

## Sparkle Evaluation of the Family Liaison Service

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Bwrdd Iechyd Prifysgol Aneurin Bevan University Health Board



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# **Executive Summary**

👚 Based at three Children's Centres in Gwent, the Family Liaison Service offers holistic support for families with a child with, or undergoing, a diagnosis of a disability and/or developmental difficulty.

It has been such a huge comfort and a truly valued service to us a family. It is so reassuring to know that there is someone you can call when you are feeling at a loss on how best to support your child.

🛧 Families accessing the service between June and December 2022 were invited to participate in an evaluation.



The most common age group and diagnosis among participants' children was 5-11 years and neurodevelopmental diagnoses.

+ The majority of participants received more than one type of support from the Family Liaison Service; the most common sources of support:



telephone conversations



	NEWS
Г	
	=

monthly

🛧 The Family Liaison Officers were described as kind, caring and genuine by participants; they listened to problems and participants were 'extremely satisfied' with the support offered.

Few suggestions for improvement were made; it is recommended that the service maximise opportunities to provide support outside of core hours, for example at evening and weekend support groups and Sparkle's family events.



would recommend the service to another family

It was found that the service provides families with 'somewhere to turn' and 'equips families with information and services'.

# Introduction

Sparkle (South Wales) directly supports children and young people, aged 0-17, with disabilities and/or developmental difficulties, and their families, in Gwent. Sparkle is the charity partner of Serennu, Nevill Hall and Caerphilly Children's Centres, and delivers specialist leisure activities for children and young people, whilst supporting families via emotional and practical support and information services, workshops and support groups, and fun activities for the whole family to take part in.



Our unique Family Liaison Service offers holistic support for families with a child or young person with, or undergoing, a diagnosis of a disability and/or developmental difficulty. Family Liaison Officers employed by Sparkle are based at Serennu and Nevill Hall Children's Centres, and a Family Liaison Officer employed by Aneurin Bevan University Health Board is based at Caerphilly Children's Centre. Parents/carers and other family members do not require a formal referral to access the service, and there is no waiting list; families are able to phone, email or visit one of the Children's Centres to speak to a Family Liaison Officer as needed.

The service offers a variety of support depending on the needs of each family, however support can broadly be broken down into two categories:

### Ongoing, generic support



Weekly information bulletin



Monthly newsletter



Support groups



Training / workshops

### Immediate, specific support



Liaison between a family and health, social care or education professional to resolve an issue or query



Informal emotional support



Practical support, for example to source and apply for financial assistance



Providing resources or advice for a specific issue

This evaluation aimed to explore the impact of the two areas of support offered by the Family Liaison Service.

# Method

This service evaluation was conducted by Sparkle's Research and Development Officer, and was approved by Aneurin Bevan University Health Board's Research and Development Department Research Risk Review Panel on 31st May 2022.

Part 1 of the evaluation used the Family Strain Index (Riley et al., 2006), which is a validated tool that aims to measure levels of stress among parents/carers of children with ADHD (Appendix A). We used it here to explore the impact of the ongoing, generic support offered by the service. This tool asks questions such as "In the past 4 weeks, how often has your child made you feel stressed or worried?". Prior to commencing our evaluation, feedback was sought on the acceptability of this tool from parents/carers receiving the weekly bulletins (3 responses), attending Sparkle's 'Little Stars' stay-and-play provision (2 responses) and attending a Family Liaison Service coffee morning (2 responses). There were mixed views regarding the tool, with some parents/carers feeling questions were not relevant. however most said they would be happy to

complete the tool as part of the evaluation as it was quite brief. The Family Strain Index was shared via an online survey in the Family Liaison Service newsletters between July and November 2022. There are approximately 1,800 recipients of the newsletters across the three centres, however only 76 responses were received: the low uptake may be due to the mixed-views regarding the questionnaire used, or time pressures. A summary of results and descriptive statistics are provided.

Part 2 of the evaluation involved exploring the impact of the immediate, specific support offered by the service using qualitative questions (Appendix B), such as "How did you feel after making contact with the Family Liaison Service?". Prior to starting the evaluation. feedback from the parents/carers suggested it would be most acceptable for these questions to be asked via an online survey which they could save, and come back to if needed. For this evaluation, 'immediate, specific support' was defined as a telephone or in-person conversation regarding a family's

circumstances and/or a specific issue which lasted more than 15 minutes and/or required a follow-up call or email from the service. All Family Liaison Officers noted cases which met these criteria and invited the parent/carer to take part in the evaluation. Once the researcher was informed by a Family Liaison Officer that someone who had been invited had taken part, the Family Liaison Officer could stop asking families to take part until the first of the next month, when data collection resumed. Between June and December 2022, 80 parents/carers were invited to take part in the evaluation and 23 participated.

A summary of demographics and qualitative responses is provided.

## **Results - Part 1**

Nearly half of those who participated in part 1 of the evaluation had a child aged 5-11 years. Half (51%) of participants' children had a neurodevelopmental diagnosis, 11% had another diagnosis (including physical disabilities and rare genetic conditions), and 13% were undergoing a diagnosis; 13% said their child did not have a diagnosis, and 12% did not respond to the question. 90% of participants had received more than one source of support from the Family Liaison Service, with weekly bulletins and monthly newsletters being the most common source of support received.





#### What support/contact have you had from the Family Liaison Service over the past month?



Family Strain Index (FSI) scores were compared with the length of time participants had been accessing the Family Liaison Service. A low FSI score indicates low strain/stress and a high FSI score suggests high strain/stress. The lowest possible score is 0, and the highest possible score is 24. Family strain appears to reduce by 2.8 (mean) to 4 (median) points after accessing the service for 1-3 months, and then plateaus. Despite this, a Spearman's Rho correlation calculator found no correlation between family strain scores and length of time accessing the service.



holistic support)

of participants would recommend the Family Liaison Service to another family



	Mean FSI score	Median FSI score
Less than 1 month (13%)	13.8	16
1-3 months (16%)	11	12
4-6 months (21%)	11.19	12.5
7-11 months (4%)	11.33	12
1-2 years (14%)	12	12
2 or more years (32%)	12.5	12



#### Family Strain Index (FSI) scores over time

## **Results - Part 2**

Similar to part 1 results, the most common age group and diagnosis among participants' children was 5-11 years and neurodevelopmental diagnoses; 43% of participants had a child with a neurodevelopmental diagnosis, 4% had other diagnoses, 13% were undergoing a diagnosis, 4% did not have a diagnosis and 35% did not respond to the question. 74% of participants had received more than one source of support from the Family Liaison Service; telephone support was most commonly accessed.





### What kind of support have you received from the Family Liaison Service?

Feelings before and after accessing the Family Liaison Service:



#### Theme 1: Somewhere to turn

Many participants reported feeling lost before accessing the Family Liaison Service, as they did not understand health, social care or education systems, or because they did not know where to go for support. Participants also described feeling very alone.

"I was embarrassed as I felt I should be able to do this all myself, but having no experience of autism or what to expect, the help available to us and how the system works is a very daunting and lonely place to be." (P11)

Participants hoped to find someone with whom they could vent their frustrations and someone to listen their concerns by accessing the service, as well as someone to provide support and information.

"Advice or support if appropriate, information, care and kindness, a friendly conversation which is often practically beneficial too. Sometimes just to share good news after a long waiting list or frustrations with school or other agencies." (P19)

The Family Liaison Officers were described as kind, caring and genuine by participants; they listened to problems and participants were 'extremely satisfied' with the support offered.

So helpful. Talked things through, provided loads of referrals and support about services I didn't even know was out there. (P3)

Having somewhere to turn and a 'go to' person resulted in participants feeling cared for and less alone.

"Not so alone, that there is someone who understands and will try and help as much as they can." (P12)

The service provides a listening ear when it 'all gets too much'.

"It has been such a huge comfort and a truly valued service to us as a family. It is so reassuring to know that there is someone you can call when you are feeling at a loss on how best to support your child, and also how to make sure our child's needs are being recognised and met in school and what they are entitled to while at school." (P9)

> I wouldn't be here if [Family Liaison Officer] hadn't been there for me. (P1)

### Theme 2: Equipping families with information and services

Before accessing the Family Liaison Service, participants reported a lack of support, information and resources.

"Overwhelmed, confused, pretty awful, unable to cope or see a way through." (P1)

Participants were seeking information, for example about leisure and respite opportunities, as well as direction and signposting to other support services. Practical support, such as help filling in paperwork and resources to help with challenging behaviour, was also sought. Participants commented on the quick response received from the service, as well as the helpful and knowledgeable information provided. "Above and beyond, I didn't expect so much informative information. [Family Liaison Officer] sent information such as useful websites, explained about workshops and toolkits and advice on how I can look after my wellbeing too." (P18)

Participants reported they received help with accessing support and services for their child, and sourcing financial support and specialist equipment.

"Helped complete the documentation and reinforced that I was doing a good job." (P23)

This resulted in participants feeling informed and better equipped to support their child.

Initially I had low expectations as we went through a stage of having meetings and referrals to so many different people at both nurseries, hospital etc., but the Family Liaison Service has been by far the most helpful and are so easy to get in contact with. The service has far exceeded my initial expectations to say the least. (P5)

## Recommendations

Participants were asked how the Family Liaison Service could be improved; the majority of participants said no improvements were needed, and some commented that more Family Liaison Officers could offer support to more families. A few suggestions were made and are addressed below:

One participant suggested the service could offer more support for siblings of children with disabilities, including use of the facilities at Serennu Children's Centre. Sparkle previously ran a sibling's group which was handed over to Helping Hands (Children's Centre Psychology), however siblings are welcome to attend Sparkle's family events, which will be emphasised in future marketing of these events.

The operating hours of the service were commented on, and participants who work during the service's core hours reported difficulty accessing support. The Family Liaison Service recently started evening and weekend support groups, where families can access support outside of core hours.

Some participants requested 'family support days' and 'more events in or near Ebbw Vale'. It is uncertain if these requests refer to the family events Sparkle offers, of which there are now four per year in each catchment area (including Blaenau Gwent), or workshops and support groups facilitated by the Family Liaison Service. It is recommended that, where possible, Family Liaison Officers are available at the family events, particularly those in Blaenau Gwent, to provide a drop-in service for information and support.

# Conclusions

Overall, the response to this evaluation was hugely positive, with a small number of practical improvements suggested. The service provides somewhere for families to turn for information, practical support and a listening ear when feeling lost and alone, resulting in families feeling better equipped to care for their child. Receiving multiple sources of support from the Family Liaison Service results in minor changes to family strain initially, however no statistically significant impact was found. It is likely that the multiple ongoing challenges presented by caring for a child with complex needs cannot be significantly altered by a single intervention such as FLS, although it is clearly highly valued by service users.

# References

Riley, A. W., Lyman, L. M., Spiel, G., Dopfner, M., Lorenzo, M. J. & Ralston, S. J. (2006). The Family Strain Index (FSI). Reliability, validity, and factor structure of a brief questionnaire for families of children with ADHD. *European child and adolescent psychiatry*, *15*(1), 172-178, doi: 10.1007/s00787-006-1010-0.



### **Appendix A**

#### **Family Strain Index**

What support/contact have you had from the Family Liaison Service over the past month? (Tick all that apply)

Received the monthly newsletter	
Received the weekly bulletin	
Received other information/support via email	
Received information/support via telephone	
Attended a support group/workshop	
Other (please specify)	

In the past 4 weeks how often has your child:	Never	Almost never	Sometimes	Almost always	Always
Made you feel stressed or worried					
Limited your time to relax or participate in social activities					
Made you feel uncomfortable inviting friends and family to your home					
Caused conflict or tension within the family					
Prevented you from going to certain places with your child (e.g. supermarkets/shows, visiting friends/family)					
Caused you to change your planned family activity (e.g. weekend plans, day trips, social arrangements)					

How likely are you to recommend the Family Liaison Service to another family?

Very likely	
Likely	
Unlikely	
Very unlikely	

### **Appendix B**

#### Family Liaison Service – Post-support questions

- What kind of support have you received from the Family Liaison Service? (e.g. telephone conversations, in-person support, help to resolve a problem or issues involving your child's care/education)
- 2. How were you feeling before making contact with the Family Liaison Service?
- 3. What did you expect to gain from contacting the Family Liaison Service?
- 4. To what extent did the Family Liaison Service meet your expectations?
- 5. How did you feel after making contact with the Family Liaison Service?
- 6. How did the Family Liaison Service help you and your family?
- 7. How could the Family Liaison Service be improved?
- Is there anything else you would like to share about the support you received from the Family Liaison Service?