

Sparkle Impact Report 2024

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Sparkle (South Wales) Charity number: 1093690



Executive Summary

Sparkle (South Wales) directly supports children and young people with disabilities and/or developmental difficulties, and their families, across Gwent.

In 2024, up to **260** children and young people accessed fortnightly specialist leisure activities.

[She] has achieved a sense of belonging and improved self-esteem from accessing Sparkle clubs. (Family-carer) of family-carers said their child achieved, or made progress against, their priority goal for the year.

By the end of the year,

3,185

family-carers and professionals were receiving regular information from the Family Liaison Service. The Family Liaison Service is invaluable to families and professionals in providing an accessible service to all who need it. (Professional)

Sparkle collaborated with a variety of organisations on projects to evaluate services for children with disabilities and their families, and shared their research findings at three national conferences, in addition to participating in Welsh Government Policy groups.

Watch our new **webinars** <u>here</u>

Watch our **video** tour <u>here</u>

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.



Sparkle has a vision that all children and young people with additional needs should be able to achieve their full potential, regardless of their disability or learning difficulties. Sparkle will work to achieve this directly with families in Gwent, and with the knowledge gained, influence change across the UK. Our aim is to achieve this through four key areas of work:

- Equitable enhanced service provision
- for children with additional needs across Gwent
- 2. Training, educating and working with other providers to enable children with additional needs to realise their potential
- 3 Advocacy within Gwent, across Wales (and ultimately the UK) to advance the optimal model of care and support

Conduct in-depth evaluations of our services and explore unmet needs among our families





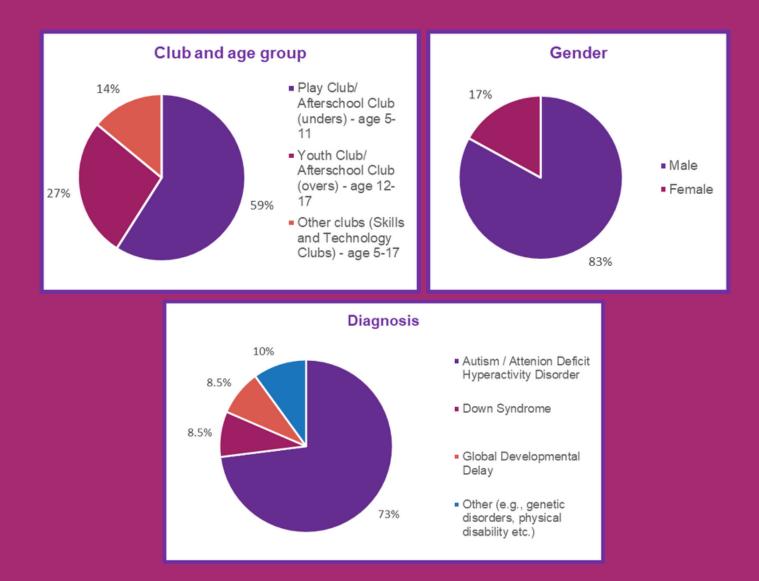
Equitable enhanced service provision for children with additional needs across Gwent

Leisure clubs

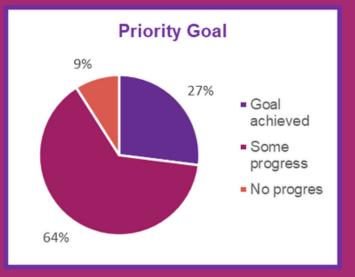
Sparkle delivers specialist leisure activities, such as play and youth clubs, tailored to meet the complex needs of the children and young people the charity supports, providing them with a range of valuable childhood experiences that they would not otherwise be able to access. Mainstream leisure activities 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 nonverbal 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.

Up until summer 2024, Sparkle provided 165 children and young people with spaces in weekly leisure clubs (135 at Serennu Children's Centre, 17 at Blaina Integrated Children's Centre, and 13 at Caerphilly Children's Centre). Following consultation with families, Sparkle leisure clubs moved to a fortnightly provision from September 2024, in order to address significant waiting lists for our leisure services. Sparkle now provides spaces in a leisure club on alternate weeks for 260 children and young people (210 at Serennu Children's Centre, 24 at Blaina Integrated Children's Centre, and 26 at Caerphilly Children's Centre).

Between September 2023 and July 2024, Sparkle conducted an evaluation of the charity's leisure clubs. 'Before' and 'after' surveys were completed by 59 family-carers of children and young people accessing Sparkle clubs.



During the first survey, family-carers were asked to put 5 previously identified goals in priority order for their child: improve general mood and wellbeing; gain confidence; develop social communication skills; develop social relationships; and try new things. During the second survey 9 months later, 91% of family-carers reported that their child had gained or made progress against their top priority goal. 'Gain confidence' was the goal most likely to be achieved by children and young people.





Family-carers also shared that they felt the clubs gave their children a sense of community and belonging:

[She] has achieved a sense of belonging and improved self-esteem from accessing Sparkle clubs. (Family-carer)

[He] loves coming to Sparkle, he says that Sparkle allows him to be himself. (Family-carer)

He feels part of something, he loves coming. (Family-carer)

Family activities and events

As well as independently accessed leisure activities, Sparkle offers family activities for children with disabilities and their parents, siblings, grandparents and other family members. Serennu Children's Centre benefits from a specially designed MediCinema and hydrotherapy pool on-site – families with children with disabilities from across Gwent are able to access cinema screenings and family swim sessions tailored to their needs. In 2024, Sparkle offered 80 family swim sessions, with on average 10 people attending each session. Sparkle also facilitated 8 children's parties, with specialist Leisure Support staff on hand to help. There were 158 MediCinema screenings offered, with 30 attendees on average per screening. A number of events were offered thanks to MediCinema, including special screenings of Inside Out 2 and Moana 2 with activities and give-aways, and a live drawalong and book signing with illustrator Henry Parker and author Adam Kay.



Sparkle runs specially tailored family events throughout the year, again providing opportunities for families with children with disabilities that any other family can access, such as summer fun days and Christmas grottos. In summer 2024, Sparkle organised a fun day at Serennu Children's Centre for children and families from across Gwent who are registered with the charity. The event was attended by more than 450 people and Sparkle was supported by a number of local organisations to provide activities such as games, animal encounters, circus skills, sports skills, making milkshakes, and meeting Gwent Police.

Above all, this is a place of safety and familiarity. All of the families here are united by similar experiences and perspectives, having been through similar situations. Moments of tension are met with understanding rather than judgement, which isn't always the case in the outside world. (Claire, mum of Cerys)



It's been a lovely morning, and witnessing the joy of all the families has been genuinely uplifting. (Mayor of Newport, Councillor Ray Mogford)



Sparkle also organised Halloween and Christmas parties in each of the charity's three catchment areas, with 216 children and their families attending at Halloween and 172 children and their families attending Christmas parties.



Family Liaison Service

The unique Family Liaison Service provides holistic support for families with a child with, or undergoing, a diagnosis of a disability or developmental difficulty. Family Liaison Officers act as a first point of contact for families, and provide informal emotional support, practical support, resources, signposting, peer support via groups and workshops, and liaison between families and health, social care and education services and other professionals. Sparkle employs Family Liaison Officers based at Serennu and Nevill Hall Children's Centres; a Family Liaison Officer employed by Aneurin Bevan University Health Board is based at Caerphilly Children's Centre.

By the end of 2024, there were 3,185 family-carers and professionals signed up to the Family Liaison Service mailing list to receive regular information bulletins. The Family Liaison Service received 732 referrals from the ISCAN (Integrated Service for Children with Additional Needs) panel, SPACE (Single Point of Access for Children's Emotional) Wellbeing/Neurodevelopmental panel, and other professionals between April and November 2024. The Family Liaison Officers had 1,791 contacts with family during the period April-November 2024. Over the summer, Sparkle asked families and professionals for their views on how the Family Liaison Service helps - we spoke to 67 family-carers and over 40 professionals from social care and health service teams, including physiotherapy, occupational therapy and psychology. Family-carers valued opportunities to connect with others who understand their circumstances and a single point of contact who can provide reliable information and guidance. Professionals agreed that the Family Liaison Officers offer a neutral, single point of contact for families and a reliable source of information and support.

> A hand to hold through the journey – knowing what the next step is, knowing what you can access, someone to help overcome all the difficulties. (Family-carer)

The Family Liaison Service is invaluable to families and professionals in providing an accessible service to all who need it. For professionals, it is hugely efficient to have a service where families can be directed to for accurate signposting and support. (Professional)

Training, educating and working with other providers to enable children with additional needs to realise their potential

Swimming lessons evaluation

This year, Sparkle and Disability Sport Wales conducted an evaluation of Sparkle's specialist swimming lessons. The evaluation included a survey, completed by 58 family-carers before and after a block of 10 weekly swimming lessons, regarding the children's progress during lessons, and an exploration of families' experiences of communitybased swimming lessons. The survey found there were small improvements to swimming ability and water safety following a 10week block of lessons, and 95% of family-carers said their child enjoyed being in the water.

Drowning is a leading cause of child traumarelated death, however 81% of survey respondents still felt there would be barriers to accessing community-based swimming lessons after accessing Sparkle's specialist lessons. These barriers included inappropriate environments, a lack of understanding and support, feeling unwelcome and even being denied access to lessons due to their child's needs. We were also shocked to learn that some children with disability are being excluded from school swimming lessons provided within the curriculum. Our evaluation report concluded with a series of recommendations for community leisure providers to break down these barriers and increase access to





swimming for children with additional needs, including offering small group lessons with 1:1 support, ensuring staff are trained in supporting and communicating with children with additional needs, and ensuring appropriate facilities and equipment are available.

The report has been shared with a variety of organisations and the local community via a press release (<u>here</u>). The report is also under discussion by the Welsh Government Cross Party Group for Disability.



Save the Children project

Sparkle was approached by Save the Children regarding a project they were undertaking to find out more about children's lives, the challenges they face and the ways their communities can support them. Save the Children designed their research project with two schools in Wales and wished to ensure the views of children with disabilities were included in their project. Sparkle advised the research team on how to adapt their data collection methods to capture the views of children with complex needs and helped organise two sessions which provided opportunities for children with disabilities to take part in Save the Children's research. The findings from this research are currently being written up, and Save the Children's report will direct how the organisation engages with the Government to influence change for children and families.

Childcare solutions consultation

Sparkle's Chair of Trustees recently joined the Childcare Expert Group for Wales. The aim of this group is to work with Welsh Government to ensure that childcare provision has the child at its heart, supports the workforce and its development, and promotes the sustainability and high quality of childcare settings in Wales. The group also works to ensure that families Wales-wide are supported. Sparkle consulted with families of children with disabilities via a focus group and survey to understand what these families want childcare to look like and provided specific recommendations to be included in the Expert Group's report to Welsh Government. Sparkle has highlighted to the Childcare Expert Group that family-carers of children with disabilities experience additional barriers and have unique needs when it comes to childcare, therefore Sparkle asked for 'children with disabilities' to be added to the group's terms of reference. We continue to be members of this Expert Group to ensure issues facing families of children with complex needs are heard.

If you would like more information on Sparkle's consultation and recommendations, please email research@sparkleappeal.org

Partnerships with sporting and enrichment organisations

Sparkle regularly brings in external organisations to deliver sports and creative sessions. By working with these organisations, we can introduce the children and young people we support to new activities they would not otherwise be able to access, helping them explore their personal interests, whilst also helping to up-skill other providers in working with children with complex needs. In 2024, children and young people enjoyed learning rugby skills with Dragon's Rugby, took part in dance sessions with Dance Blast, made clay ornaments with Inside Out Cymru, and were introduced to a variety of animals by Animals Interactive.



Advocacy within Gwent, across Wales (and ultimately the UK) to advance the optimal model of care and support

Sparkle thoroughly evaluates its support services and the model of care the charity has helped develop, to ensure they meet the needs of children with disabilities and their families and so that we can share our learnings with other organisations and policy makers across Gwent, Wales and the UK.

Conference presentations

In 2024, Sparkle shared findings from our research and evaluation work at three conferences:

- British Academy of Childhood Disability Annual Scientific Meeting on 19th June 2024 in Sheffield.
 Poster presentation: Leisure as respite - How does this benefit families of children with cerebral palsy?
- British Association for Community Child Health Annual Scientific Meeting on 9th and 10th October 2024 in Glasgow.
 Poster presentation: What is the prevalence of childhood disability in Wales? It depends who you ask!
 Virtual poster presentation: How do specialist play and leisure activities impact the wellbeing of children with continuing care packages due to disability?
- ★ Welsh Paediatric Society Autumn Meeting on 8th November 2024 in Swansea.
 - Oral presentation: Family and professional experiences of a novel model of care for children with disabilities.

Webinars project

To maximise our reach this year, we worked with As You See It Media to produce a series of webinars on professional and family experiences of Sparkle services and the novel model of care at Serennu Children's Centre.



tour here

- ★ Webinar 1 Professionals from health and social care, and a familycarer of a young person with a disability, discussed co-location at Serennu Children's Centre, including the pros, cons, learnings and hopes for the future.
- ★ Webinar 2 Representatives from Sparkle's Family Liaison Service and Aneurin Bevan University Health Board's Psychology and Care Coordination services detailed the holistic support available for families with children with disabilities.
- ★ Webinar 3 Sparkle's Leisure Team Lead, a parent representative and a young person shared their views and experiences of specialist leisure activities for children with disabilities.
- ★ Webinar 4 Sparkle's Research and Development Officer and a researcher from Cardiff University explained why research and evaluation are such important parts of service development.

As well as the webinars, a video tour of Serennu Children's Centre and Sparkle services was produced. The tour and webinars have been shared on Sparkle's website and social media, with various organisations and professionals, and at the above conferences. Between March and December 2024, the webinars were viewed on Vimeo up to 159 times (webinar 1 – 159 views; webinar 2 – 98 views; webinar 3 – 106 views; webinar 4 – 67 views). These are also available as podcasts . The full version of the video tour has been viewed 656 times on Vimeo. Watch our new



Conduct in-depth evaluations of our services and explore unmet needs among our families

Sparkle's research work evaluates the impact of our services and the services we have helped develop with our colleagues at Aneurin Bevan University Health Board. In October, we celebrated our research paper on an evaluation of the health board's Care Coordination service being viewed over 1.000 times since it was published last year. We have also shared three manuscripts on exploring how specialist leisure activities impact quality of life for children with disabilities (currently under review with academic journals) on a pre-print server this year.

With thanks to...

Sparkle would like to thank all of the organisations who have collaborated with us on research projects this year, including:

- ★Cardiff University
- ★Disability Sport Wales
- ★Royal Statistical Society Statisticians for Society
- ★Save the Children
- ★Aneurin Bevan University Health Board

Read our research papers <u>here</u>

Cardiff University student projects

Sparkle has recently partnered with Cardiff University School of Psychology to provide research opportunities for postgraduate students. Two students completed their MSc projects, which involved developing and piloting a new method for evaluating the impact of Sparkle's leisure activities on the children's emotional wellbeing and social relationships. Although their results were not statistically significant, likely due to the small number of participants, it was encouraging to see positive emotions and positive interactions between children and leisure staff in particular. Similarly, there were few negative emotions or interactions between children and their peers. We were delighted to find that this method of observing the children was both reliable and acceptable to children and staff. The students and their university supervisors also found the experience to be beneficial and enjoyable.

It made me realise I would like to pursue research as a career and doing this within a charity like Sparkle seems particularly interesting to me. I would definitely recommend conducting research with Sparkle to other researchers. (MSc Student) If you would like more information on the recent MSc projects and findings, please email research@sparkleappeal.org

I found it inspiring to see the passion that all members of staff had in making sure every child was cared for, and how they tailored activities based on the child's interests. I also enjoyed the process of collecting and analysing my own data. Sparkle staff went above and beyond to ensure we were supported. (MSc Student)

Estimating the prevalence of childhood disability

This year, Sparkle was fortunate to receive the support of a volunteer statistician via the Royal Statistical Society's Statistician for Society initiative. This allowed us to conduct a project where we analysed six publicly available datasets to estimate the current prevalence of disability among children in Wales. Current estimates are that 0.6-14% of children in Wales have a disability, with family-report sources reporting higher prevalence (8-14%) than statutory-report sources (0.6-8%). Using population projections and disability figures from the Census, which represents the average prevalence amongst the

datasets, we predict that the prevalence of disability amongst children in Wales could rise to up to 17.5% by 2035.

Our report on this data has been shared with a number of service leads and policy-makers, with the aim of ensuring the figures are taken into account when planning services for children with disabilities. The report, with a particular focus on Gwent data, has also been shared in the local news (<u>here</u>).



Conclusions

In 2024, Sparkle continued to achieve our aim of all children with disabilities maximising their full potential via four key areas of work. We have provided equitable, enhanced services for families across Gwent, including specialist leisure clubs in each of our partner children's centre's catchment areas, and family support, activities and events on a regional basis. We have delivered specialist leisure services to more children and young people with disability than ever before, and continue to expand our family activities. We have worked with other organisations to increase access to services for children with disabilities and their families, including Disability Sport Wales, Save the Children, sporting organisations, and the Childcare Expert Group. We continued to share learnings and promote optimal models of care and support across Gwent, Wales and the UK through conference presentations, academic collaboration and our new webinars. Finally, Sparkle explored unmet needs among children and families through evaluation and research, collaborating with organisations such as Cardiff University, Aneurin Bevan University Health Board and the Royal Statistical Society.