



Research & Studies
From projects

ScoPeO-Family: An alternative approach to measuring the quality of life of special needs populations

An exploratory research conducted within DPCP Project - Mali Program

Innovation, Impact and Information Division
2022

RS | FP | 42

LUXEMBOURG
AID & DEVELOPMENT 



Authors

Danielle Tan (Consultant — Research Officer)

Contributors

Lise Archambaud (MEAL, Outcomes and Impact Specialist)

Rahamatou Maïga (MEAL Officer, Mali Program)

Idrissa Hachimi (Project Manager DPCP-AC5)

Samba Coulibaly (Rehabilitation Technical Specialist DPCP-AC5)

Edition

Humanity & Inclusion, Innovation, Impact, and Information Division (3i)

English translation

Danielle Tan

Editing

Stéphanie Deygas – 3i Division

Photo credits

Cover page: © Danielle Tan / HI (Mali, 2022)

With the support of the Ministry of Foreign and European Affairs of Luxembourg. The opinions expressed in the present publication are the sole responsibility of the author.

Rights and Permissions



This work is available under the Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International license (CC BY-NC-ND 4.0). Under the Creative Commons-NonCommercial-NoDerivatives license, you are free to copy, distribute, and transmit this work, for noncommercial purposes only, under the following conditions: Attribution-Please cite the work as follows: Danielle Tan. ScoPeO-Family: An alternative approach to measuring the quality of life of special needs populations. Lyon: Humanity & Inclusion, 2022. License: Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International (CC BY-NC-ND 4.0). **Noncommercial**-You may not use this work for commercial purposes. **No Derivative Works**-You may not alter, transform, or build upon this work.

Content

| | |
|---|-----------|
| Executive Summary | 5 |
| Part 1 - Introduction | 8 |
| Context..... | 8 |
| Overall and specific objectives | 10 |
| Part 2 - Measuring the quality of life of children with intellectual disabilities: challenges and stakes | 11 |
| 1. Measuring the quality of life of children with intellectual disabilities: many challenges | 11 |
| 2. The use of a “proxy” remains an unsatisfactory and default solution | 13 |
| 3. Emergence of the QoL concept in the wake of intellectual disability studies | 13 |
| 4. Beach Center Family Quality of Life Scale or Family Quality of Life Survey 2006 ? | 15 |
| Part 3 - Methodology of the FQoL survey in Mali | 23 |
| 1. Location..... | 23 |
| 2. Study design | 23 |
| 3. Selection of interviewees..... | 24 |
| 4. Tools and modalities of data collection..... | 25 |
| 5. Data processing and analysis..... | 28 |
| 6. Ethics considerations..... | 29 |
| Part 4 - Lessons learned from the FQoL survey in Mali | 30 |
| Finding #1 : The Beach Center FQOLS is not culturally sensitive to the Malian context. | 30 |
| Finding #2. A short version of the FQOLS-2006 was designed, adapted to the Malian context.... | 35 |
| Finding #3. The measurement of FQoL is an interesting alternative approach to understanding quality of life for specific profiles for which ScoPeO has limitations..... | 36 |
| Finding #4. The FQOLS-2006 is an effective tool for planning an intervention and measuring the outcomes of HI programs with beneficiaries. | 36 |
| Part 5 - Practical guide for using ScoPeO-Family : illustration based on the DPCP-AC6 Project. | 39 |
| 1. Practical information..... | 39 |
| 2. Presentation of ScoPeO-Family..... | 41 |
| 3. Integrating a ScoPeO-Family survey into a project: the three key steps of the methodology.. | 47 |
| Part 6 - Conclusion | 70 |

| | |
|---|-----------|
| Abbreviations and acronyms | 72 |
| Bibliography | 73 |
| The ScoPeO-Family Toolbox | 76 |
| Part 1. Socio-demographic information & Part 2. The FQoL questionnaire..... | 76 |
| The FQoL score matrix (work in progress) | 76 |
| Appendices | 76 |
| Appendix 1. Revised Beach Center FQOLS for DCPC Project - Mali..... | 76 |
| Appendix 2. Final version of the FQOLS-2006 abridged and adapted to the DPCP Project..... | 76 |
| Appendix 3. Profile and scores of the 10 families | 76 |
| Appendix 4. Consent Form | 76 |
| Appendix 5. FGD Guideline for Parents of Children with Multiple Disabilities, Down Syndrome and Epilepsy | 76 |

Executive Summary

Context

Measuring quality of life has become one of the major challenges of development and international solidarity. In the field of disability, the aim is to go beyond the economic aspect by integrating a more holistic and social approach. The conceptualisation of quality of life and its measurability have been the focus of work within the Innovation, Impact & Information Division (3i) since 2013. From this approach was born the **ScoPeO-Adults** tool (Score of Perceived Outcomes) and then **ScoPeO-Kids** (children aged 5 to 17) developed with academic partners and the support of the **Ministry of Foreign and European Affairs of Luxembourg**.

Objectives

Facing difficulties in using ScoPeO in the field for certain projects, HI's 3i Division has decided to launch a study to identify and test alternative solutions for understanding the quality of life of specific groups (children with multiple disabilities and Down syndrome) by exploring the family track, based on the **DPCP Project in Mali**. A one-month field mission has been planned in Mali (October 17-November 15, 2022) in order to test the identified leads and collect data.

The aim of this exploratory research is to improve practices in order to collect relevant data on the quality of life of people with specific needs by producing guidance on appropriate tools that can be disseminated in all the countries where HI work.

Methodology

Prior to the field mission, two family quality of life (FQoL) measurement tools were identified: the **Beach Center Family Quality of Life Scale (FQOLS)** as well as the **Family Quality of Life Survey-2006 (FQOLS-2006)**. The COPIL decided to test the Beach Center FQOLS because of its simplicity and brevity.

The concept of QoL is influenced by the environmental context. **Cultural adaptation** of a questionnaire is a necessary task. This is the **first time** this tool has been adapted and tested in a local language (**Bamanankan**) and in a **low-income country**. This exploratory research allowed us to test its use in a new cultural context.

Primarily **qualitative survey methods** were used to adapt and test the questionnaire: focus groups with professionals and families, home observations, and in-depth interviews during the questionnaire administration. The quantitative results of the questionnaire allowed us to assess the relevance of the questions and domains. However, given the small sample size, these results were not intended to validate the **psychometric qualities** of the revised questionnaire.

First, the **Beach Center FQOLS was tested with professionals, associations and HI team (18 people)** in the form of Focus Groups in order to adapt the questions to the Malian context. In a second phase, Focus Groups were conducted with groups of **fathers, mothers and single mothers/grandmothers (14 families)**, beneficiaries of the DPCP Project, to understand how

Malian families of children with intellectual disabilities conceptualise the FQoL and what they perceive as their support needs, according to gender and family situation, in order to adapt the Beach Center FQOLS's questions as appropriate. Third, a **cognitive test** of the revised Beach Center FQOLS was administered to a small sample of DPCP beneficiary families in **Bamako (10 families)**. The questionnaire was administered to both fathers and mothers in the same family in order to better understand the difference in perceptions between men and women regarding family relationships and the division of labor among family members, and how these patterns affect family cohesion and intimacy, power distribution in the family, decision making, family flexibility, and family adaptation. Finally, the Beach Center FQOLS was to be administered to **5 families living in Sikasso, by telephone** — because we could not go to the field and to learn about the potential difficulties of administering the questionnaire by telephone.

Given that the study was conducted in an action-research approach, where we had to adapt to the constraints of the field and experiment with different options, we decided to adapt our data collection protocol at the end of the questionnaire administration with the 10 families in Bamako. Indeed, given the questions that the Beach Center FQOLS had raised, we decided to continue the exploratory approach by adapting the FQOLS-2006 and to test it by telephone on the 5 remaining families in Sikasso.

Findings

Finding #1. The Beach Center FQOLS is **not culturally appropriate for the Malian context**. Satisfaction is not a relevant indicator. In contrast, the "Opportunities" and "Initiatives" indicators were found to be highly relevant.

Finding #2. A **short version of the FQOLS-2006 was developed**, adapted to the Malian context.

Finding #3. The measurement of family quality of life is an interesting **alternative approach** to understanding quality of life of specific groups for which ScoPeO has limitations. A shortened version of FQOLS-2006 adapted to the different contexts and projects of HI could be an alternative tool to ScoPeO-Kids for children with severe disabilities who cannot express themselves, but also for children under 5 years of age.

Finding #4. The FQOLS-2006 is an **effective tool** for planning an intervention and measuring the outcomes of HI programs with beneficiaries.

Conclusion

The exploratory research conducted within the framework of the DPCP Project (Mali Program) has made it possible to develop a new tool for measuring family quality of life inspired by the most recent research, which we have named **ScoPeO-Family**. This FQoL survey developed as a **prototype** in Mali can be adapted to the needs of other HI's projects, in other cultural or intervention contexts. We are thinking in particular of projects for which ScoPeO-Kids is not adapted, for example, projects that reach a very young public (less than 5 years old), such as in Early Childhood Development or Education Inclusive, which works on pre-school.

ScoPeO-Family **complements the ScoPeO toolkit (Adults & Kids)** for measuring individual quality of life. This tool is fully integrated into the **social model of disability** supported by HI. Indeed, it brings a **multidimensional and holistic dimension to disability** by focusing on the whole family, with a view to **empowering** all its members, including children with an intellectual disability.

ScoPeO-Family is a comprehensive family quality of life measurement instrument that collects quantitative and qualitative data. In addition to its global orientation, this tool is based on a lifelong approach and can therefore be **used by families of children, youth, adults and seniors with or without disabilities**. Above all, ScoPeO-Family **fills a gap** in the measurement of the quality of life among specific groups, particularly children with intellectual disabilities who cannot express themselves.

Ultimately, the implementation of a ScoPeO-Family survey follows the **same procedures and requirements as ScoPeO-Adults & Kids**. The FQoL score matrix was also constructed with the same logic so that HI's teams could more easily take ownership of ScoPeO-Family. The user guide was designed to help HI's teams to use ScoPeO-Family and to adapt it to their projects. However, this FQoL questionnaire remains a prototype that needs to be tested on a larger scale and in other cultural and HI's intervention contexts.

Part 1 - Introduction

Context

Measuring quality of life has become one of the major challenges of development and international solidarity. In the field of disability, it goes beyond the economic aspect by integrating a more **holistic and social approach**. In the context of project monitoring, it allows us to better measure their outcomes, and even their impact. Thus, the concept of **quality of life (QoL)** can serve as a conceptual and evaluation framework for developing person-centred planning, as a basic principle for guiding professional practice, and as a vehicle for directing the development and implementation of public policies. Conceptualising quality of life and making it measurable has been the focus of work within the Innovation, Impact & Information (3i) Division since 2013. From this approach was born the **ScoPeO-Adults** tool (Score of Perceived Outcomes) and then **ScoPeO-Kids** (children aged 5 to 17) developed with academic partners and the support of the **Ministry of Foreign and European and Affairs of Luxembourg**:

➔ See [ScoPeO-Adults: Measuring quality of life, safety, and social and family participation of project beneficiaries](#)

➔ See [ScoPeO-Kids: A tool for monitoring the quality of life of children aged 5 to 17 years](#)

ScoPeO is a **multidimensional measurement tool** that captures how individuals perceive or feel about their quality of life. ScoPeO-Adults consists of **seven dimensions**: physical and mental health, social and personal relationships, subjective well-being; basic needs, material well-being, perceived security, and participation in society and family life. There are two versions of this tool: a **baseline** questionnaire with **27 questions** and an **endline** questionnaire with **34 questions**. Both versions are accompanied by a set of socio-demographic questions. They both produce a global score and scores out of 100 for each of the seven dimensions. ScoPeO has already been used in a number of countries (i.e. in Africa – Mali, Rwanda, Burkina Faso; in Asia – Thailand, Philippines; in South America – Colombia, Cuba).

ScoPeO was expressly developed for an adult population. Yet, HI's projects often target whole communities, including children with and without disabilities. It therefore appeared necessary to develop a tool for measuring the quality of life among children, regardless of their gender, age or disability status. To address this need, and in collaboration with the **Centre de Recherche Interdisciplinaire en Réadaptation / University of Montréal**, a research project was conducted, funded by the Ikea Foundation as part of HI's "Growing Together!" Project.¹

ScoPeO-Kids is not just an adaptation of the original ScoPeO to be used with children rather than adults: the dimensions, number of questions and answer categories are not the same. The ScoPeO-Kids questionnaire includes **20 items** covering **five dimensions**: physical well-being, emotional well-being, safety, autonomy and self-realization, and social well-being.

¹ Growing Together! Project, funded by the IKEA Foundation, aims to help communities raise socially and emotionally healthy children in displacement contexts by providing them with opportunities to learn and develop their potential safely while playing. This project targets children in vulnerable situations, namely those living in refugee / IDP camps and host communities in Bangladesh, Pakistan and Thailand.

However, both tools are based on the same principles:

- **Conceptual principles:** quality of life is subjective, multidimensional and dynamic;
- **Operational principles:** the tool is generic, applicable regardless of the gender, health status or disability status of the individuals surveyed; it serves the same project monitoring objective (measuring the outcomes of HI interventions on the quality of life of beneficiaries);
- **Methodological principles:** the same data collection modalities (direct interview with the beneficiaries) and data analysis (score and sub-scores) are recommended.

HI has endeavoured to preserve the **coherence between the two tools**, as they as they are likely to be used together on the same projects.

Within the framework of the Accord Cadre 5 (**AC5**) with the Ministry of Foreign and European Affairs of Luxembourg, a large survey was deployed in 16 countries and on 4 continents to observe, using the ScoPeo toolkit, a possible improvement of the quality of life of the beneficiaries targeted by the projects funded by the Luxembourg cooperation. However, in some cases, the **deployment of ScoPeO encountered difficulties for certain profiles**, particularly for **people with severe disabilities** that hinder the understanding of questions or reduce the possibilities of communication with an interviewer. For example, in Mali, where the intervention implemented by HI within the framework of the **DPCP project** “Detecting and managing multiple disabilities in children aged 0 to 14 years for their better social integration” is aimed at children with multiple disabilities, Down syndrome and epilepsy, the survey via ScoPeO showed a **high non-response rate**.

Out of a sample of **278 children** planned for the ScoPeo survey, **only 43 children were able to respond** to the ScoPeO-Kids baseline and the **87 parents** receiving Income Generating Activities (IGAs) responded to ScoPeo-Adults, which is **not appropriate** in this context because it is a tool for measuring individual quality of life, whereas the DPCP Project intervention focuses on **both** the child with a disability and his/her family. By default, **ScoPeO-Kids Proxy** should have been used.

In the data collection protocol, it was originally planned to **exclude children with severe disabilities (level 4 and 5)** who could not express themselves and answer the questions, and to interview only children with a disability level of 1 to 3 (which would cover children with epilepsy who could express themselves). Children with severe disabilities (multiple disabilities, epilepsy, or Down syndrome) at levels 4 and 5 were targeted through their parents who received IGAs.²

However, at the time of the baseline, it was **impossible to identify these children from level 1 to 3** because the degree of severity of the disability was never recorded, neither at the time of the confirmation of the diagnosis by the paediatrician and the physical therapist, nor at the time the child was taken in charge by the social development agents. Thus, the questionnaire administrators were mostly confronted with children who did not understand the questions and could not express themselves. Even when the questionnaire administrators were confronted with

² The IGAs were granted mainly to vulnerable families living with one or more children with severe disabilities (multiple disabilities, epilepsy or Down syndrome).

children with epilepsy or Down syndrome who were able to express themselves, they were not sure that the children understood the question because they often have developmental delays.

Facing difficulties in using ScoPeO in the field for certain projects, HI's 3i Division has decided to launch a study to identify and test alternative solutions for understanding the quality of life of specific groups for which ScoPeO has limitations, taking into account their needs, based on the DPCP Project in Mali.

Overall and specific objectives

The **overall objective** of this study is to find solutions to address the quality of life of children with special needs (children with multiple disabilities and Down syndrome) for whom ScoPeO-Kids has limitations. A one-month field mission has been planned in Mali (October 17-November 15, 2022) to test the identified solutions and collect data.

The **specific objectives** are :

- To identify, test and formalise the most promising solutions for collecting relevant information regarding the quality of life of children with multiple disabilities and Down syndrome by **exploring the family track**;
- To participate in the **production of a clear guidance** concerning the measurement of the quality of life of families living with children with multiple disabilities and Down syndrome.
- The aim of this exploratory research is to **improve practices** in order to collect relevant data on the quality of life of people with specific needs by **producing guidance on appropriate tools** that can be **disseminated in all the countries where HI works**.

Part 2 - Measuring the quality of life of children with intellectual disabilities: challenges and stakes

First, a **review of the literature** was carried out in order to clarify the orientations to be taken in the framework of this study. We conducted a bibliographic search — in English and French — using the keywords “*outil / tool*,” “*échelle / scale*,” “*questionnaire / survey*,” “Family Quality of Life / *qualité de vie familiale*,” “*qualité de vie / quality of life*,” “*déficience intellectuelle / intellectual disability*” and “Africa / Afrique” on the Internet and on search platforms (Google Scholar, academia.edu and Research Gate), which enabled us to have access to certain articles and to contact researchers specialising in the field.

This literature review allowed us to answer three preliminary questions:

1. Are there approaches or tools that allow children with severe disabilities to participate in the evaluation of their quality of life?
2. Is the use of a proxy (family member) to administer ScoPeO-Kids an alternative?
3. To what extent is the Family Quality of Life approach an interesting avenue to explore in order to collect relevant data on the quality of life of children with intellectual disabilities?

1. Measuring the quality of life of children with intellectual disabilities: many challenges

There are a variety of quality of life assessment scales for children and adolescents. However, these scales are **mostly generic**, intended for a general audience of young people, or they do not meet HI's operational needs: some are specific to a health condition (e.g., **DisabKids**), while others do not cover the desired age range (e.g., **Kidscreen**) or include dimensions that are not adapted to HI's intervention contexts (e.g., **Kindl**). Finally, of these tools, few have been used in low- and middle-income countries, and even fewer in vulnerable contexts (Brus et al., 2018). For this reason, HI developed **ScoPeO-Kids** in collaboration with **CRIR** at the University of Montreal.

The identified dimensions and response scales were first validated and completed by field experts in Bangladesh and Thailand, and through focus groups including 87 children. The questionnaire was then tested on a sample of 580 children in Bangladesh, Pakistan and Thailand.

ScoPeO-Kids targets **children aged 5 to 17** with and without disabilities and with a variety of developmental profiles. However, in order to build a tool applicable in all contexts and to all children, **children with severe disabilities were excluded from the study**.

In 2013-2014, HI explored the possibility of developing a specific tool to assess the quality of life of children with Cerebral Palsy in Sub-Saharan Africa (Heusse, 2014) but no action was taken on this project.

Studies show that it is important to hear the voices of children with intellectual disabilities but no measures have been developed by or with these children, or they have only been partially tested

with relatives who have been previously trained (Samuel et al., 2012; Haelewyck, 2016; Nunes, 2021; Alnahdi et. al., 2022).

The major difficulty in administering psychometric scales comes from the degree of understanding of the questions asked and the abilities of these individuals to answer them. Several interfering variables have also been highlighted:

- The length of the test
- Lack of experience of the evaluator
- The motivation of the people (evaluators or beneficiaries) to answer the questionnaires

Adjustments were found:

- Use of a **pretest** to judge the abstraction skills needed to understand the subjective sub-scales: **ComQol-I5**.³
- Adapt the response systems of the scales to the person's level of understanding (more limited response options, emoticons, etc.).
- Administer the psychometric scale in the form of an interview.
- To reduce the variance of results explained by the potential presence of parasite variables (length of time spent on the test, lack of experience of the evaluator, etc.), average the scores given by two evaluators to the same person.

New scales for children with intellectual disabilities have been developed in recent years — e.g. **Kidslife Scale** — but mainly in Western countries and they **still require scientific validation** (Gómez et al., 2016). In addition, the validity of these scores identified in the literature is potentially problematic because respondents with intellectual disabilities do not always understand the nature of the questions.

While some believe that specific measures can be developed by training and using a variety of observation and awareness methods, **significant challenges remain** and sophisticated approaches that would allow for hearing them have yet to be developed and scientifically validated (Brown, 2013; Davidson et. al, 2017; Karthikayini Sasinthar et al. 2021). The development of a quality of life scale is a **long and difficult task** that involves the close collaboration of clinical experts, linguists, but also statisticians to ensure that the content of the questionnaire is tailored to the patient and validated in its context of use (Heusse, 2014; Brus, 2018).

In summary, despite considerable progress over the past decade in operationalising and evaluating the concept of quality of life in the field of disability, there are still many challenges in measuring individual quality of life for children with intellectual disabilities.

³ Robert A. Cummins, Comprehensive Quality of Life Scale - Intellectual / Cognitive Disability, Fifth edition (ComQol-I5), School of Psychology, Deakin University, Melbourne, 1997. This test is interesting but remains complex to implement in the framework of HI projects.

2. The use of a “proxy” remains an unsatisfactory and default solution

As with adults, the measurement of the QoL of children should preferably be done from a self-report perspective. However, in many situations, the perception of a relative (“proxy”) remains the usual means of assessing the QoL of a child. This is **problematic** because studies have shown that there is **little or no agreement** between the judgments made by children (chronically ill or healthy) and those made by relatives (parents, teachers, or treating physician). **Proxy responses tend to assess quality of life at a lower level than self-report** (Heusse, 2014; van Boekholt, 2016; Nunes, 2021). Thus, although not common practice, Missoten et al. (2007) remind us that the **child** is the individual **best positioned to express** his or her perception of his or her life. **All possible supports should be explored before considering proxy responses.**

In some cases (patients with cerebral palsy or severe cognitive impairment), hetero-evaluation by health professionals, parents or other proxies is the only solution. In this case, care must be taken when interpreting the results, as the change in assessment of the subjective concept of quality of life must be taken into account.

ScoPeO-Kids is a **child-centred approach**, therefore, the children have to answer the questions themselves. QoL is a subjective concept and the literature shows that parents tend to evaluate subjective concepts more negatively. For this reason, the ScoPeO-Kids research team conducted a study in Rwanda in 2020⁴ to test the degree of agreement between the children’s responses and their proxies and whether it was necessary to develop a version of the questionnaire for proxies. Based on the results, the researchers concluded that there was **no need to develop a proxy version of ScoPeO-Kids.**⁵ When some children are unable to complete the questionnaire, for example children with cognitive limitations or severe communication problems, a proxy completes the questionnaire in the child’s place.

However, given the limitations of using a proxy, the use of ScoPeO-Kids/Proxy for children with severe disabilities should remain a **default solution only when absolutely necessary**, for example when they constitute a minor proportion of the survey sample.

3. Emergence of the QoL concept in the wake of intellectual disability studies

Quality of life is a major issue for families with children with intellectual and developmental disabilities. Researchers began studying the quality of life of people with disabilities about 20 years ago. While quality of life for people with disabilities was previously studied as an individual variable, research has shifted to include family members.

Notions of family quality of life emerged as a result of research in the field of intellectual and developmental disabilities. Family quality of life has become an area of considerable international interest due to advances in family-centred practices that are a natural extension of studies

⁴ CRIR. Protocol of research. The Development of the ScoPeO-Kids Phase 2: Reliability and validity, 2020.

⁵ CRIR. Discussion on the metrological properties of the tool: inter-judge fidelity (proxy), stability over time and validity of the tool, PPT, Unpublished results.

developed in the individual quality of life framework for people with disabilities (Brown, 2013). This approach is based on the principle of **family empowerment**, which recognises and values the **central role of the family in the child's life**.

The literature review indicates that the special needs of children with disabilities are a **significant challenge for the family** (van Boekholt, 2016). Their needs cause **stress** for the entire family, creating health problems and financial difficulties. Far-reaching effects affect the entire family. **Financial time and costs, physical and emotional demands, and logistical complexities** are listed as **negative effects** of living with a child with a disability (Reichman et al., 2008). These negative effects on **Family Quality of Life (FQoL)** are associated with **several negative outcomes**. Parents of a child with a disability have an increased risk of **divorce, lower employment rates**, and often have **lower rates of social participation**. Parents' physical and mental health is also affected. Compared to families without children with disabilities, they are more likely to have **poor psychosocial well-being** and **lower life satisfaction**. In addition, families living in low-resource countries, such as Mali, are more likely to experience economic and social disadvantage because of their child's disability. Often, existing household poverty is compounded by the child's disability; parents invest time in taking their child to rehabilitation centres instead of income-generating activities, siblings-most often sisters-are pulled out of school to care for their disabled sibling, and families face additional costs related to their child's disability (Tan, 2020).

The conceptualisation of FQoL has evolved in light of **two movements** (Samuel et al., 2012):

1) the growing recognition of the resilience, strengths, and positives of families with a member with a disability; and 2) the shift in understanding of disability from a view of limitations and deficits exclusive to the person with a disability and his or her family to one that considers the influence of contexts and environments, the resources they provide, and the supports that families of people with disabilities need to carry out the lives of all their members, including the person with a disability.

Until recently, research on families and disability has followed a more **medical model** and a **paradigm focused on the individual and his or her impairments**. According to this view, individuals with disabilities and their families have a duty to adjust to diverse environments by taking a neutral, non-emotional view of their adjustment to disability, developing their skills, adopting appropriate behaviour, and generally seeking to "fit in" with the environment in order to integrate. The focus is on the adaptation of the person with a disability to the environment rather than on the environment's response to the person's needs, strengths, and preferences (Alnahdi et. al., 2022).

The shift in recent years toward a **more progressive paradigm** based on a **social model of disability** in which the environment determines the perception and experience of disability has refocused the narrative to better understand the contextual experiences that shape the well-being of families of people with disabilities (Terzi, 2004; Heusse, 2014; van Boekholt, 2016).

Thus, FQoL recognises the **interconnectedness** between family members and how individual needs and well-being affect the well-being of the entire family. Zuna et al. (2010) developed a theory and model of FQoL that shows the **dynamic interaction** between individual family members and the family unit in the context of societal programs, systems, policies, and values.



Definitions of FQoL

Park et al. (2003, 368) : FQoL is ensured when “conditions where the family’s needs are met, and family members enjoy their life together as a family and have the chance to do things which are important to them.”

Zuna et al. (2010, 262) consider FQoL as “a dynamic sense of well-being of the family, collectively and subjectively defined and informed by its members, in which individual and family-level needs interact.”

In developed countries, research on FQoL is often used to inform policy and evaluate services for families. In countries with fewer resources, interest in FQoL stems more from a need to recognise the contributions of the family and to identify the service needs of families caring for children and adults with disabilities. In the context of HI projects, and the DPCP project in particular, the FQoL approach would make it possible both to **identify families’ needs** at the beginning of the project in order to improve their support and to **evaluate the outcomes of HI projects** on the quality of life of beneficiaries at the end of the project.

Exploring the FQoL approach in Mali is all the more relevant since the DPCP Project has already observed that children and their families are more vulnerable when they are affected by a severe disability. This vulnerability is found on the economic level, but also on the social level. Thus, acting at the level of the whole family can contribute to improving the quality of life of the child as well. This is why the DPCP Project provides **Income Generating Activities (IGA)** to help families of children with Down Syndrome, epilepsy and multiple disabilities. In addition, supporting families’ quality of life during early childhood can potentially improve families’ abilities and skills to cope with adversities and challenges throughout their lives (Samuel et al. 2012).

There is a **critical lack of research** on QoL in families with children with disabilities in early life in **fragile contexts**. In the field of early intervention, family QoL is increasingly recognised as an **important concept** and as an **important index for evaluating the outcomes of service delivery programs**.

4. Beach Center Family Quality of Life Scale or Family Quality of Life Survey 2006 ?

Early studies of the FQoL evaluation were qualitative, using focus groups and semi-structured interviews. These studies allowed for the construction of quantitative concepts and measures. Three instruments were developed from these studies (Nunes, 2021):

- a) **The Beach Center Family Quality of Life Scale (FQOLS)** was developed by the University of Kansas in the United States and has been recognised as an effective tool for measuring family support in disability intervention programs. The Beach Center FQOLS assesses quality of life in **five dimensions** (family interaction, parenting, emotional well-being, physical and material well-being, and disability-related support) and has already been adapted for use in countries

such as China, Taiwan, Spain, Colombia, Brazil, and Puerto Rico. It is currently used in **27 countries** (Alnahdi et al., 2022). The items in this scale were formulated so that they could be answered using a **Likert scale of importance and satisfaction from 1 to 5**.

- b) **The International Family Quality of Life Survey-2006 (FQOLS-2006)** was developed in a more international setting (Israel, Australia and Canada) (Isaacs et al. 2007). It assesses quality of life along **nine dimensions** (health of the family, financial well-being, family relationships, support from other people, support from disability-related services, influence of values, Careers and preparing for careers, recreation and leisure, and community interaction). It collects qualitative and quantitative data with the goal of assessing the QoL from a more holistic approach to life. This questionnaire can therefore be used in a **wider range of settings**, by families of children, youth, adults, and older adults with and without disabilities (Samuel et al., 2012). It has already been translated and adapted into **12 languages⁶** and **used in over 45 countries**.
- c) The **Latin American Quality of Life Scale**, which has **42 items** divided into **six dimensions** (emotional well-being, personal strength and growth, standard of living, physical and material well-being, family life, and social and community relations) and is intended to be a scale adapted to the sociocultural and economic context of Latin America.

To date, the two main family quality of life measurement tools most commonly used are the Beach Center FQOLS (**shorter**) and the FQOLS-2006 (**more robust**). Despite previous efforts to develop new research instruments, current studies that focus on measuring quality of life for families with children with developmental disabilities using a multidimensional approach often rely on one of the two measurement scales (Alnahdi et al., 2022).

| | Beach Center FQOLS | FQOLS-2006 |
|-----------------------|---|---|
| Country of design | USA | International project (Canada, Australia, Israel) |
| Format | Satisfaction scale | Scale + open-ended questions |
| Dimensions considered | 5 dimensions: family interaction, parenting, emotional well-being, physical and material well-being, and disability-related support | 9 dimensions: family health, financial well-being, family relationships, support from other people, support from disability-related services, influence of values, careers and preparing for careers, recreation and leisure, and community interaction |
| Deployment | 27 countries (including China, Taiwan, Spain, Colombia, Brazil, Puerto Rico) | 45 countries (including Europe, China, Malaysia, Japan, Iran, India) |
| Use | Measuring the support of American families in disability intervention programmes | Comprehensive lifelong approach, the tool can therefore be used by families of children, youth, adults and seniors with or without disabilities |

⁶ Questionnaires in all languages available on: <https://www.surreyplace.ca/fr/research/current-opportunities/family-quality-of-life-project/>

Perry and Isaacs (2015) recommended using the Beach Centre FQOLS as a **valid and effective measure**, but using the FQOLS-2006 to gather “**richer descriptive detail**”. Both questionnaires are based on the same theoretical framework, in which the family of the person with a disability is recognised as an important factor in the environment. This approach is consistent with the **social model of disability** adopted by HI (van Boekholt, 2016). Both instruments can be used as outcome measures to assess how effective the implementation of policies and supports for families are. The strengths and weaknesses of the two main existing tools were examined in order to select the best approach to test in the DPCP project in Mali.

Design process of the Beach Center FQOLS

The preliminary version of the Beach Center FQOLS had **10 dimensions** (family interaction, parenting, daily living, financial well-being, emotional well-being, social well-being, health, physical environment, advocacy, and productivity) and **112 items**. After further field testing, it was reduced to a brief and concise FQoL scale, the **Beach Center FQOLS version 2003**, which consists of an 11-page questionnaire with three sections: demographic questions about the family and the family member with a disability, importance and satisfaction ratings of 25 items grouped into five FQoL domains: family interaction, i.e., relationships between and within family members; parenting, i.e., the kinds of activities families undertake to facilitate their children’s development; emotional well-being, i.e., perceived stress and availability of support; physical and material well-being, i.e., basic physical needs such as medical support and transportation; and disability-related support, i.e., support in the community settings of school, work, and home (Park et al. , 2003). The **psychometric validity** of this measure has been **demonstrated** (Hoffman et al., 2006; Summers et al., 2005; Wang et al., 2006).

Beach Center FQOLS

| PROS | CONS |
|--|---|
| Short and easy to use | Bias towards families with young children (e.g., parenting issues) |
| Easily self-administrable | Sensitivity to non-traditional families (e.g., family interaction dimension)? |
| Validity tested in the USA, China and Spain | Inadequate representation of minorities on tests |
| Rapid assessment of the outcomes of an intervention on QoL for international comparisons | Not well suited to comprehensive planning and evaluation of family support projects |



Short, valid and effective but does not allow to understand the "why"

The latest version of the **Beach Center FQOLS from 2005** does not include importance scores or demographic questions, making it much shorter and allowing researchers to include this tool with other assessment tools in a project.

A **French version** was tested in **Canada**⁷ following Vallerand's (1989) cross-cultural validation process. This pilot study indicated that the measure was well received and accepted by the respondents, who completed it within the time limit and did not report any difficulties with the wording of any item. Another study was conducted in **France**.⁸ The French version differed slightly from the Canadian version to accommodate the cultural context.⁹ The abandonment by several authors of the importance section, due to a strong correlation between importance and satisfaction, associated with the objectives of the research, led to the evaluation of the items only from the point of view of their **satisfaction**.

Although the Beach Center FQOLS was found to be valid for assessing quality of life in English-speaking families living in the United States, the authors note that the manner in which the dimensions are structured **may not be replicable** in other cultural contexts or in certain socioeconomic settings and that its use among families of children with **specific illnesses** requires **further study**.

Design process of the FQOLS-2006

As described by Isaacs et al. (2007), the **International Family Quality of Life Project** created the FQOLS-2006 to provide families with a tool to identify aspects of their lives that are meaningful and supportive.

The International Family Quality of Life Project was initiated in **1997** as an international collaboration among researchers in Canada, Israel and Australia. The goal of the project was to examine the quality of life of families with one or more members with an intellectual disability. One component of the project was to develop a survey tool: the Family Quality of Life Survey (FQOLS-2000) to explore the challenges these families face and the supports and resources needed to improve their lives. Extensive field testing of the survey in Australia, Canada, Israel, South Korea, and Taiwan resulted in the development of a revised version of the FQOLS in 2006.

The FQOLS-2006 consists of **two sections**: **Section A** contains general socio-demographic questions and **Section B** includes **54 items in nine dimensions** (health of the family, financial well-being, family relationships, support from other people, support from disability-related services, influence of values, careers and preparing for careers, leisure and recreation, and

⁷ Rivard, Mélina et al. Psychometric Properties of the Beach Center Family Quality of Life in French-Speaking Families With a Preschool-Aged Child Diagnosed With Autism Spectrum Disorder. *American Journal on Intellectual and Developmental Disabilities*, 122(5):439-452, September 2017.

⁸ Aurélie Chaume, Jennifer Ilg, Céline Clément. Comparaison de la qualité de vie familiale de parents français ayant ou non un enfant avec un trouble du spectre de l'autisme. *Revue francophone de la déficience intellectuelle*, 2019, 29, pp. 36-45.

⁹ In the Canadian version, "Neighbourhood" was translated as "*communauté*" while the French version retained "*voisinage*".

community interaction) and related to **6 key concepts: opportunities, initiatives, attainment, importance, stability, and satisfaction.**

Characteristics that are common to each life area

A|Z

Opportunities: The options available to families, such as opportunities for securing family income or opportunities to take part in leisure activities.

Initiative: The degree to which families, on their own or with some support, take advantage of available opportunities.

Attainment: The degree to which the family is able to obtain or accomplish those things that it wants or needs.

Stability: The degree to which circumstances within any one life area are likely to improve, decline, or stay the same.

Satisfaction: The overall perception of family members about important aspects of family life.

Importance: Importance assesses the value or relevance an individual family places on a particular area of life.

The FQOLS-2006 also includes a dimension related to **overall impressions of family quality of life** with an open-ended question, which contributes to an in-depth understanding of families' perceived quality of life.

In an adapted version used in an Australian study, the dimension "support from other people" was divided into two: "practical support" and "emotional support." In the Slovenian version of the survey, only six of the nine dimensions were included (health, financial well-being, support from other people, disability-related services, interaction with the community, and overall family quality of life).

The FQOLS-2006 is a comprehensive family quality of life measurement instrument that collects quantitative and qualitative data. In addition to its comprehensive focus, this tool is based on a lifelong approach and can therefore be used by families of children, youth, adults, and seniors with and without disabilities.

However, this survey has **practical limitations** for organisations, primarily because of its **comprehensiveness**. The survey is **time-consuming** for both families and service providers. This is especially true when the survey is conducted face-to-face, an option that may be necessary for families facing language barriers or when follow-up interviews are required. Gathering information from families in this manner may be beyond an organisation's financial resources. In addition, some families may be unable to complete the survey in a comprehensive manner, or families may find the effort and time required to complete the survey too burdensome.

To address these potential limitations, a **shortened version of the questionnaire can be administered:** the questions in Section A are not included and respondents are presented with the questions in Section B directly. This version may be useful to researchers who are not

interested in all the demographic and service details collected by the full questionnaire and who wish to collect QoL assessments in a less tedious manner.

Alternatively, the researchers suggest developing a shortened version that matches the evaluative structures of their studies. Researchers can draw on additional QoL research to determine which dimensions could be deleted or modified while still gaining sufficient depth of information to improve support for families. Dimensions and indicators can be used to frame questions in initial interviews or general conversations with families. Of course, modifications to the survey would vary across human service sectors, organisations, and regions.

The FQOLS-2006 was pilot tested for longitudinal use as an outcome measure to evaluate the effectiveness of a family support empowerment model for urban, low-income, and minority families in the United States (Samuel et al. 2010). Results show that although the scales had moderate to strong internal consistency, the FQOLS-2006 had only a moderate degree of construct and criterion validity when used with a sample composed primarily of minorities from socioeconomically disadvantaged backgrounds (Samuel, 2017).

Although research on family quality of life that originated in high-income English-speaking countries has expanded to other countries to explore international perspectives, there is **still little research in low- and middle-income countries or in vulnerable contexts**. The representativeness of existing research could be improved by combining studies with samples from different populations that differ culturally and linguistically, to test whether the hypothetical survey construct is valid for different populations. In addition, the studies do not cover a large enough population to represent different types of cultures with different socioeconomic backgrounds.

FQOLS-2006

| PROS | CONS |
|--|---|
| Effective for planning an intervention | Long survey |
| Many measurement indicators and therefore sensitivity to small changes | Newer tool, therefore limited data validity |
| The needs of minorities are taken into account | Not representative of the whole country |
| The survey can be adapted and shortened | Very little testing in low-income countries |



Long, tedious and time consuming but allows for "richer descriptive details" to be collected

Which tool to choose?

Both tools have advantages and disadvantages. The **brevity** of the Beach Center FQOLS offers advantages for measuring some outcomes, and the FQOLS-2006 offers both a valid FQoL score and additional data that can facilitate planning and implementation of family-centred interventions.

But while the Beach Center FQOLS is brief and easy to use, it is **not well-suited to the comprehensive planning and evaluation** of family support projects that include the diverse needs of typically underserved families, many of whom live at or below the poverty line and belong to ethnic minority groups.

The Beach Center FQOLS, however, is useful for assessing projects that address the needs of parents raising young children with a variety of disabilities in their homes. The brevity of the Beach Center FQOLS is an advantage for project evaluators and service providers who want succinct and quick information about families with disabilities. Such short tools are valuable for beginning the process of measuring family-centred outcomes of formal support programs for the person with a disability or any family member of the person with a disability. In the overall exploration of quality of life in families where a child has an ASD, this scale is attractive both because of its rapid administration and for assessing the effects of an intervention on quality of life and for international comparisons. Nevertheless, to truly understand a complex social construct such as the FQoL, it is essential to have a multidimensional framework integrating qualitative and quantitative elements.

With respect to the FQOLS-2006, studies show that this survey is useful for a variety of health and social service settings and that its ability to be **adapted to different situations and life stages is an advantage**. It can be used as an instrument to describe and measure the quality of life of families. It can also be used for research in a **longitudinal study** before and after a residential placement or service allocation or as a project evaluation/monitoring tool. Indeed, this FQoL questionnaire can be useful to professionals and family members as a method of assessing support needs and implementing appropriate "s.

During the literature review, the consultant spoke with **Dr. Preethy Samuel**, one of the researchers working on these two tools. The researcher advised us to use the FQOLS-2006 because it is more appropriate for low-income settings. She encouraged us to develop a short, tailored version by suggesting templates for the questionnaires she uses.

She also cautioned us about the **limitations of the Beach Center scale** because the problem with measuring only satisfaction is the risk to face a **ceiling effect**. This means that if the score is high at the beginning of the study, there is no room for growth or change due to the intervention.

Satisfaction is a widely used but somewhat **controversial indicator of QoL and FQoL**. There is an extensive body of research on level of satisfaction across populations and service delivery recipients, and allows one to assess the relative importance of individual QoL domains and therefore assign value to the respective domains. However, studies (Verdugo, 2005) have also pointed out some drawbacks in its use, including its trait-like (i.e. stability over time) nature and its **low correlation between subjective and objective measures of QoL** (i.e., people tend to

express high levels of satisfaction even under conditions that are by no means ideal); its tendency to provide only a global measure of perceived well-being, and the lack of demonstration to date that it is a sensitive measure of good environmental design and service programs. Thus, both subjective and objective QoL measures are needed, and their relative weighting will depend on their anticipated use. In addition, data show that satisfaction scores for **FQoL seemed to be different and lower than in other QoL studies**—this finding was explored by Brown, Macadam Crisp, Wang, and Iarocci (2006).

But when we raised concern about the possibility/capacity of designing a short, tailored questionnaire for the DPCP Project and administering it to families in Mali because of the time-consuming nature of the survey, **Dr Samuel** urged us to add additional indicators for each question in addition to satisfaction, such as measuring the level of **opportunities, initiatives, attainment** (and perhaps **stability** and **importance**) for each of the **25 questions**.

Opportunities represent important external conditions necessary for achieving a good FQoL. On the family level, opportunities are best thought of as **determining factors** as opposed to outcome indicators (Cummins, 2005). The other three concepts — **initiative, attainment, and stability** — though not explicitly appearing in the previous literature on QoL, have been developed and tested by researchers and are important considerations in understanding FQoL.

Initiative also should be considered a determining factor, in that a family must take advantage of *opportunities* to put themselves into a position to be able to achieve a high FQoL. It is important to know, however, why families do not take *initiative* in accessing *opportunities*. For example, *opportunities* may not be relevant or important to families. Alternately, family members may not demonstrate *initiative* because of other circumstances such as insufficient support, poor health, financial constraints, or because they simply lack the capacity to do so.

Attainment and **satisfaction** can be viewed as indicators of FQoL in that these concepts represent what families have been able to achieve in a given life area and how they feel about their achievements, respectively. **Stability** recognises that FQoL is not static, but rather is dependent on a wide range of interacting and changing factors and circumstances.

Ratings of **importance** have been used in individual approaches to QoL assessments to **moderate the contribution** of other measures, usually **satisfaction**, to overall QoL. The logic is that items with low importance should make minimal contribution to assessments of QoL, while items of high importance should make large contributions.

According to Dr Samuel, it would also be necessary to critically examine with professionals and families whether all the questions make sense and whether there are missing dimensions that are not addressed in the Beach Center FQOLS to consider adding/removing some items that are not relevant in the Malian context or rewording some questions.

After the COPIL discussion on Wednesday, September 28, 2022, **preference was given to the Beach Center FQOLS (2005 version)** to be tested in the Mali program because of its **brevity** (an important point to take into account for this specific audience with severe disabilities) and its ease of processing (it is **similar to ScoPeo**) but also to obtain international comparisons in large surveys. However, to “enrich” the analysis, it was decided that a set of socio-demographic questions would be added to the questionnaire.

Part 3 - Methodology of the FQoL survey in Mali

1. Location

Given the current unstable security environment in Mali, it was decided to conduct a one-month field study (October 17-November 15, 2022) **only in Bamako** and not to travel to Sikasso. To overcome this problem, beneficiaries in Sikasso were interviewed by telephone. At the same time, this allowed us to test the feasibility of conducting this type of questionnaire by telephone in the event of difficulties in accessing the beneficiaries (lockdowns, security or political crises, conflicts, etc.).

2. Study design

The notion of QoL is influenced by the environmental context. **Cultural adaptation** of a questionnaire is a necessary task. The purpose of the field mission to Mali was to test the Beach Center FQOLS as part of the DPCP Project. This is the **first time** this tool has been adapted and **tested** in a local language (**Bamanankan**) and in a **low-income country**. This exploratory research tested its use in a new cultural context.

The survey methodology was **primarily qualitative** (Focus Group Discussions, household observations, in-depth interviews during the questionnaire administration). The quantitative results of the questionnaire were used to assess the relevance of the questions and dimensions. Given the small sample size, these results were not intended to validate the **psychometric qualities** of the revised questionnaire.

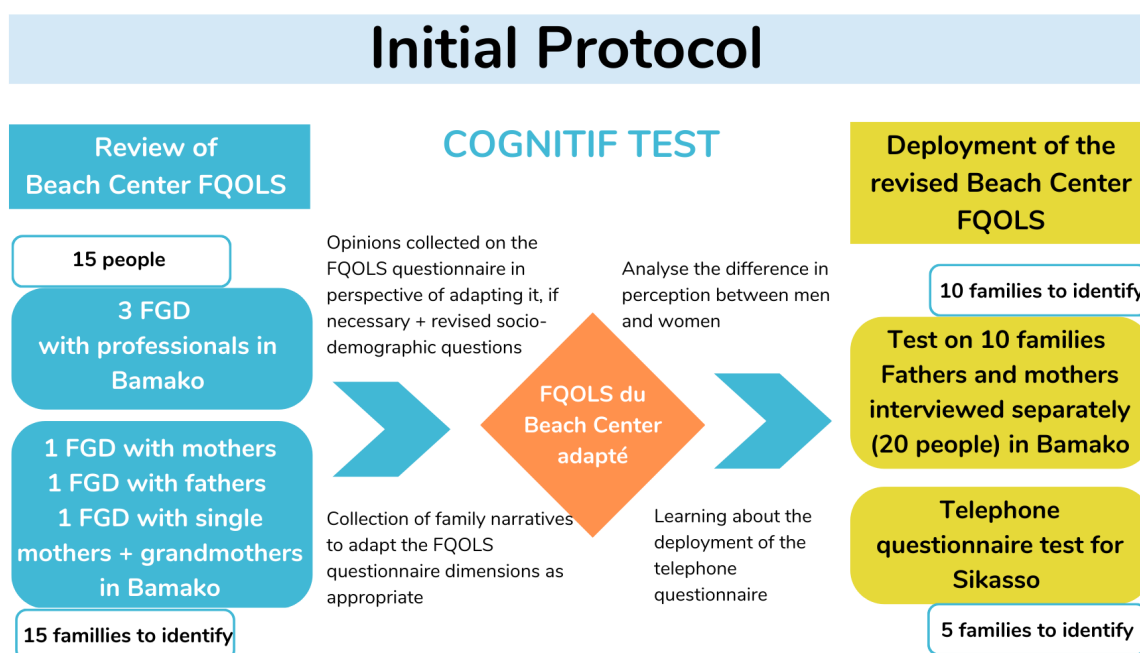
First, the Beach Center FQOLS questionnaire was tested with **professionals, associations and HI team (18 people)** in the form of Focus Group Discussions (FGD) in order to adapt the questions to the Malian context. In a second phase, FGD conducted with groups of **fathers, mothers and single mothers/grandmothers (14 people)**, beneficiaries of the DPCP Project, to understand how Malian families of children with intellectual disabilities conceptualise the FQOLS and what they perceive as their support needs, in order to adapt the Beach Center FQOLS as appropriate. Fathers, mothers, and single mothers/grandmothers were interviewed separately to learn about the difference in perception of FQoL based on gender and family status. They were also interviewed separately to allow for freer speech on the mothers' side. The FGDs allowed the mothers to be heard in a safe space, outside of their family environment. The group interview in the form of a FGD can allow mothers to speak freely. The fathers' voices are also interesting to hear because they often bring a different perspective and are rarely collected in research.

Finally, a **cognitive test**¹⁰ of the Beach Center's revised FQOLS was administered to a small sample of project families in Bamako (**10 families**). The questionnaire was administered to **both fathers and mothers in the same family** in order to better understand the difference in

¹⁰ Cognitive interviewing or cognitive testing is a qualitative method specifically designed to determine whether a survey question fulfills its intended purpose. The method relies on interviews with individuals who are specifically recruited. The survey questions are presented to these individuals in the same manner as the survey respondents who will receive the final version of the questionnaire.

perceptions between men and women regarding family relationships and the division of labor among family members and how these patterns affect family cohesion and intimacy, power distribution in the family, decision making, family flexibility, and family adaptation. Finally, the Beach Center FQOLS was to be administered to 5 families living in Sikasso by telephone.

Given that the study was conducted as an action-research project, where we had to adapt to the constraints of the field and experiment with different options, we decided to **adapt our data collection protocol** at the end of the questionnaire administration with the 10 families in Bamako. Indeed, given the questions that the Beach Center FQOLS raised (see [Part IV. Lessons from the FQoL survey in Mali](#)), we decided to continue our experimental approach by choosing to **adapt the FQOLS-2006** and to test it by telephone on the 5 remaining families in Sikasso.



3. Selection of interviewees

a) **Study sample: 30 families** living with one or more children with Down syndrome, epilepsy or multiple disabilities, benefiting from IGAs under the DPCP Project and speaking Bambara. The families were identified and contacted by the social development services and HI team to organise the interviews.

b) **FGD with families: 15 families**

Criteria: beneficiaries of the DPCP Project and living in Bamako; different types of disabilities represented (polyhandicap, epilepsy, Down syndrome).

- 1 FGD with 5 mothers at HI's office
- 1 FGD with 5 fathers at the HI's office
- 1 FGD with 4 single mothers and grandmothers (one grandmother absent due to the child's illness) at the CNAOM

c) Deployment of the questionnaire in Bamako: 10 families

Criteria: beneficiaries of the DPCP Project and living in Bamako; different types of disabilities represented (multiple disabilities, epilepsy, Down syndrome)

- 10 fathers and 10 mothers from the same family interviewed separately at home

d) Test of the questionnaire by telephone for Sikasso: 5 families

Criteria: beneficiaries of the DPCP Project and living in Sikasso; different types of disability represented (polyhandicap, epilepsy, Down syndrome); respondents must have a cell phone. The person interviewed is the person in charge of the IGA granted by the DPCP Project.

- 5 fathers or mothers interviewed by telephone

e) FGD with professionals: 18 people

Location: at HI's office

- 1 FGD with health professionals (2 paediatricians, 2 physical therapists, 1 ortho-prosthetist, 2 social services agents)
- 1 FGD with the associations (2 community-relays, 2 members of FEMAPH, 2 members of AMT21, 1 AMALDEME educational assistant)
- 1 FGD with HI team (former ScoPeO surveyor, MEAL, DPCP)

4. Tools and modalities of data collection

Review of the Beach Center FQOLS's questions

During the FGDs with professionals and associations, the questionnaire was well received and the approach understood. They found the questions relevant and interesting. **Only two questions were slightly modified** to facilitate understanding and to adapt to the Malian context:

- Q22. *Name of the kid* has support to accomplish goals at school or at workplace.

Becomes: *Name of the kid* has support to accomplish goals at school, at the place of learning, or in health care services.

- Q23. *Name of the kid* has support to accomplish goals at home.

Becomes : *Name of the kid* has support to become independent at home.

They also felt that the questions measuring opportunities and initiative were relevant. Therefore, we decided to duplicate some of the questions that seemed most relevant.¹¹

¹¹ Appendix 1 - Revised version of the Beach Center FQOLS. The questions (in dark grey) were not initially asked because they did not seem relevant during the FGDs. However, by the second day of the field survey, we decided to duplicate all questions to test them with families.

Lessons learned from FGDs with families

The FGDs with families (fathers, mothers, and single mothers/grandmothers) confirmed that certain domains were important, including the **high cost of medical care**¹² for children with disabilities, the difficulties of **transportation** to follow up on medical care, the **lack of educational facilities** for their children, the **economic impact** of the disability in their work lives, as well as the **stigma** they face because of their child(ren)'s disability.

Fathers emphasised the **important role of religion** in coping with adversity and the disability of their child(ren). Fathers and mothers emphasised the need to organise themselves into Disabled People's Organisations (**DPOs**) to get help. Mothers reported the importance of the discussions group and the WhatsApp group created by the DPCP Project's as they provide an opportunity for mutual support and advice. Even though the mothers are primarily caring for their child(ren), they are grateful for the help provided by their husbands who take on their share of responsibilities (including material but also presence with the child) and who have not abandoned them.

The FGD with **single mothers and grandmothers** showed that this audience **was the most vulnerable**. The group consisted of 3 widows and a grandmother who was repudiated and is caring for her grandson with multiples disabilities. It was **difficult to identify divorced women** for the FGD because their marital status was not recorded in the social development records and it is a sensitive question to ask. Being a single woman (abandoned/repudiated, divorced or widowed) in Mali is a burden and a shame. They live it painfully because they are constantly stigmatised. It is difficult for them to work because they have to take care of their children alone. But these women are also **less visible**. They have a **more distant relationship with the social services**. They were not aware of the discussion groups or the WhatsApp group. They were not able to benefit from medication because social development told them that there was no more money when it was just an administrative matter of replenishing their quarterly envelope.

Following the FGDs with the families, we did not add or remove any dimensions but kept in mind the difficulties described by the families to further the interviews when administrating the questionnaire.

Data Collection Process

The field survey was conducted jointly with the **MEAL team** (Rahamatou MAIGA) to facilitate the FGDs and administer the questionnaires to the families,¹³ and the **DPCP team** (Idrissa HACHIMI, Project Manager and Samba COULIBALY, Rehabilitation Officer) who identified and made the link

¹² Some ideas of the costs: 15,000 FCFA/month for medication (23€), between 1,000 and 3,000 FCFA for a physiotherapy session (twice a week); 5,000 FCFA for a speech therapy session; 5000 FCFA for transportation by taxi because it is difficult to take a bus and impossible to take a motorcycle if the family has several children with multiple disabilities, and sometimes even taxis refuse to take them because of the child's disability; 15,000 FCFA/month for special education. Technical aids are expensive and have to be replaced regularly as the child grows.

¹³ The consultant trained the MEAL focal point (Rahamatou MAIGA) on qualitative survey methods (FGD animation and in-depth interview). Cf. The training module on canva: https://www.canva.com/design/DAFP-48uLHY/wRn_V33QVlrCyOGaRpEG3Q/edit?utm_content=DAFP-48uLHY&utm_campaign=designshare&utm_medium=link2&utm_source=sharebutton

with the families and participants of the study. The translation of the questionnaire into Bamanakan was facilitated by **Sékou KAMISSOKO** of the NORAD Project's **Inclusive Education team**, who is used to facilitating FGDs with parents of disabled children. We decided to use the common and popular Bamanakan language. With Rahamatou MAIGA, they chose the words carefully and the level of language so that the questions would be understandable by all the families. Daily meetings with the study team were held to plan the survey and review the interviews as they were conducted. Discussions with Dr. Preethy Samuel during the fieldwork helped to consolidate the methodology.

Adaptation of the protocol to the field

Once the Beach Center FQOLS was revised and adapted following the FGDs, the questionnaire was to be deployed to 10 families living in Bamako, interviewing fathers and mothers separately, either at home or at their workplace. Then the questionnaire was to be administered by telephone to 5 beneficiaries in Sikasso to learn about the obstacles and conditions for deploying the questionnaire by telephone.

However, the **initial protocol was modified during the field survey**.¹⁴ During the administration of the questionnaire, based on the observation of the reactions and responses of the families, we had to add/modify socio-demographic questions; we tested different wording of the questions; initially, some questions were doubled to measure the level of opportunities and initiative, but after the second day of the survey, we doubled all the questions in order to check the questions for which it was not relevant to ask the question and we changed the scales from 3 to 5. Because of these different variations, we cannot provide stable quantitative values for the opportunities and initiative indicators.

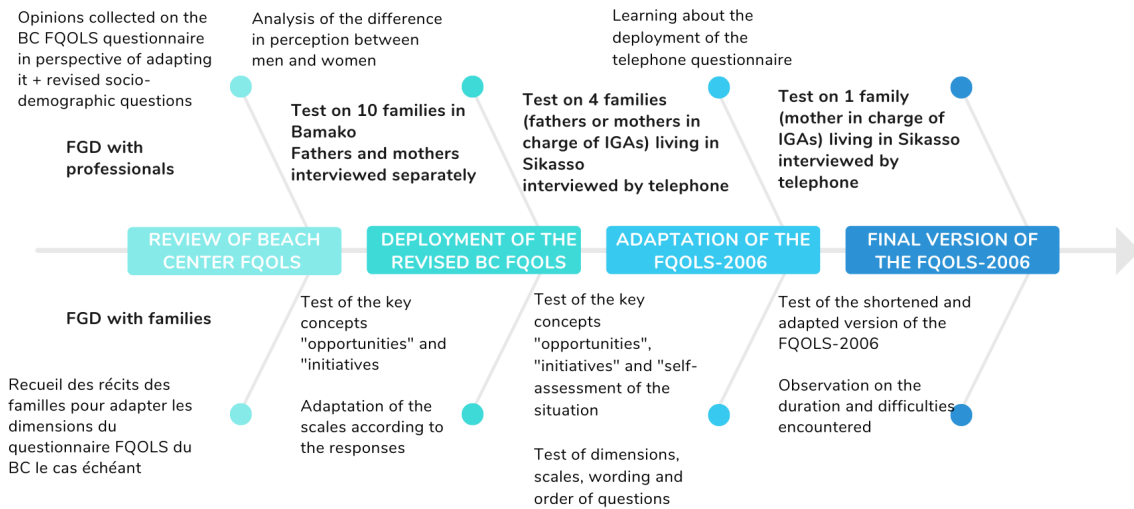
After administering the questionnaire to the 10 families (10 fathers and 10 mothers), we concluded that the **revised Beach Center FQOLS**¹⁵ was **not culturally appropriate** for the Malian context.¹⁶ Indeed, some questions were not relevant or were misunderstood, and examples had to be given systematically. Above all, the measure of satisfaction **did not seem to be very efficient** insofar as **both men and women rated their quality of family life higher**. In a cultural context where the Muslim religion predominates, it seems that people rely on religion to relativize their views of things and life's trials, a kind of acceptance that makes daily life much more bearable. This view influences their perception of the quality of life and their responses. They will not tell the truth about their living conditions, out of modesty and pride. On the other hand, it seemed more relevant to ask questions about the level of opportunity and initiative where families responded more readily and honestly.

¹⁴ Cf. Danielle Tan. Data collection protocol for the study "Measuring the quality of life of children with Down syndrome and multiple disabilities," Mali Program, October 20022 : https://www.canva.com/design/DAFOu9BeZWc/15yXPju8UD1F2gTNso7xnw/view?utm_content=DAFOu9BeZWc&utm_campaign=designshare&utm_medium=link2&utm_source=sharebutton

¹⁵ Cf. Appendix 1 - Revised version of the Beach Center FQOLS.

¹⁶ We will analyse the Beach Center FQOLS responses in more detail in Part IV "Lessons from the FQoL Survey in Mali."

Adapted Protocol



We could have continued to administer the Beach Center FQOLS to the last five families by testing the 25 questions using the key concept of **“self-assessment of the situation,”**¹⁷ which is more reliable than “satisfaction,” but we would have had to do a great deal of work rephrasing the questions, and we did not have the time. Instead, we took the opportunity to develop and test a shortened form of the FQOLS-2006 with the five IGA beneficiaries in Sikasso by telephone. After each interview, we improved the questionnaire. A final version of the shortened and adapted FQOLS-2006 was tested by telephone on the 5th beneficiary in Sikasso.¹⁸

5. Data processing and analysis

Processing qualitative data

Due to time constraints, but also because of the collective nature of the interviews and the dilution of what was said through translation, we did not use NVivo-type software to code our data. Instead, we focused on describing the parents’ main domains of influence in FQoL during the FGDs and on deepening the interviews with the parents during the questionnaire.

Processing quantitative data

We preferred to administer the questionnaire in a paper format in order to record the observations made and additional information collected during the interviews with the families.

Data analysis

The Beach Center FQOLS is quite similar to ScoPeO in its use. Each question is scored on a five-point scale (ranging from “Very dissatisfied” to “Very satisfied”). Scores are ranged from 1 to 5,

¹⁷ Key concept that we will use later instead of satisfaction to determine the FQoL score.

¹⁸ Cf. Appendix 2 - Final version of the FQOLS-2006 abridged and adapted to the DPCP Project

and then scaled out to 100, yielding scores by dimension and a total FQOLS score (see [Appendix 3 - Profile and Scores of the 10 Families](#)).

| Dimensions | Number of items | Items | Raw scores | Mean scores |
|---|-----------------|--|--|------------------|
| Family Interaction (FI) | 6 | 1, 2, 3, 4, 5, 6 | \sum values (Q1, Q2, Q3, Q4, Q5, Q6) | Raw score FI/6 |
| Parenting (P) | 6 | 7, 8, 9, 10, 11, 12 | \sum values (Q7, Q8, Q9, 10, Q11, Q12) | Raw score P/6 |
| Emotional Well-Being (EWB) | 4 | 13, 14, 15, 16 | \sum values (Q13, Q14, Q15, Q16) | Raw score EWB/4 |
| Physical and Material Well-Being (PMWB) | 5 | 17, 18, 19, 20, 21 | \sum values (Q17, Q18, Q19, Q20, Q21) | Raw score PMWB/5 |
| Disability-Related Support (DRS) | 4 | 22, 23, 24, 25 | \sum values (Q22, Q23, Q24, Q25) | Raw score DRS/4 |
| Total FQOLS score | 25 | \sum mean scores (FI, P, EWB, PMWB, DRS) / 5 | | |

6. Ethics considerations

This study was conducted in accordance with the ethical principles recommended by Humanity & Inclusion¹⁹:

- Ensure the safety of participants, partners and teams;
- Ensure a person/community-centred approach;
- Obtain free and informed consent from participants (see [Appendix 4](#));
- Ensure referral mechanisms are in place;
- Ensure security of personal and sensitive data at all stages of the activity;
- Plan and guarantee the use and sharing of information;
- Ensure the expertise of the teams involved and the scientific validity of the activity;
- However, the project did not seek approval from the Malian national authorities to conduct this experimental research because the small sample size did not require it.

¹⁹ Handicap International, "Studies and research at Handicap International: Promoting ethical data management," 2015. Available on https://hinside.hi.org/intranet/upload/docs/application/pdf/2018-07/ethicaldatamanagementgn_04.pdf?authKey=cHJvZF8yMDQzMTI0OjE2NzY0NjA3MjA3MzA6JDJhJDA0JDBHskZjdjZ4UjdMcTBFYlFKdEV5bnVYdHA4L2xneEJpV3RDdlINaVkwMjg5YTE4eG00UklH

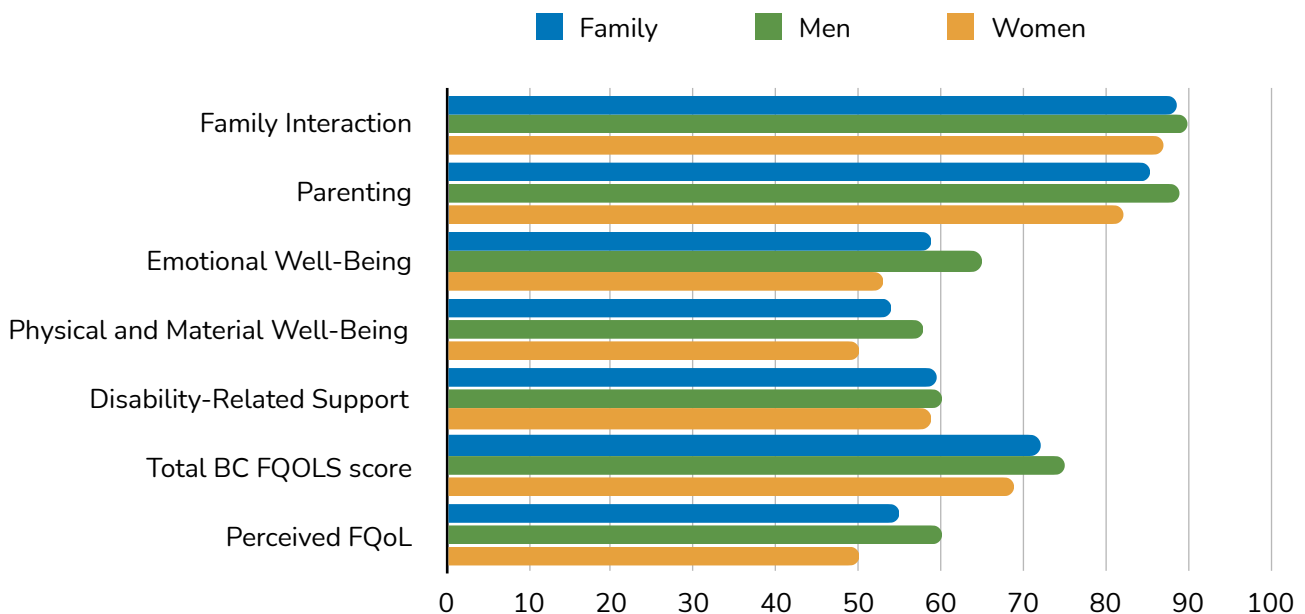
Part 4 - Lessons learned from the FQoL survey in Mali

Finding #1 : The Beach Center FQOLS is not culturally sensitive to the Malian context.

Satisfaction is not a relevant indicator in the Malian context

Revised BC FQOLS Scores

| | Family | Men | Women |
|----------------------------------|--------|-----|-------|
| Family Interaction | 88,5 | 90 | 87 |
| Parenting | 85,5 | 89 | 82 |
| Emotional Well-Being | 59 | 65 | 53 |
| Physical and Material Well-Being | 54 | 58 | 50 |
| Disability-Related Support | 59,5 | 60 | 59 |
| Total BC FQOLS score | 72 | 75 | 69 |
| Perceived FQoL | 55 | 60 | 50 |



We observed during our interviews in Malian households that, out of modesty, **both men and women generally increased their satisfaction of FQoL**. Men were more likely to increase their satisfaction than women (75 versus 69) in all domains of family quality of life.

Men's satisfaction scores with **family interactions** and **parenting** are particularly high (**90 and 89** respectively). While women often complain during the interview about "having too many responsibilities and doing everything alone," their satisfaction scores for family interactions and parenting remain high (87 and 82 respectively).

Women will accept and be content with their living conditions: *"I have no choice. If the person who governs us is like this, what can I do?"* this mother answers when we try to dig into her situation (Family 5).

Family #5



In this family, the wife rated her family's quality of life satisfaction as "fair" while her husband, an electrician, rated it as very good, "thank God". Yet this mother has the lowest total FQoL score when all dimensions of the Beach Center FQOLS are added together (**50**). She lives in a polygamous household. She has to pay half of all the household expenses and she cares for her polygamous daughter alone, without the help of her husband, who does not even lend her his motorcycle or the car so she can take her daughter to consultations and stimulation sessions. He says he gives money for the taxi but in reality she has to take the bus. She received an IGA to buy a fridge and sell bags of fresh water, but the husband took 20,000 FCFA and managed the profits from the activity.

It seems that religion (Islam) plays an important role in the perception of quality of life, in order to endure adversity. *“It is God who gave us this blessing (of having a disabled child), I take it like that”* (father in a FGD). We felt a lot of modesty when it came to talking about their poverty and difficulties.

The most telling example is that of **Family 8**. We found their house somewhat by chance because the father was unreachable by phone. We saw a hut with a tin roof on the side of the road and several children with multiple disabilities being looked after by young girls. This was the family we were looking for. The parents had 3 children with multiple aged 14, 7 and 2. 3 other children with multiple had died before. A 2-month-old baby had just been born and the other 4 children were not attending school. The 2 daughters (the oldest daughter and the mother’s niece) were taking care of the children. The family came back from Abidjan where they were working because it became too difficult to take care of their children with multiple disabilities in a foreign country. The husband is a janitor and the IGA was used to supplement the family’s income by selling coal.

Family #8



The mother rated the level of satisfaction with family quality of life as “poor”. We wanted to dig deeper by asking her why she didn’t put “very poor”. This was the poorest family we had met. “*There are things we don’t talk about,*” she replies. I push her and ask her which ones, for example. She **laughs embarrassedly** and tells us that she knows her situation but she will not talk about her poor living conditions, out of **modesty**. She is already grateful that her husband is still there and that he has not left her. Her satisfaction score with **family interaction and parenting is very high (90 and 87 respectively)** as is her emotional well-being (**75**). Her total score of the Beach Center FQOLS is **64** (compared to an average of **69**).

This example shows that the concept of **satisfaction** is a **problematic indicator** in the Malian cultural context because people will not tell the truth about their situation and will often increase their satisfaction of family quality of life. In addition, women will not want to “talk badly” about their husbands in front of a stranger and therefore evaluate parenting and family interaction positively, even though it becomes clear as the interview progresses that she assumes most of the responsibility for the children, and for children with disabilities in particular. The Malian case study thus confirms the major disadvantage of using only satisfaction as a dependent measure of FQoL highlighted in other studies, notably the reported **low correlation between subjective and objective measures of QoL** (when people tend to express high levels of satisfaction even in conditions that are by no means ideal).

Relevance of the “Opportunities” and “Initiative” indicators

In contrast, we found that the indicators measuring **opportunities** and **initiative** were **highly relevant** and that families were more likely to answer these questions truthfully. If we had not tested these indicators, we would not have seen the limitations of measuring satisfaction alone.

For example:

Q16. “My family has outside help available to us to take care of special needs of all family members.”

The mother of Family 2 responds “Very satisfied” but when we dig deeper and ask if her family has the opportunity to receive outside help, she responds “never”. And her family never takes the initiative to seek outside help. It was as a result of this interview that we changed the scale from 3 (few, some, many) to 5 (never, few, some, many, a great many) for the “opportunities” indicator as well as for “initiative” (from “hardly/a little/a lot” to “never/hardly/a little/quite a bit/all the time”).

Q22. “*Name of the kid* has support to accomplish goals at school, at the place of learning, or in health care services”.

The mother of Family 2 responded that she was very satisfied but that she had hardly any opportunities to bring them. However, she makes a great deal of effort. She has two children with multiple disabilities, a 9-year-old girl and a 3-year-old boy. She just had a baby. Her little sister lives with them and helps her. She has stopped taking her son to consultations because she has no means of transportation. Her husband, who is a self-employed car electrician, does not help her with the children. He was not present during the interview with his wife. We interviewed him at the end of the fieldwork. We had in fact already met him during the FGD with the fathers

where he appeared to be a caring father. Yet, his wife rated his family's **quality of life satisfaction as "poor"** even though her total score on the Beach Center FQOLS was high (**81**). During the interview at her home, we met a woman who is clearly very unhappy, unable to go out, and isolated, as if she was "under house arrest." She also suffers from the stares of the neighbours who live in the same yard. She was sometimes annoyed to answer in terms of satisfaction: "*How can one be happy or satisfied with such a situation or a bad thing?*" Yet she answered "satisfied" or "very dissatisfied" many times, as if she wanted to quickly end the questionnaire.

Family #2



Finding #2. A short version of the FQOLS-2006 was designed, adapted to the Malian context

Instead of rolling out the revised Beach Center FQOLS to the remaining 5 families in Sikasso by telephone, we attempted to develop a short, adapted version of the 2006 FQOLS based on the families' answers and the needs of the DPCP Project.

We tested the indicators of opportunities and initiative, which appeared to be very relevant in the administration of the revised Beach Center FQOLS, but not satisfaction. We therefore replaced the satisfaction measure with a **self-assessment of their situation** (which is closer to the concept of attainment present in the original questionnaire but simpler to explain to families).

We **tested different scales (3 and then 5, finally keeping 4)** because we noticed that the respondents, especially the women, rarely chose the extreme values and did not distinguish between “many” and “a great many.”

We changed the order of the questions and simplified their wording in order to be as understandable as possible. To break down the sense of repetition of the questions, we tested the questions by indicators (opportunities, initiative and self-assessment of the situation), but we found that the interview went more smoothly if we asked the questions by dimensions and clearly explained the process at the beginning of the interview:

“We are now going to ask you questions about key areas of family quality of life. We want to better understand the barriers families face by gathering your responses about the opportunities family members face and the initiatives you take, as well as a self-assessment of your situation.

‘Family’ includes those people (related by blood or close relationships) who are closely involved in the day-to-day affairs of the household. When one or more family members have a chronic illness or disability, it can affect other family members. So please think about your *immediate family* when answering the following questions.”

We removed the dimension “influence of values” because the questions were too vague to be understood by both families and interviewers. The influence of values seemed obvious to the parents. Whether it is religion, family, traditions, and cultural beliefs, all of these values are important to the families we met but are difficult to capture because they are ambivalent and perceived differently in different cultural environments. Further research is needed to incorporate the values dimension.

A final version of the FQOLS-2006 could be designed through this empirical approach and tested on the 5th person of the survey by telephone.²⁰ In this final form, the questionnaire was more fluid and easier to understand for the respondent.

²⁰ Cf. Appendix 2 - Final version of the FQOLS-2006 abridged and adapted to the DPCP Project.

Finding #3. The measurement of FQoL is an interesting alternative approach to understanding quality of life for specific profiles for which ScoPeO has limitations.

The shortened FQOLS-2006 adapted to different HI's contexts and projects could be an alternative tool to ScoPeO-Kids for children with severe disabilities who cannot express themselves, but also for children under age 5.

In the DPCP Project, it was difficult to identify children who could answer the ScoPeO-Kids questionnaire because the severity of the disability was not known. It is not recorded on any follow-up document. When the diagnosis is made by health and social development professionals, they explain the disease to the parents without necessarily giving a name and a degree of severity of the disability. They describe the symptoms because there is no name in Bamanakan for Multiples disabilities or Dawn Syndrome. For multiples disabilities, they speak of a nerve problem, while for Dawn Syndrome, they describe the child with "a round head and Chinese eyes". On the other hand, epilepsy has a name in Bamanakan: "*kirikirimisien*" (from *kirikiri*: "to agitate, to wriggle" associated with the onomatopoeia "*masien*" and corresponds to the generalised epileptic seizure)

In the socio-demographic questions, the degree of severity of the disability, autonomy and communication of the child is asked. These questions should be asked at the outset of projects involving children with developmental disabilities to help identify those who might respond to ScoPeO-Kids personally. However, care must be taken with epilepsy, as some children with epilepsy who can express themselves a little may not be able to understand the questions.

Finding #4. The FQOLS-2006 is an effective tool for planning an intervention and measuring the outcomes of HI programs with beneficiaries.

The field survey on Mali showed that the FQOLS-2006 could be used as an instrument to describe and measure the quality of life of families. The FQOLS-2006 can become an effective monitoring tool for planning an intervention and measuring the outcomes of HI programs with beneficiaries because it is flexible and can be adapted according to the context and needs.

The FQOLS-2006 revised takes **about an hour** to administer (no longer than ScoPeO-Kids), half of which is spent on socio-demographic questions (longer in baseline). Questions can be added endline to contribute to the final evaluation of the project.

The FQOLS-2006 allows professionals to better understand the social, cultural and community context of families. We found that families never responded simply and directly. They always gave many explanations. The questionnaire can therefore be used to support an in-depth interview about the family's needs.

The FQoL survey conducted in Mali provided a number of **lessons on gender and the multi-sectoral and holistic approach** developed in the DPCP-AC5 Project that will be used to better plan interventions in the framework of AC6:

GENDER

- **Mothers (or grandmothers) are the most legitimate respondents to the FQoL questionnaire**

The FQoL questionnaire should be administered to the primary caregiver of the child with intellectual or developmental disabilities. However, this study shows that **men are not legitimate to answer** because some of them do not even know the age of the child, nor his or her problems. Fathers take much less care of their children than mothers. In Mali, children with disabilities are often entrusted to the grandmother.

- **Single mothers are the most vulnerable and least visible households**

The FGD with single mothers and grandmothers highlights that these households are the **most vulnerable** because they are not only abandoned by their families, doubly stigmatised (as a single woman and responsible for their child's disability), but they also find it difficult to work to support themselves because they are alone to care for the children. Grandmothers, in **old age**, may find themselves taking care of the child with disabilities to relieve the mother or because she has set up another household. We have seen that these women are also **less visible**. They have a **more distant relationship with the social services**. They were not aware of the talk groups or the WhatsApp group. The DPCP-AC6 Project will have to pay particular attention to reaching this vulnerable group.

- **Young girls are weakened by the disability of their brothers or sisters**

In many interviews, parents spoke of the need to force daughters to stop going to school in order to help their mothers with the care of the child with disabilities. But contrary to popular belief, fathers are not necessarily in favour of this idea and oppose it when they can. In a family-wide approach, it will be necessary to ensure, within the framework of AC6, that the **protection** of other children in the family is developed, and that young girls are supported to stay in education.

- **Involve fathers more in early care for better FQoL**

The FQoL survey showed that when the father is involved in the child's care, the family quality of life is better for everyone, and the child makes significant progress (especially Family 6). The DPCP-AC5 Project has set up WhatsApp groups to foster cooperation and solidarity among parents (especially mothers). The objective being to promote "**parent-lights**" who could help raise awareness and **teach other parents basic life skills in rehabilitation** for early care of disabilities. As part of AC6, **fathers should be more involved in these parent groups**, which are usually composed of mothers. There are already spaces for stimulation that are neglected by parents because they are too far away. The aim of AC6 is to bring the stimulation spaces closer to the families in order to facilitate their participation in talk group activities and to strengthen solidarity between peers.

MULTI-SECTORAL AND HOLISTIC APPROACH

- **The long-term benefits of a multi-sectoral and holistic approach**

The vast majority of problems encountered by children with multiple disabilities stem from a lack of follow-up in Maternal and Child Health (MCH). The case of Family 6 shows that comprehensive

care — early detection (from the day after delivery), early MCH care and rehabilitation, and IGAs to support the family economically — led to dramatic progress for the child who suffered from brachial plexus paralysis that could have degenerated into hemiplegia and multiple disabilities. This case shows the beneficial and long-term effects of a multi-sectoral and holistic approach that will be pursued in AC6.

Family #6



- **Strengthen the economic inclusion component through IGAs**

Interviews with families showed that IGAs were **beneficial** for these families **but not sufficient to generate long-term benefits**. Some families stopped their activities because they were not profitable. In addition, **IGAs must be given to women**. The men who are in charge of IGAs are in charge of them because their wives do not have a cellphone or an identity card. Even when the woman is in charge of the IGAs, the husband takes a portion for himself and controls the financial benefits of the activity. Within the framework of the AC6, the focus will be on supporting women in the sustaining the IGAs for a better professional integration.

- **The vicious circle of poverty and disability**

This field survey confirmed the close link between poverty and disability, demonstrating the importance of a multi-sectoral and holistic approach. Indeed, the poorer the families are, the less they have the means to quickly treat the child's worsening problems. The more severe the disability, the poorer the family. The issue of **transportation** often came up in the interviews and the questionnaire as a major obstacle to the care of children, especially for families with several children with multiple disabilities. Because of this, families stop going to consultations or stimulation sessions. In addition, families were dependent on the DPCP-AC5 Project for medical and rehabilitation care. Within the framework of the AC6, it will be a question of promoting the registration of the families to the RAMED for a perpetuation of this care.

Part 5 - Practical guide for using ScoPeO-Family : illustration based on the DPCP-AC6 Project

The exploratory research in Mali has allowed us to develop a FQoL questionnaire adapted to HI's intervention contexts, which we have named **ScoPeO-Family**. The methodological recommendations proposed in this guide aim to present the conditions for using ScoPeO-Family and to provide project managers, MEAL, coordinators and partners with the keys to using an operational tool that makes it possible to measure the outcomes of HI's interventions on the family quality of life of beneficiaries. We will take the DPCP-AC6 Project as an example to illustrate how to use ScoPeO-Family.

1. Practical information

What is ScoPeO-Family?

ScoPeO-Family is a tool for examining the quality of life of families who have one or more members with intellectual or developmental disabilities. Based on a lifelong approach, this tool can also be used by families of children, youth, adults and seniors **with and without disabilities**. It is a way to address the degree to which family quality of life is enjoyable, meaningful, and supported by the types of resources that are important to family members, as well as the struggles faced by families.

What is the benefit of ScoPeO-Family?

The integration of ScoPeO-Family into HI projects allows for a better understanding of the social, cultural and community context of families. It has 3 benefits:

- It allows professionals to **identify and assess** areas of family strength and support (e.g., accessible services, family relationships).
- It allows families to consider and **communicate about difficult aspects** of their lives (e.g., limited respite time, under-investment in sibling activities).
- It **uncovers facets of their FQoL** that had not previously been considered by encouraging a broader, **holistic analysis** of family well-being.

Ultimately, these characteristics from ScoPeO-Family questionnaire can assist disability professionals by providing them with the knowledge necessary to facilitate more effective practice and services.

By developing a practical survey from ScoPeO-Family, disability professionals will gain a **holistic model of care** that takes into account the strengths and challenges of the family. A deeper understanding of families' sociocultural contexts should enable service providers to more effectively meet the unique needs of each family by building on strengths, exploring challenges, and reallocating resources. By supporting families as primary caregivers, disability professionals

can improve the quality of care provided to the person with a disability, as this support will improve the **overall quality of life for families**.

How should ScoPeO-Family be used?

ScoPeO-Family is intended for two uses:

1. It may be useful for service practitioners and family members as part of an **overall assessment of support needs and program design**
2. It may be used as an **instrument to describe and measure family quality of life** in operational research projects or as a **tool for monitoring/measuring the outcomes** of projects if one considers its conceptual limitations²¹

When to use ScoPeO-Family?

Studies show that a FQoL questionnaire is useful for a variety of health and social service settings and that its ability to be **adapted to different situations and life stages is an advantage**.

In HI projects, ScoPeO-Family could be used:

- When the intervention specifically targets **families with children under 5 years of age**, where the ScoPeO-Kids tool — which is aimed at children over 5 years of age — cannot be applied and where it is important to know the perception of family quality of life before HI's intervention. A FQoL questionnaire is all the more relevant since early detection and a holistic approach from the first years of the child's life have a decisive positive impact on the quality of life of the entire family. ScoPeO-Family recognises the place and the essential role of parents and the family in the quality of life of children. Examples: Early Childhood Development projects (with or without disabilities), or Inclusive Education projects that increasingly cover pre-school;
- As a **research tool in a longitudinal study**. The ScoPeO-Family questionnaire is adapted according to what the project seeks to know; dimensions and indicators can be added/modified/removed;
- As a **project monitoring tool**. The FQoL questionnaire does not aim to replace existing tools (e.g. **TIGA** tool)²² but to provide a **holistic and multidimensional** view at the family level, thus

²¹ See [Part 2. Design Process of the FQOLS-2006](#). As noted, there is still little research in low- and middle-income countries or in vulnerable contexts. The representativeness of existing research could be improved by combining studies with samples from different populations that differ culturally and linguistically to test whether the hypothetical survey construct is valid for different populations. In addition, the studies do not cover a large enough population to represent different types of cultures with different socioeconomic backgrounds. Using ScoPeO-Family in HI projects will improve the tool itself and provide valuable insights into FQoL.

²² TIGA (Toward Sustainable Income Generating Activities) tool was developed in Cambodia as part of a Livelihoods project and is primarily intended to provide an objective measure of the improvement in the socio-economic situation of project beneficiary households. The questionnaire is composed of four criteria. The first one is related to the **satisfaction of basic needs**; the second one measures the **different abilities** related to technology, business skills, the ability to invest in key areas of life and self-confidence; the third one focuses on **participation**, especially participation in family and community life; and the last one is a general question related to **life satisfaction**.

consolidating the **social model of disability** defended by HI. ScoPeO-Family can be an alternative tool when the project lends itself to it;

- As an **outcomes measurement tool**. The comprehensive approach of ScoPeO-Family is particularly well suited to projects that have integrated a **quality of life indicator** for beneficiaries into their **logical framework**, as is the case for the DPCP-AC6 Project. ScoPeO-Family survey is used as a source of verification. Like the ScoPeO-Adults & Kids surveys, the two main steps (**baseline and endline**) will be implemented. The baseline, carried out at the beginning of the project, makes it possible to take stock of the situation and forms the basis for comparison with the endline carried out at the end of the project. If the evaluation timeframe for the project seems too short, it is preferable to choose a less restrictive and more appropriate evaluation tool.

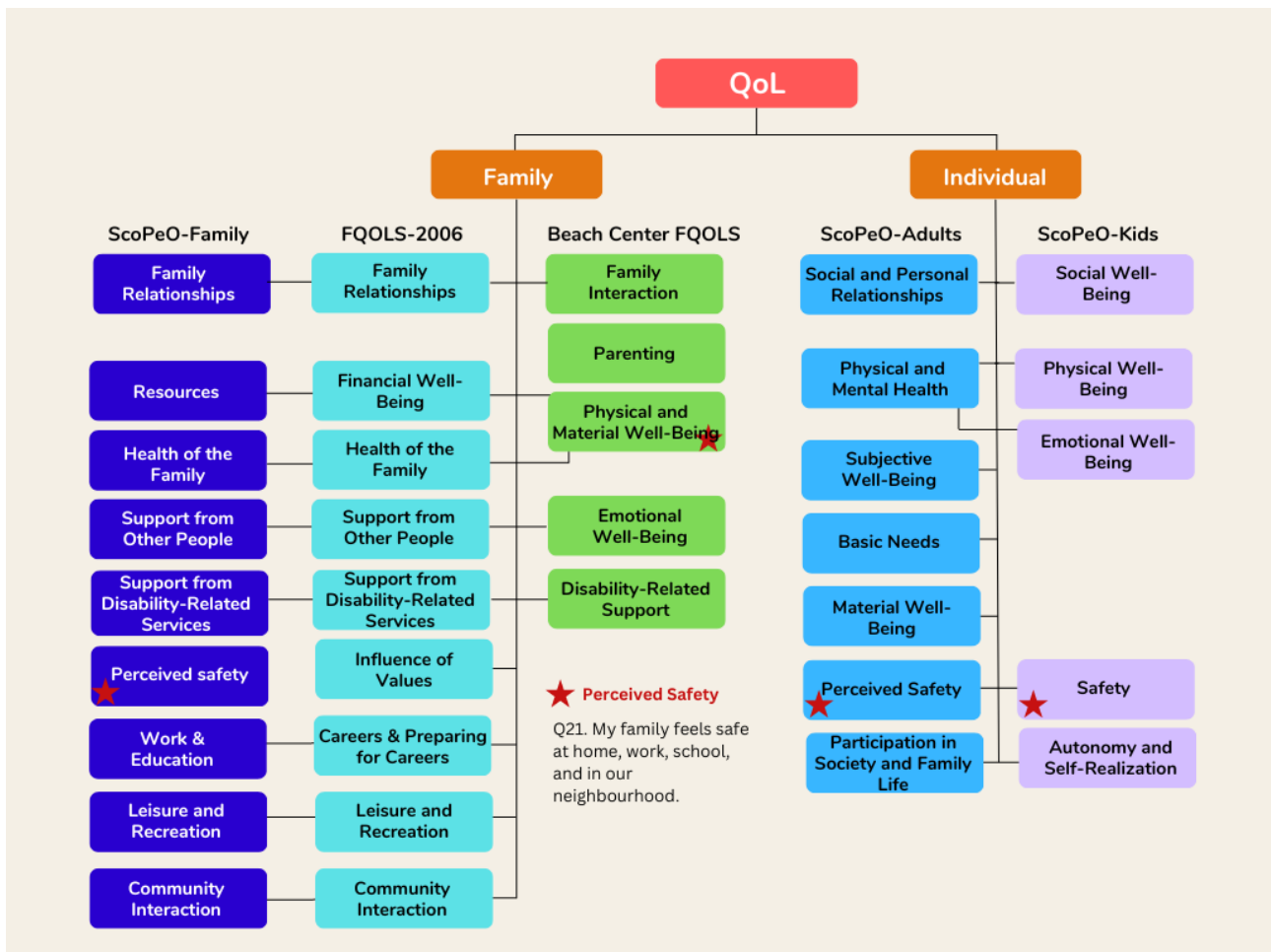
Logical framework of the DPCP-AC6 Project

| | Logic of intervention | Objectively verifiable indicators | Sources of verification | Assumptions and Hypotheses |
|--------------------------|---|---|------------------------------------|--|
| Overall objective | The quality of life of people with disabilities and vulnerable people is improved through a holistic approach | Perceived quality of life of final beneficiaries increased between the beginning and end of the intervention (disaggregated by age, gender, disability status, access to multiple services) | Surveys (Family QoL, case studies) | The socio-political and security situation in the country lends itself to interventions for vulnerable people, including people with disabilities. Tensions between the Malian authorities and the international community have eased and technical and financial partners continue to provide support. |

2. Presentation of ScoPeO-Family

Structure of ScoPeO-Family

ScoPeO-Family looks at aspects of family life that HI considers critical based on previous research and practice. It is a shortened and adapted version of the FQOLS-2006. The questionnaire was developed to fit the needs of the DPCP Project in Mali. Other HI projects will be able to use this model to develop a FQoL questionnaire that corresponds to their research, monitoring and outcomes measurement objectives.



ScoPeO-Family has two parts (see [ScoPeO-Family Toolbox](#))

Part 1. About your family

This section collects socio-demographic information about the family and attempts to identify the family's background and challenges, as well as the needs of the child(ren) with intellectual disabilities. It can be used as an interview guide when families are first identified. Socio-demographic information is important because it can help interpret the results and explain possible differences in quality of life scores.

The questions are adapted according to the project. Within the framework of the DPCP-AC5 Project, several questions have emerged: how to select the most vulnerable families who should benefit from IGAs? What criteria should be defined to establish a policy of "discharge" of families? ScoPeO-Family will help answer these questions. In the prototype version developed in Mali, the socio-demographic questions seek to identify the needs and difficulties of the family, in particular the main caregiver (usually the mother) and the child or children with intellectual disabilities. At the start of the project, these questions will be used to select the most vulnerable families who will benefit from IGAs and to identify former DPCP-AC5 beneficiaries, as some of them may continue to benefit from the DPCP-AC6 project. These questions will be used to establish a **Family Support Plan**, including rehabilitation and IGAs, with objectives that can be **evaluated at mid-term and at the end of the project**.

A **beneficiary identification number** must be set up at this first interview in order to be able to cross-reference socio-demographic information with the dimensions of the FQoL, all the more so if this information is not collected directly by HI teams, as is the case for the DPCP-AC6 Project, where it is the agents of the Local Services for Solidarity Economy and Social Development (SLDSES) who will have to collect this information within the framework of the **Personalised Social Support (PSS)** set up by the project.

Part 2. Dimensions of Family Quality of Life

This section examines, through **27 items, 9 dimensions** of family quality of life: family relationships, resources, health of the family, support from other people, support from disability-related services, perceived safety, work & education, recreation & leisure, and community interaction. All of these dimensions — with the exception of **perceived safety** — were identified and tested during the fieldwork in Mali. The dimension “financial well-being” was changed to “resources” to better cover **rural populations** who have other means of livelihood than earned money. The “Careers and preparing for careers” dimension was changed to “work & education” to cover all family members, including children. The dimension “influence of values” was removed because the questions were already not well understood by HI team and seemed too vague. In addition, in-depth interviews with families showed that the issue of the influence of values (be it religion, traditions, cultural beliefs, sense of family, etc.) was pervasive in the discourse of beneficiaries and seemed to be an obvious dimension of family quality of life in Mali but difficult to capture. We added the dimension of “perceived safety” because this dimension was missing from the ScoPeO toolkit and this dimension was also present in the Beach Center FQOLS (Q21 “My family feels safe at home, at work, at school, and in our neighbourhood”).

Other HI projects may add/modify/delete dimensions. They can identify the important dimensions to assess in their projects by conducting focus groups with families beforehand²³ and/or professionals.

Each dimension contains questions related to 3 key concepts:

- **Opportunities** (“Do your family members have the opportunity to...”)
- **Initiative** (“Are your family members making efforts to...”)
- **Self-assessment of the situation**²⁴ (“How are family relationships in your family?”)

The key concept of **satisfaction** was not retained in this questionnaire after testing it in Mali because families responded with difficulty and embarrassment to these questions (“How satisfied are you with the relationships within your family?”). **We preferred the concept of self-assessment of the situation to obtain the FQoL score.**

We chose not to include the key concept of **stability** in the questionnaire to limit the number of questions.

²³ For example, see Appendix 5. FGD interview guide with parents of children with multiple disabilities, epilepsy and Down syndrome.

²⁴ As the translation of “attainment” is not very clear in French, we preferred to speak of self-assessment of the situation.

The last section of the questionnaire is brief. It consists of two questions, one on the **three most important dimensions** of family quality of life and the other on a **general impression of overall family quality of life**:

Question 28. Which of the following areas of life are most important to your family's quality of life? (Please choose only 3 of the following areas)

- Family relationships
- Material well-being of the family
- Health for all family members
- Work and education for all members of your family
- Safety for all members of your family
- Leisure and recreation activities
- Your family's participation in community life
- The help and support your family gets from friends, relatives, neighbours and others
- The disability-related service support your child(ren) receive
- Other (specify):

Question 29. Overall, how would you describe your family's quality of life?

- Very Good
- Good
- Fair
- Poor
- Very poor

FQoL score

ScoPeO-Family calculates the FQoL (Family Quality of Life) score based on the 9 dimensions: health, resources, family relationships, support from other people, support from disability-related services, work & education, perceived safety, recreation & leisure, and community interaction. These 9 dimensions are considered critical to family quality of life by researchers. Like the ScoPeO toolkit, the FQoL score and the scores per dimension range from 0 to 100. **The FQoL score is used to measure the organisation's project indicators.**

The interest of this questionnaire is to have a **more detailed analysis of the FQoL score**. We will first look at the "**Self-assessment of the situation**" score, which is in fact the **FQoL score** (like the one get via ScoPeO).

FQoL score = average of the "self-assessment of the situation" score on the 9 dimensions

Then the “Opportunities” and “Initiative” scores will be analysed separately. The “Opportunities” indicator measures how the external environment influences the family quality of life, while the “Initiative” indicator measures family involvement and effort, i.e., what families are doing to try to improve their situation. However, it is important to know why families do not take the initiative to access opportunities. For example, opportunities may not be relevant or important to families. Family members may also not take the initiative because of other circumstances such as insufficient support, poor health, financial constraints, or simply because they lack the capacity to do so.

Finally, ScoPeO-Family also captures the three most important dimensions of family quality of life for beneficiaries and their impression of the family’s overall quality of life. This perceived FQoL score can be related to the FQoL score calculated from the scores of the 9 dimensions to enrich the analysis of the results obtained by the questionnaire.

How should ScoPeO-Family questionnaire be administered?

ScoPeO-Family is to be completed by the main **caregiver** (self-administration), or completed by a researcher, a practitioner or an interviewer with the main caregiver (face-to-face administration). When self-administered, a way should be provided for the main caregivers who have questions to contact someone with knowledge of the survey.

The main caregiver may be a parent, a sibling, a spouse or life partner, or other family member as defined in the “About Your Family” section. It is not to be completed by the family member with an intellectual or developmental disability or a family member who may assist in the care, but is not the main caregiver.

- **Interview the mother (or grandmother) first**

Studies have shown that mothers experience the greatest impact of the child’s disability (van Boekholt, 2016). Upshur (1991) found that family support from intervention programs can be perceived completely differently by fathers and mothers. Crowley & Taylor (1994) suggested that fathers have different perceptions about family functioning, identified stressors, and sources that are considered helpful. The questionnaire administered to fathers and mothers in Mali confirmed that it was essential to interview the mother (or grandmother) because fathers are much less involved with their children than mothers, and some fathers do not even know the child’s age or problems. During the fieldwork in Mali, we found that the person who brings the child to the medical consultation or social care interview is usually the main caregiver, most often the mother. The father sometimes accompanies the mother. Therefore, it is recommended that mothers (or grandmothers) be interviewed first, as they provide valuable information on the level and type of impact of the child’s disability on the family’s overall quality of life.

The first question in the “socio-demographic” section identifies the relationship to the child: “What is your relationship to the child(ren) benefiting from the DCPCP Project?”. The main caregiver may not be the mother, but the grandmother, aunt, sister or adoptive mother.

- **Choose a location that guarantees confidentiality**

Studies (van Boekholt, 2016) as well as the field survey in Mali showed that mothers were reluctant to talk about certain sensitive topics, such as the impact of family relationships, when other family members were present during the interviews. The questionnaire in Mali was administered in the homes, and it was not always possible to isolate ourselves. In addition, when interviews took place before lunchtime, mothers were not fully available to answer questions. In order to obtain a good picture of a family's quality of life, it is therefore recommended to choose the interview setting carefully, preferably in a secluded area. In addition, it is important to assure respondents that all their answers will be treated with the highest degree of confidentiality. Ideally, interviews should take place at the community centre closest to the families or at HI's office.

- **When completing the ScoPeO-Family questionnaire:**

1. Please answer every question as fully as possible.
2. Write in any additional information or comments that might help us to better understand your family's situation in the spaces beside the questions.
3. If a question is not applicable, please say so and explain why.

The survey takes about **one hour** to complete (30 minutes for the first part gathering socio-demographic and background information, and 30 minutes for the second part concerning the different dimensions of family quality of life).

Confidentiality and Ethical Considerations

All surveys must comply with ethical rules. People involved in the study must conduct themselves in accordance with the following ethical recommendations:

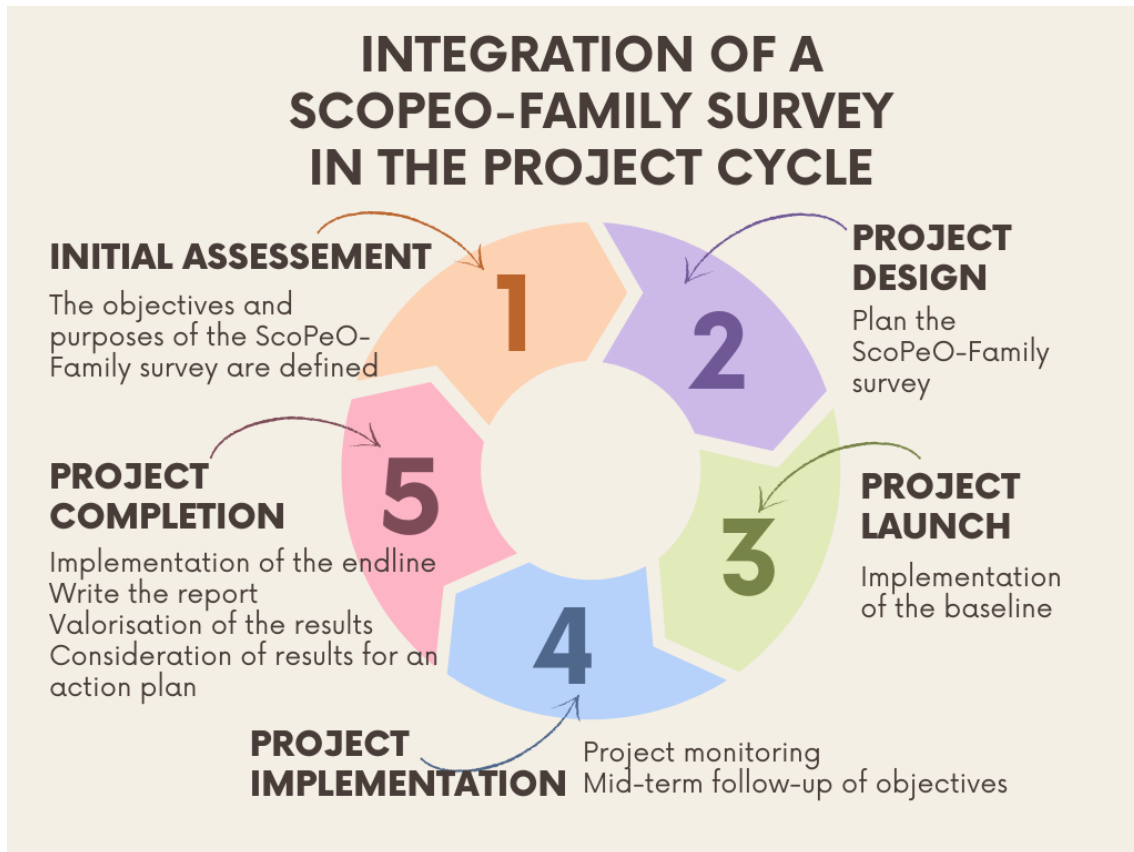
- Guarantee the safety of participants, partners and teams²⁵
- Ensure a person/community-centred approach
- Obtain free and informed consent from participants
- Ensure referral mechanisms are in place²⁶
- Ensure the security of personal and sensitive data at all stages of the activity
- Plan and guarantee the use and sharing of information
- Ensure the expertise of the teams involved and the scientific validity of the activity
- Obtain approval from the relevant authorities.

²⁵ The "Do no harm" approach can be applied at different levels, in particular: avoid creating situations of insecurity for interviewees, ensure that interviewees are the object of respectful attitudes on the part of the interviewers, or put in place the conditions for the protection and prevention of sexual exploitation and abuse, in accordance with the HI internal policy.

²⁶ Even if it is not the objective of the survey, if people in distress are identified by the administrators, it is necessary to be able to offer these people a referral to the relevant care services in the network of actors identified by HI.

➔ For more information, please refer to the guidance note: [Studies and research at Handicap International: Promoting ethical data management](#) (HI, 2015) – See in particular **Ethics checklist** (p. 31-34)

3. Integrating a ScoPeO-Family survey into a project: the three key steps of the methodology



During which phases in the project cycle, and with which key players?

The preparation of a ScoPeO-Family survey is organised in the same way as for ScoPeO-Adults & Kids surveys in relation to the key players and stages in the project cycle as defined by the [HI Project Quality Policy](#).

The baseline in this diagram is developed during the project launch phase of the project cycle using financial resources allocated to project monitoring and evaluation. If the human and financial resources are available (if there is an upstream phase for the new project requiring data collection), the baseline survey can be completed in advance during the initial situation and needs assessment phase. This can be useful when developing logical framework indicators.

The manager for the study is de facto the project manager, supported when relevant by the operational and/or technical coordinator of the mission or program, or the program's MEAL team. Some skills and knowledge are necessary (how to run a study or survey, basic statistics knowledge using Excel in particular) and prior experience in these areas is even better. Advice

should be sought from a specialist to fill in any gaps in this knowledge and experience when setting up the study. If necessary, support from the MEAL Unit within the Innovation, Impact & Information Division (3I) will be put in place to assist the project manager with implementing the study (logistics and arrangements, training and monitoring of interviewers during the data collection phase). An **in-house operator** is responsible for data input.

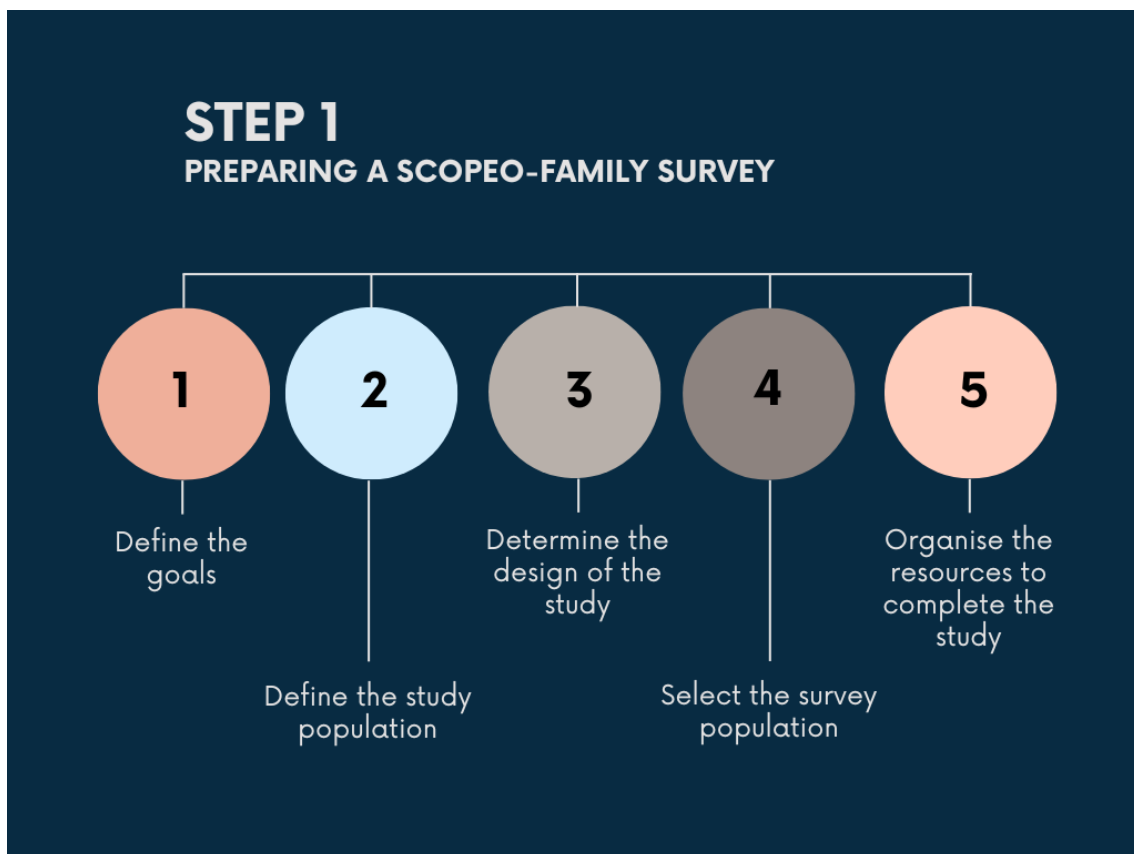
The methodology for using ScoPeO-Family survey comprises **three key phases**:

- Preparing a ScoPeO-Family survey : defining the goals, the methodology (sample design, data collection and analysis) and the needed resources;
- Preparing the data collection and input : this section details the key steps for the implementation of the study in the field;
- Leveraging the results via a range of media and channels for distributing the study results to support their practical use.

ETAPE 1 : Preparing a ScoPeo-Family survey

This first phase, which serves to scope the study, comprises five steps that must be followed in chronological order.

- ➔ For this step, use the HI reference [How to conduct a qualitative/ quantitative study?](#) practical guide and all its tools. ScoPeO-Family relies on the same methodology as any quantitative survey.



1. Determine the study goals

Determining the goals serves to lay out and define the reasons for implementing the study. “Why do I want to measure the outcomes of my project/activities on beneficiaries’s quality of life?” Answering this question will help define the goals of the study. It can also help in aligning the goals of the study with those of the project.

Looking at the goals of the study and those of the project being evaluated helps to analyse changes based on achieved results in relation to the activities carried out during project implementation. It is then possible to determine whether the dimensions that improved correspond to the project’s actions.



The question of learning

Beyond the question of measuring outcomes, the objectives of ScoPeO-Family can also be defined from a learning perspective.

Example 1: To learn about the relevance of our practices by comparing beneficiary families with and without IGAs. This configuration would allow us to learn about the **added value of a multi-sectoral approach** (social services + livelihoods), which is also an objective of AC6.

Example 2: Learn about the relevance of our practices by **comparing single and two-parent families**. Are we able to improve the quality of life of single-parent families? Are we finding solutions adapted to their needs?



Objectives of the FQoL survey in the DPCP-AC6 Project

At the end of the DPCP-AC5 Project, several questions emerged. How to select the most vulnerable families to allocate the IGAs? How to better respond to their needs and monitor their progress? How can we define a policy for the "discharge" of families at the end of the project? Indeed, what indicators can be used to assess the extent to which a family no longer needs direct support from the project? Within the logical framework, the teams need to measure the effects of the project’s intervention on the quality of life of families living with children with severe disabilities.

ScoPeO-Family will make it possible, on the one hand, to **identify at the beginning of the project the needs of the families** in order to improve their support and, on the other hand, to **evaluate at the end of the project the outcomes** of HI’s intervention on the quality of life of children with intellectual disabilities and their families.



The **Family Support Plan**, which sets out the support objectives in terms of rehabilitation and IGA in particular, will be drawn up following the first social development interview, based on the first part of the FQoL questionnaire (socio-demographic information). This Family Support Plan can serve as a **project monitoring tool** because these objectives can be evaluated at mid-term and at the end of the project. It will help determine the extent to which a family no longer needs direct support from the project.

In addition, by comparing recipient families with and without IGAs, the ScoPeO-Family survey will allow to learn more about the added value of a multi-sectoral approach (social services + livelihoods).

2. Determine the study population

Defining the study population or target group is directly related to the previously established project goals. The target group in the case of ScoPeO-Family is defined in terms of gender, age, disability status, and geographic location, for example, who has benefited or will benefit from the intervention and will therefore be the object of the study. Selecting the sample among this population is examined in [Paragraph 4. Select the survey population](#).



Study population of the DPCP-AC6 Project

These are children from 0 to 14 years old suffering from a severe disability (multiple disabilities and Dawn Syndrome; epilepsy is not taken into account in this project except in cases of association with Dawn Syndrome and/or multiple disabilities) and their families, living in Bamako (Sikasso will not be covered in the project).

- 1749 children will be cared for (including 1043 boys and 706 girls, 1539 with multiple disabilities, 182 with Down Syndrome, 28 with multiple disabilities associated with Down Syndrome, 1252 aged 0 to 60 months, 348 aged 61 to 120 months and 149 aged over 120 months).
 - 55 parents whose children have benefited from rehabilitation care will also benefit from IGA. Of these 55 families, 12 are recipients from AC5.
-

3. Determine the design of the study

To evaluate projects' outcomes using the ScoPeO-Family tool, two surveys are carried out in the same location at two different times (**t** and **t+1**) to collect the data.

Time t corresponds to the initial baseline phase ("**baseline**" questionnaire to be administered at the start of the project).

Time t+1, which provides information for monitoring over time, corresponds to the endline (“**endline**” questionnaire to be administered at the end of the project).

ScoPeO-Family questionnaire is identical in baseline and endline.

➡ See. [ScoPeO-Family toolbox — Part 2 FQoL questionnaire](#)

There must be at least one year²⁷ between the two surveys in order to observe significant changes. This interval can be adapted according to the project and its goals. The results obtained at these two different points in time are compared to show any positive or negative changes in the dimensions addressed in the questionnaire.

The “baseline” questionnaire serves to collect benchmark data and the “endline” questionnaire to identify changes in quality of life of the project’s families.



Scheduling issues to be considered

As with any social science study of people’s everyday lives, it is advisable not to administer the questionnaire at particular times of year (Christmas, Tabaski, Ramadan, holiday, natural disasters, hunger gaps, epidemics, political campaigns, etc.), to ensure the “normality” of responses to the questions. Furthermore, the “state of mind” of interviewees at the time the questionnaire is administered should not be taken into account. Individual states of mind, which might otherwise skew the questionnaire, must be offset by surveying a sufficiently large number of people (sample of at least 60 people).



ScopeO-Family survey design of the DPCP-AC6 project

The ScoPeO-Family questionnaire has been adapted to meet the objectives of the DPCP-AC6 Project and associated with the project monitoring tools. The first part of ScoPeO-Family will be used as an interview guide to establish a **Family Support Plan** within the framework of the **Personalised Social Support (PSS)** provided by the project.

In the context of family level support, international standards recommend an action plan for each family member.

The **first part of the questionnaire, About Your Family**, which collects socio-demographic information about the family and attempts to identify the family context and the needs of the child(ren) with intellectual disabilities, will be administered at the beginning of the project to all beneficiaries, at the time of the first family support interview. This section asks the questions necessary to identify the most vulnerable families and their needs.

²⁷ There is no maximum time interval between the baseline and the endline.



In the framework of the DPCP-AC6 project, the Local Services for Solidarity Economy and Social Development (**SLDSES**) providers will be in charge of implementing the Personalised Social Support (**PSS**) for the beneficiaries and their families. The tools for the implementation of the system (developed by HI) will be deployed at their level to ensure the quality of the support. In this respect, the SLDSES agents will benefit from training on the PSS methodology in order to develop the necessary capacities for the implementation of quality support to the beneficiaries (**Activity 2.2** of the logical framework).

As part of this training, the SLDSES providers will be trained to conduct these intake and follow-up interviews using the ScoPeO-Family questionnaire. Questions may be added, deleted or modified according to the context and objectives of the project.

This interview at the time of intake will allow for a better identification of the most vulnerable families, in particular to allocate IGAs to 55 families (including 12 former beneficiaries of the DPCP-AC5 Project), and to establish a Family Support Plan with objectives that can be evaluated at the end of the project.

The **second part of the questionnaire**, covering the nine dimensions of family quality of life, the three most important areas and the overall assessment of family quality of life, will be administered to the **55 families benefiting from IGAs** in baseline by trained interviewers. For the purposes of a **longitudinal** study to determine the effects of the project on the quality of life of each family, the same beneficiaries will be interviewed in endline.

However, in order to compare families that have benefited from IGAs with those that have not, and to **better understand the added value of a multi-sectoral approach** (social services + livelihoods), **55 families that have not benefited from IGAs will also be interviewed in baseline and endline.**

4. Select the survey population

The population targeted by the ScoPeO-Family questionnaire can include all types of adult beneficiaries of HI projects in any of the countries where projects are implemented. However, it is essential to strictly define the criteria for inclusion of people to be surveyed (age, gender, location, types of disability, etc.) and for the sampling methods when sampling is necessary.

- What size should the sample be?
- How to create your sample?
- Review of sampling methods

➡ See also [How to conduct a qualitative/ quantitative study?](#) practical guide and all its tools.

The choice of a sampling method or combination of methods is linked directly to the context of the project, but also to the funds and time available. Because this guide is not specifically about the sampling process, it provides no further methodological support on this topic. If necessary, you should refer to in-house guides (see above) or consult MEAL unit.



ScoPeO-Family survey sample from the DPCP-AC6 Project

The FQoL survey sample will consist of the **55 families who will receive rehabilitation therapy and IGAs**. Among these 55 families, 12 are from AC5. In order to better understand the added value of a multi-sectoral approach (social services + livelihoods), **55 families who did not benefit from IGAs** (but only from rehabilitation support) will also be interviewed in baseline and endline.

5. Arrange the resources to complete the study

Once all these elements have been scoped, the resources needed for the study must be arranged. Managers must check that the necessary resources can be mobilised and that they are fit for purpose for the study to be implemented. It is estimated that a ScoPeO-Family survey requires the same amount of time as a ScoPeO Adults & Kids survey, **about 8 to 12 weeks, both in baseline and in endline** and human resources (staff and staff skills. Resources may be internal or external, financial, time, and human (staff and staff skills).

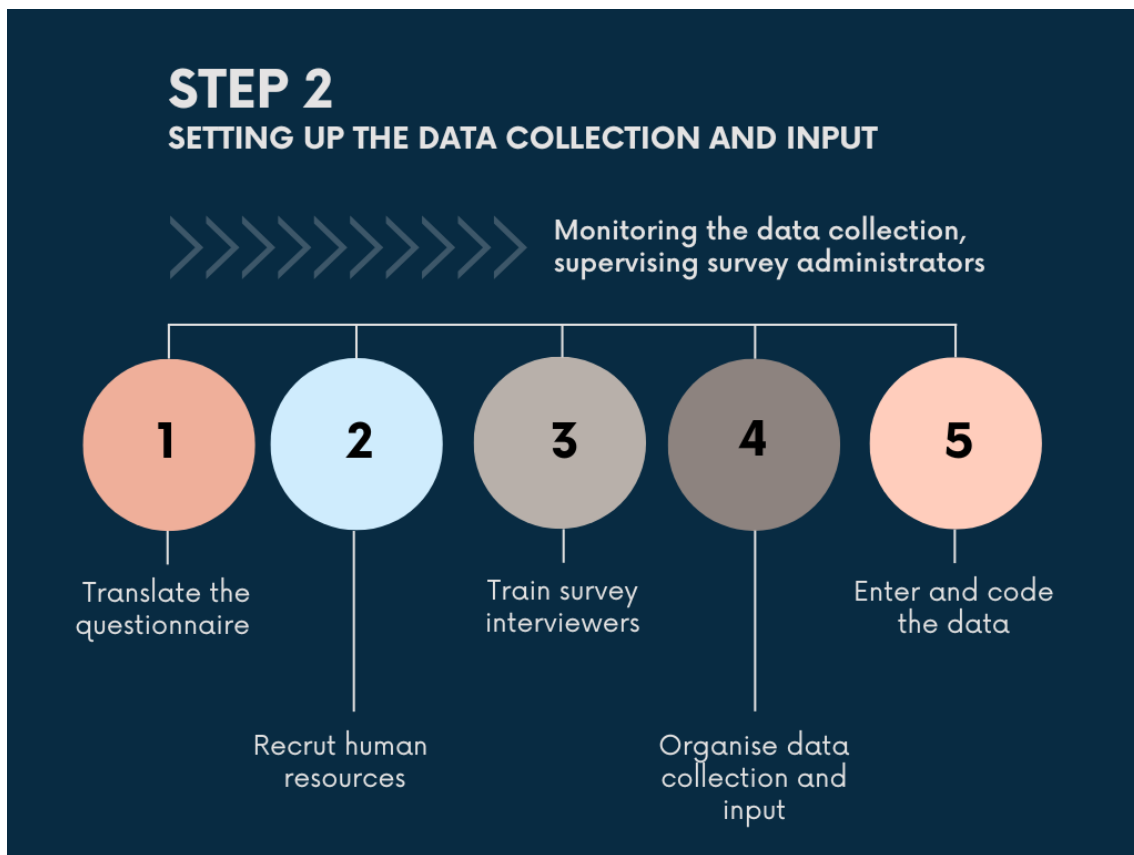
The study must be included in the project proposals submitted to funding agencies, along with a realistic cost estimate. The ScoPeO-Family survey is, like all other rigorously conducted surveys, considered to be an expensive and demanding practice.

The issue of deadlines is also very important, as the study procedure presented in this guide is quite strict. Two phases (baseline and endline) must be factored in. It is not recommended to implement this approach for a short-term project (under one year).



It is important to identify any barriers that could prevent individuals from participating when the study is implemented and to take account of the financial consequences. Care must be taken when it comes to the mobility chain, accessibility of transport and reception infrastructure, as well as accessibility of facilities, information and communication

STEP 2 - Setting up the data collection and input



This phase includes **five steps** to make the questionnaire **operational**, i.e. translating it, ensuring effective organisation, in particular in terms of human resources, and creating optimum conditions for entering and coding collected data in the input interface.

➡ For this step, use the HI reference [How to conduct a qualitative/ quantitative study?](#) practical guide and all its tools. ScoPeO-Family relies on the same methodology as any quantitative survey.

1. Translate the questionnaire

The translation must be based on the questionnaire as presented and adhere as closely as possible to the questions and proposed responses in the original version. The dimensions and questions in the tool are universal and apply to the majority of cultural contexts. It is essential to remain true to the meaning given to each question, whatever the context of the project.

The proposed translation model for this questionnaire is that of “parallel back-translation.”²⁸

This method requires the English questionnaire to be translated into the local language by two bilingual individuals, in the presence of the manager for the study who is also perfectly bilingual.

²⁸ Vallerand R.J. Vers une méthodologie de validation trans-culturelle de questionnaires psychologiques : Implications pour la recherche en langue française, in Canadian Psychology/Psychologie Canadienne, 1989, 30:4

If issues of interpretation arise during translation, the project manager provides clarification (e.g. the term “ideals” is not the same as “desires”)

Next, two other bilingual individuals translate the local language version back into English to check that their “back-translated questions” correspond to the questions in the original version.

If there are inconsistencies, the process is repeated with the assistance of the project manager until the translated questionnaire corresponds perfectly to the original version of the questionnaire.

Once the questionnaire is translated and validated, no further changes may be made to the formulations of the questions in the local language (nor is any change permitted to the French version, of course).



Oral (audio) version of the ScoPeO-Family questionnaire

When translating the questionnaire into Bambara, we made sure to use a **popular language level** so that the questions could be understood by as many people as possible (instead of choosing a more formal vocabulary in Bambara).

For the interviewers, it is preferable to record an **oral version of the questionnaire in Bambara** instead of having a written version of the questionnaire in order to facilitate the understanding of the questions because not everyone has a good command of written Bambara.

When local languages are not written but phonetic, it is best to use an **audio version** of the questionnaire: ask one of the translators to record the questionnaire and then share the audio file with the data collectors. It is a practical way of ensuring that formulation and pronunciation will be comparable from one questionnaire administrators to the next. This procedure does not prevent interviewers from supplementing their versions with notes taken during the training, if they want.

2. Recruit the human resources for data collection

A survey manager may need to be recruited to pilot the survey, monitor progress and train interviewers. This manager should have **extensive experience in implementing and monitoring studies and/or research** and be well versed in the ethical and methodological requirements of quantitative studies in the humanities and social sciences.

Interviewers must be recruited three weeks prior to the survey. The ScoPeO-Family methodology **requires rigour and expertise** equivalent to a European Master 2 level degree in social sciences, or that of professional interviewers. If there are no interviewers meeting these criteria, consider contacting national statistical institutes that regularly conduct surveys and therefore have a pool of administrators and other NGOs or universities carrying out this type of survey. If this is

unsuccessful, administration of the questionnaire may be assigned to other profiles, as long as recruits have the requisite spoken and written skills to ensure quality data collection. In this case, it is advisable to ensure closer supervision by the survey manager.

When recruiting interviewers it is important that they have **no personal or professional connection** to the individuals being surveyed. If possible, they should not live in the survey area to ensure that the persons surveyed and the interviewers are not known to each other. Testing the questionnaire showed the importance of recruiting interviewers from outside the organisation, i.e. neither employees nor partners. The questionnaire explores subjective notions related to an individual's experience. Two significant biases were identified. First, those surveyed may feel unable to talk freely because they are unwilling to discuss their difficulties with someone they know. The other is that people being surveyed may see this as an opportunity to meet with a HI employee or partner and address their difficulties, which is not within the framework of the ScoPeO-Family questionnaire).

Depending on the cultural context, it is also important to have both male and female interviewers to avoid causing any embarrassment or problems to those being surveyed.

Interviewers must be perfectly **bilingual**²⁹ (in the local language as well as French or English, the two "official" ScoPeO-Family tool languages) to be able to participate to the translation of the questionnaire and explain the questions to those surveyed in the event of any misunderstandings.



Need to recruit more female interviewers for the deployment of the ScoPeO-Family

The ScoPeO-Family questionnaire will most often be administered to women because mothers are the main caregiver of children, especially when they have a severe disability. ScoPeO-Family questionnaire examines intimate dimensions of family life that may be embarrassing to the respondent. In addition, the questionnaire will be administered at home if interviews cannot be conducted in a community centre near the home. Therefore, in Mali, for example, it would be advisable to have female interviewers so that mothers can respond more freely and without bias. It will therefore be necessary to train more women in interviewing techniques and qualitative and quantitative surveys.

3. Train interviewers in data collection

A short training for the future interviewers serves to present the ScoPeO-Family tool, the related methodology, and provide methodological and practical advice for collecting good quality quantitative data.

²⁹ They must be perfectly familiar with the vocabulary used in the questionnaire in the two translation languages.

Human resources for training: The project manager and survey manager provide training, depending on their skills and availability.

Training schedule: The training lasts **4 jours** and meets the following learning goals below.

Knowledge:

- Becoming familiar with HI and its approach
- Becoming familiar with the study objectives
- Becoming familiar with the ScoPeO-Family questionnaire
- Becoming familiar with basic quantitative data collection techniques
- Understanding your role in the evaluation and the need for high-quality data.

Know-how:

- Explaining the objectives of the study to someone
- Conducting interviews
- Directly transcribing the interviewees' answers onto the paper version of the questionnaire.

This training proposal must also include a **pre-test phase (1 to 2 day)** which will allow the interviewers to test the translated questionnaire and give them the opportunity to practice their interview technique. In this case, it is advisable to schedule a time for a debriefing with the team, in order to adjust the tools if necessary and encourage the interviewers to appropriate the questionnaire.

4. Organise data collection and input in the field

Fix appointments and decide on interview location

Appointments must be fixed by or in the presence of the interviewers two weeks prior to the survey. The administrators must have a provisional interview schedule. It is best not to exceed four interviews per half-day per interviewer. Testing of the FQOLS du Beach Center questionnaire in Mali showed that it is better for people to be interviewed in a geographically and physically accessible location that allows confidentiality and is compatible with cultural codes. Depending on the setting, this could be on HI premises or those of a partner, or in an associative and/or community facility. These criteria are designed to afford greater freedom with responses (particularly those involving perceived safety or decision-making autonomy). It is therefore crucial to allocate a budget for interviewees' transport costs. Although not ideal (notably for reasons of confidentiality), interviews can be held in the homes of people who have difficulty getting around.



Cultural dimension and gender approach

A gender approach complying with local conventions and social hierarchies should be adopted in keeping with local cultural norms. Interviews must be adapted to the working hours of interviewees (not necessarily the same for men and women); for example, holding interviews in the evening might facilitate participation of agricultural workers. Women are very busy in the morning going to the market and preparing the meal, they are freer in the afternoon. In Mali, for example, interviews must be conducted before or after prayer time.

Administer the interviews

Interviews should be conducted face-to-face as a priority, with one interviewer for one respondent. The telephone interviews conducted with beneficiaries in Sikasso showed that the administration of a FQoL questionnaire was feasible even if conditions were not ideal (disturbances, power cuts, etc.). The telephone interview is a last resort in cases of extreme urgency, such as lockdowns or conflicts that would make it impossible to reach beneficiaries.

If the individual to be surveyed is accompanied, care must be taken so that his or her responses cannot be heard so as to not influence their answers. However, the interviewee must be able to maintain visual, but not auditory, contact with the person accompanying them so as not to feel isolated (for instance, the accompanying person can stay in another corner of the room).

Certain rules must be applied when administering the ScoPeO-Family questionnaire:

- While the administrator must ask all the questions and try to obtain an answer to them all, it is strictly forbidden to answer for the person being surveyed.
- It is strictly forbidden to modify the way questions are formulated; explanations are allowed, but not reformulation of questions.
- Modifying the order of the dimensions and questions is prohibited.
- Modifying the responses is prohibited.

[Module 5 of the interviewers' training](#) provides all the rules and principles to be respected.

➡ See also [How to conduct a qualitative/ quantitative study?](#) practical guide and all its tools.

Monitoring the data collection

Once the interviewers have been trained, the interviews set up and the survey location chosen, a meeting should be scheduled for two days after the beginning of the field surveys. This enables interviewers to give any feedback they may have on the questionnaire and any adjustments to be made to the translations. Weekly half-day meetings serve to monitor and support interviewers in the field. It is important to include debriefing sessions for interviewers during this monitoring process to ascertain how they are feeling, as they may be affected by what they hear. These

sessions must give them the opportunity to share to prevent them from over-identifying with the individuals they are surveying.

The survey manager is in charge of setting up and supervising data collection monitoring.

It is important to include in this follow-up process moments of **emotional debriefing** for the interviewers (their “lived experience”) who may be affected by the answers collected. They must be given space to speak in order to allow this debriefing and to avoid a possible identification with the situation of the interviewees.

It is best to pool questionnaires and examine the responses given to each question early in the survey process to check that no erroneous data is being recorded. If this should occur, it needs to be established whether this is due to transcription errors by the interviewer or to the question being misunderstood. In the latter case, time must be taken to repeat the explanation of the question to all interviewers. Lastly, the completed questionnaires must be submitted to the survey manager and filed away for the duration of the survey. Once centralised, they are given to the data input operator.

5. Code and enter data

If a mobile data collection tool, such as Survey CTO, is not used for the survey, provision must be made for printing out the questionnaires, as the interviewers record the data on paper. Interviewee responses must be entered into the tool’s input interface (see below). This requires recruiting one or more data input operators. The survey manager must make at least one check at the end of data entry to ensure there are no errors. In a mobile data collection process, this input stage is done automatically; therefore, go on to the next stage.

➡ See a short guidance on [How to process data](#) and also [How to conduct a qualitative/quantitative study?](#)

➡ See also the [FQoL score matrix \(ScoPeO-Family Toolbox\)](#)

Data input

Data entry is done in the same way as for ScoPeO-Adults & Kids. Each question is scored on a four-point scale (ranging from “Hardly any” to “Many”; “Hardly at all” to “Quite a bit” or “Poor” to “Very good”), and then scaled out to 100, yielding scores by dimension and a FQoL score between 0 and 100.

Values associated with the answer choices of the different questions:

| Answer | Value |
|--------------|-------|
| All the time | 4 |
| Often | 3 |
| Sometimes | 2 |
| Never | 1 |

| Answer | Value |
|-------------------|-------|
| Quite a bit/Many | 4 |
| Some | 3 |
| A little/A few | 2 |
| Hardly any/at all | 1 |

| Answer | Value |
|-----------|-------|
| Very good | 4 |
| Good | 3 |
| Poor | 2 |
| Very poor | 1 |

Create a FQoL matrix

Projects can draw on DPCP-AC6's FQoL prototype matrix (see [ScoPeO-Family Toolbox — FQoL Matrix / DPCP-AC6](#)). FQoL score matrix is composed of several sheets:

- Two sheets are provided for entering raw data (one for the baseline and the other for the endline). It is on these sheets that the data from the ScoPeO-Family questionnaire will be entered from the 'paper-and-pencil' format, or imported when mobile data collection is used.
- The lines correspond to the individuals questioned, columns to variables collected (that is, the socio-demographic information of the primary caregiver and the child and the answers to the 29 items of the ScoPeO-Family questionnaire. These data will be used for the scores calculation.
- Two sheets offer mean scores per domain as well as mean FQoL score at Baseline and at Endline. All scores are between 0 and 100.
- One sheet summarises findings when comparing baseline and endline results and provides a visual comparison of mean scores of the overall population.



Missing answers to sociodemographic questions can be left blank. Missing answers on the ScoPeO-Family questionnaire must be identified using the drop-down menu and selecting 'missing data'.



Adding new questions, and new columns

If you need to add questions, you will also need to add columns to the matrix. New questions can be added but be careful: do not change any of the existing columns as they contribute to the scores calculation.



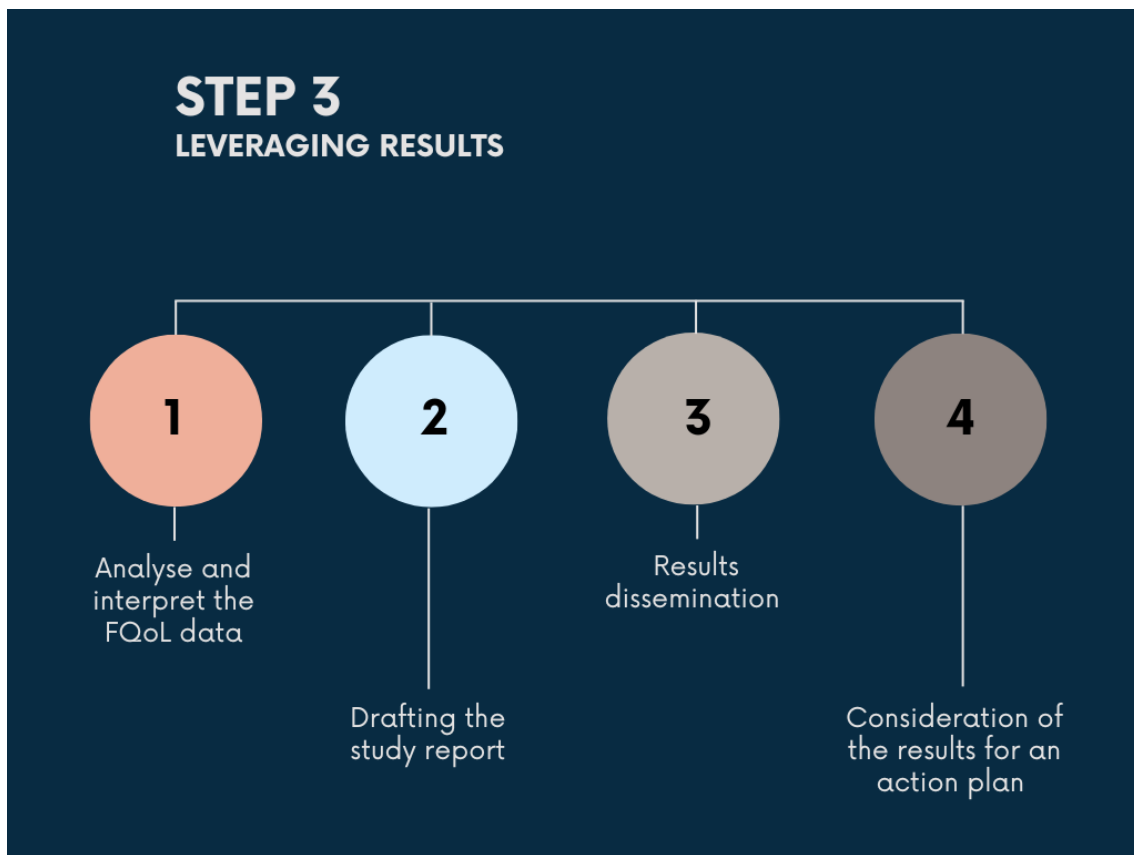
Mobile data collection (MDC)

The official MDC tool used by HI is Survey CTO. The SurveyCTO form of ScoPeO-Family questionnaire has yet to be constructed. However, the matrix must still be used to calculate scores as recommended.

Quality assurance

Once data for 50 children has been entered in the Excel matrix, it is advisable to perform a 'quality check'. This involves taking a number of questionnaires at random (approximately 10-15) and checking that all the answers on the 'paper-and-pencil' version of the questionnaire correspond exactly to the answers in the Excel Matrix. If more than 3 questionnaires contain mistakes, all the questionnaires should be reviewed and corrected as necessary.

STEP 3 - Leveraging results



1. Analyse and interpret the FQoL data



Terminology

Analyse: Processing raw data gathered in the field and producing information. The matrix makes automatic analyses, i.e. calculations of scores by dimension, and Family Quality of Life (FQoL) score.

Interpret: Giving meaning to the data analysed by linking it to the survey's objectives and context. The matrix provides the material to be interpreted; it does not provide an interpretation. This is the job of the person responsible for the ScoPeO-Family survey.

Scores calculation

FQoL total scores and dimensions scores range between 0 and 100. The Table below describes how dimensions scores and FQoL score are calculated (the excel matrix will automatically calculate those scores).

The “Situation” score corresponds to the FQoL score (like the ScoPeO score) to be taken into account during evaluations.

| Dimensions | Opportunities | Initiative | Situation |
|---|---|--|---|
| Health (H) | Q1 | Q2 | Q3 |
| Ressources (R) | Q4 | Q5 | Q6 |
| Family Relationships (FR) | Q7 | Q7 | Q9 |
| Support from Other People (SOP) | Q10 | Q11 | Q12 |
| Support from Disability-Related Services (SDRS) | Q13 | Q14 | Q15 |
| Work & Education (WE) | Q16 | Q17 | Q18 |
| Leisure & Recreation (LR) | Q19 | Q20 | Q21 |
| Community Interaction (CI) | Q22 | Q23 | Q24 |
| Perceived Safety (PS) | Q25 | Q26 | Q27 |
| | \sum scores Opportunities (H, R, FR, SOP, SDRS, WE, LR, CI, PS) / 9 | \sum scores Initiative (H, R, FR, SOP, SDRS, WE, LR, CI, PS) / 9 | \sum scores Situation (H, R, FR, SOP, SDRS, WE, LR, CI, PS) / 9 |
| | Opportunities Score | Initiative Score | Situation Score Which is also the FQoL score! |

Read the results in the baseline and endline matrices

Raw collected data is analysed. In ScoPeO-Family matrices, calculation sheets directly provide data analysis and indicate scores results. Drop-down lists facilitate data entry and values are automatically assigned to responses.

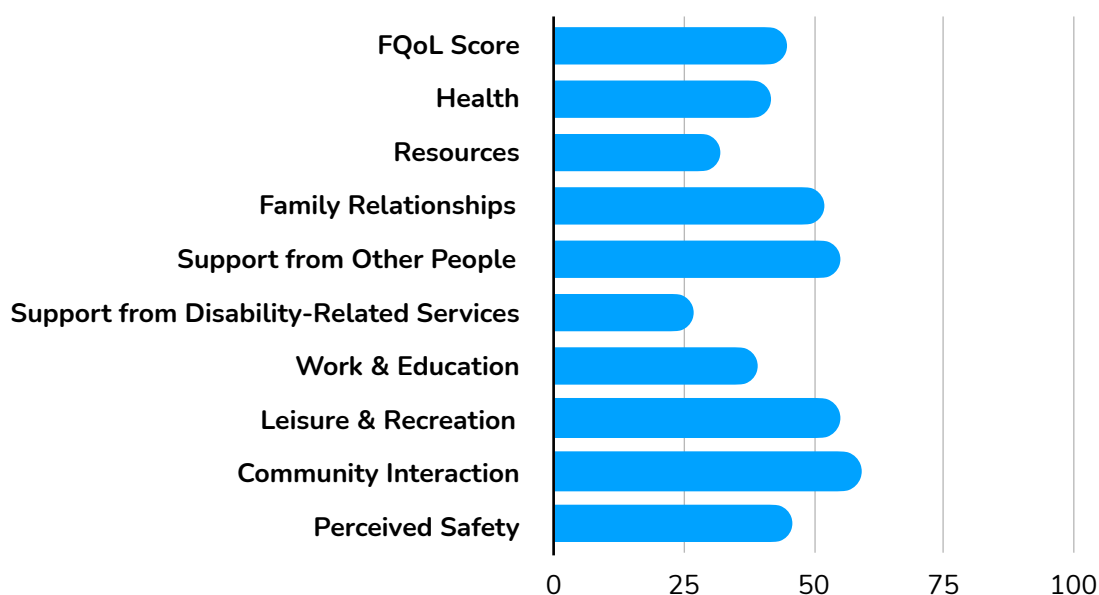
How we can use the results?

Baseline findings

The interpretation of the findings may enable the project team to adjust the activities of the related project, if needed and if possible (for instance, more activities related to one dimension). The interpretation of the baseline findings may enable the project team to specify the intervention axes of the project concerned (prospective analysis: which dimensions of ScoPeO-Family are most likely to evolve during the project depending on the activities implemented?).

Example : (fictive numbers)

Baseline FQoL score and “Situation” scores by dimension



| Dimensions | Situation Scores |
|--|------------------|
| Health | 42 |
| Resources | 32 |
| Family Relationships | 52 |
| Support from Other People | 55 |
| Support from Disability-Related Services | 27 |
| Work & Education | 39 |
| Leisure & Recreation | 55 |
| Community Interaction | 59 |
| Perceived Safety | 46 |
| FQoL Score | 45 |

Analysis : the 3 dimensions that need the most support are disability-related services, resources, work & education, followed closely by health. The strengths of the families are their interactions with the community and the support offered by others. The project should build on these strengths to develop solidarity and community mobilisation.

Example : The exploratory FQoL survey carried out in Mali showed that the DPCP-AC6 Project should rely on “parent-lights”³⁰ to encourage solidarity and the sharing of experiences between parents, particularly in training **basic life skills in rehabilitation** for early care of children with multiple disabilities and Dawn Syndrome.

³⁰ A term used by the DPCP Project team to describe parents who have experience in caring for a child with multiple disabilities or Down syndrome who are willing and proactive in helping other parents. WhatsApp groups were formed during the project and are very useful for families. In addition, during Focus Groups Discussions conducted with fathers, mothers, and single mothers/grandmothers, spontaneous exchanges of input and advice occurred.

Comparison of baseline and endline results

Drawn from a comparison between the baseline and endline scores, the results comparison indicates improvement, worsening or stagnation of the scores for the various dimensions:

- Comparison of the FQoL score between the baseline and endline surveys
- Comparison of Baseline and Endline scores for each dimension

Because the dimensions are independent of each other, notably because projects do not necessarily target all dimensions, there may be disparities. For example, it is possible that the score of the Health dimension may improve while the score of Resources worsens. This type of observation can assist HI in defining new opportunities for action.

To quantify progression in each dimension or for FQoL scores, there are two options:

- **Option 1** : Measure it using the “point” as a unit: a simple **subtraction** is adapted.
- **Option 2** : Measure it as a % of progression: apply the following formula:

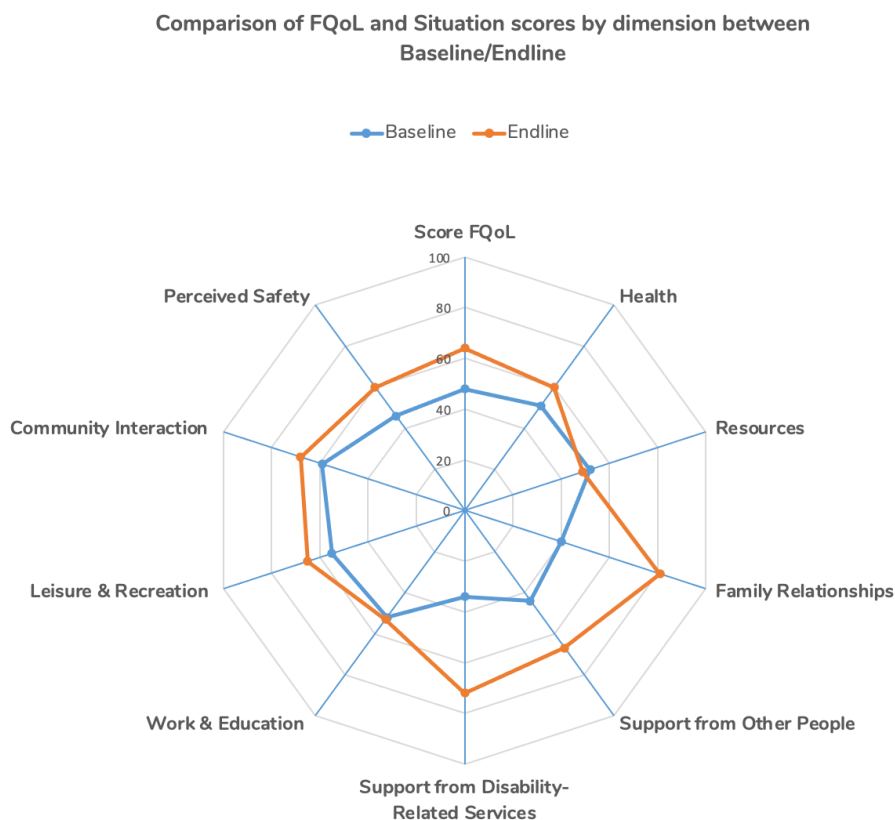
$$= ((\text{endline score} - \text{baseline score}) / \text{baseline score}) \times 100.$$

Example : (fictive numbers)

FQoL Score Baseline = 48

FQoL Score Endline = 64

- Option 1 : progression in points = $64 - 48 = 16$ points
- Option 2 : progression in % = $((64 - 48) / 48) \times 100 = 33,3 \%$



| Situation | Baseline | Endline |
|--|----------|---------|
| Health | 51 | 60 |
| Resources | 52 | 49 |
| Family Relationships | 40 | 81 |
| Support from Other People | 44 | 67 |
| Support from Disability-Related Services | 34 | 72 |
| Work & Education | 52 | 53 |
| Leisure & Recreation | 55 | 65 |
| Community Interaction | 59 | 68 |
| Perceived Safety | 46 | 60 |
| Score FQoL | 48 | 64 |

Analysis: The FQoL score increased by 33.3% compared to the beginning of the project. All dimensions (especially family relationships and support from disability-related services) improved, except for Resources, which deteriorated a little, while Work & Education remained stable. While the project’s intervention axes have focused on economic inclusion, the results are not very satisfactory. New areas of intervention will have to be developed in the next phase around economic inclusion and inclusive education/training.

For a deeper analysis

The proposed matrices only establish whether there have been changes over time. Statistical tests for establishing whether or not the changes observed are significant have not been integrated into the spreadsheets.³¹

- **Analysis by gender, age, disability status or location**

However, the data gathered can be used for other analyses, such as gender, type of disability or locality, for example. These analyses are not automatic, but can be made using statistical analysis software with the two “Data” sheets.

- **Analysis according to the “Opportunities” and “Initiative” indicators**

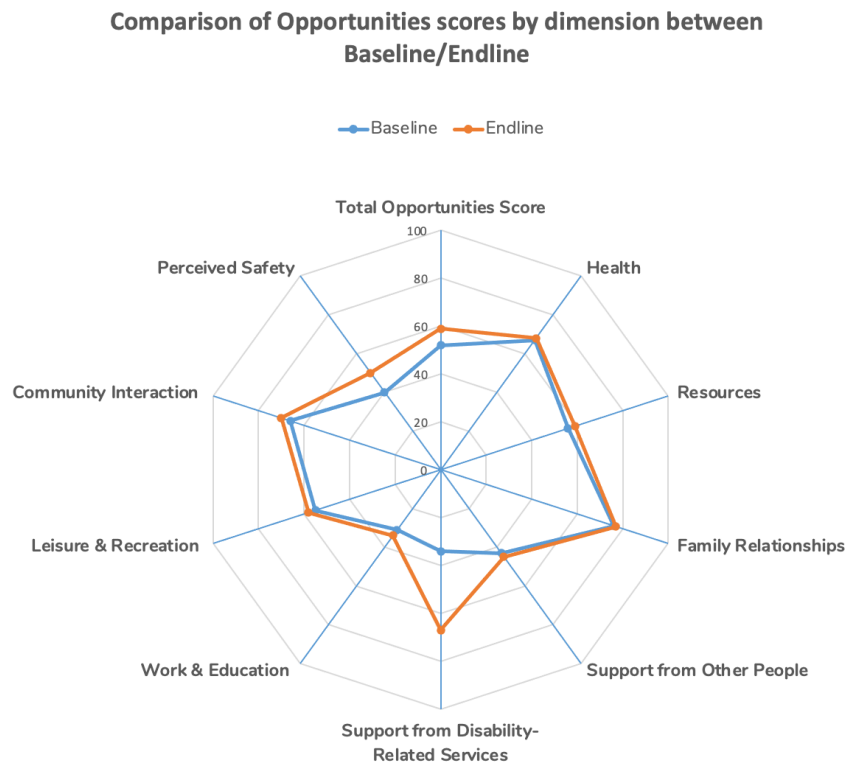
If at baseline, a dimension has a high score, there may not be much room for improvement. In this case, the interpretation of the comparison between baseline and endline scores should acknowledge a potential ceiling effect with that population rather than necessarily conclude that the intervention had little impact.

The additional interest of the ScoPeO-Family questionnaire is to have a more detailed analysis of the FQoL score by also measuring the “Opportunities” and “Initiative” scores, as determining

³¹ Chi-square tests could be used to demonstrate that the observed changes over time are significant. A difference is generally considered to be "statistically significant" if the probability p, i.e. the probability that the observed difference is due to chance alone, does not exceed 5%.

factors. Indeed, the “Opportunities” indicator allows us to see how the external environment influences the quality of family life, while the “Initiative” indicator measures the involvement and efforts of families during the project. It will be important to understand why families do not take the initiative to access opportunities.

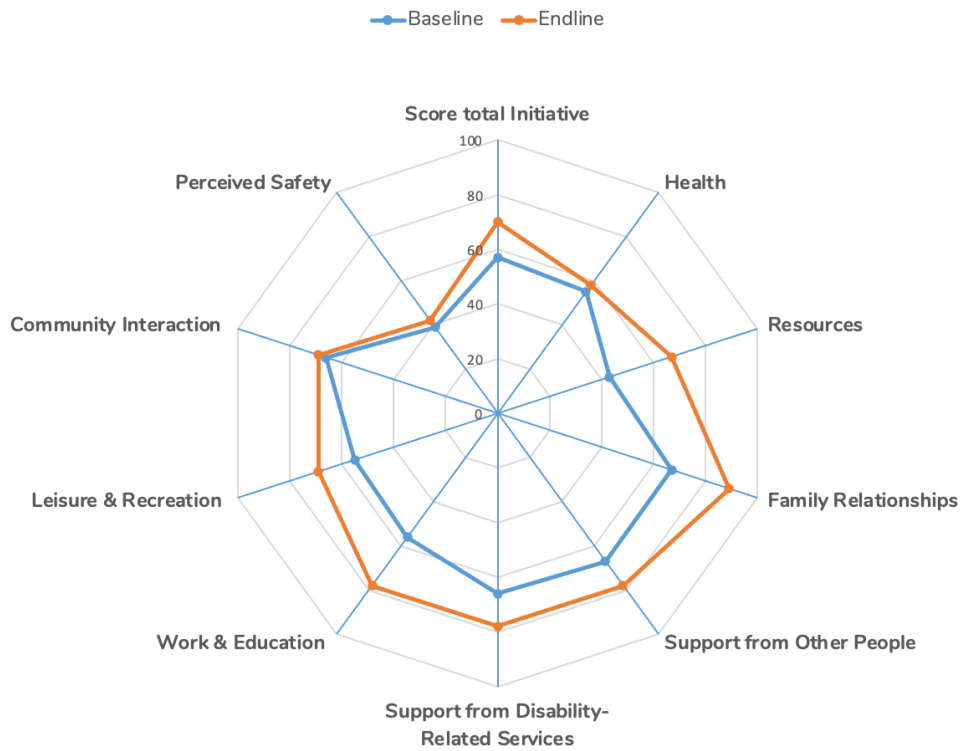
Example : (fictive numbers)



| | Opportunities Scores | |
|---|----------------------|---------|
| | Baseline | Endline |
| Total Opportunities Score | 52 | 59 |
| Health | 67 | 68 |
| Resources | 56 | 59 |
| Family Relationships | 76 | 77 |
| Support from Other People | 43 | 45 |
| Support from Disability-Related Services | 34 | 67 |
| Work & Education | 31 | 34 |
| Leisure & Recreation | 55 | 58 |
| Community Interaction | 66 | 70 |
| Perceived Safety | 40 | 50 |

➔ The “Opportunities” score increased slightly over the course of the project (+7 points). But it should be noted that families had more opportunities in the areas of support from disability-related services, meaning that the project (or other factors) had a positive effect in this domain. In contrast, opportunities scores in the other dimensions remained stable.

Comparison of Initiative scores by dimension between Baseline/Endline



| | Scores Initiative | |
|---|-------------------|---------|
| | Baseline | Endline |
| Score total Initiatives | 57 | 70 |
| Health | 55 | 58 |
| Resources | 43 | 67 |
| Family Relationships | 67 | 89 |
| Support from Other People | 67 | 78 |
| Support from Disability-Related Services | 66 | 78 |
| Work & Education | 56 | 78 |
| Leisure & Recreation | 55 | 69 |
| Community Interaction | 66 | 69 |
| Perceived Safety | 39 | 42 |

➡ The “Initiative” score increased significantly (+13 points). We can see that families made more effort in the areas of resources, work & education, and family relationships. In contrast, in the domains of community interaction, safety, and health, families’ effort remained stable.

- **Analysis by “importance” and “perceived FQoL” indicators**

Finally, the ScoPeO-Family questionnaire asks whether the three most important dimensions of family quality of life reported by baseline recipients have changed over the course of the project, and possibly identifies other dimensions.

The final question collects the overall impression of the family’s overall quality of life, on a 5-point scale ranging from “Very Poor” to “Very Good” and then scaled out to 100.

This perceived FQoL score can be related to the FQoL score calculated on the basis of the 9 dimensions to critically analyse the results obtained from the questionnaire.

Propose an interpretation of the findings

Any changes revealed by the study are partly due to HI’s activities, but other, unknown external factors may also contribute. Results should therefore be interpreted taking account of an analysis of the context in which HI is operating. Additional activities can also be undertaken to refine this analysis, such as **focus groups for beneficiary feedback**³² on the study results and discussions on the causes of the changes observed. Specific tools such as the “**Impact Grid**” (INTRAC)³³ that allow beneficiaries to identify positive and negative changes effected by the project/program and consider their causes can be used during these focus groups.

2. Drafting the study report

The study is leveraged primarily via the drafting of a final report presenting its main results, i.e. the changes observed and areas for improvement. A summary presents the context, method used, changes and conclusions for more extensive distribution of results.

To promote learning across the organisation, it is advisable to share the experience of implementing the study with the MEAL Unit by filling out a [learning paper](#) describing the main features of the study (country, project, length, cost, sample size), main results and issues encountered.

➡ Use the [ScoPeO baseline](#) and [ScoPeO endline](#) report templates as a guide.

3. Results dissemination

Audience

Conducting a study involves collecting, analysing and interpreting data, but also writing a report to communicate the results. Within the framework of HI projects, four types of audience may be

³² Cf. Access to e-learning on how to conduct inclusive focus groups: <https://hiacademy.hi.org/paths/63341c2737779c603e1bfafb/home>

³³ Cf. <https://www.intrac.org/wpcms/wp-content/uploads/2017/01/Impact-grids.pdf>

interested in conclusions drawn from studies of project effects on quality of life, perception of safety and participation in society and family life. First and foremost, **beneficiaries** who participated in the study must have access to the results as well as the partners and other entities that helped to implement the project. The study is also intended for **funding bodies** wishing to have information on the impact of the projects they fund. Lastly, HI's **MEAL Unit** within 3I Division monitors use of the ScoPeo-Family tool by collating the various experiences.



Care must be taken that the results made available to these different audiences are understandable and accessible to all those involved.

4. Consideration of the results for an action plan

The conclusions of the ScoPeo-Family survey allow the team to define an action plan for the future.



Key points

The five main criteria for successful use of ScoPeO-Family:

- The goals of the study must be clear and carefully defined;
 - Feasibility (human and financial resources) must be evaluated prior to the survey;
 - The methodology must be applied strictly and methodically;
 - An interpretation is completed at the end to link the scores obtained in the population being studied with the project's context and goals;
 - A written report is completed at the end of the survey and reports made to internal and external stakeholders, including beneficiaries concerned by the study.
-

Part 6 - Conclusion

The experimental research conducted within DPCP Project (Mali Program) has made it possible to develop a new tool for measuring family quality of life, inspired by the most recent research, which we have named **ScoPeO-Family**. The conclusive results of this field study are all the more interesting since little academic research has been conducted until now in vulnerable or low-income contexts.

This field survey of about 30 families in Bamako, and to a lesser extent in Sikasso, allowed the development of a prototype FQoL questionnaire that was adapted to the needs of the DPCP Project. This model questionnaire could be adapted to the needs of other HI projects, in other cultural or intervention contexts. We are thinking in particular of projects for which the ScoPeO-Kids tool is not adapted, for example, projects that reach a very young public (less than 5 years old), such as in the Early Childhood Development or Inclusive Education, which works on pre-school.

ScoPeO-Family complements the ScoPeO toolkit for measuring individual quality of life. This tool is fully integrated into the **social model of disability** supported by HI. Indeed, it brings a **multidimensional and holistic dimension to disability** by focusing on the whole family, with a view to **empowering** all its members, including the child with an intellectual disability.

ScoPeO-Family is a comprehensive family quality of life measurement instrument that collects quantitative and qualitative data. In addition to its global orientation, this tool is based on a lifelong approach and can therefore be used by families of children, youth, adults and seniors with or without disabilities. Above all, ScoPeO-Family **fills a gap** in the measurement of the quality of life of special needs populations, in particular of children with an intellectual disability who cannot express themselves.

The implementation of a ScoPeO-Family survey follows the same procedures and requirements as ScoPeO-Adults & Kids. The FQoL score matrix was constructed with the same logic so that HI teams could more easily appropriate ScoPeO-Family.

The FQoL survey in Mali was an opportunity to compare the perception of fathers and mothers and to better understand the division of labor that takes place within Malian families. Thus, it can be said that the mother is best placed to answer the questionnaire and the intervention must also be focused on her, especially through IGAs, as she is often the main support person for the child with an intellectual disability. The burden carried by mothers also has an impact on their mental health, which must become a more important axis of intervention in the projects. We have observed that daughters (sisters) are often in danger of not going to school or leaving school to care for the child with intellectual disabilities.

The results of this field survey show that the FQoL survey is also an interesting project monitoring tool and can be integrated with existing tools. For example, the first part of the questionnaire, which is composed of socio-demographic questions, can be carried out within the framework of care or follow-up interviews of the beneficiaries. The second part of the

questionnaire is carried out by a team of external interviewers, which reduces the time required to complete the questionnaire to about 30 minutes.

The user guide was designed to help HI teams use ScoPeO-Family and adapt it to their projects. However, this FQoL questionnaire remains a prototype that needs to be tested on a larger scale and in other HI's cultural and intervention contexts.

Abbreviations and acronyms

AC5: Accord-Cadre 5

AMALDEME: Association Malienne de Lutte contre les Déficiences Mentales chez l'Enfant

AMT21: Association Malienne de la Trisomie 21

ASD : Autism Spectrum Disorder

COFIL: Steering Committee

CNAOM: Centre National d'Appareillage Orthopédique du Mali

CRIR: Centre de Recherche Interdisciplinaire en Réadaptation

DPO: Disabled People's Organisation

FGD: Focus Group Discussions

FEMAPH: Fédération Malienne des Associations de Personnes Handicapées

FQoL : Family Quality of Life

BC FQOLS : Beach Center Family of Life Scale

FQOLS-2006 : Family Quality of Life Survey-2006

IGA: Income Generating Activities

MCH : Maternal and Child Health

MEAL : Monitoring, Evaluation, Accountability, and Learning

PSS : Personalised Social Support

QoL : Quality of Life

ScoPeO : Score of Perceived Outcomes

SLDSES : Local services of solidarity economy and social development

TIGA : Toward sustainable Income Generating Activities

Bibliography

- Alnahdi G.H., Alwadei A., Woltran, F., Schwab S. Measuring Family Quality of Life: Scoping Review of the Available Scales and Future Directions. *Int. J. Environ. Res. Public Health*. 2022, 19, 15473.
- Beach Center on Disability. Beach Center Family Quality of Life Scale: Psychometric Characteristics and Scoring Key. University of Kansas, 2015.
- Brown I. et al. Family Quality of Life Survey: Main caregivers of people with intellectual disabilities. Toronto, Canada: Survey Place Centre, 2006.
- Brown, R. I., MacAdam-Crisp, J., Wang, M., & Iarocci, G. Family quality of life when there is a child with a developmental disability. *Journal of Policy and Practice in Intellectual Disabilities*. 2006, 3(4), 238–245.
- Brown I, Hatton C, Emerson E. Quality of life indicators for individuals with intellectual disabilities: extending current practice. *Journal of Intellectual & Developmental Disability*. 2013, 51(5), 316-32.
- Brus A., Higgins J., Poissant L. ScoPeO-Kids : Un outil pour mesurer la qualité de vie des enfants âgés de 5 à 17 ans. Guide méthodologique. Handicap International, 2018 - Mise à jour 2019.
- Butler K. Family Quality of Life in Practice: A Practical Application of the FQOL-2006 Survey. *International Journal of Child, Youth and Family Studies*. 2018, 9(4), 40–48
- Chaume A., Ilg J., Clément C. Comparaison de la qualité de vie familiale de parents français ayant ou non un enfant avec un trouble du spectre de l'autisme. *Revue Francophone de la Déficience Intellectuelle, Revue francophone de la déficience intellectuelle*, 2019, 29, 36-45.
- Cummins R. A., Comprehensive Quality of Life Scale - Intellectual / Cognitive Disability, Fifth edition (ComQoL-15), School of Psychology, Deakin University, Melbourne, 1997.
- Cummins, R. (2005) Moving from the quality of life concept to a theory, *Journal of Intellectual Disability Research*, 49.10, 699-706.
- Crowley S. L., & Taylor M. J. Mothers' and fathers' perceptions of family functioning in families having children with disabilities. *Early Education and Development*. 1994, 5(3), 213-225.
- Davidson G., Irvine R., Corman M., Kee F., Kelly B., Leavey G., & McNamee, C. Measuring the Quality of Life of People with Disabilities and their Families: Scoping Study Final Report. Department for Communities, 2017. <https://www.communities-ni.gov.uk/publications/measuring-quality-life-disabled-people-and-their-families-scoping-study-final-report>
- Gómez L.E. et al. A new scale for the measurement of quality of life in children with intellectual disability. *Research in Developmental Disabilities*. 2016, 53-54, 399-410.
- Haelewyck Marie-Claire. La mesure de la qualité de vie : concepts, outils et usages, 4ème rencontre scientifique de la CNSA pour l'autonomie, 12-13 décembre 2016

Heusse C. La qualité de vie : un indicateur pertinent pour l'évaluation d'impact des programmes d'intervention de Handicap International, EHESP, Mémoire de Master 2 Situation de handicap et participation sociale, Université de Rennes 1, Septembre 2014.

____ Évaluation de la qualité de vie de l'enfant IMC en Afrique subsaharienne francophone, dans le cadre des missions de Handicap International : analyse de l'outil DisabKids et proposition de recommandations pour adaptation ". Mémoire de Master 2, Université de Rennes 1, Septembre 2014.

Hoffman L., Marquis J., Poston D., Summers J. A., & Turnbull A. Assessing family outcomes: Psychometric evaluation of the beach center family quality of life scale. *Journal of Marriage and Family*. 2006, 68(4), 1069-1083

Isaacs B. J., et al. The international family quality of life project: Goals and description of a survey tool. *Journal of Policy and Practice in Intellectual Disabilities*. 2007, 4(3), 177-185.

Jansen-van Vuuren, J., Lysaght R., Batorowicz B., Dawud S., Aldersey H.M. Family Quality of Life and Support: Perceptions of Family Members of Children with Disabilities in Ethiopia. *Disabilities*. 2021, 1, 233–256.

Karthikayini Sasinthar et al. Measuring health-related quality of life of intellectually disabled children: a narrative review. *International Journal of Community Medicine and Public Health*. July 2021, 8(7), 3652-3656.

Missoten P., Etienne A-M., Dupuis G. La qualité de vie infantile : état actuel des connaissances " *Revue francophone de Clinique Comportementale et Cognitive*. 2007;12(4), 14-27.

Nunes AC, Luiz EAM, Barba PCSD. Family quality of life: an integrative review on the family of people with disabilities. *Cien Saude Colet*. 2021 Jul, 26(7), 2873-2888.

Park J. et al. Toward assessing family outcomes of service delivery: Validation of a family quality of life survey. *J. Intellect. Disabil. Res*. 2003, 47, 367–384.

Perry A., Isaacs B. Validity of the Family Quality of Life Survey-2006. *J Appl Res Intell Disabil*. 2015, 28, 584–8.

Reichman N. E., Corman H., & Noonan K. Impact of child disability on the family. *Matern Child Health J*. 2008, 12(6), 679-683.

Rivard, M. et al. Psychometric Properties of the Beach Center Family Quality of Life in French-Speaking Families With a Preschool-Aged Child Diagnosed With Autism Spectrum Disorder. *American Journal on Intellectual and Developmental Disabilities*, 122(5), 439-452, September 2017.

Samuel PS, Rillotta F, Brown I. The development of family quality of life concepts and measures. *Journal of intellectual disability research*. 2012, 56(1), 1–16.

Samuel PS, Tarraf W, Marsack C. Family Quality of Life Survey (FQOLS-2006): evaluation of internal consistency, construct, and criterion validity for socioeconomically disadvantaged families. *Phys Occup Ther Pediatr*. 2018, 38, 46–63.

Tan Danielle. Etre fille & handicapée en Afrique de l'Ouest. La situation éducative en question. Mali, Niger, Burkina Faso. Handicap International, 2020. <https://genrehandicapao.hubside.fr>

Terzi, L. The social model of disability: A philosophical critique. *Journal of applied philosophy*. 2004, 21(2), 141-157.

Tessa Anne van Boekholt. Quality of Life of Nepalese Families Living with a Child with a Disability: a Qualitative study, Faculty of Health, Medicine and Life Sciences, Master Global Health, Maastricht University, August 2016

Upshur, C. C. Mothers' and fathers' ratings of the benefits of early intervention services. *Journal of Early intervention*, 1991, 15(4), 345-357.

Vallerand, R. J. Vers une méthodologie de validation trans-culturelle de questionnaires psychologiques: Implications pour la recherche en langue française. *Canadian Psychology/ Psychologie Canadienne*. 1989, 30(4), 662.

Verdugo M. A., et al. Quality of life and its measurement: important principles and guidelines, *Journal of Intellectual Disability Research* 49. 2005, 707 – 717.

Zuna N., Summers J., Turnbull A., Hu X., Xu S. Theorizing about family quality of life. Enhancing the quality of life of people with intellectual disabilities: From theory to practice. In: Kober R., ed. *Enhancing the quality of life of people with intellectual disabilities*. Dordrecht: Springer, 2010, 241–78.

The ScoPeO-Family Toolbox

Part 1. Socio-demographic information & Part 2. The FQoL questionnaire

The FQoL score matrix (work in progress)

Appendices

Appendix 1. Revised Beach Center FQOLS for DCPC Project - Mali

Appendix 2. Final version of the FQOLS-2006 abridged and adapted to the DPCP Project

Appendix 3. Profile and scores of the 10 families

Appendix 4. Consent Form

Appendix 5. FGD Guideline for Parents of Children with Multiple Disabilities, Down Syndrome and Epilepsy



ScoPeO-Family: An alternative approach to measuring the quality of life of special needs populations

An exploratory research conducted within DPCP Project
Mali Program

This document presents the results of the study conducted in Mali to measure the quality of life of children with multiple disabilities, Down syndrome and epilepsy.

This experimental research conducted within DPCP project has made it possible to develop a new tool for measuring family quality of life, inspired by the most recent research, which we have named ScoPeO-Family. This FQoL questionnaire, developed as a prototype in Mali, can be adapted to the needs of other HI projects, in other cultural or intervention contexts.

ScoPeO-Family completes the ScoPeO toolkit for measuring individual quality of life. This tool is fully integrated into the social model of disability promoted by HI. Indeed, it brings a multidimensional and holistic dimension to disability by focusing on the whole family, with a vision of empowerment of all members, including the child with an intellectual disability.

A user guide illustrates how to use ScoPeO-Family and how to adapt the questionnaire to projects. This guide is intended for all Humanity & Inclusion professionals, and more specifically for those in charge of developing, implementing, monitoring and evaluating projects. HI's partners can also make use of this guide.

Humanity & Inclusion
138 avenue des Frères Lumière
69371 Lyon cedex 08
France
publications@hi.org

