker during my day job and I get through or the person phones me back, it's horrible. Basically it is stating that my role doesn't matter, I don't matter. As a parent people just don't get back to me. I keep asking and phoning but nothing."

Carers stated that a less formal and more personal approach was needed, where social workers and local authorities go into the community to pro-actively disseminate information and answer questions. One option put forward by a carer was for local authorities to hold surgery like drop in sessions where somebody would be available at a set time to answer questions. Other suggestions include social workers delivering talks around a theme followed by a 'Q&A' session.

Third, a number of carers stated information needed to be standardised and condensed into a manageable resource. One carer stated that they wanted a directory of information with where they could seek further advice and guidance.

There should be a standard sheet of information that social workers provide that directs people towards other sources of information. The social worker should be required to work through this sheet, ensuring that the carer knows that they can refer back to the checklist of topics to request further information. This will ensure consistency of experience for all carers.

3.5 Local Authority Staff Awareness

A major area of concern is around the level of understanding and awareness that staff in Local Authorities possess. We have directly encountered staff that lack a solid understanding of the Act, that are unsure of their own roles, or how services are supposed to meet individuals' needs. This needs to be address urgently. The Act places a duty on Local Authorities to ensure that a wide range of community services and activities are not only provided but also signposted, we are finding that in some areas this is not happening sufficiently. Often carers are not aware of community services and activities. Carers are also reporting a lack of understanding and awareness amongst local authority staff. For example:

"They often don't know themselves, so how on earth are we supposed to know? There's been times that I've had to tell them what they are supposed to know, I am the one giving them the information".

"If a social worker doesn't know about something then how can they inform you that it's an option?".

Local authority staff awareness of the Social Services and Wellbeing Act (Wales) 2014 is often poor. Therefore, more needs to be done to inform social workers and social work teams of the Act, and their obligations to carers.

Provision of Support

3.6 Access to Services

We have encountered cases where inflexible care plans meant that they could not access services they needed. Several carers stated that care plans were too rigid and when they requested for them to be updated they were met with resistance. For instance:

"it's hard to modify it, but in reality things change, and things change a lot. How it is at the moment means that there is a need to get it right at the beginning because if they don't it's near to impossible to change. Life changes, but changing the document is so difficult. The document needs to be more flexible."

"You might find out about something and want it but you can't because it's not in the care plan, and it's so hard to change the document."

"Assistant social workers often act as gatekeepers, they say that the care plan cannot be updated, you can't access this service, you can't speak to the social worker. They shouldn't do this, it's not their responsibility, they shouldn't make this decision. I understand that this is often because they don't know enough and it's easier to say no."

Several carers also highlighted that some social workers are unreasonably refusing access to services. For instance:

"When I asked for more support they just said no. The only way I could get support is to put the person into emergency respite, I don't want that."

"They always say, 'no that can't be done, we don't do that' then we always have to say ' 'but I know a person that'…"

"They seem to view only certain things as acceptable, swimming is constantly encouraged, but she doesn't like swimming, when I suggest something else it's frowned upon, they shouldn't be allowed to decided what a person does."

3.7 Lack of respite services

For the carers that we spoke to the lack of respite services is a common concern. Several emphasized the need for respite, as one carer stated: ***"I cannot emphasise enough the value of respite services to carers of children with disabilities, they are our lifeline."*** *However,* carers also stated that access to respite services was often very difficult.

"No, most don't get it. Does it really exist? Has anyone ever used it?"

"I asked about respite, I was offered it four years later."

Some carers also stated that when they had used respite services it was often problematic and/or inappropriate. One carer stated that she had to refuse the respite that she was offered for her 19-year son as it was to be in a care home for the elderly with dementia. Others also stated that respite services were often problematic. For example:

"Respite is more trouble that it's worth, it's so time consuming to arrange and then they just sit around and get distressed, and it means more work when they come home."

Another theme that arose was fear to request respite services. For instance:

"I'm too scared to ask for respite even though we need it desperately. I worry that if I ask for respite then they will think I can't cope and the person I care for will be removed, or I will lose my direct payments. It's not either or but it's made to feel like it is."

"Asking for respite or emergency support is like asking for forgiveness for failing, or begging for forgiveness, so much shame."

This feeds in to our earlier call more to be done around the culture of care and support. It is not acceptable that many carers feel this way.

3.8 Wellbeing of Carers

The Act states that local authorities are required to promote the wellbeing of both people in need *and* carers. However, we feel that this is not fully integrated into the approach of local authorities. The main theme that emerged when speaking to carers was the fear of what will happen to the individual that they care for then they are no longer able to care for them. As one carer astutely states:

"There's a focus on the small stuff, but it's the big things that hang over us, what is going to happen when I die, this is the biggest strain on my wellbeing. It haunts us everyday. The not knowing is just awful. Where will they go when they can't live with me?"

"It's the worse feeling in the world wanting your child to die before you because that's better than what might happen to them if you die first."

"Life after us is the biggest stress for us, what will happen to our children. It's the thing that takes the biggest toil on us".

One elderly carer spoke of how whilst she was ill with cancer she considered how she could end her and her sons lives together. She felt that it was the only option available to her. It was kinder than the alternative, as she did not know where he would go and who would care for him.

If the Government are committed to improving the well-being of carers they need to ensure that this overwhelming burden is removed. Considerable work needs to be done to provide support for carers to prepare for their loved one's life after the carer, with a focus around housing and support.

3.9 Direct Payments

When we spoke to carers issues and frustration around direct payments quickly emerged. Several carers highlighted that they had received little, or no information, around direct payments. Several stated that they did not know how to use their direct payments, for instance:

"There is no information disseminated regarding direct payments. It's a complete enigma, a puzzle, it's a joke".

"We don't know what we can use it for, we look to other families and see how they use it, and most of them are making it up".

"I want to use my direct payments but I don't know how."

"I want to use mine but I struggle to understand how it works".

Some carers stated that the were not using their direct payments, but instead sending them back because they were worried about getting it wrong. For instance:

"I don't use my direct payments because I'm worried that I will do it wrong and have to pay it back".

Other carers highlighted that whilst they like being able to tailor how they spend the money and organise the support, they often feel overwhelmed by how much time and work is involved. One carer highlighted that he was unaware that he could get a direct payments account manager, whilst another spoke of their negative experience of using an account manager. For instance:

"It's too much work, I can't do it on top of everything else."

"Direct payments are OK in principle, but we have to become employers, accountants, it became another full time job, I don't have the time or energy, or the skills. I manage the account; I didn't know someone could manage it for me. I didn't know I could have an account manager. This is exactly the problem, another thing I didn't know about, nobody told me."

"When our account was managed there were errors that we then needed to pick up on. We needed to audit it. We had to go through the accounts and there were mistakes, this isn't encouraging others to take up and use their direct payments."

There is a need for clear and accessible information and guidance around direct payments. The information also needs to be readable and relatable. One method would be the use scenarios, e.g. this is how family X uses direct payments, this is how person Y uses direct payments.

4. Summary

- Carers are not routinely being offered a Carers Needs Assessment.
- Some Carers have been denied a Carers Needs Assessment.
- Many Carers are unaware that they are entitled to a Carers Needs Assessment.
- Many Carers report that the Carers Needs Assessment was a negative process. Several Carers stated that they felt judged and intimated by the process, often feeling unable to be honest about their needs out of fear.
- We are concerned with how some local authorities are using 'What Matters Conversation'. We feel that clarity is needed around where and how they are being used.

- Information and advice is not being effectively disseminated to carers. Many carers do not know their rights and entitlements.
- Carers reported frustration around access to information. Many highlighted that there were often barriers to accessing information.
- The understanding and awareness that staff in Local Authorities possess is often poor. We have directly experience staff that lack a solid understanding of the Act, and are unsure of how services are supposed to meet individuals' needed. Carers also recognised and voiced this concern.
- Care plans are often inflexible, and some social workers are unreasonably refusing access to services.
- There is a lack of appropriate respite services.
- If the wellbeing of carers is to be fully considered the Government and Local Authorities needs to provide support for carers to prepare for their loved ones' life after the carer, with a focus around housing and support.
- There was frustration around direct payments, several carers highlighted that they received little, or no information, around direct payments. Others emphasized the considerable time and work that is involved. Some carers stated that they were not using their direct payments due to a fear of getting it wrong.

5. Further information

We are happy to discuss any aspect of this response in further detail, please do not hesitate to contact us for more information if required.

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