



The Index for Children and Young People with  
Disabilities or Additional Needs

ANNUAL REPORT 2019 – 2020

Gemma Owen, Index Officer

Becky Wickett, Social Care Information Coordinator



# CONTENTS

Background	3
Summary	4
Key Data 2019-20	4
Key Achievements 2019-20	4
Priorities for 2020-21	5
Promotion of The Index	5
Enquiries to The Index	6
Feedback	7
Facts and Figures of Children and Young People on The Index	9
Registrations	9
Referrals	9
Age Range and Gender	10
Ethnicity	10
Geographical Breakdown	11
Primary Reason for Registration	13
All Reasons for Registration	15
Social Services	16
Education	16
Health	17
Summary	18
Contact Information	19

## BACKGROUND

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 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 Index was mirrored in Cardiff and became a regional Index for Cardiff and Vale. Due to its success, Cardiff will now be developing their own Index. Information on activities and services in Cardiff and other neighbouring local authorities will still be shared with Vale Families via the Vale Index.

The purpose of The Index is to directly provide families who have children and young people with disabilities and additional needs, with information on local services, clubs and activities. We offer information and guidance, signpost to relevant agencies and keep families up to date with any changes that may affect them.

Families who are signed up to The Index will receive our quarterly 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 also request specific information that may be of interest to them.

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:

Index Officer

[theindex@valeofglamorgan.gov.uk](mailto:theindex@valeofglamorgan.gov.uk)

0800 5871 014

## SUMMARY

-  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, be in the process of diagnosis or have confirmed ongoing additional needs
  - be aged up to 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

## KEY DATA

-  786 children & young people registered on The Index as at March 2020
-  126 new registrations to The Index between 1 April 2019 and 31 March 2020
-  31 children & young people have deregistered from The Index due to turning 18, moving out of the area or requesting to be deregistered
-  The majority (67%) of those on The Index in the Vale are male
-  The highest proportion (49%) of those on The Index in the Vale are aged 4-10 years
-  58% of those on The Index live in Barry
-  Autistic Spectrum Disorder is the primary reason for registration for 34% of those on The Index
-  When looking at all reasons for registration, 54% (428 children) of those on The Index have Behavioural/Emotional Difficulties and 50% (390 children) have Communication and Socialisation Difficulties



## KEY ACHIEVEMENTS 2019 - 2020

-  126 new children registered on The Index
-  Regular attendance at ADHD Clinics at Llandough Children's Centre
-  Index coffee mornings held with parents in primary schools
-  After School information session held in partnership with key partners
-  Transition working group set up to improve information for young people age 14-19yrs. January 2020 newsletter included a 4 page supplement and all newsletters now contain a section 'Planning for My Future'
-  All young people on the Index age 18yrs asked if they would like to be added to a separate 'Transition list', in order to still receive key information
-  Worked with social services professionals to promote day opportunities and support planners roles to families of young people
-  Survey sent to families asking about the The Index newsletter and respondents offered a family swim pass as an incentive to respond
-  A regional [Family Friendly leaflet](#) produced, explaining The Index
-  Improved referral process for key social services teams, including the Child Health and Disability Team, Flying Start, FACT and the Families First Advice Line. Referrals for CHAD and Flying Start are now flagged on the WCCIS and PARIS systems.
-  A referral process established for families applying for the Childcare Offer, where the parent has identified that the child has additional needs. .

## PRIORITIES 2020 – 2021

-  Link online registration form to the database
-  Improve information on transition by working with schools, transition workers and young people
-  Simplify Index registration form and data captured
-  Review production of the Index newsletter in line with survey feedback
-  Review purpose and format of Vale Index by engaging with families and key partners
-  Work with the FIS Team to deliver an effective communication programme incorporating new ways of working to reflect current climate
-  Set up a closed group on Facebook for Index families as an additional communication tool



## PROMOTION OF THE INDEX ACROSS THE VALE

### OUTREACH

The FIS Team always promotes The Index at events and meetings and here are some examples:

-  Child Health and Disability Team Meeting
-  Vale Families First Holiday Clubs (Playscheme and Teescheme)
-  ADHD Clinic at Llandough Hospital
-  Families First Providers Strand Meetings
-  Flying Start transition sessions and Family Fun Days
-  The Autism Directory
-  Special Needs Health Visitors
-  School and nursery intake sessions
-  Transition professionals and Adult Day Services
-  Job Centre Plus lone parent sessions

### DIGITAL PROMOTION

**Social media** is used as an effective communication tool. Examples of Facebook posts that have resulted in a lot of engagement include::

- Families First Advice Line (FFAL) – 1430 people reached, 35 engagements.
- Developing Dolphins – beat eating disorders – 1019 people reached, 66 engagements.
- ACES and Learning Difficulties – 1150 reached, 97 engagements.
- Connected Carers Event – 1182 reached, 36 engagements
- Family Information Service Picnic & Play Inclusive Event – 8136 people reached, 793 engagements.

**E-Bulletins** – 26 sent inbetween quarterly newsletters

**The Index web pages** have received over 1,390 page views over 7 months. Unfortunately we've been unable to obtain web stats for the whole year.

## ENQUIRIES

The FIS has received almost 200 enquiries for information on additional needs and support. This could be people enquiring about the Index or would just like some information on education, activities, support groups etc.

## FEEDBACK

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.

100% of those who responded said the information they received helped them and 89% said they were provided with the right information when they needed it 100% said they would recommend our service to other people.

### FEEDBACK EXAMPLES:

'Thank you so much for forwarding on information for family services and for taking time out to talk to me about how the index has helped me as a single parent. It's helped me to not only find groups where I could take my son and feel comfortable but also take him to activities and the parents could relate and understand how hard it is going back and forth to outpatient appointments and the worry of trying to also balance making sure they still have good attendance in school, alongside the hospital and others understanding your child's additional needs. It also helped me find support groups near my local area. I want to thank you for making this magazine and time, effort and thought you have put into it and the help and support it has given me and my son, thanks so much again.'

'I wish I'd known about the index a lot earlier when my son was originally diagnosed but finding information is difficult if you don't know what you're looking for. I think the NHS needs to promote you more at the diagnosis stage.'

'Your help and support is so very much appreciated and I don't think you know just how much - so thought I would tell you. Thank You Very Much. And as it is December, I would like to wish you all A Very Merry Christmas and a Happy New Year (from a professional)

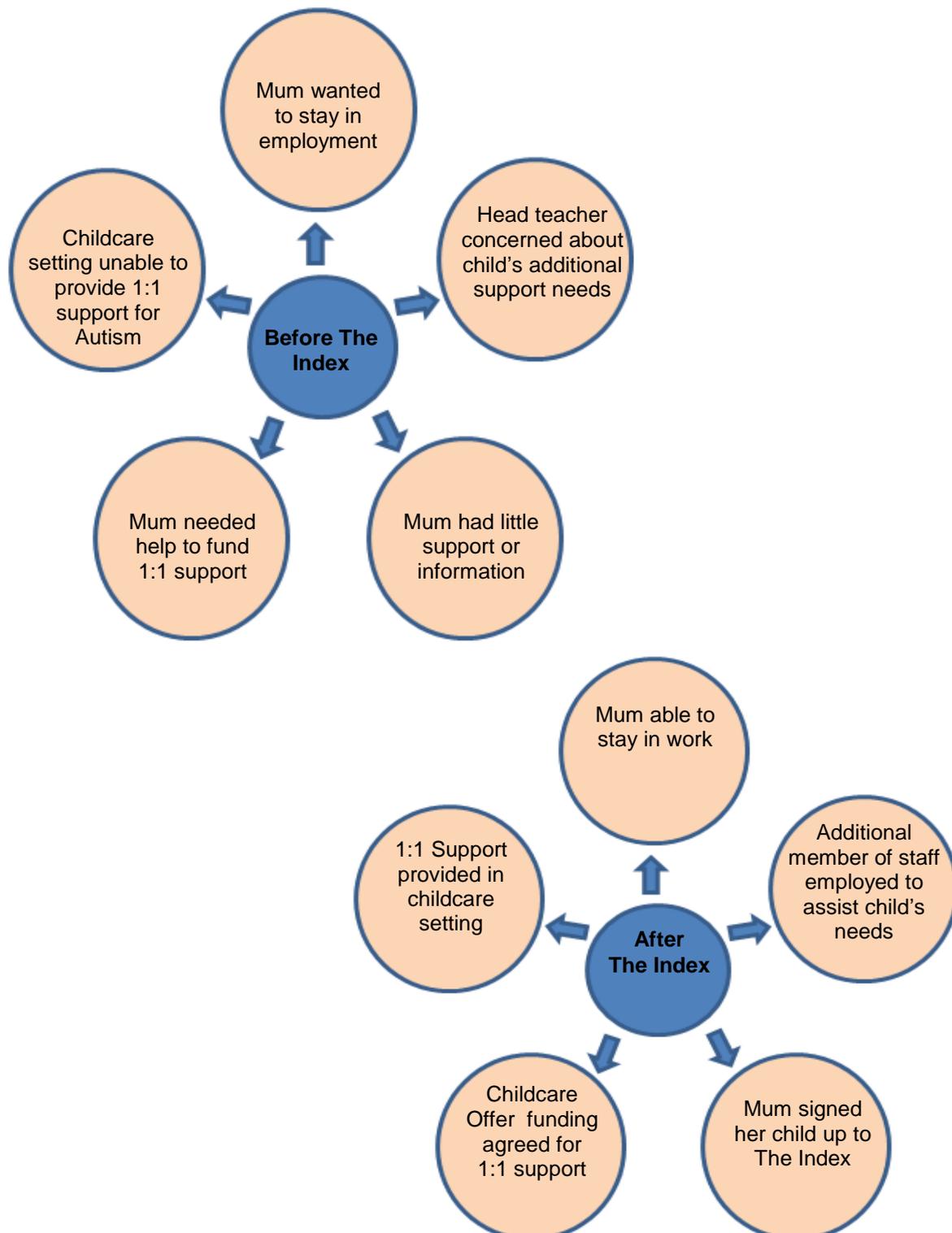
'I work for flying start, Everyone has been helpful and gives lots of advice, not just for me but for all the families I work with, Even parents I work with find the team very helpful. Also when they are not sure about speaking on the phone, they come away feeling good that they received advice and where to go. A lot of my families are starting to contact yourselves. So thank you for your support, also thank you for all the families

'All I can say is they are AMAZING and I would recommend them every time. A good support for all.'

## Case Study

A Head teacher contacted FIS enquiring about childcare, as a child attending the nursery school for ½ day sessions had Autism and was receiving additional support. The parent needed to work and current childcare arrangements had broken down.

The Head Teacher advised the parent to contact FIS.

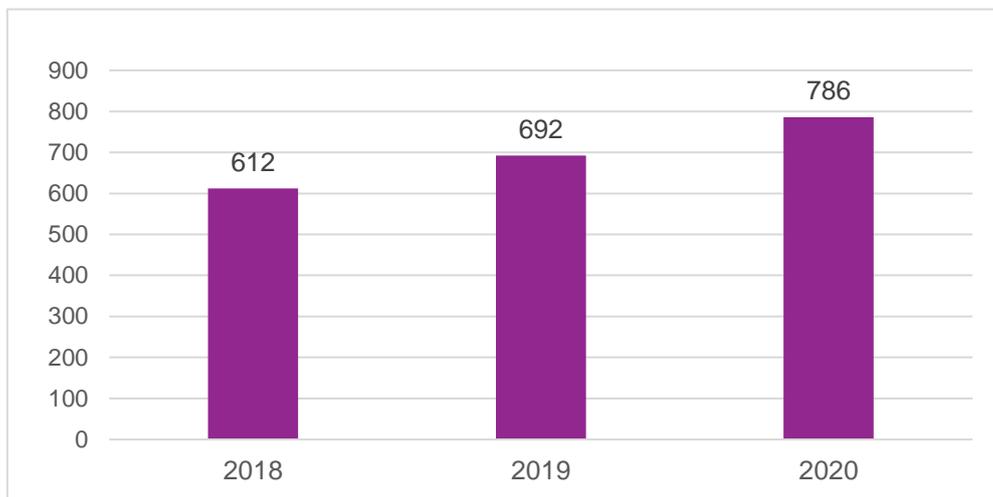


# CHILDREN AND YOUNG PEOPLE ON THE INDEX: FACTS AND FIGURES 2019-20

## REGISTRATIONS

**Currently Registered** – 786. This is a 13% increase from the previous year and a total of 126 new registrations.

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



## Deregistrations

31 (3 no longer living in area, 2 requested to be removed, 26 turned 18).

## REVIEWS

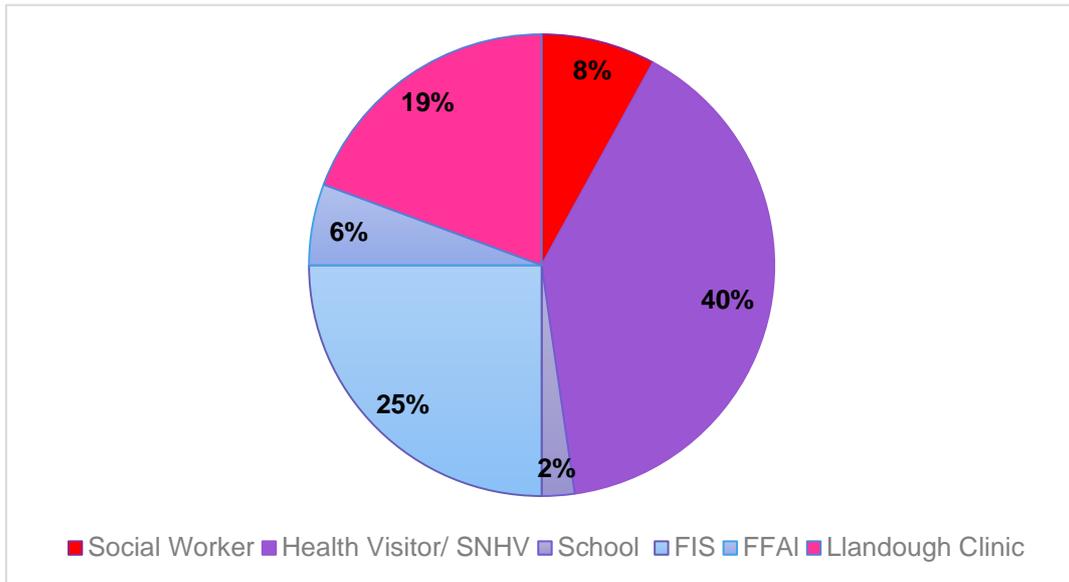
81 children were reviewed. Registrations are now reviewed every 3 years.

## REFERRALS

We ask families where they heard about the Index and some professionals refer families directly. The highest number of referrals to The Index this year have come from the Health Visitor/ Special Needs Health Visitor (40%).

- Social Worker -7
- Health Visitor /Special Needs Health Visitor- 35
- Families First Advice Line- 5
- Family Information Service -22
- School- 2
- Llandough ADHD Clinic or Hospital Visit -17

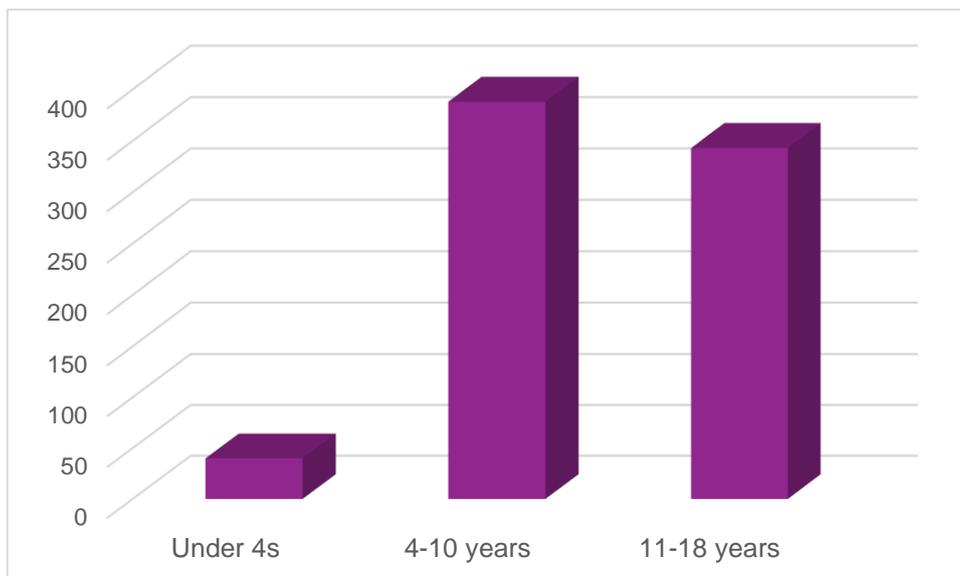
**Chart 2: Source of referrals to The Index 2019-20**



**AGE RANGE & GENDER**

- The majority of children (530, 67%) registered on the Index are male.
- 40, 0 - 3 years
- 388, 4 – 10 years
- 354, 11 – 18 years
- 4 Undisclosed

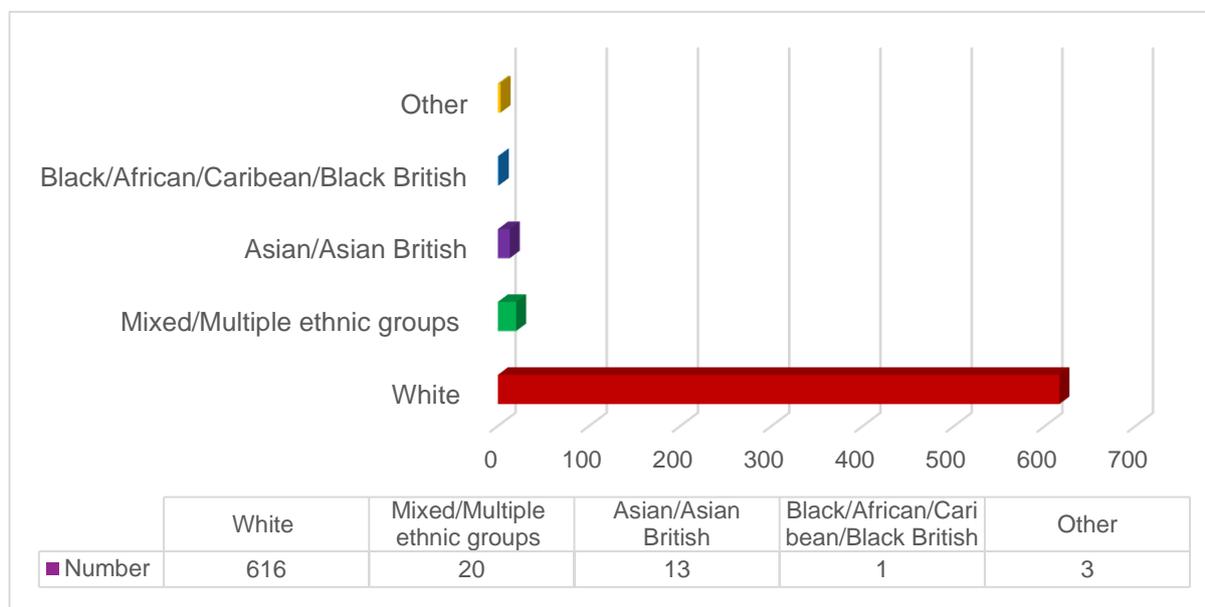
**Chart 3: Age range of children and young people on The Index**



## ETHNICITY

78% of children are white (total of 616 children) 17% have not disclosed their ethnicity and 5% (total of 34 children) are from a minority ethnic background. The Office of National Statistics Census 2011 states that only 3.56% of the Vale population are from a minority ethnic background.

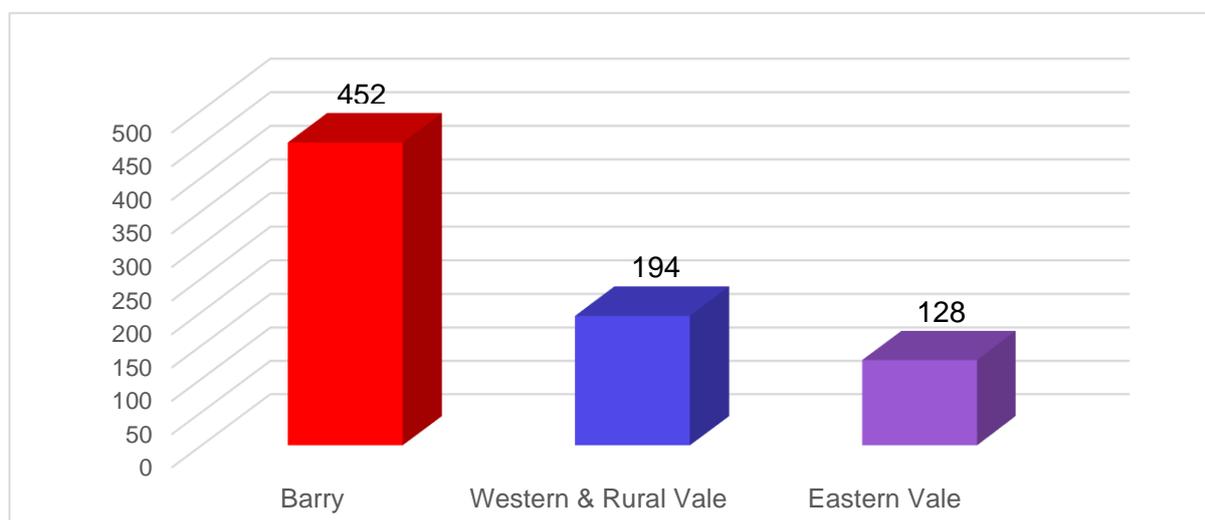
**Chart 4: Ethnicity of children and young people on The Index**



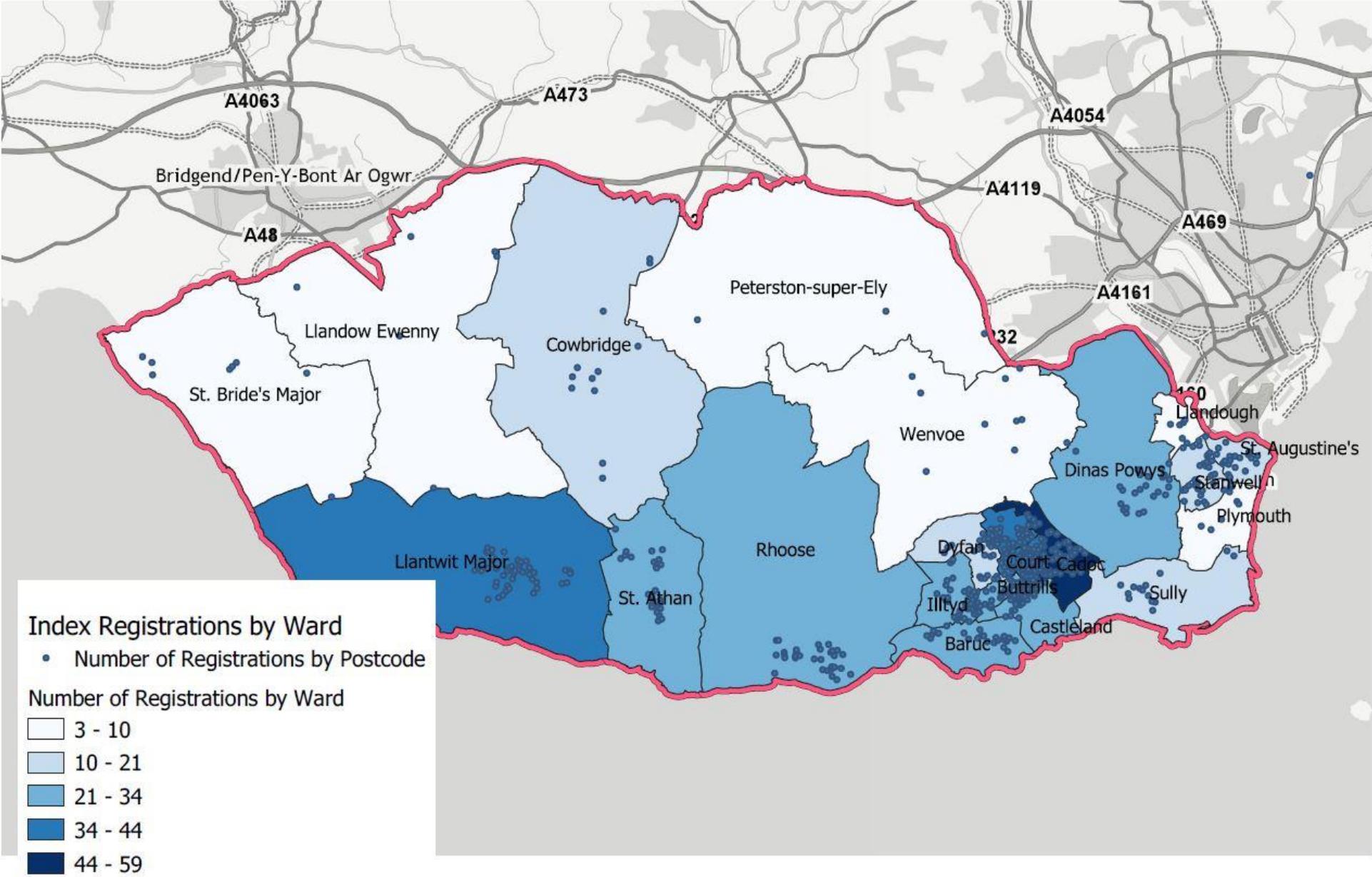
## GEOGRAPHICAL BREAKDOWN

The majority of children on The Index live in Barry (58%), 25% live in Western and Rural Vale and 17% live in Eastern Vale. The map shows 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 rural wards and some wards in Penarth have the lowest number of registrations. More promotion could be targeted at these areas.

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



### Number of Children Registered on The Index by Ward



## PRIMARY REASON FOR REGISTRATION

When signing up to The Index, parent / carers are asked to state the primary reason for registration as well as listing any other associated disabilities / difficulties.

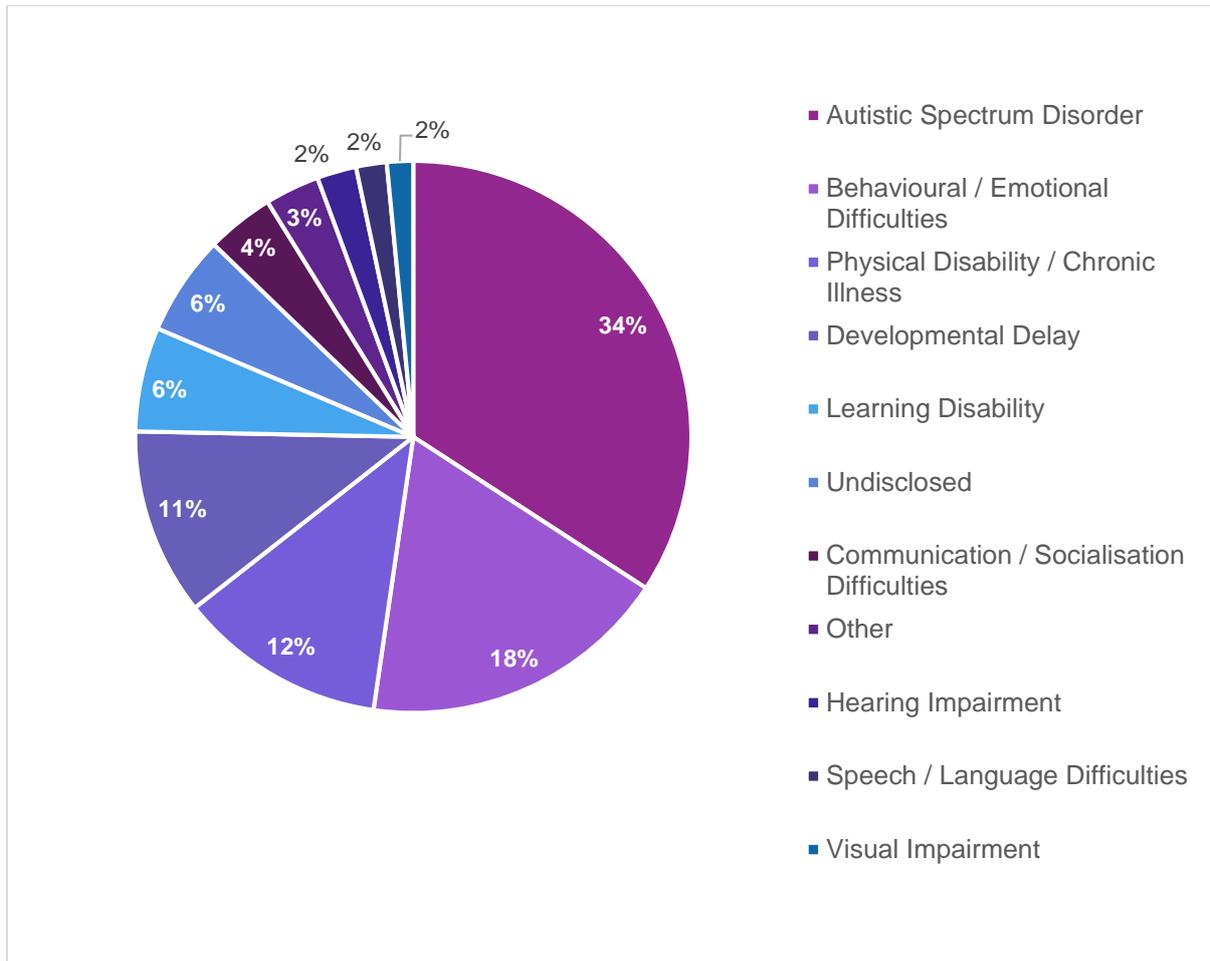
It should be noted that the parent will state their child's disability based on diagnosis (if diagnosed), and also their perception of the disability and how it impacts their family. For example, one family who has a child with Downs Syndrome may register the primary reason as Learning Disability, another as Behavioural / Emotional Difficulties, depending how their child is affected.

The Table below illustrates that the most common reason for registration remains to be Autistic Spectrum Disorder (34%). In the past year, 57 new registrations gave ASD as the primary reason for registration. The next most common reason was Behavioural / Emotional Difficulties, which accounted for 24 new registrations. The table also shows a significant increase in children with ASD from the previous year (50), Behavioural/Emotional Difficulties (43), Physical Disability (32). These aren't all new registrations, as when children are reviewed, they are asked whether there have been any updates to their diagnosis. This would explain the number of 'undisclosed' reasons decreasing from 99 to 46.

**Table 1: Primary Reason for Registration over the Last 2 Years**

Primary Reason for Registration	2018-19		2019-20	
	Total Number	Percentage	Total Number	Percentage
Autistic Spectrum Disorder	219	32%	269	34%
Behavioural / Emotional Difficulties	99	14%	142	18%
Physical Disability / Chronic Illness	63	9%	95	12%
Developmental Delay	76	14%	86	11%
Learning Disability	43	6%	48	6%
Undisclosed	99	14%	46	6%
Communication & Socialisation Difficulties	32	5%	31	4%
Other	25	4%	25	3%
Hearing Impaired	15	2%	18	2%
Speech / Language Difficulties	11	2%	14	2%
Visually Impaired	10	1%	12	2%

**Chart 6: Primary Reason for Registration on The Index March 2020**



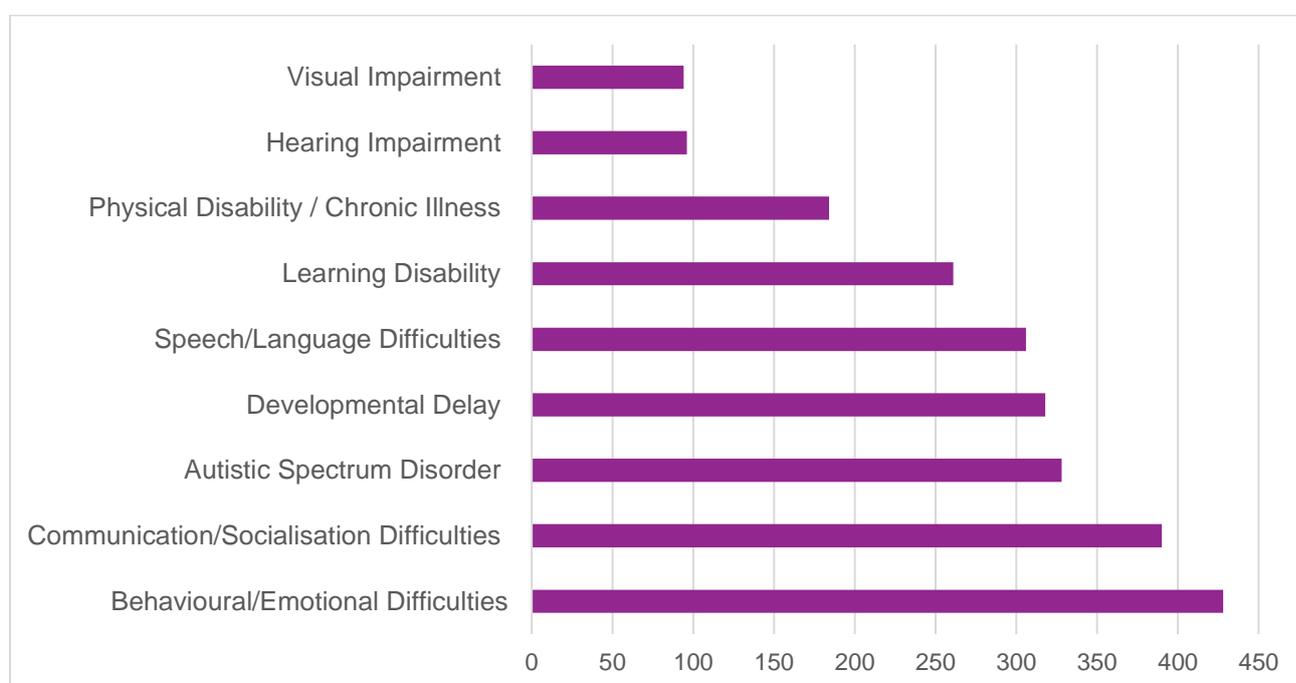
## ALL REASONS FOR REGISTRATION

Whilst families state the primary reason for registration, many of the children and young people have more than one type of disability / difficulty that has an impact on their lives. Families are asked to state all reasons for registration.

54% (428 children) of those on The Index have Behavioural/Emotional Difficulties. 50% (390 children) have Communication and Socialisation Difficulties, followed by Autism (328 children, 42%), Developmental Delay (318 children, 40%), Speech / Language Difficulties 39% (306 children). Please be aware that this includes children where the parent or professional has said that they are under assessment for a specific disability.

The following chart illustrates this in more detail.

**Chart 7: All reasons for registration on The Index**



## INFORMATION REQUESTED

During registration, we ask whether the family would like any information to support them and their child. For the past year we received the following responses:

**Table 2: Information requested 2019-20**

<b>Activities</b>	92
<b>Family Support Services</b>	78
<b>Childcare</b>	12
<b>Carer assessments</b>	31

Many parents require information on a variety of aspects.

## SOCIAL SERVICES

169 children on The Index (21%) have a Social Worker.

Following the appointment of a Carers Support Officer within the Child Health and Disability Team, a strong link was established to ensure that those new to The Index are made aware of a Carers Assessment.

From 2019 – 20, 15 carers received a carer’s assessment and 31 wanted more information or to be referred for one.

We now ask parents/carers whether they receive certain services.

**Table 3: Services Received by those on The Index**

Service Received	Total Number on The Index Register	2019-2020
Social Worker	173	17
SW for Sensory Impairment	8	1
Care in the home	1	1
Respite	16	3
Direct Payments	17	4
Other	37	2
Parent Carer Assessment	87 (plus 48 have been referred)	15 (plus 31 wanted more information or to be referred)
Young Carer Assessment	2	2

## 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 is expected the ALN system set out in the Act will be fully implemented over a three-year period. The implementation period is expected to run from September 2021 to August 2023.

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.

The number of children of compulsory school age in the Vale, who have a special educational need, according to the PLASC return January 2020, is **2,913**, which is **16.3%** of the overall school population. This is either through a Statement, School Action Plus or School Action. This may mean that additional resources are required to support these children, e.g. access to specialist equipment or additional LSA support. Although not all these children would necessarily be eligible for the Index, it demonstrates that many more children could benefit from being on the Index. The number of children who have a special educational need has significantly reduced since 2017(3,642).

Of the children and young people registered on the Index, 24% have a statement of need; this has decreased by 2% since 2018 – 2019. This is reflected in the decrease of children in school who have a special educational need.

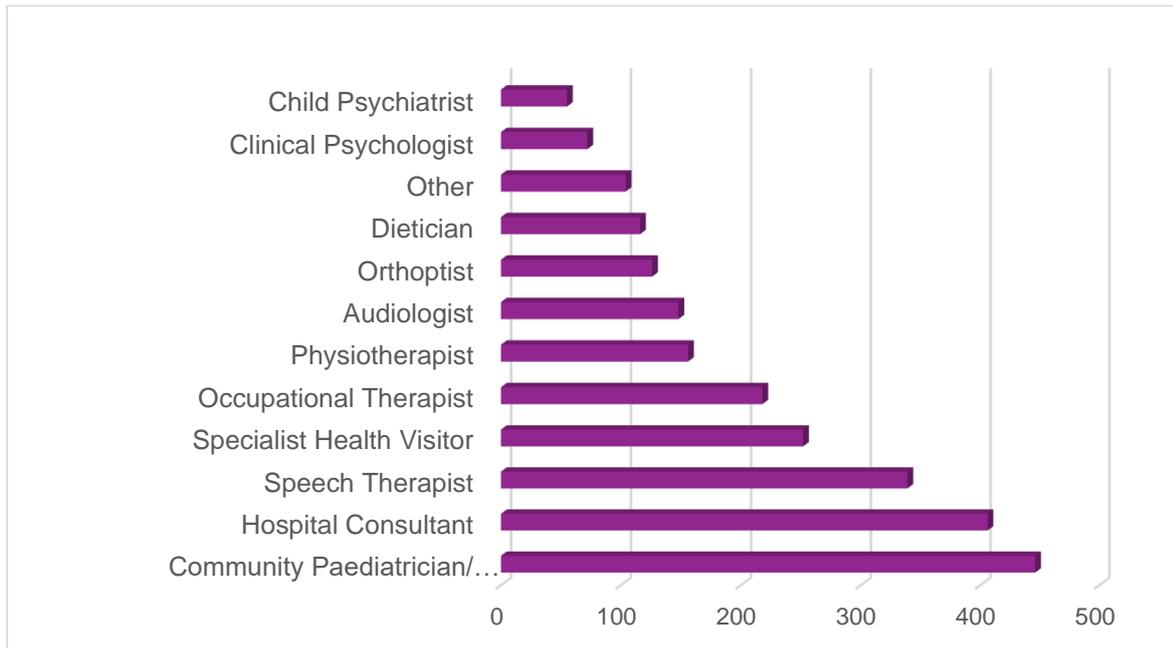
## HEALTH

It is widely acknowledged that children and young people with disabilities and additional needs have greater health needs than the rest of the population. Those with disabilities access the full range of health services to meet both their ordinary health needs and their additional health requirements through referral to specialist services.

57% of children and young people on The Index in the Vale see a Community Paediatrician / Paediatric Nurse, whilst 13% have responded with “Other” which includes: CAMHS; Emotional Wellbeing Service; Orthotics; and the Neurodevelopmental Service.

The chart below illustrates the health services being accessed by children on The Index.

**Chart 8: Health Professionals accessed by children and young people on The Index**



53 children on The Index (7%) use PECs to communicate and 24 children (3%) use Makaton.

## 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.

A priority will be to review the format of The Index, to ensure it's meeting the needs of families. We plan to engage and consult with families and people working with families via focus groups and other methods, reflecting the current climate.

## CONTACT INFORMATION

INDEX OFFICER  
FAMILY INFORMATION SERVICE  
DOCK OFFICE  
SUBWAY ROAD  
BARRY  
VALE OF GLAMORGAN  
CF63 4RT  
0800 5871014

[theindex@valeofglamorgan.gov.uk](mailto:theindex@valeofglamorgan.gov.uk)

[www.valeofglamorgan.gov.uk/theindex](http://www.valeofglamorgan.gov.uk/theindex)



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