

Carers Parliament 2019

‘Caring and You’: for families with disabled children and young people

The aims of the workshop were to provide an opportunity to:

- **Share useful information and resources** on practice and policy work of Family Fund and Contact
- Explore parent carers **current awareness of the rights** afforded to them as Carers via the Carers (Scotland) Act 2016
- Capture the **diversity of experience** in relation to accessing these rights amongst workshop participants
- Explore opportunities for families of disabled children and young people to **influencing policy, legislation and practice in the future.**

There were approximately 9 parent carers from across 8-9 local authority areas, one Scottish Government representative, 3 scribes from 3 charities in attendance and 2 presenters, Family Fund and Contact.

One parent carer raised the point that those who participate in the Carers Parliament are likely to be articulate and confident but that there are many others who could/would not attend but should also have a ‘voice’ when it comes to legislation and policy into practice.

Diversity of experience 1. Information Provision

When it came to being aware of their rights as Carers there was consensus that most information is gleaned from other parents/carers. For example, one participant works in South Lanarkshire and sits on board of Lanarkshire Carers Centre who undertake Adult Carer Support Plans (they stated that this is one of the few carers centres that offer this service). The participant found out about this service from other parent carers. Parent carers from Angus and Dundee

had good carer centres to go to, another parent in Aberdeen has never been told where to go for carer support.

2. Accessing an Adult Carer Support Plan

With regards to Adult Carer Support Plans, there is some confusion regarding where these sit with regards to the previously existing Carers Assessments. Furthermore, one parent carer expressed her fear that if she approached her Local Authority for a re-assessment of her needs as a Carer, the support plan which was previously agreed might actually be reduced. Participant quotes:

“Never been offered a plan, asked social worker who was supposedly doing assessment on my child and she couldn’t tell me.”

“I know how to access a SDS assessment, but no idea how to access a Carers’ assessment”

“I was given form to complete with no face to face guidance”

Participants wanted there to be a number of routes to being offered or requesting an Adult Support Plan. However, this would require improved training and awareness of Carers rights and knowledge of who might be a carer amongst a range of professionals, such as within health, education and social work as well as the voluntary/ third sector.

3. Carer involvement in Discharge Planning

In response to being questioned about their experience of hospital discharge of a cared for person one participant stated “ I asked senior nurse and OT about discharge and they both had no idea, 10 days later mum was discharged with nothing in place.”

It was proposed that discharge planning should start in the second week in hospital. Another parent carer’s daughter came home for palliative care but were not consulted about a care package. Another parent made sure care package in place before daughter allowed home.

4. Accessing a Break

In relation to accessing a break. One group agreed that they wouldn’t know how to get a break. In another group parent carer experience of overnight care

for 18 year old daughter who was placed in an older people's home. Often needs unmet, no suitable support locally. Another parent hadn't had a night away/break since their 10 year old son was 6 months old. Often families use family/grandparents to help with breaks and babysitters. Parent carers felt the siblings in families should be recognised as young carers especially in schools.



General comments regarding services:

Aberdeen have a policy on adult healthcare. They have **outsourced the provision of assessments** so if you request one you meet a support worker, they fill in a form but you are **not allowed to see the form as it's their form**. There would then be a five month gap before it was processed as there wasn't a social worker in post. I refused to let them submit a form for me as I was not happy about what they were doing with my data. It's invasive and I'm not happy for the information to be passed to the local authority. You have to jump through hoops to prove that your caring role is breaking down before any action is taken.

Another parent carer expressed “make access and any available discounts clear and easily found for people with disabilities, with/without their carers/PAS required e.g. when accessing leisure activities, events, places to visit. So much has improved but often have to email venue ahead to find out, rather than like everyone else e.g. online, leaflets re. admission prices. Discounts do make a difference in being able to access fun activities. I could cope with caring for longer if I could stop working so many hours (but still work!) but I can’t afford to do this. **As a lifelong parent carer, Carers Allowance is insufficient even with Scottish top-up.** We are not free! Help us, help you!!

- No training for social workers, they are good in some ways but not eligibility criteria
- In Aberdeen Quarriers are good
- There is no accountability, I have been trying for an SDS assessment for 4 years and had 4 social workers. They came out once then it is 10 weeks before you hear again.
- The social worker planned care for my child but had never met him.
- The self -direct care wing is no use.
- Social workers are not trained in the difference in SDS and YC. Young Carers cannot manage their own accounts so social workers are not separating it out. You can write your own plan but they don’t tell you that.

Key messages and suggestions from group discussions and ‘asks’:

- In order for parent carers to be identified as Carers and to be able to access their rights training for professionals across all relevant services, including health (including Allied Health Professionals), education and social work is required.
- A toolkit for professionals was suggested to support identification of carers and understanding of carers rights
- Provision should be based on need, versus resources availability/ funding and also be designed to meet the person’s needs, not just delivered via what is currently available.
- Lack of information is a significant barrier to carers accessing their rights.
- Parent Carers continue to access most information from other parent carers.
- Not everyone has access to digital technology and information requires to be accessible to all, including information on devolved disability social security benefits.

- Parent carers are frustrated at the apparent lack of accountability and co-production.
- Assessment can represent an additional burden if it does not translate into additional support being provided.

Influencing policy, legislation and practice in the future

In order that all parent carers in Scotland can access their rights as Carers, what action is required from: (Parent carers' views gathered via Post It notes/individual responses below)

Local Authority/COSLA

- Should be held accountable when they get it wrong
- Support disabled/ASN children more – financially, activities, after school clubs or care, summer Easter/October week club/help
- Make it clear who is responsible for carrying out carers assessment
- More education in schools around carers – include carers as partners in child/young person's education
- At times it feels to carers that schools feel 'they know best' parent and young person not consulted
- If parent of child with disabilities schools should be more involved in helping carers and young carers
- Access to help
- Easy read info across the board – a lot of info is very complex to understand
- Education – more specific training for teachers on ASL and processes for families going through assessments
- More interaction with parents – joined up working thinking
- Co-production – all means all
- No way to challenge decisions of the CS Plan – complaint process not applicable
- Clarification about eligibility criteria for assessments/services
- More specialised disability teams – not just general children/young people services social work
- More publicising of local authority carers information and advice services to parents
- Original carers assessment done 3/4 years ago, worried about updating in case SDS budget goes down (daughter's budget was affected by Franks Law)

- GIRFEC means Get it right for every-Child Council
- My child is 12 with no school as council can't meet his needs and are not willing to pay Grant Aided School that can, why?
- Why are decisions made by people who are more interested in their budgets than children's needs

Health Boards and SCP

- IJB carer reps to be involved in chats/discussions before board meetings and can communicate to other carers
- I know how to access a SDS assessment, but no idea how to access a carers assessment
- Provision needs to be based on need, versus resource availability/funding and also meet the person's need, not what currently available
- Impact of lack of integration in children services, no one speaks to one another or they do speak but don't ask for consent to do so. (Update professionals on DPA/Childs Plan status)
- All very well have a duty to assess but unless there is a duty to provide support, get rid of LA power to have eligibility criteria substantial and critical
- Lack of information is a significant barrier
- Training needs done with Health and Allied Professionals e.g. OT, Physio on Carers Act, anyone can 'signpost' or refer
- Involve education/schools to spread the word re. carers rights/assessment
- Already acknowledge that carers exist but need to have a toolkit to help them, (i) respite, (ii) short breaks (iii) mental health

Scottish Government

- Ring fence funds for carers - Carers allowance and income support for carers in work
- Set out eligibility criteria and dictate what they are – when they are written by LA they are subjective
- Make sure all LA have representatives e.g. IJB and volunteer carer pay time and expenses
- No point putting non mandatory framework around transitions – make it mandatory to help Get it Right

- Scottish Government have no authority and laws + acts are only good if there is obligation to action them, why?
- SG Principles into practice consultation
- SG to ensure local authorities follow legislation and enforce it
- SG taking over DWP – send information to carers as not everyone has access to internet
- No fight for DLA if I have a letter to say my child has a genetic condition it should automatically be a given to give DLA and help and support
- Co-production and ensure LA are meeting duties – accountability

Organisations that support and represent carers

- Eligibility criteria – need to locally disseminate information to carers not just give tea and sympathy
- Lack of accessible information e.g. easy read – info too complex
- What is a “Carers Centre”? They need to be available in EVERY area
- More organisational training (e.g. support groups) in Aberdeen/Highlands/others areas outside of central belt