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

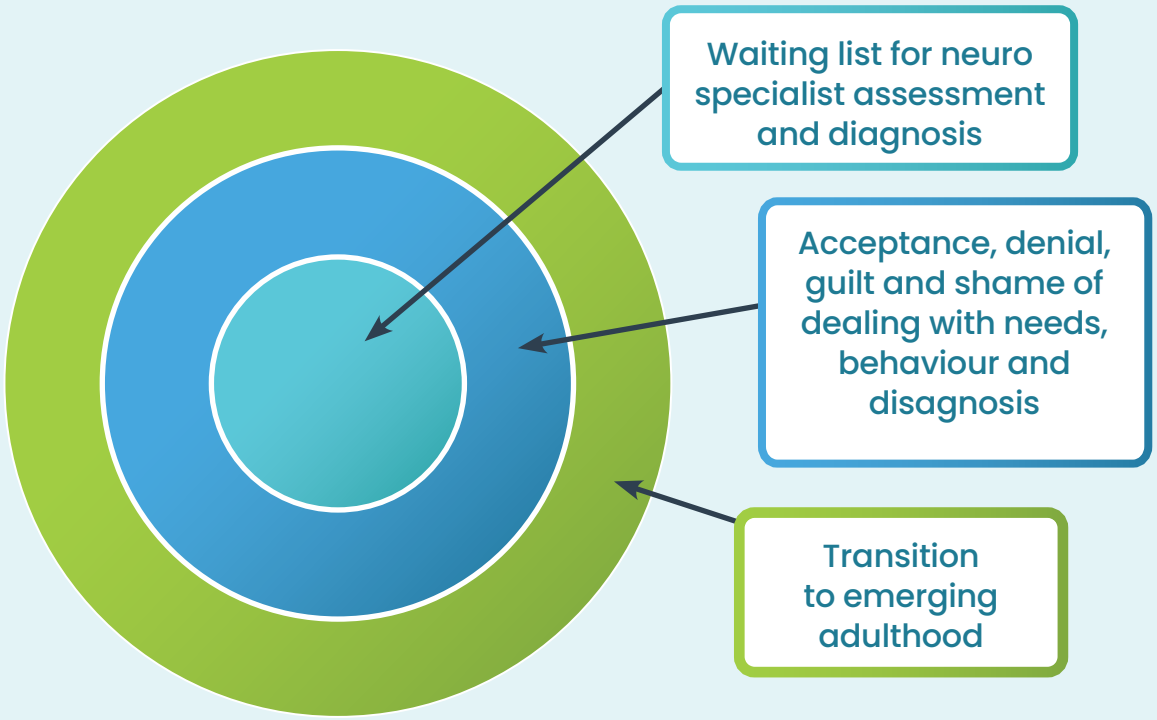
Lots of people said that the needs of specific children and their families 'fall through the net' including well-being needs. It was felt the role of Family Disability Worker could help prevent that.

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

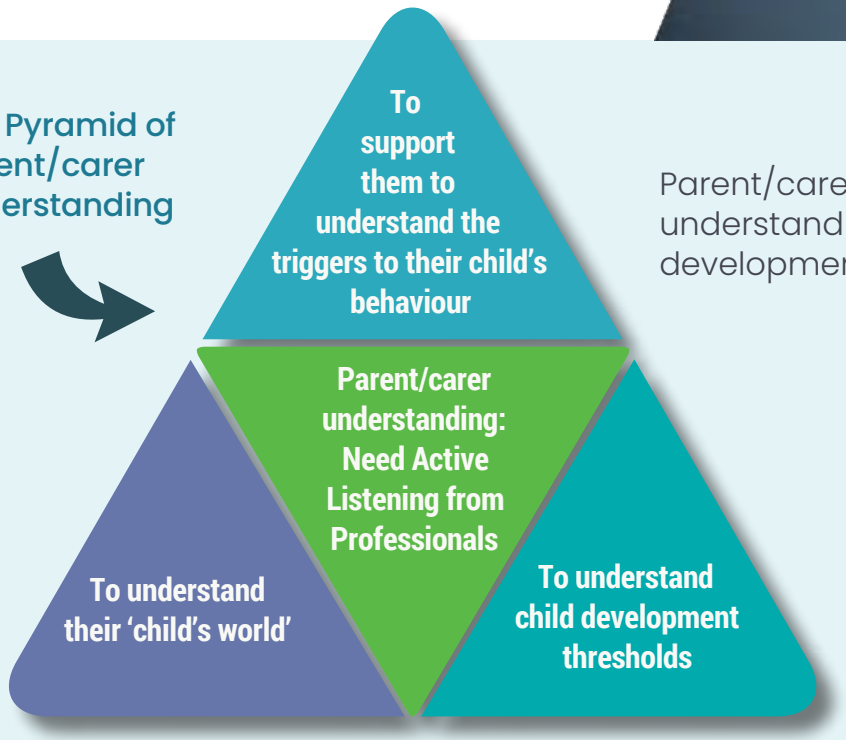
Support to access specialist services: Support to manage extensive waiting list for specialist health focused assessments

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.

An evaluation of the role of the Family Disability Worker in Conwy:

Executive Summary

April 2022

Dr Ceryl Teleri Davies, Bangor University

SUMMARY

Though our understanding of the impact of disabilities/complex additional needs on children/young people has developed over the years, there continues to be limited understanding of the impact on the whole family.

This evaluation focused on a local study completed across Conwy, which included a focus on a survey for professionals (n=23) and parents/carers (n=5) to explore their attitudes and views on the role of the Family Disability Worker (FDW). Following this, a series of semi-structured interviews were completed in order 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 participants of supporting the needs of a child(ren) with a disability or additional needs. This included an exploration of their views on working with the FDW, including their perspectives on the uses and limitations of this role. The analysis identified several key points: firstly, that a delay in a specialist neurodevelopment diagnosis has a significant impact on the whole family, which results in families experiencing the impact of significant behaviours of concerns over a prolonged period of time; secondly, the sustained impact of addressing this behaviour results in families feeling social excluded and isolated; thirdly, these family often suffer the impact of poor housing, overcrowding and poverty and finally, the overall positive impact of robust multi-agency working on the well-being outcomes for the whole family.

The findings have relevance for policy and practice and contribute to an emerging field of literature exploring the nature of disability and additional needs on families who are often perceived to be the 'missing middle'. The findings suggest the importance of preventative services to support the needs of families with children who have a disability or additional needs. A key finding is the overwhelming agreement on a multi-agency basis and across families of the importance of the contribution offered by the FDW role. This finding suggests that any future developments around enhancing this role would be a welcome additional to the multi-agency services supporting families across Conwy.

CONTEXT

Evidence suggests that the needs of children with a disability are becoming more complex (Improving Lives programme, 2018) and therefore innovative work is required to understand and meet the needs of these children and their families. Having a disability is often a lifelong condition. Children with a disability often suffer a range of disadvantages as result of a spectrum of health, development and physical needs, but also as a result of a range of barriers: including, negative attitudes and social exclusion, which all require addressing to enable them to live active and fulfilled lives within their communities. Societal attitudes towards disabilities have changed significantly in recent years. It is now widely recognised that individuals with a disability have the right to live independently within the community, with meaningful choices offered in respect of their health, social and support needs.

With increased demand for services for children with complex disabilities, the need for local community-based support for families with children with a range of disabilities is significant. For example, the number of children in need of specialist education at Ysgol Y Gogarth has increased from 185 pupils in 2015 to 245 in 2020 (Conwy PID, 2020). Multi-agency services across Wales work to address the needs of these children to provide a wide range of support and services within communities. Despite this, wide-ranging disadvantages and poorer outcomes are recorded for children with a range of disabilities, including those children on the ASD spectrum. Yet, limited research has focused on developing or measuring the impact of a wide range of care, support and interventions to meet the emotional, physical and social well-being needs of these children. In addition, there is a gap in UK-based research, in particular Welsh research, which explores the needs and well-being outcomes of children with a disability. There is also limited data and knowledge across the UK on evaluating the impact of well-being services to promote the development of a broad range of skills for children with a disability and also support for their families.

Many services across the UK tend to use medically and psychologically based criteria to define disabilities (as outlined in the Equality Act 2010). Over recent years there has been a more generalised movement in the broader field of disability to support all disabled people to live their lives as full citizens from a social prescribing perspective. This ethos is further embedded with the adoption of the Care Act [England] 2014 and the Social Services and Well-being Act [Wales] 2014. The focus is on ensuring that individuals receiving social care support are enabled to live the life that they want to live, with the focus on 'what matters' for them and their families. The support offered should focus on assisting families to achieve their well-being outcomes. Well-being is defined in a broad sense as physical, mental health and emotional well-being and having the right to control individual choices to live a full life, including when securing rights and entitlements (section 2 (3) SSWA Act (Wales) 2014). The idea of well-being is a personal, but broad concept that impacts on several key aspects of everyday life, with clarity around measuring personal well-being outcomes outlined with the code of practice in relation to measuring social services performance (Welsh Government, 2015).

The aim of this evaluation was to explore the impact of the FDW, a new role designed to promote preventative well-being services that responds to the emotional, physical and social well-being needs (including the progression of skills) of children with a disability via support offered to their parents/carers. The voices of the families accessing services shaped the design and delivery of well-being services to meet emotional, physical and

social well-being needs in a progressive and strength-based manner. This offers a unique opportunity to talk about well-being and 'what matters' to these individuals on an 'everyday' basis. Not only will this focus on community-based services, but it will also focus on promoting well-being needs and services through local community services, promoting skills through the ethos of Active Support & Positive Behaviour Support (PBS) and promoting the development of positive relationships (with the community, with family members and peers and with a broad spectrum of professionals across the multi-agency service). This evaluation offers the opportunity to explore the impact of a new community facing preventative role which promotes positive well-being. This will also assist in embedding the ethos of social prescribing as a tool to enhance people's ability to make positive changes in their lives, linking people to activities, voluntary and community groups and public services (Thomas et al, 2019). The aim of the FDW role is to provide the right advice and support at the earliest opportunity to enhance a range of opportunities for families with children with a range of disabilities by focusing on progressing their well-being outcomes and goals. The focus is on increasing capacity to support and enhance the well-being outcomes of these children and their families. Establishing a more proactive approach, seeking to identify those children/families at risk of becoming 'stuck' within services will enhance their ability to live as independent as possible at the earliest opportunity.

This evaluation offers the opportunity to measure the impact of a role to promote opportunities for children with a disability and their families to access mainstream activities so that they can be active members of their local communities.

THE EVALUATION PROCESS

Using a co-productive approach with key professionals, the evaluation was designed to focus on three key phases. A key aim of the evaluation design was to draw upon values of positive empowerment and 'active agency' to give participants a voice and therefore more power to influence the shape of the findings.

Phase 1: As part of this phase, pen pictures and family well-being profiles will be created to outline the experiences and 'stories' of the families accessing the support of the FDW. A desktop review of key documents from the electronic files of a sample group of children will be analysed. Participants will be recruited using purposive sampling as there is a need to access families and key professional that have direct knowledge and experience of the support offered by the FDW. Participants will be recruited through the referral process to access the support from this worker (up to a level of saturation point of analysis). The analysis of this data will inform the specific themes to be explored with the families as part of the semi-structured interviews to gather a sense of their experiences.

Phase 2: An attitude survey in an easy read format for parents/carers and for key professionals working with children with a disability in Conwy.

Phase 3: Semi structured interviews will be conducted with parents/carers and key professionals too.

SUMMARY OF FINDINGS

1. THEMES: CASEFILE REVIEW

Significant impact on the well-being of the whole family as a result of a delay in neuro-development and CAMHS specialist assessments;

- A broad spectrum and a continuum of needs identified across the families in the sample;
- Learning needs & diagnosis of a learning disability;
- Speech and language issues (including communication issues);
- Low mood & mental health concerns for the children and the parents/carers (often for both during the same period);
- Self-harm and suicide ideation from child with complex needs;
- Significant and often complex presentation of behaviours of concerns. Identifying these behaviours early could assist the FDW to work to address the long-term behavioural needs of these children;
- Stigma, shame, social exclusion and social isolation;
- Finance needs, in particular the requirement of support through welfare rights regarding benefit application processes e.g. DLA. The impact of finance was often due to family poverty and the requirement of additional equipment in the house. It was also a challenge for parents/carers to gain and maintain employment. Therefore, several factors associated with the disability/additional needs of a child/children within the family impacted on the finance/resources available for families.
- Housing needs around inappropriate housing and overcrowding.

The range of behaviours and needs across the cases reviewed are challenging and demonstrate a complex interplay between individual and contextual dynamics. In addition, specialist input needs to be both universal (raising awareness work etc) and targeted to meet individual needs. Whilst education was seen as a factor in some cases, it was not a primary trend/theme across the cases and, when discussed, was regarded primarily as a protective factor. Information from the cases review indicates some key information: firstly, that a delay in a specialist neurodevelopment diagnosis has a significant impact on the whole family, which results in families experiencing the impact of significant behaviours of concerns over a prolonged period of time; secondly, the sustained impact of addressing this behaviour results in families feeling social excluded and isolated; and thirdly, these family often suffer the impact of poor housing, overcrowding and poverty.

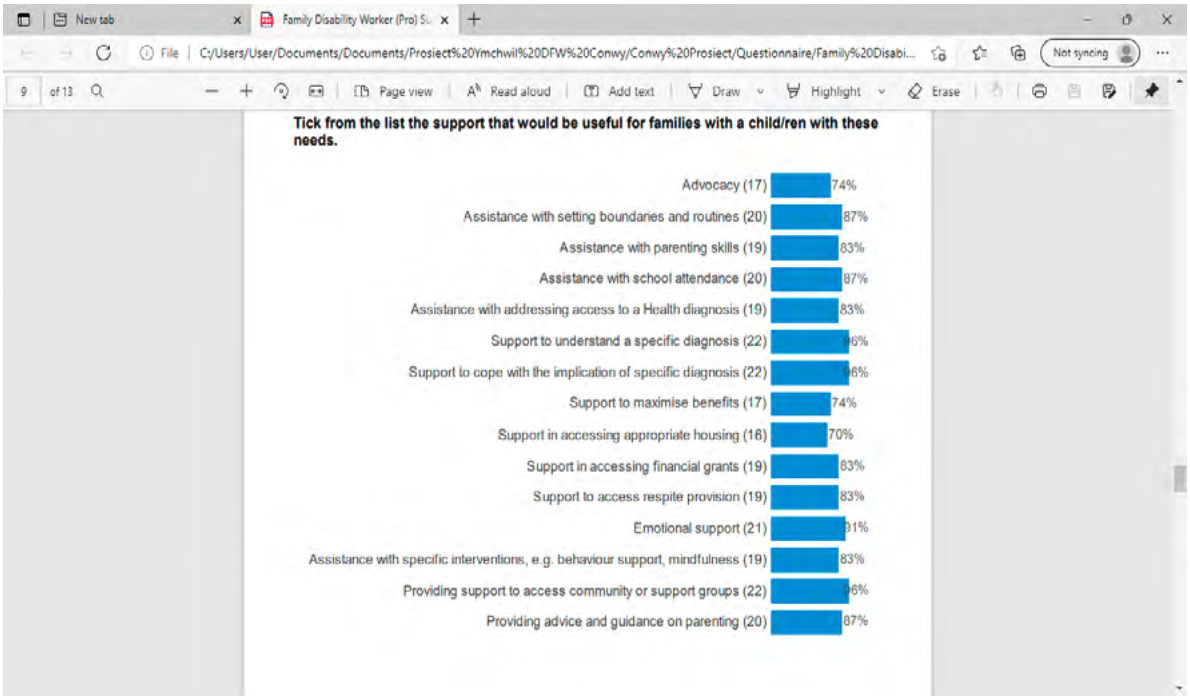
2. THEMES: QUESTIONNAIRE

Professional Questionnaires

Overall, the findings suggest that there is a good level of understanding of the role and the responsibilities of this role, with 20 of the respondents replying that they strongly agreed or agreed with this statement. When reflecting on whether the respondents felt that this role is important for families, 95% responded that they strongly agreed/agreed that this role was important (with only one participant selecting the choice 'don't know'). This offers a strong indication of the multi-agency support for this role as a key aspect of the multi-disciplinary framework supporting families in Conwy. This was confirmed with the response from respondents reflecting their view that this role contributes to multi-agency work, as again there was 96% agreement with this statement. There was also positive support for this role as part of the multi-agency framework, in a 'standalone' or distinct manner, with the respondents clearly noting that this role did not duplicate the tasks of other key professionals. Again, with over 96% of respondents noting that they believed that this role provides 'valuable' support for families, which is 'helpful' and is of 'benefit' to them. Furthermore, there was overwhelming support for a key aspect of this role, as again over 96% of participants comments that this role advocates on behalf of families with children who have a disability or additional needs. There was also a positive response towards the statements that this role empowered parents/carers and offered a broad range of opportunities for families with children with neuro-development and/or additional needs. The preventative element of this role was also appreciated, with the majority of respondents reflective their strong agreement with this statement. Respondents also favoured the statement that explored whether this role the quality of life of families accessing this support.

To further explore the key themes that emerged from the casefile review, key statements in the questionnaire explored the professionals views on the potential difficulties that families experience with accessing appropriate housing, financial challenges and their experiences of social isolation, social exclusion, stigma and shame. The data analysis reflected that 74% of the respondents either strongly agreed or agreed that the families accessing this support encountered financial barriers, with 22% commenting 'don't know' and 4% disagreeing with this statement (equating to one respondent). A similar picture emerged regarding the views on the barriers faced by these families when accessing appropriate housing, with again 74% strongly agreeing or agreeing with this statement, whilst 17% commented 'don't know' and 9% disagreed with this statement (2 respondents). A higher degree of respondents disagreed that families accessing this support encountered stigma and shame within their communities, as 30% (seven respondents) disagreed with this statement, whilst over 60% strongly agreed or agreed with this statement. This view was further echoed with the next statement which explored whether these families encountered stigma and shame from professionals, as only 26% either strongly agreed or agreed with this statement, whilst a higher percentage either strongly disagreeing or disagreeing (over 60%). This offered a firm indication that professionals viewed their role as promoting positive, anti-oppressive support for families with children with a disability or additional needs.

There was 100% support across the sample to develop and offer a broad range of interventions to support the needs of these families. This offers a form indication on a multi-agency basis that services want to offer a menu of well-being interventions to meet the bespoke needs of families experiencing difficulties. Respondents were asked to reflect on the services that would be useful to support families, with the summary of the findings outlined below in Figure 1: Useful Support List.



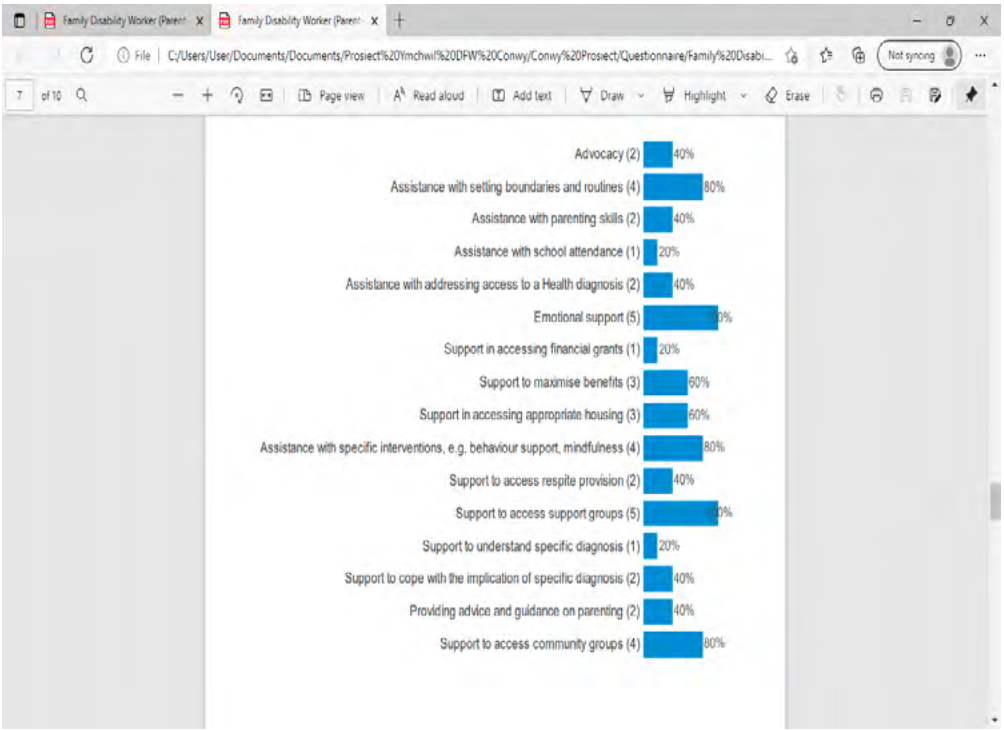
When questioned whether professionals would benefit from having access to a Well-being Toolkit to support the needs of families, 83% of respondents agreed that this would be a positive development. There was also a firm indication regarding the development of this role to the future, with 91% of respondents agreeing that this was necessary, with only 9%, equating to two respondents selecting 'don't know'.

Parent/Carer Questionnaire

All the respondents who completed the questionnaire are mothers in their 30s (age range of 30-37 years old), with four of the respondents living with a partner and one parent/carer a single parent/carer. Four of the respondents identified as white/UK, whilst one respondent identified as mixed/multiple ethnic groups. One respondent noted that they work fulltime, two work part-time hours and two of the respondents are full-time carers.

The first statement explored the level of understanding of the role of the FDW. The findings indicate a good degree of understanding of this role, with all respondents strongly agreeing or agreeing that they clearly understood the aim of this role. When reflecting on whether the respondents felt that this role is important for their family, 100% responded that they strongly agreed/agreed that this role was important. There was also agreement that this role helps families work with other professionals, with all respondents noting that this role had helped their family, had assisted in 'making their life better', and had assisted in empowering them in their parenting/caring role.

To further explore the key themes that emerged from the casefile review, key statements in the questionnaire explored the parent/carer views on the potential difficulties that families experience with accessing appropriate housing, the financial challenges they face and their experiences of social isolation, social exclusion, stigma and shame. The data analysis reflected that 80% of the respondents either strongly agreed or agreed that they had experienced financial barriers. From those families who completed the questionnaire, 40% noted that they experienced barriers when accessing appropriate housing, whilst 60% commented 'don't know'. A high degree of respondents strongly agreed or agreed (80%) that they had encountered stigma and shame within their communities, with one respondent noting 'don't know'. Only 20% of respondents felt that they had experienced stigma and shame from professionals when accessing services, whilst 60% noted 'don't know' and 20% strongly disagreed with this statement.
There was 80% support across the sample to develop and offer a broad range of interventions to support families. Respondents were asked to reflect on the support that would be useful to support their family, with the summary of the findings outlined below in Figure 2: Useful Support List.



When questioned whether families would benefit from having access to a Well-being Toolkit to support the needs of families, 80% of respondents agreed that this would be a positive development. There was also a firm indication regarding the development of this role to the future, with 100% of respondents agreeing that this was necessary.

3. THEMES: INTERVIEWS

Development of the FDW role

The aim of the development of this specific role was to enhance preventative services to support families with children with disabilities and additional needs, specifically those families who do not meet the criteria to access services from the children with disabilities team. As part of the disabilities services for children and families within social care, there had been a social work role focused on a multi-agency preventative role, working closely with Ysgol Gogarth and the CDC. When this role became vacant, it was decided that there would be an options appraisal focusing on exploring the need for this role. This review indicated that the required role should be more focused on a supporting role for families to address key needs in a practical manner e.g. housing and finance needs. It was also identified that there was a key gap in provision that needed to be integrated with the local communities through the family centres. There was also a gap in co-ordinating services to deliver support, essentially developing a role that signposted and worked to 'open doors' into services for families. This options appraisal provided the opportunity to 'pause and reflect' around the local needs, provided a rich sense of the planning process that informed the rationale to develop the FDW role. The overall aim was focused on an ambitious, creative and strength-based approach to developing five key geographical areas across the county that would link to co-ordinating preventative support for the whole family through the family centre workstreams (that would include Team Around the Family and Flying Start). Therefore, the intention was to include the FDW as a key role within this preventative model to offer support and signpost families to receive support from specialist services. 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.

The summary offered around 'accessing the right treatment' and needs is crucial for families with children with disabilities and additional needs. The focus is also 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 [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 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. To intervene, really, where needed and be a regular ... support for that family. (Participant 8).

The definition or conceptualisation of disability and additional needs was discussed with each participant. The challenges of establishing a clear definition or indeed a diagnosis was clearly summarised by Participant 2: -

> A disability is a nuanced kind of, process that we often discuss within early years services is that transition between the term global developmental delay or developmental delay and learning disability and when do we start having conversations around a child having a learning disability as opposed to them being identified as having developmental delay in their early years, the first five years of life. But I guess in terms of defining disability is you know, in relation to their chronological age and their peers of the same age that they are not perhaps at the level that would typically be expected in the different developmental domains. Also having significant difficulties with developing independent living skills. So you know, the daily, kind of, adaptive functioning skills that we need to be able to live our lives independently, and that kind of, develops and changes over time. So obviously with very young children they're much more reliant on their caregivers and those people around them to provide that support, but as they get older from a typical developmental trajectory children and young people would be developing some of those skills more independently but those with disabilities may follow a different trajectory.....having additional needs is those children that need those additional support in order to be able to access the community, the services, activities, daily life in the- you know, in as close a way as possible as their typically developing peers. And they may need support to do that. So whether that's education, you know, community use, extracurricular activities those sorts of things. The children and young people who, kind of, fall between the cracks of services, so they don't have necessarily a mental health difficulty that is considered severe enough for CAMHS, they don't have a diagnosis of a learning disability.

The summary of these specific children as those who essentially 'fall through the net' was a consistent theme across the interviews. It was also felt that the FDW aligned with the key principles of the Welsh social policy framework, in particular the Social Services and Well-being Act [Wales] 2014 and the Well-being of Future Generations Act [Wales] 2015. It was also highlighted that the development of services should align to the definition of Disability outlined in the Equality Act 2010[1]. A key need that was highlighted as a consistent theme

1 The Act defines a disabled person as a person with a disability. A person has a disability for the purposes of the Act if he or she has a physical or mental impairment and the impairment has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities (S6(1)).

when discussing both the definition of disability was the requirement to offer support to parents/carers to manage behaviours. There was also a general agreement that services were required to move away from the medical model of disability, to ensure a focus on social needs and additional needs through a well-being and social prescription approach. 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 and emotional support, focused on active listening and on exploring 'what matters' to each family to establish outcome focused well-being goals. 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 also described as a community resource focused on linking families to community resources and local intervention groupwork. Therefore, the role 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 advocate to address challenges in accessing specialist services;

Tier 3: Offering and delivering tailored interventions.

Well-being, profile of needs and multi-agency working

A definition of well-being is highlighted as a key principle of the Social Services and Well-being Act [Wales] 2014[2]. The discussion on well-being, prevention and strengths-based practice was a key theme across the interviews, with a summary conceptualised in the model below, Figure 3:

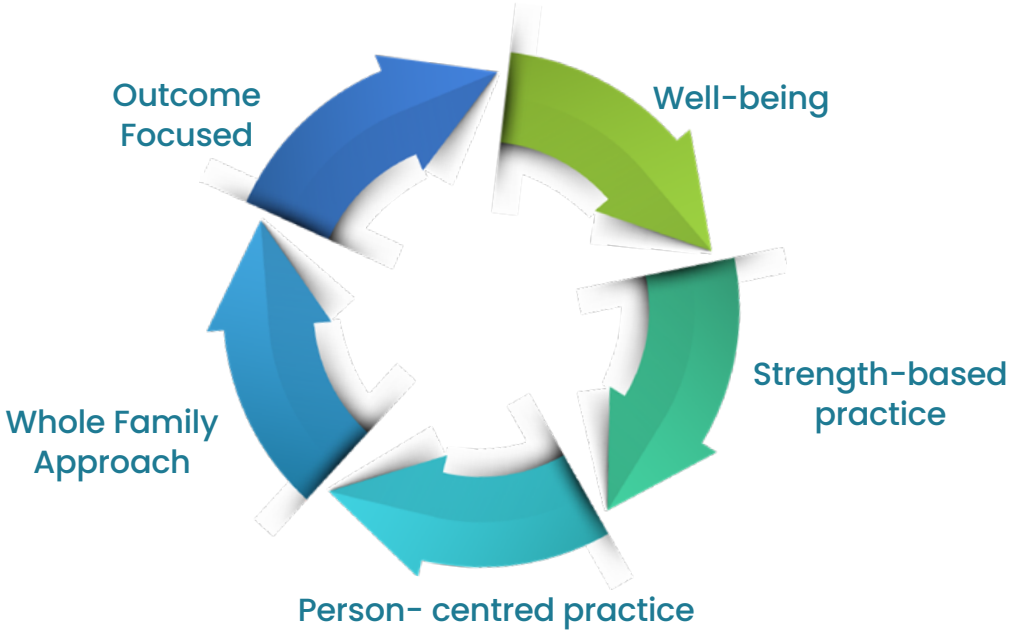
2 **Well-being duty** Section 5 of the SSWA 2014 requires persons exercising functions under the Act to promote the well-being of people who need care and support, and that of carers who need support. This overarching well-being duty applies to all persons and bodies exercising functions under the SSWA 2014, including the Welsh Ministers, local authorities, Local Health Boards (LHBs) and other statutory agencies.

Section 2 of the SSWA 2014 defines "well-being", in relation to a person, as meaning well-being in relation to any of the following—

(a) physical and mental health and emotional well-being;
(b) protection from abuse and neglect;
(c) education, training and recreation;
(d) domestic, family and personal relationships;
(e) contribution made to society;
(f) securing rights and entitlements;
(g) social and economic well-being;
(h) suitability of living accommodation.

In relation to a child, "well-being" also includes—
(a) physical, intellectual, emotional, social and behavioural development;
(b) "welfare" as that word is interpreted for the purposes of the Children Act 1989.

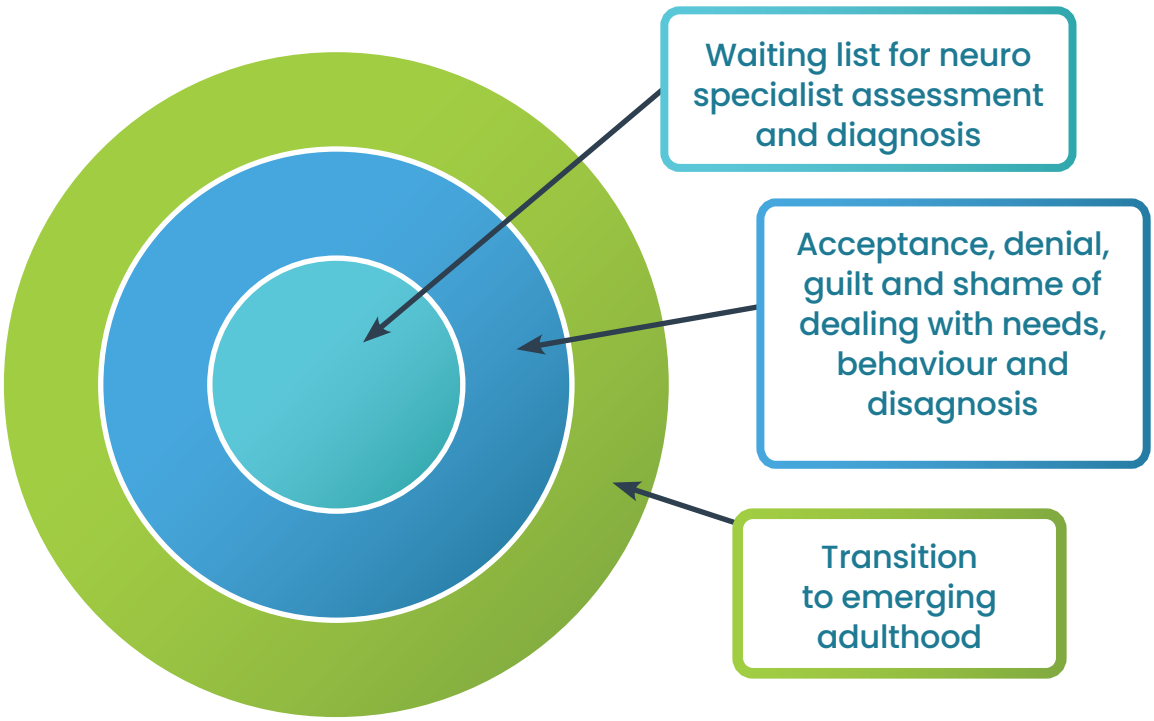
In relation to an adult, "well-being" also includes—
(a) control over day to day life;
(b) participation in work.



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. Several participants highlighted the importance of maintaining this approach, which is clearly summarised by participant 19.

> I think the interventions or the support they give families I hope they'd be a bit less bureaucratic in a way, maybe. You know, cos as soon as we have cases open, families- some of the families we work with, they can be quite non-engaging at times. And we have our statutory guidance to follow, and we have to review the cases. So maybe that approach helps some families more... But yeah, it'd be nice to see that there'd be more choice with that route [FDW route].

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 4:



This cycle of events often resulted in parents/carers required support and guidance, see Figure 5: 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

Several participants raised the significant feelings of stigma, shame and guilt felt by parents/carers when addressing the needs and behaviour of their child, Participants three clearly outlines this challenge for parents/carers.

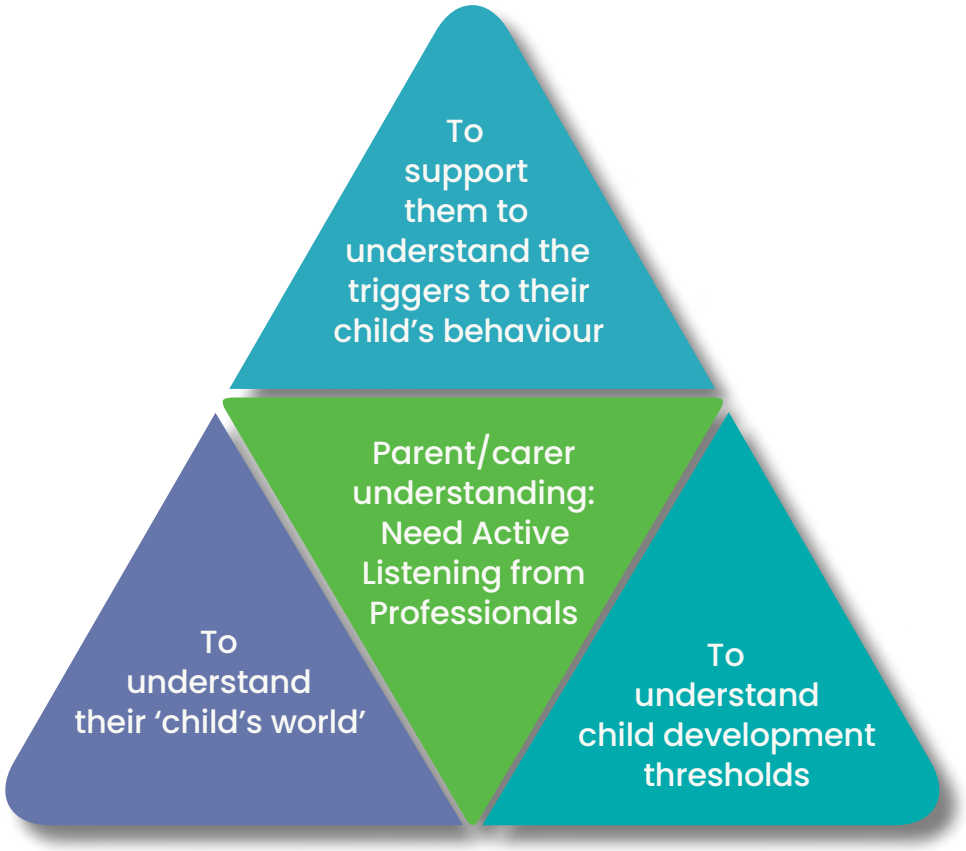
> ....there's a lot of shame around it or they go the other way and they're in denial, you know. So it works both, you know, some that don't want to leave the house with him because he causes a scene and she can't cope with him in public and he'll have a meltdown and she doesn't know, sort of, how to cope with that. But then I've others don't want to admit that there's anything wrong despite them, you know, being given a diagnosis. So yeah, complete opposite ends of the scale.

Professionals also highligted the need for all assessment and interventions offered on a multi-agency basis to be trauma informed, in particular due to the close relationship between the impact of trauma, neuro-development needs and brain development. Understandly, it is also a lenghty process to unpack the often nuanced nature of a broad specturm of needs that often underpin the behaviours of a child, as outlined by Participant 15.

> So for example, I have a child at the moment that I've got extreme concerns about their social and communication needs, but I know that there's a lot more to it than that. But we're in the first foothills of working out what's going on, when there's often a watching and seeing and then, you know. So it's a lengthy process, isn't it. You know, you've got so much social disadvantage, poverty, housing issues, domestic violence, all of those factors, those ACEs if you like, and their own early- the parenting life experiences informing all of that...

The evidence gathered throughout the interviews indicated a consistent and often overwhelming needs across a complex cohort of families who are really struggling with their children's behaviour. So there's a cohort of families out there who are really struggling

with managing children's behaviour, often in the situation of being in the waiting list for CAMHS and neurodevelopment services. Parent/carers were described as requiring an understanding which is summarised in Figure 6, the Pyramid of parent/carer understanding:



It was evident that families accessing support from the FDW are often struggling with behaviour management 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, accessing the community.
Prevention, early interventions and multi-agency working is required to support the broad range of issues identified, including co-occurring complex conditions. The key role of the FDW as part of this multi-professional team is summarised effectively 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 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" (Participant 23) and "offering a huge contribution to families from their point of view" (Participant 25).

Key strengths of the FDW role

Each participant was asked to reflect on both the uses and limitations of the FDW role, with the key strengths of the role discussed within this section. The overall key strength of the role was highlighted as their potential to function as a key role supporting across local communities in different areas of CCBC. Therefore, the combination of both

community integration and visibility through the robust link and benefits of being part of the established family centres. 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.

The FDW role is described as enhancing multi-disciplinary working, which enhances engagement with families. This is essential when reflecting on the view offered by Participant 2:

> All of a sudden families find themselves being open to a whole range of different professionals, so that can be speech and language therapy, nursing, clinical psychology you know, education, you know, and they may have, kind of, support from third sector agencies as well or, like, family workers. And actually it can be quite frustrating for families to tell their story again and again, and also it can be frustrating if they- if it's clear that services aren't communicating with each other, and that joint up care isn't happening. So that's something that has worked really well in the way that we've been able to kind of, just share information, you know, with the consent of the family, they're very happy for us to communicate, and kind of provide that holistic level of care. And something that I found particularly ... helpful and valuable with working with the family disability worker.

Participant 2 also made links to Maslow's hierarchy of needs, with reference to the start of the journey for families when attempting to enhance their family well-being and safety. This journey often started with the requirement to navigate service pathways, including the need to complete endless forms and paperwork. All of the needs across the hierarchy impacted or link together in a way that can both facilitate or hinder effective progress and change for families. Professionals who had worked closely with both individuals currently in the FDW post described them as proactive, effective problem solvers and influencers. This influencer role was described as running with it and knowledgeable of what's available in the local area, summarised as an attitude focused on:

> I can make a referral to this service or we can- you know, we've got this going on in the family centre, we've got this group, got that, is just second to none. And you know, and that knowledge that the family disability worker holds is just so vital to families kind of, day to day well-being and whereas in health we're probably not as good at that as the family centres are. (Participant 2)

The result of having this new FDW service was described as offering reassurance for professionals, in particular through their growing body of knowledge of the local area and the needs of the families within the area. This offered an enhancement to the role of other workers and the multi-disciplinary team as a whole. Despite these key strengths of this role, professional workers highlighted the growing social isolation and stigma felt by families with children with disabilities and additional needs. However, the strategies offered by the FDW was described as influential and effective as assisting parents/carer to support their child's behaviours in the community. On the value base and humanistic level, professionals outlined the impact on parents/carers of receiving

life changing diagnosis for their child. Participant 20 shared the concern that parents/carers feel the stigma, which result in wariness of the traditional or stereotypical view of social services. As a result, several of the participants highlighted that the family centres are more approachable and offer a "proactive, person-centred and values-based approach" (Participant 4), "thinking outside the box" (Participant 5) and "empowering parents to take the lead" (Participant 25).

Key limitations of the FDW role

Despite the key strengths highlighted about the potential of the role, the need to build capacity and promote the role across services in Conwy was seen as a key step forward. As part of this future promotion, the need to manage expectations is key, in particular around the non-specialist nature of this role. Several of the participants questioned whether the title of the role required further consideration to avoid the label of 'disability'. The need to use strength-based language and focus on celebrating neurodiversity. There is also a need to develop families to be more 'open minded' when accessing services, to avoid negative attitudes from families and ensure that barriers to accessing services are understood from the outset (Participants 17 and 20).

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

A key aspect of the interview explored with participants their views on potential future developments for the FDW role. The overall view was focused on the FDW role being best placed in the family centres, working across Conwy with a firm community link to each area. It was also felt that the family centres had robust systems and interventions, which are in a good place for further developments. In light of this, the next progressive step for development was focused on embedding the FDW as a key part of the family centre work in order to establish robust partnership working arrangements with the disability social work teams. The focus of this partnership working or interface would be to strengthen the 'step up' and 'step down' arrangements for families accessing support.

There were creative ideas offered around the development of a menu of choice of interventions, which can inform the content of the Toolkit which will be 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.

Participant two summarised the potential of the role to further develop the positive joint working relationship with health colleagues:

> You know, when the questionnaires were circulated, I thought, this is important, I must feed-back on this, because I know from a pragmatic perspective, obviously these-often these roles are funded and then if they're not protected, they're not funded any more, you know. It would be a great shame if these roles were to disappear. I think they really enhance our core services from a health perspective. I think the joint working up til now has been really good. I think the quality of the service that I've certainly observed the family centre disability workers to provide is excellent. And I would be highly supportive of those roles being continued.

Participant 20 further explored the issues around both the continuation and development of the role:

> I think there's definitely a place for this role and for it to develop into a bigger network of family workers to support. I think definitely one family worker for each family centre is the way forward. But yeah, there have been some good outcomes and lots of positive feedback.

There was a consistent view shared that the potential to develop this role was positive, including the potential link across the five family centres located across Conwy. As part of the interview, each participant was asked to respond on their 'magic wand' solution with regards to developing support and services to meet the needs of families with children with disabilities or additional needs.

The Impact of COVID- 19

As this research was completed during the period of the global COVID-19 pandemic, including the national UK lockdown periods, this was issues raised by participants. The overall themes shared was that COVID had significantly impacted on the overall well-being of families accessing services. Families were reporting feeling increasingly socially isolated, with reported heightened anxieties. The reduced face-to-face contact with families and the closure of schools had resulted in children having limited contact with their peers.

The FDW adapted their role to work through virtual platforms and by maintaining contact on a regular basis through telephone calls. Despite this, it was reported that there was no substitute for face-to-face interaction, particularly in terms of being supported. But that is something that, obviously, could not be helped through the pandemic. Participant highlighted this concern:

> Because a lot of services, you know, have unfortunately stopped, or they're not operating as usual. And, you know, yeah they're doing their best to operate over Zoom and Skype and Teams, but it's not- I think for a lot of families it's not the same. (Participant 3).

There were also concerns raised around the future impact on service delivery due to the increasing waiting lists, as highlighted below:

> I think really it's just- the waiting list is so long, isn't it. You mean it's two years to go to CAMHS isn't it, for your autism service. So you imagine if you've got all these problems and you've got to wait two years to have an assessment. So I'd say the services, without Covid. I mean Covid has added to it. (Participant 6).

COVID was discussed as a barrier to developing the full extend of the FDW service during COVID, in particular as the originally devised plan could not possibly have been delivered during this period. However, it was acknowledged across the sample group that the service had been flexible and willing to adapt as COVID rules and regulations were changed. This degree of flexibility was both respected and appreciated by other professionals and parents/carers.

The views of Parents/Carers

Several parents/carers were in contact with me via email and telephone during the co-productive development of this project. The families who had accessed services and support from both the FDW workers were overwhelmingly positive around the impact

of this new service. Some of the families reported practical or financial support:

> She [FDW] told me about family funding which I didn't even know about, she helped me get some of that so that we could buy a bed for my youngest who's a lot more severe. She's just been bloody fantastic. Honestly, literally I've actually cried after having phone calls with her, because I just think, Where was she? How did I not- How did I even manage without her? And not just because she got me the family support funding, just her advice. She spoke to school for me in regards to my daughter, and my eldest daughter, and she's just backed me. It's just like I had somebody on my side. (Participant 13).

Participant 13 describes the impact of the support initially supporting around financial issues, but later expanding to offer support and advocacy that empowered her relationship with other agencies. This description aligns with the professional feedback of the importance of having this role to promote the active agency of parents/carers.

Participant 13 highlights the increasing impact of COVID on their family and accessing a diagnosis for both her children, which had been delayed:

> We were told it was an eighteen-months waiting list for the neurodevelopmental team to get involved and start with the assessments. Then obviously Covid happened....we didn't start until, oh god ... July maybe. And then obviously we've had lockdown after lockdown, so it's very difficult. They weren't allowed to go into school, so it was really delayed.

With the significant impact of a sequence of national COVID lockdowns on the well-being of the family as whole:

> And then lockdown's been very difficult cos I've been on my own, my partner's off to work. It's a very tense time, very very tense, especially this last lockdown.

And the impact of a lack of 'in person' contact with services, with the feelings of isolation and stigma clearly highlighted:

> It's been very difficult not having face-to-face, not having proper actual appointments, just everything on the phone. I don't know why that would mean more if I had to go face-to-face, I don't know. I think maybe you just get a bit more, I don't want to say recognition, but you just get a bit more understanding if you were there and you can relay it properly rather than sounding like some anxious over-the-top, overbearing parent on the phone.

Also, the benefit of effective communication, even during lockdown periods was highlighted:

> Communication with the FDW is fabulous, this is a really important role which has really helped our family (Participant 22).

With the importance of having that active agency, support and empowerment, which was described as offered by the FDW:

> Look you've done a fabulous job, don't put yourself down, you can do this, you will do this, you just need to know in your own mind that you will do this... (Participant 22)

Parents/carers also summarised what they wanted from services, which is clearly described by Participant 13:

> I don't like to think that I'm better than anybody else, because I'm not just because my children are different, and I don't expect to be treated like, Oh you'll get everything because [name of child] has got a disability. I don't want them to be treated differently. I just want to be acknowledged that they might need extra support. I just want to have an easy life for the kids. But it's not nice having to feel like you're fighting to just have an everyday life, really.

With the need for the service and the previous gap in service highlighted:

> The FDW has really helped me at a point where I was just feeling a bit alone and defeated... It just feels like you're never getting anywhere, you feel like you're failing, you know. So this role, oh my god, yes I wouldn't lie, I do wish to god it had been there like, two years ago, really do. Cos who knows what the outcome might be now if- It might be much different, even more. If I could have a magic wand, I would have Vicky two years ago. I would have that person two years ago. (Participant 13).

With clear suggestions on how the FDW should be developed in the future to address the demand for service and increasing needs:

> Definitely, I think it needs expanding. I mean, I don't know how many people [name of FDW] deals with. But I guess with the amount of disabled people, disa- disability, whether it's disability, whether it's autism or whatever the situation is, there are so many people out there, and I think until you are in the situation, you don't realise, actually, how common it is. I don't think two people in the area is enough. (Participant 22).

SUMMARY & CONCLUSION

An evaluation of the role of the FDW, with a focus on preventative work to enhance the well-being of families with a child/ren with a disability in Conwy (accessing services from the FDW).

1. **What is the nature of the emotional, physical, social and well-being needs of the children with a disability in Conwy who are accessing support from the FDW?**

   The profile of the needs of families accessing services is clearly highlighted across the data, from the information outlined in the case file review to the experiences shared by professional and parents/carers. Overall, the needs are complex, often hidden and often requiring both a preventative and more targeted intervention. These families are the 'missing middle', not fitting into the eligibility criteria of specialist services. The presenting needs require a robust multi-agency response to address both the medical and social needs. The needs of the parents/carers are often 'hidden' by social exclusion, shame and the barriers to accessing services. The parents/carers require support in their own right, to ensure that their voices are heard and their emotional needs assessed and supported.

2. **Where do the parents/carers accessing support from the FDW get information to promote positive well-being in Conwy?**

   There are robust information sharing and support services across Conwy. The degree of multi-agency working highlighted by this evaluation is to be applauded. This is a unique landscape, which must be taken advantage of to ensure robust and consistent support for families. The degree of multi-agency 'buy in' and support for the FDW is significant across agencies. Again, this is a unique landscape. This provides the ideal platform to enhance and support the development of this role to further enhance the level of information, advice and support offered to families across Conwy.

3. **What factors contribute to positive emotional, physical and social well-being for the children accessing support from the FDW?**

   The key theme here is that the practical and emotional support offered and provided to parents/carers by the FDW enhances parental ability to manage everyday stresses, to navigate the complex pathways to access services and address their own well-being needs. These parents/carers described that they had often felt social excluded, social isolation, stigma and shame when attempting to integrate as part of their local communities. The empowerment and person-centred advocacy offered in a bespoke manner by the FDW 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 FDW was also clearly described as focusing on strength-based practice, offering support that built on the capabilities of each family.

4. **What factors hinder the development of positive emotional, physical and social well-being for children accessing support from the FDW?**

   A key theme that emerged from the data was focused on four main elements:

   1. The significant impact of accessing a diagnosis for their child due to lengthy

waiting list for Health services, across CAMHS and neurodevelopment;

2. The need for betters systems to address practical needs e.g. housing needs, access to benefit etc.
3. The gaps in a menu of choice of particular support services e.g. respite care;
4. The impact of COVID-19 on access to services and social isolation.

5. **What is the impact of the well-being interventions offered by the FDW in Conwy? &**
6. **What are the uses and limitations of the well-being interventions offered FDW in Conwy?**

As this is a new role implemented during the challenging period of the COVID-19 global pandemic, the degree of certain interventions that could be provided was limited e.g. groupwork. Whilst COVID-19 has proved to be a barrier to a degree, there are also several key examples in the data of creative ways of working to continue to support families during a challenging time. As a key recommendation from this evaluation, the aim is to develop a Well-being Toolkit to gather key information and outline a menu of choice of interventions to support the broad range of needs of families accessing services. This is a current gap in the service, with the aim of gathering the required information in the Toolkit to provide guidance on the role and the interventions offered in a consistent manner.

7. **What is the impact of the well-being interventions offered by the FDW in Conwy? &**
8. **What is the value and cost effectiveness of the well-being interventions offered by the FDW in Conwy?**

This sub-question will be explored further as part of the development of the Well-being Toolkit.

9. **What do the experiences of children with a disability and their families tell us about the well-being outcomes achieved as a result of accessing the support offered by the FDW?**

The overall profile of needs of the families illustrates the challenges faced by these families on an everyday basis. The data analysis clearly triangulates to offer a robust picture not only of the impact of the FDW role, but also of the potential of this role. The initial data reveals positive impact and outcomes for parents/carers, in particular around support with accessing to services, navigating complex systems and supporting their child/children's complex behaviours.

10. **How can children with a disability and their families be better supported by the FDW to develop their well-being outcomes?**

The response to this key question is focused on recommending the following: -

- Enhancing the development of the FDW role across CCBC by formulating a funding bid with the aim of increasing capacity. The focus of the bid should be on requesting funding for additional FDWs to link in with the Family Centre structure across Conwy. The focus of this new team should be on developing robust support to address the overall well-being of families with children with a disability and additional needs, and developing a robust preventative/well-being service focused on promoting interventions focused on a social prescription approach and enhancing well-being outcomes. The objective of this team would be to work closely with the Disability Team to provide support for some of the families that

would currently access support from this team, to provide a greater degree of preventative support.

- Develop a Well-being Toolkit which outlines a menu of choice of interventions.
- Using SROI tools to measure the impact the use of the Toolkit.

To conclude, Participant 3 highlights effectively how the FDW is viewed on a multi-agency basis.

> I think you can see why I think this role is so important and why I wanted to take the time out- Cos I haven't got time for this conversation today, but I wanted to have this conversation today. I'm always trying to offer views and nobody's listening, so it's really lovely to have someone that's academically interested and hopefully fights the cause. (Participant 3).

RECOMMENDATIONS, OUTPUTS & DISSEMINATION

- Establish a business case established, build a grant build to develop capacity linked with the five areas across Conwy to enhance and develop the FDW role.
- Final evaluation report & executive summary, easy read report & executive summary;
- Design and deliver dissemination workshops for children with a disability, their families, and professionals to present the results of the research;
- Production of a complimentary slide show set which communicates the results of the report and the publication of an academic paper should the findings be of academic interest;
- A series of tweets, communicating the results of the work, which can be shared with and used by Conwy County Borough Council and Bangor University.
- To develop a Well-being Toolkit for professionals, children with a disability and their families;
- Recommendations on operational matters, well-being interventions: to be included in the Well-being Toolkit (and build on the models presented in the report);
- Devise a training plan to support professional to implement the Well-being Toolkit and practice models.