

C03

Ymchwiliad i Effaith Deddf Gwasanaethau Cymdeithasol a Llesiant (Cymru) 2014 mewn perthynas â Gofalwyr
Inquiry into Impact of the Social Services and Wellbeing (Wales) Act 2014 in relation to Carers
Ymateb gan Unigolyn
Response from an individual

Good Morning,

I am unsure if my views are relevant to this consultation.

My 4 year old son was diagnosed with Autism in [REDACTED] 2018, and overnight I was defined as his mother and carer.

It was a term that didn't really affect me one way or the other. As his mother it is my main priority to make sure he accesses the best possible services, education etc that he possibly can. It is also imperative to me that we lead a happy and 'normal' life as much as possible.

Being a mother to two young sons is demanding as it is for many parents. This is my normality I don't have experience of motherhood without autism so I have nothing to compare my experience against.

What I wanted to share today was the demands and affects that being a parent and carer can have. All carers are defined as 'carers' yet we all varying responsibilities and we all have different emotional attachments to those we care for.

I don't mind sharing with you that having a son with autism has been tough. Although it is my normality, life is still difficult. I would not change him for the world and he is an incredible little boy, but his condition has take a toll on my mental health, my marriage, my family and my work. But despite this I still have to care for him and his brother, who is also showing significant signs of autism, I have to work 28 hours a week, and look for extra employment to support the home, and attend the weekly appointments , and deal with my severe anxiety.

I don't know if parent carers are overlooked slightly. Because it is expected for me to care for my son as a mother, the caring element is overlooked. But I have more demands placed on me as a parent than perhaps other parents do.

The endless battles to get the right services provided for my son, the constant appointments, the form filling etc. Then there is the home life to contend with. My son is non verbal at 4 years old. I have to accept the fact that he may never talk and I will need to be his voice. I have to deal with meltdowns that can last all day. My sons sensory needs are incredibly demanding and normal life is thrown out of the window. A 4 hour meltdown because he can't tolerate sun cream on his face. The sleepless nights, the smearing of faeces, running into the road, the list is endless.

I work for a charity and I know there is considerable support out there for carers. But you have to look and search for it. The Carers Project [REDACTED] have been great and given me access to discounted leisure facilities. I can't access support groups because my time is so stretched and respite is not an option for my son.

Although I have been in touch with social services - I was deemed to be 'managing' and wasn't offered a carers assessment - although I'm not sure I would be entitled to one.

Many areas of my life and my family's life is dictated to by autism. My mental health has suffered to such an extent that I am now needing to take medication to control my anxiety so that I can continue to care for my son and potentially my younger son if he also gets diagnosed with autism.

No one ever expects to become a carer and we are often thrust into this with no preparation, no role description, no agreement, no pay, no breaks and a loss of control over your future.

My suggestions would be:

- A specific carers assessment for parents.
- An acknowledgment that parent carers have significant additional responsibilities.
- Carers Allowance should be offered to all parent carers - currently parents can only apply for this benefit if they earn under £150 a week. This is an incredibly low threshold when most families need to earn more than this to survive. I provide daily care for my son well over 35 hours a week, but because I earn more I'm not entitled to it. This benefit would prevent me from having to work additional hours and be there for my sons who both have demanding needs.

I hope my above 'ramblings' make sense, please contact me if you need me to clarify anything.

Many Thanks

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