

# Understanding and addressing inequities in nutrition and feeding for children with disabilities: overview and case studies

June 6, 2023



# Session outline



**Carolyn Moore,  
SPOON**



**Zeina Makhoul,  
SPOON**



**Pamela  
Magero,  
SPOON/  
ARU-CCCU**



**Nkhasi Sefuthi,  
LNFOD**



**Watson  
Mwandileya,  
Access to  
Health Zambia**



## Poll question

# Inequities in nutrition and disability

- **240 million** children with disabilities
- **2x as likely** to be malnourished
- **3x as likely** to die from malnutrition



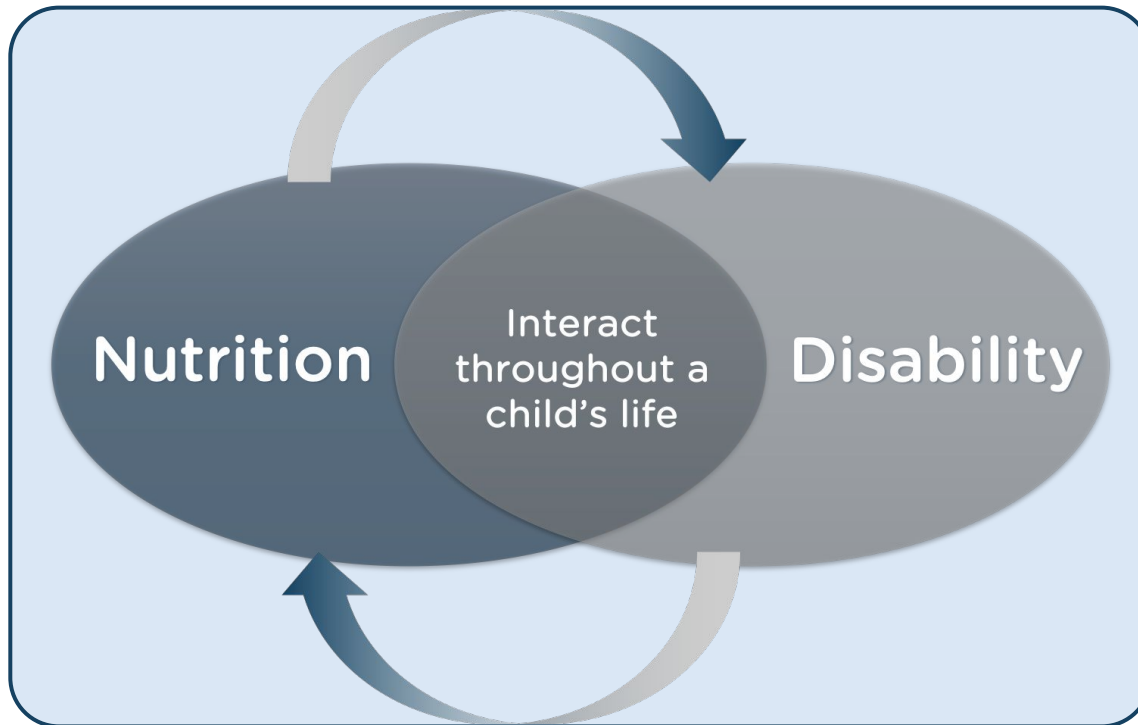


# Understanding inequities in nutrition and feeding for children with disabilities

Zeina Makhoul, PhD, RDN  
Nutrition Scientist, SPOON



# Children with disabilities are highly vulnerable to malnutrition.

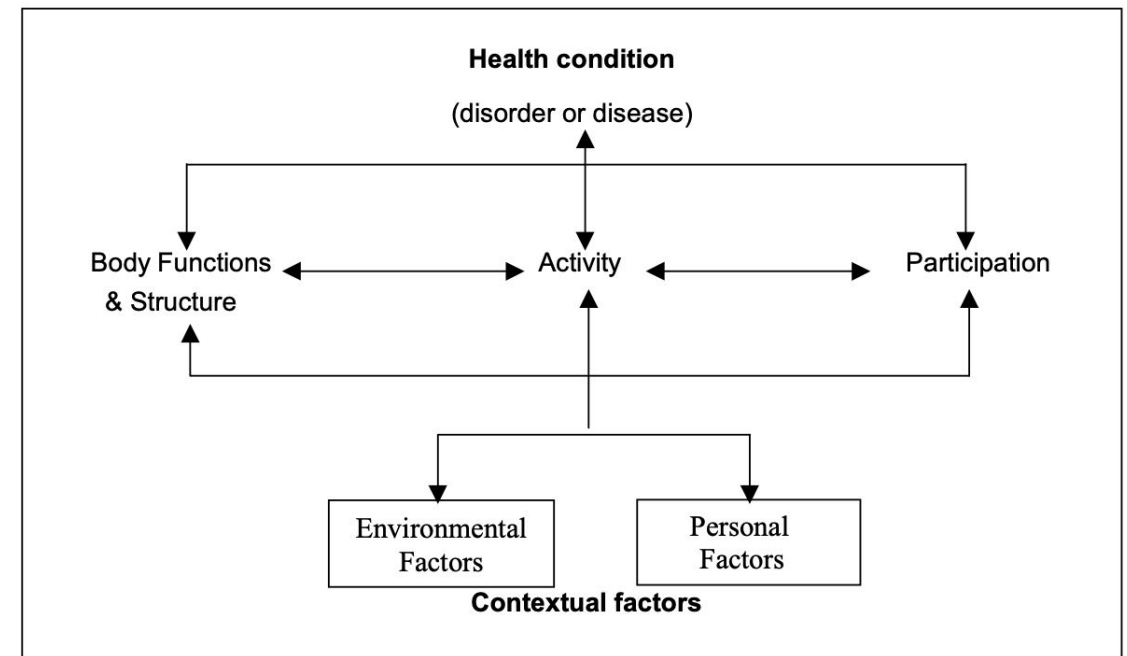


Adapted from Groce et al, 2014

- Children with disabilities are **three times more likely** to be malnourished and **twice as likely** to die from malnutrition compared to children without disabilities.
- Up to **85%** of children with developmental disabilities experience feeding difficulties.

# A framework for understanding risk and inequities for children with disabilities

- Defining disability
- International Classification of Functioning, Disability, and Health (ICF) consists of two parts:
  - Functioning and Disability
  - Contextual Factors
- Their interaction contributes to increased risk and inequities



# Functioning and disability



- Some impairments may make it more difficult for a child to eat and drink safely and efficiently.
- Some disabilities may alter children's growth potential. Others have the potential to alter growth if appropriate care plans are not in place.
- Conditions that commonly impact nutrition and feeding:
  - Prematurity
  - Respiratory disorders
  - Cardiovascular disorders
  - Autism spectrum disorder
  - Neurologic disorders
  - Gastrointestinal disorders
  - Congenital abnormalities



# Contextual Factors



- Stigma
- Restricted access to mainstream nutrition services
- Low availability of disability-specific services
- Insufficient representation in policies
- Lack of data and accountability

## Example of individual child/ children



# SPOON

Our mission is to nourish children who are highly vulnerable to malnutrition by empowering their caregivers around the globe.



Training



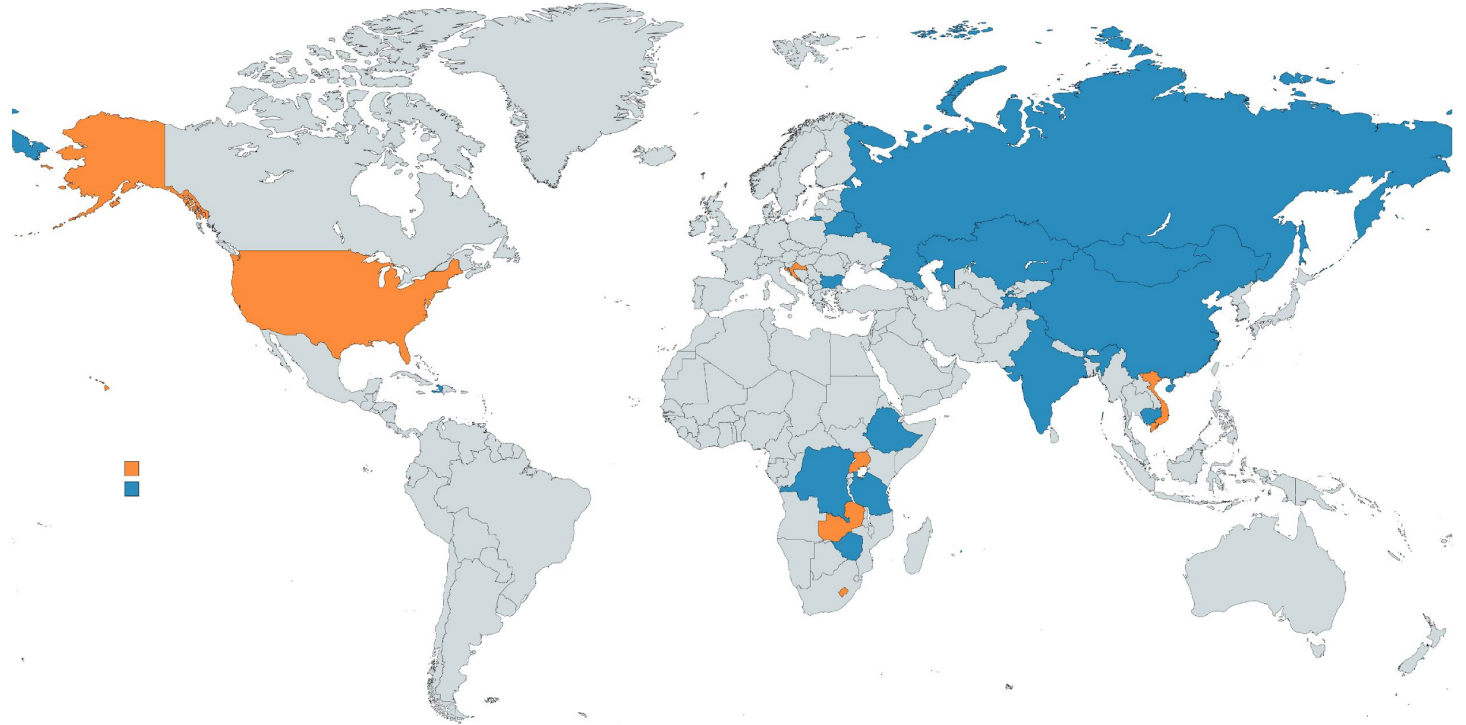
*Count Me In*



Advocacy

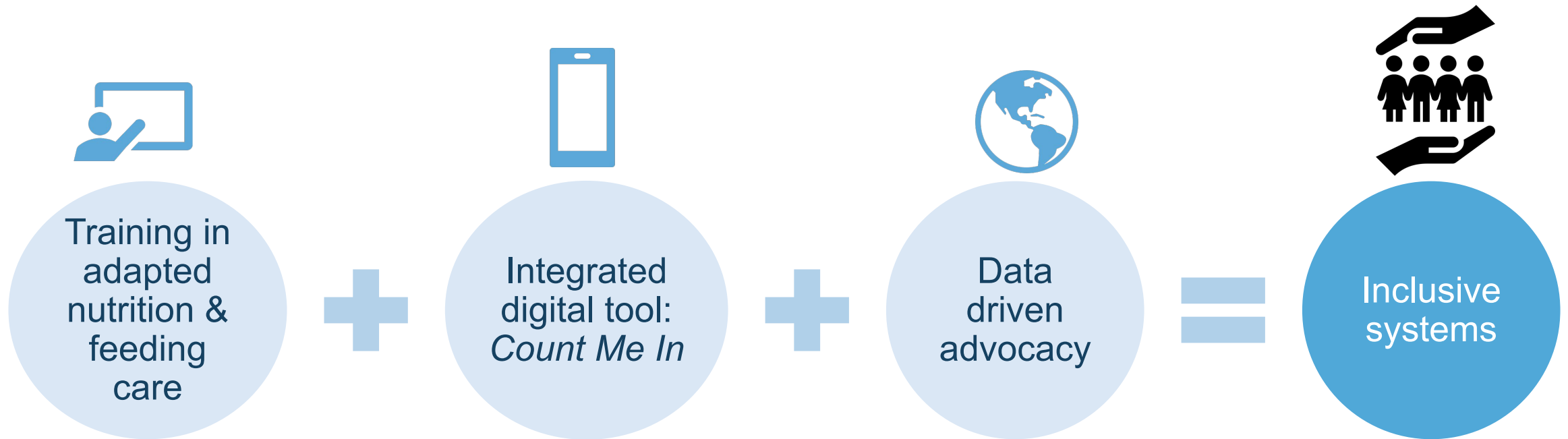
[www.spoonfoundation.org](http://www.spoonfoundation.org)

SPOON

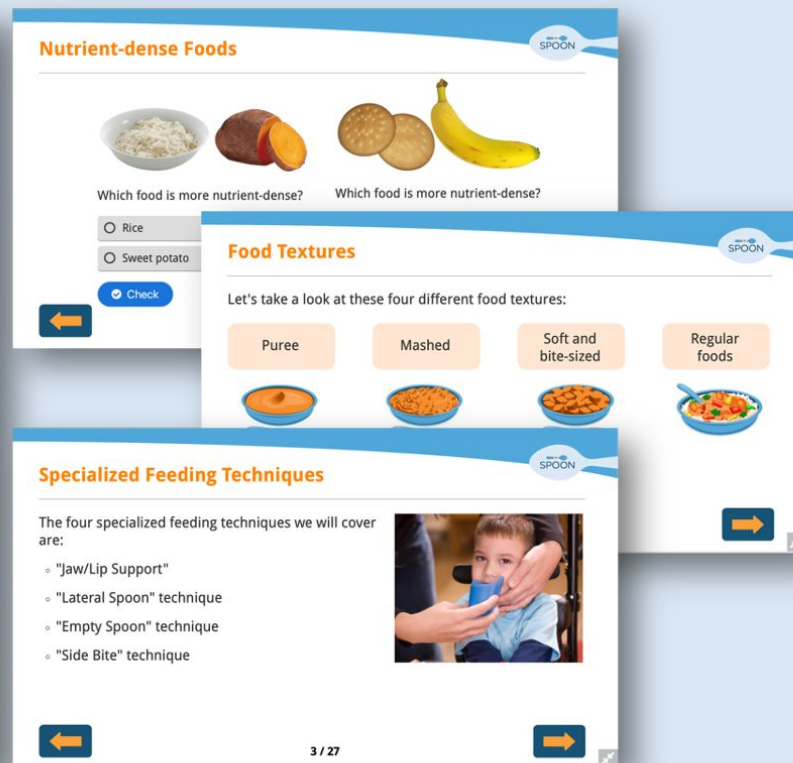


Since 2007, SPOON has implemented nutrition and feeding programs in **21 countries** and currently focuses on **6 countries**.

# Intervention Model



# Training in Adapted Nutrition and Training Care



- Foundational package
- A wide training audience
- Flexible delivery model



# Digital Tool: *Count Me In*

## Assessments & Care Plans

**Count Me In** Project Site Account

### Growth Recommendations

You are here: **Zacaba** > **Bethel Station** > **Child #133** Male, 5y 6m

**Care Plan**  
You are here: **Demonstration Care Facility** > **Santiago Fernández** (Male, 21m)

**INTERPRETATIONS**

**WEIGHT**  
**Normal for Height**  
• Weight gain appears to be normal for the child's height. [Learn more](#)

**HEIGHT**  
**Increasing sharply**  
• Child's height appears to have increased rapidly since 0  
• Child may be experiencing a spurt or catch-up growth  
• If this is unexpected, it could be an error in measurement.

**Weight for Height**  
Updated 11/17/2022

**REPORT CARD**

- Mealtimes**  
Changes to feeding technique can improve child's safety  
[See recommendations](#)  
Updated 11/17/2022
- Growth**  
Growth appears to be on track  
[See recommendations](#)  
Updated 07/13/2021
- Anemia**  
Child has mild anemia  
[See recommendations](#)  
Updated 07/13/2021

**Feeding Recommendations**  
Child's positioning while feeding needs improvement.  
Coughing and choking after a meal may be due to food left in the mouth from eating, drooling or saliva, or even reflux. Sit child upright while eating and for 30 minutes after eating. Make sure the child has the skills to eat the foods and liquids provided.  
[See full recommendations](#)

**Mealtimes: Screening**  
You are here: **Demonstration Care Facility** > **child 6-12** (Male, 8m)

**How is the child fed?**  
Please choose all that apply

☐ Bottle ☐ Spoon/fork ☐ Cup ☐ Fingers

**What is typically offered at mealtimes?**  
Please choose all that apply  
[Review food textures](#)

**LIQUIDS**  
☐ Formula ☐ Thin liquids (not formula)

**FOODS**

☐ Puree ☐ Mashed ☐ Soft & bite-sized ☐ Regular foods

**Assess Now**

## Data & Reporting

**SUMMARY REPORT**  
**Demographic Report**

Summary Reports  
[Summary](#) [Demographic](#) [Malnutrition](#) [Feeding Difficulties](#) [Mealtime Best Practices](#) [Activity](#) [Data Download](#)

**2,307**  
Children  
Includes all children who have been assessed at least once

**1,197**  
Current children  
Includes children in active sites who have not been discharged

**Sex**

**LEGEND**  
● Female: 1044  
● Male: 1263

**SPECIAL HEALTHCARE NEEDS**  
Children with Special Needs

**LEGEND**  
● With special healthcare needs: 1442  
● No reported needs: 865

**Count Me In** Project Account

**SUMMARY REPORT**  
**Malnutrition Report**

Summary Reports  
[Summary](#) [Demographic](#) [Malnutrition](#) [Feeding Difficulties](#) [Mealtime Best Practices](#) [Activity](#) [Data Download](#)

**Malnutrition Prevalence**

	ALL CHILDREN		CHILDREN WITH 2+ ASSESSMENTS		Change
	At Baseline Assessment	At Most Recent Assessment	At Baseline Assessment	At Most Recent Assessment	
<b>One or more malnutrition indicator</b>	65.4% 1,407 out of 2,151	76.0% 812 out of 1,068	70.4% 752 out of 1,068	-7.4%	
<b>Anemia</b>	48.6% 360 out of 740	62.9% 256 out of 407	37.6% 153 out of 407	-40.2%	
<b>Wasting</b>	23.2% 272 out of 1,171	19.1% 119 out of 624	15.9% 99 out of 624	-16.8%	
<b>Stunting</b>	53.3% 1,037 out of 1,947	64.1% 594 out of 926	61.9% 573 out of 926	-3.5%	
<b>Underweight</b>	47.9% 905 out of 1,888	53.1% 503 out of 948	50.5% 479 out of 948	-4.8%	

Wasting is only for assessments performed when child was under five years. Underweight for children under ten, and only considers weight-for-age.

**Intervals between first and last assessments**

	Average	Range
<b>Anemia Assessments</b>	11m	-2d - 5y
<b>Growth Assessments</b>	10m	0d - 6y

# Data-driven Advocacy

- Policy outreach
- Technical support for policies, strategies, guidelines and tools
- Outreach to practitioners and funders
- Global and national coalitions



# Inclusive Systems

- Multi-sectoral approach
- Contextualization
- Civil society partnerships
- Working towards inclusive systems: case studies



# INEQUALITIES AFFECTING CHILDREN WITH DISABILITIES: STRENGTHENING NUTRITION AND FAMILY CARE, AN EXPERIENCE OF CATHOLIC CARE FOR CHILDREN IN UGANDA

Pamela Magero

Master Trainer, SPOON / ARU-CCCU

# Project Overview

## Goal

To strengthen nutrition and feeding practices for children living with disabilities and children who are currently, or at risk of, living outside of permanent family care.

## Project Objectives

- Equip CCIs with nutrition and feeding knowledge and skills, and support them to implement best feeding and nutrition practices.
- Ensure that children served by these CCIs are eating more efficiently and safely, and are experiencing improved growth and reduced rates of anemia.
- Support CCI staff to incorporate nutrition and feeding into community outreach activities to inform and influence community stakeholders, including families.
- Develop guidelines on incorporating nutrition and feeding into alternative care and reintegration policies and programs, for use by key stakeholders in the sector.



**Catholic  
Care for  
Children in  
Uganda**



# Project Interventions

- Nutrition and feeding capacity building at 17 child care institutions
- Training in growth monitoring, anemia and mealtime modules
- *Count Me In* application for tracking, decision support and monitoring
- Advocacy for disability-inclusive nutrition policy and practice



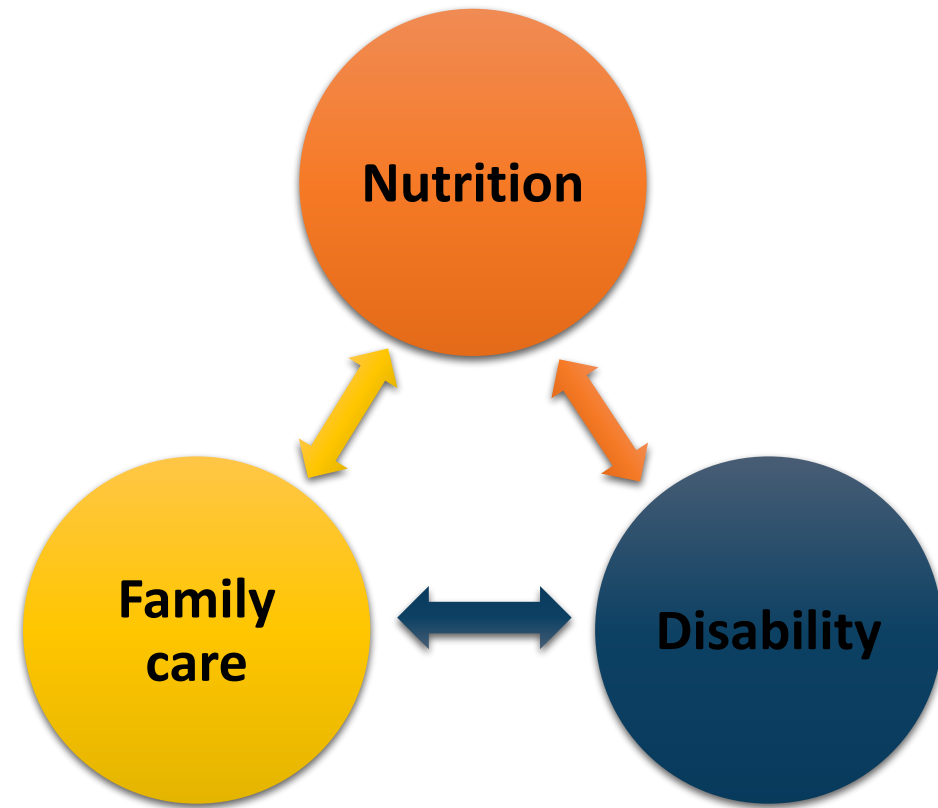
# Interconnectedness of nutrition, disability, and family care



Micronutrient deficiencies are a major predisposing factor for disability among children under five.

Anatomic differences among children with disabilities affect efficiency in feeding leading to malnutrition.

Quality of life, nutrition and feeding for children with disabilities is greatly determined by quality of family care.



**Catholic  
Care for  
Children in  
Uganda**

# Inequities for children with disabilities in nutrition and family care

- Stigma and discrimination; resulting in marginalization and exclusion from nutrition programs
- High chances of abandonment hence institutionalization
- Lack of sufficient data to support policy and programming
- Dangerous feeding practices place children with disabilities at risk for aspiration, pneumonia, malnutrition, and premature death
- Lack of inclusiveness at governance and policy levels; e.g. Uganda nutrition guidelines and local academic curriculum.
- Inappropriate feeding care; knowledge and skills to safely nourish these children



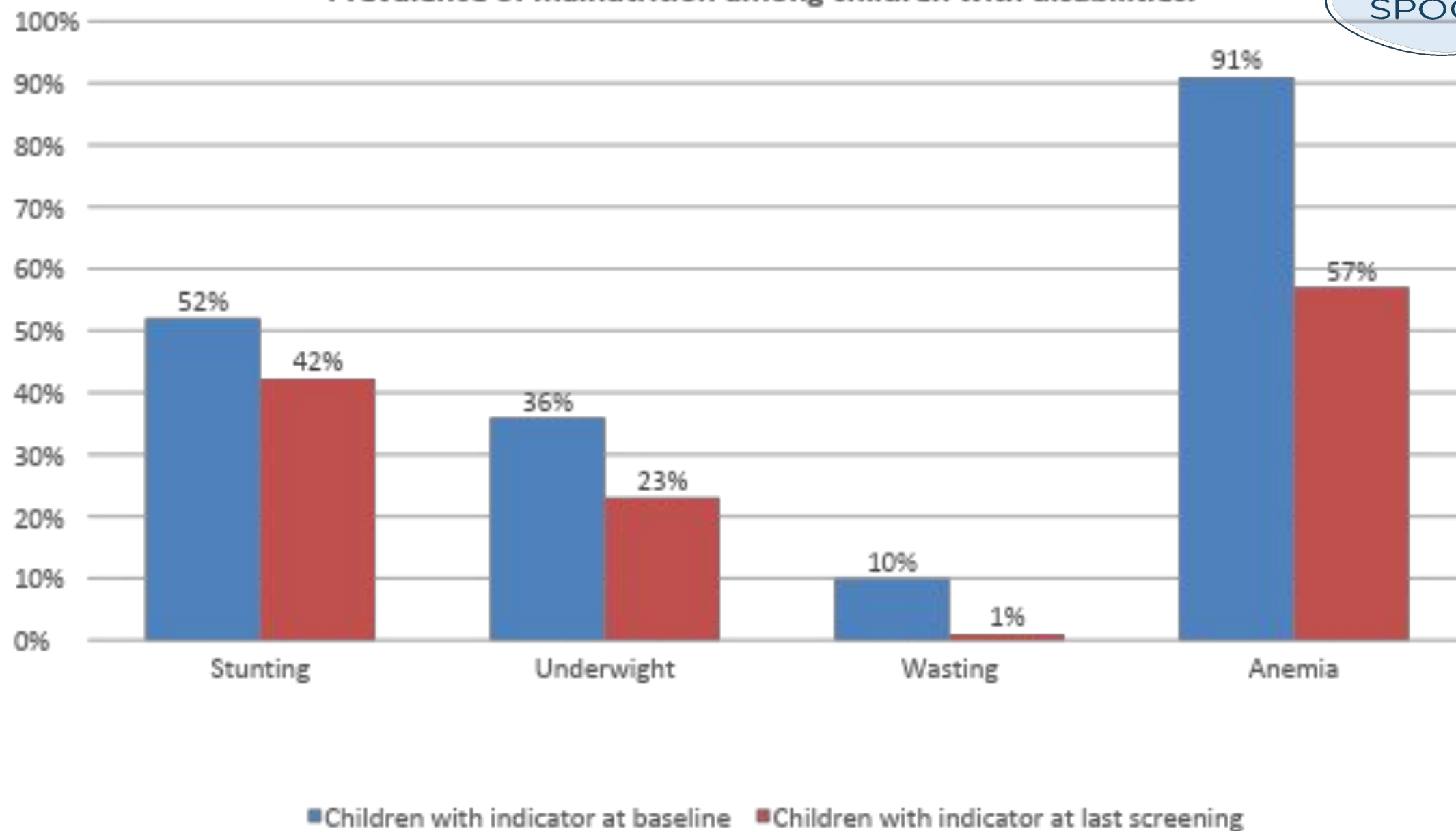
## CCCU/SPOON efforts to reduce inequities among children with disabilities



Reunification program includes ;

- Sensitizing parents and caretakers on the unique feeding aspects for children with disabilities in comparison to other family members
- Engaging community leadership and justice institutions to ensure safety of children.
- Community sensitization outreaches to promote acceptance and easy social readjustment for the children living with disabilities.

## Prevalence of malnutrition among children with disabilities.





# Recommendations

- Prioritize the role nutrition and feeding plays in successful resettlement in the care reform process
- Prioritize children with disabilities in national nutrition policies, guidelines, and legal frameworks
- Train health, nutrition, and child care professionals in disability-inclusive nutrition
- Screen all children for malnutrition and feeding difficulties in the resettlement process.
- Collect and use data on the nutrition status of children in alternative care
- Disaggregate data by disability status, and ensure accountability for inclusion of children with disabilities



# Linking developmental and nutrition screening in Lesotho

Nkhasi Sefuthi, LLM

Lesotho National Federation of Organizations of the Disabled (LNFOD)

# The Lesotho Early ID Project

The goal is to identify children 0-6 years old who are at risk of developmental delays, including growth and feeding, and link them with the appropriate services.

Developmental  
screening



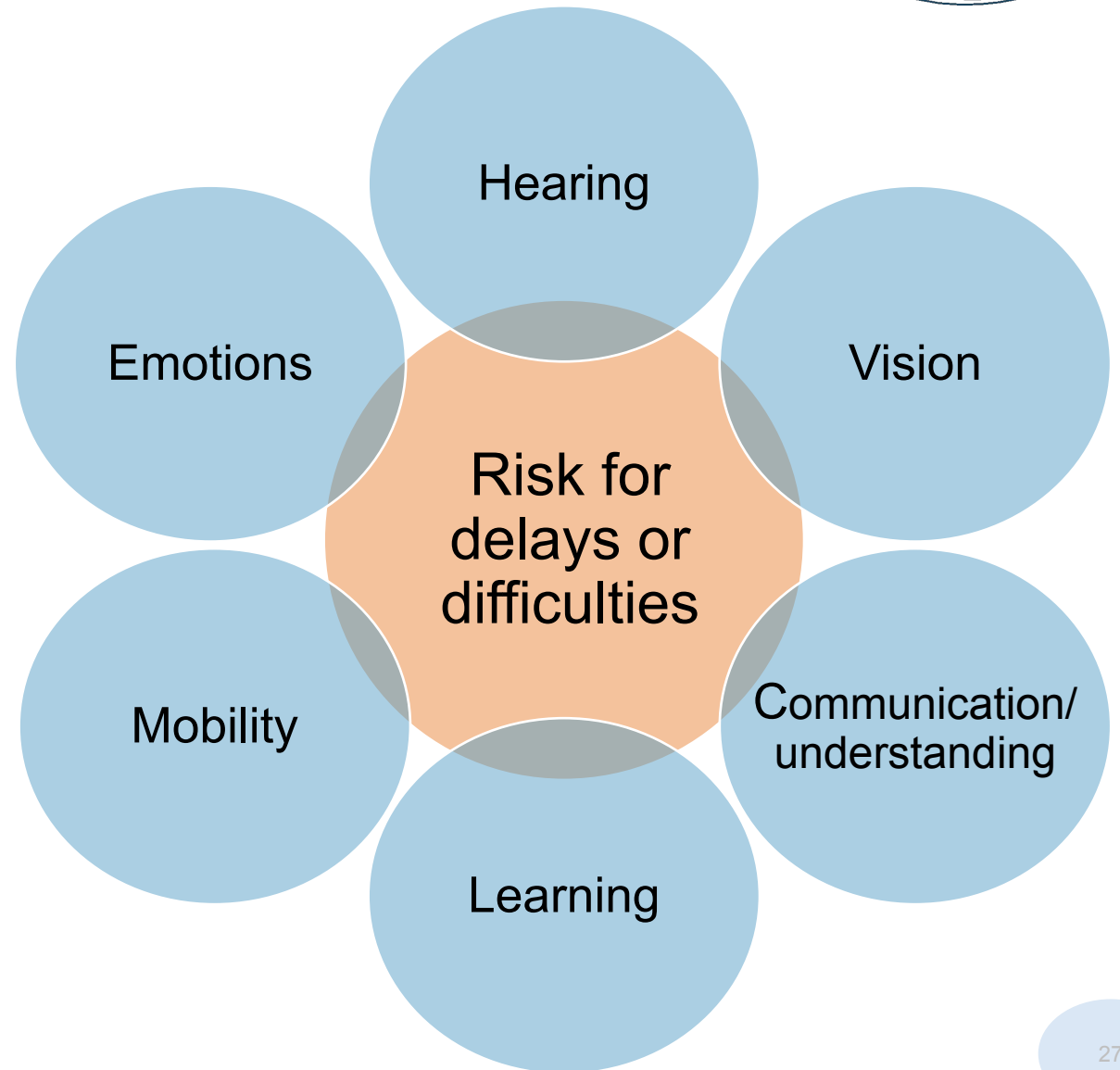
Nutrition screening

Tools  
Training  
Guidelines & standards

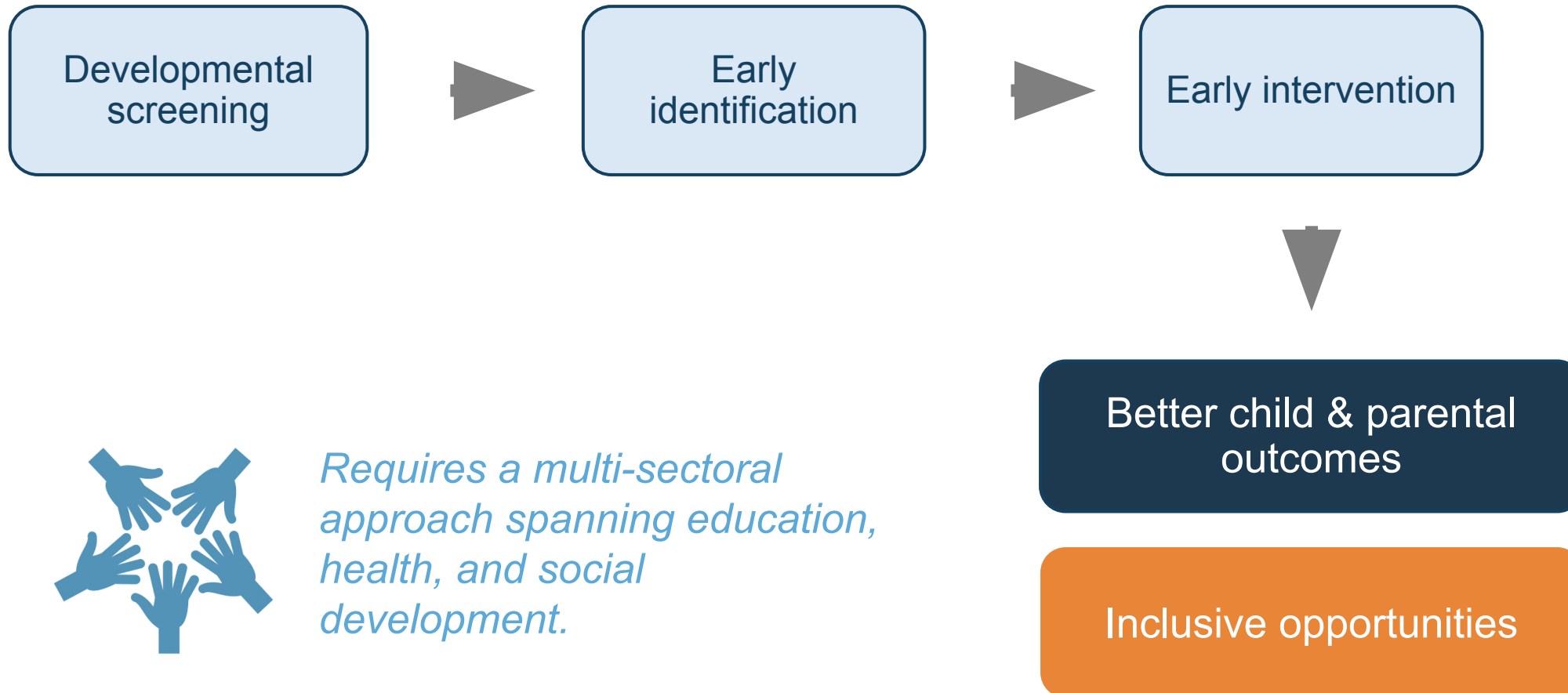


# What is developmental screening?

Process of identifying young children at risk for having a delay or difficulty in various functional areas.

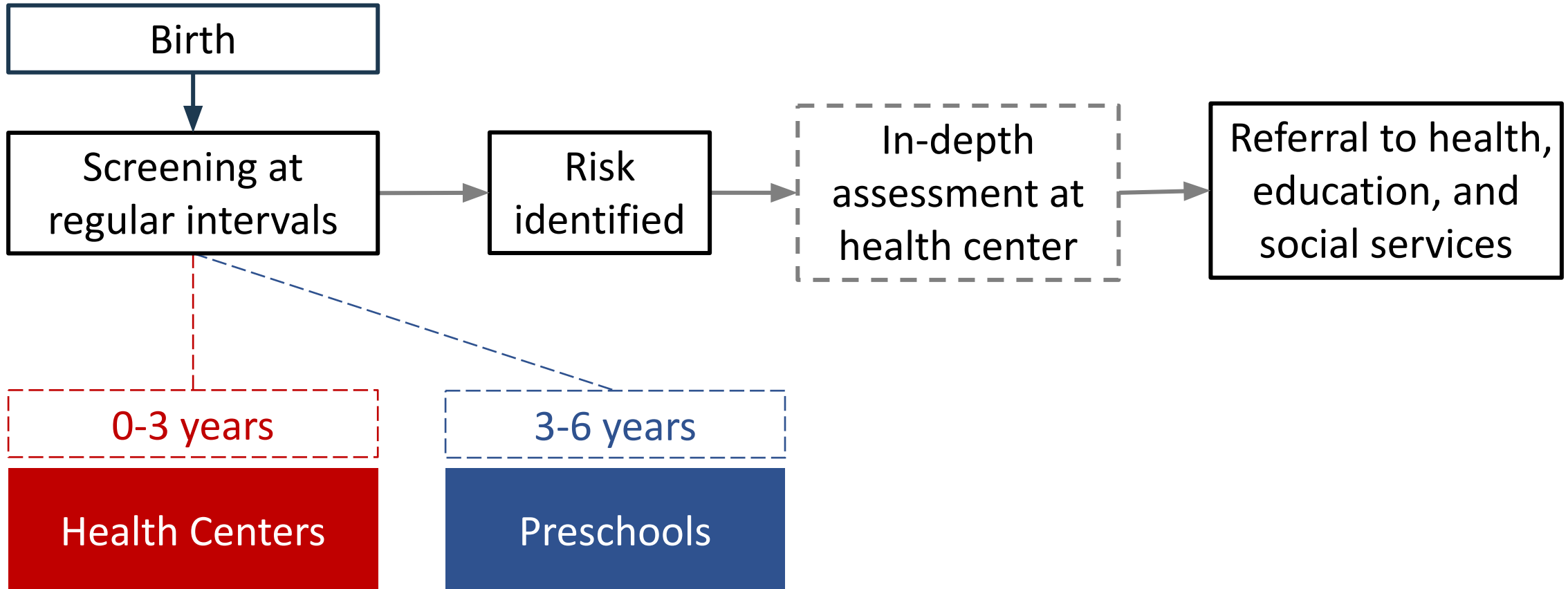


# Why is developmental screening important?





# Developmental and Nutrition Screening Pathways for Children 0-6 Years Old



# Developmental and Nutrition Screening Training and Tool



- Hybrid training model
- Digital health app, *Count Me In*
- Three modules
  - Growth
  - Mealtime
  - Development

# Developmental Screening in *Count Me In*

The logo for SPOON, featuring a stylized spoon with a heart in the bowl, and the word "SPOON" in a bold, sans-serif font.

Count Me In

HomeSite ▼Account ▼

## Developmental Screening

You are here: [Lesotho Community Site](#) > [Ziad Mak](#) (Male; 5y)

Your changes have been saved.

Does child have difficulty seeing?

No difficulty	Some difficulty
A lot of difficulty	Cannot do at all
Refused	Don't know

Save

Count Me In

HomeSite ▼Account ▼


## Developmental Screening Recommendations

You are here: [Lesotho Community Site](#) > [Ziad Mak](#) (Male; 5y)

### REFERRALS

Refer child to primary care doctor for further assessment.

### SUMMARY

 **Development**

Child may be experiencing difficulties in the following areas of development:

- Self-care
- Learning

See below for more details

### NEXT STEPS

- Discuss findings with caregiver. Provide counseling.
- Communicate results to other professionals involved in the child's care.
- The next screening is scheduled for 25/07/2023.

### DETAILS

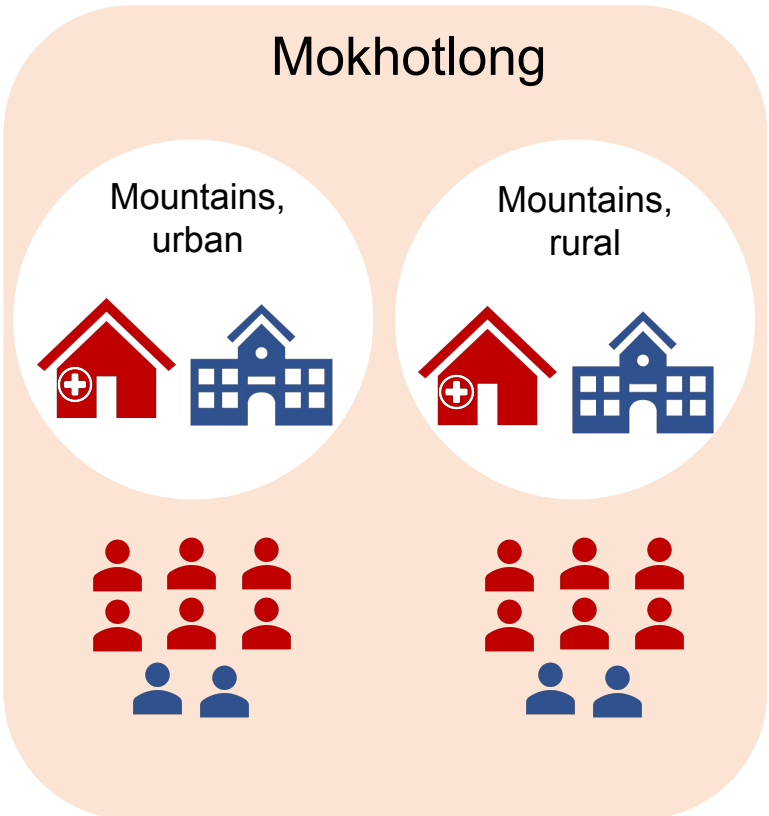
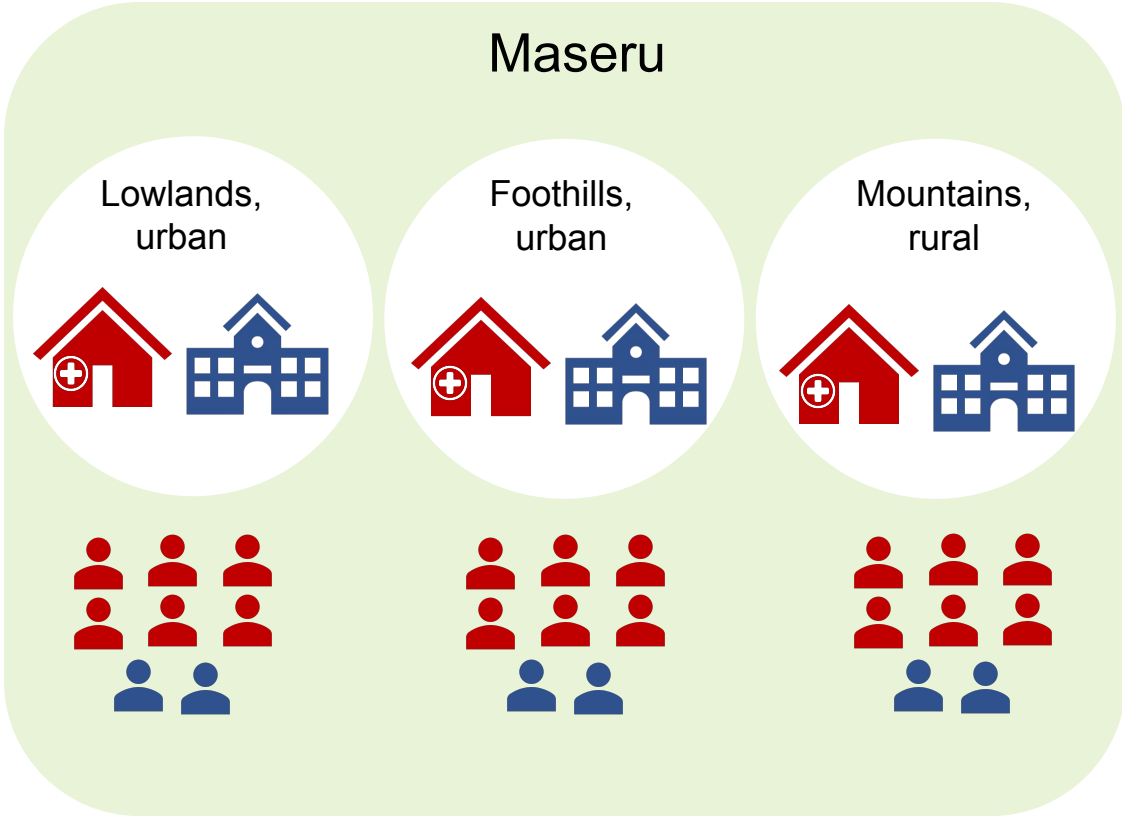
**Self-care**

The child may have difficulty with self-care.

**Learning**

Child may have cognitive difficulties. [Learn more](#)

# Pilot in Two Districts



## Preliminary Data: *Count Me In* Usage

**448**  
**children**

198 *screened by health centers*

250 *screened by preschools*

**1,391**  
**assessments**

522 *growth assessments*

464 *mealtime assessments*

405 *developmental screenings*



# Preliminary Data: Growth and Development



## Growth (ages:0-59 months)

Stunting 30.3%

Wasting 5.0%

Underweight 13.2%

## Development

Risk of developmental delay  
(ages: 2-24 months)

23.3%

Reported functional difficulties  
(ages: 2-6 years)

6.4%

# Opportunities and Challenges

## Opportunities

- Integrates well into care during under-5 clinics
- Works well in preschools
- Referrals within the same community possible
- Strong buy-in and interest
- Positive feedback from parents

## Challenges

- Slow network at times
- Increased workloads at health centers
- Lack of specialized services
- Limited government resources





# Supporting nutrition and feeding for children with disabilities and families in Zambia

Watson Shungu Mwandileya

Programs officer-child protection and health, Access to Health Zambia



- 2015 Zambia National Disability Survey:
  - 7.7% of people have disabilities
  - 4.4% of children 2 to 17 years old have disabilities
  - 40% of disabilities were as a result of birth or congenital causes, 31% due to disease/illness
- Leading causes: Yellow fever, Meningitis, non-treated Malaria, and poor nutrition in early childhood.

Challenges for caregivers include:

- Not understanding their child's disability
- Stigma and discrimination
- Poor nutrition in their children
- Lack of skills in feeding techniques
- Insufficient access to health care and assistive devices for children





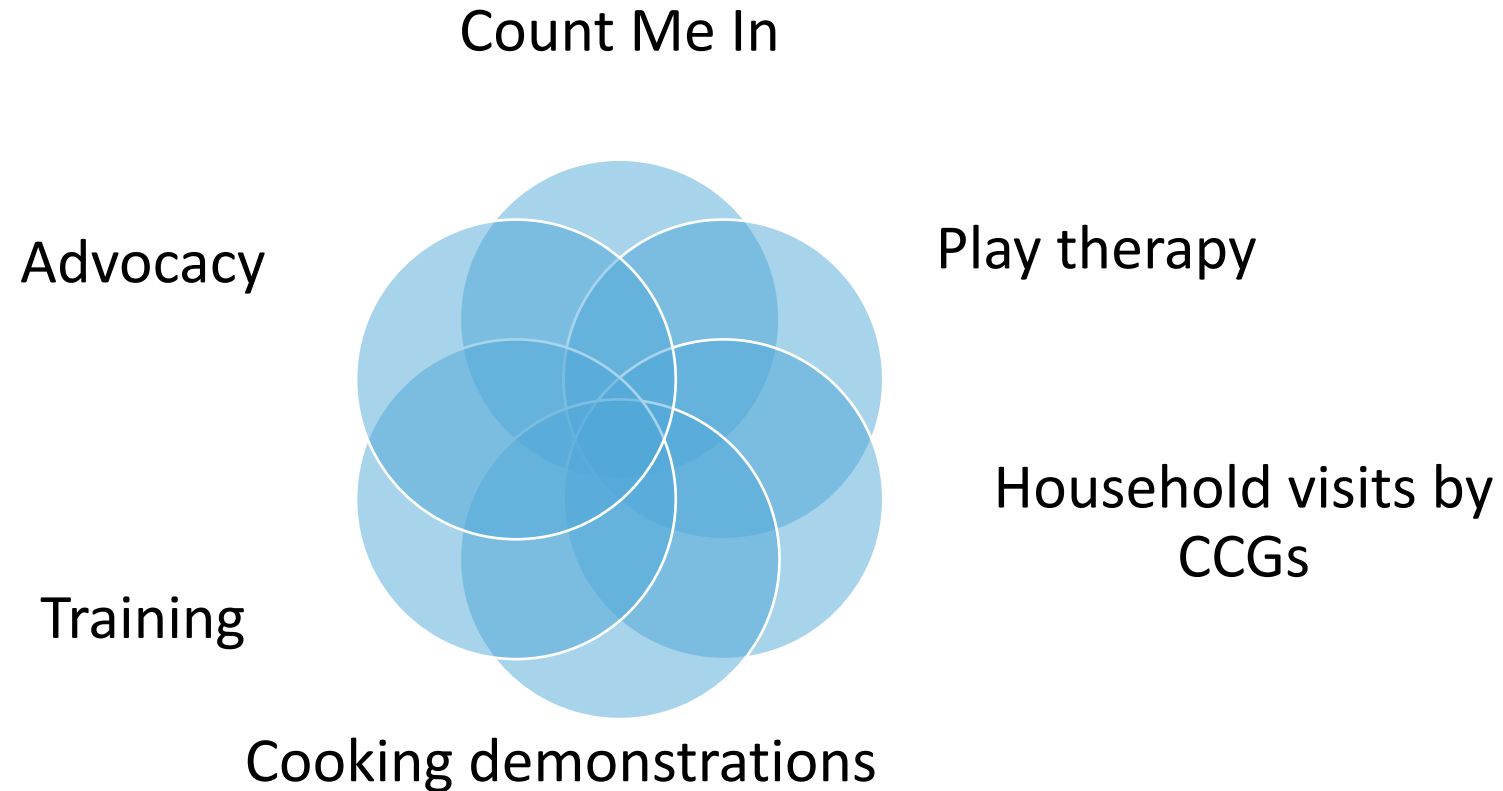
## Objectives:

- Reverse family, community, and system tolerance for harmful practices
- Build family's capacity to provide stable, protective, nurturing family environments for children.
- Build support for child-friendly practices and to reverse tolerance for those that do not support children's positive development.

**Partners:** Access to Health Zambia, SPOON, St. Catherine's University, GHR Foundation



# HOW WE WORK WITH CAREGIVERS

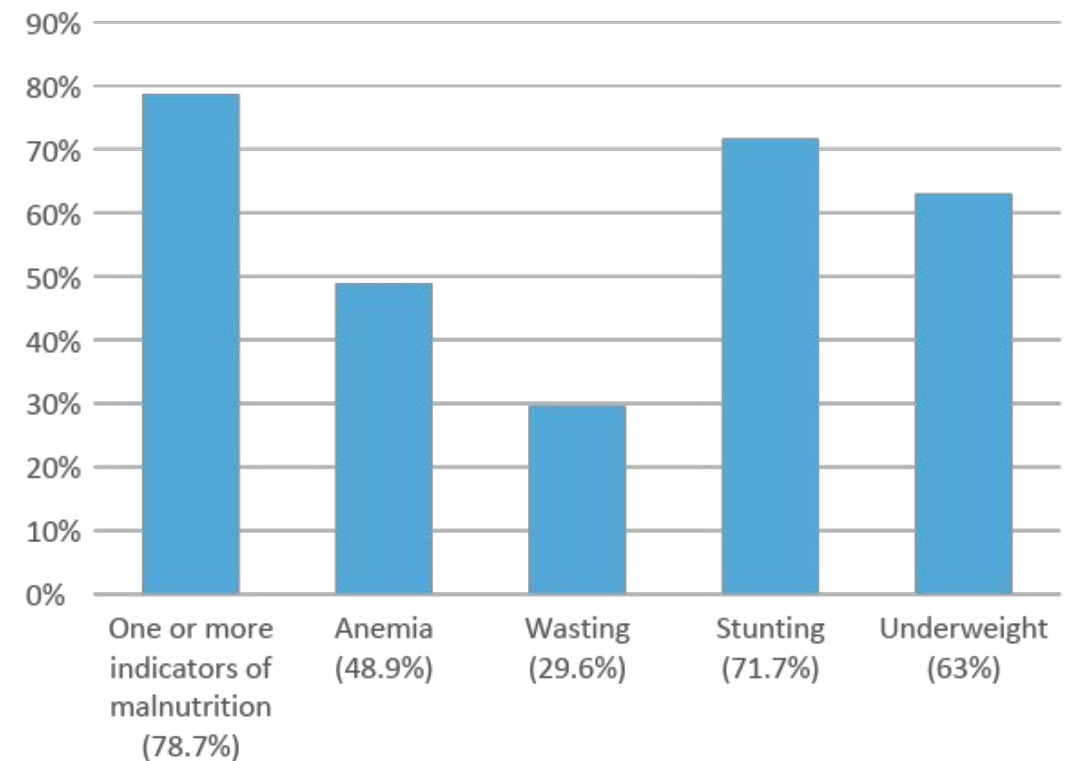


# COUNT ME IN



- Since 2019,
  - 12,700 assessments (mealtime, growth, and anemia)
  - 1,515 children
  - 1,271 children with disabilities
- Recommendations specific to child's needs, including specialized feeding techniques, responsive feeding, and ways to ensure an iron-rich diet.

Baseline prevalence of malnutrition among children with disabilities



# CCG VISITS & PLAY THERAPY

## Household visits:

- Community Care Givers (CCGs) conduct 2 household visits per month for children with disabilities in their communities
- Support services: basic physiotherapy, nutrition counseling, referral for support services and to individualized care based on CMI assessment

## Play therapy sessions :

- Help children build friendships, learn social-emotional, communication and physical skills, feel included and supported



# COOKING DEMONSTRATIONS

- MoH nutritionists and CCGs show key recipes of nutritional value
- Parents learned and applied skills for well-balanced diet and how to prepare nutritious meals from locally available foods
- Encourage backyard gardens as additional source of fruits and vegetables





# TRAININGS



- Disability and Nutrition: Supports government workers to understand disability and feeding techniques
- Care for CWDs training:
- FEED Safe: Tool to promote safe, effective, and comfortable feeding practices

- Community level
  - Church talks (stigma messages, emphasis on inclusion)
  - Health facility talks (stigma messages, disability red flags)
  - Dialogue meetings (challenges and support for CWDs)
  - Stakeholder meetings (Coordination of services for CWDs)
- National level
  - Technical Advisory Group (TAG) meetings (material review and validation, policy brief, sharing of data in CMI)

# Program Outcomes

- Unadjusted program data show positive trends in anemia and wasting; not seeing significant change in stunting
- Decreased self and community stigma
- Increased referrals for CWDs (social welfare, physio, assistive devices, nutrition)
- Increased health facility and social welfare capacities to provide support to CWDs
- Strengthened capacity and coordination of formal and informal government structures and district and community levels to support CWDs



# Recommendations

Carolyn Moore, MPH

Policy and Advocacy Advisor, SPOON

# Need for change across ecosystem



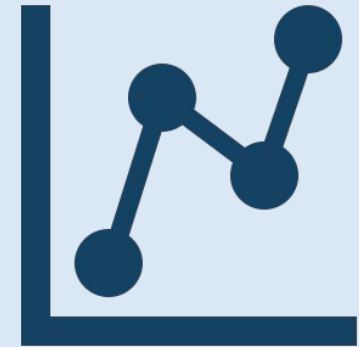
Policy



Investment



Workforce & services

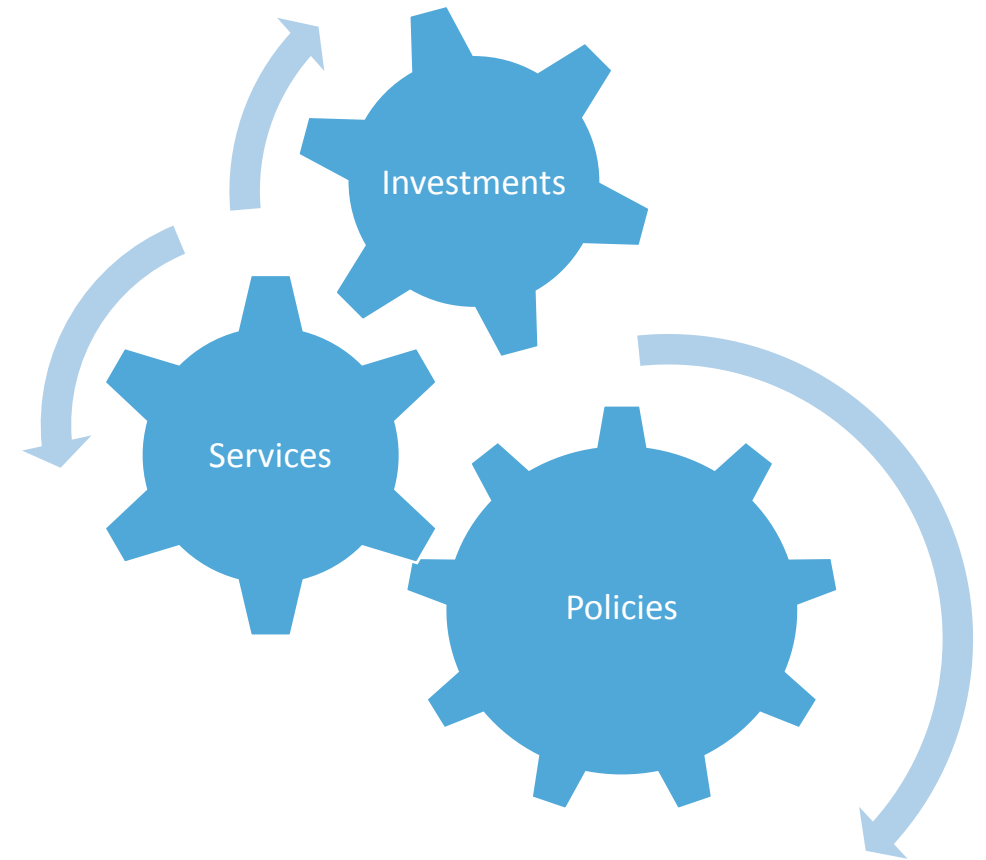


Data & accountability



# Recommendations

- Policies, guidelines, and accountability measures
- Services and programs
- Investments
- Advocacy



# Discussion



A photograph showing a stack of colorful plastic cups and jugs in red, green, and blue, arranged on a wooden surface. The cups are of various sizes and some have handles.

# THANK YOU

Learn more:  
[www.spoonfoundation.org](http://www.spoonfoundation.org)