



# Direct Payments and a Disabled People's Co-operative Model

## A Toolkit



**Citizen Directed  
Co-operatives Cymru**  
Mentrau Cydweithredol  
dan Arweiniad Dinasyddion



Wales Co-operative Centre  
Canolfan Cydweithredol Cymru



Disability Wales  
Anabledd Cymru



ARIENNIR GAN Y LOTERI  
LOTTERY FUNDED



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BIG LOTTERY FUND



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# 1. Introduction

This toolkit explores how direct payments can contribute to independent living for disabled people. It considers different models of managing direct payments and gives focus to an emerging model of a citizen or user-led co-operative approach.

You might find this toolkit helpful if any of the following apply:

- You are a disabled person who wants to live an independent life
- You want to help other disabled people to live independently
- You want to learn more about direct payments
- You are considering direct payments to enable independent living for yourself or someone for whom you care
- You are not happy with the current support in your area to help you manage your direct payments
- You want to set up a co-operative to benefit disabled people
- You simply want a challenge!

The toolkit has been designed so that you can dip in and out of topics that interest you. There are lots of links to other parts of the toolkit or other useful resources. Look out for the film icon  to view content. If you prefer, you can work through the toolkit from start to finish as you might read a book. The choice is yours.



The toolkit has been produced by Dr Alun Hughes of [20 Degrees Consulting Ltd](#) on behalf of [Disability Wales](#). The work forms part of the Citizen Directed Co-operatives Cymru project led by [Disability Wales](#) in partnership with the [Wales Co-operative Centre](#) and funded by the [Big Lottery Fund](#).

We have told people's stories within this toolkit. While the stories are real, names of participants have sometimes been changed in order to respect their privacy.

Examples and links provided within this toolkit were correct at the time of production in September 2018.



## 2. Independent Living

Personal choice and control about how disabled people live their lives is at the heart of the independent living agenda. Non-disabled people may take these rights for granted, yet people with impairments too often find themselves disabled because society puts up barriers to their choices.



Many of these disabling barriers stem from a way of thinking that can be described as a Medical Model of Disability. This model suggests the failure or limitation of a person's body disadvantages him or her. It looks at impairment as something that needs to be cured and the disabled person made well and 'normal'. The emphasis is put on a person's ability to be the same as everybody else or on the effort needed to get them back to being as 'normal' as possible.

By contrast, organisations such as [Disability Wales](#) argue for an alternative world view – that described by the [Social Model of Disability](#). It is a 'rights' based approach. This model suggests institutional, environmental and attitudinal barriers erected and enforced by society cause disablement. A person's medical condition is irrelevant. Disability is viewed as something which is imposed on people with impairments.

The term 'Social Model of Disability' was first coined by Mike Oliver in 1983<sup>1</sup> but the model was developed by disabled people from their own experiences, that most of the problems they were facing were caused by the way society was organised. Gradually, wider society beyond disabled people's organisations is recognising and adopting the model. Welsh Government, for example, adopted the model in 2002. In 2011 Welsh Government responded to the Disability Wales campaign for 'Independent living NOW!' This led to Welsh Government's [Framework for Action on Independent Living](#).

This toolkit takes the Social Model of Disability as its starting point. The Independent Living agenda seeks practical solutions for removing the barriers to equality and social inclusion that disable people, including in health & social care, housing, education, employment, transport and access to the environment.

<sup>1</sup> Oliver, M. (1983) 'Social Work with Disabled People', MacMillan, Basingstoke, UK



# 3. Direct Payments

## 3.1 Introduction to direct payments

Carers UK provides a good introduction to direct payments

“If you, or the person you are looking after, are assessed by the local council / trust as needing support, then you or they have a right to ask for a direct payment instead of having the support arranged by the local council/trust”.

(Carers UK, 2014)

Recipients of direct payments can use the money to purchase the agreed services they require instead of receiving the services from the social services department. Direct payments are intended by government to improve choice, control and [independence](#) for people.

Direct payments in Wales are governed by the [Social Services and Well-being \(Wales\) Act 2014](#) and the Care and Support (Direct Payments) (Wales) Regulations 2015. They are provided by the local authority in which the disabled person is resident. Every local authority provides information on direct payments for people living in their area. Some local authorities provide the basic information about eligibility for direct payments and a point of contact, while others go



much further. A list of links to this information can be found in [Annex A](#).

While the above framework of legislation is relatively recent, direct payments have been available much longer, as Vin West a [parent carer](#) relates.

## 3.2 Eligibility for direct payments

Direct payments can be offered to almost everyone who has been assessed by Social Services as eligible to receive social care services. In a very few cases a direct payment may not be possible, for example when prevented by court orders relating to drug / alcohol dependency.

People can have a direct payment from the age of 16, usually. There is no upper age limit. A [parent carer](#) can receive a direct payment to provide support for a child under 18.



### 3.3 Use of direct payments in practice

There are many good examples within local authority websites that illustrate how direct payments are being used in practice.

#### 3.3.1 Employing personal assistants (PAs)

The most common use of direct payments is to employ personal assistants. Short films of [William](#) ▶ and [Dylan's](#) stories ▶ from [Anglesey Council](#) gave William, Dylan, their parents and PAs opportunities to say what direct payments have meant to them. You can hear or read about the choices they can now make and the independence that gives them. The confidence that has come along with these benefits, they suggest, has been life changing and life affirming.

While [employment of personal assistants](#) ▶ is a common use of direct payments, these payments can be used in many more ways.

#### 3.3.2 Purchasing equipment

[Swansea Council](#) gives a good introduction to [different ways of using direct payments](#).

For example, it illustrates that direct payments can be used to make a one-off purchase of equipment to meet identified needs:

After some years, Gary was making good progress in overcoming long-standing mental health problems, and his care manager helped him to find a voluntary role that would help his employment prospects. However his OCD made it very difficult for him to use public transport to get there. A one-off direct payment enabled Gary to buy a second-hand bicycle which not only ensured he could get to his voluntary placement on time, but increased his self-confidence as he became more mobile.

**(Reproduced with permission from Swansea Council)**

### 3.3.3 Pooling resources

[Flintshire Council](#) illustrates how direct payments from one person can be pooled or added with direct payments from other people with the same assessed needs. This enables people to be creative in the solutions that they can develop for themselves. Examples included in their [Pooling Direct Payments Guide](#) include a mental health user-run sports and social group, a drama group and a community café. All were made possible by people co-operating and using their direct payments to achieve a common outcome.

#### Sports Group

A user-run sports and social group was set up by a group of people with mental health conditions. The group focuses on befriending and socialising, as well as a range of sports activities. They provide social support to each other in the evenings and at weekends.

The group was set up when people were given the opportunity to pool their direct payments. As well as having individual assessments to work out their individual needs, the local authority carried out group assessments.

To set up the group, they asked for the support of the direct payment lead officer at the local authority. Once ready to begin, the local authority paid the agreed money

into a community account that was managed on their behalf. This paid for the set up costs.

**(Reproduced with permission from Flintshire Council from their [Pooling Direct Payments Guide](#))**

### 3.4 What matters to you?

This idea of direct payments being used to achieve an outcome for a person, rather than being focussed on buying a narrowly defined set of services is central to the type of Welsh Government thinking set out in the [Social Services and Well-being Wales Act 2014](#). In practice it means social services assessments should focus on what matters to the person being assessed for support.

Here's an example to illustrate what we mean by outcomes and services:

Two people might want companionship to break down feelings of isolation and loneliness. For one person, that might mean they need transport to a support group to meet people with similar life experiences. For another person, companionship might be with their dog but the services of a dog walker are needed. The transport and the dog-walking are both services but in both examples companionship is the outcome.



An example from Essex illustrates the power of direct payments to achieve better outcomes for disabled people is reproduced from a publication by the Social Care Institute for Excellence<sup>2</sup>:

A 56-year-old man with early-onset dementia has a very short concentration span requiring almost constant stimulation, which he seeks out from his wife, the main carer. The situation is likely to break down if the wife does not receive regular breaks and the husband does not receive regular stimulation. He also requires support to maintain links and regular contact with his family, but he is finding it difficult to remember how to use the train to reach them.

Traditionally he would have been provided with three hours of domiciliary home care each week, plus two days a week at a day centre. The approximate cost of this service would have been £600 per month. He now receives a direct payment of £200 per month, and his wife receives a carer's direct payment of £55 a month. This is how they meet their eligible assessed needs: He now has a Sky satellite TV subscription that costs £40 per month. He can watch

sport and football, which holds his concentration and which he enjoys immensely. This facility is available seven days a week. He now has a sports club membership and goes to the gym with a personal assistant every week. He also goes swimming when he can. The cost of the PA is £100 a month and the sports club membership costs £28 a month. His wife receives a carer's direct payment to fund her membership as they enjoy swimming together. He uses £150 a year to fund transport obtained through the community volunteer transport service, to travel with his wife to Center Parcs to stay with his family for holidays. He also pays the community volunteer transport service, so he can travel with his wife to stay with their family in London whenever possible. He uses part of the money to pay for a taxi every month to attend, with his wife, a club for people with early-onset dementia and their carers. His wife pays for half the cost of the taxi from a carer's direct payment she receives in her own right.

**Example supplied by Essex Direct Payments development manager (Reproduced with permission of the Social Care Institute for Excellence).**

<sup>2</sup> Lewis, S (2005) 'Direct payments: answering frequently asked questions', Adult Services SCIE Guide 10, Social Care Institute for Excellence, The Policy Press, Bristol, UK, pp4-5 accessible at <https://www.scie.org.uk/publications/guides/guide10/files/guide10.pdf>





Despite the potential for independence offered by direct payments, [take up has not been as widespread](#) ▶ as many advocates of the system had hoped. In practice, people typically say they have been deterred from taking this option because have not wished to become an employer, lacked the confidence to manage contracts or simply did not want to engage with the levels of accountability required to manage public money.

### 3.5 Existing models to support management of direct payments

The issues deterring people from engaging with direct payments are well rehearsed:

- not wanting to become an employer of personal assistants (PAs)
- not having the experience or confidence to manage contracts
- not wanting to manage the bureaucracy associated with being accountable for public money.

Much has been done to [reduce the burden of managing direct payments](#)

▶. Various support models have been developed to help people overcome barriers to working with direct payments. The vast majority of direct payments are to employ PAs. Now it is common for disabled people to engage an [independent organisation](#) ▶ to manage the direct payments and employ staff on their behalf. These organisations can be for-profit companies but most commonly in Wales are not-for-profit, registered as charities and operating as social enterprises.

Examples of direct payment service providers operating in Wales at the time of writing included:

- [Dewis Centre for Independent Living](#)
- [Diverse Cymru](#)
- [Penderels Trust](#)
- [People Plus](#)
- [Services for Independent Living \(SIL\)](#)
- [The Rowan Organisation](#)



This list is representative and not exhaustive. At the time of writing, all held a direct payment support contract with one or more local authority in Wales. These support contracts have been put in place because local authorities recognise the barriers to take up of direct payments and want to help to reduce these barriers. Some local authorities provide this service through in-house teams and have not commissioned external providers. Some local authorities, such as [Neath Port Talbot](#) have moved to a framework of providers in order to extend choice to their

direct payment recipients.

Although direct payment service providers support the recruitment of PAs, look after payroll, ensure employment law is observed and account for direct payment expenditure, the selection of the PA and day-to-day management of tasks undertaken by the PA are undertaken by the disabled person. The purpose of direct payment service providers is to support the disabled person and remove barriers to take-up of direct payments – they exist to promote independence and control of disabled people.



## 4. Co-operating to Manage Direct Payments

Earlier we looked at some examples of disabled people assessed with similar needs [pooling resources](#) to make their direct payments stretch further or meet their needs better. These were examples of co-operation. However, it is possible to take co-operation further and establish a co-operative.

The [International Co-operative Alliance](#) defines a co-operative as

“an autonomous association of persons united voluntarily to meet their common economic, social and cultural needs and aspirations through a jointly owned and democratically-controlled enterprise”.

In practice, this means a co-operative is a business set up to achieve some social purpose, so it is an example of a type of business often referred to as a social enterprise. Many co-operatives are not-for-profit organisations, while others allow distribution of modest profits to members. However, the main driver of a co-operative is to create value for its members rather than profits.

One of the distinctive features of a co-operative is that they are owned and run by their members. Members can be users of the co-operative's services, employees of the co-operative or drawn from a particular community. Whether members are drawn from a mix of these groups or only one is down to each group



of co-operative founders to decide when the co-operative is established. Regardless of who becomes a member, all members have a vote of equal value to every other member's vote. They use their vote to shape the direction of the co-operative.

[Disability Wales](#) worked with the [Social Co-operation Forum](#) to create a series of [five short guides about co-operatives](#) for Social Care Wales. The second guide, [What are co-operatives?](#) provides a clear introduction to the history of the co-operative movement, the values and principles of co-operatives and what makes co-operatives different from other types of organisations.

# 5. User-led Co-operatives to Manage Direct Payments



## 5.1 The history

The idea of citizen-directed or user-led co-operatives to manage direct payments and employ PAs in Wales developed from an original conversation between the Chief Executive of Disability Wales and the Welsh Minister for Health and Social Care. It took the idea of direct payments extending choice and control to the logical limit of disabled people not only choosing the services but also how the service provider would be run.

[Disability Wales](#) partnered with the [Wales Co operative Centre](#) to help turn this idea into a reality. [Initial research](#) carried out in 2013 suggested there was no precedent

in the UK for a user-led care co-operative where these users were disabled people. The only examples of this model identified at that time were [STIL](#) (the Stockholm Co-operative for Independent Living) in Sweden and [ULOBA](#) (User-owned and Controlled Personal Assistance Co operative) in Norway.

Big Lottery funded the [Citizen-Directed Co-operatives Cymru \(CDCC\)](#) project under its [Big Innovation programme](#). This toolkit was produced by the project. The main outcomes pursued by the CDCC project were to promote direct payments as an option for disabled people and to establish a user-led care co-operative. One such user-led co-operative was established by the project: the [MonCare Co-operative](#) in Monmouthshire.

## 5.2 Deciding what works for you

The idea of a user-directed care co-operative may sound appealing. Indeed, it might be something you decide to establish. However, the learning from the CDCC project suggests you should pause first and work through some key thoughts.



### 5.2.1 Who will join you and what do you want to do?

In order to set up a co-operative you need a [group of like-minded people](#) ▶ with a common set of aims and objectives. Often the group of founders for a co-operative get to know each other through shared experiences, attend the same club or support group or they may be friends or neighbours and share the same concerns. However well you feel you know the other people, it is still sensible to spend some time enabling each person to talk about their lives, particularly their hopes and dreams. The [Enabling Wales](#) project, led by [Disability Wales](#), developed a [toolkit](#) which you might find helpful at this stage. Chapter 2 looks at *Working in a Group*. It provides helpful advice on how to run a meeting so that everyone gets an opportunity to share their views and everyone else listens effectively.

When everyone has got to know and understand each other, it is time to focus on the prospective business. Before sorting out the legal structure of the business or starting on the formal business planning process, there are more basic questions to answer. They underpin all of that future work. Focus on what you would like to achieve with the business. Ask yourself the following basic questions:

- What would you like to achieve?
- How big is the need? Is there a



need for a service or do you want to address the needs of yourself and a small group of other people?

- How much will it cost and where will the money come from?
- Who else could be involved?
- What resources do you need? Do you have the skills to meet the need? You might need to look for other people with the right skills to join your group or you might decide to employ people instead.

There are plenty of resources to help you with this stage. Again, you might find the [Enabling Wales Toolkit](#) helpful, especially chapters three to five – *Identifying the Challenge*, *Being Creative* and *Thinking Big*.

Once you have answered the basic questions you can test your idea through the [Care to Co-operate Toolkit](#) developed by the [Wales Co-operative Centre](#).



### 5.2.2 Is it a business?

Once you have a common understanding of the basics of what you are trying to achieve, it is time to decide how you might best take forward your venture. Questions that you'll need to answer:

- Do you need to set up a business to achieve what you want to do? Although this toolkit assumes you are heading in that direction, sometimes a loose collaboration between people or establishment of a support group is all that is needed.

- If you do decide that setting up a business is best for you, is it the kind of business where profits are distributed to the owners of the business or are primarily re-invested into the social aims of the business? The latter type is sometimes called a social enterprise or social business.

There is a lot of support available to people seeking to set up a business in Wales. A helpful starting point for people that have decided their business is primarily about achieving social aims and objectives rather than profit is [Social Business Wales](#).



# 6. A Disabled People's Co-operative



## 6.1 Back to where we began

We've intentionally taken you on a journey to explore your options before returning to the co-operative model. You are most likely to succeed if you have taken a pathway that best meets the needs and inclinations of your group. While the [Wales Co-operative Centre](#) advocates on behalf of co-operative models, [Disability Wales](#) advocates on behalf of disabled people and does not favour one legal structure of business over another.

The [MonCare Co-operative](#), a Disabled People-led Co-operative, was in the early stages of its development at the time this toolkit was being compiled. It arose from the work of the [Citizen-Directed Co-operatives Cymru project](#). The lessons learned from the project and

particularly the development of the MonCare Co-operative informed the content of this toolkit. Some of those lessons have been summarised into a short, [five-minute film](#) ▶ which we encourage you to watch as part of this toolkit.

The experiences of the MonCare Co-operative's members and the co-ordinator employed to support them may help or inspire you in your journey towards your own co-operative. A series of short films capture some of their insights. They talk about what [motivated their involvement](#) ▶ in the MonCare Co-operative through to the [benefits of joining](#) ▶ such a development. A wider list of films is available within the [playlist](#) ▶ of films produced by the [Citizen-Directed Co-operatives Cymru](#) project.



## 6.2 Starting a disabled-people's co-operative

If you have worked your way through this toolkit and feel that you would like to start a disabled people's co-operative, the [Wales Co-operative Centre](#) can help you. As a starting point, they have developed an online, interactive [toolkit](#). This will enable you to learn more about co-operatives, why they are different from other legal structures of businesses and help you begin to put together a plan for your co-operative.

Beyond this, the [Wales Co-operative Centre](#) has advisers that would be pleased to help you on your journey to developing your own co-operative.





# Glossary of Terms Used in this Toolkit



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## **CDCC**

Citizen-Directed Co-operatives Cymru.

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## **Co-operative**

A co-operative is an autonomous association of persons united voluntarily to meet their common economic, social and cultural needs and aspirations through a jointly owned and democratically controlled enterprise.

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## **Direct payments**

These are intended to empower disabled people to live independent lives, offering people more choice and control over how their care needs are met, and are an alternative to having support arranged directly by social services. Essentially, people are provided with the money to purchase the agreed services they require.

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## **Impairment**

An injury, illness, or congenital condition that causes or is likely to cause a long-term effect on physical appearance and/or limitation of function within the individual that differs from the commonplace.

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## **MonCare Co-operative**

A user-directed care co-operative established in Monmouthshire under the auspices of the Citizen-Directed Co-operatives Cymru project.

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## **PA**

Personal Assistant.

# Annex A –

## Sources of Local Authority information about direct payments

All of these links were correct at the time of publication – September 2018 – but information is updated and moved from time to time. If a link doesn't work, we suggest you find your local authority website using your preferred search engine and type *direct payments* into the search function found on the site.

Local Authority	Location of information
Anglesey	<a href="http://www.anglesey.gov.uk/health-and-care/adult-services/care-in-the-home/direct-payments/">http://www.anglesey.gov.uk/health-and-care/adult-services/care-in-the-home/direct-payments/</a>
Blaenau Gwent	<a href="http://www.blaenau-gwent.gov.uk/en/resident/health-wellbeing-social-care/getting-the-help-you-need/direct-payments/">http://www.blaenau-gwent.gov.uk/en/resident/health-wellbeing-social-care/getting-the-help-you-need/direct-payments/</a>
Bridgend	<a href="https://www.bridgend.gov.uk/residents/health-and-social-care/direct-payments/">https://www.bridgend.gov.uk/residents/health-and-social-care/direct-payments/</a>
Caerphilly	<a href="http://www.caerphilly.gov.uk/Services/Managing-your-money/Direct-payments">http://www.caerphilly.gov.uk/Services/Managing-your-money/Direct-payments</a>
Cardiff	<a href="https://www.cardiff.gov.uk/ENG/resident/Social-Services-and-Wellbeing/Adults/Care-services/Direct-payment-scheme/Pages/default.aspx">https://www.cardiff.gov.uk/ENG/resident/Social-Services-and-Wellbeing/Adults/Care-services/Direct-payment-scheme/Pages/default.aspx</a>
Carmarthenshire	<a href="http://www.carmarthenshire.gov.wales/home/council-services/social-care-health/direct-payments/#.WrjH5ExFzIU">http://www.carmarthenshire.gov.wales/home/council-services/social-care-health/direct-payments/#.WrjH5ExFzIU</a>
Ceredigion	<a href="http://www.ceredigion.gov.uk/resident/social-care-wellbeing/how-can-social-services-help/direct-payments/">http://www.ceredigion.gov.uk/resident/social-care-wellbeing/how-can-social-services-help/direct-payments/</a>
Conwy	<a href="http://www.conwy.gov.uk/en/Resident/Social-Care-and-Wellbeing/Adults/Paying-for-care/Direct-Payments-Social-Services---Arranging-your-own-support-and-services.aspx">http://www.conwy.gov.uk/en/Resident/Social-Care-and-Wellbeing/Adults/Paying-for-care/Direct-Payments-Social-Services---Arranging-your-own-support-and-services.aspx</a>
Denbighshire	<a href="https://www.denbighshire.gov.uk/en/resident/health-and-social-care/adults-and-older-people/support-budgets.aspx">https://www.denbighshire.gov.uk/en/resident/health-and-social-care/adults-and-older-people/support-budgets.aspx</a>

# Annex A

Local Authority	Location of information
Flintshire	<a href="http://www.flintshire.gov.uk/en/Resident/Social-Services/Direct-Payments.aspx">http://www.flintshire.gov.uk/en/Resident/Social-Services/Direct-Payments.aspx</a>
Gwynedd	<a href="https://www.gwynedd.llyw.cymru/en/Residents/Health-and-social-care/Adults-and-older-people/Legal-and-financial-information/Direct-payments.aspx">https://www.gwynedd.llyw.cymru/en/Residents/Health-and-social-care/Adults-and-older-people/Legal-and-financial-information/Direct-payments.aspx</a>
Merthyr Tydfil	<a href="https://www.merthyr.gov.uk/resident/social-services-and-well-being/adult-social-care/direct-payments/">https://www.merthyr.gov.uk/resident/social-services-and-well-being/adult-social-care/direct-payments/</a>
Monmouthshire	<a href="https://monmouthshire.gov.uk/app/uploads/2014/08/direct-payments-leaflet.pdf">https://monmouthshire.gov.uk/app/uploads/2014/08/direct-payments-leaflet.pdf</a>
Neath Port Talbot	<a href="https://www.npt.gov.uk/2290">https://www.npt.gov.uk/2290</a>
Newport	<a href="http://www.newport.gov.uk/en/Care-Support/How-social-services-can-help/Direct-payments.aspx">http://www.newport.gov.uk/en/Care-Support/How-social-services-can-help/Direct-payments.aspx</a>
Pembrokeshire	<a href="https://www.pembrokeshire.gov.uk/support-from-adult-care-assessments/direct-payments">https://www.pembrokeshire.gov.uk/support-from-adult-care-assessments/direct-payments</a>
Powys	<a href="https://customer.powys.gov.uk/article/1573/Apply-for-Direct-Payments">https://customer.powys.gov.uk/article/1573/Apply-for-Direct-Payments</a>
Rhondda Cynon Taf	<a href="https://www.rctcbc.gov.uk/EN/Resident/AdultsandOlderPeople/MoneyandFinance/Directpaymentsforcare.aspx">https://www.rctcbc.gov.uk/EN/Resident/AdultsandOlderPeople/MoneyandFinance/Directpaymentsforcare.aspx</a>
Swansea	<a href="https://www.swansea.gov.uk/directpayments">https://www.swansea.gov.uk/directpayments</a>
Torfaen	<a href="https://www.torfaen.gov.uk/en/HealthSocialCare/Getting-the-help-you-need/Direct-Payments/Direct-Payments.aspx">https://www.torfaen.gov.uk/en/HealthSocialCare/Getting-the-help-you-need/Direct-Payments/Direct-Payments.aspx</a>
Vale of Glamorgan	<a href="http://www.valeofglamorgan.gov.uk/en/living/social_care/adult_services/Care-Service-Costs/Direct-Payments.aspx">http://www.valeofglamorgan.gov.uk/en/living/social_care/adult_services/Care-Service-Costs/Direct-Payments.aspx</a>
Wrexham	<a href="http://www.wrexham.gov.uk/english/council/social_services/direct_payments.htm">http://www.wrexham.gov.uk/english/council/social_services/direct_payments.htm</a>

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