



The Current State of HSE Autism Services in Laois/Offaly

**A Report on the findings of LOFFA on members
experience of disability services for children with
Autistic Spectrum Disorders**

May 2015

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Foreword

Laois Offaly Families for Autism (LOFFA) is a local support group of parents for parents and families of children and adults with Autism Spectrum Disorder (ASD). We exist to provide support, encouragement and information for those whose lives are affected by ASD, by sharing information and experiences, offering an understanding environment and the opportunity to meet others living in similar circumstances.

We are dedicated to actively campaigning and raising awareness of ASD in our area and to seek health, educational and support services that are appropriate to meet the needs of our children.

LOFFA have been in existence for 15 years and currently support over **380 families** but our membership continues to rise. We receive no funding from any government body, and it is only through the generosity of our local community that we are able to provide the support we give to our families.

LOFFA set out to be a support group for families and is **not** a service provider, but over the last decade an increasing number of families have come to LOFFA seeking the help and intervention their children need. Unable to let our children suffer, LOFFA has stepped up to the mark where the HSE have failed and aided families to fund and avail of private therapies.

Despite engaging with the management of our local HSE Disability Service on numerous occasions over the years, repeatedly outlining and highlighting the crisis and hardship that our families are facing, the HSE continue to neglect their needs. This report outlines that neglect and shows in detail just how bad the provision of disability services in Laois/Offaly is and how little has been done to date to correct the wrong.

LOFFA would like to extend our sincere gratitude to the individuals and families who gave so willingly of their time and energy in assisting us to production and launch of this report. Special thanks must go to those families who contributed by sharing their difficult experiences and to Mary Dunne and Mary Lee for the work undertaken to compile the report.



Edel Shaw
LOFFA Chairperson

Key Findings

According to HSE Figures:

- 0% of Assessment of Needs carried out in Laois/Offaly in 2014 were compliant with the timeframes set out in the Disability Act 2005
- In respect of ratio of therapist to child Laois/Offaly ranked 25 out of 27 Local Health Offices
- Laois/Offaly is severely understaffed versus Local, National and Peer Locations
- To reach the National Standard (HSE Top 10) the number of Therapists in Laois/Offaly would need to double
- There are significantly more children waiting for Services in Laois Offaly than anywhere else in the HSE DML (Dublin Mid Leinster) Area
- As far back as 2010 the HSE Health Stat performance dashboards reported Laois/Offaly LHO as being unsatisfactory, needing urgent attention

Difficulties encountered by parents:

- Unacceptable waiting time for the provision of Speech & Language Therapy (SLT); Occupational Therapy (OT) and Psychology
- Lack of provision of SLT, and OT in special schools and specific ASD Classes
- Failure of HSE to inform parents of their child's right to an Assessment of Need under the Disability Act 2005.
- Delay in obtaining accurate and timely diagnosis of ASD
- Poor quality and lack of Early intervention Services
- No clear referral pathways for specialist mental health services for self-harming or suicidal adolescents with ASD.
- Discrepancies between privately sought assessments and HSE assessments
- AON assessments incomplete
- Difficulty in obtaining AON reports
- Non delivery of therapeutic services stated in service statements completed and provided by HSE
- Access to residential respite closed to LOFFA families since 2013
- There's a serious crisis with Laois/Offaly disability services that needs urgent attention

Background

Laois Offaly Families for Autism (LOFFA) has been in existence for nearly fifteen years. In the early days LOFFA campaigned for early and accurate diagnosis; therapeutic intervention for children with autism. Now 15 years on, LOFFA's numbers have swollen to almost 400 families, but those families are still being forced to fight current health service providers (HSE) for exactly the same things, in order to help their children achieve their true and maximum potential.

10 year ago:

There was 1 Autism Team – Now it's GONE

Therapists went out to schools with ASD units - Now NO therapists visit these units

Speech & Language Therapy (SLT) had a waiting list of a few months - Now it is 2½ - 3 YEARS

SLTs aspired to have a caseload of less than 10 clients - Now it's over 100

6 years ago:

Psychology had a 3 MONTH waiting list - Now its 3 YEARS

Occupational Therapy had a waiting list of 3 months - Now it is 2½ - 3YEARS

3 Years ago:

Families had a residential respite service – Now they have access to NONE

The Issues:

In 2014, LOFFA held extensive meetings with the HSE management in Laois/Offaly Disability Services, to highlight concerns at the continuous erosion of services being provided to children with disabilities.

In March 2014, members of the local management of Disability Services attended LOFFA's monthly meeting and heard directly from members who gave personal accounts of the effects that this was having on their families. At that meeting, the Disability Services Manager and the Acting General Manager of Disabilities promised that the situations our families were facing would improve.

Twelve months on; current HSE data confirms that the situation in our area has deteriorated even further.

As we have seen with previous parts of the HSE in Laois/Offaly the culture of circling the wagons to protect 'the institution' and challenging those who

dare to speak up, is very much alive, and this appears to be the same in Disability Services. Parents report a genuine fear of complaining for fear there may be retaliatory action against them such as losing any small amount of service they may be receiving.

LOFFA have been collating evidence from parents and information available from HSE over the past years and have seen a steady erosion of services and quality of services available to families.

If this erosion is quietly allowed to continue LOFFA is very concerned for the well-being of our families and their loved ones with ASD.

LOFFA Therapy Spend

LOFFA is a charity whose main aim is to provide peer support to our members. We receive no government funding and depend on the good will of communities in Laois and Offaly to assist us in raising funds. LOFFA provides subsidised Speech & Language Therapy and Occupational Therapy to our most needy families' loved ones. LOFFA are coming under increasing pressure to meet the demand from our members in the absence of therapies from HSE.

In the past 36 Months ending April 2015:-

- LOFFA has subsidised over **1,100** Therapy Sessions for Children with ASD
- LOFFA Members have spent over **€80k** on Private Therapy
- LOFFA has subsidised **€55k** of that €80k in Therapies for Children with ASD

LOFFA has subsidised €10k in Therapies for Children with ASD in 2015 alone

- All this money has generated from fundraising in the local community

We have seen a dramatic increase in demands for support:

Year	Sessions per Month
2012	23
2013	23
2014	39
2015	54

Demand for Therapies has increased by 235% in two and a half years

Following a survey of members by LOFFA in 2011 over 60% of parents admit to feeling exhaustion, anger, depression and isolated, over 90% admit to feeling stress and anxiety. Of those, 40% of parents admit to seeking help for depression with 30% being prescribed medication for the same. As a direct result of this LOFFA has been subsidising a counselling service for parents, and in the past 12 months has spent **€3875** on this service alone.

Laois/Offaly a series of waiting lists

Sourcing accurate figures for waiting lists proves a difficult task, with discrepancies regularly occurring between figures given nationally and those given locally.

However, the waiting times given locally by Laois/Offaly in Table 3 are concurrent with parent's experience as reported to LOFFA.

Table 1: Early Intervention Teams Laois/Offaly – Number of Children ¹

Children with complex needs 0-5 years	Laois	Offaly	National Average
No. of children on each EIT	246	447	168

Table 2: Waiting times for Children with Disability, reported 2014 nationally ²

Service	Waiting Time	Children with Disability
Speech and Language	8 mths-1 year	36
Early Intervention Team	>1 year	81
School Age Team	>1 year	81
Psychology Laois School Age	1 year 3 months	95
Psychology Offaly School Age	>2 years	116

¹ PQ 8768/15 HSE to Deputy Colm Keavney TD See Appendix 1

² PQ 8210/14 PQ8211/14 HSE to Deputy Sean Fleming TD See Appendix 2

Table 3: Waiting Times for Children with Disability, reported locally by Laois/Offaly HSE 2014³

Service	Number of Therapists	Waiting Time Laois	Waiting Time Offaly	Children With Disability Laois	Children With Disability Offaly
Speech & Language Therapy Early Intervention	0.8 Laois 0.8 Offaly	Not Available	Not Available	53	50
Occupational Therapy Early Intervention	2 Laois 2 Offaly (both on leave)	Not Available	Not Available	52	65
Occupational Therapy School Age	3 Laois 4 (2 on leave)	Not Available	Not Available	Not Available	Not Available
Psychology Early Intervention	1.8 Offaly Laois Not Available	Not Available	18 mths	Not available	111
Psychology School Age	1.5 Laois (.5 on leave) 1.5 Offaly (.5 on leave)	Up to 30 mths	Up to 35 mths	125	121

³ Figures provided to LOFFA by Laois/Offaly HSE Disability Services See Appendix 3

Laois/Offaly Staffing Levels⁴

In 2012 Laois/Offaly ranked **25 of 27** Local Health Offices for number of children with complex needs per therapist.

In 2014, after allocation of additional therapy posts under the Progressing Disability Services mapping exercise Laois/Offaly still ranked **25 of 27** Local Health Offices for number of children with complex needs per therapist, with **35 therapy posts**

Laois Early Intervention Team has 246 children attending, ranking **43 of 56** Early Intervention Teams. **Offaly Early Intervention Team has 447 children** attending, ranking **53 of 56** Early Intervention Teams. 20 Early Intervention Teams nationally report 100 children or less attending. Laois/Offaly have a ratio of **1 Social Worker for 1,763 children** with complex needs.

As shown on Table 3, according to local HSE, of the 35 therapy posts for all children with complex needs in Laois/Offaly there were 1.6 or < 2 speech and language therapists for 693 children attending Early Intervention in Laois/Offaly. There were 2 Occupational Therapists (and 2 on leave).

1.8 Psychologists were available in Offaly to the Early Intervention Team and no figure was able to be provided for Laois. The waiting time for early intervention was reported as 1 year 6 months in Offaly, with no figure available for Laois. 3 whole time equivalent (WTE) psychologists were available to the school age children between Laois and Offaly with 1 WTE on leave.

The waiting time for school age psychology was given as 30 months for Laois and 36 months for Offaly.

School Age Disability Services in Laois/Offaly are not yet being delivered as a network service. This is of particular concern as 44% of children assessed nationally are over 5 years of age.

The average age at diagnosis for children in Laois/Offaly with autism is reported at 4 years and 6 months, with discharge from the Early Intervention Team in Laois/Offaly occurring as soon as the child reaches 5 years of age.

⁴ Progressing Disabilities Services Mapping Exercise 2012 See Appendix 4

Table 4: Analysis of Progressing Disability Services Mapping Statistics

In the areas of Speech & Language, Occupational Therapy & Psychology

Ratio of Therapists to Children

	Ratio	
National average	71.2	
DML excluding Laois/Offaly	57.7	
Laois/Offaly	92.3	
Laois/Offaly vs National Average	21.1	37% More Children waiting for Services
Laois/Offaly vs Dublin Mid Leinster	34.6	60% More Children waiting for Services

Versus the Area South Lee

Region	Rank	Children	Therapists	Ratio
Laois/Offaly	25	1,763	19.1	92.3
South Lee	5	1,796	40.6	44.3
Gap	20	33	21.5	27.3

Results

The Populations are almost identical.

There are 21.5 more Therapists in South Lee twice the number in Laois/Offaly.

The ratio of children to therapists in Laois/Offaly is over twice the ratio in South Lee

Versus the Longford/Westmeath which both come under Midlands HSE area

Region	Rank	Children	Therapists	Ratio
Laois/Offaly	25	1,763	19.1	92.3
Longford/Westmeath	17	1,346	23.4	57.5
Gap	8	417	4.3	34.8

Results

The Population of Longford Westmeath is 25% less than Laois/Offaly

There are 4.3 or almost 25% more Therapists in Longford Westmeath than in Laois/Offaly

The Ratio of children to therapists in Laois/Offaly is over one and a half times the Ratio in Longford Westmeath

Conclusion

Laois/Offaly is severely understaffed versus Local, National and Peer Locations

To reach the National Standard (HSE Top 10) the number of Therapists in Laois/Offaly would need to double

There are significantly more children waiting for Services in Laois/Offaly than anywhere else in the HSE DML (Dublin Mid Leinster) Area.

This matters - why?

Autism frequently only becomes apparent when the child fails to acquire language or develop social skills between 2 and 3 years of age. **Diagnosis is obtained through observation of the child and assessment by a multidisciplinary team.** Speech and Language Therapy is an essential part of assessment and intervention, but a psychologist is the key lead professional for diagnosis.

Diagnosis is a process or a “pathway”, very often with referral from speech and language therapist to psychologist.

A 3 year child old with ASD constantly faces a series of waiting lists. Many children cannot access health or educational intervention and supports without diagnosis. Once a children is discharged from early intervention at 5 years, they join yet another waiting list for the school age or primary care services.

History

For the last 4 years parents of children with complex needs, in particular autism and intellectual disability in Laois and Offaly have reported significant difficulties accessing assessments, diagnosis and therapy through the Local Health Office area.

The Laois Offaly Families for Autism 2013 survey of members on health service provision highlighted the following:

The average age at referral for a child with suspected ASD was 3 years, 3 months and the average age at diagnosis was 4 years, 6 months; the average time taken to assess and diagnose was 1 year and 3 months.

25% of parents reported their child did not receive any SLT in the 12 months up to March 2013, with 42% of parents reported their child did not receive any OT in the same period and 65% of parents reported their child did not receive any psychology over the same timescale.

47% of parents who applied for Assessment of Need reported that the assessment was not completed within the timeframe and they had not received the required service statement.

In 2011 an extra €3 million additional funding for Autism services was announced. In January 2012 LOFFA wrote to HSE Laois/Offaly Disability Services manager enquiring how much of the additional €3 million was requested for Laois/Offaly.

On 27th February 2012 the Disability Services Manager responded that “To date Laois/Offaly have required none of this funding”.

Assessment of Need – Staffing Levels and Compliance with Time Limit

The HSE measured staffing levels in 2014 by the number of children with complex needs per Number of Therapists; and in 2015 by the Number of children per Early Intervention Team. Below are the staffing levels reported along with compliance with the Disability Act 2005.

Table 5: Staffing Levels and Compliance with Time Limit⁵

Local Area	No. Children complex needs per Therapist (all therapies, post allocation of additional posts by 2014)	No. of children on each EIT	% Compliance with Disability Act
Roscommon	39	119	100
South Tipp	43		100
Louth	45	200	100
Mayo	35	150	96
Galway	31	78	82
Donegal	50	237	75
West Cork	31	34	0
Waterford	31		0
Wexford	53		0
Dublin South City	41	335	0
Laois/Offaly	50	346	0

⁵ HSE AON 4th quarter 2013 Management Report

Laois Offaly Assessment of Need (AON) Process 2013-2014

The data for Laois Offaly was compared with the national data and Longford Westmeath, a similar geographical area, **under the same disability services management team**. The most recent figures for AON, broken down by Local Health Office Area are from the HSE AON 4th quarter 2013 Management report.

AON Process Data

The number of applications for assessment (36) was comparable to the national rate and the number received in neighbouring Longford Westmeath (33).⁶

The application commencement rate was comparable to the national rate and identical to Longford/Westmeath.

In Laois Offaly there were 136 applications overdue for completion by more than 3 months, representing 22% of the national figure for assessments overdue. In comparison for the same time period, Longford Westmeath reported just 4 applications more than 3 months overdue for completion

In the 4th quarter of 2013, with 36 AON applications received and 174 overdue, only 4 assessments were completed to service statement stage.

All 4 assessments completed were within deadline, indicating that for all those already overdue no further progress was made.

Laois Offaly - Disability Act Section 9

Time limits

In 2014 Laois Offaly recorded **0% compliance** with the time limits required under the Disability Act 2005 and Regulations.⁷

⁶ HSE AON 4th quarter 2013 Management Report

⁷ HSE Health Service Performance Report Jan 2015

Population Figures Laois Offaly 2012⁸

PDS Mapping 2012	Laois Offaly	% of National figure
Population	157286	3.4
Children with complex needs	1,763	3.8
No. of Therapists (all therapies)	35	3.1
No. of SLT	12	4.2
No. of OT	1.5	0.6
No. of Psychologists	5.5	3.0

Summary of Assessment of Need Process 4th Quarter 2013 ⁹

Process	National	Laois Offaly	Longford/ Westmeath
Applications received	1116	36	33
Applications overdue to commence stage 2	155	7 (4.5% of national figure)	0
Applications overdue to complete stage 2	1146	174 (15% of national figure)	16
> 3 months	618	136 (22% of national figure)	4
Reports Completed	720	10	10
Number assessed as with disability	586 (81%)	7 (70%)	7 (70%)
Of which No. completed within deadline	412	4	7

⁸ HSE Progressing disability Services Mapping Exercise 2012 - See Appendix 4

⁹ HSE AON 4th quarter 2013 Management Report

Additional Information

In 2010 the HSE Health Statistics performance dashboards reported each Local Health Office's (LHO) monthly performance and awarded a traffic light scoring system, ranging from Green meaning very good performance to Red meaning unsatisfactory and needing urgent attention.

Laois Offaly was one of only 3 LHOs (out of 32) that rated unsatisfactory, needing urgent attention for resources - the measure of whether a Local Health Office (LHO) is making best use of its human and financial resources.

Between 2006 and 2011 among larger towns Portlaoise grew the fastest with an increase of 38 per cent from 14,613 to 20,145 persons.¹⁰

In 2015, these statistics are not reflected in Local Health Office service planning for children with disability and complex needs.

In 2011 an **extra €3 million** additional funding for Autism services was announced. In January 2012 LOFFA wrote to HSE Laois/Offaly Disability Services manager enquiring how much of the additional €3 million was requested for Laois/Offaly.

On 27th February 2012 the Disability Services Manager responded that **"To date Laois/Offaly have required none of this funding"**.¹¹

In response to PQ 5422/14 HSE to Deputy Sean Fleming TD in relation to the availability of services for children with Autism in Laois/Offaly, the Area Manager for HSE Midlands informed Deputy Fleming on the 21st February 2014 of the Assessment of Need under the Disability Act 2005.¹²

Ironically, this was in the same time period when 174 AON reports were outstanding from 2013 and in the same year when compliance by Laois/Offaly Disability Services with the time frames for delivering AONs sat at 0%.

¹⁰ Central Statistics Office 2012

¹¹ Letter to LOFFA See Appendix 5

¹² PQ 5422/14 HSE to Deputy Sean Fleming See Appendix 6

Compliance with The Disability Act 2005

The HSE describes 100% compliance with the Disability Act as a target, however anything less than 100% is non-compliance.

The legislation provides a **minimum** standard for compliance, allowing 7 months for completion of an initial assessment of need for a young child with suspected disability (substantial impairment in capacity) by the health service provider.

As previously mentioned, in 2014 Laois/Offaly recorded **0% compliance** with the time limits required under the Disability Act 2005 and Regulations.

Part 2 Section Assessment of Need ..

of the Disability Act 2005 states “(5) An assessment under this section **shall** be carried out **without regard to the cost of, or the capacity to provide, any service identified in the assessment** as being appropriate to meet the needs of the applicant concerned.”¹³

And “(7) Assessment report **shall** include...determination of disability ...statement of nature and extent of disability...and statement of health and education needs...occasioned by disability”.¹⁴

Since 2014, some parents of children in Laois/Offaly who applied for assessment of need are reporting that on receipt of the assessment report, despite the determination of disability being reached; it is being noted, under nature and extent of disability that further assessment was required, leading once again to the child being placed on yet another waiting lists.

This finding is also being re-iterated by educational professionals within Laois/Offaly who are reporting to LOFFA that Assessment of Need reports received by families are not providing details of the nature or the extent of the child's disability and are instead flagging the need for further assessment.

Part 2 Section 11 Service Statements

Part 2 Section 11 of the Disability Act states: “18. The service statement shall be written in a clear and easily understood manner and it shall specify:

¹³The Disability Act 2005 Part 2 Section 5

¹⁴ The Disability Act 2005 Part 2 Section 7

- (a) The health services which will be provided to the applicant;
- (b) The location(s) where the health service will be provided;
- (c) The timeframe for the provision of the health service;
- (d) The date from which the statement will take effect;
- (e) the date for review of the provision of services specified in the service statement;
- (f) any other information that the Liaison Officer considers to be appropriate, including the name of any other public body that the assessment report may have been sent to under section 12 of the Act.

19. The service statement shall be completed within one month following receipt of the assessment report by the Liaison Officer.¹⁵

Since 2013, parents in receipt of service statements in Laois/Offaly have been reporting that service statements issued do not provide the level of detail set out in SI 263/2007. They further report that service statements are rarely implemented.

More recently parents are reporting they've been advised to seek private assessments at their own expense due to waiting lists. However, parents are being given no guidance on where to seek such assessments or if HSE will accept private diagnosis. Many parents report that HSE have refused to accept private reports in the past.

¹⁵ SI 269/2007 Disability (Assessment of Need, Service Statements and Redress) Regulations 2007

Complaints under The Disability Act

As previously noted, many parents report various difficulties with the Assessment of Need process.

Parents consistently report that they were not informed of their child's right to an Assessment of Need by HSE staff they come in contact with.

It is unclear currently how many of the **174 reports** outstanding at the 4th quarter of 2013 have since been issued¹⁶

If No Assessment report is issued, it also means that no service statement or review of Assessment has been provided. Many parents have reported that they still have not received Assessment of Need reports some two years later.

Parents have grounds for complaint as outlined in the Disability Act however, few have formally done so.

When question about this, parents report an unwillingness to make formal complaints, sighting a variety of reasons but including a fear of losing the minimal services being received; of being labelled a troublemaker; of not having the time or emotional energy to go through lengthy complaints systems; and/or not having any confidence in HSE appointed complaint officers being independent or impartial.

This would suggest therefore that **the number of formal complaints received by HSE may not be indicative of the actual dissatisfaction on the ground.**

Complaints made are not publically available. However, under the Disability Act there are certain grounds when an applicant can lodge a complaint if they are dissatisfied. If an applicant is dissatisfied with the outcome of their complaint they can appeal to the Office of The Disability Appeals Officer (ODAO).

Redacted determinations and reasons for decisions appeal reports are made available for public inspection on the ODAO website. There is only one such report identifiable to Laois/Offaly on the ODAO website titled AP0048.¹⁷

The subsequent report issued may serve to clarify and confirm some of the issues that parents in Laois/Offaly have experienced throughout the Assessment of Need process.

¹⁶ HSE AON 4th quarter 2013 Management Report

¹⁷ ODAO Determination and Reasons for decision Report AP0048

This particular report is most concerning and can be summarised as follows:-

- An application was made for an assessment of a child's needs on 31/8/2009
- A complaint made on 9/7/2010 that the child's AON was not carried out in accordance to HIQUA standards. A complaint officer's report was issued on 2/11/2010 upholding the complaint and recommending that the child be provided with a further psychology assessment.
- However, the complaint officer's report was retracted on 24/11/2010 and the complaint was reassigned to a different complaint officer who issued a second report on 11/4/2011 stating she was unable to uphold any aspect of the complaint.
- On 24/5/2011, the mother lodged an appeal to The Office of Disability Appeals Officer.
- A full oral hearing under oath was held by the ODAO on the 10/11/2011.
- On 16/12/2011 the Disability Appeals Officer issued her determination and Reasons for Decision report which upheld the complaint. Several recommendations were made.

This complaint would certainly shadow the concerns raised by parents about how HSE handle complaints both at a local and national level. This would also suggest that the level of complaints received by HSE may not be reflective of the level of dissatisfaction on the ground.

There were two relevant findings in the ODAO report AP0048 that would appear to be in conflict with the parent's experience of current practices in Laois/Offaly:

The Disability Appeals Officer in her Determination and Reasons for Decision Report AP0048 states the following:-

- 8.2: Ms AK placed significant weight upon the fact that Dr AR had carried out a diagnostic assessment... she asserts that "there is no provision under the Act for a 'diagnostic' assessment.... this diagnostic assessment need not have been completed.... but a recommendation made that it be done later..."
- 8.3: Whilst the Act provides a right to an assessment of need and not a right to diagnosis, where a diagnosis is considered to be necessary... in order to complete a comprehensive 'assessment' of an applicant's needs, a diagnostic assessment may well be required in order to adequately discharge the obligations under the Act.

According to the former Disability Appeals Officer in her Determination and Reasons for Decision Report AP0048 section 8.9 states

- "a failure to provide certain services because he was on a waiting lists for some services specified in his service statement..... there were "staffing issues".... preventing provision of services to Y..... Ms AK referred to sections 11(7)(d) and (e)..... to assert..... "in the absence of resources,..... there is no obligation on the HSE..."

This is not correct. The statutory criteria under section 11(7) is required to be taken into account by a Liaison Officer in **preparing** a Service Statement. Once a Liaison Officer determines the services... through issue of a Service Statement, ***the HSE has an obligation to provide those services... regardless of any resource issues.***

What Are LOFFA Demanding?

Despite LOFFAs numerous attempts to engage the Laois/Offaly Disability Services and to highlight the crisis in service provision to children with ASD in Laois/Offaly, no improvement has been seen. In fact the continuous erosion of therapy services is bringing families to their knees.

No family wants anything more than the opportunity to allow their child the best chance to reach their true potential, and to achieve a full and independent life,

To afford our young men and women with ASD the chance to do this; LOFFA are demanding that HSE in Laois/Offaly

- Complete compliance with The Disability Act 2005
- Immediate release of all outstanding AON reports
- Ring fencing of budget to clear the backlog of outstanding AONs
- A clearly outlined plan on how HSE intend to clear the backlog of outstanding AONs and release outstanding reports immediately
- Accurate and early diagnosis of ASD by competent and experienced psychologists
- Reintroduction of school based therapies for children attending special schools and classes
- For children in mainstream school settings appropriate and consistent level of therapies
- A seamless, well-resourced service for 0 to 18 year olds staffed by sufficient numbers of therapists; to provide appropriate assessments and an appropriate and consistent level of therapies
- Reopen residential respite service in Charleville cottage or another alternative Autism specific service
- Independent scrutiny of Laois/Offaly resource management and management of referrals and waiting lists
- Independent scrutiny of complaints process and how complaints are managed in Laois/Offaly
- A monthly publically available progress report from HSE disability services management on the progress on the resolutions sought on the issues raised

Appendices

Appendix 1

PQ 8768/15: HSE Response to Deputy Keaveney TD 23rd March 2015



Office of the Head of Operations and Service Improvement,
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23rd March 2015

Deputy Colm Keaveney,
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Dear Deputy Keaveney,

The Health Service Executive has been requested to reply directly to you in the context of the following parliamentary question, which was submitted to this department for response.

PQ 8768/15

To ask the Minister for Health if he will provide in tabular form for each local health area, the number of early intervention teams for children; the total number on each team; the numbers of children in each area waiting for a first appointment with an early intervention team; and if he will make a statement on the matter.

HSE Response

The HSE has commenced the reconfiguration of children's disability services into geographically-based early-intervention and school-aged teams as part of the *Progressing Disability Services for Children and Young People Programme*. The objective of the Programme is to provide one clear referral pathway for all children (0-18s), irrespective of their disability, where they live or the school they attend. The transition to this service delivery model is governed by a consultation and engagement process with all stakeholders, including service users and their families, and is being implemented on a phased basis.

The HSE acknowledges that some LHO areas have yet to establish Early Intervention Teams that meet the criteria laid down in the *Progressing Disability Services for Children and Young People (0 - 18s) Programme*, however all HSE areas have significant Early Intervention Services in place, provided directly by the HSE, including Beechpark Autism Services or by voluntary service providers funded by the HSE, such as Enable Ireland, Kare, Muriosa Foundation, St. John of God Services, Brothers of Charity Services, St. Michael's House, Cope Foundation, CRC, Daughters of Charity Services etc.

The table below outlines the number of HSE Early Intervention Teams (EITs) for all children with disabilities that have been re-configured as of January 2015 together with the teams to be developed in 2015/16.

Please note teams may vary in size according to factors such as local requirements, geographic and population considerations. Of more significance than numbers of teams is the attainment of full

The Current State of HSE Autism Services in Laois/Offaly

coverage so that all children aged from birth to 18 years and their families have access to a Children's Disability Network Team.

Area	Current teams	Teams to be developed
Dublin South/South East	Disability services in the area are not yet delivered as a Network service	4 x 0-18 teams
Dublin South Central	Disability services in the area are not yet delivered as a Network service	4 x 0-18 teams
Dublin South West	Disability services in the area are not yet delivered as a Network service	2 x 0-18 teams
Kildare/West Wicklow	3 x 0-18 teams 1. North Kildare 2. Mid Kildare 3. South Kildare	No further teams to be formed
Midlands	5 EITs , 1. Portlaoise EIT 2. Offaly EIT 3. Athlone EIT 4. Mullingar EIT 5. Longford EIT School Age Disability services in the area are not yet delivered as a Network service	5 SATs
Wicklow	Disability services in the area are not yet delivered as a Network service	3 x 0-18s teams
Cavan/Monaghan	2 EITs 1. Enable Ireland EIT Cavan 2. Enable Ireland EIT Monaghan School Age Disability services in the area are not yet delivered as a Network service	2 SATs
Louth	2 EITs School Age Disability services in the area are not yet delivered as a Network service	2 SATs
Meath	5 EITs and 2 SATs 1. Enable Ireland Navan EIT 2. Enable Ireland Trim EIT 3. Enable Ireland Dunshaughlin EIT 4. Enable Ireland Kells EIT 5. Enable Ireland East Meath EIT 6. Disability Service 6-18 years Team A 7. Disability Service 6-18 years Team	No further teams to be formed
Dublin North	Disability services in the area are not yet delivered as a Network service	12 x 0-18s teams

The Current State of HSE Autism Services in Laois/Offaly

Carlow/Kilkenny	1 EIT Carlow School Age Disability services in the area are not yet delivered as a Network service	2 x 0-18s teams (incorporating current EIT)
Cork North	Disability services in the area are not yet delivered as a Network service	2 x 0-18 teams
Cork North/South Lee	Disability services in the area are not yet delivered as a Network service	South Lee 4 x 0-18 teams North Lee 3 x 0-18 teams
Cork West	4 x 0-18 teams 1.WCCDS Bantry 2.WCCDS Dunmanway 3.WCCDS Clonakilty 4.WCCDS Skibbereen team	No further teams to be formed
Kerry	4 x 0-18 teams 1. KIDS North Kerry 2. KIDS Tralee 3. KIDS Mid Kerry 4. KIDS South Kerry	No further teams to be formed
Tipperary S.R	1 EIT School Age Disability services in the area are not yet delivered as a Network service	1 EIT and 2 SATs
Waterford	1 EIT EIT Network 1 (Dungarvan) School Age Disability services in the area are not yet delivered as a Network service	2 EITs and 3 SATs
Wexford	Disability services in the area are not yet delivered as a Network service	4 EITs and 4 SATs
Limerick /Clare/ Tipperary N.R	6 EITs and 6 SATs 1. Blackberry EIT 2. Blackberry SAT 3. Treehouse EIT 4. Treehouse SAT 5. East Limerick EIT 6. East Limerick SAT 7. West Limerick EIT 8. West Limerick SAT 9. North Tipperary EIT 10. North Tipperary SAT 11. Clare EIT 12. Clare SAT	No further teams to be formed
Donegal	4 EITs 1. EIT South Donegal 2. EIT Letterkenny 3. EIT Inishowen 4. EIT Dunloe School Age Disability services in the area are not yet delivered as a Network service	4 SATs

The Current State of HSE Autism Services in Laois/Offaly

Mayo	2 EITs 1. North Mayo 2. South Mayo School Age Disability services in the area are not yet delivered as a Network service	2 SATs
Roscommon	1 EIT Roscommon Early Intervention Services School Age Disability services in the area are not yet delivered as a Network service	1 SAT
Sligo/Leitrim	2 EITs 1. EIT Leitrim 2. EIT Sligo School Age Disability services in the area are not yet delivered as a Network service	2 SATs
Galway	5 EITs 1. Springtime Early Intervention Services 1 2. Springtime Early Intervention Services 2 3. Springtime Early Intervention Services 3 4. Springtime Early Intervention Services 4 5. Springtime Early Intervention Services 5 School Age Disability services in the area are not yet delivered as a Network service	4 SATs
Total numbers of teams	56	73*

* Note this number of teams may be subject to change as Local Implementation Groups progress their plans and make final decisions on whether to have separate Early Intervention Teams and School Age Teams or teams for all children from 0 to 18 years.

In 2014, the roll out of the *Progressing Disability Services for Children and Young People (0-18s) Programme* entailed targeted investment of €4m and the provision of 80 additional therapy staff, to increase services for children with all disabilities.

A further €6m allocation was announced in 2015 for the reconfiguration of children's disability services, which will enable us to drive implementation of the *Progressing Disability Services for Children and Young People Programme* through new staff appointments to reconfigured multi-disciplinary, geographic-based teams, and through using innovative approaches, involving public, voluntary and private providers, to achieve targeted reduction of waiting lists.

The HSE is also examining the feasibility of undertaking a baseline analysis of current practices in relation to how waiting lists are managed.

These measures will have a positive impact on the provision of clinical services for all children requiring access to health related supports.

The Current State of HSE Autism Services in Laois/Offaly

The table below provides details of the number of children attending EI Teams and on the number of children in each area waiting for an appointment with a team as of year end 2014.

LHO	Number of Children on each EIT Team	Number in each area waiting for an appointment with a team
<i>HSE Dublin Mid-Leinster</i>		
Dublin South	122	27
Dublin South East	75	17
Dublin South Central	335	250
Dublin South West	123	71
Kildare/West Wicklow		
North Kildare	75	10
Mid Kildare	103	23
South Kildare	87	25
Midlands		
Portlaoise	246	8
Offaly	447	0
Athlone	92	0
Mullingar	151	0
Longford	77	0
Wicklow	78	20
<i>HSE Dublin North East</i>		
Louth	200	18
Meath	584	32
Cavan	204	19
Monaghan	144	9
Dublin North West	120	107
Dublin North Central	112	26
Dublin North	80	10
<i>HSE South</i>		
Carlow/Kilkenny		
Cork North		
St Joseph's Foundation		
Charleville	150	35
Enable Ireland	35	5
Cork North/South Lee		
HSE Early Intervention South Lee	131	20
HSE Early Intervention North Lee	129	10
Enable Ireland	140	6
Brothers of Charity	138	37
COPE EI	128	0
Brothers of Charity ASD EI	59	88
COPE ASD EI	82	0

The Current State of HSE Autism Services in Laois/Offaly

Cork West		
WCCDS Bantry (0-18 Network Team)	35	3
WCCDS Dunmanway (0-18 Network Team)	28	4
WCCDS Skibbereen (0-18 Network Team)	29	3
WCCDS Clonakilty (0-18 Network Team)	45	6
Kerry	258	24
Tipperary S.R		
Waterford		
Wexford		
HSE West		
Limerick /Clare/ Tipperary N.R		
Clare EI	303	28
Clare SA	519	7
East Limerick Team EI	226	15
East Limerick Team SA	436	14
Blackberry EI	75	1
Blackberry SA	342	5
North Tipperary EI	223	20
North Tipperary SA	556	21
Treehouse EI	100	5
Treehouse SA	353	38
West Limerick Team EI	139	12
West Limerick Team SA	248	13
Donegal	237	37
Mayo	150	0
Roscommon	119	12
Sligo/Leitrim	221	16
Galway		
Galway City East Team	64	3
Galway City West Team	60	1
Galway North Team	96	2
Galway South & East Team	129	3
Galway West Team -	42	0

Yours sincerely,



Marion Meany,
Head of Operations and Service Improvement,
Disability Services, Social Care Division

Appendix 2:

PQ 8210/14 HSE Response to Deputy Fleming TD – 7th March 2014



Office of the Head of Operations and Service Improvement,
Disability Services/Social Care Division,
Health Service Executive,
31-33 Catherine Street,
Limerick,
Ireland.

Tel: 00353 (0) 61 483221
Fax: 00353 (0) 61 483211
Website: <http://www.hse.ie>

7th March 2014

Deputy Sean Fleming,
Dail Eireann,
Leinster House,
Kildare Street,
Dublin 2.
e-mail: sean.fleming@oireachtas.ie

Dear Deputy Fleming,

The Health Service Executive has been requested to reply directly to you in the context of the following parliamentary questions, which were submitted to this department for response.

PQ 8210/14

To ask the Minister for Health the current resource and staffing levels for speech and language therapists working in the disability service early intervention and school age teams in Laois/Offaly; the timescale for children waiting for this service; and if he will make a statement on the matter.

PQ 8211/14

To ask the Minister for Health the current resources and staffing levels of occupational therapists and psychologists working in the disability service early intervention and school age teams in Laois/Offaly; the waiting time for children to be seen by the occupational therapist; the maximum waiting time a child is currently on this waiting list; and if he will make a statement on the matter.

HSE Response

There are currently 11.6 wte speech and language therapists, 11.0 wte Occupational Therapists, and 6.6 wte Psychologists providing services to children aged 0-18 years with disability in the Laois/Offaly area. The HSE is the sole provider of speech and language therapy and occupational therapy to all children with disability in the Midlands Area; there are no non-statutory service providers providing this service in the area. The Muiriosa Foundation also has a psychology service and 1.2 wte of the 6.6 wte referred to above are provided by the Muiriosa Foundation.

Due to the HSE moratorium on recruitment, vacancies due to retirements and maternity leave have not been filled and this has resulted in increased waiting times for assessment and intervention. The Laois/Offaly Speech and Language Therapy, Occupational Therapy and Psychology Departments will continue to manage staffing resources in as effective a manner as possible in order to maximise the service being provided.

The Current State of HSE Autism Services in Laois/Offaly

The waiting times for speech and language therapy for children with disability are currently as follows:

0-4 months	4 months + 1 day – 8 months	8 months + 1 day – 1 year	Total
159	75	36	270

The waiting times for Occupational Therapy Services for children with a disability aged 0-18 years are as follows:

Laois / Offaly Early Intervention Teams				
0-16 weeks	17-32 weeks	33 -52 weeks	52 + weeks	Total
86	91	52	81	310

Laois / Offaly School Age Teams				
0-16 weeks	17-32 weeks	33 -52 weeks	52 + weeks	Total
67	72	67	81	287

It is important to note that children are not taken off the waiting list when they attend an assessment with the early intervention team or if they attend an Occupational Therapy drop-in / advisory session – children are only viewed as "opened" when they are offered further intervention. Due to the nature of service delivery in this area children receive a block of up to 6 sessions and are placed back on the waiting list for further interventions, thus the numbers referred to includes a large proportion of children who have previously attended the service.

The waiting times for Psychology Services for children with disability aged 0-18 are as follows:

Service	Numbers	Waiting Time
Laois EIT	7	6 months
Offaly EIT	95	9-12 months
Laois SAT	95	15 months
Offaly SAT	116	24+ months

The health service as a whole has experienced reduced employment levels since 2007. The Moratorium on recruitment has had an impact on the provision of multi-disciplinary services throughout the health service. The HSE continues to address the reduction in staffing numbers through a number of measures including;

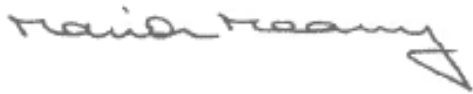
- Minimising the impact on front line services by targeting where possible, reductions in non service impacting areas.
- Maximising the flexibility provided under the Public Service Agreement (PSA) 2010-2014.
- The appointment of an additional 1,025 whole time equivalent staff in a number of priority areas such as primary care, mental health, audiology.
- Continued implementation of the Clinical Care Programmes.
- Increased use of staff redeployment
- A focused approach to addressing staff absenteeism and implementing revised sick leave arrangements
- Initiatives in the use of shared services and combined services.

However, there is a growing incidence of unfilled posts that is impacting both on the level of services that can be provided to people with disabilities and on their access to these services, particularly in the area of S&L, Physiotherapy and Occupational Therapy.

In an effort to address this situation in the short term and ensure that services are delivered in as equitable a manner as possible within available resources the HSE has introduced a number of initiatives such as therapists increasing clinic based work instead of domiciliary work and providing family centred interventions in a group as opposed to a one-to-one setting, whenever possible.

In the longer term the reconfiguration of children's disability services into geographically-based early-intervention and school-aged teams as part of the Progressing Disability Services for Children and Young People Programme will ensure an equitable delivery of services. The roll out of this Programme will entail targeted investment of €4m and the provision of 80 additional therapy staff, to increase services for children with all disabilities. This measure will have a positive impact on the provision of clinical services for all children requiring access to health related supports.

Yours sincerely,

A handwritten signature in dark ink, appearing to read 'Marion Meany', with a stylized flourish at the end.

**Marion Meany,
Head of Operations and Service Improvement,
Disability Services, Social Care Division**

Appendix 3:

Figures Provided by Laois/Offaly HSE to LOFFA – 25th February 2014

Structure:

SLT's in Laois/Offaly, Longford/Westmeath report to their respective SLT Managers.

Resources:

Resources:

SLT's assigned

	Laois	Offaly	Longford	Westmeath
EIT	0.8	0.8	0.8	1
SAT	1	1	0.5	1.2

No's on waiting list

	Laois	Offaly	Longford	Westmeath
EIT	53	50	16	46
SAT	Not available	Not available	33	106

Figures for EIT Longford/Westmeath are not available as it is not always possible to give a single measurement as SLT is not always functioning in a unidisciplinary manner but rather SLT participates in team assessment, multidisciplinary and unidisciplinary intervention as indicated.

Breakdown of therapists time:

Question not appropriate

What strategy is in place to reduce the waiting lists:

Waiting lists are addressed by SLT Managers in terms of areas of greatest clinical need and highest clinical risk in terms of a whole population approach.

Structure:

O.T's in Laois/Offaly, Longford/Westmeath report to their respective OT Manager.

Resources:

OT's assigned

	Laois	Offaly	Longford	Westmeath (2 sectors Athlone and Mullingar)
EIT (including 0-5 Community)	2	2 (both on mat leave)	1	2.86
SAT No dedicated staff. Covered from 5-18 OT Services	3 for all 5-18 Services	4 for all 5-18 Services (2 on mat leave)	2 for all 5-18 Services	3.86 for all 5-18 Services

No's on waiting list

	Laois	Offaly	Longford	Westmeath(2 sectors Athlone and Mullingar)
EIT	52 for team assessment	65 (50 for team assessment ad 15 for catch up OT assessment)	22 for team assessment	51 for the 2 Westmeath Teams
SAT	Not available	Not available	Not available	Not available

Breakdown of therapist's time:

Question not appropriate

What strategy is in place to reduce the waiting lists:

Waiting lists are verified where there has been a long period of time from time of referral. Drop in clinics are offered.

Waiting lists are addressed in terms of areas of greatest clinical need and highest clinical risk.

Psychology, Laois/Offaly, Longford/Westmeath

1. Psychologists Allocated to EITs and SATs at Feb '14 *(Note: EIT Athlone and Portlaoise figures not included. Need to be obtained from Múlosa)*

EIT LONGFORD : Total 0. 6 WTE Dr. Michelle Howard (0.6 WTE)

EIT MULLINGAR : Total 1. 4 WTE Dr. McDermott (0.8 WTE) + Dr. Michelle Howard (0. 4 WTE) *Dr. Perry Rogers and not replaced*

EIT OFFALY : Total 1.8 WTE Dr. Perry Rogers (0.8 WTE) + Anne Carroll (1.0 WTE)

SAT LONGFORD : Total 1.0 WTE Mirka Pinto (0.8 WTE)

SAT MULLINGAR : Total 1. 2 WTE Dr. Paul Cane (1.0 WTE) + Mirka Pinto (0.2 WTE)

SAT ATHLONE : Total 1.0 WTE Lee Harrow (1.0 WTE)

SAT Offaly Total : Total 1.5 WTE Dr. Edel Flanagan (1.0 WTE) + Dr. Denise O'Connell (0.5 WTE) *Dr. Denise O'Connell on M Leave and not replaced*

SAT LAOIS Total : Total 1.5 WTE Tony Rogerson (1.0 WTE) + Dr. Denise O'Connell (0.5 WTE) *Dr. Denise O'Connell on M Leave and not replaced*

2 . Waiting Lists at 20 Feb '14

Wait-List for Psychology-specific work in EIT LONGFORD	29
Wait-List for Psychology-specific work in EIT MULLINGAR	52
Wait-List for Psychology-specific work in EIT OFFALY :	111
Wait-List for Psychology-specific work in SAT LONGFORD :	58
Wait-List for Psychology-specific work in SAT MULLINGAR :	186
Wait-List for Psychology-specific work in SAT ATHLONE :	45
Wait-List for Psychology-specific work in SAT OFFALY :	121
Wait-List for Psychology-specific work in SAT LAOIS :	125

3 . Waiting times before child at bottom of list will be seen . Estimates only, as times cannot be determined until child seen .

Waiting Time EIT LONGFORD 3 months

Waiting Time EIT MULLINGAR 6 months

Waiting Time EIT OFFALY : 18 months

Waiting Time SAT LONGFORD : 14 - 18 months

Waiting Time SAT MULLINGAR : Up to 24 months

Waiting Time SAT ATHLONE : 7 - 8 months

Waiting Time SAT OFFALY : Up to 35 months

Waiting Time SAT LAOIS : Up to 30 months

4 . How many appointments by Psychologist per week / per year

EIT LONGFORD : Number appts per week: 13 -15 . . .

EIT MULLINGAR : Number appts per week: 10

EIT OFFALY : Number appts per week: 13-15

SAT LONGFORD : Number appts per week: 13-15

SAT MULLINGAR : Number appts per week: 13-15

SAT ATHLONE : Number appts per week. 10

SAT OFFALY : Number appts per week: 10

SAT LAOIS : Number appts per week: 13-15

5 . Strategies Used to Reduce Wait-List/Waiting Times:

(i) Day and evening group workshops for children with ASD (Longford, Athlone , Mullingar , Offaly EITs and Laois SAT) .

(ii) Parent consultation clinics in all SATs.

(iii) Consideration of earlier cognitive assessment for children, to facilitate Review Assessments for Transition.

(iv) Dictated reports in an attempt to reduce administrative time.

(v) Trainee Doctoral Clinical Psychologists on placement, who can take on specified caseload under supervision

(vi) Waiting list reviews

6 . Has a Risk Assessment been completed for each child who may have been affected by delay?

Individual clinical risk forms have been and are being completed for those that absolutely require it.

In some instances, as an alternative, parents are informed of the Assessment of Need process if their child is 12 years or under.

Wait-List clinical risk forms completed when numbers of children left with diminished or no services due to Maternity leave or regination,etc . Consideration being given to completion of individual risk form for each individual child on wait-list.

Risk forms completed when Psychologists on M. Leave or L/T Sick Leave .

7 . Possible Explanations for Differences in Wait-Lists:

- Population Differences
- Referral rate variations
- Variations in numbers of referrals of Assessment of Needs
- Child-related clinical complexities and lengthy assessment times
- Variations in levels of admin support
- Maternity Leave, Sick Leave and Parental Leave, Reduced hours
- Numbers of staff and Trainees to be supervised.

8. Other Relevant Information:

- The high and constant influx of A o N referrals are delaying movement from the main waitlists in all areas but particularly in Mullingar and Offaly, where AON I referral levels are approximately 6 per month for SAT (Mullingar) and 4 per month for SAT (Offaly) . This is equivalent to the number of new cases that would be opened every month, preventing movement from the current waitlist.
- Diagnostic sessions are lengthy (clinical interviews, observations, psychometrics, scoring, interpretation, formulation, diagnostic report, etc).
- Insufficient or no admin support: Significant amount of clinical psychology time spent on admin - enquiries and other calls from parents, correspondence, referral management, scoring psychometrics , writing reports, inter & intra agency contacts, filing, appointments, etc
- Part of Tipperary (? Population Number) included in L-O Population ?

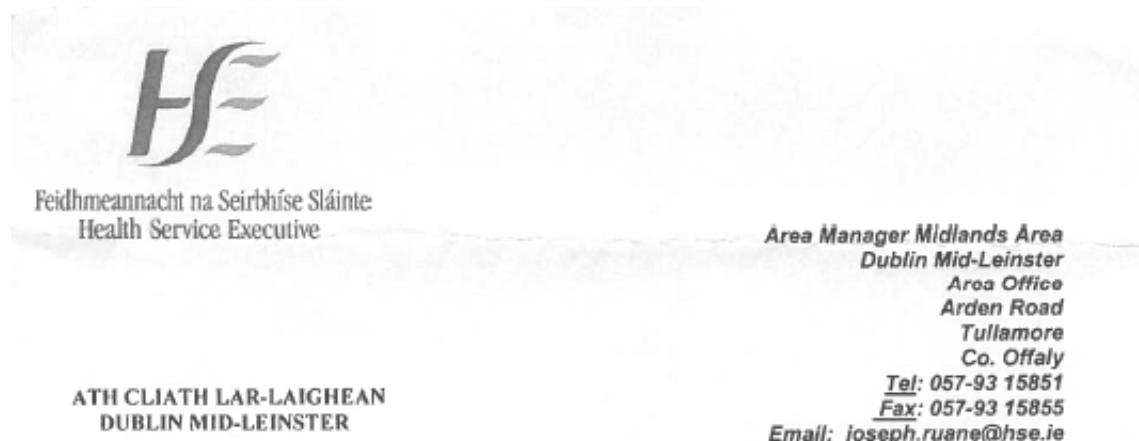
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Appendix 5:

Letter from Disability Services to LOFFA dated 27th Feb 2012



Appendix 6: HSE Response to PQ 5422/14 Deputy Sean Fleming TD



21st February, 2014

Mr. Sean Fleming T.D.,
Dáil Éireann,
Leinster House,
Kildare Street,
Dublin 2.

Re: Parliamentary Question – 5422/14

To ask the Minister for Health the services available for persons with autism in the Laois/Offaly area; if provision will be made in the new service plan to improve these services in view of fact that 350 persons are registered with autism in the Laois/Offaly area; and if he will make a statement on the matter.
- Sean Fleming.

Dear Deputy Fleming,

I refer to the above Parliamentary Question and outline HSE Midlands area response as follows:

The HSE has a range of services available to people with Autism. Any child born after the 1st June 2002 is eligible to apply for an Assessment of Need under the Disability Act 2005. There are four teams in operation in the HSE Midlands area for children with disability, including autism aged 0-18 years; this includes two Early Intervention Teams and two School Age Teams. These are multi-disciplinary teams comprising of speech and language therapists, occupational therapists, physiotherapists, psychologists, Public Health Nurses etc. More recently in recognition of a gap in the service the HSE has secured approval for the appointment of a Consultant Child Psychiatrist and support team to provide a service to children with moderate /severe/ profound disability and / or Autism.

Outside of the HSE there are a number of non-statutory organisations who provide a service on behalf of the HSE to people with a disability including autism e.g. residential, respite and outreach supports.

I trust the above is in order and please do not hesitate to contact me should you have any further queries.

Yours sincerely,

A handwritten signature in black ink, appearing to be 'J. Ruane', written over a horizontal line.

Joseph Ruane
Area Manager
HSE Midland Area



May 2015

Laois Offaly Families for Autism (LOFFA)

Website: www.loffa.ie

Facebook: <https://www.facebook.com/LaoisOffalyFamiliesforAutism>

Twitter: https://twitter.com/#!/LOFFA_Secretary

YouTube: <http://www.youtube.com/user/LOFFAautismsupport?feature=mhee>