‘It sounds really good in theory’: Exploring parents’ and carers’ experiences of accessing care and support services for their child with a learning disability

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Abstract

Research suggests that parents and carers of children with a learning disability have very mixed experiences of care and support services, despite the shift in Wales towards models of integrated care that promote closer links between social care, preventative community-based services, and health care provision. In exploring the effectiveness of this model, the evidence to date is suggestive of an *implementation gap* between the vision of care that informs policy and practice, and parents', carers and children's experiences of it. This research builds on the findings of the author's 2023 literature review, with the aim of obtaining first-hand accounts of how parents and carers experience care and support services for their child. Focusing specifically on North Wales, a purposive sampling strategy was used to recruit parents and carers, with two focus groups (n= 9) and two semi-structured interviews (n=2) conducted via Zoom. The conversations were transcribed and through thematic analysis, emerging thematic clusters were identified. The key themes to emerge from the research were then synthesised to produce findings, and a developmental narrative constructed to inform future policy and practice. The key findings of the research suggest that parents and carers have variable experiences of professionals and services; delivery of care can be fragmented, and accounts of children's needs not being met are frequent. Where experiences are good, this is overwhelmingly related to experiences where professionals are able to get to know the child and family properly, advocating alongside parents/carers for care services that meet the needs of the child. The evidence from this project suggests that the rights of children and families must be the starting point of care planning; feeling safe, valued, and part of the process (and not outside of it) is invaluable for parents and carers. Furthermore, the better the links between health, social care, and education sectors, the more positive the experiences of parents, carers, and children are. Future directions for policy and practice, inspired in part by participants' 'wish lists', would imply that better relationships with professionals, more effective integrative cross-sector provision, and having access to 'drop in' hubs that provide integrated support, may contribute to more positive experiences. Most importantly, seeing the child first, and the disability second, emerges as the foundation of good rights-based care.

1.1 Introduction

This report presents the findings from a research project commissioned by Improvement Cymru, with the aim of exploring the experiences of parents and carers of children and young people with a learning disability, living in North Wales. First, the background to the project is presented, along with its purpose and rationale. The methodology and conceptual framework for the study is then explored, with the sampling process and focus group method explained. The report then goes on to present the key emerging themes from the data, clustered under subheadings, before synthesising the themes into findings and presenting a developmental narrative. Finally, the report concludes with some reflections on future directions for strategy and practice.

1.2 Background to the study

The research project presented in this report builds on the findings of a literature review carried out by the author in the Summer of 2023 for Improvement Cymru. This evaluative literature review was commissioned to provide an evaluation of models and principles of care for children and young people with a learning disability, and the findings that emerged have provided a rationale for the project presented here.

The literature review presented several thematic findings and a clear developmental narrative around how children, young people, and their families/carers experience care, and how health and social care professionals, across a variety of sectors, deliver services. One of the findings to emerge from the review was that the experiences of families/carers is very mixed: there are some inspirational models of care that are implemented in parts of Wales, but there are also some experiences that are less good. Indeed, the need for better engagement with families and their complex needs was a theme consistently presented across a wide range of academic and grassroots literature sources. How this is experienced on a day-to-day basis, and what both the frustrations and 'high points' of life when engaging with care providers 'looks like' was, the review suggested, an area that could be further explored. In light of these findings, Improvement Cymru commissioned a further piece of work – a primary research project that centered the voices of parents and carers of children with a learning disability – to further explore and unpack the ways in which services are 'lived' by families and carers. The project discussed here involved conducting a number of focus groups and semi-structured interviews with participants, providing a safe space for parents and carers to detail in their own words what care for their child looks and feels like.

1.3 Purpose of the research

The purpose of this research was to draw out and develop some of the key insights and developmental points that the literature review presented. In particular, the need to listen and present the experiences and opinions of parents and carers as a means of ‘making sense’ of what is going well, and what does not appear to be working, serves a number of purposes. For example, the provision of narrative accounts that detail day to day living (as opposed to ‘show case’ events) adds an authenticity and ‘rawness’ to the current literature where experiences are noted but can sometimes lack depth and detail in the description (Jackson & Mazzei, 2009). In conveying the ‘messiness’ of every day with a child who has a learning disability alongside other suspected or diagnosed conditions such as autism, ADHD, poor mental health, and/or neurodiversity, the study contributes to a highly valid understanding of what parents and carers experience and feel about their lives. In other words, the stories portrayed in this study are intended to portray the complexity of disability, and how families (and professionals) may have to ‘separate out’ different ‘conditions’ (such as autism and a learning disability) that make up the child’s identity when faced with services that might have different criteria or thresholds that need to be met before their services are offered[1]. In addition to exploring the experiences of families and carers, the accounts conveyed also add further clarity to the findings of the author’s literature review carried out in 2023. The topics of integrated care, co-ordination of services, co-production and feedback, staff skills, models of care, and the complexity of need, were all topics that

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[1] There are examples in North Wales of third sector organisations that receive funding that is linked to, for example, The National Institute for Health and Care Excellence which advises that ‘a learning disability is defined by three core criteria: lower intellectual ability (usually an IQ of less than 70), significant impairment of social or adaptive functioning, and onset in childhood (NICE, 2022). As such, other ‘disabilities’ such as autism may be insufficient to meet the inclusion criteria for some organisations, even if the learning needs of children are high and help and support is needed.

were critically discussed in the review, generating an evidence base about what ‘best practice’ might look like and inspiring this project.

Once published, the findings from this project’s report will help inform Regional Partnership Boards across Wales, along with other multi-disciplinary forums and Communities of Practice. The long-term purpose of this project then is to contribute through its findings to the promotion of clearer understandings of what works well and, conversely, where there maybe shortcomings and gaps in service provision.

2.1 Understanding the policy framework

Operating under the framework of the Social Services and Wellbeing (Wales) Act (2014), part 3, Child and Adolescent Disability Services (CALDS) for children and young people with a learning disability in North Wales, adopts a comprehensive approach to delivering care and support. This is delivered by a range of professionals, including speech and language therapists, occupational therapy, education services and clinical psychologists. While multi-agency working varies in form across local authorities, with different degrees of integration between health and social care provision, the broad principles of co-produced, needs-based services, promoted in the SSWA (2014) Act, are incorporated into the vision for care across the region.

The Betsi Cadwaladr University Health Board (BCUHB) provide in their chart below a broad overview of statutory provision across the region (BCUHB, 2023).

Service	Information	Site	Area
Early Years and Child and Adolescent Learning Disability Services (CALDS)	For children aged 0-18 years.	Conwy Denbighshire	Central
Early Years and Child and Adolescent	For children aged 0-18 years.	Wrexham, Flintshire	East

Learning Disability Services (CALDS)			
Children's Learning Disability Service	Integrated service between health and local authority	Community	West
Acute Nurse Liaison Service	Work with acute services for unplanned and planned hospital admissions and hospital treatment for children with learning disabilities.	Community	West

BCUHB use categories that are linked to geographically located local authorities across the region of North Wales, including but not limited to, Wrexham and Flintshire in the East, Denbighshire in the centre, through to Ynys Mon, Bangor, and Conwy in the West. While the Health Board works primarily with a definition of 'learning disability' that uses the criteria of Intelligent Quotient (IQ) in order to determine eligibility for the diagnosis of a 'learning disability', practitioners are recognising the difficulties of receiving referrals from children and young people to learning disability services (CALDS) where the criteria for meeting the 'threshold' are not strictly met. For example, a child may be referred by a GP to CALDS with symptoms of poor mental health and suspected Autism, but any measurements of IQ that have been taken by, for example, schools, may score above the 'cut off' point for a learning disability of 70. Recognising that needs can rarely be categorised neatly, not least across the life course, CALDS in the Conwy Authority, for instance, incorporate multi-disciplinary teams into one integrated model of care. Funding in this model of practice draws from an integrated care fund and includes multidisciplinary teams that benefit from co-location of services. Evaluating the Conwy model, the Institute for Public Care (IPC 2018) provides a useful synopsis of the policy-led principles that have inspired the push to aim for integrated services for children and young people with a learning disability[2]. To quote from their 2019 case study:

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[2] See Jones (2023) for an evaluation of some of the barriers to integrative service delivery in Wales, not least the discrepancy in some regions between the age at which care transfers from child to adult services in Health and Social Care sectors respectively.

‘Four years ago, in response to the Social Services and Wellbeing Act (2014), Conwy Council restructured its provision for people with disabilities as part of their Social Services Transformation Programme. Three new teams were created: children and young adults under 25, adults over 25, early intervention and prevention and community support services working within ***one integrated disability service****. In addition, closer links have been made to the local health services with the aim of providing equality of access to support and resources across the age range based on assessed need’* (IPC, 2019, emphasis theirs).’

A similar recognition of the need to translate the principles of the SSWA (2014)[3] into local delivery strategies is seen in a piloted scheme in Denbighshire where CALDS and CAHMs are working in partnership to provide the best outcomes for children and young people through joint assessments. Echoing some of the earlier discussed complexities surrounding eligibility for Learning Disability services, this pilot scheme represents a *response to need*, where practitioners work together with families to ensure that care is needs-led, as opposed to being shaped by pre-existing service models. To quote from North Wales Together on how this model of practice emerged:

‘…It was noted many referrals were related to children and young people with a higher IQ than this [70], however demonstrating challenging behaviour and mental health concerns and perhaps a generally lower IQ indicating a learning ***difficulty*** *(as opposed to a learning* ***disability*** *diagnosis in order to access CALDS services). It was felt that partnering with CAMHS and highlighting the child’s primary health need i.e. learning disability or mental health and who was best to work with the child through their areas of expertise would give the best outcome for the child or young person.’*

2.2 Strategies and principles of care in North Wales

The overview of care provision for children and young people outlined above does illustrate how the broader principles of integrated provision, underpinned by values of co-production, inform the conversations that professionals have about how best to meet needs. Regional Partnership Boards provided for by the SSWA (2014), are designed to strategically drive and deliver integrated Health and Social Care services,

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[3] The principles of early intervention and prevention, along with the wider vision of services that are co-produced, is integral to the SSWA (2014) vision of a partnership approach to the development and delivery of social care services (Welsh Government, 2020).

and to ensure collaborative working, reflecting a vision of best practice. In addition, the North Wales Learning Disability Strategy (2018-2023)[4] provides a useful focal point in understanding the rationale behind the push for integrative working and, moreover, the promotion of shared values in Health and Social Care sectors. Approved by all six local authorities and Betsi Cadwaladr University Health Board in March 2019, the strategy has operated via the workings of the Transformation programme 'North Wales Together', which aims to develop a 'seamless model of learning disability services based on what matters to the individual'. Funded by the Welsh Government and responsible to the North Wales Regional Partnership Board, the aim of the programme is to 'deliver' the Strategy, with individuals with a learning disability and/or Additional Learning Needs (ALNs)[5] at the centre of a vision of care where services 'fit' the person, and not the other way round' (North Wales Together)[6].

While the information presented in sections 2.1 and 2.2 is by no means an exhaustive account of the service model and 'vision' that informs North Wales provision, it is hoped that it does provide a sense of the overarching framework for service delivery that will provide a context for the themes that will be presented from the focus groups/interview research presented in this report.

3.1 Research methodology and theoretical approach

The project adopted a critical realist approach to knowledge (Bhaskar, 2010; Koopmans & Schiller, 2022), reflected in the methodology chosen and the research methods conducted. This approach recognises that there is a reality independent of the mind that shapes the ways in which lives are lived, the choices that can, or can't, be made, and the outcomes that may be possible.[7]. For example, it could be said that

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[4] https://www.northwalescollaborative.wales/wp-content/uploads/2019/10/NW-Learning-Disability-Strategy-2018-FINAL-1.0-accessible.pdfis

[5] The North Wales Learning Disability strategy recognizes that additional learning needs and the category 'learning disability' have many 'overlapping synergies' and as such both are included in the North Wales Together Transformation project.

[6] https://northwalestogether.org/)

[7] To summarise Koopmans & Schiller (2022) critical realism is a way of thinking (a 'philosophical stance'), which can inform investigations into lived reality. For example, when researching the Health and Social Care sector, critical realism can help understand health and wellbeing as processes that are affected by

the principles and duties of the SSWA (2014) provide an overarching structure that shapes how local authorities plan, design and evaluate their provision of services. However, the critical realist approach also recognises that people's own personal circumstances linked, for example, to socio-economic location, place of residence, family dynamics, and what caring responsibilities might be present, will also 'filter' the ways in which this 'reality' is experienced. To give an example, the mother of a child with profound and multiple learning disabilities who lives in a rural area of North Wales may experience the reality of health and social care services and the policy frame of the SSWA (2014) differently from a mother of a child who presents with a 'mild' learning disability but who lives in a relatively urban area with good transport links and vibrant third sector care provision. In designing the project, it was intended that giving space to participants to tell their stories, led by a loose 'semi-structured' brief (**see 3.2**) was the preferred way to capture both how individuals *respond* to models of care available, while also recognising the impact that the complex needs of children may *bring to* the experience of service provision.

3.2 Conceptual Frame: Topics and issues for discussion

As discussed above, the literature review conducted by the author highlighted a number of key findings that emerged from a critical evaluation of academic and 'grassroots' texts. A number of developmental narratives for future investigations were proposed, and included the following:

- The importance of working towards a shared understanding of required *skills and competencies* between all professionals involved in the delivery of care pathways, across local authorities, third sector organisations and health boards, based around the needs of the child, and promoting a value-based, integrative understanding of need.

- That the *different models of care adopted by different sectors (*specifically Health and Social Care) are acknowledged but must not become a barrier to the facilitation of integrative working. For example, joint funding and

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interactions between individuals and their contexts, including the professionals and organisations present, and 'help to explain what we see but also what we do not see' (ibid. 2022:01).

assessments were seen to create a smoother transition between, for instance, child and adult services.

- The importance of meaningful co-production that starts with an acknowledgement of a rights-based approach to need, rather than starting with what is available. Needs, particularly those of children with a multiple and profound learning disability, were acknowledged as complex and always changing. As such, it was proposed that person-centred conversations should be part of a 'day to day' evaluation of current provision, co-producing recommendations for changes to services that may result in greater wellbeing. The importance of a named co-ordinator role, or similar, to oversee the many different services that a family may be in receipt of, emerged as a recurring finding from the literature review.

- The importance of having clear feedback processes in place, with specified dates and targets with which to measure the impact of current provision. While Regional Partnership Boards have the responsibility to co-ordinate the work of Health and Social Care sectors in the region, the need for families and carers to have a clear feedback process in place to 'feedback' and transmit knowledge about *their own experiences* that can in turn contribute to future care planning, was identified as underpinning effective models of care.

Drawing down these key principles and recommendations from the review provided a provisional 'aide memoire' to guide the discussions of the focus groups and interviews that were conducted. As will be discussed below, while the methods employed were qualitative and person-centred, with no prescriptive set of questions or research guide to follow, where the conversation allowed the author was able to introduce questions that provided scope for a discussion around the themes and issues *that had arisen out of the literature review.* With such wide-ranging topics to be explored, this created data that was able to capture the complexity and 'messiness' of participants' lives, while at the same time creating a meaningful engagement that fitted well with the purpose of the project.

3.3 Research methods: Scope and limitations

The primary research method conducted was the focus group, a guided conversation that includes as an approximate guide between 4 to 8 participants, where thoughts, feelings, and experiences are shared by those present. As Gibbs (2012) argues, one of the key attractions of the focus group method for the qualitative researcher is that it is capable of yielding data that is high in validity and authenticity. That is, while a simple, structured questionnaire will most likely create results that are high in reliability, being able to be replicated with other respondents as often as the researcher wishes, the focus group is slightly different. Being a *generative* method, one of its key benefits is the ability to record not only individuals' responses to a question but, through its interactive nature, the generation of new insights about participants' circumstances. As such, one of the key reasons for selecting this method was its ability to create discussion in a conversational space where participants would feel safe, and provide deep, authentic accounts about their lives. With the rationale of the study being to inform policy and practice, it was important that the method selected was capable of creating findings that could inform future conversations at the level of policy. Indeed, as stated by NHS England (2016) '*focus groups often yield very powerful, personal stories that can support and drive change.'* Drawing on this growing recognition in health research that qualitative study *can* be used to provide deep insights into participants' view and experiences of care, there is scope to produce a narrative that is highly valid, providing a firmer foundation on which to make decisions about improvements and future change than statistical analysis alone can do. While *statistical* generalisability with such a relatively small sample is not possible or desirable with the chosen research method, a degree of extrapolation (analytical generalisability) from the insights of participants to the experiences of those living in the wider learning disabilities community is possible. Indeed, with families' experiences of receiving services framed by the Welsh Government's Learning Disability Strategic Action Plan (2022-2026) there is scope to make meaningful projections about the likely transferability of this study's findings when considering service provision in other parts of Wales.

The study also used the interview as a secondary method alongside the primary focus group approach. The decision was made to add this method of data collection in part due to the need to change original meeting dates by some participants (n=2);

additionally, one participant (n=1) requested a one-to-one interview due to fears about potentially knowing others in the focus group, and how this might make them feel uncomfortable when sharing their experiences[8]. In keeping with the person-centred approach to the project, the author was happy to accommodate these requests, with the rationale of facilitating a safe space to talk being the overriding priority when making decisions about the research process. As with the focus group method, the one-to-one interviews were motivated by the desire to give participants greater visibility – a way to voice their opinions without feeling pressured to give certain responses – with the author using an 'aide memoir' to guide, when needed, the conversations as opposed to reading out a pre-designed list of questions.

When looking at the limitations of the focus group method, it is recognised by researchers (Nyumba & Wilson *et al.* (2018); Tausch & Menold, (2016)) that certain types of people are more likely to participate when this method is selected, regardless of how well they 'fit' the sampling criteria. For example, Gibbs (ibid.) suggests that focus groups attract, and indeed are the 'best fit', for what she calls the 'excitable extrovert,' with other less confident potential participants intimidated by the thought of sharing intimate details about their lives with strangers. The limitations of this method when used as a data collection tool in this project are discussed further in 3.5, but it should be noted that qualitative methods in general, including the focus group and qualitative interview, are limited by sample size, lack of controlled standardisation of the topics discussed for comparison purposes, and the fact that findings are not generalisable beyond the demographics of the sample selected[9]. On the other hand, qualitative, person-centred methods have been promoted as having the potential to create data that is rich in meaning and insight, allowing the researcher to 'feel', as well as to see (Krumer-Nevo, 2022) what participants lives look like, creating findings that are generative and that can create change through the authenticity of experience that they convey to the researcher.

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[8] This participant (n=1) was a professional working in the Social Care sector, with understandable concerns about information sharing with those who may be in receipt of the services they provide, as well as themselves in receipt of services for their children.

[9] Although at stated previously, there is potential transferability of findings to the regions of Wales beyond the North, where the Learning Disability Strategic Action Plan 2022-2026 is implemented.

3.4 Sampling strategy

The project utilised a purposive sampling strategy[10], with additional elements of convenience and snowball sampling[11] included after the initial sample was selected. With ethical clearance obtained from Wrexham University Ethics' Committee, the author contacted a number of gatekeepers who worked professionally in the fields of Social Care/Education across the statutory, independent, and voluntary sectors in North Wales; all were keen to distribute information about the project to parents and carers of children with a learning disability. However, despite many potential participants expressing an interest in the project, recruitment slowed. As a result, the author made the decision to publicise the project via her own (private) Facebook page on social media, aware that those who had access to the page worked, more often than not, in the field of Social Work and Social Care. This resulted in some success, and in addition to the use of snowball sampling where the project was publicised through 'word of mouth,' a satisfactory sample for the study was recruited. A total of 11 participants were recruited and consented to be involved in the project (2 focus groups, one with 5 respondents, the other with 4, and 2 one-to-one interviews). In relation to sample size, the scope of the study is exploratory in nature, seeking to convey a depth and complexity of experience that can in turn ***shape and provide direction*** to conversations at the levels of policy and practice. Data adequacy is met, based on the minimum sampling number for meaningful qualitative data being obtained (Burmeister & Aitken, 2012) with the scope and range of discussion permitted by the methods used providing a robust evidence base in contributing to a better understanding of how services are received.

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[10] Purposive sampling is a process by which the researcher deliberately identifies a particular sub-set of the population whose characteristics best fit with the purpose of the study. Also called 'judgmental sampling' this sampling method aims to identify individuals who have experience of the topic being researched, in order to provide depth and insight into the research topic (ATLAS.ti, 2024).

[11] Snowball sampling is a technique of recruitment to a study in which already-recruited research participants are asked to refer other possible participants who may be interested in being involved in the study and fit the research criteria. This is a particularly good method when trying to recruit groups that might be hard to reach (Parker, Scott & Geddes (2019)).

3.5 Sample composition

It is acknowledged, as with most purposive/snowball sampling, that there will be biases in the sampling process. For example, the promotion of a project by a local authority organisation, or a manager in a third sector charity, might inhibit participation by some individuals who may associate the request for information as linked in some way to the gatekeeper's organisation and wider role of obtaining knowledge about families. The use of gatekeepers in the distribution of invites might also create a bias whereby some families are invited, and others are not, with the former being perceived to be more likely to have something to say than other families. While the author has no evidence that this was the case with this project, non-randomised sampling as conducted in this project could not create a fully representative sample of the North Wales target population. However, as the project is exploratory and 'generative' in nature and aimed to create knowledge high in validity and meaning, as discussed above, it was not the intention to produce data that could be statistically generalised[12], particularly to areas of Wales that were not sampled.

Furthermore, there is a danger in using a purposive sampling strategy, even through a gatekeeper organisation that represents children and families in the field of learning disabilities, that individuals will 'self-select' for inclusion in the project on the basis of the *perceived characteristics* of their child. Reflecting the wider debate discussed above about what defines a child with a 'learning disability,' several potential participants got in touch with the author to clarify if their child 'met the criteria' for a learning disability. Several children did have a diagnosis, others were waiting for one, and some had been classified as having 'additional learning needs' (ALN) but an IQ above 70. All children, regardless of having a 'learning disability' (or not) had additional needs including Attention Deficit Hyperactivity Disorder (ADHD), Autism, Neurodiversity, and poor mental health. With this in mind, and in recognising that several of these conditions overlap in terms of service provision in North Wales (seen for example in the noted CALDS/CAHMS joint assessment pilot) it was decided to include in the sample a range of families that identified as having additional learning

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[12] Should this have been the case, a randomised, controlled sampling process using a quantitative method such as a structured questionnaire would have been the preferred method. Such methods, while high in reliability and generalisability, tend however to lack validity and 'deep' meaning through their use of pre-set questions often requiring 'best fit' answers from respondents.

needs for their child (the majority of which also had the traditional IQ-specific ‘learning disability’ label). Where interested participants had a child with a ‘learning difference’ such as dyslexia or Irlen syndrome[13], it was decided to exclude this group on the grounds of not having eligibility on the basis of these needs alone to access the usual service provision for children with a learning disability. As reflected on in 2.1, with the education system arguably one of the most important processes in a child’s life, a category of ALN that includes learning difficulties and/or learning disability as required to meet the threshold for additional provision, does promote a conversation about eligibility across services for children and young people in Wales outside of the formal education system.

The participants selected for the study were from a range of different locations in North Wales, including Wrexham, Denbighshire, Flintshire, Conwy, and Ynys Mon. It became apparent during the focus groups/interviews that not only do participants’ children have a range of complex needs, but that the parents/carers themselves have incredibly busy lives. Out of a sample of 11, 10 participants were female, and all 11 worked in either full-time or part-time paid employment. Employment in the majority of cases was in a professional occupation, including but not limited to the Health and Social Care sectors. Three participants identified as kinship carers, the remainder as parents. All but one member of the sample had more than one child in the family, and four members of the sample had more than one child with a learning disability/additional learning needs.

3.6 Methods in action

While the generic strengths/limitations of the selected methods have been presented in 3.3, it is useful to briefly consider the ‘doing’ of the research, commenting on the nature of the interactions, and reflecting on any issues that arose during the focus groups/interviews. First, the online nature of the focus groups and interviews does itself provide advantages, and indeed the participants in the study commented that they would have struggled to contribute to the project had there been an expectation

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[13] The categorisation of learning needs in Wales is further complicated by the replacement in 2022 of the Special Educational Needs (SEN) system with a new Additional Learning Needs (ALN) system, with requirements for all pupils with ALN to get Individual Development Plans (IDPs).

of attending ‘in person’ at a pre-arranged time and venue. Accessibility to the project was a key benefit of selecting online over in-person focus groups/methods, with some of the barriers to involvement such as transportation and the logistics of getting to a venue, removed (Englund & Sharman *et al.* 2022). From the author’s point of view, the online medium is also conducive to easier data collection, with audio-video recordings of the discussions possible. All respondents (n=11) were asked at the start of the discussions if they were happy to have the conversations recorded, and all gave their consent. The noted disadvantage of online focus groups/interviews is that of distractions in the home or office environment (Gaiser, 2016), however, this was minimal in the research conducted. On two occasions the children of parents/carers in the groups entered the rooms in which the participants were in but were not ‘on camera’ and quickly left. Nonetheless, it is possible that children or other adults in the home at the time of the discussions may have had some impact on the engagement of these participants. Further recognised limitations to the online method is the difficulty of observing participants’ body language and the usual social cues that take place in group conversations (although the recordings could be watched back, something that wouldn’t have been possible with the traditional face-to-face method). As with all group dynamics, some participants were more vocal than others, and there was an awareness that less confident participants may have felt inhibited talking, particularly when it was difficult to judge if there was a ‘gap’ in the conversation to speak when not all participants are displayed on the screen at the same time. To mitigate this happening, the participants were asked to use either the ‘raised hand’ button on the zoom screen, or to add comments using the text chat function. While not ideal, this did provide a space in which less confident participants could make sure they got their points across. A noted advantage of the focus group method in action was the way in which members of the group were quietly encouraging to each other, asking questions sensitively which allowed examples and further detail to be generated. The environment in which the research took place was, it was felt, very supportive and empathetic, conducive to the generation of a discussion where the experiences of one family would, for example, resonate with others, yielding the telling of further stories that provided validation of others’ experiences. While as the researcher, assumptions cannot be made about how the participants felt, the sessions felt very positive and affirming of the experiences of those present, creating a sense of being part of something that was shared and owned by those who participated. All sessions ran for at least an hour, sometimes longer, and were only concluded when it was felt there was a natural end to the conversation. Participants were thanked for their time and contributions, and arrangements made to send on any published work from the project so that those interested could read the findings of the study.

3.7 Data analysis: Identifying key themes from the research

Having conducted the primary research, the electronic recordings of the focus groups and interviews were then reviewed at least twice. After an initial familiarisation with the data (Byrne, 2022) key conversational moments were identified that were suggestive of a number of emerging themes. These themes were then given a code and placed into thematic clusters. The process was then repeated and reviewed methodically to ensure that the analysis reflected as far as possible *identifiable patterns* in the transcripts (Glasner & Strauss, 1967). Those patterns that came up the most frequently were prioritised in the data analysis process and given named thematic headings listed below:

(i) The importance of rights/needs-Based Provision;

(ii) The role of the parent/carer as advocate;

(iii) The need for co-ordinated services within and across health and social care teams;

(iv) The importance of being listened to and heard – of being part of the process, and not outside of it.

While the process of identifying themes was, in the main part, largely deductive, with the 'aide memoire' used composed of topic areas that themselves reflected the findings from the author's literature review (Jones, 2023) the method was also open to what Braun and Clarke (2021) call 'miscellaneous themes,' with scope to refine and revisit the data to ensure that the findings were as robust and valid as possible.

When presenting the key themes in 4.1, their overlapping nature can be seen with, for instance, the importance of needs-led provision conveyed through the experiences of multi-agency working and the need for better co-production. Experiences, of course, cannot be placed into neat clusters and headings, but for analytical reasons, these headings do help to clarify the significance and centrality of certain experiences, over others, for the parents and carers in the sample. When later reviewing and synthesising these themes (meta-synthesis) there was scope to draw out and develop the significance of the data in the presentation of key findings and a developmental narrative (4.2).

4.1 Emerging themes

The key themes that emerged from the research conducted, along with supporting quotes, are presented below.

(i) *The importance of rights/needs-led provision*

A key theme from the research conducted was the importance of health and social care professionals getting to know families so that the care provided reflects *what matters to the child and family* as opposed to ‘fitting’ families to those services the professional considers appropriate to any diagnosis made. This was seen to be particularly important for children with profound and multiple learning disabilities, where needs change and communication between parent/carer and professional is crucial with children and young people who are non-verbal.

Reflecting on the services available, the quote below conveys the frustrations of being offered services that don’t reflect the needs of the child:

> *‘I got a kind of leaflet from them…It was something about, you know, do you struggle with budgeting? And I thought well no, I don’t.* ***This is nothing at all to do with what I've been talking about,*** *and so no. So, I was like, Oh yeah, that won't help. Thanks though. And they also did refer to Action for Children, for family therapy. And I was like, there’s actually nothing wrong with my family. I was quite you know, as you might imagine, I was quite defensive about that.’*

Continuing the narrative of the limitations of label-led provision, one parent commented:

> *'So, there will be, there are some experiences that are shared and that do overlap and that do crossover and that are down to the kind of the criteria for getting the diagnosis in the first place. But what that looks like to other people* **and what that feels like to that child**, *it's really different.'*

Conversations frequently drew on the range of third sector services that were advertised on social media. While the range of support services on offer were considered positively by some participants, albeit linked to geographic proximity, others noted that the complexity of their child's needs (and wants) meant that identifying a suitable service was more complicated than they may have anticipated:

> *'Anyway, when I explained to A a little bit about the kind of things they do, well, it's like she won't go. So, like, not necessarily a fan of forced group work. And some of these family spaces, particularly around kinds of neurodivergence, can often be pretty male heavy. So A doesn't see that she has anything in common with a typical autistic 16 year old boy.* ***So the label isn't gonna just glue them together, is it?*** *And A is like 'mum, the last thing I want is to go to like a group and have like some autistic boy talking to me about trains.'*

Another parent commented that while she was aware that the services 'were there,' the complex, multiple needs of her child meant that any visit would create more stress in planning and organising than any perceived benefits accrued from the experience itself.

> *'I'm aware of local groups and stuff, but they're not really appropriate for L.'*

Discussing further issues around scheduling in care and support services for her child, the same participant went on to reflect on the implications of poor communication by care providers on meeting the needs not only of her son, but of the whole family:

> '*They used to check in with me and say, 'when would you like your Saturdays?' But now they don't, and the same with the holidays. And I've said I work*

> *Wednesdays to Fridays, so they know I need the care in the holidays then, but then the rota went astray, and they've given me the wrong days.'*

Interestingly, the importance of understanding needs as interlinked with those of the parent/carer, and siblings, was a recurring thread in the discussions. Having to book respite a year in advance in one parent's experience created logistical difficulties. In this example a sibling had their GCSEs the planned month of respite, but with exam dates not confirmed until 2 months before they were timetabled, this led to anxiety about whether or not the respite could actually be taken.

Having a named professional who had a real insight into the context of family life, and the needs of both the child and their parents/carers/siblings, ahead of any conversations about care plans, was a frequent narrative to emerge in the discussions. Where this *did* happen, the impact on the family's sense of wellbeing was notable. To quote from one participant on the level of support received from an educational professional:

> *'And she, the head of year, did kind of get to know our family. And again, we were able to talk about, you know, just like she's got four kids, and she was struggling and we kind of got to know each other as people. Rather than like, she's gonna tell me what happens with my child.'*

(ii) The role of the parent/carer as advocate

Many parents and carers spoke of how they were having to chase up appointments, repeat information, and remind professionals of their needs/care plans. A much-repeated sentiment by parents/carers was that if they hadn't been so educated and persistent that provision would have been far poorer. Alongside stories of battles and the almost overwhelming struggle to 'get heard', there were some accounts of good professional practice, usually linked to an individual practitioner who worked alongside families to advocate and empower.

The centrality of the parent/carer coordinating and negotiating care, was consistent across all research conversations, creating what was felt by participants as, at times, an almost overwhelming sense of responsibility for ‘getting things right.’ The quote from the participant below reflects the sense of the parent having to carry the mental load of not only understanding the system and the process needing to be followed, but of being ‘one step ahead’ in terms of knowledge about the resources and services that needed to be advocated for:

> *‘So, all I did was get hold of the information and the evidence and continue to present it and* ***hope that someone would listen.*** *Honestly, I read absolutely everything. I've just got, like books and journals coming out my ears to try and figure out* ***what is gonna be the best way.’***

Another participant reflected similarly on the importance of her actions in planning care for her child:

> *‘It’s largely me that ends up co-ordinating a lot of the communication-type stuff. ..I’ve had to learn about stuff…the Igaze (eye movement communication device)came about because of me going to an exhibition in Manchester.’*

All participants were very aware that their voices may not have been heard had they not been as confident and articulate in their interactions with health and social care professionals. To quote from 2 participants:

> *‘If I wasn’t the sort of person that I am, educated and confident, we wouldn’t kind of get what we get.’*

> *‘But I did know that if I could be in a position of having a conversation with them, then I was fairly confident that I would be able to articulate whatever it was that was kind of needed and that they would hear that and well, I think it like just kind of making sure that I wasn't ignored. I really was raging quite a lot of the time and wanted to scream and shout, but I didn't do any of that and I think that is also helpful because I know it's hard not to.’*

The impression gained from the discussions was that parents and carers were incredibly skilled and driven in their wider knowledge base about their child’s needs, in addition to navigating the complexities of a system that had at times to be managed so that appointments were made and letters sent:

> *'I went back to my GP and I told him exactly what to put on the referral and that went to the neuro team. And then she got assessed after that'*

As will be discussed in 4.2, a paradox exists where participants recognise the importance of their input in getting the type of care that is needed for their child, but at the same time feel 'on the outside looking in' when professionals discuss their child's needs and development.

(iii) *The need for co-ordinated working within and across health and social care teams*

The best experiences were linked to good teamwork between professionals, within and across sectors (e.g. Education and Social Care). Poorer experiences included problems with co-ordination of services, with some lack of knowledge/skills in teams observed, including information about how other sectors work and what they can offer**.** Linked to the need for relationship-based interventions inferred in the previous themes identified, participants spoke of a lack of 'joined up' provision, with different sectors 'referring on' to other sectors who they felt had responsibility for the presenting issue (for example, saying to families 'that's a health issue' or 'you'll need to go through the school for that'). There was also evidence of different teams misunderstanding how other teams they were referring to worked, resulting in children being put on the wrong waiting lists, adding to the frustration of parents/carers. More positive experiences focused on good communication between professionals who appear knowledgeable and want to help; on these occasions the importance of these professionals getting to know families and their changing and complex needs was notable. High staff turnover however, particularly amongst home care workers, was noted as disrupting parents'/carers' relationships with professionals, with children and families then having to forge new relationships which some found challenging (including the children). The quotations below reflect the experiences of parents and carers and also convey the consequences of the good, and less good practice on the levels of wellbeing experienced by families and their children.

The consequences of health and social care teams' misunderstandings about how other professionals work are noted in the following quotes:

> *‘The lack of communication between the sectors is ridiculous, isn’t it? Meetings are being held and there one sector isn’t represented…and all these people are there apparently for these families. And then, like too often, they’re just like, well, they’re not here and no-one else is sent because this person’s been called in that meeting…’*

> *‘I understand people get pulled into all sorts of different things, but I think it's just if the people are treated with such disregard like they don't matter, you know, and that OK, a decision was supposed to be made in this meeting and actually now it can't be because the people aren't present. So, we can't make this decision. So now there'll be another one [meeting] in six weeks’ time, you know, and let's just keep the family hanging on with all their worries. And by the time that it gets to that, things have already gone really, catastrophically, badly wrong.’*

The absence of different sectors in meetings and, more generally, discussions about the needs of children where decisions are made about care plans, emerged as a core theme from both focus groups and interviews. Experiences where professionals misunderstand what other sectors do or have out of date information about how the sector works, was noted by participants. Parents expressed their frustrations in trying to get the right help and support for their child, and how incorrect referrals and information about service providers resulted in poor experiences for their children:

> *‘We were told to contact Conwy social services for home care, but then they told us she was no longer under their care, but Gwynedd’s…so I don’t know, it was just really difficult, a lot of the communication-type stuff.’*

Similar reflections on the poor communication between different teams, this time across sectors, were made by most participants. To quote from another parent:

> *‘So, then we were kind of stuck in this thing of even the professionals who were referring,* ***they didn't know that there were different teams****. So, she was sitting on the wrong waiting list for quite a long time.’*

Reflecting further on the consequences of teams’ skills and knowledge, the same participant expressed frustration about a process that was meant to facilitate positive outcomes, but instead resulted in feelings of frustration.

> *‘So, for some people to be able to get specialist OT you have to go through speech and language. And there's a waiting list for that. And it's like, well, that's not the issue. And then there'll be another waiting list for the next bit, and you actually could have cut the first bit out because it's not needed.’*

The link back to theme one, with the complexity of needs not being fully understood by professionals, is clear, linking too to a need for parents to advocate for their children in light of fears that needs will remain unmet unless the parent/carer ‘steps up’ to advocate for their child.

The parent quoted below reflected on her frustrations in working within a system where needs were ‘siloed’, with health, education, and care needs allocated to different sectors:

> *‘I’ve identified training videos and stuff [for home care staff], and I’ve been the one who’s sent them to their manager and said can you give them the opportunity to watch the videos, but the staff that need the training say ‘this is education, not health, my job is health, not education’…so I’ve met a lot of resistance from them…It’s almost like their training is just ‘keep him alive for 3 hours’, that’s all you need to do.’*

Alongside critical conversations, there were also some examples of experiences where professionals were all fully ‘on board’ with the need to engage specific services but themselves frustrated by the slowness of the system. Speaking about the combined efforts of professionals, barriers to good provision were understood in some accounts as linked more to resources and staffing levels than to any lack of motivation or understanding by professionals. Quoting from one parent, the process involved a combined effort from parents and staff across a number of sectors, with…

> ‘*All of us putting referrals in, all of us chasing the referrals, all of us sending in more letters.’*

Where experiences were more positive, this was universally related to a named individual who had got to know the family, advocating *alongside* parents, and building a relationship of consistency with families. Reflecting on the importance of people acting together, with a common goal, in a way that *makes the experiences of families* *visible*, emerged as a highlight of good practice in the research. To quote from one parent:

> *‘Once she stopped going to school, then everybody wanted to help you see. So that's where we were, her head of year was extremely helpful, and I spoke to her about it. And she put in a referral to the neuro team and the school nurse put in a referral to the neuro team.* ***The school saw, and this is the thing, isn't it?****’*

Another parent, proudly discussed her achievement in getting the ‘people with power’ on side:

> *‘To be fair, I had the head of psychology and education on my side, and they supported me.’*

Continuing this theme, a kinship carer discussed how, having been told by social workers that her child didn’t meet the threshold for support as a ‘child in need’, the school stepped in to help. To quote:

> *‘So, we went to the [specialist] school and he was well-supported by the staff and special needs teachers and actually did extremely well.’*

Staff working in third sector provision were praised by participants as highly motivated, albeit limited by the funding process in terms of what they could do and how far ahead they could plan activities. Reflecting on one professional who organised a hub for parents and carers, one participant stated that, to quote:

> *‘She was brilliant, really, really, useful getting bits of money together to organise coffee mornings. Me [and another woman] were just crying cos we thought we were the only ones with a kid like this. But then the money ran out.’*

Underpinning the conversations around teams and multi-agency provision is a recognition by parents and carers that someone who understands their children, wants to help, and *knows what that help should look like* is at the centre of good practice. This reflection will be discussed further in 4.2 when considering the implications of the insights that the research has provided. It also shapes the ‘wish list’ narrative presented in 4.2(i) when presenting recommendations from the participants themselves.

(iv) *The importance of being listened to and heard – of being part of the process, and not outside of it.*

Following on from the preceding themes, integral to professionals' understanding the nature of their child's needs was the recognition in the discussions that parents, children, carers, and other family members understand their child best, and must be at the centre of any discussion about the services and support that the child (and themselves) may need. The experiences described in the focus groups and interviews varied, often from one extreme to the other, with glowing accounts of parents/carers feeling listened to alongside stories of utter despondency and hopelessness conveyed when discussing experiences of feeling excluded from the decisions that were being made about their child. With these accounts, parents spoke of being 'on the outside looking in,' of how they felt (at times) pre-judged as to what they have, or haven't done, and what the best solutions might be. Interestingly, an unexpected finding was that participants reported being given very few opportunities to 'feedback' to the service providers about the services received, and to regularly assess progress (other than via formal assessments). The quotes below reflect the emotional impact on families of feeling voiceless and lacking control in their interactions with health and social care professionals:

> *'We used to have multi-agency meetings, everyone invited, and discuss everything, like working together? But we ended up having a disagreement and put in a formal complaint [upheld]. I gave up after that and said there's no point having them anymore. I kind of lost faith in those kinds of things anyway.'*

> *'We were asking for the help, we kept asking for the help, but everywhere you turn you know…I don't know you lose faith…you just give up and get on with it.'*

> *'It is frustrating, and that's why I ended up writing to the MP because I felt you know that this is just not acceptable in any way.'*

> ‘*No-one’s ever really offered what services are available, ever…I’d do anything, use anything really. I don’t know how to help, and nobody will help me. The only social worker I’ve had help with from is an ex-colleague, and that’s because I phoned her.’*

Parents and carers recognise what should be happening and are very clear about what they see to be lacking in the services offered to them. Continuing the paradox previously identified where parents act as advocates for their child while feeling they have very little power and control over what will happen, there was a clear sense from some participants of resignation to a situation that feels quite hopeless.

More positively, there were other accounts of experiences where parents and carers felt valued and listened to. To quote from one parent speaking about her interaction with professionals:

> *‘They’d say like, what do you think about this and what do you think about that and what do you know, and I'd be like, well, I've spoken to A about this, and this is what we think. And I think that was really good.. I didn't get that feeling of like we’re the professionals and we know more and I like, I really appreciated that because I also knew that that wasn't true… We had a bit of a chat and a bit of a laugh and a cup of tea, and she was always totally fine.’*

In reporting positive examples of co-produced care, participants’ stories are suggestive of how the best outcomes can be achieved with the co-design of care and support plans. To quote from a parent on her experiences with her child’s school:

> *‘ And, she (head of year) would say we're thinking of doing this. What about this? She said what does A really like to do? And I was like well A actually really likes cooking. She [teacher] was like, could she come in and do an hour of cooking? I'd say I'd give it a go, though mostly no, she wouldn’t go!’*

Interestingly, what emerged from the discussions was not so much the importance of goals being reached, or outcomes met, but of parents and children being an *integral part of the process itself*, feeling that they had a voice and that their contributions were not ‘added on’ to those of the professionals, or in any way tokenistic.

4.2 Synthesis and developmental narrative

The themes and illustrative quotations presented in the previous section convey a sense of how the parents and carers who were sampled understand and make sense of the service provision they are receiving for their children. This section is concerned with synthesising or ‘bringing together’ the insights from the research to provide a clear evidence base on which to facilitate future conversations about how best to respond to ‘what matters’ to parents and carers of children and young people with a learning disability.

(i) Participants’ wish lists and recommendations

While the research and this report are the result of a commissioned piece of work by Improvement Cymru, the author is aware that it was a privilege, as an academic, for participants to share what were quite personal insights from their lives. The research had an intended outcome – the production of a piece of work that followed on from a previous review – and that the parents and carers spoken to were part of this. In taking care to promote a research agenda that was anti-oppressive, and potentially empowering to research participants, it was hoped that parents and carers felt that they had a voice and that their contributions were valued. To this end, in addition to the person-centred approach conducted, each focus group/interview concluded by asking participants what they would wish for if they could wave a magic wand and be granted the types of care and support that would tick ‘all the boxes.’ In so doing it was intended that participants felt able to be as open as possible in what they recommended, in addition to bringing together some of the themes discussed to inform the report’s developmental narrative. Listed below are some of the wishes that came out of the research project:

> *‘It [care and support services] would all be in one place, and it would be clear how these things all fit together, and that you could kind of try out different things as well, without having to commit to it. So that if you were kind of trying something out to see, will this work for my family or will it, you know, will it work for S or like whoever it is?’*

> *‘And yeah, that there would be some sort of comprehensive service where you can find out like what's going on and what do we do with it. And so, it's like it's all kind of wrapped up in one place really and that there isn't a waiting list.’*

> *‘Let’s give people more choice rather than just to kind of say this is all we’ve got, and if it doesn’t fit, like well, it’s tough.’*

> *‘What would have happened is that people would have taken my concerns seriously. When I first shared them.’*

> *‘Someone to listen. I mean properly listen. Starting early on too, with someone you can talk to when the health visitor has stopped visiting, or at the weekends when everything’s closed.’*

> *‘I’d like someone who understands speech and language who can be assigned as support worker, even if I could sit and explain to them her difficulties, and come and encourage her to go out, even if it was to a café, a shop, or some activity, that’s what I’d really like, so I can get some respite – and she does! And then we’ve got something to discuss and talk about that she’s done.’*

> *‘A drop-in place that you can get to on the bus, where no one looks at you funny and you can just sit and talk. Be invisible if you want and left alone with a coffee, or if there’s some advice you need, like a letter has arrived and you’re panicking, there’s help there too. But to get support there and then, and not sent away with a number to ring or an appointment for like 3 months’ time. And then be told it’s the wrong number ha ha!’*

> *‘You want to have people you can trust, that have enough time…you want people in your home that are actually interested in doing stuff with him. And I’d like a bit more flexibility in terms of when you have the care.’*

(ii) Synthesis of emerging themes

The themes emerging from the research paint a picture of services that are variable in their ability to meet the needs of parents, carers, and their children. At the centre of conversations was the overriding importance of **needs being understood and not assumed from a label or diagnosis** – and the importance of health and social care professionals **recognising that needs change over time**. That **parents know their**

children best was a clear message to emerge, with some parents and carers feeling neither listened to nor valued when decisions are made about their children.

The best care experiences seem to take place when professionals **take time to listen** and **really get to know what matters** to children and families; having a **consistency of care**, with a **named person** who understands the needs of the whole family, is considered key to good outcomes. Further, having **support in place before 'crisis hits'** from a professional who has 'oversight' of the complexities of the Health and Social Care sectors, was considered by parents as invaluable in navigating the complexities of the system. When it comes to how care is experienced within and across Health and Social Care sectors, the picture is more complex. The '**compartmentalising' of different parts of a child's identity** which is then measured according to the threshold that needs to be met for a diagnosis to be made, results in an **incredibly complex and at times confusing array of appointments and arrangements for families.** Stories were told of professionals understanding needs in different ways and applying different models to make sense of the symptoms that a child may be presenting with. This can result in referrals being made on the basis of, for example, a health professional's understanding of what the 'problem' is; once the meeting takes place, a different professional may make sense of the situation using a different set of criteria or model of understanding, resulting in frustration amongst parents when they are told they have been put on the 'wrong' list.

The **fragmentation of the care experience** that this results in for families was echoed too when listening to participants discuss their experiences of being told by professionals that they can **only help with one 'part' of a child's diagnosis**. For example, as discussed when considering theme one *('the importance of rights/needs' led provision'*) the use of a new communication tool (Iscan) that home health care professionals may need to use when caring for a child at home, was considered by staff as an educational need, and not something health-based carers need to be aware of. Heart palpitations reported by a parent of a child with Down's syndrome weren't recorded by a social care professional, despite their noted frequency when the child is in new environments/placed in a different school, and hardly ever observed at home. The parent is told to make a GP appointment as 'that's to do with the health-related part of her condition.' The link to the theme of advocacy is clear. Parents know their children better than professionals do, and this can result in the need by parents/carers to coordinate services, check, and double check appointments, follow up referral letters, and, on occasion, advise professionals about what they should be doing. The sense emerging is of services working ‘alongside’ each other, rather than through an *integrative model of care,* resulting in parents and carers who are frustrated and exhausted. In navigating the different ways in which professionals work, there is a paradox between the role parents and carers are often having to play, and the degree of power and respect that they are afforded by professionals. It is suggested that **being knowledgeable and motivated and working with other advocates in the system, co-producing care and support for one’s child, is different from *having to be* the ‘lead’ person in ensuring children’s needs are met**. In many of the conversations, parents recognised the irony of being ‘in charge of it all’ while, in reality, having little power to make decisions of importance for their child’s wellbeing.

Alongside narratives that expressed frustrations with the services provided, were some very insightful accounts of inspirational ‘magic moments’, out of which emerge some of the developmental narratives presented in the section that follows. Co-produced **care plans that go beyond ‘asking what people think’** and instead **involve an active, ongoing process of relationship-building with parents, carers, and children**, is how the complexity and ‘messiness’ of everyday life with a child who has a learning disability is best captured. The stories conveyed through the research give examples where the **most empowering experiences** often happen through, for example, conversations over a coffee, through ‘small talk,’[14] and interestingly where parents/carers are sat side by side with professionals and not facing each other over a desk in an office. Speaking informally to other family members, going for a walk with the family, and **being involved in the ‘doing’ of life,** as opposed to hearing about or observing experiences from the ‘outside’ emerged as the context in which parents and carers feel like they are **best understood and ‘seen.’** In addition, with a relationship of trust, care in the home feels less intrusive; participants spoke about the awkwardness of interactions with home care staff who they didn’t know ‘trooping through the house’ and felt unable to engage in open and honest discussion for fear of being perceived as overly critical. Good care, when it happens, can be

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[14] Engaging in small talk (‘informal sociability’) is increasingly being considered a way in which the ‘asymmetries’ of power hierarchies can be broken down, creating rapport and trust (Iverson & Flinkfeldt, 2022).

transformative in the lives of parents, carers, and children, and it was clear to see through the interactions in the focus groups particularly, how participants relaxed as they exchanged stories where, certain **professionals had worked *with the family* without preconceptions of need at a pace where parents/carers felt valued and listened to.** Feeling 'safe' for families was seen as facilitating ownership of care, with advocacy for their child shared, and, crucially, built on an acknowledgment that the parent/carer knows their child best. When discussing **positive experiences** of multi-agency teams and integrative models of care, professionals who were able to **'oversee' and 'negotiate' the complexities of different teams, and the different models of care across**, for instance, Health, Education, and Social Care, were considered invaluable. Parents who had experiences of such support reflected on how having someone advocate for them, and 'take charge' of what was going to happen next with their child, actually resulted in them feeling empowered and part of the decision process.

To briefly comment on the synergies between the **findings of this research and the literature review** conducted previously, there are many overlaps in the identified themes and findings. Evidence of the **importance of being listened to, of having a professional who understands the family's needs, and of coproducing care** and support plans were themes that were found in the review and brought to life through the narratives of participants in this project. The **importance of needs-led provision**, and the **rights of the child and family as needing to 'lead'** the identification of appropriate services, were found across both pieces of research. Where this research develops that of the literature review is in its scope to allow the reader to 'actualise' the experiences noted in the reviewed literature through the examples and stories provided. In conveying the emotional impact of families' lives through the narrative accounts provided, a snapshot of the short- and longer-term *impact* of how parents and carers experience services were conveyed, something which a secondary review of previously conducted research can only hint at. One theme that emerged more strongly in this research than in the literature review was **the need and challenge of self-advocacy**; while the literature review presented evidence of parents and carers who had to 'piece together' the many different services and professionals who provided care for their child, the all-encompassing impact of this role on the lives and identity of parents and carers was only really brought to light when engaging with the complexities of participants' lives through primary research. Interestingly, the list of participants' recommendations for future practice reflects the impact of the need to advocate daily for their children when engaging with, for example, home care workers, GPs, teachers, and hospital/clinic staff. The emotional impact on parents and carers in particular of having to co-ordinate appointments and meetings, repeat information to different professionals and explain to them what is happening in other sectors, is suggestive of the need for future research to explore further the experiences of professionals working within and across Health and Social Care.

(iii) Developmental Narrative

To conclude the report, the findings that have emerged are suggestive of the need for developmental conversations in policy and practice that engage with the insights provided by the research participants in this study. The development points to emerge are listed below:

- Where care provision works well, this is strongly linked to the development of a holistic, needs-based relationship with the family by professionals. This is almost universally found in the data where there are one or two named individuals (from a range of sectors – Social Care, Education, Speech and Language) that have spent the time to really get to know the family, including the child. This type of connection, centred on advocacy and early intervention care/support that is preventative and strengths-based, is particularly important where the needs of the child are complex and profound.

- There is a need for more meaningful co-production from all sectors that places parents/carers and children at the centre of designing and implementing care plans that are regularly assessed and build on the expertise that families and carers have about their child. When parents are positively engaged in co-producing, and evaluating services, the outcomes can be transformative. Very few parents/carers however were aware of how to 'feedback' their experiences so that professionals can better plan future care. Worryingly, only one participant had heard of Regional Partnership Boards. Relating this back to Welsh Government recommendations (2022) 'Measuring the Mountain', which are in turn related to the wellbeing outcomes from the SSWA (Wales) 2014…*'Co-production needs to be defined and embedded as a practice which is understood and utilised by all who are involved in the creation, delivery, and evaluation of social care services'* (recommendation 8).

- Some of the confusion conveyed by professionals and parents/carers about what constitutes a learning disability, and how this may, or may not, 'match up' with the criteria for a diagnosis, suggests a need for further conversations about what constitutes 'additional needs' across a range of different care and support services. While a trusted coordinator who has got to know the family over time has a role to play in navigating the range of services available to meet the changing needs of the child, findings suggest the need for ongoing conversations with professionals within and across Health, Social Care, and Education, about how different sectors understand need. Parents and carers in the sample had a preference for integrated care provision, with good outcomes more frequently reported when care was jointly funded and health and social care services *co-located,* often occupying the same building.

- Developing the above point further, recommendations from the participants themselves include the desire to have access to everyday care and support provision 'under one roof' via a 'drop-in' hub-type venue. This could include space to chat over coffee with other parents and carers who have children with a learning disability, and to have access to information and advice from both health and social care experts. Participants' discussions also conveyed the importance of getting to know families early on, so that preventative strategies can be co-designed that take into account multi-faceted needs and plan how best to meet these needs.

(iv) Future directions

Reflecting on the research conducted, the lasting impression conveyed from talking with parents and carers is of a group of diverse individuals that have in common a drive to secure the rights of their children. Threaded through the hours of discussion was the common desire to find services that felt right, based on the personalities and preferences of their children, and not through professionals matching children to services based on a diagnosis, an assumption of need, or of what is available at the time. As one participant put it, there will be commonalities between children based on their diagnosis, but this is only one variable amongst many when considering what constitutes the best package of care for a child and family. To explore further some of the barriers, and enablers, to services meeting the needs of families and children, future research initiatives might usefully consider exploring how professionals within and across Health and Social Care sectors understand how needs can be met and, crucially, what barriers, and enablers they see as impacting on the implementation of integrative models of care.

The vision of care at the policy level for North Wales is broadly based on the principles of co-produced, needs-based services, with degrees of integrative care that vary according to local authority. The shift to integrated disability services, often in response to the Social Services and Wellbeing Act (Wales) 2014, the development of Social Services' Transformation programmes, and the associated North Wales' Learning Disability Strategy, appears to be the favoured vision of Health and Social Care in North Wales. With a clear commitment at the level of local and national policy to integrated, co-produced care, there is a strong rationale to continue to work with families and professionals to find better ways of working that builds on the good practice noted in this project to better meet the need of all families in North Wales.

4.3 References

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