

## Introduction

Families raising disabled children, particularly those on low incomes, rely on a matrix of networks and services to help them provide the support they need for their children to have the same opportunities to develop and thrive as others. Many of these services are provided by local, regional or national government.

In 2016 we asked families about the areas in which the Government can make a difference for children and young people across Wales. The survey was completed by 192 families in Wales raising a child or children, with Autism Spectrum Disorder (ASD), who had received support in the last 12 months from Family Fund. We have used the findings from that survey as the basis of our response, the responses are from families across Wales, with children and young people up to 18 years old.

Family Fund is the UK's largest charity providing grants for families on low incomes raising disabled or seriously ill children and young people.

Last year, we provided 88,119 grants and services worth over £33 million to families across the UK last year. In Wales, we helped 1,686 families with grants worth £782,983, of which 461 children had ASD. Our grants to families cover a wide range of items, such as essential kitchen appliances, much needed family breaks, computers and tablets and more. Family Fund also provide grants to families at a time of urgent need.

### a) What are your views on the effectiveness of the current arrangements for improving autism services in Wales?

The Welsh Government published Refreshed Autistic Spectrum Disorder Strategic Action Plan<sup>1</sup> in 2016 which says:

“The Social Services and Well-being (Wales) Act requires local authorities to establish and information, advice and assistance service and to ensure people are signposted to appropriate services and support.

“Regional Partnership Boards are responsible for ensuring there are services, care and support in place to meet the needs of people in their local area. Autism has been identified as one of the key priority areas and

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<sup>1</sup> <http://gov.wales/docs/dhss/publications/161205asd-strategic-en.pdf>

Regional Partnership Boards will need to report on progress, including progress on delivery of the National Integrated Autism Service.”

This provides transparency for citizens in Wales to monitor the progress of the Regional Partnership Boards and the National Integrated Autism Service, however there is more that could be done to improve performance management, for example, by setting targets, and hold the relevant authorities to account on their provision and ensuring it is of a high quality and meets the needs of families in Wales.

### g) What are your views on how easy it is to access a diagnostic assessment where you live?

In 2015, the Welsh Government established the ASD Diagnosis Task and Finish Group in response to concerns about the provision of diagnostic services particularly for children. Shortly after its formation, additional funding was announced to support improvements – as part of the Together for Children and Young People Programme – to improve sustainability of Child and Adolescent Mental Health services. This includes £2 million annual funding to improve neurodevelopmental services.

Despite this commitment and additional resources, the results of our survey found that of the 101 awaiting a diagnosis or diagnosed in last 5 years, over two thirds of respondents said that they had some experienced problems. Just under half of the respondents said that the service was good / excellent overall, but this result shows that there is still room for improvement.

Response	Count	%
A couple of problems/delays, but a good overall service	29	29%
Many problems, we found the experience difficult	32	32%
N/A – we haven't received a diagnosis	3	3%
No problems – an excellent service	19	19%
Several recurring problems	7	7%
We are still waiting for diagnosis	11	11%

The comments from parent / carers who answered that they had experienced problems included:

- Waiting times for diagnosis were lengthy
- Coordination of services could be improved
- Lack of specialist knowledge from professionals
- Limited resources in specialist services, leading to delays

All leading to families having difficulties in accessing a diagnostic assessment. Families told us:

“A lack of specialist knowledge due to his syndrome being rare caused a delay in finding out his diagnosis.”

“Co-ordinating teams for diagnosis is a nightmare.”

“CAMHS is extremely over stretched and through no fault of [theirs], the wait for a diagnosis is huge and extremely stressfully for all concerned”

Another common theme from the survey results was that parent / carers don't feel like they were being listened to or taken seriously. On several occasions, parent / carers cited that the process was stressful, it felt like a battle to get a diagnosis, and unless they had pushed professionals, they wouldn't have seen any progress made for their child. For example:

“Awaiting a further assessment for diagnosis and it is very difficult at present have had to push and do it all myself for my child to get support required or it would of just been left”

“We found that even after having two children diagnosed with ASD it was still a battle to get our youngest assessed. They don't listen to the parents and make you feel as if you're making it all up. Then after assessment you still have to fight to get the right help for them.”

Another consideration around accessing diagnostic services is the other conditions and disabilities a child or young person may have, in addition to ASD. When we asked families to disclose the disabilities and conditions that their child has, of the 192 who answered ASD, over half, 58.8%, said their child also had an associated learning disability.

Over a quarter of responses said their child had a sensory impairment and almost 1 in 5 said a mental health condition.

Additional condition	Count	%
Learning disability	113	59%
Mental health condition	25	18%
Sensory impairment	51	27%

This suggests that multiple diagnoses may be required for a child, so in order to provide an efficient service the diagnosis should look at the child holistically, rather than being condition-specific.

#### h) What key challenges around how the diagnostic process works would you like legislation to address?

##### Waiting times

The Welsh Government's ASD Strategy plan pledges a 26-week waiting time target from referral to first assessment appointment. With Health Boards managing the performance of services to meet this target. Legislation would provide stronger enforcement of this target and ensure that Local Health Boards are accountable for meeting this target. As previously mentioned, this has been a problem for many of the families we surveyed.

##### Statutory guidance

Statutory guidance for the diagnostic process would provide transparency for families and a consistency in service delivery.

Many of the families surveyed had problems with diagnosis, but this was not across the board, with some citing good experiences. Statutory guidance would support Local Health Boards to provide quality diagnostic services across Wales.

##### Additional needs

The statutory guidance could also support Local Health Boards to diagnose any additional needs concurrently, so that the child is diagnosed, rather than the condition.

##### Progress reporting from Health Boards

With many parent / carers citing long waiting times, the legislation could address this by asking Local Health Boards to regularly report on their performance and the progress that has been made.

## Diagnosis Charter

In Scotland, the 2016 Care Act<sup>2</sup> includes a proposed Carer's Charter, which sets out what a carer can expect to be in place to best meet their needs. This approach could be included in the legislation around diagnosis, so families are clear on the diagnosis pathway, what they should receive and how they will be treated throughout.

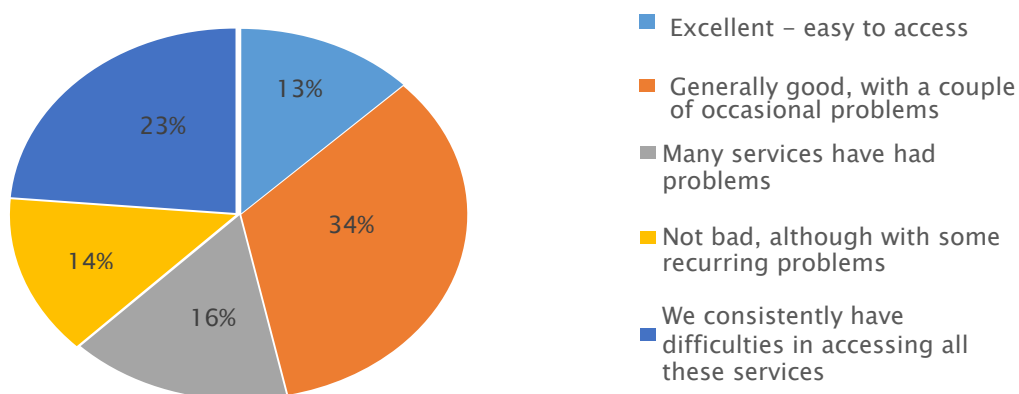
Many parent / carers feel the diagnosis process is a battle, so this may help parent / carers understand the process and what they can expect from the professionals within the diagnostic services.

### j) What are your views on the sufficiency of services currently provided to meet the needs of people with autism spectrum conditions in Wales?

We asked our respondents: "what has been your experience of accessing services, such as short breaks, clubs, personal budgets, key working, self-directed support, speech and language therapy, CAMHS and others?" We had 165 responses.

Only 13% of our respondents said that the services were excellent and easy to access. All other respondents said they had problems to varying degrees, with almost a quarter, 23%, said that they consistently have difficulties with all services they access.

What has been your experience of accessing these services?



When asked why they had given that answer, there were a number of themes:

### Waiting to access services

“There's always waiting list for accessing services”

<sup>2</sup> <http://www.legislation.gov.uk/asp/2016/9/contents/enacted>

“Extremely long waiting lists, if you move out of area you have to wait on the new areas waiting lists which can be years again!”

### Lack of local services

“Clubs and activities have virtually disappeared due to funding.”

“Only because they are all done in his school, which is out of region. I did try to receive these when he was in school in region and it was impossible to get.”

### Changing professionals

“Change in doctors. Rarely see same Doctor twice”

“Quality of speech therapy suffers from a rapid turnover of therapists”

“Key worker...constantly changing support worker... gone through 6 in the past 4 years! Autistic children hate change so this leads to many violent episodes, distress and self harming.”

“Finding a personal assistant that can stay long term is so hard. Then when they finish [it] can take six months or even longer to find a replacement so my child has been left socially isolated.”

But when a family receives a good service, they appreciate it hugely and the impact it can make to a family is not to be underestimated, despite it not meeting the families’ needs entirely. For example:

“It took time getting the respite, which is for 3 hours care once a fortnight, It allows me a little break to go out for a couple of hours. It is a tremendous service but as a single parent it is very limited time.”

We asked “Are there any services that are not (or no longer) available near you which you would find helpful?’ There were in total 96 comments. The top four responses were:

- Over a quarter said there was now reduced funding and vital family services had been cut
- Over 20% said there were a lack of opportunities and activities for their child to socialise or play
- Over 10% referenced a lack of suitably trained staff/professionals to address their child’s needs

- Over 10% made a reference to further funding for respite or short breaks

Leading us to conclude that when families get a diagnosis, getting suitable support service in place can also be difficult.

**l) Do you believe that Local Health Boards and Local Authorities in Wales should be required to establish and maintain new data collection practices around the numbers and needs of children and adults with autism spectrum conditions so that local areas can plan services accordingly?**

Yes, Family Fund believes that collecting and sharing data would enable Local Health Boards and Local Authorities to understand more about those with ASD, their requirements, and the support and services that are most beneficial. The data should be consistent across all Local Health Boards and Local Authorities in Wales, so that it can be easily monitored.

Family Fund would recommend that if data collection becomes a requirement, the Welsh Government should consult with and involve families and stakeholder groups on the data. As well as this, Local Health Boards and Local Authorities should regularly publish anonymised data so that the Welsh Government and citizens can understand the progress Local Health Boards and Local Authorities in Wales are making.

**n) Do you have a view on the current scope and effectiveness of training in Wales for key staff working with people with autism spectrum conditions?**

The Integrated Autism Service in Wales<sup>3</sup> says it will provide training and support for other professionals, the Mental Health Act code of practice recommends training for staff who work within the remit of the mental health act with people with ASD, the ASD Strategic Action plan aims to develop more tools for schools, provide more tools for employers, including a new HR training module. As well as this, the ASD Strategic Action Plan has provided many resources through ASDinfoWALES<sup>4</sup> and plans to focus training on primary care and mental health professionals.

Family Fund welcomes these positive steps forward. However, we have still found that families are struggling to get what they need from some professional services. For example, their understanding of complex cases and additional needs.

“A lack of specialist knowledge due to his syndrome being rare caused a delay in finding out his diagnosis.”

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<sup>3</sup> <http://www.asdinfo.wales.co.uk/integrated-autism-service> <sup>4</sup> [www.asdinfo.wales.co.uk](http://www.asdinfo.wales.co.uk)

Also, a recurring theme was that our families felt they weren't being listened to. As well as condition-specific training, there may be a requirement for training on soft skills, such as empathy to understand individual situations, pressures and challenges.

Finally, training may support professionals to remain in post. Poor staff retention is a theme from our survey results, which can have detrimental effects for families. Providing staff with the training and support they need to be effective may encourage professionals to stay in their role.