



The Sparkle Appeal

Care Coordination:

Evidencing the need to provide coherent and coordinated services for families who have children with disabilities and/or developmental difficulties

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7/18/2017

Contents Page

Executive Summary	Page 3
Introduction.....	Page 5
Approach.....	Page 9
Conclusion.....	Page 17
Recommendations.....	Page 18
Diagram: Multiple services, multiple professionals.....	Page 19
Diagram: An example journey for a family without care coordination.....	Page 21
Diagram: An example journey for a family with care coordination.....	Page 22
Appendices.....	Page 23

Executive Summary

An effective care coordination service has for some time been identified as a priority area for development by parents of children with additional needs at Serennu. The reason for this is clear; many parents who have children with a disability or developmental difficulty report a consistent set of difficulties, difficulties not related to the disability itself, but rather to the challenges that come with having involvement from multiple agencies, multiple contacts, and the lack of coordination between them (Appendix 6, 8 & 9). This can be as many as 20 professionals in a year, meaning multiple appointments and multiple reports for the family.

For some families, significant emotional and practical support and assistance with coordination of services is required. They might have extremely complex issues, a number of professionals supporting them and require a more tailored package of support that is based on their individual needs as a family (Appendix 8 & 9). A Care Coordination service will facilitate a multi-disciplinary team approach which will result in the production of a single plan based on their assessed needs. The aim of the service is to empower families to successfully coordinate the care of their child by providing timely intervention in a positive and coherent way.

This report is based on research conducted at both a local and national level. A literature review has been undertaken and the legislative and policy frameworks within Wales have also been examined. The report highlights the need to provide appropriate support to families of children with additional needs and recommends a new model of service delivery be adopted that will provide service efficiencies and ensure cost avoidance. Implementing the proposed Care Coordination/ISCAN model to support families with high levels of need will utilise professional's time more efficiently, reduce waiting lists and reduce costs associated with missed appointments and avoidable hospital admissions.

This report proposes 3 options for consideration:

- **Option 1 (Recommended)**
Gwent-wide ISCAN – cost £336,365 (for full model see Appendix 4)

- **Option 2**
Serennu Care Coordination - cost £105,843 (for full model see Appendix 5)

- **Option 3**
Do Nothing Option – cost £ Un-affordable

We cannot afford to do nothing. In the absence of a suitable care coordination service (Appendix 10) the support needed by families with high levels of un-met need is either; a) not being received by families, which leads to many families reaching crisis point and feeling unable to cope, or b) being sought at a later stage from the professionals working with their child. Both options are costly; costly to family's health and wellbeing (Appendix 13 & 14), and costly to the health board and local authorities. For every family that is prevented from reaching crisis point and requiring statutory intervention, the local authority could save an estimated £100,000 per year on out-of-county foster care placements, and as much as

£250,000 per year per child for the most complex cases requiring a residential placement. In Newport alone, there are currently 30 out-of-county foster placements, which is an estimated annual cost of £3,000,000. This figure doesn't include the additional 256 local authority foster placements currently in Newport.

Professionals are carrying out additional care coordination duties at Serennu, averaging 11% of their time spent going 'over and above' their core role (Appendix 1). If these duties were carried out by a Care Coordinator, considerable time and cost savings could be made; professionals would have more time to see new families, reducing waiting lists and improving morale. As a quick example, by making the recommended efficiencies, a team of six full-time experienced Band 6 Occupational Therapists could see a cost saving of £4,508.46 per year, plus 11% of their time back. For four Band 9 Consultant Paediatricians this saving could be as much as £31,347.76 per year (see Appendix 2). Care Coordination would reduce the likelihood of families missing their appointments, which could amount to an estimated cost saving of up to £100,000 per year across therapy services in Gwent, based on the data at Serennu last year alone (Appendix 3). This figure doesn't include the numerous other appointments that children are required to attend, or other professionals outside of the therapy services, such as Paediatricians, which would see further considerable cost savings.

The recommended model will aim to see the following changes:

- **Short-term** – families with the greatest need receive support early, feel more empowered & have better clinical outcomes
- **Medium term** – improved service efficiencies and reduced cost
- **Long-term** - reduced waiting lists, improved professional morale, empowered families & improved professional/family relationships

It is widely acknowledged that families with children with disabilities and/or developmental difficulties perceive services to be complex and difficult to navigate, making access to services extremely difficult. This is having a detrimental effect on the relationship between parents and professionals (Appendix 6). Already faced with health and social disadvantage (Appendix 18) it would appear that the complexity of the health and social care system may actually be exacerbating these families' already disadvantaged position (Appendix 6). By not implementing these changes and continuing to operate services in this way, ABUHB and the local authorities will continue to waste resources and not uphold their mandatory responsibility; to provide integrated, coherent and coordinated services that meet the individual needs of children with disabilities and their families in Gwent (Appendix 7).

Introduction

This report proposes a new model of care coordination across Gwent. It is based on the work of Nikki Chard, Care Coordination Development Officer, employed by Sparkle over the 12 month period June 2016-2017. As a parent of a 7-year old son with Autism, Nikki has a keen interest in re-designing and developing services so that they enable and empower families who have children with additional needs.

The term 'care coordination' for the purposes of this report, refers to the provision of a service that engages a Care Coordinator to work with a family who have a child with a disability and/or a developmental difficulty, and who require an additional amount of support to help them meet their care coordination needs. This support may involve, but is not exclusive to, the following: providing the family with a single-point-of-contact, identifying unmet needs of the whole family and signposting to services and provisions that meet those needs, coordinating the services involved with the child, improving communication between the family and professionals and developing a single plan.

Background to the Serennu Children's Centre

The Serennu Children's Centre provides integrated care, treatment and leisure activities to children and young people with disabilities and/or developmental difficulties from Newport, South Monmouthshire and South Torfaen. It was identified that children who have a disability and/or a developmental difficulty and their families have needs that require interventions from many different services, such as social services, health, education and the third sector and, therefore, one of the primary benefits of the centre is that families can access the treatment, care, information and support they need under one roof.

Sparkle is the official main charity of the Serennu Children's Centre and each year has to raise more than £500,000 to fund the suite of vital, enhanced services that they currently offer. Sparkle proactively obtain the views and opinions of the children, young people and families who access the centre by undertaking evaluations throughout the year, gathering feedback and looking at ways to improve and develop service provision at the Centre.

Background to the Care Coordination Forum

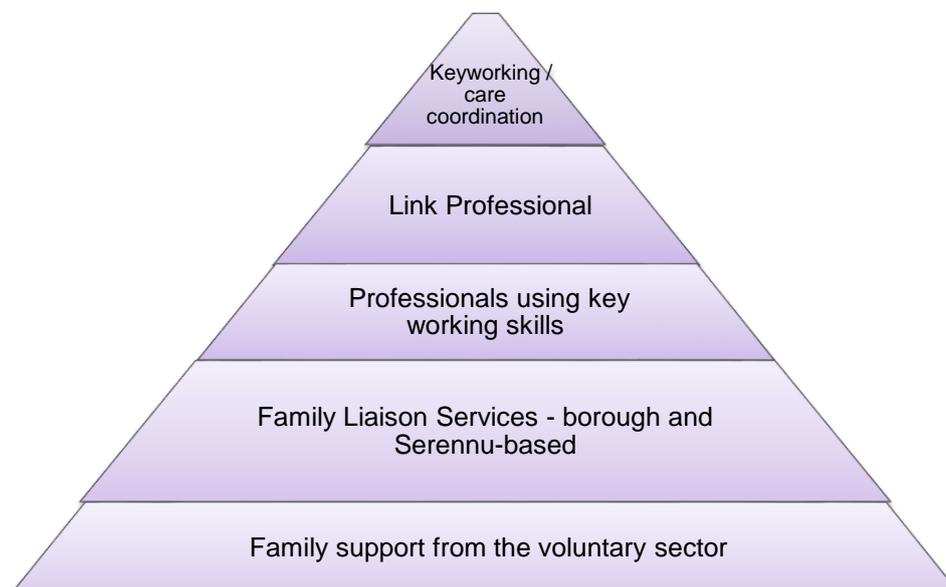
The Care Coordination Forum was set up following service-user consultation and a request from families for a forum that would bring parents and professionals together to have their voice heard and to develop a mutual understanding of each other's situation.

The Care Coordination Forum is held quarterly at the centre and is an open forum for parents and professionals from health, education, social services and the third sector to come together and discuss ways of improving care coordination. From its very first meeting, the priority for parents and professionals was the requirement for a care coordination service which would simplify the system, offer co-ordination of appointments and result in the development of a single plan for children with disabilities and/or developmental difficulties and their families.

The forum has been used to consult with parents and professionals throughout the development of the care coordination service model, ensuring that the views and opinions of its service-users is gathered and used to shape the design and implementation of the agreed model. The forum has also been used as a reference group for Welsh Government in respect of the Additional Learning Needs Bill.

The Family Support Model

Integral to an overall strategy aimed at changing the culture within which we work such that families and professionals work more in partnership and with mutual respect, the 'Supporting Children and Families is Everyone's Business' document was created (see Appendix 17). Developed by the professionals and parents who are members of the Serennu care coordination forum, it is part of a family support model (below):



The Forum also developed a Children's Centre Charter. The 14 statements contained within the charter are intended to create a framework that enables families and professionals to work together in harmony, where the needs of children are central. The role of the 'link professionals' places an onus on professionals to support as much as is reasonable and practicable within their core roles, however, it is accepted that where this extends beyond 'reasonable' this requires the support of a dedicated professional.

The charter is mapped against the Early Support Multiagency Planning and Improvement Tool (MAPIT) and aligns extremely well, strengthening our understanding of how families and professionals can best work in partnership for the benefit of children and young people. The MAPIT provides 10 principles that guide and underpin service delivery for children and families and within the tool, a series of Early Support in Action statements are identified and presented as standards against which service provision and service improvement can be considered and evidenced.

In response to families requesting and prioritising the need for a care coordination service, Sparkle generated the funding to support a development officer role, to look at what model of care coordination would be required to achieve a high quality care coordination service for families of children with a disability and/or developmental difficulty accessing the centre. Key areas of work for the development officer role include:

- **Collaborative working** with parents and professionals to gain a thorough understanding of the challenges they have with care coordination and identifying their needs.
- **Scoping** the provision of care coordination services on a local and national scale.
- **Researching** service models that support families who have children with disabilities and/or developmental difficulties.
- **Proposing** a suitable service model, in collaboration with parents and professionals which meets their needs.
- **Piloting** and assessing the proposed service model and measuring positive outcomes.

Sparkle were passionate about developing this role as their aspiration is, for services to children with disabilities and/or development difficulties and their families, to be integrated, efficient and equitable. Funded by the Big Lottery through a grant achieved by Sparkle, the aim of this pump-prime is to scope, develop and implement a fit-for-purpose service model, endorsed and funded by health and social care and developed across Gwent.

Recent developments in service re-design

Integrated Services for Children with Additional Needs (ISCAN) in Caerphilly has successfully provided a managed referral process for children with two or more developmental needs for a number of years. This provided a single point of access for referrals to the multi-disciplinary child development team.

Based on its success, the Health Board secured funding to enable the ISCAN model to be implemented and further developed in the other two children's centres, known as ISCAN North and ISCAN South. ISCAN North based at Nevill Hall Children's Centre receives referrals for Blaenau Gwent, North Monmouthshire and North Torfaen. ISCAN South based at Serennu Children's Centre receives referrals for Newport, South Monmouthshire and South Torfaen. ISCAN West, based at Caerphilly Children's Centre, continues to receive referrals for Caerphilly.

There is therefore a single, equitable, accessible first point of access for all referrals for children with two or more developmental needs and/or ASD/ADHD across Gwent.

In consideration of Phase II of the development of the ISCAN service, which will look to the co-ordination of appointments and assessments, the care coordination model is an intrinsic element of the service, going forward.

Approach

In the 12 month period, June 2016-2017 the Care Coordination Development Officer at Serennu Children's Centre undertook a multi-modal research project, which involved research at a local and national level, evidence-based academic research, and research into the legislative and policy frameworks in Wales.

Findings of research conducted at Serennu

Parents, carers and professionals at Serennu were asked to consider their views about the 'gap' in services and needs of the children and families at the centre in relation to care coordination. Research methods included focus groups (for full details see Appendix 8 & 9), an online questionnaire, and interviews. The following is a summary of the key themes identified from the analysis of the three sources of data.

Focus Groups

The results of the focus groups identified many overlapping themes in relation to care coordination. The key themes were organised into categories, to clearly distinguish the three super-ordinate themes, which are '**information**', '**coordination**' and '**needs-based services**'.

- **Information**

Information was a main theme identified with care coordination. Parents and professionals identified that having access to information and education can be a key facilitator to care coordination, as it empowers families by increasing their understanding, knowledge and confidence in their child's disability and care needs. By being provided clear and timely information or being signposting to other services that meet their social and emotional needs, families can often require less support from professionals because they have more exposure to other forms of support such as; peer-to-peer support, social groups, training, workshops and leisure activities.

- **Coordination**

Coordination is viewed as a key facilitator to care coordination, as coordinated services are perceived to be simpler, more user-friendly and likely to reduce anxiety and stress levels in parents of children with additional needs. Many parents and professionals perceive the health and social care system to be complex and difficult for families to navigate without support. Children with disabilities and developmental difficulties can require a number of services from the health board and local authority, which have different systems, processes, and referral pathways, and which parents and professionals generally report a lack of communication between both parties. This can be confusing and overwhelming for families at a particularly difficult and emotional time, increasing parental levels of anxiety and stress, which can affect their emotional wellbeing and lead to social isolation.

- **Needs-based services**

Services that are based on individual need, rather than expecting families who have children with additional needs to fit into the current services available, are perceived as facilitators to care coordination. Services that do not meet the needs of families are perceived as barriers, as they often result in families not being able to access the appropriate support as a result of unmet social and emotional needs. Children with disabilities are diverse; they can experience a range of challenges, have physical and behavioural difficulties that are unpredictable, change rapidly, and have significant impact on the daily lives of the whole family. Parents report that they often need to access services quickly; however this is often not the case and many families endure long waiting lists and barriers to accessing the support they require. This can lead to increased parental stress and anxiety and the likelihood of families requiring a higher level of intervention further down the line. Parents and professionals perceive that services should be holistic in their approach to supporting children with disabilities and their families, and identified 'early support' as a key facilitator to care coordination, as it empowers and enables families to better manage their situation at an early stage.

Questionnaire

The results of the questionnaire show that professionals and families see the key facilitators of care coordination at Serennu to be:

- the co-location of services under one roof,
- understanding the family's needs,
- offering suitable services/information/signposting that meets their needs.

Interviews

The results of the interviews suggest that professionals and families see a care coordination service as offering:

- A needed service for families who require help with coordinating the care for their child/understanding information/accessing other services
- A Single-point-of-contact/key person who understands the whole family
- Early practical and emotional support
- Improved communication between families, professionals and across services
- Simpler processes would be less stressful for families
- Improved confidence of family/empowering

Summary of data collected at Serennu

The over-riding theme from the analysis of the 3 sources of data suggests that families and professionals at Serennu perceive that effective care coordination is achieved when services are coherent, coordinated and based on the family's individual needs. The barriers for families with children with disabilities are when unmet needs arise as a result of services not being coordinated, especially when there are lots of services involved which only serves to increase the need for improved coordination. This can significantly affect parental distress and social and emotional wellbeing. The result of this leads to families becoming increasingly frustrated with services, affecting the long-term relationship that they have with professionals. Parents and professionals perceive that a Care Coordinator would be able to see the 'whole picture', which individual services can often fail to see. An understanding of the full set of challenges faced by a family will decrease the likelihood of unnecessary costs associated with missed appointments or hospital admissions (Appendix 13). In the last financial year over £33,000 was wasted on missed appointments with four therapy services alone at Serennu (Appendix 3).

At Serennu, many of the families report that they do not meet the current entry criteria for care coordination, (Appendix 10), therefore families frequently seek this support from a

professional already working with their child. This can lead to that professional going over and above their core role to support that family, especially if the family have a substantial amount of un-met need. These duties mainly involve liaising between the family and the services involved to create a more coherent and coordinated support for the family and they tend to be 'reactive' responding to things that have gone wrong (for a more detailed list of examples see Appendix 1). Consequently, for some professionals, their resources are diverted away from delivering their specialist service (and reducing waiting lists) to spending an inordinate amount of time, very often, providing low level support, signposting and coordination of services to families (Appendix 14).

Survey

To quantify the amount of time that professionals at Serennu spend going over and above their core role to support families with high levels of need for care coordination, professionals across health were asked to complete a short survey between the dates of 19th – 21st June 2017. The intention being to provide a snap-shot of how much **extra** time is currently being spent over what is expected within a health professional's core role, essentially, work which could be undertaken by a Care Coordinator.

The survey was sent out to all professionals across Health at Serennu via email. The results of the survey show that across health, all professionals feel that they provide care coordination activity that goes over and above their core role. The results also indicate that the need for care coordination is greater for professionals that tend to have early contact with families, such as Portage and Helping Hands, further evidencing the need that care coordination support will have the most impact if offered at the earliest point.

Overall, across health the average amount of time spent by professionals going over and above their core role to support families on care coordination activity is **11%**.

Research conducted at a local and national level

In order to assist in developing a care coordination service at Serennu, a UK-wide search was conducted to identify 'flagship' organisations with excellent models of care coordination; models whereby a designated Key Worker provides holistic support to families with children with a disability and/or developmental difficulty and who need significant support coordinating the services involved. The intention was that flagship models would

assist with providing a platform for comparison; help to identify 'gaps' in the way that professionals at Serennu currently support families to coordinate care for their children, and provide an effective framework by which to learn from and adapt services and support offered to meet the needs of families attending the centre.

There are 3 care coordination services in Gwent; Newport, Torfaen and Monmouthshire, all located within the local authority (Appendix 10). Each service has different access criteria, provides different services, different levels of support and has different waiting times. To obtain a better understanding of the situation of families in Gwent and the different services available to them, further research was conducted on Local Area Need (Appendix 18).

The research showed that Gwent features high on the Welsh Indices of Deprivation (2014) with many wards across the whole area experiencing higher rates of unemployment and higher incidences of single parent families compared to the Wales averages (Appendix 18). This suggests that many families attending Serennu are likely to be experiencing low-income, deprivation, debt and poor housing, particularly those from lone-parent and ethnic minority households, and they are more likely therefore to need assistance coordinating services involved with their child.

No further care coordination service models were identified in the rest of Wales when the research element of this project was being carried out. However as this project gathered interest and momentum towards its latter end, a few more local authorities were presented as beginning to look at providing services for children with disabilities and their families in a more integrated way.

Outside of Wales, across the rest of the UK, there were only 2 local authorities identified at the time as having 'flag-ship' service models that provide a holistic support to families with children with additional needs. Located in Lincolnshire and Cornwall, both models aim to improve the delivery of services for disabled children, young people and their families by supporting families with a Key Worker; a single-point-of-contact who enables the co-ordination of activity between services, providing continuity of care through collaborative working, information sharing and signposting.

Lincolnshire County Council's 'Early Support Care Coordination' (ESCO) is a way of working that helps to identify children's needs early and respond in a way that ensures the child and their family feel more in control. ESCO is underpinned by principles that include enabling children and their families to make informed choices and participate in shaping and developing the services that they use, valuing the uniqueness of children, young people and their families and ensuring service delivery is holistic, co-ordinated and seamless. ESCO

engages community-based professionals, i.e. a Health Visitor, Nurse or SENCo within the child's school, to take over the responsibility of the care coordination plan for the child and family. This enables ESCO to efficiently discharge the family in a 'step-down' approach, which effectively empowers the family by providing continuity of a single plan, and also keeps the service fluid so it can support new families who have been referred for support (Appendix 12)

Cornwall Council's 'Supporting Change in Partnership' (SCiP) provides early intervention for families and a proportionate way of providing support, thereby reducing the need for families to enter statutory social services. The service listens and responds to the voice of the parents, who had consistently said that the best way to receive information was directly from other parents, and therefore utilises Early Support Workers and trained Parent Volunteers to provide this support. The SCiP service is a preventative, time-limited approach that sets out to improve outcomes for children with disabilities and their families by responding quickly to the family's needs. It is solution focused, fosters new skills in families and celebrates success (Appendix 12).

The services are effective because they:

- Provide a dedicated Key Worker/single-point-of-contact for the family
- Work in partnership with families and other agencies
- Empower families by involving them in decision-making & identify their needs
- Provide early emotional and practical support
- Prevent families from reaching crisis point

Both ESCO and SCiP service models are now fully integrated services within their local authorities. Cornwall Council's SCiP model was originally born out of a commissioned pilot scheme which was so successful at supporting families and preventing them from needing crisis intervention, that Cornwall Council prioritised this service and decommissioned other services within their budgetary control to ensure the sustainability of this very successful service.

Evidence-based academic research

In considering academic-based research in this field it became quite notable that this is fairly scarce; there is a lack of research on childhood disability, in terms of any active evaluation of services of support or in providing any conclusive evidence that measures outcomes for children with disabilities and their families. Research from over 40 years ago provides a

consistent message to those provided today; that further research into childhood disability is needed to enable the development of services that will be successful in supporting families with children who have disabilities (Appendix 6).

There is, however, a consistent message evident in most research papers considered in this report; parents of children with disabilities consistently report the same set of difficulties, difficulties not related to the disability itself, but rather to the challenges that come with having involvement from multiple agencies and multiple contacts, and “*the lack of coordination between different agencies*”, for some families this can be as many as 20 medical visits a year (Mukherjee et al, 2006, pg 4).

Research shows that successful models of service support for parents with children with disabilities all have the same following attributes:

“They take a holistic approach to assessing and meeting family needs; the importance of relationship building between parents and professionals is recognised; they provide a consistent, single point of contact for the family; they have a flexible individualised, needs-led approach; they focus on parents’ own concerns and recognise the importance of understanding parents’ own expertise with regard to their child and family is recognised and acknowledged.” (Appendix 6)

Legislative and Political Frameworks in Wales

In line with the recommendations from the academic research, it is worthy of pointing out that under the Social Services and Wellbeing (Wales) Act 2015, there is a mandatory responsibility placed on the health board and the local authorities to work together in partnership to ensure that children, young people, parents, carers and their families receive coherent, coordinated support, which helps them achieve positive outcomes.

Currently services for children with additional needs in Gwent do not meet these requirements as they are not enabling families to achieve positive clinical outcomes:

- They are not coherent - families consistently report not understanding the information they are given, the complex terminology used, or the processes on how to access services that meet their needs.

- They are not coordinated – without a main-point-of-contact for families, individual services often fail to see the ‘whole family’ or tailor services based on their individual needs.
- Services across Gwent are unequal for families to access – they have different access criteria, different support available, and are only available in certain areas of Gwent.

Together the health board and local authorities are required to drive services that promote the child and families’ independence by giving them a stronger voice and more control in deciding which services they need. Services need to be innovative and make the most of resources available by working in a more joined-up way, avoiding unnecessary duplication of work, or re-inventing the wheel (Appendix 7).

Conclusion

There is a general lack of conclusive evidence out there that provides us with real outcome measures based on active evaluation of services that support children with disabilities/and or developmental difficulties and their families. There is no consistent method of accurately recording the number of children with a disability, largely due to the almost impossible task of obtaining one true representation of what the term 'disability' means to over 952,741 children who have a disability and their families in the UK.

Every family is unique and will perceive their child's difficulties differently to another family's, influenced by their own individual set of circumstances and resources available to them. With that in mind, we need to listen to the messages that parents have been telling us for years and develop holistic services that are tailored to meet the individual needs of the child and family.

This is no different for the families living in Gwent, many of whom are from households with very low incomes and very limited opportunities, who are coming to terms with having a child with a life-altering condition. Already dealing with the challenges that this condition may bring to their everyday lives, families then have the added burden of trying to piece together the multiple agencies and multiple contacts from Health, Social Care and Education that are part-and-parcel of having a child with significant needs. This is often the straw that breaks the camel's back. This is preventable.

The Health Board and local authorities in Gwent can prevent this happening by adopting a new service across Gwent that supports families with children with disabilities by providing them with a single contact, a single plan and a coordinated service. This will go a long way in improving families' experience with having a child with a disability in Gwent. Providing them with the right tools from the start will give families more control and more confidence to manage their child's care in the future.

Recommendations

This report proposes 3 options for consideration, detailed below, recommending that

Option 1: Gwent-wide ISCAN be adopted, located within the current ISCAN service model.

Option 1: Gwent-wide ISCAN (recommended) – cost £336,365

The Care Coordinator identifies families via ISCAN, the earliest point-of-entry; providing support for families identified as requiring significant emotional and practical support and assistance with coordination of services. They will provide an individualised package of support and facilitate a multi-disciplinary team approach which will result in the production of a single plan based on their assessed needs. The Early Support Coordinator provides a low-level of support for families who have been identified as requiring emotional and practical support and assistance with coordination of services. (Appendix 4).

Option 2: Serennu Care Coordination - cost £105,843

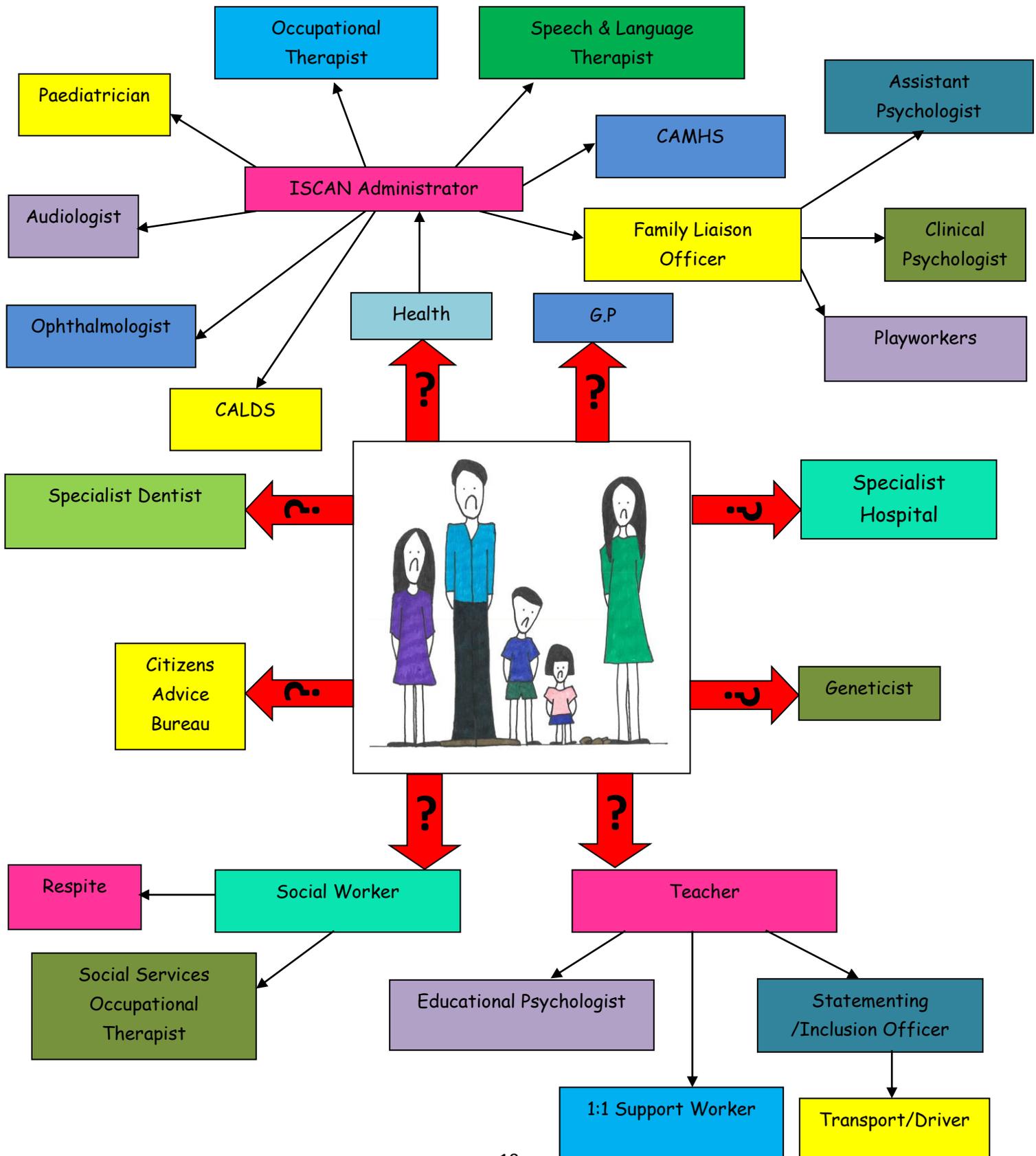
In line with the above model described in Option 1, the Care Coordinator and Early Support Worker support the ISCAN South only service at the Serennu Centre. This is not the recommended model of delivery as it would not result in optimal cost savings and service efficiencies across ABUHB, and for families across Gwent access to services would continue to be inequitable (Appendix 5).

Option 3: Do Nothing Option – £ un-affordable

The Do Nothing option may appear to cost nothing but is in-fact the *most* un-affordable option. The support needed by families with high levels of un-met need at Serennu is either; a) not being received by families, which often leads to them reaching crisis point and feeling unable to cope, or b) being sought after from the professionals working with their child. Both options are costly; costly to family's health and wellbeing, and significantly costly to ABUHB and the local authorities in Gwent.

The recommended service model will embrace the uniqueness of families with children with disabilities and/or developmental difficulties and provide them with a holistic service that meets their individual needs. In the short-term it will see families with the greatest need receiving support early, helping them feel more empowered & having better clinical outcomes. In the medium term it will see improved service efficiencies and reduced cost across both the health board and local authorities in Gwent, and in the long-term it will see reduced waiting lists, improved professional morale, empowered families & improved professional/family relationships.

A child with a disability and their family can have contact with more than 20 professionals in a year.....



For the family this can mean multiple appointments and multiple reports.....



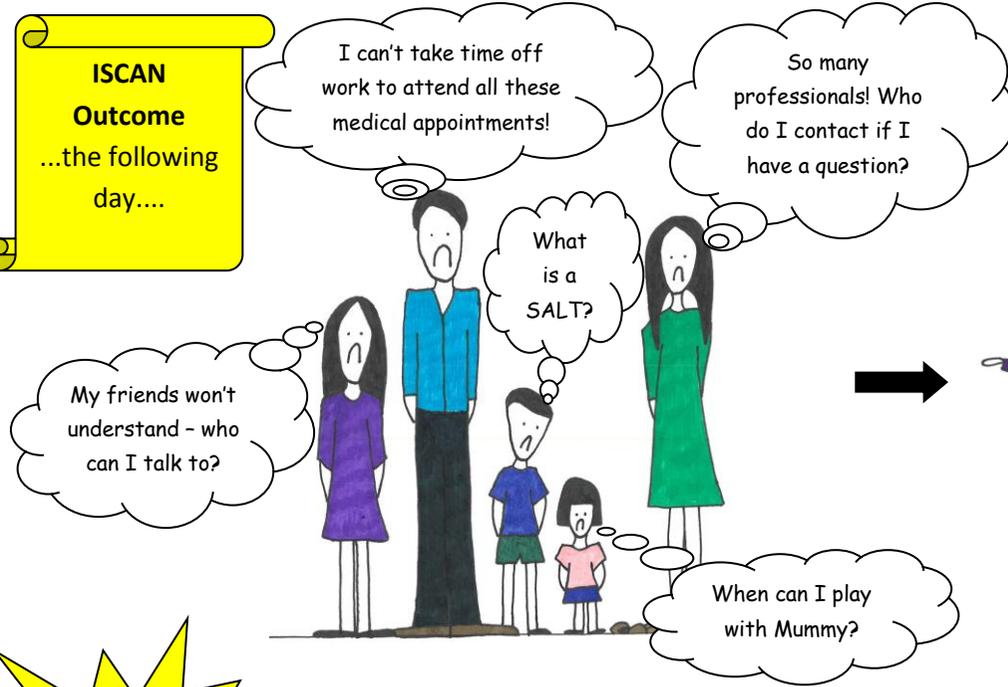
These families will have extremely complex issues, a number of professionals supporting them and require a Care Coordinator to provide them with an individualised package of support for the whole family.

The Care Coordinator will facilitate a multi-disciplinary team approach which will result in the production of a single plan based on their assessed needs.

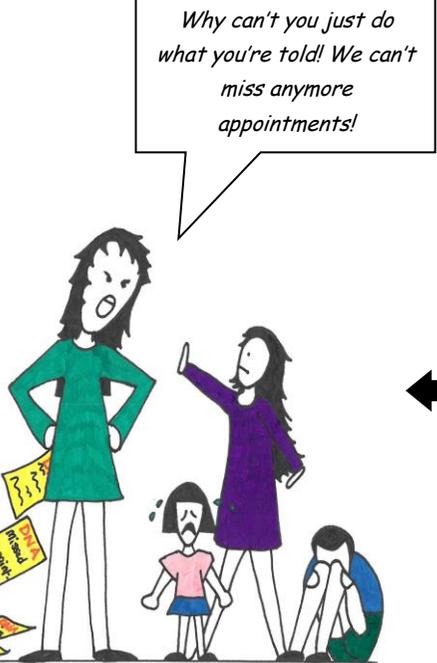
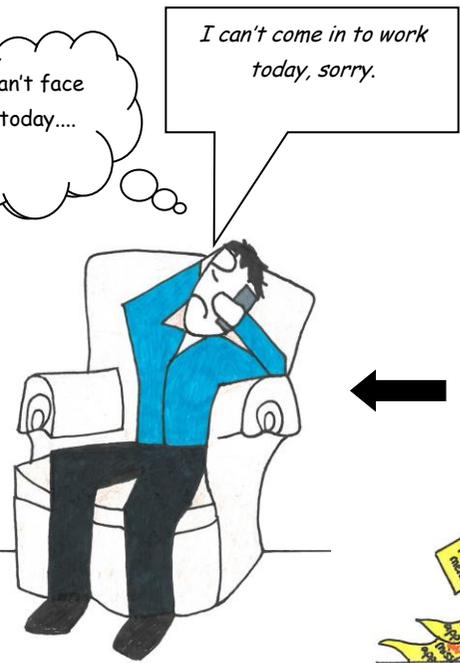
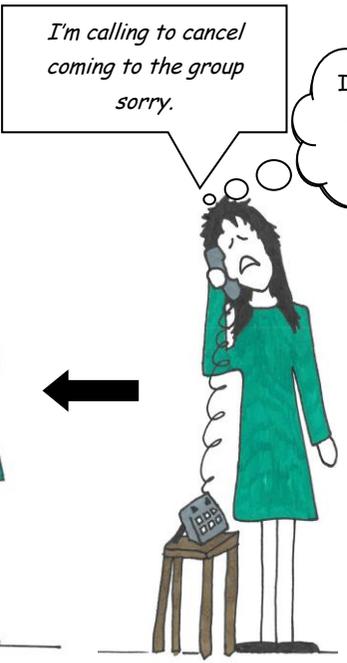
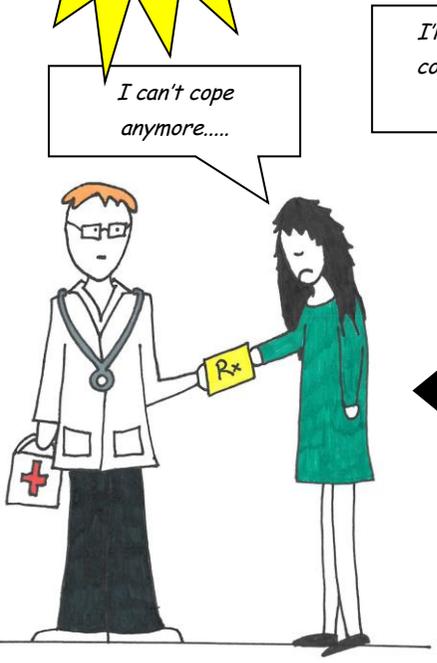
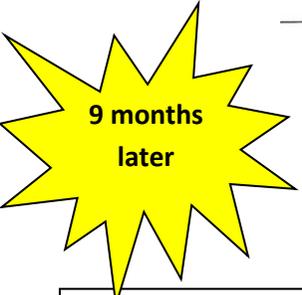
The service aims to empower families to successfully coordinate the care of their child by providing timely intervention in a positive and coherent way.



ISCAN Outcome
...the following day....



An example journey of a family without care coordination



ISCAN Outcome
...the following day....

My friends won't understand - who can I talk to?

I can't get time off work to attend all these medical appointments!

So many professionals! Who do I contact if I have a question?

What is a SALT

When can I play with Mummy?

Hi, I'm your Care Coordinator

I will provide holistic & individualised support, making your involvement with services streamlined & simpler

6 months later

Our Care Coordinator pulled all our services together & now we have a single plan to follow!

Bye!

.....with Care Coordination

All these services have different waiting lists and different goals for my child. It's so confusing.

So many medical reports! I feel like my whole life is about my disability...

Legs
Diabetic
Audiob reports
Optic
O.T reports
SALT
Paeds
Physio Report

Things are so much simpler now. Thank you Care Coordinator!

6 months later

I'm a single mum with 8 appointments a week. I wish I could have joint appointments.....no wonder I miss so many!

I can help this become more manageable, so you won't miss appointments in the future

Appendices

Appendix 1: Evidencing the Need for Care Coordination at Serennu.....	pg 24
Appendix 2: A snap-shot of cost savings by utilizing a Care Coordinator.....	pg 27
Appendix 3: Therapy information regarding the number of appointments that were reported DNA or CNA at Serennu for the financial year 2016/2017.....	pg 28
Appendix 4: Option 1- Gwent-wide ISCAN Model.....	pg 29
Appendix 5: Option 2 – Serennu Model	pg 30
Appendix 6: Literature Review.....	pg 31
Appendix 7: Legislation & Policy in Wales.....	pg 35
Appendix 8: Thematic Analysis of focus groups with parents of Serennu.....	pg 38
Appendix 9: Thematic Analysis of focus groups with professionals of Serennu...	pg 61
Appendix 10: Current Care Coordination at Serennu.....	pg 89
Appendix 11: Other services that support families with children with additional needs across Gwent.....	pg 91
Appendix 12: Care Coordination Models in the UK.....	pg 93
Appendix 13: Parent Case Study 1.....	pg 98
Appendix 14: Parent Case Study 2.....	pg 105
Appendix 15: Professional Case Study 1.....	pg 109
Appendix 16: Professional Case Study 2.....	pg 111
Appendix 17: Supporting Children and Families is Everyone’s Business.....	pg 113
Appendix 18: Local Area Need.....	pg 125
Appendix 19: References and Bibliography.....	pg 127

Appendix 1

Report - Evidencing the need for Care Coordination at Serennu 26th June 2017

In progressing with work on establishing a Care Coordination service at Serennu and looking to establish a level of need, professionals across health were asked to complete a short survey between the dates of 19th – 21st June 2017. The intention being to provide a snapshot of how much **extra** time is currently being spent going over and above what is expected within a health professional's core role, work that could be done by a Care Coordinator.

The results of the survey will be used to quantify the amount of work that is reasonably expected to be carried out by a professional working with a family, in order to quantify the amount of extra time being spent on care coordination activity.

The survey was sent out to all Team Leads across all departments based at Serennu via email, who were required to distribute to their individual team members. It was also sent via email to all Paediatricians' and professionals not based at Serennu but who provide a service that links to families at Serennu, such as CAMHS and CALDS.

Overall 39 professionals completed the questionnaire.

Professionals were asked to complete the 3 sections below, considering the list of examples of care coordination activity suggested by professionals at Serennu, activity that they have felt has required them to go over and above assisting a family:

Profession _____

How many hours do you work per week?: _____

How many hours per week would you estimate you spend on activity working with families which goes over and above what is expected within your core role?: _____

List of examples

- Chasing referrals for the family, inside and outside the trust.
- Chasing equipment for the family; wheelchairs, swings, hoists, etc.
- Assisting families with school placements.
- Liaising with professionals involved with a family, on behalf of the family.
- Fielding and redirecting calls from families not knowing who to contact.
- Finding services that meet families other health needs, e.g. specialist dentists.
- Looking up the family's upcoming appointments, e.g. Paediatrician.
- Gathering information for the family on sport & leisure activities specific to the child's difficulties.
- Signposting families to information and activities that meet the needs of the whole family.
- Dealing with issues with translation for families where English is their 2nd language.

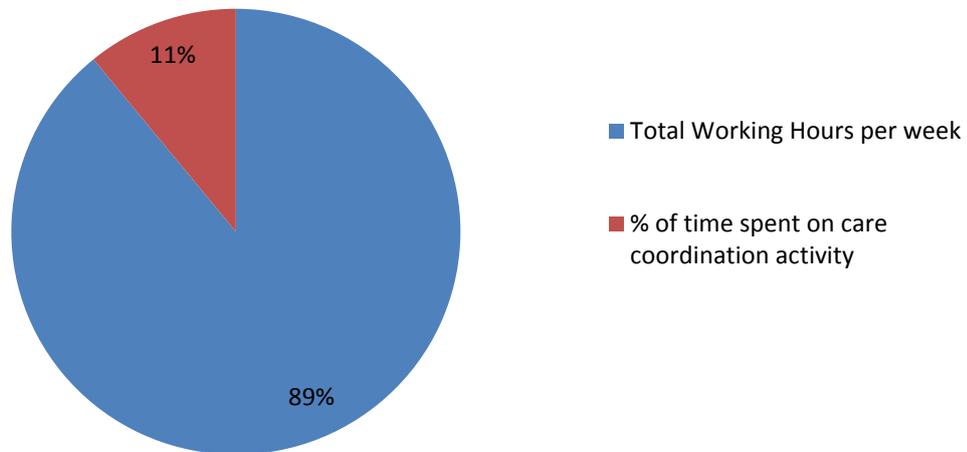
- Transport issues for children who find it difficult to get to sport and leisure activities.
- Helping families apply for a Statement/DLA - completing paperwork for those families with language difficulties.
- Children who have been transferred from another trust who do not know what is available within the area – signposting.
- Attending appointments with families to provide advocacy support, when parents feel their voice is not being listened to.
- Calming down frustrated family members.
- Explaining health and social care services and processes to families who do not understand.
- Chasing professionals on behalf of parents (for parents who feel professionals have more credibility with other professionals (added clout gets more done).
- Being a sounding-board for parents who are frustrated with other services.

The results of the survey show that across health all professionals feel that they do provide care coordination activity that goes over and above their core role. This does vary considerably across departments, as shown in the breakdown below:

Profession	% time spent on care coordination activity
Child Development Advisors (Portage)	40
Clinical Psychologist/Assistant	13
Occupational Therapists	13
Paediatricians	10
Nurses	10
Physiotherapists	8
Speech & Language Therapists	6
Dietetics	3
Orthotics	2
Audiologists	1

The results also indicate that the need for care coordination is greater for professionals that tend to have early contact with families, such as Portage and Helping Hands, further evidencing the need that care coordination support will have the most impact if offered earliest point. Overall, across health the average amount of time spent by professionals going over and above their core role to support families on care coordination activity is **11%**.

Average percentage of time spent by professionals across health at Serennu, going over and above their core role



Conclusion

The results of the survey show that a considerable amount of health professional's time (11%) is currently being spent on care coordination activity, that they perceive as going over and above their core role, work that could be done by a Care Coordinator. By employing a Care Coordinator to carry out the same duties would enable considerable cost avoidance and improve service efficiency, make available 11% of health professional's time to see new families, which would reduce waiting lists, reduce time pressure placed upon professionals and improve overall morale.

Appendix 2

A snap-shot of cost saving by utilizing a Care Coordinator

Band 5 - Care Coordinator

Working hours week	Max Annual Salary	11% of salary
37.5	£28,746	£3,162.06

Band 6 – Occupational Therapist

Working hours week per O.T	Max Annual Salary per O.T	11% of salary	Cost saving using a Care Coordinator per O.T	Cost saving per team of 6
37.5	£35,577	£3,913.47	£751.41	£4,508.46

Band 9 – Consultant Pediatrician

Working hours week	Max Annual Salary per Pediatrician	11% of salary	Cost saving using a Care Coordinator per Pediatrician	Cost saving for 4 Pediatricians
37.5	£100,000	£11,000	£7,837.94	£31,351.76

Appendix 3

Therapy information regarding the number of appointments that were reported DNA or CNA at Serennu for the financial year 2016/2017

Service Name	Attendance Status	New	Follow Up	Grand Total
Physiotherapy	CNA	76	652	728
	DNA	53	193	246
Grand Total		129	845	974

Service Name	Attendance Status	New	Follow Up	Grand Total
SLT	CNA	19	102	121
	DNA	18	108	126
Grand Total		37	210	247

Service Name	Attendance Status	New	Follow Up	Grand Total
OT	CNA	10	65	75
	DNA	3	31	34
Grand Total		13	96	109

Service Name	Attendance Status	New	Follow Up	Grand Total
Dietetics	CNA	21	57	78
	DNA	17	30	47
Grand Total		38	87	125

Total missed appointments = 1,455

An average appointment is 60 minutes and the cost for an experienced Band 6 OT or Physio for an hour is £22.75 gross cost

Appendix 4

Option 1

GWENT WIDE ISCAN

Overview: An effective care co-ordination service has for some time been identified as a priority area for development by parents of children with additional needs. Care co-ordination is inextricably linked with developing services for children with additional needs and building on the learning from the ICF funded Integrated Assessment & Planning (IAP) Pilot, it is recommended that this service is located within the ISCAN service model. By amalgamating both services, this would also create service efficiencies and allow for more effective operational management arrangements.

Requirements: It is suggested that an appropriate model of delivery would include the additional staff below at a cost of **£336,365**

ISCAN Team lead (including care coordination) - Full Time Band 7 - £52,396 (inc. on-costs)

Operational leadership and supervision of the ISCAN, Care Coordination and Family Liaison teams across the 3 sectors.

3 x Care Coordinators - Band 5 - £92,805 (inc. on-costs)

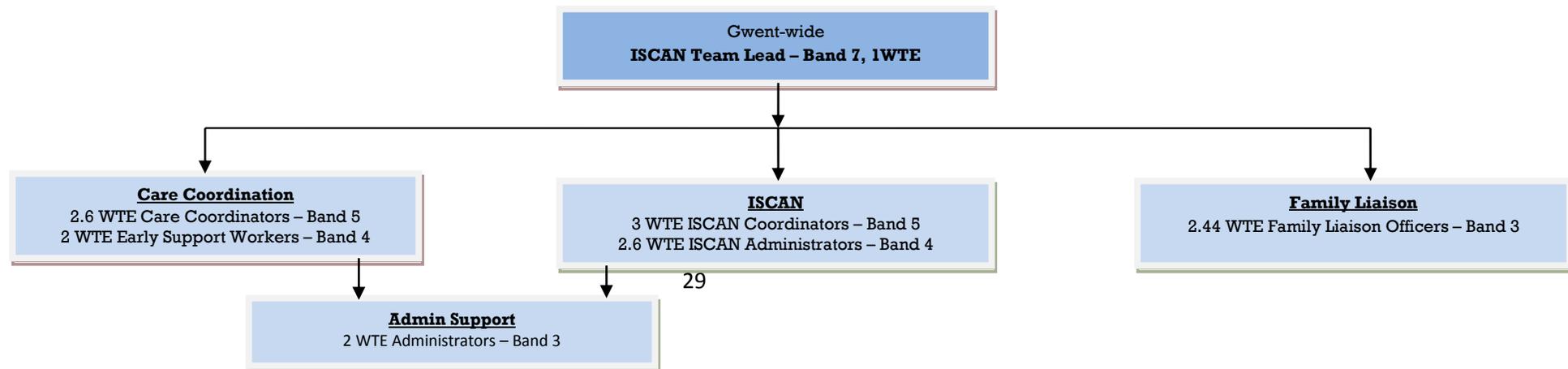
The Care Coordinator identifies families via ISCAN, the earliest point-of-entry; providing support for families who have been identified as requiring significant emotional and practical support and assistance with coordination of services. These families will have extremely complex issues, a number of professionals supporting them and require a Care Coordinator to provide them with an individualised package of support for the whole family. The Care Coordinator will facilitate a multi-disciplinary team approach which will result in the production of a single plan based on their assessed needs. The service aims to empower families to successfully coordinate the care of their child by providing timely intervention in a positive and coherent way.

3 x Early Support Coordinators - Band 4 - £55,854 (inc. on-costs)

The Early Support Coordinator identifies families via ISCAN, the earliest point-of-entry; providing a low-level of support for families who have been identified as requiring emotional and practical support and assistance with coordination of services. These families will be less complex, requiring short term intervention support, signposting and assistance with managing their child's care.

Plus

1 x ISCAN Coordinator (West) - Band 5 - £35,695; 1 x Family Liaison Officer (West) – Band 3 - £19,053; 2 x Administrators - Band 3 - £47,632 (inc. on-costs); Travel – estimated annual costs £22,410; Equipment – 11 x PC's £10,520



Appendix 5

Option 2

SERENNU

Overview: An effective care co-ordination service has for some time been identified as a priority area for development by parents of children with additional needs.

Requirements: It is suggested that an appropriate model of delivery would include the additional staff below at a cost of **£105,843**

Care Coordination Team Lead – P/T Band 7 - £25,848 (incl. on-costs)

Operational leadership and supervision of the Care Coordination team at Serennu.

1 x Care Coordinator – Band 5 - £35,695 (incl. on-costs)

The Care Coordinator identifies families via ISCAN South, the earliest point-of-entry; providing support for families who have been identified as requiring significant emotional and practical support and assistance with coordination of services. These families will have extremely complex issues, a number of professionals supporting them and require a Care Coordinator to provide them with an individualised package of support for the whole family. The Care Coordinator will facilitate a multi-disciplinary team approach which will result in the production of a single plan based on their assessed needs. The service aims to empower families to successfully coordinate the care of their child by providing timely intervention in a positive and coherent way.

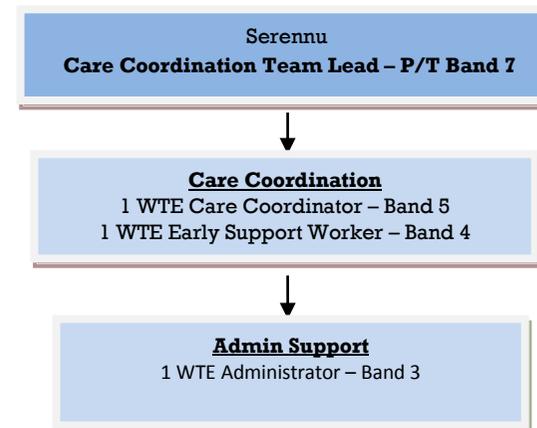
1 x Early Support Coordinator - Band 4 - £22,342 (inc. on-costs)

The Early Support Coordinator identifies families via ISCAN, the earliest point-of-entry; providing a low-level of support for families who have been identified as requiring emotional and practical support and assistance with coordination of services. These families will be less complex, requiring short term intervention support, signposting and assistance with managing their child's care.

Plus

1 x Administrator - Band 3 - £11,908 (inc. on-costs);

Travel – estimated annual costs £7,290; Equipment – 3 x PC's £2,760



Appendix 6

A Literature Review

The UK average population of children with a disability is 7%. Nationally this amounts to 952,741 children (Blackburn, Spencer & Read, 2010). It is estimated that a third of children with a disability (35%) experience two to four difficulties in daily living and 13% experience five or more areas of difficulty in daily living. Therefore it is estimated that almost half of the population of children with a disability or developmental difficulty will have involvement with more than one professional at the same time (Blackburn, Spencer & Read, 2010)

The national average figures have been calculated from data collected in the Family Resource Survey (FRS), which is based on the Disability Discrimination Act's definition of disability. The report found no consistent method of accurately recording the number of children with a disability in the UK. The difficulty of obtaining a true representation of children with a disability is explained by the notion that a definition or an understanding of a term, such as 'disability', will be inevitably shaped by the range of responses by the people participating in the research:

"The willingness of parents to identify their children as disabled, for example, may vary according to whether the definition used reflects their own definition of disability generally, their perception of any difficulties their child may experience and the implications as they understand them, of defining their child as 'disabled'. (Blackburn, Spencer & Read, 2010, pg 2)

The FRS showed that families who have children with a disability lived in different personal situations from non-disabled children and their families, and were more likely to live with deprivation, poor housing, low income and debt. This was particularly the case from minority groups and single-parent families. Rates of divorce and separation are substantially higher in parents who have a child with a disability than those that do not. The FRS reports that there has been little change since the OPCS disability survey conducted in the 1980s highlighting the poverty and poor living standards of children with disabilities and their families in Britain.

Sloper's research on models of service support for parents of disabled children suggests that an individual's perception of something differs from another individual's perception of the same thing; shaped by the range of external factors that person has been exposed to. Her research highlights that parents who have children with a disability actively interpret, respond to and deal with a stressful situation differently from each other, and that it cannot therefore

be presumed that a parent of a child with a disability perceives the child's disability as the source of stress:

"Problems of the child's behaviour or sleeping problems are more likely to be appraised as stressful, than severity of disability." (Sloper, 1999, pg 88)

Furthermore, she suggests that the way in which an individual appraises their situation is varied and that this variation is not explained by severity of disability but by the resources available to them, which include material, physical, psychological and social factors. In order to support parents who have a child with a disability; services need to understand the resources available to individual families:

"Inadequate income is a source of anxiety in itself and also prevents parents from accessing other resources.....,Mothers of disabled children are less likely to be in employment than their peers, yet research shows that employment provides both material and social resources and is associated with lower levels of distress." (Sloper, 1999, pg 89)

According to Sloper *"there appears to have been little change over the years in parents' reports of unmet need"* (Sloper, 1999, pg 85), her research spanning 25 years prior and looking more recently at models of parental stress and coping. She suggests there are many factors linked with high levels of parental stress, including inadequate housing, transport and unmet needs for support from services:

"Many mothers would like to work outside the home but are prevented from doing so by the lack of provision of services to cater for the child's needs during working hours, and the inflexibility of service systems such as hospital appointments and school transport". (Sloper, 1999, pg 89)

Sloper's findings suggest that good service models of support all have a number of similar characteristics:

"They take a holistic approach to assessing and meeting family needs; the importance of relationship building between parents and professionals is recognised; they provide a consistent, single point of contact for the family; they have a flexible individualised, needs-led approach; they focus on parents' own concerns and recognise the importance of understanding parents' own expertise with regard to their child and family is recognised and acknowledged." (Sloper, 1999, pg 95)

The 'Disability Matters in Britain 2016' report reinforces the consistent message in academic research; that not much has changed in more recent years in terms of parents of disabled children reporting unmet needs associated with the challenges they have with services:

"We also received heartbreaking testimony from parent carers who are tired of struggling, who feel alone and abandoned by society, and who see their disabled children, young people and adults excluded from the community, discriminated against by successive cuts in government funding and denied access to services that are meant to help them." (Disability Matters in Britain, pg 6)

The responses provide a clear picture today of the *"relentless challenges"* that parents and carers currently report; held back by cuts to services that they rely on to achieve their *"basic rights and have their needs met."* (Disability Matters in Britain 2016, pg 4). The report suggests that the current approach, which leaves many parents and carers feeling worn out, hopeless and abandoned, is not good enough and states that *"if those in positions of power were measured by the same standards as parents, they would stand accused of neglect and of causing avoidable harm."* (Disability Matters in Britain, pg 4).

The recommendations provided by this research are that in order to support families who have children with disabilities, services need to consider the wider range of needs that families may have:

"a shift in thinking is needed, away from the traditional, medicalised, individual mindset, to the human rights approach, which pays equal attention to environments and attitudes, as well as health conditions."

(Disability Matters in Britain 2016, pg 5)

A recent publication from the government '**Helping Parents to Parent**', 2017 also supports a more holistic approach towards parenting interventions, suggesting that, although there is a lack of evidence on what works, parenting interventions can be successful, particularly those that focus on parenting styles, the creation of a supportive home learning environment, relationships within the family and parental stress and mental health.

Summary

Research spanning over four decades suggests that there is a lack of research out there on childhood disability in terms of active evaluation providing conclusive evidence that measures outcomes for children with disabilities and their families. With that in mind,

researchers recommend that when designing services that support parents with children with additional needs, we should take what we know about the messages that parents have been telling us for years and use examples of good practice to develop holistic services that support the child, the parents and the family as a whole. These should include the following:

- *A holistic approach to assessing and meeting family needs*
- *Build relationships between parents and professionals*
- *Provide a consistent, single point of contact for the family*
- *Be flexible and individualised*
- *Needs-led approach*
- *Focus on parents' own concerns*
- *Recognise the importance of understanding parents' own expertise with regard to their child*

(Sloper, 1999, pg 95)

Appendix 7

Legislative Framework in Wales

The two key legislative frameworks that underpin the development of the Care Coordination service are The Social Services and Wellbeing (Wales) Act 2014 and the Draft Additional Learning Needs and Education Tribunal (Wales) Bill. Under this legislation, there is a mandatory responsibility placed on the health board and the local authorities to work together in new statutory partnerships to ensure that children, young people, parents, carers and their families receive coherent, coordinated support, which helps them achieve positive outcomes. Together they are required to drive services that promote the child and families' independence by giving them a stronger voice and more control in deciding which services they need. Services need to be innovative and make the most of resources available by working in a more joined-up way, avoiding unnecessary duplication of work, or re-inventing the wheel.

Political Frameworks in Wales

The two key policy frameworks that underpin the development of the care coordination service are the National Service Framework (NSF) for Children, Young People and Maternity Services in Wales, and the principles of Prudent Healthcare.

The standards within the National Service Framework are based on the 'social model' of disability, which refers to the social factors which form barriers, deny opportunities and create disabling environments. The guidelines stipulate that a service designed to support families of children with disabilities should include at a **minimum** the following:

- Clear and accurate information to empower them to make informed choices, and to gain **access to help when they need it**.
- Practical support to assist them in caring for their child.
- Access to emotional support **when they need it**.
- Advice on how to maximise their child's development and offer of training, if needed.
- Access to affordable childcare and other services to enable parents to return to work, if they wish.
- Provision of short breaks and additional services to enable the family to participate in the same lifestyle that parents of non disabled children experience.
- Access to leisure.

Instead of children with disabilities being expected to fit in with the services that are available for them, as has been the case in the past, they deserve to have services that meet their individual needs. Services need to recognise that the needs of disabled children are often wide ranging and require services from health, social care, education and the voluntary sector, requiring collaborative working to ensure streamlined delivery of services.

The NSF recommends utilising a key working/ care coordination service, perceived by parents as a valuable way of supporting them, to *“facilitate the tailoring and co-ordinated delivery of services based on the child’s assessed needs by a named key worker for the child and family”*.

The other main policy framework in Wales that is worth consideration in this report is Prudent Healthcare, which was formulated by the Bevan Commission. Established in 2008, the Bevan Commission acts as an impartial and independent expert advisory group to the Minister for Health and Social Services. The priorities determined by the Minister and the challenges being addressed within the healthcare system in Wales has been reflected in the work of the Commission to date. The Commission has been key in supporting Ministers in their strategic thinking and policy development across a range of issues, particularly in the areas of financial stringencies and in supporting sustainable health in Wales, through adopting the prudent healthcare principles (Annual Report of the Bevan Commission 2015/2016).

The principles that underpin the concept of prudent healthcare are:

- Achieve health and well being with the public, patients and professionals as equal partners through co-production.
- Care for those with the greatest health need first, making most effective use of all skills and resources.
- Do only what is needed, no more, no less; and do no harm.
- Reduce inappropriate variation using evidence based practices consistently and transparently.

In the context of care coordination, best practice principles can be used to influence policy development in Wales, which advises that services should make the most effective use of available resources to ensure high quality and consistent care across Wales. This can be

achieved by 'co-production and equal partnership', 'providing proportionate support', 'reducing variation' and 'consistent and transparent use of evidence-based practices'.

Appendix 8

Thematic Analysis of Focus Groups with Parents at Serennu

Method – Focus Groups

A focus group method was used in this study in order to explore the challenges that arise when coordinating the care of a child who has a complex disability or developmental difficulty, from the view-point of both professionals working with and parents who have a child attending the Serennu Children's Centre. The focus groups were conducted with professionals separately from parents, to enable themes to be identified from their different view-points and then the data from each was transcribed and analyzed. This report analyses the themes arising from discussion with parents.

The focus groups ran for three separate sessions, with the main body of parents remaining the same. The first session was based around discussion of the main issues that parents identify with coordinating care for a child who has a complex disability or developmental difficulty and to distinguish the outcomes that they wish to achieve by having better care coordination services. The second session focused on identifying current barriers in service provision and ways in which a new service model might help overcome these. The final session considered two different models of care coordination being used in organizations in England, as shown in Appendix 12 and 13, that have been developed to help families access more coordinated care. It was hoped that the case studies presented to them would encourage parents to reflect on support and services that they need and discuss more specifically the type of services needed for families at the Serennu Centre, which could be proposed in a new model in the future.

Participants

Participants were recruited via an opportunistic sampling method. During the period June – July 2016 notifications were sent out via letter, email and posters around the Centre, asking parents to participate in a number of focus groups to be run at the Centre between September and December 2016. Multiple email reminders were sent out at regular intervals to all parents on the Family Liaison Officer's mailing list, encouraging them to come forward, and letters were sent home with the school children attending Maes Ebbw Special School and Crownbridge Special School, as well as notices being advertised on the school's websites.

Those parents who were first to respond and able to attend at the time specified were included in the group until the quota was filled. Following this, parents who responded up to the date of the focus group were included, based on the assumption that a number of parents were likely to not be able to attend on the day due to caring commitments of their child.

The focus group was arranged for a time when parents would most likely be able to attend, during term-time, after the morning school-run and before the afternoon school-run. Lunch was offered as an incentive. Where possible the occupying of children or siblings of pre-school age was offered if a member of staff was available on the day, to enable as many parents to attend the session as possible. Transport was not offered to parents who do not drive, as this service is only offered by the Centre for medical appointments only. Eleven members opted in to the focus groups: all white female from a range of ages and professional backgrounds. A mixture of both 'carers' and 'parents' but for the purposes of this analysis they will all be referred to as 'parents'. Two parents were from the Monmouthshire area and nine parents from the Newport area.

The parents were asked to rate on a scale how they would describe their child's disability, from complex/severe to moderate to mild; 1 parent viewed their child as having a severe/complex physical disability with severe/complex developmental difficulties, seven parents viewed their children to have severe/complex developmental difficulties with a mild physical disability, 2 parents viewed their children as having moderate developmental difficulties and 2 parents viewed their children as having mild developmental difficulties.

Procedure

All participants were given a brief to read and a consent form, shown in Appendix 4 and Appendix 5 respectively. If they agreed, these were signed by both the participant and researcher. Issues of confidentiality and anonymity were re-iterated after consent and briefing forms had been read and signed, to remind participants that it was essential to respect and preserve the confidentiality of the other participants. Participants were requested to provide a pseudonym of their choice, for purposes of transcribing, or the researcher would assign one for them. The nature of the focus group i.e. that the researcher would provide a stimulus for discussion and then ask prompt questions, was stated clearly, and the participants were given an opportunity to ask questions. Participants were informed that they could leave the discussion at any time if they needed to.

Each focus group lasted approximately 2 hours and the researcher followed a topic guide, as shown in Appendix 6. The discussion was recorded on audiotape as the participants had consented. At the end of the focus group participants were asked whether they had any further questions. The discussion was transcribed and analyzed for occurring themes.

Preliminary Research

In order to identify the main themes arising from parents with regards to care coordination, 24 parents attending the Centre, representing 25 children or young people with a disability or developmental difficulty, were approached and asked a series of informal questions that encouraged a brief discussion about their experiences with care coordination in the past. The majority of parents that were asked had not received care coordination in the past and did not know that this service may have been available. The majority of parents felt that there is a need for this service now and that this would have been accepted by them and

been useful to them in the past and now, should it be offered. The themes identified from these preliminary informal interviews were used as a basis for the focus group discussions.

It is important to note that the families interviewed and participating in the focus groups are all currently accessing the Serennu Centre and although they are asked to reflect on experiences in the past and around diagnosis stage, they are still using the services of the Health Board and Social Care and are talking about their experiences in present day.

Critique

The focus group was arranged for a time when parents would most likely be able to attend, during term-time, after the morning school run and before the afternoon school-run. Lunch was offered as an incentive. Where possible the occupying of children or siblings of pre-school age was offered if a member of staff was available on the day, to enable as many parents to attend the session as possible, however transport was not offered to parents who do not drive, as this service is only offered by the Centre for medical appointments only.

Conclusion

The focus group discussions proved an effective method of identifying the main challenges that parents and professionals have with care coordination for children with complex disabilities and developmental difficulties and their families. It proved to be a suitable environment for subjects in a similar situation to talk openly and honestly and identify ways that care coordination can be developed in the future.

Thematic Analysis – Parents Focus Group

Introduction

In order to look at developing care coordination for families who have children with complex disabilities or developmental delays, it is imperative that we look at what parents view as 'good' and 'bad' care coordination and the effects that it had on their family at that time.

From studying parent discussions, it became clear that analyzing families experiences with care coordination was not going to be a simple task because all children's disabilities are different and pose different challenges for each family, dependent on any number of external factors that individual families are exposed to. For example, the family support they have available, the professional they are assigned, the postcode they live in and the access to other services they have.

During discussions with parents, stories were told, experiences were shared and a great deal of data was collected. The findings of the focus groups identified many overlapping themes in relation to care coordination. The themes were organised into categories, to

clearly distinguish the three super-ordinate themes, which are 'information', 'coordination' and 'needs-based services'.

Table to show main themes and sub-themes:

Information	Coordination	Needs-based service
• Signposting	• Single Pathway	• Availability of someone
• Inequality of provision	• Multi-agency	• Early Support
• Confidence	• Complex System	• Holistic
• Empowerment	• Confusing Terminology	• Waiting/ escalation of need
• Holistic	• Communication	• Value/Trust
	• Repetition	• Advocacy

Theme 1 – Information

The second theme identified by parents was about information, either being informed about what the professional is doing, informed by the professional about other services available (signposting) or being given information in written or verbal form. This example is about a professional informing the parent about what they had done and kept her updated on the progress that was being made. This had a really positive effect on the family as it reduced the amount of time the parent had to spend worrying about what was happening or chasing the professional. The results were impactful, as she says she was a 'life-saver'.

Lisa: Portage....the lady I had was fantastic and she went over and above what I think was her job remit... if she referred to another service or another department, she would straight away come back and did what she said she would do, she'd give you the information or say 'this might be of interest to you'..... She was brilliant! I feel that person, that wasn't her role to do that, somebody that can offer that, was a life-saver.

(Parent Transcript, Appendix 9, pg 4, line 121-125)

The parents aren't talking about a particular 'service' making a difference to them, they are talking about an individual. Parents shared many examples of good care coordination that they had experienced in the past, and a lot of examples were when an individual had provided information on other services that were of particular interest to that family. The professional had looked holistically at the family's needs and signposted them to things that might meet social and emotional needs:

Queenie: I found Portage very helpful as well. I find Jayne, the Liaison Officer Jayne; she's just got this knowledge of who to try, so I often start with Jayne. Try this or try that, or I'll try that for you. She's very helpful, very knowledgeable and very reliable.

(Parent Transcript, Appendix 9, pg 4, line 130-133)

Alfie: I think the Pediatrician...Dr Morgan... she did a lot of signposting here, we went away and we were quite knowledgeable about the information about Serennu, which was obviously a key to all the other information.

(Parent Transcript, Appendix 9, pg 5, line 154-158)

Krispy Yes I find Jayne very good. I also found Roxy from CANS, she's not here anymore, she was amazing... and then we had to find somebody, apart from Jayne and Sarah Brown that is as good as her because I do find Sarah Brown really good as well.

(Parent Transcript, Appendix 9, pg 4, line 134-135,
pg 5, line 149-151)

Lisa: I think to realize that you're not on your own because I was going to normal play and toddler sessions and everyone else's child was 'normal' and Olivia wasn't 'normal' if you want to use that word, you kind of, you come home or people would say the odd comment and you'd think "oh god, I'm going through this on my own, there's nobody else in the whole world. Just perhaps if that person can open up avenues that someone else is going through the same and just might like a cuppa, I know there is that, but at the time you can't see the wood through the trees and your whole life is just appointments and medical and your child and.....

(Parent Transcript, Appendix 9, pg 37, line 1285-1295)

Parents reported that if they understand how services ran and knew that they could refer back into services once discharged, then they wouldn't be so apprehensive about being discharged. They think if it is called 'open-access' rather than 'discharged' then they wouldn't feel so anxious about it.

Many parents discussed the anxieties that they had in the past with being 'discharged' from services and the fight that they had to re-enter at a later date. This again highlights the importance that parents place on 'early support', as they feel that having the right information and guidance given to them from the start could and help families have a good experience from the beginning. They suggest that if parents don't experience anxiety about being discharged from the beginning, by understanding how the service works, then they are less likely to become anxious about being discharged from services in the future:

Solar: if you actually say to someone from day one it is an 'open-access' service, your fears are taken away immediately. So you think 'right, well I'll take what help I get now because I know it is open-access and I just have to make a phone-call and get support when I need it.
(Parent Transcript, Appendix 11, pg 10, line 432-436)

Parents suggest that it would be really useful to have information provided to them from the start that they can take away and digest later if necessary. Parents don't really know why they aren't being provided this information by professionals if they have it, as they think it would really help them understand more and feel less anxious:

Solar: the Pediatrician should be handing out, you know the Sparkle hand-outs with all the information in, as part of that consultation they have their chat and whether they've been given a diagnosis or not they say 'if you'd like to take this away, there's lots of information for you if you want to read it and there's lots of people you can contact, like Jayne, because that's how you're getting them 'at the start'.
(Parent Transcript, Appendix 11, pg 27, line 1115-1121)

From the discussions it was clear that many parents are in the dark at the beginning and searching for the answers. They are likely to be going into their first appointment with preconceived ideas and leave feeling negative, which then contributes to them feeling negative about the service:

Queenie: Because it is scary, the first appointment. Isn't it?

All: Yes.

Solar: And you feel that they're going to have *all* the answers and that the only path that you're going to follow is what the Pediatrician is going to tell you but actually that is the *smallest*..... isn't it?
(Parent Transcript, Appendix 11, pg 40, line 1635-1639)

Parents discussed that in the early days they didn't know what they were doing or what their children needed, therefore the help and support needs to come from the professionals at the start until the parents feel confident and knowledgeable to do it themselves:

Solar: For me...for Global Developmental Delay...I had no idea what he really needed. Now, 12 years on, absolutely. I know what perhaps he should have had or what he didn't really need, or what he needs now.
(Parent Transcript, Appendix 11, pg 12, line 505-507)

Queenie: ...and that professional, say it's a Pediatrician, you don't have the time in that appointment to talk about 'other things' so how are you going to find out the things that you want help with? Or that you could have help with but you thought you just had to suffer in silence because you didn't know that that help was there.
(Parent Transcript, Appendix 11, pg 27, 1104-1109)

Parents feel that they have to have all the answers and must be well prepared to ask all the right questions, or they feel they will miss out on vital support, which increases the amount of pressure that parents are under.

Parents recognized themselves that being provided information and being informed on things can be meaningless if the parent is not coping with emotionally:

Queenie: so I didn't want to do a particular course that they were running. I'd got enough going on in my head, dealing with her, and I didn't want to do that as well.
(Parent Transcript, Appendix 9, pg 10, line 353-355)

Queenie: but you don't think objectively when you're upset.
(Parent Transcript, Appendix 9, pg 37, line 1291)

Parents identified many other barriers to parents understanding the information that was being given to them, such as Anxiety, Stress, Motivation, Learning Difficulties, Poverty, Bereavement, Religion/Culture, etc, etc, etc, which parents believe is why services need to be more holistic in their approach to get an understanding of what the family is going through and signpost to other services that meet those needs.

Theme 2 - Coordination

The third main theme that was identified in the focus groups was about 'Coordination' and the challenges that parents have navigating and understanding what they see as a very complicated system, with lots of different professionals and functions. Parents shared positive experiences of coordinated services:

Solar: Yes I had a Care Coordinator, back when Thomas was much younger and she was really good. She was a 'Key' person and helped me co-ordinate all the services and the care that Thomas needed. Anything from respite through to an appointment, so she was one person who used to come out to me and discuss things. Yes, so that was very positive.

(Parent Transcript, Appendix 9, pg 4, line 109-114)

Nutbar: Sarah Brown from Helping Hands pulled together an MDT (Multi-disciplinary Team Meeting) for us and I didn't really know if that was her role to do that but things were so desperate that she got everybody together in the board room upstairs.... so that was a really positive thing, to have everybody in one room.

(Parent Transcript, Appendix 9, pg 6, line 187-197)

Sue: I have - with CHIC - the Children's Hearing Impairment....I never know what the other 'C' stands for. I have one appointment and I see his Audiologist, the person who comes into school and his Consultant. That's every year and that's really good.

(Parent Transcript, Appendix 9, pg 4, line 105-108)

Further examples given show that parents perceive effective care coordination as organisation's offering appointments that are based on need; tailored around their child's specific disability or developmental difficulties, as they perceive this to cause the least amount of disruption for their child and themselves:

Nutbar: I'm just thinking that works so well when you can go to your child's school and see that person there and your child is brought out of the classroom for five or ten minutes, there's no disruption to their routine, especially if they're on the spectrum, that not having to bring them here before a school day or something like that, works really well.

(Parent Transcript, Appendix 10, pg 13, line 490-494)

Sue: And if your child has different disabilities that are not related to one another in any way shape or

form because he has got hearing loss, sight loss and he's ASD...they won't have one meeting for all of that because it wouldn't work from their point of view, so you are chasing up appointments.

(Parent Transcript, Appendix 9, pg 15, line 534-538)

Parents feel that services need to be coordinated so that all the different professionals and services are able to see the whole picture and tailor their services more to the individual families needs, rather than trying to fit lots of different children and their families into one service:

Sun: Sometimes in the beginning I didn't have the confidence to say "actually you don't suit my daughter". I think if someone could actually say "I know a professional that would really suit your daughter" not forcing my one-year old to fit an adult, maybe making the adult fit my daughter.

(Parent Transcript, Appendix 9, pg 16, line 559-568)

Parents perceive that their children need to meet the criteria for services, rather than services meeting the needs of their family:

Nutbar: I only just found something out recently talking to the Head of the Disabled Children's Team, that there was this Care Coordinator and we had a discussion around it being for predominantly the children with physical or medical care needs and actually I think there can be a bit of a prejudice to look at children with physical needs as 'oh that must be awful, all the support needs to go there' but when you've got a child who is mobile but has challenging behavior, learning disability, self-injury, you know CAMHS stuff going on, that can be in the home *incredibly* destructive to relationships, to the home, to lots of things, and I had a discussion with them about why is the support not here for these families as well as the children who needs medical things taken care of. He said it just predominantly always been for children with physical care needs, and so that kind of, to me, stemmed from Pediatricians predominantly caring for the *physical* child rather than the emotional, psychological wellbeing of that child and their family.

(Parent Transcript, Appendix 10, pg 17, line 643-657)

Not all children present their symptoms at the same time, which parents feel would lead to lots of children slipping through the net for services based on medical need alone:

Sue: So would you be able to refer yourself in? For example, Jon's lack of hearing wasn't picked up until school, so that was a one-off thing, and then six months later his lack of sight in his one eye was picked up....but the Autism wasn't picked up until he was five, so therefore we had this big gap....we didn't have two or more professionals at the same time really that we needed help with, so we would have slipped through the net.
(Parent Transcript, Appendix 10, pg 27, line 1017-1022)

Parents think professionals look at the medical model of disability and do not consider the social and emotional needs of the whole family:

Sun: I had one person who treated her heart and would treat her 'like she's a heart' and I had audiology here that were very annoyed that they had to treat her 'like a child' and not a pair of ears and then...I literally like had loads of professionals who wanted to treat her heart or her ears or her eyes and a bit of that and a bit of that. No-one actually, apart from Portage, wanted to treat her like a 'person'.
(Parent Transcript, Appendix 9, pg 12, line 435-440)

Parents feel that services need to be coordinated to make the whole system and processes easier to understand and less complex to navigate. Different processes for different services, different criteria, complex terminology are all perceived by parents as being barriers to having a simpler system to understand:

Sun: I have a health background as well and without that background I just don't know how I would have navigated through the first year of her life, I just don't know how I would have done it.
(Parent Transcript, Appendix 9, pg 8, line 261-263)

Parents feel that services need to be coordinated to aid communication between professionals and services. Lack of communication was a sub-theme identified and was mentioned in numerous ways through discussion with parents, as they feel that a lack of communication leads to a lack of trust in the system:

Moon: very often I'll go into an appointment and they're asking ME what the other professionals have done or what they're working on and it's like "you're working in the same building just ask each other"
(Parent Transcript, Appendix 9, pg 7, line 236-239)

Sun: I've come to a pediatric appointment here and she'd say "well they haven't sent me the report" and I'd feel like she was having a go at me about it and I would come out and feel like 'hang on a minute it's not my fault that they haven't sent you that report or it's not my fault that I had her in Cardiff, or that her heart operation happened in Bristol, I'm sorry that you can't communicate outside one Trust'
(Parent Transcript, Appendix 9, pg 8, 263-269)

Nutbar: I've had to relay everything and even when we were trying to get him diagnosed the Consultant said "I haven't had the reports through from Speech Therapy" so I said 'good job I have photocopied it and brought it with me then".
(Parent Transcript, Appendix 9, pg 7, line 249-252)

Lack of communication between professionals can also mean that parents are attending multiple appointments at the Centre, rather than professionals offering appointments that co-inside with other professionals. This leads to parents having to repeat their information over and over again, which is time consuming for the parent and again reinforces parent's frustrations with services:

Mandy: Yeah sometimes it can get on your nerves...I've had three appointments on one day at certain times and if you've got to explain yourself over and over, when you've got a child with lots of different complex needs, you feel like after ten or fifteen minutes you're still rolling things on, you're thinking "I've done this twice today already, I've had enough I want to go home".
(Parent Transcript, Appendix 10, pg 22, 857-862)

Parents feel that there is a lack of communication with parents themselves, especially when their child starts school, which can lead to a feeling of loss of control:

Mandy: OT's appointments didn't come to Serennu anymore, they got took over by school, so then I didn't get to see the OT's. Whatever was going on with Lucas in school I was on a back-burner never really knowing what was going on. It was like school's got their system, we've got a system that works for us and there was a massive lack of communication between the two.
(Parent Transcript, Appendix 10, pg 10, line 381-386)

Solar: For me, it was when Thomas went to school, and pre-school you know I went to all the appointments that I could with him and you had that home/therapy

relationship. Then you are sort of discharged because the OT's and the Physio's at school see Thomas but you don't always get that connection....

Twirl: Definitely.

Solar: ...that communication. And also I think that what they need to understand, as a parent, when you're told in those very early stages, and its full-on and you're running at a thousand-miles-an-hour trying to get everything in place, that's your life, so you're going to everything and then its school and then everything is handed over and you're out on a limb. You feel 'well how am I involved in this now?' I mean yes I've got good contact with the links but that's because I've sort of *ensured* that happened but, and I know I'm not the only parent I've spoken to lots, but they feel that when they go over to school you don't feel in control and they don't seem to understand it. It comes down to the way they have that conversation with you to explain how it's all going to be "well Thomas starts school and it's all going on in school, so whey-hey" but you don't feel like that do you? Because you don't get that contact.

(Parent Transcript, Appendix 9, 11, lines 385-403)

For parents with children with complex disabilities the lack of communication with them can have significant consequences.

Sun: I've come to a pediatric appointment here and she'd say "well they haven't sent me the report" and I'd feel like she was having a go at me about it and I would come out and feel like 'hang on a minute it's not my fault that they haven't sent you that report or it's not my fault that I had her in Cardiff, or that her heart operation happened in Bristol, I'm sorry that you can't communicate outside one Trust'

Queenie: There isn't the co-ordination between the counties even is there? We live in Newport now but we're still supported by Monmouthshire and there's a bit of that as well....they just don't click.

Nutbar: It's not even necessarily, if it's medical, within the same Trust though, we'd been to an appointment in Cardiff and they couldn't get his bloods that were done in Cardiff and should be on.... the whole

system is just....you end up being either very prepared or very frustrated.

(Parent Transcript, Appendix 9, pg 8, line 263- 278)

A sub-theme that was evident throughout the discussions with parents is the importance that parents place on feeling valued by professionals working with their child; they want to feel valued and given the time by professionals; feeling rushed and not given the time, can make them feel under-valued:

Mandy: In every department everything is challenged on a budget and I think everyone is push, push, push, to get you off their system because as long as you're on their system you're costing them money.

Nutbar: But we *feel* that, don't we? We feel that in a physical way, we feel that pressure....

Mandy: Yeah we feel like as if we don't count but we really need your help, we're begging and asking for help but because you're on such a tight budget your health is being denied.

Nutbar: And you're telling me I'm an '8' but actually I'm feeling like a '6' could become a '5' quite quickly, if one pillar is taken away and I'm going to become a '4' and I'm going to be ringing you...

Mandy: From day-by-day things can deteriorate so much.

(Parent Transcript, Appendix 10, pg 18, 699-702)

Mandy: given that bit more time you feel more confident and sometimes I think you can get a much better outcome and a more *realistic* outcome.

(Parent Transcript, Appendix 10, pg 18, 699-702)

Parents feel that services need to be coordinated because the lack of faith in the system has lead to many parents feeling like they have to care coordinate themselves, which they feel is counter-productive and actually takes time from their child and their family:

Nutbar: I would have so many appointments, so much admin to do, so many phone calls to make that I couldn't barely do any of the therapies that everybody was telling me about.

(Parent Transcript, Appendix 9, pg 14, line 489-491)

Solar:that communication. And also I think that what they need to understand, as a parent, when you're told in those very early stages, and its full-on and you're running at a thousand-miles-an-hour trying to get everything in place, that's your life...
(Parent Transcript, Appendix 9, pg 11, line 391-394)

Theme 3 – Needs-based service

One of the biggest challenges that parents identify with care coordination is having the right support when it is **needed**. Parents discussed the different stages that they need support, or needed support in the past, and recognize that families who have children with complex disabilities or developmental difficulties might need different support at different times; their need for support changes throughout their lives, therefore support needs to be available for them to access **when they need it**. For some parents this might be when their child is born, it might be pre-diagnosis, during diagnosis, post-diagnosis, after a spell in hospital, pre-school, transition to secondary school, developments in growth, developments in behavior, and so on. Parents feel that if the support is available at those trigger points, it could have a positive impact on families by reducing the likelihood of their needs escalating and reaching crisis point. So the term 'early support' refers to support being provided when the need is identified by the parent or professional.

Parents perceive 'early support' as a way of identifying families who have complex needs early on and who might benefit from being signposted accordingly. This suggests that parents view being signposted as an effective way of supporting families; by providing them with access to other services that meet their social and emotional needs:

Lisa: *Accessibility* because someone coming in can then be identified as a family that have complex needs and would then be signposted on accordingly.
(Parent Transcript, Appendix 11, pg 30, line 1197-1199)

Krispy: Even if they say 'you can go to this space' in the meantime and signposted.
(Parent Transcript, Appendix 11, pg 33, line 1351-1352)

Lisa: Yes, to feel that there is someone there.
(Parent Transcript, Appendix 11, pg 30, line 1203)

Emotional support for the parents and family was a main concern for parents and was a sub-theme running throughout focus group discussion. Parents talked a lot about the emotional impact that having a child with a disability or developmental difficulty can have on their life and their family's life. In order for the family to support the child they *themselves* need to be supported too they feel, or it can have implications on everything else:

Alfie: it is all about your child and everything but if you're not well and you're not catered for within it

then everything else can crumble away as well.
(Parent Transcript, Appendix 9, pg 22, line 793-795)

To these families, the child's disability can be all-consuming and take up a substantial part of their everyday lives but they identify that it is just one of a number of factors that make up their lives and very often there are a number of other things going on at the same time that they, as parents, have to attend to; other children, other family members, jobs, chores, etc. Parents talked about other emotional factors that can be happening at the same time, which can very often lead to an accumulation of emotional distress, leading to them needing support to help them with this:

Lisa: I had no support and Portage was months. It was literally like I didn't even get to grips with being a 'Mum' let alone having this child who was so poorly.....let alone other family issues; I'd just lost my Dad and my brother, my Mother-in-Law had just died and I had no support at all.....I was like 'oh my god, what do I do?'

(Parent Transcript, Appendix 11, pg 19, line 779-784)

Parents feel that services need to be more holistic and consider the family's emotional needs from the start, as they believe this will have a positive effect on with how they support their child and the rest of their family. Parents shared many stories about their own personal experiences where support hadn't been available for them at the time that they needed it, and the significant emotional impact that this had had on them:

Nutbar: I think there needs to be something as well *before* people start getting involved.....We lay back-to-back in bed, me and my husband, for seven months...(parent broke down crying) ...crying every night because our little boy had disappeared and nobody did anything. Just somebody to say "you could be trying this" or "you could be talking to this person" but because you're not 'in the system' you don't have access to all that is there, and I think pre-diagnosis, not having anything is horrendous.

(Parent Transcript, Appendix 9, pg 18, line 648)

The wait for services was a sub-theme that came out of the focus group discussions, especially for those families who are waiting for services to start. They shared how the waiting itself can contribute significantly to the accumulation of emotional distress and how if someone had offered some support or signposting early on, then it might have reduced them from reaching that level of distress. They feel that this had led to them having a negative view of services now because they have found out in-hindsight that there are services out there that could have been offered to them at the start:

Sun: I was offered 'care co-ordination' but just way too late because I had to wait on the waiting list for

Paeds. Everyone was like "OK so your child had Down's Syndrome, so you're going to need Speech, and this, and this, and this, and this"...fine...but then I said "I can't manage all of this" I had to say "this has to stop because she is physically unwell and I have to treat her being physically unwell first". I had the Cardiff appointments and the Bristol appointments first fixing her hearing and things but I said "no-one's treating her as an individual and I'm really struggling with it all and all the care co-ordination", so then finally a year later, it took us a year to see a Pediatrician, she said "ohhh do you want a Care Coordinator?" but by that point I had done all the phone calls and I had fought the battles already - it was a year too late. (Parent Transcript, Appendix 9, pg 20, line 724-738)

Another thing that parents feel can contribute to the accumulation of emotional distress is not being able to get hold of professionals easily or when they need to, which they find frustrating and contributory to their emotional needs escalating:

Twirl: There's nothing worse than just not being able to get an answer from someone.
(Parent Transcript, Appendix 11, pg 38, line 1549-1550)

Mandy: Yeah, quite often, I've tried going down the road of phoning but it's always voicemails and answer machines, or you can't get through, or "they're not at their desk at the minute" and do you know what, I haven't got time to be picking the phone up every two minutes to be hearing they're not there and try again in ten minutes....I don't have ten minutes...I've made the time now....to do it once is my way forward.
(Parent Transcript, Appendix 10, pg 14, line 544-549)

Nutbar: And during school hours because it is very difficult for me to take a phone call once Matty is home because he screams or he pulls me, and I'm trying to talk on the phone and very often people get back to you at 'quarter-to-four' when four kids are coming through the door, it's the busiest time, he's screaming and it's just like 'why are you ringing me now, you've had all day' but very often they've been in a meeting and they're doing their phone calls at the end of the day just before they go home.....but that kind availability within school hours...
(Parent Transcript, Appendix 10, pg 21, line 817-824)

Parents feel that having access to professionals *when they need it* actually reduces the anxiety that many parents feel when coordinating the care for their child. They felt in many situations that if they had had easy access to someone on the phone, then that would have reduced their anxieties and they would have felt supported. They felt in most cases that was all that they needed:

Nutbar: I think you *need* somebody to answer the phone, that is so important that you get hold of someone.

Lisa: It's reassuring to know where you are going through to and that there are people there that can help you....

Nutbar: And even if it says that there is one person in front of you in the queue, you think 'ahhh one, i'll wait'. You know even if it was just one person sitting on the phone that you knew you would get through to a human being....

(Parent Transcript, Appendix 10, pg 35, line 1323-1329)

Many of the parents, when sharing good examples of care coordination in the past and present, included having easy access to someone on the phone when they need it:

Nutbar: We've got really good links with school, especially if I want to phone them up and talk to the OT, I can phone up and talk to the OT anytime and if I wanted to see them they'd see me down at the school, so I think that can take away a lot of the anxieties around that, if you've got access to people.

(Parent Transcript, Appendix 10, pg 13, line 494-498)

Parents expressed their concerns that the reason why parents are not able to access early support is because they perceive services for children with disabilities to be over-stretched and only able to target families that have reached crisis point:

Nutbar: By the time you are literally saying "I'm not sure I can look after this child anymore without support" is the point they start to look at it and then it takes a year to get it addressed and put in place, by which time you are totally frazzled. You almost have to be at the point of saying "I'm not looking after this child anymore" before anybody really takes you seriously....because that's how stretched the service is. Unfortunately.

(Parent Transcript, Appendix 9, pg 33, line 1165-1171)

Parents strongly believe that if they had been given the support early, they would not have struggled so much emotionally and highlighted that they felt that if they had the right support

from the start it would have had a huge impact on their ability to be able to manage in the future:

Twirl: I think as well, if you can cope with it and have help earlier on, as you get more issues you're more equipped to deal with it because you've got that confidence in yourself.

(Parent Transcript, Appendix 11, pg 19, line 785-787)

Parents feel that easy access to support services is not only needed at the start but that where children with complex disabilities and developmental difficulties are concerned, easy access needs to be continual with the ability to re-access later on. This is because parent's needs change and the child with the disabilities needs change:

Twirl: I think the ability, if you actually say no to something, to be able to say a couple of months later "yes I do want that" because a lot of the time you have to fight to get *back* into the system they offered you, if that makes sense? Things are so overwhelming you can't always say yes when you need them - you need time to process it.

(Parent Transcript, Appendix 9, pg 21, line 754-764)

Mandy: As and when...week by week your needs could change.

(Parent Transcript, Appendix 10, pg 30, line 1154)

Nutbar: Plus children can change so rapidly so quickly, like my little boy over the summer holidays the one year became self-aggressive; he began to batter his head and scratch himself and all of a sudden you need a very different service, you need to be seeing CAMHS service, and you know what CAMHS waiting list is like! You know suddenly everyone is 'on pins' with this crazy child and you're like "ahhhhh" life has suddenly changed and I think children can change very quickly, you know, by the time you can see somebody about one particular behavior you're concerned about, that's stopped - that behavior - and a new behavior has begun and you're always on catch-up really.....if that thing has a dramatic impact on the family you can need help quite quickly really

(Parent Transcript, Appendix 9, pg 21, line 765-777)

Parents see the behaviors of children with complex disabilities and developmental difficulties as unpredictable and therefore extremely difficult to foresee and plan for. These unpredictable behaviors can have significant impact on many aspects of their lives and

parents feel that access to support when they need it would reduce the impact that it is having:

Mandy: My OT has said 'I'm always here for you' and things like that but when you've got a child that is not safe in a piece of equipment there's no alternative, no-one comes back to you saying "ok well try this in the meanwhile" that's not an option. It's literally "put them in this wheelchair, hold onto him and do not turn your back" so while you're trying to put your coat on...you've put him in the chair ready to go out, you want to put your coat on yourself and what have you, it don't happen, you've literally got to hold the chair for a continuous time.....we're going to school and I've got a wheelchair accessible car...you clamp him in the back of it, you're trying to reach and get the straps whilst holding onto the front of the pushchair so he doesn't launch back....that way the system is way too long between professionals.

(Parent Transcript, Appendix 10, pg 14, line 517-527)

Parents identified that professionals can find it difficult to see the 'whole' picture. They attribute this to professionals only seeing their child in small sections or 'episodes of care'. Parents on the other hand do see the 'whole' picture and believe that because they do, they should be recognized as being able to provide that insight:

Twirl: I think as well they're sometimes seeing a different child, if we've got this issue but they're not seeing it in school, unless we're there to say "no, this is what they're doing" they work on.....other things.

Moderator: So what are you saying? That different professionals are seeing different parts of the child to what you see at home?

Twirl: Yes, CAMHS will definitely tell you that Paul is a different child to what he is in school to what he is at home.

Krispy: Yes, Nimmie is a completely different child in school to what she is at home.

(Parent Transcript, Appendix 9, pg 12, line 406-414)

From discussions with them it is clear that parent's confidence in understanding what their child and family need develops over time. Parents feel that they should be listened to more and valued more by professionals and have more control over accessing support that they

feel would benefit them and their family. Parents unified in their response, feel that care coordination needs to be offered when identified that it is needed by *them*:

Moderator: When do you need Care Coordination then?

Sun: I needed it from the hospital - from birth is when I needed it.

Nutbar: When we need it.

Alfie: As soon as there's any indication there's something wrong, be it from birth or when that Health Visitor turns round and says "they're not quite hitting all those..."

Moderator: So as soon as identified by.....who?

Sue: Parents in my case.

All: Parents!
(Parent Transcript, Appendix 9, pg 21, line 739-747)

Summary

Families attending the Serennu Centre perceive that they face many barriers in coordinating the care of their child due to the inability to access support that meets their individual needs, including long waiting lists, un-achievable criteria, confusing terminology, poor communication and unequal access to services. Although there are many positive accounts of professionals who have gone above and beyond to assist parents, families consistently report that access to services, signposting, information and communication is unequal and inconsistent; dependent on where they live and the individual personality and attitude of the professional assigned to them. Not only are these barriers to achieving full participation in society and a good quality of life for their child with a disability, but they are also barriers in achieving social and emotional wellbeing for themselves and the other members of their family.

The knock-on effect has left families reaching breaking-point, in crisis, desperate, stressed out and feeling unable to cope, with many accounts of them feeling let-down, frustrated, angry and disappointed with services when they need them the most.

The summary of the three super-ordinate themes are as follows:

- **Information**

Parents perceive that by being provided with information that meets their needs, and is of interest to them, and being signposted to other services was a facilitator to care coordination.

Providing information is perceived as an effective method of reducing levels of anxiety and stress in parents, and having knowledge and understanding about how services operate and the processes to follow if they need to re-refer to a service, may change how parents perceive being discharged in the future. Parents seem to have an appetite for information and signposting, as they view this as key to accessing services and support that will meet the needs of themselves and their family as a whole. Parents who have not been provided with information or signposting report feeling frustrated and angry with services because they feel they might have missed out on things that could have been of benefit to them. Parents highlighted the importance of retaining control over their child's care and that being provided with information was a way for them to feel in control and more confident, rather than feeling like a burden and chasing the wrong professionals for the wrong information.

A holistic approach to signposting and providing information was highlighted by parents as key as they recognize if the parent is not coping or the family is going through something emotional then being informed on things can be meaningless. Many other barriers to parents understanding information were also identified, such as anxiety, stress, family bereavement, separation, work commitments and other family commitments. Parents feel that if information was provided from the start, in a clear and consistent method, it would really help families have a better understanding of what is available and would reduce the likelihood of their levels of stress and anxiety from increasing. It is apparent that parents grow in confidence with regards to their child's care over time but that professionals can help and support the family at the start, until the parent feels confident and knowledgeable to manage with less support.

A fair and equitable approach to providing information to parents is also seen as key because parents feel that information and signposting is based on luck. This has led to families perceiving services in a negative way, as many parents report that they only found out about something from another parent or by accident. In hind-sight parents find out that there were services out there that could have been offered to them at the start and they have been unsupported and stressed for no reason. This puts a great deal of pressure on parents who feel that they have to have all the answers and must be well prepared to ask all the right questions to the professionals in fear that they'll miss out on key support for their child. Parents suggest that training on signposting should be delivered.

A Care Coordinator is perceived by parents as a way of providing families with clear information on services that meet the needs of the whole family, both socially and emotionally.

- **Coordination**

Parents report having many challenges with navigating and understanding what they see as a very complicated health and social care system, with lots of different professionals and functions.

Parents perceive services as complex and difficult to navigate; different processes for different services, different criteria and complex terminology are all perceived by parents as being barriers to care coordination. Parents report feeling less in control when services do not coordinate efficiently and they feel the pressure to coordinate all the different services themselves.

The biggest barrier that parents perceived with coordination was the lack of communication between services, which has led to a lack of trust in the system. Lack of communication between professionals can also mean that parents are attending multiple appointments at the Centre, rather than professionals offering appointments that co-occur with other professionals. This leads to parents having to repeat their information over and over again, which is time consuming for the parent and again reinforces parent's frustrations with services. Parents feel that there is a lack of communication with professionals, especially when their child starts school, which takes their level of control away.

The importance that parents place on feeling valued by professionals working with their child is great; they want to feel valued and given the time by professionals and feeling rushed and not given the time, can make them feel under-valued. Parents feel that services need to be coordinated because the lack of faith in the system has led to many parents feeling like they have to care coordinate themselves, which they feel is counter-productive and actually takes time from their child and their family:

Parents perceive services as being based on the medical needs of the child's disability and not considering the social and emotional needs of the whole family. Parents perceive that their children need to meet the criteria for services, rather than services meeting the needs of their family. However as they point out not all children present their symptoms at the same time, which parents feel would lead to lots of children slipping through the net for services based on medical need alone.

A Care Coordinator is perceived by parents as a way to help professionals and agencies communicate better with themselves and with parents, to advocate on behalf of the parent and get their voice heard. Parents feel that a Care Coordinator needs to be someone that they have built up trust with, that knows the child and whole family and that they have confidence in to coordinate all the services, enabling the parents to spend more time with their child and their family.

- **Needs-based service**

Services should be 'based on need' including considering parental need, in order for *them* to support their child better and reduce the likelihood of their needs increasing or reaching crisis point. Parents believe that the right support if provided at the right time would impact on parent's ability to be able to manage better in the future, which would have positive implications for the whole family. Parents feel that families needs are diverse, not only in regards to their child's disability, but also in other aspects of family life, and in order for services to meet these diverse needs they need to be

more holistic and needs-led, rather than just concentrating solely on the disability itself.

Parents highlight the need for services to be accessible and available when they need them because children who have complex disabilities and developmental difficulties have needs that can change rapidly and have significant impact on family life, throughout their lives. They feel that in order to meet those needs services should be easier to access. Long waiting lists can contribute significantly to the increase in needs and parents feel that early support can reduce this need and reduce the likelihood of parents reaching crisis point.

Parents identified that services can find it difficult to see the 'whole' picture, as professionals only see their child in small sections or 'episodes of care'. Parents on the other hand do see the 'whole' picture and believe that, because they do, their knowledge of their own child should be recognized as a resource. Parents feel that if professionals listened more to parents that they would feel more valued, which would have a positive effect on their confidence in themselves and in services in general.

A Care Coordinator is perceived by parents as a way of identifying families in need of support at the earliest time and providing a single-point-of-contact when they need support, which would simplify the system and reduce the likelihood of parents becoming frustrated with services and prevent their needs increasing or reaching crisis point.

Appendix 9

Thematic Analysis of Focus Groups with professionals at Serennu

Method – Focus Groups

A focus group method was used in this study in order to explore the challenges that arise when coordinating the care of a child who has a complex disability or developmental difficulty, from the view-point of both professionals working with and parents who have a child attending the Serennu Children's Centre. The focus groups were conducted with professionals separately from parents, to enable themes to be identified from their different view-points and then the data from each was transcribed and analyzed. This report analyses the themes arising from discussion with professionals.

The focus groups ran for two separate sessions, with a number of different professionals in attendance. The first session was based around discussion of the main issues that professionals identify with coordinating care for a child who has a complex disability or developmental difficulty and identifying the barriers and facilitators to care coordination. The second session focused on looking at those barriers and facilitators and considering ways in which a new service model at Serennu might be developed, considering two different models of care coordination being used in organizations in England, as shown in Appendix 12 and 13, that have been developed to help families access more coordinated care. It was hoped that the case studies presented to them would encourage professionals to reflect on support and services that they need and discuss more specifically the type of services needed for families at the Serennu Centre, which could be proposed in a new model in the future.

Participants

Participants were recruited via an opportunistic sampling method. During the period June – July 2016 notifications were sent out via email to all professionals who work at the Serennu Children's Centre and posters were advertised around the Centre, asking professionals to participate in a number of focus groups to be run at the Centre between September and December 2016. Multiple email reminders were sent out at regular intervals to all professionals, encouraging them to come forward.

Those professionals who were first to respond and able to attend at the time specified were included in the group until the quota was filled. Following this, professionals who responded up to the date of the focus group were included.

The focus group was arranged for a time when staff would usually be at work. Ten staff members opted in to the focus group, from a variety of professional backgrounds: one Community Care Nurse, one Social Worker, one Occupational Therapist, two Physiotherapists, two Care Coordinators and one Key Worker. Two of the professionals attended both focus groups. Nine members were female and one was male, they were from

a range of cultural backgrounds and ages, and were considered representative of the whole staff team.

Procedure

All participants were given a brief to read and a consent form, shown in Appendix 4 and Appendix 5 respectively. If they agreed, these were signed by both the participant and researcher. Issues of confidentiality and anonymity were re-iterated after consent and briefing forms had been read and signed, to remind participants that it was essential to respect and preserve the confidentiality of the other participants. Participants were asked to provide a pseudonym of their choice for purposes of transcribing the data, or the researcher would assign them one. The nature of the focus group i.e. that the researcher would provide a stimulus for discussion and then ask prompt questions, was stated clearly, and the participants were given an opportunity to ask questions. Participants were informed that they could leave the discussion at any time if they needed to.

Each focus group lasted approximately 2 hours and the researcher followed a topic guide, as shown in Appendix 6. The discussion was recorded on audiotape as the participants had consented. At the end of the focus group participants were asked whether they had any further questions. The discussion was transcribed and analyzed for occurring themes.

Preliminary Research

In order to identify the main themes arising from professionals with regards to care coordination, 20 professionals from around the Centre were approached and asked a series of informal questions that encouraged a brief discussion about their experiences with care coordination in the past. The themes identified from these preliminary informal interviews were used as a basis for the focus group discussions.

Conclusion

The focus group discussions proved an effective method of identifying the main challenges that professionals have with care coordination for children with complex disabilities and developmental difficulties and their families. It proved to be a suitable environment for subjects in a similar situation to talk openly and honestly and identify ways that care coordination can be developed in the future.

Thematic Analysis – Professionals Focus Group

Introduction

In analyzing professional's discussions around care coordination, it became clear that it was not going to be a simple task because all children's disabilities are different and pose different challenges for families, depending on a number of different external factors that that individual family are exposed to, for example the family support they have, the professional they are assigned, the resources they have available and the access to services in their area.

One of the main aims that professionals are trying to achieve is for parents to be more empowered and to feel confident carrying out recommended therapies with their child with less support from statutory services.

Professionals identified the following as facilitators in helping parents to be more confident in carrying out therapies, which have been categorized into three main themes; **Empowerment, Information and Coordination**. Professionals identified many barriers and facilitators to achieving this, which are the sub-themes listed in the three categories in the table below.

Table to show main themes and sub-themes:

Empowerment	Information	Coordination
• Duty-of-Care	• Signposting	• Communication
• Discharge	• Confusion and Frustration	• Trust
• Needs-based	• Confidence	• Complex System
• Flexibility	• Miss-information/taboo	• Under-valued
• Holistic	• Holistic	• Over-view
• Education	• Social Needs	• Repetition
• Diversity of Families	• Emotional Needs	• Single point of contact

Theme 1 – Empowerment

One of the main things that professionals discussed, when coordinating the care of a child and family with complex needs, was the challenges around discharging families from services and the Duty of Care placed on the professional. Not confidently discharging a family was identified as being a barrier to empowering families to manage with less support from services and a key theme identified in discussion with professionals:

Tutu: Is there something about professional's safety-net, that you don't want to discharge?

Holly: I think so....

Lizzy: It's that duty-of-care that you feel responsible isn't it and there is that in 'law', you know if you've taken on a case they are your responsibility, again going back to the, I think that surprised us all - how much responsibility we have in care - until we discharge it to somebody else.

(Professional Transcript, Appendix 9)

Professionals shared examples of situations where they had found it difficult to discharge a family from their service. Many examples given were based on the professional's concerns over passing the responsibility to the parents. Professionals highlighted that the needs of children who have complex disabilities change over time and the professional needs to be confident that the parents are going to identify those changes when they arise and act appropriately:

Lizzy: Because obviously children are growing, so their bone structure and their musculature changes as they grow, so it might be *fine* at point of discharge but you're thinking, you know, you're handing over that responsibility then to the parent to make notice and that judgment as to when, and if, there is a deterioration.

Jenny: I think it's sometimes, from my point-of-view, it's sometimes the fear that if you've worked with a family who have been non-compliant to begin with, with medication or feeds or anything like that and you get them to the point where they're becoming more independent and they're starting to do it, if you discharge them, are they then going to regress and are they going to be back on your caseload in six months because a child's gone back into hospital?

Phoebe: and not being fed again.....

Jenny: ...because they're not being fed again or they're not having their medication and I think it's always that sort of overhanging worry that you need to be there, even if you're not there, you need to be there as a physical presence....

Phoebe: It's monitoring isn't it?

Jenny: Monitoring and making sure they're still doing it.

(Professional Transcript, Appendix 9)

Some professionals felt that it can be difficult to discharge families from services, even though they have explained to them that they can refer back into the service or make contact if they need to because not all families would be able to take on the responsibility of doing it with less support:

Phoebe: To refer back or to make contact...

Tutu: But isn't that what we *should* be doing?

Lizzy: Yeah, we do, we do...but it's a big responsibility for some parents - others you think yeah great fine - but it's a big responsibility for other parents to take on that challenge.

(Professional Transcript, Appendix 9)

This reinforces the notion that services need to fit the need of the family and that one size doesn't fit all. Malcomess training is an effective tool to help professionals feel more confident to assist families to manage with less support but not every family have the right tools to understand or take it onboard confidently. It was clear to see from professional's discussions that they had lots of different views across the sectors on how families should be supported to manage from being discharged from services:

Tutu: But that's a different issue, that's a different issue and then they should have the support to deal with that issue, that would block them doing that. You know and in some cases we could be looking at a Child Protection Issue, you know, if a parent isn't able to do that and meet its child's needs, by hand-holding are we masking that?

Lizzy: It's a duty-of-care that's been referred to you, that's what we've all been looking at isn't it? It's this 'Malcomess' - in legal terms if we've taken somebody and said that we've done an assessment and said this, this, this, this and this, what we've

found and that we're going to do something about it, we've entered into a contract...

(Professional Transcript, Appendix 9)

Professionals perceive that care coordination could be the link between professionals and families by providing support through the difficult times, such as being discharged. Care Coordination can provide the support to a family when they are being discharged from a service, which could help professionals feel more confident to discharge from their service. Professionals could also provide support to families who are being discharged from the Care Coordination service:

Lucy: That's exactly what it is. It isn't about, to my mind it's like scaffolding; it's about taking them through that difficult period where they're very confused, they're frightened, they're vulnerable. Helping them understand what's happening, what everybody's role is, what everybody does, what resources they can access, you know, its empowering them really because the idea of the support isn't to kind of be a prop that's never taken away. It's to enable them to be able to function as a family and move forward. So I'll go in and identify the main problems, or main issues, work to resolve that and then step-back.

Anna: Yes. WE may be able to fill that gap and allow you (Care Coordinator) to discharge them, in a way, and some parents may feel that's all they need. They might not need that one-to-one with you and I think it's about changing the way that we support that family.

(Professional Transcript, Appendix 10)

Discussions took place about services being very 'medicalised' and the need for them to be more based on the individual's wants and needs, and taking into consideration the child's aims and goals and getting their voice heard. Some professionals perceive that not discharging families from services at the appropriate time could be detrimental to how that child and family perceive their sense-of-self and their identity:

Tutu: Because when you think of the risks and you've got that risk and yet you've got the risk of that young person's identity, how they feel, there's been actually young kids with a diagnosis of ASD and when they get to adult-hood ask for it to be taken away because they don't want to be labelled.

Phoebe: And you can see that sort of...I suppose when they are growing up....it's just lots of medical appointments, the whole thing is perhaps 'medicalised'.

Tutu: And they want to be an individual.

Phoebe: Yes.

Tutu: They want to be an individual, so the risk to that young person - does that outweigh *your* risk? Whose risks should we be looking at?

Tutu: See that's concerning though isn't it because we've institutionalized them to think they need this care from cradle-to-grave and not only that, how about the child's development and sense-of-self?

Holly: Yeah.

Tutu: Do they view themselves as a 'child' first-and-foremost, or as a child who needs constant support?

Jenny: Constant support....yeah.

(Professional Transcript, Appendix 9)

Professionals identified that giving parents a positive view of their situation and educating them from the start that they have possibilities and opportunities then that would be empowering for them and help them to take on more responsibilities for themselves:

Tutu: But I think sometimes, instead of giving those positive messages we're very good at giving the negatives.

Fifi: Yeah.

Tutu: I've received referrals from people that say 'this child's got A therefore won't do B' you know and I'm talking about a child at two. You know, I'm sorry we'll aim for B whatever.....you know, we will be looking for that B.

Phoebe: Maximise the potential.

Tutu: And I suppose that's the difficulty isn't there because they're sort of coming down and going 'oh my god' but actually it's about that expectation as well and raising expectations and recognising that 'ok things are going to be different' but there can still be a good quality of life and actually there

are lots of services out there to address all those needs we've said. You've got 'Young Carers', you've got 'Respite', you've got many agencies that are set-up to have families with children with disabilities and able-bodied children, you know so it's about raising the profile really of what people can access, you know 'there are going to be *different* opportunities but you are *still* going to have opportunities and its going to be *good*'. Because I think when we get into that, well that's the expectations we share with parents then. You know 'oh gosh, it's going to be awful for you isn't it?' (gestures slitting throat).

(Laughter)

Fifi: So it's educating them really as well, passing on knowledge.

Phoebe: And it's about letting them know that there are things out there that you can go as a whole family and you don't just have to use respite.

Tutu: And it is I think, the research shows how Midwives, how Obstetrician's, how they deliver the information when they realise the child's got a disability actually raises the outcomes for those children and I think we've got a professional responsibility not to look at the negative all the time. *Be realistic* but actually say 'ok you know, this is the situation, what can we do to reach potential of a good life?'. You know we should be giving those messages out. Not 'you're going to need hand-holding from cradle-to-grave' because we don't want that, we want parents to be.....but also recognising that they need support at certain times.

Fifi: Yeah. We need to be explaining it to them because they're not going to know that these services are there to support unless they have the information given to them.

(Professional Transcript, Appendix 9)

Professionals think that parent's reluctance to being discharged comes from their uncertainty about needing the service again in the future and having to wait a long time for it. Professionals believe that if parents feel like this then it is because of a miss-communication problem and parents need to be explained to clearly and prepared for discharge:

Fifi: ...if they've waited to get an appointment with the particular service, I think they are reluctant to then come away from the service incase they need it in the future....

Lizzy: And they're going to have to wait a long time again.

Fifi ...and then they're going to have to wait again. So that's what I hear quite often.

Fifi: Miss-communication.

Holly: ...a lot of my parents think that when they have been discharged that's it.

Fifi: That's it forever.

Holly: ...they can never come back, they're going to have to wait but with the 'Care Aims' that we're doing now it's about making it very clear, I kind of do it a few sessions before I know I'm going to discharge or close that episode of care and then on that review...kind of *prepare* them...

Holly: ... I thought it was going to be very hard to discharge her but actually she was kind of like 'oh ok' she's kind of coming around to it because she knows there's that safety-net. She may not ever need to access it again but she knows that there's that safety net there that if she does....

(Professional Transcript, Appendix 9)

Professionals feel that educating parents on how to prioritize the care of their child would help parents to be discharged from services and also educating them about the signs to look for when they might need more support, so they are more confident about knowing when to refer back into the service:

Holly: And knowing *when* to prioritise which bit of equipment to use, just thinking of one of the girls we've got, she got a standing frame, a sitting out chair, a pushchair and she's got to spend time in all of them and on the floor and on the bench, so having that schedule which we're putting together with Physio will give them guidance on 'do I prioritise standing or do I prioritise sitting, because we need to work on hands?'

(Professional Transcript, Appendix 9)

Lizzy: It's also about educating the families about when their need is more. When they actually need us, or when they need a professional involved or when they can actually get-on themselves.

(Professional Transcript, Appendix 9)

Lucy: Helping them understand what's happening, what everybody's role is, what everybody does, what resources they can access, you know, its empowering them really...

(Professional Transcript, Appendix 10)

Professionals discussed the importance of looking at other things that the family might need support with, if they are not managing to look after their child with less support from services. This highlights that professionals feel that they need to consider the wider family picture and look at what support the family needs after they are discharged from the service and signposting to services that will support the family with social and emotional needs:

Tutu: I always think if you're identifying that, you're identifying that parents aren't able to meet their children's needs and you need to be looking at the reason why not, you know, if you're generally saying that the child might slip back into hospital and they're not doing the things that they are able to, you know, you look at the blockages, so substance misuse, blah blah, but if they're really not able to you are looking at a Social Services referral.

Jenny: Yeah.

Moderator: Does it need to be a Social Services referral or does it need to be a lower level of support/preventions? What kind of thing do you think?

Tutu: Preventions.

Jenny: But I think when you take that patient on you feel responsible for their care.

Tutu: So does that say more about the professional or the family?

Holly: Yes because this child is a teenager; going into pre-teens now, is very head-strong and the support is more around supporting Mum to implement some changes but there are other services that do that and we have helped her to access those services and

it's coming to that end date and she knows that if she needs to phone call she can, these are the other services that she's now accessing and that, if they do need in the future to come back in, to ring and discuss it on the phone and it'll be triaged then. Know that they can just....

Tutu: They've got that safety-net.

(Professional Transcript, Appendix 9)

It is recognized that signposting to other support services can lead to families not becoming dependent on to professionals so much, reducing the likelihood of parents becoming dependent on one particular professional. This can help empower parents to manage with less support from services and can aid being discharged. Signposting to other services that meet the social and emotional needs of families was also identified as helping families to be discharged from services:

Phoebe: There maybe needs to be something else out there for the family, I think to network and have that support from other families in the same situation.

Fifi: I think they're feeling lonely as well. Isolated.

Phoebe: I think it's very different for the families that don't have any wider network, wider family support, grandparents, aunts, uncles around.

Fifi: I think some families are a bit more hands-on than others aren't they? Some are a bit more confident.

Phoebe: Yes with coming to the groups here...they're meeting a lot of other people and getting that support and maybe don't necessarily feel they need the support from the therapist but if they didn't attend anything like that, and the therapist is their only contact....

Fifi: Yeah it's quite lonely then and they're more likely to latch onto that one person.

(Professional Transcript, Appendix 9)

Offering flexible appointments that suit the needs of the family was identified as an enabler for families to access other services that might meet their social and emotional needs. There were many barriers identified that prevent families from accessing other services, such as distance, time, siblings, work, school and family and therefore highlights the need for services to be more holistic and identify what those barriers might be for each family and offer services that fit their needs:

Moderator: Do you think all parents are going to want to come to the groups?

Fifi: Well they might want to but again they might not be able to because they're working, and it's all the same things then isn't it.

Jenny: ...there will be parents who work and parents with other children who are school or away and they need to think about that as well.

Tutu: ...we're running a group from 5.30pm-8.30pm, so we can get working parents and Dad's!

(Professional Transcript, Appendix 9)

It was also identified that flexible appointments can also increase the likelihood of other family members and care-givers to attend sessions as well as this might take some of the pressure off the main care-giver:

Tutu: Well that's the other thing; we tend not to include Dad's a lot as well don't we? It's usually Mum's who come along to the appointments so, and in translation, are they completely involved with how stressful that can be? Do they understand that? You know and if there were flexible appointments it would tick a lot of boxes wouldn't it?

(Professional Transcript, Appendix 9)

Professionals identified that in order to be successful at supporting the family, services need to suit the needs of the families:

Tutu: Yes it's that barrier really isn't it, there's no leeway, and it's sort of as if the service is run for its own need and not the family's needs sometimes.

(Professional Transcript, Appendix 9)

Anna: ...to centre it around the child; it's not to suit us it's to suit the *family* and we're going to be much more successful if the family feels that we are supporting them.

(Professional Transcript, Appendix 10)

Theme 2 – Information

One of the main aims that professionals are trying to achieve is for parents to be more empowered and to feel confident carrying out recommended therapies with their child with less input from professionals. The second main theme that was reported by professionals as facilitating this was about 'information' and how providing information to parents was empowering and would increase the likelihood of them feeling more confident with less support. It was recognized that parents and families who have children with complex disabilities or developmental difficulties can have a number of professionals getting involved at the same time, which can lead to confusion and frustration for the family:

Lizzy: I think a lot of families don't know who is who and what their roles are. So they may have been told that they may need somebody coming in, or somebody maybe coming to the house, or somebody will be getting in contact.....and they have *no idea* what their role is or what they're coming for, or why they need to be seen even, sometimes do they? Or how that's going to help or....and then they end up with loads of people involved or lots of appointments...

Fifi: There's confusion then for parents.

Phoebe: They just wouldn't necessarily hear at all until the appointment time, which for all different professions could be two months, six months, nine months....

(Professional Transcript, Appendix 10)

Professionals discussed the ways in which professionals could provide information in a way that might be clearer for families to understand. Professionals indicated that by preparing families for what to expect can also be an effective method of empowering them, as if they are kept informed and are given realistic timescales of what is going to happen they may not feel so confused or frustrated:

Fifi: And maybe just to clarify a little bit as well because if you're told that we'll organise for an Occupational Therapist to come in, fine that's great, but what for? If it was like 'Occupational Therapy to come in and help with cutting of food or whatever it might be, it just takes it that one step further.

(Professional Transcript, Appendix 9)

Phoebe: Or even if they were just told 'you've got a nine-month waiting list' at least then families would know.

Fifi: Information. Keeping them informed.

Holly: And knowing who to go to for, because you have so many people coming in and out don't you, so it's knowing who the best person is... we constantly get phone calls and we'll say 'oh it's more this and we'll send you over to them'.

Tutu: That's a problem - passing people along as well 'it's not my problem, I'll pass them through to someone else'.

(Professional Transcript, Appendix 9)

In recognizing that providing information to parents can be empowering, barriers to parents understanding and taking in the information was also identified. A theme running through discussions with professionals was around the frustration that parents have with services, which had led to them viewing services in a negative way. Parents being confused and frustrated by the system could block their ability to retain information that they are being given, which could have a knock-on effect with how they work with professionals and carry out therapies at home.

In identifying that education to parents is beneficial, it was also recognised by professionals that there are many barriers to parents accessing education; in terms of their understanding and retaining information, such as; anxiety, stress, motivation, learning difficulties, poverty, bereavement, religion/culture. They identified that motivation can be a barrier to parent's carrying out recommendations at home and that communication is the key to enabling this:

Tutu: So what is the barrier to that then? Why doesn't that happen?

Lizzy: Because of education, communication.....

Fifi: Maybe historically it's been done the other way.

Tutu: I suppose to what you said, there's two parts to that though because again it comes down to individual processes and how, you know professionals actually who are that first point of contact, how you describe your own inner purpose, you know that's a lot about individual responsibility as well but I suppose for families who, even if you did to the best of our ability, there are families who are still so overhauled that they are not taking that information on and I think that's a different thing,

isn't it, there's almost a process thing and an agency responsibility and perhaps even with the 'best-will-in-the-world' they need that bit of extra support.

Tutu: Motivation.

Moderator: Motivation? Do you want to go into that a bit more?

Fifi: They've got to want to do it, is it?

Tutu: Well understanding the need, especially when a barrage of referrals have gone off to Pediatricians you're not really sure, so if you don't understand the need.....well why should I hold all the bags and have time off work.....are all of them necessary? Because we sometimes forget that our parents are actually the ones who are there day-in, day-out, are parents really listened to? Is there a need for all these professionals to be involved, where do they want to go? Sometimes they need that encouragement because they should be attending them and they are not. So it works both ways really, that do we really need all these professionals involved, or are we just doing it to tick all the boxes.

(Professional Transcript, Appendix 9)

Educating parents on other services that can help support them is perceived as being an effective way to empower families. Many families, it is felt, are miss-informed about certain services and how they can support families, for example there is a taboo associated with Social Services and many families perceive themselves as successful if they have avoided them. Taboo of services is often exacerbated by the high criteria to access them and reinforces to parents that they have to be crisis to get it. Educating parents more about how services work could help to put them on a more even-keel with professionals and reduce the 'us' and 'them' mentality, which could improve working relationships between families and professionals:

Anna: There is also quite a taboo with having support from Social Services, so many families you'll find that their children are sixteen or seventeen and they haven't had any support worker helping the families out and when you ask the family 'have you had anything to do with Social Services?' they are very proud because they've never had any issues with the way that they look after their children but they've also missed out on receiving the support from Social Services because they would think that they have failed as parents. That's a huge taboo.

Jenny: I think it's this fear that Social Services are there to take your children away and that's what everyone believes but they're not, they're there to help you and signpost you but a lot of parents believe that Social Services are there primarily to take children away from bad situations.

Lucy: Yes they do. I mean, one of the things I do when I go in initially with families is go through all the services that potentially be able to support and Social Services is one of them and I do make a point of explaining the difference between Child Protection and Child in Need but I think the only problem we've got, the support that Social Care, especially in Torfaen, are able to give is...

Mary: Same as Monmouthshire

Lucy: Their criteria is so high now, for both the O.T and the Child in Need support from the Children's Team, it's practically non-existent anyway. So, yeah it is a problem.

Moderator: So the criteria is so high? So what is happening to those families that are not hitting that criteria?

Anna: But that reinforces their taboo then because that's exactly what they presume.

Lucy: In Torfaen if they're not hitting the criteria they're being referred to me.

Moderator: But if there is a stigma attached to Social Services, or a taboo, do you think that there is a need for an *independent* Care Coordinator, do you think that might help families achieve better care coordination, because if there is a stigma attached to Social Workers, are that family really going to want support from them, or from someone independent?

Mary: I think the Care Coordinators could act as a buffer and explain all the value that Social Services can bring, for example certainly in TAF in Monmouthshire have got access to and the fact that they could then access those services a bit quicker than with us. There's those sorts of things.

(Professional Transcript, Appendix 10)

Through discussion professionals highlighted that educating parents about child protection could reduce the cases of child protection arising, as it could empower parents to be aware of how things can escalate to child protection:

Anna: I think what's interesting is the Child Protection training I went on, it was a very different tone, again, it wasn't this, the 'layer' had changed I felt. It used to be Child Protection or not Child Protection and this time I felt that it was a much lower layer that they talked about. 'Behaviour' and what *could* become Child Protection, it was much more preventative and I felt, having been a parent, you know in a way it would be a good thing to offer that training to parents.

Jenny: Yes.

Anna: You know so they have that *language* because part of it is not talking about things that happened before Child Protection comes in because most parents have got an inert wish for their children to be healthy, even if things go wrong, even if there are other issues around and that can be very positive.

Anna: But it would put *them* on a more equal footing with *us*, rather than *us* sort of supervising saying 'ohhh don't do this' or 'isn't that dreadful?' We would be talking about children and saying 'how do you cope with that at home?' a bit like the Psychologists do here, often we have the Psychologists getting involved when there are behavioural issues with the children...because we're not born with those skills, just because we have children who suddenly have strange behaviours...doesn't mean that the parents have suddenly got the skills to change that behaviour when the children are better or when they need to have a different...

Jenny: And quite often it gets to...it sort of reaches kind of like crisis point before the parents even realize.

Anna: Exactly and often they would have said something and no-body picks it up because they think 'it's not really a Child Protection issue, look at the other health issues they're much more important.' But in the meantime that's all building up and then, as you say, it all comes to crisis and you think 'well we could see that months ago, years ago.'

Lucy: But as you say, care coordination, again, can bridge that gap

(Professional Transcript, Appendix 10)

Theme 3 – Coordination

The third main theme that was identified in the focus groups was about 'Coordination' and the challenges that parents have navigating through a very complicated system, with lots of different professionals and functions. Professionals highlighted that coordinated services can be an effective facilitator in enabling families to manage with less support from services, as it can prevent families from becoming confused and frustrated with services from the start. Professionals identified that if parents have a positive experience from the start it can be empowering and set families in the right direction. Examples of ways in which services can be coordinated were; flexible appointment times, joint appointments, less confusing terminology and non-repetition of information:

Anna: Yes I think from the past we've often heard that children have been seen by different people, perhaps even within the same week and we could have easily coordinated that service to make it easier for parents to not have so much time out of work, children not to miss out so much from school. That could make a big difference. Sometimes it doesn't suit them to have three appointments in one day, that's also understandable but we need somebody who looks at what suits the family best and what is possible with professionals, they can't always meet on every day of the week but it is often possible to coordinate it.

(Professional Transcript, Appendix 10)

Professionals recognize that parents are frustrated by the system and perceive this to be as a result of a number of factors, including confusing terminology that is used by professionals, having to repeat information and the difficulty for them to get appointments in the first place, which can add to the frustration. Discussions with professionals indicates that parents become frustrated because they are not able to access the right professional when they need to and are "passed from pillar-to-post" trying to get hold of them.

Tutu: Yeah because the terminology is fine for us because we work in this field but for parents.....they've probably never come across an 'O.T' before.

(Professional Transcript, Appendix 9)

Holly: That repetition of information as well...

Lizzy: Yeah I think that's a biggy.

Holly: I think every time you meet someone you've got to tell your story again.

(Professional Transcript, Appendix 9)

Tutu: I think the first barrier is *getting* the appointments. Especially if you're in a queue and then get cut-off talk talking to somebody or get sent to the wrong department.

(Professional Transcript, Appendix 9)

Waiting to be seen by the right person and not knowing when they are going to be seen by that person can have consequential outcomes for the working relationship between that family and their professional. Professionals recognize that the wait itself can lead to a build-up of stress and anxiety in parents, which some professionals feel has been a result of services not coordinating effectively:

Anna: That 'gap' creates a lot of anxiety, which by the time they then get to you, they often have so many disappointments or they have waited for so long that we've almost built up a problem for *ourselves* because we haven't coordinated and it might not be directed towards 'us' directly but it's towards the *service* and that's not good for anybody.

(Professional Transcript, Appendix 10)

Professionals also identified that parents are frustrated with the system due to not being listened to and not given the time, which has led to parents feeling under-valued and let-down by the system. Professionals identified that if parent's feel like they've been listened to and given the time that this might build better relationships with families and make working with them easier:

Jenny: I think that families need to feel valued by the service.....and I think it's that thing of feeling like you've been listened to and your views are being taken into account. I think it just helps to build trust with the families as well, which then makes working with them easier.

Tutu: ...a very annoying thing is when you're busy yourself and a professional yourself and you have a family yourself and you've made that effort to turn up and the Pediatrician waltzes in two hours later and says 'oh sorry'.

Fifi: And your appointment is delayed.

Tutu: ..we know other people have responsibilities but, like you said, I think parents need to feel valuedespecially if you're a bit nervous about it...that can really add to that stressful situation then can't it?

Anna: I think parents always feel that they have to *fight* for everything.

(Professional Transcript, Appendix 10)

Professionals perceive coordinated services as reducing the confusion for parents and the stress that comes with that and enabling better relationships with parents, so they are more likely to feel empowered and confident to listen to professional's recommendations, follow their lead and trust them when they tell them that they are ready to be discharged.

In recognizing that the main aim for professionals is to empower families to manage on their own with less support from services, professionals discussed the many barriers that exist when coordinating services for children with complex disabilities or developmental difficulties that do not enable that to happen. One of the themes that professionals identified with this was sharing information with professionals across the different agencies that support these children and their families:

Mary: Sharing data is an issue as well; data protection. People are like 'ohhh I don't know if I can tell you that'.

(Professional Transcript, Appendix 10)

Coordinating services could be a way of identifying child protection issues earlier by agencies and professionals communicating with each other. Parents not trusting services can also be a barrier to parents listening to professionals and taking their recommendations onboard:

Anna: I wasn't involved enough to know but there are issues from our professional point of view that we pick up and we would love to have a Social Worker involved to know is there something that we need to refer, is it something that is known already?.. and it isn't easy to get that contact because if they're

not accepted by Social Services we haven't really got any communication going. If they are on Social Services books we've got somebody to talk to but if they decide not to see these children for any reason, which aren't always clear to us, we are very much isolated to Social Services, we need more communication with Social Services and I think parents need to know that we talk to Social Services.

Moderator: So a Social Worker might say a family aren't eligible but they might not necessarily feed that back to you?

Anna: No, we wouldn't necessarily know *why*. We could still have concerns and that is very difficult then.

Lucy: You usually just get a note to say it's been declined.

Anna: I didn't even get a note, I was told that, this was a child that moved to another area, in a way as long as they moved I was quite happy but if they'd have stayed that would have really worried me.

Jenny: Because it is frustrating when you know there's been a Social Worker... allocated... and then they've stopped seeing them because everything's fine and then you walk in and the parents say 'I'm struggling with this, I'm struggling with that and you think 'why did you not tell them?'

(Professional Transcript, Appendix 10)

Other difficulties that professionals identify with coordinating services for families is the requirement to take on additional responsibilities that is not always their role to do, for example going outside of their remit to support a family and signpost them to other services. The issue that professionals raised with this lies in the inequality of professionals carrying out this duty, which lies heavily with certain professionals rather than others. This results in the workload of those professionals being unevenly distributed, whereas if it was everybody's responsibility it would be evenly shared and a more manageable amount:

Anna: And it does tend to be the same people as well because there are some people who are more involved with families than other professionals so they got a lot, and people got very wary of taking on that responsibility.

Mary: With the Team Around the Family in Monmouthshire, because we haven't got that much funding, we look to professionals to lead on Team Around the Family cases and I have a difficulty with this 'additionality' thing because for me we're all working, doing our best to support the family and if we could change our mindset to a certain degree, I think that care coordination would be a lot smoother, if that makes sense, because ultimately we're all working towards the same goal. It's about how we stop perceiving it to be an 'additional, added on' sort of thing and make it more about being 'part of the service' and integrate it from everybody's perspective. Does that make sense?

(Professional Transcript, Appendix 10)

Mary: For me, it's about families being listened to and I do work with quite a number of families who do feel that they're not being listened to and sometimes they ask specifically if they cannot work with one particular person, you know in the general sense, because they feel that judgements have been made about them and that these people are blocking their access to service because of what they think about them, which is quite a difficult one really because if they are concerned about their child's health but the professional thinks it's because of a particular reason, they can't go any further with that and they feel that their access to services are blocked. I don't know where that would sit within this.

(Professional Transcript, Appendix 10)

Professionals discussed the issues around parents requesting to work with another professional if they choose and feel that they have the right to request a second opinion if they are not happy with their professional but it was identified that this is not always possible in small teams. Some professionals feel that the best way to overcome this would be to have somebody impartial and non-clinical who could coordinate the services for them. Professionals identified that having someone independent would be able to see the whole situation, that perhaps professionals are not always able to see:

Anna: Well I think that the big thing is that it's *not* a person who is also 'clinically responsible', so the person that is coordinating it, I think that is

really important. To have somebody who is *not* directly involved who can have that over-view and also that impartiality with different professionals. I think that will make a big difference.

(Professional Transcript, Appendix 10)

Phoebe: And we might actually not know that they're not necessarily attending everyone else's appointments....

Anna: Exactly, we need that over-view, which as a single professional we might not always have, it takes a long time to build that up. Together we could get that quite quickly.

(Professional Transcript, Appendix 10)

Lucy: I think as well, very often, each individual professional might know what is going on with the child but the family don't always know what is happening 'as a whole' and it can become very confusing and it can add to the pressure a great deal, to the whole picture. So I think as well it's about coordinating everybody to come together and bring all the information together, just so that's its clear and parents know what's going on because a lot of the time they're under so much pressure. It just adds a little bit more pressure with all the confusion, so it's about *coordinating* everybody involved really.

(Professional Transcript, Appendix 10)

Professionals recognize that a barrier to coordinating services lies with the fact that parents do not have faith in the system and know that professionals do not communicate with each other as efficiently as they could:

Anna: But also I think it's for *parents* to know *from the beginning* that we are working together; we are talking to each other...it's almost *built* on the fact that we don't talk to each other..... and that's *really* worrying.

Lucy: That's where Care Coordination again can bridge that gap because if you have concerns about a child you

can contact the Care Coordinator, I'd be quite happy to be contacted and I could investigate that for you.

Anna: Whereas if parents *know* that we talk to each other, whenever we refer to a service if from the beginning they *know* that we *do* talk to each other, if there is a social issue we *need* to know about it...very early on.....and it will take away this secrecy in a way of thinking that perhaps we don't talk to each other.

(Professional Transcript, Appendix 10)

Professionals find it very difficult to see the whole picture and feel that Care Coordination could help professionals see more holistically by being that spokesperson for the family and providing those missing links. Professionals recognize that they need to consider the family's social and emotional needs to be able to offer services that are suitable to them. Professionals perceive Care Coordination as being able to bridge the gap with linking all the services together and helping provide professionals with the holistic view that they need:

Mary: we'd look at things like finances, emotional health and wellbeing, housing issues, so we build a picture of the family, the stuff that you were talking about, so that 'whole family' picture and then when we bring professionals together, whether it's though Education or anti-social behaviour, or whatever, we've got a general feel for where that family *is* and what sort of support is needed and obviously if there's any health things in there or any additional learning needs or anything like that.

Moderator: Is that done in the other areas as well?

Lucy: Umm hmm (agreement). Family Support Assessments.

Mary: Yeah.

Moderator: Is that done in Health as well?

Anna: We do an assessment but that stays within Health I think.....if it's relevant we have that as well on our form but often at the first assessment it isn't relevant..

Jenny: But I think what you said about learning about the family and about the finances and about the wellbeing of the family 'in general', we don't really see that because we tend to focus on 'the child' and the 'child's needs' and if we do happen

to find out anything about the family its incidental. So we might go in on a Respite shift and find out that the dad lost his job three months ago and they're really struggling, which is why they are always stressed and having a go at staff but we don't know that; it's not something we know from the off.

Moderator: Do you think it would be beneficial to have access to that information?

Jenny: Sometimes yes because it can make the relationship easier with the family if you have a basic, you don't need intimate details, but if you have a basic understanding of some of the things they are going through it can be beneficial.

Mary: And obviously if parents are stressing out then that's going to impact on child, you know.

Lucy: Yeah but that's what I find difficult with care coordination I do a lot of that, a family will come to me and say 'we don't know what's happening with Physio' or 'who do we speak to?' or 'we saw them last, this, that and the other'...so I'm kind of putting people in touch with people, it's kind of bridging a 'gap' sometimes, it's not anyone's fault a gap is there because everyone is working and doing their best but it's just there, so it's just 'bridging' that and setting that communication up and making things clearer.

(Professional Transcript, Appendix 10)

Summary

Professionals working at the Serennu Centre perceive that families who have children with a disability face many barriers in coordinating the care of their child due to the inability to access support that meets their individual needs, including long waiting lists, high criteria, confusing terminology, poor communication and unequal access to services.

Although many professionals feel that they go above and beyond to assist parents, there are many accounts of professionals who do not, and there are many families who have needs that require significantly more support than they are able to give within their professional remit and timescale. For families who require significantly more help there is nowhere for professionals to refer them onto, as criteria to access current Care Coordination services at Serennu is three or more specialist services, and often too high criteria for a lot of these families to access. This has resulted in professionals becoming wary of care coordinating for

families, which professionals report means an unbalanced distribution of workload for those that do. The result for families is that support is offered inconsistently across Serennu.

Professionals report that families are frustrated and angry with services and its having an emotional impact on their wellbeing and the wellbeing of the rest of their family. This can make working with them very difficult.

The summary of the three themes are as follows:

- **Empowerment**

One of the main things that professionals discussed, when coordinating the care of a child and family with complex needs, was the challenges around discharging families from services and the Duty of Care placed on the professional. Not confidently discharging a family was identified as being a barrier to empowering families to manage with less support from services. Main areas of concern are based on professionals handing-over responsibility to parents who might not cope with that responsibility, and having confidence that parents will identify changes in their child's need when they arise and act accordingly. It was identified by professionals that not all families will be able to cope with less support from services, even if they've followed the necessary steps to empower them, which can make discharging them from services very difficult.

Concerns were raised that not discharging families from services at the appropriate time can be detrimental to how that child and family perceive their sense-of-self and their identity. That by helping them to take on more responsibilities for themselves and giving parents a positive view of their situation, educating them from the start that they have possibilities and opportunities, can be empowering. Services not discharging at the appropriate time, it is felt, can become 'medicalised' for the family and restricts professionals from understanding the child and family's voice.

Services that are holistic enable professionals to identify the families' social and emotional needs and signpost to other services that meet those needs, which can aid the discharge process. Families who have the least social support are more likely to rely more heavily on their professionals; therefore the need for a more holistic approach was identified as a way to understand individual family's circumstances. Services that are flexible with their appointment times and suit the needs of the family will be more successful at supporting the family to manage with less support, increasing the likelihood of other family members attending appointments, taking some of the pressure off the main care-giver.

Individuals who have received the Care Aims training by Kate Malcomess perceive this an effective tool to help them feel more confident in discharging families, as the framework clearly prepares families from the start. Educating parents to identify changes in their child's needs, and knowing how and when to re-refer was key to professionals feeling more confident in discharging families.

Care Coordination is perceived as a holistic approach to enabling families to manage with less support from services, as a Care Coordinator can provide a single-point-of-contact for families, providing support and signposting that meet the needs of the family. A Care Coordinator can support the professional by monitoring the family after they

have been discharged, which would give professionals more confidence in discharging families who might be daunted by the responsibility of having less support from services, and provide that education to the family on how and when to re-refer to a particular service if their needs change or increase.

- **Information**

The second main theme that was reported by professionals was about 'providing information' to parents and how it was empowering and would increase the likelihood of them feeling more confident with less support. It was recognized that parents and families who have children with complex disabilities or developmental difficulties can have a number of professionals getting involved at the same time, which can lead to confusion and frustration for the family.

Providing information in a way that is clearer for families to understand and by preparing them for what to expect can be effective methods of empowering parents, as if they are kept informed and given realistic timescales of what is going to happen is likely to improve how a family work with a professional. By providing information in this way might reduce the likelihood of parents feeling confused, over-loaded and frustrated. Frustration that parents have with services, has led to parents viewing services in a negative way and this can be a barrier to receiving information or working with professionals down the line. Other barriers to parents receiving information can be anxiety, stress, learning difficulties, poverty, bereavement, religion/culture. Motivation was identified as being a barrier to parent's carrying out recommended therapies at home and it is felt that clear communication is the key to enabling motivation in parents. In order for services to understand the barriers to individual families receiving information they need to be more holistic in their approach.

Signposting to other support services, especially those that meet social and emotional needs of the family, can lead to families feeling more empowered and reducing the likelihood of becoming dependent on one particular professional. Families who have no or little family-support can lean more heavily on services. Educating parents on other services that can help support them is perceived as being an effective way to empower families. Many families, it is felt, are miss-informed about certain services and how they can support families, for example there is a taboo associated with Social Services and many families perceive themselves as successful if they have avoided them. Taboo of services is often exacerbated by the high criteria to access them and reinforces to parents that they have to be crisis to get it. Educating parents more about how services work could help to put them on a more even-keel with professionals and reduce the 'us' and 'them' mentality, which could improve working relationships between families and professionals.

Care Coordination was seen as a way of providing that information to parents so they were not miss-informed about services and knew how to access services that might benefit them. A Care Coordinator can bridge the gap between professionals across agencies as it is a means of seeing the whole picture, which professionals can find difficult and helping to build the relationship more positively between families and services. A Care Coordinator can refer families to services that meet their social and

emotional needs, as they will be able to offer a more holistic approach to assessing the family.

- **Coordination**

The third main theme that was identified in the focus groups was about 'coordination of services' and the challenges that parents have navigating through a very complicated system, with lots of different professionals and functions. Professionals feel that coordinated services can facilitate families to manage with less support from services, as they would be less frustrated with services and more likely to work with professionals more effectively.

The frustration that parents have with services is perceived to be a result of services not coordinating efficiently; long waiting times for services, repeating their information, difficulty getting appointments, and difficulty getting hold of the right person. It is also reported that families' frustrations with services stems from feeling like they're not being listened to which makes them feel under-valued by professionals. Parents are described as very often turning up to their first appointment 'ready to fight', which can make working with families very difficult.

Professionals recognize that the *waiting* itself for services can lead to an increase of stress and anxiety in parents, which some professionals feel has been a result of services not coordinating effectively; not holistically assessing the families' needs or signposting them to other support services in the meantime. This can have consequential outcomes for the working relationship between that family and their professional.

One of the barriers identified with coordinated services was the lack of communication between agencies and the difficulties sharing information. There is a concern that the lack of trust that families have with services has been built on the perception that professionals do not communicate with each other. Communication between agencies would enable services to be more coordinated and re-establish a better working relationship with families based on trust. Coordinated services can help identify child protection issues earlier; missed appointments across different agencies, by providing an over-view of the family which fragmented services can find it difficult to see.

Professionals perceive Care Coordination as a bridge that links all the services together and supports both professionals and families by providing a single-point-contact and a holistic approach to services. The Care Coordinator should be someone independent, so they can build trust with families and aid better working relationships between them and the professionals they are working with.

Appendix 10

The current model of care coordination at Serennu

This section provides a summary of the care coordination services currently operational at the Serennu Centre;

Newport

The Children with Disabilities Team in Newport City Council has a 'Complex Needs Care Coordinator' who provides a specialist community-based care coordination service for children with 'complex' health needs, or 3 or more professionals involved in their care.

The Complex Needs Care Coordinator offers specialist support around the time of diagnosis, and offers continued support as part of the child's care and support plan, particularly in key periods of change or transition. They are required to work with the child and family together with all relevant professionals in order to coordinate services to meet the assessed needs, and signpost to other relevant services.

The criteria for accessing this service is the child and family receiving services from 3 or more professionals and is aimed at children 0-5 years of age who have complex health needs. There is no waiting list for this service. Families accessing this service can expect support for 6+ months.

The Complex Needs Care Coordinator currently has a caseload of 9 children, aged between 0-5 years, however this post has been vacant for almost a year and the new post-holder foresees capacity to be between 15-20 children, once established in post.

Torfaen

Torfaen County Borough Council employs a 'Care Coordinator' through the Families First program to support families who have a child who has a disability or developmental difficulty. In line with the program, this model is a short-term intervention aimed at enabling families who need more help to manage with less support from services.

The criteria for accessing this service is any child or young person from Torfaen aged 0-18 years with a disability or developmental difficulty and who has two or more professionals involved in their care.

The Care Coordinator has a current case-load of 25 families, most of which are children aged between 0-12 years. Using the Team Around the Family approach, this service offers families a single-point-of-contact who works with the family to identify their goals, and offer practical and emotional support, information and signposting to other services. This service aims to prevent families who have a greater need for support from escalating to needing Social Services intervention.

Monmouthshire

Monmouthshire County Council utilise a 'Care Coordinator' within the Children with Disabilities Team. A 'non-case holder' who completes the Information, Advice and Assistance requirement of the department after a referral to the team when more information is needed. It is a brief assessment, usually by phone, to gather more information from the family before a final decision is made by management as to whether to offer the family an Initial Assessment by a Social Worker.

Appendix 11

Other services that support children with additional needs across Gwent

The Families First scheme is operational across Gwent, each local authority having the opportunity to develop their own unique program under the scheme. Families First is an anti-poverty initiative and is awarded to local authorities based on their level of poverty for a 3-year period.

Newport

In Newport, the Children with Additional Needs Service (CANS) is a Families First project providing children with additional needs and their families with practical intervention and behaviour strategies, visual aids and CYGNET training. This is a team of 4, with a current waiting time of 6 months, however unlike in Torfean, children do not need to have a diagnosis of ASD to access the service. A recent evaluation by the IPC reported that the success of the program is down to interventions that focus where possible on closing the gap between home and school by simultaneously engaging all key parties (including the child) in change.

Torfaen

In addition to the Care Coordinator, Families First in Torfaen fund an ASD Officer who provides practical intervention and support to 260 children in Torfaen who have a diagnosis of Autism Spectrum Disorder (ASD). Located within the Education department, the ASD Officer works with schools and home to provide practical support and behaviour strategies such as visual aids and schedules, as well as delivering CYGNET and Early Bird training. There is no waiting time for this service however children must have a diagnosis of ASD to access it.

Monmouthshire

The Families First team in Monmouthshire County Council also employs key workers to support families who need additional support. They have a 'general' team, there is no specific 'disability' team, for any child aged 0-18 in Monmouthshire who require more support and who have 1 or more professionals working with them. They use the Team Around the Family (TAF) approach which utilises a Lead Professional role.

Blaenau Gwent

The Families First division have two designated 'Key Workers' who are case-holders and support families across Blaenau Gwent who have a child with a disability or developmental difficulty aged 0-18 years. There are no additional criteria or waiting lists for accessing this service and in the event that their case-loads reach over-capacity, they pass the families with a lower-level of need for support over to the key workers within the non-disability strand of the division.

Caerphilly

Following the demise of the Lead Professional service in ISCAN West last year, there is currently no 'Key Worker' model of support currently in place in Caerphilly for families who have children with disabilities or developmental difficulties.

Summary

There are 'pockets' of care coordination services currently in place in Newport, Torfaen and Monmouthshire, that aim to empower families who have children with a disability or developmental difficulty by providing them with support, information and advice to varying degrees. In Monmouthshire the support is aimed at signposting, advising and providing information to families at a low-level of need, and in Newport and Torfaen the support is aimed at providing practical and timely interventions to families with a high-level of need but with different criteria and levels of support.

There are some good examples of services that support families under the Families First scheme, and from which to learn good practice from, however with each local authority developing their own programs under the scheme; support, criteria and waiting lists vary hugely for families depending on where they live.

The gap in provision across Serennu, and across the whole of Gwent, is for a consistent, equitable and sustainable service tailored to meet the needs of families who have a child with a disability or developmental difficulty, which enables them to access the right support at the right time.

Appendix 12

Care coordination service models in the UK

During the period 1st July to 30th September 2016, care coordination service models across the UK were scoped in an attempt to identify 'flagship' organisations with excellent models of care co-ordination; integrated service models that work in partnership to provide holistic support to families who need additional help from a designated Care Coordinator or Key Worker.

Identifying 'flagship' models of care co-ordination will assist with providing a platform for comparison; help to identify 'gaps' in the way that professionals at Serennu currently support families to coordinate care for their children, and provide an effective framework by which to learn from and adapt services and support offered to meet the needs of families attending the centre.

The research began locally in Gwent and then spanned out to Wales, which identified 'pockets' of care coordination services, however none identified as flag-ship in this country. These are described in more detail in the next section.

The research then went further afield to England, Ireland and Scotland, where two service models were identified in England; one in Lincolnshire and one in Cornwall.

Lincolnshire Council – Early Support Care Coordination (ESCO)

Early Support Care Co-ordination (ESCO) aims to improve the delivery of services for disabled children, young people and their families in Lincolnshire. The service provides families with a single-point-of-contact who enables the co-ordination of activity between services, providing continuity of care through collaborative working, information sharing and signposting.

What is good about the model

- **Key Worker model** – single-point-of-contact for families.
- **Early Identification** - identifies children's needs early. Based on building trusts and mutual respect.
- **Needs-based** - recognises that families vary considerably, tailored/personalised to their individual way of communicating/learning.

- **Empowering** - responds in a way that ensures the child, young person and their family feel more in control.
- **Fluid model** – engages community-based professionals in a step-down approach.
- **Holistic** - child & family at the centre.
- **Partnership working** – it is focused on supporting services and practitioners to work in partnership with each other and with children, young people and their families.
- **Raises standards** for children and young people with disabilities.
- **Doesn't duplicate the work of other services** - finds services instead of filling gaps in services that are not there.
- **Identifies changes in families' needs over time.**

Families supported by this model include children and young people with;

- Long term complex health needs including those with disability
- Life limiting conditions and palliative care
- Cognitive, sensory and/or physical impairment that significantly impacts on daily living
- Autistic Spectrum Disorder
- Behaviour that is associated with other impairments such as severe learning disabilities.

The typical length of time spent supporting with a family is between 6 months – 1 year. Typically, Care Coordinators will spend 3 hours with a family every 6 weeks and about 3 hours then doing the paperwork, chasing professionals or services, writing or updating the plans, ringing or emailing, and trying to solve the small problems for these families. This might include looking at the wider needs, including financial issues, O.T adaptations, housing issues, checking their benefit entitlements or helping them complete DLA forms.

Early Support is a way of working that helps to identify children's needs early and respond in a way that ensures the child, young person and their family feel more in control. ESCO is underpinned by the '10 Early Support Principals'. These principles include enabling children, young people and their families to make informed choices and participate in shaping and developing the services that they use, valuing the uniqueness of children, young people and their families and ensuring service delivery is holistic, co-ordinated and seamless (Lincolnshire ESCO).

Cornwall Council – Supporting Change in Partnership (SCiP)

In 2015/2016 Cornwall Council participated in the 'Social Care Innovation Programme' (SCiP), an incentive program lead by the Department of Education in England. This program provided an opportunity for Cornwall Council to test an innovative, preventative, solution-focused approach to working with disabled children, young people and their families. This service was evaluated throughout the 9 month pilot phase.

The service was aimed at providing early intervention for families and a proportionate way of providing support, thereby reducing the need for some families to enter statutory social services. The model also listened and responded to the voice of the parents, who had consistently said that the best way to receive information was directly from other parents, and trained parents would be able to provide empathetic support. As a result they utilised the strong relationship already established with parents of children with disabilities and developmental difficulties in Cornwall and incorporated them into the program as trained parent volunteers. (Cornwall's Social Care Innovation Programme, pg 4 & 5).

The SCiP service is for families that require a practical intervention. It is a preventative, time limited approach that sets out to improve outcomes for children with disabilities and their families. It is solution focused, fosters new skills in families and celebrates success. It aims to respond quickly to children and their family's needs and is delivered by Early Support Workers and trained Parent Volunteers.

What's good about the model?

- The model has good joint partnership working across two organisations that established the model; Cornwall Council and the Parent Carer Council, which is a voluntary organisation.
- Parents are involved in making decisions and setting their own goals from the start of the intervention, with the help of the professional, and identifying 3 goals to work on, which made problems seem more manageable for parents.
- Following a successful pilot phase, the Disabled Children and Therapy Team decommissioned some other services within their budget to continue to fund the delivery of the SCiP service today.

The SCiP service was evaluated throughout the pilot phase and the recorded outcomes are as follows:

Outcomes Identified

The identification of “quick wins” (support strategies to manage challenging behaviour). They are as follows; introduction of visuals, signposting and support through referrals to other services, giving parents confidence in managing child’s behaviour, improving relationships with schools, providing consistency between home and school settings.

The identification that there is a ‘need’ for this type of service model approach that works for families who have children with disabilities. This reinforces the need for a skilled, knowledgeable experienced workforce. At the end of the program, parents involved in the pilot phase talked about the intervention being “life-changing”.

There was a clear distinction between the work that the Early Support Worker did to that of the Trained Parent Volunteers, providing a step-up, step-down approach; ESW’s were more effective at providing the intervention work, and the Parent Volunteers were good at signposting and providing information and access to community groups. The mix of staff and trained parent volunteers worked really well.

Parents identified that they wanted the approach to be pro-active, direct work from skilled professionals and not just about co-ordination of a team around the child.

This new, innovative approach to working with families generated enthusiasm in professionals across the field, and staff reported wanting to work in this way.

Working with families directly identified short-falls and gaps in other service provision, for example support for families on the ASD diagnostic pathway (waiting list 12 months).

What didn’t work well?

The outcome of the pilot was that not all parents or staff felt that interventions could be completed within 12 weeks. This needs further exploration and is included in their 16/17 action plan. The intention of the approach in the pilot phase was to ‘empower, manage expectations and reduce dependency’, however at the time of the evaluation there was incomplete data on work still undergoing, but parents were still reporting not being treated as experts in their own children, not being responded to and feeling ignored.

Weaknesses in evaluation

The independent evaluation of the 'Social Care Innovation Programme' has yet to be published, therefore the only evaluation available on this service is the evaluation they did themselves as part of the pilot phase.

That being said, anticipating that the work being piloted would create successful outcomes for children with disabilities and their families, Cornwall Council began identifying alternative sources of funding several months before the funding for the pilot phase ceased, ensuring sustainability of the service. The Disabled Children and Therapy Team decommissioned some other services within their budget to continue to fund the delivery of the SCiP service today.

Summary

'Flagship' models of care coordination across the UK are sparse. Only a small number of local authorities across the UK were identified as using 'designated' Key Worker models of service to support families who have children with disabilities/and or developmental difficulties, most of which are targeted in early years provision, rather than up to 18 years of age, with the exception of Lincolnshire's ESCO and Cornwall's SCiP models. Both of these models aim to improve the delivery of services for disabled children, young people and their families by supporting families with a Key Worker; a single-point-of-contact who enables the co-ordination of activity between services, providing continuity of care through collaborative working, information sharing and signposting.

The services are effective because they:

- Work in partnership
- Empower families by involving them in decision-making
- Provide early emotional and practical support

In summary it was not possible to identify one particular flagship model of care coordination that would assist with providing a direct platform for comparison at Serennu, however there are elements of good practice in both service models in which learning can be taken.

Appendix 13

Case Study 1 – Parent with the support of a Care Coordinator

Cerys is 19 months old and has West Syndrome – a rare form of severe epilepsy.

I definitely think I'd have given up a long time ago if I didn't have the support from a Care Coordinator. I think I would have been ill. Looking after a child with a rare condition is hard, even now I dread going to hospital because the amount of people that look at you like you've got 6 heads when you say 'West Syndrome'. It was the same when our Cian was little, as 18 years ago no-one had heard of Autism, it wasn't as well known.

So it's so much easier to have a Care Coordinator because I can say "can you get hold of Cerys' doctor ahead of her appointment please, and ask him to notify them that I'm going in and explain what she needs?" It's amazing, absolutely fabulous. Anything, if I have any problems with anything...for example Cerys' Doctor prescribes Cerys' medicine which is Vigabatrin. Now Cerys takes 500mg a morning and 500mg at night, which is more than most adults would take. So the doctors who have to write the prescription and send it to the chemist which is normal practice, the chemists always question about giving her it and at one point I went to the chemist to pick it up and the woman in the chemist said that the Pharmacist had totally refused to give it. I tried to get hold of Cerys' doctor but couldn't, so my next step was to call the Care Coordinator. The very next day the medicine was in the chemist waiting for me. I don't know how she did it but she did it. The following week I received a letter through my door, which was also copied to the GP surgery and the chemist from Cerys' doctor saying that he was the baby's consultant and that under no circumstances were they to refuse distributing Vigabatrin unless he specifically told them to do so. We haven't had a problem since. If it hadn't have been for the Care Coordinator I wouldn't have been able to get her medicine because I wouldn't have known who to phone next. She knew instantly what to do and who to phone. The following day my daughter had her medicine, which ultimately saves her life. Without that medicine....we wouldn't have Cerys....because she would still be fitting constantly.

Cerys was born early at 30 weeks, she only weighed 3lb 10 but she was fine. Obviously she was in hospital for the first 5 weeks but then she came home and was doing amazingly; at 6 months she started solids, loved food, learning to sit up, a normal 6 month old baby. However she always did what I used to call a 'frog-jump', which is like you know a new-born baby if you clap your hands and you startle them, they do a little jump with their arms and legs spread out, like a frog. Well she always did that and I started to think 'oh this isn't going away' and she seemed to do it more and more the older she got.

Then at 7 months old I was actually in the shop and Cerys started doing it in her buggy but it wasn't just once or twice, she carried on doing it, so I took her to the Chemist next door and picked her up out of her buggy and gave her to the Chemist. He put her on the worktop and wiped everything off the side and Cerys was doing this frog-jump but she was also bending in half and then relaxing again, and she did that for 33 minutes, so we rushed her down by ambulance to Resuscitation, she was actually fitting for 33 minutes. She went on then to having 30 fits a day for 2 weeks because the doctors didn't want to stop her fits or give her anything because they wanted her to wait to have a brain scan, which could only be done in St Woolas, but because she was unstable because she was fitting so much we couldn't get her down there. When she finally went to St Woolas and had a brain scan, the same day I was told that she had really rare condition called West Syndrome. From that point onwards, from that first fit, she was a different baby, she looked different, she didn't smile, she couldn't eat, she couldn't sit up, and it was like having a new-born baby all over again. She regressed straight back into the baby that was born into intensive care, she even had the feeding-tube put back in.

I got told then that she may not ever learn to smile again, or sit up, or talk, or walk, or do anything, and then they started her on Pregnesclone, then she got put on a high-dose of steroids which they said would stop the fits, in most cases it stops the fits, but in Cerys' case it didn't, and when we got sent home then she was on 60mg of steroids a day, which made her put on loads of weight, plus a really high-dose of

epilepsy medication a day. The steroids she could only be on for 6 weeks because it can cause liver damage in young children but the steroids did absolutely nothing at all.

Then because her development went so far backwards obviously lots of people started getting involved; Occupational Therapists, Speech and Language, Dieticians, Epilepsy Nurses, Epilepsy Doctors, etc, etc, etc. I had to go to Cardiff to see one doctor because the doctors at Neville Hall had never heard of West Syndrome, so they're liaising with other doctors because nobody knew how to do anything really or how to treat it. So at the beginning there were so many people involved that I didn't know who was who, they'd come in and say 'oh you know your Dietician, Claire' and I'd be like 'who?' because there were that many services and you'd see that many people, constantly. Even now, there are still a lot of people working with her.

At first they tried to get Social Services Children with Disabilities team involved due to the amount of care that she would need at home but they didn't want to know. I tried phoning them and tried referring myself, the hospitals phoned them and they had big meetings and invited them but they wouldn't turn up, so then someone actually mentioned the Care Coordinator to us and then she got involved. I believe that someone put a referral through to Social Services and said that if they were not going to help then could they get somebody else to help, which is when I received a call from the Care Coordinator. I had been home about 3 weeks by the time I met her. So for the first 3 months I was totally on my own because Social Services just didn't want to help because of my baby's age. They argued that I'd be doing the same thing for her anyway because she was a baby, but I said "well you wouldn't be watching a baby for 24 hours a day on a feeding machine." I'm a bit more relaxed about it now but even now going to the toilet I'm still rushing incase she has a fit...because she can fit at any time.

So then we got told, because of her needs, that we'd have to move house, my old house had a lot of steps so pulling that wheelchair up and down was horrendous because I'm only 4ft 11, and she's going to get a lot bigger and we still don't know, even though she's smiling now and bum-shuffles across the floor, she's doing everything the doctors said she wouldn't do, it could be that she has another big fit and she goes right back to

being a newborn baby again. So we needed a home that was set-up, ready, if she did have that big fit, so it wouldn't be one big rush and trying to look after her needs then.

So the Care Coordinator came in then and she was amazing. She came in and whittled-down to me talking to her if I need anything, whereas before if something went wrong with a wheel-chair I'd be phoning the hospital to try and get hold of Physio, and if the Physio wasn't there I'd have to wait until they got back to me and it could be days if they ever got back to me, that's if the receptionist passed the message on. So now I just pick up the phone and phone the Care Coordinator and I say "this problem has gone wrong". Even with housing and the struggle I had with moving was unbelievable because housing just wasn't interested, not at all, and I'm still fighting them now. They caused more stress than the baby being ill. The Care Coordinator did call one big meeting with all the professionals that I couldn't go to as I was in hospital with the baby, and I think she actually went and sat in the Social Services office and said "you need to help this family". Then she went to her manager and said "you need to be involved, she needs help moving, she has other children with additional needs, the house isn't safe for her to live in". Social Services did get involved then, although I've not seen them for 4 months, I think the last time I talked to them was the 21st March. So the Care Coordinator does everything. If it wasn't for her I wouldn't have this house, my kids wouldn't be safe...she wouldn't be safe. She said to me "I've told the housing organisation that if you're not moved within 6 months then your children are going on a risk list because of the house, because it's not safe for a wheelchair, your daughter cannot have respite here". I don't sleep you see because Cerys is on a feeding machine 19 hours a day. So even though I could sleep, I'm awake thinking 'what if'? What if she roles and the tube gets stuck under her neck? The tube is always setting the machine off, especially as it kinks, so if she lies on her face it kinks and sets it off. So I'm up 3 or 4 times a night with the machine, even though she sleeps all night. So the Care Coordinator was amazing but the housing company didn't help me what-so-ever, but the Care Coordinator - she's like a rocket - she doesn't let it drop - she was onto them every day and even now she's been on to them because there are still issues. I had to wait 6 weeks for the keys to this house and the housing organisation said that they wanted 2 houses paid

for. I can only move on Tuesday when she has respite, I can't leave her with anybody else because of the machines and all the medication she's on. So the Care Coordinator worked with me to work out how we could get 2 houses paid for, because the only thing the housing organisation was worried about was getting their money. Even though I had the keys I couldn't move in to this property for 2 weeks because all of the work they said they had done hadn't been done but they still wanted me to pay the rent!

The Care Coordinator helped with all of this, she has been amazing, absolutely amazing. She has helped me with my other daughter Ffion as well, even though I'm not sure if that's her role. I'll pick up the phone and she'll say "oh you sound down today, what's the matter? Is the baby alright?" and I'll say "no, it's FFion, she's refused to go to school" and even she has said that I need to get her assessed too, to get her the right support. She's there when I need her. I know I can pick up that phone, no matter what time of day. If the baby is bad Sunday night I know I can text the Care Coordinator first thing Monday morning and she's on it. It's just easy. I wouldn't have been able to cope these last 6 months if it hadn't have been for her. Definitely with the housing issues, well I'd still be living in a house that wasn't safe for my kids, because I would have given up. The housing organisation said to me at first that if I wanted to move into a 4 bedroom house with wheelchair access I'd have to move to Newport. I explained that I didn't know anybody in Newport and there would be no-one I knew to help me out at 3 o'clock in the morning if Cerys is ill and needs to go to hospital. Who is going to look after my other children? So I would have just given up, I'd have just managed, I'd have just coped. But the Care Coordinator didn't let it drop. She said to them "no, you are there to help that family". So she made this house safe, she made my kids safe really. She has been amazing.

Yesterday I had respite, the Care Coordinator organised for me to have respite in the day because I don't have a break. At the moment I get 8 hours on a Tuesday but even the nurses, who are from Serennu, they don't really know what West Syndrome is and they panic when she does something new, like yesterday, she had some new nurses yesterday and she was sick, which she is sometimes due to her condition. So yesterday

she was sick 3 times on the nurses, just bright green, and they panicked. So yesterday I received a call from the nurses at 12.30pm saying could you come home just to check her please and we don't really know what to do. Do we stop the feed or carry on with the feed? So I don't really get a proper break. This is why I found moving so difficult as well because I can only move on a Tuesday when she's having respite and go up to the old house and do what needs to be done to move out. The housing organisation said that I would have to pull all the wooden floor up that I'd had fitted, pull all the decking up in the back garden, fill all the holes where you've put pictures on the walls, all the rooms need to be painted magnolia, otherwise we're going to fine you. I don't drive but some of my family had said they would help me and they organised to take time off work in 2 weeks time when they said I would get the keys but the house wasn't ready for another 4 weeks and by that time it was too late, they'd taken their leave and had to go back to work. So it's just been me. It's just been me going up there on a Tuesday during my respite and then at 12.30pm I had to come home as the nurses didn't know what to do.

The Care Coordinator is understanding, she looks at you and sees the bigger picture, the whole family and understands the difficulties that I am having managing a baby with significant needs, it doesn't just affect the baby, it affects absolutely every aspect of your life. On a day-to-day basis, even to go out shopping you have to plan. My friends used to phone me and ask if I wanted to go out but I would have to plan ahead - extra clothes to pack if she's sick, you've got to take water to do her feeding machine, you've got to charge the feeding machine beforehand for a day, its mammoth! My friends stopped asking me if I want to go out now. And the Care Coordinator sees that. I won't call it a struggle because I don't see her as a struggle.....but it is hard work.

It's so much hard work and the Care Coordinator sees that but the other organisations, the housing organisation, and the other organisations involved, they don't see that and they expect you to do all of these things with an ill baby, 4 other children who have needs too, Cian with his Autism is difficult and found moving house extremely difficult. Ffion has her own difficulties and challenges too. I would have given up. My day is

looking after my children and at the moment that is all I have the energy to concentrate on without having to fight everything else as well.

Appendix 14

Case Study 2 – Parent without a Care Coordinator

My daughter, Olivia, is 5 years old and has West Syndrome, a rare and serious form of epilepsy, which also gives rise to Global Development Delay. Permanent damage often associated with West Syndrome includes cognitive and learning disabilities, speech, language and communication difficulties, poor muscle development, walking issues and behavioural problems.

Olivia was diagnosed with West Syndrome at 5 months old, however my husband and I had concerns with her development prior to that, but being first-time parents we thought she'd be fine. She'd had a few instances of looking like her eyes were glazed over, so we took her to the doctors by which time she was fine again and the doctor said there was nothing to worry about. Unbeknownst to us she was actually having seizures. Then one day I was feeding her in her high-chair and she had a fit and went in and out of consciousness, so I called an ambulance and we rushed to the Gwent, where we spent two weeks while she was diagnosed with West Syndrome. We were told at the time to expect that she wouldn't lead an independent life but to what extent it was not known, and still now we are taking it on a day-by-day basis.

We were discharged from the Gwent, with Olivia on a very high mix of drugs, and her immune system was very low, so we had to go back to the Gwent every two days. She couldn't mix with anybody during this period because of her immunity and chicken pox would have been really serious for her, so we were quite isolated. We weren't given anyone to help us coordinate all of this, you are very much discharged and given a raft of appointments and you are kind of 'on your own'. I had no support from my Health Visitor at all and I didn't have any family support either; I had recently lost my dad and brother within 12 months of each other, and during the time of Olivia's diagnosis I lost my mother-in-law suddenly to cancer. I had no support from anybody, so there was me who had no family, a child who had just been diagnosed with a life-changing condition, and no support was offered at all. I found that really quite shocking. I did actually

write a letter to the head of Aneurin Bevan health board but didn't actually send it because I was that shocked.....but anyway.

So we were told that we were eligible for Portage and waited for quite a while for a lady to come out and assess Olivia. We were then put on a waiting list because the lady that would be our Portage lady was on maternity leave, and during that time we just had to 'get on' with life and carry on ferrying Olivia backwards and forwards to the many, many appointments that she had. I was on maternity leave at the time and had planned to go back to work part-time but because of the huge number of appointments that she had it just wouldn't have been feasible, some days she would have 2 or 3 appointments on the same day that were in different places, Chepstow, Newport, Serennu. It was full-on, full-on; at least 1 a day, 3 a week. There wasn't a week that went by when there wasn't at least 2 appointments.

So I wasn't able to go back to work and it was just left to me to coordinate it all. I'm actually quite an organised person and I just thought 'this is how it is, just get on with it'. When we finally had Portage I realised it shouldn't be that way. Our lady, Trish, was amazing. She went far beyond her duty. She was one of those people that if I said 'I'm expecting a call from Physio but they haven't rung me back' she would say 'right I'll contact them' and she did, she was a do-er, she always did what she said she was going to do. She was doing the role of a Care Coordinator, helping you and facilitating and getting departments to ring you back that hadn't rang you, knocking on doors and making people do their job. Trish became my main point-of-contact for everything. She was a god-send and we're still in contact with her now...she dropped a present off for our newborn twins. A real, real lovely lady. Absolute asset to the team.

You just kind of go day-by-day, you have no idea of what's ahead, I had to ask at the time of diagnosis 'will she be able to walk and talk?' and it's like any developmental disability, like Autism, it's such a huge spectrum and they couldn't tell you, but Olivia was doing really well and I guess me giving up work and being able to plough my time into her helped her development. She's coming on really well but there is still a noticeable disparity between her and her peers. But the days and the weeks and the

years tick by and it just becomes 'normality' and you look back at that time and you think 'gosh, however did I get through it?' but you do, like anything that you're faced with, you just have to get on with it. It's not until you look back that you realise what you went through and had to deal with.

You can see how children who come from chaotic families would slip through the net, you know, if you're not an organised person, I mean I run my life through my calendar in my iphone that alerts me about appointments because I've set it up to do that, but not everyone is like that, and if you were just left to flounder like me with loads of appointments a week and you are an un-organised person, or you couldn't drive and had to get buses, you can see how, without help, people would really suffer and children would slip through the net. Just somebody that is there at the end of the phone, because sometimes it does get too much and you just feel like 'oh god I can't cope with this' and you're on a merry-go round of appointments and you've got no life and you're just continually taking your child to one appointment after the next, your life is just sat waiting, and you're late for everything, you know. And then it's the same again the next day.

We didn't get any support, you just go to your consultant appointment and they were quite 'well how is she doing?' kind of thing, very clinical. She would write referrals to speech and language or physio but that was it. We were just told that she would do a referral and we would go away and just be waiting, waiting, waiting. It wasn't really any help as such, more clinical.

It would have made it easier having the support from the beginning, as having your child diagnosed with a life-changing condition you've got all of that to deal with and your own grief, especially when you've got a child that you don't know what the outcome is going to be of how they are going to be when they're older, you just don't know. If your child is diagnosed with x, y and z and you know what they'll be, you can do your grieving and get to grips with it and move on, but when you're living on a day to day basis of not knowing what your child will be, if they'll be able to walk, if they'll be able to talk, if they'll lead an independent life, then that wound is always open. You can't get closure on

it. If you can just pick up the phone and have a good rant, or a good cry, that would help at times, everybody needs that and then you feel better for it, you feel stronger to get on with it.

The whole family need to be taken into account, not just the child and their disability, but the whole dynamics of the family, like for me I had absolutely no family to help me through it. My Health Visitor was not helpful. After Olivia was diagnosed I approached her because I thought I was suffering with post-natal depression with everything that was going on. She said she would have to refer me. I didn't hear back from her so I chased it up and was told that she had left and that I would get a replacement, however no-one followed-up my concern and to this day, 5 years later, I still haven't heard anything about a referral and no-one has contacted me to check I'm ok. I took the initiative to get private psychological counselling, which really helped, but not all families would be pro-active like me or have the money to afford private help.

Appendix 15

Professional Case Study 1

Child Development Advisor, Portage, Serennu Children's Centre.

The child development advisory service works with families whom have a child under the age of three with significant delay in two areas or more of their development. We work with the families in their home and visit on a fortnightly basis. We assess the child's development using the Portage check list through observation, talking with the parents/carers, liaising with other professionals involved and by playing with the child. We discuss our observations, set targets and demonstrate how to work with the child to help promote their development. As well as working on the five areas of a child's development we will give advice and support with sleep, toileting, eating, behaviour strategies and attachment. If other professionals are involved with the child we will often make joint visits with them and incorporate their programmes with ours. Another part of our role is to write a detailed report on the child's development to support diagnosis and for statutory assessments.

I started working with a two and a half year old girl (Gwen) whose referral presented her as having a severe social communication difficulty and a significant cognitive delay. She lived at home with her mum, an adult brother and two teenage sisters. Her father was active in her life and still in a relationship with mum but not living in the house. The first visit when you begin to work with a child and their family involves getting to know the child, understanding the child's ability by beginning to assess the child using the Portage developmental check list and to be updated by parent / carer about any therapies that are now involved and any additional information about the child's difficulty or diagnosis. During this visit a strategy to use with the child should be demonstrated, discussed with the parent and left for the parent to use until the next visit.

It became apparent that there were greater issues than Gwen's difficulties that were causing mum a lot of anxiety and stress and that mum was not in a place to take onboard strategies to use with her child. Mum discussed that the house was not meeting her daughter's needs; it was over crowded and unsafe for her. Mum had difficulty with the neighbours over parking. There were limited parking spaces and mum needed to be able to park outside her house as moving Gwen between house and car could be problematic. The garden is overlooked by a block of flats and she reported that people had shouted abuse from them about her daughter. She was also worried that Gwen's buggy was not strong or big enough for her and that she did not have the funds to buy a specialist one. She was also struggling to buy Gwen suitable sensory toys. There was a concern about paying for a playgroup place for Gwen

and getting support. There were concerns about finding an LEA nursery place and would she be accepted. On top of all these issues mum was struggling to deal with her youngest teenager's depression and suicidal thoughts. They were getting support at the time from CAHMs but mum was feeling overwhelmed by it. Mum made it quite clear that she felt totally alone and didn't have any support to deal with her issues.

There were two options to come out of this visit. The first was that I would help support mum to deal with as many of the issues she raised. This would involve me finding a suitable playgroup for Gwen and applying for one to one support funding to Welsh preschool providers association. Helping mum then apply for a nursery place and apply for statutory assessment to be carried out via the LEA. I would need to liaise with housing to get the family assessed for a more suitable house. To liaise with occupational therapy services to get the new house suitably adapted for Gwen's needs. Apply for a blue badge and arrange a meeting with the council to discuss numbering the parking bays. Applications to various charities would have needed to be made to apply for a specialist buggy and sensory toys. There would also be the time needed to support mum to organise child care for Gwen when her daughter had appointments and to coordinate the appointments for both children.

The other option was to refer Gwen to care coordination and this is what I did. The referral was accepted and mum had been visited by a care coordinator before next visit.

The difference between the two visits was remarkable. Mum was calm and happy to engage, I was able to assess and discuss Gwen's development with mum and leave a programme for mum to follow. Mum did occasionally start talking about the issues that were going on but they were talked about in the context that she is now getting support to deal with them. If the referral hadn't been accepted by care coordination my time would have been dominated in trying to sort the family's issues out. I would have had to have spent hours telephoning, writing and arranging meetings with various services. These issues would not have involved one phone call, form or letter but ongoing activity. I believe that only when the issues were sorted that I would have had time to work with Gwen and her mum and that could have easily taken over six months. There would have been a huge impact on my work load and it would have affected how much time I could give to other families. This referral was accepted because of the complexity of the child and family situation and the need for care coordination was obvious. I have many families that are not accepted for care coordination due to not having a medical need but their need is just as great and if not greater in many cases but this hard to demonstrate to social services. With these families my role is dominated by needing to support the families and this greatly impacts my work load.

Appendix 16

Professional Case Study 2

Occupational Therapist, Serennu Children's Centre

I took over a case from an Occupational Therapist colleague for a 12 year old boy called Llewellyn Griffiths. Llewellyn has Down Syndrome and at the time had recently transitioned to secondary school. When I took over the case, the occupational therapy related issues that needed to be dealt with included mainly specialist equipment, including obtaining accessories for his home chair, getting him a bigger school chair, referring him on to wheelchair services for a bigger wheelchair, and co-ordinating him getting a specialist bed. I also referred him to a Social Services Occupational Therapist to look at long-term housing issues as Llewellyn had to be carried up and down the stairs by his parents, Mr and Mrs Griffiths, and the family home could not be adapted.

There were a couple of issues that arose in the time that I was working with Llewellyn and his family, that were outside the scope of my role, that had there been a Care Co-ordinator in place, this could have been dealt with by them. A number of different medical issues coincided at once, including cardiac issues, increase in seizures, increased frequency in chest infections, leading to insertion of a naso-gastric tube and restricted diet to improve his chest infections, orthopaedic issues with his subluxed hips reducing his mobility and an emerging spinal curve. Llewellyn needed surgical interventions, but was at high risk from the anaesthetic, and required multiple procedures/ investigations across different hospitals in different trusts (England and Wales).

When I approached the Social Services team at the time to ask if Llewellyn and his family were eligible for care co-ordination, I was told that he would no longer meet the criteria as he was too old (age 12), and he didn't meet the criteria for Social Worker input either. Although I was addressing Mr and Mrs Griffiths' main concerns, the family acknowledged that they were using me as a substitute social worker and that the issues I was supporting them with were outside of my core role. These included accompanying Mr and Mrs Griffiths to medical appointments at their request as they were not happy with the advice they were being given, and felt that there was poor co-ordination amongst medical professionals in relation to the investigations and care that Llewellyn was receiving. I went to speak with the Paediatrician privately to explain that the family were requesting care co-ordination, and that they felt that there was poor co-ordination of different medical professionals. The Paediatrician showed me numerous emails regarding management of his care, but as this had not been shared with Mr and Mrs Griffiths, they were unaware of these dialogues.

As a result of providing the family with the support that they needed, in effect I kept the case open for longer than necessary, causing confusion of roles and blurring family's expectations of our core service. Mr and Mrs Griffiths described that the insurgence of all the medical issues all around the same time reminded them of the episodes that Llewellyn had as a baby, when they did have access to the care co-ordination service, which played a crucial role for the family at that time, and that was the model of care they were looking for at that time, even though they were grateful for the support I provided.

Appendix 17



Supporting Children & Families is Everyone's Business

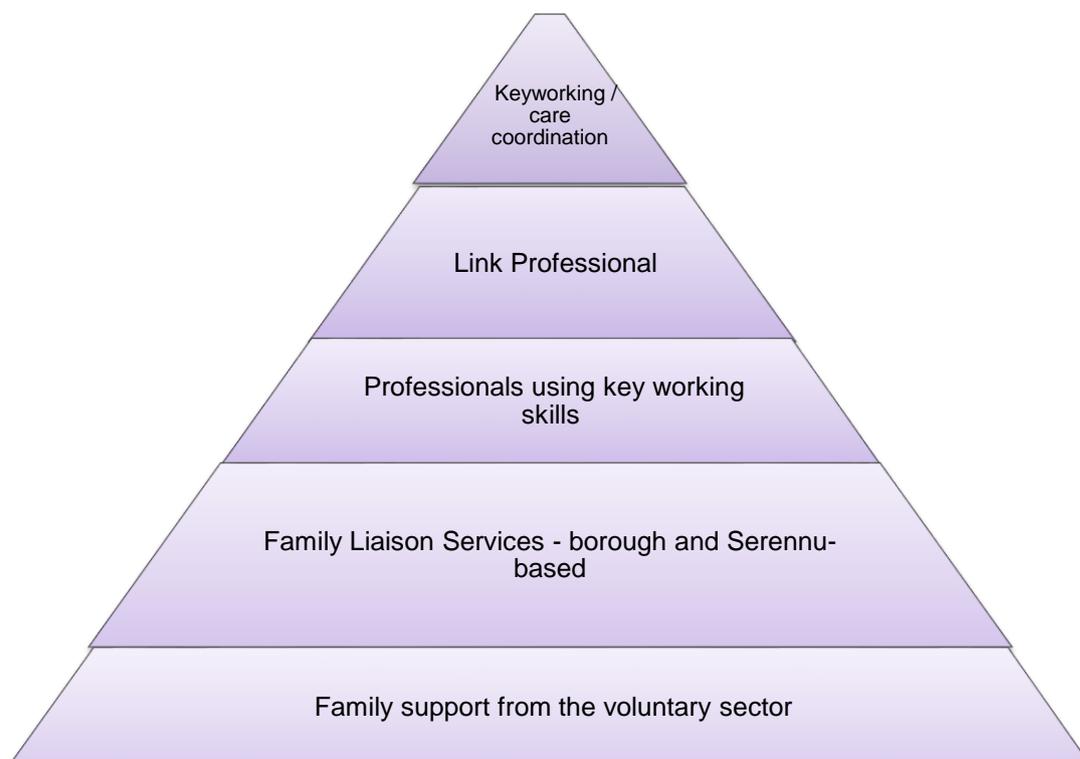
Developed by the
Serennu Care Co-ordination Forum
February 2016

This document 'Supporting children & families is everyone's business' has been developed by the professionals and parents who are members of the Serennu care co-ordination forum. It has been developed as part of a family support model (below) and is considered integral to an overall strategy aimed at changing the culture in which we work such that families and professionals work more in partnership and with mutual respect.

The 14 charter statements are intended to create a framework that enables families and professionals to work together in harmony where the needs of children are central and the role of the 'link professionals' places an onus on professionals to support families as much as is reasonable and practicable within their core roles.

The MAPIT early years tool provides us with 10 principles that guide and underpin service delivery for children and families. Within the tool a series of **Early Support in Action** statements are identified and presented as standards against which service provision and service improvement can be considered and evidenced.

The MAPIT tool has been mapped to the Serennu Charter to further strengthen our understanding of how families and professionals can best work in partnership for the benefit of children and young people.



Serennu Charter

- The needs and welfare of children is paramount and the voice of children will be listened to and heard.
- Supporting families is everyone's responsibility.
- Families and professionals will work in partnership and with mutual respect.
- Professionals will work in partnership with other professionals.
- There will be a commitment from all professionals to assist parents with queries even if it does not relate to their role.
- Families will be kept informed at all times whether it is positive or negative information in the spirit of honesty and transparency.
- Families will be listened to and will receive open and honest responses from professionals.
- Families will have help with navigating services e.g. named professionals, duty desk, Serennu family liaison officer.
- Families will be offered joined up appointments where appropriate and feasible.
- Parents will always get to talk to a member of the reception staff if they phone the centre between the hours of 8.30 am and 5.00 pm (4.30pm on a Friday).
- Formal handovers will be an essential part of multi-disciplinary team practice in the interest of seamless care.
- Support for families will be flexible and responsive to their needs at that particular time.
- Families will be supported to understand any individual plans for their child.
- Every effort will be made to support families during staff absence due to sickness, maternity leave or vacancies

Early Support Multiagency Planning and Improvement Tool (MAPIT)

Principles:

1. Wherever possible, families are able to live 'ordinary lives'.
2. The uniqueness of children and families is valued and provided for.
3. The care that disabled children receive is based on joint assessment, planning and review processes that keep parents and carers at the heart of discussion and decision-making about their child.
4. Children and families experience service delivery as holistic, co-ordinated and seamless, facilitated by a key worker where appropriate.
5. Families experience continuity of care through different phases of their engagement with services.
6. Children's learning and development is monitored and promoted.
7. Families are able to make informed decisions.
8. Families and children are involved in shaping and developing services.
9. Working practices and systems are integrated.
10. Families can be confident that the people working with them have the training, skills and experience required to meet their child's needs.

Linking up **MAPIT** and the Serennu Charter

Charter Principles

MAPIT Principles

<p>The needs and welfare of children is paramount and the voice of children will be listened to and heard.</p>	<ul style="list-style-type: none"> • The knowledge and understanding that a family has of a child’s needs and strengths is valued and used as a core part of joint assessment, planning and review processes.
<p>Supporting families is everyone’s responsibility</p>	<ul style="list-style-type: none"> • Joint discussion and planning is managed in a way that shares skills and minimises workload for everyone involved. • Families receive information that is accessible, uses everyday language and where appropriate, is available in a variety of alternative formats, media and languages. • It is clear where strategic responsibility lies for reviewing and improving the quality of integrated service delivery for families with young disabled children.
<p>Families and professionals will work in partnership and with mutual respect</p>	<ul style="list-style-type: none"> • When families are using many different services, practitioners work together in partnership with parents and carers, as a team. • There is an agreed process for identifying family strengths, needs and wishes that is sensitive and takes account of family diversity. • Families are given clear information about assessment procedures and practices, why they are needed, and how their contribution will be valued.

	<ul style="list-style-type: none"> • Families are offered appropriate training and development opportunities. • The views and experiences of families are used to inform local reviews of policy and practice, and planning for service improvement. • Parents and carers are encouraged and enabled to contribute to the strategic planning and development of services. • Joint discussion and the writing of Family Service Plans is managed in a way that promotes partnership working with families and reflects their priorities.
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<p>Professionals will work in partnership with other professionals</p>	<ul style="list-style-type: none"> • Where appropriate and possible, services work closely together to improve the quality of life for families in the home.
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<p>There will be a commitment from all professionals to assist parents with queries even if it does not relate to their role.</p>	<ul style="list-style-type: none"> • The role of lead professionals or key workers in facilitating joint assessment, planning and review processes is clearly defined and understood.
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<p>Families will be kept informed at all times whether it is positive or negative information in the spirit of honesty and transparency.</p>	<ul style="list-style-type: none"> • Families receive information that is accurate, up-to-date, relevant, joined up and tailored to their individual needs. • Families are given copies of any assessment results and reports relevant to their child. • Local policies and protocols
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	<p>supporting the sharing of information about families and children are defined and understood.</p> <ul style="list-style-type: none"> • Policies and practices are in place to support the sensitive sharing of information about disability or complex health needs with families in the early days.
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<p>Families will be listened to and will receive open and honest responses from professionals.</p>	<ul style="list-style-type: none"> • Families are supported to understand information over time and in the context of their own circumstances.
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<p>Families will have help with navigating services e.g. named professionals, duty desk, Serennu family liaison officer.</p>	<ul style="list-style-type: none"> • Families receive information that describes all the services, initiatives and provision available in their local area. • Families receive information that is accessible, uses everyday language and where appropriate, is available in a variety of alternative formats, media and languages. • Families are given information about the role of lead professionals or key workers and other services and how they can help. • Lead professional or key worker services are available to support families with young disabled children
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<p>Families will be offered joined up appointments where appropriate and</p>	<ul style="list-style-type: none"> • Where possible, appointments and the delivery of support and
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<p>feasible.</p>	<p>intervention are coordinated, so that family life is disrupted as little as possible.</p>
<p>Parents will always get to talk to a member of the reception staff if they phone the centre between the hours of 8.30 am and 5.00 pm (4.30pm on a Friday).</p>	<ul style="list-style-type: none"> • All families accessing services and settings feel welcome.
<p>Formal handovers will be an essential part of multi-disciplinary team practice in the interest of seamless care.</p>	<ul style="list-style-type: none"> • When families are using many different services, practitioners work together in partnership with parents and carers, as a team. • When a child is moving into a new childcare, early years or school setting, a transition plan is discussed and agreed with families that outlines how specialist and universal service providers will work together to support the child within the new placement and at home.
<p>Support for families will be flexible and responsive to their needs at that particular time.</p>	<ul style="list-style-type: none"> • When families move to another area or service, arrangements are in place to secure continuity of support and continued access to resources through the period of transition.

Families will be supported to understand any individual plans for their child.

- Family service plans are used to encourage the joint planning of multi-agency packages of care with families.
- When families are using many different services, assessment planning and review arrangements enable the development of agreed, shared priorities and integrated goals.
- The contributions of local joint assessment and Early Support planning and review processes are clearly explained and understood.
- Joint discussion and planning is managed in a way that shares skills and minimises workload for everyone involved.

Every effort will be made to support families during staff absence due to sickness, maternity leave or vacancies

- Changes in key personnel, including lead professionals and key workers, are managed to achieve continuity of care for families, and minimise disruption to working relationships between agencies.

Best Practice Guidance for Professionals Undertaking a Link professional Role

This applies to any professional working with children / young person with disabilities and developmental difficulties and their families

The expectations from any professional in this role would be as follows:

- To work with the family in a more holistic way being more aware of the wider needs of the child and its family.
- Alongside the core professional role to be more helpful and supportive to the family in any way that feels possible within the demands of your day to day role.
- To signpost children and families appropriately to other services to meet the child's and family's needs.
- To have an awareness of other professionals involved with the child and family to avoid duplication and to aid communication over key issues in the child's care and the family's needs.
- To have understanding and empathy for the family and to provide support for parents and carers on an informal basis e.g. liaison skills, signposting, listening.
- To be accessible for families in so far as families know where and when they can reach their link professional if they have questions or queries about their child's care on the understanding that their link professional cannot answer all questions but will help with sign posting.
- To support the family at time when continuity is an issue for as long as it is possible or reasonable within the constraints of the overall service demands. To encourage the team around the family (TAF) to consider staggered 'hand overs' at key stages of children's lives rather than an 'all at once' approach which can leave families devastated.
- To facilitate a natural transition to another link professional as appropriate to the child's needs or stage of development.
- To be aware of the key transitions in the child's life and to consider whether the family needs more support to ensure those transitions happen as seamlessly as possible.

- To attend or be aware of school reviews to be able to offer support to the parents/ carers in the join up of their child's health and education plan. *This is an issue for families whose children are not 'statemented'.*
- To undertake any paperwork that is necessary in terms of providing written information for the family as appropriate to the needs of the child e.g. profession specific reports / review reports / information about other services.
- To refer on for more formal key working / care –co-ordination if the needs of the child and or family demand more time than the link professional can give alongside their core professional role. **This is dependent on there being a service to refer to.*

This role is not a key working or formal lead professional role whereby the onus is on the therapist or other professional who is the family's link professional to arrange meetings, accompany families to appointments or deal with issues that they feel to be outside their scope of knowledge or experience.

However some of the skills and requirements for link professionals will be the same as for care co-ordinators and key workers but delivered on a more 'informal' level. It is difficult to be completely prescriptive about who does what and may depend on the family's needs and preferences for who supports them, when and how.

In essence the key role of a link professional is to be able to chat about or discuss the general well being of the child and family i.e. pre-school or school, out of school activities, family activities, general health, well being and coping strategies of both child and family and aim to find designated experts to provide support, information and advice if needed.

This link professional role needs to be viewed in the context of the Family Support Model which encourages flexibility in relation to the nature and intensity of support that any one family might need at any point in time.

How this might work in practice

- A member of the team or family around any individual child can highlight to the rest of the TAF that a family seems to be struggling and might benefit from some focussed support from a link professional. The team can decide who best can offer that support and the family can be approached. This needs to be shared with the whole TAF.

- Some families naturally 'gravitate' towards individual professionals based on a good relationship which involves regular contact for therapy or other reasons. Between the practitioner and the family they can formalise and agree that a link professional will be helpful to them in the short or longer term.
- This would be done on an 'as needs arise' basis with all Serennu practitioners aware of the work that has been done in the care co-ordination forum and the agreement that has been reached in respect of the family support model and this informal role.

Appendix 18

Local Area Need

There are estimated to be a total number of 125,142 children and young people aged 0-18 years living in Gwent. The national average disability figure is 7%, meaning in Gwent there are approximately 7,884 children and young people aged 0-18 years with disabilities or developmental difficulties, of which 1,873 will experience difficulty in two or more areas of daily living (48%).

Gwent features high on the Welsh Indices of Deprivation (2014) with many wards across the whole area experiencing higher rates of unemployment and higher incidences of single parent families compared to the Wales averages. (Shipman, S, 2015).

Four out of the five local authority areas in Gwent have multiple deprivations. Newport, has the highest percentage of Lower Super Output Areas in the most deprived 10% for the 'Income', 'Housing' and 'Physical Environment' domains, and Blaenau Gwent has the highest percentage for 'Employment', 'Education' and 'Community Safety' domains. Caerphilly has the highest percentage in the 'Health' domain, and Monmouthshire has the highest percentage for the 'Access to Services' domain.

There are wide variations of levels of deprivation across the whole of Gwent, with pockets of multiple deprivation seen in some local authorities compared to others, i.e. Newport has significantly higher deprivation compared to Monmouthshire, which as a result means that Monmouthshire receives less funding, and has significantly less access to services than Newport does. As Families First is an anti-poverty initiative, the amount of funding that a local authority receive will be largely based on the level of deprivation in that area, which is different in each local authority across Gwent.

Although parents on low incomes can provide excellent care, it is well established that poverty correlates with neglect in particular (Munro, 2011), with 590 children on the Child Protection Register in Gwent in 2016 (Local Authority Child Protection Registers in Wales, 2016), this highlights that families with children with additional needs in Gwent are vulnerable members of society, faced with a great deal of challenges and obstacles to achieve a good quality of life or wellbeing.

Overall, children with disabilities and their families living in Gwent are experiencing high levels of poverty, as well as difficulty in increasing their chances of getting out of poverty.

Already faced with health and social disadvantage, this may be exacerbated by the level of deprivation in their local area. It costs up to 3 times as much to raise a child or young person with a disability compared to raising a child or young person without a disability, and there is a high incidence of family breakdown as a result of having a child or young person with a disability. (Shipman, 2015).

Appendix 19

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