



Inclusive Futures

Promoting disability inclusion

“The situation has exposed persons with disabilities to double edged pain”: people with disabilities’ experiences of the COVID-19 pandemic in Uganda

A qualitative study undertaken as part of the Inclusion Works programme



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This paper has been funded with UK aid from the UK government. The opinions expressed are those of the authors and do not necessarily reflect the views or policies of the UK government or members of the Inclusion Works consortium.

Suggested citation: Wickenden, M., Wakoko, E., Shaw, J., Thompson S.J. & Rohwerder, B. (2021). *“The situation has exposed persons with disabilities to double edged pain”: people with disabilities’ experiences of the COVID-19 pandemic in Uganda*. Brighton: IDS, DOI: [10.19088/IF.2021.009](https://doi.org/10.19088/IF.2021.009)

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Executive summary

This qualitative study was undertaken as part of the work of the Foreign, Commonwealth and Development Office (FCDO) funded Inclusion Works programme which aims to improve inclusive employment for people with disabilities in four countries: Uganda, Kenya, Nigeria, Bangladesh. When the COVID-19 pandemic emerged early in 2020 the work of this consortium programme was adapted to focus on pandemic relief and research activities, while some other planned work was not possible.

The Institute of Development Studies (IDS) led a piece of qualitative research to explore the experiences and perceptions of the pandemic and related lockdowns in each country, using a narrative interview approach, which asks people to tell their stories, following up with some further questions once they have identified their priorities to talk about. Using a very flexible ‘teller-focused’ methodology allowed us to hear the real concerns of the participants and to probe for in-depth examples of their experiences and perceptions. This method can provide valuable insights which contrast with and complement quantitative and researcher set agendas of inquiry.

10 jobseekers with disabilities in each country were purposively selected to take part, each being invited to have two interviews with 1-2 month interval in between, in order to capture changes in their situation over time. The 10 interviewees had a range of impairments (physical, visual, hearing, intellectual, speech, albinism, sickle cell disease), were gender balanced and had various ages, living and working situations.

The study had ethical approval from IDS, all participants had information about the study in advance and if they agreed to join in, signed a consent form or provided verbal consent. All interviews were undertaken remotely by phone or a videoconferencing platform (e.g. WhatsApp, Zoom etc) and participants connection/data costs were met. Accessibility needs were also planned for in advance and met. All interviewers were nationals of the countries, so the interviews were in the language of choice of the interviewees. Interviews were recorded, translated and transcribed.

An online thematic analysis process included all in-country researchers and the IDS team. Individual stories from all 4 countries were reviewed and coded. During discussion overarching common themes were identified and agreed.

Uganda has had relatively low rates of COVID-19 infection and deaths, with a total of 40426 cases, 15052 recovered cases and 334 deaths on 5th March 2021.

There was a large amount of similarity and agreement about the key themes across the 4 countries. The two overarching types of themes emerged. First there were ‘concrete’ or material themes related to the impacts of the pandemic and lockdown on everyday life, divided into subthemes about: a) individual (and intersecting) identities linked to people’s gender and/or impairment type and disability status, b) economic/financial impacts and people’s experience of the structures, systems and civil society responses to the pandemic.

Secondly there are subjective emotion themes, which show the range of feelings that people had in response the situation and sometimes clearly linked to the concrete impacts above.

An overarching theme of ‘destabilisation, disorientation and uncertainty’ was experienced due to the extraordinary situation, with subthemes of shock, confusion, fear, loss, stress, conflict, anxiety, despair and depression in various forms.

Illustrative quotes taken from the data in Uganda are provided in the report.

“The situation has rendered me too poor to afford my own basic needs.”
(woman with hearing impairment)

“Survival continues to harden.” (man with speech impairment)

Overall the findings show that the people with disabilities experienced very negative impacts during the pandemic times and there is some evidence that their pre-existing disadvantage and marginalisation has been exacerbated. Financial concerns were an almost universal finding. Many people had lost their jobs or income due to pandemic restrictions and struggled to pay for enough food or other basic needs, which caused them much stress and sadness. Increased costs, including for transport, made accessing food and medicine more difficult. To survive during the worst of the pandemic and lockdown, many interviewees relied on using up their savings or business capital, financial support from external family members or friends, or sold their assets. Access to services such as health, education, information and social protection/emergency relief were all felt to be poor and, in some cases, discriminatory. Very few people with disabilities reported receiving government or social assistance from other organisations during the pandemic despite their need for it. Issues with the provision of assistance included people with disabilities not being included amongst the list of beneficiaries; information about relief distributions not being accessible or even passed on, resulting in people with disabilities not attending; assistance only being provided as a one-off; and assumptions that their disability organisations would provide for them. There was increased tension between men and women in the home due to the financial crisis and participants also mentioned increased gender-based violence in the wider community. Increased disability stigma and discrimination were reported by several participants.

There were some signs of improvement in people’s circumstances and more positive feelings during the second interviews, although this depended on individual situations, so that those who had found employment or resumed studies were more optimistic, whereas others were in continuing dire risk of poverty and had ongoing worries about the future for themselves and their families. Many interviewees and their family members were still unemployed, and the conditions of those who found work again were often worse than before, with fewer hours, or customers, or reduced prices for their goods. Many of the interviewees with disabilities were unable to find employment despite their best efforts, including as a result of disability discrimination. This meant many people were still struggling to survive or thrive.

Participants were also asked for recommendations about how planning and mitigation of impacts of future pandemics and other crises could be made more disability inclusive.

The key message is that policymakers, planners and service providers need to ensure that they include people with disabilities (directly or through their representative organisations) in their strategy planning for pandemics and other crises, to ensure that a disability inclusive approach is automatically ‘baked in’ in advance, rather than their needs being accidentally overlooked or deliberately deprioritised.

Easy read executive summary

- The study asked 10 people with different disabilities for their stories of the COVID-19 times.
- There were 5 women and 5 men, with different disabilities, and living in different situations.
- The interviewer was a researcher with a visual impairment called Eric.
- People in Uganda were shocked by the sudden lockdown in March 2020.
- There were strict rules about going out and special instructions like washing your hands and wearing a mask.
- Schools and workplaces were closed, and students were sent home.
- Many people with disabilities worried about money because people couldn't work or lost their jobs.
- Some people with disabilities got help from the government or NGOs but many said it was not enough help.
- For some people it was hard to understand about COVID-19 and how to stay safe as the information was not given clearly or in ways that all could understand.
- Some people with disabilities got into trouble with the police because they didn't understand about not being allowed to go out at night and what they were allowed to do.
- It was hard to get enough food for many families. People worried about starving.

- Getting services like health care and assistive devices was difficult.
- You had to pay more money for things like transport and medicines.
- Some people thought men suffered more during COVID-19, some people thought it was harder for women.
- Many people had strong feelings such as fear, worry, boredom, frustration, sadness.
- People wondered if things would ever be normal again.

The people were asked for their ideas about what should happen if there is another illness that lots of people get or another big emergency when people need help. They said:

- There should be more money to help for everyone, and it should be easy to get it.
- There should be ways to help people get a job or a loan or start a new business, especially for people with disabilities
- Information from the government should be clear and easy to understand for all.
- The government should plan ahead to make sure people with disabilities are included in what happens when there is an emergency like COVID-19.
- Organisations of persons with disabilities should be asked what they think should happen to support people with disabilities during emergencies like COVID-19.

Essomo mu Bufunze

Essomo lino lyakolwebwa ng'ekitundu ku mirimu egikolebwa ekitongole kya Foreign, Commonwealth and Development Office (FCDO) ekitekebwa mu ssente aba puloguraamu ya Inclusion Works egendelera okwongerako ku byemirimu gy'abantu abalina obulemu mu nsi nnya: Uganda, Kenya, Nigeria, Bangladesh. Senyiga omukambwe (COVID-19) bweyatandika mu mwaka gwa 2020 omulimu gwa puloguraamu eno gwakuyusibwaamu ko okussa essira ku kubudabudda n'okunonyereza, kubanga emirimu emilala gyali tegisobola kukolebwa.

Ekitongole kya Institute of Development Studies (IDS) kyakulemberamu okunonyereza okuzuula ebyafaayo n'endaba ya kazigizigi era negerageranya omuggalo mu buli nsi, ngekozesha okunonyereza okw'okubuuza ebibuuzo, okusaba abantu okunyumya ebibakwatako, nga bwebababuuzo ebibuuzo ebilala ebyetagisa kasita bamala okutegeera byebasinga okwetaaga okwogerako. Okukozesa enkola ey'okwekanya abuzibwa ebibuuzo kyatusobozesa okuwulira ebikwata ku bantu era n'okwongerako okubabuuzo okuwa eby'okulabirako ebyebintu byebayiseemu n'ebyebalwoozu. Enkola eno esobola okutumanyisa ebyomugaso era negerageranya n'okwongerako ku bwino abanonyereza gwebetaaga.

Abanoonya emirimu 10 nga balina obulemu mu buli nsi balondebwa n'obwegendereza okwenyigira mu, nga buli omu ayitibwa okubeera ne yintaviyu bbiri mu mwezi gumu oba ebiri, okusobola okulaba enkyukakyuka mu mbeera okumala ekiseera. Ababuzibwa ebibuuzo 10 balina obulemu obwenjawulo, nga sibakikula kimu era nga bawukana mu myaka, gwebabeera n'embeera ze bakoleramu. Mu bano mwaalimu: abaliko obulemu bwo butalaba (visual impairment), obulemu bwo obwekuusa ku ku tambula (physical impairment), obulemu bwo butawulira (hearing impairment), obulemu bwo kukwata mpola (intellectual impairment), obulemu bwa nalubili (sickler), obulemu bwo lususu (albinism), obulemu bwo kukalubizibwa mu njogela (speech impairment).

Essomo lyali lyakirizibwa okuva mu IDS, abenyigiramu bonna balina obubaka obukwata ku ssomo era bwebamaliriza okukiriza okwenyigiramu, bateeka emikono ku foomu ey'okuwaayo olukusa. Okubuuza ebibuuzo kwakolebwa okuyitira ku ssimu oba olukung'ana lw'okumutimbagano (okugeza WhatsApp, Zoom, nebilala) era abenyigiramu basasulibwa ebisale by'omutimbagano. Eby'okubatulikira nabyo byatekebwa mu nkola era nebisinikanwa. Ababuuzo ebibuuzo bonna bali batuuzo mu nsi zabwe, era ebibuuzo byababuzibwa mu nnimi zebalondako. Yintaviyu zakwatibwa ku butambi, n'ezivunulwa era neziwandikibwa.

Okwekenenya kw'okumutimbagano kwalimu abanonyereza b'omunsi zonna n'ekibinja kya IDS. Embooji zabuli muntu okuva mu nsi 4 zakebelebwa n'ezivandikibwa. Mu kuteseganya waliwo ebyazuuka ebifanagana ebyazulibwa nebiliziganyizibwako.

Uganda ebadde n'emiwendo mittono egyabalina akawuka ka senyiga omukambwe (COVID-19), okutwalira awamu abantu 40426, 15052 abawonye era abaafa 334 okusiziira ku alipoota ya 5th March 2021.

Waliwo ebifanagana bingi n'ebyakiriziganyizibwako ku bisinga obukulu mu nsi zino ennya. Waliwo ebyasukuluma bibiri ebyazulibwa. Ekisooka ku bikulu bino kyali 'kigumivu' oba

eky'ebintu ekikwata ku biva mu kazigizigi k'omuggalo ku bulamu obwa bulijjo, era kino kyayawulibwamu mu bino wamanga: a) Omuntu (nabalala) nekimukwatako ebyesigama ku kikula ky'omuntu ne oba obulemu obwengeri ezisinga b) eby'efuna nekimwata ku bantu byebayitamu, enkola yabyo n'ebyamateeka mu kiseera kya COVID.

Ekyokubiri waliwo ebikulu ebikwata ku mpulira, ebilaga engeri ezenjawulo abantu gyebawuliramu nga batukidwako embeera era nekiseera ekimu nga kyesigama ku bintu ebigumivu ebiwandikidwako wa ggulu. Ensonga enkulu 'eyokute (a) ganyizibwa, okukyankalanyizibwa era n'okuberawo mu lusuubo' kwatukawo kulw'embeera essukuluma kuya bulijjo, n'ensonga ez'okwekanga, okubuzabuzibwa, okutya, okufirwako, obwelarikirivu, obutabanguko, okutitiira, okunakuwala era n'okwenyamira mu ngeri ez'enjawulo.

Obubaka mu bufunze obwafunibwa mu byakung'anyizibwa mu Uganda mu alipoota eno.

“Embeera enjavuwazza nnyo era sisobola nakwetusaako byetaago byange.”
(omukyala alina obulemu bw'okuwulira)

“Okuberawo kwongera okukaluba.” (omusajja alina obulemu bw'okwogera)

Okutwalira'wamu ebyazulibwa bilaga nti abantu abalina obulemu bakosebwa mu kiseera kya senyiga omukambwe (COVID-19) era waliwo obukakafu nti embeera yabwe embi gyebalina n'okusosolebwa kweyongeramu. Obwelarikirivu mu byenfuna kyenkana bwali bwazulibwa mu nsi yonna. Abantu abasinga bali bafiirwa emirimu gyabwe oba nokufuna ensimbi olw'omuggalo era babonabona okusasulira emmere emala oba ebyetaago ebilala, ekyabaletera obunyikaavu n'okunakuwala. Ebisale ebyayongezebwamu, nga mwemuli n'ebisale by'entambula, byaleta okufuna emmere n'eddagala ekintu ekizibu. Okusobola okuberawo mu kiseera ekyakazigizigi n'omuggalo, ababuuzibwa ebibuuzo bangi besigama ku kukozeza ensimbi zabwe zebali balina oba eza bizinensi, ensimbi okuva mu b'omu maka abalala ob'emikwano, oba nebatunda byebalina. Okufuna empeereza ng'obujjanjabi, ebyenjigiriza, obubaka n'okuyambibwa okwenjawulo kwali kuzibu era, mu ngeri ezimu, nga kusosola. Abantu batono abalina obulemu abategeeza nti bafuna obuyambi okuva mu gavumenti oba okuva mu bitongole mu kiseera kyakazigizigi wadde nga bali babyetaaga. Obuzibu mu kuwaayo obuyambi bwalimu abantu abalina obulemu obutatekebwa ku lukalala lwabo abalina okufuna ebyetaago; Ebikwata ku kugabanya ebyetaago ebitasobola kubatukako oba kugabibwa, kyaviramu abantu abalina obulemu obutagenda; okuyambwa nga kuwebwayo ng'ekimu; era ebyali bitebezezebwa okubawebwa ebitongole ebilabilira abalina obulemu. Waliwo obutategeragana wakati wabasajja n'abakazi mu maka olw'ebyensimbi era abenyigiramu bayogera ku butabanguko mu maka obweyongera mu bitundu ebisinga. Okusosola abalina obulemu kwalopebwa abantu abawerako.

Waliwo obubonero obwokulongoosa embeera z'abantu era n'okuwulira obulungi mu kubuuzo ebibuuzo omulundi ogw'okubiri, wadde nga kino kyesigama ku muntu ssekinoomu, kuba abo abali bafunye emirimu oba abaddamu okusoma balina esubi lingi, ate nga abalala bali beyongerayo okwavuwala era n'okwelarikilira ku biseera byabwe eby'omumaaso n'abomumaka gabwe. Ababuuzo ebibuuzo abasinga n'abomumaka gabwe bali tebanafuna mirimu, era embeera zabo abaddamu okukola nate bakalubilizibwa nnyo, nga balina essaawa ntono ku zebalina, oba nga bakasitoma batono, oba ngemiwendo gy'ebintu byabwe gyakendeera. Abantu abasinga ababuuzo ebibuuzo abalina obulemu bali tebasobola kufuna mirimu wadde nga bali bagezaako nnyo, nga kyesigama ku kusosolebwa

olw'okubera n'obulemu. Kino kyali kitegeeza nti abantu bangi bali bakyagezaako obutaffa oba okubeera mu bulamu obweyagaza.

Abenyigiramu era babuzibwa okuwa ebiteeso ku ngeri y'okukendeeza ebiyinza okutukawo ngekilwadde kilala kibaluseewo nga bisobola okuyamba abantu abalina obulemu.

Obubaka obukulu eri abakola amateeka, abategeka n'abagaba empeereza bwa kufaayo ku bantu abalina obulemu (nga babatukirira oba mu kuyitira mu bitongole ebibakikirira) nga bakola entegeka mu kiseera ngekilwadde kimazze okubalukawo oba obuzigizigi obulala, okulaba nti enkola eyamba abalina obulemu nayo 'ekolebwako' mu bunambiro, obutelabira byetaago byabwe mu butanwa oba mu bugenderevu.

Soma ekiwandiiko mu bufunze

- Essomo lyabuuza abantu 10 abalina obulemu obwenjawulo kwebyo ebyatukawo mu biseera bya senyiga omukambwe (COVID-19).
- MwalimuWaliyo abakazi 5 n’abasajja 5, nga balina obulemu obwenjawulo era nga babeera mu mbeera ez’enjawulo.
- Eyali abuuza ebibuuzo yali munonyereza alina obulemu ku maaso nga bamuyita Eric.
- Abantu mu Uganda bewuunya olw’omuggalo ogwabalukawo mu Gwokusattu 2020.
- Waliwo amateeka amakakali kubyokufuluma n’ebyokugoberera ng’okunaaba engalo n’okwambala akakokkolo.
- Amasomero n’ebifo ebikolelwaamu byagalwa, abayizi nebasindikibwa ewakka.
- Abantu abasinga abalina obulemu belarikirira ku by’ensimbi kubanga abantu bali tebasobola kukola oba bali bafiridwa emirimu gyabwe.
- Abantu abamu abalina obulemu bafuna obuyambi okuva mu gavumenti oba ebitongole by’obwanannyini naye abasinga bagamba nti kyali tekimala.
- Eri abantu abamu kyali kizibu okutegeera ebikwata ku senyiga omukambwe (COVID-19) n’okwekuuma nga tebafunye kabi kona kubanga obubaka tebwali bulambulukuffu oba bwali tebusobola kutegerebwa bonna.

- Abantu abamu abalina obulemu bafuna obuzibu n’abakwasaganya amateeka kubanga bali tebategera bya butakirizibwa kufuluma kiro n’ebyo ebyali bibetagisa.
- Kyali kizibu okufuna emmere emala ab’omu maka abasinga. Abantu belarikirira okusula ng’enjala.
- Okufuna empeereza ng’ebyobujjanjabi n’ebyuma ebiyamba kyali kizibu.
- Walina okusasula ssente ezisingako kulw’ebintu ebimu ng’ebisale by’okusabazibwa n’eddagala.
- Abantu abamu balwooza nti abasajja babonabona nnyo mu kiseera kya senyiga omukambwe (COVID-19), abantu abamu balwooza nti kyali kizibu okusinga eri abakyala.
- Abantu abasinga balina engeri gyebali bawuliramu okugeza ng’okutya, okwelarikirira, okuwubaala, okwenyamira, n’okunakuwala.
- Abantu beralikirira oba ebintu bali bigenda kuddamu okubeera nga bwe byali.

Abantu babuzibwa endwooza yabwe ku biki ebilina okutukawo singa obulwadde obulala bubalukawo obuyinza okuletera abantu abawerako okwetaaga obuyambi. Baagamba:

- Walina okuberawo ssente endala okuyamba abantu, era zilina okubeera enyangu okufuna.
- Walina okuberawo engeri ez’okuyamba abantu okufuna omulimu oba looni oba okutandikawo bizinensi empya, naddala eri abantu abalina obulemu

- Obubaka obuva mu gavumenti bulina okubeera nga burambulukuffu era nga bwangu okutegeera eri bonna mu nnimi n'enkola.
- Gavumenti erina okukola entegeka ey'omumaaso okukakasa nti abantu abalina obulemu bagatibwa mwebyo ebiberawo wewaberawo embeera eyakibwatukira nga senyiga omukambwe (COVID-19).

Ebitongole eby'abantu abalina obulemu bilina okwebuzibwako ku ki kyebilowooza ekilina okutukawo okuyamba ku bantu abalina obulemu mu kiseera ekyakibwatukira nga senyiga omukambwe (COVID-19).

Introduction

This study was undertaken as part of the UK Aid funded Inclusion Works programme (part of Inclusive Futures) which is running from 2018 to 2022 with the aim of increasing the employment of people with disabilities in the formal sectors in four countries – Uganda, Kenya, Nigeria and Bangladesh. As part of this people with disabilities have been recruited into the programme to participate in a variety of activities to increase their employment prospects, through skills building, networking, placements etc. There are also other aims, objectives and foci of this programme which can be seen on the Inclusive Futures website: [Inclusive Futures | Towards a future that's disability inclusive](#).

In early 2020 the COVID-19 pandemic emerged globally as a major potential threat to people's health, wellbeing and livelihoods and governments' actions to mitigate this resulted in lockdowns of various types and severities in most countries. Thus, many of the planned activities of the Inclusion Works programme in Uganda, Kenya, Nigeria and Bangladesh were halted or adapted and some were 'flexed' towards COVID-19 related relief and research.

The Institute of Development Studies (IDS) as one of 12 partners in the Inclusion Works consortium carried out this piece of qualitative research in all four countries, with the aim of understanding the experiences and perspectives of COVID-19, of jobseekers with disabilities who were already involved in the programme.

Country Context

Uganda like other countries was hit by the COVID-19 pandemic in early 2020. On 18th March, the government of Uganda announced a 21-day lockdown (with additional measures from 20th April) with observance of a range of measures as a strategy to mitigate the rapid spread of the pandemic including (nb this is an edited list):

- Closure of all the educational institutions (involves 15 million young Ugandans).
- Suspension of communal prayers in Mosques, Churches or in Stadia and other open-air venues.
- A stop to all public political rallies, cultural gatherings or conferences.
- Advising the public to maintain hygiene measures and advised on good nutrition.
- Initially, all public passenger transport vehicles i.e. taxis, coasters, buses, passenger trains, tuk-tuks (tri-cycles) and boda-bodas were allowed to continue if passengers used sanitiser and wore masks. All public transport was then suspended, which was the case during the time of the first interview. Later they were allowed to continue provided they were at half capacity and everyone wore masks and used sanitiser.
- Initially, private vehicles could continue to operate with a three person restriction. Then the movement of all privately owned passenger vehicles was banned, which was the case during the first interview. Later private vehicles could continue again with only 3 people maximum per vehicle.

- Ambulances, army vehicles, garbage collection vehicles, etc., could continue.
- In order to deal with other health emergencies, permission can be sought from the Resident district commissioner to use private transport to take a sick person to hospital.
- Suspension of weekly or monthly markets such as ebikomera (cattle auction markets) and other non-food item markets
- Only food sellers were allowed to remain in the markets and some ended up sleeping in the markets to overcome travel restrictions.
- Established food markets in Kampala and the other towns continued to be open while maintaining social distancing.
- All the non-food shops directed to close. Only food shops, shops selling agricultural products, veterinary products, detergents and pharmaceuticals could remain open. Home deliveries should, instead, be encouraged.
- The super-markets should remain open but with clear guidance that restrict numbers that enter and leave the site at a given time and the handling of trolleys within the supermarkets.
- Like the farms, factories should remain open. But the owners should arrange for the crucial employees to camp around the factory area for the 14 days. If they cannot do that, let them suspend production for 14 days.
- The essential services should continue to operate.
- Gatherings of more than 5 persons were prohibited.

Although the above were to be observed by the citizens it was later realized that human congestion and uncontrolled movement from one place to another was too high. This prompted announcement of the night curfew nationwide from 7pm to 6am. At the time Uganda had registered 13 infections with zero deaths. Again, this meant that a number of people had no jobs to do and were kept at home.

The lock down relaxed on 29th June but in phases, so not all activities/ business were allowed to operate. For example, there are places that are not operational to date e.g. Bars, lodges, clubs to mention but a few while others were allowed operations with effect from December.

Currently:

- Schools continue opening as learners of different classes report on allocated dates/ months (with the expectation that all will have reported by July 2021)
- Learners of candidate classes i.e. primary seven, senior four (ordinary level), and senior six (advanced level) have sat their final papers administered by the Uganda national examination board to determine their next education levels

- Transport costs are still high because of the 50% passenger restriction (vehicles carrying half the number that they ought to carry e.g. seven instead of 14 for taxis and 40 instead of 65 for buses)
- Fair respect to the use of face masks and washing of hands as protective measures compared to observance of social distance especially in physical gatherings including high level government activities
- Vaccination against COVID-19 using the AstraZeneca vaccine has commenced, starting with high risk groups (however persons with disabilities have not been considered to be a priority group)

Uganda has had relatively low rates of infections and deaths throughout the pandemic. Statistics for 5th March are a total of 40426 cases, 15052 recovered cases and 334 deaths. The first death occurred on 25th July 2020, the numbers increasing steeply but now showing signs of levelling off (Worldometer, 2021).

Research process and methods

The aim of this research was to better understand how jobseekers with disabilities have experienced the evolving COVID-19 pandemic in Uganda.

With the UNCRPD (2007) principles as a key guidance, a research design was developed using qualitative methodologies, as these were deemed to be most appropriate for generating subjective knowledge from within a context (Tracey, 2013; Braun and Clarke, 2013; Hammett et al, 2015). Qualitative methods usually collect verbal (words people say) data from a smaller number of people than quantitative studies, which focus more on counting the numbers. A very flexible style of interviewing which invites the participants to ‘tell their story’ and talk about what is important to them (narrative interviewing) was selected for several reasons:

- Telling stories is a natural and universal form of communication - this method is accessible to everyone regardless of education level, language competence or communication mode (Jovchelovitch and Bauer, 2000).
- By recollecting and sequencing experiences as stories, participants make sense of their experiences in their own way
- As a teller-focused method, evidence about what matters to participants is generated, rather than using pre-determined questions to investigate topics that may be of less concern to them (Hydén, 2014).
- This approach can generate insights on situational, emotional and relational aspects, that may not emerge from researcher-directed interviews.

Each participant was invited to take part in two interviews, separated by 1-2 months during August to October 2020. The purpose of doing two interviews with each person was to gain deeper insight, as trusting relations and openness would develop between participants and researchers, so the narratives were anticipated to flow more easily as the interviewees’ confidence increased. Second, this revealed how the jobseekers had experienced, interpreted and responded to COVID-19, as the pandemic situation progressed over time in their country and context.

Experienced local participatory researchers who were already working with the IDS team in the four countries led the data collection process. This team had previously received training in participatory inclusive research methods and were given additional training in narrative interviewing for this study. The Institute of Development Studies (IDS) team developed the research processes and materials, provided training and supervisory accompaniment for the local researchers, and led the participatory analysis process.

Support from the Inclusion Works in-country consortium partners (Sightsavers and ADD International), and the key Organisations of People with Disabilities (OPDs) partners, were crucial to the purposive recruitment of 10 participants in each country. A range of individuals were invited with the aim to achieve gender-balance, a range of ages and experiences and representation of people from different impairment groups (see participants table in [appendix 1](#)).

To ensure that both the participants and researchers remained safe during the research process, the narrative interviews were undertaken online or by phone (Holt, 2010). Researchers were encouraged to use communication platforms such as Microsoft Teams or Zoom and use the video function when possible. This was both to aid relationship building and effective communication, especially for participants who were more reliant on visual communication modes. In all countries there was reimbursement for data costs. However, the choice of platform was ultimately informed by each individual participant's preferences, capacities and access to technology.

Ethics approval for this work was obtained from the IDS ethics committee. To mitigate heightened ethical risks compared with face-to-face interviewing (such as the additional difficulties of reading dynamics or responding supportively if strong emotions arose), the research process involved three calls with each participant during the first interview round:

During the first introductory call the research purpose and process were explained, including consent and anonymisation, the right to withdraw, and the analysis and reporting plans. The participant's access and communication support needs were also discussed so that prior to the interview, necessary accommodations could be made. For example, organising sign language for people who were deaf.

On the second call participants were asked for verbal consent to be involved. This gave them time and space after the first call to decide whether to participate, reducing any perceived pressure to participate. The interview was conducted after verbal consent was gained and the participant confirmed that they felt secure and their access needs were being met. After an initial reminder about the aims of the study, narrative interviews proceed by asking one very general and open question (Jovchelovitch and Bauer, 2000):

Participants were asked to share how the COVID-19 situation had developed for them and impacted on their lives.

The interviewers reassured them that they could share experiences in any way they liked and encouraged the story-form by suggesting they start at the beginning, when they first heard about the pandemic, and then relate what happened afterwards up to the present. Prompts and follow-up questions were used to ask for specific examples, or to expand on the key aspects that interviewees chose to talk about. Finally, there was a third call to ensure

that the participant was feeling alright and still happy to be contacted subsequently for a second interview about 1-2 months later.

The second round of interviews followed a similar process. It was anticipated that the second round of interviews would involve greater openness and narrative flow due to developing relations between the researcher and participant and this proved to be the case.

Thematic Analysis

A face-to-face participatory thematic analysis process was originally planned, involving the researchers and some participants. However, this plan had to be adapted due to ongoing COVID-19 travel and meeting restrictions. To minimise risk and comply with regulations, a series of collective analysis sessions were undertaken online, involving the IDS team and in-country researchers. Prior to undertaking the analysis, the researchers were provided with training in thematic analysis.

The analysis sessions included an initial reading of the first interviews by the team, and the sharing of selected interview narratives. From the data, themes were generated, with discussion about whether all the themes were relevant across all countries. Following further reflection, the themes were then clustered to produce a first-level analysis. Overarching themes, such as gender, impairment specific aspects, emotions and economic/financial impacts were established. Subsequently, the IDS team-members each analysed the remaining interviews using one of these lenses. Once the second interviews were complete, a second analysis session was held online with all 4 countries, where additional themes were generated based on the current situation in each country. New insights were compared with the detailed first round analysis. This process validated previous themes and indicated data saturation as there was lots of repetition of similar experiences and perceptions, but there were also changes in impacts and feelings, as well as some additional overarching themes.

Finally, the possible relationships and linkages between themes were explored with the aim of producing a conceptual map. Collectively generating overarching meanings and interpretations, ensured that the final synthesis was grounded in local perspectives supported by examples from the data.

Participants

A table detailing the characteristics of the 10 participants in Uganda can be found in [Annex 1](#).

The participants were five men and five women, with an age range of: five under 29 years and five 30-49 years. Six lived in rural areas, two in urban and two in peri-urban parts of the country. They were people from a variety of impairment groups (e.g. three physical, two visual, one hearing, one intellectual and three other groups e.g. albinism, speech impairment, sickle cell disease), were relatively well educated (1 primary, 1 secondary, 8 tertiary) and had a variety of work experiences.

Findings

Key themes which emerged from the narrative interviews in Uganda are presented below. Two different types of interlinking themes emerged and there were many similarities between Uganda and the other 3 countries where we did the same study (Kenya, Nigeria, Bangladesh).

“This COVID-19 pandemic has left many stories to be told I believe for ages, but above all it has also left scars on individual lives.” (man with speech impairment, IWCOVUGB10)

The first type were ‘concrete’ (material) themes illustrating the tangible practical impacts of the pandemic and they fall into two main types, with links and overlaps between them. There are individual (and intersecting) identity related experiences linked to people’s gender and/or impairment type and disability status. Then, there are the economic/financial impacts and people’s experience of the structures, systems and civil society responses to the pandemic.

The second type of themes are about ‘subjective’ experiences and broadly reflect the participants’ feelings and experiences during the initial COVID-19 crisis and its continuation over some months. These emotions arose in response to the loss of the stability of known life, the ‘old normal’, the pandemic risks and the lockdown restrictions, and the uncertain journey towards a ‘new normal’. We interpreted these emotions as both overarching, so ‘floating above’ and also integrated with so ‘weaving through’ and often clearly linked to participants’ experiences expressed as more ‘concrete’ or material themes. Overall, strong themes of de-stabilisation, disorientation and uncertainty were experienced due to the extraordinary situation, with subthemes of shock, confusion, fear, loss, stress, conflict, anxiety, despair and depression in various forms.

We describe these themes and bring to the fore the voices of the participants by using direct quotes from Ugandans to illustrate the themes¹. Of course, this is only a selection of the available quotes.

Overview from the interviewer

During the first interviews in August many if not all respondents had hardly any hope of seeing even the next day or for their future generally, for example students had questions about whether they would go back to school, while other workers in different jobs could no longer define their fate. Some people had made radical decisions driven by fear and perhaps anxiety, e.g. a student decided to get married as there was no information about when they would resume studies.

During the second interviews however, there was some positivity from respondents, e.g. regardless of the terms and conditions, learners in their final years had been allowed access to school, even if the transport cost was high, having to adapt to using face masks, and facing additional charges for the cost of hand sanitizers.

¹ Quotes are identified as from individuals by gender and impairment type, and interview ID number (A or B before the number indicate whether the quote comes from the first (A) or the second (B) interview)

Some respondents shared lessons learnt from this situation e.g. learning to diversify in business and become multi-skilled.

I heard respondents rejoice in the opening of places of worship. They shared that in these places they could unlearn some ancient misconceptions.

Concrete, material and system related impacts

Economic impacts

Similarly to people across the world, our interviewees with disabilities and their families in Uganda experienced major negative economic impacts due to lockdowns and other pandemic restrictions and descended into (deeper) poverty as they, or those they were dependant on, lost their jobs, businesses, or other income.

“I really saw [lockdown] as an indefinite suspension from even working, yet no work no earning. Then how could survival be? I started seeing the narrow path between keeping safe and the welfare of my family yet as a bread winner, my wife had it all to ask me every morning what the children would eat.” (man with albinism, IWCOVUGA6)

“While at home, the experience rotates around how to survive especially accessing food among other basic needs since even the relatives I could give a call are no longer working and openly stated that they have no way out of supporting me.” (man with speech impairment, IWCOVUGA10)

Especially affected by the economic impacts were those with existing financial pressures prior to the outbreak. These circumstances included lack of previous employment, common amongst many people with disabilities due to existing barriers, those needing to pay for ongoing medicine, those with family dependants and single parents.

Interviewees reported reduced food consumption and hunger as they no longer had the money to pay for regular food, and some feared they would starve. People who are on a specific diet due to their health condition, really struggled with the inability to buy the food they needed. Increased food and transport costs made accessing food more difficult.

“I now had to adjust my time for meals to eat once a day which I thought would help not to spend more of what I was not earning.” (man with speech impairment, IWCOVUGA10)

“One morning, all of a sudden my children woke up crying and my wife and I were asking why the crying, they kept mentioning one word “hunger” which was a justified reason for them to weep because we had taken two days without having a meal as such but rather snacks and warm water.” (man with visual impairment, IWCOVUGA8)

“Physicians recommend endless consumption of citrus but because our parents, guardians or even any other caregiver were no longer working, a number of us could hardly access these foods and this alone came with

adverse effects on us including emaciation”. (woman with sickle cell disease, IWCOVUGA1)

Medical costs for those with medical needs, their own or other family members, were also major concerns as they and their families struggled to pay for them, or for the increased transport costs to hospital or pharmacies. Protective items such as masks and sanitiser were noted as an additional expense that people had to manage.

“The situation has rendered me too poor to afford my own basic needs yet among them also now includes acquiring face masks and a sanitizer or even a soap to use for hand washing.” (woman with hearing impairment, IWCOVUGA2)

This financial crisis caused the interviewees and their families stress and pressure as they struggled to meet their and their families’ needs.

“My partner had not studied much about what the situation was like and from time to time she would ask me why I had not gone for work and this alone sounded frustrating because the portrayal was that it was me who had refused to go for work, yet this was not true.” (man with albinism, IWCOVUGA6)

“Life has become such a journey with endless questions but above all, I feel all frustrated and wondering if this is happening anywhere as it is in my home where getting a meal in a day has turned to be a miracle yet for no other reason but COVID-19.” (man with visual impairment, IWCOVUGA8)

The loss of income caused family tensions and left people with disabilities feeling guilty and sad for becoming dependant on others or for not being able to provide for their dependants. The inability to find work, both during the pandemic and beforehand, affected many people’s self-esteem.

“My end as a bread winner, it took me moments of thoughts, stress and even depression.” (man with visual impairment, IWCOVUGA8).

“Today, I seem to ask for a lot from [her parents] yet I am not the only one, we are about 14 in a home minus the parents, so it has crowded my mind with thoughts.” (woman with hearing impairment, IWCOVUGA2)

“When I started doing business early this year, I celebrated my journey to independence or interdependence where I would at least support myself 60 – 80 % and only require minimal support of about 20% in my day to day living but Aaahha! All has seemed as if it were a false dream because from the time the lockdown was announced, I have seen a very big and even terrible setback.” (woman with physical impairment, IWCOVUGB4)

These financial difficulties applied not only to our interviewees with disabilities but also to the people with disabilities they knew in their communities.

“I have seen quite a number of [other people with disabilities] also jobless at home and weeping for aid from sources that are hardly available. And for

some others who have been in school, they are really not benefiting from the online learning and teaching activities.” (woman with hearing impairment, IWCOVUGA2)

Our interviewees noted that financial difficulties in their wider community were resulting in increased instances of conflict in the home and potential gender-based violence, with men who were frustrated due to their lack of work. However, our interviewees observed that this decreased as men earned income again after the restrictions eased and they could work.

It was hard to find alternative work as companies faced the different challenges of lockdown and were not employing people. Continued restrictions in some parts of the country and increased transport costs also made it harder for people to move to try and find work elsewhere.

“I thought that while I wait for the institution to reopen if at all it will, I could move elsewhere to search for a job, but I can’t afford moving due to the financial limitation.” (man with speech impairment, IWCOVUGA10)

In order to survive during the worst of the pandemic and lockdown period, many interviewees relied on using their savings or business capital, financial support from external family members or friends, or sold assets such as animals. Others depended on garden work (growing food) to survive. However, not everyone had access to these resources or coping mechanisms.

“I had saved some little money to always buy materials for my work, but it would not be easy to look on when the family is going hungry so I got into this savings, but it could only sustain us for the first two months of the lockdown.” (man with albinism, IWCOVUGA6)

“I was faced with a dilemma of whether to keep money till business resumes or to divert this money into the welfare of my family and the latter took it all.” (man with visual impairment, IWCOVUGB8)

“In my neighbourhood, there is a man who is paralysed, his children are far and the wife passed on. His survival is upon the mercies of neighbours and other allies. I also remember finding him crying tears because of hunger so this experience from an elderly man means a lot.” (man with speech impairment, IWCOVUGA10)

A few of our interviewees also managed to survive the economic shock as a result of accessing more formally provided relief from government NGOs, OPDs although of this was seen to be insufficient. However, most received no such assistance, as discussed next.

Structures, systems and services

Many of the interviewees mentioned the ease or more often the difficulty with which they could access the usual services such as healthcare and those specifically set up to respond to the pandemic. Explicitly or implicitly then they were commenting on the structure and systems in the country and whether these were disability inclusive or not. There were a number of criticisms of the government’s response

“The only funny thought about it is how education could be suspended on account of COVID-19 but political activities are on.” (woman with physical impairment, IWCOVUGB4)

Government social protection assistance in response to the pandemic, as well as assistance provided by other organisations, was not provided to many people with disabilities. Issues with the provision of assistance included: not being included amongst the list of beneficiaries; rural areas not receiving the same level of assistance as urban areas; information about relief distributions not being accessible or not passed on, resulting in people with disabilities not attending; assistance only being provided as a one-off; and assumptions that their disability organisations would provide for them.

Some interviewees felt that some of these issues were rooted in disability discrimination. The issues were not always disability specific and sometimes were the result of the location they lived in, as rural areas did not really get many food distributions.

“My greatest pain is when even some organisation brought some relief food here, nobody was bothered that I could get food, (because) I had no sign language interpreter near me”. (woman with hearing impairment, IWCOVUGA2)

“The difference presents when interventions come into our communities, I am not often informed even by my local leadership. For example, many agencies have come to my area with relief food quite often, but I have had access to none. I only thank the organisation that gave you my contact because prior to their coming they gave me a call directly and supported my family with some food.... this exclusion from interventions to me is just a sign that people like me are still discriminated against.” (man with albinism, IWCOVUGA6)

“During this COVID-19 pandemic period, I could hardly access any interventions as people around me said I should wait for what NUDIPU² or disability council are about to bring. Imagine - this even happened recently when they were distributing mosquito nets and I appeared at the health centre to receive one, someone loudly mentioned it that these were not for persons with disabilities.” (man with visual impairment, IWCOVUGA8)

As a result, it was clear that many people with disabilities, our interviewees and others they knew, slipped through the net and did not receive any or enough assistance from any formal sources, with serious consequences for them.

Impairment impacts

As well as the more generic impacts of the lockdown on people with disabilities as a disadvantaged group, there were some difficulties and impacts that were specific to people with specific impairments. For example, for people with visual impairment who rely heavily on touch, restrictions on touching objects or physical contact between people had a major

² National Union of Disabled Persons of Uganda

impact. Particularly mentioned was that those who would normally guide them using touch were now not willing to do so.

“As a person with a disability, the COVID situation has continued to push me to a very different corner of operations especially the fact that I can no longer have full trust in whoever could help me navigate around by holding my hand and I am also sure that they don’t trust my health so no one can just hold my hand anyhow.” (man with visual impairment, IWCOVUGB3)

Other people’s negative or inappropriate responses to someone with a disability, which are seen in ‘non COVID-19’ times appear to have been exacerbated for some.

“For example, as a person with disability, I move very worried because people do not know my means of communication and many just rush for a hand shake the moment they see me by the road. I know how risky this is but when I try to get away with this, the same people say that I fear because I am already COVID-19 positive or others that I am proud because I went to school.” (woman with hearing impairment, IWCOVUGB2)

Access to impairment specific equipment, medicines and other products was also mentioned as a worry and could have the effect of making life even more challenging.

“Access to assistive devices (sunscreens) has continued to challenge me and other persons with albinism and this is because of lack of a job. I know that not all times people will give us things freely but in our own attempts to look for work, it is still hard.” (man with albinism, IWCOVUGB6)

There was a sense that the general public or indeed the authorities do not understand how to support people with different impairments and access needs, often making wrong assumptions and not adapting appropriately. Interesting amongst interviewees there was sometimes an indication of the difficulties of those with impairments different from their own:-

“I will just emphasise that people with different impairments require tailored support in case an intervention is being designed. This is what we should teach the whole society or and even country if possible because whenever people see me moving around, they want to guide me by holding my hand, yet I am sure this is not a need for people with hearing impairment.” (woman with hearing impairment, IWCOVUGB2)

Identity related

Other demographic or identity characteristics were also felt to have an impact on people’s experiences, so that the combination of having the status of disabled in combination with another disadvantaged identity increased the risk of extreme negative impacts of the pandemic.

Gender related impacts

In Uganda gender is seen as a binary concept, so here we talk about men’s and women’s experiences. When asked about whether the participants perceived the impacts of the pandemic and lockdown to be the same or different for men and women a variety of views

were expressed. Interestingly more than half (7) respondents felt that men had had a worse time. Based on a traditional patriarchal society where men are seen as providers it was perceived that their counterparts (women), have total reliance on them for all round support. Thus, men struggled with the responsibility to be providers and felt angry and guilty at not being able to do so adequately.

“In our communities, women still lean against men for all their needs, both family and personal. Therefore, the fact that work became/becomes more of a history, I imagine the frustration men are going through.” (woman with sickle cell disease, IWCOVUGA1)

However, others perceived that women’s experiences were more difficult. For example

“For us women, I feel it has been too much actually - more than. Let me share a story I have interacted with, because men know that we are capable of keeping the homes, they also feel we can do all the work alone. For example, a man tells you that he is not doing well to join you for garden work and that he is equally not doing well financially leaving all the roles to us, so I do not see the similarity in our experience of the COVID-19.” (woman with physical impairment, IWCOVUGA7)

“The only women who have also faced a noticeable experience are single mothers especially that they are limited financially and now some of these have had their children home for the last five months and even going forward to look after.” (woman with sickle cell disease, IWCOVUGA1)

“Some are widows and single mothers, the time has unveiled differently with a lot of stress and frustrations to them especially on how they will take care of dependants if not their own children.” (man with visual impairment, IWCOVUGA3)

“I have witnessed domestic violence and even gone to separate others during fights. Since men have not been fond of staying at home for long hours, now they observe every step their wives take and vice versa yet at the end this results into chaos.” (man with speech impairment, IWCOVUGA10)

“My husband resumed work as I shared earlier that we were all at home entirely and one could fail to ask for money from the other. In fact, like it was the case around my community when women interpreted their husbands for failing to play their role as men in the home. But with resumption to work, domestic violence has declined respectively.” (woman with physical impairment, IWCOVUGB7)

Rural vs urban living

The data hinted that people living in urban or rural settings had different experiences. It was suggested that relief agencies and other supporters were more likely to target urban dwellers, considering them more vulnerable to food scarcity, whereas rural people could

freely access their gardens for farm work and hence did not need quick support in terms of relief food. However, one participant felt that planners should think about all Ugandans:

“Government should secure COVID-19 funding to set interventions that include all the people including us in the rural areas, the mind that people in urban are badly off is a wrong one, all of us are vulnerable.” (man with speech impairment, IWCOVUGA10)

“The discrimination of persons with disabilities has doubled up in this time of COVID-19 to the extent that those in the far rural do not even have access to the information about COVID-19 yet I thought that if all other interventions fail to reach everyone, at least information should because it has a role in saving a life”. (man with speech impairment, IWCOVUGB10)

Age

The interviewer (EW) perceived that people’s age was important in relation to responding to an emergency such as the pandemic. He sensed that older people who have lots of responsibilities and the trust of the community are expected to find solutions. This is harder for younger people. Elders can provide good examples of what to do and advise young people on how they can keep stronger together.

Opportunities for income

Half of the respondents had completed some form of education with the lowest level of achievement being primary 7. Prior to the pandemic they were trying out things to supplement their survival needs (as might be expected as they are jobseekers on the Inclusion Works programme). The other half were still in education at college or university with ambitions to improve their opportunities, sometime in parallel pursuing their ‘self-initiatives such as their businesses for survival purposes. However, with the onset of COVID-19 and lockdowns this was difficult:

“As a farmer who usually takes my produce to the market, I started pondering about how I would sustain my operations/business because at that time nothing had been said about markets. No sooner had I creatively come up with a few alternative ideas than when it was said that people who go to markets should either sleep there or market operations to be suspended to those who could not sleep over at their places of work.” (man with visual impairment, IWCOVUGA8)

This employment situation left people with disabilities demoralised.

“There are some organisations where I had applied seeking for a job, from time to time, I have got calls to attend interviews, but the means of movement has deprived me off as I have to find ways of accessing transport means in one of the districts which were allowed to operate. In this situation, I have missed about five interviews to attend where I think I could try my luck”. (man with visual impairment, IWCOVUGA8)

Exacerbated stigma and discrimination

There was often some evidence of the continuation of discriminatory treatment that had existed before COVID-19 times, but also importantly some exacerbation of this during the pandemic.

“It is still a challenge to us as persons with disabilities to present ourselves before others as people who are equal to them because they see us from a distance and immediately get a different judgement and even when it comes to work, a majority of the people who were laid off were persons with disabilities in the names of being prone to contracting the pandemic.” (man with visual impairment, IWCOVUGB3)

“Persons with disabilities still remain that class under looked, stigmatised yet highly prone to contracting the pandemic if not well supported. But for society, their opinion still remains that persons with disabilities don’t matter at all. I don’t know why. So in nutshell, the situation has exposed persons with disabilities to double edged pain”. (woman with sickle cell disease, IWCOVUGB1)

“One thing I know is that persons with disabilities have suffered twice; Once for their impairment but also that they are easily suspected to be victims of the COVID-19 pandemic because everyone says we are vulnerable.” (man with albinism, IWCOVUGB6)

One participant noted how they had to leave their understanding university environment due to the closure of universities and return home, where their condition was less well understood and stigmatised.

“The time we have been home so far, every time I get a crisis because of the sickle cells condition, many around me interpret it as witchcraft. Worst even because of my appearance, others call me an HIV infected patient (3 minutes of total silence). This has made home rather a sour environment for me as compared to school where I had opened up and was getting the necessary and timely care.” (woman with sickle cell disease, IWCOVUGA1)

There was a sense that many things had changed, including relations between people with and without disabilities and that it would be hard to change this back to the ‘old normal’.

“So, COVID has even made us to earn names that we do not deserve. This situation will be too hard to forget easily”. (man with intellectual impairment, IWCOVUGB9)

In some cases, there was exacerbated disability discrimination during the pandemic.

“When I tried to access the place of worship (church) recently at the time when only 70 people were allowed in, I reached and I was told the place was already full and I could not be allowed in yet very anxious to congregate with colleagues with my face mask on, I pleaded to be allowed in and one of the ushers said to me “don’t you know that you are more vulnerable and prone to contracting this pandemic as well as infecting others around you? Some

of us can run if we see somebody sneeze but you cannot and you know that very well. So please excuse yourself and go back.” (woman with physical impairment, IWCOVUGB4)

“I will emphasise that persons with disabilities have very much been affected since the breakout of the COVID-19 pandemic. Persons with disabilities move in search for someone who will help them with something to eat or drink or even any other technical support, whereas society seeing that such persons are prone to contracting the COVID-19 pandemic, they are continuous suspected to be victims that no one even draws close to them to understand their needs time and again.” (woman with physical impairment, IWCOVUGB5)

Subjective, emotional effects

There were plenty of examples in the Ugandan data of the strength of the negative impacts on people with disabilities’ mood and wellbeing, and the types of negative feelings they experienced during this time.

Initial responses were shock and disbelief, and also fear, both of the virus itself and of its impacts on them and their families e.g. fear of starvation, fear of life never being the same again, worry about their own and their families’ safety and futures.

“The other thing to share is that people no longer attend to me like they used to. I make several phone calls and they are declined, the way of life changed as if even to change culture and tradition: people no longer greet by handshake, they do not hug, what an era!” (man with visual impairment, IWCOVUGA3)

Some of these emotions seem to be linked directly to the concrete, material impacts mentioned above such as financial worries, loss of opportunities, tensions in the home, lack of services and support, threats and dangers such as of becoming ill or of violence in the home outside.

“That I feel half a man spending a day without even a minimum of two thousand shillings in the pocket or even worse still sitting in one place from morning till evening, this has never been my way, but I admit it has challenged me.” (man with albinism, IWCOVUGB6)

Additionally, people often felt bored, frustrated or depressed by the situation

“I have sat home for a long moment now. I feel bored. The best place for me was my place of work where people understood me.” (woman with hearing impairment, IWCOVUGB2)

Some felt that their previously hard-won independence/ autonomy had taken a step backwards, which was frustrating.

“I have seen a very big and even terrible setback. For example, when we were strictly asked to stay home and stay safe, the word safe meant almost

nothing but a torment as it meant total dependence again taking me where I had moved from.” (women with physical impairment, IWCOVUGB4)

Changes over time – concrete circumstances and emotional responses

The second interviews indicated that life for some people in their communities had improved a little as restrictions eased and some people were able to start work again. However, many were observed still to be struggling, either because they could not find work or because the work available had fewer hours. A few participants’ family members, or the interviewees themselves, were able to find work again. This covered some of their family’s immediate needs and eased some of their mental stress and worries for these respondents.

“I see people move for work. Whether they have recovered fully or not is a different discussion but that they can move to make ends meet is a very big step.” (man with visual impairment, IWCOVUGB3)

One participant had turned to an alternative way of making money, by selling liquid soap, and was feeling more optimistic about their ability to survive, although it was still hard.

“I remember in my first conversation pointing to facts such as not being able to move out, even to look for survival needs like food among others but at least now, I make my liquid soap, package it properly and move around the city.... even now that I move out, it is hand to mouth.” (woman with physical impairment, IWCOVUGB7)

However, many interviewees and their family members were still unemployed, and the conditions of those who found work again were often worse than before, with fewer hours, or customers, or reduced prices for their goods. Many of the interviewees with disabilities were unable to find employment despite their best efforts, including they felt as a result of disability discrimination. This meant many people were still struggling to survive or thrive.

“Survival continues to harden”. (man with speech impairment, IWCOVUGB10)

“So all this put together still leaves my life in a situation of hopelessness as to where the end will be for both my business and all the people to whom I have to render support.” (man with intellectual impairment, IWCOVUGB9)

The money they earned was focused on immediate survival needs. This meant that things such as putting savings into village savings and loans associations were no longer possible, while paying for school fees or internet data to deal with the move to online learning were no longer affordable.

“It is very confusing - how I will always get the internet data for lectures. Worst still, the plan is that we may even be examined online. (Aaaah!! Nze kati simanyi na’kyakukola) (a local language expression to show frustration - I even don’t know what to do - in a loud and high tone). It is something I cannot even discuss with my parents because every end of day, they keep

assuring us that what we are up to is all about getting the daily bread.”
(woman with physical impairment, IWCOVUGB5)

It was also hard for interviewees who had businesses prior to the pandemic to restart because they had used up their capital or savings to survive.

“Anyway today, there has been lifting of the regulations but getting back to business is still something I see from a far as all the savings were diverted and spent for my daily basic needs.” (woman with physical impairment, IWCOVUGB4)

The rise in the price of transport and food was another burden people were facing as restrictions eased. The rise in the cost of transport had implications especially for those needing regular medical treatment or those who would need to travel to find a job.

“I was mandated to attend clinic every Wednesday but given the current transport costs, I am really unable and I know that there is something I miss by not attending to it as time tabled even when I devised means of ensuring that I don’t run short of my medication.” (woman with sickle cell disease, IWCOVUGB1)

“The idea of travelling away from home even in light of a job opportunity is still too hard. I believe it is because even in the previous (time) I had no job but now the transport costs have been doubled. So it becomes such a challenge to search for a job or even attend an interview for the one you applied and have been called.” (man with speech impairment, IWCOVUGB10)

Therefore, despite lockdowns and restrictions easing, and opportunities for employment emerging, people’s actual material conditions have very often not improved by much or at all since the first interview.

There are noticeable differences in the mood and optimism of many participants in the second interview. Those who had returned to their previous work, resumed their own business or started a new one, were more positive, and some were planning to start paying back loans.

“My mother has resumed savings with her group members and is now working around the clock to pay their loan which was borrowed before lockdown to pay my fees for first term senior five”. (man with visual impairment, IWCOVUGB3)

Some participants were resuming their studies, although with some new challenges

“Of course I received this news with gladness but later in the day, there arose questions about how I would get myself back to school having sat with parents at home not working and when I assessed the situation around us, to them it did not sound any good because they immediately started discussing between themselves on what can be done as a way forward. Anyway, as I speak to you right now, I am at school because of the good friendship between my father and the school administration. I was allowed to

come and he pays in instalments.....Sometimes we are seated in a lecture room for the whole day without even a single lecture because people have not fully picked up. They are working amidst fear of contracting the disease. So, indeed combining this experience with the bi-weekly compulsory PCR test of all students, I can only say we are operating in a very changed way of life.” (woman with sickle cell disease, IWCOVUGB1)

For others where the financial situation was still dire, the outlook and their emotions were still negative and dominated by worry, stress and fear. There was often a sense that life had changed very radically since pre-COVID times.

“I cannot leave out in my experience to talk about the changed lifestyle unlike in the past times, the costs and standards of living have totally changed.” (man with visual impairment, IWCOVUGB3).

There was some suggestion that it was felt by many in the community that the virus was not a threat anymore and that precautions were no longer necessary and indeed there was a suggestion that the government were giving mixed messages by holding large gatherings in risky ways.

“This has made people around me to feel that maybe COVID ended moments ago to the extent that they no longer take all the measures as serious.” (woman with sickle cell disease, IWCOVUGB1)

“Politicians came to our village and you know in their strive for votes. One went greeting people by hand as if she didn’t appreciate the current times and how we need to protect people’s lives but when I came up to condemn the act, the whole community around me misinterpreted my intervention and hurled all kinds of insults to me.” (man with speech impairment, IWCOVUGB10)

“I am very much concerned about the way people have ignored guidelines from the ministry of health. When I sit anywhere, I hear two mixed thoughts; some saying COVID is not there while others say even if they die, they are old enough for the grave. So I recommend to government to speak about COVID with a consolidated and similar voice.” (woman with hearing impairment, IWCOVUGB2)

Validation workshop

A joint online data validation event for the participants in Kenya and Uganda was held in mid-May, giving them the opportunity to share and learn from each other. All interviewees were invited and provided with data bundles to enable participation, as well as some representatives from NGOs and OPDs involved in the Inclusion Works programme. While not everyone was able to attend and some people had internet issues which meant they were unable to attend the whole session, 9 interviewees from Kenya and 8 from Uganda participated in the validation workshop. The main findings from the two countries were presented and then participants had the opportunity in small country groups to discuss whether the key themes reflected their experiences and if they had anything else to add.

The participants validated the findings and emphasised how the pandemic, the restrictions, and their impacts had disrupted their lives and resulted in trauma, fear, stress, and hunger. People in Uganda felt that the government had not really considered people with disabilities, while in Kenya people felt that the government had made an effort, but corruption and other issues meant that many people with disabilities were missing out on assistance. People emphasised that with COVID-19 here to stay, what was needed was not handouts or being reliant on well-wishers but income-generating support to help people cope both financially and emotionally, such as training and help setting up small businesses. There is also a need to strengthen organisations of people with disabilities so they can better support all people with disabilities. The participants also had the opportunity to ask questions of people in the other country and learn more about their respective experiences.

Achievements and limitations of the study

The study was successful in achieving its aim of hearing about the experiences of a diverse group of people with disabilities in Uganda directly from them. Because the 10 interviewees were people who were already involved in the Inclusion Works programme, and therefore identified as 'jobseekers', their experiences and perspectives do not represent the whole range of types of people with disabilities in Uganda. We were not setting out to be representative. For example, the participants educational level is probably higher, and they have perhaps had more opportunities than a broader sample from within the Ugandan disability community would have had.

The use of narrative interviewing as a specific type of very flexible qualitative interview allowed for a focus on the interviewees' own concerns and helped generate insights on situational, emotional, relational and dynamic aspects that can be missed by researcher-directed interviews. The types of issues focussed on by the interviewees was their choice, but nevertheless there were many recurring themes and similarities across the group (and across the 4 countries) in the experiences they described and concerns expressed.

The study generated rich and deep evidence on the interviewees' feelings, and some insight into the nuances of contextual impacts by gender, impairment and other intersecting influences such as gender, relative poverty or access to assistance.

Through carrying out two interviews with each person at a 1–2-month interval, we were able to identify shifts in people's circumstances and feelings as the pandemic evolved in the country. Of course, at the time of writing the pandemic is still ongoing, so what is presented cannot be the full story of our interviewees' experiences of COVID-19, which is something that comes across clearly in the continued expression of future worries from some. Uncertainty continues for everyone.

The interviewer found interviewees communicated more openly in the second round due to the established relations between them, as we had hoped. We thought this was also due to both the researchers' and participants' developing confidence in the research approach and understanding what was expected and being familiar with each other.

COVID-19 restrictions necessitated interviewing people remotely using online platforms or phones to ensure safety. This was a new experience for all. This is inevitably limiting and unsatisfactory for some participants and for the interviewers, and of course restricted the

process to those with access to the relevant technology. Those living very remotely were less likely to be able to join the research, due to the lack of technology, infrastructure and connectivity, although we did make efforts to recruit people from urban and rural contexts. Although we made great efforts to ensure that the process was inclusive and accessible, including by providing sign language interpreters and paying for the data used so that people could afford to take part, we recognise that it was less inclusive and accessible than a face-to-face process would be.

We had originally hoped to have a face-to-face participatory analysis process in Uganda which would ideally have involved at least some interviewees who were available to attend. However sadly this was not possible given the travel restrictions. Some participants expressed an interest in hearing about others experience and reading the report. The easy read and executive summary versions have been translated into Luganda and distributed to those who requested to see them.

Participants' recommendations

Existing pandemic responses have been criticised for not directly including the perspectives of people with disabilities in their design and implementation, therefore interviewees were asked for recommendations for different audiences as presented below. These have been lightly edited to retain the flavour of the discussions.

For the Inclusion Works programme

- More attention should be given to skilling the project beneficiaries up in diverse business ideas and ventures which would equip them in responding to future emergencies
- Consider business start-up support and not only formal employment
- More hard skills training not just soft skills
- Conversations with employers with regards to expectations about people with disabilities in relation to multiple roles. Counselling and advocacy for employers to recruit employees with disabilities
- Work with people with disabilities who have lost their jobs as a result of the pandemic
- Work on stigma reduction
- Support to acquire digital skills so people with disabilities can work remotely

For local organisations

- Parents have a role to ensure that their children observe all the safety measures now that some resumed school, it will be paramount to watch as the child goes and returns from school so as to prevent infections
- Parents are key stakeholders in combating the spread of this pandemic and their involvement in their children's lives should be stepped up i.e. they should know where their children are going, with whom and for what, as well as timely reminders about the precautionary measures against COVID-19

- Organisations of persons with disabilities should prioritise and play a lead role in sensitising people with disabilities, especially outside the urban areas because a majority of persons with disabilities lack sufficient information on issues of COVID-19
- Teachers should set a good example and direct learners to do the right thing, at the right time, in the right place, for COVID-19 safety purposes
- Religious leaders, in the light of opening of places of worship, should sensitise believers about COVID-19 and keep their hopes alive
- Teachers, lecturers and other instructors at different levels should endeavour to see that learners are kept healthy and safe
- Advocacy is needed to promote the quota system for people with disabilities for government jobs

For government

- The government through the different ministries, departments and agencies should put attention to Uganda as a whole, not partitioning it into places that are riskier and those that are not
- The government should explain the 'new normal' i.e. adaptations to take into considerations and if they have pros and cons to human life
- The government should not lockdown again but teach people what to do so as to cope with the COVID-19 situation and open up everything
- On poverty situation, the government should create opportunities for loans with manageable interest rates, maybe 3% for people to boost their businesses as a COVID-19 recovery plan
- Financial support to survive should be provided and there should not be age limits on support (e.g. over 35s should be included too) and include caregivers of people with disabilities
- Government should speak about COVID-19 with a consolidated and similar voice. For example, leaders talk ill of COVID-19 and then they gather people together with no face masks, no social distancing or obvious efforts to sanitise
- The government should plan and prepare the citizens to live with COVID-19 just like we have lived with some other pandemics for example HIV/AIDS, thereby not disengaging the gears of sensitisation to anyone, without leaving anyone behind
- A survey should be done on how people think they can recover from COVID-19 in their social economic life to inform the design of a proper interventions either to be implemented by government or to be used in lobbying for support from other funders i.e. national and international
- Instead of government emphasising numbers of people who can meet, emphasis should be on the social distancing, use of face masks and sanitising

- The government should support all stakeholders to effectively play their individual roles towards combatting COVID-19 or reducing its rapid spread
- The government should link farmers to international markets and organise export of their crops or plan to purchase the same from farmers at a better price
- The government should focus or engage highly in economic empowerment of the nation at large, but especially persons with disabilities, rather than preparing them to receive charity
- Information on COVID-19 should be made for and by all. This means all materials should be translated into local dialects. Consult the people about which format works best for them especially for persons with disabilities

In global/international contexts

- Provide opportunities to bring people with disabilities together (across countries) to talk to each other and share experiences

Conclusions

Overall it is clear that using qualitative methods and in particular narrative approaches which are flexible and ‘interviewee led’ generate rich, personal data, which illustrates cogently and dramatically the experiences and emotions of the respondents.

The prediction made by many agencies with a focus on disability, that people with disabilities would be disproportionately affected by the COVID-19 pandemic and associated lockdowns appears to be confirmed by our data. In Uganda, as in other countries where we did this study, is evidence of exacerbated disadvantage, discrimination and marginalisation and the loss of the progress towards equal opportunities that had previously been made. Some of the feelings and impacts felt by the interviewees are not disability specific and may well have been experienced by others in the community in similar socio-economic situations. There are some disability and impairment specific impacts and a negative interaction with poverty, gender (i.e. being female), and with being a head of household or being dependent on others (within the family or outside it) for both emotional and material support. It is clear that information and services have not been sufficiently disability aware and inclusive.

The key message is that a disability inclusive approach to pandemic or other crises management, as well as to more regular services, is needed in order that people with disabilities are not left behind.

Acknowledgements

Sincere thanks and appreciation for the participation and help of the following are due:

To our Ugandan Inclusion Works consortium partners, Sightsavers and ADD International, and Inclusion International and other participating Organisations of People with Disabilities. They helped with the recruitment of participants and aspects of logistics.

Many thanks also to the 10 jobseekers who were interviewed for giving up their valuable time to share their experiences and perspectives, and for the cooperation and honesty.

Thanks to Atlas Translations Ltd. for their translation of the executive summaries.

Thanks also to Caroline Martin and David Haddock for their organisational support.

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Annex 1 – Participants’ table

Gender		Impairment*							Age			Education**				
Male	Female	Physical	Visual	Hearing	Intellectual	Psychosocial	Other	Multiple	<29	30 to 49	50>	None	Primary	Secondary	Tertiary	Other
5	5	3	2	1	1	0	3	0	5	5	0	0	1	1	8	0

Occupation***				Marital status			Location			Dependence****				Times interviewed	
Employed/works	Unemployed	Student	Other	Married	Single	Other	Rural	Urban	Semi	Depends on others	Others depend on them	Neither	Unclear	Once	Twice
5	1	3	1	5	5	0	6	2	2	0	7	3	0	0	10

* Other includes speech impairment, albinism, and sickle cell disease

**College education included under ‘tertiary’. Other includes religion-based education and informal education.

*** The occupation category of ‘other’ included volunteers, and those with caring responsibilities who were not actively seeking employment.

**** The dependence category was open to interpretation by data collectors, as it was a category of interest decided after the interviews has been conducted so data was not systematically collected about it.