KTDRR Evidence Webcast:

Recent Campbell Collaboration Disability Research Synthesis Results

Presenters:
Pádraic Fleming, PhD
Judith Gross, PhD
Petra Lietz, PhD & Katherine Dix, PhD
Ashrita Saran, PhD

August 17, 2021
The Campbell Collaboration

https://www.campbellcollaboration.org

• **Campbell Systematic Reviews journal**
  - https://onlinelibrary.wiley.com/journal/18911803

• **Resources for Researchers**
  - https://www.campbellcollaboration.org/research-resources/resources.html

• **Coordinating Groups**
  - https://www.campbellcollaboration.org/contact/coordinating-groups.html
Disability Coordinating Group

• Disability Coordinating Group
  - https://www.campbellcollaboration.org/contact/coordinating-groups/disability.html

• What Works Global Summit 2021: Evidence for Development (October 18-27, 2021)
Featured Disability Reviews

• **Individualised Funding Interventions to Improve Health and Social Care Outcomes for People with a Disability: A Mixed-methods Systematic Review.**
  *Lead author/presenter:* Dr. Pádraic Fleming, Centre for Health Policy and Management, Trinity College Dublin.

• **Multifaceted Interventions for Supporting Community Participation Among Adults with Disabilities: A Systematic Review.**
  *Lead author/presenter:* Dr. Judith Gross, Indiana Institute on Disability and Community, Indiana University Bloomington.
Featured Disability Review and Evidence and Gap Map

• *Interventions for Anxiety in Mainstream School-aged Children with Autism Spectrum Disorder (ASD): A Systematic Review.*
  Corresponding author/presenter: Dr. Petra Lietz, Australian Council for Educational Research (ACER);
  Author/presenter: Dr. Katherine Dix, ACER.

• *Evidence and Gap Map of Studies Assessing the Effectiveness of Interventions for People with Disabilities in Low- and Middle-Income Countries.*
  Lead author/presenter: Dr. Ashrita Saran, Campbell South Asia, Campbell Collaboration.
Individualised funding interventions to improve health and social care outcomes for people with a disability: A mixed-methods systematic review

Dr Pádraic Fleming

Maynooth University Department of Psychology
Centre for Mental Health and Community Research

Trinity College Dublin, Centre for Health Policy and Management
Timeline  PhD 2013 – 2017 (Viva 2018)

- Sept 2014 – Invited to submit Title Registration
- Nov 2014 – Submitted Title Registration
- Jan 2015 – Received initial feedback and TR published
- Nov 2015 – Reviewer comments received (5 reviewers – 100 responses - general, content, methods, information retrieval)
- Jan 2016 – Revised protocol submitted
- Feb 2016 – Protocol published
- Sept 2017 – Full review submitted
- Nov 2018 – Reviewer comments received
- Jul 2019 – Systematic review published
Individualised Funding

Autonomous (Direct Payment)

What

Supported (Brokerage)

When

Where

Who

Oleksii S on Unsplash

Ocean Ng on Unsplash

Todd Diemer on Unsplash

Scott Webb on Unsplash

Georg Arthur Pflueger on Unsplash

Tyler Nix on Unsplash

Leon on Unsplash
Objectives

- effectiveness of individualized funding interventions for adults with a lifelong disability in terms of improvements in their health and social care outcomes when compared to a control group in receipt of funding from more traditional sources; and

- to critically appraise and synthesise the qualitative evidence relating to stakeholder perspectives and experiences of individualized funding, with a particular focus on the stage of ‘initial implementation’
Individualised Funding

- Pooled budget
- Independent living fund

**Independent Support Broker**

- Local Area co-ordination program
- Self-Determination Program
  - Managed account

**Individual Budget**

- Indicative allocation
- Self-directed funding

**Direct Payment**

- Host Agency Funding
- Personal Budget
  - Self-directed support

- Self-managed model / community connector

**Recovery Budget**

**Self-management**

- Managed budget

**Shared management model**

**Microboard**

- Person-centred budget
- Cash-for-care

**Notional budget**

**Cash and Counseling**

**Individual Service Fund**

**Personalised Care**

**Personal Health Budget**

**Consumer Directed Care**

**Personal Assistance Services**

**Direct Funding**

**Individualised Service Fund**

**Managed account**

**Managed budget**

**Self-directed support**
Search Strategy

- No restrictions - research design; outcomes; language
- Timeframe 1985 onwards
- Key terms based on the **Population** and **Intervention**
- Database thesauri – exploding terms to capture all narrower terms
- Free text terms – from literature

Sociological Abstracts (Subject Headings)

<table>
<thead>
<tr>
<th>Handicapped</th>
<th>Resource Allocation</th>
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<td>Alzheimer’s</td>
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<td>Disorder</td>
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<td>Senility</td>
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Search Strategy (continued)

- No restrictions - research design; outcomes; language
- Timeframe 1985 onwards
- Key terms based on the Population and Intervention
- Database thesauri – exploding terms to capture all narrower terms
- Free text terms – from literature
95,767 imported into Endnote, further 9,562 Grey Literature titles considered
Identification

Retrieved 82,274 potentially relevant titles from databases and other sources. 13,493 duplicates excluded from this figure.

Screening

7,158 titles and abstracts were independently screened by two screeners. 328 full texts were double screened for eligibility. This included 104 titles identified through ‘Forward Citation Searching’ and ‘Hand Searching’

Included


215 studies were excluded after full text double screening:

- Intervention: n = 70 (33%)
- Study Design: n = 44 (20%)
- Empirical Data: n = 41 (19%)
- Population: n = 29 (13%)
- Outcome: n = 27 (13%)
- Full text not available: n = 4 (2%)

Linked study / secondary report: n = 40

66 - Qualitative
4 - Quantitative
3 - Mixed Methods
Results
Seven studies (quantitative)

Primary Outcomes
- 4 studies – **Quality of Life** – 2 positive & 2 no difference
- 5 studies – **Client Satisfaction** – Positive x 11 measures, No difference x 1m

Secondary Outcomes
- 1 study – **Physical Functioning** – No difference x 1
- 5 studies – **Adverse impact** – Mixed across sites and measures – mainly positive, 1 measure indicated more likely to have unmet needs
- 3 studies – **Cost Effectiveness** – 1 mixed (negative / no difference), 1 – No difference
- 4 studies – **Other** measures e.g. safety / security, community participation – 1 positive & 3 – no difference
### Characteristics of studies with qualitative data

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<th>Characteristic</th>
<th>69 studies (%)</th>
<th>Characteristic</th>
<th>69 studies (%)</th>
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<td>&lt; 25</td>
<td>24 (35)</td>
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<td>Mixed qualitative</td>
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<td>26 - 50</td>
<td>16 (23)</td>
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<tr>
<td>Case study (mixed methods)</td>
<td>18 (26)</td>
<td>51 - 100</td>
<td>16 (23)</td>
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<tr>
<td>Survey (8 primarily quant.)</td>
<td>9 (13)</td>
<td>&gt;= 101</td>
<td>13 (19)</td>
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<td>Other</td>
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<td><strong>Language</strong></td>
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<tr>
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<td>68 (99)</td>
<td>Non-English</td>
<td>1 (1)</td>
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</table>
Implementation facilitators

Perceived benefits
3,295 coded pieces of text
43 meso & 32 micro subthemes

Mechanisms of success
2,702 coded pieces of text
62 meso & 25 micro subthemes

Perspectives of staff / organisational representatives
292 coded pieces of text
No subthemes
Flexibility – Needs led – Type & timing of support – How money can be used – Freedom to choose – Continuity of care / life – Community integration – Improved family life, social opportunities & self-image

“I get to choose who, where and what. I wasn't comfortable when we had the lady coming in, putting me to bed at 6 and getting me up at 9, I'm 25, I don't want a complete stranger coming in to my house and washing my hair for me. Now, I can choose somebody that I trust and that I'm comfortable around.” (PSI service user)  
(Sheikh, Vanson, Comber, & Watts, 2012)

“Everything in my life is just better, have a direction for my future...feel more confident, happy and really excited about my future”  
(Buchanan, Peterson, & Falkmer, 2014)

“We run into some of his friends around town. He has become a part of his own community. I have lived here for 30 years, but people didn’t know my son. Now they do.”  
(Conroy, Brown, et al., 2002)
Mechanisms of success

Relationships:
- Network of support
- Collaborative relationships between individuals and providers between agencies / departments
- Interpersonal relationships

Financial recognition for voluntary work:
- Control over life – Valued role – Less of a burden

Trust

“His strength, humour, and flexibility have helped him to attract and maintain a group of supports who share his interests, appreciate his individuality, and view him as their friend.” (Malette, 1996)

“Many people have very personal needs, such as assistance with bathing, and this program allows them to choose people with whom they are comfortable. As one person put it, "I can choose people I trust." (Walker et al., 1996)
Implementation:
- Local support organisations
  - provision of information / guidance / advice
  - support with staff recruitment
  - payroll / tax / paperwork
  - governance

Training / HR:
- PwD - staff recruitment and management / administrative skills
- Availability of well-trained and informed professionals

This created a sense of trust and assurance for HSE staff who were otherwise cautious about releasing funds to individuals. Governance issues were of less concern due to the presence of an ‘intermediary body’” (Fleming, McGilloway, et al., 2016)
Implementation challenges

- Perceived challenges / negative aspects
  - 2,640 coded pieces of text
  - 26 meso & 42 micro subthemes

- Potential problems / areas for improvement
  - 1,692 coded pieces of text
  - 27 meso & 63 micro subthemes

- Perspectives of staff / organisational representatives
  - 779 coded pieces of text
  - 14 meso & 11 micro

“A few pointed out that sometimes they were left without a carer, if one person left and they had to take the time to recruit another. They suggest perhaps a list of approved carers in the local area would help.” (McGuigan et al., 2016)

“When one participant expressed an interest in self-directing his arrangement with his service provider, he was asked, “What would happen if everyone wants to go elsewhere? Where does that leave us [as an organization]?”. (Rees, 2013)

“Releasing control is the issue. We’re such paternalistic agencies with well defined infrastructures. For years, we’ve had individual budget money in small sums ... Now that more money is involved, there is more tension.” (Olmstead, 1999)

“On the other hand, there are a number of service users who continue to experience stress and anxiety associated with delays after the set-up phase, for example in trying to schedule reviews.” (Sheikh et al., 2012)
Potential problems/Areas for improvement

“One manager explained that ‘[Support Planners] are giving clients missing information about what their entitlements are’. This manager felt that the Support Planners were not sufficiently informed about the SLF, which was why they did not always provide clear information.” (A. Jones et al., 2015)

Others were overwhelmed with the sheer volume of information received on entering the scheme. (McGuigan et al., 2016)

“So some people with mental health problems raised concerns that the forms used for the questionnaire were not geared towards their needs so that they had to go through a lot of questions that were not relevant to them.” (Newbronner et al., 2011)

“But subsequent contract negotiations raised concerns about moving away from a person centred approach, posing difficult questions of targets versus quality” (N. Campbell et al., 2011)

Under estimation of need - Rely on informal supports - Training needs – Learned passivity – Hidden costs – Negative emotions (daunting)
Potential problems – Staff perspective

- **Fear** – Accountability, Risk, Control, Safeguarding, Fear of abuse
- **Impact on existing services** – privatisation, poaching staff, job losses, poorer quality of care, larger providers dominate the landscape
- **Practicalities** – Accommodating diverse levels of need, governance, calculation of allocation, assessment (particularly ‘self-assessment’)
Regardless of intention (or the evidence base), individualised funding continues to be adopted globally.

This review provides a comprehensive resource of available effectiveness evidence and implementation successes and challenges to inform and promote progress.
References and credits


5. Fleming P. How personal budgets are working in Ireland: Evaluating the implementation of four individualised funding initiatives for people with a disability in Ireland. Dublin, Ireland: Genio Trust; 2016 27 May 2016. Report No.: 978-1-907711-38-1

Thanks!

You can find me:
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Judith M.S. Gross, PhD

- Director Center on Community Living and Career, Indiana Institute on Disability and Community at Indiana University
• Research Topic and Review Purpose
• Partnerships Supporting the Research
• Research Results and Implications
• Challenges
• Benefits
Research Topic and Review Purpose

• To determine the effectiveness of multifaceted interventions in promoting community participation outcomes for people with a disability

• To fulfill a deliverable on a 5-year NIDILRR grant to the Research & Training Center on Promoting Interventions for Community Living
Partnerships Supporting the Research

• Research & Training Center on Promoting Interventions for Community Living researchers (RTC/PICL)
  ▪ University librarian, Research assistant, Funding support

• American Institutes for Research, Center on Knowledge Translation for Disability and Rehabilitation Research (KTDRR)
  ▪ Statistical consultant, Research assistant, Technical support
Research Results

• Some effectiveness found in studies on the following community participation outcomes:
  - Employment (mixed – 1 sig, 1 non)
  - Quality of Life (mixed – 1 sig, 1 non)
  - Adult Learning/Education

• Mental Health – 2 studies the control group performed better

• Non-significant outcomes included: Activities of Daily Living, Autonomy, Independent Living, Social Skills, and Community Activities
Research Implications

• There is limited support for the effectiveness of multifaceted interventions suggesting a need for more research to determine effectiveness broadly as well as specifically in relation to community participation of adults with disabilities.

• A narrowed focus (in research and practice) on specific outcomes for targeted groups of adults with similar disabilities may yield greater insight into the potential effectiveness of multifaceted interventions.
Challenges

1. Knowledge of disability varied greatly among our research team members.

2. Defining key terms and determining exclusionary criteria was an incredibly long and iterative process.

3. My lack of statistical knowledge regarding meta-analysis made me uncomfortable.

4. The write-up/manuscript is quite long.
Benefits

1. There was very specialized knowledge among our research team members meant clear distribution of responsibilities and deep knowledge in those areas.

2. I have new colleagues now at AIR, and I would not hesitate to reach out if I had a question/challenge/project on which I could use their help.

3. We did a more rigorous review. Original plan was to do a narrative systematic review.

4. The meta-analysis filled a research gap (and was good for my CV).
Thank you!

Judith M.S. Gross, Ph.D.

jmsgross@iu.edu
Interventions for anxiety in mainstream school-aged children with autism spectrum disorder: A systematic review

Kylie Hillman, Katherine Dix, S. Kashfee Ahmed, Petra Lietz, Jenny Trevitt, Elizabeth O'Grady, Mirko Uljarević, Giacomo Vivanti, and Darren Hedley

2 November 2020

Australian Council for Educational Research
Overview

- Background
- Methodology
- Results
- Questions

Review question

Protocol
Search strategy – inclusion and exclusion

Critical appraisal
- evaluate risk of bias

Data extraction

Synthesis and reporting
Background and central concepts

Prevalence of ASD and Anxiety

• **Autism Spectrum Disorder** (ASD) – a group of neurodevelopmental disorders characterized by difficulty with communication and social interaction, and the presence of restricted, rigid, and routinized patterns of behaviours and interests.

• **Anxiety** – a common problem in school-aged children with ASD.

• **Cognitive Behaviour Therapy** (CBT) and other psychosocial interventions – alternatives to pharmacological intervention to treat anxiety symptoms in students with ASD without co-occurring intellectual disability.
Systematic review research question

What is the relative effectiveness of interventions for managing anxiety of school-aged children with ASD that have been used in school, family, and clinical settings?
Methodology: Criteria for considering studies for this review

**Study design:** Randomised Control Trials (RCT) and quasi-experimental

**PICO**

- **Participants:**
  - Mainstream school-aged children,
  - Diagnosed with ASD (inclusive of autism, ASD, Autistic Disorder, Asperger's Disorder, Asperger Syndrome, atypical autism, PDD-NOS) by a professional
  - Also experiencing anxiety symptoms or a diagnosis of an anxiety disorder provided by a professional

- **Interventions:**
  All treatments for anxiety for school-aged children with ASD; studies with only pharmacological treatments were excluded

- **Context:**
  Real-world settings such as school or home

- **Outcome:** Anxiety
  - The measurement of anxiety through valid and reliable approaches => diagnostic interviews, screening instruments, observational ratings, and behavioural checklists (student, parent, teacher)
Methodology: Search methods used for the identification of studies

- Search timeframe: 1996 and 2018
- Published as well as unpublished literature:
  - 12 electronic databases
    - Academic Search Complete
    - A+ Education
    - British Education Index
    - CBCA Complete
    - CINAHL
    - Education Research Complete
    - EMBASE
    - ERIC
    - PsycINFO (APA PsycInfo)
    - PubMed
    - SCOPUS
    - SocINDEX
  - Grey literature sources such as selected websites, repositories, and research registers
Methodology: PRISMA Search results

- 3417 records identified through database screening
- 177 additional records identified through other sources
- 2337 records after duplicates removed
- 2337 records screened (titles and abstracts)
- 119 full-text articles assessed for eligibility
- 95 full-text articles assessed excluded:
  - No anxiety present in participants: 19 studies
  - No anxiety outcome measured: 16 studies
  - No control group: 12 studies
  - Age range out of scope: 10 studies
  - Observational: 10 studies
  - No ASD diagnosis: 7 studies
  - Secondary study: 5 studies
  - No treatment: 4 studies
  - No comparison group: 3 studies
  - Out of scope: 3 studies
  - Not enough information: 2 studies
  - Protocol/proposal: 2 studies
  - Low quality: 1 study
  - Uses same data as an included study: 1 study

- 2218 records excluded:
  - No intervention for managing anxiety
  - Measurement of conditions only or explanation/description of conditions/behaviours; pharmaco only interventions; any intervention for populations outside the target population; review of other studies, books, guidelines etc.

- 24 studies included in quantitative synthesis (meta-analysis)
Methodology: Data analysis

• Assessment of risk of bias in included studies
• Measures of treatment effect: Preference clinician report
• Unit of analysis issues: non-standard designs (eg crossover)
• Assessment of heterogeneity: \( \chi^2 \) & random-effects meta-analysis
• Data synthesis approach:
  - overall, clinician-reported, parent-reported, student-reported
  - moderators - family involved & grouping
• Sensitivity analysis: removing outlier
Results: Included studies

24 studies: 8 not included in previous systematic reviews

- **Geographic location:** Five of the studies were conducted in Australia, 12 in the United States, 4 in the United Kingdom (England), and 1 each in Singapore, Thailand, and The Netherlands.
- **Study design:** 18 studies used a randomized wait-list control (WLC) design; 6 of the studies were classified as quasi-experimental designs.
- **Participants:** A total of 931 (764 male and 167 females) participants most of whom were of mainstream school age (6–16). Majority of the studies (21 of 24) limited participants to individuals with functioning above a certain level of cognitive ability, most commonly a full scale or verbal IQ of 70 or above.
- **Interventions:** 22 of the studies used a CBT intervention, with some developed specifically for use with participants with ASD- of these, 15 studies involved interventions that included parental involvement.
- **Outcome measures:** 12 outcome measures of anxiety were used to varying extent and with different respondents (clinician, parent, child) - most of these measures are standardized, validated measures of anxiety for use by clinicians (e.g., psychologists).
<table>
<thead>
<tr>
<th>Study</th>
<th>Treatment Mean</th>
<th>Treatment SD</th>
<th>Treatment Total</th>
<th>Control Mean</th>
<th>Control SD</th>
<th>Control Total</th>
<th>Standard Mean Difference Weight</th>
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<td>30</td>
<td>6.17</td>
<td>1.34</td>
<td>30</td>
<td>3.66% -1.75 [-2.67, -0.79]</td>
<td>?</td>
</tr>
<tr>
<td>REAV09D</td>
<td>20.02</td>
<td>10.76</td>
<td>10</td>
<td>26.09</td>
<td>12.6</td>
<td>23</td>
<td>4.11% -0.49 [-1.24, 0.26]</td>
<td>?</td>
</tr>
<tr>
<td>REAV12A</td>
<td>2.25</td>
<td>0.91</td>
<td>20</td>
<td>2.83</td>
<td>0.98</td>
<td>23</td>
<td>4.44% -0.60 [-1.21, 0.01]</td>
<td>?</td>
</tr>
<tr>
<td>SOFR05S</td>
<td>34.21</td>
<td>15.39</td>
<td>48</td>
<td>35.61</td>
<td>13.34</td>
<td>23</td>
<td>4.69% -0.09 [-0.59, 0.40]</td>
<td>?</td>
</tr>
<tr>
<td>STOR13A</td>
<td>3.38</td>
<td>1.81</td>
<td>24</td>
<td>4.9</td>
<td>1.51</td>
<td>21</td>
<td>4.44% -0.89 [-1.50, -0.28]</td>
<td>?</td>
</tr>
<tr>
<td>STOR15A</td>
<td>3.69</td>
<td>1.35</td>
<td>16</td>
<td>5.33</td>
<td>0.9</td>
<td>15</td>
<td>4.04% -1.38 [-2.17, -0.60]</td>
<td>L</td>
</tr>
<tr>
<td>SUNG11S</td>
<td>26.54</td>
<td>15.57</td>
<td>36</td>
<td>27.62</td>
<td>13.57</td>
<td>34</td>
<td>4.76% -0.07 [-0.54, 0.40]</td>
<td>L</td>
</tr>
<tr>
<td>VANS15A</td>
<td>15.66</td>
<td>17.03</td>
<td>79</td>
<td>35.25</td>
<td>21.77</td>
<td>75</td>
<td>5.01% -1.00 [-1.33, -0.67]</td>
<td>L</td>
</tr>
<tr>
<td>WHIT13P</td>
<td>14</td>
<td>3.44</td>
<td>15</td>
<td>15.47</td>
<td>5.26</td>
<td>15</td>
<td>4.19% -0.32 [-1.04, 0.40]</td>
<td>L</td>
</tr>
<tr>
<td>WOOD09A</td>
<td>2.36</td>
<td>1.15</td>
<td>14</td>
<td>4.77</td>
<td>0.81</td>
<td>22</td>
<td>3.80% -2.47 [-3.35, -1.59]</td>
<td>L</td>
</tr>
<tr>
<td>WOOD15A</td>
<td>3.28</td>
<td>2.1</td>
<td>19</td>
<td>4.04</td>
<td>1.88</td>
<td>14</td>
<td>4.25% -0.37 [-1.06, 0.33]</td>
<td>L</td>
</tr>
</tbody>
</table>

**Total (95 % CI)**

- 524

**Heterogeneity:** $I^2 = 0.52$, $Q^2 = 104.53$, df $= 23$ ($P = 0.00$)

**Test for overall effect:** $Z = -5.03$ ($P = 0.00$)

- Favours [Treatment] -5 -3 -1 1
- Favours [Control]

**Key: Anxiety Measure used in Study**
- A: The Anxiety Disorders Interview Schedule - Clinician (ADIS-CRS)
- D: Screen for Child Anxiety Related Disorders - Child/Parent (SCARED)
- N: Conners’ Parent Rating Scales (Anxiety) - Parent (CPRS)
- P: The Paediatric Anxiety Rating Scale (PARS)
- S: Spence Child Anxiety Scale - Child/Parent (SCAS)
- T: State-Trait-Inventory for Children (STAI-C)

**Key: Risk of Bias**
- A: Selection bias: Random sequence generation
- B: Selection bias: Allocation concealment
- C: Performance bias: Blinding of participants and personnel
- D: Detection bias: Blinding of outcome assessment
- E: Attrition bias: Incomplete outcome data
- F: Reporting bias: Selective reporting of results
Results: Synthesis funnel plot

The SMD score reported by Chalfant_2007 as an outlier. A sensitivity analysis was carried out by removing this study, reducing the overall SMD to −0.71.
Results: Summary

• Psychoeducational interventions for anxiety, predominantly CBT, may improve anxiety symptoms (SMD = −0.71, p < .01, after removal of outliers) for mainstream school-aged children with ASD, ultimately reducing the number of diagnoses of anxiety disorders for some participants.

• 22 of the 24 studies used CBT.

• The quality of the evidence can be considered moderate.

• The effectiveness of the interventions was generally stronger for clinician (mostly blinded) reports but lower among parent and self-report measures.
Conclusions

• There is evidence that CBT is an effective behavioural treatment for anxiety in some children and youth with ASD without co-occurring intellectual disability.

• Evidence for other psychoeducational interventions is more limited, not just due to the popularity of CBT but also due to the quality of the smaller number of non-CBT studies available.
Questions

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Senior Research Fellow

e: katherine.dix@acer.org
www.acer.org

➢ Link to review:
OUR TEAM

• Ashrita Saran, Acting Director, Campbell South Asia
• Hannah Kuper, Director of the International Centre for Evidence in Disability, LSHTM
• Howard White, Chief Executive Office, Campbell Collaboration

ACKNOWLEDGEMENT

• This project was funded by the Centre of Excellence for Development Impact and Learning, supported by UK aid from the UK Government.
• We acknowledge the support of Disability Coordinating Group and Carlton Fong for guidance.
• We acknowledge the contribution of our information specialist John Eyers
• EPPI reviewer team for support on mapping utility
TABLE OF CONTENTS

1. About evidence and gap maps (EGMs)
2. Context and background
3. Rationale
4. Approach and methodology
5. Findings
6. Implications of findings
7. Next steps
WHAT ARE EVIDENCE AND GAP MAPS

- A systematic presentation of all available, relevant evidence for a particular sector or sub-sector.
- EGMs visualise what we know (and do not know) via a graphical display of areas with strong, weak, or no evidence.
- A typical map is a matrix of intervention categories (rows) and outcome domains (columns)
This EGM provides an overview of evidence available on interventions to improve well-being of people with disabilities in low- and middle-income countries.

The EGM includes studies on all types of disabilities: hearing, intellectual, mental physical and visual.

It represents a first step towards developing an evidence architecture to inform policy, programme, and investment strategies to improve well-being of people with disabilities.

Source: https://campbellcollaboration.org/blog/how-should-we-summarize-bodies-of-evidence-the-emerging-evidence-architecture-for-knowledge-brokering.html
COMMUNITY BASED REHABILITATION MATRIX (CBR)

CBR is a multisectoral, bottom-up strategy which operates at the community level-designed to meet the basic needs of people with disabilities, reduce poverty, and enable access to health, education, livelihood and social opportunities.
**INTERVENTION-OUTCOME FRAMEWORK**

The intervention-outcome framework of this EGM is based on the CBR-matrix (WHO) which outlines five evidence-based strategies to improve well-being of people with disabilities.

<table>
<thead>
<tr>
<th>Intervention:</th>
<th>Outcomes:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health</td>
<td>Health</td>
</tr>
<tr>
<td>Education</td>
<td>Education</td>
</tr>
<tr>
<td>Livelihood</td>
<td>Livelihood</td>
</tr>
<tr>
<td>Social</td>
<td>Social</td>
</tr>
<tr>
<td>Empowerment</td>
<td>Empowerment</td>
</tr>
</tbody>
</table>
Disability Evidence and Gap Map. (This includes 59 systematic reviews and 107 primary studies)

Snapshot of disability EGM
Source: https://onlinelibrary.wiley.com/pb-assets/assets/18911803/Campbell%20Disability%20EGM-1578908907487.html
Snapshot of disability EGM
Source: https://onlinelibrary.wiley.com/pb-assets/assets/18911803/Campbell%20Disability%20EGM-1578908907487.html

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CONTEXT AND BACKGROUND

- 15% of world’s population have some form of disability and 80% of them live in LMICs.¹

- People with disabilities are more likely to experience a range of exclusions, including from employment, education, healthcare access and social participation.¹

- In 2004, the World Bank estimated the global GDP loss due to disability to be between $1.71 trillion and $2.23 trillion annually.²

1. WHO, 2011
2. Metts and Mondiale, 2014
RATIONALE

- Over the past decade, the academic literature on disability outcomes and effectiveness has grown substantially. However, several important questions have not been adequately addressed. For example, what type of evidence is needed, and what are realistic expectations, for disability inclusive interventions?

- Knowledge production to influence policy and programme action takes place across several sectors (health, social welfare and education), focuses on various populations (different ages, ethnicities or with different needs), and involves rather diverse methodical approaches (e.g., systematic reviews, impact evaluation of different designs etc.).

- A mapping of the existing knowledge base is, therefore, required to provide a comprehensive overview of existing knowledge in this area, to improve the discoverability, and thereby the use, of that evidence.
ELIGIBILITY CRITERIA

Population: The primary population of interest for this map are people with disabilities living in LMICs. Sub-population of parents, teachers and caregivers of people with disabilities were also included.

Study design: Systematic reviews and Impact evaluations of intervention studies.

Language: English
The authors systematically searched for published and ongoing studies found since the 2000 till 2018.

1. Search of relevant systematic reviews and primary studies from academic databases and international organisations.

2. Search of additional websites for grey literature and expert consultation.

9606 records reviewed

59 systematic reviews and 107 impact evaluations eligible

Articles included (n=166)

Eligibility Assessment (n=107)

Full text screened (n=547)

Title & abstracts screened (n=9606)

Data mining and duplicate removal (n=9843)

Database search (n=46348)

Records excluded (n=9113)

Records excluded (n=458)

Grey literature to include (n=94)

Records excluded (n=35)

Close to half of impact evaluations are RCTs!
### AGGREGATE MAP: INDICATING MOST POPULATED AND LEAST POPULATED CELLS OF THE MAP

<table>
<thead>
<tr>
<th>Most populated: Health</th>
<th>Health</th>
<th>Education</th>
<th>Livelihood</th>
<th>Social</th>
<th>Empowerment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health</td>
<td>102&lt;sup&gt;e&lt;/sup&gt;</td>
<td>19&lt;sup&gt;b&lt;/sup&gt;</td>
<td>11&lt;sup&gt;a&lt;/sup&gt;</td>
<td>28&lt;sup&gt;d&lt;/sup&gt;</td>
<td>1&lt;sup&gt;i&lt;/sup&gt;</td>
</tr>
<tr>
<td>Education</td>
<td>19&lt;sup&gt;c&lt;/sup&gt;</td>
<td>32&lt;sup&gt;d&lt;/sup&gt;</td>
<td>5&lt;sup&gt;a&lt;/sup&gt;</td>
<td>14&lt;sup&gt;b&lt;/sup&gt;</td>
<td>2&lt;sup&gt;h&lt;/sup&gt;</td>
</tr>
<tr>
<td>Livelihood</td>
<td>12&lt;sup&gt;b&lt;/sup&gt;</td>
<td>2&lt;sup&gt;h&lt;/sup&gt;</td>
<td>19&lt;sup&gt;b&lt;/sup&gt;</td>
<td>5&lt;sup&gt;a&lt;/sup&gt;</td>
<td>2&lt;sup&gt;h&lt;/sup&gt;</td>
</tr>
<tr>
<td>Social</td>
<td>31&lt;sup&gt;c&lt;/sup&gt;</td>
<td>14&lt;sup&gt;b&lt;/sup&gt;</td>
<td>4&lt;sup&gt;f&lt;/sup&gt;</td>
<td>26&lt;sup&gt;d&lt;/sup&gt;</td>
<td>2&lt;sup&gt;h&lt;/sup&gt;</td>
</tr>
<tr>
<td>Empowerment</td>
<td>3&lt;sup&gt;g&lt;/sup&gt;</td>
<td>0&lt;sup&gt;i&lt;/sup&gt;</td>
<td>0&lt;sup&gt;i&lt;/sup&gt;</td>
<td>2&lt;sup&gt;h&lt;/sup&gt;</td>
<td>3&lt;sup&gt;g&lt;/sup&gt;</td>
</tr>
</tbody>
</table>

**Notes:** Blue indicates concentration of evidence: (a) very low, (b) low, (c) medium, (d) high, and (e) very high. Red indicates paucity of evidence: (f) very low, (g) low, (h) medium, (i) high, and (j) very high.
STUDIES BY INTERVENTION CATEGORIES

- Difference in difference
- Single-subject design
- Regression
- Discontinuity Design
- Interrupted time series
- Quasi-experimental (CBA and UBA)
- RCT
- Systematic reviews

Studies are dominated in health sector!

- Empowerment
- Livelihood
- Social
- Education
- Health
STUDIES BY TYPE OF IMPAIRMENT

- Physical impairment: 31%
- Visual impairment: 27%
- Mental impairment: 29%
- Hearing impairment: 8%
- Intellectual/learning impairment: 5%

Very few studies assess hearing and visual impairment.
STUDIES BY OUTCOME

Limited evidence in employment and livelihood sector

- Difference in difference
- Single-subject design
- Regression Discontinuity Design
- Interrupted time series
- Quasi-experimental (CBA and UBA)
- Randomised controlled trial
- Systematic reviews

Legend:
- Empowerment
- Livelihood
- Social
- Education
- Health

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STUDIES BY COUNTRIES

Over half the studies come from 8 LMICs, 23 studies from India and 11 from China
## STUDIES BY FRAGILE AND CONFLICT AFFECTED REGIONS

<table>
<thead>
<tr>
<th>Fragility Level</th>
<th>Studies</th>
</tr>
</thead>
<tbody>
<tr>
<td>High Fragility</td>
<td>7</td>
</tr>
<tr>
<td>Pakistan</td>
<td>3</td>
</tr>
<tr>
<td>Nigeria</td>
<td>3</td>
</tr>
<tr>
<td>Entrea</td>
<td>1</td>
</tr>
<tr>
<td>Moderate Fragility</td>
<td>13</td>
</tr>
<tr>
<td>Lebanon</td>
<td>1</td>
</tr>
<tr>
<td>Iran</td>
<td>9</td>
</tr>
<tr>
<td>Egypt</td>
<td>3</td>
</tr>
<tr>
<td>Low Fragility</td>
<td>11</td>
</tr>
<tr>
<td>Ethiopia</td>
<td>3</td>
</tr>
<tr>
<td>Bangladesh</td>
<td>5</td>
</tr>
<tr>
<td>Kenya</td>
<td>3</td>
</tr>
<tr>
<td>Neighbours</td>
<td>7</td>
</tr>
<tr>
<td>Zambia</td>
<td>1</td>
</tr>
<tr>
<td>Uganda</td>
<td>3</td>
</tr>
<tr>
<td>Thailand</td>
<td>3</td>
</tr>
</tbody>
</table>

38 studies concerned Fragile and conflict states
METHODOLOGICAL LIMITATIONS IN IMPACT EVALUATIONS AND SYSTEMATIC REVIEWS

We used AMSTAR-2 checklist to assess systematic reviews and impact evaluations based on various approaches to risk of bias assessment.
PROBLEMS AND CHALLENGES AHEAD...

- Half of impact evaluations and reviews on health.
- Studies limited to only a few countries.
- Methodological limitations.
- Gaps in equity and measuring interventions for vulnerable populations.
EVIDENT GAPS

- There are major gaps in studies assessing the effectiveness of livelihood interventions and its impact on empowerment and social outcomes.
- Evidence was also lacking in studies assessing Educational outcomes.
- Limited high confidence studies in the field.
- Geographic gaps with lack of studies from low-income countries
- Limited studies identified on people with visual and hearing impairment.
- There were limited studies on vulnerable groups and ethnic minorities
IMPLICATIONS OF FINDINGS

- Identify areas of evident gaps: focus on health model of disability and not on the social model.

- Investing in research: three systematic reviews are ongoing in the areas of evident gaps; livelihood, education and social inclusion.

- Investing in better quality research: Consideration needs to be given to improve methodological conduct of systematic reviews in terms of reporting and inclusion criteria or scope by adherence to standard guidelines as PRISMA

- This EGM is important in order to guide policy and programme activity, and encourage a more strategic, policy-oriented approach to setting the future research agenda
NEXT STEPS

✓ Three systematic reviews are under-way as identified as priority area from the map, supported by Penda.
  ▪ Education
  ▪ Livelihood
  ▪ Social inclusion

✓ We are in the process of updating the map-(2020 update) and the updated map with additional studies will be published with revised report.

PENDA (Programme for Evidence to Inform Disability Action) is a consortium led by the International Centre for Evidence in Disability
Thank you.

Ashrita Saran
Acting Director

#WWGS2020.

AshritaSaran
@campbellreviews
Thank You!

Evaluation:

KTDRR Webcasts:
https://ktdrr.org/training/webcasts/index.html
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