

Senedd Cymru | Welsh Parliament

Y Pwyllgor Plant, Pobl Ifanc ac Addysg | Children, Young People and Education Committee

Gwasanaethau i blant sydd wedi bod mewn gofal: archwilio diwygio radical | Services for care experienced children: exploring radical reform

Ymateb gan Anabledd Dysgu Cymru | Evidence from Learning Disability Wales

Before care: Safely reducing the number of children in the care system

Please outline a maximum of three top priorities for radical reform of services for safely reducing the number of children in the care system.

Priority 1

Our work with parents with a learning disability

Parents with a learning disability and their children experience significant discrimination and disadvantage. While there is established positive practice in supporting these parents, provision is still poor. We aim to change this situation in Wales by influencing the development and implementation of relevant legislation, policies and practices that directly or indirectly affect parents with a learning disability.

In order to achieve this, we facilitate network meetings across Wales for parents and professionals to share experiences, ideas and good practice. We also promote positive practice across Wales to parents, professionals and practitioners and raise awareness of the specific needs of parents with a learning disability.

Our previous partnership project Working Together with Parents Network in Wales, which ended in August 2019, aimed to improve support for parents with a learning disability in Wales, England and Scotland. As well as lobbying for new guidance, we have also worked and lobbied for improvements that have arisen in the report. Including:

- Children's and adult services should work together to agree joint protocols for referrals, assessments and care pathways. Identification of needs must take place as early as possible, preferably as soon as pregnancy is confirmed.
- Parents with a learning disability need information in a format they can understand as they may have low literacy skills or communication difficulties.
- Parenting programmes need to be adapted to the specific needs of parents with a learning disability.
- Support should be on-going and long term.
- All parents should have access to an independent specialist advocate if their children are the subject of child protection and/or care proceedings.
- Training for professionals such as social workers, health visitors and court staff. We have been pleased to provide some diversity training to Cafcass Cymru.

Further details on the above are included in the attached position paper that we produced as part of the project in 2019.

There are a few specific things we want to draw attention here.

Priority 2

Improvement for victims of domestic abuse

One area that could help improve support for parents with a learning disability is better support for victims of domestic abuse. Here it would have been good to look more at the experience of disabled women and why they are more vulnerable to abuse and exploitation than other women. Disabled women, especially women with learning disability, often experience abuse at the hands of partners who they rely on for support. Leaving the abusive relationship can then also mean losing that support. While this is an issue that is particularly pronounced for disabled women, economic and other material factors can be a major factor in keeping people in abuse relationships. Welsh Government should be more explicit on how it plans to empower women to leave abusive relationships by making sure they do not lose vital support when they leave a relationship.

Women with a learning disability are also at higher risk of being targeted by men with a history of domestic violence and/or child abuse. This in turn increases their risk of having their children taken away as they are not deemed capable of protecting them from harm. Lack of understanding and awareness of abusive relationships is often a significant risk factor for mothers with a learning disability. Many people with a learning disability have experienced some form of abuse for most of their lives, from childhood bullying to being shouted at in the street or even physical assault. In these situations, abuse has simply become an accepted part of their daily lives. This can make it difficult to recognise the fact that they may be in an abusive relationship. People with a learning disability also tend to have very restricted social circles, with few friends or relationships outside their immediate family or carers. This makes them vulnerable to abuse from people who may want to take advantage of them, for example financially, sexually or emotionally. They are vulnerable to what is sometimes referred to as 'mate crime', a form of abuse where someone befriends a person with a learning disability in order to take advantage of them. People with a learning disability often believe that these individuals genuinely care about them and are very reluctant to give up these relationships, even if they are being advised that they risk having their children removed if they do not eliminate these individuals from their lives. Many also have very little knowledge or understanding of paedophilia as it has never been explained to them and therefore they do not know how to protect their children and keep them safe from abuse.

Support for victims of domestic abuse is now always accessible for people with a learning disability as professionals often do not have experience of working with this vulnerable group. Training should be provided on how best to support people with a learning disability who experience domestic abuse and services should ensure that information is provided in an accessible format.

Priority 3

Child poverty

We would like to emphasise the need to tackle child poverty in Wales and to do so by looking at the specific links between disability and poverty. A study into the finances of families of disabled children conducted in 2018 found that only 18% of respondents said that their disability benefits could cover the extra costs linked to their child's disability or health condition. These extra costs are significant, with 33% paying over £300 a month and 10% paying between £500-£1000 a month in

disability related costs. 36% reported that changes to the benefits system in the past 2 years had left them worse off. These disadvantages will have been made worse by the effects of the pandemic and the extra pressures experienced by families. The Committee should pay special attention to how policy decisions will affect economically disadvantaged families with disabled children and young people as poverty can also be a significant contributing factor to parents ability to take care of their children.

In care: Quality services and support for children in care

Please outline a maximum of three top priorities for radical reform of services for children in care.

Priority 1

Independent support

People with a learning disability often are under special scrutiny compared to the rest of the population when they become parents. Many are often already in contact with social services and the challenges they face as parents are often treated as more significant. Stigma, stereotyping and negative societal attitudes towards people with a learning disability and their ability to parent safely also contribute to increased levels of scrutiny and high levels of child removal. As a result, people with a learning disability who have children will often live in constant fear of losing their children.

At the same time that parents with a learning disability can be under additional scrutiny, they also often do not receive the level of support they need to have their own needs met, impacting their ability to be the best parents to their children. In many cases the lack of adequate specialist support for parents with a learning disability in Wales is a contributing factor in the removal of their children. Services such as the Ymbarêl project run by Action for Children in Cardiff and the Vale provide intense specialist support for families where one or more parents has a learning disability that can reduce the risk of children being taken into care. While some parents with a learning disability may only need support for a relatively short period of time, most will need some form of on-going support. Firstly, people with a learning disability may be able to learn new things but their cognitive impairment does not go away and therefore they may need assistance with daily living for the rest of their lives, especially as new situations arise. Secondly, children and their needs change over time. Support services should be available to help parents to promote their child's welfare at different ages and in a variety of situations.

We therefore emphasise the need to offer independent and person centred support to people with a learning disability. This includes specialist independent advocacy for any parent with a learning disability going through the child protection process. It is very important that parents have access to independent advocacy at an early stage and that advocates have appropriate skills and knowledge of both learning disability and child protection issues. Generic advocacy services often lack this specialist knowledge and expertise, and many are unable to accompany parents in court. Self-advocacy can also be a very important tool to help parents improve their confidence and self-esteem. This in turn can enable them to improve their parenting skills and develop strategies for dealing with bullying and harassment. Advocacy and self-advocacy organisations need adequate funding in order to provide good quality support.

Welsh Government has commissioned an important piece of work to develop guidance for professionals on supporting parents with a learning disability with the aim of reducing the number of children taken into care. When the guidance has been published, we suggest that the Committee

could conduct an inquiry into how social workers are implementing the new guidance and ensuring that parents with a learning disability get the right support to help keep more families together.

Priority 2

Getting support for disabled children

We have anecdotal evidence from our members that parents with a learning disability will sometimes struggle to get appropriate assessment and support for their children's support needs. We know that some conditions like autism or other neurodivergences run in families. This means that both parents and children may have support needs that need to be met. Our evidence from members suggests that in at least some cases parents with learning disabilities have struggled to get their child's support needs assessed as their behavioural difficulties are simply seen as a result of poor parenting. Here it is important that the support needs of parents and children are both taken seriously and given the attention they need. Again, we would also like to emphasise the importance of advocacy in this context to make sure that people with a learning disability are not denied their support.

Other research

We would like to draw your attention to the 2019 Welsh Government commissioned report Research on the number of children in Wales placed into care from parents with learning disability and the reasons behind their removal, which outlines a number of different reasons that parents who have a learning disability are more likely to have their children taken into care. We also have evidence that many of the factors that made life hard for parents with the learning disability have worsened as the result of the coronavirus pandemic and lockdown measures.

Priority 3

After care: On-going support when young people leave care

Please outline a maximum of three top priorities for radical reform of the on-going support provided when young people leave care.

Priority 1

Priority 2

Priority 3

Anything else

All of our points are about preventing children going into care needlessly. I had to spread them across the different forms.

Position paper: Parents with a learning disability in Wales – the need for research, guidance and training

Working Together with Parents Network

Our aim is to:

- improve support for parents with a learning disability and their children
- increase the chances of families where one or more parents has a learning disability to continue living together in a positive home environment that meets the children's needs. This in turn could reduce the number of children taken into care and improve long term outcomes for families.

How can this be achieved?

- Research into families where one or more parents has a learning disability.
- Guidance for professionals on how to support parents with a learning disability.
- Education and training for both people with a learning disability and the professionals who work with them.

How can Learning Disability Wales help?

We at Learning Disability Wales have over 30 years' experience in the field of learning disabilities in Wales. We are highly skilled in the provision of training and accessible information. We have a proven track record of delivering projects aimed at improving the lives of people with a learning disability including conducting research, delivering training and developing guidance. We have been working with parents with a learning disability and the professionals who support them throughout Wales for several years as part of our networks. These networks provide us with first-hand evidence of the issues that parents face, examples of good practice and a unique opportunity to consult with both parents and professionals.

Background

It is estimated that approximately 40-60% of parents with a learning disability have their children taken into care¹. We do not have any accurate data on the situation in Wales but given that Wales has a higher rate of looked after children it is likely that there are significant numbers of parents with a learning disability in Wales who do not live with their children.

Children whose parents have a learning disability and who are in contact with children's social services have high levels of needs. Effective joint working across all agencies, particularly children's and adult social services, is essential to ensure positive outcomes for children and their families. However, joint working between children's and adult services is often patchy or non-existent, with little understanding or awareness of each other's ways of working. Safeguarding and promoting the welfare of children is paramount and this must obviously apply equally to the children of parents with a learning disability. However, these families have specific needs that require specialist knowledge and skills to enable the professionals working with them to provide a fair and equitable service. Many social workers do not feel adequately equipped to provide the specialist support parents with a learning disability need, especially when trying to navigate the child protection process. Children's social workers often lack the knowledge and skills to work effectively with parents with a learning disability while adult social workers may not have sufficient knowledge and understanding of the child protection process to effectively support them. In many cases there are

¹ Wilson and colleagues, 2013

also issues around whether or not the parent meets the eligibility criteria for support from adult services.

Failure to provide adequate support to parents with a learning disability is likely to be detrimental to the children's welfare and could potentially be a breach of both the children's and parents' rights under the United Nations Convention on the Rights of the Child, United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), Equality Act 2010 and Human Rights Act 1998. For example, Article 23 of the UN Convention on the Rights of Persons with Disabilities (UNCRPD) makes it clear that people with a learning disability have a right to relationships and family life. They have the right to choose who they live with and this includes living with a partner or spouse and any children they may have. The UNCRPD also states that disabled people have the right to:

- “have access to age-appropriate information, reproductive and family planning education”
- “decide freely and responsibly on the number and spacing of their children” and
- “appropriate assistance [...] in the performance of their child-rearing responsibilities”.

Welsh Government's Learning Disability Improving Lives Programme (June 2018) makes reference to the fact that “parents with a learning disability need more tailored support to enable them to keep their children where possible”. The Care and Support (Eligibility) (Wales) Regulations 2015 include “maintenance or development of family or other significant personal relationships” and “fulfilment of caring responsibilities for a child” within the eligibility criteria for adults who need care and support. Parents with a learning disability must therefore be given every opportunity to show that they can parent safely and be ‘good enough’ parents with appropriate support. They are entitled to equal access to services, including parenting support and information services. Public bodies have a duty to “advance equality of opportunity”² for people with a learning disability and to make reasonable adjustments to policies, practices and procedures where necessary.

In many cases the lack of adequate specialist support for parents with a learning disability in Wales is a contributing factor in the removal of their children. Services such as the Ymbarêl project run by Action for Children in Cardiff and the Vale provide intense specialist support for families where one or more parents has a learning disability that can reduce the risk of children being taken into care. [Shared Lives](#) can also offer support to parents with a learning disability to develop their parenting skills, increase their confidence and improve their chances of keeping custody of their children.

Recommendations

Research

This is a complex issue with many contributory factors that will not be resolved overnight. Anecdotal evidence appears to suggest that there are many reasons for the removal of children from parents with a learning disability, not simply their IQ or parenting skills. We therefore believe that a good starting point would be to carry out some research into families where one or more parents has a learning disability in Wales. For example:

- Which parent has a learning disability eg mother, father or both
- How many of these parents live with their children
- How many have children deemed to be ‘at risk’
- How many have had their children taken into care and the reasons for this
- What support has been provided to the parents, both generic and specialist (including advocacy), and how effective it was

² Public Sector Equality Duty

- What reasonable adjustments have been made to meet the needs of the parents eg easy read information, request to court for additional time, appointment of a court intermediary etc
- Where children have been permanently removed from the family home, what support has been offered to the parents to help them come to terms with this.

The data collected during this research would enable us to have a better understanding of the reasons for children being taken into care and how this situation could be improved. It would also provide a basis for the development of guidance on providing support to parents with a learning disability.

We are aware that Welsh Government recently commissioned a piece of research into parents with a learning disability in Wales and we welcome this decision. We are, however, concerned that the researchers do not appear to have contacted any members of the parents' network as part of their research and wonder how they have ensured the full participation of parents with a learning disability in the research process. We understand that the research findings will be published soon and we look forward to reading the report.

Guidance

We believe that social care professionals in Wales need guidance on how to support parents with a learning disability. England³ and Scotland⁴ have had guidance on this subject for several years. Sir James Munby, President of the Family Division (the most senior judge in the family courts in England and Wales), recently endorsed⁵ the good practice guidance in England (developed by the Working Together with Parents Network). However, we do not have equivalent guidance in Wales. This means that social workers often do not know where to go for information and advice on how to support parents with a learning disability. It also makes it difficult for parents and their advocates to complain about the support they have received as there is no 'benchmark' in Wales with which to hold professionals to account.

Any guidance that is developed in Wales should cover the following 5 key areas:

1. Clear and co-ordinated referral and assessment procedures and processes, eligibility criteria and care pathways
2. Accessible information and communication
3. Support designed to meet the needs of parents and children based on assessments of their needs and strengths
4. Long-term support where necessary
5. Access to independent specialist advocacy.

1. Children's and adult services should work together to agree joint local protocols for referrals, assessments and care pathways in order to respond appropriately to the needs of both the parents and the children. Identification of needs must take place as early as possible, preferably as soon as

³ <http://www.bristol.ac.uk/media-library/sites/sps/documents/wtpn/2016%20WTPN%20UPDATE%20OF%20THE%20GPG%20-%20finalised%20with%20cover.pdf>

⁴ <https://www.scd.org.uk/publications/scottish-good-practice-guidelines-for-supporting-parents-with-learning-disabilities/>

⁵ <https://www.judiciary.gov.uk/publications/family-proceedings-parents-with-a-learning-disability/>

pregnancy is confirmed. Eligibility criteria should allow for consideration of each family's needs and circumstances and must take into account parental responsibility. This means that any person with a learning disability who may not have previously met the eligibility criteria for services should be re-assessed if they become pregnant or have a child. According to the Social Services and Wellbeing (Wales) Act, a person's parental responsibilities must be taken into consideration as part of the assessment.

2. Parents with a learning disability often have low literacy skills and/or communication difficulties and therefore require information in an alternative format such as easy read or Makaton. They often need someone to explain information to them in an accessible way using simple language with no jargon or idioms and plenty of reinforcement to check that they have fully understood.

3. Parents with a learning disability may have difficulty interpreting and retaining information or learning new skills and therefore require extra time, alternative teaching methods and visual aids/prompts. Parenting programmes need to be adapted to the specific needs of the parent. For example, practical hands-on demonstrations, use of role-play, videos, step-by-step pictures or props, as well as regular repetition, reinforcement and opportunities to practice. Needs must be identified and assessed at the earliest possible stage, preferably during pregnancy, and support put in place as soon as possible. This is essential if parents with a learning disability are to have the best opportunity to gain the necessary knowledge and skills to look after their children safely. This is particularly important given the timescales within the child protection process as there is very limited time available for parents with a learning disability to adequately demonstrate change in their parenting capabilities. Support should focus on building strengths and must be based on respect for the parents and for the emotional bond between the parents and their children. Parents should be seen as a resource not a problem and they should be supported to feel in control and to experience being competent. Services should consider new and innovative ways to support families where one or parents has a learning disability eg peer mentoring, Shared Lives, specialist parent and child placements etc.

4. While some parents with a learning disability may only need support for a relatively short period of time, most will need some form of on-going support. Firstly, people with a learning disability may be able to learn new things but their cognitive impairment does not go away and therefore they may need assistance with daily living for the rest of their lives, especially as new situations arise. Secondly, children and their needs change over time. Support services should be available to help parents to promote their child's welfare at different ages and in a variety of situations. For example, when children start school, move to high school or during adolescence. Parents with learning disabilities are entitled to expect that organisations providing parenting support make the necessary reasonable adjustments so that they can use these generic services too. They and their children may also need access to specialist parenting support. The children of parents with a learning disability may need support in their own right. Parents may need emotional support to build their confidence or to help them deal with their feelings both during and after the child protection process.

5. All parents should have access to an independent advocate if their children are the subject of child protection and/or care proceedings so that the parents can participate fully and effectively in the proceedings. It is very important that parents have access to independent advocacy at an early stage and that advocates have appropriate skills and knowledge of both learning disability and child protection issues. Generic advocacy services often lack this specialist knowledge and expertise, and many are unable to accompany parents in court. Self-advocacy can also be a very important tool to help parents improve their confidence and self-esteem. This in turn can enable them to improve their parenting skills and develop strategies for dealing with bullying and harassment. Advocacy and self-advocacy organisations need adequate funding in order to provide good quality support.

Training for professionals

Any professional who works with families should have an awareness and understanding of the needs of people with a learning disability. This includes social workers in both children's and adult services, advocates, midwives, health visitors, Cafcass staff, Flying Start/Home Start/Families First, solicitors, family court staff etc. Staff providing direct support to families or carrying out assessments etc should have more in-depth training on how to support parents with a learning disability. Training should be provided by learning disability experts and should preferably involve people with a learning disability themselves in some way. The training should cover a range of topics including but not limited to:

- stereotyping and negative societal attitudes
- barriers to inclusion and understanding
- relevant legislation and guidance (eg Equality Act, UNCRPD, Human Rights Act, Social Services and Wellbeing (Wales) Act, Family Court guidance etc)
- accessible information
- neurological differences (eg interpretation and retention of information)
- communication difficulties
- behavioural and social challenges
- abuse, hate crime, 'mate crime' etc
- issues with friendships, relationships and sexuality.

Sex and relationships education

People with a learning disability often do not receive good quality education and information on sex and healthy relationships. Any sex education they do receive tends to focus almost entirely on how to avoid getting pregnant and never on choosing to start a family or how to look after children. This lack of education affects their knowledge and understanding of important issues such as consent, abuse, healthy relationships, pregnancy, childcare etc. This in turn contributes to their increased risk of unplanned pregnancies, being in abusive relationships and potentially having their children taken into care.

Mothers with a learning disability are particularly disadvantaged as there is a general assumption that mothers are the main caregivers. Therefore, if only the father has a learning disability but not the mother then there is a lower risk of the child being taken into care than if the mother has a learning disability but the father does not. Women with a learning disability are also at higher risk of being targeted by men with a history of domestic violence and/or child abuse. This in turn increases their risk of having their children taken away as they are not deemed capable of protecting them from harm. Lack of understanding and awareness of abusive relationships is often a significant risk factor for mothers with a learning disability. Many people with a learning disability have experienced some form of abuse on a regular basis for most of their lives, from childhood bullying to being shouted at in the street or even physical assault. In these situations, abuse has simply become an accepted part of their daily lives and this makes it difficult to recognise the fact that they may be in an abusive relationship. People with a learning disability also tend to have very restricted social circles with few friends or relationships outside their immediate family or carers. This makes them vulnerable to abuse from people who may want to take advantage of them, for example financially, sexually or emotionally (sometimes referred to as 'mate crime'). People with a learning disability often believe that these individuals genuinely care about them and are very reluctant to give up these relationships, even if they are being advised that they risk having their children removed if they do not eliminate these individuals from their lives. Many also have very little knowledge or understanding of paedophilia as it has never been explained to them and therefore they do not know how to protect their children and keep them safe from abuse.

The new Sexuality and Relationships Education (SRE) curriculum being developed in Wales provides an excellent opportunity to ensure that children and young people with a learning disability receive good quality education on sex and relationships in a way that they can understand and engage with. However, people with a learning disability need to be able to access sex and relationships information and training at various stages in their lives, not just while they are in school. There also needs to be accessible information and training on pregnancy, parenting and childcare.