

Waiting Lists Affect Child Development

23rd May 2017

Introduction

We know childhood only lasts a short space of time and during this time children go through stages of growth and development not matched at any other point in their lives. Getting access to medical assessments and treatment when a child needs them is crucial otherwise it really can impair their ability to grow and thrive.

Unfortunately, access to medical treatment is not automatic. Some aspects of Ireland's public health system is failing children, particularly in areas such as access to speech and language therapy, mental health services or obtaining an assessment of need to determine the severity of a disability all of which must be treated and supported early for it to be most effective for the child's development. As a result, children from low income backgrounds are essentially being denied their basic right to an adequate healthcare and this can have lifelong repercussions for them. It is also evident that strong regional disparities exist across the country which influences how quickly a child will receive an assessment or treatment.

The Growing Up in Ireland study shows a strong correlation between lower income levels and poorer health outcomes. For instance the prevalence of childhood conditions such as speech and language difficulties, dyslexia and communication or coordination disorders is much higher among low income groups and has significant consequences on academic performance¹.

"Emily is 2 years 10 months old and has been completely deaf for the last 18 months as she is waiting for a basic grommets operation. She has no language at the minute and has no way of communicating. It has affected her speech development as well as her overall social development. It is appalling that the entire window for early development has been missed for the sake of a 15 minute operation." Barnardos staff member based in Dublin

Through our work, we hear stories every day from parents of children whose lives are affected and whose health is suffering because the public health system is ineffective and subsequently they are languishing on waiting lists to be assessed or receive treatment. These long delays not only have implications for their health but they also drastically affect all aspects of their lives, their ability to participate and have friends, their confidence, their hopes for the future, and their mental health. It also has implications on their school performance and long term employment prospects. The delays often mean children do not meet their essential developmental milestones, and this can have serious repercussions for them and later interventions are more likely to be unsuccessful and far more costly.

These delays make their parents feel helpless and stressed as they try to advocate for their child and fight for their access to treatments and care. In many instances parents are forced to pay for private services to access the care their child requires so that their child's condition does not get worse, but this often comes at the expense of paying their regular household bills. The strain placed upon these families is enormous. However, even securing private assessments is not automatically triggering access to treatment in the public system. Often parents are told their child must be assessed through the public system for access to treatment publicly. For other parents who don't seek a private assessment, they have no choice but to wait for assistance through the public system.

¹ Growing Up in Ireland, (2016) Cherishing all the Children Equally?, Dublin

“...because I am poor my child’s quality of life is just left in the balance. What message does that give our children, because you’re poor you don’t matter as much” Parent based in Mayo

To illustrate this issue of deficiencies and regional disparities in the public health system and their impact on children, this report relies on official HSE statistics and data gathered through a small survey of 242 parents to highlight their experiences. Barnardos ran this online survey in April 2017 and garnered responses from every county across Ireland with the sole exception of Westmeath. Barnardos also collected qualitative data from across Barnardos projects.

The results of this research are startling, but unfortunately they are not surprising. The results reinforce that cycles of poverty, disadvantage and ill-health occur when access to healthcare is denied from such a young age. We specifically concentrated on three areas: speech and language; mental health; and assessment of need largely because if interventions are not available when problems arise it sets children up to fail. These are the three areas most commonly identified in Barnardos projects that affect the children we work with.

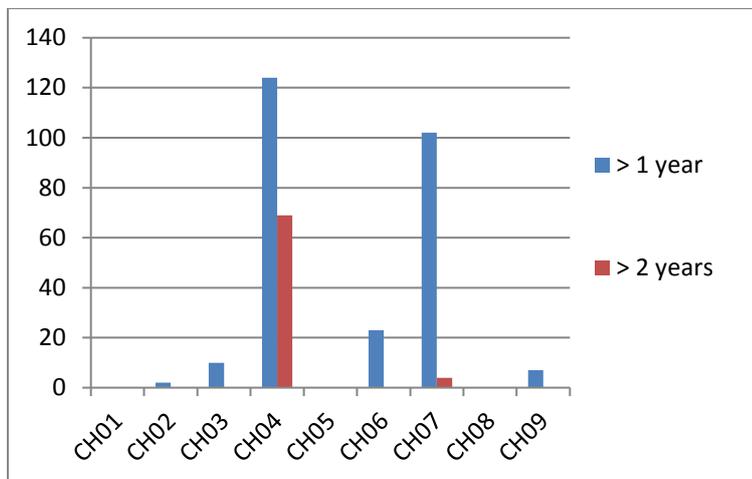
It should be noted some Barnardos projects also operate waiting lists for families seeking help due to the demand on services. Barnardos best practice guidelines is to ensure no family is waiting more than 3-6 months and usually a service is offered before three months. Our services are allocated on the basis of need rather than the length of time a family is on a waiting list. Our services offer support to parents as a stop gap while waiting for assessment or treatment or because there is no appropriate support in that locality. Barnardos offers parenting work, one-to-one with the child, and often end up assisting the parent to build up their case for consideration at the Meitheal meetings to get a more interagency coordinated approach of support for their family.

In Finglas, for example, Barnardos is lead agency in the Better Finglas Project where there are two specific initiatives aimed at supporting children who are on long waiting lists for health services. One involves training speech and language therapists to deliver the Hanen Teacher Talk training to a range of Early Years Professionals, Early Start Practitioners, and Junior Infant Teachers. This programme helps to build the capacity of professionals to support children while they are awaiting interventions. It also supports early identification of issues which may require referral on to other services. These speech and language therapists deliver a range of workshops throughout the year. Secondly, as part of the Triple P Positive Parenting Programme, Better Finglas has linked with professionals in the HSE Early Intervention Team so that they can refer parents from their HSE waiting lists who need support. Triple P focuses on reducing childhood emotional and behavioural problems and often the programme can meet the needs of the parents and children so that they do not need further services. For those who still need an intervention, such as clinical psychology and of the Early Intervention Team, it also highlights those most in need. There are now parenting programmes available all year round, with no waiting list. Both of these programmes are designed to support the needs of families whose lives are affected while they wait for services.

Waiting lists for speech and language services

According to the February 2017 HSE figures, there were a total of 10,201 children and young people aged 0-18 on waiting lists for an initial speech and language assessment. On average 78% were seen within four months which is positive. However, it is extremely worrying there are large regional differences, with CHO4 area (particularly South Lee area in Cork) having 69 children on their waiting list for over two years compared to none in most of the other areas of the country.

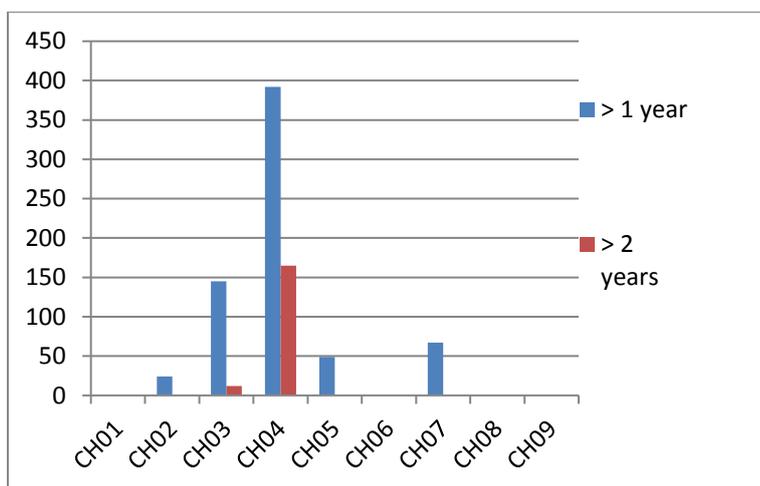
Figure 1: Waiting List for Speech and Language Initial Assessment by Region (February 2017)



CH01	Cavan Monaghan, Donegal, Sligo Leitrim
CH02	Galway, Mayo, Roscommon
CH03	Clare, Limerick, North Tipperary East Limerick
CH04	Kerry, North Cork, North Lee, South Lee, West Cork
CH05	Carlow Kilkenny, South Tipperary, Waterford, Wexford
CH06	Dublin South East, Dun Laoghaire, Wicklow
CH07	Dublin South City, Dublin South West, Dublin West, Kildare West Wicklow
CH08	Laois Offaly, Longford Westmeath, Louth, Meath
CH09	Dublin North, Dublin North Central, Dublin North West

Further to this, the February 2017 HSE figures also show there were an additional 10,118 children and young people aged 0-18 on waiting lists for further speech and language therapy. This list shows delays are more common with only 55% of these seen within four months, and almost 2% were waiting for more than two years. Again CHO4 area, particularly North Lee in Cork, fares the worst with 165 children waiting more than two years for treatment. It is conceivable that a child in that area has to wait in excess of four years before access to regular treatment is given. This is unimaginable given the short window of learning communication skills and verbal reasoning that happens in infancy and early childhood.

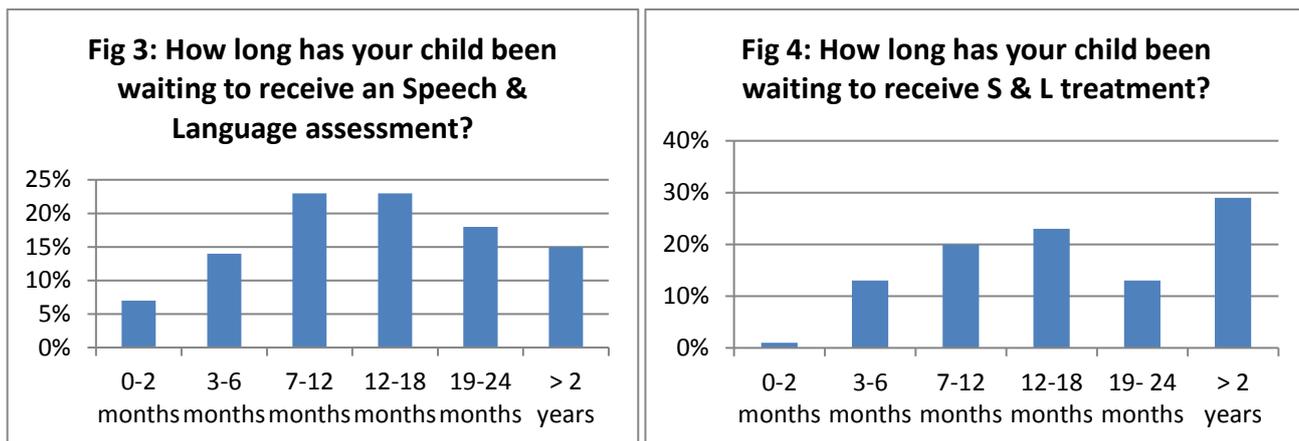
Figure 2: HSE Waiting List for Speech and Language Further Therapy by Region (February 2017)



CH01	Cavan Monaghan, Donegal, Sligo Leitrim
CH02	Galway, Mayo, Roscommon
CH03	Clare, Limerick, North Tipperary East Limerick
CH04	Kerry, North Cork, North Lee, South Lee, West Cork
CH05	Carlow Kilkenny, South Tipperary, Waterford, Wexford
CH06	Dublin South East, Dun Laoghaire, Wicklow
CH07	Dublin South City, Dublin South West, Dublin West, Kildare West Wicklow
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Barnardos survey found similar high waiting times. Of the respondents who signalled they were waiting for speech and language services, 56% had waited for more than 12 months for an initial assessment and 15% had waited for more than two years. Again those in the Cork region were waiting the longest.

Figures 3 & 4: Barnardos Waiting List Survey (2017) (Sample 242 respondents)



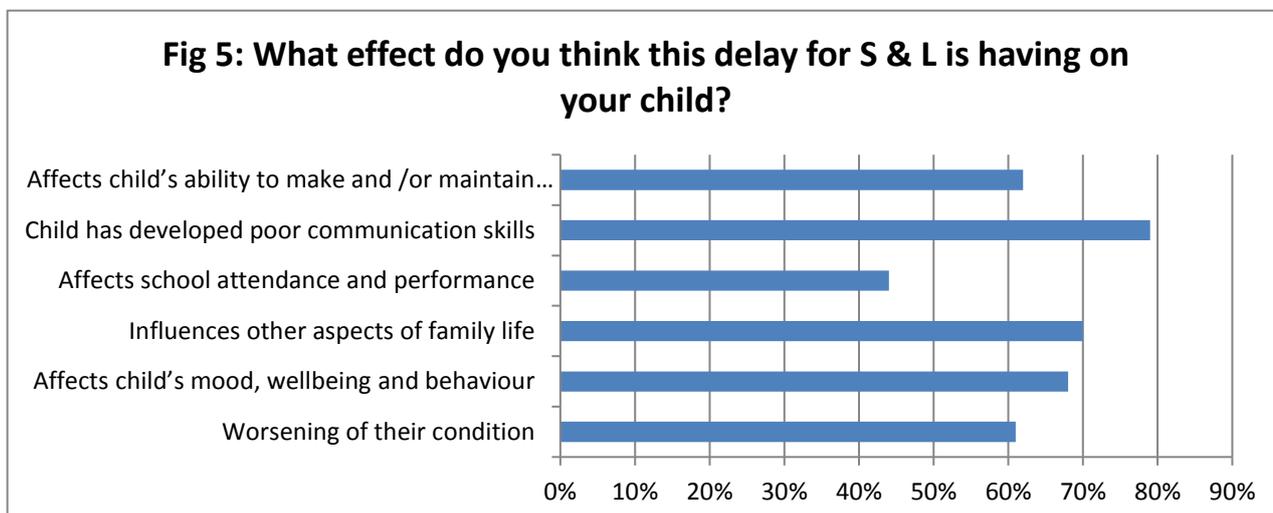
The waiting times for treatments were far worse, with 65% waiting for more than a year, and 29% waiting for more than two years. These figures are incredibly high and it should be remembered that these wait times are in addition to the time already waited for the initial assessment.

“My child is struggling every day and we have no idea how long we have to wait to see professionals to get help”. Parent based in Meath

“My child waited 9 months to be seen by a Speech and Language Therapist, he has never spoken a word and he’s 2.5 years old. The therapist noted he had a disorder not a delay but made no diagnosis and instead simply placed him back on the list for another 12 months and placed him on a list for therapy that is 7 to 9 months long. We since paid to go private, received an appointment within 2 weeks and a diagnosis, therapy began that day with regular weekly appointments which we are now having to pay €55 for each appointment. He has a severe speech condition which requires early intervention as he will spend many years in therapy and it is important to begin that work as early as possible as it will affect his daily communication, his ability to make friendships and more importantly it will affect his ability to learn in a mainstream school.” Parent based in Dublin

It is clear from the chart below that these delays are affecting all areas of these children’s lives. It is affecting all aspects of their development. It is even more frustrating to know much of it could be avoided if sufficient speech and language therapists and services were in place across the country.

Figure 5: Barnardos Waiting List Survey (2017) (Sample 242 parents)



According to the HSE National Service Plan 2016 up to €4m was provided to facilitate the recruitment of 83 posts for Speech and Language Therapy. So far there are 74 names confirmed against the 83 posts, 68 of these have commenced employment.

While these posts are much needed, the demand is still far outstripping supply. Inclusion Ireland have shown that while international research recommends caseloads of between 30-65 children for each speech and language therapist, the numbers of speech and language therapists in Ireland would have to double for these standards to be met.²

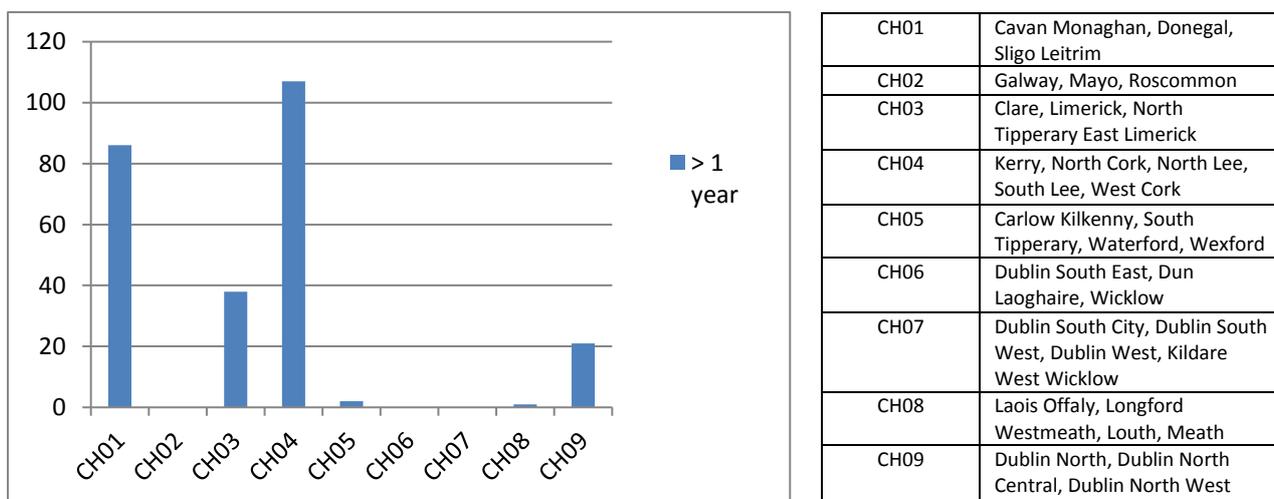
Waiting lists for mental health services

When children and young people need to access mental health services in Ireland they are referred to CAMHS –Child and Adolescent Mental Health Services. CAMHS provides assessment and treatments to young people and their families.

According to figures from the HSE for February 2017, there were 2,520 children and young people on waiting lists to be seen. This figure represents an increase of over 44% from the same period last year, so the pressures on the system are increasing dramatically.

It is extremely worrying these figures show that over 10% of these children and young people had been waiting more than 12 months for an initial appointment. Again strong regional variations are evident, with CHO4 (Kerry, North Cork, North Lee, South Lee and West Cork) recording 107 cases were waiting more than 12 months in comparison to none in CHO2 (Galway, Mayo, Roscommon).

Figure 6: Waiting List for First Appointment with CAMHS (February 2017)

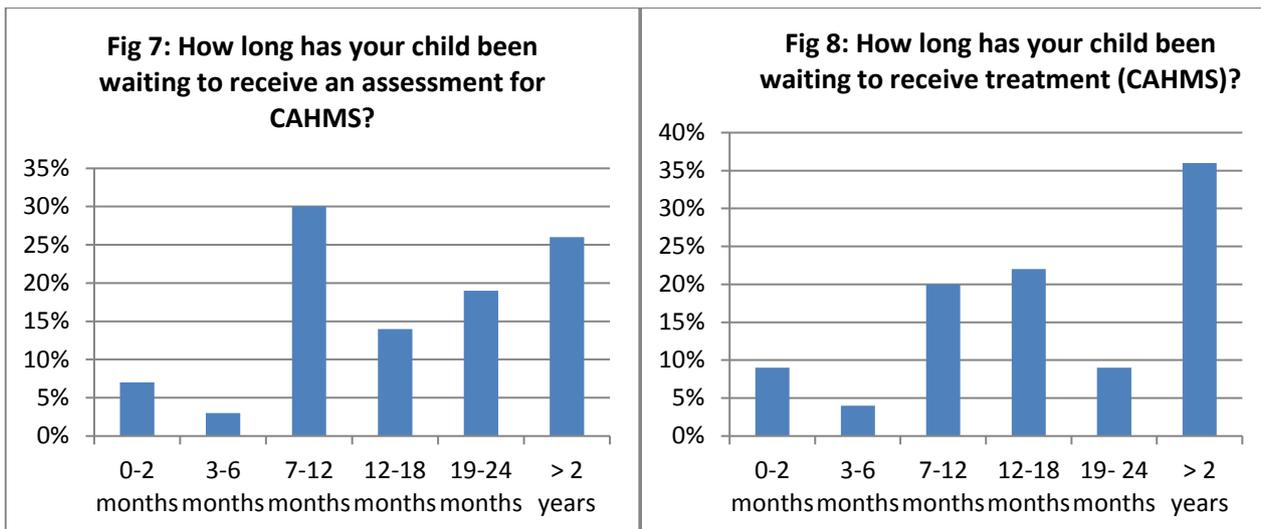


In Barnardos own survey, 24% of respondents have been on waiting lists for CAMHS services. Of these, almost 60% have been waiting for over a year, and over a quarter (26%) have been waiting more than two years for an initial appointment. Again those in the Cork region fared worst. This is before these young people even get access to the treatments they need, which involves waiting on more lists. Over a third of our respondents (36%) were waiting more than two years for the treatments their children needed.

“My child has been waiting five years to access the treatment needed, he is 12 now and his mental health has drastically deteriorated, he now has anxiety and socially feels excluded.” Parent based in Cork

² The Case of Speech and Language Therapy (2014), Pauline Conroy.

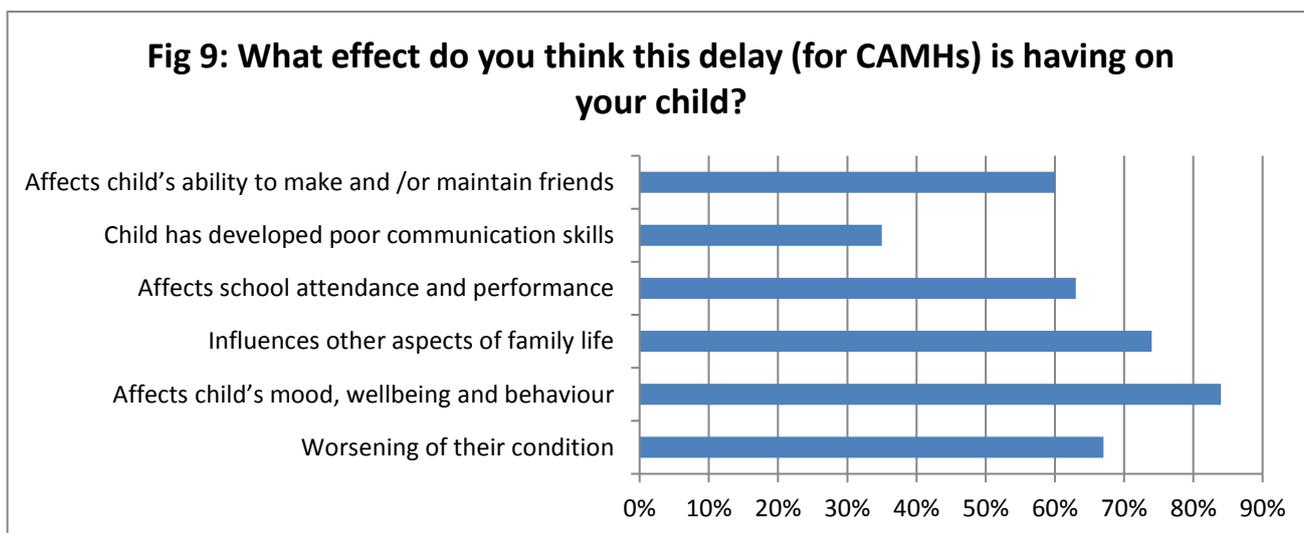
Figures 7 & 8: Barnardos Waiting List Survey (2017) (Sample 242 respondents)



Children and young people need to have services available to them as soon as they require them. These delays are having unnecessary repercussions to young people’s well-being, their development and their lives. The consequences of languishing on waiting lists is affecting all aspects of their childhood, with parent’s believing the biggest effect being on their child’s mood, wellbeing and behaviour which in turn influences other aspects of family life. Tragically, delays in accessing much needed mental health support can be fatal, with Ireland continuing to have one of the highest suicide rates among young people across Europe.

“My daughter has had to wait 2 years for autism assessments to be done by CAMHS. Her behaviour has totally taken over our lives, we are struggling to know how to support her. Barnardos has helped us but she needs medical supports too.” Parent based in Dublin

Figure 9: Barnardos Waiting List Survey (2017) (sample 242 respondents)



The HSE’s response to tackling waiting lists of more than twelve months was to introduce the CAMHS Waiting List Initiative. This requests each regional area to be very proactive in reducing their waiting lists but gives little direction how this is to be achieved. With the reality being more numbers joining the lists and a lack of investment in services, a dearth of primary care centres and staff shortages, it is difficult to see how the problem is to be addressed in any real way. As a result, many parents feel they have no option but to pay for private treatments for their children, which in many cases they cannot afford. This sentiment was

repeated over and over in our survey and points ultimately to a public health system that is not fit for purpose.

“I feel I have no alternative but to seek a private assessment which I can't afford but it has to be done.”
Parent based in Limerick

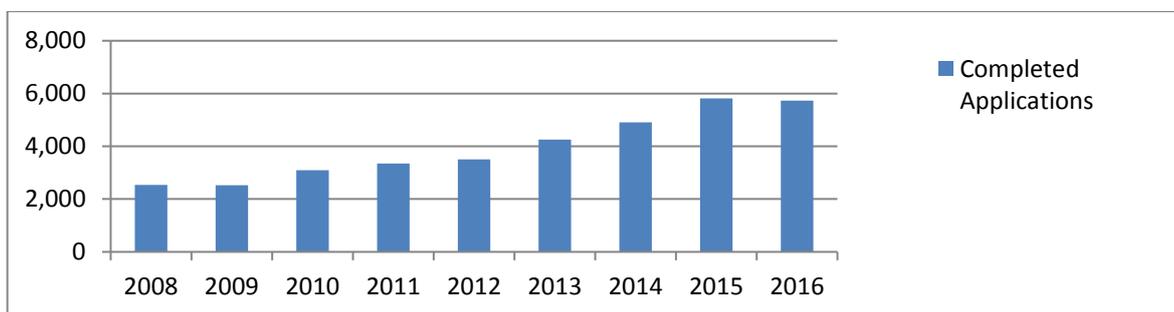
It is hoped to have psychologists as part of the multidisciplinary primary care teams and where this has already occurred, it is having a positive impact on reducing the waiting lists for CAMHS, particularly for assessing conditions like autism. However, the development of these multidisciplinary community based primary care teams is still far behind target. In August 2016 it was reported that of the 36 new primary care centres promised, only one had been completed and only a further 14 were under construction. This is despite the current Programme for Government which aims to establish 80 new centres. It is clear these targets will not be met.

“Sarah (15) is on waiting list for primary care psychology which is a six month waiting list since January 2017. Sarah was showing serious signs of trauma from November 2016 – January 2017 where she would be physically violent towards her mother on a regular basis and displayed huge emotional turmoil and distress. She is very naïve and socially isolated. While things have calmed down without therapeutic input her parents feel Sarah has been ‘forgotten about’. There is a fear that by the time she is seen by psychology, the issues that were outlined in the referral won’t be occurring at that moment and she will only be seen for a brief or one off session. This is despite her parents and services like Barnardos and Jigsaw, as well as Sarah herself, identifying deep rooted and complex underlying issues relating to her childhood”. Barnardos staff member based in midlands

Waiting lists for assessment of need by early intervention teams

Under the Disability Act 2005, children seeking a diagnosis of their disability and subsequent treatment must first undertake an assessment of need by the Early Intervention Teams in the HSE. There are clear statutory timeframes stating these assessments must be commenced within three months of an application received and completed within a further three months. However, unsurprisingly these timeframes are often not being met with the HSE admitting the average duration of the assessment process being over 11 months. There were 5727 applications received in 2016 which has grown exponentially every year beginning with 2,535 in 2008.

Figure 10: HSE Figures for Completed Assessment of Need Applications



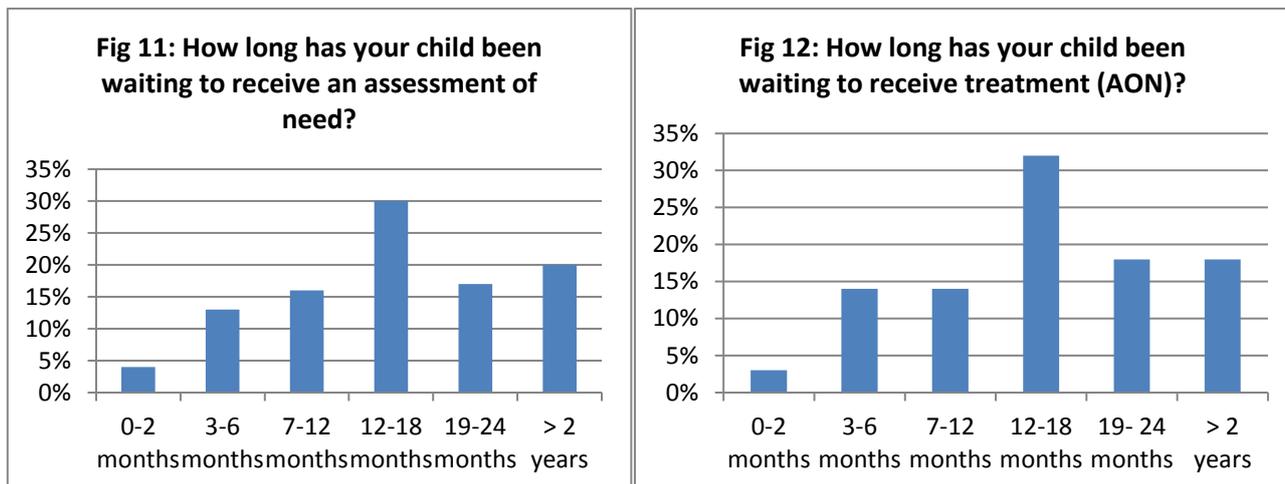
Again it should be remembered that these figures reflect the waiting times for an initial assessment, and in the majority of cases this is then followed by an extensive wait for treatment.

Figures from the HSE show that again there are huge regional differences. At the end of 2016, of the 3960 overdue applications nationally for assessment of need, 1,732 of these were from the Cork/Kerry region. This is a shocking 44% of the total number of overdue applications nationwide.

Barnardos survey found that 96% of our respondents had waited for longer than the statutory timeframe of 3 months for an assessment of need. In fact, over two thirds (67%) had waited for more than 12 months, with 20% waiting for more than 2 years.

In addition, the survey found that after this initial wait, respondents waited on average a further 12-18 months to receive treatment. These waits are simply unacceptable as the valuable learning opportunities in early childhood are being missed daily.

Figure 11 & 12: Barnardos Waiting List Survey (2017) (Sample 242 respondents)



“Brian’s mum was trying to access a preschool for her son then aged 3.5 years. But Brian has some health issues that need to be diagnosed. Brian was referred to the Early Intervention Team in January but was told it would be a further 6 months before he would be seen. The Early Intervention Team did advise that as Brian wasn’t toilet trained it would be a barrier for him accessing preschool. However, because Brian was not yet an active case for Early Intervention Team, the Occupational Therapy Team would not be able to provide tailored information to support toilet training. It is likely a full year will have passed before Brian secures a pre-school place”. Barnardos staff member, Early Years Service, Finglas

The HSE has instigated targeted actions since 2011 to reduce waiting times through holding additional clinics, prioritising assessments and reconfiguring resources. However, the effectiveness of these actions are in doubt as again strong regional disparities are occurring. For instance, some regions have access to specialist units like an Autism Spectrum Disorder Unit, while others do not. The repercussions of the moratorium on staff recruitment during the recession are still being felt as staff numbers remain chronically low. Some parts of Dublin have over 400 cases waiting to be assessed and a lot of reviews that are waiting also while others have much fewer cases pending. This can be largely due to the lack of comprehensive primary care services in areas where population sizes have grown considerably. There is also no national early intervention policy to ensure uniformity in the processes of assessment and provision of services for each child with a disability in Ireland. This no doubt encourages regional disparities.

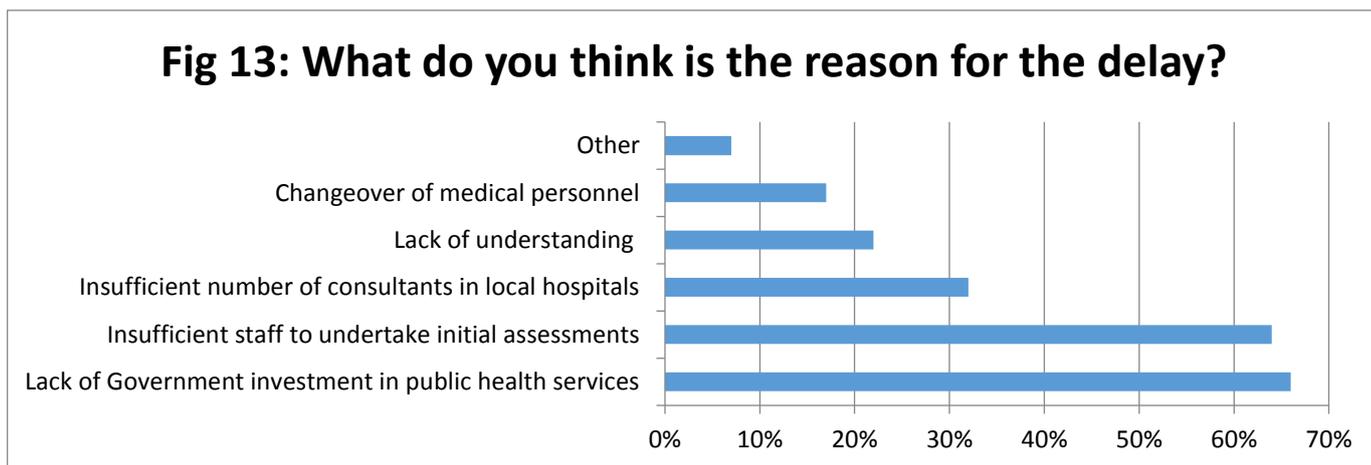
“Parents often feel they are on a merry go round of disability services, waiting for different assessments, reports and services. It is really frustrating for them as they are often desperate for support as they know their child is suffering”. Barnardos staff member based in Dublin

Also since 2014, the HSE established Children’s Disability Network Teams to achieve a consistent service to children based on their individual needs regardless of where they live. These reconfigured teams hope to have a positive impact on ability to meet statutory time-frames, yet this impact has yet to be felt.

Reasons for delay

The majority of parents in our survey perceived that the primary reason for the delay in their child getting an initial assessment or treatment is because of the ongoing underfunding by the Government in Ireland's public health system. They noted insufficient numbers of staff to undertake assessments and insufficient specialists in primary care teams to treat and support children locally in the community. However, it should be noted that despite this general perception of a lack of funding to health services, the Government committed a quarter of their entire budget to the Department of Health last year (€14.6 of €58 billion). This in turn raises worrying questions about how public finances are being used if investment is high and services are poor. Why are children languishing on waiting lists despite these levels of investment?

Figure 13: Barnardos Waiting List Survey (2017) (sample 242 respondents)



Conclusion & Recommendations

All patients need timely access to assessments and interventions but this is more acute for children given their rate of growth and development during childhood. Any delay or failure to receive treatment can have serious negative impact on other aspects of their childhood and into their future. Also given the strong correlation between health inequalities and deprivation, the sooner the interventions the better to break those cycles of poverty and disadvantage. But it is clear, too many children's health, wellbeing and overall development is being compromised because of our insufficient and at times non-responsive public health system.

Barnardos believes access to health services must be consistently based on need not on ability to pay. As a matter of urgency, the following services must be made available to tackle lengthy waiting lists:

- Fully implement the draft proposal of the Oireachtas Committee on the Future of Healthcare (2017) to stop treating private patients in public hospitals, except in cases where specialist treatment is needed. This would drastically reduce the numbers of patients on waiting lists, and would ensure more public patients can access public health services in a timely manner.
- Guarantee one Primary Care Team with a full complement of multidisciplinary professionals for every 1,500 children. These teams must comprise GPs, nurses, home helps, physiotherapists, speech and language, psychologists and occupational therapists, and act as a one stop shop for community care needs.
- Tackle regional disparities by modifying the resource allocation model in line with the reality that the prevalence of conditions such as speech and language difficulties, dyslexia and communication or coordination disorders is much higher among low income groups. This approach along with age profiling of the population areas would ensure services are distributed more appropriately and patients treated based on need and not their ability to pay.
- Develop 24/7 crisis intervention mental health services across the country. Young people have described accessing supports through hospital A&E departments as inappropriate and distressing to an individual experiencing a mental health crisis.

- Ensure CAMHs has its full staffing levels as originally envisaged in Vision for Change.
- Back fill vacancies in the HSE Early Intervention Teams as a priority.
- Implement a National Early Intervention Policy to ensure uniformity in the processes of assessment and provision of services for each child with a disability in Ireland.