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Methodological Guide:

RESEARCH FOR NATIONAL SITUATION ANALYSES ON EARLY CHILDHOOD INTERVENTION

Methodological Guide: Research for National Situation Analyses on Early Childhood Intervention

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The application of the *Methodological Guide* in Montenegro, North Macedonia and Kosovo, in that order, demonstrated that it can be successfully adapted and used to study and analyse the status of early childhood intervention services in very different countries.

UNICEF and the authors encourage other countries in the ECA region and in other regions to use the *Methodological Guide* to secure data and information on the status of early childhood intervention services. These studies should help country policy leaders and professionals to improve these services and ultimately to meet the demand and need for expanded ECI services.

The ultimate goal of this book is to ensure that more children will achieve their potential, become fully included in society, and their parents will feel well-supported in their critically important roles.

[1] All references to Kosovo in this publication is without prejudice to positions on status, and is in line with UNSCR 1244/1999 and the ICJ Opinion on the Kosovo declaration of independence.

Acronyms

AAP	American Academy of Pediatrics
ACES	Adverse childhood experiences
ADHD	Attention deficit and hyperactivity disorders
AEPS	Assessment, Evaluation and Programming System
ASD	Autism spectrum disorder
ASQ III	Ages and Stages Questionnaire III
ASQ SE III	Ages and Stages Questionnaire Social-Emotional II
CBO	Community-based organizations
CBR	Community-based rehabilitation
BDI 2	Battelle Development Inventory 2
CEDAW	Convention on the Elimination of All Forms of Discrimination Against Women
CFM	Child Functioning Module
CRC	Convention on the Rights of the Child
CRPD	Convention on the Rights of Persons with Disabilities
CSBS	Infant Toddler Checklist Assessment
CSO	Civil society organizations
DfID	Department for International Development
DHS	Demographic and Health Survey
EASPD	European Association of Service Providers for Persons with Disabilities
ECARO	Europe and Central Asia Regional Office of UNICEF
ECA	Europe and Central Asia
ECD	Early childhood development
ECDI	Early childhood development index
ECE	Early childhood education
ECEC	Early childhood education and care
ECI	Early childhood intervention
EIS	Early Intervention Specialists
EMIS	Educational Management Information Systems
ERDF	European Regional Development Fund
ESF	European Social Fund
EU	European Union
FBO	Faith-based organizations
FINNIDA	Finnish Department for International Development

GDPR	General Data Protection Regulation
GPS	Global Partnership Strategy for Early Childhood
HELP	Hawaiian Early Learning Profile
HMIS	Health Management Information Systems
ICF-CY	International Classification of Functioning, Disability and Health: Children and Youth Version
IFSP	Individualized Family Service Plan
ISSA	International Step by Step Association
LG	Local government
LMIC	Lower- and middle-income countries
MICS	Multiple Indicator Cluster Survey
NAEYC/DEC	National Association for the Education of Young Children, Division of Early Childhood
NGO	Non-governmental organizations
NICU	Neonatal intensive care unit
OECD	Organisation for Economic Co-operation and Development
PEDS	Parents' Evaluation of Development Status
PMIS	Protection Management Information Systems
RBI	Routines-Based Intervention
SDG	Sustainable Development Goals
SIDA	Swedish International Development Cooperation Agency
SPSS	Data analysis software
ToC	Theory of Change
ToR	Terms of Reference
UDL	Universal Design for Learning
UN	United Nations
UNESCO	United Nations Educational, Scientific and Cultural Organization
UNICEF	United Nations Children's Fund
USAID	United States Agency for International Development
WASH	Water, sanitation and hygiene
WG-SS	Washington Group's Short Set
WHO	World Health Organization

1. Introduction

The United Nations Children's Fund (UNICEF) is devoted to achieving children's rights, good development, and well-being. In that role, UNICEF has become a global champion for children's issues. In the Europe and Central Asia Region (ECA), in collaboration with other organizations and networks, UNICEF has promoted national policy and programme development for early childhood development (ECD). Within the ECD framework, UNICEF promotes regional and country initiatives for early childhood intervention (ECI) to support families whose children have developmental delays and other difficulties.

This *Methodological Guide on Research for National Situation Analyses on Early Childhood Intervention* was developed in response to requests to UNICEF and the RISE Institute from countries and regional and international agencies for guidance on how to conduct effective research on the status of ECI systems and their services. Little published research exists on the status of national ECI systems. National institutions struggle to secure essential data for planning their national ECI systems and for improving, expanding and developing ECI services in public institutions and civil society organizations. Knowing that the RISE Institute conducts primary research that is required to prepare national ECI Situation Analyses, UNICEF invited the institute to prepare this Methodological Guide and subsequently help to implement it in Montenegro, North Macedonia and Kosovo. Further lessons learned from the implementations have been incorporated into the Guide.[2]

Why ECI services are growing rapidly in all regions of the world

ECI services are essential for a country to achieve SDG Target 4.2: "By 2030, ensure that all girls and boys have access to quality early childhood development, care and preschool education so that they are ready for primary education" (United Nations, July 2017).

The basic *raison d'être* of ECI services is to ensure good early brain, gross and fine motor, language, cognitive, and socio-emotional development for children with or at risk of developmental difficulties. To ensure that all children attain their full developmental potential, infants should be identified soon after birth through neonatal screening or within a neonatal intensive care unit (NICU), or later through developmental screening and medical surveillance, monitoring and diagnosis. To promote good child development, primary attention must be given to ensuring family leadership, participation and support in planning and conducting nurturing ECI activities, as well as to providing all or most services in the "natural environment of the child" as a part of daily family and childcare or preschool routines.

To ensure ALL children will be able to achieve their full potential and will be prepared for primary school and full inclusion in society, ECI services must address the care and developmental needs of infants and young children from birth onward. Services that begin during the period from birth to 36 months, when the brain has a high level of plasticity and grows the most rapidly, will be most effective in attaining good child development outcomes.

ECI services are essential for parents and caregivers of all children with "developmental difficulties" including all children in at-risk situations and/or with developmental delays, disabilities, behavioural conditions and mental health needs.[3] Countries vary in their decisions regarding the age ranges of ECI services from birth to 3 years and birth to 5 or 6 years. For some countries, where early detection of children needing ECI services is lacking and ECI methods are only beginning to be used, the decision is made to continue services to 5 or 6 years of age. Also,

[2] Some elements of this Guide and the field test findings will be included in forthcoming publications on the development of national ECI systems and services.

[3] Children in at-risk situations (e.g., prematurity, low birthweight, chronic illnesses, and others), with developmental delays and disabilities in all developmental domains, behavioural conditions (such as autism spectrum and attention deficit and hyperactivity disorders), and mental health needs (e.g., depression, poor coping skills, trauma and others) will be referred to as having "developmental difficulties" in the text. Definitions are provided in **Annex 2**.

in countries lacking universal coverage of high-quality inclusive preschool education, for children over 36 months of age who have not already met the developmental goals set by their parents and transdisciplinary teams, additional services are warranted to consolidate the gains achieved and to address continuing and often chronic developmental, health or other conditions. ECI leaders in each country must reach a consensus regarding the age range that the ECI services will address.

Some major benefits of ECI services

Considerable research on ECI services in many countries has revealed various important benefits. Research into child development, nutrition, health, early intervention and neuroscience that began in the United States and Colombia in the early 1970s resulted in a watershed book that drew attention to the importance of early intervention services (Super et al., 2081; Gordon et al., 1972; Shonkoff & Phillips, 2000). Subsequently, attention was given to identifying and studying the component parts of well-functioning ECI services (Guralnick, 2011; Guralnick, 2013). They and many other subsequent researchers concurred that well-designed family-centred ECI services that include community outreach and universal systems of regular developmental screening **can identify infants and children with developmental difficulties early**, thereby giving parents essential and timely support in promoting good development and nurturing care during the critically important period of birth to 36 months (Dunst, 2006; McWilliam, 2010, 2013).

In addition to early identification and rapid service provision, **ECI uses a family-centred approach** that stresses the importance of fully involving and supporting parents and other daily caregivers. This approach has been evaluated for many years and has been found to please and support families and their service providers (Iverson, 2003; McMannus et al., 2020).

The few country-level studies regarding ECI service outcomes that have been conducted have **revealed notable improvements in family and child development**. For example, the National Family Survey Data Trends using multi-year studies of ECI outcomes in the United States shows that **families approve of ECI services conducted in the natural environment of the child**. They consistently give high marks for "knowing their rights" (89 per cent), "communicating their children's needs" (90 per cent), and "helping their child develop and learn" (91 per cent) (ECTA, 2020). Similarly, the study of ECI child outcomes including social relationships, knowledge and skills, and action to meet needs, found that, while 5 per cent of the children served, with profound disabilities, made no improvement in functioning and 30 per cent improved in functioning but had no change in their developmental trajectory. However, **65 per cent of children made greater than expected growth with many moving closer to or functioning like same-aged peers** (ECTA, 2022).[4] Essentially, after ECI services, these children were "ready for school" and had the developmental capacity to perform adequately or well. Without ECI services, many, if not most of them, would not have been ready for school or would not have been enrolled at all.

Improved child developmental capacity leads to reduced school attrition, grade repetition, poor grades and remedial and special education services. Improved educational outcomes always reduce systemic educational costs. From schooling onwards, the economic impact of high-quality ECI services is very great for individual citizens and society, as well as for the economy. The work of the Nobel Laureate Economist, James Heckman, is often referenced in this regard (García, Heckman et al., 2016).[5]

ECI services are essential for enabling the national deinstitutionalization of young children, most of whom have many developmental delays and difficulties (Vargas-Barón et al., 2016). ECI services support parents, relatives, adoptive families and foster families receiving deinstitutionalized young children into their homes, helping them understand how to enable the children to develop well. In addition, ECI services help prevent institutionalization and reduce child suffering, while improving their development.

Countries are increasingly offering culturally and linguistically appropriate contemporary ECI services for families with ECI-eligible children. This is due to the many benefits resulting from

[4] The measures in 2020 declined from 2019 due to the COVID-19 pandemic.
[5] Heckman often references both high-quality ECI and ECD services together.

ECI services and to their need to ensure that they observe universal child and parental rights, as codified in the Convention on the Rights of the Child (CRC), the Convention on the Rights of Persons with Disabilities (CRPD), and the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW). Country leaders realize that they require individualized and intensive services that are provided by ECI civil society organizations and public institutions, hereinafter referred to as "ECI organizations and institutions" or "ECI-service-providing organizations and institutions".[6]

Children needing ECI services in Europe and Central Asia

Needs for expanded, improved and new contemporary ECI services exist in most countries of Western and Eastern Europe, South-Eastern Europe, the Caucasus and Central Asia. According to a global survey, over 95 countries in the ECA and other world regions are improving or developing their ECI services, with ECI services present in at least 22 countries of Eastern Europe (Vargas-Barón et al, 2019).

Identification of ECI-eligible children

Some countries lack a national household survey and/or administrative data that accurately identify the rates of children, from birth to 60 or 72 months of age, in at-risk situations, with developmental delays, disabilities, behavioural conditions and mental health needs. Each country should place priority on securing data on the child development component as soon as possible.[7] Population-level surveys are based on a stratified random sample of households and "child development components" should be added to them whenever they are planned. However, such surveys entail a substantial investment over a multiple-year period, and for this reason, they could not be included in national ECI Situation Analyses. Where possible, administrative data should be secured. Child-tracking systems also help in this regard.

The Multiple Indicator Cluster Survey (MICS) and its Child Functioning Module (CFM), which contains the Washington Group's Short Set on Functioning (WG-SS) for children aged 2 to 17 years, has surveyed 103 countries and more are being added every year, and other surveys were also used (UNICEF, 2021).[8] Currently this is the largest dataset regarding children with disabilities. In the region of the Europe and Central Asia Regional Office (ECARO), out of a total of 55 countries, 31 have provided disability data. The regional rate of children with disabilities from birth to 4 years in the ECA region is 2.7 per cent, which represents a total of 1.5 million young children. According to the latest UNICEF report, the rates of children with disabilities in the ECA region vary from 0.8 per cent in Montenegro to 4 per cent in Kosovo (Ibid). These figures may be lower than is the case.

In addition to children with functional disabilities, the rates of children in at-risk situations, with developmental delays, behavioural conditions and mental health needs are unknown. To assess the incidence of developmental delays and other conditions, in-depth child development measures are needed. Another even more thorough approach would entail the development of child-tracking systems that have programmatic and operational goals, as well as research goals.

Country-level studies are urgently needed to identify the incidence of infants and young children in at-risk situations, and/or with developmental delays, disabilities, behavioural conditions and mental health needs. In this regard, many countries have administrative statistics regarding risk factors, such as: rates of maternal age at childbirth (with attention to adolescents), pre-term births, low birth weight, stunting, wasting and chronic illnesses. Often, children with ECI-eligible conditions are found more frequently living in households with moderate to severe poverty, ethnic minority status and in rural, island and other remote populations that are underserved by basic services (e.g., primary health and nutrition care, sanitation, inclusive education and protection services). Young children are also deeply affected by adverse childhood experiences (ACEs) such as domestic violence, abuse, neglect, community or

[6] ECI services are provided by ECI public institutions or civil society organizations and by ECI components developed within entities that provide other services, such as inclusive early and preschool/pre-primary education, disability organizations, health and nutrition services, and social welfare services.
[7] UNICEF's ECDI that is applied in the MICS in some countries is useful for securing general information on child development.
[8] Also included in UNICEF's calculations are results from the Global Activity Limitation Indicator, Demographic and Health Surveys (DHS), European Health Interview Survey (EHIS), the European Survey on Income and Living Conditions (EU-SILC) and a few independent household surveys.

cross-border conflicts, migratory/refugee status and internal displacement, for which data are becoming increasingly available.
These data, which could be secured from regional and national statistics and studies, would increase substantially the numbers of young children who should be given priority for rapid developmental screenings and referrals to ECI services. In the meantime, for ECI Situation Analyses it is necessary to estimate the numbers of children from birth to 3–5 years of age who may require ECI services, using all the available data. To see how the percentages of children requiring ECI services were estimated in Croatia, see Annex 16. This approach varies from country to country depending on the available data regarding child and family status and the socio-economic situations in each country.

Europe and Central Asia region

In-depth ECI Situation Analyses have been conducted in Belarus (Vargas-Barón & Janson, 2009), Georgia (Avaliani & Vargas-Barón, 2014), Ireland (O'Shaughnessy Carroll, 2016), Serbia (Hix-Small & Ilic, 2017), Bulgaria (Hix-Small, 2019) and Croatia (Vargas-Barón et al., 2020).

A comprehensive region-wide study of ECI systems and services is greatly needed. The Agora Project, including a regional review of Bulgaria, Hungary, Poland, Romania and Slovakia, revealed that these countries were at different levels of development regarding establishment of national ECI systems and contemporary ECI services (Dobrova-Krol et al., 2019).

More recently, the European Association of Service Providers for Persons with Disabilities (EASPD) issued a study on rehabilitation and evolving ECI services in Albania, Greece, Kosovo, Montenegro and North Macedonia, which found that legacy systems, composed mainly of rehabilitation services, still prevail in the Balkan region (EASPD, 2022). The key study findings were:

- None of the five countries had developed an ECI legal framework that "regulates, organizes, guarantees quality or finances ECI services" (p. 37). Laws for ECI exist in two countries, but they lack the bylaws and operational regulations essential for the good functioning of national ECI systems.
- Ministries providing and/or supporting ECI services vary greatly by country. Some countries involve all three sectors: education, health, and social policy/affairs, and the latter tends to be the lead ministry.
- No systems for inter-sector coordination were found.
- The better-funded services were those of public institutions that can rely on stable annual funding. In all countries, some municipalities help support ECI services; however, no regulations for decentralized ECI financing exist to encourage municipal support. Municipal funding was reported to be inadequate to meet service costs. Where studied, services of the private for-profit sector were financed by parental fees, resulting in the exclusion of families of modest means or living in poverty – who often need the services the most.
- No countries reported using ECI services to assist with the deinstitutionalization of children.
- Most ECI services were reported to be provided by NGOs and parent associations. (In a separate study, one country's public institutions of the education, health and social policy/affairs sectors provide services that are evolving to become ECI services.)
- Most of the services, currently, of the five countries are legacy rehabilitation services. In addition, depending upon the country, from a few to several service-providing public institutions and NGOs are evolving to become contemporary ECI services.
- Most services are centre-based, but increasingly visits to the natural environment of the child are being instituted.
- Reliable data on services were unavailable "… relating to the number of children and families that use or need ECI services, as well as for the structure, content and costs of these services" (p. 39).
- Community outreach, rural and mobile services tended to be lacking.
- Challenges included: little understanding of ECI services, inadequate service access, and a lack of service equity, pre- and in-service training, developmental screening and comprehensive developmental assessment instruments, quality assurance, and monitoring and evaluation.

In the absence of a comprehensive and in-depth regional study and from a review of the existing literature, in the ECA region only Finland, Georgia, Ireland, Italy, Lithuania, Norway, Portugal, Slovenia, Spain, Sweden, the Netherlands and the United Kingdom are generally considered to have established a national ECI system with a legal basis, organizational structure and predominantly contemporary ECI services.

Other countries that are working toward developing a national system of contemporary ECI services include: Albania, Armenia, Azerbaijan, Belarus, Bosnia and Herzegovina, Bulgaria, Croatia, the Czech Republic, Greece, Hungary, Kazakhstan, Kosovo, Moldova, Montenegro, North Macedonia, Poland, Romania, Serbia, Slovakia, Tajikistan and Ukraine. The status of ECI is changing rapidly in the ECA region.

All countries of Europe and Central Asia have legacy systems for child rehabilitation and/or habilitation. In Western Europe, leading medical and therapeutic centres created service organizations based on early medical research and/or practice regarding child development and disabilities. In the former Soviet Union and former Yugoslavia, defectological services for child rehabilitation were developed, and some of these services are still found in a few countries; whereas in other countries, such as Georgia, a national ECI system with contemporary ECI services has been developed, along with the Coalition of ECI Organizations of Georgia. This Methodological Guide offers some core ECI concepts, processes and approaches that may be useful for countries seeking to develop contemporary ECI services, as well as comprehensive and continuous ECI training systems.

To explain the regional differences further, in Chapter 3, Table 1, legacy systems are contrasted with evolving and contemporary ECI practices along several parameters. Increasingly, countries are moving toward the adoption of more culturally appropriate, evidenced-based and contemporary ECI core concepts, processes and methods. This transformation is being supported by several regional organizations, including the European Association on Early Childhood Intervention (Eurlyaid), the ECI Forum of EASPD, the Joint Learning Lab on ECI of the International Step by Step Association (ISSA), the European Union, RISE Institute, and Soft Tulip of the Netherlands.

At the global agency level, supporters of ECI development include UNICEF, UNESCO, the World Health Organization (WHO) and, more recently, the Global Partnership Strategy for Early Childhood (GPS).

Regarding regional commonalities, it may be confidently stated that three sectors are usually active in developing and offering evolving ECI services, among which a few have become fully contemporary services:

- The **education sector** may have initial parenting and child development services in home and/or in childcare settings, as well as in inclusive preschool education settings;
- The **health sector** provides medically based rehabilitation services and increasingly is evolving to provide contemporary ECI services; and
- The **social policy, welfare or protection sector** offers social support and child development services, some of which are evolving to become contemporary ECI services, for children with developmental delays and difficulties, and other vulnerable populations.

These sector-level ECI public institutions receive annual budgets from their ministries and/or agencies; however, they often lack officially established ECI budgetary programmes and cost studies that are essential for effective planning, monitoring, evaluating and supervising of countrywide ECI services. Without an organizational system and structure for the provision of ECI services, these separate sector-level services rarely develop inter-sectoral coordination systems. The lack of strong inter-sector coordination often leads to unnecessary duplications in services, service gaps and challenges relating to the provision of national-level coverage, quality assurance, equity and accountability.

In addition, most countries in the ECA region have ECI civil society organizations (CSOs) that serve an increasingly large part of the population needing ECI services. CSOs usually include NGOs, faith-based organizations (FBOs), community-based organizations (CBOs), university ECI programmes with field service activities, and associations of professionals and/or parents, some of which provide services to member families. These CSOs

often lead in innovation and they usually work hard to expand their services; however, at the outset they are often beset by unstable and short-term funding. CSOs usually seek and secure contracts, grants or vouchers from ministries and other public institutions, covering at least 60 to 70 per cent of their annual budgets, thereby enabling them to become sustainable. Public–CSO arrangements also make CSOs accountable to ministries that are supporting these essential services.

Although some countries in the region have decentralized budgetary support for ECI services at the sub-national (regional, provincial, district) and local (municipal levels), depending upon the governance and budgetary structures in each country, coordination systems with inter-sectoral and decentralized agreements are often lacking. In many countries, ECI services still lack a legal basis established through: ECI strategic plans and/or ECI laws and bylaws; ECI guidelines and procedures (regulations); ECI service and personnel standards; universal developmental monitoring and screening and referral systems; child-tracking systems; and ECI monitoring and evaluation systems linked to internal ECI site-level monitoring and evaluation systems. Only a few countries have a coalition of ECI organizations or a network of ECI service providers and/or parents.

Advancements in ECA countries regarding the key elements of ECI systems represent potential strengths for developing national ECI systems. Most countries of the region are dedicated to developing a competent system of contemporary ECI services. This Guide was prepared to help countries move forward in achieving their goals for instituting national ECI systems and contemporary ECI services.

2. Goal and Objectives of the Methodological Guide and National ECI Situation Analyses

Fundamental Goal of the Methodological Guide

The Fundamental Goal is to help countries prepare comprehensive National Situation Analyses of their ECI systems and services for planning an evidence-based and sustainable National ECI System that will offer effective, high-quality, equitable and accountable services for parents and caregivers of infants and young children with developmental delays and difficulties, initially in the region of Europe and Central Asia.[9]

The Methodological Guide has the following objectives:

- To assist countries to use comprehensive research methodologies for developing Situation Analyses focused on the provision of ECI services for children with developmental difficulties from birth to 5 or 6 years of age, with an emphasis on the initial period from birth to 36 months of age.
- To assist countries to establish contemporary, evidence-based and sustainable ECI systems, public institutions, civil society organizations and ECI components within education, health or social welfare institutions and organizations.
- To provide guidance for ensuring the broad participation of leaders of relevant national ministries and agencies, ECI directors in public institutions and civil society organizations, parents and parent associations, associations and federations of persons with disabilities, key academic leaders, leading national ECI specialists, and others who should be involved in developing ECI Situation Analyses and national ECI systems.
- To assist countries to secure, analyse and interpret data essential for planning and preparing well-coordinated and adequately funded national ECI systems that will provide robust, high-quality and sustainable ECI services.

Taking a participatory and decentralized approach to Situation Analyses

To be representative, useful and comprehensive, National Situation Analyses for ECI should not be prepared in a top–down manner, nor should they be drafted by writing teams isolated in ministerial offices far from parents, caregivers, ECI directors and personnel, and national, regional and local leaders.

Rather, ECI Situation Analyses should be conducted using highly participatory approaches that include field work conducted by ECI research teams that survey and consult ECI beneficiaries, personnel, directors and leaders at all levels through focus groups and interviews. In addition, during the drafting process, ample opportunity should be given to ensure ECI Reference Groups are able to review and discuss findings, conclusions and recommendations.

National Situation Analyses formulated by country teams will have objectives such as the following:

- To identify and gather reliable evidence regarding existing national capacities, needs and opportunities to develop culturally and

[9] This Guide was initially drafted based on a methodology developed during the preparation of ECI Situation Analyses in the countries of Myanmar, Georgia and Croatia. The first draft of the Guide and its instruments were field-tested in three countries of South-Eastern Europe, and 'lessons learned' have been incorporated into the present draft. We believe the Guide could be applied to develop ECI Situation Analyses in other world regions; however, for other regions or for very large countries, it should be thoroughly adapted and translated for use, field-tested and revised for further use in those regions.

linguistically appropriate, contemporary and sustainable ECI systems and services.

- To devote equitable attention to all populations of children from birth to 5 or 6 years, with emphasis on birth to 3 years, who are in at-risk situations, and/or have developmental delays, disabilities, behavioural conditions or mental health needs, with special consideration given to the needs of the most vulnerable children, including minority, impoverished, and emergency-affected families.
- To place priority on:
  - identifying barriers to service access and quality, and recommending ways to overcome them;
  - ensuring adequate service coverage in relation to the estimated needs for community outreach and services;
  - increasing the capacity of relevant sectors and disciplines to collaborate closely in creating integrated ECI systems capable of conducting key ECI contemporary organizational and service processes, principles and elements;
  - focusing on the provision of multisectoral activities and the formation of transdisciplinary or interdisciplinary ECI service teams to ensure the provision of competent ECI family-centred services leading to expanded and improved child development;
  - identifying and measuring key ECI performance indicators, including inputs, outputs and outcomes, and establishing initial national targets.

Potential users of the Methodological Guide

The Methodological Guide was prepared with the following readership in mind:

- Leaders and members of ECI research teams
- National leaders and directors of ECI systems who will collaborate with ECI research teams
- National ECI specialists who want to learn more about ECI systems, organizations, components within other organizations, services and processes
- International consultants for ECI systems and services
- Specialists of UNICEF, other global and regional multilateral and bilateral agencies, foundations and international development organizations providing financial and technical support for national ECI research and the development of national ECI systems and services

3. Vision, Scope, Continua of Services and Purposes of ECI Situation Analyses

3.1 Vision and scope of ECI Situation Analyses

The **Vision Statement** for ECI Situation Analyses reflects their main contents and purposes:

Vision Statement for ECI Situation Analyses

ECI Situation Analyses provide essential information on the needs of children with developmental difficulties and their families, the enabling policy environment for ECI systems and services as well as the strengths and requirements of their ECI public institutions and civil society organizations, services, personnel, workforce development activities, and financial and other support at all levels.

They are conducted to help countries plan effectively for establishing or strengthening National ECI Systems to enable them to provide high-quality services to:

- achieve child and parental rights;
- prevent and reverse developmental delays;
- enhance the functioning of children with disabilities and other conditions;
- enable families and caregivers to conduct stimulating developmental activities with their children in their homes, centres and other natural environments; and thereby
- help children achieve their full potential.

ECI Situation Analyses are national in scope. The establishment of a National ECI System requires a major effort at the central level, as well as vertical and horizontal coordination with regional (where present) and local governments and organizations. These sub-national governments often include regional, provincial or oblast governments within countries, as well as local governments, such as municipal and city governments. Inter-governmental coordination and financial partnerships for co-funding are essential to create a comprehensive and sustainable national ECI organizational framework that will ensure all potentially eligible children and their families will be identified at the earliest possible age, through universal developmental monitoring and screening, and will be provided with essential services of a high quality.

National ECI Situation Analyses differ from evaluations of ECI public institutions and civil society organizations and their services. They do not attempt to qualitatively assess ECI organizations, institutions or ECI components in granular detail. Instead, **they address the status of the national ECI system**, if one exists, and they provide descriptions of key components of ECI services.

3.2 Continuum of ECI services

In Eastern Europe and Central Asia, a continuum of various types of ECI services is usually found. Broadly speaking, they include: 1) legacy systems; 2) new services or legacy systems that are evolving in stages to become contemporary ECI services; and 3) contemporary ECI services. The continuum presented below is a simple illustration of a much more nuanced continuum that exists in most countries with gradations from the left to the right.

Continuum of legacy, evolving and contemporary ECI services

Legacy systems include continuing defectology centres, rehabilitation or habilitation hospitals and centres, therapy units in hospitals, child development centres that provide individual therapy services, private therapy centres that

serve children individually and intensively, and community-based rehabilitation services that conduct outreach to children through mobile units and centres usually in villages and rural areas. These services work one-on-one with the child and rarely involve parents in their activities.

Legacy and new services evolving toward becoming contemporary ECI services are found in many, if not most, countries in the region. Increasingly, the personnel in legacy services are becoming interested in receiving training in contemporary ECI concepts and methods. In several countries, training programmes have led to surprisingly rapid changes in both public institutions and civil society organizations and to the establishment of new public institutions and civil society organizations seeking to provide contemporary ECI services. As training and new certifications are provided, both the legacy and the new services continue to evolve and increasingly provide more contemporary ECI services. Most evolving services continue to exhibit some aspects of legacy systems, e.g., exclusive use of centre-based sessions, therapies conducted separately one-on-one, a lack of transdisciplinary teams, or visits with the child without the participation of parents or daily caregivers. Essentially, evolving services are at different stages of development because they adopt some of the attributes of contemporary evidence-based services at different times and in different ways. However, the changes are progressive and a rapid evolution has been observed in some countries.

Contemporary ECI evidence-based services have easily discernible attributes in terms of their concepts, procedures, methods, contents and approaches to equity, quality and accountability. As presented below in Table 1, a continuum of services, from legacy services to evolving services to contemporary ECI services, is usually found in most countries of Western and Eastern Europe, South-Eastern Europe, the Caucasus and Central Asia. Some countries predominantly offer legacy services, while others, such as Portugal and Georgia, mainly provide contemporary ECI services. Currently, most countries have several legacy services, many evolving services, and some contemporary ECI services. Selected attributes are presented below showing some of the types of differences often found among legacy, evolving and contemporary services regarding their structural frameworks, personnel, beneficiaries and their roles, and types of ECI services.

TABLE 1: Continuum of legacy, evolving and contemporary ECI services

Attribute	Legacy services	Evolving services	Contemporary services
Structural framework			
Type of model	Medical model	Evolving from medical to social model	Social model
Service approaches	Disciplinary and practice-based services	Moving toward interdisciplinary and evidence-based services	Interdisciplinary/ transdisciplinary and evidence-based services
Legal and organizational basis	Have medical policies and protocols if any	Considering the development of a costed Strategic Plan and possibly with an ECI law and bylaws	Have a costed ECI strategic plan and/or a national ECI law
Regulations	Medical protocols	Medical protocols plus beginning to develop national ECI regulations	National ECI Guidelines and Procedures adopted
Service and Personnel Standards	Rarely found	Some ECI Service Standards being developed	ECI Service and Personnel Standards adopted

Attribute	Legacy services	Evolving services	Contemporary services
Location of services	Hospital- or centre-based services	Mainly hospital- or centre-based services with some home visits	Services provided in the natural environments of child: homes used (80%) or inclusive nurseries and preschools (20%)
Support and Service Coordination	Medical support and rehabilitation service coordination	Beginning to consider nationwide multi-sectoral support and coordination	Integrated ECI support and coordination at the national, regional and municipal levels
Personnel			
Personnel	Physicians, therapists	Physicians, therapists and other specialists being added	Early intervention specialists, therapists, psychologists, social workers, and paraprofessionals[10]
Professional status	Certified professionals	Certified professionals	Certified professionals and trained and supervised paraprofessionals, in defined roles
Supervisors	Medical or rehabilitation supervisors	Mainly medical or rehabilitation supervisors	Interdisciplinary ECI-trained supervisors
Beneficiaries and their roles			
Children served	Children with disabilities; mainly for children from 3 to 6+ years of age	Evolving to serve children with at risk situations, delays, disabilities, behavioural conditions and mental health needs, 0 to 5 or 6 years with a greater focus on 0 to 3 years	Children with at-risk situations, developmental delays, disabilities, behavioural conditions, and mental health needs with a focus on children 0 to 3 years, and up to 5 or 6 years, as needed
Child- or family-centred services	Entirely child-centred services	Child-centred and increasingly becoming family-centred	Entirely family-centred services
Parenting activities	Do not focus on parenting activities	Are evolving toward giving more attention to parenting activities	Major emphasis given to supporting nurturing parenting activities
Level of parent participation in child development	Little participation in child development	Some participation in child development	Parents lead, participate fully, and make decisions regarding goals for child development

[10] Paraprofessionals are defined as non-professionals with a completed secondary education and often university education in another field, who are trained and supervised by professionals to provide specific ECI activities in ECI, e.g., home visits, community outreach visits, case management and centre-based support services. They are used in several countries of the ECARO region.

Attribute	Legacy services	Evolving services	Contemporary services
		ECI services	
Early identification and eligibility	Medical diagnosis, only physician monitoring/ surveillance	Medical diagnosis, monitoring/surveillance of child development, and beginning to use a developmental screening instrument	Medical diagnosis, monitoring/surveillance of child development plus community outreach and use a developmental screening instrument
Child assessment instruments	Medical personnel and therapists use specialized assessments	Mainly specialized assessments and some validated comprehensive developmental assessments are used	Validated comprehensive developmental assessments are always used plus selected specialized assessments, as needed
Family environment and support	Little or no attention given to family environment and support	Growing interest in understanding the family environment and providing family support	Major attention is paid to the family environment, family support and to family networks (eco-mapping)
Leadership for preparing the plan of services	Service plan, if used, is prepared by a physician or therapist	Service plan is prepared by a physician or therapist, but increasingly with the family present	Parents participate fully in the development of plans of service and are members of the transdisciplinary or interdisciplinary team
Transition plan to next services	No transition plan is prepared; professionals send the child to a specialized school	No transition plan is prepared; professionals increasingly send the child to an inclusive school	Parents are fully involved in preparing a transition plan and the child is usually transitioned to an inclusive preschool or primary school

3.3 Types of ECI institutions and organizations to include in the Situation Analysis

In each National ECI Situation Analysis, every attempt should be made to identify, locate and survey all ECI public institutions (usually found in the education, health and social protection sectors), civil society organizations and ECI components within other institutions or organizations. These entities might include: 1) a sample of legacy services; 2) all or most services that are evolving toward becoming contemporary ECI services; and 3) to the extent possible, all contemporary ECI services that exhibit many or all critical dimensions usually found in quality ECI services. National ECI Situation Analyses study the characteristics, coverage and status of ECI services for use in policy and service planning.

National ECI Situation Analyses do not attempt to study general ECD or sectoral-level institutions or organizations that lack services for children with developmental delays and disabilities from birth to 6 years of age. In some cases, one or two examples of ECI-related sectoral-level services may be included, e.g., a hospital with NICU services that collaborates with ECI services, a social work centre that provides services for parents of ECI-eligible children, or psychological

counselling services that collaborate with ECI institutions and organizations. Excluded services should include general maternal/child health and nutrition services, ECD services for typically developing children, non-inclusive preschools, and residential care institutions for children with disabilities or children without parental care.[11]

ECI Situation Analyses address community outreach activities, developmental screening, physician-based surveillance and monitoring services and processes to identify children and their families needing ECI services. These services are usually included in contemporary ECI services; however, they can also be conducted as parallel activities with other institutions, e.g., inclusive preschools, patronage nursing services within primary health care provision and others. They also focus on sequential and parallel service activities that are typically pursued by ECI organizations and institutions and ECI components within other institutions and organizations. They examine the alignment or non-alignment of policy, regulatory and methodological approaches, and the degree to which national ECI systems and services implement contemporary evidence-based practices.

3.4 Purposes of ECI Situation Analyses

The **General Purposes** of National ECI Situation Analyses include the following:

General Purposes of National ECI Situation Analyses
• Provide essential information for planning participatory processes to formulate evidence- based, culturally and linguistically appropriate national ECI strategic plans, action plans, legislation, guidelines and procedures, and service and personnel standards. • Identify areas of existing institutional and professional strengths and competencies, along with emerging interests in improving ECI services. • Ascertain geographical regions and populations that lack ECI services or lack access to existing services, including minority ethnic groups, low-income populations and families living in small towns, villages, rural and remote areas, including islands. • Create a rising demand for high-quality, equitable and effective family-centred ECI services that support parents and address their stated needs for more and improved ECI services. • Reinforce or help to build inter-agency agreements, networks, coalitions and other forms of collaboration and coordination to achieve ECI goals. • Enable good accountability through assembling existing data for establishing multisectoral ECI monitoring and evaluation systems, including indicators, targets and baselines for the measurement of inputs, outputs and outcomes.

[11] If the residential care institution provides developmental services for children living in the community, then those services may be included.

4. Background, Core Concepts and Processes of National ECI Systems and Services

4.1 Background regarding the field of ECI

To conduct research on ECI systems and services, it is essential to clarify the core concepts and general processes of evolving and contemporary ECI activities that will be studied in the Situation Analyses. In addition, Annex 2: Definitions clarifies several terms commonly used in ECI services that may be useful for researchers, interviewers, focus group leaders and ECI professionals.

The precursors of comprehensive ECI organizations were initially developed during the 1970s in the United States and Colombia. In the United States, Ira Gordon, Craig Ramey, David Weikart and others designed early longitudinal research programmes that formed the basis of ECI services in the United States and many other countries (Gordon, 1972; Ramey & Campbell, 1984). In Colombia, from 1972 to 1976, early research and ECI service development with the younger siblings of severely stunted children living in impoverished families was conducted by the Colombian Institute for Family Welfare, Harvard University's School of Public Health and the University of Giessen. This research revealed that younger siblings served from birth onward could attain typical levels of development when provided with three services: parent education for nurturing care and stimulation; basic health care; and nutrition services for the entire family (Super et al., 1981). These results motivated many young researchers, including the lead author, to pursue research and ECI service development in Colombia and the United States. In Colombia thousands of organizations were developed and in the United States, the national ECI system was launched in the 1980s.

Since then, research in the fields of early childhood intervention, child development, neuroscience, and child and community psychology, amongst others, have contributed to the growth of an extensive evidence base regarding ways to support families effectively and help them to enable the balanced development of their children with difficulties and to enable them to attain and often exceed expected levels of development.

4.2 Core concepts of contemporary ECI services

The following **core ECI concepts** guide the development of comprehensive, effective, equitable, high-quality and sustainable ECI systems and services. Together, they provide some key contemporary ECI concepts that should help ECI research teams design and conduct their research.

ECI is a social model

ECI is an integrated social model that contains elements related to education, health, therapies, nutrition, social protection, child and parental rights, and welfare. It usually has the strong support and collaboration of national ministries and agencies in the major social development sectors of education, health, nutrition, sanitation and social protection, policy and welfare. This integrated social approach differentiates ECI from diagnostic and rehabilitation services of the field of medicine that focus mainly or solely on the child's area(s) of delay or disability. Instead, **ECI focuses on the comprehensive and holistic development of the child and the family**, with special attention given to the areas of greatest need of the family and child. ECI builds on each child's strengths and then addresses emerging areas of development. Abundant research has shown that the social model is highly effective in achieving improved child development and competent functioning and participation in school and society (Kennedy et al., 2010). At no

point does ECI seek to "cure the child." Rather, it helps children with differing abilities attain their full developmental potential.

In all world regions, increasingly many, but not all, rehabilitation and habilitation services are evolving to become ECI services. This change has been slow, but once it begins, experience has shown that it tends to continue and speed up over time. This evolution is composed of small and large changes over time. Ultimately, ECI's social model has been found to be eminently rewarding to personnel, highly beneficial for families and children, and helpful to nations that have the goal of building a better developed and a more competent and productive citizenry.

ECI is family-centred

ECI services are family-centred while also focusing on the child's good and balanced development. In ECI, the important actors are the parents, close relatives and daily caregivers rather than professionals or well trained and supervised paraprofessional home visitors. ECI service personnel ask parents what they want their child to achieve and enquire about how the personnel might best be able to help parents achieve their goals for their child and their family. They suggest options and coach and mentor parents and other caregivers to assist them to achieve their goals for their child and themselves. They seek to **ensure that parents make all the key decisions regarding their child's goals and services** while also addressing the parents' voiced needs for support. Research has shown that this family-centred approach strengthens families and leads to better child development outcomes (Dunst, 2006).

ECI is early and continuous

ECI services seek to identify and support children as infants or as early in life as possible, preferably during the first weeks or months of life, and well before 3 years of age. Thus, services are provided from the earliest identification of a child with an at-risk situation, developmental delay, disability, behavioural condition or mental health need. Depending upon national policy decisions, ECI services extend either from birth to 36 months of age or up to 6 years of age. Once a child attains typical levels of development, parents are usually offered from three to six months of occasional visits to ensure that the child's developmental gains are consolidated. For children with delays or disabilities who could benefit from additional services, depending upon policy decisions, they either remain in ECI services and/or transition to inclusive preschool services. Those remaining in ECI services transition by age 6 usually to inclusive primary education, or if parents so decide, to other available services and educational facilities. Preference is given to inclusive educational services to begin the child's full inclusion in society.

ECI is individualized

ECI processes and contents focus on the strengths, needs and challenges of each individual child within the family context. It does not provide a common curriculum to be used with all children – irrespective of their needs. This approach enables ECI service providers to build on the strengths of each family and child while identifying their needs and addressing their emerging developmental abilities.

ECI is intensive

According to the needs of each child and family, the designated ECI service provider (that can include an early intervention specialist (EIS), physical therapist, speech/language therapist, occupational therapist, psychologist, special educator, social worker, other professional or a paraprofessional home visitor) provides scheduled visits to families in the natural environment of the child, which is usually the child's home. The schedule of visits is established with the full participation and agreement of the parents during the preparation of an Individualized Family Service Plan (IFSP). Visit schedules can vary according to the needs of the child and the family. During the early weeks of service, visits can be quite intensive due to identified needs, varying from two to even four visits a week. Usually, after the child's situation is stabilized, visits can be reduced to once a week. After a child and family have made major progress in attaining agreed-upon goals, visits may be reduced to once every two weeks. For the final consolidation of gains achieved, visits can be reduced to once per month. These decisions are made collaboratively between the main service provider and parents

or caregivers, and sometimes with the support of the supervisor. Some children who are already enrolled in daily services of inclusive childcare centres or preschools may receive some of their visits in those establishments, with the full participation of their centre-based caregivers or teachers. Parents are invited to participate in these visits. However, if parents are employed full-time, they are encouraged to participate in at least one visit per month in the centre. In the meantime, centre-based caregivers or teachers are instructed to regularly share the activities of each centre-based visit with the child's parents.

ECI services are evidence-based and outcomes-driven

All ECI organizations and ECI components within other organizations seek to use the latest and most reliable research results that are available to help them plan, develop and provide their services with families and children. The large international literature on ECI services and their outcomes was used as the basis for listing these core ECI concepts, framing the Conceptual Framework, and applying the Theory of Change. This evidence base should guide the development of all ECI public institutions, organizations and components, including the selection and application of research instruments, and the analysis of study findings. ECI services develop a discrete list of indicators that are related to desired outcomes. These monitoring and evaluation frameworks help guide service planning and implementation, the activities of the national ECI systems, and the functioning of their monitoring and evaluation systems. Ultimately, selected outcomes drive all ECI work, and they help ECI institutions, organizations and their components to achieve high-quality services that will improve child and family development and will achieve a wide array of other short-, medium- and long-term objectives.

ECI is interdisciplinary and usually transdisciplinary, integrated and team-based

As noted, all ECI services are interdisciplinary, including the sectors of education, health, nutrition, sanitation, child protection and child welfare, as well as several disciplines that pertain to these sectors, from social work, education and health to therapies, psychology and related social development fields. For this reason, **ECI systems and organizations are always integrated across sectors and disciplines to provide one united service to families and their children**.

Legacy systems are multidisciplinary; however, they rarely form teams. Instead, professionals from various sectors and disciplines provide separate services directly to individual children. In contrast, contemporary ECI services are always provided in teams that function in an interdisciplinary or transdisciplinary manner. ECI services are not offered by single therapists or a group of therapists in one therapeutic field. ECI teams include two or more professionals in different fields, including therapists, early intervention specialists (EIS), social workers, psychologists and others. EIS are interdisciplinary ECI specialists who are trained in skills pertaining to all disciplines, therapies, ECI guidelines and procedures, and standards used in ECI services.

In **Transdisciplinary Teams**, all or most members of the team jointly conduct comprehensive child assessments and Individualized Family Service Plans (IFSPs). They select one member of their team to become the **primary service provider** who makes most of the home visits and/or centre-based visits. Other members of the Transdisciplinary Team provide technical support to the primary service provider.

In **Interdisciplinary Teams**, team members often conduct comprehensive developmental assessments together, although sometimes they conduct separate specialized assessments and then meet to discuss their findings. They also meet as a group to prepare the IFSP with the parents. Interdisciplinary team members usually do not appoint a primary service provider. Instead, they make separate individual visits with the parent. In contrast to multidisciplinary services where each specialist usually works separately, in interdisciplinary teams they regularly confer amongst themselves and support each other before and after visits. Other variants of interdisciplinary teams may be found in some countries.

Increasingly, contemporary ECI institutions, organizations and components are using Transdisciplinary Teams because they tend to be more cost-effective, permitting them to serve

more families and children better, and usually at a lower overall cost per child.

All members of ECI Transdisciplinary or Interdisciplinary Teams focus on supporting, mentoring and coaching parents and family members as the best way to serve the child. Parents are always key members of both Transdisciplinary and Interdisciplinary Teams.

Every ECI organization or ECI component within another organization offers a discrete list of essential services and some optional ones

The national selection of essential and optional services is always presented in regulatory documents usually called "**ECI Guidelines and Procedures**", along with core ECI concepts, rules, guidance and methods.

Essential ECI services usually include:

- Community and health outreach activities to locate, identify, screen and assess children from birth to 3 years or older, if not previously identified[12]
- Referrals to and from ECI services
- Developmental monitoring and screenings for all children leading to the initial identification of children who may need ECI services
- Initial entry procedures
- Comprehensive developmental assessments and regular re-assessments over time
- Specialized developmental assessments, i.e., autism, speech/language, etc. as needed
- Decisions regarding eligibility or parent-approved referrals to other services
- Family and home-context assessments
- Preparation of Individualized Family Service Plans (IFSPs) and regular revisions, as needed
- Provision of early stimulation and development visits in the natural environment of the child (home visits or visits to inclusive childcare centres, inclusive ECE centres or other places where the child is present on a regular basis)
- Provision of occupational therapy services, including self-help skills, sensory or physical development, and adaptive behaviour and play
- Physical therapy services to improve gross and fine motor development, develop agile movements and strength, and manage functional challenges
- Speech therapy services to overcome speech delays, improve receptive language, communications skills, swallowing and other speech difficulties
- Individualized and/or group parent education services to help families to parent well in developmental, health, nutritional and other areas, to understand the needs of their child, etc.
- Case management services for parents to help them learn their rights and their children's rights, identify their strengths and needs, and to support them by means of service management
- Support parents in making their home environments more stimulating, safe and hygienic for their child and family
- Translation and interpretation services for families, if needed, to ensure services are provided in the family's home language to enhance understanding
- Help the family and child with supportive transition and completion activities from ECI services to inclusive early childhood education or primary school services

Optional services vary by the country, the needs and requests of families and communities, and the level of development of ECI systems. They may include:

- Nutrition services to help parents meet the nutritional needs of their children, such as: improvement of the child's daily diet, feeding skills, breastfeeding, complementary feeding, allergies, improving the nutritional status of a child with stunting or wasting
- Psychological support services for children or parents, e.g., administering psychological tests, assessing child behaviour, mental health counselling, family therapy
- Provision of assistive technologies and adaptive equipment to help children develop, see, hear, play, eat, learn, communicate and move better

[12] Please see the definition of community outreach in **Annex 2: Definitions**.

- Audiology services for children to identify, prevent or treat hearing loss
- Ophthalmological and other vision services to identify children with low vision, visual disorders or delays, and support their parents
- Parental peer groups, when requested with the goal of reducing parental isolation by helping them forge friendships with other parents facing similar challenges and needs
- Access to a Toy and Book Library[13] and toy-making support in ECI centres, local libraries or other community centres
- Nursing services to support the special healthcare needs of a child and to teach parents how to administer medications, provide treatments and conduct other healthcare activities
- Provision of respite care for parents and other primary caregivers to give them a break from constant caregiving
- Mobility and orientation specialists for blind and low-vision children
- Rehabilitation or habilitation services requiring specialized equipment and other technologies

ECI provides services in the natural environment of the child

ECI services are usually provided through home visits, with a focus on using the daily routines of the family and their childcare-giving activities to embed opportunities for enhancing child development. However, for children who receive daily centre-based services, some or most of the visits may be provided in the child's care centre, nursery, inclusive preschool or another similar place. Parents are asked to be present for as many of the centre-based visits as possible. Sometimes visits also occur in parks, markets and playgrounds. In some countries, services are provided in residential institutions for young children. However, increasingly ECI services are playing a critically important role in the deinstitutionalization of children, and in the prevention of institutionalization through supporting biological families to provide nurturing care, thereby reducing the risk of separation and institutionalization. They also assist with the placement of children with nurturing families and they support adoptive or foster parents with the good development of the children that they receive into their homes.

ECI is community-based and supported from the regional and central levels

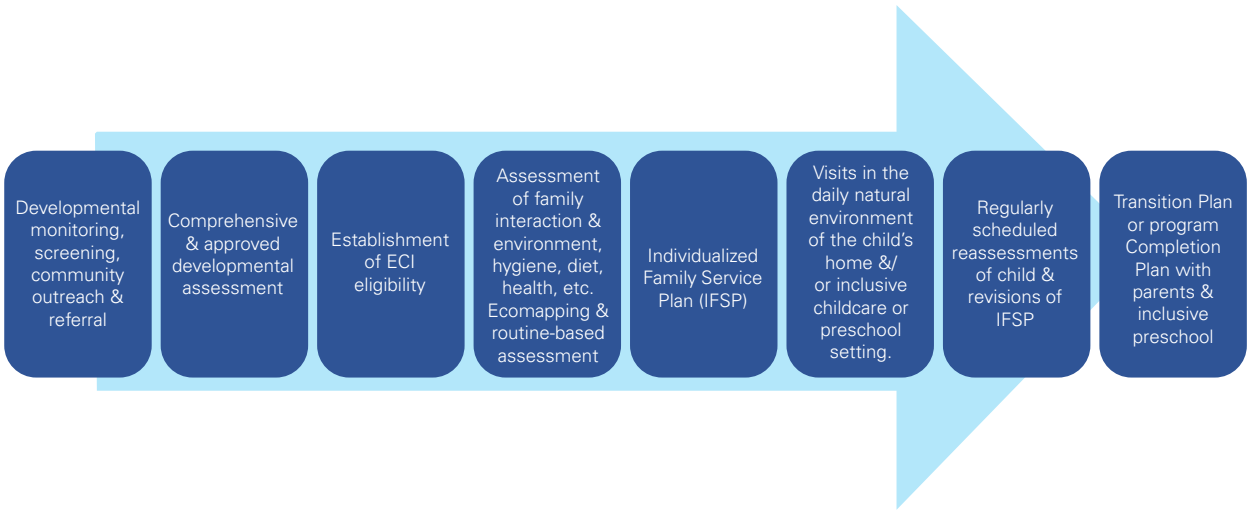
All effective ECI services are well-knit into the community. They secure local support from ECI community boards and accept community volunteers. In mature ECI systems, regional and central managers and supervisors usually support, coach, mentor, assist and monitor and evaluate community-level ECI services. Both vertical and horizontal coordination and sharing occur in large ECI systems.

The contemporary ECI service process

Contemporary ECI services follow a basic sequence of steps in usual ECI service processes. These basic steps are presented in Figure 1 and described below:

[13] A Toy and Book Library is a public place that provides open access to children's books and developmentally appropriate toys.

FIGURE 1: Contemporary ECI service process



Health services and developmental monitoring/surveillance by physicians

In some countries, many children are first identified as having a disability or other ECI-eligible condition by their neonatal intensive care unit (NICU) or by a paediatrician or family doctor during regular check-ups of healthy children (often called well-child check-ups) and immunizations. Physicians often use general developmental monitoring/ surveillance approaches[14] to identify children who are not achieving developmental milestones. This information-gathering process is intended to be flexible, longitudinal, continuous and cumulative. However, developmental monitoring/ surveillance and methods are less formal than the application of well-structured and validated instruments for developmental screening. Some children in at-risk situations, and/or with mild disabilities, developmental delays, behavioural conditions or mental health needs may go unidentified unless the physician is trained to identify them. Physicians may lack the time or training to use a simple developmental screening tool that would greatly help them to identify these children. Many countries, such as Georgia, have trained thousands of physicians to use developmental screening tools but they have found there is no guarantee that, once trained, they will use them. When a child is identified as having a possibly eligible condition, either through monitoring/ surveillance and and/or through the application of a developmental screening instrument, physicians usually refer the child to an ECI centre, if one exists in the community. If not, the physician suggests that the parents look for one in another place. Although very valuable, these physician-led services have been shown to miss numerous children who would have been eligible for ECI services at an early age when they would most have benefitted from them.

Community outreach, developmental screening and referrals

ECI services often begin with "community outreach" which is usually composed of visits by ECI personnel to homes to talk with parents about the development of their children, as well as of visits to hospitals, NICUs, clinics and physicians' offices to encourage those medical specialists and their nurses them to refer children to ECI services. Increasingly, physicians ask their nurses to sit with parents and conduct a rapid developmental screening using a culturally appropriate and validated instrument. In many countries, developmental screenings are conducted by childcare personnel, preschool teachers, the parents themselves, community health workers and other community service providers, all of whom can be trained in half a day to conduct reliable developmental screenings. In addition to identification methods, referral systems must

[14] For further information on developmental surveillance and monitoring, please refer to Annex 2: Definitions.

be constructed with specific rules to ensure children and families will receive timely initial ECI intake services, a comprehensive developmental assessment and, if the child is ECI-eligible, rapid enrolment in ECI services. Finally, systematic feedback from the ECI public institution or civil society organization to the point of referral is very important and must be conducted. Procedural safeguards regarding child and parental rights should be carefully observed. In this regard, personnel conducting developmental screenings should be supervised and observed for the manner and accuracy of their work with parents.

Comprehensive and approved developmental assessments

Comprehensive developmental assessments, such as the Hawaiian Early Learning Programme (HELP) Strands; Assessment, Evaluation, and Programming System (AEPS-3); the Brigance; or the Battelle Developmental Inventory, are conducted by a Transdisciplinary Team or an Interdisciplinary Team. In cases where they are needed, specialized developmental assessments are also used to assess language delays, auditory or visual impairments, autism spectrum disorders and other conditions.

Establishment of ECI eligibility

Based on a medical diagnosis, which may be secured at birth or anytime thereafter, and/or the results of the application of a comprehensive developmental assessment instrument within the continuum of developmental monitoring, ECI eligibility is established. In some countries with legacy systems, only medical diagnoses are accepted, although this requirement is disappearing rapidly. In contemporary ECI systems, medical diagnoses and/or comprehensive developmental assessments are used to establish the eligibility of infants and young children to receive ECI services. In contemporary ECI services, all children, including those with a medical diagnosis, receive a comprehensive developmental assessment because assessment results provide essential information for preparing Individualized Family Service Plans and for the provision of developmentally appropriate home visits and other types of visits.

Conducting family assessments

Once ECI eligibility has been established, many ECI programmes conduct family assessments with the full agreement and participation of the parents. Topics for family assessments may include questionnaires regarding levels of home-environment stimulation, parent–child interaction, child diet, home safety and family hygiene. Interviews help identify daily family and child caregiving routines that can be used effectively for routine-based intervention. In addition, ecomaps are often prepared where parents draw a diagram of their points of support in their community, including relatives, friends, services and other places where they often go. Parents often initially have relatively weak points of support, and when they discover this, their service provider or a case manager helps them to develop friendship networks, secure additional needed services and other relationships that will help them and their children to flourish within their community. The results of the application of these instruments, along with those of the comprehensive developmental assessment and basic intake information, are used to help prepare the Individualized Family Service Plan (IFSP).

Individualized Family Service Plan

The IFSP is a contract that is developed with full parental involvement. It establishes the developmental goals of the child and family, identifies child and family support needs, notes the periodicity of visits and other topics. Participants include the parents, professionals from at least two disciplines and perhaps a paraprofessional home visitor, if they are used in the country. When Transdisciplinary Teams are used, the primary service provider (the early interventionist, therapist or, in some cases, a paraprofessional home visitor) is often selected during the session. Then the IFSP is signed and dated by the parents and other members of the Team.

Visits to the child's home or another daily natural environment of the child

Visits are carefully planned and conducted by the primary service provider with the parents

or another caregiver and the child in the home or another daily natural environment of the child. They usually include activities in a few developmental areas related to goals identified by the parents. The primary service provider helps guide the parents or caregiver to do the activities, sometimes modelling behaviours and vocalizations. They frequently provide positive feedback to the parents or caregivers. The latter are encouraged to do the activities during all or most daily child caregiving routines, such as bathing, dressing, feeding and play times. Home visits include topics on child health, nutrition and safety needs, family needs and other matters of importance to the family. An easy-to-prepare visit report is completed soon after each visit. The next home visit is usually planned at the same time. At first, visit planning and reporting takes considerable time. As professionals become more adept and experienced, they only require from 15 to 20 minutes to report on a home visit and plan the next one.

Regularly scheduled reassessments of the child and family

After six months, the comprehensive developmental assessment and, depending upon the need, other specialized assessments are conducted by the Transdisciplinary Team, which includes the parents. If findings reveal that major changes are needed in the IFSP, then it is also revised and updated with the participation of the parents as members of the Transdisciplinary Team.

ECI Transition Plan or Service Completion

Children who attain typical levels of development (often after 9 to 18 months in ECI services) essentially complete and exit ECI services. Final assessments are conducted to ensure the child's developmental gains have been well consolidated. Parents of children who continue to have developmental delays, disabilities or other conditions and reach an older age usually want them to transition to an inclusive preschool, inclusive primary school or, depending upon parents' decisions, to another suitable service, such as a school for children who are hearing-impaired or visually impaired. These parents and their children enter a supportive process of developing a Transition Plan with steps for preparing the child, family and receiving institution for the child's transition. This Plan should provide considerable emotional support to families and children as well as assist the personnel of the receiving inclusive school or centre. Teachers and principals receive technical guidance from ECI personnel on how to build on the child's strengths and achievements, support the child's continuing development and ensure the full involvement of parents in their child's further growth and development.

5. ECI Theory of Change and Conceptual Framework

5.1 ECI Theory of Change

The Theory of Change (ToC) for ECI systems presents a comprehensive approach that can be used for the explanation of ECI systems as well as for studying ECI in its major dimensions. The ToC presented in Figure 2 below is composed of a sequence of seven phases:

- Pre-existing situations of children (causal conditions)
- Resulting child conditions (presenting situations)
- Dimensions of a national ECI system (organizational framework)
- Preconditions for providing quality ECI services (inputs)
- Core ECI services (outputs)
- Key service outcomes (short- to medium-term outcomes)
- Generational benefits to nation (long-term outcomes)

Pre-existing situations of children

The ToC first presents the pre-existing situations of children, including socio-economic and contextual causal issues, poor birth outcomes and disabilities, nutritional and chronic health challenges, inadequate child rearing and stimulation, and major life stressors due especially to traumatic situations that can result in behavioural and mental health conditions that require ECI services.

Resulting child conditions

The next phase presents the major types of impacts on children that can result in conditions that make children eligible for ECI services, including: a) an at-risk situation, b) developmental delays, c) disabilities and d) behavioural or mental health needs.

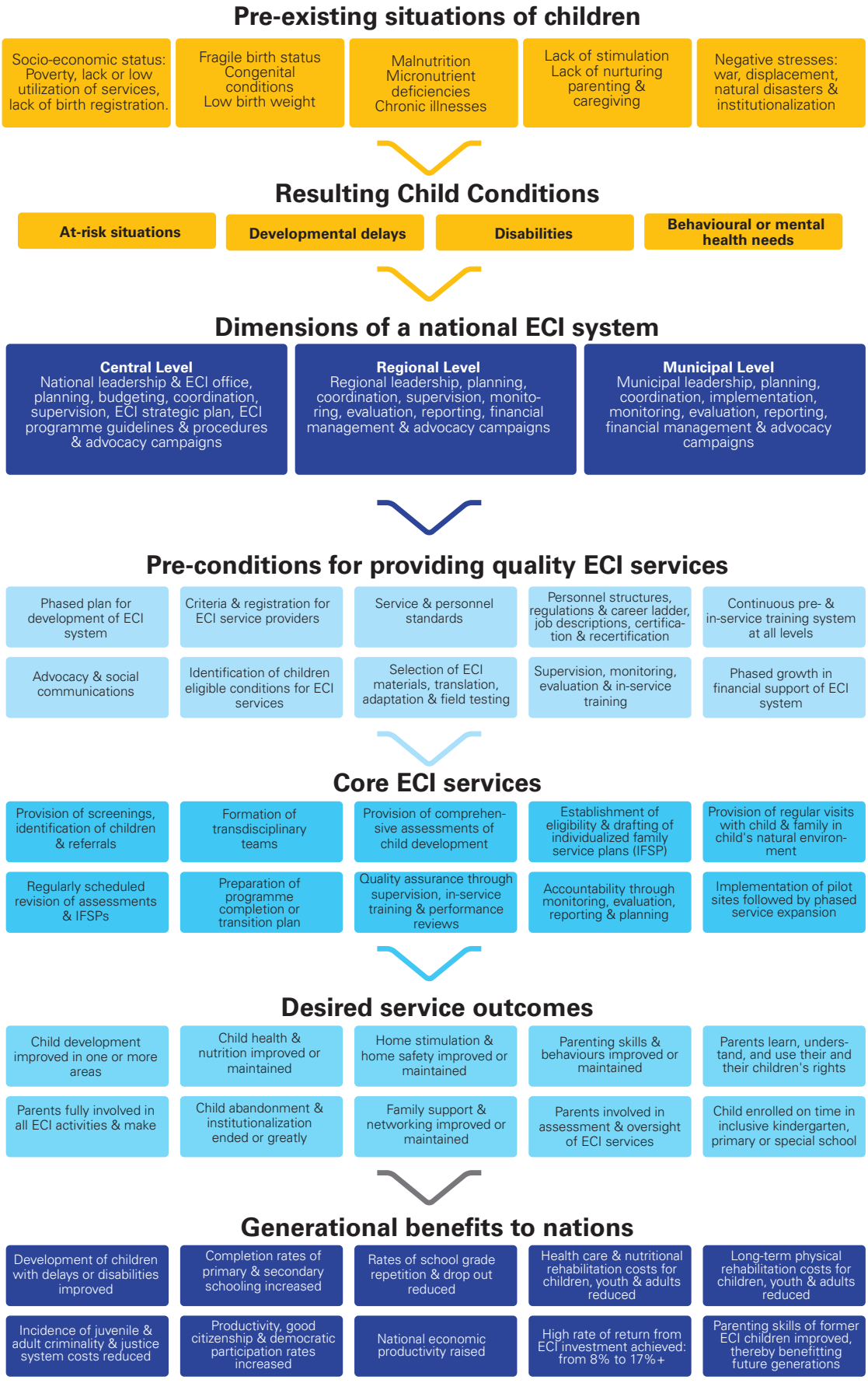
Some dimensions of a national ECI system

To create comprehensive, high-quality and universally available ECI services, an organizational framework is needed with central, provincial and municipal leadership and coordination for community-level ECI services and support for children and families. To serve all eligible children, a strong, equitable, high-quality, accessible and accountable national ECI system must be established. At the central level the legal basis of the ECI system must be established with a central management structure, ECI guidelines and procedures, support for well-coordinated, supervised, monitored and evaluated services, with annual reporting, planning and budgeting. For countries with provinces, provincial ECI leaders must conduct activities for coordination, planning, supervision, financial management, monitoring and evaluation, reporting and advocacy. Similarly, municipalities, often called "local governments" should represent community and family needs and use decentralized funds, where available, to complement central funds from ministries and agencies for the provision of ECI services and advocacy in communities. Diversified funding may be needed from a variety of sources including global and regional funds, foundations, private-sector donations and fundraising activities.

Preconditions for providing quality ECI services

A series of preconditions, including normative (regulatory) instruments, such as ECI Guidelines and Procedures and other regulations are required to develop a system of integrated, accountable and sustainable ECI services. They include a phased annual work plan, criteria and registration for ECI service providers, service and personnel standards, personnel structures, regulations, career ladder, job descriptions, certification and recertification, a continuous system of pre- and in-service training at all levels, advocacy and social communications to families and organizations, outreach and identification of children with eligible conditions, selection of service contents and adaptation, translation and field-testing as needed, supervision, monitoring and evaluation linked to in-service training and initiatives to ensure the phased growth and diversification of financial support.

FIGURE 2. **Theory of Change for Early Childhood Intervention Services**



Core ECI services

Once the national ECI system is in place, then, to meet growing demand for services, the improvement and expansion of existing ECI public institutions and civil society organizations can be undertaken, as well as the development of new ones. Core services include those listed in the chart and others listed previously.

Desired service outcomes

Once the ECI organizational framework and ECI services are well-implemented, a series of key short- to medium-term child and family outcomes can be attained that will lead to major benefits for children, families, communities and the nation. Indicators usually deal with child development, child health and nutrition, home stimulation and home safety, improvement of parenting skills, parental and child rights, parental participation and decision making, reduction or ending of institutionalization, improvement of family support and networking, parental involvement in service assessment and oversight, and the timely enrolment of children in inclusive preschool, primary or, if necessary, a special school.

Generational benefits to nation

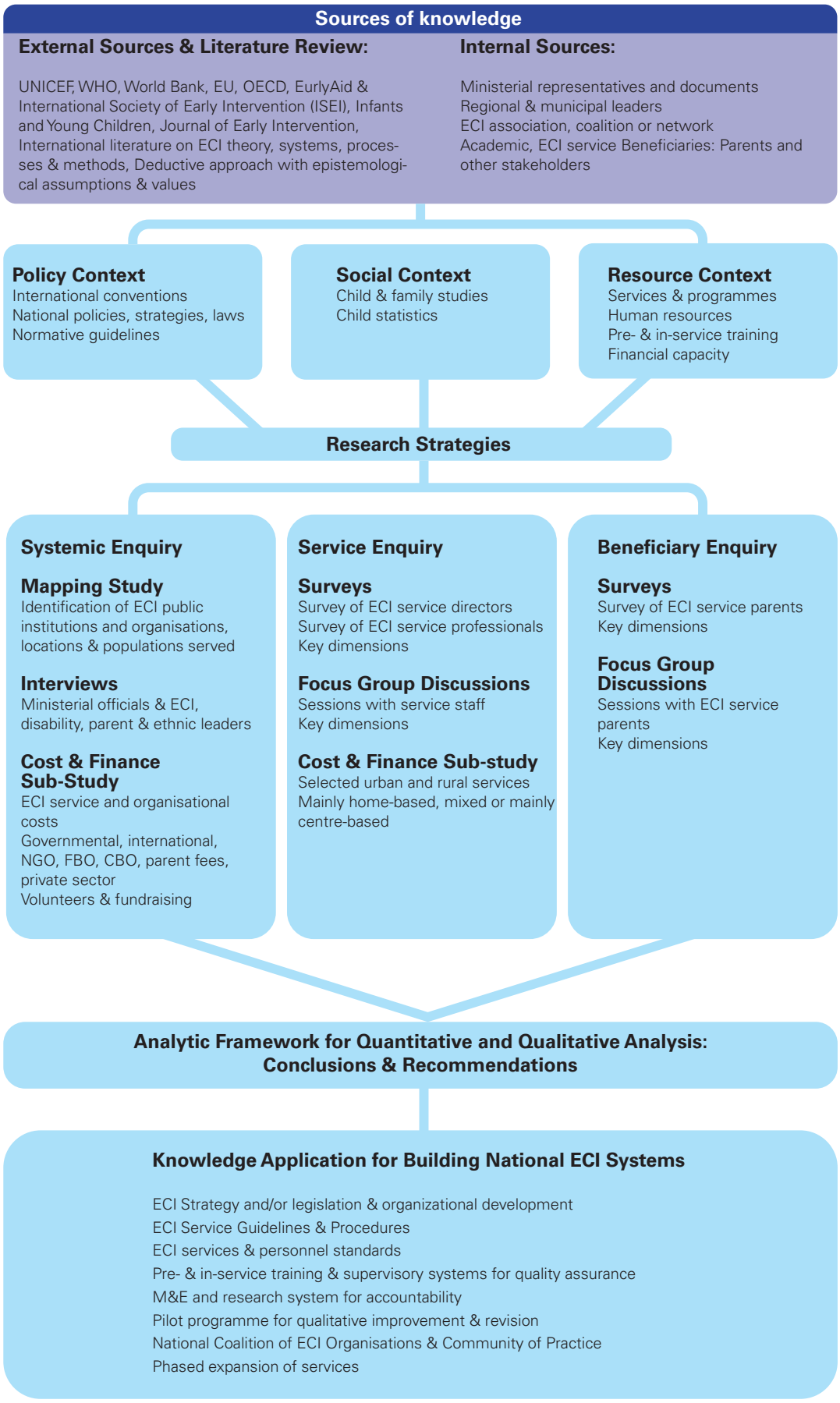
The generational benefits to a nation are multiple. They are included because supporting ECI constitutes investments that yield short-, medium- and long-term benefits. The long-term outcomes presented in the ToC are based on research findings that include improvement of individual and national productivity and wellbeing, as well as the reduction of social pathologies, treatment costs and community violence.

Together, the **ECI Core Concepts** and the **ECI ToC** guided the development of the Conceptual Framework required to structure the research design and develop research instruments for preparing a robust and useful National ECI Situation Analysis.

5.2 Conceptual Framework for Conducting ECI Situation Analyses

The Conceptual Framework, presented in Figure 3 below, outlines the major elements for conducting a comprehensive and thorough ECI Situation Analysis.

FIGURE 3. Conceptual Framework for ECI Situation Analysis



The Conceptual Framework includes the following key elements:

- Sources of knowledge, including both external and internal sources, including policy, social and resource contexts
- Research strategies, including systemic enquiries, service15 enquiries and beneficiary enquiries, with lists of the types of instruments per type of enquiry
- An Analytical Framework for Quantitative and Qualitative Analysis with Conclusions and Recommendations
- Knowledge Application for Building National ECI Systems

This Conceptual Framework outlines the methodological approaches used for the literature review and field research to secure data for the preparation of National ECI Situation Analyses. The following chapter presents the methodological approaches.

[15] Service enquiries relate to ECI organizations, institutions or to ECI components within an organizational entity. In ECI, services are the various activities provided by ECI organizations or ECI components within organizations.

6. Methodological Approaches of ECI Situation Analyses and Major Research Questions

6.1 Methodological approaches and list of research instruments

A **sequential mixed-method approach** is used for the quantitative and qualitative research conducted to prepare National ECI Situation Analyses. Data, often addressing the same topics, are gathered from different types of respondents who present different points of view. Using different types of respondents has several strengths including the potential triangulation of results, as well as the discovery and reaffirmation of major existing strengths, gaps and needs in ECI services, resources and enabling policy environments. However, a notable limitation of this approach is that certain field research methods are more reliable than others.

The main types of research methods that will be used include: 1) a literature review; 2) surveys; 3) individual high-level interviews; 4) focus group discussions; and 5) a Cost and Finance Sub-Study with survey questions, case studies of a sample of ECI service institutions and organizations, and interviews regarding costs and financial arrangements.

Programme evaluations, including observations of functioning ECI services and related activities, are not included in this approach. Observations are essential for the thorough evaluation of individual ECI institutions, organizations and components within other organizations; however, they require too much time and technical preparation to conduct them well during a nationwide ECI Situation Analysis. Situation Analyses focus on systemic issues and national capacities for purposes of planning and financial projections or simulations. Of course, the addition of comprehensive institutional evaluations would be excellent if enough time and other resources are available.

6.2 List of research instruments

Following is the Research Framework and the discrete list of research activities and instruments:

1. Literature review
2. Mapping survey
3. Survey of ECI directors
4. Survey of ECI service personnel
5. Survey of ECI beneficiaries
6. Cost and Finance Sub-Study
7. Focus groups of ECI service personnel
8. Focus groups of ECI beneficiaries
9. High-level interviews

The **literature review** provides both quantitative and qualitative information, such as a review of policy documents, other situation analyses, and peer-reviewed journal articles; however, many sources are official documents and "grey literature" on specific service institutions and organizations.

Surveys mainly yield quantitative data from a sample of legacy organizations, all evolving organizations and all contemporary ECI organizations that can be found. Sometimes, ECI service components or sub-programmes are found nested within other institutions. ECI research teams often must decide on a sample of service providing institutions and organizations.

Sampling systems used by other studies may be difficult to use due to challenges in identifying potential respondents and securing their full participation. Regional breakdowns, population clusters, gender roles, and other important factors affecting sampling will be different in each country. These factors and others may affect the samples ultimately selected for inclusion in the

study. Recommendations for possible approaches to sampling are provided for each survey and are included in the description of each instrument in the Annexes. Each country's ECI research team must establish its own sample criteria and methods for each type of organization and instrument, except for the mapping survey that entails searching for all possible ECI and ECI-related services.

Apart from interviews with ministries and managers providing data for the case studies of costs that are conducted during the **Cost and Finance Sub-Study, the focus group discussions and high-level interviews** usually provide little quantitative data. However, they yield useful qualitative information, some of which may become quantifiable. General guidance for sampling will be offered for each research instrument; however, the ECI research team must assess its needs and establish its own sampling parameters. The findings and often quotations resulting from focus group discussions will be used to: 1) illustrate major points regarding leading quantified results; 2) identify the felt needs, experiences, opinions or recommendations of the respondents; and 3) include groups that may be hard to reach using online surveys, such as ethnic minority communities, families in rural and remote regions, and people who do not use digital communications, have low literacy levels or speak different languages.

Throughout the research design, every effort needs to be made to consider gender perspectives, the equitable inclusion of all ethnic and/or disadvantaged groups, and ECI services, especially for children from birth to 36 months of age.

The greatest challenge for an ECI research team will be to reduce the number of questions to the minimum number required to meet the study objectives and provide useful results for purposes of future policy and organizational planning and evaluation. Given the complexity of the research design and the brief period usually available for conducting field research, it will be important for each research team to limit the number of questions per instrument. Therefore, many trade-offs may be made during the application of this instruments offered in this Guide.

6.3 Research questions

Some of the major research questions for conducting research to prepare National ECI Situation Analyses are presented in Table 2 below. Each question is linked to one or more specific instruments.

This key represents the columns in the table below:

1. Literature review framework
2. Mapping survey
3. Survey of ECI directors
4. Survey of ECI service personnel
5. Survey of ECI beneficiaries
6. Cost and Finance Sub-Study
7. Focus groups of ECI service personnel
8. Focus groups of ECI beneficiaries
9. High-level interviews

TABLE 2. Major research questions

Question	1	2	3	4	5	6	7	8	9
Basic information									
Where are ECI organizations (legacy, evolving and contemporary) physically located?	X	X	X	X					X
What regions, villages, towns or cities do they serve?	X	X	X	X	X		X		X
What is their coverage in terms of children served?	X		X	X	X		X		X
Enabling policy environment									
What are the national policies, strategic plans, laws, regulations, guidelines and standards in sectors, such as health, education and social protection related to ECI system and services?			X						X
What gaps exist in the policy environment to enable the establishment of a national ECI system and the improvement and expansion of ECI organizations?			X						X
Child and family status									
What is the status of children and families receiving ECI services (by developmental status, family poverty level or income quintile, gender, geographical area, etc.)?			X	X	X		X	X	
How many children in at-risk situations, and/or with delays, disabilities, behavioural conditions and mental health needs currently receive ECI and similar services?	X		X	X	X		X	X	X
What can be done to improve service equity (rural, remote vs. urban, upper- vs. low-income, majority vs. minority groups)?			X	X	X		X	X	X
What roles do parents play in ECI services and what is their level of participation?			X	X	X		X	X	X
How should ECI services ensure they become fully family-centred and enable parents to make decisions and play active roles in maximizing the development of their children?			X	X	X		X	X	X
Outreach, developmental screening and referrals									
What community outreach services are provided?			X	X	X		X	X	X
Is developmental screening conducted along with referrals?			X	X	X		X	X	X
What types of developmental screening are conducted and by which institutions or organizations?			X	X			X		X
What are the needs for more developmental screening and for improving the referral system?			X	X	X		X	X	X
ECI service provision									
What is the ECI service capacity, quality and coverage, with attention to rural and remote communities, disadvantaged ethnic minority groups and others?			X	X			X	X	X

Question	1	2	3	4	5	6	7	8	9
What should be done to overcome barriers and expand service capacity, quality and coverage?			X	X	X		X	X	X
To what extent are ECI services contemporary, e.g., include the following?									
• Community outreach to identify children									
• Developmental screenings									
• Comprehensive developmental assessments									
• Family assessments and eco-mapping			X	X	X		X	X	X
• Individualized Family Service Plans decided by parents									
• Transdisciplinary or Interdisciplinary Teams									
• Visits in the natural environment of the child									
• Revisions of assessments and IFSPs									
• Transition plans									
What more needs to be done to ensure that ECI service providers can adopt the core concepts and key services of contemporary ECI organizations?			X	X			X		X
Human resources									
What types of professionals, paraprofessionals and volunteers work in ECI organizations and what roles do they play?			X	X	X		X	X	
What are the needs for more accredited or licensed professionals, paraprofessionals and volunteers?			X	X	X		X		X
ECI workforce development									
Is pre- and in-service training provided in the country for managers, supervisors, professionals, paraprofessionals and volunteers of ECI services?			X	X			X		X
What are the gaps in pre- and in-service training and what should be done to fill those gaps?			X	X			X		X
What ECI quality assurance measures exist and what more should be done to achieve quality assurance			X	X			X		X
ECI service costs									
What are the major costs of ECI organizations in relation to the types of services they provide?						X			X
What major needs could be met through expanded financial support?						X			X
ECI financial resources									
What financial resources are invested in ECI by the type of source including parent fees, and type of services (urban/rural; contemporary ECI, evolving and legacy)?			X		X	X		X	X

Question	1	2	3	4	5	6	7	8	9
Which financial resources should be expanded and where should these resources be invested?			X		X	X		X	X
ECI systems, organizational frameworks and coalitions									
What forms of ECI systems, organizational frameworks and coalitions have been developed and what is their status?			X	X		X	X		X
What systems, organizational and collaboration gaps need to be filled? (Ref: coalitions, associations, networks)			X	X			X		X
What systems of coordination have been developed and what more is needed?			X	X		X	X		X
What is the capacity of the ECI system and/or of ECI organizations for monitoring and evaluation and reporting?			X	X		X	X		X
General questions									
What major gaps need to be filled or improvements made to achieve nationwide ECI coverage to enable the provision of services for all ECI-eligible children?			X	X	X	X	X	X	X
What types of policy advocacy and communications are needed to build more support for contemporary ECI services?			X	X	X			X	X
What should be included in the key conclusions and recommendations of the National ECI Situation Analysis?			X	X	X	X	X	X	X

To answer these major research questions and the other subsidiary questions that are found in the research instruments included in this Guide, careful attention must be given to following the many guidelines and procedures related to observing research ethics. The next chapter addresses this important dimension of conducting National ECI Situation Analyses.

7. Introduction to Research Instruments for Conducting National ECI Situation Analyses

The following eight research instruments, plus guidance for the literature review, are provided for the adaptation and use of ECI research teams. Instruments and their guidance are presented in separate annexes, as noted below.

TABLE 3

No.	Instrument or activity	Brief instrument or activity description	Annex
1	Literature review	The literature review begins at the inception of the research project and continues throughout the period of data gathering as new topics emerge requiring further explanations to interpret the data and explain the findings.	6
2	ECI mapping survey	The ECI mapping survey is the first field research activity conducted to identify, locate and categorize the service institutions and organizations that will be studied. It seeks to identify: 1) a sample of the legacy rehabilitation organizations; 2) all organizations that are evolving to become contemporary ECI services; and 3) all the contemporary ECI organizations in the country.	7
3	Survey of ECI directors	The survey of ECI directors or managers of the legacy institutions, evolving and contemporary ECI organizations or ECI components of other institutions, which secures a wide array of basic information on ECI services, is conducted next. It is an extensive questionnaire providing the largest array of quantitative data for the Situation Analysis. It is complemented by the surveys of service personnel and beneficiaries.	8
4	Survey of ECI service personnel	Shortly after the survey of ECI directors is begun, this survey of service personnel is conducted. These directors work in all types of institutions and organizations included in the study. The survey provides important quantifiable information about many factors regarding personnel needs and interests that are not addressed by other questionnaires. This information complements and extends data provided by ECI service directors.	9
5	Survey of ECI beneficiaries	This survey is conducted at the same time as the survey above. Parents and caregivers are given an opportunity to list parental needs, reveal barriers to access, explain the level and type of participation they have in their ECI services, identify concerns regarding themselves and their children, and provide information on ECI services as they experience them.	10

6	Cost and Finance Sub-Study	The Cost and Finance Sub-Study begins right after the mapping survey because its information enables the selection of institutions and organizations for case studies. The sub-study includes three major components: 1) cost and finance case studies of usually four to seven selected major types of ECI organizations; 2) a governmental finance and expenditure study conducted through interviews; and 3) finance information received from all institutions and organizations responding to the survey of ECI directors.	11
7	Focus groups of ECI service personnel	The focus groups are conducted last. A structured and open-ended list of questions is used to conduct focus groups of ECI service personnel. The responses complement and help to interpret the findings from the survey of ECI service personnel	12
8	Focus groups of ECI beneficiaries	Similarly, these focus groups include a structured and open-ended list of questions, and the results help to interpret the findings from the survey of beneficiaries as well as other findings of the study.	13
9	High-level interviews	Structured interviews can be conducted at any point in the research but are best conducted at the end because the lessons learned from other research activities help improve the questions. Interviews with leaders are held at the central, regional and municipal levels to learn about their opinions regarding ECI service needs and obtain their recommendations for the future. During the interviews, their support for ECI usually is requested.	14

All the instruments are important for gaining a comprehensive understanding of the status, challenges, gaps and needs of the ECI system and its services. However, should a research team be unable to conduct all the research activities due to the COVID-19 pandemic, a natural disaster or another situation, then, regretfully, the focus groups can be eliminated. The literature review, the ECI mapping study, surveys of ECI directors, service personnel and beneficiaries, the Cost and Finance Sub-Study and the high-level interviews are essential to securing a robust overview of the situation of the ECI system (if developed) and the ECI services in each country.

The absence of focus groups would eliminate important qualitative information that is usually gained from service personnel and beneficiaries. These data provide important explanatory information that helps to interpret quantitative results.

8. ECI Research Team, Reference Group, Research Process, and Activities for Quantitative and Qualitative Data Analyses

8.1 The ECI Research Team

If possible, a university research institute, national research agency or national private research organization should be selected to host the **ECI Research Team,** and soon thereafter the members of the research team should be chosen. Depending upon the knowledge of the members of the research team regarding contemporary ECI services, one or more international advisors may be required. The selection of the national organization is exceedingly important because it could potentially strengthen or begin to create greater national ECI knowledge and leadership for ECI. If a university research institute is selected, it could yield an additional benefit of encouraging the university to focus on preparing professors to train national specialists who would work in the ECI system and provide contemporary ECI services. The university could also provide in-service training, conduct monitoring and evaluation of ECI programmes and prepare ECI planners, supervisors and evaluators.

The Terms of Reference (ToR) for the ECI Research Team should be drafted, reviewed and revised in collaboration with UNICEF, any other participating agency and international consultant(s), if used. The ToR should include the roles of each team member and criteria for their selection. The ToR should be used to advertise for recruiting and selecting the research team leader and team members. Regarding the specialist for the Cost and Finance Sub-Study, an economist with experience in government finances, and cost and finance studies of ECI or ECD public institutions and organizations, or other related areas such as health finance and economics, will be essential. All team members should be well-trained in contemporary ECI services as well as quantitative and qualitative research methods, and have a record of excellent prior research studies, preferably published in peer-reviewed journals.

In addition, it is recommended that a **two- to three-day training workshop** be held before research activities begin to ensure that all members of the research team fully understand the research design, processes, instruments, analytic framework and methods of analysis and interpretation. Subsequently, a research advisor and research analyst might be "on call" to respond to questions and help with research activities, as needed.

8.2 The Reference Group

The Reference Group is composed of national leaders at all levels of government who lead, fund or work in areas of ECI, representatives of civil society organizations including NGOs, FBOs, CBOs, parents' associations and universities, leaders of minority ethnic groups and others depending upon the country's needs. In Annex 4 the Suggested Terms of Reference for the National ECI Reference Group are offered for consideration and adaptation to the country context.

The Reference Group is separate from the Research Team. It supports the ECI Research Team, helps to identify ECI organizations and links the Research Team to key national leaders, ministries, agencies, leading ECI stakeholders, parents' associations and other groups that should participate in planning and/or conducting the research process. The Reference Group advises the Research Team, identifies evolving and contemporary ECI organizations, and reviews the draft ECI Situation Analysis, making recommendations and comments on its contents. After the Situation Analysis has been completed, the Reference Group may continue to assist with

organizing activities for ECI strategic planning and for ECI organizational and service development. In some cases, it evolves to become a part of the National ECI Organizational Framework, and they become champions for ECI and the ECI system in the country.

8.3 The research process for preparing a National ECI Situation Analysis

The research process for conducting comprehensive research to prepare a National ECI Situation Analysis is presented in Figure 4. Some activities occur parallel to each other, but this general process is essential to achieve the goals and objectives presented in Chapter 2.

The following research process presents **the major steps** that are required to complete a well-prepared and comprehensive ECI Situation Analysis.

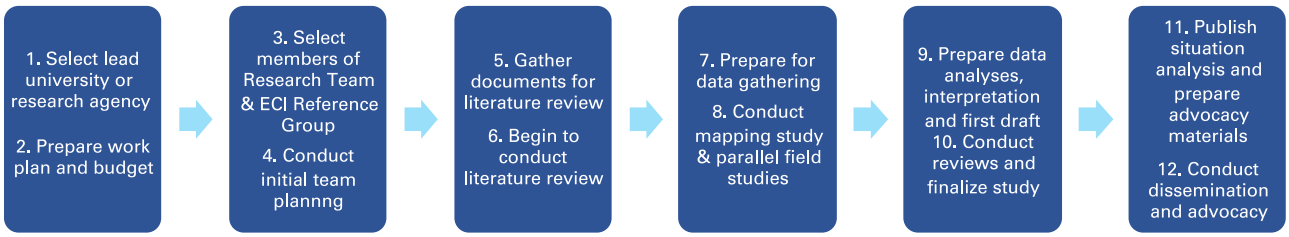
STEP 1: Select the lead university or research agency

- Hold discussions with key ministries and agencies to select the lead university or research agency to conduct the ECI Situation Analysis. It will be essential to think strategically about institutions that might help guide the future development or strengthening of the National ECI System.
  The selected agency or institute should be knowledgeable about contemporary ECI services or, at a minimum, have a record of excellent research on early childhood development, children with disabilities and related study topics, such as early childhood protection, education, psychology or sociology.
- If a lead ministry for ECI has already been selected, then the ECI research team potentially might be established by that ministry. If a lead ministry has not been selected, then this decision might be considered during the preparation of the Situation Analysis.

STEP 2: Prepare a Gantt chart, work plan and budget to conduct the ECI Situation Analysis

- Prepare an initial Gantt chart (timeline) to outline all the major tasks and steps of the entire research process. Vacations, unexpected events and challenges, such as public health situations, may require progressive revisions of the Gantt chart; however, every effort should be made to meet the internal project deadlines.
- Draft an initial work plan, using a simple chart with dates, activities, persons responsible and comments. This work plan should be revised flexibly from time to time, depending upon the need.
- Prepare the initial project budget, including:
  - Personnel (number of persons, types of roles, number of days, fee per day)
  - Communications (internet, apps, Zoom platform, survey platform, databases and costs related to data analysis)
  - Travel (air, train, bus, rental car, personal car reimbursements) and per diem for hotel, food and expenses
    - For team members (focus group discussions, interviews)
    - For participants in focus group discussions
  - Meeting costs (venue, refreshments/ lunch, services and logistics, as needed)

FIGURE 4. General research process for the ECI Situation Analysis



.- Meeting and project supplies (copying costs, office supplies, flipchart easels, paper and washable felt pens, recording devices, lockbox, etc.)
- Translation and interpretation (as needed)
- Miscellaneous.

STEP 3: Select the ECI Research Team Leader, Team Members and ECI Reference Group

The team leader, team members, and a ECI Reference Group should be selected. The team leader and members are usually selected by the organization or institute. If an international researcher is also contracted, that person often provides technical support for selecting appropriate national ECI research specialists.

STEP 4: Conduct initial team planning

Once composed, the ECI Research Team should conduct the following activities to adapt and finalize the research design and the process for implementing the project in a timely manner. The team should:

- Read and discuss the *Methodological Guide* and the proposed outline for the Situation Analysis.
- Review the objectives and procedures for the Situation Analysis.
- Review and, as needed, revise the research design to fit the national needs, including initial considerations regarding the adaptation and revision of research instruments, sampling methods, sample sizes, field logistics, the review of study results and other essential activities.
- For guidance for the adaptation of research instruments, please see Annex 5: Suggestions for the Adaptation of Research Instruments.

STEP 5: Identify and gather documents for the ECI literature review

- Identify ECI organizations for the mapping survey and the documents describing them, policy documents, studies and resources for the literature review. Begin to read and analyse these documents, statistics and information.

STEP 6: Begin to conduct the literature review

The literature review begins at the initiation of the project and continues throughout the study period. Most documents are identified early on, but increasingly, new topics and issues will emerge and require the team to expand its document search and literature review. This process is completed once the Situation Analysis has been finished. The major phases of this process include:

- Reviewing the outline of the Situation Analysis.
- Beginning by preparing the initial draft of the policy section, identifying strengths, gaps and needs. This activity can be done at the outset of the study.
- Preparing an initial review of the literature on national populations including minority groups, refugees and migrant groups, families and children, with an emphasis on parents and their children in at-risk situations, and/or with developmental delays, disabilities, and in behavioural and mental health situations.
- Preparing initial reviews of the literature on: the current human resources and needs; the legacy, evolving and contemporary ECI services; pre- and in-service training activities for ECI professionals and paraprofessionals; and financial resources for ECI organizations and their costs.
- Noting the major emerging data and information gaps and prioritizing the needs for immediate and future data gathering.
- Holding team meetings throughout the preparation period for the Situation Analysis to review and consolidate sections of the evolving study, and as the team begins to consider some initial conclusions and recommendations.

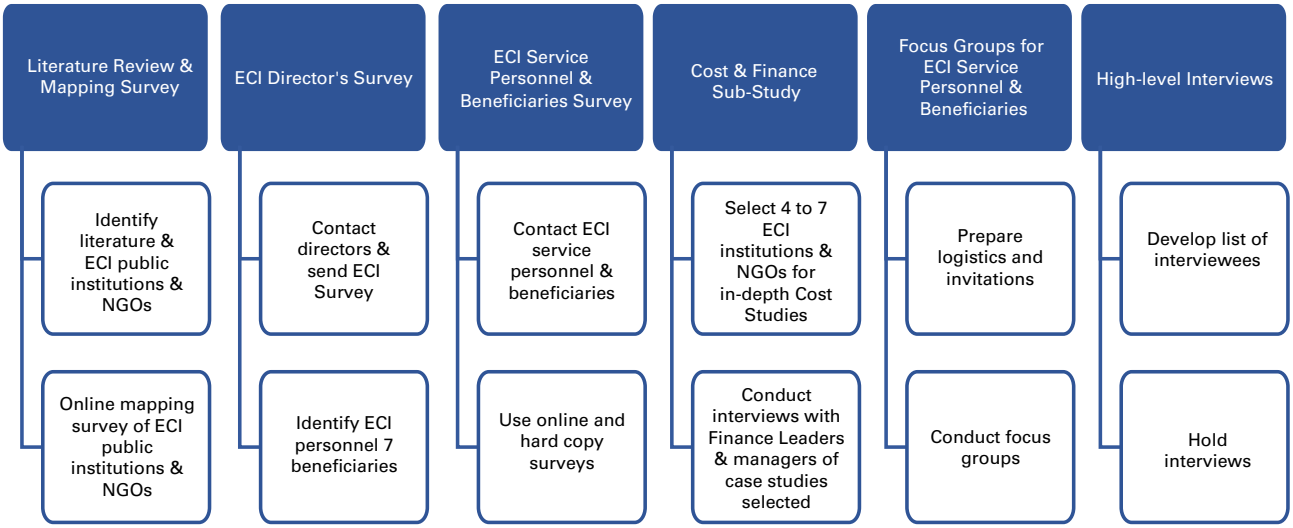
STEP 7: Prepare for data gathering by type of research activity

- Establish general roles for the members of the Research Team
- Consider identifying sub-teams and well-trained and experienced researchers for:
  - Conducting and analysing online surveys for ECI directors, service personnel and beneficiaries;

- Conducting the Cost and Finance Sub-Study;
- Planning, facilitating and reporting on focus group discussions with ECI personnel and beneficiaries; and
- Planning, conducting and reporting on high-level interviews.
- All team members usually are authors of the Situation Analysis, and they bring their research experiences into discussions on the findings, conclusions, and recommendations.

- Review, translate, adapt, rapidly field-test and prepare the final versions of research instruments.
- Prepare and revise, as needed, all papers regarding informed consent and other research ethics papers for use during field research.
- Further refine the research design as may be needed.
- Identify the location, contact persons and other basic information of all ECI organizations and evolving organizations in the country, including legacy organizations depending upon the Research Team's decisions.
- Prepare the online or in-person surveys for: 1) the mapping survey; 2) survey of ECI directors; 3) survey of ECI service personnel; and 4) survey of ECI beneficiaries.
- Begin to plan all the logistics in detail: schedules, travel, communications, online surveys, lockboxes and Zoom or in-person meetings for focus group discussions and interviews, etc.

FIGURE 5. Sequence of Research Activities.



STEP 8: Conduct parallel field studies

- Begin the literature review and continue it until the study is completed, while also identifying ECI organizations and conducting the mapping survey of national ECI organizations, which is the essential first step for conducting all surveys, focus groups and high-level interviews.
- Distribute the online survey of ECI directors, asking them for the names and contact information of a sample of ECI service personnel and beneficiaries to be included in the survey of ECI service personnel and the survey of ECI beneficiaries.
- Once the lists of ECI service personnel (including both professionals and paraprofessionals) and beneficiaries have been secured, distribute the respective surveys, offering them both online and hard copies to fill out by hand and submit for later data entry by researchers.
- Conduct the Cost and Finance Sub-Study, which has three main dimensions:
  a. Finance data of organizations are secured through the survey of ECI directors.

b. Based on the mapping survey and the survey of ECI directors, four or five organizations (urban/rural, income or ethnic groups served, and types of services: home-visiting mainly, centre-based mainly, or mixed, and/or regional representation) are selected for the study of internal costs and financial sources.

c. Interviews of ECI directors or financial managers are conducted to 1) secure more data and check the findings from the organizations that were studied, 2) obtain more information about governmental budgets for ECI at the national, regional if any, and local/municipal levels, and 3) about government leaders who might have advice for future financial planning.

- As the Cost and Finance Sub-Study moves forward and the survey data are analysed, hold focus group discussions in key regions of the country with ECI service personnel, including ECI professionals and paraprofessionals, and with ECI beneficiaries, including parents, legal guardians and caregivers.
- Finally, select the interviewer that will conduct high-level interviews with key national, regional and community leaders, either parallel to or after the focus group discussions.

STEP 9: Prepare quantitative data analyses, code data by topic and begin to interpret the findings

- Conduct all quantitative data analyses using Excel, SPSS and/or another analytical programme.
- Run basic frequencies, review them carefully, and decide whether the data are sufficiently robust to merit cross-tabulations using major variables, such as: rural/urban; type of institution in terms of sector, public or CSO status; types of services (legacy, evolving or contemporary); and geographical region.
- Analyse and cluster responses to the few open-ended questions used in the surveys for possible use while drafting the study.
- Using the list of major research questions, give a code to each question and/or topic in the survey questionnaires, including sub-codes for sub-topics as they are found.
- Place these codes and sub-codes next to the relevant questions in each survey questionnaire so that analytical results can be readily produced.
- Data pertaining to the Cost and Finance Sub-Study include both quantitative and qualitative data. This is analysed and presented separately by the Research Team's economist, using appropriate techniques for calculating accurate costs per child and per organization, and for addressing financial support for ECI public institutions and civil society organizations. It is recommended that these researchers review analyses conducted previously in other countries. In some cases, it might be helpful to secure an international specialist in this field to help conduct or to conduct the sub-study.

STEP 10: Prepare qualitative data analyses, code data by topic in both quantitative and qualitative data

- Give the same codes and sub-codes to questions that were used for surveys in each qualitative instrument for focus group discussions and interviews.
- For focus group discussions with service personnel, create a matrix with coded questions down the left-hand column and with the focus groups sessions arrayed across the top row, entering the comments from the focus groups into each cell, unless a question was not addressed in some of the focus groups. Finally, in the last right-hand column, prepare summary statements of the findings in all cells for each row (question/topic), such as, "In 11 of the 12 focus groups for ECI service personnel, they requested in-service training programmes on ECI services."

Matrix format

Questions/Topic	1 (location)	2 (location)	3 (location)	4 (location)	Summary

- Then create another matrix for focus group discussions conducted with beneficiaries.
- A similar coded matrix should be created for questions used in high-level interviews with prominent individuals.
- Representative quotations should be selected from focus group discussions and high-level interviews for insertion into the text in appropriate sections of the Situation Analysis, without attribution, in accordance with national, UNICEF and GDPR guidelines, as per country regulations.

STEP 11: Triangulate and interpret data analyses and prepare the first draft of the ECI Situation Analysis

- Review and revise the generic outline of the ECI Situation Analysis (found in Annex 15), as needed.
- Once the quantitative and qualitative findings are coded and analysed, triangulate the findings across all relevant instruments according to each code and sub-code.
- Based on the triangulation of the study results, interpret the study findings and draft, section by section of the manuscript, noting the similarities and differences in the findings by the types of respondents, e.g., "While service personnel and ECI directors ranked in-service training in ECI methods as their greatest need, interviewees and programme beneficiaries gave in-service training somewhat less attention."
- After completing the text of each section and sub-section of the study, list the major research conclusions and consider possible areas for recommendations, compiling a list that can be considered for the final chapter on Conclusions and Recommendations.
- Finally, compile and consolidate all sections of the Situation Analysis, including all annexes, except for the executive summary, introduction and preface pages, which are finalized last.
- Within the research team, discuss research experiences, and ensure that the field researchers contribute to drafting activities and/or review the draft document carefully, matching persons with their tasks, knowledge and interests, section by section.
- Finally, conduct an internal team review of the first draft of the ECI Situation Analysis and then revise it for presentation to others. The final draft should reflect the understandings of all the members of the Research Team.

STEP 12: Conduct external reviews and prepare the second and final drafts of the Situation Analysis

- Complete and present the first draft with its annexes, securing its translation, if needed, for review by the Reference Group and the sponsoring agency.
- Secure written comments from all reviewers and hold a meeting with the Reference Group and the sponsoring agency.
- Prepare the final draft and present it to the members of the Reference Group and any other designated national leaders for ECI services.
- Make any final revisions, edit the final draft and secure its final translation, if needed.
- Prepare the final draft of the ECI Situation Analysis for publication in the national language(s) and in English

STEP 13: Publish the ECI Situation Analysis and prepare and finalize advocacy materials

- Publish the ECI Situation Analysis in a hard copy and/or online, including an accessible version.
- Prepare an infographic on the main findings (four to six pages maximum).

- Prepare a paper on frequently asked questions (FAQs) of 8 to 10 pages, presenting ECI and its justification along with the main findings of the ECI Situation Analysis.
- Prepare a basic PowerPoint presentation for use with multiple audiences (parents, communities, leaders) for in-person meetings and online webinars.

STEP 14: Conduct dissemination and advocacy activities

- Prepare and schedule presentations for parents, communities, municipalities, regions, national leaders and others.
- Place the Situation Analysis and infographic on all national ECI websites and webpages.
- Hold Zoom webinars and/or in-person meetings, whichever has the greatest impact.
- Meet with ministry leaders and representatives.
- Meet with parliamentarians.
- Meet with regional leaders.
- Meet with municipal and community leaders.
- Consider establishing a National ECI Day.

9. Research Ethics and Cultural and Linguistic Dimensions

To ensure that the research does not cause any harm and fully safeguards the rights, security and wellbeing of parents, children, ECI personnel and national leaders, it is essential to follow rules regarding research ethics and to respect cultural and language differences. All possible ethical concerns or issues should be considered prior to and during research activities, and mitigation strategies should be used.

With respect to the cultural dimensions, every effort should be made to include in the study all minority ethnic groups and hard-to-reach populations living in rural, island or other remote places. Therefore, all ethics statements and field instruments originally drafted in English should be translated and, if possible, back-translated, field-tested and revised to ensure they are accurate and culturally appropriate. They should be field-tested for comprehension and cultural appropriateness with speakers of the national languages who would be typical respondents (e.g., ECI directors, personnel, high-level leaders and beneficiaries). In addition, persons conducting focus groups should speak the language(s) of all participants to ensure good and respectful communication.

Any questions or topics that are considered controversial should be revised or deleted. After field-testing for cultural dimensions, all ethics statements and research instructions should be further refined and finalized for application. Special attention should be given to ensuring that the "do no harm" principle has been observed and that any possible risk to the study participants has been avoided.

Research ethics

National ECI Situation Analyses should be conducted in line with principles of confidentiality, and prior consent must be obtained from all respondents. Each ECI Research Team should conduct its ECI Situation Analysis in full accordance with the following international and regional guidelines for research ethics and methods, including the *UNICEF Procedures for Ethical Standards in Research, Evaluation, Data Collection and Analysis; UNICEF Strategic Guidance Note on Institutionalizing Ethical Practice for UNICEF Research;* and other UNICEF documents on ethics as they are issued.[16]

In addition, several countries in the region already use or are beginning to use the *General Data Protection Regulation (GDPR),* a regulation of the European Union (EU) that requires institutions to protect personal data and the privacy of EU citizens inside and outside of the EU. Countries seeking accession to the EU usually observe GDPR rules. Other countries use a variant of GDPR or local regulations; therefore, it will be important to check on other applicable data protection regulations and/or laws that may apply in specific countries.

See Annex 3: Research Ethics and Data Protection Principles and General Draft Statement of Informed Consent for additional guidance regarding research ethics

[16] https://gdc.unicef.org/resource/unicef-procedure-ethical-standards-research-evaluation-data-collection-and-analysis

10. Generic Outline for National ECI Situation Analyses

Annex 15: Generic Outline for National ECI Situation Analyses provides a basic outline for preparing an ECI Situation Analysis using literature reviews, analyses of quantitative and qualitative data, and findings from the Cost and Finance Sub-Study.

This outline is comprehensive and flexible, and it has provided a good framework for preparing ECI Situation Analyses in several countries.

Changes can be made in the order of presentation; however, it is important to cover all the topics listed in the outline with the goal of securing all essential data and information for preparing a national ECI policy, strategic plan, and/or legislation. These government documents will provide the legal basis and pathway for developing or strengthening the national ECI system and for establishing and/or improving contemporary ECI services.

The data and observations gathered will also help with the preparation of National ECI Guidelines and Procedures, although additional consensus-building discussions will always be required to address the many topics included in these documents.

Annexes

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Annex 2: Definitions[17]

Access constitutes measures enabling the provision of referrals, intake and enrolment of children with at-risk situations, delays, disabilities, behavioural conditions or mental health needs in early childhood intervention services as well as in a wide range of activities, services and environments including the removal of physical, attitudinal, legal or organizational barriers and the offering of multiple ways to promote learning and development. In many cases, simple modifications can facilitate access for individual children. Universal Design for Learning (UDL) approaches are another way to use key principles and practices to ensure that every young child can access learning environments, the general educational curriculum, receive home and/or educational routines and activities, and if needed, secure necessary prosthetic and assistive technologies to achieve optimal development.

Assistive technologies include products and related services that improve the functioning of people with disabilities and allow them to participate in various facets of life (communication, mobility, self-care, household tasks, family relationships, education, engagement in play and recreation). They refer to any product, especially produced or generally available, that is used by or for persons with disability: for participation; to protect, support, train, measure or substitute for body functions/structures and activities; or to prevent impairments, activity limitations or participation restrictions. They include devices, equipment, instruments and software, (e.g., wheelchairs, shower seats, eyeglasses, Braille systems for reading and writing, headphones, timers, adapted games). They are also known as "assistive devices".

Behavioural conditions include young children with autism spectrum disorders (ASD) and attention deficit and hyperactivity disorders (ADHD). Increasing attention is being given to these behavioural conditions and to identifying them at the earliest possible moment. Currently, ASD can be reliably identified from 18 months of age and onwards, and many efforts are under way to move the initial age of identification to the first months of life to enable helpful services to begin as early in life as possible.

Children in at-risk situations include infants who are born pre-term, low in birthweight or have chronic diseases or conditions that may limit their development. They also include young children with stunting or wasting due to malnutrition, and those living in severe poverty, migrant camps, marginalized ethnic minority groups, and children experiencing traumas due to domestic violence, abuse, neglect or community or international conflicts. These children are at increased risk of developmental difficulties because they are exposed to multiple adversities that have been found to be precursors of moderate to severe developmental delays, disabilities, behavioural conditions or mental health needs. Therefore, children in at-risk situations are often served by ECI organizations.

Children with mental health needs includes those affected by psychological conditions and/or trauma resulting from stressful situations, depression, substance abuse, domestic and community violence, war, displacement, natural disasters, and other challenging situations resulting in sub-optimal early development, poor coping skills and self-regulation.

Children with developmental delays refers to children who experience significant variation in the achievement of expected developmental norms for their actual or adjusted ages. A norm is a range of typical development from one age to another, e.g., a child walks on their own briefly between 9 and 15 months. Young children who are developmentally screened and are found to have a moderate or severe delay should be referred to ECI services for a comprehensive developmental assessment. A child with a delay may not have a disability, yet without ECI services, some tend

[17] Several definitions were adapted from writings of the American Academy of Pediatrics (AAP), National Association for the Education of Young Children, Division of Early Childhood (NAEYC/DEC), United Nations Educational, Scientific and Cultural Organization (UNESCO), United Nations Children's Fund (UNICEF), and the World Health Organization (WHO), as well as articles in ECI peer-reviewed journals.

to develop a lifelong disability. Children with mild developmental delays often develop moderate to severe delays if they do not receive ECI services; therefore, it is recommended that they receive ECI services or be kept on a list for another developmental screening within three to six months and for regular developmental screening thereafter.

Children with developmental difficulties is a brief term often used by UNICEF, other agencies and some specialists to refer to children with developmental delays and disabilities without labelling them as such. In ECI, children are not labelled per se. A child with a medical diagnosis for a specific disability (e.g., cerebral palsy) or a functional delay (e.g., a late age for saying two words together) is first and foremost a "child" with defined strengths and capacities (e.g., able to sit well without support, expresses affection), as well as areas for next levels of development (e.g., babbles and can say one word at a time with a current vocabulary of four words). For example, early intervention specialists help parents build on their child's strengths and abilities to address emerging next levels of development to meet the parents' stated goal of helping their child to speak in complete sentences within a specific period.

Children with disabilities includes children who have long-term physical, mental, intellectual or sensory conditions that may require environmental modifications and access to therapies and/or devices to facilitate their activities of daily living and full and effective learning and participation in society on an equal basis with others. A child may have single or multiple functional conditions affecting mobility, communication, receptive and expressive speech and language, swallowing and access to nutrition or psychosocial conditions that could affect their relations with others.

Community-based rehabilitation (CBR) is a mobile service strategy at the community level for the provision of services for rehabilitation or habilitation, equalization of opportunities, poverty reduction and the social inclusion of people with disabilities. To optimize their services, it is noteworthy that in many countries CBR services are increasingly adopting the concepts and methods of early childhood intervention.

Community outreach is a continuous process of public awareness activities, visits to homes and community centres, hospitals, NICUs, clinics, childcare centres and preschools with the goal of identifying, locating and screening infants, toddlers and young children up to 3 or 5 to 6 years of age with possible at-risk situations, developmental delays, disabilities, behavioural conditions or mental health needs who may need ECI services. Upon identifying children, parents are offered referrals to ECI services where a comprehensive developmental assessment (evaluation) is conducted with the full participation of the parents. All national ECI systems should have comprehensive community outreach activities that are conducted by all ECI organizations, often in collaboration with community members and organizations.

Comprehensive developmental assessment is the process of mapping children's development in all developmental domains, including perceptual, fine motor, gross motor, cognitive, language and social emotional development, in comparison to the developmental norms of children of a similar age and culture or population group. Comprehensive developmental assessments identify a child's strengths as well as developmental areas requiring special attention. Developmental assessments should be completed only by fully trained and certified professionals. One to three reliable comprehensive assessment tools that are fully validated and psychometrically sound for each culture or population group should be selected for use in countries. In addition to conducting a comprehensive developmental assessment, in some cases one or more **specialized developmental assessments** may also be used to address specific areas of developmental need, such as for gross motor or language development. Comprehensive developmental assessments are usually reapplied every six months, followed by the revision or redrafting of the IFSP (see below).

Developmental screening is the process of applying a developmental screening tool that has evidence of reliability, validity and psychometrically sound limits based on data from a normative sample. Screening tools are administered, scored and used to facilitate discussions with parents to determine if there is a need for follow-up action.

Adequate developmental screening instruments assess child development across multiple domains (e.g., gross motor, fine motor, communication, problem-solving, personal social) and they are typically completed by a trained person who can be a parent, either independently or with the support of trained personnel, which can be a preschool teacher, a nurse, a home visitor, a patronage nurse or other community health worker, or another trained person. Although developmental screening can occur within the context of developmental surveillance and monitoring in a healthcare setting, it can also occur in other contexts such as in ECI services, homes, childcare centres, preschools, community centres, home outreach services, libraries and playgrounds.

Developmental monitoring/surveillance, often labelled as "developmental monitoring", is an information gathering process used by physicians that is intended to be flexible, longitudinal, continuous and cumulative. Developmental surveillance and monitoring are completed by a healthcare professional and include at least five components: (a) eliciting and attending to parent concerns about their child's development; (b) documenting and maintaining a developmental history; (c) making accurate observations of the child and counselling parents on child development, when needed; (d) identifying the presence of risk and protective factors; and (e) maintaining an accurate record of the process and findings (AAP, 2006; Marks, Glascoe, & Macias, 2011; Small, Hix-Small, Vargas-Barón, & Marks, 2018). Developmental surveillance and monitoring can be unstructured or structured. If **structured**, the health care provider incorporates the use of a developmental screening tool (that has strong evidence of reliability and validity) into the developmental surveillance/monitoring process. Conversely, **unstructured surveillance and monitoring** is usually guided by clinical observations or the use of a tool that lacks evidence of validity or reliability (e.g., use of an international checklist or developmental milestones).

Disability Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others. (*Convention on the Rights of Persons with Disabilities,* 2006)

Early childhood usually spans the period from preconception and pregnancy to 6 or 8 years of age. The length of early childhood for purposes of service provision is established in each country. Early childhood is the most intensive and rapid period of brain development throughout the lifespan, and the brain has great plasticity during this period, and most especially from the foetal stage to 24 months of age with a slowing to 36 months of age. Thereafter brain growth and plasticity slow down considerably. Therefore, early childhood is the most critical and foundational stage of human development, and developmental support is most effective when it begins as soon as possible in the child's life.

Early childhood development refers to the holistic development of a child in the following areas: perceptual (e.g., vision, hearing, touch); fine and gross motor (physical); cognitive; language and communication; and social, emotional and adaptive behaviours. It also includes: family development and participation; child health, nutrition, and hygiene; home and centre sanitation and safety; early learning; and child rights and protection.

Early childhood intervention services form a "social model" composed of multi-sector, integrated and transdisciplinary or interdisciplinary services and activities that are clearly specified in each ECI organization and national ECI system. They are family-centred and are designed to support families with young children from birth to 3 years and up to 5 years of age in some countries, who are at risk of or have developmental delays, disabilities or behavioural or mental health needs.

Early childhood intervention public institutions and civil society organizations include a range of family-centred, coordinated, intensive and individualized services to improve child development and resilience, and strengthen family competencies, communications and parenting skills to facilitate children's improved development. They often also involve advocacy for the educational and social inclusion of these children and their families and they work to prevent and mitigate child abuse, neglect and abandonment. Many contemporary ECI organizations assist with the deinstitutionalization of children from institutions (orphanages, transition homes, etc.) and provide support for family placements.

Early childhood intervention systems for children with at-risk situations and/or developmental difficulties include coordinated national integrated, multi-sectoral and transdisciplinary or interdisciplinary services that promote children's age-appropriate growth and development and support families during the critical early years from birth to 3 or 5 years of age. National ECI Systems usually are supported by a national policy, strategic plan and/or legislation, and they include national ECI guidelines and procedures, and service and personnel standards, and sometimes performance standards. The mission of a National ECI System is to ensure that all the families who have young children in at-risk situations, with delays or disabilities will receive in all regions of the country the same quality and types of resources and support that they require to assist them to maximize their child's physical, language, cognitive, and social-emotional development while respecting the diversity of families and communities. National ECI Systems should have a national organizational structure for coordination, planning, equity and accountability. They should be developed in phases until ECI organizations attain nationwide coverage with services that are of good quality, equitable, accountable and sustainable.

Inclusion seeks to reduce inequality and foster the transformation of systems to include everyone. Inclusive communities design universally and put into place measures to support all children's participation at home, at school and in their communities. Where barriers may exist, inclusive communities transform the way they are organized to meet the needs of all children. Inclusion involves changes and modifications in content, approaches, structures and strategies, with a common vision that covers all children of the appropriate age range and with a conviction that it is the responsibility of the regular educational system to develop and educate all children well.

Inclusive childcare, preschool education and inclusive early childhood development services include children from birth to eight years with developmental delays and disabilities, together with their peers without delays and disabilities. Children are not placed in separate groups but rather play and learn with children who have typical levels of development. These services hold high expectations and intentionally promote full participation in all learning and social activities, facilitated by individualized accommodations. They use evidence-based services and supports to foster children's development in all areas including cognitive, language, communication, physical, behavioural and social-emotional development. They also promote friendships with peers and a sense of belonging. This applies to all young children with disabilities, from those with the mildest delays and disabilities to those with the most significant disabilities. Early childhood systems that are inclusive consider the principles of access, equity, participation and support to be of primary importance.

Individualized family service plan (IFSP) is a structured and written family-centred plan that, when developed and signed, becomes a contract for ECI services between the parents, legal guardian or foster parent and personnel of an ECI organization. When well prepared, IFSPs help the family to support their child's development. Together, professionals and parents provide an assessment of the child's functioning, strengths and needs. Parents lead and/or fully participate in identifying and listing their goals for their child's development and for their family's needs and participation. Parents specify the services they want and need, including their frequency, duration, and location. A Transdisciplinary or Interdisciplinary Team, composed of parents, professionals, with any paraprofessionals as observers, collaborate in preparing an IFSP. IFSPs are usually reviewed every six months after a comprehensive developmental assessment has been conducted. Parents sign and date the IFSP thereby giving their agreement to all the services they have requested. A representative of the ECI organization also signs the IFSP.

Interdisciplinary ECI Services use teams of professionals that conduct separate developmental assessments, identify discipline-specific goals and activities, and meet as a team to coordinate their services with the child and family. However, parents must receive several visitors or make visits to different persons and places to secure the separate disciplinary assessments and subsequently, their individual services. Scheduling so many visits can become very difficult and stressful for parents, and they may find it challenging to integrate differing messages into a comprehensive approach that will support their

child's balanced development. For this reason and many others, Interdisciplinary ECI Services are increasingly converting to the practices of Transdisciplinary Services (See below).

International Classification of Functioning, Disability and Health: Children and Youth Version (ICF-CY) has been adopted by the World Health Organization (WHO, 2007). The ICF-CY regards disability as neither purely biological nor social but instead something that results from the interaction between health conditions and environmental and personal factors. The UN Convention on the Rights of Persons with Disabilities (CRPD) is based on the WHO social model of disability. It integrates environmental modification and inclusive early childhood development with healthcare, habilitation and educational access. Disability may occur at three levels:

- An impairment in bodily function or structure resulting in a limitation in physical activity;
- Limitations in cognitive functioning; or
- A restriction in participation in schools and/or other services.

Mental health needs are varied, and they can include depression, loss of coping skills and emotional trauma resulting from violent or emotionally distressing events, such as domestic violence, child abuse and neglect, community violence and war, forced migration, death of a loved one, major or cyclical natural disasters, and other harmful situations. Children with mental health needs may have parents with similar needs. ECI services often include individual, family and group mental health services provided by psychologists and other trained individuals. In addition, early intervention specialists are usually trained in identifying trauma, depression and similar mental health needs and in either providing mental health services or securing appropriate support from other members of their organization or a partner family service centre.

Multidisciplinary ECI services resemble habilitation or rehabilitation services in that each professional works separately, making separate developmental assessments only in their discipline, setting separate goals with parents only for the area of child development they represent and having little coordination with other people working in ECI. They usually only provide centre-based services and work only or mainly with the child. Most contemporary ECI organizations have found this approach to be counterproductive, and they no longer use this model.

Rehabilitation and habilitation services use a "medical model" of services that seeks to restore or improve specific areas of functioning in young children. Habilitation usually refers to improving competencies by means of developmental support rather than the restoration of pre-existing competencies. However, these approaches are often synonymous with each other, and they predate the provision of ECI services, which began in the 1970s and 1980s. Some regions, such as North America, Australia and parts of Western and Eastern Europe have increasingly adopted the ECI "social model" of family support that fully includes parents and other caregivers in all aspects of ECI services. Essentially, rehabilitation organizations in these regions have evolved or are evolving into contemporary evidence-based ECI services through modifying their core concepts, ECI guidelines and procedures, structures, contents, methods and systems for training, supervision and accountability. Rehabilitation and habilitation organizations tend to be centre-based and focus on using therapies to work directly with the child, whereas contemporary ECI organizations usually provide their services in the natural environment of the child. In contrast, ECI services are mainly home-based but may also include caregivers or teachers in early care and preschool education centres. They use a broad array of methods to assist parents in using routines-based interventions (RBI) in the home setting. Every country has specific needs for some rehabilitation and habilitation services, especially in hospitals and specialized healthcare centres for children requiring complex therapies that need specialized heavy equipment and furniture.

Transdisciplinary ECI services use teams composed of the parents and specialists of at least two different disciplines who work collaboratively to conduct comprehensive developmental assessments and prepare Individualized Family Service Plans (IFSPs) that establish the goals for the child's and family's development. Visits are provided usually in the home by only one member of the professional team who is called the "primary service provider," an early interventionist. In some cases, visits may be provided by a "home visitor",

who is a well-trained and carefully supervised ECI paraprofessional. The team communicates weekly regarding each family and supports the primary service provider who often seeks the suggestions of other team members, if needed. The transdisciplinary approach is the most effective ECI approach because it yields the best outcomes in terms of meeting the family's and child's developmental goals. Also, it is usually the least costly methodological approach. Parents usually prefer the simplicity of a single point of contact and visit with a trusted professional (or paraprofessional). This approach also enables ECI organizations to maximize the use of their professionals, expand their services and serve more children and families per year.

Universal Design for Learning (UDL) is an approach designed to provide all students of all abilities with an equal opportunity to learn in inclusive environments through flexible curricular approaches. UDL methods are being increasingly adopted in inclusive childcare centres, preschools and primary schools.

Annex 3: Research Ethics and Data Protection Principles

In compliance with data protection principles, when collecting information and data with surveys, questionnaires for focus group discussions and interviews, and instruments of the cost and finance sub-study, statements of participant consent and instructions must be provided. Prior consent should be requested of all study participants before securing personal and/or institutional data. All participants, including representatives of organizations, must be assured their responses will be kept strictly confidential. Their rights to end or withdraw from participation, request access, and correct or delete any of the information they provided should be explained. By participating in a survey, participants must acknowledge and consent to filling out a questionnaire. Focus group participants and interviewees must receive instructions informing them of the purpose of the study, the focus group or the interview. Their statement of consent should explain that all information they share will be strictly confidential, and they must be informed that they can also request that data be transmitted to a different study/researcher in a structured and readable format, as regulated by data protection requirements.

All data to be gathered using surveys must be stored electronically, with password protection in place, and when in paper form, placed in locked safe boxes kept under the supervision of one of the national researchers. No names or other personal identification should be collected in surveys, focus group discussions or interviews. During research activities, data cannot be disclosed or transferred to anyone other than members of the research team, and all data transfers from one team member to another must be recorded. Analysed data will be presented at the group level, thereby making the individual study participants unidentifiable. Whenever possible, data for the Cost and Finance Sub-Study will be presented in an unidentifiable form.

Should it prove impossible to collect data in a fully unidentifiable form, then later – during data analysis, interpretation and report preparation – special attention must be given to removing any reference to the identity of persons and institutions.

In the ECI Situation Analysis, no persons or institutions should be identified, other than ministries, because it is impossible to write a useful ECI Situation Analysis without identifying them. Lists of ECI organizations and components within other organizations and the total corpus of identified ECI organizations should not be provided in the Situation Analysis; however, maps of the territory covered by ECI services may be presented without naming any institutions. Later with the formal agreement of ECI organizations, the list of organizations and components may be used for other purposes, such as websites, brochures and guides.

A written record should be maintained of all data-processing activities, with an anonymous list of study participants, categories of personal data and modes of data collection. In summary: full confidentiality, fair and transparent data processing, and the protection of the legitimate interests of all study participants must be fully observed at all points during research activities.

Below, the **General Draft Statement of Informed Consent in Accordance with National Data Protection Requirements** is provided.

General Draft Statement of Informed Consent

(Names of entity or entities) have commissioned a research team with the support of (Name of supporter(s)) to conduct a research project to describe the situation of ECI organizations and services for families of young children who face developmental difficulties. The project will explore which ECI organizations are available, where they are located and how the needs of families and their children are being met. It will learn how organizations are structured, what they provide for various types of children and families, and whether the services are available to all who need them. All information will be reported in an aggregated and unidentifiable form. Examples and comments will be reported in a way that never identifies a particular person or organization. This project will collect information in a variety of ways:

- An extensive literature review will be conducted, along with an ECI Mapping Survey, to identify all relevant ECI organizations, institutions or ECI services included in another organization.
- Surveys will be sent to ECI directors, ECI service personnel and beneficiaries.
- High-level interviews will be conducted with key government, community and civil society leaders at the national, (regional) and local levels.
- A Cost And Finance Sub-Study will take an in-depth look at a few representative ECI organizations.
- Focus group discussions will be conducted with ECI service personnel and beneficiaries, who will largely be parents, legal guardians and regular child caregivers who participate in ECI services.

Your participation in this important study will help us better understand the currently available ECI organizations and services, what is currently working well for parents and their children, and what needs exist for expanding and improving services.

You will not receive any compensation for participating in this study and your participation is entirely voluntary.

In participating, you agree to:

- Respond to a survey, with the understanding you will not be required to answer all questions, and/or
- Engage in an interview and permit audiotaping unless you refuse to be audiotaped before the interview begins, and/or
- Participate in a focus group discussion where we request that you listen to others in the group respectfully, without interrupting the speaker, and allow the focus group to be audiotaped unless you refuse before the group begins.

You have certain rights in choosing to participate in this research.

You may stop participating at any time, withdraw your consent, and request that information you have given not be used in the reporting of results.

All information you give is confidential. In focus group discussions, every person who participates agrees to keep everyone else's opinions within the group and to not discuss them with anyone else. No information you give will be reported in a way that could identify you as the source of the information. You will not be named as having made a particular statement. Data may be reported in a way that identifies a characteristic such as "a home visitor in a rural area stated that…"

All information you give will be stored in a manner that does not identify you by name, but rather lists certain characteristics such as whether you work in an ECI organization that provides home visits or centre-based services, and whether you work in an urban or rural area. The tapes will be placed in a locked storage box and only accessible to the research team for this project. After the information is fully

analysed and described, the initial data will be destroyed (the tapes or notes). The analysed data will be kept in a secure online site that is accessible only to the research team of this project. These data may be used later in other projects, but it will only be available in a totally anonymous and aggregated form.

If you have further questions or need someone to talk with after participating in this group, please contact:

(Name and contact information of the leader of the research team)

Please sign and date the following:

_____I agree to participate in the (name of activity) on _____ held in _____.

_____ _____

Signature Witness

Annex 4: Terms of Reference for the National ECI Reference Group

Background

In (year) the country of (XXX) will conduct a comprehensive research project on the prevalence of families and children who could benefit from Early Childhood Intervention (ECI) services, the identification and developmental status of ECI organizations, their interdisciplinary personnel, pre- and in-service training needs, service costs and overall investment requirements. UNICEF (or another entity) will provide technical support and modest financial assistance for this important ground-breaking project for the children and families of our country.

Early childhood intervention services are a "social model" of multi-sector and transdisciplinary activities that are family-centred. They are designed to support families with young children from birth to 3 years, and up to 5 years in some countries, who are at risk of or have developmental delays, disabilities, behavioural conditions or mental health needs. In each country, contemporary ECI organizations include a range of family-centred, coordinated, intensive and individualized services to improve child development and resilience, and strengthen family competencies, communications and parenting skills to facilitate children's improved development. They advocate for the educational and social inclusion of children and families, and they work to prevent and mitigate child abuse, neglect and abandonment. Many contemporary ECI organizations assist with the deinstitutionalization of children from institutions (orphanages, transition homes, etc.), and they support family placements.

Early Childhood Intervention Systems are integrated, and they include coordinated national multi-sectoral and transdisciplinary services that support families and promote children's age-appropriate growth and development. National ECI Systems usually are established through the adoption of a national policy, strategic plan and/or legislation. They develop National ECI Guidelines and Procedures, service and personnel standards, and sometimes personnel performance standards. The mission of a National ECI System is to ensure that all the families who have young children in at-risk situations, and/or with delays or disabilities will receive in all regions of the country, the same quality and types of resources and support that they require to assist them to maximize their child's physical, language, cognitive, and social-emotional development, while respecting the diversity of families and communities. National ECI Systems should have a national organizational structure for coordination, planning and accountability.

To conduct the National ECI Situation Analysis, in addition to national and international consultants in the ECI research team, an ECI Reference Group will be formed to play several important roles.

Purpose and General Objectives of the Reference Group

The purpose of the ECI Reference Group is to give the knowledge and leadership experiences of Group members to the ECI research team to help ensure the ECI Situation Analysis will be comprehensive, of high quality, and useful as an indispensable foundation for planning and implementing a strong and sustainable system of ECI services in the country.

The objectives of the ECI Reference Group are to:

- Support the ECI research team in their areas of expertise;
- Help ensure the project equitably addresses the needs of families with children who are in at-risk situations, have developmental delays, disabilities, behavioural conditions and mental health needs;
- Assist in collecting policies, documents and studies that could be of use to the ECI research team;
- Help to identify ECI organizations that might be included in research activities;
- Meet with the ECI research team to learn about their progress during field research activities;
- Review the initial draft of the National ECI Situation Analysis and discuss findings and conclusions;

- Review the second draft of the Situation Analysis, with special attention given to studying the recommendations and for subject matter specialists to validate sections of the study;
- Help present and advocate for the study to additional national decision makers and opinion leaders; and
- Use the Situation Analysis to transition from research to planning activities for the National ECI System and to helping the System gain a legal status and adequate initial funding.

Composition of the National ECI Reference Group

Suggestions for the membership of the ECI Reference Group are arrayed below. Usually, Reference Groups have 15 to 20 members. Each country develops its own list of persons, listing them by name, title and organization. The following list includes suggested members, but others could be considered.

- Representative of the Office of the Prime Minster, Office of the President, or both.
- High-level representatives of ministries of finance and/or planning, education, health and social affairs.
- Representatives of relevant Ombudsman Offices, such as child rights and welfare, disabilities, social rights and welfare, etc.
- Representative leaders of one or two ECI organizations and/or a coalition of ECI organizations.
- Regional and/or municipal leaders with ECI organizations in their communities.
- Representatives of community leaders of ethnic minority group.
- Leader of at least one parent organization.
- Leader of at least one organization of persons with disabilities.
- Leader of the Ministry of Finance's budget office for social development or a comparable office.
- Leader of inclusive early education services.
- Leader of a maternal child health and nutrition office.
- Leader of a child rights and welfare office.

Chair

The chair is usually selected by the lead ministry for ECI, if one has been named. If not, the chair is usually selected by a majority vote of the members of the ECI Reference Group.

Suggested List of Meetings and Activities of the National ECI Reference Group

Meetings will be held to conduct specific activities:

- **Introductory meeting:** Members will learn more about ECI as a field and the objectives, methods and contents of planned ECI research activities. They will be asked to provide the names of existing ECI organizations, documents and other matters that could support the ECI research team.
- **Second meeting:** An update will be provided on progress regarding the inception report, adaptation of research instruments, the mapping survey, and plans and/or field work activities under way. The next steps will be presented, including the survey of ECI directors, survey of ECI service personnel, and survey of ECI beneficiaries, and plans for focus groups and high-level interviews.
- **Third meeting:** Review and discussion of the draft ECI Situation Analysis, focusing especially on findings and conclusions.
- **Fourth meeting:** Presentation of the Final Draft and a discussion of next steps for ECI strategic planning and organizational development, thereby bridging to preparatory activities to establish a National ECI System with high-quality contemporary ECI services.

Annex 5: Suggestions for the Adaptation of Research Instruments

This annex serves as an introduction to the research instruments, each of which is presented below in separate annexes:

Annex 6: Guidance for the Literature Review

Annex 7: ECI Mapping Survey

Annex 8: Survey of ECI Directors

Annex 9: Survey of ECI Service Personnel

Annex 10: Survey of ECI Beneficiaries

Annex 11 Cost and Finance Sub-Study Questionnaire and Interview

Annex 12: Focus Groups of ECI Service Personnel

Annex 13: Focus Groups of ECI Beneficiaries

Annex 14: High-Level Interview Format

All instruments should be carefully reviewed for appropriateness to the country situation. Then they should be **adapted, translated** and, if possible, back-translated for clarity and accuracy. Once prepared in semi-final form, they should be briefly **field-tested** with a small number of typical respondents, revised and finalized.

In some small countries, **only central and municipal governments exist**. Clearly, mentions of regional governments should be deleted. In the instruments, references to regional governments are often placed in parentheses.

The terms "**public institution"** and **"civil society organization"** are used to refer to ECI entities throughout this Guide. For purposes of translation, researchers should use culturally and linguistically appropriate terms in all instruments.

In the field of ECI, the term "**service provider"** is used to refer to ECI personnel who serve families enrolled in ECI services. It is not used to refer to ECI organizations.

Some countries do not use the term **"directors" of ECI organizations**. If this is the case in your country, please use an appropriate term, such as **"ECI managers."**

"Legacy services" refer to **traditional rehabilitation** and **defectological services** of the former Soviet Union and Yugoslavia that still exist in some areas of certain countries. The term "traditional services" can be used in instruments in countries where no term exists for legacy services.

The term **"ECI services"** **does not refer to institutions or entities** in this Guide, but rather to the multiple types of activities that are offered by ECI institutions, such as developmental screenings, comprehensive developmental assessments, individualized family service plans, home visits, case management, etc.

The **types of methods for measuring the economic status of families and/or family income levels** differ greatly from country to country. Some countries have simple breakdowns, such as "non-poverty status" and "poverty status" while other countries use "upper-and-middle-income" and "lower-income" or "upper-income", "middle-income" and "lower-income". Please use the breakdown most used and accepted by the government and the citizens of your country.

Please remember to **define the term "at-risk children"** whenever it is used in the instruments in the following way: infants and children who are pre-term, have a low birth weight or congenital conditions, chronic illnesses, micro-nutrient deficiencies, are stunted or otherwise considered to be at risk of developing a delay or disability.
Countries use **different breakdowns for the ages of young children**. Some use 0 to 36 months and 37 to 60 months, while others use 0 to 35 months. Some say up to 5 years while other say under 6 years. We decided to use "under 6" because it is most used internationally. Please use whatever system that statisticians in your country use for statistical formats and reports OR use international definitions, which are preferable. For this, please see the metadata charts for the Sustainable Development Goals.

A distinction is made between childcare, day care and nurseries, which usually serve children from

about 6 to 36 months of age, and preschools that usually include children 37 months and older. However, some countries in the region, such as Montenegro, offer **continuous inclusive preschool services from infancy onwards and they usually call them "inclusive preschools" or "inclusive preschool institutions**". Please adjust the wording for these terms to fit the types of early and preschool services offered by your government.

The list of types of persons to include in **high-level interviews** is provisional and the list is only for consideration. Country ECI research teams should review this list and then compose their own list to fit their country's current or potential leadership for ECI and other needs for in-depth information from key persons.

In addition to ministries, some countries have specific regulatory service agencies that play a role in supporting, monitoring and/or administering ECI services. It is important to include the term "agencies" if they are found and used in some way to work with ECI organizations in your country.

The names of ECI specializations also tend to vary from country to country. In a few countries **terms**, such a "logopeds" and "ergopeds," continue to be used. If respondents only know these terms and do not use or know about the methods of speech/language therapy or physiotherapy as practiced by many therapists working in contemporary ECI services, then it will be important to use the terms that are known and are still used in the country. In the ECA region, many persons originally trained in defectology have also received extensive training in contemporary ECI family-centred core concepts, methods and practices, as well as in evidence-based practices used in modern therapies. They usually no longer use the fields of their initial training.

Some countries will want to add other professions found in their ECI organizations, such as **special educators**. In some countries, ECI **supervisors** trained in coaching, mentoring and reflective supervision are not found yet, but they are greatly needed in ECI organizations. Thus, we encourage researchers to keep them in the list, for this is how their absence will be noted and recommendations for creating supervisory roles and for training supervisors can be made. The same applies to **early intervention specialists**, now a formal ECI profession in many countries.

Online survey platforms

We have found Survey Monkey to be easy for research teams and survey respondents to use. However, the country's preferred online survey platform might be Qualtrics or another platform.[18] The templates for online surveys should be prepared with close attention to ease of application. To respond to surveys, computers and tablets may be used by respondents. Mobile phones are not recommended for long surveys. For certain respondents, such as ECI beneficiaries and some ECI service personnel, hard copies should be used whenever they lack access to or familiarity with online methods. However, hard copies must be distributed and gathered. Then the data must be keyed into the survey platform for data analysis. In a few cases, it may become necessary to interview a few of the respondents to the surveys.

Ethics statements

Each research instrument will require an **introductory ethics statement** provided in writing or read out loud to ensure respondents are fully aware of their rights. A **draft ethics statement of informed consent** is provided in Annex 3 and others are included with instruments.

[18] <www.qualtrics.com/core-xm/survey-software/>

Annex 6: Guidance for the Literature Review

At the beginning of the research activities, a comprehensive and thorough literature review should be conducted. A document search is often the first project activity, and a documents folder for the use of all team members should be established on a secure shared platform such as Google Drive or Dropbox. Later, transcriptions of focus groups discussions and high-level interviews, translations, quantitative and qualitative data analyses, and draft sections of the Situation Analysis, can be added in separate files. This sharing is very important to enable all team members to work together in preparing a high-quality, comprehensive and coherent Situation Analysis.

The following types of document searches should be conducted to prepare the initial literature review:

- **General sources for the literature review should include:**
  - Government policies, plans, laws, normative bylaws, protocols and financial documents.
  - Peer-reviewed journals and search engines.[19]
  - Organizational and component descriptions and websites.
  - Technical guidance, studies, and monitoring and evaluation documents from multilateral and bilateral agencies and organizations (i.e., UNICEF, UNESCO, WHO, World Bank, OECD, Innocenti Centre, Eurlyaid, International Step by Step Association, Bernard van Leer, European Union, USAID, DfID, SIDA, FINNIDA, etc.).
  - Internet searches using keywords (name of country and leading topics).
  - Documents and technical guidance from national ECI and related national organizations, universities and training institutes.

- **Child and family status documents:** Using several sources, an estimate of the total number and percentage of children in the country with developmental difficulties should be established. Search for peer-reviewed articles, studies, statistical data, documents and surveys (if any) of children in at-risk situations, with developmental delays, disabilities, behavioural conditions and mental health needs. For this, the following sources are recommended:
  - National studies of rates of disability for children 5 years of age or younger, or any similar number of years.
  - National service reports providing statistics on numbers of children served by ECI organizations for children in at-risk conditions, developmental delays, disabilities and other conditions.
  - Statistical surveys and statistics from national Bureaus of Statistics, Educational Management Information Systems (EMIS), Health Management Information Systems (HMIS), Protection Management Information System (PMIS), and Multi-Sector ECD Monitoring and Evaluation Databases.
  - Studies and administrative data on general disability rates from national and international sources.
  - Country-level rates of disability estimated by a global study (Olusanya et al, 2018).
  - Rates of children at risk of developmental delays due to poverty and stunting in lower- and middle-income countries (Black et al, 2017).

- **International and national policy documents pertaining to the ECI system (if any) and services of all types:** This search should include:
  - Signature and ratification dates and national reports on key international conventions and declarations.
  - National policies, strategies/strategic plans, action plans and legislation, including national development plans and other multisector policies (ECD, women's and children's policies) that might mention

[19] For example: *Infants and Young Children* and *Journal of Early Intervention*, which include international articles or use a general search engine such as PubMed or MedLine.

contemporary ECI, evolving ECI services, and legacy services.
- Sectoral policy documents that mention ECD or ECI services: health, nutrition, education, justice, social welfare, social and child protection and others.
- Normative/regulatory documents, including: ECI Guidelines and Procedures; regulations, regulatory systems, protocols, rulebooks, registration, accreditation or licensing systems, and service, personnel and/or performance standards.

- **ECI and related services information:** To prepare for the ECI Mapping Survey, search for information and contacts regarding:
  - Current ECI or related services including: contemporary ECI services; community-based rehabilitation services; centre-based or hospital-based rehabilitation or habilitation institutions; childcare services for children with disabilities; inclusive ECD organizations; inclusive preschool centres, specialized health centres for children with disabilities; private therapy services; organizations of persons with disabilities; parent federations or associations; and ECI or inclusive ECD coalitions, networks or associations, if any.
  - Form a list of all services found, by type of organization, including their directors, office locations/addresses, telephone and email contacts, websites, and any other information available.
  - Attempt to identify a government office/s that deals with contemporary ECI organizations or organizations that are evolving to provide contemporary ECI services.

- **Human resource documents:** Search for studies and ECI documents on:
  - The ECI Workforce and ECI specialists (by field) who participate in ECI organizations or other entities evolving toward providing contemporary ECI services.
  - Level of pre-service professional or paraprofessional training, certification levels, numbers of years of service, salary scales and career ladders.

- **Training resource documents:** Search for:
  - Descriptions of national university faculties, training centres, and shorter-term training activities.
  - Data on the numbers of specialists and/or paraprofessionals and volunteers trained annually by training sites and the annual numbers of graduates per relevant field.
  - Studies of current training strengths, gaps, challenges and needs.

- **Financial resources:** Review the following types of documents:
  - Public expenditure reviews or national ministry and agency documents that might include ECI budgets and expenditures.
  - Governmental documents regarding the types of funding mechanisms that may be used at the central, regional and municipal levels where investments in ECI and other services evolving toward becoming contemporary ECI services may be listed.
  - International and regional financial support including EU, OECD, UNICEF, UNESCO, WHO, World Bank, and other sources of funding for ECI and evolving services.
  - INGOs and national NGOs, FBOs, CBOs and CSOs with ECI and evolving organizations.
  - Private sector support.
  - Foundation and corporate foundation grants.

Annex 7: ECI Mapping Survey

Introduction: The ECI Mapping Survey is the first field research activity. It is conducted to identify: 1) a sample of legacy rehabilitation organizations that serve children with developmental disabilities, 2) as many organizations as possible that are evolving to become contemporary ECI services, and 3) the total number contemporary ECI organizations in the country, if possible. A few key questions are asked regarding contact information and the size and types of services provided.

Institutions responding to the mapping study should be identified by type in the following ways. **Public institutions** should be identified by their sector and status regarding legacy, evolving or contemporary services. **Civil society organizations** should be identified by their type, such as: NGOs, FBOs, CBOs, parent or professional associations, associations for persons with disabilities, universities, institutes, and ECI or disability networks and coalitions that serve children. CSOs should also be categorized by the status of their services as legacy, evolving, or contemporary services. In some countries, the research team may decide to include a sample of private sector for-profit therapy offices; however, due to their cost, they are rarely used by families with a modest income or by single parents. Each research team decides whether it will include private therapy/rehabilitation centres.

To identify all ECI public institutions and organizations, the research team should contact leaders and specialists in all ECI-related ministries and other central, provincial and municipal governments that manage and/or fund ECI services, and request their lists of ECI institutions and organizations and their contact information. Often ministries only list and monitor those ECI institutions and organizations that they fund. Some ministries may or may not have a complete or up-to-date list of their ECI organizations. UNICEF country specialists usually know of many relevant organizations, and other international agencies may know of yet others who should be asked if they know of contemporary or evolving ECI service organizations.

Once identified, each ECI director or manager should be contacted to enquire about other similar organizations that should be included in the study. In some countries, coalitions, or networks of ECI organizations exist, and they will have lists of their members, but they may not list other evolving ECI organizations that are not members. They should be informed about the research project, and potential opportunities for institutional growth, training services, and other benefits that may become available to them and to families receiving ECI services if a national ECI system were to be established or improved and expanded.

Respondents: Directors or managers of public institutions, NGOs or others thought to provide legacy, evolving or contemporary ECI services. For-profit organizations may be included or not according to the decision of the research team.

Sample: A sample of legacy institutions, and all evolving and contemporary institutions and organizations that can be found. This list of organizations and components of institutions will be used to secure basic information required for conducting surveys of ECI directors/managers, service personnel and beneficiaries. Some organizations may later be judged as inappropriate for the research project for various reasons, including: serving only children over 6 years, providing private therapy services, being preschool institutions that are not inclusive, or conducting general maternal-child primary healthcare services, social welfare services or not serving children with developmental difficulties. Information on these organizations should be maintained in a separate file because, sometimes, once more information is gathered, initial judgements may be found to have been incorrect.

For those entities that will be sampled, such as legacy institutions, it will be important to note the total number of institutions by type, the number you plan to sample and, later, the number and percentage of respondents to surveys from your sample.

Survey: This mapping survey should be kept as brief as possible. Later the ECI director's survey will gather much more information. It is recommended that the number of questions in the mapping survey questionnaire be as small as

possible to encourage directors to respond to the survey.

Application methods: Directors or managers should be contacted by telephone or email to tell them about the project, ask for their collaboration, and then the mapping survey and informed consent form should be sent to them The mapping survey is placed online using a simple platform such as Survey Monkey or Qualtrics. Directors should be offered the option to respond using a computer or tablet. If some respondents do not want or are unable to use an online survey, then phone calls, Zoom calls, emails or a personal visit could be used. In addition, Facebook Messenger or other social media might be used, such as WhatsApp or Viber. If necessary, a hard copy could be given to them to fill out by hand.

Strengths: The mapping survey questions are simple, direct and usually non-controversial. It usually takes less than 10 minutes to complete the survey. The survey secures basic contact information and asks questions about the types and ages of children, types of families served, number of staff members, and main types of services provided. Using the responses to these questions, it is usually possible to assess whether the organization is appropriate for the study. If doubts remain, the ECI director should be called again to double-check regarding any point.

Limitations: Information is secured for purposes of planning subsequent research activities. Another more in-depth survey of ECI directors will be used to learn much more about each ECI organization's services.

Possible incentives to participate: The greatest incentives for respondents to respond are **being given a voice in national planning for ECI services, and gaining greater recognition and opportunities to have their ECI organization included in the National ECI Situation Analysis**. They should understand that the data gathered will be anonymous and used for national ECI planning and service development. It is important to explain that, upon the development or improvement of a national ECI system, all ECI organizations will benefit.

Analysis: Once the brief mapping survey questionnaire is placed into a survey platform in the language(s) of the country, it can be completed online or through the other means noted above. If the responses are not online, they are scanned and the data are entered by hand into an Excel spreadsheet. Once the data have been entered, an Excel chart of organizations should be prepared. This chart should be capable of being organized or sorted by the name of the organization, location, types of children and families served, types of services, and the number of staff members. The data can then be used to prepare the selection of organizations to be included in the study. This information should be entered into an Excel list of ECI public institutions and organizations, listing them, insofar as it is possible at this early stage, by type of services (legacy services, evolving ECI services and contemporary evidence-based services). With the permission and review of ECI directors, the list of institutions and organizations may be used later for other purposes, such as to serve them and to inform the public about their services.

The final list will be used to conduct surveys of ECI directors, service personnel and their beneficiaries, as well as to form focus groups of ECI service personnel and beneficiaries. Once you contact an ECI organization, you may find it does not fit the study definitions of a "legacy organization," an "evolving organization" or a "contemporary ECI organization". If this is the case, then it is recommended to create a separate file with a list of organizations not included in the ECI Service Provider List, because later you may find that, in fact, they do fit the study categories, and/or they may be useful to ECI services in other ways.

ECI Mapping Survey

Dear colleagues,

We kindly ask you to fill out the following Mapping Survey as we begin our study to prepare a Situation Analysis of early childhood intervention (ECI) organizations in (name of country). The services of ECI institutions and organizations focus on families with children from birth to under 6 years of age who are in at-risk situations, have developmental delays, disabilities, behavioural and emotional regulation conditions, and mental health needs. We would appreciate receiving your responses to all the following questions. Your responses will help us to conduct a comprehensive study of ECI in (name of country).

We thank you in advance for your time and effort!

1. What is the full name of your ECI organization?

2. What is the street address of your ECI organization?

3. What is the name, email address and telephone number of the ECI organization's director/ manager?
    a. Name:
    b. Email address(es):
    c. Telephone:
    d. Mobile phone:
    e. Mailing address:

4. Does your ECI organization have a website? If so, what is its internet address?

5. Does your ECI organization work with one or more national ministries or agencies? Yes/No

6. If you answered "yes" to Question 5, please name them:

7. Where does your organization provide ECI services? (State the names of rural areas, villages, towns, cities where you work.)

8. Which types of families does your ECI centre serve? (Check all that apply)
    a. Upper- and middle-income families
    b. Low-income families
    c. Ethnic minority group (state appropriate group or groups)
    d. Other (specify)
    e. Other (specify)

9. Your ECI organization provides services for… (Check all that apply)
    a. Children with at-risk conditions (pre-term, low birth weight, stunted, congenital problems)
    b. Children with developmental delays (in one or more areas of development)
    c. Children with disabilities (all types of disabilities)
    d. Children with behavioural and emotional regulation conditions (autism spectrum disorder, attention deficit and hyperactivity disorders, etc.)
    e. Children with mental health needs (depression, anxiety, children with different traumatic experiences, etc.)

10. What ages of children does your ECI organization serve? (Check all that apply)
    a. 0 to 36 months
    b. 37 to 60 months
    c. If your organization provides ECI services for children 61 months or over, please write in the age range: _____

11. What types of ECI services are provided in your organization? (Check all that apply)
    a. Early childhood intervention home visits
    b. Early childhood intervention centre-based services
    c. Rehabilitation or habilitation therapy services in a centre
    d. Community-based rehabilitation services[20]
    e. Inclusive early childhood development services in a centre, such as nurseries, childcare centres or day-care centres
    f. Inclusive preschool education services in a centre
    g. Other (describe briefly):

12. How many professionals, paraprofessionals (these are non-professionals who are trained and supervised to give competent ECI services, such as home visitors, assistants or case managers), and other types of staff members does your ECI institution have?
    a. Professionals Number:
    b. Paraprofessionals Number:
    c. Clerical, maintenance, drivers, etc. Number:
    d. Volunteers Number:

13. What sources of funding provide support for your ECI services? Check all that apply:
    a. Government sources, including ministries, agencies, and municipalities
    b. Foundations
    c. Non-governmental, faith-based and other civil society organizations
    d. Private donors
    e. Regional and international agencies and donors
    f. Parental fees
    g. Fundraising activities.

14. What other ECI organizations do you know of in your region or in other parts of the country? Please give their names, location and contact information, if possible.

    - ECI organization's name:
    - Type of organization:
    - Location:
    - Contact information:

    - ECI organization's name:
    - Type of organization:
    - Location:
    - Contact information:

    - ECI organization's name:
    - Type of organization:
    - Location:
    - Contact information:

[20] **Community-based rehabilitation (CBR)** is a mobile service at the community level that provides rehabilitation for persons with disabilities, including children. CBR is increasingly adopting ECI concepts and methods.

Annex 8: Survey of ECI Directors

Introduction: The Directors' Survey is essential for describing the status of ECI public institutions, organizations and their services in each country. It has the following objectives:

- securing essential information on all ECI organizations in the country
- addressing key topics to identify the types of ECI organizations
- describing the services that they provide
- developing a profile of ECI staff members
- securing information about training needs
- gaining an understanding of the challenges, needs and recommendations of ECI organizations.

This survey secures basic information on ECI services in each country, including their location, geographical coverage, numbers of participants, community outreach, the provision of developmental screening, comprehensive developmental assessments, family assessments, individualized family service plans (IFSPs), home visits and/or centre-based activities, types of personnel and their training, service caseloads and many more topics.

Respondents: ECI directors or managers, with the goal of obtaining complete survey responses from all respondents.

Sample: Every effort is made to include a sample of directors of legacy institutions, all or most of the directors of evolving institutions and organizations, and all the directors of contemporary ECI institutions and organizations, plus any ECI components in other institutions or organizations.

Survey: Most questions in this survey have discreet closed-ended responses, including single or multiple-choice responses. A few open-ended questions request that the respondent specify "other" points. Research teams can modify the number of questions, but care must be taken not to create "response fatigue". When reducing the number of questions, it is important to try to maintain at least one key question under each topic heading.

Application methods: First, the ECI research team should carefully review the research instrument and adapt it to fit the country needs, translate it into the national language(s), back-translate if possible, field-test it with typical respondents to ensure good comprehension and revise it for general use. The second version of the survey should be mounted provisionally on an online survey platform such as Survey Monkey or Qualtrics. Other survey platforms that provide Excel spreadsheets may be considered. The online version should be field-tested with two ECI directors. Any further revisions in the survey should be made at that time.

The cover letter (see below), the online survey and a printable copy of the survey should be sent to all ECI directors or managers via email. The researchers may also want to send the cover letter and a hard copy of the survey by mail for it to be filled out by hand. Follow-up reminder emails should be sent to ECI directors until all the surveys are completed. If some directors or managers still have not completed the survey, then telephone calls and personal visits should be undertaken. In a very few cases, it may be necessary to interview the ECI director or manager in person, using the survey as an interview questionnaire.

Strengths: All directors or managers of institutions and organizations selected based on the mapping survey are invited to complete the survey. Quantitative data are gathered, and they are easy to analyse, except for a few "other: specify" optional responses.

Limitations: Research teams may miss some ECI organizations due to lack of access to them or a refusal to participate. Given the tight schedule for conducting research work, it may prove challenging to secure responses from the directors of all the selected organizations. Some directors might not wish to participate due to lingering worries about issues of privacy, fear of being evaluated, or concern that their services might not be functioning well. Every effort should be made to allay their concerns, explaining that the survey is not an evaluation and their service personnel and the families participating in their services will not

be asked to evaluate their services. In this regard, a statement should be made that the survey is **not an evaluation of their services** but rather a way to secure basic information about their services and obtain their recommendations for the future.

Possible incentives to participate: With their agreement, recognition of their organization in a national list and website for ECI organizations could be offered along with assurances of data privacy. Opportunities could be offered to learn work with other ECI organizations and government at all levels, along with participating in initiatives to expand ECI services throughout the country.

Analysis: Survey data are entered into the database, and when all or almost all of the directors have responded, the data are adjudged to be "complete". Sometimes, it is important to call a respondent to ask about specific answers or double-check a response. Data gathered by hand should be entered into the dataset using the survey platform. Then the data are reviewed for completeness and for any possible errors, and is collated. Subsequently basic frequencies are run, and tables and charts are prepared (pie and bar charts, radar charts and others) for use in the report.

With sufficiently robust data, cross-tabulations may be prepared by transferring the dataset to SPSS for additional data analysis and the preparation of more tables and figures. Variables for cross-tabulations might include:

- Type of organization (contemporary, evolving, legacy)
- Geographical regions
- Rural/urban breakdowns
- Types of families served
- Size of organization, using the best measure and a range of about three categories. The following measures may be used: the number of different locations of the organization, the number of staff members and the number of children or families served.

The questions listed under "Types of ECI Services" are very important. The columns are presented in the following order: 1) legacy (traditional) organizations, 2) legacy organizations evolving into ECI organizations, and 3) contemporary ECI organizations. This question will provide an overview of the developmental status of the ECI organizations in each country. The items in this section could be used as an index for cross-tabulations with other study variables.

After the data have been analysed, they should be interpreted and presented in the draft National ECI Situation Analysis.

Draft Cover Letter for ECI Directors

Dear director,

(Name of entity) has been contracted by (UNICEF xxx) to conduct a National Situation Analysis of Early Childhood Intervention (ECI) organizations. These organizations serve families of children from birth to 5 or 6 years of age in at-risk situations, developmental delays, disabilities, behavioural conditions and mental health needs. ECI organizations support and assist parents and caregivers to assist their children to develop well, achieve their full potential and become productive citizens. A national reference group consisting of representatives of line ministries, state institutions and CSOs has been established to guide and monitor the analysis and validate the findings.

Early Child Intervention (ECI) organizations in (name of country) sometimes are not separate (autonomous) services. Rather, early child intervention may be provided in an organization with a wide spectrum of services for children of all ages and/or for their families. By participating in our research, we ask you to focus your attention only on activities that are within the ECI services your organization provides to children younger than 5 or 6 years with developmental difficulties and their families.

Your responses are very important for achieving the following research goals:

- Learn about the activities, contributions and needs of all ECI organizations in our country;
- Prepare a **National ECI Situation Analysis** with recommendations for expanding ECI services; and
- Secure valuable information for future policy planning, technical support, and funding of ECI services.

Your organization has already submitted a filled-in mapping survey, and we are very grateful for your support. The International/National ECI Research Team, which is leading this Project, has selected your service to be included in our research. Our research is composed of several phases: collecting information through surveys with directors, personnel and beneficiaries (parents); focus groups with personnel and beneficiaries (parents); and finally interviews with relevant individuals who will influence the future development of the Early Childhood Intervention system in (name of country).

At this step of our research process, we are sending you an online link to fill out the questionnaire for ECI directors or managers: (insert URL for online survey here).

Please complete and submit your completed survey **before (date). You will need about 45 to 60 minutes** to complete this survey, as it consists of 80 questions in electronic form. At the end of the survey, we ask for your recommendations regarding the future of ECI organizations. Your responses will be very important for ensuring your recommendations are taken fully into account.

In accordance with data protection requirements of UNICEF and the European General Data Protection Regulations (GDPR), **this information will not be shared with anyone outside of the ECI research team**. All the information you give will be strictly confidential. No information you give will be reported in any way that identifies your organization or you, personally. Data will be stored in secure databases in an online site that is accessible only to the ECI research team. You have the right to end your participation at any time. Later, you may withdraw your consent and request that information you gave not be used in reporting results. You will have the right to access information you gave, correct it or have it erased. Finally, you may choose not to answer a particular question and still respond to other questions. You will not receive any compensation for your assistance with this project and your participation is entirely voluntary. By answering the questions in this survey, you affirm that you understand how your information will be used in the project and that you agree to your participation.

Should you have any questions or need to talk to someone before or after submitting this survey, please contact:
(Insert names here)

You may also contact a person from the UNICEF Country Office:
(Insert name here)

Should you have any difficulties in completing online survey, you are free to contact above mentioned contacts.

For the next steps of our research, we request that you select **at least three (3) employees** of your organization who provide early childhood intervention services for children up to 5 or 6 years of age and their families. Please give us their names and a way to contact them, such as their email address and/or their postal address. We shall then send them a much shorter questionnaire designed for them. These persons can be professionals, supervisors or paraprofessionals (a person who does not have formal education in early childhood development but has been given special additional training) who work directly with children up to 5 or 6 years of age and their families. Their answers will be of great help in gaining an insight into their services and interests, e.g., the need to expand early childhood intervention services. They will not be asked to evaluate their ECI organizations. We expect to learn about the ideas, needs, and recommendations of staff members who provide ECI services for children in (name of country).

In addition, we request that you send us the names and contact information for **at least five beneficiaries (parents, legal guardians or caregivers)** who use the early childhood intervention services of your institution. To reiterate, this research does not aim to evaluate your existing services, but rather to understand the functioning of ECI organizations, family and child needs, and gather recommendations for future services for children and their families in (name of country).

We request that you kindly send us these contacts by (date), so we shall be able to forward to your selected service personnel and parents, the questionnaires that have been prepared for them.

THANK YOU FOR YOUR CONTRIBUTION AND COOPERATION!

(Signature(s) and title(s))

Survey of ECI Directors

Please provide **complete responses**. All the data requested are very important for planning ECI services. Thank you!

Contact information (This section is for our information should we need to check any point. It will not be included in the report. Please fill it in completely)

1. What is the name of your organization/facility?

2. What is the street address of your organization? Please include the municipality where your office is located.

3. What is your name? (Name of ECI director or manager)

4. What is your profession?

5. What is your email address?

6. What Is your telephone number?

7. If you have an organizational website, what is your website link (URL)?

ECI organization locations

8. In which municipalities do families enrolled in your ECI services live? (Which municipalities do you serve?)
(Use a pull-down menu with the names of municipalities.)

9. How many children under 6 years of age received your ECI services in the previous year? Number:

10. What was the number of children served in the previous year under 6 years of age whose families mainly speak another language(s)? Number: _____ Please note the languages:

11. Of the total number of children specified in Question 9, how many under 6 years of age live in a rural/village area OR an urban area: (State the number of children under 6 years of age who live in rural/village or urban areas.)

Areas	No. of children (0–6 years)
a. Rural/village	
b. Urban	
Total	

Characteristics of children currently served

12. Of the total number of children specified in Question 9, how many girls and boys under 6 years of age in the following age ranges received ECI services in the previous year? (Fill in rows and totals.)

Ages in months	No. of girls	No. of boys	Total
a. 0 to 36			
b. 37 to 60			
c. 61 to 72			
Total			

13. What percentage of the services your institution/organization provides are dedicated to ECI? (Choose one)

Percentage of ECI services for children (0–6 years of age)	Choose one
a. We only provide ECI services	
b. More than 75%	
c. From 50% to 74%	
d. From 25% to 49%	
e. 24% or lower	

14. Of the total number of children under 6 years of age specified in Question 9, what were their main types of conditions? (List only one condition per child.)

Child conditions	No. of children (0–6 years)
a. Children in at-risk situations (pre-term, low birth weight, stunted, chronic illness or congenital condition, mothers under age 19)	
b. Children with developmental delays	
c. Children with disabilities	
d. Children with behavioural and emotional regulation conditions (autism spectrum disorders, attention deficit and hyperactivity disorders)	
e. Children with mental health needs (depression, anxiety, traumatic experiences, etc.)	
f. Children with two or more delays and/or disabilities	
Total	

Economic status of families served

was the general economic status of the families of the children under 6 years of age receiving ECI services in the previous year? (State your estimated number of families of each category.)[21]

Economic status	No. of families
a. Living below the poverty line	
b. Living above the poverty line	
Total	

Access to services

16. What barriers have families enrolled in your ECI organization said they faced in accessing ECI services?

Barriers families faced in accessing ECI services	Check all that apply
a. ECI services are located too far from their homes	
b. They lacked knowledge about ECI eligibility criteria	
c. They lacked birth registration for their child	
d. They felt excluded due to costs related to services (transportation, fees or other costs)	
e. They felt excluded due to language or cultural barriers	
f. They feared stigma related to disability	
g. Other (specify)	

Year your organization was founded and licensed

17. In what year was your organization founded? State the approximate or exact year:

18. Is your organization officially registered, licensed or certified by a ministry? Yes/No

[21] Some countries prefer to use a poverty index or an income index that is usually used successfully in their country. Please use the economic index that functions well in your country.

Types of ECI services

What types of ECI services does your organization provide for children under 6 years of age? (Please select one response for each row in the chart below.)

Question	Option A	Option B	Option C
19. Are your services provided in:	1. a hospital or centre entirely	2. a centre with some centre-based services and some home visits	3. mainly through home visits
20. Does your organization mainly provide:	1. rehabilitation or habilitation services	2. child-centred services	3. family-centred services
21. Are your ECI personnel mainly:	1. medical and health specialists and therapists	2. therapists and other specialists, e.g., social workers, psychologists	3. trained ECI specialists, therapists, social workers, psychologists or other ECI specialists
22. Does your organization mainly serve:	1. children with disabilities	2. children with disabilities and developmental delays	3. children in at-risk situations, with developmental delays, disabilities, behavioural conditions and mental health needs
23. Does your organization mainly:	1. receive physician referrals and medical diagnoses	2. accept medical diagnoses, health referrals, and community referrals	3. receive medical referrals and diagnoses, conduct developmental screenings, and does some community outreach
24. For ECI eligibility, does your organization require:	1. a medical diagnosis only	2. a medical diagnosis and a comprehensive developmental assessment	3. a medical diagnosis or a comprehensive developmental assessment, or evidence of an at-risk status
25. Does your organization:	1. give some attention to the family environment and provide some family support	2. assess the needs of families in terms of family environment and needs for support	3. place major attention on family involvement, family environment, and support networks
26. In your organization, is the plan of services prepared by a:	1. physician or therapist for the child	2. physician or a therapist or others in the ECI organization for the child and family	3. transdisciplinary or interdisciplinary team, with the parents as team members
27. Do your service providers who meet with children:	1. work directly only with the child	2. work with the child while the parent observes the visit	3. work with the child and parent together, and coaches and supports the parent
28. When a child and family leave your services, what do you do:	1. do not prepare a transition plan to an inclusive preschool or another type of service	2. do not prepare a transition plan, but children are increasingly being sent to inclusive preschools or inclusive primary schools	3. prepare a transition plan with the parents and work with teachers to support children's transition to an inclusive preschool or inclusive primary school

29. What ECI services does your organization provide to children under 6 years of age? (Check all that apply)

Services	Check all services you provide
a. Audiology services	
b. Community outreach activities to find potentially eligible children	
c. Developmental screenings of children	
d. Comprehensive assessments of all domains of child development	
e. Specialized assessments of child development, i.e., hearing, autism or other specialized instruments	
f. Establishment of eligibility of children for ECI services	
g. Assessments of parent–child interaction	
h. Assessments of child health, nutrition, and hygiene	
i. Development of Individualized Family Service Plans (IFSPs)	
j. Physiotherapy services	
k. Speech/language therapy services	
l. Occupational therapy services	
m. Vision therapy services	
n. Psychiatric support and treatment	
o. Psychological assessment and counselling	
p. Case management services and referrals to other services	
q. Parent education during home visits	
r. Parent education in centre-based groups	
s. Parent and peer support groups	
t. Health and nutrition education services	
u. Personal and home hygiene and safety education	
v. Transition plans with parents, children and next service providers (principals and teachers in inclusive preschools, primary schools, specialized schools, etc.)	
w. Help to obtain assistive technologies (equipment)	
x. Online visits	
y. Respite-care services for parents	
z. Other (please specify)	

Outreach services

30. What are the top three ways that children under 6 years of age are referred to your organization?

Method of referral	Check top three ways
a. Your personnel visit families in the community to find children who may need ECI services	
b. Your organization receives referrals from Neonatal Intensive Care Units (NICUs)	
c. Your organization receives referrals from child health centres and hospitals	
d. Your organization conducts developmental screenings	
e. Your organization trains others (parents, nurses, physicians, preschool teachers, community health workers) to conduct developmental screenings and make referrals to your ECI organization	
f. Your organization receives referrals from nurseries, childcare centres, and/or preschools	
g. Your organization receives referrals from social welfare centres	
h. Your organization receives referrals from a commission (for directing children into the educational system) [or if this is for some other reason, please specify]	
i. Parents call or visit your organization to ask for ECI services	

Developmental screening and comprehensive developmental assessments

31. Does your organization use a developmental screening instrument to identify young children with a delay or disability? Yes/No
(If you answered "no" to Question 31, please go to Question 33.)

32. If you answered "yes" to Question 31, which of the following screening instruments is used?

Developmental screening instruments	Check all you regularly use
a. Ages and Stages Questionnaire III (ASQ III)	
b. Ages and Stages Questionnaire – Social-Emotional (ASQ SE II)	
c. Parents Evaluation of Development Status (PEDS)	
d. Denver Developmental Screening Test II	
e. Another screening instrument (specify)	
f. Another screening instrument (specify)	
g. Another screening instrument (specify)	

33. Does your organization use a comprehensive child development assessment instrument? Yes/No
(If you answered "no" to Question 33, please go to Question 35.)

34. If you answered "yes" to Question 33, which comprehensive child development assessment instrument is used?

Developmental Assessment Instruments[2]	Check all you regularly use
a. Assessment, Evaluation and Programming System (AEPS)	
b. Hawaiian Early Learning Profile (HELP)	
c. Battelle Developmental Inventory 2 (BDI 2)	
d. Brigance Assessment	
e. Munich Functional Diagnostic Instrument	
f. Other: (state name)	
g. Other: (state name)	

ECI methods of work

35. How do your personnel work with children under 6 years of age and their parents?

Methods for working with children under 6 years of age and their parents	Choose one
a. In your services, personnel work separately with each child	
b. Your personnel form Interdisciplinary Teams for planning, and each member works separately with the child	
c. Your personnel form Transdisciplinary Teams with one main service provider for each family who may also receive professional support from other team members	

[22] Additional validated comprehensive (not specialized) developmental assessments usually used in your country should be added to this list of validated instruments.

36. Do parents participate in any of the following activities?

Parent participation in	Choose all that apply
a. Developmental screenings	
b. Comprehensive developmental assessments in all areas of development	
c. Specialized assessments (i.e., language, motor development, etc.)	
d. Assessments of parent–child interaction	
e. Assessments of home safety, health and hygiene	
f. Preparation of Individualized Family Service Plans (IFSPs) which include goals for children and their families	
g. Transition Plans from ECI services to inclusive preschool	

37. Do your ECI services provide regular home visits for some children enrolled in your organization? Yes/No
(If you answered "no" to Question 37, please go to Question 42.)

38. If you answered "yes" to Question 37, what percentage of the time are home visits provided?

Percentage of the time home visits are provided	Please choose one of the following
a. Regular home visits or visits to other natural environments of the child (e.g., childcare centres, preschools, other centres) are provided for 70% or more of the children served	
b. Regular home visits or visits in other natural environments of the child are provided for between 30% and 69% of the children served	
c. Regular home visits or visits to other natural environments of the child are provided for between 10% and 29% of the children served	
d. Regular home visits or visits to other natural environments of the child are provided for between 1% and 9% of the children served	

39. If you answered "yes" to Question 37, what is the average number of home visits made per day by each home visitor?

Average number of home visits per day per visitor	Choose one
a. 1 to 2	
b. 3 to 4	
c. 5 to 6	
d. 7 or more	

40. If you answered "yes" to Question 37, what is the average number of children (caseload) from birth to under 6 years of age that a home visitor visits in one month?

Average number of children visited in one month by each home visitor	Choose one
a. 5 or fewer	
b. 6 to 9	
c. 10 to 15	
d. 16 to 20	
e. 21 or more	

41. If you answered "yes" to Question 37, what is the average number of visits that each child, from birth to under 6 years of age, receives every month?

Average number of visits each child (from birth to under 6) receives each month	Choose one
a. 1 to 2	
b. 3 to 4	
c. 5 to 6	
d. 7 or more	

42. Does your organization provide regular centre-based services for young children? Yes/No
(If you answered "no" to Question 42, please go to Question 47.)

43. If you answered "yes" to Question 42, please choose one of the following:

Percentage of the time that centre-based services are provided	Choose one
a. Centre-based services are the main services provided for over 70% of the children you serve	
b. Centre-based services are the main services provided for at least 40% of the children you serve	
c. Centre based services are the main services provided for at least 10% of the children you serve	

44. If you answered "yes" to Question 42, what is the average number of children served by each ECI professional each day?

Average number of children from birth to under 6 that each professional serves daily	Choose one
a. 1 to 2	
b. 3 to 4	
c. 5 to 6	
d. 7 or more	

45. If you answered "yes" to Question 42, what is the average number of children (caseload) from birth to under 6 served by each ECI professional each month?

Monthly average number of children served in centre	Choose one
a. 5 or fewer	
b. 6 to 9	
c. 10 to 15	
d. 16 to 20	
e. 21 or more	

46. If you answered "yes" to Question 42, on average, how many centre-based sessions does each child from birth to under 6/family receive each month?

Monthly number of centre sessions each child under 6 receives	Choose one
a. 1 to 2	
b. 3 to 4	
c. 5 to 6	
d. 7 or more	

47. Does your organization provide online visits? Yes/No
(If you answered "no" to Question 47, please go to Question 51.)

48. If you answered "yes" to Question 47, what is the average number of children under 6 years served by an ECI online visitor each day?

Average number of children under 6 served daily by an online visitor	Choose one
a. 1 to 2	
b. 3 to 4	
c. 5 to 6	
d. 7 to 8	
e. 9 to 10 or more	

49. If you answered "yes" to Question 47, what is the average number of children (caseload) from birth to under 6 that an online visitor serves in one month? (Choose one)

Average number of children from birth to under 6 served by an online visitor in one month	Choose one
a. 5 or fewer	
b. 6 to 9	
c. 10 to 15	
d. 16 to 20	
e. 21 to 25	
f. 26 or more	

50. If you answered "yes" to Question 47, how many online visits does each parent and child under 6 receive every month?

Average number of online visits parent and child under 6 receive per month	Choose one
a. 1 to 2	
b. 3 to 4	
c. 5 to 6	
d. 7 or more	

51. Is your organization beginning to provide a blend of online visits, home visits and centre-based visits? Yes/No
(If you answered "no" to Question 51, please go to Question 53.)

52. If you answered "yes" to Question 51, what blend are you providing?

What blend are you providing?	Choose one
a. Online visits and home visits	
b. Online visits and centre-based visits	
c. Online visits, home visits and centre-based visits	

ECI personnel

53. How many paid staff members does your ECI organization have? (Please include the director, supervisor, professionals, paraprofessionals, and support staff)
Total number of paid staff members:

54. What types and numbers of ECI professionals serving children under 6 years of age are employed by your organization?

Professional field	Number of professionals
a. Audiology	
b. Early childhood development	
c. Early childhood education	

d. Early childhood intervention	
e. Inclusive preschool education	
f. Law, developmental disabilities and human right	
g. Management and administration	
h. Medical doctors: paediatrics, family medicine, etc.	
i. Neurology	
j. Nursing	
k. Nutrition	
l. Occupational therapy	
m. Physiotherapy	
n. Psychiatry	
o. Psychology	
p. Public or community health specialist	
q. Rehabilitation or habilitation	
r. Social work	
s. Sociology	
t. Special education	
u. Speech and language therapy	
v. Other (please specify)	

55. What are the **primary roles** of your staff members, and how many persons conduct each type of role? (Please count each staff member once using his/her main role) [This question is optional.]

Primary roles	Number of staff members
a. Administrator	
b. Case manager or family support manager	
c. Institutional director, manager	
d. Child protection/human rights or disability specialist	
e. Early intervention specialist	
f. Early childhood development specialist	
g. Government/ministerial manager or specialist	
h. In-service trainer	
i. Medical or health specialist	
j. Occupational therapist	
k. Physiotherapist	
l. Psychologist	
m. Researcher/evaluator	
n. Services manager	
o. Social worker	
p. Speech/language therapist	
q. Supervisor/coach	
r. Other: (please specify)	
s. Other: (please specify)	

56. Does your ECI organization hire any paraprofessionals (paid non-professionals)? Yes/No
(If you answered "no" to Question 56, please go to Question 60.)

57. If you answered "yes" to Question 56, how many paraprofessionals are employed in your organization? Fill in number:

58. If you answered "yes" to Question 56, does your organization train them? Yes/No

59. If you answered "yes" to Question 56, what work do the paraprofessionals do?

Type of work of paraprofessionals	Choose all that apply
a. Assist with community outreach	
b. Make home visits to families	
c. Do activities with mothers and children under supervision	
d. Assist professionals with their work	
e. Help with administrative affairs and other office work	
f. Other (specify)	

60. Do you have volunteers assisting your ECI organization? Yes/No
(If you answered "no" to Question 60, please go to Question 63.)

61. If you answered "yes" to Question 60, How many volunteers does your ECI organization have?
State approximate number: _____

62. If you answered "yes" to Question 60, approximately what percentage of them are parents of children in your ECI services?
a. 100%
b. 75%
c. 50%
d. 25%
e. None

Quality assurance and pre- and in-service training

63. How does your organization ensure that your ECI services are of high quality?

Activities for quality assurance	Choose all activities conducted by your organization
a. **All ECI services** are based on research results	
b. **All your ECI personnel** meet pre-service training and certification/licensing requirements	
c. **All your ECI service personnel receive** some in-service training (continuing education/professional development)	
d. **At least each two weeks**, a supervisor supports all service staff members	
e. Before each home or centre-based visit, all personnel **prepare visit plans for each child and family**	
f. All service personnel **prepare visit reports** on each visit	
g. **Service personnel meet each week** to discuss their services for the children they support together	
h. Children's files are **reviewed weekly** to ensure they are complete and up-to-date	

64. Does your ECI organization provide in-service training for your personnel? Yes/No
(If you answered "no" to Question 64, please go to Question 66.)

65. If you answered "yes" to Question 64, what types of in-service training are provided each year for most of your ECI personnel?

Types of in-service training	Choose all types of that you currently provide
a. Opportunities to attend professional conferences	
b. Face-to-face training courses	
c. Online education or training courses	
d. Online and face-to-face education or training courses	
e. Professional training workshops	
f. Onsite field training	
g. Formal educational programmes at universities	
h. Inter-organizational or institutional exchange visits	
i. Continuous onsite in-service training activities	

66. Which types of in-service training (continuing education/professional development) would you most like to provide for your ECI personnel?

Types of in-service training	Choose all types of that you currently provide
a. Opportunities to attend professional conferences	
b. Face-to-face training courses	
c. Online education or training courses	
d. Online and face-to-face education or training courses	
e. Professional training workshops	
f. Onsite field training	
g. Formal educational programmes at universities	
h. Inter-organizational or institutional exchange visits	
i. Continuous onsite in-service training activities	

67. Do you have a salary scale for ECI personnel in your organization? Yes/No

68. Do you require that your ECI personnel have professional certificates? Yes/No

69. Do you have a career ladder for ECI personnel? (A career ladder is a scale from the beginning level, through junior level, to senior level) Yes/No

70. Do you have at least one ECI staff member who supervises other ECI staff members? Yes/No
(If you answered "no" to Question 70, please go to Question 72)

71. If you answered "yes" to Question 70, what types of supervision does your ECI supervisor provide? (Choose all that apply)

Types of supervision	Choose all that your organization provides
a. Observation of home visits	
b. Observation of centre-based visits	
c. Coaching	
d. Mentoring	
e. Reflective supervision	
f. In-service training	
g. Review of child and family files	

72. Does your organization have any external supervisors (from a ministry or other offices)? Yes/No
(If you answered "no" to Question 72, please go to Question 74.)

73. If you answered "yes" to Question 72, where do the external supervisors work? (State the agency/institution or office):

Monitoring and evaluation

74. Does your ECI organization have an internal monitoring and evaluation system? Yes/No
(If you answered "no" to Question 74, please go to Question 76.)

75. If you answered "yes" to Question 74, have you stated in a document your annual ECI objectives, indicators and targets for monitoring and evaluation? Yes/No

76. If you answered "yes" to Question 74, do you have an ECI monitoring and evaluation manual? Yes/No
(If you answered "yes", may we have a copy of your manual?)
(If you answered "no" to Question 76, please go to Question 78.)

77. If you answered "yes" to Question 76, does your manual have:

Elements of your monitoring and evaluation manual	Choose all that are in your manual
a. Input, output and outcome indicators	
b. Indicator targets	
c. A timetable for applying monitoring and evaluation instruments	
d. Copies of the instruments used in your organization	
e. A guide for each of the instruments	

78. Has an external evaluation been conducted on your ECI organization? Yes/No
(If you answered "yes", may we please have a copy of your external evaluation report?)

Types of funding sources for ECI services

79. What are the main types of funding sources for your ECI organization? (For each funding source, please note if it is not a funding source, a minor funding source or a major funding source)

Types of funding sources	Not a funding source	Minor funding source	Major funding source
National governmental funding			
a. Ministry of Education			
b. Ministry of Health			
c. Ministry of Social Protection			
d. Ministry of Finance			
e. Other ministry: specify			
f. Regional or district government			
g. Municipal/city government			
Insurances, vouchers and taxes			
h. National health insurance fund			
i. Vouchers for ECI services or for parents to give to your organization			
j. Special taxes for ECI services			
National civil society funding			
k. Non-governmental organizations			
l. Faith-based organizations			
m. Community-based organizations			
n. Other national sources			
Private funding sources			
o. National foundations			
p. Corporation or business donors			
q. Private benefactors/groups			

Fees			
r. Parent payment of fees			
s. Membership fees			
National fundraising activities			
t. Fundraising activities conducted by your organization			
European regional organizations			
u. European Union funds			
International organizations			
v. UNICEF			
w. Other UN organization			
x. World Bank			
y. Bilateral development agency (USAID, DfID, etc.)			
z. Agency for persons with disabilities			
aa. International foundations			

ECI inter-organizational coordination and networking

80. Does your ECI organization participate in a coalition or network of ECI services? Yes/No
(If you answered "no" to Question 80, please go to Question 83.)

81. If you answered "yes" to Question 80, which coalition or network? (Please specify) (Provide three spaces)
a.
b.
c.

82. If you answered "yes" to Question 80, does this ECI coalition or network help your organization to better serve the following types of ECI participants: (Select "yes" or "no" for each line)

Types of ECI participants	Yes	No
a. Rural and remote communities		
b. Ethnic minority communities (state which)		
c. Other communities that are underserved		
d. Families requesting ECI services		

83. Does your ECI organization coordinate and share referrals with the following types of services?

Types of services	Choose all that apply
a. Primary health centres and/or hospitals	
b. Neonatal intensive care units	
c. Social welfare centres	
d. Nurseries/childcare centres	
e. Inclusive preschool education schools	
f. Inclusive primary schools	
g. Community centres/organizations	
h. Other social services (specify)	

84. Does your ECI organization want to participate in a future ECI coalition or network of ECI organizations? Yes/No

Challenges and needs of ECI services

85. What are the top five challenges and needs of ECI services?

ECI service challenges and needs	Choose five
a. Inadequate policies, plans, laws and regulations for ECI organizations	
b. Weak ECI organizational structure for coordination	
c. Weak ECI organizational structure for inter-sector and financial planning	

d. Lack of strong leadership for ECI services	
e. Inadequate national survey data on developmental delays and disabilities	
f. Stigma and lack of inclusion of children with developmental disabilities in communities	
g. Lack of agreement regarding core ECI concepts	
h. Lack of regular developmental monitoring and screening services and referrals to ECI services	
i. Lack of awareness of ECI services on the part of national, (regional) and municipal governments	
j. Lack of awareness of ECI services on the part of families and local communities	
k. Lack of awareness of ECI services on the part of healthcare professionals	
l. Lack of advocacy for ECI services	
m. Inadequate funding to meet current ECI organizational costs and expand ECI services	
n. Difficulty accessing and serving families in remote rural areas and minority ethnic groups	
o. Inadequately trained and qualified ECI personnel	
p. Lack of high-quality ECI pre- and in-service training services	
q. Lack of supervisory services, including mentoring, coaching and reflective supervision	
r. Lack of a salary scale and a career ladder for early interventionists and other professionals	
s. Lack of an ECI monitoring and evaluation system, including a manual with evaluation instruments	
t. Lack of computers, tablets and other technologies for ECI organizations	
u. Lack of an ECI coalition or network to promote ECI organizational growth and improvement	
v. Lack of transportation for home visits	
w. Lack of ECI home-visiting services	
x. Inadequate ECI service contents: curricula, educational materials and methods	
y. Other: (specify one)	

Your recommendations for improving and expanding ECI services

86. What are your top five recommendations for improving and expanding ECI services?

Your top five recommendations	Choose five
a. Expand advocacy to reduce stigma and discrimination against children with disabilities	
b. Expand advocacy to increase demand for and expand services for ECI	
c. Develop national policies, plans, laws and regulations for services for ECI	
d. Achieve greater equity through improving access to services for ECI services	
e. Improve the organization and coordination of services for ECI with other services	
f. Establish a nationwide system for regular developmental screening and referrals	
g. Provide high-quality and comprehensive child and family developmental assessments	
h. Develop a coalition or network of services for ECI	
i. Provide more ECI home-visiting services	
j. Offer more parenting education and support services	
k. Give more opportunities for parent involvement in organizations for ECI	
l. Improve service contents for ECI: curricula, educational materials and methods	
m. Improve and expand pre- and in-service training for professionals who provide services for ECI	
n. Provide in-service training on contemporary services for personnel who deliver ECI services	
o. Develop a professional certification system linked to salary scales and career ladders	
p. Improve and expand systems for supervision, coaching and mentoring of professionals and paraprofessionals in ECI	
q. Expand services to rural regions, remote areas and minority ethnic groups	
r. Develop a national monitoring and evaluation system for ECI organizations	

s. Expand government/ministerial funding for ECI services at the central, (regional) and municipal levels	
t. Provide computers, tablets and other technologies requested by organizations delivering services for ECI	
u. Conduct national surveys to gather data on young children with developmental delays and disabilities	
v. Other: (specify one)	

Thank you for your efforts and time!

Annex 9: Survey of ECI Service Personnel

Introduction: The Survey of ECI Service Personnel is essential for describing the status of ECI service personnel in your country. It seeks to:

- secure basic information on all ECI service personnel in the country
- list the services that they provide
- develop a profile of ECI staff members
- secure a list of types of training interests
- gain and understand of the challenges, needs and recommendations of ECI service personnel.

The survey must be concise to secure an acceptable level of responses. It includes the following topics: organizational identification; work, age, gender of service personnel; municipalities served; numbers, conditions of children, and socio-cultural dimensions of children/families served; professional training; types, frequency, duration and timing of services provided; types and location of child/parent services; in-service training received and desired; top five challenges and needs of ECI services; and top five recommendations for expanding and improving ECI services.

Respondents: For purposes of the Survey of ECI Service Personnel, the ECI director is asked **to select only those persons who work directly with families and children. Service professionals should represent two or more different disciplines and roles, if possible**. These could include supervisors, professionals, paraprofessionals[23] and, occasionally, highly trained volunteers.

Sample: ECI directors are invited to select **up to three service personnel** in their organization to fill out a survey. The three staff members must be providing direct ECI services to families with young children enrolled in ECI services. This sample of personnel from all, most or a representative sample of the types of organizations studied, most especially in evolving services and contemporary ECI organizations, should provide a robust sample of current ECI service personnel across the country.

Survey: To ensure a good level of response, the number of questions should be as small as possible. Most questions are closed-ended with discrete dual or multiple-choice answers. Very few open-ended questions should be asked.

Application methods: The Survey of ECI Service Personnel can be conducted soon after sending out the survey for ECI directors. An online survey platform should be used, with options for completing the survey by means of a computer or tablet. Alternatively, personnel should be offered the option to fill out a hard-copy version or an interview might be conducted, if possible, depending upon time and connectivity.

First, the ECI research team should read the Survey of ECI Service Personnel provided below and then adapt it to fit the country needs. Then it should be translated into national language(s) and field-tested to ensure the translation is accurate, understood well and culturally appropriate. The final version of the survey should be mounted on an online survey platform such as Survey Monkey or Qualtrics. The online version should be field-tested with at least two ECI professional personnel for accuracy, clarity and appropriateness. Any final revisions in the survey should be made at that time.

The cover letter (see below), the letter of informed consent, the online survey and a printable copy of the survey should be sent to all the selected ECI service personnel. A copy of the survey should be shared with the director who will see that it is not an evaluation of their organization but rather that it seeks to gain information needed to support ECI institutions and organizations and their personnel. The researchers may also want to send the survey out to all selected personnel by mail along with the cover letter, consent form and hard copy of the survey for it to be filled out by hand, if necessary.

[23] Well-trained and supervised paraprofessionals are found in quite a few ECI organizations in many countries, and represent an important way to expand coverage and lower the costs per child served.

Follow-up reminder emails should be sent to ECI service personnel frequently until all the surveys are completed and submitted to the ECI research team. If, by the deadline set, some ECI service personnel still have not completed the survey, then telephone calls and personal visits should be undertaken. In a very few cases, it may prove necessary to interview the ECI personnel in person, using the survey questionnaire; however, hopefully this will be unnecessary.

When all the data have been gathered, it should be reviewed for completeness and for any possible errors. Because no personal identifying information is requested, it may be difficult to call the respondent to ask for the specific answers or to double-check a response. If any data are gathered by hand, it should be entered into the dataset using the survey platform. After the data have been collected, researchers may decide to transfer it to SPSS for additional data analysis and the preparation of tables and figures.

Strengths: A non-random sample is obtained of service personnel from all or most of the identified ECI organizations and evolving organizations. Also, the survey yields key quantified information that complements the findings secured from focus groups composed of service personnel.

Limitations: Research teams may miss some ECI organizations due to difficulties entailed in identifying them or to barriers in accessing them. The brief window sometimes allowed for field work may limit the number of completed responses. Some ECI personnel may not wish or have time to participate.

Possible incentives to participate: Assurances of data privacy will be given. ECI service personnel will be encouraged to help the development of ECI services through participating in the survey. Ultimately, their participation may open new opportunities to learn about and work with other ECI personnel.

Analysis: First, the basic frequencies should be prepared. The name of the organization will be known, so indices secured through the directors' survey may be used. Some cross-tabulations may be conducted using the following indices:

- Type of organization (contemporary, evolving, legacy)
- Geographical regions
- Rural/urban breakdowns

v Types of families served

- Size of ECI services, using the best measure available

After the data have been analysed, they should be interpreted and presented in the draft National ECI Situation Analysis.

Draft Cover Letter to the ECI Director

Dear ECI director,

For the survey of national ECI organizations that is being conducted by (name of agency), with the support of the UNICEF Country Office in collaboration with the (Ministry of Health, Ministry of Education and Ministry for Social Protection), we are requesting your kind collaboration in selecting at least three of your staff members who work directly with families to respond to a brief Survey for ECI Service Personnel (see attached). Your staff members may be a supervisor, a professional or a paraprofessional, who work directly with children and families. Their responses will be of great assistance in assessing the services, interests, needs and recommendations of personnel in ECI organizations in our country.

The goals of this survey are to:

- Learn about the service activities, contributions, needs and recommendations of ECI direct service staff members in our country.
- Secure information from ECI service personnel to help prepare an effective **National ECI Situation Analysis** with their recommendations for expanding ECI services for the families of children from birth to 5 or 6 years of age in at-risk situations, with developmental delays and disabilities.
- Secure valuable information for future policy, technical support and funding for ECI services.

Please invite at least three of your staff members to fill out this survey. The survey is not an evaluation of your ECI organization. Rather it focuses on their status, roles, the children they serve, training, in-service training interests, and their recommendations for expanding and improving ECI services in our country.

You will note that we do not ask for the names of the service providers. We explain their rights to them in the attached cover letter.

Please ask them to submit their completed the survey **by (date). They will need about 15 to 20 minutes** to complete this survey.

THANK YOU very much for your collaboration!

(Signature)

Draft Letter for ECI Service Personnel

Dear colleague,

Thank you in advance for completing this survey questionnaire. The goals of this survey are to:

- Learn about the service activities, contributions, needs and recommendations of ECI direct service staff members in our country;
- Secure information from ECI service personnel to help prepare an effective **National ECI Situation Analysis** with their recommendations for expanding ECI services for the families of children from birth to 5 or 6 years of age in at-risk situations, with developmental delays and disabilities; and
- Secure valuable information for future policy, technical support and funding for ECI services.

The information you give will not be shared with anyone outside of the ECI research team. We do not ask for your name, and all information you give us will be strictly **confidential**. Data will be reported in a way that identifies a characteristic such as "service personnel of ECI organizations requested the following types of in-service training". The analysed data will be stored in secure databases in an online site that is accessible only to the ECI research team.

You will not receive any compensation for your assistance with this project and your participation is entirely voluntary. In accordance with data protection requirements (or for EU countries, the European General Data Protection Regulations (GDPR)), while we greatly encourage you to participate in this survey, you have the right to end your participation at any time. Later, you may withdraw your consent and request that information you gave not be used in reporting results. You will have the right to access information you gave, correct it or have it erased. You may also request that your data be transmitted to a different study or researcher in a structured and readable format. Finally, you may choose not to answer a particular question and still respond to other questions.

By answering the questions in this survey, you affirm that you understand how your information will be used in the project and that you agree to your participation. Should you have any questions or need to talk to someone before or after submitting this survey, please contact:

(Name, title, organization, contact telephone and email)

THANK YOU very much for your collaboration!

(Signature)

Survey of ECI Service Personnel

Please provide answers for the questionnaire for ECI personnel to be able to conduct a comprehensive Situation Analysis for Early Childhood Intervention (ECI) Organizations in (name of country). Our aim is to understand the functioning of ECI organizations and services and provide recommendations for their further improvement. ECI organizations serve families of children from birth to 5 or 6 years of age in at-risk situations, with developmental delays, disabilities, behavioural and emotional regulation conditions, and mental health needs. ECI organizations support parents and caregivers to assist children to develop well, and to help every child achieve her/his full potential and become productive citizens. We would appreciate your effort to provide complete responses to all questions to produce a comprehensive analysis and effective recommendations for expanding and improving ECI services. As stated in our cover letter, your answers will be completely confidential.

Thank you for your contribution!

1. What is the name of your institution or organization?

2. What is your work title?

3. What is your gender?

Gender	Choose one
a. Female	
b. Male	

4. What is your age range?

Age range in years	Choose one
a. 20–29	
b. 30–39	
c. 40–49	
d. 50+	

5. In which municipalities do you currently work?
(Use a pull-down menu with names of municipalities. Each respondent should check all the municipalities where she/he works.)

6. How many girls and boys under 6 years of age in the following age ranges do you currently serve?

Ages in months	No. of girls	No. of boys	Total
a. 0–36			
b. 37–60			
c. 61–72			
Total			

7. Of the children under 6 years of age that you serve, how many live in each type of location?

Areas	No. of children under 6 years
a. Rural/village	
b. City/town	
Total	

8. What types of conditions do the children under 6 years of age that you serve have?

Children's conditions	No. of children
a. Children in at-risk situations (pre-term, low birth weight, stunting, stunted, stunted, mother under 19 years of age)	
b. Children with developmental delays (in one or more areas of development)	
c. Children with disabilities (all types of disabilities)	
d. Children with behavioural and emotional regulation conditions (autism spectrum disorder, attention deficit and hyperactivity disorders)	
e. Children with mental health needs (depression, anxiety, children with different traumatic experiences, etc.)	
f. Children with two or more delays and disabilities	
Total	

9. What is the general economic status of the families of the children under 6 years of age you are currently serving? (State your estimate of the number of children's families of each category) [Depending upon statistical decisions for surveys in your country, income levels could be substituted, e.g., upper-income, middle-income and lower-income.]

Economic status	No. of children under 6 years
a. Living below the poverty line	
b. Living above the poverty line	
Total	

10. Of the children under 6 years of age that you currently serve, how many are ethnic minority children?

Types of ethnic status	No. of children you serve under 6 years
a. (State ethnic minority group) children	
b. (State another ethnic minority group) children, if any)	
c. General national population	
Total no. of children you serve	

11. What is/are your professional field(s)?

Professional field	Choose one or more
a. Audiology	
b. Early childhood development	
c. Early childhood education	
d. Early childhood intervention	
e. Inclusive preschool education	
f. Law, developmental disabilities and human rights	
g. Management and administration	
h. Medical doctors: paediatrics, neurology, family medicine, etc.	
i. Nursing	
j. Nutrition	
k. Occupational therapy	
l. Physiotherapy	
m. Psychiatric diagnosis and therapy	

n. Psychological assessment and counselling	
o. Community health specialist	
p. Rehabilitation or habilitation	
q. Social work	
r. Sociology	
s. Special education	
t. Speech and language therapy	
u. Other: (please specify)	

12. What ECI services do you personally provide?

Services	Check all services that you provide
a. Community outreach activities to find potentially eligible children	
b. Developmental screenings of children	
c. Comprehensive assessments of all domains of child development	
d. Specialized assessments of child development	
e. Establishment of eligibility of children for ECI services	
f. Assessments of parent–child interaction	
g. Assessments of child health, nutrition, and hygiene	
h. Preparation of Individualized Family Service Plans (IFSPs)	
i. Physiotherapy services	
j. Speech/language/hearing therapy services	
k. Audiology services	
l. Occupational therapy services	
m. Vision therapy services	
n. Psychiatric diagnosis, support and treatment	
o. Psychological assessment, counselling and support	
p. Case management services and referrals to other services	
q. Parent education during home visits	
r. Parent education in centre-based groups	
s. Parent and peer support groups	
t. Health and nutrition education services	
u. Personal and home hygiene and safety education	
v. Transition plans with parents, children and next service providers (principals and teachers in inclusive preschools, primary schools, specialized schools, etc.)	
w. Help to obtain assistive technologies (equipment)	
x. Online visits	
y. Respite-care services for parents	
z. Other: (please specify)	

13. How often do you usually serve each child?

Frequency of services	No. of children under 6 that you serve
a. Once a month	
b. Twice a month	
c. Once a week	
d. Twice a week	

e. Three times each week	
f. Four or more times each week	
Total children served	

14. How long are your usual visits with children under 6 years and their families?

Usual length of visits	No. of children under 6 you serve
a. 30 minutes	
b. 1 hour	
c. 2 hours	
d. 3 hours	
e. 4 hours	
f. 5 hours or more	
Total children served	

15. For your service visits do you meet with the: (Include all the children that apply per type of service visit)

Type of service visit	No. of children under 6 you serve
a. Child alone, parent is not present	
b. Two or more children together, parent is not present	
c. One child, with parent looking on	
d. Two or more children, with parents looking on	
e. Child and parent together and you coach and mentor the parent throughout the visit	
Total children served	

16. Where do you meet for your visits with the child under 6 and their family? (State the number of children that are served by type of place.)

Place visits are held	No. of children under 6
a. Your ECI service centre or hospital	
b. Childcare centre or inclusive preschool	
c. Home of child	
d. Community centre or other place	
Total children served	

17. Each year, how much in-service training (continuing education/professional development) do you receive?

Amount of annual in-service training you receive	Choose one
a. No in-service training	
b. Less than 10 hours	
c. 11 to 20 hours	
d. 21 to 40 hours	
e. More than 41 hours	

18. What types of in-service training (continuing education/professional development) do you receive?

Types of in-service training	Check all types of training that you currently receive
a. Opportunities to attend professional conferences	
b. Online distance training courses	
c. Face-to-face education or training courses	
d. Professional training workshops	
e. Training at your organizational location, including practice sessions (field training)	
f. Formal educational programmes at universities	
g. Inter-organizational exchange visits	
h. Continuous onsite in-service training activities	

19. What types of in-service training (continuing education/professional development) would you like to receive?

Types of in-service training	Check all types of training that you currently receive
a. Opportunities to attend professional conferences	
b. Online distance training courses	
c. Face-to-face education or training courses	
d. Professional training workshops	
e. Training at your organizational location, including practice sessions (field training)	
f. Formal educational programmes at universities	
g. Inter-organizational exchange visits	
h. Continuous onsite in-service training activities	

20. What types of supervision and professional support do you currently receive?

Types of supervision	Check all types of supervision that you currently receive
a. Observation of home visits	
b. Observation of centre-based visits	
c. Coaching and mentoring	
d. Supportive reflective supervision	
e. Informal in-service training, as needed	
f. Review of child and family files	
g. I do not receive any supervisory support	

21. Do you also provide private fee-based services? Yes ___ No ___

22. If you responded yes to Question 21, approximately what percentage of your time is devoted to providing private fee-based services?

Percentage of time you devote to private fee-based services	Check one
a. 75% or more	
b. Between 50% and 75%	
c. Between 25% and 50%	
d. Less than 25%	

23. What are the top five challenges and needs of ECI services?

ECI service challenges and needs	Choose five
a. Inadequate policies, plans, laws and regulations for ECI organizations	
b. Weak ECI organizational structure for intersectoral planning, financing, and coordination	
c. Inadequate national survey data on developmental delays and disabilities	
d. Stigma and lack of inclusion of children with developmental disabilities in communities	
e. Lack of agreement regarding core ECI concepts	
f. Lack of regular developmental monitoring, screening services and referrals to ECI services	
g. Lack awareness of ECI services on the part of national, (regional) and municipal governments	
h. Lack of awareness of ECI services on the part of families and local communities	
i. Lack of advocacy for ECI services	
j. Inadequate funding to meet ECI organizational costs and expand ECI services	
k. Difficulty accessing and serving families in remote rural areas and minority ethnic groups	
l. Inadequately trained and qualified ECI service personnel	
m. Lack of high-quality ECI pre- and in-service training programmes	
n. Lack of supervisory services, including mentoring, coaching and reflective supervision	
o. Lack of a salary scale and a career ladder for early interventionists and other professionals	
p. Lack of an ECI monitoring and evaluation system, including a manual with monitoring and evaluation instruments	
q. Lack of computers, tablets and other technologies for ECI organizations	
r. Lack of an ECI coalition or network to promote ECI service growth and improvement	
s. Lack of ECI home-visiting services	
t. Inadequate ECI service contents: curricula, educational materials and methods	
u. Lack of transportation for home visiting	
v. Too much reporting and paperwork	
w. Lack of professional guidelines for ECI	

24. What are your top five recommendations for improving and expanding ECI services in our country?

Your top five recommendations	Choose five
a. Expand advocacy to reduce stigma and discrimination	
b. Expand advocacy to increase demand for and expand ECI services	
c. Develop national policies, plans, laws and regulations for ECI services	
d. Achieve greater equity through improving access to ECI services	
e. Improve the organization and coordination of ECI services with other services	
f. Establish a nationwide system for regular developmental monitoring, screening and referrals	
g. Provide high-quality and comprehensive child and family developmental assessments	
h. Develop a coalition or network of services for ECI	
i. Provide more home-visiting services	

j. Offer more parenting education and support services	
k. Give more opportunities for parent involvement in organizations for ECI	
l. Improve contents for ECI services: curricula, educational materials and methods	
m. Improve and expand pre- and in-service training for professionals who provide services for ECI	
n. Provide in-service training on contemporary services for personnel who deliver ECI services	
o. Develop a professional certification system linked to salary scales and career ladders	
p. Improve and expand systems for supervision, coaching and mentoring of professionals and paraprofessionals in ECI	
q. Expand services to rural regions, remote areas and minority ethnic groups	
r. Develop a national monitoring and evaluation system for ECI organizations	
s. Expand government/ministerial funding for ECI services at the central, (regional) and municipal levels	
t. Provide computers, tablets and other technologies requested by organizations delivering services for ECI	
u. Conduct national surveys to gather data on young children with developmental delays and disabilities	
v. Other (specify one)	

Annex 10: Survey of ECI Beneficiaries

Introduction: It is very important to survey ECI beneficiaries. Parents and caregivers are given the opportunity to state their needs, list barriers to service access, explain the levels and types of participation they have had during their engagement with ECI services, identify concerns regarding themselves and their children, and provide information on ECI services as they experience them. Their observations and opinions are of fundamental importance to addressing their needs, and although they are often best identified through conducting focus group discussions, it is important to try to secure some quantitative data as well.

Respondents: ECI beneficiaries are usually parents, legal guardians or regular caregivers of children eligible to receive support from ECI organizations. To the extent possible, fathers as well as mothers should be included in surveys and focus groups.
Special efforts should be made to include parents and caregivers of children from infancy to 36 months, as well as from 37 months to 6 years. Wherever they are currently served, vulnerable parents including, but not limited to, disadvantaged minority groups, low-income and geographically isolated groups should be included.

Sample: Approximately **five beneficiaries** from each ECI organization should be included. It may be easiest to include them by means of a survey; however, this is not always the case. If they are unable or unwilling to fill out questionnaires or respond to interviews, focus group discussions should be used. Both approaches are recommended in this study. The survey focuses on securing quantitative data, while focus group discussions mainly elicit qualitative data. Focus groups give researchers opportunities to include parents who are unable or unwilling to provide online information, who live in hard-to-reach communities, are members of disadvantaged minority groups or have low levels of literacy and/or computer literacy.

Survey: To ensure a good level of response, the number of questions should be kept as low as possible. Most questions are closed-ended with discrete dual or multiple-choice answers. Very few open-ended questions are asked.

Application methods: An online survey platform should be used, with options for computer or tablet responses. If the completion of an online survey is impossible, then hard copies can be filled out or interviews can be conducted.

Strengths: The survey approach gives beneficiaries an opportunity to provide information and recommendations that will be useful for planning the ECI system. Having an opportunity to express their ideas and make recommendations gives parents and caregivers agency and a voice regarding services that are essential for the development of their children. In several countries, beneficiaries responded very well to the surveys, although some had to be applied using hard copies or interviews.

Limitations: For various reasons, some parents enrolled in ECI services may not wish to participate. Some parents are unable to access and/or use online surveys, and it may be difficult to contact them personally to offer to interview them or provide them a hard copy of the survey. For these reasons, among others, capturing their points of view through focus groups will also be important. Families with higher incomes who can afford online services may dominate the list of beneficiaries surveyed unless a concerted effort is made to ensure the inclusion of underserved populations.

Possible incentives to participate: Respondents will be assured that their responses will be fully confidential. They should be told that the survey will give them an opportunity to represent families who greatly need ECI services, and they will be able to give their recommendations regarding ECI services and to contribute to improving service access and the quality of ECI services in their countries. To date, experience has revealed a high level of responsiveness on the part of parents and caregivers.

Analysis: (Same as for the directors' and service personnel surveys.)

Draft Cover Letter for Survey of ECI Beneficiaries

Dear parent of a child enrolled in Early Childhood Intervention services,
All parents of children enrolled in ECI organizations are warmly invited to fill out this survey. Only one parent per family should submit a survey. **Thank you very much** for taking **15 minutes** of your time to respond to this survey.

Our goals are to:

- Learn about the needs, experiences and recommendations of families and children enrolled in ECI services;
- Use your comments and suggestions to plan for future ECI services; and
- Produce a National ECI Situation Analysis with recommendations for ECI policies and organizations.

Please fill out this survey as completely and accurately as possible before **(date).**
At the end of the survey, **we ask for your recommendations** regarding the future of ECI organizations in your country.

All information you give will be strictly **confidential**. You are not asked to evaluate your ECI services. No information you give will be reported in any way that identifies your ECI organization or you as a person. Data will be reported at thee group level, such as "parents of ECI organizations reported that…"

Analysed data from all parents will be kept at a secure site only for the use of the ECI research team. All data will be stored in protected databases that can only be accessed by our researchers. You will not receive any compensation and your participation is entirely voluntary.

In choosing to participate in this survey, **you have the right to end your participation at any time**. You may withdraw your consent and request that information you gave us not be used in reporting results. You also have the right to access the information you gave, correct it and have it erased. You may request your data be transmitted to a different study/researcher in a structured and readable format. You may choose not to answer a particular question and still respond to other questions.

By completing the questions in this survey, you affirm that you understand what this survey is about, how your information will be used, and that you agree to participate.

If you have further questions, wish to request a paper copy to fill out, or you need someone to talk with after submitting this survey, please contact:

THANK YOU very much for your collaboration!

Survey of ECI Beneficiaries

Dear parent, legal guardian or caregiver,

If you have more than one child in an organization that provides early childhood intervention activities, please respond only for your youngest child.

1. What is the gender of your child?

Gender	Choose one
a. Girl	
b. Boy	

2. How old is your child?

Age of child	Choose one
a. 0–6 months	
b. 7–12 months	
c. 13–24 months	
d. 25–36 months	
e. 37–60 months	
f. Over 61 months	

3. What is your relationship to the child?

Relationship	Choose one
a. Mother	
b. Father	
c. Guardian or close relative	
d. Daily caregiver, i.e., nanny, grandmother, aunt, etc.	

4. Please select your city, town, village or nearest village
(Place pull down menu here.)

5. Please select the services that your child currently uses:

Services your child may currently use	Choose all services that your child uses
a. Primary healthcare centre (Please specify)	
b. Resource centre (Please specify)	
c. Centre for autism	
d. Day-Care Centre (DCC) for children with disabilities (Please specify)	
e. Organization in another country (Please specify country)	
f. Private provider of services for children with disabilities (Please name the type of treatment your child is receiving there)	
g. Special health Institute (Please specify)	
h. Services provided by an NGO (Please specify)	
i. Clinical centre (Please specify)	

j. Hospital (Please name the service your child receives)	
k. Centre for Social Work or another social service (Please specify)	
l. Inclusive creche or nursery (Please specify)	
m. Inclusive preschool (Please specify)	
Other (Please specify)	

6. Who told you about the organization with activities for early childhood intervention where your child is enrolled?

How you learned about services for early childhood intervention	Choose one
a. Personnel at a Neonatal Intensive Care Unit	
b. Someone else at a hospital	
c. Non-hospital nurse	
d. My child's paediatrician or physician	
e. Another type of physician	
f. Social worker at a social welfare centre	
g. Personnel of an organization that provides early childhood intervention services	
h. Personnel of a nursery or preschool	
i. Another parent	
j. A family member or relative	
k. A friend or neighbour	
l. Mass media	
m. Social media or a website	
n. Other (specify)	

7. Was your child on a waiting list before enrolling in the organization that provides activities for early childhood intervention? Yes/No

8. If you answered "yes" to Question 7, for how long?

Length of time on waiting list	Choose one
a. Less than 3 months	
b. From 3 to 6 months	
c. From 7 months to 1 year	
d. More than 1 year	

9. How old was your child when she/he was first enrolled in services for early childhood intervention?

Your child's age AT THE TIME OF ENROLMENT in activities for early childhood intervention	Choose one
a. 0–1 month	
b. 1–6 months	
c. 7–12 months	
d. 13–24 months	
e. 25–36 months	
f. 37 months or older	

10. Why did you enrol your child in services for early childhood intervention?

Reason you enrolled your child in ECI services	Choose all that apply
a. Child was born pre-term or with low birth weight	
b. Child had a chronic condition (micronutrient disorder, chronic illness, etc.)	
c. Child was not growing well	
d. Child had a delay and was slow to develop	
e. Child had a motor/muscular disability	
f. Child had a speech/language delay	
g. Child had low vision or was blind	
h. Child had a hearing loss or was deaf	
i. Child had a cognitive disability	
j. Child had several disabilities	
k. Child was on the autism spectrum	
l. Child had attention deficit and hyperactivity disorder	
m. Child had depression or trauma	
n. Another reason: (specify)	

11. Which barriers did you face in obtaining services for early childhood intervention?

Barriers you faced	Choose all you faced
a. I lacked information about services for early childhood intervention	
b. My child lacked a birth registration	
c. My child has a different nationality	
d. Services for early childhood intervention do not exist in my community	
e. Services for early childhood intervention are located too far away from my home	
f. It was hard to get transportation to these services	
g. It was hard to get a referral to an organization with activities for early childhood intervention	
h. There were long waiting lists for these services	
i. The enrolment process was very complicated	
j. My child's development was not screened/assessed during routine visits to primary healthcare services	
k. There are no specialists in my child's area of need	
l. I did not have the financial means to pay for services for early childhood intervention	
m. Services for early childhood intervention are not offered during my non-working hours	
n. I needed an interpreter to speak with the personnel of services for early childhood intervention	
o. Other: (specify)	

12. Did you and your child receive a **quick checklist screening** regarding her/his level of development? Yes/No/Don't know

13. If you answered "yes" to Question 12, did you:

Did you?	Choose one
a. Give answers for the screening	
b. Observe but not participate in the screening	
c. Did not participate in nor observe the screening	

14. In what ways did you and your child receive support services and/or treatments from a team of professionals?

Type of professional support	Choose one
a. One person works alone with my child	
b. One person works with me and my child separately	
c. One person works with me and my child together	
d. One person works with me, my child and two or more children together	
e. A team was formed to work with my child alone	
f. A team was formed to work with me and my child separately	
g. A team was formed to work with me and my child together	
h. A team was formed to work with me, my child and two or more children together	

15. Did your child receive one or more specialized assessments (assessments for different areas of child development)? Yes/No

16. If you answered "yes" to Question 15, was the assessment(s) conducted by:

Assessment was conducted by	Choose one
a. One professional	
b. More than one professional at different times	
c. A team of professionals at the same time	

17. Did your child receive a comprehensive developmental assessment (an assessment of ALL areas of child development)? Yes/No

18. If you answered "yes" to Question 17, was the comprehensive developmental assessment conducted by:

Assessment was conducted by	Choose one
a. One professional	
b. More than one professional at different times	
c. A team of professionals at the same time	

19. Was an Individualized Family Service Plan prepared that includes goals for your child and family? Yes/No/Don't know

20. If you answered "yes" to Question 19, who made the decisions about your child's services for early childhood intervention?

Decision makers	Choose one
a. A professional made the decisions regarding services	
b. A team of professionals made the decisions	
c. After discussing options with the team, I made the decisions	

21. If you answered "yes" to Question 19, did you sign and date the Individualized Family Service Plan? Yes/No

22. During the preparation of the Individualized Family Service Plan, were you or members of your family offered: (choose all that apply)

Services you were offered	Choose all that apply
a. Family support or counselling sessions	
b. Peer-group sessions with other parents in ECI services	
c. Parent education meetings	
d. Support groups for siblings	
e. Referrals to other services (e.g., health, education, etc.)	

23. What type(s) of specialist(s) work with you and your child?

Type of specialist	Choose all who serve you
a. I am not sure	
b. Case manager, service coordinator or family support manager	
c. Early childhood intervention specialist	
d. Nurse	
e. Occupational therapist	
f. Physician	
g. Physiotherapist	
h. Psychologist	
i. Rehabilitation specialist	
j. Social pedagogue	
k. Social worker/social welfare specialist	
l. Speech and language therapist	
m. Child psychologist	
n. Child neurologist	
o. Other: (specify)	

24. Where do you and your child receive services for early childhood intervention?

Place where ECI services are given	Choose all that apply
a. In my home	
b. Both in my home and in a centre for early childhood intervention	
c. Only in an institution or organization for early childhood intervention	
d. In a health centre	
e. In a nursery or inclusive preschool	
f. In a centre for social work	
g. In another place where my child spends time on most days such as a playground, children's centre, etc.	
h. Other: (specify)	

25. What is your participation in activities for your child during visits?

Your participation	In all visits	In some visits	In few to no visits
a. If home visits are made, how often do you participate in activities for early childhood intervention with your child?			
b. If visits are in a centre, how often do you participate in activities for early childhood intervention with your child?			

26. How many times a month do you and your child receive services for early childhood intervention?

Frequency of visits	Choose one
a. Once a month	
b. Every two weeks	
c. Once every week	
d. Twice every week	
e. Three or more times every week	

27. Do you pay a fee for your services for early childhood intervention? Yes/No

28. If you answered "yes" to Question 27, how much out-of-pocket money did you spend last year on diagnostic services and therapies for your child? (Currency may vary per country.)

Total fees that you paid last year	
Amount in euros	**Choose one**
a. Up to €200	
b. €201 to €500	
c. Over €501	

29. Do you receive any social benefits that pay for the early childhood intervention services your child receives? Yes/No

30. Do you receive any services for your child from private organizations or individual therapists? Yes/No

31. If you answered "yes" to Question 30, how much out-of-pocket money have you spent during the previous year on diagnostic services and therapies for your child?

Fees paid in the previous year for private services	
Amount in euros	**Choose one**
a. Up to €200	
b. €201 to €500	
c. Over €501	

32. What are your top five recommendations for improving and expanding ECI services in our country?

Your top five recommendations	Choose five
a. Expand advocacy to reduce stigma and discrimination and to increase demand for services for early childhood intervention	
b. Expand advocacy to increase demand for and expand services for early childhood intervention	
c. Develop national policies, plans, laws and regulations for services for early childhood intervention	
d. Achieve greater equity through improving access to services for early childhood intervention	
e. Improve the organization and coordination of services for early childhood intervention with other services	
f. Establish a nationwide system for regular developmental monitoring, screening and referrals	
g. Provide high-quality and comprehensive child and family developmental assessments	
h. Develop a coalition or network of services for early childhood intervention	
i. Provide more ECI home-visiting services	
j. Offer more parenting education and support services	
k. Give more opportunities for parent involvement in organizations for early childhood intervention	
l. Improve service contents for early childhood intervention: curricula, educational materials and methods	
m. Improve and expand pre-service training for professionals who provide services for early childhood intervention	
n. Provide in-service training on contemporary services for personnel who deliver early childhood intervention services	
o. Develop a certification system for ECI professionals	
p. Improve and expand systems for supervision, coaching and mentoring of professionals and paraprofessionals who provide services for early childhood intervention	
q. Expand services to rural regions, remote areas and minority ethnic groups	
r. Develop a national monitoring and evaluation system for organizations providing services for early childhood intervention	
s. Expand government/ministerial funding for early childhood intervention services at the central, (regional), and municipal levels	
t. Provide computers, tablets and other technologies requested by organizations delivering services for early childhood intervention	
u. Conduct national surveys to gather data on developmental delays and disabilities	
v. Other: (specify one)	

33. What is your current work? (This is an optional question)

Current work status	Choose one
a. Self-employed	
b. Employed full-time	
c. Employed part-time	
d. Unemployed and currently looking for work	
e. Unemployed and not currently looking for work	
f. Retired	
g. Student	
h. I care for my children and home	
i. Unable to work	

34. What is your level of formal education? (This is an optional question)

Level of formal education	Choose one
a. Primary school completed	
b. Vocational school graduate	
c. Secondary school graduate	
d. University bachelor's degree	
e. University master's degree or higher	

The following questions are optional, depending upon the existence of commissions in your country:

35. Is your child enrolled in any type of inclusive childcare or early education service? Yes/No

36. Was your child assessed by a special commission? Yes/No
(If you answered "no", you have completed the survey.)

37. Were you involved in the process of assessment conducted by the commission? Yes/No

38. Was the commission's decision implemented where your child is enrolled? Yes/No/Partially

Thank you very much for filling out this survey!

[25] If the services are outsourced, please see Section VII.

Annex 11: Cost and Finance Sub-Study Instruments

Introduction: The Cost and Finance Sub-Study is being conducted to: 1) learn about typical ECI organizational costs and financial sources; 2) establish a baseline for future studies of ECI organizational costs and financial sources; and 3) establish a cost basis and funding parameters for future ECI organizational planning.

The Cost and Finance Sub-Study includes three major components:

- A **Cost and Finance Sub-Study of four to six selected major types of ECI** organizations, including both evolving and contemporary ECI organizations that provide home visits, mixed home visits and centre-based activities or only centre-based activities. The sampling criteria are presented below. It is hoped that at least one ECI organization will mainly serve a minority ethnic group. This study includes the following:
  - A detailed questionnaire with several components regarding organizational costs and financing is given to each organization to complete.
  - A semi-structured interview with each ECI director and/or financial manager is conducted, after the questionnaire has been completed, with each ECI director and/or financial manager to ask key questions, double-check figures and secure additional information about their cost and finance data.
- A **governmental finance and expenditure study** is conducted in national ministries and/or agencies, regional governments (if any), and municipalities. In addition to the central ministries, three to four regions, and three to four municipalitie[24] will be selected to secure their annual budgets for ECI and related fiscal programmes, annual expenditures for 3 to 5 or 6 years, and international and regional support for ECI services (e.g., World Bank, UNICEF, EU funds for EU member countries and others as they become available, foundations, and other sources including private sector grants and parents' fees).
- **The ECI director's survey** includes questions regarding annual sources of income from diversified sources.

Respondents: ECI directors, financial managers and/or accountants as well as key ministerial finance offices (Ministry of Finance and Ministries of Education, Health and Social Protection/Social Welfare), and accounting offices of regional and municipal governments.

Samples:

- Four to six selected ECI organizations are selected for organizational-level cost and finance studies. The **criteria for their selection are:** (1) **type of services** (home visits, centre-based visits, and mixed home and centre-based services); (2) **location** (urban, rural, and remote areas and places where national minority populations live); (3) **type of populations served** (national majority, low-income families and minority groups); and (4) **main source of support** (central government, local government, non-profit organization, private for-profit business (if included)).
- All national ministries or agencies providing funding for ECI organizations or evolving organizations are visited to secure financial data and information about coordination and other matters.
- Three to four regions and/or local administrative units are visited to secure financial and expenditure data and identify the types funding that may be provided for ECI services at these levels.

Survey: The questionnaire provides several charts for entering financial and costing data, with discrete responses including dual and multiple-choice answers. Open-ended questions will be asked during the follow-up interview to clarify and check the data that have been provided.

[24] Municipalities are local government bodies with their own budgets. Regions are sub-national administrative units of a country and have their own budgets. However, the names of self-governments and other administrative units may differ from country to country.

Cost and finance specialist: In addition to possessing excellent cost and finance knowledge and experience, the team member(s) who conduct the cost and finance study should have good interviewing skills. They must command the respect and secure the trust of governmental representatives and organizational personnel.

Application methods: A hard-copy document and an online computer survey platform are used to secure quantitative data. The interviewer asks qualitative, quantitative and contextual questions, checks on data provided, and asks about topics of interest to help present and explain cost and finance data. For interviews with financial specialists a semi-structured interview is conducted because important additional questions often emerge from the discussion.

First the research team prepares a list of potential evolving and contemporary institutions and organizations to be selected for this study. ECI organizations to be selected will be those with: 1) home visits only, 2) mixed home visits and centre-based visits, and 3) centre-based visits only. One legacy rehabilitation or habilitation organization may be added. *However, inclusive preschools usually are not studied because their services and their cost parameters are very different from those of ECI organizations*.

Once four to six institutions and organizations have been selected, for the case studies a set of charts is distributed either by email or by means of an online survey to the ECI director, financial manager or accountant of evolving and contemporary ECI organizations.

It is important to identify whether different levels of the government participate in funding ECI services. The sub-study cost and finance specialist should identify, either during the literature review or through the sub-study: 1) if a legal act exists that identifies which level(s) of the government (national, regional, local) is responsible for providing ECI services; 2) which ministries, and in a decentralized system, which levels of government support specific ECI institutions and organizations; and 3) what types of coordination exist among different levels of the government in relation to the funding of ECI services.

The cost and finance specialist receives information through interviews and all other possible means (including e-mail or during visits to offices) with: 1) leaders and specialists at the national governmental level including ministries of health, education and social protection, and Ministry of Finance offices; and 2) finance officers of territorial administrative units including local and regional governments, if any)[25]

It is important that the cost and finance specialist clarify whether there is a separate cost category for ECI services in the national and administrative unit's (regions, local governments) budgets or if the spending on ECI services is done through larger social protection categories/organizations (i.e., from an organization for children with disabilities, an organization for the social protection of the population, etc.).

Regarding the time periods studied, this sub-study seeks the amounts of:

I. Annual ECI budgets for the latest three years, as available.
II. Annual actual ECI expenditures for the same years.
III. Budget plans and forecasts for ECI during the forthcoming three years, as available.

The cost and finance specialist should ask whether the ECI organizations that are implemented at the national and sub-national levels (regional and local governments) are the subject to assessment of budget implementation against stated goals and objectives. This is important because the budget for the succeeding years should be planned while considering the results achieved during prior years, financial constraints and other national macro-economic challenges.

The cost and finance specialist should establish an interview schedule with ECI directors, financial managers and/or accountants of selected ECI organizations, and with ministerial, regional and local finance representatives. Semi-structured interviews are conducted to double-check data and secure additional information, as needed.
Included below are interview formats for representatives of ministries, state agencies (e.g., state health insurance funds), and local governments.

[25] Municipalities are local government bodies with their own budgets. Regions are sub-national administrative units of a country and have their own budgets. However, the names of self-governments and other administrative units may differ from country to country.

The cost and finance specialist should provide a brief ethics statement and assure participating ECI organization representatives that information on their organizations or offices will be presented anonymously in the National ECI Situation Analysis. She/he will ask if they have any questions before beginning the interview.

Published governmental/ministerial data are public documents unless stated otherwise. It is virtually impossible to disguise such data. Furthermore, those data are essential for purposes of national planning.

At the end of each interview conducted with organizational and governmental representatives, the cost and finance specialist should express gratitude for the interviewee's time and tell her/him that a copy of the ECI Situation Analysis will be sent to every person who participated in the interviews.

Strengths: Data will be highly quantified and amply double-checked. The semi-structured interviews will add explanatory information that will enrich the text sections of the Cost and Finance Sub-Study and the ECI Situation Analysis as a whole.

Limitations: One or more directors of ECI evolving or contemporary organizations may refuse to provide or be unable to gather their cost and financial data, although they usually agree to collaborate with the study. One or more ministries, regional or local governments selected for interviews may refuse or be unable to provide requested financial data. It may prove difficult to obtain financial information during the brief period for research, but usually good collaboration is secured because respondents understand the importance of the fiscal dimension for ECI development and growth.

Possible incentives to participate: Assurances of complete data privacy are given to all ECI organizations. Opportunities to learn about new and additional sources of governmental and other funding sources may be of significant interest and use to them and to all ECI organizations.

Analysis: This sub-study must be conducted by a highly trained specialist in economics, cost and finance. The specialist calculates the ECI service costs of each organization resulting in a cost per child and a cost per ECI service within each organization. The analyses are presented anonymously. The organizations included during the Cost and Finance Sub-Study are referred to as A, B, C and D instead of stating of their names. They are noted as services in a "large city", "small city" or "rural area" – instead of giving their locations. They might also be designated as a legacy service, an evolving service or a contemporary ECI service. Finance data from ministries, regional and local governments cannot be presented anonymously but permission is given by the ministries and usually they are sharing public data with the research, much of which has been published in external or internal documents.

Cover Letter and Charts for Costs and Finance Sub-Study

Cover Letter for ECI Organisations

Dear ECI director, financial manager and/or accountant,

(Name of institution) is currently conducting a rapid National Situation Analysis for Early Childhood Intervention (ECI) organizations. These organizations serve children from birth to 3 or 5 or 6 years of age: 1) in at-risk situations such as pre-term birth, low birth weight, congenital conditions, chronic illnesses; 2) with developmental delays, 3) disabilities, 4) behavioural conditions such as autism or attention deficit and hyperactivity disorder, and 5) mental health needs, such as depression and trauma.

As you know, ECI organizations support and assist parents and caregivers to develop their children well and help them achieve their full potential.

I am writing you today to request your help in providing cost and finance information on your ECI organization. Your contributions will help our country plan the expansion, improvement and increased financial support of ECI organizations and services for families and children. Your comments will be of great importance to the future development of high-quality ECI services throughout our country.

I shall be happy to support your work on the charts below. If you have any questions or comments, please contact me by email or telephone (provide contact information).

Please kindly submit your completed charts by (date) to (state where to send them).

Kind regards,

(Name of researcher)

Cost and Finance Charts

Please fill in the information requested in the matrices below. Should you lack detailed information (breakdowns) for some of the following tables, please kindly provide the total amounts. Please indicate amounts in the **national currency** throughout all your responses.

If the salary of a staff member is monthly, and the institution or organization provides other services in addition to ECI services, the interviewer should identify what proportion of time she/he spends on the ECI services (e.g., 50% or 30%).

1. Personnel payments							
Types of Personnel		**Salary (gross) Please fill in where applicable**					
Professionals and paraprofessionals	**Number of staff members**	**Salary per hour**	**No. of hours per year**	**Daily rate**	**Number of days per year**	**Monthly rate**	**Share of time spent on ECI %**
Supervisors							
Speech/language therapists							
Physiotherapists							
Occupational therapists							
Social workers							
Psychologists							
Other professional staff (Please list below)							
1							
2							
3							
4							
5							
Total professionals							
Support staff [26]							
Cleaners							
Cook							
Driver							
Other							
Total support staff							
Administration							
Director/manager							
Accountant							
Assistant							
Secretary							
Total administration							

[26] If the services are outsourced, please see Section VII.

If there are payments in addition to salaries, please note the number of days and amounts of vacation, sick leave, insurance and allowances for the parents of a child. However, if these are not paid, then staff members only receive their salaries. In this case, please do not fill in the table below.

2. Additional payments to personnel						
Benefits (if any)	**Vacation**		**Sick leave**		**Insurance**	
	Number of days per year	**Daily rate**	**Number of days per year**	**Daily rate**	**Number of months**	**Monthly rate**
Staff						
Professionals						
Paraprofes-sionals						
Supervisors						
Early intervention specialists						
Speech/lan-guage therapists						
Physiotherapists						
Occupational therapists						
Social workers						
Psychologists						
Other professional staff (Please list below)						
1						
2						
3						
4						
5						
Support staf[26]						
Cleaners						
Cook						
Driver						
Other						
Administra-tion						
Director/manager						
Accountant						
Assistant						
Secretary						
Parents						

[27] If the services are outsourced, please see Section VII.

For ECI organizations that have in-kind support (from central, regional, where present, and local authorities, donors, or other) of the following types, please fill in your annual estimated values.
In-kind support includes goods or services received without payment by the ECI organization.

3. Types of in-kind support			
	Annual estimated value		
Type of in-kind support (if any)	Year 1	Year 2	Year 3
Office and organizational location			
Utilities (by type)			
Office equipment			
Office furniture			
Office supplies			
Office maintenance and repairs			
Transportation			
Communications (by type)			
Telephone			
Internet			
Website			
Other			
Other			
Other			
Total			

For ECI organizations that provide distant, online consultation visits, please fill in the following information if you have it.

4. Distance online consultation visits (Please fill in if a consultation cost is not part of the salary.)			
Type of professional or paraprofessional	Cost per distant consultation per beneficiary	Number of consultations per year for one beneficiary	Number of beneficiaries
Supervisors			
Early intervention specialists			
Speech/language therapists			
Physiotherapists			
Occupational therapists			
Social workers			
Psychologists			
Other professional staff (Please list below)			
1			
2			
3			
4			
5			

To assess transportation costs for providing home visits (if any), please note the number of home visits made per year and estimate the average cost of travel per staff member.

5. Annual transportation costs		
Type of professional or paraprofessional	**Number of home visits made during the year**	**Cost of trip**
Supervisors		
Early intervention specialists		
Speech/language therapists		
Physiotherapists		
Occupational therapists		
Social workers		
Psychologists		
Other professional staff (please list below)		
1		
2		
3		
4		
5		

This table should be filled in when transportation costs to the office or centre for professional meetings are not included in other costs of fuel for transportation.

6. Transportation costs to office or centre for professional meetings (if any)		
Type of professional or paraprofessional	**Number of trips to meetings during the year**	**Cost of trip**
Supervisors		
Early intervention specialists		
Speech/language therapists		
Physiotherapists		
Occupational therapists		
Social workers		
Psychologists		
Other professional staff (please list below)		
1		
2		
3		
4		
5		

Please fill in the annual costs for utilities and other related infrastructural costs when they have not been included above.

7. Annual costs for utilities and related costs	
Centre and/or office utilities and related services (if any)	**Annual cost**
Gas for heating and cooking	
Water and sewerage	
Heating (other than gas, such as coal or wood)	
Waste removal	
Fuel for transportation	
Electricity	
Communications (e.g., telephone, internet, website, web platform, postage)	
Building rental	
Building repair and maintenance	
ECI service supplies	
Office supplies, including printing and copying, as well as all office pens, folders, etc.	
Furniture	
Equipment (computers, printers, etc.)	
Cars or other transportation, if owned by the organization	
Service contracts (if any, and for what): (see below)	
Contract with cleaning company	
Contract with laundry	
Contract with accounting and auditing company	
Cooking or meal supply	
Security	
Contract with insurance company	
State standard control	
Other	
Food/meals for children and/or families	
Clothes	
Personal hygiene items	
Child development materials and small inventory items (books, toys, puzzles, etc.)	
Children's small inventory items	
Drugs	
Memberships and subscriptions	
Translation and interpretation	
Costs for supporting volunteers	
Other	
Other	

Please fill in the annual costs of trainings for parents, professionals, paraprofessionals

8. Annual training costs for parents, personnel and others			
Parents and personnel	**Cost of training and educational courses**	**Number of training sessions to be attended per year**	**Number of trainees attending the training**
Parents			
Professional staff members			
Paraprofessional staff members			
Volunteers			
Others: (specify)			

Please fill in your ECI organization's amounts of funding per source for the last three years.

9. Sources of ECI organizational funding (contracts, grants, vouchers, insurance, & other sources)			
Type of funding	**Amount in Year 1**	**Amount in Year 2**	**Amount in year 3**
National government/name of ministry (types of costs covered)			
Regional government (if any)/name of source (types of costs covered for all below)			
Local government			
International UN agencies (specify)			
International banks (e.g., World Bank)			
International foundations			
International non-governmental or faith-based organizations			
European Union			
National private support/donations			
Parent fees for ECI services			
National foundations, businesses and corporations			
Fundraising activities			
Other			
Other			
Totals			

Interviews for Ministries, State Agencies, Regional and Local Governments

This interview format should be given to the interviewee a few days beforehand to enable her/him to gather the information requested. The interviewers should ask every question even if they think the answer to a question might be "no".

For ministries and state agencies (e.g., state health insurance funds)

1. Does the ministry you represent allocate funds for Early Childhood Intervention (ECI) public institutions and/or civil society organizations, or for ECI components of education, health or social institutions or organizations? Yes/No

2. If so, are the institution(s) or organization(s) separate ECI services or are they ECI components within an education, health or social institutions or organizations?

3. Please specify the budget lines under which the funds are allocated to ECI institution(s), organization(s) or ECI component(s) of an institution or organization.

4. Please state the name of the ECI institution(s) or organization(s) and/or your ECI component(s) of an institution or organization.

5. What is the annual allocation of funds for ECI institution(s), organization(s) or the ECI components of institutions or organizations? (in absolute numbers)
   Please give a breakdown if there is more than one organization or component.

6. What is the percentage of the amounts of funds allocated to ECI institution(s), organization(s) or ECI components of institution(s) or organization(s) to the total ECI allocations of your ministry? (e.g., percentage of total ministerial allocations dedicated to ECI)

7. Do ECI institution(s) and/or organization(s) or component(s) of institution(s) or organization(s) submit reports to your ministry regarding the implementation of their ECI services? Yes/No

8. If so, when do institution(s) or organization(s) or components submit those reports to your ministry? (monthly, quarterly, half-yearly, or annually)

9. Does your ministry assess the budget performance of these ECI institution(s), organization(s) or ECI components? Yes/No

10. If so, how frequently?

11. If so, can you provide your list of indicators for the assessment of the performance of ECI institutions, organizations or ECI components?

12. Have you received donor support (e.g., EU Funds, UNICEF, others) to implement ECI institution(s) or organization(s) or ECI components? Yes/No

13. If so, please state the ECI organizations' names, year(s) and amounts.

For regional and local governments (e.g., municipal governments, city governments)

With a few variations, this interview can be used with regional governments that provide funds to ECI institutions or organizations.

To better understand the role of local authorities in funding ECI public institutions and organizations and to explore ways to strengthen their role in funding ECI, the following questions can be asked. The interviewer may also ask other ad-hoc questions.

1. Does the local government provide funding for ECI organizations? Yes/No

2. If so, please indicate whether the funded organizations are separate ECI public institutions, civil society organizations (such as NGOs, universities, or parent associations), or a component of an educational, health or social institution or organization?

3. Please provide the names of these ECI institution(s), organization(s) or ECI components of educational, health or social institutions or organizations.

4. What is the annual allocation of funds to each ECI public institution, organization, or ECI component of an institution or organization? (in absolute figures)

5. What is the percentage of the amount allocated to ECI institution(s) or organization(s) in your local government out of your total budget?

6. Does your local government provide an annual assessment of the budgetary performance of ECI institution(s), organization(s), and/or the ECI components of institutions or organizations? Yes/No

7. If so, can you provide a list of indicators that your local government uses to assess the budgetary performance of these institution(s) or organization(s)?

8. Has your local government received direct support from another source (e.g., donors, international foundations, ministries) to co-fund ECI institutions, organizations or the ECI components of institutions or organizations? Yes/No

9. If so,
   a) What is the name of the co-financing source?
   b) What is the share of the co-financing?
   c) Is this co-financing permanent (e.g., every year) or does it depend on the activity or project?

10. What needs, problems or challenges does your local government face regarding the funding of ECI services? (e.g. lack of funds for salaries of staff, equipment, facilities)

11. What do you think should be done to improve the situation?

12. Does your local government cooperate with the parents of children receiving ECI services or with an association of parents? If "yes", what are those forms of cooperation?

13. Do you think that a greater involvement of citizens (parents' associations, local civil society organizations, and others) in prioritizing problems, and in the budget planning process would help to improve ECI services and/or gain more support for ECI services?

14. How might any new reform of the government programmes (e.g., public finance reform, if any) affect your revenues and your financing of ECI services?

15. Could you share with us some possible risks for future local government financing?

Annex 12: Focus Group Discussions with ECI Service Personnel

Introduction: Focus group discussions with ECI service personnel seek to:

- Secure their opinions and hopes regarding key aspects of their work as professionals or paraprofessionals.
- Discover their interests regarding pre- and in-service training.
- Learn about their possible interest in developing or strengthening a national coalition or network of ECI organizations.
- Learn about their recommendations for ECI organizations.

A structured and open-ended list of questions is used to conduct focus groups of ECI service personnel. The data gathered through the focus groups helps to interpret the results from the survey of ECI service personnel. The questions address the types of ECI services that personnel provide, community outreach, ECI service quality, pre- and in-service training, personnel retention, career ladders and salary scales, supervision, monitoring and evaluation, networking and inter-organizational coordination, and recommendations for expanding and improving ECI services. These focus groups **do not seek to evaluate ECI organizations.** It is important to emphasize this when speaking with ECI directors.

Respondents: For the purposes of ECI Situation Analyses, those who work directly with families and children will be selected, including supervisors, professionals, paraprofessionals and highly trained volunteers. ECI directors are invited to select **two or three service staff members** from their organization to participate in regional focus group discussions. These staff members must be providing direct ECI services to families with young children enrolled in ECI services. They may include both professionals and trained and supervised paraprofessional who provide services to families and children. The focus groups will be held in places located as close as possible to their organizations to enable them to feel comfortable in a familiar surrounding and to avoid costs associated with travel. Hopefully, two or three staff members of all ECI and evolving organizations will be able to participate in a focus group.

Sample: Each selected ECI or evolving organization should choose two or three service staff members to attend a focus group. To the extent possible, organizations in rural and urban settings should be invited and having combined groups may be possible and advisable, depending upon the context; however, travel costs need to be considered because they may affect research decisions regarding: the locations, the number of focus groups that can be held, and the size of the focus groups. Generally, focus groups should be held as close as possible to the locations of their organizations. The number of focus groups to be held will depend upon the number of ECI organizations identified, the size of the country, its geographical regions and its types of populations. Usually, at least two focus groups are held in urban areas, two in villages or small towns, and two with organizations serving disadvantaged groups. It might be helpful to have legacy institutions or organizations (if included) meet separately, and evolving and contemporary ECI institutions organizations might meet together. However, it might be advantageous to have fully mixed groups. Ultimately, these decisions will be up to the ECI research team. Overall, from six to eight focus groups of ECI personnel should be held to secure a good array of responses. In the Situation Analysis, the research team should explain how and why they established their samples.

Should a major public health outbreak occur, it may become necessary to hold some or all focus groups using a virtual platform. Some countries have used a mix of in-person meetings and virtual meetings. This decision will be up to national researchers who know and understand their evolving public health situation and rules regarding in-person meetings.

Focus group guide: To encourage active discussion, no more than 15 questions should be asked. Most of them should be open-ended to encourage lively discussion.

Application methods: If possible, from 8 to 10 persons (and no more than 15 persons) should be included in each focus group to encourage open discussion. It is advisable to request to record the

focus group and to secure the prior agreement of the participants.

The ECI research team coordinates and plans the logistics for the holding of regional focus group discussions with a sample of two to three service professionals from each ECI organization and evolving organization. A letter of invitation should be emailed to all ECI directors along with the guide for focus group discussions. The ECI director will see that the focus group is not an evaluation of their organization but rather a way to gain information needed to support personnel in ECI organizations. This letter and the guide should be translated into the national language(s) and field-tested to ensure translation accuracy, comprehension and cultural appropriateness.

All focus group discussions must be completely confidential. Respondent participation will be entirely voluntary, and they will be explained their full rights. They will also be told that they will not be paid for their participation but that the experience could be valuable for their current and future work.

The focus groups are held in various regions of the country to minimize transportation costs. If possible, from 8 to 10 persons (and no more than 15 persons) should be included in each focus group discussion. The focus group questions build upon the questions in the Survey for ECI Service Personnel. After providing the ethics statement to all participants and discussing any questions related to how the discussion results will be handled, focus groups facilitators should explain that they are recording the session to ensure they will not miss any important points. They will say that the recordings will only be listened to by members of the ECI research team, and they will be destroyed once the Situation Analysis has been completed. In the meantime, they will be maintained in a secure lockbox only for use by members of the research team. The facilitators should ask all questions even though they might think an answer will be "no".

Strengths: ECI service personnel tend to speak openly in focus group discussions, and when this happens, the results can be quite valuable.

Limitations: It is possible that service personnel from some ECI organizations may not wish to participate in focus group discussions. In some cases, an ECI director may not wish to have their staff members participate in an open discussion, although this rarely happens. Directors should be told that neither the survey nor the focus group questions evaluate their organizations in any way. The brief window of time for holding focus group discussions may make it difficult to include staff members of all organizations in focus group discussions. Some personnel may fear that their comments may be shared with their directors or others, even though no attempt will be made to evaluate them or their organizations. They should be assured that the results of their focus group will not be presented individually in the study. Rather, the results of all focus group discussions will be combined and presented anonymously in an aggregated form in the Situation Analysis.

Possible incentives to participate: Assurances of data privacy will be made. They will be told that they will gain opportunities to meet personnel from other ECI organizations, thereby enabling them to learn about how ECI work is conducted in other organizations. It should be emphasized that they will be invited to make recommendations that may result in receiving opportunities to improve their skills and work situation.

Analysis: After each focus group with ECI service personnel, research team members should transcribe the results as soon as possible so as not to forget any important points. Facilitators should review the transcriptions for completeness because participants often speak at once. Arrangements should also be made to translate the transcriptions into English and/or other languages needed to prepare the ECI Situation Analysis.

As focus groups are held, the main points should be placed in a matrix with the questions or topic from the focus group guide down the left-hand column, the focus group numbers and locations in separate columns across the top, and a summary in the right-hand column.

The summary column should provide a brief quantitative and qualitative analysis of major findings per question. Some comments will stand out as being particularly important. These should be retained as quotations because some of them may be used for purposes of illustration in the ECI Situation Analysis.

Questions/topic	1 (location)	2 (location)	3 (location)	4 (location)	Summary

After these findings have been analysed and related to data gathered on the same topics using other respondents and research instruments, they should be interpreted and presented in appropriate sections (the findings or the conclusions) of the draft National ECI Situation Analysis.

Budget Categories for Planning Focus Groups

Budgets for focus groups often include the following types of cost categories:

Travel, food and lodging for facilitators (using current rates)

- Transportation expenses of focus group facilitators (variously paid at a personal car mileage/kilometre rate, or at costs of buses and/or taxis) ($/€× # persons × # of miles/kilometre per location)
- Chauffeur (if used and charged) ($/€ × # of persons/day)
- Per diem for hotel and food costs for facilitators at established rate (calculate # of days needed) **OR**
- Reimbursement of hotel and food costs for facilitators ($/€ × # of persons × # of days (round-trip travel) × # of focus groups held)

Travel and food for focus group participants

- Transportation of participants who must travel to their focus group. Their round-trip travel costs are usually reimbursed at the end of the focus group. ($/€ × # of persons × # of miles/kilometre per location or cost of bus or other transportation.)
- Rental of meeting room, if needed ($/€ × # × # of locations). Rooms are often donated by community groups.
- Refreshments (morning or afternoon) ($/€ × # of invitees plus facilitators × # of focus groups held) **AND/OR**
- Lunch ($/€ × # invitees and facilitators × # of focus groups).

Focus group materials

- Paper pads for participants (if needed) ($/€ × # × # of focus groups).
- Pens (if needed) ($/€ × # × # of focus groups).
- Recording materials. (A recording device is needed.)

Expense reporting

For expense reports, original or scanned receipts are provided along with an invoice for the total amount, divided by cost category.

Draft Invitation Letter to Participants of Focus Group Discussions for ECI Service Personnel

Dear early childhood intervention specialist,
We warmly invite you to join a focus group discussion for ECI specialists who provide important services for children and families in ECI organizations.

The focus group discussion will be held at (location) on (date).
We expect the discussion to last for about one hour.
Our goals are to:

- Learn about the needs, experiences and recommendations of ECI specialists;
- Use your comments and suggestions to help plan for future ECI services; and
- Produce a National ECI Situation Analysis with recommendations for ECI policies and organizations.

We shall ask you for your recommendations regarding the future of ECI organizations in (name of country).

All information you give will be **strictly confidential**. You will not be asked to evaluate your organization or your performance. No information you give will be reported in any way that identifies you as a person or your ECI organization. Data will be reported at the group level, such as "Professional specialists of ECI organizations reported that..."

The analysed data from all ECI specialists will be kept in a secure site only for the use of the ECI research team. All data will be stored in protected databases that can only be accessed by our researchers.

You will not receive any compensation and your participation is entirely voluntary.

In choosing to participate in this focus group, **you have the right to end your participation at any time**. You may withdraw your consent and request that information you gave us not be used in reporting results. You also have the right to access the information you gave, correct it, and have it erased. You may request that your data be given to a different study/researcher in a structured and readable format. You may choose not to answer a particular question and still respond to other questions.

By participating in the focus group discussion, you affirm that you understand what the discussion is about, how your information will be used, and that you agree to participate.

If you have any questions, please contact:

THANK YOU very much for your collaboration!

Questions for Focus Group Discussions with ECI Service Personnel

Types of contemporary ECI services that should be provided

1. In your opinion, what services should ECI organizations provide to improve child and family development?
   - *Do not prompt the members of the focus group. They might answer by mentioning: community outreach services to identify children needing ECI services; developmental screening of children; referrals to and from your organization; comprehensive developmental assessments of children; assessments of parent–child interaction; assessments of the nutrition and health status of children; assessments of home safety and hygiene; preparation of Individualized Family Service Plans (or another type of plan with goals for the child); home visits; centre-based visits for parent education or peer-group sessions; assistive technologies; respite care services for parents; and transition plans from ECI to inclusive preschools and primary schools).*

Community outreach

2. What challenges do families face in accessing ECI services? How do you ensure that families of all income levels and ethnicities are able to receive ECI services? What barriers do you face in reaching vulnerable infants and young children (birth to 5 or 6 years) and those living in remote rural areas?

Developmental screening and assessment

3. Do you currently conduct developmental screenings of infants and young children? If not, would you like to learn how to do so?

4. Do you currently conduct comprehensive developmental assessments of infants and young children? If not, would like to learn how to do so?

ECI service quality

5. What ECI guidelines and procedures, and service and personnel standards help guide your ECI services? If you do not have them, how should they be developed? (Would you like to be included in this process?)

6. How do you encourage and show parents how to conduct developmentally appropriate activities with their child during daily child caregiving activities? Would you like to receive training in how to do this?

Pre- and in-service training, personnel retention, career ladders and salary scales

7. Should pre- and in-service training in contemporary ECI methods be improved? If so, in what ways? What in-service training topics interest you, and in which ways would you like to learn, e.g., on-site training, online distance learning, regional workshops, conferences, study tours, inter-site exchange visits, other ways?

8. In your experience, do ECI organizations retain their professional personnel well or is there high turnover? Does your ECI organization have certification requirements, a career ladder and a salary scale? Do you need them? If so, what might be the best way to establish them?

Organizational supervision and evaluation

9. If you have a supervisor, is your supervisor in your organization or in regional or central offices? What recommendations do you have regarding supportive supervision, including coaching and mentoring?

10. How does your organization monitor its services and evaluate their effectiveness and outcomes? How might organizational monitoring and evaluation be developed or improved?

Networking, coordination and referrals

11. Has a coalition or network of ECI organizations been established to advocate for and provide technical support to ECI organizations and their personnel? If not, would you like to participate in a coalition or network of ECI organizations?

12. Do you currently form teams and coordinate each week with your colleagues in serving children and families in your organization? Do you also coordinate with any other providers outside of your organization for the benefit of the child you serve?

Recommendations for improving and expanding ECI services

13. What are your top five recommendations for improving and expanding ECI services?

Thank you for participating in this focus group!

Annex 13: Focus Group Discussions with ECI Beneficiaries

Introduction: Focus group discussions with ECI beneficiaries seek to:

- Obtain their opinions regarding ECI services for them and their children.
- Learn about how parents find ECI services.
- Identify the ways parents become involved in ECI organizations.
- Learn about their recommendations for ECI organizations.

Focus group discussions with ECI beneficiaries elicit observations regarding their needs and the needs of their children, explore ways they sought support for their children and themselves, identify the types of ECI services they have received, learn about their experiences with ECI services, discuss ways they participated in the services they received, and ask for their recommendations for expanding and improving ECI services. These focus groups **do not seek to evaluate their ECI organizations**, and it is important to emphasize this when speaking with ECI directors.

A structured and open-ended Guide for Focus Group Discussions is used to identify the experiences of parents, legal guardians and caregivers in accessing ECI services, their preferences regarding types of services, and their recommendations for the future.

Respondents: ECI beneficiaries usually are parents, legal guardians or regular full-time caregivers of children enrolled in ECI services.

Sample: ECI directors will be invited to select from **four to five beneficiaries to participate in focus group discussions with the goal of attaining a representative sample of selected evolving and contemporary ECI organizations**. These beneficiaries must include families currently enrolled in and receiving ECI services. For purposes of analysis, it would be best to have the same persons who filled out the survey also participate in focus group discussions. However, given the challenges of scheduling and the need to include persons who were unable to fill out the survey, it may be important to be flexible and substitute beneficiaries from other organizations. If possible, **a total of 6 to 12 focus groups might be held**, depending upon the size of the country, needs for geographical representation, and the amount of time and resources available for conducting focus groups. Beneficiaries from each major geographical region should be invited, and at least two focus groups should include or be solely composed of members of minority and other disadvantaged groups. To the extent possible, focus groups should be composed of beneficiaries from similar populations to help encourage open dialogue. The focus groups should be held in places located as close as possible to their homes and the organizations that serve them to enable participants to feel comfortable in known surroundings and to avoid costs entailed in providing transportation to distant places.

Focus group guide: To encourage animated discussion, between 10 to 15 mainly open-ended questions should be asked.

Application methods: Because of the small size of some countries, beneficiaries from each identified ECI organization might be invited to participate in focus group discussions. If transportation can be arranged, it might be best to combine beneficiaries from two ECI organizations. However, to encourage active discussion, the focus groups should be limited to no more than 15 persons. It is advisable to request to record the focus group and to secure the prior agreement of the participants.

The ECI research team coordinates and plans the logistics for holding regional focus group discussions with a sample of four or five beneficiaries from each selected ECI organization and evolving organization. A letter of invitation should be emailed to all ECI directors along with the guide for focus group discussions with beneficiaries. The ECI director will see that the focus group is not an evaluation of their organization but rather a way to gain information needed to support ECI organizations and their beneficiaries. This letter and the discussion guide should be translated into the national language(s) and field-tested to ensure translation accuracy, comprehension and cultural appropriateness.

All focus group discussions must be completely confidential. Respondent participation will be entirely voluntary, and they will be explained their full rights. They will also be told that they will not be paid for their participation but that the experience should be valuable for them as parents and for expanding and improving ECI services.

The focus groups are usually held in various regions of each country to minimize transportation costs and attain a good level of representation from all populations. If possible, from 8 to 10 persons (and no more than 15 persons) should be included in each focus group discussion. Focus group questions build upon the questions in the Survey of ECI Beneficiaries. After providing the ethics statement to all participants and discussing any questions related to how the discussion results will be handled, focus groups facilitators should explain that they are recording the session to ensure they will not miss any important points. They must state that recordings will only be heard by members of the ECI research team, and they will be destroyed once the Situation Analysis has been completed. In the meantime, they will be maintained in a secure location and will only be used by members of the research team.

After each focus group with ECI beneficiaries, research team members should transcribe the results as soon as possible so as not to forget any important points. Facilitators should review the transcriptions for completeness because participants often speak at once. Arrangements should also be made to translate the transcriptions into English and/or other languages needed to prepare the ECI Situation Analysis.

Strengths: Beneficiaries usually feel more comfortable when talking with other beneficiaries, and usually most of them want to participate. These focus groups usually yield very useful results and important quotes for the Situation Analysis. Most importantly, parents are usually happy to give their recommendations for positive changes and the improvement of ECI services.

Limitations: Beneficiaries may be fearful to speak about their services if they are not pleased with them. The limited time for research may reduce the number of focus group discussions that can be held. Some ECI directors may not wish their beneficiaries to participate, although this rarely happens. Focus groups that mix persons from different cultures, languages or income groups could result in guarded discussions and less open dialogue.

Possible incentives to participate: Respondents might be encouraged to participate in focus group discussions if they are given assurances of data privacy; offers of opportunities to meet other parents with similar situations; and encouragement to provide their recommendations for expanding and improving ECI services. Parents who do not use online resources may welcome the opportunity to join a focus group.

Analysis: As focus groups are held, the main points should be placed in a matrix with the questions or topic from the focus group guide down the left column, the focus group numbers and locations in separate columns across the top, and a summary right hand column.

The summary column should provide a brief quantitative and qualitative analysis of major findings per question. Some comments will stand out as being particularly important. These should be retained as quotations because some of them may be used for purposes of illustration in the ECI Situation Analysis.

Questions/topic	1 (location)	2 (location)	3 (location)	4 (location)	Summary
1.					
2.					
3.					

After these findings have been analysed and related to data gathered on the same topics using other respondents and research instruments, they should be interpreted and presented in appropriate sections (findings or conclusions) of the draft National ECI Situation Analysis.

Draft Invitation Letter for Focus Group Discussions with ECI Beneficiaries

Dear parent of a child enrolled in Early Childhood Intervention services,
We warmly invite you to join a focus group discussion for parent enrolled in ECI organizations.

The focus group discussion will be held at (location) on (date).
We expect the discussion to last for about one hour.

Our goals are to:
- Learn about the needs, experiences and recommendations of families and children enrolled in ECI organizations;
- Use your comments and suggestions to help plan for future ECI services; and
- Produce a National ECI Situation Analysis with recommendations for ECI policies and organizations.

We shall ask you for your recommendations regarding the future of ECI organizations in (name of country).

All information you give will be **strictly confidential**. You will not be asked to evaluate your organization. No information you give will be reported in any way that identifies you as a person or your ECI organization. Data will be reported at the group level, such as "parents of children enrolled in ECI organizations reported that..."

Analysed data from all parents will be kept in a secure site only for the use of the ECI research team. All data will be stored in protected databases that can only be accessed by our researchers.

You will not receive any compensation, and your participation will be entirely voluntary.

In choosing to participate in this focus group, **you have the right to end your participation at any time**. You may withdraw your consent and request that information you gave us not be used in reporting results. You also have the right to access the information you gave, correct it and have it erased. You may request that your data be given to a different study/researcher in a structured and readable format. You may choose not to answer a particular question and still respond to other questions.

By participating in the focus group discussion, you affirm that you understand what the discussion is about, how your information will be used, and that you agree to participate.

If you have any questions, please contact:

THANK YOU very much for your collaboration!

Guide for Focus Group Discussions with ECI Beneficiaries

Dear parents (legal guardians or caregivers),

Thank you for contributing your time to help us understand your personal experiences, the early childhood intervention services you receive, and your recommendations for expanding and improving ECI services in our country. Your voices are very important. ECI services must serve families and children effectively. Please give us your observations. They will help us to develop high-quality ECI services for more children and families of our country. (The most important questions that shall be given priority are marked with an asterisk*)

1. How did you become aware that your child needed early childhood intervention services? What efforts did you make to find support and help for your child and family?*

2. How did you learn about and find your early childhood intervention organization? Did your child receive a developmental screening?*

3. What experiences did you have in enrolling your child and your family in early childhood intervention services? How might families be better helped to enrol in the future?*

4. During the first planning meeting to decide on services for your child, did you participate in the selection of services for your child? Were services for you and your family also discussed?

5. What early childhood intervention services do you, your child and your family receive? In what ways do these services help you meet the needs of your child, yourself, and your family?*

6. Where and when are you and your child visited? Do you receive home visits? Or do you go to a centre for visits? Are you pleased with these arrangements? If you could make any changes, what would they be?*

7. Are any types of early childhood intervention services needed but currently unavailable in your area? If so, what are these services?*

8. Are early childhood intervention services free-of-charge to you? If not, what services do you pay for? Can you afford these costs?*

9. Please give us your recommendations regarding the ways you believe that early childhood services should be expanded and improved. For example, if you know of children who should be served, what do you think should be done to expand services and ensure those children will be able to be enrolled in ECI services?*

10. Please list all the ways in which you help, support or participate in your early childhood intervention services. Would you like to participate more? If yes, in what ways?

11. Have you had any opportunities to suggest changes in ECI services? What is the procedure for making changes?

Is there anything else you would like to share with us?

Annex 14: High-Level Interview Format

Introduction: Structured interviews will be conducted with leaders at the national, regional (if they exist in the country) and local levels to learn about their opinions regarding needs for ECI services. Their recommendations and support for ECI will be requested. The interviews represent an opportunity to conduct policy advocacy and secure stronger support for ECI services. The interviewees will be important opinion leaders and their collaboration can yield valuable information and increase their interest in and support for ECI services.

Respondents: First prepare a list of potential respondents. On the following page, an example of a **Suggested Interview Planning Chart** is presented, along with suggestions for major types of interviewees. From 15 to 25 high-level interviews should be conducted, depending upon national decisions.

Sample: Every effort will be made to interview all the key people identified by the research team.

Interview guide: No more than 10 to 15 questions should be asked, a few with discreet responses while others should be open-ended. Interviews should not last for more than 30 minutes; however, many leaders will want to speak for a longer time once they have the chance to do so. All interviewees should be asked about the ways they currently support ECI services, and how they could provide more support in the future. Special questions will be asked for certain leaders, professionals or representatives of specific entities or population groups.

I**nterviewer**: In addition to possessing excellent interviewing skills, the interviewer of high-level representatives must command the respect of the interviewees. This helps ensure that the interviewers can conduct effective interviews. The Research Team Leader often conducts these interviews; however, sometimes another team member is selected. Should neither wish to do this work, then a special high-level interviewer should be found, prepared and hired to conduct this work. The interviewer should have an excellent understanding of ECI Core Concepts and Annex 2 on Definitions. For reference purposes, the interviewer may wish to take these documents with her/him to the interviews to help answer often challenging questions from the interviewee.

Application methods: A semi-structured interview format is used. The interviewer should state that she/he will take notes. It is advisable to request to record the interview and secure the agreement and informed consent of the interviewee. It is best to conduct the interview in person, but if necessary, a Zoom call could be used instead.

The interviewer sets up an interview schedule and informs each interviewee or their assistant about the subject of the interview and the goals of the study. It is advisable to provide a copy of the interview format **at least four working days before the interview** so that the interviewee can be well prepared by colleagues, have time to gather useful information that may be requested during the interview, and prepare responses, comments and recommendations.

The interviewer should explain that:

- their responses will be critically important for planning ECI services to improve the status of children with developmental difficulties.

As a courtesy, the interviewer should arrive approximately five minutes before the interview. She/he should establish a warm rapport with the interviewee and avoid any confrontational situation. The interviewer should make a brief ethics statement (provided separately) to confirm that the informed consent of the interviewee has been obtained.

At the end of the interview, the interviewer should express gratitude for the interviewee's time and tell her/him that a copy of the ECI Situation Analysis will be sent to each person who participated in the interview.

Strengths: The interviews often reveal personal values and priorities, and they can be very helpful for future planning. They often encourage the interviewee to become a strong supporter of ECI services.

Limitations: Research teams might find it challenging to schedule all interviews, especially

due to limited access to high-level leaders. A short period of time might be available to conduct interviews and, because of this, preparatory planning and reminders of interview dates and times can be very important. Some leaders may not wish to participate, although this seldom occurs when they are invited to collaborate in an appropriate manner.

Possible incentives to participate: The interviewer should note that the interview will constitute an important opportunity to contribute to ensuring ECI services meet national, regional and local needs. The interviewer should assure the interviewee that data privacy will be fully observed. The interviewer should note that the visit will also give the interviewee an opportunity to learn more about ECI services and their benefits, and to consider options for expanding and improving ECI services.

Analysis: Interview responses are transcribed and analysed one by one, followed by a content analysis across all interviewees to identify common themes, observations, and recommendations. The following simple matrix may assist with qualitative data analysis:

Questions/topic	Interviewee 1	Interviewee 2	Interviewee 3	Interviewee 4+	Summary
1.					
2.					
3.					

Suggested Interview Planning Chart

Key for chart:
= Ministry, (agency,) (regional,) or municipal interviews
+ = Health/medical interviews
* = Other interviewees

Interview chart					
No.	**Institution**	**Title**	**Name of interviewee**	**No.**	**Status**
1	Ministry of Education #	Minister/deputy minister		1	
2	Ministry of Health #	Minister/deputy minister		1	
3	Ministry of Social Protection #	Minister/deputy minister		1	
4	Ministry of Education #	Department head		1	
5	Ministry of Health #/+	Department head		1	
6	Ministry of Social Protection #	Department head		1	
7	Governmental ECI Office #	National ECI Coordinator		1	
8	Ministry of Education #	ECI contact person/focal point		1	
9	Ministry of Health #/+	ECI contact person/focal point		1	
10	Ministry of Social Protection #	ECI contact person/focal point		1	
11	Ministry of Health +	Lead paediatrician for developmental screening		1	
12	Ministry of Education +	Lead specialist for developmental screening		1	
13	Office of the Ombudsperson for Child Rights *	Ombudsperson for Child Rights		1	
14	Office of the Ombudsperson for Disability Rights *	Ombudsperson for Disability Rights		1	
15	Key national parliamentarian focusing on children *	Parliamentarian – one party or region		1	
16	Key national parliamentarian focusing on children *	Parliamentarian – one party or region		1	
17	Key national parliamentarian focusing on children *	Parliamentarian – one party or region		1	
18	Regional/municipal leader #	Regional/municipal leader		1–2	
19	Regional/municipal leader #	Regional/municipal leader		1–2	
20	Regional/municipal leader #	Regional/municipal leader		1–2	

21	ECI association, coalition, network (if formed) *	Director		1	
22	Leading disability association or federation *	Director		1	
23	Professional association(s), i.e., physical therapists, psychologists, etc.)	Director/leader		1	
24	Association of parents of children with disabilities *	Director/leader		1	
25	Ethnic minority community *	Community leader		1–2+	
26	Academic leader for ECI training – one faculty */+	Academic		1	
27	Academic leader for ECI training – one faculty */+	Academic		1	
28	Paediatrics Association +	Leading paediatrician or neonatologist		1	
29	International agencies	UNICEF, UNDP, EU, etc.		2+	

Statement of Informed Consent for ECI High-Level Interviews

Dear (ECI leader),

(Names of institutions) have been contracted by (name of agency/agencies), with the support of (name of entity), to conduct a National Situation Analysis of Early Childhood Intervention (ECI) institutions. These ECI organizations serve families of children from birth to 6 years of age in at-risk situations, with developmental delays, behavioural conditions and mental health needs. ECI services support and assist parents and caregivers to support their children to develop well, help each child achieve her/his full potential, and become productive citizens. A national reference group consisting of representatives of line ministries, state institutions and CSOs has been established to guide and monitor the analysis and validate the findings.

Thank you very much for agreeing to participate in this interview. Your contribution to this important study will help us better understand the currently available ECI organizations and services, what is working well for parents and their children, and what needs exist for expanding and improving ECI services.

In accordance with data protection requirements (or for EU countries, the European General Data Protection Regulations (GDPR)), all the information you give us will be **confidential and anonymous**. No information that you provide will be reported in a way that could identify you personally as the source of the information. You will not be named as having made a particular statement. Data may be reported in a way that identifies a general characteristic such as "an official of X ministry, agency or institution observed that…."

All information that you give will be stored in a manner that will not identify you. If recorded, no person will be identified by the sound of her/his voice. Tapes will be placed in a locked storage box, and they will only be accessible to the research team for this project. After the information is fully analysed and described, initial data will be destroyed (tapes or notes). Analysed data will be kept on a secure online site that will be accessible only to the research team of this project. These data may be used later in other projects, but it will only be available in a totally anonymous and aggregated form. All information will be reported an aggregated and unidentifiable form. Examples and comments will be reported in a way that never identifies a particular person or organization.

In choosing to participate**, you have the right** to end the interview at any time. You may withdraw your consent and request that information you gave us not be used in reporting results. You also have the right to access the information you gave, correct it and have it erased. You may request that your data be transmitted to a different study/researcher in a structured and readable format (portability). You may choose not to answer a particular question and still respond to other questions of the interview.

You will not receive any compensation for participating in this study and your participation is voluntary.

In participating, you agree that you understand the project, agree to engage in an interview, and will permit audiotaping, unless you refuse to be audiotaped before the interview begins.

If you have further questions or need someone to talk with after participating, please contact:

I give permission for this interview to be audiotaped: Yes_____No_____

High-Level Interview Formats

Introductory statement for the interviewees

Place similar wording in a cover letter and read this wording out loud at the beginning of the interview.

Early Childhood Intervention (ECI) public institutions and organizations serve children from birth to 35 months or up to 5 or 6 years of age: 1) in at-risk situations such as pre-term birth, low birth weight, congenital conditions, chronic illnesses; 2) with developmental delays, 3) disabilities, 4) behavioural conditions such as autism or attention deficit and hyperactivity disorder, and 5) mental health needs, such as depression and trauma. ECI services support and help the parents and caregivers to develop their children well and help them achieve their full potential and become productive citizens.

I am visiting you today to ask you a few important questions to learn about your activities, ideas and recommendations for developing, improving and expanding ECI services in our country. Your comments will be of great importance to the future development of high-quality ECI services throughout our country.

Interview for Ministerial, Regional, and Municipal Officials[28]

(30+ minutes)

1. Does your ministry, region or municipality have a policy, strategic plans, ECI guidelines and procedures, or standards for ECI services? (If so, may I please have copies of them for our study?)

2. Are you and others currently developing, or do you plan to prepare an ECI Strategic Plan, ECI Guidelines and Procedures, or service and personnel standards?

3. Does your ministry, agency or municipality fund or support ECI services in any way? If so,
    a. How many ECI public institutions and/or civil society organizations do you support?
    b. Where are these institutions and/or organizations located? (Ask for a list of institutions.)
    c. How are they funded or supported? (e.g., grants, contracts, vouchers, other arrangements.)
    d. What services are provided by the ECI institutions and/or organizations that you support?
    e. What is the total budget for the ECI services of your (ministry, agency or municipality)?
    f. May I have a copy of your budget and expenditure reports from the last two or three years?

4. How are eligibility guidelines established, and which ministry or agency establishes them?

5. Can ECI institutions and/or organizations decide the eligibility of children for ECI services? If so, do they establish their own guidelines or do they follow guidelines established by a ministry or agency? If not, why?

6. Does your ministry, agency or municipality participate in the developmental screening of young children to find those children who should receive ECI services? If so, how is developmental screening organized and who is responsible for it?

7. What types of children and families are usually served by the ECI institutions and/or organizations that your ministry, agency or municipality support? (All types of developmental difficulties? Children of all ethnicities? Any other types of children and families?)

[28] See the *Suggested Interview Planning Chart* above.

8. Do you have any statistics regarding children and families served by your ECI institutions and/or organizations, such as the ages, income levels, types of needs or conditions, gender, ethnicity and location of the participants? (If so, may we have a copy of your statistics?)

9. How do you inform parents about ECI services and ensure they will be able to access them? (Please give me some examples.)

10. Does your ministry, agency or municipality decide where ECI institutions and/or organizations will be located? If so, how do you make these decisions? If not, who usually makes these decisions?

11. Does your ministry or agency supervise the ECI institutions and/or organizations you support? If so, how do you supervise them? (For example: submission of reports; inspection of the institutions and/or organizations; field visits to provide supportive supervisory observations, coaching and mentoring; application of participant satisfaction questionnaires, etc.) If not, what entity is responsible for supervising them?

12. Does your ministry, agency or municipality provide any pre- or in-service training for ECI personnel? If so, what training do you provide, how, when and where? If not, what entities are responsible for ECI pre- and in-service training? What are the needs for expanded pre-service professional training and for regular in-service training?

13. Do ECI institutions and/or organizations prepare reports to the government/a ministry or agency? If so, what types of reports do they submit to you? When do they report to you? (If so, may we have copies of last year's reports?)

14. Does your ministry monitor and evaluate ECI institutions and/or organizations? If so, how do you conduct this work? (Inter-agency ECI agreement, annual plan, inter-agency committee, shared indicator database, indicator templates, collaborative reporting, etc.) If not, which agency monitors and evaluates ECI institutions and/or organizations and their outcomes, if any?

15. How and in what ways should parents of children in ECI services participate in developing public policies and plans for ECI services and in evaluating ECI services?

16. What successes have you achieved and what challenges has your ministry, agency or municipality faced in managing the ECI institutions and/or organizations you support?

17. Many ECI institutions and/or organizations still work only with children who have developmental difficulties, and they rarely work with their parents and families. What should be done to ensure that ECI institutions and/or organizations become more family-centred and effective?

18. What major gaps need to be filled or improvements made to achieve nationwide ECI coverage to enable the provision of services for all ECI-eligible children?

19. Does your ministry, agency or municipality want to receive technical support for ECI institutions and/or organizations, such as planning, organizational development, supervision, training and monitoring and evaluation?

20. Are inter-agency ECI meetings held? If so, who convenes and leads these meetings? Do you or anyone from your ministry, agency or municipality participate in any inter-agency meetings for ECI coordination? How often are meetings held? What topics are addressed? If not, would you like to do so?

21. Does any coalition, association or network of ECI institutions and/or organizations currently exist? If not, is one needed?

22. What types of policy advocacy and communications are required to build more support for ECI services? Might parents and ECI personnel participate in advocacy efforts?

23. In all countries, the ministries of health, education and social protection/affairs collaborate to support integrated ECI services. If no lead ministry has been selected yet, why do you think this is the case? Which ministry might become the lead ministry for ECI? Why did you suggest this ministry?

24. What key conclusions and recommendations do you believe should be included in the National ECI Situation Analysis?

Interview for Governmental and Non-Governmental Medical and Health Leaders and Specialists[29]
(30+ min.)

1. What ECI organizations do you know about or collaborate with? (Please give us their names and contact person.)

2. In your paediatric or neonatology activities, in what ways have you worked or collaborated with ECI organizations? If so, how often do you conduct these activities with them?

3. Do you or your colleagues conduct surveillance and monitoring of the development of infants and young children? If so, how often? Do you follow any professional guidelines or recommendations for surveillance and monitoring? If not, what are your key reasons for this? (Lack of time, need more training in developmental surveillance and monitoring, not currently a part of your official responsibilities.)

4. Do you and/or your colleagues use a developmental screening instrument to identify developmental delays and disabilities in infants, toddlers or young children? If so, which ones? Has the instrument you use been culturally adapted and validated for use in our country?

5. Would you be interested in learning more about rapid, easy-to-use developmental screening instruments and methods?

6. What should be done to ensure all families with children with developmental difficulties are found and offered ECI services?

7. Do you think that health decision makers, physicians, public health specialists and nurses know enough about the important international field of ECI for children with developmental difficulties? If not, do you think that pre- and in-service training should be offered to medical and public health specialists? If so, what training topics should be included (such as developmental surveillance and monitoring, developmental screening, developmental delays and disabilities, ECI services and what they do)? What would be the best ways to provide such training?

8. What more should be done to increase the knowledge and support of decision makers, physicians, public health specialists and nurses for ECI services?

9. In your opinion, what are the biggest challenges we face in establishing, implementing and expanding ECI services? Given the needs of our children and families, how might we overcome these challenges? (What more could be done to help?)
10. In your opinion, what are the biggest challenges we face in developing a national system of community outreach, developmental monitoring, screening and referrals to ECI institutions and

[29] See the *Suggested Interview Planning Chart* above.

organizations for essential services? How might we overcome these challenges? (What more could be done to help?)

11. In your opinion how can we improve our ability to identify and serve all infants and young children who would benefit from receiving ECI services, and especially those who live in hard-to-reach places, such as rural areas, ethnic minority families, disadvantaged communities, and others?

12. Which areas of our country should be prioritised for the provision of more ECI services?

13. What major gaps need to be filled or improvements made to achieve nationwide ECI coverage to enable the provision of services for all ECI-eligible children?

14. Many organisations still work only with children who have developmental difficulties, and they rarely work with parents and families. What should be done to ensure that ECI institutions and organisations become more family-centred and effective?

15. Does any coalition, association or network of ECI organisations currently exist? If yes, are you a member of any ECI group? If not, is one needed? If yes, should neonatologists, paediatricians and family physicians participate?

16. What types of policy advocacy and communications are required to build more support for ECI services?

17. In all countries, the ministries of health, education and social protection/affairs collaborate to support integrated ECI services. If no lead ministry has been selected yet, which ministry might become the lead ministry for ECI? Why did you suggest this ministry?

18. What key conclusions and recommendations do you believe should be included in the National ECI Situation Analysis?

Interview for Other Interviewees[30]
(30+ min.)

1. What ECI organizations do you know about or collaborate with? (Please give us their names and contact persons.)

2. In what ways have you worked or collaborated with colleagues in ECI organizations?

3. Have you read about or participated in any efforts to identify families with children with developmental difficulties who might be eligible for and need ECI services?

4. What do you think should be done to ensure that all families with children with developmental difficulties are found and offered ECI services?

5. Do you think that decision makers know enough about the important international field of ECI for children with developmental difficulties?

6. What more should be done to increase the knowledge and support of decision makers for ECI?

[30] See the *Suggested Interview Planning Chart* above.

7. In your opinion, what are the biggest challenges our country faces in planning, implementing and expanding ECI services?

8. What should be done to ensure that ECI organizations adequately find and serve low-income families? Families living in remote rural communities? Ethnic minority families? Other disadvantaged minority ethnic families?

9. In which regions or communities of our country should more ECI organizations be developed?

10. What major gaps need to be filled or improvements made to achieve nationwide ECI coverage and provide ECI services for all ECI-eligible children?

11. Many organizations still work only with children who have developmental difficulties, and they rarely work with parents and families. What should be done to ensure that ECI organizations become more family-centred and effective?

12. What types of expanded ECI pre-service training and regular in-service training are needed? How should this training be provided?

13. Does any coalition, association or network of ECI organizations currently exist? If so, do you participate in it? Is an ECI coalition, association or network needed?

14. What types of policy advocacy and communications are required to build more support for ECI services?

15. In all countries, the ministries of health, education and social protection/social welfare collaborate to support integrated ECI services. If no lead ministry has been selected yet, which ministry might become the lead ministry for ECI? Why did you suggest this ministry?

16. What key conclusions and recommendations do you believe should be included in the National ECI Situation Analysis?

Annex 15: Generic Outline for National ECI Situation Analyses

Cover page

Acknowledgements

Executive summary

- **Introduction: Background and rationale**
- **ECI concepts and frameworks**
- **Goal and objectives of Situation Analysis**

1. ECI Theory of Change
2. ECI Conceptual Framework
3. Core ECI concepts
4. Processes of ECI services
5. Leading study questions

- **Research activities, methodologies, data analyses and ethics**

6. Research team and its roles
7. Roles of UNICEF, national ministries and other stakeholders
8. Research methodologies applied
9. Limitations and challenges faced
10. Data management and analytical procedures
11. Research ethics and attention of cultural and language dimensions

- **Analyses of ECI system and services**

12. Enabling policy environment for ECI services
13. Status of children and families
14. Organizational frameworks related to ECI services
15. Geographical coverage of ECI services
16. Definition and types of ECI services in country
17. Populations served by ECI organizations and gaps in services

18. Community outreach, referrals and waiting lists
19. Developmental screening
20. Developmental monitoring/ surveillance in the health system
21. Comprehensive developmental assessments and family assessments
22. ECI Transdisciplinary or Interdisciplinary Teams
23. Preparation of Individualized Family Service Plans
24. Contemporary home- and centre-based ECI services, evolving services and legacy services
25. Family support services and transition planning
26. ECI personnel, professional development, supervision and quality assurance
27. ECI guidelines and procedures, standards and accountability
28. ECI coalitions or networking and inter-sector coordination
29. Sub-Study on ECI Costs and Finance
    - Overview of the sources of funding for ECI institutions and organizations
    - Participation of the central government in ECI financing
    - Participation of regional governments in ECI financing
    - Participation of self-governments in ECI financing
    - Types of funding sources
    - Sources of funding for ECI institutions and/or organizations
    - Cost composition of ECI institutions and/or organizations by types of services
    - Conclusions and recommendations of the Sub-Study on Costs and Finance

Annex 16: Estimation of Children Requiring ECI Services in Croatia

Essentially, virtually all countries lack data need to calculate the numbers of children needing ECI services. Because of this, it is essential to estimate those numbers using all the available data. Countries usually want to include all children in at-risk situations, with developmental delays, disabilities, behavioural conditions and mental health needs. New data sources are being published frequently, and they should be added to or replace the sources listed below in a study that was conducted in 2019.

Using Croatia as an example of typical challenges encountered in estimating the numbers of children needing ECI services, estimates had to be constructed using a variety of data sources. It has been calculated that 518,081 people of all ages in Croatia, or 12% of the population, have disabilities (Government of the Republic of Croatia, 2013).

According to the *Worldometer* of the United Nations, in 2019 Croatia had a total of 230,188 children from birth to 5 years of age. Using the out-of-date WHO rate of 2.9%, this would mean that approximately 6,775 children might have moderate to severe disabilities. However, a carefully conducted global study found that for children birth to 5 years of age in Croatia, a higher rate of approximately 12,189 children (5.3%) had disabilities in 2016 (Olusanya et al., 2018).

In addition, the National Disabilities Registry Act regulates the collection, analysis and confidentiality of data secured from the healthcare, social welfare and educational systems, the Ministry of Veterans Affairs and the Croatian Insurance Institute. "By 1 September 2018, the Disabilities Registry collected 1,168,268 individual reports for 500,724 disabled persons (Government of the Republic of Croatia, 2019)." However, these reports only yielded 2,036 children or only 0.9% of the children from birth to 4 years of age. Of these children, 835 (41%) were female and considerably more 1,201 (59%) were male. This is a major undercounting of children with disabilities, and potentially also of female children. It was clear that many children with disabilities remain unidentified in all regions of Croatia, which is often the case in this region due to limited developmental screening and referrals to ECI organizations, evolving organizations and legacy services.[31]

The preceding figures only address children with disabilities. They do not include children with at-risk conditions, developmental delays and behavioural conditions, such as autism spectrum disorders (ASD), and mental health needs. Regarding children at biological and often also at environmental risk, according to the Croatian Institute of Public Health (CIPH), most women giving birth were in the age band from 30 to 34 years of age or above. It is noteworthy that there are few adolescent deliveries, and no maternal deaths were registered in 2017 (CIPH, 2018). CIPH reported that of 36,104 deliveries in 2017, infant mortality was low at 4 per 1,000 births in 2017. The annual rate of premature infants was 2.5% (913 infants), and low birth weight (under 2,500 grams) was 5.2% (1,890 infants). The latter figure usually includes most pre-term infants and it is highly reliable because skilled birth attendants usually weigh and measure all new-born infants.

Using other statistics regarding at-risk biological and environmental conditions, in 2017 neonatal disorders were reported to be 902.1 per population of 100,000 (Institute of Health Metrics and Evaluation website, 2019). Thus, over 2,000 infants are born annually with fragile birth conditions or neonatal disorders, and they alone would amount to more than 10,000 children over a five-year period. Some of these infants undoubtedly overlap with the incidence of prematurity and/or low birth weight and with children already identified to have disabilities. In many countries, the rate of developmental delays is keyed to rates of stunting

[31] The Registry also notes a high level of preventive health examinations of children in 2017: 153,418 examinations of infants (4.8 examinations per infant), and 154,176 examinations of preschool children (0.07 examinations per child). With these preventive examinations already being performed, developmental screenings might be added to them.

and poverty. However, no data on stunting are gathered or reported for Croatia (Global Nutrition Report, 2020).

Concerning the behavioural condition of ASD, data are collected as a separate disability category through the Croatian Disabilities Registry Act. "The prevalence of ASD in the child population (0–18 years) in Croatia is approximately 1 in 1000, three times more common in boys" (Benjak et al, 2009). This rate adds another 230 children per year, yielding a five-year total of at least 1,150 more children.[32]

Given overlaps between the rates of low birth weight with the rates of prematurity, and of neonatal disorders with later disabilities, by using only the rates of disability at 5.3% and of low birth weight at 5.2%, a total rate of 10.5% of all infants and children to 5 years of age could be used to calculate the rate of children who might be eligible for ECI services.

Of the 2019 cohort of 230,188 children from birth to 5 years of age, approximately 10.5% or 24,169 children in at-risk situations, with developmental delays and disabilities may need ECI services in Croatia, and the actual rate may be higher.

This rate was compared with the current reported coverage of ECI organizations and evolving organizations in Croatia, thereby permitting the government and ECI organizations to develop plans for expanding services feasibly in phases over time.

[32] The current rate of ASD must be higher than reported above because throughout the world, ASD rates have risen considerably since 2009.

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