Creating a better post-pandemic future for adolescents with disabilities

Adolescents with disabilities must have their needs prioritised in recovery and future pandemic responses to improve health, educational, and social outcomes, argue **Sarah Baird and colleagues**

Adolescents globally have been negatively affected by the covid-19 pandemic through multiple pathways. As well as the effects of contracting the disease (either themselves or a family member), adolescents have experienced increased household poverty, closure of schools and other key services, mobility restrictions, and social isolation, which can manifest in symptoms such as depression and anxiety with longer term effects on wellbeing.[1 2] For adolescents with disabilities, who were already experiencing disadvantage,[3] the response to the pandemic magnified pre-existing challenges in accessing services and highlighted social discrimination towards people with disabilities within the family, community, and policy arena (fig 1).[4 5]

Although an estimated 161 million adolescents are living with disabilities globally (box 1),[9] covid-19 policies have given little attention to their experiences and needs during the pandemic, and concerns have been expressed about their exclusion from broader global health and social protection agendas.[10] This is particularly worrying given that adolescents with disabilities are at greater risk of severe effects from covid-19 and poor outcomes after infection because of the high prevalence of poor nutrition and underlying health conditions in this group.[11]

To avoid adolescents with disabilities being further disadvantaged, they need to be considered as a priority cohort within post-pandemic recovery action plans and given greater emphasis in future pandemic responses. Intentional action is the only way to compensate for the disrupted learning and development opportunities that many young people with disabilities faced during the pandemic and to secure brighter health, education, and psychosocial trajectories so that we meet the collective global commitments to "leave no one behind" set out in the 2030 sustainable development agenda.[12]

KEY MESSAGES

- Adolescents with disabilities are at high risk of negative outcomes from the covid-19 pandemic because of multiple pre-existing vulnerabilities and challenges accessing public services
- All countries can mitigate these negative effects by stepping up social assistance and investing in inclusive programmes to address psychosocial distress and learning loss
- Countries must also create opportunities for adolescents with disabilities to be engaged in developing disability responsive policy to recover from the pandemic and prepare for future crises

Tackling widened educational disparities

Data from Bangladesh, Ethiopia, and Jordan show that adolescents with disabilities were not readily able to switch to online learning when schools closed because of covid-19.[13] Conventional distance education typically lacks modifications such as sign language interpretation, enhanced fonts, and colour and text reading features. Moreover, evidence from multiple countries shows that for adolescents with intellectual disabilities who were getting tailored services through school, disruptions not only affected their learning but also led to increased severity or intensity of behavioural problems, including aggression, conduct problems, and antisocial behaviour.[14] These challenges compounded pre-existing disparities in access to education, including overall school participation rates as well as limited or segregated schooling environments for students with disabilities.[3] For example, even before the pandemic children with severe functional difficulties were three times less likely to be enrolled in primary school than their non-disabled peers and half as likely to be in secondary school.[3]

To address these deficits, adolescents with disabilities must be given priority in learning recovery plans. Provision such as catch-up classes and mentoring would support them to get back on track and maximise learning outcomes.[15] In the longer term scaled-up and improved access to tailored education (remote, in-person, or a combination of both) could reduce the educational exclusion facing many adolescents with disabilities, especially those in low and middle income countries.[3]

Disability specific accommodations advocated for use across settings include sign language interpretation for remote lessons, reading aids or braille texts for students with visual impairments,[16] and adapted materials and online support designed for young people with learning disabilities.[17] To better prepare for future crises, governments should invest in professional development training for teachers and equip them with the skills required to provide online classes for students with disabilities.[18] Improving communication with parents, caregivers, and teachers would further underpin effective remote learning.[19]

Considering disability within social assistance packages

Households caring for young people with disabilities are more likely to experience poverty because of care responsibilities hindering full time participation in the workforce and the cost of providing for medical needs and adaptive devices.[20 21] During the pandemic these challenges were exacerbated by higher rates of household unemployment and underemployment.[16] Moreover, given that many young people with disabilities rely on school based social protection (such as school feeding programmes and social assistance for education payments), school closures increased poverty and food insecurity.[14 19]

As part of pandemic recovery efforts, social protection support must be calibrated to ensure that adolescents with disabilities are able to re-enrol in education and to access medical and psychosocial support services. Longer term, to tackle poverty and economic vulnerabilities of

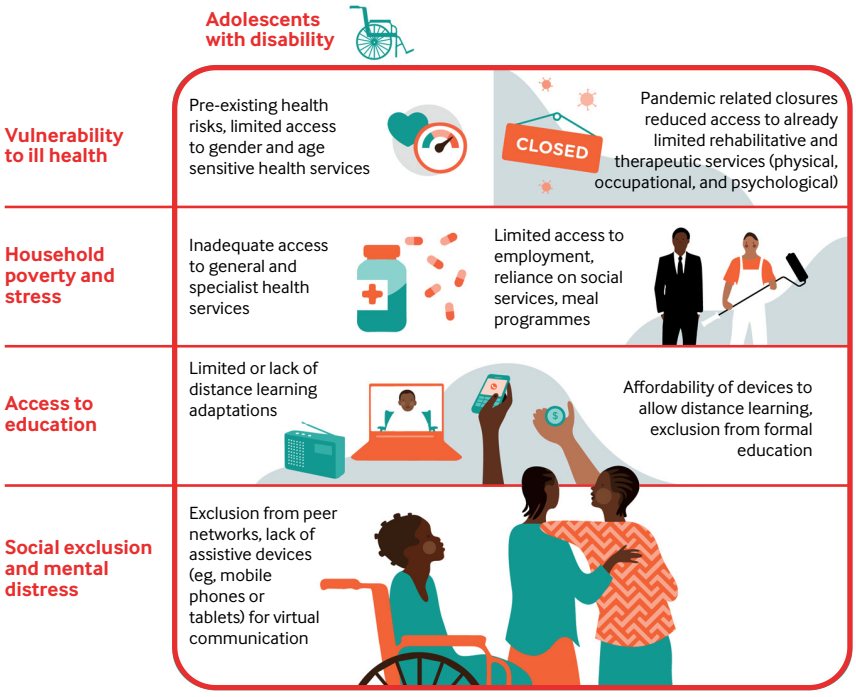

Fig 1 | Examples of pre-existing challenges that amplified the negative effects of covid-19 on adolescents with disabilities globally

adolescents with disabilities and their families during future crises, social protection platforms should be expanded and adapted to respond to shocks in a timely way, while prioritising the needs of the most disadvantaged adolescents. Programming might include cash to enable distance learning, education fee waivers, covering costs of internet connectivity and devices (for example, Unicef Jordan distributed tablets to adolescents during the pandemic[22]), financing to support access to assistive devices (such as Ghana's disability common fund[23]), or running community nutrition programmes to make up for lack of access to school meal programmes.[19]

Targeted social protection programmes are resource intensive and often exclude many people with disabilities because, for example, they are focused on poverty and do not consider the specific needs of people with disabilities. There is therefore an urgent need to ensure that function based, rather than impairment based, assessments are used that are compliant with the UN Convention on the Rights of Persons with Disabilities.[24]

Supporting adolescent connectedness, agency, and resilience

Adolescents with disabilities globally were experiencing high levels of social isolation, violence, and exclusion from services and support structures before the pandemic.[3 25] School closures, the lack of online education adaptations, and temporary closure of non-governmental organisation programmes and other support networks in response to covid-19 all exacerbated the isolation felt by adolescents with disabilities and their families.[26] In fact, parents reported that lack of social interaction was one of the most challenging effects of the pandemic for their child.[27] Social isolation is directly associated with poor mental health and violence among young people with disabilities.[28]

To mitigate the risks of social isolation, psychosocial distress, and exposure to violence, we need to invest in programmes to support adolescent connectedness, agency, and resilience as part of broader pandemic recovery efforts. These interventions could take the form of age tailored, community based mental health counselling and peer support initiatives, either in person or online,[2] as well as support from adults outside the family such as teachers, health extension workers, and social workers to reduce risks and ensure continuity of reporting and referral systems.[29] An example of such a model is the Nairobi Mind Empowerment Peer Support Group in Kenya, which works with young people with psychosocial disabilities to help them live independently and find suitable employment, healthcare, and treatment.[30] Extracurricular support for adolescents with disabilities could foster opportunities for peer interaction and counteract the social isolation they experience.[25] National governments and development partners also need to invest urgently to improve referral systems for specialised care and support.[31] Investing in accessible helplines and reporting systems for adolescents and young people with disabilities should also be a priority.[16 32]

Including adolescents with disabilities in policy development

Lack of high quality data on adolescents with disabilities and exclusion of their voices from policy development present

Box 1: Defining disability

Understandings of disability are various and contested. Our analysis is informed by the conceptual framing outlined in the International Classification of Functioning, Disability, and Health—Children and Youth (version 2007), which was developed in accordance with the UN Convention on the Rights of Persons with Disabilities.[6] This model focuses on children and young people, across five domains—body functions, body structures, activities, participation, and environmental contextual factors—to explore the interaction between a young person's physical structure and function and his or her contextual environment, which can inhibit participation and access to services.

The medical model—still reflected in the policies and services of some high income countries and most low and middle income countries—considers disability as a medical matter, and people with disabilities are commonly assessed according to the extent to which they require specialist treatment.

The social model of disability, by contrast, emphasises that people are disabled by barriers in society—whether physical, institutional, or attitudinal—rather than by their impairment. It follows that the emphasis is then on removing these barriers so that people with disabilities can enjoy greater independence, choice, and equality.[7 8] However, there are some important gaps in this approach. It pays little attention to social characteristics such as gender and ethnicity and instead treats people with disabilities as a homogeneous group.

Box 2: Experiences of covid-19 and lockdowns among adolescents with disabilities*

- "I like to draw—that would give me something to do during the lockdown— but no one cares for people with disabilities. I don't go out of the house and I have no materials, no interaction with anyone … No activities were organised in the [refugee] camp for adolescents. There was nothing."
- (16 year old Palestinian girl with a hearing disability in Jerash refugee camp, Jordan)
- "It is easier for people with no sight problem—they can copy and read any material they want. For us, it is all about listening to the teacher and trying to remember what he has said. Sometimes we ask other students to read to us to study for examinations. Now there are no students to read to us. So if we are asked to take an exam when school opens, we haven't learnt anything… There is no one [to help]."
- (18 year old Ethiopian girl with a visual impairment)
- "We asked three times to be selected for [daily labouring work]. In other cities, youth like us [with disabilities] we heard get these chances but no one has listened to us. They [the government] have done nothing for us."
- (18 year old Ethiopian boy with a visual impairment)
- "Since school was suspended, I have not done anything. The school did not tell us anything about online lessons… The Ministry of Education said there is an online education platform, but they explained nothing about how to access it… for students with visual impairments."
- (15 year old Syrian refugee boy with visual impairment living in a host community in Jordan)
- "When the lockdown happened, we had a lot of shortages at home. This affected me a lot. I didn't leave the apartment."

(12 year old Jordanian boy with a physical impairment).

*Quotes from qualitative interviews with adolescents collected as part of the Gender and Adolescence: Global Evidence (GAGE) study[5]

important challenges to directing future support for adolescents with disabilities. Evidence on the effects of covid-19 on people with disabilities in general—let alone on people with specific types of impairment (eg, mobility, visual, hearing, learning, or self-care) or on adolescents as a group—is scarce (see web appendix for a rapid review). Adolescents with disabilities were typically not consulted during the pandemic response by government task forces[33] and were overlooked as a specific group. For example, emergency response systems were not appropriately trained on how to work with adolescents with disability, social protection programmes (eg, cash for work) did not consider the specific needs of adolescents with disability, and information campaigns were not adapted appropriately.[33]

There must be more systematic data collection and monitoring efforts at country level to render adolescents with disabilities and other marginalised groups more visible and inform policy makers' decisions on allocation of scarce resources.[34] Governments should invest in education management information systems[35] and capture disability disaggregated data at health facilities. We also suggest that it is important to oversample young people with disabilities within routine household surveys, instead of relying on random sampling techniques (as is done in demographic and health surveys and multiple indicator cluster surveys). Another approach would be to invest in longitudinal studies on people with disabilities to assess the effects of crises as they unfold.[36] Adolescents should be consulted in defining both what information is collected and which metrics are prioritised in these data collection efforts.[37]

Policy makers globally rarely hear the voices of adolescents with disabilities, even though listening to and actively engaging with young people with diverse impairments is key to ensuring effective policy responses.[32] Our earlier work on the Gender and Adolescence: Global Evidence (GAGE) study highlights the ways in which adolescents with disabilities thought they had been overlooked during the covid-19 pandemic (box 2).[5] Consulting groups that represent people with disabilities, and particularly young people, would be a major step forward. One example of how this has been done was during the involvement of organisations led by young people with disabilities as part of a recent Leonard Cheshire report on the effect of the pandemic in five low and middle income countries.[33] Unless young people with disabilities are consulted and involved in designing covid-19 recovery programmes, any policy action is unlikely to achieve its aims.

Leaving no one behind

While all young people have been adversely affected by the pandemic and associated control measures, adolescents with disabilities have been particularly affected. The evidence shows that the pandemic exacerbated pre-existing economic and social inequalities, with pandemic responses failing to ensure access to online education for adolescents with disabilities and other services being disrupted altogether. There was also a lack of policies explicitly addressing the needs of young people with disabilities. These impacts are unlikely to be temporary, given that social connectedness, good mental health, education, and social protection are key to adolescent outcomes in the longer term.[38]

Furthermore, the pandemic has increased the number of young people with disabilities (around 10% of young people who contract covid-19 are thought to subsequently go on to develop long covid[39]). Ultimately, ensuring long term recovery from the pandemic for adolescents with disabilities requires a multisectoral, system-wide approach, involving a wide range of government departments, including health, education, labour, social development, justice, transportation, urban planning, water, and information and communication technology.[40] Continuing to ignore the needs of young people with disabilities in pandemic recovery efforts and future crisis prevention efforts will further entrench inequalities and undermine the 2030 agenda's global commitment to leave no one behind.

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Web appendix: Rapid review of the literature on adolescents with disabilities during the covid-19 pandemic

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