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## BACKGROUND

The global strategy for Women's Children's and Adolescent's Health supports the need for every newborn not only to 'survive' but also to 'thrive' and reach their full neurocognitive and developmental potential.<sup>1</sup>

Globally, around 8.4 million newborns a year experience complications in the first few days and weeks after birth (accounting for 202 million disability adjusted life years)<sup>2</sup> that can have life-long influence on health, development and life chances. The vast majority of this burden falls in the world's poorest countries.

Early interventions, designed to enhance a child's development in the first few years after birth, have the potential to limit and even prevent neurodevelopmental impairments following early brain injury, either directly or through their influence on the care-giving environment, and improve circumstances and quality of life of the child and their family.

## OBJECTIVES

To integrate the 'Baby Ubuntu Bundle', a programme of early identification, care and support for young children with developmental disabilities and their caregivers, into government health systems in Rwanda

## METHODS

The Baby Ubuntu Bundle is a 10-modular, participatory group rehabilitation programme, facilitated by expert parents alongside healthcare workers and embedded within government health facility Paediatric Development Clinics (PDCs). Facilitator training and supervision were provided for expert parents and healthcare workers who co-facilitate the programme. Pre- and post-training assessments evaluated knowledge, confidence, facilitation skills and fidelity of delivery. Mixed-methods evaluation examined feasibility, acceptability and impact on family quality of life (QoL) and growth (mean mid-upper arm circumference (MUAC)).

## THE BABY UBUNTU BUNDLE

### Themes running throughout the programme

- Promoting inclusion and participation of children with disability within the family and community
- Maximising a child's developmental potential, optimising health and quality of life
- Promoting empowerment of care-givers through information sharing and peer support
- Sharing maternal experiences, and particularly addressing stigma
- Promoting the human rights of children with disability



Everyday activities



Learning to move



Play



Feeding your child

## RESULTS: QUANTITATIVE DATA

In 2019-20, 31 facilitators were trained and demonstrated improved scores in knowledge (median 65% pre vs. 85% post), confidence (median 3.9 vs. 4.5) and facilitation skills (median 4.3 vs. 4.7). Fidelity checklists showed high-level facilitation skills in most areas.

Between Oct 2019 and Jan 2020, 10 PDCs enrolled 109 families (Table 1) to 12 participatory groups, providing evidence of feasibility. Acceptability was evidenced by satisfactory attendance ( $\geq 6$  modules attended) in 95.4% (104) of participants.

**Table 1: Basic demographics and clinical characteristics of study participants (n=109)**

### Caregiver characteristics

Sex distribution	107(98.2% female, 2 (1.8%) male)
Median age at assessment, years (IQR)	31.5 (25-37.5), range 18-62
Education level	
None	27 (24.8%)
Primary only	76 (69.7%)
Secondary	6 (5.5%)

### Child characteristics

Sex distribution	58 (53.2%) female, 51 (46.8% male)
Median age at assessment, months (IQR)	32 (20-44), range [2-141]

Of those enrolled, 97 completed pre- and post-intervention assessments (9 died, 3 withdrew). The median total family QoL score (PedsQL, Family Impact) was 62.5 at baseline vs. 79.9 at end-line (median difference, +12.5 ( $p < 0.001$ )), representing a 20% increase post-intervention (Table 2). Significant improvements were seen in physical, emotional, and social functioning, worry, communication, daily activities and family relationships ( $p < 0.05$ ).

**Table 2: Comparison of total Paediatric Evaluation of Quality of Life score (PedsQL 2.0, Family Impact Module), all sub-scores before and after intervention and MUAC (N=97)**

PedsQL Family Impact module scale	Median Score Pre-EIP (IQR)	Median Score Post-EIP (IQR)	Median Difference (IQR)	P-Value <sup>1</sup>
<b>Total QoL score</b>	62.5 (51.9-72.2)	76.9 (65.8-84.02)	12.5 (7.7-18)	<.001
<b>Parent QoL</b>	61.3 (50-72.5)	72.5 (60.5-85)	13.7 (6.4-17.5)	<.001
<b>Family QoL</b>	71.8 (52.8,84.3)	84.4 (65.5-93.7)	12.5 (6.5-15.6)	<.001
<b>Physical Functioning</b>	66.6 (50-83.3)	75 (62.5-100)	12.5 (4.2-20.8)	.0003
<b>Emotional Functioning</b>	40 (25-55)	60 (45-90)	25 (15.4-30)	<.001
<b>Social Functioning</b>	63 (43.8-81.7)	75 (56.2-93.8)	13 (0.5-25)	.0002
<b>Cognitive Functioning</b>	75 (60-100)	75 (65-85)	0 (15-5)	0.7
<b>Communication</b>	66.8 (58-75)	83.3 (75-95.8)	16.6 (8.3-24.3)	<.001
<b>Worry</b>	55 (45-75)	75 (65.8-74.5)	10 (5-20)	<.001
<b>Daily Activities</b>	50 (25-66.6)	66.8 (50-83.3)	16 (8.3-25)	<.001
<b>Family Relationship</b>	100 (50-100)	100 (60-100)	0 (0-0)	0.054

## RESULTS: QUALITATIVE DATA

Qualitatively, the programme was found to be acceptable to care-givers and facilitators. Caregivers reported increased knowledge, improved family relationships, reduced self-stigma, raised hope and enhanced emotional wellbeing. The quotations that follow are from participating care-givers and expert parents.



### Stigma, exclusion and social isolation:

"I was hopeless as the father of my baby abandoned us. I always complained about seeking treatment for a child whom I thought was dying soon, as I believed to be the curses from my husband's family."

"Her mother was always ashamed of taking her out as our neighbor would come and encircle the baby, but after she abandoned her, I started taking care of her, taking her out and now the mother accepted the child," Grandmother of study participant."

### Experiences of the Baby Ubuntu Bundle Programme:

"These groups have increased our confidence, [we] feel supported and found that this problem is not only happening here.....We are now good friends, whoever might be experiencing any difficulties she calls me or anyone and we are all here to help each other."



"The group has empowered me in way that I am confident to seek the appropriate treatments for my child and being able to stand up for him and embrace all the difficulties I am facing. I am now able to engage in conversations around children with developmental disabilities with my neighbors since I learned that it is happening elsewhere"



"In addition, to our commitment as mothers for advocating for children, community leaders also were committed themselves to advocated for these children as they were invited during the ninth module"



## CONCLUSIONS

Our integrated Baby Ubuntu Bundle of early identification, care and support for children with developmental disabilities was feasible, acceptable and led to improved family QoL. Participatory training improved facilitator knowledge, confidence and skills, and promoted partnership between healthcare workers and expert parent facilitators.

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