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Towards measuring the impact of projects related to the reduction of stigma associated with disability, gender and age at the community level

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Content

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Introduction

Humanity & Inclusion (HI) works alongside people with disabilities and vulnerable populations, to respond to their essential needs, improve their living conditions and promote respect for their dignity and fundamental rights.

HI operates in around 60 countries, implementing more than 450 projects. HI's Institutional Project Quality Policy (PQP) aims to ensure continuous improvement, learning and accountability; the PQP provides a common framework and reference for all HI staff directly or indirectly involved in the management of projects, and applies to all projects, regardless of context, geographical area, sectors or intervention modalities. The "Benefits" category of the PQP focuses on the changes brought about by any project(s) in the short, medium and/or long term, and on the relevance of the project to the needs of the target groups and their satisfaction. The PQP places emphasis on the achievement of positive and measurable changes for the targeted actors.

HI’s PQP is backed by complementary organisational commitments, among them: “every project must define at least one outcome indicator in its logical framework and measure it, allowing the monitoring of the changes expected by the intervention”. To this end, HI has invested in defining measurable outcomes, common to all HI sectors, to enable projects to monitor changes HI aspires to and to which HI contributes.

One of the common outcomes aspired to by HI is the reduction of stigma associated with disability, gender and age at community/ territory level. A meta-analysis of HI project outcomes was carried out in 2023; the meta-analysis took into account a total of 121 projects closed in 2022, almost 82% of projects closed in total at HI in 2022. A key finding of the meta-analysis was that several countries used outcome indicators at community level, but very few focused on the level of stigma (monitoring focused instead, for example, on changes in knowledge about people's rights). Some HI projects have used studies such as knowledge, attitudes and practice surveys, but these studies are often linked to one single sector and are influenced by social desirability bias. Indeed, observing and measuring stigma reduction remains challenging, especially in volatile/ fragile contexts; estimating the contribution of HI's actions in the reduction of stigma also remains challenging.

This 2025 study sought to help enhance HI’s PQP by developing a method for measuring changes linked to interventions aimed at reducing interpersonal stigma associated with disability, gender and age; an outcome measurement method that can be used to collect data to support project monitoring regardless of the operational context, geographical location, thematic sector and/or intervention modality.

Key parameters for this study, included:

- The focus for measurement was interpersonal stigma (i.e., interactions that occur between stigmatised and non-stigmatised people), including public stigma and structural stigma. The focus for measurement was not intended to include self stigma.
- The outcome measurement method is expected to:
    - Answer the question: What changes in disability, gender and age-related stigma has the intervention contributed to?
    - Incorporate an intersectional gender perspective, integrating the dimensions of gender as well as disability and age.
    - Be suitable for project monitoring; for projects targeting the community (including by minimising drivers of stigma and addressing negative attitudes and discriminatory practices).
    - Help capture changes in stigma at different stages in a project cycle, including as part of project evaluations.
    - Accommodate often limited resources dedicated to project monitoring, including in terms of time, budget and expertise.

This study designed and tested an outcome measurement method. This report presents study findings (including test findings from Benin and Lao PDR), shares the evidence that informed the decisions taken in developing the approach and provides recommendations for further development and finalisation of the outcome measurement method. The primary audience for this report is HI staff who we expect to: further develop, progress and roll-out the measurement method trialled in this study at the organisational level; and utilise the measurement method to capture project outcomes.

While this report is primarily intended to strengthen HI's own efforts to ensure continuous improvement, the purpose of the study is both timely and of broader relevance. Learning Reviews previously conducted by Impel identified that finding suitable ways to demonstrate or assess changes in stigma remains a widespread and persistent challenge. Developing a method to measure changes in stigma will not only strengthen HI's own monitoring of project outcomes, but will also provide leadership for the broader sector that may have a positive impact on other organisations.

I. Methodology

This section outlines key components of the study's methodology and approach.

1. Learning questions

The focus of this study was on developing and testing a measurement method; not on using a measurement method to evaluate project outcomes for changes in stigma. As a result, the lines of questioning and data analysis focused on assessing the appropriateness and practical applicability of the measurement method (including the specific tools and protocols). Key questions for this study were:

- Does the measurement method measure changes in disability, gender and/ or age-related stigma at the community-level?
- Can the measurement method be utilised by HI staff, including in low-resource contexts?
- What lessons from tests of the measurement method in Benin and Lao PDR can inform the organisational roll-out of the measurement method?

2. Overview of approach to data collection

Data collection during this study was broadly divided into two separate phases.

2.1. Data collection in Phase 1

Data collection in Phase 1 focused on designing the measurement method to test in Benin and Lao PDR, by:

- Identifying existing approaches and tools to measure changes in interpersonal stigma (and that adopt an intersectional lens) that could be replicated or adapted.
- Identifying key principles/cross-cutting features of comparable tools to guide the development of a new measurement method (if necessary).
- Understanding existing experiences of HI staff around measuring changes to stigma.

Phase 1 data collection involved:

- a desk review of selected (n.22) documents and tools (see Annex 1) focused on measuring changes in interpersonal stigma.
- key informant interviews (n.8) of selected HI staff (see Annex 2) connected to HI projects identified by the 2023 meta-analysis to have included indicators on stigma and on individuals unable to join the focus group discussion.

- a focus group discussion involving selected HQ-based global thematic leads/ specialists (n.7) to explore the barriers their thematic areas have experienced measuring changes to stigma (see Annex 2).
- co-design with a Technical Committee of an entirely new measurement method to be tested in Benin and Lao PDR, following agreement with the Technical Committee that no approach or tool existed that could be replicated or adapted. (See Box 1 for a summary of the outcome measurement method that was developed; see also Section 3.1 for the evidence that informed the decisions taken in developing the new outcome measurement method).

BOX 1: Summary of outcome measurement method developed for this study

A complete testing protocol was developed prior to any data collection (see Annex 4) for the updated version to reflect field testing findings), with country teams trained on the protocol. The outcome measurement method was designed to be as simple as possible for HI staff and partners to implement; the option preferred by Technical Committee members was an interview/ focus group discussion-based tool. The measurement method utilised the concept of *belonging and othering*[1] to explore the potential change in interpersonal stigma. The outcome measurement method broadly explores experiences or expectations (dreams) of a stigma-free environment and what that would/ does look like, then works backwards to explore 'how' with a scale for comparison of two points in time. Broadly, the protocol in both Benin and Lao PDR involved the following:

Understanding and consent: Interviewees and group discussion participants were first briefed on the purpose of the study, to ensure they fully understood the process and to obtain their consent. Interviewees and participants were asked to specify the language they felt most comfortable using: in Benin, the two primary languages spoken during data collection were French and Fongbe; in Lao PDR, participants chose Lao, Hmong or Khmu; sign language interpretation was provided, when necessary.

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[1] https://www.projectoverzero.org/media-and-publications/belongingbarometer
Powell, J. A. belonging – bridging beyond othering; Othering & Belonging Institute, USA; https://belonging.berkeley.edu/sites/default/files/2024-11/BelongingColorado_OBI_Sept2024.pdf

Introduction to the tools: Interviewees and participants were first asked to 'map' services or locations that are important to them and talk about their experiences and sense of 'belonging' there, providing any examples; they were then introduced to the tools sequentially in the following manner:

- Flower of identity: Interviewees and participants were invited to use this tool to reflect on intersecting aspects of their identity (including family, ethnicity, gender, religion, sexuality, disability, employment, professional skills, education, and wealth) and how they influence their experiences and sense of belonging.
- Bridges: This visual prop helped conceptualise *belonging and othering* and serve as a rating scale. Interviewees and participants were encouraged to reflect on societal-level efforts around inclusion and stigma, including consideration of their current relationships and support systems and how their inclusion had evolved over time. Interviewees and participants used the bridges to represent how challenging or strong their connections are/ were.
- Smileys: This visual prop also helped conceptualise *belonging and othering* and serve as a rating scale. Interviewees and participants were invited to use 'Smileys' from very sad (1) to very happy (7) to assess and express their emotional state regarding their sense of belonging; they selected the 'Smileys' they believed best represented their feelings regarding their current sense of belonging and how this had evolved over time.

Clarification and demonstration: After the initial introduction of each tool, the country team demonstrated how to use each tool, offering real-life examples. This was especially important for participants with cognitive or sensory disabilities; they typically required additional explanation to understand the abstract nature of tools like 'Bridges' and the 'Flower of identity'.

Reflection and discussion: Upon use of each tool by interviewees and participants, country teams asked open-ended questions about the interviewees'/ participants' feelings of belonging in different environments (e.g., home, school, workplace, public spaces). Probing questions were asked about their past experiences and current feelings of belonging, to ensure a deeper understanding of the perceptions and experiences of the interviewees and participants and to avoid any confusion or misunderstanding.

Closing: At the end of the interview or group discussion, interviewees and participants were invited to provide any additional thoughts or suggestions for improving their experience of social inclusion. This open-ended portion of the interview allowed participants to express any frustrations, hopes, or ideas for future improvements.

2.2. Data collection in Phase 2

Data collection in Phase 2 focused solely on testing in Benin (in Calavi and Cotonou) and Lao PDR (in Houamuang and Samnua districts) the measurement method co-designed with the Technical Committee. The focus was on collecting data to answer the overarching learning questions (see Section 2.1); indicative, more specific questions/ factors the country teams were tasked to consider during field testing included:

BOX 2: Guiding questions and considerations used during country testing

Appropriateness

- Is the concept around the 'flower of identity' understood and does it allow people to reflect on and talk about their intersectional identity factors?
- Do respondents feel comfortable to talk about 'belonging' and 'othering' as relayed via the suggested feelings (safe, welcome, accepted, in control etc)?
- Do young people understand the questions?
- Is the concept of 'bridges' as a visualisation of interaction and displayed attitudes/behaviour easy to understand? i.e. appropriate in the cultural context? Do they work as a rating system?
- Are the 'smileys' easily understood and appropriate as a rating system?

Practicality

- Do the interview guides cover enough information and instructions to help facilitators through the interviews?
- Are the main questions easy to communicate/translate in the local language(s) and easily understood?
- Are the probing questions helpful to elicit more nuanced information?
- Are the questions and rating systems (bridges, smileys) accessible, i.e. understandable for different impairment types?
- Is there enough time for the topic explanation and the question?
- Are responses easy to document?

Quality

- Do the questions in general bring out tangible/concrete and nuanced responses?
- Does the line of questions on 'belonging' elicit information on stigma?
- Does the line of questions around different identity factors help provide an intersectional lens?
- Are the questions easy to adapt and elaborated on to match the context of a given group or individual interview, e.g related to impairment type, age, gender, educational background etc?
- Do you feel comfortable interpreting responses related to 'belonging' and either or both rating systems to draw conclusions on changes in interpersonal stigma?

Testing of the outcome measurement method was qualitative, based upon individual interviews (n.41 across both Benin and Lao PDR) and small-group discussions (n.12 across both Benin and Lao PDR) with persons with disabilities.

All interviews and group discussion were conducted in a safe and supportive environment (e.g., in Benin they were conducted in a private room in a social welfare centre), ensuring that participants felt comfortable sharing their experiences. For participants with visual impairments, the images were described verbally to ensure accessibility and understanding.

The field testing started in Lao PDR and was followed by an initial round of analysis and reflection; subsequent field testing in Benin benefited from experiences and feedback from Lao PDR.

2.3. Ethics

Initial discussions with HI staff in Benin and Lao PDR indicated the study did not need to obtain ethics approval from the national ethics committee in either country; local governments were kept informed of the study at all times.

Field testing engaged community members who are the focus of HI projects, some of whom included people from vulnerable target groups and their families. Field testing was shaped by HI field staff and project partners to ensure a balanced sample.

The study adhered to all HI ethical guidelines[2] and codes of conduct regarding the design and implementation of research; the study put in place a series of processes and systems with the specific intent of ensuring high quality final products:

- **Triangulation of information:** Data was triangulated using primary and secondary sources of data, to ensure decisions and findings were evidence-informed. Technical workshops provided space for reflection and critical analysis. Regular study team discussions were also held to jointly analyse and further triangulate information and validate findings.
- **Internal review processes:** All members of the study team were familiar with the methods used; the data collection methodologies, tools and the outcome measurement method were submitted to and reviewed by a committed specialist within Impel for quality assurance.
- **Informed consent, confidentiality and safeguarding:** Informed consent protocols were put in place to ensure that all participants understood the aims of this study and how the data collected was going to be used/ stored. The consent of all participants involved in field testing was obtained, prior to any data collection. For data collection that involved respondents from communities that are the target of HI projects, information sheets and consent protocols were prepared prior to data collection; the study team worked with HI staff to ensure the safety of study

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[2] See https://www.hi.org/sn_uploads/document/EthicalDataManagementGN-04.pdf

participants at all times. Personal data files held by Impel were destroyed upon the formal completion of this study.

2.4. Limitations and mitigation measures

The desk review clearly established that no effective and proven outcome measurement method on interpersonal stigma exists that meets key aspects of HI's scoping (e.g., incorporates multiple intersectional factors, has global applicability and can be applied across all thematic sectors). The tools that offered most promise applied to specific sets of variables; all recommended further substantive testing/ refinement for them to be more broadly applicable and all documented the difficulties and complexities of gaining credible and authentic data on the sensitive subject of stigma.

The task of designing and testing a new outcome measurement method to capture changes in disability, gender and age-related stigma is complex and highly innovative. Given resource constraints, the intention of this study was not to test an outcome measurement method to the point where it is ready for 'roll-out'. Instead, the focus was on designing and conducting limited testing of a potential outcome measurement method for HI to further test and finalise. Field test was limited to two countries. The findings provide clear lessons, including how to progress the outcome measurement method to its next round of testing; the method tested cannot be treated as final.

The study attempted to gain insights and input from a cross section of key stakeholders, incorporating a high level of participation from HI staff and HI's partners to ensure the measurement method is both 'owned' by and reflects the needs of the intended 'end users'. The sampling remains limited.

People's availability for interviews and/ or participation in group discussions was restricted. The selection of personnel was communicated as early as possible in the process, so that people's time could be secured. Individuals unavailable for group discussions were sent notes of the discussion, to enable them to respond in their own time to key discussion points. It was still not possible to engage all selected individuals within the prescribed timeframe.

Field testing of the outcome measurement method focused on the appropriateness and practicality of the tool. The outcome measurement method includes rating systems ('Bridges' and 'Smileys') to help respondents 'score' levels of stigma, including levels of stigma at different periods of time or in different locations. Scores provided reflect only the perceptions of respondents, field testing did not extend to test the accuracy of reported changes in stigma or the impact of project activities on changes in stigma.

II. Findings

This section outlines the findings from both Phase 1 and Phase 2 of data collection.

1. Key findings from Phase 1

Key findings from the desk review, interviews and group discussions were:

- No tool was evidenced that measures change in interpersonal stigma across sectors and identity factors, and that is globally applicable. A lot of existing tools focus on health and/or break disability into different types of either health conditions or impairment types. There are, for example, academic studies on stigma around epilepsy and leprosy. The majority of academic studies use quantitative data and statistical analysis based on a variety of scales, association tests, self-report surveys, vignettes (quantitative and qualitative analysis) and are either fairly complicated when statistics are involved and/or have a high risk of social likability bias. Very few of the methodologies applied an intersectional perspective, nor were they easily applicable across other sectors.
- HI's Theory of Change (ToC) appears to focus very much on access to services. In order to align with HI's ToC, the measurement method used to measure changes in stigma would also have to focus on access to services. Negative attitude(s) is one of 8 key main barriers to access to services in the ToC.
- ScoPeo is a HI standard tool with a focus on quality of life looking at adults, family, and children across various dimensions. The desk review identified a focus on interpersonal stigma could be made to fit into dimension seven (participation in society and family life) and possibly dimension five (material well-being) by adding questions/ a new topic. Adapting ScoPeo was deemed inappropriate for the purpose of this study, the Technical Committee sought a standalone outcome measurement method.
- Vignettes appear promising in countering social likability bias and providing more nuanced qualitative information, but are very challenging as a method to measure change. Vignettes need to be extremely well written (including to accommodate ethical considerations and power dynamics) and well facilitated. Vignettes are difficult to use as a change measurement tool comparing two points in time, they are better used to provide a snapshot and/or as a programmatic tool to discuss and inspire change(s) in attitudes. Vignettes often compare different impairment types; intersecting with gender and age will make it a complex process to fully explore. Choices would need to be made about vignettes. If disability isn't the lead topic that gender and age intersect with, it gets even more complicated. Vignettes seem appropriate due to story-telling affinity and non-threatening conversations, but they will require extensive guidance on facilitation, documentation and analysis.

- Attitudinal barriers run throughout projects to varying degrees (less in humanitarian context) and alongside the focus on accessibility. Stigma in itself is not measured in HI's projects, but:
    - Some data on attitudinal changes is collected based on knowledge, attitudes and practice (KAP).
    - Indicators focus on participation of people, youth, children in activities and services - without necessarily checking the quality of these services, meaning there is an assumption that better 'access' implies a decrease in stigma (e.g., education enrolment).
    - There is some recognition that there's a difference in stigma between service providers and peers; for example, that stigma by teachers is not the same as by peers and so access to schools is not enough.
    - There is a perceived focus on KAP surveys with service providers and less on data on persons with disabilities and their experiences.
- Data collection in HI projects is mostly quantitative, often based on indicators and donor expectations. There is an acknowledgment that in-depth qualitative data is lacking; while there is a larger pool of local staff/data collectors collecting quantitative data based on surveys, forms etc there is a much smaller pool of thematic experts with capacity around qualitative data and analysis. Any measurement method carries implications for training, not only to the thematic experts, but ideally to also the larger pool of data collectors on how it works, how to do it effectively and well.
- Awareness of tools and methodologies is mixed. KAP surveys at output level, focus group discussions, key informant interviews, anecdotal stories, observations at service level were all referenced by HI staff. ScoPeo is known/heard of, but not used widely. Other tools were named: WHO-DAS survey; UN Women with Disabilities Stigma Inventory (with a similar tool/questionnaire having been developed by Making It Work, which was also deemed inappropriate for the purpose of the study).
- Respondents were asked what they understood by or expected in terms of the 'appropriateness' and 'practicality' of any measurement method:
    - Appropriateness: adapting to multicultural context and language, easy to collect data with tech/integrate into tech platforms, 'base' tool that then adapts to context, sensitive about topics that nobody wants to talk about, possible to use for self-reporting
    - Practical: needs to be useful (respond to donor's expectations on reporting), ownership through comprehensive understanding of the tool and approach - and having time to learn and apply it, for everyone to use easily, not too long and cumbersome, simple and adaptable, include a scale, colours, graphic stories, easy to integrate into an FGD.
- Intersectionality is seen to be a difficult concept by HI staff, with identity factors often kept in 'silos' (e.g., gender, disability and any other identity factor in parallel/separate groups). HI projects were thought of and perceived by HI staff as more focused on demographics and subsequent analysis of who said what, not as much on designing

lines of questions to explore and/or challenge intersectionality and perceptions of identities.

- HI staff see a paradox in wanting a global tool and serving the need for sensitive contextual adaptation (including accommodation of language barriers and translation challenges while retaining clarity of content and concepts). HI staff also acknowledge the question of attribution/contribution - beneficiaries do not necessarily know which organisation is doing what in their communities exactly to be able to attribute change.

Discussions with the Technical Committee helped to spotlight the following concerns:

- There are many tools available within HI but not all are known or applied; a lot of quite heavy tools and toolboxes and guidance documents already exist but are un/underused. ScoPeo is not widely used in HI yet. There was concern that this process would produce another big, complex tool that would not be applied in HI's work.
- In HI, there is often a preference for scales and ranking. Participants are often hung up on the specific scoring number whereas HI just wants to see a change/ direction of change. In either case, qualitative details tend to get missed.
- Ideally, the measurement method should be easy to embed in focus group discussions.
- Allocating the funds and time to use these approaches appropriately and well is a challenge. The new measurement method must not be resource intensive.
- Training of HI staff is as important to consider as the tool itself, not only for general robustness of data, but also specifically in regard to the bias and preconceptions that staff/ data collectors themselves bring to the conversations and accidentally embed or reinforce. HI tends to have more staff with experience in quantitative research, therefore training on facilitation skills for qualitative data is essential.

These findings from Phase 1 led the study to co-design with a Technical Committee an entirely new measurement method to be tested in Benin and Lao PDR, (See Box 1 for a summary of the outcome measurement method that was developed).

2. Key findings from Phase 2

2.1. Appropriateness of the outcome measurement method

The appropriateness of the outcome measurement method relates directly to whether the tools enabled respondents to identify disability, gender and/ or age-related stigma at the community/ territory level as well as any changes in stigma over time. The 'flower of identity', 'Bridges' and the 'Smileys' all proved effective in helping respondents explore stigma and ‘belonging’ and eliciting both concrete and personal experiences; but, the tools worked best together and not in isolation.

The ’flower of identity’ was useful in understanding and stimulating reflective thought and discussion on the complex layers of identity; it is important to recognise that this tool has **not** been applied as a measurement or rating tool, but as a tool to facilitate reflection about intersecting identities and how these may elicit specific experiences of stigma.

‘Bridges’ was especially impactful for respondents who could relate their personal experiences of exclusion or isolation to the imagery of a bridge, which symbolised both the progress made and the ongoing challenges that remain. ‘Bridges’ often elicited (from older respondents) nuanced reflections of respondents’ experiences and the support they found was available to them, including their sense of personal growth and resilience.

‘Smileys’ were instinctively used by respondents to report personal emotions and not how they felt about community-level efforts regarding inclusion; careful explanation by the country teams in some interviews and group discussions helped respondents also focus on community-level efforts. Feedback using ‘Smileys’ was often brief and lacked nuance; ‘Smileys’ was effective for gauging surface-level emotions.

The appropriateness of the outcome measurement method also relates to whether different respondents (e.g., of different ages, gender or impairment types) were able to utilise the tools:

- The ‘flower of identity’ was well received by older respondents, particularly individuals with more complex social roles and identities. Younger respondents and people with sensory impairments were also able to engage successfully with the ‘flower of identity’, although some required demonstration and careful facilitation from country teams because of the tool’s abstract nature. In Lao PDR, some respondents with intellectual disabilities or low-literacy levels found the ‘flower of identity’ challenging without significant facilitation. Gender had no apparent impact on utilisation by respondents of the ‘flower of identity’.
- ‘Bridges’ was also better received by older respondents. While younger participants typically understood ‘Bridges’ quickly, some younger respondents (and people with sensory impairments) required additional explanation or practical examples because of the abstract nature of ‘Bridges’. On multiple occasions, respondents (young, older and people with sensory impairments) perceived ‘Bridges’ to focus only on physical accessibility and not also on community-level support to strengthen inclusion nor attitudinal barriers. Gender had no apparent impact on utilisation by respondents of ‘Bridges’.
- ‘Smileys’ was widely appreciated for its simplicity and accessibility. Participants of all ages, including those with cognitive or communication impairments, found ‘Smileys’ easy to understand and use. ‘Smileys’ proved especially useful for respondents who struggled with more abstract concepts or needed a simpler, more immediate way to communicate their emotions. As a standalone tool, some older participants found

‘Smileys’ too simplistic to capture more complex emotions related to stigma and social integration. Gender had no apparent impact on utilisation by respondents of ‘Smileys’.

2.2. Practical applicability of the outcome measurement method

Practical applicability relates to whether the tools can be easily utilised by HI staff (including in low-resource settings) and how quickly respondents engaged with the tools and/ or whether respondents required more time or assistance.

The ‘flower of identity’ proved the least practical tool, its abstract nature required careful explanation and facilitation by country teams. Respondents with intellectual disabilities and/ or low literacy levels required adaptation of this tool; our country team in Lao PDR drew simple icons to represent roles (e.g., icons for female and male) or invited caregivers/ other people with disabilities to draw simple icons based upon the respondents’ suggestions. After in-depth clarifications and examples, all respondents came to appreciate ‘flower of identity’, many respondents reported it helped them consider societal dynamics in ways they hadn’t initially considered. Without tactile or sensory-friendly versions of the ‘flower of identity’, people with sensory impairments typically required a lot of time and careful explanation from the country teams; tactile versions of the ‘flower of identity’ are conceivable, but require further design (see Annex 4 for specific suggestions).

Most respondents were quick to understand the visual representations ‘Bridges’ provided meaning many respondents required little additional assistance to use ‘Bridges’. Some respondents (especially younger respondents or people with cognitive impairments) required more time to understand ‘Bridges’ to ensure they used the tool to reflect on societal structures and their experience(s) of marginalisation instead of only physical accessibility. In some cases, our country team used physical gestures (e.g., shaking or balancing hands) to represent unstable or sturdy bridge; this visual aid worked well, especially with respondents with low literacy.

‘Smileys’ proved to be the most straightforward and practical tool for use across all demographics; ‘Smileys’ allowed participants to engage in data collection quickly and easily. ‘Smileys’ proved effective for immediate feedback (but limited for deeper emotional reflection, see Section 3.2.1). One young female respondent with a hearing impairment in Lao PDR, for example, confidently used ‘Smileys’ to express her evolving sense of integration by pointing at the saddest ‘Smiley’ and then a happier ‘Smiley’. In sessions involving respondents with limited verbal communication the ‘Smileys’ became a core method of expression, especially when supported by gestures, direct support from caregivers and/ or careful probing by country teams to help confirm and elaborate upon selected ‘Smileys’.

Regarding the time required to use the tools, our country teams found that individual interviews typically required an hour and group discussions often exceeded two hours. Initially, more group discussions were planned in Benin to test the outcome measurement method; field testing was adjusted based on the realisation by the country team that the sensitivity of some of the questions led respondents to prefer individual interviews. Additionally, some respondents appeared to be influenced by the responses of others during group discussions. Data collection in Benin did not halt all group discussions, but small group discussions (with only three participants) proved more effective with interviews sometimes required to replace group discussions altogether; this also impacted the time required for data collection and has implications for future use of this tool for HI staff.

2.3. Additional key lessons regarding the outcome measurement method

Field testing in Benin and Lao PDR spotlighted findings unrelated to the appropriateness and practical applicability of the outcome measurement method, but still relevant to the revision and further development of the outcome measurement method:

- The concept of 'belonging' was not easy to translate into local languages and therefore required explanations. When presented with concrete examples (e.g., being invited to a wedding, participating in religious ceremonies and rituals, or participating in other social events), respondents engaged well. The country team in Lao PDR found it helpful to ask: "*Where do you feel most accepted or included*?" or "*When do people treat you like you are part of the group?*" In Benin, people responded well to the question of being accepted.
- Overall, younger respondents appeared to report a sense of 'belonging' that was strongly linked to basic social interactions and social acceptance (e.g., being welcomed at school or in church). Older respondents articulated a more complex sense of 'belonging' related more to self-worth and societal roles/ connections. There was no apparent difference around 'belonging' based upon gender.
- The 'flower of identity' provided a strong tool for exploring intersectionality, helping to highlight to respondents how disability intersects with other social factors (e.g., gender, age, and socioeconomic status). One key prompt used in Lao PDR was the statement: *"We are not just one thing, we are many things at once, a woman, a farmer, a mother, disabled, female or male etc."*. Women with disabilities reported facing additional barriers due to gender discrimination and older respondents highlighted how age compounded stigma and the challenges of being accepted in society. Some respondents with painful personal histories found using the 'flower of identity' triggered some negative emotions, underscoring the importance of safeguarding procedures.
- One key finding was that the way respondents were welcomed and made to feel at ease prior to interviews or group discussions significantly impacted their participation in the process:

> *"I appreciated how you explained things at the beginning and made me feel at ease. This is what laid the foundation for my open-mindedness."* - young, male respondent in Benin.

Our country teams started each interview or group discussion with a friendly introduction, often using personal stories, humour or warm-up questions to help make respondents feel at ease.

- The location proved critical to the levels of engagement of respondents; respondents were more open with country teams in environments the respondents deemed private and safe. In quiet spaces away from public areas, respondents confidently engaged with 'Bridges' and 'Smileys'. On the limited occasions where the Village Head or project staff were visible, respondents seemed less confident or willing to discuss sensitive issues like stigma and/ or exclusion. In Lao PDR, one female respondent refused to rate a recent experience at the local hospital until local government representatives stepped away. Privacy and confidentiality are essential prerequisites for effective data collection.
- The community mapping exercise used at the outset of data collection proved an especially effective entry point. Mapping the village and/ or pointing to places respondents frequented helped them relax and engage more comfortably; it created a non-verbal way to start the conversation, especially for participants who were shy, had hearing impairments, or low literacy. For younger people, mapping felt more like a playful or creative activity, and once trust was established, they were better able to engage with 'Bridges' and 'Smileys' and discuss how different places made them feel.
- At a minimum, the outcome measurement method requires a team of two (one to facilitate and create a trusting environment and the other to record the discussion, including what is said and emotions or gestures). The study team also requires a gender-balance, to facilitate sometimes sensitive discussions around intersectionality and 'belonging'.
- Each tool requires introduction and facilitation, and sometimes adaptation (e.g., utilising gestures to strengthen communication and changing the methodology from group discussions to individual interviews); this has implications for the time taken to complete the outcome measurement method as well as the skillsets required of team members (including strong interpersonal skills and strong experience of facilitation).

3. Implications of key findings for the outcome measurement method

Overall, the outcome measurement method and its constituent parts (community mapping, 'flower of identity', 'Bridges' and 'Smileys', individual interviews/ small group discussions) appears to provide a viable approach for engaging community-members on the issue of interpersonal stigma. Two parts of the outcome measurement method ('Bridges' and 'Smileys') also appear capable of helping respondents 'score' perceived levels of and changes to interpersonal stigma at different periods of time or at different locations; coding of qualitative data collected would also provide a deeper understanding of respondents' experiences and reasons for the scoring given (key considerations regarding analysis of the data collected is available in Annex 4).

Field testing spotlighted some challenges key social groups had with the abstract nature of some tools (particularly ‘flower of identity’ and ‘Bridges’), but field testing showed that all respondents can successfully engage with the outcome measurement method with careful facilitation and adaptation(s). The outcome measurement method appears to provide the potential for all likely respondents (regardless of age, gender or impairment type) to articulate and report changes in interpersonal stigma.

Field testing also demonstrated the outcome measurement method is practical. The Guidance Note for utilising the outcome measurement method (see Annex 4) is intended to outline how HI staff can collect and analyse data using the outcome measurement method; the Guidance Note is based upon the original field testing protocol, but revised to reflect lessons learned from field testing in Benin and Lao PDR. For example: the data collection process now starts with community mapping because it acts as both an ice breaker and a tool to capture gender- and age-related insights about what participants focus on as important services and places in their community; adaptation suggestions for the visual props have been provided; guidance has been added regarding the use of individual interviews compared to group discussions. While the Guidance Note provides a standardised frame for application of the outcome measurement method, it is important to note tool-specific modalities and probing questions may need to be adapted to the cultural and (possibly) political context of the location(s) of data collection.

The field testing completed to date means the outcome measurement method cannot be considered ‘final’; the Guidance Note should also not be considered ‘final’ or comprehensive. It is likely that the outcome measurement method will require further refinements to improve the data it collects; in particular, work is required to: test the accuracy of scores provided using ‘Bridges’ and ‘Smileys’; enable attribution of any stigma reduction to specific project activities. The outcome measurement method has also not been used directly by HI staff (the intended end-users), their direct involvement will help to strengthen guidance regarding both utilisation of the outcome measurement method as well as analysis and application of the collected data.

IV. Recommendations

The Guidance Note for utilising the outcome measurement method (see Annex 4) has already been revised to reflect key findings from field testing. As a result, recommendations are not focused on suggested changes to the outcome measurement method. Instead, recommendations focus on the further development and 'roll-out' of the outcome measurement method. This study was intended to design and conduct limited testing of a potential outcome measurement method for HI to further test and finalise. To help HI get the outcome measurement method to 'completion', recommendations are:

- Test the outcome measurement method in at least two more geographical locations and contexts, to identify further refinements required and/ or to validate the suggested method and its constituent parts (to help ensure it is universally applicable across diverse cultural and personal contexts).
- Verify reported changes in stigma in one or more location used to test the outcome measurement method, to help validate the scoring using 'Bridges' and 'Smileys'.
- Engage HI staff in future testing of the outcome measurement method, to examine its readiness for application by the intended end-users.
- Develop training and/ or implementation guidelines for HI staff, to inform and help standardise utilisation of the outcome measurement method.
- Review application of the outcome measurement method at regular intervals (e.g., annually or after use by five projects) to examine both the process and the data collected, in order to further strengthen the outcome measurement method and its constituent parts.
- Examine how to also assess attribution of stigma reduction efforts, to help identify HI's role in any changes in disability, gender and/ or age-related stigma.

V. Conclusion

Developing a method to measure changes in interpersonal stigma is highly innovative in the global development and humanitarian sectors; developing a method that can be applied equally to all projects, regardless of context, geographical area, sectors or intervention modalities is also highly ambitious.

This study sought to design and conduct limited testing of a potential outcome measurement method for HI to further test and finalise. To that end, this study has developed what appears to be a viable approach for engaging community-members on the issue of interpersonal stigma and for community-members to 'score' perceived levels of and changes to interpersonal stigma at different periods of time or at different locations. The discussions the outcome measurement method generates and the resulting qualitative data looks highly likely to provide nuanced evidence regarding stigma reduction.

More testing is required; the Guidance Note (see Annex 4) will help utilisation and further testing of the outcome measurement method.

Annex 1: List of reviewed documents

Direct links to the documents are embedded in the text where direct links are available.

No.	Paper
1	A literature review of methods used to measure attitudes towards disability, 2022, National Disability Authority, Ireland
2	Stigma and Disability Inclusion; Maria Zuurmond Aug 2024
3	Out of the Silos - identifying cross-cutting features of health-related stigma to advance measurement and intervention, BMC Medicine 2019
4	The use of vignettes in research on the social and educational inclusion of people with disabilities: a review of the literature, Int Journal of Social Research Methodology, 2024
5	Ableism differs by disability, gender and social context: Evidence from vignette experiments; Economic & Social Research institute Ireland, 2023
6	Using Vignettes as a Research Method to Investigate Placement and Provision for Children with Special Educational Needs in Different Countries, Athens Journal of Education 2023
7	OPERATIONAL RESEARCH PROTOCOL to measure attitudes, stigma and social norms towards children with disabilities in Europe and central Asia, UNICEF, 2019
8	Sample Measuring Tool Lebanon, UNICEF
9	Measuring health-related stigma – a literature review, Psychology health and Medicine, 2006
10	Assessment of stigma among people living with Hansen's disease in south-east Nigeria, Brakel W, 2016
11	SARI Stigma Scale (2 documents)
12	SARI Question-by-Question Guide
13	HI Theory of Change (English version)
14	ScoPeo Guide: ScoPeO-Adults: Measuring quality of life, safety, and social and family participation of project beneficiaries: Innovation, Impact and Information Division, 2019 (Third edition)
15	The ScoPeo Tool – measuring the impact of our interventions; quality of life, safety and social and family participation 2015

16	Lessons Learned in Using the Score of Perceived Outcomes (ScoPeO) Tool in Mental Health and Psychosocial Support Programmes to Measure Quality of Life: Mattern, Blanche, Zimmerman, Maximilien; Archambaud, Lise, 2023
17	“Ending stigma and discrimination in training institutions and worklaces in Tanzania”, 2023
18	UNICEF Module 7 of addressing stigma and discrimination toward children and youth with disabilities through social and behaviour change toolkit
19	The Use of Vignettes in Qualitative Research, Christine Barter and Emma Renold 1999
20	Explanatory Model Interview Catalogue Community Stigma Scale (EMIC-CSS), NTD NGDO Network
21	Measuring HIV stigma and discrimination, 2012
22	From Conceptualizing to Measuring HIV Stigma: A Review of HIV Stigma Mechanism Measures, July 2022

Annex 2 : List of interviewees and focus group participants

Interviewees :

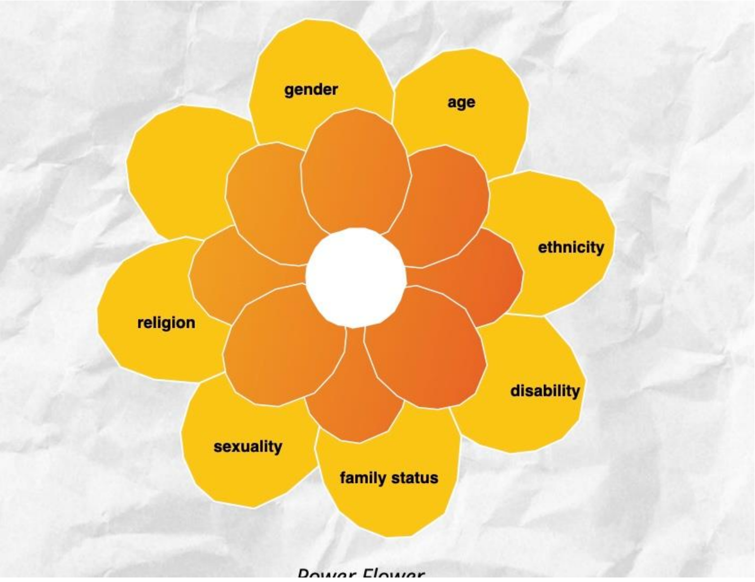
Technical Unit Manager - Tunisia
Technical Unit Manager – Latin America
Regional MEAL manager - South East Asia
Program MEAL manager - Ethiopia/Somalia
MEAL Manager - South Asia
MEAL Manager - Afghanistan
Sr Technical Officer MHPSS - Program SE Asia/Thailand
Inclusive Governance Global specialist

Focus Group discussion participants :

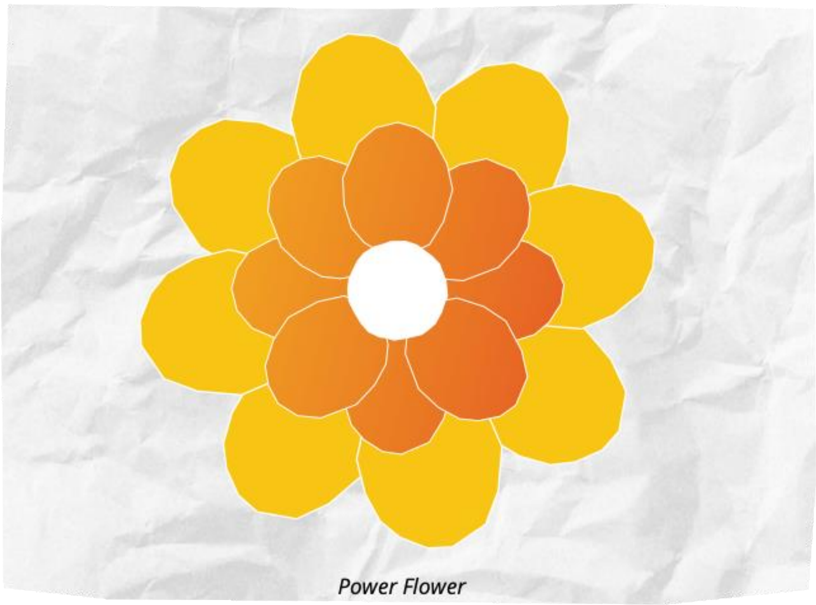
Policy Lead & Inclusive Humanitarian Action Specialist
Inclusive Health Global Specialist
Inclusive Education Global Specialist
Inclusive Livelihood Specialist
Making It Work
Environmental health specialist
Disability Gender Age Specialist

Annex 3: Visuals used for field testing

Visual 1: Flower of Identity half-completed as template



Visual 2: Flower of Identity template to be completed in local language

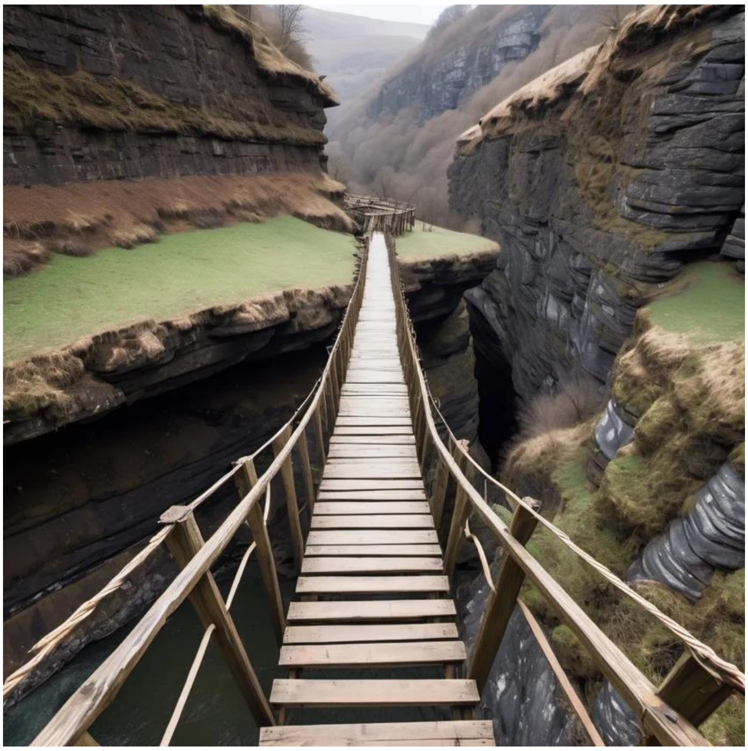


Visual 3: Almost dysfunctional/collapsed bridge

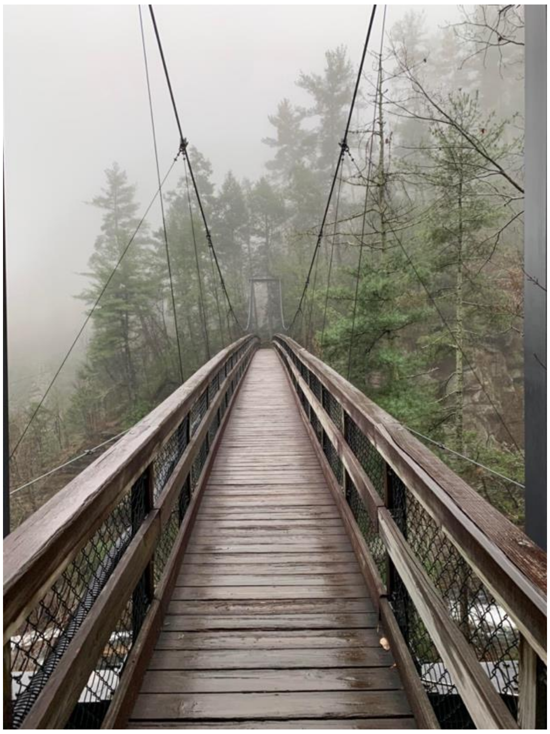
Visual 4: Very weak, wobbly bridge with steps missing and nothing to hold on to

Visual 5: Wobbly bridge but complete, with some support to hold on to

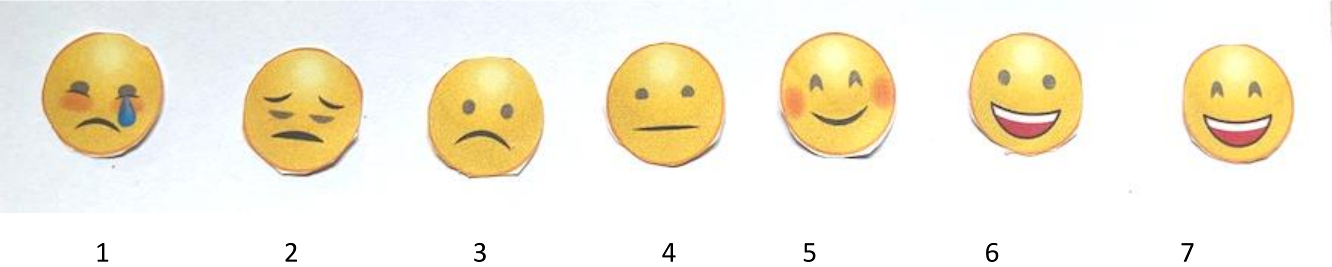
Visual 6: Stronger bridge with good support to hold on to but still has gaps between boards



Visual 7: Very sturdy with safe and steady support if needed and strong boards to move over



Visual 8: Smileys



Sources:

Visuals 1 and 2, taken from JASS, Just Power: A Guide for Activists and Changemakers (2024). Available at: https://pressbooks.pub/app/uploads/sites/14075/2024/12/JASS-Just-Power-ENG.pdf).

Visuals 3 – 8, no attribution required.

Annex 4: Guidance Note for utilising the outcome measurement method

1. Introduction and concept definition

Interpersonal stigma is approached via the concept of 'belonging' and 'othering'[3,4]. Based on the first pilot test of the method in Benin and Lao PDR, the concept of belonging has been simplified and now focuses on feelings associated with belonging and othering experienced by diverse persons in interactions with service providers, institutions and/or communities.

'Belonging' and 'Othering' are a proxy approach for considering stigma. 'Belonging' represents feeling:

- Safe
- Welcome
- At ease, comfortable
- Recognised, accepted
- In control, with agency

Not all these feelings have to be present **to the same extent**, but a strong sense of belonging could be present when a person experiences all of them to some degree.

'Othering' represents the opposite, in certain situations or places the attitude and behaviour of others towards them makes them feel:

- Unsafe
- Ignored, excluded
- Uncomfortable, overwhelmed
- Rejected, abandoned
- Without having any control, agency

This document provides guidance on how to use the outcome measurement method designed to measure changes in interpersonal stigma. The guidance recommends what to prepare, outlines the tools and visual components, and how to approach analysis of the data to conclude if change has happened or not.

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[3] https://www.projectoverzero.org/media-and-publications/belongingbarometer

[4] Powell, J. A. belonging – bridging beyond othering; Othering & Belonging Institute, USA; https://belonging.berkeley.edu/sites/default/files/2024-11/BelongingColorado_OBI_Sept2024.pdf

2. Overview of the outcome measurement method

The outcome measurement method is based on semi-structured interviews with persons with disabilities. Due to the sensitivity of the topic, we recommend individual key informant interviews so that participants may feel safer to speak out on personal issues. Small group interviews of a maximum of three persons may be considered when children or adolescents are interviewed. In these circumstances it is possible that a group setting might feel less intimidating for young people with disabilities than being interviewed by at least two adult strangers. However, this preference will need to be confirmed with prospective young persons.

If there are group discussions involving young people, these groups

- must be single-sex
- not be bigger than three (3) participants
- must not be younger than 14 (14-17 years)
- may include participants with mixed impairment but not including persons with intellectual or neurodiverse disabilities)
- may be based on ethnicity (subject to local context)

If there are small group interviews with young people, ideally, caregivers would not be present to protect the confidentiality of other participants. If young people need caregivers to participate, individual interviews will be better.

In general, if caregivers for young persons or adult respondents must be present, the facilitator(s) must take care that the caregivers only support the informants as much as needed and do not influence their response.

3. Sampling

Sampling is subject to the context of specific project activities and MEL plan (including specific project indicators and whether this outcome measurement method is being used for project baseline, midline and/or endline); the sample size depends on many factors (e.g. time, budget). Importantly, qualitative research doesn't aim for statistical representativeness but for understanding experiences and perspectives to provide rich, in-depth information on the topic, in this case interpersonal stigma. Therefore, it is critical to include a diverse range of respondents to reach conclusions on a topic from different perspectives and experiences.

It is recommended that sampling is purposive (possibly with snowballing), to establish a diverse group of respondents based on age, gender and impairment types as a minimum. Where relevant, other specific characteristics may need to be considered (e.g. ethnicity, refugee/migrant status, LGBTQ+, indigeneity, etc). An appropriate sample size has been reached when there is a level of saturation (i.e. information doesn't bring any more new insights). The recommended sample size varies between 12 and 30 interviews/ group discussion participants.

4. Data collection team

Interviews should be conducted in pairs, one person to facilitate the interview and one person to take notes of the interview and observations. A female facilitator should conduct the interview with female respondents, and a male facilitator with male respondents. If there are small group interviews with young respondents, the gender of the lead facilitator should match the gender of the group (male lead facilitator for male group and female lead facilitator for female group). Facilitators in small group discussions need to pay attention potential power dynamics, for example related to age differences. Facilitators need to be curious and listen well so that they can discern when something is 'casually' mentioned that requires follow-up probing questions.

5. Tool package

The tool package includes:

1. Interview guidelines to be used with adults (Annex 4A)

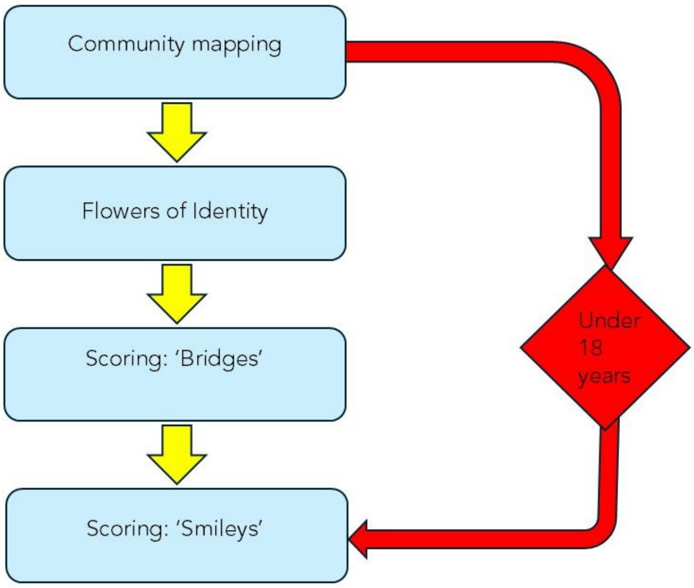
- Community Mapping exercise as ice breaker and to provide context of relevant services and places.
- Visual supports:
  - One visual to explain the concept of intersecting identity factors ('flower of identity') and to facilitate the exploration of experiences with an intersectional lens.
  - One photo series of different types of 'Bridges'. The 'Bridges' represent the **attitudes and behaviours that other people display** towards respondents in their interactions. The visuals should help nuanced discussions around the experience of interaction. The selected bridge provides a 'grade' or 'scale' of that behaviour or attitude as a statement on the **quality** of services or interactions.
  - One spectrum line of 'Smileys'; they reflect the respondents' personal feelings about services and interactions they receive and therefore rate the satisfaction of respondents with the service and/ or interaction.

2. Interview guidelines to be used with young persons (Annex 4B)

- Community Mapping exercise as ice breaker and to provide context of relevant services and places.
- Visual support:
  - One spectrum line of 'Smileys' to help discuss experiences. As above, the 'Smileys' reflect the respondents' personal feelings about services and interactions they receive and therefore rate the satisfaction of respondents with the service and/ or interaction.

Figure 1 provides an overview of the order in which the tools are to be used.

Figure 1: Summary flowchart regarding use of the tool package



6. Preparation for use

6.1. Material preparation:

- Print out the visual aids Annex 3 to show to interviewees. Print the visual aids (visuals 2-8) on separate pieces of paper. Complete visual 1 and fill in the inner petals according to the proposed identity factors in the outer petals so that you can show one completed version to respondents. As well as writing the identity factors on the 'petals', it may be helpful to consult with persons with disabilities from relevant partner OPDs on which symbols could represent the identity factors.
- Interview teams review all interview questions; Annex 4A and Annex 4B are interview guides for adults and young people, respectively. The interview questions should remain the same for small group discussions (only young persons), **if** group discussions take place.
- Anticipate one-hour for individual interviews and two-hours for group discussions. Be aware of potential extra time for mixed impairment groups to either explain visuals and/or allow for sign language interpretation or alternative communication means.

6.2. Conducting the interviews

- Collect verbal or written consent from all interviewees prior to any interview.

Reminder for making data collection inclusive:

- Provide tactile versions of the visual props for persons with visual impairments:
- a tactile version of the ‘flower of identity’ could be made by using different types of materials with different surfaces to differentiate the petals. Tactile symbols (e.g., made of string glued onto the surface of the ‘petals’ so they are a raised surface for people with visual impairments to feel) may help with identification of the identity factors.
- A tactile version of the ‘Smileys’ could be made from thick cardboard whereby mouth and eyes are cut out, or material glued onto paper/card to create each ‘Smiley’ symbol. It may be easier to use a scale of only 5 ‘Smileys’ whereby the mouths of each face are very distinct to touch to identify the feeling they express.
- A tactile version of ‘Bridges’ may be more difficult to construct, but could be represented by different materials (e.g., straw, thin rope, wood and stone).

- Record all answers provided by interviewees as much as possible and as exact as possible (audio recordings are suggested if consent has been given)
- Ensure interviews ‘do no harm’. Annex 4C provides guidance for adopting a ‘do no harm’ approach; ensure interviews are conducted in locations where the discussion cannot be overheard. For young people, their parents/guardians should remain visible but at a distance so answers cannot be overheard (if that is possible). In addition, see HI’s document on ethical data management
- Ensure respondents are welcomed and made to feel at ease prior to interviews or group discussions using initial ‘warm-up’ questions (e.g., asking about them and their lives) and personal connection techniques (e.g., highlighting common interests or experiences) to build trust before beginning structured questions.

Reminder for making data collection inclusive:

- Visual props need to be described every time the interview team references them, includes tactile props (if used).
- For persons with intellectual or neurodiverse disabilities, provide extra time in the interviews to allow for things like repeating explanations and questions multiple times to strengthen understanding and provide longer response times for questions.
- For persons with hearing impairments, remember that respondents can only look at one thing at a time (either the signing or the visual); allow enough time for translation between what you say and what you physically show to participants with hearing impairments.
- For more suggestions to accommodate data collection see HI Toolbox – Technical Sheets (provided separately).

7. Analysis for change

Key points to consider when analysing the data collected includes:

The community mapping provides a context from which to explore ‘belonging’ and ‘othering’. Information about the results from the mapping needs to be documented to understand scope and context; it narrows down which services, places and occasions of interaction with other people are investigated. If key institutions are not mapped (e.g., health facilities) it is important to probe why (e.g., not known about or not used); this requires data collection teams to have a good understanding of institutions or services deemed central to project activities/ specific target groups.

For intersectional analysis: it is important to note if there is a difference in the mapping done by women relative to men, or in age groups, or between different impairment groups. Women might draw less places when they have limited freedom of movement; women might also attach more importance to certain services or places when it relates to children or family wellbeing, or identify places of safety (or danger) differently from men. Younger people might also focus on different places to older people. These differences clarify the reach of interaction and the value different people put on services and places.

The ‘flower of identity’ (if used with respondents) is a tool for reflection on identity factors and how they might play a role in experiences of ‘belonging’ or ‘othering’. This is highly personal and sensitive data. It is not necessary to document and retain the completed flowers. Only information that explores to what extent and how identity factors from that exercise may play a role in experiences of ‘belonging’ and ‘othering’ is relevant to document and analyse.

For intersectional analysis: disability is often assumed the only or main reason for stigma and exclusion. In the interview guide (see below), probing questions aim to “challenge” that by asking if the respondent’s experience would be the same for a (fe)male person, or another age group, or from a different ethnicity or impairment group. The responses need to be analysed according to identity factors of the respondent as well as the content of the response. They may provide insights into prevailing social norms and its effects on interactions; and if/ when gender or age or refugee status or ethnicity are relevant factors for stigma that intersect with disability.

‘Bridges’ are a tool to encourage identifying and articulating experiences and feelings associated with ‘belonging’ and ‘othering’. Respondents are asked to select one type of bridge that represents a judgment on how the service provider or community member(s) interact with the respondent. The information about the reasons for the bridge selection provides a more nuanced picture which will be strengthened by specific examples. The bridge itself that is selected as an overall summary can also be used as a rating or grade. When the rating is documented and compared to previous or future times, it provides a snapshot of change that can be qualified with reasons for (and specific examples of) change. Big rating differentials indicate more meaningful change.

‘Smileys’ work in a similar way to the ‘Bridges’. The difference is the ‘Bridges’ rate other people/ services, and the ‘Smileys’ rate the respondents’ satisfaction with the services/interactions.

For the analysis, the documentation (transcripts) of interviews and the mapping will need to be coded according to themes or topics around belonging and othering. The mapping will have provided insights into the value of places and services that respondents chose to draw. Absence of normally important places/services (e.g. health centres or community centres) may have indicated lack of access or negative experiences. The themes/topics of the interviews should be aligned with the feelings associated with belonging and othering (see introduction and concept definition) and experiences of interactions (attitudes, behaviour by others) that evidence these feelings, for example, statements from respondents that recount an interaction with a service provider which made them feel welcome and accepted would be marked and collected and reviewed as per respondents’ demographics (gender, age group, impairment type): are more men of a certain age group feeling welcome with a certain service provider compared to women of a certain age group and impairment type with the same provider? This would speak to positive attitudes and behaviour.

If respondents talk about where they may have felt threatened or unsafe, had experience of maltreatment or even abuse, this will also speak to power dynamics. Again, it will be important to review and analyse the identity factors of respondents in comparison to other respondents with same or different experiences to conclude intersectional stigma.

Annex 4A: Interview guide (adults)

Section 1: Consent

This interview/discussion is part of a series of conversations we are having with a range of persons with disabilities about their sense of 'belonging' in their communities, and in interaction with service providers and community members. The purpose is to find a respectful way to talk about personal experiences of such interactions and reflect on how they may affect you. HI would like to learn about changes in community attitudes towards persons with disabilities that may or may not have happened. This learning will help improve the way programmes are implemented to contribute to positive changes towards disability inclusion in communities.

Your personal contributions to this process are important and we thank you very much for agreeing to take part in this interview. The information you give us today will be used only for the purpose of reviewing the way we talk to you and what we can learn from you. It is strictly for internal use. There are no right or wrong answers, or better or worse answers, we just want to hear what you have to say.

If it is okay with you, I/my [as applicable] colleague will be taking notes and will be recording the interview during our conversation so we can remember what you said. Everything you say will remain confidential, meaning your name will not be associated with any of the reports we write. We will store our notes in a safe place and will destroy these notes when we no longer need them.

Before I begin, I would like to ask whether you agree to take part in this interview having understood what I will do with the information you tell me in the next hour. Please note that this interview is voluntary, and that you are under no obligation to answer any or all the questions, although it would help if you did. Whether or not you decide to participate and what you tell us will **not** affect your relationship with HI.

You are welcome to ask any questions during the interview. If you agree to this interview, you can still decide not to answer specific questions during the interview. You can stop/terminate the interview at any time, and you have the right to withdraw your consent from participating in this interview at any time, without any consequences for you in any form.

If you have any questions or would like to report anything that happened during the process of conducting this research, you can contact [add applicable point of contact].

If, during the interview, you tell me something about you or anyone else being in danger, I would talk to you about how you or others could receive support and whether this needs to be reported to anyone.

Do you have any questions about anything I have just said?

Do you understand the purpose and nature of this evaluation? [record 'yes' or 'no']

Do you wish to participate in this evaluation by answering a set of questions? [record 'yes' or 'no']

[If applicable] We would also like to audio record the interview to facilitate note-taking and later analysis. The recording would not be accessed by anyone beyond our team and would be deleted following analysis. Do you consent to being recorded on this basis? [record 'yes' or 'no']

Section 2: Demographic information

[Please assign code so that transcript notes will not have name but code]

Code:

Can you please confirm your

- Age:
- Sex:
- Carer: yes/no
- Difficulties you (family member) may have doing certain activities: [utilise Washington Group Short Set]
- Location:

Section 3: Sense of 'belonging'

Note to the interview team:

In the interview guide to follow, **questions in bold are what you ask respondents directly**. Potentially probing questions continue in regular font. *Additional instructions to you as facilitators are in italics*

Section 3.1: Community Mapping:

We would like to learn a little about your community and your place in it.

- *Using pen and paper or a stick to draw on the ground (if the surface allows) ask respondent(s) to map their community with the services and functions that are* *important* *to them.*
- *Depending on their preference, they (or you under their instructions) can draw key locations (e.g., church, health centre, school, community centre, marketplace) using symbols for each function/service*
- *If relevant, i.e. if people would like, increase the size of the symbol depending on the importance they attach to the function/ service. Importance here relates to how often they go there, use the service, or how much they like it.*

- *Discuss with respondents their choices for their drawings and why/how they think these places and/or services are important to them. Follow up on unusual omission(s) of places or services and the reasons for it. For example, a hospital or health centre (like a school, or a community centre or place of worship) is normally an important part of the community but if the respondent doesn't have access to it or fears/avoids to go there due to anticipated or experienced negative experiences, it is important to note this down, keeping in mind demographic information for intersectional analysis.*
- *Also ask about places that they especially like to go to or specifically avoid. This could be within or outside communities like specific shops or markets, or parks, woods, fields, water (lake, river).*

Note to the interview team:

If respondents are not used to drawing or have impairments that make it difficult for them to draw themselves, facilitators or assistants accompanying the respondent can draw according to the respondents' instructions. Caution: If someone else is drawing for the respondent, the facilitator must pay attention that the other person is not providing their own ideas but only those of the respondent.

For the analysis, it is important to monitor differences in the drawings towards type and importance of places/services with an intersectional lens, i.e. are these differences related to gender, age, impairment, other identity factors?

Section 3.2: Identity characteristics

Show respondent(s) the 'Flower of Identity' that has been completed (it is entirely fictional, but can be adapted to reflect the interviewer). Explain:

All of us have layers of identities that form our lives and experiences. We are members of more than one community group at the same time, which gives us different levels of status and power in society and different experiences. *Explain that this flower is an example and shows the person as the central part of the flower, the outer petals indicate the categories of identity factors/characteristics, and the inner petals are the corresponding identity factors of the person.*

Now think about yourself. You are in the centre of the flower - I am (a) - what would the inner petals say about you? *Explain that these identity factors are* **not** *hobbies, interests, or personality traits (e.g. likes to sing, or is quiet, or ambitious, etc). Look for nouns, rather than adjectives. Remind respondent(s) that they don't have to write anything down. They can keep some or all the petals to themselves and don't have to share. This is just a brief opportunity to remind us all that we are more than just women/men/young/old etc.*

We come back to this flower in a little while.

Section 3.3: Belonging

Now I would like to talk to you about the sense of belonging.

What we mean by 'belonging' is that in a place or situation where you are with other people you feel comfortable, recognised, connected, safe, and/or in control. It is when you do not feel judged by others, but you can 'be' as you are, and you are welcome as you are.

Are there places where you are with other people and you feel as I just described?

Describe how people in this place behave(d) or interacted with you.

Note to *facilitator:*

This works as a baseline. If respondents can identify one place/situation where they do feel as described (safe, welcome, recognised, 'be' as they are) and can give some details about it, then this can be used to compare to other situations and places. Use the community mapping exercise to follow up on other places/services. Some examples are below. You can choose a place/service that features most prominently in the mapping, or one that is of particular significance for the project.

If the respondent cannot identify any place or situation where they feel remotely as described above, say:

This must be very hard. Would you be OK to give me some examples of how people behave towards you in the places you drew in the mapping?

Make sure to keep a close eye on the respondent regarding their emotional well-being. Remember the information from Annex 4C about Do No Harm: during interview

How do [the following are indicative and can be tailored to project]

a) **services at health facilities look and feel like…** e.g. *are medical staff friendly and supportive? or do they make judgments on the person or even refuse services?*
b) **being at school look and feel like…** e.g. *are teachers friendly and supportive, or do they ignore or even bully children with disabilities? Are peers friendly or bully?*
c) **being at work look and feel like…** e.g. *are colleagues friendly, are they being social? Are there opportunities to advance?; are clients friendly and appreciate of the work done? (if having a small business); are respondents being paid fairly?*
d) **being at community events like meetings or ceremonies look and feel like…e**.g. *are community members friendly and ask for respondents' input, ideas, participation?; or are they ignored or even uninvited or treated badly?*

Note to *facilitator:*

If necessary, probe on language (terms/words) people use when talking with respondents: the tone of voice; their facial expressions and/or body language; the type of information they give or ask (e.g. asking for intrusive personal information, or selecting information in SRH); (un)intended body contact (e.g., unnecessary or rough medical examination in health services, physical punishment or praise at school, touching without consent).]

Section 3.4: Bridges

Show respondent the photos of different bridges. For persons with visual impairments, explain that you will give them different material from which bridges are built (see Section 3). The type of material determines the strength, safety, and reliability of bridges.

Explain:

You have talked about how the people in ________ (service/place) interact with you and how you experience this (service/place). If you look at the different bridges (feel the material), which one would be a good image to reflect the type of service and/or behaviour? The bridge you choose reflects the quality of interaction (and overall service) between the people in this service/place and you.

Note to *facilitator:*

Remember and remind the respondent if necessary that this is not about how well respondents can cross the bridge in terms of impairment and accessibility. It is an image of the quality of the service/interaction.

Ask respondents more detail about why they chose a particular bridge, possibly asking them for more concrete/specific examples of behaviour/interaction they have experienced.

Remind respondent(s) of the flower of identity from the beginning of the session.

a) For good examples of belonging and strong bridge, choose another set of identities that are different from respondent:

   For example if you speak to a woman with disabilities from one ethnicity you may ask about a man with disability, or a woman with disabilities but from a different ethnicity, or with a different impairment, or something else.

   Would a man (or younger woman/ or from dominant ethnicity/religion/or with another family status/more wealth…) with disabilities have the same experiences?

b) *For any bridges that are less than sturdy and safe: Point to the flower and ask:*

Remembering your various characteristics, which of these would you say play a role in how_______________ (service provider, community members) behave towards/interact with you as you described?

Note to *facilitator:*

This should bring out a reflection on how intersecting identities might compound discrimination. If respondents only point to disability, probe: Would a man/younger woman/from dominant ethnicity/religion/other family status/more wealth…with disabilities have the same experiences?

Looking at your choice of bridge(s) again, which bridge would you have chosen a year ago (or any suitable time frame depending on the project)?

If any bridge(s) is/are different: **How did the bridge become stronger/weaker?**

Do you have any suggestions of what would need to happen make the bridge stronger/longer?

Show (or give) them the line of (tactile) 'smileys'.

Looking at (feeling) the line of faces, which represents best about how you feel about __________(service/place)?

Thank you very much for your time and your stories. You have been very helpful indeed, and we are grateful for your honesty.

Is there anything else you would like to add?

Do you remember that we said at the beginning that we are looking for a respectful way to talk about personal experiences. Would you comment on how you experienced this interview? Is there anything you would like to suggest we do differently in our next interviews?

Thank you again and good-bye

Annex 4B: Interview guides (under 18 years)

Section 1: Consent

[Note, for young people under 18 years this consent should also be adapted for use with their parent/ caregiver]

Thank you for being here and speak with us. We are talking to many different people about how they feel about being part of the community and how they experience being at health centres or at community ceremonies, church, and festivals, or at the market. We are speaking mostly with adult people with disabilities, but we also want to speak with young persons and their experiences, for example at school, or when they have to see nurses/doctors, or when they are out and about in the village/community. We would like to know how people in the community (e.g., doctors, nurses, teachers, shop owners or market traders, neighbours etc) behave towards you.

Another reason why we want to speak with you is that we want to find out, with your help, how we best talk about it with young persons like yourself. If we have a conversation where you feel happy to talk to us about your experiences, we can learn from you and help us improve our projects with your community.

If it is okay with you, I/my colleague will be taking notes and will be recording the interview during our conversation so we can remember what you said. Everything you say will remain confidential, meaning your name will not be associated with any of the reports we write. We will store our notes in a safe place and will destroy these notes when we no longer need them.

Because you are under 18, your parents have given their consent that we can speak with you. But we would also like to ask you if you want to speak with us. Please note that you do not have to answer any or all the questions. There is **no** consequence for you or your family if you decide not to answer a question or stop the interview altogether.

You are welcome to ask any questions during the interview.

If you have any questions or would like to report anything that happened during the process of conducting this research, you can contact [add applicable point of contact]. Your parents also have that contact.

If, during the interview, you tell me something about you or anyone else being in danger, I would talk to you about how you or others could receive support and whether this needs to be reported to anyone.

Do you have any questions about anything I have just said?

Do you understand the purpose and nature of this evaluation? [record 'yes' or 'no']

Do you wish to participate in this evaluation by answering a set of questions? [record 'yes' or 'no']

We would also like to audio record the interview to facilitate note-taking and later analysis. The recording would not be accessed by anyone beyond our team and would be deleted following analysis. Do you consent to being recorded on this basis? [record 'yes' or 'no']

Section 2: Demographic information

[please assign code so that transcript notes will not have name but code]

Code:

Can you please confirm your

- Age:
- Sex:
- Carer: yes/no
- Difficulties you (family member) may have doing certain activities: [utilise Washington Group Short Set]
- Location:

Section 3: Sense of 'belonging'

Note to the interview team:

In the interview guide to follow, **questions in bold are what you ask respondents directly**. Potentially probing questions continue in regular font. *Additional instructions to you as facilitators are in italics*

Section 3.1: Community Mapping:

We would like to learn a little about your community and your place in it

- *Using pen and paper or a stick to draw on the ground (if the surface allows) ask respondent(s) to map their community with the services and functions that are* important *to them. Depending on their preference, they (or you under their instructions) can draw key locations (e.g., church, health centre, school, community centre, marketplace, playgrounds) using symbols for each function/service increasing the size of the symbol depending on the importance they attach to the function/ service.*
- *Discuss with respondents their choices for their drawings and why/how they think these places and/or services are important to them. Follow up on unusual omission(s) of places or services and the reasons for it. For example, a hospital or health centre*

(like a school, or a community centre or place of worship) is normally an important part of the community but if the respondent doesn't have access to it or fears/avoids to go there due to anticipated or experienced negative experiences, it is important to note this down, keeping in mind demographic information for intersectional analysis.

- *Also ask about places that they especially like to go to or specifically avoid. This could be within or outside communities like specific shops or markets, or parks, playgrounds, woods, fields, water (lake, river).*

Notes to facilitator:

If respondents are not used to drawing or have impairments that make it difficult for them to draw themselves, facilitators or assistants accompanying the respondent can draw according to the respondents' instructions. Caution: If someone else is drawing for the respondent, the facilitator must pay attention that the other person is not providing their own ideas but only those of the respondent.

For the analysis, it is important to monitor differences in the drawings towards type and importance of places/services with an intersectional lens, i.e. are these differences related to gender, age, impairment, other identity factors?

Section 3.2: Belonging

Now I would like to talk to you about the sense of belonging.

What we mean by 'belonging' is that in a place or situation where you are with other people you feel comfortable, recognised, connected, safe. It is when you do not feel judged by others, but you can 'be' as you are, and you are welcome as you are.

Are there places where you are with other people and you feel as I just described?

Describe how people in this place behave(d) or interacted with you.

If necessary, prompt: This may relate to the language (terms/words) used around you/your family, the tone of voice, the way people use facial expression and body language, (un)intended body contact and touching without consent (e.g. during medical examination in health services; physical punishment or praise at school).]

Show young people the line of smileys or give them the tactile version to feel

Now, I would like to ask you about some of the places you drew.

Explain that feeling completely safe, very welcome, and totally comfortable all the time the child is the is the happiest face on the right. If the child never feels comfortable and never safe and always absolutely terrible, that's the left saddest face. Really exaggerate the extremes to help explain the two ends of the scale you as facilitator are seeking to capture here.

For this place/service *(let the child pick one, or you choose one most relevant to the project)*

which face would you choose that best reflects how people behave towards you and/or speak/interact with you.

Can you tell me why you chose this face? Why did you feel/not feel comfortable or welcome or at ease as you did (in the positive example that the child gave at the beginning)

Probe: was it always like that?

Note to facilitator

Depending on age and cognitive capacity you can ask about previous time frames to capture any changes over time. You could ask:

Do you remember if it was better (or worse) last year? How was it better (or worse)?

or

Do you remember a time when it was better (or worse)? What happened then?

Do you have any suggestions of what would need to happen so that you feel comfortable and safe and welcome – and get to that big-smile face?

Which face would you choose for our talk just now?

What do you think we could do better when we talk to young persons. Would that be the same for boys (if you are speaking to a girl – or the other way round), or someone younger (if respondent is 15 and older)?

Thank you, you have been great!

Annex 4C: Do No Harm

The topic of stigma is a highly sensitive subject. We will not use the term ‘stigma’ in the interview questions, but talk instead about emotional experiences, the sense of ‘belonging’ or ‘othering’. Discussions around exclusion, discrimination and absence of belonging may still prove emotional and potentially distressing.

It will be important to adopt a positive perspective - focus on positive feelings and trying to identify experiences of these positive feelings. It remains possible that respondents may realise that they rarely or never feel they ‘belong’, and that most experiences are negative. Therefore, you need to pay attention to their well-being during the interview and ensure follow-up after the interview, to prevent any negative effect.

Preparation:

- Secure a location that is quiet, safe and provides confidentiality. Ask the interviewee what their preferred location would be.
- Offer male and female interviewers (where possible), let the interviewee select the interviewer they feel most comfortable meeting with.
- Ask the interviewee if there is anyone they would like to have present for emotional support (e.g., a family member of counsellor) or any specific arrangements they might need (e.g. childcare) and try to accommodate.
- Ensure that there is a person or service to serve as a referral point if the interviewee may need support either during or at a point after the interview.

During the interview

- Allow time to help the interviewee to be at ease (e.g. refreshments at the start).
- If/when interviewees talk about negative experiences, stay calm and listen with empathy; acknowledge the experience without sensationalizing/exaggerating.
- Even if interviewees seem to talk around a point or seem to avoid a direct answer, allow time for that and gently bring them back to the topic or question. Don’t push if they do not want to answer.
- Pause after difficult moments for the interviewee. Allow them to stop or interrupt the interview if needed.

Emotional distress, anxiety, agitation etc are symptoms of (re)traumatization. These could be increased distractibility, breathing more rapidly or difficulty breathing, the sensation of increased heart rate, feeling ‘jumpy’, threatened etc. If this happens during the interview, help respondents to focus attention onto physical surroundings and items in their immediate environment and/or use grounding, i.e. ask them to:

- State their name and where they are.
- Name one object that they see (chair, bottle of water, …), touch one object in their environment, listen to and Also see: https://www.hi.org/sn_uploads/document/EthicalDataManagementGN-04.pdf

- Describe one sound they are hearing right now.
- Alternatively, ask them to look outside through the window or door and describe what is going on outside.
- Make sure that the person is starting to feel calmer, and symptoms are subsiding.
- Make sure that someone the person trusts will stay with them to monitor their well-being.
- Make sure you give them a referral for further support and follow-up.
- End the interview by focusing on the person’s strength and strengths.

After the interview

- Ask the interviewee whether there is any part of the response that they would rather not like you to use for safety or other reasons and respect their decision.
- Provide the interviewee with referral/contact person as needed.
- Ensure follow-up check-in, even if there was no visible distress during the interview.

Towards measuring the impact of projects related to the reduction of stigma associated with disability, gender and age at the community level.

This report presents the results of a study that aimed to lay a solid and evidence-driven foundation for developing a methodology for measuring changes linked to interventions that aimed at reducing interpersonal stigma related to disability, gender and age, which can be used to monitor projects, whatever the geographical area or sectors concerned (education, health, protection, etc.).

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