

Health Systems, Health Policies, and Health Issues for People with Intellectual Disabilities in England

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Agenda

- Health System in England
- Legislation Regarding the Health System in England
- Legislation Regarding People with Intellectual Disabilities
- Deinstitutionalization and its impact
- Health Care Provision for People with Intellectual Disabilities
- Conclusions and Future Directions

Health System in England

- One of four devolved nations in the UK.
- Each nation has its own health system (i.e. NHS England).
- Includes primary, specialist, and emergency care, and allied health professionals.
- Generally free at the point of access, some exceptions.
- Also social care (non-health support) but mix of public (national and local government), private, and voluntary sector.

Legislation in England

- Equality Act 2010: includes protected characteristics (ability is one).
 - Public providers must offer reasonable adjustments under this Act.
- Health system organized according to the Health and Social Care Act of 2022.
 - Changes included provision and delivery of services.
 - More integration of health and social care.

Legislation regarding People with ID

- UN Convention of the Rights of Persons with Disabilities.
- UK is a signatory (ratified in 2009).
- UK Office for Disabilities reviewed progress in light of Equality Act 2010 in 2011.
- UN Committee on the Rights of Persons with Disabilities held an inquiry on the UK in 2016, UK government response in 2021.

Deinstitutionalization in England and its Impact

- With the founding of the NHS in 1948, much care of people with intellectual disabilities was shifted to NHS-run hospitals.
- Many hospitals decommissioned in 1960's and 1970's with growth of community living movement.
- Some people with intellectual disabilities with complex needs remained in institutions.
- Possibility of abuse (e.g. Winterbourne View scandal).

Healthcare Provision for People with Intellectual Disabilities

- Role of community-based Learning Disabilities nurse.
- LeDeR report programme investigating deaths of people with intellectual disabilities and/or autism.
- Oliver McGowan Mandatory Training programme to prevent overprescribing of antipsychotic medication to people with intellectual disabilities and/or autism.
- Valuing People White Paper (2001), Valuing People Now Report (2010).

Conclusions and Future Directions

- Some positive policy and legislation to optimize health and social care for people with intellectual disabilities living in the community.
- Still some health and social inequalities remain, and care may not always be person-centred.
- COVID-19 may have exacerbated some inequalities, more needs to be done.

Thank you!



For more information,
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BACKGROUND

- Zambia – rich in natural resources
- a low-income country on the African continent which is facing a high rate of health inequalities
- Health reforms in place- ***the practical implementation of disability policies remains challenging***

BACKGROUND

- People with intellectual disabilities (ID) face barriers to accessing healthcare services in Zambia
 - *This due to geographic or socioeconomic factors, stigma, and limited specialized health professionals*
- The National Disability Survey of 2015 did not specify ID, and current specific epidemiological data on ID is lacking.
- In Zambia, formal ID assessments are rare due to **low priority** and **challenges in screening procedures and diagnosis, limited access to assessment centres, and a limited number of appropriately trained health professionals**

BACKGROUND



Why a training about health of people with ID?

People with ID often depend on caregivers and community workers who play an important role in health support needs of people with ID.

However, they may not be aware of the specific health needs of people with ID.

AIMS AND OBJECTIVES OF THE STUDY



1. Conduct a participatory needs assessment to indicate training needs of community workers regarding health of people with intellectual disabilities in Zambia.
2. Develop essential building blocks for the training programme, complemented with expertise of medical and health professionals.
3. To pilot the training programme with health workers in Zambia.

AIMS AND OBJECTIVES OF THE STUDY



1. Conduct a participatory needs assessment to indicate training needs of community workers regarding health of people with intellectual disabilities in Zambia.

Research question:

What are experiences with the everyday support in health and healthcare needs of people with intellectual disabilities in Zambia?

THEORETICAL FRAMEWORK

- Prevention , Recognizing and Follow-up health problems
- Prevention
- People with ID themselves have expressed the need for support from the social environment that help them to make healthy choices .

THEORETICAL FRAMEWORK

- Prevention , Recognizing and Follow-up health problems
- Recognizing
- The prevalence of physical-health problems is higher among people with ID compared to the general population.
- Recognizing early signs and symptoms of health problems of people with ID is crucial to timely intervention. However, due to difficulties with communication, people with ID rely heavily on caregivers and community workers to recognize health problems.

THEORETICAL FRAMEWORK

Prevention , Recognizing and Follow-up health problems

- Follow-ups
- Community workers can support people with ID following-up on medical advice, such as the use of assistive devices and communication with health professionals. Community workers can support people with ID to obtain, process, and understand health information and carry out the medical advice provided by the health professional.

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DATA COLLECTION

Liliane Fonds

open the world
for a child
with a disability

Leonard
Cheshire
Disability

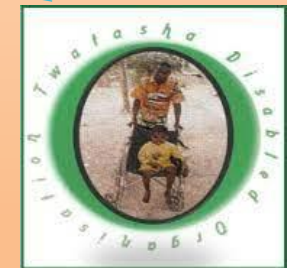
**Cheshire Homes Society
of Zambia**



Urban



peri-urban



rural

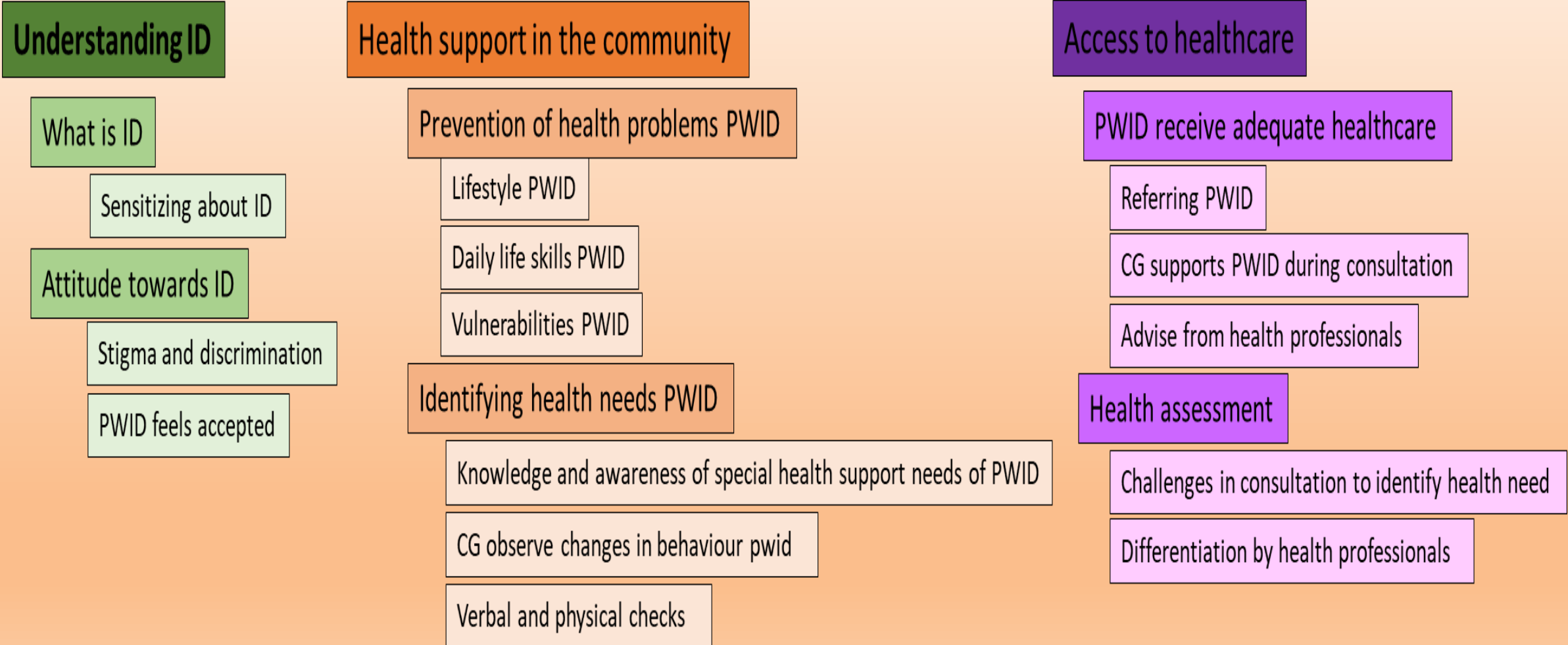


FINDINGS

The focus group discussions were done to answer the research question:

*What are experiences with the everyday **support in health and healthcare needs** of people with intellectual disabilities in Zambia?*

DATA ANALYSIS AND RESULTS OF FOCUS GROUPS



NEXT STEPS

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Expert consultation:
ID physicians and
steering committees

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Levy Mwanawasa
Medical University



Cheshire Homes Society
of Zambia



train ID

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International perspectives on healthcare for people with intellectual and developmental disabilities

A synthesis of the 13 special edition papers

Understanding the international organization of healthcare

- International knowledge exchange to improve healthcare systems worldwide
- Collaborative advocacy efforts to raise awareness about the needs of people with IDD
- Possible opportunities for joint research projects, shared resources, and cross-country initiatives



5 themes

1. General characteristics
2. History and context
3. Organization of healthcare
4. Challenges
5. Best practices



1. General characteristics

- Different interpretations of the term IDD
- Challenges in determining accurate prevalence figures
- Geographical differences

2. History and context

- Own national histories
- Cultural, and religious beliefs
- Deinstitutionalization

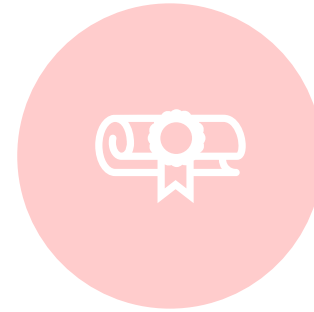
3. Organization of healthcare



DESCRIBED IN NATIONAL
RESOURCES



SAME AS GENERAL
POPULATION, BUT
INTERDISCIPLINARY
APPROACH IS NEEDED

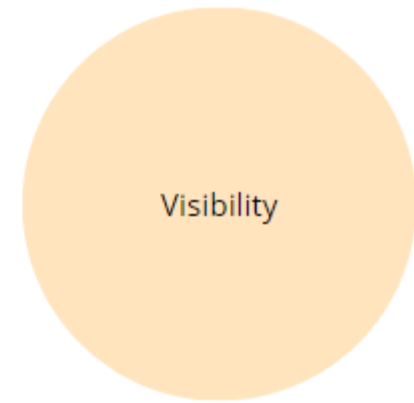
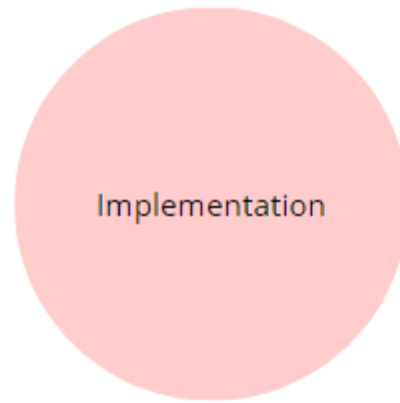


SPECIALIZED IDD EXPERTISE
IN MULTIPLE DISCIPLINES



ORGANIZED DIFFERENTLY IN
RESIDENTIAL, DAILY
ACTIVITY, OR
(RE)HABILITATION FACILITIES

4. Similar challenges

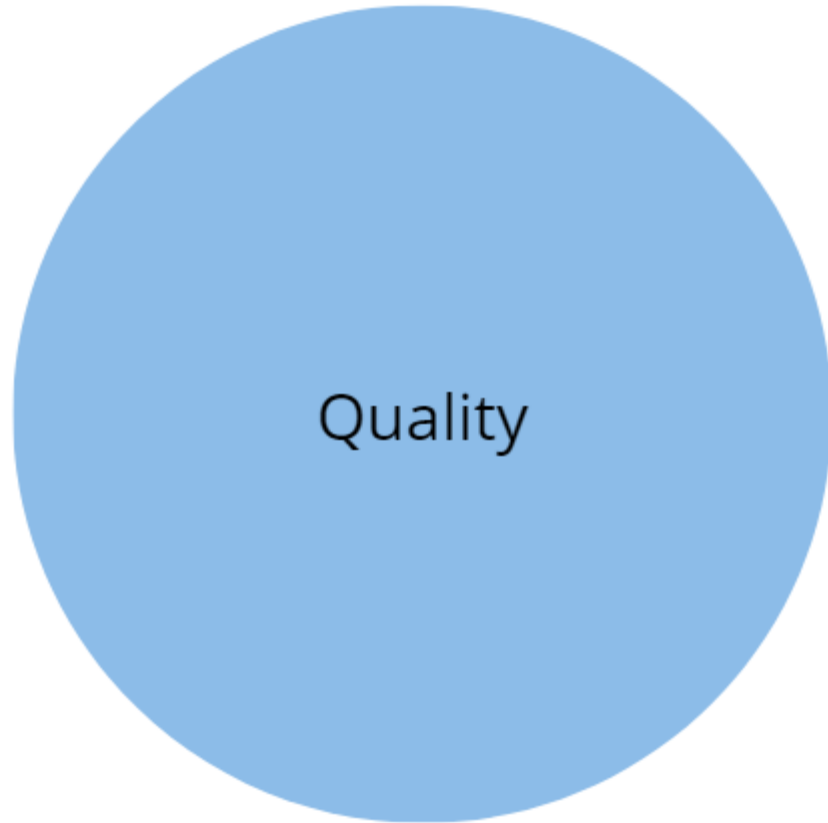




Access

Barriers

- Geographical
- Financial
- Attitudinal
- Organizational



Barriers

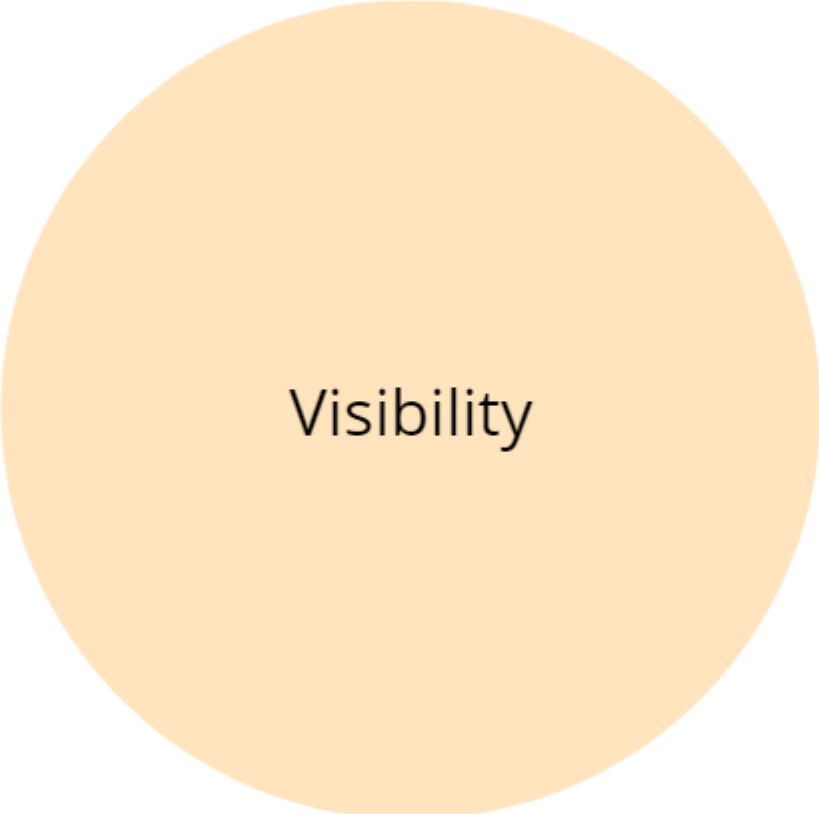
- Professionals' competence
- Negative attitudes
- Lack of confidence
- Lack of education and training possibilities



Implementation

Barriers

- Limited professional resources
- Limited financial resources
- Lack of coordination across services
- Needs of PWID not appropriately recognized in policies




Visibility

Barriers

- Identification of people with ID
- Linkage of data systems


5. Best practices



Making mainstream
healthcare services
more accessible and
suitable


Providing specialized
services

Advocating and
raising awareness



Making mainstream
healthcare services
more accessible and
suitable


- Training programs
- Priority measures



Providing specialized
services

Different forms

- Primary care vs. referral needed
- Free of charge vs. financial barriers
- Multidisciplinary teams
- Available on a small scale



Advocating and
raising awareness

- About the rights of people with ID
- Inclusion in society
- Involvement of people with ID

To conclude

- Despite differences in context, countries face similar challenges in improving healthcare for people with IDD.
- International collaboration and networking can provide essential tools in reducing health disparities that people with IDD face, starting with the challenges identified in this synthesis.

Questions?

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