

Cyflwynwyd yr ymateb hwn i'r [Pwyllgor Plant, Pobl Ifanc ac Addysg](#) ar gyfer yr ymchwiliad: [A oes gan blant a phobl ifanc anabl fynediad cyfartal at addysg a gofal plant?](#)

This response was submitted to the [Children, Young People and Education Committee](#) for the inquiry: [Do disabled children and young people have equal access to education and childcare?](#)

AEC 36

Ymateb gan: Janet Kelly, Cadeirydd Bwrdd yr Ymddiriedolwyr

Response from: Janet Kelly Chair of Board of Trustees



Welsh Parliament Consultation

Do disabled children and young people have equal access to education and childcare?

Response from: Janet Kelly Chair of Board of Trustees

On behalf of: Sparkle (South Wales): a Gwent based charity that provides enhanced leisure opportunities and enriched life experiences for children and young people with disabilities and developmental difficulties and their families.

Confidential: We are happy for the Sparkle charity's name to appear on the list of published contributors.

The Sparkle charity welcomes this inquiry from the Welsh Parliament into the rights of disabled children and young people to access education and childcare. It welcomes the reference to the UNCRC, which requires services to be 'free of charge and designed to ensure that disabled children have effective access to and receive education, training, health care services, rehabilitation services, preparation for employment and recreational opportunities in a manner conducive to achieving the fullest possible social integration and individual development, including cultural and spiritual development'.

Founded in 2001, it is the sole function of the charity to ensure that children and young people who are neurodivergent, have physical, sensory or learning difficulties have the same valued childhood experiences as their non-disabled peers. We provide, on a weekly basis, a range of clubs and

leisure activities that provide these children and young people with skills, experiences and leisure opportunities. Within 1 year of joining our clubs:

- **9 out of 10 families** found their child to be happier.
- **9 out of 10 children** made friends or played with others.
- **8 out of 10 children** tried new things.
- **9 out of 10 parents / carers** also benefitted from their child attending club.
- **7 out of 10 families** felt their home lives improved.

Leisure activities in the community are often not equipped to support those with complex needs, meaning our young people are more at risk of being isolated and missing out on valuable childhood experiences. The children we support have profound needs; many require 1:1 or even 2:1 support, are non-verbal or have significant communication difficulties, and / or have medical conditions that require constant monitoring, medication and specialist equipment. We run a variety of leisure activities for 0-17 year olds, including play and youth clubs afterschool and at weekends and swimming lessons. We also offer family activities such as stay-and-play toddler group, family swim sessions and screenings in our MediCinema in Serennu Children's Centre. Run jointly with Aneurin Bevan University Health Board, we deliver a fortnightly club for children with more complex health needs.

The 2 attached reports **Accessing Childcare for Children with Disabilities and / Developmental Difficulties (April 2022)** and **Sparkle Annual Report 2022: The views of children, young people and their families accessing Sparkle service in 2022 (February 2023)**, have been produced by Bethan Collins MSc, Sparkle's Research and Development Officer.

They speak for themselves in respect of:

- The difficulties that families have accessing appropriate childcare.
- The impact on funding for nurseries to enable them to provide support for children with additional needs since the introduction of IDPs.
- The impact on job opportunities for many parents due to lack of appropriate childcare, and the social, financial and career impact of this on carers / parents.
- The lack of appropriate leisure opportunities, afterschool clubs, holiday clubs and sports.
- The inaccessibility of local community leisure facilities for children and young people with physical disabilities.
- The breakdown in family relationships due to stress as a result of the lack of appropriate childcare and leisure opportunities.
- **What parents / carers of children and young people have told Sparkle they want and need.**

The Sparkle Annual Report 2022 clearly demonstrates that Sparkle provides a service that meets the needs of children, young people and their families. Children and young people have fun, make friends, learn new skills, have experiences that are new and exciting for them, gain independence and confidence. Parents / carers gain some respite and are reassured that their child / young person is in a safe environment with well trained staff, is happy and having fun and is participating in a leisure experience that is available to all their non-disabled peers in the community.

As chair of Sparkle, I attended the consultation event hosted on the 15th September 2023 at Serennu Children's Centre with Jayne Bryant and Naomi Stocks and welcomed their open approach to listening to the parents / families who attended the session. Listening to the stories of those parents / carers I was struck with how extraordinarily difficult their lives are and how it is incumbent on us all, law makers, statutory agencies and the voluntary sector to which Sparkle belongs, to do whatever is in our power to support these families to care for their children and young people. As a charity with funding challenges, Sparkle does what it can but could do so much more if it was commissioned by the local authorities to deliver the kind of services that these families clearly need and want, which Sparkle has a track record in delivering and which are not being provided in their local communities. Families have told us time and time again that a weekly club for their child or young person can make the difference between coping and not coping, between being in crisis and living a more normal life. It was clear at the meeting on Friday that not being able to maximise your child's life chances, whatever they may be, through school and leisure opportunities, is extremely stressful and heartbreaking for families. Sparkle therefore adds to the host of other voices taking part in this inquiry and appeals to the Welsh Government to listen to the voices of children, young people and their families and make improved provision in accordance with Article 23 of the UNCRC.

Attachment A



Accessing Childcare
for Children with Di

Attachment B



Sparkle Annual
Feedback Report 20



Accessing Childcare for Children with Disabilities and/or Developmental Difficulties

April 2022



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Accessing childcare is an important part of raising children. Childcare allows parents to maintain employment and provides opportunities for rest and social interaction, which in turn helps maintain relationships within and outside of the family. Parents of children with disabilities and/or developmental difficulties have spoken to Sparkle, the charity partner of Serennu, Nevill Hall and Caerphilly Children's Centres in Gwent (serving Newport, Torfaen, Blaenau Gwent, Monmouthshire and Caerphilly local authorities), about the challenges and barriers they have faced when trying to arrange appropriate childcare. Themes that have arisen from conversations, interviews and focus groups with parents are discussed below.

★ Sourcing appropriate childcare

★ Leisure as childcare

★ Impact on employment

★ Impact on relationships

★ What parents of children with disabilities need

Sourcing appropriate childcare

Whilst parents of typically developing children may be presented with many childcare options, from informal childcare by friends and family to formal arrangements such as childminding and nursery, for parents of children with complex needs it can be difficult to find any suitable childcare.

Parents of children who display challenging behaviour or have high support needs often cannot call on family members, such as grandparents, or friends as they would not be able to manage the child's needs. Parents have commented on not knowing where to look to locate appropriate childminders; someone who is trained, understands their child's disability and is prepared to take on the responsibility. If parents are able to find someone, this can often be short term if the childminder finds they cannot manage the situation and resigns from the role. One parent shared how finding childcare providers with experience of working with children with disabilities would put families at ease.

Parents have also commented that private nurseries are not an option as there is not necessarily funding in place to provide the additional support the child needs, as many children require 1:1 or 2:1 support, and their children would find it difficult to access 'traditional' childcare provided by schools, such as breakfast clubs and afterschool clubs.

Many private nurseries will not accept children with additional needs, because without a statement of needs there is no funding to accommodate the extra support required. This limits the time I can have my child in nursery to traditional school hours, which limits job opportunities.

The offer of direct payments to cover the cost of childcare or respite is welcomed, however families are still required to source appropriate workers, a task which families find stressful. Further stress is caused once a suitable person is found as the family have to become an 'employer', calculating wages and tax. Families with children with additional needs rarely have the time to learn about the business side and therefore these arrangements often fail.

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.

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.

Leisure as childcare

For many families, their child being able to attend an afterschool club or sports lessons during the evenings and weekends not only extends the number of hours they can work, but also provides them with opportunities for rest, to run errands or complete household tasks, and for their own social interaction. However, parents of children with disabilities again face the barrier of a lack of appropriate leisure opportunities for their children. Parents are very limited in choice and often have to travel to access suitable provision.

Children with disabilities may need to access leisure at facilities designed with those children in mind. They may need specialist equipment, for example hoists, and parents have commented

My preference would be the Children's Centre because of the accessible nature of it, familiarity of it, of the space that's there, the equipment that they have.

that sensory spaces and accessible and secure outside spaces would be beneficial for their children. They have told us that too often leisure facilities have steps, therefore wheelchairs users are not able to access provisions, and there is often no changing facilities for an older child, e.g. aged 10 who requires nappies.

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.

Families often find leisure provision that is available to children with additional needs requires a parent to accompany them, therefore ruling out any possibility of using leisure as childcare. Parents highlighted how unfair they felt this was, as parents of typically developing children would not be required to support their child during leisure activities.

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.

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 get access to things for six whole weeks, you know it's sort of it feels very unfair sometimes.

Parents who have been able to find leisure provision that is described as 'inclusive' have shared examples with us where this is not the reality. One parent described how their child, who uses a wheelchair, was introduced to an 'inclusive' play group, however they later discovered their child was left sitting in their chair next to a wall whilst other children took part in structured activities and games. The parent decided this was not appropriate for their child and removed them from sessions.

Parents also discussed how they would feel more comfortable if their child accessed leisure provision with other children with disabilities, as they would feel confident that service providers are able to support children with complex needs and that their child would be on an 'equal footing', rather than having to try and integrate themselves into mainstream activities.

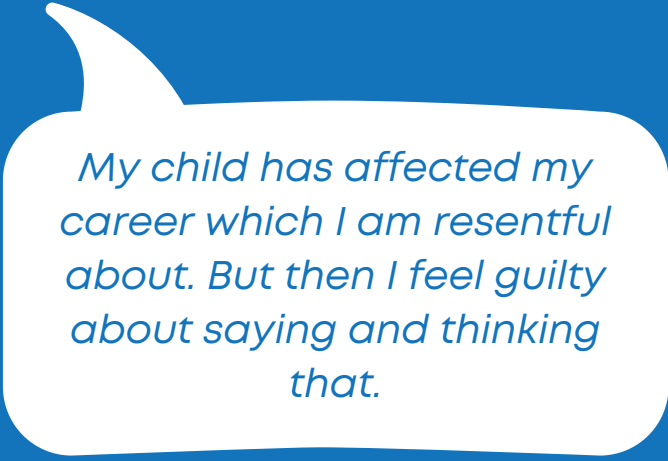
Sparkle provides specialist leisure provision for children and young people with disabilities and/or developmental difficulties living in Gwent, however overall there are very few providers catering for children with very complex needs, including severe communication difficulties, challenging behaviour or severe physical impairment.

[Child 2]'s at the stage where she's feeling very different to everyone else and her differences are becoming quite visible to her [...] 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.

Impact on employment

Parents of children with disabilities have mentioned on many occasions that keeping a long-term salaried job can be near impossible, due to the care needs of their child.

Employers need to be understanding to accommodate medical appointments, and a lack of childcare can severely restrict employment options. Parents talk of finding jobs that fit around their family commitments, rather than jobs they are qualified for or would enjoy. Many parents work at supermarkets because they can work around school hours or late in the evenings when another parent is home. These are specific employment restrictions and considerations that families with typically developing children may not face.



My child has affected my career which I am resentful about. But then I feel guilty about saying and thinking that.

One mother was working as a Personal Assistant to a very successful businessman in London, however after having a child with complex needs she had to resign from the role and has not been in employment since. Despite looking for appropriate positions to match her skills, she has not been able to find employment that would allow her to care for her child. Her daughter is now 8 years old and she feels she would not have been in this situation if her child had not been born with complex needs.

Another parent commented that when someone has a child with a disability their expectations surrounding parenting have to change; most parents expect that when their child is around 12/13 years old, they'll be able to spend an hour home alone after school, meaning the parent can work typical '9-5' hours. However, parents of children with disabilities are not able to do this due to their child's high support needs; they describe their child's lack of cognitive development as essentially meaning they care for a 12/13 year old toddler, and as they have no sense of danger they cannot be left alone for any time. Parents therefore have no choice but to be at home with their child if they cannot source appropriate childcare, limiting their employment options and the number of hours they can work.

Impact on relationships

Parents of children with disabilities often find friendships of many years break down due to their child's needs. This is because friends without children with additional needs do not understand their situation and parents often have to cancel plans or miss out on special occasions and social opportunities with friends as there is no one else to care for their child. Parents have said they tend to mix only with families who also have children with additional needs.

Parents feel there is a lack of understanding from friends and extended family, which puts a strain on those relationships. Family and friends with children will sometimes pass judgement or make suggestions on parenting techniques, which are unwelcome and not appropriate for children with disabilities.

Having a child with a disability or developmental difficulty can also impact on relationships within the home. Relationships are tested because extra time and attention is dedicated to the child with complex needs and this can create resentment with partners and siblings. Siblings may not understand why they do not receive the same level of attention, which can lead to difficult behaviours from this child, adding another layer of challenge for parents to manage.

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.

I hold my tongue with my mother because I need her on occasion to look after my son. I make allowances for what she says to me and I hate myself for this because I shouldn't have to do that but I don't want to lose that one small bit of support I have.

As well as coping with everyday tasks that any family would have, parents of children with disabilities discussed the aspects of their daily lives that they find very draining, including:

- ★ The worry of their child's medical situation
- ★ The extra time they dedicate to the child's needs
- ★ Splitting their time to be with siblings and other family members
- ★ Chasing medical appointments and challenging decisions made by medical and school professionals
- ★ If the diagnosis results in the child not sleeping well or for any reasonable length of time, which in turn keeps them awake

Parents talked about how feeling drained and tired after managing these aspects and looking after their child all day can result in negative interactions with their partners.

When you are pregnant you appreciate that a young child will need your attention, but the expectation is that this will reduce as they get older. At age 8 my son still requires my constant attention which is so draining for me and causes arguments with my husband. I find I walk on eggshells a lot.

When I have managed six meltdowns in one day, I do become snappy.

Another issue that leads to relationship tensions and even breakdowns is when one partner feels they are contributing more to the family than the other, which could be financial if one partner works whilst the other stays at home to care for the child, or time if one partner does not feel they get a break from caring responsibilities. One father commented that he resented being in work during the day and then being expected to take over tasks at home; he felt he did not have any 'down time' and this led to the family break-up.

A lack of childcare plays a massive part in relationship breakdown between parents of children with disabilities and developmental difficulties. The time dedicated to the child creates resentment regarding available personal time to share together or for personal interests and hobbies. Parents can also feel like 'ships in the night', always missing each other because one parent goes to work when the other gets home as they cannot work at the same time due to a lack of childcare. Relationships break down because parents are not able to spend quality time together or share experiences.

What parents of children with disabilities need

A well-advertised resource, possibly a directory of reliable and appropriate childcare provision that is kept up to date.

I would love for something to be produced by a respected organisation that I trust, that could offer me details for experienced childcare provision, and I would know that the listed details have been vetted.

- ★ Currently the Family Information Service in each borough should provide this information, but it is not always consistent and it will depend on the respective Council as to how useful this may be.
- ★ The DEWIS website can also be used but parents need to know what this is and how to access it, so it needs to be advertised more in schools, clinics, doctor's surgeries etc.
- ★ A point of contact, much like Sparkle's Family Liaison Service, in their child's medical settings where they can receive information on childcare and other important issues.
- ★ Schools to provide information regarding childcare for children with disabilities.



Leisure facilities and services where children with disabilities can engage in sessions with other like-minded children, in a safe and supported environment.

- ★ Holiday clubs at the school the child attends, as this will be a familiar environment for the child and parents will be confident the staff and facilities meet the child's needs.
- ★ Breakfast clubs and afterschool activities tailored to children with disabilities, which will allow parents to seek fulfilling employment.
- ★ Provision for overnight stays. Parents would be happy to pay for such provision as they feel it would help in many areas, especially regarding relationships with their partners.
- ★ Services which allow families to spend quality time together.

Wonderful to have a breakfast club and/or afterschool club at a location that is manned by experienced special needs staff, where my child could be transported to and from school. This would help me greatly to continue my career.




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Sparkle Annual Feedback Report 2022:

The views of children, young people
and families accessing Sparkle
services in 2022.

February 2023

Bethan Collins MSc
Sparkle Research and
Development
Officer



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Acknowledgements

Thank you to all the children, young people and families who participated in this year's evaluation. Thank you to all the Sparkle staff who helped disseminate the survey and to the the Leisure Support Workers who helped facilitate the feedback activity for the children and young people to share their views.

Executive Summary

This report outlines the key findings from feedback collected from families, children and young people who accessed Sparkle services and/or the partner children's centres in 2022.

174



families, children & young people

★ Feedback was received from 125 families and 49 children/young people, a sizable increase on participation during last year's evaluation.

★ Positive feedback was received regarding the Family Liaison Service, with 90% of families saying they were either satisfied or very satisfied with the support and information received.

★ Families felt children and young people had gained social skills and opportunities for social interaction by accessing Sparkle's leisure provision, as well as confidence, independence, enjoyment and a sense of community.

✓ 90%

satisfied with information & support

★ Children and young people described having fun, making friends and using technology at Sparkle clubs; 98% said they felt 'happy and confident' at club.

★ Constructive feedback regarding support groups, information bulletins and events was provided, and suitable recommendations have been made.

I personally think the club is an optimistic atmosphere and I really enjoy being here.
(Young person)



Confidence



Social interaction



Independence



Community



Enjoyment

Introduction

Sparkle (South Wales) directly supports children and young people with disabilities and/or developmental difficulties, and their families, across Gwent. Sparkle is the charity partner of Serennu, Nevill Hall and Caerphilly Children's Centres; services are provided from the centres and community venues within the catchment areas, which cover Newport, Blaenau Gwent, Caerphilly, Torfaen and Monmouthshire. The guiding principle for Sparkle is to ensure that children and young people with disabilities and/or developmental difficulties, 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.

Family Liaison Service

Sparkle employs Family Liaison Officers at Serennu and Nevill Hall Children's Centres; a Family Liaison Officer employed by Aneurin Bevan University Health Board is also in post at Caerphilly Children's Centre, who works closely with Sparkle Family Liaison Officers and

the charity as a whole. The Family Liaison Service provides holistic support for families with a child with, or undergoing, a diagnosis of a disability or developmental difficulty; this includes informal emotional support, practical support such as helping to secure financial support and providing resources, facilitating peer support via groups and workshops, and liaising between families and health, social care and education professionals. The Family Liaison Officers act as a first point of contact at the children's centres, as well as engaging with the local community.

Leisure Services

Sparkle delivers specialist leisure activities tailored to meet the complex needs of the children and young people the charity supports, providing them with a range of valuable childhood experiences that they would not otherwise be able to access. Mainstream leisure activities and clubs are often not equipped to support those with complex disabilities; many of the children and young people Sparkle supports require 1:1 or even 2:1 support, are non-verbal or have significant communication

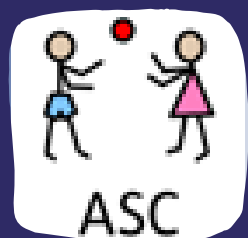
difficulties, experience challenging behaviour, and/or have medical conditions which require constant monitoring, medication and specialist equipment. The aim of Sparkle leisure clubs is to help children and young people develop important skills and increase their confidence, whilst also being fun and a safe space to interact with their peers.

Sparkle's leisure activities include:



Little Stars: A stay and play club for children aged 0 to 4 years (currently only at Serennu Children's Centre).

Play Club: An opportunity for children, aged 5 to 11, to have fun and express themselves in a supported environment (available from all three catchment areas).



Afterschool Club: An opportunity for children and young people, aged 5 to 11 and 12 to 15, to take part in activities which encourage learning and development in a fun and exciting way (Serennu Children's Centre only).

Skills: A club for 6 to 17 year olds to play sports and take part in activities which help develop skills such as agility, balance and co-ordination (Serennu Children's Centre only).



Technology Club (formerly Minecraft and Lego Club): An opportunity for young people, aged 8 to 17, with a shared interest to meet and socialise (Serennu Children's Centre only).

Youth Club: A club for 12 to 17 year olds where they can socialise and influence what activities and projects they take part in (Serennu and Nevill Hall catchment areas).



Independent Living Skills (ILS): An opportunity for 14 to 17 year olds to develop daily living skills, such as cooking and managing a budget (Serennu Children's Centre only).

Continuing Care club: A fun, fortnightly club for children and young people with complex healthcare needs, run jointly with the Health Board (from Serennu Children's Centre for all catchment areas).



MediCinema: A specifically designed 3D cinema for children and young people with disabilities and/or developmental difficulties and their families (at Serennu Children's Centre for all catchment areas).

Swimming Lessons and Family Swim: Opportunities for children and young people with disabilities and/or developmental difficulties to learn to swim and enjoy the water in a safe and supported environment (Family Swim is available from Serennu Children's Centre for all catchment areas, swimming lessons are currently offered at Serennu Children's Centre and will soon be available in the Nevill Hall and Caerphilly Children's Centres catchment areas).



Sparkle also offers activities during the school holidays in all areas, four family events in each area (Spring Fun Day, Summer Fete, Halloween Party and Christmas Party), and residential trips, during which young people can experience independence and try new things, such as abseiling and canoeing.

Evaluation

Sparkle is constantly aiming to develop and improve the services provided for children and young people with disabilities and/or developmental difficulties and their families, and therefore regularly evaluates services and asks for feedback from the families, children and young people supported by the charity. This report outlines feedback received regarding Sparkle's services delivered in 2022.



Method

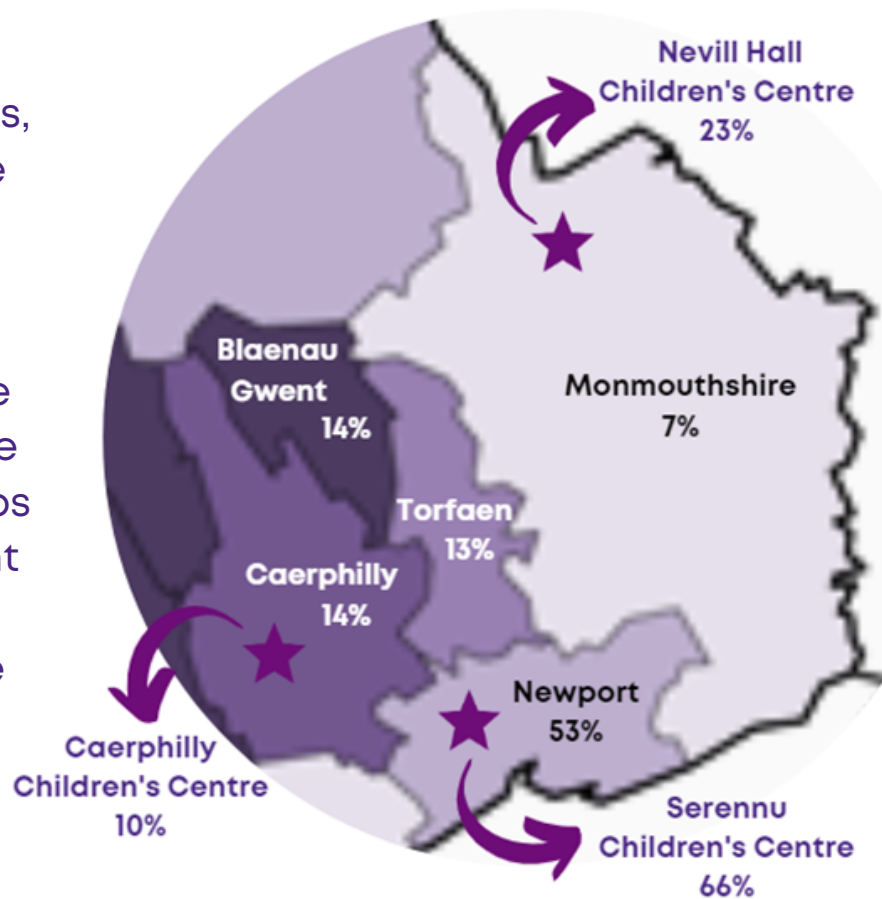
Feedback was collected from families, children and young people throughout January 2023. A family feedback survey (appendix A) was created using Survey Monkey and disseminated via the Family Liaison Officers' mailing lists, contact lists for all Sparkle leisure activities, Sparkle's social media pages and posters at the children's centres. A feedback activity for children and young people (appendix B) was also created; children and young people were given the opportunity to take part during Sparkle clubs, and they could share their feedback by choosing pictures. Quantitative and qualitative responses were analysed and descriptive statistics and summaries of qualitative responses are presented below.

Results - Family Survey

Demographics

The family survey was completed by 125 participants, more than half of which were from the Serennu Children's Centre catchment area.

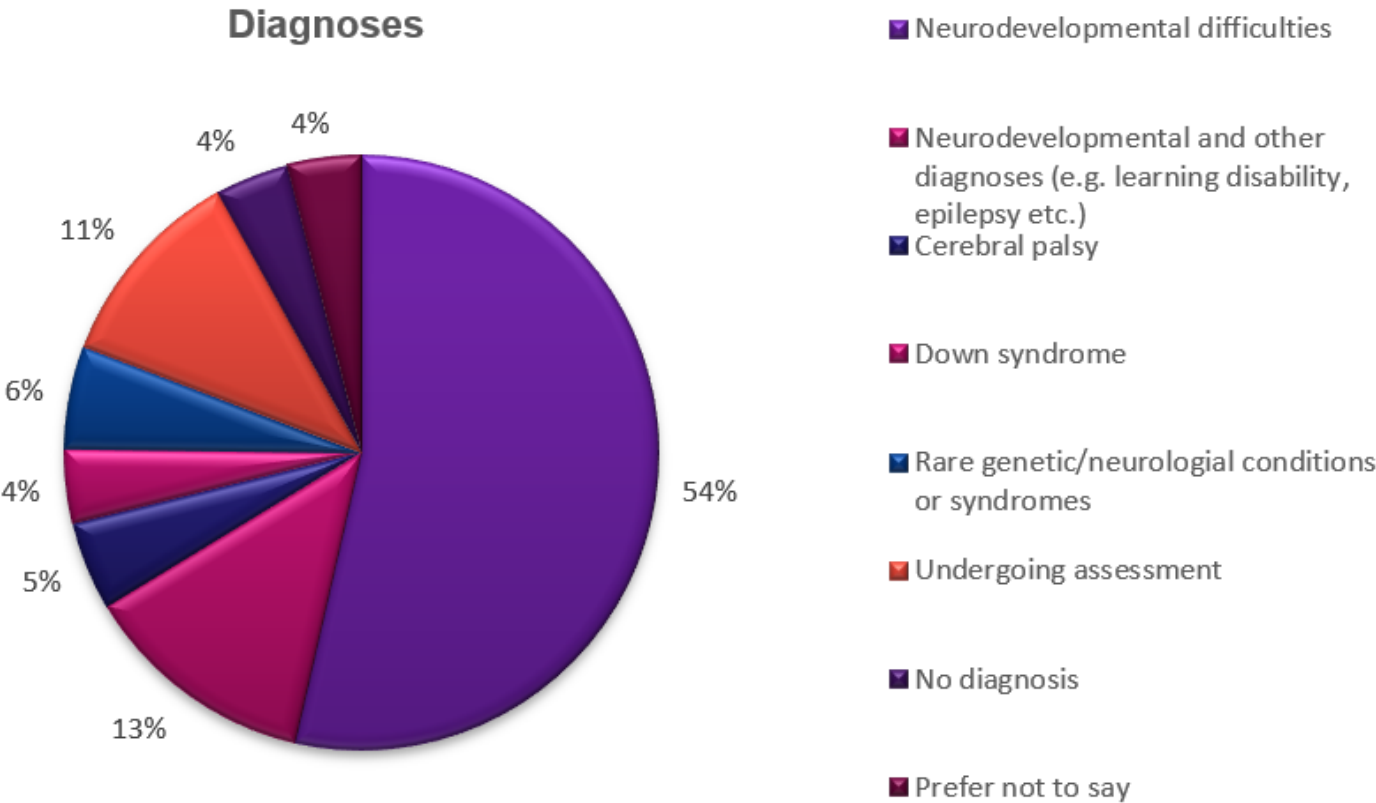
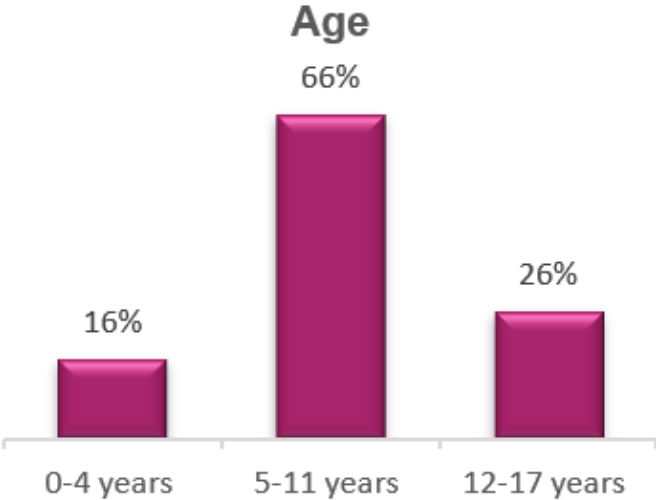
At the end of 2022, there were 151 children and young people accessing weekly leisure clubs (109 in the Serennu catchment area, 31 in the Nevill Hall catchment area, and 11 in the Caerphilly catchment area); this is slightly less than last year, however it has been found that children are presenting with more complex needs and challenging



(1% did not respond to the question regarding which Children's Centre catchment area they lived in)

behaviour, meaning Sparkle is having to provide 1:1 and 2:1 support for more children. There are 860 families across all three catchment areas registered for Sparkle’s family activities.

Participants were asked how long their child had been accessing Sparkle services or the children’s centres; 30% had been accessing less than 1 year, 24% for 1-2 years, 16% for 3-4 years, and 28% for 5 years or more (2% did not respond to this question). Two-thirds of participants had a child aged 5-11 years, and 14% had more than one child accessing Sparkle services or the children’s centres. Neurodevelopmental difficulties were most common, either as a single diagnosis or alongside another diagnosis.



Family Liaison Service

The following results are from the 96 participants who had received support from the Family Liaison Service in 2022. There are currently 1,815 families receiving support and information from the Family Liaison Service, however a more detailed evaluation of this service took place the month before this general evaluation of Sparkle services, which may have reduced uptake.

The majority of participants were either satisfied or very satisfied with the support and information received from the Family Liaison Service.

Participants cited good communication and quick responses from the service as a reason for their satisfaction, as well as the helpful and knowledgeable support offered. The Family Liaison Officers were described as friendly and approachable, and participants felt 'nothing was too much trouble'.



satisfied with
information &
support

In a moment of despair last year, I found myself at Serennu desperate for help. Although [I had] no appointment, the Family Liaison Officer took time to talk me through services and processes to help my situation. She was empathetic, calming, reassuring and guided me clearly on the steps I needed to take to start the ball rolling on an assessment for my child. I'm forever grateful for that unplanned meeting and reassured to know they are on hand to guide me as and when needed.

(Participant 8)

Feedback regarding the workshops and groups facilitated by the service suggested these are 'vital' opportunities to meet and share with parents/carers in similar circumstances who understand their situations.

Useful information and a good way to build up a support network with other parent/carers.
(Participant 97)

Participants shared their views on how the service could be improved. It was felt that parents/carers that worked during the service's 'core hours' were disadvantaged as they struggled to access support and could not attend any support groups which take place during weekdays. Sparkle and the Family Liaison Service have already taken steps to address this issue, which is discussed further in the recommendations part of this report.

Also, whilst the weekly bulletins from the service were praised for sharing important information and signposting to activities, participants felt there was 'too much information to process' and the long documents were 'hard to read' and could 'be a bit of an overload'. Some participants also commented on not finding information relevant to them in the bulletins. It was suggested that the bulletin could be a page on the Sparkle website with links to each section or piece of information, so parents/carers only have to click on the links relevant to them and the amount of information would be more manageable.

Workshops and groups attended:

- ★ Coffee morning
- ★ Helping Hands (psychology) workshops
- ★ SNAP Cymru
- ★ ADHD+ Newport
- ★ T:21 Dragons
- ★ Newport Autism Support Group
- ★ Blaenau Gwent National Autistic Society

It's very diluted now, it's all aimed at stay-at-home parents [...] Great help and courses offered but not if you work. [...] Working parents are totally forgotten.
(Participant 48)

Not attended any [workshops] as these are always in working day. [...] working parents are not included, we still need support!
(Participant 44)

Leisure Services

Half of the 89% of participants who had heard about Sparkle’s leisure services had done so from the Family Liaison Service. The following results are from the 73 participants whose child had accessed Sparkle leisure activities during 2022. The most commonly accessed leisure activity was Play Club, however as Sparkle offers nine Play Clubs across the three catchment areas this is to be expected. The majority (84%) of families access leisure activities via car, however 7% use public transport or taxis and 1% walk to activities (8% did not respond to this question).

Participants were asked, as far as they are aware, which enrichment activities and facilities their child had accessed. Sparkle partners with a number of external organisations to introduce new activities, including sports and music, into the weekly clubs, enhancing and enriching the children and young people’s experiences.

How did you hear about Sparkle leisure activities?



Family Liaison Service



Health or social care professional



Advert at the Children's Centre



Word of mouth

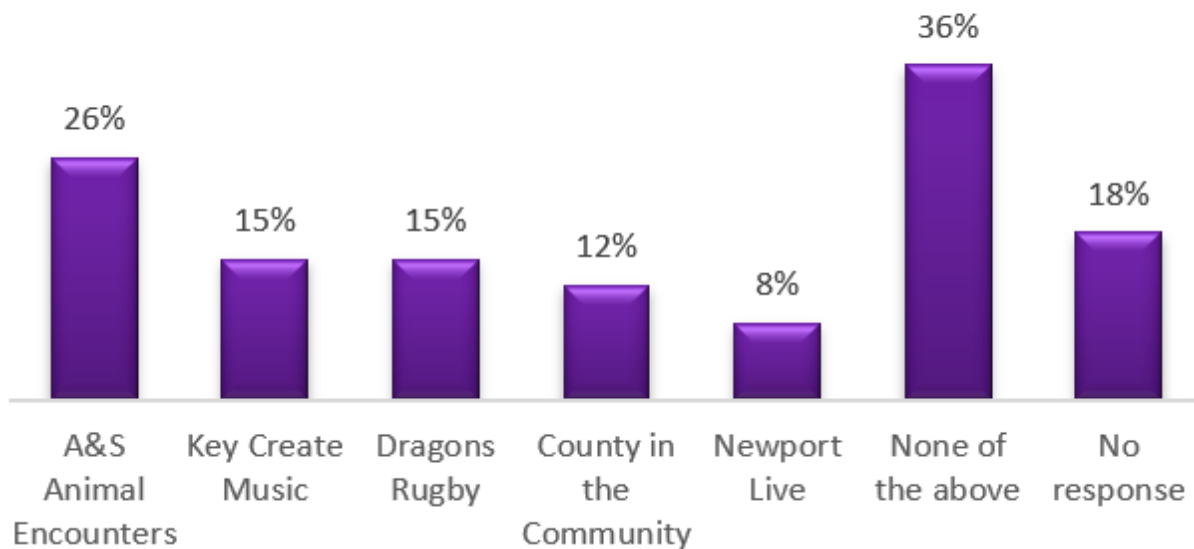


Online search/ social media

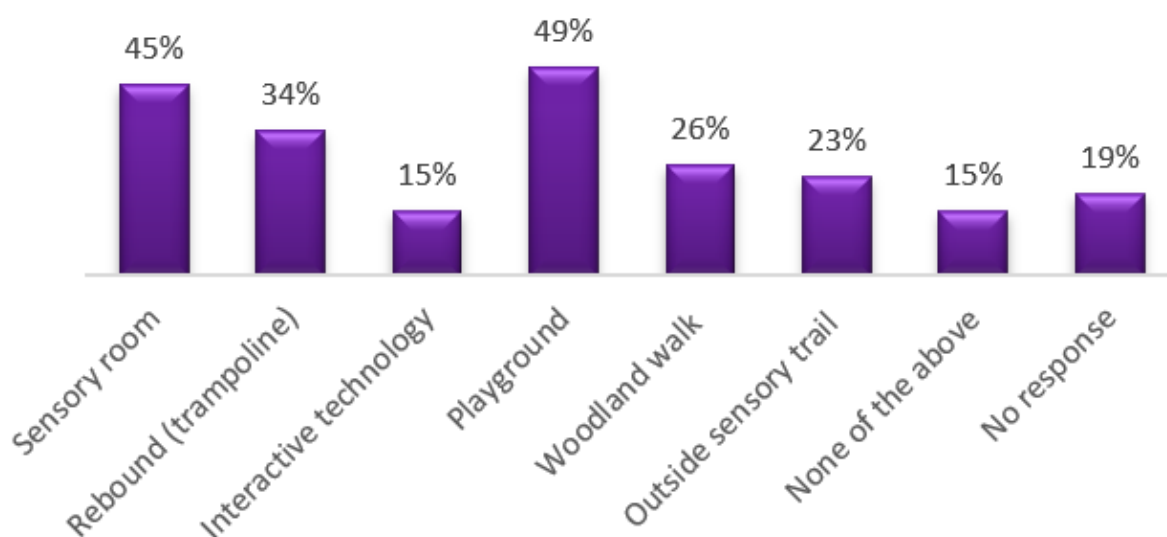


School

Enrichment activities



Facilities



There was praise for the enrichment activities, particularly the musical storytelling and animal sessions, for meeting the children's complex needs, however some participants felt there was too much sport and sessions should be changed more often. Participants felt the facilities available to their child were 'wonderful' with 'lots to see and do', however there were concerns that rebound facilities were not used enough and that Caerphilly children did not have access to the same variety of facilities as those accessing Serennu Children's Centre. There were also specific requests for floodlights so young people could play sports during winter evenings, and bikes or toy cars suitable for older children who had outgrown the 'diddy-cars'.

Lots of opportunities for my child to take part in and workers [are] very supportive and encouraging.
(Participant 14)

For those whose child was accessing or waiting for swimming lessons, participants most wanted their child to learn to swim independently, gain confidence in the water and understand water safety. Participants also wanted their child to gain enjoyment, exercise opportunities and social interaction by accessing lessons. A few participants commented on the length of the waiting list for swimming lessons; swimming lessons at Serennu Children's Centre have only recently been

able to resume at full capacity following the Covid-19 pandemic, and the Sparkle team are working hard to move children and young people off the waiting list as quickly and safely as possible. Sparkle is also attempting to resume swimming lessons in the Nevill Hall Children's Centre (NHCC) catchment area and begin lessons in the Caerphilly Children's Centre (CCC) catchment area, however this is limited by access to suitable facilities (there is no hydrotherapy pool at NHCC, and the pool at CCC is currently non-functioning) as well as increased funding required.

Regarding how Sparkle's leisure activities could be improved, there were further comments about the difference in services available to children at Caerphilly Children's Centre compared to Serennu Children's Centre, particularly the lack of activities for those aged 12-17 years. It was also suggested that an online booking system for activities would be beneficial. The most common request was for more to be offered: more sessions per week, longer sessions, more groups and activities for the 12-17-year group, and more clubs to clear waiting lists. This is a common request every year and demonstrates the high need for Sparkle services.

Sparkle makes every effort to provide activities for all children and young people with disabilities and/or developmental difficulties in Gwent; the charity has significantly expanded services over the past few years, and are constantly seeking additional funding to clear expanding waiting lists; in order to reduce stress for families whose child is on a waiting list for a weekly slot, we offer family activities, events and holiday activities open to all registered families to ensure all children are able to access some level of service. Sparkle would like to assure families that they will continue to fully utilise resources to provide as much as possible for their children, however the current provision costs over £700,000 a year and with costs due to increase in the next financial year it will not be possible to continue expanding services without additional financial support and fundraising efforts from the community.

More sessions available and also throughout school holidays. [...] Also play club to be a bit longer - extra half hour or an hour would be even better.

(Participant 58)

Participants said their children had gained opportunities for social interaction and to develop social skills and friendships by accessing Sparkle leisure provision. Children and young people had also developed skills by accessing the provision, including developing their communication skills, and gained confidence and independence. Participants commented on how the service offers children the opportunity to access clubs similar to those their siblings and other children attend, whilst also feeling safe and having their needs met. The provision provided opportunities for enjoyment and a sense of community.

My child loves coming to play club and I know she is cared for and safe and has lots of fun. The staff are great, always happy to help.

(Participant 14)

Being able to access a safe environment with staff who understand [their] needs has been priceless over the years. My child has gained confidence and really enjoys going to youth club, they have made friends and taken part in many fun activities that they wouldn't otherwise be able to access.

(Participant 21)

We are happy with the existing provision and very grateful to all staff members for their time and effort particularly the team at Caerphilly.

(Participant 20)

My little one has come on loads, she's now used to playing near others and is slowly getting used to children and singing.

(Participant 86)

Events

Sparkle offers four family events throughout the year in each of the three localities; a Spring activity day, Summer fete, Halloween party, and Christmas party . Many participants said they enjoyed these events, however there were a few comments regarding some of the events being too busy and it was suggested to have time slots with reduced numbers throughout the day, and restrict events to Sparkle families as they are unable to attend community events due to their child's needs. There were also requests for clubs not to be on the same day as events where possible, and for more information to be provided before events, such as social stories*.



Christmas party

preferred over a drive-thru style Santa's grotto



Soft play centre

or similar venue for North Gwent events

Timeslots

with reduced numbers for the spring and summer events



Halloween

disco or a specific activity



Recently some additional soft play events have been offered to families; these were praised by participants, and some similar events aimed at 12–17-year-olds (e.g., discos) were requested.

We love the events and the whole family have a great time. Again, the staff are super friendly.
(Participant 14)

We really enjoy the events at Sparkle. Don't feel judged by other people and my children can be themselves. We enjoyed the Christmas event as it was quieter and structured. My daughter enjoyed the Halloween disco.
(Participant 42)

*Social stories are available on request prior to events, however this may need to be communicated more clearly so families are aware of the option.

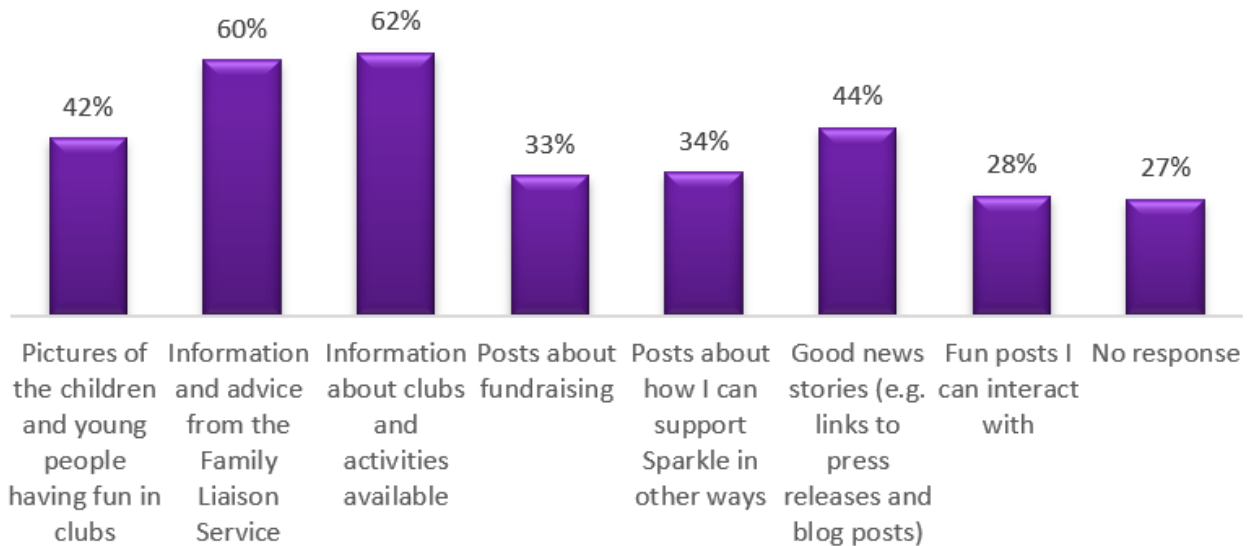
Supporting and communicating with Sparkle



Facebook was the most popular social media channel, with more than half of participants following Sparkle’s Facebook page. This was also the place participants were most likely to look for information about Sparkle, followed by emailing or phoning a member of staff, and checking Sparkle’s website. Therefore, participants most wanted to see information about Sparkle services and what they can access on Sparkle’s social media pages, particularly in the Nevill Hall and Caerphilly catchment areas.

There are some lovely posts, but the majority are about Serennu. When there are not as many facilities in our area, it can be frustrating. But it still is good to hear about the charity.
(Participant 50)

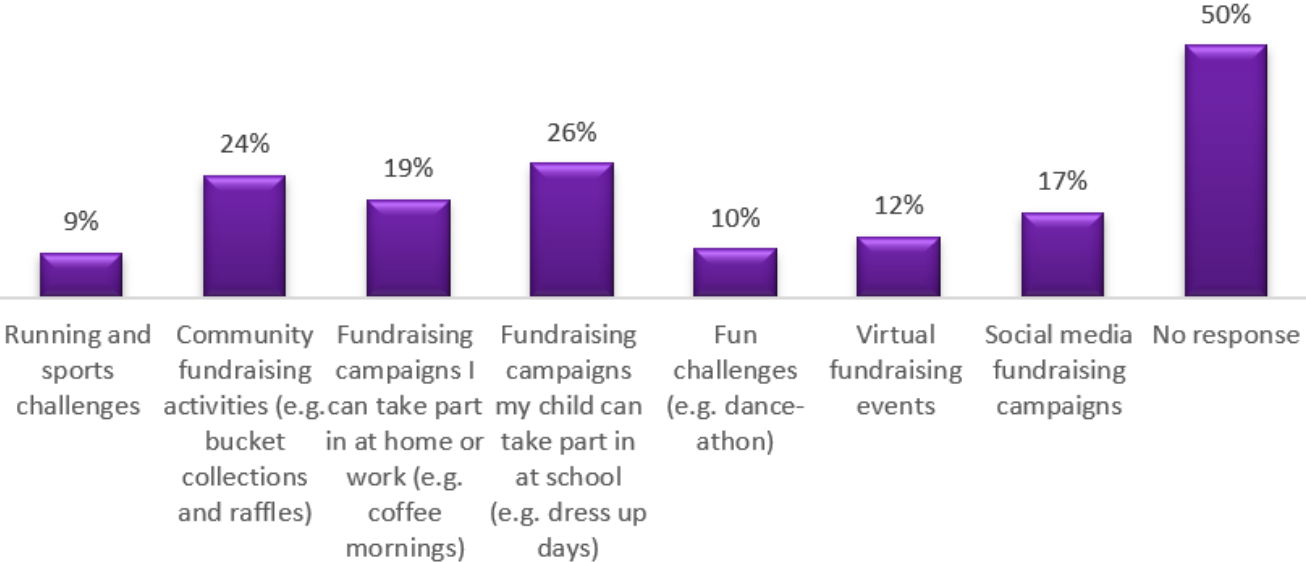
Social Media



In this last section, participants were able to share how they would like to support Sparkle; 46 participants signed up to receive information on how to support Sparkle’s research and development activities, 32 signed up to receive information about getting involved in fundraising activities, and 7 participants said they would be willing to recommend fundraising for Sparkle to their employer. Participants would most like to support Sparkle

with community fundraising activities and fundraising campaigns the children and young people could get involved in, or by volunteering with the Family Liaison Service.

Fundraising



Results - Children and Young People's Engagement Activity

The children and young people accessing Sparkle clubs were also given the opportunity to take part in a short feedback activity; 49 children and young people from across the three catchment areas took part, of which 61% were accessing a Play Club and 39% a Youth Club.

Children and young people were asked whether they felt 'happy and confident' or 'sad and nervous' at club and were able to click on a picture to represent their answer; 98% chose 'happy and confident' and 2% chose both options.

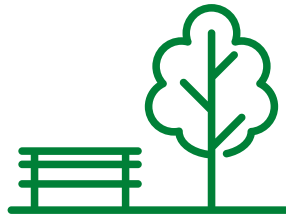


98%
feel happy
& confident

At club I...



have fun
90%



go outside
55%



play sports
35%



sing and dance
41%



am creative
59%



use technology
67%



cook
37%



have friends
73%

A few children and young people made requests, including for 'more toys', 'more Lego', 'more cooking', 'more fun stuff in rebound', 'iPads' and 'virtual reality'.

I personally think the club is an optimistic atmosphere and I really enjoy being here.
(Young person)

It's really fun and I recommend it to other people.
(Young person)

I like that I get to meet everyone, no improvements.
(Young person)

It is perfect just the way it is.
(Young person)



How did we do compared to 2021?



Participation

In our 2021 evaluation, 96 families and 14 children/young people took part; this year, 125 families and 49 children and young people shared their feedback.



satisfied or very satisfied

This year, 90% of families were satisfied or very satisfied with the support and information received from the Family Liaison Service, compared to 83% last year.



Confidence

Last year's evaluation found children and young people gained confidence, developed new skills and made friends by accessing Sparkle's leisure clubs; this year, it was mentioned that children and young people also benefitted from a sense of community.



Skills

Following the last evaluation, it was recommended that the Family Liaison Service's workshops and groups, and Sparkle's swimming lessons, be resumed as soon as Covid-19 restrictions allowed. These services were all resumed in 2022, with families describing the groups as 'vital', although Sparkle has a large waiting list to tackle for swimming lessons, having been unable to run them for two years due to the COVID pandemic. It was also recommended that virtual sessions be avoided where possible, however these were not needed in 2022.



Friendship



Community

Recommendations

The Family Liaison Service was positively received by families, and the workshops and groups facilitated by the service were felt to be a great opportunity to form supportive peer networks with other families. However, many participants felt they were missing out due to groups taking place during core working hours. It is recommended that some groups and workshops are offered during evenings and weekends, to allow more families to access this support. Sparkle and the Family Liaison Service have already begun to address this, by offering coffee mornings at Caerphilly Children's Centre on Saturdays and an evening support group at Serennu Children's Centre.

The difference between the services available in Caerphilly compared to the other catchment areas was raised by respondents; Caerphilly is Sparkle's most recent area of expansion and it is recommended that demand for services in the area is monitored and, if indicated, explore funding opportunities to provide these.

A few specific requests were made for equipment, including floodlights* and certain toys. These will be passed on to Sparkle trustees and the fundraising team for consideration.

The Family Liaison Service bulletins were praised for sharing a wealth of information with families, however participants felt there was so much included it could be overwhelming. It is recommended that the service explores hosting bulletins on a webpage on the Sparkle website, so that families can click on links relevant to them, rather than having to read the whole document.

*Temporary outside lighting has already been secured whilst Sparkle awaits the outcome of funding applications for floodlights at Serennu Children's Centre.

Participants said they were most likely to get involved in fundraising events out in the community, and campaigns that their child/young person could also take part in. It is therefore recommended that this be taken into consideration during the development of fundraising strategies. It is to be hoped that more parents/carers become active in fundraising over the coming year.

Feedback was sought on the family events offered by Sparkle. Following this feedback, timeslots with reduced numbers is recommended for events, with priority being given to Sparkle families over the wider community.

Conclusions

This annual evaluation demonstrates that Sparkle continues to provide effective services for children and young people with disabilities and/or developmental difficulties, and their families. Families have benefitted from the support, information and peer networking facilitated by the Family Liaison Service, and children, young people and families have reflected on the positive effects of accessing a specialist leisure provision.

Information gathered by this evaluation regarding Sparkle's services, events, social media and fundraising activities will have a direct impact on planning and strategies for the year ahead, and Sparkle has already begun to act on recommendations following constructive feedback provided by participants.

Feedback regarding Sparkle's leisure activities included comments on how the provision allows children and young people with disabilities and/or developmental difficulties to access the same opportunities to have fun, interact with their peers and develop new skills as any other child, demonstrating Sparkle's commitment to the charity's guiding principle and vision.

Appendix A

Family Feedback Questionnaire 2022

Your views matter.

We are constantly trying to improve our services, and we need your feedback to do this. We would be very grateful if you could take 10 minutes to complete this survey and share your views on services offered by Sparkle. Your responses are anonymous and will not have any effect on the care your child receives, but will help inform Sparkle's service development, support funding applications and help us best focus the charity's funds.

You can complete this survey online at:

<https://www.research.net/r/SparkleFamilyFeedback2022>

Your Child

1) Which borough do you live in?

Blaenau Gwent

Torfaen

Caerphilly

Monmouthshire

Newport

Other _____

2) Which Children's Centre does your child attend?

Serennu

Nevill Hall

Caerphilly

None, my child accesses Sparkle leisure services in the community

3) How long has your child been attending this Centre/accessing Sparkle services?

Less than 6 months

6-12 months

1-2 years

3-4 years

5+ years

4) How many of your children attend this Centre/access Sparkle services?

5) How old is your child/children?

0-4 years

5-11 years

12-17 years

6) Does your child/children have a diagnosis?

Yes

Undergoing assessment

No

Prefer not to say

If yes, please state their diagnosis _____

Family Liaison Service

(The Family Liaison Service is delivered by Sparkle/ABUHB Family Liaison Officers – Jayne Jones, Sarah Owen, Sarah Painter-Sims and Lisa George)

7) Have you received support from the Family Liaison Service this year and/or are you currently subscribed to the Family Liaison Officer newsletters and bulletins?

Yes No (If 'No', please go to question 14)

If you are not subscribed and would like to find out more about the service, please visit www.sparkleappeal.org for more information.

8) How satisfied are you with the support and information received from the Family Liaison Service?

Very satisfied Satisfied Dissatisfied Very Dissatisfied

9) Please give a reason for your answer:

10) Have you attended any coffee mornings, workshops or support groups hosted by/in collaboration with the Family Liaison Service? (Please select all that apply)

Serennu Coffee Morning Newport Autism Support Group
Nevill Hall Coffee Morning SNAP Cymru drop-in session
Caerphilly Coffee Morning Helping Hands workshops
T:21 Dragons group ADHD+ Newport
National Youth Advocacy Service drop-in session
Other: _____ None of the above

11) Do you have any feedback on any of the above sessions that you would like to share?

12) Is there any way the Family Liaison Service could be improved?

13) Do you have any other feedback about the Family Liaison Service you would like to share with us?

Sparkle Leisure Activities and Clubs

14) Have you heard about Sparkle's leisure activities and clubs at the Centre or within the local community?

Yes No (If 'No', please go to question 27)

If you have not heard about Sparkle's leisure activities and would like to find out more about the service, please visit www.sparkleappeal.org for more information.

15) How did you hear about Sparkle's leisure activities and clubs?

Family Liaison Service

Word of mouth

Health/social care professional

Online/social media

School

Advert at the Children's Centre

Other _____

16) Has your child accessed any of Sparkle's leisure activities and clubs?

Yes No (If 'No', please go to question 27)

17) Which of Sparkle's leisure activities and clubs has your child attended?

Activity/club name: _____

Day of activity/club: _____

Location: _____

18) How do you travel to the Children's Centre/community venue for your child to attend club/activities?

By car Walk By bus By train By taxi

Other: _____

19) As far as you are aware, has your child taken part in enrichment activities with any of the below during their club sessions/family activities?

A&S Animal Encounters

County in the Community

Key Create Music

Newport Live

Dragons Rugby

None of the above

Other _____

20) Do you have any feedback you would like to share about any of the enrichment sessions, or are there any other enrichment activities you would like Sparkle to offer?

21) As far as you are aware, has your child been able to access any of the below facilities during their club sessions/family activities, or have you and your child accessed any facilities outside of Sparkle activities?

Sensory room

Playground

Rebound (trampoline)

Woodland at Serennu

Interactive technology

Outside sensory trail at Serennu

Other _____

None of the above

22) Do you have any feedback you would like to share about any of the above facilities?

23) If your child is accessing/on the waiting list for swimming lessons, what do you hope your child will gain from accessing Sparkle swimming lessons?

24) What has your child gained by accessing Sparkle activities?

25) Is there any way Sparkle leisure activities could be improved?

26) Do you have any other feedback on Sparkle's leisure activities and clubs you would like to share with us?

Sparkle Family Events

27) Sparkle offers family events throughout the year – what would you like these events to look like going forward?

	Yes	No
Christmas event: drive-thru style Santa's grotto		
Christmas event: inside activities and Santa's grotto		
Summer/Spring event: time slots with reduced numbers		
Summer/Spring event: free to come and go throughout the day		
Summer/Spring event: a quiet hour for Sparkle families, followed by a whole community event		
Halloween event: disco		
Halloween event: specific activity (e.g. soft play)		
North Gwent events venue: leisure centre		
North Gwent events venue: soft play centre or similar		
North Gwent events venue: community hall		

28) Do you have any feedback or ideas you would like to share about our family events?

Connecting with Sparkle

29) Do you follow us on social media? (Please select all that apply)

Facebook Twitter Instagram LinkedIn YouTube None

30) What would you like to see on our social media pages? (Please select all that apply)

Pictures of the children and young people having fun in clubs

Information and advice from the Family Liaison Service

Information about clubs and activities available

- Posts about fundraising []
- Posts about how I can support Sparkle in other ways []
- Good news stories (e.g. links to press releases and blog posts) []
- Fun posts I can interact with []
- Other (please specify): _____

31) Do you have any feedback you would like to share about our social media?

- 32) Where are you most likely to look for information about Sparkle?
- Sparkle website [] Phone Sparkle [] Email Sparkle []
 - Facebook [] Twitter [] Instagram [] YouTube [] LinkedIn []
 - Other: _____

Supporting Sparkle

33) Our research and evaluation work is vital to securing grant funding for our services. Would you be happy to be contacted in the future about how you can support our research and development activities?

Yes (please provide an email address): _____

No []

(Your email address will be separated from the rest of your responses, which will remain anonymous)

34) We have to raise over £700,000 a year to run our services, and we are grateful to all those who help us do this. What fundraising activities would you be willing to get involved in for Sparkle? (Please select all that apply)

- Running and sports challenges []
- Community fundraising activities (e.g. bucket collections and raffles) []
- Fundraising campaigns I can take part in at home or work (e.g. coffee mornings) []
- Fundraising campaigns my child can take part in at school (e.g. dress up days) []
- Fun challenges (e.g. dance-athon) []
- Virtual fundraising events []
- Social media fundraising campaigns []
- Other (please specify): _____

35) Sparkle depends on corporate/business donations and fundraising to continue to deliver our services. Would you be willing to recommend donating to, or fundraising for, Sparkle to your employer? (Sparkle's Fundraising Manager can support you with this)

Yes (please provide an email address):

No

(Your email address will be separated from the rest of your responses, which will remain anonymous)

36) Would you be happy to be contacted in the future about getting involved in fundraising activities for Sparkle?

Yes (please provide an email address):

No

(Your email address will be separated from the rest of your responses, which will remain anonymous)

37) Would you be interested in any of the below volunteering opportunities with Sparkle?

Swimming lesson volunteer

Volunteering during clubs and activities

Volunteering with the Family Liaison Service (e.g. during support groups and workshops)

Volunteering at community events (e.g. raising awareness of Sparkle)

Admin volunteer roles

Fundraising and marketing volunteer roles

Other (please specify): _____

(To apply for any of our current volunteer opportunities, please visit <https://www.sparkleappeal.org/vacancies-and-volunteering>)

Thank you very much for taking the time to complete this questionnaire. If you have any further feedback about Sparkle, please contact research@sparkleappeal.org

Please note that this survey is completely anonymous and therefore Sparkle cannot respond to any individual responses. If you would like to discuss your feedback in more detail, please contact our Research and Development Officer, Bethan Collins, on 01633 748024 or research@sparkleappeal.org

Appendix B

1. Name of club: _____

2. Location of club:



Serennu o



Blaina ICC o



SenCom o



Caerphilly Children's Centre o

3. At club I feel...



Happy / Confident



Sad / Nervous

Happy and confident o Sad and nervous o

4. At club I...



have fun

have fun o



go outside

go outside o



play sports

play sports o



sing and dance

sing and dance o



be creative

be creative o



use technology

use technology o



cook

cook o



have friends

have friends o

5. What would you like to tell us about club?
