

# Breakout session 2: Children and youth with disabilities

14<sup>th</sup> March 2022



# Breakout session 2: Children and youth with disabilities

Inclusion in COVID-19 care and prevention	
Chair: Xanthe Hunt	
Joanna Morrison ( <i>No presentation</i> )	Talking to Nepali adolescents with disabilities and their peers about COVID-19 using participatory, creative and inclusive methods
Femke Bannink	'We have to try and teach them from home' – parents perspectives on the impact of the COVID-19 response on children with disabilities in Uganda
Cath Lunt	"I want my son to matter – I want him to be talked about". Using Research to Empower the Voices of Families with Disabled Children to Create Change – lessons learnt from the Disabled Children's Campaign during the COVID-19 pandemic in England
Gabriela Ramos	The impact of COVID-19 pandemic on inclusive education of children with disabilities in Peru

**Femke Bannink**  
MRC Unit, Uganda

‘We have to try and teach them from home’ –  
parents perspectives on the impact of the COVID-  
19 response on children with disabilities in Uganda

MRC/UVRI and LSHTM Uganda Research Unit



# ‘We have to try and teach them from home’ parents perspectives on the impact of the COVID-19 response on children with disabilities in Uganda

Dr Femke Bannink Mbazzi, Elizabeth Kawesa, Ruth Nalugya,  
Claire Nimusiima, Prof. dr. Janet Seeley

# COVID-19 in Uganda

- 129,578 cases, 3317 deaths (MoH, January 2022)
- Lock downs and restrictions:

Period	Restrictions	Restrictions continuous
Mar – Jun 2020	First lock down	Schools closed
Jul – Sep 2020	Tight restrictions	
Oct 2020 – Apr 2021	Average restrictions	
May – Jul 2021	Second lock down	Bars closed
Aug – Dec 2021	Average restrictions	Curfew from 7.00 (9.00) PM till 7.00 AM

# The iCOVID and Obuntu bulamu study

- iCOVID: nested qualitative study in the Obuntu bulamu RCT
- Perspectives on the impact of the COVID-19 response on children with disabilities in Central Uganda
- 5 rounds of phone interviews with 27 parents of children with disabilities between April 2020 and December 2021
- Thematic analysis

# Study population

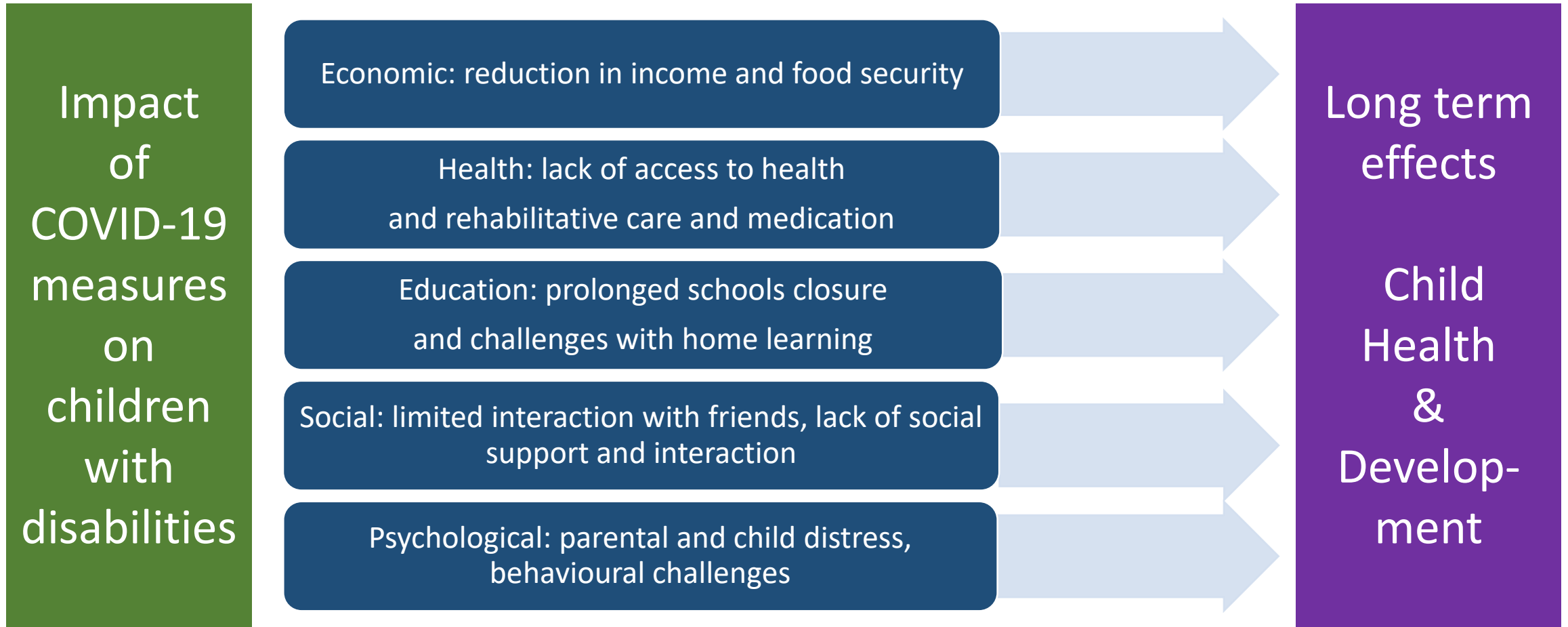
Variable	Description	Participants (N=27)	Variable	Description	Participants (N=27)
<b>Age parent</b>	< 35 years	12	<b>Gender CWD</b>	Female	16
	36 – 49 years	14		Male	11
	>50 years	1	<b>Age CWD</b>	Mean (SD), Range (8-14)	10.52
<b>Marital status</b>	Married	17	<b>Class (in 2020)</b>	Lower primary	20
	Separated	10		Upper primary	7
	Widowed	2	<b>Impairment child (primary diagnosis on medical file)</b>	Autistic Spectrum Disorder with ID	4
<b>Education level</b>	Higher education	4		Down syndrome	1
	Secondary school	11		Hearing impairment	2
	Primary school	12		Visual impairment	3
<b>Occupation</b>	Homemaker	12		Hydrocephalus with ID	4
	Self Employed	11		Intellectual disability	7
	Formal employment	4		Cerebral palsy with ID	1
				Muscular dystrophy	1
<b>Average net monthly income</b>	< 50 USD	21		Spina bifida	3
	50 – 100 USD	5		Multiple physical impairments	1
	> 100 USD	1			

# iCOVID study questions

- Participants' knowledge of COVID-19, and related public health response
- **The impact of COVID-19, and related public health response on participants and their children's, and community members day to day life**
- Participants' concerns about COVID-19, and related public health response
- Actions participants have taken in response to the information about and public health response to reduce the spread of COVID-19
- Recommendations for measures to reduce spread and help support/respond to participants concerns



# Themes identified



# Economic effects

- All families affected economically; they were unable to work during the lock-down periods, and continued to feel the impact of the restrictions and increased cost of living throughout the COVID-19 outbreak.
- All parents mentioned experiencing food shortages and rationing food during the lock down periods, some skipped meals. The situation was at its worst shortly after the first lockdown.
- A number of parents lost their jobs (mostly those in education, entertainment and tourism sectors)
- A large number of parents changed the type of income generating activity due to the COVID restrictions (e.g. from selling clothes to agriculture)

# Effects on health and rehabilitative care

- Challenges in accessing health and rehabilitation services and medication, especially during lock down periods
- Parents' distress over regression of child's development
- Negative effects of rationing medication and self medication

We can no longer get medicine as we used to. If you go to a hospital most of the health workers are working on corona patients so they don't give you treatment as we used to get it. We used to take a child and they give you attention but now the rest of us are not attended to.

# Effects on education

- Initial support home learning:

We have to try and teach them from home, we sit with them and we study

- Home learning challenges: difficulties accessing lessons on TV and radio due to electricity outages, cost of tutor and learning materials, parents work.
- Delays in school re-opening:

Children have grown up [...] This has affected us so so much! We are even starting to lose hope of children going back to schools in January like they had announced [...] Children in all other countries are studying [...] it's only ours that are not studying!

## Concerns about return to school and school fees payment

- Worries about having to repeat (two) years after reopening:

We have half-baked children, their age will qualify them to be promoted to the next class, but they have not qualified to be promoted

# Social effects

- Children miss their friends and playing together, especially during the lock down periods. Most resumed playing with children from the neighbourhood when the lock down was lifted, but school related friendships were often missed
- Children became more involved in chores and other activities at home:

He bought a rabbit, it gave birth to six babies and he is making them a house

- Parents also reported finding it difficult not to be able to attend funerals during the lock down and later on worrying about COVID spread at funerals:

There is no transport, even if you have lost a relative, you stay at home, when someone dies, its people in the community who bury the person. You stay home and cry.

# Psychological effects

- Emotional distress related to lack of food and finances in the first months:  
Children are crying saying the situation is difficult. They are unhappy because they see us sad.
- Over time more parents expressed concerns about their children's behaviour:  
When a child is at home and he doesn't do anything, he learns bad morals, they talk immoral words  
He went to the streets, he started stealing, he does not listen anymore
- Parents were specifically concerned about girls getting pregnant:  
We have girls, we are worried about them conceiving [...] You can't follow the child when she goes to toilet. You can't escort her wherever she goes.

# Conclusion and recommendations

- The COVID-19 measures have had a marked impact on the health, education, economic, and psychosocial situation of children with disabilities and their families in Central Uganda.
- Access to health services has been affected and needs to be prioritized to ensure CwD have access to specialized and general health services
- Drop out risk is high and home learning further widened the gap in education of children with disabilities. There is a need for specific attention to re-enrol and include children with disabilities when schools reopen in 2022.

# With thanks to

## Partners:

MRC/UVRI and LSHTM Uganda Research Unit



## Funders:



## More information:

Bannink Mbazzi, F, Nalugya, R, Kawesa, ES, Nimusiima, C, King, R, van Hove, G, Seeley, J (2021) 'The impact of COVID-19 measures on children with disabilities and their families in Uganda'. *Disability & Society*, DOI: [10.1080/09687599.2020.1867075](https://doi.org/10.1080/09687599.2020.1867075).

<https://www.ubuntu-hub.org/inclusive-education-obuntu-bulamu/>

<https://www.ugent.be/pp/orthopedagogiek/en/research/ongoingresearch/obuntubulamu.htm>

Questions: [femke.bannink@lshtm.ac.uk](mailto:femke.bannink@lshtm.ac.uk)



**Cath Lunt**

Disabled Children's Partnership

“I want my son to matter – I want him to be talked about”. Using Research to Empower the Voices of Families with Disabled Children to Create Change – lessons learnt from the Disabled Children's Campaign during the COVID-19 pandemic in England



*“I want my child to matter – I want him to be talked about”*

*Using research to empower the voices of families with Disabled children to create change – lessons learnt from the Disabled Children's Campaign during the COVID-19 pandemic in England*

Dr Cath Lunt

# Introduction

- Disabled Children's Partnership
- Pandemic Research Programme
- Alignment of research, campaigning, policy and media
- Policy gains for disabled children and their families
- Lessons learnt



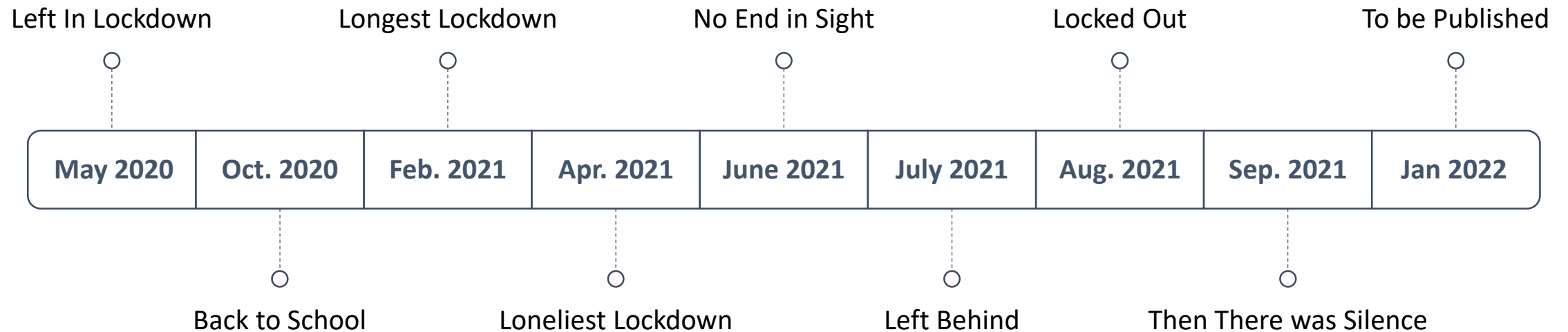
# Background

The Disabled Children's Partnership (DCP) is a coalition of over 100 charities that work with families to campaign on health and care services, led by:

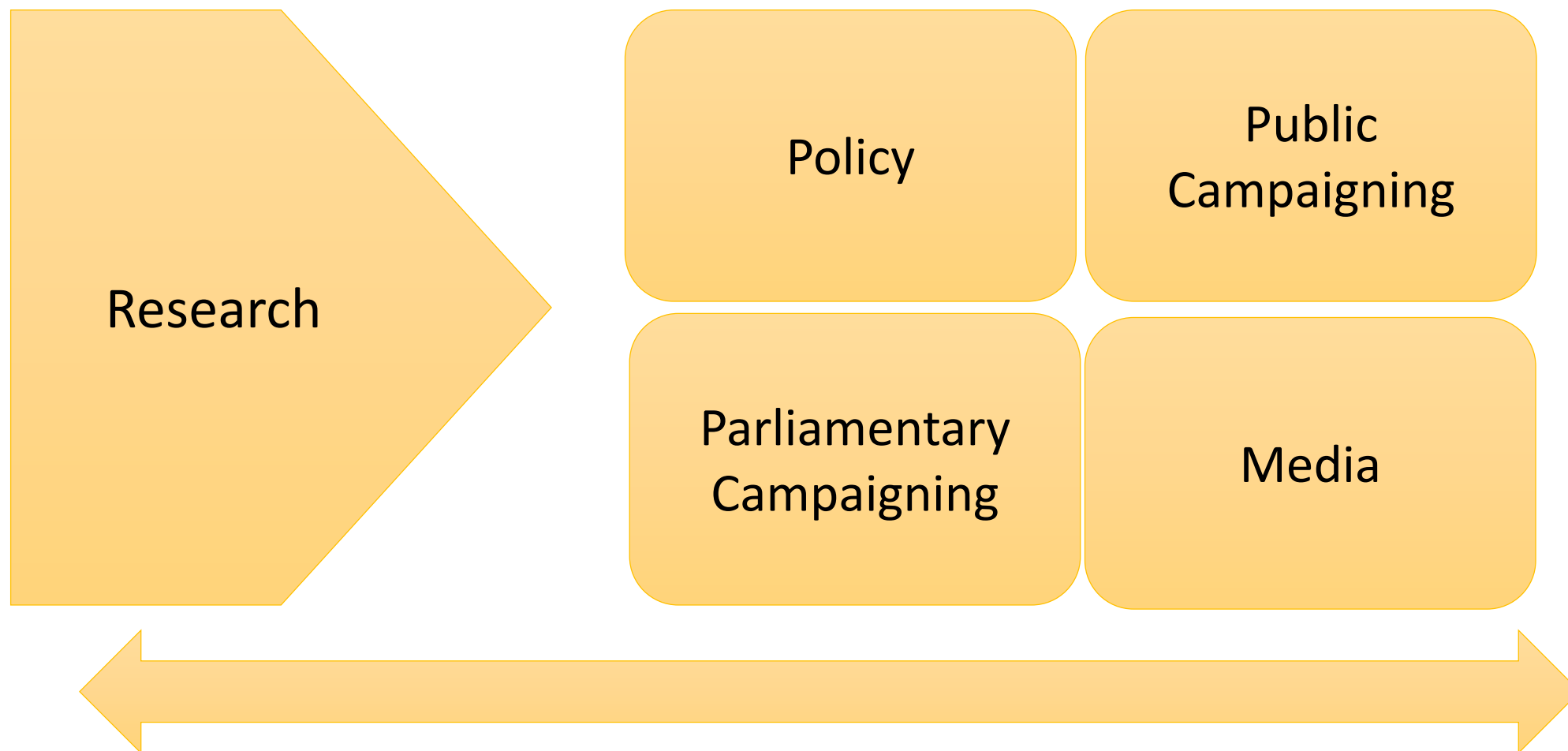


# Pandemic Research & Reports

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# Alignment of Research with Policy, Campaign and Media work



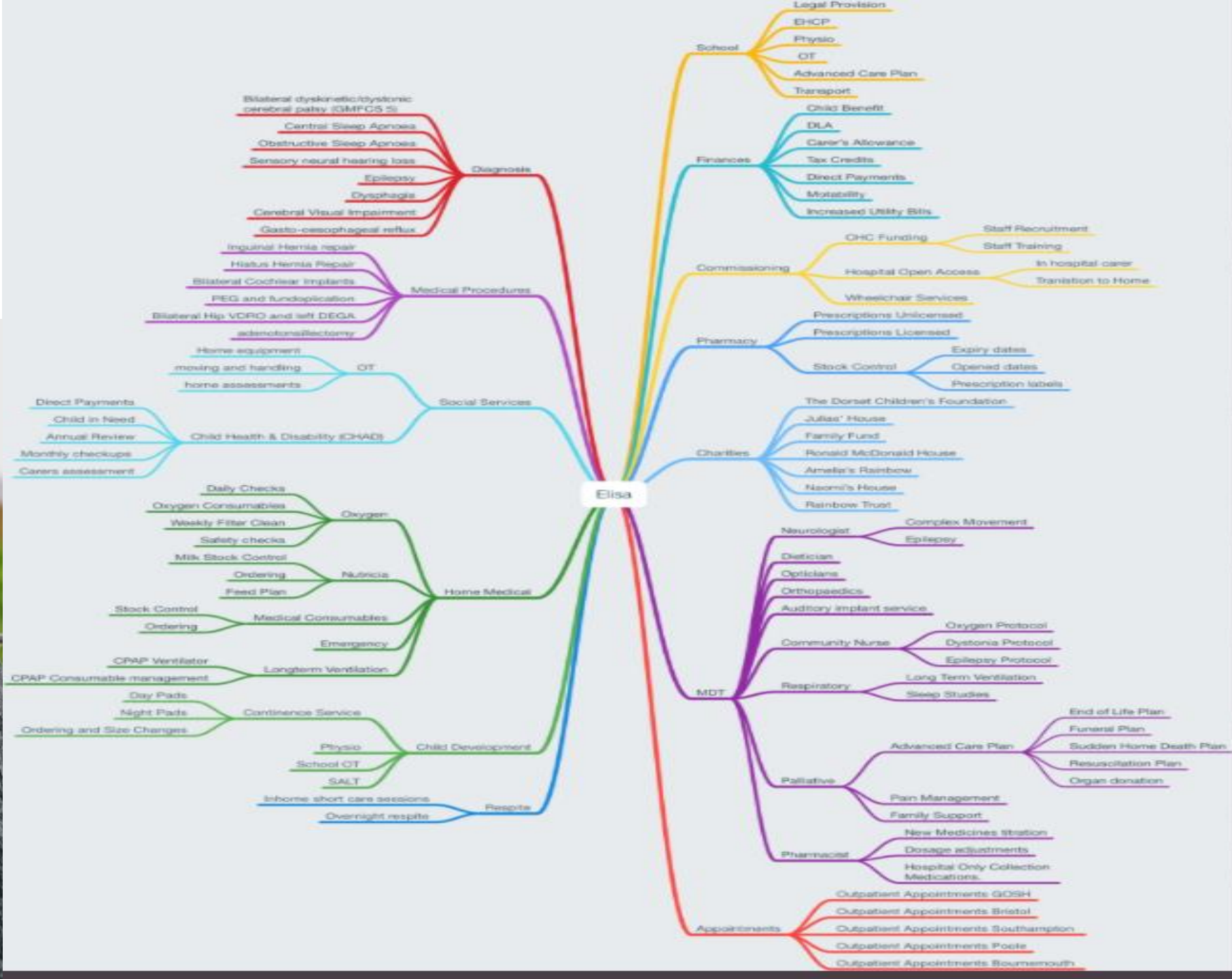
# Support for Disabled Children

- Educational Health and Care Plan
- Therapies & Equipment
- Health Appointments - Surgery
- Support within the home or community
- Informal Care or Support
- Leisure, Retail, Transport





# Complicated web of services that surround Elisa





# Key Stats

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75% of families reported delays to routine health appointments for their disabled child

70% of disabled children could not access therapies

71% of parents said that their disabled child had a

91% of parents reported that their disabled child was socially isolated

43% of disabled children did not have a friend they felt close to that they could call on for help

70% of disabled children anxious and displaying unusual behaviour

66% of disabled children had sleep problems due to the pandemic

More than 80% of parents had some form of anxiety

7 in 10 siblings of disabled children were socially isolated despite restrictions easing

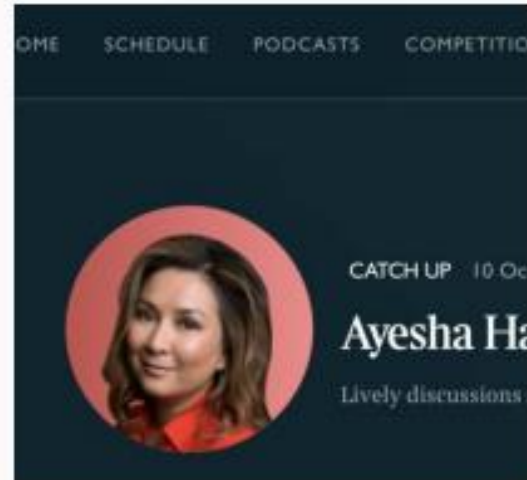
# Digital campaigning

- Blogs and videos
- Social media clips in 2021 sharing experiences from parents: over **35,000** views on Twitter.

Platform for parent blogs.



# Stories in the Media





# Public campaigning and engagement with parents



Disabled Children's Partnership



Pears Foundation



## Then There Was Silence

The Impact of the Pandemic on Disabled Children, Young People and their Families.

Dr Cath Lunt,  
Disabled Children's Partnership  
10th September 2021

### PANDEMIC TRAUMA OF KIDS HIT BY £434m SHORTFALL

**8-YEAR WAIT AND LEGAL BATTLE... FOR A SHOWER**  
LARRY HENRY, 51, from London, has a 10-year-old son with a learning disability. His son, Noah, has been waiting for a shower for eight years. Noah's family has been waiting for a shower for eight years. Noah's family has been waiting for a shower for eight years.

**THE worrying neglect of disabled children's needs by health services and local authorities during the pandemic is today laid bare by a shocking new report.**  
Families risk 'abandonment' as services disappear and essential care is cut. The report, published by the National Children's Advocacy Centre, says that disabled children are being neglected and abandoned by health services and local authorities during the pandemic.

**NO FACE-TO-FACE THERAPY**  
Faded and faded, from the heart of the pandemic, the report says that disabled children are being neglected and abandoned by health services and local authorities during the pandemic.

**MENTAL HEALTH SUPPORT**  
The report says that disabled children are being neglected and abandoned by health services and local authorities during the pandemic.

**LONG WAIT FOR BATH LIFE**  
The report says that disabled children are being neglected and abandoned by health services and local authorities during the pandemic.

**POWERLESS AND ANGRY**  
The report says that disabled children are being neglected and abandoned by health services and local authorities during the pandemic.

**STRUGGLED SO BADLY WE THOUGHT ABOUT DIVORCE**  
The report says that disabled children are being neglected and abandoned by health services and local authorities during the pandemic.

**SUPPORT FOR Lelia was withdrawn overnight when pandemic began. We heard nothing**  
The report says that disabled children are being neglected and abandoned by health services and local authorities during the pandemic.

**STUCK INDOORS WITHOUT WHEELCHAIR**  
The report says that disabled children are being neglected and abandoned by health services and local authorities during the pandemic.

## DISABLED...AND ABANDONED

**'I've missed his school. Noisy, noisy, systems that don't join up is an endless job' COMPLETELY ISOLATED**  
The report says that disabled children are being neglected and abandoned by health services and local authorities during the pandemic.

**'We got lawyers to secure a co-Dee place for Kiri because local authority refused' LEFT IN THE DARK**  
The report says that disabled children are being neglected and abandoned by health services and local authorities during the pandemic.

**'EQUIPMENT DELAYED FOR NINE MONTHS'**  
The report says that disabled children are being neglected and abandoned by health services and local authorities during the pandemic.



## URGENT: email ministers so disabled children are not forgotten in the spending review

On 27 October 2021, Rishi Sunak will announce what money will go towards disabled children's health and care at the government's Spending Review.

Nearly three quarters of disabled children and young people have seen their progress regress in the pandemic as vital support services stopped. Yet there has been no ring-fenced recovery funds for disabled children.

And the situation wasn't good enough before COVID. Too many children were in unnecessary pain, and too few parent carers



We welcome the findings of the five reports by the Disabled Children's Partnership between February and September 2021 and we are considering the impact of the COVID-19 pandemic on disabled children and their families.

Disabled Children's Partnership @DCPcampaign · Sep 7

! DISABLED CHILDREN RAISED IN PARLIAMENT PLEASE SHARE

Champion @KateOsborneMP asks a powerful question of @RishiSunak. Many children have regressed in the pandemic, as already stretched services were delayed. At the spending review, @hmtreasury must fund recovery. 1/2



2.6K views 0:03 / 0:39

1 48 53

Disabled Children's Partnership @DCPcampaign · Jun 30

Brilliant to see champion @S\_Hammond raise support for disabled children needing to self-isolate with @GavinWilliamson today in parliament.

Many children access vital therapies and health services at school. There needs to be a plan for them to access this support at home. 1/3



616 views 0:05 / 0:43

4 10 11

Grahame Morris

Labour

Easington

Comments

To ask the Secretary of State for Health and Social Care, with reference to the Disabled Children's Partnerships Left Behind report, published on 16 July 2021, what assessment he has made of the potential merits of funding specific covid-19 recovery policies for disabled children, young people and families to help them recover from the covid-19 outbreak in the upcoming Comprehensive Spending Review.

Many excellent points raised by @BaronessUddin + @SalBrinton in @UKHouseofLords earlier in the week.

- 1) Delays to health services mean some disabled children won't be able to learn.
- 2) Pre-pandemic social care £ gap.
- 3) Need for therapy catch-up.

FYI @educationgovuk @BaronessEB



171 views 0:43 / 1:58

Disabled Children's Partnership @DCPcampaign · Apr 26

Fantastic to see another MP - @YasinForBedford - raising a COVID-19 recovery plan for disabled children + families. @vickyford says that "The funding should be there" for schools to buy therapies. But this doesn't mean therapies and health appointments are reaching families 1/4



612 views 0:05 / 1:30

1 11 18


Disabled Children's Partnership @DCPcampaign · Jun 7

Watch disabled children raised today in @UKHouseofLords

Baroness @MRitchieSD eloquently raises that the government's education recovery plans must include therapies and respite catch-up.

See below for more highlights and our response to the government's messages.

1/4



319 views 0:02 / 1:02

1 4 16

# DCP Campaign Win – 1<sup>st</sup> February 2022



**Disabled Children's Partnership Retweeted**



**Amanda Batten** @Amanda\_Batten · Feb 1



Campaign win for [@DCPcampaign](#) today!! After years of campaigning we secure a £30m fund. Of course it won't solve everything, but any progress is really hard won at the moment so thanks to all campaigners everywhere

# Lessons Learnt



- Research Priority Setting by Disabled children's families and charities that support them.
- Rapid Dissemination including the voice of parents and families
- Research as a hook for media and campaign work
- Engagement with Policy Makers
- Parents have their experiences heard directly by those in power



# Thank you for Listening



[disabledchildrens.partnership@mencap.org.uk](mailto:disabledchildrens.partnership@mencap.org.uk)





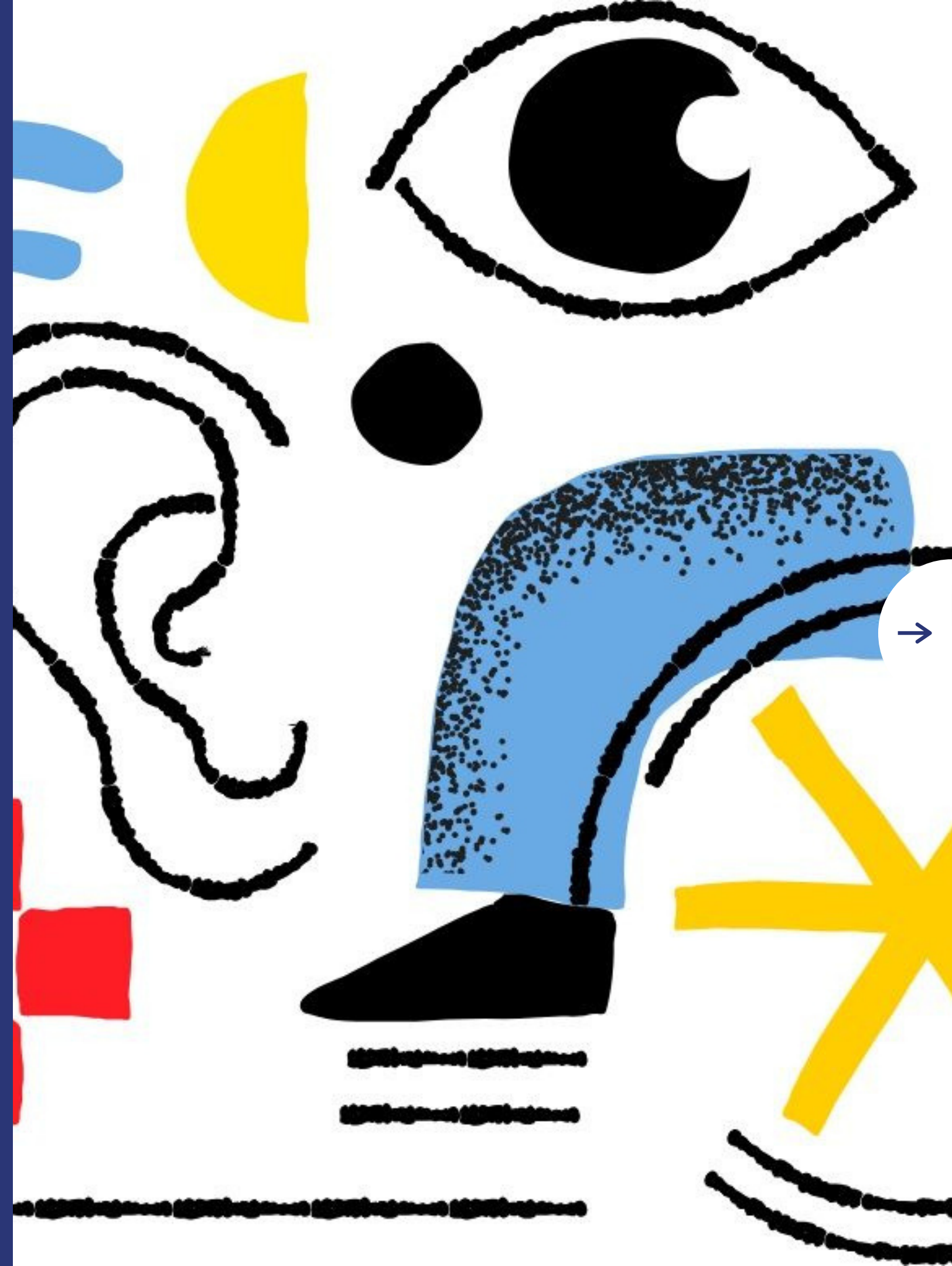
**Gabriela Ramos**  
PUCP

The impact of COVID-19 pandemic on inclusive education of children with disabilities in Peru

# The impact of COVID-19 pandemic on inclusive education of children with disabilities in Peru

Gabriela Ramos Bonilla  
PUCP

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# INTRODUCTION

1. PUBLIC PRIMARY EDUCATION IS SUPPOSED TO BE INCLUSIVE. IT IS NOT A REALITY

2. COVID-19 PANDEMIC (2020) AND THE CREATION OF THE “APRENDO EN CASA” STRATEGY FOR REMOTE EDUCATION

3. THIS STRATEGY'S RESULTS AND EFFECTS ON THE EDUCATION OF STUDENTS WITH DISABILITIES IN PERU ARE UNKNOWN.





## MAIN RESEARCH QUESTION:

How the Covid-19 pandemic has changed the way in which inclusive educational services are offered in the public sector and the ability to exercise the right to education of students with disabilities at the primary level?



# MIXED METHODOLOGY →

## QUANTITATIVE METHODOLOGICAL STRATEGY

- National Households Survey (ENAHU) 2019 and 2020
- People aged 6 to 13 years were included.
- Application: face-to-face and by phone calls
- Survey Limitations

## QUALITATIVE METHODOLOGICAL STRATEGY

- Documentary review and in-depth semi-structured interviews.
- 33 interviews including students, families, specialists, school directors, teachers, specialists of the Support Service for Special Educational Needs
- 2 regions of Peru



Section 2:



WHICH WERE  
OUR MAIN  
FINDINGS?

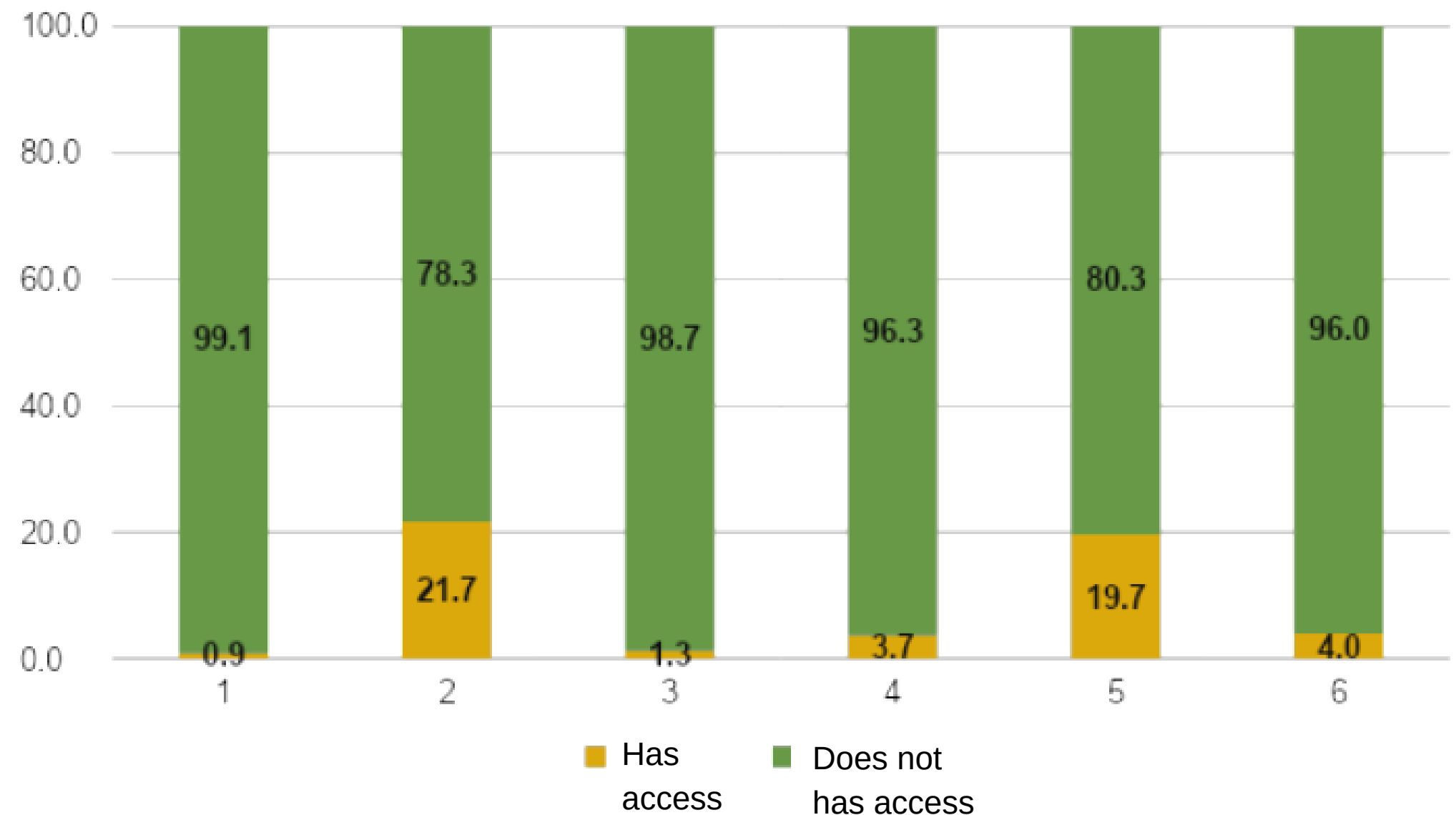
# STATE MEASURES TO GUARANTEE THE SERVICE PRESENCE

**Higher probability of access to education when:** the parents have a higher education level; households have access to ICTs and the Internet.

**Lower probability of access to education when:** the student has a disability; the student home is overcrowded.



Percentage of children with disabilities that access to education (6 to 13 years old), Peru



Source: ENAHO (2019 and 2020)

# Access barriers



1

Students and teachers lack access and use knowledge of ICT's

2

Slow implementation of public interventions

3

Persistence of attitudinal barriers and discrimination against people with disabilities in public education

4

Lack of supervision of compliance with state measures at the local level.

5

Incomplete and non-digitized data systems in schools.

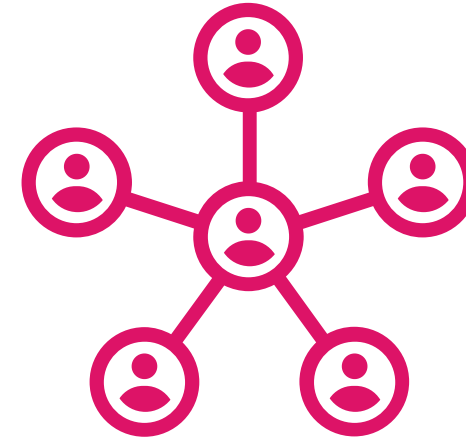
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Ministry of Education' poorly designed communication strategies



# COLLECTIVE STRATEGIES

The remote education strategy was supported by different collective strategies developed by various education community members.



**Disability advocacy organizations**



**Regional-level state specialists and schools**



**Families and students with disabilities**





# STATE MEASURES TO GUARANTEE THE STUDENTS' **PARTICIPATION**



# Barriers to participation

1

Students and teachers lack access and use knowledge of ICT's

2

Families – socio-economic and emotional issues

3

Families' lack of pedagogy strategies and teachers' lack of experience in guiding parents

8

Ministry of Education' poorly designed communication strategies

5

Teachers: no interest in adapting educational materials to their students educational needs

6

Wrong understanding of inclusive education and how to make adaptations

7

Sistemas de información y gestión de datos incompletos y no digitalizados en las escuelas.

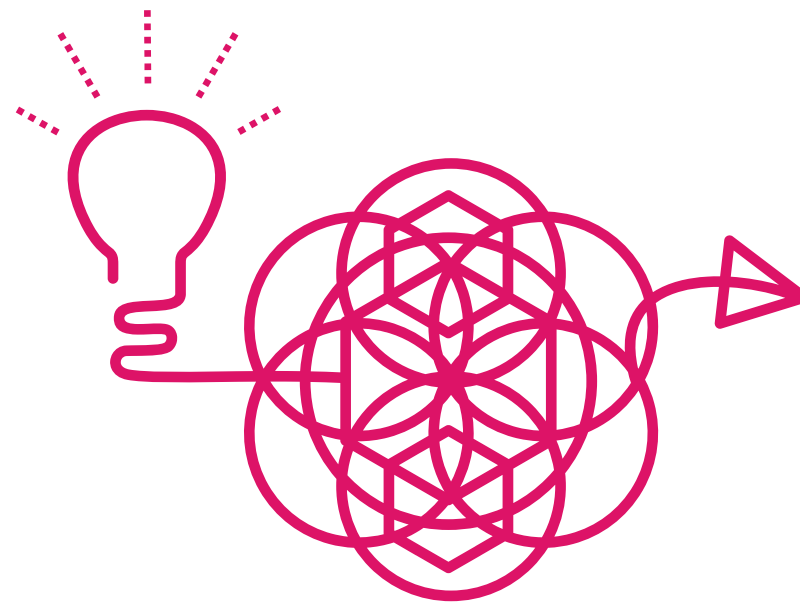
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Brecha de atención del servicio de SAANEE y concepción errónea de sus funciones

# COLLECTIVE STRATEGIES



**Diagnosis and  
characterization of  
students**



**Adaption of  
educational  
materials**



**Families'  
orientation and  
emotional support**

## Evaluation of learning achievements



Lack of guidance on how the  
evaluation processes should be  
carried out in practice

- Lack of clarity = heterogeneous execution.
- Difficulty evaluating activities that involved body movement
- No grade repetition measurement = misunderstandings, decrease of participation

# CONCLUSIONS

STATE MEASUREMENTS PRESENT VARIOUS  
BARRIERS IN PRACTICE

COLLECTIVE STRATEGIES ARE IMPORTANT BUT  
UNSUSTAINABLE

SOME POSITIVE OUTCOMES





# Thank you

Read more at:

<http://www.grade.org.pe/publicaciones/la-educacion-de-ninos-y-ninas-con-discapacidad-en-el-peru-durante-la-pandemia-del-covid-19/>

