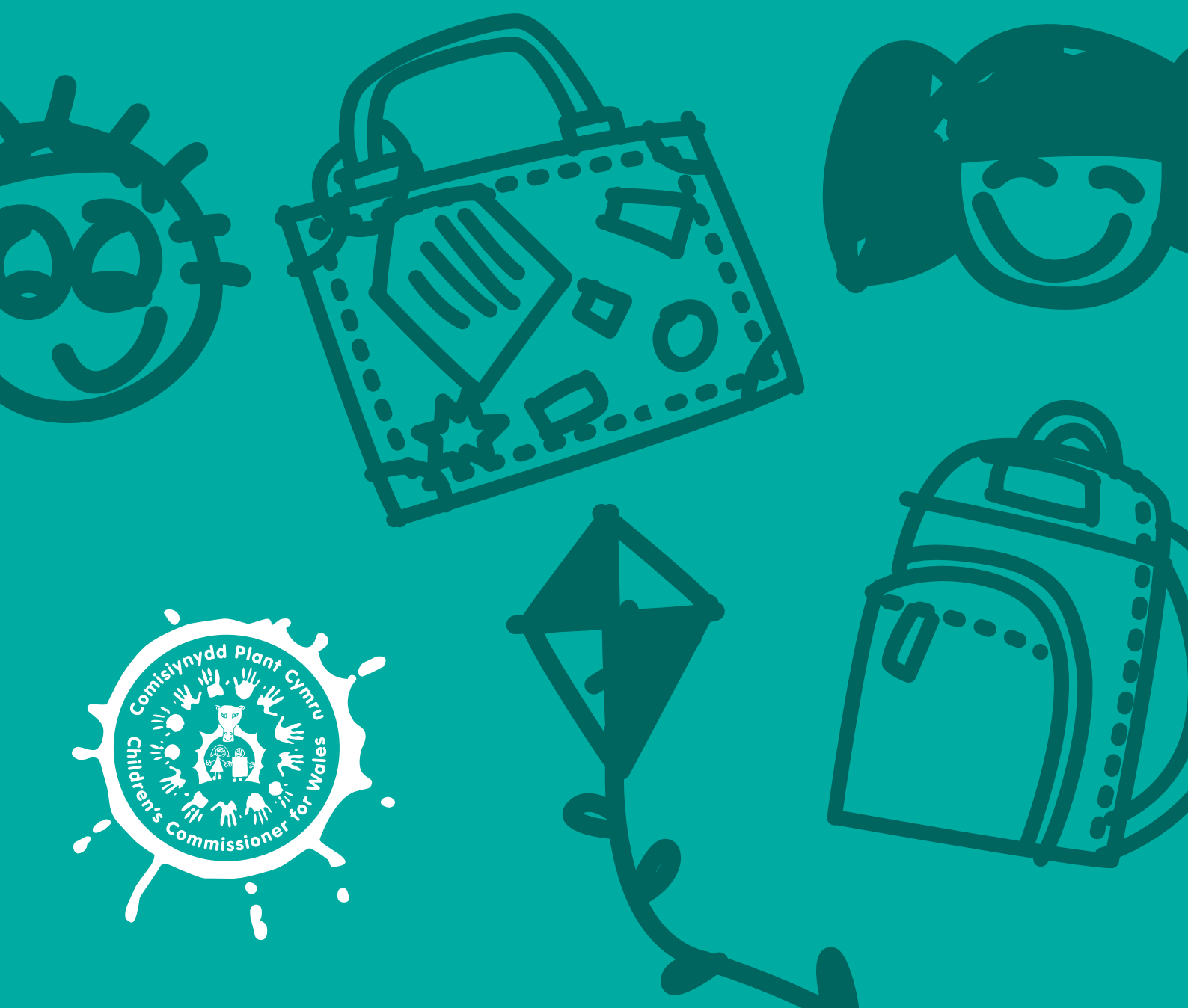


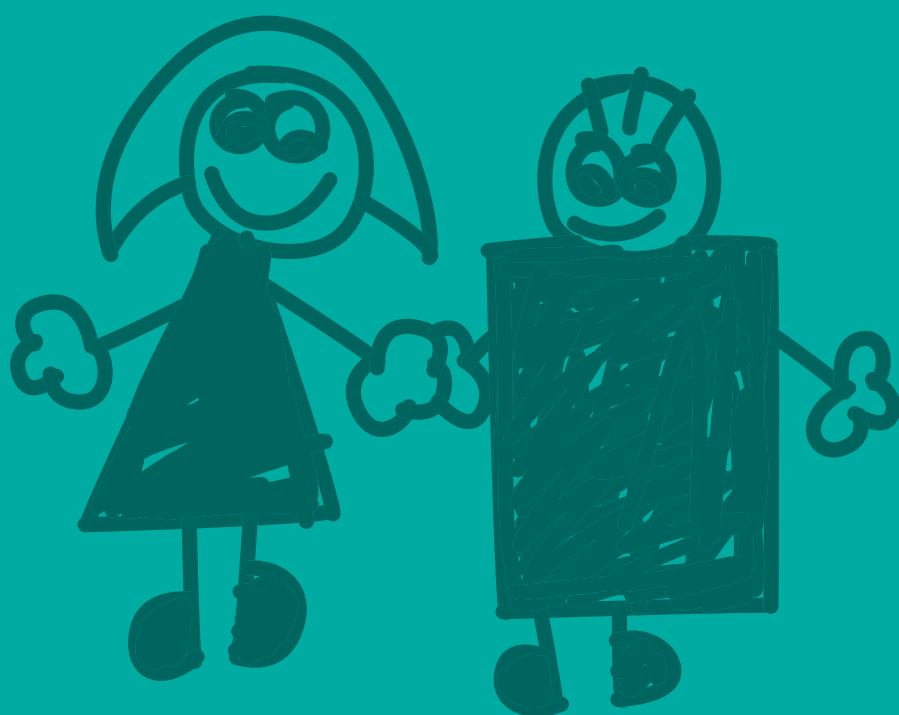
# Full Lives

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A study of short breaks provision  
for children and young people with  
disabilities and their carers in Wales.



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We want to see Wales as a country where children and young people are respected, valued, listened to and supported to lead safe and happy lives. The Commissioner works for every child and young person up to the age of 18 who lives in Wales, or who normally lives in Wales. He also has the power to act on behalf of older young people under certain circumstances.

There's a team of people who work with Keith – in Swansea and Colwyn Bay – to help him:

support children and young people to find out about children's rights

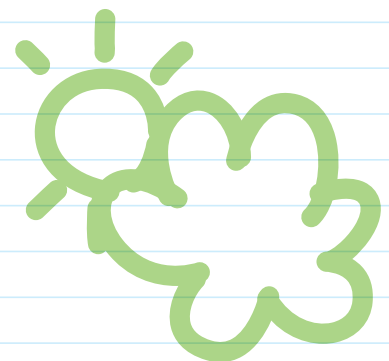
listen to children and young people to find out what's important to them

advise children, young people and those who care for them if they feel they've got nowhere else to go with their problems

influence government and other organisations who say they're going to make a difference to children's lives, making sure they keep their promises to children and young people

speak up for children and young people nationally on important issues – being the children's champion in Wales.

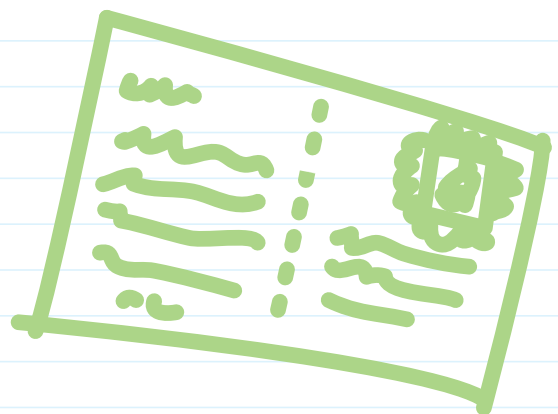
You can find and download copies of all our reports on our website: [www.childcomwales.org.uk](http://www.childcomwales.org.uk)



**There are a number of laws, including the Care Standards Act 2000<sup>1</sup> and Children's Commissioner for Wales Act 2001<sup>2</sup>, which explain the role and responsibilities of the Commissioner.**

**Under the legislation that established the Children's Commissioner for Wales, there is a duty to:**

- have regard to the UN Convention on the Rights of the Child (UNCRC) in everything he and his team do;**
- make sure that children and young people know where his offices are and how to contact him and his team;**
- encourage children to contact him and the team;**
- ask children what they think about his work and future work, and allow them to influence the work programme; and**
- make sure that he and his staff go and meet children and young people.**



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<sup>1</sup> The Care Standards Act is the predominant piece of current legislation governing the regulation of social care in Wales. (20th July 2000)

<sup>2</sup> An Act to make further provision about the Children's Commissioner for Wales. (11th May 2001)

**The work isn't confined to what are usually considered to be children's issues, like health, education and social services. Planning, transport, the environment, economic development and rural affairs also fall within the scope of the role.**

**The Commissioner can:**

- review the effects of policies, proposed policies and the delivery of services to children;**
- examine in more depth the case of a particular child or children if it involves an issue that has a general application to the lives of children in Wales;**
- require information from agencies or persons acting on their behalf, and require witnesses to give evidence on oath; and**
- provide advice and assistance to children and young people, and others concerned about their rights and welfare.**

**There is also an important additional power to consider and make representations to the National Assembly for Wales about any matter affecting the rights and welfare of children in Wales.**

**You can find and download copies of all our reports on our website: [www.childcomwales.org.uk](http://www.childcomwales.org.uk)**

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## Introduction

In my Annual Report of 2012-13 I made a commitment to undertake a distinct piece of work that would examine the implementation of the Breaks for Carers of Disabled Children (Wales) Regulations 2012.<sup>3</sup>

The regulations provide for a range of services to be put in place to meet this duty and required local authorities to prepare and publish a 'Short Breaks Services Statement' by September 2012. Whilst I have been pleased to see that the short breaks services statements published by local authorities acknowledge the important role of short breaks in supporting children and young people to engage in social and learning activities, overall, I remain unconvinced that the short breaks services statements go far enough. Some local authority short breaks statements go further than others in communicating the importance of short breaks in providing access to new opportunities that support good outcomes for children and young people with disabilities and those that care for them.

For this very reason, I decided to examine in more depth the impact that the new regulations, as interpreted through local services statements, were now having in terms of provision for children and young people with disabilities and their carers.

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<sup>3</sup> These regulations are the first regulations to be made in relation to Wales under paragraph 6 of Schedule 2 to the Children Act 1989, which imposes duties on local authorities, as part of the range of services they provide to families, to provide breaks from caring to assist parents and others who provide care for children with disabilities.



The benefits of short breaks for children and young people cannot be underestimated. The positive feedback from children and families about the value of their short breaks provision has been overwhelming. As well as providing valuable support to parents and carers, short breaks can fulfil an important role in offering children and young people with disabilities the opportunities to enjoy social interaction through play, leisure and recreation activities. Based on this, I have been particularly interested in assessing the range of available services, the degree to which children and young people with disabilities and their parents/carers believe these services meet their specific needs and whether or not their individual experiences as service users have been positive.

From my meetings with children and young people with disabilities and their carers, one of the key messages that has come through clearly as a result of this research is that short breaks provision is far from straightforward. It is complex. It is complicated in so far as consideration has to be given to a number of factors in assessing the needs of a child with a disability in relation to short breaks provision. Their age, the impact of their disability, other pressures within the home, financial demands, and other siblings in the home – there's no 'one size fits all' solution as each family's circumstance is different. Securing appropriate, tailored provision to meet individual need is fundamental, for the sake of both the child and their parents/carers. This cannot be overstated. However, I do recognise that the needs of the child need to be balanced against the resources available to the local authority.

There is no doubt that I could not have completed this work without the assistance and views of all those who have contributed to the report in various ways. From children and young people, parents and carers, to local authorities and other professionals – their honest and constructive views have been invaluable. The names of those who have contributed to this report have been removed to ensure anonymity and to safeguard confidentiality.

The United Nations Convention on the Rights of the Child (UNCRC) recognises disability as a human rights issue. Article 12 of the United Nations Convention on the Rights of the Child upholds a child's right to say what they think should happen when adults are making decisions that affect them and to have their opinions taken into account. I sincerely hope we have achieved that in this report by ensuring that the voices and views of children and young people with disabilities, and those that care for them, are heard loudly and clearly throughout this report.



**Keith Towler**  
**Children's Commissioner**  
**for Wales, 2014**

## Policy Context

The Breaks for Carers of Disabled Children (Wales) Regulations 2012 prescribe the way in which local authorities must make provision for short breaks for the carers of children with disabilities in their area. The regulations are accompanied by Welsh Government Best Practice Guidance, which includes a clear focus on the child's needs alongside that of the carers. However, it does not include direct reference to the United Nations Convention on the Rights of the Child (UNCRC) or its application.





## The 2012 regulations place a duty on local authorities to fulfil three requirements –

- to ensure that when making short breaks provision they have regard to the needs of different types of carers, not just those who would be unable to continue to provide care without a break;
- to provide a range of breaks as appropriate during the day, night, at weekends and during the school holidays;
- to provide parents with a short breaks services statement detailing the range of available breaks and any eligibility criteria attached to them.



Short breaks provision is for the benefit of both children and young people and their parents/carers. This is conveyed clearly in the 2012 regulations and accompanying guidance.

Short breaks can take different forms. They can vary considerably in terms of the activities being offered, their location and their frequency and duration.

Short breaks can involve day-time care in the homes of children with a disability or elsewhere, overnight care in their home or elsewhere, educational or leisure activities for children outside their homes, services available to assist carers in the evenings, at weekends and during the school holidays. Short breaks can last from a few hours to several days. They can also differ depending on where you live.

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**Under section 2.2 of the best practice guidance accompanying the regulations it states that local authorities must provide a range of short breaks services and that it should secure as appropriate:**

- (a) Provision of day-time care for disabled children in both their homes or another setting, including befriending, sitting (for example where someone is commissioned to look after a child who for example cannot leave home) and sessional services.**
- (b) Provision of overnight care for disabled children in both their own homes or another setting.**
- (c) Provision which will enable disabled children to participate in educational and recreational activities; and**
- (d) Emergency care, for example, due to illness in the family. If the emergency relates to safeguarding concerns the guidance in Working Together must be followed<sup>4</sup>.**

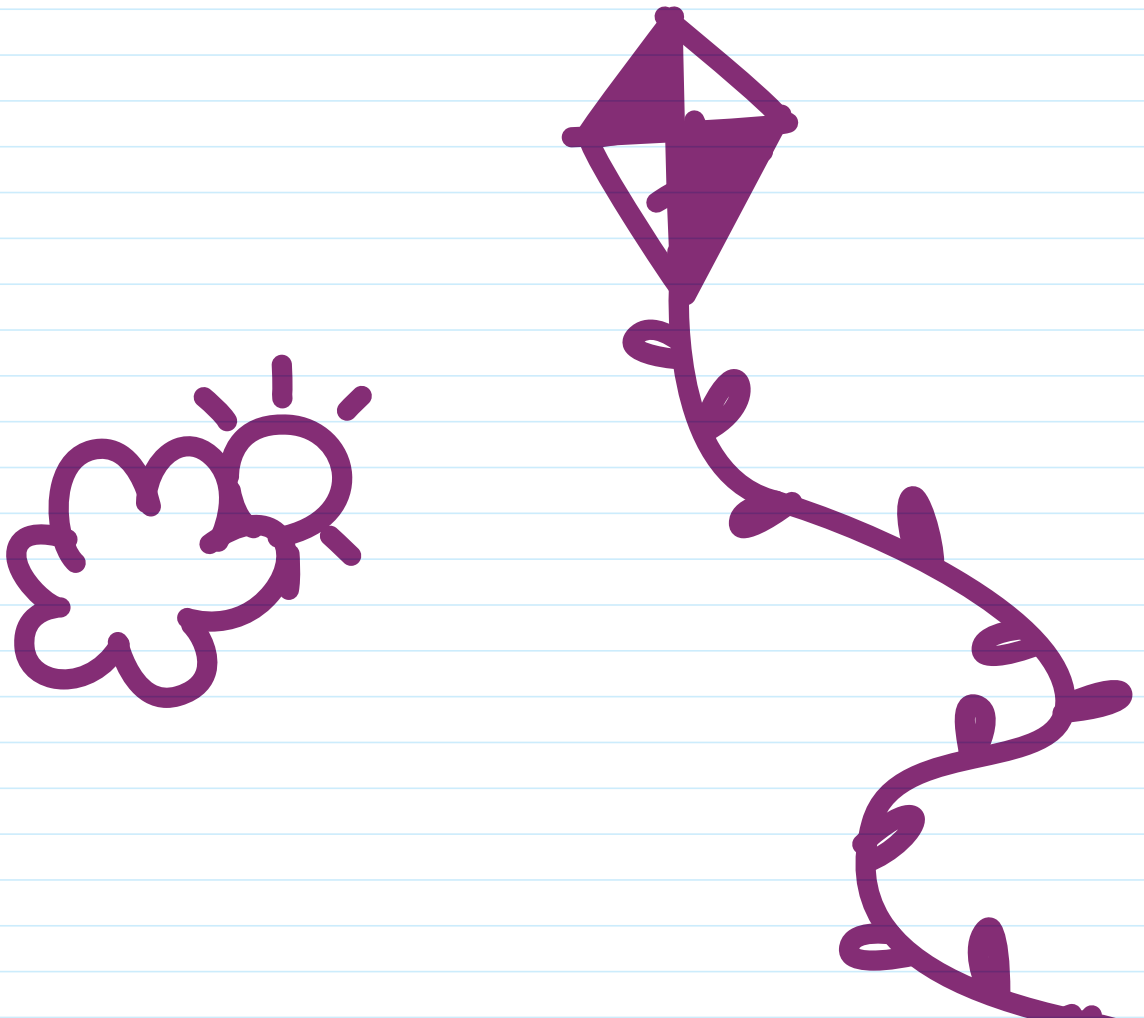
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<sup>4</sup> **Safeguarding Children: Working Together Under the Children Act 2004. This statutory guidance is for local authorities, maintained schools, academies and free schools.**

## Short Breaks Provision and the Social Services and Well-Being (Wales) Act

Welsh Government has committed to ensuring that the continuing need for short break service provision is recognised in the regulations and codes of practice which will accompany the Social Services and Well-Being (Wales) Act. The Act has provision of preventative services at its heart.

To our knowledge, Welsh Government is continuing to work with local authorities, via Short Breaks Network Cymru, in the development of their individual Short Breaks Statements and the next few years will provide the opportunity for local authorities to embed the provision of short breaks within their preventative service provision.



## Our Research

In gathering evidence for this report priority was given to secure the views of as many service users as possible. The objective was to provide children and young people with disabilities, and parents/carers, with opportunities to share their views in a variety of ways. The Children's Commissioner, and his staff, set out to establish the current status of short break service provision in Wales, and whether or not this was currently meeting the needs of children and young people with disabilities and their carers.

In order to obtain an accurate picture in relation to current short breaks provision, the Commissioner's office developed a tailored programme of information gathering sessions, which included:



## 1.

### **Establishing a Short Breaks Advisory Group to provide guidance and expertise**

The Advisory Group's membership comprised mainly of individuals representing several third sector organisations. They were approached due to their particular understanding of short breaks and/or the needs of children and young people with disabilities and their carers.

Meetings were held with the majority of the group on a one to one basis. Such meetings were invaluable as these professionals were able to provide an insight into the complexities of short breaks, as well as offering wider guidance and advice.

Members met together on one occasion as a group. This was to consider and agree the content of the online surveys.

### **Membership of the group included:**

**Keith Bowen – Carers Wales**

**Sarah Bowen – Barnardo's**

**Sue Hurrell – Parent**

**Carolyn Isles – Action for Children**

**Richard Jones – Contact a Family Cymru**

**Trudie Jordan – Tros Gynnal**

**Catherine Lewis – Children in Wales**

**Jackie Murphy – Tros Gynnal**

**Dr. Carol Robinson – Freelance Research and Development Consultant**

**Alyson Sefton – NYAS**

**Andrea Storer – Children in Wales**

**Rhiannon Williams – Action for Children**



## 2.

### A series of evidence exchanges within a range of settings

The evidence exchange was one of the primary research tools utilised. Each exchange was structured as an informal discussion with children and young people, parents/carers, teaching staff and other professionals. Evidence exchanges were held throughout Wales, in both rural and urban parts of the country. They were hosted and facilitated by schools, residential facilities, youth clubs and parent support groups. The evidence exchanges sought to generate views that could inform the Commissioner's report and would offer robust qualitative data to complement the online survey.

To enable all those taking part in the evidence exchanges to feel able to openly share their concerns in a relaxed environment, the majority of the sessions with children and young people were held separately to those involving parents and carers. This approach ensured that any comments made during the sessions could not offend the feelings of loved ones also taking part. It resulted in discussions with children and young people and parents/carers that may not have been so candid if they had come together as one group.

The evidence exchange sessions with children and young people were held mainly in schools with teachers and other staff present. The sessions included an introduction by the Commissioner, or a member of his staff, followed by an informal round table discussion. The discussions were led by the children and young people themselves, which prompted lively debate and contributions.

An evidence exchange inviting Directors of Social Services, or their representatives, was held in February of this year. 18 of the 22 Welsh local authorities were represented at the meeting held at the Commissioner's office in Swansea and also, via video conference link, at the Commissioner's office in Colwyn Bay, North Wales. The meeting was an exchange of views regarding short breaks services and provided an insight into the challenges faced by local authorities in delivering provision.

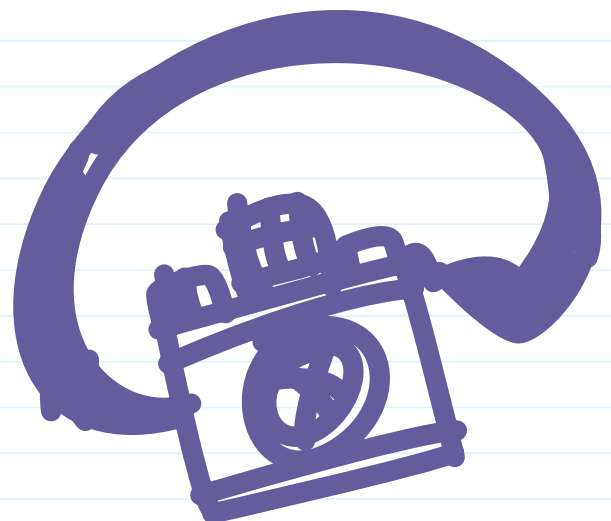
The Commissioner's team also liaised with representatives of key voluntary sector organisations and secured their perspectives regarding short breaks provision in Wales.

Securing the perspective of local authorities and other professionals working in this field was important in ensuring that the views of service providers were considered alongside those of service users.



## Evidence exchanges – who took part

- The Commissioner and his staff visited 11 schools in total
- Three schools were in North Wales and eight schools in South Wales
- In addition, two schools in South Wales also responded to the Commissioner's questions by email
- Two youth clubs contributed to the information gathering sessions – one in North Wales and one in South Wales
- Two residential units took part
- 18 local authorities attended the evidence exchange at the Offices of the Children's Commissioner for Wales
- Two parent support groups





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### 3.

#### **An online survey for children and young people and an online survey for parents/carers and other professionals**

The methodology used as part of this research included an online survey, also available in paper format. Two versions of the survey were produced - one version for children and young people and the other for parents/carers (or any other adult with an interest in short breaks who wished to respond). The surveys were constructed and facilitated by a company specialising in creating on-line surveys that are recognised as good practice for working with children and young people.<sup>5</sup>

### 4.

#### **Fieldwork visits to schools, youth clubs and residential facilities**

To ensure the survey was completed by as many children and young people with disabilities as possible, the Commissioner wrote to special schools throughout Wales asking if assistance could be given to children and young people, in receipt of short breaks provision, who would wish to respond to the survey.

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<sup>5</sup> Viewpoint online surveys - more information on Viewpoint's work can be found here [www.vptorg.co.uk](http://www.vptorg.co.uk)

## 5.

### **Attendance at a number of events targeted at those with an active interest in the well-being of children and young people with disabilities.**

The Commissioner's office attended two Contact A Family Cymru events, one in Cardiff and one in Pontardawe. The events attracted a significant number of families and provided opportunities for the Commissioner's office to raise awareness of the short breaks report and to listen to the experiences of parents/carers and children and young people with disabilities.

Also, staff from the Commissioner's North Wales office attended a Disability Rights Forum in Llandudno as well as attending a meeting with the parents of children with disabilities at a Special School in North Wales.

Also as part of the research the Office of the Children's Commissioner met with Short Breaks Network Cymru and learned about the work they, as an organisation, had been commissioned to undertake on behalf of Welsh Government. The piece of work involved a review of local authority services statements to establish if they were fit for purpose. The Commissioner and members of his staff also attended a conference organised by the network at which the Commissioner spoke.

## 6.

### Paper questionnaires

Paper questionnaires were distributed at the Short Breaks Network Cymru Conference held in Cardiff and also at Contact A Family Cymru events. However, the response level was very low and only six completed surveys were received.

### Other work completed as part of the research

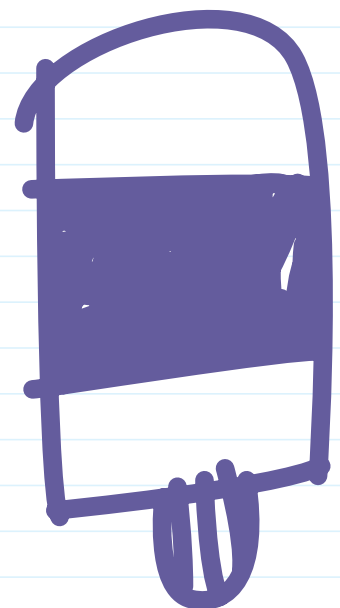
The Commissioner also wrote to all elected representatives at Assembly and Westminster level and asked if they could raise awareness of this piece of work within their respective constituencies or regions, particularly with constituents who may have previously raised concerns regarding short breaks provision.

Articles and features outlining the short breaks work appeared in a number of voluntary organisations' newsletters, as well as in local authority publications and websites. Through Contact A Family Cymru information was also distributed to over 1500 parents, inviting them to respond to the Commissioner's survey.

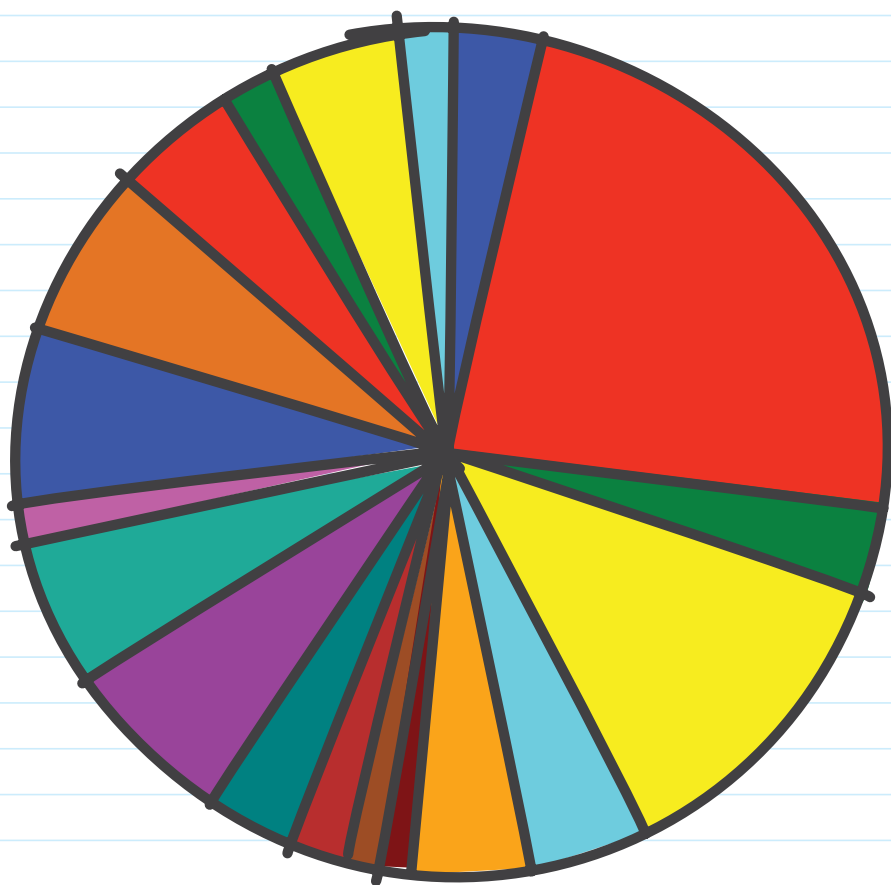
The largest cohort of children and young people who responded to the survey, was that of 14 to 17 year olds, with those aged 18 or over the second largest.

## Survey Respondents

- A total of 96 online survey responses were received
- 46 survey responses were from children and young people
- Of those who completed the survey, 45% were female and 55% were male
- 39% of respondents were aged between 14–17 and 37% were aged 18 and over



## Survey Responses by Local Authority Area

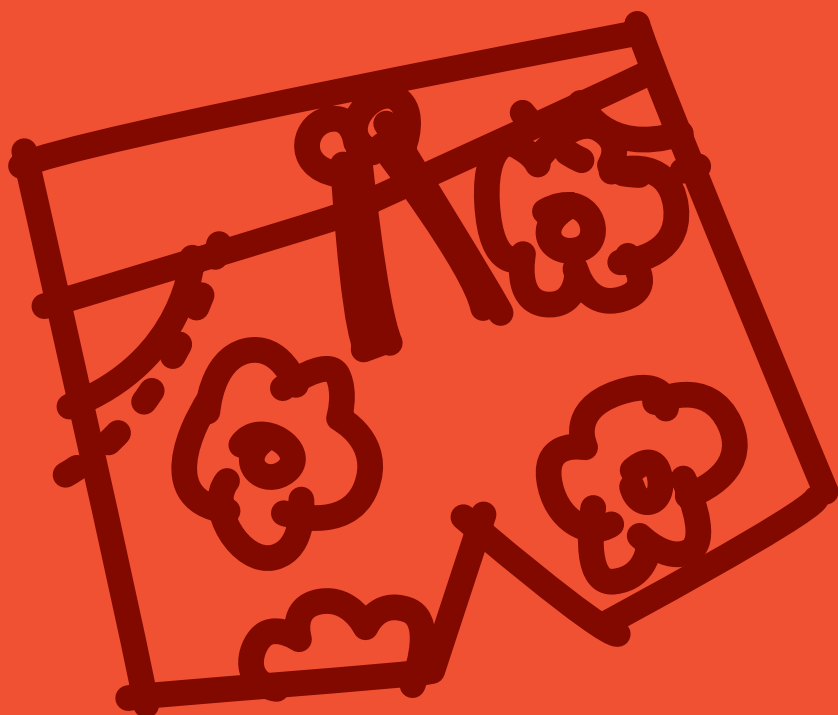


1		3	3.37%	Blaenau Gwent
2		21	23.60%	Bridgend
3		3	3.37%	Caerphilly
4		12	12.36%	Cardiff
5		4	4.49%	Carmarthenshire
6		4	4.49%	Ceredigion
7		1	1.12%	Conwy
8		1	1.12%	Denbighshire
9		2	2.25%	Gwynedd
10		3	3.37%	Monmouthshire
11		10	6.74%	Neath Port Talbot
12		5	5.62%	Pembrokeshire
13		1	1.12%	Powys
14		6	6.74%	Rhondda Cynon Taff
15		7	6.74%	Swansea
16		4	4.49%	The Vale of Glamorgan
17		2	2.25%	Torfaen
18		4	4.49%	Wrexham
19		2	2.25%	Other (did not indicate their local authority area)

## Findings

The key findings of this report are rooted in the evidence collected during face-to-face meetings with children and young people, parents/carers and professionals, as well as their responses to an online survey. The findings underpin the overarching message of this report – short breaks are a complex matter and if they are to be delivered effectively then individual circumstance and need must be amongst the foremost considerations when decisions are made regarding provision.

One of the main challenges of this report has been to unravel the issues that have emerged and to address each separately so that a greater understanding of how the issues fit together develops.



The research conducted finds that short breaks packages are reliant on a variety of services working together to ensure effective and efficient provision, e.g. Social Services, providers of short breaks, miscellaneous recreational and leisure providers. The combination of services required can differ for each child and young person and those of their parents/carers. Available services also differ from one local authority to the other, as does the eligibility criteria for accessing short breaks provision.

The children and young people who responded to the online survey experienced a variety of short breaks provision. The children and young people were asked questions about the types of short breaks they had received to date, and the responses below were as a result of children and young people having used two or more different types of short breaks.

### Types of short breaks experienced

- 60% had stayed at a house with other children and young people
- 50% had stayed with another family
- 53% had remained at home with a carer (other than their parent/usual carer)
- 61% had visited a Saturday club or after school club
- 28% had been to a holiday camp
- 29% had experienced a holiday scheme

## The experiences of children and young people

Overall, the majority of children and young people who took part in the online survey and evidence exchanges, were extremely positive about the activities they undertook on a short break, with a range of experiences and activities being cited in their answers – from cooking, swimming and kite flying to watching DVDs and playing on the Xbox, “yes, they are fun and I get to do lots of things”, is a flavour of the positive responses received in relation to residential units.

77% said “yes” when asked if they enjoyed the activities on a short break. However, a small percentage talked about missing their family and wanting to stay in their own home, highlighting the fact that not all children and young people with disabilities wished to spend time away from their loved ones and that however positive the provision being delivered, it would seem difficult for some children to understand that their families also need a break from their caring responsibilities.

Children and young people also spoke about how they felt treated during a short break, and it would seem that a significant number of children and young people, over 75%, valued the fun things they were given to do as part of their short breaks provision. When asked whether they felt safe during their short break, 85% said “yes”, however, 15% did not feel safe, which perhaps echoes some of the responses recorded in the evidence exchanges. “I’m scared of the dark”, was one comment made.



### **Do you enjoy going to "resi" and if you do why?**

**"It's beautiful. Good staff look after us. You should have a look around."**

**"I enjoy coming to residential so I can tease the girls."**

**"Because of how nice it is. Teachers always help us."**

**"I like to see my friends."**

**"Get away from annoying brother"**

**"Better food in residential than in school"**

**"Love it. Nice and cosy."**

### **If you don't enjoy going to "resi" can you tell me why?**

**"Don't like residential place. I love my house. It's my own place. I love Mammy and Daddy."**

**"If it was like my bungalow and I had my family there then that would be great really."**

**"It's boring."**

**"I don't really like going to respite, they check up on me in the night, but Dad likes me going so he can have a break."**

The language used by children and young people throughout this research to describe short breaks has varied considerably. For example, some children and young people used the term respite and not short break to describe the different residential provision they received. Some described them as “resi” and others described them as “sleepovers”.

The importance of having awareness with regard to language used in relation to short breaks is particularly important. Although there is a great deal of positive feedback from children and young people, there is also poignancy in some of their responses. This is the case when they describe the short break as being an opportunity for their family to have a break from them. Also, the fact that many brothers and sisters who have a sibling with a disability are described as young carers presents another problem in relation to their identity and how descriptions and labels of that kind make them feel.

This suggests a need for a serious re-think surrounding the term short break and a far greater appreciation that although a child or young person may have a disability, it does not equate to a lack of understanding regarding the terminology used.

“Cos family get a break as well”

“Out of Mam and my brother’s hair.”

“Very good for families.”

“They (parents) have a break. Watch TV.  
Don’t worry about me”

## The experiences of parents/carers

To give serious consideration to short breaks provision the research explored the perspectives of parents/carers as well as children and young people. The views of parents/carers who took part in the evidence exchanges were consistent with the responses to the online survey, “I’d have cracked without this place”, was one response, and “you feel you have a caring pair of hands around you”, was another. The majority of parents/carers in receipt of a short breaks package were satisfied and very clear about the benefits to them and their child/children. Parents spoke about the importance of the provision and how, when they worked closely with their short breaks provider, a greater level of trust was established, which ultimately worked best for their family as a whole. This approach was also cited as having a considerable benefit for brothers and sisters, many of whom take on a secondary carer role.

“Bottom line is we just wouldn’t cope if there wasn’t the residential unit.”

“I don’t sleep. I only sleep when my son comes in here. Two nights aren’t enough. I’ve health issues myself. Everything stops at 18 what do I do?”  
He asks, “Are you alright today Mam?”

“I’m extremely happy and lucky with the support we get as a family and think that the social worker we have works so hard to help us as do the support workers. The whole service for us has been fabulous.”

**Not all parents/carers have had a positive experience of short breaks provision indicating that access to services and the support of professionals can vary from local authority to local authority.**

**“We don’t use a short breaks service at present. We used to use one but due to my son’s anxiety he was unable to continue with overnight respite and I am told there is nothing else available for him.”**

**“We’ve never been offered any help, asked for an appointment with the social services team, but haven’t had one.”**

**54% of parents/carers also indicated that they required short breaks provision on a weekly basis, suggesting that the current frequency of their package was not adequately meeting their needs.**

**How often you would like your family to get a short breaks service?**

<b>Weekly</b>	<b>54%</b>
<b>Monthly</b>	<b>19%</b>
<b>Three monthly</b>	<b>8%</b>
<b>Every now and then</b>	<b>19%</b>

### **Do you get access to the short breaks service at the times that meet your family's needs?**

<b>Yes, whenever we need it</b>	<b>8%</b>
<b>Yes, most of the time</b>	<b>41%</b>
<b>Not usually</b>	<b>22%</b>
<b>No, never</b>	<b>30%</b>

### **The Views of Local Authorities**

**All organisations should work towards what is best for each child**

**Article 3, UNCRC**

Drawing on the evidence shared by the local authorities as part of this research, it is clear that professionals working within the field cited a number of difficulties in relation to the provision of short breaks. The transition from children to adult services is not as seamless as it could be for children and young people with disabilities. Much of the evidence was gathered during the evidence exchange with local authorities, hosted by the Commissioner in February 2014.

Professionals spoke about the difference in culture and approach between children and adult services and shared many of the concerns being outlined by the children and young people with disabilities and their parent/carers. Also, it was raised in the evidence exchange that parents/carers themselves may also be in need of advocacy support.

Transport in rural areas was also raised as an issue in terms of accessing short breaks provision and that travel costs needed to be factored into the funding of provision, again placing a greater demand on local authority budgets.

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**Universal services and the difficulties that arise when these services are not accessible to children and young people with disabilities also featured strongly in the meeting with local authorities. This was raised as an issue in relation to the impact on a parent/carer's confidence in the service, when/if part of the short breaks package is not actually accessible.**

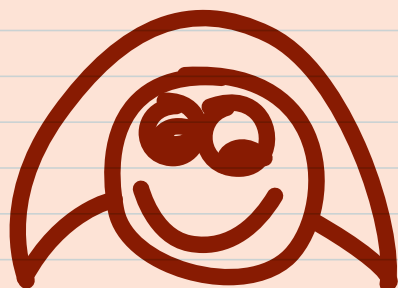
**Professionals also felt the language used to describe provision was constraining, the term 'short break' not accurately reflecting provision as an opportunity for children and young people with disabilities, to develop outside of the family home as well as being regarded as a period of mutual benefit to children and young people and those that care for them.**

**It would seem from the feedback received by the local authorities that language and terminology needs to change in relation to the term "short breaks".**

**This is due to the fact that it makes some children and young people feel that they are a burden and that time spent away from them, for their families, amounts to a burden being temporarily lifted.**

**Also, the fact that the brothers and sisters of a sibling with a disability risk being labelled as young carers and losing their own identity. This again highlights the need to choose language very carefully.**

**Feedback from one local authority also highlighted that children and young people with disabilities wanted to do the things that any other child or young person wants to do, and that the high volume of assessments were preventing children and young people with disabilities from enjoying being children.**



**Responses of Parents/Carers**

**Do you know what short breaks are available in your area?**

Yes 57% / No 43%

**Does your child stay away in a house with other children etc (residential setting)?**

Yes	39%
No	61%

**Do you know where you can get information about short breaks services in your area?**

Yes 48% / No 52%

**How would you rate the service when staying in a house?**

Poor	6%
Satisfactory	25%
Good	13%
Very Good	38%
Excellent	19%

**Does your family currently use a short breaks service?**

Yes 54% / No 46%

**How would you rate the service of someone coming to your home?**

Poor	6%
Satisfactory	18%
Good	18%
Very Good	29%
Excellent	29%

**If your family does not use a short breaks service would you like to use any of these services?**

Goes out to do activity	60%
Saturday Club/Youth Club etc	65%
Holiday Scheme	50%

**Do you get access to the short breaks service at the times that meet your family's need?**

Yes – whenever we need it	8%
Yes – most of the time	41%
Not usually	22%
No never	30%

**Are you getting the short breaks you were told your family would get?**

Yes, completely	30%
Yes, usually	22%
Rarely	26%
Not at all	22%

**Is the person you link with in relation to the short breaks your family receives easy to contact?**

Yes, always	23%
Yes, most of the time	51%
Not usually	11%
No never	14%

**Have you been asked how the short breaks services your family receives could be improved?**

Yes, often	8%
Yes, sometimes	46%
Hardly ever	12%
No never	35%





## Key themes

A number of key themes emerged from the research including:

- Purpose of short breaks and gaining independence;
- Awareness, entitlement and engagement;
- Achieving seamless provision for 18–25 year olds;
- Advocacy, continuity and quality of care;
- Universal services, discrimination and stigma;
- Siblings and young carers.

## Purpose of short breaks and gaining independence

Children who have any kind of disability should have special care and support so that they can lead full and independent lives.

Article 23, UNCRC

The Welsh Government best practice guidance, accompanying the 2012 regulations, makes clear that short breaks are services that can be used to increase the level of confidence and competence of children and young people. Section 2.16 of the guidance states, “It will be important for short breaks to be planned and provided to enhance independence with a view to continuity of provision once the young people become adults.”

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**Children and young people throughout this research have made it clear that their own personal independence is extremely important to them. 93% of children and young people who responded made it clear that they liked the people who looked after them on their short break and some explained that spending time with friends at the 'resi' allowed them to learn important life skills which helped them to develop personal daily routines, such as showering and dressing themselves. Learning to cook at many of the schools, residential units and holiday schemes, along with other short breaks, was also cited as a benefit.**

**There were parents during evidence exchanges who shared that their child had surpassed expectations in terms of what they were able to achieve whilst at a residential unit. A number of parents shared that they, and their child, had felt a reluctance, borne out of anxiety, prior to attending the first "sleepover", but once that first sleepover had taken place their child had really benefitted from their time away from home.**

**However, this research has found that children and young people discover and enjoy new experiences that their parents/carers believed were no go areas. These are experiences that can encourage greater independence and confidence.**

**“Only since he’s come here that he’s slept in a room on his own or tried a new food. I thought he’d never cope, but he did.”**

**“As for our youngest (both sons have disabilities) we think he’d live in the residential unit and come to us occasionally! He’s tried to turn our home into the unit and wants the furniture arranged in the same way.”**

**“The problem (with my son) was after one night at the residential unit was getting him out of there”!**

**“This is number one destination now. Bit upsetting for me as I used to be number one. Staff are so helpful and supportive.”**

**It is clear from the views obtained that short breaks have the ability to create new opportunities for many children and young people with disabilities that can also make positive differences to their lives. The breaks, if used and developed intelligently, can create a path to independent living for some young people with disabilities. Short breaks can be utilised to create opportunities for some that will assist in securing work experience and develop CVs. There is enormous potential and this is reinforced in section 2.4 of the guidance which states:**

**“Local authorities will want to ensure that they develop a dynamic short break provision with a mixture of both innovative short break options...”**

## Awareness, Entitlement and Engagement

As outlined in section 3.6 of Welsh Government's best practice guidance, families with children and young people with disabilities must have access to a short breaks services statement which is concise and clear.

Our findings suggest that the awareness of children and young people regarding what constitutes a short break was good. During evidence exchange sessions most knew what a short break was and the different types of breaks that existed for them. This is also evidenced in the response to the online survey question about levels of awareness, with 64% stating they were aware of what a short break entailed. However, when questioned about whether or not a short break was explained to the children and young people, nearly half of those had not been given information about what would happen to them when they went on a short break indicating that perhaps more needs to be done to ensure a greater number of children know what to expect during the break.

"Knowledge is power", a parent proclaimed quite early during this piece of work. She had done her homework in relation to short breaks provision and, to use her words, had "fought hard and persevered to secure provision." On many occasions during the evidence gathering, similar words were used – "persistence", "endurance", "battling" – all used to describe why some parents/carers believe they have secured a short breaks package with which they are content, despite rather than because of the help and support they have received from Social Services.

Many of those who have received a package of short breaks, that meet their needs, have expressed feelings of guilt when they consider other families who are receiving very little or no provision at all. There is a real sense of solidarity amongst many parents and there is much evidence of them actively supporting one another. This has been demonstrated most clearly in sessions with parents/carers groups.

There were a number of parents/carers who engaged in this research through the evidence exchanges, despite not being in receipt of any short breaks provision. Many stated that they were unaware such support existed and that they may be eligible for support.

Regrettably, statements have proven extremely difficult to locate within several local authority websites. This difficulty in itself then becomes another obstacle to overcome for parents/carers or young people when searching through websites for information that should be easy to locate.

Local authorities must publish their short breaks services statement on their website and section 3.6 of the guidance goes further and states:

“...It would be good practice for local authorities to also consider additional ways of making the information available, for example, in paper format for people without computer access. Public notice boards in doctors’ surgeries and children’s centres can also ensure information is accessible.”

There are families who are not knowledgeable about local authority processes and procedures. There are also parents/carers of children and young people with disabilities who themselves have learning difficulties and need assistance in discovering what they may be entitled to receive.

“Don’t know how to access.”

“I don’t know about it or know if I am eligible.”

“Didn’t know about them.”

“No idea, never used.”

It is a cause for concern that there is a real lack of awareness regarding short breaks amongst families who may be eligible to receive much needed support. These families have no idea of what a short breaks services statement is, let alone the information it should provide. Welsh Government places a legal responsibility on local authorities to ensure the statement is available on their respective websites. Information regarding the eligibility criteria for short breaks provision and the types of provision available. This is important especially as eligibility criteria and provision differs across local authority areas.

43% of parents/carers did not know what short breaks services were available to them in their area and 52% did not know where to go to access the information in their area. Whilst these findings could be down to a number of factors, such as lack of access to the internet, lack of promotion of shorts breaks within the local authority area and the need for greater clarity in relation to information points, it is cause for concern

that those who may be the most in need of these services were not fully aware that every local authority in Wales has a duty to publish a short breaks services statements. 69% were not aware that local authorities were required to promote short breaks service statements, which is disappointing given the fact that short breaks services statements are central to the Welsh Government 2012 regulations and accompanying guidance.

Data collected as part of the online survey indicates a greater level of awareness in relation to a carer's assessment. 75% of adults who responded had become aware of the short breaks service as part of their carer's assessment. Indeed, there were parents/carers who had engaged with this research who were familiar with the 2012 regulations and guidance. They were knowledgeable about what their local authority should be providing in terms of short breaks information and service provision, and many of these parents/carers were actively involved in groups which offered support to other parents/carers of a child or young person with a disability, seeking to engage and influence decisions at local and national level.

And finally, in Wales, are we doing all we can to ensure that information for children and young people with complex needs is accessible? Are we taking things for granted in assuming that all children and young people with disabilities have someone to advocate for them who is able to provide the information they need in a format required to adequately meet their needs? These are all interwoven components which will need to be addressed as part of future short breaks provision.

## Achieving Seamless Provision

There are potentially several key points of transition in a child or young person with a disability's life. These can include staying for the first time overnight in a residential facility, the first day at school, leaving school and starting college or moving to independent living. These are milestones that can be challenging for any child or young person. However, for many children and young people with disabilities these key times in their lives can carry additional pressures.

One particular point of transition, which evidence indicates is causing the most anxiety, is when a disabled young person reaches 18. For the majority of young people reaching 18 is a cause for celebration. Sadly, for many young people with a disability and their parents/carers the opposite is true. Perhaps this is best summed up by a Deputy Head at a special school who said that for many young people on reaching 18 it can feel as if "all the scaffolding is suddenly being taken away."

Children and young people with disabilities, and their parents/carers, have described how they feel regarding the build up to the 18th birthday and why some of the changes triggered on reaching that age can be extremely upsetting. For many families it is a time that they dread.



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One of the main adjustments at 18 that a young person with a disability has to come to terms with is the removal of entitlement to access the residential unit at which they have stayed as part of their short breaks package. This was highlighted during one evidence gathering session at a school when the children, young people and teaching staff shared what happens on the day of a young person's 18th birthday.

The local authority, through a written communication, informs the young person and their parents/carers that they will no longer be able to use the residential facility where they have had "sleepovers", on some occasions, for a number of years. The facility in question is located near to the school and is one that the children and young people describe as "amazing" and "awesome".

To be informed at 18 that you are no longer able to use a facility that you really enjoy visiting is a particular concern for parents/carers and the children and young people affected by this policy.

Children and young people have described situations when friends, still attending school, are unable to access the residential unit where other school friends yet to reach 18 continue to attend. The impact of this is compounded when one factors in the rural location of some schools and the difficulties that this brings in relation to socialising for many young people. It is no exaggeration to state that the residential unit can be one of the few places where young people with a disability can interact with their peers.

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**“Happy there.....very sad to see me not go.”  
(The words of a young person no longer able to access the residential unit he thinks is “amazing” because he has now turned 18)**

**“There should be a rule so they can continue after 18th birthday.”(Young man speaking on behalf of other young people in his school)**

**“It’s probably one of the only social activities they do, staying at residential unit.”  
(Member of teaching staff)**

**“It’s a very, very significant issue and there’s no replacement.” (Member of teaching staff)**

**There are parents/carers who have engaged with this research who are content with the post 18 transition process. However, the majority engaged with this research are not content and have shared serious concerns regarding the process for post 18 transition. It holds many fears for many parents/carers, and their anxiety, at times, has been tangible.**

**Parents and carers have described how they feel as “being on the edge of a cliff”. In the worst case examples they have no idea what is happening next for their child, even when the child’s 18th birthday may be only a week away.**

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**Unquestionably, the issue of becoming an adult at 18 causes significant concern amongst children and young people and their parents/carers alike. Indeed, it has been the foremost issue of concern shared in evidence gathering sessions and in survey responses.**

**A clear message has emerged that post 18 transition needs to start much earlier and in some cases this does happen. However, there is no evidence of consistency across local authorities or at times even within a local authority. Indeed, the Commissioner has received accounts of positive and negative experiences from families who reside within the same local authority area. This has resulted, during evidence gathering sessions, with parents who are satisfied with the transition process astonished at the clear frustration of other parents.**

**During the research the Commissioner had conversations with parents who were worried about their own mortality and were anxious about who would care for their children in the future.**

**>>>**

**“This is his lifeline and he’s interacting with other people.”**

**“With my son his needs are so complex transition needs to start sooner.”**

**“We’re all anxious when they’re going to reach 18. I think transition needs to start at 14. You can’t expect transition to happen just like that. Who suffers is the child.”**

**“He’s going to go from this lovely place, services with pals and he’s going to go to having nothing.”**

**“I wish we could take the residential unit on with us. My son will be leaving in October 2014, but the future is not clear.”**

**“The plan is left so late.”**



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## Advocacy, Continuity and Quality of Care

**Every child has the right to say what they think in all matters affecting them, and to have their views taken seriously.**

**Article 12, UNCRC**

**Best practice in short breaks provision includes the provision of an independent Residential Visiting Advocacy (RVA) Service.<sup>6</sup> This is an added safeguard for these vulnerable children and young people and is backed by the Waterhouse Inquiry 2000 Recommendations and the Carlile Review 2002.<sup>7</sup>**

**All children and young people with a disability who receive, or are offered, short breaks should have access to an independent advocate. For those receiving short breaks in a residential setting, best practice would require the provision of an independent residential visiting service which is child centred. This is supported in principle by the Waterhouse Inquiry 2000 and more specifically by the Carlile Review 2002.**

**The provision of an independent advocate is supported by research that has informed this report. For example, the responses of some of the children and young people to the online survey questions regarding whether they felt listened to and felt safe demonstrate the importance of an independent advocacy provision.**

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<sup>6</sup> RVA Service – allows advocates to visit residential units on a regular basis to meet and interact with young people, allowing them to identify any concerns or issues being expressed.

<sup>7</sup> This Review was announced in September 2000 by the Minister of Health and Social Services in the National Assembly for Wales. The Review Panel was appointed by the Minister.

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The online survey asked a number of questions regarding whether the views of children and young people were sought in relation to their short break. The responses indicate that the majority of children and young people were consulted, with 69% of those surveyed confirming that they had been asked for their feedback following their short break. However, 31% had not been consulted, which may suggest a need to strengthen advocacy arrangements in certain local authority areas. The surveys open ended questions also asked who the children and young people would speak with if they were not content with the short break, including when they were at their short break. The majority spoke about raising concerns with a family member or a member of staff, depending on the type of short breaks provision being experienced.

On closer examination, an interesting point to note were the contrasting views of those who responded to the online survey in relation to the question of whether or not children and young people feel listened to. In the face to face evidence exchanges children and young people were split down the middle regarding whether or not they felt listened to. However, the clear majority, some 92% of children and young people, who responded to the online survey, did believe they were listened to in relation to their short breaks package.

Continuity, in a number of different contexts, is of paramount importance. For example, continuity in relation to individuals who fulfil the role/s of paid carer/s is incredibly important. The majority of children and young people have made it very clear that their preference is to have carers they are accustomed to looking after them. They do not welcome change in this aspect of their care. Of course, this only applies as long as the carers are liked and trusted by the children and young people.

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**Most children and young people spoke very positively about those who cared for them – whether in a residential facility or by carers visiting their homes and/or taking them out. However, there were some children and young people who were not completely happy with the care they received and this is reflected in some of the published quotations.**

**Continuity concerning the bedrooms in residential facilities at which children and young people stay is of real importance to some. Also, there are some children and young people who do not want to share a room and there are others who want company and prefer sharing. However, there are children and young people who only like sharing when it is with a friend and not a child or young person previously unknown to them. It is important to be mindful and respect a child's right to privacy as upheld in Article 16 of the UNCRC.**

**The needs of each child and young person with a disability are different and that is why a tailored provision meeting specific needs is crucial. If this is not secured then certain short breaks provision can be set to fail before they have even begun.**

**What has also come across in meetings with parents is in some local authority areas children and young people with Autism Spectrum Disorder receive a short breaks package and in other local authorities they do not. However, it appears from the meetings convened with parents/carers as part of the evidence exchanges, that there are some local authorities that may not have any children or young people with ASD in receipt of short breaks. This may be as a result of varying criteria being used by local authorities to access short breaks.**

**“I like the same carers and the same room. I don’t like it when they change carers.”**

**“Sometimes there’s different staff. It’s okay. It’s fine by me.”**

**“I like some staff but not all staff.”**

**“If they thought their children weren’t being looked after they wouldn’t let us go there.”  
(A young man speaking about parents)**

Parents/carers have expressed, as a pre-requisite, the need to have absolute confidence in those with responsibility for caring for their children. Many parents revealed they had initially been reluctant for their children to stay in residential care. However, nearly all parents after admitting initial reservations confirmed they were very pleased with the care being given and the difference it had made to the lives of their children as well as to themselves.

Having said that, there were a minority of parents who expressed dissatisfaction with the care and/or support given, “different taxi drivers were being used, the Residential Manager spotted this and it was sorted”, was one comment made by a parent, who wished to highlight the inconsistencies in relation to the care of his child. This illustrates the importance of appropriate and effective professional interventions to support parents when things are not going right.



**Parents/carers spoke about their attempts to influence services that impact on them and their child. Whilst the responses were quite mixed, a clear sense of frustration came through illustrating a lack of empowerment for parents/carers when trying to do the best for their child.**

**“Hopefully we have been able to improve the service and quality of care that children with disabilities currently receive. I am not sure how much of the information we share influences decisions made by our local authority.”**

**“I believe there have been consultations, but I have been too busy to be involved.”**

**“Not listened to for years lip service as usual.”**

**“Questions asked but not listened to as no difference made.”**

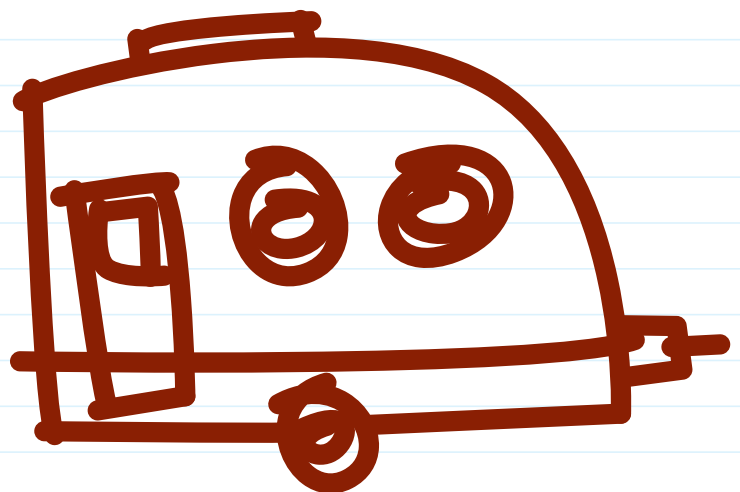
**All those caring for and working with children and young people with disabilities have a role to fulfil in recognising a child’s right to be heard and helping them reach their potential as an individual.**

**Listening to the views of children and young people with disabilities has to be at the forefront of service providers’ minds when making decisions that affect short breaks provision.**

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When questioned about the types of short breaks children and young people would prefer to undertake, the responses by the children and young people were revealing. The majority did not want to stay away from their own homes, whether in a residential facility or with another family. Neither, did they want a carer to come into their home. A clear message has emerged that if children and young people had a choice, the majority would not opt to stay away in a house with other children and young people, with 79% of those surveyed saying that they did not wish to stay away with another family.

The majority of children and young people clearly favoured going to a Saturday club, youth club or after school club, and the data reinforces why it is important, as set out in the guidance, to consult with children and young people, as well as parents/carers regarding the package of provision they are to receive. 71% of children and young people wanted to see a holiday camp feature in their short breaks package, which suggests that an activity based break is the most attractive option for children and young people with a disability.



## Universal Services, Discrimination and Stigma

**All children have a right to relax and play, and to join in a wide range of activities**

**Article 31, UNCRC**

Based on the accounts of children and young people and their parents/carers, this research indicated that universal services are not always what they purport to be, as they do not always deliver in the way they promise. Consequently, they often do not live up to their name. This has been particularly highlighted in relation to the lack of play, leisure, youth services and recreation provision for many children and young people with disabilities.

During the evidence exchanges for this report the Commissioner has been made aware of numerous examples of inappropriate and inaccessible facilities for children with a disability. This is compounded on some occasions by untrained staff, which effectively prevents a child with a disability from enjoying and benefitting from resources that able bodied children are able to use without much thought or planning. Children and young people with disabilities, as well as parents/carers, have shared their frustrations regarding the inadequacy of these important services. Many believe that whether or not a service is accessible is often dependent on nothing more than one's postcode.

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Children and young people with disabilities, along with their parents/carers have spoken about experiencing poverty on so many different levels. There are those living in households without a car and who are heavily reliant on public transport. Sadly, public transport can mean two or three buses to reach short breaks provision and some sort of social interaction with friends. Sometimes, journeys have proven too much and the break hasn't happened. One young person's response about things he would wish to change was, "be able to get bus to school, to save money and fuel", which speaks volumes about the struggles facing families in various forms.

During the evidence exchanges concerns have been raised in relation to public transport services. One incident, shared by a young woman, underlines both the extent of the accessibility issues faced by children and young people with a disability, in relation to public transport, and also the blatant discrimination that some children and young people with disabilities encounter in 21st century Wales. The young woman, who shared her story, is a wheelchair user. She explained that whilst travelling on a public service bus the driver asked her to disembark at the next stop in order to make space for other passengers to board. The young woman disembarked, in pouring rain, and waited at a bus stop without any shelter until another bus arrived.

**Whilst transport issues raised as part of this study have wider implications for children and young people with disabilities in Wales, they are particularly relevant for families needing to access short breaks provision, and is an important area to address when developing short breaks packages. If the provision isn't accessible then this will potentially impact on the family unit as a whole and at the centre will be a child or young person with a disability. Better planning is key in relation to tailoring packages and ensuring reliable and efficient transport is available.**

**"My son has to watch as other children play on the swings. There is nothing in this county to meet his needs."**

**"Transport in our rural county is always difficult. There is no real way around this."**

**"Transport issues not resolved until the last minute. This could be improved by better planning. As this added to my son's high stress levels."**

**"Very difficult to get transport."**

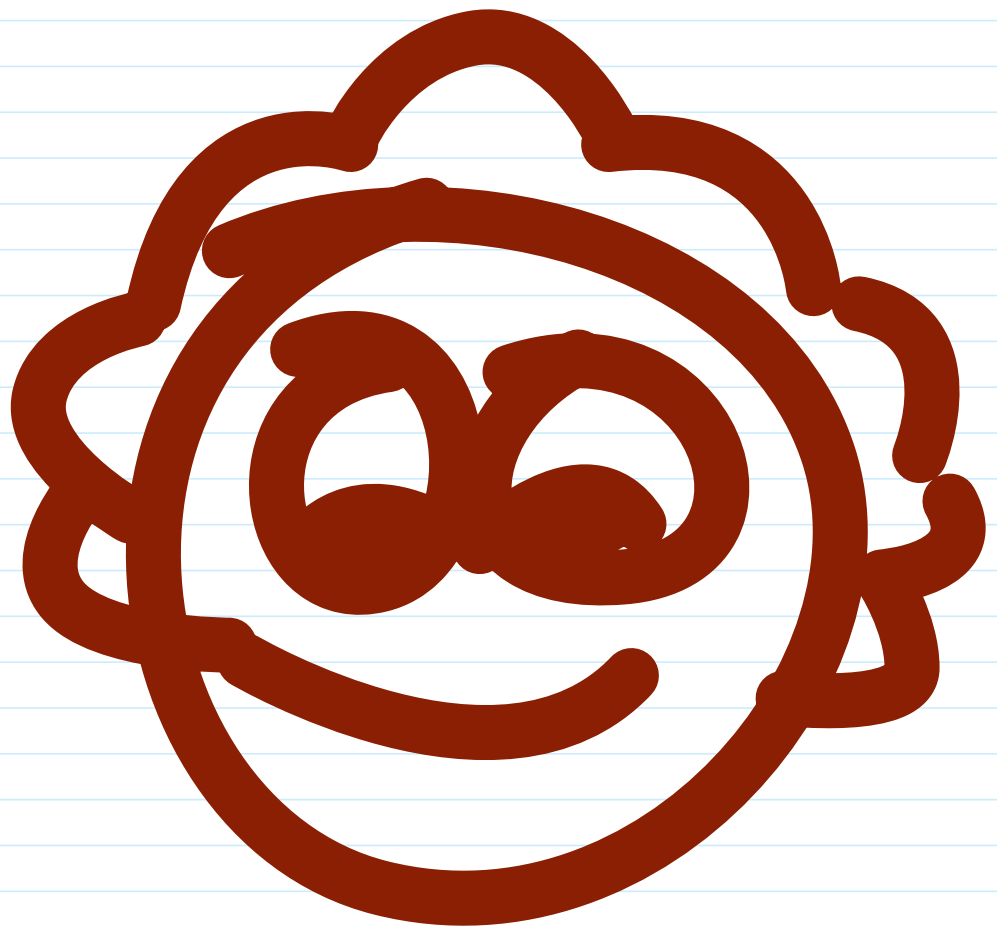
## Siblings and Young Carers

**The impact of a child's disability on their siblings must be an integral part of the family's assessment.**

**Section 1.7, Welsh Government Best Practice Guidance**

As has previously been stated in this report each family's set of circumstances are unique and this must be reflected in the short breaks package of provision they receive. There are some families with more than one child who has a disability and the needs of those children can differ greatly. There are some households in which a child or children with a disability will have a sibling or siblings and it is important that the needs of all the children in such a family are met. Such family circumstances present enormous challenges and require support from a number of services. Short breaks provision can play a crucial role in terms of providing this support.

During evidence exchanges with parents/carers the impact on the siblings of a child with a disability has been discussed in some detail. Parents/carers spoke of the strong bonds and love between siblings, but also the frustrations that can arise. They describe how their non-disabled child/children at times do not have friends to visit the family home as they are concerned that the behaviour of their brother or sister with a disability may be misunderstood and cause offence. Parents/carers have spoken about siblings feeling they have a greater opportunity to enjoy certain things at home when their brother or sister is on a short break. For example, they have greater access to the computer, television or Xbox.



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**During an evidence exchange a parent/carer speaking about her other children said, “They look at the calendar to see when respite is. They have freedom and get the computer out.”**

**Parents/carers also spoke about siblings being unhappy with the amount of attention they receive, as so much is given to their brother or sister with a disability. This in turn results in parents/carers experiencing feelings of guilt. This is why the support provided by short breaks is so important. It can allow siblings to have time with their parent/s and can stem any resentment that understandably can build up amongst children in these situations. Parents/carers have also spoken about the need for siblings of children with a disability to have a holiday in order that they too can relax and let off steam. They have also spoken about how difficult it can be to go on holiday with all their children, as finding places that can accommodate the needs of a child or young person with a disability is not easy. Parents/carers have also spoken about the lack of short breaks activities where their child with a disability could be joined by their other child/children, as there appears to be a lack of facilities catering for both the able bodied and the disabled. If facilities were inclusive this would not be an issue.**



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**Parents/carers spoke about the pressures of the caring role fulfilled by siblings. This is particularly pertinent in households where a parent/carer suffers ill health or is a single parent. Young carers have enormous pressures to contend with and their opportunities can be limited as a result. There are young carers who live in low income households where money to meet basic needs is sparse. All young carers need support and a great deal of understanding from teachers and other professionals in order to assist them in realising their full potential.**

**It is also important to remember that siblings and those children and young people who are carers can feel a loss of their own identity. There is a risk that they are not seen as individuals in their own right, but rather as being the brother or sister of a sibling with a disability or labelled as a carer. Preventing this happening is not easy, but it is an issue of enormous importance and one that must be recognised.**

**The Children's Commissioner undertook a key piece of research in 2009, entitled "Full of Care".<sup>8</sup> The report explored the concerns which have often been expressed about the sometimes inappropriate roles and responsibilities that young carers are expected to take on.**

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<sup>8</sup> Full of Care – published by the Children's Commissioner for Wales in 2009.

## Conclusion

The findings of this report underline the importance of appropriate, accessible and good quality short breaks provision for children and young people with disabilities and parents/carers. The report draws attention to several findings which underpin the key message that short breaks provision is a complex matter and as circumstances and needs change this must be reflected in provision, albeit recognising the challenges that local authorities face in providing the necessary resources and facilities in economically challenging times. The main complexities are due to a number of factors, such as:



### **Each local authority has different eligibility criteria for accessing short breaks provision.**

Although there is no requirement to have eligibility criteria in place this research indicates that most local authorities do. However, as there is no requirement this also means that there is no universal set of criteria.

### **Each local authority's range of provision is different.**

Short breaks provision can vary considerably and may include the following:

- Residential overnight service;
- Family based service;
- In home support and sitting service;
- Hospices;
- Outreach workers;
- After school clubs;
- Holiday play schemes;
- Buddying/mentoring service;
- Direct Payments;
- Residential activity holidays;
- Fun days and disability access schemes for sports/leisure
- Youth clubs
- Young carers' service
- Breakfast clubs
- School based residential provision
- Activity clubs evenings and weekends
- Community nursing teams

### **Each family has a different set of circumstances and needs.**

As some families may have more than one child with a disability, the needs and disabilities of those children may be different from one another, and as such, will bring additional pressures on the family unit. There are also factors such as location to take into account. Some families will live in an urban part of Wales and others in a rural and/or valley community – these present challenges in terms of accessing short breaks provision, particularly for those living in rural areas. Similarly, there are the differing financial situations of families. Some being able to supplement support they receive

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as they are in a stronger financial situation than others. However, perhaps the most complex of all which illustrates the differing circumstances of families requiring short breaks services, are those parents who have special needs themselves, or perhaps have physical and/or mental health to contend with on a daily basis.

In the analysis of data collected the views of service users regarding short breaks provision is wide ranging. The data points to the majority of those in receipt of short breaks provision as being content with the support they receive. However, there are children and young people and parents/carers unhappy with aspects of provision and who believe their needs are not being met. Local authorities should listen to the concerns of those who are unhappy with local services and where reasonable should seek to develop their services to address those concerns.

A concern raised repeatedly during evidence exchanges surrounded the policy to remove eligibility from a young person, once they reach 18, to continue using the residential facility that had been part of their package of short breaks provision. It is clear that this policy is the cause of enormous disappointment for many young people. It also has a negative impact on already limited opportunities for many young people with a disability to socialise with their peers.

In the Welsh Government guidance, accompanying the 2012 regulations, it states that one desired outcome of short breaks provision is the development of a young person's level of confidence and competence. Undoubtedly, for many children and young people "sleepovers" at the "resi" and other forms of provision, such as after school clubs and holiday schemes, do precisely this. They are opportunities for social interaction and assist in developing greater independence. To remove such an important service at such a significant age makes no sense. Many young people, parents/carers, teaching staff and other professionals, who engaged in this piece of work, are of the

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view that a young person should continue accessing residential provision while they remain in education. This means that they are not put in a situation where their school friends, who are yet to reach 18, are still able to access short break services and they are not.

Dialogue regarding this policy is part of a much wider narrative surrounding the issue of transition. Concerns exist regarding sufficient support for young people aged 18–25. This is a view shared by service users and professionals working in this field. They have described post 18 transition as comparable to the scaffolding of services that have provided support, for a significant part of a young person's life, suddenly being taken away. This is during a period of considerable change in the life of a young person with a disability as they move into adulthood.

For many, the transition from children to adult services is neither smooth nor seamless and evidence indicates that planning for this starts too late. The Social Services and Well-Being Act attaches significant importance to seamless provision for children, young people and adults (over 25). However, in far too many cases, this is not happening for young people aged 18–25. Their experiences are often far from smooth. For example, a young person's age is often the overriding consideration rather than their individual need and ability. This should not be the case as the young person's needs should outweigh any arbitrary age restrictions on services.

It is important to remember that service provision is not only different across local authorities, but it can also differ within the same local authority. Within the same authority there are parents/carers of the view that planning and preparation for transition is good and there are others who have a different opinion. This again highlights the fact that approach and delivery in relation to provision is not consistent and there are lessons to learn from the good practice that does exist.

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Similarly, access to universal services also differs across local authorities. This is a major issue and prompts the question, “Do universal services live up to their name?” This research has shown that children and young people with disabilities can encounter significant obstacles in accessing play, leisure and recreation services. The availability of reliable and appropriate transport provision is also a major issue for some children and young people with a disability. Their difficulties in relation to transport may be compounded if they reside in rural Wales. Service users and professionals have raised the question of what is the point of eligibility for a short breaks package of provision if the service user is unable to access key services, including the transport essential to take them to their destination. These barriers must be addressed.

Another barrier to accessing provision is the lack of awareness regarding support that may be available. This finding is recorded in responses to the survey and also during evidence exchanges. Some parents/carers indicated that they were unaware of the existence of short breaks services statements and, indeed, of what short breaks actually are. Children and young people, in a number of evidence exchanges, shared that they would benefit from having the knowledge of the services available to them in their local area. Basically, children and young people and their parents carers need information about what specialised services are going on where and when, how they can get help to access the services available, what universal services they can use, and all in a format that is easy to understand.

The actual term “short breaks” as well as perception and understanding of it amongst children and young people warrants attention. Findings show that there are some children and young people who believe the primary purpose of a short break is for parents/carers to have a break from them. The guidance makes it clear that short breaks provision is for the mutual benefit of both child and carer. This, however, is not reflected in the title of the 2012 regulations and guidance. The Breaks for Carers of Disabled Children (Wales) Regulations 2012 is a misleading title. Therefore, serious consideration should be given to amending the title of any future regulations and guidance to reflect what is actually stated in the legislation.

There is also a need to re-think the term “short break”. There has been a move away from the term “respite” and now perhaps “short break” needs to evolve and different terminology used. There needs to be a far greater appreciation that although a child or young person may be disabled this does not equate to an automatic lack of understanding regarding language and terminology used. Instead of the disability of a child or young person being the starting point surely it should be the extent of their ability. Children and young people with disabilities need to be included in developing language that describes their situation or services they access. Their participation is important and invaluable.



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However, it is important to remember that there will be occasions when children and young people with disabilities will require support in ensuring their views are heard. Research findings indicate that although the majority of children and young people with disabilities feel they are being listened to, for example when at a residential unit, there are those who do not share this view. For this reason independent advocacy provision is of fundamental importance and is a necessity for children and young people with a disability in receipt of short breaks. An independent advocate could help children and young people with a disability express their wishes and feelings in relation to short breaks. Parents/carers often act as their child's advocate, but on some occasions there can be a conflict of interest if their own needs for a break conflict with the wishes of the child.

If Article 12 of the UNCRC, supporting a child's right to express their opinion regarding decisions impacting on them, is to be truly upheld then independent advocacy is a prerequisite. What is very clear, on studying the evidence gathered for this report, is that children and young people with disabilities have the same likes and dislikes as those children and young people without a disability. They want to be listened to and not patronised. They want to spend time with their friends and, when possible, have greater independence. They enjoy a wide range of activities and are keen to try new ones. Each child and young person, whether they have a disability or not, is unique and should be treated accordingly.



Short breaks provision can play a major role in enabling children and young people with disabilities to develop and gain confidence on a number of different levels and to realise their full potential, whilst recognising and supporting their individual needs.

Appropriate short breaks provision can deliver significant long term benefits for children and young people with disabilities, as well as for their parents/carers. Its value must not be underestimated and, even during these economically challenging times, provision needs to be strengthened to enable children and young people to lead as full a life as is possible.



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## Recommendations

### Recommendation 1

Call on Local Authorities to monitor delivery against the expectation set in their Short Breaks Statements for children and young people with disabilities and their carers, and to report to corporate parents (elected members) and executive management on an annual basis to ensure scrutiny focusses on quality and access issues.

### Recommendation 2

Call on Welsh Government to monitor delivery of Local Authority Short Breaks Statements for children and young people with disabilities and their carers, by calling in and examining annual reports.

### Recommendation 3

Call on Welsh Government to ensure that the implementation of the Social Services and Well-being Act delivers a seamless provision of services for young adults with disabilities aged 18-25.

### Recommendation 4

Call on Welsh Government to work with local authorities and service providers so that children and young people with disabilities can continue accessing residential units, as part of short breaks provision, while they remain in education.

### **Recommendation 5**

**Call on Welsh Government to ensure that the Social Services and Well-being Act meets the assessed needs of both children and young people with disabilities, and their carers.**

### **Recommendation 6**

**Call on Welsh Government to uphold the United Nations Convention on the Rights of the Child (UNCRC) in any future short breaks legislation and that services for young adults (aged 18-25) are based on best interest principles and on assessment of need rather than on the basis of age.**

### **Recommendation 7**

**Call on Local Authorities to ensure that any decisions made in relation to the short breaks provision for children and young people with disabilities are clearly communicated to them in an appropriate and accessible format.**

### **Recommendation 8**

**Call on Local Authorities to ensure that Short Breaks Statements are published in a prominent place on local authorities' websites and that they are widely available in a variety of accessible formats.**



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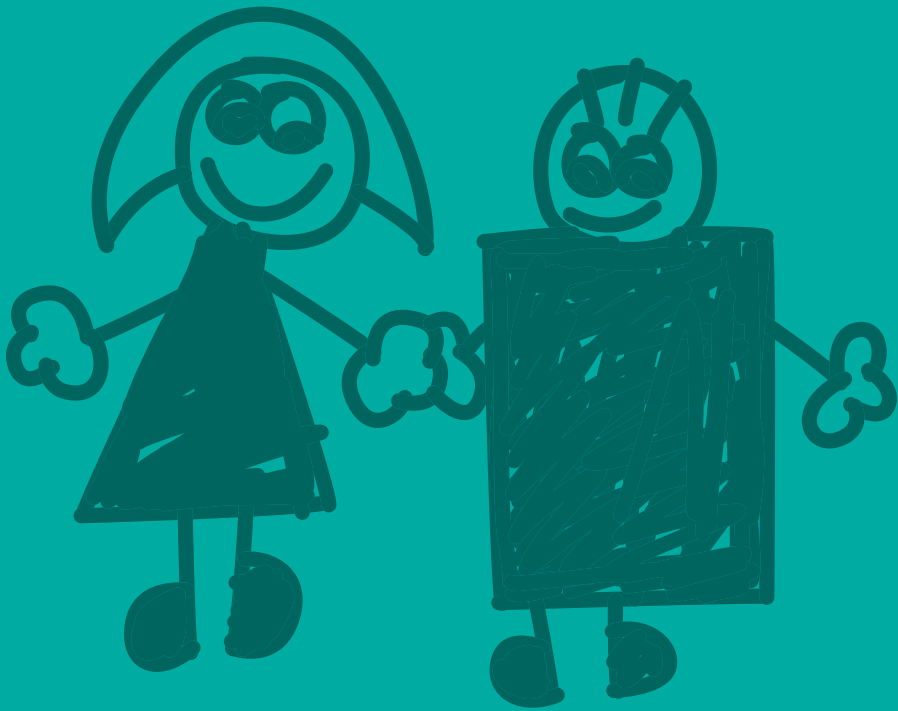
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