

'How can we enhance your life and how can we help you?':

An In-Depth Evaluation of the Family Liaison Service

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Executive Summary

*[The Family Liaison Service]
made a tremendous
difference in our lives, not just
in [child]'s but the entire
family.
(Family member)*

- ★ The following report outlines the key findings of an in-depth evaluation of the Sparkle and Integrated Service for Children with Additional Needs Family Liaison Service.
- ★ The Family Liaison Service offers emotional support, liaison service, information & advice, and training and education for families with a child or young person with a diagnosis, or undergoing a diagnosis, of a disability and/or developmental difficulty.
- ★ This evaluation aimed to explore the experiences and views of both *families* accessing the service and *professionals* involved in the care of children and young people with disabilities and/or developmental difficulties, to determine whether the service is meeting it's original aims and assess it's impact.
- ★ Interviews were conducted with families and professionals between March and July 2020. The evaluation also draws on data collected by the Family Liaison Officers regarding the number of contacts made, and feedback provided following events and workshops.

- ★ An inductive thematic analysis of the interview transcripts identified two key themes: accessibility of the service, and importance of service provider skills. Deductive coding of the transcripts was also used to explore whether the service is meeting the service objectives.
- ★ The Family Liaison Service was highly praised by participants for its uniqueness, accessibility and holistic approach. It was concluded that both families and professionals benefited from the service and recommendations for service maintenance and development were made, such as ensuring the visibility and awareness of the service within the Children's Centres.

The fairy godmother. She waves her magic wand and voila, she's got it [...] I've been nothing but impressed with the professionalism and just how kind the staff are.
(Family member)

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Introduction

In many areas, the concept of a 'Liaison Officer' has developed over time as a voluntary and independent role, which has resulted in a wide variety of models using the term. Previous work by Olley et al. (2017) identified the key roles of liaison workers in child and family health services. This included:

- ★ Facilitation of professional information sharing between services;
- ★ Providing continuity of care between services and for whole families;
- ★ Maintaining detailed knowledge of complex family situations.

Best practice guidance talks of 'family empowerment', increasing the independence of parents to seek out services that they would find useful in their specific circumstances. Parents are known to frequently rely on informal sources of support and information (Wodehouse and McGill, 2009). This can also be a strength of a system such as a family liaison service, where the knowledge of other parents facing similar challenges can be utilised.

Key factors limiting access to services for children with complex disabilities identified in the American literature (Vohra et al), include:

- ★ Eligibility;
- ★ Availability of services;
- ★ Appointment delays;
- ★ Difficulties obtaining information about services.

Meanwhile in the UK, Wodehouse (2009) found during interviews with 13 mothers of children with intellectual disabilities that access to support services usually required a formal diagnosis of a neurodevelopment condition. Participants also reported difficulties obtaining relevant information, poor relationships with professionals and a lack of respite provision.

Given the above issues, Sparkle developed the Family Liaison Service (FLS). Sparkle is the charity partner of Serennu, Nevill Hall and Caerphilly Children's Centres and directly supports children and young people (CYP) with disabilities and/or developmental difficulties (DDD), and their families, living in Gwent, South Wales.

What is the Family Liaison Service?

The FLS offers an extensive support and information service for families with a child or young person with a diagnosis, or undergoing a diagnosis, of a disability and/or developmental difficulty. The service is multifaceted, including emotional support, liaison service, information and advice, and training and education. The liaison service is offered across various domains, broadly including liaison between families, liaison between families and professionals from statutory agencies, and liaison between families and national organisations.

The FLS service, first introduced by Sparkle in South Gwent in 2014 (see figure 1), is delivered by Family Liaison Officers (FLOs) based at three Children's Centres: Serennu Children's Centre* in Newport, Nevill Hall Children's Centre in Monmouthshire, and Caerphilly Children's Centre (see figure 2). The FLOs in Serennu and Nevill Hall are funded by Sparkle, while the Caerphilly FLO is funded by the Regional Partnership Board, through the Integrated Service for Children with Additional Needs (ISCAN).

*Serennu is a unique, integrated Children's Centre where health, social care and leisure services are colocated and work together to provide the best possible care for children and young people with disabilities and/or developmental difficulties. Serennu benefits from facilities such as a hydrotherapy pool, sensory spaces, ADL suite and 3D MediCinema. Social Services and Sparkle are based at Serennu, as well as health services including paediatric clinics, physiotherapy, speech and language therapy, occupational therapy, audiology services, children's community and specialist nursing, and many others.



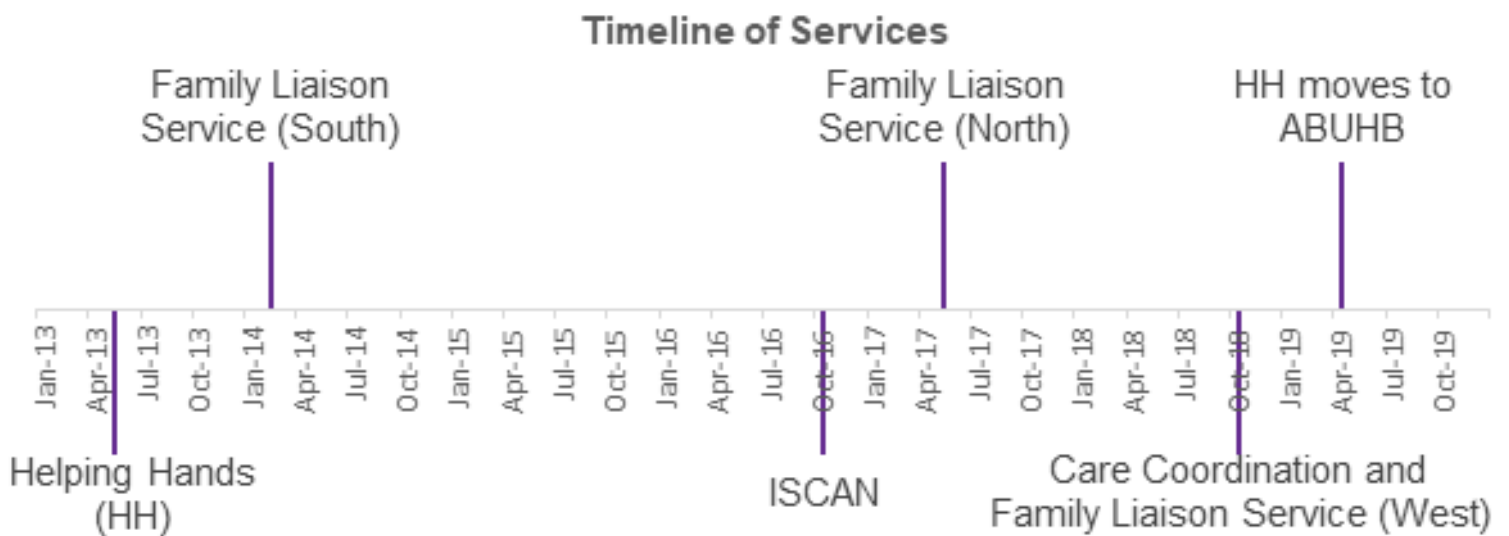


Figure 1: Timeline of services, including the introduction of the Family Liaison Service. (NB. Helping Hands, originally delivered by Sparkle before moving to ABUHB, is a psychology service in Gwent for families with children with additional needs; ABUHB stands for Aneurin Bevan University Health Board; ISCAN (Integrated Service for Children with Additional Needs) is a single point of access referral pathway for the children; Care Coordination is a service which supports families to organise their child's complex health and social care. All of these are funded by the Integrated Care Fund in Gwent.)

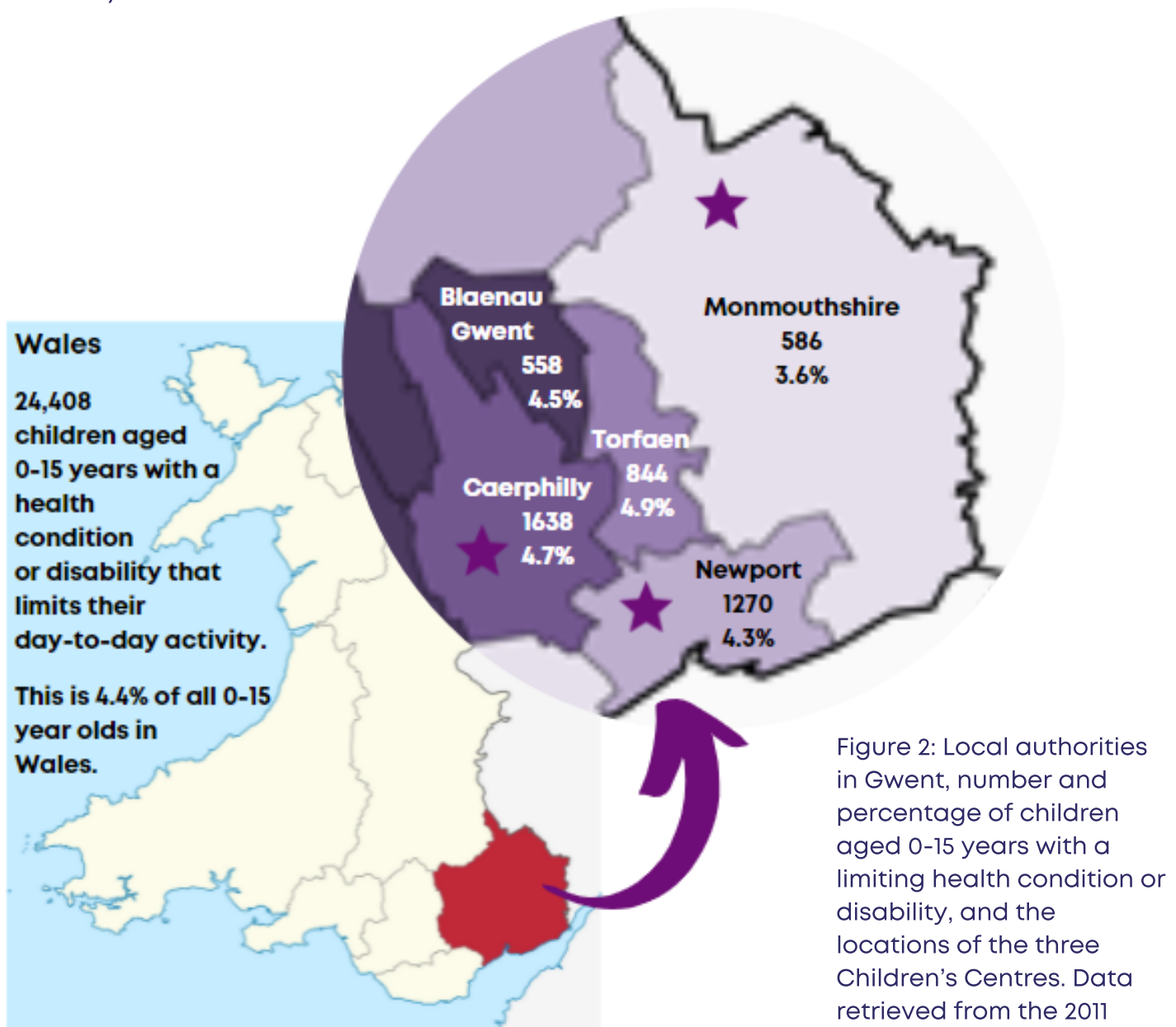


Figure 2: Local authorities in Gwent, number and percentage of children aged 0-15 years with a limiting health condition or disability, and the locations of the three Children's Centres. Data retrieved from the 2011 Census.

As this service has evolved, many components and objectives have emerged (see figure 3), all of which reduce stress among families and empower parents/carers at an extremely challenging time in their lives. A crucial aspect of the service is that it is a *free, walk in service*. Parents and carers may be referred by a professional, or they can simply speak to the FLO at any time without requiring a referral.

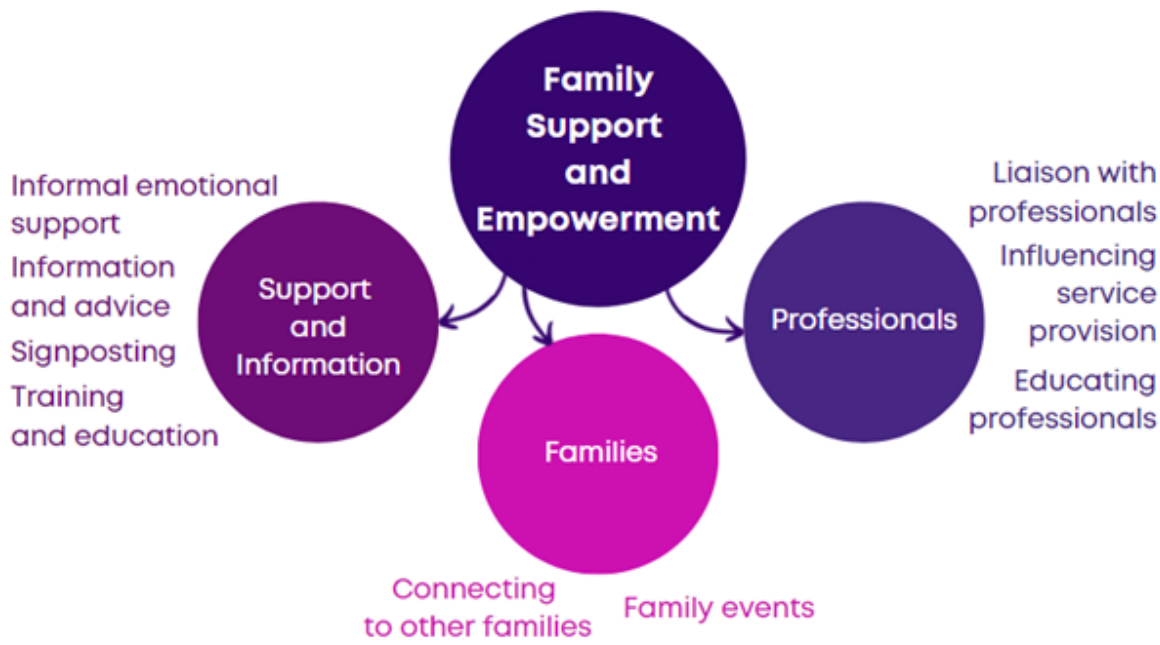


Figure 3: The components and objectives of the Family Liaison Service.




Common Support Requests	
	From families <ol style="list-style-type: none"> 1. Support for child's anxiety 2. Advice on managing challenging behaviour 3. Information surrounding transition, for example from primary to secondary school 4. Financial support, such as to identify and apply for grants and benefits 5. Support to explain puberty to their child 6. Post diagnosis support, particularly for ASD (possibly because there is little medical intervention required following an ASD diagnosis, unlike other disabilities/developmental difficulties)
	From health and social care professionals <ol style="list-style-type: none"> 1. To liaise with families they are working with, signposting to services and providing a point of contact 2. Requests for sleep and toilet training resources 3. To provide informal emotional support for their families
	From schools and education professionals <ol style="list-style-type: none"> 1. Information regarding the support available for children at school 2. Support with health and safety at school 3. Advice and resources on bullying 4. Support and advice for smooth transitions

Figure 4: Common requests for support received by the Family Liaison Officers, from families, professionals and schools.

Workshop	Description	Provider
Exploring Behaviours that can Challenge	Understanding behaviours that can challenge in children with additional needs and ways to respond.	Helping Hands
Supporting Anxious Children	Sharing ideas on how to support CYP with anxiety and worry.	Helping Hands
Supporting Transitions Back to School	Ideas to help CYP with transitioning back to school.	Helping Hands
Sleep Workshops	Understanding and supporting children's sleep.	Cerebra
Meet the Serennu Team	For professionals who wish to refer into services at Serennu or gain a better understanding of each service.	Sparkle
First Aid Training for Parents/Carers	Paediatric first aid for parents and carers, covering responding to emergency situations such as choking and scalds.	1 st Aid Services, paid for by Sparkle
Body and Behaviour Changes	What to expect through puberty and beyond.	Helping Hands
Intimate Care Plan & Personal Hygiene Skills	For those who support CYP with a disability or developmental difficulty.	Helping Hands
Supporting Siblings	Reactions of brothers and sisters, talking to children about their siblings' disability, preventing problems with relationships, and managing needs.	Helping Hands

Figure 5: Workshops for carers and interested professionals organised by the Family Liaison Service. (NB. CYP - children and young people. Helping Hands - psychological support team in Aneurin Bevan University Health Board. Cerebra - charity supporting children with brain conditions)

Research Aims

Although feedback on this service has been positive since its inception, no in depth evaluation of the impact of the service has been conducted. The current study therefore aimed to address this by exploring the experiences and views of both families accessing the service and professionals involved in the care of CYP with DDD, to find out whether the service is meeting its original aims and to assess the impact the FLS has on CYP with DDD and their families.

Method

Data Collection

Due to the uniqueness of the service, a mixed methods evaluation was conducted. This included descriptive statistics regarding the number of families reached, feedback from previous workshops organised by the service, and qualitative interviews with families who have accessed the service and professionals working at the Children's Centres from which the service is delivered, as well as professionals from social care and education. Semi-structured interviews were used to allow participants the freedom to express their views on the service; the flexibility to follow topics raised by participants, where appropriate and relevant; and to provide reliable, comparable qualitative data. Interview topic guides were created for family members and professionals, comprised of a list of topics and open-ended questions to be covered during the interview (see Appendix A). Data collected by the FLOs regarding the number of contacts made and events held in financial years 2019-2020 and 2020-2021 was also accessed.

Participant Recruitment

A purposive sampling approach was used for selecting a sample most appropriate for the purpose of this evaluation, and recruitment ceased when data saturation was reached. Informed written or verbal consent was obtained from all participants.

Family Recruitment

Between 16th March and 6th July 2020, 37 families who had accessed/were accessing the FLS at Serennu Children's Centre or Caerphilly Children's Centre were invited to participate in a telephone interview to share their experience of accessing the Service. Family members were contacted via telephone and emailed an invitation letter, information sheet about the evaluation and a consent form. The FLO at Caerphilly Children's Centre also posted on the Family Liaison Facebook page to make families aware of the opportunity to share their feedback.

In total, 10 family members participated in a telephone interview (three at Caerphilly and seven at Serennu), between 20th April and 12th June 2020. At the time of this evaluation, the FLO post at Nevill Hall Children's Centre had been vacant for six months. Subsequently, family contact details were not available for those who had previously accessed the service.

Professional recruitment

All health and social care staff based at Serennu Children's Centre and Caerphilly Children's Centre (approximately 145; 113 at Serennu and 32 at Caerphilly) were invited via email to participate in a telephone interview to share their views on the FLS. Recruitment posters were also put up at the Children's Centres. In total, 14 professionals participated in a telephone interview 12th March and 21st July 2020 (10 at Serennu and four at Caerphilly). Professionals interviewed were from health, social care and education. Professional roles included Occupational Therapists, Physiotherapists, Health Visitors, and Additional

Learning Needs Coordinators. Professionals from Nevill Hall Children's Centre (30) were also invited to take part in a telephone interview; four participated, however their responses will be summarised separately to the rest of the data due to a FLO not being in post at the time of the evaluation.

Ethical Approval

This service evaluation was approved by ABUHB Research and Development Department, Research Risk Review Panel on 5th February 2020.

Data Analysis

Interview transcripts were analysed using qualitative data analysis software, NVivo (QSR International). Thematic analysis was used as a method for identifying, analysing and reporting patterns within the data (Braun and Clarke, 2006). Inductive thematic analysis was used to allow for categories to evolve from the data and facilitate the interpretation of themes supported by the data, and deductive thematic analysis was conducted using the components and objectives of the service.

Findings

Descriptive Statistics

Financial year 2019-2020

	Children's Centre		
	Serennu	Caerphilly (Family Liaison Officer in post October 2019-March 2020)	Nevill Hall
Contacts made with the Family Liaison Service	2,218	300	Family Liaison Officer not in post
Attendees at information days* (families)	53	-	
Attendees at workshops (families and professionals)	46	43	

*Information days are organised by the Family Liaison Service and attended by multiple organisations, such as local authorities, third sector organisations and Disability Sport Wales. Families are able to discuss any concerns with the relevant organisation and gain valuable information and advice.

Financial year 2020-2021

	Children's Centre		
	Serennu	Caerphilly	Nevill Hall (Family Liaison Officer in post September 2020- March 2021)
Contacts made with the Family Liaison Service	1,158	789	576
Virtual support groups	10	-	1
Attendees at workshops (families and professionals)	No workshops or events took place due to the Covid-19 pandemic.		

Themes

An inductive thematic analysis of the interview transcripts found two key themes: *accessibility of the service*, and importance of *service provider skills*. These are discussed below. Interview participants who were family members of a CYP with DDD are identified by 'F' and a participant number, and participants who were professionals are identified by 'P' and a participant number. It is also indicated whether participants were located in South Gwent (S) or Caerphilly County Borough (C).

Accessibility of the Service

Importance of Service Provider Skills

Accessibility of the Service

The accessibility of the service is one of its unique aspects, as families do not require a referral to access support and there are no strict criteria as to whom is able to access the service; the FLS is open to any family with a child diagnosed, or undergoing an assessment for, a disability or developmental difficulty. Participants were made aware of the service from sources such as schools, health and social care staff at the Children's Centres, and word of mouth. Even if families are not made aware of the service via a health, social care or education professional, their presence at the Children's Centres allows families to access support straight away.

The **accessible** nature of the services means there are no waiting lists; families can receive support straight away, when they most need it.

“Also that they have a point in (sic) contact, it's no pressure within the family liaison service. They might need [the service] this month and not need [the service] then for another six, seven months, but no, they can just phone up or email and they'll get a response rather than needing to go back on a waiting list for something.” (PC1)

The **visibility and physical location** of the FLOs was a frequently raised issue in the interviews. Having someone present and accessible at the Children's Centres seems to be very beneficial, as both families and professionals are more likely to approach them for help.

“Yes, and just being a visible contact that families can drop in, I think that's really nice, that they see them around when they're here, rather than tucked away in an office. I just think it's a visible presence and that just makes them more approachable and they might suddenly think,

I actually just popped in on the off chance, because I didn't know where to turn. I just didn't know where to turn with issues I was having with my son. I just thought, ‘I wonder if anybody is here that I could just sort of have a chat to.’ When I walked in I went to reception and they said, ‘Yes, there probably is somebody you can have a chat to. She's probably here now.’ I wasn't expecting that. She went along and she found [name of FLO].
(FS1)

‘Yes, I was going to ask [name of FLO] about that, but I haven't got around to it.’ They will ask because they've just seen them.” (PS8)

Professionals all agreed that the FLOs should be located in areas that are accessible to families attending the Centre, and suggested when a FLO does not have a visible presence at a Centre it has a detrimental effect on the service (in Serennu, the FLO has a desk in an open waiting area, whereas in Caerphilly this is not possible, and the FLO has an office behind the main reception area).

“I think where [name of FLO] is, she's tucked away. She's not really very visible. [...] I think that could be improved is making her a little bit more visible, a bit more easy for families to get hold of really.” (PC3)

Importance of Service Provider Skills

It appears from the interviews that finding **the right person** to deliver the FLS is crucial to the success of the service. Particularly, having someone from a non-clinical background seems to help put people at ease.

“She was so warm, so friendly and so relaxing. It was like sitting with your friend having a coffee [...] Whereas if it had been a doctor, or if it had been another health professional you might have thought, ‘Hang on there's nothing wrong here,’ and gone a little bit on the defensive. Because we'd sat there and taken that time and I opened up to her. She did it in such a sensitive way it obviously felt the right time and the right way of being able to say it.” (FS1)

The FLO being **outside health, social care and education** made them appear more approachable to families, and participants commented on not being afraid to ask questions they may not have asked other professionals.

[Name of FLO] really helped explain that without you feeling stupid to ask. Whereas with school there's a lot of abbreviations and they just assume that you're quite up to date with all the education system.

(FS1)

Whilst FLOs are not healthcare professionals, they work closely with them at the Children's Centres and have a lot of in-depth knowledge about the various processes and systems in place. This puts them in the perfect position to **liaise between families and professionals**, for example to gather information.



“While I was redeployed [name of FLO] emailed me and said, ‘I’ve got a family who are really struggling to support their child to shave. Do you have any ideas and resources?’ I was able to just put a quick email together with some ideas and some signposting and then she was able to forward that on to the family. I think that’s hugely effective. It’s providing the support when it’s required at the right time pretty quickly. [...] Parents might not know to contact OT for that kind of information, but [name of FLO] knows” (PS10)*

Professionals commented on the FLOs’ **extensive knowledge and good connections with health and social care** having a positive impact for families; families have a contact who can help them find the support they require at the right time.

“It’s having a constant friendly face there, I see the family liaison role as a positive role it’s always, with us we’re going out, we’re doing the work with the children, with family liaison it’s like ‘Okay, how can I help you?’ And if they’ve got any worries then it’s signposting and it’s a positive station place to go.

Not that we’re negative, but it’s all about ‘how can we enhance your life and how can we help you?’ And I think that’s really important and it’s constant; they’re always around.” (PS2)

FLOs are a **neutral third party**, who can help resolve any issues that arise between families and professionals.

“We had a little issue with another service. I had emailed her asking, ‘Actually I don’t know whether this is something you can ask but can you help me? I don’t know what to do.’ She was marvellous, she acted like the middle person” (FC3)

Communication from the FLOs was highly praised during the interviews.

“It’s better than good. [...] they always get back to you promptly. It’s always courteous. They always gone above and beyond anything with trying to contact you and help you. It’s always extremely helpful. It’s always a lovely personal service. You always feel like you’re talking to a friend.” (FS7)

Some professionals suggested that, further to the FLO being approachable, neutral and friendly, having someone in post with **personal experience of disability** was beneficial for families. The FLOs have been described as 'role models' and it was thought that their personal experiences helped them to understand how families were feeling (the current post holders have family experience of disability).

...and because I've been in the position of a parent with difficulties, I can truly appreciate how hard it is when it's new.

(Family Liaison Officer)

"I think she's a very good role model and it does actually show, especially when families don't know, they've never experienced disability before, and this is their own child. [...] I know we've had really positive feedback from a family to say that she's given [them] hope."
(PC3)

Families also praised the FLOs for using a **whole-family approach** and including the CYP in discussions, which they did not feel always happens when accessing other services, and engaging with them.

"It was really, really nice, because like I said when you got to go for other services and things, sometimes they can talk over your child even though it's about them. Whereas she doesn't do that she involves everybody." (FS1)

The FLOs are able to build up relationships with the families that access the FLS, therefore providing a personal and holistic service. However, this meant that some professionals felt it is important for the post holder to remain as consistent as possible to maintain these relationships.

"I think it'd probably be a role that's quite important that somebody stays in post. I don't think it would work so well if they were continually changing because I think families quite like to ring up and build a relationship with a person."
(PC3)

Achievement against objectives

Deductive coding of the transcripts was used to explore whether the FLS is meeting the objectives outlined in Figure 3. Overall, it was found the service **supports families and empowers them** to have a positive impact on their own lives.

...because someone saw you, you mentally feel stronger [...] You felt taken on board. That makes you mentally stronger, like 'I can do this'. Mentally you feel stronger in that way. Physically, it sort of recharges you a bit.

(FS5)

Support and Information

The FLS offers **informal emotional support**, by providing parents and carers with a listening ear, an opportunity to off-load their worries and anxieties, and somewhere to turn when they need someone understanding to talk to. The support offered by the FLOs is person-centred and can be tailored to the individual need on a case by case basis.

“When I first heard about them, I was willing to give anything a try. Even on the first appointment, it was just so nice just to be heard, because you talk to your family and friends, and unless they've got a child who is on a spectrum, no one really can understand what you're going through. [...] For me, personally, it was a huge relief, and it was a huge help. It was a huge relief, because you can vent and you can express your anxieties, your concerns, and they understand, and sometimes, they can give you a bit of positive input on how to help you and your family.” (FS5)

The following extract is taken from an interview with a **family member** who, with the support of the FLS, **recognised the importance of looking after themselves** as well as addressing their child's needs.

"She's really sensitive, mind, in the way she approached it. She said, 'It seems like you're under a lot of strain, because you obviously can't tell me this without getting upset.' She said, 'Obviously, you're going to be upset, because it's your child and everything,' but she said, 'It seems as though it's affecting you a lot deeper. With the stress of it all maybe we've got-- If [name of child] goes down the route of the ISCAN system you'll then be able to access counsellors to help yourself as well. Be able to get things off your chest. Because it sounds as though there's a lot you've been trying to keep the lid on, as well as dealing with all of this.' I said, 'Yes, I suppose I have.' It was almost like she recognized that before I did, because I think when you're in it you just keep going, don't you? You just think, 'I've got to try to keep this together. We're a family. I've got to just keep going and keep the house going. Got to keep the kids going to school, got to try and keep dealing with what we don't know what's going on with [name of child] right now.' It just all gets on top of you and you just don't see. You take a backseat to all of it. You're the last one on the list. Whereas, she summed it up, she said, 'Because at the end of the day if you're not 100%, how can you give 100% to your family?'"
(FS1)

The FLS is also a source of **extensive information and advice** for families; they have provided parents and carers with practical advice on how to tackle different issues they are facing as well as sharing sources of information tailored to the children's needs.

"She's given me support on how to help my child while she's having meltdowns, support with links, family therapies like talking to other people and talking to other families, sporting events that she's told me that we can access, things going on at the centre" (FS2)

It was mentioned during the interviews that the **newsletters** sent out by the FLOs and the information areas they maintain at the Children's Centres were particularly useful sources of information.

“I just find it was a very good network, you found lots and lots of information while you were there, you [have] got good notice boards and good things. As [name of child] was going in for appointments, I used to always have a good look round of whatever was there.” (FS7)

One family member commented on how the newsletters could be improved by including **more information about other organisations** that can offer support.

“We've got quite a lot of very good charities in this area that aren't included at all in those newsletters. [...] I would like Ready Steady Go and Magic, and Building Bridges, and QB, those sorts of groups to be included within that. We've run quite a lot of events. There's no reasons why families can't access all of them if they want to and having a centralized system for access would be helpful.” (FS4)

The FLOs are able to **signpost** families to other sources of support, such as leisure activities suitable for their children, as well as putting them in contact with other professionals and organisations which might be able to help their child.

“She's offered support for [name of child] with colouring therapy because she loves colouring, my daughter, absolutely loves colouring. She'll talk to her, she'll ask her how she's feeling, what she likes to do, and stuff like that really” (FS2)

Various training courses and workshops are organised by the FLS, including Paediatric First Aid and workshops on managing challenging behaviour, anxiety and sleep problems. Feedback from previous courses and workshops is presented below:

Gave a really good understanding of anxiety to be able to explain to [my] daughter what is happening and things to help her cope with daily life.
(Parent)

I am going to implement [the] distraction technique, breathing [and] calming routines, use the step process towards a goal. Try and frequently confront anxiety to make it less of an issue.
(Parent)

Families

The FLOs seem to be very good at creating an inclusive community for families of CYP with DDD. Both families and professionals commented on the opportunities the FLS creates for **parents and carers to connect with other families** and to build their own support networks.

“It was almost like a really good sharing group that you would almost have a network of specialized things from other mothers that you think, ‘I’d use that. I could pass that information on to someone else.’ It wasn’t necessarily just all professional stuff. It was information that, even down to say, what was the perfect socks without seams in and things like that. If you had a child who was touch sensitive, but then it was also about getting the taxi to school for your child or getting the speech therapist, everything to do with the medical side, but as well it was proper holistic approach.” (FS7)

It was also mentioned by families that they **felt welcome and included** by the FLOs, particularly at events organised by the FLS for families.

It's the inclusiveness, that everybody is welcome. It doesn't matter what's going on with your family, you could all go along. Nannies, grandads, everybody and it's almost like the-more-the-merrier.

(FS1)



Professionals

One of the objectives of the FLS is to liaise between families and professionals, and act as a conduit for information between the two. This results in significant **time saving for professionals**, who previously felt they needed to find additional sources of support for their patients in addition to their clinical work.

Just having that time, somebody who can actually use that time to either know the information already or find out the information. It definitely allows us to focus on our clinical work.

(SC2)

Professionals also commented on how useful it is to work with a professional who takes a more general and holistic view of individuals and families, rather than just a specific area of the child's disability or development.

"Just I suppose the general thing like I said about having someone who is looking at things with more of a general overview rather than a specific profession. They might have a bit different perspective to us."

(SC4)

Support from FLS made families feel 'seen' and their connection with health and social care

professionals enables FLOs to influence service provision by being **a 'voice' for families**. One professional recounted a time a FLO made a tangible difference in a family's life, by making a small change that had a massive impact on an individual.

"I had a family who said they couldn't access the Christmas party I think it was, or Halloween, one of the two...and I said why because all of the children are supposed to access it and their child was absolutely obsessed with food and cake, and the cake stall had all the cakes out in front and they said as soon as that child clocks those cakes they will be trying to get them. So I just went up to [FLO] and said the situation, mum can't come because the cakes are at grab level what can we do, and within half an hour she'd organised so that the cakes now get displayed on the table behind and there's pictures of cakes out in front. I went back and I told the mum and she cried, because she couldn't believe that a whole system had been changed just for her child. She said that nowhere has anybody done that sort of effort, so it was life-changing for that mum." (SS2)

The FLS has also been beneficial in **educating professionals**, who are also able to access the training courses and workshops previously mentioned. It is part of the Sparkle philosophy that these are joint training events, as professionals can learn as much from the parents as the professionals delivering the training.

"I know paediatric trainees have attended some of the managing behaviour courses and things that they, I think, the Family Liaison team organised. That are then led by the psychologists and others, and things. They've appreciated those, and found those helpful."
(PS9)

The following feedback is from a professional who attended a workshop organised by the FLS:

Very practical for both parents and professionals, in how as a professional we can help parents and young people.
(Professional)

North Gwent FLS

Due to there not being a FLO in post at Nevill Hall Children's Centre at the time of the evaluation, families in North Gwent were unable to be invited to participate. However, interviews with professionals based at Nevill Hall demonstrated the need for the service as they were able to comment on the difference made by not having a FLO in post.

...moving up to Nevill Hall, there was a definite gap in provision not having the family liaison there. When [the FLS] did start up in Nevill Hall, it was a hallelujah moment I have to admit [...] It's obviously challenging at the moment because we haven't really got anyone in post.
(PN8)

Professionals in North Gwent reflected what others had said about how valuable the FLOs are as a source of information for both themselves and families and how they act as link between families and professionals.

“I think having a tangible link into health really and a named person who they can get to know and who they know they can just pick up the phone to or send an email to and get an answer from because I think a lot of the time parents feel frustrated because they're trying to find help from someone and often a lot of us are very busy and can't provide them the help that they need. It's almost like an extended family member but who is incredibly knowledgeable and helpful. [...] I find them brilliant for those kinds of difficult questions about things that go on in the community that we might not be aware of, that they're excellent at tapping into extra resources or thinking outside the box really of how to support families with difficult non-health issues.” (PN2)

It was also commented that the FLS **relieves time pressures on professionals**, who therefore have more time to attend to their own case load.

“From a professional point of view, a lot of the signposting we would take on because you wouldn't just want to leave families in the lurch, and so also, that saved us a lot of time not having to do that which time we could spend and do more clinical things really because let's face it, there's lots of demands on our time isn't there? That was really valuable.” (PN8)



Overall, these responses from professionals who did not have access to a FLO at the time of the evaluation evidences the need of the

service, for both families and professionals. A new FLO was appointed in North Gwent in September 2020.

Recommendations

Based on the findings of this evaluation, the following recommendations for service development are made:

The main recommendation to come out of this evaluation is for the **FLS to continue**, as it has clear benefits for both families and professionals.

The presence of FLOs *relieves pressure on health and other professionals*, by providing family support, education and signposting.

FLOs should continue to be given the *flexibility* within their roles to offer family-centred, holistic support.

It is crucial when appointing a new FLO that the *essential characteristics* highlighted above are part of the person specification – excellent written and verbal communication skills, patient empathic listening, eagerness to learn about services and childhood conditions, and not a professional from a health, social care or education background.

It is recommended the *FLS be regularly promoted* amongst professionals in health, social care and education to ensure awareness and understanding of the service, and how families can access it. This could possibly include physical reminders of the service, for example leaflets that can be given to families during appointments.

Professionals felt the service could be improved by the *FLOs being more visible* within the Children's Centre. It is recommended that, wherever possible, FLOs are physically located somewhere immediately accessible to families, such as reception or waiting areas, rather than in an office.

Professionals in North Gwent were able to comment on the noticeable difference the FLO position makes at the Centre, as the North Gwent post was vacant at the time of this evaluation. It is recommended long periods of vacant posts within the FLS is avoided as much as possible to *ensure continuity* of the service.

Conclusions

The findings of this in-depth evaluation suggest the FLS is a unique service whereby families of children with disabilities, or undergoing a diagnosis or assessment for a disability, receive person-centred, holistic support. The FLOs adopt a whole-family approach and facilitate a network of support and information, connecting families, other support service providers, and professionals from health, social care and education. By so doing, families not only feel heard and supported, but the FLOs significantly reduce the burden for professionals supporting these families.

The service is accessible to all families, with no referral process or waiting list to delay their access to support. However, it has been suggested to improve the service by making the FLOs more visible within the Children's Centres. Finding the right people to deliver the service seems to be imperative to its success. Those who participated in this evaluation felt a FLO should be a non-clinical third party, who is friendly and approachable. It was also suggested that where feasible, drawing on their own family experience of disability enhances the support offered by the FLOs.

The FLS makes a real difference to both families and professionals. The

service saves a significant amount of time for health professionals in particular, who no longer have to search for sources of information and support for the families they work with, allowing them to focus on their clinical work. It also improves communication between families and professionals. For families, the service is empowering and many participants commented on how relieved they felt after being listened to by a FLO. Families have also experienced tangible benefits via the FLS, for example by developing skills through courses and workshops organised by FLOs.

It is clear from this evaluation that the FLS is extremely beneficial and should be continued and promoted widely, to the benefit of families and professionals working with them.



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Appendix A

FLS Evaluation: Interview Topic Guides

On behalf of Sparkle, I'm evaluating the FLS to find out what impact it has on children and their families who access this service, and professionals. I'm interested in hearing your views on the service. Everything that you share during this meeting will be anonymised, so your name will not be used in any reports or dissemination materials.

Please speak slowly and clearly so that the recorder can pick up what you say, and if there are any questions you would rather not answer we can move on to the next. If you would like to take a break at any point please let me know and I will stop the recording.

Parents

1. How did you hear about the Family Liaison Service?
2. What did you hope to get from accessing the service?
3. What has your experience of the service been like?
(support/advice/info/signposting)
4. How satisfied were you with the service?
5. How would you rate the quality of the service?
6. How do you feel after accessing the service?
7. Is there anything that could be improved with the service?
8. Any other comments?

Professionals

1. Could you start by telling me a bit about your role please?
2. Please could you explain in your words what the FLS is and what it offers to families?
3. How does your role link-in with the FLS?
4. On average, how many families per week would you refer to/make aware of the FLS?
5. What are some of the reasons that you would refer to/make families aware of the FLS?
6. What do you think the benefits are to families who are accessing the FLS?
7. Are there any specific examples of how the FLS has benefited families that you would like to share?
8. What do you think the benefits are to professionals working alongside the FLS?
9. Can you think of anything that could be improved with the FLS?
10. Overall, how beneficial do you think the FLS is to children and their families on a scale of 1-10 (1 being the lowest, and 10 being the highest)?

Appendix B

“Evaluating the impact of the Family Liaison Service on families and professionals” Parent Information Sheet

1. What is the purpose of this research?

The purpose of this research is to evaluate the Family Liaison Service (FLS). We would like to invite you to participate in this research if you are currently accessing, or have previously accessed, the FLS at Serennu Children’s Centre, Nevill Hall Children’s Centre or Caerphilly Children’s Centre. Sharing your experience and views will help Sparkle to identify any benefits or problems with the service that will be used as evidence to develop or improve the FLS going forwards.

2. What will my participation involve?

If you would like to participate, Sparkle’s Research and Development Officer, Fiona Elliott, will come along to meetings that you have with the Family Liaison Officer (FLO) to observe how the FLO offers support/advice during the meetings. Fiona will take notes during these observations that will be used to help evaluate the service. At the end of the meeting Fiona would like to ask some questions to find out how you feel about the service. All notes taken will be anonymised, with no names or personal details recorded.

3. Do I have to take part?

No, it is your choice whether or not you decide to participate in this research. If you agree to participate and then change your mind, you can withdraw at any time without giving your reasons. Deciding not to take part will have no impact on accessing services for your child/children.

4. Are there any benefits in my taking part?

You may find that participating in the research will be a rewarding experience that will give you the opportunity to share your views.

5. Will my participation be confidential?

Yes. All data collected for the evaluation will be anonymised. You will be given a code number and your name will not be used in any written reports or research dissemination materials. If any sensitive information/ inappropriate behaviour/ bad practice relating to yourself or to others is found during the study that could cause harm, confidentiality will have to be broken and this will be reported to the relevant authorities.

6. Who can I contact for further information?

Please contact Sparkle’s Research and Development Officer, Fiona Elliott on 01633 748024 (between 9am-5pm Monday to Friday) or email Fiona.elliott@wales.nhs.uk.

Thank you for your time.

Appendix C

“Evaluating the impact of the Family Liaison Service on families and professionals” Information Sheet for professionals

1. Background information

The Integrated Service for Children with Additional Needs (ISCAN), launched in October 2016, covers the whole of Gwent and provides a single point of access to services for children aged 0-18 years who have two or more developmental needs, and those with suspected Autistic Spectrum Disorder (ASD) or Attention Deficit Hyperactivity Disorder (ADHD). The service includes the Family Liaison Service, which provides support and signposting to families. In October 2018, two new services for families were introduced as part of ISCAN, these are the Integrated Assessment and Planning and Care-Coordination services. Before the ISCAN service was introduced, children were placed on multiple waiting lists to access services, underwent several different assessment processes resulting in multiple plans, had appointments in different locations, and there was no-one to help families understand or navigate the system. Parents said they found the whole experience ‘overwhelming’. Professionals from the Health Board, Children’s Social Care and Sparkle, listened to parents views and worked together to design a new, integrated approach to service delivery.

2. What is the purpose of this research?

The purpose of this research is to evaluate the ISCAN service in terms of the impact it has on families and professionals. We are inviting you to share your views on how the introduction of the ISCAN service has impacted upon professionals working in children’s health and social care services and education in Gwent. This will help us identify any benefits or problems with the service that will be used as evidence to support the future provision of ISCAN, and inform any improvements or enhancements to the service. We are also interested in hearing your views on the Family Liaison Service (FLS).

3. What will my participation involve?

If you would like to participate, you will be invited to take part in an interview and/or focus group with Sparkle’s Research and Development Officer, Fiona Elliott.

Interviews The interview will last no longer than 45 minutes and during the interview you will be asked questions about ISCAN and the Family Liaison Service. With your permission, the interview will be audio-recorded, to help the researcher remember what you have said for analysis purposes. **Focus groups** Attending a focus group will give you the opportunity to share your experiences and views on ISCAN and the FLS in a discussion with other professionals. Provided everyone in the group gives their permission, the discussion will be audio recorded for data analysis purposes. The focus group will last for approximately 1 hour.

4. Do I have to take part?

No, it is your choice whether or not you decide to participate in this research. If you agree to participate and then change your mind, you can withdraw at any time without giving your reasons. Deciding not to take part will have no impact on accessing services for your child/children.

5. Are there any benefits in my taking part?

You may find that participating in the research will be a rewarding experience that will give you the opportunity to share your views.

6. Will my participation be confidential?

Yes. All data collected for the evaluation will be anonymised. You will be given a code number and your name will not be used in any written reports or research dissemination materials. If any sensitive information/ inappropriate behaviour/ bad practice relating to yourself or to others is found during the study that could cause harm, confidentiality will have to be broken and this will be reported to the relevant authorities.

7. Who can I contact for further information?

Please contact Sparkle's Research and Development Officer, Fiona Elliott on 01633 748024 (between 9am-5pm Monday to Friday) or email Fiona.elliott@wales.nhs.uk.

Thank you for your time

Appendix D

Participant Consent Form

This form is to give your agreement to take part in the research project:

"Evaluating the impact of the Family Liaison Service on families and professionals in Gwent".

Please carefully read the following statements and if you are happy to go ahead **initial** each box and **sign** underneath.

I am over 18 years of age.	
I confirm that I have read the information sheet and understand the nature and purpose of the research project.	
I have had time to think about the project and been given the opportunity to ask questions and discuss the project. I confirm that I have received satisfactory answers to any questions.	
I agree with the interview being recorded and transcribed. I also understand that the transcription will be anonymised.	
I understand that I will remain anonymous, identified only by my pseudonym and a brief description agreed by me.	
I understand that all information I provide will be confidential (with the exception of information about harm to children in which case the researcher, Fiona Elliott, has a duty to inform the relevant agencies).	
I understand that I will not financially benefit from taking part in this project.	
I understand that participation is voluntary and that I am free to withdraw from the project, without giving a reason, prior to my data being anonymised. After this time, it will be impossible to trace the information provided due to it having been anonymised.	
I know how to contact the researcher if I need to.	
I understand that this project may be submitted for publications, reports or presentations.	
I understand that if I feel distressed by any part of this project, I can talk to the researcher or a member of staff for information on who to talk to.	
I agree to take part in this research.	

Participant:

Name (print)
Signature
Date

Researcher:

Name (print)
Signature
Date