

“Every family needs to go on their own journey”

Short Breaks Clubs and activities for children with disabilities (CWD) research

12th and 14th April 2021



Essex County Council

Welcome

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Developing Short Breaks Commissioning Strategy



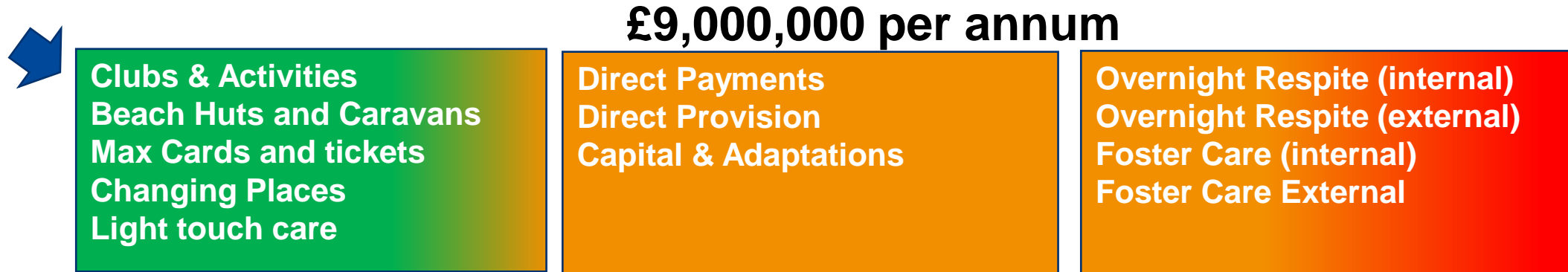
Essex Short Breaks Offer

To create a Short Breaks Commissioning Strategy which sets out:

- The entirety of our short breaks offer
- How we want to develop and improve that offer over time
- How we want different agencies to work together, to deliver better experiences for families
- How we are intending to improve outcomes for children and young people with disabilities

The Current ECC Short Breaks Offer

Section 25 of the Children and Young Persons Act requires local authorities to provide short breaks for families with disabled children.



- Earlier support for families at the right place and at the right time
- Services and support which are needs led and evidence based
- Services and support which consider the needs of the whole family
- An improved level of choice
- Good developmental outcomes for children and young people
- Long term sustainability

Delivering the Strategy

Improved Offer

Clubs & Activities
Beach Huts and Caravans
Max Cards and tickets
Changing Places
Light touch care

Direct Payments
Direct Provision
Capital & Adaptations

Overnight Respite (internal)
Overnight Respite (external)
Foster Care (internal)
Foster Care External

Good Principles

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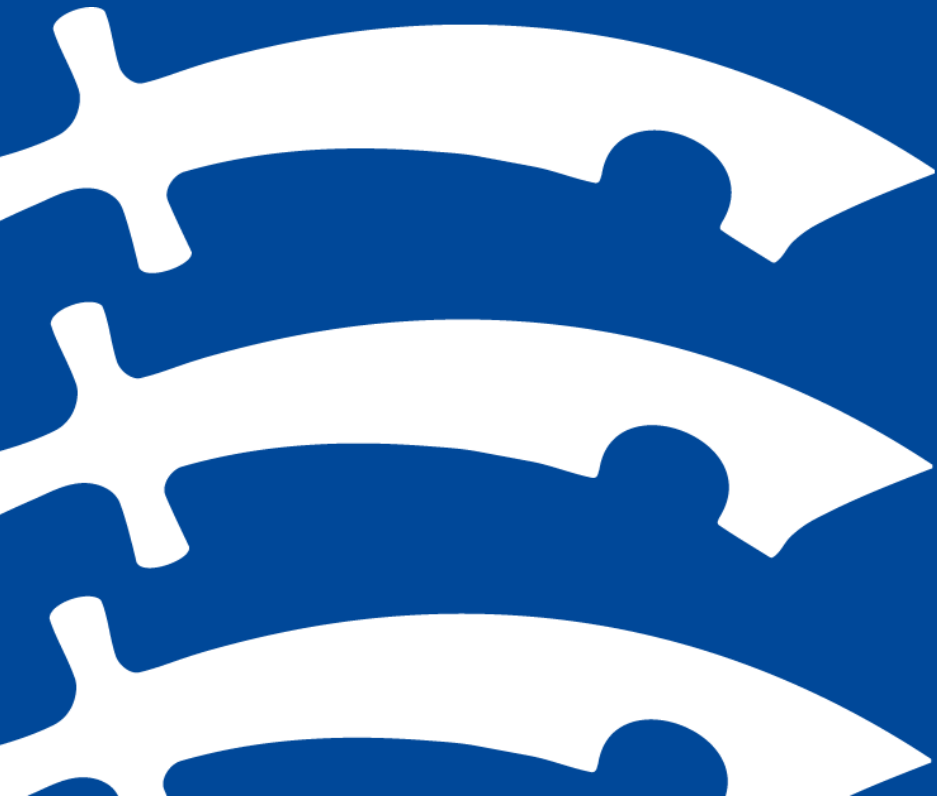
Co-designed with you

The short break offer and commissioning plans co-produced with you, the families it is for;

- ✓ Inform
- ✓ Engage
- ✓ Participate
- ✓ Influence
- ✓ Decide

Essex Family Forum

Ange Neale and Julia Brunning



Essex Family Forum



What is a Parent Carer forum?

- A Parent/Carer Forum is a group of parents and carers of children with additional needs and disabilities.
- We represent the views and lived experiences of SEND families
- We work *with* the Local Authority – **we do not work for them**
- We also work with NHS health commissioning bodies and other organisations
- We belong to the Eastern Region Parent Carer Forums and are part of the National Network of Parent Carer Forums

What is our role?



- Part of the Main Working Group
- Co-Produced the Shortbreaks Survey that went out to families
- Co-Hosted the Parent Engagement Focus Groups
- Represented the family perspective at the Market Engagement event
- Regular discussions with ECC Research & Citizen Insight Team on survey findings and parent focus groups.

Key insights from the research

Maura O'Malley

Research & Citizen Insight Team



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.

Services are welcomed and vital for families

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

A view from the provider market

Clear consistencies between what families tell us and what providers already understand as key challenges, but working together presents an opportunity to innovate and build a better service offer for families.

Some of the 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 and difficulty recruiting **male support** workers.

Problems sourcing suitable fully **accessible premises**, & providing county coverage of services is difficult, especially in rural areas

Providers not being aware of **local need** and what families need.

Time for a change & what could be different

Collaborative working between providers (i.e. share premises), explore the use of council assets.

Deliver more **life skills training** for young adults; provide a 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.

Other ideas included,: mobile service for rural areas, better links with health and a blended approach between mainstream and short breaks.



Key challenges for families

Accessibility and inclusion

On the whole, clubs are felt to meet children's needs, enabling socialising opportunities, building confidence and providing support for both children and parents. But there some challenges and opportunities to improve the offer.

Lack of access

- Lack of suitable clubs and activities available **locally**, especially for **older children**.
- Families value and enjoy the caravans, beach huts and max cards, but there is a **lack of availability** & adjustments are needed for improved inclusivity and access.
 - E.g. lack of **specific provision** for CWD in caravan parks, max card venues **lacking facilities**

Mainstream and community inclusion

- Most families feel **mainstream clubs are not an option**, as they are not suitable for their child's needs.
- **Whole systems change** is needed to move towards community inclusion, including a shift in attitudes and understanding around **disability awareness**.
- A **safe and trusted environment** is vital for families - more training and awareness is key to creating **safe and inclusive spaces**.
- Many had positive experiences of accessing **virtual clubs**, which opened up a whole new world for some.

Opportunities to improve the offer include:

- Increased collaboration between ECC & other LAs to improve access to services
- More disability awareness training for staff
- Improved facilities and adaptations to the environment
- Enabling whole family activities
- Greater use of virtual clubs and activities alongside face-to-face options

Advice and support

A whole family approach is needed, supporting families as their needs change.

Advice and information

- Accessing information can be **overwhelming** and difficult to navigate.
- Families felt there was a **lack of information from professionals** at the time they need it, which adds to stress.
- Parents **don't know where to look** for information, and find it difficult to **filter activities** and identify what provision best suit their child.

Support for families

- Families can feel **isolated** with little support, and reported a lack of communication with professionals.
- Caring responsibilities can also limit families' **employment opportunities** and impact on finances, with **additional costs** associated with caring for a child with disabilities (e.g. paying for clubs and specialist toys).
- Parents felt they have a **lack of time together** as a family, with activities not catered to the whole family.
- Families' **needs change with time**, and they need continued support throughout the child's pathway.

- **Timely information and support** could positively impact family wellbeing and **long-term ability to care** for children, and **manage future demand** on services.
- Families would benefit from **greater communication** with professionals (more **informal support**, and listening to **feedback** as part of **continuous process** to inform service improvements).
- What opportunities are there to **support parents back into work**?
- What opportunities are there for a **toy library**, or a '**try before you buy**' approach to clubs before committing to termly fees?

Lack of support to prepare young people 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.

Key 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.

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.”

There is a need for local activities to build life long skills and independence. Earlier intervention and timely support to prepare young people for adulthood can avoid escalating needs for families, and future costs for social care services.

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?

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.

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.

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.

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.

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.

Next Steps to developing the Short Breaks Strategy



Developing a long term strategy

Based on what you have told us so far ...

- ✓ You will be supported in local communities, by universal services and specialist provision according to need
- ✓ You will be able to access activities and opportunities which enable your children to achieve good outcomes and make successful transitions to adulthood
- ✓ Children and young people will be supported to be resilient and able to draw on support to enhance this resilience when needed
- ✓ Essex feels like and is a friendly and supportive place to live for families
- ✓ Our system of support for you will be collectively owned and sustainable over the longer term

Based on what you have told us so far

We should aim to ...

- ✓ Support an increase in inclusive **mainstream provision** across the County
- ✓ Work to ensure you are able to access high quality **information, advice and guidance**
- ✓ Provide an accessible community short breaks **clubs and activities** offer that meets your needs and enables good outcomes
- ✓ Support you to feel confident to use **direct payments** as a means of accessing support for you and your children
- ✓ You children are supported to make successful **transitions** to, and achieve **good outcomes in, adulthood**

The next steps will be ...

- Strategy public consultation
- Launch Strategy Autumn 2021
- Put into action the things we can change in the system now
- Continue working on the re-design and re-commissioning of the short breaks clubs and activities for October 2022
- Commence work other elements of the short breaks offer

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Overnight Respite (external)
Foster Care (internal)
Foster Care External

CYPEngagement@essex.gov.uk



If you have any questions having attended this session please either post them in the chat box or email them directly to the email above. We will summarise the questions and answers and email this to all attendees



We will circulate the full report to all attendees. This is also available on request to the above email address. A recording of today's session will also be made available via social media platforms and on request to the email address.



If you have any ideas or comments you would like to be considered in the development of our Strategy or our further work to develop our offer please contact us at the above email address.



**Thank you for
attending today's
session**