



Resources to Support Marginalized Caregivers of Children with Disabilities: Guidelines for Implementation

April 2022

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Contents

1. Introduction	5
1.1. Project rationale	5
1.2. Approach and content of the resources	8
1.3. Supporting caregivers as part of an inclusive education system	9
2. Case Studies: Proof-of-Concept Pilots	11
2.1. Overall approach	11
2.2. Country partnerships	11
2.3. Armenia pilot	12
2.4. Uzbekistan pilot	13
2.5. Findings	14
2.6. Revisions to resources based on lessons learned	15
3. Recommendations: Steps to adopt resources	17
3.1. Step 1: Engage stakeholders to align resources with existing support	17
3.2. Step 2: Adaptation of resources	19
3.3. Step 3: Planning and implementing a pilot	20
3.4. Step 4: From pilot to scaled-up implementation	21

Summary

Support from caregivers¹ is critical for children's learning both at home and at school. However, the COVID-19 pandemic and disruption of education systems globally created additional expectations for parents to support their children's learning at home. This particularly affected the most marginalized children as the crises exacerbated already existing inequalities in education. The ability to respond to the shock varied, depending on household income. Children from disadvantaged families were less likely to benefit from learning than their peers, due to a lack of Internet connectivity and devices, caregivers' support (or both).² Students with disabilities have been disproportionately excluded as remote learning methods were not adequately tailored to their needs.³

This document describes the development and piloting of a set of resources to support marginalized caregivers of children with disabilities to engage with an emerging inclusive education system and support their children's learning at home. The resources comprise:

- **Caregivers' Guide to Inclusive Education:** informing parents and caregivers of their children's rights to inclusive education, helping them to identify their children's needs and to find ways to solve the challenges they face.
- **Teacher Guide to Supporting Marginalized Caregivers of Children with Disabilities:** how teachers can support marginalized caregivers of children with disabilities to identify their children's needs, find solutions for the challenges they face, and incorporate this engagement in their own teaching practice.
- **School Guide to Supporting Marginalized Families of Children with Disabilities:** how school leaders and specialists can support teachers and caregivers in working together.
- **Workbook of Tools to Support Caregivers of Children with Disabilities:** helping caregivers, teachers and school staff to further engage in the topics raised in their respective guides and apply them to their specific circumstances.
- **Directory of Resources to Support Caregivers of Children with Disabilities:** descriptions of, and links to, freely available resources, information and materials for caregivers, teachers and schools to be used to support children with disabilities with inclusive learning.
- **Directory of Associations and Organizations Supporting Caregivers of Children with Disabilities:** a list of local associations that can connect caregivers with one another and provide further support.

The document also describes four key steps for education ministries or other education system leaders who seek to adopt the resources for their context:

1. **Engage stakeholders** to align resources with existing programming, embedding and incorporating understanding of existing services, networks and structures supporting marginalized caregivers of children with disabilities, and encouraging ownership.
2. **Adapt the resources** for use in the specific context by reviewing and revising contextual information, definitions and translations and existing resources and supports.
3. **Plan and implement a pilot** to collect data and feedback from schools, teachers and caregivers on their experience with the resources. In absence of existing measurements of the intersection of disability and marginalization, use data sources beyond the education sector.
4. **Use lessons from the pilot** for large-scale dissemination and uptake.

The pilot findings highlight the value of the interaction between school, teachers and caregivers to compensate for socio-economic barriers. They also underline the importance of understanding the overlapping deprivation of marginalized caregivers to children with disabilities requires in designing resources.

1 Throughout this document, the term 'caregivers' is used to refer to parents and other adults who regularly provide care for a child, including grandparents, older siblings, other relatives and paid carers.

2 Azevedo, Joao Pedro Wagner De, The State of the Global Education Crises, A Pathway to Recovery, World Bank Group, Washington DC, 2021, p. 6.

3 Ibid., p. 23

1. Introduction

These guidelines have been compiled for education ministries or other educational leaders (including development partners, non-governmental or private organizations working with schools or directly with caregivers) who want to adapt and adopt resources to support the marginalized caregivers of children with disabilities.

The guidance presented in this document was developed by a team of international and national experts following a proof-of-concept pilot⁴ of the resources in two countries. The work was carried out between February 2021 and January 2022. The pilots demonstrated that principles and activities described in the resources could be carried out, in practical terms, in line with existing government programmes supporting the implementation of disability-inclusive education.

This section introduces the approach and purpose of these resources. It will be followed by case studies from the proof-of-concept pilots in Armenia and Uzbekistan, including lessons learned, and then step-by-step guidelines on how to implement the resources for education ministries and others who want to include them in their education system.

The project to develop these guidelines and resources focuses on the intersection between disability and other forms of marginalization due to socioeconomic status (see Box 1 for a discussion on this concept of overlapping deprivations).

1.1. Project rationale

Support from parents and caregivers⁵ is critical for children's learning both at home and at school. Studies have identified that parental expectations and aspirations for their child have the strongest relationship with children's achievement at school, followed by communication such as showing interest in homework, aiding with homework and discussing school progress.⁶ The routine of family life can produce predictable boundaries, encourage productive use of time and provide learning experiences as a regular part of daily life.⁷

Marginalized children such as those from poor families or with less educated parents face additional challenges and are less likely to receive these forms of learning support at home.^{8, 9, 10}

The COVID-19 pandemic has disrupted education systems globally and compounded the challenges faced by children from marginalized families. The loss of income, as well as a lack of resources and lack of connectivity and devices have also been barriers.

4 These small-scale pilots were aimed not at answering questions about the impact of the resources but to test their feasibility and acceptability in supporting caregivers of children with disabilities through their schools. This is discussed further in Section III.3.

5 Throughout this document, the term caregivers is used to refer to parents and other adults who regularly provide care for the child including grandparents, older siblings, other relatives and paid carers.

6 Hattie, John, *Visible Learning: A synthesis of over 800 meta-analyses relating to achievement*, Routledge.

7 Redding, Sam, *Parents and Learning. Educational Practices Series*. International Bureau of Education, Geneva, 1997.

8 Brossard, Matt et al., *Parental Engagement in Children's Learning*, Education Innocenti Research Brief 2020-09, UNICEF Office of Research – Innocenti, Florence, 2020.

9 Sirin, Selcuk, R. 'Socioeconomic Status and Academic Achievement: A Meta-Analytic Review of Research', *Review of Educational Research*, Vol. 75, no. 3, 2005, pp. 417–453.

10 *Education Pathways in Roma Settlements*.

Box 1: Multidimensional poverty – education, disability and data scarcity

Disability is intertwined with both monetary and multidimensional poverty, with lifelong consequences for children with disabilities. ^a Children with disabilities are more at risk of experiencing chronic poverty and social exclusion throughout their lives. Worldwide, two thirds of those experiencing multidimensional poverty are living in middle income countries, although there are a wide range of differences between countries and between national and subnational levels. ^b Multidimensional poverty encompasses the various deprivations experienced by poor people in their daily lives – such as poor health, lack of education, inadequate living standards, disempowerment, poor quality of work, the threat of violence, and living in areas that are environmentally hazardous.

Disaggregated data-collection and analysis is needed to help understand and address equity issues among children with disabilities, using tools such as the Washington Group of Questions, the Multiple Indicator Cluster Survey (MICS) and the Multidimensional Overlapping Deprivation Assessment (MODA) for child poverty, in order to gather better and highly disaggregated information on children with disabilities. ^{c, d, e} The multidimensional poverty index (MPI) is a measure used by more than 100 countries.

It measures the product of incidence of poverty (who are identified as poor on the basis of the multiple deprivations they experience) and the intensity of poverty (how poor people are). ^f The MPI captures acute deprivations in health, education and living standards, with children’s access to education forming one-sixth of the measure and adult household members’ completion of primary education forming another one-sixth. ^g

The opportunity gap in students’ contextual conditions, rather than individual behaviours, explains large disparities in student achievement. ^{h, i} The study of education attainment and socioeconomic factors has long featured in education sociology research. ^{j, k} A growing number of studies is accumulating evidence that parents’ educational attainment is a powerful predictor of children’s cognitive and academic outcomes, through parental beliefs, parental behaviours and child outcomes. ^{l, m, n} Parents’ occupation and income are well-known predictors of child outcomes. However, children’s academic success also hinges indirectly on parents’ beliefs about, and expectations for, their children as well as on the cognitive stimulation that parents provide. ^o

This recognizes the multidimensional nature of poverty and the multiplying effects of overlapping risk factors; for example, that the socioeconomic situation adds to other causes of marginalization such as disability. Families raising children with disabilities are more vulnerable to poverty due to associated costs and lost earning opportunities from additional care responsibilities. Data on this issue are scarce, but what is available indicates that people with disabilities and households with a disabled member are more likely to experience multidimensional poverty than those without. ^{p, q}

Children with disabilities who are enrolled in mainstream schools are likely to be more advantaged (both in terms of having milder forms of disability and in socioeconomic terms), while many are either enrolled in special schools or out of the education system entirely, particularly in new or emerging disability-inclusive education systems. This point needs to be recognized and highlights the importance of purposeful targeting and inclusion in the pilot to ensure a broad range of contexts and experiences are represented.

A key issue in identification is the availability of data. Linking data across different databases and sources may be needed to identify and reach the most marginalized children with disabilities. Where the Education Management Information System (EMIS) does not contain information on children’s disability or socioeconomic status, other data sources include those held by the ministry department responsible for supporting such children or agency (such as a social welfare ministry) that has data on households receiving social support. Another option is to use school-, household- or community-based surveys held by government and non-government agencies in order to identify communities with high numbers of marginalized families and, in turn, the schools that serve them. Examples of how this was done in the pilot studies can be found in Section II.

References

- a. United Nations Children’s Fund, *Inclusive social protection systems for Children with Disabilities in Europe and Central Asia, Social Protection Regional Issue Brief: 3*, UNICEF, October 2019, p. 2.
- b. United Nations Development Programme and Oxford Poverty and Human Development Initiative, *Global Multidimensional Poverty Index 2020, Charting pathways out of multidimensional poverty: Achieving the SDGs*, UNDP and OPHI, 2020.
- c. *Inclusive social protection systems*, p. 9
- d. The 2018 UNICEF Formative evaluation of Out-of-school-children (OOSC) acknowledged that the availability of robust and reliable data was highly inconsistent, due mostly to limitations in financial and human resources capacities for data collection, data analysis, data interpretation, and related processes. ‘A robust contribution analysis to explain the factors that account for reductions in the number of out-of-school children is both methodologically possible, and necessary to sustain the evaluability of OOSC Initiative.’ United Nations Children’s Fund, *Formative evaluation of the Out-Of-School-Children Initiative (OOSCI)*, UNICEF Evaluation Office, 2018.
- e. Multidimensional Overlapping Deprivation Assessment, MODA.
- f. *Global Multidimensional Poverty Index 2020*, p.6. The robustness of MPI can be used for comparisons across countries or regions of the world, as well as for within-country comparisons between subnational regions, rural and urban areas, different age groups, and other key household demographics such as ethnicity, religion, and household headships.
- g. *Global Multidimensional Poverty Index 2020*, p. 29. The report makes specific reference to education inequalities, as intersectional analysis is necessary to address SDG target 4.5 because individuals experience poverty as overlapping sources of disadvantage.
- h. Niazi, Muhammad Imran and Atta Ullah Khan, ‘The Impact of Education on Multidimensional Poverty across the regions in Punjab’, *Journal of Elementary Education* Vol. 21, no. 1 pp. 77–89, January 2012.
- i. Davis-Kean, Pamela E., Lauren A. Tighe and Nicholas E. Waters, ‘The Role of Parent Educational Attainment in Parenting and Children’s Development’, *Current Directions in Psychological Science*, Vol. 30, no. 2, pp. 186–192. December 28, 2020, p. 5.
- j. Coleman, James S. et al., *Equality of educational opportunity*. U. S. Government Printing Office, Washington, D. C., 1966.
- k. Halsey, A. H., A. F. Heath and J. M. Ridge, *Origins and Destinations: Family, Class and Education in Modern Britain*, Oxford University Press (Clarendon), Oxford, 1980.
- l. Davis-Kean, Pamela E, “The Influence of Parent Education and Family Income on Child Achievement: The Indirect Role of Parental Expectations and the Home Environment”, *Journal of Family Psychology*, 19(2), 294–304, 2005
- m. David-Kean, Pamela E., Lauren A. Tighe & Nicholas E. Waters, “The Role of Parent Educational Attainment in Parenting and Children’s Development”, *Current Directions in Psychological Sciences*, 30(2), 2021
- n. United Nations Children’s Fund, *Education Pathways in Roma Settlements: Understanding Inequality in Education and Learning, Findings from MICS6 in Kosovo*, Montenegro, North Macedonia and Serbia*, UNICEF, Geneva, January 2022. This study shows the patterns of multidimensional deprivations are very clear. The result of MICs data shows that risk of school exclusion decreases if parents complete secondary or higher education.
- o. *Ibid.*, p. 12.
- p. Pinilla-Roncancio, Mónica et al., ‘Multidimensional poverty and disability: A case-control study in India, Cameroon, and Guatemala’, *SSM – Population Health*, Vol. 11. August 2020.
- q. Banks, Lena M., et al, ‘Does disability increase the risk of poverty in all its forms?’ Comparing monetary and multidimensional poverty in Vietnam and Nepal’, *Oxford Development Studies*, Vol. 49, no. 4.

The closure of schools for in-person learning highlighted caregivers' roles in supporting children's learning. The reliance on remote learning, largely online or through broadcast media, also compounds the existing challenges faced by marginalized caregivers of children with disabilities, including:¹¹

- the emotional burden of care, exacerbated by the level of family pressures including financial resources to address them (itself a challenge for marginalized families);
- extra demands such as being advocates for their and other children, managing transitions associated with schooling and accessing specialist services;
- the need to learn specialized skills, such as systematic behaviour-management techniques and the use of special equipment and assistive devices;
- the risk to losing connection to their community due to prevailing beliefs and misunderstandings about disability.

The multi layers of deprivations faced by marginalized caregivers of children with disabilities have been exacerbated by the pandemic. This guidance describes the purpose, approach and steps to implementing resources that were developed as compensatory measures to assist the caregivers of the most vulnerable children with their children's learning, in and outside their schools.

1.2. Approach and content of the resources

This guidance accompanies a set of resources to support marginalized families of children with disabilities. Because caregivers interact with their children, as well as interact and navigate many networks their children are part of – such as schools, other educational institutions, health and welfare services – it is important to create a support system at all levels to ensure that different actors have the necessary knowledge, skills and information and can collaborate on creating an effective support system. These resources were designed to assist caregivers, with the support of teachers and school staff to identify and advocate for their own needs. They are designed to be adapted to the specific context of the education system and to build on existing materials, tools and networks.

The resources are most effective if implemented at three levels, with some targeted at caregivers directly but also at teachers and schools to support caregivers. The set of resources, therefore, comprises:

- Caregivers' Guide to Inclusive Education: informing parents and caregivers of their children's rights to inclusive education, helping them to identify their children's needs and to find ways to solve the challenges they face.
- Teacher Guide to Supporting Marginalized Caregivers of Children with Disabilities: how teachers can support marginalized caregivers of children with disabilities to identify their children's needs, find solutions for the challenges they face, and incorporate this engagement in their own teaching practice.
- School Guide to Supporting Marginalized Families of Children with Disabilities : how school leaders and specialists can support teachers and caregivers in working together.
- Workbook of Tools to Support Caregivers of Children with Disabilities: helping caregivers, teachers and school staff to further engage in the topics raised in their respective guides and apply them to their specific circumstances.
- Directory of Resources to Support Caregivers of Children with Disabilities: descriptions of, and links to, freely available resources, information and materials for caregivers, teachers and schools to be used to support children with disabilities with inclusive learning.
- Directory of Associations and Organizations Supporting Caregivers of Children with Disabilities : a list of local associations that can connect caregivers with one another and provide further support.

These resources can be found as annexes to these guidelines and are open-source materials that can be adapted and adopted in any education system. They are, however, particularly valuable for emerging or newly established inclusive education systems

11 Adapted from Mitchell, David, 'What Really Works in Special and Inclusive Education: Using evidence-based teaching strategies' *Diversities in Education, Effective Ways to Reach All Learners*, Taylor and Francis, 2008, pp.69–70

1.3. Supporting caregivers as part of an inclusive education system

The resources are intended to empower and support caregivers in their contribution to an inclusive education system for children with disabilities, preparing them for their role as described in the Education Sector Analysis Methodological Guidelines chapter on disability-inclusive education,¹² in providing:

- expertise on the needs of children and support required
- support and partnership at the local and school level
- engagement in advocacy for the rights of children with disabilities.

In an inclusive approach to education, all children can learn together, in the same classroom. Making inclusive education a reality means reaching out to all learners, by eliminating all forms of discrimination. The commitment of “leaving no one behind” lies at the heart of the Education Agenda 2030 and the fourth United Nations’ Sustainable Development Goal (SDG4). Nevertheless, inclusive education is a complex process. It depends not only on supportive policies but, more broadly, on the cultural transformation of educational systems.

Children with sensory, physical, or learning disabilities are two and a half times more likely than their peers never to go to school.¹³ Those who also belong to another disadvantaged group are even more likely to miss out. Children and young people face multiple barriers to accessing education, including school infrastructure, learning materials that are not adapted for those with disabilities, and challenges connected with the management of education system. A lack of data monitoring and the social stigma surrounding people with disabilities can further hinder access.

Making education systems inclusive requires holistic thinking, improved education sector planning and taking a systems approach to create cultural change. As educational leaders are making steps towards more inclusive education systems, transforming mainstream education environments to ensure they address the needs of all children is more cost-effective than maintaining a segregated system of special schools. Ensuring that all learners benefit from good quality education also promotes social cohesion and a tolerance for diversity. Even when schools and the education system are prepared to welcome children with disabilities, several demand-side barriers may prevent the children from enrolling, attending and engaging, including the attitudes and beliefs of parents and caregivers.

The Framework for Disability-inclusive Education (Figure 1) helps with the analysis of an entire education system, from early childhood up to tertiary education, through a disability-inclusive lens. The 13 blocks of the framework provide an overview of the different aspects of an education system that need to be addressed to enable the inclusion of children with disabilities.¹⁴ They can be used as a planning checklist to consider what already exists in an education system and what remains to be considered in order to include children with disabilities in the education system.

The needs of marginalized caregivers of children with disabilities, as a component of the demand side of disability-inclusive education, interact with other aspects of the system, for example, the attitudes of teachers and administrators towards an inclusive education. Communicating regularly with marginalized caregivers of children with disabilities can also allow education system leaders to learn about the needs of children with disabilities when it comes to accessing curricula, which will enable them to set up appropriate in-classroom support, ensure access to, and within, school, understand any concerns with, or barriers to, the provision of learning support, assessment and screening as well as the availability and provision of assistive devices.

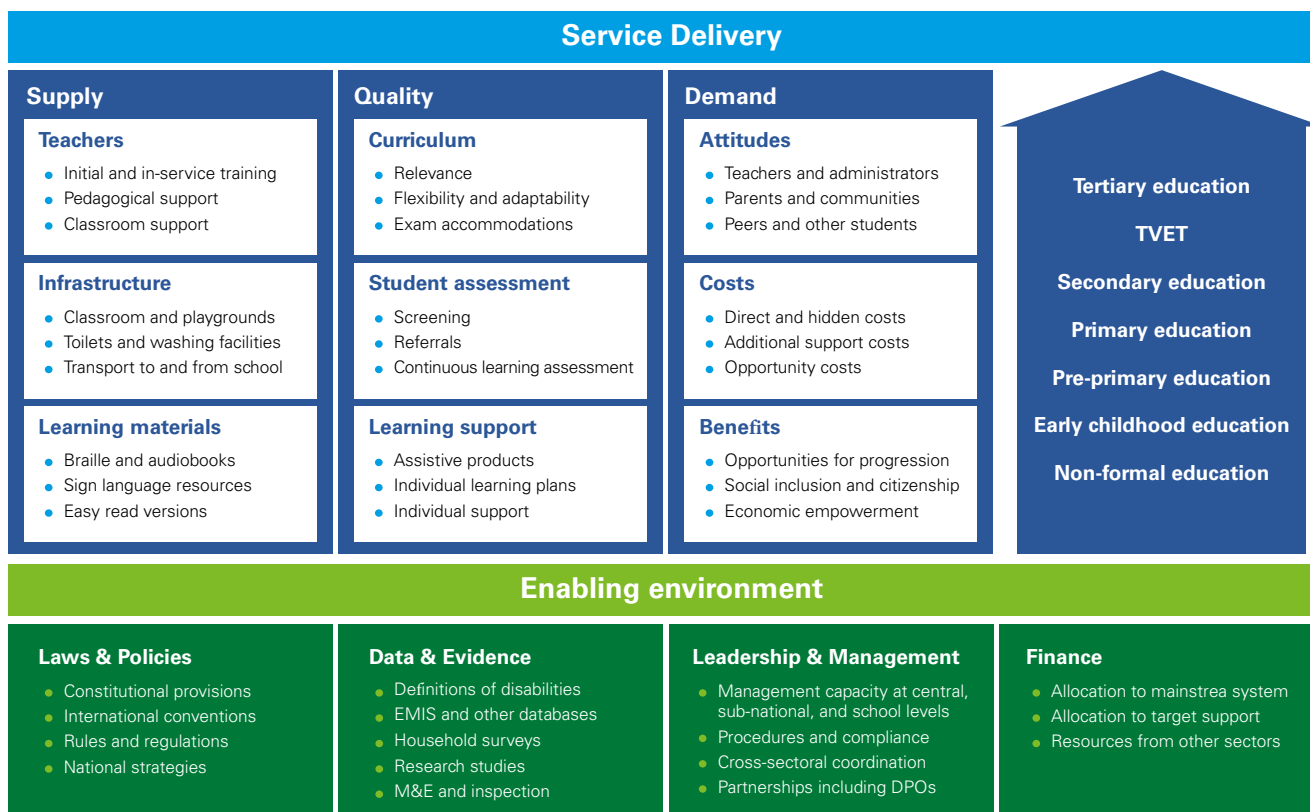
While the framework focuses on children with disabilities, it is expected that any improvements identified will benefit the participation and learning outcomes of all children, with or without disabilities.

12 United Nations Educational, Scientific and Cultural Organization, International Institute for Educational Planning, United Nations Children’s Fund, Global Partnership for Education and the Foreign, Commonwealth & Development Office, *Education Sector Analysis Methodological Guidelines Volume III, 2021*.

13 United Nations Educational, Scientific and Cultural Organization, *Global education monitoring report, 2020: Inclusion and education: all means all, 2020*.

14 *Education Sector Analysis Methodological Guidelines Volume III*

Figure 1. Framework for disability-inclusive education



Source: IIEP-UNESCO, UNICEF, Global Partnership for Education & the (UK) Foreign, Commonwealth & Development Office (2021). Education Sector Analysis Methodological Guidelines Volume III.

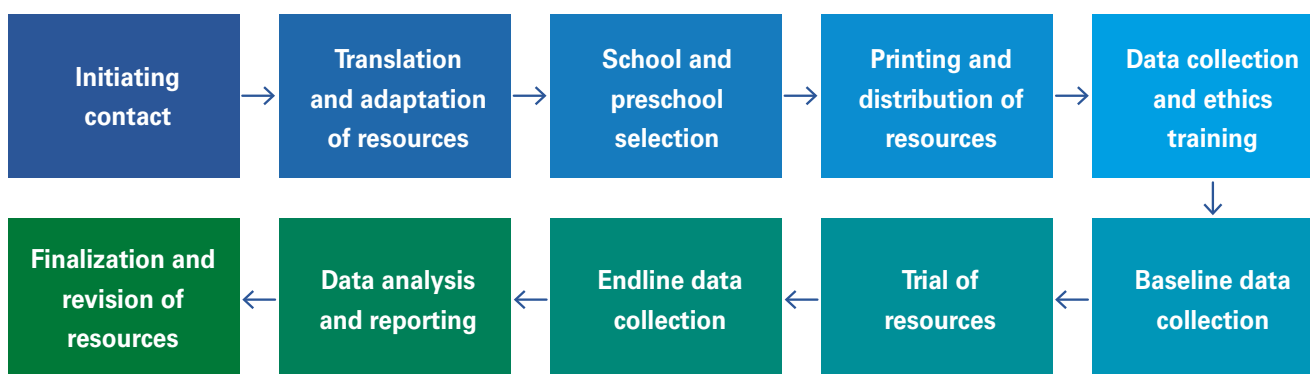
2. Case Studies: Proof-of-Concept Pilots

After prototypes of the resources were developed, they were tested in Armenia and Uzbekistan, both of which are Global Partnership for Education's (GPE) partner countries. In addition, UNICEF Tajikistan participated in the project as a peer review partner.

2.1. Overall approach

The overall pilot approach was similar in the two countries; the main stages are illustrated in Figure 2. The aim of these proof-of-concept pilots was to test the feasibility of using the resources to provide support for marginalized caregivers of children with disabilities as they engage with the education system, as well as to make improvements to the prototypes and to learn lessons on how they can be implemented. As to scope, a small number of schools and pre-schools were selected, with the focus being on collecting in-depth feedback from marginalized caregivers in schools and pre-schools that represent a diversity of contexts.

Figure 2. Main stages of the proof-of-concept pilots



Overall, 20 caregivers, 11 teachers and eight school representatives across eight schools in the two countries participated in interviews. All participants were interviewed twice: at baseline to collect background information and understand their existing experiences with inclusive education, and then again after 4–6 weeks to collect their feedback on the resources. Each interview took around 20–30 minutes, on average. Data collectors produced word-for-word transcripts based on their recording of all interviews conducted. UNICEF Innocenti then worked with the in-country data collectors to analyse the transcripts, undertaking line-by-line coding (a mix of deductive and inductive). The codes were organized into themes and these were combined with findings from the short feedback forms completed by a representative from each participating school – either a school head or specialist.

2.2. Country partnerships

UNICEF ECARO and UNICEF Innocenti contacted UNICEF offices in GPE partner countries in the Europe and Central Asia region that have a national policy framework for inclusive education. Of these, UNICEF Armenia and UNICEF Uzbekistan were able to take part, due partly to the high buy-in from national partners. The involvement of Armenia and Uzbekistan provides two distinct policy contexts against which to trial the resources: Armenia has several years of experience in implementing an inclusive education policy, while Uzbekistan was about to embark on its first year of piloting inclusive education. The contexts of these countries are described further in the next two sections.

In both countries, data on monetary and multidimensional poverty are not captured in the EMIS, making it difficult to identify marginalized children with disabilities. To address this, the project used national definitions of marginalization and combined different sources of data to identify schools that serve a higher proportion of marginalized families. Details on the data sources used in each country can be found in the next two sections, with implications for other countries discussed in Section II.3. With agreement across all partners, some key

principles in selecting schools¹⁵ and participants within schools were established. Recognizing that children with disabilities who are attending mainstream inclusive schools tend to be more advantaged than others, school selection was targeted at the most disadvantaged of eligible schools. Within schools, caregivers of children with disabilities who met the country's and schools' definition of being marginalized were invited to participate. Where more than three children met these criteria, a focus group discussion was held among their caregivers. Otherwise, they were interviewed individually.

2.3. Armenia pilot

Country context: In Armenia, inclusive education is regulated by the Constitution, the Law on General Education and several documents issued by the Ministry of Education, Science, Culture and Sports. An amendment to the Law on General Education, adopted in 2014, stated that all schools in the Republic of Armenia should become inclusive by August 2025. As a result, a three-level system for responding to a child's learning needs was to be developed and implemented. On May 6, 2021 the revised law on preschool education was adopted. It emphasizes inclusive preschool education for all children and regulates the assessment of special educational needs of children and the provision of pedagogical- psychological support services. An action plan for the transition to a fully inclusive preschool education system was also adopted in 2021. It includes the development of special educational needs and child development assessment tools and procedures, the training of pedagogical-psychological staff and regional pedagogical-psychological support centers. Consequently, children with special educational needs will receive pedagogical and psychological support at three levels: school, regional and national centers.¹⁶

The national definition of marginalization uses the term "children living in difficult life circumstances". This term is commonly used, with the Ministry of Labour and Social Affairs employing it to identify children without parental care, who are in orphanages, whose families are registered in the family insecurity assessment system and children with disabilities. According to the 2014 social assistance law, people living in difficult life circumstances have the right to social assistance in the form of consultations, legal advice, shelter and/or pensions based on their circumstances.

Partners: The in-country project team set up to adapt and adopt the resources in Armenia comprised representatives from UNICEF Armenia and the Republican Pedagogical-Psychological Center (RPPC) of the Ministry of Education, Science, Culture and Sports (MoESCS). The RPCC is a state centre which provides pedagogical and psychological services to the administrative and pedagogical staff of educational institutions, employees of territorial centers for pedagogical and psychological assistance, professional commissions, children with special educational needs and children with disabilities, their parents and representatives of other organizations interested in organizing children's education.¹⁷

The RPCC undertook the mapping of resources and organizations to inform the adaptation, while UNICEF Armenia took charge of the adaptation of the remaining resources, making them more relevant for the country context and informative for local marginalized caregivers.

Instrument pre-test: Data collectors in Armenia conducted a pre-test of the interview protocols. Two interviewers from RPCC conducted six pre-pilot interviews in total (with two school headmasters, two teachers and two parents of children with disabilities). The protocols were revised based on their feedback. A challenge was identified with the understanding of the term "children living in difficult life circumstances" which, although official, is not commonly used by the school community. A definition with examples was added to the resources and interview protocols to clarify the concept.

¹⁵ Schools are used for both pre-primary and primary schools in this context

¹⁶ The Ministry Of Education, Science, Culture and Sports of the Republic of Armenia, Inclusive Education, 2022, <<https://escs.am/en/static/inclusiveeducation?s=edu>>.

¹⁷ Republican Pedagogical-Psychological Center, History, <<https://hmk.am/en/history-en>>, accessed 19 February 2022.

School selection: As the 2014 amendment to the Law of General Education included all levels of education, pre-primary and primary schools were considered for inclusion in the pilot. Two kindergartens and two primary schools from Yerevan and Gyumri were selected by the RPCC to participate.

Firstly, the RPCC team used a database of children with special educational needs¹⁸ to identify mainstream schools with high numbers of children with disabilities. At the second stage, schools located in the poorest neighbourhoods were selected from the list. To ensure that the most marginalized would be reached at these schools (if there were more than five children with disabilities were enrolled), the team, using information from the Ministry of Labour and Social Affairs or from the school, selected five children with disabilities living in poverty or in difficult life situations. A short phone survey was conducted with pre-selected schools to discover the exact number of children with disabilities enrolled in these schools, their type of disabilities and which grades they were in.

Pilot period and data collection: The participating schools received the resources and were invited to participate in baseline interviews in mid-October, 2021 and were visited again at the end of November for final interviews. All interviews were conducted by two RPCC staff members, upon completion of data collection and ethics training. Unfortunately, due to the worsening of the COVID-19 pandemic, the usual two-week autumn school holidays were unexpectedly moved to November, in the middle of the pilot period. This effectively halved the time in which participants were in school and able to use the resources in that context, to only 2-3 weeks.

Scale-up and next steps: Immediately after the pilot was completed, UNICEF Armenia began finalizing the resources available based on the feedback received and analysed jointly with partners from the pilot. They will work with the MoESCS to distribute the resources to all schools in the country before the start of the 2022/2023 school year.

2.4. Uzbekistan pilot

Country context: In Uzbekistan, the Law on Education (2020) and Presidential Decree #4860 calls for inclusive education to be organized for all children in mainstream / regular educational institutions. The documents provide a road map for the development of inclusive education in the public education system during 2020–2025. In the first year of this plan, the Ministry of Public Education (MoPE) was to select 42 primary schools to be pilot inclusive schools. They were to enrol children with disabilities, who were to learn in the same classrooms as children without disabilities (there is another type of school which already enroll children with and without disabilities but they are taught in separate classrooms). After adaptation in Uzbekistan, the term “socially vulnerable families” was used to define “marginalized families/caregivers”. Law No. ZRU-415 of the Republic of Uzbekistan from December 2016 categorizes disabled people, the elderly, people with socially significant diseases¹⁹ and orphans or children without parental support as vulnerable groups. Current national legislation aims to address the risks and challenges that such people are facing through social insurance schemes, employer liability schemes, social assistance schemes, active labour market policies, and social services.²⁰

Partners: Uzbekistan joined the project in April 2021 and communication between partners was maintained through biweekly meetings. UNICEF Uzbekistan worked in consultation with the MoPE and the Zamin Foundation, a national body working on social projects including supporting children with disabilities. Additionally, a national consultant with experience in qualitative data-collection and who had founded an association for parents of children with disabilities was engaged to support the pilot delivery. The consultant also had access to, and information on, parental groups and organizations for caregivers of children with disabilities and undertook the mapping to inform the adaptation of the directories of resources and organizations.

Instrument pre-test: A small pre-pilot was conducted with two parents from an association of parents of children with disabilities. Minor revisions were made to the translation and language of the interview

18 This database was selected because the Education Management Information System (EMIS) does not have information on children with disabilities

19 [The socially significant diseases are those classes of diseases and separate illnesses, which rank the highest in defining the morbidity and death rate profile in a country.](#)

20 Papa, Jasmina et al., An assessment of the social protection system in Uzbekistan, Based on the Core Diagnostic Instrument (CODI), International Labour Organization, United Nations Children’s fund and The World Bank 2020.

protocol to make them more easily understandable by marginalized caregivers with varying degrees of educational attainment.

School selection: In Uzbekistan, four primary schools were selected from the group of 42, that were appointed to become inclusive in 2020-2021, to be included in the pilot. There were no indicators to indicate the degree of disadvantages faced by schools in the official data sets. To address this, the team used data from a Water, Sanitation and Hygiene (WASH) survey of all primary schools collected by UNICEF Uzbekistan the previous year. This indicated that the 42 schools were more likely to be located in urban areas, and more likely to be larger and have more WASH facilities than the overall population of primary schools. These indicators were used to create an index to select the schools closest to the 'average' school and which was located either in a 'lagging region' (based on a Multidimensional Preschool Education Needs Index constructed by the World Bank in 2018) or in a rural district. Six shortlisted schools were contacted for information on the number of children with disabilities they had enrolled for the new school year, their types of disabilities and age groups. Three were selected and, based on advice by the national foundation that an urban school should be represented, one school from Tashkent city was also added to the list

Pilot period and data collection: The participating schools received the resources and were invited to participate in baseline interviews in early October. They were visited again in mid-November for final interviews, which were all conducted by the national consultant, upon completion of data-collection and ethics training.

Scale-up and next steps: Through a partnership between MoPE, Zamin Foundation and UNICEF Uzbekistan, all 42 schools, including the 38 that were not part of the project's data-collection also received the package of resources in the middle of the school year. As part of this continuing collaboration, the caregivers' resources will be included as part of a package of support for schools in the framework of modelling inclusive schools for further scale-up, including a needs analysis and training for teachers and other school staff, which will be rolled out at the start of the 2022–2023 school year. The implementation of this support will involve cross-sectoral collaborations between education and child protection teams in the UNICEF Uzbekistan office, to improve links between schools and the existing social protection system.

2.5. Findings

Across both countries, all but one school representative reported that caregivers want to continue using the resources. A caregiver at an Armenian kindergarten said that they "*will definitely use it, cause I have seen a positive change in the child, even in this small amount of time*" [interview A3.2] and another at a primary school said that they and other caregivers will continue using them "*because it is very interesting, the information you give is very important for the education and development of the child*" [interview A5.3]. Even those who raised that they did not have enough time to use the resources stated that they plan to try in the future. For example, an Armenian caregiver said that "I will definitely use it [the guidebook], because I have seen a positive change in my child" [Interview A3.2]. The kindergarten representative in Armenia who disagreed with this statement said that it is because they already have three specialist staff at the kindergarten and caregivers preferred to receive information verbally from them rather than written materials.

However, half of the caregivers interviewed stated that they did not read or use the resources. Almost all said this was due to a lack of time, citing existing commitments and responsibilities. As a caregiver of a kindergarten-aged child with speech delays in Armenia described it, "*time is very short, so to speak. By the time I finish my child's lessons, it is already 9 or 10 in the evening, while I am preparing her, I am putting her to bed, it is already late, I do not have time, and there is no time for anything else*," [interview A10]. Some noted that the little they did see were useful, including a caregiver of a primary school-aged child in Uzbekistan, who said "*I was curious at first, I did it, now I'm busy, I can't spend any time on it, but I saw that there are some very useful things*" [interview U4].

A few caregivers raised concerns about the difficulty in navigating the resources. Some felt the materials were complicated, with one caregiver in Armenia reporting that they had to "*read [them] several times to better understand the meaning*," [interview A5.1]. Two caregivers in Uzbekistan pointed to a mismatch in the dialect they use with the standard Uzbek used in the materials. Others noted that not all the external resources linked to in the directory were available in the local language (some were only available in Russian), suggesting that more local resources ought to be included. Other suggestions made during interviews included more

visualization, clearer descriptions on how to identify solutions, introducing accompanying videos and seminars, and more information about supporting specific disabilities.

On the other hand, all school staff reported that the resources were easy to understand and use. Teachers and school staff were overall more likely than caregivers to have used the resources directly. School representatives reported that a total of 28 caregivers received the resources and estimated that 17 had used them, while they estimated 16 of the 19 teachers that received the resources used them. Interviews also supported the fact that teachers and other school staff, often specialist staff responsible for supporting children with additional needs, were most likely to use the resources and find them helpful.

This was particularly the case in Uzbekistan, where teachers and school staff in the first year of piloting inclusive schooling nationally were looking for resources and information to support newly enrolled children with disabilities (i.e. beyond supporting their caregivers). One primary schoolteacher said, *“I learned about the methods on how to identify barriers, solutions, their strengths. Before, I didn’t know how to resolve issues, but now it has become more clear to me,”* [interview U9]. On the other hand, participating school staff in Armenia, who have had several years of experience in implementing inclusive education at their schools (including access to training and resources), were more likely to report that the approach and practices advocated by the resources reiterate what they already know and practice. Despite this, there were caregivers in these Armenian schools who still reported that they learned something new from the resources including local associations and tools they were able to use at home with their children.

In Armenia, where the pilot window was cut short due to unexpected COVID-19 closures, some participants reported specific intentions to continue using the resources. Staff at one kindergarten in Armenia said that they intend to organize a seminar to disseminate the messages in the guidelines in the subsequent school year. Another kindergarten headmaster in Armenia stated that *“my educators, psychologists and speech therapists, educators, of course, will be guided by all this and will continue using it,”* [interview A17].

Despite the challenges they faced, there were caregivers, teachers and other school staff who, over the course of the pilot, were able to work through the resources. Some reported on the use of specific tools mentioned as solutions in the resources. A teacher and a school specialist in Uzbekistan, for example, reported that they have seen positive outcomes since beginning to use the individual learning plan sample, dialogic reading approach, communication board and visual schedule. Meanwhile, a caregiver in Armenia reported using some of the activities with their kindergarten-aged child, which he *“liked very much,”* [interview A3.5]. Others reported that they read the guidelines without providing specific examples of exercises or tools that they used.

Schools played an important role in helping caregivers engage with their children’s learning and development. The resources were more likely to be accessed and used in settings where different stakeholders worked together on them, especially when this was encouraged by a school leader. Several school leaders asked teachers and specialists to read through the resources together and develop a plan on how to use them. Some reported that they themselves read the materials and participated in the process. There were also instances of caregivers and school staff working together on the resources. A teacher in Uzbekistan reported that *“I used it myself first, we explained to them [caregivers] every time, and then they started to understand too, we explain as much as we can,”* [interview U13]. A caregiver at an Armenian kindergarten reported that she initiated the engagement: *“At first I tried to do something on my own after reading the book, then I tried to do a lot with the book at home with the child, I also told the teacher [name] to try to teach the child using one of the options and it worked,”* [interview A3.2].

2.6. Revisions to resources based on lessons learned

Based on the feedback and findings from interviews, the resources were revised to make more accessible and useful for caregivers and school staff. The main changes included:

- **Clarifying the purpose of the resources:** A simple introduction in the form of frequently asked questions (FAQ) section was added to the start of each resource, as well as short visual descriptions of each document in the set. This was intended to clarify that the purpose of the resources is to support children with disabilities with inclusive learning by providing targeted support to their caregivers. It also provided information on the age group and types of disability that the resources are most useful for.

- **Adding illustrations and visualizations:** To simply and ease the use of the resources, more visualizations were added including a real-life example of how the resources were used at one school during the pilot using a narrative cartoon format.
- **Encouraging closer collaboration between school staff and caregivers:** Understanding the overlapping deprivations of caregivers, an explicit collaborative approach between school staff and caregivers as well to work with others who have also received the resources were added throughout, based on the findings from more successful instances during the pilot.
- **Encouraging adaptation and practical use of the exercises:** Clearer references were added to exercises (with the specific 'appendix' document renamed 'workbook') that were intended to support users in applying specific sections in the guidelines to their specific circumstances. Formatting of the templates in the repositories were revised with explicit encouragement to identify and add local tools, materials and networks to the documents.



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3. Recommendations: Steps to adopt resources

This section presents a practical set of steps for education ministries and other educational leaders to adapt and adopt the resources, based on the lessons learned during the pilots.

3.1. Step 1: Engage stakeholders to align resources with existing support

At the end of this step, you will have: a designated project team and necessary information on existing services, networks and structures.

It is important from the outset, to bring in the right actors and take stock of what exists when addressing overlapping deprivations and the interaction between caregivers and education system. This is explored further in Step 1. Additionally, here is a quick list of some things to consider to ensure that the resources incorporate and are embedded within existing structures:

- How are children with disabilities currently being supported, including their access to schooling? It is likely that they require their caregivers to access these support services.
- How are children living in multidimensional poverty currently being supported, and what compensatory measures are needed when disability and deprivation overlaps?
- Are there existing support networks and programmes that work with marginalized caregivers of children with disabilities?
- Do schools and teachers have ways of communicating with and support marginalized caregivers of children with disabilities?
- Is there a central place where all the available resources and services are kept and managed? Who is playing that role in your education system?

Answering these questions will help you to bring the right people together and build on existing support (even if it's not currently being implemented in a systematic way). They are an important starting point to the subsequent implementation steps.

The effective implementation of a disability-inclusive education will involve many additional actors beyond the government and education system leaders themselves. Different actors can provide significant added value to the development and delivery of inclusive education. For the purposes of engaging and supporting caregivers of children with disabilities from socioeconomic disadvantaged backgrounds including the implementation of the resources discussed here, there are several key partners who should be engaged early in project inception. They are summarized in Table 1 below.

These key partners include stakeholders within the Ministry of Education as well as those outside the education system who are responsible for supporting children with disabilities and marginalized families. They may be able to provide documents on the current implementation of inclusive education; reports capturing difficulties in transitions from special schools to inclusive schools; studies looking at the situation of children with disabilities and educational placements. These may inform the adaptation of the resources (see Step 2) as well as inform project-planning in identifying and mitigating risks.

Close engagement with these stakeholders throughout the implementation of resources fosters the success of the project, as does inviting representatives of the most important partner agencies and groups to be part of the core project team.

Table 1. Key implementation partners and the relevance of their current roles

Partner	Roles	Comments
Ministry of Education	<ul style="list-style-type: none"> ■ Alignment with national priorities on inclusive and equitable quality education ■ Different departments within MOE including pre-primary, primary, teacher training, planning, curriculum design, inclusive education units 	<ul style="list-style-type: none"> ■ Having different departments represented increases ownership and supports capacity development
Ministry of Health, Social Affairs and/or Welfare	<ul style="list-style-type: none"> ■ Screening and assessment ■ Specialist services (e.g. social workers, special educators) and referrals ■ Provision of assistive devices ■ Data on children with disabilities and/or marginalized families 	<ul style="list-style-type: none"> ■ Children with disabilities and their families may be receiving or are entitled to receive support through health and/or social system
Other public sector agencies (for example, ministries of welfare, labour and social affairs, local government)	<ul style="list-style-type: none"> ■ Financial support to families of children with disabilities, and families living in marginalized situations ■ Support inclusive education ■ Fund holders 	<ul style="list-style-type: none"> ■ Ministries of Welfare/Social Affairs/local government are often providing mechanisms for social funds (for examples, funds to provide services for children with disabilities, including through schools)
Civil society including parent associations and organizations for people with disabilities	<ul style="list-style-type: none"> ■ Local resource provision ■ Access to and experience in providing direct support to caregivers and families 	<ul style="list-style-type: none"> ■ At local level, serve as gatekeepers and fund holders; may also support direct implementation ■ Other additional providers of resources, materials and support
Teacher associations	<ul style="list-style-type: none"> ■ Define teachers' roles ■ Engagement of teachers at a large scale 	<ul style="list-style-type: none"> ■ Inclusive education may be seen as an expanded role for teachers
Local community (including children, caregivers, teachers, community leaders)	<ul style="list-style-type: none"> ■ Partners in implementation ■ Define acceptability of curriculum and teachers' roles ■ Supplement resources 	<ul style="list-style-type: none"> ■ Students are active participants in all aspects of the process at the school level ■ Communities supplement programme finances at the margins

3.2. Step 2: Adaptation of resources

At the end of this step, you will have: an adapted set of resources in the main languages used in your system to be piloted in selected schools prior to wider implementation.

Once a project team is in place, it is time to examine the set of resources and adapt it for use in your education system. It may be helpful to assign an agency or individual to act as the focal point for overseeing each document. Alternatively, one core project team working with different departments and/or agencies could gather information from relevant partners during the adaptation phase.

The adaptation of the resources falls within three main areas, summarized in Table 2 below: contextual information, definitions and translations and existing resources and supports. Additionally, you may also consider adapting the resources to be used on other delivery platforms.

Table 2: Summary of adaptations to be made to resources

Contextual information	Update caregiver, school and teacher guides with information on national policies and legislation regarding inclusive education
Definitions and translations	Identify country-specific translations and definition for the key terms “marginalized”; “disability”; and others as needed
Existing resources and supports	<p>If available, add country-specific resources and tools to “Directory of resources to support caregivers with inclusive education”</p> <p>Update “Directory of Organizations” to include associations and organizations that are supporting caregivers</p>
Optional: Platform / delivery method	The content of the resources can also be adapted for any delivery platforms already being used, including electronic methods

Contextual information refers to sections in the three guides (for caregivers, schools and teachers) which discusses existing rights under international conventions and national policies and legislations. It also covers where the resources will be used in subnational contexts, any existing local policies and legislations (and what these say about the rights of children with disabilities to inclusive education in mainstream schools).

Definitions and translations refer to the importance of agreeing the country-specific definitions and translations of key terms that would be easily understood by caregivers, teachers and school staff. These terms include “disability” or “children with disabilities” and “marginalized” or “marginalized families”. The terms used should follow accepted national definitions, and the pilot used to check whether the translated terms are understood by the audience (who may not know the formal or legal terms used by government agencies). As these terms are frequently used in the documents, is important for the project team to engage their partners and test these terms, and not leave the task to translators who may not be as familiar with the context.

The repository of resources and directory of organizations should be updated to reflect country-specific tools, materials, associations and organizations. These may require a mapping exercise to identify these existing supports to be conducted with project partners. Engaging civil society partners may be particularly beneficial at this stage to be able to map the existence of such associations and organizations across the country or region served by your education system.

Finally, the content of the resources can also be adapted for any platform or delivery method that is already being used to disseminate information to caregivers, teachers and/or schools in the education system. In the proof-of-concept pilots the resources were printed and distributed in hard copy to participants. This was

considered the best way to reach the marginalized populations that were being targeted in these countries during the pilot. However, some education systems may already utilize other means and, where these exist, the resources can be shared on such platforms. For example, electronic textbooks provided online or via USB to be printed locally, or mobile-based applications used widely by schools and teachers. A hybrid model is also possible, where electronic platforms are used to reach most teachers and schools, with additional paper-based distribution to caregivers and hard-to-reach schools.

3.3. Step 3: Planning and implementing a pilot

At the end of this step, you will have: data and feedback from schools, teachers and caregivers on their experience with the resources, to inform finalization and implementation scale-up.

The resources, as they are presented in the annex to this document, have gone through a proof-of-concept pilots in two countries, as described in the previous chapter. The resources should be adapted to suit the education system that you are working in (see Step 2). They should also be piloted in this context before wider implementation.

The purpose of piloting these resources is to test and improve the content as well as the procedures to implement them. These lessons will ensure a higher likelihood of success when the resources are distributed more broadly to schools in your education system.

As a starting point to collecting feedback and refining your implementation during piloting, you may want to use the data-collection materials used in the proof-of-concept pilots in Armenia and Uzbekistan, provided in the annex. They consist of a short school survey and protocols for interviewing participating caregivers, teachers and school representatives. These tools aim to collect information on:

- **The background, context and experiences** of the participating caregivers (and their children, teachers, and schools) with inclusive learning, including what other resources and support they have access to;
- **How participants used the resources** that they received, including who initiated their use, what needs, challenges and solutions they identified, and how they intend on using the resources in the future;
- **The extent to which participants found the resources helpful and easy to use**, any issues that participants faced in using the resources and improvements they think should be made.

The instruments were designed to be used in two rounds: through baseline and end line interviews. The baseline interview is the first set of data collected on the participating schools, teachers and caregivers. Collecting baseline information provides insights into the background of the school, understanding of inclusive education and caregivers' needs. The end line data-collection will provide feedback and information on the usefulness of resources.

After deciding on the questions that you wish to address in your pilot and adapting or designing the instruments you will use to answer those questions, the key decisions to be made in planning the pilot include:

- **How many schools will be involved in the pilot, and how many teachers and caregivers in each school will participate.** This is a decision to be made based on the trade-off between ensuring that there is sufficient opportunity to capture and represent a broad range of contexts and experiences, and the cost of visiting schools. A pre-pilot with a small group of caregivers is also advisable, and can be organized by partnering with a civil society or representative organization.
- **Where the pilot will take place and which schools will participate.** One very important point to consider is how to identify and reach schools that are serving children with disabilities from marginalized families. A common challenge here is the issue of data, as discussed in Box 1. Being able to identify schools and families of marginalized children with disability will often require the use and linkages of multiple data sources, including those from outside of the education system. Again, there are considerations of being able to capture a representative set of experiences as well as accessibility and the associated cost to reach certain areas and regions.

- **When and for how long the pilot will be conducted.** The ideal timing to begin the pilot is the beginning of a school year, to allow schools and teachers to incorporate the resources in planning for the year and as they work to understand the needs of a new cohort of children and caregivers. It is important to allow pilot participants sufficient time, ideally at least 6-8 weeks, to use the resources before seeking their feedback.

Once pilot locations are identified it can be useful for your project team to include representatives from the local community (schools, organizations, local education officers). Ensuring their participation and involvement from the beginning is an important step in the process. Work with them to further adapt (if necessary) the resources adding local networks and places that offer support for children with disabilities and their families.

3.4. Step 4: From pilot to scaled-up implementation

At the end of this step, you will have: a finalized set of resources and plan to implement them in all or a wider group of schools and school communities in your education system.

Data collected from the pilot should be used to inform three elements of the subsequent scale-up or large-scale implementation of the resources:

1. **Finalization of the resources themselves**, based on feedback on their clarity and usability
2. **Design of the scale-up/large-scale implementation**, based on feedback on how participants received and used the resources
3. **Future programming and policy**, based on reported needs and challenges faced by children with disabilities and their caregivers in engaging with inclusive education.

The data collection instruments provided in the annex as starting points for capturing information during the pilot encompass the above themes. The responses received during the pilot can therefore be categorized and analysed to answer the above topics.

Engaging the partners listed in Step 2, including those that might not form part of the core project team during the pilot, will also be valuable. The final results and findings from the pilot should be shared with these partners who can play a role in subsequent large-scale implementation or dissemination to more schools.

Finally, it is important to recognize that the scale-up of the implementation of these resources can, and should be, an iterative process. By continuing to collect feedback from the caregivers, teachers and schools that use the resources, their usability and usefulness can be steadily improved for each new school year. When the resources are more broadly disseminated, it would remain important to track their uptake and usage in schools and communities where marginalized caregivers are. One way to do this is for end-users to use the feedback form provided in the annex to record their experiences and suggest improvements, and undertaking sufficient disaggregated analysis that considers relevant dimensions of marginalization.

for every child, answers

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