The mental health and wellbeing of children with disabilities

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Declaration

I, Nathaniel Scherer, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Abstract

In this thesis, I explore factors and strategies that influence and promote mental health and wellbeing among children with disabilities.

Discussion is based on findings from four published articles. Paper 1 presents a scoping review of mental health support for deaf and hard of hearing children. Qualitative research in paper 2 explores communication, inclusion and mental health among deaf and hard of hearing children in the Gaza Strip. Paper 3 outlines the process of developing mental health and psychosocial support guidelines for deaf and hard of hearing children in the Gaza Strip. Paper 4 presents qualitative research on the experiences of adults and children with intellectual disabilities and their families in England and Scotland during the COVID-19 pandemic.

Using a social-ecological framework, I synthesise and discuss findings in the context of the wider literature. I consider factors that influence the mental health and wellbeing of children with disabilities across four levels (environment, community, caregivers, child), as well as strategies for support, including treatment and methods to promote mental health. Findings show that disability inclusion is central to the mental health and wellbeing of children with disabilities, influencing the societies in which children live and the systems available to support them. Considering environment, government action (and inaction) can marginalise children with disabilities and their families, negatively impacting mental health and wellbeing. This was exemplified during the COVID-19 pandemic. At community-level, stigma and discrimination contribute to exclusion of children with disabilities, affecting mental health. At the level of the caregiver, caregiver mental health and caregiver knowledge on disability influence child wellbeing. At the individual-level, identity and self-esteem of children with disabilities influence their mental health and wellbeing.

This thesis contributes to our understanding of mental health and wellbeing among children with disabilities and examines the implications for research, policy and practice.

Acknowledgements

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I dedicate this thesis to my family and friends. Thank you for everything. The past decade has been amazing thanks to you. Thank you in particular to my grandparents and uncle for your overwhelming generosity. Thank you Mim for your love, laughter and support to get me over the final hurdle. Finally, thank you to my wonderful Mum. You made everything possible.

Format of thesis

This thesis is presented in accordance with the London School of Hygiene & Tropical Medicine research degree regulations for the PhD by Publication.

- Section 1 introduces key concepts relevant to the thesis, including disability, mental health and the mental health of children with disabilities.
- Section 2 provides an overview of the research included in the thesis and four peer-reviewed and published journal articles.
- Section 3 presents the analytic commentary, in which I critically discuss my findings within the wider literature.
- Section 4 gives reflection on my research practice and development.
- Appendices contain research paper cover sheets and copyright information for my research.

List of included studies

Paper 1

> Scherer N, Bright T, Musendo DJ, O'Fallon T, Kubwimana C, Eaton J, Kakuma R, Smythe T, Polack S. Mental health support for children and adolescents with hearing loss: scoping review. *BJPsych Open* (2021) 8 (1), e9 10.1192/bjo.2021.1045

Paper 2

> Scherer N, Smythe T, Hussein R, Wapling L, Hameed S, Eaton J, Kabaja N, Kakuma R, Polack S. Communication, inclusion and psychological wellbeing among deaf and hard of hearing children: A qualitative study in the Gaza Strip. *PLOS Global Public Health* (2023) 3 (6), e0001635 10.1371/journal.pgph.0001635

Paper 3

> Scherer N, Hussein R, Eaton J, Kabaja N, Kakuma R, Smythe T, Polack S. Development of mental health and psychosocial support (MHPSS) guidelines for deaf and hard of hearing children in the Gaza Strip. *PLOS Global Public Health* (2023) 3 (10), e0002427 10.1371/journal.pgph.0002427

Paper 4

> Scherer N, Wiseman P, Watson N, Brunner R, Cullingworth J, Hameed S, Pearson C, Shakespeare T. 'Do they ever think about people like us?': The experiences of people with learning disabilities in England and Scotland during the COVID-19 pandemic. *Critical Social Policy* (2022) 43 (3), 423-447, 10.1177/02610183221109147

Acronyms and abbreviations

ADHD: Attention deficit hyperactivity disorder

GRIPP: Getting Research into Policy and Practice

IASC: Inter-Agency Standing Committee

ICF: International Classification of Functioning, Disability and Health

LMIC: Low- and middle-income country

LSHTM: London School of Hygiene & Tropical Medicine

mhGAP: Mental Health Gap Action Programme

MHPSS: Mental health and psychosocial support

MICS: Multiple Indicator Cluster Survey

OPD: Organisation of persons with disabilities

RCT: Randomised controlled trial

UNCRPD: United Nations Convention on the Rights of Persons with Disabilities

UNICEF: United Nations Children’s Fund

WHO: World Health Organization

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1. Introduction to disability and the mental health of children with disabilities

1.1. Defining disability

The *United Nations Convention on the Rights of Persons with Disabilities* (UNCRPD) defines persons with disabilities as those with “long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” [1].

Conceptualisation of disability is complex and multidimensional, and the UNCRPD definition is an evolution of medical and social models [2]. In the medical model, disability is synonymous with impairment in functioning. In this model, impairment restricts participation in daily activities, such as education and employment, causing disability [2]. The medical model would assert that a Deaf person cannot participate in society on an equal basis to hearing peers as a result of their hearing loss, which restricts oral communication with the majority of the population and limits response to auditory environmental cues. Under this model, medical interventions are recommended to alleviate disability. For example, hearing aids or a Cochlear implant to improve an individual’s hearing. The social model of disability rejected this concept. Under this model, disability is a result of barriers in society, rather than an individual’s impairment [2]. For example, a Deaf person may have difficulty communicating with a health professional, not because they cannot hear, but because the health facility does not provide a sign language interpreter. If environmental, attitudinal and institutional barriers are removed, then people with disabilities can participate in society on an equal basis as people without disabilities. This social model was a major leap forward in the conceptualisation of disability and supported global disability activism. However, the social model has been critiqued for being too simple and for undermining the impact of impairment on disability.

More recently, the World Health Organization (WHO) *International Classification of Functioning, Disability and Health* (ICF) biopsychosocial model of disability integrates concepts from both the medical and social model [3]. In line with the UNCRPD, the ICF framework (Figure 1) conceptualises disability through the interaction of a health condition, personal factors and environmental factors.

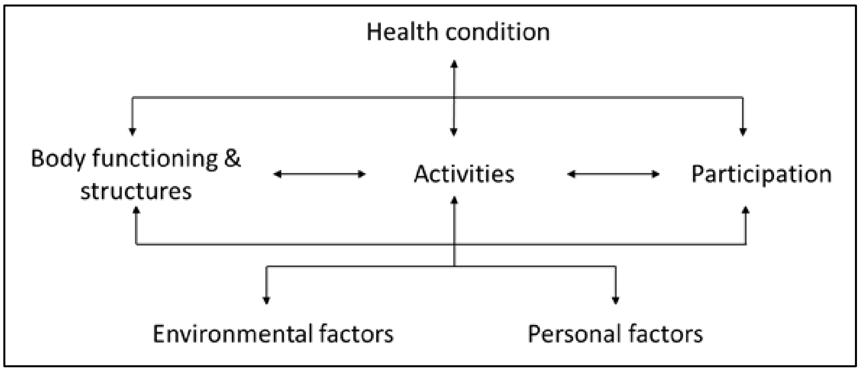

Figure 1. The International Classification of Functioning, Disability and Health (ICF)

In this model, a health condition (e.g. depression) can lead to an impairment in functioning (e.g. cognitive function), which can contribute to activity limitations (e.g. difficulty completing tasks) and thus participation restrictions (e.g. employment). The extent of activity and participation restriction is influenced by environmental factors (e.g. attitude of employer) and personal factors (e.g. family support). The components of the ICF model interact with one another to influence the extent to which a person will experience disability. In this thesis, I use the UNCRPD definition and the ICF framework when describing disability and children with disabilities.

1.2. People with disabilities globally

Approximately 16% of the global population (1.3 billion) has a disability [4]. Nearly 10% of children (240 million) have a disability [5]. Estimates indicate that 80% of people with disabilities live in low- and middle-income countries (LMICs), with prevalence higher in LMICs compared to high-income countries [6]. For instance, the prevalence in West and Central Africa (15%) and Middle East and North Africa (13%) is more than double-that of Europe and Central Asia (6%). Disability is more common in LMICs due to a combination of factors, including increased malnutrition and infectious diseases, poorer sanitation and greater exposure to environmental hazards, and lower availability of healthcare services [6].

Disability can have a major impact on people's lives. People with disabilities are more likely to live in poverty [7], less likely to be employed [8], and are more likely to experience violence and abuse [9]. Children with disabilities experience exclusion and deprivation. Compared to peers without disabilities, children with disabilities are 34% more likely to be stunted, 49% more likely to never have attended school, 41% more likely to feel discriminated against, 51% more likely to be unhappy and 20% less likely to have expectations of a better life [10].

1.3. Disability and health

Article 25 of the UNCRPD states that "persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability" [1]. Although important to note that they are not a homogenous group, people with disabilities typically have greater healthcare needs than people without disabilities [4]. They may be at greater risk of poor health as a result of an underlying health condition. For example, someone who is blind as a result of diabetic retinopathy will have diabetes, which may increase the risk of stroke. People with disabilities may also need additional support for their disability, such as rehabilitation services or assistive technology. Despite this greater need, barriers in society, such as inaccessible health facilities or stigma from health professionals, mean that people with disabilities are less likely to access healthcare services [4, 11]. Poorer access to health service results in poorer health. With greater health needs, limited access to healthcare exacerbates health inequity for people with disabilities [4]. Health inequities mean that people with disabilities have higher mortality and morbidity. Mortality among people with disabilities is 2.4 times higher than people without disabilities, people with disabilities have a life expectancy that is 10 to 20 years lower, and children with disabilities have five times the odds of being seriously ill in the last year [12, 13]. In the context of the global agenda, this inequity limits achievement of *Sustainable Development Goal 3, Good Health and Wellbeing* and the policy of "leave no-one behind" [14]. The WHO has called for renewed efforts to promote disability inclusion in the health sector to alleviate health inequalities [4].

1.4. Mental health

Mental health conditions can negatively impact a person's ability to participate in all aspects of life, including school, work and local communities. The 2019 *Global Burden of Diseases, Injuries, and Risk Factors Study* found depression and anxiety to be the two most common and disabling mental health conditions globally; they were among the 25 leading causes of health-related burden [15]. Mental health conditions accounted for 125.3 million years lived with disability, and between 1990 and 2019, mental health conditions were the second leading cause of years lived with disability globally [15]. In 2019, 21.5 million children and adolescents (<20 years) experienced a mental health condition [16]. Between 1990 and 2019, the prevalence of depression and anxiety increased by 48.1% [15]. It is expected that prevalence will continue to increase as the global population grows.

Health systems must be able to address the mental health needs of a growing population, but across the world, including high-income countries such as the UK, provision, quality of care and access to services is often poor [17, 18]. Service provision is particularly low in LMICs [19, 20]. Key challenges include inadequate policy and legislation, limited resources and funding (including limited trained mental health specialists), and limited availability of contextually and culturally adapted evidence-based mental health interventions [20]. The field of 'Global Mental Health' developed in the early 2000s to address the mental health treatment gap in low-resource settings. At the time, 80% of people in LMICs needing mental health support did not access services [21]. Ten years on from the 2007 *Lancet Series on Global Mental Health*, the 2018 *Lancet Commission on Global Mental Health and Sustainable Development* called for continued expansion of mental health within global health priorities in order to achieve the *Sustainable Development Goals* [19]. The Commission called for continued efforts to reduce the treatment gap, as well as gaps in prevention and quality of care.

Global Mental Health has traditionally focused on a medical approach to mental health. Given the gap in service provision, treatment and intervention have been prioritised. However, in recent years, the field of Global Mental Health has shifted towards human rights approaches, many of which are founded in the principles of the UNCRPD [19]. Approaches in Global Mental Health are shifting to address social determinants of mental health conditions, value human rights and better engage people with lived experience. The *QualityRights* initiative highlights this recent shift. This global initiative aims to provide training and guidance on developing health systems that are person-centred and based on human-rights, in line with the UNCRPD [22].

In this thesis, I will discuss mental health systems across both high and low-resource settings. Two of the included papers in this thesis are from a low-resource setting. One of my included papers is conducted in the UK and another is a global systematic review (of which much of the included research comes from high-income settings). However, my wider research experience has largely been conducted in LMICs and I hold an MSc in Global Mental Health. Thus, my reflections in this thesis may at times lean towards discussion in the context of Global Mental Health and low-resource settings, although I aim to present reflections applicable to diverse contexts.

1.5. Mental health and wellbeing of children with disabilities

The UNCRPD definition of disability includes people with long-term mental health conditions experiencing psychosocial disability. Mental health conditions are a substantial impact in and of themselves, but they are also associated with comorbid presentation of health conditions [23]. It is on this group that this thesis is focused. I present and discuss findings relevant to the mental health and wellbeing of children with physical, sensory and intellectual disabilities. I do not discuss children with mental health conditions or psychosocial disability that do not have a co-morbid physical, sensory or intellectual disability.

Evidence suggests that children with disabilities have a higher prevalence of mental health conditions than children without disabilities [24-29]. *The Lancet Commission on Global Mental Health and Sustainable Development* calls for directed action to address the needs of people with disabilities, who may be at increased risk due to marginalisation, discrimination, isolation and a lack of access to fundamental rights and services [19]. The Commission notes children and adolescents with disabilities, and in particular children with intellectual disabilities, who are at risk of forced detention and denial of mental health care. Although growing, current evidence on the mental health of children with disabilities is of low quality, there is limited literature from LMICs, and there is limited research into the social and environmental factors that influence poor mental health in this population [24-29].

1.6. Terminology

For the purposes of this thesis, I use the following definitions and conceptualisations regarding mental health and wellbeing:

- Mental health: The World Health Organization defines mental health as a “state of mental well-being that enables people to cope with the stresses of life, realize their abilities, learn well and work well, and contribute to their community” [30].
- Mental health conditions: Mental health conditions can be described as “common” (e.g. mild depression and anxiety) and “severe” (e.g. moderate to severe depression, bipolar disorder, schizophrenia) [31]. Severe mental health conditions are less prevalent and may result in more severe impairment. I use the term “conditions”, although other terms are common in the literature, including “disorders”, “illnesses” and “problems”. I have aimed to be consistent in my use of mental health conditions, as other language may be inappropriate or stigmatising.
- Wellbeing: The World Health Organization defines wellbeing (or well-being) as a “positive state experienced by individuals and societies. Similar to health, it is a resource for daily life and is determined by social, economic and environmental conditions. Wellbeing encompasses quality of life and the ability of people and societies to contribute to the world with a sense of meaning and purpose” [32].

In this thesis, I use mental health in the context of alleviating mental health conditions or promoting good mental health. The range of mental health conditions is broad and diverse, but in this thesis, I use the term to refer to common mental health conditions, including depression and anxiety, rather than severe conditions, such as psychotic disorders. Severe mental health conditions are important to consider, but they have not been the focus of my research and are not discussed in detail. I use wellbeing to describe a state of psychosocial wellbeing that encompasses good mental health and positive emotions, as well as feelings of self-acceptance, purpose, autonomy and positive relationships.

2. Overview of thesis

2.1. Aim of thesis

In this thesis, I present a portfolio of four published articles that explore mental health and wellbeing among children with disabilities [33-36]. The four articles were derived from two research projects conducted in the Gaza Strip and the UK during COVID-19. The analytic commentary presented alongside these articles synthesises the findings and presents my discussion of the research in the context of existing literature. In this analytic commentary, I examine factors that contribute to the mental health and wellbeing of children with disabilities and I discuss how my research has contributed to understanding on this topic. I highlight gaps in the evidence and directions for future research, policy and practice.

It is important to note that my research focused on deaf and hard of hearing children and youth with intellectual disabilities. Portions of my discussion will focus primarily on these groups, although I present discussion and draw from relevant literature on children with disabilities more broadly.

2.2. Research presented in the thesis

This thesis includes the following first-authored, peer-reviewed articles:

- Paper 1 [33]: Scherer N, Bright T, Musendo DJ, O'Fallon T, Kubwimana C, Eaton J, Kakuma R, Smythe T, Polack S. Mental health support for children and adolescents with hearing loss: scoping review. *BJPsych Open* (2021) 8 (1), e9 10.1192/bjo.2021.1045
- Paper 2 [35]: Scherer N, Smythe T, Hussein R, Wapling L, Hameed S, Eaton J, Kabaja N, Kakuma R, Polack S. Communication, inclusion and psychological wellbeing among deaf and hard of hearing children: A qualitative study in the Gaza Strip. *PLOS Global Public Health* (2023) 3 (6), e0001635 10.1371/journal.pgph.0001635
- Paper 3 [34]: Scherer N, Hussein R, Eaton J, Kabaja N, Kakuma R, Smythe T, Polack S. Development of mental health and psychosocial support (MHPSS) guidelines for deaf and hard of hearing children in the Gaza Strip. *PLOS Global Public Health* (2023) 3 (10), e0002427 10.1371/journal.pgph.0002427

- Paper 4 [36]: Scherer N, Wiseman P, Watson N, Brunner R, Cullingworth J, Hameed S, Pearson C, Shakespeare T. 'Do they ever think about people like us?': The experiences of people with learning disabilities in England and Scotland during the COVID-19 pandemic. *Critical Social Policy* (2022) 43 (3), 423-447, 10.1177/02610183221109147

Sections 2.2.1. and 2.2.2. provide an overview of the two research projects that these papers relate to. The published articles are presented immediately after, before the analytic commentary.

2.2.1. Mental health support for deaf and hard of hearing children in the Gaza Strip

There are 70 million deaf and hard of hearing children worldwide [37]. Deaf and hard of hearing children are at increased risk of mental health conditions [38, 39], but there is a dearth of high-quality evidence examining this relationship and intervention/promotion strategies, particularly in LMICs [28].

Papers 1-3 come from a collaborative research project in the Gaza Strip between 2020-2022, on which I was lead researcher. This project aimed to understand the factors that influence mental health and wellbeing among deaf and hard of hearing children in the Gaza Strip, explore mental health and psychosocial support (MHPSS) strategies and develop school-based guidelines on MHPSS for deaf and hard of hearing children. The project was conducted by the London School of Hygiene & Tropical Medicine (LSHTM), Atfaluna Society for Deaf Children and CBM International. I was lead researcher at LSHTM. The Gaza Strip is a Palestinian Territory under Israeli occupation. At the time of study, available evidence showed that youth in the Gaza Strip experienced high rates of depression, anxiety and post-traumatic stress disorder, yet faced difficulties accessing services [40, 41]. In a 2019 *Multiple Indicator Cluster Survey* (MICS), disability prevalence among children aged 5-17 in the Gaza Strip was estimated to be high at 12.8%; 7.4% had anxiety and 0.8% (~50,000 children) had difficulty hearing [42].

The process to develop the guidelines was collaborative and participatory. With local partners, we formed a local steering committee, comprised of Deaf adults, family members, members of an organisation of deaf and hard of hearing people, teachers, mental health specialists and government officials. I worked with this committee and Atfaluna to develop the research priorities and methods, to analyse and interpret findings, and to develop guideline content. Consultation with local Deaf leaders, international deaf and hard of hearing people with expertise on mental health, and the World Federation of the Deaf further supported development of these evidence-based guidelines. Research to inform the guidelines included systematic review (paper 1), qualitative research (paper 2) and pilot study (paper 3).

Paper 1 presents a systematic review of mental health support for deaf and hard of hearing children worldwide [33]. Findings identify MHPSS strategies and considerations for inclusive service provision. This was the first global review to synthesise evidence on mental health support for deaf and hard of hearing children. Paper 2 used qualitative methods to understand factors that influence the mental health and wellbeing of deaf and hard of hearing children in the Gaza Strip. In-depth interviews were conducted with deaf and hard of hearing children, caregivers and teachers in mainstream and special schools [35]. Factors that negatively influenced mental health and wellbeing included lack of accessible communication, social exclusion, and negative attitudes. Paper 3 describes the process of developing the MHPSS guidelines, including information on co-development, additional findings from the qualitative research and results from two pilot studies [34]. Briefly, the pilot studies demonstrated feasibility and acceptability of the guidelines. Teachers said they would need support from the school administration to implement over the long-term. The research project was conducted during the COVID-19 pandemic, impacting data collection methods, as described in papers 2 and 3. The guidelines are freely available online in English and Arabic.

At the time of writing this thesis, there is major crisis and conflict in the Gaza Strip. When conducting our research in 2020, the Gaza Strip was a humanitarian setting, given the occupation and blockade by Israel, which limited economic opportunities and access to daily needs [43]. However, the region had not experienced major armed conflict for some years, certainly not at the current level. Armed conflict was not reported by partners and participants as a major influence in relation to the mental health of deaf and hard of hearing children. Findings in papers 1-3 and reflections in the analytic commentary are relevant to the time of our research (2020-2022) and the data obtained. Discussion in this thesis may not be relevant to the current context in the Gaza Strip, where children and families are experiencing increased conflict, trauma and psychological stress.

2.2.2. Children with intellectual disabilities and their caregivers in the UK during COVID-19

In the UK, people with disabilities were three times more likely to die during the COVID-19 pandemic than people without disabilities [44]. Risk of death involving COVID-19 was 1.4-1.6 greater for people with disabilities [44], and people with intellectual disabilities experienced a 7.2-8.2-fold higher rate of COVID-related death [45].

Paper 4 presents qualitative research into the experiences of adults and children with learning disabilities (globally termed intellectual disability) and their caregivers in England and Scotland during the COVID-19 pandemic [36]. The research was conducted in collaboration with the University of Glasgow in response to rapid funding calls at the start of the pandemic. Findings showed that adults and children with intellectual disabilities and caregivers felt abandoned by the government. As a result, children and caregivers experienced strain on their mental health and wellbeing. The project elicited other published works, to which I am co-author and to which I refer to throughout the thesis [46-48]. The research findings have been used by disability researchers and advocates in the *UK COVID-19 Inquiry*, outlining the structural inequalities that contributed to increased risk of mortality, morbidity and hardship for people with disabilities during the pandemic [49]. The pandemic exacerbated existing exclusion and inequities for people with disabilities. As such, there have been calls for a post-pandemic response that better includes people with disabilities in policy and programme development and implementation [50].

Note that paper 4 focuses on both adults and children with intellectual disabilities. The sample comprised of adults with intellectual disabilities, caregivers and family members of adults and children with intellectual disabilities, and representatives from organisations supporting adults and children with intellectual disabilities. In the analytic commentary, I draw on findings relevant specifically to children with intellectual disabilities and their family members.

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Review

Mental health support for children and adolescents with hearing loss: scoping review

Nathaniel Scherer, Tess Bright, David John Musendo, Timothy O'Fallon, Chris Kubwimana, Julian Eaton, Ritsuko Kakuma, Tracey Smythe and Sarah Polack

Background

Children with hearing loss are at increased risk of mental health conditions, including behavioural problems, but there is limited evidence about available mental health support.

Aims

We aimed to map the evidence on mental health support for children and adolescents with hearing loss.

Method

Medline, Embase, PsycINFO and grey literature databases were searched until April 2021. Articles of any study design were eligible if they described an intervention supporting the mental health of children with hearing loss. No restrictions were placed on geography or publication date. Four reviewers independently screened results by title, abstract and full text. Study characteristics and outcome data were extracted, with results narratively synthesised.

Results

From 5629 search results, 27 articles were included. A large majority of the studies (81%, *n* = 22) were from high-income settings, with two-thirds (67%, *n* = 18) conducted in the USA. Less than half (41%, *n* = 11) of the articles adopted experimental research designs, and the majority of studies included small samples. The interventions presented were diverse, with the majority either therapy based (30%, *n* = 8) or skills training (30%, *n* = 8). Interventions included ice-skating, parent–child interaction therapy and resilience training. When measured, interventions demonstrated at least some evidence of effectiveness, although this was not always assessed with gold-standard methodology.

Conclusions

The evidence is lacking in breadth, study quality and geographical spread. That said, what is available indicates a range of effective approaches to support the mental health of children with hearing loss. Additional research is needed to improve the breadth of evidence on mental health support for this population.

Keywords

Childhood experience; outcome studies; psychosocial interventions; rehabilitation; primary care.

Background

As of 2019, an estimated 20% of the global population (or 1.57 billion) have hearing loss, with 430 million having moderate-to-complete hearing loss.[1] This is a 79% increase in reported rates from 1990, and by 2050, an estimated 2.45 billion people are estimated to have hearing loss, with 698 million having moderate-to-complete hearing loss. Although hearing loss is more common among older adults, there are approximately 70 million children aged 0–15 with hearing loss across the world.[1]

Children with hearing loss may experience language deprivation, impacting development, communication and socioemotional skills.[2,3] As a result, children with hearing loss are at increased risk of mental health conditions, such as anxiety and depression, with several studies demonstrating significantly higher prevalence of these conditions among children with hearing loss, compared with children without hearing loss.[4–9] Evidence also shows that children with hearing loss are more likely to experience behavioural problems, including conduct and hyperactivity disorders.[10,11] Half of mental health conditions start by the age of 14, yet these often go undetected and untreated.[12] Among the general population, these conditions in childhood are associated with an increased risk of mental health concerns in adulthood, lower family income, lower probability of employment and lower probability of being married.[13,14] Mental health conditions may also further disrupt ongoing child development, a challenge already present for children with hearing loss. Addressing mental health concerns, while promoting emotional, behavioural and psychological well-being, is imperative among children with hearing loss, in order to support a healthy childhood and reduce the risk of adverse experiences in adulthood.

Youth mental health has received growing attention in recent years, as evidenced by the inclusion of 104 network meta-analyses and meta-analyses of randomised controlled trials (RCTs) on mental health interventions for children and adolescents in a recent umbrella review published in 2021.[15] However, there is limited synthesised evidence on interventions and types of support available for children with hearing loss that promote psychological, emotional and behavioural well-being, prevent mental health conditions and treat conditions that do arise. In 2019, a systematic review on the assessment and treatment of behavioural disorders in children with hearing loss found limited evidence of interventions to address behavioural problems.[11] Evidence on interventions available for other mental health conditions is lacking. Information on the types of interventions applied, their characteristics and evidence of their effectiveness is needed to inform support programmes for children with hearing loss, whether these be in school, the community or delivered through the healthcare system.

Aims

This study aimed to systematically identify and map the evidence on mental health support for children and adolescents with hearing loss. We aimed to answer the following questions.

(a) What are the characteristics of the available literature describing mental health support for children with hearing loss?
(b) What mental health interventions and support have been provided or evaluated for children with hearing loss?
(c) What evidence is available on the effectiveness of these interventions?
(d) What are the current gaps in the available evidence?

Method

With expected limited and heterogeneous data, we chose to conduct a scoping review, rather than an alternative evidence synthesis, in order to map the available evidence.[16] The protocol for the review was registered on the Open Science Framework on 3 March 2020 (osf.io/8qdbz/). Ethics approval was obtained from the London School of Hygiene & Tropical Medicine Research Ethics Committee (Ref: 19144).

The scoping review has been conducted and reported according to the PRISMA Extension for Scoping Reviews (PRISMA-ScR) guideline and followed Arksey & O'Malley's framework for scoping reviews.[17,18] We conducted the review across five stages: (a) identifying the research question; (b) identifying relevant studies; (c) study selection; (d) charting the data; and (e) collating and summarising the results.

Eligibility criteria

(a) Population: children aged 6–18, with diagnosed, proxy-report or self-reported hearing loss, of any severity. Included participants did not need to have a diagnosis of a mental disorder.
(b) Intervention: any initiative designed to improve the mental health and well-being of children with hearing loss, including interventions developed specifically for children with hearing loss or those adapted from interventions aimed at the general population. Interventions promoting developmental skills and protective factors, such as emotional regulation, resilience and self-esteem, were included if connection was made to child mental health and well-being. Interventions were also included if they addressed behavioural problems or disorders, such as hyperactivity or aggression. Activities could be focused on promotion, prevention or treatment, such as social interventions, skills development, targeted recreational activities and therapies. They could be delivered by any personnel in any setting. Interventions for parents, caregivers or other adults (for example teachers) were included if children with hearing loss were an intended beneficiary. Similarly, interventions were included if provided to a diverse group, as long as children with hearing loss were one of the beneficiaries.
(c) Comparator: studies with and without a control or comparison group were included. If a control or comparator is present, they must also be children with hearing loss of the same age, but who have not received the intervention.
(d) Outcomes: studies with or without assessment of any outcome were included. Where applicable, outcomes of interest included scores on mental health screening tools, acceptability/feasibility, cost-effectiveness and other reasonable data.
(e) Study design: published literature of any study design (quantitative, qualitative and mixed methods). Descriptive literature (i.e. without research methods applied) was included, if sufficient detail was provided on the intervention(s) available for children with hearing loss. Reviews and opinion pieces were excluded. There were no restrictions placed on geographic location, although articles needed to be in English. There were no limits placed on publication date. Grey literature, including dissertations and conference presentations, was included. Only articles with an available full text were included.

Search strategy

Articles were identified through a systematic search of Medline, Embase and PsycINFO. The search was initially conducted on 27 April 2020 and updated on 27 April 2021. An example of the search strategy is available in Supplementary File 1 available at https://doi.org/10.1192/bjo.2021.1045. Reference lists of each included study were examined in search of additional articles for inclusion.

The search for grey literature was conducted through OpenGrey and Google Scholar. Additionally, experts in this field were contacted for recommendations of known reports, and the websites of notable disability and hearing loss organisations were manually searched (Supplementary File 2).

Study selection

Authors N.S., T.B., D.J.M. and T.O.'F. independently screened all titles and abstracts against the eligibility criteria. Each record was screened by two reviewers. Eligible full-text articles were then independently reviewed by two reviewers. Although excluded from the final synthesis, systematic reviews and full-length books identified in the database search were manually screened by full-text, with included articles and book chapters selected for full-text screen, if relevant. Records identified from the reference lists of included articles were also filtered into the full-text screening. Discrepancies at any stage were discussed between the two reviewers, with a third and fourth reviewer consulted if needed. This review process was conducted using Covidence software.

Data extraction and charting

N.S. extracted the data for each study, using a custom form, developed in Excel. This extraction form was first piloted on three included articles, with amendments made as necessary. T.B., D.J.M. and T.O.'F. each independently reviewed one-third of data extracted. Discrepancies were discussed and resolved with N.S., with support from a third reviewer if needed. Data extracted included:

(a) Publication details: author, year of publication, title, country, aims/objectives, study design.
(b) Characteristics of mental health support: type (promotion, prevention, treatment), intended outcome, setting, delivery agent, intervention components.
(c) Outcomes: type (effectiveness, feasibility, acceptability, service-delivery related), measurement tools, findings (both narrative and statistical).

Quality assessment

For an assessment of risk of bias, we used the critical appraisal tools from the Joanna Briggs Institute (JBI). There are various tools provided by JBI, designed for use with different designs, such as case report or RCT. Each tool can be used to determine the extent to which a study has addressed the possibility of bias in its design, conduct and analysis, via a series of relevant questions and standardised responses.[19]

Studies were assessed by N.S., with scores reviewed by S.P. Based on the assessment against a JBI checklist, each study was rated as having high, medium or low risk of bias.

(a) Low risk: all or almost all of the criteria were fulfilled, and those that were not fulfilled were thought unlikely to alter the conclusions.

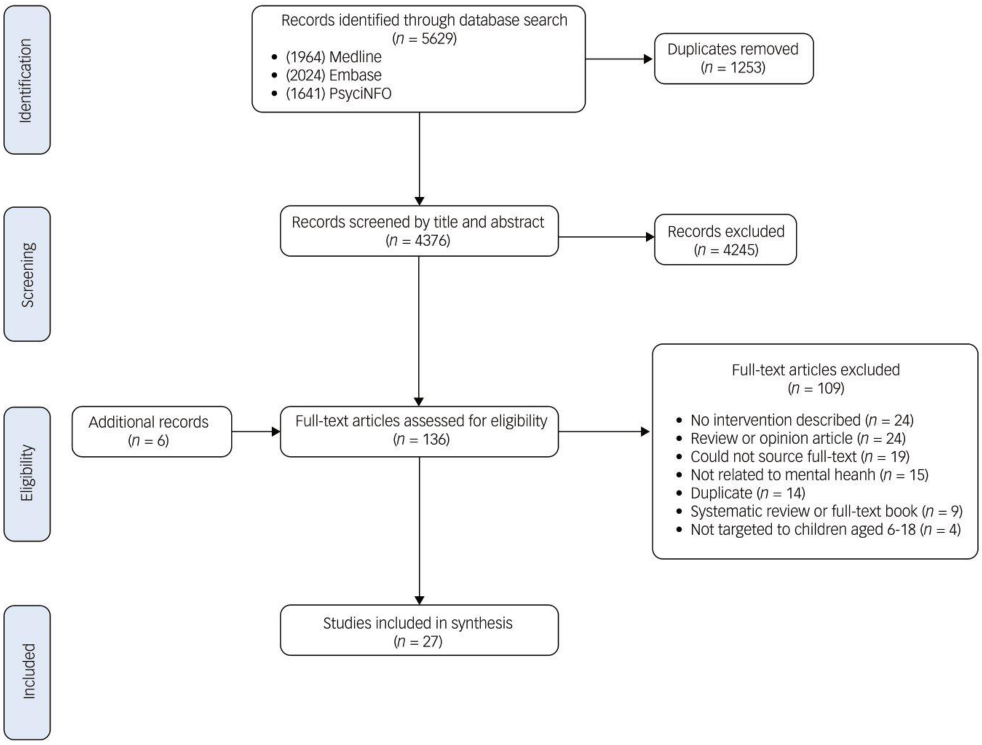

Fig. 1 PRISMA flow chart.

(b) Medium risk: some of the criteria were fulfilled, and those not fulfilled were thought unlikely to alter the conclusions of the study.

(c) High risk: few or no checklist criteria were fulfilled, and the conclusions of the study were thought likely to alter if these had been met.

Synthesis of results

Under the umbrella of mental health, the focus of this review, we have grouped articles by interventions that address psychological well-being and behavioural problems. Psychological well-being, in this instance, refers broadly to emotional well-being and mental health, and includes diagnosis or symptoms of mental health conditions, as well as related domains, such as resilience and self-esteem. Behavioural problems include disorders and concerns relating to disruptive and challenging behaviours, such as aggression, impulsivity and defiance. Specific behavioural disorders include attention-deficit hyperactivity disorder or oppositional defiant disorder.

Under these two subheadings, we grouped articles by intervention type. Findings have been summarised narratively, with the focus on the characteristics of the interventions. Information on effectiveness has been narratively presented, where this information was available.

When data presented in an article is disaggregated by age, with participants older or younger than the inclusion criteria included, only that attributable to children within the age range of 6–18 years was included in the synthesis.

Results

The database search generated 5629 results, from which 1253 duplicates were removed. In total, 4376 records were screened by title and abstract, from which 4245 were excluded based on the criteria above (Fig. 1). There were 130 full-text articles that were eligible for screening, with 6 additional records included from systematic reviews screened at full text (*n* = 3), records identified via the reference lists of included articles (*n* = 2) and the grey literature (*n* = 1). From 136 full texts assessed, 27 articles were included in the synthesis.[20–46]

Study characteristics

Of the 27 included articles, 18 (67%) come from North America, and specifically the USA (Table 1). Of the remaining, four (15%) were conducted in Europe, four (15%) the Middle-East, and one (4%) in Asia. None were from Africa, Latin America or Australasia. Nine (33%) were published after the year 2010, with 18 (67%) prior to 2010. Eleven (41%) were published prior to the year 2000.

Eighteen (67%) provide information on support focused on psychological well-being, and related domains. Of these, four (15%) targeted protective psychological factors (such as resilience and emotion management), one (4%) social anxiety disorder, one (4%) substance misuse disorder and one (4%) obsessive–compulsive disorder. Fourteen (52%) of the 27 included articles focused support

Table 1 Summary of article characteristics

Variable and category	*n*	%
Region		
Asia	1	4
Europe	4	15
Middle-East	4	15
North America	18	67
Country		
Finland	1	4
India	1	4
Iran	3	11
Poland	1	4
Turkey	1	4
UK	2	7
USA	18	67
Country income status		
High	22	81
Upper-middle	4	15
Lower-middle	1	4
Study design		
Before and after	3	11
Case report	4	15
Case series	5	19
Pilot study	2	7
RCT	6	22
Qualitative	1	4
Descriptive	6	22
Decade of publication		
1970	4	15
1980	1	4
1990	6	22
2000	7	26
2010	7	26
2020	2	7
Source		
Journal	23	85
Book	2	7
Thesis	2	7
Mental health domain		
Psychological well-being	18	67
Behavioural problems	14	52
Sample size		
≤10	9	33
11–20	4	15
21–50	4	15
51–100	2	7
>100	2	7
N/A	5	19
Risk of bias		
Low	7	26
Medium	10	37
High	4	15
N/A (description only)	6	22

RCT, randomised controlled trial; N/A, not applicable.

on behavioural problems, such as conduct disorder. Some articles focused on both psychological well-being and behavioural problems and the percentages presented therefore total greater than 100%.

Twenty (74%) of the interventions included treatment options, 17 (63%) promotion activities and 7 (26%) prevention techniques. Eight (30%) interventions were therapeutic in nature, nine (33%) were a structured training programme, two (7%) based on physical exercise, and one (4%) medical. Seven (26%) others were intervention packages, comprised of multiple single interventions.

Eighteen (67%) described activities delivered in schools, nine (33%) of which were special schools, three (11%) special education classrooms in a mainstream school and one (4%) a mainstream school. Four (15%) were conducted in residential settings, with schooling on site. Six (22%) were conducted in healthcare facilities, one (4%) a community setting, and two (7%) artificial/research settings. One (4%) study did not provide information on the setting.

Nine (33%) of the included articles presented a case report or case series, six (22%) conducted randomised controlled trials, five (19%) used quasi-experimental methods (of which two were pilot studies) and one (4%) qualitative. Six (22%) of the articles described an intervention or support structure, without any research methods applied. One-third (33%) of articles included a sample size of less than ten participants, with only two studies (7%) including more than 100 participants.

Summarising the ages and degree of hearing loss among participants included presented a challenge. Studies provided various classifications on the severity of hearing loss, and we have converted these under the same terms in Table 2. The ages of participants and severity of hearing loss overlapped across studies, and summary statistics were difficult to present with much coherence.

Quality assessment

The six (22%) articles that describe (rather than evaluate) an intervention were not included in the quality assessment. Of the 21 remaining, 7 (33%) were rated as having a low risk of bias, 10 (48%) medium and 4 (19%) high. Potential sources of bias among those rated to have a medium or high risk, included: inappropriate statistical analysis, including the absence of statistical power or sample size calculations in RCTs; no clinical information provided for participants in a case series; and unsuitable measurement of outcomes, including collection time points and screening method.

Types of support

Psychological well-being

As seen in Supplementary Table 1, 17 articles targeted psychological well-being and related factors (for example resilience).

Five (29%) of these focused on forms of counselling, psychotherapy or group support.[28,31,37,43,44] Examples included peer-support groups and therapeutic play. Four (24%) provided structured training and skills-based programmes, including group assertiveness training for social anxiety disorder.[20,23,35,36] Two (12%) were focused on physical exercise and related activities, including ice-skating and dance lessons.[26,30] One (6%) study investigated the impact of hearing aids on psychological well-being.[38]

The remaining five (29%) articles provided information on intervention 'packages' that included more than one intervention approach.[22,24,40,45,46] These were typically delivered in healthcare or residential settings. Individual interventions described in the packages were typical of those provided in mental health programmes for the general population, and included cognitive–behavioural therapy, medication, art therapy and peer-support groups.

Behavioural problems

Fourteen articles provided support for behavioural problems. In four articles, the intervention or support provided addressed both psychological well-being and behavioural problems.

Five of the 14 (36%) provided counselling or variations of psychotherapy, including video-counselling.[25,28,39,42,44] Three (21%) provided parents with training, and typically included skills-building exercises, using role-play and similar techniques.[32,33,41] Three (21%) focused training efforts on children.[29,34,35] For example, the PATHS (Promoting Alternative Thinking Strategies) curriculum, which includes daily activities at school, delivered by teachers.[34] One (7%) supported physical activity, in this instance, ice-skating.[30] A further two (14%) articles described a support package including various activities.[21,27] This included Walden House, a residential programme for children with hearing loss

Table 2 Individual article characteristics

First author (year)	Country	Mental health domain	Study design	Control group	Age, years	Degree of hearing loss	Participants (male/female)	Risk of bias
Ahmadi et al (2017)[20]	Iran	Social anxiety disorder	RCT	Y	12–16	Moderate to profound	48	Medium
Altshuler & Spady (1978)[21]	USA	Behavioural problems	Case series	N	4–10	Profound	3 (2/1)	Medium
Anonymous (1978)[22]	USA	Psychological well-being	Descriptive[a]	N	12+	Moderate to profound	N/A	N/A
Ashori & Najafi (2021)[23]	Iran	Emotional regulation	RCT	Y	15–19	Mild to severe	34 (0/34)	Medium
Bernstein & Denno (2005)[24]	USA	Obsessive–compulsive disorder	Case report	N	3–21	Mild to profound	1 (0/1)	Low
Boham & Selkowitz (1981)[25]	USA	Behavioural problems	Descriptive	N	6–19	Moderate to profound	N/A	N/A
Borowiec et al (2019)[26]	Poland	Self-esteem	RCT	Y	9–13	Severe to profound	28 (16/12)	Medium
Burnes et al (1992)[27]	USA	Behavioural problems	Descriptive	N	Not stated	Moderate to profound	N/A	N/A
Chapel (2005)[28]	USA	Psychological well-being and behavioural problems	Case series	N	Not stated	Moderate to profound	4 (3/1)	Low
Donovan (2003)[29]	USA	Behavioural problems	Case series	N	4–7	Moderate to profound	3 (2/1)	Medium
Dursun et al (2015)[30]	Turkey	Psychological well-being and behavioural problems	Before and after	N	8–16	Not stated	40 (24/16)	Medium
Elkayam & English (2003)[31]	USA	Psychological well-being	Pilot study	N	12–18	Mild to severe	15	Medium
Forehand et al (1974)[32]	USA	Behavioural problems	Case report	N	7	Moderate to severe	1 (1/0)	Medium
Garcia & Turk (2007)[33]	UK	Behavioural problems	Case report	N	10	Profound	1 (1/0)	Low
Greenberg & Kusché (1998)[34]	USA	Behavioural problems	RCT	Y	6–12	Severe to profound	57 (27/30)	Low
Hatamizadeh et al (2020)[35]	Iran	Resilience and behavioural problems	RCT	Y	12–15	Mild to severe	122 (74/48)	Low
Johnson & Sandberg (1992)[36]	USA	Substance abuse disorder	Descriptive	N	11–12	Mild to profound	N/A	N/A
Lasanen et al (2019)[37]	Finland	Psychological well-being	Qualitative	N	7–17	Mild to severe	16 (4/12)	Low
Nehra et al (2001)[38]	India	Psychological well-being	Before and after	Y	15–19	Moderate to profound	14	Medium
Osborne (1977)[39]	USA	Behavioural problems	Before and after	N	2–21	Mild to profound	280	High
Sarti (1993)[40]	USA	Psychological well-being	Case series	N	10–13	Mild to profound	5 (4/1)	High
Shinn (2013)[41]	USA	Behavioural problems	Case report	N	9	Moderate	1 (1/0)	Low
Sullivan et al (1992)[42]	USA	Behavioural problems	RCT	Y	12–16	Mild to profound	71 (51/21)	Medium
Tinsley & Jedlicka (2012)[43]	USA	Psychological well-being	Pilot study	N	7–19	Not stated	20	High
Troester (1996)[44]	USA	Psychological well-being, resilience and behavioural problems	Case series	N	Not stated	Moderate to profound	3 (3/0)	High
Vreeland & Tourangeau (2003)[45]	USA	Psychological well-being	Descriptive	N	8–21	Mild to profound	N/A	N/A
Wright et al (2012)[46]	UK	Psychological well-being	Descriptive	N	8–18	Not stated	N/A	N/A

RCT, randomised controlled trial; Y, yes; N, no; N/A, not applicable.
a. Description of an intervention with no research methods applied.

and behavioural problems, providing problem-solving skills, family therapy and role-play exercises.[27]

Theoretical underpinnings

Twenty three of the 27 articles provided information on the theory or evidence used to develop the intervention. The remaining four articles provided descriptions of logic-based arguments for the intervention model, without substantial information on evidence or theory. Of the 23 articles providing this information, 12 (52%) provided evidence of previous use or effectiveness of the intervention among children without disabilities or hearing loss, four provided (17%) evidence of its use with children with and without hearing loss, and four (17%) articles provided evidence of the intervention among children with hearing loss only. Four (17%) based the intervention on theories developed for children without hearing loss, such as the ABCD (Affective-Behaviour-Cognitive-Dynamic) model of child development.

Adaptations made to interventions

Of the 27 articles, 16 described specific considerations and adaptations made to the intervention to accommodate the needs of children with hearing loss, particularly when the support provided was initially developed for the general population.

Of these, 13 (81%) described considerations of communication methods and needs, such as reading ability. Nine (56%) used sign language or provided sign language interpretation. Three (19%) made adaptations to the physical environment in which the intervention was delivered. For instance, seating groups in a circle to maximise visual contact, or providing pictures and posters to facilitate understanding. Three (19%) adapted the core structure, components, tools and methods of established interventions. For example, established programmes for the general population, such as D.A.R.E. and the PATHS curriculum were adapted and prepared with support from hearing loss specialists.

Outcomes

Effectiveness

In total, 19 articles provided information on the effectiveness of the intervention or programme.

Eleven of these presented outcomes with regards to psychological well-being, with all but one finding some evidence of a positive impact of the intervention. Specifically, three (27%) provided evidence on the effectiveness of training programmes for children with hearing loss, including resilience training. One of these, targeting social anxiety disorder, reported no significant differences in symptomology between intervention and control groups in children with profound hearing loss, but did see a difference for those with moderate hearing loss. Two (18%) demonstrated the positive effect of physical activity interventions; dance lessons and ice-skating. Therapy-based interventions were found beneficial by two (18%) studies, one of which, a qualitative study, provided evidence of the positive perceived benefit from participants of regular peer-support groups, although changes in well-being were not measured nor observed with other standardised methods. One (9%) other found no difference in participants pre- and post-intervention after receiving child-centred play therapy. One demonstrated significant improvements in well-being, including reduced symptoms of anxiety and depression, after children had used hearing aids for 6 months. Two studies (18%) provided evidence on the effectiveness of intervention packages comprised of various approaches, including a package for obsessive–compulsive disorder. Of those described, five (45%) demonstrated improvements in scores on quantitative standardised measurement tools (such as the Strengths and Difficulties Questionnaire) after the intervention was implemented, of which four (36%) RCTs showed significant improvement in the intervention group and not the control group.

With regards to behavioural problems, 11 studies reported on outcomes, of which all but one found some evidence of a positive impact of the intervention. Five (45%) found evidence on the benefit of training programmes, including parent behaviour training and teacher delivered resilience behaviour training for children. Three (27%) demonstrated the positive impact of therapy-based interventions on behaviour, although one (9%) showed no benefit. One study (9%) showed improvements among children on the Strengths and Difficulties Questionnaire, including the behavioural domain, after regular ice-skating sessions. One (9%) showed the benefit of a triadic intervention model for behavioural problems, focused on a core of reinforcement in schools. Seven (64%) reported positive improvements in behavioural outcomes, assessed through standardised measurement tools. Three RCTs (27%) demonstrated significant improvement in the intervention group and not the control, after delivery.

Other outcomes

Four articles provided evidence about the acceptability of the intervention to participants, delivery agents and/or parents. In one pilot study, this was the primary outcome that was measured quantitatively by questionnaire, with participants reporting good acceptance of the counselling method provided to support psychological well-being. In another, teachers reported feeling motivated to deliver the functional communication training for behavioural problems, and were happy with the training provided. In the third, both parents and delivery agents (clinicians) provided positive feedback in a directed workshop, with regards to the structure and components of the Webster-Stratton programme for behavioural problems. In the final case study of parent–child interaction therapy for behavioural problem, the mother expressed the value of learning to play with her child and manage their behaviour in a way that was fun and engaging for them.

Discussion

Summary of evidence

To the best of our knowledge, this is the first attempt to systematically identify and map the evidence on mental health support for children and adolescents with hearing loss. The scoping review identified 27 articles, two-thirds of which were conducted in the USA and two-thirds published before 2010. A number of interventions and support initiatives were described in the literature, including a broad range of therapy and counselling, and targeted training programmes, for both children and caregivers.

The interventions identified were, by and large, found to be effective at supporting the mental health and well-being of children with hearing loss. Although not all articles provided information on outcomes, nor all via quantitative assessment, those that did offered some encouraging signs as to the benefits of mental health support for children with hearing loss. Dance lessons, resilience training programmes and hearing aids demonstrate the diverse gamut of effective interventions that can be utilised to support children with hearing loss. Interventions provided treatment, prevention and promotion options in various settings, supporting recent advocacy for population- and community-level support for child mental health.[47] As the evidence suggests, an effective and sustainable approach to child mental health includes support from an early age, improving information and awareness, providing social and emotional learning activities, increasing detection and identification, and improving access to treatment and rehabilitation. The interventions in this review provide some examples of interventions that may be effective within such a system, although as we will go on to discuss, the strength of the current evidence is limited.

Most of the interventions identified in this review were provided in school, which follows evidence from among the general population as to the benefits of integrated mental health provision within education systems.[48] Interventions at school level provide a continuum of care that benefits a child's mental health, as well as their educational attainment. Only one identified intervention was conducted within a mainstream classroom, despite the recent global movement towards inclusive education.[49] That said, a recent report outlines the limited transformations in education systems across the world, with most countries facing difficulties in inclusive provision, with understanding of what this means, and resources and evidence on good practice variable across regions.[50] As reform continues to spread, there will need to be evidence gathered on appropriate mental health interventions in inclusive classrooms, to ensure children with hearing loss are not excluded.

When considering interventions for children with hearing loss, it is important to note components and delivery methods unique to this group. Many of the interventions were initially developed for use in the general population, and more than half of the included articles described interventions that had been developed from evidence for children without hearing loss and adapted for the needs of children with hearing loss. Adaptations were most commonly focused on communication, and often sign language. Communication is often cited as a major barrier and facilitator to accessing healthcare for people with hearing loss, and it is appropriate to see this as the focus of many adaptations.[51] In some settings (typically high-income settings) such as the UK, and as seen in the included article from Wright et al (2012), specialist mental health services exist for children with hearing loss, where sign language and other accommodations are embedded in the service provided.[46] However, in other settings, provision of communication technologies and sign language interpretation may not always be possible, given restricted resources. Often, and especially in low- and middle-income countries, mental health interventions are adapted from one context to another, in order to meet the culture, needs and resources of a population. In low- and middle-income countries, this often includes adapting interventions developed in high-income settings, although there are good examples of adaptation in the other direction, in which we see novel and effective mental health interventions developed in low-resource settings and adapted to those in high-income settings (an example being the Friendship Bench, developed in Zimbabwe and adapted to New York City in the USA).[52] Adaptation is common and needed, and the well-evidenced stages of this process should be noted by those looking to adapt mental health interventions for children with hearing loss, in order to ensure appropriate intervention components and delivery mechanisms. This will include standard adaptations to the context, but also specific adaptation to the needs of children with hearing loss, such as those seen in this review. We did not find any studies that provided evidence of an adaptation process through formative research, theory of change workshop, feasibility study, or similar methods, and this would be a useful area of research going forwards, to promote interventions for children with hearing loss that are contextually and culturally appropriate, and hopefully then effective and sustainable. These approaches also promote the participation of stakeholders, including those with hearing loss and/or mental health conditions.

Evidence gap

Although 27 articles were identified, there is concern about the breadth, scope and strength of the evidence within the literature available. With two-thirds (67%) of articles published before 2010, and 41% pre-2000, it is evident that the published literature on this topic is not growing at a fast rate. Interest and research in disability has steadily increased since the United Nations Convention on the Rights of Persons with Disabilities (2008), and calls for further evidence on scalable mental health interventions have been delivered by leading figures for many years.[53] Despite an increased focus on global mental health and disability rights, this review suggests that mental health support for children with hearing loss is not gaining sufficient interest in the research community. The Lancet Commission on Global Mental Health and Sustainable Development, published in 2018, may stimulate additional research in the future, calling as it does for a focus on culturally appropriate and participatory approaches to translating evidence for promotion and care in mental health across diverse populations.[54] Our approach to classification using a continuum from well-being to mental health diagnosis draws on these ideas. Exploring the evidence among adult populations is also needed given the higher prevalence of hearing loss in this age group.

Furthermore, nearly all (81%) of the included articles come from high-income settings, with two-thirds (67%) conducted in the USA. Just one (4%) was conducted in a lower-middle or low-income setting. There are no articles from Latin America or Africa, and just one study from Asia. The geographical scope of study into appropriate interventions for children with hearing loss must increase. Given that 80% of the world's population and people with disabilities are living in low- and middle-income countries, there is an urgent need for evidence on contextualised interventions.[55] Relying on data from high-income settings has caused concern in the field of global mental health, as doing so reduces long-term effectiveness and sustainability of mental health interventions, especially when biomedical models of care are transferred to settings where they may not be culturally accepted, contextually feasible or appropriate.[54] There is growing evidence on new and adapted mental health interventions for the general population in low- and middle-income settings, and as shown in this review, there is the possibility of adapting these to suit the needs of children with hearing loss (for example sign language provision). Evidence is needed on the process of adaptation and contextualisation, in order to inform delivery in the given country, and to provide a research framework for others.

Most of the studies were assessed to have medium or high risk of bias. Just six (22%) of the studies available and included are RCTs. The majority of included articles offer interesting case reports, but these provide the rationale for larger-scale trials, rather than high-quality evidence in and of themselves. Most of the studies included have also been conducted with very small sample sizes. Nearly half (48%) of studies contained a sample size smaller than 20, increasing to two-thirds (67%) when including those articles with no sample size available. To improve the evidence base with which to stimulate service provision and policy, there needs to be experimental research, with large samples, with which to build confident conclusions and inform scalable interventions. Potential sources of bias must be addressed, including appropriate statistical methods, including sample size calculations for sufficient power.

Limitations

There are several limitations to this review. First, we excluded articles that were not in the English language, and there may well be evidence missed that has been published in other languages. This is particularly important when considering the limited evidence from South America and East Asia. Our age range, 6–18 years, is broad and although not necessarily a limitation, it is important that readers of this review pay close attention to the targeted age range of interventions of interest. Younger children and older adolescents will respond differently to interventions, and will have different mental health needs, and not all interventions will be applicable across age groups. Second, we could not source 19 full-text articles, in which there may have been relevant and included studies. We contacted authors directly and utilised various institutional access agreements, but still could not find these for assessment. Third, we did not assess publication bias. When interpreting the results on effectiveness, readers should be conscious of the risk of positive publication bias and a potential lack of interest to publish results on ineffective interventions. Finally, in their framework for scoping reviews, Arksey & O'Malley recommend an optional sixth step; consultation with stakeholders.[18] Such consultation is time-consuming and costly, and was not feasible when undertaking this study, and may be an important area to address in any future and updated reviews.

Implications

This review has identified a number of articles and interventions, which generally showed positive results, but there are concerns over the breadth of the evidence available. There is evidence of some effective interventions, such as dance lessons and resilience training, but the applicability of the available evidence is limited by geographic location and publication date, and there is a need for more studies applying high-quality research methods. To improve the current evidence base, we must strengthen the quality of the research methods used and provide further research from low- and middle-income countries on adapting interventions to local contexts and on interventions tested at scale. Having a community of researchers set future research priorities, as informed by practitioners and people affected, will focus and strengthen research activities going forwards.

Recommendations on mental health support for children with hearing loss

Based on the findings of this review, we have listed below a number of considerations for delivering mental health support for children with hearing loss, including adaptations to existing mental health interventions.

(a) Consider the intervention models identified in this review, including the following.
  (i) Peer-support: children with hearing loss can benefit from interaction with peers, reducing isolation, while helping them learn more about themselves and their experience as a child with hearing loss. Peer-support can act as both a treatment and health promotion option.
  (ii) Resilience training: identified by a number of studies in this review, resilience training may be an effective way of preventing mental health conditions, especially if implemented at an early age. This type of training may be particularly appropriate to integrate into schools.
  (iii) Emotional and behavioural management training: this type of structured training programme can be provided for both parents and children. Helping parents learn the tools with which to support their child's emotional regulation and behaviour may help create a home environment that promotes well-being and positive coping strategies. Training children themselves, possibly in school, will further help children with hearing loss build the toolkit with which to understand and approach the challenges they face.
  (iv) Physical activity: physical activity is a simple way to build well-being and promote mental health. In this review, the physical interventions identified were specialist in nature – ice-skating and dance therapy are not necessarily available in all settings – but adapting these techniques and principles to a different context may prove effective.

(b) Consider the following when adapting or developing an intervention.
  (i) Knowledge and awareness: it is important that the delivery agent is given appropriate training and sensitisation on disability and hearing loss. There may also be cause to provide information to children without hearing loss in the same setting, in order to reduce any apparent stigma or discrimination; for example, to hearing children in a mainstream classroom.
  (ii) Communication methods: each child will have different communication needs, depending on their severity of hearing loss and personal preferences. Include appropriate training for delivery agents on communication methods, including clarity of speech and the language used. Where necessary, provide sign language interpretation, and where relevant provide training on hearing aid or cochlear implant use, as this knowledge will facilitate improved communication and reduce stigma.
  (iii) Physical environment: consider the environment in which the intervention is delivered. This may be a mainstream classroom, for instance, that is not set up to accommodate the needs of children with hearing loss. Considering the configuration of seating in a group is one example; children sitting in a circle may help improve visual contact and support those who lipread. Keeping the environment quiet and free from distractions will also help children with hearing loss, as might keeping the door closed and adding soft material to the underside of chairs.
  (iv) Intervention materials and techniques: where suitable, use visual aids and cues to support the intervention components. One example may include pictures matched to emotions, to aid the understanding and communication of feelings. Other techniques to reinforce behaviours and actions may include role-play, storytelling and peer-feedback.

(c) Consider the following during intervention development and implementation.
  (i) Interventions identified in this review benefitted from clear communication and coordination between different groups involved. For instance, interventions in schools were strengthened when teachers and parents worked together.
  (ii) Conduct feasibility studies and pilot studies, where possible, in order to make any necessary amendments early in the implementation process. This will also help inform others in the future.
  (iii) Providing a range of interventions within a service or facility (such as a school), where this is feasible, may provide the best model with which to support a personalised approach for each child.

(d) Consultation and coordination may help promote feasible, acceptable and sustainable intervention programmes.
  (i) Consult the children, their parents, mental health and hearing specialists, and the delivery agents (such as teachers). Understand their needs and context in the adaptation or development phase.
  (ii) In all, talk to the children who are the intended target of the intervention about their own needs and preferences for intervention components, including communication methods.

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Supplementary material

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Data availability

Data availability is not applicable to this article as no new data were created or analysed in this study.

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Author contributions

N.S., T.B., C.K., J.E., R.K., T.S. and S.P. conceptualised the research question, design and methodology. N.S., T.B., D.J.M. and T.O.'F. acquired, analysed and interpreted the data, with support from all authors. S.P. provided review of the quality appraisal. R.K., T.S. and S.P. provided supervision throughout. N.S. drafted the manuscript, with input and critical review from all authors. All authors read and approved the final manuscript.

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Declaration of interest

None.

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PLOS GLOBAL PUBLIC HEALTH

RESEARCH ARTICLE

Communication, inclusion and psychological wellbeing among deaf and hard of hearing children: A qualitative study in the Gaza Strip

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Abstract

Deaf and hard of hearing children are at risk of exclusion from community life and education, which may increase their risk of mental health conditions. This study explores the experience of deaf and hard of hearing children in the Gaza Strip, with particular focus on the factors that contribute to psychological wellbeing and distress. In-depth interviews were conducted with 17 deaf and hard of hearing children, 10 caregivers of deaf and hard of hearing children and eight teachers of deaf and hard of hearing children in mainstream and special schools, across the Gaza Strip. Further, three focus group discussions were held with deaf and hard of hearing adults and disability leaders, mental health specialists and other teachers of deaf and hard of hearing children. Data collection was completed in August 2020. Key themes identified in the analysis included lack of accessible communication, community exclusion, negative attitudes towards hearing impairment and deafness and the impact on deaf and hard of hearing children's sense of self, and limited family knowledge on hearing impairment and deafness. Further findings focused on strategies to improve the inclusion of deaf and hard of hearing children and how to promote wellbeing. In conclusion, participants in this study believed that deaf and hard of hearing children in the Gaza Strip are at increased risk of mental health conditions. Changes are needed across community and government structures, including education systems, to promote the inclusion of deaf and hard of hearing children and to support their psychological wellbeing. Recommendations from the findings include increasing efforts to improve awareness and reduce stigma, providing better access to sign language for deaf and hard of hearing children, and offering training for teachers of deaf and hard of hearing children, especially in mainstream environments.

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Introduction

One in five people experience hearing impairment, of whom more than 80% live in low- and middle-income countries (LMICs) [1]. Whilst hearing impairment is more common in older persons, estimates indicate that there are 70 million children with hearing impairment globally, of whom 34 million have moderate to profound hearing impairment [1].

Deaf or hard of hearing children across the world can experience challenges in daily life, with regards to educational attainment, social inclusion and community participation [2–4]. Deaf and hard of hearing children are more likely than hearing peers to report poorer quality of life in school and social domains [3]. These negative life experiences are associated with a negative impact on emotional wellbeing and mental health, and there is increased risk of mental health conditions among deaf and hard of hearing adult and child populations, including anxiety and depression [5–13].

Context and aim of the study

Little research exists on the experiences of deaf and hard of hearing children in LMICs. The vast majority of research comes from high-income settings and findings are not representative of LMICs, where there exist different conceptions and attitudes towards disability and hearing impairment, and often more limited availability of specialised support and services. Further, little evidence is available on the experiences of deaf and hard of hearing in conflict-affected settings, where, in general, people are at greater risk of mental health conditions [14]. Deaf and hard of hearing children in conflict-affected settings may face double-jeopardy to their psychological wellbeing, both from the stressors experienced by many deaf and hard of hearing children and those that arise from being affected by conflict, such as trauma and lack of access to services [15, 16].

This study explores the experiences of deaf and hard of hearing children in the Gaza Strip, an area that has been affected by conflict and blockade, resulting in a deteriorating socioeconomic situation that has negatively impacted on the economy, education, food security, and access to basic services [17]. There is some evidence to suggest that the Gaza Strip and the West Bank has a high prevalence of hearing impairment among infants and children [18, 19]. Historically, this has resulted from high instances of consanguinity, although this practice is becoming less common [18]. However, there is scarce research available on the lived experience of deaf and hard of hearing children in the Gaza Strip, including information on experiences in school and the wider community.

Ongoing conflict, economic hardship and restricted life prospects are associated with high rates of depression, anxiety and post-traumatic stress disorder for youth in the Gaza Strip [20–25]. These stressors make it difficult for children and adolescents to develop a strong sense of self and to develop aspirations for the future [25]. Despite mental health services being available in the Gaza Strip, many young people face organisational and cultural barriers to access, and services often do not meet their need [20, 25]. Nevertheless, research has suggested that education and family support have improved wellbeing of youth in the Gaza Strip, providing inspiration and building self-esteem [25]. Although there is evidence on mental health among youth generally, there is limited information on factors that contribute to psychological wellbeing among deaf and hard of hearing children in the Gaza Strip.

Given the dearth of evidence on deaf and hard of hearing children in the Gaza Strip, this study aimed to investigate the experiences of deaf and hard of hearing children in daily life and the factors that contribute to their inclusion, quality of life and mental health. This information can help contribute to the development of context appropriate policies and interventions.

Materials and methods

This study used qualitative research methods to explore the experiences of deaf and hard of hearing children in the Gaza Strip. In-depth interviews were conducted with 35 participants, including 17 primary school age deaf and hard of hearing children, 10 caregivers, and eight teachers of deaf and hard of hearing children in mainstream and special schools. Three focus group discussions were held with five deaf and hard of hearing adults and disability leaders, seven mental health and psychosocial support specialists and school counsellors, and 13 teachers of deaf and hard of hearing children in mainstream and special education settings.

The research and analysis were guided by a steering committee of key stakeholders in the Gaza Strip. This group comprised: five deaf and hard of hearing people and representatives from organisations of deaf and hard of hearing people; two caregivers of deaf and hard of hearing children; four teachers of deaf and hard of hearing children; three mental health and psychosocial support specialists; and five representatives from government level institutions, including the Ministry of Education.

Study context

The research was conducted across each region of the Gaza Strip. In the Gaza Strip, deaf children with severe to profound hearing impairment are typically taught in special schools. Hard of hearing children with mild to moderate hearing impairment are typically taught in mainstream schools. Mainstream schools are government run and free to attend. Special schools are not supported by government financing and are often managed by non-governmental organisations (NGOs). Families pay a fee for their child to attend a special school. Each mainstream and special school is required to have a school counsellor who is tasked with promoting mental wellbeing and supporting children experiencing distress. When a child presents with severe symptoms of psychological distress, they are referred by the school to counsellors at district level who provide more in-depth assessment and support. At this district level, there are mental health specialists trained to work with deaf and hard of hearing children.

Participants

A summary of participant characteristics is presented in S1 Appendix.

Participants for the in-depth interviews were purposively sampled through mainstream and special schools across four regions in the Gaza Strip (North, Gaza City, Middle, South) in order to maximise variation, as based on Patton's maximum variation sampling strategy [26]. Participants were selected for variation across age, sex, severity of hearing impairment and type of school attended (mainstream or special school). To aid the sampling strategy, we segmented the target group by the criteria listed above, aiming for equal representation in each category. From this, we developed a minimum sample size of 32, with additional participants included if topics required further investigation [26]. In total, 35 participants were included in the in-depth interviews, comprised of 17 deaf and hard of hearing children aged 6–12, 10 caregivers of deaf and hard of hearing children, and eight teachers of deaf and hard of hearing children in mainstream and special schools. Severity of hearing impairment was confirmed by an audiologist. Hearing profiles, assistive technology usage and communication mode of the deaf and hard of hearing children are available in S1 Appendix.

Participants for the three focus group discussions were recruited through local organisations of persons with disabilities (OPDs), disability NGOs, mental health associations and schools. The first group comprised of three deaf and hard of hearing adults and sign language users, one individual with a physical impairment and one individual with a visual impairment, who also works as a counsellor. These individuals were representatives from OPDs and NGOs supporting deaf and hard of hearing people. The second group comprised five school counsellors and two mental health professionals working with children in the community. The third included seven special school teachers and six mainstream school teachers. These teachers were not the same as those included in the in-depth interviews.

Data collection

Data collection was conducted in July 2020. Interviews were held in a trusted, central location, as requested by participants, many of whom expressed concern about being audio-recorded in their own home. As the research was conducted during the COVID-19 pandemic, government guidance on safety was followed.

Semi structured, in-depth interviews with deaf and hard of hearing children, caregivers and teachers sought to explore the views, experiences, emotions and perspectives of deaf and hard of hearing children and caregivers in the Gaza Strip, both in school and the wider community. In addition, focus group discussions were held with individuals who have expertise in understanding the experiences and needs of deaf and hard of hearing children and their families. Through dynamic group discussion, these focus groups aimed to elicit multiple opinions on the experiences of deaf and hard of hearing children, as well as recommendations to improve quality of life and psychological wellbeing. Topic guides are available in S2 Appendix.

The interview guides were developed by the research team, piloted with six participants (two children, two caregivers, two teachers) and adapted as needed thereafter. Questions explored the experiences of deaf and hard of hearing children, their families and their teachers, focusing on experiences in education, healthcare and community life. Specific questions were asked on communication, mental health, wellbeing and attitudes towards hearing impairment and deafness. Topic guides for the focus group discussions aimed to further understand these areas, explore the wider context for deaf people in the community, and appraise the factors contributing to wellbeing. Data was collected during the COVID-19 pandemic, however the study sought to understand experiences in more typical times, and we did not explicitly explore the experiences of deaf and hard of hearing children and families in the context of the pandemic.

Interviews were conducted in Arabic with those using oral communication. Palestinian sign language interpretation was available for those using sign language for communication. Emotion cards were used to help children understand a question or to describe their feelings. Children were interviewed individually, unless the child or caregiver desired otherwise. There was occasionally need for a family member to sit in as interpreter, when a child communicated through a signed language developed with family at home. Each interview lasted between 30–60 minutes. Five pilot interviews were conducted, in which to practice interviewing techniques and refine the topic guides. The data from these interviews has been included in the analysis. All interviews were audio-recorded. Sign language users had their response reported orally by an interpreter. Audio-recordings were transcribed verbatim. Each was translated and transcribed directly into English, by an independent transcriber, and subsequently checked against the audio file by the interviewer. Each transcript was anonymised and stored on a secure server.

Data analysis

Data was analysed using thematic analysis [27]. In step one, NS familiarised themself with the data, noting down initial ideas for coding. In step two, NS developed a coding framework, which was discussed and refined with RH, TS and SP. NS subsequently coded transcripts in NVivo 12 using this coding framework, which was piloted and iteratively adapted throughout analysis. In step three, emerging themes were identified and refined by NS, comparing relationships between codes and across groups. In step four and five, NS reviewed these themes with RH, RK, TS and SP, mapping the themes against the data set and the emerging narrative. Where RH, RK, TS and SP had comments and queries, NS reviewed the coding and themes, refine and recategorizing codes, where needed. In the final step, participant quotes and narratives were extracted for the report. The themes, narrative and recommendations were discussed with the steering committee, before producing the final report.

Reflexivity

Interviews were conducted by a trained interviewer (RH), who received a three-day, one-to-one training with the lead author (NS), a qualitative researcher in global disability and mental health. The interviewer's background was as an experienced audiologist at a major service unit for deaf and hard of hearing people in the Gaza Strip; Atfaluna Society for Deaf Children. The interviewer knew some local sign language, but not enough to conduct interviews without support from an interpreter. The interviews themselves were held at Atfaluna's headquarters, at the request of participants. With Atfaluna known to many deaf and hard of hearing people and their families in the Gaza Strip, their responses may have been influenced by the dynamic. To mitigate this, we assured participants that their responses and data would be kept confidential and that their access to services would not be affected as a result of the interview. For many, Atfaluna offers a safe space for deaf and hard of hearing children and families, and in many instances, the interviewer reported the benefit of this association on building comfort and rapport.

The analysis was led by NS, who is based in the United Kingdom. NS supported the data collection remotely through co-training, regular post-interview discussions with the interviewer and remote participation in workshops/advisory committees as travel to Gaza strip was not possible due to the COVID-19 pandemic. To limit potential biases in analysis led by an off-site foreign researcher, the interpretations were reviewed by the research team in the Gaza Strip with experience in supporting deaf and hard of hearing children in the region. The findings were further discussed with the steering committee in the Gaza Strip.

Reliability and validity

To promote reliability, validity and rigour of this qualitative research, we adopted a number of methodological strategies, as recommended in the literature [28, 29]: (1) Reflexivity, as we've described above, our efforts to reflect on our position as researchers sought to provide transparency on our biases and the influence of their on the analysis; (2) Validation of findings was achieved by presenting our initial analysis to the steering committee and groups of deaf and hard of hearing adults, to ensure that our interpretation of the findings were appropriate to the context in the Gaza Strip; (3) Peer debriefing was utilised throughout coding and analysis between NS and co-authors, to ensure exploration into all relevant themes; (4) Triangulation was core to the methodology, with authors adopting multiple data sources and data collection methods, to strive for a comprehensive exploration of this topic; (5) Transparency of procedures was achieved by keeping a paper trail of methodology, records and explanations, and presenting these in the manuscript.

Ethical considerations

Ethical approval for this study was obtained from the Research Ethics Committee at the London school of Hygiene & Tropical Medicine (19144) and the Palestinian Health Research Council (PHRC/HC/697/20).

Informed written consent was received from all participants. Caregivers or guardians provided informed consent for children and further assent was sought from children using a simplified information sheet.

Results

Across the interviews, there was the consistent understanding from adult participants that deaf and hard of hearing children in the Gaza Strip were at increased risk of psychological distress and mental health concerns. Various associated factors were reported, including language deprivation, community attitudes and family support.

Lack of accessible communication and language deprivation

Participants reported that deaf and hard of hearing children with milder levels of hearing impairment were less likely to experience challenges with communication and community participation, and they were often able to communicate orally. However, deaf and hard of hearing children with moderate to profound hearing impairment faced daily challenges with communication and engagement with others in the community as sign language use is limited across the region. Communication challenges restricted social inclusion and participation, negatively impacting on the psychological wellbeing of deaf and hard of hearing children.

Although Palestinian sign language use is increasing across the Gaza Strip, it is still limited in healthcare, mainstream schools and community settings. Teachers, caregivers and deaf and hard of hearing adults told us how many deaf and hard of hearing children experience language deprivation, with families unable to teach them sign language or refusing to allow their child to learn.

> "I: Do they use sign language?
>
> P: No it is not allowed. . . once her uncle tried to use sign language and I prevented him from doing so. If I wanted her to learn and use sign language, I would give her sign language courses."
>
> (Father of a child aged 10–12 with severe hearing impairment)

We were told that many families in the Gaza Strip do not know Palestinian sign language and do not use it at home, even if their child uses the language at school and despite many of the children interviewed telling us that they prefer to communicate using sign language. Many of the families interviewed perceived sign language negatively and desired their child to use oral speech, even when the child had difficulty doing so. Some attributed sign language for their child's poor oral skills and some did not understand it to be a language itself and their child's natural form of communication. Limited sign language use and support resulted in examples of family and child having limited communication or regular misunderstanding and miscommunication.

> "If their cousins gather and talk, she will withdraw because she cannot hear and she cannot understand what they are saying, as they are talking fast. The same thing when my sisters and I gather. This thing bothers me and bothers her, but what we can do?"
>
> (Mother of a child aged 10–12 with moderate hearing impairment)

The lack of engagement with sign language was not the case for all families, and there were positive examples of caregivers supporting the use of sign language by their child and seeking training for themselves. After learning themselves, there were examples told to us of family members training others, including hearing siblings, aunts, uncles and cousins. Support for sign language and accessible communication was often seen in families with multiple deaf and hard of hearing children, where siblings could communicate with and support one another. One child interviewed even taught their hearing friends at a mainstream school some simple signs, so they could better communicate and bond. However, despite wishing to support sign language use, some family members reported limited awareness on where to receive sign language training and communication support. Some children used home sign language as a result of limited exposure to Palestinian sign language and can only communicate with a few others as a result; often deaf and hard of hearing siblings from whom they learned to communicate.

Communication and social inclusion

Some children interviewed had strong oral skills. They found it easier to participate in community life and were integrated into life at a mainstream school. That said, many of these children still expressed a preference for sign language, because oral communication was often tiring and difficult to maintain, especially in group situations and noisy environments.

Many deaf and hard of hearing children in mainstream schools described difficulty in keeping up with teachers and peers, who often have limited awareness of deaf and hard of hearing children's communication needs and how best to support them. We were told by many, including teachers, that difficulty with communication in mainstream schools significantly hampered the learning and education for many deaf and hard of hearing children. Limited communication also makes inclusion difficult with hearing peers in school and the community. This was reported to cause isolation and psychological distress. Some caregivers told us that they do not allow their deaf or hard of hearing child out into the community because of their difficulties communicating with others.

> "His nature is sociable, he tries to communicate with other kids and join them, but they cannot understand what he is saying, which makes him upset."
>
> (Father of a child aged 6–9 with moderate hearing impairment)

In contrast, the special school environment was more supportive of sign language and children and teachers in these settings reported very few instances of miscommunication or isolation of deaf children. A deaf adult told us how, as a child, he had to move back to a special school after joining a mainstream school, as communication in the mainstream environment was too challenging and teachers didn't account for his deafness and communication needs. For example, he lipreads and teachers regularly faced away from him when talking. He expressed regret that he had to leave, as he wanted to learn in a mainstream environment.

Language deprivation, challenges in communication and resulting social isolation were noted by many of the participants as the major influence on a child's mental health and wellbeing.

> I: Are deaf children at risk of mental health issues?
>
> P: Yes, because they cannot keep up with the family talking. What's causing a psychological problem is that a family will shorten up a long conversation into two words. This upsets a child and makes them prefer loneliness.
>
> (Deaf adult and representative from an organisation of persons with disabilities, communicating via a sign language interpreter)

Participants, including deaf adults, teachers and mental health specialists, discussed communication in the context of protecting and promoting mental health and wellbeing. Communication and the resulting social integration were described as the main source of a child's confidence, self-esteem and wellbeing. Participants recommended that families and teachers be given sign language training to combat the language deprivation experienced by many deaf and hard of hearing children in the Gaza Strip and to promote their psychological wellbeing.

> "When the student has good communication in sign language with their family members, this comforts and relieves them very much. When the mother communicates in sign language with her child, the child becomes able to express and explain everything. The same thing happens when they communicate with their teacher, they feel that they are just as other classmates. When they go on a school journey and they communicate with teachers and other people, they break the ice and overcome the fear with outside. As a result, they become more confident. . . This gradually strengthens their personalities and their self-confidence."
>
> (Teacher in a special school)

Deaf adults told that us that communication was improving in the Gaza Strip, with Palestinian sign language more widely used than when they were children. However, improvements in the attitude towards and understanding of sign language was slow, and many families were still resistant to its use. Services and programmes to support use of sign-language, as well as speech and language therapy and occupational therapy, were often unavailable to caregivers, except through one or two specialist organisations. Foremost was Atfaluna Society for Deaf Children, which was often cited as the primary support for deaf children in the Gaza Strip, although not all participants were aware of the available support from this organisation and other specialist organisations supporting deaf and hard of hearing children. They did not have information on support available, where to seek support and how to access it. Deaf adults also told us that it was difficult to find qualified sign language interpreters in the region and sign language training was sparse. The services were not sufficient to meet the need.

> "Frankly, the Department of Education hasn't given us sign language courses. I use simple, easy things for students. For example, go, come, and understand. . . I had four students with hearing disabilities and I couldn't communicate well with them."
>
> (Teacher in a mainstream school)

Assistive technology and communication

Assistive technology was commonly discussed in the context of communication. Many caregivers described hearing aids as useful for children who use them and many wanted their child to use one, even if the improvements in hearing were marginal. However, some caregivers and children spoke of ill-functioning or ill-fitting hearing aids, negating any benefits for communication and limiting their ability to engage in community and classroom activities. Caregivers told us that paying for and maintaining the hearing aids is expensive, with some caregivers forgoing food to afford batteries. Repair services are also limited and there can be long waitlists if a hearing aid is damaged, especially if originally sourced from a country out of the Gaza Strip. Cochlear implants were perceived positively among the participants, with some having gone abroad to receive them, to countries such as Egypt and Australia. However, this was not available for all families of deaf and hard of hearing children. Many of those that had done so still relied on financial support from an NGO or international sponsor. Cochlear implantation is becoming more widely available in the Gaza Strip and many families note this as an appealing option to them. Deaf adults interviewed, however, were often disparaging of such assistive technologies and encouraged families to embrace their child's hearing impairment and to cement a strong Deaf identity in them.

Community attitudes impacting confidence and identity

Stigma and discrimination in the community also presented barriers to social inclusion and participation for deaf and hard of hearing children, and had a negative impact on psychological wellbeing. This was not the case for all deaf and hard of hearing children and adults, and some reported positive relationships with neighbours and hearing peers. However, we were told that many in the community still held discriminatory views and behaviours. Awareness of disability and deafness was said to be poor. Knowledge was often based on a medical or charity model of disability and deafness, with little understanding of rights-based perspectives in line with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) [30]. This limited awareness was seen most commonly among mainstream school teachers, who often had very little knowledge of deafness and supporting deaf and hard of hearing children in their classroom.

Respondents felt that it was common for the community to look on families and deaf and hard of hearing children with sadness and pity, and we were told that deaf people were seen to be unequal or were simply not acknowledged in society.

> "For example, if we are in a car, people will stare at him [her deaf son], and some of them ask, 'Why is he like this?'. Someone said, 'Poor boy'. I said, 'Why? What's wrong with him [her deaf son]? Thank God, they are a gift'."
>
> (Mother of child aged 6–9 with severe hearing impairment)

Participants reported that negative attitudes often proceed to more overt acts of discrimination. We were told that hearing people often use derogatory terms when talking about deaf people, including an Arabic slur which translates loosely to 'dumb' or 'retarded' (derogatory terms themselves across much of the world).

> "They whisper and point at me that I'm dumb [Arabic slur]"
>
> (Child aged 10–12 with severe hearing impairment)

Discrimination was said to severely impact on deaf and hard of hearing children (and adults) in the Gaza Strip. Children and caregivers told us of the psychological distress caused when community members or other children made them feel different or marginalised. Children told us they often cried as a result. There were several examples of such instances. A father told us how he moved his family to another region of the Gaza Strip, as his son was facing such severe discrimination; others used to steal his hearing aids and run away. Similarly, a mother told us how her daughter was bullied constantly at school.

> "She was bullied at school by other children. They would remove her hearing aid and bully her. She would come home crying. I tried to speak to the teachers about this, but they didn't help. No one understands her communication or possibly needs. I decided to move her to another school but the same thing happened. I eventually moved her to a special school,

> where things got better. She has since joined a mainstream government school after her communication improved."
>
> (Mother of child aged 10–12 with moderate hearing impairment)

There were a few examples reported in which bullying and discrimination dissipated once caregivers and teachers explained deafness to other children, other teachers and community members. Some caregivers reported speaking about deafness to teachers individually, as well as presenting to other caregivers and children at the school. Some teachers with experience and knowledge about deafness instructed other teachers at their school, with support from the school counsellor and headteacher. These efforts were reported to improve awareness of the experience of deaf and hard of hearing children and helped dissipate some of the stigma and discrimination seen. Caregivers are important advocates in these initiatives.

> "It was hard at the beginning. They mocked him every single day, which made him sad. He was crying all the time. I explained his case to the children and now they understand him and they started playing with him."
>
> (Mother of child aged 6–9 in a mainstream school with moderate hearing impairment)

Special schools offered a more inclusive and supportive environment, with no discrimination reported to us amongst teachers or other children. However, there were no reports of systematic governmental or organisational training and resources for special school teachers or others to instruct mainstream teachers on supporting the inclusion of deaf and hard of hearing children in mainstream schools.

Further, few deaf and hard of hearing spaces and community structures were reported. Participants advocated for more deaf and hard of hearing friendly spaces, where deaf and hard of hearing children could learn about their hearing impairment, Deaf culture, sign language and be engaged with other deaf and hard of hearing people in a safe space. Participants also suggested that deaf and hard of hearing children need to be more included in community activities, to reduce isolation and improve psychological wellbeing.

> "For us as deaf people, not more than 3% are included in society. At the present time, the community should make more effort to give deaf people their own space, and to involve them in community activities, so that people know more about the skills and experiences of deaf people."
>
> (Deaf adult and representative from an organisation of persons with disabilities, communicating via a sign language interpreter)

Family knowledge and internalised stigma

It was clear that many caregivers and families interviewed were proud of their deaf and hard of hearing children and expressed to us deep love, but some had not fully accepted their child's hearing impairment and deafness. Caregivers were said to occasionally hide their deaf or hard of hearing child, so as not to affect their siblings' future and experience in the community. Others did not want to see their child wearing a hearing aid and refused to let them learn sign language. A deaf adult told us of a story in which a mother refused for her deaf son to marry a deaf woman, as she feared their child would also be deaf; she wanted him to marry a hearing woman instead.

Limited acceptance seemed to result from limited understanding and awareness of deafness and the rights of deaf and hard of hearing people, paired with the influence of negative community attitudes. Many of the caregivers interviewed had never received information or support on hearing impairment when their child was diagnosed, despite wishing for such. Caregivers called for structured training programmes with other caregivers, access to online resources and support from specialist organisations. Those that did receive such support reported positive benefits and typically presented with more positive attitudes to hearing impairment.

For some other caregivers, internalised stigma among families appeared to result from the challenges they perceive a result of having a deaf or hard of hearing child.

> "It affects all my life system. It takes all of me, my efforts, my time, and it takes me from my other children."
>
> (Mother of child aged 6–9 with severe hearing impairment)

As a result of negative community and family attitudes, some children told us that they did not want to be deaf or hard of hearing, or to be different, and many were embarrassed and ashamed to use sign language in public or to be seen wearing a hearing aid. One father said his daughter feared she would never get married because of her hearing aid.

> "Once she said, 'I know why they are treating me like that, it is because I wear a hearing aid.' And one time I saw her crying because her sister got engaged and she said, 'I will never get married because of my hearing aid'."
>
> (Father of child aged 10–12 with severe hearing impairment)

The discrimination in the community, and the internalised stigma among families and children, negatively impacts on deaf and hard of hearing children's sense of identity and ultimately their mental health and wellbeing. Children were said to get upset and angry at being different to others. One mother told us of how she enrolled her daughter in psychosocial counselling, as she was very down and tired of being "different".

Building a sense of self and wellbeing

Participants believed community awareness and improving understanding of deafness and hearing impairment was of the utmost importance in addressing stigma, discrimination and improving engagement with Deaf culture and norms, such as sign language. Addressing stigma and discrimination was said to be vital in improving the psychological wellbeing of deaf and hard of hearing children. Some told us that this awareness is continually improving in the Gaza Strip, particularly among the younger generation, who are more knowledgeable and supportive of deaf and hard of hearing people, as a result of greater exposure to the internet and international campaigns.

> Children that engaged with deaf and hard of hearing peers and Deaf communities reported the positive impact on quality of life and psychological wellbeing. They enjoyed having deaf and hard of hearing friends and interacting with others with a shared experience. Many deaf and hard of hearing children in mainstream education said that they had few deaf and hard of hearing friends, although they would like to. Those that did have deaf and hard of hearing friends valued those relationships. "The first is to focus on things that help to integrate them into society, and the second is to spread culture about hearing disability among

> children so that they accept deaf colleagues or any other disability without making fun of them."
>
> (Adult with a mobility impairment and representative from an organisation of persons with disabilities)

Building a sense of self and building self-esteem was said to be key in promoting mental health and wellbeing among deaf and hard of hearing children. We were told that building a sense of identity and confidence in children starts with the family. Participants told us how important it was for families to learn about hearing impairment, deafness, deaf and hard of hearing rights, communication, sign language and how best to support their child. Many participants believed that deaf and hard of hearing children develop a strong sense of self and mental wellbeing when families are accepting and supportive of their children. Participants noted that caregivers must promote belief and expectation in their child.

Further, we were told of the importance of caregiver involvement in their child's education and life experience at school, especially in mainstream education. Doing so was considered to improve awareness and inclusion at schools, and caregivers expressed eagerness to work closely with teachers to ensure consistent communication and support.

Examples of good practice were seen in some special schools, including awareness raising and psychosocial support. This included sessions with caregivers on how to communicate with and support their deaf or hard of hearing child. Further, we were recommended that deaf and hard of hearing role models visit schools, both to raise awareness amongst the students on deafness and inclusion and to help build the self-esteem and aspirations of deaf and hard of hearing children and their families.

> "We have a lot of attitudinal problems with adults and teenagers. We keep implementing awareness raising activities and psychosocial support sessions. These are very important to be included, especially as caregivers lack sign language, so they don't communicate with their children. Teachers manage the whole communication process and guide the students. We also implement awareness raising activities with caregivers to guide them on how to communicate with and treat their children. We advise them to talk to their children, to understand them, and to identify and analyse their problems."
>
> (Teacher at a special school)

Promoting deaf and hard of hearing inclusion

As presented, participants reported a number of factors that impact on deaf and hard of hearing children's mental health and psychological wellbeing. Intervention and support is needed across a number of areas to promote wellbeing, including reducing stigma and improving communication. Deaf adults and teachers emphasised that the development of support for deaf and hard of hearing children and families at school and in the community is not going to happen without government support. According to the deaf adults we spoke with, inclusion at government level was viewed as talk with no action. We were told that this stemmed from limited understanding of hearing impairment and deafness at government level, which, in turn, contributed to the lack of inclusion and awareness in the community.

> "Even the government decision makers know nothing about us [deaf people]. What we are, what we feel and what we need. They don't know us. There's no awareness of what disability

> really is. They think we deaf people are less intelligent than others, they think our learning abilities are slow and hopeless. . . We, like all other disabilities, are no different and no less."
>
> (Deaf adult and representative from an organisation of persons with disabilities, communicating via a sign language interpreter)

Deaf and hard of hearing children in the Gaza Strip were reported to be facing increased risk of mental health issues. Efforts are needed to build self-esteem and identity in deaf children, so that they may reach their potential and realise personal wellbeing.

> "When a child with disability is left behind because of their disability, this would complicate their mental health and cause them lots of psychosocial problems. We need to improve their skills, look into their talents and work on developing them. This would improve their self-trust and help them overcome their mental health and psychosocial problems."
>
> (School counsellor at a mainstream school)

For this to occur, families, teachers and the community need the understanding on how to support inclusion of deaf and hard of hearing children, which includes knowledge on communication and deaf culture.

Discussion

Participants in this study reported that deaf and hard of hearing children in the Gaza Strip are at increased risk of psychological distress, resulting from language deprivation, discrimination and exclusion from community participation. These findings are consistent with previous literature on the social inclusion and mental health of deaf and hard of hearing populations [5–13].

Children in special school environments commonly used sign language and engaged with deaf and hard of hearing peers. Often, their caregivers were well-informed on the support available, on hearing impairment, on deafness and on deaf and hard of hearing rights, as a result of support and outreach from the special schools. These children appeared to be at lower risk of poor mental health. Children in mainstream environments were most likely to feel included if they used oral communication. These children talked of having hearing friends and generally positive experiences in the community. They tended to have milder hearing impairment and/or used a hearing aid or cochlear implant. They did not often report experiences of mental distress, likely related to fewer challenges in daily life and feeling part of the wider community. As is consistent with previous literature, our interviews indicated that the children most at risk of poor mental health were those experiencing language deprivation and social exclusion, especially in a mainstream schooling environment [31–33]. Often these deaf and hard of hearing children had moderate or severe hearing impairment, yet families did not support them to learn sign language, despite their limited capacity for oral communication. Many faced challenges with learning in school, including making friends. These children appeared to live with a sense of self that is in conflict; neither part of the hearing community and neither part of the Deaf community. This is consistent with previous literature on social identity and mental health among deaf and hard of hearing populations, whereby deaf and hard of hearing people associating with neither hearing or d/Deaf groups can lack a strong sense of self, negatively impacting their mental health [31, 32, 34, 35]. In contrast, mental health and wellbeing is often better in deaf and hard of hearing people using oral language and who associate with the hearing community, or those who have a strong sense of Deaf identity and use sign language. Deaf identities and wellbeing is a nuanced area and one with limited literature. We recommend additional research in the future into these topics, especially in LMICs and conflict affected populations.

Our findings suggest that, in general, Deaf culture and awareness is limited in the Gaza Strip. Many deaf and hard of hearing children do not have a positive self-image and many deaf and hard of hearing children in the Gaza Strip experience prejudice and discrimination at some point in the community. This was not universal, with some describing positive experiences. Largely, prejudice and stigma appeared to stem from a lack of awareness on hearing impairment and deafness, and understanding of Palestinian sign language as a language. This lack of awareness and knowledge was viewed as a challenge at both community and government level, and was shown in school settings. Stigma is a common barrier experienced by youth with disabilities, but the current state of evidence on stigma-reduction activities for children with disabilities in LMICs is limited [36]. Most studies are of low methodological quality and as a result, current stigma reduction interventions are not evidence-based and often strategies do not target different levels of stigma [36]. That said, there are some promising stigma-reduction interventions for children with disabilities identified in recent systematic reviews, including community education and social contact [36]. Recommendations from additional evidence reviews include the active involvement of people with disabilities (including youth) and caregivers in the development and delivery of stigma-reduction interventions and interventions that empower people with disabilities [37, 38]. Evidence on interventions is rarely focused solely on deaf and hard of hearing children, and there must be appropriate development efforts in partnership with deaf and hard of hearing children and families if looking to implement a deaf and hard of hearing stigma-reduction intervention in the Gaza Strip.

Key in our findings is the language deprivation experienced by some deaf and hard of hearing children in the Gaza Strip. Language deprivation in early life is a fundamental issue and has lifelong consequences [39]. Beyond isolation and loneliness, language deprivation will negatively impact on a child's key developmental skills [39]. Language is also the foundation of an individual's culture and social identity. Depriving deaf and hard of hearing children the right to natural sign language limits the progression of deaf and hard of hearing children's social identity, their self-esteem and their mental wellbeing. In the Gaza Strip, there are a number of factors contributing to this language deprivation. First, is the lack of opportunities for early exposure to sign language for deaf and hard of hearing children, training services for families and a lack of sign language interpreters. The infrastructure is not currently able to meet the demand. Second, this study indicated is the lack of family commitment to sign language. This was not the case for all families in this study, but it was evident in many. The reluctance to allow deaf and hard of hearing children to learn sign language appeared to be related to community stigma and limited information and awareness both on deafness and the fact the sign language is a language. In addition, limited training infrastructure resulted in limited opportunities to learn sign language, limited motivation to do so and limited knowledge on the value of sign language. Addressing inaccessible language and communication (and language deprivation in early life) should be a priority for supporting deaf and hard of hearing people in the Gaza Strip. Promoting Palestinian sign language use across the region will promote the inclusion of deaf and hard of hearing children and will help develop stronger deaf and hard of hearing communities. In their position paper and charter on the language rights of deaf children, the World Federation of the Deaf outlined actions that governments across the world must take, in order to promote the right of deaf children to fully develop their cultural and linguistic identity, as enshrined in the United Nations Convention on the Rights of Persons with Disabilities [40, 41]. They call for governments to "implement programmes to support the teaching of sign language to family members and carers of deaf children, in cooperation with Deaf communities and deaf sign language teachers." The position paper provides specific evidence and action-based recommendations for governments and community institutions to follow, including the need for early exposure to sign language and promoting family support. As part of the programme in which this research has been placed, CBM (an international disability NGO) and Atfaluna Society for Deaf Children have developed opportunities to learn Palestinian sign language for over 1,000 deaf and hard of hearing children and their families in the Gaza Strip.

As well as improved access to Palestinian sign language, many deaf and hard of hearing children would benefit from improved access to oral-communication services and devices. Our findings reveal a need to improve access to assistive technology, including hearing aid and cochlear implant assessment, provision and maintenance. Many respondents in this study reported experiencing difficulties with poorly functioning assistive products, which hindered oral communication for those that could use and may prefer it. In order to provide early support and intervention, the government in the Gaza Strip may wish to provide systematic newborn hearing screening programmes. Regardless of a family's decision on the use of hearing aids, cochlear implants and audiology therapies, we encourage health professionals to immediately refer deaf and hard of hearing children to Deaf associations, networks of parents of deaf and hard of hearing children and schools that cater for the needs of deaf and hard of hearing children when they first identify hearing loss.

In addition to the above recommendations, training for families may be important to improve deaf and hard of hearing awareness and mitigate the risk of language deprivation. Evidence shows that early intervention with caregivers promotes better awareness on disability, rights and supporting the child [42]. Interventions may include structured caregiver training programmes, such as the Juntos programme, which comprises interventions based on 10 module programme, delivered by caregivers with lived experience to a group of new caregivers and caregivers [43–45]. These programmes help caregivers learn the skills to support their child, whilst also offering peer support and sense of community, although these programmes have not been evaluated with families of deaf and hard of hearing children. Other similar interventions include the parent-mediated World Health Organization Caregiver Skills Training programme [46]. The use of social media may also be important to connect caregivers, share information on deafness and develop community.

With the importance of education and the role that school plays in the inclusion and wellbeing of deaf and hard of hearing children, it is important that schools are be able to support deaf and hard of hearing children. Throughout the interviews, it was clear that special schools in the Gaza Strip were better equipped to provide this support to deaf and hard of hearing children, with Palestinian sign language being routinely used to communicate, aiding both education and social inclusion. With the promotion of inclusive education across the world, mainstream schools in the Gaza Strip need the resources and training to better support deaf and hard of hearing children in their classrooms, including sign language training and interpretation services [47]. The relative merits of segregated and inclusive school systems are widely debated [48]. The findings of this study highlight the importance of strengthening inclusion in mainstream schools, so that deaf and hard of hearing children can attend if they wish. Although special schools in the Gaza Strip may continue to be needed, and may be preferred by some children and families, deaf and hard of hearing children should have the option to attend a mainstream school should they wish, with facilities available to support their full integration, in line with the principles of inclusive education. There is need for structures and resources by which mainstream school administrations and teachers can receive support and training to deliver inclusive education for deaf and hard of hearing children, whether this be from special school teachers or other certified personnel. Training for teachers should also include information on mental health and psychosocial support for deaf and hard of hearing children in their classrooms, including information on promoting wellbeing, recognising symptoms of distress, and actions to take when they identify an issue. As presented in this research, central to promoting the wellbeing and inclusion of deaf and hard of hearing children at school is partnership with caregivers, teachers and the child themselves. This promotes targeted solutions to support a child, both at school and home, and it gives the platform for caregivers to help teachers improve deaf awareness and inclusion in their classrooms. Until mainstream schools in the Gaza Strip are equipped to support all deaf and hard of hearing children, there is still need for a twin-track approach, with special schools still available and well-resourced.

In efforts to support deaf and hard of hearing children, there is need for government, funders and service providers to partner with deaf and hard of hearing communities and organisations of deaf and hard of hearing people in the Gaza Strip. Evidence has shown that organisations of persons with disabilities can produce positive outcomes for people with disabilities and these organisations are key in achieving equal rights for deaf and hard of hearing people and people with disabilities [49]. In the Gaza Strip, this may include training government, communities and families on deaf and hard of hearing rights and inclusion, building confidence for participation among deaf and hard of hearing children and families, and developing networks of deaf and hard of hearing communities. These organisations are often restricted by limited financial and human resources and they may therefore benefit from capacity building and increased funding to scale-up their work and effectively partner with government and other stakeholders looking to support deaf and hard of hearing children [49].

There is also a need to develop mental health support that is targeted to the needs of deaf and hard of hearing children. Although important to address the risk factors of poor mental health, as identified in this study, it is equally important to ensure appropriate support for those that do experience distress. In a systematic review of mental health support for deaf and hard of hearing children, appropriate interventions included peer-support, caregiver-child interaction therapy and resilience training [50]. Many interventions can be provided in schools and adaptations necessary include appropriate communication, including sign language. Mental health service provision for deaf and hard of hearing people would benefit from recruiting signing mental health professionals, deaf and hard of hearing professionals, and sign language interpreters specialized in mental health. Throughout, it is imperative to consult and coordinate with deaf and hard of hearing children and families, to ensure feasible, acceptable and sustainable interventions.

Children and adolescents in the Gaza Strip are at increased risk of mental health conditions, regardless of disability [25]. deaf and hard of hearing children face additional stressors, as demonstrated in this study. They can be said to experience double-jeopardy. They face stressors to their mental health and wellbeing as a result of living in a challenging region of the world and they face stressors as a result of living in an environment that is not fully inclusive and supportive of deaf and hard of hearing people. These stressors will intersect and raise unique challenges for deaf and hard of hearing children. This population is thus a priority for support.

Interesting to note in this discussion is the limited information reported by participants on the direct impact of conflict and blockade on the psychological wellbeing of deaf and hard of hearing children. Few participants reported on these issues, instead focusing on the topics discussed in the results of this study. This may be because questions asked in the topic guides did not include conflict-specific questions. Questions asked more broadly on factors that influence the mental health of children in the Gaza Strip. There was opportunity for participants to mention conflict and blockade under these questions. It is important to note also that data collection occurred before the recent escalation of rocket fire in 2021 and there is need to assess the wellbeing of deaf and hard of hearing children (and indeed all children) since this time, so that appropriate support can be provided.

Limitations

This research encountered challenges resulting from the COVID-19 pandemic. These affected the process of data collection and the involvement of the lead researcher in the Gaza Strip itself. Several checks were in place to strengthen the integrity of data and interpretations, including remote training and supervision, and discussion of the findings with a steering committee, including people with lived experience.

It is also worth noting the greater number of female caregivers interviewed, compared to male. Fathers and other male caregivers were more difficult to recruit, as most were busy during working hours. Moreover, female caregivers in the Gaza Strip are most typically the primary caregiver for deaf and hard of hearing children and when we attempted to recruit to male caregivers, many told us that the mother or female caregiver would be able to give better information than they.

Conclusion

Deaf and hard of hearing children in the Gaza Strip experience a number of stressors that are detrimental to their mental health and wellbeing, including language deprivation, inaccessible communication and discrimination. Families, civil society actors and education providers must be empowered with the knowledge, skills and resources to provide an inclusive and supportive environment to deaf and hard of hearing children.

Supporting information

S1 Appendix. Participant characteristics.
(DOCX)

S2 Appendix. In-depth interview and focus group discussion topic guides.
(DOCX)

S3 Appendix. Questionnaire on inclusivity in global research.
(DOCX)

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PLOS GLOBAL PUBLIC HEALTH

RESEARCH ARTICLE

Development of mental health and psychosocial support (MHPSS) guidelines for deaf and hard of hearing children in the Gaza Strip

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Abstract

Deaf and hard of hearing children in the Gaza Strip may be at risk of mental health conditions and psychological distress, as a result of social exclusion and limited accessible communication. This article presents the process and research methods used to develop guidelines for schools in the Gaza Strip on mental health and psychosocial support for deaf and hard of hearing children. The process was guided by the GIN-McMaster guideline development checklist across four steps: (1) priority settings; (2) searching for evidence; (3) developing recommendations; (4) evaluation. Priority setting was spearheaded by local and international researchers, and a local steering committee comprised of deaf and hard of hearing representatives, school administration and staff, mental health specialists, family members and government officials. In searching for evidence, and in order to generate evidence-based recommendations for the guidelines, we utilised a scoping review of global mental health support for deaf and hard of hearing children and qualitative research with deaf and hard of hearing children and adults, families and teachers. Two pilot studies were conducted in mainstream and specialist educational settings as way of evaluation. The scoping review and qualitative research identified various content for the guidelines, including the importance of information on disability and deafness, promoting social inclusion and self-esteem, and accessible learning environments. The pilot studies demonstrated feasibility and acceptability among teachers and deaf and hard of hearing children, although teachers need sufficient support and resources to implement. Now finalised, the guidelines are being distributed to schools in the Gaza Strip to support the mental health and wellbeing of deaf and hard of hearing children.

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Introduction

The Gaza Strip has a population of 2.1 million, with 1.4 million being Palestinian refugees. The region has been affected by conflict and a deteriorating socioeconomic situation [1, 2]. The employment rate is 49% and access to clean water and electricity has been deemed a crisis by the United Nations [2]. These hardships are associated with mental health problems amongst youth, with evidence demonstrating high rates of depression, anxiety and post-traumatic stress disorder among children and adolescents [3–6]. Research has suggested that education and family support can improve the psychosocial wellbeing of youth in the Gaza Strip [3]. However, few young people receive formal mental health support, and many in the Gaza Strip experience challenges accessing mental health services [3, 7].

Data from the Palestine Population, Housing and Establishments Census 2017 estimate a disability prevalence of 5.8% in Palestine and 6.8% in the Gaza Strip [8]. The prevalence of disability among children aged 0–17 in the Gaza strip is 0.9%, with 0.2% reporting difficulty hearing. This equates to approximately 20,000 children in the Gaza Strip who experience difficulties with hearing. Evidence suggests that deaf and hard of hearing children worldwide may face difficulties in education, socialization, and community engagement [9–11], and are more likely than their hearing peers to report lower quality of life in school and social settings [11]. These negative experiences can impact emotional wellbeing and mental health, and deaf and hard of hearing individuals, both children and adults, have an increased risk of developing mental health conditions [12–20].

Deaf and hard of hearing youth in the Gaza Strip may face double-jeopardy with regards to maintaining psychosocial wellbeing; they may face stressors associated with living in a challenging environment, as well as those associated with being deaf or hard of hearing in a predominantly hearing world. Qualitative research in the Gaza Strip, conducted with deaf and hard of hearing children, parents of deaf and hard of hearing children, teachers of deaf and hard of hearing children, deaf and hard of hearing adults and mental health specialists, identified a number of stressors that put deaf and hard of hearing children in the Gaza strip at risk of mental health problems [21]. Stressors included lack of accessible communication, exclusion from community and community events, negative attitudes towards hearing impairment, and limited family knowledge on hearing impairment and deafness.

As deaf and hard of hearing children in the Gaza Strip are at risk of developing mental health conditions, there is need for structures to promote their wellbeing and to provide support if they are distressed. Mental health and psychosocial support (MHPSS) is a term that usually refers to promotion, protection and treatment for mental health and psychosocial wellbeing in emergency settings [22]. MHPSS takes a variety of forms, depending on context, resources and needs. Activities cover the full range of mental health needs, from (subclinical) distress, to treatment and prevention of mental health conditions, such as depression and anxiety. Activities include promotion of protective factors and behaviours that contribute to wellbeing, including social inclusion and access to community services [22]. Considering the important role that school plays in the lives of children and adolescents, educational settings are increasingly considered important environments in which to promote mental health and wellbeing. recognised schools as important environments in which to promote the mental health and psychosocial wellbeing of children [23]. Research with adolescents around the world identified school as a source of self-esteem, a setting for emotional support and an escape from adverse home environments, whilst also presenting academic pressures and a setting where children can experience abuse [24]. In a recent briefing note, the World Health Organization, UNESCO and UNICEF called on national governments to establish systems in schools that foster mental health and wellbeing, and effectively manage the mental health needs of students [25]. With deaf and hard of hearing children demonstrating unique psychosocial support needs, it is necessary to provide teachers and school staff in the Gaza Strip with tailored guidance on how to promote the mental health and psychosocial wellbeing of these children.

This article presents the methods and process used to develop guidance on MHPSS for schools to support deaf and hard of hearing children in the Gaza Strip, including information on evidence-generating activities to inform the content (such as a scoping review and qualitative research) and pilot testing of the guidelines to ensure contextual appropriateness. Throughout the study, we adopted participatory approaches to engage deaf and hard of hearing people and their families, to ensure that their voices and perspectives were heard, valued and included, in line with the principle espoused by the disability movement; "Nothing about us, without us" [26].

Method

The MHPSS guidelines for deaf and hard of hearing children in the Gaza Strip were developed in line with the principles of the GIN-McMaster Guideline Development Checklist [27], developed by the Guidelines International Network (GIN) and McMaster University. The checklist comprises 18 key development steps and 146 individual items, including budgeting, stakeholder involvement and evaluation. We adapted the GIN-McMaster guideline development process to suit project objectives and resources. For ease of interpretation in this paper, we have summarised the development process under four key steps (numbers from the GIN-McMaster topic checklist are provided in brackets):

1. Priority setting (1–9)
2. Searching for evidence (10–12)
3. Developing recommendations (13–15)
4. Evaluation and use (16–18)

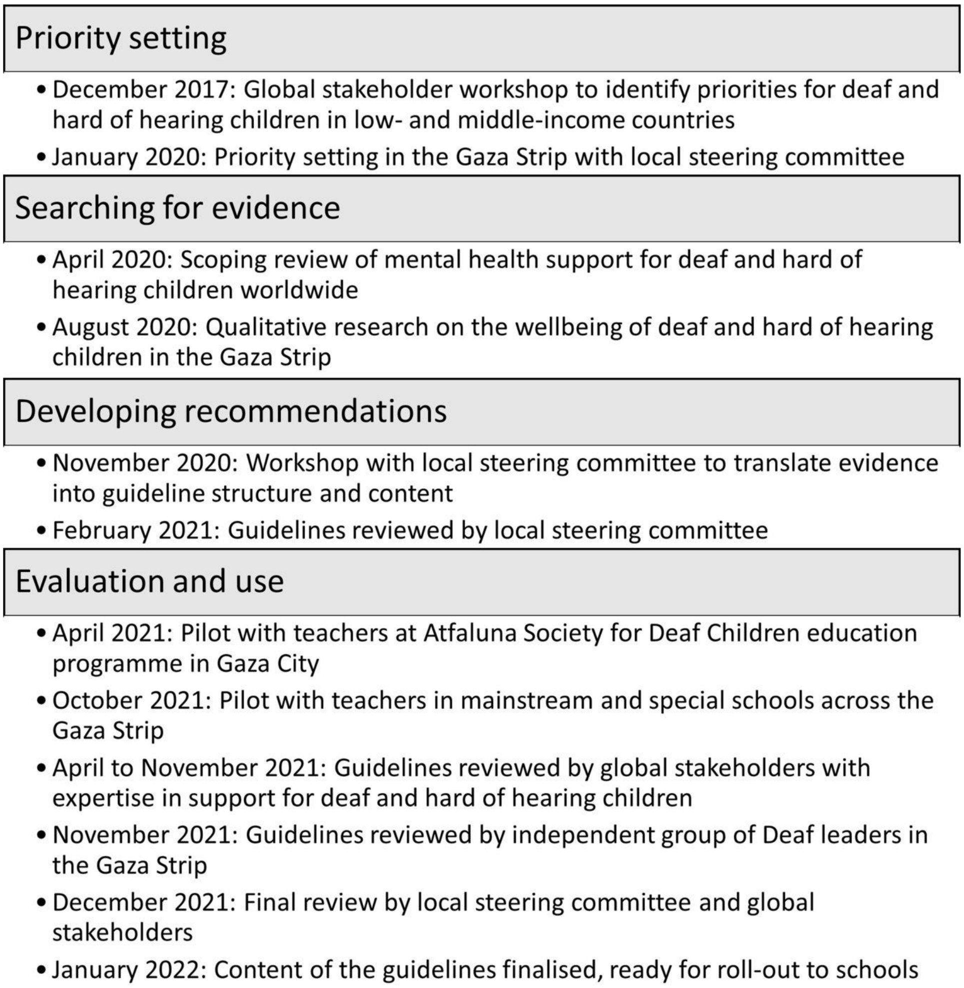
The project started during the early stages of the COVID-19 pandemic and this influenced the methods detailed and steps taken to develop the guidelines. Fig 1 provides an overview of the guideline development process.

Priority setting (1–9)

Priority setting activities were conducted across the following steps:

1. Global stakeholder workshop. In 2017, the International Centre for Evidence in Disability (ICED) at the London School of Hygiene & Tropical Medicine (LSHTM), CBM and DeafKidz International conducted a workshop to identify research and programmatic priorities to support deaf and hard of hearing children in low- and middle-income countries (LMICs). The group identified mental health and MHPSS as priorities for deaf and hard of hearing children. With little guidance available on MHPSS for deaf and hard of hearing children in LMICs, the group proposed developing guidelines that could be used by families, teachers, healthcare staff and other community stakeholders.

2. Development programme in the Gaza Strip. In 2020, ICED established a partnership with CBM and Atfaluna Society for Deaf Children to develop guidelines on MHPSS for deaf and hard of hearing children in the Gaza Strip. This partnership brought together a research institute in global disability and mental health (ICED), an international disability NGO (CBM) and a local implementing partner focused on supporting deaf and hard of hearing children (Atfaluna Society for Deaf Children).



Priority setting

- December 2017: Global stakeholder workshop to identify priorities for deaf and hard of hearing children in low- and middle-income countries
- January 2020: Priority setting in the Gaza Strip with local steering committee

Searching for evidence

- April 2020: Scoping review of mental health support for deaf and hard of hearing children worldwide
- August 2020: Qualitative research on the wellbeing of deaf and hard of hearing children in the Gaza Strip

Developing recommendations

- November 2020: Workshop with local steering committee to translate evidence into guideline structure and content
- February 2021: Guidelines reviewed by local steering committee

Evaluation and use

- April 2021: Pilot with teachers at Atfaluna Society for Deaf Children education programme in Gaza City
- October 2021: Pilot with teachers in mainstream and special schools across the Gaza Strip
- April to November 2021: Guidelines reviewed by global stakeholders with expertise in support for deaf and hard of hearing children
- November 2021: Guidelines reviewed by independent group of Deaf leaders in the Gaza Strip
- December 2021: Final review by local steering committee and global stakeholders
- January 2022: Content of the guidelines finalised, ready for roll-out to schools

Fig 1. Guideline development process and timeline.

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Guideline development was incorporated into a wider project being delivered by CBM and Atfaluna Society for Deaf Children, which aimed to provide training and interventions to promote the psychological wellbeing of children with disabilities, and in particular, deaf and hard of hearing children. The guideline development process was managed by ICED at LSHTM, in partnership with Atfaluna Society for Deaf Children. The team at ICED and LSHTM was comprised of researchers in disability and Global Mental Health, with experience in development guidance and manuals on a variety of health-related topics. The work at Atfaluna Society for

Deaf Children was led by a Project Manager and Research Assistant. The Research Assistant was an audiologist at Atfaluna Society for Deaf Children, seconded to the research project for the duration. This collaborative research team comprise the authors on this paper.

3. Local steering committee. To guide the development process and to set initial priority guideline topics, the team established a steering committee in the Gaza Strip. This group comprised: five deaf and hard of hearing people and representatives from organisations of deaf and hard of hearing people; two caregivers of deaf and hard of hearing children; four teachers of deaf and hard of hearing children; three mental health and psychosocial support specialists; and five representatives from government level institutions, including the Palestinian Ministry of Education and Higher Education. Group members were identified through the networks of Atfaluna Society for Deaf Children and the Palestinian Ministry of Education and Higher Education. Each member was provided a term of reference outlining their role as a steering committee member. The steering committee gathered with the research team three times throughout the development process, as described here and in subsequent steps. The meetings were held in-person, although the lead author from LSTHM attended virtually, with international travel restricted as a result of COVID-19. Typically, steering committee meetings were structured as half-day workshops, with opportunity for breakout sessions and group discussion. In the first meeting, the steering committee gave input to the research methodology, guideline development plan and priorities for the guidelines. The steering committee gathered two further times throughout the project, as described in the following sections.

4. Consultation with global experts. In the early stages of the guideline development, the lead author consulted with international experts in mental health and support for deaf and hard of hearing children, including expertise in intervention development and delivery within low- and middle-income and humanitarian settings. Six experts from the UK, Syria, and Spain spoke to the lead author for approximately one hour via online communication technology, discussing priority topics, useful resources and other pertinent information. This information was used to guide the planning of the research components described.

Search for evidence (10–12)

To inform the guideline content, we included two evidence-generating components: a systematic scoping review on mental health support for deaf and hard of hearing children globally; and qualitative research to explore experiences of deaf and hard of hearing children in the Gaza Strip and in schools, and their recommendations on MHPSS guideline content. Systematic review to search for evidence is explicitly recommended by the GIN-McMaster Checklist, although recommendations regarding qualitative research are absent. We conducted the additional qualitative research to provide an understanding of local contexts, cultural norms and attitudes to disability and mental health, and the experiences of deaf and hard of hearing children that may impact their wellbeing. There is a dearth of evidence on these areas, both in the Gaza Strip and globally, and this qualitative research was considered key to the development of contextually appropriate guidelines, as well as contributing to the wider evidence base.

1. Scoping review. A scoping review was undertaken to map the global evidence on initiatives and interventions designed to protect and promote mental health and wellbeing support for deaf and hard of hearing children. Further details of the scoping review methods are available in the peer-reviewed article published in 2021 [28]. The review was guided by the framework developed by Arksey and O'Malley (2005) [29].

2. Qualitative research in the Gaza Strip. To further understand the context and the experiences of deaf and hard of hearing children in the Gaza Strip, we conducted phenomenological qualitative research. This included in-depth interviews with 35 participants; 17 deaf and hard of hearing children aged 6–12 in mainstream and special schools, 10 parents or caregivers of deaf and hard of hearing children, and eight teachers of deaf and hard of hearing children from mainstream and special schools. Participants were purposively sampled from across the Gaza Strip (North, Gaza City, Central, South), and as following Patton's maximum variation sampling [30], to reach a variety of ages, genders, severities of hearing impairment, location and types of school.

We also conducted three focus group discussions. The first comprised of representatives from Organisations of Persons with Disabilities (OPDs) and Deaf focused NGOs. Participants of this group included three deaf adults, one individual with a physical impairment and one with a visual impairment, who also works as a mental health counsellor. The second group included five school counsellors and two mental health professionals working with children in the community. The third group included seven special school teachers and six mainstream school teachers from across the Gaza Strip. These teachers were not the same as those included in the in-depth interviews.

Participant characteristics are presented in S2 Appendix. Data were collected in July 2020. The Research Assistant at Atfaluna Society for Deaf Children conducted the interviews and focus group discussions after receiving online training and remote supervision from ICED due to international COVID-19 travel restrictions. The interviews and focus groups themselves were conducted in-person, with safety measures adopted, as advised by the local government.

The interview guides were developed by the research team, piloted with six participants (two children, two caregivers, two teachers) and adapted as needed thereafter. Questions explored the experiences of deaf and hard of hearing children, families and teachers in education, health and community settings. For example, caregivers were asked, "How do people in the community view deaf and hard of hearing people?", and children were asked, "How is the experience of learning in school?". Specific questions were also asked on the planned MHPSS guidelines to elicit recommendations for the content and roll-out. For example, caregivers were explicitly asked, "What information should be included in the guidelines?", and teachers were asked, "What support would you need to use the guidelines?". Interviews were conducted orally in Arabic, with Palestinian sign language interpretation available. Children were interviewed individually, unless the child or caregiver desired otherwise. There was occasionally need for a family member to sit in as interpreter, when a child communicated through a signed language developed with family at home. Emotion cards were available to help children express their feelings. Each interview lasted 30–60 minutes. Five pilot interviews were conducted, in which to practice interviewing techniques and refine the topic guides. The data from these interviews has been included in the analysis. Audio-recordings of the interviews and focus group discussions were transcribed into English and thematically analysed [31]. Analysis was guided by the six steps outlined by Braun and Clarke (2006). First, the lead author familiarised themselves with the data, developing a codebook which was reviewed by co-authors. This codebook was piloted and iteratively adapted throughout the coding process. Coding was completed by the lead author in NVivo 12, with emerging themes identified, refined, and relationships compared between codes. The key themes were subsequently reviewed by co-authors and mapped against the data and emerging narrative. Finally, participant codes and narrative case studies were extracted. The themes were discussed with the steering committee to aid interpretation. Detailed analysis on factors contributing to the well-being of deaf and hard of hearing children in the Gaza Strip have been published elsewhere [21]. In this paper, we present findings relevant specifically to guideline development.

Developing recommendations (13–15)

Next, we held a series of participatory workshops with the steering committee, in order to develop consensus on the structure and content of the guidelines. During the workshops, key themes and recommendations emerging from the evidence-generating activities were presented. These were used by the group to collectively agree on the planned structure and content of the guidelines.

Two workshops were held with steering committee members at this stage. The first was held with parents, deaf adults, teachers, head teachers and mental health specialists. The second was held with the representatives from the Palestinian Ministry of Education and Higher Education and UNRWA. This separation aimed to reduce power dynamics and to promote a bottom-up approach to guideline development. The first session developed the core outline of the guidelines, with the second session focused more on review, comment and consideration of the recommendations in the context of education systems and infrastructure in the Gaza Strip. From these recommendations, the lead author developed the initial draft of the guidelines for pilot.

The steering committee gathered for a third time once the first draft of the guidelines was complete, in order to review the draft and discuss amendments to the content. The first draft was also reviewed in an in-person workshop with a separate group of Deaf leaders in the Gaza Strip, who provided their opinions on the content and needed changes. Further, global stakeholders with expertise in supporting deaf and hard of hearing children reviewed the first draft via email, including Al Damair Society, Dair Al Balah Society for Rehabilitation, and Al Amal Society for Rehabilitation (all located in the Palestinian Territories), and the World Federation of the Deaf.

Evaluation and use (16–18)

Once redrafted, the guidelines were pilot tested twice in the Gaza Strip. Initially, the plan was to test the guidelines with teachers in mainstream and special schools, but with widespread school closures as a result of COVID-19, the team had to find other ways to test the guidelines. Atfaluna Society for Deaf Children had dispensation to continue running a face-to-face education programme throughout the pandemic and we decided this would serve as the first pilot site. Once mainstream and special schools re-opened, a second pilot was held.

1. Pilot one: Atfaluna Society for Deaf Children education programme (April 2021). The education programme at Atfaluna Society for Deaf Children provides educational opportunities, as well as broader support and counselling for children with disabilities and education challenges. All 10 teachers involved in the programme agreed to take part in the first pilot of the guidelines. Each received a half-day orientation on the guidelines and then used the guidelines within their class for three-weeks.

A pre- and post-questionnaire, based on Bowen's feasibility framework, was administered to teachers before and after guideline use [32]. The questionnaire explored four of the eight components of the framework: Acceptability (To what extent the guideline is judged as suitable?), Demand (To what extent the guideline is likely to be used?), Implementation (To what extent the guideline can be successfully delivered by teachers?) and Practicality (To what extent can the guideline be implemented with existing means and resources?). Additionally, we asked questions on knowledge about disability, deafness and mental health support among teachers before and after using the guidelines. We further included open-ended questions, in which participants could make suggestions on amendments to the content and the format.

After completing the pilot and questionnaire, the 10 teachers participated in a half-day workshop with the research team, to discuss their experience of using the guidelines and suggestions for improvement.

2. Pilot two: Mainstream and special schools in the Gaza Strip (August 2021). Once schools re-opened, we proceeded with the second pilot, within mainstream and special schools. In total, 30 teachers were included in the second pilot across nine schools; 19 from mainstream schools, 11 from special schools. Teachers were purposively selected to represent a diverse group across gender, age group taught, region and school type (mainstream/special).

As with the first pilot, teachers received orientation, used the guidelines with their class (for four-weeks) and completed pre-and post- questionnaires They also participated in a half-day workshop to discuss their experience and suggestions for improvement. Additionally, we spoke to the 10 head teachers of the included schools, with regards to their views of the teacher's experience and feedback.

It is important to note that pilot two was slightly disrupted by COVID-19, with some schools closing for periods of the pilot and school days shorter than usual. No school was closed for the duration of the pilot, however.

Based on the feedback in pilots one and two, the guidelines and orientation were updated, as described in the results. Members of the steering committee and the World Federation of the Deaf were invited to provide final review and comment to this updated draft via email.

Ethical approval

Ethical approval was provided for the qualitative research and pilot studies by the ethics board at the London School of Hygiene & Tropical Medicine (Ref: 19144 and 25113, respectively) and the Palestinian Health Research Council (Ref: PHRC/HC/697/20 and PHRC/HC/855/21). Informed written consent was obtained from all participants. Caregivers and guardians provided informed consent for children. Assent was sought from children using a simplified information sheet. For clarification, caregiver consent and child assent was obtained because of the children's age, not because the children were deaf or hard of hearing.

Results

Priority setting (1–9)

From the outset, the project partners identified schools as a setting to provide the MHPSS guidelines, given the benefits of early intervention, the important and regular contact between teachers and deaf and hard of hearing children, and the importance of the setting to aspects of importance to psychological wellbeing, such as social inclusion, peer-support and education [33–35].

In the early stages of the project, both the local steering committee and international experts recommended that the guidelines should focus on improving teachers' understanding of hearing impairment and deafness in the Gaza Strip. They believed that before supporting deaf and hard of hearing children's mental health and wellbeing, teachers must first have insight into what deaf and hard of hearing children experience. This included learning about child development, communication and learning preferences of deaf and hard of hearing children. When identifying priority topics for MHPSS specifically, we were told that teachers in the Gaza Strip needed information on identifying mental distress and information on support to provide. This should also include promotion and prevention techniques to promote wellbeing in the classroom. The committee said that it was vital to include contextually appropriate MHPSS activities that teachers would feasibly be able to deliver with the resources available. They recommended searching for evidence on low-intensity interventions, such as safe spaces for deaf and hard of hearing children, emotional literacy training and peer-support.

Search for evidence (10–12)

1. Scoping review. Results of the scoping review of MHPSS interventions for deaf and hard of hearing children are published elsewhere [28]. In summary, 27 articles were included, the majority (81%) of which were sourced from high-income settings. Interventions were typically therapy-based (30%) or skills training (30%) and included ice-skating, parent-child interaction therapy and resilience training.

From the review, key lessons taken to inform content of the MHPSS guidelines included the importance of: peer-support building resilience, emotional literacy and behavioural management, physical activity, knowledge and awareness of disability and hearing impairment, appropriate communication, accessible physical environments and materials, collaboration between teachers, parents and children, and conducting pilot studies (Table 1).

2. Qualitative research. The qualitative research uncovered key themes that contribute to psychological distress and psychological wellbeing of deaf and hard of hearing children in the Gaza Strip, including language deprivation, community attitudes and family support. Findings relevant to these themes have been published elsewhere [21]. Recommendations for the guidelines extracted from these data included the need for appropriate communication, sign language training, promoting social inclusion of deaf and hard of hearing children in school, greater provision of assistive technology and training, community awareness and reduction of stigma, and parent support and sensitisation.

Key themes derived from data specific to the MHPSS guidelines included the desire from teachers for resources and guidance, the need for information on disability and deafness, actions to promote social inclusion, developing children's self-esteem and emotional literacy, how to build inclusive learning environments, and how teachers and parents can work together.

With regard to perceptions of the proposed MHPSS guidelines and their recommendations for content, the majority of participants reacted positively. Many teachers, especially those in mainstream schools, stated that they needed and wanted training and guidance on supporting deaf and hard of hearing children.

> "[*When asked if the guide will be useful] Of course it will be. It is going to include new information and knowledge that a teacher can realize and apply with the children. As someone still*

Table 1. Summary of content derived from evidence-generating activities.

Evidence generating activity	Content included in the guidelines
Scoping review	• Importance of peer-support • Promoting emotional literacy • Behavioural management • Supporting physical activity • Improving knowledge and awareness of deafness and hearing impairment • Communication is key • Developing accessible environments • Importance of collaboration
Qualitative research	• Information on deafness and hearing impairment, improve knowledge of teachers, parents and other children • Promote social inclusion, include a buddy system with a hearing partner • Build self-esteem, give deaf and hard of hearing children responsibility in the classroom • Improve emotional literacy in deaf and hard of hearing children • Collaborate with school counsellors to help children needing support • Create an accessible learning environment, consider appropriate communication and classroom setup • Develop partnership between parents and teachers to provide continuity of support

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> *learning, this will enhance my knowledge, because you still are unaware of many things. The guide will help in filling the gaps, especially in solving problems." (Teacher at a special school)*

Key content areas that participants felt should be in the guidelines included information on disability, hearing impairment, deafness, Deaf culture and mental health (Table 1). We were told that many teachers, school staff and hearing children didn't know much about these topics and this sensitisation was vital if deaf and hard of hearing children were to be included and respected in the classroom.

Exclusion and isolation were said to be common for deaf and hard of hearing children, especially in mainstream schools, and this exclusion was an important determinant of mental distress. Suggestions to improve inclusion included encouraging group work and extra-curricular activities, to build relationships and friendships. Some participants also recommended a buddy system, in which a hearing child is partnered with a deaf or hard of hearing child in a mainstream school to help them learn and feel included in the classroom. Many deaf and hard of hearing children expressed an interest in participating in social groups with other deaf and hard of hearing children, citing a common experience and understanding.

In addition to understanding hearing impairment and deafness, participants also requested information on assistive technology, particularly hearing aids and cochlear implants. This included practical information on basic maintenance, such as changing hearing aid batteries. Many teachers expressed that they and hearing children in mainstream schools did not understand what the assistive technology was nor its purpose. deaf and hard of hearing children told us of examples in which other children removed their hearing aid, thinking they were listening to music.

> *"Once the teacher was afraid of her hearing aid, because it was making a buzzing sound, which is something annoying. When the teacher saw the hearing aid she was frightened. [. . .] They should be educated about hearing aids and such problems." (Father of a deaf child aged 10–12)*

To protect against mental distress, participants said that teachers must help develop a child's sense of identity and self-esteem. Teachers were encouraged to give deaf and hard of hearing children responsibility in the classroom, such as being class secretary for a period. To further support mental health and wellbeing, participants wanted information on emotional literacy and how to help children understand their own feelings and emotions. It was also vital that teachers be aware of how to recognise mental distress and the process to follow if they identify mental distress, including referral to school counsellors. School counsellors urged teachers to work with them when they have a concern, although teachers in the study told us that this collaboration was often not strong.

> "*Interviewer*: *What do you think would contribute to improving the psychosocial status of deaf and hard of hearing children*?
>
> *Respondent*: *By improving their skills. For example, look at what the child loves and work on improving this and improving the child's ability in this field. When a child with a disability is left behind because of their disability, this impacts their mental health and causes them psychosocial problems. We need to improve their skills, look into their talents and work on developing them. This would improve their self-trust and help them overcome mental health problems*." *(Counsellor at a mainstream school)*

As well as an explicit focus on mental health and wellbeing, participants also suggested that the guidelines include information on how to provide an accessible and inclusive learning environment, especially in mainstream education. This was echoed by the steering committee in early-stage meetings. Recommended areas to focus on included communication, accessible teaching materials and the physical environment, including consideration of seating arrangements and minimising distracting noises.

Finally, throughout the qualitative research, participants emphasised the need for teachers and parents to work together. Many parents wanted to be involved and to help teachers support their child's learning and wellbeing. They also wanted to be given the tools to continue support at home. Regular communication was said to be needed and some participants suggested a joint notebook, in which teachers and parents could keep a track of a child's experience at school and home, and actions being taken.

> *"We always prefer parents to be aware of persons with disabilities needs, sign language and support services available to them. If I'm the only one who communicates with the child and there's no communication at home, our efforts will be in vain. This is why we keep encouraging parents to communicate in sign language with their deaf and hard of hearing children. It's really dangerous to depend on the teacher only." (Teacher at a special school)*

One father told us of an instance in which his hard of hearing son, attending a mainstream school, was exhibiting challenging behaviours and difficulties with concentration and learning. The father worked with the teacher and discussed how much of this arose from inequalities and exclusion in the classroom. The teacher was responsive and made efforts in the classroom to promote the inclusion of the hard of hearing child. The child's behaviours improved thereafter.

In addition to guideline content, participants also discussed the eventual roll-out of the guidelines across mainstream and special schools in the Gaza Strip. Teachers expressed a need for institutional awareness and buy-in to support them in implementing the guidance in their classroom. It was said to be particularly important that school administration, head teachers and staff understand the value of the guidelines and give teachers the support they need. Teachers also said they would need training on using the guidelines, including ongoing mentorship from school counsellors.

Developing recommendations (13–15)

Table 2 presents the guideline structure and content summary developed with review by steering committee, Deaf leaders and experts in mental health and deaf and hard of hearing children. Throughout the guidelines, teachers are provided with practical activities to support deaf and hard of hearing children. Examples include role-play to help demonstrate positive behaviours and setting up a 'buddy' system, pairing a deaf or hard of hearing child with a hearing peer, who can help them navigate school life.

Evaluation and use (16–18)

The results of pilots one and two have been summarised against the four areas of feasibility from Bowen's framework [32]. Data from pilot one and two have been combined. Responses from open-ended questions are provided.

Acceptability: To what extent were the guidelines judged as suitable, satisfying or attractive to teachers?. Across the two pilots (n = 40), 90% of teachers reported that the guidelines met/exceeded their expectations, and 95% were satisfied/very satisfied with the guidelines. Teachers reported the perceived value of the guidelines, that were seen to be rich in

Table 2. Summary of guideline structure and content.

Section	Summary of content
Understanding mental health and psychosocial support	• What is mental health and wellbeing? • Risks to mental health and wellbeing • Mental health in the Gaza Strip
Understanding disability	• What is disability? • Barriers experienced by people with disabilities • Impact of disability • Disability rights
Understanding hearing impairment and deafness	• What is hearing impairment? • Severity of hearing impairment • What is deafness? • Deaf culture • Assistive technology (e.g. hearing aids) • Myths and facts
Impact of hearing impairment and deafness	• Communication and language • Influence on social skills • Impact on education • Impact on mental health
Supporting deaf and hard of hearing children	• Promoting understanding and information on hearing impairment and deafness • Addressing stigma • Promoting social inclusion • Accessible communication • Accessible classroom environment • Accessible learning materials
Supporting the mental health and wellbeing of deaf and hard of hearing children	• Building positive deaf and hard of hearing identity • Developing inclusion and friendship • Promoting self-esteem • Emotional literacy • Resilience training • Promoting positive behaviour • Physical health
Identifying a mental health issue	• Signs of mental distress • Steps to take on identification, including referral to school counsellor
Collaboration	• How to coordinate with other teachers • How to collaborate with school counsellors • Working in partnership with parents and caregivers • Continuing support at home
Appendices	• List of hearing services in the Gaza Strip • List of MHPSS services in the Gaza Strip • Simple Palestinian sign language • Hearing aid care • Creating an inclusive environment: self-assessment for teachers • Questions to ask deaf and hard of hearing children about their school experience • Emotions cards

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detail and easy to use. The simple language was easy to understand and commonly cited a positive of the guidelines

> *"I am satisfied with the content. It contains information that has added to my knowledge and made me aware of some of the problems facing deaf and hard of hearing children in my classroom." (Teacher at mainstream school)*

With regards to perceived effect of the guidelines, most (81%) of the teachers reported the guidelines to moderately/significantly improve their knowledge of MHPSS, with 76%

reporting moderately/significantly improved knowledge on MHPSS for deaf and hard of hearing children specifically. There was reported increased understanding of the challenges facing deaf and hard of hearing children and the need for MHPSS, increased understanding of MHPSS and how to support wellbeing, and increased understanding of inclusion within the classroom. Among those that reported a slight improvement in knowledge only, many stated that they needed more time to become familiar with the topics of the guidelines.

Nearly all (90%) teachers told us that they had moderately/significantly changed their actions and behaviours in their classroom. Teachers told us that they have started to speak to deaf and hard of hearing children and families about their needs, including communication. Teachers promoted inclusion in the classroom and held sessions in mainstream schools to explain hearing impairment, deafness and hearing aids to other students. Many encouraged deaf and hard of hearing children to talk to their class on their hearing impairment and on their use of hearing aids. Teachers also reported actively encouraging deaf and hard of hearing children to participate in classroom activities.

Further, 79% of teachers reported that deaf and hard of hearing children in their classrooms moderately/significantly accepted use of the guidelines and many teachers reported positive outcomes among deaf and hard of hearing children. Deaf and hard of hearing children and their families had reacted well to teachers showing an interest in their needs, and the children noticed a difference in the teacher's and classmates' understanding and approach with them. According to teachers, deaf and hard of hearing children were included more by their peers and they were more active in class. Many reported that deaf and hard of hearing children's confidence had grown and they were more open with the class and teachers. Teachers reported improved relationships between them and the children.

> *"We are in a better relationship now. They love the activities we are doing together and they ask for more." (Teacher at education programme)*

Teachers at special schools recognised that much of the information in the guidelines was not relevant to them, as they already have a strong understanding of disability and hearing impairment, but the elements of mental health were important and they perceived a benefit to distribution across special schools.

Demand: To what extent were the guidelines likely to be used by teachers?. All teachers said that they would be likely/very likely to use the guidelines in the future. Overall, 83% of teachers believed that the guidelines would be moderately/significantly useful for teachers to support the mental health and wellbeing of deaf and hard of hearing children. The remaining reported it slightly useful, reporting reservations over capacity.

When asked how often they apply the recommendations of the guidelines, 36% of teachers reported weekly, 48% two to three times per week, and 17% daily. Teachers told us that they often referred to the guidelines to understand a child's behaviour and to identify concerns.

> *"I read and referred to the guidance frequently. I wanted to be more aware of all aspects of MHPSS and to notice any concerns with the children I am teaching." (Teacher at mainstream school)*

The majority (93%) of the teachers said that they were moderately/very confident to use the guidelines in the future, with all teachers reporting that the induction on the guidelines was needed and useful.

Implementation and practicality: To what extent could the guidelines be successfully delivered to deaf and hard of hearing children in mainstream and special schools using

existing resources?. Although teachers were interested to use the guidelines, results from the questionnaire and workshop highlighted concerns among teachers about their capacity to use them; 40% said the guidelines would be difficult/very difficult to use alongside their current teaching schedule and activities. This increased to 53% for mainstream and special school teachers in pilot two only. For some, this reflected the situation related to COVID-19 and shorter school days. Some believed they would have capacity once normal schedules resumed. Others said it was difficult to find the time to read and implement the guidelines, although there was acknowledgement that the pilot had run for a relatively short-time only and with more time they would be able to better take in the information and make changes.

The majority of teachers said that they needed practical support from the school administration to implement the guidelines, including provision of accessible learning materials and resources, time in their schedule, and ongoing capacity-development.

> *"Teachers need training and support from the school administration to be able to apply the guideline. . . If this would be possible, the guideline will be very helpful to ensure needed positive change." (Teacher at education programme)*

Some of the teachers reported that they had received ongoing advice and support from school counsellors as they learned to use the guidelines during the pilot, citing this a significant facilitator to guideline implementation. Nearly all (95%) said that the orientation was needed to prepare teachers to use the guidelines, an important consideration when aiming to scale-up guideline use across all schools.

Concerns of teacher capacity were further reported by head teachers. In 2021, there had been a shift in the school system. The new structure consists of four quarters (instead of two semesters); the children go to school for two months, then have exams, followed by 10 days off. This is repeated four times throughout the year. We were told this results in shorter and busier days and teachers have more work to do. The teachers felt this change fostered a greater focus on academic achievement and less time for wider activities, such as mental health and wellbeing support. This was reported important to consider when rolling-out the guidelines across the Gaza Strip.

Adaptations to the guidelines. After completing pilots one and two, small adaptations were made to the guidelines, based on feedback from the teachers. Amendments included additional information on the impact of hearing impairment of child development, more examples on how to promote social inclusion of deaf and hard of hearing children in classrooms, and clarity on the referral process when a teacher identifies a child in distress. Additionally, teachers asked for more information on the impact on parents of deaf and hard of hearing children and more information on how to involve parents in their child's education. After making these amendments, the content was reviewed online by steering committee members and the World Federation of the Deaf. The guidelines were subsequently finalised, ready for use in schools in the Gaza Strip.

Guideline use. With the guidelines complete, Atfaluna Society for Deaf Children, in collaboration with the Palestinian Ministry of Education and Higher Education, are systematically rolling-out the guidelines across mainstream and special schools in the Gaza Strip. To aid this roll-out, they have developed a dissemination plan, including presentation events at schools. They have also developed a training programme for parents and school staff, including teachers, administration and counsellors, on mental health and psychosocial support, including use of these guidelines.

The guidelines are now available online in English and Arabic, and we have encouraged others to adapt and use the guidelines as suitable.

Discussion

This article has described the participatory process of developing guidelines on MHPSS for deaf and hard of hearing children in the Gaza Strip, including detail on activities to generate evidence-based content and evaluation to assess feasibility and acceptability. Developing the guidelines throughout the COVID-19 pandemic resulted in challenges, but using the GIN-McMaster checklist provided best-practice guidance to support the development process.

Practicality of the guidelines

From the outset, the research team and local steering committee identified schools as the priority setting for these MHPSS guidelines, congruent with long-standing research and practice on the suitability of schools as a natural setting to deliver mental health support [36, 37]. Children spend a substantial amount of their time in these settings and schools play a significant role in a child's social and emotional development, providing opportunity for peer-interaction, behavioural management, and academic progression [37]. Schools often have existing resources and support systems on which to scaffold mental health support, whether that be prevention, promotion or low-intensity intervention, and they are well-placed to connect children and families to further services. In the Gaza Strip, schools are meant to have a counsellor on staff, who can offer direct support or refer to external mental health services. However, our findings aligned with other research highlighting that teachers often have limited mental health literacy, skills and confidence with which to identify mental health needs and provide support [38–40]. Lack of training is a key barrier to teacher-delivered mental health support in different settings [39]. Teachers need training and guidance if they are to support the psychosocial wellbeing of children in schools, supporting the rationale for the guidelines developed.

The pilot phase was a key step in assessing the feasibility and acceptability of the guidelines. Positive feedback suggested that the guidelines included useful information, which was readily actioned by many of the teachers. However, it is important to recognise findings regarding teacher capacity and availability of time. Over half of the teachers in pilot two and 40% overall reported that it was difficult to use the guidelines alongside their current teaching duties. This is an issue seen with many school-based mental health initiatives; teachers' experience a conflict in their role, stretching their capacity [39, 41]. This is a crucial consideration when looking at the long-term viability and scalability of these guidelines in the Gaza Strip and other such mental health support structures in schools. Support of school leadership, both national and local, is needed to facilitate teachers in the delivery of mental health support [41]. Leadership must provide appropriate time and resources to teachers, to ensure that they are not overburdened. This includes hiring enough school counsellors to provide support to teachers aiming to promote wellbeing in their classrooms, as well providing more direct support to children who experience mental distress. In this development process, we included the Palestinian Ministry of Education and Higher Education from the outset, to encourage buy-in and input to the content and scale-up of the guidelines. Their support to schools and teachers is vital to the viability of guideline use. Further, the results of the pilot highlight the value of the half-day orientation and ongoing mentorship from school counsellors to support teachers to implement the guidelines. Building in these systems is important when scaling-up to all schools. As mentioned, Atfaluna Society for Deaf Children are training school staff, including school counsellors, on psychosocial support and use of the guidelines, in order to promote sustainable and effective utilisation of the guidelines.

With the guidelines being rolled-out to schools, it is important that national actors recognise that many deaf and hard of hearing children in the Gaza Strip may not be attending school and will not benefit from the support provided in these guidelines. Estimates from the

Population, Housing and Establishments Census 2017 suggest that 35% of adolescents with disabilities aged 16+ have never enrolled in school [8]. It is imperative, therefore, that additional strategies are developed to support the mental health and wellbeing of deaf and hard of hearing children without access to educational settings.

Challenges and mitigations in the guideline development process

The data collection and development process were impacted by the COVID-19 pandemic as well as periods of heightened conflict in the Gaza Strip, namely May 2021. In the context of lockdown measures, online data collection was considered for the qualitative research. However, we believed this would reduce rapport and therefore data quality. Further, this may have been challenging for children and some deaf and hard of hearing participants using a sign language interpreter. When lockdown measures were lifted, we interviewed participants in-person, following local safety guidance. With international travel limited, the UK researchers could not travel to the Gaza Strip and therefore they supported remotely, training the local researcher and attending interviews over the internet (using Zoom), utilising ICED qualitative remote data collection tools to structure the process [42].

The initial planned pilot was also disrupted, following increases in COVID-19 cases and lockdown measures in 2021. However, as a result we conducted two pilots to understand the feasibility and acceptability of the guidelines. School closures also highlighted the need for us to include information on how teachers can continue to provide MHPSS remotely, in case of future lockdowns. This is particularly relevant in a context of regular crises impacting on the delivery of education.

Strengths of this guideline development process

As recommended in the GIN-McMaster checklist, we formed a multi-disciplinary steering committee, with expertise and knowledge on supporting the inclusion and wellbeing of deaf and hard of hearing children in the Gaza Strip. This steering committee was instrumental in guiding the development and content of the guidelines, providing both input and critical review. Utilising their knowledge throughout the process encouraged discussion and consensus on the tools that would best equip teachers to support deaf and hard of hearing children in their classrooms. Utilising participatory approaches in the workshops was vital to their success [26].

The appropriateness of the content to the needs of deaf and hard of hearing children was achieved by generating evidence on best practice. Conducting qualitative research enhanced our understanding of the context for deaf and hard of hearing children in the Gaza Strip, enabling tailored initiatives in the final guidelines. This qualitative research further added to the literature on mental health and wellbeing for deaf and hard of hearing populations in low- and middle-income countries, an area lacking in evidence.

The evaluation of the guidelines further strengthened the appropriateness of the guidelines for use by teachers in the Gaza Strip and resulted in a real-world understanding of its use in practice and what teachers could reasonably achieve in their classrooms. Having the guidelines peer-reviewed by leading deaf and hard of hearing global stakeholders added further validity to the guidelines and has created an opportunity for these guidelines to be adapted to other contexts and settings, which we encourage.

Limitations of the guideline development process

The sample size of the pilot was small and it would have been valuable to conduct a larger scale pilot to understand feasibility and acceptability. Further, each pilot could only run for three to four weeks (as a result of COVID-19 restrictions and heightened conflict in the region). Teachers reported needing more time to utilise the guidelines and we do not have an understanding about sustained use of the guidelines.

We also did not have the capacity or time to conduct in-depth qualitative assessment during the pilot and were restricted to feedback through questionnaires and the workshops. Although these included open-ended questions, the understanding of the guidelines in practice would have been strengthened by further in-depth qualitative assessment with teachers. Additional qualitative research with deaf and hard of hearing children about their experience of guideline implementation would have further strengthened our understanding.

Future of the guidelines

The MHPSS guidelines are being rolled-out across mainstream and special schools in the Gaza Strip, in partnership with the Palestinian Ministry of Education and Higher Education. These guidelines are freely available online in English and Arabic, and we encourage governments and service providers in similar settings to adapt the guidelines to their context.

This study and development process identified a need for information and guidance on inclusive learning environments, communication, assistive technology, social inclusion, emotional literacy, and partnership with parents. These findings are consistent with previous literature from different settings, highlighting common needs in the context of MHPSS for deaf and hard of hearing children [35, 43–47]. However, it is important to respond to these needs in a context-specific manner, and adapting the guidelines developed in this study should include appropriate research methodologies to ensure contextual relevance. When adapting to other settings, it is important to do so in partnership with deaf and hard of hearing groups, parents, teachers, and other key stakeholders.

Future research

We recommend conducting a longer-term assessment of guideline feasibility and acceptability. Assessing deaf and hard of hearing child outcomes, including social inclusion and mental health status, would also be beneficial. In addition, it would be useful to conduct a process evaluation on the guideline roll-out procedures and long-term implementation.

Conclusion

This article has described the process of developing MHPSS guidelines for deaf and hard of hearing children in the Gaza Strip. This process was supported by a structured guideline development framework, and adoption of participatory approaches, evidence-generating activities and evaluation. The guidelines were found to be acceptable and feasible to implement, with support from school administration. These guidelines will aim to support to psychosocial wellbeing of deaf and hard of hearing children in the region and we encourage adaptation of these to other contexts.

Supporting information

S1 Appendix. Questionnaire on inclusivity in global health.
(DOCX)

S2 Appendix. Qualitative participant characteristics.
(DOCX)

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Critical Social Policy

Article

'Do they ever think about people like us?': The experiences of people with learning disabilities in England and Scotland during the COVID-19 pandemic

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Abstract

People with learning disabilities in England and Scotland have experienced an increased risk of illness and death during the COVID-19

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pandemic. Drawing on data of a longitudinal qualitative study with 71 disabled people and 31 disability organisations, this article examines the experiences of 24 people with learning disabilities in England and Scotland during the pandemic, reflecting on what rendered them vulnerable and placed them at risk. Qualitative interviews were conducted with participants and key informants at two timepoints; June–August 2020 and February–April 2021. Findings emerged across four key themes: failure to plan for the needs of people with learning disabilities; the suspension and removal of social care; the impact of the pandemic on people's everyday routines; and lack of vaccine prioritisation. The inequalities experienced by people with learning disabilities in this study are not particular to the pandemic. We explore the findings in the context of theoretical frameworks of vulnerability, including Fineman's conceptualisation of a 'vulnerability paradigm'. We conclude that the structured marginalisation of people with disabilities, entrenched by government action and inaction, have created and exacerbated their vulnerability. Structures, policies and action must change.

Key words
COVID-19, disability, health, learning disabilities, vulnerability

Introduction

The COVID-19 pandemic has had a catastrophic impact on the 1.5 million people with learning disabilities in the UK. People with learning disabilities have been more likely than the general population to contract COVID-19, and more likely to experience poorer health outcomes and mortality. In 2020, people with learning disabilities in Scotland were twice as likely to have severe symptoms and three times more likely to die of COVID-19 (Henderson et al., 2021). In England, people with learning disabilities had 8.2-fold higher rates of COVID-19 related death during the first wave (March-May 2020) and 7.2-fold higher rates during the second (September 2020-February 2021) (Williamson et al., 2021). The Learning Disabilities Mortality Review (LeDeR) indicated that 35% of people with learning disabilities who died from COVID-19 lived in residential care settings, and many who died experienced difficulties accessing COVID-19 tests, learning disability nurses and other healthcare support (LeDeR Programme, 2020). Baksh et al. (2021) further exemplified the disparities in healthcare experienced by people with learning disabilities, which have been 'magnified' during the pandemic (Baksh et al., 2021). The authors found people with learning disabilities more likely than the general population to present with severe illness at the point of admission, corresponding to late presentation at hospital and postulated a result of poor symptom recognition, communication difficulties and exclusion from digital information and public health campaigns. Despite having more severe symptoms on admission, people with learning disabilities were less likely to access appropriate treatment, including intensive care units. Research led by Hastings and Hatton, and authored by Flynn et al. (2021), found severe reductions in social care and support for people with learning disabilities, associated with negative impacts on wellbeing and mental health, with two-thirds of their sample having experienced anger, sadness or anxiety (Flynn et al., 2021). Similar experiences for people with learning disabilities have been demonstrated internationality, with evidence emerging from the Netherlands, Ireland and Italy (Buonaguro and Bertelli, 2021; Embregts et al., 2020; McCausland et al., 2021). These experiences have renewed debate on what makes people with learning disabilities vulnerable to morbidity and mortality. In this paper, we explore this vulnerability in the context of the pandemic, with consideration of Fineman's conceptualisation and theory.

Health and social inequalities experienced by people with learning disabilities in the UK are not new or unique to COVID-19. LeDeR has demonstrated increased rates of mortality among people with learning disabilities in England every year since 2016, with care reported to fall short of expected good practice (LeDeR Programme, 2019). Research over recent years has shown that people with learning disabilities face daily exclusion and inequality, with evidence demonstrating higher risk of abuse, discrimination, isolation, loneliness, unemployment and long-term mental health conditions (Cooper et al., 2015; Emerson and Baines, 2011; Malli et al., 2018; Wiseman and Watson, 2021). In 2008, the Joint Committee on Human Rights presented the UK government with a striking report on the human rights violations experienced by people with learning disabilities, resulting from the neglect of government policy towards their health and social care, in such a way to dehumanise them and create a system that allows abuse, discrimination and indifference, perpetuating a life of isolation, poverty and social exclusion (Joint Committee on Human Rights, 2008). The report highlighted the failure of government and public authorities to improve the lives of people with learning disabilities, stemming from limited understanding, funding and commitment to human rights. Further, in 2016, an inquiry from the United Nations Committee on the Rights of Persons with Disabilities concluded that since 2010 UK Government policies had resulted in 'grave and systematic' violations on the rights of disabled people, including concern on evident negative attitudes and discrimination towards people with learning disabilities, high suicide rates among this population, limited employment opportunities for people with learning disabilities, and cases in which no attempt was made to resuscitate people with learning disabilities

(Committee on the Rights of Persons with Disabilities, 2016). Despite these damning reports, people with learning disabilities remain one of the most excluded groups in the UK.

The COVID-19 pandemic has presented a unique situation, in which the disadvantages and inequalities experienced by people with learning disabilities have been amplified and brought to the public's eye. In the early stages of the pandemic, attempts to curtail the spread of the virus meant that many of their support systems had to stop, as the country tried to minimise transmission. Large numbers of people with learning disabilities require multiple and intersecting forms of support across employment, education and wellbeing, and many have complex and additional needs, requiring social care support at home or day services. Most of these services closed in March 2020, with many still not fully open towards the end of 2021. With these closures and the disproportionate impact of the virus, people with learning disabilities found themselves at risk and without formalised support (Flynn and Hatton, 2021; Shakespeare et al., 2021; Pearson et al., 2022). Evidence from the first wave of the pandemic found people with learning disabilities socially isolated and worried about lost support, lost routine, and decreased health and wellbeing (Flynn et al., 2021).

Through longitudinal qualitative research with disabled people in England and Scotland, we sought to further understand the experiences of people with learning disabilities and their families during the pandemic, including responses from national government, local authorities and social care providers. Before presenting our findings, we explore the ideas of Martha Fineman and others to discuss the concept of vulnerability among people with learning disabilities, both during and before this pandemic.

Learning disability, vulnerability and COVID-19

Much of the debate on high mortality and morbidity from COVID-19 among people with learning disabilities has focused on vulnerability, and in particular, clinical vulnerability to the virus. Courtney and Cooper (2021), in an editorial in the British Medical Journal, drew together evidence from a range of studies to point to what they described as the 'extreme vulnerability' of this group to COVID-19 (Courtenay and Cooper, 2021). They argued that people with learning disabilities often have high levels of co-morbidity, many of which make them more clinically susceptible to COVID-19 and its effects. They also highlighted high levels of prejudice and discrimination within healthcare; for example, the way in which people with learning disabilities were disadvantaged in vaccine programmes.

In a rejoinder to this editorial, Hatton (2021) warned against and challenged the systemic use of the word 'vulnerable' in relation to people with learning disabilities and COVID-19. He argued that describing people with learning disabilities as vulnerable to the virus 'locates the disproportionate risk of death from Covid 19 (and before Covid 19 too) as a property of individual people with learning disabilities. This not only removes agency from over a million UK citizens, but also can serve to remove any sense of urgency or even responsibility to see these inequalities for the injustices they are and to do something about them that matches the scale of the injustice.' (Hatton, 2021).

According to Hatton, the work cited in Courtney and Cooper's editorial focused not on clinical vulnerability, but on the way that society treats people with learning disabilities. It is this treatment, he argues, that makes people with learning disabilities 'vulnerable'. Hatton cites, as examples, the limited support received from health and social care during the pandemic, the discrimination of healthcare practitioners, and the living arrangements of people with learning disabilities, with large numbers placed in congregate settings, a hotspot for virus transmission. It is these social influences that have created the health inequalities experienced by people with learning disabilities during the COVID-19 pandemic. Hatton expresses the concerns of many disability theorists around the use of the term vulnerability, who argue that the concept may construct those deemed vulnerable as less able, less competent and more prone to harm (Scully, 2014).

Grear (2006) and Turner (2021) argue that all human beings are corporeally vulnerable, resulting not just from human embodied frailties, but through structural processes and institutions that produce social vulnerabilities (Grear, 2006; Turner, 2021). Further, Andorno (2016) defines 'vulnerability' as the ways in which some groups (in particular disabled people) are likely to experience greater harms due to their identities (Andorno, 2016). From Andorno's perspective, the purpose of understanding particular groups as vulnerable is not to construct those groups as inherently vulnerable, but rather to ensure greater protections and rights from state violence, discrimination and oppression. As such, vulnerabilisation can be understood as a social process and outcome of marginalisation, rather than being relegated to biomedical spheres and individual impairments.

We can further point to these social processes of vulnerabilisation through the work of Martha Fineman (2008) and the way she has deconstructed vulnerability to create what she termed the 'Vulnerability Paradigm' (Fineman, 2008). Fineman argues that focusing on acts of discrimination alone is too narrow; it produces an analysis of a particular action or moment of harm that privileges the individual and there is a danger that the 'historical, systemic and institutional structures that surround that moment' remain unexplored (Fineman, 2015). Equality has traditionally focused on fighting forms of discrimination with regards to race, gender, religion, etc. by providing the same treatment to all, in what Fineman has called the 'equal protection doctrine'. Fineman argues that this understanding of equality is inadequate

(Fineman, 2008). By highlighting individuals and individual actions it fails to address the impact of economic and social disadvantage on wellbeing. The equal protection doctrine does not challenge the underlying structures and practices. This is particularly harmful when applied to disability. Instead, Fineman calls for an approach that takes account of the context and structures that surround and create harm. Fineman argues that this is best achieved by focusing on differences rather than equality, by understanding the way in which different subjects are constructed in political and legal discourse. In recent years, Fineman's concepts have been increasingly applied to disability and learning disabilities (Clough, 2017; Heikkilä et al., 2020; Scully, 2014; Snipstad, 2021).

Fineman's approach starts from the basis that all people share common characteristics but that there are differences between them (Fineman, 2004). According to Fineman, we are all vulnerable; it is, she argues, part of the universal human condition. We are all susceptible to change and physical or social harm. Vulnerabilities are then embodied and embedded (Fineman, 2015; Fineman, 2017). Embodied differences are those that arise from biology, development, social relations or conventions. These include identity categories, such as ethnicity, gender and disability, and the way in which these have been constructed to create hierarchies and bias. People with learning disabilities are often excluded because they have been marked as incapable, inferior, weak or dangerous, for example. This exclusion is not universal; it is socially imposed, contingent and can take many forms (Scully, 2014). Vulnerabilities are also embedded in 'social relationships and within societal institutions' (Fineman, 2015). These economic, social, cultural and institutional relationships create embedded differences and it is these, Fineman argues, that shape our lives and create vulnerability. Emphasis is placed not on the individual, but on the structural, societal or institutional failings that cause vulnerability. People with learning disabilities are thus *made* vulnerable through social systems that exclude, actively harm and invisibilise, to render them devalued in everyday communities. These combine with and reinforce embodied vulnerabilities.

We have used Fineman's vulnerability paradigm as an overarching concept to explore the experiences of people with learning disabilities. In our analysis we have aimed to locate the experiences of people with learning disabilities during COVID-19 within the structures and practices that have rendered them vulnerable, placing them at greater risk.

Methods

The findings presented here are drawn from a subset of data collected as part of a longitudinal qualitative study into the experiences of disabled people in

England and Scotland. In this larger study, we conducted semi-structured, in-depth interviews with 71 disabled people and 31 key informants from disability support organisations across England and Scotland (Shakespeare et al., 2021). Two rounds of interview were held with this group of participants and key informants in June–August 2020, during the first wave of the pandemic, and February–April 2021, towards the end of the second. Of the 71 participants in the larger study, 24 were people with learning disabilities, caregivers or proxy respondents, from which the findings of this article are drawn.

Ethical approval for this study was obtained from the Research Ethics Committee at the London School of Hygiene & Tropical Medicine (Ref: 21878).

Participants

Participants were recruited through Disabled People's Organisations (DPOs) and other third sector organisations, via online advertisements and mail-outs. Participants were purposively selected, in order to maximise variation in line with Patton's sampling strategy, based on impairment (e.g. physical, sensory, intellectual), gender, age and geographic location (Patton, 1990).

Of the 71 disabled participants interviewed, 13 were adults with learning disabilities, six caregivers and proxy respondents of adults with learning disabilities, and five caregivers of children with learning disabilities. In total, 24 participants with learning disabilities were included (Table 1), along with 31 key informants based in organisations of and for disabled people.

Data collection

The interview guide was developed by the research team and adapted iteratively in response to participants' engagement in the first interviews. Questions explored the experiences of disabled people and their caregivers during the pandemic across key life areas including work, education, leisure, social care, health and the government pandemic response. The key informant interview guide included similar topics of relevance to the experiences of disabled people, but also focused on organisational and sector response, including changes in the organisation's work and member support, collaboration with government and other third sector organisations, and challenges in service provision.

Inclusive research

Social distancing measures were in place in the UK at the time of each interview and we adjusted research practices to maintain inclusivity (Walmsley and Johnson, 2004). Participants were provided the information sheet and consent

Table 1. Sample characteristics.

Variable	*Number (%)*
Participant	
Direct	13 (54%)
Proxy (caregiver)	11 (46%)
Location	
England	8 (33%)
Scotland	16 (77%)
Age	
<18	3 (13%)
18–65	20 (83%)
>65	1 (4%)
Gender	
Female	13 (54%)
Male	11 (46%)
Living arrangement before COVID-19	
Own home	6 (25%)
Family home	13 (54%)
Residential care	5 (21%)
Total	24 (100%)

form in easier to read formats during recruitment and were invited to interview via telephone, Zoom or email, depending on their preference. People with learning disabilities are a digitally excluded group and we worked with third sector organisations to recruit those without immediate access to online technology, ensuring their inclusion. For those that found telephone, Zoom or similar online communication technology inaccessible, we offered response via email or proxy. We encouraged participants to have a supporter present for the interview if helpful to them. Some interviews were conducted with a caregiver and self-advocate together. We also invited participants to speak with us a day or two before the scheduled interview, providing an opportunity to familiarise themselves with the online technology, to ask questions about the process and to get comfortable with the research team. Researchers used Easy Read materials to support the informed consent procedures. The methods used and described were trialled across six interviews and adapted in response to participant feedback. Each interview lasted between 30–60 min. All participants received a £20 voucher for taking part and accessible research summaries have since been provided to all.

Data analysis

Interviews were transcribed verbatim, anonymised and stored on a secure server. Each transcript was coded in NVivo 12. The research team developed an initial coding frame and adapted this as needed throughout the analysis using mechanisms of reflexive thematic analysis (Braun and Clarke, 2006). The teams at the London School of Hygiene & Tropical Medicine and the University of Glasgow cross-reviewed eight transcripts in the early stages of analysis to ensure consistent coding. During the analysis, themes were identified, reviewed and refined by the research team. Participant narratives and quotes are presented in this paper and have been anonymised through use of pseudonyms. Quotes are from people with learning disabilities, unless otherwise stated. The round of interview from which a quote is derived is noted by T1 (first round) and T2 (second round).

Findings

Findings emerged across four key themes. First, we explore the limited inclusion of people with learning disabilities in pandemic response strategies. Second, we examine how the suspension and removal of social care impacted on people with learning disabilities and their families. Third, we discuss the impact of the pandemic on people's everyday routines, which left many isolated. Finally, we explore the initial lack of vaccine support for people with learning disabilities and the fight for prioritisation.

Afterthought, lack of thought or no thought

From the outset of the pandemic, respondents described how people with learning disabilities were rarely considered in the national response. They felt invisible and ignored.

> When I watched them [news briefings] with mum I never once heard the word learning disability. We were completely forgotten about.
>
> ((voice breaking and close to crying)) Do they ever think about people like us? When they mention the word 'shielding', you think about the elderly, the vulnerable. Aren't we vulnerable? They're not the only ones shielding. We're missing out on our social care and our healthcare because of the coronavirus, because of shielding. But could they care less? No. Do they care? No. (Kelly, England, T1)

Government neglect was experienced not just in the early stages when the response could perhaps be expected to be uncertain, but throughout.

> I think we've just been pushed underneath the carpet, because I don't think the government give a damn. As long as they're okay and they've got their wage packet, they don't give a – excuse my language here – they don't give a toss. (Sally, Scotland, T2)

Policy focus was given to hospitals and it is clear from our data that people with learning disabilities were not considered a priority. At the root of this problem was neglect and limited understanding on both their needs and the way that they live their lives. This was seen among both national and local actors.

> I inveigled myself into a meeting of [Local Authority senior management] quite recently and I was just fascinated about how little they knew about people with learning disabilities and how little they knew about people in their communities who had learning disabilities.
> (CEO, national learning disability organisation, Scotland, T2)

This lack of engagement and understanding is illustrated by the failure to provide information and guidance to people with learning disabilities in multiple and accessible formats.

> Poppy: The government should give more information, that's what I think. They should give more information. They should get more information and I think they should explain it more to people with learning disabilities, 'cause some people don't understand what they're saying.
>
> Basil: No, that is the problem, isn't it?
>
> Poppy: That's what they should've… that's what they should have done. 'Cause I've found out that their words, that they're using big words, not little words. They don't break it down. (Poppy and Basil, England, T1)

As the pandemic progressed, there were attempts by governments to provide information in Easy Read format, but these were often only available online, making it difficult for digitally excluded people with learning disabilities to access. Inaccessible information resulted in misunderstanding and increased fear and anxiety, creating and deepening risk. Third sector organisations stepped in to provide accessible materials on the virus, with examples produced by Beyond Words and the Scottish Consortium for Learning Disabilities. Third sector organisations also hosted COVID-19 information sessions on Zoom and helped people with learning disabilities access the regular government briefings and other news stories.

Insufficient government consideration on the needs of people with learning disabilities impacted on the quality of care and support they received and it is to this we now turn.

Dissolution of care and support

At the start of the pandemic, many people with learning disabilities saw their social care services and packages cut. Often social care was removed overnight and with very little warning.

> [name of provider], who provide most of Maurice's care, phoned me up and said:
>
> 'Obviously this virus is getting more serious, so we've had to prioritise the support we provide, and in two days, Maurice's care will be ceasing altogether, and it's over to you. You need to now cover all of it.'
>
> So as you can imagine, that was a surprise.
> (Pearson et al., 2022) (Abby, sister of Maurice, Scotland, T1)

For the majority of our participants, support packages were cut, with no further word from providers as the pandemic progressed. Where social workers and others did get in touch, it was often cursory and had little effect. Some told us, for example, that the only contact they received was related to their annual review. This was seen by many as very poorly timed and insensitive, after no contact for months.

> The day centre called me maybe about a month ago to say it was time for his review and could they perhaps come round to do it in the garden? And I said: 'Are you having a laugh here? You haven't seen him for five months. What is there to review?'. And they said that: 'We have to do it, we've got paperwork to do'. And I said: 'No, I'm sorry, it's just a tick box exercise'. (Kris, mother of Jim, Scotland, T1)

Although the governments talked often about increased payments for unpaid family carers, our respondents reported little additional funding being made available in practice, even at the second-round of interviews in 2021. In fact, many families were asked to continue paying for support, despite support being withdrawn.

> The first wave of activity and the first wave of calls we received from families were about the withdrawal of social care support. In one or two instances we had a

> situation where some very well-known social care providers, who also are charities, not only withdrew support but asked the families to continue paying for support. Along the lines of saying to them: 'Well we need to keep your space open for your son or daughter so it would be better if you kept paying'. And these weren't isolated incidents, these were coming from a number of families across Scotland. (CEO, national learning disability organisation, Scotland, T2)

People also received little or no guidance from the government or local authority on how they could get support in their home, or how they could make that support COVID secure. We were told of occasions where staff who normally worked with people with learning disabilities were transferred to work in the care of older people. As the Care Manager of a service in Scotland told us, her service provided support to 50 people with learning disabilities before the pandemic. At the time of interview in June 2020, they supported only 14 people. The rest were left unsupported.

This shift of care staff meant a lack of consistency in the delivery of care. Where support was provided, the workers were often changed at short notice, putting people with learning disabilities at increased risk. Participants had to develop their own guidelines and procedures on COVID-19 measures in their home, and in many cases, the provision of personal protective equipment (PPE) for staff in the domiciliary sector was hard to source. It was also, for some, hard to persuade staff to wear PPE, and unlike in care homes and hospitals, it does not appear that guidelines were provided for domiciliary care staff. If they were, they were not well disseminated and there was limited accountability.

Participants often had to fight with local authorities to restart their support packages and some of our participants had still not seen these reinstated by early 2021. Throughout the pandemic, there was an expectation from governments, local authorities and service providers that families would be able to revert to becoming chief providers of care. For many family members this produced stress, burnout and mental health concerns, as they tried to juggle 24/7 care, with no support or respite. One mother told us of how she was accidentally copied into the minutes of a social care provider, who had discussed her request for short break care. They were going to refuse, as they believed she, as a mother, needed to be doing more. All of this despite her caring for her son 24/7 for five months, without a break.

> It made me understand that there was a complete lack of awareness of caring for someone in your own home in a national lockdown, 24 hours 7 days a week and not even being able to go out to work. That's unforgiveable. (Donna, mother of Ryan, England, T2)

Most participants expressed grave concern that cuts to social care packages would continue once the pandemic was over, as families had effectively 'proven' that they could undertake the role of the state, despite substantial socio-economic impact and impact on wellbeing.

> I feel as well that both social and healthcare services have a very limited – I'm going to use limited – understanding of what challenges people with learning disabilities have. I think they feel that it's like people with disabilities are making special demands… wanting special treatment. But actually that's not really it, they just want the same outcomes as other people. They just want to live their lives.
> (Abby, sister of Maurice, Scotland, T2)

Ultimately, participants felt abandoned. They were asked to fend for themselves and often without the proper means. Providers were rarely in touch, despite payment for support frequently remaining in place. In their joint interview Kris, the mother of Jim, a 30-year-old man with learning disabilities who lived with her, told us how, even by March 2021, nobody had been in touch with them:

> I've never been asked the question if it's okay, if we're doing okay… Nobody called me to see if I was managing without respite for a year, so from that point of view, I wouldn't say that the local authority had looked after us. I think it's been a case of, if we were in crisis, they would expect that we would get in touch, and because we haven't, they're assuming everything's alright.
> (Kris, mother of Jim, Scotland, T2)

Participants told us one of the major issues throughout the pandemic was the lack of consultation with them and their families from government, local authorities and social care services about their social care needs, with most having to react as best they could to a top-down approach, which resulted in withdrawn and inadequate provision.

Disrupted routines

The suspension of services and support disrupted daily routines. Of course, everyone's normal routines were disrupted during the pandemic, but the impact of closures on the lives of people with learning disabilities was profound. For many of our participants, activities such as drama groups and book clubs provided structure, routine, and security, in otherwise precarious and isolated lives. Day services also acted as platforms to socialise, and many reported missing their friends and connections regularly seen at these settings. With these closed during the pandemic, many participants felt isolated and lonely, with a sense of loss and worthlessness. Some felt they had lost their independence, and now relied too much on family.

> I also feel my independence has gone, due to now I am always with my parents or if we go out they are always supporting me but I'm not having my independence. Before I was out on my own and using public transport.
>
> Also my freedom of choice is reduced as less opportunities to choose that are of interest to me.
>
> Now I am transported by cars all of the time by my parents. It's very hard as they changed daily depending on how I am coping.
>
> I often feel sad no clubs and hobbies are available yet.
> (Frances, Scotland, T2)

These feelings of isolation and lost independence led some to show increased instances of distress; for example, through challenging behaviours, including violence towards themselves and family members.

> That was really hard, you know, people were saying that they felt they had lost their children, that their child now was so low in mood and, you know, lethargic, not carrying out activities. Self-injurious behaviours, communicating in adverse ways, had put on weight, lost skills, not able to do the things that they used to be able to do. And a couple of families saying: 'I don't know whether I'll ever have my son back again'. Oh, I mean, honestly it was enough to bring you to tears really. (CEO, national learning disability organisation, Scotland, T2)

Many expressed concern that without the stimulation provided by these services, including the social interaction central to activities, they would lose hard fought life skills. Caregivers were concerned that they could not provide as stimulating an environment or the variety of experiences as these services and as a consequence were seeing their loved ones regress.

> It's a real concern to, well, most of us, that it might just never reopen, and that has been suggested as a possible case scenario. That is a real worry, because as I was saying earlier, Lucy's health and wellbeing have been impacted on, because she hasn't been able to go to her day service. She needs to be out and about, she needs to be doing, she needs more challenge than she gets from just staying in the house all the time. (Priscilla, mother of Lucy, Scotland, T2)

With the cycle of routine broken, many were less stimulated and expressed anxiety about being able to return to their pre-pandemic routine. As the pandemic progressed, the strains and demands of lockdown started to deepen. Mental health support was, however, severely disrupted. It was removed for many, or was offered only online, inaccessible to many people with learning disabilities. One mother in England asked for mental health support from Child and Adolescent Mental Health Services (CAMHS) in March 2020, at the start of lockdown, but she did not receive a response until October 2020, with services offered only by Zoom, which was inaccessible to her son. They asked for reasonable accommodation but were told this was not possible. She paid £2000 for private mental health care instead and her son has shown substantial improvements in his wellbeing. Private mental health support is only available to a small minority of the general and learning disability population, however.

Again, third sector organisations stepped in with online activities when services closed, including online book clubs, cooking courses and quizzes, as well as mental health support lines, which were all received very positively by our participants. To overcome digital exclusion, third sector organisations provided training on how to use Zoom and some were able to provide digital tablets and laptops to those in need. That said, we were told that many people with learning disabilities remained digitally excluded throughout the pandemic.

At the second round of interviews, some had begun to see their day services and other activities resume at reduced hours, and after a few 'teething' issues on return, some had seen a boost to their mental wellbeing.

> They were really supportive within the parameters they could work in, which for a long time was no access to the day centre whatsoever, which was hellish for my brother. And they've gone back to two days a week. So, he has some access then, which has given him a bit of a routine and a bit of a sense of purpose, and his mental health has levelled out a bit. So that's helpful. (Alice, sister of Michael, Scotland, T2)

As well as social care, health management routines were also severely impacted during the pandemic. Routine health checks were suspended or delayed with consequences to the everyday health of participants. Day centre closure contributed to reduced mobility and physical health, with many of the participants missing out on organised activities, such as swimming. There were further concerns from participants with regards to foot care, dental care and diet management. Participants described how the pandemic had adversely affected the management of their epilepsy and control of their diabetes, for example.

Delayed vaccine priority

There was also concern expressed with regards to the vaccine and protection from COVID-19. For months, people with learning disabilities were ignored for vaccine priority, despite early evidence that they had a high-risk of morbidity and mortality from the disease (Mahase, 2021; Public Health England, 2020). Self-advocates, families and third sector organisations had to fight for priority status in the vaccination programme, with a number of coordinated campaigns directed towards the government.

> I have a simple example of that when I was – I'm not sure I was lobbying – but I was in a meeting with the Scottish Government's lead for vaccination… I said: 'So what I'm actually trying to help with here is the efficacy of your administration of your vaccination programme'. And the response I got was: 'that would be taking somebody else's vaccine'. And I thought, you're not even listening to the argument, you're not even engaging with me on this. It's similar to that [previous] response: 'but there's only 8000 of them' [people with Down Syndrome]. The human rights of people with learning disabilities have been absolutely trampled on. (CEO, national learning disability organisation, Scotland, T2)

Only after a media storm, brought into the public's view by well-known relatives of people with learning disabilities, such as Ian Rankin and Jo Wiley, were people with learning disabilities eventually given priority. For many of our participants, their vaccination was a good experience. However, for others, there were issues. The vaccination programme prioritised people with learning disabilities registered with a GP, but people with learning disabilities frequently fall through the net and they are less visible to health services (Buszewicz et al., 2014). Many of our participants were not invited for the vaccine because they were not registered as having learning disabilities. Many had to contact their GP themselves to arrange their vaccine and many expressed confusion with the system and the eligibility criteria.

For others who received the vaccine, the experience itself was a challenge. Although people with learning disabilities had been placed in the priority group, there were often no accommodations made at vaccination centres. Information on the vaccine process was not provided in an accessible format, and often those administering had no experience working with a person with additional needs. Donna told us how her son Ryan refused the vaccine because there were no accommodations made. She asked for support from a learning disability nurse, Easy Read materials, a private space and a longer appointment. These were denied.

> It's the same – there's no facility. It's a backhanded compliment, saying all these people with autism or learning disability can go and have their vaccine, but they're not going to take it up if they can't access it. It's so cruel really. There would be uproar, wouldn't there, with no wheelchair access to a building for vaccination. But it's exactly the same - accessibility. (Donna, mother of Ryan, England, T2)

Inaccessible vaccine procedures and delayed prioritisation increased vulnerability to the virus. Uptake of vaccinations by people with learning disabilities has been historically low (flu vaccine uptake was just 58% in 2019 to 2020) and the findings of our study reinforce the need for inclusive, targeted programmes (Public Health England, 2021).

Discussion

Our findings leave no doubt that the pandemic and the measures introduced to stop the spread of the virus had a significant impact on the lives and wellbeing of people with learning disabilities in England and Scotland. Government action (and inaction) exposed people with learning disabilities to risk and to harm. The pandemic revealed how poorly their needs are understood and how rarely people with learning disabilities are considered in policy planning.

Based on these findings, this paper has explored how people with learning disabilities have been made vulnerable during the COVID-19 pandemic. These vulnerabilities are both embodied, in that they are underpinned by greater risk of morbidity and mortality, and also embedded in social processes and practices. Vulnerabilities are produced not just because of people with learning disabilities' increased risk of acquiring and dying from the virus, but also because of inappropriate, inadequate and discriminatory social structures, and the processes and practices that they are embedded within. As Scully (2014) argues, vulnerabilities associated with an impairment can be 'amplified through structural and institutional processes that distribute unequally the resources that people might use to shield themselves and foster resilience against the impact of disability' (Scully, 2014). Our findings demonstrate the social production of vulnerability experienced by people with learning disabilities.

People with learning disabilities in England and Scotland were, initially at least, abandoned in the Westminster and Scottish governments' response to the COVID-19 pandemic. The pandemic exposed the limited understanding and neglect of governments and other statutory agencies of the needs and lives of people with learning disabilities and their families. While the marginalisation of people with learning disabilities is not new, they have, in this pandemic, faced the same crisis in a new form. To date, almost all of the official dialogue surrounding people with learning disabilities and COVID-19 has focused on their clinical vulnerability to the virus, largely ignoring the social and cultural practices that have placed them at increased risk. As we look back over the course of the pandemic and our longitudinal data, we see a focus from government on the biomedical, with little consideration for social dimensions and the impact these have on health and wellbeing.

Our findings suggest that the marginalisation and vulnerabilisation of people with learning disabilities has been the result of government action, or rather, inaction, entrenching pre-existing inequitable social structures (Fineman, 2008; Hatton, 2021). The removal of social care during

COVID-19 presents the clearest of example of this. Throughout the pandemic, social care was seen as secondary to health care; disabled people's social care needs were neglected and restricted by the UK and Scottish governments (Pearson et al., 2022; Shakespeare et al., 2021). In a 2020 analysis of national government policy response during the first wave of the pandemic, the Health Foundation concluded that government support for social care came too late and faced widespread implementation problems (Dunn et al., 2020). This led to limited protection and support for people using adult social care, increasing unmet need for social care (Dunn et al., 2020). Removing care increased demands on people with learning disabilities and their families at a time when support was most needed, causing stress, isolation, anxiety and fear. This neglect came after years of austerity-imposed erosion in social care, which was, as noted by the Health Foundation, 'underfunded, understaffed, undervalued and at risk of collapse', prior to the pandemic (Dunn et al., 2020). This neglected social care, both before and during the pandemic, has deepened legacies of exclusion and disregard for the health, wellbeing and rights of people with learning disabilities (Glasby and Needham, 2020; Martinelli, 2017; Pearson et al., 2022). Further, inaccessible COVID-19 information, delayed vaccination priority, and limited care guidance for families and providers all increased vulnerabilities experienced by people with learning disabilities, impacting their wellbeing and quality of life. Our findings are consistent with other evidence generated during the pandemic; government inaction and indifference exacerbated the pre-existing vulnerabilities of people with learning disabilities during the pandemic, whilst producing new precarities, putting their lives and wellbeing at risk (Flynn et al., 2021; Armstrong and Pickering, 2020).

In September 2021, the UK government announced plans to review strategies, policies and funding for health and social care in England. In Scotland, the Feeley Review into Adult Social Care is currently under consultation (Scottish Government, 2021). If they are to have the necessary impact, these reviews must transform the existing chronically underfunded system, rather than prop up that which already exists (Pearson et al., 2022). Governments must also prioritise areas that contribute to wider health inequalities experienced by people with learning disabilities. Emerson and Hatton have identified causes of health inequalities for people with learning disabilities, from which the government must learn and act (Emerson and Hatton, 2014). Key amongst these are the social determinants of health, which include social factors such as socioeconomic disadvantage, inadequate housing, discrimination, isolation, exclusion and violence. These are central to Fineman's model of vulnerability, and have played a key role in creating the disadvantages experienced by people with learning disabilities during the pandemic.

Entwined in this process of transformation is the need for governments to work in co-production and partnership with people with learning disabilities and their families. In part, the failure to account for people with learning disabilities during the pandemic arose because of limited consultation when planning the response, resulting in abrupt and inappropriate actions. Not only did the policies not meet the needs of this group, they served to amplify their disadvantage. People with learning disabilities were placed at increased risk because governments failed to work in partnership with them, their families and DPOs. Such engagement would have been relatively easy; there are large numbers of DPOs and other third sector organisations that could have acted as proxies at the start of the pandemic. As we discussed in an earlier article, these non-statutory agencies played a central role in covering the inaction of central government (Shakespeare et al., 2021; Cullingworth et al., 2021). DPOs across England and Scotland have called for increased funding, support and responsibility going forwards, and there must be recognition of the value they play in helping disabled people access their rights (Inclusion London, 2020; Glasgow Disability Alliance, 2020; Inclusion Scotland, 2020; Greater Manchester Disabled People's Panel, 2020).

Over the last two decades, governments across the UK have received evidence, reports and advocacy on the systematic inequalities experienced by people with learning disabilities, stemming from limited understanding, neglect and indifference (Health and Social Care Committee, 2021; Joint Committee on Human Rights, 2008; Mencap, 2007; Scior and Werner, 2015; Simmonds et al., 2018). They have had a long time to act, but have shown little willingness to do so. In December 2021, the UK Government published a follow-up report to the 2016 inquiry by the United Nations Committee on the Rights of Persons with Disabilities, covering actions in 2020 and 2021 taken in line with United Nations recommendations for welfare reform, accessible information and consultation (Department for Work and Pensions, 2021). The UK Government's reported actions to these recommendations do not, however, reflect the information told to us by people with learning disabilities and their families, and as seen in numerous pieces of research conducted during COVID-19. Independent inquiry, review and accountability continue to be needed to ensure that governments in the UK transform the health and social landscape into one that empowers people with learning disabilities to reduce health inequalities, vulnerabilities and help them to reach their potential.

In our analysis and by employing Fineman's vulnerability paradigm we have shown how the response of the governments has increased risk and vulnerabilised people with learning disabilities, exacerbating existing vulnerabilities and imposing new. Given this, it is not surprising that people with learning disabilities have suffered poor health outcomes and wellbeing during the COVID-19 pandemic. These inequalities are not new and urgent reform is needed; for people with learning disabilities, returning to the status quo is not an option. Governments must work in partnership with people with learning disabilities, families and disability organisations to build back a better and fairer society, addressing the challenges that contribute to poorer health, wellbeing and quality of life. In order to understand and respond to the harms that people with learning disabilities have experienced throughout the COVID-19 pandemic, we need to pay attention to the ways in which they are made vulnerable, the processes involved in making them vulnerable and the consequences on their lives.

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Recent publication: Pearson C, Watson N, Brunner R, Cullingworth J, Hameed S, Scherer N and Shakespeare T (2022) Covid-19 and the crisis in social care: exploring the experiences of disabled people in the pandemic. Social Policy and Society. Epub ahead of print 08 April 2022. DOI: 10.1017/S1474746422000112

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Recent publication: Shakespeare T, Watson N, Brunner R, Cullingworth J, Hameed S, Scherer N, Pearson C and Reichenberger V (2022) Disabled people in Britain and the impact of the COVID-19 pandemic. Social Policy and Administration 56(1): 103–117.

2.3. Key concepts in the analytic commentary

To guide the analytic commentary, I have utilised a social-ecological model of mental health. I did not use a social-ecological framework to guide my research in papers 1-4, but I have applied it in this thesis to structure my synthesis and discussion of the findings.

First proposed by Bronfenbrenner in the 1970s and formalised by McLeroy et al. in the 1980s, the social-ecological approach aims to understand the personal and environmental factors that contribute to development, health and wellbeing, including individual, family, community, systems and wider societal components [51-56]. Social-ecological models and approaches have often been utilised to guide international health. For example, the *Ottawa Charter for Health Promotion* is founded in social-ecological principles [57]. The Charter holds that peace, shelter, education, food, income, stable ecosystems, sustainable resources, social justice and equity are prerequisites for health.

In 2022, the United Nations Children's Fund (UNICEF) launched the *Global Multisectoral Operational Framework for Mental Health and Psychosocial Support of Children, Adolescents and Caregivers Across Settings* [58]. MHPSS is a "composite term used to describe any type of local or outside support that aims to protect or promote psychosocial wellbeing or prevent or treat mental disorders" [58]. The UNICEF framework utilises a social-ecological framework (Figure 2), life-course approach and the Inter-Agency Standing Committee (IASC) MHPSS intervention pyramid to understand mental health conditions in children across the world and to inform support, including prevention, promotion and treatment services.

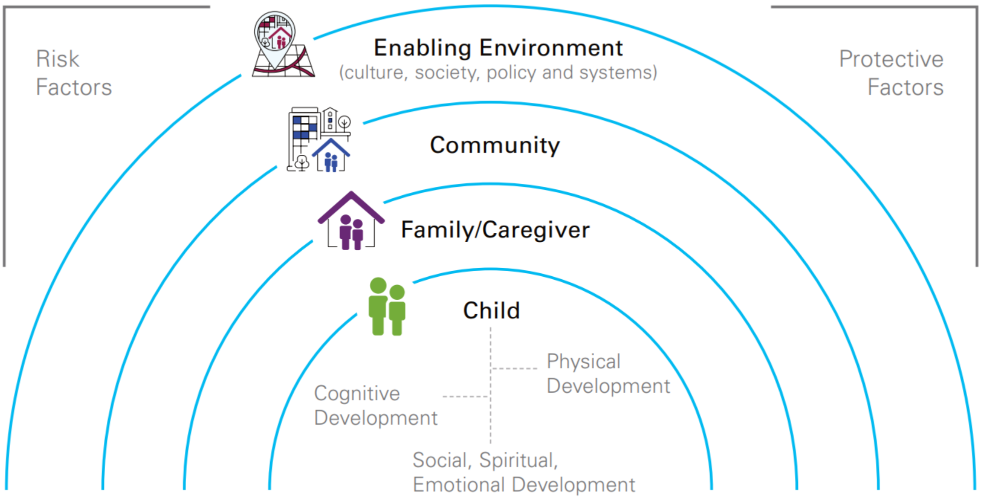


Figure 2. Social-ecological framework of mental health and psychosocial support

In this social-ecological framework, child wellbeing is conceptualised across four levels. At the centre is the child, where individual characteristics and experiences influence wellbeing, including identity, self-esteem, coping skills and exposure to trauma. Support for children at this level may include psychoeducation, access to nurturing and safe spaces, early child development activities and personalised psychological interventions. Next comes caregivers, primarily parents and family members, as well as teachers, social workers and others influential in a child's development. Risk and protective factors include family functioning, parental support, home environment, household socio-economic status, abuse and neglect. Caregivers' own mental health and wellbeing may also influence the child's wellbeing and mental health. Support for caregivers may include caregiver mental health services, peer-support groups, caregiver-skills training, and fostering collaboration between parents and teachers. The community level reflects the community environment in which a child lives, including community attitudes and culture, as well as the availability of accessible community-led MHPSS activities and multisectoral care systems across primary health care, social welfare and education. Support across this sphere may include anti-stigma campaigns, strengthened social care systems, and participation of children in community improvement and service activities. Influencing all of these factors is an enabling environment that provides the policies, systems and structures to support mental health and wellbeing. Important at this level is financing, appropriate MHPSS policies and legislation, government implementation strategies, workforce development, and research and evidence.

UNICEF have used a social-ecological framework to operationalise their global action for child mental health. In this analytic commentary, I aim to start discussion on how to operationalise the literature for action on MHPSS for children with disabilities. UNICEF include a short segment on disability and inclusion within MHPSS programming, but information on operationalising the framework for children with disabilities is limited. Social-ecological frameworks have been used to understand the experiences of people with disabilities [59, 60], but, to the best of my knowledge, they have not been used to understand the mental health and wellbeing of children with disabilities. In the analytic commentary, I apply the framework to synthesise my findings and discuss the implications of these findings in the context of the wider literature with regards to gaps in evidence and future action for research, policy and practice.

The analytic commentary incorporates critical reflection on papers 1-4, as well as broader literature, including those to which I am first or co-author. I reflect on factors influencing mental health and wellbeing among children with disabilities, including risk and protective factors associated with the four levels of the social-ecological framework. The topics listed at each level of the framework are not exhaustive. They are informed by my research in paper 1-4. There will be factors that influence mental health and wellbeing among children with disabilities in the wider literature that I have not had scope to explore. I begin my discussion at the macro-level of an enabling environment, progressing through each level to individual child experiences. This order is different to UNICEF's presentation of the social-ecological framework. Each level of the framework is affected by the policy environment and national systems and starting at the macro-level helped me to reflect on policy and national systems at each subsequent level.

Often, factors discussed relate to the social determinants of health [61]. These are non-biological factors that influence health outcomes, and are associated often with the conditions in which children grow, including access to care, environment, housing, discrimination, education and household income. In addition to discussion on factors that influence mental health and wellbeing, I examine MHPSS strategies that may support children with disabilities. My discussion includes focus on low-level interventions that can be delivered by non-specialised personnel that are trained and supported by specialist mental health professionals. This process, task-sharing, is often deployed where there are low numbers of mental health professionals to provide support, especially in LMICs and in the field of Global Mental Health [62].

3. Analytic commentary

3.1. Vulnerability and mental health

To start the analytic commentary, I want to reflect on some of the language used in the social-ecological framework and my published work. The framework used by UNICEF frequently makes use of the term 'vulnerable' when describing MHPSS for certain children across the world. But is this language always useful for children with disabilities?

In paper 4 I discussed the concept of vulnerability, with reference to the work of Martha Fineman [36, 63] and the social determinants of health [61, 64]. I argued that UK government action (and inaction), including inaccessible health information and removal of social care, *made* people with disabilities vulnerable. However, in this article, I did not consider the appropriateness of vulnerability as a term.

People with disabilities are often classified as vulnerable in legal, political and societal discourse, although the term is not used consistently across countries and context [65-68]. Proponents of this term argue that it stimulates State actors to provide special protection and care for groups that need additional support. This may include social protection or priority medical support. In the UK, this terminology likely played a role in providing people with disabilities priority vaccination. However, there are critics of the term in disability studies [65, 66]. Many consider the term disempowering and one that promotes the medical model of disability. The language places risk on the individual and ignores the wider determinants of health associated with systems and environments. Further, the term vulnerable has become synonymous with fragility and weakness and can promote stigma and discrimination towards people with disabilities. The term can therefore support systems that deprive people with disabilities of their autonomy, agency and decision-making. In a 2011 review of adult social care in the UK, the Law Commission recommended that the UK social care sector move away from the term vulnerable, as it was "stigmatising, dated, negative and disempowering" [69]. The *Care Act 2014* subsequently referred to 'adults at risk' and did not use the term vulnerable.

Despite this criticism, the term vulnerable was used extensively to refer to people with disabilities during the COVID-19 pandemic in the UK. Often the term 'clinically vulnerable' was used. Classification as vulnerable provided priority groceries, medication and access to other needs, and some people with disabilities, including participants in paper 4, described themselves as vulnerable [36]. Yet, research has shown that many people with disabilities in the UK felt embarrassed by the term and believed that it contributed to people with disabilities being perceived differently and as 'other' [70]. Many people with disabilities were also deemed 'not vulnerable enough' to receive priority support and there was widespread confusion over use of the terminology and changing classifications [71, 72].

I argue that the term 'vulnerable' should only be used in the context of children with disabilities and mental health when clearly defined as it relates to social vulnerability, as rooted in the social determinants of health and mental health [61, 73, 74]. In the analytic commentary, I do not use the term vulnerable. I aim to use language that highlights the environmental and structural conditions that exclude and marginalise children with disabilities to negatively impact mental health.

3.2. Social-ecological framework of mental health: enabling environment

In this section, I discuss the macro-level of the social-ecological framework and consider the value of an enabling environment across policy, systems and society.

3.2.1. Government policy and action

Disability inclusion paves the foundation from which to promote the mental health of children with disabilities. My findings from the Gaza Strip and the UK underline the negative impact of exclusion in community, school and government support on mental health and wellbeing. Local and national government policy and strategy is vital to ensure disability inclusion. The UNCRPD has been ratified by 185 UN Member States, but evidence has demonstrated widespread failings in implementation

[75-79]. Many countries have developed new disability policies and taken positive action, but limited knowledge on disability inclusion at government-level, limited resource allocation and gaps in monitoring compliance have led to low levels of implementation, nearly two decades on from the UNCRPD [75-79].

These failings are highlighted in papers 2 and 4 [35, 36]. Families in the Gaza Strip and in the UK did not hold trust in government support for children with disabilities. Organisations of persons with disabilities (OPDs) in the Gaza Strip felt that disability inclusion within government was “talk with no action” [35], and families of children with intellectual disabilities felt abandoned by the UK government during COVID-19 [36]. Limited and insufficient inclusion in government strategy, even in a well-resourced country such as the UK, have resulted in systems that negatively impact on the mental health and wellbeing of children with disabilities [35, 36]. My findings demonstrate systemic failures in governmental support for children with disabilities across diverse settings. They underscore the urgent need for robust policy reforms and enhanced political commitment to address deficiencies and promote the inclusion and wellbeing of children with disabilities, especially during times of crisis, such as the COVID-19 pandemic. Failure to act perpetuates systemic injustices and exacerbates the challenges faced by an excluded and marginalised group.

Failings in implementing the UNCRPD include limited engagement with persons with disabilities, caregivers and OPDs in policy-development and implementation [76, 78-80]. Globally, OPDs have reported dissatisfaction with the extent and quality of their participation [81]. Paper 4 and associated articles are consistent with these findings [36, 46-48]. My research highlighted the limited involvement of persons with disabilities, family members and OPDs in developing COVID-19 strategies, resulting in inappropriate action that effected poorer health, mental health and social outcomes [36, 47]. Where government failed during the pandemic, OPDs stepped in, providing information and support to children (and adults) with disabilities and their families, including mental health support [36, 46]. Limited collaboration with OPDs and people with lived experience is not limited to the pandemic. In 2022, the UK’s new *National Disability Strategy* was ruled unlawful because it had not been developed with appropriate consultation from people with disabilities. This decision has since been overturned, although this has been criticised by disability rights organisations [82, 83]. Well-resourced countries such as the UK should be paving the way for collaborative, participatory practice to promote disability inclusion, but failings remain. Continued avoidance of effective collaboration by government will entrench systems that exclude and marginalise child and adults with disabilities, negatively impacting their mental health and wellbeing, as well as education, employment, mortality and morbidity.

Collaboration and partnership between researchers, government, civil society and people with lived experience is essential for disability inclusion and promoting the mental health and wellbeing of children with disabilities. Although findings in the Gaza Strip indicated limited government action on disability inclusion, partnership between researchers, OPDs, people with lived experience and government was central to our research project [34]. Partnership and shared ownership from the outset increased government engagement and the quality of the guidelines developed. Opportunity to collaboratively discuss research findings with people with lived experience and in the context of practical considerations for government implementation promoted evidence-based, feasible and actionable MHPSS guidelines. This partnership and collaboration likely contributed to government commitment to implementation of the MHPSS guidelines across all schools in the Gaza Strip, although the longer-term sustained implementation and impact has not been assessed.

Collaboration can promote translation of research into policy and practice. Translation of research into policy and practice is often perceived to follow a linear model, in which government are expected to take action from research alone [84]. This does not always work in complex, real-world environments, where stakeholders have different priorities, timelines and conflicting interests. Translating research into practice is a well-recognised challenge [84]. Getting Research into Policy and Practice (GRIPP) is an important topic area, with funders, researchers and policymakers trying to find effective strategies [85, 86]. Dissemination alone may have little impact on policy and practice, although this is often the most common activity by researchers [86]. There are a number of strategies to promote GRIPP beyond the scope of this thesis to explore, but drawing on my experience in the Gaza Strip, and congruous with the literature [85, 86], effective collaboration between stakeholders and participatory approaches can promote the uptake of evidence-based policy and practice. Engagement and partnership early in our process ensured that research questions were relevant to real-world need and increased the likelihood of uptake by national stakeholders. However, time can be a limiting factor. Research funding is short-term, insecure and project-based. Longer-term research funding is needed to promote translation of research to practice [85, 86]. It can allow sustained partnership between stakeholders to promote evidence-based action and allow for researchers to more meaningfully impact policy [85, 86]. In the Gaza Strip, longer-term funding would have enabled in-depth evaluation of the MHPSS guidelines to promote uptake and sustainable practice, drawing on implementation science, such as the Medical Research Council and the National Institute for Health and Care Research guidance on evaluating complex interventions [87]. Longer-term funding would also have provided research capacity to support and monitor implementation, as well as additional opportunities for shared learning between the project partners. Longer-term funding is not guaranteed to result in greater impact or progress on GRIPP, but funders should consider long-term funding to promote evidence for systems building.

3.2.2. MHPSS systems for children with disabilities

Globally, and in LMICs in particular, mental health service provision is low [20] and the treatment gap globally remains substantial [19]. For children with disabilities, the treatment gap is exacerbated by a lack of access to health services [11], including barriers to mental health services specifically [88, 89]. In paper 4, for example, children with intellectual disabilities were unable to access online mental health support during the pandemic because of digital poverty and limited digital literacy [36].

In settings with limited human resources, innovative low-cost solutions have been developed for mental health treatment, such as the *WHO Mental Health Gap Action Programme* (mhGAP) [90]. However, scale-up of these mental health interventions presents a major challenge [19]. Limited resources (including finance and expertise), limited infrastructure, and stigma towards mental health limit implementation of innovative interventions [19, 91]. Considering disability-inclusive mental health interventions now, whilst developing solutions at scale, presents opportunity. Paper 1 indicates that many interventions for children with disabilities are adapted from interventions developed for the general population [33]. Including reasonable accommodations and guidance for disability inclusion in MHPSS means that children with disabilities will not be left behind in efforts to promote mental health and wellbeing. This process is beginning, as demonstrated in the newest mhGAP guidelines, released in 2023, which include information on psychosocial support for children with disabilities [90]. Specifically, the guidelines contain the section titled, “What is the effectiveness of psychosocial interventions (apart from caregiver skills training) to improve development, wellbeing, functioning and school participation in children and adolescents with neurodevelopmental delays and disabilities?”. The section provides an overview of evidence and suggested actions to promote wellbeing and address mental health conditions among children with disabilities. This is not limited to addressing mental health conditions but also promoting social skills, communication and academic performance. Gaps in research are also presented. It is encouraging to see a mainstream tool from a multilateral organisation such as WHO meaningfully include children with disabilities. The guidelines could be further strengthened with more in-depth guidance on recommendations for reasonable accommodation, as a lay worker with limited knowledge on disability may currently struggle to interpret and implement the guidance. Interestingly, much of the research presented is focused on neurodevelopmental disabilities, such as autism and attention deficit hyperactivity disorder (ADHD). Children with intellectual disabilities are only referenced with relation to interventions that improve communication. No information is presented on deaf and hard of hearing children or children with a visual impairment. This is not a criticism of the tool; these omissions reflect gaps in the literature and evidence base that should be addressed. Findings from paper 1 reflect this limited literature, specifically for deaf and hard of hearing children [33].

Further, paper 1 highlights that evaluation research on MHPSS for deaf and hard of hearing children is often small-scale and quasi-experimental [33]. Larger-scale randomised controlled trials (RCTs) are needed to inform evidence-based policy and practice. These should be accompanied by process evaluations to understand facilitators and barriers to implementation. Understanding and addressing barriers to implementation should be underpinned by collaboration and partnership between researchers, policymakers and OPDs, to facilitate contextually appropriate solutions to implementation challenges for iterative adaptation and evaluation. Formative research, as I conducted in the Gaza Strip [34], is also needed to inform evidence-based development of MHPSS. Without formative and evaluation research, interventions may remain siloed, small-scale projects that fail to reach desired impact at scale. This is an issue consistent in health intervention research and delivery for people with disabilities [92]. This is also a limitation of my research in the Gaza Strip. The pilot studies in paper 3 were small-scale and a larger RCT is needed.

Disability-inclusive MHPSS interventions and systems can only exist in a disability-inclusive health system. People with disabilities experience health inequity and challenges to healthcare access [4, 12]. Health systems worldwide are failing to provide disability-inclusive services. Global efforts and multisectoral action are required to improve disability inclusion. In the *Global report on health equity for persons with disabilities*, WHO outline needed action in political commitment, policy, health financing, physical infrastructure and human resources [4]. The Missing Billion Initiative also provide a framework for disability-inclusive health systems [12]. Action to develop disability-inclusive MHPSS will need to be situated and contextualised within action for disability-inclusive health systems. Disability-inclusive MHPSS is intrinsically tied to a broader disability-inclusive health system. Increased efforts are needed on both, but disability-inclusive MHPSS may not be possible until core health systems are inclusive. To promote disability-inclusive MHPSS systems, it may be beneficial to adapt frameworks such as that of the Missing Billion Initiative to the specifics of MHPSS for adults and children with disabilities. The framework outlines action needed at system level and service delivery and has previously been adapted to the needs of people with intellectual and developmental disabilities. A similar process could adapt the framework for disability-inclusive MHPSS systems.

In this section, I have primarily discussed intervention services, but MHPSS systems for children with disabilities should not focus solely on treatment. Too narrow a focus on treatment has been a criticism of scale-up in mental health support and the field of Global Mental Health specifically [93]. Intervention services and manualised tools, such as mhGap, are needed to identify and treat mental health conditions, but MHPSS systems that support the mental health and wellbeing of children with disabilities will need to extend to environments that promote inclusion, quality of life and wellbeing. This principle forms a central pillar of my discussion throughout this thesis. Disability inclusion and action to promote mental health and wellbeing are needed to support children with disabilities.

3.2.3. Crisis and complex settings

Given the contexts in which my research was conducted, it is important to consider the impact of crisis on the mental health and wellbeing of children with disabilities. Children and adolescents in times of emergency and crisis are at increased risk of mental health conditions [94-96]. In paper 4, children with disabilities experienced isolation and poor mental health during COVID-19, created in large by the removal of support and exclusion from government policies [36]. These findings are consistent with the broader literature [36, 97-99]. These failings reflect widespread failings across disability-inclusive disaster management, disability-inclusive emergency preparedness and disaster risk reduction, where limited awareness on disability inclusion, lack of prioritisation of disability inclusion and lack of partnership with persons with disabilities has resulted in exclusion of people with disabilities in emergency response [100]. These are important findings in the context of future crises. Based on learnings from COVID-19, the *PREparedness, REsponse and SySTemic transformation* (PRE-RE-SyST) model for disability-inclusive pandemic responses may provide strategic direction for future emergencies [101]. The model provides recommended action to address health and social disparities experienced by people with disabilities in a pandemic, including actions that address key challenges highlighted in paper 4, including the need to maintain essential services during lockdowns, provide accessible health information and engage with disability advocates. Specific note is given in the model to psychological support for children with disabilities. As well as actions in response to a pandemic emergency, the model supports the argument that governments need to address the root, structural and systemic causes of inequities experienced by children with disabilities. Evidence from paper 4 and the wider literature emphasise the importance of responding to a crisis from a basis of strength; i.e. a system that is inclusive and supportive of children with disabilities [36]. Crises expose existing frailties and these are exacerbated by an inadequate government response. In the UK, government response largely forgot children with disabilities and their families [36]. Taking lessons from the pandemic, the UK government and governments globally, in collaboration with people with lived experience, researchers and civil society, need to address first the systems that exclude children with disabilities, in conjunction with crisis response strategies that are disability-inclusive. Without action, children with disabilities will again experience poor mental health during future crises.

Although my research in the Gaza Strip did not focus on the impact of conflict and humanitarian settings on mental health, the current situation in the Gaza Strip necessitates attention. Children with disabilities are particularly at risk to the impact of conflict and displacement, including greater risk of psychological impact [102, 103]. MHPSS is founded in humanitarian crises and the IASC have recently developed an information note on disability and inclusion in MHPSS in humanitarian settings, including provisions for children with disabilities [104]. These guidelines are long overdue, with the original IASC MHPSS guidance released in 2007. They provide a comprehensive guide to disability inclusion in MHPSS and were developed using participatory methods. The IASC is the global leader in MHPSS in humanitarian settings and this hopefully spells optimism for disability-inclusive MHPSS in humanitarian crises moving forwards.

3.3. Social-ecological framework of mental health: community

Community-level factors can include community MHPSS strategies, but emerging strongly from my research was the role of stigma in limiting community inclusion and participation, and the negative impact of this on wellbeing. In this section I discuss findings related to stigma experienced by children with disabilities.

3.3.1. Stigma, discrimination and social exclusion

Children with disabilities are more likely to experience loneliness and isolation than peers without a disability [26]. Deaf and hard of hearing children in the Gaza Strip experienced exclusion at school and in the community [35]. Social exclusion is a major influence on poor mental health [105], and as with deaf and hard of hearing children in the Gaza Strip, children with invisible disabilities can often be at greater risk of peer rejection [106]. Social exclusion and limited opportunity for social interaction can inhibit the development of social skills, further entrenching social exclusion when opportunities do arise.

Stigma is a major driver of social exclusion [107]. Deaf and hard of hearing children and caregivers experienced stigma and discrimination in the Gaza Strip [35], consistent with previous literature [108]. In the Gaza Strip, stigma and discrimination was driven by limited knowledge on deafness and disability, where knowledge was often centred on medical models of disability, rather than social and rights-based models. This is consistent with the wider literature. Stigma and discrimination towards disability often arises from misconceptions about the cause and nature of disability, as well as limited expectations on the capability of people with disabilities [107, 108]. Stigma is typically greater towards those with more severe impairment, as they are seen to be more 'other' and less able to contribute to their community [108]. As a result of community stigma, parents and children in the Gaza Strip demonstrated internalised stigma and some families denied their child's disability [35]. As a result, many deaf and hard of hearing children were excluded from support they needed (e.g. sign language) by their families. These findings suggest a pervasive pattern wherein public stigma and internalised stigma impedes access to essential support services for children with disabilities.

For children, school offers opportunity for inclusion [106]. However, it is also an environment in which children with disabilities are at increased risk of discrimination and bullying. In the Gaza Strip, this dichotomy in school experiences was shown. Some deaf and hard of hearing children in mainstream schools thrived, whereas others experienced bullying and exclusion from peers. Addressing stigma and improving knowledge on disability and deafness was a key component of the MHPSS guidelines in the Gaza Strip, consistent with evidence highlighting the promise of school-based interventions to reduce disability-stigma in LMICs [109]. However, more high-quality research is needed on school-based interventions, including rigorous evaluation. In the Gaza Strip, teachers noted that limited time and capacity to implement the MHPSS guidelines presented a barrier. Impact evaluations of school-based interventions should always be complimented by process evaluations to understand such barriers to long-term sustainability.

In the context of MHPSS, it is important to note that mental health in children is also a stigmatised condition [110]. Children often do not seek mental health care as a result of stigma, prolonging the negative impact on physical and mental health [111]. Mental health stigma reduction interventions, largely conducted in schools, have shown long-term improvement in child and adolescent mental health literacy and reduction in stigma towards mental health [112]. In the context of MHPSS for children with disabilities, anti-stigma campaigns should thus tackle two issues; disability stigma and mental health stigma. Incorporating disability inclusion and disability stigma within anti-stigma campaigns on mental health for the general population may be beneficial. Such actions are central to mainstreaming disability inclusion and this deserves further attention.

3.4. Social-ecological framework of mental health: caregivers

Caregivers are those who are influential in a child's development. This includes family members, as well as primary caregivers at school (e.g. teachers) and child services (e.g. social workers). In this section, I focus on parents and family members. Caregivers need support to provide children with disabilities with a safe and nurturing environment. This section explores the mental health of family caregivers and caregiver knowledge on disability.

3.4.1. Mental health and wellbeing among caregivers of children with disabilities

Parents and family members of children with disabilities are at increased risk of stress and mental health conditions [113, 114]. This is true in 'normal' times and was exacerbated during the COVID-19 pandemic. Stressors during the pandemic increased the risk of poor mental health, as presented in paper 4 [36]. Findings of paper 4 are consistent with a recent meta-analysis which found 37% of family caregivers of children with neurodevelopmental disorders experienced anxiety during COVID-19, 41% experienced depression and 59% stress [115]. Paper 4 highlighted how worry, isolation and increased caregiver demands contributed to this increased risk.

It is important to understand and address the mental health of caregivers in order to support their quality of life. It is also important to consider the impact of poor caregiver mental health on children with disabilities. Caregiver mental health is associated with child development and mental health, including cognitive development and behavioural disorders [116, 117]. It may also influence secure parent-child attachment and nurturing care, vital to a child's wellbeing [118]. Caregiver mental health also influences access to mental health services by children with disabilities [27]. Thus, understanding and addressing the mechanisms of caregiver stress and mental health may contribute to improved wellbeing, development and behavioural outcomes among children with disabilities.

Considering specifically the mental health of caregivers of children with disabilities during COVID-19, we can reflect on the findings of paper 4, as well as other studies published from the same project, to which I am co-author [36, 46, 48]. During the pandemic, children with disabilities experienced negative impacts on their mental and physical wellbeing, including increased behaviours that challenge, isolation, depression and lost developmental skills [36, 48]. This placed strain on caregivers, increasing worry and caregiver demands. This strain was exacerbated by the withdrawal of social support, reducing the resources available to caregivers and increasing demands upon them. My findings in the UK were consistent with other countries [119, 120]. These findings are not necessarily unique to COVID-19 and are congruent with findings for caregivers of children with disabilities in normal times [113, 121]. However, findings from the pandemic highlight that crisis and the distress response is not static and changes as time progresses. Coping strategies and support provided prior to the pandemic (e.g. family, friends, formal care) may not have been available during and in the period after the pandemic. Caregivers may have had to develop new coping strategies based on these new conditions in order to adapt to the stressors of the pandemic. As society continues to recover from the pandemic, it may be appropriate to investigate these coping strategies outside of the immediate crisis. For example, during the pandemic, peer-support provided a source of support when formal care failed [122]. The value of peer-support is not a new concept, but evaluation research is limited for caregivers of children with disabilities [123]. Evaluating this and other coping strategies that expanded or newly developed during COVID-19 may unearth novel coping strategies and systems that can be adopted in the post-pandemic era. This requires further attention as countries look to build back better.

In addition, it would be valuable to investigate caregiver mental health and coping strategies in humanitarian settings. My research in the Gaza Strip focused on the wellbeing of children and did not explicitly explore caregiver mental health. Further research is needed to explore the mental health of caregivers in this and other humanitarian settings. For example, paper 2 and 3 highlight the limited formal support available for deaf and hard of hearing children in the Gaza Strip, which negatively impacted their mental health wellbeing [34, 35]. Limited formal support may also impact the mental health and wellbeing of caregivers in this setting. Research is needed to explore the unique factors that influence caregiver wellbeing in similar humanitarian settings.

3.4.2. Caregiver confidence, knowledge and skills

Family knowledge on disability influences the wellbeing of children with disabilities. In the Gaza Strip, many families had little information on disability and how to support their child [34, 35]. The vast majority of deaf and hard of hearing children are born into hearing families who often have limited knowledge on deafness and Deaf culture [124]. Although many caregivers in the Gaza Strip still supported their child, limited information contributed to low acceptance and internalised stigma among some. Interventions for caregivers of children with disabilities, often skills-based training programmes, can improve parental knowledge and skills, resulting in positive child outcomes, including development, educational outcomes and behavioural outcomes [125]. These interventions also improve caregiver self-efficacy [126]. Caregiver self-efficacy is associated with more positive caregiver-child relationships, more effective parenting styles and improved child development outcomes [127]. Self-efficacy is further associated with resilience and improved mental health among caregivers of children with disabilities [128]. Caregiver training programmes also provide peer-support, providing a platform for caregivers to share experiences and foster social relationships [122]. The majority of impact evaluations of caregiver programmes have small sample sizes and larger-scale evaluations are needed [125].

Although the MHPSS guidelines I developed in the Gaza Strip were designed for teachers, family caregivers in the steering committee and as study participants requested information for families. Thus, in the guidelines teachers are encouraged to work with families to jointly improve knowledge, promoting consistent support at home and school. The guidelines were developed in collaboration with family caregivers and future research should adapt the guidelines for family caregivers in the Gaza Strip. They receive limited information on disability or mental health and guidance would be valuable. In addition to adapting the guidelines, adapting existing caregiver training programmes for families in the Gaza Strip may be beneficial. Evaluation of such programmes in this context is needed.

3.5. Social-ecological framework of mental health: children with disabilities

At the centre of the social-ecological model is the child. My research and wider literature identify a number of risk and protective factors at the level of the child that will influence the mental health and wellbeing of children with disabilities.

3.5.1. Access to education

Education is a fundamental human right. Access to education is important for child development and long-term outcomes, including health, mental health, wellbeing and future socio-economic status [19, 129, 130]. Schools are an important setting for promoting mental health, and inversely, a setting that can present stress and negatively impact mental health. The UNICEF MHPSS framework recognises the need for safe and supportive education environments to promote child mental health [58]. However, children with disabilities have poorer access to education. In a study of 15 LMICs, disability reduced the probability of being in school by a median of 30.9% [131]. Neither individual, socioeconomic or household characteristics explained this inequity. Inaccessible school environments likely played a substantial role in inequitable access. Barriers in school environments include the physical architecture (e.g. no ramps) and inaccessible learning materials (e.g. no braille) [132-134].

This is consistent with my findings in the Gaza Strip [35]. Deaf and hard of hearing children in mainstream schools experienced inaccessible learning environments and discrimination at school. This included a lack of accessible language. Inaccessible environments negatively impacted on the quality of their education and their wellbeing. In 2019, only 14.6% of children with disabilities in the Gaza Strip attended school [42]. In my research, I did not interview deaf and hard of hearing children that were not attending school. All participants attended either a mainstream or special school. Research is needed to understand the barriers that prevent children with disabilities in the Gaza Strip, and other settings, from attending school. It will also be valuable to compare the mental health of children with disabilities attending school versus children not attending. This research is not currently possible in the Gaza Strip given the current context.

Inclusive education has been a major global effort in recent decades, particularly after *The Salamanca Statement and Framework for Action on Special Needs Education,* published in 1994 [135]. Evidence has demonstrated the positive impact of inclusive education on academic and social skill outcomes [136], however, most mainstream schools are not sufficiently inclusive of children with disabilities [137, 138], as my research demonstrates in the Gaza Strip. Thus, inclusive education is debated within disability studies. An in-depth exploration of this complex topic is beyond the scope of this thesis. The research in the Gaza Strip highlights some of the key complexities. Children with disabilities are not a homogenous group, and as evident in the Gaza Strip, children and parents will have different preferences and different experiences within available education systems [35]. Some children with disabilities thrive in a mainstream school when the environment is supportive and accessible. Others prefer a specialist school, where they are surrounded by peers of a similar experience in an accessible setting, with specialised resources and trained teachers. In the Gaza Strip, children with disabilities attending special schools appeared to have better wellbeing, because inclusion and support was superior compared to the majority of mainstream environments [35]. Calls for inclusive-education only may place some children at risk of psychological distress, if mainstream school environments are not fully accessible and inclusive. Ideally, children with disabilities and their families would have a choice. Either a fully accessible mainstream school that provides no difficulties with access, or a well-equipped specialist school.

It is important to consider the role of teacher knowledge and confidence in education for children with disabilities. Evidence shows that limited teacher training is a major barrier to implementation of inclusive education [139, 140]. Appropriate quality training is important to improve inclusive education practices, knowledge on disability and teacher attitudes [139]. In the Gaza Strip, teachers supported inclusive education. The MHPSS guidelines improved their knowledge of disability, improving disability inclusion in their classrooms. However, teachers reported concerns about their capacity to implement new measures for disability inclusion. Teachers need support and resources to support children with disabilities and encourage schools as a setting to promote wellbeing. Support for teachers is underpinned by assistance from school management [141]. Assistance from school management is underpinned by support from government, disability-inclusive education policies and appropriate funding. As with previous discussion on policy, inclusive-education and alleviating barriers to education for children with disabilities requires a collaborative, participatory approach [138].

3.5.2. Identity, self-esteem and wellbeing

Investigating social identity and self-esteem may provide further insight into the risk and protective factors that influence the mental health and wellbeing of children with disabilities. Self-esteem is vital for a child's mental health. Children with higher levels of self-esteem have higher levels of wellbeing, lower instances of mental health conditions and better social relationships [142-145]. Social identity theory can help us understand self-esteem, linking our understanding and value of self to our social identity [146, 147]. Social identity is often developed through group and cultural membership, in which supportive, stable groups nurture social identity and build self-esteem, promoting mental health and wellbeing [148]. In developing social identity, an individual may self-categorise to a group, based on their knowledge of that group, how they connect to others in the group and how they ultimately associate with the group identity [146]. Developing social identity is not a static process, and we grow and respond to different cultural contexts and variables in our lived environment. Our social identity is thus influenced by our own internal perceptions, as well as external pressures and stimuli [146]. Social identity and a sense of belonging offers protection to life's stressors and the onset of psychological distress [148]. Social identity and group membership can provide social support and a coping resource in times of difficulty. Inversely, those without a strong sense of social identity can experience isolation and loneliness, increasing the risk of poor mental health [148]. In the following paragraphs, I explore the association between self-esteem, social identity and mental health among deaf and hard of hearing children, drawing on findings from paper 2 and 3. This discussion links topics previously discussed, such as education and stigma.

Amongst deaf and hard of hearing people, a component of social identity revolves around deaf identity. In 1993, Glickman developed the *Deaf Identity Development Model* of four deaf identities and the psychological process by which these identities are acquired [149, 150]. The first, "hearing identity", applies to deaf and hard of hearing people that strongly identify with the majority hearing culture who maintain or adopt hearing norms and behaviours in their daily life, including oral communication. People with a hearing identity may consider deafness and hearing loss as an impairment only arising from medical pathology. Next, "marginal identity" refers to deaf and hard of hearing people that associate with neither hearing or Deaf cultures and norms. "Immersion" or "Deaf identity", describes those that align with and identify with Deaf culture and the wider Deaf community, including language, history and other cultural attributes. People with a Deaf identity may view hearing values as audist, in that the values of the hearing world are regarded by the majority of the world's population as more important. Hearing culture may be viewed negatively by people Deaf identity. People with a "bicultural identity" will freely associate with both hearing and

Deaf communities and values. Often people with a bicultural identity are comfortable communicating in both oral and sign language.

Evidence has shown that people with hearing, Deaf and bicultural identity have better mental health and wellbeing than those with a marginal identity [151-153]. The majority of evidence on this topic is from high-income settings. My research in the Gaza Strip allows exploration of this phenomenon in a LMIC [35]. I did not explicitly assess participants' deaf identity, but have assumed probable identity, based on their communication preferences and experiences in the community and school. Children in special school environments commonly used sign language, engaged with deaf and hard of hearing peers and received specialist support. Their caregivers were well-informed on the support available, on hearing loss, on deafness and on deaf and hard of hearing rights. These children would likely identify with a Deaf or bicultural identity. They were reported at lower risk of mental health issues. Children in mainstream environments were most likely to feel included if they used oral communication. These children had hearing friends and generally positive experiences in the community. They tended to have milder hearing loss and/or used a hearing aid or cochlear implant. They are likely to associate with a bicultural or hearing identity. They did not often report experiences of psychological distress, related to fewer challenges in daily life and feeling part of the wider community. Consistent with previous literature, interviews with participants in the Gaza Strip indicated that children most at risk of poor mental health were those experiencing language deprivation and social exclusion, especially those who were in a mainstream schooling environment with limited oral communication skills. These children likely experienced marginal identity. This would be consistent with the literature from high-income countries and requires further attention in the Gaza Strip and other LMICs. Marginal identity may represent a transitional stage in forming social identity, especially in younger children, and examining identity and wellbeing over the long-term may be beneficial.

Furthering discussion in section 3.3.1., from a social identity theory the association of stigma and discrimination with poorer health and wellbeing may represent the negative internalised opinions of people associated with stigmatised identities, from which they may subsequently develop lower self-esteem and poor psychological wellbeing. However, members of stigmatised populations, when connecting their identity to a group, can experience psychological support from others in the stigmatised group [154]. Thus, deaf and hard of hearing children who identify with the Deaf community, and importantly interact with and receive support from this community, may benefit from the psychological resources provided by group membership and protection from the negative impact of discrimination, if experienced. This is consistent with findings in the Gaza Strip, where deaf and hard of hearing children experienced stigma and discrimination [34, 35]. Those in special schools, who likely had Deaf or bicultural identity, engaged with other deaf and hard of hearing children and received support within a deaf and hard of hearing space, offering protection from stigma and discrimination, contributing to improved wellbeing. Many children with a marginal identity in mainstream schools had little interaction with other deaf and hard of hearing children and would have limited support from group membership when experiencing discrimination and bullying from hearing peers. Thus, they would be at risk of poor mental health, as reported. Strengthening the presence and visibility of disability organisations and groups within local communities to provide children with disabilities opportunity to engage with disabled peers and group membership. Strengthening disability organisations also has the potential to improve their capacity to collaborate in research, policy and programmes.

Among deaf and hard of hearing people, language and communication are associated with self-esteem, social identity and mental health [155]. However, many deaf and hard of hearing children experience language deprivation, resulting from a lack of access to oral or signed languages. This may arise, for instance, when a child is encouraged to focus on spoken language, at the expense of natural sign language, even if their hearing loss prevents access to oral communication [156]. Language deprivation can often occur when a family's language environment does not correspond to the child's natural form of communication. Language deprivation is associated with developmental delay and poorer mental health outcomes among deaf and hard of hearing populations [156]. Communication further influences a child's interaction with services, community and friends, and thus, language deprivation can lead to social isolation and poorer mental health. Communication with family is of particular importance for deaf and hard of hearing children. Deaf and hard of hearing children who cannot communicate with their family are more likely to experience a mental health condition [157]. Deaf and hard of hearing adults who use sign language are more likely to hold a Deaf identity and have better wellbeing [152, 158]. Communication and sign language are central to a positive identity and psychological wellbeing [159]. In the Gaza Strip, language deprivation resulted in isolation of deaf and hard of hearing children at school and in the community, negatively impacting wellbeing [35]. Deaf and hard of hearing assumed to have a marginal identity often had moderate or severe hearing loss, yet many families did not support them to learn sign language, despite their limited capacity for oral communication, associated with caregiver knowledge previously discussed. Other families did not have sign language services available in their local community, speaking further to the need for a multi-sectoral response to promote the mental health and wellbeing of children with disabilities. Within the context of a MHPSS system for children with disabilities, language and appreciation of a child's natural language is vital. This includes accessible communication for children with differing needs, whether that is sign language, braille or simplified language. This supports community participation (with both disabled and non-disabled peers), social identity and self-esteem. For deaf and hard of hearing children, more value needs to be placed of sign language internationally. Only 41 countries recognise sign language as an official language; 26 of these are in Europe [160]. What message does this send to children with disabilities and their families, especially in the context of identity? Without international and national recognition, policy and legislature will not promote sign language use among deaf and hard of hearing children, nor sign language provision in schools and healthcare. Again, this brings us back to disability inclusion. It is an example of continued exclusionary cultural and political practices that marginalise and alienate, contributing to poor mental health and wellbeing.

The literature on deaf identity and wellbeing is growing but is currently limited in low- and middle-income settings. Here, I present a start in understanding the association between deaf identity and wellbeing in these settings, and the broader topic of disability identity, self-esteem and wellbeing for children with disabilities. Developing identity and self-esteem is associated with all facets of the social-ecological model and should be a primary focus of MHPSS. In this, it is important to value the role that families and caregivers play in developing a child's identity. As discussed in section 3.4.2. families need training and support to help children with disabilities develop a strong sense of self in support of their mental health and wellbeing.

3.5.3. Resilience and self-management

Coping style is a major component of the social-ecological framework, including resilience and self-management. Resilience is associated with protection from mental health conditions [161, 162]. Resilience training has been found suitable and effective for children in various settings, including children with disabilities [163, 164]. Paper 1 and the wider literature indicate that resilience training may improve mental health outcomes and self-esteem among children with disabilities [33, 165]. This deserves attention in the context of MHPSS intervention. Evaluation research is needed on resilience training for children with disabilities, as the available evidence is limited by small sample sizes and limited geographic scope.

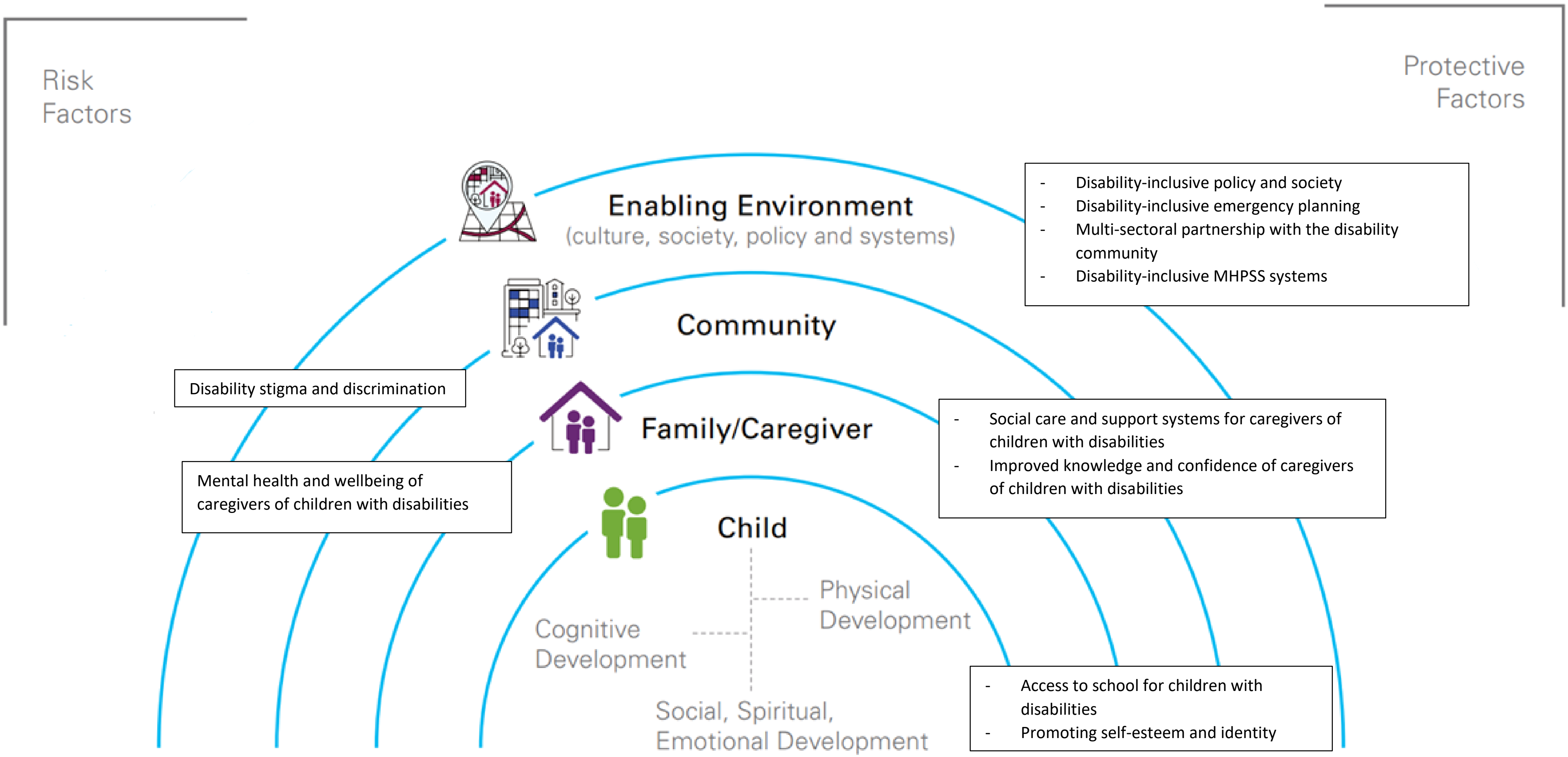
It may also be appropriate to consider self-management and self-care practices of mental health, especially for settings with limited MHPSS, whether that be in a low-resource setting or when services are removed during a crisis, as seen in the COVID-19 pandemic. Self-management and self-care techniques have been used with youth to manage emotional challenges [166, 167]. While the quality of evidence is relatively poor, self-management techniques have been used by children with disabilities to manage their disability and health [168, 169]. Future research could adapt effective self-care and self-management approaches to children with disabilities. Adapting self-management techniques for times of crisis, such as the pandemic, also merits attention.

3.6. Social-ecological framework of mental health: summary

Disability inclusion is needed to reduce discrimination, promote education, social inclusion, self-esteem and identity among children with disabilities. Factors that influence the mental health and wellbeing of children with disabilities are thus grounded in disability-inclusive systems and societies. Increased efforts are needed to implement the UNCRPD globally. As well as disability inclusion in global, national and local communities, children with disabilities need access to disability-inclusive MHPSS services and interventions. Disability-inclusive MHPSS services and interventions are not simple to implement, particularly in resource-constrained settings, and large-scale evaluation research is needed to inform policy and practice at scale.

In this thesis, I have used a social-ecological framework of mental health to examine factors that influence the mental health and wellbeing of children with disabilities, as well as suitable MHPSS strategies. The framework provides a clear, simple model with which to conceptualise MHPSS for children with disabilities. Exploration across different levels (environment, community, caregiver, child) provides salient direction and structure. The framework I used in this thesis was derived from the UNICEF *Global Multisectoral Operational Framework for Mental Health and Psychosocial Support of Children, Adolescents and Caregivers Across Settings* [58]. The UNICEF guidance includes a short section on disability and inclusion, and guidance on operationalising the framework includes reference to disability inclusion. However, reference is rare and recommendations are often generic and ill-defined. Taking lessons from this thesis and proposed future research, the UNICEF framework and guidance would be strengthened by clear, replicable actions for including children with disabilities in the actions currently suggested, including reasonable accommodations and other strategies to increase accessibility. Strengthening disability inclusion in the guidance would better mainstream disability as a priority in efforts to support the mental health and wellbeing of children worldwide. This would encourage mainstreaming of disability into actions for all children within the MHPSS social-ecological framework, including safe and hygienic housing, nutrition and protection from harm. In addition, a supplementary, standalone framework of MHPSS for children with disabilities may be suitable to provide finer information where necessary, including actions specific to children with disabilities only. A standalone framework will help strengthen direct, targeted action for children with disabilities, but it should not be used in lieu of their inclusion within mainstream activities.

My analytic commentary has explored factors that can be applied to the MHPSS framework, but I have been limited by the scope of my included research and this thesis. My research was conducted in two contexts only and focused on deaf and hard of hearing children and children with intellectual disabilities. Future work should build on this analytic commentary to explore components of the social-ecological framework of mental health and wellbeing among children with other disability types and in different contexts, whether that is in an LMIC or during a global pandemic. Figure 3 on the next page begins this process, mapping the factors discussed in the analytic commentary to the social-ecological framework. There are numerous other topics for future research to explore and add to this social-ecological framework, which I have not had scope to discuss within the context of my research and this thesis.



- Disability-inclusive policy and society
- Disability-inclusive emergency planning
- Multi-sectoral partnership with the disability community
- Disability-inclusive MHPSS systems

Disability stigma and discrimination

- Social care and support systems for caregivers of children with disabilities
- Improved knowledge and confidence of caregivers of children with disabilities

Mental health and wellbeing of caregivers of children with disabilities

- Access to school for children with disabilities
- Promoting self-esteem and identity

Figure 3. Adapted social-ecological framework of mental health and psychosocial support for children with disabilities

Although the social-ecological framework has been a useful model to structure my analytic commentary, there are considerations to take forward when aiming to adapt and operationalise the framework to MHPSS for children with disabilities. Throughout the analytic commentary, it is evident that components of the social-ecological framework interact. For example, access to education influences the mental health and wellbeing of children with disabilities, but this access is affected by policy, school resources, environmental barriers, community attitudes, caregiver knowledge and teacher training. Such interaction indicates need for holistic, multi-sectoral action. Social-ecological models are designed to understand the interacting and reinforcing nature of components at different levels of the framework [53], and although the four levels of a MHPSS framework for children with disabilities are useful to consider independently, understanding the interactions of key components will enable strategic policy decisions that make best use of resources. This said, interaction between components is not immediately obvious in the MHPSS framework presented by UNICEF (including the accompanying guidance) and the framework presented for children with disabilities in Figure 3. Guidance on a framework of MHPSS for children with disabilities will be strengthened by mapping the interactions across components, as well as the sectors and diverse actors that are involved. Such mapping will also help identify opportunities for collaboration and partnership. This will be a challenging exercise to complete for a global framework, given the different health and education systems, institutions and actors that would need to be represented. It may be sensible to provide guidance within a global framework on how to contextualise to local systems. Guidance on mapping key stakeholders, sectors and interactions across components would be useful for local leadership to develop a nationally contextualised framework. Contextually adapting the framework to the culture, resources and systems will require collaboration between government, researchers and disability stakeholders (such as OPDs). Contextualising the framework nationally will likely require additional research into mental health and wellbeing of children with disabilities in the country, given the paucity of evidence on this topic.

3.7. Recommendations for policy and research

To finalise discussion on the mental health and wellbeing of children with disabilities, I summarise below brief recommendations for global, national and local stakeholders.

3.7.1. Policy

- Disability inclusion is central to promoting the mental health and wellbeing of children with disabilities. Implementation of the UNCRPD needs to improve worldwide. Children and families cannot be forgotten.

- Governments must value and meaningfully collaborate with persons with disabilities, OPDs and civil society to promote disability inclusion.
- Mental health policy, including in the field of Global Mental Health, must contain clear, actionable recommendations to support the mental health and wellbeing of children with disabilities.
- Disaster and emergency response policies need to include strategies to support children with disabilities and their families at times of crisis.
- Language in policy is important and should respect human-rights.

3.7.2. Research

- Evaluation research is needed to promote evidence-based MHPSS for children with disabilities. Large-scale, high-quality RCTs are needed, with associated process evaluation.
- Specifically, the MHPSS guidelines developed in the Gaza Strip need longer-term evaluation. Future research could also explore adapting the guidelines to other contexts.
- There is a need for more long-term funding to promote translation of research into policy and practice.
- Continued research on the mental health and wellbeing of children with disabilities is needed in diverse contexts, including LMICs and humanitarian settings.

4. Discussion and personal reflections

In this section, I reflect on the research practices in papers 1-4 and my experience as an early career researcher. To end, I consider my positionality within the field of global disability and mental health research.

4.1. Discussion on my research

My research in this thesis was undoubtedly influenced by COVID-19. In the Gaza Strip, the process of developing the MHPSS guidelines was conducted remotely because of international travel restrictions. Regarding the qualitative research, all training and supervision were conducted via WhatsApp and Zoom. The local researcher had not previously conducted qualitative research, and the level of support I was able to provide was lower than I could have provided in-person and lower than I would have liked. This was compounded by a condensed timeline, as we looked to complete interviews in-person after local lockdown restrictions had lifted. We did not know when lockdown restrictions would be re-introduced and we thus worked to a tighter time than would be ideal. This condensed timeline limited our pilot phase, including discussion on the questions and interview techniques. The condensed timeline also limited transcription during data collection. This restricted our capacity to explore emerging codes during data collection and to iteratively reflect on and adapt the interview guides, although we held daily debriefs to mitigate this limitation. Additionally, my attending the interviews remotely rather than in-person limited my understanding of interview quality and limited advice I could provide, especially without ongoing transcription. My being present remotely during interviews may also have impacted participant comfort and response. Although I introduced myself and remained visible on screen, they may have been suspicious that others were listening in on the interview. In the UK, I conducted interviews remotely but this excluded participants for whom remote interviews were inaccessible and impacted interviewer-interviewee dynamics, potentially influencing depth of data and data quality. These challenges were not unique to my experience. Projects in health research worldwide experienced similar challenges and good practice has emerged, presenting opportunities for the future [170]. Improved video-conferencing technologies and artificial intelligence may help conduct qualitative research in diverse settings at lower cost and within shorter timeframes. I agree, but I believe that we have a way to go before online forums should replace in-person research. We need to understand how to best use these technologies without compromising relationships and data quality. Online technologies are often inaccessible for people with disabilities and may not work well in contexts with lower internet capacity and different languages. Collaboration between international and local researchers is also more difficult via remote technologies. Online qualitative research methodologies will continue improving as we gain more experience, but stakeholders, and especially funders, should not now consider in-person research support obsolete.

With regards to paper 1, there are two limitations to consider. First, there were limitations in the search strategy. I used only three databases and did not search Web of Science and LMIC databases, such as Africa-Wide Information. To overcome time-constraints, I used findings of a study of database combinations to inform a strategy that would maximise results in the least time [171]. However, excluding databases may have resulted in under-identification of relevant studies. In systematic reviews that I've conducted since, I've included a broader range of databases and will continue to do so in order to capture all possible results. Second, I consider now whether it would have been beneficial to expand the search in this scoping review to all children with disabilities. The review was undertaken specifically within a research project to develop MHPSS guidelines for deaf and hard of hearing children, and this narrower focus has its own benefits in terms of presentation and interpretation, but given the efforts expended on the literature search, expanding to children with disabilities may have been a valuable use of resources. Findings from this broader criterion could have uncovered additional elements for disability-inclusive MHPSS strategies to improve content of the MHPSS guidelines, contribute to discussion in this thesis and provide a useful addition to the wider literature. The search strategy could now be adapted to encompass other disability types and may be a useful step in developing a disability-inclusive social-ecological MHPSS framework for children with disabilities.

Considering paper 4, a major limitation in the context of this thesis is the limited participation of children with disabilities. Although caregivers were included, along with the reflections of disability organisations supporting children, the exclusion of children themselves limits our understanding. Children with disabilities are often excluded from qualitative health research [172] and we perpetuated this exclusion. Given the lockdown measures in the UK at the time of our research, we conducted remote interviews. These would have been inaccessible to some children with disabilities and there will have remained a population we could not reach. However, interviewing children with disabilities would have enabled better understanding of their personal experience. This was a strength of my work in the Gaza Strip and would have benefitted our research in the UK.

4.2. Reflexivity

In the context of this thesis, it is important to reflect on my position in the field of global disability and mental health research. I am not a person with a disability nor am I from an LMIC. Interestingly, this thesis presents findings from my home country and an LMIC in which I had no experience or prior knowledge. My experiences then are both as an ‘insider’ and an ‘outsider’. Both positions have their strengths and limitations. In the Gaza Strip, I held no prior contextual knowledge. This may have limited my analysis and interpretation. On the other hand, it may have promoted objectivity and deep-dive into contextual factors to which I had no prior knowledge. In the UK, my familiarity with the context and culture, including information on available services and systems, may have helped me gain the trust and acceptance of participants. However, there is risk of losing objectivity or methodological rigour. For example, there is risk that I ‘glossed over’ important contextual factors because of my existing knowledge. In both research projects, I would be considered an outsider because I am not a person with a disability. Even in the UK, I was an outsider in the research context as I do not have lived experience of disability. I have worked with people with disabilities and their families in the UK, but I myself have not used social care systems, applied for Personal Independence Payment or experienced barriers to healthcare. I may have been aware of the theoretical workings of systems in the UK, but I did not have an individual experience. I thus cannot fully understand experiences that I myself do not have.

This is a regular argument in qualitative research. Is the insider/outsider dichotomy useful? Many consider it overly simplistic [173]. No researcher can be fully an insider or an outsider. All researchers shift throughout the research process, depending on the situation, as we all have similarities and differences with participants, whether that is disability, race, religion, gender or sexuality. In my experience in the UK and the Gaza Strip, our diverse, collaborative teams helped us to navigate differing positionality and the relative strengths and challenges. The research teams included people from high-income/low-income settings, disabled/non-disabled researchers and diverse organisations. Analysis and interpretation were further aided by steering committees and workshops with people with lived experience and topic experts. These collaborative structures promoted reflexivity and collaborative solutions to mitigate risks. As a non-disabled researcher, collaboration with people with disabilities will always be needed. This may include collaboration with disabled researchers or collaboration with OPDs and people with lived experience to develop research aims and methods, and to interpret findings.

Working in global disability and mental health research, it is also important to continually and critically reflect on power dynamics and perpetuating inequities within research [174, 175]. This is pertinent reflection for my research in the Gaza Strip. The research was conducted within the infrastructure of an existing partnership and project between Atfaluna and CBM. Building on from a global stakeholder workshop, the need for evidence-based MHPSS guidelines were identified within the Gaza Strip and situated within a larger body of work implemented by Atfaluna and CBM. Our role at LSHTM was to conduct research and develop the guidelines in collaboration with Atfaluna. Throughout, we sought to avoid inequitable power dynamics by promoting shared learning and building research capacity. For instance, this was my first research project with deaf and hard of hearing children (or adults) and Atfaluna shared their experience working with this group, whilst I helped build the organisation's research capacity, including research methods and analysis. We aimed to develop a locally owned resource, driven by our engagement with people with lived experience, disability organisations and government. Approaches to ensure the voices of people with disabilities and families were central. Ultimately, though, LSHTM were accountable for the research funding and adhering to funder expectations. This may have created inequities. Collaboration was made more challenging by remote working during COVID-19 and time-pressures arising from the pandemic. Remote working restricted relationship building and limited opportunities for collaboration and shared learning.

It is also important to reflect on the role and influence of research funders. In the Gaza Strip, our local research partners and I asked the funder to delay the project at the start of COVID-19, in order to minimise the impact on the research and development process. The funders denied this and stated that we must continue. This highlighted issues relevant to uneven power dynamics in research. Funders are able to influence how research is conducted, potentially jeopardising quality.

This dynamic is clear within research funding calls, where topics for funding are often based on a funder's own agenda of priority themes, rather than local need. In my research, OPDs also reported that they are constrained in their activities by funder priorities. Although my research is a small example within a major topic area, it demonstrates the need for funders to be more receptive and flexible in order to address local research needs [175].

5. Conclusion

Children with disabilities are at increased risk of mental health conditions. My research and this thesis use a social-ecological framework to contribute evidence on the factors that influence and promote mental health and wellbeing. The mental health and wellbeing of children with disabilities is influenced by a variety of factors. Central to all is disability inclusion. Disability inclusion is needed across all aspects of life to improve the mental health and wellbeing of children with disabilities. Research is needed to continue investigation into the factors that influence mental health and wellbeing among children with disabilities and evaluation research is needed to inform evidence-based disability-inclusive MHPSS systems.

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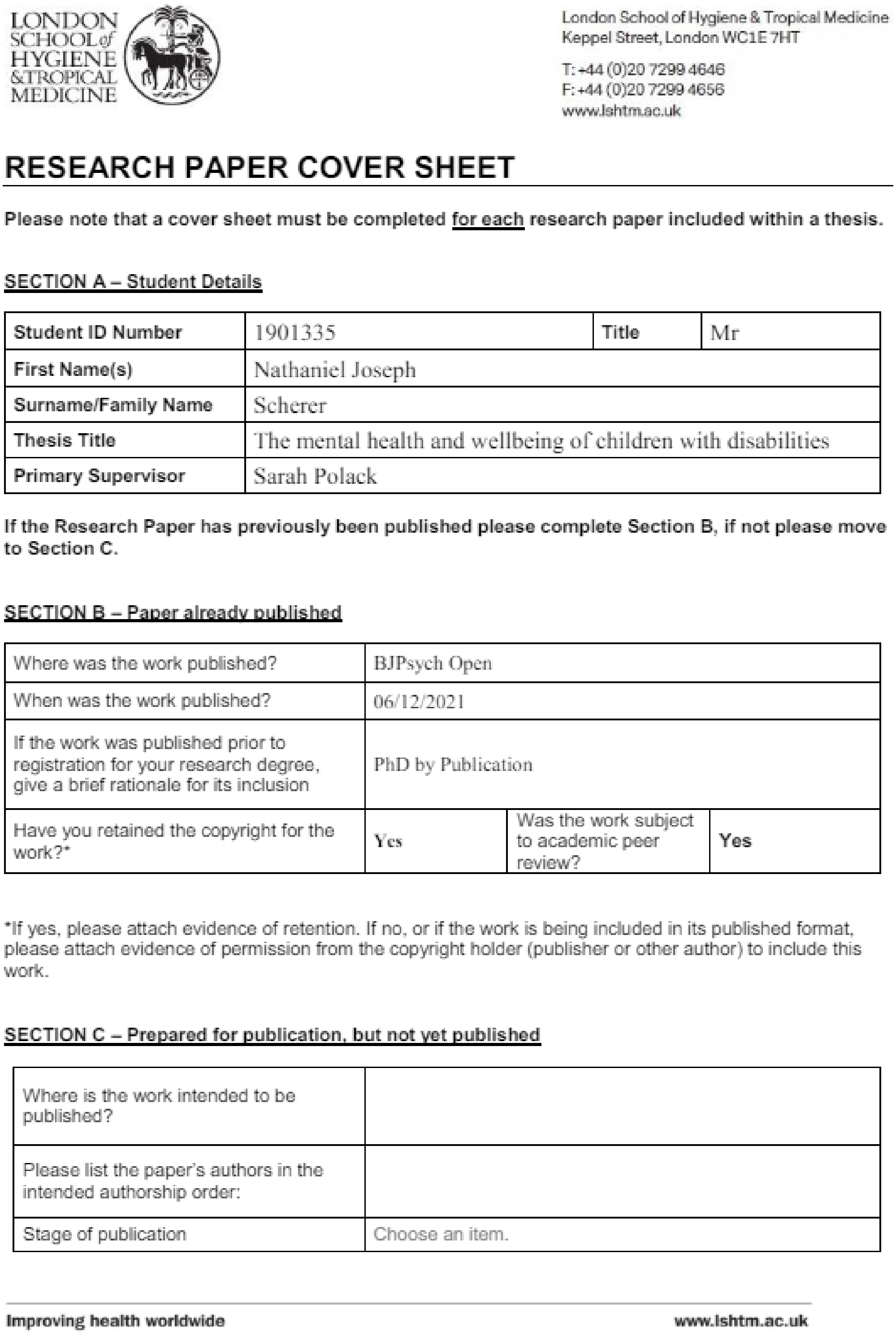
Appendices

Paper 1: Research Paper Cover Sheet and Confirmation Retention of Copyright License

Scherer N, Bright T, Musendo DJ, O'Fallon T, Kubwimana C, Eaton J, Kakuma R, Smythe T, Polack S. Mental health support for children and adolescents with hearing loss: scoping review. *BJPsych Open* (2021) 8 (1), e9 10.1192/bjo.2021.1045



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Student ID Number	1901335	**Title**	Mr
First Name(s)	Nathaniel Joseph		
Surname/Family Name	Scherer		
Thesis Title	The mental health and wellbeing of children with disabilities		
Primary Supervisor	Sarah Polack		

If the Research Paper has previously been published please complete Section B, if not please move to Section C.

SECTION B – Paper already published

Where was the work published?	BJPsych Open		
When was the work published?	06/12/2021		
If the work was published prior to registration for your research degree, give a brief rationale for its inclusion	PhD by Publication		
Have you retained the copyright for the work?*	Yes	Was the work subject to academic peer review?	Yes

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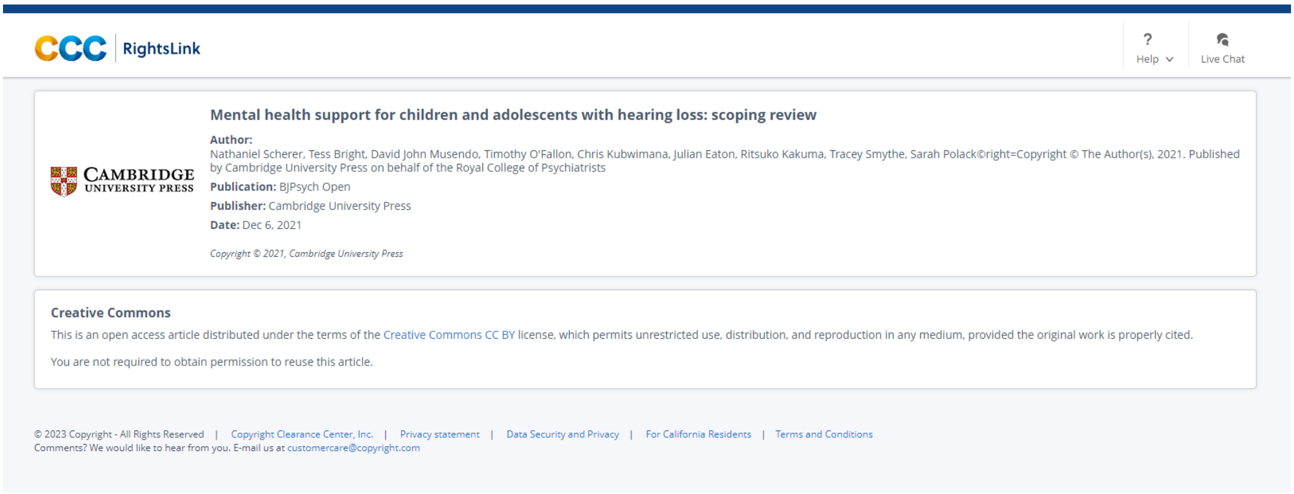
SECTION D – Multi-authored work

For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)	I managed all aspects of this scoping review. I led protocol development in collaboration with my supervisors and co-authors. I developed the search string and conducted the search across the databases. I trained the team in screening, developed the screening procedures and led discussions on the inclusion of papers. Once data was extracted by myself and the team, I led discussions on the synthesis of results and wrote the published manuscript. I finalised the manuscript for submission based on co-author comments and submitted to the journal. I took the lead responding to peer-review comments.

SECTION E

Student Signature	Nathaniel Scherer
Date	22/04/2024

Supervisor Signature	Sarah Polack
Date	22/04/2024



Mental health support for children and adolescents with hearing loss: scoping review

Author:
Nathaniel Scherer, Tess Bright, David John Musendo, Timothy O'Fallon, Chris Kubwimana, Julian Eaton, Ritsuko Kakuma, Tracey Smythe, Sarah Polack©right=Copyright © The Author(s), 2021. Published by Cambridge University Press on behalf of the Royal College of Psychiatrists
Publication: BJPsych Open
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Type	Review
Information	BJPsych Open, Volume 8, Issue 1, January 2022, e9 DOI: https://doi.org/10.1192/bjo.2021.1045
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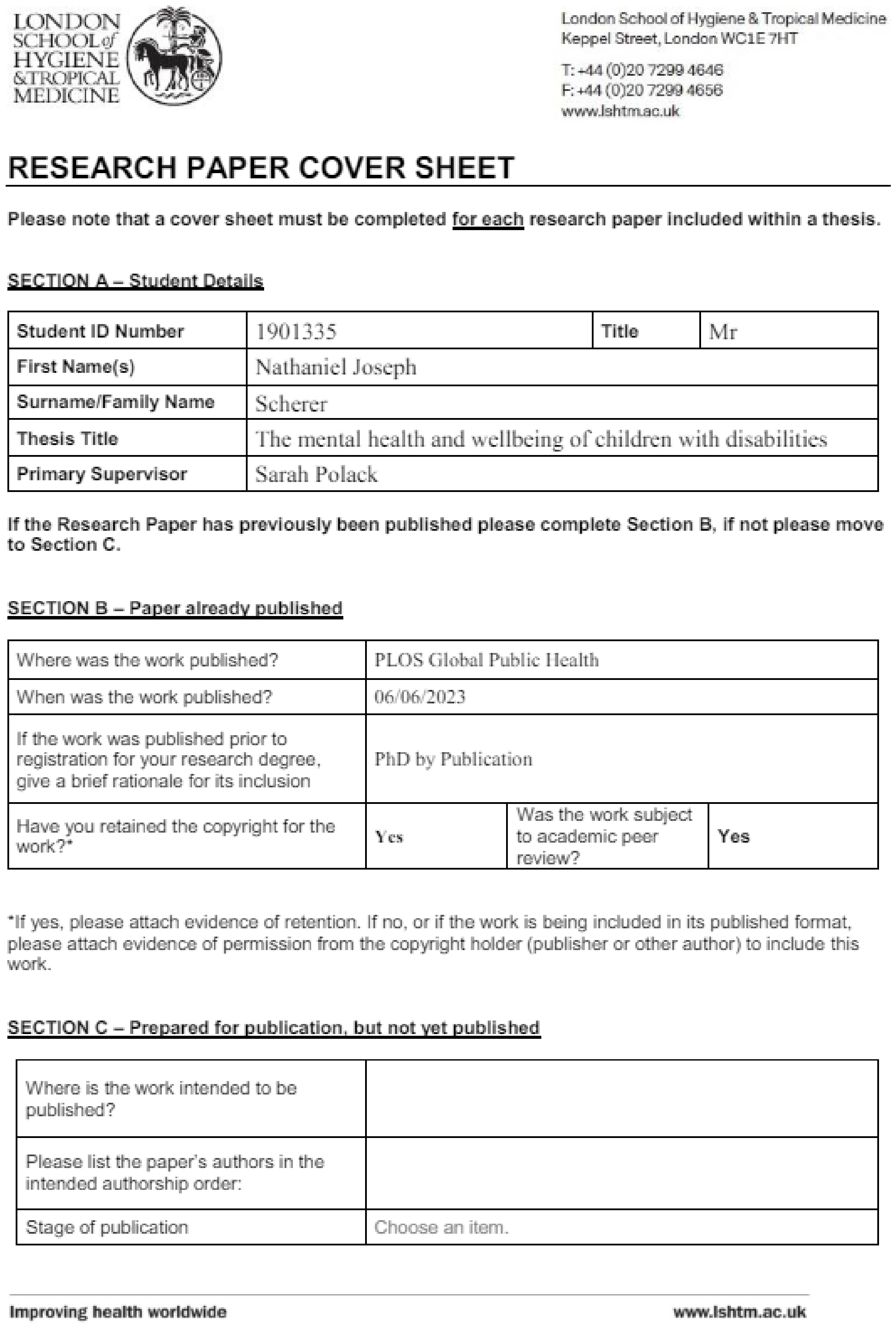
Paper 2: Research Paper Cover Sheet and Confirmation Retention of Copyright License

Scherer N, Smythe T, Hussein R, Wapling L, Hameed S, Eaton J, Kabaja N, Kakuma R, Polack S. Communication, inclusion and psychological wellbeing among deaf and hard of hearing children: A qualitative study in the Gaza Strip. *PLOS Global Public Health* (2023) 3 (6), e0001635 10.1371/journal.pgph.0001635



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Surname/Family Name	Scherer		
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Primary Supervisor	Sarah Polack		

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SECTION D – Multi-authored work

For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)	I managed this qualitative research project, developing the study design, methods, sampling strategy and data collection tools, in collaboration with a multidisciplinary team. With COVID-19, I was unable to travel to the Gaza Strip for data collection. I instead trained and managed the local research remotely. I trained a local researcher and supervised recruitment and data collection. I led analysis of the transcripts. I drafted the manuscript and finalised for submission based on co-author comments. I took the lead responding to peer-review comments. This published work was one component of a research project, to which I was the project lead and managed all aspects.

SECTION E

Student Signature	Nathaniel Scherer
Date	22/04/2024

Supervisor Signature	Sarah Polack
Date	22/04/2024

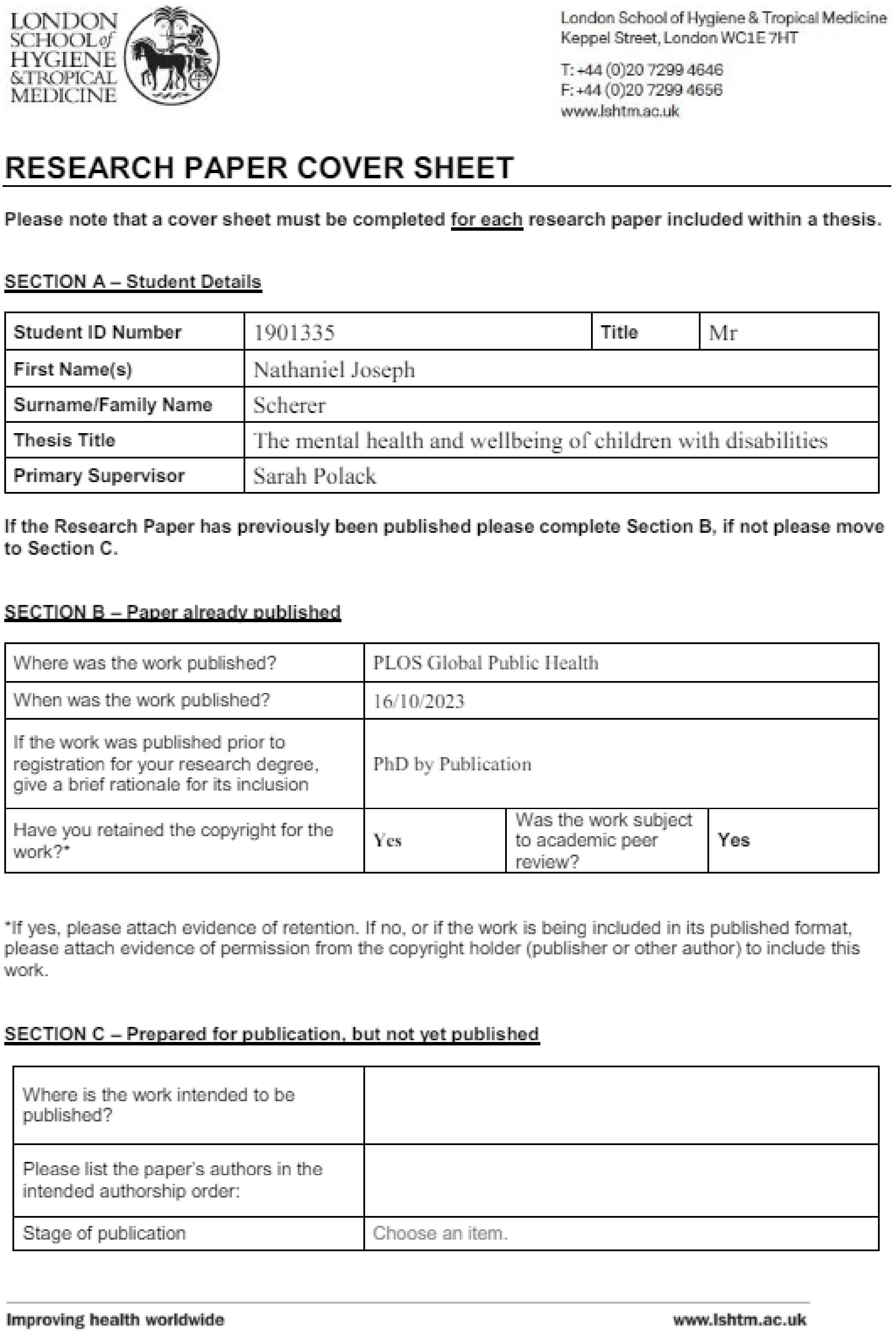
Citation: Scherer N, Smythe T, Hussein R, Wapling L, Hameed S, Eaton J, et al. (2023) Communication, inclusion and psychological wellbeing among deaf and hard of hearing children: A qualitative study in the Gaza Strip. PLOS Glob Public Health 3(6): e0001635. https://doi.org/10.1371/journal.pgph.0001635

Editor: Julia Robinson, PLOS: Public Library of Science, UNITED STATES

Received: December 5, 2022; **Accepted:** April 19, 2023; **Published:** June 6, 2023

Paper 3: Research Paper Cover Sheet and Confirmation Retention of Copyright License

Scherer N, Hussein R, Eaton J, Kabaja N, Kakuma R, Smythe T, Polack S. Development of mental health and psychosocial support (MHPSS) guidelines for deaf and hard of hearing children in the Gaza Strip. *PLOS Global Public Health* (2023) 3 (10), e0002427 10.1371/journal.pgph.0002427



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Thesis Title	The mental health and wellbeing of children with disabilities		
Primary Supervisor	Sarah Polack		

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SECTION B – Paper already published

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When was the work published?	16/10/2023		
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SECTION D – Multi-authored work

For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)	This published work describes the development process of the MHPSS guidelines, of which I managed all aspects under the guidance of my supervisors, including study design, research methodologies, data collection and managing partnership with the local researcher, implementation partner, local steering committee, and funder. This included scoping review, qualitative research and pilot. I wrote the manuscript, with feedback and support from co-authors.

SECTION E

Student Signature	Nathaniel Scherer
Date	22/04/2024

Supervisor Signature	Sarah Polack
Date	22/04/2024

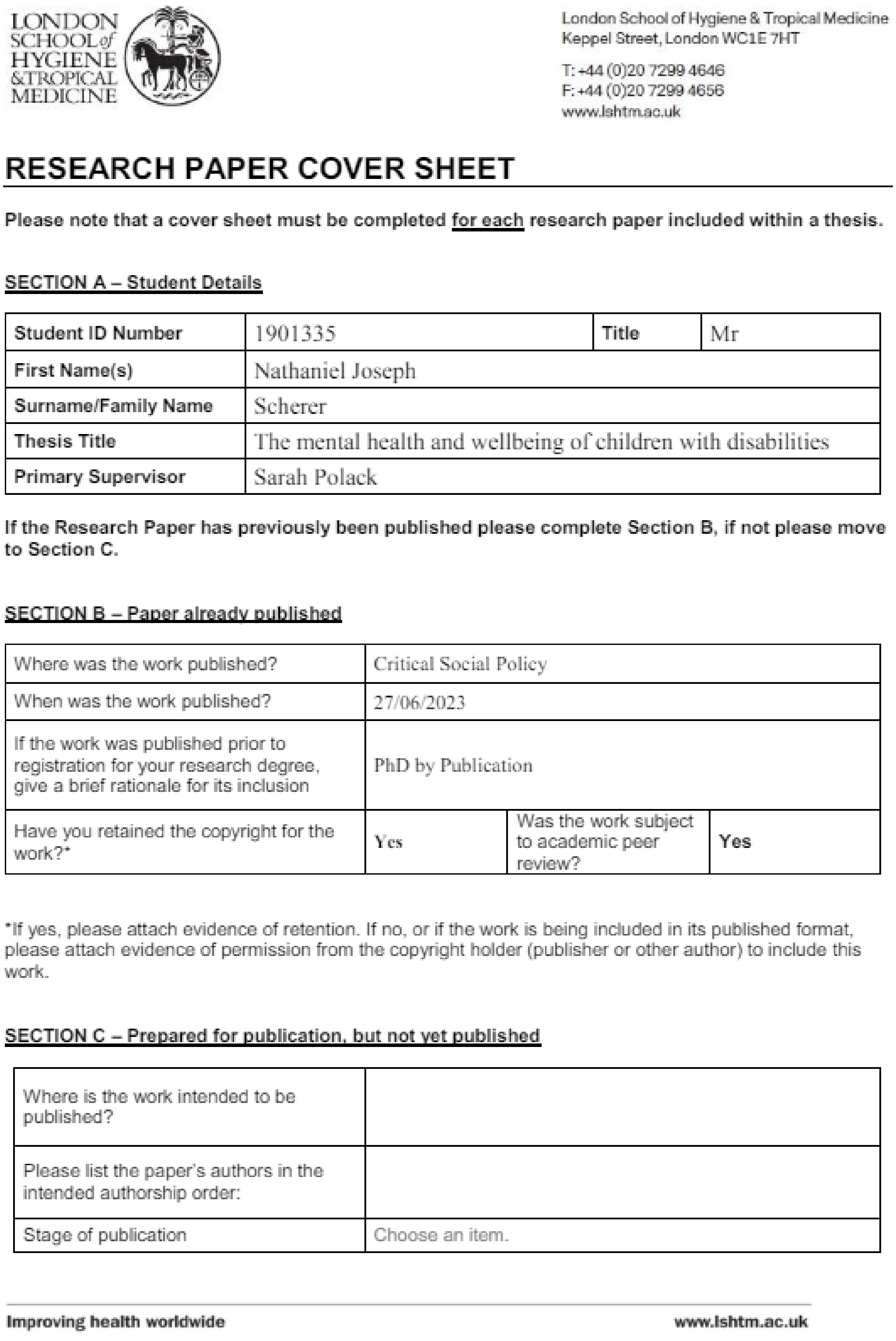
Citation: Scherer N, Hussein R, Eaton J, Kabaja N, Kakuma R, Smythe T, et al. (2023) Development of mental health and psychosocial support (MHPSS) guidelines for deaf and hard of hearing children in the Gaza Strip. PLOS Glob Public Health 3(10): e0002427. https://doi.org/10.1371/journal.pgph.0002427

Editor: Mohamed Salama, The American University in Cairo, EGYPT

Received: May 5, 2023; **Accepted:** September 2, 2023; **Published:** October 16, 2023

Paper 4: Research Paper Cover Sheet and Confirmation Retention of Copyright License

Scherer N, Wiseman P, Watson N, Brunner R, Cullingworth J, Hameed S, Pearson C, Shakespeare T. 'Do they ever think about people like us?': The experiences of people with learning disabilities in England and Scotland during the COVID-19 pandemic. *Critical Social Policy* (2022) 43 (3), 423-447, 10.1177/02610183221109147



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Thesis Title	The mental health and wellbeing of children with disabilities		
Primary Supervisor	Sarah Polack		

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SECTION B – Paper already published

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When was the work published?	27/06/2023		
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SECTION D – Multi-authored work

For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)	For this study, I worked with a team from LSHTM and the University of Glasgow to develop the research methods and data collection tools. I conducted a subset of the interviews myself, collaborating with other team members to collect others. I analysed the data included in this article, discussing my interpretation and theoretical reflections with two researchers from the University of Glasgow (the second and third authors). I wrote the manuscript and led various dissemination activities, including workshops, webinars and conference presentations.

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Student Signature	Nathaniel Scherer
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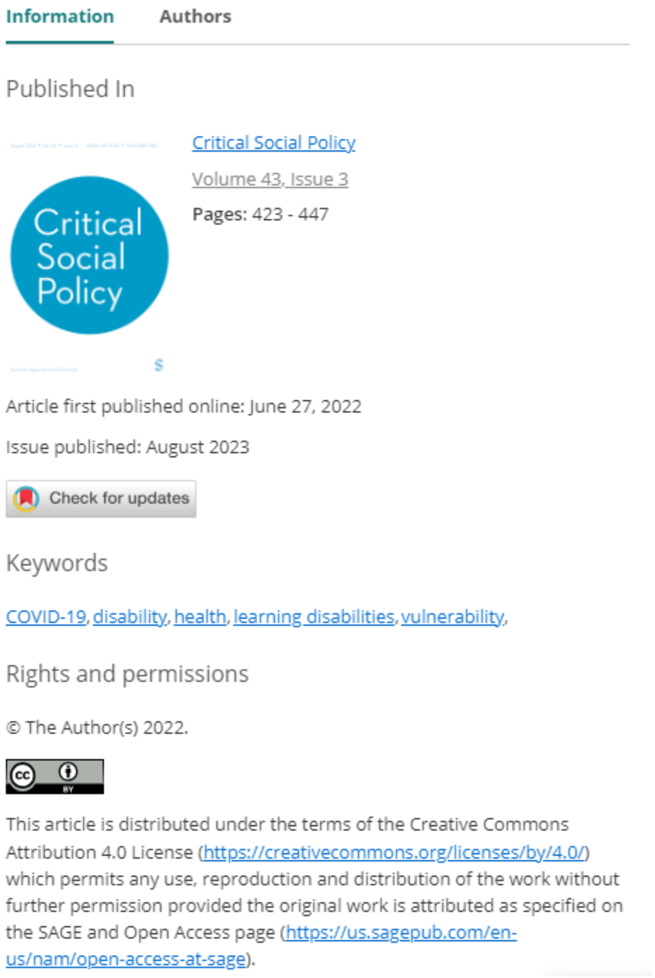

Published In

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Keywords

COVID-19, disability, health, learning disabilities, vulnerability,