

Engagement Zone

What ingredients make a good service for you?

- Being asked how you are and for them to listen to the answer
- I know that there is no magic cure but all I want to be is listened to, not judged, felt cared for and make me feel as if I am actually a human being and not a robot providing care for others 24/7. Is this too much to ask for?
- Staff who understand how to avoid language that triggers melt downs. Autism is not an illness that needs treatment, it needs proper support
- I need professionals to see that there is so much more to my daughter than her litany of medical ailments. She is a person with hopes, dreams, passions, right, hobbies, friends, potential – she is a fierce light, she deserves a seat at every table
- How do you get accountability? Local authority doesn't follow their own process – GIRFEC – is it get it right for every council? Why should a child suffer as a result of SLC failures?
- Answer we are given is SPSO however, no investigation done – ruled in favour of council – despite overwhelming evidence. My experience is this is not fit for purpose – we need action not lip service
- Children with disabilities grow into adults with disabilities and this is known before they leave school. Why all the difficulties with transitions? Sad to hear parents still going through this same as we did 10 years ago
- I need time off every day – the opportunity to come down a peg from being in a constant state of high alert. Time to recharge so I can deliver the best care possible to my child
- I need more mental health support to enable me to cope with my own problems as well as my mum's. I cannot deal with someone else's inner demons when I cannot control my own. Young carers are worthy of support and a genuine listening ear too.
- I need professionals to stop giving me homework and extra tasks. My most precious asset is my time and this is taken from me at every turn. Please meet me where I am in my journey. Ask what it is that I think I need in order to live a good life.
- I need hands on practical help to lighten the load. I need charities and professionals not to promise the earth and deliver nothing. I need access to choice of care provision and design how that looks for my family
- Devolved benefits – I'm supportive of change... however, I've great concerns re implementation e.g. just had PIP assessment for our 16 year old – will we have to go through the whole process again so soon? e.g. completing forms, 12 pages of additional information and 14 appendices? How can I help raise this issue?

- We need the right support, at the right time, without having to expend precious time and energy fighting for it. These are precious finite resources that carers need to spend wisely.
- Schools being very understanding when my son's off ill. Head teacher to STOP report ME!!!
- Current input and Child Development Centre is purely via a medical model, so have NO idea what is available locally, guardianship process, accessing social work input.
- Services don't have time to look at the full picture i.e. GPs one ailment only. Lack of mental health support services for cared for person and carers. Respite isn't them going into hospital!!!
- On a daily basis we need help. Carers Allowance should be a non-means tested benefit. Everyone with a serious diagnosis should be in receipt of DLA or PIP.

What is the icing on your cake?

- I didn't get any support apart from the young carers. The school didn't help, neither did friends. I just wish the school would help because I know it's not just me in that school – there's others.
- Renfrewshire Carers Centre – my lifesaver.
- Good service – listened to – valued as equal.
- Having information that's accessible e.g. on website, strategies, policies, procedures all in accessible fonts etc. as a point of contact.
- Benefits system that is humane.
- Services to suit care for.
- Carers needs met.
- It would be a dream and a miracle for the Government to invest in support for all young carers.

Give an example of what has worked in your area

- Raising our voice to be heard!
- We now have council paid respite in our home for our 23yr old daughter instead of her going into an 'old peoples' home.

Are there any barriers or challenges you face in getting the support you need?

What do you need for your cake to rise?

What needs to improve in your caring role?

- Some teachers don't care – schools need to give flexibility
- I was always rejected from receiving mental health services despite numerous GP referrals because the depression and anxiety I had was seen as 'my fault' so I isolated myself for a long time.
- Some helpers do not care and don't take an interest to help you about your outside life.
- I'm 16 with disabilities – Am I an adult? Am I a child? 16-18 gap in services – HELP!!!

- Being told I am allowed as much time off college when things are rough. But why should I be absent all of the time when a simple solution would be for the local authorities to invest in services to support carers and their families instead of spending it on irrelevant things. We deserve help too!!!
- More people to understand my situation
- Taking the time to listen
- Good listening – honest professionals
- Not assuming anything – carers are busy – don't assume they have time for extra tasks
- Being asked 'how are you?'
- Too many changes of staff (very high turnover)
- In my situation as legal guardian to be able to pay myself and part of my daughter's care if there is no one else to be her guardian
- Local authorities to know what they are required to do – changes of staff means they often don't
- More knowledge of Carers Rights
- Schools need more awareness
- I need someone looking out for my needs
- I need the right support at the right time without having to expend precious energy fighting for it
- To be respected as someone who speaks and understands the needs of not just disabled but the whole family
- Awareness of what's available locally
- One of my biggest challenges was 'experts' not listening
- People actually getting to know my situation/standing point in life
- My son's guidance teacher responds quickly to emails – he is a gem
- Some (not many) outside of school activities to give me a few hours of independence