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# Social and Behavioural Change Interventions to Strengthen Disability-Inclusive Programming

A synthesis of the evidence

## **About this report**

This report was produced by Oxford Policy Management and other stakeholders at the request of UNICEF.

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Cover photo: A girl with disability and her personal assistant attending classes at inclusive primary school Despot Stefan Lazarevic in Belgrade, Serbia. © Nemanja Pancic

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## Executive summary

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UNICEF engaged Oxford Policy Management (OPM), together with Leonard Cheshire and Partnership for Every Child (P4EC) Consultancy group, to undertake a literature review to identify evidence showing how communication for social and behavioural change (C4SBC) interventions and approaches can address stigma and discrimination, across a range of settings and sectors, with potential to offer learning to help strengthen disability-inclusive programming in the Europe and Central Asia (ECA) region. This involved recognizing the ableist attitudes, values and beliefs that encourage all forms of disability-based discrimination. The findings of this review are intended to inform the development of a future toolkit to support programming.

OPM researchers undertook a search of academic and grey literature in several languages, including English, French, Russian, Spanish, and other languages of the ECA region. The search terms focused on communications addressing stigma and supporting inclusion of children with disabilities and other stigmatized groups. Inclusion criteria included strength of evidence, relevance to children with disabilities, and communications for social and behaviour change at all levels, including the intrapersonal and interpersonal levels, within communities and institutions, and across wider society.

Most studies identified in this review focus on the intrapersonal or interpersonal levels, likely because changes in these areas are easier to measure. Studies offering at least some evidence of effective communications for social and behaviour change at other levels have also been identified and included. Evidence relating specifically to interventions with children with disabilities is generally lacking or weak, but some evidence relating to specific groups of persons with disabilities – notably young people and adults with mental health conditions – provides lessons and materials that could prove useful for addressing stigma. This report provides an overview of this evidence and is structured according to different socio-ecological levels.

### Key findings

- Achieving systemic social and behaviour change requires time, investment and integrated communications, programme and advocacy interventions.
- Understanding the beliefs and attitudes, characteristics, contexts and challenges of target populations is key to proper targeting and planning of complex programmes responding to drivers of exclusion and stigma. However, the formative research needed to establish this understanding is rarely discussed in the literature.
- Multi-level, integrated communications interventions over the longer term are needed in order to sustain social and behavioural change outcomes.
- Combining national campaigns with community-based group activities can achieve better results than stand-alone interventions.

- Working with journalists and other professional communicators is likely to be a key entry-point to sustaining the outcomes of communications interventions, but has not been tested over the long term.
- Parents, family members and peers of children with disabilities are important targets for tackling stigma.
- Programmes that bring children and young people with and without disabilities together to work towards a common goal show some evidence of achieving changes in attitudes and behaviours.
- Programmes that empower children with disabilities, their parents and their families to share their experiences can have an impact on policy and services. Evidence supports the use of techniques including oral testimonies, storytelling approaches and participatory photography.
- Achieving inclusion in schools requires systemic change at all levels, which entails a focus on children with disabilities themselves, their parents and families, teachers, peers, and the regulatory, policy and legislative architecture that enables education provision.
- Interventions to address stigma in the health sector are less well evidenced than interventions to achieve inclusive education.

Ultimately, more systematic, longer-term and better-quality research is required to determine the most effective and sustainable means of addressing stigma against children with disabilities and achieving social and behaviour change – as measured not only at the end of a particular programme, but over the long term.

## List of abbreviations

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ADHD	Attention deficit hyperactivity disorder
AIDS	Acquired immune deficiency syndrome
ASD	Autism spectrum disorder
C4D	Communication for Development
C4SBC	Communication for social and behavioural change
CRPD	Convention on the Rights of Persons with Disabilities
CWD	Children with disabilities
ECA	Europe and Central Asia
HIV	Human immunodeficiency viruses
IE	Inclusive education
NGO	Non-governmental organization
OPM	Oxford Policy Management
PLWD	People living with disabilities
PWD	People with disabilities
RCT	Randomized controlled trial
WHO	World Health Organization





UNICEF-supported inclusive fashion show in Sarajevo (Bosnia and Herzegovina). The main objective of this fashion show was to raise awareness of social protection and inclusion, sensitizing the society and creating a more inclusive environment.

## 1. Overview, purpose and objectives

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This report presents the results of a literature review to identify and document evidence of promising practices in social and behavioural change interventions and approaches to promote the inclusion and empowerment of children and adolescents with disabilities, including their access to and use of services. These promising practices include principles, strategies and methods to address attitudinal, informational, environmental and institutional barriers.

Children with disabilities in the Europe and Central Asia (ECA) region are the key focus of this review, but the research also explored evidence from across the world, as well as promising practices from interventions targeted at other groups experiencing stigma and social exclusion, such as people living with HIV, Roma and other ethnic minorities, and migrants.

The review was commissioned to inform the development of a global package or toolkit to strengthen disability-inclusive programming, address stigma and promote inclusion through communication for social and behavioural change (C4SBC) strategies, practices and policies, and to share experiences and recommendations globally.

This was a desk review primarily of global and regional academic and grey literature. It also considered case studies of known promising practices from the ECA region and elsewhere, as identified by UNICEF Headquarters (HQ) and ECA Regional Office. Additionally, UNICEF HQ and the ECA Regional Office

requested information from UNICEF country offices, so that a wide range of experiences and promising practices could be mapped as part of the grey literature review.

A framework was developed to organize key information from the studies reviewed. This framework serves as a tool to help determine the relevance and transferability of interventions, and offers a mechanism for UNICEF to continue to build the evidence base and search for relevant information.

This synthesis report documents and discusses the research evidence and promising practices identified during the literature review, and provides an analysis of the characteristics of effective interventions. It is accompanied by an Excel data table, organized according to the framework.

## 1.1 Communication for Development

The UNICEF Communication for Development Programme Guidance (2019) describes the term ‘Communication for Development’ (C4D) – also referred to as communication for social and behavioural change (C4SBC) – as “an evidence-based and participatory process that facilitates the engagement of children, families, communities, the public and decision makers for positive social and behavioural change in both development and humanitarian contexts through a mix of available communication platforms and tools.”

UNICEF recognizes that communication goes beyond simply providing information.

**C4D involves understanding people, their beliefs and values, the social and cultural norms that shape their lives. It involves engaging communities and listening to adults and children as they identify problems, propose solutions and act upon them. Communication for development is seen as a two-way process for sharing ideas and knowledge using a range of communication tools and approaches that empower individuals and communities to take actions to improve their lives.<sup>1</sup>**

Recognizing that communication processes reflect power relations, C4D aims to address this by taking a holistic approach and enabling people’s capacities to understand, negotiate and take part in decision-making that affects their lives.

Given the centrality of participatory processes in C4D and C4SBC, this review focuses on promising practices that facilitate engagement of children with disabilities and special needs, their families and their communities. However, it also considers evidence that touches on non-participatory or minimally

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1 UNICEF. Communication for Development (C4D). <https://www.unicef.org/cbsc/>

participatory interventions, such as mass media campaigns, that attempt to reduce stigmatizing attitudes within mainstream society.

## 1.2 Stigma and discrimination against children with disabilities

Children with disabilities face stigma and discrimination based on deeply rooted societal negative perceptions about disability. These attitudes and beliefs reflect what is known as 'ableism', a value system that discriminates against people with physical, sensory, intellectual and psychosocial disabilities based on the idea that certain standards of appearance, functioning and behaviour are essential for living a life of value.<sup>2</sup> Due to ableist assumptions, children with disabilities are considered to be in need of 'fixing', otherwise they will live a life of suffering and disadvantage. Furthermore, they are seen less able to contribute and participate, less worthy of attention and to have less inherent value than others.<sup>3</sup>

Similar to racism, sexism or ageism, ableism leads to social prejudice, discrimination against and oppression of children and adults with disabilities, as ableist ways of thinking inform legislation, policies and practices. Ableism lies at the root of discriminatory and harmful practices against children with disabilities, such as forced sterilization, institutionalization, school segregation, among others. As some authors have noted, ableism results in a compulsory 'able-bodiedness', which pressures children and adolescents with disabilities to do whatever it takes to embrace a non-disabled identity.<sup>4</sup>

The Convention on the Rights of Persons with Disabilities recognizes the multidimensional nature of disability-based discrimination. First, it states that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society.<sup>5</sup> Second, it addresses all forms of discrimination, such as direct or indirect discrimination, discrimination by association, denial of reasonable accommodation, structural and systemic discrimination, and multiple and intersecting forms of discrimination. Third, it dedicates an article to awareness-raising (article 8), acknowledging that stigma and other attitudinal barriers play a central role in the exclusion of persons with disabilities. Changing attitudes towards children with disabilities is, thus, a core international obligation.

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2 United Nations, Human Rights Council, Report of the Special Rapporteur on the rights of persons with disabilities, A/HRC/43/41, 17 December 2019, paras. 9–10.

3 Office of the United Nations High Commissioner for Human Rights, Awareness-raising under article 8 of the Convention on the Rights of Persons with Disabilities, 17 December 2019, A/HRC/43/27, para. 15.

4 Kattari, S. K., Olzman, M., & Hanna, M. D. (2018). "You Look Fine!": Ableist Experiences by People With Invisible Disabilities. *Affilia*, 33(4), 477–492. <https://doi.org/10.1177/0886109918778073>.

5 Convention on the Rights of Persons with Disabilities, Preamble (e).

## 1.3 Research questions

UNICEF grapples with many issues in its efforts to understand how best to integrate C4D and social and behaviour change interventions within disability-inclusive programming in order to reduce stigma (including self-stigma) experienced by children with disabilities. Key questions considered in commissioning this study and reviewing its findings are as follows.

1. What social and behaviour change interventions have been documented to address negative attitudes, beliefs, norms, stigma and discrimination – including among service providers – against children with disabilities and other excluded groups, such as people living with HIV, ethnic minorities including Roma, or migrants?
2. What approaches and interventions have been successful in producing a sustainable change in attitudes, beliefs and norms, and supporting social inclusion and access to services? What approaches have been unsuccessful or less successful? What elements positively or negatively influenced success and sustainability?
3. What research evidence is available for multi-level C4D and social and behaviour change interventions – that is, interventions that operate at different socio-ecological levels, such as the individual, community, institutional and societal levels?
4. What evidence is there of interventions that aim to reduce internalized stigma (self-stigma), and which strengthen self-efficacy, self-esteem or self-concept?
5. What evidence is there of interventions that empower children with disabilities and their families? Is there evidence of interventions in which children are advocates or campaigners, able to take action, express their rights and participate in decision-making, at school or at the community level?
6. Is there evidence of approaches that, while they do not directly seek to empower children and adolescents with disabilities, may indirectly have an empowering effect on children and adolescents with disabilities and their families?
7. What evidence is there of interventions at the community level? (For instance, within impairment-specific communities; with peers, such as among friends, or with children without disabilities; among parents and caregivers; in recreation; in neighbourhoods; or relating to transport?) Are there interventions that enable role models, support dialogue between members of the majority and excluded communities (for example, parents of children with and without disabilities), or support community events that bring everyone together, for instance to evaluate and enhance existing community spaces?
8. What evidence is there of interventions that are effective in addressing stigmatizing attitudes and behaviours among professionals and service providers at service delivery platforms (not only schools)? Is there evidence

of initiatives that seek to build the capacity of professionals or service providers to address stigma? Or initiatives that address systemic barriers at the institutional level?

9. With regard to school inclusion, is there evidence of efforts to achieve genuine participation in school – inclusion, rather than simple attendance?
10. Is there evidence of initiatives to change health professionals' attitudes towards children with disabilities, along with their self-efficacy as professionals and their capacity to engage and be supportive?
11. Is there evidence of interventions that address the public? Of interventions using traditional or social media?
12. Finally, there are three overarching questions: Is there evidence for the sustainability of results achieved through interventions? Is there evidence of interventions that are holistic? And is there evidence for initiatives being taken to scale?

This report is structured broadly according to these questions. First, it looks at the pattern of research on stigma and exclusion, and the extent to which interventions are multi-level. It then focuses on interventions that address self-stigma and exclusion at interpersonal level, and which enable children with disabilities to have a voice on the issues that affect them. Next, it looks at interpersonal and community interventions, and then moves to examine evidence at the institutional level, and school inclusion in particular. It then returns to multi-level interventions, with components that address barriers at the national, policy or societal level, or which involve media.

Finally, working from the premise that holistic interventions must be based on a strong understanding of underlying beliefs and social, cultural and interpersonal dynamics, the report notes evidence from studies of stigma that can inform research questions to address in formative research for holistic interventions addressing stigma.





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Syaiful (left), 12, a child with a physical impairment, sits next to his best friend Kevin Saputra (right), 9, a child with a visual impairment, at Syaiful's house in Banyumas, Central Java, Indonesia. They both attend Madrasah Ibtidaiyah (MI) 1 Ciberem in Central Java, which is part of the inclusive education programme.

## 2. Search methodology

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Three researchers searched through peer-reviewed academic literature, regional academic research, and grey literature in English, French, Italian, Macedonian, Russian, Serbo-Croat, Slovenian and Spanish. The methodology and search strategies employed in the literature review are set out in Annex A.

The original intention was to undertake a systematic literature review focusing on recent reviews, complemented by individual studies where there were gaps in the evidence. However, adopting a strict systematic review methodology would have required that researchers work together to determine the studies for inclusion, critically appraise and extract the evidence, and, where possible, pool the results. It was not possible to undertake such a review due to time and resource constraints, but a systematic approach was taken as far as possible.

The initial scoping study revealed that there has been very little work documented in the literature – whether at small group, school, community or national level – that intentionally involved participatory communication of any kind to counter stigma towards children and adolescents with disabilities or increase their access to services, and that also measured outcomes (i.e., to what extent the project or intervention was successful). The review found useful research (including action research) on a range of interventions, including participatory processes involving people with disabilities; communications campaigns to counter social stigma, primarily around mental health; community activities such as sports and games; activities to promote inclusion of

children with disabilities in classroom settings; and multi-level, health care-led approaches to counter stigma towards people with epilepsy.

It was necessary to modify the search strategy in order to report on different approaches to different challenges, while continuing to be as systematic as possible. A sequence of scoping searches was undertaken, in order to identify a comprehensive range of studies that address the different questions of interest to UNICEF. These are described in detail in Annex A.

What emerges from the literature is a 'menu' of different approaches and recommendations highlighting successful practices underpinned by at least some evidence. When complemented by case studies, this 'menu' provides insight into the way forward.

## Measurement of effectiveness

Studies identified through the literature review were assessed for (a) relevance to the questions of interest to UNICEF; (b) quality of evidence, according to a hierarchy of evidence – from anecdotal or descriptive case studies, to randomized controlled trials (RCTs), to systematic reviews of RCTs; and (c) type or level of intervention, from individual or interpersonal to multi-level.

Relevant studies with evidence of higher quality and addressing a range of levels were selected for review and included in the data table. (See Annex A for a full description of the inclusion criteria and hierarchy of evidence.) Studies that used well-designed qualitative methods, pre-post measurements and/or stronger levels of evidence were included, while case studies were only included when they had clearly defined indicators and reported that pre-post data had been collected thus permitting at least some measurement of effectiveness. According to these criteria, a large number of interesting descriptive case studies supported by non-governmental organizations (NGOs) and UNICEF were excluded from this review and the data table, but may be viewed on the Communication Initiative Network website <https://www.comminit.com/global/category/sites/global>.

Included studies use a mix of approaches to measuring change and reporting on impact. The most rigorous individual quantitative studies and reviews use standardized tools to measure social distance (acceptance of others outside their own group), such as the Attitudes towards People with Disabilities Scale<sup>6</sup> or the Chedoke-McMaster Attitudes Towards Children with Handicaps (CATCH).<sup>7</sup>

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6 Chadd, E. H., & Pangilinan, P. H. (2011). Disability attitudes in health care: A new scale instrument. *American Journal of Physical Medicine & Rehabilitation*, 90(1), 47–54.

7 Rosenbaum, P. L., Armstrong, R. W., & King, S. M. (1986). Children's attitudes toward disabled peers: A self-report measure. *Journal of Pediatric Psychology*, 11(4), 517–530.

An adapted version of the Social Distance Scale was the instrument most frequently used to measure change in attitudes and behaviours towards people living with mental health conditions.<sup>8</sup> Studies on other stigmatized conditions used scales such as the Barriers to Access to Care (BACE) scale,<sup>9</sup> the Treatment Stigma Subscale (BACE-TS) or the Berger HIV Stigma Scale.<sup>10</sup> Other quantitative studies used pre-post measures or surveys developed for a specific evaluation, or combined findings from surveys and focus group discussions.

Qualitative studies included in the review provide rich descriptive detail on factors that enable or hinder participation from the perspective of people who are excluded, their families, and sometimes professionals. They do not 'measure' specific outcomes, but report on the process by which inclusion was achieved or hindered. Findings are based on interviews, focus group discussions or observational studies.

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- 8 Link, B., et al. (2004). Measuring mental illness stigma. *Schizophrenia Bulletin*, 30, 511–41. <https://doi.org/10.1093/oxfordjournals.schbul.a007098>
  - 9 Clement, S., et al. (2012). Development and psychometric properties of the Barriers to Access to Care Evaluation scale (BACE) related to people with mental ill health. *BMC Psychiatry*, 12, art. 36.
  - 10 Berger, B. E., Ferrans, C. E., & Lashley, F. R. (2001). Measuring stigma in people with HIV: Psychometric assessment of the HIV stigma scale. *Res Nurs Health*, 24(6), 518–529.





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A joyful girl plays in a park in Bosnia and Herzegovina. Through the 'It's About Ability' campaign, UNICEF promoted the need for improving access to social protection, inclusive services and education for children with disabilities, sensitizing society and creating a more inclusive environment.

## 3. Findings

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This section presents an overview of the most relevant and useful studies addressing the research questions.

### 3.1 Studies focusing on Roma children and HIV-affected children and adults

This literature review was undertaken with the understanding that evidence on interventions addressing stigma experienced by children and adolescents with disabilities is scarce. The research therefore also covered interventions that address stigma reduction and access to services among other stigmatized groups, such as Roma, HIV-affected children and adults, and migrants, which might be relevant or applicable to C4D initiatives that address the stigma experienced by children and adolescents with disabilities.

A recent systematic review covers studies of interventions to prevent exclusion of Roma children from schools. No data emerged on interventions to address stigma experienced by migrant children. Evidence was found on the effects of mass media and communication interventions on attitudes and knowledge of HIV, along with a study of an intervention to equip recently diagnosed adolescents with the skills to tackle stigma and build self-efficacy with regard to disclosure of their HIV status. Findings on interventions to address gender norms, including through media and at the community level, may also be worth considering when designing interventions for children and adolescents with disabilities.

## 3.2 Studies focusing on children and adults with mental health conditions

The field of mental health offers the most extensive body of evidence on communications interventions to reduce stigma faced by children and adolescents and to increase their access to services. The significant body of research on mental health-related anti-stigma interventions may be the result of a significant push by the World Health Organization (WHO) between 2002 and 2012 to support such initiatives, once it was recognized that the burden of stigma associated to mental health conditions may prevent individuals from seeking help.

In line with the understanding that disability emerges from the barriers that persons with impairments face which restrict their participation in society, persons with psychosocial disabilities (i.e., persons with diagnoses of, or perceived to have, mental health conditions) are considered to be a part of the wider group of persons with disabilities. The Convention on the Rights of Persons with Disabilities (CRPD) protects the rights of persons with psychosocial disabilities as recognized by the Committee on the Rights of Persons with Disabilities, the Special Rapporteur on the rights of persons with disabilities, the Office of the United Nations High Commissioner for Human Rights (OHCHR), WHO and other United Nations experts and entities.

This recognition extends to the national level. In the United Kingdom of Great Britain and Northern Ireland, for example, the Equality Act (2010) states that a person has a disability if they “have a physical or mental impairment that has a substantial, adverse, and long-term effect on their ability to carry out normal day-to-day activities.” As such, persons with a mental health condition which has lasted for at least 12 months, or is likely to last for 12 months or more, and substantially impacts day-to-day life in a negative way, are protected by disability discrimination measures under the Act.<sup>11</sup>

Stigma against people with mental health conditions also reflects ableism – devaluing people who do not fit into desired norms of appearance, behaviour and functioning. As such, research on interventions to address stigma in mental health address the same root of stigma directed against children and young people with disabilities.

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11 Mind. *Disability discrimination*. <https://www.mind.org.uk/information-support/legal-rights/disability-discrimination/disability/>.

**Key finding:** There is very little strong evidence in the global literature on the effectiveness of C4SBC interventions in tackling stigma experienced by children and adolescents with disabilities. There is some potentially relevant evidence pertaining to stigma experienced by ethnic minority groups and people living with HIV, and on gender norms change. Studies of interventions to reduce mental health stigma, which address shared ableist roots, can contribute to taking forward work to address stigma and exclusion faced by children and young people with disabilities.

### 3.3 Socio-ecological levels

As stigma and exclusion manifest at all socio-ecological levels, they need to be tackled at all levels. As Rao et al. (2019) note in a systematic review of multi-level interventions targeting stigma, “Stigma is a global, multi-level phenomenon requiring intervention approaches that target multiple socio-ecological levels if they are to achieve more than modest impact.”<sup>12</sup>

Rao et al. seek to understand the extent and patterns of anti-stigma research, and the extent to which interventions are multi-level. In spite of the recognition that stigma reduction works at multiple levels, almost all the interventions and approaches included in their review operated at the interpersonal to community levels only. Half of the articles examined community-level interventions alongside the interpersonal and/or intrapersonal levels. Only one article examined the institutional level (along with the intrapersonal level), and none targeted the structural level.

Studies of multi-level interventions most often targeted the intrapersonal and interpersonal levels. This may be due to several factors, including that outcomes at these levels are easier to measure. Rao et al. summarize the potential reasons as follows.

**The broader stigma literature has focused almost exclusively on these two levels of analysis, thus, multi-level interventions have a larger evidence base from which to draw at these levels.**

Relatedly, research has accumulated a wealth of stigma measures at the individual/interpersonal levels of analysis. In contrast, until recently, fewer measures of stigma existed at community, organizational, and structural levels, which likely hindered the assessment of multi-level stigma interventions that incorporated communities and social structures. This focus on the individual/interpersonal levels in multi-level stigma interventions may also be due to

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<sup>12</sup> Rao, D., et al. (2019). A systematic review of multi-level stigma interventions: State of the science and future directions. *BMC Medicine*, 17(1), art. 41.

convenience – intervention studies are often easier to implement in clinical settings where people with health-related stigmatizing conditions seek care and where their family members (who are needed for research at the interpersonal level) are more easily identified and assessed. ... Researchers may consider institutional- and structural-level interventions challenging, since they require time and financial resources to examine stigma in large samples.<sup>13</sup>

Even in the comparatively rich body of data on stigma associated with mental illness, there is little or no evidence on efforts to address structural-level stigma.<sup>14</sup> Researchers continue to emphasize the need for multi-level interventions, and for efforts to tackle the power imbalances that underlie stigma. The following considerations on effective interventions to combat mental health-related stigma, from the report by Livingston (2013), surely apply also to stigma experienced by children with disabilities.

Despite the lack of empirical evidence, several trends can be discerned from the existing body of literature. Generally, there is consensus that, in order to be successful, anti-stigma strategies must target multiple levels by employing a mixture of approaches.

**So, interventions must be designed to target stigma at the individual (micro), social (meso), and structural (macro) levels. Effectively reducing stigma will also require the collective and collaborative efforts of many groups and organizations with a mix of skill sets and expertise (e.g., lawyers, activists, business leaders).**

Effectively combatting mental illness-related structural stigma also requires attending to the root causes of injustice and inequity, which essentially means creating a social movement to shift the dominant cultural ideology into one that does not just tolerate, but values and embraces human difference.<sup>15</sup>

Other studies concur in the finding that changes in attitudes or behaviour relating to stigma can only be achieved through multiple interventions at multiple levels – such that a reliance on education, information campaigns or awareness-raising initiatives alone will not lead to lasting change. Citing research by Corrigan, the review by Rao et al. concludes that stand-alone educational programmes are ineffective.

**Corrigan and colleagues found over years of research that stand-alone educational programs can lead to stereotype suppression, in which members of the public suppress – rather than reject –**

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13 Ibid.

14 Livingston, J. D. (2013). *Mental illness-related structural stigma: The downward spiral of systemic exclusion – Final report*. Calgary, Alberta: Mental Health Commission of Canada.

15 Ibid.

stereotyped beliefs upon learning that such beliefs are socially undesirable. Thus, educational programs alone are often ineffective in reducing stigmatizing attitudes in members of the public, and the little resulting stigma reduction that occurs may be short-lived and superficial.<sup>16</sup>

Approximately half the studies reviewed in this paper examined community-level stigma reduction interventions, which target non-stigmatized populations along with interventions that focus on the stigmatized population at the intrapersonal (within the individual) and/or interpersonal levels. A number of these, addressing mental health stigma, are discussed in the section on community-level interventions below.

**Key finding:** Systematic reviews indicate that interventions to address stigma must tackle multiple socio-ecological levels. There is more evidence for interventions that address the interpersonal and intrapersonal levels than for those also addressing the community or societal levels, possibly because the former are easier to measure. There is a danger that interventions that are not sufficiently holistic – addressing multiple social and behavioural determinants at multiple levels – can lead to suppression rather than rejection of stigma and therefore would not achieve lasting results.

### 3.4 Interventions addressing self-stigma

Many children and adolescents with disabilities themselves internalize ableist views, which limits their ambitions, resulting in lower self-esteem, disempowerment and decreased participation.

A pilot individual and group-based intervention for adolescents recently diagnosed with HIV, conducted in the United States of America, may have some lessons for similar work with adolescents with disabilities. The intervention seeks to promote healthy psychosocial adjustment for adolescents who have recently been diagnosed with HIV, while also improving their engagement in medical care.<sup>17</sup> This may be especially relevant for children and young people with acquired disabilities or conditions such as epilepsy, particularly with regard to how they explain their disability to peers and others.

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16 Rao et al., 2019, citing Corrigan, P. W., & Penn, D. L. (1999). Lessons from social psychology on discrediting psychiatric stigma. *Am Psychol*, 54, 765–776; Penn, D., & Corrigan P. (2002). The effects of stereotype suppression on psychiatric stigma. *Schizophr Res*, 55, 269–276; Corrigan, P. W., et al. (2000). Stigmatizing attributions about mental illness. *J Community Psychol*, 28(1), 91–102.

17 Harper, G. W., Lemos, D., Hosek, S. G., & Adolescent Medicine Trials Network for HIV/AIDS Interventions. (2014). Stigma reduction in adolescents and young adults newly diagnosed with HIV: Findings from the Project ACCEPT intervention. *AIDS Patient Care and STDs*, 28(10), 543–554.

The study describes the negative impact of HIV-related stigma on the self-acceptance, mental health and overall adjustment of youth living with HIV, and its effects on their quality of life and adherence to care. Because HIV confers a strong social stigma, these youth may not have the depth, breadth or quality of social support resources that might be available to young people who do not have HIV. Like disability stigma, the stigma associated with HIV has been shown to be associated with psychological challenges for young people living with HIV, in the form of increased symptoms of depression and anxiety, as well as decreased self-esteem. (See Box 1 for a brief description of the intervention and key findings from the study.)

**Box 1:** Stigma reduction in adolescents and young adults newly diagnosed with HIV: Findings from the Project ACCEPT intervention

Project ACCEPT seeks to equip young people with the skills to combat the negative societal impacts of HIV-related stigma, and in particular to build self-efficacy around disclosure.<sup>18</sup>

The intervention addressed stigma by providing HIV/AIDS-related information, helping young people acquire coping skills, and providing contact with other youth living with HIV to improve social support. Participant groups had two facilitators, one of whom was a peer with HIV.

Several activities focused on increasing planned, informed and strategic HIV status disclosure to others by building participants' skills and self-efficacy. In the group sessions, participants were taught decision-making skills related to disclosure, and then role-played disclosing to a significant individual. Participants also explored different potential outcomes associated with the disclosure. These activities helped the young people decide to whom they would disclose their HIV status, and to whom they would refrain from disclosing.

The intervention attempted to build and promote resistance skills that would impact the external and internal aspects of HIV-related stigma, working at both the individual (intrapersonal) and group (interpersonal) levels.

The intervention was much more effective among young men than young women. The authors posit that this stems from the very different experiences and reasons for HIV infection among young males and females. This is perhaps a useful reminder that formative research is needed to understand contextual specifics.

18 Ibid.



The literature review did not find evidence of interventions to address internalized stigma, but found research into different aspects of stigma that may support the development of such interventions. One study describes a model for internalized stigma experienced by children with epilepsy that can be used to develop clinical interventions.<sup>19</sup>

Another US study examines the attitudes of children with epilepsy towards their condition.<sup>20</sup> Although the authors do not describe an intervention to address those attitudes, they draw on their findings to show the potential value of such interventions to mental health and self-concept. They also point to the need to address mental health and self-efficacy at the intrapersonal level.

Active seizure status was associated with poorer self-concept and more behavioural problems, as well as a more negative attitude towards having epilepsy. The authors conclude that children with active seizures should therefore be targeted for attitude-related interventions. These interventions might include stigma management programmes, educational sessions about illness, self-confidence or self-esteem groups to improve self-concept, coping skills or stress management groups, and recreation-related or skill development activities.

The authors propose a group intervention – an educational game related to epilepsy – to reduce internalized stigma by helping children who do not have epilepsy understand the condition. To our knowledge, this has not been developed or tested.

**Key finding:** There is some evidence that interventions that address self-stigma, or internalized ableism, have an important role in efforts to address stigma. Those that draw on research that is undertaken to understand the challenges experienced by the target group may have a positive impact on the mental health and self-concept of children with disabilities.

### 3.5 Interventions enabling voice and participation

Interventions that enable children with disabilities to have a voice in matters that concern them are clearly central to C4D efforts to address stigma, exclusion and access to services. Addressing the root causes of

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19 Austin, J. K., Perkins, S. M., & Dunn, D. W. (2014). A model for internalized stigma in children and adolescents with epilepsy. *Epilepsy & Behavior*, 36, 74–79. <https://doi.org/10.1016/j.yebeh.2014.04.020>

20 Funderburk, J. A., McCormick, B. P., & Austin, J. K. (2007). Might attitude toward epilepsy mediate the relationship between perceived stigma and mental health outcomes in children with epilepsy? *Epilepsy & Behavior*, 11(1), 72–76.

discrimination and exclusion is critical to bring about sustainable change that can help end the cycle of poverty. Real and sustained inclusion of disadvantaged children and their families requires their voices to be heard and taken into account in decision-making at local and national levels. The active participation of disadvantaged children and families can also increase their sense of confidence and empowerment.<sup>21</sup>

Three reviews examine interventions to support children with disabilities to have a voice – one on enabling children with autism spectrum disorders to communicate, and two on participatory photography methodologies.

### **a) Enabling children with autism spectrum disorders to communicate**

A scoping review by Tesfaye et al. (2019) emphasizes the importance of research to enable children with disabilities to have a voice and communicate their first-person lived experiences.<sup>22</sup> This review primarily focuses on children with autism spectrum disorders.

The review states that such interventions have positive outcomes for research and practice, and for children themselves. The study cites previous applications of participatory approaches involving youth with and without disabilities that have informed policymaking and improved the quality of academic research and health service delivery. These participatory approaches have shown that enabling children with disabilities to have a voice is associated with their empowerment and participatory citizenship, and increases their self-esteem, self-efficacy and sense of ownership and belonging to a community.

Studies identified in the review captured the first-person perspectives of youth on a variety of topics, including living with a condition or disability; forming sexual or religious identities; community participation and leisure; transitions into adolescence and adulthood; interactions with peers, services and institutions; and participation in research studies. The review also covers feasibility studies reporting on methods to capture young people's perspectives and engagement.

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21 For further discussion on on this subject, see, for example, <https://www.worldbank.org/en/topic/social-inclusion>

22 Tesfaye, R., et al. (2019). Assuming ability of youth with autism: Synthesis of methods capturing the first-person perspectives of children and youth with disabilities. *Autism*, 23(8), 1882–1896. <https://journals.sagepub.com/doi/10.1177/1362361319831487>



## **Box 2:** Capturing the first-person perspectives of children and youth with autism spectrum disorders

A range of participatory approaches can enable children with impairments to communicate their experiences, thereby building their self-esteem and sense of belonging, and empowering them to influence decisions that affect their lives.

A review by Tesfaye et al. (2019) synthesizes and discusses methods to support children with a range of impairments, covering six distinct primary methods (questionnaires, interviews, group discussion, narratives, diaries and art) expressed through four communication output modalities (language, sign language and gestures, writing and images).

A consultation exercise held with parents of children with autism spectrum disorders highlights the importance of parents' insights into communication. The researchers identified barriers that may be encountered during participant engagement and provided insights on how best to conduct first-person research with youth who have autism spectrum disorders.<sup>23</sup>

### **b) Participatory photography**

A systematic review by Eisen et al. (2019) summarizes studies that enable children with disabilities, including those with communication impairments, to communicate through participatory photography methodologies, in school and in out-of-school settings.<sup>24</sup> The study also describes modifications to facilitate the participation of children and young people with disabilities in qualitative research. It aims to provide insights for disability rehabilitation professionals into how children and adolescents with disabilities perceive services. It recognizes that there is a risk in relying on parents or speech and language therapists to speak for children with disabilities.

Some of the studies described by Eisen et al. investigated the experiences of children with disabilities at school. They explored the general interests of primary school students, the degree of secondary school students' engagement in their education, barriers within educational settings that limit participation, the inclusion of youth with disabilities in educational settings, and student well-being. Several researchers who explored children's experiences in leisure activities sought to learn about the barriers children face while participating

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23 Ibid.

24 Eisen, I., et al. (2019). Conducting participatory photography with children with disabilities: A literature review. *Disabil Rehabil*, 41(16), 1943–1954.

in their everyday lives. One pair of researchers investigated young adults' experiences using assistive technology. Additionally, some researchers explored topics related to the meaning of adulthood and the future aspirations of children and youth with disabilities.

A scoping review by Dassah et al. (2017), covering 20 studies, mainly from the United States, Canada and Australia, examines the use of photovoice in initiatives with adults with disabilities.<sup>25</sup> The articles featured diverse adult participants with physical disabilities and chronic health problems, and demonstrated a range of approaches to data collection, analysis and dissemination. Nearly all studies identified in the review used photovoice to study physical accessibility or navigation of space, and focused on physical barriers, which are easier to identify and photograph than barriers posed by social mores or bureaucracy.

The review reports that, while the projects had some positive impact on legislation and public policy, the majority did not fully adhere to principles of co-participation central to photovoice. In many cases, researchers (i) did not involve photovoice participants in the research design; (ii) did not discuss pictures in group format, but rather used individual interviews; (iii) did not engage participants in the data analysis process; or (iv) did not engage policymakers or disseminate results through photo exhibitions. Only one project fully involved participants in all stages of planning, data collection, analysis and dissemination. The review recommends structuring photovoice studies in a way that ensures ethical, full and meaningful participation of community members involved. *(See Box 3 for a brief description of the challenges of making photovoice fully participatory.)*

Participatory photography interventions can be resource-heavy, but several studies have demonstrated their real potential to inform service delivery planning and policy to improve the lives of children with disabilities and their families. Four studies linked photovoice directly to policymaking, after participants' images were shared through photography exhibitions. In two cases, posters were used to convey participants' experiences to policymakers and community members. In a third case, 'traffic light' posters were used to explain activities children enjoyed and found challenging: photographs of activities children found easy were presented on green circles, slightly more challenging activities on amber circles, and the most difficult activities on red circles. In the fourth case, posters presented participants' images together with slogans that captured children's concerns about education.

Some researchers reported that participant-generated photographs removed some communication barriers, allowing researchers to gain valuable insights into the lives of participants with limited verbal abilities. However, others

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25 Dassah, E., et al. (2017). Photovoice and persons with physical disabilities: A scoping review of the Literature." *Qualitative Health Research*, 27(9), 1412–1422.

reported continued challenges, as children's communication impairments and the limitations of communication devices made it difficult to truly understand children's perspectives. In general, nonverbal children and those with profound intellectual disabilities were excluded from the studies reviewed – demonstrating the limits of participatory photography methodologies in enabling children with disabilities to have a voice.

### **Box 3:** Challenges in making photovoice participatory

Photovoice is designed to enable participants to communicate whatever they choose to convey – but, in practice, participants do not always fully direct the process.

In the photovoice studies included in the review by Eisen et al., it was the researchers who ultimately proposed the topics for projects, and some provided suggestions on subjects that participants could photograph.<sup>26</sup> Methods for suggesting what to photograph included providing broad and specific advice about subject matter, providing a list of ideas (while still encouraging participants to photograph what they wished), developing a checklist of ideas that supported the chosen topic, and proposing potential questions associated with the chosen topic and asking children to choose one question to explore through photography.

While many researchers provided guidance on what to photograph, others provided minimal direction to encourage participants' creativity and prevent the researchers' biases from influencing the results. Strategies to guide children on what to photograph were sometimes futile. For example, researchers in one study intended for children to photograph a different topic each week of the study by providing them with themes, including 'my family', 'my school', 'what I like', 'what I do not like' and 'what makes me happy'. Instead of focusing on the suggested topics, participants photographed their interests. In this case, researchers abandoned their chosen topics and focused instead on what motivated the children.

Some researchers found the option of one-on-one interviews beneficial for participants who had communication difficulties, found group environments stressful, or were apprehensive about talking in a group. One author recommended one-on-one interviews to discuss the photographs prior to a group session, to make the participants more comfortable.

26 Eisen et al., 2019.

The evidence on photovoice is reasonably compelling. It was designed to enable participants to inform policymakers and shape research, and to brainstorm what they want to communicate about, and subsequently to analyse photographs in participant groups with minimal direction from facilitators. These participatory aspects are important if participants are to have full ownership of the findings and messages that emerge. Still, the methodologies may need to be adjusted (as described in Box 4) to support children with specific impairments.

#### **Box 4:** Participatory photography methodologies: Photovoice and photo-elicitation

Participatory photography methodologies can enable children with disabilities to communicate their experiences, participate in research and inform policymaking to improve their lives, ensure that services meet their needs, and make their societies more inclusive.

A review by Eisen et al. (2019) describes the differences between two methodologies: photovoice and photo-elicitation.<sup>27</sup> Photovoice enables participants to photograph aspects of their lives, and then employs a range of methods to enable them to elaborate on their meaning. Photo-elicitation uses photographs or drawings by other people, including those found in the media, as a prompt for discussion.

The researchers found a range of ways to make these methods accessible for children with disabilities: modifying cameras, providing individual training, teaching consent through role play, allowing children to direct adults to take photographs, using additional forms of media, using diaries and questionnaires, providing individual interviews with simplified questions, using multiple forms of communication, and modifying how photographs are shared.

The review found that both photovoice and photo-elicitation can be effective for studying the lived experiences of children with disabilities, particularly those with communication impairments.

The academic and grey literature describe several other participatory methodologies that enable stigmatized groups to communicate their views and experiences: community mapping, participatory action research, oral testimony and peer-to-peer storytelling.

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<sup>27</sup> Eisen et al., 2019.



A young boy with disability at the playground of an inclusive school, in Fada, in the east of Burkina Faso.

### c) Community mapping and participatory action research

Community mapping is a common element of participatory action research and has been widely used by adults with disabilities and by children, together with their parents, in disadvantaged areas. Kaufman et al. (2011) describe community youth mapping that involves young people in a process of active participant inquiry that leads to analysis of community resources and conditions.<sup>28</sup>

This method enables participants to work together to create visual 'maps' and non-visual data of locations to explore problems, opportunities and questions. In spite of its frequent use in action research, where it can be used to create communication messages at multiple levels, community mapping has been much less rigorously documented in academic literature. But it could serve as a valuable C4D methodology to support children with disabilities to explore inclusion and access issues in schools, playgrounds or other environments.

Kitchin (2002) reports on a participatory action research intervention through which adult wheelchair users in Ireland described in detail the challenges, exclusion and barriers to access they faced. This was then used as a political device to lobby for change.<sup>29</sup> While change has been slow, new public buildings in Ireland now generally adhere to ideas of universal access, and access for people with disabilities is now supported by many local politicians.

28 Kaufman, L. R. (2011). *Community youth mapping: A tool for youth participation and program design*. Educational Quality Improvement Program 3 (EQUIP3). <https://www.youthpower.org/resources/community-youth-mapping-tool-youth-participation-and-program-design>

29 Kitchin, R. (2002). Participatory mapping of disabled access. *Cartographic Perspectives*, 42, 50–62.

Maglajlic (2010) introduces a note of caution with regard to child participatory action research in a study examining a short-term UNICEF initiative in Bosnia and Herzegovina.<sup>30</sup> Children acted as co-researchers in three municipalities of Bosnia and Herzegovina, collaborating with a support group comprising adults who helped them implement their activities. The children identified the need for a child-led organization, contact and cooperation with peers in their municipality, and contact with their municipality. Within months, they had achieved agreement with municipal authorities on numerous areas, including budget allocation. But the process elicited covert and overt resistance from adults, including the facilitators of the children's group and school authorities.

The study notes that, "If [adult mediators] hold inherent prejudice about the extent and content of children's participation, this presents not only practical, but also a grave ethical challenge to children's participation and its future support and development." A further problem identified was the short-term project cycle, leading to the cessation of planned activities and disappointment for the children involved.

#### **d) Oral testimony and peer-to-peer storytelling**

Other participatory methods, such as oral testimony and peer-to-peer storytelling, are documented in the grey literature and described by NGOs.

A narrative report by Burns and Oswald (2015) describes the use of structured storytelling with older people with disabilities in Bangladesh.<sup>31</sup> Peer researchers with disabilities, together with NGO staff, designed story prompts and identified peers within their communities or constituencies from whom to collect stories. Open-ended prompts, rather than interview questions, were used to collect stories, encouraging participants to share their stories and allowing storytellers to cover the issues important to them. Participants gathered stories and collectively analysed them. The stories from this intervention helped identify experiences of social and economic exclusion. Along with analysis by the participants, these stories were synthesized in a report and widely shared with stakeholders and policymakers.

Manning (2009) draws on work designed with the participation of adults with learning impairments to create an oral history of their experiences in Australia's oldest and largest purpose-built institution for people with learning disabilities.<sup>32</sup>

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30 Maglajlic, R. (2010). "Big organisations" supporting "small involvement": Lessons from Bosnia and Herzegovina on enabling community-based participation of children through PAR. *Am J Community Psychol*, 46, 204–214.

31 Burns, D. & Oswald, K. (2015). *We can also make a change: Piloting participatory research with persons with disabilities and older people in Bangladesh*. Voices of the Marginalised Consortium. <https://www.ids.ac.uk/publications/we-can-also-make-change-piloting-participatory-research-with-persons-with-disabilities-and-older-people-in-bangladesh/>

32 Manning, C. (2009). "My memory's back!": Inclusive learning disability research using ethics, oral history and digital storytelling. *British Journal of Learning Disabilities*, 38, 160–167.



The final product was a book, *Bye-bye Charlie*, and a DVD co-designed with persons with learning disabilities to ensure it was accessible.

The research signified an important advancement in oral history methodology, through its multifaceted approaches to inclusiveness and history production. The methodology offered participants multiple forms of media to construct and share their stories, and provided opportunities to cultivate skills in creativity and narration, explore innovative technologies and collaborate with peers to create and share their stories. Digital stories are typically a few minutes long and have many purposes: to inform, instruct, or tell personal stories. This could be a very interesting methodology for children and adolescents with disabilities living in institutions or going through the deinstitutionalization process, or for other groups of socially excluded adults and children.

Findings from mental health stigma interventions included in Rao et al. provide strong evidence for the impact of personal stories and narratives.<sup>33</sup> While there is a tension between small-scale participatory projects and working at scale, case studies suggest that initiatives that are genuinely participatory and foster agency can have an impact far beyond those immediately involved, especially when communications media are used to amplify such stories (with due attention to confidentiality and ethics), and when this dissemination is planned at the outset.

**Key finding:** There is evidence in the academic literature that enabling children with disabilities to have a voice can help to convey their experience to policymakers. There is good evidence to support the use of participatory methodologies that enable communication, with photovoice a notable example. Interventions do not always hold to participatory principles in practice, and modifications need to be made to support the engagement of children with disabilities. Personal stories derived from participatory interventions can have an impact on audiences, and can influence policy and service development. Case studies from the grey literature and NGOs suggest that, when participants are involved in designing and implementing interventions from the outset, the effects can be transformative.

### 3.6 Interventions focusing on parents and their voice

Intrapersonal work with parents and caregivers of children with disabilities tends to focus on their capacity and competencies to support and provide care for their children. Parenting programmes are designed to influence parent–child interactions and improve outcomes for children as a result of improved parenting skills and competencies. A systematic review by Hohlfeld et al. (2018) covers parenting interventions for parents of children with a range of

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33 Rao et al., 2019.

disabilities, mostly aged 0–5 years, and demonstrates that these are effective in increasing parental self-efficacy.<sup>34</sup>

Parenting interventions have potential as part of wider social and behaviour change programmes, by offering a platform to engage with groups of parents. But they need to be combined with other methods, like personal storytelling or oral testimony, to build parents' capacity to voice their experiences to policymakers and service providers, and to engage in decisions about which services they need, and how these services should be designed and delivered.

There is little recognition that parents may experience 'affiliate stigma', internalizing ableist prejudices towards their children with disabilities. In a systematic review, Ying Shi et al. (2019) describe affiliate stigma as composed of three parts: stereotype identification (agreeing with the public attitudes towards caregivers due to internalization of stigma), affective reactions (feelings of shame and embarrassment derived from the internalized stigma), and behavioural response (behavioural reactions, such as withdrawal and self-denigration).<sup>35</sup> While this review focuses on parents of children with mental health conditions, it is also relevant to parents of children with other disabilities – particularly parents of children with cognitive, learning disabilities and autism.

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“ There is a little recognition that parents may experience 'affiliated stigma', internalizing ableist prejudices towards their children with disabilities.

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The OPM literature review conducted for this study did not find research evidence for interventions to address stigma experienced by parents and families, but an Ethiopian study (Tilahun et al., 2016) describes the impact of stigma against children with disabilities on caregivers, and highlights the importance of addressing the needs of caregivers of developmentally disabled children.<sup>36</sup> The study notes that “interventions to improve awareness about developmental disorders, to decrease stigma, and improve access to appropriate education and support for caregivers are warranted.”

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34 Hohlfield, A., et al. (2018). Parents of children with disabilities: A systematic review of parenting interventions and self-efficacy. *African Journal of Disability*, 7, 437.

35 Ying Shi, et al. (2019). Correlates of affiliate stigma among family caregivers of people with mental illness: A systematic review and meta-analysis. *J Psychiatr Ment Health Nurs*, 26, 49–61. <https://onlinelibrary.wiley.com/doi/pdf/10.1111/jpm.12505>

36 Tilahun, D., et al. (2016). Stigma, explanatory models and unmet needs of caregivers of children with developmental disorders in a low-income African country: A cross-sectional facility-based survey. *BMC Health Services Research*, 16, art. 152. <https://pubmed.ncbi.nlm.nih.gov/27117326>



Franco Carnevale (2007) looks at the social experience of families of children with disabilities in Canada, focusing on parents whose children require mechanical ventilation at home.<sup>37</sup> This illuminating study sheds light on parents' intense efforts to protect their children from the effects of stigma, and the challenges that stigma creates for families in their relationship with the outside world.

The parents described in this study felt that they had to manage multiple roles – caregiver, advocate, activist, educator, case manager – in order to safeguard their child's well-being while navigating through highly resistant medical and social service systems. They would strive to protect their children and structure their homes to minimize the presence of the medical technology their children relied on; devices were camouflaged and barely visible. They succeeded in enabling their children to regard themselves as 'normal'. One child, who was completely dependent on his parents for his physical care, stated that a school for disabled children would not be right for him. His parents indicated that he did not see himself as 'handicapped' (their own term). Some of these parents expressed uncertainty about when and how much to tell their children about their conditions, and about the reactions they anticipated in their community.

The families in this study were distressed by their social exclusion – struggling to belong in their wider community. They felt isolated unless they could conceal their child's 'abnormality'. Family members, parents in particular, bear an extraordinary responsibility for mediating the identity ruptures between realities: the accepting, caring, inclusive 'normal' home versus the discrediting, excluding 'community of normals'.<sup>38</sup>

The silence of families about their experience is understandable, but also a real barrier to social change. Society's ableist messages are so deeply entrenched that they are hard to escape even for parents themselves. It is important to recognize that parents' perceptions may not be the same as their children's. This study and others cited here show that parents need the opportunity to voice their experience and engage in discussion of the issues that affect their families most, just as their children do.

An intervention in Ukraine used oral testimony to enable parents of children with disabilities to tell the stories of their children's birth and early years, as a way to mobilize parents' organizations to advocate for early childhood intervention services. Twelve parents of children with disabilities, including two journalists, were trained to support each other, and three other parents each, to describe their experiences and transcribe the resulting 48 testimonies. Many of these parents had been pressured to give up their babies at birth to institutions, but had refused to do so. They had never told their stories before.

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37 Carnevale, F. A. (2007). Revisiting Goffman's stigma: The social experience of families with children requiring mechanical ventilation at home. *Journal of Child Health Care*, 11(1), 7–18.

38 Ibid.

The testimonies were edited by one of the parent journalists for regional print media as well as a publication used by parent advocates to mobilize support for the development of early childhood intervention services. Parents have continued to use the methodology and to present excerpts from the testimonies to conferences and public events. Their overall advocacy efforts led to agreement from two cities and one region to develop and fund early childhood intervention services.<sup>39</sup>

Overall, however, there seems to be a vacuum when it comes to interventions to empower parents of children with disabilities, not just to support their children, but to speak out and advocate, individually and collectively, on their behalf. The lack of research evidence for such initiatives suggests a need to strengthen recognition within child disability work of how stigma affects parents and families – and of the potential role that parents can play in achieving child rights, when enabled to break through stigma, to organize, and to engage constructively and strategically with those who hold power.

A study by Krueger et al. (2019) seeks to understand the ecological systems, contexts, behaviours and strategies of parents in the United States in advocating for children with intellectual and developmental disability diagnoses, specifically Down syndrome.<sup>40</sup> Parents' primary reasons for advocating were to have a more immediate impact on the day-to-day experiences of their own children. While some parents reported wanting to gain acceptance for their child and others with Down syndrome or intellectual developmental delay, they reported seeking mainstreaming and inclusion because of other people's discrimination or judgment towards their own child, rather than because of a desire to pursue a broader social impact.

The study notes that parents and professionals could benefit from training on how to develop advocacy strategies, as most parents end up engaging in advocacy without formal preparation or training. Becoming an advocate appears to be a common role for many parents, occurring "every day in every way" across their child's lifespan.

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39 Unpublished case study provided by HealthProm: Wason, A. (2019). *Parents for early intervention: A HealthProm UK project, carried out with the Early Intervention Institute, Kharkiv, Ukraine, and the National Assembly for People with Disabilities, Kyiv, funded by the EC with additional funding from UNICEF Ukraine, the UK Foreign and Commonwealth Office, and Open Society Foundations Early Childhood Programme.*

40 Krueger, K., et al. (2019). Understanding the systems, contexts, behaviors, and strategies of parents advocating for their children with Down syndrome. *Intellectual and Developmental Disabilities*, 57(2), 146–157

**Key finding:** There is a need to strengthen recognition of how ableist views and stigma affect parents and families. There is little research evidence of interventions to support parents of children with disabilities to address the stigma they experience, and to organize and advocate to achieve inclusion. Interventions that build capacity and enable parents to play a constructive role in tackling stigma and exclusion should be developed, along with research to understand their effectiveness.

### 3.7 Community-level interventions

Across this literature review, the data on effective practice in C4D and C4SBC relating to stigma experienced by children with disabilities is generally limited. While this review considers all disability types, it found evidence mostly for interventions focused on specific disability groups. The strongest evidence identified for community-level interventions comes from stigma research related to mental health.

There is interesting evidence behind disability stigma reduction interventions that involve structured contact between children and young people with and without disabilities, through activities in which disability is not the main focus. Three studies cited below examine initiatives to bring together children or young people with and without intellectual disabilities – and with similar levels of sports skills – in the same sports teams for training and competition. Alongside the development of sports skills, these programmes offered participants a platform to socialize with peers and take part in the life of their communities. The studies evaluated the effects of these interventions on the attitudes and behaviours of the children and young people without disabilities. The interventions show promising results, although effects were modest in the largest-scale cohort study.

#### a) Unified sports

Unified sports are hypothesized to be effective interventions for changing attitudes, because sports includes “cognitive, affective, and behavioural components, and utilizes interactions of equal status contact and pursuit of common goals.” Studies by Dowling et al. (2013),<sup>41</sup> Sullivan and Glidden (2014)<sup>42</sup> and McConkey et al. (2013)<sup>43</sup> confirm existing research suggesting that contact

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41 Dowling, S., Hassan, D. & McConkey, R. (2013). *An evaluation of special olympics pilot implementation of Project Unify in five countries*. Special Olympics International & University of Ulster.

42 Sullivan, E., & Glidden, L. M. (2014). Changing attitudes toward disabilities through unified sports. *Intellectual and Developmental Disabilities*, 52(5), 367–378.

43 McConkey et al., 2013.

involving the pursuit of a shared purpose is more likely to change attitudes in a positive direction than any other kind of contact.

Another possible reason for the success of sports interventions, which these studies do not suggest, is that disability is not the primary focus of the intervention. Perhaps what is significant is that these interventions develop an environment in which children without disabilities can see the person, not the disability. The successful aspects of these interventions could be drawn on in C4D and C4SBC approaches aimed at challenging ableist assumptions and promoting inclusion of children with disabilities.

McConkey et al. (2013) conducted a qualitative evaluation through individual and group interviews with 200 athletes, partners, coaches, parents and community leaders (40 per country) in Germany, Hungary, Poland, Serbia and Ukraine, to review a multi-country initiative with particular reference to its impact on social inclusion. The main beneficiaries of the programme were athletically able youth with disabilities, rather than youth with more severe disabilities, who are at higher risk of social exclusion. Thematic analysis of the qualitative data identified four processes that appear to facilitate social inclusion of athletes: (1) development of athletes and partners, (2) the creation of inclusive and equal bonds, (3) the promotion of positive perceptions of athletes, and (4) building alliances within local communities.

Sullivan and Glidden (2014) conducted a randomized controlled trial with an additional qualitative component that assessed whether a cognitive, affective or behavioural intervention implemented in the context of a unified swimming programme could result in more positive attitudes among persons without disabilities towards persons with intellectual and/or developmental disabilities. All participants were asked if they had benefited from the intervention, and how. Two control groups did not experience the intervention. Assessment included a standardized measure of the Attitudes towards People with Disabilities Scale.<sup>44</sup>

**Key finding:** Scores for the three groups of participants without disabilities (two control groups) on the pre-test were similar, but post-intervention, the intervention group scores were significantly higher on positive attitudes and acceptance of students with disabilities compared with either of the control groups, which did not differ from each other.

Dowling et al. (2013) ran a cohort study and independent evaluation of 1,500 students and 200 teachers in tandem with an 18-month pilot for the Unify

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44 Chadd, E. H., & Pangilinan, P. H. (2011). Disability attitudes in health care: A new scale instrument. *American Journal of Physical Medicine & Rehabilitation*, 90(1), 47–54.

Special Olympics project, which aimed to promote positive attitudes towards people with intellectual disabilities, encourage social inclusion and leadership skills among participants, and develop opportunities for advocacy among people with intellectual disabilities in Austria, India, Italy, Romania and Serbia. This evaluation can be regarded as providing preliminary indications of the potential for Project Unify to deliver change. The researchers used an adapted version of the standardized Attitudes towards People with Disabilities Scale.<sup>45</sup>

The parts of the project that included youth with disabilities did not show clear impacts on social interaction, leadership skills or a sense of social inclusion, but did show a trend in the desired direction. Athletes from different regions were seen to have different starting points, and disabled participants from India reported more marked positive changes in the attitudes of peers than other participants. There is a need to understand the social and cultural contexts in which the strategy is implemented. Differences in the experiences of Indian and European participants with disabilities could be more fully explored using qualitative methods.

### **b) Interventions using theatre and drama**

Three individual pre-post intervention studies used validated measures to test the impact of theatre and drama therapy interventions. These studies examined initiatives in which young people and adults with and without mental health conditions took part in producing and delivering filmed theatre, public performance followed by discussion,<sup>46</sup> and community-based drama therapy.<sup>47</sup> All three studies used a validated measure of change in attitudes by community viewers. Orkibi et al. (2014) also assessed self-stigma and self-esteem in participants with mental illness.

All three studies report statistically significant reduction in stigmatizing attitudes by community viewers. Orkibi et al. also showed statistically significant reductions in self-stigma and increases in self-esteem from baseline to treatment and follow-up phases. Stigma from community members decreased from baseline to treatment and follow-up phases.

### **c) Interventions focused on mental health stigma**

Research into stigma experienced by young people with mental health conditions demonstrates that it is peers and friends who most frequently, and often unintentionally, demonstrate stigmatizing attitudes. School is the

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45 Ibid.

46 Michalak, E., et al. (2014). Using theatre to address mental illness stigma: A knowledge translation study in bipolar disorder. *Int J Bipolar Disorders*, 2(1), 12.

47 Orkibi, H., Bar, N., & Eliakim, I. (2014). The effect of drama-based group therapy on aspects of mental illness stigma. *Arts Psychother*, 41, 458–466.

place where most young people with mental health conditions (59 per cent) experienced prejudice, exclusion or verbal abuse. More than half of young people (54 per cent) who experienced this stigma said it came from their own friends.<sup>48</sup>

The studies of community-level interventions focusing on stigma associated with mental health conditions reported in Rao et al. predominantly used methods of interaction or contact across populations studied, examining the impact of exchanging information, making use of bi-directional learning, and including people living with stigmatized conditions in the process (e.g., through teaching or drama).<sup>49</sup> In addition, these studies tended to incorporate exchanges of support, particularly when family members and health-care workers were involved.

### **i. Open Minds**

Patalay et al. (2017) examined Open Minds. Open Minds is a structured programme of education and training for university medical students, who then deliver workshops in secondary schools.<sup>50</sup>

Pre- and post-surveys were completed by school students who received workshops and by university medical students who delivered the workshops. The main outcomes in both groups were components of mental health literacy (non-stigmatizing attitudes, knowledge, social distance and helping attitudes). Perceived teaching efficacy and interest in mental health careers (university medical students) and workshop acceptability (school students) were also examined. Knowledge and attitudes improved in both samples. Social distance improved only in the university sample and knowledge of helping behaviours increased in the school sample. University students' confidence in their teaching improved. There was no change in their reported interest in pursuing psychiatry in their career. Acceptability was high, as the majority of students enjoyed the programme. All in all, the Open Minds programme shows potential but requires further evaluation.

### **ii. Mental Health Awareness in Action**

Pinfold et al.'s (2005) qualitative and pre- and post-survey examination of Mental Health Awareness in Action, an anti-stigma programme for police, schools and community members, used education, social marketing and

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48 YMCA. (2016). *I am whole: A report investigating the stigma faced by young people experiencing mental health difficulties*. UK: National Health Service.

49 Rao, D., et al. (2019).

50 Patalay, P., et al. (2017). A pre-post evaluation of Open Minds: Sustainable, peer-led mental health literacy programme in universities and secondary schools. *Prev Sci*, 18, 995–1005.

contact strategies.<sup>51</sup> Police received two 2-hour educational sessions. Schools received 50-minute sessions. Personal contact was predictive of positive changes in knowledge and attitudes for school students but not for police officers or the community adult group.

### iii. Open Doors programme

Gaebel et al. (2008) measured the impact of the Open Doors programme in Germany, a three-year anti-stigma campaign delivered either as a stand-alone information campaign or an information campaign combined with a stigma reduction project.<sup>52</sup> Six German cities were randomly assigned to participate in either the awareness campaign alone (two cities), the awareness programme combined with a range of stigma reduction projects (two cities) or no intervention (two cities). Social distance decreased significantly only in the two cities where stigma reduction projects were implemented in conjunction with the information campaign.

The German study highlights the importance of combining information, education and contact-based strategies as the most effective way to achieve lasting gains in knowledge as well as the positive attitudinal and behavioural changes needed to decrease stigma associated with mental health conditions.

The key factors identified across these studies are the stories and testimonies of mental health service users. Hearing individuals' own experiences of mental health problems and contact with a range of services had the greatest and most lasting impact on the target audiences in terms of reducing mental health stigma.

**Key finding:** There is good evidence in the literature showing that interventions involving contact between people with and without disabilities have impact in reducing stigma, as do those that involve documenting and sharing personal stories and testimonies. Contact that puts participants with and without disabilities on equal footing and involves the pursuit of a shared purpose is particularly likely to be effective. While the literature does not mention it, it is possible that activities that do not focus on disability, but enable children with disabilities to be seen for who they are, are likely to be effective.

51 Pinfold, V., et al. (2005). Active ingredients in antistigma programmes in mental health. *Int Rev Psychiatry*, 17, 123–131.

52 Gaebel, W., et al. (2008). Evaluation of the German WPA Program against stigma and discrimination because of schizophrenia – Open the Doors: Results from representative telephone surveys before and after three years of antistigma interventions. *Schizophrenia Research*, 98, 184–193.



### 3.8 Institutional-level interventions

While there is a strong body of international evidence on efforts to achieve inclusive education, there is little evidence on efforts to influence the attitudes of health professionals.

#### a) Information and contact with people with disabilities as core components in initiatives to reduce stigma in health and education

Anderson et al. (2011) conducted a qualitative study with focus groups and semi-structured interviews to study the process and results of a day-long workshop designed to foster empathic listening skills in a mixed group of medical and health-care students.<sup>53</sup> The project used the power of storytelling by people with disabilities and their assistants/carers to encourage health and social care students to reflect on the human factors central to effective communication. Students were in mid to late training of medicine, midwifery, nursing (all branches), pharmacy, social work, and speech and language therapy.

Medical and social care students were first coached in listening skills in order to fully 'hear' the lived experiences of people with disabilities. This was followed by a contact session with service users with disabilities in which the latter shared their experiences and gave feedback on students' communication skills. The final workshop module was delivered to over 400 students in one academic year. An annual cycle of at least six workshops has now been integrated into the Inter-professional Education (IPE) curriculum developed in the authorities covered by the research and is assessed using the IPE reflective portfolio. Service user participants are drawn from a contact list, which at the point of writing comprised around 60 people.

Similar one-off educational interventions, though without the contact element, have been developed to tackle mental illness-related stigma in school settings. For instance, a lesson plan for teachers to use was developed in consultation with UK psychiatrists, a psychologist, a general practitioner, a university outreach professional, a teacher, and secondary school-aged children. It was trialled and then revised.<sup>54</sup>

A participatory educational intervention to explore and improve 14-year-olds' attitudes to schizophrenia in Greece was tested in a randomized controlled trial, in which 1,081 secondary-school students from 20 schools were randomly

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53 Anderson, E., et al. (2011). Learning to listen: Improving students' communication with disabled people. *Medical Teacher*, 33, 44–52.

54 Parker, S., et al. (2013). To create an intervention effective at tackling stigma and empowering adolescents to recognise signs of poor mental health and access services appropriately. *European Psychiatry*, 28(suppl. 1), 1.



allocated to control and intervention classes.<sup>55</sup> A two-hour discussion session with psychologists explored myths about serious mental health conditions and provided accurate information to the intervention class, while the control class held a two-hour discussion on immunization. Stigma levels were assessed with a 'free association' card and a questionnaire before and two weeks after the intervention. The intervention yielded substantial changes in students' beliefs, attitudes and social distance levels, as well as in their associations with the term 'severe mental illness'.

## **b) Inclusive education initiatives**

While such one-off initiatives may be interesting, systemic inclusive education is the key focus of this section examining interventions both in the supply of inclusive education (aimed at ensuring that the school setting provides inclusive education) and the demand for and acceptance of inclusive education (aimed at lowering stigma in the community and among children without disabilities and their families).

### **i. School-based initiatives: Working with teachers and peers to create genuine inclusion within schools for children with disabilities**

#### *Teachers*

A systematic review led by Van Mieghem (2018) examined 26 articles to identify themes examined in previous reviews on inclusive education, findings emerging from this literature that are relevant for practice, and gaps in research.<sup>56</sup> It includes studies that examine attitudes towards inclusive education among teachers, parents and students without disabilities. The review underlines the importance of focusing on attitudes towards inclusive education and using professional development to stimulate the implementation of inclusive education.

A central finding is that teachers' sense of professional self-efficacy is aligned with the attitudes endorsed in the wider school environment. A school climate that embraces difference requires positive attitudes towards inclusive education and children with disabilities from teachers, parents and students without disabilities. This is evidence for the importance of a holistic approach to change: you cannot expect to achieve lasting attitude and behaviour change if the institutional 'scaffolding' does not support it. A review of six dissertations in Russia interviewed a range of respondents before and after the introduction of an inclusive education law, confirming the findings of

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55 Economou, M., et al. (2014). The influence of an anti-stigma intervention on adolescents' attitudes to schizophrenia: A mixed methodology approach. *Child and Adolescent Mental Health*, 19(1), 16–23.

56 Van Mieghem, A., et al. (2018). An analysis of research on inclusive education. *International Journal of Inclusive Education*, 24(6), 675–689. <https://doi.org/10.1080/13603116.2018.1482012>

the Van Mieghem et al. study, in that the attitudes (or at least the declared attitudes) of teachers towards inclusive education were aligned positively after the introduction of the law.<sup>57</sup>

Research on promotion of mental health and prevention of bullying in schools reinforces the importance of a 'whole-school approach'.<sup>58</sup> A whole-school approach involves all parts of the school working together and being committed to a culture of inclusion and nonviolence. This requires the active engagement of the school community: the school Board, the Head, all teachers, support staff, all students, parents, carers and the wider community. This systemic strategy always includes young people with disabilities or special needs as well as anyone else who might be bullied or excluded. However, the widespread implementation of whole-school approaches requires a public policy and resource allocation at national and regional levels.<sup>59</sup>

A number of themes emerge in the van Mieghem et al. review, relating to the attitudes of teachers, parents and students without disabilities towards inclusive education. Positive attitudes among teachers, peers and parents are related to their knowledge of disabilities and their experience of inclusive education. In general, teachers' attitudes to inclusive education were found to be more negative than those of parents and peers, while teachers, parents and peers are less positive towards children with behavioural problems and severe cognitive impairments compared with children with physical disabilities and sensory impairments.

Because teachers have such a key role in implementation of inclusive education, it is essential to influence their ableist bias. A further study in Russia found that supporting teachers to address their hidden stigma is one of the key factors in enabling inclusive education.<sup>60</sup>

Van Mieghem et al.'s review did not include evidence of C4D initiatives with a specific focus on teachers' attitudes, but included reviews of professional development support. This was found to be more effective when it focused on

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57 Samokhin, I. S., Sokolova, N. L., & Sergeeva, M. G. (2016). Attitude to children with disabilities in the context of Russian inclusive education. *Nauchnyy Dialog*, 10(58), 364–376 (in Russian).

58 See for example, Goldberg, J.M., et al. (2019). Effectiveness of interventions adopting a whole school approach to enhancing social and emotional development: A meta-analysis. *Eur J Psychol Educ*, 34, 755–782.

59 Adi, Y., et al. (2007). *Systematic review of interventions to promote mental wellbeing in primary schools*. National Institute of Health and Clinical Excellence (NICE); Stewart-Brown, S., et al. (2004). Promoting and building resilience in primary school communities: Evidence from a comprehensive 'Health Promoting School' approach. *International Journal of Mental Health Promotion*, 6(3), 26–33; Weare, K., & Markham, W. (2005). What do we know about promoting mental health through schools? *Global Health Promotion*, 12(3–4), 118–122.

60 Alekhine, S. V. (2017). Inclusive education and the psychological readiness of a teacher (in Russian). *ВЕСТНИК МГПУ: СЕРИЯ «ПЕДАГОГИКА И ПСИХОЛОГИЯ»*, 117–127.



With the help of their sister and brother, Marva, 12, and Mahar, 11, (in the wheelchairs) make their way home in the Za'atari camp for Syrian refugees, in Mafraq Governorate, near the Syrian border.

the specific needs of students or specific disabilities, rather than on inclusive education in general. Training programmes considering specific teachers' concerns and their teaching context are the most helpful in encouraging change in teachers' practices. Teachers' practices are enhanced through co-teaching with other teachers or support from teaching assistants to teach children with disabilities.

### *Peers*

Peer support practices like cooperative learning or peer tutoring increase the social skills of students with emotional and behavioural disorders and enhance the reading comprehension and phonological skills of students with reading and/or moderate learning disabilities. In general, students are found to be open to friendships with their peers with disabilities, but the risk of building barriers – such as putting students without disabilities into 'caretaking' roles – should be considered carefully. Mixed classes, with a minority of students with disabilities and a larger number of peers without disabilities, foster positive relationships.<sup>61</sup>

A Russian study in a higher education college practising integrated education measured change in social distance and tolerance among students without disabilities towards students with disabilities at the beginning of integrated

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61 Adi, Y., et al., 2007; Stewart-Brown, S., et al., 2004; Weare, K., & Markham, W., 2005.

study and after one year.<sup>62</sup> The results suggest that the students without disabilities developed a more conscious understanding of their peers with disabilities just by being in the same classroom and interacting in the same setting.

A systematic review of 35 peer-reviewed studies by Garotte et al. (2017) summarizes evidence of preschool- and primary school-based interventions to increase social acceptance of children with disabilities aged 2–13 by their peers without disabilities.<sup>63</sup> As the majority of included studies focus on children with autism spectrum disorders, more intervention studies on children with different impairments are needed.

The review suggests that social interactions between children with disabilities and their classmates are the most essential dimension for social participation. Without social interactions with classmates, it is impossible for



May 2018, Belarus: Three-year-old Agatha gets physical therapy from her mother, Ekaterina, at home in Minsk, the capital. Agatha has cerebral palsy and other disabilities.

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- 62 Gladilina, L. S. (2014). Social distance and tolerance of students secondary vocational inclusive schools [Elektronnyi resurs]. *Psikhologicheskaya nauka i obrazovanie PSYEDU.ru [Psychological Science and Education PSYEDU.ru]*, 3.
- 63 Garrote, A., et al. (2017). Facilitating the social participation of pupils with special educational needs in mainstream schools: A review of school-based interventions. *Educational Research Review*, 20, 12–23. [https://www.zora.uzh.ch/id/eprint/129689/1/EDUREV\\_Manuscript\\_Garrote\\_SemierDessementet\\_MoserOpitz\\_2016.pdf](https://www.zora.uzh.ch/id/eprint/129689/1/EDUREV_Manuscript_Garrote_SemierDessementet_MoserOpitz_2016.pdf)

children with disabilities to build friendships or to be socially accepted by them. The review identifies four dimensions of social participation in inclusive classrooms: (1) the acceptance of pupils with special educational needs, (2) the pupils' perceptions of their acceptance by their classmates, (3) the presence of positive social interactions between pupils with special educational needs and their classmates, and (4) social relationships and friendships.

The strongest evidence supports teaching social interaction strategies in pre-school and primary school classes. In most of the studies, these were taught only to the children without disabilities, but in some cases children with and without disabilities were both taught strategies to communicate with each other.

The study cites three other types of intervention that show promise but require further research.

- Group activities in the academic context, such as cooperative learning and peer tutoring, were found to have a positive effect on the social acceptance and social interactions of children with disabilities in five studies. No effect sizes are reported.
- Other types of group activities, such as interest groups, structured play and friendship activities in preschool classrooms, show promise, but there is insufficient evidence for sustained positive social interaction.
- Training and coaching paraprofessionals has a positive effect on social interactions between pupils with autism spectrum disorders and their peers, with three studies showing medium to large effect sizes.

Findings are mixed regarding the effects of these interventions for children with behavioural disorders, who are at greatest risk of negative perception by both peers and teachers in school settings.

These interventions in school settings are education programme interventions that can be part of an integrated approach to communications for social and behaviour change. In such an approach, technical and programmatic interventions to improve the quality of inclusion in the classroom are combined with communications approaches that support teachers and peers to understand and address their own biases and negative attitudes, and build self-efficacy.

The importance of a holistic approach that takes into account the need for work to create genuine inclusion within schools, as well as to stimulate demand for and acceptance of educational inclusion outside of schools, points the way to the need for multi-level interventions to address stigma.



## ii. Outside of schools: Communications for social and behavioural change creating demand for and acceptance of inclusive education for children with disabilities

UNICEF and the national government in Montenegro ran a public campaign at scale from 2010 to 2013 to strengthen support for inclusion of children with disabilities in schools.<sup>64</sup> It achieved a change in attitudes and knowledge among the public, according to annual knowledge, attitudes and practices (KAP) surveys conducted during the three-year programme. The percentage of citizens who would accept a child with a disability attending the same class with their child increased from 35 per cent before the campaign to 80 per cent at the end of the campaign. The percentage of citizens who would accept a child with a disability as their child's best friend increased from 22 per cent before the campaign to 51 per cent at the end of it.

The campaign, however, did not focus on the systemic barriers to educational inclusion within schools. Subsequent discussion with UNICEF suggests that these changes were not sustained, and that greater inclusion of children with disabilities in mainstream schools still remains to be achieved.<sup>65</sup> A major communications campaign, targeted at the public, does not necessarily have an impact on the development of services, and it is now recognized that approaches are needed that focus on ensuring supply as well as stimulating demand, and that effective, genuinely inclusive education requires time, effort and investment to come into being.

The Georgian initiative See Every Colour,<sup>66</sup> implemented by UNICEF in 2015–2017 with strong support from parents' organizations and communities, included a focus on strengthening the capacities of teachers and health workers to understand and address the needs of children with disabilities. It also included discussion and debate at the community level between teachers, doctors and parents of children with disabilities, both about the reasons for exclusion of people with disabilities, and the actions needed to create proper conditions for their social inclusion. *(See Box 5 for a summary of key aspects and results of the initiative, as documented in an evaluation conducted in 2017.)*

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64 Perovic, J., & Obregón, R. I. (2017) Communication for development and social change: Influencing social norms for an inclusive society in Montenegro. *Revista de Comunicación y Ciudadanía Digital*, 6(1), 130–147.

65 Discussions during preliminary review of data for this literature review, 2019.

66 Unpublished UNICEF case study of 'See Every Colour', Georgia.



**Box 5:** Case study: See Every Colour programme, UNICEF Georgia

The See Every Colour programme in Georgia addressed the most widespread misconceptions and false beliefs around people with disabilities. It reached more than 1 million people and contributed to a reduction of stigma related to disability. In 2015, some 41.5 per cent of respondents held stigmatizing attitudes towards children with disabilities, but in 2017 this had fallen to 28.3 per cent.<sup>67,68</sup>

The communications for social and behaviour change were targeted at multiple levels: individuals, families, peers, communities, institutions (teachers, doctors, media), policy and systems (at the municipal level). The platforms used for the initiative were community engagement, media and service delivery.

The initiative used approaches including social change communication and social mobilization, community engagement and advocacy using the following platforms for C4D engagement: mass media, digital media, community and local government mechanisms, networks and civil society organizations (CSOs), schools, universities and health facilities.

Activities at the individual level included production of a video series called *Peer Journeys*, which depicted young people with and without disabilities going through everyday situations and reflecting on their own experiences. The stories showed how attitudes and beliefs could be changed through communication and friendship.

The study notes, "Communication campaigns are effective in reaching large audiences in a short period of time, but they should be complemented with community engagement and institutional building activities." The change achieved by such campaigns "is more sustainable if it is driven by communities, and investing in communities should be the focus of any further initiative."

The case study underlines a key final point: "The campaigns may raise awareness and change attitudes, but this change needs to be sustained by comprehensive and long-term government strategies."

67 Unpublished Summary of description UNICEF case study of 'See Every Colour', Georgia.

68 Unpublished Summary of description of Data from Welfare Monitoring Survey 2017, UNICEF case study of 'See Every Colour', Georgia.

All three UNICEF initiatives noted here used a range of activities with different audiences, including bringing together children with and without disabilities to undertake a collaborative task, storytelling, community engagement, media, and integrating programming on capacity-building, service development and advocacy. Lessons learned nevertheless emphasize the need for sustained, longer-term engagement. The Georgian case study supports the findings from the Van Mieghem et al. review, that professional development processes are an important entry-point for institutionalizing changes in attitude and translating them into genuine inclusive education within schools.

**Many service providers share same attitudes and beliefs as local communities. This requires time and investment to help them become aware of their bias and negative attitudes and transform into supporters of the campaigns. The service providers – teachers and health professionals – have gained, though workshops and trainings, knowledge and skills, but there is a need to institutionalize positive practices and skills in their professional development process.<sup>69</sup>**

This again highlights the need for communications aiming at social and behaviour change to be integrated with relevant programmes focused on capacity-building, system change, technical advice and advocacy with government on policy and legislation. Communication platforms and networks that facilitate *sustained* community engagement and citizen participation are important, as is engaging with government institutions at the national and local levels to ensure ownership, accountability and sustainability of activities and results.

C4D has an important role, but it has to be accompanied by efforts to institutionalize positive practices and skills in the professional development process, and to achieve the political support necessary for broader institutional change – both of which, of course, take time.

### **iii. Learning from inclusive education for other excluded groups of children**

Studies on inclusive education initiatives for children from minority communities may offer valuable insights for achieving inclusive education for children with disabilities.

#### *Children from cultural and linguistic minority groups*

Cobb (2013) has reviewed Canadian studies that identify barriers to the involvement of parents belonging to cultural and linguistic minority groups in special education.<sup>70</sup> The studies suggest that:

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69 Unpublished UNICEF case study of 'See Every Colour', Georgia.

70 Cobb, C. (2013). Critical entanglement: Research on culturally and linguistically diverse parental involvement in special education. *Exceptionality Education International*, 23(1), 40–58.

- School professionals need to understand that parents have a right to different perspectives, and should incorporate that understanding into the ways in which they foster collaboration. It would also be beneficial to study ways in which pre-service education as well as ongoing professional development programmes prepare educators in this regard.
- A key aim should be to prepare school professionals to create opportunities for the exchange of ideas (i.e., when identifying learning needs and developing learning plans) and to foster rich dialogue and collaboration with parents in a variety of situations, such as Inclusive Education Plan meetings, staff meetings and school council meetings.
- It is important to establish multiple and varied opportunities and safe spaces for dialogue in settings and at times that are convenient for parents. Interactions with parents do not necessarily have to take place on school property within the hours of a school day.
- When dialoguing with parents, professionals need to listen and respond in ways that acknowledge the different manners in which parents view parent-school collaboration.
- It is important to create multiple and varied opportunities for parents to review communications, decisions and education plans for children with special educational needs, using regular and multiple modes of communication, such as phone calls, face-to-face conversations and clearly worded notes, to share their views with parents and engage in meaningful discussion and collaborative planning.



16-year-old Hafisa Salisu washes her hands at an accessible latrine block at Bungudu Primary School, Zamfara State, Nigeria.

- A move towards respect for diverging perceptions, nurturing human relationships, and fostering collaboration needs to be supported at the systemic level.
- A shift in the culture and language of inclusion will help counter negative views of cultural and linguistic minorities. For educators, this requires training in culturally diverse and inclusive education.
- Schools need to be provided with resources, such as adequate amounts of preparation time and established partnerships with community organizations that support them as they apply the ideas of respect, reciprocity and empowerment in their day-to-day practices.

### *Roma children in European countries*

Measures for reversing the high rates of absenteeism, dropout and school failure among Roma children are examined in a systematic review by Salgado-Orellano et al. (2019), covering 17 articles on programmes and interventions to promote the educational inclusion of Roma students in Austria, Cyprus, Greece, Hungary, Latvia, Portugal, Serbia, Spain and Turkey.<sup>71</sup> While most interventions took place in school settings, some focused on community and extracurricular contexts. The majority of studies report some change in integration, student confidence, academic achievement, social skills, or reduction of absenteeism or attrition. The review does not examine articles that seek to understand unsuccessful initiatives.

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“ The majority of studies report some change in integration, student confidence, academic achievement, social skills, or reduction of absenteeism or attrition.

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All projects are grounded in the tenets of intercultural education, aiming to (i) foster Roma students' academic success, (ii) develop their sense of cultural identity, and (iii) develop their critical thinking skills. The studies included in the review focus on a range of programmes, using teacher training, parental involvement, the development of Roma teaching assistants, participatory techniques, action research and communication-focused activities. Key findings are summarized in Box 6.

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71 Salgado-Orellana, N., Berrocal de Luna, E., & Sánchez-Núñez, C. A. (2019). Intercultural education for sustainability in the educational interventions targeting the Roma student: A systematic review. *Sustainability*, 11(12), art. 3238.

## **Box 6:** Learning from successful inclusive education interventions in Roma communities

Interventions that have been effective in promoting inclusive education for Roma students have focused on valuing Roma culture, establishing cooperation strategies, and family and community participation.<sup>72</sup> Some of these interventions yield lessons that can be applied to initiatives to promote disability-inclusive education.

A key finding is that inclusive education requires joint work by schools and representative bodies of local Roma communities. This suggests that joint work between schools, representative organizations of people with disabilities and organizations of parents of children with disabilities could similarly promote inclusion.

The studies also found that:

- being in a neighbourhood and social environment where their culture is valued plays a vital role in children's school outcomes;
- the engagement of classroom assistants and/or intercultural mediators from the Roma community, as role models for the students, is effective; and
- Roma families may need to be approached through trusted intermediaries, Roma organizations, or both.

These findings suggest that schools could work with people of a range of disabilities to gain insights and understanding of the needs and specific adjustments required for children with a range of disabilities.

Another finding is that participation of the whole family is critical. The presence of the family in the life of the school, whose cultural mores differ from those of the school in some respects, enables the family and the school to develop a shared understanding of Roma norms and those of the school, helping to create and sustain communication and trust. Similarly, the participation of family members of children with disabilities can facilitate a supportive educational environment for each child and reduce stigma against the whole family.

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72 Unpublished UNICEF case study of "Be fair, for a childhood without barriers" – #THISAbility initiative in North Macedonia, 2015–19.



Communication-focused projects using music and storytelling fit well with the rich musical cultures and oral traditions of Roma culture. Extracurricular activities such as music, choirs or training in action research can help strengthen pupils' inclusion and retention within the formal school system.

Programmes are based on the recognition that it is not just children who are stigmatized, but the whole Roma community. This is relevant to disability stigma. While parents and families may not themselves have disabilities, and the issue is not so much one of culture as of the effect on families of the stigma and difficulties that their children experience; families may often experience exclusion and be stigmatized, and siblings can suffer. Parents' organizations and community groups are often a lifeline for families of children with disabilities, and have the potential to engage constructively with schools and with parents of children without disabilities to enable or enhance inclusion.

Several interventions have sought to understand and develop strategies to address the cultural aspects of inclusion. A Portuguese randomized controlled trial with structured observation reviews a structured storytelling initiative for children aged 10–12. Building on the importance of oral traditions in Roma culture, the initiative resulted in increased school engagement and reduced dropout of Roma children.<sup>73</sup>

A second randomized controlled trial with 30 Roma children studied the 'Knock knock, it's time to learn' initiative addressing a key cultural issue that hinders school attendance, namely that Portuguese Roma parents do not wake their children: only another child or a young person is permitted to wake a child. For a four-year period, the research assistant knocked on the doors of the children in the experimental group to invite them to school. Children in the experimental group showed significant improvement in school attendance, behaviour and mathematics grades.

While such initiatives may not be obviously transferable to inclusive education for children with disabilities, there is clear value in the development of creative and innovative strategies that help identify and address barriers to inclusion or build on strengths that may not immediately be apparent.

Several initiatives, including music programmes, have sought to identify and build on strengths within the Roma community. An ethnographic and qualitative study of 40 students, 58 per cent of whom were Roma, identified the effect of a music-based programme on school inclusion of Roma and immigrant children through participant observation and semi-structured interviews.<sup>74</sup> The development of a community choir led to reduced absenteeism, better integration of students in the school community, and better academic achievement by Roma and immigrant children.

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73 Rosário, P., et al. (2016). Promoting Gypsy children school engagement: A story-tool project to enhance self-regulated learning. *Contemp Educ Psychol*, 47, 84–94.

74 Aparicio Gervas, J., & Leon Guerrero, M. (2018). La música como modelo de inclusión social en espacios educativos con alumnado gitano e inmigrante. *Revista Complutense de Educación*, 8(29), 1091–1108.



A qualitative study combining mixed methods, analysis of demographic data, participant observation and interviews reviewed the experience of 32 Roma children who took part in Music Workshop, a choral education project conducted by Uludag University and the Roma Association of Central Bursa to strengthen the confidence, socialization, and musical and communicative abilities of Roma students.<sup>75</sup> The study sought to identify the effect of the training on children's social and educational outcomes, musical skills and knowledge.

The outcome was positive, with reported improvements in communication and musical skills, peer relationships, sense of belonging, motivation at school, school attendance and cultural awareness. However, the children were drawn from a primary school attended only by Roma children. While the intervention's impact on self-stigma was significant, it did not tackle stigmatizing attitudes on the part of other communities or inclusion within wider society.

A Spanish qualitative study with an ethnographic component examined an initiative to support 18 Roma students and students of mixed Spanish and Roma descent taking part in compensatory education<sup>76</sup> in a secondary education institute for older adolescents.<sup>77</sup> The aim was to support Roma students and the wider educational community to identify the needs of the school and develop a plan of action and activities aimed at inclusive education. The study reports better self-esteem, motivation, grades and integration into school activities, and a decrease in disciplinary action and absenteeism.

The author notes that the presence of the family in the life of the school, especially in the case of Roma children, is key to supporting the compensatory learning of young people. It is important that schools and families understand each other's norms, and have channels for communication.

#### *Participatory action research with Roma children and young people*

Two studies consider the value of training Roma children and young people to take an active role in participatory action research. These initiatives could be highly relevant to children and young people with disabilities. A Serbian study used participatory action research methodologies to train 20 children and young people aged 15–24 (55 per cent Roma) in participatory action research while exploring their views on access to education and opportunities.<sup>78</sup>

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75 Gül, G., & Eren, B. (2018). The effect of chorus education in disadvantaged groups on the process of general education: Cultural awareness and socializing – The sample of Gypsy children. *J Educ Learn*, 7, 125–133.

76 Compensatory education services aim to overcome, compensate for, or forestall the impact of, disadvantage that can lead to educational underachievement, especially for different population sub-groups such as ethnic minorities impacted by different factors such as cultural difference or poverty. They can be provided in the school setting as well as through extracurricular activities.

77 Iguacel, S., & Buendía, L. (2010). Evaluación de un programa para la mejora de un aula de educación compensatoria desde un enfoque inclusivo. *Bordón Revista de Pedagogía*, 62, 127–135.

78 Bhabha, J., et al. (2017). Reclaiming adolescence: A Roma youth perspective. *Harv Educ Rev*, 87, 186–224.

The aim was to strengthen the capacity of young researchers to benefit their community and to develop research strategies and community-level action following the young researchers' suggestions. The participants developed skills and knowledge relating to leadership, communication, civic identity, ethnic identity, self-esteem and critical thinking. In addition to developing a strong commitment to social justice and equity, they learned to design small-scale education-related projects within their communities.

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These studies on participatory action research, culture and compensatory education offer some relevant learning for initiatives to support inclusive education for children with disabilities, as they document effective interventions that support children and young people to have agency in addressing stigma and exclusion. Children and young people who play an active role in this way disrupt prevailing narratives of lack of ability and powerlessness, and can offer role models and solidarity to their peers with disabilities. Several initiatives that support these methodologies will be considered in the next section.

**Key findings:** Efforts to achieve school inclusion must take a holistic and systemic approach.

Evidence from interventions focused on teachers indicates that they are best sustained through professional development mechanisms, and that teachers' professional self-efficacy needs to be aligned with the attitudes endorsed in the wider school environment – that is, it needs to be supported by social norms held school-wide.

Peer interactions are key to inclusive education, and the strongest evidence supports teaching social interaction strategies in preschool and primary school classes, preferably to both children with and without disabilities.

Evidence from interventions focused on creating demand for and acceptance of inclusive education in the wider community show that sustained results can only be achieved if communications initiatives are integrated with initiatives that focus on supply, including through professional development in the education sector and activities aimed at achieving political support for institutional change and development.

Evidence from interventions with Roma children point to the importance of involving families and communities in inclusive school initiatives and the value of focusing on the strengths of the stigmatized community.

## 3.9 National- and societal-level interventions

Interventions focusing on the national and societal levels include those using mainstream media, social media, and information and communications technologies. They are often combined with participatory and grass-roots initiatives at the local or community level.

### **3.9.1 Mass media and media combined with community-level activities**

Mass media campaigns are often carried out in conjunction with interventions at other levels, and it is therefore not simple to isolate the impact of the media component.

A cross-sectional general population survey in South Africa sought to assess the effect of HIV/AIDS education communication campaigns.<sup>79</sup> A structured questionnaire was used to assess media reach (number of people who had heard these campaigns), their knowledge of HIV, and their perception of stigma associated with HIV. Respondents were asked questions related to mass media reach as well as their knowledge of campaigns and perceptions of HIV/AIDS communication in general. The impact of the HIV mass communication programmes was measured in terms of HIV knowledge, sexual behaviours and risk-taking (multiple sexual partners, condom use, HIV testing), and stigmatizing attitudes towards people with HIV.

The study found high exposure to 18 different HIV communication programmes across different age groups (the median exposure was 6 programmes, and over 30 per cent were exposed to at least 14 programmes). Most programmes were more often seen or heard by young people aged 15–24 years. Multivariate analysis showed that greater exposure to HIV mass communication programmes was associated with greater HIV knowledge, higher likelihood of condom use at last sex and getting tested for HIV in the past 12 months, and less stigmatizing attitudes towards people living with HIV/AIDS.

The study did not find any association between higher HIV mass communication exposure and reduction of the number of sexual partners, as found in some other studies. Trend data from population-based surveys in South Africa seem to confirm an increase in condom use, in particular among young people, but not a reduction in the number of sexual partners.

Two studies of the effect of mass media on changing attitudes and behaviours to advance gender equality, which included some form of outcome measures,

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79 Peltzer, K., et al. (2012). Impact of national HIV and AIDS communication campaigns in South Africa to reduce HIV risk behaviour. *The Scientific World Journal*, 2012(8), art. 384608.

were evaluated in an annotated bibliography.<sup>80</sup> These studies considered television, radio and multi-level campaigns, and point to the impact of mass media – in particular through programme series, entertainment programmes and, above all, soap operas – in changing gender norms.

One case study researched the impact of cable television on social norms around the status of women in India.<sup>81</sup> This study involved a survey of 2,700 households in four cities, with data collected annually over three years. The introduction of cable television was associated with significant positive changes within less than a year, with the strongest effects in villages with the most unequal attitudes.

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“ Areas reached by the Globo signal had significantly lower fertility, comparable to the effect of a two-year increase in women’s education.

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Increases were seen in women’s reported autonomy and female school enrolment, while decreases were seen in school dropout among girls, the reported acceptability of domestic violence, reported son preference, and fertility (primarily via increased birth spacing). The effects were large, equivalent in some cases to the effects of about five years of education, and gender attitudes of individuals in rural areas moved much closer to those of people in urban areas. Between 45 per cent and 70 per cent of the difference between rural and urban areas disappeared within two years of cable introduction.

A study in Brazil used census data to measure the impact on women’s fertility before and after cable television was introduced.<sup>82</sup> Areas reached by the Globo signal had significantly lower fertility, measured by the number of children born to women aged 15–49. The magnitude of this effect – a 6 per cent decrease in the probability of giving birth, or 6 per cent of the mean, is comparable to the effect of a two-year increase in women’s education. The introduction of another channel, Sistema Brasileiro de Televisão (SBT), did not significantly affect fertility patterns. This may be because SBT broadcasts programmes are imported and are generally not perceived as realistic portraits of Brazilian society.

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80 Marcus, R., et al. (2014). *Drivers of change in gender norms: An annotated bibliography*. London, UK: Overseas Development Institute.

81 Jensen, R., & Oster, E. (2007). *The power of TV: Cable television and women’s status in India*. Working Paper 13305. Cambridge, MA: National Bureau of Economic Research.

82 La Ferrera, E., Chong, A., & Duryea, S. (2008). *Soap operas and fertility: Evidence from Brazil*. Working Paper 172. Durham, NC: The Bureau for Research and Economic Analysis of Development, Duke University.

**Key finding:** The studies in India and Brazil showed that soap operas in particular can have a powerful impact on social attitudes and behaviour change, which seems to be associated with the extent to which viewers can identify with the characters. In Brazil, the importance of portraying characters with whom viewers can identify was noted by two trends. First, decreases in fertility were seen in the years immediately following the broadcasts of soap operas that portrayed messages of upward social mobility, suggesting that viewers desire to conform with behaviours that leads to positive life outcomes. Second, the effect was stronger for women whose age was closer to that of the main female characters portrayed in any particular year. There may be other factors also contributing to the impact of soap operas, such as the compelling style and drama of the narrative.

These studies are consistent with other research that indicates the value of compelling human stories in communication content. A narrative synthesis by McGinty et al. (2018) of media strategies to strengthen public support for people with stigmatized conditions – primarily mental illness and substance abuse, but also HIV – summarized recommendations from an expert forum convened at the Center for Mental Health and Addiction Policy Research at Johns Hopkins University, noting that the most effective strategies use personal narratives to engage audiences and highlight structural barriers to treatment.<sup>83</sup> Research cited in the paper also suggests that while such strategies can increase the public’s support for policies benefiting people with mental illness or substance use disorders without increasing stigma, they are less successful for conditions that are perceived to be a result of character or moral failure.

While the Brazilian and Indian studies on gender norms are specific to the impact of media interventions, the review by McGinty et al., which looks at multiple drivers of social change, concludes that change in gender norms and relations has typically been driven by several factors simultaneously.

This is important: development interventions are delivered in the real world, and the intervention strategies must therefore take into account social and political changes, either by harnessing or resisting them. According to Marcus et al., authors of the annotated bibliography-cum-review that includes the Brazilian and Indian studies, social norms are influenced by changes in education and the economy; exposure to new ideas; social mobilization; and political shifts. However, as the authors note, overall, few studies probe the way increased access to communications has led to changes in social norms.

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83 McGinty, E., et al. (2018). Communication strategies to counter stigma and improve mental health and substance use disorder policy. *Psychiatr Serv*, 69(2), 136–146.

## a) Media interventions with a community-level component

There is good evidence for the effect of national media campaigns used alongside community-level initiatives. Solórzano et al. (2008) measured the impact of a communications strategy on HIV, gender and sexuality implemented in a multi-level programme, *Somos Diferentes, Somos Iguales* (SDSI, or 'We are different, we are equal'), which aimed to change behaviours, attitudes and norms that increase the risk of HIV, including gender inequity, partner violence, stigma and discrimination.<sup>84</sup>

The programme linked community-level group activities to promote critical discussions about social and cultural issues that hinder HIV prevention, including at youth camps, to content delivered through national media: an accessible and entertaining television soap opera series called *Sexto Sentido*, with characters who modelled gender-equitable behaviours, and a youth-directed radio show. The study measured the effect on several domains, including gender equity, stigma reduction, interpersonal communication, HIV prevention practices, and personal and collective efficacy for HIV prevention.

Three household surveys were administered over three years to the same group of 3,099 young people aged 13–24 years at baseline. In-depth interviews and focus group discussions with participants, non-participants and key stakeholders were used, alongside a longitudinal panel study to evaluate the quantitative impact of the strategy on individuals.

Overall support for gender-equitable norms increased over time. Individuals with the highest level of exposure to the intervention became significantly more 'gender equitable' – for instance, rejecting violence towards women – compared to those with lower levels of exposure. There was also an increase in knowledge and use of HIV-related services, and a significant increase in interpersonal communication about HIV prevention and sexual behaviour.

These findings suggest that media-based communication programmes for social change can both reach large numbers of young people and effect measurable change in gender attitudes and norms on a population level. The study recommends that programmes aimed at changing behaviour include interactive, small-group sessions and community-based activities, and use the media to promote change in attitudes and behaviour.

Overall, Solórzano et al. concluded that institutions (in this instance, health-care settings) should be helped to acknowledge that stigma exists and needs to be addressed in the institutional environment, and that involving people with HIV/

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84 Solórzano, I., et al. (2008). *Catalyzing personal and social change around gender, sexuality, and HIV: Impact evaluation of Puntos de Encuentro's communication strategy in Nicaragua – Horizons Final Report*. Washington, DC: Population Council.



AIDS in service delivery, for instance as peer counsellors, helps reduce stigma among service providers, strengthens self-esteem and improves community perceptions. This conclusion may be relevant to campaigns that address stigma experienced by children with disabilities.

## **b) Community involvement in media content**

Riley et al. (2017) reviewed the use of participatory methods to enhance the development, production and evaluation of entertainment-education (EE) communication content using a range of communication platforms – including theatre, radio, television, games and social media – in low-income countries. The review examined the extent to which this approach could “increase knowledge, shift attitudes and promote social change” among marginalized populations.<sup>85</sup>

While EE content can be disseminated at all levels – within communities and through social media, as well as to national or cable television audiences – Riley et al. mainly reviewed participatory interventions directed at the community level, in their formative, implementation and evaluation stages.

The review works from the premise, evidenced in previous reviews, that participatory approaches are more effective than top-down communication approaches, as they draw insight and ideas from the population to strengthen audience engagement. Characters are designed to resemble audience members, and the issues addressed are relevant to audiences’ lives and experiences. At the formative research level, researchers work with stakeholders to identify culturally relevant indicators of change and gather information about the assets and needs of affected communities.

Apart from a key role in formative research and design, participatory engagement can take place when planning and assessing or evaluating communication outputs, to learn to what extent the themes portrayed reflect audiences’ experiences, or to enable community members to look beyond planned subjects or topics.

Riley et al. give examples of how participatory photography, photovoice in particular, and other visual methodologies can be used to enable communities exposed to EE storylines and characters to express and determine their own needs, and to raise awareness and mobilize audiences to take action. Participatory sketching, before and/or after exposure to EE content, has been used successfully with children (see Literat, 2012) and may be particularly relevant to children with disabilities.<sup>86</sup>

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85 Riley, A., et al. (2017). Participatory methods for entertainment-education: Analysis of best practices. *Journal of Creative Communications*, 12(1), 62–76. [https://www.academia.edu/32248523/Participatory\\_Methods\\_for\\_Entertainment\\_Education\\_Analysis\\_of\\_Best\\_Practices](https://www.academia.edu/32248523/Participatory_Methods_for_Entertainment_Education_Analysis_of_Best_Practices)

86 Literat, I. (2012). “A pencil for your thoughts”: Participatory drawing as a visual research method with children and youth. *The International Journal of Qualitative Methods*, 12(1), 84–98.

Because of its playful nature and its lack of dependence on linguistic proficiency, this kind of participation and engagement linked to EE storylines and characters is especially suitable for work with children with disabilities when designing and evaluating communication outputs, especially children with communication impairments, across a variety of backgrounds and cultural contexts.

**Key finding:** There is good evidence that media content that delivers compelling human stories and includes characters that audiences can identify with can achieve social and behaviour change. Soap operas have been particularly effective. Media and other interventions should be designed to align with 'real world' social and political change, which results from many factors. Participatory engagement, including interactive, small-group sessions and community-based activities, can be very valuable in informing, planning, developing, implementing and evaluating media initiatives.

### **3.9.2 National- and societal-level interventions that build the capacity of communicators and empower young people to be change agents**

Most evidence for social and behaviour change resulting from communications initiatives and programmes is derived soon after a communication intervention. Results often look encouraging, but without further testing, it cannot be assumed that they will be sustained.

Moreau et al. found that the media contribute to the stigmatization of men who have sex with men (MSM) by communicating negative and sensational stories about them.<sup>87</sup> The project team held a workshop for media providers in Dakar, Senegal, that included the participation of MSM, putting a human face to the issues and helping journalists better understand the hidden realities of the men's lives, which are often punctuated by stigma, discrimination and violence. Over the next 18 months, the project team reviewed local newspapers and found that no offensive or stigmatizing articles had been written about MSM.

Similar initiatives have been used by NGOs to build the capacity of journalists to report on issues faced by other stigmatized groups, including children with disabilities.<sup>88</sup> It would be important to test the value of such efforts in the medium to long term.

87 Moreau, A., et al. (2007). *Implementing STI/HIV prevention and care interventions for men who have sex with men in Senegal. Horizons Research Summary*. Washington, DC: Population Council.

88 See, for example, the publication, written by parents of children with disabilities in Ukraine, 'See the child, not the disability: Recommendations for journalists' – **Видеть ребёнка, а не его особенности** (in Russian and Ukrainian). <https://naiu.org.ua/wp-content/uploads/2019/06/74bc3f05b07a36523dbb20c16154dd.pdf>

A number of innovative interventions have sought to mobilize and support members of stigmatized groups to act as change agents and communicators in national- or societal-level initiatives. Oxfam's initiative My Rights My Voice (MRMV) engaged marginalized young people across eight countries – Afghanistan, Georgia, Mali, Nepal, Niger, Pakistan, Tanzania and Vietnam – to work for their rights to health care and education.

Oxfam's final report, published as a case study, describes how the project's support for the young people enabled them to become a positive force for change, and increasingly set their own rights agendas.<sup>89</sup> As youth became more aware of their rights and gained the confidence to demand them, they began to take over from Oxfam and its partners in designing and delivering their own activities to raise awareness about their needs with peers and decision makers. This often resulted in a more focused influencing strategy, with increased attention paid to country-specific topics including sexual and reproductive health rights, gender-based violence, child marriage, and female genital mutilation (FGM).

The programme had a particular focus on gender equality, especially the participation – and leadership – of girls and young women. Even in very conservative societies, where girls' participation was initially very restricted, there were important shifts in attitudes and norms, and girls got involved in ways that were not possible at the start of the programme – and were even supported by their communities to do so.

In most countries, the programme initially had to invest substantial efforts to be able to work directly with youth – particularly girls and young women – and ensure their effective participation. The authors emphasize that the work took time and required Oxfam and its partners to rethink traditional roles and ways of working. All stakeholders, including the young people themselves, had to take a leap of faith – but duty-bearers in each country took action in response to the young people's demands.

Communication was central to the initiative. While the programme led many of the communication and awareness-raising activities, it sought, and over time achieved, young people's meaningful participation in content development. Radio dramas, debates and information shows were an essential component of awareness-raising and campaigning efforts in the majority of MRMV country projects, alongside television soap operas, live debates, reality shows and mass text-messaging communications to enable participation in programmes.

In Mali, an e-learning platform on sexual and reproductive health was integrated into the national curriculum, while in Vietnam, game show

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89 Davies, I., van Mellaert, L., & Garton, J. (2016). *My Rights My Voice completion report 2011–2016*. Oxford, UK: Oxfam. <https://www.scribd.com/document/340894832/My-Rights-My-Voice-Completion-Report-2011-2016>

software taught schoolchildren about their rights in an interactive way, and a photovoice initiative enabled ethnic minority children to communicate their education rights and aspirations to duty-bearers. Youth participants in all country programmes received training in blogging, photography, video production, social media and digital communications skills to improve their ability to engage with new technologies and use these in their campaigning and awareness-raising work.

Advocacy process indicators and the advocacy results achieved by the young people were used to monitor and evaluate the project. Attributable in part to awareness-raising C4D initiatives, and in part to mobilizing, empowering and building the advocacy skills of young people, the impressive results suggest real progress on the targeted rights issues, as well as a high level of agency, skills and empowerment among the young people. In Niger, for example, the Ministry of Education adopted a declaration on access to education for all children and young people, with special attention given to girls' education. In Nepal, advocacy work resulted in more than 1,600 women elected to local decision-making bodies, where they influenced male counterparts to ensure gender-responsive planning and implementation.

Could an approach of this kind, combining communication for social change and advocacy, work with similarly marginalized young people and adolescents with disabilities? A project by Leonard Cheshire and partners, '2030 and Counting', currently in progress in Kenya, the Philippines and Zambia, recognizes that young people with disabilities aged 18–30 can be agents of change at the national level.<sup>90</sup> It supports and draws on youth advocates with disabilities, as citizen journalists, to monitor and report on national progress towards the Sustainable Development Goals (SDGs), and specifically the SDG disability targets related to poverty eradication, education, employment, reducing inequalities, sustainable and inclusive cities, and peaceful and inclusive societies. In addition to disability-specific indicators, the global monitoring framework includes an overarching principle of data disaggregation by disability.

Case studies suggest that advocacy, dialogue and C4D around a shared and achievable goal can mobilize people with disabilities and their allies, and can lead to important outcomes at the national level.

The Association for Self-Advocacy in Croatia enabled adults with intellectual disabilities to campaign for a change in the law that had deprived 16,000 people with disabilities of the right to vote. A television and radio campaign in which advocates participated is considered to have played a key role in

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90 Unpublished case study provided by Leonard Cheshire. See also Leonard Cheshire. (2019). *Making it count: The power of youth advocates in the disability movement*. London, UK: Leonard Cheshire. <https://www.leonardcheshire.org/sites/default/files/2019-10/Making-it-Count.pdf>

achieving a change in the law, making it possible for people with intellectual disabilities to vote in local and regional elections and two state referenda. The project brought together self-advocates and a variety of civil society organizations to raise the general public's awareness on the rights of people with disabilities and to provide workshops on democratic and voting procedures for self-advocates at the community level.<sup>91</sup>

A programme led by HealthProm, supporting parents' organizations to advocate for early childhood intervention, commissioned a participatory research study to provide evidence for parents to present to policymakers.<sup>92</sup> This mixed-methods research, conducted with 238 parents of children with disabilities in two regions of Ukraine, sought to understand the challenges experienced by families in the first years of their children's lives, assessed their psychological well-being and examined the extent to which available services corresponded to families' perceptions of their needs.

The research provided strong evidence of the need for early intervention services and enabled parents' organizations to make a case for policy change based on evidence as well as personal experiences. Ten parent leaders, 'experts by experience', received basic training in research methods and principles and participated in the development and implementation of the research, which built their ownership of the project and their commitment to disseminate the results. The research helped influence local and regional authorities to support early intervention services in three regions of Ukraine.<sup>93</sup>

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91 Zero Project. *Voting without legal capacity*. <https://zeroproject.org/practice/udruga-za-samozastupanje-association-for-self-advocacy-croatia/>

92 Добрава-Кроп, Н., Вейсон, А, Пирогова, Д., Сахно, Ю., Максименко, О., Близнюк, Е., Качмар, С., Кукуруза, А. (2017). *Прислушиваясь к голосам родителей: анализ опыта получения услуг для детей с особыми потребностями в возрасте от 0 до 4 лет, а также инновационной услуги Раннего вмешательства*. HealthProm. <http://rvua.com.ua/media/310/632e986d76cd471d9f111d778b175159.pdf> English language summary: *Heeding the voice of parents families' experience of services for children with disabilities and/or special needs, aged 0-4, in Ukraine, including experience of an innovative Early Intervention Service*. <http://rvua.com.ua/media/314/128e8e3c23aff2f467ad6aca6dbc9697.pdf>

93 Unpublished case study provided by HealthProm: Wason, A. (2019). *Parents for early intervention: A HealthProm UK project, carried out with the Early Intervention Institute, Kharkiv, Ukraine, and the National Assembly for People with Disabilities, Kyiv, funded by the EC with additional funding from UNICEF Ukraine, the UK Foreign and Commonwealth Office, and Open Society Foundations Early Childhood Programme*.

**Key finding:** Building the capacity of key communicators such as journalists to address stigma (or at least not to perpetuate it) shows potential to be highly effective. By speaking out publicly, children and young people with disabilities and their parents can make an important contribution as ‘experts by experience’, countering the notion that they are to be pitied or patronized. Child protection issues need to be borne in mind, but supporting children and young people with disabilities, as well as their families and peers, to speak out as disability activists enables them to drive social change and create powerful, public role models for others. Parents’ organizations engaged to conduct research and advocate from their own lived experiences can be highly effective in achieving policy change and new services.

### 3.10 Formative research

Few of the articles examined in this paper discuss the appropriateness of formative research undertaken prior to the design of interventions, or the need for context-specific research into the beliefs and information needs that underlie stigma and exclusion.

An understanding of the target population’s underlying beliefs and attitudes and the wider context for the intervention has an important bearing on the design of interventions addressing disability stigma. Data on the dynamics of stigma, and how it operates in specific environments and for different impairments, can inform formative research questions. The following articles offer such insights on a range of topics.

- Voevodina and Gorina (2013)<sup>94</sup> and Korostelyeva et al. (2014)<sup>95</sup>, on university students’ attitudes of towards people with disabilities in Vladimir, Russia, and Karaganda, Kazakhstan, respectively.
- Kinnear et al. (2016), on the challenges facing parents of children with autism, and the extent to which stigma is a factor.<sup>96</sup>
- Rydström et al. (2015), on HIV-related stigma in Sweden.<sup>97</sup>

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94 Voevodina, E. V., & Gorina E. E. (2013). Social portrait of people with disabilities in the student community as a factor of social adaptation to the conditions of the university (in Russian). *Вестник Томского государственного университета*, 373, 60–65.

95 Korosteleva, N. A., Krasnov, A. M., & Leonov, V. V. (2014). Aktualnost problemy formirovaniya tolerantionogo otnosheniya k studentam-invalidam v sovremennom sotsiume (in Russian). *Nauchno-pedagogicheskoe obozrenie Pedagogical Review*, 1(3), 24–33.

96 Kinnear, S. H., et al. (2016). Understanding the experience of stigma for parents of children with autism spectrum disorder and the role stigma plays in families’ lives. *Journal of Autism and Developmental Disorders*, 46, 942–953.

97 Rydström, L.-L., et al. (2015). HIV-related stigma and health-related quality of life among children living with HIV in Sweden. *AIDS Care*, 28(5), 665–671.



- Bogart et al. (2019), on the differences in stigma experienced by people with congenital or acquired disabilities.<sup>98</sup>
- Wiener et al. (2012), on the self-perceptions of children with attention deficit hyperactivity disorder (ADHD).<sup>99</sup>
- Cooney et al. (2006), on the perception of stigma by young people with intellectual disabilities attending mainstream and segregated schools.<sup>100</sup>
- Mikami et al. (2015), on the impact of parents' affiliate stigma on children with ADHD.<sup>101</sup>

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98 Bogart, K. R., Rosa, N. M., & Slepian, M. L. (2019). Born that way or became that way: Stigma toward congenital versus acquired disability. *Group Processes & Intergroup Relations*, 22(4), 594–612.

99 Wiener, J., et al. (2012). Children's perceptions of their ADHD symptoms: Positive illusions, attributions and stigma. *Canadian Journal of School Psychology*, 27(3), 217–242.

100 Cooney, G., et al. (2006). Young people with intellectual disabilities attending mainstream and segregated schooling: Perceived stigma, social comparison and future aspirations. *Journal of Intellectual Disability Research*, 50(6), 432–444.

101 Mikami, A. Y., et al. (2015). Implications of parental affiliate stigma in families of children with ADHD. *Journal of Clinical Child & Adolescent Psychology*, 44(4), 595–603.



Mozambique: Lidia is a cheerful 15-year-old, who lives with her mother and brother. She has a physical disability and does not talk, but she developed her own method to communicate.

## 4. Key findings and conclusions

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### 4.1 High-quality data on effective communications for social and behaviour change initiatives related to children with disabilities are generally limited

This review aimed to discuss and clarify the effectiveness of different types of interventions to address stigma and exclusion at a granular level. Search terms and inclusion criteria for the literature search are described in Annex A. The following inclusion and exclusion criteria were applied.

- i. Children living with a disability or special educational needs, or another population that experiences stigma or discrimination, including people living with HIV/AIDS, ethnic minority populations such as Roma, migrants, people with mental health conditions, or people facing gender-based discrimination.
- ii. A project, programme, campaign or intervention with a participatory communication component, or a project, programme, campaign or intervention designed to counter stigma.
- iii. Improving self-concept (self-efficacy, empowerment, reducing internalized stigma, increasing confidence and agency of stigmatized or excluded people), countering social stigma and promoting inclusion as desired outcomes.
- iv. Reported effect of the programme on achievement of these outcomes.

Much of the data uncovered using these terms and criteria came from clinical, therapeutic and educational interventions, some of which have relevance for C4D and C4SBC. Less research evidence emerged specifically for relevant communications interventions, and the research that emerged generally did not provide a nuanced level of discussion of what did or did not work. This may reflect the fact that C4D and C4SBC interventions, particularly beyond the interpersonal and intrapersonal level, do not lend themselves to strong evidence.

Social change and communication interventions take place in environments with multiple factors influencing change over long periods of time, which makes it extremely difficult to isolate specific communications components or other social and behaviour change interventions and link them to clearly defined outcomes. A proposal to expand the search to include social+change or behav\*+change could be used in future searches, but it is not clear that these would produce considerably different or more relevant research evidence than the search terms used for this literature review.

#### **4.2 Evidence on longer-term, sustained impact and outcomes from communications for social and behaviour change interventions is even harder to identify**

The literature review did not find any studies that discussed or examined the *sustainability* of communication initiatives. While it should be acknowledged that such research is difficult to undertake, given the multiplicity of factors influencing behaviour and social change, there seems to be a general lack of attention to sustained outcomes in the design of C4D or social and behaviour change interventions. Most evidence for change is derived soon after a communication intervention has ended, and while results often look encouraging at that point, it cannot be assumed, without further testing, that results will be sustained. Recent unpublished case studies provided by UNICEF, Oxfam, Leonard Cheshire and HealthProm recognize the need to work towards greater sustainability and to support young people, young people with disabilities, and parents of children with disabilities to advocate and communicate for themselves.

#### **4.3 Effective interventions that seek to empower stigmatized people and address stigmatizing attitudes and behaviours generally have a strong participatory element**

Interventions that address self-stigma at the intrapersonal level and build self-esteem and self-efficacy can empower children and adults with disabilities to speak out and share their experiences. Effective interventions, whether at the interpersonal, community or societal levels, all involve contact between people with disabilities and people without disabilities, first-hand testimony and human stories.

- First-hand contact with a member of the stigmatized group is associated with effective interventions – for instance, in the case of adolescents living with HIV acting as peer facilitators in group work with HIV-affected adolescents.
- Contact that involves the pursuit of a shared purpose such as sport or theatre is a particularly effective way of changing attitudes in a positive direction.
- Interventions and research that enable children with disabilities to have a voice and convey their first-hand lived experiences have positive outcomes for research, practice and the individuals themselves. Enabling children with disabilities to have a voice is associated with empowerment and participatory citizenship; increases self-esteem, self-efficacy, ownership and the sense of belonging to a community; and reduces self-stigma.
- There are many participatory methodologies that enable children with disabilities to have a voice. There is good evidence for photovoice, which enables a high level of subject participation from agenda-setting to analysis, informing policymakers or shaping research.
- The stories and testimonies of mental health service users, and the experience of hearing individuals' own experiences of mental health problems and of their contact with a range of services, are the key factors identified across effective community- and municipal-level intervention studies in the field of mental health awareness. These stories had the greatest and most lasting impact in terms of reducing mental health stigma among target audiences.
- The effectiveness of personal narratives to engage audiences and highlight structural barriers is also evidenced in efforts to address stigma and raise awareness through mass media.

Case studies that combine C4D content with mobilization and capacity-building of prospective advocates show potential for young people, including those with disabilities, to be change agents in their own right. These initiatives have potential for sustainability and for impact at the national and societal levels. The agendas set by children with disabilities and young people with disabilities do not have to focus directly on disability stigma issues. It would be interesting to research, for instance, the extent to which Greta Thunberg has influenced not only attitudes on climate change, but also attitudes towards young people with autism.

#### **4.4 Integrated, multi-level strategies have greater potential for sustained change than stand-alone initiatives**

While the evidence in the literature is strongest mainly in relation to intrapersonal- and interpersonal-level interventions, this may be because they are easier to measure.

There is nevertheless some good evidence for multi-level interventions, for instance an initiative that linked a national media campaign with community-

level activities that engaged audiences in discussion and achieved the desired change. There is potential for participatory methodologies that enable children with disabilities to engage to enhance education-entertainment media content. This can be a way of linking participation to at-scale change initiatives. We did not find research evidence specifically for interventions that focus on bringing participatory initiatives to scale, but there may be unutilized potential for this.

The effectiveness of combining information, education and contact-based strategies is also evidenced in an awareness campaign on mental health conducted in cities in Germany. This was the most effective in achieving lasting gains in knowledge, as well as positive attitudinal and behavioural changes needed to decrease the stigma associated with mental illness. As with many such campaigns, the effect was studied soon after the intervention ended. Attitudinal or behavioural results may taper off if not reinforced through longer-term engagement strategies.

UNICEF case studies from Georgia and North Macedonia point to the importance of integrated communications and programmatic approaches. There is a need to strengthen research to identify successful and effective strategies that sustain change over the longer term.

#### **4.5 Building capacity and raising awareness among journalists for sustainable social and behavioural change**

A key potential entry-point for building sustainable social and behaviour change is working with journalists and other professional communicators to build their knowledge and awareness, as well as their capacity to engage with adults and children with disabilities and their allies – parents, caregivers, assistants and professionals in disability services.

Interventions to build the knowledge and awareness of professional communicators have potential for sustainability. Print media journalists in Senegal ceased production of negative and sensational content on men who have sex with men for 18 months – the duration of the programme – after a contact and awareness-raising intervention.

Some mass media interventions – which may not have had a specific focus on building media producers' capacities – have demonstrated significant impact on gender norms. Soap operas with compelling human stories and characters with whom audiences can identify have been especially effective, including in studies in India and Brazil. A study of HIV mass media campaigns in South Africa found evidence for changes to knowledge and stigmatizing attitudes – but not for reduction in the number of sexual partners, a key behaviour change.

We can surmise that engagement with journalists and professional journalists is most likely to be sustainable when integrated within holistic, multi-level

interventions supporting change in a range of settings over longer periods of time, including legislative, regulatory and professional behaviour change,

#### **4.6 Peers and families are important targets for addressing stigma experienced by children with disabilities**

Interventions to address stigma experienced by children with disabilities need to recognize the importance of their families and peers. Parents, siblings without disabilities and caregivers may experience 'affiliate stigma', whereby they internalize public prejudice. There is some evidence for small-scale interventions to address peer attitudes and behaviours that are often very significant for children and young people with stigmatized conditions.

Parents clearly need the opportunity to voice their experience and engage in discussions of the issues that affect their families most, just as their children do. Given the opportunity to break through silence and isolation, they may play a vital role in collective and individual advocacy for their children's rights.

Movements of parents of children with disabilities have played a key role in the development of rights and services for children with disabilities in many countries. In the United Kingdom, for instance, parents of children with disabilities are the founders of almost all the national child disability organizations, and of the Council for Disabled Children, which brings government, professionals and non-governmental organizations (NGOs) together to achieve policy change. However, the role of leadership by parents of children with disabilities in this work has not been documented. Supporting parents to mobilize, develop civil society organizations and work with government authorities to achieve inclusion of children with disabilities is a very promising direction for C4D and C4BSC interventions, and would be valuable to research.

#### **4.7 A holistic approach at the institutional level is key to addressing stigma and supporting inclusion for children with disabilities**

A holistic approach to change at the institutional level is vital. Stigma is only one barrier to inclusive education: there needs to be a whole-system focus on the supply as well as the demand for inclusive services. Teachers' sense of professional self-efficacy is aligned with the attitudes endorsed in the wider school environment. Systemic change, with attention to national policy and resource allocation, is needed to provide 'scaffolding' for behaviour change among front-line educators and enable inclusive education. Advocacy to achieve inclusion is not simply a matter of making demands: local platforms need to be developed for sustained discussion and development of solutions that work for schools, parents and the community.



There is little evidence from the literature review of efforts to influence health professionals' attitudes. There is some evidence of attitude change from short-term interventions to address mental illness stigma among health and social care professionals during their training.

Some learning can be drawn from interventions to promote the inclusion of children belonging to cultural and linguistic minorities. Studies of Roma school inclusion interventions generally focus on efforts to reverse high rates of absenteeism and school failure. A key finding is that inclusive education requires joint work by schools and representative bodies of local Roma communities, and inclusion of families in the life of the school. This finding might be relevant in terms of the possible effectiveness of joint work between schools, disabled persons' organizations, organizations of parents of children with disabilities and local communities.

Schools can usefully seek ways to ensure that people with disabilities are not discriminated against in the selection of teachers and teaching assistants, and by making reasonable adjustments to enable such staff to be recruited. Schools can be encouraged to make efforts to normalize disability in the school environment.

Two studies review interventions to support Roma adolescents to engage in participatory action research. Both studies report that participants' self-esteem increased and that there was a positive impact on a range of indicators regarding their commitment to their communities and their education. As other studies have indicated, however, child participatory action research needs to be undertaken with awareness of the risk of resistance from unsupportive adults.

In addition, it would be important to understand how the notion of ableism, often invisible in research initiatives around disability stigma, can contribute to reduce stigma and discrimination against children and youth with disabilities.

#### **4.8 Formative research is key to developing effective, integrated, multi-level social and behavioural change initiatives and impactful communications**

There is little discussion in the literature reviewed of the formative research used to develop interventions or the extent to which they form part of a wider theory of change. Communication initiatives need to be integrated with initiatives that focus on other drivers of social change, and designed on the basis of strong formative research and in conjunction with initiatives developed by other actors, such as government and NGOs. Examples of relevant formative research on disability, stigma and attitudes to people with disabilities are numerous in the Europe and Central Asia (ECA) region and globally, but the extent to which they are informing social and behaviour change programmes is not clear.

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### Multi-level stigma interventions

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Syaiful (left), 12, a child with a physical impairment, is pushed by his best friend Kevin Saputra (right), 9, a child with a visual impairment, at Syaiful's house in Banyumas, Central Java, Indonesia. They both attend Madrasah Ibtidaiyah (MI) 1 Ciberem in Central Java, which is part of the inclusive education programme.

## Annex A Methodology and search strategies for the literature review

### Search methodology

Communication for Development (C4D) is now recognized as more than the unidirectional dissemination of information. Recent guidance published by UNICEF on C4D with regard to violence against children describes C4D as:

an evidence-based and participatory process that facilitates the engagement of children, families, communities, the public and decision makers for positive social and behavioural change in both development and humanitarian contexts through a mix of available communication platforms and tools. It draws on learning and concepts from the social, behavioural and communication sciences. Central to C4D is the idea that communication is a dialogue, a two-way process that enables community stakeholders to be involved in decisions relating to them, and enabling solutions and messages to be locally contextualized and culturally relevant.

C4D entails the sharing of ideas and information, and the use of mass media, social media, community engagement and dialogue to enable and empower individuals and communities to participate in decisions that affect them.<sup>103</sup>

103 United Nations Children's Fund. *Communication for development*. New York: UNICEF. [https://www.unicef.org/cbsc/files/C4D\\_VAC\\_Technical\\_Guidance.pdf](https://www.unicef.org/cbsc/files/C4D_VAC_Technical_Guidance.pdf)



A review of this kind, taking into account the time and resources available, involves a systematic process for the identification and selection of evidence, but has a narrower scope than a full systematic review. It is (i) informed by an a priori protocol, (ii) involves a systematic search, (iii) aims to be transparent and reproducible, and (iv) ensures that data is extracted and presented in a structured way.<sup>104</sup>

Because the aims addressed are very broad and necessitate covering literature with a high level of published global output of varying quality (stigma interventions), we sought to prioritize the 'highest level of evidence' – evidence to emerge from systematic reviews and reviews of reviews. Reviews were then scrutinized for the studies most relevant to the aims of this study. Thus, for example, the systematic review by Rao et al. (2019) on multi-level strategies to counter stigma included several papers that contained an explicit communications component. These original studies were examined and reported on in further detail in separate data entries. The advantage of this approach is that the quality of included research has already been appraised, so the recommendations that emerge from them are based on evidence. In cases where a recent study with a high level of evidence was found, we did not seek out earlier studies.

Where no limited or no recent review-level evidence could be identified, a second search was conducted for individual studies of any design, included in peer-reviewed journals between 2000 and 2019.

Finally, we searched for grey literature using manual searches of Google, Google Scholar, and web pages such as the Communication Initiative site [comminit.com](http://comminit.com). The inclusion criteria for grey literature were as stringent as those for academic literature. Unpublished papers had to report on a programme or intervention that aimed to counter social stigma and promote the inclusion of the stigmatized group, and it needed to report on relevant outcomes. UNICEF and project partners provided some unpublished case studies. More detail is given on the search strategies below.

Two researchers undertook the search between 15 November 2019 and 3 February 2020. Researcher 1 focused primarily on peer-reviewed academic research, researcher 2 primarily on regional academic research and grey literature. The searches were conducted in English, French, Italian, Macedonian, Serbo-Croat, Slovenian and Spanish. A third researcher searched in Russian from 3 to 13 March 2020.<sup>105</sup>

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104 Munn, Z., et al. (2018). What kind of systematic review should I conduct? A proposed typology and guidance for systematic reviewers in the medical and health sciences. *BMC Med Res Methodol*, 18, art. 5. <https://doi.org/10.1186/s12874-017-0468-4>

105 Researcher 1 extracted data from 51 peer-reviewed academic journals or databases available globally. Researcher 2 extracted data from 38 peer-reviewed academic journals or databases and from 35 grey literature reports, case studies, books and other non-academic literature. Researcher 3 extracted 16 articles from Russian-language academic databases.

### **A.1.1 Researcher 1: Academic literature (peer-reviewed)**

#### ***Identification of the literature: Initial search and revision of terms***

An initial search using the terms 'communication for development' or 'C4D' revealed a limited number of published studies that met our inclusion criteria. Thus, for example, a search for these terms in EBSCO (the portal for social science, communication science, education, psychology, medical and nursing databases) produced only 125 results. Screening revealed that many of these results did not meet the inclusion criteria. Many studies were about participatory communication (as opposed to mass communications) but related to irrelevant populations (e.g., farmers) or aimed at objectives (e.g., encouraging vaccination) that were only tangentially pertinent to work involving children and adolescents with disabilities or special educational needs affected by stigma.

In order to meet the objectives of the search – the identification of approaches that could have a measurable effect in countering self-stigma and social stigma towards children and adolescents with disabilities or special needs – it was necessary to undertake several different rapid searches, and to use proxy terms for 'Communication for Development'.

#### ***Academic databases***

- **Search 1: Systematic and review-level evidence on communications aimed at countering stigma and promoting inclusion.** Priority was given to evidence relating to children and adolescents with disabilities or special needs, but the search was widened to include some other stigmatized impairments or socially excluded populations.
- **Search 2: Systematic and review-level evidence on specific participatory techniques and approaches** (e.g., action research, participatory photography, video, radio, theatre, sports, community mapping or mobile media) that have been used by people with disabilities or special needs, or other stigmatized groups such as people living with HIV/AIDS, ethnic minority groups or migrants.
- **Search 3: Individual studies on participatory techniques and approaches to promote empowerment of children with disabilities or special needs.**
- **Search 4: Systematic and review-level evidence of strategies to promote engagement of parents and caregivers** of children with disabilities or special educational needs in advocacy and campaigning.
- **Online sources:** Search of Google, Google Scholar, and specialized resource centres, including [communit.com](http://communit.com). No time limits were applied.



### **Databases searched**

- EBSCO Discovery (APA PsycInfo, CINAHL Plus, Education Research Complete, ERIC, JSTOR, Global Health Archive and MEDLINE).
- Web of Science.

### **Inclusion criteria**

Studies that included:

- i. Children living with a disability or special educational needs, or another population that experiences stigma or discrimination, including people living with HIV/AIDS, ethnic minority populations such as Roma, migrants, people with mental illness, people facing gender-based discrimination.
- ii. A project, programme, campaign or intervention with a participatory communication component, or a project, programme, campaign or intervention designed to counter stigma.
- iii. Improving the self-concept (self-efficacy, empowerment, reducing internalized stigma, increasing confidence and agency of stigmatized or excluded people) and countering social stigma and promoting inclusion as desired outcomes.
- iv. Reported effect of the programme on achievement of these outcomes.

### **Search 1: Systematic and review-level evidence on communications aimed at countering stigma and promoting inclusion.**

**Search terms:** AB (AB (stigma\* OR prejudice\* OR discriminat\* OR stereotyp\* OR exclusion OR shame) AND AB (intervent\* OR program\*)) AND AB (C4D OR communication OR particip\* OR action research)) AND AB (systematic review OR review OR scoping study)

**Limiters:** Peer-reviewed journals; date: 2015 01 01 – 2019 12 31. (Limited to studies published over the previous five years because of the wide scope of the search.)

**Results:** 917 titles reduced to 593 titles after removing duplicates; 20 papers were selected on title, and six on abstract, and included. A search was then undertaken for the original studies included in the systematic review, in order to look at these papers in more detail. Of these, 13 were selected in accordance with the inclusion criteria.

### **Search 2: Systematic and review-level evidence on specific participatory communication techniques and approaches (e.g., action research, participatory photography, video, radio, theatre, sports, community mapping, and mobile media) that have been used by people with disabilities or special needs.**

**Search terms:** AB “communication for development” OR AB “action research” AND AB (disability OR disabilities OR disabled OR impairment OR impaired OR special OR special needs). This was not limited to review-level evidence.

**Limiters:** Peer-reviewed journals; date: 2015 01 01 – 2020 12 31.

Narrowed by subject sub-category terms in EBSCO Discovery Service (EDS): comunicacion para el cambio social; autism spectrum disorders; attitude (psychology); communication for social change; communication for development; education; human; communication.

**Search modes:** Boolean/Phrase.

**Results:** 268 titles reduced to 127 after removing duplicates; 45 papers selected on title, 4 on abstract and included in accordance with the inclusion criteria.

**In addition under Search 2:** separate, targeted searches were conducted with search terms *disabil\** OR “special need\*” OR *impairment* OR *impaired* OR *handicap\** OR *CWD* OR *PWD* OR *PLWD* OR *HIV* OR *AIDS* OR *Roma* OR *migran\** OR *migrat\** OR *refugee\** in conjunction with ‘systematic review’ using Google and Google Scholar. Material on Roma and HIV has been included, and there was no material on C4D with migrant children that met the inclusion criteria.

### **Search 3: Individual studies on participatory techniques and approaches to promote empowerment<sup>106</sup> of children with disabilities or special needs**

**Search terms:** AB=(*disabil\** OR (*special need\**) OR *impairment* OR *impair\** OR *handicap\**) AND AB=(*child\** OR *adolesc\** OR *teen\**) AND AB=((*systematic review*) OR *review* OR *metaanalysis* OR (*meta-analysis*)) AND AB=(*action research*, *participatory photography/photovoice*, *radio*, *storytelling*, *community mapping*, *theatre*, *sport\**).

**Limiters:** Peer-reviewed journals; date: 2012 01 01 – 2019 12 31.

**Results:** This produced 119 results, some of which overlapped with findings from the previous searches; 60 were selected on title and 6 on abstract and included.

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<sup>106</sup> Empowerment is defined as the process of becoming stronger and more confident, especially in controlling one’s life and claiming one’s rights. See Rappaport, J. (1981). In praise of paradox: A social policy of empowerment over prevention. *American Journal of Community Psychology*, 9(1), 1–25.

**Search 4: Systematic and review-level evidence of strategies to promote engagement of parents and caregivers of children with disabilities or special educational needs in advocacy and campaigning.**

**Search terms:** AB=(disabil\* OR (special need\*) OR impairment OR impair\* OR handicap\*) AND AB=(child\* OR adolesc\* OR teen\*) AND AB=((systematic review) OR review OR metaanalysis OR (meta-analysis)) AND AB=(parent\* OR mother\* OR father\* OR caregiver\*) AND AB=(parent\* OR mother\* OR father\* OR caregiver\*) AND AB=(advoc\* OR campaign\* OR particip\*).

**Limiters:** Peer-reviewed journals; date: 2000 10 10 – 2019 12 31.

**Results:** This produced 31 results; 15 were selected on title and 3 on abstract.

**Search 5: Online and hand searches. No time limits were applied, but in the selection, preference was given to most recent studies.**

In addition to the database search, an online search was conducted of the C4D site The Communication Initiative ([comminit.com](http://comminit.com)) and Johns Hopkins University resource centre. Peer-reviewed academic publications contained in these sources were predominantly duplicates of material already identified in the database searches.

Finally, a hand search was conducted using Google and Google Scholar. This included, for example, 'participatory research' (which often involves a communications component) involving children with visual impairments.

**Results:** This produced 13 further individual studies of interest.

Online resources, such as The Communication Initiative [comminit.com](http://comminit.com) web page, proved to be rich in reports and descriptive studies but contained relatively few evaluations with robust outcome measures related to stigma. However, these reports and case studies contain detail on implementation across different contexts, and they are an important complement to more robust evaluations.

### **A.1.2 Researcher 2: Academic and grey literature**

Researcher 2 hand-searched a range of online resources for additional academic literature as well as grey literature.

A list of organizations (NGOs, international NGOs, associations, self-help groups) was obtained by Google search from different primary sources:

- <https://www.disabled-world.com/disability/foundations/us-organizations.php> <https://www.friendshipcircle.org/blog/2016/01/14/10-special-needs-organizations-you-should-know-about/>

- <https://ncdj.org/resources/organizations/>
- <https://www.angloinfo.com/how-to/germany/healthcare/people-with-disabilities/disability-organisations>
- <https://www.afdo.org.au>
- <http://www.edf-feph.org/about-us>
- <http://www.internationaldisabilityalliance.org/content/history>
- <https://hi.org>
- <https://www.erionet.eu/>
- [https://ec.europa.eu/info/policies/justice-and-fundamental-rights/combating-discrimination/tackling-discrimination/non-governmental-organisations-fighting-against-discrimination\\_en](https://ec.europa.eu/info/policies/justice-and-fundamental-rights/combating-discrimination/tackling-discrimination/non-governmental-organisations-fighting-against-discrimination_en)

The websites of international, national and regional partners cited by these organizations were also searched.

Systematic checking of the names on the list identified those whose projects or actions include the topic of children with disabilities (general, theme-specific, region-specific, etc.). This produced a list of search terms for a cross-check performed with a Google search. Valuable data were gleaned in the process, for example, that actions or programmes for children with disabilities implemented by these organizations constitute merely 4 per cent of all programmes.

Few of the organizations that work on issues faced by children with disabilities provide written reports or evaluations of ongoing, past or planned actions. Most of their websites provide general information about awareness-raising campaigns on specific issues, training programmes, legal advice, and support for national or international legislation. Many websites provide generalized information with links, usually to national governmental agencies that deal with disability, large umbrella organizations, or to various United Nations or WHO bodies.

Of the grey literature, six reports matched the criteria for inclusion, from the United States, the United Kingdom and Canada.

UNICEF proposed that we also search the following disabled persons' organizations' websites:

- African Disability Forum <https://www.africadisabilityalliance.org/>
- Arab Organization of Persons with Disabilities <http://www.aodp-lb.net/> (Arabic)
- <http://www.pacificdisability.org/>
- ASEAN Disability Forum <http://aseandisabilityforum.org/digaleri/>
- Down Syndrome Int <https://www.ds-int.org/>
- Inclusion Int <https://inclusion-international.org/>
- World Blind Union <http://www.worldblindunion.org/English/Pages/default.aspx>

- World Federation of Deaf <http://wfdeaf.org/>
- International Federation for Hard of Hearing People <http://www.internationaldisabilityalliance.org/IFHOH>

These sites returned two documents (a toolkit, and an action report) that were reviewed for their tangential relevance.

### **A.1.3 Approach to assessing hierarchy of evidence**

The research team used the Joanna Briggs Institute Levels of Evidence for Effectiveness<sup>107</sup> as follows:

Level 1 – Experimental designs

Level 1.a – Systematic review of randomized controlled trials (RCTs)

Level 1.b – Systematic review of RCTs and other study designs

Level 1.c – RCT

Level 1.d – Pseudo-RCTs

Level 2 – Quasi-experimental designs

Level 2.a – Systematic review of quasi-experimental studies

Level 2.b – Systematic review of quasi-experimental and other lower study designs

Level 2.c – Quasi-experimental prospectively controlled study

Level 2.d – Historic/retrospective control group study

Level 3 – Observational – Analytic designs

Level 3.a – Systematic review of comparable cohort studies

Level 3.b – Systematic review of comparable cohort and other lower study designs

Level 3.c – Cohort study with control group

Level 3.d – Case – Controlled study

Level 3.e – Observational study without a control group

Level 4 – Observational – Descriptive studies

Level 4.a – Systematic review of descriptive studies

Level 4.b – Cross-sectional study

Level 4.c – Case series

Level 4.d – Case study

Level 5 – Expert opinion and bench research

Level 5.a – Systematic review of expert opinion

Level 5.b – Expert consensus

Level 5.c – Bench research or single expert opinion

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107 Joanna Briggs Institute. (2013). *JB I levels of evidence*. [https://joannabriggs.org/sites/default/files/2019-05/JB I-Levels-of-evidence\\_2014\\_0.pdf](https://joannabriggs.org/sites/default/files/2019-05/JB I-Levels-of-evidence_2014_0.pdf)

