Waiting List Report

December 2017

Introduction

In spring 2017 Barnardos' *'Waiting Lists Affect Child Development'* policy-briefing examined the existing state of waiting lists for a number of children's health services and the impact they are having on children's development. We found widespread inconsistencies in the delivery of some children's health services. These inconsistencies mean children's access to healthcare is determined by where they live or if their parents can afford private treatment. Delayed treatment can have profound effects for a child's health, development and well-being. All children deserve equitable access to healthcare, timely assessment of their need and treatment without delay. Barnardos is now revisiting our examination of waiting lists to determine if there has been any improvement for the thousands of children waiting for treatment.

Childhood Spent Waiting

Through Barnardos' work with families we hear constantly from parents of children who are suffering while languishing on waiting lists. For these children childhood is on hold. 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. Tragically oftentimes the longer a child waits for an intervention the less likely the treatment will be effective. This is particularly true for very young children whose physical, mental, social and emotional development happens at a speed not matched again in their lifetime. If children don't receive the right treatment in time damage is done. They won't get another chance.

> "For a three year old who only has a few words, waiting a year for Speech and Language treatment is like waiting a lifetime." - Barnardos' Project Worker

The impact is not only felt by the children. For parents watching your child struggle with a treatable health problem without knowing when they will be treated is agonising. Parents champion and advocate for their children as best they can but frequently the only option is to fund their child's assessment or treatment themselves. The cost of each appointment with a Speech and Language

Therapist or child psychologist is often around €100. For parents who can ill afford to pay this means taking money from elsewhere in the household budget and trying to make ends meet. For parents who cannot afford to pay it means waiting and watching your child suffer. Either way the stress and strain placed on families should not be underestimated.

Also paying for private assessments is not always a guaranteed route to access publicly funded treatment. Parents may be told they need to have their child assessed through the public system to access public treatment. This is not always the case however and is an example of a health system riddled with inconsistencies. Not only do these inconsistencies mean children are treated differently based on their parents ability to pay; but also based on where they live in the country. Children in certain parts of the country are undoubtedly worse off than others due to sometimes vast differences in waiting times. This research looks at the differences between HSE Community Healthcare Organisation (CHO) areas with regard to accessing speech and language services and Child and Adolescent Mental Health services.

> "We've had to go private as my daughter doesn't have time to wait for the Government. It's very expensive but the delay was putting huge pressure on the family." - Parent, Donegal

Barnardos services offer support to parents as a stop gap while 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 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.

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. The first 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.

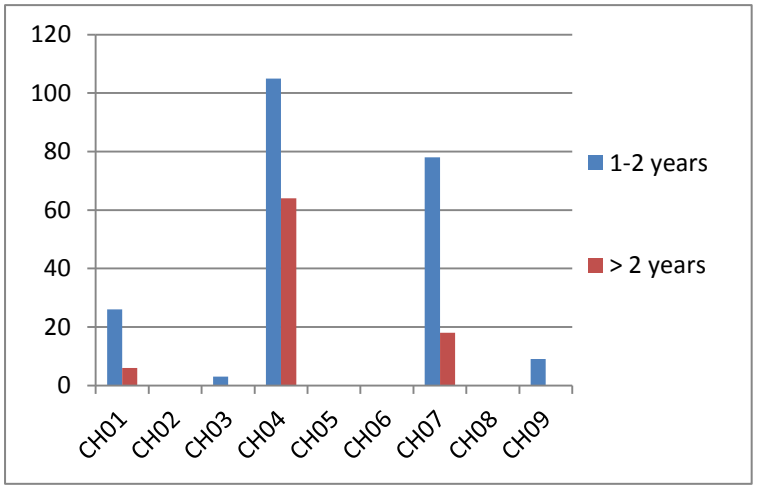
Speech and Language Therapy

"In this country, adequate health services are only available to those who can afford to pay. We have put ourselves under unbearable pressure to pay for a private Speech and Language assessment for my 4 year old son because of the length of the waiting list for assessment in West Dublin. We were then told the wait is 10 months for treatment. We are now unable to pay gas and electricity bills because we feel our only option is to continue paying €60 per half hour for private treatment." - Parent, Dublin

Speech and Language Assessment:

In September 2017 there were a total of 10,390 children waiting for Speech and Language (SL) initial assessment; around a 2% increase on February 2017. Most children (71%) are assessed within the first four months, which is welcome, although the percentage of those seen early is down slightly from February (78%). As per Fig. 1, CHO 4 (Kerry, North Cork, North Lee, South Lee and West Cork) is still the worst performing region. There has been both good and bad news for those children waiting the longest for an initial SL assessment. The good news, as shown in Fig. 2, is that at a national level there has been a sizeable decrease (35.2%) in the number of children waiting longer than one year for an initial assessment. Unfortunately, however there has also been an 11% (n = 15) increase in the number of children waiting more than two years since February 2017. This increase can be accounted for by CHO 1 (Cavan/Monaghan, Donegal, Sligo and Leitrim), and CHO 7 (Dublin South West, Dublin West, Dublin West, Kildare West and Wicklow); while the number waiting longer than two years in CHO 4 remains high. This represents a small but significant cohort of children but a most worrying development.

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



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
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CH08	Laois Offaly, Longford Westmeath, Louth, Meath
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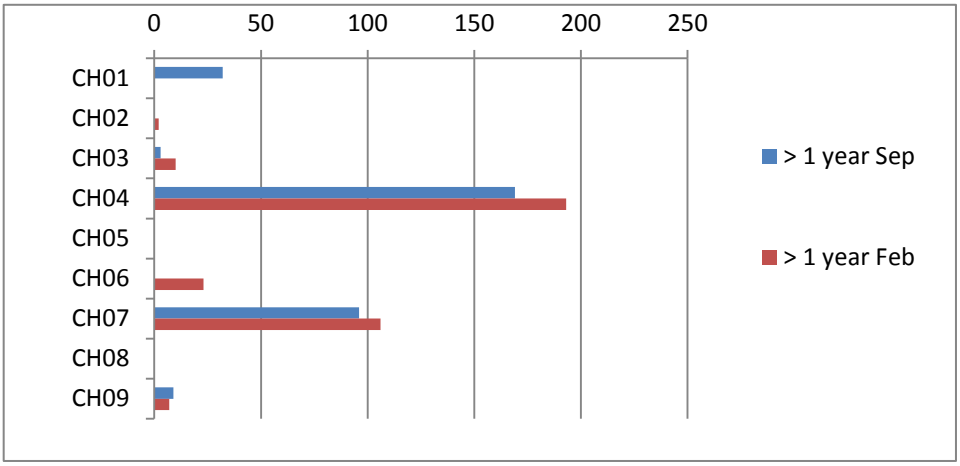
Figure 2: Waiting List for Speech and Language Initial Assessment by Region (February & September 2017)[2]

[1] Data collated from response to PQ Ref. Nos. 51588/17 & 51589/27.



Speech and Language Therapy:

There has been a very welcome reduction in the number of children on a waiting list for SL therapy during the same period, with almost 25% fewer children waiting for therapy in September (7,610) as there were in February (10,118). Just under half of the total 7,610 children in September were waiting less than four months. As Fig.3 shows CHO 4 remains a particular problem region in terms of the numbers waiting and length of wait; however there has been a considerable improvement since February 2017. Fig 4 clearly demonstrates that CHO 7 and CHO 5 (Carlow, Kilkenny, South Tipperary, Waterford and Wexford) meanwhile have seen notable increases in the number of children waiting more than one year. Coupled with the length of time waiting for an initial assessment in CHO 7, this means some children could be waiting more than four years for treatment.

Figure 3: HSE Waiting List for Speech and Language Further Therapy by Region (September 2017)[3]

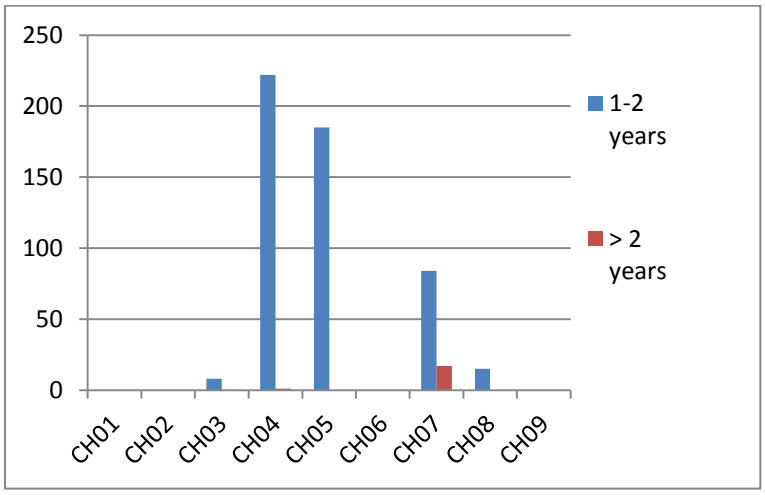


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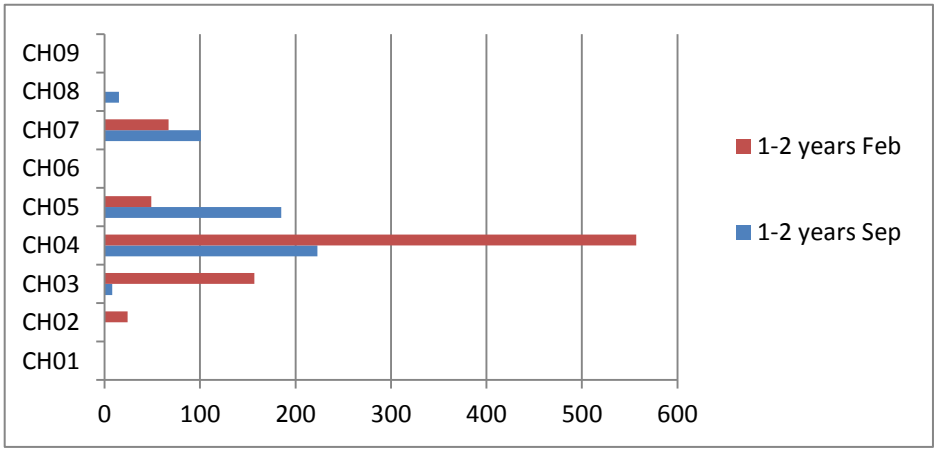
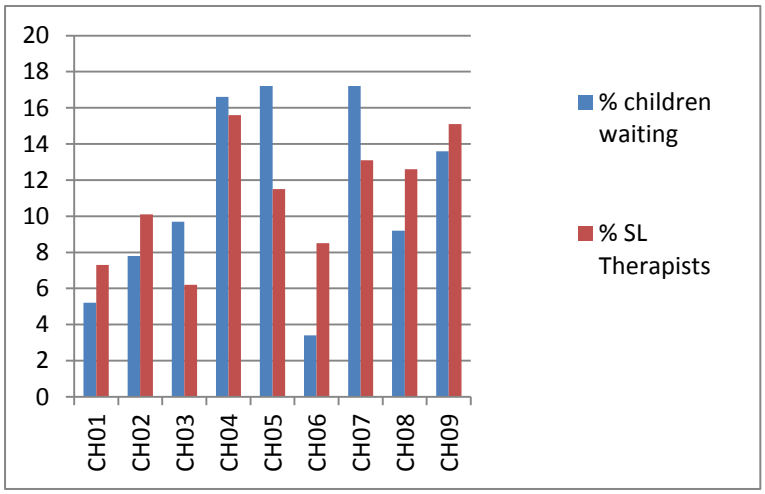
Figure 4: Waiting List for Speech and Language Therapy by Region (February & September 2017)[4]

[2] Data collated from response to PQ Ref. Nos. 51588/17 & 51589/27 (September) and PQ Ref. Nos. 17208/17 & 17209/17 (February).
[3] Data collated from response to PQ Ref. Nos. 51590/17 & 51591/27.



It is clearly evident that overall, demand for Speech and Language Therapy outstrips supply. 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.[5] Furthermore the regional disparities between lengths of waiting time points to misallocation of resources. It's clear from Fig 5 that certain areas have a higher level of demand comparative to their allocation of SL Therapists. In CHO 5, CHO 4 and CHO 7 the result is longer waiting times for children. In CHO1, however, there is a comparatively high level of SL Therapists compared to need and yet children are still waiting longer than other areas of the country.

Figure 5: HSE Waiting List for Speech and Language Assessment & Therapy compared with number of SL Therapists[6]



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[4] Data collated from response to PQ Ref. Nos. 51590/17 & 51591/27 (September) and PQ Ref. Nos. 17210/17 & 17211/17 (February).
[5] Conroy, P. (2014) *The Case of Speech and Language Therapy*. Dublin: Inclusion Ireland. Available: Available: http://www.inclusionireland.ie/sites/default/files/attach/article/1158/thecaseofspeechandlanguagetherapy1.pdf
[6] Data collated from response to PQ Ref. Nos., 45504/17, 51590/17 & 51591/27.

Greater investment and better reallocation of resources is required. The Government announced €2 million to fund a pilot scheme for Speech and Language Therapy in schools in 2018.[7] This is a very welcome development which will hopefully yield positive results for the children affected and result in a broader investment in the future; yet it is unlikely to make any real difference for the those children and young people currently waiting.

Child and Adolescent Mental Health Services (CAMHS)

> "The waiting list for CAMHS in our area is nine months. My son is still waiting. In emergency and urgent situations CAMHS are unable to respond as their resources are too low and they are missing consultants. I've tried complaining but I get nowhere"
>
> - Parent, Clare

Children and young people are referred to CAMHS for assessment and treatment for mental health services. According HSE figures for September 2017, there were 2,333 children and young people on waiting lists to be seen. This figure represents a decrease of 9% since February. While this decrease is welcome, worryingly there has been a 20% increase in the number of children waiting longer than one year for their first visit. This is an unacceptable situation for anyone experiencing mental health difficulties; but especially for children and young people.

Fig. 6 demonstrates there is a big regional disparity in the length of time children and young people are waiting for mental health services. While four areas (CHO 2, CHO 5, CHO 6 and CHO 7) have very few children waiting longer than one year, four other areas (CHO1, CHO 3, CHO 8 and CHO 9) have quite similar levels of delays. As we found earlier in the year, Fig. 7 shows CHO 4 (Kerry, North Cork, North Lee, South Lee and West Cork) remains a particular black spot for CAMHS waiting times. In fact, shockingly the number of children and young people waiting in the area has doubled in the seven months from February to September. This is a situation which requires close monitoring and allocation of targeted resources.

[7] Government of Ireland, (2017) *Expenditure Report 2018: Part II - Expenditure Allocations 2018-20* (p.74). Available: http://budget.gov.ie/Budgets/2018/Documents/Part%20II%20-%20Expenditure%20Allocations%202018-20.pdf

Figure 6: Waiting List for First Appointment with CAMHS (September 2017)[8]

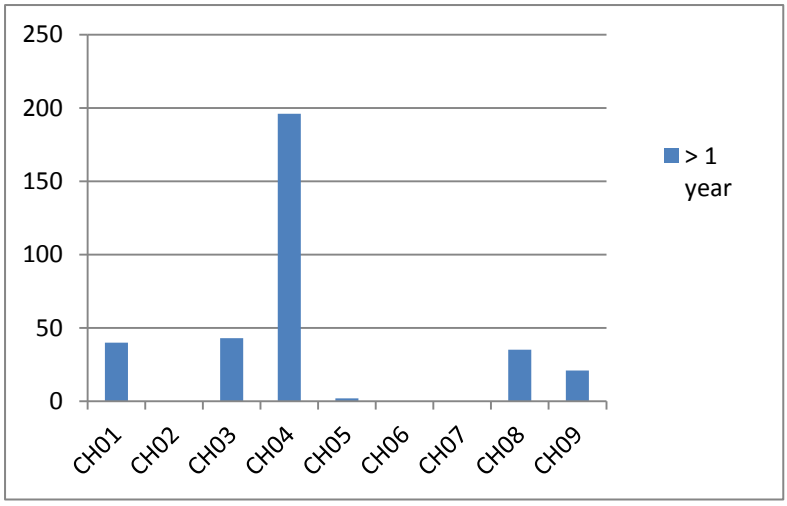

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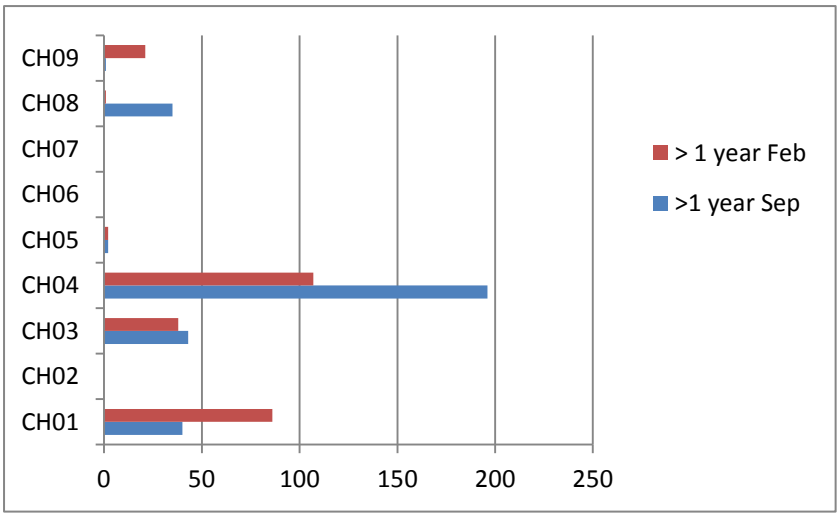
Figure 7: Waiting List for First Appointment with CAMHS (February & September 2017)[9]



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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 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. 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 and experience by parents points ultimately to a public health system that is not fit for purpose.

[8] Data collated from response to PQ Ref. No. 51586/17.
[9] Data collated from response to PQ Ref. Nos. 51586/17 (September) and PQ Ref. Nos. 17207/17 (February).

As per the 2001 Primary Care Strategy it is hoped to have psychologists as part of the multidisciplinary primary care networks 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. 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.[10]

Conclusion and 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. The reality is 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 actions must be taken to tackle the child waiting list crisis:

- Fully implement the proposal of the Oireachtas Committee on the Future of Healthcare Slaintecare (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

[10] Government of Ireland, (2017) *Expenditure Report 2018: Part II - Expenditure Allocations 2018-20* (p.74). Available: http://budget.gov.ie/Budgets/2018/Documents/Part%20II%20-%20Expenditure%20Allocations%202018-20.pdf

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.