Serving Children with Disabilities

Formative Assessment Report

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September 24, 2016

Acknowledgements:

Funding provided by the Children in Families Initiative, GHR Foundation. We would like to especially acknowledge Ashley Johnson for her support in the desk review. Catholic Relief Services, Zambia staff Katie Juanario and Patience Vilinga for providing the foundation of the work happening in Catholic institutions, providing contact names, assisting with organizing lodging and ground transportation and interest in collaboration. We thank the many community organizations, non-governmental and governmental entities that spent time discussing the conditions, challenges and opportunities for children with disabilities in Zambia. Finally, we thank the families and community members who opened up the homes and life stories for us to better understand the conditions of children with disabilities. We hope that our future efforts help support families and children while addressing the significant areas of need.

Background – Desk Review Summary

> "Disability is defined as a physical, mental, or psychological condition that limits a person's activities. Traditionally the model of disability was established solely on one's ability to function and interventions included medical rehabilitation and provision of social assistance. Current models encompass an individual's physical, cultural, and policy environments."[1]

Children with disabilities are among the most hidden populations in many countries, bearing the consequences of stigma, poverty and neglect, and Zambia is not an exception.[2] In 2010, the prevalence of disability was 2.1% overall, including 0.4% for children ages 0-14.[3] However, preliminary results from a recent national survey undertaken by the Zambian Government, Community Development Mother and Child Health Division, indicated a prevalence of disability between 7.2-13.0% of the whole population.[4] Yet, children and youth living with disabilities in community or institutional settings are undercounted leaving inaccurate prevalence estimates necessary for prevention, intervention and ancillary services. Some of the following information is specific to children; however, not all of the various aspects related to life with disability were available for children only. In those cases, information is provided for children and adults with disability.

According to the 2010 Zambian Census, the most common categories of disability are physical disabilities, partially sighted, hard of hearing and mentally ill.[3] See appendix for description by category, sex, age and education. The primary causes of disability in Zambia include malnutrition, injury, infectious disease, congenital birth anomalies and other anomalies during childbirth, and non-infectious disease.[5] The most common cause of disability is due to infectious and non-infectious diseases, accounting for 38.9% of the total disabled population.[6] There are many consequences of disability in childhood and adulthood. The consequences include, but are not limited to, isolation and stigma, poverty, co-morbidities and secondary disability, limited opportunity to participate in society (e.g. school, work, civil society) and early death.

Children with disabilities are found in community and institutional settings. Contrarily, institutions are another place where children and their conditions are hidden. Approximately 1/3 of children in institutions are children with disabilities.[4] There are roughly 170 institutions in Zambia. Children are placed in institutional care for many reasons. First, the high degree of stigmatization and social exclusion of the children with disabilities and their families often leaves families with few options.[4,7] There are limited supports for families caring for children with disabilities such as adequate transportation, access to adaptive education resources and social services.[7] For example, parents who have a child with a disability may have to forgo work to care for the child resulting in economic hardship for the family. The combination of stigma, lack of adequate transportation, poor educational opportunities, lost income and poor social service support forces families to make difficult decisions about the care of their child with

disabilities. Another reason for institutionalization is a belief in the medical model of disability, meaning children with disabilities can only be cared for by trained professionals. Unfortunately, there is limited interest in foster care or adopting children with disabilities (if parents forgo their rights),[4] thus children spend their lives in institutions. The life in institutions is not always kind - children with disabilities living in institutions are at higher risk for neglect and abuse[7] and may only be given the most basic care from caregivers with little training on feeding, nutrition and development.

There is a significant gap between the need for services and services that are available. The top five areas of expressed service needs by persons with disability in 2011 (percentage of the total number of people with disabilities who expressed a need for the service) were healthcare (76.7%), medical rehabilitation (63.2%), welfare services (62.6%), assistive devices (57.3%), and counseling (51.2%). The proportion who expressed a need and received such services was healthcare (79.3%), medical rehabilitation (37.5%), welfare services (8.4%), assistive devices (18.4%), and counseling (14.3%).[2] Educational services was an expressed need by 47% and a met need for 17.8% of the disabled population.[2] Children with disabilities are growing up and entering the adult world of unmet service supports.

Community and family perceptions of disabilities and the barriers faced by families play an important role in the well-being of a child with disabilities remaining at home and engaged with community versus being either 'hidden' or placed in institutional care. A Master Thesis completed by Magnussen[8] provides a summary of barriers, beliefs and community interactions briefly described here.

> "The main barriers to health care are long distances, lack of available transport and shortage of staff, equipment and skills at the rural health centers to manage childhood disability. Referral to higher-level health facilities is done extensively, but is difficult for families to make use of. Parents become tired of trying to respond to episodes of illness and they consequently give up. Primary health care in Zambia is not able to provide adequate care for disabled children, and their health needs are therefore assessed and managed within a family unit strongly influenced by poverty."[8]

Community-held superstitions reinforce barriers for families. Families that have a child with disabilities often report visiting a traditional healer before reaching out to a healthcare provider. The traditional healer may view the disability as a bewitchment requiring herbal remedies or the releasing of the bewitchment (by cutting the skin with a razor blade). Bewitching is not the family's fault, but is brought on by someone in the community, perhaps a jealous neighbor. This type of treatment puts the child at risk of pain, infection and scarring and may further isolate the family if they believe their friends and neighbors bewitched their child. It also creates further isolation of the child as people fear contagion.

The educational system in Zambia is both an opportunity and a barrier. The governmental education system provides free primary schooling (7 years) for Zambian children, although not all children attend or attend beyond age 13 years.[i] The school experience and opportunities for children with disability are vastly different than children without disabilities. It is estimated that 24 % of children with disabilities have never attended schools compared to 9% of children without disabilities.[10] Estimates from Cheshire Homes indicate as many as 40% of children with disabilities have never attended schools.[11]

> "Many families and communities do not see the value of educating them; families that do want to send their disabled children to school face a range of physical and social barriers including a lack of accessibility, negative attitudes and few appropriately trained teachers."[11]

There are special education teachers being trained in country. From 1995–2008 a total of 605 teachers were awarded Diplomas in Special Education by the Zambian Institute of Special Education.[12] From 1990-2005 despite several governmental programs (Poverty Reduction Strategy Program, Program to Advance Girls' Education, Affirmative Action for Orphans and Vulnerable Children) special education for children with disabilities did not make significant improvements.[12] The proposed reasons for a lack of advancement in education for children with disabilities are greater focus on addressing the gender gap, an economic recession due to a decline in the copper market and the devastation due to HIV/AIDS.[12]

Despite challenges, there were some benefits to the additional teacher training in special education and community outreach that occurred. There were individual children and families who received support; community based rehabilitation was deemed feasible, with identified limitations; prevalence estimates of disability were more accurate; and the introduction of the idea of educating people with disability became part of the discourse in communities with a trained workforce to implement ideas. The approach to educating children with disabilities settled on creating specialized schools rather than integrating children with disabilities into existing classrooms. Teachers, however, expressed limitation in their training and reported that their training was limited to training in few types disabilities, was overly theoretical rather than practical and there were few resources available once in the field.[12] There was little incentive to continue teaching children with disabilities. Many specialist trained teachers preferred to become administrators as it was less demanding and more rewarding than teaching in the special education unit.[12] Approximately 5% of schools in the capital Lusaka areas have certified special education teachers compared with 1-2% in the other provinces.[12] No information was

[i] Parents must provide a uniform and supplies for their child to attend school which is a barrier for low-income families. Among all children in Zambia, few students graduate from primary education and move on to secondary education. Children begin leaving school around age 13. One contributing factor is that Zambia has a high rate of early pregnancy and child marriage, with 42% of women aged 20-24 years married by the age of 18 and 9% married by the age of 15. 9. UNICEF. *The State of the World's Children: Reimagining the future.* Geneva: UNICEF;2015. Approximately 3.7 million children who should be in school, but are not, is due to being involved in non-paid agricultural work to help family, working low paid jobs, or stay home without higher expectations from family.

found on children with disability success rates in schools with more special education teachers compared to schools with fewer special education teachers.

There is limited access to medical and ancillary services for families with children with disabilities, particularly in rural areas and low-income families throughout the country. [ii] Ninety-nine percent of urban households live within 5 km of health facility compared to only 50% of rural households.[14,iii] There is a severe shortage of healthcare workers in Zambia at all levels making access to specialty care for children with disabilities especially challenging. Despite this shortage of workers, there are efforts to increase the numbers of health oriented professionals in country. Occupational therapy education is just beginning in Lusaka; physiotherapy at the certificate, bachelor and master level are available; an intensive 2-year Master of Education in Speech, Language, and Communication Disorders at the University of Zambia; and several options for nutrition specialization, social work, nursing and public health.[iv]

National organizations and branches of government do exist to support persons with disabilities. Twelve organizations were identified whose mission it is to support children with disabilities and their families.[15] Governmentally, the Ministry of Community Development, Mother and Child Health (MCDMCH) is entrusted with formulating policy for people with disabilities. The Zambia Agency for Persons with Disabilities (ZAPD) has the responsibility to coordinate the implementation of the National Policy on Disability and acts as an advisory body to the Ministry. For the general population, *including* persons with disabilities, the Ministry Education, Science, Vocational Training and Early Education (MESVTEE) has responsibility for developing science and technology and for the provision of technical education and vocational training. In addition, the government does provide limited aid for those in need. For example,

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[ii] The medical care system Zambia's health system is based on decentralization. 13. World Health Organization. The Health System. *African Health Observatory* 2000; http://www.aho.afro.who.int/profiles_information/index.php/Zambia:The_Health_System. Accessed July 27, 2016.There are three levels of public health facilities: 1) hospitals (divided into primary (district), secondary (provincial), and tertiary (central) facilities); 2) health centers; and 3) health posts. 14. Ferrinho P, Siziya S, Goma F, Dussault G. The human resource for health situation in Zambia: Deficit and maldistribution. *Human resources for health.* 2011;9:30. There are 1327 healthcare facilities with 85% government, 9% private and 6% religious affiliated. 14. Ibid.

[iii] Health posts are intended to care for populations of 500 households or ~ 3,500 people. 14. Ferrinho P, Siziya S, Goma F, Dussault G. The human resource for health situation in Zambia: Deficit and maldistribution. *Human resources for health.* 2011;9:30.

[iv] Occupational therapy education is just beginning in Lusaka. The program of study is a Bachelor of Science, course duration is 5 years. There is a Zambia Society of Physiotherapy in Lusaka and they are members of the World Confederation of Physical Therapy since 1982 with 167 PT members. There are at least two programs, including a Bachelor of Science program, as well as a Master of Science in Physiotherapy in Orthopedics. There is an intensive 2-year Master of Education in Speech, Language, and Communication Disorders at the University of Zambia in Lusaka developed in partnership with Connective Link Among Special needs Programs (CLASP) International. They do work with children with disabilities in school systems. Nutrition is a growing field in Zambia, with two Universities offering 4-year degrees. The University of Zambia offers a Bachelor of Science degree in Human Nutrition and the Natural Resources Development College offers a degree in Food and Nutrition.

individuals who become disabled after working can receive a pension or lump payment if they meet disability criteria. Despite these supports and given the barriers for families in community, the responsibility of caring for and educating the children with disabilities largely falls on the family and community.

Formative Assessment

The formative assessment aimed to answer three fundamental questions. First, can the quality of life of children with disabilities living in institutions be improved? Second, what are the conditions of children with disabilities living in community? If excellent, how can those conditions be supported and expanded? If poor, how can the quality of life of children with disabilities and their families be improved? Third, are there effective strategies that can be implemented and disseminated nationally to assure good quality of life for children with disabilities?

The formative assessment was completed by an interprofessional team in June, 2016. Team members met with key informants and community leaders in rural and urban settings; conducted community assessment; interviewed six to ten families with a child with disabilities; assessed training and environmental support needed at two to four orphanages; met with policy makers to further understand current and future policy goals; and met with university educators to assess needs and capacity. The primary outcome/indicator was that the team demonstrated increased knowledge of the conditions of children with disabilities and found onsite readiness for change.

Seven team members were due to travel to Zambia June 19-25. One team member was unable to acquire a visa and did not arrive in Zambia. Planning meetings, emails and skype calls were used to arrange visits with families, community leaders, schools, institutions, nonprofit organizations, international non-governmental organizations, government institutions and academic settings. The team agreed upon broad questions to answer and SPOON team created a detailed document to be used as a guide for information gathering (see Appendix).

In the Appendix is a sample of the daily schedule, an example of one site meeting agenda and the daily meeting notes. The following represents the key findings.

Family level factors

- Many families are struggling to meet basic needs. This is more acute for families with children with disabilities if a caregiver needs to stay home with the child rather than earn money for food and shelter. Families may leave a child with disabilities locked in the home or alone in the yard to work.

- Many families either walk or rely on local transportation. A child with a disability can be carried only for a few years, and then becomes too heavy. The cost of the local transportation is too much to seek medical care, therapy or education.
- Parents feel isolated and lack social support.
- Parents feel shame and stigma. Parents may hide their child with disabilities in the home.
- Husbands are known to leave wives who bear a child with disabilities, particularly if early in marriage.
- Families do not have adequate skills and equipment to care for children with disabilities, particularly if they are significant.
- Some fathers were noted to leave or ignore a child with disabilities, placing further stress on the mother for caregiving and providing for the family. Men may feel that the child has no hope of contributing to the family or doing anything for him, so he either abandons the family (further stigma) or ignores the child.
- In some cases, parents are dead and the children are living with grandparents. This provides additional economic burden and the aging grandparent may not be physically able to care for the child depending on disability and/or provide food.

Community level factors

- The compounds and rural areas are quite poor, with low quality housing, communal latrines that are not handicap accessible, and poor road quality.
- Practice of isolation of children with disabilities and their families.
- The community belief in witchcraft, resulting in children being ignored and/or have the bewitching spell released from them through cutting.
- Elevated social risks due to poverty such as alcohol abuse and drug use in the community, further placing children at risk for disability.
- There continues to be a belief that if you have sex with a virgin or girl with disabilities (assume a virgin) that you can rid yourself of HIV. Safety is a big concern for girls in general, but especially those with disabilities.
- Other practices in the community include ‘huffing’. In one compound this particular practice among pregnant women resulted in a high number of stillborn children. It is not know the condition of children who survive, but they are at increased risk for disability.
- A belief was reported that drinking dark beer while pregnant will allow you to have a light skinned child. Alcohol consumption during pregnancy causes fetal alcohol syndrome.

Institutional (orphanages, schools, INGO, government) level factors:

- The access to rehabilitation services is unequal and difficult.
- There is limited availability to equipment.

- There is limited training or qualified care workers to support the complexities of caring for children with disabilities.
- Schools are generally poorly equipped to integrate children with disabilities.
- The education system does not offer a lot of support or opportunities, further reinforcing that the children do not have a valuable future.
- Limited training and resources in schools resulted in children classified as disabled at one school, thus placed in 'special education' were only in need of glasses.
- Schools are not accessible for wheelchairs or other assistive devices, including the outhouses.
- School staff are not trained in supporting feeding, adaptive writing equipment, etc.
- Many INGO and NGO programs are working towards family preservation, specifically related to economic development and support. However, no one is specifically focused on children with disability. However, they all agree it is an important and overlooked population. Some organizations reported that by not excluding children with disabilities they are somehow included.
- Concerns that many organizations are working in the area of family preservation but the organizations are not talking to each other so there is poor coordination of services.
- Depending on the institution, the focus and ability to address needs of children with disabilities varies wildly. Those that function as boarding schools do not provide support and training for families when the children are on break.
- No institution acknowledged having skills and training to address unique nutritional needs and any special feeding needs.
- There is training of professional at universities, but there seems to be a lack of teachers and mentors in the newer programs (OT), enough shortage of workforce that low skill professionals work alone in community settings (diploma PT); and there is limited continuing education and mentoring available in general.
- There is modest to low focus by the government on children with disabilities specifically.

Answers to three fundamental questions of the formative assessment

1. *Can the quality of life of children with disabilities living in institutions be improved?*

Institutions where children with disabilities reside can be improved. One important gap for these children is that staff lack resources and sufficient training on best practices for the care of children with disabilities. This need for training around feeding and nutrition was heard and observed in orphanages and schools. Providing adequate nutrition and rehabilitative strategies could significantly improve children with disabilities' quality of life.

2. *Second, what are the conditions of children with disabilities living in community? If excellent, how can those conditions be supported and expanded? If poor, how can the quality of life of children with disabilities and their families be improved?*

The conditions for children with disability in the community vary based on the type of disability. Regardless, children with disabilities and their parents living in the community face substantial stigma and isolation. We heard that parents who have a child with disabilities is at greater risk of spousal abandonment, has more difficulty seeking and keeping gainful employment and lacks social support by the community due to the belief that disability may be caused by witchcraft. Subsequently, parents make difficult choices – hide the child, discard the child, place the child in an institution, or risk deepening poverty. Not all families are faced with these decisions. Rehabilitation centers do exist – more so in the urban versus rural areas. Transportation becomes a barrier – both in terms of accessibility of the transportation, the size of the child, availability of equipment that supports mobility (i.e wheelchairs) and the amount of time it takes which further restricts employment. There are opportunities for children with disabilities to attend school. The barriers include school accessibility, transportation, recognition that the child should be educated and further training of educators.

There are many organizations working with children with disabilities and supporting families, but it appears the need outweighs the capacity. Other than alleviating poverty, the next most important factor to address is the perceptions and knowledge regarding disability at the family and community level.

3. *Third, are there effective strategies that can be implemented and disseminated nationally to assure good quality of life for children with disabilities?*

Community-based rehabilitation is operational in several areas in Zambia. The model used by one site includes an interprofessional team that provides services to children and families through outreach clinics and trained outreach workers. The approach not only brings services to families in the community, it provides an opportunity for children to reach their potential and has been effective in reducing stigma. There are existing organizations that have the structure to allow the replication of this approach, including the Catholic Medical Mission Board.

The communication between organizations and government departments is also being improved. The Children in Families Initiative seems to be a very effective approach for bringing key informants across levels of practice and policy to enhance care for children and families in need. In addition, there is a strong organization (Zambian Association of Child and Youth Care Workers) who have a system/infrastructure for networking, education and

mentoring. Finally, all the family, community, education, NGO and government representatives recognize the great need for children with disabilities and would like to be included in further discussions and have desire to engage with our team in the future.

Next Steps

We propose a two-pronged approach.

1) One important gap for these children is the lack of staff training and resources for working with children with disabilities. This need for training around feeding and nutrition was heard and observed in orphanages and schools. In addition, support around providing adequate nutrition and rehabilitative strategies could significantly improve their quality of life.

Therefore, we propose to address the immediate needs of children living with disabilities in institutional settings using a train-the-trainer approach for nutrition and feeding skills for children with disabilities living in institutions.

2) Stigma and isolation are important limiting factors for children with disabilities and their families. The community based rehabilitation model is an effective approach to "enhance the quality of life for children with disabilities and their families; meet their basic needs and ensure their inclusion and participation" in society (http://www.who.int/disabilities/cbr/en/).

Therefore, we propose to further strengthen relationships with existing organizations, children with disabilities and their families in Zambia to expand / enhance current models of community-based rehabilitation model.

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Address the immediate needs of children living with disabilities in institutional settings

SPOON Foundation, a member of the Serving Children with Disabilities team, has implemented feeding and nutrition trainings around the world. It is agreed and supported that SPOON be asked to initiate and implement a feeding and nutrition program in Zambia with partner institutions that serve children with disabilities. There are 16 sister run institutions that house children with disabilities.

Build relationship with existing organizations to establish a community based rehabilitation model.

Based on the desk review and formative assessment, a key area of intervention should focus on attitudes and knowledge related to children with disabilities. Addressing attitudes and knowledge has the potential to reduce stigma, thus opening the door for social support, services, and improved quality of life for children with disabilities. To do this work, a comprehensive, community based and partnership model must be in place.

Several steps are underway and need to occur for this goal to be successful. First, preliminary conversations are needed to explore a possible partnership. This conversation is underway

with Catholic Medical Mission Board as a potential key partner. Conversations will also be had with the Zambian Association of Child and Youth Workers as a second key partner. Second, more information is needed about community based rehabilitation and how it is established and implemented. Third, further detailed feedback is needed from children with disabilities, caregivers, community, schools and other stakeholders. And fourth, funding needs to be sought and secured, likely from several sources, to implement, monitor and evaluate any initiative. Table 1 shows a proposed timeline.

Table 1: Proposed timeline of activities for Serving Children with Disabilities: Phase II

Qtr/yr (1=J-M; 2=A-J; 3=J-S; 4=O-D)	Q4/16	Q1/17	Q2/17	Q3/17	Q4/17	Q1/18	Q2/18	Q3/18	Q4/18
SPOON assessment institutions									
SPOON train the trainer									
Institution M&E									
Skype conversations with CMMB									
Skype conversations with ZACYCW									
Meet with CMMB, ZACYCW in Zambia									
Develop Phase II proposal, submit									
Travel to Zambia for extended stay to observe CBR, ZACYCW, CMMB									
Photovoice and focus groups									
Synthesis, dissemination, planning									
Identify possible funding sources									

Address immediate needs in institutions
Relationships and CBR

References

1. Mont D. Measuring Disability Prevalence. Social Protection; 2007.
2. World Health Organization, The World Bank. *World Report on Disability.* Geneva: World Health Organization,;2011.
3. Central Statistics Office of Zambia. Zambia National Descriptive Population Tables. 2010; http://www.zamstats.gov.zm/nada/index.php/catalog/63. Accessed July 24, 2016.
4. Better Care Network. Disability and childcare reform. 2016; http://www.bettercarenetwork.org/sites/default/files/Disability%20and%20Child%20Care%20Reform.pdf
5. Central Statistics Office of Zambia. *2010 Census of Population and Housing: National Analytical Report.* Lusaka: Central Statistical Office;2012.
6. Disabled ZFot. *National Plan of Action (NPA) on Disability in Zambia.* 2008.
7. UNICEF. *Children With Disabilities.* UNICEF;2013.
8. Magnussen H. *Childhood disability in rural Zambia : a qualitative study on the use of health care services*: Department of Community Medicine, University of Oslo; 2011.
9. UNICEF. *The State of the World's Children: Reimagining the future.* Geneva: UNICEF;2015.
10. SINTEF. Living conditions among people with activity limiations in Zamiba. 2006; https://www.sintef.no/globalassets/upload/helse/levekar-og-tjenester/zambialcweb.pdf.
11. Leonard Cheshire Disability. Inclusive education in Zambia. 2016; https://www.leonardcheshire.org/international/inclusive-education/zambia-comic-relief.
12. Serpell R, Jere-Folotiya J. Basic education for children with special needs in Zambia: Progress and challenge in the translation of policy into practice. 2011; http://pds.sagepub.com/content/23/2/211.
13. World Health Organization. The Health System. *African Health Observatory* 2000; http://www.aho.afro.who.int/profiles_information/index.php/Zambia:The_Health_System. Accessed July 27, 2016.
14. Ferrinho P, Siziya S, Goma F, Dussault G. The human resource for health situation in Zambia: Deficit and maldistribution. *Human resources for health.* 2011;9:30.
15. International Labor Organization. Inclusion of people with disabilities in Zambia. 2013; http://www.ilo.org/wcmsp5/groups/public/---ed_emp/---ifp_skills/documents/publication/wcms_115100.pdf.

Appendix

Contents

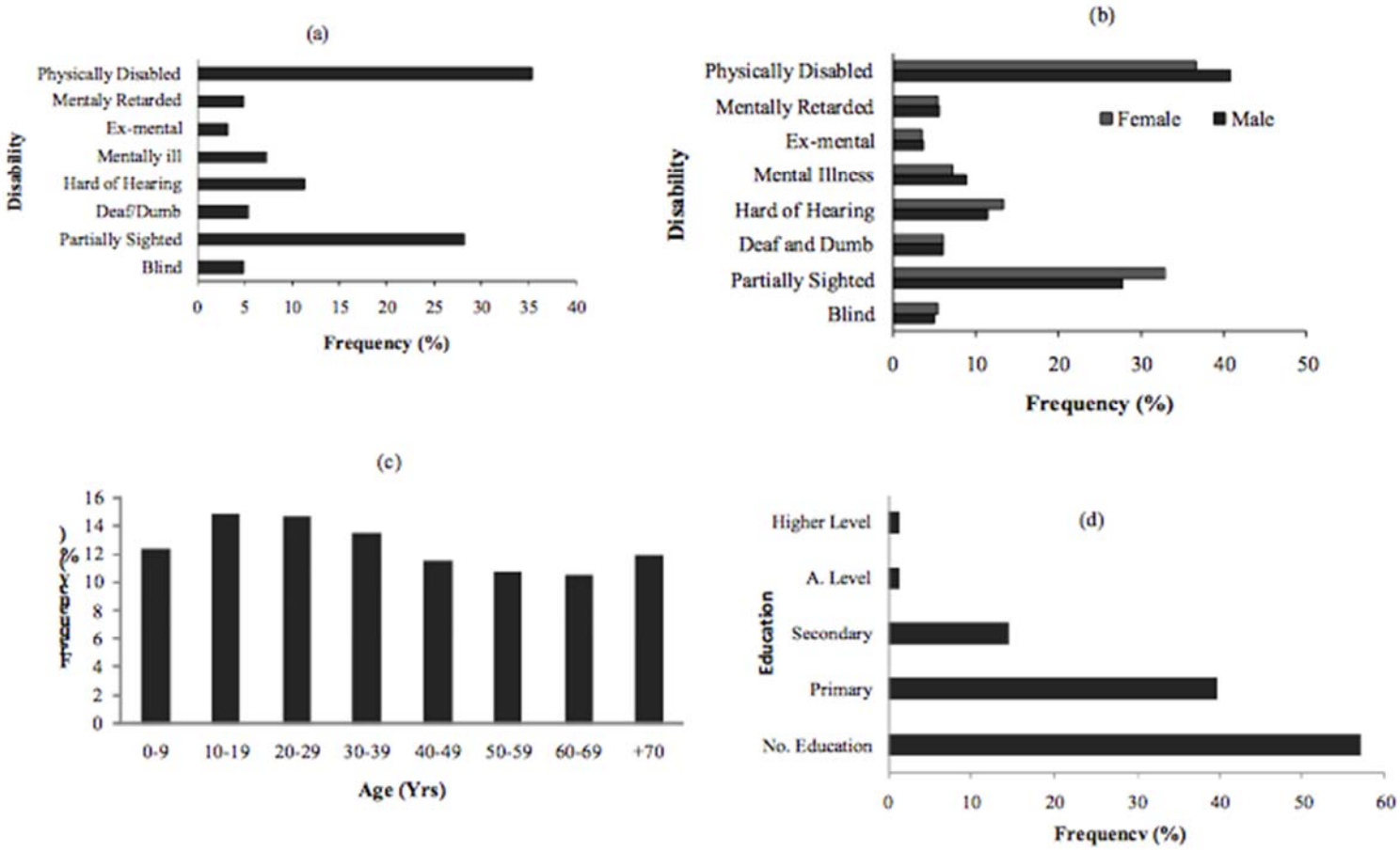

Figure 1. Disability by category, gender, age, and education group. Zambia National Census 2010

Notes from call with CRS April 2016

Background

Useful links:

http://www.ghrfoundation.org/news/category/zambia

http://www.ghrfoundation.org/children-in-families.html

Currently, Catholic Relief Services and UNICEF are doing an assessment of orphanages throughout the country, engaging institution leadership and communities. The intent was to both understand the care model of children living outside of parental care and the potential for de-institutionalization.

UNICEF is reviewing state run institutions (n~131). They are just starting.

CRS is reviewing institutions that are run by faith based organizations (n=39). Their data collection is complete. They are hosting a dissemination meeting June 28-29 with institution directors. They will be working on developing a multi-year proposal mid-July, submitting a grant to GHR by the end of August. They will be proposing to have some work aimed specifically at children with disabilities. We discussed finding ways to have synergy between our skill set and both of our intentions to support children with disabilities.

Additional notes about faith based institutions:

There are three types (???? – what are the three types) ranging from huge facilities to small houses. There are about 170 facilities with 5000-8000 children overall.

-Three types of care short term (transition: 3-7 years), long term, and reintegration. They seemed to like the Holy Family model with the parents coming and learning different techniques for children with disabilities care. Though they pointed out the lack of resources regarding food, shelter, and overall funding. With this model children can also return home with parents over the weekend.

Other details:

- Holy Family model: Parent coming and learning different techniques for CWD care. However, there is a lack of resources regarding food, shelter, and overall funding.
- Community-based approach
- Cheshire

- https://www.leonardcheshire.org/international/inclusive-education/zambia-comic-relief
- https://www.facebook.com/Cheshire-Homes-Society-of-Zambia-461991467237250/
- http://www.crosscatholic.org/uploads/0351_2013_2.pdf

- http://www.cbm.org/programmes/Cheshire-Community-Rehabilitation-Programme-300912.php

Dominique Muntanga is looking at the specific numbers of children with disabilities and the types of disabilities children have. They are unsure when he will be finished, but shows that there is very limited data regarding this.

http://abilitymagazine.com/Zambia.html

Thinking of institutions as such:

	CRS (faith)	UNICEF (public)
Short term (transition 3-7 yrs)		
Long term		
Re-integration		

The government is working to establish a national network focused on reintegration and family care. They are going to need a lot of support, strengthening skills of professionals. There is a consultation for review May 3-5. GHR is working with the Better Care Network. The report will come out the end of May/June.

BEFORE TRAVEL:

Recommend we connect with

- the Ministry of Community Development and Social Welfare (introduction – GHR will help with this)

- Zambian Association of Sisters (just a greeting, introduction, GHR will provide contact)

- Meet with CRS June 20

- Meet with Save the Children

-CMMB

-Bethany Christian Services

Logistics:

Hotel Protea (check for CRS discount)

Driving firm (CRS will connect)

Hi Mary,

So nice to talk with you and Ashley today. We will plan on meeting with you and your team on either June 20th or 21st. As mentioned, here are some of the contacts so you can plan your meetings and logistics. Please don't hesitate to reach out to Patience or myself with any questions- we can't promise we will have the answer but can hopefully lead to you the person who may. Just mention Patience and I when you reach out to any of the contacts below.

Hotel recommendations:

1. Protea Tower: Arcades Shopping and Entertainment Complex, Lusaka 50100, Zambia; Phone:+260 21 1254664

-This is the one we recommend due to its proximity to other restaurants and shopping areas- everything is within walking distance. It is also a SA chain, so they have great accommodations, breakfast is included and the spread is huge, 24 electricity and reliable internet.

2. Intercontinental: Haile Selassie Ave, Lusaka, Zambia, Phone:+260 21 1250000

-This is another hotel we use a lot. As mentioned they have a convention center and restaurants on the property but it really isn't within walking distance to anything on the outside. It does have the same standards/benefits as above.

Transport:

CRS uses Cubit for any taxi transport outside of our own fleet. http://www.cubitgroup.org/transport.php

CRS has a company rate that we may be able to give to your group as well.

UNICEF:

Maud Droogleever Fortuyn

Chief Child Protection

UNICEF Zambia

Mobile: +260 978 778 153

Email: mdfortuyn@unicef.org

Dominic is working on a dialogue around education for children with special needs.

|Dominic Muntanga | *Education Specialist*|
| UNICEF Zambia United Nations House, P.O. Box 33610 Lusaka, Zambia|

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Better Care Network- National Consultation on Child Care Reform in Zambia- May 4 – 6th

1. Lucy Hillier- consultant working with Ministry of Community Development Social Welfare (MCDSW) for the National meeting in May. She works out of Jo'burg. lucy.hillier@bettercarenetwork.org

2. Florence Martin is the director of BCN: Florence.martin@bettercarenetwork.org

University of Zambia (UNZA)

1. Benson Chisenga is the director of the National Association of Social Workers as well as faculty at UNZA benson.chisanga@unza.zm

We are working with a qualitative researcher from UNZA- Dr. Joseph Zulu is actually at the Dept of PH and also has a degree in social work. He happens to be at Johns Hopkins right now taking a course over the next couple of months. He could direct you to some other contacts at UNZA. Joseph Zulu josephmumbazulu@gmail.com; joseph.zulu@unza.zm

University of Zambia,
Health Promotion and Education Unit,
Dept. of Public Health,
School of Medicine,
Ridgeway Campus,
Box 50110,
Lusaka,

Zambia Needs Assessment

I. General

What are the major health statistics for the country?

Statistical Indicator	Value	Source
Total Population		
GDP per capita		
Life expectancy at birth (m/f) years		
Child mortality <5 (m/f)		
Infant mortality <1 (m/f)		
Adult mortality (m/f)		
Malnutrition (can include % <5 underweight for age, % <5 moderately or severely underweight)		
Vaccination coverage (can include % one-year-olds fully immunized against TB or measles)		
Physicians per 100,000 people		
Adult literacy (m/f)		

What is the population in the community?

Gender	<5 years	5 - 15 years	16 - 59 years	60+years	TOTAL POPULATION
Male					
Female					

Are there important practices, beliefs or gender issues which affect people's health? e.g breast feeding practices, delay in seeking medical attention or preference for traditional treatment for specific illnesses

Are there culturally sensitive issues or taboo subjects around health, CWD, or nutrition?

What percentage of CWD in Zambia are living in institutions?

Where are services for CWD located? Are they accessible to families with CWD?

II. Nutrition

Health/Nutrition Statistics:

Severe acute malnutrition (< -3 z-scores wasting and oedema) 6-59 months (disaggregated by age and gender if possible)

Global acute malnutrition (< -2 z-scores wasting and oedema) 6-59 months (disaggregated by age and gender if possible)

Health statistics:

- % oedema 6-59 months (disaggregated by age and gender if possible)
- % underweight (moderate + severe, severe) 6-59 months (disaggregated by age and gender if possible)
- % stunted 6-59 months (disaggregated by age and gender if possible)
- % infants with low birth weight
- % children 6-24 months with anaemia
- % vitamin A deficiency in children
- % of vitamin A coverage in children

What is the typical protocol for the treatment of severe malnutrition?

Availability of food:

% HH consuming adequately iodized salt

What are the **main foods** normally consumed in this area?

Number of meals and snacks eaten by adults and children

What are the **normal seasonal fluctuations** in food availability? Is there a time when food is less available?

How is food assistance funded? Is there government funding to purchase food? Who determines what is served?

Are there gender-based differences in access, use and/or consumption of food and does data analysis reveal gender-based nutritional differences?

Availability of food:

Specify the most commonly eaten foods for each:	**Currently available in the market:**	
Cereals:	**□ YES □ NO □ DNK**	
Roots and tubers:	**□ YES □ NO □ DNK**	
Pulses and legumes:	**□ YES □ NO □ DNK**	
Oils and fats:	**□ YES □ NO □ DNK**	

Meat, fish and eggs:	**□ YES □ NO □ DNK**	
Vegetables and fruits:	**□ YES □ NO □ DNK**	
Milk and cheese (dairy) foods:	**□ YES □ NO □ DNK**	
Commercial infant formula:	**□ YES □ NO □ DNK**	

Water/Sanitation:

What is the current drinking water source? What water source is used for bathing, washing clothes and other domestic use?
How much water is available per person per day, and do all groups (e.g. men, women, CWD etc.) have equitable access to it?

Who is involved in the management and maintenance of the water sources ?
Is the water source contaminated or at risk of contamination (microbiological and chemical/radiological)?

Please describe typical handwashing practices.

__ Before food preparation
__ Before feeding the children
__ After defecation
__ After attending to a child who has defecated.
__ Never

III. Schools/Institutions

Population of the Institution/School:

How many admissions to the institution/school do you have per year? How has this changed in the past 5 years?

Gender	0-12 months	12-24 months	2-5 years	5-15 years	15+ years	TOTAL POPULATION
Male						
Female						

What are the most common special needs and disabilities you see among admissions into your institution/school?

What are the contributing factors to CWD being institutionalized?

What is the HIV/AIDS prevalence for CWD/their parents? Is this a contributing factor to institutionalization?

Are there Foster Care options for children in the institutions?

What is the average and range of length of stay for children?

What are the reasons that children are usually discharged from the institution (adoption, foster care programs, transferred to a different facility, complete the program/schooling, etc.)?

What is the capacity for re-integration into the community for CWD currently living in institutions? Do Foster Care programs exist?

Are CWD integrated into classrooms and activities with typically developing children?

What are your thoughts regarding the capabilities and potential of children with disabilities? What is your primary goal when caring for children with disabilities?

Institution/School Staff:

Please describe the role and skill level of professionals (i.e., nurses, doctors, cooks, caregivers, teachers, other staff) in the institution/school.

Please describe prior (or ongoing) trainings for staff at the institution/school. Were they successful? Why or why not?

Please describe how staff are evaluated and who is responsible for their supervision.
In general, how long do staff stay in their roles (months, years)?

How are staff compensated for their work? (Government funding, private funding, food/transportation subsidies, other)
How are staff motivated to perform with high quality and provide best possible care?
Please list other partners or connections with whom staff partner or relate (health workers from the MoH, local hospitals, NGOs, etc).
Please describe communication between staff at the institution/school and government health workers.

Who is responsible for overseeing the feeding/nutrition/care/education of CWD?

Health of the children: (for institutions)

Do you believe that nutrition is better in the orphanage/school or in the community? Why do you feel this way?

What is the typical protocol for the treatment of severe malnutrition?

How are medical records kept and accessed?

Is growth monitoring performed at the institution?

Who is responsible for health data collection? How often is it collected?

How is health data collected and stored? Is health data required to be reported to MoH and if so, for what purposes?

How is health data reported?

Please describe any problems hindering the health data collection process.

Is health data used to improve services? If yes, how is health data used to improve health in the institution?
Has there been a nutrition survey performed in the institution within the last year?
If yes, what is the percentage of children under 5 years of age (less than 60 months) with severe malnutrition?
If yes, what is the percentage of children under 5 years of age (less than 60 months) with moderate malnutrition?

How does the institution handle cases of malnutrition?

Does the institution participate in government-sponsored programs on a regular basis (e.g. immunization campaigns, etc.)?
If yes, please describe the institution's involvement in these programs.
If no, please indicate why the institution does not participate in government-sponsored programs.

Are children with disabilities fed with adaptive equipment/ utensils? If yes, list available equipment/utensils.

Is there formula available for children with special needs?

What kinds of nutrition support would be most useful to your institution?

What are the greatest obstacles to introducing a training program for clinical staff?

IV. Government Policies

CWD Policies/Services:
What government services exist in the community for CWD?

What types of government policies protect the rights of CWD or PWD?

What types of funding are available for programs supporting CWD?

Examples of successful interventions for CWD and why you believe they succeeded.

What is the capacity for re-integration into the community for CWD currently living in institutions?

What systematic change is needed/possible for re-integration and/or improvement of quality of life for CWD?

What types of therapeutic equipment is available in the country? How do families, schools, and institutions access needed equipment?

Do all CWD attend school? Are they integrated into schools with typically developing children or do they attend separate schools? How are schools for CWD funded?

Nutrition and Health Interventions:

Is health data collected for CWD? If yes, how is data collected, how often is it collected, and what information is collected?

Define the nature, magnitude and causes of malnutrition and areas most affected and the vulnerable groups

Describe the nutritional needs of the population.

Please give examples of constraints to successful implementation of health interventions in the past. How are projects monitored and evaluated? What are some of the specific indicators that are evaluated? Who provides the monitoring and evaluation?

Existence and use of national and international nutrition policies and protocols (e.g., therapeutic and supplementary feeding, foods for PLWHA)

Availability of nutrition programs, RUTFs, cooking kits, vitamin A, multi-micronutrients, iron folate supplements, CSB or other supplementary foods, ORT/ORS, therapeutic milks

What are the current and/or threatened shocks to food security and nutritional status? (ex: drought) What are the expected impacts, and are there any programs planned to mitigate the impacts?

V. Training Programs/Universities

Please indicate what approach to schooling is preferred (on-the-job training, Classroom/Book Learning, other).
What types of degree programs exist, and what are the requirements/qualifications?

How many years do the programs take to complete? Is there a hands-on portion of the training?

How are these education programs funded?

What means are used to support/reinforce knowledge gained in training?

How are trainings usually administered? Are there any cultural norms around training?

VI. NGOs

Examples of successful health, nutrition, or CWD interventions and why you believe they succeeded.
How are CWD interventions funded?

Please give examples of constraints to successful implementation of interventions in the past.
What is the capacity for re-integration into the community for CWD currently living in institutions?

What systematic change is needed/possible for re-integration and/or improvement of quality of life for CWD?

Does the government support NGO's efforts to implement programs for CWD?

How are projects monitored and evaluated? What are some of the specific indicators that are evaluated? Who provides the monitoring and evaluation?

What services exist for CWD?

VII. Health Care System

What health services are available for CWD? e.g. hospital, clinic, temporary health post, outreach system, health promotion

Who provides the health services? e.g. the State, INGOs, local NGOs, church providers, traditional practitioners, private/commercial services

Is the health service provision adequate for the needs of CWD? e.g. accessible re. cost and distance, sufficient re. provision of trained staff, facilities,medicines, etc.

What kinds of health equipment and supplies are the hardest to obtain in country and why?

What types of therapeutic equipment is available in the country?
Which drugs are available/used by healthcare personnel for CWD?

What types of assistive technologies are available in the country?

What capacity do local health services have to provide treatment? Do local health services have access to medications, understanding supplements, infant formula, gastric and naso-gastric tube placement, TPN availability?

Are there any cultural issues that isolate people or groups of people (such as CWD) from health care services?

What specialists are available for children with disabilities? Are there dental services available? How do CWD access specialists?

What type of hospital services exist? How do CWD access hospital services, if needed?

Example of Day with community partner (CMMB)

Scene-Setter

Event: Assessment on children with disabilities living in community and institutional settings in Zambia

Date: 22nd June, 2016

Time: 08:30-13:00

Location: Lusaka District

Contact: Mrs. Batuke Walusiku-Mwewa, bwalusiku-mwewa@cmmb.org, Cell phone number +260 978 773067

Key participants:

CMMB

1. Country Director, Mrs. Batuke Walusiku-Mwewa
2. Operations Director, Mrs. Elizabeth Mushinda
3. Project Manager, Mrs. Esther Chileshe
4. Mobilization, Marketing and Comms. Director, CMMB

GRZ

1. Lusaka District Social Welfare
2. Chawama Hospital
3. Evangelical Fellowship of Zambia
4. Child Care Facility
5. Child and Youth Care
6. Family which has a child with disability

Host Partner- CMMB Zambia/Evangelical Fellowship of Zambia.

Scenario:

In the interest of time but also to beat traffic, EFZ and Lusaka Department of Social Welfare could come for a meeting at CMMB offices at 08:30. During the meeting, St Catherine University, Evangelical Fellowship of Zambia, Social Welfare and CMMB will share the general background and experiences in working with families that have children with disability and level the understanding on the assessment. Led by Social Welfare, the team will then visit two child care facilities that have children with disabilities. The team will also visit two families that have children with disability within the community and are currently working with the Kusamala Project trained Youth and Child Care Workers to learn more on their perceptions, experiences, causes and challenges.

Tentative Program:

St Catherine University -21st June, 2016		
Time	Activity	Lead
08:30-09:00	Meeting at CMMB offices	Batuke
09:30-10:00	Child Care Facility	Social Welfare
10:30:11:00	Child Care Facility	Social Welfare
11:30-12:00	Family Visit	Evangelical Fellowship of Zambia
12:00-13:00	Family Visit	Evangelical Fellowship of Zambia
13:30	Debriefing at Chawama Hospital, then departures.	

Zambia Itinerary	Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Contacts/Sites:
	June 19	June 20	June 21	June 22	June 23	June 24	June 25	Florence Martin/Director/Better Care Network (BCN)
Morning:	Group Arrival and Check-in	Team 1/ Mercy House , OM South Africa Makalulu - Monday 20 June 2016 - Anne Davidson (Contact nr: 0964721156) NEED TRANSPORT to Kabwe Dana, Donna, Paula	Team 1/ZACHW - Copperbelt: Renee and Maureen - MAY BE OVERNIGHT -NEED ADDITIONAL. Start 6 am Driver provided, pay gas	Team 1: RETURN - back by 1400	Team 1/Mumbwa Secondary School: Donna, Maureen CAR PROVIDED PAY GAS	Team 1/Nanga Primary School: Donna (All Day) CAR PROVIDED PAY GAS		Lucy Hiller/Better Care Network (BCN)
		Team 2: Maureen, Renee, Mary. CSO-SUN @ 10:30am. Offices are on Olympia, Chiwalamabwe Road http://www.csosun.org/index.php/contact-us. More about: http://www.csosun.org/index.php/about-us	Team 2/CMMB: Donna and Dana 8:30 start	Team 2 /Kabulonga Cheshire Home: Paula and Donna/Dana and Mary join later (10am-2pm)	Team 2/Holy Family: Paula, Dana	Team 2: Bethesda, Nakoli - Wednesday 22 June 2016 – Peter Chila [Contact nr: 0973910190] OM South Africa NEED TRANSPORT to Kabwe Mary	Team Meeting - Conference Room (All Day)	Eric Rosenthal/Disability Rights International (DRI)
		Team 3:	Team 3:Bethany: Offices (House of Moses) at 10:00am in Chelstone Need to get to meeting and then they will transport Paula and Mary	Team 3: /Ministry Meeting: Mary, Dana (?) (9:00am - 10:00) then to Kabulunga	Team 3/Save The Children: Renee, Mary (Office, Sites & Families?)	Team 3:	meet with World Vision sometime today	Lori Ahern/Disability Rights International (DRI)
								Agness Mumba/Exec. Director/Forum for African Women Educationalists of Zambia (FAWEZ)
Afternoon:	Team Meeting at Hotel	Team 1: Team 1/ Mercy House , Makalulu - Monday 20 June 2016 - Anne Davidson (Contact nr: 0964721156)	Team 1: ZACHW: Renee and Maureen	Team 1: Kabulonga Cheshire Home: Paula, Donna (10-2?)	Team 1: Mumbwa Secondary School: Zeina, Donna	Team 1: Nanga Primary School: Paula, Maureen, Renee (All Day)		Holy Family/Brother Robert Chakan and Brother Mweene
		Team 2: Renee, Mary, Maureen meet with Felix	Team 2/CMMB: Donna, Dana	Team 2 : 3:00 Paula to meet with Dr Khondowe about OT and PT	Team 2: Holy Family: Paula, Renee	Team 2		Mbillya and Kristi
								Felix Mwale/Director for ZACCW
		Team 3	Team 3: Bethany may go into afternoon nPaula and Mary	Team 3 -	Team 3: Save the Children: Maureen, Dana, Mary (Office, sites and families?)	Team 3		Katie Januario/CRS
Dinner:	Group Meal	Group or on own: Dinner with Chesswa Vwalika, meet at hotel 6:30 (DANA AND DONNA for sure)	Group or on own	Dinner at 5:30 with CRS (Near Hotel)	Group or on own	Group or on own		Chilobe Kambikambi, Jean Milo, Nicole Richardson and Sandi Michaelson/Save the Children Zambia
								Reverend Sihubwa
Evening:	Free Time	Debrief/Free time	Debrief/Free time	Debrief/Free time	Debrief/Free time	Free time		Sarah Banda Sambelo/Ministry of Community Development and Social Welfare, Lusaka
								Hamakumba/Mumbwa Secondary School
								Innocent Mwansa/Mumbwa Secondary School/Special Education Unit
								Grace Mulenga/Kabulonga Cheshire Home
								CSO - SUN - Contact is Nelly Phiri, http://www.csosun.org/index.php/about-us, Mrs Dorothy Sikazwe 0955905589
								Chesswa Vwalika
								my# +37257576364

Working calendar sample of meetings while in Zambia

Organizations Serving Persons with Disabilities

- Zambia National Association of Disabled Women
- Zambia National Association of the Deaf
- Zambian National Association of the Physically Handicapped
- Zambian Association of Children and Adults with Learning Disabilities
- Zambia Association of Parents of Children with Disabilities
- Mental Health Users Network of Zambia (MHUNZA)
- Zambian National Federation of the Blind
- Disacare Wheelchair Centre
- Zambia National Library and Cultural Centre for the Blind
- Zambia Association on the Employment for Persons with Disabilities
- Zambian National Association of the Hearing Impaired
- Zambian National Association of the Partially Sighted

Summary of Meetings: Serving Children with Disabilities

Zambia on-the-ground Formative Assessment

Monday, June 20, 2016		
CSO-SUN (Maureen, Mary, Renee)	Met with 2 program officers from CSO-SUN: Ms. Nelly Phiri (nutrition specialty) and Mwandwe Chileshe (studies development of economies)	Focus of group is on advocacy, not implementation As part of First 1000 days, working on maternal nutrition during pregnancy, infant nutrition during early critical period. Includes ALL children in mission statement but no specific target for CWD GAP identified in the data collection showing the relationship between nutrition and CWD outcomes. Recommended securing official government endorsement of research in order to have data considered valid by Zambian funding sources. 2 primary projects: 1. Advocacy through outreach to political parties 2. Adolescent health project (HIV, nutrition focus for girls) This is an election year, so nutrition initiatives are being presented to all political parties/candidates. Current response is positive but no funding has been secured. Higher level speeches of candidates and VP are now including nutrition in them. CWD: understanding of family's perspectives. Some isolate CWD because: · They worry the child will be harmed · They feel angry that child is a burden · They experience judgment/shame (many fathers have divorced the wife when a CWD is born in order to distance themselves from a poor bloodline) ZEMMISSE: acronym for a college that trains teachers to work with CWD Sunshine project: located in Woodlands. Strives to integrate young adults with disabilities into the community by offering them work opportunities Nutrition issues identified in the meeting: · 40% of all children in Zambia are stunted · obesity in women is a growing issue · micronutrient deficiencies: this is due in part to the dependence upon maize for nutrition. Culturally, maize is a staple, the more refined it is, the more status perceived (this removes much of the riboflavin, fiber and B vits) · Breastfeeding is recommended exclusively for babies until 6 months, complimentary foods introduced, and breastfeeding recommended simultaneously until 2 years. Not practical for working moms. (HIV protocol varies a bit) Initiative: FISP- Family Input Support Program Initiative to add carotene to maize (orange maize) in pilot phase, will hope to fortify beans with iron in next phase Under 5 clinics: Child has a health card Measurements are taken using a sling for babies and a digital scale by those that can stand (or measured in mom's arms) (Not clear if equipment is standard or available in cities only) MUAC, HC, height/length, and weight are taken ideally

		Anemia testing is focused on mothers not children Vit A is administered 2 times per year to all children Perception seemed to be that this is a very successful program with some gaps. Including: · If baby has a few good visits, parents stop coming to clinic · Lines are long, decreasing incentive to come · Many mothers who work cannot come Mary shared experiences in rural clinic. Gaps included: · Women walked a long way to clinic · System for tracking data was complicated and included many transfers of information by hand and finally compiled into a database · Missing information indicated a lack of true monitoring of growth, often weight or height stopped being measured along the way Partners had not attended the nutrition conference in the past and vaguely thought they might know of the upcoming conference in Nairobi. Had reviewed the Global Nutrition Report from a recent South African conference.
Zambian Association of Child and Youth Workers (Maureen, Mary, Renee)	Met with Felix Mwale (Executive Director) and Louis XXXX	ZACYW is a professional society created to promote professionalism in child care institutions, centers and community. Their goal is to build capacity for those working with children. The purpose of the meeting was two-fold. 1) Information in preparation for Tuesday's trip to the Copper Belt and 2) discuss how ZACYW functions and observed gaps/needs. The government has a pattern of creating programs or policies that are weak or non-existent support for implementation. For example, the government created a program called Child Care Upgrading Program, bud did not include any curriculum development. The intent was a desire to standardize care and bring all work. ZACYW wants to work towards standardizing care and bring all child care workers together under one umbrella. There are currently minimum standards of child care that exist which includes institutional care. There are not special standards specifically for CWD> The Better Care Network Consultation was done to create child care sector reform. The result was resolutions (as the director of the Ministry of Comm Dev). Sara Rand (also with the Ministry) presented on children with disabilities. We will meet with them on Wednesday. Key areas of need/focus:

		1. Community-Need more outreach in the communities for CWD. Cheshire homes does this. While there are children seen in the community who have disabilities, many families hide these children or keep them in the house because of stigma, limited knowledge, lack of knowledge about services or at least not much awareness of services/resources to decrease stigma. There are more CWD living in communities than are living in institutions. The problem is that they don't come in contact with services (i.e. not in school) so don't get connected to other resources. One idea was to 'assign' care workers to several families in the community to help families manage and be able to work. 2. Education - there are some special schools for CWD and some go to the common school. These are funded by the Ministry of Education. There is a "Trust in Me" policy held by the school that schools embrace <u>all</u> children, but the schools lack the infrastructure to manage CWD. In addition, there are family capacity issues. Not only are there very few schools that can accommodate CWD, families have to weigh the time it takes, transportation, community infrastructure, distance to school in their decision to have their child in school. Finally, even when they do go to school and move into a trade, there are very few opportunities for people with disabilities to secure employment. 3. Policy - There is a need to re-examine policy to suit the present environment. There are gaps in child care/welfare policy in general but specifically for CWD. There is an opportunity to influence where policy may go/include that will provide informed environment/way of thinking of government. There is a social welfare policy on CWD coming out but it is very broad. Then, who is going to be the custodian of the policy. Currently the policies are divided and managed by different offices (comm develop, health, education). There is no one home. Need one that is very comprehensive. And of course, have funding for implementation. ZACYW hold leadership seminars to educate care workers about what government policies exist. There is poor dissemination of policies to public. ZACYW provides them to trainees. 4. Coordination - There is a general lack of information, between organization, within government, etc. How do people who work with CWD perceive themselves? Professionals or workers? Do they have identity with an organization? ZACYW has created local chapters to help with this coordination. They have professional meeting for sharing and problem solving. They hold 3 forums. They have a WhatsAp forum - one for trainers and one for regular

		members. It is used as a forum for asking questions, problem solving, etc. For each issue presented, the trainers come to consensus on WhatsAp or through the app decide to meet in person then send out a recommendation to the regular members. They also produce a Zambian Child Newsletter 2 times per year to education the public, government offices, etc. We can submit an article after we have synthesized our information. This was an exceptional meeting - they are well connected, do trainings, potential great partners. The trend is for deinstitutionalization. The trick is to not leave behind the CWD in institutions (maybe think of new models of care) while supporting community/families for both transitioning children out of institutions and keeping them at home in the first place. Felix is going to draw up a conceptual model to share - he clearly has a vision!
OM ZAMBIA, Mercy House (Dana, Donna, Paula)	-Liz West (Liz.west@om.org) (Human resources officer) Mercy House is coordinated by Anne Davidson (biganne.davidson6@gmail.com)	OM Zambia has been in this country for 20 years-they run Mercy House, Bethesda (School for disabled children). They also have a sports ministry, AIDS ministry, and training program for those working with vulnerable children on the street. They have 2 community schools-7 students training for teaching at the moment. They have had medical volunteers but find it difficult to get them credentialed by the health ministry. However, CMMB does not have this problem and feels it's because of the strong, trusting relationship they have with the Ministry. They are an organization that supports evangelization (missionary work) and require discipleship training for 3 months for their volunteers. It's interdenominational and international. They are all volunteers who all have to raise their own funds for support. They also have Ships that sail port to port to evangelize, help with projects, and provide some disaster support. They do work with orphans (nonresidential) who are primarily with their grandparents. They have no medical programs. There is a clinic in the settlement but is a fee for service that Anne often pays. She will also transport to hospital if needed. Bethesda school has about 15 children with disabilities with 1 physiotherapist from Germany. (to be visited later) Mercy House is in Makalulu settlement/township. Makalulu has about 65,000 to 90,000 persons (hard to always count) and is the second largest settlement in sub-Sahara Africa. It is the poorest in Zambia. Mercy House is coordinated by Anne Davidson (biganne.davidson6@gmail.com) of Scotland. They service between 30 and 60 children. One of the teachers from the neighborhood itself (he is janitor and teacher) recruits the children (all have a different story). There are 2 children currently there with disabilities (one blind, one with epilepsy and left arm amputation). They feel ill-equipped to handle children with disability. With the 2 children that they do have, they aim to provide food and safety for them.

		3 classrooms divided by age (4-6, 6-10, 11 and up) -Morning and afternoon sessions that overlap lunch (one group of children comes in the morning has lunch, then the next group comes for lunch and has school in the afternoon). Most of the children have had no schooling. Their designation is daycare rather than school- they are stepping stone to other schools in the community- some scholarships available. -They focus on teaching hygiene. The facility has girls and boy's bathrooms with showers for the children (most do not have flush toilets or shower access at home). -Main goals were to teach hygiene, self-esteem, self-control, and prepare them for other schooling. They also aim to provide safety. -The children get one meal per day (lunch). They do not follow specific nutritional guidelines from anywhere but strive to provide a balanced diet that includes nshema, some meat (sausage and chicken), vegetables, beans, and sometimes extra protein with nuts. -They have their own water supply at Mercy House. -There is a sewing project for moms and they are hoping to start providing parenting classes for moms -Staff are paid through Anne's own private funds (about 700 kwacha per month)
Tuesday, June 21, 2016		
Travel to Ndola with Renee, Louis, Maureen	ZACCW Attendees: Anthony Mwansa Zambia Agency for Persons with Disabilities Ganazo Phiei " " Agatha Chiwele Ndola Central Felistus Bwembya Ndola Cheshire Home Paxina Kaoma Kaonga Social Welfare Sister Karen Chileshe Community Based Rehab (CBR) Alick Chenle Ndola Central Hospital- Daycare Charles Mufwafwi " " Scholastica Muuzna Jesus Cares Ministries Kitwe Chileya Mufuzi Child Life Touch Orphanage Jessy Banda Kapazo Gellophina Skills Academy for Persons with Disabilities Doris Mwenya Association Pope John 23rd Holy Family Specialty School: Charles Maclula " " Charles Mwambo Samaritan Strategy Zambia Maureen Kueeto St. Anthony Children's Village	Adventures: road blocks, traffic, police stops, car emergency brake stuck, flat tire (after we arrived thank goodness!) Estimated arrival 9-9:3- Actual arrival 10:30- room full of people waiting for us eagerly. Boot placed on tire after poor parking during lunch- had to offer bribe to avoid an expensive ticket. Discussion of government role: Government body developed a manifesto, part 6 included Persons with Disabilities section resulting in the following primary responsibilities: 1. Register ALL persons with disability -all ages -using the medical model (form is filled in at the hospital indicating diagnosis, when it was acquired, degree of severity- Anthony will share this form with us via Maureen's email) 2010: 1.4% of population identified as having a disability (this was from a census report) WHO estimate was 10%. 2015 a survey was completed that showed 7.6% of population had disability. This increase may have been due to cash incentives that were established for those with disabilities. Only 2.5% of all children with disabilities are attend school according to census. 2. Register all organizations working with persons with disabilities, monitor for appropriate care, complete inspections, determine if mobility access exists in buildings

		3. Coordinate community based organizations. - Assist with access to services in the area, provide equipment Discussion of Stigma: - Widely held belief that if a man or woman is HIV+ and has sex with a child or person with disabilities, the HIV will be cured. This contributes to abuse of PWD and CWD. - CWD are not seen as human - Teased by community - Abused by family (sexual or physical) - Seen as a burden - Seen as unable to contribute to society or care for parents - Shame - Increased likelihood that husband will leave family and start again with a new one (especially for intellectual disability rather than physical disability although the level of mobility restriction contributes to this as well) - "Mothers become the first targets of discrimination" Visited the following institutions: Association Pope John 23rd Holy Family Specialty School: - Children had boarded the bus to return home for the day- visited briefly Child Life Touch Orphanage - Number of CWD was low - Mainly included hearing loss St Anthony Children's Village - These may be the most malnourished CWD I have seen. Tiny tiny tiny. o High numbers of CWD o CP o Hydrocephaly o Seizure disorders o Osteogenesis imperfecta o Genetic conditions o Intellectual disability o Range of ages include infants/toddlers, children with severe disabilities in "CP room" up to 29 years Feeding practices observed in "CP room" o Children fed lying down or seated on floor o Spoon scraping o Some self feeding for children who could lie on side and bring food to mouth o No one seated at a table o Between 30-35 children in this room approximately 4-6 caregivers during feeding time o Seating options lined up at the wall (pics) o Fork mashed texture of meats/veggies (pics) o Rapid feeding o Large spoons/bite size o Infants/toddlers seated on floor o Finger fed by caregiver-no hand washing between bites for each child o Self feeding when able

		o Formula and complementary foods for babies 6-12 months, milk for toddlers o No hygiene observed o No idea of formula content/prep o Food was nshima dipped in gravy Transition Age Children: · Several programs working on skills training for older children (i.e., Community Based Rehabilitation, Gellophina Skills Academy for Persons with Disabilities, Association Pope John 23rd, Holy Family Special School, and Cheshire Homes). · Individuals receive skills training related to personal care (both genders). For women: homemaking, handiwork (i.e., beading, sewing, crochet, rug making, etc.). For boys: agriculture. · Some programs have limited ability to keep children once they turn 18. o Individuals receiving skills training then move back with their families – often these are the higher functioning individuals. o The question becomes – What to do with the individuals who require a more significant amount of support. · Concerns: o Presently no options for adults unable to care for themselves who have no family who are willing to live with them. o Capacity issues: Programs available are now full and there are many other i individuals who are getting older and will need this service as well. o These individuals who do move back into the community can be very vulnerable to abuse, exploitation, or stigma. · Gellophina Skills Academy for Persons with Disabilities – developing entrepreneurial work with participants. PWD make handiwork -- getting close to being able to see merchandise that they make (quality is becoming higher). Limited Resources: · All of the programs discussed concerns about limited resources. Several areas of concern: staffing, transportation, infrastructure, and funding · Staffing: Sister Karen Chilebe (Community Based Rehabilitation) indicated a staffing ratio of one staff to 15 or 20 children (ages: 0 to 25). · Transportation: A main goal is to educate children, but "how do we get children with disabilities to the school?" · Infrastructure: aging facilities, lack of facilities, and non-accessible buildings o Aging facilities: Andola Central Hospital and Day Care – using a building that was built in 1984. Services grown, but building has not kept up. Holding classes in a closet and using the dinning room as a playroom.

		o Lack of facilities: Gellophina Skills Academy received a plot of land to build a daycare for children with disabilities, so that parents could then work. Have not been able to build the facility – no $$ o Non-accessible buildings: The 2012 Persons with Disabilities Act included a provision for accessible buildings. These rules have not been released. Buildings continue to be built with steps and not ramps or no access to multi-level buildings. This includes schools. · Funding: Many organizations working under very limited budgets. They will ask parents to pay for some of the instruction provided to their CWD. However, many parents will not pay for services or for food. Belief from workers is that parents don't want to pay for services, because they don't see the value in paying, since they believe that the CWD will never be able to work or support themselves or help to support the parents when they are no longer able to work. o Government Sponsored Programs to help relieve financial burdens on families. § Service Delivery – find durable medical equipment for CDW (i.e., wheelchairs, crutches, etc.) § Educational Support – limited funding to help fund primary and secondary school (Only for children with a physical disability or hearing loss and with no cognitive concern) § Medical Support – funding to help with medical bills or purchasing specialty item (i.e., incontinence supplies for kids with spina bifida) and transportation to medical specialty appointments. § Empowerment Program – for parents of CWD – 2 options: 1. provide micro-finance when families develop a business proposal. Can receive up to $1000 K. 2. Gift program – give families 5 chickens to raise when they have chicks, then those chicks given to another household who has a CWD. Group's Recommendations to Fill Gaps: 1. Develop a campaign to address stigma of having a child with a disability -- Help to educate and provide printing for posters, pamphlets, etc.

		2. Assist with communication/collaboration between the various government entities responsible for children with disabilities (ie., between Ministry of Health and Social Welfare)
CMMB-Catholic Medical Missions Board (Donna and Dana)	Met with 3 program officers; Batuke Walusikuy-Mwewa, Country Director, Elizabeth Mushinda, Director, Operations and Esther Ngulube, Project Manager, Kusamala Program.	Once focused primarily on HIV education, prevention and treatment, now CMMB has long range plans to improve health care in general for women and children by strengthening care at the health facility level and increasing involvement of the community in disease prevention. The concept involves a facility-community exchange of information with emphasis on holistic care such that the two become integrated to foster not only the best health outcomes but to increase the safety of children and youth and limit the number of street children and abandonments. CMMB intends to work with the community and traditional leadership while trying to identify organizations with which to partner. Specific initiatives include: · Reducing child morbidity and mortality by improving the quality of nutrition, water and sanitation. · Poverty alleviation · Protection of children through reduction of gender-based violence · HIV prevention and treatment again focusing on gender-based violence This project has been funded by GRH Foundation and involves a coordinated effort between CMMB, a local district hospital, the Evangelical Fellowship of Zambia and Makalulu Home Based Care Center. The Dreams Project funded by the Bill and Melinda Gates Foundation, Nike and Johnson and Johnson, is focused on empowering adolescent girls and young women to make their own decisions about their health. Parent education is also a portion of this program. Small cash transfers are planned to permit young women to purchase needed items while helping them avoid transactions that place their health and welfare at risk. In terms of nutrition, they are seeking families where children display good nutritional status and then to use these “model” families to teach diets and cooking techniques to families whose children are nutritionally at risk. While they are certainly aware of the problems faced by disabled children and their parents in their communities and expressed an interest in incorporating this population into their programs, they have no special expertise or experience in this area. Family Interviews, Chawama Township (Donna and Dana) Together with Esther Ngulube from CMMG and representatives from the Department of Social Welfare, Ministry of Community Development and Social Welfare, we interviewed two mothers of children with disabilities within the Township. The first mother had a 7-year-old boy, Kalukusha Miti who has cerebral palsy likely caused by bilirubin encephalopathy (kernicterus). He had no recognizable speech but could make some needs known, no bowel or bladder control, no independent mobility and no ability for self-care or feeding. This mother lives in a family compound owned by her brother as she and her husband

		could not afford to live independently. Her husband is unemployed. While her son was her only child, she shared their small suite of rooms with three additional children of ages 9, 10 and 19 years. The second mother has a 9-year-old daughter Elizabeth who contracted meningitis at 3 months of age and has been developmentally disabled since. She can walk short distances but has difficulty on uneven terrain. She is not toilet trained and cannot communicate or participate in self-care. Elizabeth is mostly fed by her mother. She does, however, have a limited ability to feed herself when food is cut into small pieces. The family has 5 other children, 3 older and 2 younger and the 7th child is on the way. Her husband is involved and occasionally provides care when he's not working. The issues facing both mothers are identical: · No or limited ability to work outside the home due to overwhelming child care responsibilities. Elizabeth's mother sews in the home but often has difficulty procuring needed supplies as Elizabeth is a safety concern when left with others. Kalukusha's mother has no marketable skill which would enable her to earn money while remaining at home. Neither has reliable respite care. · Difficulty accessing services. Both children are growing larger and progressively more difficult to carry. While hospital-based services are available, such facilities are at least two bus rides away and the families would find it difficult to bring the children to therapy any more than one day/week. · Lack of needed equipment. Special chairs, standing frames, wheelchairs etc. are impossible to purchase. · Both parents spoke about their fears about their child's future and lack of educational opportunities . Bauleni Special Needs Project (Donna and Dana) Met with Sr Lynn Walker (SSHUM, MA), Makela the Head Teacher and Mabel the program administrator. Committed to providing a service of Christian love in partnership with other stakeholders, they respond with passion and integrity to the needs of the most vulnerable to empower them to live in love, peace and justice, with full recognition in society. Current funders include the missionary arm of Irish Aid as well as numerous small donors throughout the UK. Founded 16 years ago the project goals include: · Promoting good quality, meaningful education for orphans and vulnerable children, especially those with special needs which currently include, hearing and vision impairments, Down syndrome, micro- and hydrocephaly, cerebral palsy, autism, etc. · To develop a center of Excellence so that other establishments may learn from the good practices that they demonstrate. Programs include a community school where high and low functioning children are educationally

		integrated. Vocational skills training is provided in tailoring, catering, weaving, knitting, gardening, carpentry and needlework for older children with limited prospects for advancing within the formal educational system. A residential option is available from M-Th night. Children are not charged fees for schooling through elementary grades and on a sliding scale or in-kind for upper grades. There is a cost for residential care on a sliding scale or in-kind. Bauleni has assisted in establishing similar programs throughout Zambia and has now started work in Malawi. · To provide specialized therapy to children within the school. Currently these include physio- and psychological therapy. The school also provides a training site for teachers in University and College Level Special Education training courses. · To offer training courses in Home-School Based Education and Good Child Practice to teachers and carers from other institutions or programs. These home-school programs are staffed by volunteers who spend one half-day/week teaching basic rehabilitation and educational techniques to parents of children with disabilities within their homes. Bauleni provides a 5-day training course and then ongoing supervision and child assessment. Currently they have over 3,100 children in the home-based program throughout Zamia. The program has recently been manualized into publication entitled *Karios Program Home School-Based Care*. · To collaborate and foster interdisciplinary cooperation with line ministries such as the Ministry of Education, Science and Vocational Training and Early Childhood Education and the Ministry of Labor, Youth and Sports, in order to provide better services for children with profound disabilities. · To make the project self-sustaining through development of viable income generating projects. These include, fish farming, vegetable farming and meat production, products from their vocational training programs, brick production, take-away food and corn meal production. Priorities in the future include developing a sheltered workshop for young adults and working with the appropriate Ministries to implement an adaptive curriculum to help mainstream children with disabilities into the public schools. They would also like to expand special services in speech and language and occupational therapy.
House of Moses, Bethany Global (Mary and Paula)	Mbiliya and a parent with a CWD	House of Moses functions as a crisis center for children who are abandoned, families who have their child removed or other condition such as severe malnutrition. The children are able to stay for 6 months at the center. Only for children 0-5. They work with the families or relatives or foster/adoptive families to integrate the children after 6 months. They work with the families/caregivers during their stay. In addition, they have a family preservation program. The program used to include providing eligible families in the Family Preservation Program (FPP) with formula for children

		0-6 months, formula, mini meal and ground nuts for children 6 months-1.7 years, and oil, mini meal and ground nuts for children 1.7-5 years. The families became dependent on the food and the food alone did not provide them enough support to become less at risk. So, last year they began programs to reduce dependence including vocational training, mini grants, training of 15 woman in business/management skills. Families are more open to adoption than foster care – there is concern about developing attachment with the child and then the child is taken back. The challenge with adoption is that parents are not necessarily willing to give up parental rights. They see their child doing better in an institution (fuller cheeks) so just want their child to stay in the institution. The other issue is that families do not want to foster or adopt CWD. They do not target CWD directly, but have 4 families part of the FPP. One mother and child came to meet with us. She had two children, then triplet. One of the triplets is disabled – maybe hypotononic CP – she has to stay at home to care for him and the other children. He receives PT every Wed but the clinic is far away and she has no money so they walk. He is nearly 3 years old. He is a picky eater but can chew and swallow. He was more sick as a child than his brothers and they had to go to the clinic. PT teaches her techniques to do on her own at home. She does not see that he is making much improvement. She has some community support (not feeling a lot of isolation by neighbors) however her husband says it is her fault, ignores the son and says he has nothing to offer the father. He provides no support. He drinks heavily and then yells insults at the wife. There are no schools for the child nearby and the local school does not take CWD. A nearby community – Chomwa – has CWD. There are over 100 families (not necessarily CWD) who receive child support services, farming, tailoring. The pastor there does home visits and has found CWD locked up, tied to chairs, etc. One good source of dissemination will be the CIF workgroup, but also to send a summary to each group we met with – CIF is important so they can coordinate.
Wednesday, June 22, 2016		
Ministry of Community Development and Social Welfare (Mary and Dana)	Anna Mubukwanu-Sibanze, Sr. Social Work Officer and Sarah Banda, Sr. Social Work Officer. Both work in the Social Welfare portion of the Ministry.	The Ministry is responsible for coordinating the GRH-funded Children in Families Working Group which includes the Ministry of Youth, Sport and Child Development, a magistrate from the Ministry of Justice as well as partners such as CMMB and Bethany. The goal of the working group is to decrease the number of children within institutions through family preservation and reunion programs, foster care and domestic and intercountry adoption. Better Care Network has recently finished the first phase of a national assessment of child care institutions funded by GHR Foundation. Within the the most densely populated regions of Zambia including Lusaka and the Copper Belt, there are 189 government and private (including faith-

		based) institutions caring for ~8,000 children. Almost all children in care (98%) have families with the primary reasons for abandonment being poverty or child disability. The second phase will survey the remainder of the country with the goal of a final report by year's end. This survey, along with one being carried out by CRS for Catholic institutions will enable the government to determine which child is where, the reasons for abandonment and help determine what type of support is needed and available to promote family unification. There are many governmental programs that could potentially support family preservation. Several examples were discussed such as cash transfer programs within the most urban areas of the country, a food security program administered by the Community Development that provides free seed and fertilizer for vulnerable families and the JEWEL program that assists in returning girls to school. Since 98% of institutionalized children have families, the goal is to break down governmental service silos to provide coordinated care. The goal is electronic case management where trained individuals can access family records, assess their qualification for assistance programs and facilitate provision of aid. Foster care has been slow to develop perhaps due to lack of understanding of the role of this system in child protection. Some success has been achieved in foster care for trafficked children from other countries and an active foster family training program is in place. Domestic adoption is quite popular with long waiting lists but families are interested primarily in babies and have little interest in adopting children with disabilities. Zambia placed 136 children for adoption by US families during FY 2015. Zambia is a signatory of The Hague Convention on Intercountry Adoption and has applied to UNICEF to fund implementation of treaty requirements in Zambia. Regarding individuals with disabilities, Act 602012 established the Zambian Agency for People with Disabilities under the Ministry of Community Development and Social Welfare. Unfortunately, the mission of this quasi-governmental agency is hampered by lack of accurate data. In a 2010 survey disability prevalence was 2.1% including 0.4% of children ages 0-14. However, a more recent survey using the UN Washington Group on Disability questionnaire < http://www.cdc.gov/nchs/washington_group/wg_questions.htm> indicated a prevalence of 7.2%. In 2011 only 20% of individuals with disabilities in Zambia received support for services needed.

		Better Care Network estimates that 1/3 of children within institutions have disabilities. Children with disabilities are overrepresented because of the following factors: • High degree of stigmatization in society and subsequent social exclusion • Limited support to families caring for children with disabilities and subsequent high poverty levels • A belief in the medical model of disabilities that children with disabilities can only be cared for by trained professionals • Limited interest to foster or adopt children with disabilities. The government realizes that information campaigns designed to combat stigmatization and acquaint the public with the need for early identification of children with disabilities are both necessary to help disabled children achieve their maximum potential. As the Ministry proceeds forward in improving care for children with disabilities, they are most interested in developing small pilot projects in one or two institutions with a high percentage of children with disabilities. In terms of community care, both were quite enthusiastic about a program based in Livingston and funded by the Norwegian Association of the Disabled. This program identifies children with disabilities then links them to a variety of center- and home-based services. They are currently running 6 schools based in this community-based rehabilitation model (CBR). Our hosts also provided a summary statement following a child care reform forum held in Lusaka on May 6, 2016. In "Accelerating Child Care Reform in Zambia: A Call to Action", the government urged Ministries and cooperating partners, civil society and all stakeholders working with children to support the implementation of the following strategic actions to accelerate child care reform in Zambia. 1. Establish a national technical working group on child care reform; 2. Develop a child care reform strategy including costed implementation plan with focus on prevention of family separation, provision of appropriate alternative care and ensuring the linkages between the child and family welfare system, child protection system and social protection system; 3. Develop a national alternative care framework with the following components (I) coordinating mechanisms on alternative care at community, district, provincial and national level, (II) gatekeeping mechanisms; (III) alternative care regulations/guidelines and related standardized operational procedures: (IV) skilled and mandated competent social welfare workforce, (V) Family

		based alternative care options such as foster care, kinship/extended family care; adoption (domestic and international). (VI) Public awareness campaign on the importance of family based care 4. Strengthen the social welfare workforce through standardized training and accreditation and increase resources to deliver coordinated care services for children; 5. Address the specific needs of children and families affected by disability as part of the child care reform strategy and national alternative care framework; 6. Undertake quality research and evidence building around child care including the development of effective platforms for information sharing; 7. Awareness raising and advocacy for political and social mobilization to support the child care reform, especially ensuring the participation of children, youth and family as actors of change for child care reform; 8. Secure human and financial resources to accelerate the child care reform process.
Cheshire House Kabulonga(Paula Rabaey and Donna DeGracia, Mary and Dana)	Sister Grace, Sister Nancy, Sister Clara, Muwanga	Sister Nancy: helps with the care of the children in the home Sister Grace Malenga: Was trained as a secondary school teacher and taught language arts in the school for disabled children in the Copper Belt for 10 years before being transferred to Cheshire Homes where her role is in administration. She is planning to retire from the Ministry of Education so that she can transition from her role as secondary school teacher to teaching preschool. Her work at Cheshire homes has instilled an appreciation for early childhood education and the young children have won her heart. Muwanga is a physiotherapist who has completed his 3 year College physiotherapy program, but not the 4 year University program. He also often has physiotherapy students with him. About Cheshire Homes Cheshire Homes are under the umbrella of the Cheshire-Leonard organization that was founded by an Englishman named Leonard Cheshire and operates in 55 countries. There are 8 Cheshire Homes in Zambia. Cheshire Kabulonga was founded in 1972 and is one of 3 Cheshire Homes in Lusaka. It is considered the central Cheshire branch due to its proximity to two orthopedic hospital:, St. John Paul II and Biet Cure. The Cheshire Home is run by the Franciscan Missionary Sisters of Assisi. This Cheshire Home currently houses 25 children who reside in the home during the school calendar time and return to their families during breaks. They are usually on campus for 3 months at a time with a month with family in between school terms. The school also has 3 to 5 day students whose families are able to bring them to school each day and pick them up after school. Children at the school range in age from 6 to 12 although criteria for admission allows for children ages 5 to 12. Other criteria include physical condition and social and

		economic status with a preference for vulnerable children. The school is considered a transit school with children returning home during breaks and eventually moving on to traditional schools or, if unable to attend traditional schools, being transferred to a partner school for disabled children in the Copper Belt. Cheshire Homes provides education from preschool through grade two. The school in the Copper Belt has grades one through twelve. Children are referred to Cheshire House through outreach programs and through priests and sisters in outlying areas. Pre- and post-op care Because of their proximity to orthopedic hospitals, Cheshire Kabulonga provides housing and care for children from distant areas while they are being evaluated for surgery and during their pre- and post-op periods. The most common surgeries performed are tendon release surgeries. Services for these children include housing and physiotherapy. Types of Disability About 50% of the children have cerebral palsy A few have osteomyelitis A few have Osteogenesis imperfecta Others have other forms of neurologic impairment Some are hearing impaired Some have cognitive impairment although the focus of the program is on physical disability One infant lives in the home. Seraphina was found abandoned in a latrine after a failed suffocation attempt. She did not die. Some children heard her cry and rescued her. Seraphina is hearing impaired. Services Provided School through second grade Housing and food Physiotherapy: with residents, with pre- and post-op patients, precepts physiotherapy students, makes referrals for patients beyond his scope of practice.provides fee-for-service physiotherapy for adults when the children are in school Caregivers A Sister who is a pediatric neurologist at the teaching hospital nearby comes to the home each Friday to evaluate and treat children. Income generating and related activities Garden to grow vegetables for the table. Of interest, the gardener has no hands. An exercise gym and aerobics classes Suites for rental to businesses Adult physiotherapy

		Challenges Lack of staff and money to pay staff Transportation. They have a mini-bus that is over 20 years old and breaks down frequently. Transportation is needed for outreach and to take patients to and from the hospital Long term goals Continue learning and growing to provide better care for the children More outreach to areas beyond where they can presently access More home and community based care More teachers and more training for teachers in techniques for children with disabilities More staff in general More and better adaptive equipment such as special chairs, standing frames, electric scooters and wheelchairs More training for parents More training and more help for the physiotherapist
CRS- full team	Patience Vilinga, CRS	The team met with Patience Vilinga from CRS for dinner. We shared who we have met with, what we have heard and our the top key learning. She was not surprised and felt what we have learned is consistent with what CRS learned. They identified 42 Catholic institutions with 10 or more children. They visited 38. There was an institutional assessment of the number of children, ages, any diagnosis, reason for being there, etc. The second phase was to interview families who have either left children at institutions, were reunited with children or those at risk of being relinquished. The biggest surprise from these interviews was families stating they sent their child to an institution for education. These families were too poor to pay the government fees but knew they would receive education at the institution. CRS is completing putting the final results together by the end of next week, will disseminate to partners in a few weeks and submit a grant to GHR in August. They will include an element of CWD but have not yet defined it. They think it will include community based rehabilitation CBR program. We will be in touch.
Lusaka Apex Medical University staff (Paula Visited)	Dr. Oswell Khondowe *Dr. Oswell Khondowe PhD, MSc PT, MSc APA, BSc PT, Dip PT* *The Dean of the Faculty of Health Sciences* *Lusaka Apex Medical University* *Lusaka, Zambia* *+260 963 66 76 10* *oswellkhondowe@gmail.com*	-Dr. John Mudenda (Chairman and Chief executive officer, Lusaka Apex Medical University. Director of Medical Education. Mudendajohn772@yahoo.com) -Sayela Walubita (physiotherapist with children, coordinator for the new OT program-hoping to complete his degree for OT. walusayela@gmail.com) They are starting the very first OT degree program in Zambia. They have been accredited by the World Federation of Occupational Therapists and hope to start in January 2017. They are still working on their curriculum and stated it is difficult to find professors- need to be at a Master's level in OT. The program is 5 years and equivalent to Bachelor's degree. You can also get a diploma (lower than a bachelor degree in OT, but they want to educate OT's at the degree

		level). Currently there is 1 OT in Zambia who works at Livingstone General Hospital (Eckiwe-Livingstone) with a degree and 2 OT at the diploma level (in the country). A major challenge lies in educating the public and others about OT and recruiting students to join their program. Physiotherapy-there are 2 programs in Zambia. It is also a 5 year degree and has a diploma level and a degree level. One physiotherapist noted that it is a male dominated career and not many want to work in pediatrics. (all students in the first year-in all health professions take pre-med classes that are the same-they are pushing for interdisciplinary education among health professions). Right now lines between PT and OT are somewhat blurred. Opportunities for continued training beyond initial schooling are very limited and difficult to access. They noted that UTH (University Teaching Hospital in Lusaka) has a speech center, which is a component of the ENT department. Education is not certification, but rather by apprenticeship. (Very little was known) Dr. Khondowe has formed an NGO with multiple chapters around Zambia focused on creating funds for assistive devices for children with disabilities. They are having the first Disability Day in August, 2016 to raise awareness of disability and want to target persons at all levels from therapists, lawmakers, businesses, and schools. Major issues noted: stigma around disability, myths exist about CWD being "bewitched". Often children are hidden, access to therapy is difficult (transportation key problem). Physiotherapy exists at hospitals, clinics, and some private practices, and only rarely in schools. There is a problem with outreach to the community, most people need to travel to access the therapy services and is usually a fee for service, thus follow through is a problem or they stop going to therapy. They recognize that they need more therapists to travel out into the community and into people's homes, but transportation was again a problem. Services are very medical model. The University was eager to collaborate in any way that is possible. They stated they need human resources for teaching; especially in specialized areas. They stated they would like to explore any type of faculty exchange, guest lecturing, sharing of resources, ideas for curriculum, books. Other ideas they put forward are partnering students, collaboration on projects in the community, and possible shared grant writing. They also indicated they could help us identify hospitals, and clinics with therapy for CWD. They see children with disabilities as a huge issue and also would be interested in our report. They would like to keep in touch and continue conversations. Other resources they recommended: UHT-University teaching hospital Munali School-secondary school for CWD
Thursday, June 23, 2016		

Mumbwa Secondary School
Donna & Renee
	Fabiano Mwanza Faweza Programme Officer
	Headmaster for the school
	Mwansa Innocent -- Mumbwa Secondary School -- Teacher in charge of special unit
	Lubasi Makoma Nicholus -- Special Education Teacher -- Mumbwa School.
		Information about the School:
		• Opened in 1976 and accepted 'special students' from the beginning.
		• Total of 1,822 students
		• Currently 13 students identified as CWD. 4 boys and 9 girls. Most have low-vision (nearsighted), one child had a neurological condition caused by Malaria as a child (difficult with use of right side of body), 2 students with albinism. Currently no students who are hard of hearing.
		• School is unable to take 'high disability' students, such as individuals in wheelchairs or with significant ambulatory concerns.
		• School does not accept children with intellectual disabilities.
		• It is a boarding school. Fee is 1,000 KW per term (3x a year)
		  • Some children with special needs receive grants to attend school.
		• CWD have a high passing rate on the National Exams, which allows students to attend a University and go on to further school.
		  • Success story: One Child with significant visual impairment went on for his Ph.D.
		
		Service Provided to CWD:
		• Receive integrated instruction with children not identified with special needs.
		• CWD also given additional instruction during 'free time' or second half of the day.
		  • Purpose: Help with lessons that they receive while in the classroom.
		• Accommodations: 1. Seated at the front of the classroom, 2. Given extra time for tests, and 3. Given modified exams (large font or braille).
		Barriers to Attending School:
		• Potential parent factors:
		  • Unaware of the school -- no outreach about services
		  • Social factor -- parents believe they are the only ones who can properly care for their child and unwilling to send them to a boarding school.
		  • Financial -- Cost associated with the boarding school -- can be prohibitive for families.
		• School factors:
		  • Schools tell parents that there is nothing more for students.
		  • Don't give information to parents about the secondary school.
		
		Children's Concerns:
		• Met with all but one student at the secondary school receiving special services.

		• Most in need of eyeglasses or some adaptive equipment • Many indicated that it would be helpful to have text books written in larger font. Holy Family Rehabilitation Center in Monze, Zambia (Dana and Paula) Meeting with: Brother Robert Chakana (chakanabob@yahoo.co.uk), Titus (program management) Holy Family was started in 1986 by the Hospitaller Order of St. John of God Brothers. Vision: To be a center of excellence in provision of rehabilitation and disability services Mission: To provide holistic rehabilitation and disability services, quality health care, social and educational support, and spiritual guidance. Their aim is to collaborate with the communities that they serve. They provide rehabilitation services to both children and adults. Services: • Community Based Rehabilitation (CBR) • Rehabilitation programs for neurological and orthopedic disabilities • Early Childhood intervention (from 0-7 years) • Center based programs for CWD • Vulnerable Children project Three program areas: • CBR at rural health centers • Home visits • Special schools They have a multidisciplinary team model. Their team includes: physiotherapists, nurses, social workers, and special education teachers. They follow the WHO guidelines for CBR. Their model includes trained community volunteers who help identify, refer, and follow up with families with CWD. They identify and train key community leaders and involve the community in all aspects, thus working to help change attitudes toward disabilities. The community volunteers receive trainings at least 2x per year and training includes the following: • Basic skills in physical therapy (to help follow through on programs) • Training on different conditions • Vital signs training • Knowledge on social welfare and other government policies • Family and community structures • Nutrition The community volunteers keep in constant contact with the “home base” people and are given phones to help with their work. They are also given bikes, spare bike parts, gum boots, rain coats, t-shirts, and a monthly food incentive to

		help with their community outreach work. The volunteers help to identify persons with disabilities in the community and the type of services they may need. The CBR team travels to the different community based sites and meet with clients on a monthly basis. They provide training for the parents on the following: • Nutrition (nurses do cooking demonstrations) • IGA's (income generating activities) • Medical conditions • Social issues—once they know their rights, parents have often sucessfully organize to pressure official to provide needed schooling/service. • Food supplements (protein) for children 0-7 years • Community involvement—Leaders are targeted for education on disabilities and the potential of disabled individuals in the community. When asked specifically about whether this community involvement has reduced abandonment, Fr. Robert felt strongly that CBR not only capacitates families to parent CWD but that an enlightened community instills in them a sense of responsibility to do so. <u>Rehabilitation services:</u> (Goal is to maximize potential and promote independence) • Orthopedic services • Prothesis for amputees • Complications from HIV/AIDS • Manufacture appliances and devices (prosthetics, AFO's, splints, and seating adaptations) • Get other equipment from Lusaka (standers, special chairs made from a hard cardboard substance) • w/cs are usually obtained from World Vision, crutches from another organization • Buy their own splinting and braces supplies (order from Germany) • Needed surgeries performed at Monze Mission Hospital <u>Child Development Center:</u> Purpose is to provide an environment that facilitates a holistic approach to treatment and education for children (has a mother's shelter) • Provide educational assessments • Education services for preschool, Level 1, 2 • Advocacy for CWD and families • Conduct a monthly mother's group meeting • Home based programming Who attends: children who live outside Monze areas that are not covered through the CBR programs. Often children with CP, hydrocephalus, spina bifida, Down syndrome, and cognitive delays

		Assessments include: Functional activities, participation in society, all ADL's, and education. They believe in a play-based model and work to be culturally appropriate. They often have volunteer students who come for 3 mos-mostly from Ireland, Germany, and Holland They also have student interns from other countries (mostly European) in physiotherapy. <u>Home Based services (for birth to 3 years)</u> • Provide early intervention and identify kids with special needs • They implement the "portage model"-meaning that they believe parents are the first and best teachers of their children <u>Vulnerable Street Children Project:</u> • Started in 2014 • Address concerns of the increased number of vulnerable children roaming the streets • Aim is to reintegrate with the family and back into school <u>Funding:</u> Comes from a variety of sources, but is always tight: • The combined English and Irish Province of St. John of God ministries • Annual budget • Capital development <u>Identified needs:</u> • OT! • Constant change of government personnel • Funding stream fluctuations • Increase in the # of clients • Cost of materials • Equipment needs • Ensuring sustainability • Need for continued expansion
Save the Children (Mary and Maureen)	Gladys Munala STC, program manager for children in inappropriate care Leah works with a volunteer faith based organization (Jesus Cares) that is acting as SAve the Children's community partner.	Save the Children works to identify high risk households at risk of separation due to things such as HIV, child headed households, older guardians/parents, parents with disabilities. The focus is on strengthening families. Their interventions include 1)increasing caregiving through train the trainer model and 2) positive parenting training. Trainers have an education background and work off of a set curriculum (Gladys will send it to me). Families at risk are identified by community based care givers, sometimes from other community members. Other interesting components are that caregivers are taught to identify developmental delays and either then

		how to engage or connect to resources. There are also livelihood activities to increase economic status related to their risk category. Another and related project is with the street children. The average age of street children is around 12 (range 6-18). Activities include, family training, transit center, counseling with child and family and reunification. If the street child is unable or unwilling to name who their family is or are unwilling to leave the street, they are provided with life skills training. Many of the children on the street are addicted to alcohol, sniff glue, smoke (something), may get pregnant. The children tend to form small groups for safety, with younger children joining older children. The situation is going from bad to worse with the worsening economy. The children are at risk of all sorts of violence. They end up functioning as gangs, with territories and sometime violence. If they are found and willing to be reunited, they go to a transit facility for up to 6 months during which time there is counseling for both the child and the family, feeding, maybe detoxing. The center is only funded through donations and they have trouble affording food, clothes and any medical treatment. There is limited skills in detox. While programming does not focus on CWD, this is an important area. Currently, it is unknown in the community at large what the definition of disability is, what is the scope. It would help to get appropriate resources, build capacity of family and community around disability. As they look toward foster and adoptive care, will need to be able to support those families. Basically, there is little understanding of disability - need to increase capacity. Also, need to increase training of social workers on the care of CWD. We then visited Misisi compound. We visited two families at risk of separation. Family 1 was grandparents, grandpa was blind, who owned their house and had custody of 2 children (parents died). The grandmother sorts beans and if she gets paid with money or food, her family eats. The second was a semi-disabled grandmother caring for two granddaughters. Their parents died. Both of the grandmother's sons were dead. They lived with a friend in her one bedroom house. When the friend drank too much, she became abusive and threatened to throw the woman out of the house. One daughter wanted to go to school but was not registered because they could not afford clothes, books and shoes. The grandmother had crutches, but when she used them she fell over. She just crawls to get around. She was sick and isn't warm enough at night. Details of the compound · Extreme poverty

		· Homes are very small block homes with a curtain for a door (even though it's very cold out) · Latrines are outhouse style and shared by many. No hand washing station is evident · Babies sit on the ground eating dirt, pieces of metal, glass, stones · Very few children have shoes · Some do not have clothes · Most are very dirty · Urban setting near city center allows for begging or selling piecework · Thousands of people living in small area · Access to water is limited · Those that have plots near the water charge others to have access to it · Water must always be transported to home by bucket · Many children from babies to 10-11 year olds are observed sucking thumbs or placing items in their mouths to chew or suck on (likely due to hunger) · Young girls becoming pregnant is very common · Many young girls are smoking (something) that results in a high number of spontaneous abortions- stillborn babies are often found in a water area that was dammed up · No infrastructure exists so garbage is piled up all around · Many green, drippy noses observed
Friday, June 24, 2016		

Bethesda Mercy Ministry -- School for CWD -- affiliated with OM (Mary, Dana, Renee)		**School Information:**
		• Began in 2009 and selected the community, because people already knew of OM and welcomed the school. The project grew out of the vision of the current director along with a woman from Germany (since returned) who shared the same vision to help disabled children. While sanctioned and administered by OM Zambia, the program is not integrated into a net of medical service providers and functions much as a stand-alone provider.
		• Services provided to children: school from 8:00 AM until 1:00 PM.
		  • Includes skills training, religion, and lunch
		  • Attempt to include a protein such as beans or nuts along with nshima and greens. On the day we visited one of the volunteers had bought chicken.
		  • Also has a physiotherapist who works with the children. She is from Germany and recently finished year 1 of a 2 year stay at Bethesda.
		  • Another volunteer from the Netherlands with a two year commitment also works with the program.
		  • Has a partnership with a hospital in Lusaka to help with braces.

		• Provide bus service to offer transportation to children who live in another town. • Fees: Charges 20 KW every 3 months to help with food expenses/supplies (hard to get parents to pay this). • Most funding comes from Germany. • Information about students: 3 girls (1 of whom does not attend any further); 16 boys. • Dx: FASD, CP, Down syndrome,strabismus, epilepsy, low-vision (could be helped with glasses?) • Ages: 3 to 24. • Services for Families/PWD: offers several fellowship times during the week for men with disabilities, women with disabilities, and mothers of CWD (learning to sew and do other handicraft to sell at the Fig Shop) • Community Beliefs: • If you drink beer during your pregnancy, you will have a light skinned child. • Witchcraft causes disabilities. • Children in Community not accessing services. • Identified 6 or 7 other children in the community who would benefit from programming. • Bethesda tries to maintain contact with these families through home visits. Visitted with John, a 22 yo boy with profound stunting and a long history of seizures. John who is considered bewitched is staying with a woman (grandmother) felt to be a witch. John comes to the program when able but recently has not been walking well (??? reason neurologic, nutritional etc.) Their home within the village provides only basic shelter. Food was in very short supply and what we brought was the first thing they'd had to eat that day.
Nanga Primary School (Paula, Donna)	Mazabuka, Zambia (approximately 24 km from the town) Meeting with Hansangu Milambo Wyller (Deputy director of the school), 4 teachers, and 3 parents (all fathers)	-Mission Statement: To provide quality education and practical skills in a conducive and friendly environment effectively and sustainably to learners with special needs to enable them to live independently and contribute positively to national development. -Nanga school is a government run boarding school under the Ministry of Education started in 1995 -Currently there are 32 students (16 boys and 16 girls) ages 7-21 years with a variety of disabilities -Grades 1-7 primary school -Classrooms are in 2 buildings, there is one girls dormitory and one boys dormitory, latrines are out in back of the dorms-they have one for students to be able to sit down, there is no

		kitchen or dining facilities-the kitchen is a small shed in back and the children usually eat outside -Accept all disabilities including hearing impaired, visually impaired, physical disabilities, and cognitive/intellectual disabilities -Currently they have 2 children in w/cs (standard hospital transport chairs) with what looks like CP -They follow the normal Zambian school calendar which is 3 mos of school followed by 1 mos at home (total of 9 mos of school) -Children come from surrounding villages and from far away -5 classrooms total-the children are grouped according to disability and level of functioning (for example, all the hearing impaired children are in 1 class together), the children then come together for other activities such as physical sports -No physiotherapist or access to one. They have some donated physiotherapy equipment but no space to put it currently, so it is not being used. -They offer academic and technical training for children with disabilities, their aim is for the students to have a skill that is employable when they graduate. They emphasized finding something the child likes and can do well and then working on that skill as a potential income source -The school is a government institution with very little funding. Families subsidize what the government gives. Each family is asked to pay a fee (based on what they can offer), many of the families have high needs themselves including poverty -Critical needs identified by the school • Dining hall and kitchen facility • Boarding houses need patching and fixing • Structures need to be painted • No electricity (need cables) • Toilet and shower structure for the staff • They would like to have 8 new structures for staff to live in-they currently have 2 that need renovations • Families of the children need sponsorship • Computers-they have none • Braille books • Fence for security purposes around the property • Additional room for physiotherapy-have some donated equipment, but not able to assemble it due to space issues • Store room • Hearing aides • Walking canes for visually impaired

		• w/c's-they have 2 which are being used • Play materials for the children • Nutrition supplementation program • Would like their own sick bay. There is a clinic nearby, but transportation is difficult and they indicated that the doctors often don't know how to deal with some of the issues of the children with disabilities. The nearest hospital is 24 km • **Training!! Physiotherapy, more resources for teaching the children, training for parents-they emphasized this several times Strengths: • They have family and community members who are involved and feel passionate about the school-even those who do not have children who attend the school • PTA group • They indicated that more acceptance was happening of these children, but more sensitization was still needed in the community. They stated that the children with disabilities often come last (when getting needs met) • They have started initiating parent training and had their first one last year where the parents came to learn some sign language and braille. They want to continue these, but getting parents there is a challenge (transportation issues again). They recognize that involving the parents is important • They have extensive gardens and grow their own vegetables. They indicated the children's diets were lacking in fruits and they are not hooked up with any other feeding program • Parents indicated that the school was very positive for their children and the community
Saturday, June 25, 2016		
World Vision International (Donna, Maureen(	Kristi Urich: stationed in Seattle Doreen Chizyuka: stationed in Lusaka Donna: St Kate's Maureen: SPOON	Kristi and Doreen shared the focus of their Baby WASH program. · Moving toward integration, away from silos · Evidence based · Working with University of NC on research, tracking, monitoring, standardizing programs · Looking at hygiene, nutrition, maternal health and early child development as 4 connected components WV is updating their Global strategy- these two ladies are pushing for more understanding and inclusion of CWD in programs with specific solutions for them Partnering with Messiah College on equipment needs, need more work on inclusive designs for water access Want to increase understanding of disability among staff, include PWD in guidelines and then take specific action

		Currently include PWD in all community meetings, if no one with a disability is present, they cancel the meeting and re-schedule Infant feeding: current practice is to discourage use of bottles for premature infants in government run hospitals, using tiny cups, spoons and syringes to feed preemies. This has been due to the poor sanitation of bottles In private hospitals, use of bottles is encouraged Stigma · Belief that drinking a dark beer during pregnancy will result in a light skinned child · Belief that use of contraceptives leads to having a CWD Focus of WV is on social inclusion of CWD/PWD WV has a "Global Health Fellowship" opportunity for student placements Would love to collaborate with SPOON and team to improve the Tool Kit by including information addressing CWD and infants' special needs Advice · Best way to address programs is through CBR · In order to change perceptions around disability, need to expose people to individuals with disability, allow individuals to find a voice and assist them with advocacy-documentary "Channels of Hope" highlights success · Approach communities on issues of Child/maternal health/disability through Faith leaders: Muslim, Christian, Tribal · Incentives can be limited to those that make sense for program (i.e. bicycles for those that need to travel) · Identify barriers through observation and by asking community members/PWD to identify them Groups who unify disability programs in Zambia · Disability rights Watch (private organization) · Zambia Persons with Disability (Gov't org) · Zambia Federation of Disability Organization (charges a subscription) Technology Info for Zambia · 3 major cellular carriers o Zamtel (local) o Airtel o MTN · Each carrier provides varied coverage depending upon the area and how many towers they have · Most people have cell phones · Talk minutes, texting, and internet minutes are purchased through a credit · Credits are available on the street (literally as you wait in traffic) · Phones and tablets are well received by community
Debrief		3 questions: 1. Can QofL of CWD living in institution be improved? 2. What are the conditions of CWD living in the community? 3. Community readiness? Interventions should be evidence-based, tested, and then proposed at the policy level. Current situation at every level Policy level

		Government Role: have written general policy on PWD/CWD, not specific · Identification · Registration · Provide access and equipment Fragmented departments, poor implementation due to funding Government is overwhelmed with needs Professional Education level · Special education certification allows teachers an opportunity to find jobs and be promoted · OT program is accredited- will begin in 2017, 3 OTs in Zambia currently- 5-year program · 2 Physiotherapy schools in Zambia- 5-year program · Lusaka Apex Medical School is pushing for interdisciplinary work · Social work school has a program, there is a professional group · SLP- is a component of ENT. Acts as an apprenticeship, not a certification · Several orthopedic hospitals in Zambia that perform surgery on CWD and treat. Will provide care but transportation and follow up are still issues (Beit Hospital, St Johns the 2nd) Institutional level · Visited primary and secondary schools · Teachers are present · Teaching Braille and Sign language · All schools are lacking specialized equipment, basic supplies, food · Provide both academic and technical training · Barriers include school fees, transportation, basic supplies such as shoes, uniforms, books, specialized equipment · Capacity to take students in specialty schools is very low · Training needs: i.e., physiotherapy techniques, family training St. Anthony's (institution): great opportunity for training · Limited materials · Limited interaction · Poor feeding practices · Poor supervision/ratios · Poor nutrition Cheshire (boarding school for CWD): training opportunities · Overall care of children · Run out of food/malnutrition · Close school when food runs out Bethany: ok-ish Community level Barriers · Stigma beliefs · Poverty · Access Resources · Wonderful people doing great work · Great understanding of sustainability · Great understanding of need for community based workers

		Children and Family Initiative Ideal Situation · Community based rehabilitation model · Raise standard of living of CWD's families · Reduce stigma around CWD · Use resources to address prevention o Two components of prevention Prevent admission to an institution Prevent demise of children living within institutions Utopia Situation · Use St Anthony's compound to operate as a hospital/clinic center · Reintegrate children who can be with families · Provide family care settings for CWD on site · Provide shelter and food to caregivers and their families who act as foster parents · Allow families to live on site with caregivers/CWD to create a family unit · Provide training/education to all · Provide appropriate growth/nutrition/feeding practices monitoring through CMI (Count Me In SPOON app) Action plan/next steps: · Spend time with Holy Family · Continue to develop relationship with sisters in the Copperbelt · Revisit conversations with outreach programs and conduits in the communities