Index Annual Report 2023-2024







Lyndsey Richards - Index and Family Information Service (FIS) Officer

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1. Meet the FIS Team



The Index is funded by Welsh Government's Families First Grant and administered by the Family Information Service, led by Lyndsey Richards and overseen by Becky Wickett. The team demonstrate a wide remit specialising in their own areas but knowledged across the board enabling the team to answer varied and complex enquiries.

2. BACKGROUND

This Index report will provide an overview of Index activity over the last year.

- The Children Act 1989 requires all service providers to work closely together, in partnership with parents, to set up a system to assess the needs of children and young people with disabilities and additional needs, and their families. In order to do this, each local authority must set up what the Act calls a 'register' the Vale of Glamorgan calls it 'The Index'.
- The Social Services and Wellbeing Wales Act (2014) requires local authorities to keep a register of children who are disabled, have a physical or mental impairment which gives rise, or may in the future give rise to, needs for care and support.
- The Index was initially launched in the Vale in April 2005 and, through Families First Grant funding support, was re-launched in April 2012. The Index Officer sits within the wider framework of the Family Information Service (FIS). The Families First Grant funds a Temporary Index Officer post and the production of The Index newsletter.
- The purpose of The Index is to directly provide families who have children and young people with disabilities or additional needs, with information on local services, clubs and activities. Families who are signed up to The Index will receive our newsletter 'The Index' and regular mail outs on workshops, benefit advice, networking, clubs and services, training opportunities, carers support and any relevant information from other agencies. Families can request specific information that may be of interest to them. The Index is also a way for parents to have a voice they can contact us directly and we consult with them via survey and ebulletins.
- The Index also assists service providers in planning their services and budgets. It can give a clearer picture of how many children and young people there are with disabilities or

- additional needs in the Local Authority area. Having a clearer picture of the level of need will enable the agencies to work together to plan better services.
- The children and young people included on The Index have been referred by their parent /
 carer, health visitor, social worker and other agencies. The information gathered is a factual
 record of the child's needs and the information is held confidentially on a stand alone secure
 system within the Family Information Service Team.

If you have any comments or queries in relation to this report, please contact:

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3. WHAT IS THE INDEX?

- The Index is Vale of Glamorgan's voluntary register of children and young people with disabilities or additional needs.
- In order to be included on The Index, the child / young person needs to:
 - have a diagnosed disability or confirmed ongoing additional needs or on the pathway waiting an assessment that could lead to a diagnosis
 - be aged 0-18 years
 - live in the Vale of Glamorgan
- The Index aims to provide information to:
 - Families keeping families up to date with services, support and activities
 - Professionals keeping professionals up to date with the needs of children and young people with disabilities or additional needs
 - Organisations promoting existing services and support
- The Index is a point of contact for families and professionals

4. SUMMARY OF INDEX REGISTRATIONS 2023-24

- 1008 children & young people registered on The Index as at March 2024.
- **153** new registrations to The Index between 1 April 2023 and 31 March 2024, which is a minor decrease of **7%**.
- **149** children & young people have deregistered from The Index due to turning 18, moving out of the area or requesting to be deregistered.
- 83 reviews carried out.

- The largest number of referrals to The Index have come from the Families First Advice Line (FFAL) (32%), closely followed by a health professional (21%). FFAL continue to be the highest referral pathway to The Index.
- In the last year, the majority (67%) of new registrations were male.
- Over half of all new registrations live in Barry (54%).
- (42%) of all new registrations have recorded they have received a formal diagnosis for their child.
- (23%) of all new registrations recorded Autistic Spectrum Disorder (ASD) as a diagnosis their child had received. Many of these young people have received a second or third diagnosis. 63% of all new registrations recorded Neurodiverse Condition as a Presenting Need.
- Over half of new registrations (64%) recorded they were under assessment and yet to receive a diagnosis.
- FIS Team have received **223** enquiries from parents, carers and professionals asking about services and support for children with additional needs over the past year. This is an increase in comparison to the previous two years (2021-2023) where FIS Team took **372** enquiries combined averaging 186 enquiries per year.
- In March 2023, just outside the parameters of this report, we went live with a brand new registration form following full consultation with partners and parents with an aim to make the end user experience more efficient and for it to align with a new back end database. This has been a positive experience overall.
- In December 2023 the records on the existing Index register were carefully transferred to the new back end database. The new register does not require input on primary and secondary reasoning for registration as it did previously. We now ask whether a diagnosis has been received and if so, what the diagnosed condition(s) is or alternatively, if they are awaiting an assessment that could lead to a diagnosis.

5. KEY ACHIEVEMENTS 2023 - 2024

- 153 children and young people signed up to The Index in the last year, which is a minor decrease of 9 registrations compared to the previous year (162).
- Achieved the Families First Quality Award (FFQA) with The Index highlighted as a strength in the assessors report.
- Kept families informed about Additional Learning Needs updates from Welsh Government about the ongoing implementation of the new Additional Learning Needs (ALN) Code.
- Attended ALNCo training days on key topics and provided an Index presentation at 2 online ALNCo training days and 1 in-person ALNCo event.
- Promoted the Index via Bro Radio, Index animation, leaflets, newsletters, eNews bulletins, social media, web and outreach within the community.

- Produced 2 newsletters as a digital flipbook, accessible PDF as well as hard copy.
- Produced 35+ eNews bulletins to parent carers and professionals signed up to the Index.
- Utilised links with internal staff to continue improving knowledge around accessibility of materials produced. Now working from a check list for consistency as a result.
- Engaged with new health pilot 'Community Connectors Project' to introduce new families on the waiting list to the Index. For these families to receive support whilst awaiting a neurodevelopmental assessment that could lead to a diagnosis.
- Completed a review of activities and services, providing specialist support for children with disabilities. Enhanced their record on the Childcare Information Wales website, making it easier for parents and carers looking for these services. Also produced a step by step guide.
- Migrated records on Index register to new database linked to new Index registration form.



6. PRIORITIES 2024 – 2025

- Establish a referral pathway for The Index for key partners in Education, Health and Child Health and Disability Team (CHAD).
- Review FIS and Index web pages to improve accessibility of information and act as an information 'hub' for families.
- Continue to develop the Index service by identifying and publishing new resources for parents, carers & professionals.
- Consult with parents, carers, providers and partners to develop our service and ensure our information is accessible.
- Identify and publish new services on the Dewis Cymru website, feeding through to the Childcare Information Wales website.

7. PROMOTION OF THE INDEX ACROSS THE VALE

7.1 OUTREACH



Outreach has continued to increase giving many opportunities to engage in-person with parents, carers and professionals. This has included large-scale events over the Summer 2023 such as the Flying Start Fun Day and in December 2023, FIS team hosting their first Christmas parties since 2019 for pre-school children and school-age children in the Vale of Glamorgan.

In our FFQA report, the assessor commented, 'The FIS Christmas Family Party, which welcomed over 700 attendees, was identified as an excellent opportunity for parents to connect with partners and learn about the local support available to them".

The Index Officer produced a video to capture the event: Christmas Party Video 2023



Health

There has been new opportunities such as engaging with the new Health 'Community Connectors Project' and representing The Index at their parent carer sessions across the Vale of Glamorgan. Parent carers that attended had children on the waiting list for a neurodevelopmental assessment that could lead to a diagnosis. This has enabled The Index to lend it's expertise and connect families to activities and services that do not require a diagnosis.

Education

There has been opportunities to provide Index presentations at ALNCo training days online, and inperson at an ALNCo event. These have proved very useful in engaging with ALNCo's, education staff and staff working in Local Authority specialist provisions across the Vale. Invites to specialist provisions coffee mornings have occurred since and been attended by The Index Officer as a result.

Flying Start

The Index Officer and FIS colleagues attended the Flying Start Family Fun day during the Summer 2023 which was a large-scale event well attended by families and professionals in Barry. The Index had a large stand and hosted an activity for children enabling parents to engage with staff. We were also invited to an Early Years event, hosted by Flying Start, to have a voice on the development of Early Years services for children 0-7 years. This enabled plenty of opportunity to establish new links and working relationships with those professionals present.

Families First

The Index managed a stall at the Families First Networking Event in March 2024. Over 110 individuals attended over the day from a variety of service areas and organisations. This was a fantastic opportunity to engage with similar services that offer a service to families in the Vale of Glamorgan.

Unpaid Carers

The Index Officer has also relished the opportunities to attend organised unpaid carers events hosted internally by the Unpaid Carers Service. These events enabled the Index Officer to relay knowledge and expertise around the mental health and wellbeing services that exist across the region and other relevant information.

Community

The Index Officer has also attended the second Understanding Disability Awards since there was a gap during the covid pandemic. The ceremony recognised and celebrated the individuals and organisations who have really made a positive difference to the lives of those with disabilities. It was fantastic to see 3 Vale Schools highly commended in the schools category.

Large scale events

The Index Officer attended and exhibited at the Autistic Minds Live annual event for the autism community, providing them with face to face access to services like The Index; resources and provisions that are there to help those with Autism, their families and professionals. Another great opportunity was attending the Kidz to Adultz exhibition, making links with new services and bringing the information back and promoting it to families and professionals signed up to the Index.





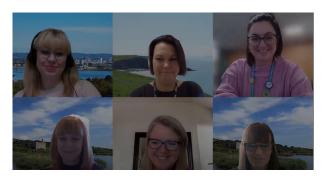
7.2 DIGITAL PROMOTION

Q&A video:

The Index Officer takes enquiries from parent carers about the new additional learning needs (ALN) system that supports children and young people aged 0 to 25 in Wales with ALN which replaces the Special Educational Needs system in schools across Wales. The Index can act as a buffer for Education colleagues, reducing the need to escalate enquiries to them. As the gradual implementation of the ALN system in schools has extended until August 2025, families who sign up their children to the Index are still receiving the recorded Index Q&A session, devised and led by the Index Officer, with education professionals, to provide them with relevant information.

This recording has received over 650 views.

Moving to the new ALN system - for parents, carers & professionals - YouTube



Social Media:

Social media has continued to be an effective marketing and communication tool and we have over 4.4k followers on Facebook, which is continuing to increase year by year. The most successful post overall was our Easter activity post in March 2024 which reached 20701 people and resulted in 115 new followers during the time the post went live. The most successful Index post was the Winter Newsletter, which reached 1945 people and resulted in almost 24 clicks to the website and 34 new followers to the page that month.



Animation:

We promote our video to help explain The Index to parents and carers in a visual and accessible way. It is sent out to all new referrals that cannot be reached by phone initially. It has been shown on a laptop at outreach events and it is sent out to partners to share with parent carers they are in touch with digitally. We are aiming to get this shown on screens in GP surgeries, hospital concourses and libraries. We have used this on social media, website and during presentations to professionals.

It's been viewed over 500 times which is an increase of over 100 views since we reported this in our previous report.

Index Animation

Radio and live streaming:

Our radio advert through Bro Radio, the local radio station for the Vale of Glamorgan, is getting 2 or 3 plays per day across the full 24 hour period.

E-bulletins:

We send e-bulletins to families and professionals in between the newsletters, containing information on family support services, financial help, events, training and activities. Some articles focused on the mental health and wellbeing of parent carers and national and world raising awareness campaigns such as the Young Carers Action Day or World Down Syndrome Day.

Website:

The Index has its own web pages on the Council website: www.valeofglamorgan.gov.uk/TheIndex

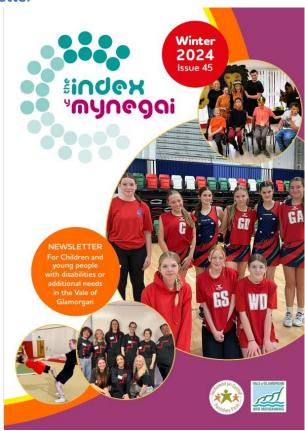
Parents and professionals can access the <u>family friendly leaflet</u> explaining The Index and the benefits of signing up. They can also complete the <u>online registration form</u>, view <u>past newsletters</u> and we have a section on Transition: Beginning to Plan for My Future.

The Index web pages sit within a larger section called 'Children with Additional Needs'.

One of our priorities is to improve the webpages next year and ensure they continue to act as a hub of information for families.



7.3 The Index Newsletter



The Index Officer produces <u>The Index newsletter</u> twice a year in Summer and Winter as a digital flipbook, an accessible PDF and a hard copy. The hard copy is available in the community and copies are sent to ALNCo's in the schools, health visitors, libraries, hospitals and key partners.

The aim is to make sure that the information is available to as many families as possible, and also to encourage families to sign up to The Index.

8. ENQUIRIES

The Family Information Service has received **223** enquiries from parents, carers and professionals asking about services and support for children with additional needs over the past year. This is an increase in comparison to the previous two years (2021-2023) where The Index took **372** enquiries

combined, averaging 186 enquiries per year. The majority of these then signed up to The Index. Enquiries are varied ranging from a parent concerned about her child in school to a parent wanting to know more about groups and activities. We also receive enquiries from professionals such as ALNCOs, health visitors and school nurses.

9. FEEDBACK

Feedback is requested at the time of an enquiry or after getting in touch with the Family Information Service. Enquirers are contacted to gain feedback on the service they received from FIS and more specifically, The Index.

It is difficult to gain feedback and quite often we will contact a parent carer and they haven't yet used the information provided, and so it's difficult to measure the impact The Index has had on a family.

"I have two children with disabilities. I can access the Family Information Service using different media, which is good for me, as I have autism and disabilities as well".

"The FIS first helped me with information about how to get reasonable adjustments in school for my children, and I have since been able to access grants via the Index".

"They always follow-up after my calls to check if I still need help, which is great when you are neurodiverse".

"They advocate on my behalf and make me feel listened to and empowered."

"The registration process was very easy and I'm sure the information received will be of use to us as a family in the future. I would recommend the register to to others".

"Because my son is only 3 I haven't found anything on ebulletins so far but I think the service is very useful and would recommend it to other people".

"I have found the emails really useful and have booked on a few things. It really helps to have all the information like that, the lady went above and beyond for me, she was very helpful and friendly".

"I found the registration process really easy. I haven't received any ebulletins yet but I would definitely recommend registering to others".

10. FACTS AND FIGURES OF CHILDREN AND YOUNG PEOPLE ON THE INDEX

10.1 REGISTRATIONS

There are **1,008** children registered on The Index and the chart below illustrates the number of new registrations, de-registrations and total number of registrations over the last five years. There has been a very slight dip of 11 registrations over the past year so we have been consistent with our conversions in comparison to new registrations received 2023 and prior. We can see below that the main reason for this is the consistency with FFAL providing the highest amount of professional referrals to the Index.

Over the last year, **149** children have de-registered. This was due to the young persons reaching 18 years old or moving out of area.

For those turning 18 years old we ask if they would like to be placed on our transitions mailing list and they will still receive our newsletters and ebulletins. There are currently 38 young people on this list.

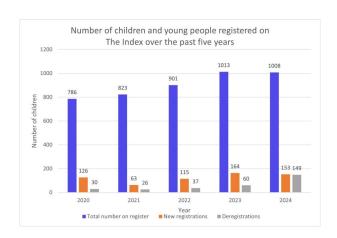


Chart 1: Number of children and young people registered on The Index over the past five years

10.2 REVIEWS

A 'Review' can take place at least every three years, or sooner if a parent contacts us to update their details. Over the last year, **83** children have had their details reviewed.

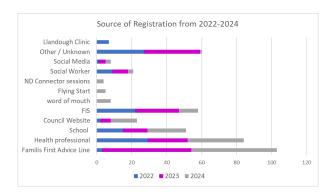
10.3 REFERRALS

We ask families where they heard about the Index and some professionals refer children directly. Over the last year, the highest number of referrals were from the Families First Advice Line (FFAL 49 referrals), closely followed by the Health Visitor / Special Needs Health Visitor (27 referrals).

When we compare the last year, referrals remain fairly consistent. However, referrals from FFAL continue to be the highest referral pathway, as there were only 3 referrals in 2021-22; and 51 in 2022-23 and 49 in 2023-24.

Please be aware that the high number of referrals classed as 'other/unknown' is due to the huge variety of ways people hear about The Index and the chart would be too big to name every source of referral. This information can be provided if requested.

The Index Officer has worked closely with the FFAL Team Manager and referrals automatically come through to the Index Officer on WCCIS, the Social Services information sharing platform. Following the parent/carer's initial conversation and assessment with a FFAL Advisor, The Index is discussed and if they would like to receive ongoing information about services and support, a referral can be made to The Index Officer. This way of working reduces staff resources, duplication and is a more efficient service for the parent/carer.



10.4 AGE RANGE & GENDER

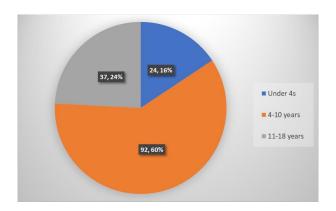
The majority of children (688, 68%) registered on The Index are male.

In the last year 67% of new registrations were male, 32% were female and 1% stated 'prefer not to say'.

In the last year, the majority (60%) of new registrations were age 4-10 years.

- 24 children age 0 3 years
- 92 children age 4 10 years
- 37 children age 11 18 years

Chart 3: Age range of children and young people on The Index



10.5 ETHNICITY

80% of children are white, 16% have not disclosed their ethnicity and 4.3% (total of 44 children) are from a minority ethnic background. The Office of National Statistics Census 2021 states that only 5.4% of the Vale population are from a minority ethnic background.

10.6 GEOGRAPHICAL BREAKDOWN

Chart 4: The Geographical Breakdown of Children on The Index

The majority of children on The Index live in Barry (57%), 25% live in Western and Rural Vale and 18% live in Eastern Vale. This has remained consistent over the last 4 years. The map below illustrates the location of children and young people on the Index.

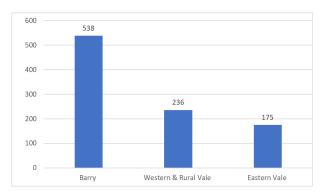


Chart 5: Location of children and young people on The Index

The map below illustrates the location of children registered on The Index.

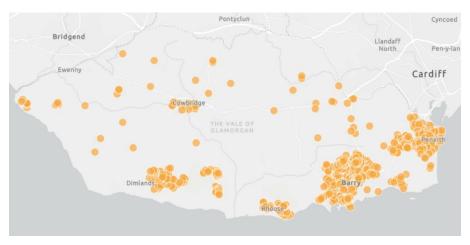


Chart 6: Map of children and young people on The Index

The map below illustrates Index registrations by ward. The darker shaded wards have a higher number of Index registrations. Some wards in Barry and Llantwit Major have the highest number of registrations. Whereas some rural wards have the lowest number of registrations.



10.7 PRESENTING NEED OF CHILDREN ON THE INDEX

Historically when signing up to The Index, parent carers were asked to state one primary reason for registration as well as listing any other associated disabilities / difficulties. Since the new registration form went live in March 2023, Parent Carers are now asked if their child has received a formal diagnosis and if so, the name of the disability / additional need.

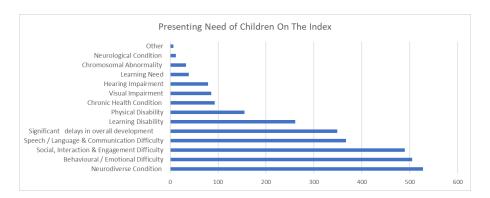
Naming primary reasons for registering on the Index did not declare if the named condition had been received as a formal diagnosis or not. Therefore, when reporting, it was left open to interpretation and there were grey areas within our information.

For those who have not received a diagnosis but awaiting an assessment, this information is helpful as we can ensure we are providing information on specialist activities and services that do not require a diagnosis. Furthermore, during reviews we can determine if a diagnosis has been received later down the line enabling us to update our register and reflect in reporting.

The chart below looks at all children registered on The Index (1,008) and the number of children who have received a diagnosis.

Chart 7: PRESENTING NEED OF CHILDREN ON THE INDEX

The chart below illustrates that those with a neurodiverse condition are among the highest reasons for Presenting Need. This includes diagnosed conditions such as Autism Spectrum Disorder, Attention Deficit Hyperactive Disorder and Dyspraxia but not limited to. To follow is those with non-diagnosed behaviour/emotional needs and social, interactive and engagement difficulties. As this is the first time we have reported Presenting Need it is difficult to provide an exact comparison but we can report that a diagnosis of Autism Spectrum Disorder has always been the highest primary reason for registration which now sits within the neurodiverse condition category.



- (42%) of all new registrations have recorded they have received a formal diagnosis for their child
- (23%) of all new registrations recorded Autistic Spectrum Disorder (ASD) as a diagnosis their child had received. Many of these young people have received a second or third diagnosis. 63% of all new registrations recorded Neurodiverse Condition as a Presenting Need.

Over half of new registrations (64%) recorded they were under assessment and yet to receive a diagnosis.

10.8 INFORMATION REQUESTED

During registration, we offer a tailored service that meets the need of the parent carer and is based on the interests and needs of the child/young person. Over the past year, we have received a huge variety of requests including: family support services, parent support groups, disability benefit information, financial help i.e grants, activities and inclusive sports clubs, childcare and respite services, parent / carer assessments, young carers support and the ALN system being implemented in schools across the Vale of Glamorgan until August 2025.

10.9 EDUCATION

The Additional Learning Needs and Education Tribunal (Wales) Act 2018 ('the Act')

Aims to create:

- A unified legislative framework to support all children of compulsory school age or below with additional learning needs (ALN) and to support young people with ALN who are in school or further education (FE)
- An integrated, collaborative process of assessment, planning and monitoring which facilitates early, timely and effective interventions
- A fair and transparent system for providing information and advice, and for resolving concerns and appeals.
- It was expected the ALN system set out in the Act would be fully implemented over a three-year period. The implementation period was expected to run from September 2021 to August 2023. Welsh Government has since announced this implementation period has been extended until August 2024.
 - During implementation, the ALN system will operate in parallel to the existing special educational needs (SEN) system, which will gradually be phased out during the implementation period.

Further information is available here: Additional learning needs (ALN) system: parents' guide

237 (23%) registrations on the Index stated their child has a Statement or Individual Development Plan (IDP). This is in comparison to 1,235 children and young people in education, who have a Statement or IDP, according to PLASC data July 2024.

In the last year, 63 parents stated their child has a Statement or IDP (41% of new registrations). This data would be useful to scrutinise in conjunction with Health data, but we haven't been successful with accessing this yet.

10.10 COMMUNICATION

- In the last year of the 153 new registrations (12%) use Gestures to communicate, 4 children (3%) use PECs, 2 children (1%) use Makaton and 0 children use British Sign Language. It is important to note that many of these children and young people use a combination of communication methods so there is overlap captured on The Index.
- Looking at all registrations (1008), 130 use Gestures, 77 children use PECs, 38 children use Makaton and 7 children use British Sign Language.
- 127 (13%) of all children registered on the Index are a wheelchair user.
- 371 (37%) of all children are in receipt of either Disability Living Allowance (DLA) or Personal Independence Payment (PIP).

11. SUMMARY

As can be seen, The Index provides a vital service to families with children with disabilities or additional needs, ensuring that they receive accurate, up to date information, on services and support they can access.

The Index includes children and young people age 0-18 years and covers a wide range of individual requirements. Therefore, one of the challenges is to ensure that the information provided to families is beneficial to their specific situation. To monitor this we obtain feedback on our service and carry out a survey annually.

The last year has seen an increase in targeted outreach therefore, there has been some fantastic opportunities to engage with families and professionals, with many converting into Index registrations.

12. CONTACT INFORMATION

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