# Children and Young People – Continence Services Transfer

NHS Lincolnshire

## Public and Staff Engagement Report

## 13 April 2026 – 8 June 2026

# Executive Summary – Key findings

## Introduction

NHS Lincolnshire Integrated Care Board (LICB) is making changes to how children and young people's continence services are delivered.

Lincolnshire County Council (LCC) currently provide tier 1 continence support services (providing advice, guidance and signposting for day and night time wetting and bowel concerns) as part of their core responsibilities and some tier 2 continence support services (specialist support such as bladder and bowel assessments, scans, advice and intervention) on behalf of Lincolnshire Integrated Care Board.

To enable Lincolnshire County Council to focus on their core responsibilities, they will continue to provide tier 1 continence support services, but from 1 January 2026, Lincolnshire County Council are no longer providing tier 2 continence support services as part of its children's nursing offer.

Therefore, a new provider is planned to deliver the tier 2 continence support services, with the aim of having this in place by July 2026. In the interim, some aspects of tier 2 services will still be delivered by Lincolnshire County Council while others, like medication reviews and assessments for enuresis alarms, will be referred back to general practice (GPs).

## Aims of the engagement

The engagement sought to understand:-

- What is working well with the current children and young people specialist continence service.
- What requires improving with the children and young people specialist continence service.
- Views on what a future specialist service should look like for children and young people.
- Feedback will help shape the future service and ensure it meets the needs of children, young people, carers and families.

## Public feedback engagement overview

A total of **164 survey responses** were received.  Public and staff engagement indicate that the children and young people's continence service is widely valued but constrained by capacity and access challenges.

### Public feedback

**Public feedback -** A total of **138 survey responses** were received which highlighted strong satisfaction overall driven by knowledgeable, compassionate care.  Response numbers vary per question but feedback indicates a service that is highly valued with 75% satisfaction driven by knowledgeable, compassionate staff, strong relationships and meaningful outcomes such as improved continence and reduced family stress. Families appreciate the personalised, specialist support and practical help provided.  However, significant challenges affect the overall experience particularly long waiting times, limited capacity, inconsistent service quality and poor communication.  Concerns were also raised about reliance on telephone consultation, variability in clinical approaches and issues with continence product provision.  Broader system issues including unclear referral pathways and limited awareness of the service further impact accessibility and continuity of care.

## Recommendations and next steps

- The feedback from our engagement should be used and triangulated with other ongoing patient experience data which is collated.  Where there are particular areas highlighted, it should be discussed whether further engagement should be undertaken.
- The Lincolnshire Community and Hospitals NHS Trust Group Performance Review meeting and Group Leadership Team are asked to note the feedback to help inform action planning for improvements, together with using the insight to inform re-procurement decisions.
- The findings should be used to help inform the programme of work associated with continence services.
- This report will be published on Lincolnshire Integrated Care Board web-site and complete ongoing involvement of people and communities and feedback on how on how this has influenced continence services in the future.
- Consideration should be given as to how patient experience feedback can be collated on an ongoing basis.

# Methods of Engagement
# Survey promotion

## Marketing materials

The NHS Lincolnshire ICB Marketing Team created marketing materials and social media assessments to build awareness of the survey, signpost/link people to the survey, share with stakeholders to encourage participation, promote across social media channels and encourage people to take part in conversations.

To make the survey directly accessible to a range of patients, the public and staff, we circulated it regularly via our ICB Engagement Bulletin – The Contributor - which is received in Lincolnshire. Phone number and email details were also included should people wish to request the survey in an alternative format, seek support in completing the survey from the Engagement Manager, together with an opportunity for the Engagement Manager to visit groups. Posters/fliers were distributed to the following individuals/groups/venues for promotion.

- Promoted in the GP Primary Care and Primary Care Network bulletin for promotion via waiting rooms and social media.
- Communication and Marketing Teams across the Lincolnshire NHS Trusts for promotion internally and externally for promotion within bulletins, communications and social media.
- Communications Team at Lincolnshire County Council.
- Circulated to Patient Participation Groups in Lincolnshire.
- Children's Services Leads at Lincolnshire Integrated Care Board.
- Procurement Lead, Arden and GEM CSU.
- Children and Young People Transformation Board.
- Children and Young People Neighbourhood Team leads.
- Lincolnshire Voluntary Executive Team for circulation.
- Every-One for promotion within their co-production newsletter.
- Lincoln Parent Carer Forum.
- Karen Stengel, Healthy Communities Team, South and East Lincolnshire Councils Partnership for circulation to networks.
- Lincolnshire Resilience Forum members.
- Public Health Officer, Lincolnshire County Council to circulate to relevant contacts.
- Children's Links.
- Family Hubs in Lincolnshire.
- Children and Young People Leads, Lincolnshire County Council- shared as News Item on Sharepoint, shared to service and on Facebook page.
- General Manager and Deputy Director of Operations for Children and Young People's Clinical Business Children and Young People Leads, Lincolnshire Community and Hospitals NHS Group for promotion in relevant clinics.
- Service Manager, Children and Young People's Clinical Business Unit for promotion in relevant clinics.
- Promoted to special schools within Lincolnshire – Aegir Community School, Boston Endeavour Academy, Eresby School, Sandon School, St Francis School, St Bernards School, St Christophers School, Tulip Academy, Warren Wood School, Willoughby School.
- Lincolnshire Integrated Care Board web-site.
- Lincolnshire Integrated Care Board social media.
- Distributed to our extensive stakeholder database that includes groups from the following; Traveller community, LGBTQ+, BAME, Disability, Carers, Young people, Older people, Faith and Religious and various community groups across Lincolnshire.
- Promoted every 2 weeks between via Lincolnshire ICB Engagement Team's newsletter between 13 April 2026 – 8 June 2026.
- Promoted on the Nextdoor App across Lincolnshire.

# Social media/web-site engagement during the engagement period

**Lincolnshire ICB facebook:-**

- **Posts – 7**
- **Total Views – 17,792**
- **Reactions - 6**
- **Post reach – 11,640**
- **Link/post clicks – 27**

NHS Lincolnshire Integrated Care Board
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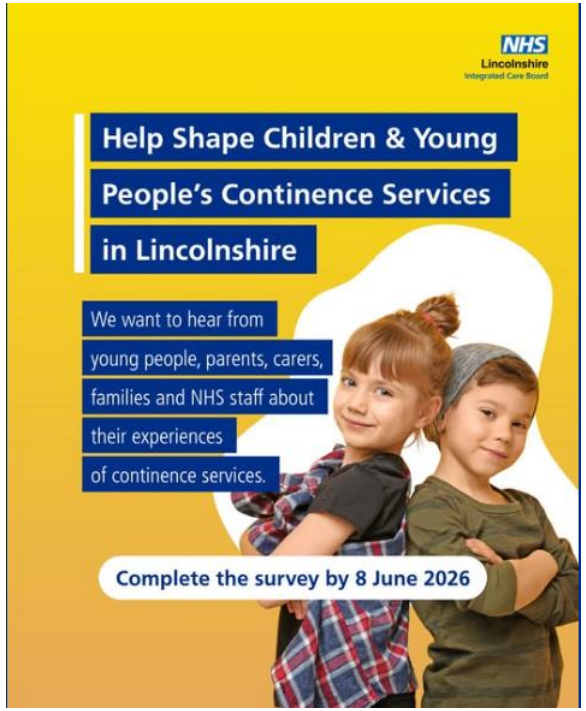
NHS Lincolnshire Integrated Care Board is making changes to children and young people's continence services, with a new provider planned for July 2026.

We want your views on what's working well, what could be improved, and what future services should look like.

Have your say by completing our short survey before 7 June 2026: lincolnshire.icb.nhs.uk/continence-services See less




**Lincolnshire ICB web-page**

**Page views - 175**

**Survey link clicks – 320**

**Nextdoor**

**Posts - 1**

**Reactions - 8**

**Impressions – 25,413**

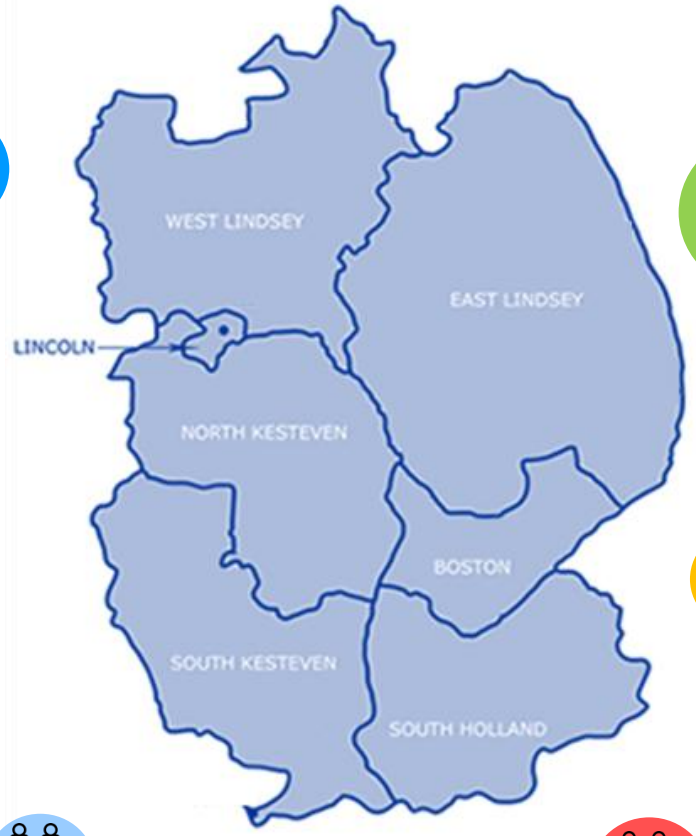
**Geographical locations, where specified, of 85 respondents are shown below including, where stated, the town or villages they live. The highest number of respondents (22%) lived within the East Lindsey district.**
**1% (1/85) did not know which district they lived in and 1% (1/85) was responding as an individual who lived out of area in Peterborough**

**11% (9) West Lindsey**
Gainsborough (3)
Nettleham (3)
Market Rasen (1)
Saxilby (1)

**16% (14) Lincoln**
Lincoln (14)

**19% (16) North Kesteven**
Sleaford (6)
Bracebridge Heath (3)
North Hykeham (3)
Metheringham (2)
Heckington (1)
Ruskington (1)

**9% (8) South Kesteven**
Grantham (4)
Bourne (2)
Barrowby (1)



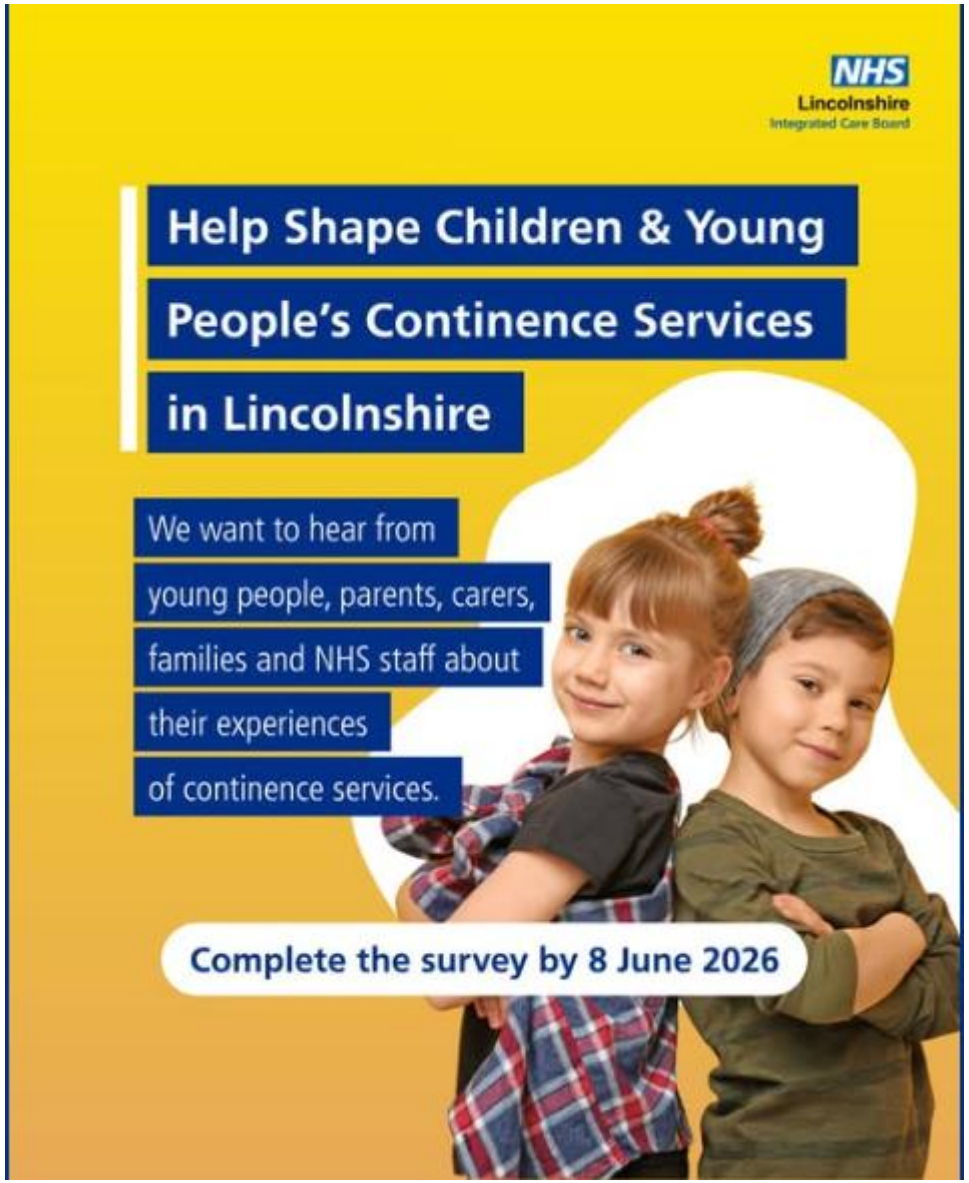

**22% (19) East Lindsey**
Skegness (9)
Louth (5)
Horncastle (2)
Woodhall Spa (1)
Wragby (1)
Alford (1)

**9% (8) Boston**
Boston (5)
Kirton (2)
Wyberton (1)

**11% (10) South Holland**
Spalding (7)
Holbeach (2)
Long Sutton (1)

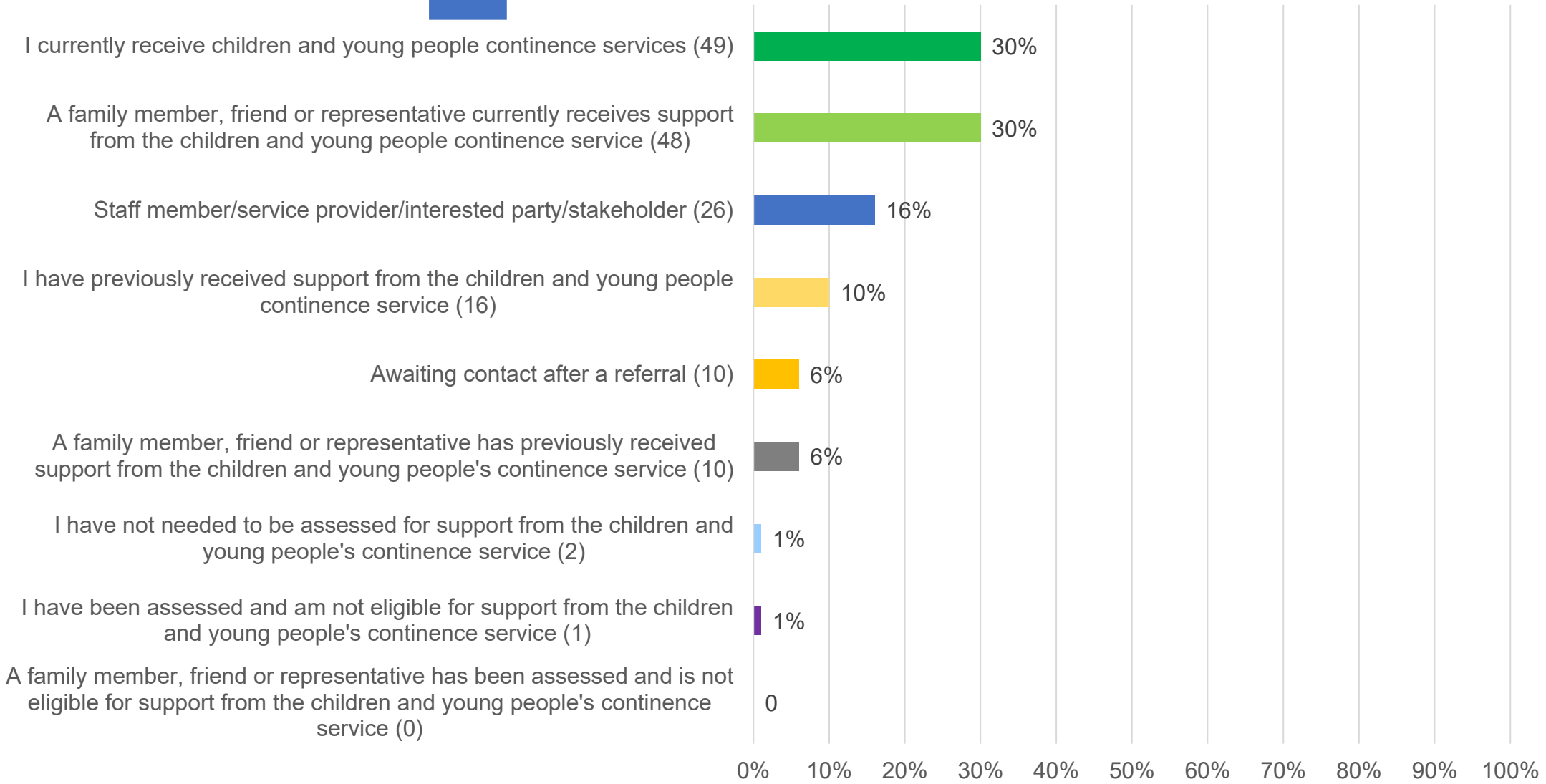
# Section 1

## Results and Findings from the Public Engagement



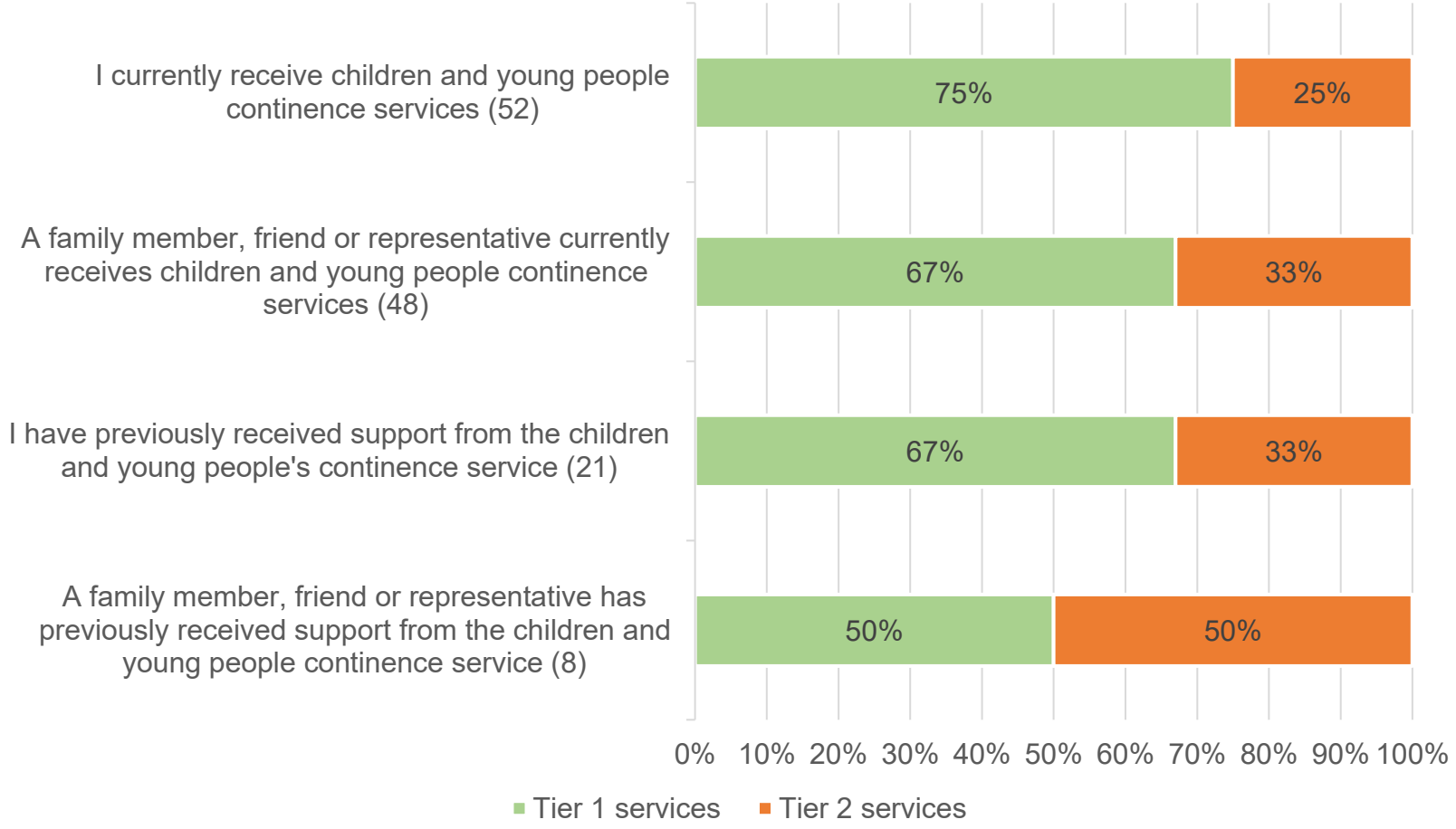
# Respondent profiling

**From 162 responses, the highest number of responses (30%) (49/162) were from children and young people currently receiving continence services**

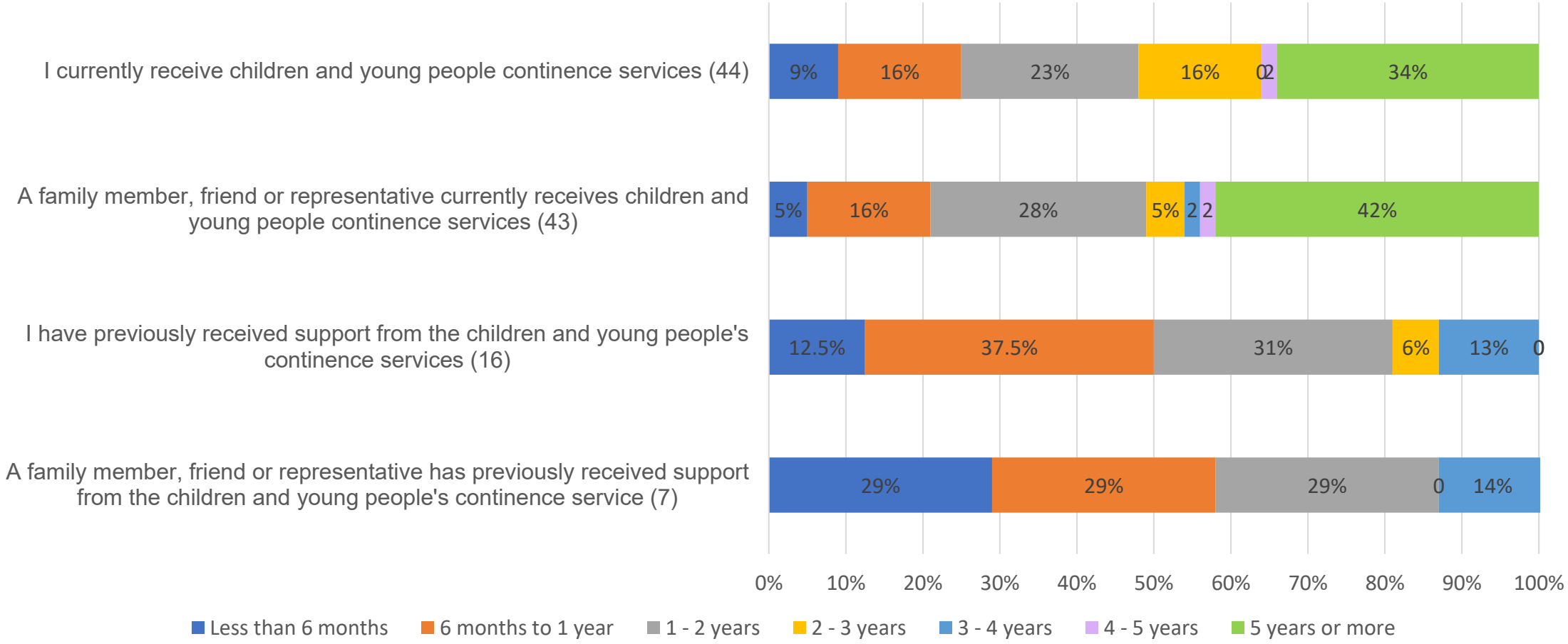


## We asked respondents to tell us which service they, or the person they are responding on behalf of, have received

## Overall, 69% (95/138)of respondents use/have used Tier 1 services and 31% (43/138) Tier 2 services



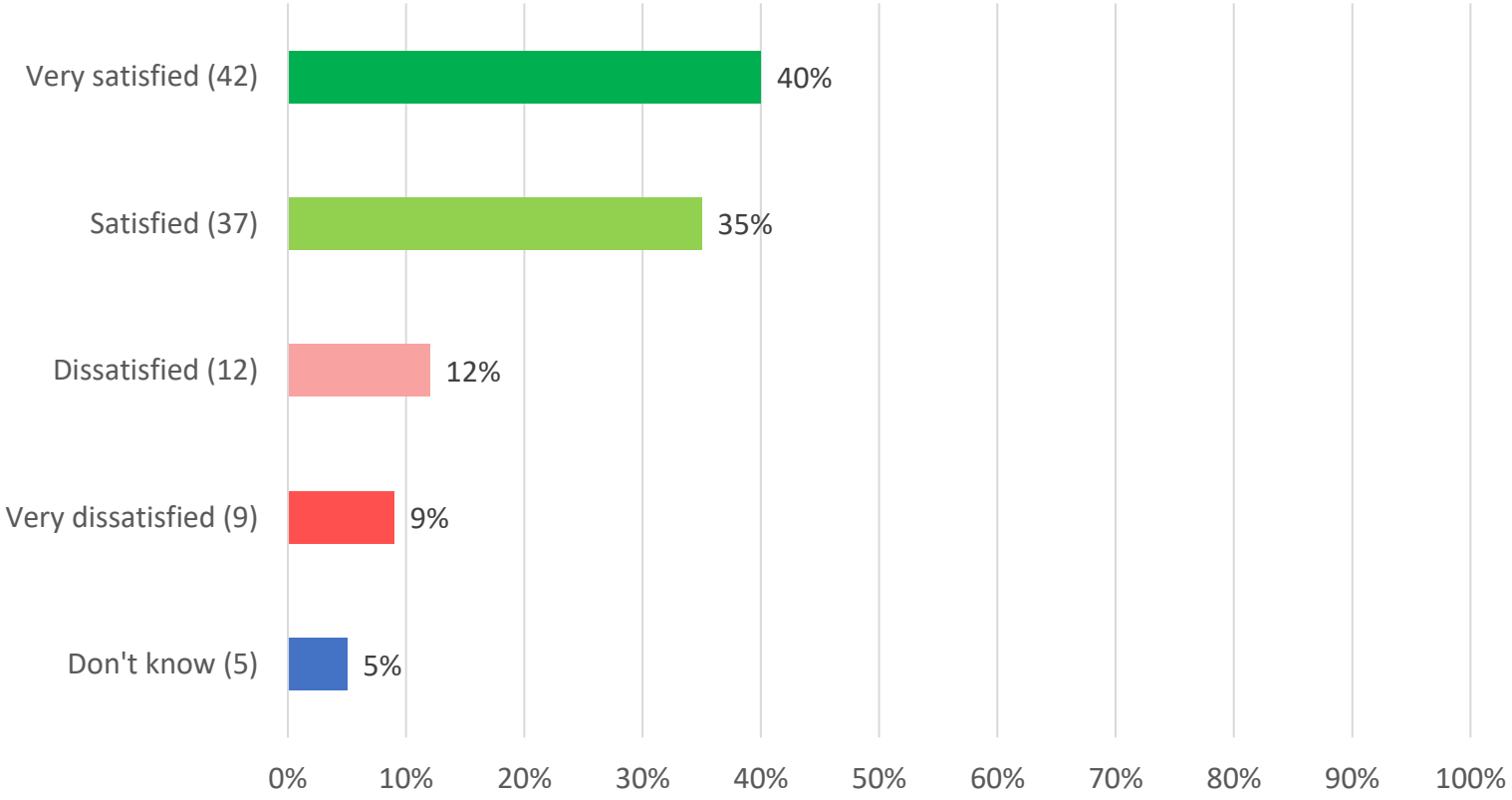
# Overall, 29% of respondents have used the continence for over 5 years (32/110)




Some children who have been referred to the continence service are experiencing significant delays with reports of no contact after 6 months and in some cases no appointment or communication over 2 years.

# We asked respondents to tell us to what extent they are satisfied with aspects of the service provided by Lincolnshire County Council up to 31 December 2025

## 75% (79/105) were satisfied and 20% (21/105) dissatisfied with the service



## The reasons that individuals were satisfied with the service were:-

| Positive themes | Comments |
|---|---|
| **High quality, responsive and knowledgeable staff** | Staff frequently described as friendly, helpful, knowledgeable and respectful.<br>Positive examples of:-<br>• Listening to parents and children.<br>• Acting as advocates and signposting to other services.<br>• Going “above and beyond” (eg, fast follow-up, proactive appointments).<br>Value placed on consistent contact, particularly:<br>• Regular reviews.<br>• Ongoing medication monitoring.<br>• Having a single point of contact or case worker. |
| **Helpful advice and improved outcomes** | Advice described as clear, understandable and practical<br>• Particularly strong around bowel management and continence strategies.<br>Many reported:-<br>• Improved symptoms.<br>• Access to treatment plans, referrals and medication.<br>• Some noted the service succeeded where GP support had not. |
| **Access to continence products and delivery reliability** | High appreciation for:-<br>• Regular delivery of nappies/pads.<br>• Products often described as good quality.<br>• Convenience of home delivery.<br>Reliable logistics:-<br>• Deliveries arriving on time.<br>• Easy ordering processes. |
| **Feeling supported and listened to** | Positive feedback when:-<br>• Parents’ opinions are considered.<br>• Individual child needs are recognised.<br>• Families feel “heard”. |

## The reasons that individuals were dissatisfied with the service were:-

| Negative themes | Comments |
|---|---|
| **Long waiting times and delayed access** | Frequent reports off long waiting times:-<br>• No follow-up after initial appointment.<br>• Difficulty contacting the service.<br>• Long gaps between reviews (months or years).<br>• Some cases are still waiting for first appointment.<br>• Care ending with no resolution. |
| **Product issues** | Problems reported:<br>• Incorrect sizing (too big, poorly fitting).<br>• Leakage due to poor design (adult-focused products unsuitable for children).<br>• Decline in product quality over time.<br>• Forced product changes due to procurement/tendering.<br>• Parents frustrated that practical realities (movement, positioning) not considered. |
| **Insufficient quantities and restrictive eligibility criteria** | Concerns about too few pads allocated, especially for complex needs:-<br>• Requirement to “prove need” (eg, weighing nappies).<br>• Products withdrawn or refused despite ongoing need.<br>• Some families had to fight for appropriate provision. |
| **Poor communication and not feeling listened to** | Reports of:-<br>• Staff not taking parent feedback seriously.<br>• Reliance on manufacturer claims rather than lived experience.<br>• Dismissive attitudes in some cases.<br>• Lack of continuity in communication |
| **Limited face to face care and over-reliance on phone support** | Complaints about:-<br>• No in-person assessments.<br>• Telephone-only consultations even for complex cases.<br>• Some felt this delayed diagnosis or reassurance. |

# The reasons that individuals were dissatisfied with the service were (continued . . .)

| Negative themes | Comments |
|---|---|
| **Gaps in clinical management and co-ordination** | Issues raised:-<br>• Limited investigation of root causes (especially bowel issues).<br>• Over-reliance on certain treatments (eg. laxatives).<br>• Poor co-ordination between Children and Young People service and GPs.<br>• Some children remain incontinent despite long-term involvement. |
| **Administration burden and slow processes** | Examples include:-<br>• Complex paperwork for product changes.<br>• Slow sizing adjustments.<br>• Trial-and-error processes with samples. |

**Overall satisfaction is driven by:-**

- **Strong relationships with knowledgeable staff.**
- **Clear advice and improved outcomes.**
- **Reliable delivery of appropriate products.**

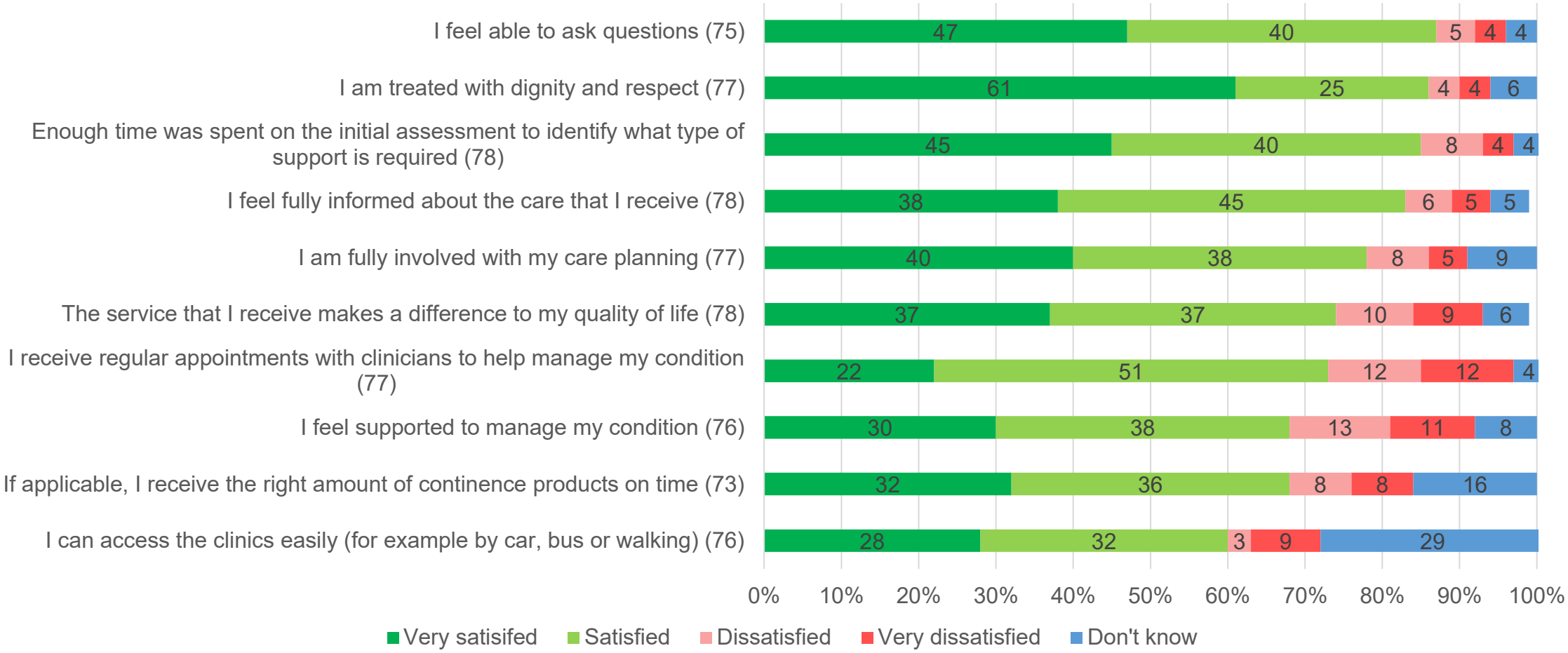
**Dissatisfaction is driven by:-**

- **Poor access, delays and lack of follow-up.**
- **Inadequate or unsuitable products.**
- **Rigid policies around provision and eligibility.**
- **Communication gaps and not being listened to.**

**We asked respondents to tell us how satisfied they feel about the care and treatment that they receive**

**The greatest satisfaction is feeling able to ask questions and being treated with dignity and respect**

**The greatest dissatisfaction is not receiving regular appointments with clinicians to help manage condition and not feeling supported to manage condition**



## We asked respondents to tell us what worked well up to 31 December 2025

| Theme | Comments |
|---|---|
| **Strong support and knowledgeable staff** | • Staff were consistently described as kind, caring, respectful and genuinely invested in children's outcomes.<br>• High levels of clinical knowledge and expertise, particularly around bowel/continence conditions and medication.<br>• Staff built positive relationships and rapport with children and families. Families valued being listened to, understood and taken seriously. |
| **Effective communication and accessibility** | • Good communication between professionals, parents, schools and GPs.<br>• Easy access to staff for advice, follow-up questions and reassurance.<br>• Regular contact and open access (eg, 6 weekly appointments, ability to reach out sooner).<br>• Communication helped parents better understand conditions and management. |
| **Collaboration and integrated working** | • Strong multi-agency working (eg, with schools, GPs, paediatrics, early years services).<br>• Tiered model (Tier 1 and Tier 2) enabled early support (toileting readiness) and specialist intervention for complex needs.<br>• Professionals could liaise directly with GPs, improving medication management.<br>• Reduced unnecessary referrals to paediatrics, easing wider NHS pressures. |
| **Individualised, holistic and family centred care** | • Care was tailored to individual children and family needs.<br>• Holistic support considered physical, emotional, social and educational impacts.<br>• Thorough assessments and personalised care plans were highly valued.<br>• Families felt supported as a whole, not just treated clinically. |
| **Regular reviews and continuity of care** | • Routine reviews and structured follow-ups ensured progress was monitored.<br>• Consistency of seeing the same clinician improved trust and continuity.<br>• Allocated case workers provided clear ownership of care.<br>• Annual and ongoing assessments supported long-term management. |
| **Convenience and flexible delivery models** | • Use of telephone and Teams appointments improved accessibility.<br>• Flexible scheduling worked better for school and family commitments.<br>• Combination of home visits, clinics and remote support.<br>• Community-based service increased ease of access. |

## We asked respondents to tell us what worked well up to 31 December 2025

| Theme | Comments |
|---|---|
| **High quality clinical support and outcomes** | Strong support for:-<br>• Constipation management.<br>• Daytime wetting and enuresis.<br>• Clear guidance on medication use which filled gaps left by GP prescribing.<br>• Evidence of significant positive impact on:-<br>- Child health outcomes.<br>- Emotional wellbeing.<br>- School attendance and participation.<br>• Prevented escalation (eg, hospital admissions, A&E visits). |
| **Practical support (products and equipment)** | • Efficient prescription processes – medications issued quickly.<br>• Reliable product delivery systems (including automated ordering).<br>• Access to appropriate continence products and equipment.<br>• Practical support enabled dignity and day-to-day management. |
| **Education and empowerment of families** | • Parents gained confidence and knowledge to manage their child's condition.<br>• Clear explanations helped families:<br>- Understand treatment plans.<br>- Recognise symptoms.<br>- Prevent relapse.<br>• Education improved long-term sustainability of outcomes. |
| **Positive impact on children and families** | Service made a meaningful difference to daily life:-<br>• Reduced embarrassment and stigma.<br>• Improved confidence and independence.<br>• Better school engagement.<br>• Families described the service as "invaluable" and life-changing.<br>• Provided reassurance and reduced stress for parents. |

Up to 31 December 2025, the service was widely valued for delivering accessible, specialist and compassionate care. Its success was driven by skilled staff, strong relationships, integrated working and personalised support leading to improved health outcomes, increased family confidence and reduced pressure on wider NHS services.

## We asked respondents to tell us suggestions on how the service can be improved

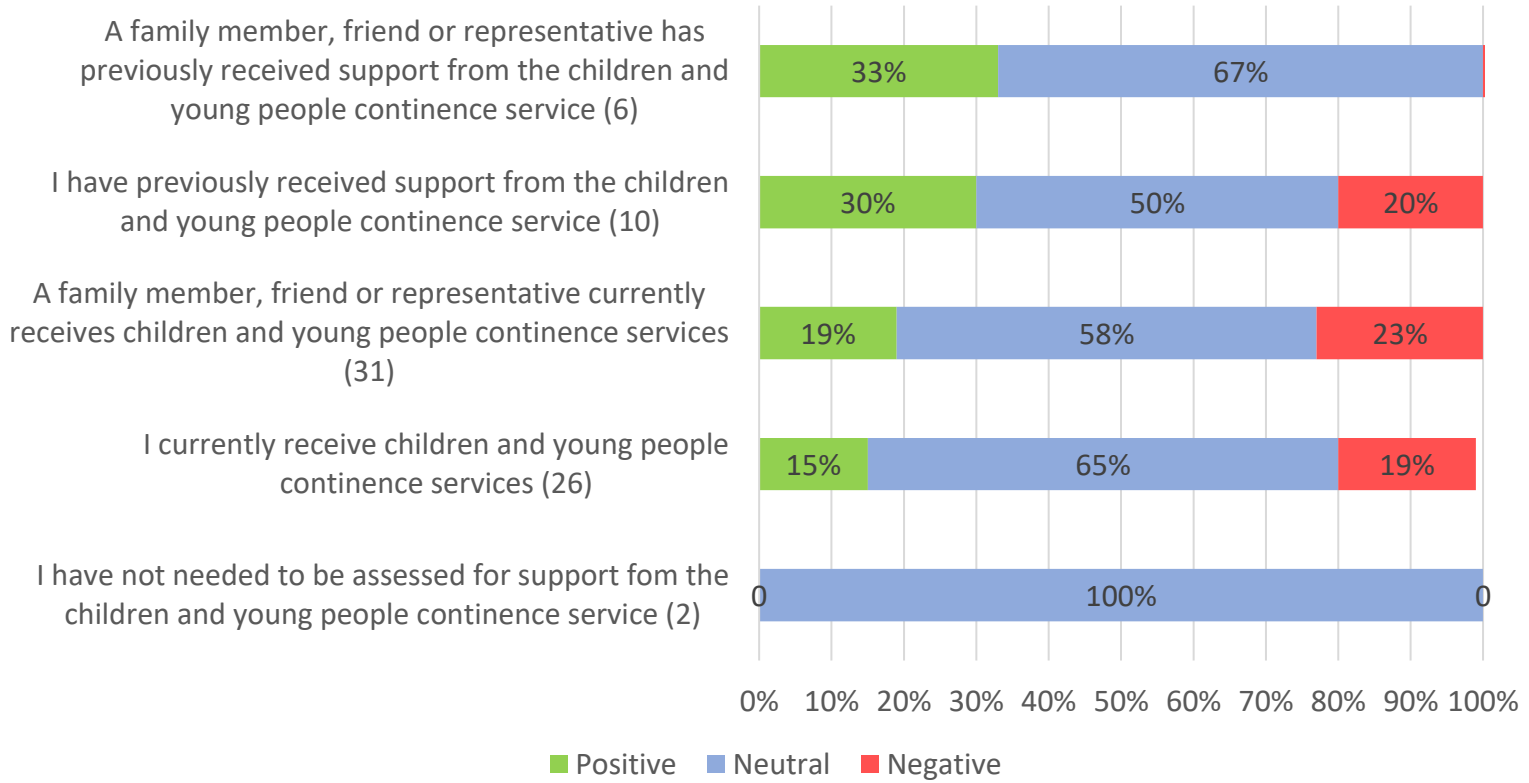
| Theme | Comments |
|---|---|
| **Patient centred care** | • Greater emphasis on listening to parents and children.<br>• More individualised support, especially for children with complex needs.<br>• Better understanding of emotional, developmental and trauma-related needs.<br>• Avoid families having to repeat their story multiple times.<br>• Ensure times are convenient for individuals.<br>• Ensure that quality of service is prioritised over funding. |
| **Resources and capacity** | • Requests for more staff to reduce pressure on the service.<br>• Concerns about limited treatment options.<br>• Need for increased support around medication and specialist input.<br>• Perception that services are under-resourced. |
| **Facilities and equipment** | • Better access to continence products.<br>• Need for appropriate sizing and suitability of products.<br>• Concerns about reduced specialist provision (eg, incontinence nurses).<br>• Avoid waste through better product matching.<br>• Provide choice of product for individuals.<br>• Suggestion for delivery every 1 month as storing supplies can be a lot to store. |
| **Access and waiting times** | • Improve waiting times as there are long waiting lists.<br>• Delays in referrals and follow-up.<br>• Difficulty accessing specialist advice quickly.<br>• Face to face support. |
| **Service co-ordination** | • Need for better earlier referral pathways, especially from GPs.<br>• Earlier identification and referral at a younger age.<br>• Improved integration between services (eg, GP, hospital, specialist teams). |
| **Staff skills and continuity** | • Desire for consistent staff rather than frequent changes.<br>• Concerns about knowledge gaps, particularly in primary care (eg, GPs).<br>• Importance of staff who listen and demonstrate understanding. |
| **Communication and information** | • Need for clearer communication about services and support available.<br>• Easier ways to contact the service.<br>• Better up-dates and guidance for families |

**So Lincolnshire County Council can focus on their core responsibilities, it has been decided that Lincolnshire County Council will continue to provide tier 1 continence support services. However, as from 1 January 2026, Lincolnshire County Council are no longer providing tier 2 continence support services as part of its children's nursing offer.**

**Therefore, a new provider is planned to deliver the tier 2 continence support services, with the aim of having this in place by July 2026. In the interim, some aspects of tier 2 services will still be delivered by Lincolnshire County Council while others, like medication reviews and assessments for enuresis alarms, will be referred back to general practice (GPs).**

**We asked respondents to tell us what impact the proposal would have on the service received**

**Overall, 54% thought it would have a neutral impact, 25% negative and 21% positive**



## The reasons for this are:-

| Positive impact | Comments |
|---|---|
| **Improved access and responsiveness** | • Faster ability to adjust treatment or try alternatives<br>• Reduced waiting times for follow-up or testing. Examples:-<br>  • "Less waiting to try different treatment"<br>  • "Medication is actually having an effect" |
| **Perceived effectiveness of care** | • Confidence that treatment or service changes could deliver better outcomes.<br>• Some recognition of benefit when services are working well. |
| **Need for modernisation and improved provision** | • Requests for updated products/services (eg, sensory-friendly products).<br>• Desire for services that better meet current needs. |

| Neutral impact | Comments |
|---|---|
| **Lack of awareness and understanding** | • Lack of understanding. |
| **Uncertainty/inability to judge impact** | • Respondents feel unable to comment without more detail and until in operation. |
| **Not directly impacted** | • Some people feel that the changes do not apply to them. |

## The reasons for this are:-

| Negative impact | Comments |
|---|---|
| **Loss of continuity and relationships** | • Strong concern about losing trusted professionals.<br>• Emotional impact of changing known care providers Examples: “My child is bonded… real worry about who will take over”.<br>• “Lack of consistency… having to explain things twice”. |
| **Reduced quality of care/expertise** | • Perception that specialists may be replaced by less experienced providers (eg, GPs).<br>• Concerns about generic rather than specialist care. Examples: “GPs do not have the time, knowledge or experience”<br>• Lower quality of service for the end user. |
| **Increased delays and access issues** | • Reports of longer waiting times or difficulty accessing care.<br>• Delays in treatment leading to worsening conditions Examples: “Care has been delayed and my son has suffered” “Waiting times are too long”. |
| **Cost driven decisions over patient needs** | • Belief that financial pressures are driving the changes.<br>• Perception that patient needs are secondary - Examples: “Feels like money saving”. “Always comes down to cost before needs”. |
| **Service disruption and withdrawal** | • Reports of gaps in service availability Long periods without specialist support Examples: “Patients left for 6+ months without access”, “Stopping of the service has added stress and anxiety” |
| **Confusion and lack of clarity** | • Unclear plans and poor communication.<br>• Lack of understanding of how changes will work Examples: “Not a clear plan” “Don’t know what impact the change will have”. |

## We asked respondents to tell us if there are any aspects of the service that are not currently being provided that should be included within a future service

| Theme | Comments |
|---|---|
| **More contact and follow-up** | • Requests for regular check-ins and “regular contact” - Feeling “just left” without follow-up.<br>• Need for continued support even after discharge. |
| **More face to face and personalised support** | • Requests for face-to-face appointments.<br>• Calls for 1:1 support, particularly for autistic children.<br>• Comments that care feels standardised rather than personalised. |
| **Listening to individuals** | • Multiple responses emphasised not being heard:<br>• “Really listen to the needs of the person… or their families”<br>• Concerns that carers’ insights are overlooked<br>• Frustration with a “one size fits all” approach |
| **Gaps in clinical scope and holistic care** | • Support for constipation, bowel and urinary issues.<br>• Help with medication management.<br>• Advice for transitioning to adulthood. |
| **More access to specialist support and referrals** | • There were requests for better integration and escalation pathways:-<br>- Need for referrals to specialists or paediatrics.<br>- Desire for the service to take a more active role in coordinating care. |
| **Product provision and choice** | • Not enough samples for trials.<br>• Requests for wider product range (eg, pull-ups).<br>• Concerns that allocation is not tailored to individual needs. |
| **Prescribing and practical support gaps** | • Suggestion that the service should handle prescribing directly.<br>• Need for clearer medication support and guidance. |
| **Increase in waiting times** | • Need for earlier referrals and better GP awareness. |

## We asked respondents to tell us if there is any further information, comments or suggestions that should be considered as part of the future continence service in Lincolnshire

| Theme | Comments |
|---|---|
| **Service accessibility and continuity of care** | Families experience delays, gaps, and withdrawal of support, often at critical points.<br>• Long and "unacceptable" waiting times are impacting children's daily lives.<br>• Sudden withdrawal of services (e.g. termination after telephone reviews) creates stress and regression.<br>• Lack of interim provision leaves families feeling "abandoned."<br>• Difficulty accessing support, with some needing to self-refer through professional knowledge. |
| **Personalised, child centred care** | "One size fits all" approaches are failing - many children require individualised and complex care plans.<br>• Children with disabilities or long-term conditions are being treated as if improvement is expected.<br>• Some conditions are lifelong, yet services are designed around short-term improvement models.<br>• Neurodivergent children (ADHD, autism) need tailored approaches beyond standard toilet training. |
| **Workforce capacity and service structure** | The service is perceived as understaffed and overstretched, particularly following removal of Tier 2 support.<br>• Loss of Tier 2 support has halted progress and increased reliance on medication.<br>• Concerns that severely disabled children are not receiving specialist input.<br>• Requests for more staff and clearer role separation. |
| **Communication and trust** | Parents frequently feel dismissed, judged, or not believed.<br>• Reports of being labelled as "lazy parenting" or children as "lazy."<br>• Lack of meaningful dialogue or exploration of symptoms.<br>• Positive feedback exists where staff are compassionate. |
| **Delivery of the service** | Over-reliance on telephone appointments is insufficient.<br>• Families feel telephone assessments do not capture the full picture.<br>• In-person assessment is particularly important for complex or long-term cases. |
| **Assessment processes** | Current assessment processes are viewed as undignified, intrusive, and burdensome.<br>• Annual pad assessments (including weighing pads) are stressful and impractical.<br>• Children's dignity is compromised, particularly for those with additional needs.<br>• Repetitive data collection yields little change in outcomes. |
| **Early intervention and preventative support** | A lack of early support leads to worsening conditions and prolonged dependency.<br>• Children are reaching older ages (eg, 9 years) without effective intervention.<br>• Parents want earlier access to guidance and structured support. |

## We asked respondents to tell us if there is any further information, comments or suggestions that should be considered as part of the future continence service in Lincolnshire – continued . . .

| Theme | Comments |
|---|---|
| **Product provision and practical support** | Provision of continence supplies is insufficient and inflexible.<br>• Standard allocation (e.g. 4 pads/day) does not meet individual needs.<br>• Families are forced to purchase additional supplies.<br>• This creates financial and emotional burden. |
| **Transparency and service clarity** | • Families lack clarity about what the service provides and what to expect.<br>• Confusion about waiting times, support available, and next steps.<br>• Lack of structured pathways increases anxiety and frustration. |

A future continence service should be:-

- Child centred, flexible and needs led.
- Provide clear pathways with no gaps in care.
- Invest in staffing and specialist roles.
- Deliver early intervention and ongoing support.
- Ensure dignity, respect and partnership with families.
- Balance efficiency with compassionate, personalised care.

# Section 2

## Results and Findings from the Staff Engagement

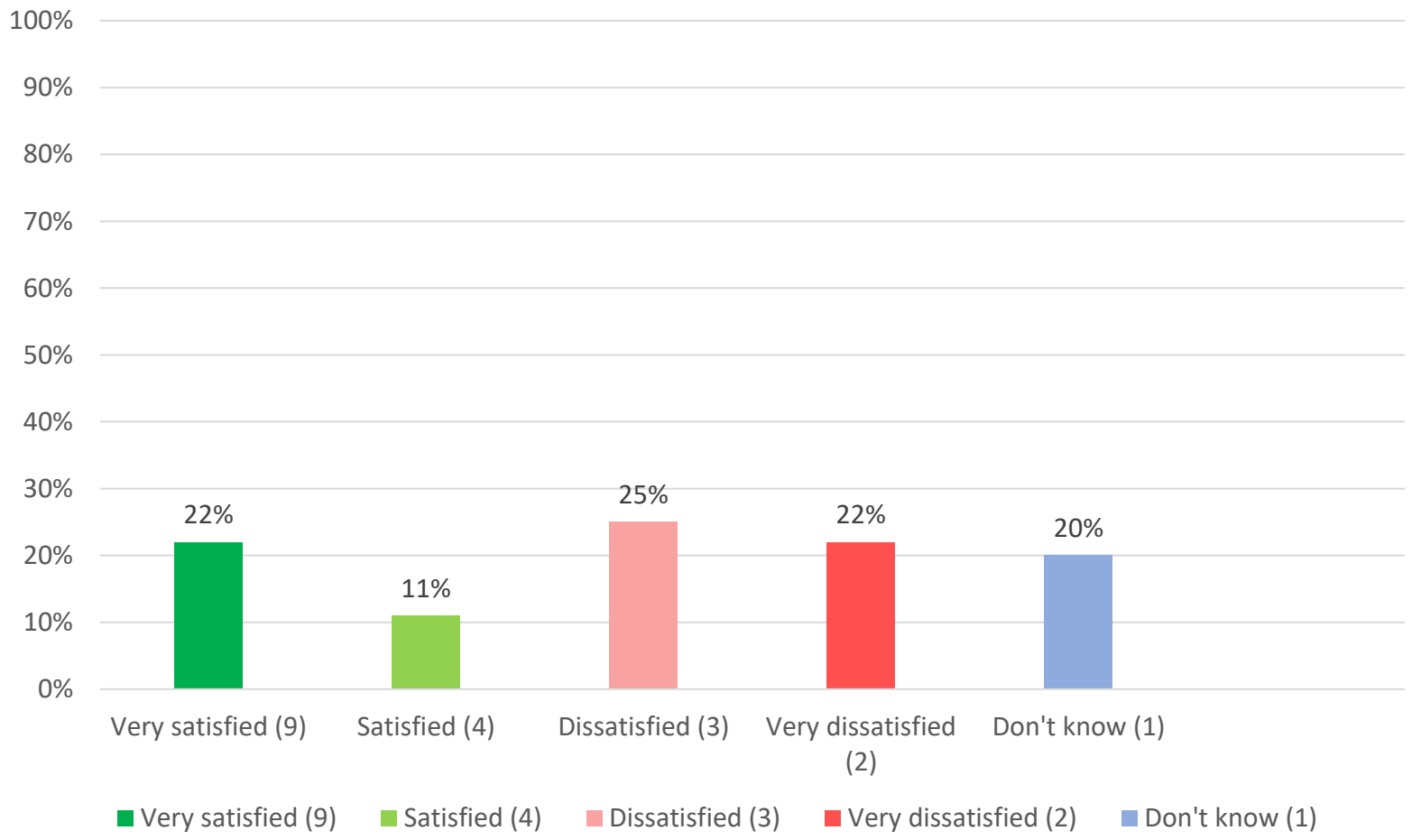
**Staff feedback** - A total of **26 survey responses** were received. Responses **where stated** were from:-

| Role | Responses |
|---|---|
| Lincolnshire County Council – CYPN (2), Business Support Assistant (1), Children's Health Worker (2), not stated (1), Children's Continence Lead (1), Deputy Continence Nurse (ICB funded)(1) | 8 |
| Continence Team | 3 |
| Education (1) not stated, (1) Teaching Assistant at primary school | 2 |
| Consultant Paediatricians, ULTH | 2 |
| CYPN (organisation not stated) | 1 |
| Retired Registered Nurse | 1 |
| Health Visitor | 1 |
| GP surgery | 1 |

**Staff feedback** highlights that the continence service is highly valued, clinically effective and critical to the wider system with 68% staff satisfaction and strong confidence in its specialist expertise, person centred approach and ability to improve outcomes for children and families. Responses vary per question, but the service is seen as pivotal in bridging gaps between primary care and paediatrics, delivering holistic support, reducing system demand and preventing escalation through early intervention and education. However, these strengths are undermined by significant capacity and resourcing pressures leading to long wating times, access challenges, inconsistent communication and risks to continuity of care. Staff emphasise that without increased investment, strengthened workforce capacity, clearer referral pathways and a more robust tiered model, the service's sustainability and ability to meet growing demand will remain at risk.

**We asked staff to tell us how satisfied they were with the service provided up to 31 December 2025**

**33% (13/19) of staff were satisfied with the service and 47% (5/19) dissatisfied**



## The reasons are:-

| Positive reasons | Themes |
|---|---|
| **High quality specialist support** | • Staff value the expert knowledge and professionalism of the team.<br>• The service is seen as bridging the gap between primary care and paediatrics.<br>• Provides trusted advice and guidance to professionals. |
| **Positive impact on children and families** | • Improves outcomes and quality of life for children.<br>• Reduces stress for families.<br>• Parents report being happy with the service and support received.<br>• Offers more thorough care compared to short outpatient appointments. |
| **Reduces pressures on wider services** | • Decreases GP workload and paediatric referrals.<br>• Relieves demand on outpatient clinics and health visiting teams.<br>• Keeps care appropriately in the community setting. |
| **Valuable and essential service** | • Described as “pivotal”, “invaluable” and “a success”.<br>• Recognised as meeting an important unmet need.<br>• Staff appreciate having a dedicated service to refer into. |
| **Supportive and person centred approach** | • Staff highlight kindness, helpfulness, and going above and beyond.<br>• Strong advocacy for children’s needs.<br>• Builds positive relationships with families. |

## The reasons are:-

| Negative reasons | Themes |
|---|---|
| **Long waiting times and delays** | • Waiting lists of 30–40 weeks reported.<br>• Delays mean children are not seen early enough.<br>• Concern about missed opportunities for timely intervention |
| **Insufficient staffing and funding** | • Repeated concern that the service is understaffed and underfunded.<br>• Demand has increased without matching workforce growth.<br>• Limits the service's ability to expand or deliver timely care. |
| **Access and communication issues** | • Service described as difficult to contact.<br>• Poor communication and lack of up-dates.<br>• Some staff unsure about how the service works or how to access it. |
| **Lack of awareness and visibility** | • Service is not widely known or understood.<br>• Leads to underutilisation or confusion among professionals. |
| **Gaps in continuity and responsibility** | • Concerns about prescribing without follow-up.<br>• Responsibility sometimes passed back to GPs without clear rationale or communication. |
| **Inconsistent provision/unmet need** | • Some cases report no support received despite need.<br>• Indicates variation in access or delivery. |

Staff overwhelmingly view the continence service as highly valuable and impactful but constrained by capacity and resource limitations.

## We asked staff to tell us what worked well up to 31 December 2025

| Theme | Comments |
|---|---|
| **Strong collaboration and communication** | • Staff consistently highlighted good communication and joint working between services.<br>• The Tier 2 service supported collaborative working, allowing teams (eg, CYPN) to refer for specialist input when needed.<br>• Regular meetings helped maintain co-ordination.<br>• The service also supported wider system partners (schools, early years, 0–19 teams, parent forums). |
| **Access to specialist expertise (Tier 2)** | Tier 2 provided specialist continence knowledge and clinical support, especially where Tier 1 had not been sufficient.<br><br>Staff valued:-<br><br>• Expertise in complex constipation and continence issues.<br>• Ability to identify red flags and escalate appropriately.<br>• Families benefitted from access to trained, knowledgeable staff. |
| **Individualised holistic care** | The service delivered child-centred, family-focused care with an emphasis on:-<br><br>• In-depth assessments.<br>• Personalised care plans.<br>• Treating each child as an individual.<br>• Staff highlighted the importance of listening, explaining and involving families in decisions. |
| **High quality support for constipation and continence issues** | Constipation management was identified as a major strength. Support included:-<br>• Ongoing review and management.<br>• Prevention of escalation (including hospital admissions).<br>• The service also effectively supported Enuresis (bedwetting).<br>• Daytime wetting. |
| **Education and medical support for families** | A key benefit was clear education and practical guidance to parents. Staff repeatedly noted that:-<br>• Families often receive prescriptions elsewhere without understanding how to use them.<br>• Continence service provided crucial instruction on medication (eg, laxatives), dosing and regimes.<br>• Education improved treatment adherence and long-term outcomes. |

## We asked staff to tell us what worked well up to 31 December 2025 – Continued . . .

| Theme | Comments |
|---|---|
| **Positive impact on children and families** | Staff described significant improvements in:-<br>• Emotional wellbeing.<br>• Confidence and dignity.<br>• School attendance and participation.<br><br>The service reduced:-<br>• Embarrassment, bullying and distress.<br>• Family stress and crisis situations.<br>• Families reportedly viewed the service as “invaluable”. |
| **Preventative and early intervention approach** | Tier 1 support (eg, toilet training for school readiness) helped:-<br>• Reduce unnecessary use of continence products.<br>• Promote independence.<br>Early intervention reduced:-<br>• Long-term health issues.<br>• Escalation to acute care. |
| **System wide benefits and cost efficiency** | The service helped:-<br>• Reduce unnecessary referrals to paediatrics.<br>• Relieve pressure on GPs and consultants.<br>• Avoid A&E attendances.<br>• Community-based delivery was viewed as cost-effective.<br>• Better for patient access and outcomes |
| **Skilled and valued workforce** | • Staff described the team as: “Amazing”, “well informed”, and highly skilled.<br>• The specialist knowledge and dedication of staff were seen as a key success factor. |

Overall, staff felt the continence service worked well because it provided accessible, specialist and holistic support delivered through strong collaboration with a clear focus on education, early intervention and individualised care – resulting in improved outcomes for children, families and the wider health system.

## We asked staff to tell us suggestions on how the service can be improved

| Theme | Comments |
|---|---|
| **Workforce capacity and resourcing** | Repeated emphasis on the need for more staff across the service. Insufficient staffing is contributing to:-<br>• Long waiting lists.<br>• Reduced ability to review patients.<br>• Limited support for families.<br>Need for a broader skill mix, including:-<br>• Specialist nurses.<br>• Support staff for toilet skills development<br>• Additional staffing seen as essential to meet increased demand and deliver a comprehensive service. |
| **Access, waiting times and timeliness** | Long waiting times for initial appointments highlighted as a major concern. Families are waiting "a very long time," delaying care. Need for:-<br>• Prompt assessments.<br>• Faster pathways into the service.<br>• Delays impacting engagement and outcomes. |
| **Structured service and tiered support** | Strong call to reintroduce or strengthen a two-tier (Tier 1 and Tier 2) model. Tier 2 particularly noted as essential to:-<br>• Bridge gaps in care.<br>• Support children with complex or ongoing needs.<br>• Loss of previous elements (eg, toilet skills support) seen as a gap.<br>• Need for clear pathways between tiers, including for continence product assessments. |
| **Communication, awareness and referrals** | Need to improve communication and signposting. Issues identified:-<br>• Difficulty accessing advice and guidance.<br>• Lack of awareness of the service among users.<br>• Better advertising and promotion of the service.<br>• Clearer referral pathways, especially for GPs and schools. |
| **Integrated and joined up working** | Desire for stronger collaboration with:-<br>• Paediatrics/hospital services.<br>• Wider multidisciplinary teams (MDTs).<br>Joint working seen as beneficial for:-<br>• Managing complex patients.<br>• Reducing unnecessary referrals to secondary care.<br>• Opportunities for clinical supervision and shared expertise highlighted. |

## We asked staff to tell us suggestions on how the service can be improved – Continued . . .

| Theme | Comments |
|---|---|
| **Clinical capability and service offer** | Current service seen as limited in treatment options Suggested enhancements:-<br>• Expanded clinical skills (eg, physical examination).<br>• Access to investigations (eg, uroflowmetry, bladder ultrasound)<br>• Need to ensure a comprehensive end-to-end continence service.<br>• Importance of ongoing patient review when treatment is prescribed. |
| **Education and training** | Need for:-<br>• Improved GP knowledge, particularly around constipation management.<br>• Further training and funding for specialist nurses.<br>• Education seen as key to: Improving care quality.<br>• Reducing unnecessary referrals. |
| **Family support and engagement** | Service should better:-<br>• Support and engage families in care plans.<br>• Encourage continuation with treatment plans.<br>• More frequent reviews and contact would improve engagement Goal to empower families and increase independence. |
| **Compliance and quality standards** | • Importance of continuing to follow NICE guidance.<br>• Ensuring consistency and quality across the service. |

Staff feedback consistently highlights that the continence service is under resourced, difficult to access and lacking in clear structure and integration. The most critical improvements centre on:-

- Increasing staffing and capacity.
- Restoring a clear tiered service model.
- Reducing waiting times.
- Strengthening communication and referral pathways.
- Enhancing clinical capability and integration with other services.

These changes are seen as essential to deliver a timely, comprehensive and family centred continence service.

**So Lincolnshire County Council can focus on their core responsibilities, it has been decided that Lincolnshire County Council will continue to provide tier 1 continence support services. However, as from 1 January 2026, Lincolnshire County Council are no longer providing tier 2 continence support services as part of its children's nursing offer. Therefore, a new provider will deliver the tier 2 continence support services, with the aim of having this in place by July 2026. In the interim, some aspects of tier 2 services will still be delivered by Lincolnshire County Council while others, like medication reviews and assessments for enuresis alarms, will be referred back to general practice (GPs).**
**We asked staff to tell us what impact the proposal would have on the service received**
**Overall, 54% thought it would have a neutral impact, 25% negative and 21% positive**

**53% (9/17) of staff thought that the proposal would have a negative impact, 29% (5/17) positive impact and 18% (3/17) neutral impact. The reasons are:-**

## Positive impact

Potential for more children to be seen. A restarted or strengthened tier 2 continence service could:-

- Provide better support beyond products.
- Reduce pressure on GP surgeries.

If adequately resourced, the service could:-

- Deliver comprehensive and effective care.
- Improve outcomes for children and young people.
- Have a positive impact on NHS funding, GP workload and secondary care demand.

Upskilling tier 2 services (including prescribing) could improve outcomes through:-

- Lifestyle support and short-term medication.
- Stronger community-based care.
- Better advice and guidance could reduce inappropriate referrals.
- Improve waiting times.

## Neutral/unclear impact

Several responses highlight:-

- Lack of detail or unclear proposals.
- Uncertainty about what the new service will look like.

Impact depends heavily on:-

- How the service is implemented.
- Whether it is properly resourced and comprehensive.
- Some recognition that changes could be beneficial, but only under the right conditions.
- Desire for involvement of experienced staff in shaping the service.

## Negative impact

- Reduced or unclear support for families.
- Lack of timely advice.
- No dedicated 1–2–1 support service.
- Families having “nowhere to go”.
- Increased reliance on GPs, who are not continence specialists.
- Are already under pressure.
- May not prescribe according to NICE guidance.
- May struggle with additional workload (e.g. medication, alarms).
- Risk that children do not receive appropriate treatment or support.
- Experience worsening conditions or delays.
- Develop long-term health issues.
- Impacts on school attendance, friendships and wellbeing.
- Potential system impacts: More GP appointments and referrals to secondary care.
- Increased NHS costs (eg, more continence product provision).
- If service is reduced (eg. products-only) there will be a lower quality of care.
- Significant negative impact on quality of life for children and families.
- Concern that changes may be detrimental if not focused on improving capacity (eg, additional staff). Some children may be missed by the service entirely.

## We asked staff to tell us if there are any aspects of the service that are not currently being provided that should be included within a future service

Staff responses highlight a need to strengthen and expand children's continence services, particularly by improving access, clinical capability and early intervention support. There is a strong emphasis on aligning care with NICE guidelines (eg, constipation, nocturnal enuresis), increasing face to face support for families and ensuring more comprehensive assessments and treatment options.
Staff also noted the importance of clearer service structure across tiers (tier 1 and Tier 2) with stronger prevention, earlier toilet training support and better co-ordination with other services.

| Theme | Comments |
|---|---|
| **Increased face to face and community based support** | • More in-person appointments in community settings for families.<br>• Stronger community-based support alongside clinical care. |
| **Enhanced Tier 2 clinical capability** | • Ability for Tier 2 staff to prescribe medication.<br>• Improved clinical skills (eg, physical examinations).<br>• More thorough assessments to reduce need for additional referrals. |
| **Restoration and expansion of clinical interventions** | • Medication support for constipation and nocturnal enuresis.<br>• Access to enuresis alarms.<br>• Consideration of additional investigations (eg, uroflowmetry). |
| **Stronger focus on toilet training and intervention** | • Reintroduction or expansion of toilet skills development within Tier 2.<br>• More support for "ready for school" toilet training at Tier 1.<br>• Earlier intervention to reduce reliance on continence products. |
| **Improved continence product provision processes** | • Clear assessments linked to provision.<br>• Active toilet training alongside product provision.<br>• Better support for children with additional needs. |
| **Better integration and joint working** | Stronger links with:-<br>• Emotional health and wellbeing services.<br>• Children's therapy services.<br>• More robust referral pathways. |
| **More comprehensive and detailed continence support** | • Greater depth of specialist bladder and bowel input.<br>• More structured reviews and ongoing management. |

## We asked staff to tell us if there is any further information, comments or suggestions that should be considered as part of the future continence service in Lincolnshire

In summary, it was felt that a high quality continence service should be accessible, well resourced, multi-disciplinary and community focussed with strong clinical support and workforce capability building on existing success to further improve outcomes and reduce system wide pressures.

| | |
|---|---|
| **Awareness and accessibility** | • Ensure people (families, professionals and communities) are aware of the continence service.<br>• Maintain equitable, county-wide access to reduce health inequalities and ensure all children and families can benefit. |
| **Service model and approach** | • Develop a comprehensive paediatric bladder and bowel service.<br>• Focus on functional continence issues, where outcomes are often improved through lifestyle changes.<br>• Short-term medication where appropriate.<br>• Strong community-based support.<br>• Continue to build on an already effective service that has demonstrated positive impact on children's lives. |
| **Workforce and capacity** | Increase staffing levels across the service to:-<br>• Reduce waiting times.<br>• Meet demand.<br>• Include a multidisciplinary team (MDT) approach, incorporating Continence Nurses, Children's Health workers.<br>• Provide sufficient workforce to sustain and enhance existing service quality. |
| **Skills and capability development** | Upskill Tier 2 services, particularly to:-<br>• Support prescribing.<br>• Manage more cases without escalation.<br>• Strengthen workforce capability to manage the majority of functional cases effectively in community settings. |
| **Clinical collaboration and pathways** | Introduce or strengthen regular consultant input (eg, monthly case discussions) to:-<br>• Manage complex cases.<br>• Reduce unnecessary onward referrals.<br>• Encourage joint working and face-to-face discussions between teams to improve co-ordination and shared understanding. |

## We asked staff to tell us if there is any further information, comments or suggestions that should be considered as part of the future continence service in Lincolnshire

| | |
|---|---|
| **System impact and value** | Recognise the wider benefits of continence services:-<br><br>• Reduced pressure on other health services.<br>• Positive impact on schools and families.<br>• A well-functioning service prevents escalation, supports early intervention, and improves overall system efficiency. |
| **Risks of service changes** | Reductions or changes to the service could:-<br><br>• Increase pressure on wider health services.<br>• Negatively impact families.<br>• Reverse progress made in reducing inequalities. |

# Section 3

## Equalities and Health Inequalities Monitoring

**Under the provisions of the Equality Act 2010, all NHS organisations are required to demonstrate that their processes are fair, and that they are not discriminating or disadvantaging anyone because of their age, disability, gender reassignment status, marriage or civil partnership status, pregnancy or maternity, race, religion or belief, sex or sexual orientation.**

| Ethnicity | Responses | |
|---|---|---|
| White: Welsh, English, Scottish, Northern Irish, British | 94% | 89 |
| Asian or Asian British Indian | 2% | 2 |
| White Canadian | 2% | 2 |
| South African | 1% | 1 |
| Prefer not say | 1% | 1 |
| Answered | 100% | 95 |

| Disability | Responses | |
|---|---|---|
| Yes the health problem/disability limits me a lot | 31% | 17 |
| Yes the health problem /disability limits me a little | 18% | 10 |
| No | 49% | 27 |
| Prefer not to say | 2% | 1 |
| Answered | 100% | 55 |

| Main language | Responses | |
|---|---|---|
| English | 99% | 86 |
| Africaans | 1% | 1 |
| Answered | 100% | 87 |

| Age | Responses | |
|---|---|---|
| Age 16 and below | 27% | 26 |
| 17 – 20 | 5% | 5 |
| 21 - 29 | 5% | 5 |
| 30 – 39 | 19% | 18 |
| 40 – 49 | 25% | 24 |
| 50– 59 | 14% | 13 |
| 60- 69 | 3% | 3 |
| 70-79 | 1% | 1 |
| 80 – 89 | 0% | 0 |
| 90 + | 0% | 0 |
| Prefer not say | 1% | 1 |
| Answered | 100% | 96 |

Under the provisions of the Equality Act 2010, all NHS organisations are required to demonstrate that their processes are fair, and that they are not discriminating or disadvantaging anyone because of their age, disability, gender reassignment status, marriage or civil partnership status, pregnancy or maternity, race, religion or belief, sex or sexual orientation.

| Religion | Responses | |
|---|---|---|
| **Christian** | 43% | 34 |
| **No religion** | 30% | 24 |
| **Atheist** | 20% | 16 |
| **Prefer not to say** | 6% | 7 |
| **Any other religion** | 0% | 0 |
| **Buddhist** | 0% | 0 |
| **Hindu** | 0% | 0 |
| **Jain** | 0% | 0 |
| **Jewish** | 0% | 0 |
| **Muslim** | 0% | 0 |
| **Sikh** | 0% | 0 |
| **Agnostic** | 0% | 0 |
| **Answered** | **100%** | **81** |

| Sexual orientation | Responses | |
|---|---|---|
| **Heterosexual** | 79% | 60 |
| **Rather not say** | 17% | 13 |
| **Prefer to self – identify** | 1% | 1 |
| **Bisexual** | 1% | 1 |
| **Lesbian** | 1% | 1 |
| **Gay** | 0% | 0 |
| **Answered** | **100%** | **76** |

| Gender | Responses | |
|---|---|---|
| **Female** | 75% | 67 |
| **Male** | 21% | 19 |
| **Non-binary** | 0% | 0 |
| **Prefer not to say** | 1% | 1 |
| **Intersex** | 1% | 1 |
| **Prefer to self identify** | 1% | 1 |
| **Answered** | **100%** | **89** |

| Pregnancy and maternity - are you an expectant mother or given birth in the last 26 weeks? | | |
|---|---|---|
| | Responses | |
| **No** | 100% | 43 |
| **Yes** | 0% | 0 |
| **Rather not say** | 0% | 0 |
| **Answered** | **100%** | **43** |

| Are you the same gender that you were assigned at birth? | | |
|---|---|---|
| | Responses | |
| **Yes** | 100% | 38 |
| **Prefer not to say** | 0% | 0 |
| **No** | 0% | 0 |
| **Answered** | **100%** | **38** |

| Please indicate your disability | | |
|---|---|---|
| | Responses | |
| **Learning disability/difficulty** | 33% | 26 |
| **Physical impairment** | 22% | 17 |
| **Long standing illness** | 14% | 11 |
| **Other (not stated)** | 6% | 5 |
| **Sensory impairment** | 15% | 12 |
| **Mental health condition** | 10% | 8 |
| **Answered** | **100%** | **79** |

| Carer - Do you look after, or give any help or support to family members, friends, neighbours or others? | | |
|---|---|---|
| | **Responses** | |
| **Primary carer of child/children (under 18)** | **54%** | **27** |
| **Primary carer of disabled child/children** | **36%** | **18** |
| **Primary care of disabled adult (18 and over)** | **10%** | **5** |
| **Primary carer of older person** | **0%** | **0** |
| **Secondary carer (another person carries out the main caring role)** | **0%** | **0** |

# Health inequalities data

| Employment status | Responses | |
|---|---|---|
| Employed full time | 32% | 25 |
| Employed part time | 27% | 21 |
| Homemaker | 9% | 7 |
| Not employed and looking for work | 1% | 1 |
| Not employed and not looking for work | 3% | 2 |
| Retired | 5% | 4 |
| Self employed | 4% | 3 |
| Student | 9% | 7 |
| Prefer not to say | 3% | 2 |
| Other | 8% | 6 |
| **Total** | 100% | 78 |

| Experience of any of the following:- | Responses | |
|---|---|---|
| Currently serving in the reserve or regular armed forces | 12.5% | 1 |
| Have served in the armed forces | 50% | 4 |
| Currently working in the farming industry | 25% | 2 |
| Have worked in the farming industry | 0% | 0 |
| Currently homeless | 0% | 0 |
| Experience of being homeless | 12.5% | 1 |
| Refugee, asylum seeker or immigrant | 0% | 0 |
| Previous experience of being a refugee, asylum seeker or immigrant | 0% | 0 |
| Total | 100% | 8 |