



An In-Depth Evaluation of ISCAN Care Coordination

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Executive Summary

The following report outlines key findings from an in-depth evaluation of the ISCAN Care Coordination service.

Care Coordination was introduced in October 2018, funded by the Regional Partnership Board in Gwent, adopting the model proposed in Sparkle's 2017 report 'Care Coordination: Evidencing the need to provide coherent and coordinated services for families who have children with disabilities and/or developmental difficulties'.

Interviews were conducted with families accessing Care Coordination, and with health and social care professionals delivering services from Serennu, Nevill Hall and Caerphilly Children's Centres.

The interview transcripts were analysed thematically and three key themes were found: navigating and organising care, empowering relationships, and holistic support.

Based on these findings, the service appears to be meeting the original aims set out in Sparkle's 2017 report.

Whilst very few recommendations for development have been made, overall, the findings were incredibly positive.



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Introduction

In the UK, there are an estimated 800,000 children and young people (CYP) living with disability (Disabled Living Foundation, 2017). Of the CYP with disability and/or developmental difficulties (DDD), almost half will have input from more than one professional at a time (Chard, 2017). According to the Council for Disabled Children report (2017), the number of children with complex needs rose by 50% between 2004 and 2017.

Parents of these CYP can experience elevated stress and depressive symptoms and higher rates of general ill health, contributing to adverse mother-child attachment with implications for timely care seeking behaviour (Masefield, et al., 2020). Children with disabilities are more likely to be born into poverty, and families are more likely to experience missed workdays and further economic difficulty (Anderson, et al., 2007; Looman, et al., 2013). Thus, these CYP and their families experience detriments to their health outcomes, family functioning and wellbeing (Sloper, 1999; Masefield, et al., 2020).

The children's charity The True Colours Trust reported that in the last decade, successive UK governments have expressed commitment towards improvements in care and support for CYP with disabilities and complex needs (TCT, 2015). However, parents of CYP with disability continue to report unmet needs related to cuts in the services they rely upon (Chard, 2017). Greater integration of care services, and care coordination have been recommended in the international literature, to improve health service cost-effectiveness, improve service-user experiences and decrease reported parental stress (Breen, et al., 2018; Edelstein, et al., 2017; Turchi, et al., 2014). Care coordination is described by Turchi, et al. (2014) as:

[Paediatric] care coordination is a patient- and family-[centred], assessment-driven, team-based activity designed to meet the needs of children and youth while enhancing the caregiving capabilities of families. Care coordination addresses interrelated medical, social, developmental, [behavioural], educational, and financial needs to achieve optimal health and wellness outcomes. (p. vii)

ISCAN Care Coordination

Care Coordination was identified as being vital for families with CYP with complex needs who required care from three or more professionals, by the health and social care professionals working with these families. At that time, individual health professionals often effectively worked as 'lead professionals', although they did not have time allocated within their jobs for this role. At the suggestion of the Health Board, Sparkle undertook a full exploration of this potential service, culminating in the 2017 report 'Care Coordination: Evidencing the need to provide coherent and coordinated services for families who have children with disabilities and/or developmental difficulties'. It was proposed that Care Coordination was needed to facilitate a multi-disciplinary team approach which would result in a single point of contact, a single plan and a coordinated service, thereby improving families' experience of having a child with a disability, reducing the risk of families reaching crisis point and being unable to cope, and reducing health board and local authority costs relating to statutory intervention in these cases. (The full report can be accessed here: [Care Coordination: \(sparkleappeal.org\)](http://sparkleappeal.org)).



As a result of the outcomes of this report, the Care Coordination Service was introduced in October 2018 (see figure 1) as phase two of the Integrated Service for Children with Additional Needs (ISCAN) in Gwent, funded by the Regional Partnership Board, with the Care Coordinators working within the Health Board. The service is delivered by three sector teams made up of a Care Coordinator and Family Support Worker based at Serennu Children's Centre (SCC), Nevill Hall Children's Centre (NHCC) and Caerphilly Children's Centre (CCC). The service is available to children who have multi-agency complex needs with input from three or more services, and provides families with a single point of contact, coordinates services involved with the child and aimed to facilitate integrated assessment and planning (IAP) in the most complex places.

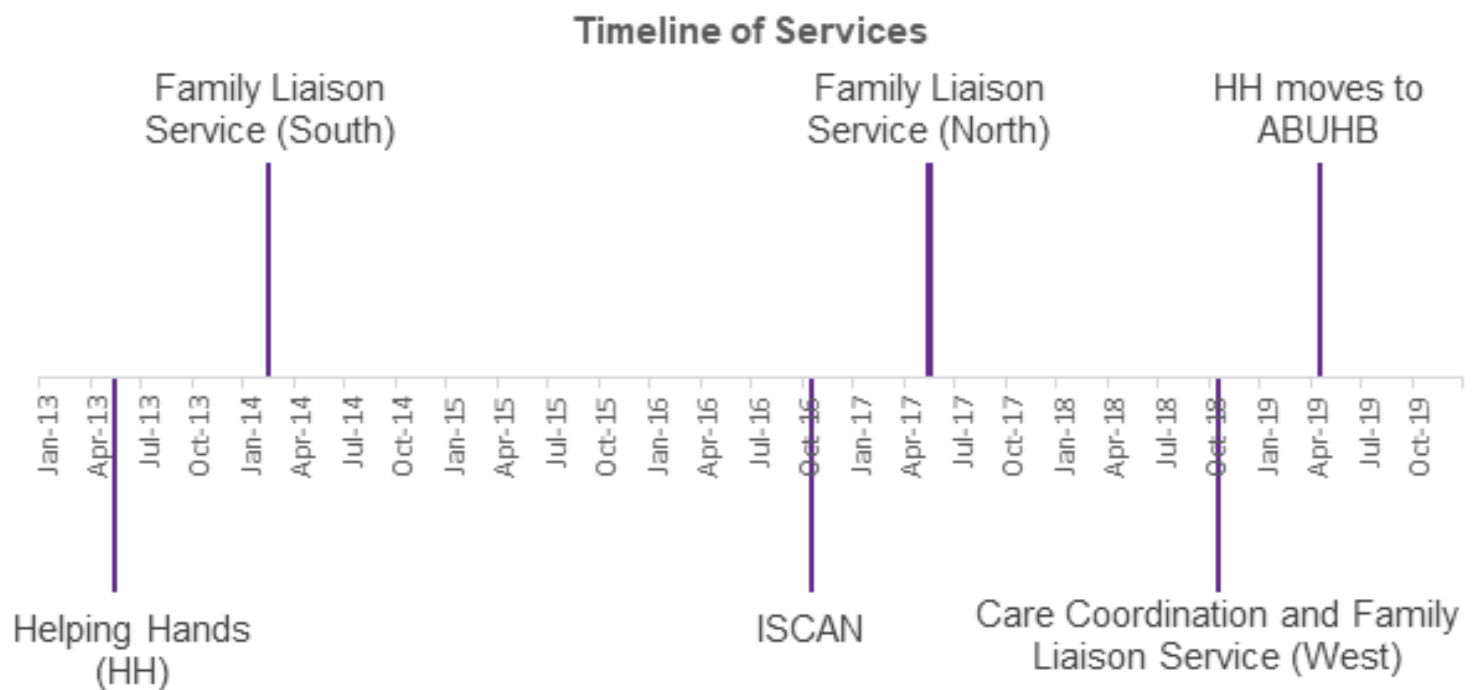


Figure 1: Timeline of Services, including the introduction of Care Coordination.

The aims of the Care Coordination service include: fewer CYP being on multiple waiting lists, receiving earlier intervention and more integrated care, families having better relationships with professionals, feeling more empowered, and more effective use of scarce agency resources (National Commissioning Board Wales, 2019).

Research Aims

Since its inception in 2018, the Care Coordination service in Gwent has yet to undergo a formal, in-depth evaluation. The current study therefore aimed to address this problem by analysing feedback from both families accessing the service, and professionals involved in the care of CYP with DDD, to find out whether the service is meeting its original aims, and to assess the impact Care Coordination has on CYP with complex needs and their families.

Method

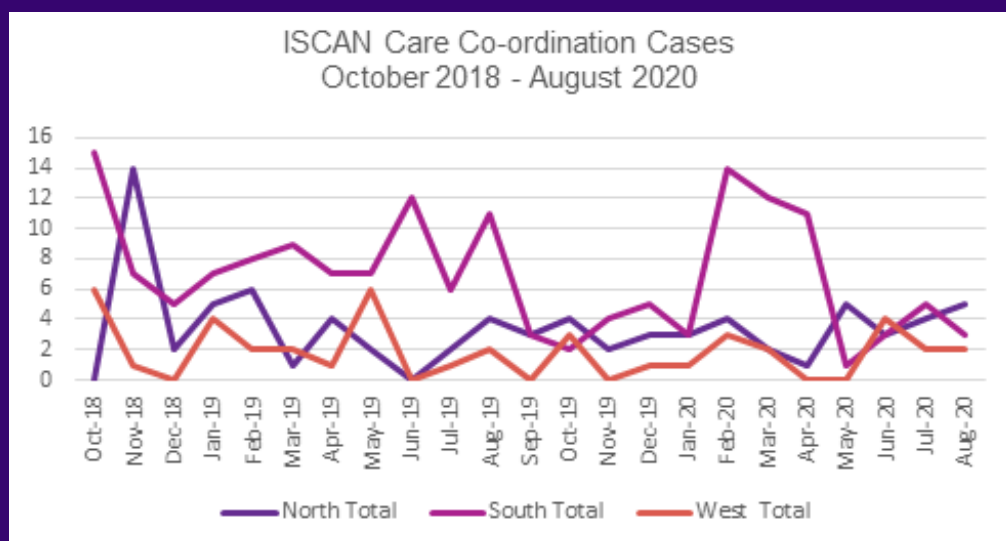
Design

Semi-structured interviews were used to allow participants the freedom to express their views on the service; the flexibility to follow topics raised by participants, where appropriate and relevant; and to provide reliable, comparable qualitative data. Interview topic guides were created for family members of CYP and professionals, comprising a list of topics and open-ended questions to be covered during the interview (see Appendix A).

Participant Recruitment

In total, nine family members and 14 professionals participated in this evaluation between 12th March and 11th August 2020. A purposive sampling approach was used for selecting a sample most appropriate for the purpose of this evaluation, and data saturation was reached. Informed written or verbal consent was obtained from all participants.

Figure 2: Number of families accessing Care Coordination between October 2018 and August 2020.



Family Recruitment

Between 27th May and 5th August 2020, 38 of the 284 families who had accessed/were accessing the Care Coordination service at SCC, NHCC or CCC were invited to participate in a telephone interview to share their experiences of accessing the service. In total, nine family members participated in a telephone interview (3 at SCC, 3 at NHCC and 7 at CCC), between 8th June and 11th August 2020. Participants had accessed Care Coordination for 6 to 15 months between October 2018 and the period of evaluation, ending August 2020. On average, participants had accessed for 10 months.

Professional Recruitment

All health and social care staff based at SCC, NHCC and CCC (approximately 177; 113 at SCC, 30 at NHCC and 34 at CCC) were invited via email to participate in a telephone interview to share their views on Care Coordination. Recruitment posters were also put up at the Children's Centres. In total, 14 professionals participated in a telephone interview between 12th March and 21st July 2020 (6 at SCC, 4 at NHCC and 4 at CCC). Professionals interviewed were from health and social care, including Occupational Therapy, Physiotherapy, Speech and Language Therapy, and Care Coordination.

Ethical Approval

This service evaluation was approved by ABUHB Research and Development Department, Research Risk Review Panel on 5th February 2020.


Data Analysis

Interview transcripts were analysed using qualitative data analysis software, NVivo (QSR International). Thematic analysis was used as a method for identifying, analysing and reporting patterns within the data (Braun and Clarke, 2006). Inductive thematic analysis was used; this is a widely used method of analysis which allows for categories to evolve from the data and facilitates the interpretation of themes supported by the data.



Findings

A thematic analysis of the transcripts of the interviews found three key themes: (1) navigating and organising care, (2) empowering relationships, and (3) holistic support. These themes are discussed below. Interview participants who were family members of a CYP with DDD are identified by 'F' and a participant number, and participants who were professionals working with CYP with DDD are identified by 'P' and a participant number. It is also indicated whether participants were located in South Gwent (S), North Gwent (N), or Caerphilly County Borough (C).



**Navigating
and
Organising
Care**

**Empowering
Relationships**

**Holistic
Support**

Navigating and Organising Care

In this section, it is discussed how Care Coordination helps increase engagement in healthcare for families and provides support for healthcare professionals. Care Coordinators have been able to facilitate better engagement in healthcare by reducing stress and easing anxieties for families.

“I think just to tie up all her care and all the professionals together, so that it wouldn't be too confusing and so that things wouldn't get missed because she's seeing so many professionals.” (FS9)

“If you've got a family that is stressed and worried about all these little things, you then don't get that same engagement do you really? Or that potential to work with the child is less, isn't it? Because they're worried about lots of things.” (PN8)

Families also engage better in their child's healthcare if they feel the care is more person-centred and tailored to the family's goals, as demonstrated in the following quote:

“It is because we're working on the family's goals that their intervention is meaningful to them so that they are more likely to attend an appointment because they can see the benefits as opposed to maybe working in a different way is, actually it's not my goal, the physio, or the OT wants me to do, and maybe they're not so motivated to attend.” (PC3)

Care Coordination can help facilitate engagement by exploring potential barriers to engagement and helping families understand the healthcare system.

“A lot of families don't realize that by not attending appointments, there's a safeguarding concern of neglect. Once we've raised that with them, that often has an impact. Again, we've gone in; we've supported the family and looked at what are your barriers, why aren't you coming in. It could be simple things like transport. It could be things they can't read English, or they don't understand that they have to, or they've been

referred to and why they need to attend appointments.” (PS12)

Better engagement in healthcare and understanding the system can have a huge impact on a family and their child’s care, for example professionals believe intervention from a Care Coordinator can help reduce the number of missed appointments and ‘did not attend’s.

“Yes, we had a couple of families really that could be hit and miss with appointments, but then not always [wanting to miss] appointments. It was just their lives were so hectic and busy.” (PN7)

“You’ve got families who DNA appointments is an awful lot, or they can’t, they’ve got no transport to get to appointments. Again, the care coordinator made sure that appointments were met and made and that transport was arranged. It was just a little bit

that vulnerable families need, just to help them access services, really.” (PS7)

The reduction in missed appointments could also be due to Care Coordination lessening the burden of appointments, for example by helping to organise appointments so that they occur on the same day in one place, rather than having appointments on different days or at different sites.

Both families and professionals commented on how the service improved multidisciplinary working and helped facilitate joint appointments.

“It was really good because when he was in the nursery, speech and language therapy

It's just that they couldn't cope with ridiculous letters coming through the door and just not coping with it... We're working on some more joint therapy [appointments] and trying to coordinate it, seeing patients, not at the same time but, actually, on the same half a day so they don't have to come in on different [days].

(PN6)

and the dietician and his physio were able to come into the sessions to work with him then.” (FC5)

“The IAP is that if it's identified that say OT, physio, and speech and language all need to do an initial assessment the idea would be that you would all try to coordinate the appointments. It would take place rather than them going to an OT appointment on one week and then physio appointment in another week that you would try to have it so the assessments all takes place at the same time, at the same place, on the same day.” (PC2)

One participant believed this increase in joint working helps improve communication between professionals.

“I think being able to do some of those joint visits can be really helpful because that sharing of information is really useful. [...] It's great having them at the other end of the corridor and at the end of an email, and they're always quick to respond or call you back.” (PS10)

Professionals felt the introduction of Care Coordination had eased

the pressure they felt to provide informal support for families in addition to their work. Participants spoke of how they felt Care Coordination complemented other services by providing specialist support, further to the support they felt they were able to provide for families.

“It could have been seen as a threat, but I don't see it like that at all I just feel we complement each other. The services complement each other.” (PS4)

“As therapists, we can do so much but you're not necessarily trained in that giving that support from that, and knowing what's out there for them. Again, we could find it out, but it's not always having the time to do it.” (PN6)

However, some professionals said that while the service had its merits, it was not yet reaching its potential in some areas.

“I can see the potential benefits, but I think there's just a lot of work that needs to be done in setting up that service up properly.” (PN2)

“See IAP - I just think we need to do, get it off the ground.” (PN6)

A few participants suggested the service is restricted by staffing capacities and capabilities, and felt more staff were needed to provide an efficient service.

"I think it's just because we need more staff in the South because it's an extremely busy area, and quite complex. [...] I think that the structure of the team would be better if there was a band six who supervised staff. [...] My concern is if somebody doesn't have the capacity to recognize a safeguarding concern, who do they have to point that out to them? Structurally, I would say it would be handy." (PS12)

"Rather than having a waiting list they turn people away if there's no capacity." (PS4)

There was also confusion expressed by some professionals regarding the service. They felt the Care Coordinator role could be more clearly defined and related services, such as IAP and Team Around the Family (TAF) needed to be explained fully.

"I was probably still slightly unclear as to what role is going to be what because we went from having just FLO to then care

coordinators coming in and very briefly there was a crossover" (PN8)

(On IAP) "I'm really unclear of what it is to be honest. I hear the acronym all the time, I'm like, what's that?" (PS10)

A few professionals were also concerned the service may not be clearly explained to families, resulting in further confusion.

"They get the list of people who will be involved in their care and one of whom is the care coordinator, and they're not really sure what that job is or what that appointment will involve." (PN2)

"I think if there are care coordinators involved, there has to be a social work assessment. I had one family who were very confused because they thought that because a social worker was coming round to see them with the care coordinator, that there was safeguarding issues, and they were really upset because they thought that they'd been referred to Social Services." (PS7)

Empowering Relationships

It was evident from the data that relationships between Care Coordinators and families were empowering. Care Coordinators are able to build a rapport with families, due to the way they work and the consistency between Care Coordinators and families.

“I suppose, they come to your house. They come to your house to visit, and the amount of times that you see them builds up a relationship.” (FS9)

This leads to families feeling comfortable with Care Coordinators, allowing them to be more open.

“I just feel like I can talk to her as well.” (FN3)

“We don't feel conscious about asking them a silly question.” (FS10)

“For one we could be ourselves, they never judged us.” (FC4)

Participants felt it was particularly beneficial that Care Coordinators are not ‘clinical’ professionals as this made them more approachable and resulted in a different relationship to those between families and medical or healthcare professionals.

“It's having that, somebody who isn't necessarily clinical actually.” (PN6)

“She's really approachable and willing to help. She's always said if I can do anything to help you, just let me know.” (FC5)

“I feel because sadly lots of families have a negative opinion of, say social workers, but the care coordination team, I think families see them as more approachable.” (PC1)

Participants suggested that this relationship between Care Coordinators and families resulted in more person-centred care.

“I think that's the care coordinating body encourages that more family-centred way of working, I think.” (PC3)

This may be because Care Coordinators get to know families and therefore focus on the issues that are important to them personally, tailoring the support they offer to be more effective.

“Well, she just came in and asked me what she could help me with. What we felt that we needed help with.” (FN6)

Care Coordination also encourages family involvement in a CYP's care, for example via TAF.

"It's about having people from all different agencies and professions there with the family at the forefront and looking actually what's the most important thing for them at the moment." (PN6)

In the following example, a parent felt a lack of control over their child's care, however involvement from Care Coordination helped them understand the process and regain control:

"When the information started coming out that he would be assessed, it felt like decisions were being made without us. We were thinking, well, if somebody is coming to assess and then they've obviously got


a decision made, and [name of family support worker] was able to explain once we were there once she'd met with the representative. No, it wasn't the decision made, it was part of the assessment process. We were feeling that things were being taken out of our hands." (FS10)

In cases such as this, Care Coordinators can act as an advocate for families to help facilitate communication between professionals and families.

"The parent is equally able to communicate to all of us their frustrations or their needs that they might have felt aren't being met, and we can make sure that those are addressed." (PN2)

Communication with Care Coordination was praised by families during the interviews:

They listened to us with our concerns with [name], and they gave us all the advice when we had concerns. Every step of the way they were telling us what they were going to be doing.
(FC4)



She was very clued up with what we had on and who we were seeing which was great because there's nothing worse than going back over what you've already told them really. She always had all our medical information about [name] with her. It was helpful that she was already was a step ahead.

(FC6)

Care Coordination provides families with a single point of contact. This empowers families as they are able to access information about their child's care in a timely and efficient way without having to contact multiple sources.

"She was very helpful, we could ring her when we needed anything."
(FS11)

"I think having that single point of contact is really, really useful and having someone who you can create a relationship with, who can support you through that is really beneficial." (PS10)

Families also benefited from receiving support from someone who understands the needs of the CYP and the wider family.

"It was really helpful because she understands [name]'s needs. I know the school do but it's from a different point of view and it's a different perspective. The school are just looking at it from what can we do to meet his educational needs where she can put a lot more input on why he's behaving the way he is." (FN3)

Holistic Support

The relationship between Care Coordinators and families results in all-encompassing support, both practical and emotional. Practical support mentioned in the interviews that had been provided by Care Coordination included help with housing, finances and other aspects of daily living.

“She's also helped me with housing. With supporting letters and stuff for that.” (FN4)

“She was amazing because she helped fill in all of the DLA forms we had to fill in for [name] because no one else told us that we could fill in these forms or apply.” (FS9)

“They've helped me, oh gosh, with different things. I got a grant to get a washing machine because I didn't have one” (FN3)

Care Coordinators have also been able to help families access resources and equipment for their child.

“They've also sorted out Tumble Form chairs for him as well.” (FC5)

The service is a source of emotional and moral support for families. The relationship between

Care Coordinators and families, coupled with the knowledge and skills of the Care Coordination team, results in highly efficient emotional support, tailored to each family. Participants seemed to really appreciate having access to someone who understood their situation and felt this allowed Care Coordinators to support them in ways other people in their lives were not able to.

“The emotional comfort of having somebody that understands you.” (FS10)

“I don't really have anyone that I can talk to about how tough things are. [...] You know people have their own problems so just having someone there like your care coordinator who you can talk to and they understand it. It makes such a huge difference. You can offload a bit you know.” (FC5)

In some cases, Care Coordinators attend consultations with families as moral support and a second set of ears. This was reassuring for families, and they felt more comfortable after appointments with the reassurance and understanding of the Care Coordinator.

“If something that you might think is a big problem but actually isn't. It's that reassurance.” (FS10)

This all-encompassing, holistic support results in reduced stress for families.

“I would say the main benefits are less stress.” (FC6)

She just came in, and basically took all the stress out of our daily life.

(FC5)

Meeting the Aims

In the 2017 report outlining the need for Care Coordination, three key themes were found regarding the aims of the service: information, coordination, and needs-based service.

Participants in the feasibility study which led to the Care Coordination service, felt it should provide a source of information for families as this will empower them. The findings of this evaluation suggest Care Coordination has addressed this aim, offering both information and empowerment to families. Likewise, it was suggested that Care Coordination should help families access further sources of support; this is touched on in the evaluation, however not as explicitly. It could be that signposting to other sources of support would fall under the remit of the Family Liaison Service rather than Care Coordination.

The second theme that this service aimed to improve was coordination. Participants suggested Care Coordination should help families navigate the healthcare system, as well as improve communication between the different services. This evaluation has found that Care Coordination is reaching these aims well, resulting in reduced stress for families.

Finally, it was determined that Care Coordination should be a needs-based service, providing holistic support for families which is based on individual need, rather than using a strict criterion. Again, this evaluation has found Care Coordination to be meeting these aims, and delivering both practical and emotional support for families, providing support where it is needed and delivering a truly person-centred service.

Recommendations

Based on the findings of this evaluation, the following recommendations for service development are made:

The main recommendation to come out of this evaluation is to continue with the current Care Coordination service, which has clear benefits for both families and professionals.

It is recommended that the very few concerns raised in this evaluation are addressed. This includes assessing the current capacity of the Care Coordination team, documenting requests for the service that cannot be met, and ensuring the role of the Care Coordinator is clearly defined for both professionals and families.

An in-depth evaluation should be conducted again in 2023 to assess the continued effectiveness of the service.

Additional Comments

Since this evaluation was conducted, Social Services have commented on how many low-level enquiries Care Coordination has relieved the service of, thus allowing more time to be dedicated to the more complex cases.

Conclusions

Overall, the findings from this evaluation are incredibly positive and it is evident from their responses that both families and professionals find Care Coordination to be a highly beneficial service. The service has been found to help families navigate the healthcare system and organise their child's care, resulting in better engagement and fewer missed appointments. Also, it has been suggested the service improves communication between professionals and services, and facilitates multidisciplinary working and joint appointments.

The relationship between Care Coordinators and families was thought to be empowering, by offering families a single point of contact and person-centred support from someone who understands their individual needs. Care Coordination provides all-encompassing, holistic support. Practical support offered to families included help to access resources and with housing and finances, and Care Coordinators provided emotional and moral support and reassurance, including at medical appointments where necessary.

The results of this evaluation also found the service to be meeting its original aims. Whilst very few recommendations for improvement have been made, such as assessing the current capacity of staff and ensuring the Care Coordinator role is clearly explained to families and professionals, it is clear that having a dedicated professional to coordinate the care of CYP with complex needs and input from multiple services results in positive outcomes for the whole family.



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Appendix A

Care Coordination Topic Guide: Parents

Prior to CC:

- How were you finding the co-ordination of your child's healthcare before CC were involved?
- How many professionals involved in your child's care?
- How often were your child's appointments? And locations? Convenience?
- How was the CC service introduced to you/expectations?

1.Experience of receiving support with from Care Coordination (CC)

a. Describe what kind of support was given – examples

Needs of child/family understood? How?

Action plan tailored to your child/family's needs?

All family members feeling listened to?

Central & involved in your child's care?

Information sharing/signposting?

Single point of contact? Which professional(s)?

b. Timeliness of support – examples (how satisfied – Likert scale)

c. How did you feel about receiving this support?

d. Satisfaction with support + satisfaction with continuity of support (Likert scale)

e. Experience of Integrated Assessment and Planning (IAP)

f. Experience of Team Around the Family (TAF)

2.Communication with the CC team

a. Who with

b. How they communicated – examples

c. Information shared – examples

d. Feelings about how the parent was communicated with

e. Satisfaction with communication (Likert-scale)

f. Describe relationship with professionals

3.Describe any benefits for:

a. Health (child & family) – e.g. attending appointments? Better health outcomes?

b. Emotional – greater resilience? (parent) Improved wellbeing?

c. General (child & family) –

d. Empowerment (parent) / greater sense of control over life?

4.Issues

a. Describe any issues experienced with CC

b. Resolution of issues

c. Impact of these issues

5.Overall satisfaction with the CC service (Likert scale)

6.Any other thoughts/feelings to share

Appendix B

Care Coordination Topic Guide: Professionals

1. The Care Co-ordination service
 - a. What it provides – examples
 - b. How it works – examples
 - c. Key processes – examples (+ Likert scale for efficiency)
 - d. How decisions are made – examples (+ Likert scale for quality of decision-making)
 - e. How it links in with other services – examples
 - f. How Integrated Assessment and Planning (IAP) works – examples
 - g. How Team Around the Family works – examples
2. Communication with families and professionals
 - a. How families are communicated with – examples
 - b. Information shared – examples
 - c. Communication within the CC team – examples
 - d. Communication with the wider ISCAN team and other services – examples
 - e. Quality of communication (Likert scale)
 - f. Relationships
3. Describe any benefits of CC/ IAP/ TAF for:
 - a. Families (e.g. earlier support, empowerment, reduced waiting lists)
 - b. Professionals (e.g. time gained, morale, relationships)
 - c. Any other benefits (e.g. reduction in non-attendance at appointments, reduction in parent complaints)
4. Issues with CC
 - a. Describe any issues with CC/ IAP/ TAF
 - b. Resolution of issues
 - c. Impact of these issues on families and professionals
 - d. Areas for improvement
5. Overall effectiveness of the CC service (Likert scale) & elaborate
6. Any other thoughts/ views to share