



## **Research and Development Project:**

The views of parents and professionals on  
specialist provisions for children with disabilities  
and their families in North Gwent

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## Acknowledgements

Thank you to all of the young people, parents and Sparkle staff that participated in this research and development project.

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## Summary

In May 2019, Sparkle (South Wales) Limited, extended its reach from Serennu Children's Centre in Newport, to continue the work of the Umbrella Appeal by becoming the official charity of Nevill Hall Children's Centre (NHCC), in Abergavenny. Sparkle's new geographical reach extends to families living in the NHCC catchment area of North Gwent, namely Blaenau Gwent, North Monmouthshire and North Torfaen. To understand how Sparkle can deliver service enhancements/new services moving forward that will meet the needs of children and their families across North Gwent, the views of parents and professionals were sought via questionnaires, focus groups, and interviews, between April and September 2019.

A key finding was that services currently available for children with additional needs and their families in North Gwent include children's activity groups and clubs, support groups for parents, parent workshops and family events. MAGIC Parent and Carers Network, the Family Liaison Service, Families First, the Gwent Primary Care Mental Health Service, 4YP and the National Autistic Society, all provide services and support for children with additional needs and their families across the whole of *North Gwent*. Children living in *Monmouthshire* are also able to access Quest Busters (for 8-14 year olds), and The Building Bridges Project (for 14-25 year olds); in *Torfaen*, there's TOGs (for 8-18 year olds), Action for Children and Hope GB (all ages), which provide a range of support services. Parents of children with Down's syndrome living in *Monmouthshire* can also access 21 Plus, and there is a support group called One Life for parents with autistic children in *Blaenau Gwent*.

However, whilst the findings indicate that these current services and support are meeting some of the needs of some children and families living in North Gwent, parents and professionals highlighted that there's a lack of awareness, and limited access to, services and support depending on where families live; a lack of services and support for children less than 8 years old across North Gwent, and for children of all ages in Blaenau Gwent; and a lack of emotional support for families post-diagnosis and with transition. Unmet needs of families in North Gwent include emotional support for children and their families, service provision and support during school holidays, development of communication and social skills for teenagers, integration into the community, and the needs of siblings of children with additional needs.

Service enhancements that were suggested by parents and professionals, to better meet the needs of children and families include enhancements to the facilities at NHCC, such as a sensory room/area and an outdoor play area; making services more accommodating to children's individual needs; pooling resources across North Gwent; improving communication between key workers, services and families; creating more networking opportunities between professionals to share information and work more collaboratively; and increasing the provision of information, advice and signposting for families.

In terms of suggestions for new services, parents would like to access the same range of facilities and services that are offered by Serennu Children's Centre. Suggested new services most commonly selected by parent questionnaire respondents were warm water swimming lessons, fun day events and holiday activities; whereas professionals most commonly selected Independent Living Skills (ILS) club, warm water swimming lessons, and stay and play club (ages 0-4 years). Parent focus group participants expressed a particular need for sensory-based activities that would accommodate the needs of teenagers as well as younger children; warm water swimming lessons; and activities and clubs during the school holidays. Professionals also highlighted a need for service provision during school holidays, as well as

suggesting that new services should focus on providing ongoing emotional support for young people, and engaging more children and young people in sporting activities for their physical and social development, as well as supporting children's integration into their local community.

Challenges that are likely to present barriers to Sparkle's successful delivery of new services to children with additional needs and their families living in North Gwent were identified. The key challenges identified were issues with travelling and parking, including poor transport links, families not having their own transport, and poor parking facilities at NHCC; accessing school facilities to run activities; making services accessible for working and non-working parents, and for children who may have additional needs without a formal diagnosis; engaging with families in North Gwent; poor communication between different services; and lack of space at NHCC for expanding current service provision.

Recommendations for approaches to service delivery were given by parents and professionals. In terms of prioritising services, the consensus amongst parents was that it was difficult to prioritise as they felt all of the suggested new services were equally important to provide support to families as a whole. Professionals were in agreement that integrating children and families into their local communities, working collaboratively with other services, providing families with continuity and not overwhelming them with information were all important considerations when delivering new services. Differences in opinions between professionals emerged as to what services and support they felt were highest priority, although there was some agreement that offering support for families during the summer holidays was a high priority, as this would provide activities for children as well as providing respite for parents.

Potential locations in North Monmouthshire, Blaenau Gwent and North Torfaen were suggested by parents and professionals where services and support could be made available. The suitability and estimated costs of delivering services in these suggested locations will be established over the coming weeks.

## **1. Introduction**

Sparkle (South Wales)'s guiding principle is that children with disabilities and/or developmental difficulties should have the same opportunities as other children to access a range of activities and support, have valuable childhood experiences and integrate into their community. Guided by this principle, in May 2019 Sparkle extended its reach from Serennu Children's Centre in Newport, to continue the work previously undertaken by the Umbrella Appeal by becoming the official charity of Nevill Hall Children's Centre (NHCC), in Abergavenny. Sparkle's new reach extends to families living in the NHCC catchment area of North Gwent, which includes Blaenau Gwent, North Monmouthshire and North Torfaen. Sparkle has already established some support and services in North Gwent, including the Family Liaison Service, parent and staff workshops, and family fun days. However, it was felt that an in-depth consultation with families and professionals was required to understand how Sparkle can deliver service enhancements/new services moving forward, that will meet the needs of children and their families in North Gwent.

The aim of this research was to capture the views of families and professionals on services and support, to inform and develop enhancements to current services, and potentially introduce new services, for children with additional needs and their families living in North Gwent.

## **2. Methods**

A mixed methods approach was used to collect both qualitative and quantitative research data. Questionnaires were created for parents and professionals, which comprised questions with tick-box and free text answers. Paper copies of the questionnaires were made available at NHCC and links to complete the questionnaire electronically via Survey Monkey were emailed to parents and health and social care professionals based at NHCC and within children's disability teams across North Gwent. To facilitate participant engagement Sparkle's Research and Development Officer visited NHCC regularly between June and August 2019, to make parents and staff aware of the opportunity to complete a questionnaire. Professionals were also encouraged to make families aware of the research at the end of appointments and/or home visits.

Recruitment posters and flyers for focus group participants were made available at NHCC, the Heart of the Valleys Integrated Children's Centre in Blaenau Gwent and Pen-y-Cwm Special School in Ebbw Vale, between August and September 2019. On the recruitment posters/flyers and email message to parents it was stated that 'Sparkle are looking for parents and children (aged 7-18) living in Nevill Hall Children's Centre catchment area, who would like to take part in focus groups in September and October 2019.' Parents on the NHCC Family Liaison mailing list and health and social care professionals were emailed to give them the opportunity to register their interest in attending a focus group. Focus groups were conducted to allow participants to interact with each other in a group discussion, with the aim of promoting the sharing and generation of ideas and perspectives. For the parent and professional focus group schedules please see the appendix.

Semi-structured interviews were also conducted with parents and professionals, for which interview guides were created, comprised of a list of topics and open-ended questions to be

covered during the conversation. This guide was followed by the Research and Development Officer, with some flexibility to follow topics raised by participants, where appropriate and relevant to the research. This approach to interviewing allows participants the freedom to express their views in their own terms, and can provide reliable, comparable qualitative data. For the interview topic guide please see appendix. Focus groups and interviews were audio-recorded and transcribed verbatim, by the Research and Development Officer.

### Analysis

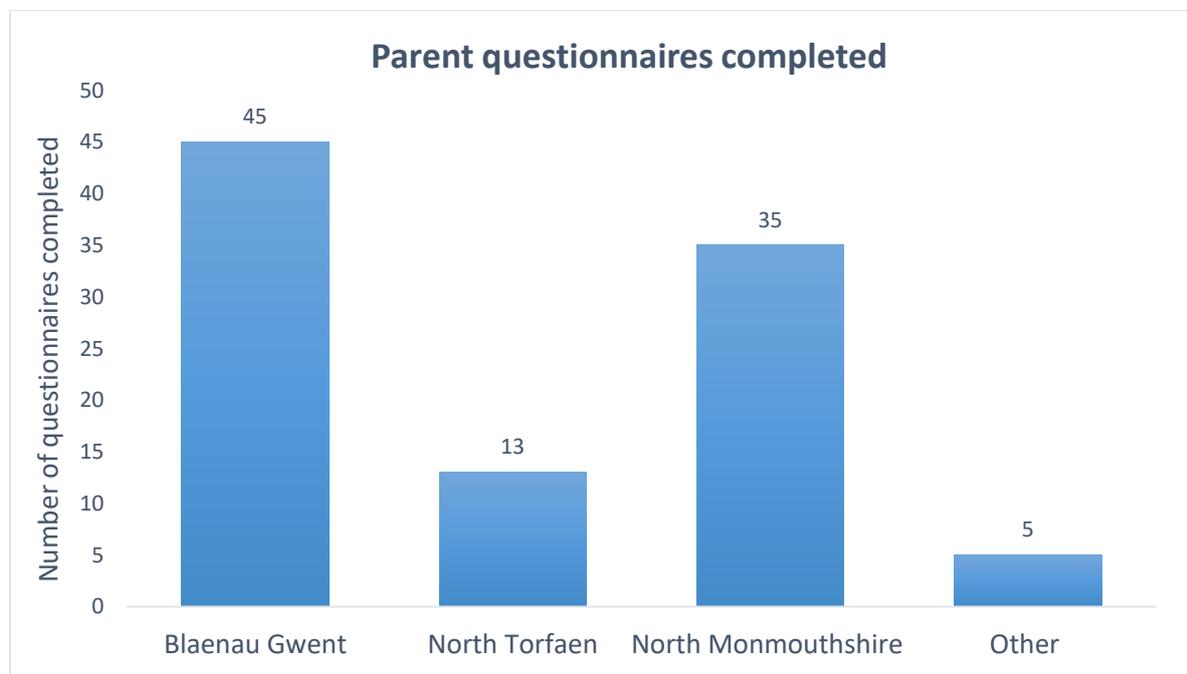
Data from questionnaires completed on paper were manually entered into Survey Monkey and were analysed alongside questionnaires completed electronically. Focus group and interview transcripts were analysed thematically, which involved line-by-line coding in NVivo to find patterns in the data and subsequent identification of key themes.

## 3. Findings

### Questionnaire respondents

A total of 100 parents completed the parent/carer questionnaire, and 30 professionals completed the staff questionnaire between April and August 2019. As displayed in Figure 1, the majority of parent questionnaires were completed by parents living in Blaenau Gwent, followed by North Monmouthshire, and North Torfaen. Professional respondents worked across North Gwent, with 67% (N=20) being based at Nevill Hall Children’s Centre.

**Figure 1. The number of questionnaires completed by parents living in each local authority.**



### *Focus group participants*

The staff focus group was held on 12.08.19 at NHCC, and was attended by nine professionals. Professional roles included a social worker, a social work senior practitioner, an occupational therapy senior practitioner, a family liaison officer, a care coordinator, a paediatric physiotherapist, a childcare development advisor and a development officer. Three participants were based in Blaenau Gwent, one in Torfaen, and five in Monmouthshire. Five parents and one staff member attended the parent focus group, held on 30<sup>th</sup> September at Abergavenny Community Centre; five participants from Monmouthshire, and one from Blaenau Gwent. Both focus groups lasted approximately one hour. Only one parent expressed an interest on behalf of her child to participate in a focus group for young people, therefore there were insufficient numbers to hold the group.

### *Interview participants*

Interviews were conducted with three parents via the telephone; two living in Monmouthshire and one in Blaenau Gwent. Two interviews with parents lasted 20 minutes, and one lasted forty minutes. Interviews were conducted with four health and social care professionals, two based in Monmouthshire and two based in Blaenau Gwent, which lasted between 20 minutes and one hour.

## **3.1 Current service provision**

A number of services, support groups and events for children with additional needs and their families living in North Gwent were identified from analysis of the data. These include; Monmouthshire All Ability Group for Inclusive Communities (MAGIC), The Building Bridges Project, Quest Busters, Torfaen Opportunities Group (TOGs), 21 Plus, Family Liaison, NHCC family events and parent workshops, Families First, Hope GB, the National Autistic Society, One Life, Gwent Primary Care Mental Health Support Service and Gofal 4YP.

### **3.1.1 Services accessible across the whole of North Gwent**

#### **MAGIC**

MAGIC is a parent carer network for the whole of South Wales, with the majority of parents and carers accessing the network living in Monmouthshire. MAGIC is open to parents of children of any age, with or without their child having a diagnosis. Nearly 950 families have joined the MAGIC network (as of 30/09/2019), which has an active Facebook group which parents use to share information, as well as offering support and advice to other parents. The group organises parent workshops that provide opportunities for parents to participate in creative activities and meet other parents. In addition to parent and carer support, MAGIC organises regular activities for children that can be enjoyed by the whole family, such as trips to Techniquet in Cardiff, and Surfability in Swansea.

*“MAGIC as well has been brilliant. It’s been good to do some, I guess sort of different things there, both girls really like music and so they both loved the two music things they’ve been to, and they both really enjoyed the surfing as well.”* (Parent P7, Monmouthshire)

## Family Liaison

The Family Liaison Service, based at NHCC, is open to all children with additional needs and their families living in North Gwent. This service provides families with information, support and advice, and signposting to other services. Parents and professionals expressed their appreciation for the wealth of information provided by the Family Liaison Officer (FLO).

### Parent feedback

*"Such a wealth of information."* (Parent P9, Blaenau Gwent)

*Things have vastly improved since [name of FLO] has been in post.*

(Parent questionnaire respondent)

### Professional perspectives

*"[name]'s really helpful and useful in terms of knowing exactly what is available, what is age appropriate...really useful."* (Professional)

*"My knowledge base has become increasingly reliant on the FLO service which is such an advantage."* (Professional questionnaire respondent)

## Nevill Hall Children's Centre Events

A minority of parent questionnaire respondents said they had previously attended events at NHCC; such as the Christmas, Easter and Halloween parties, and parent workshops. Of the parents who had attended these events, the majority of feedback comments were positive, however some parent focus group participants were in agreement that some of the events had been overly stimulating for their children, and did not accommodate for their needs. Parents were also in agreement that the lack of parking spaces at NHCC had put them off attending events.

### Parent feedback

*"Christmas party. Nice to meet other families who have an understanding of some of the things you are dealing with."*

*"We have attended many different events, i.e., pantomime... they're great fun for all the family. Halloween disco, again very accommodating for all families with children with additional needs."*

*"I just access the MAGIC events, I've found that the events put on through Nevill Hall are perhaps are angled a bit more at high functioning children who can cope with loud noisy places. My son's way too anxious to access any of those events."*

## Families First

Families First is a Wales-wide Welsh Government programme that offers a range of support to families experiencing difficulties in every county, through projects, activities and training organised by parts of the council, charities and other organisations. Depending on a family's needs, support can include help with disability, early years, health and wellbeing, and education.

Projects that are currently funded by the Families First programme in Monmouthshire include:

- The Acorn Project – supporting parents to improve their parenting skills, confidence, wellbeing and relationships with their child/children
- The Inclusive Acorn Project – supporting the needs of disabled children
- Face 2 Face Counselling Project – providing a range of confidential services for young people in Monmouthshire; community based counselling, play therapy and family system therapy
- Young Carers – supporting young people who have a significant caring role for a family member with a recognised physical or mental disability
- Inclusive Play and Leisure – providing children with disabilities or support needs the same opportunities as any other child through play and leisure activities

Torfaen's Families First programme is developing a prevention and protection model to provide a whole family approach to service delivery, with a focus on developing and implementing preventative early interventions in family support for families with complex needs.

Parents from Blaenau Gwent commented on the support available from Families First in their area.

### Parent feedback

*"They have a youth club for children with special needs."*

(Parent P4, Blaenau Gwent)

*"I know Families First in Blaenau Gwent deliver some stuff as well, but I think a lot of that is more around sort of autism parenting courses and things. There is a parent group in Blaenau Gwent but it meets in the day, I think it meets once a month in the day, its run by families first; but because we work we can't access that."*

(Parent P9, Blaenau Gwent)

## The National Autistic Society (NAS)

The NAS offers people with ASD support, companionship and opportunities to learn new skills, as well as support, advice and information for parents. A couple of parent focus group participants were aware that the NAS provide an advice service to parents, however it wasn't clear as to whether this service was currently accessible across all local authorities.

*"There's the National Autistic Society, [name] who comes out to give advice...does she come under Blaenau Gwent?"*

*“No she’s Monmouthshire only, but there should be her equivalent in the other counties.”*

### **Emotional support available for young people with additional needs**

Services providing emotional support for children and young people with additional needs living in North Gwent include the Gwent Primary Care Mental Health Support Service (PCMHSS) and Gofal 4YP. The PCMHSS is open to individuals of all ages who are experiencing mild to moderate, or stable severe and enduring mental health problems. The service employs Children and Young Persons Specialist Practitioners (CYPSP), for specifically helping children and young people with mental health problems, including children and young people with additional needs. During an interview, a CYPSP explained the therapeutic approach she takes to working with young people with additional needs and their families.

*“Dialectical behaviour therapy...it’s all about emotional regulation, it’s good for teenagers... I’ve got a few sort of, between 8 and 10, I try and work with mum and dad where possible, with the child.”*  
(Professional, PCMHSS)

A professional mentioned a service recently set up by Gofal called 4YP, which works with young people throughout Wales, using a combination of peer support and training to develop skills and strategies to promote wellbeing. However, a professional indicated that there may be barriers to accessing this service, and it is unclear whether or not the service is appropriate for young people with additional needs.

*“We’ve got 4YP service and things, but it’s a referral process...”*  
(Professional, NHCC)

### **Emotional support available for parents**

Professionals highlighted that support for parents in North Gwent is available through the Family Liaison Service, the Integrated Service for Children with Additional Needs (ISCAN) and charities.

#### **Professional perspectives**

*“There is a lot of support out there at the moment for parents with the workshops we run and there’s charities that support parents.”*

*“We’ve had families that have really been supported by the whole ISCAN process”*

*“I guess again MAGIC is a good parent support group.”*

*“And your service (Family Liaison) so from our experience in Blaenau Gwent I think those early years, especially portage as well it’s quite positive I think once they’re discharged from portage and getting that advice for themselves that’s when they start to struggle that little bit more.”*

Groups providing emotional support to parents of children with additional needs include MAGIC (open to parents across South Wales), and 21 Plus (for parents living in Monmouthshire). Parent participants living in Monmouthshire felt that there was a lot of support available to them, and another parent had recently become aware of a counselling service called Scope, however other parents lacked awareness of this service.

### **Parent perspectives**

*“There’s lots of people that are out there that provide support to us.”*

(Parent P7, Monmouthshire)

*“We’ve been on mindfulness courses, we’ve been on language courses, we have over the years done various courses to help us as parents, I think we would just access those as and when we needed them.”* (Parent P8, Monmouthshire)

*“Apparently you can get six counselling sessions to help you through your post-diagnosis with Scope.”* (Parent P5, Monmouthshire)

A parent from Blaenau Gwent advocated parent support groups for their value in terms of providing an understanding and supportive space for parents to share similar experiences, learn from other parents experiences and perspectives, and have the opportunity to give and receive advice.

*“It’s good to hear that thing of you’re not on your own, that there are other people going through the same thing as you, especially for us because [name]’s so young, meeting with parent’s who’ve got older children that’ve already gone through the challenges that we’re just starting on is really reassuring to get their perspective and know how they managed with things, or things they found useful, or services they can recommend.”* (Parent P9, Blaenau Gwent)

### **3.1.2 Services accessible in Monmouthshire**

#### **The Building Bridges project**

This project, for 14-25 year olds with additional needs living in Monmouthshire, supports and encourages young people to engage in their local communities, broaden their social networks, make friends, build confidence and develop social skills. In order to facilitate this, Building Bridges have set up and are involved in regular youth clubs, drama and dance groups, swimming groups, football groups and golfing sessions. Together with young people, they have run events and managed business endeavours, which have provided young people with valuable learning experiences about their local communities, the environment and disabilities awareness amongst others. Some examples of positive outcomes for young people who have been involved in this project are moving out independently, getting jobs, going to college and passing their driving test.

## **Quest Busters**

Quest Busters is a joint project recently set up by MAGIC and Building Bridges, for children with additional needs aged between 8 and 14 years and living in Monmouthshire. Quest Busters aims to support 150 children and young people to access positive, needs-led experiences in supported community settings that promote wellbeing; and provide training and support for 100 families. In the parent focus group, a participant from Monmouthshire shared that Quest Busters are *“creating activities and events for this age group with their siblings and with their families....accessible youth clubs, family trips away and events.”*

## **21 Plus**

21 Plus is a support group for families with children who have Down's syndrome in Monmouthshire, the Forest of Dean and surrounding areas. The group holds bi-monthly meetings and social events to bring together children and parents, shares information and resources, raises awareness of Down's syndrome locally, funds and organises training for parents and education professionals.

Parents spoke about the support they access through 21 Plus. One parent commented:

*“We access quite a lot of our stuff through 21 plus the Downs syndrome charity...At the moment we access the speech and language ‘talk time’. We’re looking at some of the educational resources, my little ones’ not far off nursery so they will go in and support the nursery with her needs; they also do that with schools as well, they help as well. They do lots of family based activities, um things like Easter egg hunts...so supporting the whole family rather than just the child.”*

(Parent P5, Monmouthshire)

### **3.1.3 Services available based in Torfaen**

## **TOGS**

TOGs (Torfaen Opportunity Group) Disabled Children's Centre, based in Pontypool, is a charity that provides services to children and young people aged 8-18 years with physical, learning or sensory disabilities who live in and around the borough of Torfaen. TOGs run a youth club twice a week offering young people a wide range of indoor and outdoor activities, and the use of a sensory room and sensory garden. In addition, TOGs run day trips, music projects, residential trips and family events.

A parent commented on her family's experience of accessing TOGs.

*“TOGS is fantastic, the girls both love going there, they do lots of things with them when they're there that's obviously certain accessible settings they can cook with them, get water out, sand, loads of different things they can really sort of adapt what they want, what the girls like to do whenever they go in there, they love that...so both very positive experiences.”*

(Parent P7, Monmouthshire)

## **Action for Children**

Action for Children are a charitable organisation that protect and support children and young people across the UK, providing practical and emotional care and support, ensuring their voices are heard and campaigning to bring lasting improvements to their lives. In Torfaen, Action for Children are based at the TOGs Centre, providing services that are accessible to children with additional needs and their families living in Torfaen and Monmouthshire. The Torfaen service, Tafarn Newydd, provides children who have emerging disabilities with a range of substantial and highly complex needs, opportunities to play, learn and develop. The Monmouthshire service, MTP Children with Disability Support, works in partnership with Monmouthshire Disability Teams to provide sessions to young people with disabilities, from the ages of 5-18 years. Children who have been assessed by a Social Worker from the Child Care Disability Team are eligible to access this service. Sessions provided are 1:1, 2:1 or in a group setting at venues in the local community, and play schemes are also run by the service.

## **Hope GB**

Hope GB is a charity based in Torfaen, founded in 2009, providing a range of support services to children and adults with Autism including information and guidance, youth clubs, stay and play, training and development experiences, and running events to raise awareness and understanding of autism. A parent focus group participant commented on her experience of accessing Hope GB's services and awareness of the support they currently offer.

*"There's Hope GB, they, we actually started with Hope GB and got quite a lot of advice from them, they have an advice phone line...I think they have a youth club, they do trampolining once a month."* (Parent P6, Monmouthshire)

### **3.1.3 Services available – Blaenau Gwent only**

#### **One Life**

One Life is an autism support group based at the Ebbw Vale Institute in Blaenau Gwent. One parent shared their thoughts on One Life and the NAS.

*"There's two groups um National Autistic Society group and One Life, which are really active in Blaenau Gwent, they're fab."* (Parent P9, Blaenau Gwent)

### 3.2 Lack of awareness of services and support

Comments made by parent focus group participants indicated that they lacked an awareness of the services and support currently available for their child/children and for themselves as parents.

#### Parent perspectives

*"I know about half of the things that have been spoken about here, and actually I probably should have been aware of those but somebody needed to tell me about them."*

(Parent P5, Monmouthshire)

*"I didn't know MAGIC existed to be completely honest, I've been told nothing."*

(Parent P4, Blaenau Gwent)

*"Even now I'm still finding new things, like at the autism show on Friday I found out we can access six counselling sessions through Scope, but I didn't know that until Friday."*

(Parent P6, Monmouthshire)

Professional focus group participants were in agreement that there is a notable lack of awareness amongst *professionals* of the different services available to children with additional needs and their families across North Gwent.

*"Sometimes we don't really, we're not really aware of the activities and services that different organisations can provide, and it's hard to pool all that information..."*

(Professional)

### 3.3 Lack or a loss of services

There was a consensus of opinion, both in the parent and professional focus groups, that the current provision of support services and community resources were lacking or limited, and variable across local authorities.

#### Parent perspectives

*"It's quite a postcode lottery if you just happen to live somewhere where there is support then you're lucky and if not, you're probably quite on your own."*

(Parent P5, Monmouthshire)

*"We had yeah diagnosis then nothing." (Parent P6, Monmouthshire)*

*[Other parents in agreement, making comments such as, "we weren't given any information about additional support that we could look for."]*

### Professional perspectives

*"Limited."*

*"It's a lack of community resource."*

*"If there were more services out there and more activities and community groups, these families would never need to be known to social services."*

*"...You get families... [Inaudible] in Blaenau Gwent, they've got that and what's in Monmouthshire...nothing sorry."*

Parents and professionals shared this view that there are a lack of services supporting parents after their child receives a diagnosis, for parents with children of all ages.

*"A lot of people come back to me after diagnosis going well "what do I do now? Don't really know what to do with this", which is a real gap. Absolute gap." (Professional)*

One parent highlighted that there was a lack of emotional support services post-diagnosis.

*"It's that emotional side of things that's really lacking for families, especially with young children." (Parent P9, Blaenau Gwent)*

Parents and professionals also commented on there being a lack of support with transitions.

*"Our portage working was great...then all of a sudden, as soon as you access education there's nothing and I remember that scary feeling of going to nursery, and the only contact I had was with a nursery teacher, there was nothing else there."*

(Parent P3, Monmouthshire)

*"I think there's a major gap, all young people anyway but particularly for children with sort of ASD traits is the transition, from primary to secondary, it is **huge**."*

(Professional)

Another point raised by parents was not being able to access any services locally.

*"I went to Barry for a sensory room...we were prepared to travel because we can't access anything locally." (Parent P5, Monmouthshire)*

*"I find that difficult that there's not a lot of things local to us, because even though they're in Monmouthshire at least everything's half an hour to an hour's drive from where we live." (Parent P8, Monmouthshire)*

One parent living in Monmouthshire shared that the loss of respite and summer schemes had been difficult for their family.

*"The respite home in Herbert Road used to be a shared resource with Torfaen...but then they said they weren't going to give the facility to Torfaen children anymore it was purely for Monmouthshire children....The other thing that we used which is actually Torfaen-based as well, during the summer, when Monmouthshire stopped doing the*

*summer schemes it caused a serious issue for us as a family.”*  
(Parent P8, Monmouthshire)

Loss of services was also pointed out by professionals in the focus group.

*“In a way we’ve lost some of the services I think, we were talking about some of the play schemes we used to have years ago.”*

*“Yeah.”*

*“That did offer respite, and actually did offer opportunity for young people to gain skills, working with young people, you know behavioural and physical challenges but those seem to have been depleted.”*

Services being funding dependent was raised as an issue in relation to the loss of services, resulting in a lack of continuity for families.

*“A lot of these (services) are funding dependent as well and, you tend to you hear of something that sounds really good and families will access it and then 6 months down the line that’s ended...there’s nothing really...continuity -”*

*“It tends to be grant-funded and short-term, quite small pockets of support...”*

### **3.4 Unmet needs**

#### **3.4.1 Emotional support for parents**

Parents and professionals felt that emotional support for parents was an unmet need.

##### **Parent perspectives**

*“I’m just constantly on the go with my kids telling them what they should do...every day we have to go through the same routine and if we don’t then it’s a nightmare.”*

(Parent P4, Blaenau Gwent)

*“I think it’s that emotional side of things that’s really lacking for families, especially with young children...I find parent support groups really useful, we do pop down to the one in Nevill Hall, when it runs, but like there’s been times we’ve gone and we are literally the only parents who’ve turned up.”* (Parent P9, Blaenau Gwent)

A professional commented on the emotional needs of parents of children with additional needs.

*“There’s a massive amount of stress and emotional turmoil for parents and they’re seeking advice and support from everybody...”* (Professional)

### 3.4.2 Support during the summer holidays

Summer holidays were viewed as a particularly challenging time of the year by parents, due to the lack of support to help meet their child/children's needs. Parents spoke about other parents having to give up their jobs and finding it hard to cope throughout the 6 week break on their own.

#### Parent perspectives

*"A lot of parents that I knew basically just gave up their jobs when they didn't have the summer holiday scheme, or you know they had to make difficult arrangements...and some people just didn't access the schemes..."*

(Parent P8, Monmouthshire)

*"I'm gonna have three children with additional needs on my own for six weeks, and I dread it."*

(Parent P4, Blaenau Gwent)

#### Professional perspectives

*"It is a massive transition to all of a sudden not have this structure of a school routine to now...the school holidays really impacts upon the family."*

*"It's a difficult time for families with children without ASD never mind...it's known to be an expensive time and stressful time and parents...I think the majority of parents are dreading six weeks off, never mind when you've got with additional needs who are outside of the general routine of school."*

*"So the families, they're in crisis but also they want something there and then" – other professionals in agreement.*

Professionals shared their views that the school holidays are a drastic change of routine for children with additional needs, which can cause parents to feel stressed and overwhelmed. Social care professionals highlighted that they have an influx of referrals a couple of weeks before the summer holidays, with many parents at 'crisis' point without the level of support that they need for their children.

### 3.4.3 Gaps in service provision

Parents raised that they were unable to access services for their child due to a gap in service provision for young children, highlighting an unmet need.

*"We don't access anything because she's too young to benefit from what's going on."*

(Parent P5, Monmouthshire)

*“It’s just for that younger age group, I do see stuff advertised for kind of 5 plus or 8 plus, but then we can’t access those because [name]’s so little, or it’ll be like baby and toddler, so they are kind of at an in-between kind of age if you like at the minute.”*

(Parent P3, Blaenau Gwent)

#### **3.4.4 Unmet needs of siblings of children with additional needs**

Parents also spoke about having difficulty finding activities to meet the needs of their child without additional needs, indicating that the needs of siblings are not currently being met.

*“My other child is five and like I said he hasn’t got any additional needs so it can be hard to find things that we can do as a family that will meet the needs of them both.”*

(Parent P9, Blaenau Gwent)

*“The other thing that I think there’s very little of is sibling support as well, again from statutory services.”*

(Parent P2, Monmouthshire)

#### **3.4.5 Unmet needs of teenagers with additional needs**

Parents and professionals highlighted an unmet need for teenagers, specifically in regards to supporting their need to develop communication and social skills, as well as support for mental health issues and transitioning into adulthood.

*“For your 12, 13, 14 year olds who may have social communication...the lack of skills and that, there’s nothing out there for people like that to go to club-wise.”*

(Professional)

*“But also for young people I think that growing up, becoming an adult.”*

(Professional)

*“Desperate for more help for kids with mental health issues. We need help.”*

(Parent questionnaire respondent)

#### **3.4.6 Access to affordable swimming lessons**

Parents raised the need to access affordable swimming lessons for their child, and one parent highlighted that being able to access warm water swimming is necessary to meet her child’s sensory needs.

*“You end up having to pay for a one-to-one, which is really expensive, because your child can’t access the regular swim.”*

(Parent P2, Monmouthshire)

*“Some sort of sensory based stuff would be lovely, um like family swim the warm water swim, because of [name]’s seizures, the change of temperature of coming out of the cold into the changing rooms can trigger his seizures, so we tend not to go swimming as a family, so if we could access the warm water swimming, that would be great.”*

(Parent P9, Blaenau Gwent)

Professionals also felt that accessing swimming facilities is an unmet need, one professional commented that;

*“I think that is an unmet need because we’ve got some really good facilities within Pen-y-Cwm, but at the moment, so for example a lot of the children that go to Pen-y-Cwm have direct payments...so they could probably benefit from the hydro pool.”*

### **3.4.7 Opportunities for community integration**

Opportunities for families to integrate into their community was another unmet need identified by a professional.

*“Realistically we have families we refer to social services to do an initial assessment...the only needs are that they need to be integrated more into the community and need to be taking part in activities...”*

In the focus group, parents also expressed their frustration with their child’s appointments not being well-coordinated, and raised that more support with speech and language development was needed for non-verbal children. One parent shared that she felt that children with complex needs were not having their needs met by current service provision.

*“I **hope** that with all this, the more complex children are included in this...I think the complex children, as far as I’m concerned are the ones who are being missed.”*

(Parent P2, Monmouthshire)

## **3.5 Suggested enhancements to current services and support**

Parent and professional questionnaire respondents indicated that they felt the facilities at NHCC could be enhanced in the following ways: more parking, a sensory room/area, an outdoor play area and an in-floor trampoline for children’s physiotherapy sessions. Parents also suggested that improvements could be made to the waiting areas by having an area for teenagers and a quiet area for children who may be sensitive to noise. In addition, professionals suggested installing ceiling track hoists in assessment and therapy rooms, and suggested that the Family Liaison Service could be more visible in the reception area.

In the focus group, parents raised that they would like to see services enhanced so that they are more accommodating to their child/children’s needs.

### **Parent perspectives**

*"It would be nice to have something that is for autism specific, because there is no doubt that a lot of children I think don't go to those events now because they are too noisy, or too much, so actually having more than one event."*

(Parent P2, Monmouthshire)

*"It's not just autism though, there's also learning difficulties as well would be nice..."*

(Parent P4, Blaenau Gwent)

Professionals suggested pooling resources, such as sensory equipment, across local authorities and setting up a "Gwent equipment library."

*"Would it be better to buy sensory suitcases where families can hire them for a small fee? They can take them home and hire them for the week or weekend and different things rather than having an all singing all dancing room, but how often is actually getting full access?"*

Parents were in agreement that 'Key Workers' have an important role in improving communication between services and parents.

*"When [name] was diagnosed we were given a piece of paper and that was it...so you've got these huge gaps in communication which I think comes under the key workers, every parent should walk out of there knowing what their next step is going to be."*

(Parent P2, Monmouthshire)

It was evident that the parent group felt that the introduction of 'Key Workers' would be supportive for parents.

*"You almost want a key worker, just one person if you've got a problem you just pick up the phone."*

(P1, Quest Busters)

Professionals suggested more networking opportunities would lead to service enhancements through professionals working together and sharing information.

### **Professional perspectives**

*"I think that would be an enhancement, more networking, sharing days."*

*"Yeah, and it's an opportunity for those services to get to know what's going on as well and talk about collaborative working, and maybe they can work together-"*

*"Because that would be the enhancement, they work together."*

One professional felt that healthcare professionals could signpost families more often to the Family Liaison Officer, to access information and services.

*“If the doctors and nurses, could signpost people better towards the family liaison officer because that’s such a wealth of information, they hold so much.”*

Enhancements to the provision of information and advice were also suggested by parents.

### **Parent perspectives**

*“It would be really useful to have information, some sort of information pack when you first access services. So it might be almost like an index pack, just enough information that would allow you to decide whether you need to access that service or not...because I know about half of the things that have been spoken about here, and actually I probably should have been aware of those but somebody needed to tell me about them.”* (Parent P5, Monmouthshire)

*“Knowing what’s coming up and when it’s coming up and how much it’s going to cost is for me the important thing...have like a 6 month of possible to be confirmed, but so we know what is coming up in the future. Cos what [name of FLO] does is great, but I don’t always get his emails, I don’t always read them because I’m busy.”* (Parent P4, Blaenau Gwent)

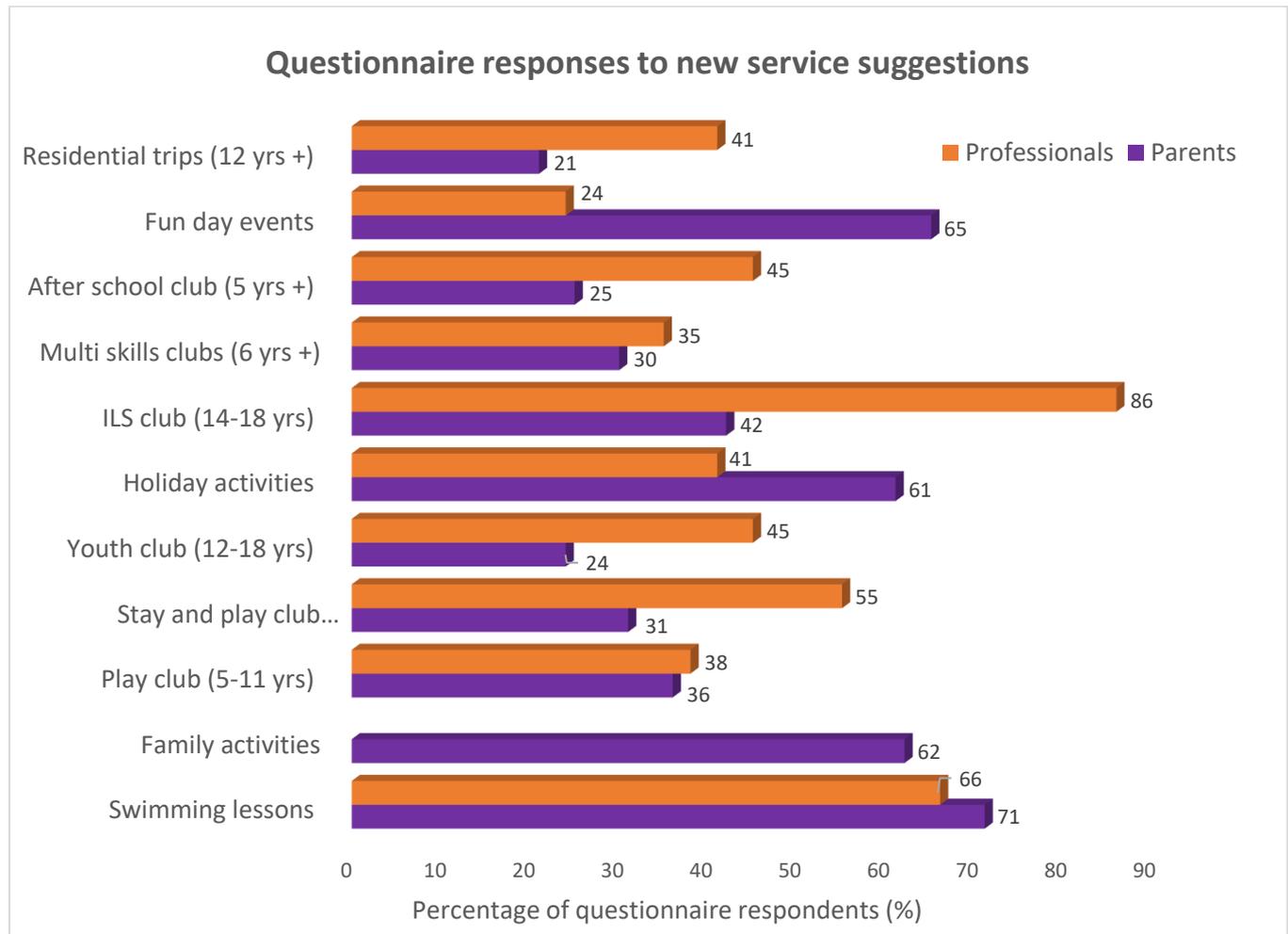
*“I find with those emails that there’s not enough information for me decide whether its age appropriate as well.”* (Parent P5, Monmouthshire)

## **3.6 Suggestions for new services**

### **3.6.1. Questionnaire feedback on suggested new services**

Parent and professional questionnaire respondents indicated which new service suggestions they would most like to see for children aged 0-18 with additional needs and their families living in North Gwent, as shown in Figure 2. From this feedback, it is evident that the three most commonly selected services by parents were warm water swimming lessons (71%, N=69), fun day events (65%, N=63), and holiday activities (61%, N=59); whereas professionals most commonly selected Independent Living Skills (ILS) club (86%, N=25), warm water swimming lessons (66%, N=19), and stay and play club for ages 0 to 4 years (55%, N=16).

**Figure 2. Parent and professional questionnaire responses to suggested new services they would most like to see for children with additional needs and their families living in North Gwent.**



### 3.6.2 Suggestions for new services made by parent focus group participants

In response to being asked for new service suggestions for children and their families to access in North Gwent, parent focus group participants all agreed that they would like to be able to access the same range of facilities and services that are offered by Serennu Children’s Centre.

*“Serennu, which is an amazing place. Why have we not got that here, why?... I mean the stuff you can access in Serennu...the sensory rooms, we can’t access any of that here.”* (Parent P5, Monmouthshire)

*“MediCinema.”* (Parent P3, Monmouthshire)

*“Build a Serennu!”* (Parent P2, Monmouthshire)

*Other parents say “yeah!” in agreement.*

Some parents shared that they wanted to see more sensory-based provision that would accommodate the needs of young adults as well as younger children.

*"[name] is 14, a lot of the indoor play things he loves like ball pits and play things...For us, it would be nice to have some sort of provision to allow children and young adults like [name] to be able to play like little children if you like in a safe environment that's open to them."* (Parent P8, Monmouthshire)

*"Some sort of sensory based stuff would be lovely, um like family swim."*

(Parent P3, Monmouthshire)

Other parents in the focus group were in agreement that swimming lessons would be a beneficial opportunity for their child/children. Parents also shared their suggestions for regular afterschool and evening activities.

*"Regular activities would be good, things like...children without needs access without a problem, Brownies and things like that, that's not so straightforward if you've got children with additional needs where they sort of have that regular after school type of activity where they do a range of things."* (Parent P7, Monmouthshire)

*"I think that the evening sort of youth club type things would be good, you know something with a social aspect as well to it, that's relatively regular I think would be really good."* (P1, Quest Busters)

There was a consensus from parent focus group participants for the provision of more outdoor activities during the summer holidays.

*"My kids hate craft they want to play nerf guns, do like forest school, outside activities, not just sat inside a hall doing arts and crafts...Something safe like an outdoor forest school over summer holidays where parents can give them freedom, somewhere safe and secure."* (Parent P4, Blaenau Gwent)

*"Yeah forest school type stuff would be good yeah."* (Parent P6, Monmouthshire)

One of the parents who participated in a telephone interview also suggested that it would be beneficial for her children to spend more time outdoors, and try activities that may not be easily accessible to children with a disability, such as abseiling.

*"We're surrounded by beautiful outdoors and that accessibility to those outdoors, the hills and Brecon, the Forrest of Dean and stuff, anything that might help to support children with, particularly physical disabilities, and their ability to access that...when you're in a wheelchair I think you often miss out on those sorts of quite important, the sort of scary things that are quite character building."* (Parent P7, Monmouthshire)

### **3.6.3 Suggestions made for new services by professional focus group participants**

Professional focus group participants were in agreement that new service developments should focus on running clubs during school holidays.

*"If we had like a holiday club, they (families) wouldn't need social services."*

Professionals also highlighted the importance of introducing new services that focus on providing ongoing emotional support for young people with additional needs.

*“I think it’s about looking at long-term stuff as well, the play schemes is the 6 weeks every summer...but I think, as soon as you get to adult services there’s a lot less. So I think making sure that emotional support, and they’re ready for that; because otherwise it’s easy to concentrate on 6 weeks every summer once a year, but you’ve missed out on that emotional support that’s going to make a massive difference to them long term.”*

A professional shared his perspective on the role of sport in helping children with special needs with their physical development.

*“It’s about how we can really highlight how sport and activity can help with a child’s physiotherapy as well, and get that across to the parent. So we could use our local community clubs as exit routes, which again will help that child.”*

Parents shared their thoughts on the possibility for their child/children having the opportunity to go on a residential trip.

*“I would be very interested in that because I think it’s good for [name] because apart from the respite he’s started having, he’s never really been away from home or away from us.”*

(Parent P8, Monmouthshire)

*“Yeah. It all depends on the cost, and the support the children will get.”*

(Parent P4, Blaenau Gwent)

Responses to the parent/carer questionnaire indicated that 88% (N=78) of parents would like to have the opportunity to attend training sessions (e.g. paediatric first aid, sleep workshops). 71% (N=63) of parents would like the opportunity to attend information and networking events.

### **3.7 Current challenges**

#### **3.7.1 Issues with travel and parking**

Travel-related issues and difficulties parking were frequently raised by both parents and professionals. Some of the issues raised were travelling with children who have additional needs, parking at Nevill Hall Hospital, parents not having their own transport, poor local transport links, and parents having to travel out of their local area to access services.

### **Parent perspectives**

*“With all the Nevill Hall stuff it’s always going down to Nevill Hall, I don’t want to sit in the car with my kids. I have a 7 seater car for a reason, I have to literally have 1, 2, 3 because they fight it’s dangerous, even with the props I’ve brought to help them be calm with pictures, I try to avoid Nevill Hall mainly because the car park as well.”*  
(Parent P4, Blaenau Gwent)

*“Me and my husband both drive, but a lot of parents don’t have cars and they can’t access some of the services because of travelling to places. I find that difficult that there’s not a lot of things local to us, because even though they’re in Monmouthshire at least everything’s half an hour to an hour’s drive from where we live.”*  
(Parent P8, Monmouthshire)

Professionals also raised travel being an issue, particularly for families living in Blaenau Gwent.

*“Crossing over the valleys is very difficult in Blaenau Gwent...we were looking at the bus routes and the taxi costs, and yeah very difficult for people in Blaenau Gwent.”*  
(Professional)

### **3.7.2 Making services accessible to all families**

Some parents shared that they were unable to access services and support during the day because they are at work.

*“A lot of them are offered during the day time, which is great for non-working parent but if you’re a working parent, especially if you haven’t got many holiday days and even when you work for a good employer, there’s only so much you can say “oh can I have a day off this week because I want to go on a course in such and such”, it is quite limited really.”*

(Parent P8, Monmouthshire)

A parent raised that accessing services is dependent on having a diagnosis.

*“The thing is I can’t get much support because my children don’t have them special little letters on that special bit of paper.”*  
(Parent P4, Blaenau Gwent)

### **3.7.3 Engaging with families in North Gwent**

From her experiences of working with families in Blaenau Gwent, a parent shared that the families who are in most need of support are those who are most difficult to engage with.

*“What I have found working in Blaenau Gwent specifically, is that some of the most kind of in need children and families are the ones that are the most difficult to engage.”*

(Parent P9, Blaenau Gwent)

Professionals discussed poor engagement from families in North Gwent, for example poor attendance at family events.

### **Professional perspectives**

*“Certainly the uptake is um...varied shall we say...typical example would be the storytelling event we had May this year, run by a charity that supports all the hospitals throughout the UK, we got to fight for that event. We had 30 families booked in, 3 children turned up.”*

*Other participants “Hmm” [as if unsurprised]*

*“That’s a massive issue from our clubs and stuff, last year we had 4 days of activities every day for the summer and no one came, bar the last two weeks, and I lost a month’s worth of staffing.”*

Some of the reasons that professionals gave for poor engagement with families include; North Gwent is a large geographical area which presents a number of challenges, transport links are poor between the local authorities, and difficulty parking, particularly at Nevill Hall, discourages families from coming to events. In response to being asked what could help with engaging families in the future, one professional suggested:

*“I think it’s finding out what families want, where they want it because parking here, it would put you off.”*

### **3.7.3 Using school facilities for running activities and clubs**

A professional raised the issue with using school facilities to run activities and clubs:

*“The issue is with education, opening up their schools. So in terms of local need, there’s loads of school facilities but because of how they’ve always run, you can’t get access to them in the holidays.”*

### **3.7.8 Poor communication between service providers**

Parents and professionals raised that poor communication between service providers presents a barrier.

*“I find it quite frustrating because I’m dealing with different, I’m dealing with Torfaen, I’m dealing with Monmouth; they don’t seem to talk to each other...”*

(Parent P8, Monmouthshire)

*“You’ve got these huge gaps in communication which I think comes under the key workers.”* (Professional)

*“And for me I think it’s getting other services to work together and be more savvy, but what I tend to find is a lot of people don’t want to let go...I think the hard thing is, a lot of people you see are scared of losing their jobs.”* (Professional)

### **3.7.9 Long waiting times to access services**

Parents and professionals also commented on waiting times being very long for services such as portage and diagnostic assessment.

*“We’re on a 6 month wait to access portage.”* (Parent P5, Monmouthshire)

*“Our son was referred for therapy 16 months ago and is still on a waiting list.”*

(Parent questionnaire respondent)

*“Gosh the wait is probably about three quarters of a year isn’t it...it’s a really long time. The target is 26 weeks, so it’s half a year, but I think they’re running at around 34 weeks at the moment; so it’s quite a long time before you get a diagnosis.”*

(Professional)

### **3.7.10 Lack of space at NHCC for delivering new services**

Professionals felt that NHCC was not a suitable location for delivering new services and support due to a lack of space.

*“The lack of space is an issue at Nevill Hall Children’s centre. There is no room for clubs for children.”* (Professional questionnaire respondent)

*“Our building is far too small to accommodate these lovely ideas.”*

(Professional questionnaire respondent)

## **3.8 Recommendations for approaches to service delivery**

Parents felt that services should be delivered that meet the needs of the whole family, with an emphasis on activities during the school holidays and emotional support for parents.

### **Parent perspectives**

*“I would say the emotional support for us would be the biggest thing, but I think probably as he gets older, the school holiday stuff would be, it would kind of change because I know that’s a real...I already worry about how we’re going to manage in the holidays and how are we going to fill like the six weeks of summer as they both get older.”* (Parent P9, Blaenau Gwent)

*“Probably priority would be anything that provided a sort of fun range of experiences and sort of that social aspect outside of school.”*

(Parent P7, Monmouthshire)

Professionals discussed approaches to delivering new services, highlighting the importance of integrating children and families into their local communities, working collaboratively with other services, not overwhelming families with too much at once and providing continuity.

### **Professional perspectives**

*“You want to be integrating children and families into the community.”*

*“I think it’s about working with Action for Children, they’ve got that 1:1 support...can they work with the sports development team, can we put some sports on, can we get a youth service involved, and make a 3 hour thing...if we get a few different partners around a table and actually work together on a project and actually work collaboratively, you’re getting a better outcome.”*

*“There’s too much sometimes and I think that continuity hasn’t been there and I think families feel really let down. It’s to try not to overwhelm, because they’re already in quite an overwhelming situation.”*

Differences in opinions between professionals emerged as to what services and support they felt were highest priority, although there was some agreement that offering support for families during the summer holidays would also offer respite and emotional support.

### **Professional perspectives**

*“I would say family activities as long as our other funding’s protected for what’s in place.”*

*“And I think followed by information and advice to parents more so than support groups-“*

*“Not all families want to be with other parents, but they want to be informed. They want to know what advice is out there, but that may not necessarily be a support group.”*

*“I think the emotional support is high and the respite that that play scheme and the school holiday support can bring”*

*“They go hand-in-hand”* [Some agreement from other participants.]

Offering a choice of children’s activities locally, and for children with more complex needs to be better supported, were highlighted as important considerations by parents and professionals.

*“It would be nice to think that in an ideal world there would be a choice of things that they could go along to and...a bit closer to home.”* (Parent P7, Monmouthshire)

*“It’s those children who, it’s great having youth clubs and everything, but they need support workers or parents need to be there.”* (Professional)

Parents indicated when it would be convenient for them to access new services and support to be made available.

### **Parent perspectives**

*“Parent activities actually run within school hours. Within school hours would be great, for like parent-led groups.”* (Parent P4, Blaenau Gwent)

*“It would be nice if there were services that were offered at different times of the day, for children and for parents...more flexibility in what’s offered so that all parents could access.”* (Parent P8, Monmouthshire)

*“Weekend things would be lovely.”* (Parent P9, Blaenau Gwent)

*“When planning activities, groups, etc. please take into account that working parents already take a huge amount of time off for medical appointments, illness, hospital stays so are unable to take additional time off for leisure activities as much as we would love to be able to do this.”*  
(Parent questionnaire respondent)

### 3.9 Potential locations for delivering new services in North Gwent

Based on the feedback from parents and professionals, and searching for suitable locations in North Gwent, potential locations for services and support to be made available are:

#### Potential locations for delivering new services in Monmouthshire, Blaenau Gwent and North Torfaen

##### ***Monmouthshire***

- Abergavenny
  - Abergavenny Community Centre
  - Acorn Centre at Deri View Primary School
  - Gilwern Outdoor Education Centre
- Monmouth
  - Osbaston Church in Wales School
  - Overmonnow Primary School
  - Rockfield Park Community Centre (large function room, fully equipped kitchen, outside picnic area, large car park)

##### ***Blaenau Gwent***

- Brynmawr
  - The Tabor Centre (a multi-purpose community hub with a café)
  - The Bert Denning Centre (small hydro pool and sensory room)
- Ebbw Vale
  - The Ebbw Vale Institute
  - Pen-y-Cwm Special School
- Aberbeeg (2 miles from Abertillery)
  - The Eden Centre (soft play centre also used by the NAS)
- Blaina
  - Blaenau Gwent Heart of the Valleys Integrated Children's Centre
  - Ystruth Primary School
  - Coed-Y-Garn Primary School
- Tredegar
  - Tredegar Sports Centre (a disability-friendly Centre, Blaenau Gwent Otters Swimming Club hold sessions here)
  - Tredegar Comprehensive School
  - Glanhowy Primary School

##### ***North Torfaen***

- Crownbridge School
- Abersychan School
- Pontypool Park

Parent perspectives on potential locations included delivering services in Monmouth and finding a more accessible and less clinical location than NHCC.

### **Parent perspectives**

*“Location wise, I think to cover the whole of the north you may need to have something in Monmouth...Somewhere with good parking, easy to find.”*

(Parent P5, Monmouthshire)

*“Why would you want to come to Nevill Hall, I think that’s a thing as well. If it’s meant to be something that’s fun...it shouldn’t be in a hospital.”*

(Parent P2, Monmouthshire)

There was a general consensus amongst professionals that new services would be best delivered in the community, for example accessing school facilities, community halls, leisure centres and supermarkets.

### **Professional perspectives**

*“It’s great to try and harness the services here, but actually we still need to do a lot more locally...in the community.”*

*“It’s got to be in the community hasn’t it.”*

*Other participants say “yeah” in agreement for “the space.”*

*“Specialist schools I think Pen-y-Cwm, Crownbridge where the facilities are already there.”*

*“Community halls are much cheaper; you can probably get a community hall for ten pound an hour. Whereas you’re looking at maybe thirty, forty pound at a leisure centre.”*

*“Even some of our local, I know our local Sainsbury’s were offering a cafe of an evening for free, if you wanted to use it for a community thing...A lot of the supermarkets have free space.”*

## 4. Conclusions

Based on the findings from the research data, the following conclusions can be made:

- Current services available for children with additional needs and their families living in North Gwent include children's activity groups and clubs, support groups for parents, parent workshops and family events.
- The needs of some children and their families are not currently being met due to gaps in service provision, particularly for children below the age of eight, and a lack of awareness of services; loss of services and play schemes over the school holidays; limited access to services and support depending on where families live; and a lack of emotional support for families post-diagnosis and with transition.
- Suggestions for service enhancements to address these unmet needs include enhancing the facilities at NHCC, making services more accommodating to children's individual needs, and increasing the provision of information, advice and signposting for families.
- Suggestions for new services to address these unmet needs include warm water swimming lessons, fun day events, activities and clubs during the school holidays, stay and play club, and an Independent Living Skills (ILS) club.
- Key challenges to introducing service enhancements and new services were identified as; issues with travelling and parking for families, particularly in Blaenau Gwent, accessing school facilities to run activities, making services accessible, engaging with families, poor communication between services and a lack of space at NHCC.
- Recommendations for approaches to delivering service enhancements and new services include meeting the needs of the whole family, facilitating greater integration of families into their local communities, working collaboratively with other services, and providing families with continuity.
- Parents and professionals suggested a number of potential locations in North Gwent for the delivery of new services

## Appendix A: Participant information sheet



### Participant Information Sheet

#### **Research project: “Enhancing services for children with additional needs and their families in the Nevill Hall Children’s Centre catchment area”**

Please note this geographical area includes Blaenau Gwent, North Monmouthshire and North Torfaen. These areas will be referred to for the purpose of the research as “North Gwent”.

#### **Background information**

Continuing the work of the Umbrella Appeal, Sparkle are actively consulting with children and families who attend Nevill Hall Children’s Centre about potential service enhancements and new services, either to be delivered at Nevill Hall or within their local communities. To enable this to happen, it is important for us to capture the thoughts and opinions of children and their families about what enhancements they feel would meet their needs in a supportive and sustainable way.

#### **What is the purpose of this research?**

The purpose of this research is to capture the views of children, families and professionals to inform and develop enhancements to current services, and potentially introduce new services, for children with additional needs and their families living in North Gwent. Your participation will help to provide a more in-depth understanding of the current service provision, and how this can be enhanced to address unmet needs across North Gwent.

#### **What is the purpose of a focus group?**

Focus groups allow individuals to interact with each other in a discussion that promotes the sharing and generation of ideas and perspectives. Focus groups are

a useful research method for a number of reasons including: discovering how different groups think and feel about a topic and why they hold certain opinions; verifying or clarifying results from surveys, enabling participants to suggest potential solutions to problems and to gain a deeper understanding of a topic or issue by gathering multiple perspectives.

### **What will I be expected to do in the focus group?**

The researcher (Fiona Elliott), will start by opening the session with giving each participant the opportunity to introduce themselves. The researcher will then ask questions that generate discussion around service enhancements for children with additional needs and their families. Participants will be encouraged to share their thoughts and opinions openly with the group. At the end of the discussion the researcher or assistant facilitator taking notes will summarise discussion point to check for clarity and understanding.

### **Do I have to take part?**

No, it is your choice whether or not you decide to participate in the focus group for this research. If you agree to participate and then change your mind, you can withdraw at any time without giving your reasons.

### **Are there any benefits in my taking part?**

You may find that participating in the group will be a rewarding experience that will enable you to share your views and gain an understanding of the views of others. The information you share will help to inform and enhance service provision for children with additional needs and their families living in North Gwent.

### **Will be participation be confidential?**

Yes. Transcription of the focus group will be anonymised. You will be given a code number and your name will not be used in any written reports or research dissemination materials.

If any sensitive information/ inappropriate behaviour/ bad practice relating to yourself or to others is found during the study that could cause harm,

confidentiality will have to be broken and this will be reported to the relevant authorities.

**What happens with the data being collected?**

These findings will be used to recommend enhancements to services, or the development of new services, to the Board of Sparkle Trustees who will then decide as to how funds that are raised for the charity will be invested in these service enhancements.

**Who can I contact for further information?**

Please contact Fiona Elliott on 01633 748024 (between 9am-5pm Monday to Friday) or email [Fiona.elliott@wales.nhs.uk](mailto:Fiona.elliott@wales.nhs.uk).

**Thank you for your time**

## **Appendix B: Parent focus group schedule**

### **Greet participants and welcome them to the group**

- \* Ensure all participants have completed a consent form and check against register
- \* 3 minute mindful breathing exercise
- \* Suggest that participants sit next to people they haven't met before or don't know very well
- \* In pairs/3's – find 3 things that they have in common and feed back to the group.

### **Instructions**

[Explain that I am going to read out the focus group instructions so that all groups follow the same schedule]

“Thank you all for agreeing to participate in today's focus group. As the official charity of NHCC, Sparkle are capturing the views of children (aged 0-18) with additional needs, their families and professionals to inform our delivery of service enhancements. We are really interested in gathering your experiences, thoughts and ideas so that we can gain an understanding of how Sparkle can support and meet the needs of children and their families in North Gwent.

I am going to ask you some questions that I hope will generate discussion amongst you. I will not be contributing to the discussion, but I am here to facilitate by ensuring that we cover off all the topics of conversation that are of interest to the research, and I will be summarising key points as we go along. Please ask me to repeat a question or ask for clarification if you're not sure. If I have to interrupt you, please don't think I'm being rude, but I might have to move the discussion on to ensure I have time to ask all the questions within an hour.

I've had everyone's consent to record the discussion so I will be using an audio-recorder which will greatly assist me in remembering the discussion and for analysis and reporting purposes. Please speak clearly and at a steady speed. Remember that the tape recorder will not pick up anything non-verbal such as nodding in agreement with someone, so please speak up if you would like to agree or disagree. Also, please do not interrupt or talk over someone else. ”

**Does anyone have any questions before we start?**

**Start recording (facilitator)**

**Start note taking (assistant facilitator)**

**Part 1: Introductions (10 mins)**

Let's start with introductions. Please can everyone say their name and share with the group which borough you live in.

**Part 2: Introductory Questions (10 mins)**

- 1) What services do you **currently access/or are aware of**, for your **child/children** (aged 0-18) with additional needs?
- 2) What services do you **currently access/or are aware of**, for **parents** of children with additional needs?

**Part 3: Transition Questions (15 mins)**

- 3) What are everyone's thoughts on how well current services are meeting the needs of your child/children, and your own needs as a parent?
- 4) Where are the main gaps in service provision in your area?

**Part 4: Key Questions (20 mins)**

- 5) Would everyone like to share their suggestions for enhancements to existing services that Sparkle could make across North Gwent to better meet your child's and family's needs?
- 6) Would everyone like to share their ideas for new services that Sparkle could deliver to support children and families whose needs are not currently being met?
- 7) What service enhancements/new services should be prioritised?
- 8) What does everyone think about where these services can best be delivered so that they are accessible to children and their families across North Gwent?

**Part 5: Closing Question (5 mins)**

- 9) Is there anything anyone would like to add that they feel is important for Sparkle to be aware of when thinking about the services we can deliver in North Gwent?

**Summarise the key points of the discussion.**

**Thank everyone for their time and participation**

**Appendix C: Professional focus group schedule**

## **Greet participants and welcome them to the group**

- \* Ensure all participants have completed a consent form and check against register
- \* Suggest that participants sit next to people they haven't met before or don't know very well
- \* 3 minute mindful breathing exercise
- \* In pairs/3's – find 3 things that they have in common and feed back to the group.

## **Instructions**

[Explain that I am going to read out the focus group instructions so that all groups follow the same schedule]

“Thank you all for agreeing to participate in today's focus group. As the official charity of NHCC, Sparkle are capturing the views of children (aged 0-18) with additional needs, their families and professionals to inform our delivery of service enhancements. We are really interested in gathering your experiences, thoughts and ideas so that we can gain an understanding of how Sparkle can support and meet the needs of children and their families in North Gwent.

I am going to ask you some questions that I hope will generate discussion amongst you. I will not be contributing to the discussion, but I am here to facilitate by ensuring that we cover off all the topics of conversation that are of interest to the research, and I will be summarising key points as we go along. Please ask me to repeat a question or ask for clarification if you're not sure. If I have to interrupt you, please don't think I'm being rude, but I might have to move the discussion on to ensure I have time to ask all the questions within an hour.

I've had everyone's consent to record the discussion so I will be using an audio-recorder which will greatly assist me in remembering the discussion and for analysis and reporting purposes. Please speak clearly and at a steady speed. Remember that the tape recorder will not pick up anything non-verbal such as nodding in agreement with someone, so please speak up if you would like to agree or disagree. Also, please do not interrupt or talk over someone else. ”

**Does anyone have any questions before we start?**

**Start recording (facilitator)**

**Start note taking (assistant facilitator)**

**Part 1: Introductions (10 mins)**

Let's start with introductions. Please can everyone say their name and share with the group their professional role and a brief description of what your role involves.

**Part 2: Introductory Questions (10 mins)**

- 1) Within your professional roles, what enhanced services are you aware of that are available for children (aged 0-18) with additional needs and their families living in North Gwent?
- 2) What are everyone's thoughts about the services currently available from your experiences of working with children and their families?

**Part 3: Transition Questions (15 mins)**

- 3) Reflecting on your professional experiences, what's everyone's thoughts and opinions on the unmet needs of the children and families that you work with?
- 4) Where are the gaps in service provision for these children and their families?

**Part 4: Key Questions (20 mins)**

- 5) What enhancements to existing services can be made across North Gwent to better meet their needs?
- 6) Are there any new services that can be introduced to support children and families whose needs are not currently being met?
- 7) What service enhancements/new services should be prioritised?
- 8) What does everyone think about where these services can best be delivered so that they are accessible to children and their families across North Gwent?

**Part 5: Closing Question (5 mins)**

- 9) Is there anything anyone would like to add that they feel is important for Sparkle to be aware of when thinking about the services we can deliver in North Gwent?

**Summarise the key points of the discussion.**

**Thank everyone for their time and participation**

## Appendix D: Interview topic guide

Adapt the below questions for parents and professionals (parent/professional)

- 1) Which borough do you live/work in?
  
- 2a) How many children do you have?
- 2b) What age(s) are they?
- 2c) What are their needs?
  
- 3a) What services are currently available for your child/children in your area?
- 3b) What are your thoughts on these services?
- 3c) Are these current services meeting the needs of your child/children?
- 3d) What are your thoughts on how current services could meet the needs of your child/children?
- 4a) Are there any new services/support that we could offer that you think would benefit your child? *Probe: why would this be beneficial?*
- 4b) How should new services for your child/children be prioritised?
  
- 5a) What services are currently available for yourself, as a parent? (e.g. information and advice service)
- 5b) What are your thoughts on these services?
- 5c) Are these current services meeting your needs as a parent?
- 5d) How could services meet your needs?
- 6a) Are there any new services/support that we could offer that you think would be beneficial to yourself or to other family members/family as a whole? *Why?*
- 6b) How should these new services for yourself/your family be prioritised?
  
- 7) Which locations can these services be delivered that are accessible to your family?
- 8) When would be most convenient days and times for your family to access services?
- 9) Anything else that you would like to add that you feel is important for Sparkle to be aware of when thinking about new services we can deliver in North Gwent?

## Appendix E: Participant consent form



### Participant Consent Form

This form is to give your agreement to take part in the research project: “**Enhancing services for children with additional needs and their families in the Nevill Hall Children’s Centre catchment area**” (this includes Blaenau Gwent, North Monmouthshire and North Torfaen). Please carefully read the following statements and if you are happy please **initial** each box and **sign**.

I am over 18 years of age.	
I confirm that 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 that have received satisfactory answers to any questions.	
I agree with the interview/focus group discussion being audio recorded and transcribed. I also understand that the interview transcription will be anonymised.	
I understand that I will remain anonymous, identified only by my pseudonym and a brief description agreed by me.	
I understand that all information I provide 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 that I am free to withdraw from the project, without giving a reason, prior to my data being anonymised. After this time, it will be impossible to trace the information provided due to it having been anonymised. I understand that my withdrawal will not affect my child’s current or future care and treatment from Nevill Hall Children’s Centre.	

I know how to contact the researcher (Fiona Elliott) if I need to.	
I understand that this project may be submitted for publications, reports or presentations.	
I understand that if I feel distressed by any part of this project, I can talk to the researcher or a member of staff for information on who to talk to.	
I agree to take part in this project.	

**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 .....