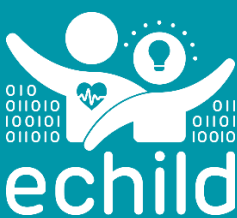UCL

Priorities for research using the ECHILD (Education and Child Health Insights from Linked Data) database

A survey of views from children and families conducted in collaboration with Scope

echild

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Authors

Claire Grant and Colleen Chambers
With input from Katie Harron, Ruth Gilbert, and Matthew Lilliman

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ECHILD website

https://www.ucl.ac.uk/child-health/echild

Scope website

https://www.scope.org.uk/

Background

The ECHILD database has been created by researchers at University College London, Great Ormond Street Institute of Child Health to conduct research to improve understanding of health and educational outcomes for children and young people with additional needs (sometimes called "vulnerable groups"). These groups include children and young people (CYP) with chronic health conditions, who receive support or adaptations for special educational needs, or who are in contact with children's social care services.

The ECHILD database links routinely collected, coded information from health, education, and social care services to understand how these services meet the needs of children before and after the onset of the COVID-19 pandemic. The linked data contain no names, addresses or details that could be used to identify someone. The data is held in a secure environment and only approved researchers can access the data.

Public engagement survey

This public engagement survey was conducted by researchers at University College London (UCL) in collaboration with Scope, a disability charity in England and Wales. The aim was to understand the view of children with additional needs and their families on how the ECHILD database should be used. This survey was voluntary and asked children and their parents/carers questions about ECHILD and potential research priorities.

We thank Scope and all the children, young people, parents, and carers who contributed to this survey.

Overview of report

This report summarises responses to questions on three topics:

1. **How children and parents feel about the use of the ECHILD database for research**
2. **Their views on priorities for research using ECHILD**
3. **Their experiences of additional support and the effects of COVID-19 pandemic**

Who responded to the survey?

A total of 78 parents/carers and 17 children and young people responded to the public engagement survey (n=95). Parents were asked to think about their youngest child with additional needs when they responded. Children were asked to answer questions about themselves. All responses were anonymised, preventing any identification of respondents,

including where parents and children and young people from the same household responded to the survey.

The children and young people discussed were most frequently white (83%) and male (59%). The most common type of impairment was neurodivergence (63%) and the greatest area of need was communication and interaction difficulties (65%), although many reported multiple impairments and needs (see **Table 1**).

**Table 1. Characteristics of the child or young person considered in response** (n=95)

Age of child/young person *(years)*	Number	Percent
0-5	5	5%
6-10	24	25%
11-15	29	31%
16-20	19	19%
21-27	13	14%
No response	6	6%
Ethnicity		
White	78	82%
Asian or Asian British	6	6%
Black, African, Caribbean, or Black British	<5	<5%
Mixed or multiple ethnic groups	5	5%
Other ethnic group	<5	<5%
No response	<5	<5%
Gender		
Female	30	32%
Male	55	58%
Non-binary, other or no response	10	11%
Type of impairment*		
Neurodivergence (including autism, social or behavioural differences or ADHD)	60	63%
Social and/or emotional needs	48	50%
Learning, understanding, or concentrating	47	49%
Chronic or long-term condition	34	36%
Mental health	33	34%
Speech or language	29	33%
Area of need*		
Communication and Interaction	39	65%
Cognition and Learning	42	55%
Social, Emotional and Mental Health difficulties	45	50%
Physical and/or Sensory Needs	41	30%
*Respondents could report more than one type of impairment or area of need		

Key findings

1. ECHILD and research priorities

Over 85% of respondents were comfortable with their own/their child's anonymised data being used for research that might benefit the health of children or families in the future. Most respondents felt comfortable with **charities** (84%), **researchers** (79%) and **government analysts** (77%) using ECHILD, so long as they could not identify individual children. Just under half (48%) of respondents felt comfortable with commercial, for-profit organisations using these data, although 29% disagreed with this statement. Concern with the database being used to track individuals was predominantly neutral, with 42% neither agreeing or disagreeing and similar proportions agreeing and disagreeing (19% and 28%, respectively). This could reflect lack of clarity in the question.

Figure 1. Views on different interest groups using the ECHILD database (n=95)

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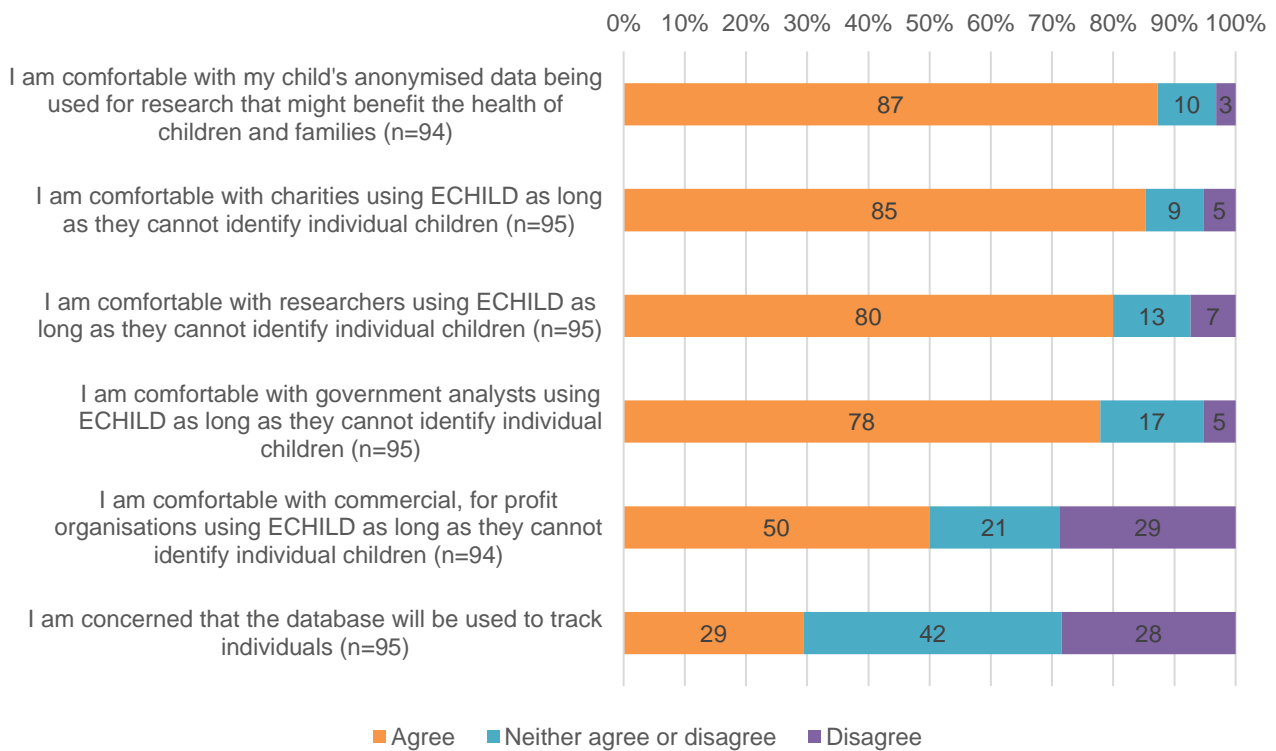
2. Areas for future research

Respondents felt it was most important to prioritise research related to **community child health services** for children with special educational needs (98%), **GP health care** for children with special educational needs (96%) and **mental health care** for children with special educational needs (96%). Research related to school responses to children being absent from school was the lowest priority (63%) for respondents.

Figure 2. Research priorities for researchers using the ECHILD database (n=95)

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Research priority	Important	Don't know	Not important
Community child health services for children with SEN (n=95)	98	2	0
GP's health care for children with special educational needs (n=94)	96	3	1
Mental health care for children with special educational needs (n=94)	96	1	3
Whether adjustments for children with special educational needs improves their experience in school (n=95)	93	3	4
Impact of SEN in school on children's lives as adults (n=95)	93	5	2
Health problems of parents or siblings of children with SEN (n=94)	87	4	9
Whether support for special educational needs in school affects the lives of siblings or parents (n=95)	85	8	6
Long-term impact of disruptions to services during the COVID pandemic on health and educational outcomes (n=95)	83	11	6
School responses to children being absent from school (n=95)	63	13	24

In free-text responses, respondents suggested specific research questions they felt should be research priorities for ECHILD. **These included:**

Long-term outcomes

1. What happens to children and young people with additional needs after they leave school?
2. What are the lasting impacts of COVID-19 and associated restrictions on education and health outcomes for children and young people?

Impact of support

1. What are the differences in outcomes between children with similar challenges who receive different types of support (e.g., specialist schools, home learning, special educational needs support in mainstream)?
2. Can mainstream schooling be detrimental to the wellbeing of children and young people with additional needs?
3. What are the outcomes for children and young people who do not meet thresholds for additional support or are undiagnosed?
4. What is the variation in support and service provision across mainstream schooling?

Changing patterns of need

1. Can waiting times for specialist support and diagnoses impact on children and young people health outcomes?
2. What about the needs of children and young people who acquire disabilities (i.e., brain injury)?
3. What are the variations in type of need for children and young people across the country?

3.1 Experiences of additional support

The survey asked young people and parents to answer questions about a specific child in their family with additional needs. **What kind of support were these children getting?**

- **Adaptations to learning** (mentioned in 35% of responses), including extra time for classes and assessments, as well as breaking down instructions for tasks.

- **Specialist equipment** (mentioned in 30% of responses), including laptops, sensory toys, mobility equipment, adjustable desk spaces and specialist apparatus, e.g., trampolines

- **One-to-one support** (mentioned in 35% of responses), including teaching assistants and support with learning, as well as for facilitating socialising with peers.

- **Break-out spaces** (mentioned in 25% of responses), including non-stimulating environments to escape to when overwhelmed or in need of a break.

- **Wellbeing activities** (mentioned in 21% of responses), including movement breaks, animal therapy, sensory circuits, music, yoga, swimming, art therapy and Touch Talk.

- **Professional input** (mentioned in 18% of responses), including speech and language therapists, occupational therapists, and medically trained staff.

- **Supporting activities of daily living** (mentioned in 9% of responses), including eating and going to the toilet, as well as developing life skills, e.g., going to the shops.

- **Communication with parents** (mentioned in 9% of responses), including frequent contact with caregivers (by email or phone) throughout the day with updates.

This was felt to help CYP

"Participate more fully"
"Feel safe"
"Experience pleasure & enjoyment"
"Gain confidence"
"Make friends"
"Improve behaviour"

This was felt to help families

"Feel validated"
"Improve school-home relationships"
"Reduce parental stress"
"Improve family function"
"Communicate better at home"

3.2. Impact of COVID-19

Only 7% of children and young people referred to in this survey continued to attend school throughout the COVID-19 pandemic. Of the children and young people who stayed at home during lockdowns, 28% did not have to do schoolwork when not attending school. For students who participated in home learning, over half (54%) felt that educational experiences worsened during this time. Although some (32%) reported that educational experiences were better than when attending school.

How did school closures affect children and young people's physical health?

30%
54%
16%

■ Better ■ Same ■ Worse

Better monitoring of conditions at home

Shielding reducing overall infection risk

Lack of physical activity

Reduced access to healthcare professionals
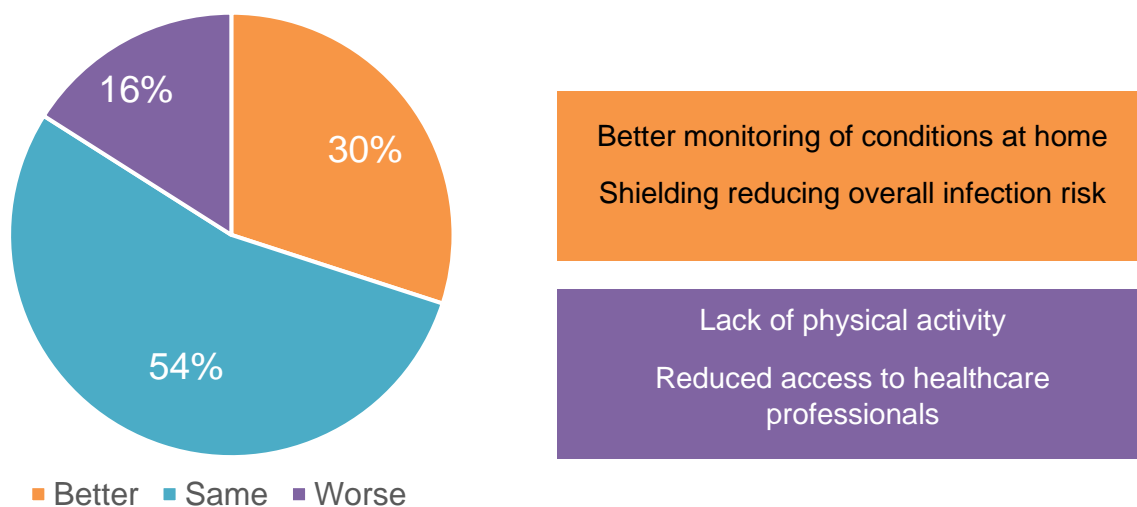
How did school closures affect children and young people's mental health?

Reduction in anxiety at home

CYP feeling in control of their routines

Fear, stress, and anxiety

Agitation and aggressive behaviour

Loneliness, isolation and lack of socialising

33%

39%

28%

■ Better ■ Same ■ Worse
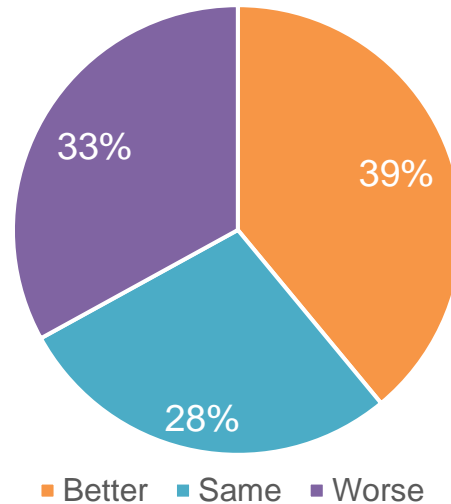
Key messages

In this survey of 95 parents and children and young people with additional needs, there was support for using the ECHILD database for research, with respondents most positive about use by charities, research from universities, and government, and split views about use by commercial companies. The three most important research priorities were related to community child health services, GPs health care, and mental health care for children with additional needs. **Findings from this survey will help shape the use of ECHILD for research, policy, and practice.**

echild - Partnerships:

@ucl_echild

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