

Family Disability Worker

Looking at the role and the difference they make to families.

Summary April 2022



The emotional, physical, and social well-being of children with disabilities is important to Conwy County Borough Council.

We want to make sure they have all the support they need when they need it. Part of our team is the Family Disability Worker (FDW). This is a new role focusing on stepping in early to support parents and carers of children with a disability.

We wanted to check the difference this role was making so we asked Dr Ceryl Teleri Davies, from Bangor University to do this evaluation.

Why is this important

The needs of children with a disability are becoming more complex. (*Improving Lives Programme, 2018*). We want to understand what families need and find new ways of working to meet these needs across Conwy.

How



Surveys



23 professionals



5 parents/carers took part.



Semi-structured interviews



23 professionals



3 parents/carers took part.



What did the study find?

The evaluation found lots of different things including:

1. Delays in getting a specialist neurodevelopment diagnosis affected the whole family. It meant they had to deal with behaviour that caused harm to their child's wellbeing.
2. Dealing with these behaviours left families feeling socially excluded and isolated.
3. Families often faced challenges like poor housing, overcrowding and poverty.
4. When services worked together to give support it had a big impact on the well-being outcomes for the whole family.

Other findings

There were similar needs identified across the families:

- Learning needs and diagnosis of a learning disability
- Speech and language issues, including communication issues
- Low mood and mental health concerns
- Self-harm and suicide thoughts
- Significant behaviours of concern.
- Stigma, shame, social exclusion, and social isolation
- Money needs including for equipment and help with benefit forms
- Challenges for parents/carers to gain and maintain employment.

Themes from the surveys

There is a lot of support for this role. **100%** of respondents agreed that this role was necessary.

95% responded that they strongly agreed/agreed that this role was important

96% agreement with the statement "This role contributes to multi-agency work"

96% said that Family Disability Worker advocates on behalf of families. They:

- empower parents/carers
- offer a broad range of opportunities
- provide 'valuable' support for families.

Professionals viewed their role as promoting positive, anti-oppressive support for families.

Most felt that:

- there was a good understanding of this role.
- it had assisted in 'making their life better'.
- it had assisted in empowering them in their parenting/caring role.

Themes from Interviews

Participant six offers a good summary of the role: -

Well, I think it's very good because they are there to make sure that people are accessing the right services, that they're being supported in the right way and that person has got someone that they can go to sort out things for them. They're obviously specifically, you know, dealing with people with disabilities um because sometimes- I know sometimes people may have other things wrong with them, but they've never talked about it or they've never gone to the right professionals. So this is making sure that they're accessing the right treatments as well.

I think it's going [the FDW role] to be able to give them [the FDW role] 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, you know, to get them the help that they need, really. So ... I think they're going to be really good roles to have. It's going to be an asset, I think, to the family workers.

The idea of developing the **Family Disability Worker** role as a key part of 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. To intervene, really, where needed and be a regular ... support for that family. (Participant 8).

Well-being needs

Lots of people said that the needs of specific children and their families 'fall through the net' including well-being needs. It was felt the role of Family Disability Worker could help prevent that.

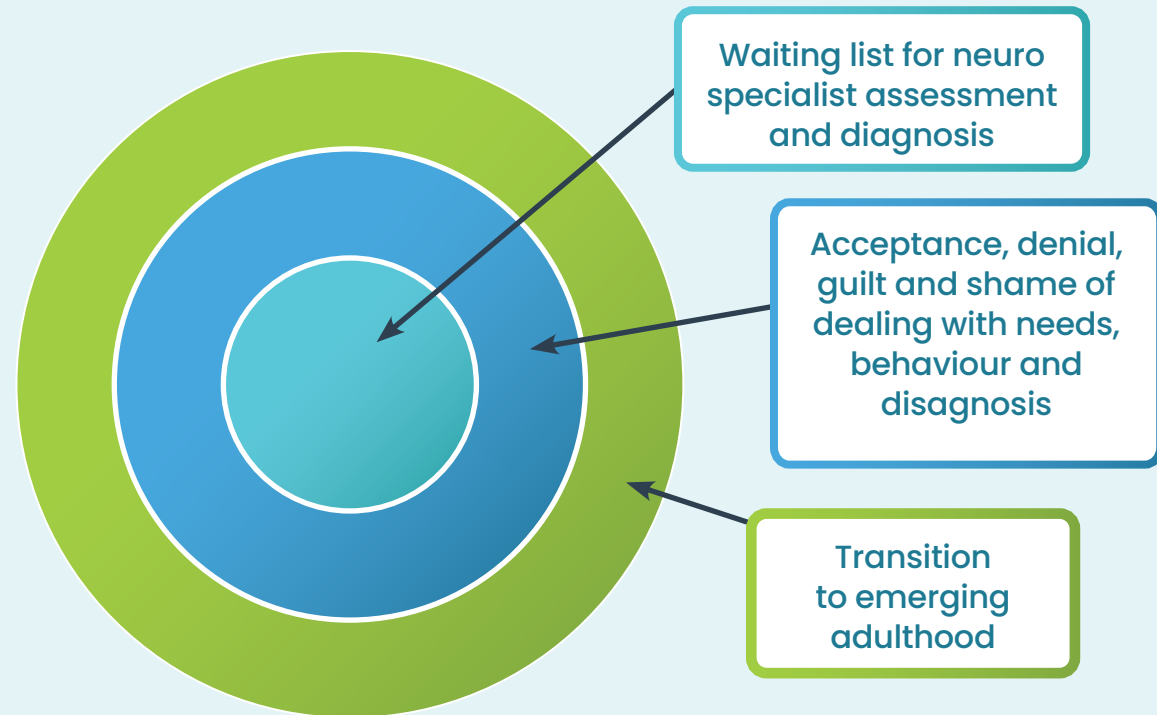
Lots of people discussed well-being, prevention and strengths-based practice. A summary of these discussions is set out in the model below.



Assessment and support needs

The Family Disability Worker and the assessment tools they use encourage conversation with families and helped support plans to meet their needs.

Family's needs are complicated and very different. They were described as revolving around three key cycles of events:



Information and guidance needs

This cycle of events often resulted in parents/carers needing support and guidance.

Pyramid of parent/carer support



Support to access specialist services:

Support to manage extensive waiting list for specialist health focused assessments

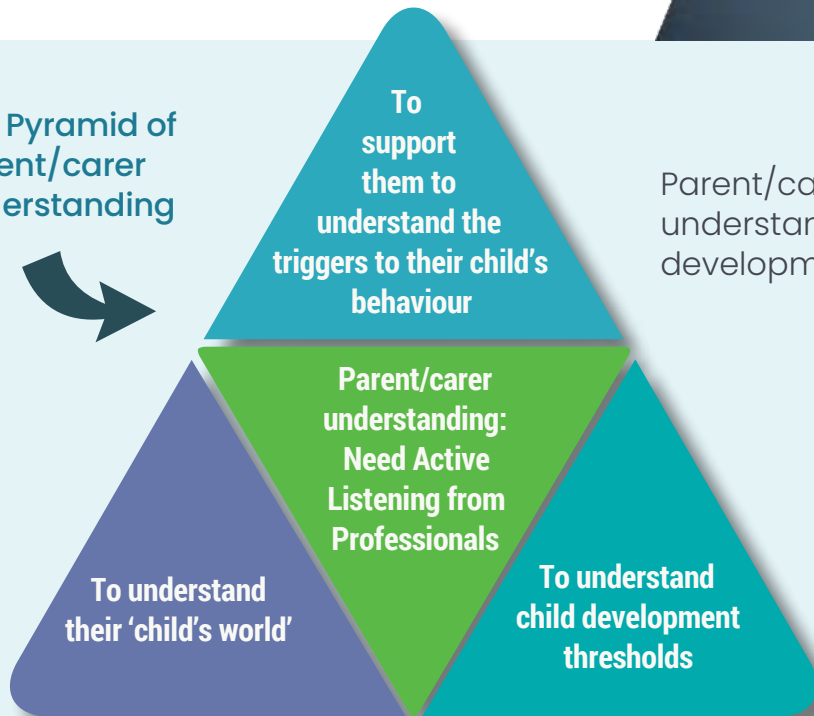
Support with maximising rights:

Support to access appropriate housing and welfare benefits

Accessing the community: Support to remove stigma, shame and barriers to accessing services and community support: to avoid loneliness and isolation

Support with 'Everyday' tasks: Support with shopping, managing finances and becoming independent

The Pyramid of parent/carer understanding



Parent/carers needed support to understand their child's needs and development milestones.



Key strengths of the Family Disability Worker role



For the child and family

The importance of the Family Disability Worker is summarised by Participant 25:

You know, I just think that they're the go-to person, especially when we're trying to make sure that the child's needs are being met or if we've got any worries about whether the child's needs are being met. I just feel like they potentially are gonna be you know, the most important person to pull all of us individual people together.

A golden theme across the data was the potential 'bridge' that the Family Disability Worker could build between parents/carers and services. This 'bridge' helps to build and expand a pathway across all services.



For Co-workers

Co-working with the Family Disability Worker was described as "enjoyable" (Participant 23) and

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

The 'added value' provided by the role is highlighted by Participant 2:

Having worked very closely alongside one of the family disability support workers, just the additional- you know, the added value that they've been able to provide to supporting particularly some of the really complex families that we've worked with has been absolutely invaluable.



Linking to Family centres

As a result, several of the participants highlighted that the family centres are more approachable and offer support that is:

- "proactive, person-centred and values-based approach" (Participant 4),
- "thinking outside the box" (Participant 5)
- "empowering parents to take the lead" (Participant 25).



Conclusion

The key theme is that the practical and emotional support offered and provided to parents/carers by the Family Disability Worker enhances parental ability to manage everyday stresses. They help families access services and address their own well-being needs.

The empowerment and person-centred advocacy offered in a bespoke manner by the Family Disability Worker had proven to address a long-standing gap in services.

The outcomes for these families have been positive for their overall well-being, often supporting them to address and remove long-standing barriers.

The Family Disability Worker was also clearly described as focusing on strength-based practice, offering support that built on the capabilities of each family.



Recommendations

From this evaluation it's been recommended that we:

- develop the role of Family Disability Worker across Conwy
- give Family Disability Worker more ability to support disabled children and their families as part of the multi-agency teams .

This report should be available for people to read, so it's recommended that we:

- make this report available in lots of different formats including easy read report
- design and deliver workshops for children with a disability, their families, and professionals to present the results of the research
- produce a slide show set which communicates the results of the report
- send out tweets, communicating the results of the work, which can be shared with and used by Conwy County Borough Council and Bangor University.

It's also recommended that we:

- develop a Well-being Toolkit for professionals, children with a disability and their families
- develop training to support professional to use the Well-being Toolkit.