

Perspectives on Disabilities among Congolese Refugees in Iowa

Leadership in Diversity & Disability Fellowship Capstone Project by Julia Ganda

Overview

- Fellowship
- Fieldwork and Community Development
- Congo Demographics
- Capstone Project
- Takeaways

Fellowship Timeline



Course Studies

- History of Disability and the Disability Movement
- Family Centered Care
- Autism Spectrum Disorder – Medical Model, Neurodiversity Model
- Federal and State Disability Legislation and Policy
- Service Models, Funding, Medical Home
- Assistive Technology
- Employment and Post-Secondary Education for people with disabilities
- Mental Health and Intellectual/ Developmental Disabilities
- Health Equity and Cultural Humility
- Social Determinants of Health

Fieldwork & Community Development

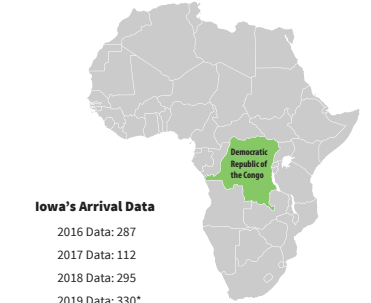
- Clinical observations – Neurodevelopmental Evaluation (NDE) and Healy Clinic
- Child Health Specialty Clinic in Dubuque
- Community Partnership Advisory Committee (CPAC) Meeting
- Olmstead Consumer Taskforce
- Refugee Alliance of Johnson County
- Hello, It's US!

Objectives

- Learn about how disabilities are perceived and defined in the Congolese community
- Identify needs for services that are potentially not being met
- Begin a conversation/dialogue about disabilities among the Congolese community

Congo Demographics

- Democratic Republic of the Congo, DR Congo, DRC
- 2nd largest country in Africa and 11th largest in the world.
- 2019 estimated population of 86.79 million
- 80-95% Christian (most Christian nation in Africa)



Iowa's Arrival Data

2016 Data: 287
 2017 Data: 112
 2018 Data: 295
 2019 Data: 330*

*moratorium on new arrivals will start in the federal fiscal year

- Secondary Migration**
- Why do secondary migrants want to come to Iowa?
 - Family
 - Employment
 - Education
 - Cost of living
 - Wages
 - Safety
 - Impact on the community

COUNTRY	IOWA PRIMARY REFUGEES
Dem. Rep. Congo	26.0%
Burma/Myanmar	25.3%
Bhutan	12.1%
Syria	10.2%
Somalia	8.7%
Iraq	5.2%
Eritrea	4.1%
Sudan	3.1%
Burundi	1.6%
Afghanistan	1.4%
Other	2.4%

Materials and Methods

- Checked with human subject research – no IRB needed
- Created interview questions
- Interviewed 16 Congolese adults
- Audio recorded 10-40 minute interviews
- Transcribed and translated interviews
- Provided \$15 grocery store gift cards for participants

Interview Questions

1. Do you know anyone who has trouble seeing, hearing or speaking?
2. Assuming there is an interpreter do you know anyone over the age of 18 who has difficulty or needs support understanding information? Why do you think they have trouble?
3. Do you know any kids over the age of 8 who have trouble with understanding information? Why do you think they have trouble?
4. Do you know any school-age children or adults who have trouble controlling their actions?
5. If you know someone with a disability, do you know if they are getting any help? If so, what type of help are they receiving?
6. What role does family play in people seeking out help/services?
7. What have you seen in the United States in terms of disabilities that is different from what you saw in Congo?

Cognitive Data Analysis

- Reviewed transcripts
- Identified and coded key statements
- Grouped themes into codes
- Determined relationships and hierarchy between themes



Perceptions

- Impact of disability
- Medication – no medical treatment needed
- Stigma
- I don't know
- Denial of disability
- Fear of seeking help

Perceptions Quotes
 "People abandon you and see you just like (a) mad person"
 "It's not something that's a medical thing that needs to be treated"

Disability

- I don't know
- Denial of disability
- Perceived cause of disability
- Type of disability
- Burden to society – Hopelessness
- Overlooked
- Fear of seeking help

Disabilities Quotes
 "Parents say that they are still just kids and that once they grow up it will all go away"
 "Some people think it's a western thing and that Africans do not get those sort of diseases or disabilities in general"
 "We tend to ignore a lot of the signs and say maybe its just one of the behaviors that they have"

Society

- Cultural impact in US
- Cultural impact in Congo
- Community role
- Religion
- Language
- Burden – Hopelessness
- Overlooked
- Family role
- Fear of seeking help

Society Quotes
 "[For] mental health you look to God instead of medication"
 "Maybe it's witchcraft that causing them to be that way"

Services

- Don't know where to receive services
- Services available in the U.S. – Department of Human Services
- Services not available in Congo
- Family role
- Stigma
- Fear of seeking help

Services Quotes
 "[They] don't know where to go or how to begin the process of getting help. Many that I know never want to get help because of the stigma that is connected with receiving help"
 "Within our community, people shun trying to get help. They think that a lot of things are supposed to be private and that it's embarrassing to have any health issues most of the time"

Barriers Identified

- Fear of seeking help
- Tend to not talk about disability and deny existence
- Belief that no medical treatment is needed or that it will go away
- Belief that it's only the family's responsibility to care for people with disabilities
- Belief that disability is caused by evil, sin or witchcraft

Takeaways

- Service providers must develop culturally relevant disability resources
- Increased need for community education
- Increased Congolese literature needed

Possible Partners for Disability Initiatives

- Partner with:
 - Congolese Health Partnership
 - African Communities Network of Iowa
 - Refugee & Immigrant Association
- Coordinate with existing community efforts
- Involve local pastors/churches/community leaders to discuss disability, stigma, and services
- Provide culturally responsive care
- Recruit staff from the Congolese community and other Africans

Citations

- Iowa Department of Public Health, Refugee Health Program, Bureau of Immunization and Tuberculosis, Refugee Health Program Annual Report 2019, Des Moines: Iowa Dept. of Public Health, 2019. Web. <https://idph.iowa.gov/immtr/rh>.
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- Office of Disease Prevention and Health Promotion. (2019). Social Determinants of Health. Retrieved from <https://www.healthypeople.gov/2020/topics-objectives/topic/social-determinants-of-health>

