



## **Seminar report - Young Carers in Glasgow: health, wellbeing, and future expectations**

Wednesday 19 July 2017

### **About this seminar**

From April 2018 onwards Scotland's councils and health board areas will be legally required to offer a carers statement to identify and support the needs of young carers. Young carers tend to have poorer health, education and employment outcomes. The majority also conceal their caring roles from education staff, health and social care services (both children and adult services), alongside other public agencies in contact with their family.

A new GCPH report used data involving 11,215 secondary school pupils in Glasgow to look at the prevalence of young carers; types of health conditions requiring care; and, the impacts of caring on their health and future aspirations, after leaving school. The report findings were discussed within the context of the scale and challenges that Glasgow could face when the new Carers Act is introduced in 2018.

The seminar aim was to explore how existing responses to young carers could be developed with a particular focus across education, children and adult services, community planning and financial inclusion. The remainder of this report provides a summary of the presentations and key themes from round table discussions.

### **Seminar presentations**

The event was chaired by Susan Orr<sup>1</sup> who set the scene by identifying the importance of the transformation agenda in children's services and the importance of developing services, focusing on early intervention and family support, and how this could contribute towards enabling better support for young carers. In a climate of constrained budgets, she recognised the challenges facing services, alongside identifying and supporting those young people not accessing services.

Oonagh Robison and James Egan delivered a presentation on the key elements of the GCPH study which included: prevalence and characteristics of young carers from

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<sup>1</sup> Head of Children's Services and Criminal Justice, Glasgow city HSCP (South)

the school survey; comparisons between identified carers and non-carers; differences in health and post-school expectations when other important factors were taken into account; and, the wider implications of the findings for key stakeholders.

*Fred Beckett*<sup>2</sup> presented on past national legislation and strategic and service delivery responses at a city level. He outlined some of the key features of the forthcoming Young Carers Statement, such as preparing the statement, identifying outcomes and support needs, eligibility criteria and providing support. He concluded by reflecting on the varying degrees of past success when engaging with young carers; in particular, defining the young carers' agenda, identifying 'hidden carers', and the hazards of a "one size doesn't fit all" approach.

Both PowerPoint presentations can be accessed here:



GCPH Young Carers  
and Carers Scotland /



young carers oonagh  
and james.pdf

## Round table discussions

Around 30 participants took part in three round table discussions which focussed on the following areas:

- Preparing for the Act
- Achieving a balance between specialist and mainstream services
- Sharing examples of good practice and how future approaches can avoid a 'deficit approach' when offering support.

NB: More detailed notes from the round table discussions and a list of all participants can be found in the appendix.

### **1. Who needs to be prepared when the Act begins in April 2018?**

Key agencies that need to be prepared for the Act included: education services, including careers guidance, further education, carer services, Glasgow's youth council, the Scottish Youth Parliament, community planning partnerships, social work, primary care, hospital discharge teams, pharmacy services, addictions teams, mental health services, other adult services, as well as carers and young people themselves. It was noted that everyone with any responsibility towards children must be prepared.

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<sup>2</sup> Young Carer Lead, Glasgow city HSCP

Agencies need to communicate with each other, act holistically, address young carers' needs together, and not in silos.

Legislation must be translated in a way that is accessible and useful to the young people that it affects.

The named person was discussed at length: is there the possibility of confusion between the 'named person' as part of mental health legislation and the 'named person' in a young carers' statement? Will the named person help identify 'hidden' young carers?

What impact will the new legislation have on agencies sharing data?

**2. *Support can vary from 'light touch' support to regular contact with specialist services. How can we strike a balance in providing future support?***

Groups and services identified in question 1 will have training requirements to help increase their awareness of the extent of caring and young carers' needs to ensure services identify and respond effectively.

Some of the barriers that might prevent young people from coming forward included:

- **Young carer label:** this could be problematic as not all providing caring are struggling and there could be positive aspects to caring that are being overlooked. There may be a spectrum of caring with all young carers not requiring specialist services. The analogy with mental health was mentioned. In other words, most people requiring mental health support do not need to be in contact with specialist mental health services.
- **Specialist carers groups** were not viewed as being the first point of contact for young carers. For example, temporarily providing the young person with a break from their family will not significantly change their circumstances. Attending carer groups could also create distance from mainstream youth activities that they may want to take part in.
- **Stigma:** the type of illness or disability that the young person is providing care for can impact on how likely they would seek help or identify themselves as a young carer. For example, those with a parent/carer with mental health or addictions issues could be less likely to seek help than one with more "acceptable" issues.
- **Defining care:** young people that do not see themselves as providing "care" may not think they are entitled to support. Equally, if they do not think they "do enough" how can they feel entitled to support? Would a change in the language used help?

**3. Are there examples of good practice and can future approaches focus on what young people value doing and have the means to pursue them?**

The Young Carers Statement, which starts April 2018, must focus on a wide range of outcomes that goes beyond a young person's current needs. This will involve services working together to remove the barriers that prevent the young person from working towards their future goals. A family centred approach could be part of the solution - looking at the family unit as a whole and putting supports in place to allow the family to function as it would like to.

Do we need a child centred approach that considers them as children and young people first, instead of as young carers?

A rights-based approach: what rights do young people have and how can services support them to achieve these? Can the rights of young carers be presented as part of a wider rights based approach for young people?

Could Equal Partners in Care (EPiC), national framework for workforce learning and development related to unpaid carers, be used as basis for training? How far does this cover young carers as opposed to adult carers?

Could community-based approaches such as the dementia friendly approach be adopted e.g. carer friendly community?

Emotionally intelligent workers needed to see the full range and spectrum of support required by having an awareness of a range of services and not just carer groups, as well as being able to respond to people dealing with trauma.

Whole school approach: emphasis on wellbeing, GIRFEC, awareness of pathways - education are already doing it, but it just needs formalizing and tools given with regards to young carers.

## Appendix

Thank you to Katharine Timpson, Rachel Hewitt and Ida Norberg for scribing during the three round table discussions.

### **Round table discussions: group 1**

#### ***Who needs to be made aware of the Act?***

Education, carer services, carers and young people need to be aware of the Act. The question was posed: is the Act concentrating on a range of agencies, or on the HSCP services?

- *Youth Organisations*

The Glasgow Youth Council is an important link between Young People and decision makers. A Young Carers' reference group talks to young people about legislation in a user-friendly way that attempts to convey important messages. Often young people do not know their rights as carers and do not self-identity as a "young carer". Presenting the issue of rights more broadly can avoid the idea that young carers are different from their peers. In other words, difference conveyed through specific legislation, instead of a range of legislation covering all young people. There could be merit in developing links to the Youth Parliament and to the national campaign on rights.

There is a need to consider data on younger carers still in primary school.

- *Communication*

There is a need to address the legislative language to ensure that it is accessible to the age group, including the different digital and online ways that young people communicate. Social media, mobile apps, as well as an internet presence, could help young people identify and make choices for themselves. Online peer support, such as the Glasgow Youth Council Facebook, alongside many friends and peers being aware of caring responsibilities could be helpful.

Legislative information needs to address the question "what does it mean for me"? The problem of the legislation is the use of the label "carer", stigmatisation, problems of self-identification and language. We need to change the language to avoid polarisation. By using the term "young carer" or "carer" are we defining and applying labels to people, or describing them? There is an emphasis on a term or a definition for 'young carer', rather than focussing on those with a caring role (more broadly, and away from labels). Caring viewed as being problematic or a matter of resilience can often overlook the majority of young carers residing in the middle ground. There is a need to ensure that everyone knows what caring means.

- *Education services*

Professionals, especially in education services, need to start working with the Carers Act. One aspect in education is the focus on careers guidance, especially as physical and mental health affects the energy and capacity for learning. The Statement should therefore focus on outcomes as far ahead as possible, in particular aspiration and a focus on how services can help the young person in achieving that outcome.

Education services should therefore support and nurture positive skills gained from caring, while services should remove barriers that prevent the young person achieving that outcome. This is the case with young carer groups and community partnerships.

- *Young Carers' groups*

Are young carer groups preventing them from accessing mainstream groups such as sports or activities, therefore retaining a separation between them and their peers? Young carer groups may have benefits alongside being restrictive in some instances. Mainstream and specialist services need to strike a balance between stigma and support, so that services provide necessary specialist support without removing access to mainstream support. This could help make mainstream services more appealing. Important not to package into a “strategy” but to encourage a more appealing emphasis so that young carers can come forward. Young carer groups are fun, so other creative ways in addition to groups are needed to offer support.

- *Learning from other approaches?*

There is a gap between those in contact with specialist services and those who would benefit. Mainstream staff will need the right tools and skills when identifying young people with caring responsibilities in order to enter effective dialogue that enables young people to come forward for support. However, not all young people will require specialist support. Therefore, can we learn from other approaches, for example the majority of adults receiving mental health support are in contact with primary care and not specialist psychiatric services. Moreover, caring can be viewed as broad a term as “mental health”.

A shift towards including a population approach, as with mental health and first aid responses, could ensure that those not necessarily requiring specialist services can open up about ‘hidden caring’ roles.

The whole school approach in England works and could be applied, as well as learning from “dementia friendly communities” that emphasise wellbeing.

There is also the shared learning from Getting it Right for Every Children (GIRFEC). Moreover, well-being indicators are the same for young carers as for their peers.

## ***How can specialist and mainstream services strike a balance in providing future support?***

There are problems around not articulating other skills related to caring like managing money, timekeeping and organisation skills. Education Services could help young people articulate these skills - employability dimension. It could be an important aspect of partnership work. This includes education services nurturing the skills and aspirations of young people alongside specialist services removing the barriers that prevent them from realising their aspirations.

- *Primary care*

With regards to primary care and disability services, are conditions like physical disabilities, mental health and long-term illnesses viewed as being distinct and separate? Some carers' services have attempted to encourage referrals from Deep End GPs<sup>3</sup> which is a challenge due to the 7-10 appointment slots. In other words, asking a GP clinically addressing an adult's symptoms, wellbeing, lifestyle etc. to also consider other aspects, such as a young carer in the household. However, it could take additional pressure off GPs, as they are in a position to refer on to other services. There is the issue of GPs asking the right 'carer questions' and how the questions can be asked to a young person when, for instance, an adult is present with mental health problems, or they might be experiencing physical problems relating to their caring duties.

This is a need to speak to people at the point of diagnosis alongside an awareness of how people process and uptake health information. People often say "they gave me a leaflet" which could be an important cue for undertaking a brief and early intervention. GP receptions are often well placed in terms of their in-depth understanding, acquired over a long period of time, of patients regularly making appointments or receiving prescriptions. Often, reception staff will know the carers. Finally, there is also space for the Link Workers programme<sup>4</sup> and primary care development officers to develop links with GP practice staff.

- *Adult services*

Adult services, such as addictions and mental health, are apparently making progress with this agenda. For instance, the parental addiction impact assessment should help identify children or young people in the household with a caring role. Child protection committees have a good awareness of the impact of neglect on young people. They also use the impact assessment to identify young people with a caring responsibility.

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<sup>3</sup> GPs at the Deep End work in 100 general practices serving the most socio-economically deprived populations in Scotland.

<sup>4</sup> The Links Worker programme aims to support GP patients with complex needs by strengthening links between community resources and primary care services.

### **Other points discussed**

Planning processes need to weave through everything e.g. all strategies recognising the role of the young carer.

Do we need to move away from viewing caring as a problem or “deficit” to a more nuanced approach?

It is not just about a role but a person. We need to think how they can achieve what they want to achieve. In the Statement, the outcome is not just to join a young carers’ group but to examine self-esteem etc.

Everyone needs to be treated differently as they benefit from different things with different family situations. One outcome may be to go to a group because they need it, not to go to a young carers’ group because “that’s where young carers go”. Other outcomes might be improving the skillset and confidence of carers, “to look after my mum better” or “am I doing it properly?” or to feel safe and secure in their role, or to have the energy to be a young person. What information needs to be given without hindering aspirations? Outside the care role, what do they like to do?

We can take away elements of the caring role if they are struggling. With higher education, we need to assess why they feel they cannot leave, reinforcing a necessity to look out for the cared-for person.

Challenges for “assessment”: what if young people say “I don’t want to be a carer”, or even asking “Can I say that?”

Support under legislation when not in school to live independently, or to stay on in the family home. Are there issues when a child has been removed from the home and caring responsibilities are only then identified?

Is caring bound into family responsibility?

### **Round table discussions: Group 2**

The new data sharing law that’s coming in May (Children and Young People (Information Sharing) (Scotland) Bill) was identified as a huge future problem because it is going to make facilitation of services more difficult.

- Further education should be more involved when the Carers’ Act is developed
- Young people living with parents that have more “acceptable” conditions are more likely to identify themselves as carers, whereas tis might not be the case for those living with more stigmatised conditions, such as addiction or mental health issues.
- People need diverse levels of support.



- Services need to speak to each other more than currently. They don't interface very well – round table agreement.
- Stigma prevents young people from coming forward - they don't see their behaviour as going above and beyond - "it's my mum", it's a normal family dynamic.
- A previous case (documentary) interviewed young carers - they were frustrated that services did not recognise the positive aspects of caring and felt that services were patronising.
- Kelvin College (Glasgow) offers adjusted timetables, time off for appointments, pastoral care and class tutors as support.
- Emotionally intelligent workers are necessary and are required to stop punitive approaches when people are dealing with trauma.
- We shouldn't just be taking young people temporarily out of the community/situation but rather figure out how to allocate money to the community through a family based approach.
  - According to some research those who stay in the family have the worst outcomes.
- Is Basic Income a potential solution? Difficult to know because one thing might work for one family but not for another.
- How do we nurture the positive aspects from caring? Skills as employability?
  - Some found it difficult to see caring as a positive because they dealt with a lot of the addictions work and saw many extreme cases.
  - But the majority agreed with the view that it was important to note the positive as not everyone faces dire circumstances – there is a spectrum.
- Ultimately, we need to think holistically, don't compartmentalize and services need to speak and coordinate with each other more. (data protection laws might make this more difficult)

### **Round table discussions: Group 3**

There is a need to have one organisation responsible for young carers. Integration and a wider focus require more work but we gain from collaboration.

We need to look at things differently – not everyone who is caring is suffering and not all in the same ways. In promoting the cause of young carers there has been a lot of labelling. We need to see young carers as children first and foremost.

Clarity: young people as citizens, they each fit into lots of categories, not just carer/non-carers.

Carer support is not always the best or first contact for young carers. We don't want to encourage service use when it's not best for the young carer or family. We need to support children to access services that are not specifically for young carers.

Past example of bus trips – we would take all young carers away together, now this only done for those who really need it. Others get allowances given to their family, so they can take a family trip.

Emphasis on the need for doctors, nurses and teachers to be trained better in how to help young people who might be caring – could Equal Partners in Care (EPiC) principles help? Are many of these professions unaware of the needs of young carers?

Similar to looked-after children, we need to treat them as individuals who need different types and levels of help. How do we support children for whom community support is not enough and require extra support? Better links through education to assess support needs.

Need to treat young carers like ‘ordinary’ children.

Children’s plan and the Young Carer statement can fit well together.

Self-Directed Support (SDS) package – it goes to the adults and not the young carer. SDS only for extreme situations, general aim is to support young carers away from being carers.

Need to unpack some of the issues around carers’ benefits: what the money is for, do they need it? Others need more than they have. Sometimes the state is paying twice: to get the care and then to support the young carers who are still providing the care for free. Carers allowance about to be devolved – changes coming up in eligibility (but it’s quite limited). Are we promoting taking monetary benefits but neglecting to promote ideas of life outside of caring? On paper, care hours are often undercounted.

Need to involve carers in hospital discharge decisions. However, people want to get out of hospital quickly and often haven’t fully grasped what their care needs will be until later. Challenge of recognising the role of the young carer in healthcare settings e.g. young carers being able or unable to pick up prescriptions from pharmacies. Could we set up a pharmacy delivery, so they do not have to pick up the prescriptions? Discussed how children often felt not just invisible but ignored.

EPiC principles: do their updates cover more on young people? Unsure, we need to find out more – under review.

We need to alleviate caring role. If we provide good support then the young carer will no longer be the main carer. Legislation will hopefully help – pointed out the differences between the young carer statement versus adult care version – will the young carer be asked if their caring role was ‘appropriate’? Who decides the appropriateness - young carer or someone else?

When we ask children what they need and how they are, they generally tell us – problems come when we make assumptions. Confidentiality is difficult and we need more guidance on that. How will the family-centred approach actually look? It should make workers re-consider their role, think about what they are actually doing for the family and what role they play in the family's life – and give the family more clarity on that as well. It should focus on the strengths of the family and the child.

Good practice – lots of activities are happening or about to start, but how do we measure their effectiveness?

Working with Glasgow Teachers Council and Education Scotland to get information from teachers and with young carer groups to map the schools in Scotland – not likely to publish, but should helpfully show more about young carers in education.

Do schools capture/know about young carers?

School information management system: asks if a child is a carer but don't know how well it is completed or whether all teachers take notice.

Need more from GPs/primary healthcare to help identify likely carers – schools don't always know.

Not all young carers have a child plan and so not all their named persons/social work contacts are alerted to their circumstances. Children have various different issues - young carer may only be one of them.

If named person informed about the impact of addictions more young carers would be identified and supported. Addiction may not be under current legislation for caring. Children growing up in families with mental health problems could get earlier support.

Caring becomes a child protection issues.

Named person will help us to identify young carers.

Are there ways of offering wider support which do not rely so much on identification?

Need research that is not from young carer groups and looks at the mainstream population – so far, it's mainly about people who have already accessed their services.