

## **Agenda – Equality and Social Justice Committee**

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Meeting Venue:	For further information contact:
Committee Room 5 (Hybrid)	Rhys Morgan
Meeting date: 16 October 2023	Committee Clerk
Meeting time: 13:15 – 16:15	0300 200 6565
	<a href="mailto:SeneddEquality@senedd.wales">SeneddEquality@senedd.wales</a>

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### **Pre-meeting registration (13.00 – 13.15)**

- 1 Introductions, apologies and substitutions**  
(13.15)
- 2 Papers to note**  
(13.15)
  - 2.1 Correspondence from the Cardiff and Vale University Health Board regarding the Public Health approach to preventing gender based violence**  
(Pages 1 – 2)
  - 2.2 Correspondence with the Deputy Minister for Social Services regarding the public health approach to preventing gender based violence**  
(Pages 3 – 6)
  - 2.3 Correspondence with the Football Association of Wales regarding the public health approach to preventing gender based violence**  
(Pages 7 – 9)
  - 2.4 Correspondence with the Minister for Health and Social Services and the Chair regarding the public health approach to preventing gender based violence**  
(Pages 10 – 15)
  - 2.5 Correspondence from the Minister for Social Justice and Chief Whip to the Legislation, Justice and Constitution Committee regarding Inter-Institutional Relations Agreement: Safety, Security and Migration Interministerial Group**  
(Pages 16 – 19)



- 2.6 Correspondence from the Chair of the Children and Young People Committee to the Minister for Health and Social Care, the Deputy Minister for Social Services and the Deputy Minister for Mental Health and Wellbeing regarding the 2024/25 draft budget**  
(Pages 20 – 25)
- 2.7 Correspondence from the Finance Committee to the Minister for Finance and Local Government regarding evidence papers supporting the 2024–25 draft budget**  
(Pages 26 – 27)
- 2.8 Correspondence from the Minister for Health and Social Services regarding sexual harassment in surgical settings**  
(Pages 28 – 29)
- 2.9 Correspondence with Welsh Women's Aid regarding the "Ask and Act" programme**  
(Pages 30 – 33)
- 2.10 Correspondence from the Children, Young People and Education Committee regarding Child Poverty**  
(Pages 34 – 47)
- 3 Motion under SO17.42 (vi) and (ix) to exclude the public for items 4, 5 and 7 of today's meeting**
- 4 Inquiry into the Welsh Government's Draft Child Poverty Strategy: consideration of draft report**  
(13.15 – 14.00 ) (Pages 48 – 91)
- 5 Forward work programme**  
(14.00–14.45) (Pages 92 – 101)
- BREAK (14.45–15.15)**

**6 Data Justice: the use of personal data in the Welsh NHS – evidence session 4**

(15.15–16.00)

(Pages 102 – 122)

Alyson Thomas, Chief Executive, Llais

Professor Hamish Laing, Swansea University

**7 Data Justice: the use of personal data in the Welsh NHS – consideration of evidence**

16.00–16.15



**GIG**  
CYMRU  
**NHS**  
WALES

Bwrdd Iechyd Prifysgol  
Caerdydd a'r Fro  
Cardiff and Vale  
University Health Board

Executive Headquarters / Penodfa Gweithredol

Woodland House  
Maes-y-Coed Road  
Cardiff  
CF14 4HH

Ty Coedtir  
Ffordd Maes-y-Coed  
Caerdydd  
CF14 4HH

# Agenda Item 2.1

Eich cyf/Your ref:  
Ein cyf/Our ref: SR-jb-0923-10292  
Welsh Health Telephone Network:  
Direct Line/Llinell uniongychol: 029 2183 6010

**Suzanne Rankin**  
**Chief Executive**

20 September 2023

## **Private & Confidential**

Ms Jenny Rathbone MS  
Chair, Equality and Social Justice Committee  
Welsh Parliament  
CARDIFF BAY  
Cardiff  
CF99 1SN

Dear Ms Rathbone

Thank you for the opportunity for Cardiff and Vale UHB to contribute to the Equality and Social Justice Committee Inquiry into the public health approach to preventing gender-based violence.

The question you raise is “how statutory services deal with allegations of gender-based violence internally and to set out what procedures are in place for handling allegations of gender-based violence raised by or against employees.”

Gender-based violence by, or against, employees is taken very seriously within the Health Board. The People Assurance & Experience team and the Safeguarding team oversee all allegations of gender-based violence. The Adult Safeguarding procedures are instigated and all alleged cases of gender-based violence will always be reported to the Police and Local Authority to ensure multi-agency referral and oversight. Employees are also encouraged and supported to self-report directly to Police.

The UHB is committed to taking their responsibilities to protect employees from gender-based violence;

- Giving assurance to employees they will be heard with confidentiality
- Freedom to Speak Up process is promoted to ensure they are aware they can always contact senior members of the Executive and Board
- Assurance to employees their voice is heard and we will work with them to ensure they feel safer in the workplace
- Enforce and monitor compliance to the Lone Worker policy
- All employees identified at risk are provided with health and safety personal alarms
- Employees who have reported gender-based violence will not be moved from the work environment but the alleged perpetrator will be moved

Bwrdd Iechyd Prifysgol Caerdydd a'r Fro yw enw gweithredol Bwyrdd Iechyd Lleol Prifysgol Caerdydd a'r Fro  
Cardiff and Vale University Health Board is the operational name of Cardiff and Vale University Local Health Board

Croesawir y Bwrdd ohebiaeth yn Gymraeg neu Saesneg. Sicrhawn byddwn yn cyfathrebu â chi yn eich dewis iaith. Ni fydd gohebu yn Gymraeg yn creu unrhyw oedi  
The Board welcomes correspondence in Welsh or English. We will ensure that we will communicate with you in your language. Correspondence in Welsh will not lead to a delay



- Health & Safety team are integral to review any identified work-based risks and incidents
- The Executive Nurse Director is responsible for all safeguarding which includes any reports of gender-based violence and there is a monthly Executive oversight of all professional safeguarding concerns
- The Board receive training and awareness of all forms of gender-based violence and are briefed on all employee's gender-based violence within hospital environments

Training is key to ensure employees are informed as to what constitutes gender-based violence and how to deal with any concerns. One of the main policies is the Violence Against Women Domestic Abuse and Sexual Violence (VAWDASV).

The implementation of the Violence against Women, Domestic Abuse and Sexual Assault (Wales) Act 2015 has seen a change in the referrals, training and width and breadth of the domestic abuse agenda within the UHB.

The Regional Multi-Agency Domestic Abuse Strategy for Cardiff and Vale incorporates a plan to address service need and training actions across the locality of Cardiff and Vale of Glamorgan council area. The UHB is fortunate to have four health Independent Domestic Violence Advisors (IDVA); this service is available for employees. Domestic abuse and other forms of violence can impact negatively on an employee's health and wellbeing and staff morale. The health IDVA supports staff members experiencing domestic abuse, and within the reporting period 2022-2023 has received 45 referrals. The health IDVA has supported the staff by completing regular risk assessments and working in a client-led way to develop safety plans for them at home and in work; this includes working closely with managers, the UHB Health and Safety team and UHB security. The health IDVA has also worked closely with the Health and Safety team to put in a successful bid to the Health Charity for lone worker devices for staff experiencing domestic abuse and stalking.

In summary, we are working on a multi-faceted approach to ensure that we have a safe culture, where individuals feel empowered to call out and report any poor behaviour. When gender-based violence occurs in the workplace, we have policies to ensure that individuals are dealt with appropriately while supporting those who raise concerns. Finally, we are very clear as a Health Board what our values are, and how we operate a zero-tolerance approach to any form of gender-based violence.

Yours sincerely



**Suzanne Rankin**  
Chief Executive

Julie Morgan AS/MS  
Y Dirprwy Weinidog Gwasanaethau Cymdeithasol  
Deputy Minister for Social Services



Llywodraeth Cymru  
Welsh Government

Our ref: MA/EM/2188/23

Jenny Rathbone MS  
Chair, Equality and Social Justice Committee  
Welsh Parliament  
Cardiff Bay  
Cardiff  
CF99 1SN

10 October 2023

Dear Jenny,

Thank you for your letter of 25 September requesting further evidence for your inquiry on public health approaches to preventing gender-based violence (GBV).

**Does the Welsh Government provide targeted support to social workers to deal with cases of VAWDASV among women and children?**

There are strong links between the social services workforce teams and the delivery of the VAWDASV through a tiered training framework organised and delivered through the Regional Safeguarding Boards. Through VAWDASV grants and Social Care Workforce Grants, both funded via Welsh Government, specialist training is delivered to the social care workforce to support identification, assessment and support for cases of VAWDASV among women and children.

The ongoing specialist training social workers receive specifically develops knowledge necessary to understand domestic violence and abuse, and defines the role of professionals in ensuring people's safety. [Recognising and responding to domestic violence and abuse - A guide for social workers](#) advises social workers that if their role is specifically about safeguarding, they 'should also be confident in identifying and assessing risk (often by using the DASH – domestic abuse, stalking and harassment and 'honour'-based violence – tool), safety planning and liaising with specialist support services'.

It is important to recognise that overall responsibility for tackling VAWDASV is within the responsibilities of the Minister for Social Justice and Chief Whip's portfolio, however, the Health and Social Services sector has a vital role to play. We have published a number of statutory guidance documents under powers conferred by section 15 of the VAWDASV Act. This includes 'Ask and Act' guidance, published as part of the National Training Framework on violence against women, domestic abuse and sexual violence. The aim of

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[Correspondence.Julie.Morgan@gov.wales](mailto:Correspondence.Julie.Morgan@gov.wales)

Rydym yn croesawu derbyn gohebiaeth yn Gymraeg. Byddwn yn ateb gohebiaeth a dderbynnir yn Gymraeg yn Gymraeg ac ni fydd gohebu yn Gymraeg yn arwain at oedi.

We welcome receiving correspondence in Welsh. Any correspondence received in Welsh will be answered in Welsh and corresponding in Welsh will not lead to a delay in responding.

the Framework is to ensure that high quality and consistent training is available across the breadth of the public and specialist sector.

'Ask and Act' is a key part of the Framework and professionals who work within the field of Health and Social Services are recognised as a priority group for Ask and Act training in our statutory guidance. The 'Ask and Act' programme is a national programme and is fully operational across all regions of Wales.

### **What work is being done to protect women and their children from post-separation abuse?**

Children's and Adult's Services work alongside Domestic Abuse Resource Teams for cases pre and post separation to support safety planning. We know that the greatest risk period is when someone is separating from a perpetrator. This support can include access to a refuge, local authority housing, an allocated Independent Domestic Violence Advocate, specialist therapeutic intervention for children within the family unit, along with practical support. Such services are funded via a Welsh Government VAWDASV revenue grant, Police Crime and Commissioner, local Authorities and wider third sector funding. Children's and Adult's Services are core participants in Multi-Agency Risk Assessment Conferences, which are multiagency meetings where information is shared on the high risk domestic abuse cases, to optimise information sharing and multiagency coordination of risk management planning. Additionally, there have been developments in perpetrator programmes to develop a tiered intervention approach to address risk spectrums.

In 2020, UK Government's Ministry of Justice Harm Panel published their report '[Assessing Risk of Harm to Children and Parents in Private Law Children Cases](#)'. The report highlighted the work of Cafcass Cymru which has, as part of Welsh Government, played a positive role in the [Family Courts Pathfinder pilot](#) in North Wales since February 2022. This project aims to better safeguard and improve the experiences of victim-survivors of Domestic Abuse and other forms of harm, and specifically engages with children encountering the Family Justice system. A brief update on the progress of the Pathfinder implementation following the first year of operation can be found [here](#). Cafcass Cymru is advocating for the UK Government to roll out the pilot to other parts of Wales.

Developing this pilot would bring targeted support and protection for women and their children from post-separation abuse, as current provision falls under the remit of the VAWDASV support services. These services enable women to protect themselves from further abuse and their children from the impact of a former partner who wants to use the 'system' to extend their coercive control. Despite the effectiveness of these support services, we recognise we need to do more and I am working with the Minister for Social Justice through the VAWDASV blueprint to increase our offer here.

Responses to the consultation on the draft VAWDASV strategy highlighted the importance of understanding the impact of VAWDASV across a whole life span. There is a danger that needs of children and young people have not been adequately recognised to date. Objective 2 of the national strategy is to increase awareness in children, young people and adults of the importance of safe, equal and healthy relationships and empowering them to positive personal choices.

We are delivering this strategy and objective with a specific blueprint workstream addressing the needs of children and young people. Together with the work already done on Safeguarding and Education policy development, the group will ensure that there is clarity and cohesion in parallel approaches to Safeguarding and VAWDASV and the needs of children and young people are met.

## **How do Social Services work with schools, Cafcass and other partners to advocate on behalf of children and young people to ensure their voice is being heard?**

You ask about the role social services play in working with partners to ensure children's voices are heard. Social care practitioners are advocates for children and adults and draw wider practitioners and agencies together to ensure the individual is at the centre of planning and shaping the responses to their needs. Cafcass Cymru practitioners have a specific statutory function to ensure children's voices are heard and listened to and are appointed by the Courts.

It is imperative that children's rights are embedded throughout practice and accessible. Since 2017, as part of the National Approach to Statutory Advocacy (NASA), children and young people have a right to an 'active offer' of advocacy from a statutory Independent Professional Advocate (IPA) when they become looked after or become subject of child protection enquiries leading to an Initial Child Protection Conference. This offer enables local authorities and advocacy providers to deliver a national consistent approach to advocacy support.

A further example of national action can be seen through the All Wales Safeguarding Procedures. The Procedures and the Practice Guides which support them require each practitioner and organisation to play their part and to contribute to safeguarding and promoting the well-being of the child. This involves intra and multi-disciplinary working in order to better understand the individual and their circumstances and their needs for care, support and safety.

I hope this information is useful.

Yours sincerely,



**Julie Morgan AS/MS**

Y Dirprwy Weinidog Gwasanaethau Cymdeithasol  
Deputy Minister for Social Services

Julie Morgan MS  
Deputy Minister for Social Services

25 September 2023

Dear Julie

**The public health approach to preventing gender-based violence**

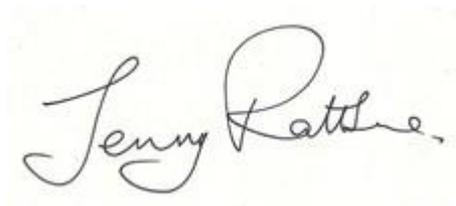
Thank you for giving evidence as part of our inquiry into the public health approach to gender-based violence.

Further to our session, we would be grateful if you could respond to the following, additional points:

- Does the Welsh Government provide targeted support to social workers to deal with cases of VAWDASV among women and children;
- what work is being done to protect women and their children from post-separation abuse; and
- how do Social Services work with schools, Cafcass and other partners to advocate on behalf of children and young people to ensure their voice is being heard?

As we are now at the end of our evidence gathering, we would be grateful to receive a response by 9 October if possible.

Yours sincerely



Jenny Rathbone MS  
Chair, Equality and Social Justice Committee

4<sup>th</sup> October 2023

Dear Jenny

Many thanks for your letter dated 27<sup>th</sup> September. We at the Football Association of Wales (FAW) recognise the power and influence of football in relation to societal issues and take this responsibility very seriously. We seek to use our position and influence to help tackle misogyny and challenge toxic behaviour. We are currently working with Welsh Government on their 'Sound' campaign and have recently filmed videos for this campaign with three of the Men's Cymru team players. We have also worked with the Welsh Government on similar campaigns previously. You can find further information on this at the following links:

[Tackling online misogyny | Herio casineb at ferched ar-lein - YouTube](#)

[CYMRU 'CALL OUT ONLY' \(aws-skybrid.co.uk\)](#)

[Cymru footballers and Welsh Government team up to tackle online sexual harassment \(aws-skybrid.co.uk\)](#)

We take a number of steps to ensure that people feel, and are, safe at events, including:

- Ahead of all senior International matches the FAW publishes supporter information that includes details of how discrimination of any sort can be reported, please see an example of this [here](#).
- This information is published to the FAW website and is linked to from newsletters that are sent to ticket holders ahead of our matches.
- The information is also accessible via the Cymru Tickets App, which every ticket holder must have to enter the stadium. As you will note, we provide a text number to report any such incidents in addition to reporting features on the FAW website.
- This information and text number is displayed on posters around the stadium on match days.
- We have a dedicated safeguarding lead in attendance at all of our home games to whom any incidents can be directly reported by stewards/match day staff.
- A dedicated safeguarding lead will also be present for all senior away fixtures going forward.

The FAW holds regular match meetings in the build-up to any games at the stadium and these procedures are regularly reviewed through this process and we seek to continuously improve.

In addition to the actions that we take on match days we are also very aware of our responsibilities as an employer. We aim to live our values of Excellence, family and respect through our behaviours and organisational culture, and we are working towards becoming a White Ribbon accredited employer.

Please do not hesitate to get in touch with us if you require any information further to the above

Yours sincerely



Noel Mooney

CEO Football Association of Wales

Noel Mooney  
Chief Executive  
Football Association Wales

27 September 2023

Dear Noel,

**Inquiry into the public health approach to preventing gender-based violence**

The Equality and Social Justice Committee is currently carrying out an inquiry into the public health approach to preventing gender-based violence. Full details for the inquiry, including our terms of reference, are available on our [website](#).

Given the potential influence of sport and sporting events on changing the culture of what is acceptable behaviour, we would be grateful if you could set out what steps are being taken to ensure that all those who attend events are made to feel safe, and what procedures are in place across sites to deal with any situations which may arise.

As we are now at the end of our evidence gathering, we would be grateful to receive a response by 11 October if possible. I am copying this letter to Sioned Williams MS in her capacity as Chair of the Cross-Party Group on Violence Against Women and Children.

Yours sincerely



**Jenny Rathbone MS**  
Chair, Equality and Social Justice Committee

Croesewir gohebiaeth yn Gymraeg neu Saesneg. We welcome correspondence in Welsh or English.



Llywodraeth Cymru  
Welsh Government

Our ref: MA/EM/2188/23

Jenny Rathbone MS  
Chair, Equality and Social Justice Committee

9 October 2023

Dear Jenny

Thank you for your letter of 25 September requesting further evidence for your inquiry on public health approaches to preventing gender-based violence (GBV). I will answer the questions in the order you posed them in your letter.

**Which health professions are required to undertake Ask and Act under the current duties and whether you have a view as to whether that duty should be expanded and to whom?**

All staff working for Local Health Boards and NHS Trusts have been and are able to access Ask and Act training.

The initial emphasis was to provide Ask and Act training to the following categories of health profession:

- Midwifery and health visiting
- General practitioners and primary care teams
- Emergency department
- Substance misuse
- Mental health
- District and community nursing
- Ambulance service
- School nursing
- Sexual health services

An independent evaluation of Ask and Act in January 2022 found overwhelming agreement about the need for Ask and Act. Many saw Ask and Act as an effective way of putting violence against women, domestic abuse and sexual violence (VAWDASV) on the agenda within organisations. Respondents recognised the gap in training that Ask and Act was filling, and it was felt to fit well alongside other VAWDASV training. The consistency that the approach brings across Wales was felt to be valuable.

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Rydym yn croesawu derbyn gohebiaeth yn Gymraeg. Byddwn yn ateb gohebiaeth a dderbynnir yn Gymraeg yn Gymraeg ac ni fydd gohebu yn Gymraeg yn arwain at oedi.

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The VAWDASV (Wales) Act 2015 requires Ask and Act to be delivered to staff in a “relevant authority”, namely a local health board, NHS Trust, a local authority or a fire and rescue service. Because of the importance of this training in preventing all forms of VAWDASV and protecting and supporting victims and survivors, and demand from organisations outside the definition, the Ask and Act programme has been extended to organisations not covered by the Act.

### **Could you confirm whether GBV will be included in the Women's Health Plan?**

The Women’s Health Plan will be an NHS Plan. The NHS Executive is establishing the Women’s Health Network. The Network will be responsible for the development of the Plan. Welsh Government officials will include gender-based violence in the list of possible inclusions for consideration by the network.

### **Could you elaborate on what the Welsh Government policy is for supporting GPs to implement 'relationship-based care' given the current pressures on GP services?**

Our priority is ensuring a sustainable model of general practice for the future which retains the principles and ethos of relationship-based care by embedding person-centred models of service delivery.

In modern general practice, GPs draw on the support of a multi-professional practice team. These contacts also present opportunities to deliver relationship-based care – where practices take a person-centred approach, effective and compassionate continuity of episodes of care can be delivered by the most appropriate member of the team, not just the GP.

We are seeing an increase in the number of nurses and direct patient care staff employed in general practices, supporting patient access to care. There were 478 more wider practice staff in September 2022 compared to September 2020.

We have worked with the GP profession to develop the new GMS Unified Contract, with the 2023 Regulations which underpin this coming into effect on 1 October. A key aim of the Unified Contract is to reduce administrative bureaucracy for practices, freeing up more time for patient care.

### **British Crime Survey data reports that 38% of domestic violence incidents are alcohol related. Could you set out how this figure is influencing Welsh Government alcohol policy, for example, have you had conversations with Public Health Wales and/or Ministerial colleagues about any potential changes to approach?**

We are aware of the devastating effects that alcohol misuse can have on individuals and their families in a range of ways, including domestic violence. Addressing alcohol abuse can be expected to reduce the incidence of VAWDSV, just as it can other harms associated with substance misuse.

Our focus in terms of alcohol policy is very much on reducing the harms of alcohol (and drugs) on individuals and families – this is the approach we have taken in Wales for a number of years, and we work with a range of partners on this agenda. We have increased our investment in tackling substance misuse, including alcohol misuse, to £67m this year and this will increase by a further £2m in 2024-25.

We have not seen any evidence that a specific approach to alcohol abuse is necessary to address the particular problem of VAWDSV, and of course our VAWDASV support is tailored to the needs and circumstances of the individual. However, my officials have not had any specific conversations with Public Health Wales on this topic or any potential

changes to our approach to alcohol policy given the data from the British Crime Survey. I have asked that they pick this up and we can consider any adaptations to our approach that are necessary.

Our wider actions to address alcohol misuse include the introduction of a minimum unit price (MUP) for alcohol. We believe introducing an MUP will help reduce alcohol related harm and support people to drink responsibly. Scotland has seen a decline in the amount of alcohol that is consumed since the introduction of MUP, and we hope that we will see similar results in Wales.

We will continue to work with our Substance Misuse Area Planning Boards to ensure a range of services and support is in place to help people who are experiencing alcohol problems. Preventing the harms caused by alcohol misuse is a key part of our substance misuse agenda and it continues to be through our current Substance Misuse Delivery Plan and will be in any future work.

We recognise the vital importance of education and prevention when it comes to reducing alcohol-related harms. We are working to promote the UK Chief Medical officers' low risk drinking guidelines, which aims to support people to make informed decisions about their drinking. Public messaging around minimising the health risks from alcohol is also key in encouraging people to reduce both the amount of alcohol they drink and how often they drink. To support the promotion of responsible drinking and reduce alcohol harms, we fund Alcohol Change UK-who support people to reduce their alcohol consumption through their education programmes and work.

Alcohol prevention remains in the Public Health Wales (PHW) long-term plan to develop collective priorities for reducing alcohol-related harms across Wales. PHW are producing a series of evidence reviews which will help us understand which groups to take action with to address under-age drinking and highlighting risk and protective factors. PHW is also redeveloping the alcohol brief interventions approach, which will enable health professionals to raise concerns about problem drinking and direct access to treatment services in a sensitive, non-judgemental manner.

**Could you provide details relating to access to counselling services in schools for young people who may have witnessed or experienced GBV, including a timeline for training?**

In 2020 we issued our revised school and community-based counselling toolkit. The toolkit supports local authorities in developing and implementing their counselling policies and services. The toolkit also highlights the need to promote the service and that it should be fully inclusive, ensuring equality of access. Schools can make referrals direct to the service or individuals can self-refer, or family members can refer on their behalf. The service should also be available in the community and accessible for those children not in school, such as children home educated or in EOTAS settings. Data published in March 2023 showed that 12,500 children and young people accessed the service in the 2021/22 academic year.

In relation to training, the toolkit emphasises that services must employ counsellors and supervisors who are members of professional bodies relating to counselling or psychotherapy and, as such, have an established ethical code or framework and complaints procedure. These should be available and accessible to clients, schools and service providers. Local Authorities (LAs) and commissioned services are advised to ensure that counsellors are 'competent to practise' with children and young people. That would usually mean that they have completed adequate core counselling training, together with specialist training for work with children and young people.

In March 2022 we published independent research into the counselling services which demonstrated good practice but also highlighted variation and issues around awareness. We have established a counselling group with representation from all LAs which is seeking to improve provision and extend support to younger children below the current Year 6 threshold. This work reports into the Whole School Approach to Wellbeing Ministerial Oversight and Delivery Board, jointly chaired by the Minister for Education and Welsh Language and Deputy Minister for Mental Health and Wellbeing.

I hope this information is helpful.

Yours sincerely

A handwritten signature in blue ink, appearing to read 'M. E. Morgan'.

**Eluned Morgan AS/MS**

Y Gweinidog Iechyd a Gwasanaethau Cymdeithasol  
Minister for Health and Social Services

Eluned Morgan MS  
Minister for Health and Social Services

25 September 2023

Dear Eluned

### The public health approach to preventing gender-based violence

Thank you for giving evidence as part of our inquiry into the public health approach to gender-based violence. We would be grateful if you could respond to some additional points we were not able to cover in your evidence session:

- Which health professions are required to undertake Ask and Act under the current duties and whether you have a view as to whether that duty should be expanded and to whom.
- Could you confirm whether GBV will be included in the Women's Health Plan.
- Could you elaborate on what the Welsh Government policy is for supporting GPs to implement 'relationship-based care' given the current pressures on GP services.
- British Crime Survey data reports that 38% of domestic violence incidents are alcohol related. Could you set out how this figure is influencing Welsh Government alcohol policy, for example, have you had conversations with Public Health Wales and/or Ministerial colleagues about any potential changes to approach.
- Could you provide details relating to access to counselling services in schools for young people who may have witnessed or experienced GBV, including a timeline for training.

As we are now at the end of our evidence gathering, we would be grateful to receive a response by 9 October if possible.

Yours sincerely

A handwritten signature in black ink on a light yellow background. The signature reads "Jenny Rathbone" in a cursive, flowing script.

Jenny Rathbone MS

Chair, Equality and Social Justice Committee

# Agenda Item 2.5

Huw Hutt MS  
Gweinidog Cyfiawnder Cymdeithasol a'r Prif Chwip  
Minister for Social Justice and Chief Whip



Llywodraeth Cymru  
Welsh Government

Ein cyf/Our ref: Safety, Security and Migration IMG

Huw Irranca-Davies MS

Chair

Legislation, Justice and Constitution Committee

Senedd Cymru

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Cc Jenny Rathbone MS, Chair of the Equality and Social Justice Committee

25 September 2023

Dear Huw,

## **Inter-Institutional Relations Agreement: Safety, Security and Migration Interministerial Group**

I am writing further to my letter of 21 June, and in accordance with the Inter-Institutional Relations Agreement, to report on the second meeting of the Safety, Security and Migration Interministerial Group (IMG), held on 11 July.

The meeting was attended by the Home Secretary, the Rt Hon. Suella Braverman KC MP, as the Chair, by the Scottish Government's Cabinet Secretary for Social Justice Shirley-Anne Somerville MSP and Northern Ireland's Senior Officials Cathy Galway and Julie Cummings.

The meeting provided me with an opportunity to express the concerns the Welsh Government has on aspects of the Illegal Migration Bill and the UK Government's delays with processing asylum applications. I also raised concerns with regards to the ongoing issues with accommodation.

In addition to the discussions around immigration I highlighted the need for improved engagement and data sharing on all aspects of Safety and National Security to ensure a successful collaborative approach to tackle drug crime and national security threats across the UK.

The next meeting is due to take place in November and I will inform you once a date has been finalised.

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Rydym yn croesawu derbyn gohebiaeth yn Gymraeg. Byddwn yn ateb gohebiaeth a dderbynnir yn Gymraeg yn Gymraeg ac ni fydd gohebu yn Gymraeg yn arwain at oedi.

We welcome receiving correspondence in Welsh. Any correspondence received in Welsh will be answered in Welsh and corresponding in Welsh will not lead to a delay in responding.

Further information on the meeting can be found at: [Interministerial Group for Safety, Security and Migration Communiqué: 11 July 2023 - GOV.UK \(www.gov.uk\)](https://www.gov.uk/government/news/interministerial-group-for-safety-security-and-migration-communicue-11-july-2023)

I am copying this letter to Jenny Rathbone MS, Chair of the Equality and Social Justice Committee.

A handwritten signature in black ink that reads "Jane Hutt". The signature is written in a cursive style with a long horizontal stroke above the first name.

**Jane Hutt AS/MS**  
**Gweinidog Cyfiawnder Cymdeithasol a'r Prif Chwip**  
**Minister for Social Justice and Chief Whip**



Llywodraeth Cymru  
Welsh Government

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## **STATEMENT BY THE WELSH GOVERNMENT**

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**TITLE**        **Safety, Security and Migration Interministerial Group**

**DATE**        **25 September 2023**

**BY**            **Jane Hutt MS, Minister for Social Justice and Chief Whip**

In accordance with the Inter-Institutional Relations Agreement, I am giving notification that I attended the second meeting of the Safety, Security and Migration Interministerial Group (IMG), which took place virtually on 11 July, bringing together members of all four governments.

The meeting was attended by the Home Secretary, the Rt Hon. Suella Braverman KC MP, as the Chair, and the Scottish Government's Cabinet Secretary for Social Justice Shirley-Anne Somerville MSP. Senior Officials from the Northern Ireland Executive and Northern Ireland's Department of Justice were in also in attendance in the absence of Ministers.

At the meeting I expressed my disappointment that the vote by the Senedd to withhold consent to the Illegal Migration Bill was not considered by UK Government. I highlighted the concerns that Welsh Government have on the negative impact the bill will have on unaccompanied children in Wales and the need for us to be involved in the development of guidance to ensure Welsh Governments legislations are not over written.

During the meeting I also re-emphasised the Welsh Government's focus on Wales as a Nation of Sanctuary and our continuing commitment to asylum dispersal and community cohesion; and how thorough and consistent communication between the Home Office's private provider and Local Authorities is vital in ensuring Wales meets its accommodation target. I raised concerns on the increasing timescales for processing asylum applications and the negative impact this is having on both applicants and the economy and re-iterated my previous requests for a review of the current UK Government's policy which prevents asylum seekers for working for the first twelve months of entering the UK.

I praised the hard work being undertaken by Border Force officials to tackle the increasing influx of illegal drugs into the UK and welcomed the current work being undertaken to develop a memorandum of understanding with Welsh Government to improve information sharing. I expressed that the Welsh Government would welcome the opportunity to be engaged on all matters of crime and highlighted the benefits of a collaborative approach when tackling crime and threats to National Security.

A short joint Communiqué is published on the UK Government website at: [Interministerial Group for Safety, Security and Migration Communiqué: 11 July 2023](#)

—  
**Children, Young People  
and Education Committee**

Minister for Health and Social Care  
Eluned Morgan MS

Deputy Minister for Social Services  
Julie Morgan MS

Deputy Minister for Mental Health and Wellbeing  
Lynne Neagle MS

9 October 2023

**Welsh Government Draft Budget 2024-25**

Dear Eluned, Julie and Lynne,

As last year, we would like written information to support our scrutiny of the Welsh Government's Draft Budget 2024-25. The annex to this letter sets out in detail the information that we would like to receive.

I would be grateful to receive the written information no later than 19 December 2023. I note that the Welsh Government intends to publish the Draft Budget on 19 December 2023. While we usually ask for the written information a few days after the publication of the draft budget, due to the planned publication date of the draft budget, we are asking for this information on the same day. To help alleviate some of the issues in preparing the written evidence and provide you with the maximum time possible to prepare the submission we are issuing our request earlier in the autumn term. Please contact my clerks if you are concerned about meeting our proposed deadline in light of the budget timetable.

Given the shared interest across committees in some of the areas listed in the annex to this letter, I have copied in the chairs of the Health and Social Care Committee and the Equality and Social Justice Committee.

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Yours sincerely,

Jayne Bryant

Jayne Bryant MS

Chair

Croesewir gohebiaeth yn Gymraeg neu Saesneg.

We welcome correspondence in Welsh or English.

# Annex A: Request to the Minister for Health and Social Services regarding CYPE Draft Budget scrutiny 2024-25

## 1. Allocations for children and young people

Allocations in the Health MEG by Action, and Budget Expenditure Line (as directly relevant to children and young people):

- Draft Budget 2024-25
- Final Budget 2023-24 allocations
- 2023-24 First Supplementary Budget
- Forecast 2023-24 out-turns
- 2025-26 indicative budget (if set)

A description of any changes to baselines used in the Draft Budget 2024-25 from the First Supplementary budget June 2023.

## 2. Impact assessments

- **Combined CRIA across all portfolios:** The overall Child's Rights Impact Assessment (CRIA) undertaken by to inform allocations in the draft Budget 2024-25.
- **CRIA for Health and Social Services MEG:** The CRIA for the Health and Social Services MEG for 2024-25.
- **Other impacts:** Details and/or examples of any changes made to allocations within the Health and Social Services MEG following considerations of equalities, sustainability, the Welsh language, and the Wellbeing of Future Generations.

## 3. Programme for Government

Allocations in the Draft Budget 2024-25 and the latest position on funding for:

PFG Commitment	Requested allocations and narrative detail
Advocacy services for parents whose children are at risk of coming into care.	Allocations for the roll out of support for parents whose children are on the edge of care, which is to be delivered in accordance with a national framework.

Fund regional residential services for children with complex needs.	<p>Allocations for 2024-25 for the Regional Partnership Boards for the 8 projects which are now operational (and how many additional placements this funds).</p> <p>Allocations for delivery of any new projects (and how many additional new placements this funds).</p>
Eliminating private profit from the care of children looked after.	<p>An annual breakdown of how the commitment to spend £68m is broken down by total over the three years 2022-23, 2023-24, 2024-25.</p> <p><b>Final outturns for 2022-23</b> / breakdown of who that was allocated to and for what purpose (by local authority and third sector)</p> <p><b>Forecast outturns for 2023-24</b> / breakdown of who that was allocated to and for what purpose (by local authority and third sector)</p> <p><b>Detailed planned allocations for 2024-25</b> (or the process by which that will be decided)</p>
Specialist support for children with complex needs who may be on the edge of care.	<p>Details of the 32 projects so far identified by Regional Partnership Boards cover the whole of Wales and how these are funded by the Health and Social Care Regional Integration Fund as detailed in the most recent <a href="#">PfG Annual Report</a>.</p>
Fund childcare for more families where parents are in education and training or on the edge of work.	<p>Overall allocations for the Childcare Offer in 2024-25.</p> <p>The cost in 2023-24 of the additional 438 families and the total costs allocated in 2024-25 for the estimated 3,000 more eligible families as referred to in the most recent <a href="#">PfG Annual Report</a>.</p>
Phased expansion of early years provision to include all 2 year olds, with a particular emphasis on strengthening Welsh medium provision.	<p>Allocations and what they are intended to deliver in 2024-25</p> <p>Information on whether it will be a full 30 hour offer for all two year olds, and by when this will be delivered</p>
Flying Start.	Revenue and capital

#### 4. Sustainable Social Services Grant Scheme

The total amount for the Scheme and a breakdown of all grants relevant to children and young people.

## 5. Care Experienced Children Change Fund

The total amount for the Fund and a breakdown of all allocations.

## 6. Children's Social Care workforce

Any allocations associated with supporting local authorities to address the instability of the workforce in children's social care, such as vacancy rates and the use of agency staff, identified both in our Report on [Radical Reform for Care Experienced Children](#) and the recent [Care Inspectorate Wales rapid review of child protection arrangements](#) September 2023.

## 7. Children's Health

- Allocations in the Draft Budget 2024-25 and the latest position on funding for:
  - Public health as it relates to children and young people, including vaccination
  - Obesity strategy
  - Mental health services, including child and adolescent mental health services, and services to support perinatal mental health and parent-infant relationships
  - Eating disorder services
  - Suicide prevention as it relates to children and young people
  - Substance misuse, including vaping among children and young people
  - Neurodevelopmental services

## 8. Cost of living

- **Health Boards:** The delivery of services to children and young people by the Health Boards in Wales and the impact of the rising costs of energy on this provision.
- **Social Services:** Policy and oversight of the provision of all social service activities of Local Authorities in Wales and any associated discussions with the Minister for Finance and Local Government.
- **Child poverty:** Details of what discussions have taken place with other relevant Ministers in respect of allocations which have a significant impact on children's health and social care, for example the Minister for Social Justice in terms of the budget of the Children's Commissioner for Wales and broader policy issues such as child poverty.



## 9. Costs of legislation

- Financial implications or anticipated in 2022-23 and 2023-34 of any subordinate legislation relevant to children and young people within the Minister's portfolio.
- Information on the financial impact of any relevant UK Parliament legislation.

Senedd Cymru  
Welsh Parliament

# Agenda Item 2.7

Welsh Parliament  
**Finance Committee**

Rebecca Evans MS,  
Minister for Finance and Local Government

22 September 2023

Dear Rebecca,

## Evidence papers supporting the 2024-25 Draft Budget

Many thanks for your [letter](#) of 8 September.

I am grateful for the constructive manner in which you have engaged with the Finance Committee on ways that ministerial written evidence on the Welsh Government's Draft Budget proposals can be improved, with the aim of addressing the issues identified in my [letter](#) of 23 June.

I welcome your intention to confirm when Ministers will provide their evidence papers to Senedd Committees ahead of the 2024-25 budget round. I am also grateful that Senedd Committees will be offered a technical briefing on the Draft Budget.

In terms of your request for a clear indication from the Finance Committee on what would be considered essential for inclusion in ministerial evidence papers, it would not be appropriate for me to provide a single list of proposals without consulting Committee Chairs first.

Whilst I see benefits in developing a high level template for evidence papers, and although I am supportive of co-operation between committees to avoid duplication and overlap in its areas of focus during budget scrutiny, a consistent



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approach may be difficult to achieve in practice given that Committees will naturally have different priorities and areas of focus.

I would also want to guard against the development of a template that may foster a prescriptive approach to the provision of written evidence, which may end up diluting the information made available to individual Committees as they seek to hold ministerial spending decisions to account.

The difficulties faced by Ministers in providing specific details for Committees relating to each MEG during the 2024-25 budget is a case in point. Although I recognise the challenges posed by this year's budget timetable, this should not restrict Committees from requesting detailed information relating to individual portfolios as this is crucial to informing public evidence sessions with Ministers, particularly when time to consult with stakeholders is limited.

I am therefore willing to explore ways in which a template could be developed, although I also acknowledge that developing consensus on this issue may take time and that it is unlikely that any changes will be agreed for the forthcoming budget round.

I am copying this response to all Senedd Committees with an interest in budget scrutiny to facilitate further discussions, and will raise this matter at the next meeting of the Chair's Forum on 23 October.

Yours sincerely



Peredur Owen Griffiths MS  
Chair of the Finance Committee

Croesewir gohebiaeth yn Gymraeg neu Saesneg.

We welcome correspondence in Welsh or English.





Llywodraeth Cymru  
Welsh Government

Russell George MS  
Chair  
Health and Social Care Committee  
[SeneddHealth@senedd.wales](mailto:SeneddHealth@senedd.wales)

Jenny Rathbone MS  
Chair  
Equality and Social Justice Committee  
[SeneddEquality@senedd.wales](mailto:SeneddEquality@senedd.wales)

4 October 2023

Dear Russell and Jenny

You are doubtless aware of recent press reports about female surgeons being sexually assaulted in the workplace, and are as appalled at such behaviour as I am. I asked my officials to seek assurances from all medical directors in Wales regarding the actions they have in place to prevent incidents of overt discriminatory behaviours; misogyny and/or a breach of sexual safety.

All medical directors have shared their safeguarding policies which are in line with national requirements. Not all organisations have specific sexual safety policies and those without acknowledged that they would reinforce their controls by providing staff with guidance on sexual health and well-being and outlining the process by which they can report sexual incidents. All have expressed a desire to promote a clear commitment to preventing sexualised harm.

Prior to the press reports, the NHS Wales Executive had already started to establish a National Coordinating Group for Sexual Safety in NHS Wales. The Group is utilising a task-and-finish approach to complete a brief assurance exercise, primarily in response to the report by the Women's Rights Network, *When We Are At Our Most Vulnerable*, which included a concerning high frequency of reports of sexual violence occurring in hospital settings.

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Rydym yn croesawu derbyn gohebiaeth yn Gymraeg. Byddwn yn ateb gohebiaeth a dderbynnir yn Gymraeg yn Gymraeg ac ni fydd gohebu yn Gymraeg yn arwain at oedi.

We welcome receiving correspondence in Welsh. Any correspondence received in Welsh will be answered in Welsh and corresponding in Welsh will not lead to a delay in responding.

The Group has focused on actions to complete the required immediate assurance functions including:

- a data collection exercise across NHS Wales organisations and Sexual Assault Referral Centres
- ensuring organisations complete a self-assessment on how they prevent sexual harm to patients and staff and how they respond where sexual harm, including criminality, is disclosed or observed.

We are widening this debate and are clear about our expectations across the wider NHS which includes the recently-published Welsh Health Circular [NHS Wales speaking up safely framework](#). The Framework contains practical toolkits, developed in partnership with our employer and trade union colleagues and, in due course, resources will be published on Health Education and Improvement Wales's Gwella platform. We will also share the sexual safety work which the Welsh Ambulance Services Trust has developed to address the use of power and influence.

Yours sincerely

A handwritten signature in blue ink, appearing to read 'M. E. Morgan'.

**Eluned Morgan AS/MS**

Y Gweinidog Iechyd a Gwasanaethau Cymdeithasol  
Minister for Health and Social Services



Dear Jenny,

We are writing in response to your letter dated 25<sup>th</sup> September 2023 requesting further information regarding Ask and Act, the delivery of which has been the responsibility of Welsh Women's Aid since its initial development in 2016. For context, Welsh Women's Aid are funded to provide accredited Groups 2 and 3 Train the Trainer training to public and specialist sector practitioners across Wales as part of the National Training Framework for Violence against Women, Domestic Abuse and Sexual Violence (VAWDASV). This training is commonly referred to as Ask and Act. Currently, the relevant authorities under the National Training Framework include county and borough councils, local health boards, fire and rescue authorities, and NHS trusts.

Complementing Ask & Act, we also deliver Trusted Professional training as part of our Change that Lasts whole systems approach to tackling gender-based violence and abuse. This is a one-day training course for professionals throughout Wales who come into contact with survivors of VAWDASV. The course trains individuals to respond appropriately to disclosures and refer survivors and perpetrators to specialist support services. In the last three years, we have trained 180 professionals through this route.

### *Funding Received*

Welsh Women's Aid was funded by Welsh Government to develop the Ask and Act training materials for the initial Train the Trainer courses in 2016. We continued to develop and deliver the training for the cross-Wales rollout, with our contract being renewed in 2018 and then again in 2022.

The current contract awarded to Welsh Women's Aid totals £132,650 and runs from November 2022 to March 2025. The Welsh Government also provides funding directly to relevant regional authorities for onward delivery of Ask & Act training sessions to staff and they submit returns to Welsh Government directly.

### *How are you reporting progress to Welsh Government?*

We complete quarterly reports which are provided to the Welsh Government and meet regularly with Welsh Government officials to monitor progress. The regular reports provided to Welsh Government include the following information:

- Number of practitioners trained to deliver Ask and Act
- Number of practitioners who have completed assessments
- Of the above, the number who have passed and the number of resubmissions
- Qualitative feedback from learners
- Emerging themes and/or patterns
- Challenges and learning from delivery





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**Cymorth i Ferched Cymru**  
**Welsh Women's Aid**

Rhoi Merched a Phlant yn Gyntaf  
Putting Women & Children First

*How are you measuring the success of the training you deliver?*

Welsh Women's Aid pride ourselves on our robust evaluation processes which aim to demonstrate the impact of Ask and Act training on learners. These processes include:

- A pre-course survey which aims to establish the level of knowledge and skill of the learners before taking part in the training
- A post-course survey to measure learner confidence, knowledge, practice, and skills
- A further survey between 3 and 9 months post-training to gather longer-term reflections and to understand how learners have embedded learning from training into their individual practice
- Practitioners are also asked to provide case studies, if possible, to give us further opportunities to increase engagement with learners and improve the training

This year, we have trained a total of 80 learners. All learners who completed feedback for Group 2 and Group 3 training rated the trainer's subject knowledge as 'excellent'. Learners who provided feedback stated that the training left them *'more empowered to continue supporting others'*.

*Please can you outline any discussions you may have had with the Welsh Government about expanding the Ask and Act scheme to other organisations, including your view on who this might include?*

Discussions have taken place regarding the expansion of Act and Act to practitioners outside the public sector, including those in the police, housing, and the private sector. In our view, the training could be expanded more widely to professionals, for example, in housing associations, food banks, GP surgeries, public transport, Citizen's Advice, Job Centre plus and organisations such as Sports Wales. This would ensure the appropriate individuals are adequately trained and confident to encourage disclosures and respond effectively. We believe such an expansion would ensure every interaction between survivors and the relevant professionals counts and would guarantee the provision of consistently high-quality services across Wales.

*The additional funding that would be needed to roll out the scheme further, and whether Welsh Women's Aid has the capacity to deliver it?*

It is challenging to provide a definitive response regarding the additional funding required as it would be dependent on several factors such as the types of training required and the number of people to be trained.

However, Welsh Women's Aid and our nine implementation partners (DASU North Wales, Threshold DAS, RASASC, West Wales DAS, Calan DVS, Bawso, Swansea Women's Aid, Thrive and Safer Wales) have sufficient capacity to deliver the training if it were to be rolled out further. The implementation partners are located in different regions across Wales, which we believe bring vital local knowledge to the training provision.

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Welsh Women's Aid is a registered charity in England and Wales, No. 1140962  
and a company limited by guarantee registered in England and Wales, No. 07483469



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**Cymorth i Ferched Cymru**  
**Welsh Women's Aid**

Rhoi Merched a Phlant yn Gyntaf  
Putting Women & Children First

We hope the information contained in this letter is of use to the Committee, we are happy to provide any further information as required.

Yours Sincerely,

Jennifer Mills  
Policy Officer, Welsh Women's Aid

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Welsh Women's Aid is a registered charity in England and Wales, No. 1140962  
and a company limited by guarantee registered in England and Wales, No. 07483469



Llywodraeth Cymru  
Welsh Government

Sara Kirkpatrick  
Chief Executive  
Welsh Women's Aid

25 September 2023

Dear Sara

**The public health approach to preventing gender-based violence**

Thank you for providing written evidence to our inquiry on the public health approach to preventing gender-based violence.

During our inquiry we have heard of the importance of Ask and Act, the delivery of which we understand is the responsibility of Welsh Women's Aid. Could you set out what funding you receive from Welsh Government to deliver the Ask and Act training, how you are reporting progress to Welsh Government and how you are measuring the success of the training you deliver. Please can you also outline any discussions you may have had with the Welsh Government about expanding the Ask and Act scheme to other organisations, including your view on who this might include, the additional funding that would be needed to roll out the scheme further and whether Welsh Women's Aid has the capacity to deliver it.

As we are now at the end of our evidence gathering, we would be grateful to receive a response by 9 October if possible.

Yours sincerely



**Jenny Rathbone MS**  
Chair, Equality and Social Justice Committee

Croesewir gohebiaeth yn Gymraeg neu Saesneg.

We welcome correspondence in Welsh or English.

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## Children, Young People and Education Committee

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Jenny Rathbone MS

Chair, Equality and Social Justice

10 October 2023

### Child Poverty

Dear Jenny,

Thank you for inviting members of our Committee to participate in your current work on the Welsh Government's Draft Child Poverty Strategy for Wales 2023. Such invites enable us to make connections and share relevant evidence to help strengthen each others work. It also helps maximise the impact of individual pieces of evidence.

My involvement in your work has enabled us to identify some issues that we wanted to bring to your attention and which we hope will be useful to your deliberations.

Earlier this year, we launched our inquiry asking whether disabled children and young people have equal access to education and childcare. The scope of the inquiry covers all childcare and statutory school provision from 0-16, and encompasses neurodiversity; physical, sensory or learning disabilities.

Alongside our formal written and oral evidence, we have been speaking to families more informally. Both through visits to special educational needs schools, and to the Serennu Centre in Newport and ASD Rainbows in Mountain Ash. We have also been bringing examples from our work as individual MS.

Our Citizen Engagement team have conducted over 30 family interviews covering all areas in Wales. While we are still finalising the summary note of this work, we can share with you some of the relevant stories. We have been hearing very powerful testimonies from children, young people and their

families of the impact unequal access to education and childcare has on every aspect of their lives, and the longer term impacts this unequal access can have.

While we are still continuing to gather evidence on this inquiry, we wanted to share some of the information we have gathered so far which is relevant to your child poverty work. This includes the impact a lack of accessible childcare and school provision can have on a parent / carers' ability to work, as well as the additional costs that have to be met by these families.

While we have gathered a range of evidence on this issue, it was not a specific strand of our terms of reference. It is therefore possible that if this had been included in the terms of reference, we would have gathered even more information. However, the fact that this has become a clear theme throughout the evidence suggests it is a big issue for children, young people and their families.

We will also be writing to the Minister for the Economy and Minister for Social Justice on these issues, but we wanted to ensure that the relevant evidence could be taken into account for your current work. We will also copy you into the future correspondence to these Ministers.

### **Barriers preventing parents and carers from working**

We have a number of personal testimonies from families who are either unable to work at all or cannot work the number of hours they would like because they cannot access the right type of childcare. This issue continues for many families as the child gets older and goes to school.

#### Accessing inclusive childcare

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We heard powerful testimony from a parent who worked in paediatric nursing, who is currently on a career break from a job they love because they have been able to secure appropriate childcare. When they did eventually find some childcare, they were unable to increase the hours, despite being willing to pay for this themselves. The parent continues to be unable to work because they now cannot secure wrap-round provision from the school nursery provision.<sup>1</sup>

Mudiad Meithrin quoted a single parent who "had to stop working because there was no funding available by now for her child with intensive needs to attend wraparound care on school premises". This parent said that it was easier when their daughter was younger but "now I cannot work because there isn't suitable childcare or anywhere that offers wrap around care for her school". The parent has described the loss of work as a "double blow" because of both the financial and mental health impacts.<sup>2</sup>

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<sup>1</sup> [CYPE Committee, Note from Sparkle Focus Group, 15 September 2023](#)

<sup>2</sup> [Written evidence, AEC 51 Mudiad Meithrin](#)



Even in those instances where childcare is secured, there can still be issues. One parent described securing a childcare place. There was a number of successful settling in sessions, yet the day before the childcare started, the provider told them they could not support the child. The parent said she was fortunate her employer was supportive but flagged both the practical and emotional impacts of losing out on a childcare placement the day before it was due to start.<sup>3</sup>

Mudiad Meithrin highlighted the impact staffing issues for childcare providers can have on being able to provide regular and sustainable childcare. They said parents had told them that staffing was often the reason their children couldn't attend as regularly as other children, and that this inconsistency "will cause problems for working parents / carers..."<sup>4</sup>

One of the parents who took part in our family interviews described how childcare did not work out for their family:

*"... I struggle to find a place that can deal with his needs [...] not a lot of places can do that [...] I tried child care and he was there twice and they just couldn't make it work, I had to keep picking him up."<sup>5</sup>*

We have heard of the struggle to juggle working responsibilities, and the pressure this places on families. One parent told us that their son who is eligible for 12 hours of early years education, only receives 5 hours, and in terms of childcare, is entitled to 17 hours but gets nothing:

*"I am left doing a full time job on 5 hours childcare a week. ...is missing out on the early years foundation phase he's entitled to. He spends large parts of his days underestimated in front of screens as I have no other way of keeping him occupied so he doesn't cause disturbance while I take work calls, many of which are of a sensitive nature. I work with victims of domestic violence and modern day slavery.*

*As a full time working parent I am reaching crisis point. I have no family members who can care for... I cannot use a childminder as... is impulsive around roads and runs very fast and there is a high risk he would run into a road and a childminder be unable to catch him. I own my own home with a mortgage. I cannot stop work as won't be entitled to benefits."<sup>6</sup>*

Stakeholders also raised concerns about limited inclusive childcare provision. The Royal College of Occupational Therapists said:

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<sup>3</sup> [CYPE Committee, Note from Sparkle Focus Group, 15 September 2023](#)

<sup>4</sup> [Written evidence, AEC.51 Mudiad Meithrin](#)

<sup>5</sup> CYPE Citizen Engagement (published note to follow)

<sup>6</sup> [Written evidence, AEC.04, Individual](#)

*"Our members are concerned that private nurseries are difficult for children with special education needs and disabilities (SEND) to access to enable parents to go to work. They suggest there is inequitable access to funding for the additional support or equipment necessary to include children with additional needs in settings across Wales - some areas will fund equipment/support while others will not."*<sup>7</sup>

While Early Years Wales flagged that families often have to fund the shortfall of funding:

*"If a child needs additional adult support or resources to attend childcare, this can often be limited, for example, if a local authority scheme only offers 5 hours one to one support a week but the child needs to attend for 15 hours to enable the parent to work how is this shortfall managed."*<sup>8</sup>

Oxfam Cymru said that childcare "remains one of the main reasons for women to be economically inactive." They said that 25.5% of economically inactive women are not working because of family and homecare responsibilities.<sup>9</sup>

#### Accessing inclusive school provision

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Even when children reach the age to access statutory school provision, families are finding they have to be available throughout the day, making work often impossible.

One respondent to our consultation described the ongoing struggles they have had in accessing education for their son who has brain damage following a brain tumour.

*"He is in ....primary has one to one support for 7.5 hours a week!!!! There have been horrendous behavioural issues in school to the point.... stays in school 20-30 mins unsupervised then has to be collected. The only way.... remains in school currently is if myself or my son go in with him, stay with him, supervise him, try to teach him and ultimately take responsibility for him.*

*"I was working but had to give up my job as what employer will let you leave after 20 minutes on a repeated basis. Childcare options for children with needs are very limited, I'm a single parent with no local family support and am ex husband who is very intermittent in his commitment to my son."*<sup>10</sup>

Another parent told us that their child is often "kicked out of school" because the staff cannot cope, and they are repeatedly contacted to come and pick her up. As a result it's impossible for the parent

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<sup>7</sup> [Written evidence, AEC 30, Royal College of Occupational Therapists](#)

<sup>8</sup> [Written evidence, AEC 53, Early Years Wales](#)

<sup>9</sup> [Written evidence, AEC 57, Oxfam Cymru](#)

<sup>10</sup> [Written evidence, AEC 12 Individual](#)

to work, as they don't know when they will be called by the school.<sup>11</sup> For another parent the reduced timetable their child follows means:

*"I have had to give up work – I'm classed as a carer, if there were options out there for me I would have taken them, I loved to work but the reduced timetable made things very restrictive. Now we have to survive on benefits."*

They went on to say that they would be happy for their child to follow a reduced timetable if it was accompanied by "wrap around care" where they are not learning but under the care of the school. This would enable the parent to access work opportunities.<sup>12</sup>

The Third Sector Additional Needs Alliance also highlighted the impact of reduced timetables or exclusions can have on a family's ability to work:

*"But we know that where pupils are regularly excluded, actually, parents are far more likely to only be able to work part time because they know that they've got to keep picking them up, and I think SNAP alluded to that—that parents were being disciplined in work. So, an exclusion for a child, apart from them missing out on so much socialisation, let alone education, really has an impact on the whole family and the parents as well."<sup>13</sup>*

One of the parents who took part in our family interviews was asked if they are able to work under the child's current school hours, replied saying "no one would want me for like two hours a day, no one."<sup>14</sup>

Oxfam Cymru quoted a parent who said:

*"If you have a disabled child, it is impossible to work full-time. Childcare for disabled children is next to non-existent. School holidays are impossible. They don't even get the same amount of time in school as non-disabled children. Her school day is 30 minutes shorter every day; she has 2.5 hours less schooling per week than her nondisabled sibling! We have to use hours meant to be for respite to cover the gap between school finishing (early because she doesn't get a full school day - why??) and work finishing. Disability discrimination at its finest."<sup>15</sup>*

The All Wales Forum also told us about the other care factors that could impact on a parent / carer being able to work:

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<sup>11</sup> CYPE Citizen Engagement (published note to follow)

<sup>12</sup> CYPE Citizen Engagement (published note to follow)

<sup>13</sup> [CYPE Committee, 7 June 2023, Record of Proceedings, paragraph 292](#)

<sup>14</sup> CYPE Citizen Engagement (published note to follow)

<sup>15</sup> [Written evidence, AEC 57, Oxfam Cymru](#)

*"... That lack of specialised support—and this is extensive, because that specialised support could be tube feeding, it could be toilet changes, it could be sensorial needs, it could be specialised autism support—the lack of that means that the parent is going to have to have an impact on their own life and employment, having to come and pick up the child early, being reprimanded both from the school and their job, but also it's watching your child struggle through years of education and having to make the decision of, 'Am I going to watch my child struggle or am I going to put my well-being in second place, my job, my interests, my life, and stay at home and home school my child?'"<sup>16</sup>*

We are also hearing examples of families feeling that they have no choice but to homeschool their children:

*"I've always had to homeschool my child. The schools around where we live wouldn't take them and the nearest school was so far away logistically it wouldn't make sense, we would have spent all day travelling back and forth and with my child's disabilities, that wouldn't be possible." Ceredigion"<sup>17</sup>*

#### Accessing after-school and holiday childcare

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There are also significant issues with families being able to secure inclusive after-school and holiday club provision. Parents and carers have described being only able to work in jobs that offer term-time working, or having to stop working altogether. You may wish to be aware of the report by Contact on [holiday club provision for disabled children](#).

Adele Rose-Morgan, who is an inclusive education campaigner gave evidence on behalf of Learning Disability Wales and described trying to access childcare for her son:

*"On childcare, we eventually moved him to a unit for deaf children, because we found out late that he was deaf, and there was a breakfast club there. He could only go there with support, and the support came from a fund outside of education. And at one time, the funding criteria changed, and my husband's wage had gone up a little bit, so it was outside the criteria. So, the headmistress called me in and said, 'Look, you're no longer entitled to this but we will pay it'—out of the parental contributions that they used to collect. I just couldn't do that, so I used to just pay for the breakfast club. I used to give £10. It was one day a week, just so he had that social inclusion. I also refused a taxi. I insisted on taking him, and I was able to do it. He was my youngest, and we were able to have a second car, so it worked. He started and finished at different times. That posed a problem because*

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<sup>16</sup> [CYPE Committee, 7 June 2023, Record of Proceedings, paragraph 296](#)

<sup>17</sup> [Written evidence, AEC 05 Third Sector Additional Needs Alliance](#)

*the private childcare within the school didn't start their session until 10 minutes after he'd finished, and they weren't sure, because he would need one to one, whether it would cost a lot more. I applied for a job and I couldn't pursue that because I couldn't work out the childcare around that.*"<sup>18</sup>

A parent who is a member of the Swansea Parent Carer Forum said:

*" My child is now 12. He still needs childcare. At the same age I was able to leave his sister for short periods of time. He cannot access holiday schemes, childminders as he would need 1:1 care and the cost makes this inaccessible and he is too old for private nurseries. Breakfast clubs and after school clubs are not an option because the school cannot afford to cover 1:1 and still run these. I can't work as a result"*<sup>19</sup>

## Impacts on families

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As you can see from the examples above, parents are having to give up jobs / careers in order to look after children. In some cases because of the caring responsibilities across the family, both parents / carers have had to give up work. The strain of coping with these pressures can result in the breakup of families which will have an impact on household income.<sup>20</sup> We were told that four out of five marriages with a disabled child fail.<sup>21</sup> Sparkle said that relationships often break down because parents cannot spend "quality time together or share experiences" because they are often "ships in the night" missing each other because one parent will work when the other is at home, because they cannot work at the same time because of a lack of childcare.<sup>22</sup>

One respondent described the particular impact on their family:

*"...Because of his needs I was not able to find any childcare for him at all. This meant his father had to give up work to care for him and this eventually helped contribute to the breakdown of our nuclear family as financial pressures were building. The rate of divorce in families with a child with disabilities is far higher than the average population because of the isolation from society and lack of support that other parents can access."*<sup>23</sup>

In the research they have done, Sparkle have highlighted:

*"Parents talk of finding jobs that fit around their family commitments, rather than jobs they are qualified for or would enjoy. Many parents work at supermarkets*

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<sup>18</sup> [CYPE Committee, 7 June 2023, Record of Proceedings, paragraph 122](#)

<sup>19</sup> [Written evidence, AEC 55 Swansea Parent Carer Forum](#)

<sup>20</sup> [CYPE Committee, Note from Oak Hill Focus Group, 15 September 2023](#)

<sup>21</sup> [CYPE Committee, Note from Ysgol Bryn Derw school visit, 29 June 2023](#)

<sup>22</sup> [Written evidence, AEC 36, Chair, Sparkle](#)

<sup>23</sup> [Written evidence, AEC 31 Individual](#)

*because they can work around school hours or late in the evenings when another parent is home. These are specific employment restrictions and considerations that families with typically developing children may not face."*<sup>24</sup>

The challenges of securing employment that fits around caring responsibilities will also be a much longer-term issue for these families:

*"Another parent commented that when someone has a child with a disability their expectations surrounding parenting have to change; most parents expect that when their child is around 12/13 years old, they'll be able to spend an hour home alone after school, meaning the parent can work typical '9-5' hours. However, parents of children with disabilities are not able to do this due to their child's high support needs; they describe their child's lack of cognitive development as essentially meaning they care for a 12/13 year old toddler, and as they have no sense of danger they cannot be left alone for any time. Parents therefore have no choice but to be at home with their child if they cannot source appropriate childcare, limiting their employment options and the number of hours they can work."*<sup>25</sup>

This will also have an impact on parents / carers ability to work, along with the additional costs that can come from home education.

#### Longer term impact on household incomes

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As well as reducing income in the present these issues result in a long term impact on household income. In particular, in relation to overall household income, pension income or causing restrictions on a family's ability to buy or rent their preferred home in their preferred area. One parent said they hadn't been able to work for 15 years because of a lack of appropriate childcare, and that as a result they have no pension resulting in the need for more state support. They said if they had been able to access childcare, they would have been able to work reducing their reliance on state support and saving the state money.<sup>26</sup> We were also told that not being able to work limits future opportunities and that "it changes your future."<sup>27</sup>

#### Additional costs faced by families with disabled children

For many families they face additional costs which further reduce household income. Many of these costs are for services or equipment which they feel should not be borne by the individual family.

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<sup>24</sup> [Written evidence, AEC 36, Chair, Sparkle](#)

<sup>25</sup> [Written evidence, AEC 36, Chair, Sparkle](#)

<sup>26</sup> [CYPE Committee, Note from Oak Hill Focus Group, 15 September 2023](#)

<sup>27</sup> [CYPE Committee, Note from Ysgol Bryn Derw school visit, 29 June 2023](#)

## Costs of childcare

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This starts early with the costs of childcare. At a focus group, one parent told us that she had to pay for private childcare provision for her disabled child, yet there was funded provision for non-disabled children.<sup>28</sup> While the National Autistic Society also raised concerns about the cost of specialist private provision saying:

*"Even where specialist private provision exists, the financial cost can be a significant barrier. Families tell us they feel discriminated against in accessing free childcare because mainstream public-run nurseries often do not cater to their child."<sup>29</sup>*

Oxfam Cymru quoted a parent who had children with a range of differing needs that the cost of childcare "has rendered it impossible for me to return to work."<sup>30</sup>

Mudiad Meithrin quoted a parent who has not been able to access holiday / respite care saying:

*"We're not eligible for [respite] either, and we have to pay a family friend to do this for us. The holidays are a nightmare. We need more help and support. It's costing us a lot of money. Our son's costs are so much more expensive than other children so we must continue to work on very little sleep and very little respite in order to fund the extra needs. It's lonely and we're exhausted."<sup>31</sup>*

## Costs of equipment / transport

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Parents we spoke to as part of our citizen engagement raised the additional costs that their families face:

*"Anything that's got "special needs" written in the title you can guarantee will cost more than anything else."*

While another parent said:

*"When you speak to parents of anyone with a disability, in order to achieve the things that you would like your child to have, you normally have to go further afield. And that then becomes expensive."<sup>32</sup>*

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<sup>28</sup> [CYPE Committee, Note from Sparkle Focus Group, 15 September 2023.](#)

<sup>29</sup> [Written evidence, AEC 05 Third Sector Additional Needs Alliance](#)

<sup>30</sup> [Written evidence, AEC 57, Oxfam Cymru](#)

<sup>31</sup> [Written evidence, AEC 51 Mudiad Meithrin](#)

<sup>32</sup> CYPE Citizen Engagement (published note to follow)

We have heard examples of families having to provide specialised equipment to be used in the childcare and nursery settings.<sup>33</sup> This equipment can often be very expensive. The Royal College of Occupational Therapists highlighted that in some areas there are “partnership agreements across health and education” which allows for the purchasing and recycling of such equipment, but that this is not consistent across Wales.<sup>34</sup>

A parent of a college student told us that they were quoted a weekly charge of £178 for an accessible taxi to take their child to college. Yet if they lived in a neighbouring local authority, this would be fully funded. When they raised this discrepancy in provision, they were told their child should not have been enrolled in the college when they knew they did not have transport. As a result the parent has had to change their working pattern to enable them to take their child into college, with the taxi picking their child up. This is still costing £88 a week. Their child said to us, that non-disabled young people can access subsidies to reduce the cost of transport but this is not available to disabled young people.<sup>35</sup>

### Accessing private support

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We heard examples of people either accessing private support, or wishing that they could afford to access private support.

One parent, whose child has suspected autism, said their child has been waiting for assessment since April 2021 (despite requests for assessment starting at an even earlier age.) Their child will not be seen until April 2024, and since their child went on the waiting list, the list has lengthened, and the wait is now approximately 3 years.<sup>36</sup> Another family described a wait of 7.5 years in securing a diagnosis, in which time their child’s mental health “has taken an absolute battering and she has tried to take her own life twice.”<sup>37</sup> The Royal College of Paediatrics and Child Health, said that the waiting time for an autism /ADHD assessment ranges between 47 and 166 weeks across Wales.<sup>38</sup>

In this context, it is therefore unsurprising that we have heard of families accessing private diagnosis if they are in a position to do so. Obviously this length of wait is all time that is being lost in ensuring a child gets the right support in place, and is time that cannot be regained either in terms of education outcomes or wider emotional and mental wellbeing. Yet this can come at a huge financial cost, and clearly entrenches further inequality, as not everybody will be able to fund private support. One family described the potential cost of £6,000 for assessment for two children in a single family who needed

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<sup>33</sup> [CYPE Committee, Note from Sparkle Focus Group, 15 September 2023.](#)

<sup>34</sup> [Written evidence, AEC 30, Royal College of Occupational Therapists](#)

<sup>35</sup> [CYPE Committee, Note from Sparkle Focus Group, 15 September 2023.](#)

<sup>36</sup> [Written evidence, AEC 10 Individual](#)

<sup>37</sup> [Written evidence, AEC 33 Individual](#)

<sup>38</sup> [Written evidence, AEC 49, Royal College of Paediatrics and Child Health Wales](#)

assessment.<sup>39</sup> Another family told us they do not have the “financial means for legal support if needed, and I do not have a home that I can re-mortgage to provide private support for my children.”<sup>40</sup>

The parent who described the breakdown of their relationship as a result of the financial stress placed upon them (see above), also highlighted that they had to take out loans to access private healthcare:

*“Indirectly, we have been adversely impacted because of the financial strain of losing one income. This was a factor in causing our family to split and father and I are now divorced. The lack of external help caused us to seek out private speech and language appointments as the wait was nearly 2 years to be seen despite not talking. He also had extreme pain every night due to compacted ears and because of his ALN he would need to be put under a general anaesthetic to have this treated. We ended up taking out loans to pay for this privately to ease his pain. Neurotypical children could have been treated with microsuction while awake. He also had bi lateral grommets inserted as he was found to have glue ear (being non verbal he cannot explain the pain he has) and it was not until 3 years after he started screaming in pain every night that he finally saw an ENT on the NHS. I don't know how we would have survived had we not sought private surgery on his 3rd birthday.”<sup>41</sup>*

We have also heard about the legal costs of having to go through tribunals to secure appropriate support for their families.

#### Impact of the cost of living crisis

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We have also heard that the cost of living crisis is also preventing families from accessing activities that might benefit their children. The Royal College of Occupational Therapists told us:

*“Occupational Therapists report that the cost-of-living crisis is affecting opportunities for children and young people to benefit from extra-curricular activities. 56% of Welsh survey respondents said families were cutting back of activities that would support their child's health, development and wellbeing (such as swimming lessons) due to their cost.”<sup>42</sup>*

#### Direct payments

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<sup>39</sup> [CYPE Committee, Note from Sparkle Focus Group, 15 September 2023.](#)

<sup>40</sup> [Written evidence, AEC 33, Individual](#)

<sup>41</sup> [Written evidence, AEC 31, Individual](#)

<sup>42</sup> [Written evidence, AEC 30, Royal College of Occupational Therapists](#)

Although outside of the scope of the inquiry, we have also heard significant issues with the direct payments system. In particular the administrative burden and the challenges in securing personal assistants.<sup>43</sup> We have heard that the administration is overwhelming. One of the parents said:

*"I don't feel the direct payments are empowering or do what they are supposed to do. You don't have the head space to deal with things as they are happening. You are living hand to mouth. You are trying to cope with the daily challenges. Which there are just so many of because I've got one child who wants to go a millions miles an hour, gets really overwhelmed if they get hungry or cold or hot, they cannot wait, they have no patience whatsoever and another child who's mostly limited to a wheelchair, that can't do everything fast, and you have to be patient."<sup>44</sup>*

We acknowledge that this is a non-devolved issue, but wanted to highlight it as it should be a tool that helps families access support, but is not working as it should.

The charity, Sparkle shared research they have undertaken, and the issue of direct payments was raised with them:

*"The offer of direct payments to cover the cost of childcare or respite is welcomed, however families are still required to source appropriate workers, a task which families find stressful. Further stress is caused once a suitable person is found as the family have to become an 'employer', calculating wages and tax. Families with children with additional needs rarely have the time to learn about the business side and therefore these arrangements often fail."<sup>45</sup>*

## Entrenchment of disadvantage

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We are aware that families with disabled children are more likely to be living below the poverty line, and that this then can create additional barriers to them accessing inclusive services and support that meet the child's and wider family needs, further entrenching disadvantage longer term.

Organisations such as Disability Wales raised concerns about the impact faced by disabled children who have to live both with the impact of their disability and their poverty, and what this can mean for children's educational outcomes. They cited differences between the number of disabled people leaving education without qualifications and those who are not disabled.<sup>46</sup>

*"It is well established that educational outcomes for disabled people differs to non-disabled people. In Wales, from June 2020-2021, 37.9% of nondisabled people's*

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<sup>43</sup> [Written evidence, AEC 19 Individual](#)

<sup>44</sup> CYPE Citizen Engagement (published note to follow)

<sup>45</sup> [Written evidence, AEC 36, Chair, Sparkle](#)

<sup>46</sup> [CYPE Committee, 7 June 2023, Record of Proceedings, paragraphs 64- 65](#)

*highest qualification was a degree or equivalent, compared to 21.5% of disabled people. In the most even statistics, 21.6% of non-disabled people's highest qualification was a A-level or equivalent, compared to 20.7% of disabled people. 18.8% of non-disabled people's highest qualification was GCSE grade C or above or equivalent, compared to 24% of disabled people. 9.4% of non-disabled people's highest qualification was another form of higher education, compared to 7.3% of disabled people. 5.9% of non-disabled people had no qualifications, compared to the significantly higher 16.4% of disabled people."*<sup>47</sup>

Clearly educational outcomes can have a life-long impact on a person's opportunities to earn money, so that this is another angle that needs consideration within the Child Poverty Strategy. The intersectionality of these issues also needs careful thought and should be addressed within any strategy seeking to reduce child poverty.

In relation to provision for childcare, Oxfam Cymru called for this, particularly for the provision of childcare and early education access for "children from different ethnic backgrounds and disabled children." They said that only by "recognising and addressing" these children's "unique needs and challenges" can we ensure that childcare and early education is "truly inclusive and equitable."<sup>48</sup>

We are concerned that for many of the families we have spoken to they will face a combination of all of these issues. We are also acutely aware that our evidence gathering has only allowed us to take a "snapshot" of evidence, and that there will be families who may be experiencing other issues which we are not aware of.

We will continue to pursue these issues through our current inquiry, but we wanted to ensure that this was brought to your attention and could help inform your current work. We will keep you updated with any relevant information or developments in this area of work.

I hope this evidence is useful to your Committee.

Yours sincerely,



Jayne Bryant MS  
Chair

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<sup>47</sup> [Written evidence, AEC 09 Disability Wales](#)

<sup>48</sup> [Written evidence, AEC 57, Oxfam Cymru](#)

Croesewir gohebiaeth yn Gymraeg neu Saesneg.

We welcome correspondence in Welsh or English.

# Agenda Item 4

By virtue of paragraph(s) vii of Standing Order 17.42

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# Agenda Item 5

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# Agenda Item 6

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# SUBMISSION TO THE INQUIRY ON DATA JUSTICE AND THE USE OF PERSONAL DATA



# ACCESSIBLE FORMATS

This document is also available in Welsh.

If you would like this publication in an alternative format and/or language, please contact us at [enquiries@llaiscymru.org](mailto:enquiries@llaiscymru.org).

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## About Llais

We are pleased to provide this submission to the Senedd Equality and Social Justice Committee for the inquiry on data justice and the use of personal data in the Welsh NHS.

Llais is the independent body that reflects the views and represents the interests of people living in Wales in their National Health Service (NHS) and social care services. We encourage and support people to have a voice in the design, planning and delivery of NHS and social care services.

We operate locally, regionally, and nationally. We work with people and communities in all parts of Wales so that everyone's voice is heard, and used, to drive the design, development and delivery of health and social care services for everyone. We:

- ④ Reach out to hear from people within our local communities through an on-going programme of engagement activities. We do this so that people know about and understand what we do, and to gather their views and experiences of NHS and social care services. We do this in lots of ways, face to face and digitally, including visiting places where people are receiving health and social care services.
- ④ We use what we hear to help health and social care services better understand how those of us who may need, and use services think services are meeting their needs, in the way that matters most to them. We help make sure the NHS and social care services takes action to make things better where this is needed.  
  
This includes working with health and social care service managers when they are thinking about making changes to the way services are delivered, so that people and communities have their say from the start.
- ④ Provide a complaints advocacy service that is free, independent, and confidential to help people to raise their concerns about NHS and social care services.

We have operated in Wales since 1 April 2023. Our submission draws on what we, and the former Community Health Councils in Wales have heard about what's important to people living in Wales about using personal data in the Welsh NHS.

## Using personal data to provide my care and treatment

Since the beginning of the Covid-19 pandemic, people living in Wales saw the rapid development, introduction, and use of digital healthcare services. This helped many people feel safer when they needed care and treatment. This is because it meant avoiding a need to travel to traditional healthcare settings, helping people to stay connected by accessing their healthcare teams in a remote way.

This also meant that people's personal and sensitive information was collected and handled electronically by healthcare providers more than ever before.

## Knowing what data is held about me and why

The rapid increase in digital healthcare services meant that many people got more used to sharing their personal data with NHS services on-line. They did this verbally through telephone and video consultations, and in writing, through on-line appointment booking and advice services, like Ask My GP and E-connect.

During this period, many people saw a big shift away from the more traditional paper-based data collection and record keeping they were used to in the NHS. For lots of people this was a welcome development, becoming more like other day to day services they were used to getting on-line.

But it also meant that, although in the longer term, the opportunities for providing a more accessible, flexible, and person-centred approach to the provision of healthcare were high, the speed and focus of its introduction –

to enable essential services to continue – meant that the opportunity to design and develop these new ways of working with people, driven by what matters to them, simply wasn't there.

This also meant that there wasn't a meaningful opportunity to talk about and build a strong understanding amongst people about:

- 🗣️ how their personal data was being collected electronically
- 🗣️ how it was being held
- 🗣️ who would be able to see it
- 🗣️ how it would be used
- 🗣️ how they could be reassured that it would be properly protected, and
- 🗣️ what their rights are around their data.

This doesn't mean that information wasn't available to people about the use and storage of the data they provided electronically. People using online services are used to seeing lots of long, detailed information about their rights and how their data will be stored and used through things like privacy notices.

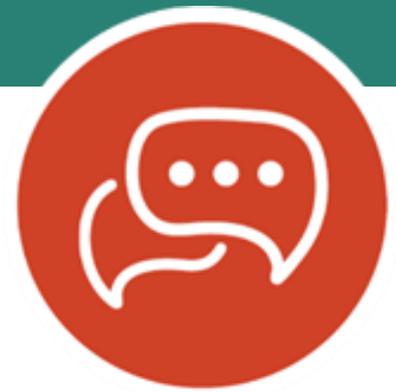
But this very familiarity means that people don't always read the detail – and simply providing it doesn't inevitably mean that people understand what it means for them practically – unless they can see and feel it for themselves.

So, for example, feeling confident to share personal and sensitive information safely when seeing healthcare professionals through a video conference arrangement needs some active reassurance from healthcare professionals that the environment is a confidential one.

This is not something that only applies to electronic data collection. We know, for example, how important it is that people understand why their personal data is being asked for, who will use it, and what for – it's an essential ingredient in the trust needed between people using services and those providing them.

This was clearly shown when there were changes to the way in which personal data was used within GP practices during the pandemic. So that

reception staff were able to help refer people to the right healthcare professional, many GP practices changed the way they handled requests for an appointment.



This meant that reception staff were often asking for personal and sensitive information from people about their symptoms when they may not have done so before. Where people didn't understand the reasons for this – because it wasn't clearly explained to them – this often led to a reluctance amongst people to share such personal information up front.

## **Having confidence in the accuracy, completeness, and use of my data to meet my needs**

We know that people's trust and confidence in their healthcare services, and the people providing it, is directly affected by how well healthcare systems and healthcare staff work in understanding and responding to people's individual needs and circumstances.

Simple but important things, like knowing and using a person's preferred title or name can make a big difference in how they feel about their care and treatment experience.

Other things, like knowing and using the best ways to communicate with someone about their healthcare not only makes a difference in how people experience care, but how confident they are about the quality and safety of that care - and how much control and involvement they feel they have in their own healthcare.

In general, people expect their NHS to hold, use and share their personal data safely and securely between everyone responsible for their healthcare and treatment - including themselves. So, when this doesn't happen, not only is it very frustrating, it can lead to a much more fundamental loss of confidence in the efficiency and effectiveness of the service and their involvement in that service.

For example, we hear about people's concerns that:

- because data systems are not joined up, they have to repeat the same things over and over again to different healthcare staff because the information about them hasn't been made available to the person providing their care.

When this happens, for example in an emergency, e.g., when families in distress are asked to share information about their loved one's medication, the stress and anxiety about getting things wrong or missing something out makes a difficult situation so much worse.

We hear the frustration from people about services not having their personal data when it's needed in the way it's needed across all parts of the healthcare system, eg., between GPs, pharmacies, and hospitals, between wards in the same hospital, within Wales and between Wales and England where people access services over the border.

- because their data hasn't always been shared meaningfully between different healthcare staff, the way in which care and treatment is provided doesn't always reflect what's needed and what's most important to people, eg., engaging with people in their language of choice, recognising the role and involvement of carers, understanding how people's lived experiences may trigger certain behaviours and reactions, etc.

- because their personal data is held, used, and controlled by the NHS and those working within it, it's sometimes harder than it should be to find out about and receive their own healthcare records.

Often when they do receive it, they can't understand much of it because it's not written or retained in a way that helps people understand what it means for them – making it harder for people to have more control and responsibility over managing their care.

because they don't have a clear picture of the healthcare data the NHS holds about them, and they don't have easy access to it in one place, some people have concerns that the information held about them may not be accurate and complete, and they haven't got an easy way of checking it.

We also hear some concerns and fears from people that sensitive, personal data relating to their involvement with healthcare services may be shared or used negatively. For example:

People often worry that if they make a complaint or raise a concern about their service, it will be held on their record and affect how they continue to receive care and treatment

People are sometimes concerned that their personal data may be shared and misused outside the NHS, eg., between healthcare providers and others, without their knowledge and consent, and without good reason

People sometimes worry that their sensitive personal data about their conditions or characteristics may be misused to make wider judgements about themselves and their care.

## Using data to benefit others by informing and influencing healthcare developments and delivery

In general, people expect and understand that their personal data is needed and should be used by the NHS to provide their healthcare – so that they receive the best possible advice, support, care, and treatment to help them to stay well, manage a long-term health condition, recover from illness, or support them when they are reaching end of life.

Before the pandemic, much of our public awareness about the collection, use and sharing of healthcare data was raised through concern when things went wrong, for example in response to stories about problems or breaches in keeping data safe and secure.

People also saw through the Covid-19 pandemic how bringing together and sharing data more widely, and on a much bigger scale, could help both our understanding of the impact of the virus on our different people, communities, and groups, what action was needed in response and what difference these actions were making.

It also showed people that there were big gaps and differences in the way healthcare systems collected, used, and reported on its data.

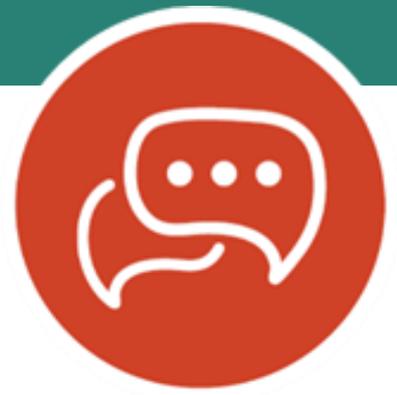
So even though there is a much better general awareness now, there is a lot more to do. It's important that people are helped and supported to understand the connection between the personal data that is collected, attached to their personal healthcare records, shared, and used to provide their individual healthcare, and the data (identifiable or otherwise) that is shared and used to inform and influence healthcare plans and developments more broadly.

We know that people's willingness to share their own healthcare data and experiences to inform and influence healthcare more broadly depends heavily on whether they feel that doing so will make a difference for others.

We hear this most often when people share their concerns with us about their care and treatment through our complaints advocacy service.

We also hear about this when people are undergoing care and treatment for a particular healthcare condition and agree to share their data to support more research and development into the condition and its treatment.





## Using opportunities to build a better understanding of data collection, sharing and use

The development in Wales of a new NHS app provides real potential for people who are able and want to use digital services to have easier access to their personal health data held by the NHS in Wales.

One of the key elements described for the app is that it gives people the ability to “take control over their data and see and decide where it goes. For example, the app will allow people to set up personal preferences for how their data is used....<sup>1</sup>.”

It will be important that all developments like these provide a real chance for everyone involved in NHS care to work closely with people and communities to help develop a clearer framework within Wales to identify, collect, manage, use, and share data.

Doing this should help everyone involved to design, develop, and deliver healthcare services in a way that identifies and responds to the things that matter most for all our people and communities. There is little point in collecting data if it is not used to build a strong understanding of our different needs so that our healthcare services respond and meet those needs fairly.

So these kinds of developments shouldn't simply be about providing digital ways of giving access to the data that's currently held.

It should continue to ask people what's important to them, what they want and how they want it so it can meet people's needs - based on their experience of getting and using their data, and how they want to see and use their data in the longer term.

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<sup>1</sup> Digital Services for Patients and Public - Digital Health and Care Wales (nhs.wales)

We know that how people feel about collecting and sharing personal health data can be affected by lots of different things. Striking a balance between the benefits of data sharing for healthcare and research and peoples' natural concerns around privacy is a challenge that needs thoughtful approaches, clear safeguards, and ongoing discussion with patients and the public.

These are some of the things the NHS in Wales needs to think about when developing and using data:

Be upfront about the benefits and risks of data collection and sharing with patients, families, and the wider public. Say why collecting and using data is needed, why it matters if that data is not available or shared, and who with

Involve people in the design and development of data collection systems and arrangements – in ways that build trust, understanding and ownership, particularly amongst those whose voices often go unheard

Be clear about what people can and can't control in decisions about their data capture, use and sharing. Be clear about why, and how their rights and data will be protected

Don't leave anyone behind. Not everyone is able or wants to get their NHS services or data digitally, and not all NHS services or data are held or provided digitally

Remember that for data to be useful, it needs to be more than just easily available. It needs to be right, it needs to make sense, it needs to cover the things that are important, and it needs to make a difference.

