Sparkle, Helping Families to Take the Next Step – Evidence of Need; Review of the Literature

Historical context

The Serennu Children's Centre is an integrated children's centre that aims to holistically meet the health and social care needs of children with disabilities and/or developmental difficulties and their families. The South Gwent Children's Foundation, (registered charity no: 1093690) known as the "Sparkle Appeal," is the driver of change to genuine joined-up and holistic care, the provider of enhanced facilities and activities to aid a child's development and the actioner of the needs and desires of children, young people and their families in enriching their life and that of their family.

Through a Big Lottery grant (People and Places), Sparkle has been able to develop a holistic and family-centred approach to support services for children with disabilities and/or developmental difficulties and their families across Newport, South Torfaen and South Monmouthshire.

Sparkle has been able to begin to address the factors that are known to have an impact on families' resilience and ability to cope with a child with a disability, that are in addition to the complex health needs and social care needs, which fall to the statutory services. We know that child and family wellbeing/coping is influenced by a complex interaction of factors including the child's health needs, adaptive skills, developmental needs (sleep, behaviour, toileting etc), systemic factors (such as family coping, isolation, socio-economic factors) and also family reactions and psychological factors.

At the Serennu Children's Centre, Sparkle has provided parents, children and siblings with much-needed leisure, social and psychological support. We have aimed to provide our families with a sense of safety, security and community, thereby reducing the sense of isolation and hopelessness that parent's and families of children with disabilities tell us they experience. We have benefited from the co-location of statutory services and Sparkle services in a highly appropriate and accessible building.

While we have made substantial progress from our earlier grant, we recognise that changes are needed to further improve the lives of this particular and numerous group of families within Gwent.

- We want to build on the benefit of co-located services and the community that has been created towards truly integrated and coordinated leisure, care and treatment services.
- We seek to improve communication between professional networks and families, to value children and families as equal partners in the development of services and interventions.
- We must continue to innovate and offer new or different services to cater for the needs of those children with the most complex needs, who cannot access any leisure/recreational activities/facilities.

- We must reach out to new beneficiary groups, with a focus on those recently diagnosed or new on their journey to diagnosis, as well as those approaching the key transition stages where they do need additional and tailored support.
- We must support the adoption of the recommendations in the 3 centre review to ensure equitable provision to children throughout the whole of Gwent, extending our geographic reach if required and thereby reach many new potential families.

Through our ongoing evaluation and conversations with children and families, we recognise that there are factors that contribute to family resilience and coping that we could address more effectively - we could improve on the emotional and psychological support for children and families at times of transition, we could address developmental factors through parent and professional education programmes, we could reduce social isolation through a roll-out of Face2Face and providing further opportunities for families to connect with other families facing similar challenges in their daily lives bringing up a child with disabilities/developmental difficulties.

Why are these outcomes important for our families?

Morris et al. (2014)[1] have compiled a substantial review into the most desired health outcomes for children with 'neurodisability' as described by young people, parents and professionals. The authors define neurodisability as "conditions associated with impairment of the nervous system and includes conditions such as cerebral palsy, autism and epilepsy". Young people and parents prioritised the outcomes communication skills, social lives and community relationships, and emotional well-being and mental health, as well as managing pain, self-care, independence and future aspirations. This reflects our own evaluation findings from children/young people, parents and health/social care professionals. Collectively, the above research highlights that young people and their families are concerned about ensuring effective development in the four outcomes we will deliver, should our grant application be successful.

Social needs

Children and young people wish to engage socially in all aspects of life that are available to children without a disability[2]. Such an example is through participation in social and leisure activities, with young people with disabilities valuing the opportunity to participate in social activities with others, but recognise that they are given less opportunity to do so[3]. In addition, parents want the ability to engage in support that is flexible enough to accommodate all their children's needs, and are concerned that the social needs of the siblings are not effectively addressed[2].

Indeed, research highlights the need for healthcare providers to recognise individual children's interests and overcome the barriers that may restrict participation in these activities[4]. Children and young people value the opportunity to engage in leisure

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[1] Morris et al., 2014
[2] Abbott et al., 2006
[3] Shikako-Thomas et al., 2013
[4] Dahan-Oliel et al., 2012

activities for four key reasons: 1) the enjoyment; 2) the freedom they have to choose the activities they want to engage with 3) developing and encouraging their potential and skills; and 4) the sense of friendship and belonging they receive by participating[5].

There are clear benefits to addressing the social needs of the child with a disability and their families. Participation in social activities has been 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)[4]. Social participation in leisure activities also promotes improvements in the overall self-worth and motivation to succeed at physical tasks of young people with disabilities[4].

Our parents at Serennu recognise the importance of their children developing effective social skills:
"*He has the rest of his life to become a maths wizard or a literacy genesis. If he is not sociable he can't talk to another person there is no point in him being a wiz at anything*."[6]

Emotional needs

Children and young people with disabilities are likely to experience increased risk of poor psychological and emotional well-being, such as anxiety and depression[7]. This is exacerbated by exposure to psychosocial disadvantage[8]. It is hard for children with learning disabilities to learn communication skills and to control the world around them. Because of this a high number of children with learning disabilities develop behaviours that challenge (things like aggression or self-injury). Behaviours like this have a negative impact on the wellbeing of the child *and* family carers. Without intervention challenging behaviours tend to persist (often into adulthood)[9] and often require costly long-term service provision.

Parents of children with disabilities are also likely to report poorer physical and emotional health when compared to parents of non-disabled children[10,11], including higher levels of stress[12]. This is particularly the case for parents of children with Autism Spectrum Disorders, with Bromley et al's (2004) study showing higher levels of psychological distress for these parents compared to parents of children with other developmental disabilities.

Factors that influence parental wellbeing include the increased financial cost of caring for a disabled child, the time demands of medical/therapeutic interventions, parental grieving for the loss of the healthy child they expected, social isolation and strained family relationships[13]. For the parents of children with ASD, higher levels of

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[5] Powrie et al., in press
[6] Parent consultation, 2014
[7] Young Minds, 2014
[8] Emerson & Hatton, 2007
[9] Emerson & Enfield, 2011
[10] Miodrag, & Hodapp, 2010
[11] Gallagher and Whiteley, 2012
[12] Shedden et al., 2015
[13] Woolfson, 2004

psychological distress were associated with low levels of family support and managing a child who has behaviour that is challenging. As a parent who uses Serennu notes: "*That is hard to deal with. It comes with lots of other issues for you and your family. It is the marital stress the financial stress the emotional baggage all sort of things. The sadness lots of lots of things.*"[6]

Risks to parents' emotional well-being may be experienced throughout their child's life, particularly at key transitional stages. For example, when parents first experience their child having a diagnosis of a disability, they will likely feel a number of negative emotions, such as anxiety, confusion, grief, self-blame, as well as a perceived loss or change of their identity as a parent[14]. It is this diagnosis stage that parents often find the most stress-inducing life event of being a caregiver for a child with a disability, but parents will also likely experience greater stress when their disabled child transitions into school, and also when their child transitions from school into the workplace[15].

Fathers may also be at particular risk of high stress as a consequence of providing care for their child[16]. Siblings of children with disabilities may also be at risk of decreased emotional well-being, with research indicating that brothers and sisters may experience heightened anxiety and depressive symptoms[17].

Educational needs

Access to appropriate education and chances to learn are essential for children with disabilities and their parents to develop a good quality of life.[2] However, children with disabilities may face barriers to effective participation in the educational setting[18], and may experience significant difficulties when transitioning into the school context, such as having poorer behaviour and impaired social and self-regulation skills[19].

For example, children and young people are concerned about having the opportunity to develop future independent skills, such as effective education and qualifications, as well as access to employment and the additional support that may be required to achieve these goals[1]. Parents are also keen for their child to learn new skills in order to encourage future adult independence[1]. This centred around being able to wash and toilet independently, as well as being able to communicate their choices to others. In focusing on these issues, parents wanted to ensure that their child's dignity was maintained and respected by others. These concerns are also discussed by our parents at Serennu, who report wanting to learn more about their child's disability and needs, particularly around their life concerns around transition.

"*I went back to the doctor and got different leaflets, information and all things like that. (My child) has really coped terribly with going through puberty*."[6]

"*I wanted to know how do I help my child. I don't know what I expected but I felt like I had come out of this with this life changing diagnosis for (my child), for my husband,*

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[14] Smith et al., in press
[15] Baxter et al., 1995
[16] Rivard et al., 2014
[17] Barlow and Ellard, 2006
[18] Department for Education, 2015
[19] McIntyre et al., 2006

for me his siblings, with two leaflets. What use is that to me? I am a practical person and I look for practical support and I felt very let down."[6]

Communication needs

Besides these health needs, both young people and parents have a desire to ensure that they have choice and control over their care needs, so that the care they receive is individualised to ensure that specific concerns and goals are addressed.[20] Consequently, young people and parents remain positive towards different agencies providing care for their child being connected and collaboratively working together with them to ensure the best needs for the child and family. For example, parents having access to a key worker for the care of their child with a disability show improved quality of life scores, and report greater satisfaction with the care service they receive,[21] as well as improved emotional well-being.[1] Parents who attend the Serennu Children's Centre are also extremely positive towards introducing a co-ordinator to help them manage the complexities of their child's care, which is considered one of their top priorities.

Extending this to the professionals working with children with disabilities and their families, Abbott, Townsley and Watson (2005) have shown that staff also value the opportunity to work as part of a multi-agency service, and noted many improvements over the traditional healthcare system: improved professional development, communication and collaboration with other staff, a sense that they were providing a more efficient service for, and had better relationships with, parents and their children. Given these benefits, Serennu is developing our approach to fully advocate and enact the multi-agency style of working. A recent example includes a staff training away day, which involved professionals from many health and social care departments coming together in order to highlight the collective strengths of Serennu in achieving this style of working, but also discussing where potential improvements to the centre can be made. In addition, the Clinical Psychology Helping Hands service, have piloted several staff training programmes, which we hope to make available to all Children with Disabilities health and social care teams in Serennu, Torfaen and Monmouthshire.

UK Figures of Disadvantage

In the UK[22] 462,000 families have a child (0-16) who is long-term sick or disabled. Of these:

- 32% are single parent families
- 10% have more than one child who is long-term sick or disabled
- 33% has at least one adult (parent) who has a long-term illness or disability
- 23% have no access to personal mode of transport

Contact A Family's research in 2011[23] revealed that it costs up to 3 times as much to raise a child with disabilities compared to raising a child without disabilities. There are also barriers to employment for parents of a child with disabilities including caring

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[20] National Voices, 2015

[21] Sloper et al., 2006

[22] 2001 Census Figures

[23] Forgotten Families: The impact of isolation on families with disabled children across the UK, Contact A Family, 2011

obligations and numerous appointments to attend as well as forms to complete, high incidence of family breakdown (21% say that isolation experienced as a result of having a child with disabilities is contributing to family breakdown) putting a larger share of the care onto one parent, inflexible employers and lack of appropriate childcare for children with special educational needs. Only 16% of mothers of children with disabilities work compared to 61% of other mothers, yet 57% would like to be supported so they can work.

Newport and Surrounding Areas – Showing Disadvantage

Gwent features high on the Welsh Indices of Deprivation (2014) with 14 wards in Newport and 5 wards in Torfaen appearing in the most deprived 10% of wards in Wales, including Stow Hill, RIngland, Always, with areas of Pillgwenlly ranking 11/1909. These areas also experience high unemployment (approximately 8% and 10% in Newport and Torfaen respectively compared to the Wales average of 7%)[24], as well as a high incidence of single parent families (10.02%)[25].

25.5% of children in Newport live in poverty, as well as over 23.8% of children living in Torfaen, and 13.1% in Monmouthshire[26]. In addition, over 20% of children living in Newport are eligible for free school meals, as well as over 23% of children in Torfaen, and 11% in Monmouthshire[22]. Young people experience high levels of unemployment after leaving school (18.4% and 16.3% in Newport and Torfaen respectively, compared to the Welsh average of over 15.7%) and have more than 50% higher percentages of NEETs (not in education, employment or training), with 6.7% in Newport and Torfaen compared to the Wales average of 4%[22].

Overall, children, young people, and their families living in the Gwent boroughs experience high levels of poverty and disadvantage, as well as difficulty in improving their prospects of moving out of poverty (e.g. education and unemployment).

Information on Disability in Wales – Double Disadvantage

In Wales, over 25,000 (5.7%) male and 20,000 (4.3%) female children and young people aged 0-24 years are diagnosed with a disability or long-term health problem[27]. Children with disabilities face health and social disadvantage anyway and this may be exacerbated given the levels of disadvantage in the local areas, as outlined above.

The estimated number of children (0-19) in Serennu’s potential catchment of Newport, North Monmouthshire and North Torfaen is 4,234, as in the table below showing a breakdown of the population estimates along with the total number of 0-19 year olds and ABUHB’s estimation of 7% of all children with disabilities.

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[24] National Assembly for Wales, 2015

[25] 10.02% is the rate for Newport, compared to 8.23% for the whole of Wales (2011 Census, ONS)

[26] Health of Children and Young People, 2014

[27] Public Health Wales Observatory, 2013, Health of Children and Young People in Wales

	Caerphilly CC	**Nevill Hall CC**	**Serennu CC**
TOTAL Population	178,806	161,788	236,160
Blaenau Gwent		69,814	
Newport			145,736
Monmouthshire		49,434	41,889
Torfaen		42,540	48,535
TOTAL 0-19	45,690		
Blaenau Gwent		17,252	
Newport			38,253
Monmouthshire		11,909	10,145
Torfaen		10,713	12,081
Estimate CWD (7%)	**3,198**	**2,791**	**4,234**

Whilst there are a potential 4,234 children in Serennu's catchment area, not all would be eligible to attend for Sparkle's activities (for eg it is estimated that 10% of all people with disabilities are disabled due to mental illness,) and we estimate that in any given year there are 1,200-1,500 children who would be accessing Serennu. We focus our services at those children who cannot access mainstream activities and facilities, including those with multi-diagnosis and more complex needs.

Medical advances and public health improvements have altered the patterns of disability. Mortality rates for infectious diseases, congenital heart defects, cystic fibrosis and being born prematurely have declined substantially whilst at the same time the number of children with neurodevelopmental and behavioral conditions, such as autism, attention-deficit/hyperactivity disorder, and developmental disabilities, has increased. In the USA between 2001-2011, the percentage of children with disabilities rose by 15.6%[28], of which a substantial amount was due to an increase in neurodevelopmental conditions, compared to disability due to physical conditions, which decreased.

In the UK we can show an increase in learning/developmental disability through the data from GP learning disability registers in England, but only for adults (18+).[29] In 2010-2011 on average across England 4.3 people in every thousand had a learning disability up from 4.2 in 2009-2010, 3.7 in 2008-2009 and 3.4 in 2007-2008. However some of the regions figures' reached up to 6% (Yorkshire and the Humber) with rises of 19% between 2007-2011. We could not locate any such figures for Wales.

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[28] Houtrow, A.J. Larson, K. Olson, L.M. Newacheck, P.W. Halfon, N. Changing Trends of Childhood Disabiliy, August 2014

[29] Emerson, E. Hatton, C. Robertson, J. Roberts, H. Baines, S. Evison, F. & Glover, G. "People with Learning Disabilities in England" 2011. *Improving Health & Lives: Learning Disabilities Observatory*

Policy initiatives that have sought to improve health and social care services for disabled children in UK and Wales

SEND reforms in England

In the Children and Families Act, 2014, the UK government sought to change the support system for children with special needs in England. This law proposes that children and young people will receive a co-ordinated care plan of their needs across education and health and social care, which will stay with the child until the age of 25. Consequently, the Education, Health and Care assessment will assist in ensuring that the young person can transition effectively into adulthood beyond education. Also included in this plan is the provision of personal budgets, which allow the child or young person and their family to control, which services they access and how their money is spent. This is a major challenge for Sparkle, as this is not currently happening in Wales, and the IDP (Individual Development Plan) consultation in Wales will only mandate education to feed into the single plan and not health nor social care.

The Health and Social Care Act

The Care Act, 2014 aims to improve the rights of individuals looking after the needs of vulnerable people. Through this legislation, carers will have greater control over the information and support they receive for themselves and the individual under their care from their local authority. This will allow carers to have a better understanding of their support/respite options, and to plan accordingly for the support that is required. In deciding and requesting appropriate support, rather than the needs of the individual alone being discussed, provision of support is also allocated on the needs of the individual carer and the wider family unit.

The Care Act also assumes that the individual requiring care and the carer should have authority and control over their support needs via direct payments. By doing so, this also ensures that carers and families have financial protection over the care they wish to access.

Aiming High for Disabled Children: Better Support for Families (2007)

This review by HM Treasury highlights the need for children, young people and their families with disabilities to be empowered to choose quality and timely care and support that is right for their needs, in order to encourage emotional and social support, as well as effective transition.

Healthcare Changes in Wales:

National Service Framework: Wales (2005)

The Welsh government propose a series of standards which ensure that disabled children, young people and their families will have access to quality services and equipment that are suitable for, as well as centred around, their individual needs (such as short breaks for children with disabilities away from their family). In addition, young people with disabilities beyond the age of 18 will also receive personalised and co-ordinated family-centred care to promote successful transition from childhood to adulthood.

The Bevan Commission

The Bevan Commission was established in 2008, and tasked with highlighting how health services could be improved in Wales. Their report in 2013 recognises that the current priority for improving patient health remains within the emergency sector (e.g. A and E), meaning that resources at the primary and community levels are often under-utilised. Improvements to the healthcare system could be made by ensuring that patient care incorporates effective preventative, early interventional, and management strategies of patients with chronic conditions (e.g. child health, intellectual disability, mental health), as less demands are placed on patients accessing emergency services once health concerns have arisen. Within this service modification, the report also recommends redefining healthcare from an individual/diseased-focused, reactive, and curative approach, to instead focusing on preventative strategies, as well as the wider and holistic contexts encompassing the individual patient.

MAPIT

The Welsh Assembly Government has recommended that a programme of 'MAPIT' (Early Support Multiagency Planning and Improvement Tool, 2010) be introduced in order to create a series of person-centred and care co-ordination principles that should underpin the service that an early-years child with a disability receives, such as: use of a key worker for co-ordinated, and holistic appointments, in order to maintain continuity through different interactions with, and transitions of, disability support, and that children and families are in control over their support needs and access.

In Summary

The literature research supports and reinforces the findings of our own consultations and evaluations with parents, children/young people and professionals working at Serennu. The key recurrent themes are those that Next Step seeks to address; social, emotional, education and communication development for all involved in the care, treatment, therapy and support of a child with disabilities or developmental difficulties.

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