

# Disability, **SEX**uality and Quality of Life: The Missing Discourse

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'A qualitative study which aims to explore disability, sexuality and Quality of Life as intertwining facets which encompass the life experience of a male named Dirk Diggler, who lives with Acquired Brain Injury'

#### **Background:**

Sexuality is a key component which binds together to make up an individuals overall Quality of Life and sexual health experience (2 & 5). It is often neglected and ignored for people living with a disability, due to the belief that people living with a disability are asexual, or have no need for sexual expression and should therefore be protected from their own sexuality (4).

#### **Research Question:**

The guiding question which underpins my research is to explore the interconnections which exist between Quality of Life, sexuality and sexual pleasure through a case study of one male, named Dirk Diggler who lives with Acquired Brain Injury. I have situated Dirk's individual case study at the centre of my research as it is from his central and personalised experience that I have explored the six radiating zones which encompass the external world of disability.

# **Data and Methods:**

Due to the deeply individualised and personalised nature of my research and the limitations which exist in terms of current literature in the area of disability and sexual health, I utilised an ethnographic interview process as a key method. This allowed Dirk Diggler's firsthand knowledge and experience to be captured in regards to his personal Quality of Life, sexuality and sexual pleasure experience. Once the central case study was established, I then extended my ethnographic interview process to encompass the six radiating zones of the external world of disability which documented the perspectives of a disability carer, disability service provider, disability policy maker, and lawyer. As an overarching facet of my research, I explored how sexuality was measured as a component of Quality of Life for people living with a disability within formal Quality of Life assessment scale reviews.

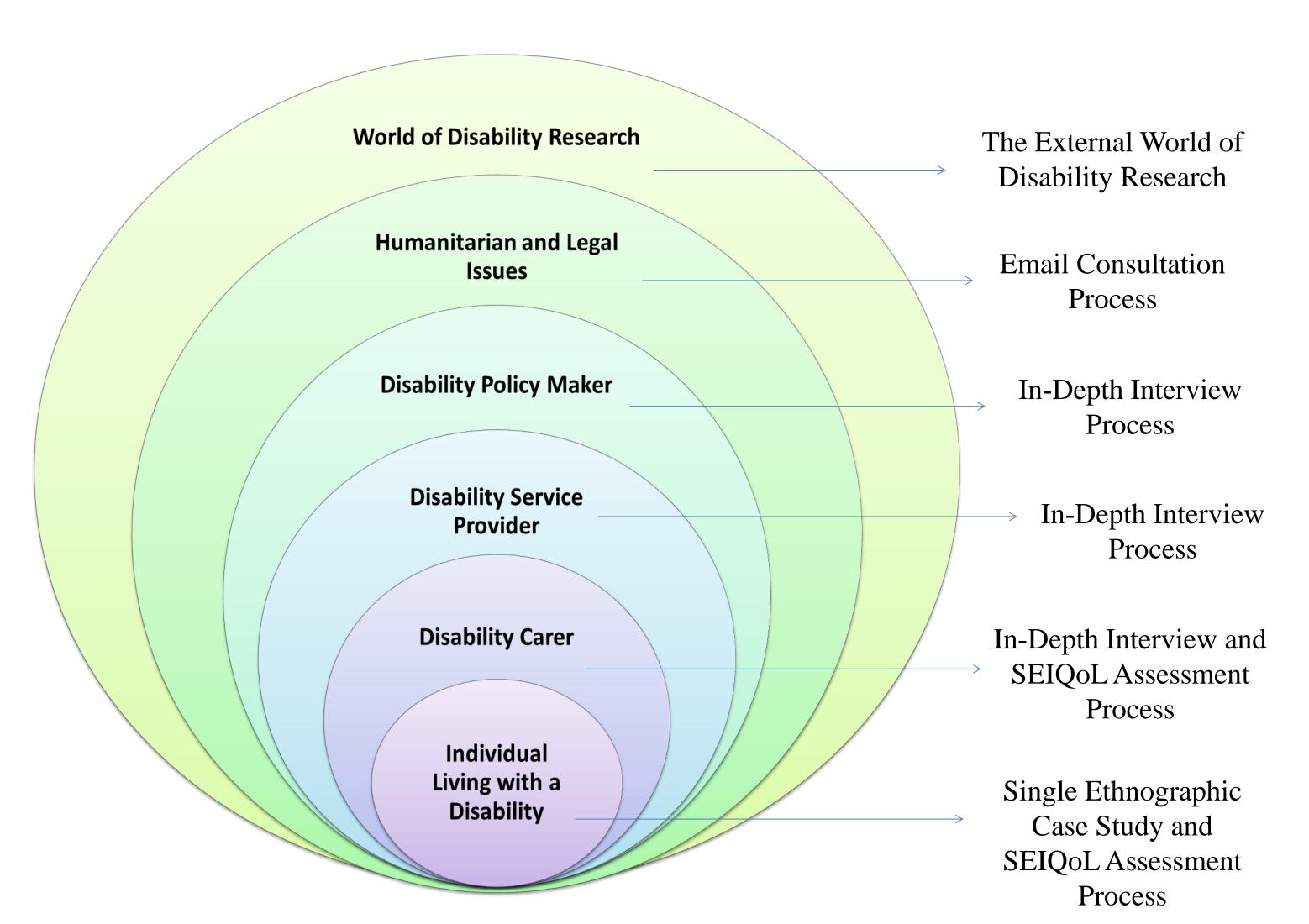


Figure 1 – The Six Radiating Zones of the External World of Disability

#### **Results:**

Sexuality is presented in Maslow's hierarchy of needs as fundamental for human existence along with air, water, food, clothing and shelter (1). This research adds to existing knowledge, which demonstrates the missing discourse of pleasure which exists among disability, sexuality and Quality of Life research.

#### **Discussion:**

It became evident from my research that not a single disability focused Quality of Life assessment scale review neither identified nor presented sexuality as a Quality of Life measurement component (3). This reinforces that sexuality is either not considered when thinking about the needs and desires of people living with a disability, or it is considered to be a luxury only to be experienced by those deemed worthy by society.

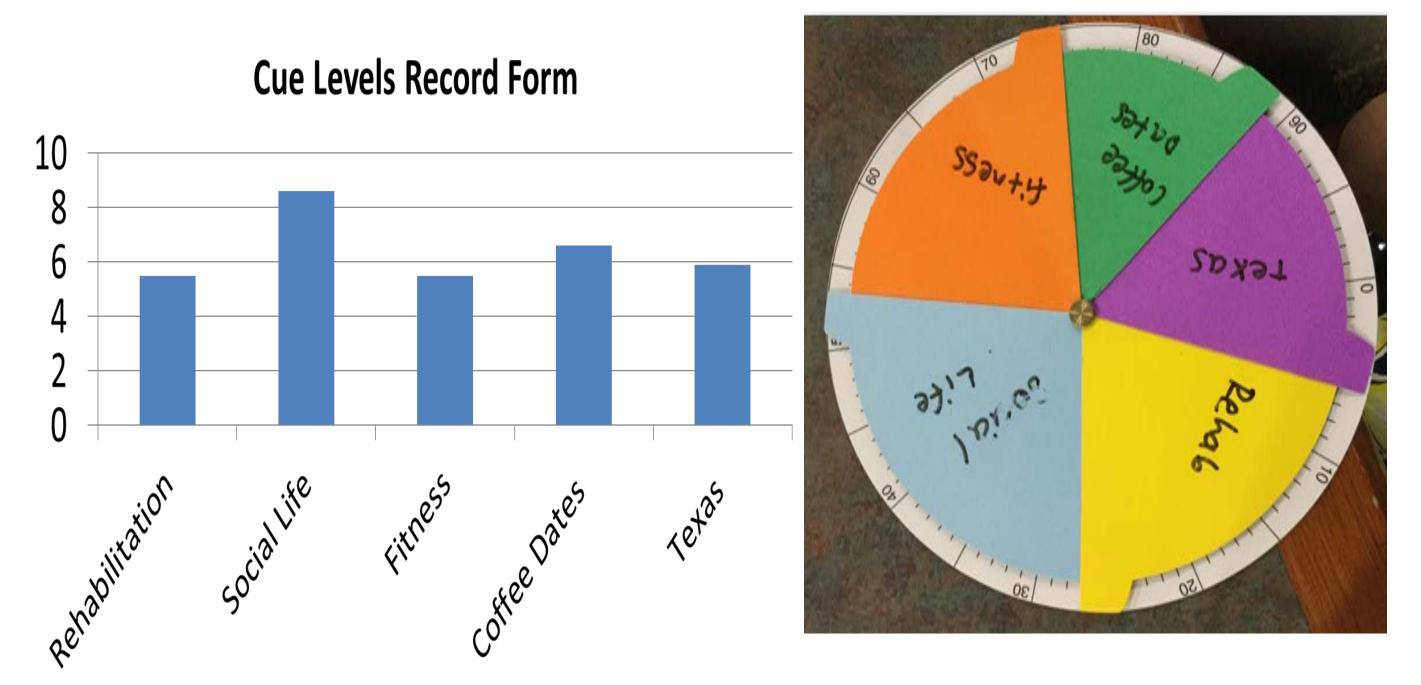


Figure 2 – Dirk Diggler's Schedule for the Evaluation of Individual Quality of Life (SEIQoL)
Assessment Profile Results

### **Conclusion:**

Sexuality as a human need and a fundamental component of Quality of Life is required to be present among all Quality of Life research and measurement assessments in order for people living with a disability to be able to express their individual sexuality as an integral facet which underpins as well as encompasses their overall Quality of Life.

# **Acknowledgements:**

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Disability Carer, Disability Service Provider, Disability Policy Maker, Lawyer

Primary Investigator/Supervisor

University of Wollongong, Australia

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