

Laois Offaly Families For Autism (LOFFA) a survey on service provision in 2013

Introduction:

Laois Offaly Families for Autism (LOFFA) is a local support group for the parents and families of children and adults with Autism Spectrum Disorder.

We exist to provide support, encouragement and information for those whose lives are affected by Autism.

We actively campaign to raise awareness of autism in our area and seek health, educational and support services that are appropriate to meet the needs of our children and adults with autism.

Founded over ten years ago, with an initial membership of 80 families LOFFA has grown to a membership of over 250.

It is well documented that early and accurate diagnosis along with early intervention for children with Autism Spectrum Disorder is critical. Primary therapeutic services such as Speech and Language Therapy (SLT), Occupational Therapy (OT) and Psychological intervention are well known and documented to have a massive impact on communication skills and life skills that a child with autism can learn, and remain top priority for the families of children with autism.

To date LOFFA has carried out 3 surveys of our membership; in 2006, 2008, and 2011, to look at our group profile, to find out which services our members have need of and to consider how well these needs are being met.

In March 2013, a number of LOFFA parents met with Minister Kathleen Lynch (Minister of Disability) to let her know and hear first-hand exactly the situation with regard to the lack of disability services provision on the ground in Laois/Offaly.

As time was short and only a few parents got to meet with and speak to the Minister, LOFFA decided to survey the membership once again to help accurately gauge how much therapeutic intervention and support was been given to children / adults with autism across the Laois/Offaly area.

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Method:

On online survey was created, asking questions on the diagnosis process for the child with ASD, along with the provision of Speech and Language Therapy (SLT), Occupational therapy (OT), Psychology and Respite in the last 12months from 1st March 2012 to 1st March 2013.

In addition the members were asked a number of questions regarding access to Assessment of Needs, the assessment process itself and any subsequent review.

Parents were asked to complete the questionnaire on line.

Results:

The following are the results of that Survey:

Number of Survey completed = **65** (representing 22% of the families in LOFFA)

Average age the child first referred to HSE service (Early Intervention / Speech & Language Therapy / Occupational Therapy / Psychology / Other Service)? = **3yrs 3months old**

Average age the child when diagnosed with ASD? = **4yrs 6mths old**

Provision of Speech & Language Therapy (SLT):

66% of parents confirmed their child received at least 1 session of individual 1: 1 Speech & Language Therapy in the 12mths up to March 2013.

The average number of individual 1:1 session received by these children was **5.7 sessions** over the 12mth period!

9% of parents confirmed their child received at least 1 session of group SLT in the 12mths up to March 2013.

The average number of group SLT session received by these children was 3.5 sessions over the 12mth period!

25% of parents confirmed their child **DID NOT receive any SLT** in the 12mths up to March 2013.

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Provision of Occupational Therapy (OT):

49% of parents confirmed their child received at least 1 session of individual 1: 1 Occupation Therapy in the 12mths up to March 2013.

The average number of individual 1:1 session received by these children was **4 sessions** over the 12mth period!

9% of parents confirmed their child received at least 1 session of group OT in the 12mths up to March 2013.

The average number of group OT session received by these children was **4 sessions** over the 12mth period!

42% of parents confirmed their child **DID NOT receive any OT** in the 12mths up to March 2013.

Provision of Psychology Intervention:

43% of parents confirmed their child received at least 1 session of individual 1: 1 Psychology in the 12mths up to March 2013.

The average number of individual 1:1 session received by these children was **1.8 sessions** over the 12mth period!

2% of parents confirmed their child received at least 1 session of group Psychology in the 12mths up to March 2013.

The average number of group Psychology session received by these children was **4 sessions** over the 12mth period!

55% of parents confirmed their child DID NOT receive any Psychology in the 12mths up to March 2013.

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Assessment of Needs:

46% (30) of parents who completed the survey confirmed that they had received an assessment under the Disability Act 2005.

Only **53%** (16) of those confirmed that they received a Service Statement

44% (7) of the Service Statement were due to be review prior to March 2013 –
Less than half **19%** (3) of those received an review and only 1 (**6%**) has received an updated Service Statement.

Respite:

8% of parents received home-based / community based respite, at an average of 124 hrs per year

11% of parent received residential respite, at an average of 50hrs per year.

81% of parents confirmed their child DID NOT receive any Respite service in the 12mths up to March 2013.



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Conclusion:

The results of this survey concur with the issues that LOFFA are being presented with at our monthly meeting. Parents are reporting:

1. Delays of time taken to obtain an accurate diagnosis of ASD
2. Waiting lists for primary therapeutic services
 - a. 3 years for Occupational Therapy and
 - b. 2 years for Speech & Language Therapy
 - c. 18 months for Psychology
3. Lack of information on AON process under Disability Act, delays with AON process, delay in AON reports being issued and subsequent delays in issuing service statements, lack of reviews of AON being carried out and when carried out review of AON reports not being issued
4. Removal of and lack of provision of SLT and OT in ASD units /special school educational placements.
5. Lack of appropriate respite service.

LOFFA have taken the opportunity to highlight these results and findings to Minister Lynch in follow up communications and to the local HSE management in Disability Service.

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/LOFFAutismsupport?feature=mhee>

LOFFA is a group member of Irish Autism Action Charity Number CHY 14565