When will my child be cured?: Challenges of social workers supporting African children with intellectual disabilities and their families.

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Story behind the work

- Research inspired by a question from practice: "when will my child be cured?

Implications of the question

Lack of understanding?

Misunderstanding?

Aspiration of a father?

Wish or hope of a (every) parent?

Perspectives of the studies
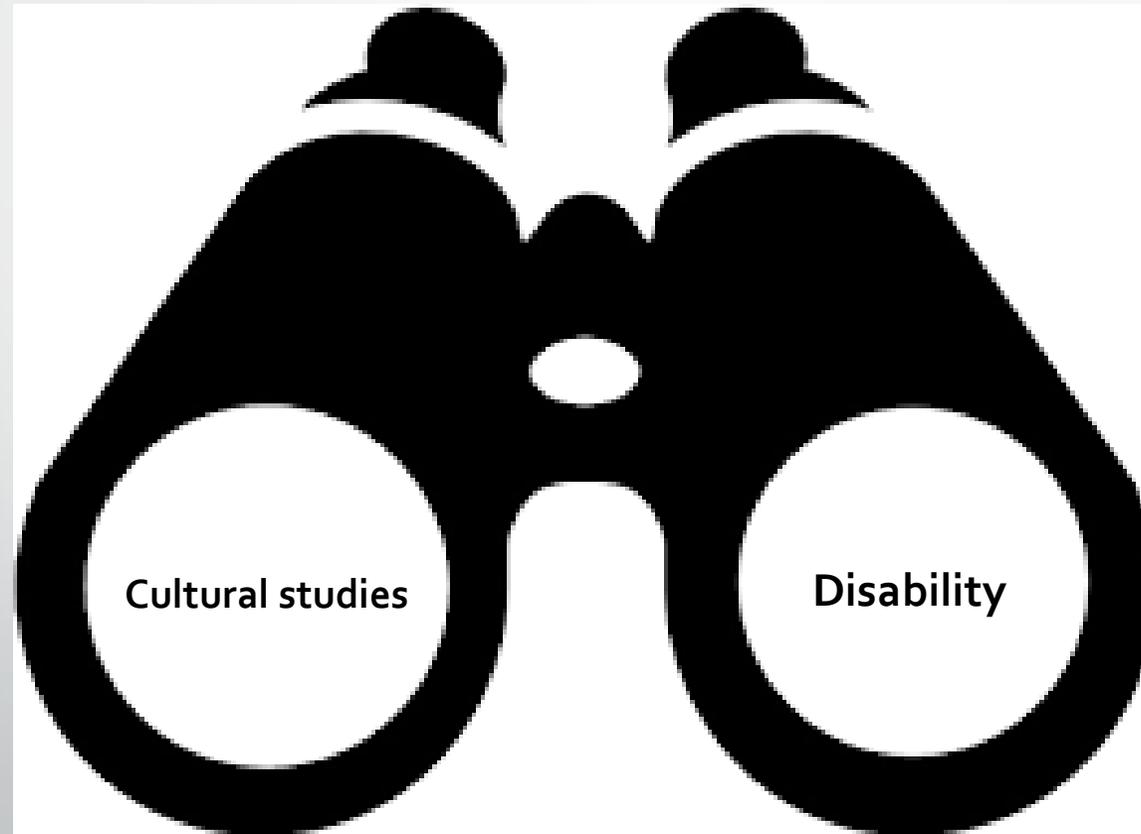
Demography: Immigration

❑ 3rd factor of population change, after fertility and mortality (UN, 2012):

❑ Immigrants constitute 10% of European population.

❑ Ireland's population ➜ 12% (593,600) "non-Irish nationals" from over **200 countries** (CSO, 2016; 2017).

❑ Africans in Ireland:

➢ 57,850 and majority between 25 and 39 years

➢ 28,336 children

➢ 54 countries of African represented, except 4 (Comoros, Djibouti, Gabon, Sao Tome and Principe).

➢ Mostly urban and semi-urban residents with highest concentration in Dublin's surrounding areas, especially Drogheda (CSO, 2017).

Demography: Intellectual disability

- 28,388 people in Ireland
  - 59.1% men and 40.9% women
  - 10,032 children
- Sligo has the highest prevalence while Leitrim the lowest.
- Africans represented (but no figures available)

Africa: scope of the study
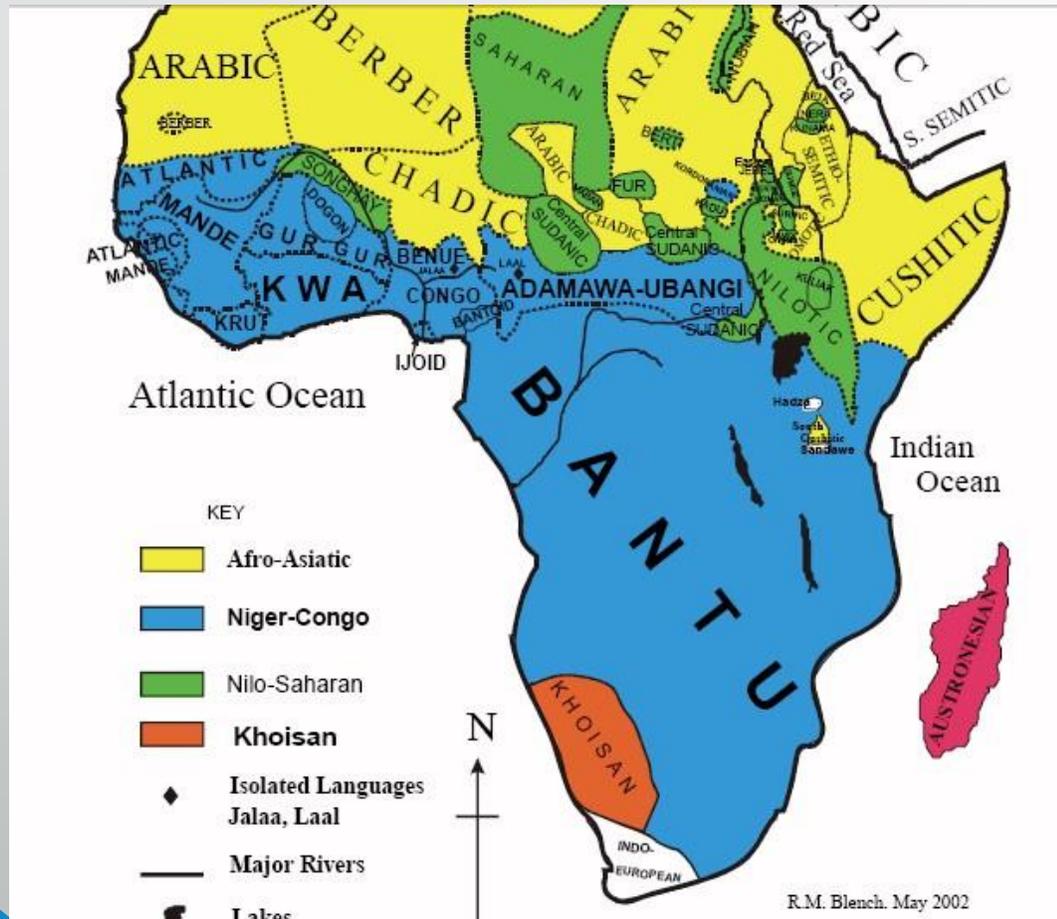
- Black Africa
- Bantu people
- Religion
  - Christianity
  - African Traditional Religion
- Any commonalities?

The Study/Research

❑Aim:

➢ Challenges encountered by Social Workers supporting children with intellectual disabilities from African background and their families.

❑Objectives:

➢ Construct of intellectual disability among Africans.

➢ Impact of acculturational factors (migration and religion) on those constructs and beliefs

➢ Impact of children's intellectual disability on their families.

➢ Certain approach used in supporting children with disabilities and their families.

Overall and study design

❑Qualitative research method used:

➢Qualitative research method.

➢Appropriate to study human experiences, beliefs, perceptions, intentions and behaviours.

Sampling

❑Sampling frame:

➢Social workers working with African children with intellectual disabilities and families within the last 5 years

➢All CORU registered and practising in Ireland

❑Approach/technique:

➢Purposive sampling

❑Access:

➢ Head of Social Work Departments of the organisations

➢Members of Senior Management Teams of Tusla and HSE

Sampling

❑Sampling size:

➢8 Social Workers based in two major Irish cities

- ○ 4 Africans and 4 Irish
- ○ Gender parity: 6 women and 2 men
- ○ Practice experience: 2 to 25 years.
- ○ Age: Ranged from mid 20s to mid 50s.
- ○ Education: Level 9

Data

❑Collection method:

➢Face-to-face interviews using semi-structured questionnaire

➢Duration of interviews: Between 30 and 45 minutes

➢Audio recorded and later transcribed.

❑Analysis:

➢Thematic analysis

Findings

❑ Making connection: Cultural and linguistic references

➢ Families' residency in Ireland: Variable (from a few years to 15 years).

➢ Parent(s)

o Consider Ireland as home at the same time strongly to their African roots.

o Bi- or multi-lingual (speaking at least one African language).

o Knowledge of spoken and written English varied.

Findings

☐ Making connection: Cultural and linguistic references (Contd)

➢ Children with intellectual disabilities:

  ○ All born in Ireland.

  ○ Use Lámh sign language or speak English, but no African language.

➢ Siblings of the children with Intellectual disabilities

  ○ Born either in Ireland or other countries

  ○ Speak English (all) and Irish (very few) but no African language.

Findings

❑ Quest for meaning

➢ Understanding of medical diagnosis of their children:

- ○ Ignorance
- ○ Difficulties in accepting
- ○ Refuse to name
- ○ Change the name e.g. sickle-cell
- ○ Understand

Findings

- Cultural perspective:
  - "Others-like-me"
    - Hereditary
    - Ritual practice by a enemy of the family
    - Witchcraft.
  - "Others-higher-than-me"
    - Evil/spirit/ancestors
    - God (curse)

Findings: Map summarising quest for meaning
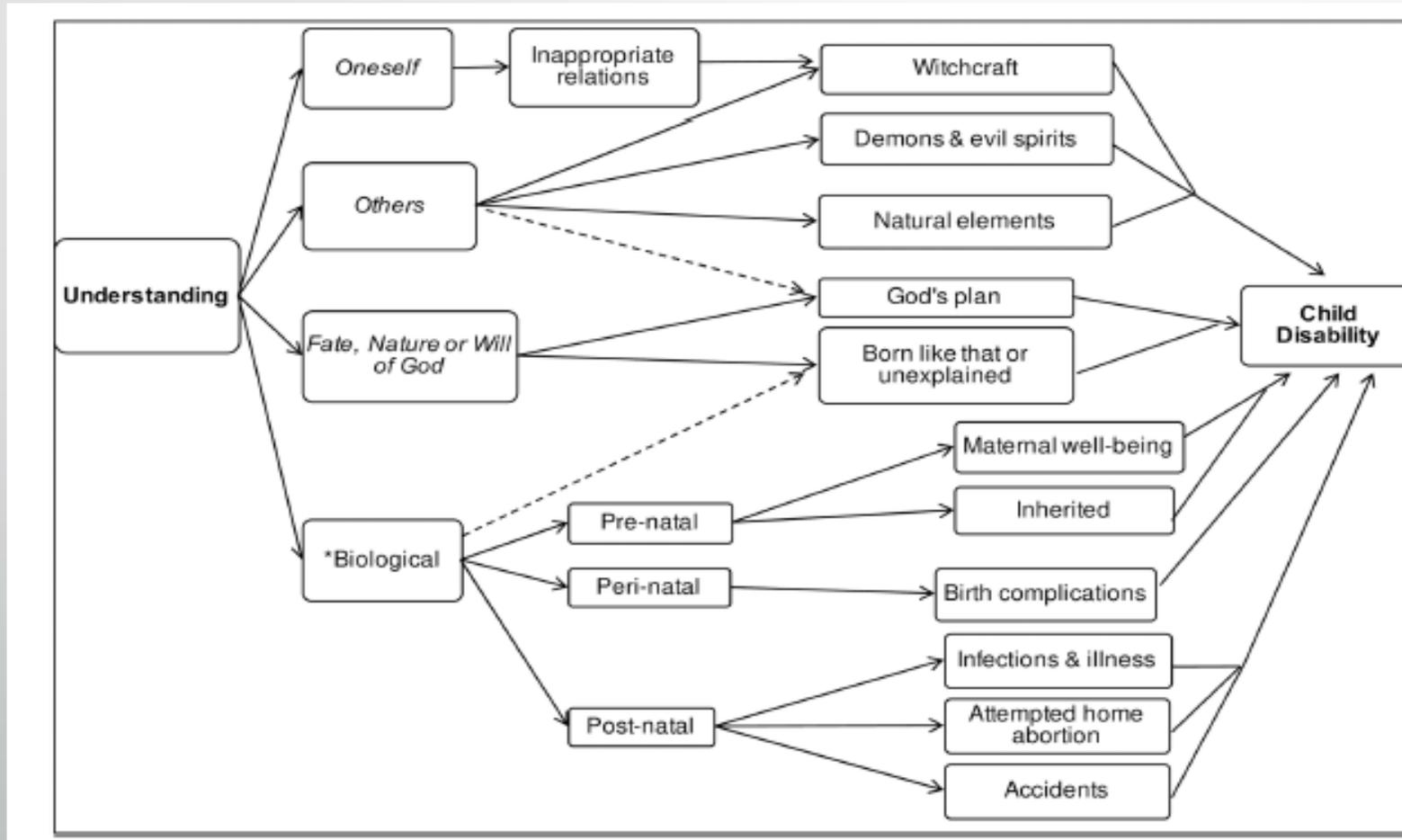
(Bunning et al., 2017, p. 7).

Findings

□ Attitudes of the families:

➤ "Others-higher-than-me"

○ Spirituality, prayers and miracle-seeking response

➤ "Others-like-me":

○ Internalised (psychological) response ➜ self-blame, guilt and fear.

○ Sociological response ➜ "shielding the young person, shame, isolation and avoiding contacts with other people. For example, a family preferring the placement of their child in Irish rather than African family.

Findings

❑ Coping mechanism/skills:

➢ Family (including those outside Ireland) and social network

➢ Formal support from local communities and professionals

➢ Religious personalities and communities

Findings

❑Revisiting some approaches

➤Person-centred approach

○ Individualistic verse Community oriented cultures.

❑Training needed

➤For professionals

➤For families (parents)

Application to Practice/Policy change

❑ Practice prejudice:

➤ Considering all members (generations) of an African family as being culturally at the same level.

❑ Implications of "shielding" of a child with disability by their family

➤ For example, preference for placement in an Irish to an African family.

○ This questions literature and research promoting "same-race placements" for African children as the ideal practice (Goldstein & Spencer 2000; Rabun, 2018; Selwyn & Wijedasa, 2009).

○ Those advocates overlook the differences and prejudices existing among African cultures themselves (Robinson 2016; 2017).

Application to Practice/Policy change

❑ Quest for meaning and the risks involved

  ➢ Diagnosis as human fault (often input to mothers in patriarchal society) ➜ Human Rights issues

  ➢ Evil or God as origin of diagnosis:

    ○ Reinforced by retributive justice commonly present in the theology of many Pentecostal churches.

    ○ Risk of stereotyping people with disabilities and exploiting their families (Amanze, 2013; Kalu, 2008; Kangwa, 2016).

  ➢ Conflict with Irish legislation (GoI, 2000; 2004).

  ➢ Need for a policy on vetting and training of religious community leaders in human sciences, human rights and Irish legislation ➜ such initiatives considered/attempted in Belgium, France and Netherlands (Husson, 2007; Peter, 2003; 2006; Sözeri, Altinyelken & Volman, 2018)

Further research

- Preference for placement in Irish rather than in an African family

- Study on the constructs of intellectual disability done directly with African families themselves instead of the perception of professionals working with them.

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