

**Preventive and creative approaches to social work practice:
Understanding and responding to the needs of families with children with
disabilities and additional needs**

Davies, Ceryl Teleri; Job, Deborah

Practice: Social Work in Action

DOI:
[10.1080/09503153.2024.2396322](https://doi.org/10.1080/09503153.2024.2396322)

E-pub ahead of print: 19/09/2024

Publisher's PDF, also known as Version of record

[Cyswllt i'r cyhoeddiad / Link to publication](#)

Dyfyniad o'r fersiwn a gyhoeddwyd / Citation for published version (APA):
Davies, C. T., & Job, D. (2024). Preventive and creative approaches to social work practice: Understanding and responding to the needs of families with children with disabilities and additional needs. *Practice: Social Work in Action*. Advance online publication. <https://doi.org/10.1080/09503153.2024.2396322>

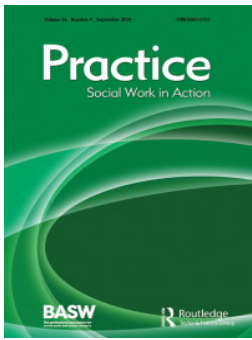
Hawliau Cyffredinol / General rights

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal ?

Take down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.



Preventive and Creative Approaches to Social Work Practice: Understanding and Responding to the Needs of Families with Children with Disabilities and Additional Needs

Ceryl Teleri Davies & Deborah Job

To cite this article: Ceryl Teleri Davies & Deborah Job (19 Sep 2024): Preventive and Creative Approaches to Social Work Practice: Understanding and Responding to the Needs of Families with Children with Disabilities and Additional Needs , Practice, DOI: [10.1080/09503153.2024.2396322](https://doi.org/10.1080/09503153.2024.2396322)

To link to this article: <https://doi.org/10.1080/09503153.2024.2396322>



© 2024 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group



Published online: 19 Sep 2024.



Submit your article to this journal [↗](#)



Article views: 32



View related articles [↗](#)



View Crossmark data [↗](#)

Preventive and Creative Approaches to Social Work Practice: Understanding and Responding to the Needs of Families with Children with Disabilities and Additional Needs

Ceryl Teleri Davies and Deborah Job

To address the gap in preventative support, the aim of the Family Disability Worker (FDW) role is to offer support for parents and carers of children with disabilities and additional needs, who do not meet the criteria to access services through the children with disabilities social work team. This Welsh evaluation included a survey for professionals ($n=23$) and parents/carers ($n=5$) to explore their attitudes on the new FDW role. Following this, a series of semi-structured interviews were completed to gather the experiences of professionals ($n=23$) and parents/carers ($n=3$) of working with the FDW. The findings suggest the development of preventive social work practice to reduce isolation and support these families to feel connected to their community. The participants shared attitudes and experiences supporting the development of the FDW role, to enhance and develop creative and strength-based approaches to social work practice to be operationalised through a new FDW practice toolkit.

Keywords: Family Disability Workers; toolkit; strength-based practice; children with disabilities and additional needs

Introduction

This article discusses the outcome of an evaluation focused on exploring the impact of a new Family Disability Worker (FDW) role to support parents and carers with children with disabilities and additional needs, including the creative social work practice to support these families. The FDW offers support for families of children, who often have neuro-developmental needs and do not meet the criteria for support through the children with disabilities social work team.

This evaluation was completed in one local authority area of North Wales, which included a casefile review of families accessing support ($n=12$), professionals survey ($n=23$) and parents/carers survey ($n=5$), followed by a series of semi-structured interviews to gather in-depth information from professionals ($n=23$) and parents/carers ($n=3$). The aim of the interviews was to explore the experiences of professionals and parents/carers in accessing support provided by the FDWs. This included an exploration of their views on working with the FDWs, including the potential influence on enhancing social work practice.

The focus of this article is on exploring how the findings from the interview phase informed the development of a creative toolkit to enhance social work practice to support these families.

Background

The Social Services and Well-being (Wales) Act 2014 focuses on creating a landscape of responding to current and future population and community needs, through the ethos of prevention and strength-based multi-agency practice to address holistic well-being needs of the whole family. The focus is on enabling families accessing services to live the life they want to live by identifying 'what matters' to them. The idea of well-being is a personal but broad concept that impacts on several key aspects of everyday life (Welsh Government 2015).

The aim of the FDW role is to work in partnership with families to address their well-being needs through a preventative approach that builds on both community assets and the strengths of the family. The FDW role is focused on providing support to enhance the quality of life and well-being outcomes for the whole family, for example, practical support based on the needs of the family, signposting to resources and groupwork interventions. Evidence suggests that the needs of children with a disability are becoming more complex (Welsh Government 2018) and therefore innovative work is required to understand and meet their needs. Children with a disability often suffer a range of disadvantages as result of a spectrum of health, developmental and physical needs. These families are often the 'missing middle', not aligning with any diagnostic or perceived service eligibility criteria, including challenges in accessing timely specialist support, for example, neuro-development assessment, as voiced by Participant 6: 'So you imagine if you've got all these problems and you've got to wait two years to have an assessment'. As a result, they face barriers to accessing support or otherwise experience multiple service referrals without any clarity around service outcomes or interventions to be delivered to support their needs. This barrier often results in additional social isolation and reduced emotional wellbeing. Evidence indicates the impact of social isolation, social exclusion, stigma and shame experienced on an everyday basis by families with children with disabilities (Children's

Commissioner for Wales 2019). This often leaves families in impossible situations of having to cope with their everyday life, or in many cases unable to cope (Marrable 2014). The constant and often challenging interactions with a broad range of professionals can be relentless, stressful and time consuming. The barriers to accessing a medical diagnosis, the complexities surrounding various diagnosis and ambiguities involved are also a challenge, if the condition is rare and/or with common symptoms to several other conditions (White and Featherstone 2005; Griggs and Bussard 2017).

Undertaking and 'living' the role of a parent/carer of a child or young person with disabilities or additional needs is a life altering experience. Whilst there is a plethora of evidence reflecting the challenges and limitations of the parent/carer role, there is also research focusing on the transformative benefits of having a disabled child, due to the degree of personal growth and attitudinal changes across the whole family (Blake, Bray, and Carter 2019). Even when considering these potential benefits, the challenges and adversities caused because of additional financial pressures and housing and employment demands should not be underestimated. This is further compounded by managing the demands of the multiple professional appointments, the barriers to accessing services and the stigma often associated with this. With increased demand for services for children with disabilities, the need for local community-based support for these families is significant.

Methodology

This evaluation was conducted according to the SRA (2021) Research Ethics Guidance, with ethical approval gained from the School of Health Sciences, Bangor University, for all stages of this process. Upon consent, all data was stored and managed according to General Data Protection Regulation (GDPR) compliance. A purposive sampling approach was used, with all families accessing support from the FDWs contacted to offer participation in the evaluation. The inclusion criteria were:

- a. All families who have or are accessing support from the FDWs within this specific local authority area.
- b. All practitioners in contact with the FDWs undertaking their roles across this specific local authority area.

Using a co-productive and mixed methods approach with key professionals, the evaluation was designed to focus on three key phases to gather different datasets (casefile analysis, attitude survey and living experiences) to provide a holistic picture of the experience of families and practitioners, as the main actors of this evaluation.

Phase 1: Secondary analysis of key documents from the electronic files of a sample of families ($n = 12$). Participants were recruited using purposive

sampling, through a list of 15 open cases provided by the Social Care Leader, with a response rate of 80%.

Phase 2: An attitude survey for parents/carers ($n=5$) and for key professionals ($n=23$). All families accessing support were invited to participate (15), with a response rate of 33% and a response rate of 96% for practitioners.

Phase 3: Semi-structured interviews with parents/carers ($n=3$), with a response rate of 20% and key professionals ($n=23$), with a response rate of 96%. The sample included professionals from health, psychology, social care and the third sector. Due to the specialist or individual nature of roles and responsibilities of each participant, it is not possible to include specific job roles to protect the anonymity of all participants.

Following discussion with the project advisory group, a decision was made not to offer incentives to any of the participants, with all data collection undertaken online during the COVID-19 pandemic. This proved a limitation of this study, in particular the ability to undertake face-to-face research with families. Due to the potential sensitive nature of the evaluation, a decision was made that online interviews rather than focus groups would be offered to gain a sense of their experiences of working with the FDWs. The aim was to use 'mixed methods' to enhance the reliability of data and explore the relationships across and between the data sets. All research tools were designed with the project advisory group and piloted and tested to improve reliability.

Summary of Findings

The findings focus on the analysis of the data gathering for phase 3 of the research. The key themes that emerged were: -

Development of the FDW Role

The role development was focused on supporting families in a bespoke and person-centred manner, centring on building relationships as explained by Participant seven.

I think it's going [the FDW role] to be able to give them more knowledge about what exactly is going on with the family, because if you've got somebody in there who is a specialist working with the family, you're going to get more knowledge and more information out that they can share and maybe process and take further ... , to get them the help that they need.

The idea of developing the FDW role as a key role to co-ordinate multi-agency support, to enhance and develop consistent family support to offer assurance and advocacy for parents was also highlighted.

For me, their role is to bring all the services together, to see what the needs of those families are and rather than having twenty million people involved, maybe to coordinate it, but obviously to get the right support at the right time for that family. (Participant 8)

The discussion across agencies indicated the need to develop a FDW role that was flexible to the needs of the family. As a result, a conscious decision was made to avoid establishing a strict or 'official' criteria to access support. This ensured that the focus of the role remained as offering parenting support, focused on active listening and on exploring '*what matters*' to each family, including providing emotional support around adapting and coming to terms with a different family life than expected, due to their child's additional needs. The aim of flexible support was also to enhance the preventative role at the earliest point, to link in families as needed with specialist services to avoid the need for long-term support. In addition, the FDW was described as a community resource focused on linking families to community resources and local intervention group work. Therefore, it was described as a three-tier role focused on: -

Tier 1: Enabling and person-centred signposting for the whole family.

Tier 2: Empowering and active listening to advocate and address challenges in accessing specialist services.

Tier 3: Offering and delivering tailored interventions.

Well-Being, Profile of Needs and Multi-Agency Working

There was also a firm sense that the current assessment tools used by the FDW, specifically the Family Well-being Tool, assisted in encouraging a collaborative conversation with the whole family to tailor the support plan to their needs in both a fluid and bespoke manner.

A detailed review of the interviews revealed a consistent understanding of the family needs on a multi-agency basis. These diverse and often complex needs were described as revolving around three key cycles of events, see [Figure 1](#): This cycle of events often resulted in parents/carers required support and guidance, see [Figure 2](#): Pyramid of parent/carer support. Parent/carers were described as requiring an understanding which is summarised in [Figure 3](#), the Pyramid of parent/carer understanding.

It was evident that families accessing support from the FDWs are often struggling with positive behaviour support and are often uncertain of how their child's behaviours align with normative child developmental levels. The evidence indicates that parents/carers often require advice about managing everyday scenarios, whether it's mealtimes, bedtimes and accessing the community, highlighting the need for constant personal growth across the whole family (Blake, Bray, and Carter 2019).

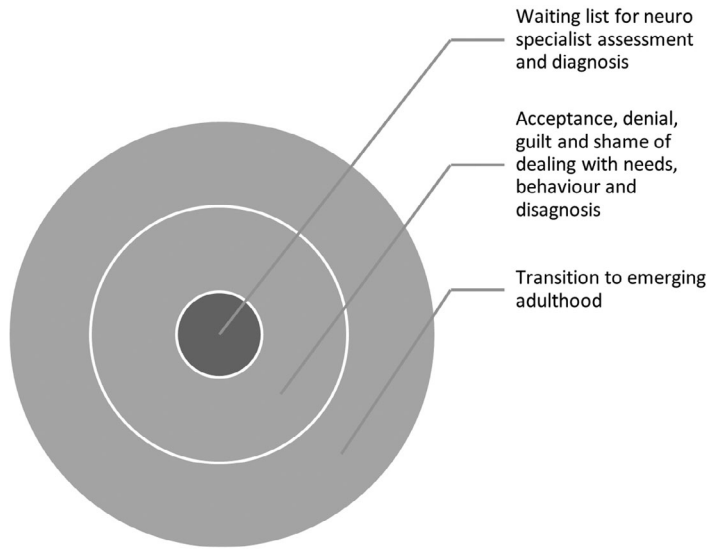


Figure 1. Three key cycles of events

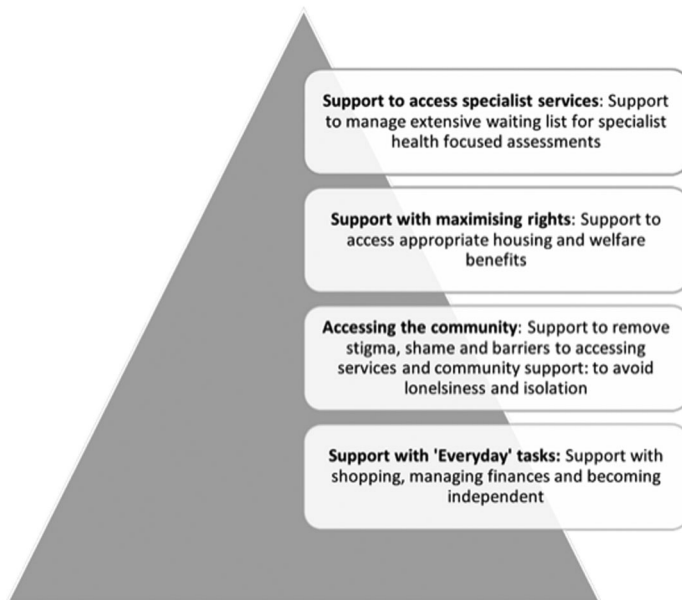


Figure 2. Pyramid of parent/carer support

Key Strengths of the FDW Role

A golden theme across the data was the potential ‘bridge’ that the FDW could build between parents/carers and services, with this ‘bridge’ having the potential to build and expand a pathway across all services. The experience of co-working with the FDW and other services was described as ‘enjoyable’

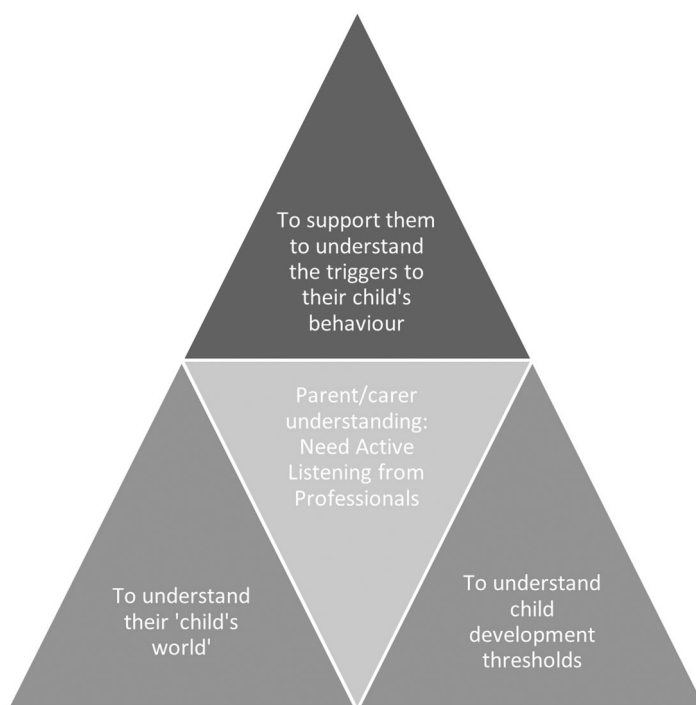


Figure 3. Pyramid of parent/carer understanding

(Participant 23) and 'offering a huge contribution to families from their point of view' (Participant 25).

Key Limitations of the FDW Role

As part of the discussion, key barriers faced by families were highlighted which are not directly related to the FDW role. These include access to direct payments, the lack of respite places and the key gap in the market of providers registered to work directly with children and young people.

Future Developments

There were creative ideas offered around the development of a menu of choice of interventions, which can inform the content of the toolkit which was produced as a key output of this project. For example, the development of parental/carer peer support groups for families with children with disabilities and additional needs, with the aim of reducing social isolation (Children's Commissioner for Wales 2019).

Concluding Reflections: Practice Development as a Catalyst to Change

The evaluation of the Disability Family Worker pilot and the resulting practitioner toolkit has been invaluable in consolidating and enhancing social work practice through the benefits and additional support capacity offered by the FDW role. Through discussion with strategic and policy leads, funding was secured to increase the team and recruit full time posts to each of the locality-based Family Centres, across the rural and urban areas of the county. Locating the role within local communities along with family support services enabled the integration of families of children with additional needs rather than cause further social isolation. These families access activities, services and peer support alongside other families in their area, bringing them in to contact with people facing similar challenges and reducing the stigma of asking for support.

One parent shared that her daughter felt 'at home' for the first time in the 'Let's Get Sensory group', as it was a safe and comfortable environment; this meant that the parent also felt relaxed and not judged in a community environment, sharing:

It's become one of the only places my daughter has free rein without being judged for her behaviour. She loves coming every week and I am so grateful to have somewhere like this to go to. It has been so helpful having somewhere to go with other parents who understand your everyday life.

Taking place in the local community and advertised as a quieter group which focusses on sensory play, the FDWs use the opportunity to model the strategies and activities they recommend to families in their one-to-one work, for example, a craft activity producing an item for a calm box.

During the support sessions, one theme identified was the concept of grief and loss for parents coming to terms with their child's difficulties or diagnosis; in response, a session was co-produced on this theme with a local charity, social workers and families. Parenting and well-being courses have been adapted to shorter and more focussed sessions, presenting the principles and applying practical strategies for parents. The FDWs support families to communicate with schools and other services, enabling families to articulate their worries and needs and work collaboratively to find solutions. In one case, the FDW coached the child and parent to explain their concerns to the school prior to a meeting, which resulted in a joint plan and a child who felt listened to, validated and empowered to take control of their school attendance.

Despite the additional resource, it has proved challenging to respond to the demand, as the families that this role seek to support have more complex needs and often require longer term input. The aim is to empower families to take control and move forward, within the safety net of continued contact through the community groups.

The toolkit has provided an evidence based enhanced tool to add detail to the ‘what matters’ conversation with families on all aspects of their family life. This enables the workers to get to the heart of the family strengths and areas to build on. The role continues to develop and evolve within the Family Centres, and the feedback has been overwhelmingly positive by families and partners. The aim is to further evaluate progress and impact on social work practice in the future. The toolkit is now implemented by the FDWs as part of their everyday practice.

The findings suggest the importance of preventative social work practice to support the needs of families with children who have a disability or additional needs. There was overwhelming agreement on a multi-agency basis and across families of the importance of the contribution offered by the FDW role. Further research could be undertaken to focus on other areas of neuro-development support for children and young people, for example, within the educational arena.

Disclosure Statement

No potential conflict of interest was reported by the author(s).

References

- Blake, Lucy, Lucy Bray, and Bernie Carter. 2019. “It’s a Lifeline”: Generating a Sense of Social Connectedness through Befriending Parents of Disabled Children or Children with Additional Need.” *Patient Education and Counseling* 102 (12): 2279-2285. <https://doi.org/10.1016/j.pec.2019.07.012>.
- Children’s Commissioner for Wales. 2019. “‘DON’T HOLD BACK’: Achieving the Best for Young People with Learning Disabilities.” *Dont-Hold-Back.pdf* (childcomwales.org.uk).
- Griggs, J., and L. Bussard. 2017. *Study of Early Education and Development (SEED): Meeting the Needs of Children with Special Educational Needs and Disabilities in the Early Years: January 2017*. London: Digital Education Resource Archive (DERA) (ioe.ac.uk).
- Marrable, T. 2014. “Emotion in Responses to the Child with ‘Additional Needs’.” *Child & Family Social Work* 19 (4): 401-410. <https://doi.org/10.1111/cfs.12035>.
- SRA (Social Research Association). 2021. “Research Ethics Guidance” [Online]. Research Ethics Guidance (the-sra.org.uk).
- Welsh Government. 2015. “Social Services and Well-being (Wales) Act 2014: Code of Practice in Relation to Measuring Social Services Performance” [Online]. <https://gov.wales/sites/default/files/publications/2019-05/code-of-practice-in-relation-to-measuring-social-services-performance.pdf>.
- Welsh Government. 2018. “Learning Disability Improving Lives programme” [Online]. <https://gov.wales/learning-disability-improving-lives-programme>.
- White, S., and B. Featherstone. 2005. “Communicating Misunderstandings: Multi-Agency Work as Social Practice.” *Child & Family Social Work* 10 (3): 207-216. <https://doi.org/10.1111/j.1365-2206.2005.00372.x>.

Ceryl Davies is a Lecturer in Social Work based at the Centre for Health Economics and Medicines Evaluation (CHEME) at Bangor University, North Wales. Ceryl is an applied social scientist, focused on leading on social care economics research, including exploring the impact of low cost preventative interventions. Ceryl is also a qualified social worker.

Deborah Job is a manager in Family Early Intervention and Prevention Services in Social Care (Conwy County Borough Council), currently on secondment as North Wales Regional Lead for Suicide and Self-harm Prevention hosted by the Wales NHS Executive.