

We Care: Perspectives on young carers in Edinburgh

Mel Aitken, 5-9 Development Worker, Edinburgh Young Carers

Mae Shaw, University of Edinburgh.

Introduction

When discussing the Special Issue on care, I leapt at the chance to include a piece on young carers. Mae Shaw and I arranged interviews with colleagues at Edinburgh Young Carers in order to gain insight into their thoughts about young carers - the tensions and the opportunities. Needless to say, what started as a simple exercise involving 3 questions evolved into a far more stimulating experience for us all.

I have worked at Edinburgh Young Carers since early 2020 and feel an immense passion and pride in the work we do. As a development worker for the 5-9 age group, I am faced daily with the joys and challenges of this type of work. Young Carers by definition are children and young people between the ages of 5 and 25 who provide a caring role at home, whether that be physical or emotional. The roles of the young people vary greatly across the age groups and the organisation. Some children care for parents, whilst others are impacted by the disabilities and health needs of their siblings. What unites them is the reality of being 'different' from their peers and ultimately fulfilling a role no child nor family member would naturally choose. The following article explores some of the tensions in interviews with three practitioners - Gary, Jenny and Laura - and a young adult carer, Oliwia.

Each worker has a different background, and this brought a unique perspective to their role and our discussions. Their passion for the project and wider work with young carers was unmistakable and our conversations were both full of hope and, at times, deep frustration. They spoke of systemic issues relating to how young carers are identified and the lack of support within education, social work and mental health services, as well as more societal failings – the hidden nature of care, the shame, stigma and judgement. Poverty was repeatedly mentioned as a factor in perpetuating and exacerbating caring roles through inappropriate housing, dampness, malnutrition and their effects on parents' mental health. Workers spoke of the impact on their own

mental health too as they worked within a system that offers so little in the way of financial or statutory support for these families.

Situating this within the wider context, they highlighted a fundamental conflict in the reliance upon young carers and the resulting sacrifice these children must inevitably make. The term 'young carer' itself feels somewhat sanitised; widely accepted in politics and policies. If it were to be framed as 'unpaid child carers' would we be so comfortable with it as a part of our lexicon. Are young carers, like food banks, just part of life now that health and social care are so stretched and decimated by cuts? Are we a sticking plaster for a problem far beyond the scope of the work? And if not us then who else is caring?

Thankfully, our conversations did not end on this somewhat despairing note. Instead, Gary, Laura and Jenny spoke of what 'keeps them going'. This part of the discussions brimmed with enthusiasm, dynamism and at points, grim determination. What shone through was the power of the collective. The collaborative and supportive culture within the organisation and the relationships nurtured both with colleagues and with the young people and families that are part of the EYC community. Every worker highlighted the young carers themselves as their main motivation and hope for the future. The strengths of the incredible young carers we work with were exemplified in our meeting with Oliwia who has been a young carer since she was 9 and involved in the service since 2016.

Oliwia, now 19, has been a carer for her brother Victor since he was born 10 years ago. Her mother has had recurrent problems over many years with alcohol dependency but does not consider herself an alcoholic. Oliwia has therefore had to navigate both the instability of her mother's behaviour and the detrimental effects on her brother, whose development has already been adversely affected by alcohol in pregnancy. This means she lives with the constant threat of things deteriorating and has the responsibility for being there 'just in case' mum doesn't have the capacity. Her caring role includes taking Victor to school, to medical appointments and getting him out of the house to have fun and be a child. When she was 16, her relationship with her mum broke down and Oliwia became scared to go home. She was helped by the Rock Trust to find temporary accommodation and was set up in her own flat. This

was a new phase because, for the first time, it gave her both space for her own 'peace of mind' and a safe space for her young brother, if and when needed. But it also meant that she worried that something might happen to Victor if she wasn't at home. At times, he had to stay with her full-time and she became a temporary kinship carer.

Although her caring role has brought many serious challenges, Oliwia is passionate in saying she 'wouldn't change it for the world'.

Oliwia's story was powerful and emotive. Her intelligence and eloquence brought some of the key challenges to life as we heard how she has supported her younger brother and mum. Her account highlighted the lived experience of a young carer – bringing the personal struggles to the political realities whilst displaying remarkable resilience within an undeniably flawed system.

Below you will find a more in-depth account of each of the discussions. These have been abridged but feature key themes and quotes by the interviewees.

Mel Aitken

The interviews:

1. Gary Shaw, Youth Development Worker, Under 12s

Gary works with young carers aged 10-12 supporting them with transitions and providing respite from their caring role. He has led on a research project specifically aimed at sibling young carers.

What are the main challenges for the young carers you work with?

a) Identity conflicts

This age group (10-12) is typically going through puberty which is generally associated with insecurity about identity, wellbeing and recognition of the situation they're in. This is particularly relevant for young carers who face very challenging personal circumstances. Young people who spend a lot of time in the home can

become disconnected from, and awkward with, their peer group: inclined to over-relate to the adults present.

Young carers also often have identity conflicts as child/carer and between freedom and responsibility. Coping skills for themselves or other aspects of life are often underdeveloped, resulting in problems with other relationships. They are often defined in relation to their caring role and 'conditioned to worry'. This can set them aside from their peers. These tensions can be addressed to some extent in group relations and activities.

b) Poverty

Both the reality of poverty for families and young carers' awareness of the problems it creates. Young carers are often treated by their parents as adults, so they are exposed to pressures not appropriate for their age.

What keeps you going/gives you hope?

a) A positive work culture

Mutual respect and expertise of team. Co-operation. Commitment: 'It's just a job and it's not just a job'. Sense of humour.

Responsive management - regular supervision, but not micro-managed. Two-way process. Mutual trust. Freedom to try and fail.

Professional autonomy. A culture where you can make a case and be listened to.

b) The young carers

'I believe in the cause of my job'. Seeing kids develop - able to have a laugh - thrive - come out of their shell. Targeted work means it can be bespoke, with a clear purpose, manageable numbers and person-centred.

2. Laura Piunti, Drug and Alcohol Development worker

Laura works with young carers aged 5-25 who are impacted by parental substance use – whether historic or ongoing. She provides intensive support to the young

person, builds close links with other professionals, supports in developing core skills and provides respite from their caring role

What are the main challenges for the young carers you work with?

a) Identity conflicts

Caring has negative connotations. The caring role is often hidden for a range of reasons: worry, fear, stigma, secrecy, loyalty. This can make identifying young carers difficult and workers need to be alert to a wide range of factors; to pick up what's going on eg low school attendance.

Lack of acceptance of their role by families: 'families don't get it sometimes'. They don't (want to) see themselves as being cared for. Added to this can be family trauma, domestic violence, drug and alcohol abuse.

b) High level of crisis work required - low level of available resources

The level of support required leads to a heavy emotional load for carers and support workers.

The lengthy waiting list for support and unfilled job vacancies add stress for both workers and young carers. With the cost of living crisis and the increasing pressure on services, the workers 'are bracing ourselves for what is to come'. The young carers are not immune to the worsening situation and absorb worry from all around them. They tend to be hyper-vigilant which makes them worry more than their peers which, in turn, isolates them from their peers.

Young carers often suffer from a range of difficulties: lack of boundaries and routines; poor social skills; lack of sleep; inappropriate behaviour; underdeveloped language; insufficient opportunities to develop and thrive; low school attendance leading to poor socialisation and low attainment. These difficulties have long term effects for many young carers and can create a spiral of hopelessness and resignation which leads some to homelessness: 'the choice of staying at home or homelessness' is not so significant if neither offer security.

Young carers are typically dealing with trauma of various kinds which makes trusting professionals challenging for both.

A primary aim of the project is to reinforce to young carers that they are cared for, but their own life experience tells them the opposite. This creates tensions for the workers. Having to acknowledge that they can't give them all they need; that they can't fill the void which many young carers experience. Workers know they have to recognise their limitations, and to plan their intervention accordingly, but how this translates into their work is a constant professional and personal challenge.

c) Negative stereotyping

They sometimes feel themselves treated as a 'moral underclass' which makes their position even more difficult.

d) Lack of mental health services (particularly after 16 years of age)

Young carers don't automatically come under child protection legislation. This puts a burden on the project which they are not sufficiently funded to manage.

What keeps you going/gives you hope?

a) The young carers themselves

Seeing them developing in spite of everything. The impact of our work on some young people can make a real difference. Seeing positive changes, even when they are small - a high proportion of the young people involved experience positive change of some kind. This gives validation that the job is worthwhile.

b) Collegiality, solidarity and family

The support provided within the project, the unity of purpose and the encouragement of family are all essential for keeping going. The positive atmosphere amongst colleagues and the non-judgemental nature of their interventions. Commitment to the core purpose of caring for young carers. Honesty about what the work entails and the personal resources available.

3. Jennifer Lewis, School Project Manager

Jennifer's role is to engage schools with the charities School Awareness Project to increase identification of hidden young carers through training, assemblies and workshops.

What are the main challenges for the young carers you work with?*a) The status of young carers*

Lack of awareness of the existence and experience of young carers in the school setting can lead to a lack of empathy. A common response is 'there are no young carers in our school'. This lack of awareness and empathy can lead to a denial of the problem which 'closes the door to any kind of dialogue'.

In schools, more attention tends to be given to 'cared for' young people ('care-experienced') than young carers. They are even grouped together in some schools, as if they share the same experience. This is inappropriate and highly insensitive since 'the biggest fear of young carers is that they'll be taken into care', leaving a sibling or parent without support.

Because young carers do not have as significant legal status as those 'in care', they are not a priority for schools or social work, whose resources are already overstretched.

For example, their entitlement to respite is not guaranteed. There has been so much great work around care experienced young people and 'The Promise', we want to take that model, that dedication and that drive and apply it to young carers.

b) Processes of recognition and support

Identification: on average, it takes a young carer four years to be formally identified ie from when their role begins to when a relevant professional - social worker, teacher, youth worker - 'finds' them.

Age: Young carers are on average getting younger (currently a bottleneck between 5 and 9), requiring extra support. Since the organisation does not have the staff resources to cope with extra demand, this results in a lack of access to support.

If the young person has extreme behavioural problems, they can't be supported by our young carer service even if they are fulfilling that role. In addition, the consent of the family to designation of young carer is required.

Definition of inappropriate care: In some cases, there are child protection concerns which a social worker is required to identify/follow up. The process of identification is not straightforward or quick. There is no formal definition of what constitutes an

inappropriate caring role so it is up to professionals to decide what is acceptable (for children to do within their caring role) and what is not.

c) Lack of resources

A serious lack of government support. We have some amazing examples of good practice from schools but there is not a national standard for schools to reach in terms of their young person support. For example, some schools have a dedicated Young Carer Coordinator who I contact regularly but others do not; they still hold the view that they have no young carers in their school and therefore no dedicated staff member is required. Furthermore, the Young Carer's grant is restricted to those in receipt of certain benefits, relates to caring for a specific number of hours, and raises fear for some of losing other benefits. A one-off payment is available in theory, but the conditions for over 16s are so complex that only 2 applications so far been successful.

What keeps you going/gives you hope

a) Collegiality

Colleagues are all committed to working creatively and co-operatively in the interests of young carers. An atmosphere of personal and professional support keeps staff morale high.

b) The young carers

Respect for their commitment to their role; watching them develop through activities.

c) External support

Willingness to speaking up about young carers from a range of people/groups. For example, schools becoming more interested in the issues raised.

4. Oliwia, Young Adult Carer

What are the main challenges for you as a carer?

a) Managing the psychological/mental consequences

You're doing so well for so long then suddenly you're at a point where you don't know what do. Not many people understand.

b) Keeping a sense of yourself and your own needs

Trying to organise your life so you have one. It's too easy for your sense of identity to become that of 'carer'. Trying to keep on top of it is exhausting. It's not always easy to ask for help: you're supposed to manage.

What could improve your situation?

a) *The knowledge that there are appropriate resources available*

Having that knowledge offers huge reassurance: clarity on what's available; contact with groups of people in similar situation; not being judged - not having to explain anything; uncomplicated fun; someone to listen.

b) *Practical help*

Organisations like Young Carers, Rock Trust and so on. During my 10 years as a carer the main support available has been from the voluntary sector. Statutory services are totally inadequate and unnecessarily bureaucratic. The care system is broken.

What keeps you going/gives you hope?

a) *Family*

My young brother keeps me going. I do my best for his best.

I have my own place now and he has a safe space there.

b) *Caring is enhancing as well as restricting*

I wouldn't have it any other way.

c) *The self-confidence gained from doing the right thing, of knowing you can do it.*

d) *The necessity to speak up/out*

Unrealistic expectations of young carers by their parents: 'it's what families do'.

Caring comes at a cost: 'No is such a powerful word'. There needs to be care for the carers too.

e) *The kindness of family, friends, allies, strangers*

The support worker boosts my confidence constantly; gets angry on my behalf.

f) Knowing there are options

g) Anger at the broken system

There aren't nearly enough resources, those at the bottom get least, or resources go to the wrong people. It's a political as well as a personal problem.