

The Bottom Line

**What do parents want from the
continence supplies service for
children and young people in Wales?**

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Introduction

The supply of continence products is always one of the top five topics for discussion whenever we meet with a group of parents. Back in September 2003, Contact a Family Wales conducted a consultation with parents of disabled children as part of the development of the National Service Framework for Children, Young people and Maternity Services in Wales (The Children's NSF).

"Why if you live in one area do you get more than in another, one person gets three the other gets eight? If a child is ill and more are needed, you can't get them – the delivery service is dreadful, they are often left outside for everyone to see."

Parent – The National Service Framework for Children, Young People and Maternity Services, Parent Consultation, Disabled Child Module Report, Welsh Assembly Government and Contact a Family Wales, September 2003

During the spring of 2007, Contact a Family Wales was approached by a parent from Conwy who told us of the problems she still faces because her daughter uses continence supplies and asked us to help her campaign to improve continence services for children and young people. By chance, conversations with two other parents in Swansea and Wrexham revealed that they too had experienced difficulties with the service.

This short report has been based on the responses to questionnaires completed by parents in Conwy and Denbighshire, Swansea and Wrexham, but, the aspirations it contains are very much those of the families we work with right across Wales. The purpose of the report is to highlight the problems faced by the families of children and young people who use continence supplies and to make suggestions for improving the continence service in all parts of Wales.

Contact a Family Wales would like to thank all the parents who took part.

What would the ideal service look like?

- **A service which is the same wherever you live in Wales**

Just looking at three areas of Wales, Swansea, Conwy and Denbighshire and Wrexham has shown us that continence supplies services are not equitable and that some families get a much better deal than others.

Why do families in Swansea have to travel to a central collection point in the centre of town to pick up their supplies whilst families in Conwy and Denbighshire and Wrexham are able to have their supplies delivered? Why can some parents have extra nappies or pads if they run out when others are refused?

For some time now, Welsh Assembly Government policy documents - the *National Service Framework for Children, Young People and Maternity Services in Wales (The Children's NSF)* for example – have talked about providing quality services which are the same wherever you live in Wales. In support of this, we would encourage the Assembly to develop an all Wales policy for continence supplies.

• A service which places the dignity of the parents, children and young people at its core

For parents, a fundamental concern is that they and their children should be able to access the service without embarrassment and loss of dignity. This issue underlies many of the points raised later in this report such as having enough nappies or pads.

“ The continence service, although reasonably helpful, say they can't supply any more. Ultimately, it is a question of health and well-being as well as a dignity issue. They say keep pad on until full – they are sagging by this point and smelly. This is not acceptable. ”

Parent

or being provided with the right product:

“ Nappies are embarrassing for her, especially in the summer - when she wears shorts the nappy falls between her legs. ”

Parent

but it is also about the attitude of staff members and the way service users are treated:

“ We should be able to access further supplies without BEGGING and then being refused by some unfeeling woman on the end of the phone who has *no* idea what our lives are like and couldn't care less! ”

Parent

“ A more understanding and caring attitude from the person who takes the orders would be an advantage. ”

Parent

Any policy for the supply of continence products should place the dignity of service users and respect for them as core values.

• A service which provides families with the number of nappies or pads they need

The number of nappies or pads allocated varies greatly. We know of parents who are allocated 2.5 pads per day and also some who are allocated 8 pads per day. The most important factor is for parents to be allocated sufficient products to meet their child's needs.

“ Being allocated 2.5 nappies per day is insufficient, the continence department are inflexible and are not really concerned with the welfare of the child. ”

Parent

The fact that parents are not allocated sufficient continence supplies to meet their children's needs, coupled with their inability to obtain further supplies free of charge when they run out means, of course, that many parents are paying for nappies and pads on a regular basis.

“ I do not get enough supplied for my child, but told that's why I get DLA to buy extra pads. ”

Parent

Illness can mean that children and young people need more nappies or pads. A parent who has hitherto managed with the supply they have been allocated can suddenly find that they have run out whereas for those parents who have not been allocated sufficient supplies, the problem is made worse.

“ My daughter is allocated 2.5 nappies per day so we frequently run out and have to buy pull ups from the shops. If we exceed our allocated use, even due to illness, we are not able to get any more. ”

Parent

“ Our daughter has bowel and bladder problems in addition to severe developmental delay, so she has to be changed regularly in order to prevent skin soreness and infection, we do find that 8 pads per day is often not enough but this is the maximum we can get and we had to fight to get this amount. ”

Parent

Continence supplies should be allocated on a needs basis and not rationed. Parents should be able to obtain the appropriate number of nappies or pads without having to beg or fight.

The Continence Supplies Service should be flexible enough to allow parents to obtain an increased supply when they need it (during times of illness for example).

Parents should not have to pay for continence products for their children.

• A reliable delivery service for continence products

Continence supplies are bulky and heavy, yet some parents, those in Swansea for example, do not have their supplies delivered. Instead they collect supplies themselves from the town centre, parking the car some distance away and walking:

“ Having to pick them up is very inconvenient. There is no parking and the supplies are very heavy. ”

Parent

“ I pick my supplies up from Orchard St Central Clinic, it is very difficult to park in this area and the pads are heavy and awkward to carry a long distance. ”

Parent

In other areas, continence supplies are delivered to the home address, but there are still problems:

• Ordering via answer-phone

There were parents who felt that this was an unreliable method. Some had ordered products via an answer-phone and not received them:

“ We just hope each month that the order has been received as it's an answer machine. We recently had to go 2 weeks without any as the order wasn't placed their end and it takes 2 weeks from order to delivery. ”

Parent

“ ...have left messages on the answer machine but not received the products. ”

Parent

“ The way of ordering them (i.e. leaving an answerphone message) is not a reliable method. ”

Parent

• Deliveries which are unreliable and not knowing what day supplies will be delivered

“ Not delivered on the day arranged. We had to wait three days. ”

Parent

“ We have to phone two weeks before they are due to order our supply. Always get answer machine – Never sure of delivery date. Why can't they just deliver same time every two months? ”

Parent

- **A delivery service that is inflexible**

“ We have been basically happy with the service, but it is rather inflexible - especially as to delivery date, e.g. if we ask for early delivery due to holidays etc, this does not happen, but no-one calls to tell us. ”

Parent

Boxes and packs of continence supplies are bulky and awkward to handle. Some parents are unable to collect them. A delivery service for continence supplies is a prerequisite.

All orders for continence products should be acknowledged, whether by telephone call or e-mail.

A mutually convenient date for delivery should be agreed and, if arrangements need to be changed, families should be informed.

- **A service which provides good quality products which are fit for purpose**

The major issue at stake here is for parents to be supplied with products that do exactly what they are intended to. In particular, nappies and pads need to fit properly and not leak:

“ Not sufficient enough absorbency now for a growing 14 year old. ”

Parent

“ Even with a pad in the nappy, he still can soak the bed, because he lies on his side and it seeps that way. ”

Parent

Parents need to be provided with good quality continence products which work properly.

The products supplied should be reviewed regularly to ensure that they are still fit for purpose.

- **A service which is flexible, offers choice and responsive to the needs of those who use it**

The continence supplies service needs to be flexible in a number of ways. Different children and young people have different needs and at different times. We have already seen that some children need more nappies or pads than others, particularly when they are unwell. It is also true that a product which suits one child or young person is not necessarily going to suit another.

A number of parents felt that their children would benefit from using a less bulky product:

“ The pads are massive and plastic coated. They heat my daughter up, thus inducing fits. They are also very bulky between her legs. She has a problem with splaying her legs anyway – The pad makes it worse. She wears a lycra orthosis suit to try to bring her legs together which makes no sense with the size of the pad. ”

Parent

“ They are good in absorbency but much too bulky. My child splays his legs and has a second skin to try to combat this, but the nappies work against this because of the bulkiness between his legs. ”

Parent

Other parents wanted products which fitted in with their child's age and stage of development:

“ My daughter is a young lady and would be better in pull-ups rather than nappies. ”

Parent

Other children have allergies:

“ (My son) is sensitive to latex in the elastic of nappies. The nappies provided Pampers Extrafit have a lot of elastic in them which makes his eczema worse. I have to buy a Tesco own brand version which has less elastic in them. I asked if there could be an alternative nappy supplied with less latex. I was advised this was not possible. ”

Parent

The continence supplies service should offer a choice of products to suit the needs of all children and young people.

The product supplied should be reviewed at regular intervals to ensure that it is still the most suitable product available.

Summing up – What the parents of disabled children and young people want from the Continence Supplies Service

• A service which is the same wherever you live in Wales

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Notes