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Denyireth Machado and Adalay Zabala, Ambassadors of Inclusion, smile and share during the closing ceremony and presentation of certificates of the "Ambassadors of Inclusion" program, Venezuela, 2023

MODULE 1

Inclusive Evidence Generation for SBC

Addressing stigma and discrimination toward children and youth with disabilities through social and behavior change (SBC).



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FOREWORD

Fifteen per cent of the world's population – at least one billion people – have some form of disability, whether present at birth or acquired later in life. Nearly 240 million of them are children. One in every 10 children globally has a disability.

Inclusion starts with the understanding that disability is the result of interactions between inaccessible environments and a person who has long-term impairments. Inclusion can be achieved when people work to break down physical barriers, when services are accessible to everyone, when policies equally benefit all individuals, when communications reach every person, regardless of if they are blind, deaf or have low literacy. But acting to move the world further in this direction requires an inclusive mindset as foundation.

Unfortunately, many people in most societies across the world still have negative, pitying, patronizing attitudes toward people with disabilities. As a result, over one billion people continue to experience stigma and discrimination. This sometimes manifests in violence, institutionalization or exclusion from society, and sometimes in silence or overprotection. Breaking the stigma will require multilevel strategies co-developed with children and adults with disabilities. Governments and partners need to invest in integrated, evidence-based social and behaviour change (SBC) interventions to address the negative attitudes, beliefs and norms that fuel stigma and discrimination against children with disabilities, and to make services more accessible and inclusive. Service providers and communities need to be empowered to support the inclusion of children and adults with disabilities and to enable their access to services. Policies that address stigma and discrimination against children with disabilities and their families need to be put in place, with enough resources allocated to implement them. Drawing on various disciplines – sociology, psychology, communication and behavioural economics – SBC encompasses a broad set of strategies and interventions that influence drivers of change and support local action towards better societies. In every sector, UNICEF's SBC programmes bring together local knowledge with scientific insights to support the most vulnerable. Based on the reports, In 2023, over 100 UNICEF country offices are already implementing SBC interventions to promote disability inclusion. This toolkit will support them, and contribute to rallying additional country offices to further advance inclusive SBC interventions so that all children have equal opportunities.

This toolkit was developed through extensive consultation with UNICEF employees, organizations of persons with disabilities, SBC experts, government partners, academics, and youth with disabilities. It provides insights, tools and resources to help users understand barriers to the inclusion of children with disabilities. It offers practical support to help design and implement SBC programmes that engage and empower children with disabilities and their families to be agents of change in their communities, and to enjoy the same opportunities as their peers.

We hope you will enjoy diving into this toolkit as much as we enjoyed developing it with many of you.




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Addressing stigma and discrimination toward children and youth with disabilities through social and behaviour change (SBC).




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The students of the Junior Secondary school will act in the Children's Parliament of Congo

MODULE 0

Foundation Module




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Danielynn Marabato and Adelle Zabala, Advocates of inclusion, smile and share during the closing ceremony and presentation of certificates of the 'Inclusión de las Mujeres' program, Venezuela, 2022

MODULE 1

Inclusive Evidence Generation for SBC




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Children of an inclusive advocacy activity promote children's rights of the launch of mobile phones on protection, water, hygiene, and sanitation, Venezuela, 2022

MODULE 2

Empowering Children and Families




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Children with autism from Bangladesh are enjoying the event of the Blue Campaign program, organized by UNICEF Bangladesh to mark the World Children's Day

MODULE 3

Understanding and engaging communities




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Mahmoud, Sama Region, Jordan is a person with disability, community health worker and president of the independence committee. He assists individuals during gender-violence campaigns

MODULE 4

Disability-inclusive services




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The students of the Junior Secondary school act in the Children's Parliament of Congo

MODULE 5

Strengthening partnerships for advocacy




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The collapsed house of Mr. Duong Van Nam, 40 years old and Mr. Chu Thi Hoa, 30 years old during the flood. The couple have three children: the eldest daughter is 7 years old and the 2nd and 3rd children were born with visual impairments, Viet Nam

MODULE 6

Disability-inclusive SBC in humanitarian settings



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Bachien, 7 years old has received an eye braille from UNICEF during the lesson at school with his teacher Hayana

MODULE 7

Monitoring, evaluating and measuring

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Sarah's story, part 1

Since I was little, I have visited many doctors. My mom did her best to find a way to 'cure' me. In conversations with doctors, social workers and non-governmental organizations, she was asked lots of 'what?' questions – like, 'What are my symptoms?' But they did not talk to us about 'What are our options?', or 'What services are available?' I was given a wheelchair, because they assumed that I needed one. It is still with us, often used to bring something heavy from the market.

Even when I got older, my mom was the primary contact in making decisions about my health. Health workers usually spoke to her, without discussing anything with me. They asked, 'What do I need to get to school?', and 'What cane do I prefer?' – but they had no patience to listen to my responses or to create an inclusive environment for me to respond. But things are changing now.



INTRODUCTION



About this toolkit

This toolkit was developed to help achieve a world where “all children, including those with disabilities, live in barrier free and inclusive communities, where persons with disabilities are embraced and supported, across the life cycle, to realise and defend their rights, and to achieve full and effective participation” (UNICEF Disability Inclusion Policy and Strategy, 2022-2030).

SBC programming has a critically important and urgent role to play in identifying and implementing solutions that empower children with disabilities and their families and support their social inclusion. We are therefore pleased to share this practical guide to understanding and tackling the social norms and behaviours that limit the inclusion of children with disabilities in their communities.

This toolkit aims to provide insights, tools and resources to help you understand the barriers to the inclusion of children with disabilities, with a focus on stigma and discrimination, and to offer practical support for designing, implementing, monitoring and evaluating social and behaviour change (SBC) interventions that include children with disabilities and their families and empower them to be included in their communities and enjoy the same opportunities as their peers.

A range of users can benefit from this toolkit – including SBC specialists, organizations of people with disabilities (OPDs), education specialists. Whatever your specialization, you are encouraged to approach this toolkit with your specific priority interventions in mind.

This toolkit is built to be both comprehensive and flexible, to accommodate a range of needs and circumstances. Its primary approach is to promote multi-layered interventions that comprehensively target disability stigma. Because resource constraints may not allow such multi-layered interventions in some cases, this toolkit offers a spectrum of options for you to choose from. Whether you are guiding practitioners through complete programme cycles or assisting in the thoughtful design of a specific, targeted intervention, you will find guidance here.

This toolkit comprises an introduction, a foundational module, seven thematic modules, a user guide and a PowerPoint presentation. The modules are as follows:

- Module 0: Foundation
- Module 1: Inclusive evidence generation
- Module 2: Empowering children and youth with disabilities and their families
- Module 3: Understanding and engaging communities
- Module 4: Building disability-inclusive services
- Module 5: Strengthening partnerships for advocacy
- Module 6: SBC for disability inclusion in humanitarian action
- Module 7: Monitoring, Evaluating and Measuring

Taken together, the modules describe the key elements of achieving sustainable social and behaviour change.

Sustainable social and behaviour change starts with a clear understanding of the stigma and barriers to inclusion experienced by children with disabilities and their families in a particular context (**Module 0**). Participatory research informs all interventions, so that they support an in-depth understanding of the communities they serve (Module 1).

The keys to effecting behaviour change are programmes that sustainably empower children with disabilities and their families (Module 2), create space for thoughtful community engagement (Module 3), design and implement inclusive services that are available to everyone in the community (**Module 4**), **forge strong partnerships** for advocacy (Module 5), respond to the needs of children with disabilities in humanitarian contexts (Module 6) and measure progress in clear and objective ways (Module 7).



“It’s not our differences that divide us. It is our inability to recognize, Accept and celebrate those differences”

Audre Lorde

Each module begins by explaining how its particular focus area contributes to the broader goals of improving SBC practice for children with disabilities. We have organized each module according to a simple framework that reflects the project cycle: **Ready?, Steady..., Set., Go!**. The intention is to provide you, the user, with the opportunity to engage with the content, wherever you are in your project or programming journey.

Whether you are an expert in disability inclusion or SBC, or if you're new to both fields, start with Module 0, which covers fundamental concepts related to disability and SBC. It's essential that you start with a solid grasp of the basics of these concepts. If you feel the need to delve deeper, you can explore additional resources in the 'Tools' section.

This toolkit is aligned with [UNICEF's SBC Programme Guidance](#) and [UNICEF's minimum quality standards and indicators for community engagement](#). It is intended as a tool for the implementation of the [UNICEF Disability Inclusion Policy and Strategy, 2022-2030 \(DIPAS\)](#).

● Children with disabilities and key barriers to inclusion

Fifteen per cent of the world's population – at least 1 billion people – have some form of disability, whether present at birth or acquired later in life. Nearly 240 million of them are children. Each has the right to be nurtured and supported through responsive care and education, to receive adequate nutrition and social protection, and to enjoy play and leisure time.

Too often, however, these rights are denied. The reasons vary: stigma, lack of accessible services, lack of access to assistive devices, physical barriers. When children with disabilities are excluded from society, their chances to survive and thrive are diminished, as are their prospects for a bright future. But this can and must change.

The Convention on the Rights of Persons with Disabilities defines disability as a long-term physical, mental, intellectual or sensory impairment that – in interaction with the environment – hinders one's participation in society on an equal basis with others. This means that as societies remove barriers, people experience fewer functional limitations.

impairment + barrier = disability
impairment + accessible environment = inclusion



On their own, impairments are not disabilities. Understanding the difference is the key to addressing barriers to inclusion.

Children and adolescents with disabilities are a highly diverse group with wide-ranging life experiences. They live in every community, and are born with or acquire distinct impairments that, in relation to their surroundings, lead to difficulties in functions like seeing, walking, communicating, caring for themselves or making friends. But the extent to which children with disabilities are able to function, participate and lead fulfilling lives depends on the extent to which society is inclusive.

Example: If a young girl from a village has low vision, but no access to glasses – an assistive device that is often taken for granted – we would say that her environment does not allow her to exercise the same rights as other children: to receive education, to learn and go to school. Unable to view learning materials in the classroom and to fully participate, she may not be able to keep up with other students, and may eventually drop out of school.

Children with disabilities face a range of barriers that limit their ability to function in daily life, access social services like education and health care, and engage in their communities. These include:

- **Physical barriers**, for example, buildings, transportation, toilets and playgrounds that cannot be accessed by wheelchair users.
- **Communication and information barriers**, such as textbooks unavailable in Braille, or public health announcements delivered without sign language interpretation.

- **Attitudinal and behavioural barriers** like stereotyping, low expectations, pity, condescension, harassment and bullying.
- **Policy barriers**, such as policies and laws that discriminate against people with disabilities, or the lack of legal frameworks for the fulfilment of equal rights.

Each of these barriers is rooted in stigma and discrimination that reflect negative perceptions associated with **ableism** – a system of beliefs, norms and practices that devalues people with disabilities. Because of ableism and the barriers that stem from it, children with disabilities are among the most marginalized people in every society.



UNDERSTANDING STIGMA

Stigma is one of biggest barrier to inclusion. There are two types of stigma: public stigma and self-stigma.

- **Public stigma** is a social process that contains three interdependent components: stereotypes, prejudice and discrimination.¹
- **Stereotypes** are collectively held beliefs that allow people to quickly generate impressions and expectations of individuals who belong to a particular social group – often at the price of distorting reality. One common stereotype is that people with disabilities are incompetent, unable to live and work successfully.²
- **Prejudices** are negative attitudes towards a group of people,³ resulting from endorsement of stereotypes that generate negative emotional reactions. An example of a negative attitude is that people with disabilities can't and shouldn't be included in society and services. When measuring attitudes, it is very important to measure implicit (unconscious) biases as well as explicit (conscious) ones, as they can significantly differ. See module 4 for more information on implicit biases.
- **Discrimination** is a behavioural response based on prejudice towards a group, which may result in harm towards members of that group.⁴ Examples of discriminatory behaviours include avoidance and segregation.
- **Self-stigma** – also referred to as internalized, experienced or anticipated stigma – occurs when people apply stereotypes to themselves, develop prejudices that are harmful to themselves and engage in self-discrimination.⁵ For

example, someone may hold the self-stereotyping belief, “I am incapable,” which evokes a negative attitude – “I can't and shouldn't be included in society” – leading them to self-isolate.

example, someone may hold the self-stereotyping belief, “I am incapable,” which evokes a negative attitude – “I can't and shouldn't be included in society” – leading them to self-isolate.⁶

Children who acquire disabilities early in life often contend with stigma throughout childhood. It is embedded in caregivers' paternalistic attitudes, overprotective parenting, low expectations, ableism in schools and the widespread neglect of the voices, needs and capacities of children with disabilities. Stigma is the root of such as school segregation, institutionalization and forced sterilization of children with disabilities. Due to ableist assumptions, children with disabilities are frequently seen as in need of 'fixing' and help, less able to contribute and participate, less worthy of attention and having less inherent value than others.

Addressing stigma and discrimination against children, adolescents and adults with disabilities require systematic, multi-level approaches. It entails addressing negative attitudes, harmful beliefs and norms, misconceptions and ableism in society – and empowering children and adults with disabilities, their families and OPDs to demand their rights and participate in processes aiming to make policies, services and communities more inclusive.

1 Corrigan, 2000. For full references, see the reference list in module 0.
 2 Pescosolido et al., 1999; Cohen and Struening, 1962; Kermode et al., 2009; Kobau et al., 2010; Pescosolido et al., 1996; Van 't Veer et al., 2006.
 3 Corrigan, 2000.

4 Crocker et al., 1998
 5 Corrigan et al., 2006.
 6 Corrigan et al., 2006.
 7 UNICEF, n.d.

PROPOSED THEORY OF CHANGE

Understanding and addressing social issues requires a thorough diagnosis, and effective Social and Behavior Change (SBC) strategies are grounded in a proper understanding of the problem. To design impactful programs, it is crucial to answer the fundamental question: "Why are people doing what they are doing?". In this case, the question is "why are people excluding people with disabilities?". Unraveling the 'why' is essential to inform the 'how'.

A theory of change (ToC) is the cornerstone of any evidence-based programme which answers this "why"; serving as the blueprint for understanding and addressing the issue. Hence, this global toolkit features a thorough ToC that was carefully crafted through extensive research and insights from practice. It serves as a universal reference point for practitioners, offering a solid foundation to adapt and personalize their own strategies. Packed with comprehensive insights, it is an invaluable resource that includes everything practitioners need to contextualize their approaches effectively. It consists of two integral parts: a problem analysis and a solution analysis. The problem analysis identifies the drivers of stigma, while the solution analysis specifies the outputs and outcomes required to achieve the goal of reducing stigma.

The journey begins by defining stigma, particularly ableism, directed at people with disabilities. Stigma is dual-natured, divided into public stigma—a social process involving stereotypes, prejudice, and discrimination—and self-stigma, an internalized or anticipated form that varies among individuals within a stigmatized group.


When exploring the reasons behind disability stigma, the TOC points to three main drivers: psychological, sociological, and environmental. Within the psychological drivers, three crucial elements stand out—attitudes, self-efficacy, and interest. Sociological drivers cover social learning, social norms, and the impact of social movements. Environmental drivers include inclusive spaces, the communication environment, and moral development in schools. To provide development in schools. To provide practitioners with a thorough understanding, each of these drivers is further unpacked to reveal second and third-layer drivers. This detailed breakdown aims to offer practitioners a comprehensive insight into the root causes of each of the driver.


This ToC is both research-based and practice-oriented, functioning as a comprehensive global reference that blends practicality with evidence. It serves as a versatile guide for practitioners, designed to be adaptable to specific contexts. Practitioners from any country can refer to and customize it based on their contexts. Please see the [PowerPoint Presentation of proposed detailed TOC](#). The short version is available in Module 0.


THE PERSON-FIRST APPROACH


The toolkit introduces the person-first approach, which is not the same thing as person-first language. A person-first approach starts with the recognition that everyone is a person first. Everyone has multiple dimensions to their identity, and their impairment is only one component. A person-first approach hinges on a change in mindset, confronting the unconscious biases and legacies of ableist thinking that may influence individual decision-making and, ultimately, social and behaviour change.

The responsibility to take a person-first approach lies with each of us. To take a person-first approach means to internalize these changes and champion person-first ways of working. The shift in mindset facilitates a shift in the way programmes and services are delivered to children and youth with disabilities and their families, towards a focus on person-led or human-centred approaches. Programmes and services that take a person-first approach are:

 **Intersectional** – recognizing the compounding impact of multiple marginalizing barriers. People may experience marginalization on account of disability, gender, race, sexual identity, ethnicity, culture, rurality and other factors relating to identity – and multiple forms of marginalization intersect to multiply the challenges they experience. For instance, the experiences of a girl from a rural community are profoundly different from those of an adult man from a city, even if they have the same impairments.

 **Empathy-led** – understanding stakeholders' pain points, emotions and motivations enables us to build empathy. We avoid blaming or finger-pointing, and invite all stakeholders to embrace a new way of working that's premised on empathy and person-first thinking. This, in turn, is key to sustainability.

 **Trans-sectoral** (multidisciplinary) – every sector is responsible for ensuring inclusive services, instead of shifting the responsibility to disability services or experts. For instance, policymakers from the education, health and social sectors need to work together to enable children with disabilities to be able to access education.

 Based on a **twin-track approach** – recognizing that general interventions may need to be complemented with specific interventions to address current inequalities. For example, the success of an SBC strategy to decrease stigma experienced by youth with disabilities seeking sexual and reproductive health services may require programmes to empower youth as advocates for inclusion.

Participatory and representative – ensuring that initiatives engage children and youth with disabilities and their families, and are planned with representation in mind – especially representation of the people who are the focus of the initiatives. For instance, a programme seeking to tackle stigma and discrimination against children with disabilities is not participatory if it engages only parents of children with disabilities, or only people of one gender or with one type of impairment.

OVERVIEW



This module will provide you with the knowledge and skills you need to create participatory evidence generation activities that support the inclusion of children with disabilities in social and behaviour change (SBC) programmes. It includes practical tools and techniques for participatory research approaches that will support and inform inclusive decision-making and the design of robust, evidence-informed SBC programmes and activities.

After completing this module, you will be able to:

- Advocate for the use of participatory research approaches in SBC programming, particularly programming that includes children with disabilities.
- Explain how participatory research approaches fit into the 'big picture' of SBC evidence generation.
- Assess the applicability of several participatory methods and choose the right one for your programme.
- Apply evidence generation tools and approaches that will support SBC programming.

 **READY**

Quality SBC programmes depend on robust evidence. However, children and people with disabilities are often left out of the research through which that evidence is generated and used. As a result, SBC programmes may fail to address their needs.

By adopting participatory approaches, you can make sure to include children with disabilities and their caregivers in your SBC research. Their participation can yield unexpected insights into the drivers of stigma and discrimination in their communities. And these insights, in turn, can inform the development of powerful SBC programmes to address these drivers and effect change that makes programmes, services and communities more inclusive for children with disabilities.

“Persons with disabilities are experts on their problems. People cannot continue to represent the interest of a group of people they are not a party to. They do not experience the problems that group goes through. This status quo should be ended, as persons with disabilities themselves must now be given an opportunity to sit at decision-making tables and be allowed to make meaningful contributions to what they think the problem is and the solution they think will best address the problem”,

Youth with a disability, Leonard Cheshire

WHY INCLUSIVE RESEARCH MATTERS

The Convention on the Rights of the Child (CRC) states that all children have the right to be heard in matters that concern them. This includes children with disabilities, who are best positioned to provide information on their own situation. When children with disabilities are given the opportunity to participate in research, its findings are more accurate. At the same time, the experience of participation reinforces their agency and sense of power to change the status quo.

When children and youth with disabilities and their families, as well as organizations of people with disabilities (OPDs), are engaged in research, you can:

- Generate data that is more relevant, more sensitive and of higher quality.
- Build the confidence and capacity of children and youth with disabilities to engage in community decision-making.
- Provide positive examples of how to include children with disabilities in SBC research and programmes.
- Challenge negative stereotypes about participation and encourage others to be active participants in SBC activities.
- Create entry points for broader disability inclusion dialogues and strategies.¹

Including children with disabilities and developmental delays in research to support SBC is always the right thing to do. The best way to do it is through processes and tools called **participatory approaches**.

Meaningful participation

One goal of participatory research is to create opportunities for meaningful participation. Decisions typically controlled by researchers that could instead be shared with participants include:

- Which research projects are conducted.
- Which research questions are asked.
- Which methods are used to answer research questions.
- Who will participate in a research project.
- What participants are asked to do.
- How research findings are interpreted.
- How research findings are published or shared.

Marginalized communities experiencing stigma should be engaged before defining research questions, in order to zero in on the underlying issues.

Source: J. den Houting (2021). [Participatory and Inclusive Autism Research Practice Guides](#). Autism CRC.

¹ Bush, A., et al. (2015). Collecting and using data on disability to inform inclusive development. Plan International and CBM Australia-Nossal Institute Partnership for Disability Inclusive Development. https://www.did4all.com.au/Resources/Plan-CBM-Nossal_Disability-Data-Collection-Practice-Note_2016Update.pdf



“The voices of people with disabilities must be present in every policy, every system, every panel, every meeting and every conversation, as co-designers and paid lived-experience experts. This should occur in the conception, design, implementation and evaluation stages”

Oceanic Pacific Regional Convening of the Women Deliver 2023 Conference

WHAT IS A PARTICIPATORY APPROACH TO RESEARCH?

A participatory approach is a mindset that aims toward the full inclusion of all people affected by an issue, a methodology for the implementation of research, and a set of tools and methods that create open, inclusive spaces where everyone can have a say. Creating such spaces for **meaningful participation** of affected communities and individuals is an approach that has been used in development work for decades.

A participatory approach to research parallels the principles of the **person-first approach**. A participatory approach:

- Is a **co-learning process** through which community members, stakeholders and researchers develop knowledge.
- Adapts participatory methods to **include people with any disability** by engaging participants’ auditory, visual, oral, written and numeric skills.
- Captures data reflecting **multiple identities** and intersectional barriers.
- Allows participants to take on **various roles** within the design, implementation, analysis and distribution of data.

- Makes the research process itself **empowering** and demonstrates that participants can gain more control over their lives through participation.
- Empowers participants by **building skills**.
- Initiates **critical dialogue** with a range of stakeholders and sectors.

Not all research is participatory, and sometimes when we say we are conducting participatory research, we do it in ways that are not participatory or inclusive. For this reason, one of the most important parts of participatory approaches is the mindset you adopt toward inclusion and research. You’ve already explored disability stigma in **Module 0**. Having a **participatory** mindset towards SBC programming and the research that supports it means viewing the inclusion of children with disabilities as crucial to all your SBC work, and investing time and financial resources in making sure that your research includes everyone.

But what does it mean to be inclusive? Figure 1 describes two aspects of how SBC programmers may increase stakeholder influence on research – goals for participation and promises made to stakeholders. Move along the figure from left to right to go from the least to the most participatory goals and promises. While research methods vary, it is always important that stakeholders are (at a minimum) involved in the design and implementation of research.



Figure 1: Increasing stakeholder influence on research.

Now that you know why it’s important to use participatory approaches to ensure inclusion of children with disabilities and developmental delays, let’s talk about the approaches and how they fit into SBC research.

HOW PARTICIPATORY APPROACHES FIT INTO SBC RESEARCH

SBC research generally falls into three categories – **formative research, monitoring or process research**, and **evaluation or impact research** – that support SBC in several ways:

- **Formative research** helps SBC programmers understand which behavioural drivers influence a specific behaviour or practice, and provides a framework for the design of SBC programmes to address these drivers.

- After an SBC programme has been designed and during its implementation, **monitoring or process research** helps SBC programmers understand if their programme activities are reaching the people and communities they intended to reach, and if they are having the expected effects.
- At certain points in the life of an SBC programme, it is important to conduct **evaluation or impact research**, to determine whether your SBC activities are making a difference or having the impact you planned for.

Participatory approaches can be used in all three categories of SBC research. For example, you may use participatory approaches with children with disabilities in formative research to understand how stigma and discrimination affect them in their communities. As you conduct monitoring activities, you may ask them for feedback on how your SBC activities are affecting their situation. And it is critical to include them in impact evaluations, so that you understand whether your investment in SBC activities has had the desired impact on their communities, from their perspective.

Participatory research captures data that is specifically relevant for SBC, because it:²

- Enables in-depth examination of the thoughts, beliefs and practices of participants.
- Raises participants' consciousness about previously unarticulated behaviours and beliefs.

- Determines the assets and needs of community-based organizations and actors.
- Provides insight into culturally relevant issues.

A participatory approach to research is useful when trying to understand the issues affecting marginalized and disenfranchised communities. Participatory approaches give participants the opportunity to shape how their experiences are understood and communicated, while giving researchers and SBC practitioners the chance to address past inequalities.³



KEY TAKEAWAYS: READY

- Including children with disabilities in SBC research is important because it ensures that all voices are heard, improves the quality and fidelity of the data collected, and thereby enables the design of more effective SBC programmes.
- A participatory approach to research entails both a mindset that considers the participation of children with disabilities as integral to the research, and a set of actions that ensure that children with disabilities have a say in the design and implementation of SBC programmes.
- The ultimate goal of participatory research is to create the conditions for meaningful participation, which means that children with disabilities have the opportunity to contribute to decisions that affect their lives.

² Sood, S., et al. (2020). Participatory Research Toolkit for Social Norms Measurement, UNICEF.

³ Cronin, C., et al (2019). Systematic review and assessment of approaches to research and data gathering on knowledge, attitudes and practices (KAP) related to children with disabilities in the CEE/CIS Region. UNICEF Europe and Central Asia Regional Office.



STEADY

Conducting high-quality research entails a series of stages, from conception and design to implementation, analysis and reporting. Figure 2 shows a basic framework for community research. Every stage offers opportunities for incorporating participatory, inclusive approaches.

RESEARCH STAGES

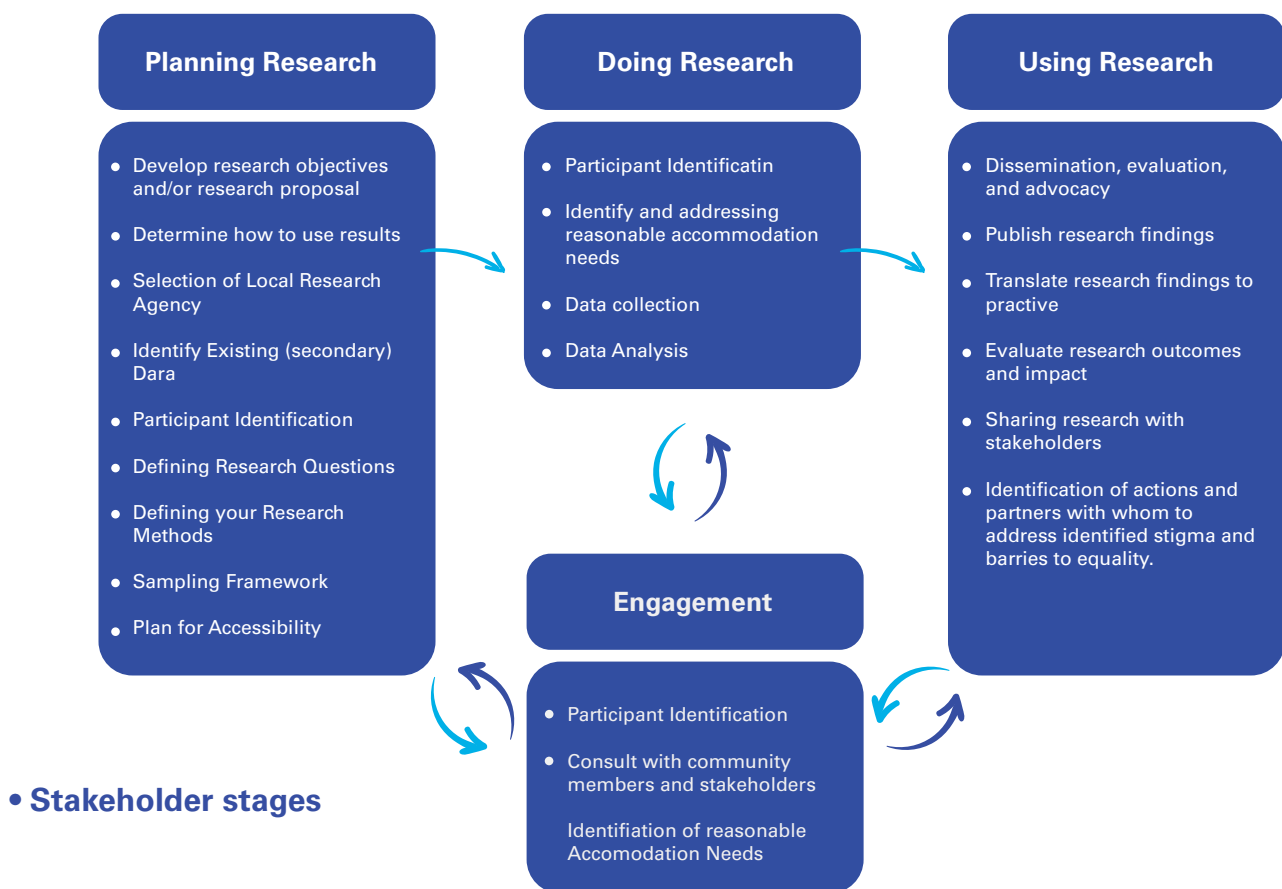


Figure 2: Stages of research
Adapted from J. den Houting (2021). Participatory and inclusive autism research practice guides. Autism CRC.

▶ ETHICAL CONSIDERATIONS FOR PARTICIPATORY RESEARCH

There are ethical principles that you need to consider when undertaking any kind of research, which include honoring the dignity, well-being, participation and personal agency of everyone involved.

The [UNICEF Procedure on Ethical Standards in Research, Evaluation, Data Collection and Analysis](#) is binding on all UNICEF staff undertaking or commissioning evidence generation activities involving human subjects or analyzing sensitive secondary data. It stresses the importance of participatory research with children with disabilities and their families, and warns that not including them in the process reinforces social exclusion and can even cause harm.

Engaging children with disabilities in research has its own specific ethical considerations. Resources like the UNICEF's '[Exploring Critical Issues in the Ethical Involvement of Children with Disabilities in Evidence Generation and Use](#)', which includes a checklist of key challenges and mitigation strategies, can support practitioners in remaining vigilant of these considerations when designing their evidence generation activities. Key considerations include:

- **Accessible communication and documentation.** This may involve measures such as changing text size, layout, density or contrast in a document or app to improve visibility; providing audio output, Braille or sign-language interpretation; or using pictures to elicit responses from non-verbal participants. Research agencies may need to

provide assistive devices, translation, audio support or other accommodations to ensure that everyone has the opportunity to take part in the research. [The CBM Disability Data Advocacy Toolkit](#) offers concrete tips on how to create accessible materials.

- **Researcher positionality and adult-child relations.** The race, age, gender and status of the researcher can influence the truthfulness of the responses. Power dynamics and culturally accepted ways of showing respect may make it hard for children with disabilities to opt out of research activities or take an active part in decision-making.
- **Child protection and safeguarding.** Children with disabilities are more vulnerable to exploitation and abuse than children without disabilities. They may be unable or unwilling to speak up when violations occur, and their caregivers may be unwilling to speak up for fear of losing access to benefits or resources that they believe are connected to their participation in the research. All research with children with disabilities and their caregivers must be reviewed by a Human Subjects Protection committee, and researchers and research agencies need to be trained on the principles of protection of human subjects, informed consent, and how to conduct research ethically.

Before you start, check yourself

What is your understanding of disability, discrimination and stigma?

It is vital to check what you have internalized and to debunk any myths to which you, your research and implementation team and all stakeholders involved in co-design and delivery might unconsciously subscribe.

You can read about models of disability and drivers of discrimination in Module 0. In addition, you are encouraged to use the [Check Yourself](#) and [Mythbusting](#) tools.



“Persons with disabilities are experts of their problems. People cannot continue to represent the interest of a group of people they are not a party to. They do not experience the problems that group go through. This status quo should be ended as persons with disabilities themselves must now be given an opportunity to sit on decision making tables and allowed to make meaningful contributions on what they think is the problem and the solution they think will best address the problem”

Youth with disability, Leonard cheshire disability young voices

- **Informed consent** is necessary for all ethically conducted research. Everyone who participates in any research must be informed about its purpose, any potential risks and benefits of participation, and how the data collected will be used. After being informed, they must explicitly agree to participate in the research.

Obtaining informed consent from children or from people with disabilities may require additional steps. For example, you may need to adapt informed consent documents

to formats accessible to people with low or no vision or those who are deaf or hard of hearing. Engaging children under the age of 18 in research generally requires their parents’ informed consent – but children themselves must always be informed about the purpose of the research and given the opportunity to ask questions about how their information will be used. And, even if a parent consents to their child’s participation in research, the child always has the right to either assent or decline to participate. Children may not be forced by anyone, ever, to participate in research.

Make sure that you conduct your participatory activities in ways that do not inadvertently contribute to additional marginalization or stigmatization of children with disabilities or their caregivers. For example, if you conduct participatory activities that unintentionally (or intentionally) favour children with certain types of disabilities and leave out others – or if you focus on certain children or caregivers because they are ‘easier’ to interact with or able to participate in activities without assistive technologies – you are further marginalizing children with disabilities as a group.

In addition, make sure that you conduct your research in a culturally sensitive way. For instance, in some contexts, it may not be appropriate to engage a male facilitator to work with a group of girls or women.

When designing your research, be sure to engage with an entity that can review your procedures to ensure that you conduct your research ethically. Stick to the processes they recommend and do not decide that informed consent is too difficult or time-consuming. All researchers have an obligation to conform to the highest ethical standards.

► PLANNING YOUR RESEARCH

In the initial stages of your research, you will determine your objectives (considering how the evidence you generate will be used) and select a research topic, research questions and a methodology. The process of developing the research proposal serves to clarify your research design and methodology and guides the process of identifying the research participants and

stakeholders you may wish to involve. There are three important steps in developing a research proposal:

- **Decide on your research topic.**
- **Decide on your research objectives.**
- **Decide on your research questions.**

You can vary the order of these steps. Sometimes, your research topic will be provided and you will need to come up with research questions. Or, you’ll find that the research questions have been provided and you need to fit them into an SBC programme, and can then set your objectives.

Make sure that children with disabilities and their parents or caregivers participate in each step. They are not only subjects from whom you collect data – you should also include them (and their parents or caregivers) in the design of your research. The disability community has a saying: “nothing about us, without us”⁴ – and this applies to the design and conduct of research as well as the use of data.

► DECIDING ON A RESEARCH TOPIC

The topic or focus of your research can be as broad as a general survey of behavioural drivers to help design a systemic strategy, or as specific as examining barriers in one sector – for instance, looking into what prevents children with disabilities from receiving adequate health services.

A participatory mindset means including children with disabilities and their parents or caregivers when selecting research topics. You can also work with OPDs in your community to identify the topics that are most important to them.

⁴ Charlton, J. I. (1998). [Nothing about us without us](#). University of California Press.

If your SBC programme will address disability stigma and discrimination, you may find it useful to review the theory of change (TOC) in this toolkit and decide on topic based on the drivers that seem most applicable to your context. You might consult colleagues from sectors in your office or external stakeholders and see how their work could be supported by research. Or, you might look for inspiration in the following lists of ideas: [112 Disability Topics for Research](#) and [Disability Essay Topics](#).

In any research, always use existing sources of information and data, rather than starting from scratch. Check the existing literature to see if there is already published research that covers the topic you're interested in and can serve you in meeting your objectives. Often, if you review existing sources of data, you will find gaps that can be filled through primary research.

► DEVELOPING RESEARCH OBJECTIVES

Your research objectives are your reasons for undertaking the research. What does your research seek to achieve? Are you conducting formative research to gain information for planning activities? Do you want to establish a baseline to inform a future evaluation? Are you seeking to understand the scope and scale of a problem?

UNICEF uses the data and evidence derived from research to inform programming, policy design, advocacy and other interventions that can improve the lives of people with disabilities. SBC research, in particular, aims to identify key behavioural drivers of a practice, inform programme design, provide insight into processes or evaluate the effectiveness of an intervention and replan accordingly.

You may wish to work with sector or other colleagues to decide on your objectives. And whatever these objectives may be, you can (and should) include participatory methods in your research design. And again, always include children with disabilities and their parents or caregivers in decision-making about how your research will be used.

► DEVELOPING RESEARCH QUESTIONS

Once you have your topic and objectives, the next step is to develop research questions.

Research questions are specific aspects of your research topic that you will investigate in depth. For example, if your research topic is on stereotypes and how they contribute to stigma, and your objective is supporting SBC programming to disrupt or challenge stereotypes, you could ask questions that would help you understand what stereotypes exist and how they contribute to stigma. Perhaps your research topic is about parents' and caregivers' knowledge about the laws and policies that support children's participation in school, with the objective of contributing to advocacy activities to strengthen these policies. You could then ask specific questions about people's current levels of knowledge about these laws and policies.

In deciding on your research questions, consider your local context, how the results of your research will be used, and the resources you have for research. You can adapt existing questions and use existing tools. Review some of the examples in this module and elsewhere in this toolkit, and use the questions you think will best respond to your research objectives. Get input from stakeholders and partners about how they might also use the results of your research. And always work with children with disabilities and their parents and caregivers throughout the design of your research so that your topic, objectives and questions are relevant and inclusive.

There are several ways to go about developing your research questions. They could be related to:

- **Drivers of stigma and discrimination.** Research addressing these questions can help increase inclusion or reduce stigma and discrimination by addressing drivers directly.
- **Experiences of children with disabilities.** Research addressing these questions can increase inclusion or reduce stigma and discrimination indirectly by building understanding of how children with disabilities are affected by stigma and discrimination, and how they can benefit from inclusive environments.
- **Prevalence of disabilities in a community or population, or impacts of stigma and discrimination on children with different disabilities.** Research addressing these types of questions can help you develop appropriate interventions – for example, to provide assistive technologies or advocate for policy changes.



“Youth with disabilities deserve a seat at the decision-making table, because we are the best writers of our own stories and we can create sustainable solutions”

Maria A. 21, , Bulgaria

If your research requires defining the range of **disabilities** in your sample group, use the [Washington Group Questions](#), which include the Child Functioning Module co-developed with UNICEF. These question sets provide a consistent way to define the population and disaggregate data by disability. More information about them is available in the Go! section, below.

When articulating research questions related to **stigma**, consider which specific constructs of stigma will be most relevant to your research and build questions around those. For example, you could ask, “What stereotypes are associated with children with disabilities in this community?” **Module 0** includes a theory of change for understanding and addressing stigma and discrimination that can be used to generate questions specific to your context.

To define research questions related to social norms, consider that they are a function of both our own attitudes and beliefs, and our assumptions about other peoples' attitudes and beliefs. First, identify the reference group – the social group whose expectations influence participants' behaviour. Then, ask questions to understand what norms they hold, by observing what behaviours they exhibit, defend, uphold, celebrate and sanction. You can learn more about using social norms in SBC programmes in UNICEF's [Everybody Wants to Belong](#).

The following data sources can help you formulate your research questions:

- Global statistics on disability are a good place to start, especially where national-level data is not available. UNICEF's 2021 report [Seen, Counted, Included: Using data to shed light on the well-being of children with disabilities](#) examines the lived experiences of children with disabilities and compares indicators of their well-being to those of children without disabilities, globally and across regions.
- UNICEF's [Multi-Indicator Cluster Surveys \(MICS\)](#) can provide good entry points into the development of research questions that will support your research objectives. Consider how MICS data can help you identify relevant drivers from the **theory of change** for stigma and discrimination.
- Explore the [Global Indicator Framework for the Sustainable Development Goals \(SDGs\)](#), considering which SDGs are relevant to your research. Once you have identified relevant indicators for your research (and your SBC programming) you will be able to develop research questions that can respond to those indicators in your own context.
- Review national reports to the [Committee on the Rights of Persons with Disabilities \(CRPD\)](#), reports of [National Human Rights Institutions \(NHRI\)](#) or sector-specific national plans to implement the requirements of the CRPD.
- If you can't find local or regional SBC research on disability, research from other regions may be informative and help you identify research questions that apply to your context.

Selecting the right participatory methods

How can participation be implemented most effectively?

You want to fully engage people from affected communities from the start of your research. But not all participatory methods are appropriate for all members of every community.

For example, a transect walk may not be appropriate for children using mobility devices in certain communities, but a social mapping exercise may be.

It is important to select the participatory methods that will create the greatest engagement and participation of children with disabilities and their caregivers.

Next steps

Once you have your topic, objectives and research questions, you can draft tailored terms of reference to recruit a local research company to help you conduct your research, including to collect and analyze data. For a complete overview of the research process, as well as resources and tools to help you understand the process and select methods and tools for inclusive and participatory research, see the Go! section, below.

STEADY KEY TAKEAWAY

- Ethical considerations are one of the first things to think about when designing a research project that supports and includes children with disabilities and their caregivers, in order to protect them and ensure the most inclusive outcomes from the research process.
- Conducting ethical participatory research with children with disabilities entails developing accessible research tools, acknowledging and addressing the researchers' and facilitators' inherent biases, safeguarding children and undertaking a robust informed consent process.
- Research requires careful planning, including selecting a research topic, defining objectives and asking questions. A participatory approach requires that children with disabilities and their caregivers are involved each of these steps.
- When planning your research, start by using existing resources to develop your research questions and guide how you conduct the research.

At this point, you have a sense of why participatory approaches are important, how they fit into the SBC research process, and what you need in order to conduct ethical participatory research with children with disabilities and their families.

Now, let's review some examples of participatory research conducted by UNICEF and others – and then provide you with some tools for [your own participatory research](#).





- [Voices of Adolescents and Young People with Disabilities on Discrimination, Bullying and Violence: Results of a rapid assessment in 11 Latin America countries](#) (UNICEF, 2022). Through the voices of adolescents and young people with disabilities, this report presents the results of a consultation conducted in 11 Latin American countries on the violence, bullying and discrimination they experience in their families, schools and communities. The report analyzes the implications for family, school and community settings, and shares recommendations resulting from the analysis.

- [The Role of Social Norms in Decisions to Provide Schooling to Children with Disabilities in East and Southern Africa](#) (S. Brouwers, 2021)

This UNICEF report examines the social norms surrounding disability and provides evidence from Eswatini, Kenya and Namibia to gauge how these norms influence people's thinking about and behaviour towards children with disabilities. It starts with a broad, context-based model of the social problem of disability, building on work by Cristina Bicchieri,⁵ but adding a richer contextual and cultural component with dimensions

related to behaviour systems of maintenance and control as well as the persistence of behaviour over time. With the help of local governments, the model was qualitatively tested through 90 focus group discussions, engaging parents, teachers, children (including children with disabilities) and local experts in two economically contrasting regions of each country.



“I Wish Someone Would Ask Me Questions”

[The unheard voices of adolescents with disabilities in Jordan](#) (K. B. Odeh et al., 2021)

The Gender and Adolescence: Global Evidence (GAGE) programme conducted research with Jordanian and Syrian refugee adolescents in the capital, Amman; in Irbid governorate, which includes Jordan's second-largest city; and in Mafrqa, a rural governorate. The research included Syrian adolescents in the Zaatari and Azraq camps and those living in informal tented

5 C. Bicchieri (2017). Norms in the wild: How to diagnose, measure and change social norms. Oxford University Press. <https://academic.oup.com/book/6479>

settlements, as well as young people from stateless Palestinian communities in the Jerash refugee camp. The sample included over 500 young people with disabilities. The interviews were conducted in the adolescents' homes, in a place chosen by them. Where possible, caregivers were interviewed at the same time to give each respondent more privacy. The researchers received intensive training by expert researchers and disability advocates on supporting participation in the research on a case-by-case basis, and a range of interview tools were used to reflect the diverse strengths and interests of participants, including peer research, participatory photography and social network analysis.

- [Voices of Pacific Children with Disability: Identifying the needs and priorities of children with disability in Vanuatu and Papua New Guinea](#) (E. Jenkin et al., 2015) Conducted by Deakin University in partnership with Save the Children, the Vanuatu Disability Promotion and Advocacy Association (DPA) and the PNG Assembly of Disabled Persons (PNG ADP), this research aimed to develop a method of data collection and communication that would enable children with diverse disabilities to speak for themselves. Researchers collected data from 89 children with disabilities aged 5-18 years living in urban and rural areas. Local researchers (including people with disabilities) were trained, while a range of tools for communicating with children with diverse disabilities were developed or adapted to help children express their views about their lives. These included audio recordings of local sounds, a photo library of local images, a camera, a walking tour of the community, drawing and dolls. These resources were compiled in [Inclusive Practice for Research with Children with Disability: A guide](#), to support the involvement of children with disabilities in future research, consultation, policy and

service development, monitoring and evaluation. A selection of tools is described in the Go! section, below.

- [Violent Discipline in North Kivu, Democratic Republic of Congo: The role of child gender and disability status in cross-sectional analysis](#) (A. H. Blackwell et al., 2023) This study aims to understand the use of violent discipline by caregivers in conflict-affected communities and how it varies by the child's gender and disability level. Using cross-sectional data collected from 394 respondents in North Kivu, Democratic Republic of Congo, the researchers used logistic generalized estimating equations, stratified by gender, to assess the association between the perpetration of violent discipline during the three months preceding the study; caregiver demographics, conflict experiences and attitudes towards disability; child demographics (age, gender, disability level); and the interaction of gender and disability.



“The biggest misconception in the world about people with disabilities is that we are less than”

Alexis H, 21, Canada

- [We Can Also Make Change: Piloting participatory research with persons with disabilities and older people in Bangladesh](#) (D. Burns & K. Oswald, 2015). Peer researchers with disabilities, together with NGO staff via the Voices of the Marginalised Consortium, designed story prompts and collected stories from peers within their communities or constituencies. They used open-ended prompts, rather than interview questions, to encourage participants to share

their stories and allow them to cover the issues important to them.

Once they had gathered the stories, the participants collectively analyzed them to identify experiences of social and economic exclusion. The stories and analysis, synthesized in this report, were widely shared with stakeholders and policymakers.

- [Hear My Voice: A community-based participatory study gathering the lived experiences of people with disabilities and older people in Tanzania](#) (M. Greenwood et al., 2016) This study examines the nature and experiences of people with disabilities and older people from their own perspectives in rural and urban Tanzania, aiming to inform efforts to provide services for and improve the lives of people living in those regions. It used a community-based participatory approach, involving collaboration with the community. Peer researchers and research partners collected and analyzed interviews, presenting their findings at the individual, interpersonal and societal levels and framing them in terms of how physical, social and attitudinal factors affected experiences of participation and inclusion. The findings demonstrate how lack of access to health care and education, social limitations and powerful community attitudes were interwoven and exacerbated poverty. They informed policy and advocacy recommendations and early-stage plans.
- [The Economic Empowerment of Youth with Disabilities in Uganda and Improving Livelihoods for Youth with Disabilities in Uganda: Joint end term evaluation](#) (Sightsavers, 2021)
An end-term evaluation of two projects aiming to provide youth with disabilities with vocational, business, soft skills and financial literacy training. The evaluation used a range of methods and tools: focus group discussions with project participants, family and community members and OPDs,

and key informant interviews with vocational training institutes, employers, financial institutions and project leaders.

- [Breaking the Silence: Violence against Children with Disabilities in Africa](#) (African Child Policy Forum, 2010)
This report highlights violence against children with disabilities in Cameroon, Ethiopia, Senegal, Uganda and Zambia. The country studies collected survey data through 956 in-depth structured interviews with young people with disabilities aged 18-24 in Cameroon, Ethiopia, Senegal, Uganda and Zambia. There were also semi-structured focus group discussions and semi-structured interviews with key informants. The report notes widespread apathy and negligence at the state, local and community levels, and highlights a lack of financial and medical aid, inadequate and inaccessible state facilities and systems, and insufficient community understanding. It documents the negative effects this has on children with disabilities and makes a number of recommendations to improve the situation.

UNICEF Knowledge, Attitudes, Beliefs and Practices (KABP) studies
- [Baseline Knowledge, Attitudes, Beliefs and Practices \(KABP\) Study in support of a C4D Strategy for Early Childhood Development and Children with Developmental Delays and Disabilities](#) (UNICEF Palestine, 2019)
- [Knowledge, Attitudes and Practices \(KAP\) Study on Children with Disabilities](#) (UNICEF Bhutan, 2017)
- [National Survey of Attitudes and Social Norms toward Children with Disabilities and Developmental Difficulties in Bulgaria: Summary of data](#) (UNICEF Bulgaria, 2022)



Here is a step-by-step guide on how to design and implement research with and for children with disabilities. Under each step, you can find the relevant tools. If you are conducting an evaluation, refer to the [UNICEF Adapted UNEG Quality Checklist for Evaluation Terms of Reference](#) for guidance.

It is crucial to involve individuals with disabilities throughout the research design and implementation process. The [Participatory and Inclusive Autism Research Practice Guides](#) offer valuable insights for ensuring meaningful participation. While the guidance is geared towards individuals with autism, many of the tools can be more broadly applied. Pages 42-50 provide tools to evaluate the quality of participants' engagement in research, including:

- The Quality Involvement Questionnaire.⁶
- Sample questions for a semi-structured evaluation interview.
- The Community Engagement in Research Index,⁷ which assesses participants' involvement at various stages of the research process by asking, "To what extent were you engaged in each of the following phases of the research?"

⁶ Morrow, E., et al. (2010). 'A model and measure for quality service user involvement in health research'. *International Journal of Consumer Studies*, 34(5), 532-539. doi.org/10.1111/j.1470-6431.2010.00901.x

⁷ Adapted from Khodyakov, D., et al. (2013). 'On measuring community participation in research'. *Health Education & Behavior*, 40(3), 346-354. doi.org/10.1177/1090198112459050

1. Decide on your research question.

What do you want to find out? For example, if you are working on education, you might ask, why are children with disabilities dropping out of school in a certain district in Tanzania? See 'Planning your research' in the Steady section above for an in-depth guide to formulating research questions, and how these relate to your research topic and objectives.

2. Identify the evidence you already have.

Collecting SBC evidence can be a time- and resource-intensive task. Before you begin collecting new data on barriers and levers, consider the evidence you already have. For example, there may already be evidence showing that the school curriculum is not inclusive of children with disabilities.

3. Decide whether further research is needed. Based on your findings from step 2, decide whether your research question has already been answered. If so, you already have the evidence you need. If not, go on to the next step of your research.

4. Choose your research partner.

[Selection of a research agency](#) is a tool to help you select a research partner and develop a terms of reference (TOR) for research that includes or targets children with disabilities. UNICEF has several long-term agreements for services (LTAS) in place with agencies that can assist with research design and implementation.

5. Choose your conceptual framework.

People are quick to rush to knowledge, attitudes and practices (KAP) studies – but these are rarely enough to design an SBC intervention or strategy. A strong conceptual model is needed to answer 'why' questions. For example, to identify why children with disabilities are dropping out of

school, you need to identify the drivers of this behaviour. The [Behavioural Drivers Model \(BDM\)](#) is a UNICEF framework that helps practitioners identify the psychological, sociological and environmental drivers of any behaviour. See the theory of change in [Module 0](#) for a theoretical framework of the drivers of stigma.

6. Design your methodology.

Your choice of methodology will be informed by the scope of your research question, existing resources and opportunities. Generally, research methods are categorized into two separate groups: quantitative (e.g., surveys) and qualitative (focus groups, in-depth interviews, observations, etc.). You may decide to use different methods at different stages of SBC programmes.



Here are some useful resources on research methods:

- [Methods of monitoring and evaluation](#) provides a one-stop resource with hundreds of tools, methods and processes.
- [Reporting guidelines](#) includes guidelines for interviewing children.
- [Interviewing](#) provides UNICEF guidance for when to use interviews.
- [A guide for designing and conducting in-depth interviews for evaluation input](#) offers detailed guidance and a reflection on the advantages and disadvantages of this method.
- [Human-Centred Design 4 Health \(HCD\) resources](#) offers tools to apply a human-centred approach to challenges relating to health services.
- [Demand for Health Services Field Guide: A human-centred approach](#) introduces human-centred design as an approach to address challenges related to community demand for basic health services such as immunization.
- [Social mapping tool](#) allows you to organize information about the individuals, groups and organizations that form the social and institutional context of your work.
- [Kobo Toolbox](#) includes simple, robust and powerful tools for data collection.

[Operational Research Protocol to Measure Attitudes, Stigma and Social Norms towards Children with Disabilities in Europe and Central Asia](#), developed by Drexel University and the UNICEF Europe and Central Asia Regional Office in 2019, provides important tools for research on stigma and social norms. One such tool is [empathy mapping](#), through which participants explore what they know about a particular actor or group (for instance, themselves, parents and caregivers, or other groups within the community), in terms of what they say, think, do and feel.

Whichever methods you choose, make sure to choose data collection techniques that are inclusive of children with disabilities. [Best practices for research with children with disabilities](#) offers considerations for how to collect data from children with disabilities. [Inclusive Practice for Research with Children with Disability: A guide](#) (developed as part of the 'Voices of Pacific Children with Disability' research project described in the Set section) presents a set of tools to support the participation of children with a range of disabilities:

- [Getting to know the child](#) is an icebreaker activity to help child participants feel comfortable, while you learn more about them, their lives and preferred modes of communication. It can help you pick the best tools to use in asking them your research questions.
- You can use a [doll](#) to help children communicate consent or dissent and to answer the research questions.
- Participants can select images from a [photo library](#) to show and explain their answers to research questions. This tool can help children and adults, including those with

cognitive disabilities or limited life experiences, communicate about things they have not yet experienced or have difficulty articulating.

- The [sound library](#) provides short audio recordings of local sounds to help children, including those with visual impairments, communicate answers to research question. The children can listen to the sounds and select those that help them answer.
- In an adaptation of PhotoVoice or photo elicitation, providing a [camera](#) enables children with diverse impairments to communicate their answers to research questions by taking photos.
- [Story in a bag](#) uses a selection of familiar objects that children can select to help them communicate answers to research questions.
- [Drawing](#) pictures can help children communicate answers to research questions. Children of various ages tend to enjoy drawing and art, which have long been used as tools in child research.
- Through the [walkabout](#), children guide the researcher on a walking tour of their community to help answer research questions.
- Children can communicate answers to research questions through [storytelling](#) and discussing stories – a common way of sharing and documenting information in communities with a strong oral tradition.
- [Feeling OK](#) is a strategy to ensure children's safety during data collection, by noticing their emotional reactions, prompting them to share anything that upsets them, listening and offering positive activities and encouragement.

7. Train the data collectors.

If your data collectors don't have experience working with children with disabilities, consider holding a half-day or day-long workshop to help them address their biases. You can use resources from [Module 4](#), as well as these [12 tips for research on children with disabilities](#).

8. Collect the data.

Be sure to use the participatory tools, techniques and approaches described in this module. Review these [quality control procedures](#) for important guidelines to help you collect high-quality data.

9. Use the evidence to design an SBC intervention or strategy.

Refer to the other modules in this toolkit to design interventions that respond to the findings of your research.

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