

# Putting families with one or more children with special educational needs and disabilities (SEND) at the heart of family hub planning

## National Centre for Family Hubs Implementation Toolkit

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## Introduction

This module is intended to support those who are working together to develop family hubs in a local area, to consider the needs of families with one or more children with special educational needs and/or disabilities ([SEND](#)) in the development process. The module shares practical strategies for ensuring families with one or more children with SEND have equitable access to services, easy connections to local information and the support they need, and relationships with those with whom they work.

### Who is the module for?

This module is aimed at those who can integrate SEND services within family hubs for the benefit of families, for example, those responsible for and working within:

- Supporting Families
- respite and short breaks for disabled children
- early help parenting support
- SEND information, advice and support services (SENDIASS)
- other health, social care, psychological and educational services that cover the age range of pre-birth to 19 years, or up to 25 years for those young adults with needs that qualify for continued support.

### What are the objectives of the module?

For local authorities and their partners in family hub development:

- **to raise awareness** of key issues impacting on families with one or more children with SEND
- **to inform** about statutory responsibilities and guidance relating to SEND
- **to advise** on data, strategies and good practice
- **to support** planning, doing and reviewing, for the inclusion of families with one of more children with SEND
- **to make the case** that SEND should be built into family hub development, not bolted on to it.

### Content collaborators

#### Co-produced by those with lived experience from:

Bristol and Isle of Wight

#### and representatives from:

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Association of School and College Lecturers (ASCL)

Black Asian and Minority Ethnic Educators (BAMEEd), Bristol and the South West

Barnardo's Family Centres, Isle of Wight

Brighton and Hove City Council

Bristol City Council

Children's Disability Council

Croydon Council

Department for Education (DfE)

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Department of Health and Social Care (DHSC)

Department for Work and Pensions (DWP)

Derby Council

Kings College London

Rochdale Council

Solent NHS Trust

Warwickshire County Council

## **Why is it important to integrate SEND provision into the development of your family hub vision, policy and practice?**

Family hubs will work with families who have one or more children with SEND every day, so it is vital that staff recognise and have the skills to respond to their needs:

- Sixteen per cent of school-aged children in England, have special educational needs at any one time ([DfE](#)) and eight per cent of the child population are disabled ([Scope](#)).
- Sixty-nine per cent of parents and carers with disabled children in UK, say they never receive any support outside the family and ninety per cent say they have to fight to get the services their disabled child needs ([Disabled Children's Partnership](#)).
- Fifty-three per cent of parent carers have been forced to give up a paid job to care for their disabled child, and forty per cent of parent carers in UK have experienced relationship breakdown with a partner since diagnosis. Of these, 64% say a lack of support had a major impact on the breakdown of a relationship ([Disabled Children's Partnership](#)).
- There has been an increase in education, health and care plans (EHCPs) in England every year since 2010. There was a 11% increase in the number of EHCPs made in 2021, compared to 2019 ([DfE](#)).
- Parents and carers report that trying to get their child's needs recognised by professionals is a constant 'fight'. This can have an impact on their personal relationships, and frequently becomes a source of [parental conflict](#). These findings were among those which prompted the Government's Special Needs Review and the Education White Paper (Spring 2022). and the Education White Paper (Spring 2022).
- Which primary school a child attends makes more difference to their chances of being identified with SEND than anything about them as an individual, their experiences, or what local authority they live in ([Education Policy Institute](#)).
- Children and young people with SEND may struggle with identity, bullying, isolation, anxiety, stress related to poor progress, or a range of unmet needs that they do not understand. This can cause stress in family life for parents, carers and siblings, and in the context of high levels of family stress, there is a risk of forgetting this is hard for the child or young person too.
- Identifying, understanding and meeting a baby, child or young person's additional needs as early as possible, when their educational, social or emotional progress

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starts to be affected, is important in improving their outcomes. [Best Start for Life](#) recognises the role family hubs can play in meeting local authorities' statutory duty in ensuring services are accessible to parents and carers who have children with SEND.

- The [Commission on Young Lives](#) notes that if needs are not identified early, there is an increased risk of children developing a poor experience of learning, which can result in poor attendance and exclusions. Young people whose needs are identified late or whose needs are not met are particularly vulnerable to extrafamilial harm, such as gang violence and sexual exploitation.
- Children with SEND experience higher average levels of absence from school, leaving them more at risk of slipping under the radar for SEND assessment. It is important to consider how children's SEND needs can be assessed effectively at home if they are out of school for a period ([Education Policy Institute](#)).
- Further research is needed to unpick whether ethnic disparities represent real deficits in support, and if so, where and why ([Education Policy Institute](#)).
- Safeguards need to be in place to ensure the visibility of the most disadvantaged children as well as children who move house or schools frequently.

### **Key messages from families with lived experience who have co-produced this module:**

1. Listen to us and respect our expertise.
2. Don't blame us.
3. Don't just smile and tell us we're doing a great job.
4. When we are tired or frustrated, give us a bit more of your time, not less.
5. Where relationships are not effective, we can experience the feeling of being in 'constant battle' or on an 'emotional roller-coaster'
6. Share the excellent training and programmes we have helped to put together with all staff who work with our children.
7. Build provision for children and young people with SEND into your family hub planning, don't just bolt it on.
8. Take a whole-family approach where this will make a difference to us.

### **What are special educational needs and disabilities (SEND)?**

In England, [the SEND code of practice, 2015](#), provides the statutory guidance for organisations that work with and support children and young people up to the age of 25 who have SEND. It may appear that the code of practice is for schools and colleges and local authority education departments, but the code states clearly that health partners and youth offending teams are also bound by the guidance.

SEND is defined in [section 20 of the Children and Families Act 2014](#):

*A child or young person has SEND if they have a learning difficulty or disability which calls for special educational provision to be made for them.*

*A child of compulsory school age or a young person has a learning difficulty or disability if they:*

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- *have a significantly greater difficulty in learning than the majority of others of the same age, or*
- *have a disability which prevents or hinders them from making use of facilities of a kind generally provided for others of the same age in mainstream schools or mainstream post-16 institutions*

In addition:

*A child under compulsory school age has a learning difficulty or disability if they are likely to fall within the definition above when they reach compulsory school age or would be likely to if special educational provision was not made for them*

The [SEND code of practice](#) defines 'disability' using wording from the Equality Act 2010: "...a physical or mental impairment which has a long-term and substantial adverse effect on their [the person's] ability to carry out normal day-to-day activities".

A disabled child does not necessarily have a special educational need (SEN), for example a child with a prosthetic leg would be recognised as disabled and needing regular medical check-ups, but this disability may not impact on their ability to access learning in school.

What family hubs need to do for a disabled child who does not have SEN will be different from what they do for a child who has SEN but is not disabled. This is an important distinction for family hub staff to understand, especially when focusing on services outside education settings (e.g., social care) where eligibility may be determined by a child's disability but is not linked to SEN.

## **Commissioning**

The Department of Health and Social Care provides separate [guidance](#) relating to the commissioning of health services jointly for children and young people (up to the age of 25) with SEND. The requirements are to:

- *work with the local authority to contribute to the local offer of services available*
- *have mechanisms in place to ensure practitioners and clinicians will support the integrated EHC needs assessment process*
- *agree personal budgets, where they are provided for those with EHC plans.*

## **Age range**

The [SEND code of practice](#) allows young people with SEND to remain in education beyond the age of 18, and potentially to the age of 25 where this is appropriate for the individual. Further education (FE) colleges may continue to provide for the young person until they reach the age of 25, and a change of funding systems or institutions isn't always needed. However, a young person will need to transition [into adult social care or health services](#) once they reach 18□.

Although a young person's needs may begin to be met by adult services once they are 18, integrated care systems (ICS) – which will replace all clinical commissioning groups by July 2022 – are required to:

- *commission services jointly for children and young people (up to age 25) with SEND, including those with education health and care (EHC) plans*
- *work with the local authority to contribute to the local offer of services available*
- *have mechanisms in place to ensure practitioners and clinicians will support the integrated EHC needs assessment process, and*
- *agree personal budgets, where they are provided for those with EHC plans.*

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## Who decides if a child or young person has SEND?

Disabilities and difficulties or delays which affect developmental progress may be identified pre-birth, or may be identified when babies are born by a range of professionals. This includes midwives, ☐ such as nursery staff child-minders☐☐for SEND is<sup>1</sup>medical services, such as a community paediatrician. . . .

The Best Start for Life recognises the importance of integrating SEND services into wider services to provide a better universal offer for families who have a baby with SEND. It notes "how essential it is for families with disabled babies to have a co-ordinated plan of care offered by a lead professional" (p.51). Family hubs have a role to play in supporting this universal offer.

Parent-led developmental assessments such as the Ages and Stages Questionnaire (ASQ-3), which can be carried out with children aged two to two and a half, give prime caregivers the opportunity to voice any concerns. Family hubs can support integrated working between health visitors and others working with a family. Information sharing agreements can reduce the need for families to repeat the narrative of their child's needs with multiple professionals.

Once a child is in an early years setting or a school, staff will notice the additional needs of individual children and then adapt the task or lesson, where necessary, in order to support the child's understanding. This is sometimes called 'ordinarily available provision'.

All education settings are required to identify, assess and meet the needs of children with SEN at every stage. The [SEND code of practice](#) requires this of early years settings and FE as well, but they are not explicitly under the same duty as schools. As part of the assessment process, other specialist health professionals, or an educational psychologist, may need to be involved.

The process of 'assess, plan, do, review' is called the 'graduated approach'. Many local authorities (including [Derby City Council](#)) provide clear information to families about this through dedicated webpages and through their local offer.

## How can family hubs support children and young people with a special educational need or disability and their family??

The range of support a family hub can offer a family will depend on the level of integration within each local authority.

### Health professional

*"Family hubs might be able to provide that key navigator role that is often missing for families and also act as mediators between families and services to aid understanding and relationships on both sides."*

### Advice and support

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[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/502913/Health\\_Professional\\_Guide\\_to\\_the\\_Send\\_Code\\_of\\_Practice.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/502913/Health_Professional_Guide_to_the_Send_Code_of_Practice.pdf)

Well-informed family hub staff with good networks, enable families to benefit from advice from the most appropriate person for their query, for example school health, speech and language therapy or CAMHS. Family hub staff should also be aware of the services parents and carers have a statutory right to request, such as a social care assessment ([s.17 Children Act 1989](#)), a carer's assessment ([s.97 Children and Families Act 2014](#)) and an EHC assessment. Staff should be able to signpost or directly refer families to the relevant teams.

Family hub staff also need skills to be professionally curious in a non-judgemental way. Family hubs can play an important role in asking how relationships are going for parents or carers of one or more children with SEND, as the incidence of relationship breakdown for this group is very high.

### **Advocacy**

Parents and carers report that they often find the procedures relating to SEN, and disability, overwhelming and disempowering. With the right skills and strategies, family hub teams may be able to advocate for parents and carers, supporting them to explore options; express themselves at meetings; putting them in touch with other helpful services and build the skills to advocate for themselves in time. Trained volunteers, many with lived experience, advocate effectively in some areas. Family hubs may also work with other services that can provide advocacy, such as [SENDIASS](#).

### **Digital solutions**

There are a number of innovative digital apps in use, and being trialled, across the country to support SEND needs for parents, carers and children and young people. See resources section below. Digital solutions can also be a source of outreach support in rural areas.

### **Individual or group support**

Children with disabilities and their families may benefit from short periods of time away from home, provided by [or, by visiting?] family hubs. Family hubs will also be able to offer individual and group support through SEND stay and play, parenting support, youth options, play therapy, supervised contact, etc. Reducing Parental Conflict strategies will be an important offer for families with one or more children with SEND, [Evidence from a UK study](#) shows that over a third of parents (34%) of children with a learning disability were in distressed relationships, and they were more likely to be in distressed relationships than other parents (26%).

### **Information sharing**

A commitment to sharing information and data, with the family's consent, limits the number of times parents, carers and young people need to tell their story. Relating a narrative can be very empowering for a family if they have ownership of the telling, but it is also a source of frustration when someone feels they are repeating the same thing over and over and nothing is changing.

### **Language**

Shared language that is inclusive, respectful and easy to understand is crucial – avoid acronyms!

### **Listening**

Family hubs will often be the place to go when parents and carers get frustrated with their child's school or the wider system, and good relationships between family hub teams can help to communicate consistency and calm.

Often, professionals such as teachers can feel powerless in situations where there is a disagreement between a parent or carer and the school. However, it is important to

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remember that the parent or carer can also feel powerless. Finding a solution through empathetic listening and acknowledgement of each other's perspective is important. Strength-based approaches can also reduce the risk of a parent or carer feeling they are being blamed. Breakdowns in these relationships can sometimes require mediation. If appropriately trained to provide mediation, family hubs could play a key role here. Alternatively, staff can signpost or liaise with independent services such as SENDIASS (see below).

## **Reducing stigma**

Family hubs will be committed to reducing stigma associated with SEND, promoting positive messages through the choice of images used in publications and posters in buildings and on social media.

## **Signposting**

Signposting includes making links to the local offer available, and providing information about voluntary community and faith services, local networks (including social media groups), drop-ins, and training. Family hubs might also provide links to local parent and carer forums or other groups that are part of local decision-making processes. Family hubs can also signpost to their local SENDIASS – these services are already hosted by early-adopting family hubs. SENDIASS is a funded service to support families in negotiating the SEN system (both SEN support and EHC processes).

## **Shared experience**

Family hubs can provide opportunities to meet people who have had similar experiences, needs or disabilities. This can be particularly powerful for young people with disabilities in mainstream schools who sometimes don't see their identity reflected in books or other resources, or among their peers. Mainstream schools can provide excellent education for children and young people with SEND, but family hubs can work with schools and colleges to extend opportunities outside of the school day to share experiences and meet good role models.

## **Supporting early intervention or diagnosis**

It is important that families are supported in the early days of realising a baby has a delay, difficulty or disability. A lead professional linked to a family hub can provide support into the longer term too, helping to liaise with other professionals involved.

According to the [SEND code of practice](#), professionals should be able to meet a child's needs within the education and health system without a formal diagnosis, but many parents and carers and children and young people express the relief they experienced once they had a diagnosis, for example of autism or attention deficit and hyperactivity disorder (ADHD).

### **Parent**

One parent explained why it helped him to have a 'label' for his child: "I'm then able to research and get a good in-depth idea of how he works." A diagnosis helped some young people to make sense of their own needs and enabled them to factor this into a revised sense of identity and belonging. It also gave families access to support groups and information.

## **Training**

Your family hub may choose to show a commitment to becoming attachment and trauma aware and autism friendly. Family hubs may decide to develop their understanding of relationship-based working, such as mentalization (e.g, through [AMBIT training](#)). A good

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understanding of the impact of unconscious bias will also support open, trusting and positive relationships for families.

Family hub staff will benefit from training to understand more about the challenges that children and young people with various types of SEND might experience, and how different types of SEND might present. This will help them to better understand the issues families face and will help them to signpost to appropriate support or offer a service (see the individual and group work section above). For example, many parents and carers are aware of their own child's masking behaviours, which are often associated with neurodiversity and can act as a barrier to the child communicating their needs effectively. Parents and carers can get frustrated that this masking behaviour is often misinterpreted as a sign that their child is coping well and say they would welcome more professionals recognising this type of behaviour.

## **Transition**

Family hubs can play an important role in supporting the transition of young people from children's services to adult services, through information giving, advocacy, benefits advice, support for families, managing conflict, etc. A knowledge of the opportunities available through FE colleges and workplace schemes for young people with disabilities, such as [Access to Work](#), are an important part of signposting for this older age group. Family hubs may also bring together options for best value for personal budgets. Working with groups such as SENDIASS, family hubs can host sessions for young people and their families (see, for example, [Coventry SENDIASS](#)).

*The following section outlines considerations if SEND is to be at the heart of family hub development, using a process of 'assess, plan, do, review'.*

## **Things to consider as you begin your family hub development process – assess:**

- What can your data tell you about outcomes for your families in which one or more children have SEND?
- How does your SEND data relate to your commitment to equity, diversity and inclusion?
- What does your data show about gender differences in SEND locally?
- What picture does your data paint about SEND and minoritised ethnic communities in your area? Do some explanations for disparity or 'stuckness' in SEND data need reviewing?
- Are families and young people with SEND part of the team who look at the data?
- Can you share and discuss your conclusions with people with lived experience to gather their ideas and views?
- How can you build in other ethnographic or qualitative data to add to your picture?
- What role can schools and FE colleges play in gathering the views of children and young people with SEND?
- What role can health visitors or school nurses, Mental Health Support Teams and other workforces, such as health commissioners, social workers, educational psychologists, paediatricians have in feeding back trends, opinions and data?
- How can you manage data protection while gathering information from people with lived experience? If 'red tape' acts as a barrier to gathering views, can your procedures be amended to make it easier to hear people's voices, while maintaining safe practice?

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- Are you listening to the lived experience of local families in which one or more children have SEND? This is essential in developing family hubs to better meet local need.

## **Things to consider when designing your family hubs approach – plan**

Are you planning for inclusion?

- It is important not just to think about those with needs relating to neurodiversity when considering children and young people with SEND. Parents and carers and children and young people with physical disabilities, moderate learning needs and complex health needs can feel their child's needs are not always acknowledged. .
- What offer is available for siblings of children and young people with SEND?
- How are siblings recognised when they are providing care, and what support is available for young carers?
- Consider young people with SEND who don't live within a family.. What does support for them look like, in conjunction with other services?
- How can you reflect the diversity of needs and cultures of the families who are accessing the services in the physical and online environments? For example, Anna Freud Centre Young Champions noted that having the option to dim the lighting can be helpful for autistic people and others who have sensory differences.
- It is important to consider reach and how to engage with all families, ensuring inclusivity of under-served families, including those from minoritised ethnic groups. Children from Gypsy, Roma and Traveller families for example, have disproportionately high levels of SEND. What role can family hubs play in enhancing a better understanding of Gypsy, Roma and Traveller culture and providing supportive strategies to respond to poor attendance or social, emotional and mental health needs for some Gypsy, Roma and Traveller pupils within schools? This is important even if there is not an established Gypsy, Roma and Traveller community in a local authority, as it supports a welcoming environment for all.
- How can you ensure that all services available via the family hub take account of SEND needs and offer suitable support? For example, some parenting courses may have a specific focus on certain conditions (e.g., Down syndrome or Prader-Willi syndrome), while others will be valuable for recognising generic issues like sleep and eating.
- In what ways will your family hub proactively reduce the stigma that can be associated with SEND?

Are you planning for accessibility?

- How can you make any digital offer accessible to families with one or more children with SEND?
- Are you involving young people champions locally? They can be excellent problem solvers when thinking about making physical spaces more accessible for those with SEND. As Portage works so well for young children with SEND, in what ways can families with older children with SEND be supported at home?

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- How do you empower and inform families so they can navigate support across the education, health and care systems?

## **Is the language you use inclusive, respectful and easy to understand in all of your communications?**

Are you planning for consistency across services?

- What services within the wider family hub offer, including from the voluntary, community and faith sector, may be suitable for families with children with SEND?
- What does 'only needing to tell your story once' mean for services and systems?
- How can you make good use of assessments that have already been completed, in planning for your service to meet the needs of a child or young person with SEND?
- How can you ensure consistency of practice among professionals working as part of the family hub?
- Is your focus on what works for the community and understanding how to meet the needs of all families?
- How can you work more effectively alongside schools and FE colleges? In her work on inclusion, [Mel Ainscow](#) notes the benefits for families when "what schools do is aligned in a coherent strategy with the efforts of other local players – employers, community groups, universities and public services'." This has implications for school, college and system leaders in the transformations that can make a difference. There are also many strategies that schools use successfully for inclusion that can be shared with family hubs.

### **Case Study:**

*A school in Bristol has appointed Somali family support workers. Recognising that many Somali parents like to meet in person and that some who are new to the UK may not yet be fluent in reading English, the workers invite families (over the phone, not by text or letter) to come and learn about the education system and how to support literacy at home. The scheme/programme has been positively received with 60 families regularly attending.*

## **Things to consider when implementing your family hubs – do**

Many children and young people with SEND and their families may also experience complex needs related to material poverty, poor health and discrimination based on their race, ethnicity or other aspects of their identity. For example, there is some [evidence](#) that autistic young people are more likely to experience gender dysphoria than the rest of the population. However, professionals working with a young person who is having difficulties with their identity may wish to focus on only one of those aspects – autism or gender identity. The young person may feel better supported if the professional looks at the crossroads of these needs and ensures that the young person has a say in the support they receive.

'Intersectionality' is a term that is used to describe how distinct aspects of social categorisation interconnect', where these factors cross over, that discrimination and challenge are more likely to occur.

Family hubs are well-positioned to listen to the stories of the families they are supporting. Together, the team around the family, *with* the family, can better understand

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the range of needs that the family is experiencing, the impact of these overlapping needs and how best to support them.

#### Teacher

*Too often, a child is recognised by the need that presents most obviously; 'He has ADHD'; or 'She's got dyslexia'. Without meaning to, the use of the label starts to identify who the child is in too simple a way, which can result in strategies or provision meeting a single need, leaving the child and the family still bereft of the help that might make a real difference to them.*

Family hubs will need to be both proactive and responsive in providing a range of universal and targeted services for families with one or more children with SEND, dependent on the circumstances that are presented. It can take time to understand what will make a significant difference for the family, as often the presenting need is not the main problem. Getting to the nub of the any issues they are experiencing requires good relationships, trust and time.

Based on the responses to the assessment and planning stages outlined above, every family hub programme will be expected to take steps to enable delivery, for example:

- training staff
- identifying governance arrangements for the programme
- agreeing any co-location of other staff members and teams
- planning the timetable of activities in the hubs and online
- advertising and communicating about the services available.

**Case study – complex needs:** Consider a family of five children, in which one child has global delay related to a premature birth. At the age of six the child is given an additional diagnosis of autism. The child is non-verbal in school and has medical needs such as a feeding tube and a stoma because of medical issues relating to his prematurity. These medical needs are identified within his EHCP and the child has an individual plan to address those needs in school.

These are complex needs for any child and for any school, but the family also has needs that are not recognised by an EHCP: economic poverty, the social, emotional and mental health needs of siblings, domestic abuse by a previous member of the household, racially targeted abuse within the neighbourhood, and regular low mood experienced by the mother. Too often, those working with the family will try to address the needs outlined in the child's EHCP or his other health needs, but will then (often unknowingly) form judgements about the family for the circumstances they find themselves in.

A family hub approach would mean a trusted person would be able to:

- gather the narrative of the parents of the child enable the siblings to share their accounts of life so far
- speak with the children's key workers
- liaise with social care services to see if the child is entitled to respite/a short break (if the child meets the Equality Act 2010 definition of having a disability).
- consider thresholds to request a 'child in need' assessment if the difficulties the family is experiencing (e.g., the mother's mental health needs) persist.

With the family ideally only needing to tell their story once, the team around the family will be able to share key issues that are presenting and, together with the family, consider the impact of:

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- being young carers (to the little brother with SEND, and sometimes to the mother)
- bullying and racial abuse
- social isolation
- trauma from historic domestic abuse
- managing the complex medical and educational needs of the child in focus
- negative relationships

Strategies can then be agreed with teachers, special educational needs and disability coordinators (SENDCOs), speech and language therapists, young carers services, educational psychologists, benefits advisors, Reducing Parental Conflict advisors, and the Mental Health Support Team (in school). Each professional bringing their expertise, combined with the parents' expertise, to agree a plan that is added to the EHC process and regularly reviewed by the family's key worker.

**Case study - peer support:** *Through co-production with parents and carers, health partners, SEND specialists, education and others, Kent County Council is implementing a dedicated service that offers robust and consistent support to parents and carers whose child has either received a diagnosis, is awaiting diagnosis, or being considered for a referral to the Neurodevelopmental Pathway.*

*The service aims to address the issues raised by parents and carers, such as the need to wait for a diagnosis before support can be accessed or the feeling that the current offer is fragmented and hard to navigate.*

*Through a range of delivery options, facilitated by practitioners with lived experience, Kent County Council anticipate that self-help support will be provided via parent-facilitated one-to-one family advice sessions, workshops, support groups and delivered as an addition to services currently on offer across the county.*

*Parent-facilitated programmes and support are integral to this offer. Parents and carers as service users have robustly reported that lived experience is key to their engagement with the programmes. In addition, placing parents and carers at the heart of delivery will ensure continuous improvement of the offer.*

*The aim is to reduce anxiety and consequently the number of parents and carers reaching crisis point while on the waiting list. This work will also join up with Parent and Place Workshops that will bring together a range of professionals that parents can access as they explore and support their child's neurodiversity. part of their neurodiversity journey*

**Case study - integrated working:** [Rochdale's Integrated Family Offer](#) delivers services for families in which one or more children have SEND. This provision "cuts across a range of service areas and levels of need and includes a range of early help, children's emotional mental health, support for older children and those with complex needs.". Examples include a voluntary, community and social enterprise offer to support young adults aged 16-25 experiencing transition with low mood, with a particular focus on SEND and looked after children.

Some local authorities are developing ways in which children and young people can share their views in relation to SEND, both online and peer to peer. This is an important part of listening to the **voice of the child**.

**Language** is increasingly important to ensure that children and young people have a genuine say in the decisions that affect them, in line with the United Nations Convention on the Rights of the Child. They should feel included by the language used and not stigmatised, 'othered', or made to feel that difference is a negative.

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Acceptable language changes with use and time and one healthy way to avoid getting stuck on language is to ask those with lived experience what terms they are comfortable using, rather than assuming that the language currently in use will fit.

### Young adult

One debate (summarised by Dr Chloe [Farahar](#)) is about whether to use the term 'people with autism' or 'autistic people'. One autistic adult argued that using the word 'with' suggests that she can "put autism down", that she is somehow 'carrying' autism, whereas the identity-first term 'autistic' enables her to positively feel part of a group.

### Parent champion

One parent champion argues that referring to 'children who learn differently' is not a helpful simplification of neurodiversity, as "we all learn differently."

### Parent

Finding ways to support children and young people with SEND to belong is as important as finding ways to meet their differing needs. One parent noted how she was very happy that her son was able to go to his mainstream school, but for years he didn't have an opportunity to meet children who had similar needs to him and so missed out on that aspect of his identity and belonging. The mother recognised the value of her son's inclusive education, which enabled her son to access a mainstream curriculum, she added that her son didn't receive one party invite throughout his primary years in school. This is not a unique story. Whilst schools are probably better placed to build social skills and a circle of friends, family hubs can plan a role in signposting and organising groups that will potentially build esteem and reduce anxiety.

What can family hubs offer to families of children and young people with SEND so they can feel a sense of pride and belonging in multiple groups and settings?

It is also useful to maintain a shared language with all professionals from multidisciplinary backgrounds. You can achieve this by creating a glossary of key terms.

### Things to consider when monitoring and evaluating your family hub – review:

- Governance arrangements are important – who is carrying out the review? How will they identify whether the family hubs programme is meeting its aims? What action can they take if it is not? Are these arrangements clear and transparent?
- Build in co-production to ongoing review and reflection of whether your services are meeting needs. Put strategies in place to gathering the views of those who communicate in diverse ways.
- Consider how you could use local SEND data, for example data on exclusions, attendance, pupil premium, and ethnicity.
- Capture the views of professionals within your ongoing review process. It is important to keep a record of how responding to the views of others has made processes more effective.

## Resources

**Must read: [SEND Code of Practice 0-25 \(2015\)](#)**

**[Health Professionals Guide to the 0-25 SEND Code of Practice](#)**

**[Making It Personal: A guide to personalisation, personal budgets and EHCPs \(for education and local authorities\)](#)**

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**Should read: Let Us Learn Too - Money Survey** Family survey on the cost of the 'fight' for a child with disabilities, highlighting the inequity and the further disadvantage to families.

**Autistic Girls Network report, Keeping it all inside**

**UK disability Research report June 2021**

**Could read: Build back fairer: the COVID-19 Marmot Review. The pandemic, socioeconomic and health inequalities in England**

**Factors affecting teacher retention qualitative investigation**

**CooperGibson 2018**

**Place and belonging in school: Why it matters. NEU 2020**

## **Glossary**

Kids national charity has a useful glossary of terms that is clear to read, but many local authorities will have their own explanations, often within their Local Offer pages, which anyone can access to find services for children and young people with SEND in their area.

Kids' Glossary

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