

Oxfordshire Parent Carers Forum

Children's Integrated Therapies (CIT) Survey Report

March 2021

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1. Executive Summary

This report summarises feedback gathered from parent carers of children and young people who access one or more of the children's integrated therapy services (CIT) in Oxfordshire. These therapies are Speech and Language Therapy, Occupational Therapy and Physiotherapy. Respondents completed an online survey created by Oxfordshire Parent Carers Forum (OxPCF) and disseminated to parent carers in June 2020. This report has been written by OxPCF and aims to present the results of this survey in a way that gives useful insights that may help shape service improvements.

Respondents indicated that they felt their child/young person was well supported. They found therapists offer good advice, provide good input and are pleasant to work with.

The specific interventions that the therapists and the service offer were felt to be very valuable, but generally parents felt there was not enough input to meet need. The key themes identified in this survey, suggest operational problems with the service, that may be a direct result of under-resourcing.

The key themes from the survey responses were:

- The service is highly valued.
- There was praise for the service and therapists.
- Accessibility.
- Referral times.
- Inappropriate/Early discharge.
- Frequency/Intensity.
- Consistency and Continuity.
- Personalisation.
- Communication.
- Staffing levels/Funding.

Other themes identified from responses included:

- Training.
- Early intervention.
- Lack of integration of therapy services.
- Lack of training of Autism Spectrum Disorders and Sensory Processing issues.
- Poor Educational Health and Care Plans (EHCP).
- Transparency/Decision making around access and level of need.
- Failure to assess and diagnose dyspraxia.
- Professional Integrity.

These themes are explored in more detail in the report.

In writing this report OxPCF are mindful of the many challenges facing Oxfordshire's therapy services and the dedication shown by those working for the service, who strive to do their absolute best for the children and young people of Oxfordshire.

2. Background

Oxfordshire Parent Carers Forum (OxPCF) exists to support the development of parent carers participation, a process in which parents work together with professionals to make improvements to local services. The forum is run by and for parents and carers of children and young people with additional needs.

OxPCF believes passionately that 'Every Child Matters' and that all disabled children and young people in Oxfordshire, should have access to the same opportunities, experiences and information as any other child.

A member of the OxPCF steering group has been working with the children's integrated therapy service team to reflect on what is working and is not working. Following a focus group on the CIT service, it was decided that OxPCF would produce a survey to collate feedback on the services received in Oxfordshire.

This survey was distributed widely through OXPCF's networks and contained in this report is a summary and analysis of the responses to this survey.

We would like to extend our heartfelt thanks to all the parents and carers who took the time to complete this survey. We know how precious their time is and it is very much appreciated. We would also like to thank the Oxford Health NHS Foundation Trust for engaging with us on this report and exploring opportunities to address the feedback received.

3. Responses to the Survey: Settings and Services

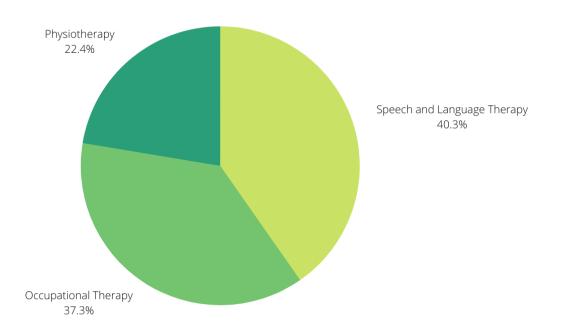
3.1 Therapy service/s accessed by respondents' child/young person

Q1. Please tick which therapy service/s your child/young person is accessing or accessed.

Q2. Please indicate if the child/young person is a current user of these services or a previous user?

23 of the respondents indicated that their child/young person is a current user of one or more therapy services. and 11 respondents said their child/young person had previously used one or more therapy services, 9 had done so since 2015 and 2 prior to 2015.

Several respondents received input from multiple therapy services (Two thirds of respondents indicated that their child/young person accessed 2 or more therapy services and over a third accessed all three). Speech and Language was the most frequently used service with 27 respondents, Occupational Therapy was accessed by 25 and Physiotherapy by 15.



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3.2 Educational setting of respondents' child/young person

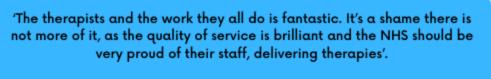
Q3. Please tick the setting in which your child/young person accesses this service/s.

We had a total of 35 responses to the survey (34 of these were submitted via our online survey via surveymonkey and 1 of these was returned in paper format)

Setting	%	No.
Pre- School/Nursery	11.43%	4
Mainstream Primary	25.71%	9
Mainstream Secondary	11.43%	4
Special School Primary	8.57%	3
Special School Secondary	20.00%	7
Primary School Resource Base	2.86%	1
Secondary School with Resource Base	0.00%	0
College	2.86%	1
Traineeship/Apprenticeship	2.86%	1
At home: Electively Home Educated	0.00%	0
At home: Missing Education	2.86%	1
Outpatient/Community	5.71%	2
Other	5.71%	2
Total		35

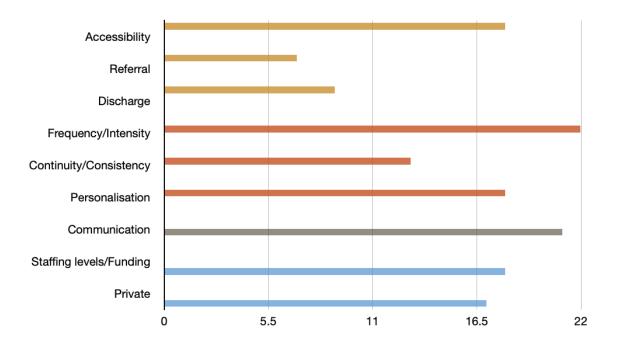
4. Key Themes

Overall respondents were supportive of the service and therapists. Respondents fed back positive attitudes towards personal attributes of staff and their rapport building skills. Respondents reflected that staff have particularly good interpersonal skills, approach service users with constructive compassion and have appropriate knowledge and technical skill levels.



'The CIT staff are wonderful, brilliant, caring and couldn't have been better face to face, with the limited time available.'

It is important to note that the survey was designed to explore the challenges and gaps faced by families and as such the majority of the feedback in this section addresses that. The chart below identifies the key themes raised in the survey.



 Accessibility: Over half of all respondents expressed concern about lack of access to all therapy services in a majority of settings.

- Referral times: Approximately 20% of respondents mentioned that referral times are too long for all therapy services.
- Discharge: Premature discharge from services was a theme identified by around a quarter of all respondents.
- Frequency/Intensity: Over 60% of respondents reported that gaps between appointments are too long and/or that not enough time is spent with each child.
- Consistency and Continuity: Over a third of respondents said that staff turnover happened too often and there was inconsistent delivery in the service provided.
- Personalisation: Over half of respondents felt that the service was not meeting the specific needs of individual children/young people.
- Communication: Around 60% of respondents said there was inadequate communication between services, parents and educational settings.
- Staffing levels/funding: Over half of respondents said there needs to be more staff and a larger budget for children's therapy services.
- Private: Around half of respondents indicated that private services were being used due to lack of NHS provision.

In addition to the key themes, a number of other themes were also identified, but to a lesser extent:

- Training: Specifically, a lack of training for Teaching Assistants; Teachers and Parents.
- Early intervention: The service is not preventative, anticipatory or proactive.
- Integration of therapies: People felt that services are not joined up around the child/young person.
- Autism Spectrum Disorder and Sensory Processing: A lack of training around this via lack of Occupational Therapy.
- Equipment either not being issued or not being issued in a timely manner and not always meeting the needs of the child/young person.
- Educational Health and Care Plans (EHCP): There were a range of issues identified with EHCPs and Annual Review of EHCPs including: provision not quantified and specified/meeting need holistically; therapists not contributing a report or having input to EHCP; EHCP not reviewed frequently enough and out of date; not regular enough assessment of need.
- Transparency: Decision making around access and level of need.
- Failure to assess and diagnose the condition Dyspraxia.
- Professionalism/Professional integrity: Implication that professionals portray the view that the level of input they give is adequate and meets need.

5. Challenges and Gaps

Q4. Please tell us what problems you have encountered whilst using the Children's Integrated Therapy Service. Please indicate which of the Therapies you are referring to if you access more than one service.

Q5. Please tell us if there is something missing or a gap in the Children's Integrated Therapy service that we need to address? Please indicate which of the therapies you are referring to, if you access more than one service.

Q6. Can you tell us how the problems or gaps that you have encountered, whilst using the Children's Integrated Therapy Services, impacts on the outcomes that you want for your child/young person? Please indicate which of the therapies you are referring to, if you access more than one service.

We have drawn out the keys themes to these questions, identifying the feedback relating to the specific services.

The key problems and gaps across all services, settings and age groups, identified by respondents, were:

- Services are understaffed.
- It is difficult to access services, support and equipment and therefore children and young people are being let down.
- There is not enough early and intensive intervention (pre-school) which can lead to 'too little, too late'.
- Not enough time is allocated to each child/young person.
- Therapists do not have enough time to do thorough assessments or deliver therapy.
- Some respondents reported a lack of continuity of care and that there seemed to be little 'joined up thinking' or integration between different therapies and therapists.
- Community therapists don't communicate well with hospital based therapists and when children/young people are in schools out of Oxfordshire.

In addition, across most age groups and settings, these gaps and problems were identified:

- Therapists are not always working collaboratively with parents.
- There is insufficient monitoring of the outcomes of therapy and schools do not consistently implement programmes
- Targets are not sufficiently clear.
- Caseloads are too big.
- Continuity of care is poor including too many changes of therapists providing care.
- Needs are not always fully identified in EHCPs and it can be difficult to make sure the provisions stipulated are met.

As young people move towards and through transition to adult services a range of problems and gaps were identified:

- The transition to adult services is not smooth and continuity in therapy provision is lost.
- Respondents felt adult services were not needs led and provision was inadequate.
- EHCP stipulated needs are not being met and there is a need to bolster provision for those still in education up to the age of 25.

In the following sections, we describe the key themes in more detail by service.

6. Services Key Themes

6.1 Speech and Language Therapy (SALT)

Concerns were expressed by respondents about long waits for referrals and long waits for appointments after referral. This leads to therapists not being involved early enough with the child/young person. Respondents also indicated that as a result of concerns expressed by school and an inability to access NHS services they are driven to access private provision.

Two common threads throughout responses were that there is a long gap between appointments leading to insufficient input and a lack of continuity of care due to frequent changes of therapist. There is also a sense of inequity in terms of frequency of input per child. This was experienced across a range of settings and age groups. There are also concerns being expressed about inequality and unfairness in the system for children where English is not their first language.

> 'I have no faith in the professional integrity of the therapists. Their roles have been reduced to such an extent, that they are a hair's breadth away from making their roles redundant'.

Several respondents also expressed concern with discharge processes in terms of discharge being premature, lack of transition planning as young people move from school to college and communication of services ending. These concerns are experienced across settings and age groups.

Respondents also indicated that input was not sufficiently personalised to the child/young person's needs. Some concern was expressed about whether diagnosis is appropriately identifying severity of needs and thus impacting on provision offered. There is concern that in college settings, that there is a focus on communication devices and not on other areas of support.

'Speech and Language Therapy service stopped when my child left special secondary school in July 2018. No provision at college in the Life skills department. Just told no provision/ funding for adults other than for communication devices'.

Poor communication seems to be a common experience. There are concerns with communication between hospital SALT and community SALT. This can result in hospital SALTs recommending private SALTs, to families, as they find they will work more closely together. Several respondents expressed concern about lack of timely feedback to parents about discharge, therapy input/provision and how to support their child/young person at home.

'NHS therapists are extremely stretched and busy and not being able to get hold of them and subsequent chasing is gruelling.

Respondents also expressed concerns about lack of guidance offered to schools and concern was expressed about whether TAs, who are expected to deliver therapy, have sufficient training to do so. These types of concerns were seen across age groups and settings.

'Lack of communication and clear guidance about what is being offered by the service caused unnecessary stress and anxiety to my child and myself'.

6.2 Occupational Therapy (OT)

As with SALT, respondents report long waiting times for referral and slow follow up leading to delays in treatment. There is an impression, in this survey, of very sparse provision and a feeling of there being a 'postcode' lottery and the service being too centred around Oxford. Concern was expressed about the challenges and difficulty of getting an OT assessment, that criteria for OT involvement was unclear and that they have to 'chase' the service, which can be hard to get hold of. These experiences appear to happen across settings and age groups.

Respondents indicate that there is not enough OT access or advice and that the 12 week pre referral course is not always relevant. All of these concerns result in a lack of timely OT support for children and young people.

There are specific concerns around housing support from OTs and assessment of needs at home and school (specifically in respect of self-care) that can lead to a significant impact on families, especially siblings. It can then be difficult to re-refer to OT for further assessments.

Once referrals and assessments have been undertaken respondents report a patchy service. There are reports of insufficient input to deliver outcomes and a lack of connection with the wider system (e.g. lack of input to EHCP reviews). These issues appear to arise across settings and age groups. There also appears to be a mixed experience of good and bad provision, depending on the therapist, which is leading to inconsistent provision. In addition there are reports of when OTs move or leave, no replacement OTs are provided, which is then impacting on the ability to use equipment as no one has been trained.

Concerns were expressed about a lack of OT training to assist autistic children with sensory issues leading to insufficient support and advice for sensory issues particularly at school. Respondents reported a lack of play skill courses, insufficient training for school staff and equipment not being provided (even after ordering there are excessive waits) to fully access the curriculum.

'Not enough advice to staff at school and no training for staff from OT'.

There are specific issues and concerns about the diagnostic limitations around dyspraxia and no clear pathway for support for children and young people in this group.

Respondents report poor communication about what OT services would offer. Within college settings it is reported that there is confusion about OT roles from different providers including social care, housing, learning disability and college.

Across settings and age groups there is a sense that the service is under resourced leading to piecemeal provision. Respondents report having to resort to accessing private OT services to address concerns as they are unable to access NHS OT services.

'More funding, for more hands on, needed.'

'All of the services are understaffed. None of the therapists have the time, or the inclination to deliver therapy.'

6.3 Physiotherapy

As with the other therapies respondents reported that there are long waiting lists for physiotherapy which leads to late interventions. There was also concern expressed about the number of sessions being available through the NHS being limited, leading to premature discharge.

Respondents commented on the lack of input and monitoring at school and at home. They indicated that provision was often not regular, it lacked intensity and there were issues with supply and adjustment of equipment. Respondents reported that it was challenging to find appointments and rooms that were available at the same time. It was reported that the impact of COVID has had a detrimental effect, leading to families feeling overwhelmed and being isolated because of services and contact being stopped. It was noted that the service offered lacks a preventative element in the interventions provided.

> 'Clear procedures need to be in place for equipment assessment/ordering process and staff should not discuss how it is funded in front of a parent unless they ask or raise this. There have been disputes between OT services and Physio too often over who pays for what and especially in regards to our Son being out of catchment but equipment in the home is nothing to do with school'.

My send my child to private physio every 6 weeks. It has made a tremendous difference. My child gets about 1-2 hours every 3 months. That frankly isn't physio, that's just checking for problems with her joints and any issues that may be happening due to her conditions. Physio should be preventative, in NHS from the experience we have had it is to check as problems develop and happen. Not to stop them happening. My child isn't seen enough to improve her, she's seen to mointor the effects and damage the CP causes. I take her to private physio as I want her to have the best possible chance at a pain free and mobile if able life. Concern was expressed when hospitals and community physiotherapists did not work together and had mismatched recommendations.

Respondents said that they had sought private physiotherapy but had to stop as it was too expensive. There was reporting of inappropriate use of adult services, where the environment is unsuitable for a child, to deal with lack of child services. This led to increased anxiety for the child. As with the other therapies there was a sense that the service was underfunded leading to insufficient physiotherapy staff.

7. Impact on Families, Children and Young People

Q7. Can you tell us how the problems or gaps you have encountered, whilst using the Children's Integrated Therapy Service, impacts on the wellbeing of your family? Please indicate which of the therapies you are referring to, if you use more than one service.

Respondents gave a range of examples of how they felt the wellbeing of the family was affected when therapies were not, in their view, meeting the needs of the child/young person.



8. Potential Solutions

Q8. What might the solutions be to the problems you have told us about, within the Children's Integrated Therapy Service? Please indicate which therapy you are referring to.

Q9. What might the solutions be to the gaps in the Children's Integrated Therapy Service you have told us about? Please indicate which therapy you are referring to.

A large number of suggestions and ideas were made. We have grouped them into different categories and start with some general ideas that can be applied across the whole service:

- Remove postcode lottery and inequalities of input.
- Earlier, more frequent, more specific interventions for all therapies, particularly pre-school.
- Do not put children into adult clinics.
- Make sure actions and programmes are implemented in all settings.
- Improve staff turnover by incentivising therapists to stay in the NHS.
- Reduce the caseloads of all therapists.
- Reduce staff turnover.
- There is a need for better integration of all therapies around the child and better communication with all parent carers and professionals.

The remaining suggestions we have grouped into the following themes:

Speeding up the Process:

- Make access to all therapies easier by ensuring there is a clear referral process.
- Reduce waiting/referral times.
- More routine assessments and faster follow ups.
- Develop a clear process that identifies families who move into the area.
- To help with waiting times outsource to private providers if the service can't provide what is needed or offer families the choice of a budget so they can buy private therapy.
- Clearer procedures for equipment assessment and ordering

Additional Resources:

- More hands-on therapy that is preventative, more specific, frequent and intense.
- Lack of OTs has been a predominant issue in this survey particularly at school, for sensory Issues and housing OTs
- Generally there was a suggestion to employ more OT; SALT; Physiotherapy staff to enable more time to be allocated to each child needed.
- Separate budget for bespoke equipment.

Training and Awareness:

- Provide better training and awareness for OTs around ASD and sensory issues.
- Better understanding of specific OT roles/functions.
- Provide better training, for TAs and wider school staff, about the delivery and importance of therapy input.
- More hands on group training sessions with therapists for parents, TAs and teachers.
- More hands on personal training of programme delivery for parent carers of individual children/young people to increase confidence to continue therapy at home.

Service innovations and Developments:

- Develop a drop in centre for OT
- Play therapy should be provided by the OT service.
- OT should be more focussed on self-care issues.
- Recognising OT 12-week pre-referral courses is not always appropriate/accessible.
- More individualised approaches should be implemented, particularly for SALT services.
- There need to be clearer targets set by therapists.
- The physiotherapists service should develop more contracts with equipment providers to help reassess and alter equipment.
- There should be separate budgets for bespoke pieces of equipment that meet a child's needs. Therapists should be sensitive to the impact on carers, if present, when discussing funding issues.

Communication:

- There should be a centralised point of manned contact, or web page, so people can get queries answered quickly without having to 'ring around'.
- Make criteria for involvement of all therapies clear and transparent. Have an appeal process, if people can't access.
- Clarify dyspraxia diagnosis process and pathway beyond diagnosis, via bespoke communication.
- Clear information and agreement about what different OT services provide/do eg. housing; Social care; educational access; College etc.
- There should be clearer procedures for equipment assessment and ordering.
- There needs to be clear ownership of deliverables between agencies.
- Facilitate multi-disciplinary meetings to join up private and NHS provision.
- With Families:
 - Need to work more collaboratively with parents.
 - All therapists should touch base with families regularly to see what is working/not working and to make sure the child is receiving what they need.
- With Schools:
 - Need to work more collaboratively with staff. There should be stronger links between the therapist and school.
 - More guidance needs to be provided to schools.
 - There need to be clearer targets set by therapists and better monitoring of outcomes from work delegated to schools.
- With Other Professionals:
 - There needs to be better joint working and communication between hospitals, consultant specialist therapists and CIT.
 - CIT needs to be more willing to accept advice and specialist therapy plans, from hospital therapists.
 - Community teams should have procedures for corresponding with out of catchment therapy teams.
- Within CIT
 - There needs to be more consistent joint working between different therapy disciplines around the child leading to more continuity of care.
 - There needs to be better handovers when staff leave, at the least notes should be passed on.

EHCPs:

• There need to be more needs led quantification and specification in EHCPs and more regular reassessment of need for EHCPs.

Transition to Adulthood:

- Set up transition teams or assign to each young person a lead therapist trained in preparing for the workplace and adulthood agenda, moving the young person from CIT into adult services, to bridge the cliff edge.
- Commission more therapists to meet need in EHCP's for 19-25 year olds in community placements such as apprenticeships, traineeships, supported internships etc
- Therapy teams needed to specialise in 'access to the work-place' for Young People in work based educational provision e.g. apprenticeships, traineeships, supported internships.
- Equitable access to therapy across all college settings to ensure young people can choose the setting with the most appropriate educational provision for them.

9. What's going well?

Q10. Can you tell us what the Children's Integrated Therapy Service is doing well and should therefore keep doing? Please indicate which therapy you are referring to.

Overall respondents indicated that they felt their child/young person was well supported. They found therapists easy to contact or found that they responded promptly to calls and emails. Therapists offer good advice and resources are provided as needed. Overall, there was a feeling that the children's integrated therapy service was good but there was just not enough input to meet needs.

Due to the nature of the report, people tended to focus on the negatives, and where they did provide a positive response this was then caveated with a less positive comment.

Twenty six people answered this question, of these nineteen responses specifically related to Speech and Language Therapy (SALT) and Physiotherapy. The comments related to the personal individual qualities of the staff working in the service. It was clear from the people that people valued the individual staff members working within the service and welcomed the strategies and interventions offered to them. However, many

of the comments were caveated with further comments around lack of funding and that there was insufficient resource within the service, or sessions offered to young people and their families.

Some of the respondents felt they were too early in their experience to provide feedback, and others skipped the question, saying it wasn't applicable.

'CIT staff are friendly and pleasant to work with.'

'The therapists and the work they all do is fantastic. It's just a shame there is not more of it as the quality of service is brilliant and the NHS should be very proud of their staff delivering therapies.'

My child received support from speech and language therapy throughout the whole of their time at a special primary and secondary school. They had regular assessments and a planned programme of support, with regular reviews. I have no doubt that this enabled them to make progress and develop. It is so essential that this support starts from a young age - it makes the difference.'

'The knowledge and skill of the CIT staff is unquestionable.'

10. Accessing the Private or Charitable Sector

Q11. If you access therapy/s from the private or charitable sector, why did you feel that your child/young person needed this input? Please specify the therapy you used.

Q12. If you access therapy/s from the private or charitable sector, please tell us how it supported the outcomes you wanted for your child/young person. Please indicate which of the therapies you are referring to.

Over half of respondents indicated that they had made use of private therapists for their child/young person. They gave a range of reasons for doing this and explained how it had (or they hoped it would) supported the outcomes they wanted for their child/young person. Responses covered the range of settings and age groups. What respondents told us can be broadly grouped into the following categories:

Access to NHS services

- Recommended by hospital therapist due to NHS community waiting times.
- Therapy not provided by the NHS despite clear needs.
- To get assessments to secure the correct setting for children with an EHCP.
- Excessive waiting times.
- Lack of timely provision to meet needs.

Quality or effectiveness of NHS/private therapy services

- Child/young people make poor progress as NHS provision is not adequate in terms of quality and quantity.
- NHS service is reactive rather than preventative.
- Seeking a second opinion to get an answer to child/young persons issues.
- NHS therapy not personalised to individual needs, it is not needs led.
- NHS service puts too much demand on Parent Carers to chase it up.
- Private therapy is more proactive, frequent, intense, targeted, measurable, effective and efficient, as no limitations are put on them.
- Private provision offers better communication, including feedback and updates.
- Private therapists communicate and work more effectively with hospital therapists than CIT therapists do.

Other

- Social skills ASD interventions.
- To avoid invasive surgery.
- To improve outcomes including help with feeding, oral motor therapy, lung function, maintain safe transfers, recovery of mobility from surgery, helped child cope in education (improved writing and communication), general mobility, help child walk, pain prevention and preparing for the start of school.

11. Next Steps

Over the coming months OxPCF will continue to work with Oxford Clinical Commissioning Group and Oxfordshire County Council through the Children's Integrated Therapy Project board.

We will work in partnership to use the evidence gathered, from this survey and other information gathering exercise including the focus groups attended by parent carers, to co-produce recommendations with professionals. The aim is for these recommendations to inform and impact the ongoing design and delivery of the Children's Integrated Therapy Service.

We will support the implementation of these recommendations and let parent carers, and those who contributed to the consultation on the Children's Integrated Therapy Service, know what has changed in the design and delivery of the service.

Appendix 1: Survey Questions

Q1. Please tick which therapy service/s your child/young person is accessing or accessed.

Q2. Please indicate if the child/young person is a current user of these services or a previous user?

Q3. Please tick the setting in which your child/young person accesses this service/s.

Q4. Please tell us what problems you have encountered whilst using the Children's Integrated Therapy Service. Please indicate which of the Therapies you are referring to if you access more than one service.

Q5. Please tell us if there is something missing or a gap in the Children's Integrated Therapy service that we need to address? Please indicate which of the therapies you are referring to, if you access more than one service.

Q6. Can you tell us how the problems or gaps that you have encountered, whilst using the Children's Integrated Therapy Services, impacts on the outcomes that you want for your child/young person? Please indicate which of the therapies you are referring to, if you access more than one service.

Q7. Can you tell us how the problems or gaps you have encountered, whilst using the Children's Integrated Therapy Service, impacts on the wellbeing of your family? Please indicate which of the therapies you are referring to, if you use more than one service.

Q8. What might the solutions be to the problems you have told us about, within the Children's Integrated Therapy Service? Please indicate which therapy you are referring to.

Q9. What might the solutions be to the gaps in the Children's Integrated Therapy Service you have told us about? Please indicate which therapy you are referring to.

Q10. Can you tell us what the Children's Integrated Therapy Service is doing well and should therefore keep doing? Please indicate which therapy you are referring to.

Q11. If you access therapy/s from the private or charitable sector, why did you feel that your child/young person needed this input? Please specify the therapy you used.

Q12. If you access therapy/s from the private or charitable sector, please tell us how it supported the outcomes you wanted for your child/young person. Please indicate which of the therapies you are referring to.