

Transforming Lives & Health Outcomes for At-Risk Children in Rwanda

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Speakers

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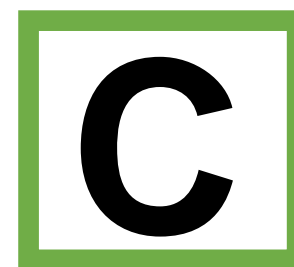
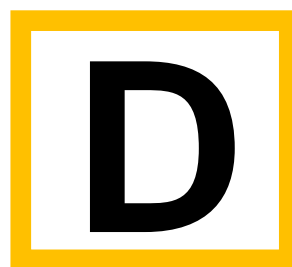
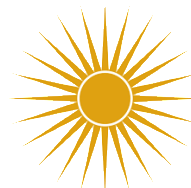
Moderator

Leslie Friday

Director of Content



<https://www.youtube.com/watch?v=2vdb5yeyhmk&t=2s>



The Pediatric Development Clinic

A Model to Support Early Childhood Development for High-Risk Children Under Five

Background

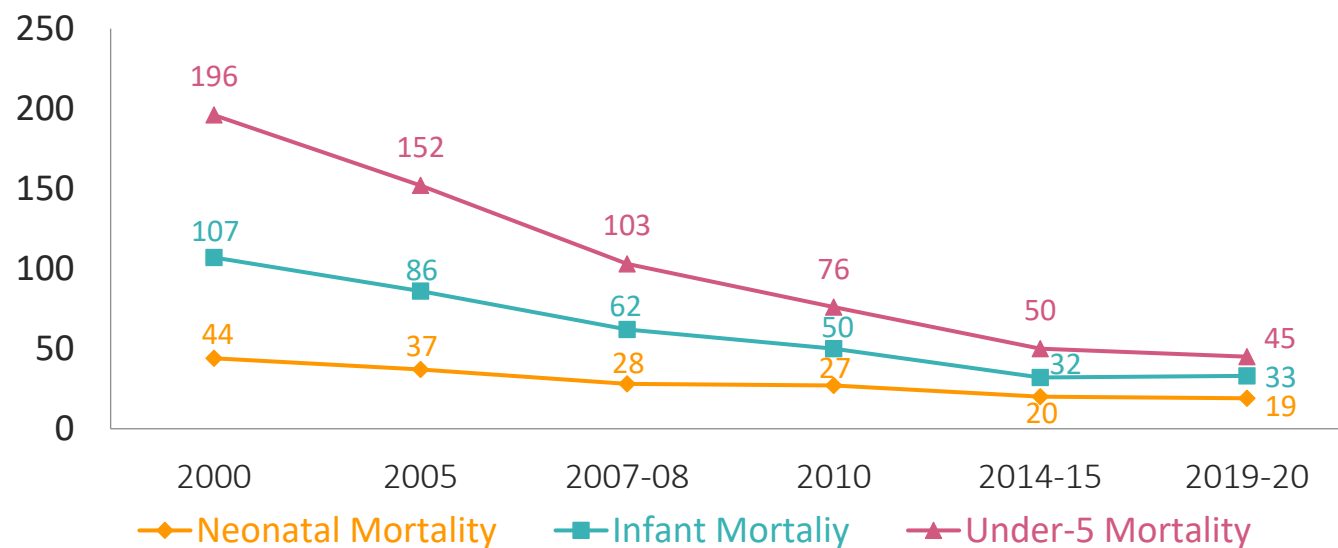
- Over the last decade there has been improved neonatal survival and increasing focus on longer-term outcomes for newborns...*for all newborns to thrive!*
- Neurodevelopmental impairment is common after newborn conditions*
- Early identification and intervention is crucial to improve outcomes and support families, however, there is limited access to specialized services in many LMICs
- Discrimination and exclusion are commonly experienced by families and are additional barriers to accessing services
- Empowering parents and HCW with knowledge and skills is essential to improve care and outcomes

*Pediatr Res, Beyond Survival series, 2013



Rwanda Context

- Tremendous improvement in neonatal survival



- Emerging group of vulnerable infants at higher medical, nutritional, and developmental risks – long-term disability
- Need for systematic follow-up and integrated early interventions

Vulnerabilities of High-Risk Infants



Poor Nutrition

- Feeding difficulties
- Malnutrition and stunting



Poor Development

- Developmental delays: motor and speech
- Cerebral palsy
- Hearing and vision problems
- School problems: learning disabilities, attention deficits



Poor Health

- Infections
- Chronic lung disease
- Non-communicable diseases:
 - Cardiovascular diseases
 - Insulin resistance, diabetes



Increased risk of mortality in infancy and early childhood

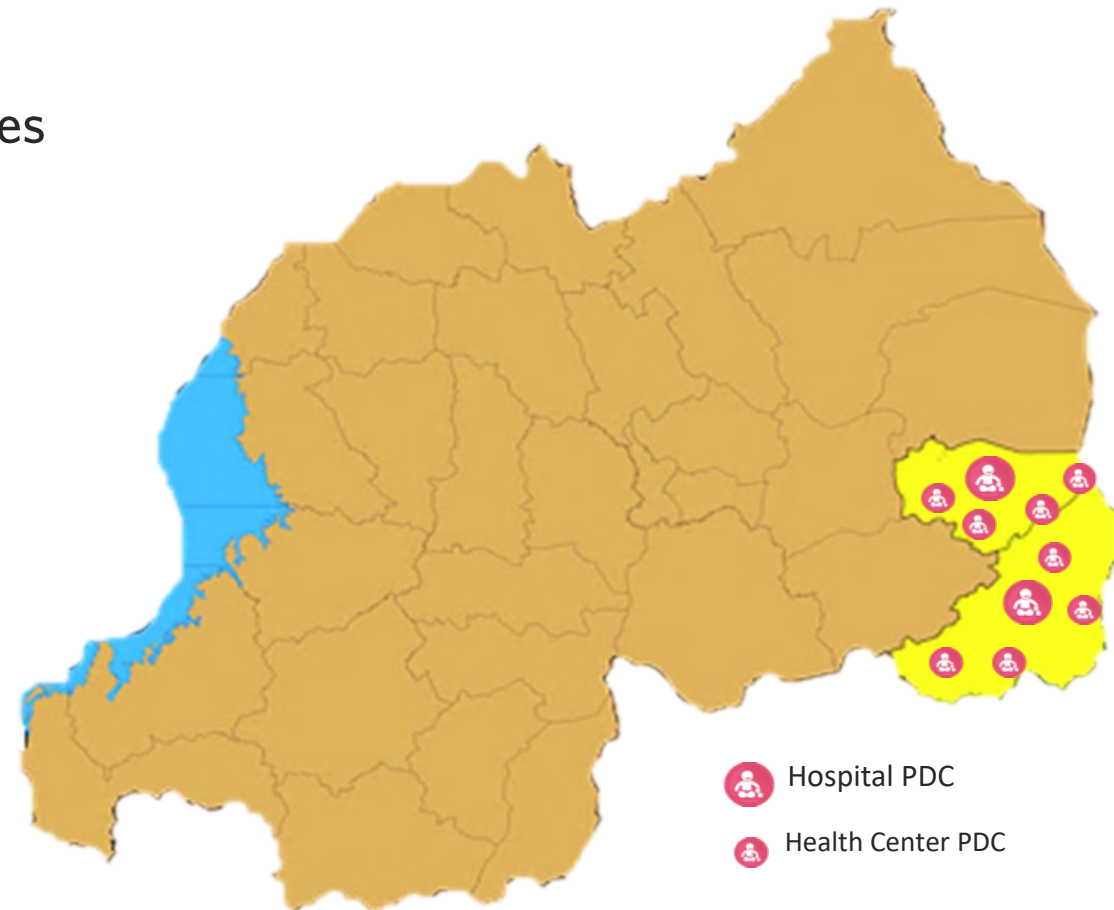
Pediatric Development Clinic (PDC) 1

- Started in 2014 in Rwinkwavu by PIH/IMB in collaboration with MOH and UNICEF; expanded to Kirehe in 2016
- PDC: Integrated model of structured medical, nutritional & developmental follow-up for high-risk infants, 0 – 5 years
 - Low birth weight & prematurity
 - Brain injury (encephalopathy following asphyxia)
 - Hydrocephalus
 - Cleft lip/palate
 - Trisomy 21
 - Global developmental delay
 - Severe acute malnutrition <12 months old child
 - Post-CNS infection (cerebral malaria, meningitis)

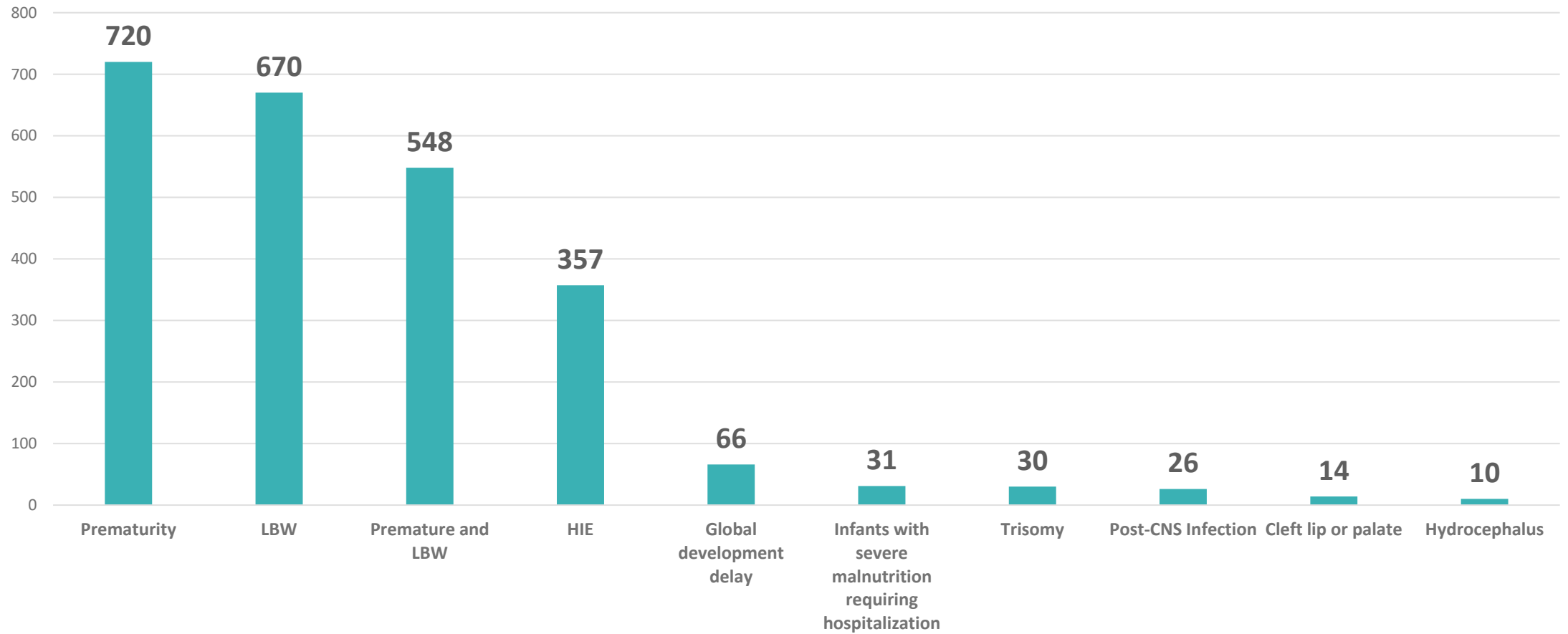


Pediatric Development Clinic (PDC) 2

- Integrated into public health facilities
- Using task-shifting approach - trained nurses and social workers to deliver PDC services
- 10 clinics operating in 2 districts - Kayonza and Kirehe districts in Eastern province of Rwanda
- Over 2,600 children enrolled to date



PDC Enrollment

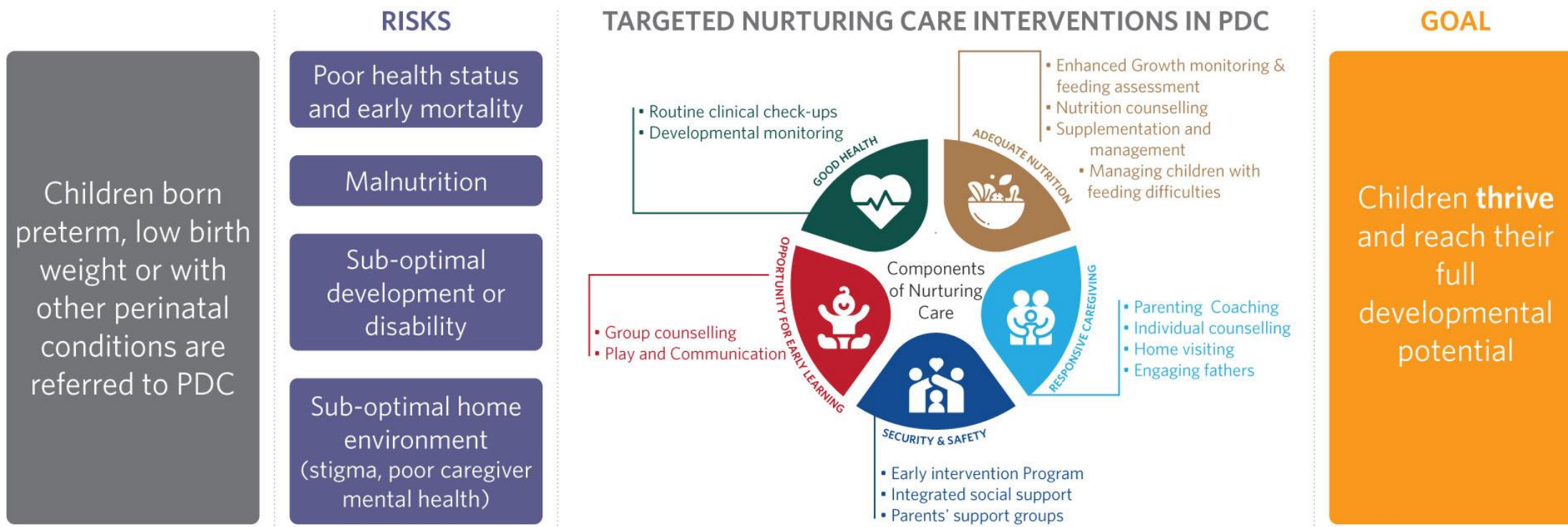




The Approach

Pediatric Development Clinic (PDC)

Approach for Follow-up Care of Small and Sick Newborns



Pediatric Development Clinic Visit Flow

Group Counseling

Health, nutrition, and development topics, with the opportunity for play, communication practice, and peer support



Clinical Consultation

1. Medical monitoring and care
2. Growth monitoring, feeding assessment, and interventions
3. Development monitoring
4. Referral



Social Worker Consultation

1. Social risk assessment
2. Additional Social Support Determination:
 - Individual counseling
 - Nutritional support
 - Home visits



Impact of the Pediatric Development Clinic



GOOD HEALTH

IMPROVED SURVIVAL

Children in PDC had

50% fewer deaths

after neonatal unit discharge



SECURITY & SAFETY

IMPROVED CAREGIVER MENTAL HEALTH

**21% reduction in symptoms of
anxiety and depression**

which were strongly associated with violent discipline



ADEQUATE NUTRITION

IMPROVED NUTRITION

Children in PDC had

10% less stunting



OPPORTUNITY FOR EARLY LEARNING

&



RESPONSIVE CAREGIVING

EMPOWERING CAREGIVERS

"I was taught how to interact with my child. Before I thought my child couldn't learn anything [...] Before coming here I did not know I should do this. Now I see that he can still learn."

Mother in PDC Program

"We learnt a lot from here, how we should look after and take care of children. [...] We should help each other. There shouldn't be any dispute [in the family] about who should be looking after the kids. That is not reserved to women only."

Father in PDC Program

Important Cross-Cutters

Stigma, exclusion & discrimination

- High social and emotional impacts. Stigma and exclusion are common
- Traditional beliefs around etiology of developmental disability contribute to blame, stigma, and exclusion

Gender

- Mothers are frequently the primary caregivers
- Fathers are the decision makers and gatekeepers, but also advocates, if engaged and empowered

Literacy & language

- Low levels of literacy, particularly amongst women, are a barrier to program access and fidelity

Poverty

- High cost of care and substantial loss of income due to care needs and exclusion/discrimination - barrier to impact

Access to care

- Low levels of confidence & knowledge about caring for children with disability means they are often turned away from care..."nothing can be done"

COVID

- Need a risk-based approach to facilitate group activities and community visits



Early Intervention Program (EIP)

Parents' Support Groups for Children with Developmental Disabilities & Their Families

Early Intervention Program (EIP)

- A 10-modular, **participatory group-based rehabilitation program** facilitated by a trained expert parent and health care provider
- Uses a participatory approach to engage all and make learning practical and fun



Aims:

- Promoting inclusion and participation of children with disability within the family and community
- Maximizing a child's developmental potential, optimizing health and quality of life
- Promoting empowerment of caregivers through information sharing and peer support
- Understanding the child and family experience, and particularly addressing stigma
- Promote the human rights of children with disability





Early Intervention Program (EIP) CONTENT



Referral to and Enrollment in Pediatric Development Clinic (PDC)

High-risk infant identified at birth and referred to the hospital neonatal unit

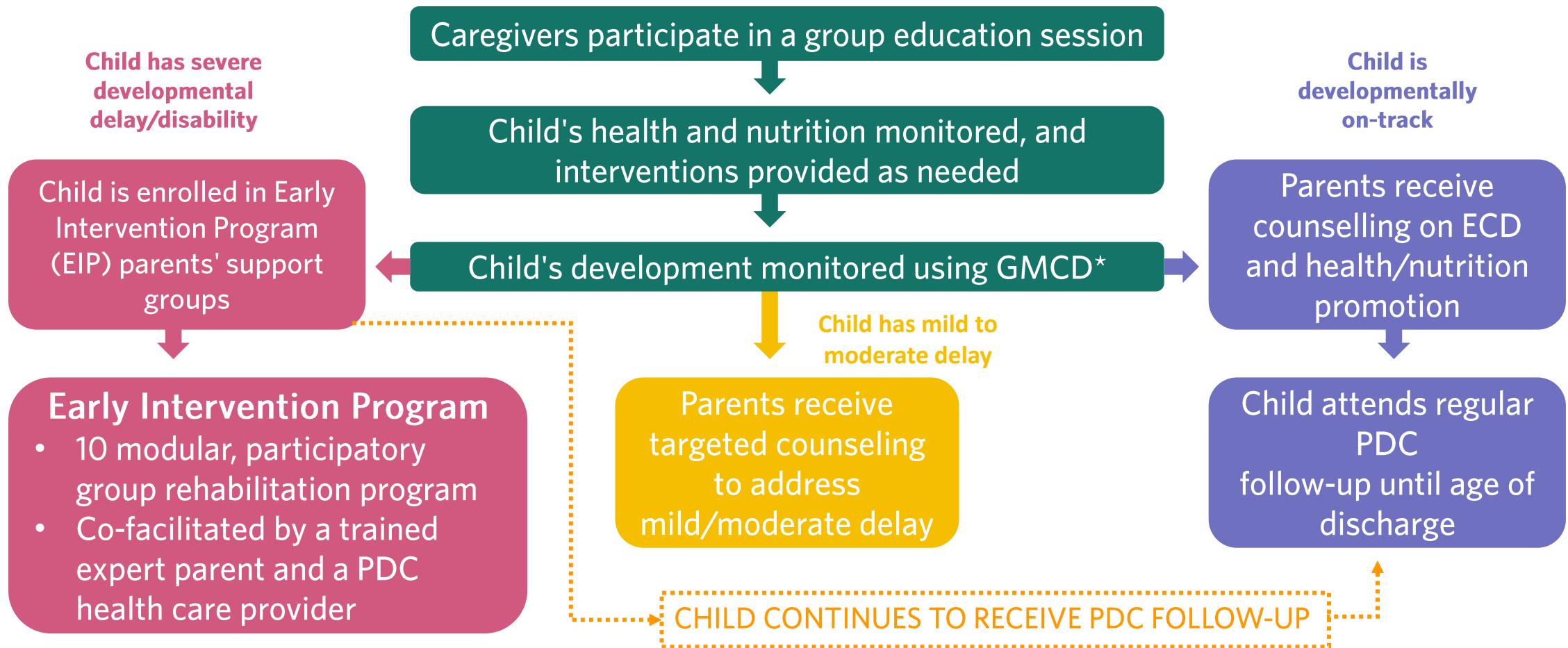
Newborn managed in neonatology until stable and safely gaining weight

Newborn discharged from hospital and referred directly to PDC for outpatient follow-up

Child enrolled at the PDC closest to their home and starts regular follow-up schedule



Follow-up and Monitoring in the PDC During Routine PDC Visits



Next Steps and Plans

Next Steps and Plans (1)

- PDC policy advocacy at the national level for its adoption across Rwanda
- PDC decentralization to new 14 HCs in Kirehe for TOTAL DISTRICT COVERAGE
- Integration of hearing and vision screening
- Strengthen habilitation-rehabilitation interventions for children with disability – diagnosis & treatments, regular occupational therapy outreaches, equipment



Next Steps and Plans (2)

- Strengthen and expand early intervention program (EIP) parents' support groups for children with disability and their families
 - Scale up the program
 - Pilot tablet app providing an INTERACTIVE resource for both Facilitators and Families with DYNAMIC & ACCESSIBLE content



Next Steps and Plans (3)

- **Gender, Equality & Empowerment:**
 - Engage fathers - learn from RWAMREC experiences to enhance our programming with gender transformative interventions
- **Social inclusion and community engagement**



PDC Impact Story 1



- ELBW and VLBW preterm twins born from a delayed 4-day interval
- Deliveries at Kirehe MCH COE in September 2020
- Both twins stayed for 2 months in NCU, safely reached discharge, and are now followed in PDC at their nearest HC

PDC Impact Story 2



- Born on August 12th, 2016 and did not cry at birth
- Neonatal encephalopathy, hospitalized and received care at PIH-supported Kirehe Hospital NCU for 2 months
- Followed up in PDC
- Identified with cerebral palsy
- B's mother had just started her dream career in education, where she was a mathematics teacher at a local primary school. She had to quit to take care of her child full-time.
- **"I miss my students a lot, but I have to find ways to repress that feeling. It's difficult!"**
- Mother trained as an expert parent to support other caregivers with children with developmental disability in early intervention program
- Child continues to receive occupational therapy and rehabilitation care



Thank you