

# Home Care and Support Services for Children

The Need for Independent Oversight

2025



ombudsman  
do leanaí  
for children

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## Section 1: Introduction

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Home care and support services provide a vital lifeline to children with complex healthcare needs and their families, enabling them to be supported to live at home. However, there is currently no regulatory framework for these services in Ireland. While we are still waiting for the final draft of regulations from the Department of Health setting out minimum requirements for home support providers, children have been excluded from the framework.

This report outlines why we believe independent oversight of home care and support services provided to children is needed. We also highlight the story of baby Luke,<sup>1</sup> whose father made a complaint to us over his concerns about how his young son's home care was being managed and shows first hand why regulation is needed.

## Section 2: Background

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The terms 'home care' and 'home support services' have been used interchangeably over time and across services.<sup>2</sup> These services aim to facilitate people to live in their own home and community for as long as possible and reduce admissions to, and unnecessary stays in, health or social care settings. Currently, paediatric home care packages are provided by the HSE Primary Care services to children with complex healthcare needs and comprise the provision of home nursing care that support families to care for their child at home.<sup>3</sup> HSE Disability Services also provide home support services to children, as well as adults, with intellectual disabilities, autism and/or physical and sensory disabilities and may comprise nursing, disability or public health supports.<sup>4</sup>

The packages provided by Disability services are within the remit of the Department of Children, Equality, Disability, Integration and Youth (DCEDIY), with those provided by Primary Care services coming under the Department of Health. The HSE delivers these services either directly through its own staff or indirectly through funding to voluntary or private providers. Families may also purchase home care and support services through private providers. In this report, the OCO uses the term 'home care and support services' as an all-encompassing term.

Without data, it is not clear how many children use these services. In 2024, the HSE estimated that its Primary Care services would provide 651 paediatric home care packages.<sup>5</sup> The HSE provides estimates of the intensive support packages and home

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1 Anonymised for confidentiality.

2 See further: HIQA (2021), [Regulation of Homecare: Research Report](#); HIQA (2022), [Evidence Review to inform the development of National Standards for Homecare and Support Services in Ireland](#)

3 HIQA (2021), [Regulation of Homecare: Research Report](#), pp. 26-34.

4 Ibid.

5 Health Service Executive (2024), [National Service Plan 2024](#), p. 99.

support services provided to a person with disabilities by Disability services,<sup>6</sup> however it does not disaggregate its data to show how many of these services are for children.

There is currently no legislation or regulation specifically governing home care or support services in Ireland. The HSE and the service providers that it commissions are themselves responsible for monitoring the delivery of home care and support services to children.

The HSE in its own review of home care packages for children in 2014 noted that service provision has developed in response to demands from services and families rather than in a planned and structured way.<sup>7</sup> It identified the need for a national policy and standard service development and service delivery frameworks for children. Similarly, a national model of care for paediatric healthcare services produced by the HSE and Royal College of Physicians Ireland called for a standardised, coordinated and integrated approach to community services for children.<sup>8</sup> HIQA has also recently called for an overhaul of the home care sector and for the regulation of home care services that is inclusive of all who receive it.<sup>9</sup> The commitment in the Programme for Government in 2020 to introduce a statutory framework for home support services was therefore welcome. However, the commitment did not include children. The Programme for Government that was agreed in January 2025 similarly presents its commitments relating to home care and support services exclusively within services for older persons.

While home care and support services provided to children only represent a small proportion of the total home care and support services nationally, an increasing number of children and families are being provided with these services in their homes. HSE figures show that the number of paediatric home care packages in place annually had risen by 37% from 474 in 2016,<sup>10</sup> when figures were first reported in its National Service Plans, to 651 in 2024.<sup>11</sup> However, despite both children and adults using these services, home care and support is framed in policy and public debate as a service provided to adults, meaning that children rarely feature in discussions about services that also affect them. While data is regularly reported on home care and support services provided to adults, the equivalent data on services provided to children is unavailable.

Having ratified the UN Convention on the Rights of the Child in 1992, Ireland has an obligation to ensure that children's services are subject to regular, independent inspection for compliance with appropriate standards in order to guarantee that the rights of children receiving services are respected, protected and fulfilled. As the HSE is both a provider and funder of home care and support services, the current oversight

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6 See, for example: Health Service Executive (2024), [National Service Plan 2024](#), p. 102; Health Service Executive (2024), [PQ 34031-24 - Pauline Tully](#)

7 Health Service Executive (2014), [Review of current policy and practice in the provision of home care to children with complex medical conditions](#)

8 Health Service Executive and Royal College of Physicians Ireland (2016), [A National Model of Care for Paediatric Healthcare Services in Ireland Chapter 18: Community Services for Children with Ongoing Health Needs](#)

9 HIQA (2021), [Regulation of Homecare: A Position Paper](#); HIQA (2022), [Evidence Review to inform the development of National Standards for Homecare and Support Services in Ireland](#)

10 Health Service Executive (2017), [2017 National Service Plan](#), p. 23.

11 Health Service Executive (2024), [National Service Plan 2024](#), p. 99.

arrangements in place are insufficiently independent to align with the children's rights standards that Ireland has signed up to. It is vital that children are also assured of the same level of independent regulatory oversight of the services they receive.

### What the OCO has done on this issue to date:

The OCO has been raising concerns about access to home care and support for children and the oversight of services for some time:

- In 2012, we called for a national standardised approach to home care packages.<sup>12</sup> Since then, the OCO has received a number of complaints about the provision of home care and support services for children with complex health needs and disabilities, including concerns about safety, the competence of staff to meet the child's needs, and management of service, including the management of complaints about the service.<sup>13</sup> These complaints clearly demonstrate a need for independent oversight of the provision of home care and support services to children.
- In July 2021, the OCO wrote to the Department of Health to express concerns over its plans to progress with the development of a regulatory framework that excludes children from its remit and to call for the inclusion of children.
- In September 2022, we made a submission to the Department of Health on its consultation on the Draft Regulations for Providers of Home Support Services.<sup>14</sup> In this submission, we recommended that children should be included in the regulatory framework and that the regulations should include services provided by healthcare professionals, including nursing care, which is the primary form of care provided to children as part of paediatric home care packages.
- Between 2022 and 2024, the OCO engaged with the Department of Health and the DCEDIY to seek assurances that children would be included in the regulatory framework.
  - In response, the Department of Health stated that paediatric home support services differ greatly to home support services for adults included under the proposed regulatory framework and that paediatric home care packages are monitored on an ongoing basis by the HSE and the commissioned service provider.
  - DCEDIY expressed the view that children should not be included in the initial proposed regulations, and that at a minimum, their inclusion should be on a phased basis, and following comprehensive consideration and consultation.

<sup>12</sup> Ombudsman for Children's Office (2013), [Annual Report 2012](#), pp. 23-24.

<sup>13</sup> See, for example: Ombudsman for Children's Office (2021), [Childhood Paused: Ombudsman for Children's Office Annual Report 2020](#), pp. 23-24.

<sup>14</sup> [OCO Submission on Draft Regulations for Providers of Home Support Services](#)

- In July 2024, the OCO wrote to the Oireachtas Joint Committee on Health as part of its pre-legislative scrutiny of the General Scheme of the Health (Amendment) (Licensing of Professional Home Support Providers) Bill 2024.
- We welcome the recommendation made by the Oireachtas Joint Committee on Health in its report on its pre-legislative scrutiny in October 2024 that the regulations should include children, as well as all State-funded services, including nursing care.<sup>15</sup>

## Section 3: Privately Provided Paediatric Home-Care

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### Package: Baby Luke<sup>16</sup>

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Baby Luke was born with complex healthcare needs which resulted in him needing a tracheostomy, two cardiac surgeries and a pacemaker. Luke spent the first year of his life in Crumlin Children's Hospital and, at the time of the complaint, still required ventilation support.

Luke's dad came to us with a complaint about how his son's home care package was managed and overseen by a Private Service Provider and the HSE between August 2022 and January 2023.

### Resourcing Baby Luke's Contract

- The HSE contracted a Private Provider to provide Baby Luke with a home care nursing support package of 70 nighttime hours and 18-hours during the day. However, the Provider was unable to fulfil these contracted hours from Friday to Sunday. Therefore, despite being medically fit enough to be discharged completely, from August 2022 Luke had to spend the weekends in hospital. Luke's dad told us that there were also multiple occasions on weekdays each month where cover could not be sourced for a care shift, and where communication from the agency was limited and at very short notice.

### Complaint & Termination of Contract

- Luke's dad told us that on 10th January 2023, a nurse caring for Luke overnight allegedly fell asleep during their shift. His dad reported this to the Private Service Provider and outlined his grave concerns. On 13th January, Luke's dad was notified that Luke's contract with the Provider

<sup>15</sup> Houses of the Oireachtas, Joint Committee on Health, [Report on the Pre-Legislative Scrutiny of the General Scheme of the Health \(Amendment\) \(Licensing of Professional Home Support Providers\) Bill 2024](#), p. 10.

<sup>16</sup> Anonymised for confidentiality.

had been terminated. He told us that he submitted a formal complaint to the Provider on January 19th about the resourcing of the contract, the cessation of the contract on foot of raising concerns to the Agency and the alleged incident on January 10th. An initial acknowledgement and commitment to investigate the incident was received on January 24th. Luke's dad received no further contact about his complaint until six months later when he submitted an FOI request to the service and, as part of the materials provided, received an undated 'Complaint Report.'

### 3.1. What We Did

The OCO undertook a preliminary examination (PE) of both the Private Service Provider and the HSE to identify if any administrative actions/inactions had occurred which may have adversely impacted on Luke. Our examination identified the following:

- The HSE did not progress a Service Level Agreement (SLA) with the Private Service Provider for Luke's Home Care Package. When the OCO requested a copy of the SLA between the HSE and the Provider, a blank, draft, version was provided

HSE management could not account for why an SLA was not in place. The absence of an SLA between the HSE and a paediatric home care provider for the care of a child is hugely concerning.

***The HSE confirmed they held no records with respect to the complaint submitted on behalf of baby Luke by his parents, with respect to the resourcing issues and the alleged incident.***

In the PE response provided by the HSE, they confirmed their obligations with respect to the management and oversight of complaints made to a commissioned body, as per the Health Act (2004), stating;

***Paediatric home care packages are delivered as a managed service; where a complaint or incident occurrence arises on a monthly basis, agencies will advise HSE and the HSE must seek assurance that the company are managing this through their own complaints mechanism with appropriate timelines and levels of escalation including as appropriate an internal review...HSE do not manage the specific complaint process but at all times is obliged to follow up with service users and families on notification of complaints... The HSE public health nursing management are however obliged to ensure that the company notifies them of significant complaints and incidents and to get assurance that follow up has occurred within the submitted policy, process and timeline.***

However, the HSE confirmed it had no record of Luke's complaint relating to the Private Service Provider. HSE management told us that the complaint concerned a 'clinical incident' and was therefore not subject to its 'Your Service, Your Say' process. The complaint in fact proposed a number of issues, including concerns around contract resourcing, complaint management and the termination of the contract within day of the family's formal complaint. The HSE was also made aware of the Private Provider's decision to end the contract at the time.

The blank SLA for commissioned services provided to the OCO noted that complaints made to commissioned services should be discussed at the Children with Complex Health Care Needs Governance Group. The OCO has confirmed that the complaint was not brought to, or discussed, in this forum.

### **3.2 Next Steps: Engagement with HSE Local & National**

The OCO convened a meeting with the local Community Health Organisation (CHO) area representative and HSE senior management. The HSE acknowledged there were shortcomings in how baby Luke's care package was managed and resourced, including a lack of oversight of complaint management with the Private Provider. The local CHO area management agreed to meet with Luke's family and have since provided a verbal and written apology and outlined what steps were being taken to prevent these issues arising for another family.

#### **Redress proposed by HSE following OCO Examination**

HSE senior management agreed to progress actions relating to oversight and quality assurance with respect to private providers of paediatric home-care packages, which include:

- Engagement with other CHOs using the provider concerned and any other private providers, to confirm that SLAs are in place for all of these arrangements which include: the recording and oversight of clinical incidences, that all complaints are discussed at the Paediatric Home Care Package Governance group that meets quarterly, and to identify an escalation clinical lead within the HSE if complaints are not resolved satisfactorily through the provider.
- A HSE lead has been appointed to meet with families and private providers for issues like fill rates or the quality of care being delivered in the home. If issues can't be resolved, they are escalated to the Director of Nursing.
- To improve parents' awareness of their rights and the complaints process, an updated parent's leaflet has been distributed to all CHOs, and issued to all parents who currently hold a private home care package



### 3.3. The Outcome for Baby Luke

Baby Luke is currently supported by a home-care package with a different provider and the local CHO area continue to manage this care, with ongoing communication with his family.

The OCO welcomes the HSE's proactive engagement with us around our examination of this complaint, and we continue to engage with HSE senior management in progressing actions to address the issues it raises.

## Section 4: Conclusion

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The broader issue of the exclusion of children from the proposed regulations for home support services remains a huge concern for the OCO. Without independent regulation, we cannot be assured that these most vulnerable children are being provided with consistent, high quality and safe care.

In February 2025, the Minister for Health stated that the legislation – Health (Amendment) (Licensing of Professional Home Support Providers) Bill 2024 General Scheme – has been referred to the Office of Parliamentary Counsel for final drafting and will be presented to Cabinet in Q3 2025.<sup>17</sup> To ensure that children's rights are adequately considered in the provision of home care and support services in Ireland, they need to be included within the regulatory framework currently being finalised. Failing this, we strongly recommend that the Departments of Health and Children develop a standalone plan for children to include them within a regulatory framework that will provide independent oversight of home care and support services provided to them. This should apply to services provided through Primary Care and Disability Services.

The OCO will continue to engage with the Department of Health and Department of Children, Equality, Disability, Integration and Youth on this issue.

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<sup>17</sup> Houses of the Oireachtas, Dáil Éireann Debate, [Home Help Service](#), 5 February 2025.

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