



ISBA 2016

The 10th international short break conference

13–15 September 2016
Edinburgh, Scotland

A conference report exploring the barriers experienced in accessing short breaks and how these have been overcome

www.isba.me



Foreword

Shared Care Scotland was delighted to have the opportunity of hosting the 10th International Short Break Association conference in Edinburgh in 2016. We were fortunate to have the support of many organisations in the planning of this event, including Iriss who worked closely with us on designing and carrying out this modest, but we hope useful piece of research. Thanks to Iriss we also have an audio record of our keynote contributions which are available to download on the Iriss FM website.

Before and during the conference, delegates, workshop contributors and keynote speakers were invited to share their knowledge on how people and organisations in their countries have overcome the barriers faced when trying to access short breaks. Having such a wide range of organisations and countries represented provided us with a unique opportunity to compare different experiences, and to highlight themes and good practice examples that can be further explored at future ISBA conferences.

Thank you to everyone who contributed.



Research partners

The International Short Break Association (ISBA) was established in 1995 and is a world-wide 'community' of short break service providers concerned with the effective delivery of short breaks (respite care) across all ages and care groups.

ISBA exists to create opportunities to share knowledge and experience across international and cultural boundaries. ISBA's purpose is to support developments in policy and practice which improve the experience of short breaks for families. Underpinning this is a shared belief that short breaks play a vital role in supporting the caring relationship and promoting the health and well-being of the carer, the supported person, and other family members affected by the caring situation.

The work of ISBA is channeled through its biennial conferences which have taken place around the world with each hosted by a different member organisation.

For further information see: www.isba.me

The Institute for Research and Innovation in Social Services (Iriss) is a third sector organisation promoting positive outcomes for the people who use Scotland's social services. Its focus is on supporting the social services workforce to achieve this by creating positive change through research, creativity and innovation.

Iriss acts as a hub for knowledge and innovation and provides a bridge between research and practice, ideas and implementation.

For further information see: www.iriss.org.uk



ISBA10 Conference, Edinburgh 2016

The 10th ISBA conference took place in September 2016 in Edinburgh with 300 delegates from 18 different countries attending. The title of this event was, 'Unlocking the Potential of Short Breaks'.

The conference aims were:

- * *To inspire* – by sharing experiences of short breaks and their impact from around the world
- * *To explore* – in particular the opportunities for developing flexible, personalised short breaks
- * *To challenge* – by reflecting on attitudes towards risk and how we balance this with delivering more choice and control
- * *To strengthen connections* – through learning together, and by developing our shared vision for short breaks

Through key note speakers, presentations, workshops and discussion the conference considered:

- * What does the evidence say about short breaks and how is this shaping development?
- * What is working and why? What are the factors helping and limiting progress?
- * What can we learn that can be applied in our own countries?



Analysis summary

This section presents an overview of what was discovered through 11 interviews conducted at the conference and 21 survey responses (8 of these respondents also took part in interviews). Interviews and the survey followed the same questions which aimed to capture barriers to short breaks and solutions found by individuals and organisations. Interviews explored people's experiences of barriers and solutions in greater depth.

Barriers

A range of barriers were identified and are grouped in this section in terms of personal and service related barriers. Barriers tended to be related and to cut across these categories. The barriers surfaced through the interviews and survey echo those highlighted in [Rest Assured?: a study of unpaid carers' experiences of short breaks](#) (Shared Care Scotland & Iriss, 2012) suggesting they are persistent. Barriers from this project which surfaced in Rest Assured? included:

- * lack of information
- * battling to be heard by statutory social services
- * lack of appropriate provision
- * guilt

Solutions

Solutions shared some key features including a person-centred focus which helped to ensure the design and provision of tailored, flexible and timely short breaks. Solutions also demonstrated the importance of thinking creatively about ways to provide short breaks that meet the needs of carers and cared for people. Some reported that 'taking a punt', or asking 'what if?' led to support that really made a difference to people's lives. Other solutions involved challenging attitudes and inspiring others by demonstrating what's possible with a more flexible, personalised approach to risk.

Personal barriers

Personal barriers related to how people felt about short breaks. Barriers of this type were common across the data and included guilt; worry; fear; difficulty asking for help; lack of trust and confidence to leave the caring role to others; difficulty with planning a break; and reluctance of the cared for person to have a short break. One survey respondent reported a 'lack of strength to fight' as a key barrier, which echoes the language in Rest Assured? where carers describe 'battling to be heard' by services. In places, personal barriers were in response to or exacerbated by service barriers – for example, a lack of personalised short break provision increased a carer's guilt that the cared for person might not enjoy their short break or where carers found accessing a break difficult, the more disempowered and hopeless they reported feeling. What came through strongly from some people's experiences was a deep distrust of services and negative experiences resulting in 'heartache and bitterness' (*Interview 7*).

Solutions to personal barriers

A number of solutions were highlighted as addressing and reducing personal barriers.

The Family Managed Allocation approach used by the Australian organisation [Interchange](#) seeks to readdress the power relationship between carers and the cared for and to 're-establish that feeling of equality' (*Interview 7*). The Interchange approach recognises that many people 'don't want the traditional paid model' (*Interview 7*) of care and prefer support provided by friends and family. The model means people can 'chose quarterly or monthly payments into their bank account to reimburse family and friends for providing respite support ... It can do things like purchase a meal out, some flowers and chocolates...' (*Interview 7*). The impact of this model is profound and taps into the way people naturally want to be supported. Importantly, this approach helped change the conversation to ensure the starting point was the individual needs of the carer and the cared for person rather than the parameters of the service:

“ So it took a long time and a lot of advocacy but they let us individualise his funds early... before he was only able to access either centre based respite or a paid worker doing something in the community or in home respite. Now basically – it was crazy – I was asked, 'What needs to happen for you to have a break and for him to get into the community?' That was the question that was asked instead. And so we had a conversation about that. (*Interview 7, young carer, Australia*) ”

The Family Managed Allocation model means that support is not 'formalised' into a transaction between a person and a service but enables people to use their natural support networks of friends and family or a volunteer if they wish:

“ My brother was quite happy with this arrangement because as far as he was concerned Alex, who is his support worker, wasn't Mr Disability. He was just an ordinary guy a few years older than him who was interested in doing anything you need and my brother was fine with that. (*Interview 7, young carer, Australia*) ”

Similarly, the Family Directed Respite Funding model used by Canadian organisation [Wesway](#), enables family caregivers to decide how they would like to receive their respite and Wesway pays for the approved costs. Families are able to use the funding in a variety of ways and settings including for respite provided by friends, family and / or community group.

Other solutions to personal barriers are founded on building relationships with families to allay fear, anxiety and guilt. When services worked together to reassure carers positive outcomes were realised:

The carer could not believe that she could leave her husband and have a break. She felt that everything would fall apart if she left him. Working with the local dementia advisor and carers centre, the carer was encouraged to gradually introduce day-care and respite services. When they were in place the lady could finally take the break to spend time with her daughter who had a terminal cancer diagnosis. They went away together and spent precious time, safe in the knowledge that dad was safe and services were there to support them. (*Survey respondent 4, Scotland*)

Tackling the barriers of guilt and worry were key concerns for [Aberlour Child Care Trust's Options Adventure](#) service. A pilot model, the service aimed to provide adventure short breaks for children and young people with disabilities including kayaking, canoeing, rock climbing, archery, and trekking. One worker in the service who was interviewed reflected on the impact of a young person's enthusiasm on parent's guilt:

“ ...when you have young people coming back from an adventure short break ... just bursting at the seams to tell their family what they've done, and being genuinely excited about that, going back to school and telling their peers what they've done, that goes a long way to mitigating against that [guilt]. *(Interview 1, Options Adventure worker, Scotland)* ”

Those running Options Adventure further reassure parents and families by involving them as much as possible in planning and consulting about the service. They provide information in user-friendly formats and ensure the structure of short breaks is easy to understand with clear contact details. Breaks are flexible and young people can come home anytime. Similarly, Action for Children's approach to short breaks ensures the child has a voice in the planning process and 'that when they have their time away that time is filled with things they wanted to do so they didn't perhaps feel it was some kind of punishment or separation, but that actually it was something that they were looking forward to and benefiting from.' *(Interview 2, Action for Children worker, UK-wide)*



Service barriers

Lack of availability / flexibility



There was only one provider that could provide that [respite] service... there was a lack of flexibility for carers and if that service provider was at capacity then there was nobody else to go to. *(Interview 4, Dundee Carers Centre worker, Scotland)*



I could not get the break at the time required as the service was being used by other families, or as I was told: 'because of the needs of the service' *(Survey respondent 5, Scotland)*



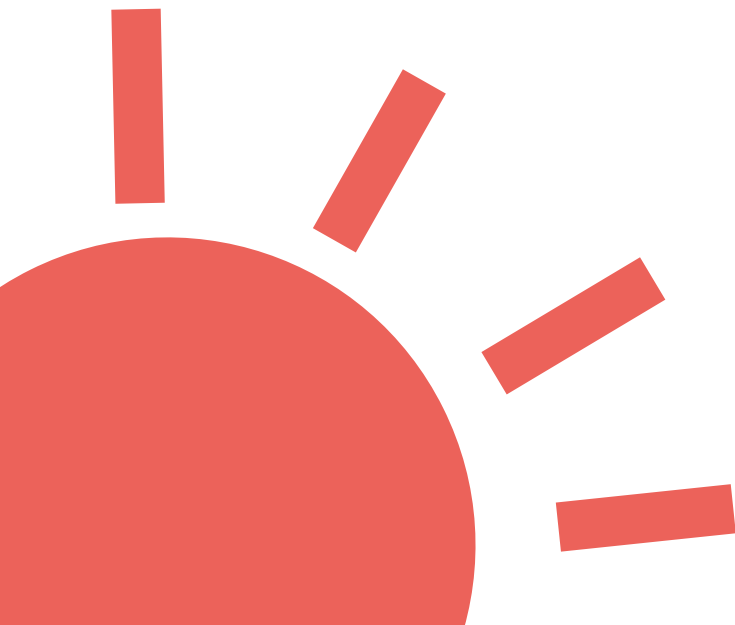
A lack of availability and flexibility are interlinked and both result in the carer / cared for person not being able to access the support they need when they need it. This can be particularly apparent in rural settings where transport is a compounding factor. One example explored through an interview tackled this barrier through some creative thinking and partnership working to enable a young person with autism living in a rural area to attend a befriending service:



We took a punt and thought that we would ask Education because this lad got Mobility Assist which allows him to go back from school. So we said could you change the rules and be adaptable and allow that person still have that journey, which you pay for, but have it a bit later? ... Pure luck, pure fluke as well... They agreed to it, which we couldn't believe, and it all worked beautifully. *(Interview 8, [Interest Link](#) worker, Scotland)*



By having the confidence to 'take a punt' and initiate a collaboration between different sources of support for this young person made a huge difference to his life. The impact on the young person of being able to access the befriending service was described as 'absolutely huge' and addressed the social isolation he had experienced as well as helping him develop independence skills.



Lack of personalised services

The lack of personalised short breaks described in the data often related to provision that separated couples and families which exacerbated personal barriers of guilt, fear and worry for carers:

“ They don't necessarily want their loved one to be placed somewhere, and that somewhere is generally either a hospital or a care home. Traditional respite as it's referred to, but it's not actually a break for anybody because the family worry about that person all week and they often come back worse than when they went because the people looking after them don't know them. *(Interview 11, Dementia Adventure worker, UK-wide)* ”

Other examples related to services failing to engage with the cared for person's interests:

“ ...she's very good at art, or was, loves animals and this is what I think is so dreadful. The services they fell down ... They went car washing one day a week. There were three times she rang to do volunteer work with an animal shelter and nobody replied. But why didn't the staff follow up? [...] One hospital said, 'Well she didn't engage in the activities that they are offering' ... And when I thought about it later I thought, No, that language is wrong. It's not that she didn't engage, you didn't engage her. You're the professional. How many times did you try? *(Interview 5, parent carer, Australia)* ”

Other service barriers noted in the data included a lack of continuity of staff (example from Australia); lack of connectedness between services (France); lack of funding and volunteers (Scotland); and a lack of understanding from policy makers about the importance of short breaks (Croatia).



Solutions to service barriers

Shared breaks

When carers and cared for people were enabled to enjoy short breaks together, this was highly valued and avoided the distress of families and spouses being separated. Shared short breaks also provided the opportunity for people to transcend the roles of carer and cared for:

“ ... we're doing something together where it's not just about a caring role or about having a disability. It's about maybe just doing something as mother and daughter. *(Interview 7, young carer, Australia)* ”

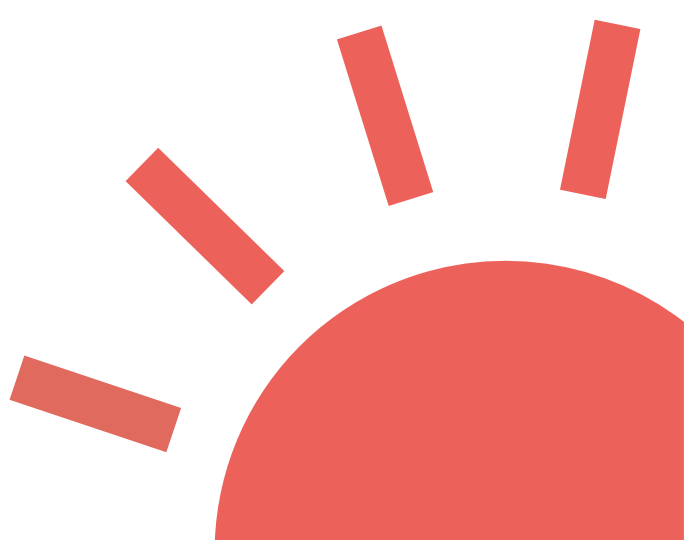
[Dementia Adventure](#) is a charity dedicated to supporting people to live well with dementia and have a sense of adventure in their lives. Their breaks involve the person with dementia taking a short break or holiday with their carer. Part of the service includes arranging all the logistics (travel, tickets, accommodation, itinerary) and each couple is supported by a trained Dementia Adventure team member throughout the break:

One of our clients was 50, living with dementia, with a 10 year old son and a husband trying to support them both. They were desperate for a family holiday but the dementia and a lack of funds made this seemingly impossible. Dementia Adventure Trust raised money to pay for this family to go on holiday and organised a bespoke trip to meet their needs. Our adventure leader picked them up and they spent five days enjoying activities together with hands on support each day. *(Survey respondent 13)*

[MindforYou](#) also provide supported holidays for people living with dementia and their relatives/ carers to enjoy together. Their service recognises the potential of a short break not just to be respite but to be about 'creating memories' (Interview 9). They also appreciate the importance of providing short breaks and holidays with others who have a shared experience of dementia:

“ Carers like being with like-minded people... they're not embarrassed about their loved one with Dementia that they keep repeating themselves or asking the same questions. Because everybody's the same. *(Interview 9, MindforYou worker, UK-wide)* ”

Both Dementia Adventure and MindforYou are examples of personalised, tailored services designed and delivered around the needs of carers and cared for people to enjoy short breaks together.



From further afield, the [Latika Roy Foundation](#) runs [Latika Vihar](#), an inclusive activity centre for children with disabilities where able bodied siblings, parents and grandparents are all planned for:

“ What we are finding is that a lot of parents, because they have ‘typical’ children, as well as children with disability, they are finding it harder and harder to come as often as they would like, because the typical children have to do their homework, and that’s a big, big deal in India – you don’t waste time playing – you get your kids out of school and they immediately go to another school basically, tuition centres, where they get coached in all the things that they didn’t understand in school. *(Interview 10, Latika Roy Foundation worker, India)* ”

Parents are offered the chance to participate in discussion groups, craft activities, dance, music and counselling sessions, while their children do everything from drama, storytelling, water play, cooking, pottery, bamboo crafts along with special guests from the community who volunteer their services. With thousands of families having benefited from its unique version of respite and recreation, Latika Vihar is a low-cost, community-based neighbourhood solution to every family’s need for a short break:

“ What if we offered coaching at the Centre and only children who played would be able to go to the Coaching Centre, because we know how important that is for them. So they have to have an hour of play before they get to do their homework, and the kids with disability who don’t have burden of homework would be able to just be involved in all of the activities anyway. So the parents would be able to justify it at home that the siblings can also come along and they get the benefit of people who speak good English and can help them with Math and help them with Science and whatever they are struggling with... So they still get to come for their short break, but we are solving their dilemma of providing homework support. *(Interview 10, Latika Roy Foundation worker, India)* ”

Dundee Carers Centre addressed both service and personal barriers when they approached other local providers to propose working in a new way. This was about working together to provide a more personalised respite service for carers and cared-for people:

“ One of the first things I did was to go round the other providers to see if they would be willing to take on the role of respite provider in addition to what they already did... So the challenge for me and the challenge for carers as well was to persuade these people that it wasn’t a threat to their block contact, this was actually an additional income source. *(Interview 4, Dundee Carers Centre worker, Scotland)* ”

This not only increased availability of short break options and partnership working but also mean that short breaks would be provided by specialist services. This more specialised support would help address personal barriers of worry and guilt:

“ ...the thinking behind that was if you have a carer who's looking after someone with a mental health issue, wouldn't it be better if you went to a mental health provider to provide that respite? Because the carers' now more comfortable knowing that they've got a specialist carer, that the carer gets a better break instead of spending it worrying, what's going on at home... whereas, the original provider was like a jack of all trades, well, he had to be by default. *(Interview 4, Dundee Carers Centre worker, Scotland)* ”


Re-thinking risk

A common barrier was the risk averse attitudes, fear and lack of confidence of some services which was seen to limit short break options and potentially infringe a person's 'human right to get outside':

“ The danger is, with this label of dementia is that, there is a tendency to do a safety-first approach in that, it's my job to keep this person safe. Ultimately what that means is that people are often in one room or in a property, or in a building too much of the time. Because the outdoor environment is perceived as a risky thing... the perception of something going wrong generates a lot of fear... *(Interview 11, Dementia Adventure worker, UK-wide)* ”

Solutions to averse and fearful attitudes to risk lie in a combination of challenging these beliefs and demonstrating the benefits to a 'more balanced approach to risk that looks at the risks really carefully ... so it needs to be personally assessed' *(Interview 11)*. Looking at risk differently means appreciating that 'some degree of risk is inevitable' and acknowledging the risks of the traditional 'safe' option:

“ There are going to be some risks that we need to take in doing anything. I mean, even just sitting at home in bed all day, the risks are pressure sores, depression ... social isolation, there's no risk free option [...] what we don't do is look at benefit... *(Interview 11, Dementia Adventure worker, UK-wide)* ”



Similarly, for a young person with disabilities, they might be excluded from a school trip which involves adventure of some sort. The Options Adventure service aims to showcase what's possible for a young person to do and to feedback to the school that 'this is very doable'. Getting a taste of the sort of activities on the adventure break can 'plant a seed' for something the young person can access locally:

“ We put a lot into the kind of ethos of it and the values of it and that seems to really support young people to then take that back and live that in some way in their own local area. *(Interview 1, Options Adventure worker, Scotland)* ”

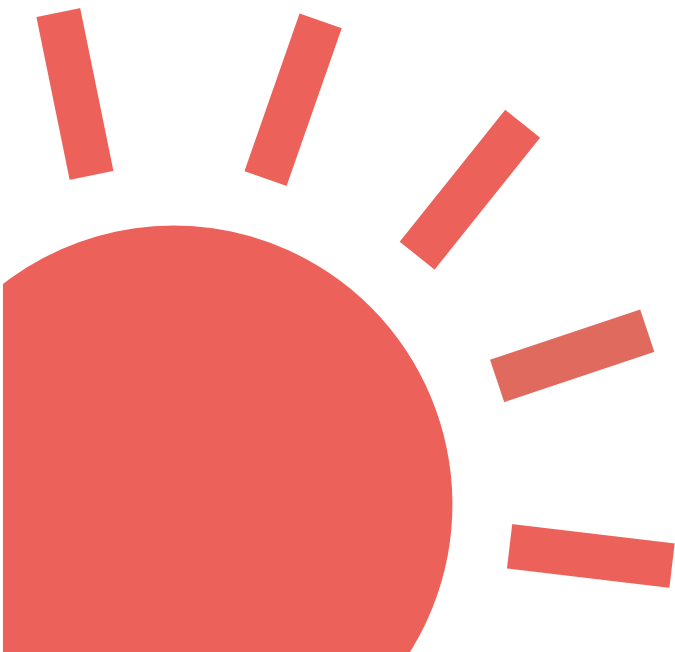
Dementia Adventure echoes this belief in demonstrating what's possible and offers support to care home to do day trips: 'We're giving people the information and the inspiration around what people can do differently.' *(Interview 11)*

A project undertaken by Grŵp Gwalia, a housing association whose services include supported housing for disabled and older people in Wales, also looked at risk differently. The project involved the collective exploration of evidence on mental wellbeing and relationship centered practice through dialogue techniques and storytelling. Part of the focus was on a positive approach to risk management. This work led to the replacement of a Professional Boundaries Policy with a "Sharing Lives and Professional Boundaries Policy which supports reciprocal and kind relationships." *(Survey respondent 3).*

Addressing lack of information

People reported a lack of information as a key barrier. Related to this were lack of awareness and understanding of what's available:

“ It's a labyrinth. It's an absolute maze to figure out who does what, you know there's lots of services there but to navigate the system and find something that's okay for you... *(Interview 5, parent carer, Australia)* ”



A compounding barrier was a lack of time to seek out relevant information:

“ I was unable to plan my break on my own, even though I have access to info. My paid carers have no time to spare to help me. I found a dedicated short breaks enabler who supported me to look at options, to design and plan, to support me to book a short break. *(Survey respondent 15)* ”

“ If I, as a professional experienced with dealing with health and social care have struggled, God knows how ordinary folk manage. In the absence of proactive assistance from primary care staff, social services, and rehabilitation services, one is left having to do all the legwork oneself. *(Survey respondent 2)* ”

However, even when services want to be ‘proactive’ in their outreach, they’re also affected by information barriers and difficulty accessing those they want to reach:

“ Accessing the families living with dementia is more complicated that you might think... There’s all sorts of gatekeepers... you have to try all sorts of routes to try and break that information barrier...breaking the information challenge is a real tough one but ultimately you have to use multiple routes to reach different people... We got a lot of success with reaching people on Facebook. Other times you need to physically go and meet people at cafés. *(Interview 11, Dementia Adventure worker, UK-wide)* ”

One solution surfaced in the interviews sought to address a number of information barriers. The [SARAH](#) Information System developed by the French organisations [GRATH](#), was originally designed to enable carers and professionals to find short breaks and respite across the country. SARAH is a free system and allows managers and parents to know in real time the availability of temporary accommodation places. They can search the schedules of other organisations offering respite and short breaks, with access at anytime and no need to wait for office hours or to spend time on the phone. Changes to the time or date of a short break can be simply and quickly changed on the system. Another consequence of the SARAH system is increased awareness between services who despite being in a local area were not aware of each other.

Another solution to an information barrier was described as a legal reform which prompted the publication of clear information of multiagency short break provision across local areas in England:

Across England policy changes had led to the requirement for all Local Authorities to publish a ‘short break statement’ from 2011. This explained what they were, who was eligible and how to access support. Subsequent legal reforms require all Local Authorities to publish what is known as a ‘Local Offer’ which details what support is available from health, education and social care which includes short breaks. This has to be published and accessible on and off line which helps overcome the information barrier experienced. *(Survey respondent 8)*

Focus on outcomes

A common aspect of the solutions highlighted in the data was an outcome-focused approach and when 'professionals are skilled in using person-centred planning tools' (Interview 2). The 'outcomes conversation' gets to the heart of what a person needs and the impact this will have on their life. When short breaks are designed and planned with the outcomes of the supported person at the centre this can reduce personal and service barriers:

“

Now we have planned in a more outcome based focus, things are much better.
(Survey respondent 5)

”

“

I was able to get the Social Worker who was working with this service user to do a new assessment... I got the service user to invite me to the assessment. So when the carer manager was asking the questions, you know, 'What is it you need? How will it change how you're feeling? I'd already had that conversation.'
(Interview 3, *Grampian Opportunities* worker, Scotland)

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Conclusion

This section outlined a range of barriers to short breaks experienced by a small sample of people from across the world. It demonstrates that broadly the barriers are the same across different countries. However, the solutions are also transferable and could be adopted in a range of contexts. The inspirational examples highlighted here show that it is possible to address persistent barriers. These approaches could be used to spark ideas, generate discussion and to promote creative solutions to barriers to ensure positive outcomes for carers and cared-for people.



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