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Overview

• Life, Love and Laughter
• Bio-psychosocial-cultural approach
• Observations from practice
• Literature review
• Our vision support group
• My PhD & Future directions
• Lack of empirical data on life, love and laughter (LLL)
• LLL some of the core ingredients of mental health (MH)
• How do people who are DB experience LLL?
LIFE

• “Can we keep working, do people really respect you?”
• “All people face challenges and question themselves but can people with disability break these shackles of doom and gloom just as easy as other people without disabilities?”

LOVE

• “Will my child love me regardless?”
• “Is it possible to have a long term relationship without being so dependent on another”

LAUGHTER

• “I hardly ever laugh”
• “First sign of depression or states of anxiety is when life has no fun. Where did it go?”
Bio-psychosocial-cultural Approach

- Physical factors
- Understand the whole person e.g. intellectual, personality and psychological
- Social environment of person/family
- Impact of culture (identity and meaning)
Organizational Issues

• MH is central to practice but not talked about explicitly
  • Culture of silence

Lack of:
  • Time to discuss MH issues
  • Staff training
  • Clinical guidelines and training packages for professionals
Observations from Direct Practice

- Australian DB community has a unique culture
- No empirical research exploring the meaning and impact of DB culture on MH
- Positive and negative impacts on MH
- Not all people identify with DB culture and community
Stigma, Shame and Silence

- Few DB had ever talked to another peer about MH
- Many use words like “crazy people” “mental people” “they are mad”
- Embarrassed about accessing support
- Worried that people will find out
Lack of Mental Health Education

- Lack of education about MH issues
- DB Services geared towards disability not MH
- MH services not equipped to respond to DB
- Few targeted programs and services
Common issues associated with Mental Health

- Depression & anxiety
- Poor self esteem
- Chronic pain
- Suicidal thoughts
- Self harm
- Psychosis
- Diabetes and weigh issues
- Lack of exercise
- Social isolation and withdrawal
- Relationship issues
- Trauma
Life, Love and Laughter
Systematic Review of the Literature

Search criteria:
• DB adults, and
• Mental health and wellbeing, or
• Culture and community
• No language or year limiters
• 10 Academic Databases

• Authors and grey literature sourced
• Over 1,500 articles screened
• Aprox 120 articles included in the review
Results of my Systematic Review of the Literature

- Majority of the literature: children, education and vocational outcomes, technology, O&M, communication, sign language etc
- Lack of data on DB MH
- No best practice DB clinical guidelines or training programs
- Range of methodological issues in the data
Themes that Emerged Within the Literature

• No empirical study exploring DB culture, community, MH & LLL
• Lack of DB authors and DB perspectives
• Lack of studies reporting on: DB MH assessment diagnosis and interventions
• Most interventions, programs and services not empirically evaluated
Pathologizing DB

- “Deaf and blind psychotic patient” (Peterson, 1977)
- 21 DB persons were found to have 3-11 psych problems (No DSM, clinical assessment or DB perspectives (Hassinen, 2013)
- “28 year old DB man periods of mild and extreme rage, hitting & biting (Jacobsen, 2009)
Lack of a Voice

• Hersh (2013) semi structured interviews, communication & isolation, gatekeepers reduce the control DB (some interviews interpreted by family members)

• Jacobsen (1983) reducing self injurious and aggressive behaviors in deaf-blind person through overcorrection

(No ethics, consent, how did staff feel, only 1 psych perspective)
Negative Attitudes

• DSI causes reduced morality (Schnider, 2011)

• Negative societal attitudes towards disabilities and DB people specifically create stigma and barriers (Brennan, 2007)

• Aging population, more is needed, they are deserving, not just part of life (Lidoff, 2003)

• Miner (1995) pitty prevents DB from being seen as real people, don’t assume symptoms are “normal” for DB
Does DB Culture Exist?

- No DB culture in UK
- DB do not meet regularly
- Absence of unique language (although aspect of touch is unique)
- Some DB do not identify as being DB
- “Pure” Deafblind culture can only exist with CDB
- Cannot define “pure” CDB culture in meaningful way due to complex and profound disability
  ADB have influences of hearing and sighted world; they are not “pure” DB (Barnette, 2007)
DB Perspective on Culture

- DB is unique, gives DB people identity and pride
- Despite the diversity in language, communication style, degrees, types, causes and age of onset of DB people stick together and have a “community”
- The very diversity in communication modes constitutes a “culture” (Pope, 2005)
Deafblind Culture?

- DB have pride, can be empowered, positive attitude of “I am deaf-blind so what
- “I can still enjoy my life and not let my disability limit me”
- DB community provides a place for acceptance, pride, role models and self-esteem
- DB community require organisations to help facilitate this cultural experience (Pope, 2005)
More Research is Needed....

• Does DB culture exist in Australia?
• What does LLL mean to DB, and the links with MH?
• How does culture and community impact MH?
• How can services and agencies promote DB culture & LLL?
Our Vision Support Group

- Create a safe space to share and form friendships,
- Challenge myths and stigma,
- Psycho-education,
- Build self-esteem, confidence and self advocacy skills,
- Self care and relaxation skills,
- Reduce and manage MH issues
Our Vision Support Group

• “If people are fully deaf and blind and confident, its so interesting to meet them”

• “Her attitude is: ‘I'm deaf, and I’m blind” SO!

• “I envisage change, and I want the Deafblind community recognized as a culture”

• “I belong to both communities”
Our Vision Support Group

• “How do we get our stories out and educate people about the DB community”

• “The Deaf community don’t always understand our culture”

• “When I was in the Deaf community I didn't’t feel like a strong member”

• “We’re in the same world”
Our Vision Support Group

- “It’s easy to isolate yourself and stay at home, but you need to go out and communicate with people and share our stories”

- “We should all show compassion and support each other, because it's exhausting using tactile”
• “We need to start talking positively about Deafblindness. I’ve just only realized that I’ve been talking negatively”

• I think we really need to start talking positive about things, become role models

• “I’m interested in how we change the negative self talk we have, change that into a positive. I don’t know how”
My PhD & Take Home Message

- Utilize the Bio-psychosocial-cultural approach
- Lived experience of DB culture & community (LLL)
- DB experience of MH, services, professionals & organizations
- Survey experts (professionals and people who are DB) in the field “what is best practice?”
- Design and evaluate a clinical best practice frame work & training package
Q & A

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