

## RESEARCH ARTICLE

# Care coordination for children with a disability or developmental difficulty: Empowers families and reduces the burden on staff supporting them

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**Abstract**

**Background:** Almost half of all children and young people with a disability or developmental difficulty (DDD) have complex disability and are likely to require multidisciplinary care. Care coordination (CC) aims to provide a single point of contact and a coordinated service, thereby improving care experiences, meeting unmet needs and empowering families. The impact of CC for children with DDD was evaluated.

**Method:** Between May and August 2020, an in-depth evaluation of CC in Gwent, South Wales was conducted. Of 284 families who accessed CC, 38 were approached, as well as 177 health and social care professionals based at Serennu, Nevill Hall and Caerphilly Children's Centres. Nine families and 14 professionals completed semi-structured interviews. Interview transcripts were analysed using thematic analysis.

**Results:** This evaluation found perceived improvements in families' abilities to navigate, organize and understand care and increased parental engagement. Professionals observed fewer missed appointments, and both professionals and families described CC as a source of holistic support, including practical advice regarding housing, finances and emotional support. Professionals commented on CC easing pressure on their service. Potential limitations included restricted staff capacity and the role not being defined clearly for families and professionals.

**Conclusions:** At a time of increased stress for families of children with DDD, and scarce resources to support them, care coordinators play a vital role in assisting families to engage with health services, while feeling supported and empowered. CC reduces the burden on professionals, while enhancing relationships with families.

**KEYWORDS**

care coordination, children, developmental difficulties, disability, empowerment

## 1 | INTRODUCTION

In the United Kingdom (UK), there are an estimated 800 000 children and young people (CYP) with disability and/or developmental

difficulty (DDD) (Disabled Living Foundation, 2017). Almost half have complex disability (Blackburn et al., 2010) likely requiring multidisciplinary care. Parents may experience elevated stress, depressive symptoms and poor health, contributing to adverse mother-child

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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 may experience missed workdays and further economic difficulty (Anderson et al., 2007; Looman et al., 2013). Thus, these families experience detrimental impacts on their health outcomes, family functioning and well-being (Masefield et al., 2020; Sloper, 1999).

Successive UK governments expressed commitment towards improvements in care for CYP with DDD (True Colours Trust, 2015). However, parents continue to report unmet needs. Integration of care and care coordination (CC) are recommended in the international literature, to improve health service cost-effectiveness and service-user experiences and decrease reported parental stress (Breen et al., 2018; Edelstein et al., 2017; Turchi et al., 2014). CC is defined in Figure 1.

In 2017, the official charity of three Children's Centres in South Wales, Sparkle (registered charity: 1093690), identified CC as vital for families caring for CYP with DDD, following an in-depth feasibility study (Chard, 2017). CC was introduced in October 2018 as phase two of the Integrated Service for Children with Additional Needs in Gwent (National Commissioning Board Wales, 2019), funded by Welsh Government through the Integrated Care Fund, available to children with DDD requiring input from three or more health professionals. The service is delivered by three sector teams consisting of a care coordinator and family support worker based at Serennu, Nevill Hall and Caerphilly Children's Centres.

Brenner et al. (2018) proposed that integration of care for CYP with DDD living in Europe currently requires improvement, and data to improve understanding of these families' needs are not being collected. More work is needed so that patients and families are engaged as *partners* in assessing experiences and outcomes of CC (Kuo et al., 2018.) The current study presents the voices of families, and professionals caring for CYP with DDD, in seeking to assess the impact of CC for CYP with complex needs, and their families, in a UK context. A case study of CC is included in Appendix A.

## 2 | METHOD

### 2.1 | Design

To explore whether the service was meeting its original aims and objectives (see Figure 2), a semi-structured interview schedule was co-produced with Family Liaison Officers, employees of Sparkle who support families of CYP with DDD, to ensure the language used and topics covered were appropriate. The topic guides composed of open-ended questions to be covered during interviews (see

### Key Messages

- Families of children and young people with disability and/or developmental difficulty can experience increased stress and scarce resources.
- Care coordination assists families to engage, navigate and organize care for their child when requiring input from three or more services.
- Care coordination helps families feel empowered, improves multi-disciplinary working and reduces the burden on professionals and services.

Appendix B), which were audio recorded and transcribed verbatim using Go Transcript. Interviews were conducted by Sparkle's previous Research and Development Officer, who is female, a master's degree graduate and had previous experience of conducting qualitative interviews.

### 2.2 | Participant recruitment

Between 27 May and 5 August 2020, 38 of the 284 families who had accessed/were accessing CC at Serennu, Nevill Hall or Caerphilly Children's Centre were invited via email to participate in telephone interviews. Purposive sampling obtained a representative sample from across the three Children's Centre. Nine individuals participated (3 at Serennu, 3 at Nevill Hall and 3 at Caerphilly) between 8 June and 11 August 2020. Data saturation was felt to be reached with recurring similarity in responses from participants. On average, families had accessed CC for 10 months at the time of interview, and interviews lasted 23 min.

All health and social care staff based at the Children's Centres (177 in total) were invited to a telephone interview; 14 professionals participated between 12 March–21 July 2020 (6 at Serennu, 4 at Nevill Hall and 4 at Caerphilly). Health professionals approached included those from Occupational Therapy, Physiotherapy, Speech and Language Therapy and CC, and social care staff included local Children's Disability Teams.

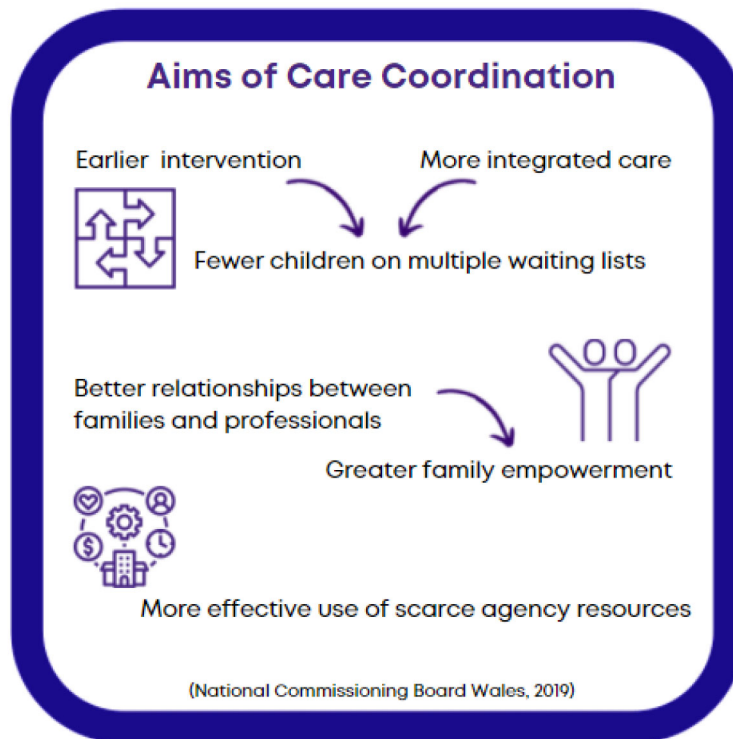
### 2.3 | Ethical approval

This service evaluation was approved by Aneurin Bevan University Health Board (ABUHB) Research and Development Department,

"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. e1453)

**FIGURE 1** Definition of care coordination by Turchi et al. (2014).

FIGURE 2 Aims of care coordination.



Research Risk Review Panel on 5 February 2020. Informed written or verbal consent was obtained from all participants. We report no conflicts of interest.

## 2.4 | Data analysis

Interview transcripts were analysed using qualitative data analysis software, NVivo (QSR International). Inductive thematic analysis was used for identifying, analysing and reporting patterns within the data (Braun and Clarke, 2006). Data were double coded by Sparkle's Research and Development Officer and an ABUHB Paediatric Registrar, neither of whom were involved in CC service delivery. Both researchers met to discuss the codes, re-coded the transcripts independently and met again to agree final themes. Neither of the researchers were involved in CC service delivery. Interview transcripts were not returned to participants to check before analysis, which the authors acknowledge as a limitation.

## 3 | RESULTS

Three key themes were found and are discussed below. *Family* members are identified by 'F' and a participant number and *professionals* by 'P' and a participant number. It is also indicated whether participants were located in South Gwent/Serennu Children's Centre (S),

North Gwent/Nevill Hall Children's Centre (N) or Caerphilly County Borough (C).

Participants agreed to the use of ID codes, and researchers felt the participants remained unidentifiable due to the large numbers attending and working from the centres and their catchment areas.

### 3.1 | Empowering relationships

It was evident that **relationships** between care coordinators and families were **empowering**; they are able to build a rapport.

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.

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

Participants felt it was **beneficial** that **care coordinators are not 'clinical'** professionals as this made them more approachable. Participants suggested this relationship resulted in more person-centred care.

She introduced what she does, what she can help with and it's all down to what I want. If I want loads of help, she'll help me loads. If I only want a little bit, she'll help me a little [...] I think it's better because they're actually doing what the parents actually want, not 'Well, you need this help, you need that help'

(FN6).

It is because [they're] working on the family's goals that the 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 [Physiotherapist] or the [Occupational Therapist] wants me to do it, and maybe they're not so motivated to attend

(PC3).

In the following example, a parent felt a lack of control over their child's care; however, CC 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 then they've obviously got a decision made. [Member of the Care Coordination team] 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 act as an **advocate** for families to help facilitate communication between professionals and families. **Communication** with CC was praised by families:

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).

CC provides families with a **single point of contact**, empowering families to access information about their child's care in a timely and efficient manner.

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).

### 3.2 | Navigating and organizing care

CC helps **increase families' engagement** in healthcare by easing stress and anxiety, exploring barriers to engagement and helping them understand the healthcare system.

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).

A lot of families don't realise 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

(PS12).

Better engagement and understanding the system can 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 attends'.

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).

The reduction in missed appointments could also be due to CC lessening the burden of appointments, for example, by helping to **coordinate appointments** rather than having multiple appointments on different days or at different sites.

It's just that they couldn't cope with ridiculous letters coming through the door [...] 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).

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 and the Dietician and

his [Physiotherapist] were able to come into the sessions to work with him then

(FC5).

A few participants suggested the service is restricted by **staffing capacities** 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

(PS12).

Some professionals felt the care coordinator role could be more clearly defined, for both themselves and families.

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).

### 3.3 | Holistic support

The relationship between care coordinators and families results in all-encompassing support. **Practical support** mentioned in the interviews that had been provided by CC 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 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).

Professionals felt CC **eased the pressure** to provide informal support for families, in addition to their work.

As therapists, we can do so much but you're not necessarily trained in giving that support 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).

I think it has just taken the more time-consuming cases off us

(PS7).

The relationship between care coordinators and families, coupled with the knowledge and skills of the CC team, results in highly efficient emotional support, tailored to each family. Participants seemed to appreciate having **someone who understood** their situation and felt care coordinators supported them in ways other people were not able to.

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).

Care coordinators sometimes **attend consultations** with families. Families said 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.

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

(FC5).

## 4 | DISCUSSION

There were perceived improvements in families' abilities to navigate, organize and understand care, as well as increased parental engagement following CC involvement. The personalized nature of CC, and the empowerment of carers to understand the system, leads to greater satisfaction and engagement in care, which is consistent with literature from the United States of America (Turchi et al., 2009, 2014). Professionals suggested there were fewer missed appointments, especially for vulnerable families. Professionals perceived improved multidisciplinary working and information sharing, which are aspects of integrated care (Baxter et al., 2018). Attendance is a proxy to participation, engagement, adherence and compliance, which are negatively affected by socio-economic disadvantage (Phoenix et al., 2020). This CC service is in an area of high deprivation, and thus, the priority is even greater. A community-based evaluation by Eastwood et al. (2020) also found that CC aided vulnerable families to navigate the system, by improving their confidence, outcomes and engagement. Greater empowerment of families was identified, and crucially practical support to prevent multiple appointments across multiple locations, likely improving attendance.

In their systematic review, Baxter et al. (2018) found that integrated care enhanced client satisfaction, perceived quality of care and access to services, but may be detrimental to service costs and capacity. This was mirrored by challenges reported in this study regarding staffing capacity, which are corroborated by Kuo et al. (2018). Finally, lack of role definition as a barrier to navigating the system was also found in a large survey by Purves et al. (2008).

Increasing a parent's knowledge is key to parental empowerment (Alsem et al., 2017; Ufer et al., 2018). We highlighted an example of CC helping a parent feel more in control by improving knowledge of the diagnostic process. Shared decision making and a sense of belonging are important for a parent's sense of empowerment (Itzhaky & Schwartz, 2001). Participants reported the parent-coordinator relationship resulted in greater family-centred care, which according to Turchi et al. (2014) results in greater parent empowerment. A key finding in this evaluation is that parents felt more comfortable with a care coordinator who was *not* a health professional. This should be borne in mind by those planning on developing or implementing this service.

Care coordinators were described as a single point of contact; Eastwood et al. (2020) described how approachability and accessibility enable parent engagement, although they also reported over-reliance that was not raised in the current study. It could be that limited staff capacity, which was a challenge identified in the evaluation, limited over-involvement and promoted timely discharge from the service. Greco et al. (2004) highlighted a single point of contact as a parental and policy priority for children with disability in the United Kingdom, which CC provides.

Both professionals and parents in the current study described CC as a source of holistic support, including practical advice regarding housing and finances, and emotional support, largely in concurrence with existing literature. In their evaluation of a UK-based CC model, Appleton et al. (1997) found that adequate CC reduced financial burdens, missed employment hours and the burden of CC for the families. A randomized control trial by Farmer et al. (2011) found CC is associated with declines in unmet needs, greater parental satisfaction and improved perceptions of health outcomes and family functioning. In a large survey, Drummond et al. (2012) found parents who experienced more family-centred care for their child reported better coping with the demands of caring for a child with complex needs. These findings may also explain why parents in the current study expressed that CC helped alleviate feelings of stress.

This evaluation may have been limited by low up-take in participation; this was due to the effects of the COVID-19 pandemic and that the CC supported families, by definition, juggle multiple appointments and often other complexities at home. Representation was sought across three Children's Centres, which cover five local authorities in South Wales, and despite low numbers of participants, this was achieved. Data collection ceased once no new themes emerged. The findings of this evaluation may support the continuation of existing, or the development of new, CC services; the development of a CC service could be explored by health services experiencing a high number of missed appointments, as this evaluation found

empowered families and improved multi-disciplinary working as a result of CC.

## 5 | CONCLUSION

CYP with DDD and their families are more vulnerable to negative impacts on health outcomes, family functioning, family finances and well-being. Effective CC may address these unmet needs, while improving their ability to cope with challenges they face. Overall, findings from this evaluation of a UK-based CC model were positive. In particular, parents and professionals reported CC led to improvements in navigation of the diagnostic system and organization of care, parents were empowered by care coordinators, and CC resulted in holistic support. The presence of care coordinators also eases pressure on healthcare professionals, affording them more time to undertake their own work. Highlighted limitations included restricted staff capacity; however based on recommendations from this evaluation, service leads have since implemented changes to address this, such as waiting lists for each sector and the three sector teams working in collaboration to address waiting lists. The impact of this will be reassessed in the future. The positive impact reported by families and professionals reiterates the value of CC in the context of wider health service challenges faced by CYP with DDD and their carers.

## ACKNOWLEDGEMENTS

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## CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

## DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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## APPENDIX A: CARE COORDINATION CASE STUDY

**Integrated Services for Children with Additional Needs (ISCAN) Care  
Coordination (CC) team intervention case study**



<p><b>Introduction/Background</b></p> <ul style="list-style-type: none"> <li>S was referred to ISCAN at the age of 4 months by their consultant neonatologist. They had a diagnosis of Down syndrome and developmental delay, and was accepted for assessment and input from physiotherapy, portage, community paediatrician, speech and language therapy, and CC. They were also under the care of paediatric cardiology tertiary specialists at this time.</li> <li>S was discharged having successfully met the targets in the episode of care and was re-opened to CC later at the age of 3 years old due to the need for support with transition to education.</li> </ul>	
<p><b>Needs</b></p> <ul style="list-style-type: none"> <li>It was agreed for CC to act as a single point of contact for the family and to support with multi-agency co-ordination.</li> <li>Following an initial assessment of need, it was identified that finances were having a significant impact on the family. This was impacting S accessing their appointments and leisure activities. As a result of this, the care co-ordinator referred the family to families first where they were accepted by the resilient communities' team who continue to support with managing finances and accessing the wider community.</li> </ul>	<p><b>Interventions</b></p> <ul style="list-style-type: none"> <li>CC referred the family to Families first and Citizen's Advice for support with finances. CC also supported with family fund application, Disability Living Allowance application and discretionary assistance fund.</li> <li>CC has supported to attend appointments and acted as a point of contact for parents when they had forgotten appointment days/times. The care coordinator also supported with the navigation of services to ensure that parents understood the purpose of the services involved.</li> <li>The care coordinator referred S for occupational therapy (OT) intervention (via the Disabled Children's Team), to ensure the family home is appropriate and accessible for S's needs.</li> <li>Parents have been made aware of the services available at the Serenu Children's Centre and were referred to services from Sparkle. The family accessed Little Stars "Stay and Play," for a period of time.</li> <li>CC have supported parents throughout the educational statementing process and S has secured a specialist placement in a local nursery. The care co-ordinator arranged and chaired a Person-Centred Planning meeting prior to this transition to ensure that all was in place to meet their needs, and liaised with the transport team and OT to ensuring that a crash tested wheelchair was available.</li> <li>CC continue to provide support for parent accessing services for their own mental health and to ensure that they engage with appropriate services and understand the outcome of these appointments.</li> <li>During a recent sleep study and Ear, Nose and Throat specialist appointment, it was established that S would benefit from oxygen during sleep and that they would require their tonsils removed. This has been followed up and chased by CC.</li> </ul>

## APPENDIX B: INTERVIEW TOPIC GUIDES

Care Coordination Topic Guide: Parents

Prior to Care Coordination (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?

Experience of receiving support with from CC

- 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)?

- Timeliness of support – examples (how satisfied – Likert scale)
- How did you feel about receiving this support?
- Satisfaction with support + satisfaction with continuity of support (Likert scale)
- Experience of Integrated Assessment and Planning (IAP)
- Experience of Team Around the Family (TAF)

**Communication with the CC team**

- Who with
- How they communicated – examples
- Information shared – examples
- Feelings about how the parent was communicated with
- Satisfaction with communication (Likert-scale)
- Describe relationship with professionals

**Benefits**

Describe any benefits for:

- Health (child & family) – e.g. attending appointments? Better health outcomes?
- Emotional – greater resilience? (parent) Improved wellbeing?



- c. General (child & family) –
- d. Empowerment (parent) / greater sense of control over life?

#### Issues

- a. Describe any issues experienced with CC
- b. Resolution of issues
- c. Impact of these issues

Overall **satisfaction** with the CC service (Likert scale)

Any other thoughts/feelings to share

#### Care Coordination Topic Guide: Professionals

##### 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

#### 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

#### Benefits of CC

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)

#### 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

Overall effectiveness of the CC service (Likert scale) & elaborate

Any other thoughts/ views to share