

# Changing THE WAY WE care



Photo by Philip Laubner / CRS

## Toolkit for Disability Inclusion in Care Reform

Communication  
Strategies to  
Promote Family  
Care for Children  
with Disabilities



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# Acknowledgement

The aim of this **Guidance on Communication Strategies** to promote family care for children with disabilities is to build the capacity and confidence of family strengthening and care reform practitioners to use communication strategies and messaging in raising awareness on the importance of family for all children and the use of residential care *only* as a last resort. The following document reinforces the importance of putting family care for children with disabilities at the top of any care reform agenda. The messages contained within advocate family care for children with disabilities as the best option and with recognition that families must be strengthened to provide safe and nurturing care. For children with disabilities who cannot be with their family of origin, family-based alternative care needs to be available and accessible. This document provides tools and examples for: planning communication strategies, creating key messages, determining audiences and communication methodologies, and building contextually-appropriate support networks among the different actors working in children's care.

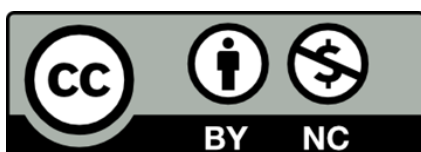
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# Section 1: Communication Versus Advocacy

Raising awareness of disability, disability inclusion and the rights of children with disabilities are key parts of the care reform processes in all countries. Through influencing those who currently operate, fund, support or develop policies around the residential care facilities (sometimes called institutions, children’s homes or orphanages) we can ensure that children with disabilities are not left behind. The policy makers with responsibility for systems of care and protection, providers of services for children, families and communities all may stigmatize or discriminate against families of children with disabilities. They may, with purpose or unconsciously, not include children with different abilities in their work and daily lives. With a cohesive and well-planned communication strategy, much can be achieved toward awareness, behavior change and the inclusivity of care services for all children.

**Communication** refers to the delivery and reception of information or messages to a target audience; whilst **awareness-raising** is a process that informs and educates on a topic or issue with the intention of influencing their attitudes, behaviors and beliefs and **advocacy** is the process of influencing decisions, actions or broader change. Within awareness raising and advocacy, communication that is strategic and planned, with clear objectives and actions leads to behavior or policy change. Communication without a strategy is unlikely to achieve its aims.

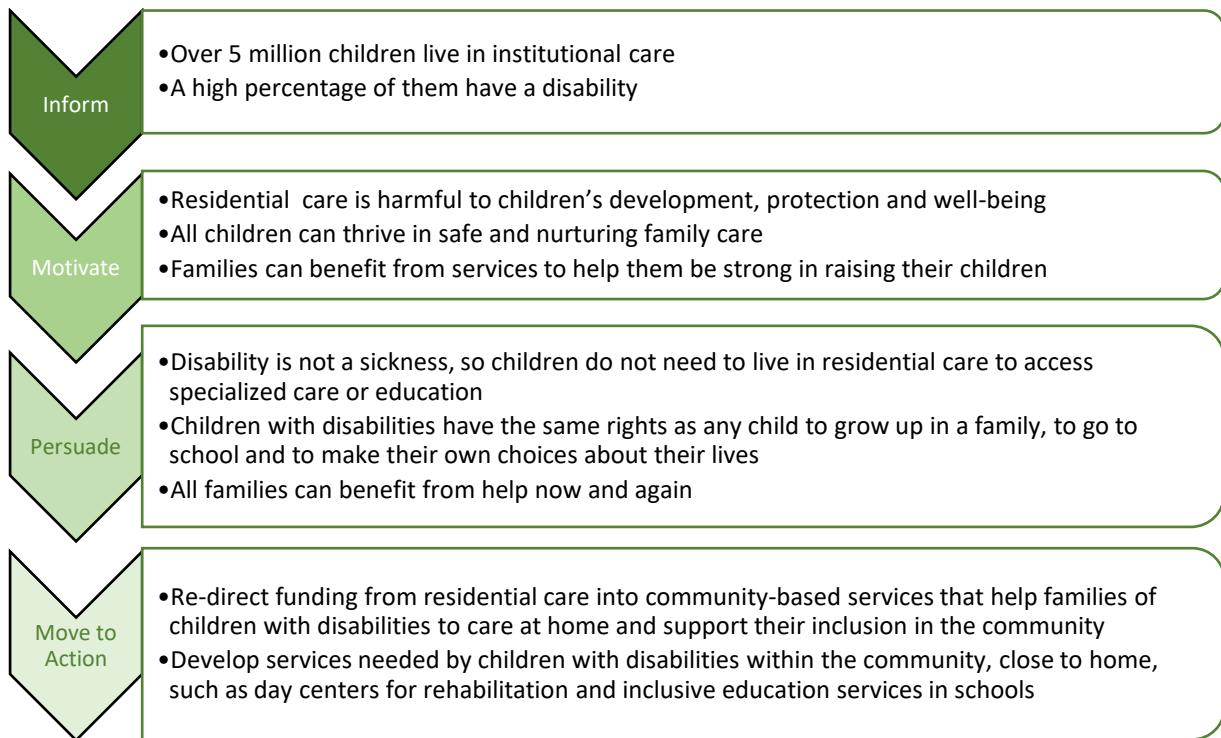
**Advocacy** is a continuous process which leads to positive change in attitudes, behavior and relationships within the family, workplace, community, state and society (i.e., all social institutions)

- *The Action Guide for Advocacy and Citizen Participation*

In the case of this document, the awareness raising and advocacy is on behalf of or to benefit children with disabilities—many of whom may struggle to communicate because of their disability or whose voices are not heard—and because adults, systems and services often do not consider the opinions of children and children with disabilities are often left behind in changing or improving systems of care. Wherever possible, include children’s own participation in raising awareness and advocacy efforts. This can have a very powerful influence on key actors and decision-makers. Giving adults with disabilities and their families a platform to share their first-hand experiences is also crucial.

With communication, a story is being told. With awareness raising education and information is shared. With advocacy, the target audience is being moved toward action. It is important to understand the difference.

## Example for Understanding Awareness and Advocacy



Think about who you need to communicate to; who needs to be part of change in your context. Use this model and fill in your own facts to inform your target audience (the person or group of people whose awareness, attitude or behavior you want to change). Completing the model will help outline the arguments to motivate and persuade and what actions you want your target audience to take or lead. This information is critical to developing your communication strategy and key messages.

*For more on defining the key audience see section 3.*

## Section 2: Communication Strategies

Developing a communication strategy with the aim to raise awareness and advocate for change requires clear goals, methods for communication or tools and resources. A good communications strategy identifies the potential allies, opponents and target audience.

- **Opponents:** Individuals or organizations who may oppose or disagree with your messages because they may be impacted negatively by the changes advocated, because of disagreement about underlying values or merely because they may not like being educated or corrected.
- **Allies:** Beneficiaries, individuals or organizations who will directly benefit or who can be persuaded to support your advocacy effort because of sympathetic concerns and similar values.
- **Targets:** Individuals or organizations that have the power to affect the change outlined in your advocacy goals.

### Matrix for Determining Influence of Opponents and Allies

Attitude of the audience on disability and family care	Very supportive				Main allies Key people / groups to influence Main opponents
	Supportive				
	Neutral				
	Opposed				
	Anti				
		Low	Medium	High	
		Influence level of audience on children's care			

	Primary allies & opponents
	Secondary allies & opponents
	Ignore

From the completed matrix, you can identify the strategies that may be most appropriate for which type of audience, for example:

- Build alliances with allies
- Persuade the allies with high influence that the issue is important
- Persuade the influential neutrals and soft opponents on your position
- Increase the influence of allies with low influence
- Reducing the influence of opponents with high influence

You will need to prioritize the audience groups you can target and plan your communications strategy according to available human and financial resources. There should be strong messages for the target audience/s; one that expresses what we need them to understand, know or do. Each audience has its own interest or perception about an issue. Our message

must be flexible so we can amend it to gain their attention. The core message, however, is defined by the goals we want to achieve.

How we deliver the message will determine whether our target audience does or does not receive it and pay attention to it. The channels of communication are, therefore, extremely important to consider and utilize effectively. The channels of communication include:

- **Mass media:** TV, radio, newspapers, magazine and internet
- **Printed material:** leaflets, posters, billboards, newsletters
- **Face-to-face:** one-to-one meetings, community meetings, roundtables, conferences, workshops
- **Social media:** Facebook, Instagram, twitter, YouTube, WhatsApp, messenger (and many others)
- **Formats:** website, blogging, articles, video clips, success stories, direct emails, updates, policy papers, research, advertisements, public service announcements (and many others)

**Influencers** are individuals and groups who can serve as messengers of the communication strategy and key messages. In some countries, for example, the church is well respected and has a lot of influence on the community. Local church groups can be influencers, able to help spread the messages. In other countries, organizations for persons with disabilities may have a lot of influence and be able to share messages with their members and allies. There may be a well-known celebrity who has a child with disabilities and is ready to raise awareness using their celebrity platform. Locate the persons who are influential in the communities where you work and reach out to them for support. They are your allies! Also take into consideration the differences in urban and rural populations, because different channels work better for the different locations.

The remainder of this section outlines three types of communication strategies—those which promote understanding, awareness and action.

## **Strategies to Promote Understanding**

Lack of understanding and awareness about the causes of disability and their characteristics leads to stigma and discrimination. Misconceptions about disability are often caused by cultural or religious beliefs, for example: *disability is a result of the sins of parents, a past life, a result of witchcraft or a punishment from God*. These misconceptions lead to inhumane treatment, abuse and discrimination. They can lead to children with disabilities being separated from their families or being stigmatized within the family. In some countries, it is the medical model which informs misconceptions, for example, the belief that a disability is a sickness which cannot be cured, that the child or person with disabilities cannot be educated, work or have relationships.

*Prior* to formulating messages, it is critical to understand the local beliefs and attitudes toward disability within your country context. Remember that there will be differences between urban and rural areas and sometimes even from one region to the next.

Communications strategies to combat stigma are essential for any program that promotes inclusion and family care for all children. Your strategies may focus on one or more key issues, including terminology, types of disability and barriers/accessibility. You may also want to promote positive messages to dispel the myths in your community about disabilities. For example:<sup>1</sup>

- ***People with Down syndrome experience a full range of emotion.*** They feel sadness, fear, anger and anxiety—just like anyone else. In fact, people with Down syndrome have a higher risk of depression and anxiety than others, although it often goes untreated.
- ***Persons on the autism spectrum can feel a full range of emotions, including love.*** Sometimes emotions can be even more pronounced than usual.
- ***A person can develop cerebral palsy in utero or later in life.*** Ten percent of people with cerebral palsy developed their disability later in life due to other causes, such as an infection (e.g. meningitis), stroke or severe head injury.

### *Disability Terminology*

Words are important because they can reinforce stereotypes, stigma and discrimination or, alternatively, they can be used to educate and promote positive values, beliefs and attitudes. Using the correct disability terminology is helpful in creating understanding and empathy. For example, some people with a disability do not like it when someone says they are “vulnerable” and need “care.” They prefer to think of themselves—and to be thought of by others—as capable and able to be independent. They prefer the focus to be on the barriers to their inclusion that have been created by society and how to break down those barriers. There can be barriers to children with disabilities being cared for in their families.

Here are some ways that people with disabilities are described.<sup>2</sup> People-first language is most respectful and should be used to describe different disabilities. This means that the “person” or “child” comes before the descriptor word. In children’s care some common examples are: use “children with disabilities” versus “disabled children” or “children in institutional care” versus “institutionalized children.” However, what is acceptable language for some people may not be for others. If you do not know what to say, ask a person how he/she likes to be described or listen for how they describe themselves.

<sup>1</sup> For more see: <https://www.aruma.com.au/about-us/blog/10-myths-about-disability/>

<sup>2</sup> For more information visit Kids As Self-Advocates: [http://www.aucd.org/docs/add/sa\\_summits/Language%20Doc.pdf](http://www.aucd.org/docs/add/sa_summits/Language%20Doc.pdf)



Disability	Respectful Language
Blind or Visually Impaired	Blind/visually impaired; person who is blind/visually impaired
Deaf or Hearing Impaired	Deaf or hard-of-hearing; person who is deaf or hard-of-hearing
Speech/Communication Disability	Person with a speech/communication disability
Learning Disability	Learning disability; cognitive disability; person with a learning or cognitive disability
Mental Health Disability	Person with a psychiatric disability; person with a mental health disability
Mobility/Physical Disability	Wheelchair user; physically disabled; person with a mobility or physical disability
Emotional Disability	Person with an emotional disability
Cognitive Disability	Cognitively/developmentally disabled; person with a cognitive/developmental disability
Short Stature, Little Person	Someone of short stature; little person
Health Conditions	Survivor; someone “living with” a specific disability (e.g., “someone living with cancer or HIV”)

Legal terminology may also promote a medical understanding of disability by referring to disabilities as conditions of limited health opportunities. Instead, the preference is for person-first and rights-based language.

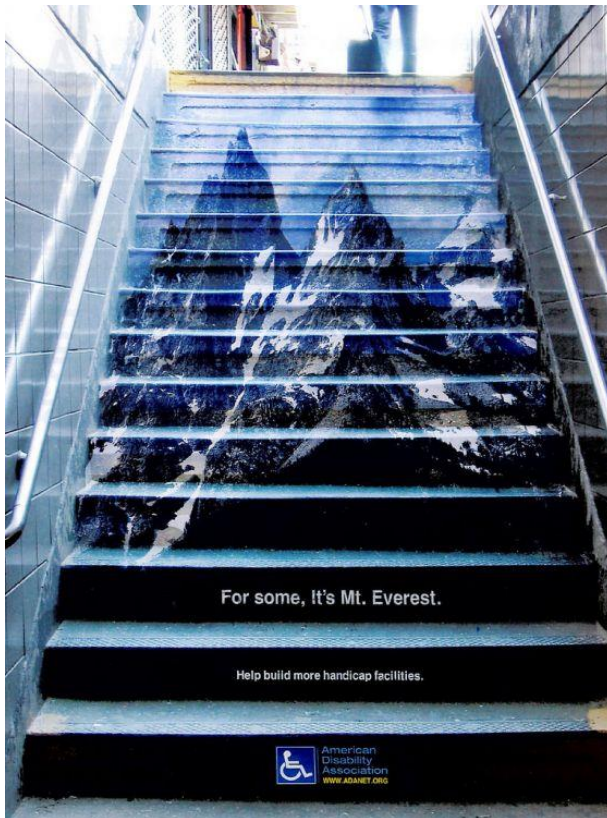
Consult with the key groups of people with disabilities, non-governmental organizations and civil society organizations to ask what terminology they consider as appropriate in your country context.

### *Barriers and Accessibility*

Many people are unaware or do not understand that accessibility is a crucial issue for people with disabilities, and that accessibility is a barrier to inclusion. Physical barriers are everywhere—from lack of lifts and wheelchair ramps, to narrow doorways and handles that are impossible to grip. These physical barriers make it hard for many children and adults to have equal access in their communities. When a child is small, a parent may be able to carry the child. But as he/she grows bigger and heavier, the lack of accessibility for wheelchairs and other walking aids can lead to abandonment. Although physical barriers faced by people with disabilities may be the more obvious ones to include in communication campaigns, it is equally important for communities and service providers to understand other forms of accessibility—namely attitudinal, information, communication and financial.

You can find many examples of communication campaigns and messages around this issue. A [short video clip](#)<sup>3</sup>, such as this one, can be adapted for any country to make the general public aware of accessibility challenges in a city. At the same time, it sends a message to people with disabilities that they have a right to be part of society and to be in the community.

<sup>3</sup> <https://www.youtube.com/watch?v=cDPrfRC5bq0&t=1s>



Pictures can also be used in both online and printed communication campaigns to promote understanding about barriers. In this picture, the flight of stairs is being compared to climbing Mount Everest.<sup>4</sup> It is promoting the action of building more facilities that are accessible to people with disabilities.

Image sourced from the U.S. Department of Justice, Civil Rights Division.

## Strategies to Promote Awareness

Awareness-raising campaigns are designed to bring education, facts and information to target audiences. A more informed audience should display less stigma and discrimination toward people or children with disabilities. The messages you select will depend on the knowledge gaps of your target audience. However, keep in mind that your audience may include multiple stakeholders with differing information needs and different modes of hearing/seeing those messages. The following awareness campaign examples and topics are especially relevant to care reform initiatives that are inclusive of children with disabilities and their families. These examples may be useful to tailor to your country context.

### *Promoting Inclusive Education*

“Education for All” is a simple message/campaign slogan that can be used in a strategy that targets all audiences to promote inclusive education. The same message can be adjusted according to the audience, as demonstrated below.

*For policymakers,* Education for All can be the key message that promotes inclusive policies.

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<sup>4</sup> “For some its Mount Everest” a campaign from the U.S. Department of Justice, Civil Rights Division. More at: <https://www.ada.gov>

- **Why?** All children have the right to an education as stated in the United Nations Convention on the Rights of the Child (UNCRC): Article 28 of the UNCRC says that children and young people have the right to education regardless of race, gender or disability, if they are in detention or if they are a refugee.



Article 24 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) protects the right to education of persons with disabilities. It proclaims the right to inclusive education and prescribes the steps that must be taken to this end.

*For parents,* Education for All can be the key message to empower parents of children with disabilities and parents of children who are scared that their child will suffer in an inclusive classroom.

- **Why?** Every child has the right to an education, as stated in the UNCRC and UNCRPD. Inclusive education benefits all children and helps reduce the stigma and discrimination that is caused by segregation. Inclusive education for children with disabilities means that they have the right to access quality education on an equal basis with all children. In practical terms, this means they are given the opportunity to attend school and, when required, are provided with extra support to do so.

*For schools,* Education for All can be the key message to persuade teachers and school directors that all children have the right to an education.

- **Why?** Not all disability is visible—many children are developmentally delayed or have a learning disability that may be misunderstood, leading to the child being excluded from a class. Inclusive education means understanding that all children have their own way of learning and accommodating for that possibility.

### *Understanding and Incorporating Different Types of Disabilities*

Regardless of the type of disability that is creating stigma in your community, it is important for communities to know that anyone can be affected by disability at any stage of life, whether at birth or later in life. The slogan “*nobody is insured from disability,*” can help convey this concept, so everyone has an interest to improve life for people with disabilities.



Recreation of [image](#) created by grumpy littles, 2015.

The image to the left is an example of a message that expresses the difference in visible and invisible disabilities. Intellectual disabilities are often invisible but significantly impact the lives of children, adults and their families, leading to exclusion from education, work and family life. It is important to raise community awareness of those impacts on the everyday experience. This (Spanish

language) [clip](#) and another [clip](#)<sup>5</sup> from Zambia provide information about the inclusion of people with intellectual disabilities.<sup>6</sup>

A valuable communications tool for any campaign is to use international days (such as International Day of the Child) to send a message to communities about different types of disabilities. These international days have either their own websites or through UN organizations, and will help you with messages, images, clips and ideas to raise awareness about different disabilities.

Many organizations and governments use these days to hold events for children to be broadcast on mass media, or to gather communities together around the children.

- 21 March, [World Down Syndrome Day](#)
- 01 June, International Child Protection Day
- 13 June, [Albinism Awareness Day](#)
- 06 October, [World Cerebral Palsy Day](#)
- 03 December, [International Day of People with Disabilities](#)

### *Improving Detection and Intervention*

When working with parents or caregivers of children with disabilities, many projects provide information about different types of disabilities, detection and early intervention. Below are examples of facts that build parent and caregivers' awareness on these issues. This communication targeted to parents, other caregivers and communities is also very important.

**Early identification and early intervention** refer to the processes in which the relevant system for children 0–3 years identifies a congenital disability or a developmental delay and immediately intervenes to help the child and their family.

**Video communications examples**

[What is an intellectual disability?](#) (Spanish)

[What is an intellectual disability?](#) (English)

The following are examples of messages targeted toward early childhood development practitioners, health providers, social workers and other

<sup>5</sup> <https://www.youtube.com/watch?v=zaS2PhQkWLg>

<sup>6</sup> <https://www.youtube.com/watch?v=WZi97uGQ37I&t=32s>

community service providers working with parents and caregivers of children with disabilities. Note the more technical language. The aim of these messages is to share facts about early detection and intervention.

- Neural circuits, which create the foundation for learning, behavior and health, are most flexible or “plastic” during the first three years of life. Over time, they become increasingly difficult to change.
- Persistent “toxic” stress—such as extreme poverty, abuse and neglect, or severe maternal depression—can damage the developing brain, leading to lifelong problems in learning, behavior, and physical and mental health.
- The brain is strengthened by positive early experiences, especially stable relationships with caring and responsive adults, safe and supportive environments and appropriate nutrition.
- Early social/emotional development and physical health provide the foundation upon which cognitive and language skills develop.
- High-quality early intervention services can change a child’s developmental trajectory and improve outcomes for children, families and communities.
- Intervention is likely to be more effective and less costly when it is provided earlier in life rather than later.

### *Promoting Family-Based Care Through Personal Stories*

Personal stories are a powerful medium to raise awareness in communities. They can be shared by a family coping with their child’s disability or by a person who has grown up in residential care. Lumos Foundation gathered [children’s stories](#) about their experience of living in residential care and the difference for them when they moved to family-based care.<sup>7</sup> This [video](#) from Hagar in Cambodia further illustrates how recorded interviews can provide valuable information to raise awareness amongst case workers, case managers and parents/caregivers. In the video Sreyna and Chenda, two practitioners, discuss their learning regarding the impact of the care setting on child rehabilitation.<sup>8</sup> Remember to carefully follow your organization’s guidance on safeguarding and ethical storytelling. Always ensure permissions are in place and tell a respectful story.

#### **Example key messages from the video**

*Moving a child from one place to another adds another traumatic experience for the child.*

*Why?* Children who can stay in their community do not need time to adjust to a new environment since support is individualized and tailored, making rehabilitation much easier. Additionally, they receive positive support and influence by their family.

<sup>7</sup> <https://www.wearelumos.org/stories/category/childrens-voices/>

<sup>8</sup> [https://www.youtube.com/watch?v=jsodCX\\_q37k](https://www.youtube.com/watch?v=jsodCX_q37k)

*If the family is strengthened, they can better support the child. Services focused only on the child have proven to be ineffective.*

*Why?* Children in shelters were distanced from their family and community. When they went back home, they had to readjust to village and community life. Putting children in such a challenging process could be avoided by preventing family separation in the first place with appropriate support services close to home.

*When children cannot be reintegrated with their family or extended family, alternative family care (foster care) is the best option.*

*Why?* The process of adjustment is less challenging than being placed in residential care because the environment is familiar and children can continue to be in the community. Safe and nurturing family care gives the child the opportunity for individualized care and love necessary for their growth and development.

In the Children in Families A Better Life Experience (ABLE) project in Cambodia disability inclusion is promoted. In this [video](#) Sorn Sreyny and Lisa Yunker share their experience of making family-based care inclusive for children with disabilities.<sup>9</sup> They discuss their key learning with respect to supporting caregivers to care for children, including the importance of managing stress and expectations, developing trusting relationships and taking a whole family approach for support-giving.

### **Example key messages from the video**

*Therapy can enhance child development and child functioning but not “cure” the child.*

*When expectations are unrealistic or too high, families can get discouraged and reject the child.*

*Why?* When the child is placed with relatives or a foster family, the workers take time to get to know the family first and understand their routines and habits. Building a trusting relationship is very important. If caring for the child means that the family must radically change their normal daily life, that would add stress to the family. If the family is continuously under severe stress it is going to interfere with their bonding with that child and negatively impact the quality of care. If the root causes of stigma and stress in the family are not addressed, the likelihood of placement breakdown or abandonment increases significantly.

### ***Building Awareness on the Harm of Institutionalization to Child Development***

Many actors around the world, even those with genuine heart and experience working with children, are not aware of how harmful institutionalization (or separation from family and placement into residential care) is to the child. This is particularly important data to share with operators, founders, supporters, policy makers and donors to residential care facilities. Institutionalization is equally harmful to children with disabilities as it is to children without, in fact it may be more harmful when needed medications, rehabilitation or other services are not accessed. The message on the harm of institutionalization is backed by over eight decades of evidence and is conveyed in the following excerpt from the Lancet Group Commissioned

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<sup>9</sup> <https://www.youtube.com/watch?v=w42t7UwfOkc>

Series on the Institutionalization and Deinstitutionalization of Children, published in June 2020:<sup>10</sup>

*Institutionalization often has a profound effect on a child's physical and psychological development and can be associated with long-term mental health problems. The greatest effects are on physical growth and cognitive development: at least 80% of institutionalized children were below the mean of comparison groups in these domains. Institutionalized children are also at greater risk of attachment problems. Longer stays in institutions lead to more problems, and exposure between 6–24 months of age might be especially damaging.*

This evidence can be crafted into key messages using language and communications avenues appropriate for different audiences. It can be important to communicate an appreciation for the care that many have shown in operating, supporting or working in children's care. Most did so out of a desire to help, not harm. Providing the evidence can promote their helping in ways healthier for children and families.

## Strategies to Promote Action

A comprehensive communication strategy will inform, motivate and move someone to take action. Commonly used strategies to promote action include petitions, advocacy campaigns, joining social movements and policy or white papers. Again, the message and mode of delivery will depend on who you are trying to move to action and what action you want to bring about. Some examples of each are:

- Establish a petition among parents to lobby for legislation changes in support of services for their children with disabilities or present your work, evidence and practice examples to your legislators.
- Form a network with like-minded organizations to advocate together, such as in the example of [ReThink Orphanages](https://rethinkorphanages.org)<sup>11</sup>, calling for the end of orphanage tourism (i.e., voluntourism) Hashtags are used to link all social media messaging together, such as #endvoluntourism and #AlwaysFamilyNeverOrphanages.
- Utilize and join together with faith-based movements, such as the [Faith to Action Initiative](https://www.faithtoaction.org)<sup>12</sup> to advocate for faith engagement in family-based care. They use a wide range of tools, such as research, blogs, calls-to-action, stories and guidance to communicate their core messages:
  - *children grow best in families and thrive in community*

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<sup>10</sup> The full commission can be accessed via: <https://bettercarenetwork.org/library/principles-of-good-care-practices/transforming-institutional-care/lancet-group-commission-on-the-institutionalisation-and-deinstitutionalisation-of-children>

<sup>11</sup> <https://rethinkorphanages.org>

<sup>12</sup> <https://www.faithtoaction.org/take-action/>

- *an orphanage cannot replace a family*
  - *supporting families to care for children is the better choice*
  - *as Christians, we have an important role to play in promoting family care and strengthening families*
- Engage faith-based leaders in advocacy campaigns to reduce community stigma and promote inclusion of children with disabilities. One example is a comprehensive set of advocacy tools from [Kupenda for the Children](#)<sup>13</sup>.
  - Inform, motivate and move-to-action the need for community-based services. One example of such an effort around mental health services is [Break the Chains](#)<sup>14</sup>, an impactful cause-based website that uses the most modern communications tools. Hashtags, video clips and strong messaging convey the key message: *people should live in dignity, not chains*. Users are encouraged to share online petitions on social media and create personal avatars using the campaign’s filters.
  - Deliver direct messages via written documents. The UNICEF white paper on “The role of small-scale residential care for children in the transition from institutional to community-based care and in the continuum of care in the Europe and Central Asia Region”<sup>15</sup> is one such example, which relayed these key messages:
    - *Children in need of alternative care have diverse and complex needs that should be met through a comprehensive childcare, welfare and protection system that offers a range of high-quality care and support options for children and their families.*
    - *Children under the age of 6 years should not be placed in any form of residential care setting.*
    - *Children should never be separated from their family or placed in any alternative care setting because of poverty, disability, ethnicity, gender, religious affiliation, sexual orientation or mental health status.*

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<sup>13</sup> <https://kupenda.org>

<sup>14</sup> <https://www.hrw.org/BreakTheChains>

<sup>15</sup> The full paper can be accessed here: <https://www.unicef.org/eca/media/13261/file>



## Section 3: Message Development

A **message** is a statement which can be tailored to different audiences. It defines the issue, states the solution, and describes the actions to be taken.

### ISSUE + SOLUTION + ACTION = MESSAGE

Developing impactful messages is a process. The message should be aligned to your communication strategy’s defined goals and adapted to suit the influence you want to have on the key audiences you determine. It should also fit with the mode of delivery. The following steps give illustration of how messages might be crafted in step-by-step process, using the example of children with disabilities and institutionalization. This is only an example of how you can use the process.

#### *Message Development Format - audience donor or government example*

<b>Action desired</b>	Reallocation of funding to family- and community-based services
<b>Message content</b>	<ul style="list-style-type: none"> <li>• Residential care can have a negative impact on children’s growth and development, including long-term consequences that influence over a lifetime</li> <li>• Children with disabilities are disproportionately separated from their families and institutionalized, even while they have the same rights as all children, including to be protected in family, to go to school, etc.</li> <li>• Residential care is up to 6 times more expensive than family care; 8 times more expensive than providing social support to vulnerable families; and 2 times more expensive than providing community-based residential care or small group homes</li> <li>• Examples of family- and community-based services and their costs as compared to residential care – where possible mapping of services and shows where gaps are</li> <li>• Quotes from children with disabilities and their families about the difference this reform will make to their lives</li> </ul>
<b>Format / channel</b>	White paper, policy advocacy presentation
<b>Messengers</b>	Program staff, child and parent advocates
<b>Time and place of delivery</b>	Sent out to legislators, presentation at legislative session

### Steps for Developing Key Messages

#### **Step 1: Identify the problem to be addressed**

Example: Parents relinquish children with disabilities to residential care instead of being empowered to care for them at home.

## Step 2: Define the causes, consequences and potential solutions

Causes	Consequences	Solutions
<ul style="list-style-type: none"> <li>• Fear of not being able to cope with the child's care</li> <li>• Fear of what other people may say about them</li> <li>• No services in community and too far to travel to access what exists</li> <li>• Local school will not take the child</li> <li>• Parents must work and there is no one to take care of the child</li> </ul>	<ul style="list-style-type: none"> <li>• Children grow up in residential care without adequate care and attention and have long term harms to their development</li> <li>• Stigma continues, because nobody sees children with disabilities in their community</li> <li>• Governments/donors continue to bear the cost of operating residential care</li> <li>• Families are disempowered to care for their children with disabilities</li> <li>• NGOs and community organizations are disincentivized to provide community services for children who are not "seen" as in their community</li> </ul>	<ul style="list-style-type: none"> <li>• Raise awareness about the needs and rights of children with disabilities for family care</li> <li>• Raise awareness about the causes of disability and the harms of institutionalization</li> <li>• Campaign for community-based services that support families to take care of their children</li> <li>• Prepare a cost/benefit analysis to demonstrate that community-based care will be cheaper than institutional care in the long run</li> <li>• Support the development and activities of an advocacy group of parents or young people who have experienced separation</li> </ul>

## Step 3: Identify the target audience for key messages and actions

1. Parents and family members
2. Residential care providers
3. Communities
4. Government/donor organizations

*See also information in Section 2 on identifying allies and opponents and defining audiences*

## Step 4: Create the message

The following are tips for developing the key message. The messages and delivery approach will be different or nuanced for each audience and country context.

- **Information/image:** what is the central idea/main point you wish to give to the audience with written or visual content?
- **Language:** the words you choose will be different for each target audience, so remember to reflect those differences – consider non-verbal as well as spoken word.
- **Messenger/source:** who will be giving the message and how will their influence resonate with the defined audience?
- **Format/channel:** these include meetings, announcements, press releases, briefing packet, posters, radio/TV announcements, social media posts and etc. Consider how

your audience best receives messages – there may be considerations for the age of your audience, the country context, etc.

- **Time + place:** Is there a better timing and/or place for delivery of the message? For example, social media posts have more impact if posted at the start of the working day or in the early evening when more people are online.

## Examples of Key Messages

### Examples of messages *for parents and family members:*

- Your child has feelings and the need to be loved, just as any child. Places like orphanages or children’s homes or institutions do not provide the same care and attention as you can at home.
- All families benefit from support sometimes – it’s okay that you might need support to raise your children.
- Disability is not a sickness. It is not a barrier to life. It is society that creates these barriers, by treating disability as a sickness. Loving support will help your child overcome these barriers, even if they may always have different abilities than you.
- Residential care like orphanages or children’s homes can cause harm to children and expose them to risks like violence or abuse. Children with disabilities are the most vulnerable because they can be dependent on adults to look after them. Families are able to protect children better than orphanages, especially when they have support to do so.

These are just a few examples of messages that you can use to help overcome stigma or misconceptions within the family. You can develop your own messages based on how parents or other family members view disability in your own country context and with an understanding of their fears and worries. Better still, work with families to develop the messages they want others to hear or that they wished they heard! Use message development to build a group of family advocates! Children, too, can be great message developers! You can find resources on how to engage children in advocacy at the end of this document.

### Examples of key messages *for residential care providers and other service providers:*

- Deinstitutionalization does NOT mean closing residential care facilities; it does not ONLY mean reunifying children to their families; it does NOT mean people will lose their jobs.
- It actually means building strategies which aim to solve the REASONS for children being placed in residential care and transforming into the services needed to strengthen and support families to raise their children.

- Care reform is NOT only about deinstitutionalization or the reintegration of children and families. It is also about developing prevention services to keep children with families and strengthening families to provide for children’s care, and about new kinds of family-based alternative care for children who cannot be with their families.
- Residential care facilities CAN play a valuable role in care reform with their heart for children’s care, resources (budget, staff, buildings and equipment) and their role in providing services in the community. What MUST change is their purpose; their model; their services.

#### Examples of key messages *for communities:*

- 10–15% of the community affected by disability. Many disabilities are not visible. People with disabilities – adults and children – are valuable community members. Public services must be accessible to children and adults with disabilities and support all our families in order for the community to be strong.
- A child with a disability has the same rights as any child: to be protected in a family, to go to school, to play, to have their opinions heard, to get a job and be productive, and to have friends, relationships and raise a family of their own. The barriers to these rights are created by society, by the community, not by the disability.
- Disability is not contagious. It is nobody’s fault. It is not a disease. Disability can be a result of poverty, poor health care during pregnancy, virus, mosquito bite or an accident. We are all vulnerable to disability so let us support, not stigmatize.

#### Examples of key messages *for governments/donors:*

- Disability rights are human rights. Children with disabilities have the same rights as any other child to live in a family, go to school and participate in society.
- Residential care facilities such as orphanages and children’s institutions are the problem, not the solution. This clip from [Disability Rights International](#) uses emotion to share the message that family care is best for children with disabilities, just as it is for all children, and community donations may be well-meaning but continue to support segregation.
- Residential care is up to six times more expensive than family care, eight times more expensive than providing social support to vulnerable families and two times more expensive than providing community-based residential homes (commonly called “group homes”).<sup>16</sup>

For any of these messages use the information you have from your contexts to strengthen your message with facts, evidence and add the action or actions outlined in your communications strategy.

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<sup>16</sup> More information available from Lumos Foundation: <https://www.wearelumos.org/what-we-do/policy/cost-of-change/>

## Creating Accessible Messages

Modes, formats and channels of communication for advocacy and awareness are diverse. Choosing modes, formats and channels that are fully accessible can be an important step into being fully disability inclusive in your communication strategy and actions. Section Two of the World Blind Union and CBM Global Disability Inclusion's [Accessibility Go!](#) provides helpful considerations for creating accessible messages and using communication technology (e.g. Easy Read documents, large print or alternative formats). When developing accessible content consider:

- Starting with good design that considers accessibility from the beginning.
- Listen to children and adults with disabilities about their preferences and what works.
- Get the language and the images right.
- Learn to use online accessibility tools<sup>17</sup>
- Follow best practices
- Be sure to understand online safety and safeguarding for children!

It is important to set aside resources for accessible communication and technologies to assist people in both producing and receiving/hearing the content of your communication strategy and actions. Before using social media for awareness and advocacy messaging consider accessibility challenges faced by people with disabilities and how you might make the messaging more accessible, for example using alternative text for images and closed captioning for videos. As you select images for your communication, try to represent a wide variety of people and children with disabilities, including age, gender and ability diversity. Remember many disabilities are not visible! Include people and children with disabilities in the planning, design, review and delivery of the communication strategy as an effective means to promote participation and accessibility.

**Accessibility** means taking appropriate measures to ensure access to persons with disabilities, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas. These measures include the identification and elimination of obstacles and barriers to accessibility.

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<sup>17</sup> Resources can be found in the CBM Digital Accessibility Toolkit:  
[https://www.cbm.org/fileadmin/user\\_upload/Publications/CBM-Digital-Accessibility-Toolkit.pdf](https://www.cbm.org/fileadmin/user_upload/Publications/CBM-Digital-Accessibility-Toolkit.pdf)

## Section 4: Additional Resources

### Tools for advocacy:

- World Blind Union and Christian Blind Mission (CBM) Global Disability Inclusion resources and toolkits: <https://worldblindunion.org/programs/accessibility/>
- Keeping Children Safe tools and resources - child safeguarding – online safety: <https://www.keepingchildrensafe.global> and [https://www.keepingchildrensafe.global/wp-content/uploads/2021/08/KCS\\_OnlineGuidance\\_2020.pdf](https://www.keepingchildrensafe.global/wp-content/uploads/2021/08/KCS_OnlineGuidance_2020.pdf)
- Communicate to Advocate: Driving Change for Children, UNICEF Global Communication and Advocacy Strategy 2018–2021: <https://www.unicef.org/rosa/media/2436/file/ROSA%20C4D%20Strategic%20Framework.pdf>
- Catholic Relief Services – Resources and Tools for Action: <https://www.crs.org/get-involved/lead-way/action-center>
- Global Social Service Workforce Alliance, Advocacy Toolkit for the Social Service Workforce: <https://bettercarenetwork.org/library/social-welfare-systems/social-service-workforce-strengthening/global-advocacy-toolkit-for-the-social-service-workforce>

### Disability resources:

- Disability Stigma in Developing Countries by Brigitte Rohwerder, Institute of Development Studies: <https://opendocs.ids.ac.uk/opendocs/handle/20.500.12413/13795>
- United States Agency for International Development on disability language: [https://pdf.usaid.gov/pdf\\_docs/Pnadm699.pdf](https://pdf.usaid.gov/pdf_docs/Pnadm699.pdf)
- National Youth Leadership Network on Respectful Disability Language: [http://www.aucd.org/docs/add/sa\\_summits/Language%20Doc.pdf](http://www.aucd.org/docs/add/sa_summits/Language%20Doc.pdf)
- Family Care for Children with Disabilities: Practical Guidance for Frontline Workers: <https://bettercarenetwork.org/library/particular-threats-to-childrens-care-and-protection/children-with-disabilities/family-care-for-children-with-disabilities-practical-guidance-for-frontline-workers-in-low-and>

### Care reform and disability inclusion:

- Enabling Reform: Why supporting children with disabilities must be at the heart of successful child care reform: <https://bettercarenetwork.org/library/particular-threats-to-childrens-care-and-protection/children-with-disabilities/enabling-reform-why-supporting-children-with-disabilities-must-be-at-the-heart-of-successful-child>
- Lancet Commission Series on Institutionalization and Deinstitutionalization of Children: <https://bettercarenetwork.org/library/principles-of-good-care-practices/transforming-institutional-care/lancet-group-commission-on-the-institutionalisation-and-deinstitutionalisation-of-children>

- Deinstitutionalization and quality alternative care for children in Europe: Lessons learned and the way forward by EuroChild and Hope and Homes for Children: [https://www.openingdoors.eu/wp-content/uploads/2014/11/DI\\_Lessons\\_Learned\\_web\\_use.pdf](https://www.openingdoors.eu/wp-content/uploads/2014/11/DI_Lessons_Learned_web_use.pdf).

### **Parents and children as advocates / participation of children in advocacy:**

- Nine Basic Principles for Meaningful and Ethical Children’s Participation: <https://bettercarenetwork.org/library/principles-of-good-care-practices/child-participation/the-nine-basic-requirements-for-meaningful-and-ethical-childrens-participation>
- International Parent Advocacy Network’s Online Toolkit for Transformation: <https://toolkit.parentadvocacy.net/>
- International Review of Parent Advocacy in Child Welfare: Strengthening Children's Care and Protection Through Parent Participation: <https://bettercarenetwork.org/library/principles-of-good-care-practices/parent-participation/international-review-of-parent-advocacy-in-child-welfare-strengthening-childrens-care-and-protection>
- How to Engage Care Leavers in Care Reform: <https://bettercarenetwork.org/library/principles-of-good-care-practices/leaving-alternative-care-and-reintegration/how-to-engage-care-leavers-in-care-reform>
- Webinar: More than Our Stories: 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>

### **Examples of campaigns, alliances and advocacy messages:**

- Disability Rights International Media Gallery: <https://www.driadvocacy.org/media-gallery/>
- Changing the Way We Care: <https://www.changingthewaywecare.org>
- ReThink Orphanages: <https://rethinkorphanages.org>
- The Love You Give Campaign: <https://www.loveyougive.org>
- Opening Doors Campaign: [www.openingdoors.eu](http://www.openingdoors.eu)
- Transform Africa Alliance: <http://transformallianceafrica.org/resources>
- Humanity and Inclusion: <https://www.hi-us.org>