Advancing early Support for Children with Disabilities

In resource limited settings

This information brief is for government officials, donors, non-governmental organisations, organisations of persons with a disability, organisations of parents, technical experts, and anyone involved in early support or interested. The purpose of this brief is to present a key summary of emerging findings from a cross-regional initiative on early support for children with disabilities in resource-limited settings. To inform key actors, and mobilize global collaboration for more coherent, inclusive, and early responses to the needs of children with at risk or with a disability, parents and carers.

Context and Urgency

Globally, over 240 million children live with disabilities, 95% of whom are in low- and middle-income countries. Many of these children are not identified or supported until after age five, missing a critical window for early development. Lack of early identification and intervention contributes to poorer developmental outcomes, avoidable deaths, and lifelong exclusion. The disability sector remains fragmented, with limited coordination across health, education, and social services.

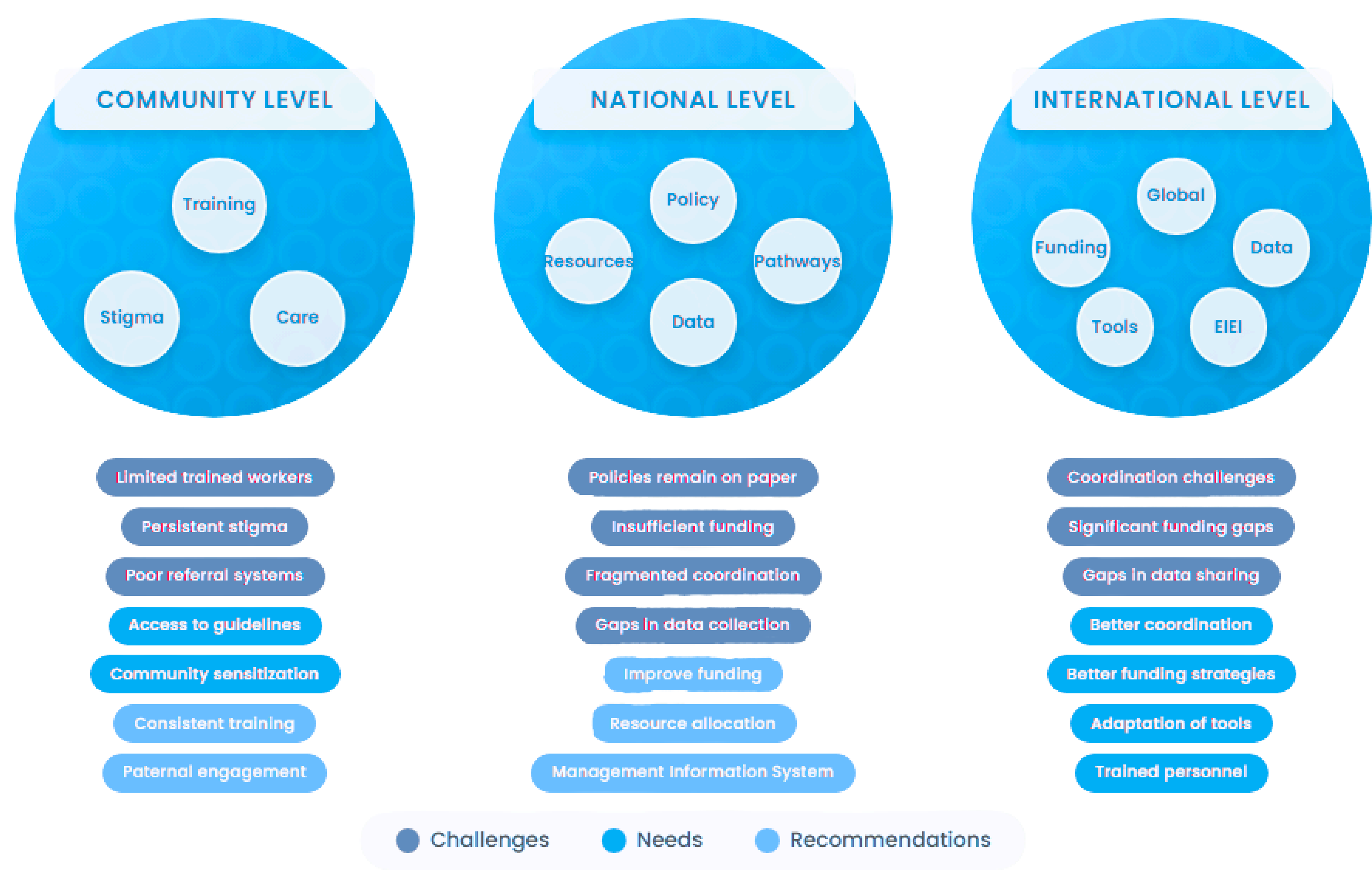| Literature review	Survey
Global stakeholder interviews	Focus Group Discussion

The Early Identification and Intervention Global State Initiative

- Gathers, synthesises, and scales best practices for early support
- Focuses on resource-limited settings in Africa and Asia
- Develops a Global State Report
- Sets up an online resource hub that will expand over time
- Explores a coalition for coordinated advocacy

Findings | Good practices

COMMUNITY	NATIONAL	INTERNATIONAL
Basic Assessments Early identification, screening, and developmental assessments using tools like TQMICS, MDAT IDEC, and newborn hearing tests.	**Inclusive Systems and Services** Develop inclusive, evidence-based services for children with disabilities. Integrate early support into routines.	**Collaborative Efforts** Support local initiatives with funding, technical assistance, and best practices. Collaborate with UNICEF, WHO, and others.
Family-Centred Interventions Educating caregivers, home-based interventions, parent support groups, STEP training, and resource provision.	**Government Systems** Collaborate with health services and integrate into community systems. Implement effective policies with funding.	**Resource Development and Sharing** Develop and share resource materials. Use standardized tools like MDAT. Knowledge sharing is crucial.
Awareness and Education Raising awareness, educating communities, capacity building, Baby Ubuntu, peer support, and training sessions.	**Training** Include 1-2 day training sessions for HCWs and CHWs. Use objective hearing screening tools for different workforce levels.	**Monitoring and Research** Utilize play-based learning strategies. Implement monitoring frameworks. Support research and funding. Address developmental disabilities.
Community Stakeholder Collaboration Collaborating with stakeholders, community health workers, daycare teachers, volunteers, and referral systems.	**Multistakeholder Collaboration** Emphasise multi-disciplinary collaboration. Integrate early intervention programs into community health systems.	
Integrated Approach Combining feeding, parent education, childcare, playful learning, CBR, early detection, and vaccination campaigns.	**Financial Sustainability** Allocate sufficient funding for EIEI services. Establish partnerships and cost-sharing arrangements with institutions.	
Resource Materials Utilising ICF framework, pictorial toolkits, Sambhav, WGSQ, ARSS, ECCD checklists, AKTIBU, and Ubuntu Toolkit.		

COMMUNITY LEVEL

- Training
- Stigma
- Care

NATIONAL LEVEL

- Policy
- Resources
- Pathways
- Data

INTERNATIONAL LEVEL

- Global
- Funding
- Data
- Tools
- EIEI

Community Level:
- Limited trained workers
- Persistent stigma
- Poor referral systems
- Access to guidelines
- Community sensitization
- Consistent training
- Paternal engagement

National Level:
- Policies remain on paper
- Insufficient funding
- Fragmented coordination
- Gaps in data collection
- Improve funding
- Resource allocation
- Management Information System

International Level:
- Coordination challenges
- Significant funding gaps
- Gaps in data sharing
- Better coordination
- Better funding strategies
- Adaptation of tools
- Trained personnel

Legend: ● Challenges ● Needs ● Recommendations

COMMUNITY

Capacity Building
- Invest in training programs for community and health workers
- Continuous professional development opportunities

Parental Involvement
- Train and empower caregivers
- Promote home-based interventions
- Provide ongoing support and education

Awareness
- Conduct campaigns to reduce stigma
- Educate communities on early intervention
- Address nutrition issues

Community-Based Models
- Strengthen community engagement
- Involve community leaders
- Develop service delivery models

Factors to Scale
- Deliver integrated EIEI services
- Enhance collaboration
- Promote inclusive practices
- Integrate into community health systems

NATIONAL

Policy Implementation and Resource Mobilisation

CHALLENGES
Gaps in practices, insufficient funding, variability in implementation

KEY STEPS
Unified EIEI policies, mobilizing resources, government commitment

Training and Mentorship Systems

CHALLENGES
Gaps in practices, need for robust training programs

KEY STEPS
Capacity building, comprehensive training, referral pathways

Integrated Service Delivery

CHALLENGES
Fragmented coordination, need for stronger integration

KEY STEPS
System-level integration, multi-sectoral involvement, multidisciplinary teams

Tool Development and Harmonisation

CHALLENGES
Gaps in practices, need for standardised tools

KEY STEPS
Harmonise tools, standardised tools, monitoring

INTERNATIONAL

Collaboration and Cross-Pollination
Strengthening collaboration between organizations, sharing experiences and best practices, fostering partnerships, addressing gaps and challenges in existing practices.

Advocate and Promote
Adopting a whole-of-government approach, strengthening various sectors, advocating for neonatal screening, supporting comprehensive EIEI policies, addressing social stigma.

Develop, Share, Offer
Adapting early detection tools, offering training, raising awareness, developing online resource hubs, prioritizing early childhood development, conducting economic analyses.

Role of Assistive Technology
Recognizing the importance of assistive technology, need for comprehensive reporting, examples of technologies used, understanding their effectiveness.

Resource Allocation
Providing adequate funding and resources, addressing gaps in training and service provision, supporting local initiatives, encouraging comprehensive interventions.

What is next?

Liliane Fonds, JF Kapnek Zimbabwe and CHAI are working to finalize and launch the Global State Report in 2025. We plan to host an online resources hub on Liliane Fonds' website, which can be accessed using the below QR code. Through this work, we seek to foster a community of practice, hosting global and regional learning events on early identification and intervention of children with disabilities. We seek to galvanize support to scale up services in priority countries.

Future hub

Call to Action

Momentum is building around Inclusive Early Childhood Development - but lasting change depends on committed.

1. Engage with the early support knowledge hub to share tools, case studies, and implementation experiences, which is hosted on the Liliane Fonds website: www.lilianefonds.org.
2. Integrate early support good practices into national policies, systems, and funding frameworks.
3. Advocate for early supportas a foundational child's right linked to equity, inclusion, and sustainable development.
4. Collaborate across sectors and regions to scale contextually relevant solutions for early support, to help children with disabilities thrive.

Acknowledgements

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JF KAPNEK ZIMBABWE

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Annex

Key tools and guidelines for Early Identification and Early Interventions for Children with Disabilities
The tools below are grouped into three categories: 1. those used primarily for early identification, 2. those for early intervention, and 3. tools that serve both purposes (cross-cutting)

1. Examples of Early Identification tools identified:
• Ages and Stages Questionnaire (ASQ)
• Guide for Monitoring Child Development (GMCD)
• Malawi Developmental Assessment Tool (MDAT)
• Parents' Evaluation of Developmental Status (PEDS)
• Ten Questions Screen (TQS)
• At Risk Surveillance System (ARRS)

2. Examples of Early Intervention tools identified:
• Caregiver Skills Training (CST)
• Early Childhood Care and Development Checklists (ECCD)
• Early Intervention for Motor Delays Program
• Inclusive Education Training Manual
• WHO Community-Based Rehabilitation Guidelines

3. Examples of Cross-Cutting tools:
• Survey of Wellbeing of Young Children: Brief Parent Scales, which includes:
- Baby Pediatric Symptom Checklist (BPSC, <18 months)
- Parent's Observations of Social Interactions (POSI)
• Parents' Evaluation of Developmental Status (PEDS)
• Guide for Monitoring Child Development (GMCD)
• Early Childhood Care and Development Checklists 1 & 2 (ECCD)

A full repository of over 70 tools, training materials, and country adaptations will be available soon on the online knowledge platform.