Summer Waiting List Report

June 2018

Introduction

In 2017 Barnardos published two reports examining the issue of children waiting for health and developmental treatment. Our reports uncovered widespread delays and inconsistencies in the delivery of children's health services. Significant delays in accessing treatment can have profound, long lasting impact on a child's health, development and well-being. Lack of treatment can result in a childhood lost. Yet when a child is physically lost, the world takes notice. Search parties are formed. Front-page stories are printed. We are captivated by the terror and we will all work hard to find that child because we know it's important. The same impetus must also apply when their childhood is being lost, yet unfortunately thousands of children continue to languish on waiting lists.

All children deserve equitable access to healthcare, timely assessment of their need and treatment without delay. Barnardos is revisiting our examination of waiting lists to determine if there has been any improvement in the areas of speech and language therapy, mental health treatment and the assessment of need.

Childhood Spent Waiting

Barnardos works with more than 15,000 children and their families each year. We see first-hand the effect that delayed treatment can have on children's lives and their futures. Waiting for assessment and treatment often also means waiting to participate fully in school, waiting to develop confidence or waiting to build positive relationships with their peers. Anecdotally we are aware of children who face long delays for assessment only to be told they require a different treatment and are pushed to the back of another assessment list. Unfortunately the longer a child waits the less likely the treatment will be effective. If children don't receive the right treatment in time, damage can be irreparable.

"A child in our early years' service has been awaiting for a developmental assessment for 3 years. The child will be 5 in August, but they are unable to move on without an assessment being completed. This means the child will take a place for the third year in our service as there is no way to move forward".

- Barnardos' Project Worker

Childhood is a period of enormous change in skills and capacities and is marked by periods of rapid physical growth.[1] Delayed treatment can impact every aspect of a child's life. School life can become difficult. Struggling with a speech and language, mental health or other developmental problem can delay learning. This can lead to ongoing issues as school becomes a place of stress for a child who is unable to keep up with their peers. Children and young people are very susceptible to real or perceived stigma from their peers and wider social group. They can become isolated and withdrawn or act out due to frustration.

The consequences of delayed treatment does not only affect the child; the whole family can suffer. For parents watching a child struggle with a treatable health problem without knowing when they will be treated is distressing. Parents champion and advocate for their children as best they can but many feel forced to fund private treatment for their child. The cost of each appointment with a Speech and Language Therapist or child psychologist is usually around €100; but paying for private assessments is not always a guaranteed route to public treatment. For parents who can ill afford private treatment this means cutting back on bills and essentials. For parents who cannot afford to pay it means waiting and watching your child suffer.

"My child waited 9 months to be seen by a Speech and Language Therapist, he has never spoken a word at the age of 2 1/2 years. The therapist noted he had a disorder not a delay but made no diagnosis, 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. Which I find ridiculous considering we had already waited 9 months.

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 will affect his ability to learn in a mainstream school environment".

- Parent

[1] Barnardos. (2017) *Partnership with Parents Staff Guidance- Birth to 2 Years*. Dublin: Barnardos.

Barnardos services offer support to parents as a stop gap while they are waiting for assessment or treatment. Parenting work, one-to-one work with the child, and assisting the parent to build up their case for consideration at the Meitheal meetings to get a more interagency and coordinated approach of support for their family are just some of the supports available to the families we work with. Some Barnardos projects also operate waiting lists for families seeking help due to the demand on our 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.

The analysis below sets out how long children are waiting by HSE Community Healthcare Organisation (CHO) area. There are nine CHOs dividing the country geographically.

Speech and Language Therapy

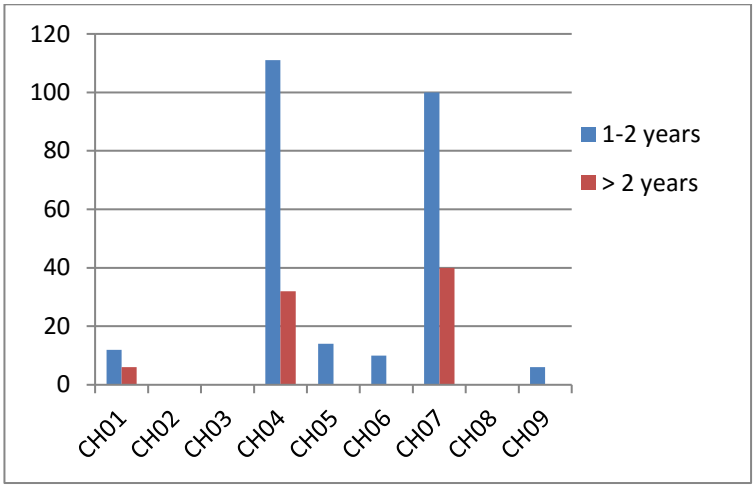
> "My child has a stammer and we finally got a speech and language assessment but have yet to hear back at all about any follow up treatment or programmes, etc. My child's stammer greatly affects her confidence and ability to communicate with her peers and teachers, and it appears to be worsening over time. We were told at her initial assessment that she could participate in a play group with other children her age who also have stammers, but that was months ago now and there has been no further follow-up".
>
> - Parent, Dublin

Speech and Language Assessment:[2]

In March 2018 there were a total of 10,966 children waiting for initial Speech and Language (SL) assessment; a 5.5per cent increase on September 2017.[3] Most children (69per cent) are assessed within the first four months, which is welcome, although the percentage of those seen early has fallen significantly since the same time last year (78per cent).[4] A further 28per cent of children are waiting up to a year for an assessment, while almost 3per cent or 315 children are waiting more than a year for an initial assessment.

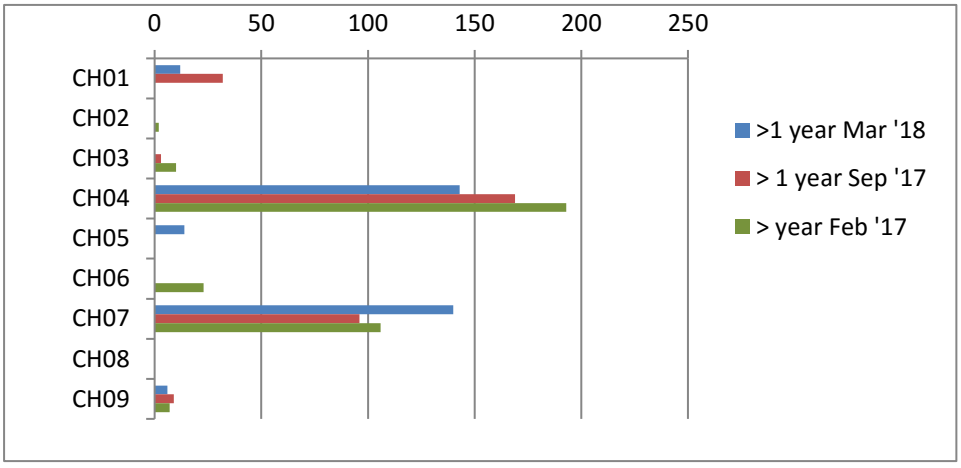
[2] Data collated from response to PQ Ref. Nos. 20360/18.
[3] Barnardos. (2017) *Waiting List Report December 2017.* Dublin: Barnardos.
[4] Barnardos. (2017) *Waiting List Report May 2017.* Dublin: Barnardos.

Figure 1: Children waiting longer than one year for initial speech and language assessment by region (March 2018)



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

Figure 2: Waiting List for Speech and Language Initial Assessment by Region (March 2018, September and February 2017)

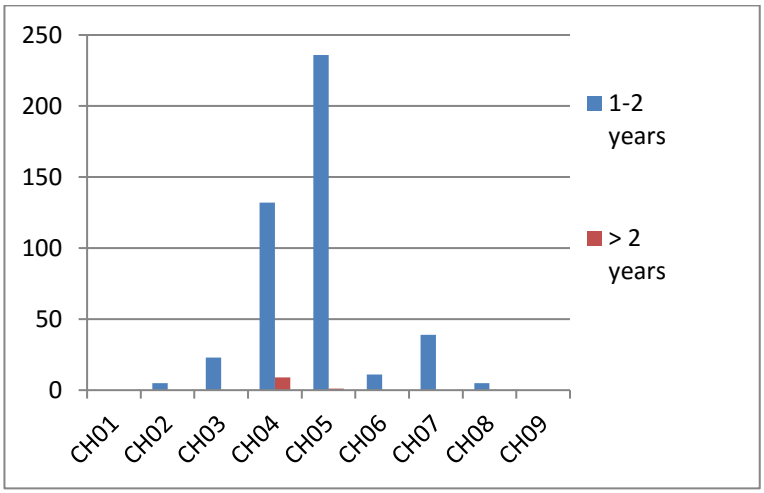


As per Fig. 1, CHO 4 (Kerry, North Cork, North Lee, South Lee and West Cork) remains the worst performing region, followed closely by CHO 7 (Dublin South West, Dublin West, Kildare West and Wicklow). Nationally, as shown in Fig. 2, there has been a sizeable increase (44.5per cent) in the number of children waiting longer than one year for an initial assessment. This increase is accounted for primarily in CHO 7 and CHO 5 (Carlow, Kilkenny, South Tipperary, Wexford, Waterford), while CHO 4 remains poor. In 2017 we found a sizeable decrease in number of children waiting more than a year from 341 children in February to 221 children in September. By March 2018, however, the number has gone back up to 315. It remains to be seen whether this fluctuation is a seasonal phenomenon perhaps driven by speech and language issues being identified in a child's first term in school.

Speech and Language Therapy:[5]

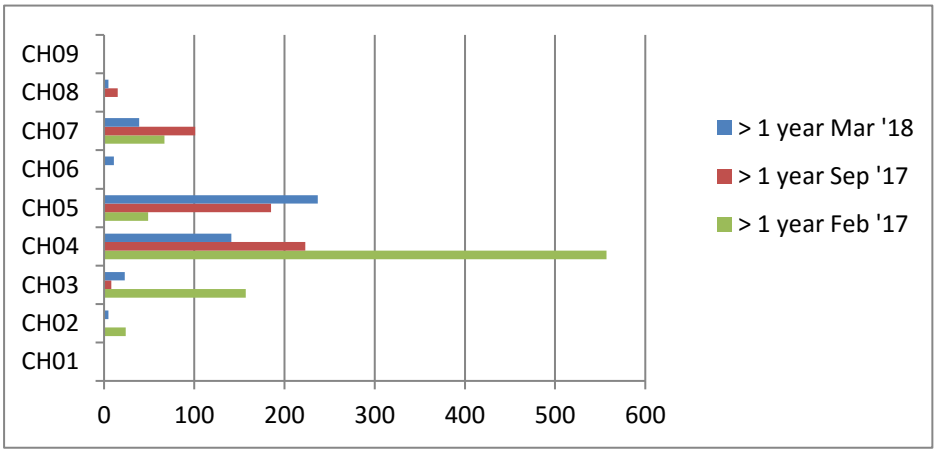
The downward trend in wait times for initial SL therapy we observed in autumn 2017 thankfully continues. In March 2018 there were 7,071 children waiting for their first therapeutic appointment nationwide, 539 fewer than September 2017 which represents a 30per cent reduction since February last year. Just under half of the total 7,071 children in March were waiting less than four months. As Fig.3 shows CHO 5 replaces CHO 4 as the area with the most children waiting longer than a year for initial treatment. Coupled with the increase in the number of children waiting over a year for assessment, this represents a worrying trend for children in the south east. In Fig. 4 we can see the significant progress made in CHO 4 in reducing the number of children waiting longer than a year for their first treatment appointment.

Figure 3: Children waiting longer than one year for initial speech and language therapy by region (March 2018)



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

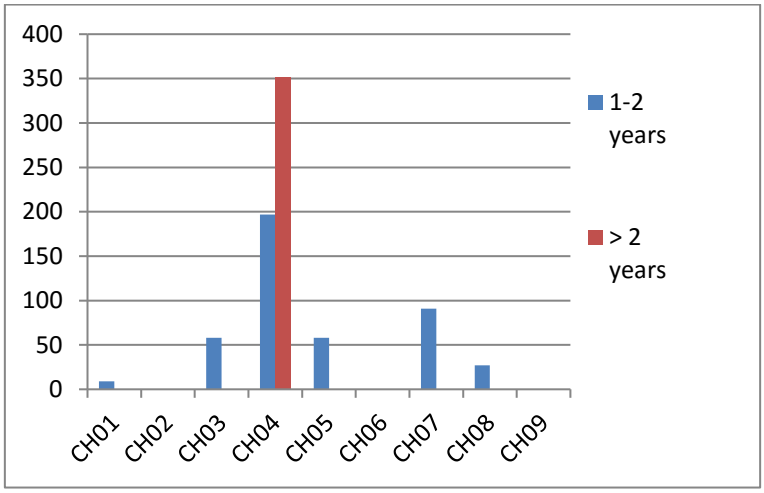
Figure 4: Waiting list for initial speech and language therapy by region (March 2018, September & February 2017)



[5] Data collated from response to PQ Ref. Nos. 20361/18.

In addition to those waiting for their initial SL treatment, there is another large cohort of young people who are waiting for further treatment (n=11,444). The proportion of children seen in the first four months, at just less than half, is low. Worryingly the number of children waiting more than a year (n= 791) is very high. This can be accounted for mostly in CHO 4 where the backlog of children waiting for further SL treatment is extreme; 548 young people are waiting more than a year for further treatment with 351 of these waiting more than two years.

Figure 5: Children waiting longer than one year for further speech and language therapy by region (March 2018)



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

Analysing the assessment and treatment waiting list data together it is clear that demand for SL services outstrips supply considerably. In total there are 29,481 children and young people waiting for SL assessment or treatment nationally, with 1,567 of them waiting longer than one year. Cumulative delays in assessment, initial treatment and further treatment means a child in a CHO with bad delays could be waiting more than four years to fully avail of SL therapy. Bearing in mind the narrow window of speech development in a child, having to wait four years is totally unacceptable.

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.[6] Furthermore the regional disparities between lengths of waiting time points to misallocation of resources. Greater investment and better reallocation of resources is required. The Government launched its pilot scheme for Speech and Language Therapy in schools in 2018.[7] This is a welcome development which will hopefully yield positive results and mean in a broader investment in the future; however, it is unlikely to be beneficial to the

[6] Conroy, P. (2014). *The Case of Speech and Language Therapy*. Dublin: Inclusion Ireland. Available: http://www.inclusionireland.ie/sites/default/files/attach/article/1158/thecaseofspeechandlanguagetherapy1.pdf

[7] Gallagher, G. (2018) 'School speech and language scheme launched worth over €2m', *The Irish Times*, 14 May, [online]. Available at: https://www.irishtimes.com/news/education/schools-speech-and-language-scheme-launched-worth-over-2m-1.3493737 [accessed 15 June]

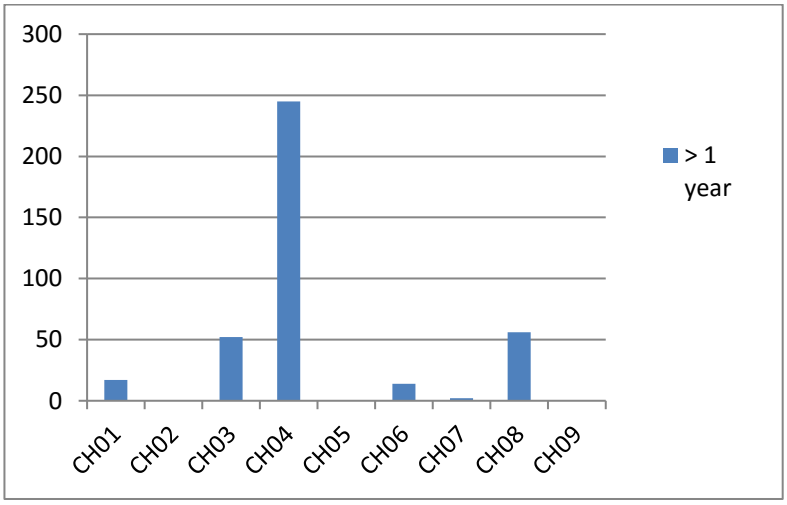
large proportion of children who require intervention before school age. Barnardos supports greater availability of speech and language therapy for school aged children, but as early intervention is crucial it is important existing services are bolstered in tandem with this new scheme.

Child and Adolescent Mental Health Services (CAMHS)[8]

> My child is struggling every day and we have no idea how long we have to wait to see professionals to help.
>
> - Parent

Children and young people are referred to CAMHS for assessment and treatment for mental health services. In March 2018 there were 2,691 children and young people on waiting lists to be seen by CAMHS. This figure represents an increase of 15 per cent since September. This steep rise in the number of children waiting is accompanied, in most areas, by a rise in the number of children waiting longer than one year. Almost 14 per cent (n= 386) of young people have been waiting more than a year for an initial appointment. Again CHO4 is a particular black spot with 208 children waiting more than one year.

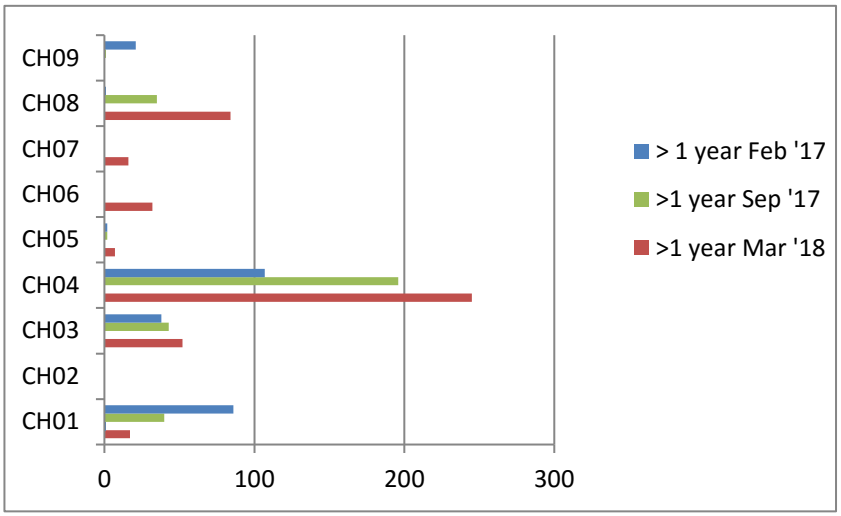
Figure 6: Children waiting longer than one year for initial CAMHS Appointment (March 2018)



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

[8] Data collated from response to PQ Ref. Nos. 20361/18.

Figure 7: Children waiting longer than one year for an initial CAMHS appointment (March 2018, September and 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

The HSE's response to tackling waiting lists of more than twelve months was to introduce the CAMHS Waiting List Initiative. This initiative requires each regional area to be proactive in reducing their waiting lists but gives little direction how this is to be achieved. With the reality being longer waiting times, 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. Ongoing recruitment challenges persist leaving vacancies unfilled for significant durations. The Government claimed it was allocating €35 million increased funding for mental health in its Budget 2018 announcement; however as the dust settled it became apparent that €20 million of this was funding already promised in 2017. That the Government would choose to spend just €15 million out of an extra spend of €1.2 billion on improving mental health services speaks volumes to those children and families suffering on waiting lists.[9]

Many young people on waiting lists for CAMHS would be best treated in primary care; however waiting lists for primary care psychology services are longer than those for CAMHS. In March 2018 there were 6,584 children nationally waiting for an appointment with the primary care psychology service, with 1,684 of these young people waiting more than a year. Despite waiting lists for these services also, where they are available they are having a positive impact on reducing the waiting lists for CAMHS. The Oireachtas Committee on the Future of Healthcare recommended the

[9] Government of Ireland, (2017) *Expenditure Report 2018: Part II - Expenditure Allocations 2018-20* (p.74). Available: http://budget.gov.ie/Budgets/2018/Documents/Partper cent20IIper cent20-per cent20Expenditureper cent20Allocationsper cent202018-20.pdf

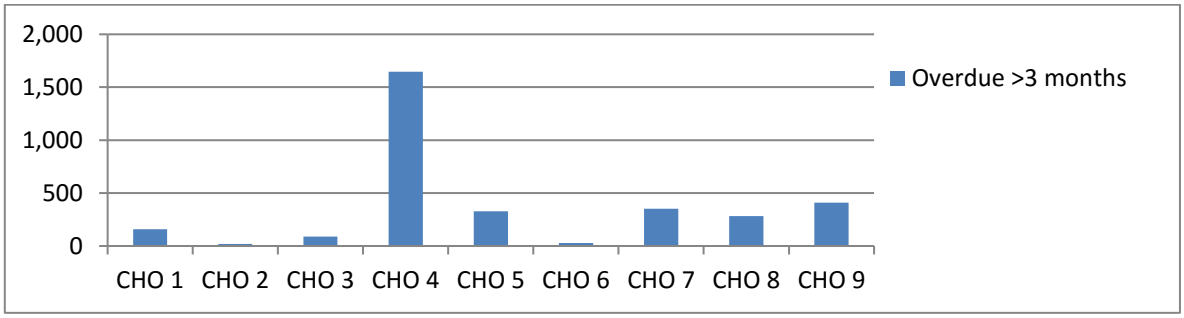
recruitment of 114 assistant psychologists and 20 child psychologists.[10] These positions are being recruited currently, however greater investment is needed in wider primary care services to alleviate the backlog for both primary care psychology services and CAMHS. The development of multidisciplinary community based primary care teams and networks is far behind target. HSE plans for CAMHS in 2018 include increasing the number of young people seen by 27%, an out-of-hours liaison service and a seven-day response service; however there is little sign on the ground of any improvement.[11] Indeed, there is evidence on the ground of a system which is creaking under the strain of lack of resources and shortages of staff.[12]

Assessment of Need[13]

Assessment of need is undertaken by HSE Early Intervention Teams (EIT) for children aged 0-6 years who require a diagnosis of disability or developmental needs and subsequent treatment. The teams are made up of Occupational Therapists, Clinical/Educational Psychologists, Physiotherapists, Social Workers and Speech and Language Therapists. Children can be referred by their GP or any other health or social care professional. Under the Disability Act 2005 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.[14] However, the number of new applications for assessment following commencement of the Act in 2007 has risen year on year. Delays have resulted in number of court actions being taken by families of children forced to wait beyond the statutory limit for assessment. In 2017 Barnardos highlighted how the statutory timeframes are not being met, despite the development various improvement initiatives at CHO level.

[10] Oireachtas Committee on the Future of Health Care. (2017). Sláintecare Report. Dublin: Houses of the Oireachtas.
[11] Minister for Mental Health and Older People, (Jim Daly), Ceistenanna- Questions- *Dáil Éireann,* vol.53, 19 April 2018
[12] Burns, S. (2018). Psychiatrists resigning as position 'untenable and unsafe'. *Irish Times*, 13 June 2018, [online]. Available at: https://www.irishtimes.com/news/health/psychiatrists-resigning-as-position-untenable-and-unsafe-1.3529628
[13]Data collated from response to PQ Ref. Nos. 20362/18.
[14] Government of Ireland. (2005) *Disability Act 2005.* Dublin: Government Publications Office.

Figure 10: Applications for Assessment of Need which are more than 3 months overdue for completion (March 2018)



In March 2018 there were 4,242 children waiting for assessment of need to be carried out. Of these, 4,104 children, 80 per cent, have been waiting beyond the statutory time limit of three months. Yet again, CHO 4 comes out the worst in terms of the number of children waiting for assessment, representing half the national figure for delays of more than three months.

Additional funding was secured by the HSE for therapeutic services and has been invested in the Progressing Disability Services for Children and Young People (0-18s) Programme (PDS) which has been in operation since 2014. In 2017 all CHOs developed improvement plans to address areas of non-compliance with statutory time frames. The HSE has stated it is targeting resources in CHO areas of 'particular difficulty'; however it would appear in the case of CHO4 this has not been successful. The recent introduction in April 2018 of a new Standard Operating Procedure for Assessment of Need by the HSE has been met with outcry from a variety professionals and professional bodies working with children in need of assessment.[15] There are concerns proposed changes would allow the HSE to remove the diagnostic assessment from the process and instead refer or sign post families to available services, as well as concerns over restrictive time limits being placed on assessments. This may result in more families feeling they have no option but to seek private assessment.

Conclusion and Recommendations

Children experience a rate of development unparalleled in their lifetime. When faced with a health or developmental challenge they need access to timely assessment and treatment. Delays can have serious and sometimes irreparable negative effects on other aspects of their childhood and into their future. Furthermore, given the strong correlation between health inequalities and deprivation, the sooner the intervention the better to break cycles of poverty and disadvantage. However, it is clear that too many children's health, wellbeing and development are being compromised because of the overall deficiencies and regional disparities that exist in our public health system.

[15] Baker, N. (2018) Psychologists slam plans for assessment of children. *Irish Examiner*. 05 April 2018. Online. Available at https://www.irishexaminer.com/breakingnews/ireland/psychologists-slam-plans-for-assessment-of-children-835845.html

Barnardos believes access to health services must be consistently based on need not on one's ability to pay. As a matter of urgency, the following actions must be taken to tackle the child waiting list crisis:

- Where recruitment of personnel is an issue review entry criteria for and invest in additional places on training courses.
- Invest €5 million to increase the number of Speech and Language Therapists by 100 to reduce waiting list backlog for speech and language assessment and treatment.
- Guarantee one Primary Care Team with a full complement of multidisciplinary professionals for every 1,500 children. These teams must comprise of GPs, nurses, home helps, physiotherapists, speech and language, psychologists and occupational therapists, and act as a one stop shop for community care needs.
- Expand the Counselling in Primary Care Service to provide counselling in the community for children and young people.
- Ensure referral pathways and criteria are clearly defined for GPs and other health and social care personnel. Create a resource for parents which outlines what services are available and how to access them.
- 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.