**Research Report**

# A Literature Review and Evaluation of National Care Models and Frameworks providing Care for Children and Young People with Learning Disabilities in Wales

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# A Literature Review and Evaluation of National Care Models and Frameworks providing Care for Children and Young People with Learning Disabilities in Wales

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# Extended Abstract

Current Welsh legislative frameworks (Social Service and Wellbeing (Wales) Act 2014 (SSWA, 2014), Wellbeing of Future Generations Act, 2015 (WFG, 2015)), National Clinical Framework, (2021), A Healthier Wales (Welsh Government 2021b)) are supportive of an integrated service model of care delivery, which includes children and young people with a learning disability who have care and support needs. The provision of 'seamless services', informed by the active involvement of children and young people and their families andcarers in the design and delivery of their care, is a stipulation of the SSWA (Wales) 2014. However, research suggests that there is currently not one consistent service model or set of core principles of care in Wales that shape provision for children and young people with a learning disability. Furthermore, reviews highlight the variability of care across and between health boards and local authorities, which can result in inconsistent experiences for children, young people and their families andcarers.

This literature review presents an evidence-based exploration of the service models and principles of care that aim to deliver integrated care to children and young people with a learning disability, and to assess their success. The review adopted a thematic, narrative method, drawing on a wide range of literature including government reports, academic research papers, third sector published reports, and a range of grassroots sources. The aim was to produce an evidence-based review for professionals, that would provide an in-depth understanding of some of the barriers and enablers to positive well-being, utilising a solutions-focused approach.

The key findings from the literature review are:

- There is evidence of positive, creative care pathways implemented by integrative care teams in Wales, in the spirit of the National Clinical Framework and the evidence suggests these could be helpfully built upon and inform a national core offer and standards.

- The literature reviewed suggests that experiences are better where there is collaborative working within and between teams, overseen by a care coordinator.

- Positive, innovative practice is evidenced by care that is planned *with* and not just 'around' children and young people. This suggests a need for a more *consistent* understanding of what co-production means amongst health and social care sectors.

- An agreed data collection system (with clearer alignment across sectors) is essential to inform and evaluate the provision of care pathways to ensure

over-sight of the quality of care provision, and to capture the experiences of children and young people, both positive and negative.

- There is a need for robust mechanisms that actively engage with the voices of children and young people, families and carers, to deliver authentic co-production in the planning of multi-agency strategies across the life course. This finding is of particular significance where the care and support needs of children and young people are complex and profound.

## 1.1 Background and Introduction:

This evaluative literature review has been conducted as a response to growing concerns about the current variability of approaches to the care of children and young people with a learning disability, and their families and carers, in Wales. With the recognition of a lack of consistent models and principles of care in this sector, comes a growing evidence base from the voices of individuals and families/carers that the complexity of presenting need is not being consistently and universally met. While the promotion of models of integrated, seamless services between, and within, health and social care providers is an approach reflecting recent policy shifts in Wales (Social Services Improvement Agency 2022) the alignment of principles of care across sectors *consistently applied*, and reflective of integrative, holistic practice, is rare (Kaehne & Kiernan, J. *et al*, 2018, Care Inspectorate Report, 2021). It is increasingly recognised in the literature that positive well-being outcomes for children, young people and their families andcarers are dependent on the extent to which professionals and organisations work effectively, both together, and with individuals and their families andcarers. This report addresses some of the key barriers and facilitators to these outcomes being met.

## 1.2 Aims of the Review

The aim of conducting this review was to provide a critical, thematic analysis which explores and synthesises a range of literature sources. With a clear need identified from the off-set to explore the barriers to implementing integrative care, informed by the voices of children, young people and their families and carers, the aim was to produce findings that were both knowledge-focused and practice-orientated. Knowledge-focused with respect to producing a critical, robust review of a wide range of peer-reviewed and grassroots literature sources that was both reliable and valid; and practice-oriented in that the findings of the review would aim to help inform future thinking about the direction of care, and crucially, the values and principles that underpin such care. As such, the report presented here aims to present an evaluative, evidence-based literature review focused on current service models and principles of care which are utilised to deliver integrated care to children and young people with a learning disability.

## 1.3 Objectives of the Literature Review:

In order to achieve these aims, the review had the following set objectives:

- To review relevant Welsh policy and legislation pertaining to this group;
- To complete a desk-based analysis of research of peer-reviewed publications and grey literature to outline the evidence base for children and young people's Learning Disability services;
- To identify and *evaluate* the main principles and models of care that emerge in relation to children and young people with a learning disability, with a particular focus on *integrative* models or frameworks of care identified in the research literature;
- To produce a clear summary of outcome-focused findings that address the gaps/barriers to positive outcomes that will fit Wales both regionally and nationally, based on the evaluation of the research reviewed.

## 1.4 Key areas of focus

In keeping with the research problem outlined above, and the brief from *Improvement Cymru,* the thematic review presented in this report has focused on the following broad study themes:

- Principles and models of integrative care, with focus on planning, structure, resourcing and delivery;
- The design and implementation of service models, with reference to the skill mix of integrated teams;
- The complexity of need as presenting from the voices of children, young people, and their families/carers;
- Co-production, Advocacy and Rights;
- Data collection, national standards, and the challenge of outcome measurement.

These initial areas of focus emerged from a 'first read' of the literature scoped and have provided a targeted way of directing the more in-depth search strategies employed when conducting the review. Interestingly, what started off as discrete broad themes from the initial literature search, were soon revealed to be co-dependent, interrelated areas of focus, with issues raised in one area reflecting similar concerns in another. For example, concerns in the literature about the quality of collaborative working across health and social care sectors, 'feeds into' the frustration felt by some self-advocacy groups that being consulted about objectives can be tokenistic, when the services they are in receipt of are not always 'joined up' in their provision (Learning Disability Wales, 2022).

## 1.5 Policy context:

While a range of Welsh government reports and reviews do themselves form part of the literature assessed in this report, it is useful to provide an initial brief overview of current government policy frames in the field of health and social care that provide legal stipulations for levels of care provision in Wales. In so doing, the principles they promote provide a benchmark against which to later evaluate the evidence presented from the literature reviewed. In addition, it is useful to see the genesis of many of the core principles and models of care that shape current provision, and to appreciate the statutory duties that shape the direction of practice when presenting recommendations from a synthesis of the literature reviewed.

***Social Services and Wellbeing (Wales) Act, 2014 (SSWA (Wales) 2014)***
The key driver of this Act is to facilitate the improvement of well-being outcomes, for all. A variety of reports are considered in this review that detail how the core principles and models of care promoted by the Act are to be implemented and delivered. The promotion of an integrated model of care between health and social care providers is one of the key guiding principles of the 2014 Act. In the context of this literature review topic, Regional Partnership Boards (RPBs) have the responsibility to coordinate and mobilise local authorities, health boards, and third sector providers in the implementation of integrated models of care provision for children, young people and their families, informed by person-centred assessments of need. As such, the promotion of person-centred care plans, designed and implemented around prevention and early intervention, and incorporating sustainable levels of service delivery, frame many of the government reports that form part of the sources assessed in this review. The development and promotion of streamlined, effective services, underpinned by *co-production* - the active involvement of children, young people, and their carers, in the design, development, and review of this care, is a *key conceptual frame* that underpins the development of Welsh national care models that much of the reviewed literature in this review evaluates.

***Well-being of Future Generations (Wales) Act (2015) (WFGA, 2015); National Clinical Framework (2021); Social Services Improvement Agency.***
The vision of developing a holistic, whole systems-approach to design health and social care pathways for children and young people reflects the recognition in Welsh government of its objective of achieving ‘seamless services’. Reflecting the wider principles of the WFGA (2015) this vision incorporates, in line with the SSWA (Wales) Act 2014, the need for collaborative planning across a range of public bodies, to deliver integrative, sustainable strategies that aim to improve the well-being of future generations. In relation to the topic of this review, the policy frame incorporates a vision of well-being as an inclusive concept that places a statutory duty on local authorities to ensure that the needs of children and young people with a learning disability, and their carers, are communicated effectively. Accompanying the drive to ensure integrative provision across and between health and social care sectors, the National Clinical Framework (Welsh Government, 2021) aims to coordinate public sector organisations in the planning of clinical service delivery. In terms of assessing the success of current strategies in achieving well-being

outcomes, the importance of measuring and reviewing the care and support provided is key to the achievement of this national model of care. In addition, the Social Services Improvement Agency has as one of its key objectives the need to explore how best to facilitate the development of collaborative approaches to service development and transformation, that is both sustainable and person-centred. While the principles of integrative, collaborative care can be considered as to some extent as the 'mainstream' now in the planning and delivery of health and social care across Wales, this vision does build on and complement the wider principles that underpin the 1999 All Wales Strategy for Learning Disabilities.

The extent to which these overarching principles and models of care are understood and incorporated in care planning by professionals, and realised through the experiences of children, young people and their families/carers, is the key question that has driven this literature review. In this sense, the review's recommendations reflect not only the body of evidence presented in the literature, but also the degree to which key Welsh Government priorities in the field of learning disabilities are being met.

# 2.1 Methodology

A comprehensive, thematic review of a varied range of literature was conducted, including peer-reviewed academic papers, government and third sector reports, and grass-root accounts from across the learning disabilities community. The search of literature was conducted across each of the identified focus areas for study (1.4) The key methodology adopted in this review was a thematic approach (Labra & Castro *et al*, 2019) that has at its core an approach to the literature that is *outcome focused* and directed towards the synthesis of emerging themes and findings that provide a solution-focused approach. With the author's background as a sociologist, the rationale of approaching literature sources with the aim of 'doing good', and of potential benefit to the lives of vulnerable groups, created an approach to the literature task that has been described as emancipatory (Dominelli, 2002). The importance of including sources that have as their focus the voices of individuals in the field of learning disabilities was also seen as an essential component of a review of research literature that is evaluative in tone. For example, a thematic analysis is focused on reaching *an evaluation* of a current issue (for example, multi-agency working) in relation to the broader research problem identified, seeking to provide the most valid data possible.

### Conceptual Framework

In terms of the conceptual framework for the review, the approach taken adopts a critical realist position. Consistent with this position, the knowledge that we can have of social processes and experiences will necessarily be subjective and constructed by individuals (Tikly, 2015). However, the knowledge that individuals construct is

generated by social structures that, to a certain degree, shape the space in which we come to understand the world. Relating this conceptual framework to the review conducted, there develops a strong rationale for the promotion of a method that sees literature sources, of whatever origins (for example, government reports, grassroots narratives) as both interpretations of individuals' experiences, reflective in part of their social locations (e.g. mother of a child with a learning disability) but also *as a response* to social structures that enable and constrain the meanings that we give to our lives. For example, the parent/carer narratives that consider their experiences of interacting with a healthcare professional will be shaped by the wider social structures (for example the policy frame that defines the services that are available across the statutory and voluntary sector, the skill set and value-base of the professional) as well as the experiences and values that the parents themselves bring to the interaction.

Utilising this approach has allowed the researcher to examine the existing literature with a critical, analytical lens, synthesising a variety of voices and perspectives across the literature reviewed to reflect some of the barriers and enablers to well-being. As such, the approach taken works to…

- Ensure that the findings from the review are presented critically, and not simply described. In other words, to present the emerging themes as a means of focusing attention on possible *strategies that can be developed* to best improve the health and well-being of children and young people with a learning disability, and the adults involved in their care.

- Identify in the literature current gaps/barriers in service provision including the design and implementation of services, and the outcomes of current practice. Additionally, to identify evidence from the literature of good practice and positive outcomes ('facilitators' or 'enablers') with the rationale of producing developmental narratives that build on existing good practice to improve the wellbeing of children and young people with a learning disability, and their families/carers.

## 2.2 Method

Utilising a qualitative, thematic method, the review has followed the broad principles of the SALSA Method (Grant & Booth, 2009) which incorporates the processes of broad literature Search, Appraisal of evidence, Synthesis of qualitative themes, and Analysis of emerging findings. In the context of this report and the objectives of the commissioned task, this review also includes a number of practice-oriented observations that correlate to an Analysis of Synthesised Findings. Focusing in this method on the *quality* of experiences of those involved in the learning disability communities, including professionals, it is the synthesis of emerging themes that allowed identified findings and think points to emerge. Using the techniques of

interpretive, qualitative meta-synthesis (Tickly, 2015), there was scope to develop a narrative that was both comprehensive in range and also rich in detail and depth.

*Advantages of this method:*

- High in validity; able to clarify and make sense of complex issues and processes that other types of reviews (e.g. chronological, systematic) can only describe.
- Evaluative in focus, with a strong rationale to provide an *assessment* of current practice.
- A good 'fit' with the wider ontological 'social justice' agenda of social care and the Welsh Government agenda, providing a good response to the need to address what the scoping review has identified as a need for developmental narratives to further inform future care provision.

*Disadvantages of this method:*

- As a qualitative method, there is the danger that the process of identifying and interpreting 'themes' may be overly subjective and contain an element of bias (Labra & Castro, *et al.,* 2019) . This was managed through the use of the constant comparative method (Glasner & Strauss, 1967) to ensure that the themes identified are as evidence-based and robust as this method allows.

- The thematic approach to a review of literature is not able to produce generalisable results of the same order as quantitative methods (for example, the traditional systematic literature review). However, it does, arguably, conform to the principles of generalisation, '*using data to infer conclusions without extrapolating universal principles*' (Labra & Castro *et al*, 2019:2).

## 2.3 Search Strategy

The author's initial search focused on academic journals, research databases, and sources of grey literature that were available to them through their institutional links. These included the following data bases, in addition to a more generalised 'rapid' Google search:

- Resource Finder (Wrexham Glyndwr University)
- Community Care Inform
- Social Care Online

- Sage Journals
- Oxford Journals
- Medline
- JSTOR

The search criteria employs a purposive sampling method and included the following sources:

1. Peer-reviewed research papers that consider the service models and principles of integrated care.
2. Peer-reviewed research and grey literature (including grassroots accounts) that are *outcome focused* in relation to children and young people with a learning disability, with an emphasis on the voices and narratives of children, young people, and their carers.
3. Government reports that provide a 'trigger' to, and/or response to, relevant Wales and UK social policies in this area.
4. Peer-reviewed research and grey literature that directly addresses the structure and organisation of integrated teams, including the skills mix and current levels of care implementation.

### Inclusion/Exclusion Criteria:

In keeping with the methodology employed, the key criteria was to be topic-focused, with learning disabilities amongst children and young people the key driver in the identification of potentially relevant sources. This included too the voices of parents and/or carers for this group, as long as children/young people with a learning disability were part of the study sample/research population being investigated or discussed in some way.

Care was taken to be sensitive to wider debates around definitions of what, precisely, a 'learning disability' constitutes. While the author is aware that there is some overlap and cross-over in the UK, with the related terms 'learning differences' and 'additional learning needs', the intention in this review was to avoid conflating 'learning disabilities' as a 'catch all' that incorporates 'differences' and 'additional needs'. In other words, while the author is very aware that many children who have, for example, autism also have a recognised learning disability (so an 'association' is

recognised) for the purposes of this review a distinction between these categories was retained, in keeping with NHS Wales definitions[1].

To quote from Cardiff and Vale University Health Board: *'Often the terms learning difficulties and learning disabilities are used interchangeably – but it important to distinguish between them.*

- *A person with a learning disability will be intellectually delayed in every aspect of their life, this will have been present since childhood and is a lifelong condition*
- *Whereas a person with a learning difficulty will have difficulty in learning that is more specific for example – dyslexia, dyscalculia, dyspraxia'.*

(Cardiff & Vale University Health Board, Learning Disability Liaison Service).

In a similar vein, in exploring papers published outside of the UK, care was taken to be mindful of the cultural context of the term 'learning disability' in published and grey literature searched, where the term was sometimes used interchangeably with 'learning differences' or learning difficulties'.
In order for peer review papers to be included in the review they were additionally required to meet the following criteria:

- Research question(s) provided.
- Method/methodology articulated.
- Published/available after and including 2015.
- Published in English.

In keeping with the rationale for the methodological approach taken, grey literature that is unpublished and frequently included the voices and narratives of children, young people, and their families/carers, formed a key part of this review. Formal search strategies that involved following on-line links from government reports and reference lists to third sector web pages was used, in addition to more informal information retrieval from colleagues who work in the field of learning disabilities (third sector and statutory) who were able to signpost to some smaller initiatives and organisations whose on-line presence was less well-known to the author. In order to facilitate as wide a range of authentic voices as possible to inform this review, non-traditional sources such as blogs and films, produced by members of the learning disability community, were also accessed. As noted above, while the selected research methodology is not a scientific, systematic approach, and as such lacks generalisability, the method selected is high in validity and meaning, characteristics considered by the author as essential when trying to *explain and account* for the current gaps in provision.

[1] It was noted however that in Education children with a learning disability are included in the additional learning needs wider definition (Welsh Government, 2018b).

Key ideas emerged from an initial reading of sources, which were then placed into loosely related groupings, before a re-reading of source materials was made to consolidate the identification of key themes (Glasner & Strauss, 1967).


Identified themes were given sub-headings under which the relevant literature was discussed. Even at the stage of the review where the emerging key themes or 'insights' about the literature emerge, it is possible to see some initial 'overlapping' between the different thematic clusters that are identified. Meta-synthesis, where literature themes are reviewed and the findings of the review integrated, takes place throughout, but is summarised and re-focused in section 4.1. After re-stating the key findings of the review, a summative, developmenal narrative is presented, reflecting the end stage of a holistic, evaluative approach that it is hoped can constructively inform practice and policy.

In the next section, the key themes arising from the review are presented.

## Thematic Findings: synthesising the literature

Through exploring in increasing depth and detail a range of peer-reviewed literature, government reports, and grassroots third sector narratives, **initial key themes** were identified through applying a conceptual framework that seeks to *evaluate* and *make sense of* the current 'state of play' for children and young people with a learning disability, and the adults in their lives. The synthesis of these themes into findings, with summary discussion is provided in section 4.1, after the identified key themes are presented below. Four key thematic 'lenses' through which to understand current practice are identified. These are discussed under the following headings: ***'Inconsistency in the design and delivery of integrative models and principles of care'; 'Variable skills and knowledge within and between health and social care teams'; 'A need to further develop consistently delivered, meaningful, person-centred co-production that reflects the complexity of need'*** and ***'A need for a clearer, more reliable data collection process to inform and continually evaluate the provision of care pathways'.*** While the literature reviewed does imply that there are some challenges to be addressed in current provision, care was also taken to highlight good and innovative practice across the sector from which robust models of care and good practice can be 'scaled up'.

## 3.1 Inconsistency in the design and delivery of integrative models and principles of care.

There is clear evidence from the literature reviewed of a *commitment* from government to the promotion of integrated models of care that meet the care and support needs of the target population, seen through, for example, the development of Regional Partnership Boards across Wales for the delivery of streamlined, effective and 'prudent' care (Welsh Government 2021). Reflecting the core principles of the SSWA, literature from a range of sources, including peer-reviewed reports and journal articles, in addition to grassroots sources, reflects a consistent belief in the principles of prevention and early intervention, and integration of service provision through partnership and multi-agency working, informed by a rights-based model of community care (Care Inspectorate Wales, 2021, National Clinical Framework, 2021, North Wales Together, 2019). Many of these principles of care are reflected in the implementation of Transformation Programmes that reflect a shared commitment to a locality-based improvement of health and well-being for children and young people with a learning disability, and their families and carers (North Wales Together, 2022). However, in terms of outcomes and the implementation of this commitment, the literature suggests that there exists a 'policy-implementation gap' (Hudson, 2019), with fragmented service provision from partners across health and social care resulting in an inconsistent implementation of person-centred, holistic care (Moss & Miller, 2019). It is further suggested that the current 'blend' of care provided for children and young people with a learning disability reflects differing understandings and knowledge bases about what 'needs' are, and how such needs can be met (North Wales Social Care and Well-being Improvement Collaborative, 2018). As such, the literature suggests some inconsistency between (and within) health and social care sectors, reflected, for example, in discussions when staff are questioned about what 'integrative care', 'collaboration', and 'co-production' mean (Lewis, 2015; Kaehne & Kiernan, J. *et al.* 2018; Kozlowka & Leonard *et al,* 2018). This can lead to what has been seen by researchers who have reviewed the *design and delivery* of current provision, to imply an 'adversarial' approach in some teams, seen particularly at key points in children's lives when health, social care, and education needs overlap significantly – for example during the transition from pre-school to school, and from school to employment/adult services) (Kaehne, 2018; Children's Commissioner for Wales, 2022).

While the Welsh Government acknowledge the challenges of implementing a fully integrated service model (Welsh Government, 2018) , the literature reviewed to date points to variable outcomes for some Local Authorities in ensuring that good quality, co-designed pathways of care are *made available* to those in need of care and support in the learning disability community (SSWA (Wales) 2014, section 17). This is echoed too in grass-roots narratives where young people, families and carers comment on the lack of fully integrated, long-term, co-produced projects based on the needs and assets of the local community, resulting in the frustration of working with a model of care that can resemble a 'battlefield' (*North Wales Together* website). The need for greater meaningful engagement with children, young people, and their families andcarers about the nature of need, suggests challenges in some current care models to understand what might be required to facilitate authentic

participation in the *design and planning of care*, particularly for those with complex needs (North Wales Social Care and Well-being Improvement Collaborative, 2018; Welsh Government, 2018(b), Care Inspectorate Wales, 2021).

In critiquing current models of provision that promote the need to ensure that the rights of children and young people with a learning disability are 'actualised', the literature suggests that services such as *independent* advocacy (a legal duty under part 10 of the Code of Practice, SSWA (Wales) 2014) are offered inconsistently, that can result in disempowered and disengaged individuals (Mencap Cymru, 2017; Windell, 2019; All Wales People First, 2023).

In reviewing literature that has explored some good practice in the development of integrated models and principles of care, some key insights have emerged from reviews of the learning disability transformation programmes that reflect the work of Llearning disability participation groups responsible to Regional Development Boards in Wales. The importance of shared systems and a multi-disciplinary team approach that is coordinated by a named care coordinator, emerges as a key finding from research that has evaluated Transformation programmes for learning disabilities across Wales (Institute of Public Care, 2015, 2018) with third sector contributions that focus on integrated support, involving shared budgets and commitments to pooled funding across health and social care, particularly valued (ibid.). Consistency in applying strengths-based approaches to care, across different providers however, is also noted as lacking, and is considered a priority if the needs of individuals are to be met (North Wales Together, 2019).

### *3.2 Variable skills and knowledge within and across teams in health and social care.*

Drawing down further the focus on models and principles of integrated care outlined above, the literature reviewed explores some of the explanations *for* the current *implementation gap* between what is a widely supported model of integrative care at the level of policy and decision making, and what is reflected in the *outcomes and experiences* of children and young people with a learning disability and their families andcarers. While a strengths-based, person-centred skill set is recognised as important across the sector in Wales, consistent value-based practice is noted from the sources explored, to be mixed.

The literature reviewed suggests that there are various 'pinch points' in the life course of young people (e.g. post-school transitions) where the 'clash' between the principles and service models across health and social care are most obviously seen and experienced (Welsh Government, 2018 (b)). The impact of fragmented, sometimes contradictory values/models of care can at times result in confusing and inconsistent care planning for young people, that can continue into adulthood (Care Inspectorate Report, 2021). Poor communication and different understandings of what the 'problem' or issue is, can also result in delays and responses that don't

meet the expectations of children, young people, and families (North Wales Learning Disability Strategy, 2019). The literature reviewed suggests that one source (amongst several) for the inconsistency in delivery and outcomes of provision across health and social care relates to the *lack of co-ordination* between staff and departments, and the 'knowledge gap' between medical and social models of care, with different interpretations of what, for example, 'reasonable adjustments' mean (Children's Commissioner for Wales, 2018).

Staff can present as suspicious of requests for information from other sectors, and when information is received 'cross sector' it is rarely integrated into a holistic, 'whole systems'/'No Wrong Door' approach that families can easily navigate (Kaehne & Kiernan, 2018). Interestingly, research explored from grassroots sources (Learning Disability Wales, 2022) also reflects conflicting understandings from service providers about what integrated models of care should 'look like', and also what 'support' and 'advocacy' should entail *within* social care (for example, between Local Authority and Third Sector agencies).

A lack of consistency for young people across Wales in the types of care models provided – for example between medical and social models- is also noted, resulting in very mixed experiences for children, young people and their families in accessing support (All Wales Forum.org.uk). More positively, there is evidence of increased collaboration and information sharing between agencies in some of the regions in Wales (for example, in North Wales and Gwent) with new roles being created to support the ongoing provision of a collaborative partnership between health and social care; for example, the appointment of Additional Learning Needs coordinators in education settings and in health (North Wales Social Care and Well-being Improvement Collaborative, 2018), reflecting more widely the importance attached in reviews of provision to the need for 'oversight' of joint working arrangements[2].

Looking at how health and social care teams work in conjunction with children and young people with a learning disability and the adults in their lives, the evidence suggests that staff engage inconsistently with this group in the *design and planning of care and support services*. Evidence from the literature reflects different understandings from different staff members/sectors about their roles as professionals, and the scope of their role and function when working with children, young people, and families (Children's Commissioner for Wales, 2018). In ensuring that some of the hidden needs of children and young people are met, the need for teams to promote advocacy support to ensure that the complexity of needs is communicated and 'acted on' emerges from the literature (Windell, 2019; Mencap Cymru, 2017; All Wales People First, 2023). While 'seamless service provision' is presented in much of the government policy documentation as the vision to aspire to

[2] Conwy Country Borough Council – All Age Disability Service is represented in the literature reviewed as a positive example of a member-led integrated disability service, heavily focused on preventative work with children and young people, who stay with the Child and Young people team until the age of 25. The Integrated Service for Children with Additional Needs (ISCAN) referral service in Gwent is another example of positive, integrative practice.

across health and social care, some of the narratives in the third sector and grassroots literature accessed convey the need for a stronger focus on active, rights-based citizenship as a means through which care that is truly integrative can be implemented (Moss & Miller, 2019). As part of this process for change, the need for 'integration' to be understood at the level of planning and evaluation, and not just delivery, emerges from the literature (Institute of Public Care, 2018) in addition to the need for collaborative governance arrangements to provide an 'overview' of effective practice within and across health and social care teams[3]. Shared culture and mutual understanding of need, in all its complexities, is seen in the literature reviewed to be a key facilitator to good practice and positive outcomes (Andrews & Calder, 2023), with its absence a source of frustration for both professionals and individuals alike.

As a participant on the *North Wales Together* website puts it, reflecting on the uncoordinated nature of services received:
'*A lot of carers and myself included would like the battle to be took out of it immediately. Because it becomes a battlefield that's stressful for everyone involved, and stress then makes situations even worse and perpetuates a lot of things going wrong'* (northwalestogether.org)

### *3.3 A need to further develop models of consistently delivered, meaningful co-production that reflect the complexity of need.*

Meaningful, person-centred co-production as a key variable in the design and delivery of services for children and young people with a learning disability is a core principle of the Social Services and Wellbeing (Wales) Act, 2014, and as detailed in section 1.4 of this review, threads through all of the legislation that frames current models and principles of care in this sector. The lack of consistently meaningful engagement with children, young people, and their families and carers in the learning disability community is one of the key findings of this review. Indeed, the lack of *authentic engagement* with a model of co-production that involves the target community from the inception of care design and planning, through to continual review, is highlighted by many in the research community (Mencap Cymru, 2017; Windell, 2019, Children's Commissioner for Wales, 2018; Ellem, Checnoweth & Edwards, 2019; Ruebain & Peart, 2016, 'New Horizons', North Wales Together, 2019, Andrews & Calder, 2023)). The literature paints a picture of a population that lacks active involvement in the design and development of their care, as well as having inconsistent access to the correct information (Mencap Cymru, 2019). The 2018 Welsh Government Programme *Improving Lives* includes narrative accounts from families where experiences are defined as 'battles' and 'struggles', with inflexible care systems and delays in service provision resulting in young people and families who feel stressed and unsupported. Several pieces of research argue that there is a need for more accessible, consistently implemented *formal mechanisms* through which the views, experiences, and desires of children and young people with

a learning disability and their families and carers can be recorded, not as a single action, but as ongoing and embedded in long term strategies for better service provision (Lewis, 2022, NWT, Children's Commissioner, 2022). To present some of the voices from the North Wales Together Bulletin (2019) the need for more *accessible mechanisms* through which to communicate with professionals is a recurring theme. In addition, observations were made by young people and their families that there are differences in the value base and approaches to co-production from different care providers in health and social care respectively, with varying approaches also noted across different geographical regions in Wales. Issues around communication for children and young people with profound needs that may be challenging for current models of co-production and collaboration also emerged from a range of literature sources as the 'elephant in the room' when engaging in discussions around needs and person-centred care, for both young people and for children and carers.

To quote from one parent:
'*Me and you, maybe we can claim to have communication skills, I can speak, you can speak, we've got ears, we can listen, we got the kit. We're the ones that should take that step towards her. She's the one that's so-called got communication problems and difficulties, but actually, that's us*' (North Wales Together website).

The identified complexity of need and the lack of a consistently unified understanding by different professionals of what is required to fully engage with what children and young people feel, is also an emerging theme in the literature, with what on occasion feels like 'consultation' with young people reflecting a planning process that is designed 'around' the young person, and not 'with' the young person. Regional Partnership Boards, for instance, are seen in both government publications and grassroots narratives as bearing some responsibility for the lack of robust pathways through which effective care plans can be mobilised (Children's Commissioner for Wales, 2022; McElwee, J. McManus, M, & Ball, E. (2022), Andrews & Calder (2023)). The broader cultural context in which children's needs are understood also emerges as a consistent focus in the literature, with the *context of care* misunderstood by some professionals. For example, in considering the challenges for families in person-centred planning, Ellem, Chenoweth & Edwards (2019:397) point to the *'apathy and discrimination to disability from extended family, wider community, and **service providers'*** [emphasis mine] that needs to be navigated if models of co-production can be anything more than tokenistic. The complexity of need, and the ways in which needs evolve throughout the life course, also presents in the literature as a further barrier to effective service provision, resulting in on-going challenges for care providers in actualising the rights of this group (All Wales People First, 2023). Recognising that children and young people have needs that are related to, *though not always reducible to*, their learning disability – for example the prevalence of poor mental health in children with a learning disability - presents challenges both for the process of effective co-production and for the provision of co-produced, well-resourced services that can meet these complex needs (Windell, 2019). What seems to combine these accounts together is the recognition within the literature reviewed that the principles of co-production should be seen as embedded into day-to-day routine practice, and not just promoted in 'showcase' events (ADSS Cymru, 2019, Andrews & Calder, (2023)). The need for a 'cultural' shift where co-

production isn't equated with consultation or the 'gathering of views from service users', still noted to occur in some government reports (Learning Disability Wales, 2019) underpins many of the grassroots narratives evaluated in this review, with a need to re-establish rights-based frameworks of care that go beyond the current focus on service provision. In a similar vein, there is a recognition across the literature reviewed that the rights of children and young people with a learning disability to communicate their preferences, and for any barriers to communication to be addressed, is a statutory duty under the SSWA (Wales) 2014 codes of practice, incorporating Local Authority Learning Disability implementation plans (4.1) (Mencap, 2017, Windell, 2019). Advocacy, and the right for the provision of formal advocacy services, is also recognisedin the literature reviewed as a means of facilitating meaningful co-production, and fully engaging children, young people and families, in contrast to being mere 'recipients' of services (Moss *et al*, 2018; Mencap Cymru, 2017). Again, while it is noted in the literature that legislation is in place to ensure that the voices of children and young people with profound and multiple learning disabilities are heard, if need be through the services of professional advocacy, research suggests that this group in particular are at high risk of having little, or no, voice, choice or control over the decisions made on their behalf (Welsh Government, 2018).

On a more positive note, there are some exceptional examples of authentic co-production that are documented in the literature reviewed, found frequently in the third sector, and located across Wales. New collaborations that are formed and developed through lengthy conversations and continual engagement with children and young people have resulted in programmes and initiatives whose impact has been positively evaluated by children and parents, highlighted in the bulletins and multi-media publications in several third sector organisations (North Wales Together, 2021, All Wales Forum, 2022). Some examples of what is possible when creative, co-production is implemented, are listed in the box below:

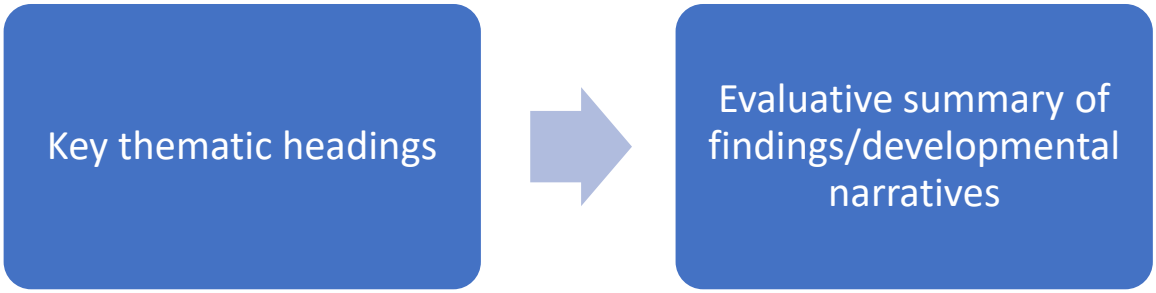
- Conwy Connect Makaton choir
- Gig Buddies (cross-Wales)
- E-PAtS Parent Support programme )(co-produced) Ynys Mon.
- Conwy Connect Forum: self-advocacy group that 'feeds forward' to All Wales People First and the National Council.
- West Glamorgan Regional Partnership Coproduction toolkit.

### *3.4 A need for a clearer, more reliable data collection process to inform and evaluate the provision of care pathways.*

Integrated health and care needs are required to be regularly assessed, and plans to meet those needs put in place, through Regional Population Needs Assessments, conducted by Regional Partnership Boards (Part 2, COP, SSWA (Wales) (2014)). However, while the principles of integrated, person-centred care have helped to shape the processes in place to 'capture' the complexity of population needs for children and young people with a learning disability, the literature reviewed suggests that there are some barriers to consistent and reliable collection of data and information about this sector (Welsh Government, 2018(b)). Having the information/data required to be able to plan services both accurately and appropriately, and therefore meet the needs of children and young people with a learning disability, is key to the planning of services that work to address need, but research suggests that this is a process that is currently confusing and lacking direction (Kaehne, 2018). A lack of oversight of the scope and scale of the challenges facing children and young people with a learning disability, with no national standards existing for this group, is a clear theme in the literature, stemming in part from confusion around the defining of what a learning disability *is* across social care, education, and health. For example, in education children and young people who have a learning disability are included in the data collection process with those children who have additional learning needs (Welsh Government, 2018b). Data and information on outcomes and destinations of young people with a learning disability is also poor, contributing to assessments of care that are partial and lacking insight into the 'bigger picture' (Kaehne & Kiernan, 2018). Additional barriers to effective and meaningful data collection and utilisation in an *integrative health and social care service model,* relate to the dominance of 'performance measures' and 'key performance indicators' that relate solely to one or the other sector (Lewis, 2015). Furthermore, there is a recognition in the literature that the lack of participation of children and families in providing knowledge and insight into what their needs *are,* and the suitability of the services that they may need, contributes to data collection and knowledge production that may lack validity and relevance when Population Needs Assessments are carried out. This was seen, for instance, in Learning Disability Wales' response to the current Wales Learning Disability Action Plan that noted the need for a new relationship between care providers and those in receipt of care, where '*different forms of knowledge and expertise are recognised and contribute to co-designing an understanding of the problem and then possible ways forward'* (2022:4). While documentation such as the Learning Disability Strategic Action Plan (2022) outlines the importance of an integrative approach and is outcome-focused, there is currently *no formal process in place to measure the impact of strategies that has time-bound targets*; clear objectives, it is argued, need to be set in order for meaningful data to be produced (Ware, 2019, Care Inspectorate for Wales, 2022). Time-specific target setting, clarity about what is being measured, and how each data collection exercise links together in informing future holistic care emerge as key insights from organisations such as Learning Disability Wales (Lewis, 2022). While the *Learning disability delivery and implementation plan 2022 to 2026* includes a statement which calls for appropriate, measurable, outcome-focused actions and monitoring arrangements, *information about the mechanisms through*

*which this can be developed*, and the lack of formal targets and delivery dates to measure the impact of the strategy, is seen as needing greater clarity and specification (Learning Disability Wales, ibid).

### 4.1 Evaluative summary of findings




This section of the review moves on from the identification of key literature themes to summarise the key findings of the review. While the key themes identified in the preceding sections reflect clusters of common findings in the research and narratives of experts, both professional and experience-based, it remains to reflect on how these themes *link together*, summarising the overall vision that they provide about what is happening in the sector.

Reflecting a similar point made in section 1.4 the *interrelated* nature of each of the identified themes, becomes clear. To give an example, *variable knowledge in social care/health teams* about the complex needs of individuals and what 'reasonable' adjustments' might need to take place, reflect both inconsistent *data collection processes*, in addition to the need for more accessible mechanisms through which *authentic, co-produced knowledge* can inform the work of health and social care professionals. This in turn results in *service models* that can be difficult to navigate, and work with different understandings of what 'needs' are, resulting in care planning that can at times lack relevance and meaning for young people and their families and carers.

Presented below is a summary of the review findings which highlight good practice, barriers to achieving positive outcomes, and a brief developmental narratives to conclude:

- The promotion of an integrated model of care, provided by local authorities, health boards, and third sector providers, and co-ordinated by Regional Partnership Boards (RPBs), provides a framework for the design and implementation of person-centred, co-produced care for children and young people with a learning disability. The research reviewed suggests that while there is a broad agreement across the sector of the benefits of this approach, that there exists an 'implementation gap' in the delivery and receipt of this

service model of care. This results on some occasions in a ‘disconnect’ between the aims and principles of holistic, integrative models of care and the outcomes experienced by children and young people with a learning disability and their families and carers. The development of collaborative approaches, informed by the voices of the learning disability community, and co-ordinated by RPBs, is a model that is inconsistently applied across Wales. There are some very good models of practice, and some inspirational ‘magic moments’ where co-production goes way beyond ‘voice and choice’ (see textbox) but the reviewed research suggests that on a day-to-day basis many of those in receipt of care feel frustrated and disconnected from the design and delivery of their care.

- It was found from reviewing the literature that principles of integrative, collaborative care are broadly accepted by health and social care teams, but that there are varied understandings of what some of the key concepts and principles of an integrative, person-centred approach actually mean *when applied in practice*. As a result, differing understanding of what, for instance, ‘co-production’, or ‘reasonable adjustments’ mean, can occur. This is then seen in the challenges that different professionals face, within and across different sectors, in working together effectively in the design and delivery of specific, needs-based pathways of care. In terms of ‘actualising’ the rights of children and young people, where properly integrated, cohesive services are lacking, this can result in disempowerment. Where good practice is evident, the existence of consistently shared systems for planning and delivery was often attributable to the presence of a named care co-ordinator who can play a mediating role between different health and social care providers. Such models of care provide a potential starting place to drive the integrative model of care forward, with care co-ordination forums, named care co-ordinators, and family liaison workers emerging from the literature as important practices in facilitating the positive initiatives identified in the literature.

- Inconsistent approaches to joint working and continual, on-going engagement between health and social care professionals about what integrated, person-centred care should look like, was noted in the literature, reflecting a need for further on-going communication between professionals who may have very different approaches and skill sets when understanding disability, rights, and needs. Echoing the previous point, where practice and outcomes are considered good in the literature reviewed, this was often attributed to the existence of ‘co-ordinator’ roles, working to help promote a shared vision of integrative models of working (echoing a ‘one door’ approach) while remaining appreciative of the contributions that different approaches to care can bring. Developmentally, an acceptance of historical ‘silo working’, and the acknowledgement that true integrative service models will require ‘organisational patience’ (Andrews & Calder, 2023) may be needed. That

professionals across sectors would appear to have a shared vision of the need to empower individuals, is reassuring and motivating in the pursuit of integrated care and seamless services.

- The literature suggests that co-production, an underlying principle of the SSWA (Wales) 2014 Act can at times be understood by professionals to be about the 'gathering of opinions' despite shared good intentions about the need for person-centred care. The best practice, received most positively by children, young people and families, comes when co-production places the individual at the centre of care, adopting a rights-based approach where individuals and their families are involved in the design, implementation, and review of plans that address what they need. Findings from the review suggest co-production should be on-going and integral to care planning and implementation, and not just 'added on'. Needs change, and a good working reciprocal relationship of co-production is a means through with insights into these changing needs can be gauged and addressed. The best practice, often (though not exclusively) in the form of third sector initiatives, was able to see co-production as on on-going conversation, particularly important when children and young people were at risk of triggers to poor mental health, such as when transitioning to adult services. This is particularly important in relation to the statutory duty of local authorities to facilitate communication with children and young people who have complex and/or profound needs. Edwards and Gharbi (2021) in their review of early years help for children with a learning disability recommend the involvement of children and families in the provision of training for professionals across the sector, facilitating a 'grassroots' understanding of need, while strengthening a rights-based approach to co-production and care planning.

  Research from service user-centred organisations, in addition to academic reviews, noted that the need for greater use of formal advocacy, a legal duty under section 17 of the SSWA (Wales) 2014 Act, was a necessary component in ensuring that the needs of those with complex, profound needs, could be met; a necessary ingredient in facilitating authentic co-production. Alongside this, the findings suggest that there is a need to ensure that there are clear mechanisms through which knowledge about *what matters* to children, young people, and their families and carers, can be transmitted to professionals, including RPBs in their collection of data. Planning *around the child*, and not *with the* child, in some parts of Wales, was observed in some of the literature to be problematic, while recognising that the former approach also has its merits (Edwards & Gharbu, 2021). Nonetheless, a need for better mechanisms both when working *with* children to communicate their preferences, and in communicating that knowledge more effectively to Regional Partnership Boards, was noted, in order to enable more robust and meaningful care planning.

- Currently data collection around needs and outcome is confusing and lacks reliability. The literature reviewed reflects a lack of consistency across sectors (health, education, social care) about which groups should be included under the category 'learning disabilities', and how and when outcomes should be assessed. While applauding attempts to develop current learning disability strategies in Wales, feedback from service user groups reflects the need for targets to be set from the outset, with dates in place when formative assessments can be made, and any required changes arising out of this evaluation implemented[4]. The need for the involvement of children, young people, and their families and carers in discussions about the setting of targets and in the ongoing assessment of current care packages, is an important finding in the literature reviewed. Questions were also raised in the review from families about what mechanisms are in place to collect, evaluate, and 'feed back' to RPBs and parliamentary groups such as the Learning Disability Ministerial Advisory Group. Measuring progress, setting targets, and communicating the outcomes of these measures was seen in the literature as an essential part of providing a robust evidence base with which to inform future policy development.

## 4.2 Developmental narrative

The findings from the literature reviewed reflect that there is a broad adherence to the key principles of person-centred, holistic, integrated care pathways, developed co-productively, with children, young people and their families. There is, however evidence currently of an implementation gap between the vision that guides policy and practice, and the experiences of individuals in the sector. Barriers to positive outcomes have been identified in this review, alongside insights from the literature that promotes a vision of what good quality care experiences look like. 'Rights not services' seems to be the motto that emerges from service user organisations – that looking at children and young people as people first, and as having a disability second, is the place to start when thinking about how professionals should best engage with this group. In promoting a model of care that looks at 'need' as an ongoing conversation between professionals, children, and families, there is scope to facilitate more consistent and effective planning, assessment, and delivery of services that best fit Welsh Government objectives of delivering rights-based, integrative care pathways.

[4] To quote from the May 2022 newsletter from the *North Wales Together* service user group '*It is paramount we are clear what the outcomes for people with learning disabilities are, and how this will reflect the Welsh Government outcomes'*

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