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Being a Young Carer

Views from a Young
Carers Workshop

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www.rights4me.org

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Introduction

The Commission for Social Care Inspection (Children's Rights Director) Regulations 2004 set out my legal tasks as Children's Rights Director for England. As part of my job, and with my team at the Office of the Children's Rights Director, I ask children and young people for their views about social care services. I then give advice to the Commission for Social Care Inspection and to the Government in line with what children and young people tell me. Reports of children's views (including the top ten messages from children and young people on each subject) are published on the Commission's children's website (www.rights4me.org). The full reports as published can also be found on the publications section of the Commission's main website, www.csci.org.uk

It is important that local councils know, and take into account, what children and young people themselves think when they provide them with services. It is also important that inspectors who check up on local council services know and take into account what children think, so that they have in mind what is most important to children and young people when they are deciding on whether a service is doing well, or not so well, for children.

Young carers look after someone else – often their own parent - with major care needs in their family. In other consultations with children and young people, I have met some young carers, and have heard how they have very clear views about what they do, about how other people react to them, and about the sort of help they do – and don't – need from councils, schools and other people.

The Young Carers' Workshop

To find out more, and so that I could write a report for inspectors, the government, and people in councils who are responsible for services to children, I and my team invited young carers from a number of young carers' groups to a workshop to tell me what they wanted me to write in such a report. We held the workshop as a pizza lunch meeting in London. Sixteen young carers came to the workshop, from four different groups, from different parts of the country.

I and another member of my children's rights team ran the workshop, and it was also attended by the Earl of Listowel, who wanted to hear directly from young carers to help him in his work in the House of Lords. We allowed the support workers who had brought the young carers to sit in on the discussion, but not to speak – all the views in this report came from the young carers themselves, not from any adult.

Some of the young carers at the workshop had seen our list of questions before they came to the workshop, so that they could write down things they wanted me to put in this report, in case they didn't have the chance to say them in the workshop itself. Seven young carers handed me in their written thoughts while they were at the workshop. I have included what they wrote for us, as well as what was said in the workshop meeting, in this report.

About this Report

This report says what the children themselves think, not my views or those of my staff. I have added together everything the young carers told us at the workshop. I have written a quote from one of the young carers where this sums something up particularly well, and the others in the workshop agreed with it. I have the permission of the person who said each quote to use it in this report.

This report is being sent to Government officials, to Ministers and other key people in Parliament, to every council in England which provides social services for children, and to all the senior managers in the Commission for Social Care Inspection. It is also being put on our website, and, most important of all, it is being sent to the young carers who came to the workshop so that they can check that I have set out what they think properly in the report.

I want to thank all the young carers who came to tell us about their experiences and ideas, the adults from their young carers' groups who brought them to the workshop, and the staff of the Young Carers' Initiative who arranged for and enabled young carers to attend, without all of whom we could not have written this report.

What Young Carers told us

What main tasks do young carers do?

Young carers told us that a major task for all of them was to give other people **emotional support**. This is often very demanding, and means a lot more pressure than other children are under. Sometimes it means coping with the person they are caring for being extremely upset or emotional themselves.

The practical tasks of many young carers involve giving **24 hour personal support, including toileting, washing and putting someone to bed**. Many young carers have responsibilities to **be the support and backup person** to whoever is the main adult carer, and this often means doing many **jobs around the house that the adults cannot do**, and being **the one who looks after other children** in the family. An important job is being the person who **takes messages** and answers the phone. **Shopping** is one of the jobs many young carers need to do. You also have to **look after yourself** more than most other children and young people, because fewer things get done for you.

“Mum spends lots of time alone, so it doesn't seem right not to keep her company”

Because of the condition or disability of the person being looked after, it can be difficult to get out of the house for “down time”. Sometimes you feel you need to **keep the person you are caring for company** even if there are no jobs to do; *“Mum spends lots of time alone, so it doesn't seem right not to keep her company”*.

A major and worrying task is that most young carers are responsible for giving out **medication** to the person they care for. Many were extremely concerned at this responsibility. They may be responsible for giving out dozens of different tablets and medicines every day – and for getting them all right. They were worried that one mistake could be fatal. Yet they are given no training or support in making sure that the right medication is given at the right times, in the right way and in the right dose. It would be good if a Doctor gave the training they need to any young carer who has to give out medicines. It would also be **useful for all children to know about how to give out medicines safely**, and what sorts of things to look out for when people are taking medicines or changing their medicines, so this could be part of everyone's Personal, Social and Health Education at school. It's not just a matter of reading the label on the box.

Another main task is **taking the person they are caring for out and about**. Often

this means **pushing an adult in their wheelchair**, and coping with all the difficulties of getting around with a wheelchair that anyone would find when pushing one – except that many young carers do not have the same strength as an adult pushing a wheelchair.

How does being a young carer affect you?

“I can’t do stuff that involves using legs because its not fair on them”

All the children and young people at our workshop agreed that being a young carer meant doing much **more work and taking on much more responsibility than other children** and young people of the same age, not being able to get out much for yourself, and definitely **giving up part of your childhood**. Some young carers tried not to do some things that they might like to do, but which the person in their family with a disability couldn’t take part in. One said *“I can’t do stuff that involves using legs because its not fair on them”*. Young carers did however want to keep on caring, for the sake of the person they were looking after; *“but I’m not bothered, because I don’t mind helping people”*.

Being a young carer does have **a cost to you and your future**; like being unable to do the sorts of things other children do, being under pressure and stress all the time, and **suffering your own emotional and stress problems** that begin to damage your own mental health for the future. Some of the young carers at our meeting told us that they found it emotionally difficult to cope, and that

being a young carer had sometimes led to depression and to self harming. As one young person put it, speaking of their parent: *“they have the disability – we’re at risk.”*

“but I’m not bothered, because I don’t mind helping people”

“they have the disability – we’re at risk”

All those at our workshop saw being a young carer as something you just did for everyone’s survival, **“something you just get on with”**. Sometimes, you simply did get on with it, and didn’t realise you were doing anything particularly unusual; *“I didn’t know I was a young carer”*.

An important point was that each young carer has different needs, and so do the people they are caring for. What it means to be a young carer therefore varies from one person to another, and how much difference it makes to your life varies too.

“something you just get on with”

Some young carers told us that their caring tasks were so great that it was very difficult to do the sorts of things they would want to do for themselves, but others said that they managed to keep a reasonable balance between their caring tasks and doing their own things.

One of the biggest problems for most of the young carers in our workshop was the way the general public looked at people with disabilities. Young carers have to cope with the **reactions and prejudices of the public** to the person they are caring for, and the lack of public awareness that there are such people as children who look after a parent or other family member with a disability. Young carers have to cope with this as well as doing the caring job. You have feelings, and are made very self conscious by all this. Sometimes when you are going down to the shops, people just stare at a young carer as a child pushing an adult in a wheelchair. You get looked at in a *“patronising, sorry sort of way”* – but people are more likely to barge past you than to help hold open a door for you while you are struggling through it with a heavy wheelchair. If you take the person you cared for somewhere like the swimming pool, you have to cope with the public all staring at you both.

Some young carers thought that **schools need to teach all children more awareness – and basic politeness – towards people with disabilities and their carers**, alongside all the other more usual things you get taught about in personal, social and health education (like sex, drugs and smoking).

We asked whether people at our workshop ever got bullied because they were young carers. The answer was clear and very strong: no, **you didn’t get bullied for being a young carer, but just as bad as being bullied yourself was having to put up with all the comments**, sometimes nasty, that other children and young people made about your parents who have a disability. This was made worse by **staff at school who**

kept asking you for explanations for things like being late handing coursework in, or for being tired at school. Other children and young people of course hear your explanations about having to do the caring, and that usually leads to more unpleasant comments about your family for you to have to put up with.

Also, rather like being bullied in many ways, **being a young carer often makes you the outsider in school**, not always

“I didn’t know I was a young carer”

“patronising, sorry sort of way”

*“social services
come in and out
of our lives, but
never stay long
enough to help”*

accepted by the others and often not able to take part in things others do outside school time.

We were told about how some families, especially if they have more than one family member with a disability, had suffered being attacked by the public – even physically at times. Attacks like this are especially likely to happen if your parent has a mental health problem. Even if nothing physical happens, it is extremely hard to bear when other people keep saying things like they think a member of your family, who you are doing your best to help and defend,

should be locked up. **It is your family who get bullied, rather than you**, and that is in many ways worse for you than the usual sort of bullying between children in a school class.

Sometimes a young carer has to put up with waves of comments about their family members going round the school bus. It is very hard to have to put up with all this as well as doing the hard tasks of caring. It all boils down to the **need for other people to be understanding towards people with disabilities**.

What help do young carers get?

The young carers who came to our workshop told us that **they did not get much support for themselves from organisations like social services**. Out of the sixteen young carers at our workshop, only two said they had a social worker, and a third said their brother had one. Some spoke of having once had a helpful social worker, but they had moved on and no-one had taken their place. Some had got special adaptations at home from social services, like a walk-in shower or a lift. Most in the workshop said that **having the same social worker for a continuous time** was very important, as you needed to get to know them and to trust them before they could really advise and support you through your caring pressures and crises.

Some had experienced social services staff coming to their homes to do assessments, but these had not often led to help for the young carers and their families. Some young carers had met social workers who were looking at what their parent needed, and those often seemed satisfied if the young carer was doing a good job looking after their parent, but didn't seem to pay too much attention to what the young carer was going through themselves. What often happened, we were told, was that **social services did an assessment but decided that all was well because the young carer seemed to be coping**. What this didn't do was to take into account what it was costing to the young carer to keep coping. One young carer said *“social services come in and out of our lives, but never stay long enough to help”*. Another

commented *“because we can cope day to day they say we can manage – but we need help as well.”* One said that it would be very useful to **know what your rights to help are as a young carer.**

The group at our workshop agreed that it would help if whenever an adult is seen by a doctor and their care is discussed, the doctor should **always have to ask if any of the caring will involve a young carer, and then think about what that means and what support the young carer might need.** Doctors tend to treat the patient, but are not always aware of the effects on the people in the family around them. For example, they might be trying out a new medication with their patient, but it might be the patient’s child carer who has to cope with it if the medication doesn’t agree with the patient – but who isn’t usually told about the medication, its effects and what to look out for. If a young person is doing the caring, they need to be told these things. As well as this, young carers themselves would not usually know what sorts of services their cared-for adult might need, and how to get hold of them when they are needed, unless they are told this too.

“because we can cope day to day they say we can manage – but we need help as well”

In the Office of the Children’s Rights Director, we get calls from children asking for our help and advice, and we often take up their concerns with social services or children’s services for them. We have recently helped a young carer with exactly the problem that was raised at our workshop. Social services were giving help to their parent who needed care, but now that a different council department was dealing with services to children, nobody had yet worked out what help and support the young carer needed for themselves, and nobody had told their school about them being a young carer. From both our workshop and a case such as this, there is the clear message from young carers

that **their needs and problems should be looked at for them, as well as the needs and problems of the adult they are looking after,** with the different parts of the council linking up to do this.

One of the main sorts of support young carers wanted was **better support for the adults they were caring for,** both for those adults’ sake, and to help with the burden on the young carers. One sort of help wanted was more funding for **respite care,** to give the young carers a break. The young carers we spoke to were also clear that services for adults with disabilities who are also parents needed to **make it easier for young carers to get access to the services their parent might need.** Some said that they simply couldn’t understand why the person they were looking after, who might have a very serious disability or be bedridden, did not qualify for continuing

healthcare and staff to look after them from the health service or social services instead of relying on their children to care for them. Young carers often found it much harder to get services for the person they were caring for than adult carers would do, because it was a child doing the asking.

“We need someone to fall back on”

There was another problem with people from social services visiting, talking to the young carer, and saying that they were coping all right and didn't need help. This was that **things might be all right until something went wrong**, like the parent they were caring for falling ill, and then the young carer had no-one to back them up or take over, even if they could no longer get out to do the shopping, or manage the extra caring jobs. ***“We need someone to fall back on.”***

“first option is to take you into care, not help or solve problems”

Some said that they had met social workers who mainly thought about how their parents were looking after their children, not about how to support one or more of the children as young carers. These sometimes seemed to want to take the child into care rather than support them being a young carer; ***“first option is to take you into care, not help or solve problems”***. They had not got it right for what the young carers wanted. They wanted support, not to move out.

The young people at our workshop did however speak very highly indeed of the **young carers' groups** they were all members of. These groups were important because they gave you days to escape your responsibilities and have time for yourself, with other people who understood what you were going through. It was not activities and things to do that were important about these groups, but just being with people who understand, *“just knowing how you feel”*.

The young carers groups are also able to **put you through to people you might need help from**, especially people like counsellors who you could talk to. You could though always talk to the people in young carers' groups and the adults running them because they were consistent people who you can trust. If you needed to, you could have a one-to-one conversation with someone at the group to get things off your chest. You could also rely on what you said being confidential if you wanted.

“just knowing how you feel”

Young carers groups could organise activities for young carers themselves to enjoy together, which could *“let you be a child again”*, and give you something back for yourself. Sometimes young carers’ groups organised an activity **weekend away** for everyone – where you could get away, relax, laugh and just enjoy being with other young people, without lots of responsibilities.

“let you be a child again”

We asked what the young carers thought councils or the Government should do if there was ever extra money to do more for young carers. They all agreed that **what was needed was more of the same sort of support they got from young carers’ groups**. The young carers were clear that they needed help that fitted in with their individual situation; *“we are not text book*

“we are not text book cases”

cases”. What they didn’t want was a lot of new ideas or new projects – they said that it was a **problem that when there was some money, people always seemed to want to do something new** and different, which was never as good. In short, do more of what already works, and *“don’t keep coming up with new stuff”*.

One of the problems with some of the caring support that adults get at home, which could give the young carers time off, is that the support tends to come at times when there isn’t always a need. You might, for instance, get a nurse round every Tuesday and Thursday, but that was of little help if a crisis you had to cope with didn’t fall on a Tuesday or a Thursday, but on some other day when you were on your own. You need support when you are under pressure in your caring, but that pressure is unpredictable and any support you get usually has to be regular and predictable, so **your support and when you need it happen at different times**.

Many young carers told us that they felt that they were seen as a low priority by social services and other helping organisations. They were not in immediate danger – of abuse or anything like that – but were at risk of longer term repercussions through not being able to get the grades they deserve at school, missing out on enjoying the usual things of childhood or being a teenager, or of physical and mental health problems later on. These weren’t things that led to them getting much help.

“don’t keep coming up with new stuff”

Sometimes you just needed some **very practical help - which was hard to get**, so you were left on your own to sort things out for yourself. One example was the young carer who needed to get

themselves to meetings with Connexions, but were on their own to try to find out about what local transport would get them there and back at times that meant they were not away from their caring jobs too long.

One very practical sort of help young carers told us they needed was **being taught about best ways of caring, and about the disability of the person they are caring for**. Young carers were often left to do their caring without being taught anything at all about how to go about it or about the problems of the person they are looking after. One young carer gave us the example of how the person they were caring for had cramps, but they didn't know the best way of helping them with this. Things would be easier, and they could do a better job of caring for someone, if they were taught something about it.

“they can miss out on so much and have to grow up so fast”

One young carer told us that adult carers are able to get some **benefits** from the benefits system for looking after someone, but if you are a child, you can't get that. Sometimes those benefits might help you to get some help for yourself, or help you get things that would make it easier or safer to look after the person you care for.

One practical idea from one young carer was that **each young carer should get a regular phone call** from someone they know and trust, to check up on how they are doing and whether they need any more help.

The young carers at our workshop were mainly teenagers. But they told us that they are by no means the youngest carers – they said **there are some very young carers, still at primary school**, and were very concerned about them; *“they can miss out on so much and have to grow up so fast”*.

Are young carers' views listened to?

The young carers in our workshop were concerned that **their views were not likely to be taken on board by officials because they were still children**. However, many said that this didn't take into account the fact that young carers are carrying adult responsibilities – and indeed, heavier responsibilities than many adults do. *“Most young carers are grown up because of their responsibilities – though many adults are not.”*

“Most young carers are grown up because of their responsibilities – though many adults are not”

Lack of understanding of what it means to be a young carer could lead to you **not being listened to when you tried to explain not being able to complete school work, or gave reasons for missing school**. One young person told us how their teacher had accused them of 'skiving' when they missed school because the parent they cared for had got worse and had to be admitted to hospital.

What difference does being a young carer make at school?

Many at the workshop told us that they had difficulties at school because the demands on them as carers were not constant, but were unpredictable. **Sometimes your peaks of heavy caring demand happened at the same time your school was putting a peak of pressure on you too**. Schools do not understand this, or give flexibility in meeting things like coursework deadlines because a young carer is coping with a major caring peak or crisis at home. It is **important that teachers are aware of what it is like having varying demands on you as a young carer, and that they make allowances** for this. It is also important that all your teachers know about this, without you having to keep telling new people all about being a carer whenever you don't make a school work deadline because of it: *"it feels like I've got to explain myself so many times."*

"it feels like I've got to explain myself so many times"

Another thing about being a carer that can make a big difference to your school work is that **if you have been doing caring tasks for someone at home, sometimes during the night, you are simply tired and can't concentrate at school**. Again, many in our workshop did not find their teachers prepared to make allowances for this.

Some in the workshop did have special support teachers to help them, but there was often the usual basic problem with this. Like any help at home, having support at school has to be pre-planned, and is usually something regular, but your needs and the times you can and can't cope at school are not predictable, caring demands can happen in peaks and when not expected, and so **your needs and the support the school may plan for you are not in phase**. You may get help, but not when you most need it, or sometimes when you aren't able to make good use of it.

One thing young carers told us they would like schools to provide to help them was a **person on the staff that they could talk to at any time about their caring pressures**, who could help sort out any school pressures happening at the same time, or the sort of help you might need at school. That person should be fully aware of what being a young carer means, and should be someone you chose and trusted.

One very simple but important issue was that some schools did not let a young carer phone home during the day to check up on whether the person they were responsible for there was OK. **Schools need to understand that being able to keep in touch is important for both the person being looked after, who may be left home alone, and their young carer.** A young carer who is forbidden to check that their parent is OK at home is not likely to be very good at concentrating on their school work.

One very practical point one person made about their school was that the building had very **poor wheelchair access** – so the young carer had not been able to bring their parent in their wheelchair to attend a parents' evening.

What are the risks in being a young carer?

We asked the young carers whether they thought there were any special risks involved in being a young carer. Some of these were to do with things we have already written about, like making a mistake in what medicines you gave to the person you were caring for, or risks of not doing as well as you could at school, or the risk that you might have emotional problems of your own. There were some more detailed risks that we heard about in our workshop.

One of these was the **risk to you of lifting someone heavy**, for example into and out of the bath. You could injure yourself doing this, as well as injuring the person you were looking after. Often a child is the only person around to get someone into and out of the bath, or up to dress or undress. It would help if you were taught the safest ways of lifting, like adults often are, and if you were given the right aids and adaptations at home to help get the person you were caring for around. One example of a very useful aid, that was not easy to get hold of, was a "spinning top board".

"I didn't want to be treated differently"

Sometimes, the person you looked after **could lash out at you**, without meaning it, if you accidentally hurt them or touched them where they might be sensitive.

More generally, like with giving medicines out, there is a risk for everyone involved that you **might be getting something wrong in the way you were doing the caring job** for your parent or other family member. You usually have to work out what to do for yourself, and leaving you to do this is risky for everyone. Again, it would be better if you got taught what was the best way of doing things.

Because you are often exhausted, and often not able to get sleep at night, you are more **at risk of getting ill yourself**, and even getting a common cold can be a problem if there is no let up in the caring job while you are unwell.

Because so many young carers are responsible for the safety of the person they look after when out and about and when travelling, where there are many risks, they thought that young carers should be taught about **how to make travelling less risky**, such as for someone in a wheelchair.

Finally, some young carers told us that they were worried at the risk of not knowing what to do if the person they were caring for fell or had an accident of some sort. **Young carers need to know first aid** – things like the recovery position, resuscitation, dealing with possible broken bones, and any special first aid they might need to know for the sort of disability their family member had.

What should staff working with children and young people be taught about young carers?

The main thing we were told is that staff such as **teachers need to be taught awareness of disabilities and what young carers do**. They need to know that caring is tiring and can have its crises, and that they need to **be flexible in what they expect** of children and young people who have caring responsibilities as well as responsibility to do school work. Young carers can't always keep home and school separate.

Staff need to be aware that young carers will **sometimes be stressed**, which might either make them lose their temper at school, or perhaps want to be left alone at school and not be asked lots of questions. It is important that staff notice when you may need to talk or need help, but that they shouldn't keep asking if you're OK; *"I didn't want to be treated differently"*

Staff need to be able to **offer young carers practical help** if the child or young person wishes, but also to realise that young carers are all sorts of different people themselves – some want practical sorts of help, some just need someone to talk things through with, and some will leave things until they get to boiling point before telling anyone or asking for help. It all **depends on the needs and wishes of each individual carer** – and of course, those can be different at different times for the same person, too.

Social care staff as well as teachers need to draw the “***fine line between helping and intruding***”, and to realise that “*everyone trying to help you at once*” may not be so helpful after all – especially if you happen to be coping well at the time.

Staff also need to know how **being a young carer can make a difference to how you get on with other children or young people**. It can make it difficult to make friends, and you can come across as having emotional problems yourself. Friends you do make sometimes don’t stick around when things get tough. Practical things like going out with friends and going on sleepovers can be very difficult for a young carer to do, and this does make a difference to how you get on with other people your own age.

Since it would be so helpful to be taught more about the disability problems you come across as a young carer, it would be very helpful if **staff such as teachers could help either teach, or find the right person to teach, each young carer more about the particular disability of the person they are looking after**.

*“fine line
between helping
and intruding”*

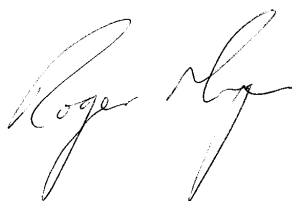
Conclusion

The young carers in our workshop gave us very clear messages, and told us sometimes very difficult personal stories. The caring task is something that “*never stops*”, but has peaks of demands on you sometimes. It is hard to keep going with caring, but that is what you want to do, because you are doing it for a parent or family member you want to look after as well as you can.

People need to recognise that caring for someone costs a lot to you. It can stop you getting on with much of your own life as a child or a young person, it can make it hard to balance what you need to do at school with what you need to do to care at home, and it can make it likely that you will not do well at school. That can make your chances of getting a good job later in life less than they would have been. It can make it hard to get and keep friends. It is stressful and there are risks to your own health. You suffer from the negative way people generally react against people with a disability, like the person you are caring for.

As a young carer you need help, knowledge and more understanding from others. You need help when you need it, not just the sort of help that has to be regularly scheduled whether you need it at the time or not, and you need practical things like equipment to move or lift a heavy adult. You need knowledge – of how best to care for someone, about their particular disability, and about risky things like how to give medication and how to lift people. You need your teachers to know what it means to be a young carer (without keeping on asking you), and to be flexible over school demands and deadlines when caring demands are so unpredictable. And you need the general public, as well as other children, to have a better understanding of what it means to have a disability, and to give help rather than rejection.

To get you the help you need, you need doctors and council officers to check what you need, both for yourself and to help you look after your family member, rather than just leaving you to get on with it if you seem to be doing the caring OK. You need the help you need, when you need it, and this is just more of the usual sorts of help, not the sort of new projects people sometimes seem to want to set up for young carers. Young carers’ needs always need to be looked at alongside looking at the needs of the person you are caring for.



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If you have any comments regarding this report
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