<u>Urgent Concerns About Paediatric Long Covid</u> Services in Scotland

Children and young people with Long Covid continue to be overlooked, with limited access to care, no dedicated funding, and no oversight of government action. Without urgent intervention, Scotland risks failing an entire generation of children affected by Long Covid.



We would welcome the opportunity to discuss how we can work together to ensure that children receive the care and support they need.

Key Issues at a Glance:

- 1. Limited and Inconsistent Paediatric Long Covid Services
- 2. Failure to Implement the Long Covid Inquiry (2023) Recommendations
- 3. Lack of Transparency on Funding
- 4. No Parliamentary Oversight Since the COVID-19 Recovery Committee Was Dissolved
- 5. Failure to Conduct an Equality and Human Rights Impact Assessment (EQIA) for Children
- 6. Lack of Public Awareness and Stigma Around Paediatric Long Covid

What Needs to Happen Now

- 1. Ensure full implementation of the Scottish Parliament's Long Covid Inquiry recommendations.
- 2. Press for an urgent EQIA review to ensure legal compliance.
- 3. Seek transparency on Long Covid funding allocations for children.
- 4. Support the development of a national paediatric Long Covid service in every health board.
- Encourage the Scottish Government to strengthen public health messaging on paediatric Long Covid.

By Email

hscs.committee@parliament.scot



31st January 2025

Dear Convener and Members of the Health, Social Care and Sport Committee,

Urgent Concerns Regarding the Scottish Government's Approach to Paediatric Long Covid Services

I am writing on behalf of Long Covid Kids and our members to highlight urgent concerns about the ongoing challenges faced by children and young people (CYP) with Long Covid in accessing appropriate healthcare and support.

While we recognise the steps taken to acknowledge Long Covid as a significant health issue, the current service provision for children remains limited, fragmented, and inconsistent across Scotland. We ask the Committee to give this issue urgent attention to ensure that children and families receive the specialist care and support they need.

The Impact of Long Covid on Children and Families

Long Covid is not just a health condition, it is a life-altering challenge that affects every aspect of a child's life, including their education, friendships, physical and mental health, and future opportunities. Many families have found themselves acting as full-time carers, often at the expense of their own well-being, employment, and financial stability. The emotional and social toll is profound, leaving many struggling to access even the most basic support.

The Health, Social Care and Sport Committee plays a vital role in helping to address this crisis, ensuring that the Scottish Government's response aligns with both legal obligations and the

commitments made in the Long Covid Inquiry (2023). As the parliamentary body responsible for carrying forward the work of the COVID-19 Recovery Committee, your leadership is crucial in ensuring that children's health needs are not overlooked.

We appreciate the Committee's time and consideration of this issue and welcome the opportunity to discuss how we can work together to strengthen paediatric Long Covid services across Scotland.

Current Paediatric Long Covid Services

While the Scottish Government has indicated that a CYP Long Covid pathway exists (Appendix 1), significant gaps remain in accessibility, consistency, and sustainability of services across Scotland.

According to the National Strategic Network for Long-Term Effects of COVID-19 CYP Pathway Report, only three NHS boards currently offer any form of paediatric Long Covid care:

- NHS Grampian Established summer 2024.
- NHS Lothian Temporary occupational therapy service, beginning January 2025 and ending August 2025 (not a full medical service).
- NHS Greater Glasgow & Clyde Only available to children aged 14+, meaning younger children do not have access to specialist care.

Many children still do not have access to a dedicated paediatric Long Covid service, and the existing services primarily rely on rehabilitation models rather than comprehensive medical support. Additionally, short-term funding has created uncertainty, making it difficult for services to plan or expand.

These challenges highlight the need for further action to ensure that children across all NHS health boards have access to the care they need.

Lack of Focused Support for Children and Young People

The Scottish Parliament's Long Covid Inquiry (2023) recognised the urgent need for targeted paediatric Long Covid services. However, there is little evidence that these recommendations have been fully implemented.

Absence and Delayed Access to Specialised Care

- Paediatric Long Covid services remain limited in both availability and funding.
- General practitioners may not always have the necessary training to recognise and manage Long Covid in younger patients.
- Many children experience delays in diagnosis and access to appropriate care, which can significantly impact their education, social development, and overall well-being.

This situation raises serious concerns about compliance with Scots law, particularly under the UNCRC (Incorporation) (Scotland) Act 2024, which came into force on 16 July 2024.

Under Article 24 of the UNCRC, every child has the right to the highest attainable standard of health. Ensuring equitable access to appropriate Long Covid care is a key part of upholding this legal obligation.

We ask the Committee to work with the Scottish Government to accelerate the implementation of the Long Covid Inquiry recommendations and ensure ongoing oversight to support the development of a sustainable national paediatric Long Covid service.

Lack of Transparency on Funding

The Long Covid Inquiry recommended that funding be ring-fenced for paediatric Long Covid services, yet:

- There has been no clear allocation of resources specifically for children and young people.
- Children's needs have been absorbed into broader Long Covid initiatives, rather than having dedicated funding.
- Paediatric Long Covid services are competing with overstretched general healthcare budgets, making service expansion difficult.

Without transparency on funding, it remains unclear whether the necessary investment is being made to meet the needs of children.

We urge the Committee to seek clarification on how Long Covid funding is being allocated and to advocate for dedicated resources to ensure the sustainability of paediatric services.

Lack of Parliamentary Oversight Since the COVID-19 Recovery Committee Dissolution

Since the dissolution of the COVID-19 Recovery Committee, there has been a lack of structured parliamentary oversight to ensure progress on Long Covid service development.

Key Oversight Gaps:

- No successor committee has taken on full responsibility for monitoring the implementation of the Long Covid Inquiry recommendations.
- There has been limited scrutiny of the Scottish Government's response, particularly in relation to funding, service development, and health inequalities.
- Without regular committee discussions, the specific needs of children with Long Covid are not being raised at a national level.

Greater transparency and oversight would help ensure that the Scottish Government is delivering on its commitments and that children are not left behind.

We encourage the Committee to consider how ongoing parliamentary scrutiny can be strengthened to support the delivery of sustainable, equitable paediatric Long Covid services.

The Need for an EQIA for Paediatric Long Covid Services

While an Equality and Human Rights Impact Assessment (EQIA) was conducted for adult Long Covid services in 2022, no equivalent assessment has been completed for paediatrics.

This raises significant concerns in relation to:

- The Equality Act 2010, which requires public bodies to ensure policies do not disproportionately impact protected groups, including children and disabled individuals.
- The Fairer Scotland Duty, which places an obligation on public bodies to reduce inequalities of outcome for marginalised groups.
- The UNCRC (Incorporation) (Scotland) Act 2024, which legally protects children's rights in Scotland.

Completing an EQIA for CYP Long Covid services would help identify and address existing inequalities, ensuring that service provision meets the needs of all affected children.

We respectfully ask the Committee to support the urgent completion of an EQIA to strengthen policy decisions and ensure legal compliance.

Limited Awareness and Public Health Messaging

The lack of public health messaging about Long Covid in children continues to be a major

challenge.

Healthcare professionals, teachers, and parents may not always be aware of how to

recognise or manage Long Covid in young people.

The COVID-19 Recovery Committee recommended action on tackling stigma and

misinformation, but there has been little progress in implementing this.

A lack of awareness leads to delays in diagnosis, disruptions in education, and poorer

health outcomes for affected children.

We ask the Committee to encourage the Scottish Government to prioritise public health

messaging around paediatric Long Covid to ensure that families and professionals have access

to the right information.

Call for Ongoing Parliamentary Oversight

We appreciate the Committee's time and consideration of these concerns and would welcome

the opportunity to discuss how we can work together to ensure children with Long Covid receive

the support they need.

Yours sincerely,

Helen Goss

COO & Scotland Lead

Long Covid Kids









