



social care  
institute for excellence

# Northern Ireland Family Support Hubs

Interim Review Report







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- informing, influencing and inspiring the direction of future practice and policy.

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## Executive summary

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### Introduction

This review analysed the key impacts of the Family Support Hubs with a specific focus on families with children with disabilities. It also explored the interactions between hubs, hub members (voluntary and community organisations delivering local early intervention services) and statutory services to better understand the referral system and the contributions of the hubs to the local service network.

The methodology included a workshop with hub coordinators, interviews with parents, hub members and stakeholders and an analysis of a five-year administrative data set with detailed information on the referral activities from all hubs.

### The key findings included:

- **Benefits of the hubs:** families highlighted that the hubs offer accessible and timely support that are community-based, trauma-responsive and non-stigmatizing. For hub members, the key benefits included having access to accurate and up to date information about the community and local services, better integration between services, and having the access to families who are reluctant to engage with support facilitated. On the strategic level, participants highlighted that hubs are key in providing information and influencing strategic developments at the local level and across Northern Ireland.
- **Referral System:** hubs are contributing to developing strong local networks of services and the referral system has played an important role in facilitating the integration between local services. Participants highlighted key strengths of the referral system, including regular meetings for collective decisions on referrals. It was also noted a difference in the use of referrals tools – such as monthly meetings and referral forms – that may influence the quality of the referrals in some hubs. Participants suggested that a more consistent use of referral tools across all hubs could improve the effectiveness of the system. However, the specific requirements for each Trust area in relation to a range of issues - including information sharing – needs to be observed.
- **Interaction between hubs, hub members, and statutory services:** hubs are playing an important role in supporting families on waiting lists for Autism Spectrum Disorder assessments and mental health services for children and families. Families have been affected by the low capacity of services aggravated by the Covid19 pandemic and are, in the meantime, relying on the support offered by hubs to cope with challenges.
- **Challenges faced by families with children with disabilities:** families highlighted the difficulties in accessing services and activities that are adapted to their children's needs as one of the key challenges faced. This is due to lack of capacity in services, use of non-inclusive approaches, and lack of availability of group activities in their local areas that meet their needs. For many families, the support offered by the hubs is the only accessible support available.
- **Administrative data analysis:** a comparison of referral activity between hubs with complete and partial Sure Start coverage located in urban and rural settings was undertaken highlighting the following key messages:

- By analysing 3 time points, 2016-17, 2019-20 and 2020-21 it was possible to consider change over time more generally and then change due to the pandemic separately.
- There was a 31% overall increase in referrals to hubs during the pandemic. Hubs with complete Sure Start saw an increase of 52% from 2019-20 to 2020-21 compared with a 19% increase for hubs with partial Sure Start. Rural areas saw the greatest percentage increase of 71% compared with 31% in urban areas.
- Self referrals and community organizations are the top two sources of referrals in 2020/21, and both of these increased during the pandemic.
- Essential to the work of the hubs is the emotional and behavioural difficulty support for children, and for parents. These three referral categories together account for the majority of referrals for all years.
- The greatest change in reasons for referrals over time can be seen in 2020-21 where referrals for financial support increased from 5% of referrals to 22% reflecting the financial pressures on families during the pandemic.

### Recommendations from participants

- **Improve hubs' reach towards BAME communities:** Participants highlighted the importance of improving responses to engage with BAME families. Each trust region may have different needs for improvement and this should be addressed locally, however, some of the improvements highlighted by participants included: increasing availability of services that are compatible with specific cultural and religious needs of BAME families, and increase access to interpreting services for hubs facing communication issues.
- **Improve consistency of the referral system across hubs:** participants highlighted the need for standardising the use of referral forms to improve the quality of the referrals across all hubs. It was also highlighted that the collective discussions of cases and collective decisions on referrals adopted by most hubs have significantly contributed to the integration between services and effectiveness of support. Therefore, it is suggested that this approach is adopted across all hubs observing the specific requirements of each trust area.
- **Improve access to funding (e.g. transformation funding) to allow hubs to deliver key services:** participants from all groups highlighted the importance of hubs having access to funding to develop activities that improve engagement and facilitate greater understanding of families' needs.

### SCIE's recommendations

- **Improving the continuous evaluation of the model:** acknowledging the robust data collection system already in place, we suggest that a proactive approach to data analysis is taken to draw comparisons between different aspects of the hubs across time, across regions, and across hubs with different hubs set ups – such as programmes available, funding configuration, rural/urban settings, deprived/affluent areas.
- **Develop further research to create indicators and track cases that are at the high end of tier 2 threshold:** We suggest the creation of indicators to monitor cases that do

not need level 3 intervention but have complex needs. This would be key in understanding how hubs are preventing the escalation of cases to level 3 intervention.

- **Develop further research to analyse the economic impacts of the hubs:** we suggest an analysis of the economic impacts of the hubs to understand the cost-benefit of the support offered, particularly for cases that have been prevented from escalating to level 3 interventions.
- **Create a collective of hub coordinators:** to provide coordinators with the opportunity to share concerns, find collective solutions, align practices and principles, receive peer support, and access training and professional development support.



## Introduction

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This report presents the findings of the review of the Northern Ireland Family Support Hubs undertaken during 2021. It is a complementary piece to the first review undertaken in 2016 by the Social Care Institute for Excellence (SCIE) on behalf of the Northern Ireland Health and Social Care Board. The present review focuses on key aspects of the hub model, aiming to understand significant changes and improvements that occurred in the last five years in relation to the impacts of the hubs on families and local services, the interaction between the hubs, community services, and statutory services, and the access of families with children with disabilities to local services. To achieve this, a qualitative research approach was adopted to capture the narrative of key participants to better understand their experiences of using the hubs. The methodology included a workshop with hub coordinators, semi-structured interviews with representatives of local services that are hub members, stakeholders with strategic input to the hubs, parents of children with disabilities. The review also included an analysis of the regional administrative data set of hub activity, with information on referral activities and the profile of beneficiaries of hub services. More information on the methodology can be found in the next section of the report.

### The Northern Ireland Family Support Hubs

The Northern Ireland Family Support Hubs model is one of the key policies and service delivery strategies that aims to provide families with access to early intervention support. To achieve this, the hubs provide a collaborative interface across statutory, voluntary and community sectors with the purpose of:

- Raising communities' and families' awareness of family support services available
- Improving access to early intervention family support services by matching the needs of families to family support providers
- Coordinating early intervention family support services by creating a collaborative network of providers
- Assessing the level of unmet need for early intervention family support services and inform strategic developments.

The model adopts a community-based approach to integrate local services and coordinate early intervention support to meet the specific needs of local families. The hubs are a single point of contact that enables families to access key services in a timely and simplified way, significantly impacting on reach and quality of service delivery. Last year the 29 hubs in Northern Ireland supported 7,590 families – 8,486 children – working with over 600 statutory and non-statutory organisations across Northern Ireland (Health and Social Care Board, 2020).

### The 2016 Family Support Hubs Review

In 2016 SCIE completed a review of the family support hubs' conceptual, strategic, and operational aims, benefits and challenges. This included an analysis of hubs' impacts on families and communities, challenges faced by the hubs, the interaction between hubs and

hub members, and the governance and policy context of the hubs. The 2016 review provided a full overview of the hubs and provided some key insights for policymaking and strategic developments. Key findings included:

- Hubs were effectively providing a collaborative interface across the statutory, voluntary and community sectors, and involved representation from approximately 664 statutory departments and non-statutory organizations.
- Hubs were contributing to an effective integration between services, creating conditions for interagency work to address families' needs holistically.
- With the hub model and its holistic approach, families had access to personalised services that were accessible, timely and flexible, and in a non-stigmatising way.
- Hubs were key in informing strategic developments by assessing local needs, identifying gaps in service provision, providing intelligence for policy-making at local and national levels.

Since the completion of the 2016 review, the hubs have further developed, expanding the network of services and increasing the number of families supported from 6,077 in 2016/17 to 7,590 in 2019/20 and most recently reaching 8,405 families in 2020/21 with the increased demand caused by the pandemic (CYPSP, 2021). With the unexpected challenges imposed by the pandemic, hubs adapted to new ways of working to address the rapidly evolving needs of communities and families. Moreover, the 2016 review had raised some key topics of interest for future research to explore the challenges faced by families with children with disabilities and to further understand the interaction between services and variations in approach.

With this in mind, the Department of Health commissioned the SCIE to undertake this review to address the above topics and to provide an overview of the key changes, good practices, and impacts on families with particular reference to those families with children with disabilities.

## Review objectives and methods

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### Objectives

This review aims to understand the key impacts of the family support hubs on families with children with disabilities, and the key impacts of the hubs on local early intervention services. As previously highlighted, this review is complementary to the 2016 review and focuses on three key objectives.

- To understand the challenges faced by families with children with disabilities and the benefits of the support offered by hubs.
- To understand the interaction between hubs, hub members, and statutory services with a focus on the integration between services, the referral system, and thresholds between services.

- To map the variations in service provision with a focus on referral activities between hubs with complete and partial Sure Start Programme, and between hubs within rural and urban settings.

## Methodology

Interviews with families, hub members and stakeholders were the primary method with some supporting administrative data analysis of referral activity for each hub. This data was collected during the summer and autumn of 2021, and so occurred after COVID-19 restrictions had eased, but following on from lockdown and still very much within the wider COVID-19 context.

### Workshop

25 Hub coordinators – representing 28 hubs - took part in a 90-minutes workshop aimed to discuss the impacts, challenges and value of the hubs. The workshop was structured in three parts: introduction, focus groups, and feedback plenary. In the introduction, a round of introductions was facilitated followed by a presentation on the key messages from the previous review. Following on this, participants were split into three focus groups of 8-9 participants each and discussed the differences made by the hubs (impacts), the challenges faced by the hubs, and the value of the hubs. To close the workshop, groups presented their views to all participants followed by concluding reflections and comments made by the facilitator.

### Interviews

Semi-structured interviews were undertaken via online video calls or phone calls. Interview guides were used, with follow-up questions to encourage participants to explore further relevant themes. The interviews were audio-recorded – with consent – and detailed notes were taken for each, including highlighting key quotes.

*Informed consent:* All participants received an information sheet and had the opportunity to ask questions and discuss any implications of participating in the review. After demonstrating that they have understood the implications and all ethical protocols adopted, participants were asked to provide informed consent before each interview.

*Participants:* A total of 20 participants took part in the interviews:

- Parents of children with disabilities – 8 participants: this group provided narratives of their experiences and challenges they face while accessing local services and facilities. They also provided information on the impacts of the hubs in their lives and ideas for improvements.
- Hub members – 8 participants: hub members are service providers that hold a membership with hubs. They are a vital part of the hubs, receiving referrals and liaising with the hub while providing support to families. This cohort was drawn from different geographical areas across Northern Ireland (across the 5 trust areas), reflecting those with partial Sure Start coverage and those from areas with full Sure Start Coverage. The participants were also chosen to be representative of larger national voluntary sector and smaller community-based organizations. This group contributed with an insider view of the hub network of services, providing their account on the benefits, impacts, and challenges of the hub model.

- Stakeholders – 4 participants: this group was formed by key staff in leadership positions responsible for strategic decisions on children and family service provision in Northern Ireland. This group contributed with a strategic overview including strategic impacts and future developments of the hub model.

Analysis: Coding and analysis of the workshop and interview data was undertaken with MAXQDA software, to highlight the key messages and themes raised by each participant and then compare these across groups.

### **Administrative data analysis**

Data for each hub is collected quarterly at a regional level by the Children and Young People's Strategic Partnership on behalf of the Health and Social Care Board. The data includes referral activities and profiles of families and children supported, as well as information on the length and outcome of the intervention. Data was available for the period between 2016 and 2021 and is compared at 3 time points 2016, 2019, and 2020. A more detailed analysis comparing rural and urban hubs, and hubs with and without Sure Start programme coverage was undertaken for the 2020/21 data with some comparisons made across the 3 time points.

## Findings

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This section presents the findings from the analysis of the interviews, workshop and the administrative data sets. The qualitative contents are organized under five main headings covering the key strengths of the family support hubs, the referral system between hubs and hub members, the interaction between hubs, hub members and statutory services, and challenges faced by families with children with disabilities as well as their experiences of services delivered through the hubs.

### The Value of the Family Support Hubs

In this section, some of the key benefits of the hubs according to families, hub members, and stakeholders are presented. Families have emphatically described a variety of positive impacts that the hubs have had on their lives. In many cases, families displayed significant emotion and appreciation for the support they received.

*I am thankful to the family support [hubs], for what they have done for us and how they have done it for us. I can't even thank them enough, and they are still there for us (...). I am getting emotional here in saying this, please keep the family support [hubs] for the future, for kids and families.*

(Parent)

The level of appreciation expressed indicates how hubs have been important in supporting families, empowering them to face the challenges of raising a child with disabilities in such a challenging context – including during the pandemic. The recognition of the value of the hubs also comes from other groups of participants. Hub members and stakeholders have expressed this in different ways with some saying that they are a “*big supporter of the hubs*” (hub member) or that they are “*a fan of the model*” (stakeholder) and that they are “*a great advocate of the hubs because there is a simplicity on how they work in (...) it is beautiful how it works*” (stakeholder).

### Benefits for families

Parents, hub members, and stakeholders highlighted several benefits that hubs offer to families. Below we present some of the key benefits according to each group.

#### Parents' views

Parents highlighted many challenges they face daily when supporting their children with disabilities. In presenting these challenges they also talked about the support they receive from the hubs that allowed them to cope with the daily routine and support their children before, during, and after restrictions related to the pandemic. Some of the aspects identified as crucial for them to cope with such challenges included:

**Timely and immediate available support:** families reported that they felt confident in contacting the hub at any time, knowing that they would be heard and supported with little delay. Moreover, the close relationship between families and hubs meant that the hub was

already aware of their details and circumstances, contributing to quicker decision making and more precise and personalised support.

*There is no 'I will get back to you' and leave it for a week, they came back to me half an hour later with 'here is what we are going to do, here is what we are going to put in place. If needed they would 'jump in the car' and visit us*

(Parent)

**Personalised support:** The hubs' staff invest time in listening to the families and can understand their needs in more depth.

*...if they had 30 min and [the child] was not communicating well, they would go over 30 min and give [the child] time, (...) they know they were going to get somewhere, they would stay longer (...) and they know [the child] and know how to work with him*

(Parent)

The deep understanding of children's and families' needs was highlighted by parents as an essential part of the support that allows them to have access to services and activities that would work for them, particularly for children with disabilities.

**Community-based support:** For most families, the hubs are the main point of contact with support services. The fact that the hub is in the area where they live is a great advantage that makes a significant difference on whether they engage – and remain engaged – with hubs. Additionally, this often means that members of staff are aware of the issues in the region and can better understand families' needs.

*A lot of people here are [from] working-class [background] and most wouldn't have their own transport, and because they [the hub] are locally based and they are aware of the working class [life] they come to you and they are in the heart of it, they are in the heart of the community. They can even speak to the schools (...) and talk to the teachers and put things in place.*

(Parent)

Having awareness of the challenges faced by local families and being able to work in partnership with local services, was often highlighted by parents as one of the key advantages of engaging with the hubs.

**Non-stigmatizing approach:** Parents expressed that they trusted hub staff. Families reported several situations where they felt safe and comfortable to share private issues without being judged. Some of these issues were related to the lack of food and other precarious conditions at home due to poverty.

*I had a problem with the heating [and had no money to fix it] and I could talk to Sara and they came here and gave me vouchers for the electricity to help with the heating and gave me vouchers for the butchers too and I was happy and surprised that they thought about me in that way and didn't judge (...).*

(Parent)

Parents also highlighted that staff members interacted with their children in a non-patronizing way "talking to [them] as a human being" (Parent), particularly when the child had limited

communication as part of their disability. They also described situations where they were offered support without pre-judgement or favouritism as illustrated below.

*(...) what I like so much about the hub is that there is no favouritism, they had no clue who I was and they still [supported me] and were ringing every week just to see if I am ok.*

*(Parent)*

#### *Hub members and stakeholders' views*

Hub members and stakeholders presented complementary views on the benefits that hubs offer to families accessing the services. Below are some of the key messages raised by these participants.

**Preventing escalation to Tier 3 services:** Hubs are working closely with families and communities, so they are able to identify cases that require intervention at an early stage. At the same time, hubs have a close relationship with local services and can offer timely and personalised support that, many times, prevents situations from deteriorating and being referred to statutory services. They are also more readily available to support families that do not meet eligibility criteria for statutory intervention, yet still, need support.

*Some cases don't meet the threshold for gateway services and require some community-level intervention but present some complex needs (...). It is extremely valuable that [the hub] can keep families from [needing] a higher level of support (...).*

*(Hub member)*

*Sometimes when you actually get in and talk to families [you find that] their needs are more complex than thought.*

*(Hub member)*

*"The hub sits in a gap [between tiers 2 and 3]" (Stakeholder).* This is a significant location meaning that hubs potentially prevent cases escalating to Tier 3 services. They do this by working with families that require community-level intervention, perhaps providing intensive support to mitigate the risk of needing higher-level interventions, and potentially a child protection response. Moreover, as illustrated in the second quote, in many cases hubs are the first point of contact and can identify the specific needs of families at an early stage, being able to support the family and prevent deterioration in family circumstances.

**Inclusive community approach:** Hubs have become part of their communities and are well established as the first point of contact between services and families. Being close to the ground means that hubs have a community awareness that allows them to adapt their approach and reduce barriers between families and services.

*It is fact that the hubs are present in the community making the support accessible, it is also the fact that families are requesting the support, which is different from a referral, and that the hubs are 'working with' them and not 'to them' (...) the language we use can determine if a family will use the service or not and the big thing that I like about the hubs is that they are not working with families that are tier 2, they are working with families like yours and mine (...) that are needing support and we can give that support, and hopefully, they will continue on their journey once that hurdle is overcome.*

(Hub member)

As illustrated above, being part of the community also means that hubs can develop a person-centred understanding of individuals and families that goes beyond simply classifying them into levels of case complexity. This seems to be an important principle that allows hubs to understand that the challenges faced by families are situational and can be overcome if the right support is in place.

**Holistic approach:** for hub members, one of the important roles of the hub is the ability to synchronise services and address multiple needs presented by the families.

*When a child is acting out at school and the parents and school are concerned, sometimes it may be that that child is experiencing stress and that there is a situation at home that needs to be addressed, maybe a 2-year-old sibling is in and out of the hospital because of health issues, and the parent's relationship isn't good. So, the advantage for the family is that the hub can assess the family needs and we will support the older child but then Sure Start support the younger child and the parents could get support from the parenting support service.*

(Hub member)

In the example above, the child's behaviour at school can be understood as a symptom of the current family dynamic that is being affected by health and relationship issues. In this case, the holistic approach taken by the hub is crucial to address the systemic causes of the symptom (child's behaviour) and significantly improve the effectiveness of the intervention.

**Trauma-informed and trauma-responsive approach:** having a non-stigmatizing approach (described in the previous section) and investing in the relationship are key conditions that allow families to build trust and confidence and disclose sensitive information that is essential in understanding the causes of emotional and behavioural issues. This enables families to - supported by hub's practitioners - address traumas that are the real causes of their current issues.

*Someone presented with a social, emotional, and behavioural need but in actual fact, there were other stuff there and it wasn't until they began their journey [with the support service] and near the end, they felt comfortable and confident and disclosed the situation that was impacting in their parenting and how they have closed to other people.*

(Hub member)

In addition, many of the hubs operate in geographic areas characterised by deprivation and poverty. Being from or located in a community gives them acceptance and credibility with populations affected by social deprivation and intergenerational trauma.

### **Benefits for hub members**

As previously described, hub members are a collective of organisations that work in partnership with the hub co-ordinators, and with each other, to deliver services at the community level. Hubs have played an essential role in maintaining the focus of the support on families' needs, synchronising multiple services and minimizing overlaps. As well as benefiting families, this approach also brings several advantages to hub members. Below are some of the key benefits identified by participants.



**Strong local network and multi-agency approach:** through the hubs, local services have the opportunity to build relationships and develop long-lasting partnerships to support families with multiple needs.

*One of the benefits is that you sit with all these different agencies and can hear what is going on and who is delivering what and you build those working relationships, working jointly, and sourcing that to the families as well (...). We discuss the referrals with all members and we all make the decisions.*

*(Hub member)*

The hubs provide hub members with the opportunity to meet regularly, opening a space for them to work together based on the needs of the families. It is through collective case discussions and joint referral decisions that services get to know each other and are able to work closely addressing the multiple needs of the same family in an integrated way. This also *“helps the service [hub members] to provide a more holistic service to that family” (hub member)* that will increase the effectiveness of the intervention.

**Accurate and up to date information sharing:** hub members value the hub as a reliable source of information, not only about the services available in the area but also about the community. Hub members also have the opportunity to share their own information and intelligence with other members. It is an important way to get to know the issues faced by families that are specific to that area and to adapt their service provision where needed.

*When I attend the hub’s meeting, that is when I hear about what is going on in the area, and I take lots of notes of what is going on, the issues in the area and share with other team members (...) so it is a great information sharing tool as well.*

*(Hub member)*

*We get all the information we need. For example, this morning they sent information about a service for children with anxiety that is going to start next month and, coincidentally, I was speaking to a parent whose child had anxiety so I was able to tell them about this service.*

*(Hub member)*

Having up to date information means that services' staff members are aware of the service's availability and capacity at a given moment but most importantly, they are also aware of future changes in service provision and are able to better plan their support to further benefit families.

**Receiving referrals that are suitable for their services:** working with hubs means that hub members receive appropriate referrals for families that have been pre-assessed by the hub coordinator who can collect and share detailed information about the case.

*[working] with the hubs means that referrals are more finely tuned to the individual needs, because of those discussions that we had about the specific needs of the family. It is definitely more specific rather than generalised information (...). So, we get the whole story when you go through the hub.*

*(Hub member)*

This significantly reduces the risk of inappropriate referrals and provides the opportunity for hub members to have an in-depth discussion to align their approach and deliver integrated support.

**Engagement with families is facilitated:** having more clarity of the specific needs of the family and being able to see the whole picture of the case – as illustrated above - are two aspects that allow services to offer tailored support from the start, and approach families in a personalised way. In addition, the fact that in most cases the hub has already started the relationship-building process and prepared the family to engage with the service, contributes to creating favourable conditions for the initial engagement. This gives the families more confidence to accept support and build a relationship with practitioners. This engagement process also has the potential to secure participation from families and lead to successful outcomes.

*By the time we get the referral, the hub coordinators have already had a conversation with the family so they are expecting us and [it makes it easier to engage]*

*(Hub member)*

## **Strategic Benefits**

The hubs play an important role in providing insights that contribute to the evidence base that underpins strategic decision-making. Their strong presence in the community enables them to build an in-depth understanding of the community needs, and local services that are essential for local and national developments. Below we present some of the hubs' key contributions to government policy, planning, and commissioning of services.

**Influencing strategic developments to benefit communities and improve services across Northern Ireland:** working along with Locality Planning Groups and Outcomes groups, hubs have the opportunity to influence strategic developments bringing to the table an in-depth community-level qualitative knowledge that is essential for designing services at a local and regional level.

*That is where the strength of the model, the hubs [with] the Outcomes groups and the overarching CYPSP form a golden thread (...) that can change things strategically and put a qualitative narrative around quantitative figures, and to be absolutely able to say 'I can see why you are thinking of this service for this part of NI but what if we were able to share this out [nationally]'. A great example of that was the early intervention support service where hubs did make a difference and did write to their Locality Planning Groups and Outcomes groups and strategically influenced how that service would be rolled out across NI.*

*(Hub member)*

**Collecting key data to inform policy and service developments:** hubs have a robust data collection system that provides a reliable picture of families' needs and service provision in specific localities quarterly. The level of detail of the data offers accurate and current information that is of great importance for decisions about policy and planning of services for children and families.

*The hub referral data is a really rich source of information (...) and it is current. This data is a window into families' needs and families' life at that point in time (...) this is really about day to day lives of families (...) and in terms of strategic developments I do think that this data gives such an insight of families' needs, gaps in services in particular localities, and this is a big thing in terms of contributing and informing strategic developments.*

*(Stakeholder)*

**Optimizing early intervention:** The hub model means that hubs are well placed to be a core component of the family support continuum of service delivery across Northern Ireland.

*Hubs [have the potential to] form the cornerstone of the early intervention offer, responding to the needs of individuals [and families] with the locality groups responding to the needs of communities (...) and [with them] you really have the bones of a good coordinating function within early intervention that can respond and move very quickly, can look at needs quickly and can respond to needs quickly.*

*(Stakeholder)*

Having strong relationships with local partners and being close to the community give the hubs great ability to coordinate services and contribute to optimizing early intervention. This is key to improving the effectiveness of early intervention and reducing the demand for tier 3 services.

## Referral System

As previously described, the hubs have an important role in integrating early intervention services to provide families with holistic support. To achieve this, the pathways for referrals and the interaction between services are key as they will allow for the collective development of strategies for support, and systematic communication between services. Overall, hub members have reported great efficiency of the referral system currently in place with one suggestion for improvement regarding the consistency in referral communication. The points raised are described below.

**The referral system is effective:** in general terms, hub members and hub coordinators are satisfied with the referral system arguing that it has enabled early intervention services to develop an “*effective multiagency work*” (*hub coordinators, key messages from the workshop*) to deliver integrated support for families. Participants have commented on different aspects of the referral system identifying good examples of practices for each part of the referral system, as listed below.

**Hub member meetings:** this was pointed as the key part of the referral system that brings several benefits to the network including encouraging relationship building, development of partnerships, information sharing, case discussion, and providing a space for collective decisions on referrals and support strategies.

*[in] the meetings we [go through] the referrals and discuss what is the best support, it is almost like a screening of cases (...) and you know that the referral is appropriate as it has been discussed (...). The hubs wouldn't work unless there are*

*services to refer them to so it is very important that the services are all involved (...) and develop a community partnership so everyone takes ownership and contribute to best meets the need of the family.*

*(Hub member)*

Participants consistently indicated that there is a general sense that the hubs are collective of local services that take ownership of service provision. They often pointed to the sense of collegiality emerging from the monthly meetings, where they work in partnership and play a lead role in matching families with services.

**The relationship is key for the referral system:** hub members highlighted that the good relationship they have with the hub is essential to make the referral process more effective.

*The referral system is working well because of the personal contact that you have with the hub [and partners] and it is based on how well we know each other and it is essential that we all [invest in relationship building].*

*(Hub member)*

One of the reasons pointed for the effectiveness of the referral system is the openness that services have in maintaining fluid communication and making joint decisions on support strategies. This highlights the importance of space for informal interactions and relationship building between members.

**Daily communication:** online (email and video calls) and telephone communication between services and hubs are another key part of the referral system. Referrals and follow up case discussions are often made over the phone and e-mail which is an important way to share complementary information and to keep colleagues updated. While it works well as a form of liaising with partners, it does not offer the space for relationship building that hub meetings can offer but it allows for quick exchange of information.

**Referral forms and reports:** referral forms and case reporting systems are two tools that appeared to be used in some hubs more than others. The use of referral forms, was identified as good practice that can provide more structured and systematic information about cases, minimising the need to make follow up contact with hub/hub members. It was also pointed that there is a need to create a template that could be used across all hubs to standardise the minimum level of information needed in a referral. The reporting system was also highlighted as a good practice that can help the hub/hub members to identify key milestones as families progress, and provide an overview of all cases. It enables the professionals involved to further assess and plan the next steps.

**Quality of the referrals:** in general, hub members are satisfied with the quality of the referrals. The good relationship with the hubs and the opportunity they have to discuss cases collectively, provides hub members with all the basic information needed to initiate the support. It was also pointed that *“the family is always aware of the referral”* (hub member) which is not only an important part of GDPR requirements but it also facilitates the engagement with the family. Good practices (as described above) could be implemented regionally to enhance the quality and suitability of referrals received by hubs.

## Interaction between hubs, hub members, and statutory services

**The transition between tier 2 and 3 services:** hub members demonstrated good awareness of thresholds and clear internal protocols for escalating cases to statutory intervention.

*We have our own protocol and I would be the designated officer, so the family support workers would come to me in the first instance, and we would fill the CP1 form internally and then we will decide whether that needs to be escalated to the gateway and if we need to do the Unocini form. If they do need to become involved with gateway we must close the case.*

*(Hub member)*

It was also observed by hub members and hub coordinators that the partnership with “CAMHS and Gateway services is stronger” (*Hub coordinators, workshop key messages*) than in previous years. In some regions, Gateway and CAMHS are more actively involved with the hubs and are contributing to conversations about which tier families should be supported at (level 2 or 3). This is significantly contributing to a clearer understanding of thresholds especially for cases that are marginally under the threshold for tier 3 services, and may be presenting with elements of risk. One of the benefits of working in partnership with Gateway services (and having clarity on thresholds) is that the early intervention system can address key needs of families that are situated at the high end of level 2, but not necessitating a tier 3 response with the aim of preventing escalation in the longer-term.

**Gaps in statutory services (CAMHS and ASD assessment waiting lists):** hubs are playing a crucial role in supporting families who cannot access statutory services due to long waiting lists, with capacity further aggravated by service closures during the COVID-19 pandemic. The support offered to these families has helped to sustain families to manage emotional, behavioural, and practical challenges related to children's disabilities.

*We have been told that there is a two-year waiting list (...) and the only people here that we could turn to was the hub and without them, it would just be a nightmare they did a lot (...) for us.*

*(Parent)*

In the above example, the child was on the waiting list for ASD assessment and could not access further support from the school before receiving a diagnosis statement and the hub was the only support available. This demonstrates how hubs are playing a crucial role in filling a gap when other services are unavailable, and assisting families to manage with a minimum level of support while waiting for assessments and more intensive interventions.

**Supporting children with disabilities in schools:** participants highlighted that schools are short of resources to adapt to children's additional needs and therefore have not been able to fully support them. Hubs are addressing the needs of school-aged children, who have not been able to access extra educational supports.

*We are almost acting as an additional educational support, a lot of the children with ASD that we are supporting are on reduced hours at school. So, parents are having a real hard time with the child at home, they are sending the child to school (...) and the schools are*

*telling them 'we can't have your child in for a full school day', so they are staying 9-11 am and then they need to pick the child up. And that is really common at the moment.*

*(hub member)*

With schools unable to obtain extra educational support, parents and hub members highlighted that reduced timetables are becoming more common for children with disabilities. With families under further pressure, hubs have been essential in supporting them to manage children's needs at home as well as facilitating their interactions with the education system.

*They helped us to get in contact with the education board and came to school meetings help to put stuff in place for [the child] (...) he has lots of sensory issues and needed lots of things (...) they helped [the school and the child] to use a quiet time and quiet corner [strategy] for when he was getting overwhelmed and also helped to increase the hours gradually*

*(Parent)*

Hubs were the first – sometimes the only – option for parents to seek support, demonstrating how crucial they have been in supporting families with children with disabilities.

## Families with Children with Disabilities

There is increasing demand for services that support children with disabilities and their families. Their specific needs, combined with the challenges of designing effective and accessible services, means that service providers struggle to reach out to families with disabled children. The hubs have played a crucial role in engaging with these families and providing them with access to suitable services that meet their needs. To further understand the challenges faced by these families and the impacts of the support offered by the hubs, we describe below some of the key aspects raised by participants.

### Challenges faced by families

**Difficulties to access local services and activities for children with disabilities:** for most families, the hubs were the only service offering support and activities that fit well with their needs. Beyond the support offered by hubs, families have difficulties in accessing services and activities that could benefit their children's development. This impacted families in different ways.

In some areas, there is a general lack of options.

*In our area there is nothing for us to interact with [their child], we don't have our own transport (...) and we don't have facilities near us that we can take him [for an activity other than the hub] and they have activities there but it is the only place.*

*(Parent)*

While in other areas the options available are not considered appropriate for children with disabilities.

*There are some activities nearby but there is none that focus on children with disabilities, especially for autistic children. (...) There should be more activities, with smaller groups maybe four or five only, that would be good for them.*

*(Parent)*

These also impact on parents' access to information and peer support

*Things like autism are very common today but it is still difficult to know, sometimes us parents don't know what to do. There should be more information at school, and groups for meeting other parents, or giving materials with information. I didn't receive anything like that at the beginning [before the hubs].*

*(Parent)*

**Difficulties to access CAMHS and ASD services:** the lack of capacity, long waiting lists, and communication issues were some of the barriers faced by families who needed mental health and ASD support. Although the Covid19 pandemic exacerbated these difficulties, families reported that these are persistent challenges in previous years.

*I am worried (...) he is moving to a bigger school now and (...) his colleagues will see his body movements [related to ASD] and the teachers will see that he has concentration problems, and we don't have any document saying what is going on with him, and I don't know if we will receive enough help.*

*(Parent)*

In the case above, the child – waiting for ASD assessment - is at the end of primary school getting prepared to be transferred to a local high school. So far, they have received limited support, mainly because the parents were not able to apply for further educational support before receiving a diagnosis statement. While this is a specific case, parents, hub coordinators, and hub members notice that cases like this are “*increasingly more common in the communities that the hubs support*” (hub member).

Other challenges related to the low capacity of specialised services and consequences for accessibility are also highlighted by participants.

*We met twice [with CAMHS] we went to their offices and they didn't find a way to communicate with him [their son] and because he didn't speak and kept his head down as they were asking questions they said that there was not much they could do and passed us back to family support [hubs] (...). If they had time and patience rather than the fifteen minutes [appointment] they would have been able to communicate (...). With family support [hubs] they listen to what we explain about him and take the time.*

*(Parent)*

This extract illustrates how the lack of capacity can affect professionals on the front line, restricting them from adapting approaches to accommodate additional needs of children with disabilities. In this example, the initial relationship-building process was affected by the lack of flexibility which did not provide the conditions for the child to build trust and confidence to communicate. Participants also highlighted that the pressures that specialised services are facing are making challenges such as the one described above increasingly more common.

**Covid19 pandemic and lockdown restrictions:** families with children with disabilities were severely affected by social distancing and lockdown restrictions in place during the pandemic. Difficulties in keeping a structured routine, lack of opportunities for socialisation, and closure of most services were some of the factors that directly impacted families' wellbeing. This has caused several challenges related to emotional and behavioural management, impacting on the dynamics of the whole family.

*[And you wonder] 'is it normal to hate your children sometimes in the middle of a pandemic', and then you cry. And your child asks 'why are you crying?' And I say I don't know why I am crying', and then they cry and then you need to go to them feeling like 'oh god this is terrible', and feeling like not everybody is going through this and some people are sailing through this lockdown and enjoying it but I am hating every minute of it*

(Parent)

In some cases, these challenges would persist and affect parents' and children's mental health.

*My mental health was really bad at this time [pandemic] there was no other support [other services were closed], I just had to take anti-depressants and see how it would go (...) I just felt that I couldn't do anything, but I had to do it for the kids, it was hard to get them up and get them dressed and fed.*

(Parent)

*She [the child] was so frustrated and angry, and [the other child] was becoming withdrawn and getting increasingly angry, I had to be the balance but I was not feeling well either.*

(Parent)

This was also combined with the fact that families were having to deal with extra educational responsibilities that increased the pressure and affected relationships within the family.

*We would start [the home learning] and it would end up with another fight because things didn't go the way they wanted, and having a tantrum after tantrum and throwing [themselves] around.*

(Parent)

The closure or limited access to other support services meant that parents were feeling like they had to deal with these challenges on their own. This also included the closure of services that are linked to schools such as after school clubs.

*[apart from the hub] I had no support from other services, everything was shut.*

(Parent)

*[it was only the hubs, other services were closed] when the pandemic hit, you were left on your own because the health care visitors were overwhelmed with everything and had no time to give advice*

(Parent)



## Support provided by the hubs before, during, and after lockdowns

**Hubs are the key point of contact between services and families:** for most families, the services offered by hubs were the main form of support received even before the pandemic. This became clearer during lockdown restrictions when hubs “*quickly adapted and played a central role in informing and referring families to key services, contributing to mitigating the impacts of the pandemic*” (hub coordinators, workshop key messages). Overall, families have expressed appreciation and rated the support received as overwhelmingly positive. Below we present some of the most significant forms of support received and their impacts according to families.

**Support and advice:** providing information about children’s disabilities and relevant services were crucial for parents to develop awareness about their children’s condition and about the rights to access services and support.

*[I didn’t know] where to go and that there were options. I didn’t feel that I had an option to receive support (...) and I was stuck in a point that I didn’t know what to do.*

*(Parent)*

In the case above, the parent had no awareness of their right to access support nor about the options available. The advice received from the hub was crucial for them to understand their rights as a family and actively look for further support for their child with disabilities.

**Emotional and behavioural management:** these are some of the key challenges faced by families, and hubs were essential in supporting them to access resources and build resilience to cope with the daily routine.

*They helped us, including the other two brothers, to understand why [the child] was banging his head against the wall. [They advised us on] how to calm him down and how to talk to him, how to use the stress ball and get him to breathe. Before nobody could get him out [of that state] but it is working now.*

*(Parent)*

Learning about tools and methods for managing behaviour and emotions, gave the parents the confidence to address their child’s needs independently, contributing significantly to the wellbeing and resilience of the family.

**Practical and financial support:** with some families struggling financially, hubs were key in providing access to food, energy and heating, and essential house utilities such as white goods. This was an important relief for families struggling to meet the basic needs of children.

*We needed so many things, like white goods, we needed a washing machine and a tumble drier because [the child] is PEG fed and have other conditions so she uses a lot of clothes daily. So, they helped with the white goods and it was coming up to Christmas so they also helped with getting presents for the children.*

*(Parent)*

*He is very impulsive and if he has the idea to go out he would get out through the window or through the door and run, with no sense of safety he would cross the street. That was my biggest fear (...) and the hub was the first to offer help and they helped to put locks in place and make the house safer.*

*(Parent)*

The above extracts illustrate how hubs have helped families to access practical and financial support to meet the health and safety needs of their children. This is an important part of the support as it helps families to have more autonomy in their daily lives, alleviating concerns around children's safety and allowing them to focus on relationships and on the wellbeing of the family.

Building family's confidence and providing new life experiences: most families with children with disabilities experience additional challenges when doing things that are out of their routine due to concerns around being able to keep their children safe in environments they don't have control over. These experiences however, are a vital component of children's development. Hubs have offered a variety of support that contributed to building families confidence and enabling them to have new experiences.

*They would help to take him out of the house (...) and before that I was never able to take them to the park on my own because I would always need to chase him to make sure he was safe and the baby would be left alone. With their help, I was able to go out with my children (...). After, they offer a service where they could take him to a safe play space for two to three hours, and I knew that he was safe, and that gave him a chance to know a world without me, and to know that I would always come back (...) it was the first time.*

*(Parent)*

**Emotional Support for parents:** the hubs were crucial in supporting parents and helping them to cope with challenges related to managing their children's additional needs alongside other family tasks. During the pandemic, this was exacerbated and some parents relied on hubs' support to maintain some level of emotional stability.

*They [hub staff member] called me every week, it was during the pandemic time (...), I had a person who I could talk about my problem. They gave me lots of information about autism, I told them about all the problems that I had at home, they taught me about the evening routine and it worked, it was one less problem (...). I also had some emotional support because as parents we had to do everything during the pandemic, be a teacher, use apps that we didn't know how to use (...) and they helped me a lot and I didn't feel alone.*

*(Parent)*

Parents were overwhelmed with the behavioural and emotional needs of their children and had to deal with additional educational demands, while also dealing with their own emotional needs. The support offered by the hubs was deemed essential to help families to manage crises and maintain some level of stability during the pandemic.

## Referrals comparison: Sure Start, rural and urban areas.

This section presents an analysis of the administrative data highlighting the variations in referrals between hubs with complete and partial Sure Start Programme coverage, and hubs in rural and urban settings.

### Method

Three time points have been analysed: 2016-17 is the first full year following the previous review. 2019-20 is the most recent, mainly pre-pandemic year from which to understand changes since 2016-17. 2020-21 is the most recent set of data, but also pandemic data which can usefully be compared with the previous year to understand some of the impact of COVID-19. Some information was not collected in the same way in 2016-17 as it is now and there is some variations between hubs.

Three sets of analysis were undertaken: Firstly, looking at the totals across hubs combined. Secondly comparing hubs with Complete Sure Start programmes (CSS) to those with Partial Sure Start (PSS). Thirdly comparing hubs in rural areas to those in urban areas.

There were three of hubs whereby data was not available for individual hubs, only for the region. These were Lisburn, North Down & Ards, and Downpatrick hubs from the south-eastern region, and could not be included in the analysis as the data contained a mix of urban/rural areas.

### Total number of referrals and referral type

The total number of referrals increased by 1,205 between 2016-17 and 2019-20, but there was a significant increase the following year of 2,608 (a 31% increase) reflecting the impact of the pandemic. The breakdown of these totals highlights that the distribution of this increase during the pandemic was not even. CSS saw an increase of 52% from 2019-20 to 2020-21 compared with a 19% increase for PSS. Rural areas saw the greatest percentage increase of 71% compared with 31% in urban areas.

Total numbers of children supported					
Years	Complete Sure Start	Partial Sure Start	Urban	Rural	TOTAL
<b>2016-17</b>	3,136	4,052	4,512	1,620	7,188
<b>2019-20</b>	3,114	5,279	5,125	1,980	8,393
<b>2020-21</b>	4,740	6,261	6,710	3,390	11,001

The referral type was split into either Children or Parents. There has been some change over time with an increase in the percentage of child referrals, but with no noteworthy variation when we looked at CSS/PSS and urban/rural.

Referral type			
	All hubs		
Referral type	2016-17	2019-20	2020-21
Child / Children	63%	70%	67%
Parent / Parents	37%	30%	33%

### Child referral characteristics

It is helpful to consider the variation in the ages and support needs of children that are referred and if some types of hub tend to work with some groups more.

There wasn't a helpful distinction between the spread of children's ages when looking at urban/rural, but for CSS and PSS there is some difference with CSS supporting a higher percentage of children aged 0 to 4 and PSS a higher percentage aged 11-15. It is important to highlight that the Sure Start programme aims to provide support to families with children aged 0-4, which explains the higher percentage of children within this age band in CSS hubs. There is a higher proportion of children aged 5-10 in both complete and partial Sure Start areas and this is consistent across the three years. Both CSS and PSS saw an increase in referrals for 0-4 year olds during the pandemic.

Children's age						
	Complete Sure Start			Partial Sure Start		
	2016-17	2019-20	2020-21	2016-17	2019-20	2020-21
0 to 4	29%	26%	32%	27%	21%	26%
5 to 10	42%	45%	40%	41%	45%	41%
11 to 15	23%	25%	22%	27%	28%	27%
16 to 17	5%	5%	6%	6%	6%	6%

The proportion of male and female children supported by the hubs remained consistent through the 3 years comparison and across CSS/PSS and urban/rural hubs. The average proportion is 44% female and 56% male.

Hubs with partial Sure Start had an increase in children with disabilities supported while CSS hubs had a reduction in the proportion of children with disabilities supported across the three years. However, it is important to highlight that CSS hubs only support children under the age of four, and this may have reflected on the proportion of children with disabilities supported as the majority of the disabilities are often diagnosed at later stages in life. Hubs in urban areas had a reduction in the proportion of children with disabilities supported while hubs in rural areas had an increase in children with disabilities supported across the three years. Overall, the percentage of referrals for children with disabilities reduced during the pandemic, due to the large increase in referrals for financial support (see reasons for referrals section below).

Percentage of children with disabilities* supported			
	Children with disabilities		
	2016-17	2019-20	2020-21
Complete Sure Start	27%	24%	14%
Partial Sure Start	13%	20%	18%
Urban settings	25%	24%	16%
Rural Settings	8%	14%	13%
All hubs	19%	22%	16%

\* physical disabilities, learning disabilities, autism spectrum disorder, ADHD, ADD, and disabilities listed under "other" including brain injury, epilepsy, and hydrocephalus.

Ethnicity: The percentage of children recorded as 'white' remains consistent throughout the three timepoints and across CSS/PSS and urban/rural settings. The average is 85% of children recorded as 'white'. However, in rural areas there is a high percentage of "not stated" ethnicity status particularly in the years 2019-20 and 2020-21 with up to 20% and 34% of "not stated" ethnicity respectively.

### Referring agencies

The top 7 referring agencies were compared across years and across Sure Start and urban/rural settings.

Self referrals and community organizations are the top two sources of referrals in 2020/21, and both of these increased during the pandemic.

Top 7 referring agencies			
	All hubs		
Referring Agency	2016-17	2019-20	2020-21
Self referral	20%	17%	21%
Community organisation	7%	5%	13%
GPs/Nurse	11%	21%	11%
School	11%	12%	9%
Health Visitor	11%	9%	7%
Gateway	9%	5%	6%
SureStart	2%	1%	5%

Self referrals are higher overall in hubs with CSS and in urban areas, however hubs with PSS and hubs in rural areas have had a significant increase in self referrals across the three years.

Referrals from GPs/Nurse are consistently much more common in PSS than CSS. In all settings the percentage of referrals from GPs/Nurse significantly fell during the pandemic. For CSS and urban hubs, referrals from community organisations more than doubled.

Top 7 referring agencies						
Referring Agency	Complete Sure Start			Partial Sure Start		
	2016-17	2019-20	2020-21	2016-17	2019-20	2020-21
Self referral	33%	27%	28%	10%	11%	14%
Community organisation	12%	11%	24%	3%	2%	4%
School	12%	11%	9%	10%	12%	8%
SureStart	4%	4%	8%	1%	0%	3%
Health Visitor	11%	8%	6%	11%	9%	8%
GPs/Nurse	3%	10%	4%	17%	27%	17%
Gateway	7%	4%	3%	10%	6%	8%

Top 7 referring agencies						
Referring Agency	Urban			Rural		
	2016-17	2019-20	2020-21	2016-17	2019-20	2020-21
Self referral	25%	20%	24%	14%	17%	18%
Community organisation	10%	7%	18%	2%	2%	4%
School	10%	10%	9%	16%	18%	8%
GPs/Nurse	8%	17%	8%	12%	16%	9%
SureStart	3%	2%	6%	1%	1%	6%
Health Visitor	11%	8%	6%	12%	12%	10%
Gateway	7%	5%	5%	13%	7%	8%

### Reasons for referrals

The reasons for referrals is very mixed, with the top 7 being shown below. Between 2016-17 and 2019-20 there was a slight decrease in the percentage of all the top 7 reasons for referral except for counselling services for children/young people, which went up. The greatest change can be seen in 2020-21 where referrals for financial support increased from 5% of referrals to 22% reflecting the financial pressures on families during the pandemic. Looking in more depth at financial support, the greatest increases were in CSS setting (from 9% to 35%) and in urban settings (from 7% to 29%). Further indication of financial pressure on families is the increase of practical support (e.g. furniture/appliances) from 3% to 5% of all referrals and the greatest increase in CSS (from 5% to 8% and in urban settings (from 4% to 8%).

Top 7 reasons for referrals			
	All hubs		
Reasons for referrals	2016-17	2019-20	2020-21
Emotional and behavioural difficulty support for parents	6%	4%	3%
Practical support e.g. furniture/appliances	4%	3%	5%
Counselling services for children/young people	5%	9%	6%
Emotional and behavioural difficulty support for post primary school children	12%	9%	6%
Emotional and behavioural difficulty support for primary school children	22%	18%	13%
Parenting programmes/ parenting support	16%	15%	13%
Financial support	6%	5%	22%

Top 7 reasons for referrals						
	Complete Sure Start			Partial Sure Start		
Reasons for referrals	2016-17	2019-20	2020-21	2016-17	2019-20	2020-21
Emotional and behavioural difficulty support for post primary school children	6%	12%	4%	13%	22%	8%
Counselling services for children/young people	3%	8%	4%	4%	10%	7%
Emotional and behavioural difficulty support for parents	7%	7%	5%	4%	2%	3%
Emotional and behavioural difficulty support for primary school children	13%	12%	8%	22%	22%	16%
Practical support e.g. furniture/appliances	5%	5%	8%	2%	1%	4%
Parenting programmes/ parenting support	11%	9%	9%	14%	18%	16%
Financial support	7%	9%	35%	3%	2%	12%

Top 7 reasons for referrals						
Reasons for referrals	Urban			Rural		
	2016-17	2019-20	2020-21	2016-17	2019-20	2020-21
Emotional and behavioural difficulty support for parents	7%	6%	4%	4%	1%	3%
Emotional and behavioural difficulty support for post primary school children	8%	16%	6%	11%	6%	7%
Parenting programmes/ parenting support	11%	9%	8%	17%	12%	21%
Practical support e.g. furniture/appliances	4%	4%	8%	3%	1%	2%
Counselling services for children/young people	4%	13%	9%	5%	2%	1%
Emotional and behavioural difficulty support for primary school children	14%	16%	11%	16%	6%	10%
Financial support	6%	7%	29%	5%	7%	14%

### Hub decisions and support time

One indicator of hub activity is the percentage of referrals that are ‘accepted and signposted’. The proportion of cases accepted and signposted is slightly dipped across all hubs from 84% in 2016-17 to 82% in 2019-20. This change was not even across setting though, with the percentage in rural settings increasing by 6% and in urban areas decreasing by 4%.

There are increases across all settings in 2020-21, possibly related to the uptake in referrals for financial support.

Decision made by the hub			
Referral Accepted and signposted			
	2016-17	2019-20	2020-21
Complete Sure Start	86%	83%	91%
Partial Sure Start	82%	82%	87%
Urban settings	84%	80%	89%
Rural Settings	83%	89%	90%
All hubs	84%	82%	89%

Another helpful indicator is the timescale in which support is provided. Looking just at the percentage of referrals where support within a 4 week timescale was achieved, this had gone down from 92% in 2016-17 to 88% in 2019-20, with a percentage drop in all settings, but particularly in CSS. All setting saw an increase in support being provided within 4 weeks of referral during the pandemic, with an overall increase of 8%.



Support timescale			
4 weeks from referral to hub achieved			
	2016-17	2019-20	2020-21
Complete Sure Start	90%	80%	95%
Partial Sure Start	94%	92%	96%
Urban settings	93%	87%	95%
Rural Settings	91%	87%	95%
All hubs	92%	88%	96%

Overall, there are some notable differences in the pattern of referrals both between 2016-17 and 2019-20 and further significant differences during the pandemic. The patterns of work, types of challenges and volume of referrals all changed between 2019-20 and 2020-21. The percentages of referrals accepted and signposted and timescales within 4 weeks increased, a notable achievement in the circumstances.

There is value in considering hubs with complete and with partial Sure Start programmes separately and also urban and rural settings. The patterns of referrals differ. Some of that will reflect the local populations, but it will be useful to reflect on where differences are due to how referrals are made, by whom, and if some groups may be at risk of being more overlooked in some areas.

## Conclusion

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This review explored the key impacts of the family support hubs on families with children with disabilities, highlighting the challenges faced and the benefits they gain when engaging with the hubs. It also explored how hubs interact with early intervention services – hub members – and statutory services, with a focus on the referral system, service thresholds, including a comparison of referrals activity between hubs with complete and partial Sure Start programme and hubs in rural and urban settings. The data was collected through interviews with parents of children with disabilities, hub members representatives, and stakeholders. This was complemented by an analysis of the administrative data set from all hubs with information on the referral activity and profile of beneficiaries for the period 2016-2021.

For families, the hubs have been essential in providing access to a range of support, significantly contributing to their resilience and enabling them to better cope with the challenges of addressing the needs of their children with disabilities before, during, and after lockdowns related to the pandemic.

### Some of the benefits of the hubs for families include:

- **Timely and immediate available support:** families felt that they could contact the hub at any time and get immediate support.
- **Personalized support:** hubs take the time to listen to families and find solutions together based on their specific needs.
- **Community based:** for families, being a short distance from home and being aware of the issues in the community is an important aspect of the hub
- **Non-stigmatizing:** families feel comfortable in contacting the hub and are likely to return without hesitation if they need to.
- **Preventing escalation to tier 3:** hubs can provide access to a range of services that respond to specific needs of the family and in many cases prevents the need to escalate cases to other tiers.
- **Holistic approach:** hubs facilitate families' access to a range of services and encourage collaboration between services to address multiple needs with the minimum overlap in support.
- **Trauma-informed and trauma-responsive approach:** hubs work closely with families assessing their needs, encouraging and facilitating their access to services that will respond to their specific needs and traumas.

Hub members and stakeholders also identified benefits of the hubs to early intervention services including: strong local network and multi-agency approach; accurate and up to date information sharing; efficient referral system. On the strategic level, participants identified that the hubs are contributing to developments to benefit communities and improve services across Northern Ireland; collecting key data to inform policy and service developments; contributing to optimizing the early intervention system.

### Key challenges faced by families with disabilities included.

- **Lack of local services:** some families reported a lack of services/activities in their areas that are appropriate for their children. Sensory issues are common among other reasons.
- **Difficulties to access CAMHS and ASD services:** Long waiting lists, pandemic backlog, and short-term interventions that limit engagement with the child, have restricted children's access to these services.
- **Difficulties to keep children engaged in education:** with schools having difficulties accessing additional support to address the needs – particularly around behavioural and emotional issues – children with disabilities are having limited engagement with schools, often with reduced hours of attendance. This is also reflected in the administrative data where it is observed that schools are the sector with the third higher percentage of referrals, demonstrating how much it has relied on the support offered by hubs in the last five years.
- **Covid19 pandemic and lockdown restrictions:** families have struggled to manage their children's needs during and after lockdowns. Key issues were related to behavioural and emotional challenges, change of routines, stress, and anxiety related to the return of schools and activities.

### **Key support offered to families with children with disabilities**

Parents have highlighted the key types of support received that have significantly impacted their capacity to address their children's additional needs. This included: support and advice to raise awareness of children's conditions and how to address specific needs; emotional and behavioural management; practical and financial support; emotional support for parents. According to parents, receiving support in these areas was essential to help them to cope with the challenges related to their children's disabilities that have been aggravated by the difficulties to access specialised services due to the pandemic and lack of service capacity. This is also reflected in the administrative data where it is observed that emotional support for children and parents represented 28% of the reasons for referrals in 2020/21 and have been consistently high in previous years. The data also shows a sharp increase in demand for financial and practical support in the same year highlighting one of the key impacts of the pandemic on families.

### **Administrative data analysis**

The analysis of the administrative data was focused on identifying variations in referral activities between hubs with complete and partial Sure Start programme coverage, and hubs in urban and rural areas. Some of the key messages included:

- Self-referral is the top source of referrals across all categories of comparison and across the three years consistently.
- Hubs with complete Sure Start provision had a reduction in the proportion of children with disabilities supported, while hubs with partial Sure Start had an increase in providing support to children with disabilities across the three years.
- Hubs in urban areas had a reduction in the proportion of children with disabilities supported while hubs rural areas had an increase in children with disabilities supported across the three years.

- The three categories of emotional support (children and parents) make for the highest proportion of reasons for referrals. This indicates the high need for emotional support across all hubs and across all years.
- There was a sharp increase in demand for financial support and a slight increase in demand for practical assistance in the pandemic year.

## Recommendations

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### Recommendations from participants

**Improve hubs' reach towards BAME communities:** It was highlighted the importance of progressing hubs' responses to engage with families from BAME backgrounds. Although this is raised as an overall need for hubs' development, different regions and trusts face different challenges that should be addressed locally. For example, in some regions, hubs have difficulties in accessing funding for interpreting services and communication is a major barrier for hubs to engage with non-English speaker families. Other development needs may include increasing availability of services that are compatible with specific cultural and religious needs of BAME communities, and raising awareness of local services on how to address the specifics of BAME communities present in their locality.

**Improve consistency of the referral system across hubs:** it was noted that the referral system is working well but it is heavily reliant on the relationships between professionals and more informal communication modes. Participants have highlighted that the level of information and the format of the referrals can vary significantly from one hub to another. It is suggested that regular collective discussion of cases and decisions on referrals are adopted across the hubs and that the referral form be standardised to ensure that the essential information about the case is provided on the first instance. To complement this, we highlight the relevance of the "10 Standards" tool already implemented in the hubs, to ensure the consistency in approach across all hubs, particularly the section 7.1 on referral pathways. This could further support hubs to reflect on and implement the above recommendations as well as encourage a continuous self-evaluation and improvement of the referral system.

**Improve access to long-term funding to allow hubs to deliver key services:** parents, hub members, and stakeholders highlighted the importance of hubs having the capacity to deliver key services that could further contribute to engagement with families and facilitate a more in-depth assessment of their needs. Families also suggested hubs to engage with services that run specific activities - such as sensory and arts and crafts - for children with disabilities particularly in areas where they have limited access to group activities that are adapted to their specific needs.

### SCIE's recommendations

**Improving the continuous evaluation of the model:** a significant and detailed data is being collected from hubs every quarter generating relevant reports that have been key to demonstrate achievements and challenges faced by the hubs. To improve the existing

continued evaluation system, we suggest that a proactive approach to analysing this data is taken to draw comparisons between different aspects of the hubs across time, across regions, and across hubs with different hubs set ups – such as programmes available, funding configuration, rural/urban settings, deprived/affluent areas. This could provide insights on the variations in hubs activities according to their context and raise important questions to feed future strategic developments.

**Develop further research to create indicators and track cases that are at the high end of tier 2 threshold:** tracking these cases can further demonstrate the impacts of the hubs in preventing the escalation of cases to tier 3 services. This would be key in understanding how hubs are (or are not) meeting one of the key objectives of the model and would provide insights about how to increase the effectiveness of the support offered to families that have complex needs but also need community-level support.

**Develop further research to analyse the economic impacts of the hubs:** creating indicators for complex tier 2 cases (as outlined above) would allow hubs to track the number of cases that have potentially been prevented from escalation to tier 3 support. This would also allow the hubs to map the range and length of support offered to these families, and to compare the costs of intervention received in level 2 against the cost of level 3 interventions if the case had been escalated.

**Create a collective of Hub coordinators:** hub coordinators have provided positive feedback to the workshop and showed appreciation for the opportunity to meet other coordinators and discuss common challenges and good practices. We suggest that a collective of hub members is created to organise events that could provide coordinators with the opportunity to share concerns, find collective solutions, and align practices and principles. This would also be key to providing hub coordinators with informal support from their peers as well as providing a space for training and professional development.