

Public Petitions Committee  
Thursday 8 October 2026  
4th Meeting, 2026 (Session 7)

## PE2237: Create a “stage not age” health and social care and benefit system for people with exceptional complex medical needs

### Introduction

**Petitioner** Allan Petrie

**Petition Summary** Calling on the Scottish Parliament to urge the Scottish Government to create a “stage not age” health and social care and benefit system for people with exceptional complex medical needs, including a lifelong foster care model so that such young people do not lose vital paediatric and family financial support at 18.

**Website** <https://petitions.parliament.scot/petitions/PE2237>

1. This is a new petition that was published on 29 July 2026.
2. A full summary of this petition and its aims can be found at **Annexe A**.
3. Every petition collects signatures while it remains under consideration. At the time of writing, 939 signatures have been received on this petition.
4. A SPICe briefing has been prepared to inform the Committee’s consideration of the petition and can be found at **Annexe B**.
5. The Committee seeks views from the Scottish Government on all new petitions before they are formally considered.
6. The Committee has received submissions from the Scottish Government and the Petitioner which are set out in **Annexe C** of this paper.

### Action

7. The Committee is invited to consider what action it wishes to take.

**Clerks to the Committee**  
**October 2026**

## **Annexe A: Summary of petition**

### **PE2237: Create a “stage not age” health and social care and benefit system for people with exceptional complex medical needs**

**Petitioner:**

Allan Petrie

**Date published:**

29 July 2026

**Petition summary:**

Calling on the Scottish Parliament to urge the Scottish Government to create a “stage not age” health and social care and benefit system for people with exceptional complex medical needs, including a lifelong foster care model so that such young people do not lose vital paediatric and family financial support at 18.

**Previous action:**

I raised these issues in a meeting with the former Cabinet Secretary for Health and Social Care and five of his advisers, who promised action but, after months, only sent generic transition proposals. They failed to mention exceptional complex needs, ignored the collapse of adult services, offered no lifelong foster care solution, and made no reference to a Stage Not Age model showing a clear lack of understanding or meaningful action as their proposals did nothing to improve the situation.

**Background information:**

Children with exceptional complex medical needs in Scotland receive intensive paediatric support including specialist teams, therapies, rapid hospital access and 24-hour clinical respite. However, when they reach adulthood these essential services are lost, not because their needs change, but because adult services aren't designed for individuals who remain medically and developmentally child-like for life. Families face crisis, unsafe care, and collapsing support. For young people in foster care the situation is worse: foster carers are told to either continue caring with no financial support or return the young person to institutional care. This denies stability, family life and equality.

Such young people lose vital paediatric support and family financial support when moved to adult institutional services that cannot meet their lifelong child-level needs. It is my view that Scotland must ensure continuity, safety, dignity and proper lifelong support for such young people.

Despite raising these concerns with the former Cabinet Secretary for Health and Social Care and advisers, no meaningful action has been taken. A “stage not age” system is urgently needed to provide lifelong specialist care, therapies, proper respite and a lifelong foster care model. This petition is supported by many paediatric professionals.

## Annexe B: SPICe Briefing



### **Briefing for the Public Petitions Committee on petition PE2237: Create a “stage not age” health and social care and benefit system for people with exceptional complex medical needs, lodged by Allan Petrie**

#### **Brief overview of issues raised by the petition**

The petitioner wishes to see a change in approach in policy and services as children age into adults. They argue that children with profound and complex health and care needs, who will never be able to assume adult responsibilities and independence, are still subject to the same transition journey as other children who are not living with the same ongoing needs, because services for children and adults are radically different.

Further, they argue that for young people in foster care, the situation can be even more stark. The petitioner brings together overlapping areas of policy – healthcare, ‘corporate parenting’ and social work and social care services.

The stage not age approach would presumably mean that someone’s physical age would not be the marker for how services are assessed for or organised, but instead consider the situation and developmental stage of the young person on a case by case basis.

A complicating factor for any people navigating the period of transition, who are reliant on some support, is that the age at which someone is considered an adult varies according to different legislation and policy.

The [Scottish Government issued advice and guidance to support disabled children, young people and their families](#), which was last updated in November 2023. This has dedicated sections on transitions, transitions in health and social care, in education, and in employment.

#### **Ongoing health needs**

The Scottish Government acknowledges that because health and care services are organised differently for children and adults, the move from one to the other can be difficult to negotiate:

“If a young person has ongoing healthcare needs this this should be highlighted in a Transition Plan so that the right adult service is in place once children's services stop. The school team helps coordinate planning and making sure that the right healthcare services are involved... In some circumstances there may be no equivalent adult service and support services like respite might be more difficult to access... Young people with serious long term conditions or chronic health problems can benefit from having an [Anticipatory Care Plan](#).”

If a child is receiving treatment from Child and adolescent mental health services (CAMHS) then a [transition care plan](#) can be drawn up, although this assumes capacity (see below) on the part of the young person.

### Healthcare “passports”

According to the Scottish Government information:

“Healthcare “Passports” can help address communication challenges of children with complex needs summarising important aspects of a young person's healthcare and can assist communication during transition, e.g. the [Promoting a More Inclusive Society Digital Passport](#) and the [My Communication Passport](#)

See the [Inclusive Communication](#) section of this site for more”.

### How social services are organised as children transition to adulthood

Children with disabilities and additional needs will inevitably transition into adulthood but their needs – physical, health, emotional and mental - might not change significantly. However, most services are set up such that they are either for children or adults, and different legislation and policy applies. Social workers also tend to either work in children's or adult services. Transition planning should ideally begin from age 14, with the social work and extended team. Some local authority areas have dedicated transition teams in place.

There are differences in how children's and adult services are designed and delivered because some of the legislation governing the two are distinct. As a result, there is no automatic seamless transition for most people, although the challenge of transitions in this context has long been highlighted and acknowledged.

[All the relevant social work legislation](#) is listed by the National Social Work Agency in chronological order from 1948 to the present with links to the legislation itself.

Local authorities are responsible for providing local social work and social care services. Much of the work is overseen by integration joint boards, who commission social care services. However, in some areas children's social work remains the sole responsibility of the local authority, and in others it is delegated to the integration joint board. Adult social work and social care is delegated to all local authorities. This means that, while overall policy and legislation are the same across the country, there will be some local variation because of the different approaches and local policy decisions made on how services are organised and delivered.

### Capacity to make decisions

Unless Legal Guardianship or Power of Attorney is in place, parents don't have the right to be involved in decisions around health and welfare needs because of confidentiality issues. Power of Attorney can be granted by a young person, as *long as they have capacity*, to someone else to act on their behalf and to carry out their wishes. By law, if a young person isn't able to make key decisions or take actions to look after their own welfare, a court can appoint a 'welfare guardian' to do this for them. Welfare guardians can make decisions about where a person lives, their personal and medical care. The [welfare guardian](#) might be a relative, friend or a carer. In the case of someone in foster care, then the state is the 'corporate parent'.

## National Transitions Strategy

There is a [National Transitions to Adulthood Strategy](#) for young disabled people which aims to ensure that every young person 'is empowered and supported to control their own path to success.' This aim implies that everyone will continue to develop and learn and become more independent, which, as the petitioner argues, is not always the case.

[The Strategy](#) presents a detailed timeline of work since 2009 undertaken by the Scottish Government ([GIRFEC – Getting it right for every child](#), and stakeholder partners such as [ARC \(Achieving Real Change for a more inclusive Scotland\)](#) and [CELCIS](#) (Centre for Excellence for Children's Care and Protection Scotland).

ARC developed a set of [Principles of Good Transitions](#) in 2017, which is now in its third iteration. It provides a framework to inform, structure and encourage the continual improvement of support for young people with additional needs between the ages of 14 and 25 who are making the transition to young adult life. [ARC has also developed online tools – Compass](#) - to help families navigate policy and legislation

ARC defines 'transitions':

"Transition is the period when young people develop from children to young adults. This is not a single event, such as leaving school, but a growing-up process that unfolds over several years and involves significant emotional, physical, intellectual and physiological changes. During this period young people progressively assume greater autonomy in many different areas of their lives and are required to adjust to different experiences, expectations, processes, places and routines. Transitions also impact on the family or on those who care for the child or young person."

This definition again assumes that as a young person ages, they will become more autonomous.

ARC also highlights ongoing challenges for parents, carers and people with additional support needs as they become adults being exacerbated by:

- "Organisational processes taking priority over individual needs
- Lack of support for carers and families
- Insufficient planning
- Unclear transitions pathways
- Limited options
- Lack of clarity about accountability"

The [Principles document](#) goes on to summarise the main legislative drivers relating to transitions.

## Corporate parenting and looked after children

[The Children and Young People \(Scotland\) Act 2014](#) defines [corporate parenting](#) as "the formal and local partnerships between all services responsible for working together to meet the needs of looked after children, young people and care leavers". This includes those in, or leaving, foster care.

## Social security benefits

In terms of social security benefits, disabled children are entitled to Child Disability Payment (CDP) which, if claimed before the age of 16, they can continue to receive until 18. There is no automatic transfer to adult disability payment (ADP) – the young person or their parent/carer [needs to make a new application](#). A [2024 evaluation](#) of how people managed the transition from CDP to ADP found that overall, the process worked well, but did note that: "Some clients and formal representatives felt that the need to re-apply for ADP was unfair, particularly for those with lifelong or long term conditions that are unlikely to change."

## Key Organisations and relevant links

- [ARC](#)
- [CELCIS](#)
- [National Social Work Agency](#)
- [The Fostering Network](#) – a membership organisation and charity supporting foster carers
- [Talking about Tomorrow](#) – preparing for adult life in Scotland (for families of children with disabilities and learning difficulties. Provides detailed information on all aspects of transition.

**Anne Jepson**  
**Senior Researcher**  
5 August 2026

The purpose of this briefing is to provide a brief overview of issues raised by the petition. SPICe research specialists are not able to discuss the content of petition briefings with petitioners or other members of the public. However, if you have any comments on any petition briefing you can email us at [spice@parliament.scot](mailto:spice@parliament.scot)

Every effort is made to ensure that the information contained in petition briefings is correct at the time of publication. Readers should be aware however that these briefings are not necessarily updated or otherwise amended to reflect subsequent changes.

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## Annexe C: Written Submissions

### PE2237/A: Create a “stage not age” health and social care and benefit system for people with exceptional complex medical needs

Scottish Government written submission, 3 September 2026

**Does the Scottish Government consider the specific ask[s] of the petition to be practical or achievable? If not, please explain why.**

The Scottish Government appreciates and understands the concerns highlighted by this petition. However, the proposals made in the petition are not considered to be practical or achievable and there is already a range of legislation and policies in place to support the improvements requested (more detail is provided below and in Section 4). While the Scottish Government has not assessed the costs associated with developing, administering and implementing all of the changes, given the broad scope of the proposals in the petition, they are likely to be significant.

There is already a range of legislation and policies in place to support young disabled people as they transition to adulthood, and move from children's to adult services. The Scottish Government recognises that transitions can be challenging, particularly for young people with complex needs and that more needs to be done to improve transitions for these young people and their families. In recognition of this, the Scottish Government and the Convention of Scottish Local Authorities (COSLA) published Scotland's first National Transitions to Adulthood Strategy (2025-2030) for young disabled people in June 2025. The aim of the Strategy is to ensure that every young disabled person in Scotland feels confident in their transition to adulthood and is empowered and supported to control their own path to success.

The Transitions Strategy is underpinned by 'Getting it right for every child' (GIRFEC) and 'Getting it right for everyone' (GIRFE). **GIRFEC** is Scotland's approach to supporting the needs of children, young people and their families with the right support at the right time, so that every child and young person can reach their full potential. A core component of the GIRFEC approach is the child's plan. The child's plan remains an important element in the way children's and related services can work in a co-ordinated way to support the wellbeing of children, young people and their families. The child's plan should be used to support quality transitions by enabling those involved to effectively plan for changes together, and in time, to ensure co-ordination and continuity of support.

Through **Getting It Right for Everyone (GIRFE)**, Scotland is taking forward a person-led, multi-agency approach to health and social care support from young adulthood onwards. This is designed to ensure that services work together around the individual and respond to the whole of a person's needs, rather than in a fragmented way. GIRFE was developed in response to concerns from people using services about having to repeat their story multiple times, deal with complex information, and attend multiple appointments with different professionals. The approach is intended to make it easier for people to get the help they need, to place them at the centre of decision-making, and to support more consistent and coordinated care. The GIRFE Team Around the Person toolkit recognises that transition from child to adult services is often difficult. It emphasises the importance

of individuals being actively involved in developing their own transition plan, receiving the right information at the right time, and having consistent support from a named practitioner or professional.

Introducing a **single disability benefit** available at any age would require an entirely new entitlement framework, application and determination processes, and delivery system. This would come at a considerable cost, involve an extensive development process taking many years, and would require a fresh agreement to be reached with the UK Government to treat this new form of Scottish disability assistance in the same way as the reserved benefits. The Scottish Government is instead focussed on continuing to improve our existing forms of disability assistance, so they can best meet the needs of disabled people.

**Continuing Care** is one component measure introduced in the Children and Young People (Scotland) Act 2014 to improve outcomes for young people leaving care by supporting and developing positive transitions to more independent living. The intention of Continuing Care is to promote a needs-based approach which allows young people to maintain and build upon the often strong and positive relationships developed in their care settings. This should enable young people to make the transition to adulthood and interdependent living when they are more ready to do so. The legislation places a duty on local authorities and the care sector to work collaboratively to minimise the multiple, simultaneous disruptions that can happen in a young person's life as they approach adulthood. Continuing Care enables a 'looked after' young person to remain in the care setting they were in on their 16<sup>th</sup> birthday. This applies to those looked after in foster, formal kinship and residential care settings. [The Continuing Care \(Scotland\) Order 2015](#) (the 2015 Order) specifies that the period to provide Continuing Care is from the date on which an eligible person ceases to be looked after by a local authority until the date of that person's 21<sup>st</sup> birthday.

The Scottish Government does not consider that extending foster care into a lifelong model would be the appropriate policy mechanism for meeting the lifelong needs described in the petition. Foster care is fundamentally a provision for children and young people, whereas the longer-term health, social care and financial support required by adults with exceptional complex needs would engage a number of different adult services and frameworks. That does not detract from the importance of ensuring continuity of relationships, care and support as young people move into adulthood.

**What, if any, action the Scottish Government is currently taking to address the issues raised by this petition, and is any further action being considered that will achieve the ask[s] of this petition?**

As mentioned in Section 3, there is a range of policies and legislation which are already in place and which support the issues raised by this petition, these are detailed below.

#### National Transitions to Adulthood Strategy

The Scottish Government has committed to the social model of disability, which recognises that disabled people are disabled by barriers within society and systems

rather than by their impairment or condition. In considering this petition, it is important to recognise that equality does not always mean treating everyone the same. The Social Model requires services to be designed around individual needs and circumstances. Transitions between children's and adult services should therefore ensure continuity of support and avoid creating gaps that place disabled people and their families at a disadvantage.

There is already a range of legislation and policies in place to support transitions to adulthood for young disabled people. Recognising this, the Scottish Government and the Convention of Scottish Local Authorities (COSLA) published Scotland's first National Transitions to Adulthood Strategy for young disabled people in June 2025. The aim of the Strategy is to ensure that every young disabled person in Scotland feels confident in their transition to adulthood and is empowered and supported to control their own path to success.

The Strategy is a response to the lived experiences of young disabled people and their families, who have consistently highlighted the complexities and challenges they can face during this period. There can be challenges where support changes as a young person moves into adult services. The Strategy focuses on early, person-led planning; better coordination across services; and supporting young people and families to feel confident and supported in their transition. The Strategy emphasises that improving transitions requires action across health, social care, education and social security. In February 2026 the Scottish Government published a supplementary report detailing how we will ensure a joined-up approach. We have also committed to publish a Progress Report on actions in the transitions strategy by the end of 2026.

The Transitions Strategy is underpinned by 'Getting it right for every child' (GIRFEC) and 'Getting it right for everyone' (GIRFE):

- **GIRFEC** is our national approach to promoting, supporting and safeguarding the wellbeing of all children and young people. At the heart of this is providing all children and young people, and their families, with the right support at the right time. GIRFEC policy and guidance recognise that well planned and supported transitions are key for children and young people.
- A core component of the GIRFEC approach is the **child's plan**. The child's plan remains an important element in the way children's and related services can work in a co-ordinated way to support the wellbeing of children, young people and their families. The child's plan should be used to support quality transitions by enabling those involved to effectively plan for changes together, and in time, to ensure co-ordination and continuity of support.
- Using the GIRFEC approach, practitioners and lead professionals should support a child or young person's wellbeing through transitions by working alongside them and their family, and other practitioners involved in transition planning. They should ensure the views and rights of the young person and family are considered in decisions throughout a transition. Effective transfer of information between services during transitions, in line with information sharing guidance, is also essential to achieving successful outcomes for the child or young person and their family. GIRFEC outlines that particular

consideration throughout transitions should be given to disabled children and young people.

- The Scottish Government recognises that transitions can be challenging for young people and families, particularly where a child has developed trust in a longstanding clinician and is supported across a range of interrelated needs. Through **Getting It Right for Everyone (GIRFE)**, Scotland is taking forward a person-led, multi-agency approach to health and social care support from young adulthood onwards. This is designed to ensure that services work together around the individual and respond to the whole of a person's needs, rather than in a fragmented way. GIRFE was developed in response to concerns from people using services about having to repeat their story multiple times, deal with complex information, and attend multiple appointments with different professionals. The approach is intended to make it easier for people to get the help they need, to place them at the centre of decision-making, and to support more consistent and coordinated care. The GIRFE Team Around the Person toolkit recognises that transition from child to adult services is often difficult. It emphasises the importance of individuals being actively involved in developing their own transition plan, receiving the right information at the right time, and having consistent support from a named practitioner or professional.

#### Learning Disability Annual Health Checks

- People with learning disabilities experience significant health inequalities, are twice as likely to die from preventable illnesses and, on average, die around 20 years earlier than the general population. Annual health checks were introduced by Scottish Government in May 2022 to identify unmet health needs, reduce preventable illness, and improve access to preventative care.
- Scottish Ministers committed £2 million annually to NHS boards to deliver LD annual health checks, which are comprehensive yearly health reviews for people aged 16 plus with a learning disability, undertaken by a registered nurse or medical practitioner.
- As well as being effective measure in improving general health and care, both the Coming Home Action Plan and the National Care Service Advisory Board identified the important role of LD annual health checks in supporting successful transitions into the community, reducing the risk of community placement breakdown, and helping prevent unnecessary hospital admissions and re-admissions for people with learning disabilities.

#### Self-Directed Support

- It is vital that people have informed choice about how their social care support is provided to them, and that their needs, rights and preferences are at the heart of the decision-making process. This includes all adults, children and unpaid carers.

- The Scottish Government has overall responsibility for health and social care support policy in Scotland, while local authorities and Health and Social Care Partnerships (HSCPs) have the responsibility for commissioning appropriate services for local needs.
- The Scottish Government is committed to improving the implementation of Self-directed Support in Scotland and ensuring the principles of SDS are embedded within wider social care reforms.
- Consistent implementation of SDS is key to the successful delivery of social care support in Scotland.
- Under the Social Care (Self-directed Support) (Scotland) Act 2013, local authorities have a legal duty to work in partnership with individuals, or their representatives, to develop support that meets assessed needs and personal outcomes. The legislation recognises that people are experts in their own lives and promotes flexibility in how support is used, provided it aligns with agreed outcomes and the purpose of the funding.
- If someone is unhappy with their Self-directed Support package, they can raise their concerns with their social worker or local authority in the first instance, request a review of their assessment or support plan, use the local authority's complaints procedure, seek independent advocacy or support, and, if the issue remains unresolved, escalate the complaint to the Scottish Public Services Ombudsman.
- Through the Support in the Right Direction (SiRD) programme, the Scottish Government funds independent support providers across Scotland to support people by providing advocacy, information, and advice on social care support at a local level.
- The NCS Interim Advisory Board has selected SDS as one of its initial priority areas, with one of its initial areas of interest focusing specifically on flexibility of spend.

### Dynamic Support Registers

- Dynamic Support Registers were launched in 2023 across Scotland. The use of a Dynamic Support Register (DSR) was a key recommendation of the [Coming Home Implementation](#) report. The purpose of the Dynamic Support Register is ultimately to avoid adults with learning disabilities and complex support needs living in hospitals, or in out-of-area placements which they/their family have not chosen. The Dynamic Support Register has improved the visibility of people with learning disabilities and complex care needs at local and national levels, and provides a tool to track progress and to support local planning and decision making.
- The Dynamic Support Register is applicable to adults (aged 18 plus) who have learning disabilities and complex care needs whose support is funded by a Local Authority or NHS Board. In March 2026, Scottish Government and COSLA published our [Coming Home Action Plan](#), which was supported by

investment of up to £20 million to get people out of hospital and inappropriate out of area placements. The Action Plan includes a commitment to explore the implications of extending the use of the Dynamic Support Register to include under 18s.

### Social Security

- The Scottish Government's approach to providing social security is based on dignity, fairness and respect, ensuring disabled people are treated as individuals and supported in a way that meets their needs. The Social Security Independent Advocacy Service, delivered by Advice Direct Scotland offers free and independent advocacy to disabled people who require support to engage with the system. Advocacy is available at any stage throughout the social security journey across all devolved benefits, including Child Disability Payment, to ensure disabled people and those who support or care for them can access the support they are entitled to.
- In response to feedback from parents and carers of disabled children about how stressful life can be for families as young people approach 16, the Scottish Government extended eligibility to Child Disability Payment (CDP) to age 18. This provides continuity and reduces anxiety at a time when young people are going through significant transitions in other areas of life. It required us to reach agreement with the Department for Work and Pensions for CDP to be treated as a qualifying benefit for reserved premiums and additional payments despite this difference in eligibility.
- Adult Disability Payment (ADP) provides financial support with the additional costs people experience because they are disabled. The ADP criteria relate to the help a person needs with various tasks of daily living and with their mobility, with those unable to manage any part of an activity receiving the highest level of support.
- To avoid the stress and anxiety which unnecessarily reviewing entitlement can cause, we introduced indefinite awards for people on the highest level of Adult Disability Payment, with needs that are highly unlikely to change. People with the type of complex needs described in the petition are very likely to be in receipt of ADP on an indefinite basis, providing them with long-term financial security.
- Children in receipt of benefits will have a parent, guardian or other representative acting on their behalf until reaching 16 years of age. When a young person reaches age 16, consideration must be given to whether they can manage their benefits independently or require someone to act on their behalf, as they are now considered an adult. Where there is no one with legal authority to act for the individual, Social Security Scotland, on behalf of Scottish Ministers, may appoint an appointee. Appointee assessments are undertaken in advance of the transition from CDP to ADP to ensure individuals continue to receive the appropriate benefit without interruption.
- In addition to extending the age of entitlement for CDP to 18, we have ensured that clients who apply for ADP before reaching 18 will continue to

receive their CDP until their first payment of ADP. This provides disabled young people with financial continuity and eases their transition to the adult benefit. Social Security Scotland do not conduct scheduled reviews of Child Disability Payment for clients older than 16, further easing the journey for people moving through this transitional period.

- The Scottish Government is committed to continuing to improve disability benefits and to that end commissioned an Independent Review of ADP, the final report of which was published in July 2025. We have since begun implementing a range of improvements in line with the report's recommendations including measures to make the process more accessible.

### Continuing care

- Continuing Care is one component measure introduced in the Children and Young People (Scotland) Act 2014 to improve outcomes for young people leaving care by supporting and developing positive transitions to more independent living.
- The intention of Continuing Care is to promote a needs-based approach which allows young people to maintain and build upon the often strong and positive relationships developed in their care settings. This should enable young people to make the transition to adulthood and interdependent living when they are more ready to do so.
- The legislation places a duty on local authorities and the care sector to work collaboratively to minimise the multiple, simultaneous disruptions that can happen in a young person's life as they approach adulthood.
- Continuing Care enables a 'looked after' young person to remain in the care setting they were in on their 16<sup>th</sup> birthday. This applies to those looked after in foster, formal kinship and residential care settings.
- [The Continuing Care \(Scotland\) Order 2015](#) (the 2015 Order) specifies that the period to provide Continuing Care is from the date on which an eligible person ceases to be looked after by a local authority until the date of that person's 21<sup>st</sup> birthday.

### Changes to Continuing Care by the Children (Care, Care Experience and Services Planning) (Scotland) Act 2026

- The Children (Care, Care Experience and Services Planning) (Scotland) Bill passed unanimously at Stage 3 on 19 March 2026 and gained Royal Assent on 15 May 2026.
- The Act creates various changes to the provision of Continuing Care. Continuing Care will no longer be restricted to the 'same accommodation' that a 'care leaver' was in before they ceased to be looked after and will be extended to any alternative accommodation that a local authority considers appropriate.

- Young people aged 16 and up to 21 years of age who leave Continuing Care and request to return to the accommodation will have a right to return to Continuing Care.
- Local authorities will have the power to provide Continuing Care up to age 26 if satisfied that doing so will promote or safeguard the person's welfare.
- Ministers are taking a considered approach to the commencement of the changes to Continuing Care brought about by the 2026 Act.
- The Scottish Government is aware that changes can only happen when the care system is ready. The Scottish Government will continue to have open, honest and constructive talks with delivery partners to support them to deliver these changes to Continuing Care.
- Further engagement is required to understand the relationship between legislative reforms and current system pressures. Commencement planning will continue to take account of workforce capacity and operational readiness.

**Is there any further information the Scottish Government wish to bring to the Committee's attention, which would assist it in considering this petition?**

The Committee may wish to consider whether current arrangements adequately protect the rights, dignity, family life and wellbeing of disabled people with lifelong complex needs. In doing so, it may also wish to consider the principles of the Equality Act 2010, which seeks to protect disabled people from disadvantage arising from policies, practices or arrangements that do not properly take account of disability-related needs. In particular, consideration should be given to whether age-based transitions are resulting in the loss of effective support despite there being no significant change in the individual's level of need.

**Children's Service Reform, Care Experience, Children's Service Reform and the Promise Division  
Directorate for Children and Families**

**PE2237/B: Create a "stage not age" health and social care and benefit system for people with exceptional complex medical needs**

**Petitioner written submission, 21 September 2026**

I welcome the Scottish Government's response to PE2237. However, I believe it reinforces rather than answers the fundamental issue raised by the petition.

The question is not whether Scotland has legislation, strategies, guidance and transition planning, it does. The question is whether the services available to children with Exceptional Complex Healthcare Needs (CEN) when they transition into adulthood are actually capable of continuing to meet those needs, they are not.

The Scottish Government itself acknowledges that transitions remain challenging, particularly for young people with complex needs and that "more needs to be done". Its National Transitions to Adulthood work has also acknowledged that transition from

paediatric healthcare can be experienced as a “cliff edge”, with adult services fragmented and support changing or disappearing, that is precisely the problem PE2237 seeks to address.

### **Exceptional Healthcare Needs are different**

This petition concerns a very small and exceptionally complex group, the recognised CEN criteria require severe impairment across multiple areas combined with needs such as enteral/parenteral feeding, ventilation/CPAP, sustained or expected to continue for more than six months, non-verbal, non-mobile, tube-fed, ventilated and dependent upon specialist equipment, medication, seizure management and highly trained carers. their eighteenth birthday changes none of this, their condition does not become less complex, their feeding requirements, epilepsy, ventilation does not disappear, their needs remain the same, it is the system around them that changes.

### **Planning is not provision**

The Government relies heavily upon the National Transitions to Adulthood Strategy, GIRFEC, GIRFE, annual health checks, Dynamic Support Registers and other existing initiatives, these may improve coordination, but they do not solve the fundamental problem, a transition plan cannot create a specialist nurse, health passports do not provide overnight medically supported respite, an annual health check cannot replace specialist ongoing clinical care.

Coordination is not provision and planning is not treatment neither is a strategy a service, where no equivalent adult service exists, better planning merely organises the journey towards inadequate provision.

I am particularly concerned by the Government's statement:

“While the Scottish Government has not assessed the costs associated with developing, administering and implementing all of the changes... they are likely to be significant.”

That is not an evidence-based financial assessment, the Government acknowledges that it has not calculated the cost, yet immediately suggests that the cost is likely to be significant.

Before cost can reasonably be used as an argument against reform, Parliament should know how many people are actually affected. NHS National Services Scotland reported 699 children and young people on the CEN Clinical Audit System in 2021/22, while cautioning that the database might not capture every eligible child, we are therefore discussing a very small national population, only a proportion of that population will transition into adult services in any single year.

Rather than assuming the cost would be significant, the Government should establish the actual number transitioning annually and calculate the cost, it should also calculate the cost of not providing appropriate continuity, emergency hospital admissions, unsuitable placements, delayed discharge, crisis intervention and the transfer of increasing levels of responsibility onto unpaid family carers, when

professional support disappears, the cost does not disappear, it is frequently transferred to the family.

The Government's own response highlights Continuing Care, which allows some care-experienced young people to remain within existing care arrangements beyond the normal age boundary where this is appropriate to their needs, this demonstrates an important principle, Scotland already accepts that chronological age should not automatically determine when an appropriate care arrangement must end, PE2237 asks that the same principle be considered for a tiny population whose medical needs can be among the most profound in Scotland.

Stage Not Age does not mean treating adults as children, it means that transition should occur when a safe, appropriate and clinically capable adult pathway exists, rather than simply because a birthday has occurred, where equivalent adult provision exists, transition should proceed, where it does not, the appropriate specialist pathway should continue until a safe alternative is available.

I respectfully ask the Public Petitions Committee not to close PE2237 on the basis of the Scottish Government's response, but instead to request that the Government provide:

1. Current numbers of children and young people meeting the CEN criteria, broken down by age and NHS Board.
2. The number of CEN young people who have transitioned into adult services in each of the last five years.
3. Details of which specialist services available within paediatric CEN provision have no directly equivalent adult provision.
4. Evidence of the specialist training available to adult health and social-care staff supporting people with these exceptional needs.
5. An explanation of what statutory protection prevents an essential service being withdrawn solely because a young person reaches an age threshold where no equivalent adult provision exists.
6. A proper financial assessment of Stage Not Age, including the cost of maintaining continuity for the actual annual transition cohort and the potential costs arising from failed transitions.
7. Evidence of how the National Transitions Strategy creates additional specialist clinical capacity rather than simply improving coordination between existing services.

I would also ask the Committee to take evidence directly from families caring for young people with Exceptional Healthcare Needs who are approaching, undergoing or have recently undergone transition.

## **Conclusion**

Medical advances have enabled children with profound and exceptional healthcare needs to survive and live into adulthood, our public services must adapt to that success, we cannot develop paediatric medicine capable of keeping these children alive and then expect them to fit into adult services that were never designed around their exceptional complexity.

The central question remains unanswered, if a young person's medical condition and level of need are unchanged the day after their eighteenth birthday, why should an effective service disappear simply because they have reached an arbitrary age?

Where the need remains, appropriate care must remain until a genuinely equivalent and safe adult pathway exists.

That is Stage Not Age.