



PUTTING CHILD AND YOUTH PARTICIPATION AT THE HEART OF CARE REFORM:

AN INTRODUCTORY MANUAL
FOR PRACTITIONERS



CONTENTS

Acknowledgements	3	Co-design of new services	36
Foreword from self-advocates	4	Recruitment of staff within the new services	37
Glossary	6	Assessing and improving services	38
Introduction	8	Peer-to-peer support	39
What is Care Reform?	10	Mentoring	39
Legal framework for child participation	10	The role of children and young people driving care reform at local, national, and international levels	40
What do we mean by child and youth participation?	11	Training	40
Why is child and youth participation important?	13	Advocacy	42
Chapter 1 – Working with Children and Young People	16	Research	47
Laying the groundwork for safe and meaningful work with children and young people	17	Collaboration with other national and international child and youth networks	49
An ethical framework for child and youth participation	17	Chapter 3 – Keeping Children and Young People Safe	50
Expectations	19	The basics of child protection and safeguarding	51
Compensation and Remuneration for children and young people’s participation	20	Safe storytelling: Trauma-informed practice	53
Participation work in action	20	Practical considerations for keeping children and young people safe	55
Creating a safe space and strengthening motivation in group work	21	Consent	56
Finding your group	21	Keeping children and young people safe online	58
Supporting child and youth participants	21	Working with children and young people over the age of 18 in the same group	58
Motivation	21	Data protection	59
Ways of bringing together children and young people	22	Chapter 4 – Inclusive Participation	60
Adapting to emergency situations: Lessons from the COVID-19 pandemic	24	Meaningful inclusive participation	61
Budgeting for child and youth participation work	25	Practical examples of inclusive participation in care reform	62
The role of staff supporting participation	26	How to achieve disability inclusive practice: embracing the social model of disability	65
Background and skill set	27	Practical ways to make your work more inclusive	66
Training and support needs of participation leads and other professionals supporting participation	28	Appropriate support	68
Important considerations for increasing meaningful and inclusive participation across care reform	29	Accessible information	68
Sustainability	29	Meet Ben	69
Chapter 2 – Child and Youth Participation in Care Reform	30	Chapter 5 – Participatory Approaches for Monitoring and Evaluation	70
Supporting children and young people’s rights to be involved in their own care	31	Ethical monitoring and evaluation of children’s participation	72
Accessible information	32	Practical tools for monitoring and evaluation	72
Consultation and the decision-making process	32	Methods and tools for use with children and young people in monitoring and evaluation	73
Developing an individual care plan	32	Tools for use with adults	75
Preparing to move	33	Analysis and use of monitoring and evaluation data	75
Child-friendly case conferences and court hearings	35	Conclusion	77
Involving children and young people in local care reform	36	Annex – Additional resources	78

ACKNOWLEDGEMENTS

This manual was supported by Changing The Way We CareSM (CTWWC), a Global Development Alliance funded by USAID, the MacArthur Foundation and the GHR Foundation, and implemented by Catholic Relief Services and Maestral International, along with other global, national and local partners working together to change the way we care for children around the world. CTWWC’s principal global partners are the Better Care Network, Lumos Foundation, and Faith to Action.

Special thanks go to the children and young people who have contributed their expertise, experience and energy to this resource and driven forward the work it is based upon.

ABOUT LUMOS

Lumos is fighting for every child’s right to a family by transforming care systems around the world. We are an international charity striving for a future where every child is raised in a safe, loving home, supported by family to help them thrive.

On average more than 80% of children in orphanages have living parents or relatives, and research proves that these institutions can harm a child’s growth and development. Yet there are still an estimated 5.4 million children trapped in institutions globally.

Lumos sheds light on the root causes of family separation – poverty, conflict and discrimination – and demonstrates that children can safely be united with families. By pressing governments to reform care systems, and by building global expertise and capacity with partners, we ensure no child is forgotten.

Founded by author J.K. Rowling, we are lighting a path to a brighter future where all children can grow up in a safe and loving family.

We believe in a family for all children. We are Lumos.



ABOUT CTWCC

Born out of the MacArthur Foundation’s 100&Change competition, Changing the Way We CareSM was launched in October 2018 as a global initiative to solve one of the World’s greatest global issues – children growing up outside of family care.

Changing the Way We CareSM fundamental belief is that all children deserve to grow up in family homes rather than in residential care centres – sometimes referred to as “orphanages” – and this is possible no matter where the child lives or what his or her challenges may be. Since October 2018, we have been actively working to make this a reality.

Changing the Way We CareSM is funded by the MacArthur Foundation, the U.S. Agency for International Development (USAID), the GHR Foundation and other private donors. We work with national governments as well as other partners, including the Better Care Network and the Faith to Action Initiative. We collaborate closely with individuals, coalitions, NGOs, policy makers, country governments, and those who have aged out of residential care.



“I see my role as a self-advocate as being someone who can present children’s views on things to others. I have a chance to speak for other vulnerable children to increase awareness of the problems they have and the challenges they face.”

(Veronika, self-advocate, Czech Republic)

“Listen to what children and young people want to tell you. Observe what they do and how they react to different situations.”

“Help them to achieve their full potential, according to their needs and what they really can do.”

“Be kind with all children – they need love and understanding.”

“Do all things together.”

“Ask the child if he can or can’t do something.”

“Consult children’s opinions – they have a lot to say.”

(Self-advocates, Moldova)



© Lumos / Paco Anselmi

FOREWORD

“Children from institutions, especially those with disabilities, have limited rights and freedom to express themselves, their thoughts and feelings. If you are a child from an institution, probably you haven’t had the right to choose or decide for yourself. If you are a child with disability, you have even less opportunities to participate in your own life. I know that first-hand. Children should be active participants when adults make decisions about their lives. They need support so that everyone is included and recognised. If a child in care is not allowed to participate, to make choices, how do we expect that child to be an active citizen when they become a young person and leave social care? Every country and institution should have accessible ways of asking us and taking our opinions into consideration.”

(Mihaela, pictured left, a professional self-advocate from Bulgaria)

Children and young people have a right to participate in their own lives. It’s written in both national and international law. Participation is not just a right, it is also a powerful tool in care reform. When we respect children’s rights and make sure they are involved in decisions that affect them, things get better not only for the children and young people themselves, but for society as a whole.

From an early age, children should be supported to participate in their own lives. The way they participate should be adjusted to their needs and potential, and their involvement should shape their care in the most authentic and meaningful way possible.

Creating participation processes and genuine involvement in decision-making is complex. Meaningful participation must happen within the family, school, and wider society, and must be promoted and strengthened by different policies and practices. Participation is essential to children’s development, enabling them to become independent adults and active members of society. And so, participation underpins and builds democracy.

Unfortunately, this right is not respected for all children. Those who live without parental care, in alternative services, and those living with disabilities, are even more likely to find their rights violated. They have fewer opportunities to express their opinion and make decisions in their own lives. The systems they grow up in imprison them by making them dependent.

To truly reform the way we care for children – to prepare children to become independent, leaving services with the capacity to become active members of society – we must support and encourage participation, showing every individual that they have the power to shape their own life and the lives around them.

This manual is designed to facilitate, develop and encourage meaningful participation in alternative care and care reform settings around the world. For the benefit of children and young people, the communities around them, and for the future of our society.

As one self-advocate from Moldova puts it: “If you take our liberty, you take our responsibility as well.”

GLOSSARY

Alternative care: a formal or informal arrangement whereby a child is looked after outside the parental home. This may be a result of a decision by a judicial or administrative authority or other duly accredited body, or by the child, their parent(s) or primary caregivers, or another care provider. Forms of alternative care include residential institutions, foster care, kinship care and small group homes among others.

Best interests of the child: a concept derived from Article 3 of the United Nations Convention on the Rights of the Child (UNCRC)². Most simply, it refers to what is best for the child in question, as determined by a holistic assessment of their individual circumstances and needs.

Care leaver: a person who has left the care system. The term often refers to individuals who have left care at the legal adult age (18 in most countries), however the definition used in this document extends to include all children and adults who have spent time in any forms of public and/or private alternative care under the age of 18 – regardless of the placement type or duration.

Care leavers can face significant challenges upon leaving care and in later life. They can lack the protective support of families and personal networks, and may have had fewer opportunities than their peers to develop professional and life skills. They may also encounter social stigmas.

Caregiver: a person with whom a child lives, who provides daily care to the child, irrespective of whether they are their biological parent. A primary caregiver can be the mother or father, another family member such as a grandparent or older sibling, a foster parent, or a care worker. The term can extend to informal arrangements in which the caregiver does not have legal responsibility for the child.

Care reform: changes to systems and mechanisms that: promote and strengthen the capacity of families and communities to care for their children; address the care and protection needs of vulnerable or at-risk children to prevent separation from their families; and/or decrease reliance on residential care and promote reintegration of children, ensuring appropriate family-based alternative care options are available.

Care system: the legal and policy framework, structures and resources that determine and deliver alternative care.

Case worker: a professional who manages children's care plans. Depending on the context this could be a social worker or psychologist.

Deinstitutionalisation (DI): the process of closing residential care institutions and providing alternative family-based care and prevention services within the community.

Children and young people in care: children or young people who are living outside their biological families in institutions or other forms of residential and/or family-based alternative care. In line with the United Nations (UN) definitions for children and youth, our use of the term refers to children as aged 17 and under and young people as aged 18-24 years old³.

Child and youth participation: the empowerment of children and young people with lived experience to be decision-makers in their own lives, leaders in their communities, and to have a voice in policymaking. This requires a shift in power, and an acknowledgement of their important contributions.

For participation to be “**meaningful**”, participants must understand the purpose of their participation and the level of influence they can expect to have. They must be listened to and their ideas properly acted upon. Finally, they must receive adequate feedback and follow-up from their participation.

Conversely, “*tokenistic*” participation is participation that is superficial rather than meaningful, perhaps done as a “box-ticking exercise” where participants do not have substantial influence. Participation can be tokenistic when people with lived experience are involved only to share their personal stories – in fact this can even cause harm, as detailed in Chapter 3.

Family-based care: the short-term or long-term placement of a child in a nurturing family environment with at least one consistent parental caregiver, where children are part of supportive kin and community. Foster care, adoption and kinship care are forms of family-based care.

Peer-to-peer support: in the context of this report formal or informal arrangements in which people use their lived experiences to support one another. There are different types of peer support but all aim to bring together people with shared experiences; to provide a space for acceptance and understanding; to treat everyone's experiences as equally important; and involve both giving and receiving support.

Person/people with lived experience: in the context of this report, someone with personal experience of the care system, including children in different forms of alternative care, care-leavers, and parents or caregivers (such as foster or kinship carers) of a child who has experienced alternative care.

Re-traumatisation: when somebody is consciously or unconsciously reminded of a traumatic event, causing them to experience the same sensations and/or emotions felt at the time of the original incident.

Self-advocate: a person who draws on their lived experience to advocate for their own rights and the rights of their peers, or who does not have lived experience of care but advocates alongside peers who do.

The work of self-advocates may involve voicing the things that are important to them, and expressing their needs, wishes and feelings. Self-advocacy requires an understanding of rights, in particular the right to be involved in making decisions about one's own life.

Youth Advisory Boards (YABs): structures set up by Lumos in programme countries to support children and young people to actively and meaningfully participate in our work. YAB members go through a recruitment process and have a formal membership. They meet regularly to feed into different areas of Lumos' work, including development of policies and learning products. With Lumos' support, Youth Advisory Boards also pursue activities led by their own ideas and priorities.

Safeguarding: broadly, an organisation's approach in meeting their responsibility to keep people safe, including children, young people, vulnerable adults, and its own staff.

The values and protocols to be followed by an organisation's staff to meet this responsibility should be detailed in a safeguarding policy. Organisations that work directly with children, young people and at-risk adults should also have a designated safeguarding lead to advise colleagues on appropriate safeguarding practices and ensure the policy is adhered to.

INTRODUCTION

All children and young people have the right to grow up in a family environment and be included in the community. States are obliged to deliver services which prevent unnecessary separation and ensure families can provide adequate care. Where it is not possible for a child to live safely in his or her biological family, an alternative family-based care placement should be determined through an assessment of their best interests and individual needs.

Whether living with their biological families or in alternative care, all children and young people have the right to meaningfully participate in the decisions that affect their lives, including those around their care.

It is the responsibility of everyone working with children and young people to ensure this right is respected.

If you are reading this manual, it is likely that you already play an important role in protecting children and young people within and/or at risk of being in alternative care. Whether you are a social worker, psychologist, service provider, child participation lead, or a professional otherwise involved in care reform in your country, we hope to provide the inspiration,

principles, and practical tools for you to meaningfully engage children and young people in your work. When done well, the participation of those with lived experience can be transformative and can lead to more effective solutions which genuinely meet the needs of participants and their peers.

This manual was written by the international child and youth participation team at Lumos, based on their expertise of involving children and young people in care reform, alongside Lumos self-advocates – children and young people who advocate for their own rights and the rights of their peers – and with input from the work of Changing the Way We CareSM (CTWWC) and practitioners from the field. It documents lessons learned through Lumos' experience of child and youth participation during more than a decade working on childcare system transformation, and draws on the three years of work of CTWWC in Guatemala and Kenya. It provides practical examples and explains how approaches are underpinned by international legal and theoretical frameworks.

Lumos was founded by author J.K. Rowling in 2005 to light a path to a brighter future for children living in harmful orphanages and other institutions. By tackling the causes of family separation – poverty, abuse, domestic violence and disability discrimination – children can grow up in loving families where they can thrive and be supported to reach their full potential. For the past ten years, we have collaborated with children and young people with lived experience of institutional care, including those with disabilities, to inform our work and drive forward change together.

Changing The Way We CareSM (CTWWC), an initiative led by Catholic Relief Services and Maestral International, is promoting safe, nurturing family care for children reunifying from institutions or at risk of being separated from their families. CTWWC works in three demonstration countries – Guatemala, Kenya, and Moldova – to strengthen families and reform national systems of care for children through family reunification and reintegration and alternative family-based care.

THE DIFFERENT WAYS LUMOS WORKS WITH CHILDREN AND YOUNG PEOPLE

Providing support and services

Lumos works with children in alternative care services, including residential institutions, in schools, and with care leavers, supporting them to be involved in decisions that affect their lives and to prepare for independent living.

Supporting child and youth participation in care reform

Lumos promotes and supports the active participation of self-advocates in advocating for and implementing care reform. We work with children and young people at institutional, local, national, and global levels as self-advocates, co-trainers, researchers, evaluators, consultants, and experts.

Lumos' approach to working with children and young people has evolved over time – moving from primarily project and activity-based participation, to working with them as partners within the organisation. Lumos set up Youth Advisory Boards (YABs) in three of our European programmatic countries – Czech Republic, Bulgaria, and the Republic of Moldova. YABs were established to provide children and young people the platform to engage with one another and work with Lumos in a more collaborative way.

Over the years, several youth allies have also joined us in advocating for children's rights. While they do not have direct experience of alternative care themselves, they are passionate about the right of all children to grow up in safe and nurturing environments. Their contribution has enriched our work and enabled us to partner with more mainstream youth initiatives – increasing our reach.

We hope that learning about our experience and approach will help you develop a model of child and youth participation that meets the needs of both your organisation and the children and young people you work with.



WHAT IS CARE REFORM?

Readers of this manual are likely already involved in care reform in some capacity. For those new to the concept, care reform refers to the changes to the systems and mechanisms that:

- promote and strengthen the capacity of families and communities to care for their children
- address the care and protection needs of vulnerable or at-risk children to prevent separation from their families
- decrease reliance on residential care and promote reintegration of children and ensure appropriate family-based alternative care options are available.

Under the umbrella of care reform, deinstitutionalisation or 'DI' involves reunifying children in institutions with their families, through a planned process to promote healthy and sustainable reintegration, avoiding secondary separation or where this is not possible, developing good quality family-based alternative care services which meet their individual needs, such as foster care, kinship care, and guardianship.

Many intelligent and well-meaning organisations and individuals fund institutional care because they think they are helping at-risk children and young people. They are often completely unaware of the extensive and potentially irreparable harm this can cause to children's physical and cognitive development, social and emotional wellbeing, and long-term life chances.⁴ Advocacy and awareness-raising is therefore crucial in working to end child institutionalisation and unnecessary family separation. This work ensures valuable funds tied up in institutions are redirected to support children to thrive in families and communities.

LEGAL FRAMEWORK FOR CHILD PARTICIPATION

Every child's right to full and informed participation in decisions about their life is enshrined in international law. Article 12 of the UN Convention on the Rights of the Child (UNCRC)⁵ states that children have the right to express their views freely on all matters affecting them, and that these views should be given due consideration in line with their age and maturity.

Specifically, the right of children in – or with lived experience of – alternative care to participate in decisions that affect them and their peers is reaffirmed in the UN Guidelines on the Alternative Care of Children and the 2019 UN General Assembly Resolution on the Rights of the Child (focused on children without parental care). In the context of alternative care, the right to participation can mean anything from children choosing what they want to eat and who they want to be friends with, to deciding what type of placement they will live in.

The right to participate does not necessarily mean having the final decision, as ultimately important legal decisions must always be led by what is in the child's best interests. However, **it is always in the child's best interests to ask their opinion, to genuinely take this into consideration and to explain decisions and outcomes in accessible language.**

The UNCRC also states that children have the right to freedom of expression (Article 13) and to access information (Article 17), both vital principles of participation work. The rights set out in the Convention apply to every child without discrimination (Article 2).

Children with disabilities are provided further guarantees under Article 7 of the UN Convention on the Rights of Persons with Disabilities (UNCRPD),⁶ which states that they should receive support to fulfil their right to participation that is appropriate for their age and ability.

Although these rights exist in theory, far too often adults make decisions on behalf of children, without consulting them. For example, we have encountered caseworkers assessing where children in institutions should move to, based solely on their case notes, without ever meeting the child in person. Everyone working in global care reform, whether as a policymaker or as a direct care giver, must find ways to ensure that the right of all children and young people to actively participate in the decisions that affect them is fulfilled, both on an individual level and more widely in their community. This must be done in an inclusive and non-discriminatory way so that all children are able to participate regardless of their background.

WHAT DO WE MEAN BY CHILD AND YOUTH PARTICIPATION?

In our work we often find that people do not fully understand what child and youth participation really entails. This manual explores different forms of participation but, broadly, it means listening to children of all backgrounds, ages and evolving capacities

(including those with disabilities) and creating appropriate opportunities for them to express their opinions and receive feedback, ensuring that they can take an informed and active role in decision-making about their own lives and societies.

WHAT SELF-ADVOCATES SAY PARTICIPATION MEANS

“Involvement in what young people want, like and need, considering their potential and looking for their personal growth and development.”

“Direct involvement in decisions and issues that affect the young person.”

“To be active, to have the interest to change something in their own life, to be open to change and to get out from their comfort zone.”

“To have their say and to pay attention to each detail that is important in their life – this will help others to understand that not everything is like it's presented as first sight.”

“Participation means, when a child is moved to a different service, first to be informed, to be asked and consulted.”

“The voices of young people must be taken on board in decision-making processes, policy and legislative formulation and programming. We are the best communicators of our own needs. Nothing should be done or decided for us without us”.

(Self-advocates from Moldova and Kenya)

There is no 'one-size-fits-all' approach to participation. The approach you use will depend on the nature of the project, the needs, interests and expectations of the children and young people, and the experience of the professionals working with them. At Lumos, we employ three main approaches to working with children and young people, which were adapted from Hart's ladder of participation:⁷

- **Consultation** – where adults ask for children and young people's opinions to help them make decisions. For example, when developing a new policy, the opinions of children and young people are often sought through focus group discussions or questionnaires. The policy is then written by adults, who take into account different considerations including the young people's ideas.
- **Collaboration or co-production** – where children and young people work together as equal partners with adults and can influence the decision-making process. For example, children and young people might be involved in co-designing a service which they and their peers will use.
- **Child or youth-led participation** – where children and young people make decisions and lead their own projects with adults supporting if necessary. For example, young people might organise their own awareness raising campaign or research project.

Different participation approaches can be used at different stages of the project cycle. There are many ways that children and young people can initiate and lead their own work, but in our experience, it can be challenging to aim for child-led participation, for example when developing a complex organisational strategy. Whichever approach you take, it is vital that child and youth participants are aware of the level of influence they will have from the beginning to manage expectations.

An important lesson we have learned is that the process of participation can be more important than the outcomes – this is particularly true for children and young people who have had limited opportunities to express their views and make decisions in the past.

“We are not invisible anymore but recognised and respected.”

(Self-advocate, Bulgaria)

WHY IS CHILD AND YOUTH PARTICIPATION IMPORTANT?

Care reform involves many different stakeholders – politicians and policymakers, donors, caseworkers, parents and caregivers and other family members, and NGOs to name a few. It is easy to lose sight of the children and young people, who should be at the centre of everything we do. Child and youth participation brings a range of benefits which can contribute to successful care transformation and ultimately leads to better outcomes for all.

Our participation work aims to help transform the perception of children and young people from 'beneficiaries' to active participants in their own lives and genuine partners in care reform. Other potential benefits for children and young people can include:

- Greater awareness of their own rights to a family life, to be included in the community, and to have a say in decision-making.
- Increased confidence and self-esteem.
- Improved communication skills.
- Better preparedness to become independent adults.
- Opportunities to express opinions, be heard, and have their views taken seriously in decision-making; for some of the young people we support this is an entirely new experience.
- Development of new life and employment skills that increase prospects for further studying or paid employment.
- Increased knowledge of how to protect themselves and others from abuse.
- Potential opportunities to travel (in their home country or abroad) and to learn about other cultures.
- A sense of achievement from influencing change and improving conditions for other children.
- Development of positive relationships with peers with similar experiences and staff who genuinely care about them – this can lead to life-long friendships which help young people feel more hopeful, stronger, and free.

- Improved mental wellbeing – although participation is not therapeutic work, many children and young people find that talking through issues and shared experiences helps them process their own history and find positivity in the challenges they've faced.



Benefits to the family can include:

- Improved parenting capacity and promotion of children's individual development and autonomy.
- Enhanced family relations.
- Opportunities for children's socialisation and development of social connections.



Benefits to the wider community can include:

- Children are supported to claim their fundamental rights and play an active part in civil society.
- Improved service design resulting in better outcomes for children and families.
- Better inclusion and reduced stigma – children and young people with experience of institutional care, particularly those with disabilities, are among the most marginalised in society. Working in partnership with them, promoting their visibility and abilities can help catalyse greater inclusion in society and reduce stigma.
- Greater recognition and prioritisation of children's rights and issues.
- Better decision-making and engagement with communities, professionals, staff of services, and local authorities.
- More understanding of and trust in the child protection system, services, and workers in this area.



Benefits to care reform can include:

- New services, campaigns, or projects are more successful and child friendly.
- Stakeholders are more receptive to messaging when it comes from children and young people.
- More authentic advocacy activities.
- Unique and vital expertise shared by people with lived experience helps improve the design of services and practices.



Benefits to organisations, professionals, and policymakers:

- Better-designed policies and more impactful and cost-efficient services.
- Perspectives offered by children and young people are creative and give a different understanding of challenges.
- Enhanced organisational authenticity, credibility, and reputation.
- Greater accountability to the children, young people, and communities the organisation supports.
- Fulfils obligations under international legal frameworks (including Article 12 of the UNCRC).

- Increased job satisfaction for facilitators – many stakeholders working in care reform are far removed from the children and young people they serve. By working together with them, staff will have a better understanding of the impact they are making, which can serve as a powerful reward and increase motivation.
- More effective policies and practices, better tailored to the needs of children and young people. Co-developing policies and services with those who will actually use them helps ensure they are relevant and informed by what people actually want and need. This leads to increased effectiveness and better cost efficiency.
- Improved communication and collaboration between service providers or policymakers and children and young people.
- Better understanding of the importance and practicalities of participation, which can create a legacy that extends beyond the care transformation process.
- Opportunities for mutual learning and development for both children and adults.
- Better understanding of the harm of separation from family and institutionalisation.
- Opportunities for mutual learning and development for both children and adults.
- Better understanding of the harm of separation from family and institutionalisation – those making policies and decisions, and developing and implementing services, have a better understanding of the impact of institutionalisation and family separation, through listening to the voices of those with lived experience.
- Meaningful participation can be attractive to donors.

“Nothing beats experience, and certainly not the experience of young people who grew up in care. As we join other world leaders and experts to put an end to the institutionalisation of children, there is no key ASK greater than “Nothing about us without us”. Involvement and participation of children and care leavers in care reform should be at the core, not just through storytelling but all through from policy design, formulation to evaluation. We are experts through experience – you know policy, we know practice!”

Ruth, Kenyan self-advocate

Young people on how they have personally benefitted from participation

“What has changed for me is that I can communicate better, not arguing, but listening to others’ opinions and discuss[ing them]. I’m not afraid to meet people and express my opinion.”

(Pavel, self-advocate, Czech Republic)

“I became more independent, brave to fight for my rights, more active in different life situations, and ready to help my peers.”

(Self-advocate, Bulgaria)

“Lumos offered me a life experience, supported me to gain more self-confidence and to learn how to overcome the difficulties in life.”

(Olga, self-advocate, Moldova)

An example of how we as an organisation have benefitted from participation

By listening to a care leaver from Kenya we learned first-hand how institutions often fail to meet children’s cultural and identity needs. As a young boy he was placed in an orphanage in Nairobi, far away from

the village where he was born. When he returned as a teenager, he had forgotten his native language and could no longer communicate with his family or community. This is just one individual example of how participation continually enriches and strengthens our knowledge about children’s experiences and must then be used to improve programming.

CHAPTER 1



WORKING WITH CHILDREN AND YOUNG PEOPLE

The potential for child and youth participation in care reform is vast, ranging from co-designing services to youth advocacy. Chapter two goes into detail about the different ways children and young people can be engaged, whereas this chapter focuses on the basics of working with children and young people, including the practical things to consider. It is not exhaustive, but we hope it will help you lay the foundations for safe and effective participation work with children and young people. When applying these methods, it is important to adapt where necessary, based on the cultural context, age and needs of the group you are working with.

LAYING THE GROUNDWORK FOR SAFE AND MEANINGFUL WORK WITH CHILDREN AND YOUNG PEOPLE

An ethical framework for child and youth participation

We strongly recommend implementing a set of overarching principles for how you work with children and young people. Having principles provides an ethical framework which underpins participation work and forms a basis for monitoring and evaluation. The United Nations Committee on the Rights of the Child developed standardised principles which you might adopt. They are:

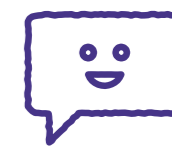
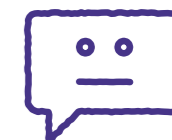
Transparent and informative – children and young people must be provided with full, accessible, diversity sensitive and age-appropriate information about their right to express their views freely, how the participation will take place, its scope, purpose and potential impact.

Voluntary – children and young people should never be coerced into expressing views against their wishes and they should be informed that they can cease involvement at any stage.

Respectful – children and young people's views must be treated with respect and they should be provided with opportunities to initiate ideas and activities. Adults working with children and youth should acknowledge, respect and build on good examples of children's participation, for instance, in their contributions to the family, school, culture and the work environment. They also need an understanding of the socioeconomic, environmental and cultural context of children and young people's lives. People and organisations working for and with children should also respect children's views about participation in public events.

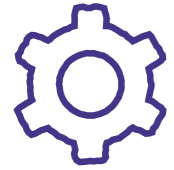
Relevant – the issues on which children are invited to express their views should be of real relevance to their lives, so they can draw on their knowledge, skills and abilities. Space also needs to be created to enable children to highlight and address the issues they themselves identify as relevant and important.

Child and youth-friendly – environments and working methods should be adapted to children's capacities. Adequate time and resources should be made available to ensure that children and young people are prepared and have the confidence and opportunity to contribute their views. Consideration needs to be given to the fact that children will need differing levels of support and forms of involvement according to their age and evolving capacities.





Inclusive – participation must be inclusive, avoid existing patterns of discrimination (based on gender, nationality, language, disability, age, family background, etc.), and encourage opportunities for marginalised children including all genders to be involved. Children and youth are not a homogenous group and participation needs to provide for equality of opportunity for all, without discrimination on any grounds. Programmes also need to ensure that they are culturally sensitive to children and young people from all communities.



Supported by training – adults need preparation, skills and support to facilitate children and young people’s participation effectively, to provide them, for example, with skills in listening, working jointly with children and engaging children effectively in accordance with their evolving capacities. Children and young people themselves can be involved as trainers and facilitators on how to promote effective participation; they require capacity-building to strengthen their skills in, for example, effective participation and awareness of their rights, and training in organising meetings, raising funds, dealing with the media, public speaking and advocacy.



Safe and sensitive to risk – in certain situations, expression of views may involve risks. Adults have a responsibility towards the children and young people they work with and must take every precaution to minimise the risk to children of violence, exploitation or any other negative consequence of their participation. It’s crucial to develop a clear child protection strategy, which recognises the particular risks faced by some groups of children, and the extra barriers they face in obtaining help. Children must be aware of their right to be protected from harm and know where to go for help if needed.



Accountable – a commitment to follow-up and evaluation is essential. For example, in any research or consultative process, children must be informed as to how their views have been interpreted and used and, where necessary, provided with the opportunity to challenge and influence the analysis of the findings. Children are also entitled to be provided with clear feedback on how their participation has influenced any outcomes. Wherever appropriate, children should be given the opportunity to participate in follow-up processes or activities. Monitoring and evaluation of children’s participation needs to be undertaken, where possible, with children themselves.⁸

At Lumos we decided to develop our own principles in partnership with children and young people, however they are similar to those set out by the United Nations.

When done well, participation in care reform can be a positive and empowering experience, but it is crucial that this work is safe, respects everyone’s rights and does not risk re-traumatisation. Children and young people who have experienced family separation and institutionalisation have often experienced significant trauma, which can make them more susceptible to certain types of harm. We have dedicated a whole chapter to safeguarding considerations because there are many. From protecting children from violence and abuse, to obtaining and storing children and young people’s data, to organising residential events, there are multiple safeguarding and health and safety obligations that need to be carefully planned for. It is essential to have a robust safeguarding/child protection policy and procedures in place before you start working directly with children, young people and at-risk adults. All staff, volunteers and project partners who work directly with children, young people and at-risk adults must understand and sign the safeguarding policy and follow the outlined procedures to ensure appropriate responses to any safeguarding concerns that arise. Background checks must also be undertaken for all staff who have direct contact with children, young people, and at-risk adults before they start work.

Tokenistic vs meaningful participation

When children and young people meaningfully participate, both they and the organisation benefit from the process. The experiences of children and young people are complex and diverse, and it is important that this is reflected in the way their stories, opinions and ideas are communicated by the organisations working with them. Children and young people should be recognised as valuable contributors whose views and voices are genuinely considered. Organisations should take care to not cherry-pick stories or ideas that they think fit what the audience wants to hear.

“Tokenistic participation is false participation, without the direct involvement of a child or young person. This happens when the adult dictates to the child or young person what to do, without taking into consideration their point of view or/and interests. Meaningful participation is when children and young people’s participation is treated seriously and decisions are made by them both.”

(Self-advocate, Moldova)

EXPECTATIONS

When children and young people with lived experience are meaningfully engaged, it is clear how much wisdom and insight they have. However, it is important to remember that they are not professionals and are not working for us. They often have busy and complicated lives outside their work with us, so we need to manage our own expectations and adapt our working practices when seeking to engage children and young people. This includes planning work so that we do not place pressure on young people to meet unrealistic deadlines. The main priority in any piece of work involving children and young people is their safety and wellbeing, not the completion of the project. Children and young people must never be seen as a tool for achieving the goals of our organisations.

As our participation work has progressed, the young people we support have received many requests, from within our organisation and external partners to consult and collaborate. Most are completely well-meaning, but we need to continually assess the benefits of participation for children and young people and ensure it is in line with their interests and priorities. As an organisation, you need to be honest about your expectations of children and young people, and consider what your activities offer them. At the same time, it is important to be transparent in this process and to avoid favouritism to ensure attractive participation opportunities are fairly distributed across the group of children and young people you work with.

COMPENSATION AND REMUNERATION FOR CHILDREN AND YOUNG PEOPLE'S PARTICIPATION

Children and young people who participate in our programmes do so on a voluntary basis according to their own interests, however they should never be out of pocket due to their participation. It is vital that their expenses are factored into project plans and budgets. These can include safe transport, refreshments and data for the internet. It may not be possible for them to pay for these things and be reimbursed, therefore you may need to think ahead of how to provide necessary expenses.

There are also specific instances where we ask them to participate in order to meet our organisation's needs. This may include:

- sitting on interview panels for staff recruitment
- delivering training or workshops
- consultancy on initiatives, strategies, documents, projects, etc.
- editing materials.

We believe participation in these situations meets a threshold for financial remuneration. Organisations should also keep in mind that young people may be missing out on other paid work to participate.

Remuneration is not always straightforward. It is important to be aware of local child employment laws, to check whether the payment will create

tax implications for young people, and to identify any other risk factors that could be associated with remuneration. Where possible and if preferred by the young people, organisations may look to explore alternative forms of remuneration such as vouchers or scholarships. Despite the potential complexity, remuneration is a crucial part of valuing the skills and rich perspectives that people with lived experience bring to our work. It can also offer young people paid experience in purposeful work.

There are often concerns that paying young people can influence their contributions, become the main motivation for their participation or create competition between young people. Developing a policy to determine where remuneration is appropriate and how young people are selected to participate in paid activities can help address this by providing transparency and avoiding favouritism.

PARTICIPATION WORK IN ACTION

Children and young people may participate as individuals or as part of a group. Groups may already exist, for example a school class or residents of a small group home or may be established with the support of professionals or an organisation – sometimes as a result of initiatives by children and young people who want to work together. Creating participation groups is an effective way to engage children and young people in care reform.

Working as a group can give children and young people a sense of belonging, enabling them to pool their knowledge and skills to tackle more complex problems than they could on their own, share diverse perspectives, give and receive social support, and establish a shared identity with other members of the group. Groups might be established to accomplish tasks or activities within a specific project, or as longer-term structures working on a broader range of activities over time (for example, Lumos' YABs).

CREATING A SAFE SPACE AND STRENGTHENING MOTIVATION IN GROUP WORK

Child and youth participation work is voluntary and extracurricular. To keep participants motivated, the programme must be engaging and fun. We advise using a range of activities such as group work, discussions, workshops, conferences, field trips and camps, and making sure you have plenty of energising games and warm-ups prepared.

FINDING YOUR GROUP

When establishing groups, we recommend identifying children and young people with lived experience of alternative care by visiting services such as schools, children's homes or support groups for foster carers, and introducing yourself and the project. Sharing child-friendly information sheets and online advertisements through relevant networks and on social media is also an effective way of finding members. Once the group is up and running it will often get new members through word of mouth. Diversity strengthens participation by ensuring a range of perspectives and experiences are represented and it is important to ensure groups are fully inclusive in terms of age, gender, ethnicity, disability, faith, sexual orientation and identity.

SUPPORTING CHILD AND YOUTH PARTICIPANTS

Children and young people can be influential agents of change in care reform; however, they are likely to need a great deal of support. Self-advocates have often experienced significant trauma in their lives and may continue to struggle with challenges such as low self-esteem, in addition to practical challenges such as managing finances once they are living independently. Staff should be receptive to their emotional wellbeing, providing pastoral support and, where needed, helping them to access medical or professional support. Signposting to other services such as legal support, careers advice and other opportunities may also be helpful.

To facilitate their meaningful participation, children and young people may require significant encouragement and clear explanations of how their participation can make impact. All adults working with them will need to have clear and realistic expectations of the children and young people. Mutual working agreements make this easier, although it is important to be flexible and make allowances if young people have other important things going on in their life.

There should never be pressure on young people to share their personal stories, even if they have done so in the past.

Children and young people should always be given the training and support they need to participate in projects with confidence; this needs to be factored into planning and budget processes. Support should reflect the needs of the group, promoting an inclusive approach and avoiding participation being dominated by the most confident and articulate children and young people. You should also consider the benefits of participating for the young person, and continuously check that you are not falling into the trap of using young people to fulfil your own agenda, which can be done with the best of intentions. As discussed in chapter one, there are projects where financial remuneration is appropriate for the level of engagement and expertise provided by young people. Finally, the importance of having fun together should not be underestimated.

MOTIVATION

When participants join the group, it is helpful to find out their motivations and what they want to achieve. This can be done informally and can be written into an individual plan for each young person. Having a plan makes it easier to review what the young person has achieved and if their expectations have been met. It is helpful to have a review process (eg, quarterly or annually) with each participant to track the success of their participation from a personal and organisational perspective and identify areas in which the programme can be developed to better meet their needs. It also helps the young person reflect on what they have worked on over the year and the impact it has made.

Regularly dedicating specific time to each young person ensures that we understand their skills, interests, and support needs. It also shows them they are valued as an individual, which can be an important part of building trust. Professionals supporting participation will find it helpful to have regular individual check-ins with young people, particularly if they are having a difficult time.

Having a dedicated staff member overseeing child and youth participation work can help ensure that participation is meaningful. They should receive support from the wider team and have access to necessary information and training on child and youth participation.



WAYS OF BRINGING TOGETHER CHILDREN AND YOUNG PEOPLE

There are a range of ways you can bring children and young people together. These include one-off events, regular meetups, or multiple-day events such as residential camps.

Regular meetings

Regular meetings can happen for a couple of hours after school, or perhaps a half-day during weekends or school holidays. It is important to ask children and young people when it is convenient for them to meet and any times to avoid. For example, we never schedule meetings during exam periods. We try to keep meetings informal and fun. You could use your office, but we recommend thinking about the arrangement of the room to avoid meetings feeling too formal. Using a youth centre or other child-friendly space where possible is ideal.

Things to consider:

- Health and Safety – does it meet local health and safety standards? Is it appropriate for children and young people? Will anyone else be using the building while you are there?
- Accessibility – will the venue meet the needs of the group, especially those with disabilities?
- Location and transport – is it a convenient location for participants? How will they get there? Is it close to public transport links or will this need to be arranged?
- Comfort of the meeting room – is there adequate light and ventilation? Is there a separate space if anyone needs some privacy?
- Suitability of the space – is it a child/youth friendly space? Will you need breakout space for group work? Is there enough room to move around and play games? Access to outside space is particularly helpful, especially in warm weather.
- Food – this is important. Whenever we meet with children and young people, we always provide food and soft drinks – asking them what they like and making sure we cater for dietary requirements. Not only is this an incentive but eating together creates a sense of community.
- Programme of activities – does the programme consider the needs and abilities of all participants?

Having an agenda ensures meetings have purpose and structure. Agendas should be sent to participants ahead of the meeting. At the same time, we recommend that participants be involved in designing the agenda to help ensure all important issues are covered.

When forming new groups, it is important for the children and young people to set ground rules that they will stick to during their work together. These should be child-led and often include respecting each other's opinion, giving everyone the opportunity to participate and keeping sensitive information confidential. This activity can be done easily by asking children and young people to write or draw ground rules on post-it notes and stick them to flip chart paper if you have it. It is helpful to keep the ground rules somewhere visible during sessions.

Initial meetings should also include several 'getting to know you' activities and team building exercises. The role of facilitator is extremely important, particularly in the early stages, to ensure everyone has a role and feels included. We recommend trying to stick to agreed timings, building in sufficient time for questions and discussion, and ensuring enough breaks, taking into account the ages and any additional needs of those in the group. If planning an all-day meeting, it is often helpful to tackle the most demanding and important subjects in the morning and do something more creative and interactive in the afternoon.

Although we ask young people to commit when they join, all meetings are voluntary. This can bring challenges around attendance, punctuality, and motivation. While this can be frustrating, it is important to remember that they are children and young people, with full and often complicated lives. Often their work with us will not be their main priority, which we need to understand. However, building a sense of belonging, community and purpose can increase children and young people's commitment to the group.

Things to consider

- Young people often have multiple commitments, including studying, clubs, and jobs, so they may not be able to attend every meeting. We encourage you to keep everybody informed by preparing a short summary of what was discussed at each meeting that can be shared with participants and anybody who could not attend.
- It is helpful to be aware of school exam periods and avoid planning big projects around these times – this is particularly pertinent in light of the impact of the COVID-19 pandemic on academic calendars.
- It is important to ensure planned activities are not prohibitively long or demanding and respect children's right to play and leisure.
- We also avoid organising anything during school time, instead meeting during evenings, weekends and school holidays. Occasionally, an important opportunity will take place during school time. In these circumstances, formal consent will be needed from both the child's legal guardian and their school.



Multi-day meetings

Residential, multi-day meetings are useful for team building, strategising and getting through larger pieces of work that cannot be completed in a one-day session. They provide time to discuss topics in greater detail and offer training to build children and young people's skills to participate more effectively. Useful topics for training include presentation and communication skills, advocacy and film making.

Residential meetings are often popular with young people and can be an incentive or reward for their engagement. At Lumos we aim to have two residential meetings per year at the national level and one at the global level. While there are particular safeguards to consider for these (see Chapter 3 for more detail), residential meetings are often where deeper friendships are formed and the team is strengthened, creating a greater sense of purpose. This often happens outside the formal sessions, so it is important to factor in free time and fun activities such as cooking together, games, sports, campfires, and karaoke. Providing a relaxed space with board games can be helpful for young people who prefer quieter activities or for those who feel tired after sessions.

ADAPTING TO EMERGENCY SITUATIONS: LESSONS FROM THE COVID-19 PANDEMIC

Lumos' participation work safely continued during the COVID-19 pandemic, demonstrating that participation is possible during emergency situations. Staff were available to support the children, young people and their families when needed and the following adjustments were made:

- The health and wellbeing of self-advocates was the priority for Lumos during the pandemic. All activities were adapted to ensure they met with government restrictions. Most face-to-face activities were cancelled or postponed and online platforms such as Zoom, Skype, Google Meet, Teams, or social media channels were used instead.
- Participation staff, in collaboration with other stakeholders, provided accessible information about staying safe, practical, and psycho-social support. Financial and material support was also provided to young people at increased risk.

- Due to challenges with meeting online in large groups, many activities shifted to an individual and small group basis.

Examples of activities undertaken by self-advocates during the pandemic:

- Attending virtual meetings to discuss the impact of COVID-19, create a sense of normality and share ideas on how to spend time during lockdowns in a fun and meaningful way.
- Taking part in activities to acquire new skills and knowledge, such as online English classes.
- Creating advocacy materials related to COVID-19 to highlight the impact of the pandemic on children in alternative care and care leavers, and what support they need.
- Developing and distributing materials to help their peers understand how to stay safe. For example, short videos on social distancing and how to wash your hands properly were made by young people with intellectual disabilities for their peers in small group homes.
- Adapting planned activities such as training for caseworkers and judges, by self-advocates. This was originally postponed, but then took place online.
- Organising social media campaigns and challenges between self-advocates and their peers.
- Reintroducing face-to-face meetings when restrictions were eased, ensuring a comprehensive risk assessment was carried out and rigorous safety procedures were put in place.



© Lumos

BUDGETING FOR CHILD AND YOUTH PARTICIPATION WORK

Budgets can be tight in many organisations and participation is not always prioritised. You may need to do some internal advocacy to help senior leaders understand the benefits of meaningfully engaging children and young people, so that it is not seen as a luxury or 'nice add-on' but as an integral part of the organisation's work.

Meaningful engagement is often attractive to donors, so depending on the nature of your organisation, it may be possible to fundraise for participation or build it into other funding proposals. You may also be able to collaborate with other organisations working on participation or tap into existing structures or spaces, such as care leaver networks and youth conferences.

Potential costs and resources related to participation:

- Staffing. We strongly recommend that you have a dedicated lead for participation. If this is not possible, you could include participation projects or activities in the job descriptions and work plans of staff who work directly with children and young people.
- Venue costs for meetings.
- Food and travel costs for participants and staff.
- Creative materials such as paints, balls, or games.
- Cameras or tablets. If you want to promote child-led creative content and budget is available, these tools can be a worthwhile investment.
- Equipment hire. For residential meetings you may need to hire additional equipment or pay for activities or trainers.

- Translation. International participation work will often require professional interpretation and translation for meetings and documents. If children and young people cannot understand what is going on or communicate effectively, meaningful participation is impossible.
- Supervision. You will need to factor in extra staffing costs as children and young people need constant supervision. Some children with disabilities will require additional support.

Where budgets for participation are proving prohibitive, you may wish to consider whether there are any existing youth networks, clubs, partner organisations or local government projects with which you can collaborate. Working together can be both cost effective and help create a greater collective impact.

Lessons learned: There will be often be unforeseen costs related to participation. For example, at one of our youth forums there was a problem with the water supply at the venue for 48 hours. For health and safety reasons, we had to order in food, bottled water and plenty of hand sanitiser. We also had to pay another hotel to let our group of 30 take a shower. For any activity you organise with children and young people, try to plan some extra funds for emergency situations.

THE ROLE OF STAFF SUPPORTING PARTICIPATION

Safe and effective participation work requires skilled facilitation. As mentioned above, this could be led by somebody whose job is focused on this, or who does it alongside their other tasks. Every Lumos office has a dedicated Child and Youth Participation Officer who leads the participation work in that country. This will not be possible for all organisations, but whatever your model, we strongly recommend that you have a dedicated lead for participation.

The role of participation leads is varied and will probably include:

- working directly with children and young people
- setting up and coordinating groups and meetings
- supporting children and young people to lead their own projects
- creating child-friendly documents
- running workshops and focus group discussions
- acting as the bridge between the children and young people and the wider organisation, ensuring good communication between the two
- making children and young people aware of opportunities to participate in projects, activities or events, and working with them to decide whether and how they want to be involved
- working with colleagues to identify opportunities for increased participation across the organisation
- providing support to the children and young people, including signposting to other services where necessary
- responding to safeguarding concerns, in line with the organisation's safeguarding policy.

LUMOS EXAMPLE – SUPPORTING HIGH-LEVEL INFLUENCING

Lumos and Changing the Way We Care supports children and young people to engage in high-level policy discussions at the United Nations and the European Union. Child and Youth Participation staff are responsible for preparing self-advocates to participate, ensuring their involvement is safe and meaningful, and accompanying them as chaperones if they need to travel away from home. Additional responsibilities for chaperones and supporting staff are detailed in the safeguarding chapter.



Raising awareness of the importance of participation, and improving participation practice, are also important aspects of the role, particularly as it increases the impact of our work and makes it more sustainable. This can be done in a number of ways, for example:

- Our participation leads train and support direct care providers on how to involve children and young people in decision-making, particularly children with disabilities that affect their communication. They also train policymakers and caseworkers on the importance of child-centred practice.
- Participation leads partner with mainstream youth organisations to increase opportunities to participate for children and young people with experience of alternative care, including those with disabilities. For example, in Bulgaria, Lumos Child and Youth Participation Officers supported a self-advocate to become the first young person with an intellectual disability to be a member of the national youth parliament, spreading the message of inclusion and community-based care to an untapped audience.

BACKGROUND AND SKILL SET

Participation leads can come from a range of different training and backgrounds – for example, Lumos' Child and Youth Participation team includes professionals with backgrounds in education, psychology, drama therapy and social work. Participation work is varied, requiring staff who are flexible, creative, and most importantly, skilled at working with children and young people.

We asked young people to describe what makes someone well-suited to work on child and youth participation. They said:

“Supporting adults should respect and value the opinion of each child. They should have very strong sensitivity towards children and act in such a way that children trust them. They need to be a good listener and able to create a cosy and friendly atmosphere, to be full of energy and creativity and use ordinary language without any jargon.”

“They need to have an open mind, be patient, supportive, honest, informed, not to pretend, to help children find the solutions and let them make mistakes. They should also be amusing and sometimes flexible.”

Other important skills and qualities include:

- strong understanding of participation and its importance
- empathic and able to communicate sensitively and effectively with diverse groups of children and young people
- capable of responding well in a crisis
- strong understanding of how to keep children and young people safe and how to respond to safeguarding concerns
- conscious of maintaining boundaries
- excellent organisation and coordination skills
- good understanding of group dynamics and strong group facilitation skills
- ability to think strategically and help the group plan the direction of their work
- commitment to children's rights, inclusion and the mission of the organisation
- ability to communicate with a range of stakeholders, both professional and non-professional
- reflective and capable of monitoring and evaluating their own work and the progress of members of the group
- creative, fun and does not take themselves too seriously.

If advocacy is part of your organisation's work, it may be helpful for the participation lead to have advocacy experience as this is an area in which child and youth participation can create a big impact. Because advocacy is such a strong focus of Lumos' participation we provide advocacy training for staff supporting young people to become self-advocates. Alternatively, the participation lead could work together with advocacy experts within their organisation to ensure the participation work is informed by expertise in this area. The same is true for other kinds of specialist work, such as research or communications.

TRAINING AND SUPPORT NEEDS OF PARTICIPATION LEADS AND OTHER PROFESSIONALS SUPPORTING PARTICIPATION

The participation lead's role can be complex and their duties will include assessing, mitigating and managing risk. There are a number of areas in which training is essential:

- It is crucial that they undertake advanced safeguarding training so they can confidently respond to a range of safeguarding issues. Sometimes, while working with us, children and young people open up about abuse or other situations which indicate that they are or have been at risk, so participation leads need to know what to do.
- Staff involved in participation should be trained in health and safety and know how to conduct thorough risk assessments.
- Basic data protection training is also essential, as they will be involved in obtaining and processing sensitive information about children and young people as part of their role.

There are a number of other areas in which training can be valuable. These will depend on the background and skills of the practitioners, the type of work your organisation does, and the needs of the children and young people you work with. Those skills may help when doing direct participation and, at the same time, could be shared directly with children and young people involved in your programmes. Some of these areas might include:

- Training on trauma-informed practice, psychological first aid, and resilience building can be valuable, so participation leads know how to support children and young people to share their stories in a safe and empowering way (see Chapter 3 for more information on trauma-informed practice). At Lumos, participation leads receive training on this led by care leavers from the UK.
- First aid training.
- Monitoring and evaluation training, to ensure the effectiveness of participation work, is also crucial, so additional training or support may be required.
- Public speaking, storytelling and facilitation.
- Project and time management.
- Fundraising and outreach.
- Advocacy and influencing.

You may find experts within your own organisation who are able to provide training, or alternatively you may need to find experts or trainers from external organisations and partners.

Supervision is important for all practitioners working with at-risk children, young people and adults. Positive supervision involves regular meetings between the practitioner and a senior colleague where they discuss their work and reflect on their practice, and through this they develop both personally and professionally. It also helps them process any challenging situations they have encountered in their work, such as supporting a young person during a mental health crisis or responding to a disclosure of abuse which the young person shares due to the relationship of trust they have with the practitioner.

IMPORTANT CONSIDERATIONS FOR INCREASING MEANINGFUL AND INCLUSIVE PARTICIPATION ACROSS CARE REFORM

Sustainability

The following chapter illustrates the many ways that children and young people can and should be included at all stages of care reform. However, to increase the breadth of engagement and make it sustainable requires a significant shift, both in thinking and ways of working. People in power need to be convinced of the benefits of working *with* children and young people, not just *for* them; and they must be willing to share power.

Meaningful participation requires buy-in from stakeholders at all levels (within the services, in families, at local/national and international level, etc.), and changes in working practices. It needs to be factored in from the beginning of project cycles, not as an afterthought. This may require staff to develop their knowledge and skills, so they understand what meaningful participation is and how to do it well. In our experience, the key to scaling up the approach and ensuring sustainability has been: 1) convincing influential people of the importance of participation, and then 2) training the people who will be delivering the work. To be sustainable, it must become a fundamental way of working, rather than a time-limited project.

Supporting children and young people to create their own initiatives ensures that the participation is being driven by them and will continue once a project or programme finishes. The Kenya Society of Care leavers (KESCA)⁹ is an excellent example of a care leaver-led initiative, whose members are now key actors in care reform, both at the national and global level. KESCA was set up by care leavers, for care leavers. Their mission is to promote the wellbeing of care leavers and advocate for the rights of institutionalised children. They strive to enhance the social and psychological coping mechanisms of young people who have left residential care and create supportive networks for the young adults to achieve better life outcomes.

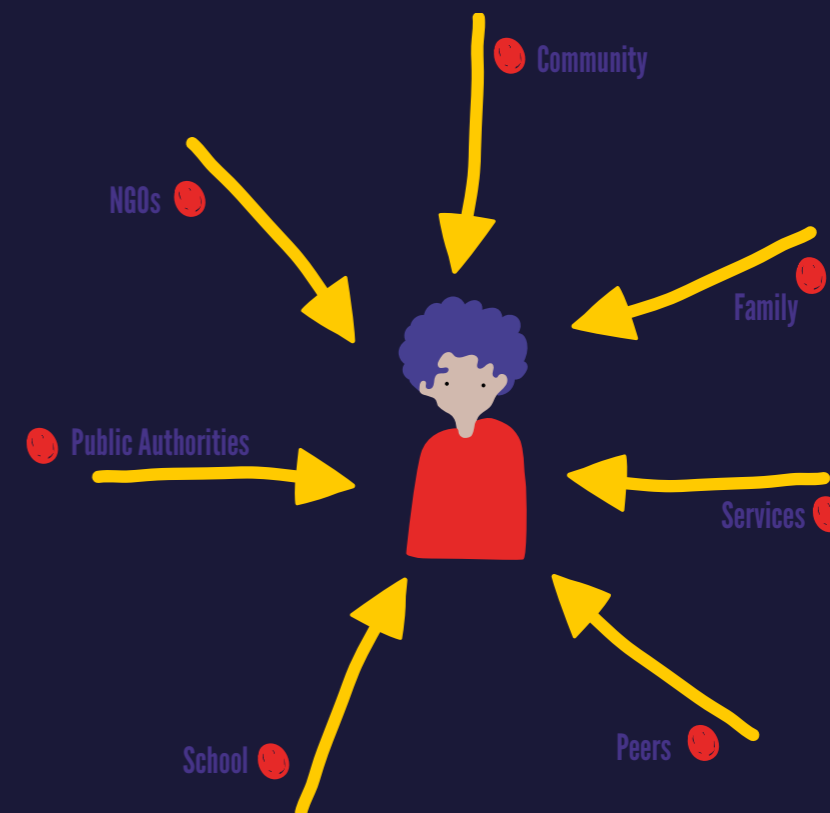
CHAPTER 2



CHILD AND YOUTH PARTICIPATION IN CARE REFORM

This chapter identifies the important ways children and young people should be involved in care reform, helping to transform the perception of children and youth from 'beneficiaries' to active participants in their own care, and change makers in the care reform process.

The first section explores how those stakeholders directly responsible for care reform (government staff, service providers, programmatic partners, family and community actors) should involve children and young people in all stages of the process – from advocacy, to shaping their individual care plans and designing new services.



All too often, care systems function as one-way systems with stakeholders failing to consult the children and young people they work for or to consider their individual perspectives and needs. Meaningful participation aims to reverse this trend and ensure the right of children and young people to participate in decisions around their care.

SUPPORTING CHILDREN AND YOUNG PEOPLE'S RIGHTS TO BE INVOLVED IN THEIR OWN CARE

The importance of participation in child-centred case management

Child-centred case management refers to the process whereby an allocated caseworker (or other trained professional) works with a child, their family, caregivers, and any other stakeholders in their care, to develop, deliver and monitor a holistic plan tailored to their individual care and protection needs. Child-centred case management is key to safely supporting children and families throughout the transition from institutional care to family and community-based care.

Child-centred case management is, in itself, participatory. The process is key to developing a child's individual strengths and protective factors and can help caseworkers and participation staff understand their individual circumstances and how they might want to participate, and plan the additional support they might require to do so. Participation leads should liaise with responsible caseworkers and the child to ensure these needs are met and the child can meaningfully participate.

Changing the Way We Care has developed a helpful package of guidance and tools to support remote case management and virtual monitoring during the COVID-19 pandemic and other circumstances in which in-person case management is not possible.¹⁰

ACCESSIBLE INFORMATION

Changes to children and young people's living situations and caregivers can be frightening and confusing. Even if they are unhappy in an institution, moving out often causes deep anxiety. Children and young people should be informed about all decisions that will affect them, in a way that is appropriate for their age, understanding and needs. For example, explaining through drawing or play can help younger children understand better than just talking to them.

Adults often withhold information from children to protect them. However, the overwhelming consensus from the children and young people we work with is that they want as much honest and detailed information as possible, and to be updated as often and as soon as possible when things are going to change.

Adults should think carefully about how they deliver news, being sensitive that it may cause anxiety or distress. They should explain why and how decisions were made, in appropriate detail for their age, maturity and understanding. Sufficient time for the child or young person to ask questions should be factored in. It is likely that children and young people will need time to process big news, so there should be follow up with them and they should know who they can go to with questions or concerns – ideally an allocated caseworker. Family members should also be involved in these discussions wherever appropriate.

CONSULTATION AND THE DECISION-MAKING PROCESS

Wherever possible, children and young people must be actively included in decisions about their care. They need an allocated caseworker who is consistent throughout the transition process and has enough time to build a relationship with them. Building trust is extremely important. It is not always easy to achieve but a good place to start is for caseworkers to make time to get to know the child or young person – to find out what they like and do not like, what their hopes and fears are. Lumos has several resources to help guide these conversations. Moving to My New Home¹¹ is an interactive tool to help children and the adults supporting them to navigate their transition from institutions to their new placement, whether that is back home to their birth family or to an alternative placement. There are two versions of this book, one for 8- to 16-year-olds and another for younger children.

Children and young people have the right to be asked how they feel, what they want to happen and what support they need. This is known as expressing their wishes and feelings. This does not mean that everything they want will necessarily happen, as all decisions are ultimately determined by what is considered to be in their best interests, but they must be listened to and their views considered and responded to by the adults making decisions about their care. During this process, children and young people should be informed that they may not get everything they ask for, to avoid unrealistic expectations. Decisions should also be explained in an understandable way, especially if it goes against the child or young person's wishes and feelings.

This process of listening to children and explaining what will happen helps build children's trust in those responsible for their care and can help ease their anxiety about what will happen next.

DEVELOPING AN INDIVIDUAL CARE PLAN

Whether reintegrating with their biological families, moving to an alternative family-based care placement, or transitioning to independent living, all children and young people preparing to leave institutions need an individual care plan. The care plan should be explained to them in an age-appropriate way – they should understand the purpose of the plan, how it will be used and who it will be shared with. Children and young people should be involved in developing the plan, together with their caseworker and other relevant stakeholders. The plan should be holistic, covering their health, social, educational and emotional needs. Many children and young people with experience of out-of-home care say that they did not feel in control of their life or what was happening to them. By involving them in their care plan as much as possible, children and young people will have greater sense of ownership over the plan and hopefully feel more in control of what is happening to them.¹²

PREPARING TO MOVE

Helping children and young people prepare to move is a critical part of the care reform process.

Timing is very important; unless the child is in immediate danger, they should never be moved suddenly. However, a lengthy process can create additional anxiety. Once it has been decided where the child or young person will move to – whether it is back home to birth family or to an alternative service – they should get the opportunity to visit and meet the people they will be living with, before they move. Their caseworker or another supportive adult should go on this visit with them and help them plan any questions they want to ask beforehand.

It can be really helpful for new primary carers (foster, kinship, adoptive) or alternative services to produce child-friendly information for children ahead of their move, to reduce anxiety by helping them understand what to expect.¹³

It is also helpful for new caregivers to receive information about the child so they can understand their likes and needs. Involving the child in preparing this information for their caregivers can be part of their preparation to move; this is particularly helpful for younger children and children with disabilities, and could involve drawing, writing, or making a video.

AMILCAR'S* STORY, GUATEMALA

When he was six months old, Amilcar was admitted to a residential care facility because his father was imprisoned. During the first assessments, it was not possible to locate another member of Amilcar's biological or extended family, so he was placed in the residential care facility. However, a psychosocial team from Changing the Way We Care took over the case and were able to identify extended family.

The team identified Amilcar's aunt, Guillermina, who was determined to be an appropriate care option for Amilcar, although they had not seen one another for a long time. This was a concern, as having a bond or attachment with a child is important. Following the case management methodology, a plan was made to prepare Guillermina and Amilcar for reunification. The psychologist worked with each of them on ways to promote affective bonding. The social worker managed weekly visits to residential care between Amilcar and Guillermina and constant video calls so Amilcar could get a sense of the environment that awaited him. After two months of preparation, the team observed trust and bonding between them, and the legal procedures started for the reunification.

Amilcar's case was followed up for two years, including regular home visits. The case plan was informed by benchmarks set to track their path towards successful reintegration. Amilcar still lives with Guillermina today. His case was closed because both developed an affectionate bond and a secure attachment.

* Names have been changed to protect identities.

Communication passports, also known as one-page profiles, are a powerful tool for children with disabilities to communicate information about themselves, including their likes, dislikes, and support needs. They are produced with children and young people, alongside their caregivers or other relevant specialists. When a child or young person doesn't speak, communication passports can be informed by observations and speaking to the people who know them best. They can help new caregivers to prepare for their arrival and plan how they will meet their individual needs.

Peer-to-peer support can also be valuable for children who are moving out of institutions, for example through building supportive networks between children still in institutions and those who have already left.

In Moldova, Lumos runs a successful peer-support programme which was initiated by care leavers and young people in alternative care. Most were already members of the Lumos Moldova YAB. The young people visit institutions due to close to offer friendship and support to children who are preparing to move. They talk to those children about their concerns, the challenges they might face, what to expect, and explain what support is available. They also do fun activities together.

Another crucial part of preparing children and young people to move is helping them say goodbye, to staff, other children, and the place they have been living in. This can include taking photographs, having a message book, or getting people to sign a T-shirt. Having a party or a meal together can also be a nice way to mark the end of a chapter in someone's life. Again, even if their experience in the institution has been traumatic, the child or young person will often have mixed emotions about leaving, so it is important to support them during this transition.

Staff may need to help the child with their packing and should allow them to take a memento or special object with them, such as a favourite toy. Having a

familiar object can help them as they settle into their new placement. For babies and some children with disabilities, smell can be important, so taking bedding or objects with familiar smells with the child to their new home can be very helpful.

Follow-up is crucial when a child moves to a new placement. The child or young person's caseworker should visit as soon as possible, taking into account national legislation, to check how the child is doing and listen to their concerns. There will often be teething

In the Czech Republic, Lumos supported children with disabilities as they moved from a large residential institution to community-based care. Training was provided to the children's new caregivers on working with children with complex needs. The training covered how to include children in decision-making and how to help them adjust to their new home. The new caregiving staff also received the children's communication passports prior to their move so that they could understand more about the individual children's needs, strengths and interests. All children moved with a 'suitcase of security' – a suitcase containing things to support their transition, such as a photo album, a toy they were familiar with, a new toy, a mug or other souvenir from the institution, and a notebook with messages from their friends. Wherever possible, the children were involved in choosing what went into the suitcase.

problems in the early stages of a placement, which the caseworker should help resolve.

Close monitoring, alongside the caseworkers/care givers, of the child or young person who has recently moved is extremely important and should continue until the child and their caregivers have adapted to the child's new living situation. Continuing to facilitate peer-to-peer support and providing any additional support and information the child needs can have a significant impact on how they adapt to their new home.

THE STORY OF THE MARTÍNEZ BROTHERS*, GUATEMALA

The Martínez brothers entered residential care in April 2019, due to neglect by their father. Their mother was also unable to care for them due to historic neglect and suspicions of child trafficking. In August 2019, the Changing the Way We Care psychosocial team identified a maternal uncle who was willing to take care of the siblings. The team prepared the brothers to leave residential care by organising visits to the residential centre by the uncle and his family. The preparation time was not very long or complicated because the brothers and the uncle already had a bond. By November 2019, the boys were reunified with their uncle.

The follow-up process began with weekly home visits to the uncle's house to monitor how the family was adjusting and support the implementation of the care plan. After two months, only bi-monthly follow-up visits were needed. During visits, positive

parenting practices were used to support the family to adjust to having two new members. Practical and financial support were also provided to enable the uncle to start a small chicken farm, greatly increasing the family's income.

After two years of follow-up, a case conference was held with the psychosocial team, the uncle, and the siblings to determine if everyone considered the placement to be a success. All agreed that it was a safe, stable and nurturing environment and steps were made to officially close the case. As part of this closure, the psychosocial team ensured that the brothers had opportunities to voice their opinions in private as well as in front of their uncle. Community resources – such as people and groups – were also identified as places that could offer support if needed in the future.

* Names have been changed to protect identities.

Child-friendly case conferences and court hearings

Children and young people should be involved in case conferences and other meetings about their care. These should always be conducted in a way that is appropriate for their age and ability, and that they are comfortable with. For example, they may wish to attend the meeting in person, or they may prefer to write or draw something to explain to people making decisions about their care how they feel and what they want.

In the Czech Republic, Lumos Youth Advisory Board has partnered with the Judicial Academy – the national body responsible for training judges. The aim of the partnership is to improve children's participation within family court processes, with a specific focus on children in institutions, those in foster care and those affected by parental conflict.

The YAB was approached by the Judicial Academy to advise them on how to make family courts more accessible for children and what judges should do to ensure children feel heard. In addition to providing their own advice, the YAB members also co-facilitated focus groups with wider groups of children and young people affected by family court processes. Their recommendations included:

- Understanding the importance of feeling valued – it is vital that children feel that the court has a genuine interest in their opinions. Communication does not need to be perfect, as long as it feels authentic and sincere.
- Making time to listen to children, which helps judges to see the situation through their eyes. It helps them understand their feelings and how the situation affects them.
- Allowing children to speak directly to judges who make important decisions about their lives – this is critically important. Things that help make children feel more comfortable when talking to judges and other professionals include having a child-friendly space, and being spoken to in simple language, in a warm manner. They also said the judge's appearance can affect how open they feel, with a preference for less formal attire.
- Having a consistent person to guide them through the whole process, in a way that is understandable for them. And enabling them to ask questions and give their feedback.

Feedback from judges participating in the project:

“I have to say that what we have heard from the young people assured me that the new way we want to train and educate judges towards child and youth participation is the right one. There were moments during the discussion when the young people’s thoughts shifted my thinking a bit further and I could understand them better.”

Judge Jana Zapletalová Koláčková

As a result of this partnership, the Judicial Academy are establishing their own child and youth advisory board.

INVOLVING CHILDREN AND YOUNG PEOPLE IN LOCAL CARE REFORM

Co-design of new services

Children and young people with experience of care should be involved in designing and assessing the services which replace institutions, such as family support services, community resource centres, foster care and small group homes.

They are well-placed to determine the kinds of support they and their peers require and how it can be delivered. They can advise on the type of services and support needed. For example, older children and young people often need support to develop independent living skills, such as cooking, managing finances, and accessing employment or further education. They may prefer this support to be delivered by a skilled youth worker, rather than a professional caseworker. Young people can advise on whether they would prefer to go to a youth centre for these sessions in a group, or for the worker to meet them individually in their home, or a combination of both. The important thing is to not assume what children and young people need; if asked directly they can help develop relevant and useful solutions. Being involved in designing services can also improve their trust in services and staff working there, increasing the likelihood they will take up the support on offer.

The crucial part of involving children and young people in designing new services is that it happens from the beginning of the planning process when all options are still on the table. Consulting them later, when the service is already designed, is far less meaningful.

Service co-design can begin by creating an advisory group, or holding focus groups, workshops and consultations with children and young people. It is easy to overlook younger children and those with intellectual disabilities when co-designing services, but when given the right support they can make valuable contributions. They may require individual consultations or may use art or play to express their ideas.

“The child or young person may come with a different perspective, from the inside; what they expect from the service, what it should look like and what it should provide.”

“It is important that people who will benefit from the services are involved in designing it.”

(Self-advocates, Moldova)

In 2017, Lumos began the process of developing services for care leavers in Moldova to support them in their transitions to adulthood. Previously, when children in care reached the age of 18, they often left the system with very little support. A number of focus groups and consultations with care leavers were held to identify the care leavers’ needs and involve them in determining what services were required to ensure their needs were met. The groups also recommended the types of specialists who should work in the services and how to make the services youth-friendly and accessible.

Once the new services were developed, the young people that used them were involved in assessing the impact of the services and helping to improve them.

RECRUITMENT OF STAFF WITHIN THE NEW SERVICES

Staff working in services for children and young people play an important role in the lives of those they serve. It is therefore important that children and young people are involved in staff recruitment. This can be done in various ways:

- Children and young people can feed into the job description and person specification. It is likely that they will be looking for different attributes than adults.
- Children and young people can be involved in interview panels – either by having a separate youth panel or by having one or two young people on the main panel.
- Candidates could be asked to complete an exercise set by children and young people. Examples might include writing a child-friendly letter of motivation for the role, which can be reviewed and scored by the children and young people, or asking them to deliver a brief workshop or presentation to the children and young people.

Involving children and young people in staff recruitment sets a precedent for their important role in decision making, which new staff will see before they join. Children are perceptive and can usually identify if staff will be able to build a good rapport with children and young people. It also increases children

and young people’s sense of control over their care. This is particularly important in residential care, where staff will have a great deal of input in the children’s lives and may even provide personal care. Being involved in staff recruitment also identifies the background checks required for carers, which can increase children and young people’s confidence in the staff and systems responsible for their care.

Self-advocates from Moldova shared their views on recruitment:

“Involvement of children in staff recruitment is important, but you have to take care of few key moments: to prepare them by informing them about the position and the requirements of the role; to take into consideration the previous experience of the child with possible candidates (for example if they already know the candidate from a residential institution). Having someone independent to facilitate this process will help the children feel free to share their views.”

(Self-advocate, Moldova)

During the care reform process in Moldova, small group homes were established for children whose best interests could not be met in a family setting. In one institution which was closing, staff could apply to be redeployed to work in a new small group home. Children from the institution were involved in selecting which staff would work in the new services. Due to the sensitivity around this, questionnaires were developed to ensure children could share their opinion on specific candidates, anonymously, without fear of repercussion. The children’s feedback formed an important part of staff selection. In one case a carer did not score as highly with the adult interview panel but had excellent feedback from the children. She was hired on the basis of the children’s recommendation and continues to work successfully in the small group home today.

ASSESSING AND IMPROVING SERVICES

Children and young people can also be involved in monitoring and evaluating services and play an important part in improving them.

In Bulgaria in 2017, a national assessment of small group homes was conducted to determine whether the quality of care and outcomes for children and young people with disabilities had improved since they moved from large residential institutions. As part of this process, Lumos self-advocates (both with and without intellectual disabilities) decided to undertake their own assessment of the small group homes. With support from participation staff, they created and administered a questionnaire for different people they felt could provide them with useful information. They processed 211 completed questionnaires, visited small group homes to talk directly with their peers and met with professionals in the social sector.

The self-advocates shared their findings and recommendations with politicians directly responsible for social care. These included:

“Children do not meet with their family often. How to strengthen the relationship? This can be done in two directions – the child can visit the family, and parents or relatives can visit the child.”

“Parents should be informed about the child’s good results and trigger the parents’ interest towards the child, so they start meeting more regularly: during vacations, holidays, weekends.”

“Movement and play make us healthy! There are children who stay in bed. They do not move enough! Therefore, we suggest they have morning exercises in the small group homes, even if simple ones.”

“Children have a GP and they are well, but the dentists’ offices should be improved because not every child can be treated in a typical dentist’s office”.

(Self-advocates, Bulgaria)

Children and young people should be involved in improving the residential and non-residential services they use. For example, children in small group homes should have regular opportunities to feed back on the service they are receiving, through questionnaires, group feedback sessions or individual consultations. There should also be procedures for children to make complaints, compliments or other feedback to a professional outside the service. Informal discussions, regular house meetings, catch-ups with key workers and suggestion boxes can create a culture of listening to children within services.

PEER-TO-PEER SUPPORT

Peer-to-peer support fosters a supportive relationship between two or more people who have had similar experiences or face similar challenges. Children and young people are often more receptive to ideas and advice presented by peers than if those same ideas were presented to them by adults. Lumos facilitates peer-to-peer support between care leavers, children still in care and children and young people with disabilities, with an emphasis on supporting children and young people through periods of transition such as moving to a new home or learning to live independently. Topics covered by peer-to-peer support should be led by the children and young people, based on the challenges and opportunities arising in the young person’s life. This may include developing communication skills, conflict management, interpersonal relationships or managing money.

Formal peer-to-peer support should be facilitated by an adult, whose role is to ensure that the peers are trained in providing this kind of support and feel confident in their role. They will provide the framework for the peer-to-peer support and ensure everyone is aware of what to expect. As with any participation staff, facilitators need background checks and regular supervision sessions to ensure they are suitable to work with children. They will also need to undertake safeguarding training and understand how to report safeguarding concerns.

In Moldova, members of the Lumos youth advisory board provided peer-to-peer support to children in institutions and foster care. One of them said,

“This is a beneficial experience for both participants – those who attend and those who organise. Children and young people are more open to their peers than to adults. We are a real example, and children and young people who attend our workshops are inspired by us and they can see that changes can happen.”

(Self-advocate, Moldova).

In Uganda and Kenya, care leavers have established WhatsApp groups to provide informal peer-to-peer support. The groups are led by care leavers to communicate, spread information about services or resources as well as provide psychosocial support to one another.

MENTORING

Mentoring is a form of one-to-one peer support. The mentor shares their own experiences and knowledge to support the mentee as they grow and develop.

In Moldova, the development of inclusive education has been instrumental in reducing the number of children with disabilities in institutions. But the prospect of starting at a community-based school was daunting at first for many children who had previously been denied the right to be educated alongside their peers within their communities. To support these children and provide more cohesion within the school, a mentoring programme was developed, particularly for children with complex needs. The mentoring focused on the needs and interests of both parties, but often included help with schoolwork, activities to promote independence, or fun free time activities that develop confidence and build relationships. Mentors have also supported their peers to create communication passports which present essential information about each child in an easy-to-read format.

THE ROLE OF CHILDREN AND YOUNG PEOPLE DRIVING CARE REFORM AT LOCAL, NATIONAL, AND INTERNATIONAL LEVELS

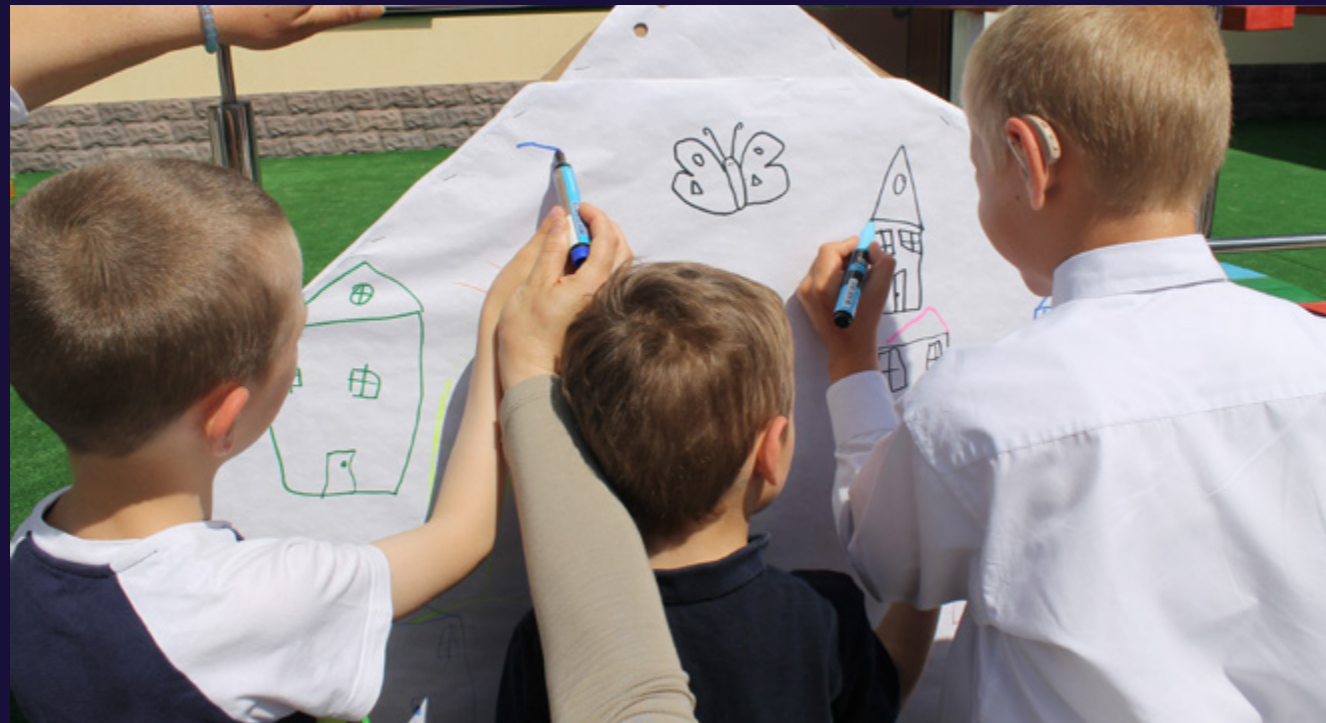
TRAINING

Care reform involves a complete shift in approach to caring for children and young people, and training is an important part of changing practice. In their work with Lumos, young people have participated in delivering training sessions to a wide range of stakeholders including caseworkers, staff of small group homes, foster carers, and public authorities. Session topics are tailored to the specific audiences and depend on the focus of the training programmes: child and youth participation; preparation to leave the services; decision-making processes; involvement of children/young people in developing the services, etc.

Involving children and young people in training is crucial to changing the culture around participation – promoting the value of listening to them and developing solutions with them, rather than just for them. If they are comfortable sharing their experiences, children and young people with lived experience can provide insight into what it feels like to be separated from your family, to live in an institution and to change placements. They also generally make training more authentic, engaging and fun.

There are a number of ways that children and young people can be involved in training, for example:

- design of the programme and content of training sessions
- planning of exercises and creating tools
- leading and co-delivering training sessions
- evaluation of the training session after it has finished: how the audience received the information and what else to discuss and improve in subsequent sessions (methods used, language, terms, etc.); what other actions need to be developed when working with professionals, what kind of impact such sessions may produce, etc.



The way that children and young people are involved will depend on their age, interests, and abilities. For example, it would not be appropriate to have young children delivering an in-person workshop. However, you could include videos of them sharing their opinions or include their drawings or poems. You can also include younger children and those with complex disabilities in designing content for training, by asking them specific questions based on the topic and target audience. For example – what should case workers take into consideration when they decide where children will live? What advice would you give them? It is important that older, more confident young people do not dominate opportunities to participate. Training, support and intentionally seeking diverse groups will increase participation among less experienced children and young people, including those from marginalised groups.

A self-advocate from Moldova who participated in a training event said:

“The first time I participated in a training for specialists, it was a very emotional experience. It was a new experience for me. It’s good that young people can give advice to specialists on what to do better and what to avoid. We are more credible because we have a lot of experience in alternative care services.”

In Bulgaria, young people with intellectual disabilities co-facilitated nationwide training for local authorities and professionals from different fields on children’s participation in the care reform process. During their workshops, they directed questions to the adult participants which were chosen to provoke discussions on topics important to young people. These included:

“At what stage of care reform process do you think it is important to involve children?”

“What do adults need to know to make children’s participation meaningful?”

“How can we develop policies that can be understood by children and young people?”

During the training they also shared their own experiences and those of their peers in small group homes. They also disseminated books, practice materials and videos they had produced.

Working with young people with intellectual disabilities in this way, and giving them platforms from which to influence, showcases their capabilities and helps reduce stigma.

Participation groups in Haiti were also involved in training on positive parenting. The aim of the training was to strengthen families’ capacity in order to prevent separation. Self-advocates co-facilitated the training session alongside Lumos staff. They shared their experience of institutional care with parents, for them to understand the reality of orphanages and the impact they can have on children and young people.

There are a number of things to consider when involving children and young people in training. It is crucial that they receive their own training in advance – this is sometimes known as ‘training the trainer.’ They will also need support to prepare for each session. It can be helpful to buddy up more experienced trainers with those with less experience, making sure the less experienced trainer has opportunities to input and contribute.

We have encountered hostility towards some youth trainers from adult participants who are not ready to view them as equal partners. This requires careful facilitation to protect the young trainer while not taking over if this would be disempowering for them. Having detailed debriefs with young trainers can help facilitators understand what children and young people need in such situations and how they can enable them to develop their strengths and identify areas to develop strategies for dealing with challenging participants.

TOOLS FOR CHILD AND YOUTH PARTICIPATION

As well as delivering training, children and young people can develop practical tools on how to increase their role in different aspects of care reform. These can be completely youth led or developed in partnership with adults. Changing the Way We Care and the Kenyan Society of Care Leavers have developed an excellent tool showing practical ways to increase care leavers’ engagement in care reform.¹⁴

ADVOCACY

Helping donors, decision-makers and other key stakeholders understand the harms caused by institutionalisation, and what changes are needed, is key to ensuring effective care reform strategies. Children and young people with lived experience can and should play a central role in local, national, and global-level advocacy and campaigning.

“We are here to ask you, you, who are decision-makers, please, the resources that are used at global levels to support institutions, could you think about them? They could be better used when they are channelled to families, to help to strengthen family units and to support young people in families, and also young people who don’t have families. To help young people to acquire the skills and knowledge they need to live a productive life.”

“In the world today, we’re often looked at as objects to be traded, but we’re not objects, we are human beings, and just like everyone, we want to have a future.”

(Self-advocate from Colombia)

For children and young people to be effective self-advocates, they should be supported to develop their understanding of the national and global care reform context, so they can be clear about their position and the things they want to advocate for. This can be done through:

- training
- workshops
- discussions

- study visits for self-advocates to different types of social and educational services
- attending conferences
- peer-to-peer exchanges.

It is important to remember that children and young people are advocating for themselves, not for an organisation, even if that organisation is offering significant support. Therefore, it is crucial not to push an agenda onto them, rather support them to develop their own beliefs and priorities.



© Lumos

Global example: In 2018, Lumos brought together self-advocates from eight countries at a global conference in Brussels to advocate for a change in how the European Commission prioritised funding for children and families. The aim of the conference was to determine how the Commission might cease funding institutional systems and instead fund family and community-based services and support. At the opening of the conference the self-advocates presented a set of recommendations they had developed together. These included:



“Money should not go to institutions but to support families to be able to take care of their children – more families, no institutions!”

“Prevent children ever entering institutions, especially babies and children with disabilities.”

“STOP THE BUSINESS OF INSTITUTIONS.”

Later in the conference one of the self-advocates who has an intellectual disability said:

“Every child has the right to a family. It’s so simple.”

“There is no way a hundred children in one house can become a family. One hundred kids together is not a family! Even 20 kids is not.”

“When you live in a house with one hundred children, wherever you are in the world, you are nobody, you exist only in documents.”

“I was in an institution for three years. In the beginning I was isolated for three months in a room with bars. Now I live with my family. I am a self-advocate with Lumos, and I have realised that this is what I love to do.”

“I am not good at math, but with a little help I counted how much money my expenses are for my family” (she showed a slide with her annual expenses).

“I also found information about the same expenses for a person living in a small group home” (she showed another slide).

“It is twice as cheap to live in your home. It is so simple.”

“I have friends in small group homes – Desi, Ivaylo, Ivan. They are individuals with different needs. It is not possible to give the same amount of money for the needs of one hundred children. The support is individual for every child.”

“There are still baby homes in Bulgaria. They have to be closed immediately. I was told there was a smaller number of children, but the buildings are the same, and the expenses are as big as they are for more children. No benefit for anybody. It is so simple.”

Since this conference the European Commission has committed to stop supporting institutional care in its funding outside the European Union.

Sharing personal stories is a tool self-advocates can use to make compelling arguments. However, self-advocates are more than their stories and their arguments are about more than any one person. Changing the Way We Care’s webinar with care leaver networks from Kenya and Uganda provides excellent insight on the damage caused by seeing child and youth participation as solely storytelling.¹⁵ We have also dedicated a whole chapter to safeguarding to help you ensure participation work is safe and non-exploitative.

As participation workers, our job is to help self-advocates develop a range of tools they can use to shape their arguments and create impact. For example, we teach them how to effectively prepare for meetings with policymakers by helping them research the person they are meeting and find out what their interests are. We support them to tailor their messaging to catch the individual’s attention. We also help them consider what they are hoping to achieve from their meeting – do they want the person to commit to something? And what are the key messages they want to leave with the person? Preparing for meetings in this way helps the self-advocates assess how successful their meetings have been, gives them tasks to follow up on, and helps them adapt their strategy for the future if an initial meeting was not effective.

Other ways that self-advocates can participate in advocacy and campaigning include:

- **Delivering speeches and interventions at local, national, and international events and appealing directly to decision-makers and key stakeholders.** For example, in 2019 a self-advocate from the Kenyan Society of Care Leavers (KESCA) directly appealed to a high-level audience of philanthropists at the House of Lords. The event took place shortly after the UK government had committed to stop funding orphanages and institutional care in their international aid programming. As a result of the event, several influential private donors committed to transition to fund family and community-based care.

- **Creating public exhibitions.** For example, Lumos self-advocates in Bulgaria created a photography exhibition focusing on the abilities of young adults with intellectual disabilities, and their desire to have meaningful, paid employment and be included in society. The exhibition travelled across Bulgaria, was exhibited in the national parliament, and travelled abroad to different events. Several members of this group are now in paid employment.
- **Producing and appearing in campaigns or video materials.** These can be led by young people themselves or together with adults. During the COVID-19 pandemic, self-advocates in Moldova developed a video on the impact of pandemic and lockdowns on at-risk children, offering advice to authorities and civil society on how to respond. The group decided on the concept, target audience and key messages together. The self-advocates filmed and edited the film themselves with some support from Lumos staff.¹⁶ Self-advocates also supported Lumos’ #Helpingnohelping campaign by speaking at the launch and engaging in the communications.

- **Raising awareness through community and public events** marking specific issues or days. For example, in Moldova, self-advocates participated in the Chisinau International Marathon and discussed their work with other participants – they also held a stall at the event so civil society groups and the public could learn about care reform from those with lived experience. This was a fun, interactive and meaningful way for children and young people, including those with disabilities, to campaign for rights to family care, inclusive education and participation. It also gave self-advocates the opportunity work alongside staff from across Lumos.¹⁷ In Haiti, children and young people participate in radio shows with civil society organisations. These are often linked to special events, such as the International Day of the Child. They speak on several themes, including their opinions on the link between trafficking and institutionalisation in Haiti.

- **Staging national advocacy campaigns.** The *Tour of Dreams* was one such campaign planned and delivered by young people with and without intellectual disabilities in Bulgaria. The aim was to advocate for their right to an independent life, employment, and equality. They travelled to four towns to meet with their peers with disabilities living in social care, and with local authorities and professionals from different areas. During the tour, the group raised awareness about their needs and abilities, advocated for their right to be respected in society, and discussed the issues they see as important. They put forward a simple ask which was written in their manifesto: "It is my

right to be independent, to have a job, and to be like everybody else, despite my disability or being in care!". The final meeting in the tour was with the Bulgarian Ombudsman on Child Rights who had supported the campaign from the very beginning. When they met with him, the young people shared the messages, opinions and recommendations they had gathered from their discussions nationally. With the support of the Ombudsman, their recommendations were sent to key policymakers in the Bulgarian government.



© Lumos / Toni Perjec

“For me, self-advocacy means to fight for my own rights and for the rights of my peers.”

(Self-advocate, Moldova)

“I am a self-advocate because I want policymakers to stop the institutionalisation of children. I have participated at advocacy events with my colleagues from Moldova, Czech Republic and Bulgaria, and consider that all of them were successful.”

(Self-advocate, Moldova)

Some of the self-advocates have offered advice to participation workers:

“You must keep in mind that when you involve a child or young person in advocacy events, you must prepare them very well.”

“Advocacy should always be done voluntarily.”

(Self-advocate, Moldova)

“When you plan with young people and children to speak and share their experience, it is possible to re-traumatise, and that they will re-live the difficult moments from their past. So, be sensitive about this and be prepared for their reactions. As well, make sure you think about the public’s feedback; many times they can be rude and ask inappropriate questions to children and young people.”

(Self-advocate, Moldova)

RESEARCH

Children and young people can be involved in research, both as participants and as researchers. Participation in research offers children and young people the chance to develop new skills, knowledge and practical experience and can help them generate further evidence to support their advocacy efforts. When supporting young people to develop their own research project or to participate in a project led by others, you may need to help them to:

- identify their aims, objectives, and purpose (why the research will be conducted, and how it will be used)
- design the methodology and any data collection tools, such as questionnaires or interview schedules
- think through ethical questions, consent and data protection requirements, and risk management protocols
- identify and collect data from research participants, with an onus on diversity and inclusion

- analyse their data and identify key findings
- effectively present and disseminate their findings to relevant audiences.

Organising research skills training is helpful if young people want to lead their own research projects. There may be someone within your own organisation who has the skills to deliver this. We find that colleagues in other teams often enjoy supporting young people’s work and are happy to help. They may be able to offer support throughout the process, for example helping the group analyse the data, or making suggestions on how to improve their findings report. If you have communications colleagues, they may also be able to help with presenting the findings, although many young people are extremely creative and may prefer to design it themselves. When bringing in the expertise of colleagues, it is important to negotiate this with them and their line manager, to ensure it is built in to their workplan.



Self-advocates took on the role of researchers during the transformation of children's homes in Pardubice County, Czech Republic. They visited and interviewed children who had moved from institutions into supported living about the main changes they had experienced. The self-advocates believed that being interviewed by peers helped the participants to feel comfortable and speak openly. The study recorded the observations, experiences and suggestions of children and young people to determine what had been done well in setting up the community-based apartments and new services, and what areas still required improvement. The group's findings could be valuable in informing future policy and practice. For example, the quote below from one participant explains how living in the apartments can help young people prepare for independent living in the future. They said:

“We think it helped the children to express their views because we interviewed them, and the Lumos employee was there only to record the interview; and because we were closer to them, we could get a more open insight into their situation.”

Children in the apartment learn more about having privacy – they have their own rooms, but in the past they were used to being together, in a common room. Now, by learning to use their space and be with themselves in the apartment, they will be better prepared for change after leaving, for independent living.”

(Eliška, aged 17)

COLLABORATION WITH OTHER NATIONAL AND INTERNATIONAL CHILD AND YOUTH NETWORKS

There are many examples across the globe of youth councils or similar groups of young people who are interested in children's rights. They may work on slightly different issues or in different countries, but collaboration between these groups can present fantastic learning opportunities for the children and young people involved. Working together gives groups the opportunity to strengthen their advocacy and campaigning skills by learning from one another.

In the Czech Republic, Lumos' youth advisory board (YAB) has established a strong connection with the National Child and Youth Parliament (NCYP). The NCYP shared good practices in advocacy, public speaking and mentoring with the YAB. In return, the YAB helped the NCYP to learn about working in an inclusive environment and engaging with children and young people from different backgrounds. Together, members of the two groups developed training workshops on inclusion and children in institutional care which they presented in several mainstream schools. They also produced an illustrated book on children's rights which toured the Czech Republic in a travelling exhibition.

As highlighted by this example, one of the great benefits of collaborative participation is the joining of worlds of young people who might not otherwise meet or have the opportunity to work together.

Existing care-leaver networks can also provide rich expertise to those wanting to engage children and young people in care reform. In Guatemala, Changing the Way We Care collaborated with members of DONCEL. This Argentina-based care-leaver association was commissioned by CTWWC to design and implement a virtual training session providing first-hand experience on how to establish a care-leaver association, including lessons learned, successes and challenges. These first-hand accounts from DONCEL were instrumental in providing the building blocks of a foundation upon which CTWWC could start to explore ways to engage in and potentially support the formation of a care-leaver association in Guatemala.

CHAPTER 3

KEEPING CHILDREN AND YOUNG PEOPLE SAFE

Keeping children and young people safe and protecting them from harm are the foundations of all work with children and young people. Participation work with children and young people who have experienced institutionalisation carries significant risks which need to be handled sensitively. This chapter identifies the key considerations that must be built into organisational policies and procedures to ensure participation is safe and ethical.



THE BASICS OF CHILD PROTECTION AND SAFEGUARDING

All organisations working with children and young people, whether they are a small NGO or a local authority, should have a comprehensive safeguarding policy in place, compliant with national legislation. The policy should address how the organisation will keep children safe within their scope of work and how it will respond if safeguarding concerns arise. It must apply to everyone working with the organisation, including contractors, partners and volunteers.

Safeguarding policies should include a code of conduct, which all staff must agree to follow as part of their terms of employment. This is important for many reasons, for example to avoid blurring of the personal and professional boundaries of participation staff, by providing staff with a framework of obligations. It can be a useful tool for helping young people to understand your actions or reasoning, for example, using it to explain that you cannot accept their friend request on social media because it is not appropriate and would breach your code of conduct. It also helps young people understand what appropriate and inappropriate behaviour from staff is, for example, that they should be treated with respect and dignity. It is therefore vital that the policy is shared with children and young people in an accessible format.

Keeping children and young people safe means making sure that those people who work directly with them are safe and appropriate. Background checks should always be conducted to ensure that children and young people are not exposed to people who may harm them. This could include police, former employers, other local agencies or organisations they have worked with. Seek advice locally on the legal and best practice framework for background checks.

Child protection training is essential for all staff and volunteers (including young people) working directly with children and young people. Training should be based on your organisation's policy and emphasise everyone's responsibility to keep children safe. It should have a strong focus on what to do if a child or young person discloses a safeguarding concern. Safeguarding concerns occur relatively commonly in participation work as children often feel safe to share things that have happened to them.

Taking time to go over the safeguarding procedures can ensure staff can address situations confidently and effectively, ensuring the child or young person is well supported. Some points to consider include:

- It is possible that a young person will share historic abuse, which may have happened many years ago. It will be the responsibility of the organisation's designated safeguarding lead to consider the concerns in the legal contexts and determine if the information needs to be reported to official authorities like children's services, police or others.
- Children and young people will often ask for sensitive information they've disclosed to be kept secret. It is important that participants are aware from the beginning of their involvement with a project that it will not be possible to keep confidential anything they share which indicates a risk to themselves or another child. Telling them this from the outset will reduce possible feelings of being misled.
- Once a child or young person has made a disclosure, it is crucial to let them know who you are going to share this information with and follow up with them as soon as possible to let them know what will happen next. It is likely that they will feel extremely anxious.
- If you believe the child or young person will be in immediate danger, for example if they share abuse currently happening to them where they live, the designated safeguarding lead may decide that immediate action is necessary. Follow-up will also be needed to check on the young person's emotional wellbeing. In some situations, they will require support to access therapeutic support.

In situations where disclosures of abuse are made in front of other children or young people, it is important to talk to them about how they are feeling about what they heard. It is likely that it will affect them and possible that it will trigger memories of their own experiences, which may be distressing. The staff that respond to these situations may also need some additional support from trained professionals (such as psychologists) to process their own feelings of shock or sadness about what they have heard. This highlights the importance of always having more than one member of staff present when working with children and young people to ensure someone can respond to the person who has disclosed, while the other continues to work with the rest of the group.

Due to the nature of the work and the background of the children and young people we support, it is inevitable that they will reflect on their experiences and history. They may feel the participation groups are a safe space in which to do this; we tend to find that a sense of trust and community is built up between children and young people with shared life experiences – this has been the case in every country we have worked in. However, it is important to be clear from the beginning that participation groups are different from therapeutic or self-help groups. In the next section we will discuss storytelling and supporting children to share their experiences, which must be done carefully and sensitively.

However, it is important to stress that although much of our participation work is shaped by children and young people's experiences, we try not to focus on their individual stories. Instead, the emphasis is on improving systems of care for all children and young people. For example, when co-designing a leaving-care service, we would focus on 'what support do young people need when leaving care,' rather than 'tell us what happened when you left care.' Of course, personal experiences often come out during such discussions, but framing it this way can help avoid young people feeling that they are expected to share their story, which can be traumatising, both for themselves and other young people. It also helps them think beyond their own experience and consider what wider changes are needed. This work requires skilled facilitation by someone who is able to create safe spaces where children can share but also help them move beyond their own experience.

Our position on volunteering with children and young people

We recognise that volunteering can be an immense force for good and actively encourage young people to volunteer in ethical placements and programmes which are suitable for their experience and skillsets. However, we believe that if an individual would be considered unqualified for a task as a professional, they should not perform it as a volunteer. This principle extends to overseas volunteering and we suggest that prospective volunteers explore opportunities in their own community where they may be positioned to have a greater impact.

Organisations must carefully consider whether it is appropriate and safe before involving volunteers in participation projects and other direct work with children and young people. As with paid staff, any adult volunteer working with children and young people must be subject to appropriate background checks, safeguarding training and supervision.

In acknowledgement of the documented harms of unskilled volunteering in orphanages¹⁸ and in line with UK government issued guidance,¹⁹ we strongly advise the public against volunteering in residential institutions unless they possess specific qualifications and skills (eg, in physiotherapy, speech therapy, clinical psychology) which are not available in the local community and only if in the context of supporting the safe reintegration of children in institutions back into family and community-based care. More information and resources can be found on the #HelpingNotHelping campaign website.



© Lumos

SAFE STORYTELLING: TRAUMA-INFORMED PRACTICE

Most children and young people that have lived in institutions have had difficult and complicated lives, and many have experienced forms of abuse and neglect. It is important to get the right balance between treating these children and young people as survivors rather than victims, while being sensitive to the trauma many of them may carry. Trauma-informed practice promotes awareness of the impact of trauma and prevents re-traumatisation through the work we do with children and young people. This is why nobody should ever feel pressured to share their personal story. Changing the Way We Care and UK charity Young Minds have both created excellent resources offering practical guidance for frontline workers on trauma-informed practice.²⁰

In the right context, sharing stories can be empowering and even therapeutic. However, it can also be exposing, distressing and cause children and young people to re-live their trauma. This can be amplified by people responding to children and young people's stories with pity, doubt or inappropriate questions.

Lumos and Changing the Way We Care support self-advocates to participate in high-level advocacy events so that decision-makers can hear and understand their views. It is important that self-advocates fully understand the brief before agreeing to participate in such events, including whether there will be media coverage and whether they will be expected to speak from their personal perspective. Although some self-advocates prefer to develop their own speeches, they are always offered support from a staff member with advocacy and communications experience to help them develop their messaging and structure their speech. This includes deciding which parts of their personal experience they feel comfortable sharing and which parts are relevant to make the point they want to make. It might be that, 'I lived in an institution for nine years' is enough. When preparing self-advocates, we stress that they are not only representing themselves, but their peers, so they should try and think beyond their personal experience and articulate what change they want to see.

High profile events are usually most appropriate for more experienced self-advocates who are comfortable enough speaking in front of larger audiences. If budget allows, buddying an experienced, with a less experienced self-advocate can be a positive experience for both parties. Immediately after self-advocates have spoken at events, it is likely they will be approached by several people telling them what a fantastic job they did. Some self-advocates enjoy this level of attention, while others find it overwhelming. The supporting adult's role is to be led by the young person. If the self-advocate is comfortable remaining in the situation, then staff should remain close by and be ready to intervene or help them move to a quieter space if it becomes too much.

Preparing adults is another key part of trauma-informed practice. It is important to make colleagues, consultants and volunteers aware that asking personal questions is not appropriate and staff should be advised on when to intervene if they see this happening; this may seem like common sense but will not be instinctual to everyone.

If you are supporting young people to be interviewed by a journalist or to speak on a moderated panel discussion, remember that the journalist or panel members may not have been trained to work with children and young people who have experienced trauma. It is crucial to help the self-advocate identify in advance what questions they are comfortable answering and what topics are off-limits.

For interviews, the agreed questions should be clearly communicated to the journalist in writing in advance. A member of staff should always be present during interviews to ensure agreements are respected. At Lumos, we have had to intervene when a journalist did not stick to the agreed questions and asked invasive questions about a young person's family dynamics. Providing self-advocates with media training can help them navigate questions they do not wish to answer. Some young people are able to handle these situations themselves, but ultimately supporting adults should be prepared to step in if necessary.

If a self-advocate is speaking on a panel discussion, the moderator should meet with them in advance. They should explain the format and the self-advocate's role. If questions are going to be taken from the floor, it is helpful for the moderator and self-advocate to agree a way of signalling if they are comfortable answering specific questions. It is important to help moderators understand their responsibility to support the self-advocates and that self-advocates

do not have to answer any questions they do not want to. If appropriate, we ask self-advocates if they would like to 'plant' a question from the audience, or whether they want the moderator to ask a specific question to help them articulate a particular answer. This can be a useful technique for young people with intellectual disabilities.

With these kinds of activities and events, it is important to remember the role of self-advocates; they do not work for our organisations and they are not our spokespeople. Therefore, most press after big events will be more appropriate for staff members or highly experienced and confident self-advocates who have been fully briefed and genuinely wish to participate.

Sensitive and comprehensive follow-up after an event is a critical part of our duty of care to self-advocates, particularly if they have shared their personal stories. It is important to check how they are feeling and provide or help them access any follow up support they need. There are some self-advocates who share their stories with passion and confidence, but it is important not to rely too heavily on them, as sharing their story over and over again may be causing damage. While some self-advocates will go on to work in the sector or wish to continue being a self-advocate into their late twenties, many will go on to university, other forms of employment or parenthood. It is important to respect the life cycle of youth-advocacy and support them to move on at the appropriate time for each young person.

PRACTICAL CONSIDERATIONS FOR KEEPING CHILDREN AND YOUNG PEOPLE SAFE

While engaging in your work you have a duty of care to keep participants safe. Carrying out a comprehensive risk assessment of your programme based on the needs of the participants and the planned activities will help you identify potential risks and put in place measures to reduce them. For example, a risk assessment will identify whether your venue is safe and accessible for all children and young people in the group. It will consider how the young people will safely travel to and from the venue and whether you will need to provide transport. It will address if the food meets safety standards and if they have adequate fire safety systems. The risk assessment stage is an important way of making sure your programme will meet the needs of participants with disabilities.

Risk assessments should also cover safeguarding considerations, for example making sure that staff know what to do if there is a safeguarding concern and that adults involved in the programme have had the right checks and training.

Before meeting with children and young people, you should be aware of any allergies, dietary and access requirements, whether they are on medication and if there are any medical conditions you should know about. You will also need their next of kin details in case of an emergency. You will need to consider how you store these types of personal information to comply with data protection obligations. One option is to store the information on an encrypted iPad or other tablet, particularly if the event is residential and you are away from an office with lockable storage for paper files.

There should always be at least two members of staff available during face-to-face group meetings, in case there is an emergency. It is important that both staff members have received safeguarding training and are able to manage unpredictable and complex sensitive situations that may arise. A manager and designated safeguarding lead should also be on call. For larger groups we do not subscribe to fixed ratios of staff to children and young people; instead, we base staffing levels on the type of event and needs of the group. Some participants will need more intensive support than others and there should always be increased staffing during residential meetings as staff will be responsible 24 hours per day.

Meetings with children and young people should never take place alone or in private as this increases the risk for both children and staff and can make children and young people uncomfortable. We recommend working in pairs as much as possible or always meeting and conducting work in a place where you can be seen by others.

Safety must always come before budget restrictions, but if budget is an issue you should identify what can be done safely within the budget available. For example, you could collaborate with another organisation, source a background-checked volunteer to provide additional support, go for fewer days, or reduce the number of children and young people who attend.

Children and young people should agree to their own code of conduct in advance of meetings so that they clearly understand expectations of behaviour and reduce the chances of causing harm to each other. At Lumos, we ask all self-advocates to sign up to the same code of conduct, regardless of their age. Getting them to develop the code of conduct themselves can reduce feelings of it being imposed on them, and increase buy-in. Some rules can be up for debate, whereas others are non-negotiable, such as no bullying. Some rules may be controversial, such as blanket no alcohol restrictions; self-advocates over the legal age may disagree with the rule but discussing the reasoning can help young people understand why you believe it is necessary. Young people can then make an informed decision about whether they are willing to participate. As far possible, it should be clear what will happen if young people break the rules.

In addition to the code of conduct, offering safeguarding training to all children and young people helps create a culture of child protection. We also recommend producing a child-friendly version of your safeguarding policy and developing a mechanism for children and young people to report concerns, similar to a whistleblowing procedure.

CONSENT

Informed consent is one of the core principles of participation work. All work must be voluntary and self-advocates must have the right amount of information, in a format which is accessible to them, to understand what they are agreeing to. For anyone under the age of 18 or an adult who has a legal guardian, consent must also be obtained by the parent or guardian.

Consent is particularly important when self-advocates share their personal stories. Before agreeing to speak at an event, self-advocates need to know the purpose of the event and their participation, the size of the audience and who they will be, whether it will be filmed and the level of publicity surrounding it. This information enables them to give informed consent. Any media activity must be agreed prior to the event, and the wishes of self-advocates should be accommodated wherever possible, for example by negotiating filming arrangements with organisers if self-advocates do not want to be filmed.

Whenever we gather quotes, images, case studies or video footage from self-advocates, we must obtain their written consent. We must explain to them how and where it will be used, for how long, and if it will be possible to retract consent in the future. It is possible that as self-advocates move on in their lives, they may no longer want a virtual record of them telling their story as a teenager. This kind of information is straightforward to remove if it is on our website, whereas if they have been quoted in an online news article it may not be possible to get it taken down. It is important that they have this information when they give their initial consent, but wherever possible children and young people should have the right to withdraw consent at any time.

A Moldovan self-advocate spoke about the importance of informed consent:

“Because your life is yours and you must know what will happen with your information. Consent informs us about what will happen, about the rules that will be followed... Also, our participation includes our personal data – this consent process makes it clearer. It is good to understand the activities I am involved in.”

During the consent procedure you must also consider if there are any risks involved in self-advocates sharing their identities. This can be particularly important if they have experienced abuse or trafficking. In these situations, it is possible to choose a pseudonym and to not use any images of them. Some self-advocates sometimes prefer this for their own privacy reasons.

Self-advocates from Moldova spoke about the risks for children and young people when participating in care reform:

“If children and young people participate in an advocacy event where they can be recognised, it is possible that they can be discriminated against afterwards. There is the risk that they could be rejected. If children and young people are not prepared enough, the processes may have bad consequences for all involved. Also, there is a risk of re-traumatising the child or young person when they are involved in different tasks. All people who work closely with that child or young person should know their story, in order not to ask inappropriate questions or to say something that will hurt them.”

(Olesea and Mihai, self-advocates, Moldova)

Having a child-friendly consent form, translated into self-advocates' first language, is vital for helping them give informed consent. It is crucial to train staff on how to explain this to children and young people in a way that does not put them under any pressure.



KEEPING CHILDREN AND YOUNG PEOPLE SAFE ONLINE

During the COVID-19 pandemic, we have been increasingly working with children and young people online. Although most appear tech-savvy, it is important to make sure they are aware of how to stay safe online. We communicate with self-advocates via closed platforms such as private Facebook pages, WhatsApp groups and secure online meetings monitored by our Child and Youth Participation Officers.

If our organisation shares something about a self-advocate, we only use their first name with no other identifying information. This reduces the risk of anyone tracking them down online.

Staff facilitating online communication with children and young people should use work social media accounts which are completely separate from their personal accounts. All communication should be done on work computers and phones, so it is important that staff have the equipment they need.

The National Society for the Protection of Cruelty Against Children have produced several useful resources for organisations to keep children safe online.²¹

WORKING WITH CHILDREN AND YOUNG PEOPLE OVER THE AGE OF 18 IN THE SAME GROUP

The example of drinking alcohol identifies just one of the challenges you may encounter when working with children and young people over 18 in the same group. Young people may see little difference between being 16 and 18, but our legal responsibilities towards them are different. For that reason, we do not allow young people aged 18 or over to share a bedroom with children aged 17 or younger during residential events.

We insist on mandatory background checks for anyone over the age of 18 with direct access to children. This may involve having difficult conversations but having the safeguarding policy as a reference helps people understand that it is not personal, and that ultimately the rule is in place to keep everyone safe. We stress to young people that having a criminal record will only exclude someone from the programme if it poses a risk to other children or at-risk adults, and details of any criminal convictions will be kept confidential.



© pexels / Andrew Neel

DATA PROTECTION

In participation work, we often need to gather personal information about the children and young people we work with to allow for regular communication and ensure we know who to contact in case of an emergency. So, it is important that you make yourself aware of any national or regional legislation governing data protection and privacy in your location²² and develop appropriate organisational policies and practices to ensure compliance.

Given our operating locations, Lumos is bound by The General Data Protection Regulation (GDPR),²³ which states that organisations should only gather information that they actually need for their specified purposes. GDPR also dictates that organisations must be clear about why they are gathering the data, how it will be used, and who it will be shared with. For example, in our work with children and young people, we ask what pre-existing medical conditions self-advocates have, to ensure that they are properly insured for their trip, to enable us to carry out a comprehensive risk assessment, and so we can pass on the participant's health information to medical professionals in the case of a medical emergency. Self-advocates and their legal guardians should be asked to consent to their data being used in this way.

Data must be stored securely and only be accessible to the people that need it. For example, when travelling internationally with self-advocates, the security manager at head office would have access to the self-advocates' next of kin details in case of an emergency. Children and young people you work with also have the right to request to see any data which is stored about them and ask for it to be removed. Organisations should periodically delete any data that they no longer require.

CHAPTER 4



INCLUSIVE PARTICIPATION

Children and young people who have experienced institutionalisation and family separation have often been subject to high levels of social exclusion. It is crucial that those seeking to support children to claim their rights do not perpetuate structures of exclusion. Being inclusive is a key part of our ethical framework for meaningful participation, which is described in Chapter 1.

Although this chapter has a strong emphasis on disability as a particular area of expertise and experience at Lumos, inclusion also refers to gender, ethnicity, religion, sexual orientation, identity and any other characteristic which can cause children and young people to be marginalised. When planning participation work, it is important to consider who the children and young people in your target group are and ensure that your programme is accessible to everyone – particularly those who are the most marginalised. As one self-advocate from Bulgaria said, it is also important to “be informed about each individual child or young person’s personality and needs in advance; be aware of his/her potential and interests; use accessible games for all.”

Lumos’ participation programme initially focused on children and young people with intellectual disabilities with a project called Turning Words into Action (TWIA).²⁴ We decided to focus on children and young people with disabilities because they are disproportionately overrepresented in institutional care. They are also excluded from most mainstream participation initiatives, especially if they have an intellectual disability or do not use verbal communication. The aim of TWIA was to empower young people with intellectual disabilities to hold governments accountable for commitments they had made in a World Health Organisation initiative called ‘Better Health, Better Lives’.

For many of the participants, it was the first time they realised they had rights, let alone that they could challenge policymakers to uphold them. However, through this project they developed the skills and passion to advocate for their rights.

“Being aware about our rights for the first time, we were provoked to pass on and show them to our peers.”

(Teodora, Bulgarian self-advocate)

“Afterwards, I remember, I tried to exercise my rights at home, for example, to choose what to wear by myself. Later I was confident enough to speak up at school.”

(Veliko, Bulgarian self-advocate)

MEANINGFUL INCLUSIVE PARTICIPATION

“Now I can say what I think with more confidence.”

“We are more visible and recognised in the community.”

“People invite us for partnership and events; people trust us as a youth group.”

(Self-advocates, Bulgaria)

Inclusive participation offers many benefits, both to children and young people and stakeholders working with them:

- It provides insight into how to achieve more effective policies and services for all children and young people (with or without special needs).
- It demonstrates how the principle of inclusion can be put into practice in other areas.
- It promotes decision-making and independence and supports children and young people with disabilities to discover and achieve their potential, allowing them to see themselves as people who can contribute meaningfully in their own lives and communities.
- By including people with disabilities, everyone benefits from their skills, experience, and friendship. The whole group develops mutual respect, empathy, acceptance, and tolerance, as well as learning how to give and receive support.

Although the first Lumos participation programme was specifically for children and young people with disabilities, we soon decided to broaden the focus and develop an even more inclusive approach to participation. Our participation groups now include children and young people with and without disabilities, from all care backgrounds – those that have been reunified with birth families, or who live in foster care or other alternative services, care leavers and those who have never been in alternative care at all. We also have many members from Roma and other ethnic minority groups, and a range of educational backgrounds. This broad range of backgrounds and experiences makes our participation work stronger and richer. It also models the inclusive society we are trying to achieve. Many children with disabilities are separated from their families solely because of their impairments, so if we were to focus on specialised groups for children with disabilities, we would be reinforcing segregation.

“The benefit of staying together is that only together can we achieve changes for all of us, children or young people with disabilities – whether you live in a family or in care. We learned that from our experience.”

(Self-advocate, Bulgaria)

PRACTICAL EXAMPLES OF INCLUSIVE PARTICIPATION IN CARE REFORM

When given the right support, children and young people with disabilities can meaningfully participate in care reform processes at local, national, and global levels. Below are some examples of how Lumos self-advocates have participated.

Local Level – Supporting peers and shaping practice in their own care or communities

Many of the skills we use in our everyday lives – such as cooking simple meals or deciding what we want to eat and when – are taken for granted, but children and young people who have left institutions to live in small group homes may have never been taught to cook for themselves.

On World Youth Skills Day (15 July) 2018, Lumos self-advocates in Bulgaria worked with children and young people from small group homes and across the local community to produce *A Pinch of Salt for Self-Esteem*, a simple cookbook to help give them the confidence to begin cooking for themselves, and for friends and family.²⁵



© Lumos

National – Championing their rights and those of others

In 2012, Veliko, 12, joined a group of self-advocates at his school. Veliko has intellectual disabilities and this group, initiated together with Lumos, included other children like him. Veliko grew up at home, but at school he and a fellow classmate were bullied by the other children.

Following events and discussions through the group, the children started to learn to put themselves in the shoes of others. Veliko became a self-advocate in the group and the violence against Veliko and others became less frequent.

Through his involvement in the group, Veliko’s self-confidence began to grow. He became a staunch advocate for equality and the rights of all children, always refusing to separate children with disabilities from those without, or children from institutions from those in families.

With increased confidence and some appropriate support in place, Veliko’s opportunities are limitless. In 2017, he became the first young person with an intellectual disability to sit on Bulgaria’s national youth parliament and in 2019 he spoke at the United Nations General Assembly in New York.



© Lumos

Regional and Global – Influencing International Policy

In October 2020, self-advocates from Haiti and Kenya joined author J.K. Rowling to launch Lumos' #HelpingNotHelping Campaign.²⁶ The aim of the campaign is to encourage young people not to volunteer or donate to orphanages while they are travelling internationally. Drawing from their own experiences of encountering international volunteers growing up, the self-advocates were able to powerfully articulate why volunteering in orphanages can be so problematic.

“I lived in an orphanage for 12 years. I remember that I saw more than 90 volunteers. They came, they brought their support to the orphanage, such as clothes, food, water and money. Unfortunately, the support they gave to the orphanage director never met the needs of children and young people. When volunteers come, the children hope to get a better life because they play, they sing and enjoy. When volunteers leave, they carry with them all the hope and joy that their presence had provided.”

(Self-advocate, Haiti)

“Children are not tourist attractions; they are not animals. They [have] lives and destinies.”

(Ruth, Kenyan self-advocate)



© Lumos

HOW TO ACHIEVE INCLUSIVE PRACTICE: EMBRACING THE SOCIAL MODEL OF DISABILITY

Being inclusive is a choice, which may require a shift in an organisation's approach. The social model of disability offers an important lens through which to think about inclusion. The model was developed by a group of people with disabilities in institutional care in the 1970s, who said:

“In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society.”

The Union of the Physically Impaired Against Segregation (1975)

Definition of impairment: an injury, illness, or congenital condition that causes or is likely to cause a loss or difference of physiological or psychological function.

The social model emphasises that people are disabled by barriers in society, not by their impairment or difference. This takes the onus off people with impairments to change and places the responsibility on society to work together to remove barriers which prevent people's full inclusion. This is in contrast to the medical model, which says people are disabled by their impairments or differences; this can mean that if they cannot be 'fixed' or adapt to fit into society, then their segregation and exclusion can be justified. This is arguably a key reason why children with disabilities are overrepresented in institutional care.

Definition of disability: the loss or limitation of opportunities to take part in society on an equal level with others due to social and environmental barriers.

Embracing the social model of disability is fundamental to ensuring children and young people with disabilities are fully included in our work. It forces us to consider the barriers within our own organisations and places the responsibility on us to remove these barriers so all children and young people can participate. These barriers can include:

- lack of physical access to buildings and transportation
- lack of interpretation for children with hearing impairments
- programmes that have not been designed or adapted to ensure those with intellectual impairments can understand
- the use of jargon or inaccessible language
- stigma and unhelpful attitudes to difference, like assuming people with disabilities cannot do certain things.

When considering barriers, we often default to physical barriers such as steps and bathrooms, however our attitudes can be far more disabling. A powerful shift in thinking is to focus on what children and young people can do, rather than what they cannot do, and building from there. We also recommend investing in disability equality training for staff – ideally led together with people with disabilities – which includes challenging stigma, assumptions, and unconscious bias.

“Everyone enjoys my singing! You wouldn't believe all the things I can do! I am just different. Try to understand me.”

(Ivaylo)

“I am learning to help others. I believe that with the proper support EVERYONE can contribute to the world and be useful with their work.”

(Teodora)

(Quotes from the “We Can Too” exhibition in Bulgaria)

PRACTICAL WAYS TO MAKE YOUR WORK MORE INCLUSIVE

The first step is to embrace the social model and be committed to making your participation work as inclusive as possible. You will not get everything right all the time (no one does), but children and young people understand when they are valued and when people genuinely want them to feel included.

The next step is to ask them what they need. Never assume, even if you have worked with similar groups of children or young people before. Some children and young people may need support to communicate what they need, but always ask them first and include them as much as possible.

Once you have assessed what the child or young person needs, you will need to consider what barriers might prevent them from participating and what adaptations you need to make to the environment. These may include:

- Making sure information is in clear and in accessible language.
- Creating safe spaces where children can take a break if they need to.
- Using art, drama or music to help children and young people express themselves.
- Giving children and young people clear choices on what they want to participate in.
- Making sure the venue will meet their needs – how will they get there? Is there an accessible toilet? If there is no lift, could you move the activity to the ground floor?
- Will you need additional staff to meet the child or young person's needs?
- Do staff need additional training?

It is important that the rest of the group understands if there is anything they need to be aware of, for example if someone has hearing loss and lip reads, the group need to know what they can do to make communication easier. However, medical, or personal information should never be shared where it is not necessary and should only ever be given with explicit consent from the individual concerned. Creating an inclusive culture within groups encourages all members to feel comfortable to express their needs and be aware of the needs of others.



© Lumos



© Lumos

Additional considerations to promote inclusion

- As with participation more generally, it is important that inclusion does not become a tick-box exercise. Simply having children and young people with disabilities involved does not make it inclusive or meaningful. Ensuring that all children and young people are actively included, and you have proactively created an accessible environment avoids tokenism.
- Inclusive participation is not just about participating in or speaking at events, and it certainly does not start there. For many children and young people with disabilities, it starts with having autonomy to make decisions about their own lives, from mundane everyday choices to important decisions about their care.
- Ensure you have enough resources to facilitate inclusive participation. It will usually require additional support staff. Extra costs may also need to be factored in, such as accessible transport. It is important to ensure you can provide an accessible environment, any technical devices needed, materials, food and drink, interpretation for international meetings, and other things to ensure everybody is included.
- Ensure all staff have received training on disability equality.
- Remember that not all disabilities are visible. In our work we have found that people with psychosocial difficulties often require more support than those with physical disabilities.
- Observe and take into account the interests, willingness to participate, capacity and requirements of all participants.
- Promote positive, non-discriminatory and accessible communication between all young people, including those with special needs.



© Lumos / Toni Percec

67

APPROPRIATE SUPPORT

With the right support, almost every child and young person can be involved in decision-making and advocacy in their own way and at their own level. However, many children and young people with disabilities who have grown up in institutions have had limited opportunities to express their opinions or make meaningful decisions, even about basic things like what they want for breakfast. Therefore, they may need additional time and support to develop their confidence and decision-making skills. They may also need help to challenge their own perceptions of what they can achieve.

Caregivers who work directly with children and young people with disabilities could benefit from training on inclusive practices. Such training might include how to promote decision-making, and how to explore alternative ways children and young people with disabilities may communicate, such as through pointing, facial expressions, physical gestures and vocalisations, so that even those with the most profound impairments can have as much autonomy over their life as possible.

Many people now accept that children and young people with physical disabilities can participate in mainstream activities, but they may not think it is possible to include those with intellectual disabilities. But by providing additional support and adapting programmes, we have achieved high levels of engagement of children and young people with intellectual disabilities in a range of activities, including research, co-designing services, training, and advocacy.

ACCESSIBLE INFORMATION

When working with children and young people it is vital to use simple, positive and understandable language, avoiding jargon. This is true with both written and spoken language. There are different approaches you can use, depending on the age and needs of the children and young people you are communicating with, including using pictures, photos, symbols, games, facial expressions, gestures, body language, and sounds.

It is important to frequently check if the child or young person understands the message, and if not then consider alternative methods. Some of the approaches you might employ include:

- **Child-friendly documents** are aimed at younger children. They include short and simple sentences and lots of illustrations.²⁷
- **Youth-friendly documents** are aimed at older children. Language should be simple and easy to read to ensure it is accessible, but without using childish language which could be considered patronising. Using images and presenting information in visual ways makes text more engaging.²⁸
- **Easy reads** are designed specifically for people with intellectual disabilities. They use a combination of short, simple statements and symbols.²⁹

Lumos has learned a number of lessons through our work on child and youth participation:

- Children and young people are usually much better at embracing inclusion than adults.
- Be flexible and expect the unexpected. Sometimes even the best made plans will not work because of the mood of the group or unexpected circumstances. It is important to be ready and willing to adapt, and do not worry if things do not go according to plan.
- When planning sessions, make sure you factor in enough breaks. Some children or young people may need additional breaks, or to let off steam during free time by doing something physical.
- Committing to inclusive practice will make your work richer and more authentic. Although it can feel daunting at first, it is worth the extra effort!
- It is important to provide any additional support that children and young people with disabilities may need, but also to keep in mind the needs of other members of the group. Balancing everyone's needs ensures you can create an inclusive environment.
- Participation is an individual process. Every child or young person will participate in their own way, according to their interests and potential. Do not expect the same level or form of participation from everyone.

MEET BEN

Ben is 17 years old and has been a member of Lumos' Czech YAB for two years. He likes sports but over the past two years he has developed a new passion – advocating for children's rights.

Ben has been living in an institution since he was nine. For many years he had been told by the staff that the institution was the best place for him to live, but he was starting to doubt that this was true. Then he began engaging with Lumos and heard the exact opposite to what he had been told for so many years. He took time to consider these new perspectives and decide his own position on institutions.

He joined Lumos' YAB so he could begin advocating for better alternatives for young people like him. He spoke at his first conference very shortly after he joined. He was very nervous before his speech as there were a lot of people in the audience and he felt a sense of responsibility. But right after he finished his speech, he felt great. He was happy and proud of himself and his work with Lumos still helps him to feel that way today.

Ben says the most important thing for him is that through his participation work, he can meet other self-advocates and hear their stories. He was surprised to learn that there were young people in other countries who had had similar experiences to his. Ben likes to be a part of that community and feels a lot of hope and positivity thanks to the people he has met.

When he looks back at the two years that he has spent working with the YAB, Ben says that a lot has changed. He feels more empowered and supported; and that he now has a unique chance to be heard by people who can really improve the lives of children. He truly means what he often says in his speeches to the audience – he wants to use his own bad experience for the benefit of other children. He would love it if no other children ever had to experience the things that he did.

Ben also enjoys a lot of other things that his work brought into his life – such as travelling to new places, learning new words in English, and getting used to wearing a suit, which he did not enjoy before.



CHAPTER 5



PARTICIPATORY APPROACHES FOR MONITORING AND EVALUATION (M&E)

How can we be sure that our child and youth participation work is on the right path? Robust monitoring and evaluation systems, which should be built into project plans, are important to ensure planned objectives are being met. This takes time and focused effort. In this chapter we share some of the tools we use to monitor and evaluate our participation work. We also highly recommend *Save the Children's Toolkit for Monitoring and Evaluating Children's Participation* for more information about monitoring and evaluation (see Annex).

Monitoring is the continuous assessment of the implementation of planned objectives, to identify whether activities are progressing according to plan and to identify if any changes or adjustments are needed. Routine monitoring increases accountability to all stakeholders involved – partners, donors, and most importantly the children and young people themselves.

Evaluation is a periodic assessment of the outcomes and impact achieved or contributed to by the programme or project's activities. It looks at the relevance, effectiveness and impact of the project's objectives and activities, and whether the plans and expectations were realistic. In the context of child and youth participation, it may involve measuring the outcomes and impact of a campaign or the design of a new service in the community.

Capturing children and young people's feedback and perceptions in the monitoring and evaluation process can enable us to understand whether and how the project is positively impacting their lives. This is essential to improving ongoing and future participation work. Even negative feedback is useful, and often demonstrates that children and young people trust us enough to share their honest views.

How can we measure the impact of child and youth participation? First, we look at the scope: to what extent were children and young people involved in the project? This information could be drawn from the routine monitoring data. Then at the quality: how did the participatory processes meet the standards for good practice?³⁰ You can use an ethical framework to guide this (see Chapter 1). And finally, what was the impact? How did the project create impact, short and long term, for the children and young people themselves, their families, communities, practitioners, policymakers, civil society and the work of the organisation?

Children and young people should be kept informed of how a project progresses, even after their involvement has ended, and adult practitioners should give feedback about how their involvement affected the outcome.



ETHICAL MONITORING AND EVALUATION OF CHILDREN'S PARTICIPATION

Some of the steps you can take to ensure monitoring and evaluation of participation work is ethical include:

- Providing clear rules for M&E staff when you are beginning a monitoring or evaluation activity.
- Making sure the children and young people understand why you are conducting the monitoring and evaluation activities and how the information they provide will be used.
- Involving children and young people in conducting monitoring and evaluation, not just as participants in it, so they can develop their skills. Try to involve them as partners in finding and designing the best methods and approach to gather the feedback, monitor and evaluate specific projects, tailored to specific audiences and stage of development/implementation.
- Making sure monitoring and evaluation activities are fully inclusive.
- Assuring children and young people that the information they provide will be kept confidentially, and only shared with others in an anonymised way unless they give their permission otherwise. Inform them that they can withdraw their data even after they participated (up to a certain point in time).
- Making clear that children and young people can choose whether or not to participate in evaluations, and that they can withdraw at any time – even if they have already agreed to participate. They should know that their decision to withdraw or not participate will not affect the support or services they receive in any way.
- Giving them clear feedback regularly on how their contributions to the M&E process were used by adults and share with them the relevant documents related to this (specific reports, decisions, next steps, etc).
- Making the process enjoyable and fun for all!

PRACTICAL TOOLS FOR MONITORING AND EVALUATION

When starting to think about monitoring and evaluation, it can be useful to think about the benefits of child and youth participation (many of which are outlined in Chapter 1) and use these as a starting point to measure if these benefits have been achieved.

Monitoring and evaluation tools should be tailored to the individual needs and potential of the children and young people involved, the local and cultural context, and the project's objectives and activities.

Most of the tools presented in this chapter are designed to capture qualitative data, but it is worth remembering that quantitative data can also help determine progress against objectives and the impact of our work. Examples of quantitative indicators to consider when creating monitoring plans are:

- the number of children and young people who participated in our work throughout the year
- the number of views a video received
- the number of people who signed a petition
- the number of stakeholders, such as policymakers or service providers, who participated in an event, training, or workshop
- the number of activities and initiatives led by children / young people.

METHODS AND TOOLS FOR USE WITH CHILDREN AND YOUNG PEOPLE IN MONITORING AND EVALUATION

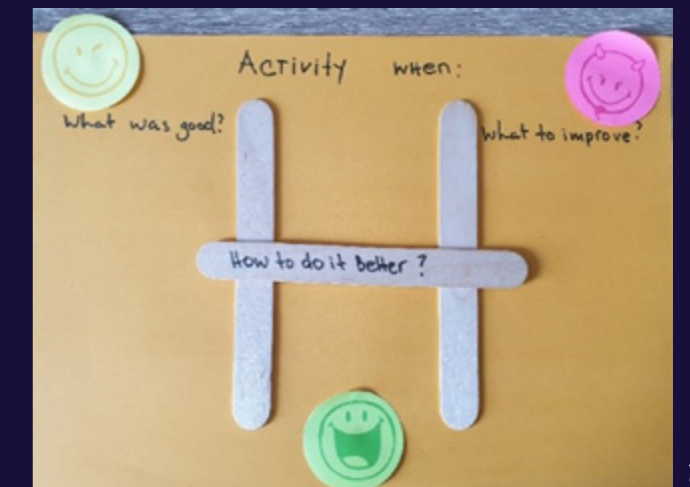
Some of the methods you could use in monitoring and evaluation to explore and document children and young people's experiences and opinions include:

- Group discussions: small or big groups of children or young people discuss a common issue/topic, trying to find the benefits and risks of it, what solutions are, how to achieve the expected results, how to reach the audience, etc.
- One-to-one discussions: necessary when discussing sensitive or individual issues, or when the child is not ready to openly speak up in a group.
- Storytelling activities: storytelling is a powerful way to share knowledge, experience, attitude, and benefits of participation, depending on the context and goal. It also could be an individual or group story of some important life moments which could inspire others. When using this method, it is important to be vigilant in terms of safeguarding and trauma-responsiveness as detailed in Chapter 3.

After participating at a global conference on child participation in Switzerland, a group of children and parents supported by Lumos Bulgaria wrote their own fairytale called "The Castle of Children". They shared the draft with each other, and everyone wrote their own part of the story. This helped to identify the big changes, impressions, and lessons the group had learned during the event.

- Question time sessions: when we have one big question and ideas session before we start planning further activities. This is very similar to group discussions.
- Surveys and questionnaires in written or oral format. These are useful for getting feedback from larger groups, and written surveys can be completed anonymously by participants, so can be a good way of eliciting honest feedback on more sensitive topics. They might include yes/no or true/false questions, or multiple choice.

Whichever methods you use, it is important to use accessible language appropriate for the ages and abilities of your group. Visual tools can be very helpful and can help create a safe, friendly space to express feelings and emotions. Children and young people can advise on what tools work for them or create their own. Below are some examples that we have found useful in our work, including in our work with children and young people with intellectual disabilities.



The 'H' assessment tool is a simple but effective way to ask children and young people to share what went well, what was challenging, and how things could be improved in the future. This can be a useful tool to capture participants' reflections on events or activities, or review performance and attitudes over a certain project or period of time.

The body map is a helpful tool for multi-day events, as you can use it you to monitor how the young person is developing as the event progresses. It can be used collaboratively by groups, or by individual participants. Each day, you can ask the young people to write on the relevant part of the body:

- the skills they have gained (hands or head)
- the emotions they are feeling (heart)
- their plans for what they will do or change after the event (legs).

The memory book can be used to evaluate children and young people's experiences at the end of each day during residential events. Children and young people discuss within groups how they feel, what has been useful and not useful about the event so far, and vote on how child-friendly, inclusive, respectful, and safe their experience was each day. These group thoughts and feelings are recorded in the memory book. Alternatively, each child or young person could have an individual memory book.

Measuring participants' moods before and after activities can be done by asking them to rate their feelings on a scale or according to a category (such as good/bad). It can also be done by getting them to show with their arms how much energy they have or how much they agree with a statement. What you measure will depend on the information you are trying to capture, but may include their confidence, enjoyment, or feelings of safety. To make it even more interactive, you can assign one end of the room as 'strongly agree' and the other end as 'strongly disagree' and ask children and young people to stand in the place which most represents how they feel about different topics.



Questionnaires filled out by children and young people at the end of an activity or event can be a good way of finding out how they found the experience and what could be improved. Images like the ones above can help participants convey their feelings.

Yes/no questions and questions where they can rate their thoughts and feelings can be helpful, but always include open-ended questions as well to give opportunities for more detailed feedback.

Quotes from children and young people which capture their thoughts, opinions, reactions, can be used for evaluations. They can be given verbally, in writing, or through drawing or other creative methods. Children and young people must be appropriately informed on how their quotes will be used and it is important to get their consent on this, even if they are going to be used anonymously.



Peer-to-peer surveys designed by children and young people and administered to other children and young people can be an excellent way of doing monitoring and evaluation in a participatory way. This not only enables children and young people to develop skills in monitoring and evaluation, it can also help you capture useful information as some children and young people feel more comfortable and talk more openly to their peers.

A group of self-advocates in Bulgaria who had intellectual disabilities, developed a questionnaire and ran a focus group with other children and young people who had moved from institutions into small group homes. They found out about the impact of the move and what life was like for their peers in their new living situations. Their findings helped Lumos to evaluate the impact of care reform in Bulgaria.³¹

TOOLS FOR USE WITH ADULTS

Child and youth participation work often involves working closely with adults, such as parents, caseworkers, teachers, public authorities or other stakeholders in the care reform process. It is important to include them in monitoring and evaluation. It is valuable for children and young people to know how their participation and contributions have been perceived by others, so gathering the views and opinions of adults and feeding this back to the children and young people is important. At the same time, using these tools with adults is valuable to shape the work going forward, the challenges and benefits of participation, and what impact it has compared to what was planned.

There are a range of methods for collecting the views and feedback from adult participants, including:

- Questionnaires, either paper or online versions. There are several software options for creating online versions, including free options, which can also reduce the amount of time you spend analysing your findings.
- Group discussions and focus groups – this is an effective way to assess our work with parents and care givers, for different activities and at different stages.

Parents and carers from a child and youth programme in Bulgaria took part in a participatory review covering 2011–2019. They provided feedback on the main activities year by year and evaluated their performance as a group. One of the main outcomes shared during the group discussions was their transformation from individual parents/carers supporting children to the creation of the Parents in Action Group which now advocates for children with disabilities not only from families but in institutions or in care.

ANALYSIS AND USE OF MONITORING AND EVALUATION DATA

Once data has been gathered from children and young people and appropriate adults it is important to ensure that it is put to good use. This step is often overlooked and not well planned for. Start by clearly defining the purpose and intended audience. This can be done by listing the monitoring and evaluation questions you intend to answer, which decisions the findings will inform, and who should be involved in making those decisions.

Plans for analysis include thinking about how data will be recorded, stored and processed so that it becomes useful information. For quantitative data, this may mean running simple computations to find out totals or averages, or running more complex statistical analysis to understand variations, distributions or correlations. Building useful visuals, such as bar graphs or infographics to display findings will help them to become useful. Qualitative questionnaire responses, discussion transcripts or drawings should be read through/looked over multiple times, so common themes can be highlighted and illustrative quotes or examples brought out. These findings can be shared in short descriptive paragraphs with connected quotes and pictures.

Children and young people can be supported to participate in this stage of monitoring and evaluation. Reading through transcripts (or having transcripts read out loud) in a group and discussing them together can be a powerful experience. Engaging children and young people in presenting quantitative data through drawing diagrams or selecting images to build infographics will help to ensure that findings are presented in an accessible way for other children and young people.

Discussion of findings should be held with those who were involved in providing feedback and those who will be able to put recommendations into action. Discussions should focus on whether objectives were met, what this tells us about the way the activities were undertaken and what needs to change in future.

Findings, along with conclusions and recommendations, should be reported in an appropriate and accessible format, especially for feedback to children and young people. Consideration should be given not just to written reports but also to videos, presentations, infographics and cartoons. Once a monitoring period or evaluation is complete, it is important to follow up on and support the use of the findings, so that all the hard work makes a difference to future efforts on children and young people's participation.³²



CONCLUSION

All children and young people have the right to meaningfully participate in decisions that affect their lives, including those around their care. Everyone working with them has a responsibility to ensure this fundamental right is respected.

The examples and practices shared here are based upon the experiences of Lumos and CTWWC and work with children and young people around the world. They are not exhaustive, but we hope they have helped you consider how you can integrate participation into your work or build upon your existing practices.

There is no one-size-fits-all model for participation. Your methods may vary depending on your organisation's role in the care reform process, your operating context, and the children and young people you work with. We would encourage you to continue researching and consulting with children and young people to determine your next steps; to connect the participation structures you work within to others in the country; to ensure enough support staff for genuine participation; and to make sure of funding allocations. Above all, you must ensure whatever approach your organisation adopts is meaningful, inclusive, and safe.

To end with some final advice from young people:

“If you are involved in care reform – we, young people with experience, are very receptive to provide ideas and recommendations for reform to succeed.”

“Think, together with beneficiaries, to the long-term effects, and have common objectives; do not just work on short, specific tasks that have only limited results.”

“It is important to do your work with dedication and as well as possible, because the lives of many children depend on your actions.”

“Evaluate and monitor as often and well as possible.”

“Encourage children and young people to participate in decisions that affect their lives, don't do this task for them; encourage them to speak up and to progress daily.”

(self-advocates)

ANNEX – ADDITIONAL RESOURCES

Below is a list of additional resources and sites you may find helpful as you look to integrate child and youth participation or strengthen existing practices:

- Better Care Network Library – Child Participation Resources. Available at: <https://bettercarenetwork.org/library/principles-of-good-care-practices/child-participation>
- Save the Children (2014). Toolkit for Monitoring and Evaluating Children's participation. Available at: <https://resourcecentre.savethechildren.net/document-collections/toolkit-monitoring-and-evaluating-childrens-participation>
- Keeping Children Safe Coalition (2014). Children's Participation in Child Protection Tool: Tool 4. Available at: <https://codeofgoodpractice.com/wp-content/uploads/2019/03/KCS-Childrens-Participation-in-Child-Protection-Tool-4.pdf>
- Kenya Society of Care Leavers & Changing the Way We Care (2018). How to Engage Care Leavers in Care Reform. Available at: https://bettercarenetwork.org/sites/default/files/care_leaver_guidance_2018_final.pdf

REFERENCES

1. The glossary here includes universally agreed definitions from the Better Care Network (BCN) Toolkit Glossary. Additional terminology used throughout is based upon definitions developed by Changing the Way We Care. For the BCN full glossary, visit: <https://bettercarenetwork.org/sites/default/files/attachments/glossary.pdf>
2. UN (1989). UN Convention on the Rights of the Child. United Nations, New York. <https://www.ohchr.org/EN/ProfessionalInterest/Pages/CRC.aspx>
3. United Nations Youth (2021). Frequently asked questions | United Nations For Youth. [online] Available at: <https://www.un.org/development/desa/youth/what-we-do/faq.html>
4. Marshall, P.J. & Fox, N.J. (2004). A comparison of the electroencephalogram between institutionalized and community children in Romania. *Journal of Cognitive Neuroscience*. 16(8): 1327-1338.
Nelson, C.A. et al. (2007). Cognitive recovery in socially deprived young children: The Bucharest Early Intervention Project. *Science*. 318(5858): 1937-1940. [Abstract] <http://science.sciencemag.org/content/318/5858/1937>
Rutter, M. (1998). Development catch-up, and deficit, following adoption after severe global early privation. *Journal of Child Psychology and Psychiatry*. 39(4): 465-476. [Abstract].
Vorria, P., et al. (2006). The development of adopted children after institutional care: a follow-up study. *Journal of Child Psychology and Psychiatry*. 47(12): 1246-1253. [Abstract] <http://onlinelibrary.wiley.com/doi/10.1111/j.1469-7610.2006.01666.x/abstract> [accessed 3 May 2017].
5. UN (1989). UN Convention on the Rights of the Child. Article 12 (UNCRC) states:
 1. Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.
 2. For this purpose, the child shall in particular be provided the opportunity to be heard in any judicial and administrative proceedings affecting him, either directly, or through a representative or an appropriate body, in a manner consistent with the procedural rules of national law.
6. UN (2006). UN Convention on the Rights of Persons with Disabilities. United Nations, New York. <https://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx> [accessed 9 Apr 2021].
7. Hart, R. (1992). Children's Participation: From Tokenism to Citizenship. *Innocent Essays No. 4*. UNICEF. See page 8. https://www.unicef-irc.org/publications/pdf/childrens_participation.pdf [accessed 9 Apr 2021].
8. See D. Basic requirements for the implementation of the right of the child to be heard, in UN Committee on the Rights of the Child (2009). General Comment No.12 The right of the child to be heard. <https://www2.ohchr.org/english/bodies/crc/docs/AdvanceVersions/CRC-C-GC-12.pdf> [accessed 28 May 2021].
9. See Kenya Society of Care leavers (KESCA) www.kesca.org for more information.
10. See Changing the Way We Care (2020). Package of COVID-19 Case Management and Virtual Monitoring Guidance and Tools. Available at: <https://bettercarenetwork.org/library/particular-threats-to-childrens-care-and-protection/covid-19/package-of-covid-19-case-management-and-virtual-monitoring-guidance-and-tools>
11. See Lumos (2017). Moving to My New Home. Available at <https://www.wearelumos.org/knowledge-portal/moving-my-new-home/>
12. For more examples and guidance around participation in the context of reunification and reintegration, see Inter-agency Group on Children's Reintegration (2016). Guidelines on Children's Reintegration. Available at: <https://resourcecentre.savethechildren.net/library/guidelines-childrens-reintegration>
13. For an example of a child-friendly information resource, see Lumos & Child Rights Centre (2017). Nobody is Allowed to Harm You. Available at <https://www.wearelumos.org/resources/nobody-allowed-harm-you/>
14. How to Engage Care Leavers in Care Reform. https://bettercarenetwork.org/sites/default/files/care_leaver_guidance_2018_final.pdf
15. Webinar Recording: More Than Our Stories - Strategies for how to meaningfully engage care leavers in care reform <https://bettercarenetwork.org/library/principles-of-good-care-practices/leaving-alternative-care-and-reintegration/webinar-recording-more-than-our-stories-strategies-for-how-to-meaningfully-engage-care-leavers-in>
16. To watch the video and learn more about the self-advocates' work, visit: https://www.wearelumos.org/moldova/media-centre/films/COVID-19_child_rights_protection/
17. For more information, visit https://www.wearelumos.org/moldova/media-centre/news/Marathon_2019/
18. See Helping Not Helping – Frequently Asked Questions. Available at: <https://www.helpingnothelping.org/advice>
19. See UK Foreign & Commonwealth Office (2019). Guidance: Gap years, volunteering overseas and adventure travelling. Available at: <https://www.gov.uk/guidance/safer-adventure-travel-and-volunteering-overseas#volunteering>
20. See Young Minds (2019). Adversity and Trauma-Informed Practice: A short guide for professionals working on the frontline. Available at: <https://youngminds.org.uk/media/3091/adversity-and-trauma-informed-practice-guide-for-professionals.pdf>
21. Resources on keeping children and young people safe online can be found here: <https://www.nspcc.org.uk/keeping-children-safe/online-safety/>
22. To see what data protection and privacy legislation applies in your country and region, visit the UN Conference on Trade and Development website: <https://unctad.org/page/data-protection-and-privacy-legislation-worldwide>
23. The GDPR is a regulation in EU law on data protection and privacy in the European Union and the European Economic Area.
24. More information and resources from the Turning Words Into Action are available at: <https://www.wearelumos.org/what-we-do/youth-participation/turning-words-action/>
25. Visit <https://www.wearelumos.org/stories/2018/07/12/pinch-salt-self-esteem/> to learn more and download the recipes!
26. Visit <https://www.youtube.com/watch?v=vXEeljibisU> to watch the self-advocates' powerful presentation.
27. For an example of a child-friendly document, see Lumos (2017). Moving to My New Home. Available at https://lumos.contentfiles.net/media/documents/document/2017/02/Moving_New_Home_Younger_Children.pdf
28. For an example of a youth-friendly document produced with the involvement of self-advocates, see Lumos (2020). What? How? Who? A Guide for Children and Young People who are About to Leave or Have Left Alternative Care Services. available at: https://lumos.contentfiles.net/media/assets/file/LUMOS_book_EN.pdf
29. To learn more about easy-read resources, visit <https://www.photosymbols.com/pages/easy-read>
30. For more information, see 'How to measure the scope, quality and outcomes of children's participation. Booklet 3', in A toolkit for Monitoring and Evaluating Children's Participation. Available at: <https://resourcecentre.savethechildren.net/library/toolkit-monitoring-and-evaluating-childrens-participation-how-measure-scope-quality-and>
31. More information about the self-advocates' research project can be found in Lumos (2017). Ending Institutionalisation: Moving from an Institution to a Community. Available at <https://www.wearelumos.org/resources/ending-institutionalisation-moving-institution-community/>
32. The charity BetterEvaluation offers lots of suggestions on how to report on and support the use of evaluations: <https://www.betterevaluation.org/sites/default/files/Report%20-%20Compact.pdf>



MacArthur
Foundation

Changing
THE WAY WE
careSM

For more information visit our website wearelumos.org

Lumos Foundation, founded by J.K. Rowling, is a company limited by guarantee registered in England and Wales no. 5611912. registered charity no. 1112575. ©