

## The Index, for Children and Young People with Disabilities or Additional Needs, Survey 2021

As an Index subscriber you benefit from relevant, timely information through receiving our quarterly newsletters and ad hoc e-bulletins.

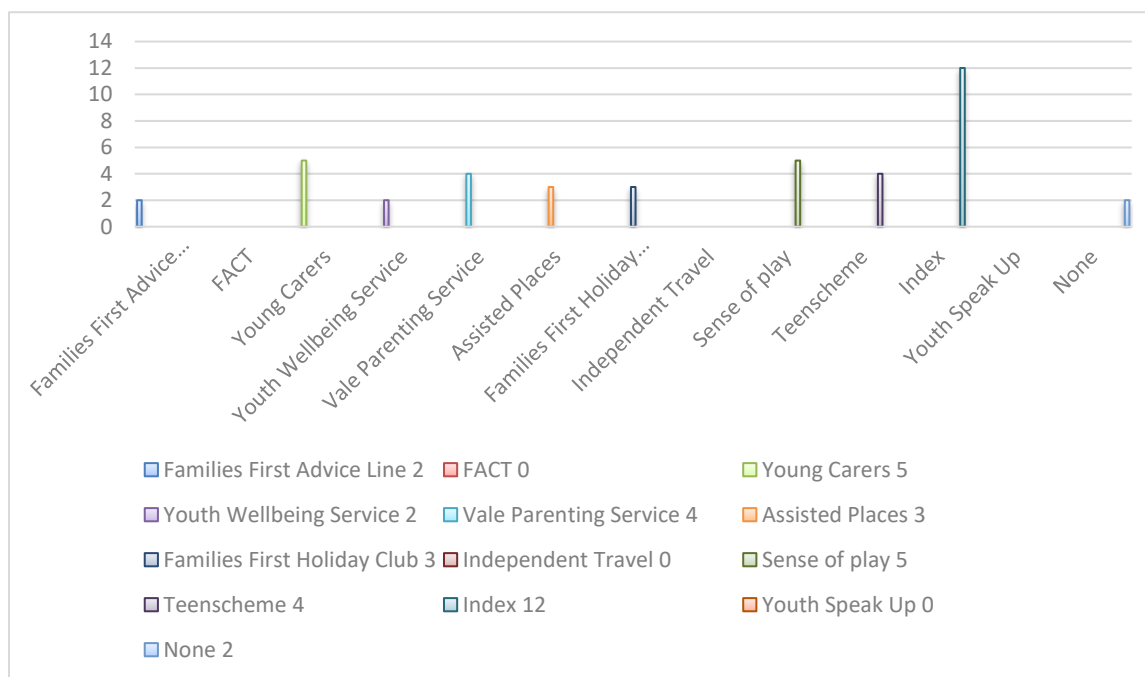
There are currently 849 families signed up to The Index and we are passionate about delivering a newsletter and key information through an e-bulletin that meets the needs of all in terms of format and content.

The Index survey was sent out to all parents registered with The Index in The Vale, to obtain their views about the services they have accessed, whether they feel there are any gaps in services, and the delivery of The Index newsletter in general.

We received 19 responses, all 19 were online and 1 Welsh response was received. We fully appreciate the current climate has put extra demands on people and we were expecting a lower response as we continue to transition out of the pandemic and acclimatise to regular change. However, the responses we have received have been very helpful to us and we have already started to consider how we will take this feedback forward.

## Findings

### 1. What Families First services have you used in the past:



The majority of respondents have used The Index, followed by the Young Carers Project and Sense of Play Project.

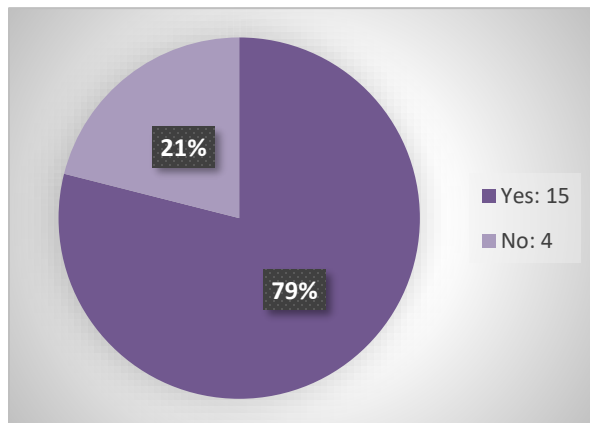
Comments about Families First Services
Positive comments
The Index is great & gives access to things you wouldn't normally know about.
Just like to say, Thank you.
Excellent resources.
Teenscheme is excellent, both my autistic children love it. Just started on a course with Vale parenting - seems really good.
Excellent variety of support much needed.
Families first services gave me advice on the avenues to follow in order for a diagnosis to be made.
I didn't know that the sense of play service was available, and I think this would be very helpful for my 3 year old son with additional needs.
Other comments
Services are not widely known to parents; I have found out about a lot of services through my job rather than as a parent.
I wasn't aware of all these services - do they go to age 25 or just 18?
Teen scheme was very similar to playscheme for our son.

None of these services are set up for children with complex support needs and did not meet our needs.

From the comments above, the majority of respondents felt that the Families First services are excellent. Although some respondents have commented that these services are not widely known to parents. We do feature many Families First Services in our Index newsletters. However, an action we can take forward is to ensure that all of these services are included in future editions.

Families First services have their own [web pages](#) and social media pages. Over the pandemic face to face outreach services have not existed in the same way due to the government restrictions but this is slowly starting to improve. We attended our first outreach event 'Our Community Roadshow' in Cogan, Penarth on 20 May 2021 to understand from parents what gaps they feel there are in their area in the current climate. We always take leaflets, promotional materials and our own knowledge of Families First, Local Authority and wider services and discuss these with parents as appropriate. We plan to visit as many areas as we can with Llantwit Major being our next stop. Dates to be issued soon.

## Q2 Do you feel there are any gaps in activities in the Vale of Glamorgan?



The majority of respondents feel there are gaps in activities in the Vale of Glamorgan. Please see comments below identifying where it is felt the gaps are.

### Comments on gaps in activities in the Vale of Glamorgan

#### Transition into adulthood / older children

Transition to adulthood - HUGE gap, we are currently feeling like our daughter is being dropped off a cliff and at serious risk of isolation

Not much for 16 to 18 age group

More outdoor based pursuits for older children

Young adults with disabilities are missing out on all areas of social inclusion and interaction. No youth clubs, no outreach, no support.

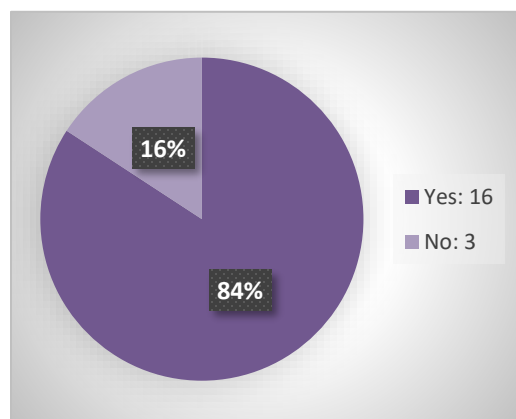
#### Meeting specific needs

Individualised services are required for children with complex support needs, ideally alongside typically developing children to model e.g. development, behaviour etc. and to avoid social isolation of families with disabled children from society. We have also not used Families First Holiday Club or Assisted Places because they cannot meet

my child's needs. There are also difficulties with sport and leisure provision to meet the needs of children with complex support needs: they should provide suitably trained 1 to 1 support for children to learn skills alongside their typically developing peers.
Opportunities for wheelchair users to be active outside of their wheelchair Physical activities for people with ASD who may be more difficult to engage Warm water accessible swim.
Activities for ASD children who are non-verbal and like physical play such as soft play, trampolining.
Wrap around care 'before and after school' for children in a special school setting.
No overnight respite care provided by VOG
<b>More or improved activities</b>
I feel that there could be more of a variety of activities.
More local sport activities for children with disability. My son is desperate to play rugby but there are no disability groups local to the Vale of Glamorgan.
I would like to see more art, creative writing courses and general creative courses for teenagers. Art in particular as it is such a great way for them to express themselves.
We used sense of play and it was discontinued. It always seems to start off ok but struggles with continuity.

This feedback is particularly helpful and although it is outside of our remit to create new activities, we can feedback to providers within the Vale of Glamorgan for them to consider when planning new or improved activity programmes. In terms of Transition, The Index chairs a Cardiff and Vale Transition Meeting on a regular basis and we feature a lengthy article on Transition in every newsletter. We also feature Transition on our website. We will continue to look into this and hopefully address some of this feedback in upcoming communications from The Index.

### Q3 Do you feel there are any gaps in services in the Vale of Glamorgan?

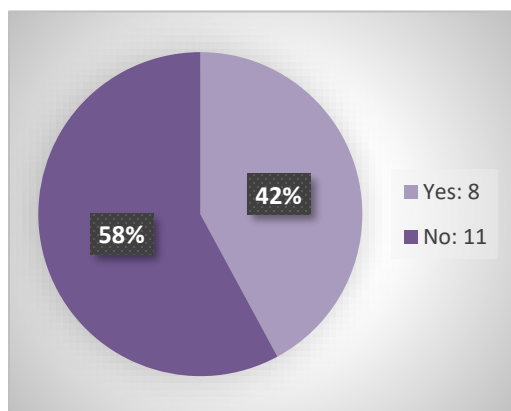


The majority of respondents feel there are gaps in services in the Vale of Glamorgan. Please see comments below identifying where it is felt the gaps are.

Comments on gaps in services in the Vale of Glamorgan
<b>Services for older children</b>
After making enquiries I was advised there is no support for my teen i.e life skills etc until they are 18yrs and then available to be referred to adult services. You think there would be services available to support children into the transition into adulthood.
Desperately need youth clubs and places for teens to meet and form friendships.
I receive no support for my son with autism who is still transitioning to adult services, 3 years! No support no services to help.
<b>Services offering support</b>
A support group would be helpful.
I feel it would be really helpful if the CAMHS and the Vale were more linked up e.g. CAMHS could provide parents in the Vale information about the services listed above. I would like to see more opportunities for autistic teenagers to meet up together and learn social skills.
It would be good to have access to support for large families with no wider family.
Social services support - very difficult to get hold of them.
Support for children in Welsh-medium schools so that children with additional needs can stay in the Welsh-medium school rather than move to an English-medium school.
<b>Services meeting specific needs</b>
Accessibility for wheelchair users - lack of accessible changing rooms for wheelchair dependent people who cannot access disability toilets but may be continent.

The comments were varied in this instance, having identified gaps in services for older children, support services such as a support group and more join up in services and improved accessibility services for wheelchair users. As readers will be aware, services have taken a hard hit from the pandemic and it has not been possible to run as they were more than a year ago. It is hoped that steadily services will start operating a new normal and, in some cases, new improved services to attract more users after a difficult period.

#### Q4 Are there any services or activities you know of outside of the Vale of Glamorgan that would be beneficial to your child(ren) or young person(s)?

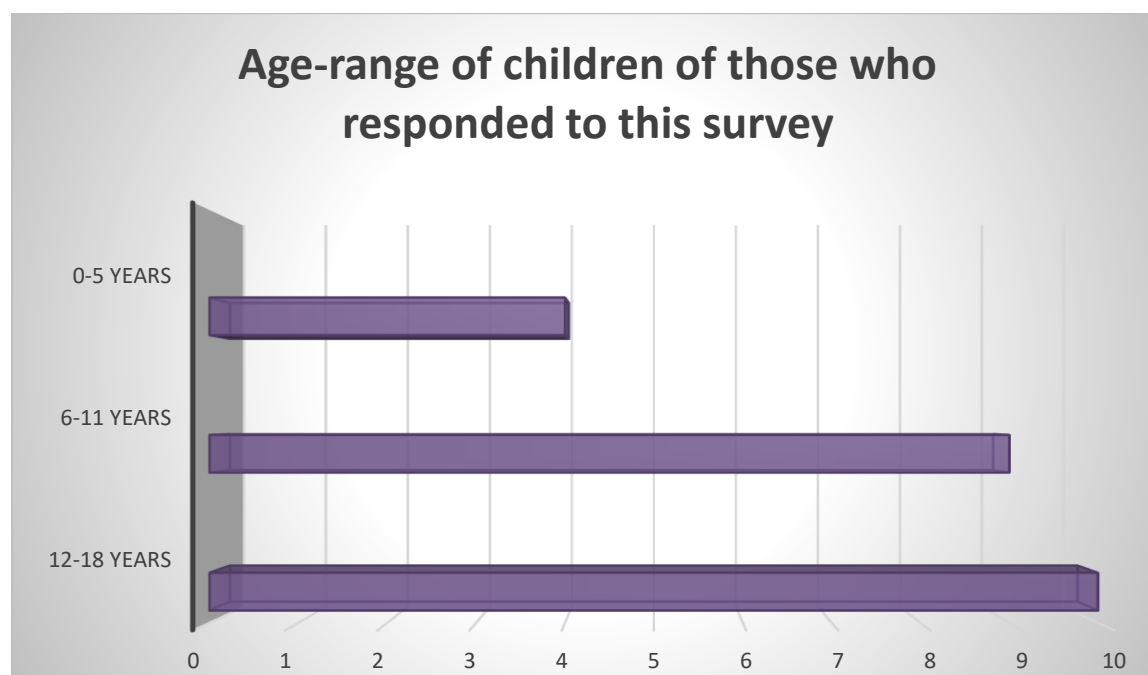


The majority of respondents were not aware of any services outside the Vale of Glamorgan that would benefit their child(ren) or young person(s).

<b>Existing services outside of the Vale of Glamorgan that would benefit the children of those who responded to this survey</b>
<b>Sport</b>
Rugby Basketball
Whizzkidz Dancing - DanceBlast Abergavenny
Running in a supported frame (frame running) – Race running Dragons, Cardiff and Chamwell Centre, Gloucester
Additional needs swimming lessons
In your newsletter we found Trampolines Rebounders (now Twisters) tie which has been great for my additional needs children, but it's in Cardiff.
<b>Peer group support activities</b>
Cathays youth club Cardiff, have sessions for young adults with disabilities.
Peer group support activities for individuals who have Down's syndrome.
Vision 21

The responses received will be shared with providers within the Vale to identify if these services do exist or to identify if there is any scope for these types of services to exist going forward. We will continue to provide information on this via our newsletters, e-bulletins and/or social media.

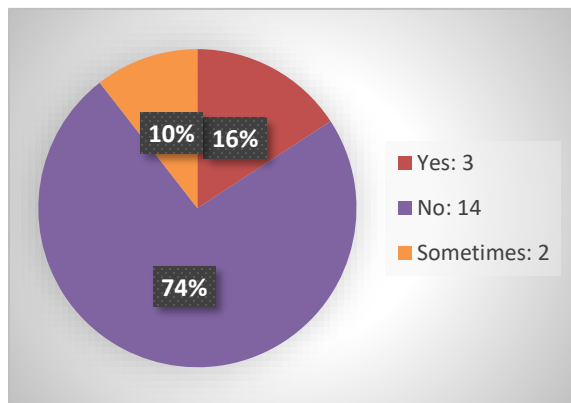
#### **Q5 How old is your child(ren)/young person(s) registered on The Index?**



As noted in the graph above the majority of respondents have children of an older age at the time of taking this. Therefore, they will have been considering activities and

services of this age group and those approaching transition age as well as their children's individual needs.

## Q6 Have you ever used our phone line or social media for enquiries?



The majority of respondents have not contacted us for enquiries.

Our phone line and social media are some of the ways Index subscribers can make contact with us with an enquiry. However, we also receive emails from Index subscribers and members of the public with enquiries. We are a one stop shop for information which we provide on a regular basis therefore, the need

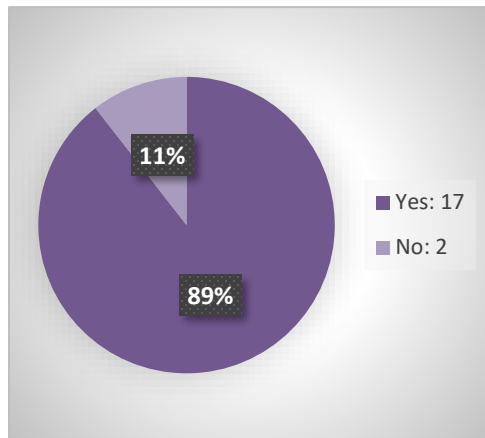
for people to contact us is usually minimal unless they want to sign up to The Index, query something that we have issued or have a specific enquiry of their own. Although, as per the chart above, our social media hasn't been used very much 'for enquiries' by those who took part in the survey this time; we have an active following of over 3000 people on Facebook with lots of engagement on our posts so we know that the information we are producing online is useful, but we appreciate communicating via social media is not for everyone. We anticipate an increase in these communication channels as weeks go on as we are aware many children have suffered a loss of social skills during the current climate and wanting to get their children back into social activities has become a priority.

Additional comments regarding use of phone line or social media for enquiries	
No enquiries / sought through another professional	
Coped on our own.	
I usually go through the health professionals involved in my child's care including Special Needs Health Visitor.	
Types of enquiries when calling our phone line	
To contact the playscheme run at ysgol y deri.	
Information on parents network.	
Unaware of service	
Again, as above did not know about the services.	
Phoned and met a member of staff at Llandough Children's Centre. We discussed that there were no activities or services to meet need.	

The comments suggest that information is being provided by other professionals in addition to ourselves, which is fantastic. We have a good working relationship with many key professionals including the Special Needs Health Visitor and we are glad this join up is proving to work well. In addition to providing information and receiving

enquiries; we also conduct a review of personal records held on The Index register, every 3 years, to ensure that the information we hold is up to date. We also make contact with Index subscribers for feedback occasionally, such as this survey for example. So, we have opportunities to engage with parents even if they have not made a specific enquiry and this gives us the opportunity to check in, remind people of our service and what we offer as needed.

### Q7 Do you find the information in our bulletins or newsletters helpful?



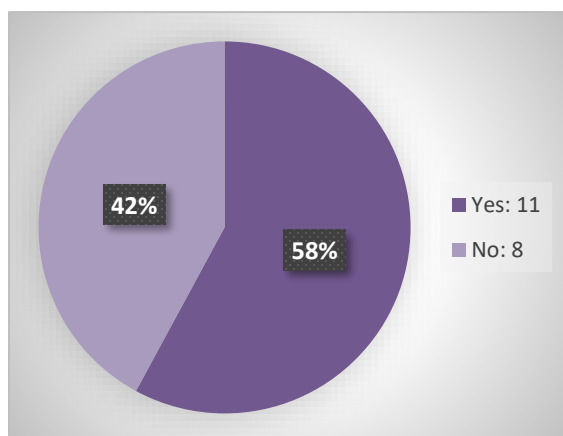
The majority of respondents felt that the information in our bulletins or newsletters is helpful. We are passionate about providing a variety of information that encompasses the needs of our Index subscribers.

Additional information about finding our bulletins or newsletters helpful
<b>Good</b>
Informative.
It keeps me up to date with what is available in the area and I can advise parents and professionals.
Very useful to find out what is going on. Sometimes feels that the information comes through in dribs and drabs but that's understandable, especially with the COVID situation.
I am able to ascertain if any activities are suitable for our family.
Yes I do.
I do find helpful but as I have previously noted as I work full time and am a single parent it is not always possible for me to attend the events etc.
<b>Feedback to be used for future planning</b>
We don't get sent these anymore - wondering if the service should be extended to age 25 in line with education?
Any information related to teens I find useful though there aren't many things for them especially early teens.
My child cannot attend as no support is provided.
Good information for children but not adults with disabilities.
Young people who are "high-functioning" with Asperger Syndrome may need more suitable activities.



From the information provided most respondents find our information informative and useful. Other respondents had some very useful feedback for us which we will factor in to our future planning.

**Q8 Have you ever used the information contained in our bulletins or newsletters to access activities or services for your child?**



Just over half of all respondents have used the information to access activities or services for their child.' This is really positive as it shows that people are accessing services as a result of The Index information.

Additional comments on utilising our information
We've accessed play scheme before and disability sports.
Advised families and professionals on what is available and who to contact.
To attend playscheme.
Teenscheme.
Activities.
I used information to go to Disabilities sports wales.
Not appropriate or already aware.
Classes and activities are held at times when I am either in work or my child is in school.
Motion Control Dance.
As above due to working full time and being a single parent.
Advised nothing until they are 18.

Most comments told us that they have accessed 'activities' as a result of the information we have provided via The Index. We are aware that many of our parents are working parents and sometimes limited with support. We are passionate about providing an activity programme that has lots of options in terms of the timings that they are run offering flexibility but that doesn't mean the activity that interests the child will be at an accommodating day/time. We can feed this back to service providers. We encourage our parents to stay up to date with The Index Newsletter and bulletins, especially as there may be changes with the days/times of activity programmes going forward as a

result of the current restrictions and the different ways activities are being run. We will continue to bear in mind working parents in all that we do and please feel free to contact us or the activity provider to see what is possible.

Final comments
Keep up the good work as I know how hard you all work but let's get communicating to families that these services are available to them as I do believe that earlier interventions will prevent families getting in to crisis.
Really impressed with the services I have used i.e. teenscheme and Vale parenting.
I think services are excellent, but the need for children and young people and their families to recover their fitness and engagement from pre pandemic is absolutely huge and will require more of your services and hopefully extra recovery funding. People with limited mobility have been unable to exercise at all as they often depend on expensive equipment and storing and space is now more expensive and more difficult to access.
Definitely need youth clubs, more outdoor pursuits and experiences to explore the world and develop crucial social skills for teens.
Extremely hard to get a diagnosis for a child (my child was diagnosed at a later age). Made to feel I was insane to think my child was outside the norm. Once you finally get a diagnosis there was no support or advice given, had to phone around and search for services myself only to be told nothing until 18 Even attended a session held by Cardiff services, to understand and help my child, as nothing under the vale provided.
Thank you for offering your service and information in Welsh.

We are very grateful for the final comments above. Although it is outside of our remit to implement a physical activity; we are an effective platform with excellent links within the sector to incorporate all the feedback that sits outside of our remit and get it heard by the right people. We will ensure that feedback that sits within our remit is incorporated into future planning.

## Summary and Recommendations

1. Most people (63%) have accessed The Index based on the 19 people who responded. Families First services: Sense of Play and Young Carers also proved popular amongst those that responded. The feedback from those who had accessed Families First services was excellent.
2. 79% felt there were gaps in activities in the Vale of Glamorgan. The gaps were in activities for complex needs, accessibility for wheelchair users, sports, arts and crafts and particularly activities for older children and those of transition age.
3. 84% felt there were gaps in services in the Vale of Glamorgan. The gaps were felt in transition to adulthood, feeling a loss in life skills courses, youth clubs, support particularly from Social Services and Accessibility.
4. 42% were aware of activities and/or services outside of the Vale of Glamorgan that would benefit their child. These included sports such as rugby, basketball and more specific sports that could accommodate additional needs such as

frame running and additional learning needs swimming. Respondents also referred to peer group support such as Cathays Youth Club, peer support group for Downs Syndrome and Vision 21.

5. The respondents to this survey were mainly parents of older children (9+ years).
6. 26% reported to have made enquiries by phone or social media. As noted above, we produce information on a regular basis suggesting minimal need to be contacted unless signing up to The Index, enquiring about the information we have produced or had a specific enquiry. We also receive emails and engage with existing Index subscribers and wider members of the public at our outreach events, which is a big part of our service.
7. 89% felt that the information in our bulletins and newsletters is helpful noting that they are informative and keeps them up to date with what is going on in the area. We will put more emphasis on teenagers and those approaching transition age going forward.
8. 58% reported to have used the information in our bulletins and newsletters to access playschemes, teenscheme, dance or sports. We will continue to factor in working single parents in advertising an activity programme that offers weekdays, evenings and weekends to try and make it possible for as many to attend their preferred activities as possible. We will also feed this back to providers to highlight the need for activities and services to take place outside normal working hours.
9. During the further comments the majority informs that our service is excellent, and they are impressed with the services they have accessed. We will take on board the comments around services not widely known and ensure we include information about these services in future Index newsletters. We hope that as our outreach part of the service increases as restrictions ease; we will be getting back into communities and raising awareness face to face as well as online.

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