Lifelong Care for Children with Chronic Conditions: Session 2

Re-imagining the Package of Care for Children Subgroup

June 25, 2021
Series objectives

• Share and get feedback on UNICEF’s working “Integrated Chronic Lifelong Care for Children and Adolescents” framework

• Present case studies on specific chronic conditions

• Draw lessons for broader programming and implementation
UNICEF’s Integrated Chronic Lifelong Care for Children and Adolescents Framework

• Chronic Conditions affecting Children and Adolescents: HIV, Diabetes, Rheumatic Heart Disease, Asthma, Disabilities, Sickle Cell Disease, Cancers, Hep B, Syphilis

• In contrast with high-income countries, Chronic Care for children and adolescents is a less-developed area in low-and-middle-income countries

• These countries have typically focused on “episodic” management of common childhood illnesses that significantly contribute to child mortality

• With shifting epidemiologies, in part due to improving economies and gains in child mortality; and with UNICEFs focus on a survive, thrive and transform agenda, chronic conditions come more into focus
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Global Communities
Botswana

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Senior Pediatrician, KATH
Ghana

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Adjunct Professor, University of
Sydney Australia
Botswana Comprehensive Care and Support for Orphans and Vulnerable Children Project 2016 – 2022
Botswana Comprehensive Care and Support for OVC Project

Project Goal and Objectives

Strengthening community agency to seek, support, and provide HIV-related services to AGYW, OVC, and their families

**IR 1:** Strengthen household and community to support OVC and AGYW

**IR 2:** Increase uptake of HIV prevention, care, and treatment services among OVC households and AGYW

**IR 3:** Improve policy implementation for delivery of coordinated quality social service

**IR 4:** Strengthen capacity of local organisations to sustain program delivery and outcomes

**Priority sub-populations**

- Children and adolescents living with HIV
- HIV-exposed infants including infants of young mothers
- Vulnerable adolescent girls and young women
- Children of female sex workers
- Survivors of violence

**Children and adolescents**

- Living with HIV

**HIV-exposed infants**

- Including infants of young mothers

**Vulnerable adolescent girls and young women**

**Children of female sex workers**

**Survivors of violence**
Contributing to the clinical cascade for the chronic care of HIV+ OVC in Botswana

Providing linkages to HTS and ART treatment and monitoring retention and viral load suppression

OVC Project funded by:
Botswana Comprehensive Care and Support for OVC Project

OVCA Services

- Technical Support
- Case Management
- School-based intervention
- Group Activities

HEALTHY SERVICES
SCHOOLED SERVICES
STABLE SERVICES
SAFE SERVICES

USAID
PEPFAR
PCI
Botswana Comprehensive Care and Support for OVC Project

Geographic Locations

- OVC and AGYW services
- OVC services only
The HIV Management Approach

- **Approach used for client identification:** Referrals from clinics and community members, and through household assessments
- **Populations served:** HIV+ children, pregnant women, and HIV exposed infants
- **Model of delivery:** Household visits
- **Service providers:** Community Service Providers (CSPs)
Our partner Baylor University provides training and technical support for CSPs in children and adolescent HIV treatment management.

Baylor also runs a teen club model where HIV+ adolescents who know their HIV status meet regularly to support each other. They receive life skills training and group adherence counselling.
Identifying HIV+ clients during visits

1. CSP asks what client s/he knows about HIV and provides education where there are gaps.

2. CSP asks client their HIV status and when they had their most recent HIV test.

3. Where client is HIV+: CSP determines whether client is on treatment (if not, CSP links them to treatment) or is adhering to medication (supports viral load monitoring).

4. Where HIV-: CSP continues with HIV education and works with the client to develop prevention strategy including linkage to DREAMS for AGYW.

5. Where HIV status is unknown, CSP administers a risk assessment. Those at high risk for HIV are referred for HIV testing and followed up.
Duration of Care for HIV+ Children

1 year = 418
2 years = 313
3 years = 146

4 years = 212
5 years = 334
Total children = 1432
Duration of Care for HIV+ Children

Female Participation by Age and by Year

Male Participation by Age and by Year
Working towards the 95-95-95

Source: PCI Global Communities Botswana database

98% HIV+ children were retained on treatment each year over the last 3 years

Tracking of HIV retention amongst OVC over the past 3 years

- Total HIV Positive on ART
- Viral Load Tracked/Documented
- Viral Load Suppressed

<table>
<thead>
<tr>
<th></th>
<th>FY19</th>
<th>FY20</th>
<th>FY21 (6mths)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total HIV Positive on ART</td>
<td>957</td>
<td>1028</td>
<td>1102</td>
</tr>
<tr>
<td>Viral Load Tracked/Documented</td>
<td>891</td>
<td>1023</td>
<td>997</td>
</tr>
<tr>
<td>Viral Load Suppressed</td>
<td>880</td>
<td>988</td>
<td>996</td>
</tr>
</tbody>
</table>
Thank you
LIFELONG CARE OF CHRONIC DISEASE
SCD – CASE STUDY

BY
Vivian Paintsil MD
Senior Lecturer-KNUST, Senior Specialist Paediatrician KATH
Overview
Overview of the burden

- SCD is an inherited disease in which there is the inheritance of 2 abnormal Hb, one of which is Hb S
- Over 400,000 newborns screened since 1995
- In Ghana, about 1.8% of newborns have SCD
- Routine clinic attendance of about 150 a week
- Hydroxyurea treatment offered to patient
- Paediatric, Adolescent Clinic and transition clinic (Mondays, Tuesdays, Thursdays, Fridays)
- Hydroxyurea clinic on Fridays
Overview of SCD

- High Incidence of SCD - similar to most sub-Saharan African Countries
  - Est. 15,000 with SCD born annually
  - 56% SCD-SS; 1% SCD- $\alpha^+$ thal – Severe
  - 42% SCD-SC; - Moderate
  - 1% SCD- $\alpha^-$ thal - Mild

- Major contributor to under-five mortality (9-16%)
Overview

- Newborn Screening for SCD
  - *National Policy in place since 2011; very slow scale-up*
  - *Only 3% of newborn screened annually*
  - *Newborn with SCD provided penicillin prophylaxis and comprehensive care*

- Hydroxyurea offered to patients currently through a partnership with Novartis where patients get free HU.
Available guidelines

- Training for healthcare workers on hydroxyurea use
- Guidelines for hydroxyurea use
- Guidelines for managing SCD at the different referral levels also in the process of being field tested prior to roll out
Case study

- Name: BO
- Gender: Male
- Age: 15 yrs
- School: JHS 3
- School Performance: Currently not doing well
CS 2/6

- Was diagnosed by newborn screening which showed a possible SCD FS
- Parents tracked by the screening office and results disclosed to them
- Both parents have Hb AS
- BO is the last of 2 children.
- 1st is a girl with Hb AS
Patient’s 1st visit was at 4 mths of age and caregivers defaulted for their next appointment

Caregivers were educated and given Folic acid and Penicillin prophylaxis

Came back at 9 months of age with dactylitis and fever.

Admitted and managed and parents recounsellled and educated.

Improved adherence to clinic visits and compliance to medications thereafter

Patient managed severally on inpatient and OPD basis for varying degrees of Vaso-occlusive Pain events, hyperhaemolysis and recurrent infections.

Hb was always around 6 - 7g/dl
At age 8yrs, had a generalized tonic clonic seizure with weakness on the Right side of the body.

Power -0/5 on the Right LL and UL but 5/5 on the left UL and LL

Reflexes was reduced with reduced tone.

CT scan showed a left frontoparietal infarct

Imp: SCD – SS with CVA (Infarctive stroke)
Admitted and transfused
Continued on prophylactic medications
Started on physiotherapy – patient currently able to walk but with a hemiplegic gait
Issues identified
Low Hb – 6 – 7g/dl g/dl (Reluctance of parents to have transfusions)
Recurrent visits to hospital to pain episodes and loss of school hours
At 10 years of age, HU was introduced to the family
Had baseline labs done and started on 20mg/kg.
Dose Escalation done and currently on 30mg/kg
Recurrent pain episodes and absence from school all subsided.
Had episodes of staring gaze and tonic seizure.
Scans still showed the old infarct – chronic left frontoparietal infarct with associated atrophy
Seen by the neurologist and put on AEDs.
No seizures subsequently and doing well
<table>
<thead>
<tr>
<th>date</th>
<th>Hb g/dl</th>
<th>WBC</th>
<th>Neut</th>
<th>MCV</th>
<th>Plt</th>
<th>Retics %</th>
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<td>26/03/2021</td>
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<td>5.85</td>
<td>2.04</td>
<td>97.4</td>
<td>261</td>
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<td>20/08/2020</td>
<td>9.4</td>
<td>6.98</td>
<td>3.18</td>
<td>91.5</td>
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<td>3.01</td>
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<td>07/05/2020</td>
<td>9.4</td>
<td>6.01</td>
<td>2.17</td>
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<td>8.0</td>
<td>7.82</td>
<td>3.22</td>
<td>82.8</td>
<td>523</td>
<td>6.59</td>
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<tr>
<td>02/2018</td>
<td>7.9</td>
<td>10.3</td>
<td>4.48</td>
<td>82.9</td>
<td>367</td>
<td>3.5</td>
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<td>01/2017</td>
<td>7.7</td>
<td>10.6</td>
<td>6.56</td>
<td>86.8</td>
<td>298</td>
<td>6.9</td>
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<td>04/2016</td>
<td>7.4</td>
<td>8.9</td>
<td>3.68</td>
<td>80.8</td>
<td>471</td>
<td>4.9</td>
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<tr>
<td>02/2015</td>
<td>6.3</td>
<td>9.2</td>
<td>3.17</td>
<td>78.5</td>
<td>513</td>
<td>3.17</td>
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</table>
Learning points/Implementation

- Importance of NBS program. This is not fully accessible for everyone in Ghana. 3% of population can access it
- Importance of enrolment in an SCD clinic for comprehensive care
- Patient / parents education is key for success of management
- Availability of prophylactic medications – folic acid, Pen V
- Availability of disease modifying medications – Hydroxyurea and other newer ones - NHIS
- Availability of facilities for screening – TCD, ECHO, Urine R/E,
- Support for mental health issues
- Management of acute and chronic complications – Guidelines
Acknowledgements

- Patient BO and family
- KATH SCD management team members
Child Health Task Force
18th June, 2021
Dr Graham Ogle
Challenge of diabetes in children

- Mainly type 1 – autoimmune
- Quickly die without treatment
- Requires
  - insulin injections at least twice per day
  - Fingerprick blood glucose tests
  - HbA1c testing
  - Diabetes education
  - Expert care
- Tightrope each day
- Risk of life-threatening acute complications
- Social implications
Many cases die before diagnosis

Many others die quickly of ketoacidosis or hypoglycaemia

Others develop early and devastating complications

1.1 million children and adolescents have type 1 diabetes

Around 300,000 of these are in great need of help
Mali

• 1999 publication (Sidibé et al.) + follow-up data:

18 of 20 children with type 1 died within three years
Full provision of insulin by Government for children <15 years

<table>
<thead>
<tr>
<th>Income Group</th>
<th>% of countries</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low Income (n=19)</td>
<td>0.0%</td>
</tr>
<tr>
<td>Lower-middle Income</td>
<td>10.5%</td>
</tr>
<tr>
<td>Upper-middle income</td>
<td>57.1%</td>
</tr>
<tr>
<td>High income (n=20)</td>
<td>95.0%</td>
</tr>
</tbody>
</table>

Full provision by Govt. of 2+ blood glucose strips per day for children <15 years

Income Group

% of countries

0% 20% 40% 60% 80% 100%

Low Income (n=19) 0.0%
Lower-middle Income (n=18) 0.0%
Upper-middle income (n=14) 35.7%
High income (n=20) 90.0%

(After a period of illness when I was seven) I was finally labelled with type 1 diabetes. Me and my family literally felt shattered. Life stood still.

There came a time, when I along with my family started praying to God to put a full stop to my life. My family is not financially strong, on top of that expenses on insulin injections, meters and strips, lancets, and managing hypoglycemia.

Shirin, age 17, India
Life for a Child Program

• **Commenced** 2000

• **Vision** *No child should die of diabetes*

• **Mission**
  Support the provision of the best possible health care, given local circumstances, to all children and youth (under 26 years of age) with diabetes in less-resourced countries, **through the strengthening of diabetes services in these countries.**

• Conduct clinical research and international advocacy, and where possible help both young adults and also recipient countries with **achieving sustainability.**
2021 Life for a Child Program – Over 23,000 children in 42 countries
Major Partners and Donors

• Diabetes NSW & ACT
• Leona M and Harry B Helmsley Charitable Trust
• JDRF
• Diabetes Australia

• Direct Relief
• ISPAD
• Insulin for Life
• International Diabetes Federation

• Eli Lilly and Lilly Foundation
• Becton Dickinson
• Siemens Healthineers
• LifeScan
• Trividia Health

• Many individual donors
Other Partners

- Children’s Hospital Oakland Research Institute
- University of Pittsburgh
- University of Sydney
- University of Florida
- London School of Hygiene and Tropical Medicine
- Marjorie’s Fund
- Team Type 1
- Barbara Davis Center
- Orbis International
- McGill University
- Caring and Living as Neighbours (CLAN)
Support

- Insulin and syringes
- Meters and strips
- HbA1c

- Training of health professionals
- Diabetes education

- Complications screening
- Assistance with transport costs, communications
- Capacity building
- Technical advice and mentoring
- Research
- Diabetes camps
Process

• Assist diabetes centres caring for children

• Request received, bona fides assessed, questionnaire sent

• Questionnaire reviewed, priorities (e.g. insulin, monitoring, HbA1c, education) are identified

• Joint decision made to support a specific list of the most needy children with specific costed supplies +/- funds, according to a pre-agreed budget

• MOU signed with requirement for clinical and financial feedback

• Ongoing monitoring and evaluation
Mali

• 1999 publication (Sidibé et al.) + follow-up data: 18 of 20 children with type 1 died within three years

• Since 2007, numbers <26 years of age have grown from 14 to >650
Mali – diagnoses per year

[Bar graph showing the number of cases in Mali per year for different age groups (Cases < 15 years, Cases < 20 years, Cases < 25 years).]

Sandy, Besançon et al. Pediatric Diabetes 2021
2013 awareness campaign
1,600 posters distributed
It was when I was in Primary School and 12 years old that it started and it was just like a joke. It started coming through urine until it became very critical........

After some months in that hospital, they taught me how to inject myself and immediately I learnt that, we went back home.

Awayo, aged 17, Nigeria
Moseka & her friends

French (DR Congo)

also:

English
Bahasa (Indonesian)
Swahili
Nepali

Kinyarwanda
<table>
<thead>
<tr>
<th>Language</th>
<th>Language</th>
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<tbody>
<tr>
<td>Amharic</td>
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<td>Bangla</td>
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<td>Fransais</td>
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<td>Kinyarwanda</td>
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<td>Marathi</td>
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<td>Tamil</td>
<td>Sindhi</td>
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<td>Tagalog</td>
<td>Swahili</td>
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<tr>
<td>Urdu</td>
<td>Tiếng Việt</td>
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Life for a Child / ISPAD Pocketbook Guidelines
Tanzanian Diabetes Youth Alliance (TDYA)
Importance of blood glucose control

Key metric – HbA1c. Measured every 3-4 months

• Target is <7.5%
Complications Rates

Estimated from Pittsburgh EDC data

Research Article

Incidence and Mortality Rates and Clinical Characteristics of Type 1 Diabetes among Children and Young Adults in Cochabamba, Bolivia

Elizabeth Duarte Gómez, Gabriel Andrew Gregory, Miriam Castrati Nostas, Angela Christine Middlehurst, Alicia Josephine Jenkins, and Graham David Ogle

1Centre Vive con Diabetes, Av. Simón Lépez, No. 375, Cochabamba, Bolivia
2International Diabetes Federation Life for a Child Program, Gabe, NSW 2037, Australia
3NSMRC Clinical Trials Centre, University of Sydney, Sydney, NSW 2006, Australia
4Diabetes NSW, Gabe, NSW 2037, Australia

Providing quality care for children and adolescents with diabetes from lower-income families in Mexico

María Elena Mota-Oropeza, Hannah Elizabeth Bartley, Norma Daniela Hernández-Pérez, Arelly Gutiérrez Lara, Nancy Alejandro Vázquez-López, María Francisca Flores, Maríana Marroquín Velázquez, María José Castañeda-Saldivar, Angela Christine Middlehurst, Alicia Josephine Jenkins and Graham David Ogle

Abstract

0.0–2.0 years), with a mean ± SD subject age at check-up of 13.3 ± 4.3 years. Of the TID subjects, 10%, 6.7%, 13.7% and 78.6% were receiving 1, 2, 3 and ≥4 insulin injections/
US data courtesy T1D Exchange
Bolivia data: Duarte-Gómez, Gregory et al. J Diab Res
Mexico data: Mota-Oropeza, Bartley et al. J Ped Endocrinol Metab 2019
Mean HbA1cs in LFAC centres

Mean HbA1c (%) 2018 - 2019

[Bar chart showing mean HbA1c levels in various countries]
<table>
<thead>
<tr>
<th>Tier</th>
<th>Level</th>
<th>Insulin</th>
<th>Blood glucose monitoring</th>
<th>HbA1c</th>
<th>Complications screening</th>
<th>Diabetes education and team care</th>
<th>Intra-clinic range of clinic mean HbA1c</th>
<th>Mortality and Complications</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Minimal Care</td>
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<td></td>
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</tr>
<tr>
<td></td>
<td>1A</td>
<td>Human premixed insulin only, twice daily injections</td>
<td>Only at clinic</td>
<td>None</td>
<td>None /just weight</td>
<td>Minimal or no diabetes education. Care from general physician or paediatrician.</td>
<td>12.0-14.0% (108-130 mmol/mol)</td>
<td>High mortality from misdiagnosis and acute complications. Serious early-onset long-term complications very common in survivors</td>
</tr>
<tr>
<td></td>
<td>1B</td>
<td>Human premixed insulin only, twice daily injections</td>
<td>1-2 tests / day</td>
<td>Done in lab or point-of-care</td>
<td>Weight, height, blood pressure, visual acuity and light touch</td>
<td>Some diabetes education. Care by adult diabetologist or paediatrician.</td>
<td>9.5-12.0% (80-108 mmol/mol)</td>
<td>Substantial mortality, serious early-onset long-term complications common</td>
</tr>
<tr>
<td></td>
<td>1C</td>
<td>Human short- and long-acting insulin, twice daily injections</td>
<td>2-3 tests / day</td>
<td>Point-of-care</td>
<td>Weight, height, blood pressure, eyes, feet, urinary albumin, creatinine, lipids. Treatment as indicated. Access to glucagon if possible.</td>
<td>Education about insulin dose adjustments.</td>
<td>9.0-10.5% (75-91 mmol/mol)</td>
<td>Infrequent mortality, serious long-term complications rare unless less-than-optimal blood glucose control.</td>
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<tr>
<td></td>
<td>Intermediate Care</td>
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<td></td>
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<tr>
<td></td>
<td>2A</td>
<td>Human insulin, multiple daily injections (&quot;basal bolus regimen&quot;)</td>
<td>4+ tests / day</td>
<td>Point-of-care</td>
<td>Full complications screening – including all above plus fundal photography, thyroid, coeliac – at frequency according to guidelines.</td>
<td>Diabetes education appropriate for age. Care by paediatric or adult diabetologist, nurse educator, dietitian and social worker if possible. Diabetes camps. Peer &amp; school support. 24-hour emergency call service.</td>
<td>8.0-9.5% (64-80 mmol/mol)</td>
<td>Mortality very rare, long-term complications long-delayed or prevented entirely except if blood glucose control is suboptimal</td>
</tr>
<tr>
<td></td>
<td>2B</td>
<td>Human insulin, basal bolus regimen +/- insulin pens</td>
<td>5+ tests / day</td>
<td>Point-of-care</td>
<td>Treatment as indicated. Access to glucagon.</td>
<td>Diabetes education appropriate for age. Multidisciplinary team with paediatric diabetologist, nurse educator, dietitian, social worker, psychologist. Diabetes camps. Peer &amp; school support. 24-hour emergency call service.</td>
<td>6.5-8.5% (48-69 mmol/mol)</td>
<td>Mortality very rare, long-term complications long-delayed or prevented entirely except if blood glucose control is suboptimal</td>
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<td>Comprehensive Care (ISPAD Guidelines)</td>
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<td>3A</td>
<td>Analog insulin, basal bolus regimen, insulin pens</td>
<td>Continuous glucose monitoring (CGM) + consumables</td>
<td>Point-of-care</td>
<td>Continuous glucose monitoring (CGM) + consumables</td>
<td>Continuous glucose monitoring (CGM) + consumables</td>
<td>Continuous glucose monitoring (CGM) + consumables</td>
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<td>3B</td>
<td>Insulin pump + consumables</td>
<td>Artificial pancreas + consumables</td>
<td>Continuous glucose monitoring (CGM) + consumables</td>
<td>Continuous glucose monitoring (CGM) + consumables</td>
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<td>Insulin pump + consumables</td>
<td>Artificial pancreas + consumables</td>
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<td>Continuous glucose monitoring (CGM) + consumables</td>
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</tbody>
</table>

*Ogle, von Oettingen, Middlehurst, Hanas, Orchard. Pediatric Diabetes 2018;20:95-98*
Complications Rates

Estimated from Pittsburgh EDC data

30 Year Country Survival Rates

## Cost of a Healthy Life Year as a percentage of country GDP

<table>
<thead>
<tr>
<th>Countries</th>
<th>HLYs per individual (minimal/intermediate care)</th>
<th>Cost of HLYs gained as % GDP/capita (minimal/intermediate care)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mali</td>
<td>12.4/21.1</td>
<td>141.1%</td>
</tr>
<tr>
<td>Tanzania</td>
<td>14.0/22.0</td>
<td>110.0%</td>
</tr>
<tr>
<td>Pakistan</td>
<td>19.3/24.9</td>
<td>52.3%</td>
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<tr>
<td>Sri Lanka</td>
<td>20.3/25.7</td>
<td>41.8%</td>
</tr>
<tr>
<td>Bolivia</td>
<td>17.1/24.4</td>
<td>17.0%</td>
</tr>
<tr>
<td>Azerbaijan</td>
<td>22.5/26.5</td>
<td>15.6%</td>
</tr>
</tbody>
</table>

as per the approach used in the WHO CHOICE framework

*Gregory, Guo et al. Pediatric Diabetes 2020*
Know the numbers – e.g. Uzbekistan

female > male
5.6% annualised increase

Key components

• Build on what is there – local champions
• Engage Ministry of Health as much as possible
• Build expertise through a hub and spoke model
• Education – of children and their families, and health professions is critical
• Flexible approach

• Monitoring outcomes
• Internal and external evaluation
• Partner and network with other groups, pharma, and academic centres – expertise and supplies

• Collect data for health planning and advocacy
• Encourage governments to provide cost-effective care
Expansion: “Vision 2030”

Ten years 2021-2030:
• Number of children and youth helped: 23,000 to 150,000+
• Number of countries helped: 43 to 65+

• Expand footprint in large countries
• Help in ‘new’ countries
• Deepen support in all countries helped – education, training, quality of care, research, advocacy

• Supported by Eli Lilly, the Helmsley Charitable Trust, JDRF, and other donors
Leonard Thompson, Toronto, 1921-22, aged 14
For no child should die of diabetes
Engage with the co-chairs:

- Cara Endyke Doran - cendykedoran@globalcommunities.org
- Raoul Bermejo - rbermejo@unicef.org

Series Dates & Case Study Discussions:

**May 14th:** Congenital heart disease
**June 25th:** HIV, type 1 diabetes & sickle cell disease
**July 9th:** Integrated NCD package of services

**Time:** 9 - 10:30am EDT [GMT-4]

Check out the Child Health Task Force Website for important resources!

Subgroup information, recordings and presentations from previous webinars are available on the subgroup page of the Child Health Task Force website: www.childhealhttaskforce.org/subgroups/expansion

Become a member of the subgroup: www.childhealhttaskforce.org/subscribe