Arolygiaeth Gofal
Cymru
Care Inspectorate
Wales

‘Let me flourish’

National review of early help, care and support and transition for disabled children in Wales



Contents

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Mae'r ddogfen yma hefyd ar gael yn Gymraeg.
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Foreword

I am pleased to be publishing this national review. This report presents the main findings from our review of how well local authorities, working with their partners, are providing early help, care and support and transition for disabled children in Wales.

The national review programme began November 2019. Part way through the review programme the COVID-19 pandemic hit us. In March 2020, as infection rates increased and Wales entered the first lockdown, we suspended our inspection and review programme to enable local authorities to focus fully on responding to the unprecedented situation. Despite the challenging circumstances we considered it essential to continue this important work given the potential impact of the pandemic on services for disabled children and their parents/carers. We recommenced a revised and shortened review programme in September 2020.

As we begin to recover from the pandemic, I have reflected on what we have learned from this review. What stands out is the importance of social care and health care services working seamlessly together with disabled children and their families, to promote the well-being of children in Wales. Supporting disabled children to flourish and achieve positive outcomes, promoting their independence and preventing escalation of needs can only be done effectively and efficiently when local authorities, health boards, service providers including the third sector work together ensuring children's well-being remains central to everything they do.

I am pleased this review included a 'pilot peer inspector programme', which involved the inclusion of three practitioners employed by local authorities who worked as part of the inspection teams undertaking the inspections. The pilot was a great success with positive benefits identified by all involved. The two-way sharing of knowledge and skills is so important for continuous development and can only be of benefit to those involved in the review. I would like to thank the practitioners and local authorities who volunteered to be part of this valuable pilot.

Healthcare Inspectorate Wales (HIW) also supported us with the review. Reinforcing our commitment to working together to enable inspectorates to consider how people are being supported seamlessly across both social care and health care services.

Our findings highlight positive practice and also areas where improvements are needed. The landscape of social care and health care services has changed as a result of the pandemic, and may not be the same as it was when we began this review. There is, however, the opportunity to build on the learning from the pandemic and the innovative responses to it by our social and health care services. Regional Partnership Boards should take account of the findings of this report as they reflect on the pandemic and plan future integrated service delivery, which places the best interests of disabled children at the centre of decision making. I cannot stress enough the importance of promoting the rights of disabled children and their parents/carers, ensuring their voices are central to decisions made.

I would like to take this opportunity to draw your attention to the publication of our national overview report of assurance checks of children and adult social services.

Finally, I cannot end without recognising the exceptional dedication of social care and health care staff across Wales. On behalf of everyone in Care Inspectorate Wales (CIW), I should like to express our deepest admiration and thanks.

G. Baranski

Gillian Baranski
Chief Inspector
Care Inspectorate Wales

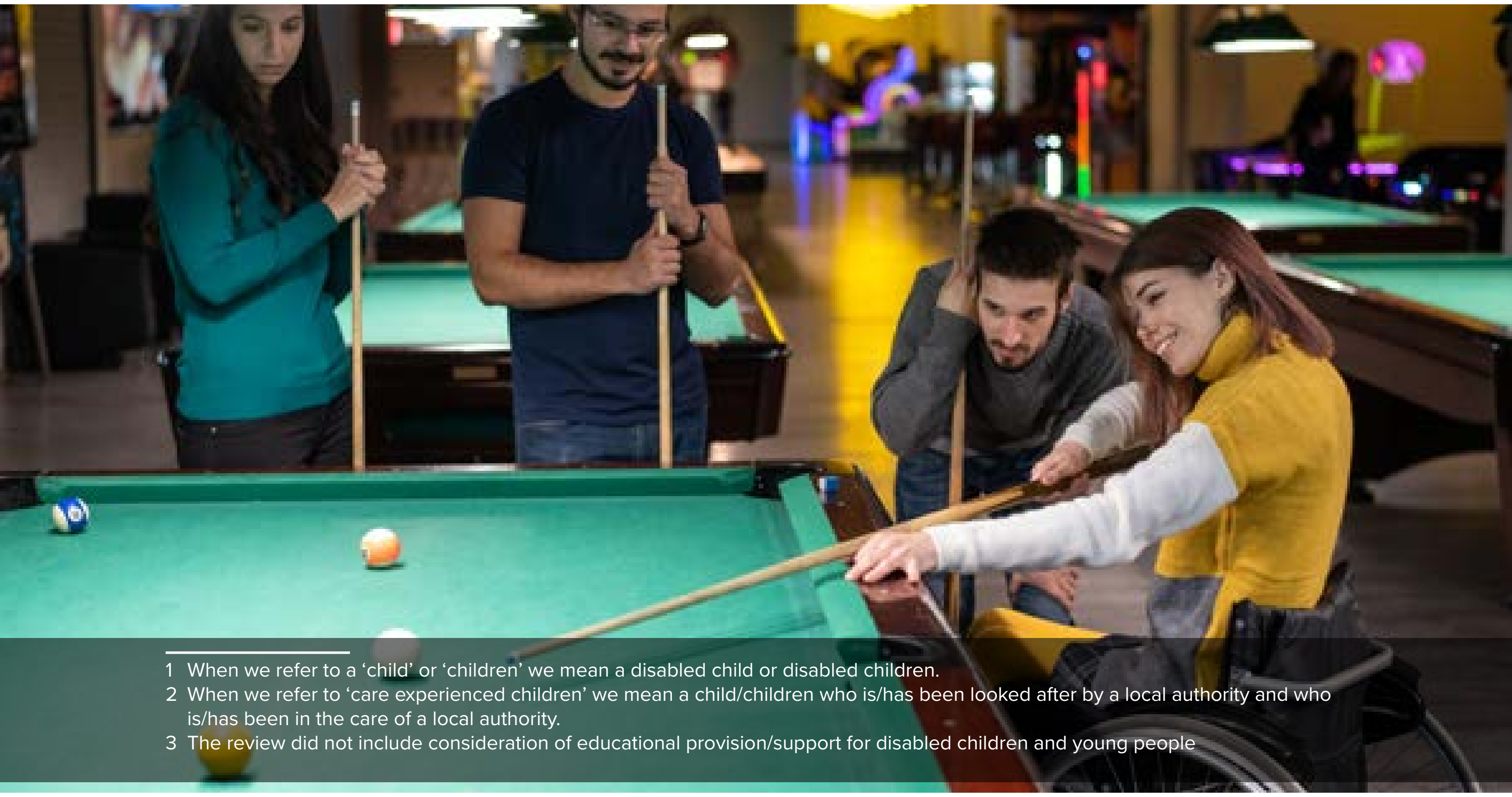
Introduction

All children require support to enable them to reach their full potential. How well disabled children are supported to flourish and reach their full potential can be dependent on how different professionals and organisations work together and in partnership with families to ensure children [1] have access to and receive the right support at the right time.

The focus of our review was on the experience of disabled children and their families as they encountered social services and received advice, were signposted to community services, participated in assessments and received care and support. We also considered care experienced[2] disabled children and how disabled young people were helped to manage the transition to receiving care and support from adult services.[3]

Achieving a child’s full potential should never be reliant on how tenacious and assertive their parents/carers are, nor where they live in Wales. Disabled children and their families in Wales who require support should not be ‘falling through gaps,’ involved in overly bureaucratic processes nor in disputes between health, social care and or other professionals/organisations.

This report sets out our key findings, including areas of strength and areas for improvement, practice learning points and most importantly actions required to improve well-being outcomes for disabled children and their families.



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[1] When we refer to a ‘child’ or ‘children’ we mean a disabled child or disabled children.

[2] When we refer to ‘care experienced children’ we mean a child/children who is/has been looked after by a local authority and who is/has been in the care of a local authority.

[3] The review did not include consideration of educational provision/support for disabled children and young people

Framework and context of the national review

We took a rights-based approach to our review. The social model of disability[4], United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), United Nations Convention on the Rights of the Child (UNCRC), Rights of Children and Young Persons (Wales) Measure 2011, Equality Act 2010, Well-being of Future Generations (Wales) Act 2015 and Social Services and Well-being (Wales) Act 2014 ('the 2014 Act') provided the legislative and principle/ethical framework for the review.

The delivery of duties and functions of the 2014 Act is intended to ensure people are supported to enact their rights and are protected from abuse and neglect, produce positive well-being outcomes for people who need care and support and carers who need support.

The 2014 Act supports greater multi-agency working, new models of community led care and sustainable social services. It puts in place requirements for regional collaboration, and a legislative framework to enforce this, if required, between local authorities themselves and between local authorities and health boards.

The review included consideration of how the four underpinning principles of the 2014 Act were making a difference to the well-being of disabled children and their families:

- **People - voice and control:** How well are local authorities ensuring disabled children and their parents/carers are having their voices heard, making informed choices, and maintaining control over their lives?
- **Prevention**: To what extent are local authorities successful in promoting prevention and reducing need for increased or formal support from statutory agencies?
- **Well-being**: To what extent are local authorities promoting disabled children's and their parents/carers well-being and supporting them to achieve positive outcomes that matter to them?
- **Partnership**: To what extent are local authorities promoting and maximising partnership working, integrated service delivery and driving service development and service sustainability?

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[4] Social model of disability sets out a different way to view disability – rather than defining people as disabled by their impairment (i.e. the medical model of disability), people with impairments are considered to be disabled by physical, attitudinal and organisational barriers created by society.

Limitations of the review

Promoting the voice of people underpins all CIW activity. However during the review the COVID-19 restrictions and the inherent vulnerability of some disabled children meant we had limited opportunities to engage directly with children and their families.

We worked as interactively as possible during the review. We were able to undertake some limited focus group activity with children prior to the beginning of the pandemic, as well as some virtual and telephone interviews with people during the pandemic. We also extensively promoted a bespoke electronic parent/carer survey with the support of local authorities.

The methods[5] used for obtaining information for the review were kept under review and were revised/adapted according to the national and local situation. Despite the impact of the pandemic on our programme it is pleasing the work undertaken has enabled us to identify existing positive practice as well as areas of improvement that remain firmly focused on the experience of children, young people and their families.

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[5] The approach used to gather evidence for the review is detailed in the appendices.

Actions needed

For local authorities:

- a rights-based approach when working with disabled children and their families must be promoted and taken
- carers' rights and entitlements must be actively promoted
- effective arrangements must be in place for communication with disabled children. The child's preferred method of communication should be used, their voice should be consistently sought, heard and captured
- eligibility criteria for access to statutory services must be fully aligned with the 2014 Act
- practitioners working with disabled children must be sufficiently skilled and trained in relation to the tasks they perform/are expected to perform when working with children and their families
- opportunities for consultation with disabled children and their parent/carers should be developed and maximised
- review and take the necessary action to ensure sufficient and accessible information, and timely advice and assistance is available for disabled children and their families
- ensure the 'Active Offer' of a service delivered in the Welsh language is consistently promoted and provided
- ensure the 'Active Offer' of independent formal advocacy is consistently promoted and provided
- review and ensure effective quality assurance systems and information recording systems are in place to assess and evaluate the quality and impact of work with disabled children and their families, and for the purpose of service planning, delivery and adherence to statutory requirements
- safeguarding thresholds and processes must be well understood by practitioners and partners and as rigorously applied in relation to disabled children as they are for non-disabled children
- sufficiency of suitable local placements, and play, social, recreational, training and employment opportunities for disabled children must be maximised to meet the needs of disabled children and young people
- transition planning must be undertaken in a timely manner and include disabled children, their families and relevant professionals/agencies
- ensure adherence to the Children and Young People's Continuing Care Guidance – January 2020
- opportunities for greater collaboration and joint commissioning with regional partners must be maximised
- ensure required action is taken to comply with the requirements of the Statutory Code of Practice on the Delivery of Autism Services
- ensure suitable arrangements are in place for the forthcoming implementation of and compliance with the Liberty Protection Safeguards (LPS)

For local health boards:

- review health provision for disabled children with a view to identifying unmet needs and gaps in service provision and take action to address the deficits in health provision
- ensure there is sufficiency of suitable local placements for disabled children with complex health needs/continuing care needs
- ensure adherence to the Children and Young People's Continuing Care Guidance – January 2020
- opportunities for greater collaboration and joint commissioning between regional partners must be maximised
- ensure required action is taken to comply with the requirements of the Statutory Code of Practice on the Delivery of Autism Services
- ensure suitable arrangements are in place for the forthcoming implementation of and compliance with the LPS

Key Findings

We identified 19 key findings from our review.

We have aligned our key findings under the four underpinning principles of the 2014 Act. The overall level of improvement needed in relation to our key findings is represented in terms of colours. Red indicates improvement is needed; amber indicates some improvement/strengthening is needed; green indicates positive findings which should be maintained and developed.

We have included data, practice learning points and areas for improvement, positive practice examples and a sample of comments received from people who provided us with their views.

Key Findings

People - voice and control

People

1. Obtaining and hearing the voice of disabled children must be strengthened and actively promoted

2. The active offer of advocacy to disabled children must be strengthened

3. The promotion of rights and entitlements of parents/carers must be improved. This is a priority area for improvement.

4. Registers of disabled children must be established and maintained in accordance with the 2014 Act

5. Committed and dedicated workforce

Key finding 1: Voice of the child: Obtaining and hearing the voice of disabled children must be strengthened and more actively promoted

‘Every child has the right to express their views, feelings and wishes in all matters affecting them, and to have their views considered and taken seriously.’ Article 12 UNCRC

Disabled young people told us how important it was for them to feel their social worker was trying to get to know them. Although professionals had read the young person’s file, one young person told us

> **“it doesn’t make them really know you or know what it feels like to be you.”**

People told us:

> **“My foster child has an excellent relationship with their social worker and looks forward to seeing them.”** *(Foster carer)*

> **“My son has a wonderful relationship with our social worker.”** *(Parent/Carer)*

> **“For kids who can’t speak at all or who are quiet, they [professionals] need to work hard to get to know them.”**
> *(Disabled young person)*

> **“My social worker and doctor talks to my aunty rather than me. That’s annoying. They should be talking to me.”**
> *(Disabled young person)*

Overall, we found variable practice across Wales regarding how well the voice and choices of disabled children were sought, heard and captured.

We saw some good examples of the efforts made by staff to develop professional relationships with children and families. In the best examples, evidence of direct work was prominent within the case records; and it was evident practitioner[6] knew the child well and had taken care and time to obtain their views, identifying and using the child’s preferred method of communication.

Practice example: A social worker had engaged in direct work with a child whose method of communication was a picture exchange communication system (PECS). The work undertaken by the social worker included obtaining the child’s wishes and feelings. The social worker met with the child and used the PECS to ensure the child was able to express their wishes and preferences.

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[6] When we refer to ‘practitioner’ we mean local authority staff working with disabled children and their families.

The majority of parents/carers surveyed whose disabled child/ren had a social worker felt the social worker had got to know the child/ren well or very well. Just over half the parent/carers felt the social worker communicated well or very well with their disabled child/ren. The responses to these questions were variable across local authorities, with some local authorities having a significantly higher percentage of parents/carers responding positively to the questions.

Information about disabled children's communication methods and details of communication with the child was not always made clear in individual case records. Practitioners told us they had access to communication tools to facilitate communication with children, although evidence was not always available to demonstrate the efforts practitioners had made to use these. Some practitioners told us they sometimes find it challenging to communicate effectively with a child with complex communication needs and in these cases they use observations and views provided by the child's family/people who know the child very well.

We found examples of the 'Active Offer'[7] being made to provide a service through the Welsh language, although the offer was not always consistently available across all services in all local authorities.

Overall, we found practitioners working with disabled children were provided with a range of training. Not all practitioners had received relevant training specific to the communication needs of the individual children they were working with and they identified they would benefit from receiving specialist training.

During the pandemic, we saw an increase in the use of digital communication. While some people find this can be as effective as meeting in person, for some disabled children particularly those with complex communication needs or cognitive impairments digital communication can pose a challenge.

Practice learning points and areas for improvement:

- **effective communication with disabled children is vital in ensuring the child's voice is sought and heard. It is important practitioners working with children have the time and opportunities to get to know the child well, to ensure a better understanding of the child's strengths, needs and preferences and to ensure person-centred practice[8]**
- **a 'one size fits all' approach to communicating with disabled children should not be adopted. Local authorities must routinely assess the most appropriate method of communication for use with individual children**
- **practitioners must be provided with opportunities to develop their communication skills and knowledge. This will support effective communication with disabled children and their parents/carers**

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[7] Active offer: Providing a service in Welsh without someone having to ask for it

[8] Person-centred: Involves putting the person at the centre of all decisions and plans about care and support. Person-centred services see people as equal partners in planning, developing and assessing care and support needs to make sure service delivery is appropriate for individual needs and will achieve well-being outcomes.

Key finding 2: Advocacy: The active offer of independent professional advocacy to disabled children must be strengthened

Section 21 (7) of the 2014 Act gives a statutory entitlement to independent professional advocacy for all children in need of care and support. The 2014 Act also includes a presumption that any child with a disability is a child who will need care and support in addition to, or instead of, the care and support provided by the child's family.

Whilst we saw many examples of parents/carers and practitioners advocating on behalf of disabled children, we found disabled children are under-represented in referrals for independent professional advocacy. We saw advocacy awareness raising training/sessions for practitioners, however, we saw some examples where there was a lack of awareness among practitioners of the relevance of independent professional advocacy, including non-instructed advocacy.

Practice learning points and areas for improvement:

- improvement is needed to ensure an active offer of advocacy is made to disabled children and opportunities provided for development of self-advocacy
- practitioners should have an understanding of the value and function of independent professional advocacy, including non-instructed advocacy

Key finding 3: Parents/Carers: The promotion of the rights and entitlements of parents/carers must be improved. This is a priority area for improvement

‘A local authority must assess whether the carer has needs for support (or is likely to do so in the future) and if they do, what those needs are or are likely to be. A carer is defined in the Act as a person who provides or intends to provide care for an adult or a disabled child.’ Part 3 Code of Practice (2014 Act)

The 2014 Act places a duty on local authorities to assess the needs of carers, including young carers and carers of disabled children. Practitioners we spoke with were generally aware of the significant caring role of many parents/carers of disabled children/young people, and the impact of their caring role. Despite this the data submitted by local authorities across Wales identified very few parents/carers of disabled children had received a carer’s assessment or support plan.

Parents/carers told us:

> **“I was not offered a carer’s assessment, but after fighting for 15 months, I eventually got one.”**

> **“The carer’s assessment took years to be completed and was done when he was much younger. The situation has changed here quite a lot over the last 5 years but I haven’t had another.”**

Documents viewed and feedback received from parents/carers confirmed carer’s assessments were not routinely offered nor completed in line with legislative requirements.

When asked if they had been offered a carer’s assessment, approximately 66% of parent/carers who responded replied “no.”

We saw missed opportunities to support parents/carers. A number of practitioners told us many parents/carers refuse a carer’s assessment. Evidence was not always available to confirm this.

We saw examples of support provided to parents/carers which included access to parents/carers support groups and sessions. We saw examples of carer’s grants being used creatively to support parents/carers for example to fund the purchase of a washing machine and short break for a parent/carer.

Practice example: Parents/carers who attend a support group in Conwy identified they would benefit from a course on Makaton (Makaton is a unique language programme that uses symbols, signs, and speech to enable people to communicate). The local authority provided funding through the Integrated Care Fund for members of the group to receive Makaton training. Additional funding was also provided for the group members to access mental health and well-being sessions.

The pandemic has had an impact on support services for parents/carers. We found some services had stopped operating and others were provided in different ways. Many parents/carers told us they were not receiving the level of support they needed and described the detrimental impact on them, their disabled child/ren and their family.

Practice learning points and areas for improvement:

- local authorities must take a 'rights-based' approach in relation to carers. This includes taking a proactive approach by informing and promoting the rights and entitlements of carers to an assessment and where eligible, support
- it is important local authority practitioners are aware of the requirements of the 2014 Act in relation to carer's assessments and meeting eligible needs
- improvements are needed in relation to the way in which local authorities routinely capture information about carer's assessments
- local authorities should consider monitoring the number of parents/carers who decline an assessment and wherever possible capture the reasons for this, to inform future service developments
- it is important local authorities and their partners review the support available to carers to ensure their well-being is promoted and protected. Leaders should ensure this is a priority area for improvement

Key finding 4: Registers: Registers of disabled children must be established and maintained in accordance with the 2014 Act

‘Local authorities must establish and maintain a register of children who are within the local authority’s area and who are disabled, have a physical or mental impairment which gives rise, or may in the future give rise to, needs for care and support.’ Part 2 (2014 Act)

We found not all local authorities had complied with the requirement of the 2014 Act to maintain and establish a register of disabled children. This information is crucial for planning services to meet the current and future needs of disabled children.

Practice learning point and area for improvement:

- local authorities must take the necessary action to comply with the requirements of the 2014 Act and establish and maintain a register of children who are within the local authority’s area and who are disabled, have a physical or mental impairment which gives rise, or may in the future give rise to, needs for care and support

Key finding 5: Practitioners: The workforce are dedicated and committed

Disabled children have the right to say what is important to them, be treated with respect, have their dignity, privacy, preferences, culture, language, rights, beliefs, views and wishes respected, and receive the support they need to stay safe. Practitioners working with disabled children should be honest, trustworthy and reliable and be trained to do their job properly.

During the review we spoke with and obtained feedback from a wide range of professionals across social care, health and education services, and third sector. Professionals were dedicated and committed to ensuring good outcomes for disabled children.

People told us:

> **"Our social worker has been amazing at finding us the help we need, she's second to none."**
> *(Parent/Carer)*

> **"It's difficult to get to know new social workers when they change. I prefer to talk to my friends. They know me better."**
> *(Disabled young person)*

We found local authority practitioners working with disabled children promoted respect and dignity. Practitioners felt supported by colleagues and managers and workforce morale was generally good. The majority of practitioners we surveyed felt their caseloads were manageable. We saw the efforts made by local authorities to support staff well-being.

We were told about children and families who had experienced a number of changes of practitioner. There were vacancies in some teams with some local authorities reporting challenges in recruiting skilled and experienced social workers. Local authorities identified workforce recruitment and retention as a priority area for them.

Practice learning point and area for improvement:

- maintaining the same practitioner is important in helping disabled children develop a positive relationship in which they feel the practitioner knows them well and there is effective communication

Key Findings

Well-being

Key finding 6: Safeguarding: Disabled children are safeguarded

‘Every child has the right to be protected from all forms of violence, abuse, neglect and bad treatment.’ Article 19 UNCRC

Safeguarding children and young people is a priority under the 2014 Act. Disabled children have the same human rights, to be safe from abuse and neglect, protected from harm and to achieve good outcomes as non-disabled children. Disabled children do however require additional action because of negative attitudes about disabled people and unequal access to services and resources. Disabled children may also have additional physical, sensory, communication needs and/or cognitive impairments.

There has been an overall increase in the number of children (including disabled children) who were receiving care and support but not looked after by a local authority who were named on the child protection register. As at 31 March 2019 there were 2,115 non-disabled children receiving care and support but not looked after by a local authority who were named on the child protection register. This number had risen to 2,195 (4% increase) as at 31 March 2020. As at 31 March 2019 there were 95 disabled children receiving care and support but not looked after by a local authority who were named on the child protection register. This number had risen to 115 (21% increase) as at 31 March 2020.[9]

We found local authorities and their practitioners recognised safeguarding as a priority. Safeguarding processes for disabled children were satisfactory. Generally, there was an emphasis on ensuring a shared understanding about safeguarding and the need to keep children safe. We found evidence of good joint working between partners. We heard how some local authorities provide opportunities for practitioners working with disabled children and their families to reflect and learn from safeguarding practice including from national child practice reviews. This provided an opportunity to highlight areas for improvement.

For a very small number of disabled children, we found the focus on their impairment(s) meant safeguarding concerns were not always sufficiently recognised and the subsequent care and support plan did not ensure the risks to and needs of the child were addressed.

It was positive to note some local authorities had provided practitioners with information and training specifically in relation to safeguarding disabled children.

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[9] Appendices - figure 2. Source: Welsh Government Children receiving care and support census 2020 - Children receiving care and support by looked after status and disability

Practice learning points and areas for improvement:

- local authorities must ensure safeguarding thresholds and procedures are as rigorous for disabled children as they are for non-disabled children
- it is important practitioners and professionals recognise the increased vulnerability of disabled children to abuse and neglect. Understanding the barriers disabled children may face around communication is also important, as is providing for any additional safeguards needed to protect them

Key finding 7: Access to information, advice and assistance (IAA): Provision of IAA for disabled children and their families, must be strengthened

‘A child with a disability has the right to live a full and decent life with dignity and, as far as possible, independence and to play an active part in the community. Governments must do all they can to support disabled children and their families.’ Article 23 UNCRC

The majority of disabled children live with supportive parents/carers who ensure their needs are met and advocate on behalf of their child/ren.

Disabled children who attended our engagement events told us the most important adults in their lives were family members who advocated for them, fought their corners, and took them to appointments. It was noted that for young people to be helped to become independent, their parents and carers may need help to feel confident in attaining their child’s entitlement.

It is likely some disabled children and their parents/carers will require some IAA to help them achieve good outcomes.

Parents/carers told us they did not always know where to go to access advice or information about services, activities or community resources. Not all parents were aware of the Dewis Cymru resource.[10] Nor did all practitioners make use of Dewis Cymru to signpost families to community support and social opportunities.

What parents/carers told us:

> **“I feel that there is not enough information available for parents/carers about who what or where to go for help about disabled children and their siblings/families.”**

> **“We are confident (pushy?) parents and drive the process. Sharp elbows needed.”**

When we asked parents/carers of disabled children what improvements could be made in relation to services for their child/ren comments included:

> **“Provide clear information about carers and disabled children’s rights.”**

> **“Inform families of the support and services available in the community. You don’t know what you don’t know.”**

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[10] Dewis Cymru is a website providing a one-stop shop for well-being in Wales. It provides a directory that allows people to access a range of services in areas such as health, money management and safety. Visitors to the Dewis Cymru website can select the category they are interested in and a range of advice and links to services is available.

Just over half of parents/carers surveyed told us in the year prior to completion of the survey they had requested IAA from their local authority. Of these, a majority had found the response received was either slightly helpful, helpful or very helpful.

The provision of high quality and timely IAA is a preventative measure and where required, should be provided in a timely manner and offer support to assist people before needs escalate or they reach crisis point.

Practice example: Single point of access for children's emotional well-being and mental health (SPACE-Wellbeing) panels, which are in place across the five local authority areas of Gwent. The panels meet weekly and take referrals from multiple sources including parents and families. The panels consist of representatives from a wide range of services including social services, health, youth and sports and leisure services, housing, school based counselling, young carers, third sector. The panels aim to take account of the family's individual circumstances and respond to needs, as far as possible

Parents/carers whose disabled children received support from social services generally valued the support. Some, however, told us they had experienced delays in their child/ren receiving the support they needed.

What parents/carers told us:

> **"It makes all the difference if you have a good social worker that you can talk to."**

> **"Initially I was offered 3 hours a fortnight respite and a couple of hours of social activities per month for my son. I fought for another 12 months for more."**

> **"How are we supposed to know about getting support from social services? I have no breaks from caring and am on my knees emotionally as I can't get any space to myself."**

We saw examples of good quality IAA services, with evidence of timely and efficient response to enquiries, and appropriate signposting to other organisations or to other local authority services. In these examples, people were able to access the right information, advice and or assistance at the right time and this had a positive impact on their well-being. We also found some examples where delays in receiving appropriate information, advice and or assistance had led to escalation of need and increased the risk of crisis.

Practice learning points and areas for improvement:

- improvements are needed to ensure disabled children and their families consistently receive the right information, advice and assistance at the right time
- there should be 'no wrong door'[11] for disabled children and their families

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[11] The Children's Commissioner for Wales report - 'No Wrong Door: bringing services together to meet children's needs.' The report identifies how children and their families who seek support for a range of needs often find they have to navigate a very complex system, may fall through gaps where there are no services to meet their needs, or be on a waiting list for a long time only to be told they were waiting in the wrong queue, or have been knocking on the wrong door all along.

Key finding 8: Assessment, care and support plans: Assessment, and care and support planning must be strengthened

‘A local authority must assess whether a child has needs for care and support and if so, what those needs are. In carrying out the assessment the local authority must assess the developmental needs of the child, and seek to identify the outcomes that the child wishes to achieve (to the extent it considers appropriate having regard to the child’s age and understanding), and the outcomes that the persons with parental responsibility for the child wish to achieve in relation to the child (to the extent it considers appropriate having regard to the need to promote the child’s wellbeing).’ Part 3 Code of Practice (2014 Act)

There has been an increase in the number of children (including disabled children) who are receiving care and support. As at 24 March 2020, there were 16,580 children across Wales who were receiving care and support (16,420 in 2019, an increase of approximately 1%). Of these, 3,600 (3,575 in 2019, an increase of approximately 1%) were disabled children.[12]

It is important the approach to assessment is based on a full understanding of what is happening to a child in the context of their family and the wider community, and examines carefully the nature of the interactions between the child, family and environmental factors. Overall we found parents/carers are generally involved in assessment of needs and care and support planning for their disabled child/ren.

The quality of assessments and care and support plans varied across local authorities in Wales, as did the quality assurance processes in place to monitor them. The best examples ensured the voice and choice of the disabled child and family members were prominent within assessments and care and support plans. There were clearly defined strengths, risks and barriers, they were outcome focused and clear contingency planning was in place. In other examples we found improvements were needed as the voice and choice of the child was not prominent, and strengths, risks and outcomes were not clearly identified.

A number of local authorities across Wales had or were taking action to strengthen assessments and care and support planning.

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[12] See appendices figure 1. Source: Welsh Government Children receiving care and support census 2020. The children receiving care and support census is based on the definition of eligible children who have care and support, i.e. children (under the age of 18) who have a care and support plan (see appendices).

Arrangements for the review of care and support plans varied across Wales. In the best examples we saw the reviews had been undertaken in a timely manner, the voice of the disabled child and their parents/carers had been sought, heard and captured. Relevant professionals/agencies involved with the child and family had been provided with the opportunity to contribute to the review. Progress in relation to meeting identified outcomes was clearly detailed.

Practice learning points and areas for improvement:

- improvements are needed to ensure all assessments and care and support plans are strength based and outcome focused and comply with the relevant codes of practice
- quality assurance systems should be effective in driving continuous improvement and compliance with statutory requirements

Key finding 9: Sibling/young carers' support: Support for siblings/young carers must be strengthened

'Every child has the right to rest, relax, and play and to take part in cultural and creative activities.' Article 31 UNCRC

In their self-evaluation responses, local authorities reported they generally consider the needs of siblings/young carers of disabled children as part of the assessment process. Many practitioners described how they had considered the support required for siblings/young carers but this was not always reflected in the assessments or care and support plans we viewed.

We saw examples of support being provided to siblings/young carers of disabled children. Most parents/carers surveyed said siblings would benefit from additional support.

There are waiting lists for some services for siblings/young carers. Some of the services for siblings/young carers are provided using short-term funding, resulting in uncertainty of the sustainability of these services.

> **"My eldest child was part of the Young Carers Project and absolutely loved it but they asked her to leave after a year because of waiting lists. Having to leave affected her badly."**
> *(Parent/carer)*

Overall, we found support for siblings/young carers of disabled children is inconsistent across Wales. The focus on their needs must be strengthened and consistently applied.

Practice learning point and area for improvement:

- local authorities should review support available to siblings of disabled children with a view of identifying any gaps in service provision and unmet needs. This information should inform commissioning strategies

Key finding 10: Direct payments: The offer of direct payments must be strengthened and provided as a viable and informed option for disabled children and their parents/carers

‘A local authority must develop its direct payment scheme to be responsive to solutions and outcomes, and more relevant to the communities they serve.’ Part 4 Code of practice (2014 Act)

Direct payments enable people to purchase services in a way that suits them, or to employ a personal assistant (PA). Direct payments can offer greater flexibility and are intended to improve choice, control and independence for people. We saw many examples of local authorities providing information about direct payments and of direct payments being used creatively by disabled children and their parents/carers, as a means of achieving personal well-being outcomes.

Practice example: In Merthyr Tydfil County Borough Council we saw how direct payments were used to support a disabled child to access activities in the community. We were told the PA was a great role model for the child and how accessing the community activities had increased the child’s self-esteem, well-being and social interaction.

What parents/carers told us:

> **“I now get 3 hours a week so I can spend some time with my daughter but I’ve been unable to recruit anyone to provide this support.”**

> **“Very reliant upon availability of direct payment employees and their flexibility. Support fails if they cannot work.”**

We found whilst direct payments offer flexibility in relation to care and support and are clearly valued by many disabled children and their parents/carers, some told us of the extreme difficulties and frustrations they faced in recruiting skilled PAs to fulfil the hours of support set out in their direct payment agreement. We also heard of a shortage of Welsh speaking PAs. We were not always confident families were presented with other options for support alongside direct payments.

Practice learning points and areas for improvement:

- further work is required to ensure direct payments are seen as an integral part of the assessment and care planning process, and as an important means, where appropriate, to meet a disabled child's needs and/ or a parents/ carers need for support
- local authorities must ensure there is sufficiency and choice of services for disabled children to make the take up of direct payments a positive and viable option for achieving identified outcomes and not a 'last resort' because of waiting lists or gaps in service provision
- where direct payments are in use, contingency arrangements should be discussed with the disabled child and their parents/ carers and include consideration of alternative care and support arrangements, if needed in case of emergencies

Key finding 11: Care experienced disabled children: Placement options and pathway planning for care experienced disabled children is a priority area for improvement

The 2014 Act places clear duties on individuals and local authorities when carrying out their functions in relation to looked after and accommodated children and young people. Part 6 Code of Practice (2014 Act)

There has been an increase in the number of children looked after by local authorities. As at, 31 March 2020, there were 6,935 children in Wales who were looked after by a local authority, 620 of these children were disabled children, this number had risen from 595 in 2019.[13]

Safely reducing the number of children looked after, including disabled children, is a priority for local authorities. Many local authorities have/are reviewed/reviewing systems in place to support children (including disabled children) to remain living with their families, wherever possible.

Information gathered from local authorities self-evaluations identified that of the disabled children who were looked after by a local authority approximately one-third were in placements outside of their home area. In addition, 42% were living with foster carers, 22% were living with kinship carers[14] and 5% were placed under the guardianship of parents. The proportion of non-disabled children placed under the guardianship of parents is significantly higher when compared to placements for disabled children at 17% compared to 5%. The review did not include analysis of the reasons for this. We recommend local authorities collate and analyse this information and take action to ensure, where possible, disabled children are provided with equal opportunities to remain under the guardianship of their parents and living within their community.

Local authority self-evaluations also identified a higher proportion of disabled children placed in residential care/special schools and other settings (such as supported living) in comparison to non-disabled children. Some of these placements are outside of the local authority area where families live because of the lack of specialist provision locally to meet the complex needs of some disabled children. Even moderate distances away from the family home can impact on a child's contact with family and friends and may involve change of school.

There are examples of looked after disabled children being placed in unregistered placements because local authorities were unable to find registered placements that could meet the child's needs. Placement sufficiency is an area many local authorities have identified for improvement. We saw action taken by some local authorities in order to try and address this issue, including exploration and development of local services, where disabled children are cared for within their own local authority area, close to their friends and families.

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[13] Appendices - figure 2. Source: Welsh Government Children receiving care and support census 2020. The Census collected individual records on all children receiving care and support, including those looked after by a local authority, who had an open case with a local authority on the 31 March that had been open for the three months from 1 January to 31 March.

[14] Kinship care means a relative or other adult known to the child is caring for them. Section 81 of the Social Services and Well-being (Wales) Act 2014, sets out the ways in which looked after children are to be accommodated and maintained.

Practice example: In Ceredigion County Council we found the local authority was focused on reducing the number of disabled children and young people placed out of county. Their Camu Ymlaen initiative for 18-25 year olds, is an example of social services, housing and education working together to deliver a clearly identified need for disabled young people with complex needs to access services in their local community. The aims of the initiative included provision of opportunities for young disabled people to remain living in their communities and to receive their education locally, through personalised curriculum based learning. Preparing them for independent living and future employment. The local authority had given consideration to the Additional Learning Needs and Education Tribunal (Wales) Act 2018.

We saw some good examples of care experienced disabled children receiving sufficient support from their social worker with sufficient oversight of the placement and quality of relationship with caregivers. We also saw some good examples of independent reviewing officers (IROs) consulting with disabled children. However, this practice was not consistent, as we found some examples of care experienced children who were not receiving visits within statutory timescales and some IROs told us there was room for improvement in their consultation with care experienced disabled children prior to the review meetings to ensure their views were central.

The transitional period when care experienced young disabled people approach independence and the time immediately after they leave care can present significant challenges to their emotional well-being. Preparation work for young people leaving care should include helping care leavers to develop and maintain relationships with people who will be able to continue supporting them after they leave care. The assessment and pathway planning process for a looked after child must involve a measured evidence-based analysis of the young person’s continuing need for accommodation and care and support, including whether they should continue to remain looked after.

We reviewed case records where young people had pathway plans in place and allocated personal advisors (PAs). Pathway plans did not always contain outcomes and it was not clear how progress was measured. Some pathway planning had been undertaken in anticipation of young people leaving care and was mapped out in some instances at ages 14 or 15 years. However, we also found evidence of care experienced young people, who were nearly 18 years old, who did not have pathway plans in place and assessments for eligibility for adult services had not yet taken place. The lack of certainty about arrangements for young people does not support positive well-being outcomes and may increase a sense of anxiety amongst young people.

We found inconsistency across Wales in relation to 'When I am Ready' [15]arrangements for disabled young people. Like their non-disabled peers, disabled young people are likely to benefit from remaining in a stable and nurturing family environment up to the age of 21, or up to age 25 if they are completing an agreed programme of education or training. This can provide them with the opportunity to develop their skills and confidence and assist them with future transitions.

Overall, we found placement options for care experienced young disabled people need improving. Pathway planning processes need strengthening to ensure they comply with the requirements of the 2014 Act and relevant codes of practice.

Practice learning points and areas for improvement:

- local authorities must ensure the arrangements for oversight of disabled children's placements are satisfactory and meet statutory requirements
- the lack of appropriate local residential placements is most problematic for children with complex needs. This is a priority area for improvement for local authorities
- assessment and pathway planning processes must comply with the requirements of the 2014 Act and relevant codes of practice
- improvements are required to ensure disabled children have access to 'When I am Ready' options, and to increase practitioners understanding of their roles with regards to this option

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[15] When I am ready scheme set up by the Welsh Government in 2015 to prepare local authorities for their new legal duties under the Social Services and Well-being (Wales) Act 2014. It enables young people in foster care to continue living with their foster carers once they turn 18.

Key Findings

Partnership and Integration

Key finding 12: Partnership and Integration: Some elements of partnerships and integration need to be strengthened

Local authorities should work collaboratively and with a variety of partners and stakeholders, including Local Health Boards, to develop and deliver required range and level of preventative services…. local authorities may choose to provide some types of preventative services themselves, others may be more effectively provided or arranged in partnership with other local partners including … third sector.' Part 2 Code of Practice (2014 Act)

The 2014 Act promotes integration between the health and social care sectors to the greatest extent possible in order to achieve improved well-being outcomes. A Healthier Wales our Plan for Health and Social Care [16] produced by the Welsh Government sets out how regional partnership working will be at the heart of the development of high value models of integrated health and social care. How Regional Partnership Boards (RPBs) will have responsibility to bring together local authorities, health boards and third sector providers, and how RPBs will occupy a strong oversight and co-ordinating role.

What parents/carers told us about partnership working:

> **"The departments don't seem to speak with each other at all."**

> **"It took a lot of asking to get them all together and listening to each other."**

> **"We feel well integrated with the professionals involved with our son."**

> **"Arranging a multi-disciplinary meeting has been very difficult. The social worker has tried to email all the professionals but lots haven't replied."**

We found a range of team and service structures across local authorities and health boards in Wales, which support disabled children and their families. Where disabled children's teams/practitioners were integrated or co-located, these arrangements were generally viewed very positively by practitioners and partners, with clear benefits identified for disabled children and their families.

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[16] 'A Healthier Wales our Plan for Health and Social Care' - sets out a long term future vision of a 'whole system approach to health and social care', which is focussed on health and well-being, and on preventing illness.

At its most effective multi-agency work was based on good trust and professional working relationships and organisational capacities to support the work. Practitioners told us good professional relationships and communication were important in making multi-agency work successful, as was strategic and organisational commitment to multi-agency working. Quality of practice, sufficient resources, and effective partnership working were viewed as important to achieve good outcomes for disabled children and their families.

Practice example: In Gwynedd Council we saw how a multi-disciplinary team worked together to support disabled children and their families. Examples of support provided included provision of aids and adaptations, emotional support, behaviour management advice provided by a psychologist who was a member of the multi-disciplinary team.

We found well-co-ordinated multi-agency support at an early stage was important in tackling any early emerging concerns and promoting people's well-being.

Practice examples:
In Pembrokeshire County Council we found the disabled children's team was integrated within the social services and housing directorate. Team members were positive about the integration and expressed the significant benefits of working with other teams within the directorate to deliver a joined up service, improving safety and well-being outcomes for people.

In Carmarthenshire County Council we found a strong emphasis on professional disciplines working together; for example an educational psychologist was part of the 0-25 Disability Team. There were other specialist posts in the team providing specialist knowledge.

We saw how local authorities and health boards were making efforts to achieve a more joined up strategic approach to the advantage of disabled children and their families. There were some examples of disabled children with very complex needs, where there was little evidence of joint working or reference to significant professional health involvement in their care, where we would have expected to see this in place. We also found examples where disabled children would have benefitted from jointly funded care and support.

Supporting children and young people with complex needs requires integrated commissioning and collaborative services, which are flexible and resilient enough to meet ongoing and changing needs in a sustainable way.

There were many positive examples of effective partnership working and regional collaboration, particularly during the pandemic, between local authorities, health, education, housing and care providers. We saw positive examples of a multi-agency approach to risk management with local authorities and their partners sharing information to ensure disabled children's well-being was promoted and protected.

The best outcomes for disabled children and their families were achieved when partners worked co-productively to find solutions with a focus on people and their outcomes and the delivery of seamless and sustainable services.

Practice example: Gwent Regional Complex Care panel discusses children's cases where issues of dispute / barriers to multi-disciplinary team working have arisen relating either to service provision, practice approaches or financial contributions. This panel seeks to achieve greater consistency of practice and funding agreements at a regional level so that children with complex needs and their families experience seamless co-ordinated support. Through the Partnership Board, a regional decision making pathway was developed to support partnership working for children with complex needs and disabilities.

Overall, during the pandemic we have seen partnerships developing and strengthening. Further work is required to maximise partnership working at all levels.

Practice learning point and area for improvement:

- with the anticipated challenges ahead for local authorities, health boards and service providers, it is vital they continue to focus efforts to achieve a more joined up strategic approach to the advantage of disabled children. This includes greater collaboration and an increase in joint commissioning arrangements, which focuses on people and outcomes

Key finding 13: Transition: Transition arrangements for disabled children must be strengthened

‘A child with a disability has the right to live a full and decent life with dignity and, as far as possible, independence and to play an active part in the community.’ Article 23 UNCRC

What people told us about transition arrangements for disabled children:

> **“Our daughter is 18 and has one more year at school. We have had very little input about next steps and transition to further education or independent living. All actions have been self-initiated.”** *(Parent /Carer)*

> **“There’s a sense that transition is done to rather than with the young person. They need information sooner and clarification of what will change and who will be doing what.”** *(Professional)*

> **“I have a child transitioning from child to adult. No social worker due to staff sicknesses and obviously lockdown. There needs to be more forward planning for parents and carers and better support. Many parents and carers are worried what will happen next.”** *(Parent/Carer)*

Overall, we found varying transition arrangements in place across Wales. In some local authorities, pressures on adult care and support teams, at times resulted in the late allocation of adult social workers to young disabled people, transitioning from children’s to adult services. This meant there was less time for planning and relationship building with young disabled people and their families. We found funding pressures, workforce capacity and a lack of a shared vision of those involved were barriers to effective transition.

Some improvements were required with regards to transitions within health. For example, the handover of care and support to psychiatrists for young people with severe cognitive impairments worked better than the handover to general practitioners (GPs) for young people with moderate cognitive impairments. Review systems were in place to co-ordinate the transition of inputs from health and social care professionals for young people with severe physical impairments or multiple impairments. Some health managers we spoke to believed management of transition within health worked better for young people with a learning disability than for other disabled children. We were informed transitions for young people with less complex needs sometimes resulted in a gap in service provision and more could be done to prevent the risk of crises for these young adults.

We saw examples of PAs involvement with care experienced disabled young people. Some PAs were less confident or clear in their role with disabled young people. Senior managers should convey clear expectations to PAs in line with their relevant code of practice and address any training needs.

Children leaving residential schools and/or moving into adult living arrangements did not always know of plans sufficiently in advance. This does not allow for the co-productive approach to disabled young people expected from the 2014 Act.

Some parents/carers told us planning for their child's transition between schools, to adult services, to independent or supported living could have been better. Of the parents/carers surveyed approximately 44% of those who responded to the question felt professionals from social services, education, health and other agencies had worked 'well' or 'very well' together and with the parent/carer to plan for changes/transition in respect of their disabled child/ren.

The best examples of transition were based on effective communication, strength-based practice, good relationships and partnerships, effective planning involving the disabled child, their parents/carers and where applicable relevant others for example service providers, education, health and housing.

Practice example: Cardiff Council had made significant progress for disabled children and young people following the development of a regional joint protocol and the additional investment from the Integrated Care Fund supporting the transition team. The implementation of a multi-agency panel process for planning had significantly improved communication and joint working across children's and adult's services and other agencies. The leadership provided by education services alongside social services had enabled a joint approach to transition planning, and alignment of delivery across the Social Services and Well-Being (Wales) Act 2014 and Additional Learning Needs and Education Tribunal (Wales) Act 2018.
The multi-agency planning forum has also added appreciation across service areas of the roles and responsibilities for those involved in supporting a young person's transition.

Some local authorities had developed strategies around supporting accommodation options, education, employment and training for young disabled people. We saw examples of disabled young people accessing a range of further education, employment and social activities to pursue their interests and maximise their independence. Approximately 39% of parents/carers who responded to the statement 'I feel supported to help our disabled child become as independent as they can be,' answered either 'agree' or 'strongly agree'.

Practice learning points and areas for improvements:

- disabled young people must be actively involved in planning for their future and provided with information in a timely manner
- improvements are needed to ensure transition planning across Wales is undertaken in a timely way and is a collaborative process, which prepares disabled children for the transition to adulthood, including the development of skills
- options and access for disabled children in relation to accommodation, education, training and employment need to be strengthened and maximised

Key finding 14: Children and Young People's Continuing Care: The understanding and application of the Children and Young People's Continuing Care Guidance needs to be improved and embedded

The Children and Young People's Continuing Care Guidance issued by the Welsh Government sets out an equitable, transparent and timely process for assessing, deciding and agreeing bespoke packages of continuing care for those children and young people under the age of 18 who have continuing care needs that cannot be met by existing universal and specialist services alone. The guidance has been designed for use by all those planning and providing children's continuing care services in Local Health Boards (LHBs) and local authorities and their partners. It describes the interagency process, led by LHBs, that all organisations should implement in assessing needs and putting in place bespoke packages of continuing care for those children and young people who require it because their needs cannot be met by existing universal or specialist services alone.

From our findings in relation to care and support plans for disabled children with more complex needs, and interviews with senior managers from local authorities and health boards, there was not always a shared understanding of their financial responsibilities for children subject to continuing care.

Use of the Children and Young People's Continuing Care Guidance issued by the Welsh Government will help agencies ensure:

- children, young people, their families and carers are actively engaged in the continuing care process
- the continuing care process is co-ordinated and consistent between organisations
- health, education and social care practitioners, (including those working in the independent and third sectors) and service users, understand the continuing care process and use it effectively

Practice learning point and area for improvement:

- further work is required to raise awareness, implement and embed the Children and Young People's Continuing Care Guidance – January 2020

Key Findings

Prevention

Prevention

15. Opportunities for timely early intervention for disabled children and their families must be strengthened

16. Improvements must be made to ensure sufficient service provision that promotes the well-being of disabled children

17. Consultation with disabled children and their parent/carers needs to be strengthened

18. The provision of aids, adaptations and assistive technology to disabled children must be strengthened

19. Opportunities for disabled children to access to a range of inclusive play, social and recreational activities needs to be strengthened

Key finding 15: Early intervention: Opportunities for timely early Intervention for disabled children and their families must be strengthened

‘Prevention is at the heart of the Welsh Government’s programme of change for social services. There is a need to focus on prevention and early intervention…to make social services sustainable….It is vital that care and support services do not wait to respond until people reach a crisis point.’ Part 2 Code of Practice (2014 Act)

The 2014 Act reinforces the principle of supporting families in caring for children, keeping families together in a safe, supportive and stable environment. It focuses on earlier intervention to prevent needs becoming critical.

What parents/carers told us about early intervention:

> “It is OK once you are in the system – getting in is the problem.”

> “They keep telling me my child does not meet their criteria. I do not know who else I can go to.”

The provision of preventative and early intervention services can reduce the escalation of need and risk, and improve personal outcomes. Identifying need at its earliest point and providing appropriate information, advice, assistance, when required can delay or prevent escalating need which can often be detrimental in terms of people’s well-being.

Practice example: In Rhondda Cynon Taf County Borough Council we found the Children with Additional Needs Service (CANS) which is part of the early help Resilient Families Service, was an effective and valued service which focused on family strengths and the achievement of personal outcomes. Disabled children receiving ‘early help’ from CANS benefitted from clear plans which focused on individual outcomes and reflected the family’s existing strengths. Practitioners working in CANS had received a wide range of training in behavioural and therapeutic approaches. Data provided to us indicated 95% of parents felt more able to manage independently following their involvement with CANS.

We saw a range of preventative services across Wales for disabled children. Although some parents/carers and professionals talked about a ‘postcode lottery’ in relation to services and access to services. Some parents/carers described numerous attempts to access support without success. Many parents/carers described confusion or misunderstanding about the eligibility criteria to access statutory services and were not clear of the reasons why their disabled child/ren did not meet the eligibility criteria to access statutory services.

We found a number of local authorities were focusing on strengthening prevention and early intervention and reviewing models of practice/service provision.

Practice learning points and areas for improvement:

- opportunities for timely early intervention for disabled children and their families need to be strengthened
- clear and accessible information should be provided in relation to eligibility criteria to access statutory services

Key finding 16: Service provision: Improvements must be made to ensure sufficient service provision is available to promote the well-being of disabled children. This is a priority area for improvement

Section 15 of the 2014 Act requires local authorities to provide or arrange for the provision of a range and level of services which it considers will contribute towards preventing or delaying the development of people's needs for care and support, promote the upbringing of children by their families where that is consistent with the well-being of children, reduce the needs for care and support of people who have such needs.

What parents/carers told us about service provision for disabled children:

> **"Whilst our key worker does make an effort on our behalf, their hands are somewhat tied by lack of resources."**

> **"Accessing support for our family is very difficult. Services are difficult to find. Information is sparse, spread out and not readily accessible. Services lack a coherent or joined up model."**

Parents/carers who were receiving support generally valued the support they and their disabled child/ren received. However, many felt they and their disabled child/ren would benefit from additional services/support. Of the parents/carers surveyed a majority told us they had asked social services for support, for example sitting service, short breaks - including overnight breaks to enable them to have a break from their caring role. Not all were provided with the support they had requested and felt was needed.

The range of services available to disabled children varied across Wales.

People told us of gaps in service provision and of waiting lists for some services including but not limited to: short break services (including overnight/ residential short breaks), behavioural support and occupational therapy services. Before the pandemic there were gaps in some service provision, pressure on some services and waiting lists for some services for disabled children and their families. Factors related to the pandemic have compounded the situation.

We heard of pressures in child and adolescent mental health services (CAMHS). We also heard of long waiting times for children to have an autism assessment and the significant impact this had on families seeking to understand their child and know how best to care and support them.

During the pandemic services for disabled children and their families were significantly disrupted. Some services such as 'short break residential services' closed entirely or for periods of time as a result of local circumstances. Problems encountered included workforce shortages due to various reasons including staff shortages and imposition of restrictions. Many services operated differently. Some service provision was reduced and/or offered on the basis of need, risk and impact on disabled children and their families.

Leaders and senior managers were aware of gaps in service provision and pressure on services. We saw examples of action taken by some local authorities to address gaps in provision for example the use of funding to employ a psychologist, commissioning of behavioural support and therapeutic services to support disabled children and their families. However, very often capacity of services were insufficient to meet demand and need, for example short break overnight/residential provision.

Generally, local authorities had oversight of waiting lists. Having to wait for services can adversely impact the well-being of disabled children and their parents/carers and families.

Practice learning points and areas for improvement:

- local authorities and health boards should ensure those waiting for a service are regularly reviewed, risk assessed, interim arrangements explored and contingencies plans are discussed and agreed with families
- current service provision for disabled children and their families must be evaluated and planning of services undertaken against projected future needs, focusing on a 'whole system' approach to service provision

Key finding 17: Consultation: Consultation with disabled children and their parents/carers needs to be strengthened

We saw some examples of consultation with disabled children and their families regarding service development and delivery. When asked if their local authority had sought their views on how services for disabled children and their families could be improved, approximately 64.5% of parents surveyed who responded to the question replied "no."

Practice learning point and area for improvement:

- further work is required to ensure the views of disabled children and their families are sought regularly and feed into the systems for mapping of unmet need, service gaps and service development

Key finding 18: Assistive technology, aids and adaptations: The provision of aids, adaptations and assistive technology to disabled children must be strengthened

‘Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life’ Article 26 UNCRPD

We saw aids and adaptations provided to support disabled children’s needs. During the pandemic, the length of time for the provision of aids and adaptations increased due to a number of reasons.

We found occupational therapy waiting lists existed in many areas. Local authorities were monitoring and risk assessing waiting lists.

We saw some evidence of the use of assistive technology to support parent/carers, reduce risk, and promote independence for disabled children/young adults.

Practice learning points and area for improvement:

- waiting times for occupational therapy, aids and adaptations do not meet with the intentions of the 2014 Act and must improve to support disabled children and their families’ well-being
- local authorities should consider how they can maximise the use of assistive technology to support disabled children’s well-being and maximise their independence

Practice example: In Conwy County Borough Council we heard how assistive technology was used to reduce risks for a disabled child. The use of the technology had also resulted in improved outcomes for the parent/carer who described the technology as “an absolute life saver.”

Key finding 19: Inclusion: Opportunities for disabled children to access a range of inclusive play, social and recreational activities needs to be strengthened

The Equality Act 2010 places a legal duty on service providers and those providing goods and facilities to make reasonable adjustments for disabled people so they are not at a disadvantage compared to non-disabled people.

We found the opportunities across Wales for disabled children to access inclusive play, social and recreational activities was variable.

Children we spoke with had varying experience of accessing out of school social and recreational activities. Activities accessed included horse riding, sports clubs, scouts and guides, youth clubs, dance and drama groups. Of the activities attended, some were inclusive and some were activities specifically aimed at disabled children. The children we spoke with expressed no distinct preference between the two, some who attended activities solely for young disabled people enjoyed being with people they felt were similar to them, where they felt understood but equally enjoyed being in more inclusive environments with a broad variety of other young people. There were a few examples given where young disabled people described being ‘pushed aside’ in inclusive activities or not given the support they needed to engage on a similar level to their non-disabled peers. The children identified further activities they would like to get involved in which they believed were not accessible to them for a range of reasons.

Overall, approximately 35% of parents/carers surveyed who responded said they ‘agreed’ or ‘strongly agreed’ their disabled child/ren had access to a range of activities outside of the home to have fun and make friends. Some parents felt there was not enough childcare, for example nurseries, playgroups and child minders available in their area for their disabled child/ren.

Practitioners we spoke with had a good understanding of the social model of disability and were aware of the barriers for disabled children and their right to equality of access.

We saw positive examples of inclusive play and community services some of which were run by third sector organisations. We saw the efforts made by local authorities to develop inclusive sports and leisure opportunities for disabled children.

Practice example: The Play Service provided by Torfaen County Borough Council provided play and recreational support packages to over 200 children who required support. This included children with a range of needs including complex needs. Through multi-agency working, tailored support packages were put in place to enable disabled children and young people to access play and recreational provision within their community and champion their right to play. By working in partnership with families, schools, Community Nursing Teams and third sector partners, the Play Service was able to provide play support to disabled children.

Practice learning points and areas for improvement:

- improvements are required in relation to the provision and range of childcare and social and recreational services for disabled children and young people
- the views of disabled children and their families should be sought in relation to identifying gaps in services provision and the development of inclusive community services/resources for disabled children

Conclusion

We found local authorities and their partners demonstrated a desire and commitment to supporting disabled children and their families to achieve good outcomes. They need to build on their expressed desire and commitment to progress their plans for service delivery, which are consistent with the requirements of the 2014 Act. A rights-based approach must be at the core of planning and service delivery.

Social and health care services are facing unprecedented challenges in responding to the pandemic. The pandemic has had an impact on all of us, but particularly children and young people, disabled people, unpaid carers and older people. The pandemic continues to make worse the existing barriers disabled people already face, has exposed new issues and highlighted where things need to and can change quickly to improve people's outcomes. For example, many local authorities during the pandemic have fast tracked their processes to enable more timely decision making.

Welsh Government's 'Social Care Recovery Framework – Improving Health and Social Care (COVID-19 Looking Forward)' sets out the recovery priorities that need to be in place to support:

- people (including children and young people) who need care and support, or who are at risk of needing care and support, and their families
- unpaid carers who need support
- the social care workforce
- service providers (including regulated care providers), employers, and commissioners

The Welsh Government's white paper Rebalancing care and support (2021) proposes the current arrangements for social care need to be strengthened and re-aligned to respond to the range of challenges facing the sector, and to achieve the vision for social care set out in the 2014 Act, supporting people to achieve their well-being outcomes.

It is essential moving forward there are adequate resources to enable services for disabled children and their parents/carers to fully recover, develop and improve. Local authorities and partners need to build on what has worked well during the pandemic, maximise opportunities to innovate and reshape services. This will help to meet the needs of disabled children and their families and create inclusive communities which enable disabled children to flourish.

Public services in Wales will need to comply with the requirements of the Statutory Code of Practice on the Delivery of Autism Services, which was implemented from September 2021. The Code sets out what autistic people, their parents and carers can expect from public services in Wales. RPBs will need to ensure they consider the needs of autistic people when they are future planning. They will need to take account of all aspects of public service delivery including assessing how charities and the third sector can help. Local authorities, local health boards and NHS trusts must have regard to any guidelines set out within the Code and accompanying guidance.

This review identified similarities and differences relating to the provision of information, advice and assistance for disabled children and their families across Wales. We identified key findings, areas of good practice and areas which need strengthening and improving. Some of our key findings echoed some key issues identified by the Children's Commissioner for Wales.[17]

At times there was disconnect with what local authorities told us and what parents/carers told us. This highlighted the importance of local authorities and partners seeking the views and listening to disabled children and their parents/carers, and effective regular consultation with disabled children and their parents/carers. This is vital in ensuring there is a shared understanding of what is working well and what needs to improve to support disabled children to reach their full potential and flourish.

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[17] Children's Commissioner for Wales Annual Report 2020/21 (childcomwales.org.uk)

What happens next

The findings from our review should be considered by local authorities, local health boards and their partners to help support improvement across social and health care services for disabled children and their families across Wales.

Local authorities, local health boards and service providers are likely to face challenges as they continue to provide services for disabled children and families whilst responding to the pandemic. As services begin to recover, it is imperative local authorities and their partners work together to ensure disabled children and their families achieve good outcomes and drive a rights-based approach. Our ongoing programme of inspection and review will take into consideration the risks and challenges facing local authorities, as well as their achievements and developments. We look forward to hearing and seeing positive examples of practice which promote good outcomes for disabled children and their families.

Acknowledgements

We express our thanks to everyone who contributed to this review, in what has been a particularly challenging time.

We thank everyone who shared their views including key stakeholders who provided us with information which informed our key lines of enquiry; practitioners and local authorities who participated in our peer inspector pilot; local authorities and health boards for their positive response to the review, even at the most challenging stages of the pandemic; Learning Disability Wales for their support in developing the easy read parent/carer survey and overview report, and facilitating engagement events with disabled children; HIW for supporting our work; and finally the disabled children and parents/carers who took the time to share their views.

All contributions have been greatly valued and appreciated.

Appendices

Our Approach

What we did. We:

- worked with key stakeholders to develop the key lines of enquiry for the review
- worked with HIW to understand how health and social care services interact and contribute to the experience and outcomes for disabled children and their parents/carers who need support
- issued all 22 local authorities in Wales with a self-evaluation. Despite the disruption of the pandemic, local authorities completed their self-evaluations, which provided detailed information about services for disabled children across Wales. The self-evaluations provided both quantitative and qualitative information[18]
- carried out inspections of disabled children's services in Ceredigion County Council, Conwy County Borough Council, Rhondda Cynon Taf County Borough Council, and Torfaen County Borough Council. In total, during these inspections we viewed 180 case files. We received survey responses from 162 parents/carers and 172 local authority staff
- spoke with and/ or received feedback from disabled children, parents/carers, and professionals from local authorities, health, independent and voluntary care sectors
- in addition to the four inspections we undertook performance review/ assurance activity in Cardiff Council, Pembrokeshire County Council, Carmarthenshire County Council, Gwynedd Council and Merthyr Tydfil County Borough Council, all of which included a focus on disabled children, including review of 20 case files. We spoke with parents/carers of disabled children and a range of professionals from local authorities, health, independent and voluntary care sectors. We issued a 'parent/carers survey' and received 114 responses from parents/carers living in the local authority areas. In addition to these responses we received a further 22 survey responses from parents/ carers living in six local authority areas where we did not undertake a specific focus on disabled children. The rate of parent/carer survey responses received in respect of individual local authorities in which we had undertaken an inspection or performance review/ assurance activity varied considerably across Wales. 85 responses was the highest response rate received and 10 responses was the lowest rate received
- arranged three engagement events with disabled children from across Wales
- reviewed the Welsh Government's official statistics and research in relation to disabled children receiving care and support, available at https://statswales.gov.wales

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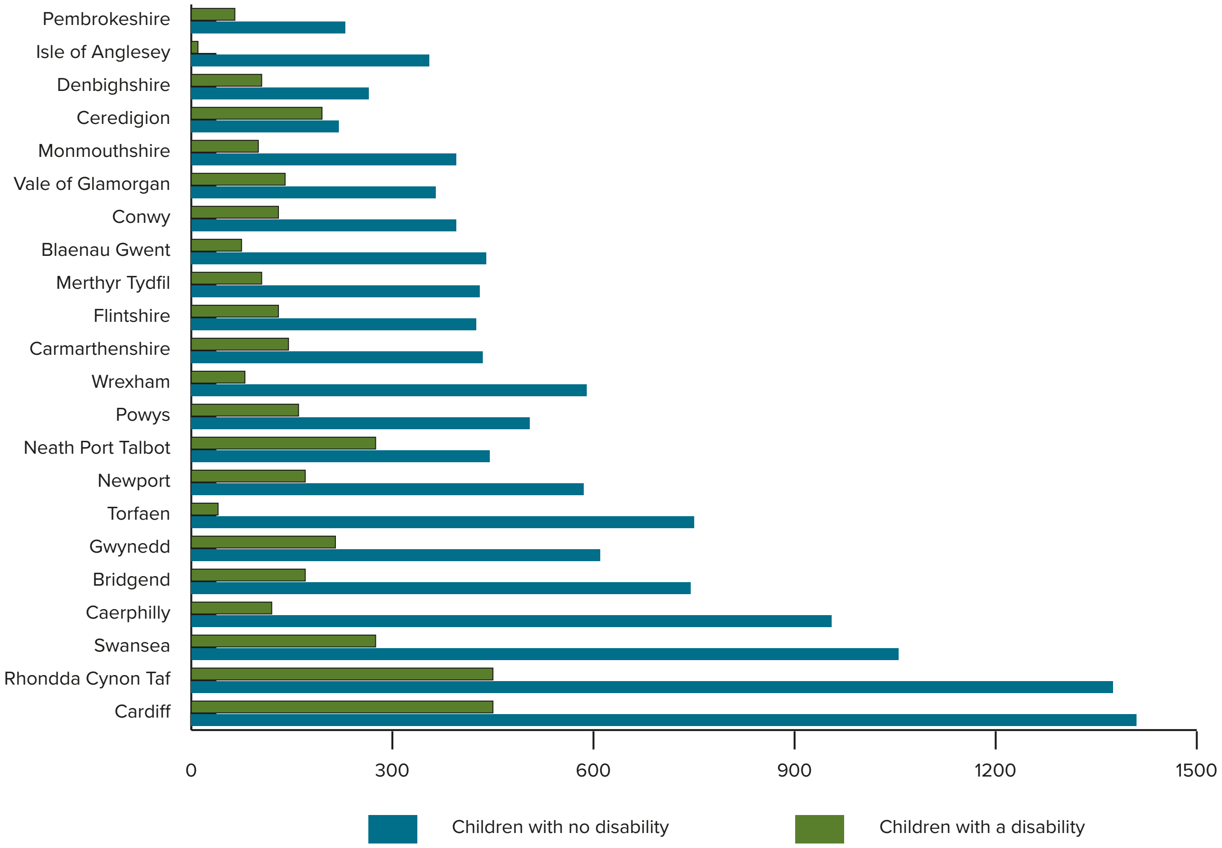
[18] Data disclaimer: The data presented from self-evaluations made by local authorities across Wales during the timeframe of 1 October 2018 to 30 September 2019 for the four local authorities who had a disabled children's inspection, and 1 October to 31 December 2019 and 1 May to 31 July 2020 for the remaining 18 local authorities. Inaccuracies and inconsistencies can exist where questions have been misinterpreted, therefore the data should be viewed as illustrative only. CIW cannot be held responsible for any inaccuracies in data provided by organisations other than Welsh Government.

Children receiving care and support at 31 March 2020, by local authority and disability



Children receiving care and support at 31 March 2020, by looked after status and disability