

## Agenda – Y Pwyllgor Iechyd a Gofal Cymdeithasol

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Lleoliad: I gael rhagor o wybodaeth cysylltwch a:  
Hybrid – Ystafell Bwyllgora 3 Senedd a Sarah Beasley  
fideo gynadledda drwy Zoom Clerc y Pwyllgor  
Dyddiad: Dydd Mercher, 12 Mehefin 0300 200 6565  
2024 [Seneddlechyd@senedd.cymru](mailto:Seneddlechyd@senedd.cymru)  
Amser: 09.30

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### Rhag-gyfarfod preifat (09.00–09.30)

- 1 **Cyflwyniadau, ymddiheuriadau, dirprwyon a datgan buddiannau**  
(09.30)
- 2 **Bil Iechyd a Gofal Cymdeithasol (Cymru): sesiwn dystiolaeth gyda phobl anabl ynghylch cynigion i gyflwyno taliadau uniongyrchol ar gyfer Gofal Iechyd Parhaus y GIG**  
(09.30–10.30) (Tudalennau 1 – 12)  
Nathan Lee Davies  
Chris Hall  
Shahd Zorob  
John Hunt  
Cecilia Kenny

Briff Ymchwil

### Egwyl (10.30–10.40)

- 3 **Bil Iechyd a Gofal Cymdeithasol (Cymru): sesiwn dystiolaeth gyda sefydliadau sy'n cynrychioli pobl anabl a gofalwyr**  
(10.40–11.40) (Tudalennau 13 – 22)



Samantha Williams, Rheolwr Polisi a Chyfathrebu – Anabledd Dysgu Cymru

Jake Smith, Swyddog Polisi – Gofalwyr Cymru

Kat Watkins, Swyddog Datblygu Confensiwn y Cenhedloedd Unedig ar  
Hawliau Pobl Anabl – Anabledd Dysgu Cymru

Papur 1 – Anabledd Dysgu Cymru

Papur 2 – Gofalwyr Cymru

## **4 Papurau i'w nodi**

(11.40)

### **4.1 Llythyr gan y Cadeirydd at randdeiliaid yn dilyn y sesiwn dystiolaeth ar 17 Ebrill 2024**

(Tudalen 23)

### **4.2 Ymateb gan y Ganolfan Iechyd Meddwl i'r Cadeirydd yn dilyn y sesiwn dystiolaeth ar 17 Ebrill 2024**

(Tudalennau 24 – 28)

### **4.3 Llythyr gan y Cadeirydd at Ysgrifennydd y Cabinet dros Iechyd a Gofal Cymdeithasol ynghylch atal gwasanaethau mamolaeth ym Mwrdd Iechyd Prifysgol Bae Abertawe**

(Tudalen 29)

### **4.4 Ymateb gan Ysgrifennydd y Cabinet at y Cadeirydd ynghylch atal gwasanaethau mamolaeth ym Mwrdd Iechyd Prifysgol Bae Abertawe**

(Tudalen 30)

## **5 Cynnig o dan Reol Sefydlog 17.42 (ix) i benderfynu gwahardd y cyhoedd o weddill y cyfarfod hwn**

(11.40)

## **6 Bil Iechyd a Gofal Cymdeithasol (Cymru): trafod y dystiolaeth**

(11.40–12.00)

## **7 Gofal Iechyd Carcharorion**

(12.00–12.20)

(Tudalennau 31 – 42)

Papur 3 – Nodyn Ymchwil

Papur 4 – Llythyr gan Dr Robert Jones, Canolfan Llywodraethiant Cymru

[Llythyr at y Gweinidog Iechyd a Gwasanaethau Cymdeithasol yn gofyn am ddiweddariad ynghylch argymhellion Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon y Bumed Senedd mewn perthynas â darparu gofal iechyd a gofal cymdeithasol ar yr ystâd carchardai i oedolion](#)

[Ymateb gan y Gweinidog Iechyd a Gwasanaethau Cymdeithasol i lythyr y Pwyllgor yn gofyn am ddiweddariad ynghylch argymhellion Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon y Bumed Senedd mewn perthynas â darparu gofal iechyd a gofal cymdeithasol ar yr ystâd carchardai i oedolion](#)

Mae cyfyngiadau ar y ddogfen hon

## Proposed changes to legislation on social care and continuing health care

### Consultation Response Form

Your name: Dr Grace Krause

Organisation (if applicable): Learning Disability Wales

### Questions on Chapter 1: Eliminating profit from the care of children looked after

**Question 1.1:** Do you think that introducing provision in legislation that only allows 'not-for-profit' providers to register with CIW will support delivery of the Programme for Government commitment to eliminate profit from the care of children looked after?

We are very happy to see Welsh Government moving towards removing private profit from provision for children's services. We would like to encourage Welsh Government to explore the possibility of also doing so for adult social care services.

The Policy Proposal makes a convincing case for why private profit has no place in the provision of children's services. You write that:

*Our aim is to ensure that public money invested in the care of children looked after does not profit individuals or corporate entities, but instead is spent on children's services to deliver better experiences and outcomes for children and young people, addressing service development and improvement and further professional development for staff (page 3)*

You also state that up to 20% of the money put into residential care for children is lost to private profit. We would like to know what the equivalent number is for adult services and ask Welsh Government to explore the feasibility to come to similar resolutions in terms of addressing the issue.

While we do not have up-to date information for Wales, we note that a 2016 report from the *Centre for Health and Public Interest* on the impact that privatisation had had on the quality of care in England found that "Both the quality of care in adult social care and the terms and conditions of the workforce have declined over the past two decades as a result of privatisation. The report also shows that turnover rates are higher, and rates of pay considerably lower, in the private care sector than in the public sector.

In addition, 41% of community-based adult social care services, hospice services and residential social care services inspected by the Care Quality Commission since October 2014 were found to be inadequate or requiring improvement<sup>1</sup>". We believe that findings like that may imply a strong case to critically investigate the role of private providers in adult social care in Wales.

**Question 1.2:** What in your view are the likely impacts of the proposal? You may wish to consider, for example:

- Benefits, and disbenefits;
- Costs (direct and indirect), and savings;
- Impacts upon individuals and groups with protected characteristics;
- Other practical matters such as cross-border issues.

Your views on how positive effects could be increased, or negative effects could be mitigated, would also be welcome.

Please explain your reasoning.

**Question 1.6:** Are there any issues in relation to transition for children looked after, local authorities and service providers you would like to draw our attention to?

A significant amount of work will need to be done to ensure that those individuals currently being supported by for-profit providers are successfully transitioned to new providers with continuity of care and minimal disruption to their daily lives. There is a risk that some for-profit providers might suffer significant financial difficulties if this goes ahead and this could lead to some going into liquidation or simply withdrawing services overnight, potentially leaving vulnerable people with no care and support. It is essential that contingency plans are in place to avoid people ending up being transferred to expensive out-of-area placements away from their families, friends and communities due to a lack of alternative, good quality local provision.

**Question 1.7:** What are your views on the issuing of guidance to support the implementation of the primary legislation?

It is important that all guidance around this is produced with accessibility in mind. We urge Welsh Government to take accessibility more seriously, given the inaccessibility of this process. The proposals in this document have a clear and important impact on people with a learning disability as well as young people. As such it is extremely disappointing that this consultation was not conducted in a more accessible way. There was no easy read material for this consultation available originally. An easy read summary was published approximately two weeks before the submission date. As it was only a summary, the easy read document was too vague for anyone to develop a real understanding of the

proposals and be able to make informed decisions about the content. There was also no easy read questionnaire available.

It is also worth noting that the proposal itself was not written with accessibility in mind. It would have been good to give the document another edit to make sure things are phrased clearly and questions are asked in the most straightforward way possible.

## Questions on Chapter 2: Introducing direct payments for Continuing NHS healthcare

**Question 2.1:** We have outlined our proposals to introduce further voice and control for adults receiving Continuing Health Care (CHC) in Wales. Do you agree or disagree with these proposals? Please explain your reasoning.

We support the implementation of direct payments for health budgets as they are something disabled campaigners have been asking for a long time. People with a learning disability often do not feel like they have control over their lives. We also know that many disabled people do not feel they have the control over their medical treatment that they should. Giving people more control over their medical decisions is a good step towards this.

**Question 2.2:** What in your view are the likely impacts of the proposal?

You may wish to consider, for example:

- Benefits, and disbenefits;
- Costs (direct and indirect), and savings;
- Impacts upon individuals and groups with protected characteristics;
- Other practical matters such as cross-border issues or transition to the new arrangements.

Your views on how positive effects could be increased, or negative effects could be mitigated, would also be welcome.

Please explain your reasoning.

Our concern however is that these changes could possibly disadvantage people with a learning disability by placing a disproportionate administrative burden on them.

You give the reason for wanting to implement personal health budgets as enabling greater voice and control for adults and moving towards more integrated, person centred provision within health and social care. You write that you are also

promoting fairness and continuity to care is important. We agree that all of these are important goals and that Personal Health Budgets can play an important part of addressing these issues.

However, we are concerned that in times of austerity and systematic underfunding of the NHS people may choose to accept Personal Health Budgets because they cannot get the care they need. It is important that NHS funding is protected and people's choices and autonomy are given the support they need.

We are concerned that people with a learning disability might feel pressured to take on health budgets because the care they get otherwise is not adequate. They then might find that they struggle with the administrative burden that comes with health budgets. It is important that people with a learning disability and family carers receive substantial support in using the budgets if they chose them.

Support also needs to be put in place to make sure people with a learning disability who chose the Personal Health Budgets get support when something goes wrong with the services they are buying. Measures need to be put in place to make sure predatory providers do not take advantage of people using the budgets.



## Consultation Response Form

Your name: Beth Evans

Organisation (if applicable): Carers Wales

### Questions on Chapter 1: Eliminating profit from the care of children looked after

**Question 1.1:** Do you think that introducing provision in legislation that only allows 'not-for-profit' providers to register with CIW will support delivery of the Programme for Government commitment to eliminate profit from the care of children looked after?

If it is a legislative requirement then yes.

**Question 1.2:** What in your view are the likely impacts of the proposal? You may wish to consider, for example:

- Benefits, and disbenefits;
- Costs (direct and indirect), and savings;
- Impacts upon individuals and groups with protected characteristics;
- Other practical matters such as cross-border issues.

Your views on how positive effects could be increased, or negative effects could be mitigated, would also be welcome.

Please explain your reasoning.

There may be some unintended consequences of moving 'for profit' care for looked after children. Some organisations will inevitably close their doors, however there seems to also be adequate 'lead in' time to enable other not for profit organisations to develop and take their place. There must however be enough information to support 'for profit' providers to possibly turn their business around into 'not for profit' and also enough information and support for other providers to come forward and develop services.

**Question 1.3:** One approach could be for the legislation to define 'not-for-profit' in terms of the types of organisation that would qualify. Do you consider that the restriction should also be expressed in terms of the way that any trading surplus is expended? What would be the effects and implications of this?

If it is truly to be a 'not for profit' service then any surplus should be returned to the commissioning body or be used to develop further services. There should not be the taking out of 'excessive fees' by parent companies and the fees that are acceptable should be detailed at the outset by Government and via commissioning contracts.

**Question 1.4:** Do you think the primary legislation should include a power for Welsh Ministers to amend the definition of 'not-for-profit' through subordinate legislation?

It would be useful to have the power available even if that power is not immediately used.

**Question 1.5:** What are your views on the proposed timings for the primary legislation to come into effect?

There needs to be adequate lead in time but during that lead in time adequate information provided on process, practice, guidance, transition, commissioning processes and the development of Codes of Practice to accompany legislation should be available in plenty of time.

**Question 1.6:** Are there any issues in relation to transition for children looked after, local authorities and service providers you would like to draw our attention to?

**Question 1.7:** What are your views on the issuing of guidance to support the implementation of the primary legislation?

It must be done as soon as possible.

**Question 1.8:** What are your views on using legislation to place a restriction on local authorities to commission placements from 'not-for-profit' organisations only? In particular:

- Do you think it would support us to deliver the commitment to eliminate profit from the care of children looked after in Wales?
- What would be the benefits, disbenefits and other implications of such an approach?
- What would be an appropriate timescale for implementing such an approach, if it were to be adopted in Wales?

I think it will go some way to deliver the commitment to eliminate profit from the care of looked after children but it needs to be done in co-production with organisations to ensure that the views are taken into account in terms of timescale and what they actually need in terms of support, guidance etc and especially for organisations to transition from 'profit' to 'not for profit'.

Appropriate timescales should be co-produced with local authorities, commissioners and the not for profit services to ensure that they are realistic and can be met. This may help with transition and give organisations time to adjust/develop services.

**Question 1.9:** What are your views on the possibility of approaches being taken in response to these legislative proposals which would undermine the intention to eliminate profit from the care of children looked after in Wales? Are there any actions which would guard against such activity?

Again, I would suggest that you work with organisations/local authorities to co-produce and decide what is acceptable in terms of what can/cannot be deemed as profit, and where there is a profit, how that profit is to be used to develop further services. There needs to be robust accounting, transparency and effective monitoring of services/commissioning processes.

**Question 1.10:** We would like to know your views on the effects that the legislative changes to eliminate profit from the care of children looked after will have on the Welsh language, specifically on opportunities for people to use Welsh and on treating the Welsh language no less favorably than English. What effects do you think there would be? How could positive effects be increased, or negative effects be mitigated?

There is potential for more Welsh language services to evolve and develop.

**Question 1.11:** Please also explain how you believe the legislative changes to support delivery of eliminating profit from the care of children looked after could be formulated or changed so as to have positive effects or increased positive effects on opportunities for people to use the Welsh language and on treating the Welsh language no less favourably than the English language, and no adverse effects on opportunities for people to use the Welsh language and on treating the Welsh language no less favourably than the English language.

**Question 1.12:** This chapter has focused on how we can achieve the commitment to eliminate profit in the care of children looked after, and we have asked a number of specific questions. If you have any related issues which we have not specifically addressed, please use this space to report them.

## Questions on Chapter 2: Introducing direct payments for Continuing NHS healthcare

**Question 2.1:** We have outlined our proposals to introduce further voice and control for adults receiving Continuing Health Care (CHC) in Wales. Do you agree or disagree with these proposals? Please explain your reasoning.

I wholeheartedly agree with the proposal. For many years carers have raised this very issue with us that when the person they care for moves on to CHC, any direct payments they were receiving for various aspects of their care was then withdrawn by local authorities. This has often had a devastating effect on disabled people and their family carers as the services and staff they were accustomed to were no longer an option and no longer available to them. This has meant a loss of choice, voice and control about when and how care and support needs were met. There has always been legislation in place to encourage joint working between health and social care, however with each sector having their own budgets, inevitably arguments have arisen over who provides what. The outcome is that often, service users and carers are left foundering between services. Anything that can be done to ensure that the NHS and Local Authorities tailor joint packages of care will be very much welcomed.

**Question 2.2:** What in your view are the likely impacts of the proposal?

You may wish to consider, for example:

- Benefits, and disbenefits;
- Costs (direct and indirect), and savings;
- Impacts upon individuals and groups with protected characteristics;
- Other practical matters such as cross-border issues or transition to the new arrangements.

Your views on how positive effects could be increased, or negative effects could be mitigated, would also be welcome.

Please explain your reasoning.

Benefits would obviously be for the person in receipt of care and support, enabling them to start or continue with their direct payments package. This in turn could be more cost effective and save the NHS money in staff time as well as other resources to meet care needs.

There may be difficulties however for individuals to recruit care work support due to the Direct Payment rates involved and lack of social care workers. This may be more acute in rural areas due to travel costs etc. It must also not be seen as a way to pass the onus on to individuals to find their own care workers. This has also been

happening, where someone has been assessed as having an eligible need, no care workers to meet that need so offering direct payments and expecting service users to find someone to provide care, that in effect doesn't exist.

It must also be made clear that family members can be paid using Direct Payments.

Direct Payment rates also need to reflect the care market in local areas to ensure that hourly rates are comparative or better than other employment sectors to encourage care workers to take up the jobs.

Ensure that where there is a dispute over which statutory organization provides what, that the service user is provided with the necessary payment as soon as possible and that any dispute is resolved later between the bodies. This will ensure that continuity of care continues, if someone is already in receipt of a direct payment or where someone wants to take up a direct payment they can do so as soon as possible.

**Direct Payments for carers in need of support should also be included in this legislation.** Often carers have told us that because someone is on CHC that wrongly LAs have refused services to them as they believe that the NHS should provide them with the support. This also needs to be urgently addressed and clarified.

**Question 2.3:** What lessons can we learn from other countries' practice in this area?

**Question 2.4:** Do you believe there are any other or complementary approaches we should be considering to achieve the same effect? If so, please outline below.

Not to my knowledge.

**Question 2.5:** We will work to ensure that any legislative change is supported by robust guidance to help both payment recipients and practitioners understand how the system will operate. Can you identify anything that it would be helpful to include in this guidance? What other support should be provided?

Explicitly say that the law has changed

That LAs and LHBs by law are now required to work together

How and who will have the responsibility for supporting the unpaid family carers

That DP recipients have the choice of who they employ, including family, people on self employed contracts etc

**Question 2.6:** We would like to know your views on the effects that introducing direct payments for continuing NHS healthcare would have on the Welsh language, specifically on opportunities for people to use Welsh and on treating the Welsh language no less favourably than English. What effects do you think there would be? How could positive effects be increased, or negative effects be mitigated?

It enables people to have the choice of whom they employ to meet their needs, this includes welsh speaking care workers

**Question 2.7:** Please also explain how you believe our proposals for introducing direct payments for continuing NHS healthcare could be formulated or changed so as to have positive effects or increased positive effects on opportunities for people to use the Welsh language and on treating the Welsh language no less favourably than the English language, and no adverse effects on opportunities for people to use the Welsh language and on treating the Welsh language no less favourably than the English language.

**Question 2.8:** We have asked a number of specific questions in this chapter. If you have any related issues which we have not specifically addressed, please use this space to report them.

**Direct Payments for carers in need of support should also be included in this legislation.** Often carers have told us that because someone is on CHC that wrongly Las have refused services to them as they believe that the NHS should provide them with the support. This also needs to be urgently addressed and clarified

**In relation to the remainder of the consultation we have no particular comments as this is not our area of expertise.**

**Y Pwyllgor Iechyd a  
Gofal Cymdeithasol**

**Health and Social Care  
Committee**

Andy Bell

Y Ganolfan Iechyd Meddwl

Oliver John

Grŵp Cynghori Arbenigol Iechyd Meddwl Colegau Brenhinol

Yr Athro James Walters

Coleg Brenhinol y Seiciatryddion

9 Mai 2024

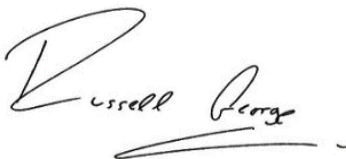
Annwyl gyfeillion

Diolch i chi am ddod i gyfarfod y Pwyllgor ar 17 Ebrill i roi tystiolaeth ar gyfer ein hymchwiliad i gefnogi pobl â chyflyrau cronig, ac am y wybodaeth ychwanegol y gwnaethoch gytuno i'w darparu.

Byddai'r Pwyllgor yn falch o gael eich barn am un mater arall, sef a ydych yn credu bod digon o gymorth iechyd meddwl ar gael i blant a phobl ifanc â chyflyrau cronig, yn enwedig wrth iddynt symud o ofal pediatrig i ofal oedolion.

Byddwn yn gorffen casglu tystiolaeth ar 19 Mehefin, pan fyddwn yn clywed gan y Gweinidog Iechyd a Gofal Cymdeithasol, felly byddai'n ddefnyddiol cael eich ymateb erbyn **3 Mehefin 2024**, os yw'n bosibl.

Yn gywir,



Russell George AS

Cadeirydd y Pwyllgor Iechyd a Gofal Cymdeithasol

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

## Supporting the mental health of young people with chronic conditions

Additional evidence from Centre for Mental Health

May 2024

### Introduction

The Chair of the Health and Social Care Committee wrote to us to seek our views and evidence relating to the mental health support that is offered to children and young people with chronic (physical) conditions. We have explored this as part of research into the emotional and psychological needs of people living with chronic kidney disease, in partnership with Kidney Research UK.

The evidence below is drawn from our report of that work (Wilton, 2023). References cited in this evidence paper are all available in the full report:

[https://www.centreformentalhealth.org.uk/wp-content/uploads/2023/05/CentreforMHKRUK\\_TheCaseForChange.pdf](https://www.centreformentalhealth.org.uk/wp-content/uploads/2023/05/CentreforMHKRUK_TheCaseForChange.pdf).

While our evidence relates to kidney disease, we believe that it is applicable across long-term conditions. Every young person is different, and the challenges of living with different (and, for some, multiple) long-term conditions will differ, too, but the themes identified in this work will apply broadly.

### Key points

- Having a long-term condition places especial pressure on the mental health of children and young people.
- Poor mental health can affect the physical health outcomes for young people living with a long-term condition.
- The transition from paediatric to adult care is a time when having the right psychosocial support in place is especially important. Children will also experience transitions prior to this, for example after diagnosis or when changing schools.
- Families, friends, and peers all play an important part in supporting the mental health of children and young people with long-term conditions.
- Children and young people are not just small adults. They have distinct needs, preferences and risk factors, which must be considered in their own right when developing psychosocial support for these age groups.
- The model of 'whole person care' for long-term conditions needs to be adaptable to fit the diverse needs of children and young people. Psychosocial support should not be 'just another medical appointment' on top of those they already face.



## Mental health impacts of chronic conditions

Kidney disease, like many long-term conditions, has a significant negative impact on the quality of life and mental health of children and young people (Francis et al., 2019; Hamilton et al., 2019; Splinter et al., 2018; Tjaden et al., 2016; van Muilekom et al., 2021). This impact is seen across their emotional, social, physical and educational wellbeing and functioning (Kerklaan et al., 2020; Ruidiaz-Gómez & Higueta-Gutiérrez, 2021; Rupp et al., 2021). And, as in adults, there is evidence that psychosocial issues have a negative impact on the medical outcomes of children and young people (Clementi & Zimmerman, 2020; Hamilton et al., 2018).

In a multinational interview study of 30 young adults (aged 18-36) living with kidney disease, Kerklaan and colleagues (2020) identified six themes relating to their psychosocial wellbeing:

1. Struggling with daily restrictions (from symptoms and side effects, giving up valued activities, impossible to attend school and work, trapped in a medicalised life, overprotected by supporting adults and cautious to avoid health risks)
2. Lagging and falling behind (delayed independence, failing to keep up with peers and struggling socially)
3. Defeated and hopeless (incapacitated by worry, an uncertain and bleak future, feeling unworthy of relationships, low self-esteem and shame)
4. Reorienting plans and goals (focusing on the day-to-day, planning parenthood and forward and flexible planning)
5. Immersing themselves in normal activities (refusing to miss out, finding enjoyment, determined to do what peers do and being present at social events)
6. Striving to reach potential and seizing opportunities (encouragement from others, motivated by the illness, establishing new career goals and grateful for opportunities).

While some of these themes hold true for adults living with kidney disease, others are more distinctly tied to the challenges and opportunities of young adulthood.

## Transitions during childhood and adolescence, and into adulthood

Childhood, adolescence and young adulthood are life-stages full of changes. The needs of a two year old are very different from those of a ten year old which, in turn, are very different from those of a twenty year old. One of the most significant changes over these life-stages is from complete dependence on families and caregivers at the start of life to, for most young people, relative independence by their early twenties. This development is gradual and does not happen at the same pace for all.

For some of the young people and parents who spoke to us, the transition from paediatric to adult care was relatively abrupt and took place at a 'cut-off' age. About 35% of young adults lose a successfully functioning kidney transplant within 36 months of moving from paediatric to adult care (Harden et al., 2012), making this an especially high-risk time in their life.

One young person said: *"It would be nice to be introduced to the new doctors beforehand. Yeah, there was not much to it, there was not much thought behind it."*

And a mother, talking about her daughter's transition from paediatric to adult care, described it as "being thrown in at the deep end". This transition is a vulnerable stage for young people, when their condition and their psychosocial wellbeing may deteriorate (Dallimore et al., 2018).

Young adults have worse outcomes following a kidney transplant than any other age group (Hamilton et al., 2020; Pankhurst et al., 2020). This is likely to have an impact on overall life-expectancy, as well as reducing health, quality of life and ability to work (Pankhurst et al., 2020). Providing the right support during this complex period in a young person's life is, therefore, crucial. Such support needs to focus on the young person's wellbeing, not solely on using psychological interventions as a means to increase adherence to treatment.

### Families and carers

Families and other unpaid carers play an essential role in the psychosocial support of people living with chronic conditions. This is especially true for children and young people (Clementi & Zimmerman, 2020). Research has shown that, when a child has kidney disease, it has an impact on family dynamics and the relationships between all family members and that, to quote from one study, "the whole family constitutes a unit of care" (Agerskov et al., 2020).

Families caring for children and young people with kidney disease face many sources of distress and they have a range of psychosocial needs. Family members often experience overwhelming challenges, and there are gaps in the resources available to help them to cope (Wee et al., 2022). The psychosocial needs of these families, identified in a focus group study with 21 parents, include information, emotional support and practical support (Geense et al., 2017). A suggestion is that the psychosocial needs of the whole family should be taken into consideration (Abrão et al., 2021; Zhang et al., 2023).

### Friends and peers

Two themes that stood out in our conversations with children and young people were the importance of play and of peers. Children and young people with kidney disease often spend a lot of time in medical environments. This comes at the expense of the time spent with friends and at school, meaning they have fewer opportunities for social interaction and for activities appropriate to their stage of life. One mother, whose young son is living with kidney disease, spoke to us about the struggle of balancing all his medical appointments against "mak[ing] time for him to be a kid".

Children and young people also spoke about the effect of kidney disease on their relationships. Their symptoms and treatments may make it harder for them to form friendships. They described living with kidney disease as "kind of isolating" and "[a] very lonely place". It could be especially difficult when their friends had little knowledge or experience of kidney disease. One of the children and young people who spoke to us said:

*"Most dialysis units have patients who are over 50. But if you're a 16, 17, 18 year old, that's a fairly shocking place to spend three days of your week. Because not only are you around older people and it doesn't feel like it's your kind of thing, it's also that you can see, potentially, the trajectory of your life. I don't think we pay enough attention to that."*

Because kidney disease is relatively rare among children and young people, those with a diagnosis are unlikely to meet others with a diagnosis outside of a clinical setting. This may mean they have fewer opportunities for conversations about their experiences with people their age who 'get it', compared to adults living with kidney disease.

In our interviews and focus groups with children and young people, much more so than in those with adults, the importance of being able to talk to peers came up. One young person told us, "I have met someone [my age] with kidney disease before and I found that talking to them is really helpful." This is echoed by Agerskov and colleagues (2020) who found, "Getting together with peer children with [kidney disease] resulted in a positive sense of belonging."

It may be important – even more so than for adults – to avoid psychosocial support taking the form of yet another intervention that takes place in a formal clinical setting, and to provide children and young people with opportunities to interact with people their own age who are living with kidney disease.

### **Psychosocial support for children and young people**

Children and young people face increased and different barriers than adults to being proactive in finding psychosocial support. They often lack the knowledge and the resources to be able to search for help independently. As a result, it's especially important that this information is visible in clinics (e.g. in the form of posters) and communicated to them by health care professionals.

*"Kidney health isn't something that I see talked about a lot or in the same way as other conditions might be [...] and that just adds to the lack of understanding and the scariness of that, I guess."*

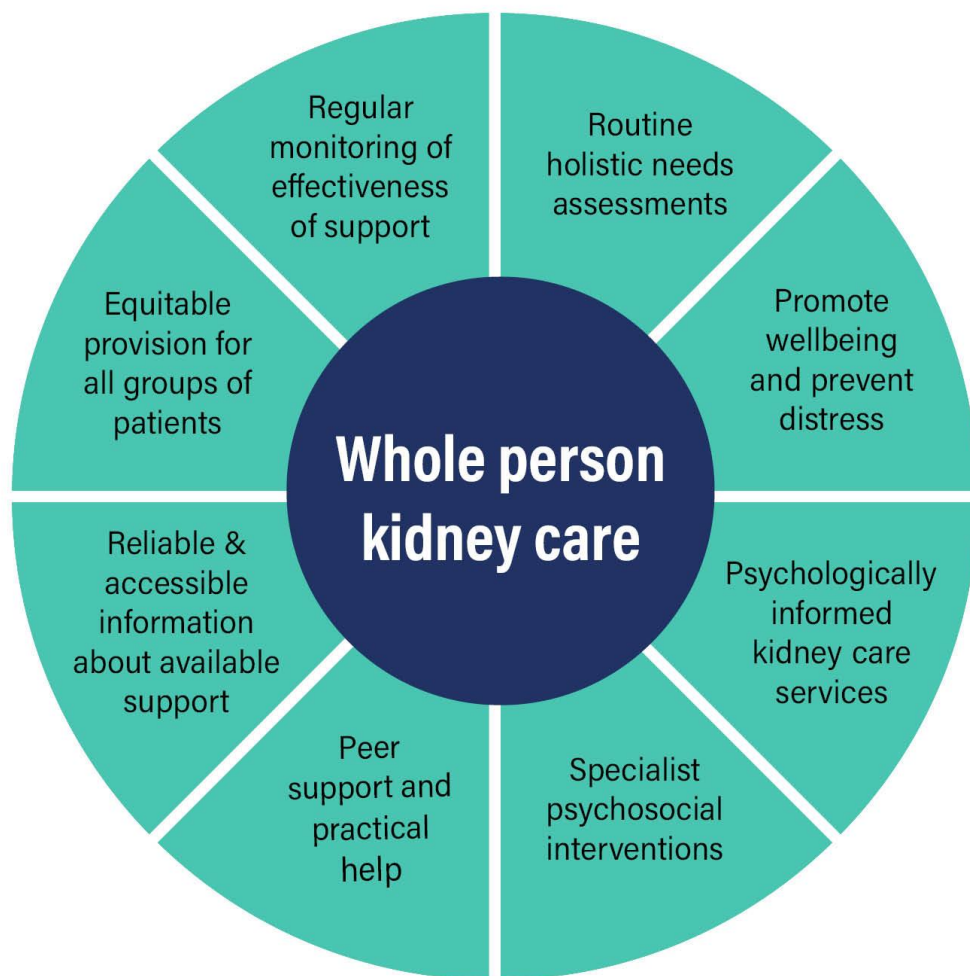
*"Once you are able to access the support, it's amazing... but it's just being able to find out about the support."*

*"I've never seen any kidney leaflets about kidney disease at GPs or anything... I'm in my early 20s and I'm suddenly told that having a child might not be an option for me, or I might die younger [...] and there is no support afterwards, they kind of go 'here is all the stuff' and there is no real support network."*

Research has noted the importance of designing clinical pathways for children and young people living with kidney disease that suit their lifestyles (Harden et al., 2012). The barriers faced by older young people may be connected to the way care is delivered. Many move frequently, if they are studying for qualifications or pursuing work experience. Some may spend part of their year in one location, another part somewhere else (on a university

campus and at their family home, for example). They sometimes face a trade-off between continuity of care and convenience of location. Place-based support may be less appropriate to the needs of this age group.

Centre for Mental Health and Kidney Research UK produced the following model of 'whole person care'. It is crucial that this model is responsive to all age groups, with adaptations to make it suitable at any age and to respond to the diversity of the children and young people who have long-term conditions.



**Y Pwyllgor Iechyd a  
Gofal Cymdeithasol**

**Health and Social Care  
Committee**

Eluned Morgan AS

Ysgrifennydd y Cabinet dros Iechyd a Gofal Cymdeithasol

25 Ebrill 2024

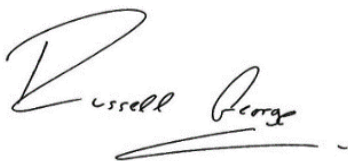
Annwyl Eluned,

Rydym wedi cael gohebiaeth ynghylch atal gwasanaethau mamolaeth BIP Bae Abertawe, yn benodol atal y gwasanaeth geni yn y cartref a chau Canolfan Geni Castell-nedd Port Talbot.

Gwnaethoch gyfeirio yn eich datganiad i'r Cyfarfod Llawn ar 12 Rhagfyr 2023 at fuddsoddiad ychwanegol o £750,000 mewn gwasanaethau mamolaeth ym Mae Abertawe, a fyddai'n galluogi ailagor canolfan famolaeth Castell-nedd Port Talbot ac ailgyflwyno'r gwasanaeth geni yn y cartref ddechrau eleni.

A allwch roi'r wybodaeth ddiweddaraf am y sefyllfa bresennol a chadarnhau pryd yr ydych yn rhagweld y bydd y gwasanaethau hyn yn cael eu hadfer.

Yn gywir,



Russell George AS

Cadeirydd y Pwyllgor Iechyd a Gofal Cymdeithasol

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

Eitem 4.4

Eluned Morgan AS/MS

Ysgrifennydd y Cabinet dros Iechyd a Gofal Cymdeithasol  
Cabinet Secretary for Health and Social Care



Llywodraeth Cymru  
Welsh Government

Russell George AS  
Cadeirydd  
Y Pwyllgor Iechyd a Gofal Cymdeithasol  
Senedd Cymru

[Seneddlechyd@senedd.cymru](mailto:Seneddlechyd@senedd.cymru)

3 Mehefin 2024

Annwyl Russell,

Diolch am eich llythyr dyddiedig 25 Ebrill, yn gofyn am yr wybodaeth ddiweddaraf am atal y gwasanaeth geni yn y cartref a chau Canolfan Geni Castell-nedd Port Talbot.

Yr wythnos diwethaf, cymeradwyodd bwrdd rheoli Bwrdd Iechyd Prifysgol Bae Abertawe ailagor Canolfan Geni Castell-nedd Port Talbot ac adfer y gwasanaeth geni yn y cartref, yn amodol ar gael cymeradwyaeth derfynol gan y Bwrdd yn ei gyfarfod cyhoeddus ar 23 Mai. Roedd hyn yn dilyn adolygiad cynhwysfawr o'r broses gyda mewnbwn ac ymgysylltiad sylweddol gan staff.

Fodd bynnag, o ganlyniad i faterion a godwyd yr wythnos hon gan un o undebau cydnabyddedig y bwrdd iechyd, mae fy swyddogion wedi cael gwybod y bydd oedi byr cyn dod â'r cynnig ffurfiol gerbron y Bwrdd i'w ystyried. Bydd hyn yn sicrhau bod y Bwrdd yn cael ei frifio'n llawn am unrhyw faterion a bod ganddo ddigon o sicrwydd cyn gwneud penderfyniad terfynol.

Yn gywir

**Eluned Morgan AS/MS**

Ysgrifennydd y Cabinet dros Iechyd a Gofal Cymdeithasol  
Cabinet Secretary for Health and Social Care

Bae Caerdydd • Cardiff Bay  
Caerdydd • Cardiff  
CF99 1SN

Canolfan Cyswllt Cyntaf / First Point of Contact Centre:  
0300 0604400

[Gohebiaeth.Eluned.Morgan@llyw.cymru](mailto:Gohebiaeth.Eluned.Morgan@llyw.cymru)  
[Correspondence.Eluned.Morgan@gov.wales](mailto:Correspondence.Eluned.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.

Tudalen y pecyn 30

Mae cyfyngiadau ar y ddogfen hon

Mae cyfyngiadau ar y ddogfen hon