



Developing a Universal Definition of 'Care Experience'

Response to the Scottish Government's public consultation

January 2025

Who we are

Who Cares? Scotland (WC?S) is Scotland's only national independent membership organisation for Care Experienced people. Our mission is to secure a lifetime of equality, respect, and love for Care Experienced people in Scotland and we currently have around 4300 members.

At the heart of Who Cares? Scotland's work is the rights of Care Experienced people, and the power of their voices to bring about positive change. We provide individual, relationship-based independent advocacy, and a range of participation and connection opportunities for Care Experienced people across Scotland.

Every year, our advocacy workers support around 1,600 people with around 6,000 individual advocacy issues across all 32 Local Authorities in Scotland. As we take a human rights-based approach to our work, around 10,000 individual rights are logged every year in supporting these issues. We bring Care Experienced people together to connect and shape the world around them. Around 700 unique individuals come together every year to take part in around 800 of our activities across Scotland.

We work alongside Corporate Parents and various communities to broaden understanding and challenge stigma faced by Care Experienced people. We work with policy makers, leaders, and elected representatives locally and nationally to shape legislation, policy and practice. We do this collaboratively to build on the aspirations of The Promise and to secure positive change.

Summary

This consultation response provides Who Cares? Scotland's organisational comment on the Scottish Government's proposals on developing a universal definition on 'care experience'. Our response has been developed by drawing on evidence from our advocacy service and participation work, covering Care Experienced people across a diverse range of care settings, ages, and backgrounds. In particular, our 'Summer of Participation' work took place between June and August 2023, where we carried out a large participation exercise which engaged over 200 Care Experienced people.

Who Cares? Scotland is calling for:

- A broad and inclusive universal definition to describe 'Care Experience' to create a sense of belonging among the community and support Care Experienced people who want to embrace this as part of their identity.
- The definition to encapsulate the lifelong impact that being in care can have. It should give all Care Experienced people, regardless of their age or type of Care Experience, the option to identify with the term and access supports necessary to bring about equity for Care Experienced people.
- Care Experienced people who come off their Compulsory Supervision Order before their 16th birthday should be eligible for support if they need it.

Response to the consultation questions

Q1. Do you agree or disagree that there is a need for a universal definition to describe 'care experience'?

- a. Agree strongly
- b. Agree
- c. Neither agree nor disagree
- d. Disagree
- e. Disagree strongly

Q2. What are your views on the potential advantages of developing a universal definition of 'care experience'?

At Who Cares? Scotland, we believe that there are a number of advantages of developing a universal definition of 'care experience'.

Identity and Belonging

Many Care Experienced people do not identify with the terms 'looked after' and 'care leaver', as outlined in our response to questions 4 and 5 in this consultation. Not everyone who could consider themselves 'Care Experienced' meet the legal definition of 'looked after' or 'care leaver,'. Due to this, many Care Experienced people feel these terms do not represent them. The term 'care experience' has been in public consciousness since 2012, and used consistently by Who Cares? Scotland since 2015. Having a broad and inclusive universal definition of 'care experience' which covers the widest group of individuals, will help to create a sense of belonging among the community and support Care Experienced people who want to embrace this as part of their identity.

"I wish it was more focused on because then I wouldn't have always grown up feeling lost, I would know where my identity was, and I would have been able to know that I was Care Experienced and to access supports and to come to groups. But because I didn't know I feel like it limited me..."

- Care Experienced person, Communities that Care Stakeholder Interview Focus Group Report, 2020.

There continues to be a widespread lack of knowledge and understanding of care, and the impact this can have on someone, among the general public. Our 'Communities that Care' Whole School Approach involves educating entire school communities on care experience with the aim of creating more empathic and inclusive communities. An important element of this work involves teaching school pupils about care experience. A key theme that has emerged from this work is that many Care Experienced people do not know that they are Care Experienced. This has been particularly true for those who have experience of kinship care, or are being looked after at home. Through learning about care at school, Care Experienced people have had the opportunity to learn more about, and embrace, their care identity:

3

"Without the project [Communities that Care] I don't think I would know I am Care Experienced."

- Care Experienced person, Communities that Care Stakeholder Interview Focus Group Report, 2020.

Who Cares? Scotland are Scotland's only national membership organisation for Care Experienced people. Any Care Experienced person can become a member for free and access a wide range of benefits, including the opportunity to attend belonging and connection events, and weekly groups. We bring Care Experienced people together to connect and shape the world around them. Around 700 unique individuals come together every year to take part in around 800 of our activities across Scotland. Our engagement activities are attended by a wide range of care-experienced people living in different types of care. Over the past two years, around 18% of participants lived in their own tenancy, 15% lived in foster care, 15% lived in kinship care, 14% lived in residential houses, 10% are looked after at home, and 5% live in residential schools. Despite their varied experiences of care, most of our members still choose to identify as 'Care Experienced', and together, have built a strong shared identity. Below are some examples of feedback provided to us by Care Experienced people who participate in our connection and belonging offers:

"I met other people like me and felt like I could be myself."

"I have a deep sense of belonging here and from the very beginning to end of the event I felt so much love, care and inspiration."

"It's like a family."

"I don't usually belong and I did feel like I did at this event."

"It's like an unbreakable bond.".

These quotes highlight a strong sense of belonging and shared identity among the Care Experienced people who participate in our activities, which seems to traverse age, and types of care. This is why, in 2013, we consulted with our members to create the 'Care Experienced Tartan' (https://www.whocaresscotland.org/blog/care-experienced-tartan/). The tartan is colourful and made up of five different colours. These main colours represent different aspects of Who Cares? Scotland: pink – love, blue – equality, respect – yellow, teal – belonging and dark green – voice. Our tartan represents the fact that all Care Experienced people belong to a global community. They are unique, diverse, and all connected by their shared experience of care. This sense of belonging is so important to Care Experienced people, as outlined in our 'Belonging and Connection' issue paper (https://www.whocaresscotland.org/wp-content/uploads/2024/12/Lifelong-Rights-for-Care-Experienced-People-Belonging-and-Connection-Issue-Paper.pdf).

By having an inclusive approach, and not excluding anybody based on the type of care they have experienced, Care Experienced people have the choice to come together and claim a care identity where they feel that they belong. This shared identity has allowed our members to build strong relationships with each other, with many citing that they are excited for our events to get to see their peers:

[&]quot;Yes makes me feel more connect[ed] with my care family"

"I'm included and we all love and respect each other".

If this approach is used to develop a universal definition, it allows 'care experience', to be a holistic identity which Care Experienced people can choose to identify with, rather than the restrictive eligibility which currently exists under 'looked after' and 'care leaver'.

Lifelong impact of care

Another advantage of creating a universal definition of 'care experience' is that it can encapsulate the lifelong impact that being in care can have. 'Care experience' can be used by anybody who has been in care, regardless of their age. This includes infants, children and young people, and adults.

"I never told anyone or talked about it until around 40 years after I left care."

• Care Experienced person, Summer of Participation, 2023.

"The full effect of a childhood in care for me wasn't felt until I was well into my 20s. The emotional damage it caused was only apparent long after I was eligible for any type of support from after care services. That meant I had to go it alone and seek out support independently."

- Care Experienced person, Summer of Participation, 2023

A universal definition of 'care experience' would allow older age groups to be captured under the definition. This is vital, as Care Experienced adults bear the cost of care, which can impact on a person's education, finances, self-esteem, identity, and health. As outlined following the Independent Care Review, Care Experienced adults are almost twice as likely to have poor health, over twice as likely to have no educational qualifications, and more than twice as likely to have experienced homelessness (Follow the Money, 2020 - https://www.carereview.scot/wp-content/uploads/2020/02/Follow-the-money.pdf).

"We sometimes don't deal with our trauma until later – so support needs to be offered for older age groups."

Care Experienced person, Summer of Participation, 2022.

The term 'care experience' also provides older Care Experienced people, who have not realised until adulthood that they had experiences of care, the opportunity to identify with the term.

"We hadn't heard about care experience until we were older, and it is a vital part of who we are... We missed out on so much support we should have had but because we didn't know about care experience".

 Care Experienced person, Communities that Care Stakeholder Interview Focus Group Report, 2020.

Access to supports

As outlined throughout section 1 of this consultation, there are a number of supports available for Care Experienced people across Scotland. However, there are stipulations to this support, meaning that some Care Experienced people are unable to access it, depending on where and when their care took place. Care Experienced people often tell us that, on paper, they are entitled to support, but in reality it is extremely difficult to access. We discuss this further in questions 3, 4, and 5.

We believe that the current supports that are offered to 'looked after' children and young people, and 'care leavers', should be widened to include all Care Experienced people, to ensure that nobody is falling through the cracks. Developing a universal definition of 'care experience' would also create consistency across the sector and allow organisations to have a joined-up approach.

By introducing a universal definition of care, lifelong support should be offered to Care Experienced adults to ensure they have access to the support that they need to thrive.

"You get to a certain age and it feels like there isn't anyone that truly cares anymore. When you turn a certain age it feels like all the support has stopped."

Care Experienced person, Summer of Participation, 2023.

"Age doesn't mean at one point there's a fairy wand waved that fixes my issues and concerns brought about by my disability and care experience. I think no matter the age, this burden can follow you so the appropriate supports should be alongside you"

- Care Experienced person, Summer of Participation, 2023.

Furthermore, during our Summer of Participation in 2023, the majority of people we spoke to were in strong agreement of the need for equity in the protection of rights between Care Experienced people and their non-Care Experienced peers.

"We need to ensure that we wrap a rights based legislative framework of rights [around] care experienced people so that we can ensure children and young people grow up loved, are able to heal, and get everything they need, want and deserve, but as they grow into adults, they aren't forgotten."

- Care Experienced person, Summer of Participation, 2023.

The Who Cares? Scotland Lifelong National Advocacy Helpline is available to **all** Care Experienced people (and those who support them), regardless of age or type(s) of care they have experienced. The majority of our callers are no longer in care, with the average age of our callers being 29, and a high percentage of them having their own tenancy. The Lifelong Advocates who work on our Helpline support Care Experienced people with a wide range of issues, including finance, applying for the Care Experienced bursary, housing, and mental health struggles. It is vital that **all** Care Experienced people, regardless of their age, have access to the support that they need to thrive.

One of the ways that we have saw this support being extended to all Care Experienced people is through Corporate Parenting. Many Corporate Parenting organisations have chosen to extend the support they offer to Care Experienced people beyond the age of 26, in recognition of the lifelong impact of care. Furthermore, there is a growing number of Corporate Parents in Scotland who have chosen to treat 'care experience' as a protected characteristic. This includes Edinburgh, Falkirk, and North Ayrshire Councils, SQA, and ILF Scotland. Additionally, the Scottish Funding Council have asked all colleges and HEIs in Scotland to treat 'care experience' as a protected characteristic. Considering 'care experience' as a protected characteristic provides Care Experienced people with protection from discrimination because of their care identity. This protection is also lifelong, meaning that protected characteristic status could be the bedrock protection that stays in place throughout a Care Experienced person's life. Developing a universal definition of 'care experience' should give all Care Experienced people, regardless of their age, the option to identify with the term and access supports.

Q4. Do you have any views on the definition of 'Care Leaver' as set out above?

As outlined in our response to question 2, Care Experienced people have been telling us, for over forty-five years, that whilst they may leave 'care', the impact of being in care does not leave them. 'Care Leaver' is an eligibility, not an identity.

"Care experience doesn't ever really leave you."

- Care Experienced person, Summer of Participation, 2023

The term 'Care Leaver' is restrictive in who it covers and does not encapsulate the full Care Experienced population. We believe that the definition of 'Care Leaver' is too narrow and allows too many Care Experienced people to fall through the cracks and be ineligible for support. For example, the aim of Continuing Care (https://www.gov.scot/publications/children-young-people-scotland-act-2014-guidance-part-11-continuing-care/) - as set out in Part 11 of the Children and Young People (Scotland) 2014 Act - is to ensure that young people who have been cared for out with the family home can stay within stable, safe, and settled placements for as long as they need.

As explained in this consultation paper, only young people who meet the legal definition of 'Care Leaver' are currently eligible to access Continuing Care. This therefore excludes young people who did not have a legal order (granted by the Children's Hearings System) in place at the time of their 16th birthday – regardless of the experience of care that an individual may have had, or if a legal order was previously in place before this birthday.

"18 yr old is homeless and struggling to find support as was removed from CSO just before their 16th birthday."

- entry to our advocacy database.

During a discussion with the Citizen Participation and Public Petitions Committee about Jasmin's petition (PE1958), Care Experienced people discussed being removed from their Compulsory Supervision Order (CSO) before their 16th birthday,

meaning they are not eligible for aftercare support. Care Experienced people tell us that coming off their CSO is viewed as a positive step, e.g. by being able to have more independence, but they are not being made aware of the consequences for ongoing support by coming off of this before they are 16 years old. Some Care Experienced people have been 'looked after' for their whole lives so far, but are taken off their CSO a few months before their 16th birthday, therefore have no support after turning 16.

"18 year old was on a CSO and Child Protection Order until just before they turned 16. Allocated a discretionary Through Care Worker. Through Care have said that they weren't entitled to any financial support/section 29 monies to help furnish their flat. Through Care have said as they were not looked after until after their 16th birthday, they will not support them financially."

- entry to our advocacy database.

"[There is a] loophole of leaving care before 16th birthday then no duty on social work to support through 20s - can lead to social work service predominantly being to get care experienced people back home before their 16th birthday to ensure no ongoing financial commitments. Everything is categories - we are all care experienced."

- Care Experienced person, Who Cares? Scotland's Summer of Participation, 2023.

Although a Care Experienced person may have ceased to be formally 'looked after' before turning 16, therefore do not qualify as a 'Care Leaver', they may still require support. By developing a universal definition of 'care experience', we would encourage the Scottish Government to extend the supports that are currently only offered to 'Care Leavers'; Continuing Care, Aftercare, Corporate Parenting, and the Council Tax Exemption; to all Care Experienced people. This will allow all Care Experienced people aged 16-21, who may require support, to benefit from the stability and support on offer and have the best start at adulthood.

Q5. Do you have any views on the statutory definition of 'Looked After' as set out above?

As outlined in our response to question 2, Care Experienced people have shared with us that they do not identify with the term 'Looked After (and Accommodated) Child'. Care Experienced people have often expressed that this term is stigmatising - the child is a passive object and not an empowered subject - and an example of cold, process-driven language.

This is something that was highlighted throughout the Independent Care Review, as outlined within The Promise (https://www.carereview.scot/wp-content/uploads/2020/02/The-Promise.pdf). Care Experienced people have shared that this term is often shortened to 'LAC/LAAC', which, when spoken aloud, sounds like the word 'lack'. We have heard anecdotally from those who we support that this can feel that the term is implying they themselves are 'lacking' in some way. This is othering and has a profound impact upon Care Experienced people's identities and how they view themselves.

Furthermore, the term (and in turn, the support available) only refers to those who are currently 'looked after', and not those who previously have been. This can again

have an impact on Care Experienced people's identity, as they feel they do not fit in with the definition:

"I would really like to bring previously looked after to the table, I feel they are being failed and excluded under Care Experienced... Include previously looked after in the definition of Care Experienced regardless of when the supervision is terminated and focus on needs over timescale."

- Care Experienced person, Navigating the World of Rights, 2020.

In addition to this, we would also like to highlight that the majority of organisations, including Corporate Parents, across Scotland are no longer referring to Care Experienced people as 'looked after'. Following on from The Promise, 'Care Experienced' is now the widely used and accepted definition that those who we support have told us that they prefer. It is vital that the Scottish Government take Care Experienced people's views into consideration and listen to the views that have already been shared with them around the term 'looked after'. As a result, we would encourage the Scottish Government to consider whether 'looked after' still has a place within the landscape of care in Scotland.

A potential disadvantage of introducing a universal definition of 'care experience', as outlined within section 1 of this consultation paper, is that "it is felt adding another definition to the care landscape could complicate this further and add confusion around the supports and entitlements available at different stages of a person's journey through care.". Instead of 'looked after' and 'care leaver', a broad and inclusive universal definition of 'care experience' could be adopted which would enable **all** Care Experienced people to feel represented.

Q6. What experience of care would you expect to be covered by any definition of 'care experience'?

- Looked After at Home
- Kinship Care (looked after children who have been placed with kinship carers by the local authority)
- Kinship Care (non-looked after children who live with a kinship carer, these children may be subject to an order under Section 11 of the Children (Section 1) Act 1835 or may be living in a completely private arrangement with extended family, with no local authority involvement)
- Foster Care
- Residential Care
- Residential Special School
- Supported Accommodation
- Secure Care
- Adoption
- Other please provide details

Other – We would also expect Unaccompanied Asylum-Seeking Children to be covered by the universal definition of 'care experience'.

Q7. Do you have any other comments about a proposed universal definition of 'care experience'?

Following on from question 6, we would strongly recommend the Scottish Government to consider a broad and wide definition of care experience', such as the one that Who Cares? Scotland uses:

"The term 'Care Experienced' refers to anyone who is currently in care or has been for any length of time regardless of their age. This care may have been provided in many different settings, such as:

- Kinship Care Living with a relative who is not your mum or dad. This includes both formal and informal.
- Looked After at Home With the help of social work.
- Residential Care Living in a residential home or school.
- Foster Care Living with foster carers.
- Secure Care Living in a secure accommodation.
- Adoption Living with adoptive parents."

During our Membership survey in 2024, we asked our members what they thought of our definition of 'care experience', and whether they agreed with it. Some of our members fed back:

"The current settings cover all bases and reflect what it means to be care experienced well."

"I'm happy to see kinship care included, as I believe they face the same struggles as me. with less support from the government."

"It should be as wide and inclusive as possible."

At Who Cares? Scotland, we believe that having a universal definition of 'care experience' would ensure that **all** Care Experienced people are represented within the term. It is important that those who have previous experience of care are included within the definition too. This is why, in Who Cares? Scotland's definition, we include "anyone who is currently in care, **or has been for any length of time**". As outlined in our response to question 2 in this consultation, it is imperative that a universal definition of 'care experience' includes Care Experienced adults, and those who are no longer in care.

As outlined in our response to question 3 in this consultation, one potential disadvantage of introducing a universal definition of 'care experience' is that it may not be wide enough. We want to highlight the importance of including kinship care and looked after at home within the definition of 'care experience' – based on evidence that already exists in Scotland, and also evidence that our members have provided to us through advocacy and participation projects.

Kinship Care

As outlined in our response to question 2 in this consultation, key learning from both our Communities that Care project, and Jasmin's petition (PE1958), has been that kinship care is not widely understood. This is felt by Care Experienced people living in kinship care, and also by their carers.

- "A lot of people don't know what kinship is and now you can tell them. It's important to learn this at school."
- Kinship carer, Communities that Care Stakeholder Interview Focus Group Report, 2020

Care Experienced people have highlighted that this lack of understanding can lead to stigmatising behaviour, including being treated differently by professionals, and their peers. Through our Communities that Care project's work educating school pupils, Care Experienced people now feel more accepted and included within their schools, due to improved attitudes of their non-Care Experienced peers:

- "They [peers] used to always ask questions about like why I stayed with my Nana and they didn't get what it meant. I feel like, I think now they understand more and now they don't look at you as if you're weird. Because it [the project's input to the class] helped."
- Care Experienced person, Communities that Care Stakeholder Interview Focus Group Report, 2020

It is important that all kinship care arrangements that are in place due to care and protection concerns, regardless of whether the arrangement is formal or informal, are included within a universal definition of 'care experience'. Furthermore, the support that is offered to those in formal kinship care, should be extended to those in informal and private arrangements too. Informal/private kinship care is often not recognised as a form of 'care experience' by organisations providing support. For example, the Student Awards Agency Scotland (SAAS) require families with private arrangements to have "been [in] contact with the local authority or social work regarding the arrangement to be eligible for support, even if they did not arrange the placement". This is something which is out of the Care Experienced person's control, and can result in them losing out on support.

"People think it's our fault that we have ended up in care when it isn't. I think the law should do more to protect us. It shouldn't put us at a disadvantage when it isn't our fault."

- Care Experienced person, Summer of Participation, 2023.

This contributes to Care Experienced people feeling their 'care experience' is invalid, and can have a detrimental impact upon their identity.

Looked after at home

Whilst those who are 'looked after at home' are, in theory, eligible for supports offered to 'looked after' children in Scotland, there is evidence that this group of Care Experienced people may require further support to help them reach their potential. Every year, the Scottish Government publishes information on the attainment and destinations after leaving school of 'looked after' children, - Education Outcomes for Looked After Children 2022/23. This year, like every year prior, children who are 'looked after at home' continue to have worse educational outcomes when compared to their other Care Experienced peers – they have lower attainment levels, lower attendance rates, and are less likely to be in a positive destination after leaving school (https://www.gov.scot/publications/education-outcomes-for-looked-after-children-2022-23/documents/). Furthermore, Care Experienced people who have been 'looked after at home' have told us that they have been refused, or only offered limited support, despite being recognised as a 'Care Leaver' in law.

"I was in Care for eleven years, in both Looked After at Home and Kinship care placements.. Throughout and after the moving process, I was unfortunately denied a lot of support that I considered to be crucial. I was not entitled to a grant for household goods, I had to move all of my belongings myself, and I had to set up the gas and electricity by myself too. I was denied this support because I was not in 'accommodative care'. I felt ashamed. I felt like my Care Experience was not valid enough."

Care Experienced person, Somewhere to Call Home Report, 2019.

When types of 'care experience' are excluded from definitions, or not offered support, it has a profound impact on Care Experienced people's identities. It leads to some Care Experienced people feeling like their experiences are not valid and that they cannot identify with the term.

Q8. Do you have any comments on the existing language of care? Please refer to our answers to questions 4 and 5.

Q9. Do you have any suggestions on potential ways to change and improve the language of care?

Please refer to our answers to questions 4 and 5. We would also like to highlight that Care Experienced people are not a homogenous group – what is preferred by one Care Experienced person, may not be preferred by another. It is important that organisations take an individualised approach when working with Care Experienced people, to ensure they are using the language that individuals prefer. As outlined in The Promise, 'system language' should be avoided. It is important that everybody within an organisation, regardless of their job role, has a basic understanding of care experience and how this can impact an individual, and uses warm and loving language when discussing care experience.

Q10. Are you aware of good practice to change and improve the language of care?

Across Scotland, we are seeing a positive shift in language, with organisations moving towards using more inclusive language, as outlined in The Promise (https://www.carereview.scot/wp-content/uploads/2020/02/The-Promise.pdf). However, we would like to highlight that Care Experienced people have told us that sometimes, changes in language has a limited impact upon actual practice across the workforce. It is important that any changes in language are embedded throughout an organisation, and incorporated into all practice with Care Experienced people.

In August 2024, Who Cares? Scotland held the first Corporate Parenting Awards Ceremony. The 'Changing the Narrative' award sought to recognise and celebrate a Corporate Parenting organisation that has demonstrated a commitment to inclusive, empowering, and caring language. We received a wide range of nominations for this category, and the following three organisations were shortlisted for the award by a panel of people, of which 50% were Care Experienced.

St. Peter's Primary School, Renfrewshire Council (winner of the award)
St. Peter's Primary School have committed to creating a positive shift in language across their school. One example of this is changing their 'positive behaviour' policy

to ensure that nurture and wellbeing is at the core. Within this policy, there is a section on shared language, adapted from The Promise, to encourage all staff to use inclusive language which is preferred by Care Experienced people. This has helped to change the narrative within the school, with recent surveys issued to pupils showing that children feel included and nurtured within the school. St. Peter's Primary School also ring-fence spaces on their Pupil Council for Care Experienced pupils, to ensure their voices are heard when changing school policies.

East Dunbartonshire Health and Social Care Partnership

East Dunbartonshire's Health and Social Care Partnership have introduced a Language and Communication Group to understand the issues and concerns in terms of the language used across social work and wider services. They entered consultation with Care Experienced people, foster carers, and practitioners to gain further insight into preferred language and communication methods. Following this consultation, East Dunbartonshire's Health and Social Care Partnership recognised that rather than simply creating a list of what language should and should not be used, all practitioners need to take an inclusive approach and that every Care Experienced person may have different preferences. This consultation led to further changes in practice and policy relating to language and communication, including the embedding of life story work as common practice.

Police Scotland

Police Scotland are committed to changing the language they use when talking to, and about, Care Experienced people. They collaborated with Each and Every Child to deliver a Language and Stigma event to a wide range of officers, and are exploring delivering this at probationer stage going forward. Police Scotland have also taken feedback from relevant partners and Care Experienced people, and created a poster highlighting words and phrases which are stigmatising and offering alternatives. This poster has been shared across the organisation and is planned to appear in all Police buildings.

Should you wish to discuss the contents of this response, please contact:

Policy and Public Affairs Team, policy@whocaresscotland.org