



MAKING IT REAL for young carers



Dear everyone,

Welcome to the booklet written by young carers for the sharing of information about young carers.

Being a young carer can be very taxing on our free time. We juggle our lives on looking out for our loved ones who need our support. Being a young carer, you can find that you are isolated without knowing you're isolated.

We need someone who will listen to us long term, who really knows us as a family, not just reading notes. For example, these are some of the things we say we need:

"I need the people that are helping my mum to be appropriate and not make the situation worse."

"I need a bus /train card because the places I need to get to are a good 40 minutes walk from my house."

"I need time with my family where my caring role is not a priority."

"I want to be able to focus on my future and my studies without neglecting my caring role."

"TIME: everyone needs it but we need it more. At school we need more time to finish homework or college work."

We worry about what will happen in the future and the responsibility of future roles. What's going to happen to the person we care for when we're not there; what's going to happen to us when they aren't there?

We worry about the decisions we have to make and the impact these have on us and our families.

PLEASE LISTEN. Don't just think we are talking rubbish. Notice us! Don't push us to the back of the queue. Understand our abilities!

Surrey Young Carers Forum

About Making it Real

Making it Real (More information on Making it Real is available at: www.thinklocalactpersonal.org.uk/MIR) was launched by Think Local Act Personal (TLAP) on the 17th May 2012 and is a tool to help organisations move towards more personalised and community-based support. The aim of Making it Real is to support organisations in taking practical steps to make personalisation a reality.

The programme was developed and co-produced with members of TLAP's National Co-Production Advisory group – a group of people with experience of using services and carers drawn from across the country. The document consists of a series of 'I' statements which describe what people might say if personalisation was working well for them.

About this guide

Young carers all too often go unnoticed and don't get the help and support they need to prevent them undertaking inappropriate caring and have a good life. No care or support package for a parent or sibling should rely on excessive or inappropriate caring by a young carer to make it sustainable.

If we are thinking about making personalisation real, then everyone in the family needs to be listened to, recognised, respected and supported and this includes young people who take on caring responsibilities for family members.

The Government's Care Bill emphasises the need for a whole family approach to assessment and support planning. Looking at the needs of the whole family means being mindful of the caring roles that many young people take on within their families, looking at the support they need to live their lives and supporting their parents in their parenting roles.

Making it Real for young carers has been co-produced with young carers. Each of the six themes has been explored with them through words and illustration to explain what is important to them. This document has been written in young carers' own words.

We are very grateful to all the young carers who shared their experience and knowledge to help get recognition and a better deal for all young carers across the country.

Making it Real is divided into six themes:

- Information and advice – having the information I need, when I need it
- Active and supportive communities – keeping friends, family and place
- Flexible and integrated support – my support, my own way
- Workforce – my support staff
- Risk enablement – feeling in control and safe
- Personal Budgets and self funding – my money.

This document follows these themes and supports them with statements from young carers on what they think needs to be happening, and what they should be experiencing, when an organisation is making good progress towards personalisation.

Information and Advice – having the information I need, when I need it

“At 11 years, I started managing mum’s medicine. No one spoke to me or told me about mum’s condition; no one explained the behaviour. The pharmacist didn’t speak to me when I picked up the prescription. Doctors don’t tell you what’s going on. They didn’t register me as a carer and didn’t explain what services would be available to me.”

- Talk to me, really listen and don’t make assumptions about what I do or don’t know. Give me a chance to ask questions.
- Be open about what’s going on with the person I care for. Don’t keep useful information too private.
- Don’t underestimate my expertise and knowledge. Ask my opinion. What is my experience?
- Make sure information is easily available at times that suit young people, like evenings and weekends. I should also be able to access information whilst at school or college e.g. via school library.

Active and Supportive Communities – keeping friends, family and place

“I need time to be my mum’s daughter as well as her carer.”

- We need the chance to have fun as a family.

- I need time to be a young person and to look after myself. Young carers should have the same opportunities and expectations as their friends.
- It helps to meet other young people in similar situations and to have our own space to talk.
- Young carers should be helped to understand how the skills we have developed in caring can be useful in the world of work e.g. prioritisation, planning, sorting out and managing emergencies.
- We need support to think about the future and information on the opportunities available to us and how to access these.

Flexible integrated care and support – my support, my own way

“Don’t promise what you can’t deliver, but deliver what you promise.”

- We need really good support for the person we care for so we are not relied on to do too much which affects our wellbeing and education.
- Arrange assessments and reviews at a time when I can be available so that you can hear my opinion and include me in planning support.
- Have one named person who makes all the arrangements and one phone number.
- We need support for the whole family and to think about the needs of the adult as a parent to support the young carer.

- We shouldn't go from loads of support to nothing when we are 18. It's almost impossible to think about having a life and caring at the same time with nothing.

Workforce – my support staff

“It was scary (reference to being assessed by social services). We were scared we were going to be taken away. It felt like it was like a quiz and I might get the answers wrong. They should make you feel comfortable.”

- Don't talk down to me, or at me, or ignore me.
- Give us basic information about who's who. I don't get the jargon. Tell us who you are, what your role is and leave us with a card/contact details.
- Respect my expertise and knowledge and think about how to support me to express my views.
- Schools need to know we are young carers. There should be an identified teacher for young carers.
- I need staff with good listening skills who get things sorted and know how to signpost to the right support and services.

Risk Enablement – Keeping me safe

“Young carers often don't say about safety issues e.g. moving and handling or child protection matters for fear of being removed from

the family home or the parent getting in trouble for not being able to look after the young carer.”

- I need a back-up plan to help me feel more secure about leaving to go out, or leaving to go to university and a support worker to contact in an emergency.
- As a young carer, I need to learn about first aid and taking care of my body when I am providing care.
- Be open with me about what’s going on with the person I care for.
- There are real issues about time for homework, I am busy doing other things like washing, making coffee for mum etc.

Personal Budgets and Self-funding – my money

“I got a grand last summer for one year.” “I got a new laptop. I could use the laptop for course work.”

- We should have free travel and help with costs of activities. The cost of transport and high cost of some activities is a big problem.
- Make sure any money ear marked to support me is not just absorbed into the family budget.
- There can be worry and extra work for me and my family managing money and support arrangements. We need good information and good support.
- Help us understand how to manage money and budgets.

Use this guide to make personalisation real for young carers in your area

The statements in this guide can be used to prompt a discussion about what is happening locally for young carers, help identify what could be done better and how this can be achieved.

Actions focusing on improving support to young carers and encouraging whole family approaches can be included in an action plan that organisations can put on the Making it Real website. Organisations that put their information on the website will see themselves as part of the Making it Real map. All organisations on the map can contact one another to learn from each other.

Anyone can check the progress of organisations in their area, comment on how they are doing and how they are including young carers in their action plan. If your local council or carers' organisation is not already signed up to Making it Real, you can encourage them to do this and to work towards achieving a Making it Real Kitemark to show that they are a Making it Real organisation.

For information and tools to help you use this guide and develop your Making it Real project go to:

www.thinklocalactpersonal.org.uk/Browse/mir/aboutMIR/supportMaterials

Useful resources

Documents

Working Together to Support Young Carers and their Families.
A Template for a Local Memorandum of Understanding [MoU] between
Statutory Directors for Children's Services and Adult Social Services.
August 2012.

www.adcs.org.uk/download/misc/working-together-to-support-young-carers-adcs-adass.pdf

Young carers: personalisation and whole family approaches. ADASS
and ADCS October 2011

www.adass.org.uk/images/stories/Young%20carers.personalisation%20whole%20family.print.11.pdf

Making it Real for Carers. Carers Trust, ADASS and TLAP May 2013

www.thinklocalactpersonal.org.uk/BCC/Latest/resourceOverview/?cid=9483

Improving support to young carers – family focused approaches.
Department for Education February 2011

www.gov.uk/government/publications/improving-support-for-young-carers-family-focused-approaches

Whole Family Pathway. Children's Society 2012

www.youngcarer.com

Hidden from View: The experiences of young carers in England.
Children's Society 2013

www.childrenssociety.org.uk/sites/default/files/tcs/report_hidden-from-view_young-carers_final.pdf

Commissioning Services for Young Carers and their families. Carers Trust. Phelps, D (2012)

www.carers.org/sites/default/files/commissioning_services_for_young_carers_and_their_families_final_copy_for_web.pdf

Really Useful Book for Young Adult Carers

<http://shop.niace.org.uk/ruble-yac-2011.html>

Supporting Young Carers: A resource for schools (Carers Trust and The Children's Society 2012)

<http://professionals.carers.org/young-carers/articles/schools-resource-pack,6282,PR.html>

Websites

Making it Real

www.thinklocalactpersonal.org.uk/Browse/mir

The Children's Society's Young Carers Initiative

www.youngcarer.com

The Carers Trust YCnet www.youngcarers.net

Supporting Young Carers and their Families: Examples of Practice

<http://professionals.carers.org/young-carers/articles/supporting-young-carers-and-their-families-examples-of-practice,7139,PR.html>

Young Carer Aware E learning in use in several parts of England – see link to version in use in Dudley:

http://etraining.dudley.gov.uk/nolms/young_carer_aware/launch_nolms.html

This graphic illustrates the discussions of the Surrey Young Carers Forum:



Think Local Act Personal is a sector-wide commitment to moving forward with personalisation and community-based support, endorsed by organisations comprising representatives from across the social care sector including local government, health, private, independent and community organisations. For a full list of partners visit www.thinklocalactpersonal.org.uk