



Climbing a Mountain: Parents Access to and Experience of Services in Tallaght West



CHILDHOOD DEVELOPMENT INITIATIVE

TÚSLA

An Gníomhaireacht um
Leanaí agus an Teaghlach
Child and Family Agency

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Acronyms

ADD:	Attention Deficit Disorder
ADHD:	Attention Deficit Hyperactivity Disorder
AON:	Assessment of Need
ATTI:	Ante-Natal to Three Initiative
CDI:	Childhood Development Initiative
ENT:	Ear, Nose and Throat
EYI:	Early Years Intervention Team
FG:	Focus Group
HSCL:	Home-School-Community Liaison
ODD:	Oppositional Defiant Disorder
OT:	Occupational Therapy
PHN:	Public Health Nurse
SLT:	Speech and Language Therapy/Therapist
SNA:	Special Needs Assistant
SOS:	Stop Only Sugar

Foreword

One of the very exciting developments in the Tusla Prevention Partnership and Family Support (PPFS) programme was the creation of the Parental Participation Seed Funding Project.

Parental Participation is about providing opportunities for all parents to have a say in decisions affecting their lives and the lives of their children. The Parental Participation Seed Funding Project sought local areas to creatively encourage parents' participation in their own children's care and education and to promote their participation in the planning, delivery and evaluation of services.

CDI through its Antenatal to Three Initiative (ATTI) proposed research to capture parents' experience of parental support in the Tallaght West area, particularly through the Parent Care Facilitator programme in Early Years Services in the area. This work was titled "*Parent's Voices – research on parents' experience of parental support, their needs, what works and how accessible services are for them*". This research hoped to facilitate an increased opportunity for parents to influence services targeted at them and their children, and increased parental participation in the planning, delivery and evaluation of services.

The feedback from parents of their experience of support for their children's needs speaks to some positive experience of parents feeling heard and supported. Some of the stories also speak to challenges experienced by parents in advocating for their children and their needs. As Service Managers, we want parents to find it easy to be signposted to the right person or service when they have a worry for their child. And if that parent is working with us, I want our team to help parents understand what our role is or how we can help, or if we can't help now, why.

As this research focused solely on capturing parents' voices, I think it is important that the valuable feedback from the parents involved is explored by the services in this area, to consider how we can continue to champion parental participation in the work we do, helping true participation between parents and services, with us both united in building brighter futures for their children.

Caroline Sheehan
Senior Manager
Prevention Partnership & Family Support
Tusla

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Thanks also to Tusla, and in particular the Parental Participation Seed Funding Project, for the opportunity to learn directly from parents about their experience of accessing and engaging with services in Tallaght West.

And finally, we are deeply appreciative of the parents who took the time to sit and talk with us; open up to us and share their stories. Many of these families have multiple burdens. They are required to negotiate with several different services and navigate complex systems. Their days are often stressful, exhausting and frustrating. We are hugely indebted to them for having the tenacity to believe that things can get better, and the confidence to recognise that their experiences should inform that process. We hope that the insights contained in this report, and the honesty with which the participants spoke, enables us all to collectively consider better ways to support parents and their families.

Marian Quinn
CEO
Childhood Development Initiative

Executive Summary

As part of the Tusla Parental Participation Seed Funding Project, CDI successfully applied to undertake a consultation process with parents in Tallaght West which would:

- Identify how parents access and utilise parenting services;
- Help us to understand what participants perceive as beneficial about parenting services;
- Identify issues that hinder and support parental engagement;
- Consider how parenting services can better respond to and address parents' needs.

A total of 25 parents and carers participated in this consultation process, through completing questionnaires, participating in Focus Group discussions, and /or providing a case study. Between them, respondents had 66 children, aged between one and 19 years of age, including one set of twins, and one grandparent with five adult children and 14 grandchildren.

Whilst the majority of participants were Irish, (60%) almost a quarter were black or black Irish (24%).

The socioeconomic background of the participants was largely reflective of the wider Tallaght West population, with the following being notable:

- Only three fathers participated;
- Black/black – Irish were overrepresented in the sample group, compared to the wider Tallaght West population;
- Two-parent families were also overrepresented in the sample compared to the population in the community, which has a high proportion of families headed by a lone parent.

Key findings from consultation with parents in relation to their experience of and access to services were:

- Responsivity of services varies depending on the individual contact, resulting in very inconsistent experiences;
- Parents focused on services for their children and clearly saw these as mechanisms to support them;
- Communication between services, and in particular aspects of the health service and parents, tends to be problematic;
- Many parents are hugely resourceful, resilient and determined when seeking support for their children;
- Informal supports and social media are important sources of information and advice for parents;
- Lack of clarity regarding how and when to access services is a source of extreme stress and frustration.

Methodology

This report is based on three data collection processes: Four Focus Groups were held and eight individual case studies documented. In addition, all participating parents/carers were asked to complete a short questionnaire detailing key sociodemographic information (Appendix II). Focus Groups were facilitated by the author, using a set format but with flexibility to allow discussion of experiences as they arose (See Appendix III). Case studies were written by individual parents with the support of either a member of CDI staff or a professional with whom the parent was already engaged. In one Focus Group, and one case study, participation was enabled through a friend of the parent translating.

CDI drew on existing relationships with professionals working in Tallaght West in order to gain access directly to parents. A list of those invited to support parents to engage in the consultation is included in Appendix I. Participants were not prompted to discuss specific services, issues or concerns, but rather were encouraged to think widely about where they get support and who they look to for help.

Inevitably, gathering parents for these discussions was problematic for a number of reasons. Some services do not have space which could appropriately facilitate a group session; most parents have many demands on their time, including younger children to mind or collect, and the budget did not allow for the provision of childcare costs; some parents are working and therefore unavailable or have very limited availability; and finally, some simply aren't able to or interested in prioritising time to participate in research.

Ultimately, 25 parents and carers participated in the consultation process, with 20 attending Focus Groups and eight case studies collected. Of these, only three were fathers and one was a grandparent. For the purposes of this report, all participants are referred to as parents.

Ethical approval was gained through Tusla's internal processes. All participants signed a consent form and agreed to their anonymised information being used. Names have been changed in all case studies and Focus Groups, and any identifying information omitted.

A draft of the individual case study was sent to each participant for review in order to ensure that information was accurate and appropriately described their experiences. All Focus Group participants were also sent a copy of the overall description of these discussions, to ensure that their voice was adequately represented.

In addition to the above processes, a roundtable discussion for local service providers was also held to consider the final draft of this report. A total of ten professionals attended from the HSE, Tusla, County Childcare Committee and Better Start. Whilst there was general agreement in this discussion regarding the challenges for parents in navigating services, there were different opinions on whether or not there have been positive changes since the original consultation was undertaken.

The experiences documented here are all illustrative, and given the numbers involved, are not intended to be considered representative of parental experiences. Indeed, it is very likely that those who contributed to this report are the most capable, driven and motivated in getting access to

services and there are likely many other families for whom engagement in a process like this is beyond their reach.

Demographic Profile

Demographic Information

All participating parents, whether joining a Focus Group or providing a case study were asked to complete a short questionnaire. The survey sample consisted of 25 parents with a female to male gender ratio of 22:3. A summary of the demographic information of the sample and of Tallaght West as a whole is presented in the Table below.

Table 1: Sample and Tallaght West demographic information.

Family Size & Structure:	% of Sample	% of Population¹
Small (1-2 children)	40%	60%
Medium (3-4 children)	52%	40%
Large (5≤ children)	8%	20%
Lone Parent Rate ²	24%	38%
Ethnic Background:	% of Sample	% of Population
Irish	60%	71%
Black or Black Irish	24%	8%
Irish Traveller	4%	2%
Other White	12%	8.5%
Educational Attainment³:	% of Sample	% of Population
Low (no formal education or primary education only)	0%	17%
High (Higher certificate or higher)	24%	21%
Medium (between above)	60%	63%
Non-responses	16%	-
Respondents' Economic Status:	% of Sample	% of Population
Full-time paid employment	12%	50% ³
Part-time paid employment	8%	
Unemployed	8%	15%
Homemaker/Work at home	52%	9%
Unable to work due to disability	16%	5.7%
Non-responses	16%	

¹ CSO 2017

² The proportion of families with children under the age of 15 headed by a lone parent.

³ Levels of education as defined in the Census

Compared to the overall Tallaght West population, the sample group included fewer lone parent families (24% rather than the Tallaght West 38%). Over half of the cohort did not work outside the home, compared to just 9% in the wider community, and 16% were unable to work due to a disability, compared to the Tallaght West figure of 5.7%. This profile suggests that the cohort is at considerable risk of poverty, but is not necessarily representative of the wider community.

There was a higher level of participation by black and black Irish than the wider population (24% rather than 8%). Levels of educational attainment were largely in line with the Tallaght West population, apart from the fact that no respondents indicated low levels of education. A significant minority (16%) of respondents however did not answer this question.

In terms of age breakdown of children, these can be summarised as follows:

Table 2: Ages of children:

Age of child	N =	%
0 - 4	14	26
5 - 9	15	28
10 - 14	19	35
15 - 19	6	11

(Dates of birth were not provided for two children).

Given the services which supported this consultation process, it is not surprising that most families had very young children. However, almost half the children considered in this process were aged 10 or over, so the issues reflected here go beyond early years and primary school age children.

Parents Experiences

A total of 20 parents participated in Focus Groups. Each began with introductions and an explanation of the purpose of the discussion, and how confidentiality would be managed. Consent forms were signed and the questionnaire (Appendix II) was completed.

1. What parent support services do you currently access?

Participants were asked to name all the support services they use. Responses included the following:



2. Tell me about those services and what they offer.

Participants described the kinds of services they receive, and reasons for engaging with them. Whilst the focus of the consultation was on parent support, a great deal of the discussion was on services which work directly with children. It was apparent that parents see interventions for their children as being a direct support to them.

Community centres were noted as being important points of contact, not just for meeting friends and joining activities but as a source of information about things in the community, and advice about how to access support. *'It's a real hub in the community'* was used on a couple of occasions to describe the added value it brings.

Public Health Nurses (also referred to as 'the baby nurse' or 'community nurse') were most frequently mentioned, and undoubtedly were seen as an important and accessible source of information and sign-posting to other services.

3. What were the difficulties in accessing or engaging with the service?

The most recurring issue which parents sought help with related to children with an additional need and so there was significant discussion of health and disability related services and processes.

These experiences were almost universally described as being stressful, complex and unsatisfactory. Poor communication, no connection between disciplines ('even when they're in the same building'), lack of follow up and no clarity were all referenced. Parents talked about making daily phone calls, keeping a diary of correspondence, and having to be consistent in communicating in order to achieve any progress for their child:

'The main problem with waiting lists is that you don't know where you are. The admin in the (name) clinic is very poor. Sometimes you're on one waiting list to even get onto the main waiting list,' (FG 1).

Not being able to speak to someone who could provide information was a clear source of frustration, with stories of phones not being answered, messages not being responded to, or not being able to make contact with someone who could provide clear accurate information:

'I rang again this morning and am waiting to hear back from them. Same thing, answering machine and leaving a message. Nobody seems to be getting back to you,' (FG3).

'I kept a diary and I took a record of who I spoke to and what time and what date, and I was constantly on the phone. It was like you were passed from Billy to Jack so I said, enough is enough. Keep a record of who I speak to on such a date and they told me this information so that I could say "no, well I was told something else," ' (FG1).

Even when there is access to the service, communication can remain a problem. Parents articulated a need to feel they were being listened to, and being given time to share their experience. One parent recounts the following experience with GPs in one Health Centre:

'I didn't feel they were really listening to what I had to say... they were looking up a medical book! In (another clinic) they sat and listened to you. They didn't even have to open a book. They sat and then asked you questions when you were finished. They went through everything with you,' (FG1).

Another described experiences with Community Welfare Officers (or 'the Social') as follows:

'Once they're in an authority position they think they got everything and look at you like you're a piece of dirt. You're not welcome. The first thing they ask you is your PPS number, then you take a ticket. Everything is a number before you go near them,' (FG1).

'Some of them speak down to you. I think it's the authority they get in that place. People are vulnerable enough as it is,' (FG2).

However, parents also gave instances of individual professionals who took the time to listen, explain and follow up, and these were clearly appreciated. GP's, Public Health Nurses, School Principals and early years staff were referred to as having offered support and advice, as well as being empathetic and responsive:

'You're seen straight away. It's not like you have to make an appointment and come back in a week's time. There's no waiting around,' (FG2) .

'The school is very hands on. They say 'this is your school, not ours',' (FG2).

'They listen to me, '(FG1).

The complexity of some children's needs, and inherent requirement to engage with a number of organisations and disciplines, was clearly stressful for many parents. Their ability to navigate these complicated, inter connected but not joined up services, was remarkable and their determination to access the services their child needed was palpable:

'They thought he had [diagnosis]....they were kinda watching him. It was the head lag, then they said he had [diagnosis], then from there they started questioning things and just left me with stuff I didn't understand. So you start googling these things cause nobody is helping me,' (FG 3).

'I think there is a lot of miscommunication about information, the correct information and what is right for you.Sometimes they (service providers) like to just pass it on. A lot of times people go down to Chamber House (HSE Primary Care) saying "I was told you could do it", but they say "no, go back to your doctor";' (FG2).

For some issues, parents were unable to identify a resource or professional who could advise and support them. One parent noted:

'My son was having nightmares. I took him to the GP but there was nowhere to refer him to, nowhere I could take him for support. It's not a major thing but it affected him because he wasn't sleeping, he was tired in school, he couldn't concentrate. Sometimes he would want to come home from school early, he was just tired. I didn't know who to turn to,' (FG2).

'It's horrible thinking that no one is there to support you. No one is there to listen to you. Just even to talk to someone. It does feel horrible when you've no one to turn to, '(FG3).

Waiting lists were also a recurring theme, with every Focus Group mentioning this, and almost every parent expressing frustration and disappointment at how long it took from the time of referral to receive an appointment. Length of time waiting for services was linked to a number of other issues such as stress and worry over the impact on the child; the time and energy given to chasing and pushing for a service; managing problematic behaviours in the absence of support or guidance; and consideration of private services, and the financial concerns inherent in this:

'(My son) is on the waiting list for the next one (Speech and Language Therapist - SLT) which was going to be 18 months, now that's gone to two years. We've had to go private with carer's allowance. €60 a week; that's my carer's allowance gone to pay for speech therapy,' (FG1).

Financial restraints were another factor inhibiting access to services. Two parents talked about GPs being expensive in the absence of a medical card, especially when there are also prescription costs, or where one visit doesn't resolve the issue and there is a further cost for the second visit. Some parents also referred to the fact that they had (or planned to) accessed private assessments for their children due to waiting lists for HSE services, even though this was a strain on their finances. This was specifically referred to in relation to assessment of children with suspected additional needs, driven by the fact that without a diagnosis, which requires an assessment, children cannot be allocated supports, such as a Special Needs Assistant (SNA). However, even this is fraught with complications:

'They wouldn't see David because we went private, so we had to start the assessment project all over again. It was a very traumatic time....there was a lot of calls been made and other stuff,' (FG3).

'I thought if I did (go private) that it would of opened doors for me and kind of help me and get things moving, and it didn't make a difference. I just got a piece of paper to say what was going on, and I was left with that. He (the private psychologist) didn't even look at the child. When we went into the room he just asked questions andwe just answered them and at the end he gave a report. How can you label someone with that, a child for the rest of his life? He didn't even look at the child. We were there for about 15 minutes..... We brought it (the report) back to his key worker; she was saying it was wrong. They (the early year's staff) were saying this is wrong; they are with him all day so they must know. To think you give €400 to a person to write something on a piece of paper and it to be wrong,' (FG 3).

Concerns over the quality of private assessments were raised by three parents who had taken this route.

Whilst finance was a barrier to accessing services for some, it was also the reason for engaging with services for others, in particular for contacting the St Vincent de Paul charity, and Community Welfare Officers. A small number of parents referred to these supports, with one noting:

'They ask too much, too much questions. Why is one working? How many hours, where? They ask everything..... My washing machine is broken so I go to the social. They say 'I can't help'; they say 'no, your husband is working, show me your pay slip'. They make me not want to go back here, too much talking; too much trouble,' (FG2).

Similarly, form filling and the level of information required (often having previously been provided) was named by some parents as being problematic. This was in part due to time pressure and it being an additional task to complete, and for those for whom English is not their first language, it was something which they needed support with, adding further layers to the process.

This same parent talked about the level of financial constraint which motivates her to engage with these services, even though she finds the questions difficult:

'The money is not enough. a lot of the time, my children ask; 'why can't we find food in the house?'. They say there is not a lot of food,' (FG 2).

Lack of support for parents, especially after their child has received a life changing diagnosis, was named by a small number of the parents:

'I just thought he had ADHD, but when you see autism (on the diagnosis) and I went on my own cause nobody could come with me and I was pregnant and I was so emotional. When I came out I knew there was something there but I started thinking about how severe it was, that he would never go to normal school and it was heart-breaking. I didn't know where to go with it, and I was just at home wondering what was I supposed to do with that?' (FG4)

For those participants for whom English is not their first language, an ability to converse in English was an issue. Whilst all had been offered a translator, some didn't like taking this support as they wanted to be able to tell their own story. One parent said she asked her children to talk to service providers on the phone when trying to make or follow up on appointments but her children didn't like doing this, and encouraged her to try herself.

4. What worked well with the services you have identified?

Focus Group participants were asked what has helped or worked well for them when engaging with local services.

Parents referred to informal networks as being an important source of information. Finding out about local activities and services was often through word of mouth, or advice from family and friends:

'I find a lot of the information we get is from fellow parents. Our son has a speech problem and it was other parents who said look out for this and if you go to so and so you can get this or that. Word of mouth from parents in the meantime as well,' (FG1).

As well as being important sources of information, other parents were vital to combat a sense of isolation, and foster a feeling of collective experience:

'Talking to other parents, you don't feel like you're on your own. A lot of people feel isolated and they don't want to talk or they're embarrassed. When they talk they realise, it's not only me. It helps to share experience with other people,' (FG1).

The barriers to parents engaging with new people in an unfamiliar environment were acknowledged and so strategies to facilitate this, and enable people to come together were also named. These included parents 'buddying up' with parents of new children coming into the school, and teachers holding meetings early in the school year in the parents' room, so that everyone knows where to find the room, and is assured of its welcome.

Social media was also referenced as being very helpful, particularly in relation to specialist services and a number of website and chat rooms were repeatedly referenced as providing useful, practical

information. These were all peer-led. Public Health Nurses, GPs and Home School Community Liaison (HSCL) teachers were all referred to as advising and linking parents into relevant services or providing information on local supports, whilst GPs making referrals to other specialist services such as hospital or Lucena Clinic, was also named as being straightforward and easy.

Having access to professionals without needing an appointment, and which facilitates informal check-ins or a sounding board, were also referenced as important supports:

'...when you go to (school principal)...you're seen straight away. Same with (HSCL). It's not like you make an appointment and come back in a week's time. There's no waiting around,' (FG1).

Texting seems to be effective and efficient, and a number of parents talked about this as a key method of communication about events, reminders for appointments, and generally checking in. HSCL and early year's providers in particular were referenced as using this method effectively.

5. Is there anything that would make a difference to your experience of services?

Whilst generally parents recognised that there are no easy solutions to establishing effective, responsible services, key areas for development focused on communication:

'If there was someone there to answer the questions and someone to talk to us,' (FG4).

'It's a big question. You see yourself giving out (about services) and then if they give you a bank cheque you don't know what to even write in it,' (FG1).

'If they just turned around and said every four weeks, we'll send you an email and tell you how long the list is and where you're at and that you're not forgotten. You feel like you're forgotten. Just to be acknowledged, to know that you're still on the list. Keep us up to date,' (FG3).

Conclusion:

It is apparent from the Focus Group discussions that accessing services is often a source of considerable stress for parents, and that poor and inconsistent communication, coupled with under-resourcing, are at the heart of this.

Exceptions to this, noted by parents, serve to underline the element of chance in how parents will experience their engagement with services, rather than there being a consistent approach and agreed protocols. Many parents had positive experiences of individual professionals, who they found to be accessible, responsive and helpful. Parents demonstrated creativity, resourcefulness and resilience in how they accessed information, maintained their focus and motivation and persisted in their efforts to access services. As noted previously, these parents are likely the most capable and motivated, so it is possible others are not able to undertake these processes.

Case Studies

All names have been changed to protect the families and any identifying information removed, but otherwise the case studies are presented just as they were given by the parents:-

Cian

My son was born six and a half weeks early and I felt he'd some developmental delay, however he was progressing and I felt he would catch up in time as I know all children develop at different stages. I enrolled him in pre-school in January 2014 and while he was there I was advised by his keyworker that he may need a Speech and Language assessment.

We attended the Speech and Language Therapist linked in through the pre-school. Cian began therapy, and then it was advised that he may require an Assessment of Need (AoN). My son also went for an ENT (Ear, Nose and Throat) referral which resulted in his adenoids being removed and grommets fitted. We went private for that as the waiting list was too long.

When my son's AON came back through the post I was left with no explanation and found the thickness of the report overwhelming. It was recommended that he have speech and language therapy which he was already receiving and I was sent homework to complete with him. It was also recommended that my son visit a paediatrician and that he attends an SOS (Stop Only Sugar) approach to eating programme. There was also a recommendation to visit an ophthalmologist which I have yet to receive. At this stage I was left with a report in my hands that I did not fully understand and I was confused as to where to go next.

I turned to the pre-school and together we began to sort through it. The pre-school and myself began a search for the SOS programme and could not find one here in Tallaght let alone Dublin. My son's eating was concerning me for some time and I would have appreciated support with this. By far the most unbelievable thing happened when the Pre-School with my permission got in touch with the nutritionist that recommended the SOS approach to eating. We were told that unfortunately the programme does not exist here and that it is a part of their job to supply recommendations in their report. Again I was in limbo!

My son went to school in September and in October I was asked if I would like to put him forward for another AON, so here I am again in the same position as a year and a half ago and still none the wiser how to support my son. I was asked if I would like a review of his files and I said yes. From this I was given a one hour once-off appointment with a nutritionist and from this a referral letter was sent to the head in Tallaght hospital and I am now awaiting that appointment.

I feel that through this whole process which has been emotional, physically and mentally draining I have been left with nowhere to turn other than the pre-school who I am still in contact with and little information as what to do next.

The Doyle Family.

This case study was provided by the children's grandmother, who is the primary carer.

Our main objective was to provide them with a stable home life and attendance in school. I soon became linked in with a range of services I had not used before. My main port of contact became my youngest grandchild's pre-school. The eldest grandchild was attending Barnardo's for support and this was carried out in the school. The youngest grandchild required an appointment with the hospital. I got the secretary's name and number from the pre-school who had already been in contact with them, however he needed a referral letter to forward on to the hospital. We also needed an appointment for the eldest grandchild.

I attended the doctor for the youngest child relating to toilet issues. The children's dad and myself changed the children's medical cards into a new doctor and proceeded to have medicals for the children.

The youngest child was attending a Speech and Language Therapist through the pre-school and I attended appointments for this, and carried out the homework received while the pre-school provided time during the day for one to one.

My son approached the council for housing as my home is now overcrowded and he was put on a waiting list. There is a possibility that he will rent with his children if he can afford it.

A phone call was made to Chamber House (the HSE) for an application for my eldest grandson to attend a speech and language assessment, we are still awaiting the forms to be sent out.

At the moment, my son is awaiting his court date to apply for full custody of his four children. We have gathered as much information as we can relating to the case from professionals that are involved with the children. He has also applied for children's allowance as he is now the primary care giver.

Our biggest obstacle in all this has been to contact a social worker as the children are not a Child Protection and Welfare concern any more (which is great news). We are awaiting a social worker to be assigned to us. We also had trouble contacting the Gardai in the case to obtain information relating to the children.

It has been a long road of appointments, miscommunication and heartache; however with support we feel we are now turning a corner and most importantly the children are safe and secure while having all their needs met.

Rachel:

My daughter attended preschool for two years from September 2012. Before she started preschool she had been put on the waiting list for speech and language therapy with the HSE. I was told it might be a two year wait and might not start before she started primary school.

Soon after she started going to preschool I found out they have speech and language therapy. Rachel got her first assessment in that December. The sessions took place in a room in the centre and this made me and Rachel at ease as we were both comfortable there. We attended weekly sessions throughout the school year. My daughter quickly went from having little to no words to a child who could communicate with others easily. She continued the speech and language therapy in her second year at pre-school but don't need them as often. She was discharged at the end of her time in there. She didn't need to continue on the sessions in primary school.

I believe that early intervention was key to my daughter's success with her speech and language therapy and if the service wasn't in the pre-school my daughter would have only began that journey in primary school. I believe it would have had a negative effect on her self-esteem if she had to wait that long and her schooling would have suffered. As it stands she is a confident and happy girl who is able for primary school and needs no additional support.

Another additional service that I took part of was the parenting course held in the centre. I found it very helpful. It was friendly and non-judgemental and as a result I felt very comfortable there. The advice I received there was practical. I have put it into practice with both of my children. I also found it a nice way to get to know the other parents whose children attended. It made me feel more part of my child's experience in pre-school and not just like I dropped her off and collected her.

Over all I would say that me and my daughter benefit from additional services provided in the pre-school.

James

My journey with services began when my son James was a baby and he was referred to Tallaght hospital for tremors. He also presented with breath holding. Nothing was discovered.

An Assessment of Need was carried out at two and a half years of age, mainly relating to autism, and it was recommended that the assessment be reviewed in a years' time. He attended another psychological assessment at three and a half years, this time the recommendation was for speech and language therapy. The report read that they could not rule out Attention Deficit Hyperactivity Disorder, ODD and behaviour. Another review was recommended before he attends school.

James received speech and language therapy in his pre-school through CDI. I handed in all of his reports and myself and the pre-school contacted Chamber House (HSE) to ask about his review.

We were told that I would need to apply for the review in writing which was not mentioned on his report. We wrote the letter and waited.

Myself and the pre-school again contacted Chamber House and discovered that at the moment reviews were on hold and there was no Assessment Officer in the post.

During all this through the pre-school we applied for James to go to Junior Infants. We handed over all his reports and even made an application for SNA and resource teaching. I felt this would support my

son's learning from day one in school. Unfortunately, because my son's report did not have a diagnosis on it he would not be given an SNA and we were unsure about resource teaching.

In October, the school approached me and asked if I would like another assessment for my son. I feel I am now back to the beginning after years of this.

I have made phone calls and have been passed from one department to another and with staff and numbers changing I feel I never get to talk to anybody. I am emotionally drained through this whole experience and yet have no answers.

I could be waiting another year for the assessment to take place and feel at this stage I have no option but to put myself in debt and go private.

Oisín and Michael:

My two boys attended the speech and language service for one year in Junior Infants and then it was like a cut off point and then they were back in the cycle again. It was like limbo. They got the service when they were in the crèche and they were able to continue it when they went into school. The staff in the crèche arranged an interview type assessment. One of the boys had a language problem and one had a speech problem. Totally different but similar needs. After Junior Infants my eldest son Michael went back into the HSE, Chamber House, and they thought he had a speech impairment but he had behaviour problems and was still going through the Assessment of Need, so she couldn't refer him for a language class. That's what she wanted to do. Then Lucena assessed him and said he had autism, so that service didn't suit him and then after Junior Infants it was like he was discharged even though he had a speech and language need. Lucena referred him back to the HSE to the school age team and it took me a year and a half to get him in there.

He was on a disability list and there was an officer to contact but you had to be constantly talking with her to get updated. Constantly. That's why I kept a diary of who I spoke to if I got through; if I left a message; if I got any update on information. Any information, I would put it down whether it was positive or negative, I would stick it all in.

They said it could be 18 months for him to be seen. It was longer.

The Assessment of Need said it wasn't autism; it was a [diagnosis] so that was classed as a disability. That gets passed on to a disability officer and then she refers him for whatever he needs then and the book keeps going and going. I know they're different services, and I know they have to be divided into whatever, but there is no information. Even with CDI, the SLT was fantastic, but he was discharged even though he still needed speech and language and there was nothing more she could do. She was in a predicament as well.

When I went back with my younger boy, the SLT asked how was Michael and I was saying he still needed SLT and she said you can get him a referral if I wanted, for whatever typical service and then when I got information on that I was told no, you can't do that. It was like being told one thing and then another. It was probably just that they didn't want to have another child on the list.

That period wasn't as tough as the first assessments and referrals in speech and language. I was just in contact with the one person so that was really good. That was the secretary but it was like 'Oh no we didn't get the referral', where I knew the SLT had sent a referral for it and Lucena too. I knew they had all went in and what dates because I took a note. They said, 'No, we didn't get it until' whenever it was. It was hard. So we had to get back onto Lucena and back to the SLT and say we definitely sent it in.

Having the one person to deal with, the Case Officer, she took care of all of that which made it easier. When he went to the Disability Officer, that was no good. That was the worst. I didn't know the Case Worker was on sick leave, no one told me, and she was the one sorting the waiting lists.

Once Michael was diagnosed I was told by another parent that there is a Facebook page called DCA Warriors and it was run by parents and they were totally active in what services need to be provided and who to go to about getting them. Even down to getting domiciliary (allowance). Even filling out forms, this is the information that you need to give. Just brilliant and they're all parents! That's where I went to for support. And I still do, I still go back and see if anything has changed, if there is any new information about anything. Even his behaviour, I'll go to that because they're all brilliant.

The SLT was a good source of information. I'd ring her or just pop in to see if she was there in her office. Lucena were good too. They told me where I needed to go and what I needed to do. They were helpful to a point and then he got discharged and then no contact so it was good and bad. They were helpful when they needed to be and then once he was discharged they couldn't do anything else because I did go back, Michael was going through a stage of putting things around his neck from the bunk beds so I went back for help but I never got an appointment.

Now that he's in the school age team, it's multidisciplinary so he has a psychologist, OT, SLT, well she left but there is supposed to be SLT; physiotherapy; a social worker. I think there's another but I'm not a hundred percent. Speech and language is gone; the OT won't help him with his sensory needs, and his psychologist is on maternity leave. You get your foot in the door and then bang, it's up in the air again.

It's really tough because you've no one to turn to. I would come into the school a lot when something is worrying me about him, like behaviour. He still has a lot of accidents so I would be in and out of the school to see what's happened. I brought in wet tissues, spare pants etc. that are in the toilet so he doesn't have to take anything out of his bag. Again, that was trial and error.

I go to the Home School Liaison a lot if I need help with anything or had any questions. Michael gets the July provision⁵ and the first people I went to was the school to get informed about it, where do I go and they just did everything for me then. They were brilliant like. If someone in the school couldn't do it they phoned up their friends who were teachers so they were brilliant, very good.

I'm always in with the school principal too. Michael wouldn't present with any difficulties in school, it's when he comes home. He'll go to his room or come home in foul humour or bite his nails. All these different behaviours. Extended family would say he's grand, doesn't look like there's anything wrong with him. You don't live with him! There might be others that are worse off than him but I fight for him and I'll always do it.

⁵ "July Provision" is an additional month of support for children with a disability.

He needs grommets but with the hospital, there's no ENT surgeon. There's no surgeon to do the operations. That's another waiting list that he is on. You go for these appointments and the doctor tells you that the surgeon has actually left and Tallaght Hospital haven't opened up a position and it's frustrating. He's only a year waiting but once they're six months supposedly there's another service that can send him to another hospital but when I enquired about that service, the grant, all the money has gone. So that's another kick in the teeth.

His hearing is a lot to do with his language problems and his behaviour. He can't hear like!

Oisín has had his OT and he gets discharged and gets a group session of six weeks so every week last month and the month before we were going to every session with him and he would go in with another two children so it came to the end of that and I was asking his Key Worker what happens next and she said if he is still presenting with OT problems just put him back through. So he just goes through it again. He has attention problems so the School Principal, she's going to get an educational psychologist in. He was through the Assessment of Need as well and he was too young to say whether he had ADD or ADHD so they said once he's in school for six months and is still presenting the same and not settling I can re-refer him so I tried to do that and I was told no, he had to be in school for over a year so that was that. I waited and waited and the HSE rang me last week about his speech and language problem and I said he doesn't have those needs anymore. I said he has OT needs still and I was asking about the Educational Psychologist so she said there's a new officer in charge of Assessment of Need, and gave me her number. I've left a message and heard nothing back.

It's not that I want a diagnosis; it's just that if he has one, there is more options and help. He was diagnosed with [diagnosis] as well but I think if he had another diagnosis, I know he has attention problems. The school principal was saying bring him to the doctor and get him Ritalin to keep him calm but he's crazy. He's a good kid but doesn't sleep and I think if we got his sleep under control then everything else might fall into place for him. God love him. So hopefully that's September, another assessment for him.

The school have faults as well, they are not perfect and there is some miscommunication about them as well but they are still hundred percent. They are brilliant. And they do a lot for other parents too I'm sure. I'm always here! I like being involved and to know what's going on so that if you have a problem you can just come in.

My kids think I work here (in the school)!

Keeping the diary made a difference. Compared to Oisín, I was more on their back with Michael than Oisín because I could help Oisín at home and so I wasn't as pushy to get him services but because Michael needed so many I had to be constantly on the phone. With Oisín I would ring up and let it lie and then ring again. I suppose as well as them being different children with different needs, I didn't think I had any fight in me left as I put so much energy into Michael. I thought I could sort stuff out myself.

Oisín's needs are constant, even though Michael has more needs. Oisín needs movement breaks from the time he wakes up, to help him function throughout the day and sometimes he is really hard work. That's where my energy really needs to go, as opposed to being constantly on a phone.

So, what would help? Just to provide the service that's needed, that's the number one. Instead of saying your child needs X, Y and Z, actions. Definitely. For all of the children that need it. That's why I asked you in the beginning, is your service not for children with disabilities as well? They are in the HSE, that's it, they're in it but I think if they were open to be on other waiting lists, that way if CDI came up first, you could go with CDI. You should be allowed to have that option. I was ringing Enable Ireland, trying to get in everywhere but they said they wouldn't take him on because he is with the HSE with disabilities.

That would really take pressure off parents to know that your child can be on as many lists as you want in your area and if the service comes up then that's it, you can go with that service and then go from there. I think that would be very good.

Fiona:

My son John attended the early year's service for his free early pre-school years and I was very happy with the service that he received. The staff there ensured that his school transition was smooth. I was living in Tallaght at that time renting a private property. I was there for a couple of years and without notice, I was told I had to vacate the premises as the landlord hadn't maintained the payments on his mortgage and the house was being re-possessed. I went to SDCC who put me on a homeless list and I was allocated a room in a B&B while waiting on social accommodation. It came to the time when my daughter Fiona was due to start her Early Start. She had some behavioural issues and the crèche were questioning whether or not they were a suitable service for her.

I was called to a meeting with the Manager of the crèche who explained the situation and who advised that we reduce my daughter's time in the crèche, so instead of attending for three hours per day, she'd be attending for one and a half hours. It was hoped that by reducing the time she'd be able to stay in crèche. This didn't work out as she was high risk as she would climb up and jump off presses; she was quite tall so she'd try to open and run out of doors and she wasn't able to play with other children, unless she had one to one attention. Fiona had an initial assessment for speech and language and had done six sessions and was on a waiting list for an Assessment of Need. I was getting nowhere and was extremely stressed with the communication barrier, for both me and my child and the frustration of living with two children in a tiny room. When the children went to school, I spent my time walking around as I had nowhere else to go, so when Fiona was no longer in crèche, I felt awful that we had nowhere to go during the day. The Manager, once aware of what was going on for me, got me to meet with the Parent Carer Facilitator.

Sarah met with both me and my ex husband (who did a lot of my communication) and I explained to her everything that was going on. Sarah made requests to many specialised pre-schools, who refused to take my daughter because she didn't have a diagnosis. She made appeals to Chamber House (HSE) to find out what the delay was, and to tell them how urgent this was. At this stage, we were informed that it would be several months before the EYI⁶ would be able to offer us an appointment. Through all of this going on, my mother died and I became extremely depressed and upset with the constant

⁶ Early Years Intervention Team

struggle. Sarah told me that she could organise an ‘interagency’ meeting if I gave consent to the ‘Meitheal’⁷ process.

As a result of this I was referred to Focus Ireland and was given a key worker from Focus who became actively involved in supporting myself and my family. We got into the emergency housing in Tallaght Cross and got housed within a few months; we also got referred to Barnardo’s who offered some child support for my daughter, and Focus paid for an interpreter so that I could communicate my needs and concerns without my ex husband.

My daughter still does not attend school, but Sarah and the manager did their best to get a school for her. She got a start in one school but was asked to leave after a few weeks. We were told the assessment will be soon and I feel that without the support of the crèche, I would still be in the situation I started in. It gave me relief to know that there were people working and supporting me and that things are beginning to move in the right direction for me and my children.

Bobby:

I am a single parent living in Tallaght for the last seven years. I’m originally from England, but I left home and came to Ireland to set up a new life for myself. I met a man and we got involved, but when I found out I had got pregnant, he ended the relationship and I’ve had no contact with him since. For two years I was alone and isolated with no friends and no support.

My son Bobby started in crèche when he was two years of age, as I felt that he needed to mix with other children for his development and social skills. I met Liz, the parent facilitator and confided in her. She was very supportive and understanding and she linked me into local adult services where I did arts and crafts and got to meet other adults and women in a similar position. Liz also organised coffee mornings which I attended and she introduced me to other parents in the crèche, some who I have become good friends with. She also offered me some one-to-one support and some space to talk about my depression and low moods before referring me to a counsellor.

I feel very happy that I picked this crèche for my child. Their support and friendliness helped me to get strong in myself and rebuild my confidence and self esteem while my son enjoyed his time in the crèche. The friendships he made there are still good and play dates after school and on the weekend are regular for him.

Bobby is now in school and I have a part-time job while he is in school which I am delighted about.

Tom:

My son Tom has autism. It started when he was 18th months old. He is now five, and I’m still fighting services for him and I’ve got nothing. I had to go private last year to get a diagnosis for him. He finished his whole assessment needs process and he was waiting for his reports to be signed off and to be sent

⁷ Meitheal: An interagency approach to supporting families in need of a range of interventions.

to the early intervention team but his case worker left and his report was basically left on her desk for nearly two years.

When he got his Assessment of Needs done it was recommended that he needed occupational therapy and speech and language therapy. He was still non verbal. They also suggested that he needed clinical psychology but they have only put him on a waiting list for occupational therapy and to be re-assessed because it looks like Chamber House (HSE Primary Care) isn't taking the diagnosis that I got privately. They haven't even put him on the list for speech and language therapy which can't be explained to me because he is non verbal. That's the main thing with his autism that causes his frustration.

He might be two years on the list to get a psychologist to re-assess his diagnosis again. It's just red tape and fighting from day one, even getting the health nurse to see there was something wrong in the first place.

He had started to mimic and to copy sounds and he was saying the basic words like mam and dad and then all of a sudden he regressed, he just blanked out. I had three other children and that was a warning sign, so I went to speak to the health nurses about it but I got an awful hard time trying to get them to push for the Assessment of Needs. I actually got 'it must be hard for you having three other kids and a boy who's quite hyper'. He's not actually hyper, it's just the fact he zones out so much. I had to insist on seeing the actual doctor that sits in with the health nurses.

She was fantastic. She understood and took the time to sit with Tom and recognise what I had seen in him, what I was concerned with. He was doing the hand flapping which I knew at that stage wasn't typical for a child of his age, and then she sent me onto Chamber House for the assessment need process. I think she was the most efficient.

She was willing to give information. She was very good at telling me this is what you should expect; and these are people who you might want to get into contact with, who might be able to help you. She seemed to have a lot of understanding of when you're sitting there and trying to tell someone how you think there is something wrong with your child. She made sense when I wasn't making sense.

We had the assessment for occupational therapy and the psychological assessment, and the last one was the Assessment of Needs in Tallaght Hospital. I rang his case worker to check what was happening and to explain I haven't heard anything or got the final report with the diagnosis. I was starting to chase for schools and preschools but they couldn't take him because they were looking for his care needs, but I had nothing to give them.

I was absolutely put through every department in Chamber House where people were fobbing me off to the next person until after months I was put through to a person who is in charge of recommendations. They're the one to make sure the Assessment of Needs process is done and they look over reports and recommends what waiting list you should be on and what services. Tom's files hadn't been sent over to the early intervention team so they could do absolutely nothing. They recommended going private if it was in my capability because I'd be better off at this stage.

I found out my case worker had left and that no one was looking after my son through a preschool where I was volunteering. The manager told me. After that more phone calls and basically I spent

a year and eight months bouncing back from different people being told 'sorry we can't help you', 'sorry we can't help you'.

So then we come to enrol him in one ASD⁸ unit in a preschool. They were the only ones to allow me to enrol him like that because I couldn't tell them his care needs. I contacted everyone and followed up every one that was suggested. I just couldn't get any information, no nothing. They didn't understand the problem I was having trying to register him into schools.

He did great in preschool. He was coming on and they put a key worker with him which was one on one which was brilliant. Both my sisters are SNA's so I got tips off them; speaking to him constantly so he started copying the sounds, words and so on. Getting him into school was another problem though and I and the school principal had a disagreement because I chose to enrol him in a mainstream school. We all know it's not the best place for my son. He needs an ASD unit because he is non verbal. He is well able to use a bathroom but he's not capable of telling you he needs to use the bathroom and I know he had a couple of frustrations in the classroom cause of that.

When I enrolled Tom the school principal said to me do I think it's the best place? I got so annoyed cause at this stage this is my only option. I don't wanna fob my child off but I can't apply for an SNA so on so forth.

He ran off at one point. Last summer he learnt how to unlock the doors and windows and he got out and onto the field near the house before we realised. I found him at the same time as the Gardaí. Someone had rung them. We explained about his autism so they had to alert the social worker. I was excited about this which I know sounds terrible but I thought, if a social worker was involved they might recognise that he is actually been neglected; not at home but because he has absolutely no support and I'm being neglected as his carer cause I have no support and I have three other children to think of too.

There's absolutely nothing in the way of support systems in Tallaght other than the volunteering ones like the Tallaght autism group page on Facebook where parents share information and organise outings, so you don't get as many looks or tuts when you're out.

Everyone talks about stopping the behaviour before it starts, and how early intervention is so important but my son has now went on the same waiting list as newly assessed children. He's in the same waiting list as three year olds even though he's five now and been on the waiting list for two years. Something should have been done when his case worker left. They should have replaced her and they need more help with the back log.

I've put in a complaint with the HSE and I got nothing back within the six weeks that I was suppose to hear back. Eventually after 15 weeks I got a reply that I was right with my concern that Chamber House was in breach of the Disability Act 2005 on three counts. I goes ok, what we going to do about it? But they just said because of the back log we will be back in contact with you. Then about two months ago I got a letter off the complaint officer saying they have been back in contact with Chamber House and they're going to close your case, so I rang and said I don't want my case shut, I want it pushed forward because after two years he is still not getting anything.

⁶ Early Years Intervention Team

I was recommended to claim carers allowance but my partner is self employed so I can't claim carers right now. We are breaking down how much he earns for the year to see if I could get it. Even if I got 20 euro I'd be registered in the system as a carer and I could get access to respite. I can't access grants for the work that's needed in the house either, redoing the locks and that. But I can't get that without the diagnosis.

They need to look at the support system with the parents where the service and the parents come together. I was told he had sensory issues and I was told nothing about that and I was like what are sensory issues? I had to suss all this out myself with my son to see what his sensory needs were in order to meet them myself. Someone should have explained what that meant and what Tom needs. They're scared to say your son needs this or your daughter needs this in case we say why aren't you doing this?

Information for parents and tips on how to support your child would mean so much. Maybe a speech and language therapist could meet parents once a month, have an open night and parents with any questions can come.

Living in Tallaght West I do find me being more proud of my community with the situation I'm in with Tom because when you're down in the dumps other parents with the exact same issue come and help you and that gives you that push you need.

The main problem, and throughout all the services I contacted, is no communication. People aren't talking to each other. It's very frustrating. When you make a phone call, even though they're in the same building as someone else you've spoken to, you have to start from scratch again; explain the whole of everything and I'm reading out reports to them cause they hadn't got access to them, even though they are the system and supposed to be looking after him.

The person I am is that I'm not scared to make phone calls and send emails and etc., I'm happy to do my part to fight for things. I'm well informed. I know teachers and social workers and I've got information about how the system works. I'm more capable than a lot of other parents, might be because I've sisters that are SNAs and I'm involved with the community and I have more networks of informal contacts.

I spend so much time phoning places, trying to get through to people, to find the right person to talk to. And there is days where you're just so emotional you cannot make them phone calls because if you do you're either gonna be abusive to someone or have an emotional breakdown and will start crying on the phone. I get to that point of breaking. What am I supposed to do? This is my son and I'm going to do 150 percent to make sure he is happy and healthy and he's getting everything he needs but when you can't and there's nowhere to go to, it's soul breaking. When the kids are sleeping I just sit there and cry and cry cause you have no options, you have no nothing to push forward. It is tough dealing with all these emotions. Saying to people 'do you understand that what I'm going through? and what my husband is going through? and what my daughters are going through?' Asking people to try and understand how our household has changed over the last three to four years and everything is about Tom and trying to get his needs met. I shouldn't have to fight so much. My other three children haven't got as much time with their mammy. We don't get girly days and wouldn't be able to go the cinema. We are restricted to what we do.

Summary

From the parents' perspective, they experienced some extremely complex needs, complicated and often seemingly incoherent referral systems, and services which they felt were ineffective, uncommunicative and inaccessible. Conversely, the parents demonstrated incredible fortitude and tenacity whilst simultaneously articulating how exhausting the need for persistent pushing for services is. The importance of informal connections and knowing that others are facing similar difficulties, is also noted here as part of what sustains parents.

It is very apparent that some of the children focused on in these case studies are not having their needs met, and that an early intervention approach is not being taken, despite policy commitments to this.

The case studies also highlight individual professionals who are noteworthy for their empathy, knowledge, ability to listen, and who are able and willing to connect parents and their children to services which can offer support.

As this research was tasked with capturing solely parents' experience of parental support, services involved in providing supports or interventions were not engaged with during the research, to illicit their views, or give opportunity to respond to the feedback from parents.

Conclusion and Recommendations

The following themes emerged as key issues for parents in Tallaght West through the case studies and Focus Group consultation processes.

Communication with service providers is often extremely difficult, time consuming and stressful for parents. This is due to a number of factors: staff leaving or being on leave, and not being replaced, leaving no one with the relevant responsibility; phones not being answered and messages not being returned; difficulty knowing who to speak to, or finding someone to talk to who can provide clear, accurate answers.

Related to communication, difficult experiences with some service providers were named, in terms of lack of engagement or an intimidating approach, whilst for some participants, translation and ability to understand the information provided were factors.

Parents of children with additional needs spoke about needing to expend considerable energy in negotiating complex pathways between services, and understanding the processes required to be completed before their children can access support services, and being able to interpret technical reports and assessments. The level of knowledge of services, and inter disciplinary functions, held by many of the parents participating in this consultation was striking.

Perhaps inevitably, waiting lists were also discussed as being problematic, but again, the communication in relation to these was critical – people wanted to know where they are on the list, and the likely timeline. The lack of information seemed to be the most stressful aspect of this process, whilst the difficulties managing ongoing issues in the absence of a diagnosis or intervention were also noted.

The processes which support parent utilisation of services were almost universally about individual practitioners taking the time to listen to parents; understand their needs and those of their child, and to explain next steps. Even where there were long waiting lists involved (such as a GP referral to Lucena) parents were satisfied because they felt they had clarity.

Informal supports such as a space to chat with other parents, particularly where there are similar experiences, were critical for parents, not only as a source of information and guidance, but to combat isolation, and give a sense of not being alone in these complexities. This seemed to be key to sustaining parental motivation.

Recommendations

As a result of the above, the following actions are recommended:

Statutory services and particularly those provided by the HSE, Tusla, and their funded agencies, to develop communication protocols which include the following:

- Mechanisms to inform service users of their place on waiting lists, and anticipated timeline for an appointment;
- Named link person (administrator) to engage with while on the list;
- A commitment to respond to messages within an agreed time, and monitoring of same;
- Protocol for informing service users if a member of staff has left or is on leave for one month or longer, and explaining who is now responsible for managing their case;
- A requirement to ensure that reports provided to service users are free of jargon, technical or medical language, and that they provide information which is accessible, clear and indicates next steps;
- There should be protocols on sharing assessment reports and diagnoses with parents, and where a child attends multiple services, a clear interagency plan should be established with a named lead worker (along the lines of the Meitheal process);
- A protocol to be developed and widely communicated regarding the utilisation of private assessments by statutory services;
- The 'my name is...' campaign should be extended to all public services so that the first engagement with a service user is personal and welcoming.

Other recommendations are as follows:

Consideration should be given to exploring supports to parents while they are on a waiting list (e.g. phone in advice clinic one half day per month or a triage service).

This report should be disseminated and discussed widely, with a view to informing future planning, resourcing, staff training and recruitment. In particular, HSE services, disability services and primary care professionals should be facilitated to openly engage in the findings from the report and to consider its implications. This process should include consideration of what is working well, and affirmation of these aspects, as well as discussion regarding areas in need of improvement.

The provision of a space where parents can meet informally is invaluable. Whether this is based in a school, early year's service or a community centre does not seem to be as crucial as the importance of it being accessible, welcoming and freely available. An accompanying plan to proactively encourage and enable parents to utilise the space is equally important, as there is recognition that some parents will need support to overcome fears or a sense of intimidation.

The participation of fathers and documenting of their experiences as parents needs further consideration. Models of effective engagement with fathers should be identified and promoted.

Additional recommendations include the following:

- Full implementation of the key working model described in the “Progressing Disability Services” policy;
- Consultation be undertaken with professionals working with children with additional needs to identify their views on the barriers and solutions to more effective, responses services;
- A process be undertaken to identify and map existing models of case management, support and tracking which might offer lessons for the development of systems to better manage families with a child with additional needs;
- The development of community-based parent advocates who can provide support, information and sign-posting for parents on a peer-led basis, but supported by up-to-date and accurate information on service provision, referral processes, and key roles;
- A regulation and complaints procedure for private therapy/assessments to be developed and made readily available;
- That recommendations made in child assessments only refer to services which are available locally.

Appendices:

Appendix 1: Agencies invited to facilitate parent engagement

- Scoil Caitlin Maude;
- An Turas, Jobstown Childcare Centre;
- St Aidan's National School;
- Fettercairn Community Centre;
- Barnardos Lorien Project;
- Foroige;
- Focus Ireland;
- Barnardos Millbrook Lawns;
- Mount Seskin Community College;
- An Cosan;
- St Anne's Primary School;
- St Marks Community School;
- Fettercairn Community Centre;
- Coombe Women & Infants University Hospital;
- South Dublin County Childcare Committee;
- HSE – Public Health Nurses;
- St Brigid's National School;
- Sacred Heart National School;
- St Thomas Junior National School;
- Fledgling's Nursery & Pre-School's;
- St Elmo's Pre-School;
- Brookview Childcare Centre.

Appendix II: Parent Questionnaire

About You and Your Family

ID Number :

1. Are you : Female Male

2. How old are you? _____

3. What is your ethnic or cultural background?

White	
Irish	
Irish traveller	
Any other white background	
Black or Black Irish	
African	
Any other black background	
Asian or Asian Irish	
Chinese	
Any other Asian background	
Other, including mixed background	
Other – write in description	

4. How many children do you have? _____

5. Can you tell me the dates of birth for each of your children?

Child 1 ___ / ___ / ___

Child 2 ___ / ___ / ___

Child 3 ___ / ___ / ___

Child 4 ___ / ___ / ___

Child 5 ___ / ___ / ___

Child 6 ___ / ___ / ___

6. Can you tell me the type of household you live in?

7. Lone parent _____ Two parents living together _____

8. Can you tell me about you and / or your partner’s work situation?

Just tick the box that best describes your situation/ partner’s situation	I am	My partner is
Homemaker, looking after my family and home		
In full- time paid employment		
In part-time paid employment		
Unemployed		
A student		
Retired		
Not able to work due to illness or disability		
Paid state- supported training		
Unpaid state- supported training		
Other (please specify)		

9. What is your highest level of education completed?	I am	My partner is
Primary Education		
Lower secondary (left before Junior or Inter certificate)		
Junior/ Group/ Inter Certification		
Upper Secondary (left before the Leaving)		
Applied Leaving Certificate		
Leaving Certificate/ A- Levels		
Non – degree qualification (diploma)		
Primary Degree		
Post- graduate qualification		
Other (please specify)		



Parent Consultation: Information about Case Studies

Dear Parent/Carer,

We would like to invite you to help us in some research about services for parents, and particularly what helps people to use these services and what could be improved. CDI is doing a small piece of research for Tusla: The Child and Family Agency. Tusla wants to better understand how to improve services for parents and how to make services easier for parents to use. This research will help to inform their plans.

We are inviting a small number of parents or carers to provide us with a case study. This is a way of telling us your story about how you have used local services, what you have found difficult and also the things that really helped. (name) will help you to write your story, in your own words. We don't want to include any names or addresses or any other information which would mean others could work out whose story it is.

In order for us to use your Case Study, we need you to sign a consent form which is attached here.

If you have any questions about this Case Study or the research it is informing, you can contact me on the details below, or ask the person who gave you this information sheet.

With thanks

Marian Quinn
Tel: 01 4940030
Mobile: 087 3158836
Email: marian@twcdi.ie

Parent Consultation: Consent Form

Please sign below to confirm the following:

- I have received information about the case studies and I understand that they will be used in a report which CDI will write for Tusla;
- I understand that the report will not use names or any other information which would allow people to identify me;
- I understand that I can withdraw my case study at any time, and that my contributions can be removed any time up to the report being finalised;
- I understand that the report will be publicly available once it is completed.

Signed: _____
(Name)

Date: _____



Appendix III: Focus Group Structure

Content:	Time allocated:
Welcome and ice breaker: Your name and why you were given this name	10 mins
Explanation of background, purpose and consent for the Focus Groups	10 mins
Completion of consent forms and questionnaires NB questionnaire to be on a power point and talk through this for people	10 mins
1. What parent support services do you currently access? (Brainstorm to flip chart)	10 mins
2. Tell me about those services and what they offer?	15 mins
3. What were the difficulties in accessing or engaging with the service?	15 mins
4. What worked well with the services you have identified?	10 mins
5. Is there anything that would make a difference to your experience of services?	10 mins
Anything to add?	
Close: Thank participants, clarify consent and feedback; One thing I'm looking forward to...	10 mins



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TÚSLA

An Ghníomhaireacht um
Leanaí agus an Teaghlach
Child and Family Agency

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www.doodleden.ie
www.parenting24seven.ie
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