

Appendices

Appendix A: Copy of ethics committee's approval letter for the IPA study



Coláiste na Tríonóide, Baile Átha Cliath
Trinity College Dublin

Ollscoil Átha Cliath | The University of Dublin

11/01/2016

Application Academic Year 2015/16

Applicant: Eibhlin Gorman

Title of Research: Parents' perspectives of therapy roles in Speech and Language Therapy.

Dear Eibhlin,

Your fast-track submission for ethics approval for the research project above was considered by the Research Ethics Committee, School of Linguistic, Speech and Communication Sciences, Trinity College Dublin, on Monday, 11 January 2016, and has been approved in full. We wish you the very best in your research activities.

Best wishes,

Dr Lorna Carson
Chair, Research Ethics Committee
School of Linguistic, Speech and Communication Sciences
Trinity College Dublin



An Lárionad Léinn Teanga agus
Cumarsáide,
Scoil na nEolaíochtaí Teangeolaíochta,
Uirlabhra agus Cumarsáide,
Coláiste na Tríonóide,
Baile Átha Cliath 2, Éire

Centre for Language & Communication
Studies,
School of Linguistic, Speech &
Communication Sciences,
Trinity College,
Dublin 2, Ireland

T 353 (0)1 896 1560
F 353 (0)1 896 2941
clsinfo@tcd.ie
www.tcd.ie/silscs/clcs

Appendix B: Participant information leaflet for IPA study



Participant Information Leaflet

An Exploratory Pilot Study of Parents' Perspectives of Therapy Roles in Speech and Language Therapy with School Aged Children with Autism Spectrum Disorders.

What is this information sheet about?

This information sheet gives parents information about a new research project about parents' expectations and experiences of speech and language therapy. You are invited to read this information sheet and decide if you would like to take part.

Why have I been asked to take part?

You have been invited to take part in the study because you have a school-aged child who has a diagnosis of Autism Spectrum Disorder (ASD) and requires speech and language therapy.

What is the study about?

The study looks at parents' opinions about the different people involved in speech and language therapy. It focuses on the role of the parent, the speech and language therapist and the child in therapy. I will be collecting information from parents whose children are attending a school, are aged between 5 and 18 years and have a diagnosis of ASD.

The results will be used to improve speech and language therapists' understanding of working with parents of children with ASD. The information collected will also be used for educational purposes, as part of my doctoral degree/ PhD. The findings may be published.

Who is the researcher?

My name is Eibhlin Gorman. I am a qualified speech and language therapist. I am currently working with children with ASD. I registered for my PhD in 2015 and my PhD supervisor is Dr Martine Smith in Trinity College Dublin.

What does taking part involve?

I would like to meet you and talk to you about your views on speech and language therapy. This would involve one meeting. The meeting will last 60 to 90 minutes. I will begin meeting with parents from January 2016. I will be asking questions about your views and experiences of speech and language therapy. I will also ask you about your opinions on your role in therapy, as well as the role of the speech and language therapist and your child.

This meeting/ interview can take place in your home or any other place that is convenient to you. If you do not wish to answer any questions during the meeting, you can tell me and I will move onto the next question.

The conversation will be tape recorded. I will then type out the conversation. I will send you a copy of the typed out conversation. You can then read this copy and request any changes if you think there are errors.

The information you and other parents involved in the study give, will be analysed to help us learn more about parents' experiences of speech and language therapy. I may use quotations of what you say in the final report but will NOT include your name.

Ref: 18.01.2016

Will my information be confidential?

Everything you say in the interview will remain anonymous and confidential. The only people that will have access to your information will be myself and my supervisor. I will ensure that all information and recordings are stored securely.

The copy of the conversation and all other records will be anonymous. Your name, your child's name and other identifying information will not be used. You can choose another name (pseudonym) which will be used in writing up this research. Any details which identify you or your child in any way, such as place names, names of service providers or the name of the school will not be used.

None of the information you provide will be discussed with your speech and language therapist or your service provider.

Your child's safety will always be a priority. If something is said in the interview that indicates your child is at risk of harm, I will follow the same procedures as all health professionals. I will be obliged to contact the duty Social Worker in your local area to inform them of what was said.

Do I have to take part?

Your involvement in this study is voluntary. You do not have to participate. If you do decide to take part, you can change your mind and stop participating at any point. If you decide to stop taking part, any information you have given and the contents of your interview will be deleted.

What are the benefits of taking part?

Participating in the study will allow you to reflect on the progress your child has made and what role you played in achieving this. By taking part, you will also help improve our understanding of what parents expect and want from therapy and what speech and language therapists can do to improve their practices.

What are the potential risks of taking part?

There are no anticipated, serious risks associated with your involvement in the research. When discussing past negative experiences of speech and language therapy, however, you may become distressed. If this occurs you will be offered the chance to stop the recording and you can withdraw from the study if you wish.

What will happen if I don't take part?

There will be no consequences if you choose not to participate. Deciding to participate or not to participate, will not affect the services your child receives from your speech and language therapist.

Who has reviewed this study?

This study was reviewed by the Ethics Committee for the School of Linguistic, Speech and Communication Science, Trinity College Dublin. Ethical approval was granted on DATE.

Do you have any questions?

If you have any questions please phone me at 0872807444 or alternatively you can email me at gormane@tcd.ie . I would be delighted to answer your queries.

Ref: 18.01.2016



Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

SCHOOL OF LINGUISTIC SPEECH AND COMMUNICATION SCIENCES

Researcher Eibhlin Gorman, Tel: 087-2807444	(PhD Candidate, Trinity College Dublin) Email: gormane@tcd.ie
Research Supervisor Dr. Martine Smith	

Ref: 18.01.2016

Appendix C: Consent form for IPA study



Trinity College Dublin
 Coláiste na Tríonóide, Baile Átha Cliath
 The University of Dublin

Parent Consent Form

Identification Number _____

Research Project: Parents' Perspectives of Therapy Roles in Speech and Language Therapy

Investigator: Eibhlin Gorman (PhD Candidate)

I (full name) confirm the following:

	Please tick
I have read the information leaflet (Ref: 18.01.2016)	
I was able to ask questions and these have been answered satisfactorily.	
I have received enough information about this study.	
I understand that my participation is voluntary.	
I understand that I can withdraw from the study at any point.	
I understand that voice recordings will be made during the interview.	
I understand that the voice recordings will be used by the researcher from Trinity College Dublin and direct quotes from this recording may be used when the study is written up.	
I understand that in the analysis of these recordings my right to privacy will be respected and that the recordings will be kept anonymously.	
I understand that all information collected about me during the course of the research will be kept strictly confidential, and any information about me will have my name, my child's name and other identifying information removed so that I cannot be recognized.	

I consent to taking part in the above named study.

Signature of parent *Printed name* *Date*

This consent form was signed in the presence of:

Signature of researcher *Printed name* *Date*

Copy for parent

Copy for researcher

Appendix D: Interview Schedule

1. Can you tell me about what speech and language therapy support your child is receiving now and what support they have received in the past?
2. What was your best experience of SLT to date?
3. What was your worst experience of SLT to date?
4. Has there ever been a time when your child received no speech and language therapy? Can you tell me about that?
5.
 - a. What does speech and language therapy look like currently for your family?
 - b. What does the speech and language therapist do? Why do you think the he/she is working this way?
 - c. What involvement do you have currently in therapy?
 - d. What role (if any) does your child have in therapy?
 - e. Who else is involved in therapy?
 - f. Where does therapy happen?
 - g. How often does therapy happen? What does this mean for you?
6. In an ideal world, what would speech and language therapy with your child involve?
7.
 - a. Speech and language therapists sometimes work with teachers. What difference (if any) do you see between teachers and speech and language therapists in relation to your child's communication development? What relationship do you think does exist between speech and language therapists and teachers?
 - b. Sometimes SLTs make recommendations for school. What was your experience of this like?
8. Speech and language therapists often use terms like review, therapy, consultation, liaison, training, direct intervention, indirect intervention. Have you ever heard your therapist(s) use these terms? What is your understanding of these terms?
9. What factors do you think impact on the speech and language therapist's involvement with your child?

10.
 - a. What factors impact on your involvement in therapy?
 - b. What factors impact on your child's involvement in therapy?
11. Speech and language therapists sometimes work with parents only and the child is not present at all appointments. Have any of your speech and language therapists worked this way? Tell me about this.
12. Sometimes speech and language therapists work in schools. Have any of your speech and language therapists worked in your child's school? Tell me about this.
13. Speech and language therapists often use terms like speech, language and communication. What is your understanding of these terms?
14. What do you think are the most important things that help your child to continue to develop their communication skills?
15. When (if ever) will you know that speech and language therapy is no longer needed?
16. How would you describe working with speech and language therapists? What do you wish speech and language therapists knew/ did more of?
17. Have your expectations of speech and language therapy changed since you your child was first referred for therapy? How?
18.
 - a. What impact (positive or negative) has speech and language therapy made on your child?
 - b. What impact (positive or negative) has speech and language therapy made on you personally?
19. What is/ should be different about speech and language therapy, now that your child is a little bit older?
20. What is/ should be different about speech and language therapy because of your child's diagnosis of Autism Spectrum Disorder?

21. They are talking about changing disability services in Ireland. If this goes ahead, it is hoped that services will then be provided more locally so that people have to travel less to see therapists. It also means your child's speech and language therapist would work with children that have a variety of different disabilities. What are your thoughts on this?
22. Finally, can you list the top five things that you are worried about at the moment? If we add your child's communication to that list, what number would it be?

Appendix E: Transcription Key

Symbol	Meaning
...	Pause.
[whole word or phrase]	Nonverbal behaviour. This may refer to laughing, crying etc., as well as the behaviours such as pointing or showing something.
<u>Text Underlined</u>	Stressed intonation or emphasised word in utterance.
<unintelligible speech>	Speech not intelligible and not possible to transcribe.
word-	Incomplete word or utterance. Typically constitutes the speaker being interrupted or suddenly discontinuing this word or utterance and starting a new word or utterance.
I	Interviewer.
R	Respondent.
[Bold text]	Exact verbatim text not included and a description given instead in order to protect anonymity. For example, [town name] may be used rather than giving the specific named town.
Emm	hesitation or filler

Appendix F: Sample of Initial Noting from Gloria's Transcript

Gloria Interview Transcription - Excel Eibhlin Gorman

File Home Insert Page Layout Formulas Data Review View Help Table Design Tell me what you want to do Share

C946 So I based all my ... Excuse me [coughs] - I suppose my helping Jake on the

	A	B	C	D	E	F	G	H
1	Line No	Speaker	Original Transcript	Descriptive Notes	Linguistic Notes	Conceptual Notes	Possible Emerging Themes	Possible Emerging Themes
946	941	R:	So I based all my ... Excuse me [coughs] - I suppose my helping Jake on the		my helping - who else is helping? Do different helpers have different types of helping?	Gloria as helping Jake's development	helping communication along	
947	942		Hanen programme and I, I- It was so difficult, because he, he, you know - You're			Trying Hanen strategies and feeling like they're not working - why does she feel this way?	not seeing progress	therapy involvement can be hard
948	943		trying to intrude on his work or ... you know trying to do other stuff, you know,					
949	944		he would- He just didn't mind, you know. He had his own agenda -					
950	945	I:	Mmm					
951	946	R:	All the time ... emm you know he was always an own agenda child. He was	Not feeling like Jake has progressed through Hanen stages		understandings what autism looks like for Jake	not seeing progress	autism and Jake
952	947		never you know ... a, a requester. He was never - I still don't think he's moved					
					really hard -			

Themes Transcription People Involved Key Possible gems Thoughts

Edit Display Settings 95%

Type here to search Rain... 14:48 08/01/2022 ENG

Gloria Interview Transcription - Excel Eibhlin Gorman

File Home Insert Page Layout Formulas Data Review View Help Table Design Tell me what you want to do Share

C952 never you know ... a, a requester. He was never - I still don't think he's moved

	A	B	C	D	E	F	G	H
1	Line No	Speaker	Original Transcript	Descriptive Notes	Linguistic Notes	Conceptual Notes	Possible Emerging Theme	Possible Emerging Theme
952	947		never you know ... a, a requester. He was never - I still don't think he's moved					
953	948		past that to be honest, you know. He does his own thing. So it was really hard		really hard - difficult to keep trying and feel like its not working?		hope	therapy involvement can be hard
954	949		to get- to try and get in and -					
955	950	I:	Mmm					
956	951	R:	Involve yourself in his stuff. Emm and I just didn't know how to. And Hanen is		I just didn't know how to - is this how the activity?		implementer of new ideas	confidence
957	952		great ... but you know when she told me that, "Oh you're doing a great job" - And it					
958	953		wasn't just me. It's my two friends- Brenda will tell you the same. "You're doing		wasn't just me - does she feel I might not believe her?	Repeatedly assures me that her friends have had the same experiences - why? To show me it's not a one off experience; that it's not her being difficult?		
					if I was doing a	success in fulfilling		

Themes Transcription People Involved Key Possible gems Thoughts

Ready Display Settings 95%

Type here to search Rain... 14:49 08/01/2022 ENG

Gloria Interview Transcription - Excel Eibhlin Gorman

File Home Insert Page Layout Formulas Data Review View Help Table Design Tell me what you want to do Share

C964 X ✓ fx Yeah. He- If I'm doing such a great job then why is his speech not coming on?

	A	B	C	D	E	F	G	H
1	Line No	Speaker	Original Transcript	Descriptive Notes	Linguistic Notes	Conceptual Notes	Possible Emerging Themes	Possible Emerging Themes
959	954		a great job." You know if I was doing a great job, I wouldn't still need to bring my	guilt	if I was doing a great job I wouldn't still need to bring my child here - again very binary thought process	success in fulfilling her role equals not needing to come to therapy; does coming to therapy signal failure in her role already?	guilt	understandings of therap
960	955		child here ...					
961	956	I:	That's what it felt like?					
962	957	R:	Yeah.					
963	958	I:	Ok					
964	959	R:	Yeah. He- If I'm doing such a great job then why is his speech not coming on?		why is his speech not coming on	what is gloria's understanding of language disorders and what impacts on language development?	understanding communication	guilt
965	960	I:	Mmm			taking all blame and responsibility for Jake's perceived	understanding	

Themes Transcription People Involved Key Possible gems Thoughts

Ready Display Settings 95%

Type here to search Rain... 14:51 08/01/2022 ENG

Gloria Interview Transcription - Excel Eibhlin Gorman

File Home Insert Page Layout Formulas Data Review View Help Table Design Tell me what you want to do Share

C966 Do you know what I mean? Why is his language - Why is his comprehension not

	A	B	C	D	E	F	G	H
1	Line No	Speaker	Original Transcript	Descriptive Notes	Linguistic Notes	Conceptual Notes	Possible Emerging Theme	Possible Emerging Theme
966	961	R:	Do you know what I mean? Why is his language - Why is his comprehension not			taking all blame and responsibility for Jake's perceived limited progress	understanding communication	guilt
967	962		coming on?					
968	963	I:	Mmm					
969	964	R:	You know, if I'm doing such a fantastic job - Yeah, I was using the strategies ... I					
					given - why does she emphasise this word? It almost feels like she is chastising herself that the fact that she needed to be given the strategies and that she didn't naturally have them. Or is it that she feels she held up her end of the	Linking child's progress to her own role		

Themes Transcription People Involved Key Possible gems Thoughts

Ready Display Settings 95%

Type here to search Rain... 14:58 08/01/2022

Gloria Interview Transcription - Excel Eibhlin Gorman

File Home Insert Page Layout Formulas Data Review View Help Table Design Tell me what you want to do Share

C971 but you know "Ok we'll tick her off our list now. She's done." Yeah ... You know

	A	B	C	D	E	F	G	H
1	Line No	Speaker	Original Transcript	Descriptive Notes	Linguistic Notes	Conceptual Notes	Possible Emerging Theme	Possible Emerging Theme
970	965		was <u>given</u> , but ... you know, emm that just - It was just- Not even condescending		given - why does she emphasise this word? It almost feels like she is chastising herself that the fact that she needed to be given the strategies and that she didn't naturally have them. Or is it that she feels she held up her end of the bargain?	Linking child's progress to her own role performance	guilt	
971	966		but you know "Ok we'll tick her off our list now. She's done." Yeah ... You know		tick list; she's done - therapist working off a to-do list rather than with people?		negative attitudes of professionals	

Themes Transcription People Involved Key Possible gems Thoughts

Ready Display Settings 95%

Type here to search Rain... 14:59 08/01/2022 ENG

Gloria Interview Transcription - Excel Eibhlin Gorman

File Home Insert Page Layout Formulas Data Review View Help Table Design Tell me what you want to do Share

C975 and she'd say, "Ok so what's the plan for today?" Right? And "Oh well we'll just

1	A	B	C	D	E	F	G	H
Line No	Speaker	Original Transcript	Descriptive Notes	Linguistic Notes	Conceptual Notes	Possible Emerging Theme	Possible Emerging Theme	
972	967	just because they thought you could. And the OT's were <u>exactly</u> the same. And	comparing professionals	you could - professional views you as competent even if you don't feel competent yourself		professionals as a group	power or powerlessness	
973	968	they said the same things to you know, friends of mine as well ... emm and a girl	Talking to other parents about therapists		Again assures me this wasn't just her. Why?			
974	969	I know who would say to the speech and language therapist Nuala- She'd go in						
975	970	and she'd say, "Ok so what's the plan for today?" Right? And "Oh well we'll just		plan - repeatedly refers to this	Looking for certainty, something more concrete? Is this important for hope or stemming from mistrust of the particular professional?	focus on concrete	a plan	
				actually going to do - why actually? Discrepancy				

Themes Transcription People Involved Key Possible gems Thoughts

Ready Display Settings 95%

Type here to search Rain... 15:00 08/01/2022 ENG

Gloria Interview Transcription - Excel Eibhlin Gorman

File Home Insert Page Layout Formulas Data Review View Help Table Design Tell me what you want to do Share

C981 and everybody talks.

Line No	Speaker	Original Transcript	Descriptive Notes	Linguistic Notes	Conceptual Notes	Possible Emerging Themes	Possible Emerging Themes
976	971	see what it is?" "But what are we actually going to do today?" Because there was		actually going to do - why actually? Discrepancy between what is said and done?		expecting the therapist to do something	
977	972	just- There was no plan ...		no plan		trust	
978	973	I: Mmm					
979	974	R: You know and every - And the problem with, you know when we meet at				us/ them	
980	975	[name of parent organisation]. You run into people here, there and everywhere,	Talking to other parents about therapists		Does this add to the mistrust of professionals?	talking to other parents	trust
981	976	and everybody talks.		everybody talks - everybody in the parent group that Gloria belongs to or everybody in general?			us/ them
982	977	I: Mmm					
983	978	R: And then you hear the same story and you go, "Oh my God, it's not just me!"		not just me	feeling alone?	feeling alone/ different	
984	979	And you just think, "It's always me. I'm the one always giving out," and you know,		I'm the one	Feeling that you're difficult/ seen as difficult	guilt	

Themes Transcription People Involved Key Possible gems Thoughts

Ready Display Settings 95%

Type here to search Rain... 15:01 08/01/2022

Gloria Interview Transcription - Excel Eibhlin Gorman

File Home Insert Page Layout Formulas Data Review View Help Table Design Tell me what you want to do Share

C989 that this is what we have to work with and no guarantees at the end of it- It's

	A	B	C	D	E	F	G	H
1	Line No	Speak	Original Transcript	Descriptive Notes	Linguistic Notes	Conceptual Notes	Possible Emerging Theme	Possible Emerging Theme
985	980		but then you hear it from somebody else and you just think, "I'm <u>not</u> going		I'm not going crazy	Does the discrepancy between expectations and perceived reality make Gloria feel like she is going crazy?	mental health	expectations not met
986	981		crazy." You know, she- I <u>am</u> - What I'm feeling is right, you know ... She is saying,		what I'm feeling is right - why was she questioning this?	why was she questioning her feelings?	mental health	expectations not met
987	982		"Oh you're doing a great job" and whatever and nothing else is being done ... you		nothing else is being done	what does Gloria want to be done? Is it direct therapy or more concrete, individualised ideas?	hope	trust
988	983		know. Whereas if a <u>plan</u> was in place; they <u>explain</u> things to parents, you know	Communicating with parents	plan again		a plan	
						Gloria appears to be acknowledging that she knows that		

Themes **Transcription** People Involved Key Possible gems Thoughts

Ready Display Settings 95%

Type here to search Rain... 15:02 08/01/2022

Gloria Interview Transcription - Excel

Eibhlin Gorman

File Home Insert Page Layout Formulas Data Review View Help Table Design Tell me what you want to do

C992 You know? "Gloria there are no guarantees ... But the odds are like 70 to 30."

	A	B	C	D	E	F	G	H
1	Line No	Speaker	Original Transcript	Descriptive Notes	Linguistic Notes	Conceptual Notes	Possible Emerging Themes	Possible Emerging Themes
989	984		that this is what we have to work with and <u>no</u> guarantees at the end of it- It's		no guarantees - this is repeated. Is this Gloria trying to signal to me that she knows there's no "magic wand"?	Gloria appears to be acknowledging that she knows that there is a chance that therapy might not bring about the changes she is hoping for but she still wants to feel that she has tried.	no certainty	hope
990	985		like my back operation.					
991	986	I:	Mmm					
992	987	R:	You know? "Gloria there are <u>no</u> guarantees ... But the odds are like 70 to 30."		no guarantees - understands Jake may or may not respond or does this language indicate he may or may not dramatically improve?	Odds- Gamble of therapy or gamble of life?	hope	

Themes Transcription People Involved Key Possible gems Thoughts

Ready

Type here to search

Display Settings 95%

Rain... 15:03 08/01/2022

Gloria Interview Transcription - Excel Eibhlin Gorman

File Home Insert Page Layout Formulas Data Review View Help Table Design Tell me what you want to do Share

C999 Yeah

	A	B	C	D	E	F	G	H
1	Line No	Speak	Original Transcript	Descriptive Notes	Linguistic Notes	Conceptual Notes	Possible Emerging Them	Possible Emerging Theme
993	988		They were good enough odds for me to do it, you know?		odds for me to do it - to take the risk, to invest the time and energy	costs/ benefits appraisal?	hope	costs/ benefits
994	989	I:	Mmm					
995	990	R:	And - It's just being very up front. Obviously without crashing the parents' spirit	Being direct and honest with parents	very up front	Balance between being direct and dashing hopes all together	professionals not being straight	hope
996	991		like-					
997	992	I:	No					
998	993	R:	No, we're not going to- You know-					
999	994	I:	Yeah					
					a bit empowered - does this imply she didn't feel empowered? Give them something - is therapy gifted to parents? Does this tell me anything about	What is the difference between empowering someone and giving them hope; you can be hopeful but not empowered but can you be		

Themes Transcription People Involved Key Possible gems Thoughts

Ready Display Settings 95%

Type here to search Rain... 15:04 08/01/2022 ENG

Gloria Interview Transcription - Excel Eibhlin Gorman

File Home Insert Page Layout Formulas Data Review View Help Table Design Tell me what you want to do Share

C999 Yeah

1	Line No	Speaker	Original Transcript	Descriptive Notes	Linguistic Notes	Conceptual Notes	Possible Emerging Theme	Possible Emerging Theme
1000	995	R:	Just to, to give them something that they come away feeling a bit empowered		a bit empowered - does this imply she didn't feel empowered? Give them something - is therapy gifted to parents? Does this tell me anything about perceptions of power?	What is the difference between empowering someone and giving them hope; you can be hopeful but not empowered but can you be empowered without hope?	hope	power or powerlessness
1001	996		that ... you know "This isn't so difficult to do. I can, I can work on this at home or	Feasible and attainable responsibilities and involvement	I - again this points to a desire to take an active role	being asked to do something that's doable	gloria taking active role	feasible versus impossible involvement
1002	997		...You know and we can"- Rather than the whole thing - "This is your issue Eibhlin		we - so the difference here is not me and you but rather us and you ... whole thing - 100% burden on parent	who carries the responsibilities?	taking all the burden alone	

Themes Transcription People Involved Key Possible gems Thoughts

Ready Display Settings 95%

Type here to search Rain... 15:05 08/01/2022

Gloria Interview Transcription - Excel Eibhlin Gorman

File Home Insert Page Layout Formulas Data Review View Help Table Design Tell me what you want to do Share

C999 X ✓ fx Yeah

	A	B	C	D	E	F	G	H
1	Line No	Speak	Original Transcript	Descriptive Notes	Linguistic Notes	Conceptual Notes	Possible Emerging Theme	Possible Emerging Theme
1003	998		and if, if you can't do this at home well then your child is going to suffer." And	guilt	your child is going to suffer - this is very emotive	Certainly doesn't feel like Gloria perceived herself to be in any form of equal partnership with professionals here.	guilt	taking all the burden alone
1004	999		that's exactly [inhales loudly] what it was. Probably because of the amount of kids					
1005	1000		they have, the volume of kids. They just couldn't give the individual attention. I	resources dictating approach			public v private	money
1006	1001		don't know.					
1007	1002	I:	And is that what it felt like? That, that approach was taken because of the					
1008	1003		volume of children they were seeing?					
1009	1004	R:	I think that- For definitely the model, the overall model of the parents for, for	Professionals juggling responsibility to caseload versus individual			public v private	money
1010	1005		all four disciplines were ... "That was the model that we're going to use because		going to use - professionals as decision-makers		power or powerlessness	
				number of children				

Themes Transcription People Involved Key Possible gems Thoughts

Ready Display Settings 95%

Type here to search Rain... 15:06 08/01/2022

Appendix G: Sample of Initial Noting from Mila's Transcript

Mila transcript - Excel

File Home Insert Page Layout Formulas Data Review View Help Table Design Tell me what you want to do

Eibhlin Gorman

C334 a rushed decisions at that time. And if I would know more and if I would get

1	A	B	C	D	E	F	G	H
Line No	Speak	Original Transcript	Descriptive Notes	Linguistic Notes	Conceptual Notes	Possible Emerging Theme	Possible Emerging Themes	
284	280	R: I couldn't get past emm, emm, emm through that autism and emm ... But living		Couldn't get past/ through - stuck, force past; not easy; sense of loss of power here, needs help to move; autism feels like a physical force here/ an object.	meaning of autism at time of diagnosis	power	trying to get past	
285	281	the you know and doing the therapies and doing the research and you know,	Finding a way forward after diagnosis			power	trying to get past	
286	282	doing all the, the, the emm the programmes for parents and looking and	Parent programmes and knowing more about autism give mum power to move again		Here is mum saying that participation in therapy helped her as well- helped her to be able to adjust to the	power	trying to get past	
					Why does mum separate the parent programmes from knowing more? Does this signal that her 'knowing' did not come from the parent			

Themes Transcription People Involved Key Possible gems Thoughts

Ready Accessibility: Investigate

Type here to search

Rain... 15:58 22/01/2022

Mila transcript - Excel

Table Tools

Eibhlin Gorman

File Home Insert Page Layout Formulas Data Review View Help Table Design Tell me what you want to do Share

A287 283

1	A	B	C	D	E	F	G	H
Line No	Speak	Original Transcript	Descriptive Notes	Linguistic Notes	Conceptual Notes	Possible Emerging Theme	Possible Emerging Themes	
287	283	knowing more about it emm ... We are incredibly lucky-		Lucky	Why does mum separate the parent programmes from knowing more? Does this signal that her 'knowing' did not come from the parent programmes but only from her own research?	lucky	knowing more	
288	284	l: Mmm			Why does she equate being lucky with very basic needs being met? Did she fear or expect that Nina wouldn't gain these basic skills? Or she highlighting that she tries to look at all that Nina CAN do ... Is she showing that Nina is different from the			

Themes Transcription People Involved Key Possible gems Thoughts

Ready Accessibility: Investigate

15:58 22/01/2022

Mila transcript - Excel

Table Tools

Eibhlin Gorman

File Home Insert Page Layout Formulas Data Review View Help Table Design Tell me what you want to do Share

A289 285

1	A	B	C	D	E	F	G	H
Line No	Speak	Original Transcript	Descriptive Notes	Linguistic Notes	Conceptual Notes	Possible Emerging Theme	Possible Emerging Themes	
289	285	R: With, with Nina because she is verbal. She sleeps. Emm she eats.	Nina has basic skills so they are lucky		Why does she equate being lucky with very basic needs being met? Did she fear or expect that Nina wouldn't gain these basic skills? Or she highlighting that she tries to look at all that Nina CAN do ... Is she showing that Nina is different from the version of autism she imagines/ ed?	lucky	trying to get past	
290	286	I: Mmm			We can work - Mum feels confident and hopeful that she has the ability but just needs the support. What does this support look like- is it			

Themes Transcription People Involved Key Possible gems Thoughts

Ready Accessibility: Investigate

Type here to search

Rain... 15:59 22/01/2022 ENG

Mila transcript - Excel

Table Tools

Eibhlin Gorman

File Home Insert Page Layout Formulas Data Review View Help Table Design Tell me what you want to do Share

A291 287

Line No	Speak	Original Transcript	Descriptive Notes	Linguistic Notes	Conceptual Notes	Possible Emerging Theme	Possible Emerging Themes
291	R:	Emm and the rest, we, we can work on it. But we need the support there and I	feeling unsupported	We can work - Mum feels confident and hopeful that she has the ability but just needs the support. What does this support look like- is it someone to direct, offer reassurance, have answers???		back up	
292		feel we are not getting it.				back up	
293	I:	Mmm					
294	R:	And that's very upsetting because emm I am busting my bum, literally doing my	Mum working hard;	I am busting my bum - Physical pain again.	involvement in therapy is hard work	busting my bum	
295		own research and doing visuals and doing you know, what I can-	Mum as researcher; Mum as maker of visuals.	What I can - Limit here, mum can only do so much, not everything.		busting my bum	
296	I:	Mmm				busting my bum	
				I don't mind - Willing to do this ... Back-Up -			

Themes Transcription People Involved Key Possible gems Thoughts

Ready Accessibility: Investigate

Type here to search

Rain... 16:00 22/01/2022

Mila transcript - Excel

Table Tools

Eibhlin Gorman

File Home Insert Page Layout Formulas Data Review View Help Table Design Tell me what you want to do Share

A297 293

Line No	Speak	Original Transcript	Descriptive Notes	Linguistic Notes	Conceptual Notes	Possible Emerging Theme	Possible Emerging Themes
297	293	R: To help her ... But ... And I don't mind doing that, but I need back-up and I need		I don't mind - Willing to do this ... Back-Up - military/ sporting language here. Feels like mum is the first attack sent in, with no one behind her to come in if she falls ... Switch from we to I here- Back up from Dad or professionals?	importance of feeling supported	busting my bum	back up
298	294	to know-					
299	295	I: Mmm					
300	296	R: That if I - we need help, it's going to be there and I don't want to be chasing	Wanting readily available support	Switch back to we here ... chasing again - one sided game in which Mila is always doing the chasing?	Lack of confidence in professionals; unsure if help will be available when needed unless she goes and finds it.	uncertainty	chasing
					Somebody - does this suggest a need for an allocated,		

Themes Transcription People Involved Key Possible gems Thoughts

Ready Accessibility: Investigate

Type here to search

Rain... 16:01 22/01/2022

Mila transcript - Excel

Table Tools

Eibhlin Gorman

File Home Insert Page Layout Formulas Data Review View Help Table Design Tell me what you want to do

A305 301

Line No	Speak	Original Transcript	Descriptive Notes	Linguistic Notes	Conceptual Notes	Possible Emerging Theme	Possible Emerging Themes
301	297	anybody. I want it to be there and if emm there will be a problem or somebody		Chasing - suggests mum is alone, searching for help and all the others are running away from her.	Somebody - does this suggest a need for an allocated, accountable person rather than 'an institution' such as the HSE where accountability might be lost?	anonymous system	chasing
302	298	will be telling me, "Ok we will touch base with you." ...	support	Telling me - directive ... touch base - sporting language again	does Mila feel that she has to initiate everything; that if she didn't she would be left alone,	back up	chasing
303	299	I: Mmm					
304	300	R: "And we will see how she's progressing and emm we will re-jig the programme	support		Does this suggest that professionals need to be reminded that her child will progress and isn't static? Is this linked to hope?	back up	hope
305	301	for her and- or we will just work on it and she will have more sessions ... as			support to help Nina progress	back up	quantity of therapy
				As much as she			

Themes Transcription People Involved Key Possible gems Thoughts

Ready Accessibility: Investigate

Type here to search

Rain... 16:01 22/01/2022

Mila transcript - Excel

Table Tools

Eibhlin Gorman

File Home Insert Page Layout Formulas Data Review View Help Table Design Tell me what you want to do

A306 302

1	A	B	C	D	E	F	G	H
	Line No	Speak	Original Transcript	Descriptive Notes	Linguistic Notes	Conceptual Notes	Possible Emerging Theme	Possible Emerging Themes
306	302		much as she will need."		As much as she needs - suggests that she does not get what she needs now.		back up	quantity of therapy
307	303	I:	Mmm					
308	304	R:	That's what I want. And it makes me very angry that we are not getting it ...	anger	We- Service needed for family not just child; Mum's anger		anger	
309	305	I:	And you've used the word 'chasing' twice.					
310	306	R:	I know.					
311	307	I:	Does that- That's what it feels like?					
312	308	R:	It is because even ... and even when we got emm the autism diagnosis first,					chasing
313	309		and I said "Ok. Where are we going?" Like "What do I need to-" Like nobody	Let down		feel like a lack of plan or certainty from professionals	back up	chasing
						In some ways does this feel like too much is left in the hands of the parent, almost as if they have a choice of services etc when this is not really the case unless the choice is		

Themes Transcription People Involved Key Possible gems Thoughts

Ready Accessibility: Investigate

90%

Type here to search

Rain... 16:02 22/01/2022

Mila transcript - Excel

Table Tools

Eibhlin Gorman

File Home Insert Page Layout Formulas Data Review View Help Table Design Tell me what you want to do Share

A314 310

Line No	Speak	Original Transcript	Descriptive Notes	Linguistic Notes	Conceptual Notes	Possible Emerging Theme	Possible Emerging Themes
314	310	told us, "Ok. Well, <u>that's what happened.</u> <u>That's what Nina needs.</u> We will			In some ways does this feel like too much is left in the hands of the parent, almost as if they have a choice of services etc when this is not really the case unless the choice is between public and private?	back up	chasing
315	311	emm, emm send ... emm we will send emm her reports <u>there</u> and we will					
316	312	secure- Or we will secure- No I don't mean we will <u>secure</u> her place.		Secure - protect; bring comfort and feeling of safety rather than uncertainty and feeling of uncertainty and danger?		uncertainty	back up
317	313	I: Mmm				uncertainty	back up
				Take her on- this almost feels like take on a challenge; or even			

Themes Transcription People Involved Key Possible gems Thoughts

Ready Accessibility: Investigate

Type here to search

Rain... 16:02 22/01/2022

Mila transcript - Excel

Table Tools

Eibhlin Gorman

File Home Insert Page Layout Formulas Data Review View Help Table Design Tell me what you want to do

A318 314

Line No	Speak	Original Transcript	Descriptive Notes	Linguistic Notes	Conceptual Notes	Possible Emerging Theme	Possible Emerging Themes
318	R:	I- It's just they will take her on, and that's what's going to happen. It, it, it	Not knowing what will happen next	Take her on- this almost feels like take on a challenge; or even a physical support taking over the weight that Mila is carrying		uncertainty	back up
319		doesn't work like that. They will give you suggestion ... sort of, but then it's up		Suggestion sort of- Mum here feels like she direction or more action on the part of the professionals. ?medical model?	What kind of a suggestion is it when the choices are so binary?	falsehood of choice	paperwork
320		to you as a parent to do all the paper work and all the- And especially I - Like it	Parent taking on all the work... Paperwork			uncertainty	paperwork
321		was absolutely overwhelming emm, emm for us ... And emm I sort of felt ok	Feeling overwhelmed/ Not knowing what to do			uncertainty	paperwork
322		she was at the - in emm a preschool at that time and emm I was like, ok so I				uncertainty	
323		was- I didn't know the system, Emm ... We ... I sort of felt ok she- We need to	Not knowing the system			uncertainty	
				get help for her-			

Themes Transcription People Involved Key Possible gems Thoughts

Ready Accessibility: Investigate

Type here to search

Rain... 16:03 22/01/2022 ENG 90%

Mila transcript - Excel

Table Tools

Eibhlin Gorman

File Home Insert Page Layout Formulas Data Review View Help Table Design Tell me what you want to do

A324 320

Line No	Speak	Original Transcript	Descriptive Notes	Linguistic Notes	Conceptual Notes	Possible Emerging Theme	Possible Emerging Themes
324	320	get help for her emm in, in a preschool-		get help for her-help is external not something that Mila can offer alone in her current circumstances		uncertainty	external help
325	321	I: Mmm					
326	322	R: So we made rushed decisions... And emm I - Especially I did ... Emm we, we	Time pressure	rushed decisions	Does this signify an experience of guilt?	uncertainty	guilt
327	323	met- Like I knew emm, emm other, other mums from the preschool -				uncertainty	
328	324	I: Mmm					
329	325	R: And emm, I, I you know, I was sort of - She was giving me advice.	Being advised by other parents not professionals		informal support rather than professionals/ service acting as a support	uncertainty	back up
330	326	I: Mmm					
331	327	R: She did. You know. Nobody else.	Advice coming from other parents not professionals. Feeling alone.	nobody else			back up
332	328	I: Mmm					
333	329	R: And I just thought like, "You need to do this, this and this." And emm we made		Rushed decisions - why rushed; feeling that time		uncertainty	

Themes Transcription People Involved Key Possible gems Thoughts

Ready Accessibility: Investigate

Type here to search

Rain... 16:03 22/01/2022 ENG

Appendix H: Copy of ethics committee's approval letter for the survey studies



Trinity College Dublin

Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Application: Academic Year 2018/19
Application Code: HT22 and HT 23
Applicant/Supervisor Name: Eibhlin Gorman (PhD Student); Martine Smith (Supervisor)

Titles of Research Projects:

1. speech and Language Therapy Care Pathways for Children with Autism Spectrum Disorders in Ireland (HT22)
2. Parent Expectations and Understandings of Speech and Language Therapy (HT23)

Date of this letter: 16th April, 2019

Dear Eibhlin,

Your submissions for ethics approval for the two research projects listed above (HT22 & HT23) were considered by the Research Ethics Committee (REC), School of Linguistic, Speech and Communication Sciences, Trinity College Dublin, on April 16th 2019, and have now been approved in full.

Please note

- (i) that on completion of research projects, applicants should complete the *End of Project Report Form* (which can be found at: <https://www.tcd.ie/slscs/research/ethics/>) and submit one signed hard copy for each project to the School Office (Room 4091, Arts Building) as well as an electronic copy for each project (to slscs@tcd.ie)
- (ii) the REC requests that you attend, in particular, to your commitments as regards the storage and destruction of data arising from this research, in keeping with REC policy and General Data Protection Regulation (GDPR) guidelines.

We wish you every luck with your research,

Best wishes,

Professor Irene P. Walsh

Chair, Research Ethics Committee, School of Linguistic, Speech and Communication Sciences

Scoil na nEolaíochtaí Teangeolaíochta,
Urrlabhra agus Cumarsáide,
Coláiste na Tríonóide,
Baile Átha Cliath 2, Éire

School of Linguistic, Speech &
Communication Sciences,
Trinity College,
Dublin 2, Ireland

T 353 (0)1 896 1560
slscs@tcd.ie
www.tcd.ie/slscs

Appendix I: Information provided to potential respondents of parent survey

Expectations of Speech and Language Therapy

WHAT IS THIS SURVEY ABOUT?

This survey is designed to gain information about parents' expectations of speech and language therapy for children in the Republic of Ireland. In particular it is interested in what parents expect of the speech and language therapist and what role (if any) they expect parents to have in speech and language therapy for children.

WHO IS THIS SURVEY FOR?

This survey seeks to get information from parents who have never worked with a speech and language therapist before. These may be parents whose children have no reason to see a speech and language therapist or parents whose children are waiting to be seen for the first time by a speech and language therapist.

HOW LONG WILL IT TAKE?

This survey should take 10 – 15 minutes to complete.

WHY IS THIS DATA BEING COLLECTED?

The data collected will be used as part of a PhD research study being conducted by Eibhlin Gorman (Speech and Language Therapist and PhD Candidate). This wider PhD project aims to explore the experiences of parents of children with Autism Spectrum Disorders = who are accessing speech and language therapy in Ireland. In particular the project focuses on parents' perception of their role in therapy. The data may be published as part of this research project and/ or presented at research conferences. As the data may be used for publication, any data collected will be retained securely for a five-year period to comply with potential audits from publishers.

WHAT DOES TAKING PART INVOLVE?

Taking part in this survey will involve giving 10 minutes of your time. You will be asked to provide information about what work you imagine a speech and language therapist to do, what work you imagine parents do, as well as general expectations and understandings about speech and language therapy.

WHAT ARE THE RISKS AND BENEFITS INVOLVED?

You may risk developing inattention or temporary fatigue by taking part. If you have a child who is waiting for a speech and language therapy assessment you may become anxious when completing this questionnaire, as you may begin to think about your child and the reasons they require an assessment. However, participating may help to improve the information provided to parents who are awaiting their child's first assessment. This may help to improve user experiences of the health service.

WILL MY ANSWERS BE CONFIDENTIAL?

Yes. All information gathered will be anonymous. Details regarding your country of residence are requested. However, identifying information such as names of participants or exact geographic areas are not required. All data collected will be held confidentially and individual survey responses will only be available for view by the researcher and her research supervisor (Dr. Martine Smith)

IS PARTICIPATION VOLUNTARY?

Yes. You can withdraw from the survey at any point by ceasing to respond to the survey questions. However, any information provided prior to the point of withdrawal will be saved and cannot be deleted.

WHO CAN I CONTACT FOR MORE INFORMATION?

You can contact Eibhlin Gorman at gormane@tcd.ie. Alternatively, you can contact Martine Smith

(mmsmith@tcd.ie)

EU General Data Protection Regulations (GDPR) Statement:

Please note that no personal data will be stored or retrieved for the purposes of this research. Data held will be anonymous and stored confidentially.

Appendix J: Information provided to potential respondents of SLT
survey

SLT Services for Children with ASD in Ireland

WHAT IS THIS SURVEY?

This survey is designed to gain information about the type of speech and language therapy services available to children with Autism Spectrum Disorders (ASD) in the Republic of Ireland. In particular it seeks to gather information about pathways of care available to children with ASD in Ireland.

HOW LONG WILL IT TAKE?

This survey should take 5 to 15 minutes to complete.

WHY IS THIS DATA BEING COLLECTED?

The data collected will be used as part of a PhD research study being conducted by Eibhlin Gorman (Speech and Language Therapist and PhD Candidate). This wider PhD project aims to explore the experiences of parents of children with ASD who are accessing speech and language therapy in Ireland. In particular the project focuses on parents' perception of their role in therapy. The data may be published as part of this research project and/ or presented at research conferences. As the data may be used for publication, any data collected will be retained securely for a five-year period to comply with potential audits from publishers.

WHAT DOES TAKING PART INVOLVE?

Taking part in this survey will involve giving 5 - 15 minutes of your time. You will be asked to provide information about how your current service provides SLT assessment and intervention for children with ASD.

WHAT ARE THE RISKS AND BENEFITS INVOLVED?

You may risk developing inattention and temporary fatigue by taking part. However, partaking will help to map current service provision for children with ASD in Ireland and help build understanding about the types of intervention provided in Ireland for children with ASD.

WILL MY ANSWERS BE CONFIDENTIAL?

Yes. All information gathered will be anonymous. Details regarding the type of service and general geographic area are requested. However, identifying information such as names of participants, employers or exact geographic are not required. All data collected will be held confidentially and individual survey responses will only be available for view by the researcher and her research supervisor (Dr. Martine Smith).

IS PARTICIPATION VOLUNTARY?

Yes. You can withdraw from the survey at any point by ceasing to respond to the survey questions. However, any information provided prior to the point of withdrawal will be saved and cannot be deleted.

WHO CAN I CONTACT FOR MORE INFORMATION?

You can contact Eibhlin Gorman at gormane@tcd.ie . Alternatively you can contact Martine Smith at mmsmith@tcd.ie .

Appendix K: Copy of Parent Questionnaire

Do you consent to taking part in this survey?

- Yes
- No

Do you confirm that you are over 18 years?

- Yes
- No

Is this the first time that you have completed this questionnaire?

- Yes
- No

Are you the parent of a child under 18 years?

- Yes
- No

Do you live in the Republic of Ireland?

- Yes
- No

Do you have any direct experience of working with a speech and language therapist?

- Yes, my child is waiting for an assessment by a speech and language therapist.
- Yes, my child attends or attended a speech and language therapist
- Yes, I attended speech and language therapy
- No
- Other

Speech and Language Therapists Working with Children

Please choose the pictures below that show how you think a speech and language therapist works. You can choose as many pictures as you wish.





Speech and Language Therapists Working with Children (Part 2)

How confident are you that you understand the role of a speech and language therapist?

1

5

1= Not confident at all; 2 = a little confident; 3= fairly confident; 4= certain; 5 = very certain

Please choose which professional you think is most similar to a speech and language therapist. You can choose as many as you wish.

- Teacher
- Doctor
- Nurse
- Child Minder
- Occupational Therapist
- Physiotherapist
- Psychologist
- Counsellor
- Other:

Tick the areas that you think that a speech and language therapist can help children with

- Pronunciation
 - Emotional Development
 - Co-ordination
 - Memory
 - Grammar
 - Muscle development
 - Social skills
 - Stammering/ Stuttering
 - Behaviour
 - Voice
 - Eating, drinking and swallowing
 - Understanding
 - Story-telling
 - Play
 - Attention
 - Other
-

Speech and Language Therapy for Children

The statements below relate to ASSESSMENT. Please choose the statements that you think describe how a speech and language therapist assesses a child. You can choose as many as you wish.

- The therapist asks the parent questions about the child
- The therapist observes the child playing
- The therapist observes the child interacting with the parent
- The therapist uses toys to assess the child's communication
- The therapist uses picture books to assess the child's communication
- The therapist looks inside the child's mouth
- The therapist examines the child's hearing.
- The therapist asks the parent what they are worried about.

In relation to THERAPY, please choose the statements below that you believe to be TRUE.

- Speech and language therapists do exercises with the child's mouth
- Speech and language therapists use flashcards to teach children to speak
- Speech and language therapists use toys and play for therapy.
- Speech and language therapists teach parents to change their communication styles
- Speech and language therapists give parents exercises to do at home with their child.
- Speech and language therapists give ideas of how to develop communication skills through everyday interactions.
- Speech and language therapists often send a child for an operation on their tongue.

Parent Involvement in Speech and Language Therapy

Please choose the pictures that show how you imagine parents to be involved in speech and language therapy. Choose as many as you wish.





How confident are you about the role of parents in speech and language therapy?

1

5

1= Not confident at all; 2 = a little confident; 3= fairly confident; 4= certain; 5 = very certain

Please choose the statements below that you believe to be TRUE.

- Parents usually wait outside while speech and language therapists do therapy with the child.

- Parents must stay in the therapy room at all times, but only for insurance reasons.
- Parents usually stay in the therapy room to observe the therapist and learn.
- Parents usually stay in the therapy room and are involved in the therapy activities.

Do you believe the following statements to be true or false?

	True	False	I don't know
Parents are experts on their own child			
Therapists only work with the child. The parent's job is to observe.			
With intensive therapy at a young age all of a child's difficulties will resolve.			
Parents have to do therapy exercises at home with their child.			
Therapy can involve mostly working with the parent and working very little with the child.			
Children need to attend therapy appointments every week for as long as possible to make progress.			
Therapy is most effective if done primarily by the therapist.			

Causes of Communication Difficulties

Which of items below do you think causes communication difficulties in children?

- Hearing difficulties
- Weak muscles
- God
- Genetics/ Family History
- Lack of parent stimulation
- Another diagnosis, e.g., autism spectrum disorders
- Speaking more than one language in the home
- Bad luck
- Too much time spent with TV or screens.
- The cause isn't always known
- Other

Responsibilities in Speech & Language Therapy

Who do you think is responsible for the following:

	Therapist only	Parent only	Mostly the Therapist, but also the parent	Mostly the parent, but also the therapist	Other
Keeping other professionals, e.g., teachers, up to date					
Making a diagnosis					
Setting goals for therapy					
Leading therapy					
Completing therapy tasks or activities					
Providing expert knowledge					
Learning					
Training others					
Helping the child					
Listening					
Problem solving					

Attitudes Involved in Speech and Language Therapy

Who should adopt the following attitudes/ feelings in therapy?

	Therapist only	Parent only	Mostly the Therapist, but also the parent	Mostly the parent, but also the therapist	Neither
Openness to learn					
Confident to try new things					
Willingness to do as instructed.					
Feeling comfortable asking questions					
Willingness to give advice					
Openness to differing points of view					
A desire to help					
Flexibility					
Value team work					
Commitment to hard work					

Appendix L: Copy of SLT Questionnaire

Do you consent to taking part in this survey?

- Yes
- No* (If the participant ticks this box, they will be re-directed to the final page of the questionnaire that thanks them for their time and they will not be asked any of the questions below)

Is this the first time that you have completed this questionnaire?

- Yes
- No* (If the participant ticks this box, they will be re-directed to the final page of the questionnaire that thanks them for their time and they will not be asked any of the questions below)

Do you work as a speech and language therapist in the Republic of Ireland?

- Yes
- No

Do you work with children with ASD or suspected ASD in your current post?

- Yes
- No

In your current post, what area do you primarily work in?

- HSE Primary Care
- Publicly funded (e.g., HSE) Early Intervention Team
- Publicly funded (e.g., HSE) School Aged Team
- Child and Adolescent Mental Health (CAMHS)
- Publicly funded service for children with a primary diagnosis of a learning disability
- Publicly funded service for children with a primary diagnosis of autism spectrum disorder
- Publicly funded service for children with a primary diagnosis of physical disability
- Paediatric hospital
- Assessment of Need service
- Private practice
- Other

What county in Ireland do you work in? _____

How would you describe your caseload?

- Rural
- Urban
- Mixed

Where does your service first meet with a family?

- In the clinic

- In the home
- At school
- Other. Please specify

Who is the main referral source for your service? Please choose no more than 3.

- Public health nurse
- GP
- Area Medical Officer
- School
- Paediatrician
- Self-Referral
- Allied Health Professionals
- Other speech and language therapists
- Multidisciplinary team
- Other

Does the service you currently work for offer team diagnostic assessments for ASD?

- Yes
- No
- Other

This section relates to services that DO provide ASD diagnostic assessments for children.

When is a referral for an ASD diagnostic assessment typically accepted?

- As soon as a query of ASD has been noted or reported by parents and/or professionals?
- Only after the child has completed intervention with a health professional or team and signs of ASD persist?
- Other

This section relates to services that do NOT provide diagnostic assessments for children with ASD.

If you suspect a child may meet the criteria for ASD what is the recommended care pathway?
(Please choose one only.)

- Immediately refer for a diagnostic assessment and discharge the child from your service
- Immediately refer for a diagnostic assessment, continue to offer intervention until the child commences their diagnostic assessment
- Immediately refer for a diagnostic assessment, offer a single block of intervention and then discharge.
- Offer therapy first and if signs of ASD persist refer onwards and discharge

- Offer therapy first and if signs of ASD persist refer onwards but the child remains active on your caseload pending the outcome of the team diagnostic assessment.
 - Other. Please specify.
-

Does the service you currently work in offer SLT intervention for children with ASD?

- No
- Yes, any child with ASD and speech, language, communication and/ or feeding needs can access therapy
- Other

What areas does your SLT service target with direct intervention (face to face work with the child)? Please tick all relevant areas?

- No direct intervention is offered
- Speech
- Language
- Social Communication
- Augmentative Alternative Communication
- Feeding
- Other

What areas does your SLT service target with indirect intervention (e.g., parent education, parent mediated intervention)? Please tick all relevant areas.

- No direct intervention is offered
 - Speech
 - Language
 - Social Communication
 - Augmentative Alternative Communication
 - Feeding
 - Other
-

Therapy Care Pathways

Does your service have formal care pathways that are used to guide intervention for children with ASD?

- Yes
- No
- Other

Which of the following care pathways are available for children under 5 years in your service who have ASD? (Choose as many as appropriate)

- I don't work with children under 5 years.
- Parent education only (i.e., advice and information provided)
- Parent mediated intervention groups with opportunity for individual coaching sessions (e.g., Hanen More Than Words)
- Individual therapy that is primarily based on coaching the parent in parent-child interaction strategies
- Parent training in using AAC
- Direct, impaired based intervention
- Direct intervention targeting child's use of AAC
- General preschool education (general advice and information)
- Consultation with preschool staff with child specific recommendations given
- Preschool training with individual coaching provided for preschool staff
- Preschool programme
- Home programme
- Other

Which of the following care pathways are available for primary school aged children in your service who have ASD? (Choose as many as appropriate)

- I don't work with primary school aged children
- Parent education only (i.e., advice and information provided)
- Parent mediated intervention groups with opportunity for individual coaching sessions (e.g., Hanen Talkability)
- Individual therapy that is primarily based on coaching the parent in parent-child interaction strategies
- Parent training in using AAC
- Direct, impaired based intervention
- Direct intervention targeting child's use of AAC
- General education for school staff (i.e., advice and information provided- no coaching)
- Consultation with school staff with child specific recommendations given
- School training with individual coaching provided for staff
- School programme
- Home programme
- Other

Which of the following care pathways are available for secondary school aged children in your service who have ASD? (Choose as many as appropriate)

- I don't work with children who are secondary school age.
- Parent education only (i.e., advice and information provided)
- Parent mediated intervention groups with opportunity for individual coaching sessions (e.g., e.g., coaching in use of comic strip conversations and other ASD strategies))
- Individual therapy that is primarily based on coaching the parent in using communication strategies
- Parent training in using AAC
- Direct, impaired based intervention

- Direct intervention targeting child's use of AAC
 - General education for school staff (i.e., advice and information provided- no coaching)
 - Consultation with school staff with child specific recommendations given
 - School training with individual coaching provided for staff
 - School programme
 - Home programme
 - Other
-

Care Pathway Flexibility

If your service's outlined care pathway does not appear appropriate, can you modify how intervention is provided?

- Yes, always
- Yes, but only in agreed circumstances (e.g., individual therapy may be provided for parents who require additional support due to cognitive abilities or social circumstances)
- No
- Other

If a family do not agree with the recommended care pathway, can your service offer flexibility in how intervention is provided?

- No
 - Yes, always
 - Yes, but only if resources allow
 - Other
-

Your Service

If your service offers parent mediated interventions, which of the following statements are TRUE in relation to your service?

- Not applicable
- My service co-ordinates with other departments involved to ensure that families have enough time between separate blocks of parent mediated intervention (e.g., between a Hanen and a block of parent-based OT)
- My service offers the opportunity for reviews or further coaching if needed to help consolidate learning.
- My service allows the family to choose which interventions they want to do.
- My service allows the family to choose the order of interventions.

- My service provides information about the advantages and disadvantages of therapy (e.g., time commitment, results might not be immediate)

If you offer direct interventions, which of the following statements are TRUE in relation to the therapy you provide?

- Not applicable
 - The family and/or child is usually involved in setting goals for therapy.
 - The family and/ or child is usually involved in choosing the type of therapy provided.
 - The family and/ or child is given information about the advantages and disadvantages of the chosen therapy approach.
-

Why do you discharge a child with ASD from your SLT service? Please tick all that are relevant.

- Child's Age
- Child's speech and language skills are in line with the rest of the child's development
- Therapy goals have been achieved
- Non – attendance
- Family request discharge or transfer
- Child and/ or family have exhausted all therapy pathways available
- Professionals involved are confident that the family can self-manage.
- Professionals AND family are confident that the family can self-manage
- Other