



Participation and power: sharing stories safely

A toolkit to promote ethical and meaningful co-production with young carers

Why should we listen to and amplify young carers voices?

Young carers are the experts in their own lives, yet too often they report that the services and policy makers that affect their lives do not include them in service design or decision-making. It is therefore vital that we work with young carers to amplify their voices, views and expertise to ensure that policy and services are co-designed with them, in order to best understand and meet their varied and complex needs. It is also vital, however, that this is done sensitively and safely, to ensure young carers are not exposed to additional risk or harm as a result.

Why is this toolkit needed?

Many practitioners want to help amplify young carers' voices but are limited by capacity and resource. This toolkit aims to give practitioners tools and ideas for making this easier, whilst ensuring that participation work is done as ethically and meaningfully as possible. All the information in this toolkit has been developed by young carers and by young carers participation workers who have worked with a diverse range of young carers for over 15 years.

Research base and background

This toolkit is based on the findings of a study conducted by Hambling, Quinn and Bell, with the University of Gloucestershire, Gloucestershire Young Carers and Sheffield Young Carers, funded by the Paul Hamlyn Foundation. The study aimed to learn more about best practice in co-production and co-delivery with young carers, building on work by Daniel Phelps (2017).

The focus of the study was to evaluate young carers' experiences of co-production and delivery of training and awareness raising, specifically where they have lived-experience of familial substance misuse and/or mental ill health. Themes that emerged included the impact of stigma and shame, the complexities of 'consent', and the importance of good support and preparation. It also illustrated the feelings of empowerment and solidarity and the practical skills development that can be achieved.

Further details are available in the accessible research report [here](#) or via Davy Hambling (dhambling@glos.ac.uk).

What's in this toolkit?

- 2) Participation opportunities, benefits/risks
- 3) Key recommendations
- 4) Participation checklist
- 6) Session plan template
- 8) Resource: 'My Story' template
- 11) Resource: Scenarios to explore stigma

This toolkit, although created for use with young carers, can be adapted for any young person sharing their lived experience.

What kinds of opportunities are there for young carers voices to make an impact?

These are examples from two young carers organisations (YCOs) with active participation groups:

-  • Speaking at conferences/workshops to raise awareness and train professionals
-  • Being interviewed by the media (newspapers, radio, or TV)
-  • Making films to help raise awareness
-  • Devising and co-delivering training sessions and workshops for professionals or students
-  • Speaking to politicians and policy makers (e.g. the Lord Mayor, Members of Parliament, councillors)
-  • Sharing experiences with YCO staff for them to share at meetings, events, or training courses
-  • Working with and becoming members of YCO Boards of Trustees
-  • Informing YCO strategy planning and service delivery
-  • Sitting on staff interview panels for YCOs or other relevant agencies (e.g. social care, schools etc)
-  • Planning and hosting YCO conferences and events
-  • Sharing stories through social media
-  • Writing newsletters for other young carers

Benefits and risks of young carers participation

The research illustrated some clear benefits of young carers sharing their lived experiences, but also highlighted a range of risks.

BENEFITS

- Feelings of solidarity and connection - 'you're not alone'
- Importance of being seen, heard and recognised – feelings of empowerment
- Feeling valued for the importance and impact of stories and contributions
- Can be part of a healing process – making sense of experiences
- Can build confidence and raise aspirations
- Helps develop skills and experiences to enhance future education and careers

“

The most beneficial aspect of sharing your story is the empowerment it brings. As a carer you often feel like things are beyond your control, but the opportunity to participate in active change brought a positive aspect to my caring role.

”

RISKS

- Stories are complex and can have unintended impacts e.g. negative responses towards young people or family members
- Future regret – it's very difficult to withdraw information once it's in the public sphere

“I do kind of wish that I hadn't put that out there, that I hadn't said that to professionals...”

- Being seen or 'outed' as a young carer without control over this (for example, a video being seen at a young carers secondary school that was made when they were at primary, a neighbour or community member being at an event, meeting someone who attended training delivered by a young person at a later date)

“It got spread around my school...everyone just knew everything at that point. There was nothing left to hide, I felt vulnerable.”

- Anger and frustration at lack of change and social injustice
- Can create time demands and feelings of responsibility on top of existing caring and life pressures/burnout
- Feeling overwhelmed and underprepared

“There's the conferences that I have attended...everyone's swarming you, asking you questions... and you feel a bit lost...it can be quite overwhelming.”

- Young people feeling obliged to take part (a sense of duty or wanting to thank services that have supported them)
- Young person may consent but do they understand the long term impact?

Key recommendations

Support their identity as a young carer

- Evaluate if the young carers (YCs) feel comfortable with their own identity as a young carer.
- Ensure their needs as a young carer are understood and they are receiving appropriate support before participation activities.

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You have to consider what [the] people you look after want to be out there, because it's as much their story as yours. It's your story, but also it is the story of people you care for.

”

Address stigma, shame, and judgement

- Discuss with YCs the stigma, shame, and judgment they may have experienced before planning sessions, especially with YCs who have family with mental ill-health or substance misuse issues. These conversations can help address feelings that may have previously silenced them or made sharing their experiences difficult. It can also help them think through potential impacts that stigma and judgement may have if they decide to share their story.

Assess emotional readiness

- Evaluate YCs' emotional readiness for participation, because this work can sometimes be challenging.
- Provide support and resources to help them cope with emotional difficulties that may arise.

Plan for safe sharing

- Carefully consider the ethics and permanent nature of video, radio, TV, and social media content once shared. Discuss potential impacts on their personal lives, including family dynamics, friendships, community relationships, and overall safety. A YC may consent at the time but have they considered the longer term impacts of sharing their story without being able to recall/delete this at a later date. Consider the 'what if's' e.g. your parent sees this when they are drunk?
- Support YCs to talk about the impacts of caring and the issues they want to share and address, instead of personal details about their caring experiences or family situation. Where possible, it can be helpful if they include information and issues gathered from other YCs, not just their own experiences, so they are amplifying multiple voices and ideas, not just their own. This helps raise awareness of a diverse range of issues experienced and will be more representative.
- Help YCs carefully consider and plan what they feel comfortable sharing. Develop scripts or guidelines to help them articulate their stories in a way that respects their boundaries and those of their family members. Give permission for a YC to not overshare, this will help protect their dignity and self-worth.
- Plan for how to manage questions that they don't want or don't know how to answer. Spend time ensuring they know and have strategies for saying no to requests and questions.

Communicate purpose

- Clearly communicate the purpose of the work and the potential changes it aims to create. Ensure that YCs understand why their participation is valuable and how it can contribute to meaningful change, whether operational, structural, or otherwise. Be clear as to who will be the audience and how many people will be there.
- Be open and realistic about the barriers to change and predicted timescales for any outcomes of the work.
- Being transparent about the goals, objectives and challenges of the initiative helps to manage expectations and fosters a sense of purpose and motivation among YCs.

Establish feedback loops

- Create a robust feedback loop to maintain ongoing communication after presentations. Implement a "YOU SAID / WE DID" approach to demonstrate that the input provided by YCs is being taken seriously and acted upon.
- This approach helps to build trust and ensures that the impact of their contributions is recognised and valued. Providing timely and meaningful feedback helps to prevent the process from feeling tokenistic and performative.
- Consider various ways to show appreciation for YCs involvement. This could include certificates, public acknowledgments, or small rewards (e.g. vouchers or respite activities), as well as accreditations and/or references for education/work applications.

Participation checklist

Key:



Young Carer



Parent/carer



Organisation



Audience

BEFORE PARTICIPATION

SHAME AND STIGMA



- Have you explored stigma/shame/judgement with the YC prior to deciding if they want to participate?

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SUPPORT AND PREPARATION



- Have you explored ways to minimise any risk posed to them as a result of sharing their lived experience publicly? (e.g. planning and practising what they want to say)
- Have they been trained in how to address negative comments or unwanted questions from the audience?
- Have they been made aware of barriers to change e.g. sharing their lived experience may or may not have an instant and/or long-term impact?

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- Have you ensured outcomes and a feedback loop has been established?

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CAPACITY



- Is the YC Gillick competent?
- Have you explored the motivation of the YC and whether they have feelings of expectation, loyalty, and/or duty to the YCO or individual members of staff?
- Have you considered if the family member's condition mean that their capacity varies over time?

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CONSENT



- Has the YC been informed about consent being flexible and that it can be withdrawn?

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SAFEGUARDING AND ASSESSING RISK



- Are there any current/former safeguarding issues that might increase the risk for the young person?

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- Are there any current/former safeguarding issues that might increase the risk for the family?

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- Are there any risks to the reputation of the organisation if the young person shares their experiences?

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BEFORE EVENT

SUPPORT AND PREPARATION



- Have the details about the purpose of the session and logistics of the day been clearly communicated to the young carer (YC)?

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- Have the audience been informed that YCs will be sharing their lived-experiences?

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CONSENT



- Have you clarified timescales for where content will be used and if/when it will be deleted? (Including explaining that it is impossible to guarantee all material will be withdrawn as it is difficult to control material once it is in the public domain)
- Have you asked if they want to create a back-up recording or made another plan, in case they cannot make it on the day? (this can help relieve pressure and feelings of guilt if they do need to cancel)

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SAFEGUARDING AND ASSESSING RISK



- Is the organisation prepared to halt the session/presentation if the circumstances indicate an increase in risk? (e.g. young person openly sharing information of a child protection issue?)

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ON THE DAY

INFORMATION AND PREPARATION



- Have YC's been reminded of what they are expected to do and the plan for the day?
- Have they had the chance for a final run-through/rehearsal?



- Has the audience been given 'trigger'/emotional health warnings and a 'safe space' if needed?
- Has the audience been reminded about confidentiality and respecting needs and rights of YC?

CONSENT



- Have you reminded the YC again that they can withdraw consent at any time?
- Have you got a plan around being able to 'pull a young person out' if they feel uncomfortable or withdraw consent on the day?

RESPECT AND COMFORT



- Have you reminded the YC to say or indicate if they feel uncomfortable? Prearrange an easy way for them to do this.



- Has the audience been reminded that the YC might need time to pause or might become distracted?
- Has the audience been reminded they need to show consideration and respect to the YCs by engaging with the workshop/presentation? (e.g. keeping screen on in an online session)
- Has the audience been reminded to ask questions sensitively and that YCs have the right not to answer them?

FEEDBACK



- Have you prepared the process for collecting feedback? (e.g. Evaluation form)
- Does the feedback tool include impact and action questions?



- Have all audience members got access to the feedback form/link?
- Have the audience been reminded of the importance of giving their feedback?

AFTER THE EVENT

REVIEW AND FEEDBACK



- Have you done a debrief/review? (e.g. how the YC felt, what the YC learnt, what could be changed in future)
- Have you checked YC is happy with choice of pictures or videos before posting on social media?
- Have you shared the feedback from the session with the YC?



- Have you shared feedback with parents/family?



- Has the audience been chased for any missing evaluations?
- Has the audience been sent slides, resources, certificates (where relevant), reminders about agreed actions, and any appropriate websites or helplines?

Session Plan Guide

Session plan: a guide to exploring stigma and stereotypes (2.5 hours)

Date:

Staff:

Young people in attendance:

Aims – What we want to get out of the session

- To relax, socialise and have fun
- To help improve other services through sharing our voices
- To learn more about stigma and stereotypes, specifically surrounding mental ill-health and substance misuse.
- For young people to draft 'My Story'

Resources

- Food ☐ Blank A4 paper ☐ Pens (biro/felt tip/markers) ☐ Blank flipchart paper ☐
- Flipchart ☐ Ground rules ☐ 'My Story' sheets ☐ Stigma scenarios ☐

Activity

Time

Introduce session and wellbeing check ins

- Go over ground rules for session.

10 mins

Icebreaker game (choose 1)

Smarties game:

- Open a packet of smarties (or othered coloured sweet) and ask each person to pick 2 different coloured sweets.
- Each colour correlates to a question to answer. You can either create your own or find some online.
- Reveal your questions to the group.
- Go around the room until everyone has had a turn to answer their questions.

10 Mins

2 truths and a lie:

- Each person thinks of 3 statements about themselves. Two that are true and one that is a lie.
- Share in turn and as a group discuss which you think is the lie.

Stigma icebreaker:

- Have participants pair up and share a time when they felt judged or misunderstood.
- Encourage them to discuss how it made them feel and what they wished others had understood about them.

Discussion – Stigma and stereotypes

Split into 2 groups.

Each group to discuss:

What do we mean by a stereotype?

- A stereotype is a belief that all members of a given group share the same fixed personality traits or characteristics as a result of this group membership. It can be positive or negative.
- Can you think of any examples?
- Why do people stereotype?

25 mins

What do we mean by stigma? How is this different to a stereotype?

- Stigma is negative attitudes, beliefs, and stereotypes people may hold towards someone/a group because of particular traits or characteristics.
- Can you think of any examples?
- Why might there be stigma around a particular group?
- How might this affect people?

Come back together as a group and feedback.

Discuss together:

- Stigma for young carers (in particular, mental health and substance misuse)
- How can this affect young people (YP) and their parents?
- How might this affect YP coming forward/asking for help/talking about their experiences?

Group activity – Explaining stigma

- Split into different groups (number of groups depends on amount of YP) and present each with a different scenario card.
- Have each group discuss the scenario:
 - Who is experiencing stigma?
 - What could be a supportive response?
 - How could we reduce this stigma?
- Each group to feedback and discuss suggestions to wider group.
- Discuss what was learned and how supportive responses can make a difference.

25 mins

This could be delivered as role play, discussion, or art based.

Break

30 mins

My Story

- Discuss idea of consent.
- Think about what you and your family are happy for you to share today.
- Who would you be happy to know about your experiences?
- Who would you not like to know about your experiences?
- Think about what you and your family will be happy with in 5 years?

40 mins

Show a draft version of 'My Story' to the group and explain each section.

YP to start writing their story on worksheets.

Quick game or shake out activity (the writing may have brought things up for people) e.g. would you rather

Note to workers: It is a good idea to ensure you can make time for 121 conversations at the end of the group if anyone needs this after writing their story.

10 mins

Finish

Note to workers: This will need a follow up session to revisit their worksheet, with time to make edits, then a chance to share their story with the group. This can be an emotional session, so it is important to:

- Discuss the importance of listening supportively at the start.
- Give trigger warnings that hearing other people's stories may be upsetting.
- Ask young people to share their stories one by one (with some time to prepare first if they want this).
- Celebrate each young person after they have shared their story (for some, this might be the first time they have said some of these things out loud in a group or at all).

My Story

We share our stories with professionals, the media and with other young people so we can:

1. Raise awareness about what it's like to be a young carer.
2. Break down stigma about being a young carer and mental illness, disability and substance misuse.
3. Help other young people in similar situations realise they're not on their own.
4. Help inform professionals that can identify young carers and provide support for them and their families.

If you decide to do this, the questions below will help you plan what you would like to say. Please answer as many questions as possible but do not answer anything you do not want to. If you have any questions, please speak to your worker.

You and your family

About you

What's your name? How old are you?

Can you tell us something fun/interesting about yourself? (e.g. hobbies, interests)

Your caring role

Who do you care for?

Why do they need your care? (please be specific)

How does their condition affect them?

What do you do as a young carer?

Identification

Can you remember when your caring role started? What age?

When were you identified as a young carer?

Can you remember who identified you?

How this affects me

How does caring impact your life? (e.g. school, hobbies, friends, family)

Why do you think your life is different to other young people?

What have been some of the hardest things about being a young carer?

What are the positives about you being a young carer?

Achievements and support as a young carer

Support

What support have you had from [young carers organisation]?

Young carers forum/participation (only answer if part of this)

Why did you join the forum/group?

What have you got from being in the forum/group? (you might need to add these bits after you've been in the group a bit longer)

Achievements

Since being with [young carers organisation], what are you most proud of achieving and why? (this could be with the organisation or in your personal life)

Stigma Scenarios

Please find below a selection of different scenarios to use in the 'Explaining Stigma' section of the session plan.

Jamie, an 11-year-old, cares for his mother who is in treatment for her substance misuse issues. At school, Jamie overhears classmates gossiping about his mother's past, making him feel isolated and embarrassed. Jamie has had an assembly about young carers but is scared to talk to anyone about his caring role.

Ruby, a 16-year-old, looks after her father who has severe depression. When Ruby tries to explain her father's condition and her caring role to a friend, the friend responds with, "Everyone gets down sometimes – he just needs to get over it and man up".

Jamal, a 12-year-old, helps care for his younger brother who has autism. During a family outing, a stranger makes a rude comment about Jamal's brother's behaviour, causing Jamal to feel defensive and upset.

Jordan, a 13-year-old, cares for his grandmother with dementia. She sometimes shouts out of the window when she is distressed, and he has heard some young people in the area call her 'that crazy old lady'.

Alisha, a 15-year-old, cares for her father who struggles with alcoholism. At a family gathering, a relative makes a joke about her father's drinking habits, causing Alisha to feel embarrassed and hurt.

Sarah, a 14-year-old, helps care for her older brother who has a history of prescription drug misuse. At school, a teacher makes a comment about "useless drug addicts" in a negative context, making Sarah feel ashamed and defensive. She has never told anyone about her brother or her caring role for him.

Lily, an 11-year-old, helps care for her father who has a mental health condition. Her father, fearing judgment from others, downplays his condition and doesn't acknowledge the support that Lily gives him, making Lily feel undervalued.

Ahmed, a 17-year-old, cares for his mother who has a substance misuse problem. In their community, there is a strong stigma against substance misuse, leading Ahmed's mother to deny her condition and any help she receives from Ahmed.

With thanks to research conducted by David Hambling,
Mandy Bell and Aiden Quinn which formed the basis of this toolkit.



The three organisations would like to thank all the young carers and professionals that have contributed to the creation of this resource.

For more information or any questions on the toolkit please contact the co-authors Hana Gill and Laura Selby via the details below.

“

Saying your story, you're also voicing experiences of so many people, and hope that it will change something...or inform someone that can help.

Young Carer

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