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Prifysgol Wrecsam Wrexham University

'It's never just about the label'

Exploring professionals' experiences of working with children and young people with a learning disability in Wales

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Contents

Abstract

Despite the promotion of an integrated, collaborative model of care for children and young people with learning disabilities in Wales, research suggests that outcomes for these children are mixed. The author's previously published research for NHS Wales Performance and Improvement (formerly Improvement Cymru) suggests an implementation gap exists where the vision of seamless services and 'no wrong door' are not often met, with parents reporting frustrations with service provision which they considered fragmented and lacking coherency. The research presented in this report aimed to explore in detail how professionals working in health, social care, and education across Wales experience and make sense of the services they provide for children and young people with learning disabilities. The research adopted a qualitative approach, conducting semi-structured interviews with 20 participants via an online platform. A number of key themes consistently emerged from the interviews, providing evidence of a workforce that tries hard to actively engage with the vision of integrated, joined up, collaborative provision. However, the extent to which professionals in different sectors felt able to *deliver* effective, integrated care and support was mixed. While there were some very positive examples provided of constructive multi-agency working in teams, many participants experienced frustration with colleagues in different sectors who worked with different models of care, funding, and service thresholds. At the same time, a broad commitment to putting the needs of children and families first, wherever possible, was a consistent finding of the research, although what person-centered, co-produced care should (and could) mean did vary. In order to best meet the needs of children, the findings of the research suggest the importance of a robust and sustainable resource base, more transparent communication between sectors, including between statutory and third sector providers, and the embedding of the principles of co-production into the design, delivery and evaluation of service provision.

1.1 Introduction

This report presents the findings from a research project commissioned by NHS Wales Performance and Improvement to provide an in-depth understanding of the experiences of professionals across Wales who are working with children and young people with a learning disability. The background to the project is first discussed, with the rationale for the research explained. The current policy frames and models of care which shape professionals' practice are then briefly discussed. The report then goes on to present the research methodology and theoretical framework that has guided the project, before presenting the key themes that have emerged. A critical evaluation then follows where data themes are synthesised and the findings of the project discussed in-depth. To finish, the report proposes a developmental narrative where future directions for policy and practice are presented.

1.2 Background to the study

This study emerged in response to findings from the author's previous project, published by NHS Wales Performance and Improvement in May 2024. This project, itself developed in response to the author's commissioned literature review by NHS Wales Performance and Improvement in 2023, conducted a range of interviews and focus groups with parents and carers to explore their experiences of receiving care and support for their child with a learning disability. The findings of this project mirrored much of what the literature review had revealed and are listed below. It was found that:

- The experiences of parents and carers in the sample were varied, with some inspirational stories of professionals and services recalled alongside many experiences that were far less positive.

- Delivery of care was reported to be fragmented, with many accounts given of unmet needs from parents and carers.

- Where good experiences were reported, these were overwhelmingly related to cases when professionals get to know a child and family properly and can advocate together for services to meet their needs.

- The better the links between health, social care and education sectors, the more positive the experiences were of families and children.

A focus on the complexity of needs was a strong message that emerged from the research with parents and carers. Seeing the child first, and the disability second was discussed as the foundation of good quality care, with the need for rights-based, rather than service-led provision, a key finding of the research conducted. However, as detailed below, despite health and social care policy in this field promoting a person-centred integrated approach to the delivery of services, the gap between vision and experience was seen to be significant. In light of these concerns, a rationale for the current research discussed in this report emerged, considered in more detail below:

1.3 Purpose of the research

Developed as a response to the previously conducted research discussed above, the purpose of this project was to explore in depth the perceptions and experiences of a range of professionals that work with children and young people who have a learning disability. The rationale for the research came from the research discussed above, where findings suggested that parents and carers can experience services for their child that are fragmented , with the care and support received felt to be disjointed. As such, parents and carers frequently reported feeling frustrated, being left to 'piece together' signposted services that were designed to respond to different 'parts' of their child's identity and needs. Narratives were heard where professionals would make referrals to their

colleagues in different sectors according to a clinical diagnosis which, while meeting a professional criteria or threshold, may not address the needs of the child as understood by parents and carers. The picture emerged of an *implementation gap* where the vision of care, of 'seamless services' providing an integrated, multi-agency response to needs that are understood through a process of co-production with families, not often meeting the reality experienced by parents, carers, and children.

In light of these findings, the current research presented in this report was motivated to explore, through semi-structured interviews, how *professionals themselves* who work with children and young people with learning disabilities, across Wales, understand and 'make sense' of the ways in which they work with children and families. In so doing, the aim of this research focuses on understanding how professionals understand need, seek to address it in their day-to-day working lives, and how they see their role in relation to other professionals who may be working with the same families. While this research does directly stem from that previously conducted, there was also scope to discus in depth and detail the feelings and emotions that professionals have about their roles, exploring not simply the practicalities of the job, but more significantly their hopes, fears, challenges, and motivations. As a result, the objective was to provide a safe, confidential space in which participants felt comfortable and could talk freely about the barriers they experience to good practice, in addition to practices that facilitate positive outcomes.

Before discussing in more detail the research design and methodology for the project, the section below provides an overview of the key principles and policy frameworks that shape work with children and young people with a learning disability across Wales. This provides a knowledge base for understanding some of the broad models of care that shape practice, albeit framed in different ways across different geographical locations across Wales.

1.4 Policy frames and guiding models of care

In order to contextualize the experiences of professionals presented in this report, it is important to provide information about the guiding policy vision, and wider policy frameworks that shape the day-to-day working practices of professionals. To provide a comprehensive, detailed breakdown of the varied ways in which different counties across Wales organise and deliver services across health, social care, and education is a challenge and not considered necessary in light of the scope and purpose of this report. Instead, a brief overview of some of the key guiding policies and strategies is provided below. In order to convey the vision that informs such strategies, particular attention is given to the *principles and values* that inform policy and practice. As highlighted in previous research (Jones, 2022), however, different service providers across Wales interpret and implement the 'sprit' of government strategies (for example, the importance of 'co-production') in different ways. As such, the implementation of key principles and guidance set at government level by different health and social care providers

does have some variability, albeit working within the broad framework and vision set by government.

1.5 Integrated models of provision: the vision

Care and support for children and young people with learning disabilities is designed and delivered through the policy frame of the Social Services and Wellbeing (Wales) Act (2014), with particular reference to Part 3 of the Act that places a duty on local authorities to assess a child's need for care and support. In terms of delivering care and support, the Act promotes an integrative model with a coordinated, multi-agency approach where professionals work together effectively to deliver meaningful and effective care pathways. Key to the implementation of this vision is the principle of centring the voice of the individual, with family and practitioners working together as equals to plan and deliver services that target need effectively. Regional Partnership Boards provided for by the SSWA (2014), are designed to strategically drive and deliver integrated health and social care services, facilitating a comprehensive approach to best meeting the needs of children, young people and their families. In terms of who delivers this model of care, an integrated team approach would typically include learning disability nurses, social workers, clinical and educational psychologists, care assessors, transition managers, speech and language therapists and audiologists, in addition to a range of associated health and social care staff members (for example social care workers, support workers, and health care assistants) [1]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 nation.

To better understand the vision and direction that guides much current practice by professionals across Wales, it is useful to briefly discuss Wales's Learning Disability Strategic Action Plan (2022-2026) to a provide a more focused, directive understanding of the cross-cutting themes that shape and inform the ways in which professionals deliver services.

1.6 The Learning Disability Strategic Action Plan 2022-2026

The Learning Disability Strategic Action Plan for Wales sets out the Welsh government's overarching strategy for the development and implementation of Learning Disability policy in Wales from 2022 up to 2026. Co-produced with Welsh government policy leads, the Learning Disability Ministerial Advisory Group, and

[1] The involvement of Parent-Carers in the delivery of services (such as Early Positive Approaches to Support (E-PAtS)) may also occur, in addition to third sector delivery of services that provide a marked contribution to the overall Welsh vision of providing an integrated Wales-wide approach that empowers children and young people with a learning disability.

key stakeholders and partners, the strategy identifies the key actions and areas of policy focus to be addressed during this period. Building on the Improving Lives programme (2018) and the principles of the Wellbeing of Future Generations (Wales) Act (2015), the Plan promotes a number of cross-cutting themes, which in terms reflect the broader principles and duties of the Social Services and Wellbeing Act (2015). For ease of reference, the most pertinent themes as they relate to the guiding vision for professionals working in the field of learning disabilities with children and young people, are set out below:

(i) ***Joint working, co-production and collaboration***.
The needs and opinions of young people, their families, and carers should be considered fully in all decisions about care and support that affect them. This theme relates to the *development and implementation* of policies and services across Wales, in addition to being set as an measurable outcome.

(ii) The promotion of voice and choice for people with learning disabilities and their carers.
Services should be developed that ensure voices are *heard, listened to, and supported*. Included in this process is the need to promote both professional advocates and self-advocacy.

(iii) **The promotion of *collaborative working* with stakeholders and service providers,** including transition services, across health, social care and education.

In promoting these themes, the intended outcome is a Wales-wide approach to children's services that is 'consistent, recognised, and easily understood' (LDSAP). In relation to staff teams specifically, the vision of an engaged integrated team of professionals who have a stake in the vision that they are working to implement, through co-producing care with individuals that is based on an understanding of need, is a powerful one.

To provide an understanding of how this vision of care has been understood and applied to different models and frameworks of care across Wales, the next section details some examples of how professional across Wales work together in aiming to deliver this vision of care. The examples provided are not exhaustive but are included in order to convey a sense of how the principles and strategies developed 'translate' to the delivery and 'doing' of care and support on a day to day basis with children and young people.

1.7 Approaches to delivering integrated, person-centred care and support services across Wales

The following indicative examples provide an overview of some of the approaches taken within local authorities across Wales to delivering the vision of the LDSAP. In addition, examples of initiatives and projects that work to implement a provision based around rights and needs, are also included so as to provide a more focused look at the scope and range of services that are offered across Wales.

(i) *Child and Adolescent Leaning Disability Services* (CALDS)

The CALDS model of care and support is implemented extensively across Wales, and promotes an integrative model of care where health, social care, education and third sector providers work together to deliver a package of care that best meets the needs of the child. The focus is frequently on early intervention and preventative care, with children between the ages of 4 and 18 who have a moderate to severe learning disability. While the composition of teams varies across local authorities, CALDS teams are frequently composed of a range of professionals, including speech and language therapists, occupational therapy, education services and clinical psychologists. Working closely with health boards, both in the development of care packages, and assessing eligibility for needs as children grow up, the aim is to provide a comprehensive, holistic service for children and families. How care is paid for does differ within different local authorities, with differing degrees of integration in financing provision across health and social care.[2] Similarly, in some local authorities, what are considered social care needs may continue to be delivered up to the age of 25[3], while others 'transition' children and young people to adult services at 18. Additionally, with the move in health services to 'Continuing Care' often taking place at the age of 18 if eligibility criteria is met, in some local authorities a young person may have their 'health needs' met by adult services, while social care/education needs may remain under the remit of children's services beyond the age of 18.

(ii) *'Whole systems' approaches: working holistically with children, young people, and their families.*

[2] Packages of care are frequently funded '50/50' across health and social care. Staff and projects may also receive funding through the Integrated Care Fund, a pot of Welsh government money that helps health boards and partners in the local authority to plan and work together.

[3] The Integrated Disability Team in Conwy, formed in 2015 as part of the county's Social Services Transformation programme, are an example of a multidisciplinary team where children and young adults up to the age of 25 are supported within the same team.

In the spirit of the SSWA (2014) Act, the importance of collaboration with a range of statutory and third sector providers, in a 'joined up' way, is seen as a crucial part of meeting the range of needs that children and young people with learning disabilities present with. Many local authorities in Wales work creatively with government funded projects; for example, the North Wales Together Transformation Project that works with young people to find out more about their needs and wants. Third sector providers (for example, Conwy Connect in North Wales) also offer a range of age-appropriate, needs-based provision for children and families that work closely with families, using person-centred, relationship-based approaches that aim to see the person first, and the disability second. The importance of developing a model of co-production that incorporates children, siblings, parents and carers in the design and delivery of services, is seen across the whole of Wales, with the promotion by both local authorities and health boards of co-produced support programmes to parents of children and young people. For example, the Early Positive Approaches to Support programme (E-PAtS) promoted by Cardiff and Vale University Health Board offers a range of needs-based services delivered by professionals and parent carer facilitators. Such schemes, drawing on the legacy of the *Improving Lives* programme, work to promote the voice and experiences of families as being at the centre of what care and support should look like. In 'drawing together' the information and feedback from families and providers, Regional Partnership Boards collect and collate information about their region in planning for the delivery of future 'whole systems' approaches to health, wellbeing and support for children and young people with learning disabilities in the local population.[4]

(iii) Meeting the criteria for inclusion in learning disability services provision.

While the abilities and experiences of children and young people who have a diagnosed learning disability are varied, there is nonetheless a criteria that needs to be met for service providers through an assessment process before services can be offered. While professionals themselves have recognised that learning disabilities present in many different ways, and can be especially difficult to 'capture' for children who communicate in non-typical ways and/or are non-verbal, nonetheless for access to statutory services (and some third sector providers) referrals must be made that will usually involve an IQ based assessment by a clinical psychologist (NICE 2022). When exploring the criteria across Wales that must be met by children in order to have access to learning disability services, most commonly there is a requirement for a child to have:

'(a) Areas of developmental delay **and**

[4] The NEST/NYTH framework is a Regional Partnership tool for planning mental health, well-being and support services for babies, children, young people, parents, carers, and their wider families across Wales (NHS Wales Health Collaborative, 2021).

(b) Significant, generalised cognitive difficulties **(IQ under 70)**

(c) Significant generalised difficulties with adaptive skills (communication, self-care, relating to others, academic functioning, understanding complicated information, and interacting with other people).'

Betsi Cadwaladr Health Board (2024)

While there is much current debate within and outside of Wales about if, for example, neurodiverse diagnoses such as autism should 'count' as a learning disability, the current consensus is that a clinical diagnosis based on impaired intelligence (an IQ below 70) is generally required in order for the threshold for a learning disability diagnosis to be reached. While additional learning needs' support may be provided by a service *alongside* learning disability provision (for example by some third sector providers who may be happy for families to 'self- refer' based on their assessment of their child's needs) funding even for third sector organisations is often restricted to those who have received (or in some cases are awaiting) a clinical diagnosis.

2.1 Research Methodology

With an overview of the policy frames and principles that shape the space in which professionals practice provided above, this section discusses the research approach taken in the project. Mirroring the conceptual framework used for the author's previous research with parents and carers, this project adopts a critical realist methodology that states that the interventions made by professionals in health, social care, and education, emerge through a complex interplay of factors (Koopmans & Schiller, 2022). Specifically, it argues that there is a 'reality' that exists independently of our day to day experiences, that shapes the scope and range of our actions, but that our own subjective understandings of that reality will also impact on our working practice and how we make sense of it. To give an example, the Social Services and Wellbeing (Wales) Act (2014) provides a statutory framework within which all professionals should work, providing a set of principles and expectations to guide practice. How professionals make sense of, and engage with such frameworks however will vary, with the day to day lived reality of working life being shaped by a number of factors, including individuals' level of training, adherence to the principles of the Act, beliefs about the legitimacy of the Act, time and resources available to successfully implement its principles, and crucially, what children and families themselves bring to professional interventions with the family. Drawing on this approach to frame this research, it was aimed to provide a research methodology that had the potential to critically explore the complex space in which policies, principles, beliefs, and institutional

barriers/enablers intersect to shape the 'lived reality' of participants' experiences.

2.2 Research Method and Sampling Strategy

The research method selected for the project was the semi-structured interview. With the main rationale for this method being to provide sufficient scope for participants' own 'world views' to emerge, a qualitative semi-structured interview was considered the most appropriate method to facilitate a person-centred approach. Embracing a feminist, interpretivist methodology[5] (Oakly, 2005) the intention was not to scientifically measure the responses given to a pre-set list of questions, but to instead guide the conversations with a series of topic areas or themes to encourage experience-rich dialogue (Denzin, 2009). With participants free to develop and expand on their responses as they so wished, there were few limits on which direction the conversation could take. Nonetheless, in order to provide some consistency to the 'guided conversations', and allow scope for comparison between interviews, a number of topics areas were identified in order to add focus to the discussions. These topic areas are discussed in more detail in section 2.4 and are informed by the emerging themes and findings from the authors' previously conducted research, outlined above.

Sampling strategy

The project aimed to recruit research participants from across Wales, from a range of professionals working in health, social care, and education with children and young people with a learning disability. Inclusion criteria for sampling focused primarily on the ages of children and young people (<18 but with flexibility up to 25 to reflect the differing thresholds that health and social care organisations across Wales work with) and the requirement for children and young people to have a diagnosis of a learning disability *or* be in the process of awaiting one. In short, sample requirements meant that as a minimum criteria for recruitment participants must be employed (or have been employed) in a relevant occupation (health, social care, education provision) across statutory, third sector, or private sectors, and working within Wales. With the methodology of the research qualitative[6] in nature the expectation of the research was to provide rich, insightful data that emerged through reflecting on the 'living experience' of those working

[5] As argued by Oakly, 'A feminist methodology of social science requires abandoning the mythology of 'hygienic' research with its accompanying mystifications of the researcher and the researched as objective instruments of data collection' (2005:231).

[6] 'Qualitative' research aims to explore the 'whys', and focuses on an exploration of 'values, processes, experiences, language and meaning' (D'Cruz & Jones, 2004:60)

in the field. With a focus on relevant, meaningful data, the intention was to produce findings that were high in validity, but not necessarily high in reliability[7]. As such, a purposive sampling strategy was applied, deliberately seeking to recruit participants with a purpose in mind, and who matched the inclusion criteria. With the aim being to recruit a sample that would be 'information rich' (Marlow, 2001: 133) snowball sampling was also present, with scope for interested respondents to mention the project to colleagues who may also be interested in participating. This helped to ensure recruitment of a cross-Wales sample composition, and to satisfy number requirements (n= 15-20). With the help of gatekeepers across both North and South Wales, invitations were sent to a variety of local authorities, charities, and third sector organisations across Wales. Interest in the project was very positive, and while there had been a concern that there may have been an imbalance of interest from one sector over another (e.g. health over social care) a proportionate number of professionals across health, social care, and education were recruited, with all who responded meeting inclusion criteria requirements. In total, 20 interviews took place from across a range of sectors, geographical regions of Wales, and professions. These included learning disability nurses, social workers (including social work managers), speech and language therapists, clinical psychologists, educational psychologists, audiologists, and social care assessors.

2.3 Research Method: Scope and limitations

The primary purpose of the research was to produce an *in-depth* understanding of the experiences of professionals who work across Wales with children and young people with learning disabilities. As such, the rationale for the selected method was to facilitate a relaxed space in which professionals recount their experiences, feelings, and opinions without judgement. The semi-structured interview, where participants have the freedom to articulate in their own words their feelings and experience, while having the security of a guiding 'thread' of topic areas, presented to the author as the most suitable research method to select. It was acknowledged in designing the research approach that participants would have their own motivations for volunteering to be interviewed, and that these would shape the ways in which they approached the topic areas, affecting degrees of openness and

[7] Qualitative research uses semi- or unstructured methods of carrying out research, with, in this case, each interview varying not only in length but also in the wording of questions, the use of additional questions/prompts where required, and the balance of conversation between researcher and participant As such, interviews are not standardised and repeating and scientifically evaluating participants' experiences is both impossible and undesirable; the focus is instead on understanding, rather than measuring and calculating statistical probabilities (Tilly, L. 2022).

transparency. It is also acknowledged that where the gatekeepers for the project had a managerial role and who forwarded invitations to participate to staff, that this may have a motivating effect, as opposed to more neutral pathways to participation such as a poster in a communal workplace. At the same time, involvement in the project was on a self-selection basis, providing scope for participants to be able to speak openly and without fear of identification which can be acknowledged as providing a space in which individuals can feel empowered in reflecting on their own roles in addition to freely reflecting on wider systemic issues (Ross, 2017). Nonetheless, as other have noted in the field, there is always the possibility in 'real time' research that an evaluative research project such as this will attract participants who have strongly felt beliefs about their role/the sector, and as such may not be truly representative of the wider target population.

In relation to the limitations of the semi-structured interview, with conversations being shaped by loose topic areas, rather than pre-set questions, the research process lacks standardisation in that conversations may differ, with the time spent discussing an issue varying between participants. While this does limit the researcher's ability to replicate the same question schedule across time, the strength of non-standardisation is its person-centred nature, led by the complexities of the participants' story, and not the rigidities of the interviewer's schedule. Furthermore, while the data that this method produces may be 'free floating' and 'messy', with contradictions and inconsistencies, it is also what many consider the best type of qualitative data: high in validity and authenticity (Coffey, 2018). A further limitation that is associated with the interview method *per se,* and not specifically the semi-structured interview, is the possibility of the interviewer effect. This can occur where the participant is influenced by the presence of interviewer, and might give responses that they think are desired, rather than share their honest opinions and experiences. As with all 'talking methods', it is never possible (or desirable) to achieve 'data' that is 'uncontaminated' by the wider social and cultural conventions of communication, but with the researcher in this case being an academic, and not a practitioner, it was anticipated that any perceived need to provide the 'right answers' would be extremely minimal.

2.4 Methods in Action and Conceptual frame

The project recruited well, with a total of 20 participants taking part from across North, South, and Mid-Wales populations for Health, Social Care, and Education. To break down the sample the ration by profession was Health (n=9), Social Care (n=8), Education (n=3). Within Health professions there was a balanced mix of Learning Disability nurses, Health Care Co-ordinators, and Clinical Psychologists. In Social Care,

the majority of participants were qualified Social Workers (including Managers) in addition to Care Assessors and Transition Officers). In Education participants included Educational Psychologists, Further Education Officers/Co-ordinators/Teachers, and Educational Transition Officers.

Interviews took place on-line via Microsoft Teams at a time convenient for participants and lasted between 40 minutes and 1 hour. Interviews were recorded and transcribed in note form (full automatic transcription was also downloaded from the recording). Signed consent forms were received in advance of the interviews taking place, and verbal consent was additionally requested to record the interview audio-visually. While comprehensive participant information sheets were provided in advance of the interviews that outlined the anonymity and confidentiality of the interview data, additional assurances as it related to the anonymisation of what was said during the interview was provided.

Guiding Topics for Discussion:

As considered above, the rationale for conducting this research stemmed from the findings that emerged from the author's previously conducted research for NHS Wales Performance and Improvement with parents and carers of children and young people with learning disabilities. The study's findings provided an opportunity to explore further some of the key issues that this research highlighted, this time looking at how professionals themselves experienced and made sense of current provision for children and young people across health, social care and education. With these findings in mind, the researcher made reference to an 'aide memoire', a list of guiding themes and prompts, reflecting some of the key discussion points that had emerged from the project with parents and carers. These are listed below, and while there was no fixed order that these areas were discussed, all topics were addressed in each of the interviews conducted:

- Definition of learning disability used in your role: IQ-related or other criteria?

- What input do parents/families/carers have in contributing to the decisions that are made about children and young people. Are care plans and decisions about the future co-produced?

- How do you in your role/sector work with other providers who deliver services across Health/Social Care/ Education. Do you work in partnership/integrated teams/independently? Is this relationship positive and productive or are there barriers to positive working relationships?

- Models of care: do you work with specific models of care, such as the medical model, in mind? How does that fit with other

professionals you work with who may use different models of care and assessments of need?

- Needs/Rights: Reflection on barriers/enablers to good practice; magic wand: what would your ideal service look like?

Providing just a starting point for the guided conversations that commenced, these topics/prompts were able to facilitate a range of stimulating, participant-led discussions out of which emerged a range of inter-related themes, discussed below in 3.1.

2.5 Data analysis

Using the constant comparative method (Glasner & Strauss, 1967), each interview was watched again soon after taking place to familiarise (Byrne, 2022) and key conversational moments captured through a basic system of coding. A research journal was also used by the author to note down any 'miscellaneous' themes identified, in addition to any reflections on tone of voice, contradictory statements made by participants, and any additional observations. Thematic categories were ascribed to interview data to capture the identification of similar experiences and perceptions expressed by different participants, as a means of best capturing a reading of the data that was high in validity. Once this had been systematically done for each interview, the initial transcribed notes were revisited and initial themes refined. The final thematic categories reflected the issues that were identified most frequently, and are listed below:

1. *Service*-led provision as opposed to *needs*-led provision.
2. Models of care: medical or social model?
3. The importance of effective multi-agency working.
4. Lack of resources: staffing, money, services.
5. Co-production and voice: differing approaches

As will be discussed later in the report, the overlapping, co-dependent nature of the themes that have been identified cannot be overstated. While it is necessary to initially 'separate out' each theme in order to provide focus and build the evidence base for the study's findings, the interrelated nature of these themes will be explored more fully in section 3.2 where the key themes are synthesised and the study's findings critically discussed. The next section addresses each of the identified themes in turn, including supporting quotations from participants.

3.1 Emerging themes

(i) *Service*-led provision as opposed to *needs*-led provision.

Many participants acknowledged that while the needs of the children and young people they worked with were complex, the services available and the *systems* in place did shape the direction and focus that care plans and pathways took. This often resulted in children's needs being 'compartmentalised' or split up into different parts in order to be assessed and treated. To quote from one participant:

'It becomes about breaking each part of the child down into these tiny parts. They're not talking? We need to go to Speech. They've got sensory needs? They need a bit of OT. And so, the whole child gets broken down cos they're going to be fixed.' (Clinical Psychologist).

Many participants acknowledged the impact this could have on parents who may feel that their child's needs should be understood and addressed in ways that conflict with the direction that professionals take in addressing needs according to the procedures in place in their local authority/health board. To quote from an Educational Psychologist:

'So even if it was a need identified at home, with the parents saying that he [the child] *should be doing this and not doing that, but then if it was then linked in a meeting to school, it would go to the educational psychologist.'*

Reflecting on the arrangement of services in their area, another participant noted how different service providers identified needs according to different sets of criteria, resulting in children being referred to different services, on separate waiting lists, with professionals losing sight of the 'whole child':

'So, it feels like that's their thing. This is our thing. Not in terms of individual children, in terms of services, you know?' [Health professional]

The impact on families, and how this might impact on parents' confidence in the belief that their child's needs were being met, was noted by many professionals across all roles and sectors. To quote from a Health professional:

'So, I think all professionals just feel pressure to open, get the stuff done, and close the case. And unfortunately, that means being like really bound. You know, they [parents] *might say 'well, while we're here can we talk about this?' And you're like 'Nope, this is a referral for sleep. We're going to talk about sleep'.*

Participants across sectors were very aware of how different waiting times across sectors resulted in families waiting for different 'pieces of the jigsaw' to be slotted together, sometimes months apart. Different models of assessment and thresholds for a diagnosis of 'learning disability' and 'blanket referrals' based on clinical diagnosis, also created confusion not just for families, but for professionals too:

'Compartmentalising works well for children who have a specific, isolated deficit or deficiency, where everything else has come together in their development. It

doesn't work that way at all for our population [early years provision] but we're still as a sector setting it up as if that's the case.' (Health professional)

More positively, there were examples in the interviews from participants who acknowledged the rigidities of the system but yet nonetheless were able to keep the preferences of the child and family at the centre of their practice. To quote from a social worker:

'I suppose it could be argued that it's more service-led sometimes, but again it does depend on the complexities of the individual; what exactly they want to achieve as well.'

On other occasions, the security of having in place a comprehensive process that can 'capture all bases,' where non-presenting needs may not otherwise be noted, was recognised:

'You can get it where the parents are saying 'there's nothing wrong with my child's hearing', and then because a referral has been made, it turns out that there is.' (Audiologist)

Nonetheless, the overriding impression from professionals was that the complexity of children's needs was frequently unacknowledged, with the drive to diagnose and treat across discrete sectors providing a barrier to a holistic and collaborative understanding of the needs of children and young people:

'We have to follow quality standards for the way we deliver our services, but a lot of the time I wonder whether, you know, we are actually helping patients. At the end, you know, it makes things more streamlined possibly, and it makes it more equitable across Wales, but is it actually helping some of them? I'm not sure.' [Health professional]

(ii) Models of care: medical or social?

The vision of integrated service provision across health, social care and education is promoted by the Welsh government, encouraging seamless services and positive multi-agency working. While there is variation across Wales in how health and social care staff work together, whether in co-located teams, or where health or social care have differing age criteria for what constitutes transition to adult care, for parents and carers there should be 'No Wrong Door' (Children's Commissioner for Wales, 2022). While practitioners in health, social care, and education work with different specialisms and expertise, the range of skills across sectors should benefit the individual through person-centred provision that works around the needs of the family. Where service are 'joined up', differing approaches should complement, resulting in a professional curiosity that should contribute to understanding needs as holistic. When interviewed, participants across all sectors acknowledged that different models of care – specifically social models and medical/clinical models – at times complemented each other, resulting in an exchange of ideas that was mutually beneficial. To quote from a social work professional to support this point:

'It's best when you get everybody involved because we'll be talking and suddenly it's a case of, you know, well, hold on a minute I could perhaps look at this from a different angle. Or perhaps they could look at something from a different angle…and sometimes it's those impromptu conversations you might have with someone as well.'

Many participants found that real progress with other sectors was being made, with accounts from around one third of participants (n=7) indicating a willingness to share models and approaches to care and assessment of needs when reaching decisions with families. This was seen primarily when discussing social care/education and speech therapy working relationships but also observed between health and social care sectors. Reflecting on the developing relationship between health visitors and child psychology, one professional reporting a growing willingness by the former group to move away from a 'fix and cure' model of care, recognising that families need to be supported to understand that there are no quick and easy 'fixes.'

Other professionals (n=14) however found that health based clinical decision-making processes often dominated, obscuring the impact of environment as a contributing factor to displayed behaviours in children and young people:

'They [health] always want to know what the missing need is, what the missing health need is. And that's the difficulty for us, particularly when a child has more kind of behavioural based needs and displays challenging behaviours… It's hard to pick out the health bit.' (Social Worker)

The need for some health practitioners to strive to identify solution-focused strategies, which were time bound and measurable, was reported by some participants across (interestingly) both health and social care professions as providing parents and carers with a false impression of the nature of their child's needs. To quote from a child psychologist:

'*There's no way our children are going to go to a speech and language therapist and are going to be talking within the 6 weeks they've been given, or whatever that period is.'*

The benefits of box ticking and decision tools as a means of understanding children's needs had a place for some of the participants in the study- albeit a minority voice in the interviews conducted- with a focus on 'prudent approaches' where '*risks and uncertainties are avoided where possible'.* Some of those based in clinical environments, for instance, appreciated the power of a clinical diagnosis in providing parents with a definitive answer to what was 'wrong' with their child. To quote from a Health care professional:

'I get it that life is messy for families, for everyone really, but there's something to be said for a clinical approach on occasion. These families don't know whether they're coming or going and referring them on to a professional in a hospital or a clinic can mean for some people that they're not going mad, imagining things that aren't there… Not that there's anything wrong with a nice talk and a panad [cup of tea] *but still… it' not the same as a diagnosis and a plan, is it?'*

For the vast majority of participants however (n=17) understanding need requires looking beyond narrow clinical models in order to address the complexity of needs that children and young people with learning disabilities have:

'*It's never just about a toileting problem. There's way more. Way more. And people keep on trying to reduce it down to simple things, and I think as a team we keep pulling it out broader. And of course, that's just not…people* [other professionals] *don't want that…*

'When families say to me, 'my child's banging his head. What do I do? I'm like, oh, that's a huge, huge, piece of work. Like, it's not all about what you 'need to do.' [Psychologist]

(iii) The importance of effective multi-agency working

While the preceding section has focused on participants' perceptions of working alongside different models of care to their own, this section focuses more substantially on the day to day working relationships that professionals across health, social care and education have with each other. The need to develop meaningful partnerships with professionals in other sectors in order to best serve the complex and changing needs of children and families was a consistent finding across all of the interviews conducted. While there was evidence of working relationships that were positive and fruitful, different ways of working – specifically relating to assessment criteria and the differing length of waiting lists – created for many participants a sense of stress and frustration.

One important issue that several participants discussed was that simply having practitioners located in the same team didn't always result in joined up, integrated approaches to working with children and families. To quote from one health practitioner, working in the same team as social care professionals:

*'Social care? They're separate. I mean, not really separate, they're in the same team with us, but you know… (*laughs).'

A similar sentiment was expressed by a social work professional, discussing how differences in assessment criteria and waiting times created a fragmented experience for families when professionals don't always fully understand what other professionals are doing:

'*I wouldn't say we* [social care] *have a bad relationship with health, but I think sometimes there's a difference in expectations. They don't fully understand what we do as a statutory service, and maybe we don't fully understand what they do as a statutory service either. But we are trying to sort out and balance out any kind of differences. It's hard for us as they [health] have a waiting list, but we couldn't just turn around to families and say we can't take you on because we've got a waiting list.'*

Similar sentiments were expressed by social care practitioners working with education professionals, suggesting that better knowledge about what other teams do, and how they assess need, is an area that needs to be addressed further:

'*Schools don't always understand the criteria for social work interventions. So, not every child in the ALN school will have a social worker, and I think sometimes there's a lack of clarity around why someone would be eligible for the support in our team…and that can throw up a barrier and lead to expectations for the parents and then disappointment.' (Social Worker)*

Reflecting on not just the importance of joint working, but of the right people within each team contributing to decisions about care, the importance of those with knowledge about the child attending multi-disciplinary team meeting was frequently highlighted. To quote from a social work professional:

'*I do find a lot of the time with education, you know, it's kind of the senior team, the managers, who attend rather than someone that maybe knows the child well. So, if we're asking them for feedback then it's more about their attendance – statistical stuff – rather than what they're like day to day in the class.*'

One of the most frequent reflections (n=18) on barriers to good multi-agency working was the complexities of the funding system where different models of care, and perceptions of what constitutes the 'health bit', and what constitutes 'social care' needs, was for the vast majority of participants the key barrier to implementing effective outcomes for children and families. To quote from a social worker:

'*We're always working with two different budgets and that causes barriers to getting support in a timely manner…and while that's going on, the family are not getting the support that they need because we, the local authority and the health board are to-ing and fro-ing over who's responsible for payment. So, it'll be 'I think that's a social need… I think that's a health need.'*

The key frustrations for professionals stemmed not only from what was perceived to be bureaucratic conflicts with other sectors ('a key sticking point') but from the impact that the resulting delays and miscommunication had on families.

Despite funding issues being one of the most frequent themes raised by participants in the interviews, there were also very positive stories of partnership working, where difficulties were acknowledged but solutions found. To quote from a social worker:

'*We've got an excellent relationship with our health colleagues…I just think communication is the key, isn't it? You can pick the phone up and you can be civil.'*

While evidence of misunderstandings about what each sector 'does' was found, other professionals saw co-location of colleagues from other sectors in the same building as being key to 'smoothing out' any differences before they impacted on

decision making. Reflecting on their (integrated) team all being in the same building, a psychologist noted that…

'*It works better because you've got the contact with social workers daily…even just bumping into each other in the corridor and having spontaneous conversations…I mean, I went in on Wednesday and somebody's like, oh I've just seen so and so… so, like the informality really helps with relationships, and how accessible we are to each other.'*

Multi-agency visits to families were also seen to be very positive, albeit happening more with integrated, co-located teams than with professionals who were less familiar with their cross-sector colleagues:

'You just develop working relationships with them, like I usually have lots of joint visits with social workers because we're both working with the same family…so yeah I think that's a really positive thing about our service as well.' (Health Professional)

While experiences reported were on the whole mixed when reflecting on relationships with other sectors, there was an acknowledgement of some very positive examples of excellent practice, alongside the need for improvements to be made. As one social worker states:

'*I've had some really good outcomes with really good nurses who have picked up the family, worked alongside me…We've got the support in place, and we've agreed 50/50 funding…Those outcomes are not as frequent as the ones that we sort of argue over though…'*

(iv) Lack of resources: staffing, money, services.

Discussions about multi-agency working and the ways in which the needs of children and young people are understood by professionals made frequent reference to services being negatively impacted by issues relating to staff turnover and the quantity and quality of services available. The theme of resources was particularly significant where professionals worked with children and young people with profound and multiple learning disabilities, resulting on occasion in care plans that reflected what was available[8] rather than what was needed for the child or young person. To quote from one social worker:

'*The lack of resources we've got to communicate with our young people who are non-verbal, or who have one or two words, means we don't actually have a pool of resources to use as a team. So, a lot of the time it's making our own stuff to take out. I think not having resources, that's a massive barrier to getting the views and opinions of young people'.*

[8] There are clear links when discussing resources with the theme of service-led provision earlier identified.

Interviews with practitioners also conveyed an awareness of when interventions/resources could be implemented. Long waiting lists for some practitioners meant that by the time a referral was picked up, staff teams had changed, leaving a family needing to get to know a new professional, often at crucial times in a young person's life, such as when transitioning to adult services. This could result in 'bolted on' care plans, working with what seems to be a 'best fit' solution, rather than services that properly meet the needs of the young person. Reflecting on the implications of waiting lists and a high turnover of staff, a social worker reflected on a recent case:

'I've just picked up a couple of young people that were finishing school a few months later, and it's like, I don't even know them…I have to reply on what the school are telling me… So, we go around day services, see if they're any good for anybody. You know that sort of thing.'

The implications of trying to address complex needs but with only limited resources was also noted by the same social worker as resulting in placements for young people that may meet medical need (clinical diagnosis), but not wider social needs:

'Young people with more, you know, severe learning disabilities sometimes have to go to services because unfortunately that's the only place that's got, you know, your hoists and your proper changing facilities.'

Staff skills, particularly those of care and support workers, were seen to be variable, with participants reflecting on how support staff not having the knowledge, or failing to use the knowledge they have, about a young person's needs, resulted in negative outcomes for the young people concerned. To quote one participant's account of a young person with complex needs:

'*The staff who were supporting him didn't know how to communicate or cope with his needs. A lots of experienced people had left, with lots of new people coming in. Even though we were telling them what to do, how to approach it, it just wasn't happening. In the end it escalated to such an extreme that he had to leave and we had to find him a residential placement…It's sad because his ability is so much more than that.'*

Even with children and young people whose needs are less complex, almost all participants interviewed (n=19) raised concerns about reducing budgets and increasing waiting lists. The perceived impact on the child was clearly understood:

'*Ultimately, I think it's the child that suffers as they're just waiting, waiting, waiting.'*

'I think people are under pressure to make everything take as little time as possible, but the longer the wait, the more difficult the needs present as…and then managers worry that cases are taking too long to close. But you can only do so much with limited resources, and…it's always in the context of feeling like we've not got enough time.' (Health Professional)

The impact of increased waiting lists but decreasing staff and budgets on the mental health and wellbeing of practitioners was clear to see. While the vision and commitment of those interviewed shone out from the interviews conducted, the toll on professionals' wellbeing was clear to see. To quote from a social worker:

'*We've got a really happy team. But at the moment we are really struggling. We have less than 50% of the team in and that's because of long term sickness mainly… And this is what I believe really impacts services and means that families are suffering and not getting the support they need. We have 50 families for the first time ever on a waiting list. We've never had a waiting list.'*

While the passion and commitment from every professional interviewed was clear for the author to see, the pressures of trying to do their best for vulnerable children and families, while managing increasing caseloads with diminishing resources, results in high levels of workplace stress:

'Everybody's run absolutely ragged. I have to give myself a talk every so often. Sometimes I can feel myself getting palpitations and heightened anxiety and stuff. You can only do what you can do, but then I think that's the same everywhere.'

(v) Co-production and voice: differing approaches

All participants were familiar with the word 'co-production', across all services, although how participants *understood* the concept did differ. This ranged from seeing co-production as 'running things past the family' to long-term, person centred planning built on genuine engagement with children and their families, including siblings and individuals who may have profound and multiple learning disabilities. Co-delivery of services working with parent-carers in organisations such as EPAtS, was also highlighted as a model of good practice, by both participants who delivered the programme, and by those who were aware of its existence.

Regardless of participants explicitly mentioning the philosophy of co-production, as a minimum the importance of *including* the voices of families when understanding the needs of children was threaded through all of the interviews conducted. An explicit discussion of the need for a co-produced, holistic approach to need assessment, care planning, and delivery however was fully embraced by three quarters of the participants of the study (n=15). Of these, most were fully 'on board' with the values and principles of co-production, but cited lack of resources (time, staffing) as a barrier to meaningful engagement with families. As one professionals stated,

'*Everybody says that they do it, but they don't.'* (Health professional)

Another reflected that…

'I'd say I always did. Now it's a little. I don't feel it's quite the same at the minute. It just feels very busy at the minute.' (social worker)

There was also an acknowledgement by some participants that *different providers* had very relationships with the notion of co-production. To quote from a health professional reflecting on the use of 'patient experience officers' to find out what people think and feel about services:

'*I feel that health has a fear of doing it* [co-production] it's not going to be good. Nobody really want to hear about it everyone is sort of really stretched…So I think it's not really embedded in our services. We're still really at the beginning of the journey.'

While all participants expressed that they believed in the value of listening to children and families, at one extreme there was a reluctance for some to open what they called a 'can of worms' *('You don't go looking for problems'*), feeling that raising expectations by 'opening up the conversation' would inevitably lead to disappointment and resentment by families. Others understood co-production more as a process of communicating knowledge and coordinating discussion through providing a space in which the voices of families could be heard and shared:

'Yeah, they [families] *can ring the customer care officers. They're very accessible. They're set up well; they've got WhatsApp for families. They've got that set up to be really flexible with parents, responsive.'*

Others saw the need for a for more extensive incorporation of families' voices than just providing communication support. Reflecting on the current limitations of the 'system', one participant argued that true co-production went far further:

'*I wish we* [psychology] were more involved at the beginning…Having these discussions with families at the beginning and, you know, what does it mean to be referred to a LD service, and that's missed. And I think that's where kind of confusion turns to worry, and then problems spike. That's my kind of wish that there we were more 'front door.'

The importance of holistic assessments, with the lived experiences of children and families *embedded* into working practice *within and across* professions was cited by many professionals (n= 15), ranging from a commitment to value-led practice in line with the principles of the British Association of Social Workers (BASW) to a more radical, emancipatory Rights-based approach to *designing, providing, and assessing* provision. To quote from two social work professionals:

'*The principles of co-production let me be a social worker, you know, because I feel being immersed in people's lives is what I should be doing anyway*.'

'*I believe that I work in partnership with families always, and I always believe that the families are well, they're experts in their own situation, aren't they? And I don't disregard what they say.'*

More radical expressions of co-production were seen in a small, but significant number of participants' accounts, with a recognition that co-production required going far beyond simply asking families what they wanted. To quote from one respondent, working in Child Psychology:

'*Sometimes families are not even in a place to even know what they want. They're so overwhelmed and so, you know, so fed up with it all. And so, like at the end of their tether. And what they want? What they want is it not to be like this, like you know, it's too hard a question.'*

That co-production requires the recognition that needs can't be neatly 'fed back' from parents, but instead require professionals to work with families, over time, to think through and reflect on, was a clear message from a sizable minority of participants. For instance, these participants championed the role of the parent-carer as providing a meaningful channel through which the voices of parents, carers and children could be heard, in an environment that was removed from the power-hierarchy of the clinical expert/patient relationship. To quote from one participant reflecting on parents and carers' reception of information when conveyed by a parent carer, rather than a professional:

'*And then she'll* [parent carer] *give this lovely story about something, or she'll say, 'well, when I learnt about that, this is where I started to feel...' and you can see the parents just looking up going, 'oh yeah, yeah, yeah…WE GET IT! Oh my God, Oh my God!'. It's not about information. Information is important but it's how it's got across, how it's understood, how it, you know, makes sense to people and as a professional I am literally just talking from the book.'* (Health professional)

In addition to an understanding of co-production as going far beyond collecting feedback, but as something embedded in how parents and carers are valued as experts in their own experiences, was a significant theme from the research, threading across health and social care sectors. While the more radical expressions of coproduction often (but not exclusively) came from professionals working within the third sector, where examples of less conventional approaches to working with children and families were found, there was also caution expressed by those working within local authorities and health boards that the notion of 'co-production' might become 'siloed' into something the 'third sector do', unless it was embedded within and across all sectors. That co-production needs embedding into the *funding and commissioning of all services* and not just reserved to show case '*fluffy stuff provided by the third sector for 'high functioning kids'* was a sentiment expressed passionately by a significant minority of participants (n=5). To quote one social worker:

'There needs to be thought about some kind of funding model that actually brings together what services NEED to be commissioned, and what families WANT to be commissioned, and then it gets co-produced in the middle.'

As illustrated from the preceding discussion, the theme of co-production was the most complex topic to discuss with participants, with levels of engagement and familiarity with its principles shaping their ideas about both the barriers to its implementation, and, more significantly, *what co-production actually means.*

In the section below, the emerging themes that have been considered in this section are brought together and synthesised, in order to provide a commentary

on what the research conducted has found in its consideration of the barriers and enablers to effective practice with children, young people and their families.

3.2 Discussion: Synthesis and development narrative

When presenting the key issues that emerged from the interviews with professionals, it became apparent that each identified theme was interrelated and co-dependent on the occurrence of each of the other themes identified. Synthesising, or 'bringing together' the key themes that have emerged from this research helps to provide a coherency to professionals' stories that can sometimes get 'lost' when presenting the findings of qualitative research. In so doing, a distinctive narrative emerged, with what some saw as 'service-led care' for children and families resulting in the 'fragmentation of needs' in order to 'fit' into the current models of care that many services provide. Reflecting their own distinctive organisational approaches, many services were identified by participants as 'compartmentalising' need into 'health/, 'education' and 'social care' strands. Compartmentalisation then becomes *reinforced* through the application of *differing criteria for assessing needs*, which in turn *provides a rationale* for funding models that work to 'divide out', assess and respond to the needs identified.

Reflecting on the degree to which this process creates barriers to effectively meeting the needs of children and young people, participants recognised how current practice either needed better funding, communication between sectors, and more resources, *or*, more radically, a 're-imagining' of what a truly integrative service might look like. Co-production, understood variably by participants, often (but not always) relating to professionals' current levels of engagement with co-produced and delivered services, was seen as one way in which the process outlined above could be interrupted, and new ways of working forged.

Children with profound and multiple learning disabilities were recognised by all participants (n=20) as appearing to bear the brunt of almost universally recognised barriers to effective care: a lack of available resources, be these time, money, staffing, or facilities. In these cases, children with the most complex needs are having to 'fit' into services that match neither their, or their families' preferences, or most poignantly, their intellectual abilities. Again, a solution for some participants was seen through an authentic form co-production, where services *and* funding models should follow need with the acknowledgement that parents and their children often have more expertise than the professionals.

All participants recognised the barriers that exist to effective practice – with all acknowledging that ineffective practice should be measured by the extent to which children and families themselves feel that their needs are being met. Closing a case in a timely manner, after issues are raised, a referral made, and a target reached was not considered by many participants who were interviewed

as reflective of a child's needs necessarily being met. Indeed, the ways in which needs were labelled differently by different sectors, sometimes not resonating at all with how *parents themselves* understood their own child's needs, meant that it was incredibly difficult for families to feel that their child was being understood holistically. With different waiting lists meaning that care is provided to different timescales, professionals are aware of the stress and anxiety felt by families who may feel a full understanding and assessment of their child's needs is 'on hold'. Additionally, a key concern by those working with young people transitioning into adult care, was how in many cases a 'reassessment' process would have to take place (for example from paediatric care to adult continuing care) with the criteria required for reaching the threshold to receive such care frequently met with anxiety by both professionals and families.

More hopefully, the experiences recounted by participants contained not just a vision of *how* services should look, but in some cases provided very real examples where teams were managing, and often excelling, in their promotion of rights-based care for children and families. This might be where professionals that had formally worked with differing models of care and understanding from other teams about what a 'learning disability' implied for the child and family, had started to really communicate with one another, acknowledging that each might have something new to say about a family that was being worked with. There were also some very inspiring stories of how professionals had started to 'step away' from their taken for granted assumptions about expert knowledge and had really started to listen to children and families, without starting from a place where they (the professional) had to 'find out what was wrong with the child'. In these cases, it was recognised by participants that there needed to be an equal valuing of power between families and professionals, with a recognition that good care starts from a 'politics of recognition.' (Lister, 2008)

Developing the narrative

Implementing a model of integrative care that reflects the policy frame of the Welsh government, and its commitment to seamless services, person-centred practice, and a commitment to genuine coproduction was recognised by all participants in the project to be challenging. Implementing a strategy for children and young people across Wales that is shared by all sectors, funded equitably and jointly, and empowers children and young people, was considered a worthy, yet immense task. The learning disability strategic action plan (2022-2026) aims to create an engaged workforce who have a stake in the vision that informs practice, and it is clear to see from this research at least, that this aim resonates with the commitment of the professionals in the sample. A key finding from this research however was that alongside a general consensus that children and young people should be at the centre of this vision, different *sectors can interpret what this vision means and looks like in practice in different ways.* For some, the solution lies in better facilities, more staff, a bigger budget, and improved communication with other sectors who must become more receptive to different ways of understanding need and what collaborative solutions might look like. For others – a significant minority – the answers were more radical, with a need for staff to think 'outside' the current system and culture where

families are 'referred on' to experts who then manage need according to their own criteria[9].

One way in which the author tried to 'broaden out' the discussion with participants away from tangible barriers/enablers such as resources and partnership working, was by asking about what professionals would wish for if they had a magic wand and could conjure up their dream service. In providing a shift away from 'real life' restraints, this exercise allowed scope to imagine a world where services matched the vision. Nonetheless, there was some variation in those who wished for concrete changes such as more respite facilities, shorter waiting lists, and more staff, and those whose wish list extended far beyond 'system repair'. For these professionals the ultimate dream was the realisation of 'capable environments', with enablement through the mainstreaming of a social model of disability considered key to the acceptance of difference for people with learning disabilities and the embedding of a rights-based approach to care and support services. Acknowledging that we as a society are far from this radical model of care, there was nonetheless a discussion of the possibility of services that mirrored some existing approaches currently implemented by third sector organisation across Wales. The model of E-PAtS (Early Positive Approaches to Support) and its incorporation of parent-carers working in partnership with professionals was seen both by those working with this approach, and those just familiar with it, as reflecting the importance of *understanding* and not labelling, of working with families to find solutions (if needed) based around what might be best for the family *at one point in time*, as opposed to rushing into services in order to get a diagnosis and care plan. Acknowledging the differences in how third sector organisations work, there was also some discussions by those working in local authorities and health boards about the need to integrate far more effectively with the third sector to deliver a package of care that best meets the needs of the child. Integrated care, in this model, would need to extend to funding models too, that would also be reactive to the needs and wants of children and families. How this could manage without the 'magic wand' was difficult to see, though one participant did talk about the possibility of a cross-sector co-production forum that could provide a framework within which statutory and third sector providers could work alongside parents, carers and children.

4.1 Final thoughts

It was a privilege to speak to such a range of very different professionals, with different levels of experience and time in the sector, different training, and very different working environments. Some were relatively new to their profession, other well-established, having had various roles in different teams and sectors, with some careers spanning 40 plus years. Despite the identification of many barriers to fulfilling the vision of Welsh policy frameworks identified in the many, lengthy conversations that were had with participants in the project, all without

[9] There are echoes here of the NEST framework for children and families that discusses the need to 'hold on, not refer on'.

any exception, were unified in wanting to make the lives of children and young people with learning disabilities better and more fulfilled. In one sense, it is harder to promote a value base and set of principles in a diverse working population than it is to instil new ways of working, and it was good to see such a positive level of engagement from people who were working under immense pressure, and with such vulnerable populations. Collaborative, co-produced models of care where the needs of the child come first, regardless of how difficult or lengthy it may be to understand a child's situation, were considered 'the dream', but with a recognition that there needs to be a commitment to improved ways of working in local authorities and health boards to facilitate genuine engagement and understanding of what matters to children and families. The importance of continuing to talk with professionals, and for them to feel that they have a voice in shaping the vision of care that they are trying so hard to promote, is considered crucial by the author in fully understanding how any strategies for improvement can best be implemented.

References:

Byrne, D. (2022) 'A worked example of Braun and Clarke's approach to reflexive thematic analysis' *QualQuant* 56, 1391-1412.

Children's Commissioner for Wales (2022) '*No Wrong Door: bringing services together to meet children's needs'*, Children's Commissioner for Wales.

Coffey, A. (2018) *Doing Ethnography*. Sage Qualitative Research Kit. London: Sage Publications.

Denzin, N. (2009) *The Research Act: A Theoretical Introduction to Sociological Methods*. New York: Routledge.

Glasner & Strauss (1967) *Discovery of Grounded Theory: Strategies for Qualitative Research*. London: Aldine Transaction.

Koopmans, E., & Schiller, C. (2022) 'Understanding Causation in Healthcare: An Introduction to Critical Realism', *Qualitative Health Research*, vol. 32, issue 8-9.

Lister, R. (2008) 'Recognition and voice: the challenge for social justice'. In Craig, G. Burchardt, T., & Gordon, D. (eds.) *Social Justice and Public Policy: Seeking fairness in diverse societies.* Bristol: Bristol University Press.

Marlow, C. (2001) *Research Methods for Generalist Social Work* (3rd edition). Belmont, California: Brooks/Cole.

NHS Wales Health Collaborative (2011) *Nest Framework: A Bird's Eye View.*

NICE (2022) *Learning Disabilities;* NICE CKS, April 2022 (UK access only).

North Wales Together (2024) *Learning Disability Transformation Programme Response to the Senedd Disability and Employment Consultation.*

Oakley, A. (2005) *The Ann Oakley Reader: Gender, women and social science*. Bristol: Policy Press.

Ross, K. (2017) 'Making Empowering Choices: How Methodology Matters for Empowering Research Participants', *Forum: Qualitative Social Research*, Volume 18, no.3, Art.12, September 2017.

Tilly, L. (ed.) (2022) *Health & Social Care Research Methods in Context – Applying Research to Practice*. Oxon: Routledge.