DEVELOPING AN EARLY INTERVENTION PROGRAMME FOR CHILDREN AT HIGH-RISK OF NEURODEVELOPMENTAL IMPAIRMENT IN UGANDA

BACKGROUND
The global strategy for Women’s Children’s and Adolescents’ Health supports the need for every newborn not born to “survive” but also to “thrive” and reach their full neurocognitive and developmental potential. Globally, around 8.8 million newborns a year experience complications in the first few days and weeks after birth (accounting for 202 million disability adjusted life years) that can have life-long impact on health, development and life chances. The vast majority of this burden falls in the world’s poorest countries.

Early intervention, designed to enhance a child’s development in the first few years after birth, have the potential to limit and even reverse 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 develop and evaluate a modular, facilitated, participatory early intervention (EI) programme for infants at high-risk of neurodevelopmental impairment and examine its feasibility, acceptability and impact on child and family quality of life (QoL).

METHODS
A 10 modular programme was developed, adapted from an established programme for older children and supported by an expert advisory group including local parents, Disabled Persons Organisations and experts in early intervention and child development.

Term-born survivors of neonatal encephalopathy were assessed 6 months after birth using the Griffiths Mental Development Scale and the Hammerman-Infant Neurological Examination (HINE). Infants with moderate or severe neurodevelopmental impairment, were eligible to enter the EI programme.

A pre and post intervention mixed-methods evaluation was conducted to ensure fast-cycle learning and inform continued programme development. Pediatric QoL inventory tools (PedsQl-2, Family Impact Module) qualitatively assessed changes in family QoL. Wilcoxon signed-rank tests allowing for paired data were used to compare pre and post intervention scores.

Feasibility, acceptability and impact on family QoL were evaluated using small group and individual in-depth interviews amongst recruited care-givers, programme facilitators and study staff.

RESULTS: QUANTITATIVE DATA
In total 35 infants were eligible to enter the programme and 28 completed the programme and evaluation (Figure 1). Table 1 describes baseline characteristics of study infants. Total PedsQl score significantly increased post-intervention. Significant improvements in QoL were seen in emotional functioning, worry, physical functioning and communication (Table 2).

Figure 1: Flow chart of study Participants

Table 1: Basic demographics and clinical characteristics of study participants (n=28)

<table>
<thead>
<tr>
<th>Subscore</th>
<th>Post-EI programme assessment</th>
<th>Pre-EI programme at recruitment</th>
</tr>
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<tbody>
<tr>
<td>Mean age at assessment (months) (standard deviation)</td>
<td>8.7 [7.0-10.0]</td>
<td>6.7 [5.5-7.9]</td>
</tr>
<tr>
<td>Mean attendance of programme (range)</td>
<td>8.7 [7.0-10.0]</td>
<td>8.7 [7.0-10.0]</td>
</tr>
<tr>
<td>Sex distribution (%): female (female), male (male)</td>
<td>12 females (43%), 5 male (57%)</td>
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</tr>
<tr>
<td>Median global DQ (IQR)</td>
<td>27.25 [15.5-75.1]</td>
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</tr>
<tr>
<td>Median Haemoglobin (g/L) [range]</td>
<td>134 [105-145]</td>
<td>134 [105-145]</td>
</tr>
<tr>
<td>EIP</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>MUAC &lt;11.5 cm, severe acute malnutrition (%)</td>
<td>13.9 [10.5-15.8]</td>
<td>13.9 [10.5-15.8]</td>
</tr>
<tr>
<td>MUAC &lt;12.5 cm, moderate acute malnutrition (%)</td>
<td>7.0%</td>
<td>7.0%</td>
</tr>
<tr>
<td>MUAC ≥12.5 cm, severe acute malnutrition (%)</td>
<td>0%</td>
<td>0%</td>
</tr>
</tbody>
</table>

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

“Some mothers describe facing stigma and social isolation.

Even my husband abandoned us. He said that he does not give birth to such hopeless children and he does not support us.

“My neighbour told me that I delivered a ghost so I better take it to the lake and throw him in there. I refused—me, I want my baby.”

“Experiences of the Early Intervention Programme:

“Meeting mothers of children with the same condition comforted us. We got to know we are not alone. We got the courage to work towards the wellbeing of our children. Whenever we would see one of the children achieve a certain milestone, we would say oh, let me also put in more effort.”

“We regretted the time we spent visiting witch doctors, pastors and blaming ourselves thinking we had a problem and that our children were night drinkers yet the problem could easily be understood.”

“It comforted us and changed our perceptions.”

“Experiences of the Early Intervention Programme:

“She was very floppy but since now she is growing a bit more firm. Even I thought the baby was bewitched but when I was taught, then I come to know what happened. I went home and explained to my husband. Now there is hope growing”

CONCLUSIONS
Evaluation of a facilitated, participatory EI programme for infants at high-risk of neurodevelopmental impairment showed significant improvements in family QoL, and was feasible and acceptable in this urban Ugandan facility based setting. Follow up is underway to assess the longer term impact of the EI programme and a randomised control study is planned.

REFERENCES

PROGRAMME DEVELOPMENT
Themes running throughout the programme
Promoting inclusive 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 caregivers through information sharing and peer support
Sharing maternal experiences, and particularly addressing stigma
Promoting the human rights of children with disability

Other programmes to be included in the future: social skills, communication, feeding, emotional

EXPERIENCES OF THE EARLY INTERVENTION PROGRAMME

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