

# **Laois Offaly Families For Autism (LOFFA)**

## **a profile of members, needs and service provision in 2011**

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### **Introduction:**

Laois Offaly Families for Autism is a local support group for the parents and families of children and adults with Autism. 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.

To date LOFFA has carried out 3 surveys of our members, in 2006, 2008 and this most recent in late 2011/ early 2012, 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.

This paper details how the 2011 survey was conducted and the findings in comparison to those previously conducted by this group.

### **Method:**

A 10 page questionnaire was circulated to LOFFA families by email and printed copies were made available at monthly meetings.

Families were asked to completed the survey and return them to the committee as soon as possible.

### **Results:**

LOFFA has over 200 families in contact with our group. We have 168 registered members equating to an increase of 237% increase on the numbers documented in our 2006 survey.

Our families come are mainly from Laois and Offaly, but families from the neighbouring counties of Kilkenny, Kildare, Carlow and Westmeath has also made contact. On average, our monthly meetings have an attendance of 30 to 40 members.

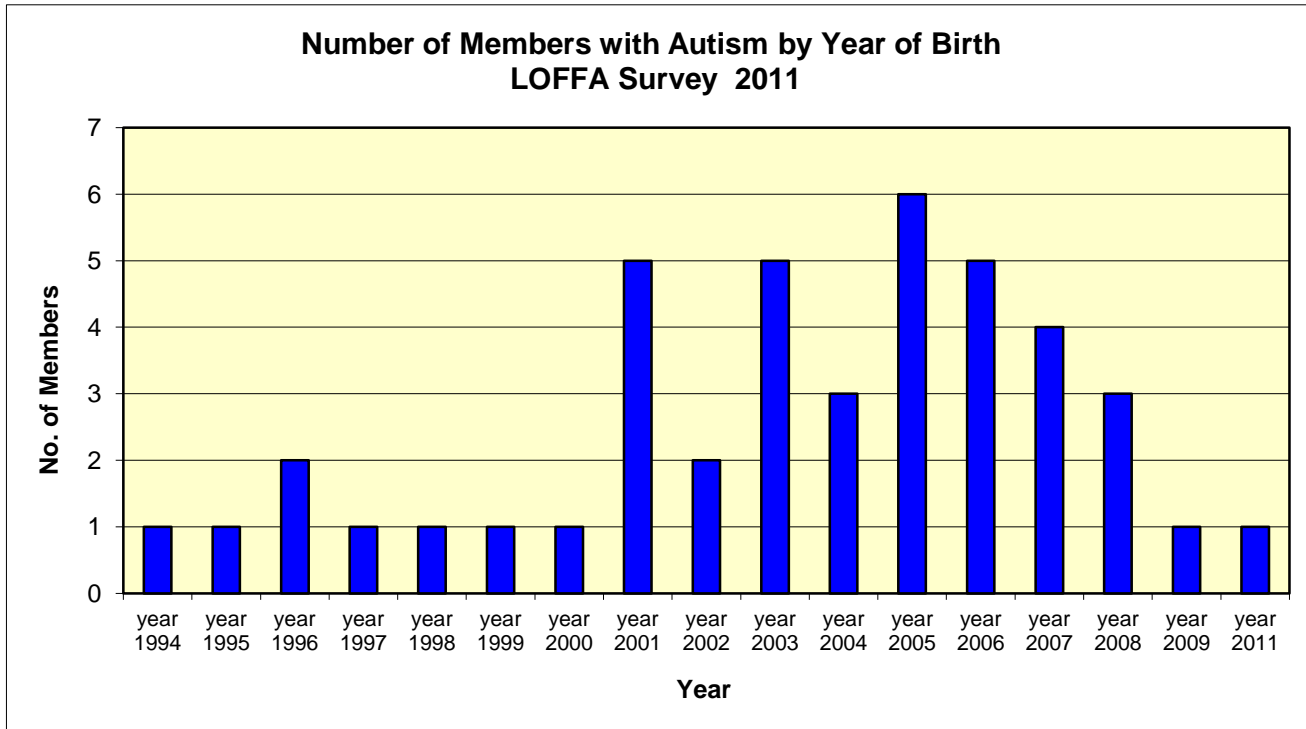
43 valid survey questionnaires representing 26% of total family membership and was great response based on normal attendance at meetings. Of the 43 completed forms 33 (76%) were male and 10 (24%) female.

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### Survey Section A: Demographics

#### Who are our members?



This is our group profile, measured by age of our members with Autism.

**The Male to Female ratio of members with Autism is 76% male to 24% female.**

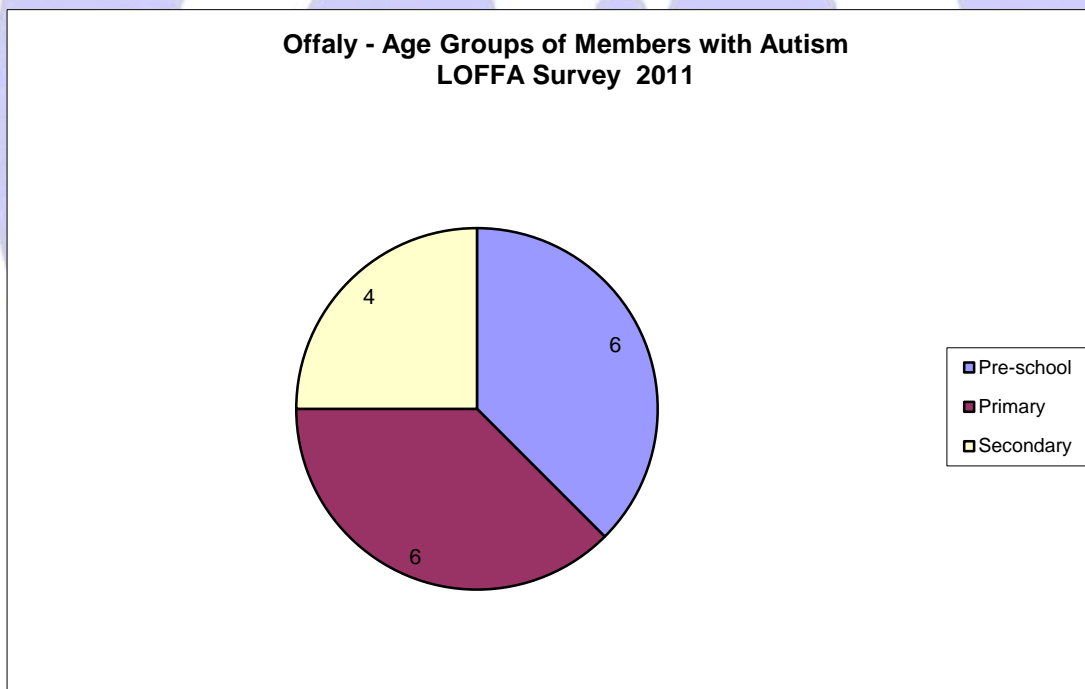
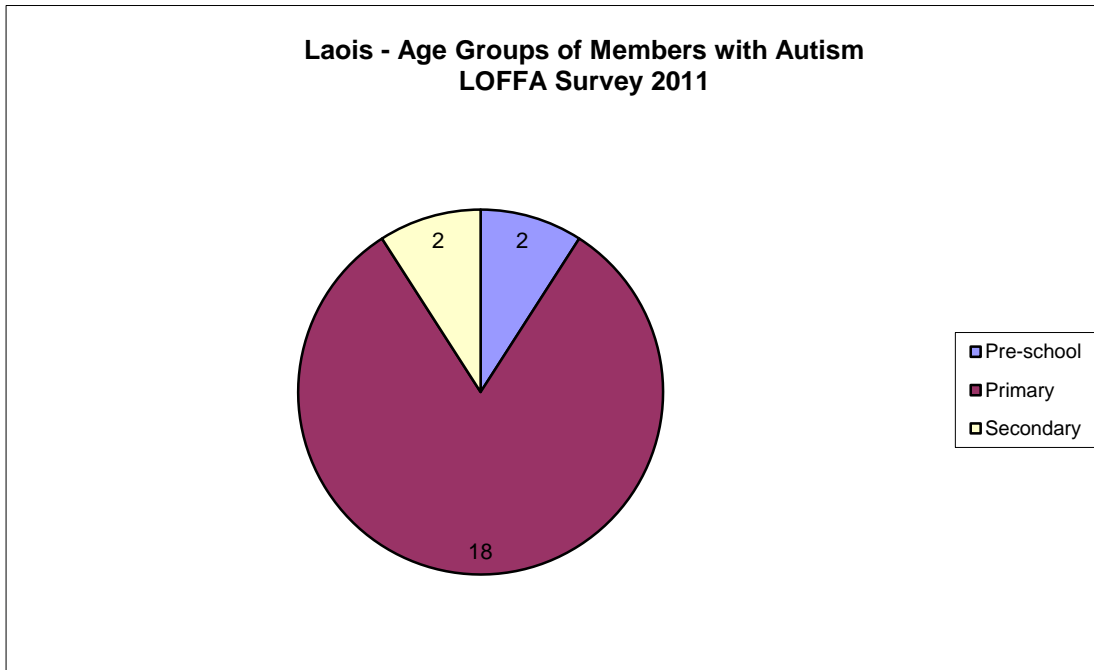
33% of families with pre-school children aged 5 years or under; 56% of families with primary school aged children (6-12 yrs) and the remaining 11% of families of children in second level education.

#### What is the Profile of our Members in Laois and Offaly?

It is interesting to note that the profile in the 2 counties is very different and will constantly change as each new child is diagnosed. **Service provision needs to be based on measured need and not on county boundaries.**

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## Survey Section B: **Diagnosis**

Parents completing the forms were asked to state if the person with Autism Spectrum Disorder (ASD) had a diagnosis of Autism, Asperger Syndrome or PDD-NOS and whether mild, moderate or severe (a copy of the survey is attached in the Appendix at the end of this paper).

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Based on the information received the following profile emerges:

### Autism - Severe

In this report when we describe a person with severe autism we typically mean that person has difficulties in all areas, significant learning difficulties, significant language delay, possibly non-verbal and physical ability more than 2 years behind their peers. They have social difficulties ranging from frequent problems to being completely socially aloof and behavioural difficulties which require professional advice, some to the point where carers fear for the personal safety of the individual e.g. total lack of awareness of environmental dangers and requiring constant vigilance on the part of those responsible for their care.

### Autism – Mild

At the other end of the spectrum those we describe as having a diagnosis of mild Autism or mild Asperger's Syndrome (also referred to as High Functioning Autism) who tend to have difficulties in some fields and not in others, or mild difficulties in each field. Learning and language ability could be age appropriate or even ahead of peers.

For some social and behaviour present the areas of greatest difficulty, ranging from occasional to moderate/frequent difficulties.

### The Spectrum

Those surveyed ranged from those with a severe expression of autism to those more able with a diagnosis of Mild Autism and a very varied and often individual and complex range of profiles in between.

**All members**, whether diagnosed with Autism or Asperger's Syndrome, are generally included under the term **Autism** and described as **mild, moderate or severe**, which reflects the actual degree of difficulty with daily living or disability they experience.

### Diagnosis of Person with Autism

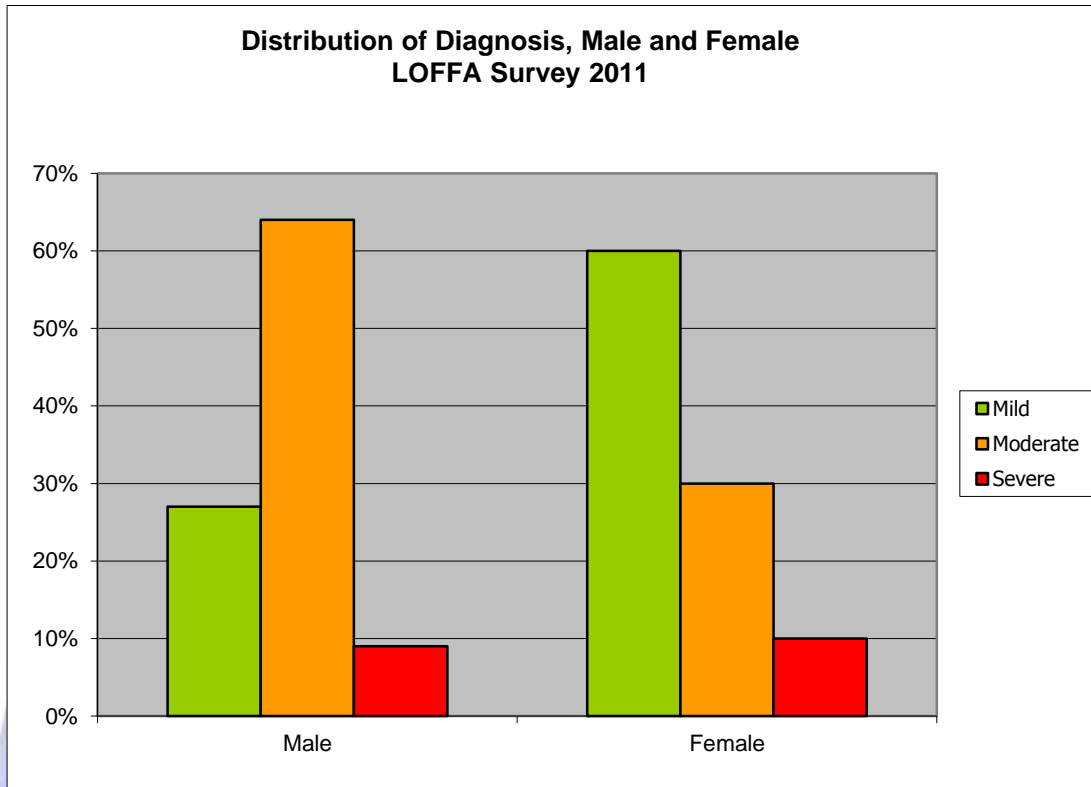
37% of diagnosis were Aspergers Syndrome and 63% Autism.

No respondent indicated a diagnosis of PDD-NOS.

Diagnosis	Mild	Moderate	Severe	
<b>Autism</b>	8	15	4	<b>27 (63%)</b>
<b>Aspergers Syndrome</b>	7	9	0	<b>16 (37%)</b>
<b>Total</b>	<b>15 (35%)</b>	<b>24 (56%)</b>	<b>4 (9%)</b>	<b>43 (100%)</b>

\*For the survey all members, whether diagnosed with Autism or Asperger's Syndrome, are generally included under the term **Autism** and described as **mild, moderate or severe**, which reflects the actual degree of difficulty with daily living or disability they experience.

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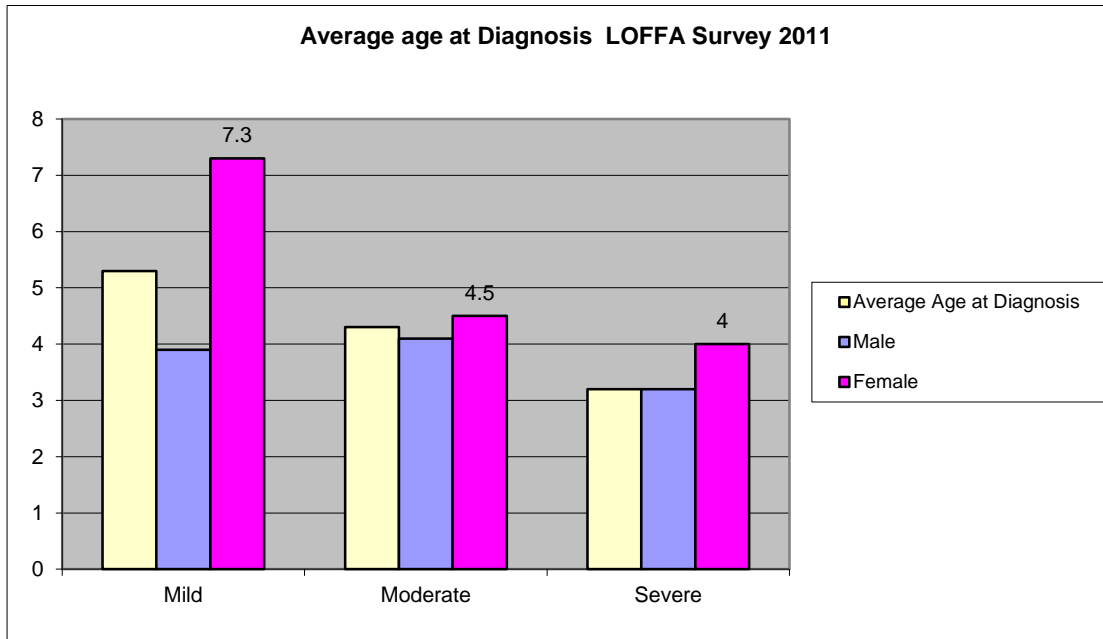
## ***By whom was Diagnosis Given***

**70%** of respondents (30 out of 43) received diagnosis through **HSE** services, the remaining 30% accessed services for diagnosis privately.

## ***Age at Which Person Diagnosed.***

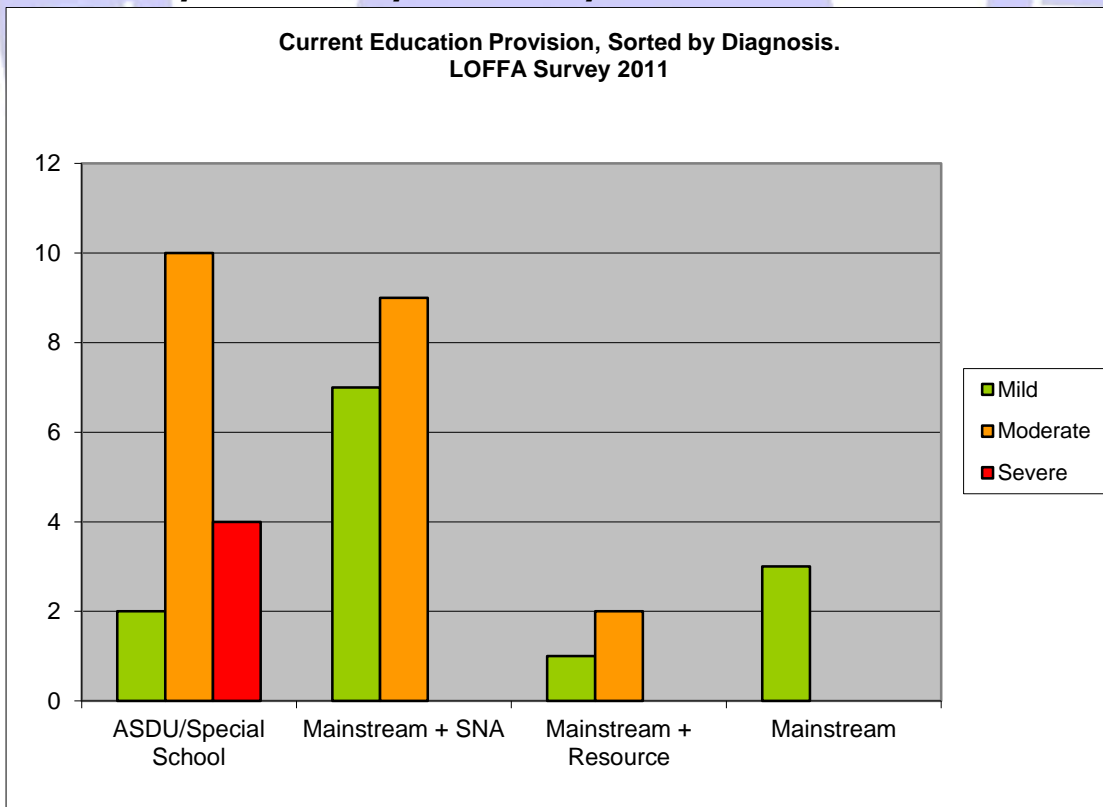
The average **age at diagnosis** ranged from **3.2 years** for those with a diagnosis of severe to **5.3 years** with a diagnosis of mild. Those with a diagnosis of Autism had an average age a diagnosis of **3.4 years** whereas those with a diagnosis of Aspergers Syndrome had an average age at diagnosis of **6.4 years**.

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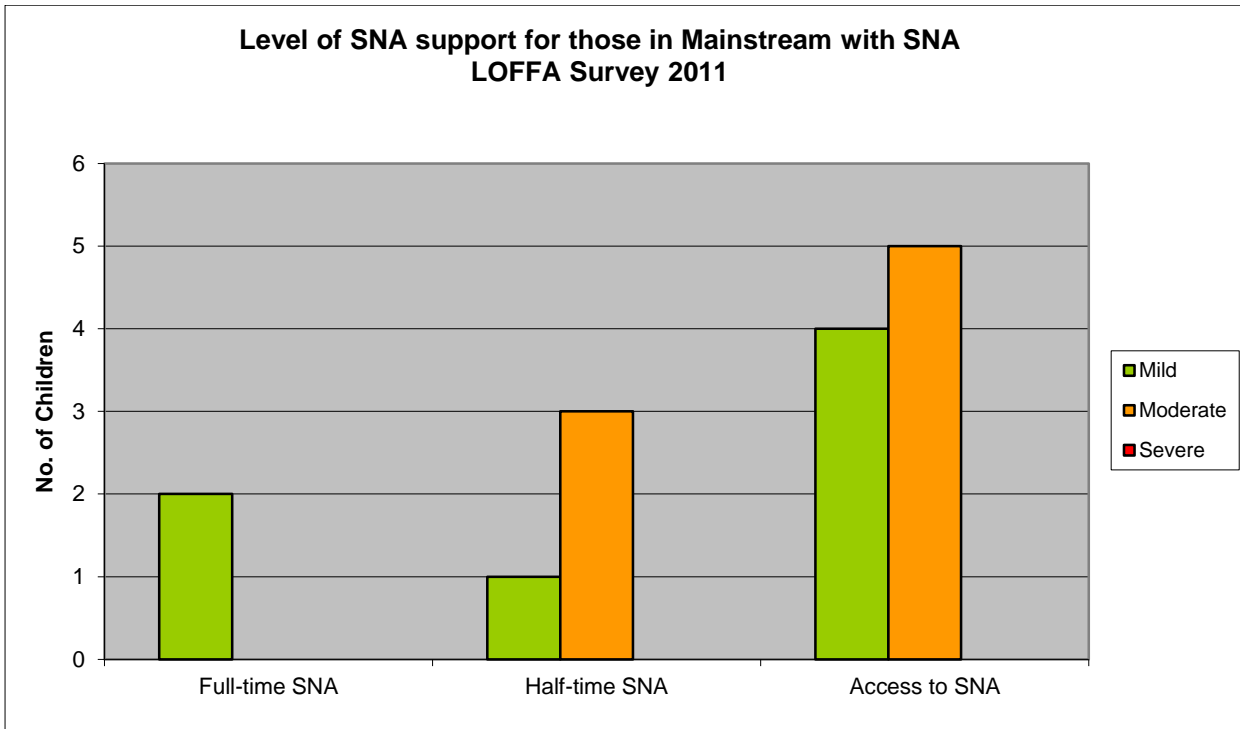
## Section C: Current Education Provision

### What education placement is provided at present?



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***For those schooling with SNA support does the child have an SNA: Full-time, Half-time or Access to an SNA?***



***Did the school provide a July programme in 2011 or did you apply for Home Tuition in lieu?***

54% of respondents had attended a July Programme in 2011 or employed a Home Tutor in lieu. For children attending an ASDU 70% had attended a July Programme or received Home tuition in lieu.

***Does the person with ASD have an Individual Education Plan?***

73% respondents attending school had an Individual Education Plan.

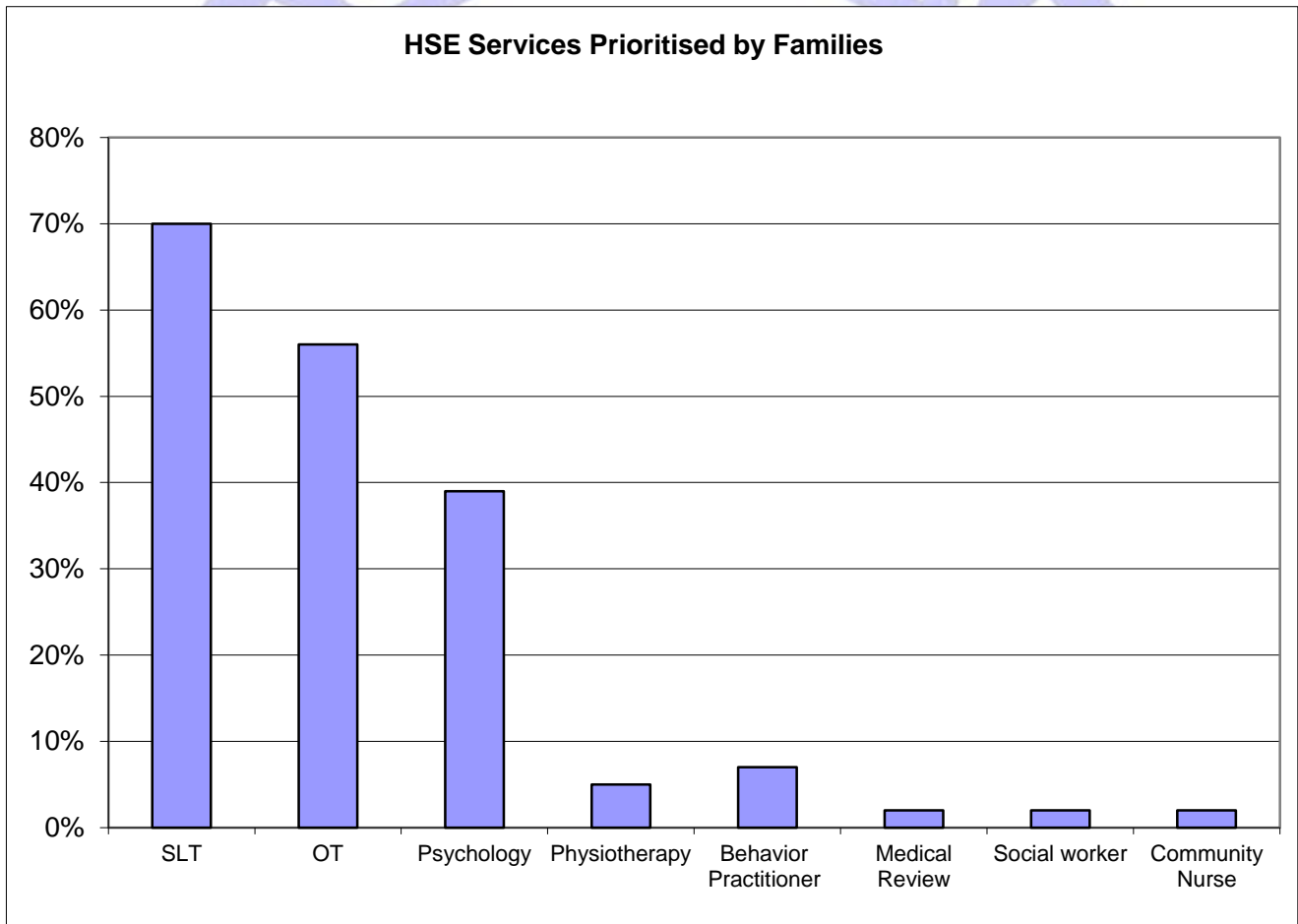
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## Section D: Current Health Provision

### **Which HSE services the person with Autism requires.**

Based on those services the respondents **prioritised as 1 and 2**, the services determined to be essential were, in order:

1. Speech and Language Therapy (SLT),
2. Occupational Therapy (OT),
3. Psychology,
4. Physiotherapy
5. Behavioural Practitioner.

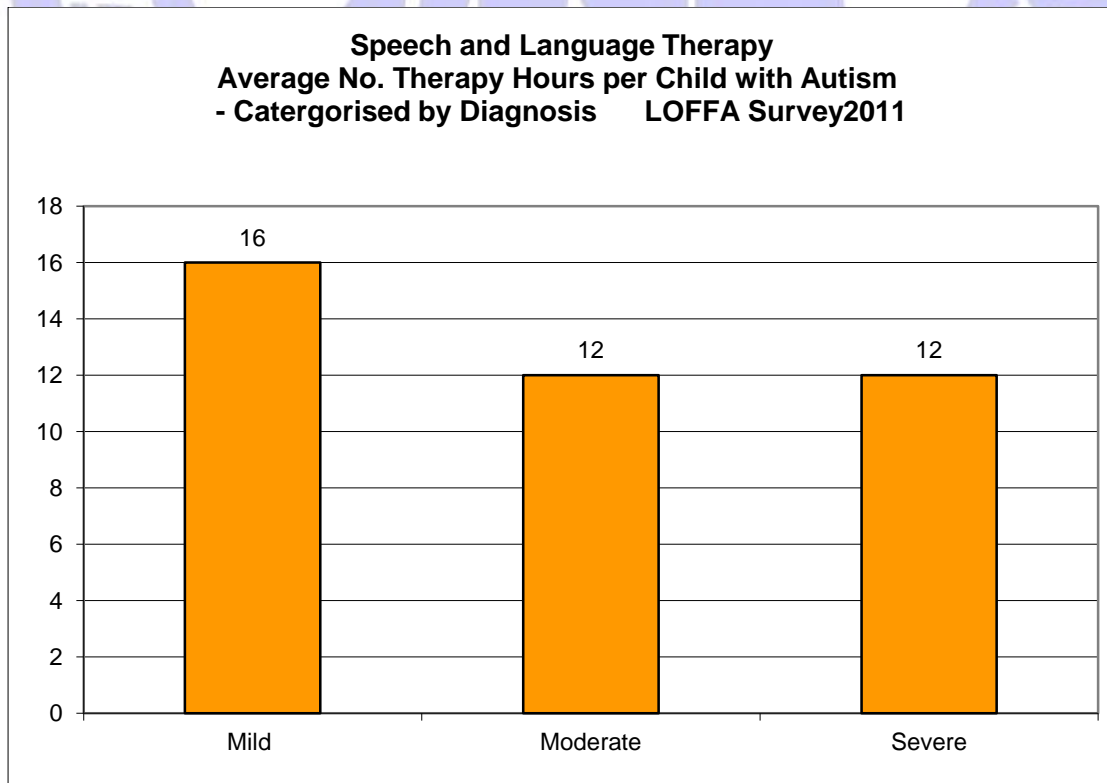
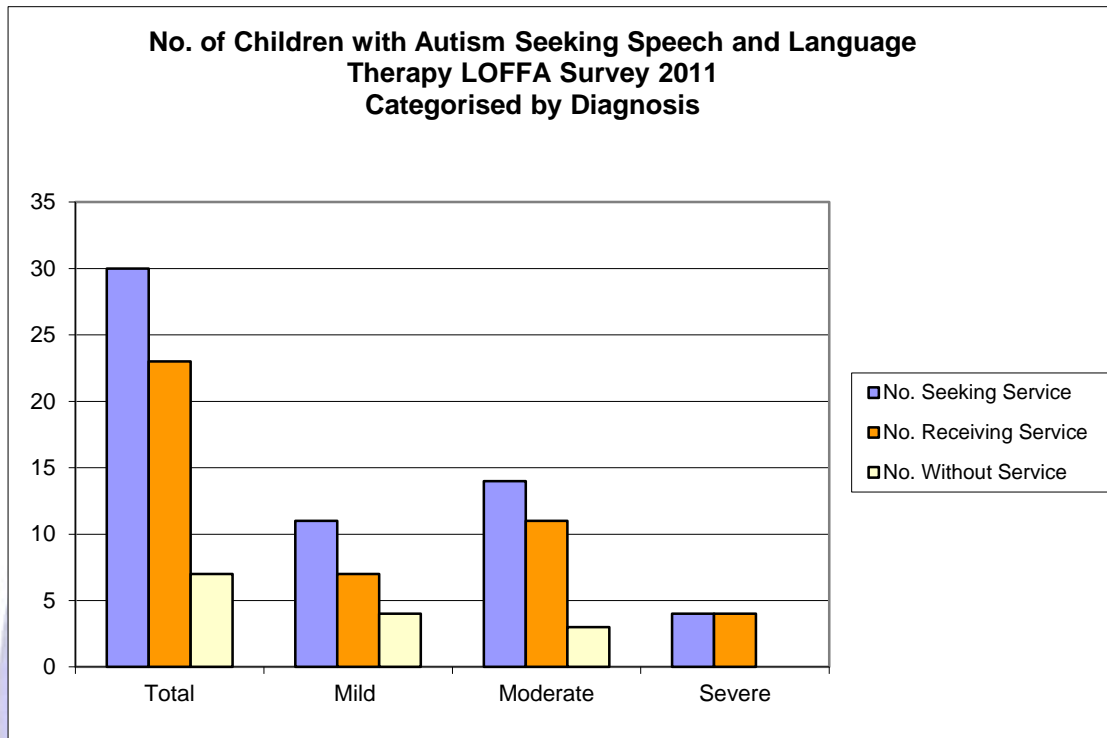




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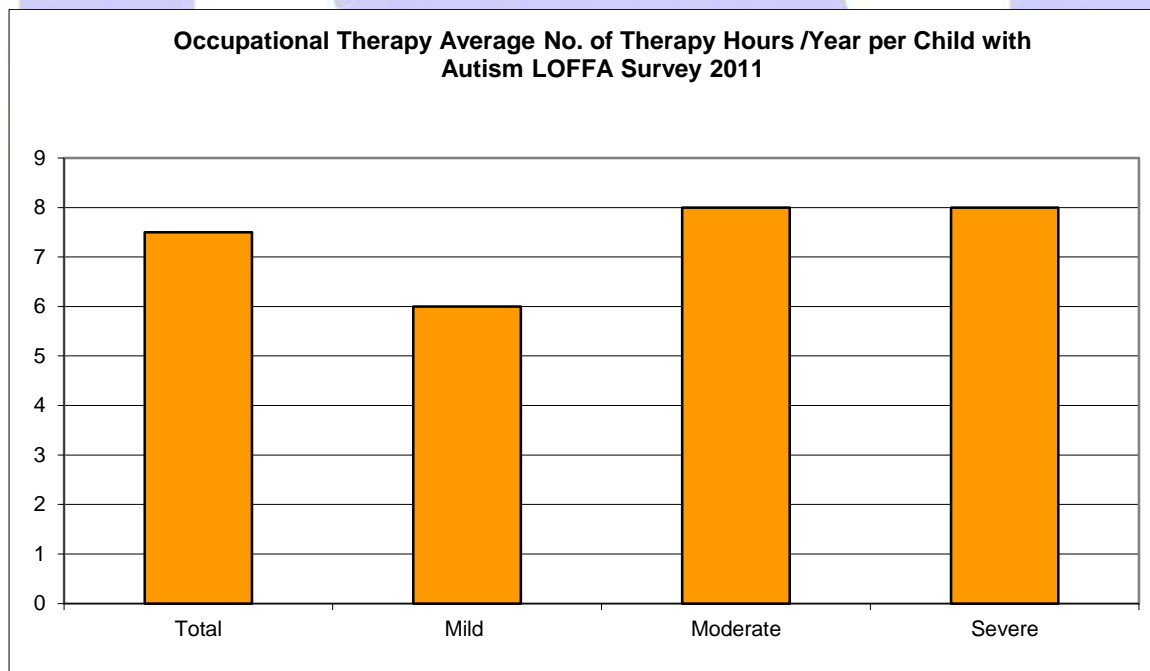
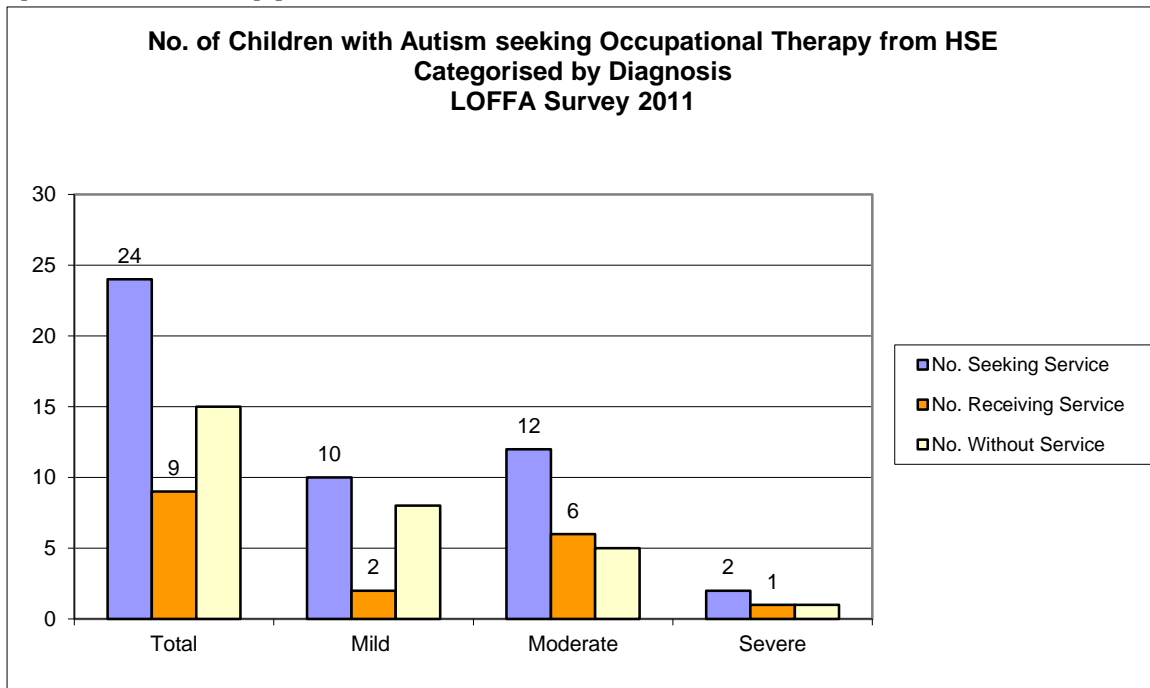
## Are They Receiving these Services?

### Speech and Language Therapy



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## Occupational Therapy

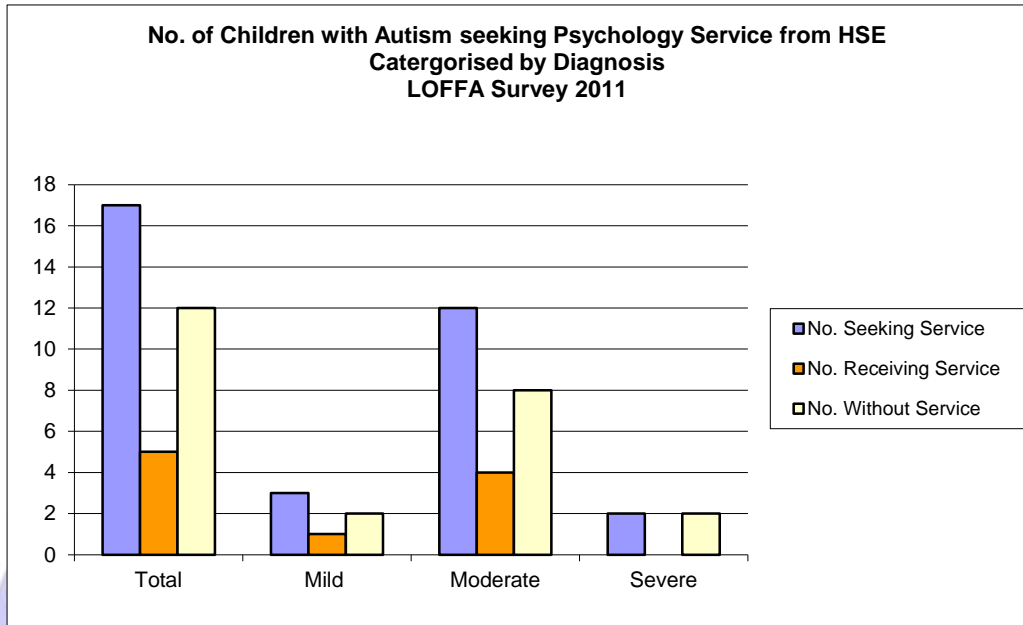


Of our survey group, 24 respondents prioritised occupational therapy. In 2011, 9 of 24 received Occupational therapy, averaging 7.5 hours therapy each in the year.

The total amount of occupational therapy received was **67.5 hours** Or 2 weeks work for 1 WTE Occupational Therapist.

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## Psychology



### **Current Respite provision**

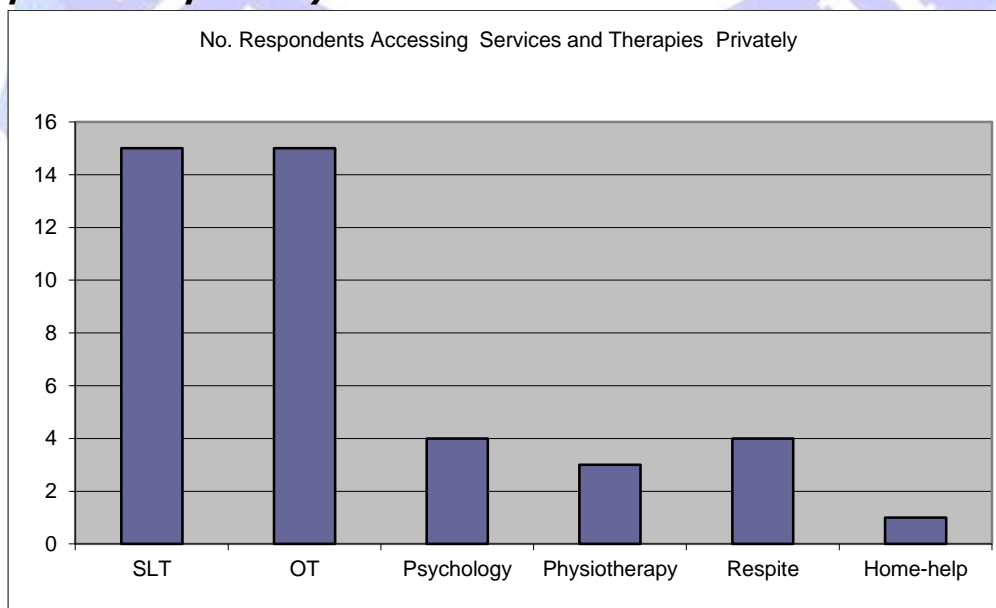
Only 21% (9 responders) are in receipt of respite service for the person with Autism.

3 respondents receive 3 hours per week home based respite from a private homecare service.

4 respondents avail of residential centre-based respite, typically for 1 or 2 days per month, 2 of these respondents also avail of 1-2 nights respite per month.

2 respondents, who prioritised respites as a service for their child, are not in receipt of any respite services with any additional 2 respondents are paying privately for respite service.

### **Services purchased privately in 2011.**



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20 of the 43 respondents (46%) accessed one or more therapies or services privately in 2011, predominantly Speech and Language Therapy, Occupational Therapy and Psychology.

**Expenditure for private therapy services ranged from €200 to €2300 per family.**  
The average cost per family, who accessed private therapy in 2011, was **€1013.75.**

### ***Section G: Entitlements***

The range of benefits claimed by respondents was varied, as it is generally dependant on personal circumstances.

#### ***Domiciliary Care Allowance***

30 respondents (70%) were in receipt of the DCA, 18 (42%) of who received it on first application and the remainder after oral hearing or on appeal.

7 respondents (16%) application for DCA was currently under appeal.

Of those cases under appeal 4 surveyed had a diagnosis of mild ASD and 3 had a diagnosis of moderate ASD.

6 respondents had not applied for the allowance.

### ***Section H: Coping with a Person with ASD in the Family.***

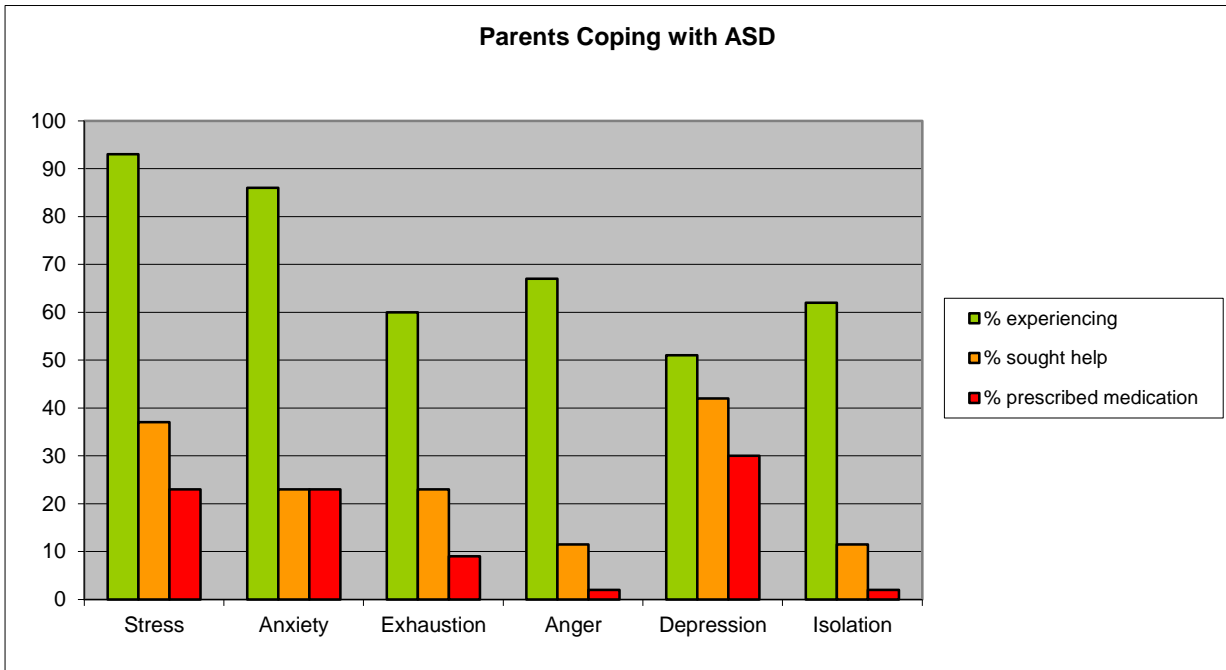
Responders where asked what feelings they think, having a person with ASD in your family has contributed to?

Over 60% of responders admit to feeling exhaustion, anger, depression and isolated, over 90% admit to feeling stress and anxiety.

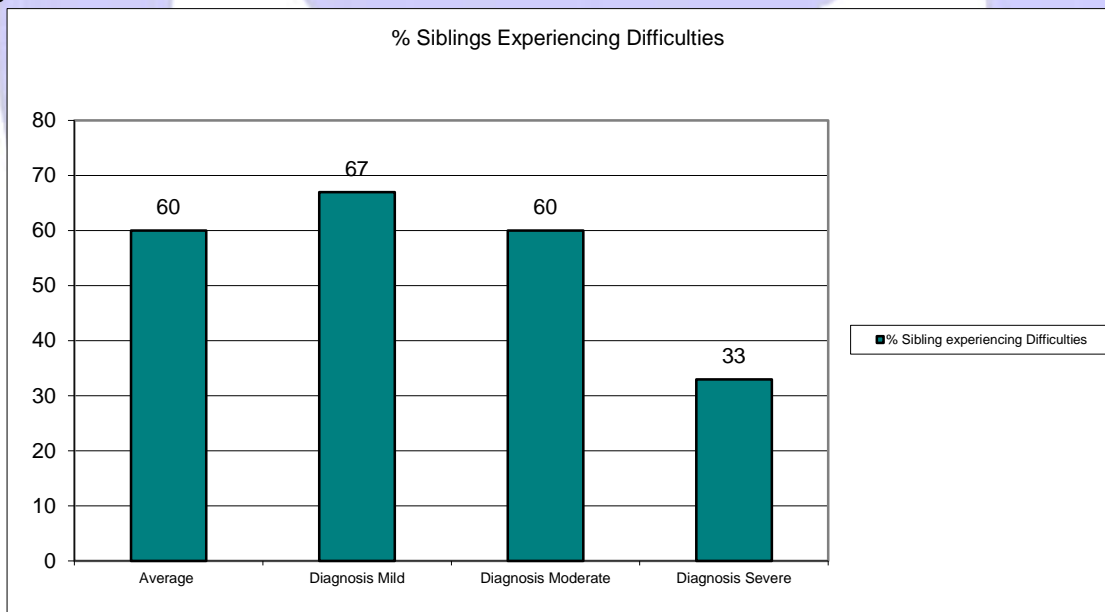
40% of responders admit to seeking help for depression with 30% being prescribed medication for the same.

Less responders seek help or medication for feeling stress, anxiety, exhaustion, anger or isolation.

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When asked if having a person with ASD in their family has contributed to problems with siblings?



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### Conclusion:

Since 2008 the number of parents contacting LOFFA for support and information has increased by a massive 237% indicating most definitely that there has been significant increase in the number of children diagnosed with ASD in the Laois/Offaly area. The increase in numbers also continues to indicate that family are willing to and obtain support from meeting other parents in the same situation as themselves.

LOFFA continues to be made up of predominantly families of younger children, when parents are trying to come to terms with diagnosis and establish appropriate services for their child. Longer-term members remain in contact and are an important source of information and advice for younger families.

In the survey the age at diagnosis also varied when male and female are compared. This may be due to what Tony Atwood, psychologist and author describes as the variation in expression of features between boys and girls.

More detailed examination of each case would be needed to determine the exact reasons.

In our 2008 survey just 50% of respondents had received diagnosis through the HSE, whereas in 2011 that number has increased to 70%.

In 2011 like in 2008, primary therapeutic services such as Speech and Language Therapy and Occupational Therapy which are known to have a massive impact on communication skills and life skills that a child with autism can learn are still the top priority that families are seeking for their children with autism.

Respite is generally listed as the most common need after therapeutic services such as speech and language and occupational therapy. In contrast to common therapeutic services, respite care would generally be considered to be for the carers benefit.

From our survey families in coping with a person with autism commonly experience stress, anxiety, exhaustion, anger, depression and isolation.