

# **Sparkle Research and Development Project:**

**The views of families and  
professionals on specialist provisions  
for children and young people with  
disabilities and/or developmental  
difficulties, and their families, living in  
Caerphilly County Borough.**

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Bethan Collins MSc, MBPsS  
Research and Development Officer  
Sparkle (South Wales) Limited



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## Acknowledgements

Thank you to all the families and professionals who volunteered their time to participate in this consultation, and to Caerphilly Children's Centre's Family Liaison Officer, Lisa George, and everyone else who supported Sparkle to recruit participants. Thank you to GAVO's Voluntary Sector Recovery Fund for supporting the Activity Taster Days and helping give the children and young people of Caerphilly a voice.

# Executive Summary

★ Sparkle supports children and young people with disabilities and/or developmental difficulties, and their families, via their specialist leisure services and family information and support service. Sparkle is the charity partner of Serennu Children's Centre in South Gwent and Nevill Hall Children's Centre in North Gwent. In November 2020, Sparkle became a charity partner of Caerphilly Children's Centre.

★ This report outlines the findings of a consultation with families and professionals on any unmet need within the service to inform the development of Sparkle services in Caerphilly.

**102** families & professionals



★ The consultation was conducted in 3 stages: a questionnaire was sent to families and professionals, participants were invited to take part in a virtual or telephone interview and children and young people were consulted via a 'Sparkle Activity Taster Day'.

*She went to a base unit in [a mainstream school] and there is quite a gulf between what things are accessible for children in a base unit compared to things that are available for children say in Trinity Fields. [...] They had like children discos, inclusive discos, fairs and fetes and all the rest of it and base unit children at that point and I still don't think they're very much included, they had nothing, yet they couldn't also access anything to do with the mainstream part of the school. [...] I know like [child 2] is in a base unit now and that's not a Trinity satellite and I 100% know they're not invited to anything that Trinity puts on, even though a lot of their children will end up going to Trinity for secondary school, so again, there's that disconnect.*

(Family member)

- ★ Findings indicate that families of children with additional needs are currently supported by information and advice services, however *leisure* services for the children and young people are **not** meeting their needs.
- ★ The friendly staff were considered the best thing about Caerphilly Children's Centre. Frustration was expressed that the facilities at the Centre are not available out of hours and suggestions for improvement included the introduction of leisure and family activities, and improvements to facilities and working spaces.
- ★ There were mixed views regarding whether health and social care services should be co-located with leisure in Caerphilly or if leisure services should be accessible across the community; some possible community venues for Sparkle leisure services are suggested.
- ★ The current boundaries placed on services for children and young people with disabilities and/or developmental difficulties in Gwent was a much discussed issue in the interviews, and both families and professionals suggested families would benefit from being able to access the Children's Centre that was most convenient for them.
- ★ It is clear that children attending Caerphilly's special school, Trinity Fields, have access to excellent facilities and enhanced leisure opportunities, but that the large number of children with complex needs attending *base units in other schools* in Caerphilly have little appropriate leisure provision.
- ★ The most commonly requested leisure services included family activities and swimming lessons. Interview participants commented that they simply wanted their *children to be able to access the same leisure provisions any other child* would be able to access, such as afterschool activities and sports clubs.

**67%** wanted all services under one roof\*



**76%** requested swimming lessons\*

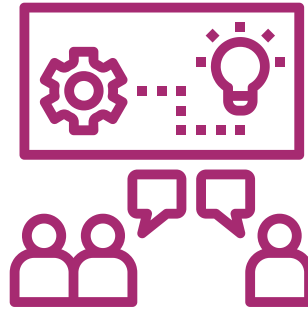


★ The lack of access to swimming lessons for children with disabilities and/or developmental difficulties is denying children both water safety and an appropriate sporting activity available to all other children in the County.

★ Activities marketed as being 'inclusive' within Caerphilly appear to only be accessible for children with minimal additional needs.

★ There were requests for opportunities for peer support and *practical training for families of children with additional needs*, which would fill the gap in the current service provision for families.

**74%** asked for training workshops for families\*



★ Sensory spaces and an accessible playground were highly requested facilities, however in the interviews participants commented that many facilities already exist at the Children's Centre but access is restricted.

★ Recommendations for Sparkle service development are made based on the findings of this consultation.

*There are no leisure facilities that are safe enough for my family at this point to go to together, where it's not like really, really super busy full of other families, where it is accessible, where there is equipment that both my girls can use. Where it's quite a safe and controlled area and there was always a lot of reasons why it couldn't be done rather than looking into reasons why it could be done so it's quite sad for a lot of families to see resources in your area that weren't being accessed.*

(Family member)

\*Of those who responded to the relevant question



# Introduction

Sparkle directly supports children and young people (CYP) with disabilities and/or developmental difficulties (DDD) and their families. The guiding principle for Sparkle is to ensure that CYP with DDD, and their families, are fully supported and able to participate in valued childhood experiences, with access to the same range of opportunities, life experiences, activities and community services as any other child and their family.

Sparkle is the official charity partner of Serennu Children's Centre, where they support over 300 families per week from Newport, South Torfaen & South Monmouthshire. CYP with DDD are able to access Sparkle's specialist leisure activities at the Centre, including clubs such as Play Club, Youth Club and Independent Living Skills and family activities such as MediCinema screenings and family swim sessions in the Centre's hydrotherapy pool. Families are supported via Sparkle's Family Liaison Service, which provides parents, carers and other family members with information, advice, training and informal emotional support.

In May 2019, Sparkle became the charity partner of Nevill Hall Children's Centre and families in that catchment area can now access support from the Family Liaison Service and Sparkle's leisure activities in community venues. Sparkle now covers Newport, Torfaen, Monmouthshire and Blaenau Gwent, meaning Caerphilly is the only local authority in Gwent without access to Sparkle's services. Sparkle were invited to become a charity partner of Caerphilly Children's Centre in November 2020, carrying on the work of Action for Children and joining Enable, the charity supporting the Assessment Nursery at the Children's Centre.

Families in Caerphilly already had access to information and support from the ISCAN Family Liaison Officer based at Caerphilly Children's Centre, funded by ICF through the Integrated Services for Children with Additional Needs (ISCAN). An in-depth consultation with families and professionals was required to identify any unmet needs for families of a child with DDD in Caerphilly, and to explore how Sparkle could potentially fill this gap.

# Method

The consultation was conducted in three stages, using a mixed methods approach.



## Stage 1: Questionnaire

A questionnaire (Appendix A) was created online using 'Survey Monkey' and was distributed to families in Caerphilly with a child with DDD and professionals working with CYP with DDD. The questionnaire was disseminated via the Family Liaison Officer's mailing list, social media channels, was shared with the local special school and Special Needs Resource Bases at mainstream schools, and was emailed directly to professionals working with children in Caerphilly. The questionnaire was open from 1st February 2021 until 13th July 2021. The questionnaire included: demographic information about participants, information regarding participants' current involvement with Caerphilly Children's Centre, and participant views on the needs surrounding leisure services, family support and facilities in Caerphilly. There were 68 responses from family members of CYP with DDD, 33 responses from professionals working with CYP with DDD, and 1 response from a young person (the young person's response has been included with the family responses below). There was a considerable drop-off in responses throughout the questionnaire, however this has been reflected in the findings section of this report. Quantitative responses were analysed and descriptive statistics are presented below. Qualitative responses were analysed thematically and are summarised in the findings section.

## Stage 2: Interviews

All participants who completed the questionnaire were asked to indicate whether they would like the opportunity to discuss their responses further via a virtual or telephone interview; 3 family members took part in interviews via Microsoft Teams and 5 professionals took part in telephone interviews. All participants received an information sheet (Appendix B) and consent form (Appendix C) which had to be signed or initialed and returned via email before the interview took place. The interviews took place between 6th May 2021 and 22nd June 2021. Interviews with family members lasted between 34 and 98 minutes

(average 58 minutes) and interviews with professionals lasted between 22 and 32 minutes (average 26 minutes). The interviews were semi-structured, with schedules (Appendix D; Appendix E) being used to guide the conversation but allowing for participants to bring up their own topics. The interviews were transcribed and anonymized, and a thematic analysis of the transcripts was conducted. Key points raised during the interviews with family members were sent to other families of CYP with DDD via the Family Liaison Officer in Caerphilly; 2 further parents responded and agreed with the points raised in the interviews, therefore data saturation was reached.

### **Stage 3: Children and Young People's Voice**

Activity Taster Days were organised for CYP with DDD living in Caerphilly to experience a session of Sparkle leisure activities. The taster days were advertised via the Family Liaison Officer at Caerphilly Children's Centre, professionals working with families across the borough and Sparkle's social media pages. The number of families interested in the taster days and feedback from the families and CYP who attended, as well as the leisure staff who ran the sessions, was used to help inform the recommendations at the end of this report. A taster day was run at St David's Community Centre in Rhymney for families from the North of the borough, however interest in this day was very low; there was two children booked onto the first session for 0-4 year olds, three booked onto the session for 5-11 year olds and one booked onto the session for 12-17 year olds. The latter two sessions were combined due to low numbers, however on the day only one child attended the session for 0-4 years (this family was from Caerphilly, however were not able to attend the taster day at Caerphilly Children's Centre) and two children (aged 5 and 11) from one family attended the combined session for 5-17 year olds. A second taster day was run from Caerphilly Children's Centre for families from the South of the borough; the sessions for 0-4 year olds and 5-11 year olds were fully booked at 10 children per session and a waiting list held a further





20 children, the majority for the 5-11 years session, and six were booked onto the third session for 12-17 year olds. A few last minute cancellations were received and spaces were offered to families on the waiting list, however further no-shows meant the session for 0-4 year olds was attended by 5 children, the session for 5-11 year olds was attended by 7 children, and only one young person attended the session for 12-17 years olds\*. The Activity Taster Days were offered to families free of charge thanks to funding from the Gwent Association of Voluntary Organisations' Voluntary Sector Recovery Fund Small Grant Scheme, administered by Third Sector Support Wales on behalf of the Welsh Government.



\*However this family were not from the Caerphilly Borough and seemed to have booked onto the event in error, as it was not what they were expecting.

# Findings

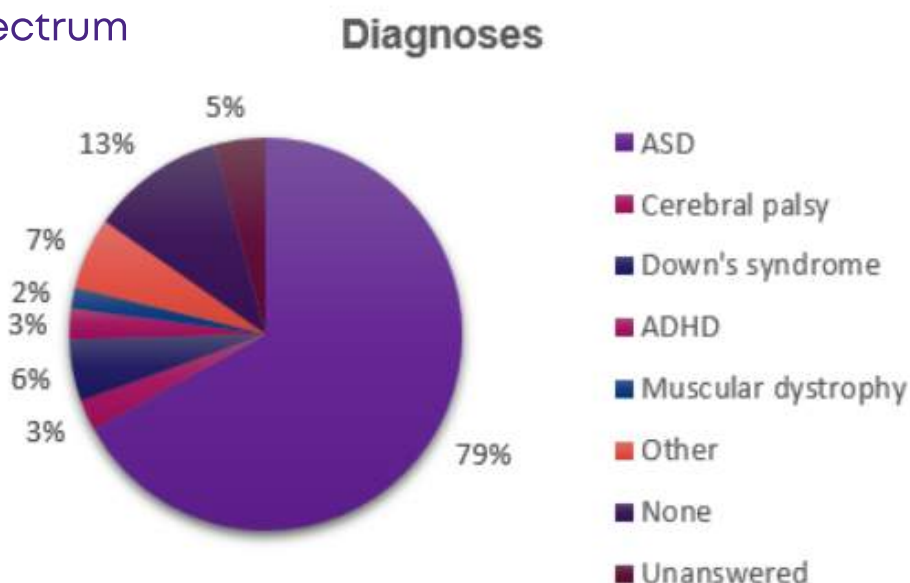
## Demographics: Families

The location of the 69 families are presented below. Only two participants were from the Rhymney area of Caerphilly, with the majority of participants being spread across mid- and south-Caerphilly; Blackwood and Caerphilly town were particularly well represented areas.

More than half of participants (43) had a child aged 5-11 years; 17 participants had a child aged 0-4 years and 14 participants had a child aged 12-18 years (some participants had more than one child). The majority of participants' children had received a formal diagnosis, the most common of which was Autism Spectrum Disorder (ASD).



Figure 1: Location of families who completed the questionnaire, retrieved from Google Maps on 30th June 2021.



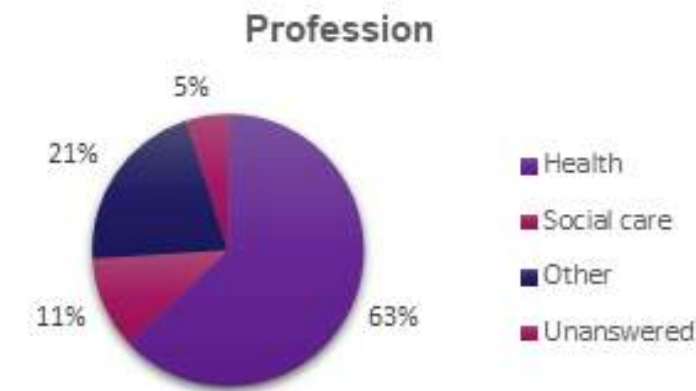


Half of participants do not attend Caerphilly Children’s Centre for treatment. Out of those who do attend, the majority (23%) have been attending for more than three years. Participants were asked if they had ever attended an event at Caerphilly Children’s Centre; seven participants had attended a bonfire night event with silent fireworks, which was highly praised.

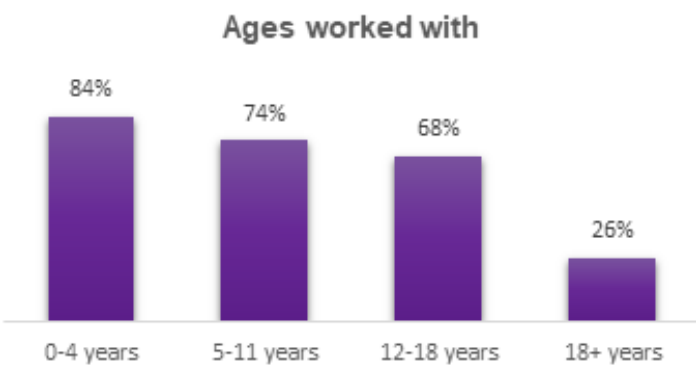
Of the three family members who participated in interviews, one was from the South-West of the borough, one from the South-East and one from Mid-Caerphilly; no family members from the North of the borough chose to participate in interviews. The most common diagnosis among participating families was ASD; two participants were parents with children with ASD, however the children had differing needs, for example some were non-verbal and/or had significant mobility difficulties, whilst another had more social difficulties. The third family member was a parent of a child with Down’s syndrome who has complex healthcare needs. Between the participants, all three age categories mentioned above were covered.

**Demographics:  
Professionals**

Despite 33 professionals beginning the questionnaire, there was an immediate drop off of 14 participants. Therefore, the following results are taken from the 19 remaining responses. More than half of these participants were from health services, such as paediatrics, occupational therapy and physiotherapy. Participants from social care included case workers and participants from ‘other’ included those working in third sector services. A breakdown of the age groups professionals worked with is presented.



Participants were asked whether they work from or deliver services from Caerphilly Children’s Centre; 42% did so daily, 26% did so a few times a week and 32% did not work from or deliver services from Caerphilly Children’s Centre.



# Current Service Provision

Sources of support and specialist leisure provisions that are currently available for CYP with DDD, and their families, were identified via the Family Liaison Service, internet research and interviews with family members and professionals. These are summarised in the following table:

Name of Provision	Type of Group/Provision	Details	Criteria and restrictions
<b>Leisure activities for children and young people</b>			
Trinity Fields Leisure Service	Trinity Field Special School	Deliver a Saturday Play Club, school holiday activities and a respite service.	Only for children attending Trinity Fields who have been referred via the Children with Disabilities Team (Social Services). Children aged 8-18 years.
Disability Sports	Company with charitable status	Promotes and supports inclusion in mainstream sports clubs and runs disability sports camps during school holidays.	All children with disabilities are eligible to access Disability Sport.
<b>Family activities</b>			
Sparrows ALN Group	Community group run by volunteers	Organises inclusive sessions at local soft play centres, swimming pools and other leisure providers.	All children with disabilities are able to attend, age restrictions are imposed on some activities by leisure providers, and parents/carers must attend with the child.
Valley Daffodils	Community group run by volunteers	Organises inclusive sessions such as swimming, horse riding and other leisure activities.	All children with disabilities are able to attend, age restrictions are imposed on some activities by providers, and parents/carers must attend with the child.
POPSY (Parents of Partially Sighted and Blind Youngsters)	Charity	Fundraises to subsidise costs of wheelchair accessible and inclusive activities, such as surfing and holidays.	Families with children with complex special needs.
<b>Family Support and Information</b>			
Families First	Social Services	Programs providing early support for families to prevent problems escalating.	Families living in Caerphilly County Borough with children aged 0-25 years.
Flying Start	Welsh Government	Intensive support services focusing on language, cognitive, social and emotional skills, physical development and early identification of high needs.	Families with a child age 0-3 years living in targeted postcodes.
National Autistic Society	Registered charity	Offer support to families, bimonthly support group with the Caerphilly Autism Service.	Parents/carers of children with autism only.
Family Information Service, Caerphilly	Welsh Government	Provides information and guidance for families and carers.	All families in Caerphilly are able to access the service.
Assessment Nursery	Supported by Enable (registered charity)		Referral required.



Family Liaison Service	ISCAN/ ABUHB/ Sparkle	Information, advice, signposting and emotional support for families with children with disabilities and/or developmental difficulties.	Open to all families with a child diagnosed, or undergoing a diagnosis, of a disabilities and/or developmental difficulty. No referral required.
Early Years Support	Caerphilly Council	Provides family support services to enable families to reach their potential. Supports children with speech, language and communication, to learn and develop, and helps with childcare costs and provision.	Families with children aged 0-7 years. Referral from a GP, health visitor, teacher or childcare provider. Parents and carers can also self-refer.
Caerphilly Community Hub	The Autism Directory	Support group for parents.	Parents and carers of children with autism, however no formal diagnosis or referral required.
<b>Education Support</b>			
Caerphilly Autism Spectrum Service (CASS)	Based at Trinity Fields Special School	Families can be referred to CASS for support at home if a child has a confirmed diagnosis of autism and their difficulties are affecting their ability to access education. Training is also provided for schools with students with a confirmed diagnosis of autism, as well as courses for families and young people referred to CASS.	Referral required. Children and young people with autism only, and their families/schools.
SNAP Cymru	Registered charity	Provides advice and support surrounding education for children and young people with additional needs or disabilities.	Parents, carers and young people are able to phone the free support line for information and advice. For some services information may be required from a professional working with the child/young person.
Early Years Education	Caerphilly Council	Provides free, part time early years education for children aged 3-4 years.	All children in Caerphilly. No mention of support available for children accessing who have additional needs.

A professional who participated in an interview suggested there was a lot of enhanced support available for children and families, especially for those that attend Trinity Fields Special School, and families are able to access support via the Family Liaison Service or Families First.

*“There’s quite a lot of additional services, sometimes I do lose track of them especially because I don’t work in the community as much I work more in Trinity Fields, but I know there are things like the Family Liaison Officer in Caerphilly whose amazing, there’s lots of things like Families First, I think they’re an umbrella for lots of support groups”*  
(PC3)

Family members agreed there were a lot of services available to children attending Trinity Fields.

*“[Trinity Fields Special School] would put on amazing things that I would hear about from friends whose children went there [...] like you know they had sensory workshops for parents to go to so that you could learn to, you know bring cheaper sensory items into their home. They had like children discos, inclusive discos, fairs and fetes”* (FC1)

However, other professionals and family members commented on the lack of services for all children with additional needs.

*“It would just be accessing the normal council play schemes that they run but there is no provision for children with special needs.”* (PC5)

*“She goes with her dad to football because he coaches 6-to-8-year old's but because of her [disabilities] she really struggles with it and she falls a lot and she just generally can't keep up at the same pace as the other children so something more focused for children with those additional type of needs would be perfect”* (FC3)

One family that attended the Activity Taster Day in Rhymney said that there was ‘nothing’ offered to families in Rhymney and the taster day was the first time they were aware of any leisure activities for children with additional needs being offered in the area. It was suggested during the interviews that there was a lack of awareness of services that are available in the borough.

*“I think unless they are actively involved with either Care Coordination or they’ve been in contact with the Family Liaison Officer, I don’t know whether they would necessarily know about those organisations, I’m not sure if they’re something that health or social care or education are passing that information on [...] some of them you can find doing a simple Google search, but some of our families, they’re so busy coping with the day to day things they won’t necessarily think to do that.”* (PC4)

Family members commented that, whilst they appreciated the support offered by voluntary groups such as Sparrows and Valley Daffodils, they are not always able to meet the needs of the children.

*I know Valley Daffodils are great and offer a range of activities however they're not inclusive for physical restrictions [...] It's a lovely little group but it's for the more abled children.*

(FC1)



*"So Valley Daffodils and Sparrows, they're both groups for children with additional needs, again they have some organised activities but they tend to be, you know soft play, obviously not running now, just meets at soft play or that type of thing. [...] I think they're easy to access, I think it's again what I find is they don't really offer anything that I couldn't really do myself. So I would take [child] to a soft play outside of a group run session, so it's nice you get to catch up with people, but it's not really meeting the child's needs any differently to what I could do with her on my own. [...] so obviously I'm not going to have someone shout at me if she behaves in a certain way or something like that but I feel that's more for my needs, because [child] wouldn't notice if someone was looking at her a different way or anything like that."* (FC2)

Similar was said about the activities provided by Disability Sport in Caerphilly.

*[Child 2] actually went to disability sport swimming sessions and there was no one in the pool with her [...] there's no chance on earth that [child 1] could get into a pool without someone next to her [...] disability sport within Caerphilly, they put lovely activities on for children with less support needs that they're quite focused on activities for say, wheelchair bound children who maybe don't have learning difficulties.*

(FC1)

*“Caerphilly Sport does have a Disability Sports Officer that we did link with occasionally but we didn’t have any kind of firm links with him and there wasn’t anything organised you know like a regular thing for any of our kids” (PC5)*

Due to the Assessment Nursery located at Caerphilly Children’s Centre, children and families seem to be able to access support and play services up until the age of 8, at which point family members and professionals said sources of support and leisure became virtually non-existent.

*So from [child 1]’s perspective, after 8 when she stopped going to the Children’s Centre, they had a holiday club during the school holidays where up to 8 years old she could access that for I think it was like a day a week for 4 weeks during the summer holidays, so as soon as she turned 8, you know there was nothing.*

(FC1)

*“The assessment nursery ran a sort of early year’s play scheme in the holidays [...] I think off the top of my head it was under 8s” (PC5)*

Family members and professionals also commented on how previous sources of support and leisure are no longer available, such as swimming lessons and overnight respite.

*So her awareness of it and her safety in the water came on massively but not just that she could then swim [...] from one end of the children centre pool together with a pool noodle and just to see that it was like, it was something we never thought [child 1] could achieve and then they just stopped.*

(FC1)



*"I know that some children go for overnight respite, but I think those kind of things are happening a lot less. Obviously because of Covid but also I think there's less resources, that's what I seem to hear from the families I work with, they don't get much respite and that's reduced over the years." (PC3)*

One parent who attended the Activity Taster Day in Caerphilly commented that, whilst they are eligible for direct payments and respite services, support has been very unreliable and they had recently lost 7 hours of respite due to staff cancelling last minute.



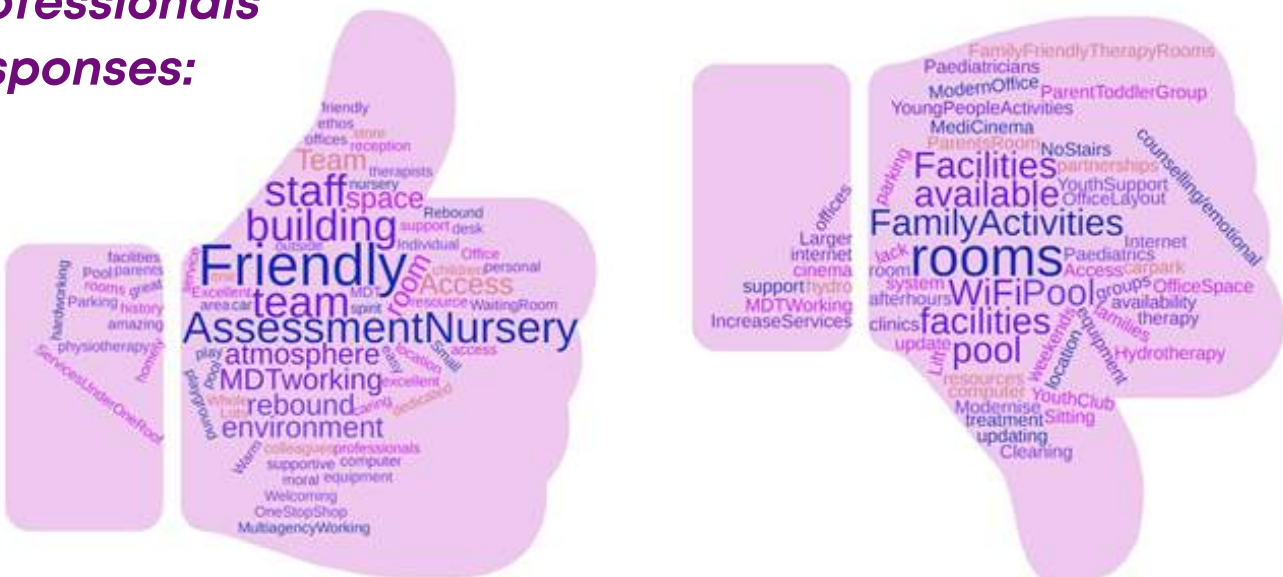
# Caerphilly Children's Centre

There was further drop-off in questionnaire participation at this point, therefore the following findings are taken from the remaining 56 family members and 17 professionals. Participants were asked what three things they liked most about Caerphilly Children's Centre and what three things they thought could be improved at the Centre. Both family members and professionals highlighted the *friendly staff* as being one of the best things about the Children's Centre, whilst family members highlighted a *lack of leisure services* being something that could be improved at the Centre and professionals mentioning the working spaces and *facilities being in need of updating*. Responses to these questions are presented below.

## Families' responses:



## Professionals' responses:



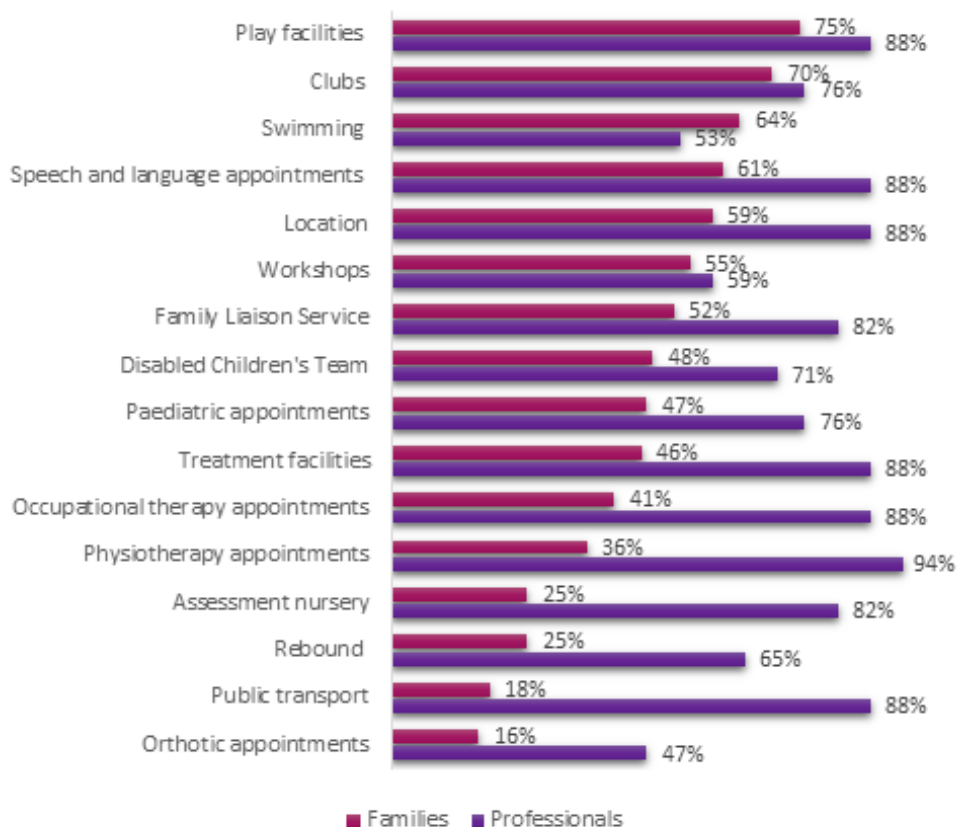


When asked what they felt was important in a Children's Centre, families and professionals had different priorities. Families felt play facilities, leisure clubs and activities such as swimming were most important, however professionals rated health appointments and the location of a Children's Centre as being of equal importance to play facilities. One family member also suggested eye tests should be available at a Children's Centre, and professionals suggested Portage, ISCAN, psychology and dietetics should be present

The importance of multidisciplinary working was brought up by the professionals interviewed as part of the consultation.

All professionals who responded to the survey and took part in an interview agreed services should be housed under one roof as this facilitates multidisciplinary and joint working, provides a 'one stop shop' for families and results in better communication between services and an overall better experience for families.

Important in a Children's Centre



*It's helpful to have services under one roof. It is also really helpful to have social services under that same roof as well, if possible.*

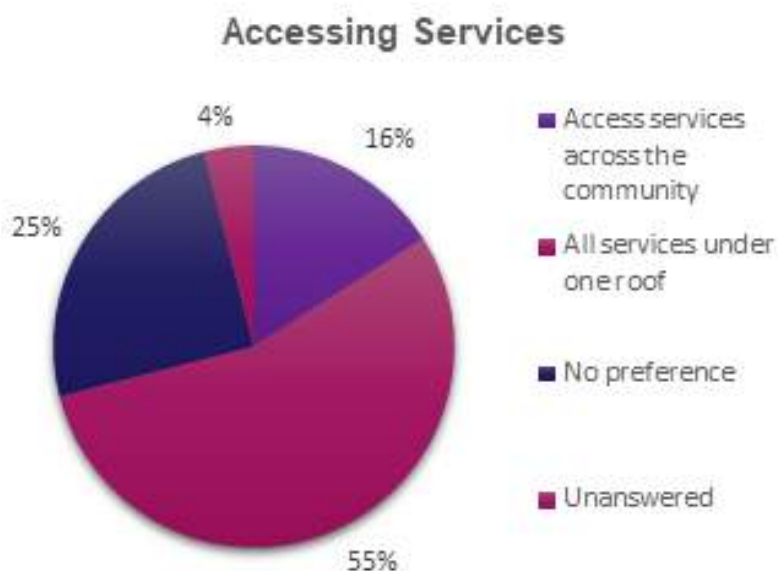
(PC1)

*I think it's really useful to have all sort of professionals and practitioners working under one roof, it's so much easier to organise joint appointments.*

(PC2)

More than half of family participants also said they would prefer all services to be located in one building, as this makes attending joint or multiple appointments easier and allows the child to become familiar with the environment, rather than having to be regularly introduced to new places and people. However, those

who said they would prefer services to be accessible from community venues across the county commented on the current difficulty they experience accessing Caerphilly Children's Centre due to the location and *public transport* options.



In the interviews, it was discussed how, though participants would like to have all health and social care services housed under one roof, they would be open to accessing leisure services from community venues. One family member said it would depend on the child's needs, as one child may benefit from the specialist equipment and the familiarity of the Children's Centre whilst another child may be more comfortable accessing a community facility.

Another family member commented they would be happy to access community facilities, as long as the specialist support was in place.

*[For child 1], my preference would be the children centre because accessible nature of it, familiarity of it, of the space that's there, the equipment that they have. For [child 2] I would be happy if activities happened in a Community Centre.*

(FC1)

*"I think it's having that safe environment, you can go to the pool and you know it's not going to be really crowded and you've got people there that know how to teach your child how to swim and its more of a structured activity [...] so for me using Trinity Fields would be brilliant because if she goes there in the future it will be a familiar environment."* (FC2)



One professional also mentioned that accessing services in the community would help children and young people eventually transition to mainstream activities and integrate with their communities.

*“Maybe some people would prefer to access facilities like that in the community rather than coming to the centre where you know it is kind of separating the children from the normally developing children so is it about enhancing facilities in the community so that children with additional needs can access facilities in the community rather than on separate sites” (PC3)*

Potential community venues for delivering Sparkle leisure activities in Caerphilly County Borough were considered during the consultation. The following list is made up of recommendations from families and professionals and venues identified through internet searches.

#### Flying Start Venues (not including schools):

- ★ Parc Y Felin Integrated Children’s Centre, Caerphilly.
- ★ Penllwyn Community Centre, Blackwood.
- ★ Barnardos Family Centre, Caerphilly.
- ★ Flying Start rooms, Ty Coch, Rhymney.
- ★ Graig Y Rhacca Flying Start, Graig Y Rhacca.
- ★ Fochriw Flying Start Family Centre, Bargoed.
- ★ Trinant Flying Start, Crumlin.

#### Leisure Centres:

- ★ Caerphilly Leisure Centre, Caerphilly.
- ★ Risca Leisure Centre, Risca.
- ★ Heolddu Leisure Centre, Bargoed.
- ★ Pontllanfraith Leisure Centre, Blackwood.
- ★ Newbridge Leisure Centre, Newbridge – mentioned by a family member.
- ★ Cefn Fforest Sports Centre, Blackwood.
- ★ Markham and District Sports and Community Centre, Blackwood.
- ★ New Tredegar Sports Centre, New Tredegar.
- ★ Ael y Bryn Sports Centre, Rhymney.



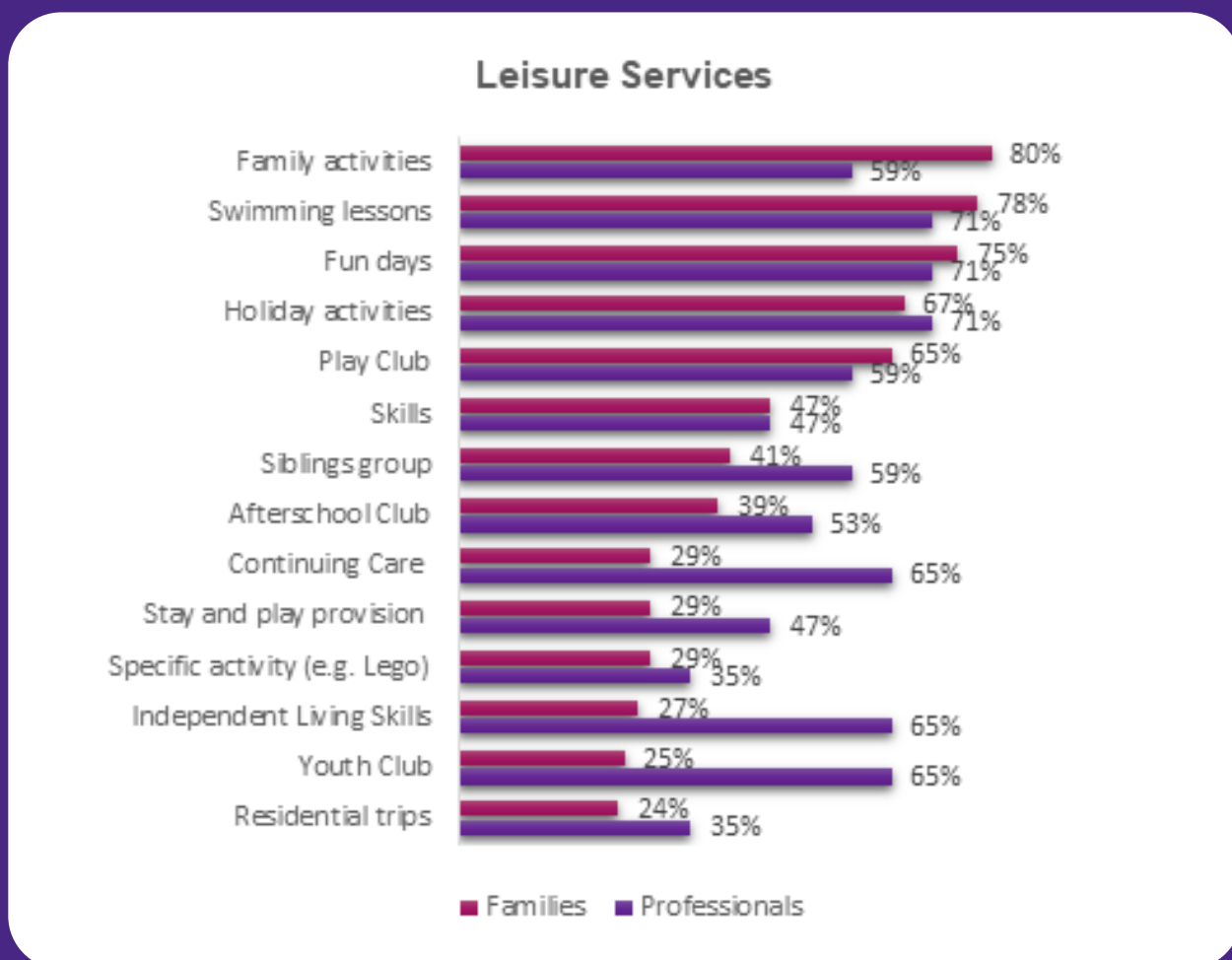
- ★ Touchbase Cymru, Caerphilly Business Park – mentioned by a family member.
- ★ Rhymney Integrated Health and Social Care Centre, Rhymney – mentioned by a professional.
- ★ Trinity Fields School and Resource Centre, Ystrad Mynach.

[illegible]

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## Leisure Services

Among family participants, 51 answered the following questions, with 17 professionals responding. Participants were asked what leisure services they would like to be available for their child or for the children and young people they work with. Family members and professionals had similar priorities, with family activities, swimming lessons, fun days and holiday activities being most highly rated. There was also a lot of interest in family activities from families that attended the Activity Taster Days. However, professionals felt clubs such as Continuing Care, Independent Living Skills and Youth Club were much more important than families did (this may be because, despite brief descriptions being provided, families did not fully understand what these activities entailed). Other suggested leisure activities included cinema screenings, yoga classes and supported gym sessions.



The Activity Taster Days were organised to resemble a Sparkle Play Club, where the CYP were able to play with toys of their choice as well as engage in sensory activities, outside play and crafts.

At the end of their session, the CYP were asked to put a counter in a 'happy' box if they'd had a good day or a counter in a 'sad' box if they'd had a bad day. The majority put their counter in the 'happy' box; the one child who put their counter in the 'sad' box said this:

*I put mine in the sad box  
because we have to go  
home now.  
(Child, age 5)*



One family member who participated in an interview brought a list of requested leisure activities from other parents of children with disabilities. This included music sessions, swimming, trampolining, arts and crafts, Minecraft and computer clubs, Lego clubs, and sporting activities where the children can develop skills but not necessarily have to participate in team activities. This participant also mentioned another parent who has to take their child to Cardiff for leisure activities due to it being the closest facility with equipment such as hoists. It is notable that both Caerphilly Children's Centre and Trinity Fields School could accommodate many of these activities, due to their specialist facilities.

*She's got to go to Cardiff to this Sense place  
and she saves up all year now so that she  
can pay for his summer holidays, to go to  
Sense because they've got hoists and  
they've got trained staff that know what he  
needs [...] it's lovely that she's found that but  
it's sad that she's had to save up all year  
and go to another area to get it for him.*

*(FC1)*



For other parents, they just wanted their child to simply be able to access the same provision as any other child.

*"I always think back to if I had a neurotypical kid what would they be able to access, like I would drop them off at football club and I wouldn't necessarily have to stay with them, or gymnastics club I would be sat outside with a cup of coffee while someone did gym with them [...] For me it's like anything that allows my daughter to experience what neurotypical kids would, because if she saw the same faces every week in that club or holiday club, I think sometimes we assume because people are autistic they have to have their parent there all the time and that's certainly not the case." (FC2)*

*"If [child 1] and [child 2] were typical children they would have easy access to breakfast clubs, after school clubs, holiday clubs, after school activities [...] but for families like us those things don't exist [...] sometimes it feels like we are all really grateful for that one week out of five, when you look around all the other families happily going along the way who got access to things for six whole weeks, you know it's sort of it feels very unfair sometimes and I get there's money issues and barriers and things like that but it doesn't even feel like within Caerphilly there's been any progress in bringing these things forward." (FC1)*

A family that attended one of the Activity Taster Days shared the following feedback:

*"Thank you everyone for a wonderful session! [Child 1] came home and keeps saying 'I had fun' 'Can we go next time'. [Child 2] thrives off all the activities and attention. It was so exciting to have something up the top end of Caerphilly County Borough. We really hope there is a next time." (Family member)*

Family members suggested afterschool, on weekends and during the school holidays would be the best times for leisure activities to take place, with professionals also mentioning evenings and weekends.

One interview participant did suggest the children may be too tired to attend a club afterschool and therefore weekends and school holidays would be preferred.

*"One thing most of us that I've spoken to and we are in agreement with is that our children wouldn't probably be able to do things after school, they are wiped out." (FC1)*

One parent who attended the Activity Taster Day in Rhymney mentioned that weekend activities would be better for their family, as their one child has to travel to from Rhymney to Trinity Fields School in Ystrad Mynach and their other child attends a base in Gelligaer, therefore they get home from school later and would struggle to attend an afterschool provision. Another who attended the Activity Taster Day in Caerphilly had to leave their session early due to Sunday bus times, however said they would not have a problem attending afterschool or on Saturdays when buses are more regular.

An interview participant said it would depend on the activity and who it was aimed at as to what time would be best.

*"If we're talking about sort of a mother and baby or mother and toddler or preschool age type of group, that would be great in school time because [child 1] would be in school, I'd be able to do something with [child 2], but if it's like for both of them like a sibling's activity out of school hours, weekends or school holidays that would be great" (FC3)*

When asked where they would like to be able to access specialist leisure services, many families said 'any location' or that they would be happy to travel to access high quality services for their children. However, some mentioned specific locations that would be more convenient, such as Caerphilly town, Ystrad Mynach, Risca, Blackwood, Newbridge and Hengoed. Professionals suggested locations such as Risca, Blackwood, Caerphilly, Bargoed, Tredegar, Oakdale and the Rhymney Valley. One professional who participated in the questionnaire commented that staff only work 9am to 5pm,

perhaps suggesting there was concern over whether the Children's Centre would be available for leisure activities to take place out of hours. Sparkle leisure staff who helped deliver the Activity Taster Day at Caerphilly Children's Centre discussed how they thought the venue could be used out of hours for Sparkle leisure clubs, for example the taster day sessions utilised the playroom, sensory room and secure outside area with accessible playground on a weekend day when the facilities and Centre were not being used by other professionals. Sparkle staff also commented that the rebound room could be used as a number of Play Workers will be undertaking rebound training at Serennu Children's Centre, and there is a kitchen at Caerphilly Children's Centre which might also be useful for clubs.

One of the themes found in the qualitative data was how isolated the children and families in Caerphilly were.

*"So this is my one friend that's got a son, 'outside of school he has no engagement or social interaction with others. I don't want him to be stuck with this continuously'." (FC1)*

Professionals also commented on families being isolated, either due to their location or because of the caring needs of the child.

*"I know that the siblings group at Serennu has been quite successful and I think that would be helpful here [...] obviously they get a lot of attention and they have appointments and everyone's talking about them, so I think it would be lovely to have something for the siblings where they can all get together and be the focus of attention and do some fun things and for it to be all about them, I think that would be really helpful" (PC4)*

*I would like to find out what is available to the children up in Rhymney. I feel they are quite isolated and it can be quite difficult sometimes to engage them.*  
(PC2)

Family members commented that specialist leisure services would create a community for families and provide CYP with a sense of belonging.

*“[Child 2]’s at the stage where she’s feeling very different to everyone else and her differences are becoming quite visible to her, and she knows she has autism and she knows [child 1] has autism and she can’t see her autism in [child 1] because [child 1] is so much, you know, she’s got so many more needs and she’s not verbal and she’s not toilet trained, and so it’s very hard to explain to a child like [child 2], yes [child 1] has autism too, because it’s so very different. So it would be lovely for [child 2] to be able to go to clubs [...] so she’s sort of with her peers then as such, rather than trying to fit her in a little hole of her peers but she’s not quite like them, because she’s noticing these things it would just be lovely to give her the experience of knowing children like herself so that she can see she’s not so different and there’s lots of people that are like her you know.” (FC1)*

Direct payments were also brought up during the interviews with family members; parents commented that, whilst they were eligible for direct payments, finding someone suitable to employ and suitable places for the child to access was difficult.

*“They’ll give you direct payments, but then as a parent I’ve got to employ someone then [...] the service we are short on is having people who are trained and experienced with children with needs.” (FC2)*

*Direct payments you’ve got to try find someone, you got to make sure that person understands the child needs and it’s a massive burden on a parent.*  
(FC1)

It was suggested that specialist leisure activities would provide families with an alternative to employing someone to use their direct payments or provide a source of suitable staff to recruit from, therefore reducing the stress and burden. Another theme to come out of the interviews was how the need is more important than the diagnosis.

*“A one size fits all is not really suitable when you’re dealing with services for children with disabilities [...] there probably is a need for different groups for different children’s needs” (FC3)*



One parent commented that children with different diagnoses may have similar traits or challenges, therefore they require access to the same services, and separating support services into different diagnoses may create a barrier.

*“I think it’s the need, so it doesn’t matter what diagnosis, so like the example I gave there with attention, so people with Down’s syndrome, people with ADHD or ASD, any could have problems with attention, so I don’t think the diagnosis matters it’s the need [...] some of these sessions, people ask do I need to have a diagnosis, it almost creates like a barrier if they have to have that to be on the session, but if what they’re describing resonates with you and you think it will benefit your kid, do it.” (FC2)*

A professional suggested that mixing groups so that children with a variety of abilities can socialise could be beneficial, however families may benefit from receiving peer support from other families with children with similar needs as their child.

*“When families come together, if their children have similar needs they can discuss you know what strategies they’re using, what help and support they access, but I think it would also be really good for the children who have you know mixed abilities and different social skills to all come together and socialise and families to get different perspectives on things as well” (PC2)*

## **Support for the Wider Family**

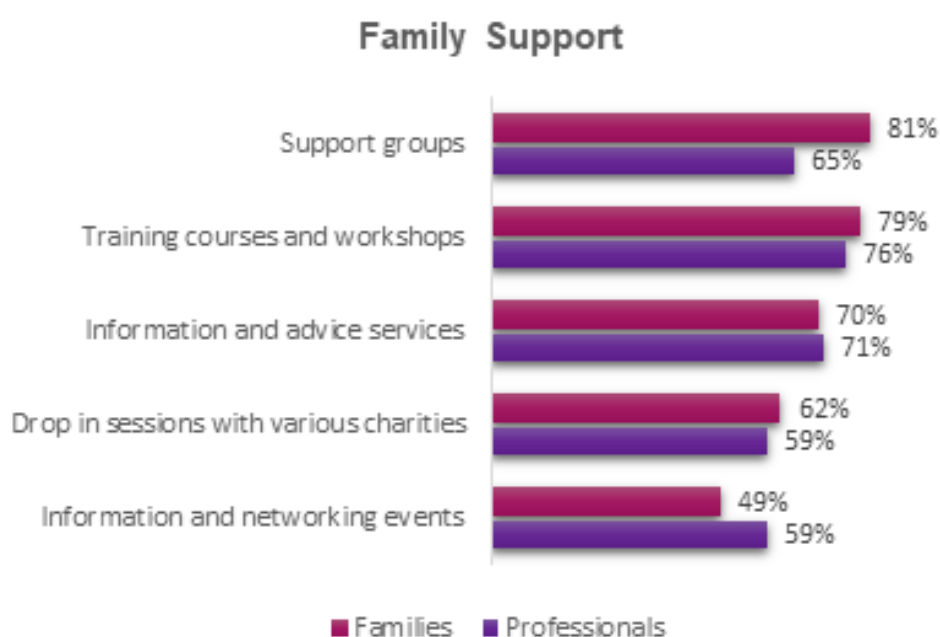
The following findings are taken from the remaining 47 family participants and 17 professional participants. When asked what support they would like to be available for families of children with disabilities, family members and professionals largely agreed that support groups, training courses and workshops, and information and advice services would be most beneficial.

The impact of a child with disabilities on the wider family was discussed during the interviews. Again, the isolation faced by these families was brought up.

*When you have a child with a disability and particularly one with such high needs as [child 1], you decline a lot of invites at the start because your child can't cope, the invites stop, your house isn't quite as fun a place to come, so people stop coming, so you lose a lot of friendships that you had for a long time because people just don't, they don't know how to be around you anymore.*

(FC1)

One parent mentioned how, even though they knew other families with children with disabilities, the lack of services and the boundaries in place for services still left them isolated.



*I guess for me personally I just feel like outside of the you know the children's appointments and stuff I don't feel very like supported or included in anything community based for parents of children with disabilities [...] the stay and play [Little Stars], we were actually in Serennu last week for a multi-agency meeting, saw one of our friends with her little boy who's also like maybe a few months older than [my child] and she was like 'oh you want to join?' and I was like we'd love to but we can't [...] I know that there are people within our Downs Syndrome support group that attend so we can't socialize in that way because of our postcode.*

(FC3)

This quote suggests that, due to the boundaries and catchment areas currently enforced on services, family members would only be able to receive peer support from other families within their catchment area, whereas in reality friendship groups and support networks are not confined to certain geographical areas. One professional commented on the toll having a child with additional needs takes on the wider family, including siblings and grandparents.

*“The siblings take on an awful lot, they either end up as young carers or they end up, not being neglected by any stretch of the imagination but they probably do lose out on things because of the care their siblings require, and a lot of our young people have extended families that support and care for them, so you know grandparents, they tend to get a bit forgotten because you have appointments with the parents but the grandparents might have a big part in the caring but don’t have the follow up and the support for that” (PC5)*

Opportunities for peer support and information were requested by interview participants, particularly so families could learn from others who have been through similar experiences as them.

*“It would be nice to meet other parents [...] how lovely would it be to get to chat to someone who's got a 14 year old version of [my child] you know and be able to like discuss things that I wouldn't be asking on online, private things like how to get through puberty you know” (FC1)*

*“I think we would feel supported if we felt included just being able to access things for our kids and make our family life easier because something's available for our children is what we ultimately want as parents, to be able to connect with the other parents in meetings and groups and things like that, peer support is invaluable so being able to talk to like-minded parents, parents who understand what it is to have a child with a disability” (FC3)*

Families were able to connect at the Activity Taster Days whilst their child was engaging in activities with Sparkle Play Workers; parents were observed talking to one another and swapping contact details. One parent, whose child attend a session for 0-4 year olds, said this:

*We would love to attend a group on a regular basis. I would happily attend to meet other parents like ourselves too.*  
(Family member)

A professional suggested that peer support and information would be beneficial, however having a professional who can moderate and ensure the information shared is accurate would provide a safe space for families.

*“Definitely having support groups for families, somewhere they can meet other families with children who have similar disabilities so they can have sort of, not only the tips and ideas and advice on what’s worked and what hasn’t, but I think just having that emotional support of oh there are other families that are going through similar things to us and we’re not the only ones, because I think sometimes you know in school they might be the only child in a class who has a certain diagnosis and it can be a bit overwhelming sometimes, so I think if they had access to support services, and I think something that is well run as well, something where the information provided is good solid information rather than some of the things we hear about vaccines and conspiracy theories and all that kind of stuff, I think it needs to be an environment that is very safe so that the information that is presented is accurate and helpful” (PC4)*

Practical support and training was also requested by family members.

*I think it’s like practical things, so again your child gets diagnosed, you go on an early bird course, and then you get nothing in terms of like parental training [...] so for me it’s just anything where professionals can impart their knowledge to me.*  
(FC2)

*“I think that even manual handling, I struggle to move [child 1] and she’s got mobility problems [...] I’ve pulled my back out about 6 times, I’ve never been on like a ‘how to safely move your child’ [course]” (FC1)*



Finding an ideal time for these events to take place may be difficult, as some families suggested evenings and weekends would be more convenient for them to attend around work, whereas others said if these events happened during school hours they would not need to organise childcare to attend. Professionals commented that both options would be necessary due to families having different circumstances. This was echoed by interview participants, who also suggested recording training events and sharing slides with families who cannot attend due to the time of the course would be beneficial.

*“The fact that they’re always in the day, so there’s like this theme where parents of disabled kids don’t work so they have time to attend these things in the day, so again if they have to work in the day because that’s when people are employed and they can’t run in the evenings, then if they could be recorded or have the slides sent out, so that people like us who work don’t miss out on them” (FC2)*

Of the 47 families responding to the questionnaire at this point, 32% were already subscribed to the Family Liaison Service mailing list. Of those who were not subscribed, 94% said they would be interested in receiving information from the Family Liaison Officer (details of how to subscribe were provided).



# Facilities

Participants were asked what facilities they would like their children or the children they work with to be able to access. Families and professionals both felt sensory spaces would be most beneficial to the children, whilst families also wanted access to an inclusive playground. A specialist soft play area, swimming pool, ball put and trampoline were also very popular amongst families.

Sensory spaces



68% of families  
65% of professionals

Accessible playground



68% of families  
59% of professionals

Specialised soft play



64% of families  
53% of professionals

Hydrotherapy pool



62% of families  
59% of professionals

Activities for Daily Living flat



38% of families  
53% of professionals

Rebound Centre



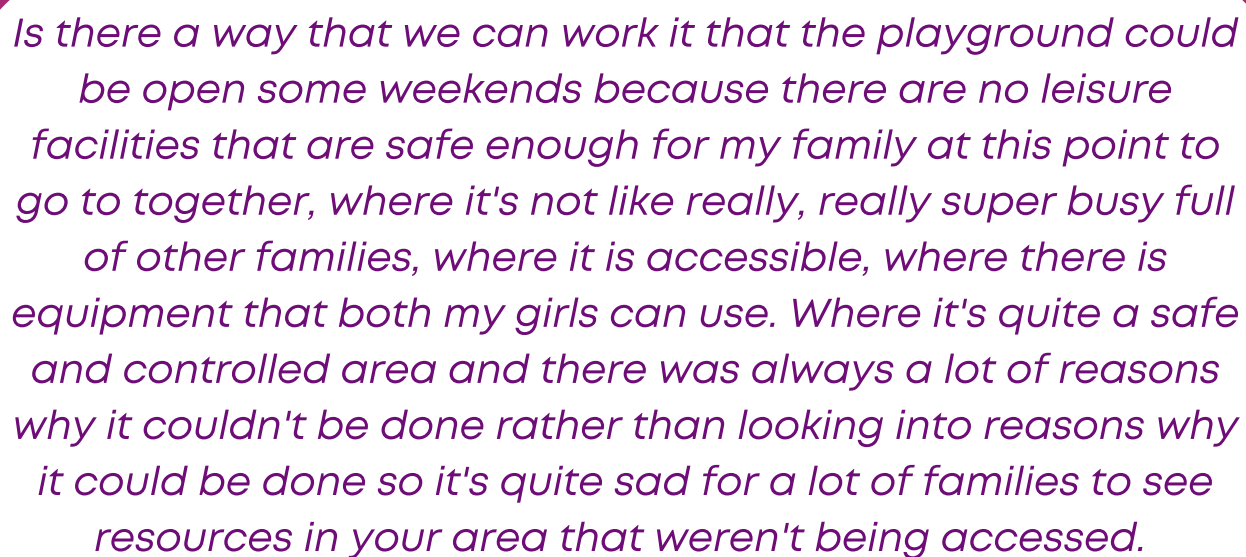
38% of families  
47% of professionals

It was discussed during the interviews that Caerphilly Children's Centre has a lot of facilities already, however these are restricted and therefore not being fully utilised, such as the playground at the Centre, which is not accessible to the public, the rebound room and the swimming pool\*.

*"So all those things exist there as equipment, but they never get used, so again a trampoline club or a swimming club or something like that would be just great" (FC2)*

*"I don't think there is unless you are there for an appointment, I don't think you get access to those, you definitely don't have access to hydrotherapy unless you have an appointment with a physiotherapist for it. So, you can't go for a swim session" (FC3)*

\*The swimming pool at Caerphilly Children's Centre has been condemned and is currently closed.



*Is there a way that we can work it that the playground could be open some weekends because there are no leisure facilities that are safe enough for my family at this point to go to together, where it's not like really, really super busy full of other families, where it is accessible, where there is equipment that both my girls can use. Where it's quite a safe and controlled area and there was always a lot of reasons why it couldn't be done rather than looking into reasons why it could be done so it's quite sad for a lot of families to see resources in your area that weren't being accessed.*

*(FC1)*

Families that attended the Activity Taster Day at Caerphilly Children's Centre praised the facilities; one family member commented on how the facilities at the Children's Centre are tailored to meet the needs of children with disabilities.

*"All the toys and activities were arranged with her needs in mind and featured lots of sensory toys. She particularly enjoyed the sensory room, which we had not come across before and the park behind was an added bonus. This place is fab and set up with SEN children in mind."* (Family member)

Professionals used the interviews as an opportunity to share what facilities they required as part of their work, such as a dedicated space for weighing and measuring children with wheelchair scales and mats for measuring children who cannot stand to be measured. Participants also commented on facilities not being available at the Children's Centre.

*"We use rebound frequently, it's part of our day to day, you know we do hydrotherapy but at Caerphilly at the moment the pool is condemned so we can't currently use that, so we would look at taking the kids that need hydro to Serennu to do the session or having access to the pool at YYF at the hospital"* (PC5)



Some families who participated in the questionnaire suggested a lending library could be useful so that they can borrow specialist toys and equipment that they cannot afford, or try pieces of equipment to see if they are suitable for their child before deciding to make expensive purchases. Interview participants were asked for their thoughts on this, and the responses were very positive.



*“That would be fantastic, basically [my child] is very sensory and if you look at the costing of anything sensory wise it's very pricey, so yeah being able to lend something sensory before you decide to invest or even apply for a grant for it would definitely be worth it” (FC3)*

*“Sometimes the stuff that you give the kids for fun, maybe it isn't something that's part of the discussion with OTs, I think for me it's just we've bought stuff before where it's just been a big waste of money so it's, yeah for me that would be brilliant.” (FC2)*

Professionals were able to suggest a few pieces of equipment or resources that may be beneficial to be available as part of a lending library. Educational tools such as mood models and books on communication were suggested, as well as low tech communication aides and toys to work on interaction and attention. However, when asked about how the lending library would work practically, there was a number of challenges identified that would need to be addressed. Family members seemed happy to pay a deposit for items, however professionals were concerned some of the families they work with would not be able to.

*“I wouldn't mind paying a deposit to lend things, yes it's expensive equipment so you can't expect to have it, if you broke it it's your insurance to fund it at the end of the day so it comes back so yeah, I wouldn't mind paying” (FC3)*



*“I think it varies what financial situations these families are in you know, I think some would be more than happy to pay but others would really struggle with that” (PC2)*

There was also concerns over how families would receive and return the items, however participants were able to offer some suggestions on this challenge.

*“It’s a bit of a nightmare you getting stuff back, so maybe it’s just you come along and try them at the centre or something [...] maybe just you could email round a list of what’s in the centre and if anyone just wanted to come and try things or have a little go they could arrange an appointment to come in and try if there was something specific there, like I don’t know if there is but like an adapted bike or adapted seat or specialist equipment, you can go in and give it a whirl at the centre, that might be better than lending stuff.” (FC2)*

*“I suppose maybe if parents could access like a catalogue see what they wanted, I would be more than happy if I was in the area to drop things off for families” (PC2)*

One professional was concerned about families borrowing equipment which was not suitable for their child, therefore it was suggested that for certain items a recommendation should be required from a professional working with the child.

*“I suppose it depends what sort of thing we’re talking about, like families have gone out and bought walkers on their own or like handling equipment, like the [Upsee Mobility Harness] [...] it’s something that families really like but for some children it’s something that we really wouldn’t recommend” (PC5)*



## Location and Equity of Services

The professionals who took part in interviews all agreed there is a huge discrepancy between what families in Serennu Children's Centre catchment area can access and what families in Caerphilly can access.

*"I think the biggest thing that comes out is some of our families have appointments in Serennu for example even though they're based here, and they know oh they've got a pool there and oh they've got the cinema there and there's siblings group and lifestyle groups and all those things going on that aren't going on in Caerphilly"* (PC4)

*I don't think they have access to the same services as what the children of Newport have to access by SCC, certainly the facilities and probably the MDT work that occurs* (PC1)

Both families and professionals have commented on how some families have to attend Serennu Children's Centre for certain appointments, yet are still unable to access the Centre for other appointments or for leisure as they live in Caerphilly Children's Centre catchment area.

One professional also commented that Caerphilly leisure facilities are generally sub-par to public facilities in other areas.

*I think Caerphilly is at a disadvantage because the leisure facilities aren't great, compared to Newport [...] just within the local authority.*  
(PC5)

Children with disabilities in Caerphilly who attend bases in mainstream schools are at a further disadvantage, as there is a discrepancy between the services and facilities available to children who attend special schools and mainstream schools. The special school in Caerphilly has a variety of specialist facilities and offers some leisure activities, as described previously, however both professionals and family members have said these are not open or available to children who do not attend the school, even if the child is likely to attend the school for secondary classes.

*"The school have got a rebound room a hydrotherapy room a light sensory room, so they have got a lot of facilities, but Trinity at the moment they're not*

accessed by anyone in the community, and I can't say for certain if they were before Covid." (PC3)

*She went to a base unit in [a mainstream school] and there is quite a gulf between what things are accessible for children in a base unit compared to things that are available for children say in Trinity Fields. [...] They had like children discos, inclusive discos, fairs and fetes and all the rest of it and base unit children at that point and I still don't think they're very much included, they had nothing, yet they couldn't also access anything to do with the mainstream part of the school. [...] I know like [child 2] is in a base unit now and that's not a Trinity satellite and I 100% know they're not invited to anything that Trinity puts on, even though a lot of their children will end up going to Trinity for secondary school, so again, there's that disconnect.*

(FC1)

These issues triggered discussion during the interviews around the locations or the Children's Centres and the boundaries between the catchment areas. Whilst some participants found Caerphilly Children's Centre easy to access as it was close to home and they had access to their own transport, others struggled to access the Centre due to the location and said they would find it much easier to attend Serennu Children's Centre due to the transport links.

*"The bus from [home] to the Children's Centre can take anytime from one hour to two hours and it always involves 2-3*

*bus journeys and I have 15-minute walk with the two bus journeys or like a 10-minute walk with the three bus journeys [...] We love Caerphilly children's centre, we've been going there for years, the professionals there are amazing, so if it was just based on that I'm sure it's completely equal, but for the ease of access and for the facilities, the activities and things we would love to be able to come to Serennu, and I wouldn't need to get my husband to book annual leave every time we had a medical appointment, it would be much easier for the children's medical care." (FC3)*

It has already been mentioned that one family from Rhymney that attended the Activity Taster Day has to travel to different locations for their children to attend a school. This family commented that they live near the Caerphilly-Blaenau Gwent border and may find it easier to attend activities in Blaenau Gwent than in Caerphilly. Professionals who were interviewed also recognised that families may find it easier to access Children's Centres or services outside of their catchment area.

*"Some of my Rhymney families might even be better travelling into Blaenau Gwent for some things [...] I think there's better links for them to get into Tredegar and then on to Ebbw Vale than going all the way down to Caerphilly, I know there's a train but it is probably quicker just to shoot down the heads of the valleys if you've got access to a car [...] I think if families did have that choice of you know which one it would be easier for them to attend" (PC2)*

*You've got families in Risca and actually the children's centre is quite far away from them but they can see Serennu down the road [...] the Rhymney valley families might want to go to BG, but the Risca families would definitely prefer to go to Serennu because it's so much closer, and then the bit in the middle would go to Caerphilly.*  
(PC5)

*"I think we expect some families to travel a long way with children with really complex needs, it is not always possible and is not just sometimes you know it could be numerous appointments in that month or week, that is quite a lot to expect from some families to be able to do that." (PC1)*

Initially some professionals were concerned about the effect families being able to access their most convenient Centre would have on their work, however participants felt strongly that whatever is best for the families is what should be done.

*"I'm obviously used to contacting and running meetings and having discussions with the staff that*



are attached to Caerphilly Children's Centre [...] so whenever you step outside of that if you are working with a family involved with lots of different professionals that we don't necessarily have that same relationship with it just, it can make things a little bit trickier and things can take a little bit longer to get done so it sort of increases your work load a little bit." (PC4)

"I think people tend to live in certain areas closer to where they work as well, so, but you know at the centre of everything is the families and we have had

families where they live very close to Serennu and then they're questioning why they have to travel here to see you, and I think we have tried to accommodate that, so you know we just need to build in that flexibility really because it should be about what's easier for them" (PC3)

Some professionals commented that they are already seeing families and children in multiple places, such as at school or home, therefore it could be suggested that seeing families at a different Children's Centres would not have a negative effect on their workload. It was also suggested that this could lead to staff being more appropriately located within Gwent.

So it was a mixture of seeing them in the Children's Centre, I did cover special schools, mainstream schools, occasionally went to nurseries, we used to see them quite frequently in the assessment nursery that was at the centre, and we used to go to patients homes as well [...] it would impact on how many [staff members] were based at each centre, it would be, we would need that information to make the decisions rather than guessing [...] But to be honest some of where we are based now is based on history rather than actual numbers, so it wouldn't be a huge problem if we needed to relocate staff if that makes sense.  
(PC5)

*“So an alignment of our staff to where the demand is and where those, how many staff you need according to the demand in each area. So it might be that currently a lot of staff existing in CCC at the moment aren’t necessarily best placed there and could be moved to another site” (PC1)*

*In the end, professionals were willing to be flexible and were open to change, as long as it resulted in the best possible outcomes for the families they work with.*

*“All my case loads are in Caerphilly, but I would be more than happy you know if a family wanted to have their initial appointment in a different centre, as long as it was easier for the family we could be quite accommodating, so as long as there was prior warning that this family from Rhymney would find it easier to go to Nevill Hall then, either myself could go or I would give a heads up to my colleagues in Nevill Hall that this family was going to there and they could do the initial assessment and then they would come over to me, but I think it’s more about giving options and choices for the families, I think some of my families having to come down to Caerphilly when it is not easily accessible at the moment, it’s in the middle of a housing estate, the bus links aren’t great, there’s a train but there’s still quite a big walk at the end especially if there’s a child with physical difficulties or social communication difficulties or in a pushchair, but yeah I think we could work collaboratively with the other centres and offer appointments where it suits the families, it would be really useful” (PC2)*



# Recommendations

The findings of this consultation suggest there is a clear need for more fully inclusive leisure services in Caerphilly County Borough. There are also other areas of service development which Sparkle could inform, and the following recommendations are made:

It is clear that from a transport perspective the current boundaries for accessing the three Children's Centres in Gwent do not make sense. Families and professionals are in agreement that families should be offered their appointments, and leisure opportunities, from the Centre that is easiest to get to. Specifically, families in Risca should be offered access to Serennu, and those in the Rhymney area access to Nevill Hall and Sparkle leisure services in Blaenau Gwent.

Families would like their children to be able to access the same leisure provisions offered to other children, such as afterschool where the CYP can take part in activities with their peers and experience independence from their parents. It is recommended that Sparkle prioritises the development of a Play Club at Caerphilly Children's Centre, where children would have access to specialist facilities such as a sensory room, secure and accessible playground and rebound room. This would only be possible if the Centre could be used by Sparkle staff *outside of core working hours*. Access to the Assessment Nursery facilities at Caerphilly Children's Centre for a wider range of children outside the nursery operating hours should be explored to enhance access to leisure provision for children in Caerphilly.

Alternatively, provision for **all** children with disabilities and/or developmental difficulties could be delivered outside of school hours from Trinity Fields School, which is described as having a 'resource centre', or from community venues that have access to some facilities, such as a playground.

Responses to the questionnaire and interviews suggested that a Youth Club provision was needed as families mentioned that young people over 8 years are particularly in need of leisure clubs. However, there was a significant lack of interest in the Activity Taster Day sessions for 12-17 year olds compared to interest in the other sessions. It is therefore recommended that a waiting list be started for a Sparkle Youth Club and a provision be developed if/when suitable interest is received.

Family activities and school holiday provision are currently desired by families, therefore these may also be appropriate services for Sparkle to prioritise.

There is clearly an urgent need to commence swimming lessons for children with complex needs in Caerphilly. If the swimming pool at Caerphilly Children's Centre is unlikely to be functional in the near future, use of the hydrotherapy pool at Trinity Fields School should be explored, for both children who attend the school and those who attend bases in mainstream schools.

There was significant interest in the 0-4 years Activity Taster Day session at Caerphilly Children's Centre, and some families may benefit from being able to access Sparkle's 'Little Stars' stay and play provision in Serennu or North Gwent, particularly families who are already attending Serennu for health and social care appointments.



Families in Caerphilly appear to already have access to information and support services, however it is recommended Sparkle works with existing services, such as the Family Liaison Service at Caerphilly Children's Centre, to offer opportunities for peer support and practical training.

A lending library should be explored by Sparkle so that families are able to borrow toys and equipment to support their child's development. This could be something that is offered Gwent-wide as this service is not currently available at any of the Children's Centres.

It is recommended that Sparkle leisure services be flexible so that *families can access their most convenient leisure provision*. Sparkle has extended their access due to the COVID pandemic, and a continuation, or extension of this could be considered in the future.



# Conclusions

Based on the findings of this consultation, the following conclusions can be made:

- ★ Current services available for CYP with DDD, and their families, include sources of information and support for families and some leisure provision for certain CYP, such as those attending the special school in the Borough. However, leisure and family activities are *not* meeting the needs of all CYP with DDD in Caerphilly County Borough; specifically, those children who attend a base unit in a mainstream school have little appropriate leisure provision.
- ★ Both family members and professionals celebrated the friendly staff at Caerphilly Children's Centre, and families and Sparkle staff who attended the Activity Taster Day praised the inclusive facilities at the Centre. However, professionals felt the spaces at the Centre were in *need of updating* and families commented about the *lack of access* to the facilities.
- ★ Families in particular requested that play facilities and clubs be available for their children, as well as family activities and a pool where CYP with DDD could access specialist swimming lessons. However, most of all families seemed to want **equity** of service provision; parents wanted their children to be able to access the same opportunities and experiences as any other child, regardless of disability or which school they attend.
- ★ Professionals and most families were keen on services being co-located to facilitate joint or coordinated appointments, however both were open to leisure services being located in the community as long as the necessary equipment, facilities and trained staff were available.



- ★ From the questionnaire responses and interviews with families and professionals, it appears peer support and practical training are most needed for the wider family. This would fill the current gap in service provision, as information and support is already available to families through services such as the Family Liaison Service.
- ★ Sensory spaces and specialised playgrounds and soft play were the most commonly requested facilities among families. Interview participants suggested that they would like to be able to access the facilities that are already in place at Caerphilly Children's Centre, which attendees at the Activity Taster Day commented were well tailored to meet the needs of CYP with DDD. It is clear that if the facilities at Caerphilly Children's Centre were improved (particularly the hydrotherapy pool) that both this site and Trinity Fields School would be appropriate sites for leisure activities for children with disabilities and/or developmental difficulties.
- ★ A lending library was suggested by questionnaire participants, and the idea was praised by all interview participants.
- ★ The location of services was a much discussed issue during the interviews, and both families and professionals felt families would benefit from being able to access their most convenient Children's Centre, despite the changes this would result in for professionals delivering services.
- ★ Based on the findings of this research and development project, recommendations are made for Sparkle's service development in Caerphilly County Borough. A full costing of potential leisure provision will be developed.



# Appendix A

## Sparkle Consultation in Caerphilly

Sparkle recently became a charity partner of Caerphilly Children's Centre. We are constantly aiming to develop and improve the services we provide for children and young people with disabilities and/or developmental difficulties, and their families, and we would be very grateful if you could therefore take a few minutes to complete this survey. Your views and opinions are very important to us and will be used to help us improve and inform the development of new enhanced services for families living in Caerphilly County Borough.

Today's date: \_\_\_\_\_

I am:

- ☐ A child or young person with a disability and/or developmental difficulty (and I have a parent or carer's permission to take part in this survey) Go to 'About You'
- ☐ A parent or carer of a child or young person with a disability and/or developmental difficulty Go to 'You and Your Child(ren)'
- ☐ A professional working with children or young people with disabilities and/or developmental difficulties Go to 'Professionals'

### About You

1) What town in Caerphilly County Borough do you live in/near?

\_\_\_\_\_

2) How old are you?

\_\_\_\_\_

3) Do you have a diagnosis?

Yes (please specify):\_\_\_\_\_ No ☐

4) How long have you been attending Caerphilly Children's Centre?

- ☐ Less than 6 months Go to 'Caerphilly Children's Centre'
- ☐ 6-12 months Go to 'Caerphilly Children's Centre'
- ☐ 1-2 years Go to 'Caerphilly Children's Centre'
- ☐ 3-4 years Go to 'Caerphilly Children's Centre'
- ☐ 5+ years Go to 'Caerphilly Children's Centre'
- ☐ I do not attend Caerphilly Children's Centre Go to 'Children's Centre'

### You and Your Child(ren)

1)What town in Caerphilly County Borough do you live in/near?

\_\_\_\_\_

2)How old is/are your child(ren)?

0-4 years ☐ 5-11 years ☐ 12-18 years ☐

3)Does your child(ren) have a diagnosis?

Yes (please specify):\_\_\_\_\_ No ☐



4)How long have you been attending Caerphilly Children's Centre?

- ☐ Less than 6 months Go to 'Caerphilly Children's Centre'
- ☐ 6-12 months Go to 'Caerphilly Children's Centre'
- ☐ 1-2 years Go to 'Caerphilly Children's Centre'
- ☐ 3-4 years Go to 'Caerphilly Children's Centre'
- ☐ 5+ years Go to 'Caerphilly Children's Centre'
- ☐ I do not attend Caerphilly Children's Centre Go to 'Children's Centre'

Professionals

1)What is your role?

\_\_\_\_\_

2)What are range do you work with?

0-4 years ☐ 5-11 years ☐ 12-18 years ☐ 18+ ☐

3)How often do you work from or deliver services from Caerphilly Children's Centre?

- ☐ Daily
- ☐ A few times a week
- ☐ Weekly
- ☐ A few times a month
- ☐ Monthly
- ☐ Less than monthly
- ☐ I do not work from or deliver services from Caerphilly Children's Centre

4) What 3 things do you like most about Caerphilly Children's Centre?

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_

5) What 3 things do you think could be improved at Caerphilly Children's Centre?

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_

6)Are you aware of any existing services for children and young people with disabilities and/or developmental difficulties in the Caerphilly Children's Centre catchment area which you believe to be particularly valuable?

\_\_\_\_\_  
\_\_\_\_\_ Go to 'Children's Centre'

Caerphilly Children's Centre

1)Have you attended any events or activities at Caerphilly Children's Centre? (For example, parties, play club etc.)

Yes ☐ No ☐

2)If yes, what have you attended and what did you think of the event or activity?

\_\_\_\_\_  
\_\_\_\_\_

3) What 3 things do you like most about Caerphilly Children's Centre?

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_

4) What 3 things do you think could be improved at Caerphilly Children's Centre?

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_

#### Children's Centre

1) What is important to you in a Children's Centre?

- ☐ Location
- ☐ Good public transport options
- ☐ Treatment facilities
- ☐ Play facilities
- ☐ Clubs (e.g. holiday club, afterschool club etc.)
- ☐ Swimming lessons
- ☐ Rebound therapy
- ☐ Paediatric appointments
- ☐ Orthotic appointments
- ☐ Workshops
- ☐ Physiotherapy
- ☐ Speech and language therapy
- ☐ Occupational therapy
- ☐ Assessment nursery
- ☐ Family Liaison Service
- ☐ Disabled children's team
- ☐ Other (please specify) \_\_\_\_\_

2) Would you prefer to have all of these options in one building, or access to facilities and services in multiple places in the community?

- ☐ Everything under one roof
- ☐ Access facilities and services across the community
- ☐ No preference

3) Please give a reason for your answer:

\_\_\_\_\_

#### Services for Children and Young People

1) What leisure services would you and/or your child(ren) most like to see within the Caerphilly Children's Centre catchment area?

- 1)
  - ☐ Warm water swimming lessons
  - ☐ Family activities (e.g. family swim)
  - ☐ Play club (5-11 years)
  - ☐ Stay and play club (under 5s)
  - ☐ Youth club (12-18 years)

- ☐ Holiday activities
- ☐ Independent living skills (14-18 years; opportunities to learn and develop new skills, such as communication, cooking, cleaning etc.)
- ☐ Multi skills club (6 years and older; team sports and activities)
- ☐ Afterschool club (5 years and older; fun activities that encourage learning and development)
- ☐ Fun days
- ☐ Residential trips (12 years and older)
- ☐ Continuing Care (specialist play club for children with complex healthcare needs)
- ☐ Specific activity club (e.g. Minecraft and Lego club)
- ☐ Siblings club
- ☐ Other (please specify): \_\_\_\_\_

1)What days and times would be most convenient for you/your child(ren)/children you work with to attend leisure activities/clubs?

---



---

2)What locations within the Caerphilly Children's Centre catchment area would you/your child(ren)/children you work with be able to attend leisure activities or clubs?

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#### Services for Families

1)What services for family members would you most like to see at Caerphilly Children's Centre?

- ☐ Information and advice service
- ☐ Support groups
- ☐ Drop-in clinics run by various charities
- ☐ Training (e.g. paediatric first aid, sleep workshops etc.)
- ☐ Information and networking events
- ☐ Other (please specify \_\_\_\_\_)

2)What days and times would be most convenient for you/families to attend the above?

---



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3)Are you currently subscribed to the Family Liaison Officer Parent emailing list?

Yes ☐ No ☐

4)If no, would you like to subscribe?

Yes ☐ No ☐ N/A ☐

(Subscribing will mean you will receive information on a variety of things including; Caerphilly Children's Centre events and service updates, local leisure activities, local ASD friendly cinema screenings, local support group meetings etc. To subscribe, please email [lisa.george2@wales.nhs.uk](mailto:lisa.george2@wales.nhs.uk))

## Facilities

1) What facilities would you/your child(ren)/children you work with like to be able to access?

- ☐ Sensory room
- ☐ Hydrotherapy pool
- ☐ Rebound centre
- ☐ Specialised playground/games area
- ☐ ADL (activities for daily living) facilities
- ☐ Specialised soft play area
- ☐ Other (please specify) \_\_\_\_\_

## Anything else?

1) Do you have any other views on the provision of services for children and young people with disabilities and/or developmental difficulties, and their families, at Caerphilly Children's Centre?

---

---

2) Are you happy to be contacted in the coming months to discuss your answers further?

Yes ☐ No ☐

3) If yes, please provide your name and email address below:

---

Thank you for taking the time to complete this survey.

# Appendix B

## Participant Information Sheet

**Research Project: "Consulting families and professionals on the development of Sparkle services in Caerphilly County Borough."**

Thank you for expressing an interest in participating in an interview or focus group, which will give you the opportunity to share your thoughts and opinions on this topic. Please read the following information to find out more about what this entails.

### Background information

Sparkle supports children and young people, aged 0-18, with disabilities and/or developmental difficulties through supported leisure activities, such as Independent Living Skills and specialist Play Clubs and Youth Clubs. We also support the wider family via our Family Liaison Service, support groups, training workshops, and siblings club. In November 2020, Sparkle became an official charity partner of Caerphilly Children's Centre. We are now able to support children and young people with disabilities and/or developmental difficulties, and their families, across Caerphilly County Borough.



What is the purpose of this research?

The purpose of this research is to capture the views of families and professionals on the enhanced support services needed in Caerphilly County Borough, to inform our service development. We will be conducting interviews and focus groups to further explore the answers given to the consultation survey. We want to gain participants' views on the need for Sparkle services in the area, the services that should be prioritised during the planning of our service delivery, and any other issues families and professionals believe we should address in the area.

If you agree to take part in this research, you will be invited to take part in a telephone interview or virtual focus group with other families, via Microsoft Teams, to share your views and discuss your ideas. You will be asked similar questions to those that you answered when you completed the survey, however we will be discussing certain ideas and issues in more detail.

Do I have to take part?

No, it is your choice whether or not to participate in the interview or focus group. If you agree to participate and then change your mind, you can withdraw at any time without giving a reason.

Are there any benefits to taking part?

There are no financial or material benefits to taking part in the research, however you may find participating a rewarding experience that will enable you to share your views. The information you share will help inform the development of new support services for children and young people with disabilities and/or developmental difficulties, and their families.

Will my participation be confidential?

Yes. The interview or focus group will be transcribed and all identifying information will be anonymised. Your name will not be used in any written reports or research dissemination materials. However, if any information about harm or possible harm to children is shared during the interview or focus group, confidentiality will have to be broken and the relevant agencies will be informed.

What happens with the data being collected?

These findings will be written up and presented to the Board of Sparkle Trustees and other interested parties, who will then plan Sparkle's service delivery in Caerphilly County Borough.

Who can I contact for further information?

Please contact Sparkle's Research and Development Officer, Bethan Collins, on 01633 748024 (Monday to Friday, 9am-5pm) or email [research@sparkleappeal.org](mailto:research@sparkleappeal.org) if you have any questions about this project or the consultation.

Thank you for your time.

# Appendix C

## Participant Consent Form

This form is to give your agreement to take part in the research project: “Consulting families and professionals on the development of Sparkle services in Caerphilly County Borough”. Please carefully read the following statements and, if you are happy to take part, please initial each box and sign at the bottom of the form.

I am over 18 years of age.	
I confirm I have read the information sheet and understand the nature and purpose of the project.	
I have had time to think about the project and been given the opportunity to ask questions and discuss the project. I confirm I have received satisfactory answers to any questions.	
I agree to the interview/focus group being recorded and transcribed. I also understand that the interview/focus group transcript will be anonymised.	
I agree to respect and preserve the confidentiality of the other participants.	
I understand that I will remain anonymous, identified only by a pseudonym or participant number.	
I understand that all information I provide during the interview/focus group will be confidential (with the exception of information about harm to children, in which case the researcher 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 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.	
I know how to contact the researcher (Bethan Collins) if I need to.	
I understand this project may be submitted for publication, 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 where to access support.	
I agree to Sparkle processing my personal data in accordance with the UK GDPR and Data Protection Act 2018 for the purposes of this research.	
I agree to take part in this research.	

Participant:

Name (print) .....

Signature .....

Date .....

Researcher:

I confirm that I have explained to the participant the purpose and nature of the project.

Name (print) .....

Signature .....

Date .....

# Appendix D

## Caerphilly Consultation - Family Focus Group Schedule

### Introductions

- Recording and ethical recap.
- Introductions – a bit about myself and Tracey, let everyone introduce themselves but make it clear they don't have to share anything they are don't want to. Some ideas:
- Do you currently attend CCC?
- Where do you live?
- Does your child have a diagnosis?

### Current service provision

- What services for children and young people with disabilities and/or developmental difficulties are you aware of that are already available in CCB?  
(Prompts: are you accessing any of these services? Who are they for, what age group? Where are they? How easy are they to access? How do they benefit CYP?)
- What do you think are the current gaps in service provision?  
(Prompts: Are there any age groups or specific disabilities that are being forgotten? Are there any areas within CCB without access to support services? Is there a gap in school holidays?)

### New services

- What enhanced services would you like to be available in CCB?  
(Prompts: What does your child need right now? Any particular areas they require support? If they were to create their own specialist leisure club, what do you think it would be like? Does your child access residential trips through school? If not, is this something you would be interested in? What times of day/ days of the week would be most suitable? )
- What support for the wider family do you want available?  
(Prompts: What would you like for yourselves? One-to-one support, or group support? What would your ideal support group look like? When would be best, during school hours or after school or on weekends? What about your partner/co-parent, what support do you think they might need? How about other children in the family, would a siblings group be useful? Would a dad's group? What about counseling services – are they aware of the Helping Hands service?)
- There were some suggestions in the survey responses which I would like your opinion on. It was suggested that there is no specific support available for children with ADHD, what are your thoughts on this?  
(Prompts: Do you agree? What support do you think would be helpful? Should we offer support to specific groups, or develop clubs for children with a mixture of different needs?)
- One participant also suggested a lending library, so that families can borrow different pieces of equipment, such as sensory toys and OT resources, and 'try before you buy'. What are your thoughts on this?  
(Prompts: Is this something you would use? What would you want to be able to borrow? How long for? How would booking items out and returning them work? A deposit would have to be paid for the item while it is on loan, what would be a reasonable amount?)

## Activity

·I have a few videos and pictures here of the different leisure clubs Sparkle currently runs in South Gwent. I'm going to give you a short description of each club and play the video or show the picture, and then I want you to write down any thoughts. After we've seen all the videos and pictures, I would like you to tell me which clubs you think would be most beneficial and how we should prioritise setting up new clubs in CCB.

## Facilities

·Are there any specialist facilities that you currently access?

(Prompts: Sensory room/garden? Hydro pool? Rebound? Where do you access them? Who can access/how easy are they to access?)

·Are there any facilities that you currently do not have access to that you think would be beneficial for your child/other children in the area?

(Prompts: Sensory spaces, hydro pool, rebound? Where would you want to access these? How often? Why would these be beneficial for you child?)

·Are there any community facilities that you access which you would like to see more specialist clubs operating from?

(Prompts: leisure centres, special schools etc.)

·If you could attend clubs in Serennu, Caerphilly CC or a new Centre in Ebbw Vale, which would be most convenient for you?

(Prompts – would you be happy for your child to attend a club in a Children's Centre? Special School? Other facility?)

## Close

·That's the end of my questions, is there anything else anyone would like to share?

·Does anyone have any questions?

·Thanks and goodbye.

# Appendix E

## Caerphilly Consultation – Professionals Interview Schedule

### Introduction

·Introductions

·Ethical recap and recording

### About you

·Please could you start by stating your profession and explaining a little about your role?

(Prompts: Where are you based/what area do you cover? What age groups do you work with? Where do you usually see families – CC, YYF, Special Schools, their homes?)

### Current service provision

·What enhanced support services for children and young people with disabilities and/or developmental difficulties are you aware of that are already available in CCB?

(Prompts: Who are they for, what age group? Where are they? How easy are they to access? How do they benefit CYP?)

·What do you think are the current gaps in service provision?

(Prompts: Are there any age groups or specific disabilities that are being forgotten? Are there any areas within CCB without access to support services? Any time of year e.g. school holidays? Residential trips?)



## New services

·What enhanced services would you like to be available for CYP in CCB?

(Prompts: What do you think the CYP you work with would benefit from? What services do you think should be prioritized?)

·What support for the wider family do you think should be available?

(Prompts: What support do you think parents would benefit from? One-to-one support, or group support? How about other children in the family, would a siblings group be useful? Dad's group? Counselling?)

·There were some suggestions in the survey responses from families which I would like your opinion on. It was suggested that there is no specific support available for children with ADHD, what are your thoughts on this?

(Prompts: Do you agree? What support do you think would be helpful? Should we offer support to specific groups, or develop clubs for children with a mixture of different needs?)

·One participant also suggested a lending library, so that families can borrow different pieces of equipment, such as sensory toys and OT resources, and 'try before they buy'. What are your thoughts on this?

(Prompts: Is this something you would recommend to families? How do you think booking items out and returning them would work? Deposit costs?)

## Facilities

·Are there any specialist facilities that you currently use as part of your work?

(Prompts: Sensory spaces? Hydro pool? Rebound? Where do you access them? Who can access/how easy is it to access? Does the travel time impact on who you offer these treatments to? If you use a special school, are there any restrictions on which children you can bring to access these facilities? What about during school holidays?)

·Are there any facilities you think CYP would benefit from being able to access?

(Prompts: Sensory spaces, hydro pool, rebound, outdoor facilities, sports?)

·In the survey responses, the majority of families and professionals said they would prefer all facilities and services to be under one roof, what are your thoughts on this?

(Prompts: Why do you think this is preferred to having services and facilities in different venues across the community? What are the benefits? CCB is a large area, if everything is in one place how would we make this accessible for all families? If there were three equivalent Centres – Serennu, Caerphilly and Ebbw Vale – where do you think you would see children?)

## Close

·That's the end of my questions, is there anything else anyone would like to share?

·Do you have any questions?

·Thanks and goodbye.