WELSH GOVERNMENT INTEGRATED IMPACT ASSESSMENT

Title of proposal:	Introduction of Direct Payments for Continuing Health Care (CHC)
Official(s) completing the Integrated Impact Assessment (name(s) and name of team):	Complex Care team
Department:	Social Services and Integration
Head of Division/SRO (name):	Rhiannon Ivens
Cabinet Secretary/Minister responsible:	Dawn Bowden MS, Minister for Social Care

SECTION 1. WHAT ACTION IS THE WELSH GOVERNMENT CONSIDERING AND WHY?

Introduction

Direct payments are not currently possible in Wales under the NHS (Wales) 2006 Act. In England, direct payments have been permissible for Continuing NHS Health Care (CHC) via Personal Health Budgets (PHBs) since 2014 (following amendments to the NHS Act 2006 which took effect in 2013). Over several years, stakeholders in Wales have raised issues around the compromise of people's voice and control when transferring from local authority provided social care, with the ability to make direct payments in lieu of service provision, to NHS funded CHC, where the option of direct payments is lost. For many, it means a loss of voice and control and that they are no longer able to employ personal assistants they have become familiar with and whom they choose to deliver their care.

The proposal to introduce direct payments for CHC is intended to reinstate this voice and control for those who have assessed needs under CHC.

Trends, challenges and opportunities

The cost of CHC across Wales is growing, therefore it can be assumed that the number of those facing reduced voice and control will also be rising. Such growth is also causing pressures for LHBs. In 2012-2013 the total expenditure on CHC across Wales was £280m, by 2022-23 it had risen to £450m and is still rising.

Health Boards have attributed this additional cost to a combination of increased patient numbers, increased patient complexity and price inflation. Demographic trends due to Wales' ageing population will add to this demand.

With CHC costs rising, it is timely to consider alternative models of care. Direct payments support the provision of care in a person's own home and studies in England have shown that this provides better value for the public purse. There is also strong evidence to show that better health outcomes are achieved when someone has a greater say in their own care, thereby resulting in less ongoing health interventions and lower hospital admissions.

There will inevitably be challenges in introducing a new model of CHC, and these are laid out in the consultation responses which can be accessed at Proposed changes to legislation on social care and continuing health care | GOV.WALES

Conversely there are a number of opportunities offered by the proposal including, most importantly, further strengthening the voice and control of disabled and seriously ill adults and their carers, and better supporting people to maintain their independence.

Breaking negative cycles related to poor health and poverty

The evaluation of the PHBs three-year pilot in England found that use of personal health budgets was associated with a significant improvement in quality of life and psychological well-being. PHBs (in the main delivered via direct payments) showed higher ASCOT-measured net benefits than conventional services for the CHC and mental health sub-groups. In addition, using care-related quality of life (ASCOT¹) measured net benefits, personal health budgets were cost-effective relative to conventional service delivery.

Currently, anecdotal evidence across Wales suggests that a number of people will refuse to transition to a CHC package of care (which is fully funded by the NHS) and would rather continue to subsidise their existing social care package costs (where means-tested personal contributions apply). They do so to retain their current care package and to avoid losing their voice and control by transitioning to CHC. Were direct payments to be possible under CHC, this particular cohort would have more funds available for other essential costs.

Contribution to policy agendas

The proposal is a Welsh Government Programme for Government commitment - 'To improve the interface between Continuing Health Care and direct payments.'

It is strongly aligned with the Healthier Wales and More Equal Wales goals of the Well-being of Future Generations (Wales) Act 2015 (WFGA). As well as the health benefits cited above, using direct payments to deliver CHC would also promote equality for disabled people and those with complex health care needs by introducing models of healthcare which are person-centred and allow the individual to have voice and control over their lives.

The proposal is also in line with 'A Healthier Wales', the Welsh Government's plan for health and social care, in particular the goal to improve value for patients by giving a greater focus to the outcomes that matter to individuals. It also contributes to the range of options for 'social models of community based-care which cut across traditional organisation and service boundaries' within the plan.

The proposal can be linked to other key public health agendas, for example the shift towards Value-Based Health Care (VBHC) which can be defined as involving patients and clinicians together in making shared informed decisions.

¹ The ASCOT quality of life measure was developed originally to assess the consequences of social care services, but its focus on care-related quality of life implications makes it highly relevant for general use with people managing long-term conditions. Other studies have shown that people value care-related quality of life as measured by ASCOT in that they are willing to exchange shorter life expectancy for better ASCOT-measured quality of life.

It can also contribute to wider public policy agendas such as support for the foundational economy, ensuring that money is spent on healthcare in a way that will benefit our people and our economy. Recruiting and employing locally based PAs to deliver CHC will encourage greater spend of Local Health Board (LHB) budgets within local communities. For example the funding dispersed via payroll to care staff will remain local as compared with being spent on contracts with companies providing domiciliary care which may not be locally-based or may have headquarters outside Wales.

Collaboration and involvement

This proposal has been developed throughout with representatives of key stakeholder groups including health boards, local authorities, disabled people's organisations, disabled people and people with lived experience, and third sector groups.

Equalities, human rights and the Social Model of Disability have been overarching guiding principles within this policy development work and will continue to be central to any implementation plan.

Impacts and arguments for and against the proposal

The main impacts can be summarised as follows:

Strengths

- Fairness in terms of mechanisms available to ensure voice and control whether care is provided by local authority or health board
- Potentially more individuals agreeing to CHC assessments, without fear of losing direct payments, therefore having their complex health needs better managed
- Avoiding the issue of local authorities continuing to meet people's complex needs, if they have refused CHC assessment due to fear of losing direct payments
- More responsive and personalised care, sensitive to a person's preferences (eg. cultural and language) and delivered in the person's own home with resulting wellbeing benefits
- Evidence of better value for money than CHC delivered conventionally, and more valued by recipients of the care

Weaknesses

A number of potential issues to resolve have been highlighted by stakeholders, particularly NHS CHC Leads including:

- Resource, time and training to introduce a new system
- Adapting and enhancing governance & risk management processes including robust eligibility guidance
- Ensuring quality and safety of care which has been delegated to Personal Assistants
- IT, financial infrastructure, procurement processes and support for those in receipt of direct payments
- Choices regarding how healthcare needs are met can be very limited, there is a balance between choice and what is clinically assessed as necessary to meet a health need, therefore there will be a need to manage expectations

- The opportunity to learn from guidance, case studies and evaluations of what has worked well in England – since October 2014 people eligible for CHC have been given the legal right to a personal health budget and to access direct payments.
- The potential for less control over the terms and conditions of staff employed via direct payments as compared to those in the healthcare system, and therefore a worsening of those terms and conditions.

Note - A great deal of time has been spent on identifying any potential issues and planning how they can be resolved and mitigated. Learning from relevant measures in England as well as drawing on existing frameworks in Wales eg NHS Delegation Framework, Social Care DPs Code of Practice etc.

Opportunities

- Tailor a new approach suitable for Wales, learning from PHBs and rollout of short term measures in Wales and coproducing with stakeholders
- Opportunity for unpaid carers and family members to become paid employees as personal assistants – creating jobs and rewarding unpaid carers
- Opening up new ways to deliver care, reducing strain on domiciliary care services and providing respite and support for unpaid carers
- Moving towards more person-centred care and voice and control for individuals receiving health and social care services
- Amending the 2006 Act in a broad way to allow LHBs to provide direct payments, would allow the option to expand direct payments to other areas beyond CHC, via Regulations, in the future, if that was desired

Threats

- Potentially higher number of individuals transferring to CHC, especially initially, therefore increased costs for health boards
- Potential risks around Personal Assistants (as opposed to registered staff) undertaking care tasks*
- Perceived risk of a form of increased privatisation of healthcare, however LHBs already commission services from the private sector under CHC. Also Regulations and Guidance can set out specifically what can and can't be included under direct payments.

*Will require clear delegation procedures (already in place). Tasks will be routine, with escalation for any non-routine care needs

Children's Rights

This Bill's provisions do not focus initially on CHC for children or young people, and therefore there has been no requirement for a full Children's Rights Impact Assessment at this point.

There will be positive impacts for those young adults (18+) who have transitioned from children's services where direct payments may be an option via the social care component, to adult healthcare services where at present direct payments are not an option. These young adults will be able to opt to keep their personal assistants and care package as they could under children's services.

SECTION 8. CONCLUSION

8.1 How have people most likely to be affected by the proposal been involved in developing it?

Officials have engaged with disabled people as well as their representative organisations as part of this process. A working group which includes disabled people's organisations, disabled people and those with lived experience of direct payments was established early on in the process to coproduce and consider aspects of the policy. This group has been kept up to date on progress throughout the development stages.

Presentations have been given to key disabled people's groups and forums, including the Disability Equality Taskforce and the Disability Rights Taskforce. Along with this, as part of the consultation exercise, we shared and encouraged responses from all possible affected stakeholders. The consultation was sent to disabled people's organisations who were asked to share with their networks to ensure that we were able to hear from as many viewpoints as possible when considering the potential impact of the changes. We also offered a bespoke BSL session specifically on the consultation in response to a request to do so, in order to maximise accessibility and participation for individuals who are deaf or have hearing impairment.

Welsh speakers have been involved in the development of the proposals as well as those in rural areas. Parents and carers of disabled children have taken part in consultation sessions about the proposals.

We will continue to include representation from across all relevant sectors as this work develops, using our networks to ensure that the voices of individuals, especially those with protected characteristics under the Equality Act 2010 are heard.

8.2 What are the most significant impacts, positive and negative?

Certain groups of people in Wales will be positively impacted by the proposal. For those in receipt of complex care, the message emerging above all else from the consultation has been that the ability to feel more in control is particularly important. There are well-documented health benefits of a personalised care plan delivered via direct payments. Evidence from direct payments for CHC in England has shown that a person who is a partner in shaping their care will in all likelihood engage more positively with treatment, experience less breakdowns in their care and access fewer instances of unplanned care including hospital admissions.

In line with the Social Model of Disability, the direct payments approach, according to the subjects of many case studies, brings positive wellbeing outcomes associated with voice and control, which are often overlooked in a medical model approach to healthcare provision.

Using direct payments to deliver CHC would promote equality for disabled people and those with complex health care needs by introducing models of healthcare which are person-centred and allow the individual to have control over their lives. Older people make up a large proportion of those in receipt of CHC. Direct payments will provide an option for elderly and frail people in receipt of CHC, should they choose, to be cared for at home in familiar surroundings and by people chosen by themselves or by their families.

Due to the nature of this proposal, most individuals who would be affected by the proposed changes would fall within one of the protected characteristics categories and may well also be experiencing socio-economic disadvantage. Individuals who would be eligible to access support via CHC could be classed as some of the most vulnerable in society in terms of needing a high level of care and support to manage health or other long-term conditions, and also as being the hardest to reach by services.

Flexibility in the design of services will help health services to better reach groups traditionally considered 'hard to reach'. Disabled people's support organisations stress that services should be designed around individuals' needs rather than fitting people into a limited range of expected services. Care services which are patient-centred and give people, and those supporting them, choice, voice and control are likely to be far more accessible and case studies from England show that direct payments are very highly valued by those who access them for CHC.

In relation to Welsh language and culture, the proposal will enable an individual to seek arrangements to have their care needs met through the Welsh language, and to attend social and recreational activities within the local area, allowing them to integrate more into their own community and engage with culture and heritage, arts, sport and recreation.

The changes would also be likely to benefit people from ethnic minority groups and LGBTQ+ individuals giving them more choice to employ a person of their choosing and who makes them feel comfortable when delivering their care. For instance, an individual may wish to employ another individual from the same cultural background/religion who would be more aware of cultural practices, beliefs or dietary requirements and is able to accommodate these when providing support. There would be likely to be substantial benefit to the individual in such cases.

8.3 In light of the impacts identified, how will the proposal:

- maximise contribution to our well-being objectives and the seven well-being goals;
 and/or,
- avoid, reduce or mitigate any negative impacts?

The Wellbeing of Future Generations Act aims to tackle a number of major challenges now and in the future. Those most closely associated to the current proposal include tackling health inequalities as well as improving people's access to jobs if they are in receipt of CHC and able to work, and thus helping to promote their independence and raise them out of poverty.

As outlined in section 8.2 above, the proposal will bring a range of health benefits, thus contributing to the goal of 'A Healthier Wales'. The evaluation of the PHBs three-year pilot in England found that use of personal health budgets was associated with a significant improvement in quality of life and psychological well-being. PHBs (in the main delivered via direct payments) showed higher quality of life net benefits than conventional services for the CHC and mental health sub-groups. In addition, using care-related quality of life measured net benefits, personal health budgets were cost-effective relative to conventional service delivery.

The proposal is also in line with 'A Healthier Wales', the Welsh Government's plan for health and social care, in particular the goal to improve value for patients by giving a greater focus to the outcomes that matter to individuals. It also contributes to the range of options for 'social models of community based care which cut across traditional organisation and service boundaries' within the plan and accords with the vision of creating 'new community-based models of health and social care...so that people can have the same high quality of support in their own home as they would in a residential care setting, or in a hospital.'²

In terms of the goal for 'A More Equal Wales', the proposal to use direct payments as an option to deliver CHC would also promote equality for disabled people and those with complex health care needs. It would also help them attain financial parity as currently, anecdotal evidence across Wales suggests that a number of people will refuse to transition to a CHC package of care (which is fully funded by the NHS) and would rather continue to subsidise their existing social care package costs where means-tested personal contributions apply. They do so to retain their current care package and to avoid losing their voice and control by transitioning to CHC. Were direct payments to be possible under CHC, this particular cohort would have more funds available for other essential costs.

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² A Healthier Wales (gov.wales) p9

There are also some aspects of the proposal which would contribute towards the goal for 'A Wales of Cohesive Communities'. Direct payments could have an impact in terms of combatting loneliness and isolation, providing an individual with the ability to employ PA's to support them to access social opportunities in their community. This would be beneficial both to the individual and to their community as more individuals will potentially be able to access community facilities and the resulting increased engagement will in turn strengthen community amenities and promote cohesion.

The proposal demonstrates a clear link with the goal of 'A Wales of Vibrant Culture and Thriving Welsh Language', as it does with the Cymraeg 2050 strategy – in particular in terms of increasing the use of Welsh in the workplace and in care-related services. This in turn would lead to the creation of favourable conditions for the further use and development of the Welsh language within the community and local economy.

Care and support services for individuals provide a level of interaction which enable communication to be conducted in a way that meets the needs and preferences of those who use its services; thus supporting one of Cymraeg 2050's aims of increasing the use of Welsh. The Welsh Government's strategic framework for Welsh language services in Health, Social Services and Social Care 'More than Just Words' further supports these principles by promoting the active offer of services in Welsh without someone having to ask for it.

In 'More than Just Words' the former Minister for Health and Social Services stated that 'the use of Welsh language in health and social care is about individual centred care based on their emotional well-being and need and this is why it is so important.' Direct payments is a model which fully supports that vision of individually-centred care, and the fact that people receiving their CHC via direct payments will have a greater choice and control over the language in which their care is offered will strengthen their emotional well-being.

8.4 How will the impact of the proposal be monitored and evaluated as it progresses and when it concludes?

In order to assess this proposal's effectiveness, we will undertake an independent evaluation. This evaluation will cover both the implementation and the impact of the proposal. The implementation will be assessed through a process evaluation, which may include the development of a Theory of Change, which maps the inputs and activities undertaken through the proposal into immediate outputs, then into longer term outcomes and impacts.

The process evaluation will also include interviews with those involved in implementing the proposal to explore any barriers or issues which may have an impact on the effectiveness of the final implementation. This helps shape the proposal's delivery in the future and makes sure that the proposal is being delivered as intended.

The impact evaluation will then go onto test those outcomes and impacts with the intended recipients of the proposal. This evaluation will make use of a variety of methods, such as using published datasets, a survey and/or in-depth interviews to explore the impact of the proposal. This will then help inform future policy development and assess the final effectiveness of the proposal.

LHBs' own datasets will also be requested to provide a picture of take-up of direct payments for CHC across Wales, and this will be monitored over time to see if the option remains accessible and if, as was seen in England, demand for the option grows.