Short Breaks Clubs and activities for children with disabilities (CWD) research: Informing the CWD offer and commissioning strategy

“Every family needs to go on their own journey”

January 2021

Maura O'Malley

Research & Citizen Insight

Essex County Council

We would like to express our gratitude to the Essex Family Forum for supporting Essex County Council in this work.

Listening to the experiences and views of parents, children and young people will help us to better plan and shape future services.

Thank you to everyone who took the time to share their views with us.

> **“Nice to know you can have your say even if you haven’t joined anything yet.”**
>
> [Parent of 0-4 year old,
> with complex physical needs]

Contents

Introduction

Situation

The insight from this research will primarily be used to:

- Help shape the commissioning intentions for the re-procurement of the children with disabilities short breaks offer.
- Inform the refresh of the short break strategy for children with disabilities.

This work will also inform part of wider system changes.

Considerations

This research was undertaken during the Covid-19 pandemic with:

- Families being unable to access the full short breaks offer.
- While impacts were cited, respondents clearly focused responses on the full short breaks offer pre-Covid.
- High response rate of families wanting to engage further, we needed to ensure our sample represented an equitable range of demographics.

Key areas explored

- Families' experiences of the current short break services and how equal they are for families across Essex.
- Identify any areas for improved service delivery.
- What could the future service offer look like for families?
- Identify any new ideas and innovation.

Beyond the Short Breaks story…

The intention of this work was to primarily explore experiences and issues around the current short breaks offer and use these insights to help shape the future service offer.

The insights from this research went beyond our original scope and the findings could prove beneficial in informing work programmes and strategic priorities in other areas of ECC and beyond.

Where did we gather our insights from

Sound evidence is based on gathering insights from different perspectives.

Families, including children & young people

Childrens & Families Social Care

Multi Schools Council

Interact Essex

Provider Market

Essex Family Forum

ECC Data & Analytics team

The primary methods of gathering research for this report was via the **one-to-one interviews**, **focus groups** with parents and the **survey**.

However, to help gain a broader understanding of the current landscape, we have included information from the provider market, relevant areas with ECC, and other existing data.

Research with families: methodology

A mixed methodology for research with families was used in order to gain a wide breadth of insights.

This included a countywide survey to capture views, and as a way to recruit parent carers to take part in interviews.

400 survey responses from parent carers

(Out of a database of **3,420** - over **10%** sample achieved)

Proportion of responses by quadrant:

- 24% North Essex
- 30% South Essex
- 30% Mid Essex
- 15% West Essex
- 1% ‘other’

Age of children represented:

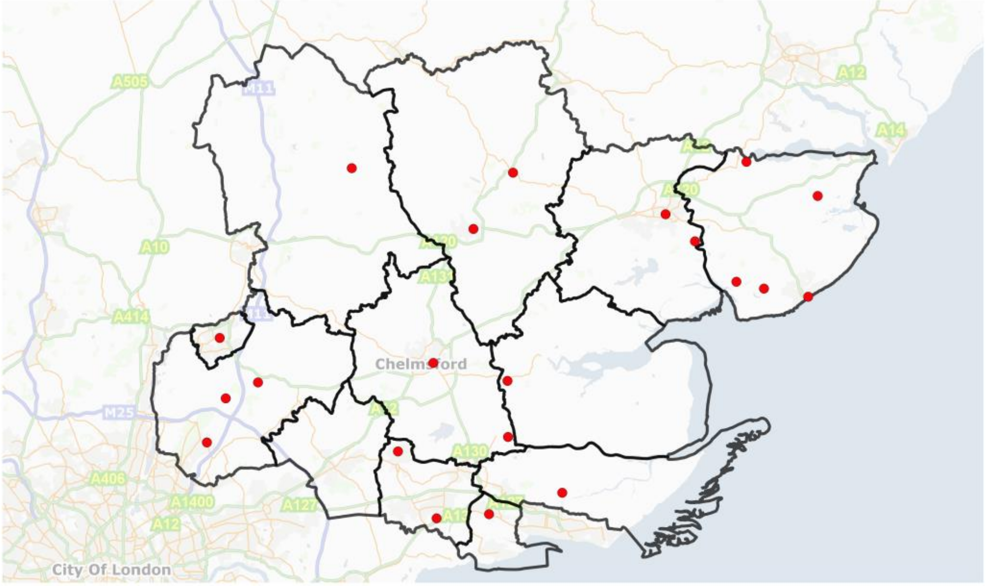
0-4	5-7	8-11	12-15	16-18	19-25
6%	**17%**	**37%**	**28%**	**9%**	**4%**

20 virtual depth interviews

Participants were selected to represent a diverse sample of families, with consideration given to distribution across districts, as well as children’s ages, disability, and services accessed.

3 virtual focus groups with parents carers, including one for those representing **young adults** approaching transition.

Map showing approximate location of interview participants across Essex:

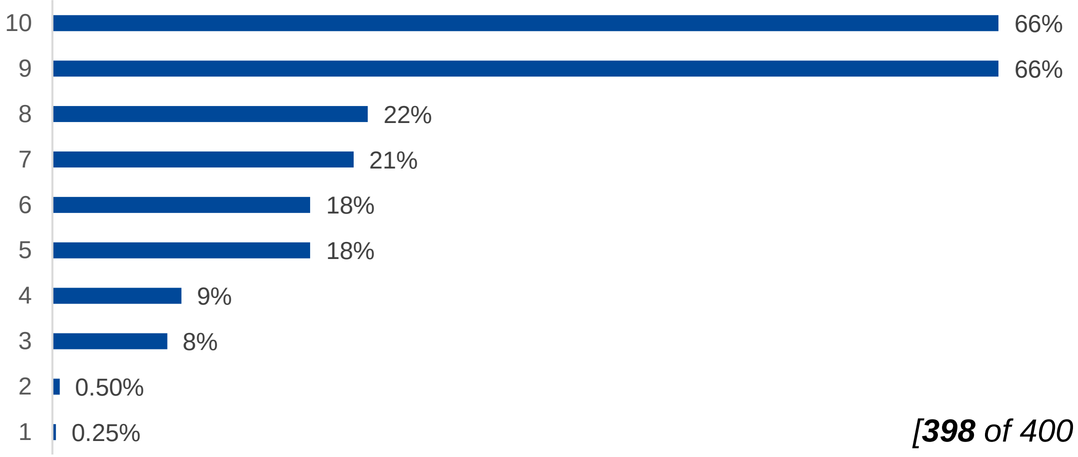


[A more detailed demographic breakdown of survey respondents is available on request.]

Further survey demographics

Autism and LD were the most common conditions among children represented within the survey.

Child’s condition/disability (%)

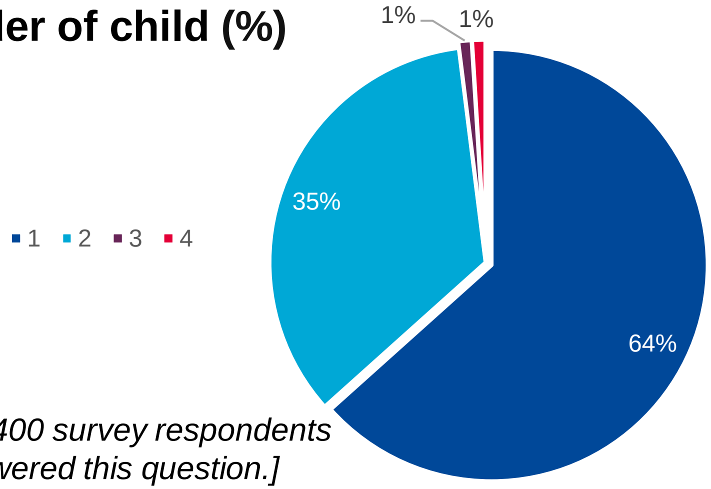


Many children had more than one condition. **103** respondents also selected **‘other’.** Conditions specified under other include:

- **ADHD** - around **34%** of ‘other’ comments
- **Specific physical conditions** (including Down’s Syndrome and other chromosomal conditions) - around **30%** of ‘other’ comments
- **Sensory issues** (including sensory processing difficulties) - around **18%** of ‘other comments’
- **Speech and language difficulties** - around **8%** of ‘other’ comments
- Other conditions mentioned include global development delay, hypermobility, and epilepsy.

*[**398** of 400 survey respondents answered this question. Respondents could tick more than one option.]*

Gender of child (%)



*[**396** of 400 survey respondents answered this question.]*

Type of education accessed (%)

*[**398** of 400 survey respondents answered this question.]*

The current landscape

A snapshot of current position of what families access.

The current short breaks offer

Children must be registered on ECC’s short breaks database to access any element of the current service offer.

Clubs & activities	Light Touch Support	Caravan & beach hut hire	Max Cards& tickets
Includes after school, weekends & holiday clubs for **0-19.** Parents don’t pay for any support needs children have but will be asked for a contribution to attend.	For parents when child does not qualify for social care, offers up to 28 hours within a six-month period, for children aged 0-18.	Families can book a range of reasonably priced, adapted and standard caravans as well as accessible beach huts in Essex.	The Max Card and tickets is a discount card for foster families & families of CWD & can be used at venues across the UK to get free or discounted admission.

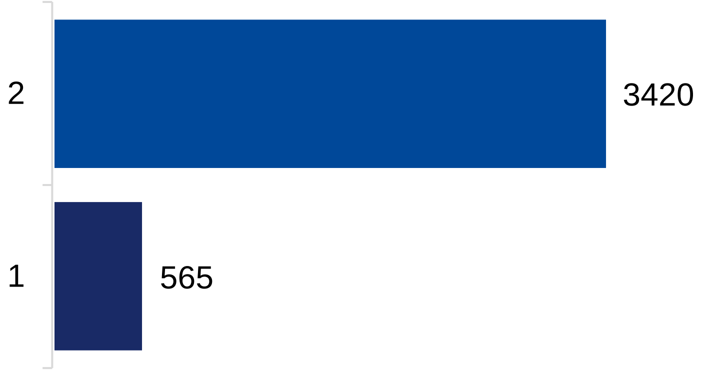
Mainstream clubs & activities in the community are accessed independently

Mainstream relates to any **universal club** or activity a family use or a child attends independently, for example brownies, scouts or swimming lessons at the local pool. However, there may be cases when children do need support to attend.

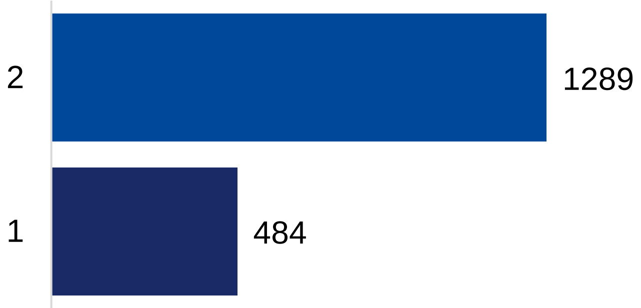
Families' access to services

Of those known to Children with Disabilities (CWD) and Young People with Disabilities (YPWD) teams, a large proportion are not currently registered with Short Breaks.

- There are **3,420** children registered with Short Breaks
- **565** of these are **open to social care** **(17%)**
  - **69%** of those open to social care are on a **CIN plan**
- **2,855** are **not open** to social care **(84%)**



- Of the **1,289** children/young people with disabilities open to CWD/YPWD teams:
  - **484** are registered with Short Breaks **(37%)**
  - **805** are not registered with Short Breaks **(63%)**



[Data recorded December 2020.]

Families’ access to services

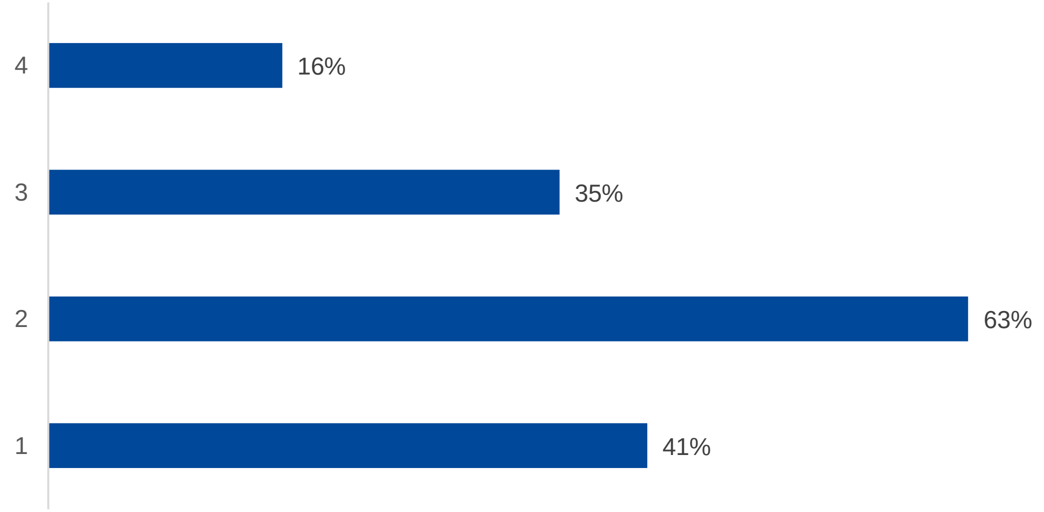
[*Data recorded December 2020.]

There are 3,420* families registered with the short breaks service. Of the 400 survey respondents, the majority are registered with the service, however many are not accessing anything.

93% of **survey respondents** are **registered** with short breaks and **57%** are **accessing** short breaks clubs & activities.

(N.B. Those registered or accessing short breaks are overrepresented in our survey sample).

Which short breaks clubs or activities does your child access? (%)



*[Of the 400 survey respondents, only **222** answered this question - due to survey routing.]*

Breakdown of other services accessed:

Activity tickets **46%**

Max Cards **43%**

Caravans **39%**

Beach huts **35%**

Competition tickets **26%**

None of these **23%**

Breakdown of those receiving a service:

78% have an Education, Health & Care Plan.

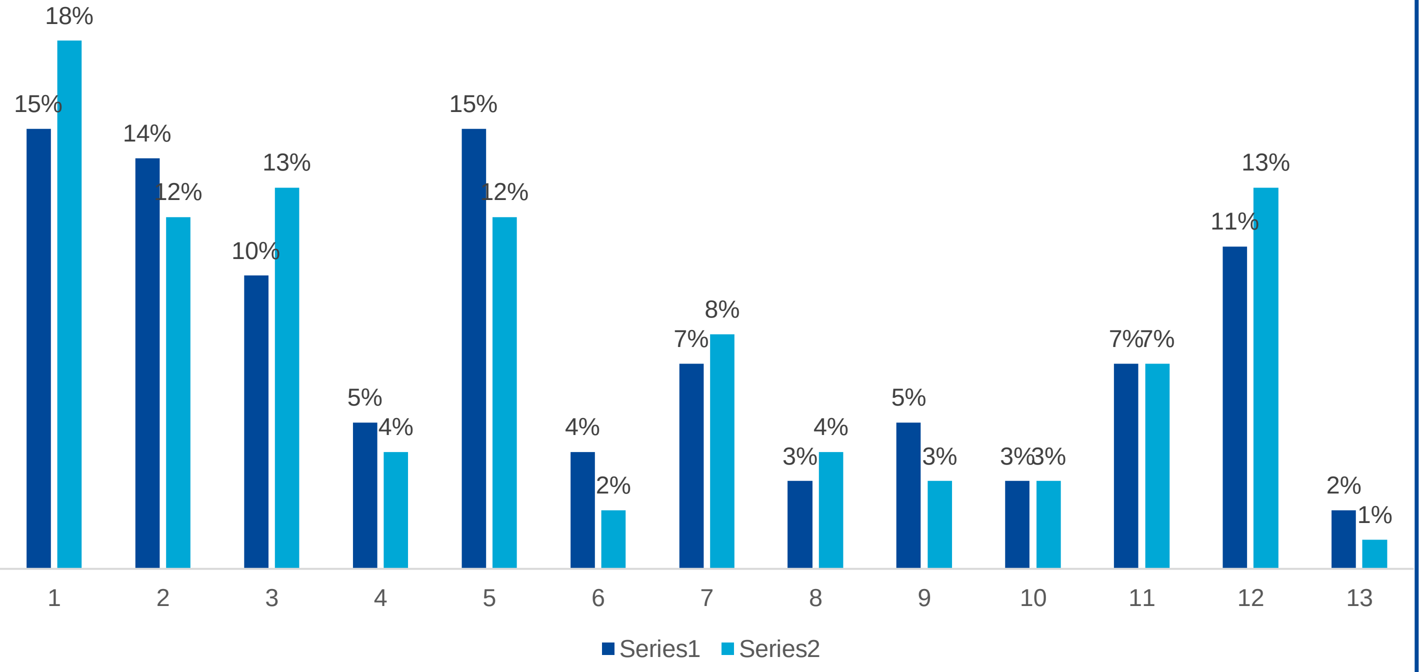
20% receiving service such as Direct Payments.

27% have a social worker.

Families’ access to services

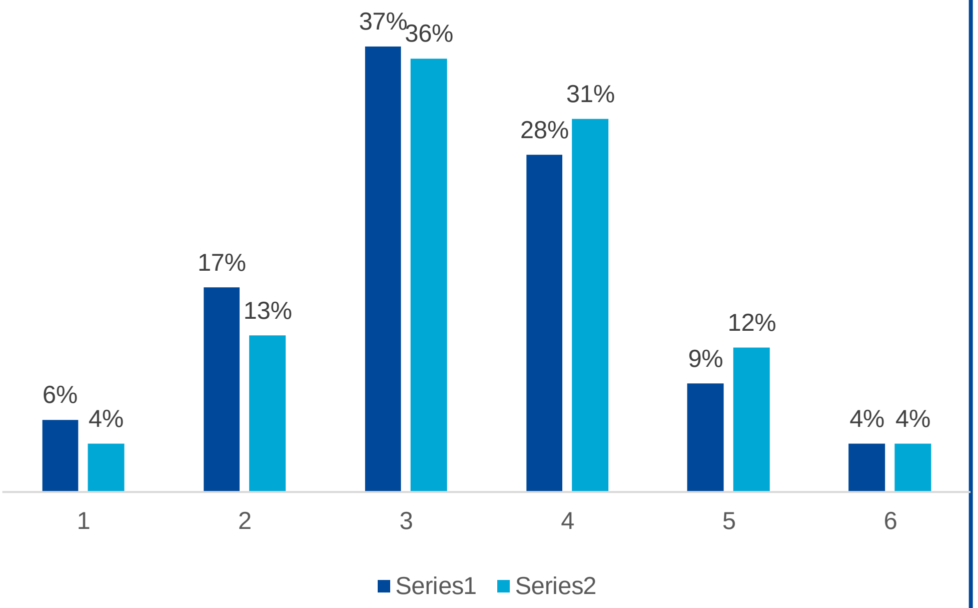
Access to short break clubs and activities is more prevalent in Chelmsford than in any other district. The age group most likely to be accessing these services are 8-11 year olds.

District breakdown of those accessing short breaks clubs & activities compared to total survey respondents (%):



*[Of the 400 survey respondents, **398** answered this question.]*

Age breakdown of those accessing short breaks clubs and activities compared to total survey respondents (%):



*[All **400** survey respondents answered this question.]*

The Essex picture

Those in West Essex are less satisfied with how clubs are meeting their child's needs.

WEST

53% accessing short breaks & activities.

58% feel clubs & activities are meeting child's needs very or fairly well.

30% have a Social Worker.

24% receiving services from Children's Social Care team (e.g., Direct Payments).

MID

65% accessing short breaks & activities.

66% feel clubs & activities are meeting child's needs very or fairly well.

32% have a Social Worker.

22% receiving services from Children's Social Care team (e.g. Direct Payments).

NORTH

58% accessing short breaks & activities.

64% feel clubs & activities are meeting child's needs very or fairly well.

27% have a Social Worker.

21% receiving services from Children's Social Care team (e.g. Direct Payments).

SOUTH

50% accessing short breaks & activities.

67% feel clubs & activities are meeting child's needs very or fairly well.

21% have a Social Worker.

14% receiving services from Children's Social Care team (e.g. Direct Payments).

[More information on survey responses from each quadrant or district is available on request.]

What are our children and young people telling us about clubs and activities?

Young people value opportunities to socialise and learn new skills, but there are some concerns around current provision and opportunities to improve the offer.

What is good ?

- Clubs give a sense of **community** and **routine** and help with **physical & mental health**
- A good way to meet friends & **socialise**, especially during Covid
- The **range** of activities, where you can learn **new skills** & give something back

"I like Mistley kids clubs because they are really nice, good park trips and walks"

What is not so good?

- Need for better **understanding** of different disabilities, especially for children with a sensory need
- Staff need to **listen** more to concerns raised by children & young people
- Children feel that staff do not always give them the **time** they need
- **Fairer process** for rewards/recognition system across all abilities & disabilities

"Not given the chance to lead because they thought I couldn't handle it."

Anything else you would like to see & what could be better?

- More **playschemes** in Basildon
- Too much focus on **sports clubs**
- Need more alternative types of clubs
- **Lack of consistency** and structure at some clubs
- Need to look at **social skills**
- More **inclusive** clubs needed

"They judge me before they know me."

[Insight gathered via Multi Schools Council virtual focus group, and young people attending Interact Essex.]

The voice of children and young people

"I love singing and dancing and spending time with my friends at clubs. It is lovely to do things with just other children and making new friends."

"I don't like the ones [clubs] that are based at a school or a school-like setting because it's holiday time and that means no school. I don't go to any short breaks because I don't want more school."

"I do think that there should be more clubs aimed at the 15 to 20 year olds. I also believe that the Coz Club is very good but the activities are aimed more at 10yr olds."

"I like to see my friends at club, I enjoy the activities especially the cooking, which I am able to plan and be involved in what we cook each session. I also like to see the staff that work at the club. I love routine and the staff know me very well, I am happy and confident when I am at the club."

What more can be done to capture the voice of children and young people to better understand their wishes and priorities?

A view from the provider market

There are clear consistencies between what families tell us and what providers already understand as the key challenges. While encouraged by the positives, they recognise there is a need for change.

Challenges faced by the providers

Providers are seeing an **increased number** of children with disabilities across the county and say there are some families who need support from social care with some **"families left out of the loop".**

Finding the right support for **direct provision** and Light Touch services is an issue, as is sourcing support workers with the right qualifications.

(N.B direct provision is not in the scope of this work.)

Problems sourcing suitable fully **accessible premises**, & providing county coverage of services is difficult, especially in rural areas. Some providers set up in other areas, but take up from has been low, especially in west. There is an appetite to deliver **life skills training** to young adults, but this would need funding.

Other challenges include:

- Providers not being aware of **local need** and what families need
- Difficulty recruiting **male support workers** and making the role appealing.
- A **lack of transport** and supply of drivers
- Not having **clear guidance** for advertising and promoting their service offer.

A view from the provider market

Working together presents an opportunity to innovate and build a better service offer for families.

Time for a change

Providers offer families invaluable services and a lifeline of support, but they are aware of **gaps in services** and acknowledge the need to operate differently in the future.

Sharing **early insights** enabled providers to generate new ideas for future delivery.

What could be different?

- **Collaborative working** between providers (i.e. share premises) and explore the use of council assets (i.e. minibuses for transport –Essex Youth bus).
- Deliver more **life skills training** for young adults; provide a male mentoring/ recruitment scheme and build on the **virtual services** happening during Covid-19.
- Better **support for parents**, including training around the child's condition, and production of a **'tell us once'** child profile for parents to share.
- Develop a **promotional/advertising strategy** and a **"short breaks brand"** enabling parents to know services are vetted and **"safe".**
- Other ideas include; a mobile service for **rural areas**, build better links with **health partners**, a **blended approach** between mainstream and short breaks.

Central findings

Services generally well received – yet, inconsistencies in location, accessibility and age appropriateness result in some families inability to access suitable provisions to meet needs.

Services are welcomed and vital for families

Scope to leverage offer to improve on each area to ensure equal, suitable, opportunities for all.

Light Touch Support

Families who use the service have good experiences.

Yet, there is a **lack of awareness** and access to the service has proved difficult, sometimes due to staff being unavailable in their area or being unable to meet the needs of families.

Short breaks, clubs & activities

Highly valued and appreciated by the many families accessing them.

However, services are **not equal** across Essex, with some families unable to access anything that meets the needs of their children.

Caravans, beach huts & Max cards

Breaks are cited to be of great benefit to families, offering the opportunity to get away from routine.

Yet, **better information** is needed on what disabled facilities are available at venues, with families needing more information on how the booking system works.

Key themes identified across services

These areas not only impact experiences of the short breaks offer, but are relevant to other areas of families lives. Learnings can be used within ECC and its partners.

Advice and information

Accessing information can be overwhelming and difficult to navigate.

Ensure families receive **timely and relevant information** to help ECC manage demand on future services.

Clear communication with professionals can aide families to navigate the system.

Support for families

Families' needs inevitably change with time. They need continued support throughout the child's pathway.

Timely support for parents could positively impact family **health and wellbeing** and long-term ability to care for children.

Listening to **families' feedback** as a part of a continuous process would assist to inform service improvements.

Access & community inclusion

Community inclusion and increased awareness of disability can improve outcomes for families.

Increased disability and **sensory awareness** will help to make the 'environment' safer and more accessible for families.

Improving access in the wider community and environment will enable families to have **greater choice and control.**

Innovation and quick wins

Through our conversations with families and providers, a number of 'quick win' ideas emerged.

1

Essex Disability Charter mark

Organisations are formally recognised and awarded a 'tick' if they meet set criteria around access, inclusion and safety.

- Providers are incentivised to make improvements towards access and inclusion.
- Increased numbers of children with disabilities are able to access activities in the community.

2

Toy library

A library for families to hire specialised toys suitable for children with a range of disabilities.

- Through hiring toys locally families are able to 'try before they buy', reducing costs of buying toys for their children.
- May aid in child development.

3

Role models

Introduce a role model scheme for young people in a single parent household.

- Provide a role model scheme for young people where one parent may be absent.
- Encourage young people to become more motivated, responsible, resilient & independent.

4

Max Card fast track

Venues/attractions implement a 'fast track' system for Max Card holders to skip queues.

- A fast track system would reduce stress, enabling families to better plan their day.
- Improve experience and encourage families to have days out together.

Detailed findings

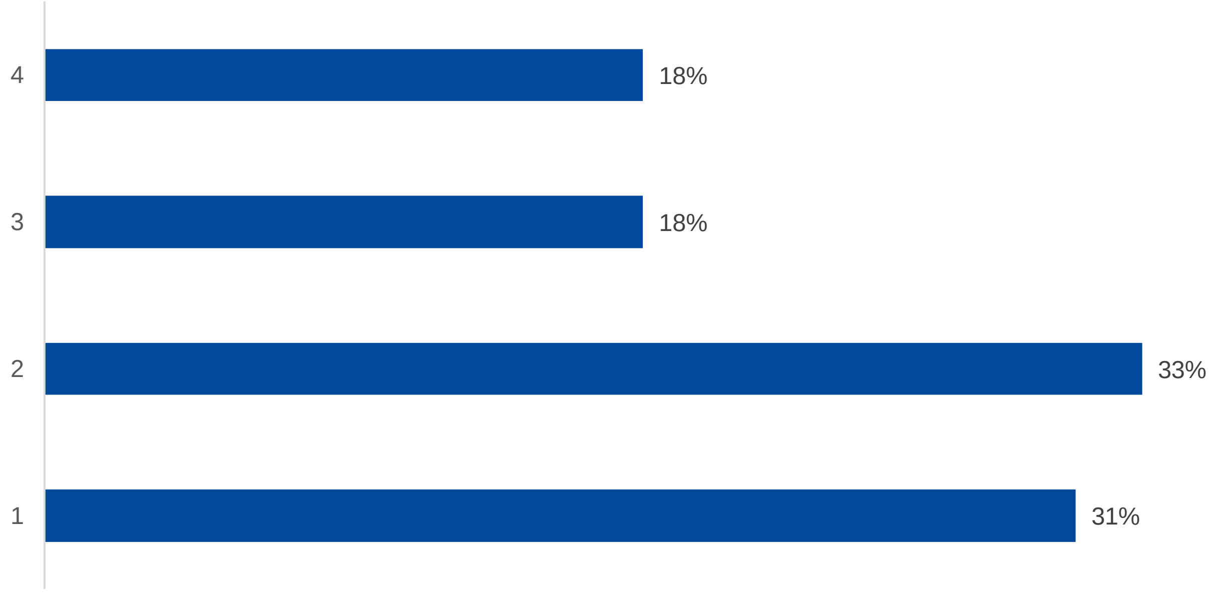
Our current service offer

Services are highly valued by some, but the offer needs to be more accessible to all.

Short breaks, clubs & activities

👍 **On the whole, clubs are felt to meet children's needs, enabling socialising opportunities, building confidence and providing support for both children and parents.**

How well are the clubs and activities meeting needs? (%)



*[Based on **282** responses to this question after 'not answered' and 'not applicable' responses have been removed.]*

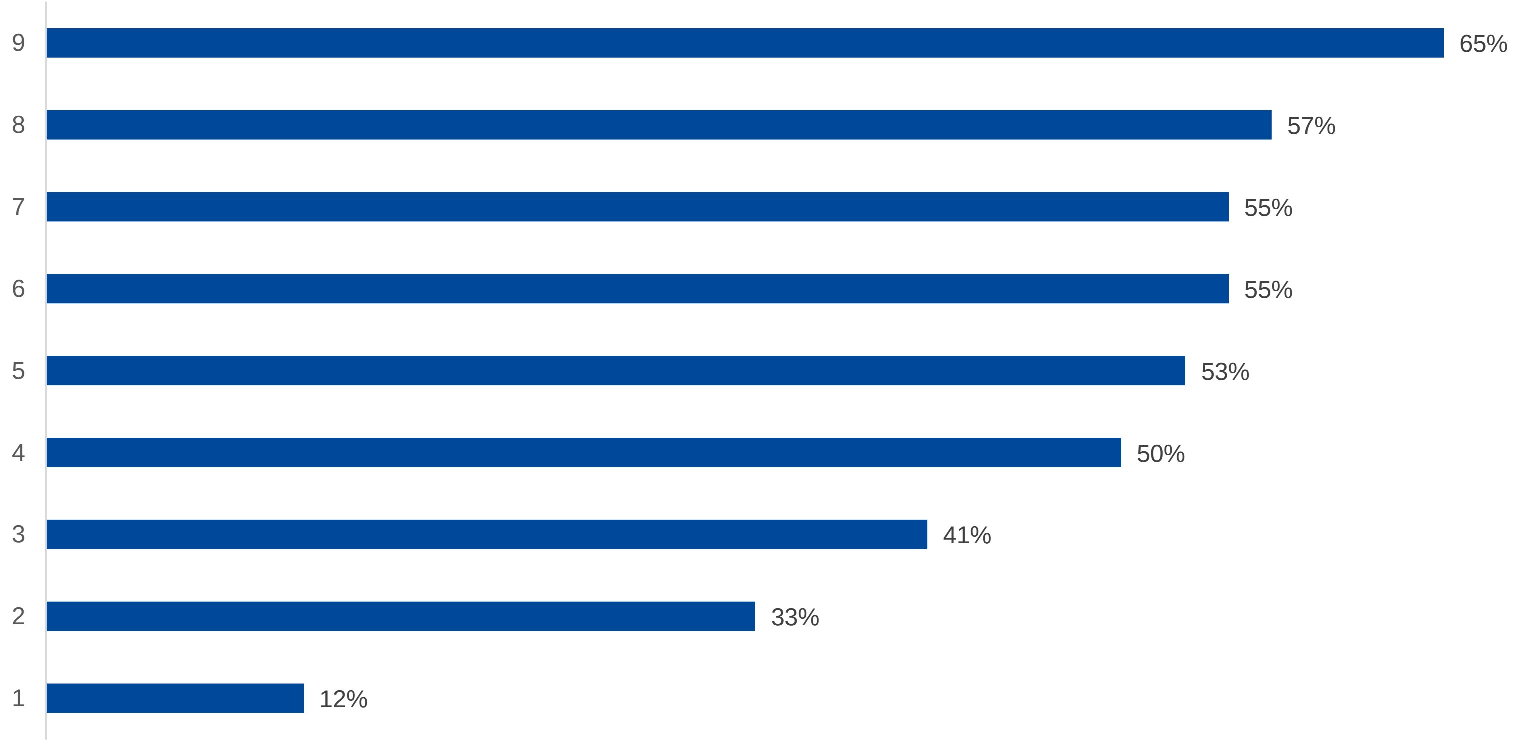
Those who feel clubs are meeting needs well mention a range of benefits for their family:

- School holiday clubs are a **lifeline** for some.
- Short breaks enable parents to have a **break** and spend time with their other children, form **peer networks** and share experiences with others, minimising feelings of isolation.
- Children gain **confidence** and have opportunities to make friends and **learn new skills.** Clubs can help with separation issues.
- **Reasonably priced** services in an inclusive and safe environment for children.

Short breaks, clubs & activities

Having trained staff is important to parents when accessing clubs and activities.

What do parents most value about the service? (%)



*[Of the 400 survey respondents, only **327** answered this question - due to survey routing. Respondents could select more than one option.]*

The top responses shown here (including having trained staff, a break from caring role, availability, and children developing relationships), were also reflected within the interviews with parents around what they most valued.

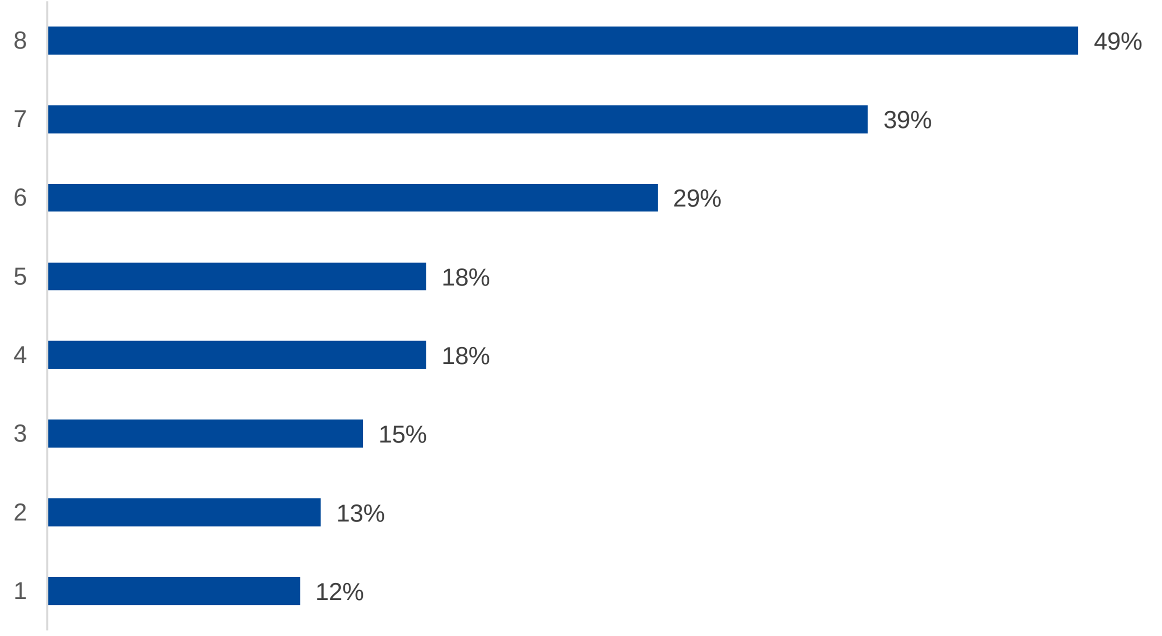
"Clubs are a godsend to give my child fun things to do and me some respite to focus on my other child."
[Anonymous survey quote]

Short breaks, clubs & activities

Families feel the key barrier to accessing clubs or activities is having nothing local to them.

36% of those registered with the service are **not accessing** short breaks.

What are some of the barriers to accessing short breaks? (%)



*[Based on **279** responses to this question after 'not answered' and 'not applicable' responses have been removed.]*

A large number of comments under 'other' further highlight a **lack of local provision** suitable for their child's needs or age group.

Several others mention a **lack of information** about what is available.

These themes were also widely supported during **interviews** with parents.

"There are no clubs or activities in my area. Everything is too far away to participate in…Everything is Chelmsford centric."

[Anonymous survey quote]

Short breaks, clubs & activities

Giving a choice of local services is most important to families.

What do families need	What changes could be implemented
Families want a **choice** of **local** services, a priority in cases where children are **unable to travel far** due to their disability. Local services mean less transport & travel costs.	Services need to **prioritise** local families, venues need to be suitable for **different ages & disabilities** with sessions needing to be at more suitable times. More variety of clubs **(i.e. sport vs. art)** and some children want clear **separation** of school and clubs.
More life skills support needed as young people approach **transitions** and prepare for adulthood.	There needs to be more skills training (**i.e. money handling/social skills)** for **young adults** needed earlier on in the pathway as well as **bespoke** clubs and activities that are more age appropriate.
Families need a more **holistic** approach to support and information.	Information on the offer needs to be clearer, there needs to be better support for the **whole family**, especially in cases where children in families have different diagnosis & support needs.

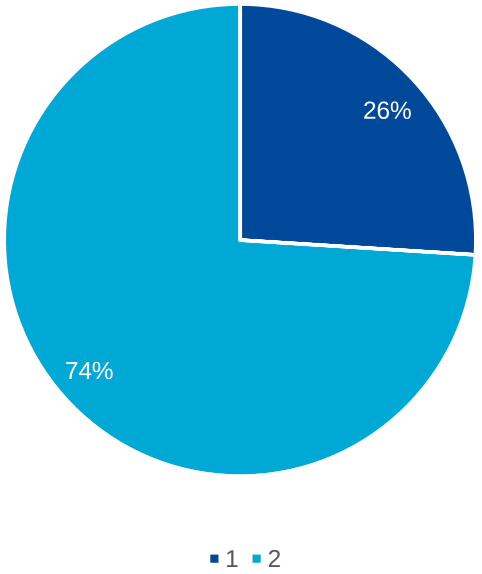
"Having 2 children with SEN, really hard to find regular clubs they can both join in where both their needs are met and is not far so can be done in between routines of daily life without being stuck in A12 traffic."

[Anonymous survey quote]

Short breaks, clubs & activities

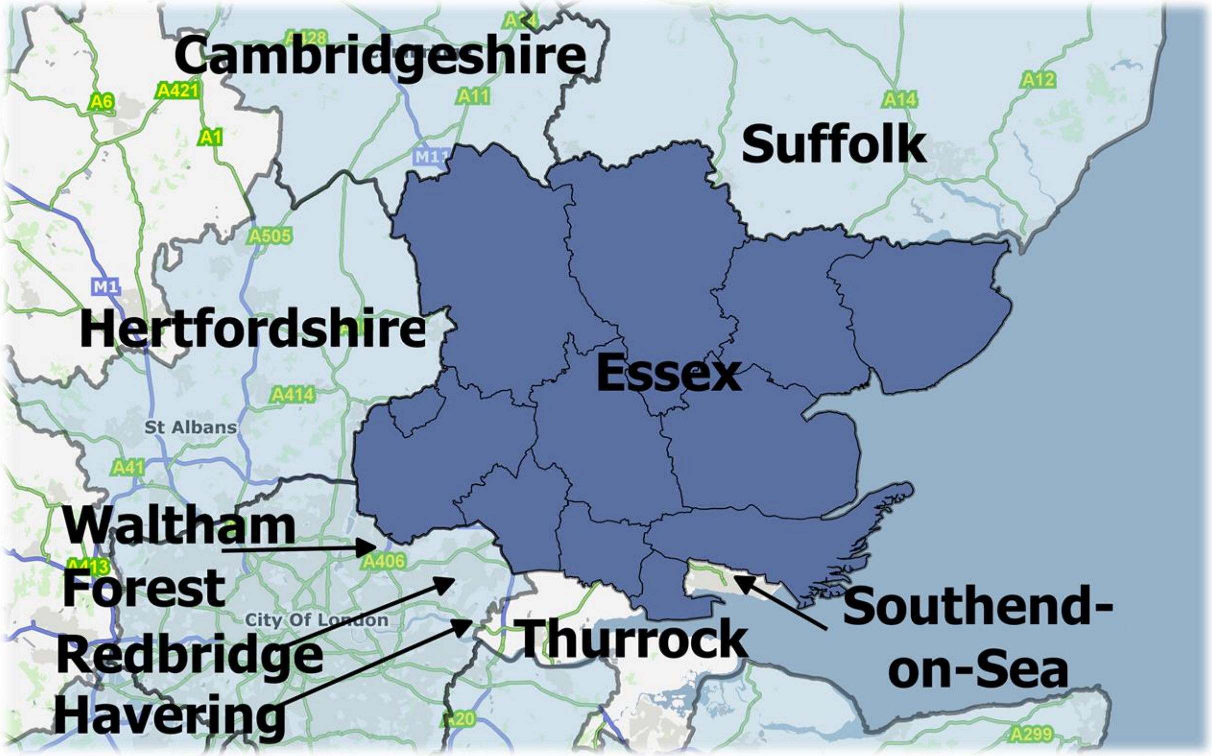
Of respondents living near a border, around a quarter feel there are clubs or activities in other areas that their child could benefit from.

If you live near a border with another local authority are there any clubs and activities your child could benefit from? (%)



*[Based on **100** responses to this question after 'not answered' and 'not applicable' responses have been removed.]*

Essex has borders with several other local authorities. How could ECC open up these opportunities for families?



Short breaks, clubs and activities in areas outside Essex

Families could benefit from increased collaboration between ECC and other local authorities, to enable access to appropriate services irrespective of location.

Some families are aware of services in other local authority areas…

- Other local authority services are sometimes **more convenient** in terms of location e.g. Suffolk and Southend.
- Provisions in other LAs can be **beneficial/more appropriate** for some children, e.g. sensory provision in Hertfordshire.

There are barriers in accessing services outside of the local area

- Access is difficult due to **'red-tape'** between councils and **‘postcode lottery’.**
- **Affordability** can be an issue when services are not commissioned by ECC.
- **Uncertainty** of which services **outside** own district council can be accessed.

“We live on a border with Hertfordshire and Broxbourne and are not really aware of clubs they do, but find they have got things much closer to us then most of the Essex ones.”

[Survey comment]

Light Touch Support

Awareness and uptake of Light Touch Support is very low.

3,420 families are registered with the short breaks service.

Pre-Covid: approximately **90 families (2.6% of those registered)** were receiving Light Touch Support.

Jan 2020: approximately **60 families (1.7% of those registered)** are currently receiving Light Touch Support.

[Figures from service data December 2020.]

Given the low awareness and usage of Light Touch Support, what is the future for the service?

What are the implications of closing the service and could this result in increased numbers receiving a social care service?

"I don't know what this is or if it would be something we would require."
[Survey respondent]

"Haven't heard about it, even though I am with short breaks."
[Survey respondent]

Light Touch Support

Some of those accessing the service have experienced several challenges.

400 survey respondents in total

36 (9%) have tried to access

(Of those potentially eligible, i.e. not receiving services)

9 (2%) received Light Touch Support

☺ Some reported **good experiences** with carers which their children enjoyed.

☹ Several commented on the **inconsistency** and **limited availability** of carers, with **lack of flexibility** of support hours. This resulted in the service not continuing for at least **3** of those families.

217 (54%) not aware of service

(Of those who haven’t tried to access)

- Several others commented that they weren’t sure **what the service was**, how they might **access** it or if they would **qualify** for support.

> ***“It was inconsistent. We struggled to get a suitable person to help my daughter at her social activities. The agency arranging the care couldn’t find a replacement when the one we had left.”***
>
> [Parent of 8-11 year old with Down’s syndrome]

Caravans, beach huts and Max cards

While families value and enjoy these services, there is a lack of availability and adjustments need to be made for a more inclusive environment and improved experience.

What families value

- Familiarity of going to same place is important. Enjoy **family holiday** together.
- **Caravans:** good location, spacious, *"child loved sensory lights".*
- **Beach huts:** spacious, close to facilities, cheap, *"information sent beforehand was amazing".* Provides a **break** from the **daily routine**.
- **Max cards:** value free and low cost days out as a family.

"I was looking at beach huts for £60-70 but couldn't justify costs…saw beach huts for £5 for the day in Clacton and got excited!"

What are the challenges

- **Lack of information** about the offer and how to book
- **Limited availability** of caravans and beach huts
- Some felt caravans were **too expensive** compared to other offers (e.g. Sun holidays)
- **Nothing specific for children with disabilities** on offer in the caravan park - clubhouse too noisy, lack of provision in swimming pool/other activities etc.
- Max card venues don't always have **facilities**/set up required to meet needs of children with disabilities.

"Some of these days out – it's great it's free but they're not all set up for SEN."

"We had the Max card but didn't know there was a whole offer…didn't know about the caravans or beach huts…just googled 'holidays for families with special needs' and it came up 'Essex short breaks'…

…Facilities/activities in the caravan park are not set up for SEN…there's not much in Walton apart from the beach. We would spend the day at the beach, but then you're stuck in the caravan for the evening."

[Parent of 6 year old with ASD & ADHD]

Caravans, beach huts and Max cards – opportunities

We have identified several short-term opportunities/quick wins that will help improve families' experiences of using caravans, beach huts and max cards.

How could we improve families experience in the short term?

- **Disability awareness training** could help providers better understand families' needs.
- Venues to implement a **"fast track"** system that allows families not to have to wait in long entry queues.
- Partnership work to ensure the right equipment is in place at these venues to ensure children can have access to the environment - ***"can't use inflatable wheels, too hard, gave up"*** *[in relation to equipment near beach hut]*
- Provide **calming spaces**, **quiet hours** in the swimming pool, club house etc at the caravan parks.
- **Better promotion** is needed and families need **clearer information** on what is available at locations and how suitable venues are for children's needs.

> ***"Have used the Max card to access activities i.e. Marsh Farm, theme parks which is great, but a big blocker is having to queue as this is stressful for my child (and other children for disabilities) to understand."***
>
> *[Parent of a 10 year old with LD]*

Caravans, beach huts and Max cards – opportunities

Looking to the future we have also identified some longer-term opportunities for future consideration that will help improve families' experiences.

How could we improve families experience in the long term?

- Explore any **commercial opportunities** that could expand the range of caravans/break locations in the county and beyond (some parents suggested caravan hire in other parts of the county).
- Parents have suggested having **quieter (i.e. woodland areas)** locations for caravan parks would better suit some children and **enhance** the overall family experience.
- Review the **current provision** of sites and how well these are meeting the families' needs, and investigate if provision could be improved and be more **disability friendly** for some SEN children and their families.

"Only managed to stay 2 nights…exhausted [looking after son], not a break for us…caravans do not meet son's needs. Should have lockable windows, ramp, wide doorways, security."

"Need ECC caravan not in Essex."

[Parent of 16 year old with complex needs]

Adapting to the virtual world during Covid-19

Experiences of accessing virtual activities during Covid-19 were mixed.

Many had positive experiences of accessing virtual clubs, provider check-ins and support calls. But many felt that despite clubs doing all they could to engage virtually, their children still struggled with the lack of physical presence.

- **Social interaction** and positive impact on wellbeing
- Sense of **normality** and something to look forward to
- Encouraged **physical activity**
- **Continued communication** with services
- Provided a **break** and enabled parents to spend time with their other children
- **Reduced travel** – opportunity to access even more
- Providers say Zoom is a good way of **introducing** children to clubs and they can meet virtually first

"Zoom lifts her spirits and makes her happy...and helps her mental health."

[Parent of 12 year old]

- Some clubs **did not provide** any virtual activities
- Child **lost interest** or got too easily distracted
- Child found it **hard to interact** via the computer
- Technical and **connectivity issues** – apps not adequate
- Clashes with school sessions – **recorded sessions** to access later would be beneficial
- **More contact** from services through Covid would be welcome

"Technical issues made it difficult and the children did not see any benefit in watching a computer screen, quickly got bored and went off to do other things."

[Parent of 12-15 year old with sensory and PI,
LD and complex medical conditions]

Accessing virtual services and activities in the future

There is some appetite for virtual services alongside face-to-face. Appetite may be increased with wider promotion in the future, as the shift towards virtual communication grows.

19% of families accessed virtual short break activities or support for their child during Covid.

52% of survey respondents said their child is **not able or will not engage** in this way.

11% said their child wants a **face-to-face option only**, and **2%** said they **do not have the technology** to access virtual activities.

19% would use this **alongside a face-to-face** option, and **11%** would be happy to use as an **alternative to face-to-face** options.

> *"To connect with his friends, peers and staff once a week gave him a social connection to the outside world. He looked forward to these immensely and these were the highlight of his week, he would come out on cloud nine."*

[Parent of 12-15 year old with PI & LD]

What opportunities are there for more virtual services and activities in the future?

How might this impact on demand?

What opportunities are there to enable access to technology for those currently without?

Case Study

While Covid opened up a digital revolution, we need to keep a balance.

Maisie* is a young teenager and attends a special school. She has many complex medical needs, and other conditions including sensory, learning & physical disability. Her family said services are improving and "**I'm able to say wow! You've really stepped up in your provision for children with complex medical needs.**"

She is unable to attend mainstream activities as suitable changing places are not available, so really value the short breaks activities as they are what helps to stimulate their daughter outside of school.

The online session organised by providers during Covid has made it possible for her to "attend" sessions even when she was not feeling well and helped her to recover quicker.

This has been a great new experience and while this is something their daughter is benefiting from; they want choice and "**would like the flexibility to have both face to face and online.**"

"Covid actually opened up a whole new world to our daughter…we were able to access loads more support than normal. Our daughter's complex health needs mean she's often too unwell to access services…Everything going online, meant she didn't miss out on anything and was busier than she's ever been in her life!...

She experienced full inclusion for the first time in her life and was able to access as many things as her brother does. We felt she was finally seen as an equal."

[Parent of a young teen with PI, LD and complex medical conditions]

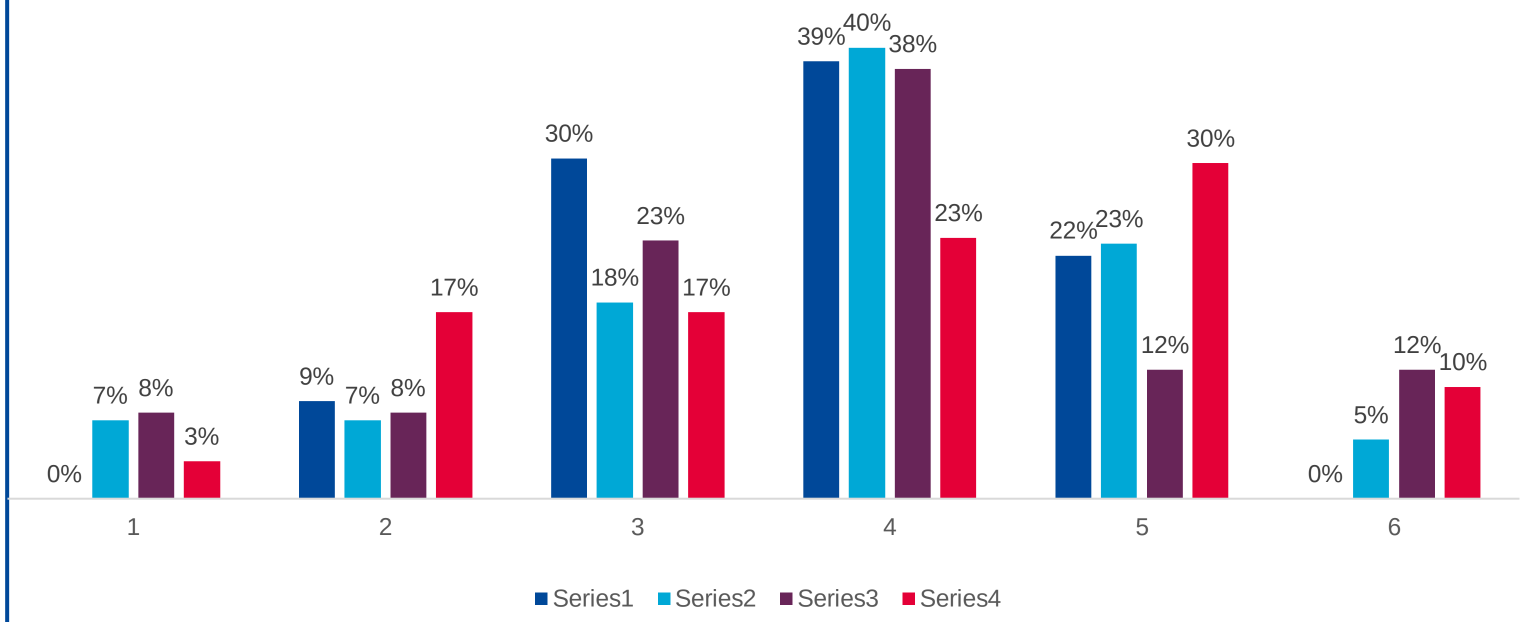
Preparing for adulthood

The current short breaks, clubs & activities only extends until the age of 19. Families are concerned about the lack of support available for young people as they approach adulthood.

Short breaks transition - preparing for adulthood

Those young people approaching transition age are less likely to feel short breaks are effectively preparing them for adulthood.

How well do you think short break clubs and activities are helping to prepare young people for adulthood? (%)



*[Based on **134** responses to this question after 'not answered' and 'not applicable' responses have been removed. This question was targeted at those aged 14+, however some of those with younger children still responded and the data is presented here for transparency.]*

How could ECC and providers better prepare young people for adulthood, based on what families tell us would be helpful?

> ***"I don't really see how the current activities do help prepare much for adulthood. I think there should be more directly targeted at this area. They currently help with confidence and independence to a degree but not really future career prospects or independent living although they are very good for helping him cope with other people and build social skills".***
>
> *[Anonymous survey quote]*

Short breaks and transition - preparing for adulthood

The current short breaks, clubs & activities only extends until the age of 19. Families are concerned about the lack of support available for young people as they approach adulthood.

What are the challenges for families?

A lack of **future planning** for their young person - assurances needed that the right support and services will be in place to enable young people to 'grow', meet their individual potential and become **independent.**

Parents are unsure **where to look** for information on post-19 options or when to start this process.

"I don't know how soon we need to be looking at that before his EHCP runs out."

Young people currently have to be **known to social care** to access services post 19.

There is a current **gap in provision** available for 19+ meaning that families can be left without **any support** once their young person reaches adulthood.

Young people take time to build **good relationships** with staff – risk of negative impacts if **continuity is lost** in transferring to adult services.

"Going [to club] for quite a few years and knew staff really well, taken away when you get to a certain age."

Lack of activities available for **older age groups** which may help to prepare young people for adulthood.

"We are really struggling with teenage activities. This is the key age [for development] that they want friends, parties, boyfriends/girlfriends but it is so hard to find anything from 13-19."

Short breaks and transition – preparation for adulthood

Identified opportunities that offer young people a route into independence and deliver better outcomes.

A vision for the future

In response to asking parents about aspirations for their young people…

“Opportunities they might not have had 10 years ago…valued by society, independent & confident with support to achieve this…do activities with friends not with parents, moving towards living independently…go out straight after college and do what they want to do. Do things with peers…just enjoy life.”

[Excerpt from parent focus group]

Innovation / opportunities to help achieve this vision?

- Develop links with **mainstream colleges** to work with providers and deliver after school clubs and activities which help develop skills and grow independently.
- Explore opportunities for young people to experience an **age-appropriate** social life and create a **safe social media environment**, to keep in contact with friends and avoid becoming socially isolated.
- Offer more purposeful **‘real life’ activities** and opportunities with achievable goals that build confidence and evidence personal development.
- Extend ‘membership’ to clubs for another year post-19 and offer **volunteering** opportunities to young people as they ‘age out’ of service.
- Nurture better links with **adult services** and **forums** (i.e. Collaborate Essex) ensuring families are aware of what universal support could be available post-19.

Case Study

Need for local activities to build lifelong skills and independence.

Jake* is a teenager living with his mum in a rural part of Essex and attends a special school. He has many conditions including autism, dyslexia and sensory issues. The family do not receive any support from social care.

Mum said there is a lack of clubs suitable for her **teenage** son in the local area. They have tried clubs further away, but Jake does not travel well and there are also travel costs to consider. Mum asked, **“what do I do when he is at a club far from home?”**

Jake’s mum gave up work to care for her son and said they both feel **“isolated and forgotten”** and for those middle children (those not at the higher or lower end of the scale) there is a clear lack of activities. Mainstream activities were unable to cope with her son and having tried to access light touch support, could not even get accepted onto the waiting list.

Having to attend a club with my son ***"kind of defeats the point for me – if I’m accessing stuff it needs to encourage independence and social skills, not me constantly having to watch him, because I could do that at home.”***

Learning life skills for the future is very important. Mum wants her son to be able access more **life skills activities**, like learning how to shop, handle cash and social skills.

She also highlighted that as a single mum her son would benefit from **positive male input** in his life and has tried several schemes, but they could not accommodate her son.

[Parent of 12-15 yearold with autism, dyslexia & sensory needs]

Case study – preparing for adulthood and prevention

Earlier intervention and timely support to prepare young people for adulthood can avoid escalating needs for families, and costs to social care services in the future.

Matthew* is approaching adulthood and has high functioning autism, anxiety, and limited social skills. He does not have a learning disability; ***"which has been the problem as most services are for that demographic of SEND CYP."***

Matthew receives some help from his social worker, but the family have been **unable to access Direct Payments** or any services to help **prepare Matthew for adulthood.**

Matthew is doing **very well in college** and has the potential to be independent, but the family feel they **have to fight** for what they are entitled to and are **not getting the support they need**.

*"We need help to prepare my son for adulthood…he now needs adult care as he just turned 18. We've been trying for years…**I've been told so many times that Direct Payments do not exist!***

*We identified our son's needs, found the service on Local Offer that meets them, were not allowed it. **He is now an expensive adult to support.** We get a tiny bit of help from a CYP support worker. **It's not enough** to address his complex needs regarding preparing for adulthood at all."*

*"I can see there are opportunities for volunteer work for SEND young people, CV writing, getting a job...But what about the **basics of being an adult?** Going to the shop alone, being home alone, talking to strangers? **That help exists on Local Offer but needs paying for."***

[Parent of teenager with autism and mental health needs. Continued on next slide.]

Case study – preparing for adulthood and prevention

[Continued]

“What we really need for our SEND CYP in Essex are the ***basics****! To be* ***listened to about what our needs*** *are, and to not spend hours and hours of our lives fighting for what we are entitled to…****early intervention*** *saves money in the long run!”*

“He ***needs to know other young adults*** *of a similar cognitive ability….tiny groups who have been matched based on ability and interests. Also* ***mentoring*** *- we'd love to know* ***others who are autistic****, a few years older than my son, that have become independent who can share how they manage...****That could be invaluable*** *as right now* ***he doesn't know anyone else*** *who is autistic. Or anyone else his age really!”*

“He is doing amazingly in mainstream college, he ***got a distinction*** *last year,* ***he has the potential to work one day.*** *He could pay tax, have a life! But now he cannot leave the house alone or be home alone, let alone work! What a waste, I thought Meaningful Lives Matter!”*

“With a bit of help now, my son could be independent…Right now, we foresee him being quite a ***burden on social services*** *in future…he will be an expensive adult to support without this help. I warned everyone about* ***prevention of escalating needs****, and nobody listened.”*

From our engagement with families, Matthew’s story is typical of the battles many parents face in accessing the right support.

This story also highlights the risks of these missed opportunities for early intervention, and the potential impact on social care services.

How can we better listen to what families are telling us, and ensure they receive timely support to meet their needs?

Advice & information

Accessing information can be **overwhelming** and **difficult to navigate.**

Advice and information

Parents felt information on services is not easy to access.

Which local clubs & activities are available to me?

What support can my child get?

Where do I look for information?

> ***“Would be nice if we could have it [information on what’s available locally] more targeted, signpost a bit better on the website, I think sometimes they forget how busy or how overwhelmed parents can get, especially now.”***

[Parent of 12-15 year old with LD&A and sensory needs]

What are the issues?

- Parents don’t know **where to look** for information, and find it difficult to **filter** and identify what activities best suit their child
- The PDF version of the Local Offer is not **mobile accessible**

What’s needed?

- Information could benefit from being **categorised** or the ability to filter. E.g. by area/age/condition/need etc.
- Parents could benefit from more information on:
  - **Transition** into adulthood
  - Support for **young carers**
  - **Accessibility issues** in the wider community, e.g. travelling with a disabled child/young person.

What opportunities are there to improve access to information based on user needs?

How can we ensure information is shared in accessible formats?

Could improved access to information reduce future demand on ECC services?

Advice and information

A lack of information at the right time on what's available can increase stress on families.

A lack of information from professionals:

- Not provided until point of diagnosis
- Assumption that parents are already aware of services

Early information needs to be provided from professionals (e.g. health visitors/GPs/therapists) to relieve family pressures

Additional support needed for key cohorts:

- Foster carers requiring relevant information in a timely way
- Approaching the transition to adulthood

Improved information on what services/community support is available for **adults** is vital in preparing young people for transitioning into adulthood

How can we ensure that professionals across organisations have information on current services that they can share with parents?

How can we ensure families receive information on the adult services offer, to help prepare them for transitions?

> ***"I did not get any information until my son was diagnosed."***
>
> *[Parent of ……..]*

Support for Families

Needs inevitably change with time. Continued support throughout child’s pathway should reflect this.

Support for Families

Families can feel isolated with little support, and a lack of communication with professionals.

What are the challenges?

Feeling isolated	Struggle with family time	Lack of support	Lack of communication with professionals
Feeling **socially isolated with limited peer networks** to share experiences. Some children do not cope well with visitors to the home which increases isolation and loneliness for the wider family.	Parents find it **hard to do things as a family** and enjoy time together**.** ***“Difficult to find anything to do as a family and that the children can do together and “we split up one of us with one child one with another.”***	Some children need 1-to-1 support at clubs, which can result in **no break** for parents. Parents with their own **health conditions** cannot always support children in attending clubs. ***“Everything I go to I have to stay…You cant get a break.”***	**Not sharing techniques** of what works well for children in sessions that parents could replicate. Some parents felt if they tell professionals they are not coping this can result in being told to go on a course, making them **feel like a bad parent.**

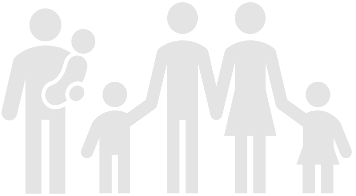
Support for Families

There is a need for more continued support through the pathway as their needs change.

What's needed?		
Tackling isolation	Support tailored to whole families' needs	Greater communication with professionals
Proactively identifying and supporting families where there is greater **risk of social isolation** and family breakdown. Opportunities to facilitate informal **peer support**, e.g. between parents in local areas.	Services to **adapt to families' changing needs** and ability to care as their child gets older, to support wellbeing throughout the pathway. A **whole family approach** which is responsive to changing needs. More support for siblings, young carers, and single parent families with no male role model in the child's life. Opportunities for parents to spend time exclusively with **other siblings**, as they can feel excluded.	Greater **communication with professionals** has the potential to have a big impact on **family wellbeing**, and avert family breakdown: • **More informal support** and sharing knowledge could help parents with implementing coping strategies to managing behaviours at home and ease familial pressures. • **Listening to families' feedback** to inform service improvements.

Case Study

Reducing social isolation and accessing the community is important to families.



Toby* is aged between 17-19, lives with his family and has severe autism, anxiety and continence issues. He was on the CIN register, mum has since unsuccessfully sought support and now thinks they felt he ***“wasn’t worth the hassle”.***

She said her son does not get on with some of his siblings. Due to his behaviour the family get **little support** from family and friends so ***“having him at home full time is very stressful.”*** During Covid there were even fewer visitors (which he likes) to the house and the family are becoming **more isolated.**

Toby has tried several clubs in the past, but thought people were getting ***“too close”*** and stopped going as he needs to be in a **small group**. Before Covid-19 he had started at a sports club and really enjoyed this and responded well to the trainer. He has **aspirations for future** and would like to be a computer programmer.

The family have not used the caravans or beach huts as they **need help** to take Toby out,but do want to do things as a family. Mum **does not drive** and there are no local clubs for Toby’s age group.

To help **reduce social isolation** mum has suggested that ***“different families could all chip in for a minibus so they could all access activities as a group”.*** They have tried to access mainstream activities, but mum feels ***“people aren’t kind…it is just too difficult for us to do”.***

Toby loves animals and has used a local private organisation that run forest and bat walks and who are trying to branch out to include **activities for disabled cohorts.**

Is there potential for new commissioning opportunities to support access in the community and reduce social isolation?

Support for Families

Caring responsibilities can limit families' employment opportunities and impact finances.

From our interviews **8** are **working mothers.**

One mother had to give up her job due to the **stresses of caring** for her child, and another had to leave her previous job after maternity leave as they **did not allow flexible working**.

6 of those we interviewed are **single parents.**

Employment

- Some in employment felt that ***"going to work is a break"*** from caring.
- For most, balancing employment with caring for a child with disabilities is a **struggle**.
- Many mothers we spoke to were not working or **limited to part-time work.** This was often due to one or more of the following:
  - **Stress** and feasibility of balancing work with caring responsibilities
  - **Lack of flexibility** from employers
  - **Affordability of care** a barrier to work
- No suitably priced breaks for children during **school holidays** impacts carers' ability to work and support the family.

> ***"Unable to go to work…would like to be out making a positive contribution to society."***
>
> *[Full time carer]*

Support for Families

In addition to limited employment opportunities, families face additional costs.

Finances & ability to pay for short breaks and activities

- **Loss of income**/employment during Covid could reflect on ability to pay for future short breaks.
- Parents want to ensure their child is settled at a club before paying termly fees in advance, and **don't want to "pay to test".**
- **Specialist toys** for disabled children are expensive. Hiring toys locally would be welcomed by parents.
- Parents are generally **happy to contribute** financially to services if they are available.
- **94%** of survey respondents told us their children were in receipt of either **Disability Living Allowance** (DLA) or **Personal Independent** Payment (PIP), which can be used to offset travel costs & activities.

"Parents are quite willing to pay…as long as she's getting something out of it I don't have a problem with costs."

[Parent of 17 year old with LD&A]

How can we support parents back into work?

What opportunities are there for a 'try before you buy' approach for clubs before committing to termly fees?

Are there opportunities for a toy library?

Access to mainstream & community inclusion

Many feel unable to access mainstream clubs due to their child’s needs. A safe and trusted environment is vital. Staff training and disability awareness is required for full inclusion.

Experiences of mainstream activities in the community

While there may be some appetite to access mainstream activities, for most families we spoke to the changes required are such that they do not currently consider it a possibility for their child.

This includes **whole systems change** to move towards community inclusion and access, and a seismic shift around **disability awareness and understanding.**

Within the survey, **25%** of children and young people are accessing mainstream clubs & activities, and **75%** are not.

Challenges with accessing mainstream clubs include:

- Child's **needs are too complex** or they would not cope with the environment. Clubs are not equipped to meet their child's needs.
- Staff do not have the **understanding or training** required – several had experienced their child being seen as 'naughty'/disruptive and had been asked not to return.
- Concerns about child not 'fitting in' due to clubs **not feeling inclusive**, or judgement from others.
- Many mention **swimming provision** in particular being unable to meet child's needs (around **1/3** of comments said 'swimming', in response to question on other activities they would like to access).

How can ECC support providers of mainstream activities to make necessary adjustments, improve inclusion and become disability friendly?

Could we implement an **Essex Disability Charter** whereby organisations are formally recognised and awarded a 'tick' if they met set criteria?

"They [staff] just kept shouting at him…others don't see his disability, they see him as an annoyance."
[Parent of 6 year old with autism & ADHD]

Through the eyes of a parent…

One parent has tried to access a number of mainstream clubs and activities but all have been **unable to meet her son’s needs.**

[Parent of 12-15 year old with learning disabilities and autism, mental health needs]

“My son used to attend swimming lessons at the local pool but they were unable to meet his needs and spent the majority of the time ignoring him or telling him off. I had to arrange additional one to one sessions for him to learn to swim. The experience of group lessons was extremely traumatising for my son…

All the mainstream activities which we have tried to attend have assumed that all children are able to understand, remember and carry out instructions. They have also assumed that all children are able to stay still and maintain their attention.

My son finds it very difficult to do this and it became very confusing and upsetting for him. This resulted in my son being constantly disciplined or told off for things which he didn't understand and was unable to change.

When he constantly met this negative approach it resulted in him isolating himself away from the local community and becoming afraid to socialise. It has been very damaging to his self-esteem and has destroyed his confidence.”

Community inclusion & access to mainstream

Community inclusion and increased awareness of disability can improve outcomes for families.

What could enable families to engage better in mainstream activities in the community?

IMPROVED ACCESS AND INCLUSION

- Better **changing facilities** at mainstream venues, and more information on changing places (improved key system).
- Better **access for wheelchairs** in public spaces, and more disabled equipment in parks/playgrounds.
- Improved **training and awareness** for staff and other parents.
- Increased **access to mainstream** clubs for children with lower level SEN, to enable child to mix with school peers.
    - Helps to build confidence and prevent isolation.
    - Suggested **adaptations** include smaller groups and quiet spaces, more supervision, and tailored activities.

"My child wants to mix with non-wheelchair users too."
[Parent of child with physical disabilities]

ENABLING FAMILY ACTIVITIES

- Clubs and activities which can be done **as a family.**
    - Siblings spending time together
    - Some might need support to help achieve this.
- Several spoke positively about accessing family biking and gaming sessions **out of county**.

"Siblings need to play and do things together."
[Parent of a child with SEN]

Can we work better with stakeholders to improve access and promote inclusivity?

What 'family' opportunities can we build into the new model?

How can we engage better with local communities?

Community inclusion & access to mainstream

More training and awareness is key to creating safe and inclusive spaces; a safe and trusted environment is crucial for families.

Families need clubs and activities (short breaks & mainstream) which provide a **safe and nurturing space.** This includes professionals they can trust in being **disability aware** and having the expertise to work with their child.

Challenges resulting from a lack of training/awareness or where spaces don't feel safe:

- Behaviour of children **misinterpreted as being disruptive**.
- The wrong environment could mean **giving up** on clubs/activities - *"could learn to fail and does not want to go anymore".*
- Some older children could be **easily led** and taken advantage of by others, leading to being pushed into bad or **risky behaviours** - *"giving money to others, being pushed into bad behaviour."*
- Parents said other users in mainstream settings make comments about "how my child looks". One parent said *"people just need to be kind."*

"I know what teenagers are like, they are horrible at times and he is easily led."
[Parent of 16 year old with LD&A]

"Clubs can't meet children's needs as they don't understand the children."
[Parent of child with SEN]

"She's got disabilities but because they are all hidden, they just see a normal 17 year old girl…she's only got to say something wrong and she's kicked out."
[Parent of 17 year old with LD&A]

Community inclusion & access to mainstream

Increased awareness training could have a big impact on inclusion within mainstream activities in the community.

For families, safe and secure spaces include:

- Trained staff who **understand difference and abilities**, e.g. between a disabled 10 year and other children the same age
  - This can be an issue in mainstream clubs where activities can be **results driven**.
- Activities in **small groups** and quiet spaces - *"safe space, low numbers are good."*
- The right **tone and language** when communicating with children
- Taking time for children to **build up confidence** and feel safe at a club/activity

"[Need staff who are] understanding and get to know my child before attending."
[Parent of child with SEN]

What difference could increased awareness training make?

- More **social inclusion** and acceptance in local communities
- **Increased use/revenue** for some mainstream clubs
- Families could be more likely to use **mainstream clubs** and activities
- Children and young people have **more choice** of activities in local areas
- Mainstream clubs have opportunities to be **beacons of good practice**

"It's the inclusion that I really like, it makes it normal doesn't it."
[Parent of 5 year old]

Could increased opportunities for children with disabilities to participate in mainstream activities, increase short breaks spaces?

How can we work with partners towards an Essex Charter mark for good practice?

Conclusion and recommendations

Areas for consideration

Building a service for all.

1 Deliver a more equitable and accessible locally targeted service that meets the needs of families.

2 Considerations to extending the offer to include age 19+ making sure this builds in opportunities for becoming independent.

3 Build and expand on the digital offer that was rolled out as a result of covid-19.

4 Increase awareness training with professionals and the wider community to embed better inclusion and access.

5 Deliver holistic support for families through the pathway responding to changing needs.

6 Provide the right information at the time in the right format and enable better navigation of the system.

“There is a need for change and choices. Children and young adults, whatever their ability, need to be given choice.”

This information is issued by:
Essex County Council
Research & Citizen Insight

Contact us:
Maura.o'malley@essex.gov.uk
003330136500

County Hall
Market Road
Chelmsford
CM1 1QH

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