Assessing Capacity to Improve Pediatric Care Transitions in Low-income Countries

Global Alliance on Disability and Healthcare Innovation - Children and Adolescents

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Background

- An estimated 15% of the global population is living with a disability, 80% of which lives in developing countries with inadequate access to healthcare services.1 Children share a disproportionate burden and comprise one-third of the world’s population with a disability.2
- In February 2017 the World Health Organization (WHO) hosted Rehabilitation 2030: A Call for Action, an international stakeholder meeting to coordinate and strengthen rehabilitation in health systems of low and middle income countries (LMICs) in order to address this unmet need and improve quality of life.3
- In LMICs, approximately 85% of children will have a surgically treatable condition by the age of 15 years. Many of these surgical conditions carry the risk of lifelong disability, even if treated, and require proper follow-up and rehabilitation.1
- Children with disabilities (CwDs) are an especially vulnerable population, facing barriers to education and community integration. However, the Uganda Society for Disabled Children (USDC) estimates only 10% of children in Uganda have access to rehabilitative services due to expense, distance, and lack of perceived value.4

Objectives

- To conduct a comparative analysis of health system indicators, burden of disability, availability of rehabilitation services, and related national policies for school-aged children (ages 5-14) in the U.S. and Uganda.
- To assess availability of resources for school-aged children transitioning home after surgery in Uganda through a geographic information system (GIS) mapping study.
- To advocate for improved care coordination in low-income countries supporting school-aged children living with a disability.

Methodology

- Comparative Country Analysis: Data were extracted from the WHO health statistics database, the World Bank, and government websites to compare pediatric disability, rehabilitation, and community reintegration in the U.S. and Uganda. Based on sociocultural theory, the impact of disability was assessed at the levels of the individual, family system, health services, community, and society.
- GIS Mapping Study: Community-based resources were identified using public data sources, including Google and directories compiled by USDC, UNICEF’s research study on children with disabilities living in Uganda, and the Community Based Rehabilitation Africa Network (AfriCAN), between June and October 2016. These resources included rehabilitation services, assistive devices and technologies, social and family support services, and school re-entry programs. Geographic coordinates were determined using Google Maps and then mapped using ArcGIS software.

Results

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Key Findings of Comparative Country Analysis</th>
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<tbody>
<tr>
<td>Population ages 0-14 (% of total, 2013)</td>
<td>Global Average</td>
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<tr>
<td>31%</td>
<td>48%</td>
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</tbody>
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Top 3 leading causes of DALYs (ages 5-14, 2014) | Diarrhea/LRI/Other non-communicable, nutritional deficiencies | Diarrhea/LRI/other, HIV/AIDS & tuberculosis, NTD & malaria | Other non-communicable, nutritional deficiencies, mental & substance abuse |
| 5.1% | 13% | 6.1% |

Children with any disability (% of population ages 0-15, 2014) | Distribution highest in Northern region |
| 5.0% | 5.1% |

Children without disability that complete primary school | Individuals with Disabilities Act (IDEA) of 1975: all children ages 3-21 will be provided a free and appropriate public education |
| 72.3% | 92%

Children with disability that complete primary school | 99%

Children with access to rehabilitative services | Global estimate not available |
| 10.0% |

National Guidelines for Rehabilitation Aged Staffing in Hospitals | -2 OTs per 10,000 people (UK DoH recommends 1.6 OTs per 10 beds for stroke rehabilitation) -Rehab management community of British Columbia suggests 1 PT per 75 hospital beds (DoH) |
| No national guidelines exist, but the estimated national Health Human Resource ratio is 6.2 PTs per 10,000 people |

Specialist surgical workforce (per 100,000 population) | 30.6% |
| 64.6% |

Physical therapy workforce (estimated total) | 1,397,922 |
| 198,668 |

Out of pocket payment for health (% of total expenditure on health) | 18.2% |
| 42% |

Total Health Expenditure (% of GDP) | 9.3% |
| 7.2% |

Ministry focused on advocating for vulnerable populations | Ministry of Gender, Labor, and Social Development (MOLSD), Uganda Society for Disabled Children (USDC) |
| Office of Disability Employment Policy (ODEP) and Office of Special Care Act (OSCEP) |

| Americans with Disabilities Act (1990), Rehabilitation Act of 1973 |

National Translational Care Policy | None |
| Established by the Affordable Care Act (2010) |

Note: - DALY = Disability Adjusted Life Years. - LRI = Lower respiratory infection. - NTD = Neglected tropical disease.

Conclusions

- In Uganda, the rights and representation of PwDs and CwDs have been made a higher priority in the last two decades.
- Additional resources are needed to improve access to post-surgical rehabilitation services in order to reduce the financial burden on households, promote school and community integration, and enhance quality of life.
- The Northern region of Uganda represents both the area with the highest prevalence of child disability (data not shown) and the least access to rehabilitative services.
- Improving coordination and increasing availability of post-surgical rehabilitation services for school-aged children in order to match the geographic distribution of need could be a cost-effective approach to improve long term health and societal outcomes.

Next Steps

- Conduct stakeholder interviews to identify barriers within the transition from acute to community-based care school-aged children with disability in Uganda.
- Disseminate GIS map to stakeholders in Uganda to better allocate rehabilitation resources for school-aged children.
- APTA members could play an important role in the discussion of promoting quality and coordination of acute and community based rehabilitation in order to address physical disability among school-aged children in low income countries like Uganda.

References:

- Therapy; = Persons with Disabilities.
- Ekeji
- Additional resources
- per 10,000 people
- Physical
- have been
- PT = Physical Therapy.
- = Department of Health.
- School
- CRC = Convention on Rights of the Child.
- United States
- USDC, UNICEF’s research study on children with disabilities living in Uganda, and the Community Based Rehabilitation Africa Network (AfriCAN), between June and October 2016. These resources included rehabilitation services, assistive devices and technologies, social and family support services, and school re-entry programs. Geographic coordinates were determined using Google Maps and then mapped using ArcGIS software.

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