The Serennu Children's Centre Evaluation

Determining the impact of the Serennu Children's Centre, its facilities, ethos and activities, on children and young people with disabilities or learning difficulties and their families.

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SCC	Serennu Children’s Centre
DDD	Disabilities or developmental disorders
PedsQL	Pediatric Quality of Life Inventory^{TM}
Sibs	Sparkling Siblings Group
HRQOL	Health-Related Quality of Life
SLDOM	The Sheffield Learning Disabilities Outcome Measure
FLS	Family Liaison Service
FLO	Family Liaison Officer
NHCC	Nevill Hall Children’s Centre
ADL	Activities of daily living
LA	Local authority

Executive Summary

The Serennu Children's Centre (SCC) is a flagship Centre that opened in 2011 serving children aged 0- 18 years with disabilities and/or developmental difficulties (DDD) living in South Gwent. This catchment area consists of Newport, South Monmouthshire and South Torfaen, serving an estimated total population of 240,993 and an estimated 19,279 children with DDD. The Centre is a purpose built, integrated, multi-agency base for professionals across Health, Social Care and the third sector. Sparkle, the official charity of SCC, were the founding organisation for the development, design and building of the Centre. Their support includes enhanced services such as leisure activities for children, access to support for parents and a Family Liaison Service.

To determine the impact SCC has on children and young people with DDD, and their families, a mixed methods evaluation of the services and facilities at the Centre was conducted, to inform future developments at the Centre, and disseminate the learning from this unique model. This evaluation involved consultation with children, families and professionals using the services and facilities at SCC. Three predominant themes emerged from the evaluation in relation to the impact of SCC, namely: (1) Social and Emotional Well-being; (2) Environment and (3) Co-location of services.

Key findings: Social and Emotional Well-being

Evidence was found in support of SCC having a positive impact on children with DDD's social and emotional wellbeing; particularly in relation to friendships, improving confidence, and development of social skills. A range of benefits for children and their families were identified from the enhanced services available at SCC including: participation in leisure activities promoting social inclusion for children with DDD and their siblings; improved awareness and access to other services; and parents feeling supported and empowered as a result of attending parent support groups, workshops and counselling sessions.

Key findings: Environment

The environment at SCC was described by families as being friendly, welcoming, supportive and inclusive, which fundamentally facilitates social inclusion for children with DDD and their families. The broad range of indoor and outdoor leisure and therapeutic facilities available were highlighted by families as being extremely beneficial, and many professionals expressed a preference for SCC's community setting over a typical hospital environment. SCC is well-placed to address developmentally appropriate healthcare, since it offers a supportive and safe environment that breaks down the barriers presented by stigmatisation around disabilities, by giving children with DDD a community presence. Overall, the evidence from this evaluation implies that the environment at SCC has a positive impact on the experiences of families who attend the Centre, and crucially, has a critical role in increasing confidence and empowering parents to understand and manage their child's needs.

Key findings: Co-location of services

Families and professionals indicated that co-location of services at SCC has a positive impact on children, families and professionals. Key benefits of co-location identified were: improved communication between professionals leading to improved relationships and joint working; more efficient use of time and resources; improved integration of care for children and enhanced service user experience; improved access to services such as Sparkle leisure clubs; greater opportunities for professional development and learning; and improvements in child protection due to a multi-agency approach. These benefits are supportive of the case for co-location of services as an essential component of fully integrated care for children with DDD.

What does the future hold?

The findings from this evaluation will be used to inform future developments of services and facilities at SCC to further enhance the positive impact of the Centre on children with DDD and their families. One area of potential development will be addressing how the leisure services at SCC can offer support to young people with DDD who are transitioning into ‘mainstream’ provision. As Sparkle expands its model into new geographic areas, future evaluations will combine quantitative and qualitative data on services such as: specific leisure clubs, Family Liaison, Key Working, and the Integrated Service for Children with Additional Needs (ISCAN). It is hoped that this initial evaluation will inform more in depth future evaluations, including longer term outcomes for young people and families.

1. Introduction

1.1 Previous research on Children's Centres

Children's Centres are designed to bring together a wide range of services and support, tailored to the needs of children and their families in a safe, relaxed and supportive environment. An outcomes framework for Children's Centres to help inform their activities and priorities, developed by Bowers et al., (2012), outlined key outcomes considered high priority for Children's Centres. These outcomes were categorised as follows: *(1) Children's health and development (2) Parenting and (3) Parent's lives.* With reference to these categories, firstly, all Children's Centres should support children's health and development in the areas of cognition, communication and language, social and emotional skills, and physical health; all of which are critical for children to thrive as they grow and prosper in adulthood. Secondly, with respect to 'Parenting', Children's Centres can offer a range of interventions and opportunities to support parents to improve their own approaches and skills to generate/ enhance attachment between parents and their children. Thirdly, Children's Centres can support parents to improve factors that act as enablers or barriers to nurturing their children's development such as their health, social networks, financial resources and knowledge about parenting. All of these outcomes sit within a wider context of neighbourhood and community, with Children's Centres having a fundamental role in protecting and safeguarding children in their community. A key finding from this review was that two areas of particular significance were found to enable positive contributions to outcomes; *(1) Well-trained and highly qualified staff and (2) Outreach and engagement with families.* Furthermore, as a guiding principle, Children's Centres should play a core role in local systems that identify and respond to children who have particular needs.

A six-year national evaluation of children's centres and their impact (2009-2014) found positive effects, especially improvement in family outcomes linked to engagement with children's centres and service use (Sammons et al., 2015). The evidence indicated a range of benefits for children including; developing skills which support their 'Personal, Social and Emotional Development', 'Physical Development', and 'Understanding of the World'; as well as school readiness and social interaction. Evidence of benefits for adults including improved parenting skills, greater knowledge of child development, and increased confidence in parenting, as well as receiving more general support for their personal needs. The most disadvantaged groups showed stronger positive effects, and were more likely to use services at their local children's centre rather than services at other centres. In the UK, there has been a growing need for evidencing the impact of Children's Centres on the lives of children and their families (Bowers et al., 2012). However, the above publications relate only to 0-6 year olds in deprived areas, whereas there is an evident lack of published research conducted on the impact of children's centres for children with disabilities and/or developmental disorders (DDD), particularly throughout childhood.

1.2 Serennu Children's Centre

Serennu Children's Centre is a flagship centre for children aged 0-18 years with DDD difficulties living in South Gwent, UK. This catchment area consists of Newport, South Monmouthshire and South Torfaen, serving an estimated total population of 240,993 and estimated 19,279 children with DDD. Located in the community of Rogerstone in Newport, South Wales, SCC sits in the local community, within rural landscapes, has a large designated car park, a children's playground and a sensory garden within five acres of landscaped grounds. The building includes a wide range of facilities including a hydro-therapy pool, a sensory room, clinic and therapy rooms, gym, Aids to Daily Living (ADL) Flat, café, and a fully accessible MediCinema.

The centre is an integrated, multi-agency base for professionals across Health, Social Care and the third sector, all of whom provide services to children with disabilities and their families. Located at the centre are a range of healthcare professionals from Aneurin Bevan University Health Board (ABUHB), including Speech and Language Therapists, Physiotherapists, Occupational Therapists, Dieticians, and Children's Community Nurses. It also provides rooms for other healthcare professionals such as Paediatricians and Audiologists, to host clinics at the centre. From a Social Care perspective the centre is also home to the Newport Disabled Children's Team, as well as the Children with Additional Needs Service team (CANS) from prevention services. Currently the Disabled Children's Teams for South Monmouthshire and South Torfaen are not based at the centre.

Alongside these services, the centre houses a third sector organisation, Sparkle, which offers additional services for children with a disability and/or a developmental difficulty and their families. Sparkle were the founding organisation for the development, design and building of the Centre. Their support includes leisure provision such as After School Clubs, holiday clubs, residential 'outward bound' trips, toddler groups and Swimming Lessons, access to psychological support for parents and support groups, in addition to a family liaison service. Parents and young people (YP) are involved in every stage of the planning and development of services at Serennu, and are represented on the executive board.

Families in Gwent who are outside the catchment for SCC, e.g. North Torfaen, North Monmouthshire and Blaenau Gwent, have access to Nevill Hall Children's Centre, a traditional children's centre within the same health board. This centre is sited within the grounds of an acute hospital, and provides community paediatric clinics and therapies, with liaison out to other relevant services. Some comparisons are made between this traditional model, and the Serennu model.

The overarching aim of this evaluation is to determine what impact the SCC, its facilities, ethos and activities, has on children and young people with DDD and their families.

2. The Impact on Social and Emotional Wellbeing

2.1 Previous research on social and emotional wellbeing of children with DDD

Academic literature has long established that children with learning disabilities can lack appropriate social skills, causing them to struggle with interpreting social situations and tend to have low levels of involvement with other children during play activities (Brooks, Floyd, Robins and Chan, 2015). As a consequence, children who lack social skills are at a greater risk of social isolation, which further restricts opportunities for social development, and causes less acceptance in mainstream services than typically developing children (Brooks et al. 2015). In addition, children with learning disabilities are more likely to report more severe anxiety and depressive symptoms than typically developing children (Mammarella et al. 2016). Not only do children experience greater vulnerability in their social and emotional wellbeing, but parents are similarly faced with unique social and emotional challenges. Literature indicates that parents and carers of children with autism report lower quality of life, greater depression, higher levels of parenting stress, anxiety and notice negative reactions such as shame and disapproval from strangers for their child's challenging behaviours (Neff and Faso, 2015). These demands on parental/caregiver emotional wellbeing are typically paired with an expectation to maintain stability in the family, to ensure their young person has access to appropriate services, and to coordinate their young person's care and medical appointments (Li, Shaffer and Bagger, 2015). In effect, young people with disabilities and their families are potentially at an increased risk of poor social and emotional wellbeing.

A main goal at SCC is to fully support children with DDD and their families, including social and emotional support. SCC provides a fully integrated centre tailored to cater to the needs of each individual child or young person with DDD, in addition to providing support to parents and siblings. It emphasises a model of care based on improving the social wellbeing of families, who are the primary support network for children and young people with DDD. Participation in social activities has been shown to positively influence children's perceptions of feeling physically well, as well as promote improvements in their social and emotional quality of life (e.g. self-perceptions, self-esteem, self-confidence and psychological well-being) (Dahan-Oliel et al.,2012).

Gwent features high on the Welsh Indices of Deprivation (2014) and families who have children with disabilities in the UK are more likely to live with deprivation, poor housing, low income and debt (Blackburn, 2010). Therefore, children with disabilities have an increased vulnerability to social disadvantage and have a heightened need for appropriate and timely service provision. Many families also face the prospect of exclusion from mainstream services, for example, when specialist equipment, staff training, or 1:1 support is required. SCC attempts to address some of these needs through the co-location of statutory, voluntary and leisure services, and its enhanced services. This section outlines the impact that SCC has on social and emotional wellbeing.

2.2. Service User Perspectives: What do families think?

To understand the impact of SCC on social and emotional wellbeing, the voices of children, young people and their families are central. Wellbeing is subjective and something that happens within the individual, yet it is inherently difficult to measure and quantify (Teghe and Rendell, 2005). Nevertheless, it is useful to review a range of evidence in understanding the impact of SCC on its service users.

How were service user perspectives evaluated?

Feedback from a questionnaire, delivered to users of the children's centre in March 2018 begins to construct a picture of service user perspectives around social and emotional wellbeing, using indicators such as friendship, social skill development, confidence, supportive relationships, feelings and access to community activities. Therefore, the questionnaire loosely aligns with key indicators of social wellbeing identified in literature, such as: *social acceptance* (accepting others as they are), *social actualisation* (positive comfort level with society), *social contribution* (a feeling that one has a contribution to make to society), *social coherence* (understanding the social world as predictable and comprehensible), and *social integration* (feeling as part of a community) (Keyes, 2002). The following results derive from this questionnaire, and are considered alongside the key indicators of social wellbeing.

What were the findings?

In March 2018, a total of 264 parents and 43 children attending SCC completed the questionnaire. Since coming to SCC, 89% of young people self-reported that they had made friends (from a total of 38 responses), which suggests that they are building **social skills** and developing bonds with peers during sessions. Likewise, the majority of parents (60% of 231 responses) felt that their child had developed a new friendship. **Friendships** are an important aspect of social development and a natural part of childhood. Both parents and children themselves also felt that the primary skill development since attending SCC was social skills (50% of responses from both caregivers and children described social skills). This indicates that SCC has had an impact on social wellbeing, as children are better able to make meaningful connections with others and gives reasonable belief to conclude that their social skills have developed, thus potentially improving social coherence, social acceptance and social integration. Yet to further evolve a young person and their family's sense of social integration, it is important for service users at SCC to have the opportunity to access other **community activities.** Leisure services at SCC should act as a stepping stone to wider community provisions, offering support to young people and ultimately transitioning them into 'mainstream' provision. However, of 211 responses, 59% did not feel like SCC supported their child to access other community activities.

When reporting on **feelings**, 53% of young people reported feeling less worried since coming to SCC. The questionnaire also found that 53% felt happier about themselves, although 47% reported feeling the same. This might suggest that SCC is making a positive impact on young people's emotional wellbeing; they generally feel less worried and happier. SCC offers a welcoming environment, where young people with DDD can be themselves and find solace in what the centre offers. However, if nearly half of young people report feeling the same, it may indicate that the impact of SCC on emotional wellbeing is limited. Nevertheless, these results should also be considered with the fact that a high number (98 of 233 on Sparkle's leisure group consent database; 42%) of young people attending the centre have a primary diagnosis of autism spectrum disorder (ASD). Young people with ASD often find difficulty in identifying their own emotional processes, report higher levels of depression, yet can also have difficulties in completing self-report measures which sometimes use abstract concepts (Hill, Berthoz and Faith, 2004). This means that some young people may not have noticed an increase or decrease in happiness or worry since attending the centre, as these are abstract concepts and can be difficult to define. Therefore, this lack of conceptual understanding may have led to confusion in this question. It should be noted that demographic data detailing a diagnosis was not collected on the child and young person questionnaires, thus, this can only be speculated and cannot definitively be suggested as a causal factor in this result. Therefore, the centre may need to think of new ways to increase emotional wellbeing in all young people.

When asked about **confidence**, 30 young people report they felt more confident, 2 did not feel more confident and 11 were not sure. This highlights that 70% felt that their confidence had increased since attending SCC for leisure or treatment. Parent/caregiver questionnaires also reveal that overall, 93% of respondents feel that their child's confidence had improved since attending the centre (214 of 230 respondents; 101 felt that their child's confidence had improved 'a lot'). Below documents the comments left by young people, giving an example of how they are more confident:

"Speaking to people"

"Able to run in active group"

"More confident in the gym and doing sport"

"When ask to do a presentation in front of a class"

"To meet new friends"

"In active group"

"Lego, talking/making friends"

"Doing active group"

"Singing, talent show"

"Presentation to class at school, playing games"

"Lego building"

"Running in active group"

"Doing a talent show"

"Being more sociable

As evidenced by the examples, young people focus on their improved confidence in making friends, attending new groups and learning new skills. This is an important finding and contributes to the argument that SCC is having a positive impact on social and emotional wellbeing.

2.3 Professional Perspectives: What do professionals think about the enhanced services at Serennu?

What are the enhanced services at SCC?

Serennu is a unique Children's Centre in that it offers a range of enhanced services including; Information and Advice, Family Liaison, Helping Hands psychology service, and support groups for parents, children and young people. In addition, there are also a number of leisure activities on offer such as swimming, independent skills club, fun day events, and residential trips.

How were the views of professionals captured?

To evaluate the impact of enhanced services at SCC, four focus group(s) were held with professionals based at SCC and Nevill Hall Children's Centre* (NHCC), and professionals working within Torfaen* and Blaenau Gwent*. For details of the focus group participants, topics discussed and analysis approach please see Appendix A. * many staff in these areas have worked in Serennu previously

Findings: What do professionals think about the enhanced services at Serennu?

Seven themes in relation to the impact of enhanced services emerged from analysis of the focus group transcripts; these themes are presented in the table below with examples of comments made by professionals for each theme.

Table 1. Themes identified from professionals views on the impact of enhanced services

Theme	**Comments from professionals based in Serennu (SCC), Torfaen (TF), Blaenau Gwent (BG), and Nevill Hall (NHCC).**
1) Social inclusion	"*For the children themselves….they probably make better relationships and friendships with like-minded youngsters."* (SCC3) *"The other aspect of it is that social side of it, with all the clubs and activities."* (BG1)
* 2) Emotional wellbeing	*"They don't feel like they're isolated. They don't feel like they are on their own in this world."* (SCC6) *"For some children actually, although we would all want children to access, you know, activities within the community…. for some children they will avoid doing that because they feel different and it can really boost confidence."* (SCC8)
3) Access to leisure services for children with DDD and their families	*"Some of the Sparkle clubs, the after-school ones, I mean I can remember if we worked late going down there…. and they would be having a brilliant time, wouldn't they? The kids seemed to really enjoy it and they do loads of things…"* (TF7) *"The services they do provide are all positive from families I work with, and the stuff they can access is great...yeah, like the Cinema club and the Siblings ones – where they can go in with their siblings that's good for the family."* (TF6) *"…that's how the 'Little Stars' came about really, because of families saying they didn't enjoy going to the conventional parent toddler groups, because they were being asked "what's wrong?" and "why are they doing that?" So, they just weren't going."* (SCC7)
4) Signposting to other services	*"The family liaison role, really promotes that informal conversation with you about discussing, you know what does social services do?"* (SCC1)

	"Working with the families at Serennu it's much, much more beneficial and I think it is great that we can always signpost them so much better there." (NHCC4)
5) Support for parents	*"Parent workshops…..it is something very beneficial. I know that when I was in Serennu they got to network with the parents then which was very nice and supportive…..But also the mother and baby group ran. They were just a great opportunity for parents to meet each other for that discussion, for that support. They, you know, they were invaluable really." (NHCC7)* *"Some of the groups at Serennu that work well are like the Father's group on a Saturday morning."* (NHCC4)
6) Professionals linking in with enhanced services	"*I found it useful having the playgroup at Serennu, we don't have any play groups in Monmouthshire like we had at Serennu. I did use to like that in Serennu and I used to link in quite closely."* (NHCC1) *"As therapists you could go in there and see quite a few kids in one morning playgroup."* (NHCC2) *"I think that's the same with the Social Workers, they will go down at the end of the day just to see a Sparkle activity. Just spending 15 minutes observing a child. Behaving in different environments……..It's convenient. They perhaps wouldn't do it otherwise."* (SCC1)
7) Psychological support for families	*"I find Helping Hands absolutely brilliant."* (SCC6) *"Yes, I've had a lot of families access it."* (SCC5) *"Psychologically, we have a huge gap in healthcare and in core services that absolutely essential for families in terms of accepting whether it's the tiniest thing where a child is never going to straighten their little finger or whether they have some degenerate disease doesn't make it any different, its knowing those services are out there to give you that psychological support."* (NHCC9)

How can these findings be interpreted?

Professional perspectives highlight a number of benefits of the enhanced services at SCC for children, their families and professionals. One of the main benefits raised was in relation to facilitating social inclusion for children with DDD. Research studies have shown that participation in activities that encourage social interaction with peers promotes children's development of friendships (Kampert & Goreczny, 2007). Friendships and relationships in childhood can contribute to quality of life, provide opportunities for social and emotional development, companionship, intellectual growth and social support, as well as develop resilience for coping with stressful life events (Geisthardt et al, 2002). A thematic analysis of the literature conducted in 2012 found evidence for important relationships between leisure participation and quality of life (QoL) for children with neurodevelopmental disabilities (Dahan-Oliel, Shikako-Thomas and Majnemer, 2012). Participation in social activities was shown to positively influence the child’s perceptions of feeling physically well, as well as promote improvements to their social and emotional quality of life (e.g. self-perceptions, self-esteem, self-confidence and psychological well-being). Social participation in leisure activities also promoted improvements in overall self-worth and motivation to succeed at physical tasks. The authors concluded that participating in leisure activities and therapeutic programmes that focus on leisure, contribute to improving the QoL of children with neurodevelopmental disabilities. Moreover, a key aspect to consider is the child’s ability to participate in his/her preferred leisure activities, and any environmental adaptations that can be made to ensure that the leisure opportunities meet the child’s capabilities and contribute positively to their QoL.

Enhanced services for parents, such as parent workshops, support groups, and psychological support (one to one counselling and trained peer support), offer a range of perceived benefits including the opportunity to meet other parents in similar situations and share experiences in a supportive group environment. This links in with previous research on the benefits of mutual support groups for parents of children with disabilities; one study found that such support was helpful across three broad domains: (1) the socio-political, which involved developing a sense of control and agency in the outside world; (2) the interpersonal, which involved a sense of belonging to a community; and (3) the intra-individual, which involved self-change (Solomon, Pistrang and Barker, 2001). Enhanced services for both children and their families, for example the Cinema, provides the whole family with the opportunity to enjoy social experiences together; promoting positive emotional wellbeing. The impact of enhanced services on *professionals* received less attention during the focus groups, however there was some indication that being able to attend group activities enabled professionals to see more than one child at a time, and to assess them in a more naturalistic setting.

Overall, enhanced services at SCC are vitally important for facilitating social inclusion and contributing towards QoL for children with DDD, especially as community provisions may not be as socially inclusive or meet their individual needs. Enhanced services at SCC are also hugely important for supporting parents and enabling families to access services that the whole family can enjoy together.

2.4 Evaluation of Dad’s Group

Background

Research studies have found that caring for a child with DDD impacts the whole family (Baldwin and Carlisle, 1994). Support groups are one form of supportive service for parents of children with DDD, however these are predominantly attended by mothers, with a lack of support for fathers (Carpenter and Towers, 2008). Emerging research suggests that fathers can often feel unheard and unseen (Herbert and Carpenter, 1994; Baurn, 2015).

What is Dad’s Group?

Dad’s group was established in 2015, as a monthly support group open to fathers, grandfathers and male carers of children with DDD. Important functions of this group were that the group took place on a weekend, in the hope more fathers would be able to attend due to work commitments in the week, a ‘lead’ dad as well as a professional co-facilitated the group and fathers could attend the group as and when it suited them.

How was Dad’s Group evaluated?

A qualitative method, whereby all 15 members of the group were invited to take part in semi-structured interviews, was utilised. Participants were asked to rate how beneficial they found the support group on a scale of 0 to 10 (where 0 = strongly not beneficial and 10 = strongly beneficial). Interviews were conducted, recorded and transcribed by the Assistant Psychologist who co-facilitated the group. The data was analysed, following Braun and Clarkes (2006) thematic analyses framework.

What were the findings?

Seven members of Dad's Group participated in the study, all of whom had attended the group between 1 and 48 months. Please see Table 1 in Appendix B for participant demographics and characteristics of their child with a DDD.

All of the dads rated how beneficial they found going to Dad's Group as between 8 and 10 on the scale. Six predominant themes directly relating to the dad's experiences of attending a male-only support group emerged. These themes, sub-themes and quotes are displayed in Table 2 below.

Table 2. Primary and secondary themes identified from interviews with Dads. All names used are pseudonyms, to maintain confidentiality.

Theme	**Sub-theme**	**Comments made by participants**
1) Feeling understood and connected	n/a	*"I think it's just being around other **dads that know about kids with disabilities**, the **understanding**, because there is no pressure… with these guys they've been through it, they've done it, **it's like it's all the same**.*" (Jake)
2) Father peripherality (A sense of exclusion from elsewhere)	a) Excluded from female dominated support groups b) Excluded from the 'other' parents c) Excluded from family	*a) "Problems of like breast feeding and not sleeping in the night, those are **experiences that are unique to that gender**. And in a way they're very sensitive issues that you just can't get involved in or relate to. So quite often **you're blocked out."** (*Curtis) b) *"I have had **judgment from 'outside' parents**."* (Alex) c) *"I've had lots of issues with my own family not understanding the situation and telling me that my parenting skills are lacking because my child's behaviour is not right. So **that can be isolating and it can be difficult**."* (Luke)
3) Male identity	a) The 'banter' b) The role c) The language	a) "S*ometimes the guys need to have the '**banter'** that sometimes it's not the same as if it was a mixed group*" (Rick) b) *"**As a dad your role is as the protector.** We're taught as children that when we grow up we're supposed to be the ones who look after our families. **Societal pressures** to be that person*

		who protects everyone in the family.” (Tony) c) *“It’s not just about the support, it’s about the* ***comradery”*** (Tony)
4) Problem solving	n/a	*“I think that the* ***mums tend to moan*** *about what’s going on… Whereas,* ***the dads are quite proactive in looking… they look at options of how to rectify it…****how things can be* ***changed for the better”*** (Tony)
5) Support	a) Receiving support b) Providing support	a) *“I know that it’s* ***the only place*** *that a lot of the dads can go to get access to any kind of* ***support.”*** (Tony) *b) “So for me it was about being involved with the group* ***to be able to offer that support to that I didn’t get*** *so much to other people when I was growing up to give to other people.”* (Tony)
6) Practicalities for service development	**a) Barriers;** i) ASD diagnosis, ii) Work-related barriers iii) Fear of being too formal **b) Facilitators** i) Very informal support - Co-facilitation ii) The SCC iii) Previous support group experience iv) Time of the group **c) Improvements** i) 1:1 introduction ii) Length of group (more of it) iii) Consistency of venue	ai) ***“We’re not getting dads in of children with other disabilities and other developmental sort of issues****.”* (Tony) bii) *"W****e wouldn't talk in the same way as we would when we come here****. It's because we have-- it's* ***within the umbrella of Serennu****”* (Rick) ciii) *The* ***consistency's important*** *I think so that when you describe it to people, when they turn up it's what they think.”*

How can these findings be interpreted?

The six themes identified from the dad’s personal accounts revealed that support groups open to both parents may be neglecting the needs of dads, where issues around parenting are often gender specific to women, which fathers cannot relate to or feel involved in. Dad’s Group allows fathers to be with others in a similar situation, where they feel they are understood and can connect to other fathers, where elsewhere they felt excluded. Behind this felt exclusion lies the powerful influence of gender. It can be concluded that the reasons for fathers feeling so excluded from elsewhere were the reasons why they felt they truly belonged and were accepted in Dad’s Group.

2.5 Evaluation of ‘Sparkling Siblings’ Group

Background

Research has estimated that 80% of children with a disability will have one or more siblings (Cicirelli 1996). Although there are perceived benefits of being a brother or sister of a child with a disability (Taunt and Hastings 2002), research has also shown the impact can be negative. Existing literature suggests that these siblings may experience the perception of reduced parental-attention, and in turn this may lead to feelings of being isolated and neglected by their parents (Dyson 1989), with an increase in internalizing feelings leading to low self-esteem and anxiety (Dunn et al., 1994). Support groups for *siblings* of children with DDD have been developed as one way to provide a supportive service to these children. Research suggests that such groups lead to positive outcomes for the children that attend (Smith and Perry 2005).

What is the Sparkling Siblings Group?

Sparkling Siblings Group, which will be referred to as “Sibs” in this report, was set up in 2015 as a weekly therapeutic groups for brothers and sisters (aged 7-11 years) of children with DDD that attend SCC. At the group the children have the opportunity to play and talk with other children in a similar situation, while being supervised by staff who are very experienced in helping children cope with distress or difficulties they may be experiencing. The children choose some of the activities that they would like to do, including baking, games and outside play.

Fundamentally the group is underpinned with psychological models and therapeutic approaches, such as self-soothing exercises, facilitated by the Assistant Psychologist and Sparkle play workers. These approaches aim to help the children develop their emotional coping skills, and offers them a safe space to process their thoughts and feelings about living with a sibling with DDD.

How was the group evaluated?

All 14 members of the weekly Sibs group, were invited to take part in a qualitative focus group, of which 5 children participated. An interview was also conducted with one child in a 1:1 format, due to planned focus group participants not arriving on the day of the focus group. Children were also given the opportunity to express themselves in the form of drawings. The focus group and interview took place in September 2018 and were recorded and transcribed. The data was analysed following Braun and Clarkes (2006) six-stage, non-linear thematic framework. Participatory visual methods in the form of drawings were also used, and these will be reported with interpretive analysis in this evaluation.

What were the findings?

Seven predominant themes directly relating to the children’s experiences of attending Sibs emerged from the analysis: 1) Respite; 2) Friendship; 3) Mixed-feelings about Sibs; 4) A true sense of belonging and feeling accepted; 5) Feeling heard; 6) Education about self and sibling and 7) Impact of having a brother or sister with DDD. Table 4 displays some of the comments that were made by the children relating to each theme.

Table 3. Themes identified from the focus group/interview with children who attend Sibs.

Theme	**Comments made by the children**
1) Respite	*"So **I can get away from my little sister,** not in, like, yay, but because I spend a lot of time helping her. **So I get a break**."*
2) Friendship	*"I think being with all my **friends** is all I want to really do is to be with my friends and feel happy…"*
3) Mixed-feelings about Sibs	Positive: *"I think **it's fun** when we do all kinds of things and we go out in the garden and time when we go out and play"* *"So the likes I like about SIBS is the leaders."* Negative: "*Some people don't let other people talk when they're not-- when other people are trying to talk…"* *"We hardly do sports days."*
4) A true sense of belonging and feeling accepted	*"I think everyone here isn't very judgemental. **I think it is really accepting**."* *"SIBS means to me that I can be **free**"* ***"…a place where I can be myself,** because **at school I feel quite judged…"***
5) Feeling heard	*"I get to talk about my day when no-one else will listen"*
6) Education about self and sibling	*"I like it that it teaches me how to look after my brother and others."* *"Past was hard… because I didn't know what to do. But now I kind of know what to do, and it's not that hard anymore."*
7) Impact of having a sibling with DDD	*"There's me carrying my sister, the end"* *"We fight a lot, and we argue a lot, and I'm not sure that's going to get any better."*

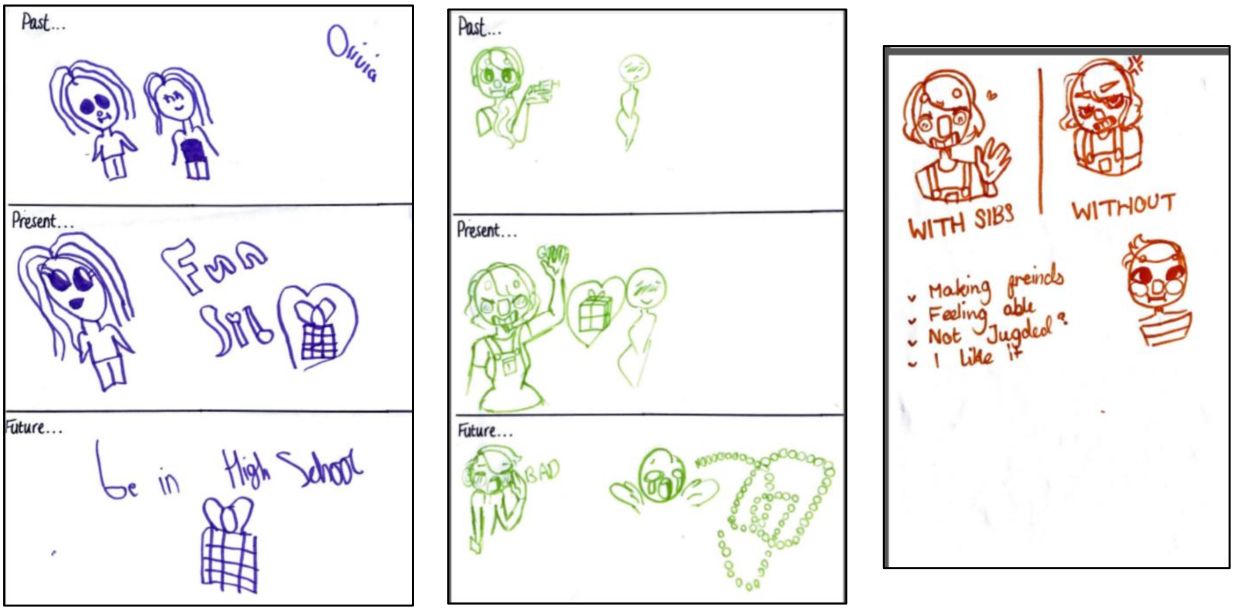
Children indicated respite from home, school and their sibling was important to them. Friendships within the group allowed siblings to be themselves, have fun and offer each other support. For example, the children were talking about issues that their sibling with DDD causes for them, and offering each other helpful suggestions.

> *"I have a suggestion for Toby. Instead of, maybe to stop carrying her all day you can get a stair lift or something"*

Most children felt positively about attending Sibs, using words such as *"happy*", *"fun"* and "*helping*" to describe their feelings about the group. However, some children made comments that were quite negative relating to children speaking over each other and a lack of sporting activities. The children also revealed how their sense of belonging to the group was important to them, they would feel sad if the group ended, with the intention of petitioning to keep it. Furthermore, the children identified that the group was the one place they felt listened to and heard. All of the children in the focus group showed good knowledge of their brother or sisters' diagnosis, this included knowledge about ASD, ADHD and cerebral palsy. The children also spoke about how the Sibs group allowed them to think of ways to help their brothers and/or sisters.

The drawings from the visual research methods were also reflected in the seven predominant themes. Furthermore, the visual methods highlighted that siblings perceived their past as hard, the present more joyful and positive, and the future as more mixed. This was in keeping with their verbal responses to questions relating to past, present and future.

Figure 1. Examples of children's drawings from Sibs focus group



How can these findings be interpreted?

These findings suggest that Sibs provides children who have a sibling with a DDD with a safe space to explore and recognize their feelings, be children themselves, enhance their self-identity, and potentially improve resilience to challenges. The group also provides children with an educational space where they can learn about themselves and their emotions, their siblings and disabilities/developmental disorders.

2.6 Evaluation of children's health-related quality of life using PedsQL

Background to PedsQL

Health-related quality of life (HRQOL) has emerged as an important health outcome measure in many areas including healthcare services research and evaluation, particularly for individuals with disabilities. HRQOL is a multi-dimensional concept that includes domains related to physical, mental, emotional and social functioning. For children with Disability or Developmental Delay (DDD), previous research has compared children and adolescents with Autism Spectrum Disorder (ASD) against typically developing children and adolescents. Stokes et al., (2017) found that children with ASD were able to adequately report on their own quality of life (QOL), however parents of children with ASD significantly *underestimated* their child's QoL (Stokes et al., 2017). The value of obtaining children's self-reports about their health, functioning, abilities, and emotions is increasingly being recognised within both medical care and child health research (Cremeens, Eiser & Blades., 2006). PedsQL Measurement Model is a modular approach to measuring HRQOL in healthy children and adolescents, and those with acute and chronic health conditions, which integrates both generic core scales and disease-specific modules into one measurement system.

Method

The Pediatric Quality of Life Inventory^{TM} Generic Core Scales (PedsQL^{TM} 4.0; Varni et al., 2001) was chosen to measure HRQOL for children attending Sparkle Leisure Clubs at SCC. The PedsQL version 4.0 consists of 23 items with 5 response selections that range from "never" to "almost always". The scales included:

1) Physical Functioning (8 items),
2) Emotional Functioning (5 items),
3) Social Functioning (5 items), and
4) School functioning (5 items).

The Generic Core Scales were comprised of parallel child self-report and parent proxy-report formats. The child self-report versions included ages 5 to 7, 8 to 12, and 13 to 18 years. Parent proxy-report versions for the same age ranges were used as a way of assessing parent's perceptions of their child's HRQOL. The items for each of the forms are essentially identical, differing in developmentally appropriate language, or first or third person tense. The instructions for completing the scales ask how much of a problem each item has been during the past month. All children attending Sparkle Leisure Clubs such as Swimming, Afterschool club and Friday Play Club were encouraged to complete the scale, as were their parents.

Scale items were scored and then linearly transformed to a 0-100 scale (i.e. 0=100, 1=75, 2=50, 3=25, 4=0) such that higher scores indicate better HRQOL. If more than 50% of the items in the scale were missing, the scale score was not computed (2.4% of our sample). For each respondent three mean scores were calculated; a physical score (a mean of all the physical functioning scores); a psychosocial score (a mean score comprised of the emotional, social and school functioning scores); and a total score (comprised of the physical and psychosocial scores). Responsiveness was assessed by calculating improvement scores for those participants who completed the scale at a 3-month and 6 month follow-ups with the aim of evaluating the impact of attending a leisure club on HRQOL. Improvement scores were derived by calculating the difference between the total, physical and psychosocial scores on initial completion from the follow-up scores. Higher improvement scores reflected greater improvement in HRQOL.

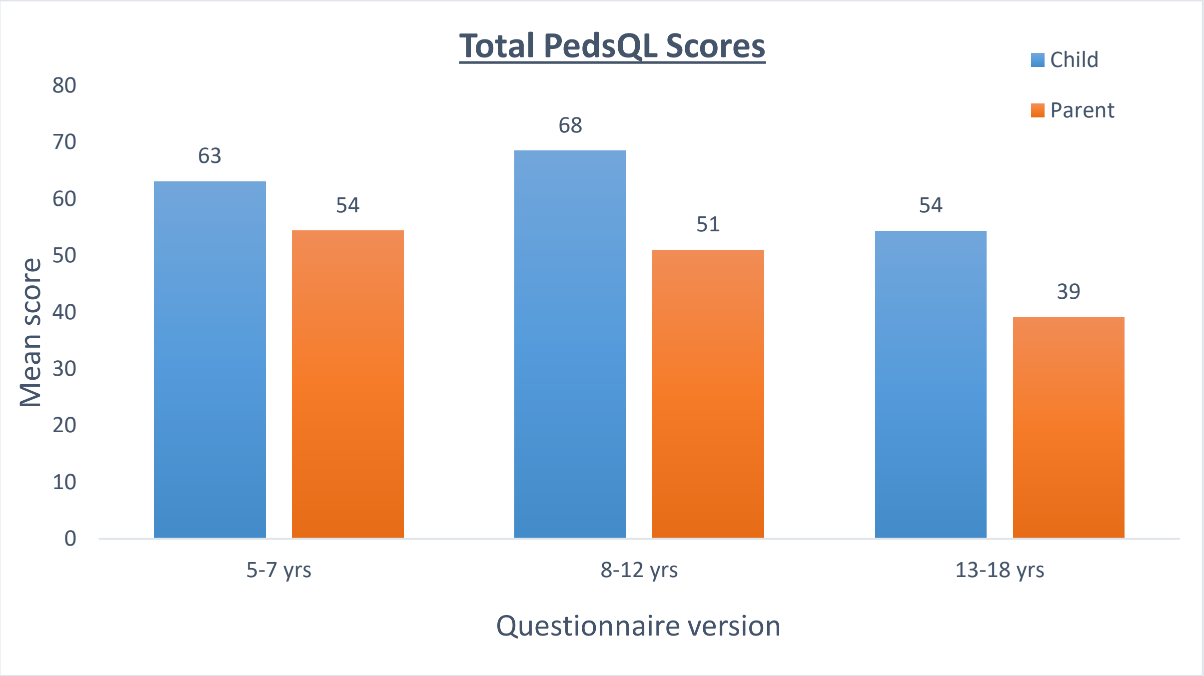
What were the findings?

Between 06/09/2017 and 03/02/2019 ninety-two children aged 5-18 years and their parent (185 people in total) were given the opportunity to participate the PedsQL^{TM} 4.0 upon joining one of Sparkle leisure clubs or via accessing the Helping Hands Psychology Service. The initial response rates for completion were 95.6% (N=88) for child participants and 36.6% (N=34) for parent participants. However, due to difficulties around obtaining written informed consent for the children to participate in the research, a large proportion of completed PedsQL forms were discarded (Child: 57.6%, N=53; Parent 2.2%, N=2). From those participants remaining, the response rates for initial completion were 26% (N=9) for children and 91% (N=32) for parents. Response rates for 3-month follow-up completion were much lower at 3% (N=1) for children/adolescents and 31% (N=10) for parents; and response rates for 6-month follow-up completion dropped to 0% for children and 6% (N=2) for parents.

PedsQL Scores

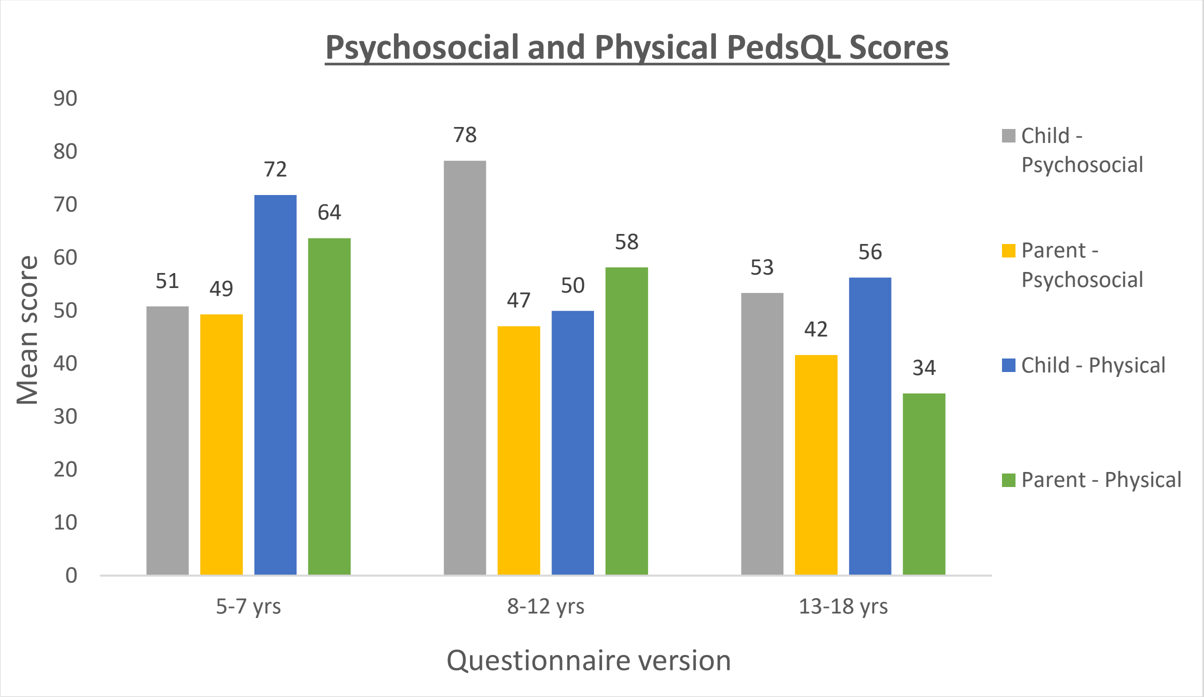
With reference to the graph below, it is evident that the initial total PedsQL mean scores for children were higher than parent scores across all three age range versions of the scale. Thus, children initially reported a *better* HRQOL than their parents, indicating that at the time of joining a club/accessing the Helping Hands service at SCC, parents underestimated their child's HRQOL.

Figure 2. Graph of total PedsQL mean scores



Psychosocial and physical health mean scores are displayed in the graph below. As with total scores, it is evident that psychosocial health mean scores for *children* were *higher* than parent scores across all three age range versions of the scale, and especially evident in the '8-12 yrs' age range. However, with reference to mean physical health scores, parent scores were higher than children's scores for this age range, indicating that parents overestimated their child's perception of their physical HRQOL. Whereas, for children in the age range of 5-7 and 13-18 the opposite was found, with the greatest disparity in physical health scores between children aged 13-18 and their parents.

Figure 3. Graph of psychosocial and physical PedsQL mean scores



Response rates at 3 and 6 month follow-up were particularly low, especially for children. There was insufficient data to warrant reporting and thus longitudinal data has been omitted.

How can these findings be interpreted?

Although a high proportion of completed PedsQL scales from child participants were excluded from the analysis due to issues with consent, all of the children's scales (53 in total) were completed successfully. This finding is supported by previous research that has found evidence for children with a DDD being able to adequately report on their own quality of life (Stokes et al., 2017). The PedsQL scores also highlight that on average parents underestimated their child's HRQOL, when their child joined a club.

There are a number of limitations that need to be considered when interpreting these findings. Firstly, engaging children to complete a PedsQL scale during a visit to the Centre was challenging for a number of reasons such as; (1) the child being engaged with an activity; (2) the child being disinterested in completing the scale and (3) time constraints. Parent participation also presented challenges, the main one being that parents would take a PedsQL scale home with them to complete and fail to return it. It is also important to note that the nature of children's disabilities and developmental difficulties means that capacity and ability to provide consent fluctuates day to day. As only half of completed scores could be analysed, consequently the sample size was relatively small, reducing the power of its conclusions.

2.7 Evaluation of 'Friends Group'

Background to Friends Group

The emotional health and wellbeing of children is just as important as their physical health and wellbeing (Public Health England, 2016). However, there are an increasing number of young people developing mental health disorders, of which depression and anxiety are the most common (Global Burden of Disease Paediatrics *et al*. 2016). Mental health is the issue most commonly raised with the Children's Commissioner for Wales by children, young people, their parents and carers, and was highlighted as a key priority in 2016 (Children, Young People and Education Committee, July-September 2016). A recent study found that in a cohort of 423 children aged 6-17 years with an intellectual disability (ID) (63% male), the prevalence of depression and/or anxiety problems was 35.4% (Whitney *et al.* 2019). This study is supported by previous research indicating that rates of depression and anxiety are elevated among individuals with multiple co-morbid neurodevelopmental conditions and Intellectual Difficulties, such autism spectrum disorders (ASD) (Rosenberg *et al*. 2011), epilepsy (Kanner *et al*. 2012), cerebral palsy (Rackauskaite *et al*. 2016) and attention-deficit/hyperactivity disorder (ADHD) (Meinzer *et al*. 2014). Furthermore, depression or anxiety disorders in childhood are strongly associated with risk of mental health disorders into, and throughout adulthood (Pine et al. 1998).

FRIENDS (Webster and Turner, 2000) is a 10-12 week resilience intervention designed to reduce depression and promote positive mental health for children and young people. With this in mind, it was anticipated that running a 'FRIENDS Group' would have a positive impact on the emotional health and wellbeing of young people with DDD who attend SCC. The materials, utilising the "My Friends Youth: Activity Book" version of the FRIENDS Resilience Programme, had to be considerably modified in order to make it accessible and engaging for the young people attending. The program was delivered by the psychology assistant, research and development officer and two play workers.

How was Friend's Group Evaluated?

An evaluation of the group was conducted by the Assistant Psychologist in February and March 2019 using qualitative research methods including questionnaires, and a focus group/interview.

What were the findings?

The key finding from this evaluation was that young people were very reluctant to engage in an evaluation. The group did not want to fill out any post-intervention questionnaire and parents whose children attended the workshop failed to complete the post-questionnaire. Only three young people attended the focus group; their behaviour was extremely challenging and many comments made by the young people were contradictory.

Group Leaders reflections: General Feedback on the Friends Resilience Programme

The following feedback is from the Assistant Psychologist who led the group:

Aspects of the programme really were not suitable for some of our (YP) with DDD. Even with flexibility of the sessions some of the concepts were very hard for our YP to understand. Further, the YP books were not very suitable for the cohort as many had dyslexia so lots of words and writing in the book unsettled some of the young people. The suggested pace of delivery was also very fast with not enough time in the 1.5 hours (1.5 hours for each session for 10 sessions) to cover all aspects with many of the group needing lots of breaks.

However, the psychological approaches and theories underpinning the programme were really sound. Some aspects/activities were understood by the YP but as a whole, the group found it quite challenging.

2.8 Evaluation of the Family Liaison Service

The Family Liaison Service (FLS) is delivered by the Family Liaison Officer (FLO), based at SCC. The FLO is accessible to all families attending SCC and offers an extensive support service for families that includes:

- Acting as a first point of contact for all families and help with enquiries about the services and leisure activities that children and young people can access both at SCC and within the local area
- Guiding and supporting families to navigate the 'system', signpost to the correct professionals and helping to co-ordinate appointments
- Offering support with form filling, such as for Disability Living Allowance
- Ensuring that all families are provided with access to appropriate services at SCC and obtaining feedback to inform service development
- Supporting Parent Support Groups that are held at SCC on a monthly basis
- Running information events twice a year where families can seek information from health, education, sport and voluntary sectors
- Organising drop-in sessions where families can meet with other charities
- Producing a regular monthly newsletter highlighting current developments at SCC and maintaining an up-to-date notice board in the Family Information Area.

How was the Family Liaison Service evaluated?

A formal independent evaluation of the FLS has not yet been conducted, however the number of families accessing the service has been collected along with spontaneous feedback from families and comments from professionals who attended the focus groups. This information provides an indication of the impact of the FLS on children and young people with DDD and their families.

What were the findings?

As of 07/03/2019, 539 families were accessing the FLS and 404 families were regularly receiving information from the FLO via email correspondence. During 2018, 60 compliments and 27 complaints from families were registered with the FLO. Six themes emerged from analysis of the information recorded on the FLS and feedback from parents, as detailed below.

Table 4. Themes identified in relation to the Family Liaison Service

Theme	Feedback from families and professionals/Outcomes reported
1) Provision of Information and advice	*"The Family Liaison Officer is available to speak to and is a font of knowledge…she is brilliant for advice."* (Parent) *"I am so grateful for this information…"* (Parent) • The FLO has reported that information resources such as toolkits (*developed by Sparkle psychology team, covering themes such as anxiety, making friends etc.)* are popular with families, being requested on a regular basis. • It has also been reported that workshops and toolkits are appreciated by the Integrated Services for Children with Additional Needs (ISCAN) team because if their service has

	a waiting list, it is something that can be offered in the interim. - The FLO has reported that feedback from families on information events such as at the Cygnet and Early Bird parenting courses, highlighted the value of delivering these events to raise awareness of the support available for families and how to access this support.
2) Community outreach	- For example, between 01/10/18 to 31/03/2019, the FLO met with 6 external organisations to share information about Sparkle and the services/facilities at SCC. This outreach proved to be beneficial; one of the outcomes following a meeting with the National Youth Advocacy Service (NYAS), was setting up a monthly drop-in session for families to receive face-to-face advice. - The FLO has maintained a strong link with local schools, attending parent’s evenings and careers fairs, as well as arranging visits to SCC for 6th form students.
3) Signposting	Professionals have commented on the benefit of the FLO raising awareness of the most appropriate services for families to access: *“…that support is just crucial and means that you can provide appropriate services at the right time because you’re not hanging onto people to just reassure them.”* (Staff member)
4) FLO approach	“*It’s not very often I experience something I'm blown away by but here I am met with your exceptional customer* service and kindness. If *only there were more people like you this journey would have felt a little less bumpy along the way.”* (Parent) *“…I didn't think I would be listened to!”* (*Parent)*
5) Empowering families	*“Fingers crossed that we are finally moving in the right direction and it is thanks to you for suggesting to go back to the school as I would never have done that because I didn't think I would be listened to! Thank you thank you thank you”.* (Parent)
6) Improved communication between professionals	*“The family liaison role, really promotes that informal conversation with you about discussing, you know what does social services do?”* (Staff member) *“It is certainly useful to be able to direct families to [Name of Family Liaison Officer] for advice/support about the additional services available to families at SCC & to be able*

	to direct families to the various workshops that take place.” (Staff member) • ‘Meet the team’ events bi-annually are co-ordinated by the FLO, enabling professionals working outside of SCC to listen to presentations regarding services offered here. Previous attendees have included, Health Visitors, Doctors, Family First staff and external therapists. The FLO has reported that these events are well attended and result in an increased number of referrals from health visitors.

How can these findings be interpreted?

As a formal, independent evaluation of the FLS has not yet been conducted, the findings reported here are limited due to a lack of standardised methods for collecting evidence; however, they can be interpreted as an indication of the impact of the FLS on children and young people with DDD, their families, and professionals. Comments from families expressing their appreciation of the information and advice that they have received from the FLO highlights the value of this service. There is also some indication that the service provided by the FLO empowers parents to take responsibility for their family needs, and facilitates communication between families and professionals, which was a primary aim for the service. The community outreach work has proven critical for establishing and maintaining strong links within the local community. Going forward, a formal, independent evaluation will be undertaken to further investigate the impact of the FLS on children and young people with DDD, their families, and professionals.

2.9 Parent Support Groups

SCC offers facilities for parent support groups to hold their monthly meetings, two of which were chosen for this evaluation: the Newport Autism Support (NAS) group for parents, carers and grandparents of children or young people who have an Autism Spectrum Disorder (ASD) in Newport, based at SCC since 2012; The T: 21 Dragons, a support group for parents of children with Down’s syndrome, who have been holding meetings at SCC since 2014.

How were Parent Support Groups consulted for the Centre Evaluation?

Both groups were invited to share their views on holding their support group meetings at SCC during their monthly meetings on 2nd and 4th April 2019. For the NAS group, there were eight members present and for the T: 21 Dragons there were 3 members present, including the Parent Participation Officer. All members gave their verbal consent to participate. Five questions were posed to each group to determine feedback on the advantages and disadvantages of holding support groups at SCC, the benefits of attending a support group, any changes that the group would suggest and any other feedback about the support group or SCC. Each member was given the opportunity to verbally respond.

What were the findings?

Members of the NAS group felt that there were a number of advantages to holding the support group at SCC. The location of the centre was considered to be an advantage with it being central to all of the attendees and easy to get to. The group commented on the “pleasant” environment and liked that the building had space to accommodate a large group. Other advantages raised were; the centre is somewhere that everyone is familiar with; the Family Liaison Officer is available to speak to and is a “font of knowledge”; and the group agreed that they were always made welcome. One of the advantages put forward by a member of the T:21 Dragons was that parents are able to bring their children with them to the group because of the facilities at SCC for young children, such as the sensory room. Another member felt that being able to speak to professionals at SCC while attending the centre for the group was highly convenient. In particular, being able to speak to the Family Liaison Officer on site was found to be helpful for parents, “Jayne is brilliant for help and advice, she knows a lot.”

In terms of disadvantages, members of the NAS group commented on the limited parking at the centre, and one participant voiced her frustration that there are allocated spaces for children with autism but no allocated spaces for adults with autism. It was also suggested that the spare land next to the centre could be put to use as an additional parking facility[1]. Members of the T:21 Dragons felt that there were no major disadvantages of holding support group meetings at SCC, however one member did comment that “for parents without their own transport it is tricky to get here.”

When asked to share their views on the benefits of attending a support group, there was a consensus amongst the NAS group that the social aspect of meeting up with other people in a similar situation to share information and advice helps alleviate feelings of isolation. One member commented that “If it wasn’t for this group, I wouldn’t have anyone else to speak to.” Another member commented; “I wouldn’t always want to speak to professionals….here we share information rather than the information being given to us, it’s a peer group.” Some of the views shared by the group indicated that there are benefits such as feeling that you are helping others, gaining comfort and perspective through listening to other people’s problems and feeling empowered. For example, one participant commented, “You realise you’ve got something to give to other people of value.” It was also suggested that attending the support group indirectly benefited their children because parents felt more relaxed and more able to cope with their problems, “it’s good for the children.” The T:21 Dragons also felt that the opportunity to talk to like-minded people in a similar situation and “get advice that you wouldn’t get from professionals, only from lived experience” was an invaluable benefit to attending the group. Forming new friendships was also seen as a great benefit, especially as parents expressed feelings of isolation as a result of losing other friendships due to caring for their child/children; one member commented “I’ve lost so many friends.”

Members of the NAS group from Caerphilly felt they should be able to access the services at SCC and other members shared the view that there should be more support put in place for children over 18 to get to know their local community[2]. The views from members of the T:21 Dragons was that there wasn’t really anything they could think of changing at SCC. One comment made was that it would be good if Sparkle could advertise online or around the centre to raise awareness of the T:21 Dragons to encourage more parents of children with Down’s syndrome to join the group[3]. In terms of general feedback, members of the NAS group felt that services should be more co-ordinated between different areas and that everyone should have a choice of services that are accessible to all, regardless of where people live. One member expressed her frustration that there is “no help” for autistic adults, with the Newport Autism Support group being the only form of help and support available. Generally speaking, one member of the T:21 Dragons felt that; “It’s just nice to be able to talk to people without judgement.” Another member added; “Having a support group is very much needed, socially for me and for him (referring to his child), to get out of the house and build up his immune system; and be in an environment that’s not going to make him ill. I will only take him to SCC.”

[1] The land referred to here is not owned by Serennu Children’s Centre, thus not available for purchase.

[2] Caerphilly is outside the catchment area for Serennu Children’s Centre.

[3] Current promotion of Parent Support Groups is via the Sparkle newsletter, paper and website.

2.10 Evaluation of the Helping Hands service

What is the Helping Hands service?

Helping Hands is a specialist self-referral psychological support service for the families (parents, grandparents and siblings) of children with DDD, living in Newport, South Torfaen and South Monmouthshire. This service was originally set up and delivered by Sparkle and funded by The Big Lottery. As of 1st April 2019, it has been transferred to Aneurin Bevan University Health Board, operating as a Gwent-wide service. Helping Hands offers individuals a confidential space with a Counsellor to talk about issues that are important to them, and to empower families to feel more confident in supporting their child/children.

How was the Helping Hands Service evaluated?

To evaluate the impact of this service, the Sheffield Learning Disabilities Outcome Measure (SLDOM) was used. SLDOM is reported to be a measure of confidence in parenting a child with a learning disability and has been used frequently across children's learning disability services. Research suggests that the use of this measure gives an indication of parental understanding, confidence, and self-efficacy.

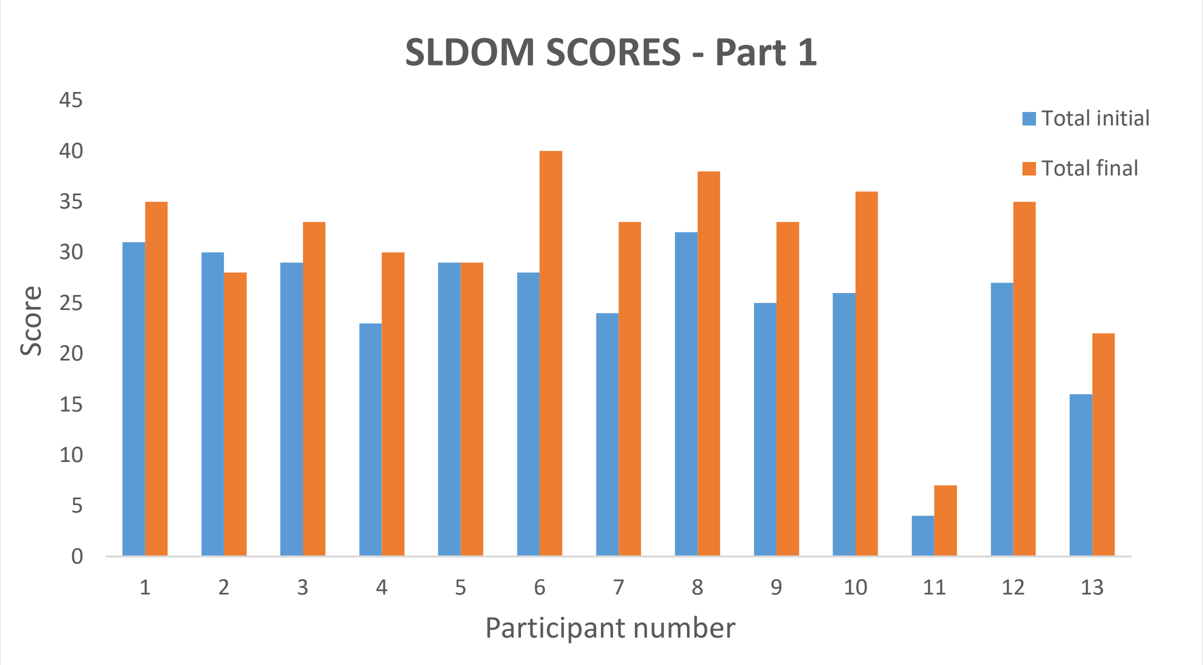
The SLDOM questionnaire is divided into three parts; for the first two parts responses are given on a Likert scale, which ranges from 'strongly agree' to 'strongly disagree' (1-5, respectively), and with a 'not applicable' option. Part 1 includes eight items relating to understanding the child's behaviour, and looks at the relationship between carer/parent and child, level of confidence and views about the future. Part 2 includes 10 items asking about how the service works, and how it is delivered. The third part is a free text section which allows the respondent to write down their views about what they found helpful about the service, whether there was anything they weren't happy with and suggestions for improvements. Part 1 is designed to be completed during the first and last sessions, whereas the whole measure (Parts 1-3) should be completed during the final session. For Part 1, the maximum and minimum scores possible are 40 and 8, and current advice is positive outcomes for scores obtained at 25 or above; whereas for Part 2, the maximum and minimum scores possible are 50 and 10, and positive outcomes for scores obtained at 30 or above.

What were the findings?

Between 24/01/218 and 24/01/2019, 71 parents attended sessions with the Helping Hands counsellor. Of these parents, a sample of 13 who had completed the SLDOM questionnaire at their initial and final sessions were included in this evaluation. The number of sessions that each parent attended varied between a minimum of 2 and a maximum of 9 (mean, SD; 5, 1.9).

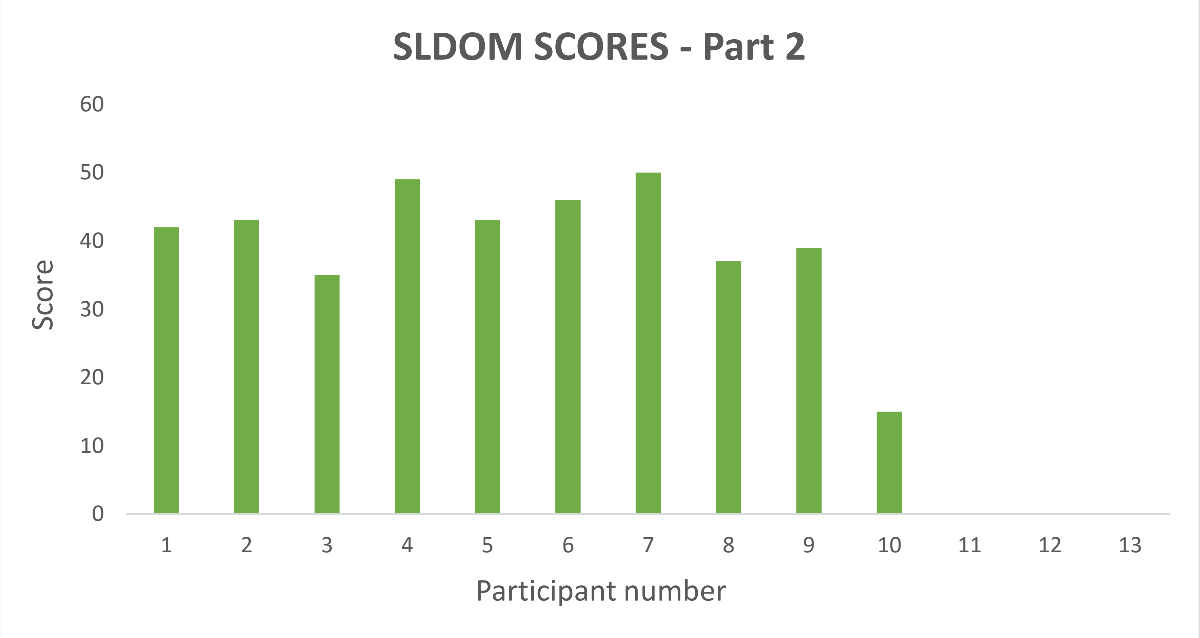
Parent's total scores for Part 1 at first and last sessions are shown in the graph below. On their first session, 69% (N=9) of parents scored 25 or above, with a mean total score of 25 (SD: 7.25). At the final session, there was a 16% increase (N=2) in the number of parents who scored 25 or above (85%; N=11, with a mean total score of 31, SD: 8.17). It is clear from the graph that one parent (participant 11), scored considerably lower in comparison to other parents at both initial and final sessions.

Figure 4. Graph of SLDOM scores – Part 1 of the Questionnaire



Completion rates for Part 2 of the questionnaire were 83.3% (N=10) parents. Participant scores for this part of the questionnaire are shown in the graph below. The number of participants who had a score of 30 or above was 90% (N=9).

Figure 5. Graph of SLDOM scores – Part 2 of the Questionnaire



Ten out of thirteen parents (77%) completed the third part of the questionnaire during their final counselling session. Please see Appendix A for examples of responses to this part of the questionnaire.

How can these findings be interpreted?

Findings for Part 1 of the SLDOM questionnaire indicate that attending sessions with the Helping Hands Counsellor had positive outcomes for the majority of parents; specifically with regards to improving their understanding of their child's behaviour, their relationship with their child, and confidence in parenting a child with a DDD. Findings from participants who completed Part 2 of the questionnaire indicate that on their final session most parents (90%, N=9) were pleased with the service and how it was delivered.

Parent responses to the third part of the questionnaire provide insight into parent's thoughts and feelings about the service on their final session. Counselling sessions helped parents to feel more confident in their parenting abilities and be more understanding and accepting of their feelings. Parents commented that they found it helpful to take time for themselves to talk through issues, and be listened to without judgement. One parent felt that this resulted in gaining an increased understanding of the reasons behind their behaviour, leading to creating solutions to their issues going forward. Another parent pointed out that being listened to helped to alleviate feelings of loneliness. Receiving advice on coping mechanisms to deal with anxiety, and recommendations for helpful reading material, were also considered valuable by parents.

It is evident that parents found counselling sessions also benefited their child/children, and their family as a whole. For example, one parent felt that being "emotionally stable" directly benefited their child, whilst another parent felt able to provide greater support to meet the needs of their child following a course of counselling. Parents reported that counselling sessions had helped them to manage their anxiety, which had an "unbelievably positive" impact on their family, as did communicating in a more open and honest way.

In terms of anything that parents felt they didn't like or needed improving, one parent suggested having the opportunity to meet other parents in a similar situation[4]. General feedback from parents on the Helping Hands Counselling service was extremely positive. Parents expressed their thanks for the opportunity to talk to a supportive professional during difficult times, and liked the friendly and welcoming attitude of staff. Parents were grateful for receiving helpful advice that they felt would be useful in future. From this evaluation it is evident that the Helping Hands service supports parents to feel empowered to cope with difficulties in their lives, and in many cases enhances parent's confidence in their parenting abilities, as well as their own self-confidence.

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[4] There are Parent Support Groups that hold monthly meetings at Serennu including the T:21 Dragons and NAS.

2.11 Evaluation of Workshops for Parents and Professionals

What workshops have been delivered?

The Helping Hands service hold workshops for **parents and professionals** (together) at SCC on a quarterly basis. These workshops have been running since 2015 and have covered a variety of topics including supporting transition, developing friendship skills, and first aid. Evaluation of the workshops held in 2018 will be reported here. Key topics covered in 2018 workshops were: (1) Understanding and Managing Behaviour; (2) Supporting Anxious Children; (3) First Aid and (4) Transition. The aims of each workshop were as follows:-

(1) To give parents an opportunity to talk about **behaviour** management support. It also covered functional analysis and strategies for teaching positive behaviours, and managing unwanted behaviours. This workshop was based on Positive Behaviour Support, which is an evidence based approach to working with people who show challenging behaviour.

(2) To give parents and professionals the opportunity to think about understanding and supporting children experiencing **anxiety**, covering strategies for helping children develop emotional literacy skills, and practical strategies for supporting emotional security.

(3) To provide parents and professionals with knowledge and practical training in **first aid.**

(4) To give parents and professionals information and advice on supporting their child/children with **transitions**, such as going to secondary school, to share their thoughts and experiences of transitions and talk about any anxieties or problems with transition.

How were the workshops evaluated?

Following the workshops participants were given ‘Evaluation Feedback’ forms to complete comprised of both quantitative and qualitative feedback questions. For quantitative feedback, participants were asked to rate how they felt about different aspects of the workshop on a scale of 1 to 4 (1= ‘Not at all’, 2= ‘Slightly’, 3= ‘Somewhat’, and 4 = ‘Very Much’). This included outcome measures such as feeling informed, empowered and more confident. Qualitative feedback was collected in the form of written responses relating to participants thoughts and feelings about aspects of the workshop, which were analysed to enable common themes to be identified.

What were the findings?

A total of seven workshops for parents and professionals were held in 2018. Three ‘Understanding and Managing Behaviour’ Workshops, two ‘Supporting Anxious Children’ workshops, a First Aid workshop, and a Transition workshop.

The first graph below displays the average attendance as a percentage of workshop capacity, and average evaluation feedback form completion rates based on the attendance for each of the seven workshops. The overall average attendance for the workshops was 82.5%, and on average, 76% of participants completed an Evaluation Feedback form. The second graph shows the average participant scores for rating how informed and empowered individuals felt after attending a workshop (from a total of 4.0).

Figure 6. Graph of average workshop attendance and feedback form completion

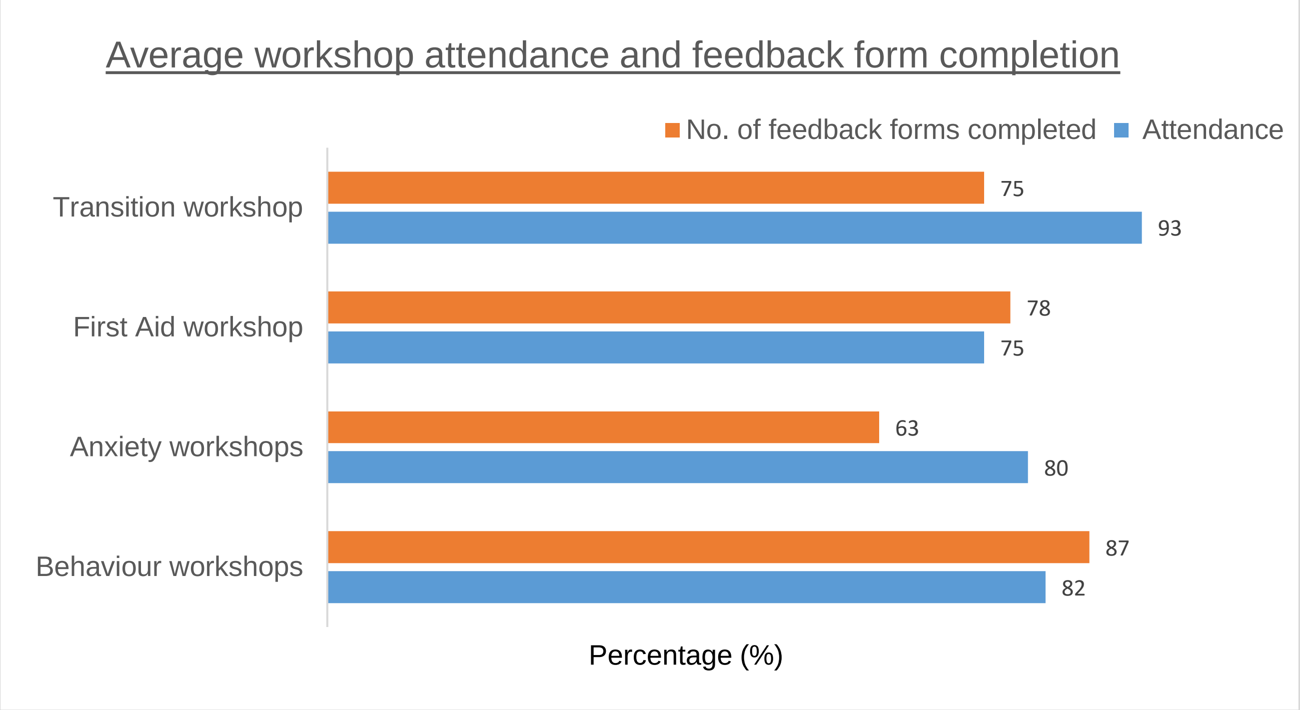
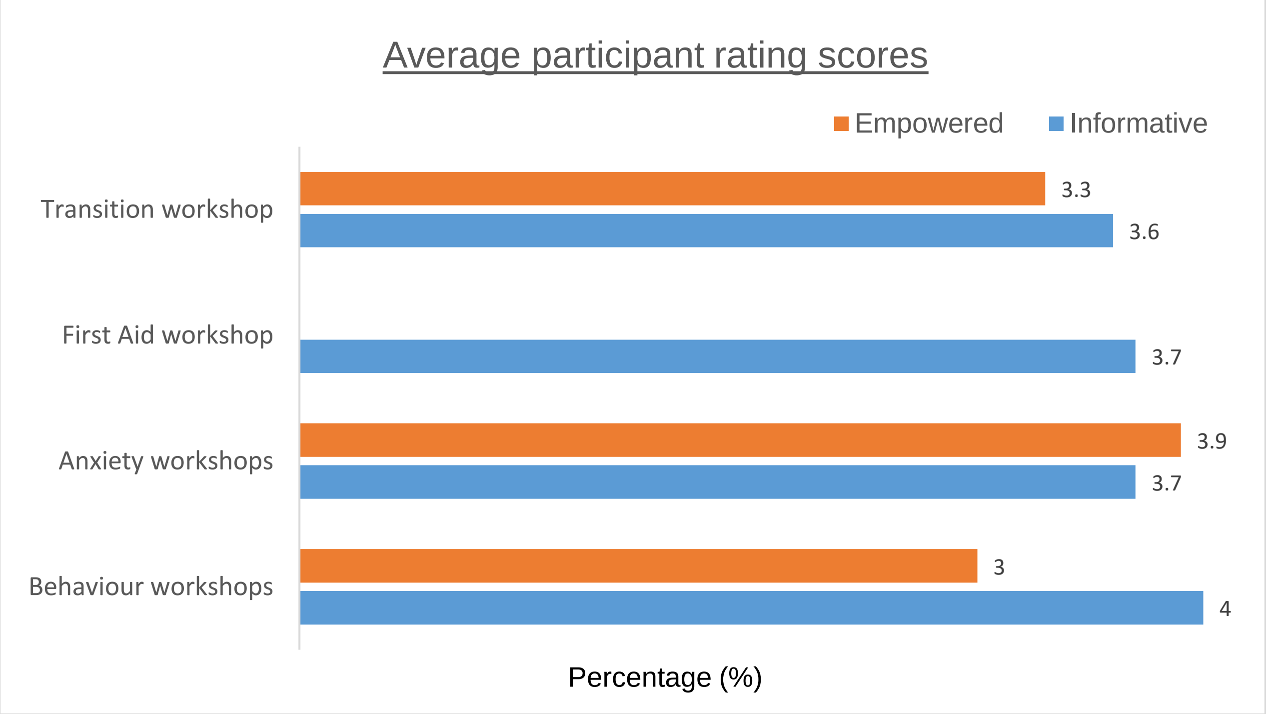


Figure 7. Graph of average participant rating scores for workshops



One of the ‘Supporting Anxious Children’ workshops also evaluated the impact of the workshop on participant’s confidence with regards to supporting children with anxiety. The average score was 3.2 out of a maximum of 4.

Analysis of written feedback from participants following each workshop led to five common themes being identified: 1) Informative; 2) Practical advice; 3) Sharing with others; 4) General feedback and 5) Suggested Improvements. Examples of participant comments from the Evaluation Feedback forms for each theme are shown in the table below.

Table 5. Themes identified from parents and professionals feedback on different workshops

Theme	**Feedback from parents and professionals**
1) Informative	*"Gave a really good understanding of anxiety to be able to explain to daughter what is happening and things to help her cope with daily life."* *"The information and strategies proposed were very informative. I was particularly pleased that there was an emphasis on children speciality"* *"Analysis of behaviour, appreciating the factors which contribute to behaviours."* *"This course is very informative. Relevant for helping out children and confidence to deal with any first aid incident."*
2) Practical advice	"*Made me think and understand more and strategies to try*." *"Very practical for both parents and professionals, in how as a professional we can help parents and young people."* *"I am going to implement distraction technique, breathing calming routines, use the step process toward a goal. Try and frequently confront anxiety to make it less of an issue"* *"How to improve my skills and attention towards my child."* *"Planning for short term and long term and transition differences between education providers."*
3) Sharing with others	*"Discussing scenarios and sharing with peers."* *"Listening and discussing with other parents in the same or similar situation."* *"Being able to talk to people in the same situation, feeling less isolated."*
4) General feedback	*"Superb."* *"Workshop was great – needed longer though."* *"All aspects useful."*

	"Whistle stop workshop but very informative. Really good to listen to parent's perspectives."
5) Suggested Improvements	*"More experiences of parents managing things such as, fussy eating, sleep etc."* *"Do a few workshops as a 6 week course rather than a few hours?"* *"A chance of discussion/questions"* *"More in-depth"* *"Lots of parents keen to come but no child care."* *"I didn't understand the resilience framework table handout."*

How can these findings be interpreted?

Workshops held for parents and professionals have been well attended with a majority of participants completing an Evaluation Feedback form. It is evident that all workshops were deemed informative, and on average, participants felt empowered after attending a workshop. Participants who attended the 'Supporting Anxious Children' workshop indicated that this workshop helped parents to feel more confident supporting their child/children with DDD cope with anxiety.

The five themes identified from participant's written feedback highlight commonalities across the workshops, namely that they found them highly informative and improved their understanding of the topic. Receiving practical advice, such as the strategies parents had learnt during the workshop could be put into practice with their children at home, for example, planning for short-term and long-term education transitions. Parents found that being able to share their experiences and discuss scenarios with other parents in similar situations was particularly useful, and helped with alleviating feelings of isolation. Despite the positive feedback overall, it was felt that some handouts were over-complicated. Many parents and professionals expressed a desire to extend the length of the workshop in order to cover the topic in more depth, and allow more time for questions/discussion at the end of the workshop. Limitations to be considered with this evaluation are that questions on the Evaluation Feedback forms for different workshops were inconsistent, and 24% of participants did not complete a form.

2.12 Residential trips

Each year since 2014, Sparkle has given young people aged between 12-17 years who attend SCC the opportunity to go on an overnight residential stay. The location and activities of the residential provision each year have been based upon the needs of the young people attending. For example, in February and March 2018, Sparkle sent out a survey for young people and their parents to find out what their preferences were for future residential trips. There were 43 responses to the survey (63% young people and 37% parents). The majority of respondents (86%) preferred the choice of having a one night residential trip every year rather than two nights every two years; 60% of respondents preferred the choice of going to a local facility (with travel time of around one hour), which is not a disability specific centre rather than a specialist facility (with a travel time of approximately 1-3 hours), with fully accessible activities for all young people. For the purpose of this report, the focus will be on an evaluation of the 2018 residential trip to Red Ridge Outdoor Centre.

Red Ridge 2018 Residential trip

The criteria agreed by Sparkle trustees for Red Ridge was for priority to be given to those young people 12 years and over who had not previously attended a Sparkle residential trip. Red Ridge Activity Centre was chosen where specialist provision was available for young people with manual handling needs. An information evening was offered by Sparkle prior to the trip to give parents to find out more information and ask questions about the trip. Out of 30 available places on the trip for young people, 22 attended, along with 7 members of staff. The total cost of the trip was £5,158.24, largely funded by Sparkle, through a grant from O2E.

How was the residential trip evaluated?

The residential trip to Red Ridge was evaluated by asking young people and their parents for verbal feedback on the trip. Staff also provided feedback by writing case studies of their observations on each young person's experience on the trip.

What were the findings?

Staff recognised throughout the residential trip that there were significant personal outcomes achieved for each of the young people attending, especially those that had not attended a residential experience with Sparkle previously. For example, one of the young people who had never previously participated in outdoor activities such as climbing and kayaking before the residential trip, and while initially nervous, with encouragement from staff he gave the activities a try and was proud of himself for doing so. In the evening, the young person was upset because he was missing being home, but staff were able to comfort him and showed him pictures of the activities he had participated in which cheered him up. The young person said that he was having a "*wicked time*" and "*loved kayaking.*"

Feedback on the residential trip from Sparkle staff

The information evening offered prior to the trip had limited uptake, however for the parents that did attend it was well received and parents reported that it was helpful and reassuring to meet other parents who had similar worries and whose children had been on residential trips before. Payments for the trip were required to secure a place therefore parents were happy to pay the £25 towards the trip to ensure that their child/young person had a space confirmed.

A number of parents needed support prior to the trip to manage their worries and anxieties about their child being away from home for the weekend, however after reassurance and information given from the Sparkle team their anxieties were alleviated. There were lots of opportunities for the young people to gain information and ask questions with staff about the trip during their sessions at the Centre, and they were also engaged in consultation regarding the outdoor activities, room plans, meal options and "down time" activities. Social stories and visual cues were provided to those with communication difficulties that required them.

Feedback on the residential trip from parents

Parents reported that they felt reassured and enjoyed seeing updates and photos on social media, especially as there was no signal on mobile phones. Some parents were unable to commit to residential stays during the summer period as they had their family holiday. Feedback and visual evidence from the young people's reactions and participation in the activities, and their experiences during the residential trip, was extremely positive. The trip was a success for both the young people attending for the first time, and those that had been on previous residential trips with Sparkle. Feedback from the young people and staff indicated that they thoroughly enjoy the activities, the positive interactions with staff and their peers, and the experience of being away overnight. The personal achievements and outcomes for each and every young person who attended the overnight residential were exceeded, ranging from being away from home for the first time, having the opportunity to share a room overnight with a friend, facing their anxieties and fears including being away from home and family, to being able to participate in activities they would not have had the opportunity and courage to do before. The feedback from families was very positive, for example, parents were delighted that their child had been able to participate in new activities and positive life experiences.

3. The Impact of Serennu's Environment

3.1 Previous research on environments for children

Environment has a vital role in supporting and nourishing a child's physical, mental and social development (WHO, 2001); and either supporting or hindering participation of children in home, school, and community settings (Lim et al., 2016, Benjamin et al., 2017). Through actively engaging with their environment, children intuitively discover, understand, and learn about the world around them. For young children who have or are at risk for developmental disabilities, the Division for Early Childhood (DEC) Recommended Practices (2014) suggest aspects of physical (e.g., space and equipment), social (e.g., attitude and relationship of peers and other family members), and temporal (e.g., sequence of routines and activities) environments that can be altered to support young children's learning. Practitioners and families are encouraged to provide inclusive and enriched learning environments that fosters children's overall health and development. However, research indicates that children with disabilities encounter environmental constraints that limit their active participation in the daily life of our communities. Consequently, their daily activity patterns are less varied and more socially isolated than peers without disabilities (Bedell and Dumas, 2004). Previous research on this topic has focused on school-age children with disabilities, in which inaccessible physical environments, negative societal attitudes, and lack of supports, assistance, and resources were frequently identified barriers to participation (Majnemer et al., 2008; Kang et al., 2010).

3.2 The environment at Serennu Children's Centre

Serennu Children's Centre is an award winning purpose built centre located in Rogerstone, a small village community on the outskirts of the city of Newport, Gwent. Set in five acres of its own landscaped grounds, SCC provides a supportive environment for families with children who have disabilities and developmental difficulties. Facilities in and around the centre include:

- Multiple consulting rooms for paediatric clinics
- Purpose built hydrotherapy pool 10m x 6m with inbuilt hoisting
- Physiotherapy gym facilities for individual and group treatment
- Large treatment rooms for football and bike skills groups
- Small treatment rooms for individual treatment
- Fully equipped sensory room
- Specialist technology room
- Specialist audiology and speech and language facilities
- Family and sibling facilities including an information area
- Plastering, splinting and orthotic facilities
- Aids to Daily Living suite, including a dining room, kitchen, bedroom and bathroom to assess potential for supported and independent living
- Wheelchair training facilities
- 3D MediCinema
- Leisure and play facilities including a Multi-Use Games Area (MUGA), outdoor seating and Cycle / wheelchair track around the perimeter of the grounds
- Sensory garden
- Fully accessible playground and Wendy House

How was the impact of the environment evaluated?

Different methods were used to evaluate different aspects of the environment. Young people and families were given the opportunity to complete a questionnaire, and professionals working across Gwent were invited to participate in focus groups (please see Appendix A for further details of focus group topics and participants).

3.3 Service User Perspectives: What do families think?

Following the March 2018 questionnaire, which obtained 264 responses, the environment emerged as a significant benefit to parents. When asked “what do you like most about the Serennu Children’s Centre”, 54% answered ‘the environment’ with 292 comments. These included the comparison of the building to a hospital, how the centre was a safe and welcoming place to bring children, the amount of toys available in the waiting areas, the convenience and affordability of the café, ease of parking and the security/cleanliness of the building. A computer-generated word cloud (see below) shows the collation of comments made regarding the environment, with larger words appearing more commonly in the responses.

Figure 8. Word cloud of the words used by families to describe the environment at SCC

As identified in the word cloud, the most commonly used words used by families were: friendly, welcoming, facilities, parking, play, MediCinema and atmosphere.

"The relaxed atmosphere which makes you feel comfortable as soon as you enter the building"

"The accessibility and layout of the centre"

"Plenty of toys to entertain the child whilst they wait for their appointment"

"Support and help from all different departments in one place"

"Parking is good"

"The café is very reasonably priced"

"I love being able to take my son swimming and to the cinema in a safe, non-judgmental environment"

"[Child] feels safe, happy and secure here"

The environment not only provides a positive experience and impression of SCC, but has been valuable in empowering parents and improving their confidence in managing their child's needs. Out of the 235 respondents, 140 felt that the centre helped them feel 'a lot' more confident or empowered in managing their child's needs, 15% of whom specified that the environment had made this difference. Remarks were made about the range of provisions in the centre, the ease of having all professionals under one roof, and comments relating to the centre as being a non-judgemental place where children and families are alike and understand each other. In effect, Serennu's environment seems to impact positively on the experiences of families at the Centre, and importantly, plays a role in increasing confidence and empowering parents to manage their child's needs.

Whilst families accessing the Centre clearly regard the environment positively, they also mention two environmental features which needed improvement: facilities and capacity of the activities and support. Of a total of 161 comments relating to improvements, 36% felt that the facilities at the Centre needed improving, such as parking, and the availability of refreshments. In addition, 47% wish that there was a larger provision of activities, longer café hours and additional provisions such as a crèche or respite care.

3.4 Professionals Perspectives: What do professionals think?

Serennu Children's Centre is characterised as a community setting, distinct from the typical hospital environment and experiences. Coyne (2006) found that children had many concerns about hospitals, for example, being in an unfamiliar setting with unfamiliar people, being separated from family and friends and receiving investigations or treatments. Children identified hospitals with fears such as operations, needles, being in pain, dying and loss of independence (Coyne, 2006). Environment is therefore an important aspect of healthcare to children and young people, and potentially becomes even more important for those with disabilities and/or developmental difficulties who may have more difficulty understanding medical environments, yet often have a greater number of appointments and medical experiences than a child of typical development. SCC could offer a more positive experience through its multi-purpose building, where children attend not only for their medical appointments but also for leisure clubs, and family activities such as swimming and the cinema.

Focus groups with professionals from health, social care and the third sector have commented on this distinction between the typical hospital environment and SCC, weighing up advantages and disadvantages of this setting.

Most professionals expressed a preference of the community setting over the hospital setting for families and children with DDD. In comparing the two, professionals expressed that hospitals were generally a negative experience for families and children, who are more likely to experience fear and anxiety due to past medical experiences. In comparison, SCC offers a non-hospitalised environment which can assist in breaking down the barrier of fear, since many young people also attend the centre for leisure and activities, such as swimming, the MediCinema and clubs, which are perceived as more enjoyable.

> "*Oh it's much better…the fear factor of going for a medical appointment. If they are used coming here for the 'leisure side' then they also won't run a mile from the 'health side'"*
>
> (SR7)

On the other hand, professionals in the focus group also highlighted the benefits of a hospital environment, opposed to a community environment. They expressed the view that families might take appointments more seriously in the hospital setting, and that the SCC setting does not prepare families, children and young people for the 'real world' and post-18, adult settings.

> *"I think it is great to have a facility in Serennu where people want to congregate but that is not 'real life'. It's like before, it's not real and you want to make it real"*
>
> (NH7)

These perspectives draw attention to an underlying concern of whether attending the Serennu Children's Centre adequately prepares a young person for adult-orientated healthcare settings, particularly if the young person has ongoing health issues requiring frequent appointments. Research has already identified that transition from child to adult health services is inconsistent and often leaves young people and families confused or, at times, distressed (CQC, 2014). If SCC is significantly different from the hospital environment it is possible that young people would find the transition to adult services harder.

On the other hand, new recommendations in the NHS place a priority on providing 'developmentally appropriate healthcare' (healthcare that takes into account maturity, cognitive ability, circumstances and needs) (Northumbria Healthcare NHS, 2017; NICE, 2016). Thus whilst SCC is distinct from typical hospital environments, which may be more adult-orientated, the Centre could be better placed to address developmentally appropriate healthcare since it offers a comforting, supportive and safe environment. SCC is a distinct space for children, as toys, games and films are provided in more colourful and child-friendly waiting rooms, which may also encourage a different attitude and culture in professionals, inspiring them to deliver age-appropriate healthcare.

Stigmatisation was also a central topic discussed in the focus groups. Disability stigma is where a disabled person might be labelled, stereotyped, excluded, not considered an equal or discriminated against by another individual, organisation or authority (Link and Phelan, 2001). In the focus groups, professionals perceived hospitals as being stigmatising because families have to park further away from the building than at the children's centre. Rohwerder (2015) describes this as an environmental barrier to participation and inclusion, since inadequate parking facilities could make the hospital inaccessible for some families with disabled children. This is especially problematic when no disabled parking spaces are left and families need to park in unsuitable spaces. Parking was seen as an issue for both families and professionals in hospital sites.

In addition to parking concerns, focus groups also identified the attitudinal barrier presented by a hospital environment. Professionals perceived the hospital environment as a place where someone might go to be treated for an illness, so when a child with a disability goes to hospital it might give the impression that the child has an illness instead of a disability.

> *"You can have a child with a disability who is not poorly. They haven't got an 'illness' they've got a disability haven't they… but it is hospital and people who go to hospital are generally ill… and when you walk into hospital you've got that very distinct smell, and distinct feeling and it's very clinical…"*

(BG6)

In this case, the hospital environment may have the potential to impact a child's identity by influencing them to believe they are unhealthy or ill. Reflecting on models of disability, hospitals may still be understood and influenced by a medical model of disability; a model which considers "disability a problem of the individual that is directly based by a disease, an injury or some other health condition and requires medical care in the form of treatment and rehabilitation" (Mitra 2006). In considering the focus group discussion around stigmatisation and the hospital environment, professionals seem to be uneasy with the medical model of disability. Although the Welsh Government now supports a social model of disability, perhaps we are not fully reflecting this in practice by directing children with DDD to hospitals for appointments. Nevertheless, there is evidence of an attitudinal change as professionals seem to fit their descriptions of the environment within a social model which sees disability as "created by the social environment, which excludes people with impairments from full participation in society as a result of attitudinal, environmental and institutional barriers" (Mitra 2006).

In comparison, professionals in the focus groups perceived SCC as less stigmatising due to it being part of the local community; giving young people with DDD a community presence and supporting social inclusion. Therefore, the community environment offered by SCC may be promoting positive attitudes about disability and developmental difficulties to surrounding areas.

3.5 Use of Facilities and Grounds: Are we making the most of specialist facilities?

A number of specialist facilities can be found in SCC, in particular, the ADL flat, sensory Room, swimming pool/hydrotherapy, orthotics workshop, audiology listening bus and the MediCinema.

3.5.1 The Swimming Pool

The swimming pool at SCC has two main uses: hydrotherapy and Sparkle swimming lessons or family swim sessions. The lessons are available to any child or young person who has a disability or developmental difficulty aged 0-18 years of age who cannot access mainstream swimming lessons. These lessons run in 10-week blocks over 48 weeks of the year and take place on Thursday, Friday and Saturday each week. There are 6 places available in each lesson (some children require 2:1 support) and 4 lessons per day. This means at full capacity there will be 72 children accessing swimming lessons every week at the centre. Typically children access two 10-week blocks, therefore, if at full capacity, an average of 150 children will access swimming lessons over a year. Furthermore, families can book the pool for ‘family swim’ sessions, with Sparkle providing fully qualified life guards.

How was the use of the swimming pool evaluated?

To understand the use of the swimming pool, parents and carers whose children access swimming lessons at the centre were asked to complete a short questionnaire. The main aims were to gather information relating to how they found out about swimming lessons, and whether a professional recommended its use, such as a physiotherapist, following or in place of hydro-therapy.

What were the findings?

Of the 50 respondents, 27 found out about swimming lessons through Sparkle. The remaining respondents found out about swimming via a health professional (15 respondents), a friend or another parent (5 respondents) from visiting the Centre (2 respondents) and social services (1 respondent). As suggested by these findings, health professionals have a clear impact on the use of the swimming pool facilities offered at SCC, with 57% of health referrals being received from physiotherapists. Furthermore, of 47 respondents, 16 had attended hydrotherapy sessions in the past. These findings indicate two important environmental impacts, 1) the co-location of leisure activities and health professionals such as physiotherapists, paediatricians and occupational therapists, promotes usage of the swimming pool and 2) the swimming pool provides an opportunity for children and young people to continue practising core skills learnt in physiotherapy and/or hydrotherapy.

While professionals may emphasise the continuing practice of skills, parents and carers also describe an array of important reasons for their child attending swimming lessons. Parents identified ‘swim technique’ as the most important reason for attending swimming lessons, with social skills as the next most important reason. Therefore, it is evident that the swimming pool is used to achieve a number of beneficial outcomes ranging from improving motor skills, increased confidence, to teaching a child to be safe in and tolerant of water. Ultimately, with an average of 150 children accessing swimming lessons at SCC per year, this could result in

30 children per year who could be discharged at the appropriate time from a health service. Swimming lessons, therefore, provide an important service which has the ability to 1) facilitate timely and appropriate discharge from specialist therapies, or in some instances achieve water confidence, such that hydrotherapy sessions can be more productive 2) lessen the burden on healthcare caseloads and reduce waiting lists, 3) provide an opportunity to those who cannot access mainstream swimming lesson, and 4) aid the continued development of skills for children and young people beyond specialist services, e.g. water confidence may lead to independent washing at home.

3.5.2 The ADL Flat

The ADL Flat at SCC offers a fully functional kitchen and dining table, with height adjustable countertops and hob, ironing board, low sinks, a bedroom, bathroom and interactive whiteboard. The flat is fully accessible, with consideration for wheelchair users, and utilises automatic doors. This facility provides an opportunity to learn important daily living skills within a safe, accessible space and is available to young people and all SCC staff at request.

How was the ADL Flat evaluated?

As the ADL flat is used for multiple purposes, including training in specific independent living skills by OT, and within the 'Independent Living Skills' club as well as providing a venue for other clubs such as cooking, craft activities etc. As an indirect measure of utlisiation of the ADL flat, data was collected on the number of times the key for the ADL flat was signed out of reception from 26th October 2016 to 1st November 2017.

What were the findings?

In 2018, the key to the flat was signed out 108 times, averaging twice per week. The charts below outline key details in the usage data.

Figure 9. Pie chart of ADL Flat usage by department

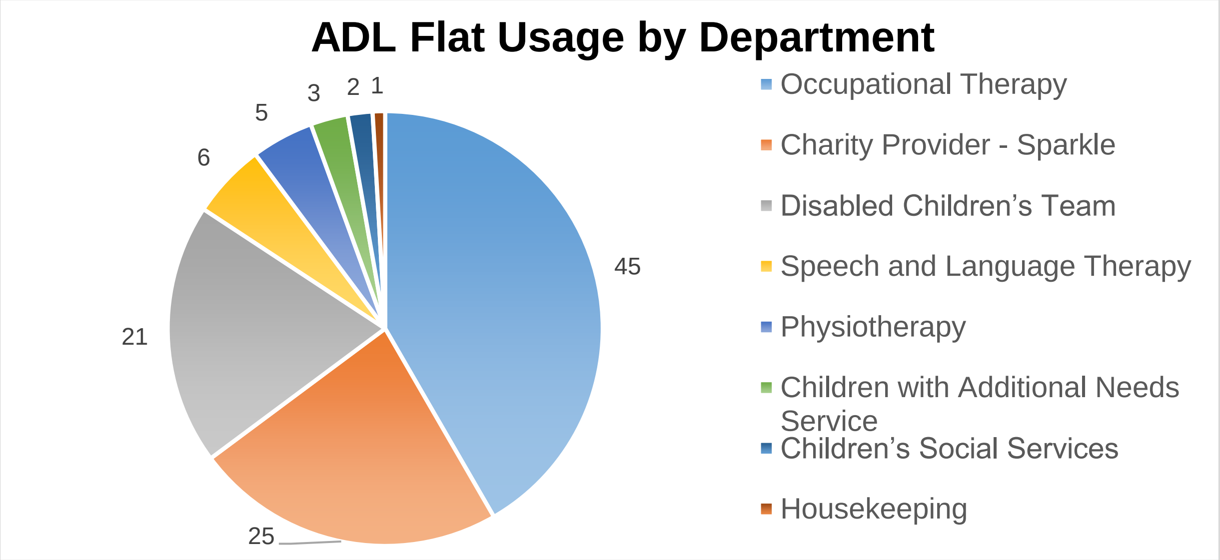
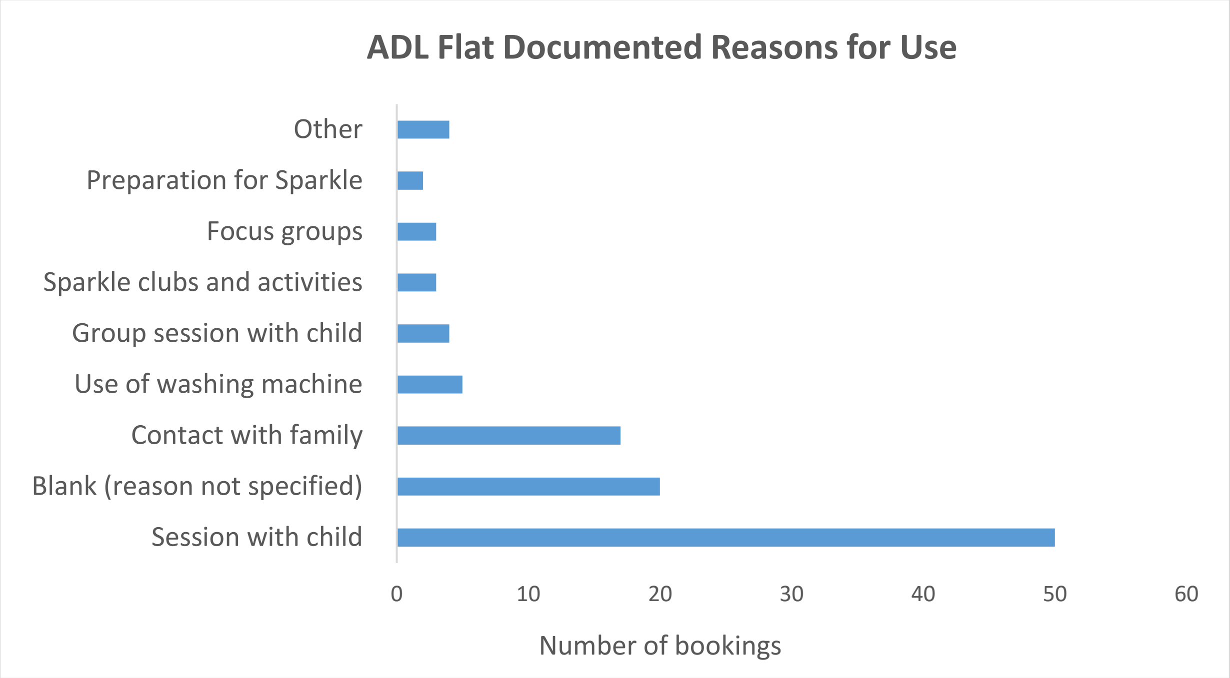


Figure 10. Graph showing ADL Flat documented reasons for use



As presented by the charts, occupational therapy was the largest user of the ADL flat according to this data. Therefore, the flat provides a key facility for professionals to meet with families, whether that be for a therapy session with a child, meeting with a family, leisure activity or for research purposes.

*Not recorded accurately in this data are the number of times the ADL flat is used for Sparkle clubs and activities. The main users of this facility after hours are ‘Monday Afterschool Club’, ‘Tuesday Afterschool Club’, ‘Friday Play Club’ and ‘Saturday Play Club’. It is also used within our ‘holiday activities’ for cookery classes, and during the ‘Family Fun Days’ which occur four times a year. Data collected from the centre room booking system suggest that the ADL flat is used weekly, with some clubs running 48 week of the year. Therefore, an estimated total of 66 further uses are documented for Sparkle leisure clubs and psychology service. Furthermore, this figure does not account for times where the room was used without booking.

Overall, ADL flat usage is convenient for professionals and leisure clubs alike, however, documenting accurate usage is problematic. The flat has become a weekly part of leisure club sessions, yet its key features may be under-utilised by specific groups, particularly where the key aim of the club is ‘free play’. Nevertheless, the flat offers an important facility for professionals to assess potential for supported and independent living.

3.5.3 The Sensory Room

The Sensory Room at SCC offers a specialist room targeted at children and young people who may have a dysfunctional sensory system. These spaces can be particularly helpful to those with developmental disabilities, learning difficulties or sensory impairments. Possible benefits include sensory stimulation, enhanced learning through play, improved balance, movement and spatial orientation and reduction in challenging behaviour. Families can also book the room for family use, supported by Sparkle play staff.

The Sensory Room is used both by professionals, and by Sparkle staff during clubs. A formal evaluation of its impact has not yet been completed, however feedback from Occupational Therapists (OTs) and the Sparkle Leisure Team Lead has been collected.

Feedback from OTs

Reasons given by OTs for their use of the Sensory Room included introducing the room to families and holding treatment sessions. Feedback given on the perceived benefits of the room were:

- Cause and effect/switch work assessment opportunity
- Engaging environment
- Possible increase in success of the treatment sessions given the novelty/different environment
- Opportunity for sensory stimulation and exploration, which otherwise may not be possible
- Different play opportunities
- Visual assessment opportunities

OTs also commented that they find an increasing number of nurseries and schools have sensory rooms, so they tend to use these rooms instead because the environment is familiar for the child.

Feedback from the Sparkle Leisure Team Lead

“Overall the sensory room is a fantastic resource that the leisure activities make use of daily. It’s the perfect space for Sparkle’s Little Stars parent and toddler group providing an engaging and interactive space for 0-5 year olds. The sensory room provides our children and young people accessing our Complex care play club the opportunity to experience a play environment that is safe and appropriate for their needs, and the hoisting facilities in the room meet any manual handling requirements that the children/young people need.

The sensory room is also used as a calming space to support de-escalation of behaviours that could challenge. For example, if staff observe a child/young person beginning to display anxiety or stress, the sensory room will be given as an option to help calm the child/young person avoiding escalation of challenging behaviours. The sensory room is also used by the sibling group and Independent living skills group, as an environment to practice mindfulness and positive well-being.

The cons regarding the sensory room would be that on occasions the equipment can fail or need maintenance/repair, that can be costly, and the equipment could be out of action for some time.

3.5.4 The MediCinema

Serennu Children's Centre has a state-of-the-art MediCinema that was opened in 2012, fully equipped with the latest technology, including Dolby surround sound, RealD 3D technology and a large silver screen. This cinema provides children with DDD and their families the opportunity to enjoy a fully immersive cinema experience. Current film releases are shown every Tuesday at 6.30pm and every Saturday at 10.30am, with capacity for 59 people (51 seats and 8 wheelchair spaces). The cinema has been specifically designed and built to comfortably accommodate children and young people with DDD, as well as their family and friends.

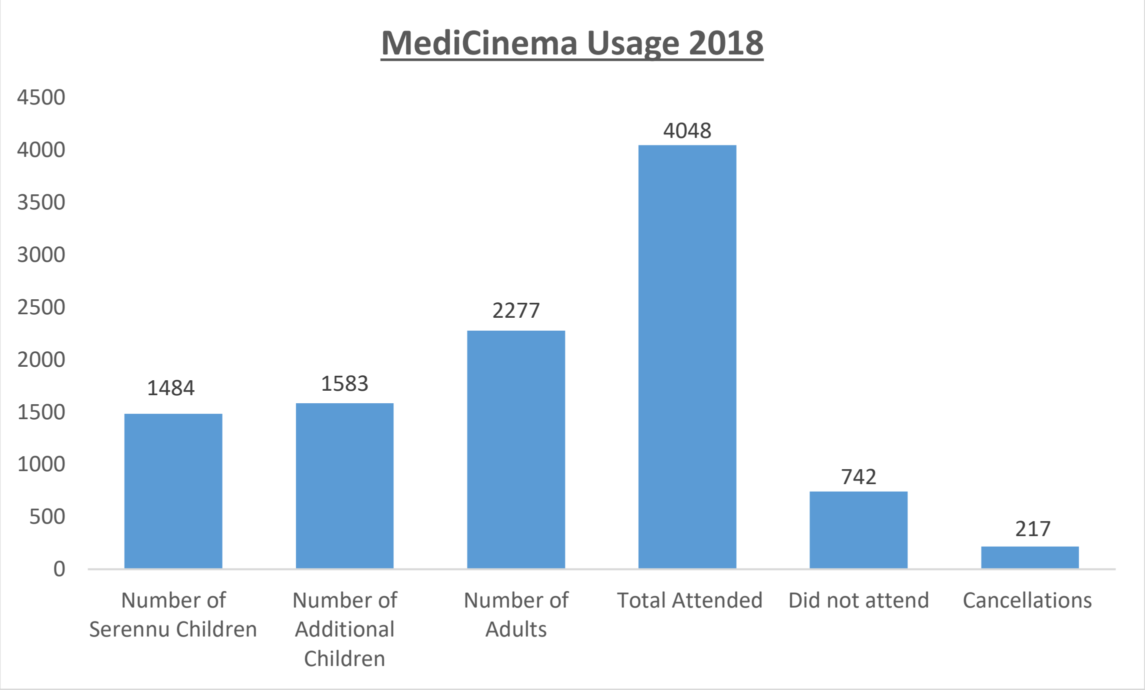
How was the MediCinema Evaluated?

The MediCinema was evaluated using quantitative data collection which involved collating numerical records of the number of children and families who used the facility in 2018.

What were the findings?

MediCinema usage in 2018 is displayed in the graph below. From the graph it is evident that the MediCinema is very popular with children with DDD, their siblings and adults, indicating that it offers an activity that appeals to children and their families.

Figure 11. Graph showing the breakdown of MediCinema usage for 2018



3.6 The Sparkle Wish List

Professionals are able to request items for use in the Centre, such as equipment and toys, as well as training, via Sparkle's Wish List. The number of items requested on the Wish List and total spend for 2016 to 2018 are shown in the following charts.

Figure 12. Graph showing the number of items requested via the Sparkle Wish List between 2016 and 2018

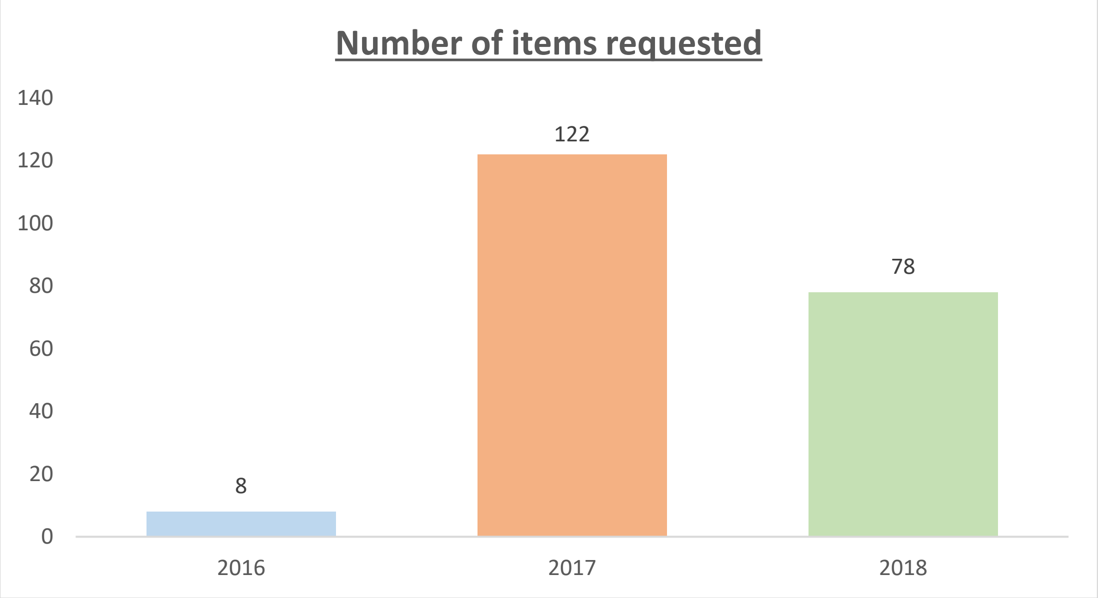
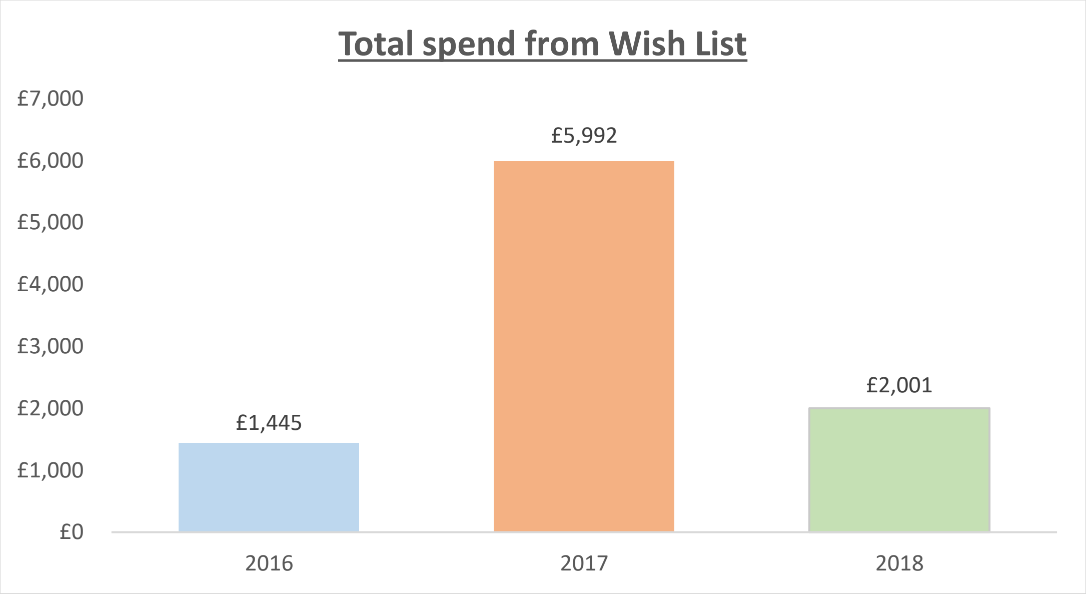


Figure 13. Graph showing the total spend from the Sparkle Wish List between 2016 and 2018



From these graphs it can be seen that the number of items requested peaked in 2017, corresponding with an increase in total spend. Major capital build projects, such as the sensory room (£62,986), hoisting equipment (£22,258) and the outdoor playground (£133,392), have also been funded via Sparkle's Wish List.

How can these findings be interpreted?

Environment has a vital role in supporting and nourishing a child's physical, mental and social development (WHO, 2001); and either supporting or hindering participation of children in home, school, and community settings (Lim et al., 2016, Benjamin et al., 2017). The impact of the environment at SCC on children with DDD, families and professionals was evaluated using different methods for different aspects of the environment. Families described the environment at SCC as being friendly, welcoming, supportive and inclusive, which fundamentally facilitates social inclusion for children with DDD and their families. The broad range of indoor and outdoor leisure and therapeutic facilities available were highlighted by families as being extremely beneficial, and many professionals expressed a preference for SCC's community setting over a typical hospital environment. SCC is well-placed to address developmentally appropriate healthcare since it offers a supportive and safe environment that breaks down the barriers presented by stigmatisation around disabilities by giving children with DDD a community presence. Overall, the evidence from this evaluation implies that the environment at SCC has a positive impact on the experiences of families who attend the Centre, and crucially, has a critical role in increasing confidence and empowering parents to understand and manage their child's needs.

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4. The impact of co-location

4.1 Previous research on co-location of health and social care services

The term co-location is used for the organisational strategy of grouping different professionals in the same facility. Support for co-location of health and social care services can be found in the literature, with evidence for the benefits for children and their families as well as staff (Doyle 2008). Benefits for families accessing health and social care services include the convenience of professionals being in the same place, and the opportunity to participate in their child's multi-agency assessments (Cigno and Goire, 1999). A study that investigated the impact of co-location on professionals found that co-location offered a range of benefits such as; gaining a better understanding of other services' practices, processes, and work routines (Kaehne and Catherall, 2013).

4.2 Co-location of services at Serennu Children's Centre

At SCC, health services, Newport Social Services Children's Disability team and Sparkle Leisure Services are co-located. The ultimate aim of co-location at SCC is for children with DDD to benefit from the integration of health, social care and leisure services.

How was the impact of co-location of services evaluated?

To evaluate the impact of co-location of services at SCC, four focus group(s) were held with professionals based at SCC and NHCC (who do not have co-location), and professionals working within Torfaen and Blaenau Gwent. For details of the focus group participants, topics discussed and analysis approach please see Appendix C.

What were the findings?

Eight themes relating to the impact of co-location emerged from analysis of the focus group transcripts; these themes are presented in the table below with examples of comments made by professionals for each theme.

Table 6. Themes identified from professionals views on the impact of co-location at SCC

Theme	**Comments from professionals based at Serennu (SCC), Torfaen (TF), Blaenau Gwent (BG), and Nevill Hall (NHCC).**
1) Communication	*"Lots of informal conversations which would probably not happen anywhere else. It would just be the odd little bit of information and that actually makes a big difference to the case that you are working on and all that. Communication."* (SCC5) "…*that was the thing about Serennu having other people- sometimes you just want to sound stuff off to other people as opposed to writing an email to them."* (NHCC8) *"It's changed portage's job completely, I'd say. Whereas before it was nearly impossible to get someone, it was very hard talk to someone [we'd be ringing physio or speech or whatever and because they would be doing visits it was very hard to talk to someone] and now we know their faces we are doing a lot more joint. It's completely changed the way that we work."* (SCC6)

	"I know that I have far easier communication if I have a child in Newport." (SCC8)
2) More efficient use of time and resources	*"These things can be extradited so much quicker. You don't have to wait for someone to get back to you. I mean obviously if they are not in the building …. but generally, it seems as if there's flow [and umm] obviously the care for the child then is umm more effective really."* (SCC3) *"Sometimes I manage to fit more in. Say if there is MATS meetings downstairs or a physio appointment that I want to see the family for, I can do that a lot better here, because I can nip down and I can't do that in a different building. If it was in a hospital or a different centre, there would be no way I could fit that in sometimes. So, it's good having everyone here as sometimes you can interact with everyone at the same time."* (SCC2) *"Cost effectively the number of meetings that we professionals have, if you've got them all co-located, it's going to be reducing travelling time for professionals, actual meeting times. It's got to save money actually …"* (BG3) *"Less meetings maybe…One meeting instead of having several, in different areas."* (BG1)
3) Improved integration of care for children and their families / service user experience.	*"I've witnessed a family being in an appointment, it was a physiotherapy appointment, and something was identified at that appointment and they immediately came up to the Social Services team who had a representative come down. And that family walked out feeling so much better than if they'd been told "we will get in touch or send you an email" …because it was dealt with,* ***there and then****…"* (SCC7)
4) Improved access to services	*"Co-location of the leisure as well, I think it's easier for our families to access the leisure because they see it when they come for appointments. So, it's not going to be unfamiliar and vice versa when they are going to the leisure – we do Hydrotherapy they are like "Oh, I know where that is". So, it's a sort of benefit, both ways."* (SCC6)
5) Relationships between professionals	***"Knowing*** *people fosters good working relationships*." (SCC8) *"In theory being based in the same place should make us appear 'one team'."* (SCC8) *"I have been working in Serennu before and it was very positive having the social workers there on site as well."* (NHCC2)
6) Professional development / Learning	"We get a better understanding of each other's roles." (SCC1)

	"I think it is important for our professional development as well… I find it really useful." (NHCC1) "Sharing expertise…" (BG1)
7) Improvement in child protection	*"It improves the ability for us to safeguard children…. it's important that we have that multi- agency perspective really*." (SCC1)
8) Barriers to co-location	*"I think it's also, that unless you work here, you don't understand what it's like to work here. If that makes sense, because I came from Nevill Hall, I'd been a Dietician there for years and I still don't think that the departments in Dietetics really get this place…*" (SCC4) "*I think there are a lot of issues that need to be sorted out at a higher level, within Social Services and Health and Education. I think those barriers are quite significant…*" (SCC1) "We would like to work a bit ***more*** with education." (SCC8) *"If we are all in the same place that isn't in the area of the locality that we are serving…that's not very helpful for parents because we might be in one place, but we are actually miles and miles away*." (TF7)

How can these findings be interpreted?

These findings highlight that the health and social care professionals who participated in the focus groups recognise the positive impact that co-location of services at SCC has on children, families and professionals. Key benefits of co-location identified were: improved communication between professionals leading to improved relationships and joint working; more efficient use of time and resources; improved integration of care for children and enhanced service user experience; improved access to services such as Sparkle leisure clubs; greater opportunities for professional development and learning; and improvements in child protection due to a multi-agency approach. Professionals working in Torfaen, NHCC and Blaenau Gwent, where services are not currently co-located, felt that not having services co-located was disadvantageous for children, families and professionals. Professionals from these localities also identified barriers to co-location which included: facilities not being based in the locality of the families that they are supporting, a lack of awareness and understanding of the potential benefits of co-location, existing issues within social services, health and education, as well as having sufficient space to accommodate the co-location of services.

The benefits of co-location identified at SCC are consistent with those found in the literature, in that co-location supports the case for improved access to services, information and advice; and ensuring improved co-ordination of assessments of need (Miller and McNicholl, 2003). The literature also supports the experience that co-location leads to enhanced collaboration between professionals from different teams; an essential component for the development of effective clinical networks and the delivery of high quality care, education, training and research. Effective collaboration has been reported as the most clinically and cost-effective way of delivering high quality care for those children and adults with co-morbidities and long-term conditions (NHS Future Forum, 2011). Co-location of services is an essential component for the movement towards service integration and ultimately integrated care; along with other components such as care co-ordination, case management, centralised information, inter-professional networks and shared accountability of care (The King's Fund, 2011). Integration can be defined as the combination of processes, methods and tools that facilitate integrated care; considered to be successful if it contributes to better care experiences, improved care outcomes, and cost-effectiveness. Integrated care is found to be most effective when it is population based and takes into account the holistic needs of individuals. With evidence indicating that children whose families are not accessing mainstream services such as primary care and schooling are at a disadvantage, these findings support the case for the co-location of services; a key priority being integrated care for children with DDD.

4.2 The impact of co-location on child protection

Background to child protection

As children with disabilities are three times more likely to be abused than their non-disabled peers (Sullivan & Knutson 2000), a model that increases joint working alongside better knowledge and communication around child protection should be hailed to have wider implications than just cost efficiency. For example, joint working between Social Care professionals and Dieticians can contribute to better child protection in a number of ways. Not only are Social Workers better informed about the nutrition a child is receiving, and able to challenge if plans are not being followed, but it also opens up clear communication between all parties involved, and presents a multi-agency front. Although this is a specific example, this was found to be a key theme and a co-ordinated approach to child protection has been highlighted as an effective and efficient way of working for all of those involved (Department of Education, 2013).

Evaluating the impact of staffing arrangements on reducing child maltreatment

We explored the value of SCC, through co-location and enhanced services, in reducing child maltreatment. Data from neighbouring Local Authorities (LA's) with similar deprivation scores, provided the number of children in need, and those on the child protection register, with and without a disability. Data was acquired from 2011, prior to the Centre opening (2012), to 2016.

What were the findings?

Since the model commenced (2012), the Centre's LA has seen a reduction in the number of disabled children classed as a 'child in need' (Table 7).

Table 7. Number of Children in Need and Children on the Child Protection Register 2011-2016

Children in Need						
Year	**2011**	**2012**	**2013**	**2014**	**2015**	**2016**
Disability	345	270	185	145	140	125
Non-Disability	690	825	855	935	965	920
Children on the Child Protection Register						

Disability	6	6	5	12	18	3
Non-Disability	105	104	132	180	166	135

Table 8. Number of children in need with and without a disability, and the number of children on the child protection register with and without a disability between 2011 and 2017 by LA.

Disability CP	**2011**	**2012**	**2013**	**2014**	**2015**	**2016**	**2017**
Blaenau Gwent	2	0	1	1	1	1	2
Newport	12	14	20	28	26	11	9
Torfaen	9	8	9	11	4	7	4
Monmouthshire	1	0	1	0	1	1	1
Non-disability CP	**2011**	**2012**	**2013**	**2014**	**2015**	**2016**	**2017**
Blaenau Gwent	98	70	59	69	64	69	83
Newport	110	96	115	162	159	129	111
Torfaen	171	142	86	124	96	143	116
Monmouthshire	61	79	54	37	50	32	90
CP Register Wales/Total			**2013**	**2014**	**2015**	**2016**	**2017**
Wales			2,955	3,135	2,935	3,060	2,690
CP Register/Local Authority	**2011**	**2012**	**2013**	**2014**	**2015**	**2016**	**2017**
Caerphilly	225	245	165	215	205	195	160
Blaenau Gwent	100	70	60	70	65	70	85
Torfaen	180	150	95	135	100	150	120
Monmouthshire	62	79	55	37	51	33	91
Newport	110	110	135	190	185	140	120
CP Register/Local Authority	**2011**	**2012**	**2013**	**2014**	**2015**	**2016**	**2017**
Caerphilly	225	245	165	215	205	195	160
Blaenau Gwent	100	70	60	70	65	70	85
Torfaen	180	150	95	135	100	150	120
Monmouthshire	62	79	55	37	51	33	91
Newport	110	110	135	190	185	140	120

How can these findings be interpreted?

The investment in comprehensive early family support services for children with disabilities has led to a reduction in those being at risk for child maltreatment. Although which components of the model add most value has not yet been determined, a holistic children's centre clearly contributes to enhanced support for families, and closer working relationships between health and social care professionals, thus potentially protecting children with disabilities from maltreatment.

Overall conclusions

This mixed methods approach has highlighted considerable advantages for families whose child has a DDD, and the professionals caring for them. While not all aspects of the complex enhanced services has undergone a detailed evaluation, it is clear that having a well-designed, welcoming facility within its own grounds in a community setting provides an optimal environment for families to receive services and support. Staff and families clearly gain from co-location, and the enhanced service provision has clear benefits for the emotional and social wellbeing of children and their parents. This would suggest that policy makers should look to provide such facilities, in order to meet their own goals of ensuring all children and young people reach their full potential, in a developmentally appropriate environment and within a social model of disability. Future evaluations should focus on detailed evaluations of provisions such as the Family Liaison Service, and individual clubs and activities.

Appendix A: Professionals focus group's participants and topics

Professionals were asked to share their views on the impact of the environment at SCC, enhanced services, enhanced facilities and co-location of services on children, families and professionals. Four focus groups were held: the first on 25/09/17 with professionals from NHCC (N=9); the second on 04/10/17 with professionals from SCC (N=8); the third on 17/10/17 with professionals from Torfaen (TF, N=7), and the fourth on 19/10/17 with professionals from Blaenau Gwent (BG, N=6). In total, 30 professionals participated in the focus groups including social workers, support workers, team managers, speech and language therapists, care co-ordinators, occupational therapists, family liaison officers, a physiotherapist, a paediatrician and a paediatric dietician. The focus group discussions were audio-recorded and transcribed. The transcript was analysed using Braun and Clarke's (2006) six-stage, non-linear procedure to identify any common 'themes' within the discussion.

Appendix B: Responses from the SLDOM Questionnaire - Part 3

3. What has been helpful about the care received from the team?

3.1) For you?

“Talking through issues allowed me to see the reason behind behaviour and subsequent solutions.”

“I feel more confident that I am correctly parenting my child. At a time when I felt I was losing control of my own emotions and therefore was not the parent I wanted to be. My counsellor helped me regain control and get back to being the parent I need to be.”

“I feel more confident with looking after my children and myself. What I feel is okay and is a lot to deal with which is okay. Julia has helped me understand my feelings and made me feel okay about them.”

“I've received some really good advice on coping mechanisms to deal with anxiety and have been given recommendations for literature to help follow these up.”

“To be listened to. To be heard free from judgement. To have space to take the time I needed for me and my needs. Not to feel alone on this special needs journey.”

***3.2)* For your child?**

“My child clearly benefits from my own emotional stability.”

“I can be there for them fully and know everything will be okay because I am capable to notice when things are going wrong.”

3.3) For your family?

“Helped us relax more and giggle and not take everything too seriously.”

“I am more honest and open which now makes communication better so we can be a family unit for anything that is thrown our way.”

“My family benefit greatly when I am able to manage my anxiety - the impact on family life Is unbelievably positive! :)”

4. Was there anything you did not like or needs improving?

“It would be lovely to have the opportunity to meet parents in a similar situation as myself (parents of young children going through a diagnosis process or with ASD).”

5. Is there anything else you would like to tell us about the service you received?

“For me I think more than 5 sessions would be helpful.”

"I think the service really offers parents a life line when they are experiencing extreme difficulties and anxieties. It is beneficial as it allows thinking time and provides with much needed support from a professional at a crucial time."

"I feel so much better/positive now and feel like I've been given the tools to 'help myself' in future but I know that if I need any more help I can contact the team again. Because of how friendly and welcoming everybody is, I didn't feel ashamed or that I was failing as a parent because I needed some help. I'm really grateful that this support was available to me. Thank you."

"I appreciated having the space to be me. The waiting list was very short and Julia was very helpful. Thank you for your time :) "

Appendix C: Dad's Group cohort demographics

Table 1. Fathers demographics of participating members of a male-only psychological support group and the characteristics of their child with a disability and/or developmental delay

Pseudonym	**Age in years**	**Family characteristics**	**Child's age in years**	**Child's condition**
Tony	42	Married, 3 other children (aged 16, 13 & 10)	20	Asperger's Syndrome (Anxiety & Depression)
John	41	Married, 1 other child (aged 2)	4	ASD (Pathological Demand Avoidance traits)
Curtis	49	Married, 1 other child (aged 12)	17	Medical syndrome (Hydrocephalus, severe hearing loss)
Jake	47	Married, no other children	8	Cerebral Palsy (learning disabilities, motor difficulties, visually impaired)
Rick	48	Married, 2 other children (15 & 12)	14 17	ASD (hearing/sight impaired) Coeliac disease (hypermobility, ASD traits)
Alex	32	Married, 1 other child (15 months old)	3	ASD
Luke	55	Married, 1 other child (aged 10)	13	ASD (hypermobility genetic syndrome, epilepsy)

*Legend: *DDD – Disability and/or developmental delay, **ASD – Autistic Spectrum Disorder, ***Medical syndrome – details withheld to avoid breaching confidentiality*

Appendix D: Dad’s Group research dissemination

Please double click on the image below to open the PowerPoint presentation.

“They just get it”: An exploration of fathers’ experiences of a support group for men caring for children with disabilities and/or developmental delay (DDD)

Molly Batchelor BSc

Assistant Psychologist

Serennu Children’s Centre, Newport,

South Wales

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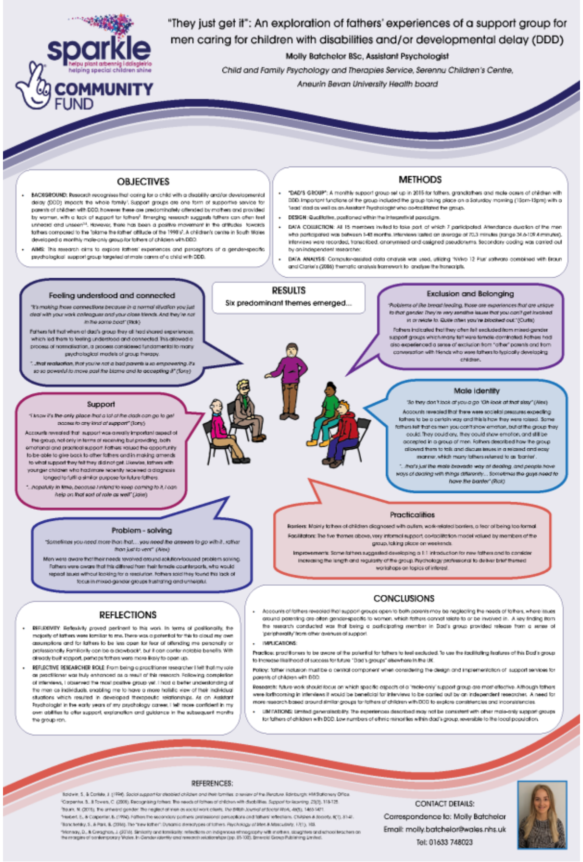
helping special children shine

Please double click on the image below to open the full-size poster.



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COMMUNITY FUND

"They just get it": An exploration of fathers' experiences of a support group for men caring for children with disabilities and/or developmental delay (DDD)

Molly Batchelor BSc, Assistant Psychologist

Child and Family Psychology and Therapies Service, Serennu Children's Centre,

Aneurin Bevan University Health board

OBJECTIVES

- **BACKGROUND:** Research recognises that caring for a child with a disability and/or developmental delay (DDD) impacts the whole family[1]. Support groups are one form of supportive service for parents of children with DDD, however these are predominately attended by mothers and provided by women, with a lack of support for fathers[2]. Emerging research suggests fathers can often feel unheard and unseen[3,4]. However, there has been a positive movement in the attitudes towards fathers compared to the 'blame the father' attitude of the 1990's[5]. A children's centre in South Wales developed a monthly male-only group for fathers of children with DDD.
- **AIMS:** This research aims to explore fathers' experiences and perceptions of a gender-specific psychological support group targeted at male carers of a child with DDD.

METHODS

- **"DAD'S GROUP":** A monthly support group set up in 2015 for fathers, grandfathers and male carers of children with DDD. Important functions of the group included the group taking place on a Saturday morning (10am-12pm) with a 'lead' dad as well as an Assistant Psychologist who co-facilitated the group.
- **DESIGN:** Qualitative, positioned within the interpretivist paradigm.
- **DATA COLLECTION:** All 15 members invited to take part, of which 7 participated. Attendance duration of the men who participated was between 1-48 months. Interviews lasted an average of 70.3 minutes (range 34.6-109.4 minutes). Interviews were recorded, transcribed, anonymised and assigned pseudonyms. Secondary coding was carried out by an independent researcher.
- **DATA ANALYSIS:** Computer-assisted data analysis was used, utilizing 'NVivo 12 Plus' software combined with Braun and Clarke's (2006) thematic analysis framework to analyse the transcripts.

RESULTS

Six predominant themes emerged...

Feeling understood and connected

"It's making those connections because in a normal situation you just deal with your work colleagues and your close friends. And they're not in the same boat" (Rick)

Fathers felt that when at dad's group they all had shared experiences, which led them to feeling understood and connected. This allowed a process of normalisation, a process considered fundamental to many psychological models of group therapy.

"...that realisation, that you're not a bad parent is so empowering. It's so so powerful to move past the blame and to accepting it" (Tony)

Exclusion and Belonging

"Problems of like breast feeding, those are experiences that are unique to that gender. They're very sensitive issues that you can't get involved in or relate to. Quite often you're blocked out." (Curtis)

Fathers indicated that they often felt excluded from mixed-gender support groups which many felt were female dominated. Fathers had also experienced a sense of exclusion from "other" parents and from conversation with friends who were fathers to typically developing children.

Support

"I know it's the only place that a lot of the dads can go to get access to any kind of support" (Tony)

Accounts revealed that support was a really important aspect of the group, not only in terms of receiving but providing, both emotional and practical support. Fathers valued the opportunity to be able to give back to other fathers and in making amends to what support they felt they did not get. Likewise, fathers with younger children who had more recently received a diagnosis longed to fulfil a similar purpose for future fathers.

"...hopefully in time, because I intend to keep coming to it, I can help on that sort of role as well" (Jake)

Male identity

"So they don't look at you a go 'Oh look at that sissy" (Alex)

Accounts revealed that there were societal pressures expecting fathers to be a certain way and this is how they were raised. Some fathers felt that as men you can't show emotion, but at the group they could. They could cry, they could show emotion, and still be accepted in a group of men. Fathers described how the group allowed them to talk and discuss issues in a relaxed and easy manner, which many fathers referred to as 'banter'.

"...that's just the male bravado way of dealing, and people have ways of dealing with things differently... Sometimes the guys need to have the banter" (Rick)

Problem - solving

"Sometimes you need more than that... you need the answers to go with it, rather than just to vent" (Alex)

Men were aware that their needs revolved around solution-focused problem solving. Fathers were aware that this differed from their female counterparts, who would repeat issues without looking for a resolution. Fathers said they found this lack of focus in mixed-gender groups frustrating and unhelpful.

Practicalities

Barriers: Mainly fathers of children diagnosed with autism, work-related barriers, a fear of being too formal.

Facilitators: The five themes above, very informal support, co-facilitation model valued by members of the group, taking place on weekends.

Improvements: Some fathers suggested developing a 1:1 introduction for new fathers and to consider increasing the length and regularity of the group. Psychology professional to deliver brief themed workshops on topics of interest.

REFLECTIONS

- **REFLEXIVITY:** Reflexivity proved pertinent to this work. In terms of positionality, the majority of fathers were familiar to me. There was a potential for this to cloud my own assumptions and for fathers to be less open for fear of offending me personally or professionally. Familiarity can be a drawback[6], but it can confer notable benefits. With already built rapport, perhaps fathers were more likely to open up.
- **REFLECTIVE RESEARCHER ROLE:** From being a practitioner researcher I felt that my role as practitioner was truly enhanced as a result of this research. Following completion of interviews, I observed the most positive group yet. I had a better understanding of the men as individuals, enabling me to have a more holistic view of their individual situations which resulted in developed therapeutic relationships. As an Assistant Psychologist in the early years of my psychology career, I felt more confident in my own abilities to offer support, explanation and guidance in the subsequent months the group ran.

CONCLUSIONS

- Accounts of fathers revealed that support groups open to both parents may be neglecting the needs of fathers, where issues around parenting are often gender-specific to women, which fathers cannot relate to or be involved in. A key finding from the research conducted was that being a participating member in Dad's group provided release from a sense of 'peripherality' from other avenues of support.
- **IMPLICATIONS:**

Practice: practitioners to be aware of the potential for fathers to feel excluded. To use the facilitating features of this Dad's group to increase likelihood of success for future "Dad's groups" elsewhere in the UK.

Policy: father inclusion must be a central component when considering the design and implementation of support services for parents of children with DDD.

Research: future work should focus on which specific aspects of a "male-only" support group are most effective. Although fathers were forthcoming in interviews it would be beneficial for interviews to be carried out by an independent researcher. A need for more research based around similar groups for fathers of children with DDD to explore consistencies and inconsistencies.

- **LIMITATIONS:** Limited generalisability. The experiences described may not be consistent with other male-only support groups for fathers of children with DDD. Low numbers of ethnic minorities within dad's group, reversible to the local population.

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Appendix E: Sparkle Workforce

Current workforce profile

The National Council for Voluntary Organisation (NCVO) 2018 Almanac, which uses general charity data from 2015- 2016, recognises that 63% of the employed voluntary sector workforce are female as opposed to 41% in the private sector. Within Sparkle, this figure is even higher at 85% overall and 88% within the leisure team. In contrast, our child and young person population is only 22% female. This statistic, whilst appearing low, compares favourably with The Department of Education, Child Care and Early Years Providers Survey 2013 which reports that the proportion of paid male staff working in childcare and early education settings was reported as 3% of the overall workforce.

Sparkle recognises that Newport has a very diverse community, whereas South Torfaen and South Monmouthshire's population is mainly white, with 97% and 96%, respectively, of the overall population reporting as white British/ Welsh/Northern Irish in the 2011 Census. Within Sparkle, 88% of the leisure team staff are white British which is reflective of the children and young people accessing Sparkle services, where 93% are white British and 7% identify as an ethnic minority. Whilst all children and young people accessing Sparkle services have an emerging or confirmed diagnosis of a disability and/or developmental difficulty, only 6% of the Sparkle workforce identify as having a disability.

It is acknowledged that 92% of leisure posts are part time, with the shortest contract being 2.25 hours per week. Due to the nature of the work, most of our contracts are delivered in the evenings and on a Saturday. Within the leisure service there are also a number of staff members who are engaged by Sparkle on a relief basis, i.e. as and when required. Of the current staff team, 97% are employed on a fixed term basis, due to the nature of funding for their posts via external, time limited grants. In contrast, the NCVO 2018 almanac identifies that 91% of those employed in the voluntary sector have a permanent contract, and of those that are on a temporary contract 66% are on a fixed term basis.

In terms of the age profile of our staff, including those employed via commissioned, services, 6% are under 18, 42% are aged between 18 and 24, and 52% are aged 25+. Therefore, 48% of the overall Sparkle workforce are under 25 years, and 70% of those under 25 years are employed within the leisure team. Due to the nature of the work being highly active and the number of contracted hours available being limited, the leisure team generally attracts younger staff, or, those who have a full time role and are seeking supplementary work opportunities. As such, staff tend to have a limited level of experience and skills. This therefore necessitates the requirement for a high level of training to ensure the needs of our children and young people can be met. This has high resource costs in terms of both time and finances, but one that is necessary to deliver quality, responsive services.

Sickness absence

Managing sickness absence effectively is crucial for ensuring the delivery of high quality services. For the 12 month period – April '17 to March '18, the percentage of days lost through sickness was 1% for office staff and the percentage of shifts lost through sickness was 2% for the leisure team. These sickness levels are comparatively low and the fact that occupational sick pay is limited to 5 days per 12 month period is likely to be a major contributor to the effective management of sickness.

The main causes of sickness absence were sickness/diarrhoea and anxiety/depression. Sickness/diarrhoea related absences (where policy requires a period of 48 hours clear of symptoms is achieved) accounted for 26 lost shifts out of a total of 54 in the leisure service and 8 lost days out of a total of 18 days for office staff. The next highest cause was anxiety/depression where there were 10 shifts lost in the leisure service however, it should be noted that this recorded absence related to only one member of staff.

Recruitment, selection and retention of Sparkle staff

Sparkle is committed to a fair and consistent approach to recruitment and selection, and encourages applications from people with a disability. On each occasion, vacant posts will be subject to a review process to identify; whether the work, in total or in part is required; any potential for the work to be redistributed, or the possibility of reduction of hours, salary, etc. Every post will be defined in terms of a job description (outlining the main responsibilities of the post) and a person specification (stating the requirements to fulfil the role). Each vacancy/ job role identified is considered individually and advertised internally and/ or externally as deemed appropriate, with regard given to the desirability to import fresh and wider experiences; capacity and demand, and costs of external advertising.

Sparkle's selection process is based upon the ability of a candidate to undertake the job role, their ability to make a contribution to Sparkle's effectiveness and their potential for development. Through the selection process all interview questions relate to the job description and person specification and are free of discriminatory bias. All offers of employment are subject to a candidate satisfactorily completing: a medical fitness check, enhanced disclosure and barred list checks, alongside proof of essential qualification/ professional body registration and the receipt of two satisfactory references (one from the current/most recent employer and one other personal reference). In addition, where necessary, all relevant work permits must also be sought and granted prior to commencing in post. A commencement date is not agreed until all checks have been completed satisfactorily and all appointments will be subject to a minimum three month probationary period.

Between 1st April 2017 and 31st March 2018, 14 applicants were appointed, of which 11 commenced and 3 withdrew during the recruitment process. The following table shows the shortest, average and longest length of time that it took to complete the required recruitment checks from point of acceptance of a role.

Check	Shortest	Average	Longest
Disclosure and Barring Service	11 days	21 days	35 days
Occupational Health	15 days	29 days	45 days
References	6 days	28 days	41 days

Sparkle aims for the recruitment process to be completed within 56 days (8 weeks) and we are exceeding this at all times with a maximum recruitment period of 45 days (6.4 weeks). Whilst this seems lengthy, this is now the expected duration within most industries requiring enhanced disclosures and occupational health clearance. ABUHB has a fast track appointment system with a target 75 day turnaround for example.

Sparkle recognises that it is paramount that we continue to retain and attract employees with the right skills and qualities required for our future workforce. The following actions, alongside offering learning and development opportunities, are utilised to support the recruitment and retention of staff.

- **Succession planning and internal recruitment**
  Planning to allow us to grow our own talent is as important as attracting new talent to Sparkle. Effective succession planning, and where appropriate internal recruitment,

allows us to continue to develop aspiring leisure Supervisors, for example, of the future.

- **External recruitment**
  The recruitment process is managed by the Sparkle Office Manager, and vacancies are advertised widely and where appropriate, targeted for example recruitment to the psychology service.

- **Exit interviews**- Sparkle will offer all leaving members of staff an opportunity to attend an exit interview where there will be the chance for staff to indicate why they have chosen to leave Sparkle but also identify any areas of learning/ improvements that they feel could be made.

Length of service

The length of service data for the current Sparkle workforce of 44 staff, identifies that of the 11 office staff, 27% of staff members have been employed for less than 1 year, 46% of staff have been employed between 1 and 3 years and 27% of staff have been employed over 4 years. In relation to the Sparkle leisure service, out of the 33 staff members, 51% have been employed for less than 1 year, 49% of staff have been employed between 1 and 3 years and there are currently no leisure staff members that have been employed for over 4 years. Due to this level of turnover, it is accepted that to ensure a skilled and appropriately trained workforce, investment in a staff member, i.e. in relation to training, is higher than in any other area of the Charity; however, training costs will always be higher in the leisure team due to the need to respond to individual children and young people’s needs, alongside many training programmes that have a ‘set lifespan’ i.e. are only valid for 1 year, with a requirement for renewal of three years.

For the period 1/8/17 to 31/7/18, of the 13 office staff employed at the commencement of the period, 4 staff members left during the 12 months, giving an annual turnover of 31%. The equivalent statistics for the leisure service are, of the 53 staff employed at the commencement of the period, 18 staff left during the 12 months, giving an annual turnover of 34%. It is reported, that on average in the voluntary sector, for 2017 that the average staff turnover was 12%, and the private sector average staff turnover is 14%. Therefore, Sparkle appears to have a significantly higher staff turnover then the average figure. All staff leaving Sparkle are invited to attend an exit interview. For the period 1/8/17 to 31/7/18, 22 exit interviews were offered and 12 interviews were undertaken.

From the information gained from completed staff exit interviews 75% stated they were looking for fulltime employment or had gained alternative employment, 17% went into full time education, and 8% (which equates to 1 individual) left due to moving out of the geographical area. The challenge that this presents is the continuous need for advertising and recruitment of staff. This is a time consuming process and very often there is a substantial gap between a person leaving and the commencement of employment by the newly appointed member of staff. During this time, the service relies on relief staff which results in inconsistency for the staff teams and the children/young people accessing the provisions. Consistent regular relief staff is preferable, and maintained wherever possible, but this can be difficult depending on availability of staff members. The high turnover of staff can impact on the dynamics of the existing staff team, it takes time for the staff to develop good working relationships with new colleagues whose duties may increase whilst new staff upskill, settle into their roles and get to know the children and young people.

Volunteers
Sparkle currently has 41 volunteers who make a vital contribution towards, and enhance, the delivery of Sparkle services. From supporting children who are learning to swim to providing support to parents, working in the café or providing 'meet and greet' services on reception.

2660 volunteer hours were logged for the period 1st April 2017 to the 31st March 2018 in support of Sparkle events, plus 160 volunteering hours per week (for 48 weeks) from our regular volunteers. This make a total of 10,340 hours, which based on an hourly rate £7.75 per hour represents a cost saving of £80,135 to Sparkle. We cannot therefore underestimate the contribution that volunteers make to the services of Sparkle. In terms of the age profile of our volunteers, 15% are under 18, 32% are between 18-25, 32% are aged 25 to 60 and 21% are aged 60+. Within the volunteer team 98% are white British and 15% identify as having a disability. The length of service data for the 41 volunteers identifies that 44% of volunteers have been in their role for less than 1 year, 24% have been in their role between 1 and 3 years and 32% of volunteers have been in their role for over 4 years. It is also notable that a number of Serennu 'graduates', i.e. young people with DDD who previously attended Serennu, have joined as volunteers once they are over 18 years. For many of these young people, this may be the only activity they have outside the home at this stage. This has multiple benefits, both for the young people themselves in terms of giving them a sense of purpose, gaining skills, and learning about the 'work environment', and for other families. Both young people attending SCC, and their parents, can see that others like them have gone on to take responsibility and become involved in a work environment.

Between 1st April 2017- 31st March 2018, 19 volunteers were appointed, of which 15 commenced and 4 withdrew during the recruitment process. The table below shows the shortest, average and longest length of time that it took to complete the required recruitment checks from point of acceptance of role. It should be noted that for volunteer recruitment, the completion of the DBS is an in-house function and due to this, the process is recognised as taking a shorter period of time to complete.

Check	**Shortest**	**Average**	**Longest**
Disclosure and Barring Service	3 days	8 days	16 days
Occupational Health	15 days	30 days	69 days
References	2 days	17 days	58 days

Sparkle aims for the recruitment process to be completed within 56 days (8 weeks) and whilst the average length of time is 31 days (4.4 weeks), the longest is 69 days (9.9 weeks).

External commissioning

Sparkle has engaged in various forms of partnership working for more efficient and effective delivery of services. This has been developed in areas where developing skills/expertise internally is either too expensive or not sustainable.

The three core partnerships are below:
- CB Training Ltd. - swimming lessons service;
- Julia Shearn- (Psychology) counselling services;
- Dr Sarah Butler- (Psychology) delivery of workshops.

These partnerships are monitored through Service Level Agreements (SLA) and General Data Protection Regulations (GDPR) contracts. With the transfer of the Sparkle psychology service to Aneurin Bevan University Health Board, which took place on 1st April 2019, it is envisaged that CB Training Ltd. will be the only ongoing commissioned service for Sparkle over the next 3 years.

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