



## Working towards inclusive and equitable trauma treatment guidelines: a child-centered reflection

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### ABSTRACT

Clinical practice guidelines, such as those focusing on traumatic stress treatment, can play an important role in promoting inclusion and equity. Based on a review of 14 international trauma treatment guidance documents that explicitly mentioned children, we reflect on two areas in which these guidelines can become more inclusive and equitable; a) representation of children's cultural background and b) children's opportunity to have their voice heard. While a few guidelines mentioned that treatment should be tailored to children's cultural needs, there was little guidance on how this could be done. Moreover, there still appears to be a strong white Western lens across all stages of producing and evaluating the international evidence base. The available documentation also suggested that no young people under the age of 18 had been consulted in the guideline development processes. To contribute to inclusion and equity, we suggest five elements for future national guideline development endeavours. Promoting research and guideline development with, by, and for currently under-represented communities should be a high priority for our field. Our national, regional and global professional associations are in an excellent position to (continue to) stimulate conversation and action in this domain.

### Trabajando hacia pautas de tratamiento del trauma inclusivas y equitativas: una reflexión centrada en el niño

Las guías de práctica clínica, como las que se centran en el tratamiento del estrés traumático, pueden desempeñar un papel importante en la promoción de la inclusión y la equidad. Basados en una revisión de 14 documentos internacionales de orientación sobre el tratamiento del trauma que mencionaban explícitamente a los niños, reflexionamos sobre dos áreas en las que estas guías pueden ser más inclusivas y equitativas; a) representación de los antecedentes culturales de los niños y b) oportunidad de los niños para que se escuche su voz. Si bien en algunas pautas se mencionó que el tratamiento debería adaptarse a las necesidades culturales de los niños, hubo poca orientación sobre cómo hacerlo. Más aún, todavía parece haber una fuerte perspectiva occidental blanca en todas las etapas de producción y evaluación de la base de evidencia internacional. Las directrices disponibles también sugirieron que no se había consultado a ningún joven menor de 18 años en sus procesos de elaboración. Para contribuir a la inclusión y la equidad, sugerimos cinco elementos para futuros esfuerzos de desarrollo de directrices nacionales. Promover la investigación y el desarrollo de directrices con, por y para las comunidades actualmente subrepresentadas debe ser una alta prioridad para nuestro campo. Nuestras asociaciones profesionales nacionales, regionales y mundiales se encuentran en una excelente posición para (continuar) estimulando la conversación y la acción en este ámbito.

### 努力达成包容和公平的创伤治疗指南:以儿童为中心的反思摘要

临床实践指南,如关注于创伤性应激治疗的指南,可以在提升包容性和公平性方面发挥重要作用。在对14项明确提及儿童的国际创伤治疗指导文件综述的基础上,我们对这些指南可以变得更具包容性和公平性的两个领域进行了反思; a) 儿童文化背景的体现, b) 儿童表达其声音的机会。尽管有几条准则提到应根据儿童的文化需求量身定制治疗方法,但关于这一点如何实现的指导却很少。而且,在产生和评估国际证据基础的各个阶段,似乎仍然有强烈的西方白人眼光。现有指南还意味着在指南开发过程中未咨询18岁以下的青年。为了促进包容性和公平性,我们建议了未来国家指南制定工作的五个要素。对于目前代表性不足的群体,与其一同以及针对目前代表性不足的群体来促进研究和指南开发,应该是

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### 关键词

循证干预; PTSD; 公平性; 青年; 临床实践指南; 全球精神卫生; 儿童和青少年

### HIGHLIGHTS

- Children's cultural background is minimally discussed in clinical guidelines; the evidence base and production process still have a strong white Western lens.
- Children's voice is not yet heard in the guidelines development process.
- Inclusion and equity should be high on our research & practice agenda.

我们领域的高度优先事项。我们国家、地区和全球专业协会在（继续）促进这一领域的对话和行动方面处于优势地位。

The COVID-19 pandemic and the anti-racism protests fuelled in part by the death of George Floyd have underlined the urgency of achieving health equity globally (see e.g. Devakumar et al., 2020; Resnick, Galea, & Sivashanker, 2020). Clinical practice guidelines, such as those focusing on traumatic stress treatment, can play an important role in promoting equity. While guideline recommendations themselves are a key driver in improving access to quality care across settings and populations, how these recommendations are derived is crucial too. All stages of guideline development, from the primary evidence available to the composition and decision-making processes of guideline committees, are opportunities to promote inclusion and equity (cf. Akl et al., 2017; Bryant-Davis, 2019).

In this commentary, we focus on areas in which traumatic stress treatment guidelines can become more inclusive and equitable for children. We specifically consider two aspects: a) representation of children's cultural background and b) children's opportunity to have their voice heard. Our reflection is born out of an effort to compare traumatic stress guidelines that paid explicit attention to children. We reached out to 121 colleagues in 94 countries and received 14 relevant sets of guidance from Australia, Chile, England and Wales (National Institute for Health and Care Excellence [NICE] Guidelines), German-speaking countries (Austria, Germany, Switzerland), the International Society for Traumatic Stress Studies (ISTSS), Japan, Mexico, the Netherlands, Scotland, South Africa, Spain, Sweden, the USA, and the World Health Organization (WHO).

## 1. Representation of children's cultural background

The guidelines included in our review considered children's cultural background to a limited extent. A few (e.g. WHO, NICE) mentioned that treatment should be tailored to

cultural needs, but with little guidance on how this could be done. This gap may be due to a lack of diversity in the evidence base itself and in those who created it. To better understand this, we explored the evidence base for the guidelines produced by the ISTSS, the most recent explicitly international effort to examine child trauma treatment studies. The ISTSS guidelines committee sourced randomized controlled trials (RCTs) worldwide (Bisson et al., 2019) and the selected set of child-focused studies initially looked reasonably diverse: 61 trials across 22 countries (see Box 1). However, only 17 (28%) of these RCTs were conducted in low- and middle-income countries (LMICs). This is in line with traumatic stress studies overall (Fodor et al., 2014) and reflects a larger challenge for our field. Further, our online biography and portrait searches suggested that at least 80% of all papers and close to 50% of the LMIC papers were published by white lead authors based in high-income, Western countries. Only about 7% of the overall 4433 child participants were involved in an RCT that was first-authored by a person of colour and/or based in a LMIC. In this same context, the ISTSS guidelines committee appeared to include 0% – and our current author team only 14% – people of colour and/or based in LMICs. Thus, there appears to be a strong white Western lens across all stages of producing and evaluating the current international evidence base. The social dynamics in field research, publishing and guideline development, such as real and perceived hierarchies and group-think in decision making, make it highly likely that important cultural and ethnic issues are not identified and addressed (see e.g. Bryant-Davis, 2019).

## 2. Children's voice

With regard to children's voice, as far as we could gather from the documentation, no young people under the age of 18 were consulted in the development

### Box 1. The child-focused evidence base for the ISTSS guidelines: country & author diversity.

- 61 RCTs across 22 countries, including a total of 4433 child participants
  - 51 (84%) published by white lead authors based in HICs (49 of 51 in Western countries)
  - 8 (13%) published by lead authors who were of colour and/or based in a LMIC
  - 2 (3%) unclear
- 17 (28%) of the 61 RCTs were conducted in LMICs
  - 9 (53%) published by white lead authors based in HICs (8 of 9 in Western countries)
  - 7 (41%) published by lead authors who were of colour and/or based in a LMIC
  - 1 (6%) unclear
- 307 (7%) of all participants were included in a trial first-authored by a person of colour and/or based in a LMIC (unclear for 96, or 2%)

RCT = randomized controlled trial. HIC = high-income country; LMIC = low- or middle-income country (according to World Bank classification). Author biography & portrait searches constitute a crude measure, purely aimed at giving some initial insight into (lack of) diversity.

process for any of the 14 guidelines reviewed. The UN Convention on the Rights of the Child (1989) established that children's opinion on decisions that affect them should be heard and taken into account (see also Lundy, 2007). Trauma treatment decisions are clearly decisions that affect a child. While some guidelines (e.g. Australia) stipulated that children should have a say in individual assessment and treatment decisions, their influence should not only be at the end of the decision 'pipeline' but also at its base; the guidelines themselves and the evidence that underpins them. While caregivers and educators are important interpreters of children's voice, evidence from multiple domains shows that direct child participatory involvement can be done effectively. Young people under the age of 18 have been active contributors to policy conversations, including as representatives on committees and in policy forums (see e.g., the involvement of children in domestic violence policy in Scotland; Houghton, 2017, and in democratic reform in Chile; Defensoría de la Niñez, 2020).

### 3. Additional observations

In addition to the concerns regarding representation of children's cultural diversity and voice, we noted two other issues that have relevance for inclusive and equitable child trauma treatment guidelines. First, countries' unique profiles can have implications for trauma treatment guideline content or implementation. This relates to a country's demography and resources of course, but also its history and social situation. For example, in Rwanda, during the yearly period that the genocide is commemorated, there is an increase in mental health difficulties and/or help seeking, and related interventions (Kabakambira et al., 2018). Second, only one of the guidelines (from South Africa) actively considered the costs of treatment for the individual. Other guidelines considered cost-effectiveness, but from an overall, policy perspective. Cost of treatment for individual families is a crucial topic, with those living on low incomes having little opportunity to pay for and attend treatment sessions.

### 4. Steps to foster inclusion & equity

Guideline development based in empirical research depends on the diversity and quality of that evidence base; thus promoting research with, by, and for currently under-represented communities, led by investigators who themselves represent those communities, should be a high priority for our field. Acknowledging that the lack of diversity in the evidence base cannot be solved rapidly however, what are the options for teams developing trauma treatment guidelines to strengthen inclusion and equity? Taking the example of

developing a new national guideline and building as much as possible on already existing guidelines, the approach could involve the following:

- a. Establishing a guidelines committee that includes young people and parents as members, including from disadvantaged groups and cultures within the remit of the guidelines, with explicit attention to making sure that power dynamics are managed to really hear those committee members' views.
- b. Including historians, sociologists, anthropologists, educationalists, public health economists and local ethicists in the committee or its advisory team, to understand the local history, culture, norms, strengths and vulnerabilities of the population, and make considered decisions in the context of this information.
- c. Reviewing one or more recent guidelines (e.g. ISTSS, NICE) and their underlying systematic reviews, assessing potentially relevant studies for cultural competence and representation of children's voice. This includes asking questions such as 'Do the researchers recognize their own cultural framework and its influence on the research approach?' 'Were cultural brokers, including young people, involved in the analysis and interpretation of the data?' (cf. Riggs et al., 2014).
- d. Gathering already available local evidence on needs and opportunities, and where possible, local treatment studies and reports of cultural adaptations (see Bernal, Jiménez-Chafey, & Domenech Rodríguez, 2009), with attention for evidence that has been communicated in a local language only.
- e. Including equity as a standard agenda item throughout the guideline development process, from setting priorities to evaluation and implementation (see Akl et al., 2017).

Equity issues should be high on the agenda of our research and practice community. Our national, regional and global professional associations are in an excellent position to (continue to) stimulate conversation and action. From facilitating the careers of young scholars from disadvantaged backgrounds to advocating for improved access to trauma treatment with policy makers, all aspects of guideline development and implementation matter in our support for children and families across communities and contexts.

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## Data Availability

There is no dataset associated with this paper.

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## References

- Akl, E. A., Welch, V., Pottie, K., Eslava-Schmalbach, J., Darzi, A., Sola, I., ... Stanev, R. (2017). GRADE equity guidelines 2: Considering health equity in GRADE guideline development: Equity extension of the guideline development checklist. *Journal of Clinical Epidemiology*, 90, 68–75.
- Bernal, G., Jiménez-Chafey, M. I., & Domenech Rodríguez, M. M. (2009). Cultural adaptation of treatments: A resource for considering culture in evidence-based practice. *Professional Psychology, Research and Practice*, 40, 361.
- Bisson, J. I., Berliner, L., Cloitre, M., Forbes, D., Jensen, T. K., Lewis, C., ... Roberts, N. P. (2019). The international society for traumatic stress studies new guidelines for the prevention and treatment of posttraumatic stress disorder: Methodology and development process. *Journal of Traumatic Stress*, 32(4), 475–483.
- Bryant-Davis, T. (2019). The cultural context of trauma recovery: Considering the posttraumatic stress disorder practice guideline and intersectionality. *Psychotherapy*, 56(3), 400.
- Defensoría de la Niñez. (2020). *Estudio de opinión niños, niñas y adolescentes 2019. Levantamiento en hogares*. Santiago de Chile: Author.
- Devakumar, D., Selvarajah, S., Shannon, G., Muraya, K., Lasoye, S., Corona, S., ... Achiume, E. T. (2020). Racism, the public health crisis we can no longer ignore. *The Lancet*, 395(10242), e112–e113.
- Fodor, K. E., Unterhitzberger, J., Chou, C. Y., Kartal, D., Leistner, S., Milosavljevic, M., ... Alisic, E. (2014). Is traumatic stress research global? A bibliometric analysis. *European Journal of Psychotraumatology*, 5(1), 23269.
- Houghton, C. (2017). Voice, agency, power. In Holt, Overlien & Devaney (Ed.), *Responding to domestic violence: Emerging challenges for policy, practice and research in Europe* (pp. 77–96). London: Jessica Kingsley Publishers.
- Kabakambira, J. D., Uwera, G., Hategeka, M., Kayitesi, M. L., Malu, C. K. K., & Hategeka, C. (2018). Burden of post-traumatic stress disorder acute exacerbations during the commemorations of the genocide against Tutsis in Rwanda: A cross-sectional study. *The Pan African Medical Journal*, 30. doi:10.11604/pamj.2018.30.216.15663
- Lundy, L. (2007). 'Voice' is not enough: Conceptualising article 12 of the united nations convention on the rights of the child. *British Educational Research Journal*, 33(6), 927–942.
- Resnick, A., Galea, S., & Sivashanker, K. (2020). Covid-19: The painful price of ignoring health inequities. *BMJ Opinion*, 18.
- Riggs, E., Gussy, M., Gibbs, L., Van Gemert, C., Waters, E., Priest, N., ... Kilpatrick, N. (2014). Assessing the cultural competence of oral health research conducted with migrant children. *Community Dentistry and Oral Epidemiology*, 42(1), 43–52.