

Changing THE WAY WE Care

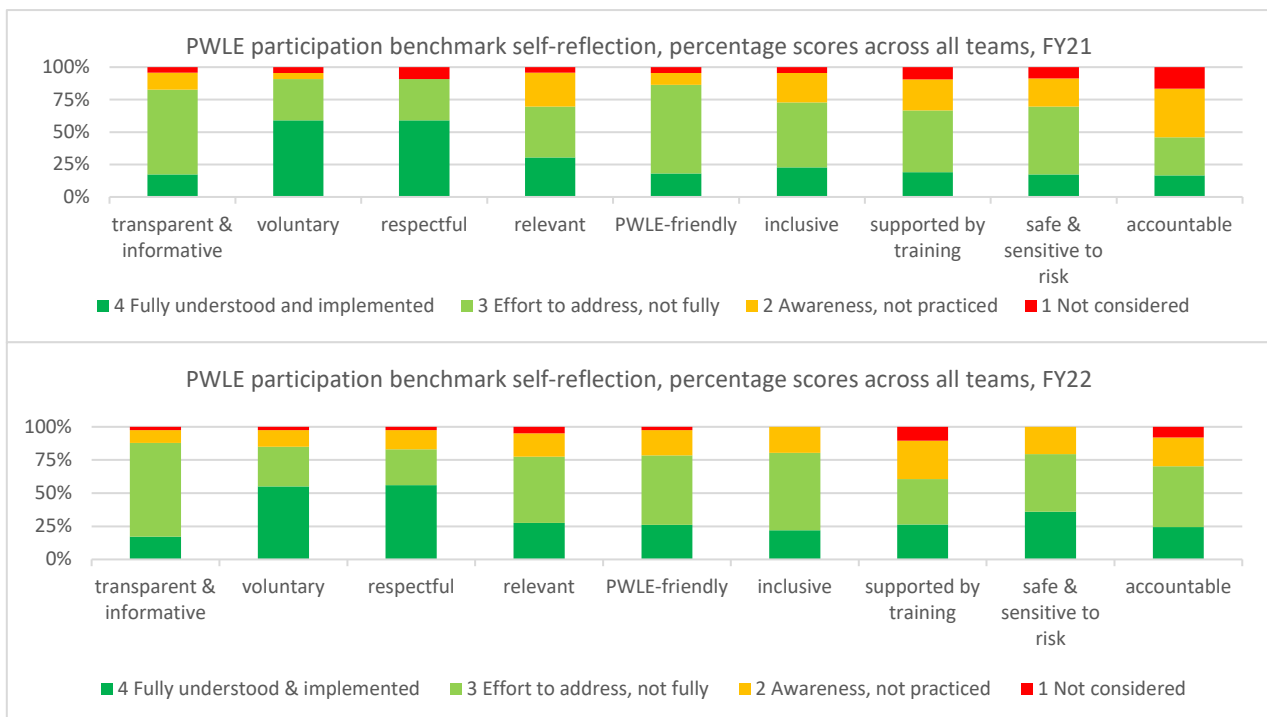
Learning Brief: Participation of people with lived experience

Introduction

Changing the Way We Care’s (CTWWC) first publication was, [How to Engage Care Leavers in Care Reform](#), produced shortly after the initiative’s inception and written by the Kenya Society of Care Leavers (KESCA). In 2020, CTWWC worked with people with lived experience on an initiative-wide strategy, *Putting the Voice, Influence and Participation of People with Lived Experience at the Center of Care Reform*, making a commitment to meaningful participation based on global best practice principles. Learning from dissemination and implementation of that strategy, in 2021, CTWWC added a cross-cutting result (IR) to measure our commitment: People with lived experience of care (children, youth, care leavers, caregivers) play an active role transforming care nationally, regionally and globally. The following brief summarizes what CTWWC is learning about meaningful participation of children, youth, young adults and caregivers with experience of care in care reform.

Bringing meaningful participation to care reform

When we pause and take stock, we are often surprised at how many ways children, young people and caregivers are participating in CTWWC and in wider care reform, but we also need to ask ourselves - is it always meaningful? In 2021 and 2022, CTWWC teams undertook a self-evaluation benchmarking our commitment to meaningful participation against the nine principles of participation outlined in the strategy: transparent and informative, voluntary, respectful, relevant, PWLE-friendly, inclusive, supported by training, safe and sensitive to risk and accountable. The graphs below show where CTWWC teams self-scored and how those ratings have changed between 2021 and 2022. The areas of strength are voluntary, respectful and safe/sensitive to risk, while the areas for continued growth are training, accountability and relevance.



Empowering people with lived experience as advocates

One of the outcomes that CTWWC is tracking around participation of people with lived experience is change in organizational capacity of youth/care leaver groups, associations and individuals that are supported in some way by the initiative. Evolving capacity is notable in groups across **Kenya** and **Guatemala**, whilst in **Moldova** a care leaver came forward wanting support to form a network. CTWWC solicited feedback from care leavers on participation in the initiative and opportunities to network and strengthen associations. Several described how this participation led to personal and professional growth in areas such as public speaking, presenting, research skills, and leadership skills.

In July 2022, CTWWC and Kenya's Department of Children's Services (DCS) in Kilifi County organized a county care leavers forum aimed at establishing a network. Forty-four care leavers participated. In September 2022, the newly formed Kilifi County Care Leavers Network (*pictured at the right*), with support from DCS and CTWWC, organized a follow-up meeting and determined that a legal entity should be established so the group could have stronger influence over the quality of services for care leavers and children in care.

KESCA has been a long-standing partner for CTWWC. Since 2018, the national association has grown and diversified in membership, bringing in new members from demonstration counties and beyond. In 2021, KESCA approached CTWWC to support them in developing a five-year strategic plan. In July 2022, 20 care leavers were involved in the first workshop to brainstorm the components of the strategic plan based on organizational strengths and weaknesses identified by a review that CTWWC supported and the opportunities that KESCA members see. The strategic plan is under development. KESCA was also successful, with CTWWC's support, in receiving funding to celebrate international youth day that was attended by 46 participants on 27th August.

Diversity of ways people participate

- Child and caregiver's involvement in case management and decision-making
- Care leaver networks of care leavers, both formal and informal
- Caregiver groups, formal and informal
- Advocacy and awareness-raising activities
- Government strategy and policy discussions and government working groups
- Visiting, training and supporting children and young people in residential care
- Regional and global working groups and taskforces
- Research, reflection and learning events
- Developing guidance, curricula, strategies, mappings and reflections



Word Cloud: What I gain from participation... in three words or less

On October 14, 2021, twelve care leavers from **Guatemala** gathered to officially launch the first network of care leavers, "*Unidos por el Cambio*" (United for Change), with the aim of advocating for family care, becoming spokespersons of care reform by sharing their experiences and promoting changes, and supporting other care leavers in learning to live independently. The group developed an annual activity plan and completed two training modules on the child protection system and the child rights. As part of strengthening this group the



Guatemalan National Council on Adoption (CNA) is providing *Unidos por el Cambio* office space for their monthly meetings. The picture to the left is from the launch event.

Young people and caregivers with lived experience have been part of the last two CTWWC annual reflections, providing their views and helping CTWWC learn and adapt. In Guatemala, one key takeaway from the reflection was that the network allows young care leavers opportunities for development, growth, empowerment and new learning in their lives. Speaking about the experience of working with young people to undertake a regional mapping of care leaver advocates and advocacy networks, a regional care leaver network leader reflected, *"I have a lot of tasks in my position, which is regional. It was the first time I worked with some of these youth. It really touched me how inspired they were to learn from others – sometimes all we have to do is little, but the impact (can be big). One of them described what the experience was like to learn and to listen – usually he would be talking about himself, and he appreciated the perspective he gained from listening. How they are able to move away from thinking only about their worlds... I really liked getting to see this."*

In their words

"Being part of the group has helped me to improve my life and to really be who I am. That it is the only place where I feel able to express myself and know that if I make a mistake they will guide me and not judge me." Guatemalan member of *Unidos por el Cambio*

"Because of the groups' role in care reform advocacy, people are more understanding, knowledgeable and see the need of children growing up in a family and not in an orphanage." Kenyan member of KESCA

"When I found out about the group, my way of thinking changed. Emotionally. I met other people. People like me. We have to believe in ourselves. How can we reach more young people?" Guatemalan member of *Unidos por el Cambio*

"The opportunities I have gotten to engage in (with) Changing the Way We Care through the various activities has been a game-changer. It has enabled me to network through participating in different forums and engaging with various stakeholders like (a global group) on parenting." Kenyan member of KESCA and parent

"I've really been thinking a lot about how activism can change the career trajectory (for many care leavers). Participation provides professional opportunities and ways to interact differently with the world." Argentinian member of Doncel

Building capacity for safe and meaningful participation

One of the significant learnings about participation of people with lived experience is that it requires time and attention to build the capacity of our own teams and others. Part of the annual reflection is the opportunity to review the participation strategy and brainstorm about different ways people with lived experience had participated in CTWWC activities. It has been important to discuss and reflect what support, information, training and feedback the initiative's teams need to improve participation practices beyond bringing "the voice" of care leavers into activities.



Learning from participation work, CTWWC is trying to ensure caregivers have participation opportunities. For example, in Kenya, work with organizations of people with disabilities has led to more engagement of caregivers, either with disabilities themselves or caring for children with disabilities, in the family care dialogue at the community level. This year, two meetings of a group of foster parents in Guatemala were held (*pictured on the prior page*). With the support of the Secretariat for Social Welfare and the National Council for Adoptions (CAN), these caregivers shared their passion for children, as well as the challenges they face in their role as foster carers. They have expressed a desire to form an independent association, but for now, they gather more as a support group for one another. Under the Transforming Children's Care Global Collaborative Platform, CTWWC has been facilitating the participation of a parent from Kenya in the *Taskforce on Parent Advocacy*, and a foster parent from

Uganda was supported to join a panel discussion on lived experience for the East and Southern Africa Regional Learning Platform. These are small examples, but CTWWC will be learning from them to ensure we can broaden participation work. Care leavers and caregivers, alike, provided their suggestions on addressing the barriers to participation (*see text box*).

Since 2018 and that first publication by care leavers, a number of resources have been developed, aimed at building capacity for meaningful participation. [Putting Children and Young People at the Heart of Care Reform](#) is an introductory manual aimed at practitioners. It provides a comprehensive overview of how to meaningfully engage children and young people in care reform. The [Participation and Advocacy Workshop Resources](#) are part of the Toolkit for Disability Inclusion in Care Reform and are designed to build the capacity and confidence of those working with children with disabilities and their families. In 2021, CTWWC designed a [household survey with child and adolescent defined well-being](#). We learned how working with children and families on research can be contextualized through participation. The research team could not identify existing measures of well-being tailored for children who had lived in residential care and to fill this gap, focus groups with children and young adults were conducted to inform a new measure of well-being relevant to them. It is these new learnings and small strides that CTWWC and our partners with lived experience grow in the confidence to take partnership even further.

Addressing the Barriers to Meaningful Participation *Recommendations from people with experience of care*

- Ensure inclusive, accessible and meaningful communication – including timing of meetings to accommodate work schedules, ensuring access to internet or phone data, supporting transportation costs and accommodations for differing abilities.
- Take care that information reaches new people and joining in networks and activities is open to all, or that participation is determined in fair and transparent ways. Help networks to ensure everyone gets to participate to the degree they want to and all voices have the chance to be heard.
- Understand caregiver schedules and family responsibilities and be creative in setting up meetings – including timing, providing child care or meals, supporting transportation costs, and accommodating different ways of participating (in person, virtual, hybrid).
- Address language barriers by providing interpretation by experienced interpreters familiar with the context and content. Help meeting / event participants to consider language barriers. Provide accommodations for the deaf and hard of hearing, and speech or language difference, such as sign-language interpretation and closed captioning.
- Identify point people within networks and systems for communicating, informing and activating and make sure they know their responsibility to communicate with or activate others.
- Consider the relevance of meetings, events, engagements for the person participating. Give consideration to the ways they desire to participate, their knowledge, experience or expertise, their capacity and needed support or facilitation to participate.
- Ensure everyone in the meeting, event or other activity understands the parameters for discussion, and that general safeguarding and safeguarding of stories is always respected.
- Provide capacity building and preparation opportunities so that those participating feel confident, supported and ready.
- Always follow up and give opportunities for feedback!

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