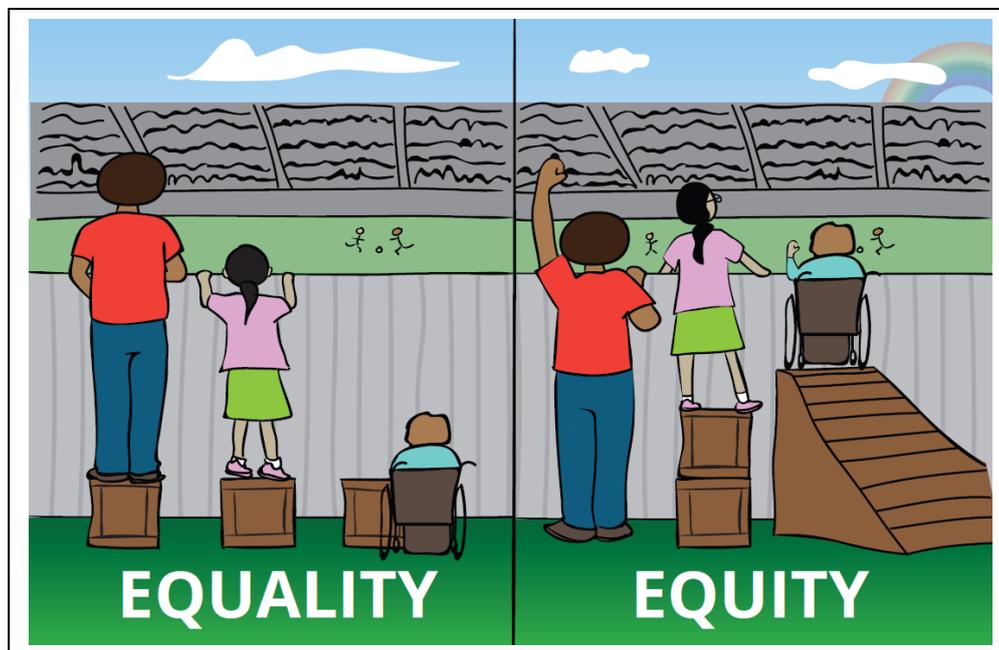


“Going into Lockdown”

A report on the impacts of reducing playscheme provision on the children attending St Crispin’s Special School and their families



Sarah Kyambi, St Crispin’s Parents and Carers Council
December 2017

The City of Edinburgh Council has decided to reduce the maximum allocation of its Holiday Activity Programme (hereafter termed 'playscheme') for disabled children from 6 weeks to 4 weeks per year, starting in January 2018. This report is based on 8 case studies gathered within St Crispins Special School on the impacts of this change. It is written on the back of the widespread concern within our school that the reduction in playscheme threatens the very survival of our families. These families are already struggling to cope; losing 2 weeks of playscheme will push many over the edge. One case study describes the periods without school or playscheme as 'lockdown'. Many of us recognise the sense of being under siege by the needs of your child during those times and feel we are already in lockdown for far more of the year than we should be.

The case studies have been anonymised and do not use the children's real names. They can be read in full in the appendix. They show the extremely difficult situations the families in our school face when trying to care for children they love and want to look after. Many report feelings of desperation and great upset as families already struggle to do more than they feel able to. The prospect of losing further support in a situation when we already feel under-supported has families feeling panicked about the future viability of looking after their children. It also fills parents and carers with sorrow that the lives of our children, who already can access so little in terms of entertainment and enjoyment, would be furthered narrowed. Many of our children are marooned at home, with nowhere to go and no one to see. The reduction in playscheme will limit their lives even further.

Our school and the children who go there

St Crispins is a special school with capacity for about 50 pupils. It is a school for children with severe learning disabilities who need a significantly modified learning environment. Children are placed in the school following an assessment by an educational psychologist. The children are ambulant and do not require hoisting. However, their learning disabilities are severe and, if they were cognitively more able, they would be placed in schools for children with moderate or mild learning disabilities. The extent of their learning disabilities means our children are very limited in their understanding of the world and of themselves. They need help with all aspects of self-care and have very limited understanding of the purpose of self-care. They need help staying safe and don't understand the dangers posed by their physical environment and how to navigate it. They need support with their behaviour and often cannot understand why they need to behave in certain ways. They have extremely limited communication - this means they often cannot tell people what they need and they can become very frustrated when their needs are not met. They often struggle with sensory processing and are unable to cope in environments that are too loud or

Challenging behaviour:

John requires a very high level of supervision to keep him safe because of his PICA he drinks and eats lots of non-edible substances some of which can be toxic. His behaviour has become more challenging since becoming a teenager. He is prone to self-harm particularly when stressed or unhappy.

Julia ... smears faeces when she gets a chance

David shows some very challenging behaviour, ranging from tantrums (where he will scream, jump up and down and bang his hands on tables or walls), to pinching and scratching himself and anyone within reach. He will also head butt people when frustrated or angry, as well as walls, doors and door frames

Gregor stripped in the street while it was snowing. The worker could not manage the situation, a passer-by intervened and provided support, and they walked Gregor home, half-naked through the snow. He was home and sick with fever for four days.

Jemima is non-verbal with a loud range of vocalisations. Her sleeping pattern is erratic and her behaviours challenging. Caring for Jemima is a full-time commitment. It would not be possible to hold down a job and care for her. The sleep deprivation alone is a huge factor

too hot for example. Given their disabilities, and their very limited capacity to understand what is going on, seriously challenging behaviour is common. Children at our school frequently hurt themselves and others, they head bang, bite, scratch and lash out to try to make themselves understood, or, to try and cope with sensory inputs they find intolerable. Many engage in repetitive behaviours. The staffing ratio at St Crispins is one of the highest in the city – this reflects the extent of the difficulty of managing the children who attend our school.

Our families

The families of children attending our school work hard to meet their children’s needs. They have to provide a lot of care in the home. They will have needed to make big adjustments to their lives and homes to accommodate the needs of their severely disabled children. They will have lost out on employment and career progression opportunities, their relationships will have been put under strain, they will have had to adapt their homes to make them a safer environment for a child with extremely little understanding. They live with rigid routines and have to constrain their activities because their severely disabled child is unable to cope in certain environments or requires certain routines to remain calm.

They will need to take time to attend health and social care appointments. When their child is ill they often need to get help to access healthcare that is properly adapted to accommodate their child’s disability. For instance, our children can’t self-report symptoms like dizziness, pain or nausea. Our children also cannot co-operate with routine medical examinations like monitoring blood pressure, blood tests or having their temperature taken. Children at St Crispins will have a higher incidence of conditions that require monitoring and management: sleep disturbances, digestive difficulties, epilepsy, ADD and ADHD. Diagnosis and treatment is far more difficult to manage.

Families caring for children attending our school struggle with the physical and emotional impacts of having to provide a great deal of care almost all the time. Many struggle with physical and mental health problems as a result. Many note the adverse impact on their relationships. Any siblings have to cope with putting their own needs second in ways that are hard enough for adults, let alone children. Several of the case studies note the feelings of despair within families as they struggle to continue caring for children they love dearly, but for whom they have had

High Care Needs:

Harry is hard work. He is relentless and it’s severely affecting my own mental health, my husband’s mental health and also our marriage. We are constantly tired, irritable and not our best as parents. The thought that you will look after your child until the day you die is one of the most difficult things I face each day

We are a resilient family but I cry a lot, especially when Gregor is home for long stretches of time because he has nowhere else to go. My husband and I have a gulf in our relationship where Gregor resides which is to say that we do not have much time for each other. Gregor takes up so much emotional space and his physical needs are such that when he has nowhere to go, we really do all suffer.

Losing my job and the prospect of satisfying work of any sort will be profoundly depressing. Having to give up my career has been really difficult for me and I would worry about the impact on my mental health of losing more of my professional identity. – Polly’s mum

It is very difficult for the other children; my oldest son went off the rails age 15 as he couldn’t cope with all the chaos that Victor brings in the house. He loves his brother but hated all the screaming and spitting out of food. He wouldn’t bring his friends home and just stayed out all the time and he dropped out of school. He got into trouble with the police and was eventually referred to Camhs

to sacrifice and compromise core needs such as sleep, health, relationships, friends, the needs of siblings and work.

Difficulties in using childcare

As our children grow, the distance between them and their peers widens and there are fewer and fewer mainstream goods and services available that we can use. As such, we increasingly have to turn to specialist provision which is less common and far more expensive. This includes childcare. Families with severely disabled children provide a lot of care. They need to dress and undress their children, brush their hair and teeth, wash them, cut their nails, change nappies and pads or bring a child to the toilet and help them to use it. Severely disabled children also need help to feed themselves. With many of these tasks our severely disabled children are unable to understand the purpose and may refuse to co-operate, making it more and more difficult to care for them adequately as they get bigger and stronger. So, families need help looking after their children.

In the beginning, help can be a bit easier to get. While children are small, it's possible to use mainstream childcare. However even when our children are very young their limited understanding and problems with sensory issues means they need one-to-one care. This means that cheaper childcare options like childminders are not suitable and families need to hire more expensive 1:1 care or even specialist care with 2 or more adults for 1 child. Playdates and informal childcare swaps are close to impossible as our children lack the ability to play with their peers and it's difficult to swap childcare when your child needs far more care than neurotypical peers.

Using family to help care for your child is also difficult. Some parents find that as their children get bigger, relatives are less able, or simply less willing, to take up the more difficult aspects of caring for them – especially those parts that are physically strenuous or those that are unpleasant. Even where relatives are willing and able they frequently need a lot of help understanding our children and how to look after them as our children have such limited communication. So, parents have to work hard to make use of care available within their own family. They effectively need to train their relatives to provide care appropriately.

Childcare:

We've placed ads and searched for childcare but Gregor's needs are such that we get no response or people have come briefly but not returned.

[Julia has] a PA who comes for approximately 30 hours a month...Unfortunately, as she works at school, she usually goes away in school holidays, and if not away works, at playscheme (as do most of the PAs), so we have little to no childcare in holidays.

While we currently have access to some childcare, it's very expensive as we have to pay for someone to be 1 to 1 with Polly. ... Paying for 1 to 1 nannies helps give us a break, but it does not provide Polly with time to play with other children.

Victor has complex needs and requires experienced support and safety provided in a group setting. Even if he were to have 1 to 1 personal assistant it would not provide the same level of safety for both carer and Victor. Victor is unpredictable and due to epilepsy 1 to 1 trips out of the home could prove impossible. Playscheme allows Victor to access activities that are not met by any other service.

It gets increasingly difficult to find appropriate childcare as children get older. The difficulties in managing children like ours are magnified as they get older. Challenging behaviour and the need for help with toileting means parents need to pay increasing premiums to attract carers and often require

2 to 1 or higher ratios of care to keep children safe. Finding, buying and using care gets more and more difficult, even as families need more and more care.

Lack of leisure and recreation for our children

Alongside the difficulties in finding and paying for care, there is the issue of what carers (and families) can do with children as disabled as ours. Finding fun activities that are accessible to a child with a severe learning disability is difficult. It's also difficult to get them to and from the activity. Often children sit down when walking, or bolt suddenly, or they have difficulty using buses. Difficult situations may require more than one adult to ensure a child is safe. Parents find it difficult to find carers who understand how to manage their child. This includes understanding how to use your child's communication systems and tools or routines for managing behaviour, such as visual time tables or needing certain types of sensory toys or input. It also includes knowing how to react to challenging behaviour, making proper risk assessments and decisions. Therefore, arranging appropriate, safe, care for our children is incredibly difficult and exposes both the child, and any carer, to risk.

In addition, there are few places for our children to go; popular venues and activities are often too busy for our children to use. Older children may need access to an adult size changing table - the floors of disabled changing rooms are generally filthy. Our children may need to eat lunch somewhere reasonably quiet or find it impossible to play in areas where food is within reach – all of this restricts where parents or other carers can take children. Using hired childcare may give parents a break but it leaves little scope for our children to spend time with others. Being in a special school means parents often don't know local peers and our children's lack of play and social skills means they have limited opportunities to spend time with friends outside school, even if they enjoy being around other children.

Access to leisure and recreational facilities in the city of Edinburgh for children from our school is extremely limited. The pools are too noisy and cold. Their disabled changing facilities are difficult to use for children who wear pads and can soil themselves. The safe play facilities are too busy and noisy to use without incidents to children with sensory processing difficulties. The special needs drop-in sessions for children with disabilities run on weekends have proved unusable due to levels of noise and the types of play activities offered. Similarly, the activity programmes offered by Edinburgh Leisure for children with special needs are inaccessible because they are pitched at a level too advanced for more severely disabled children like ours or only available at times when our children are preparing for bed. Special facilities for disabled children like The Yard have opened

Recreation opportunities:

We have tried to access some drop-in events but these are not suitable for children as impaired as [Harry]. We have had to leave these drop ins as they were unsafe. There was either no secure doors, food out on display (my son has Pica and will eat anything), no appropriate toys (my son cannot play with age appropriate toys, he needs baby/toddler toys). Not enough support workers (I could not even get time to go to the toilet myself), no appropriate changing facilities for my son (he requires a change no bench suitable for an adult, not a baby changing table).

[Polly] cannot make use of any of the special needs clubs and activities provided by Edinburgh Leisure or other providers as she would need to be accompanied by 1 to 1 support and the activities are pitched at a level too advanced for her.

[Playscheme] is [John's] only opportunity to access suitable play activities that other children take for granted and his two siblings rely on this time to be able to access some of the things they enjoy e.g. having friends over, going out to eat, cinema and bowling, all of which their brother finds too difficult to cope with.

their doors to all children on Sundays making it unusable for almost all our families for half of the weekend.

Playscheme reduction

For the last three years INC Consortium provided a holiday activity programme across four venues. It allowed disabled children to apply for up to 6 weeks of Playscheme per year. Allocation was on a first come, first served basis. As of next year, this maximum allocation is reduced to a maximum of 4 weeks a year. The families in our school are reliant on a 6 week a year provision of playscheme to survive as the case studies in this report show. Several families report accessing 6 weeks every year and acting to ensure they could secure the 6-week provision each year because it was vitally important to them. This indicates the great need for the playscheme service in for families of children attending our school. We would very much like for all disabled children in Edinburgh to be able to access 6 weeks playscheme if they wish to do so. However, if that is not possible due to funding constraints we argue that at least a proportion of places need to be protected for those children with the highest needs. This is because those children have the greatest difficulty accessing other opportunities for play activities, and because their families are having to provide the greatest amount of care. We would expect the vast majority of children in our school to be amongst those disabled children with the highest needs.

The need to reduce the maximum allocation of playscheme is due to increased uptake. Current uptake data shows that in recent years children in mainstream schools are taking up approximately a third of places, children in the 3 schools with the most severely disabled children (St Crispins, Braidburn and Oaklands) take up another third, and the children from the other special schools take up the final third. The difficulty in providing 6 weeks for those with the highest needs arises from the council's conviction that places on the playscheme for disabled children need to be offered to all children with disabilities, regardless of the level of impairment. They have argued that all families face difficulties but simply in different ways. This is simply not the case, distinguishing the level of severity of a disability and its impacts is a clearly established practice. The welfare system distinguishes between levels of impairment when determining the level of benefit, with disability living allowance provided at three different rates: high, medium and low. The children in our school will be receiving high rates of disability living allowance in both the care and the mobility components. Similarly, the education provision across the city distinguishes between the different levels of care required by children within the different special schools through the different staffing levels across the special schools. St Crispins, alongside Braidburn and Oaklands schools, has the highest levels of staffing per pupil in recognition of the greater difficulty of providing proper care for the children attending these schools.

Families in our school have sacrificed a great deal in order to provide for the needs of their children. Many have seen a reduction in their capacity to work, if they remain in employment at all. Many struggle with exhaustion and poor mental and physical health due to the demands of caring and dealing with children with seriously disrupted sleep patterns. The current school year provides 39 weeks of schooling, along with the previous 6-week maximum provision of playscheme, that left 7 weeks in which parents in our school struggle to look after their children at home. Many find that just a few days without structured activities gives rise to escalations in challenging behaviour and all are struggling with the almost complete lack of appropriate activities and venues for keeping our children occupied. Extending the period without school or playscheme by 2 weeks will push many over the edge of what they can manage. The case studies provide testimony of the impact of this additional burden and provide extremely worrying insights as to the impact of a reduction in playscheme

provision. Safeguarding a proportion places for the children with the highest level of needs, to ensure them a 6-week provision, is necessary to prevent consequences that are highly distressing.

Council officers have argued that playscheme provision is not a statutory service and therefore should not be assessed by level of need. However, if sufficient support cannot be provided for the families who currently require playscheme in order to survive, then a universal service is not the right approach for determining playscheme provision. Our children have rights to access the community and to leisure and recreation. Currently, there are close to no facilities we are able to use. Without playscheme our children face being marooned at home and isolated in ways that leave them frustrated and bored and lead to an increase in behaviours that anyone would describe as extremely distressing with many driven to hurting both themselves and others. Other children with less severe disabilities have more options to access play opportunities and do not need playscheme the way our children do. Furthermore, families of children at our schools do not have access to the amount of respite that would allow them to cope with the reduction in playscheme. Indeed, current respite packages are based on a presumption of the ability to access a full 6 weeks of playscheme. Without the option of 6 weeks of playscheme those respite packages would need to be reassessed and additional respite would need to be awarded. How any additional respite provision could then be made practically available is difficult to see. There are insufficient respite services to meet even current levels of need and those with self-directed support find it almost impossible to find suitable services to purchase with these funds. We would question whether current levels of respite provide the families of children attending our schools with the support they need given the situations described in the case studies in this report.

Impacts of playscheme reduction:

To put it simply, when Gregor is home for days and days on end, he begins to abuse me out of sheer frustration.

[Playscheme] has been invaluable in allowing me to work and allowing the other children enjoy a small part of their holidays too. It is hard being a sibling of a disabled child and they have made far too many sacrifices as it is. My family could barely cope with 6 weeks let alone 4. – Victor's mum

To avoid family/foster care breakdown Jemima requires a minimum of 6 weeks playscheme.

Julia is so happy at playscheme that she has cried when she has heard us discussing it not being on as much ... She enjoys seeing other children and her friends from school and especially thrives on the continuation of routine from school and going somewhere every day. She would be bored, lonely and stressed without this routine and miss it very much indeed.

To lose 33% of our playscheme allocation would have a dramatic impact on our family. We barely cope as it is, at times. ... we would struggle as a family. ... Tamara [less severely learning-disabled sibling] may be able to cope with the loss of 2 weeks playscheme, as she is not as severely affected as David, but David absolutely would not!

I don't see any light at the end of this tunnel and when things like playscheme get cut it's like a blow that hurts so much you feel an actual pain, worrying about when the point where you snap will come. – Harry's mum

Appendix: Eight Case Studies on Playscheme from St Crispin's Special School, Edinburgh

Case Study 1: Gregor

1. Family Details

Gregor¹ is 16 years, a male and attends St Crispin's Special School. Disability: autism, epilepsy. At home: Gregor lives with me, his mother and his step-father. He is an only child. His dad works full-time. I am educated and employable but for several years I've been either under-employed or unemployed so I can care for Gregor. Extended family are all abroad.

2. Description of Child at St Crispin's

Gregor was recently assessed by CAMHS as cognitively functioning at about the age of an eighteen-month-old. His highest rated areas placed him at three years. He receives disability payments at the highest rates due to his inability to care for himself. He is nonverbal, unaware of any dangers, unable to care for his own most basic needs such as washing himself or knowing when to eat or drink, and he requires supervision in most tasks including how to spend his leisure time.

We bathe Gregor every morning. We brush his teeth and clip his fingernails and toenails. We cut his hair at home. We prepare all his meals and sit with him to make sure he eats. We prompt him to drink so he doesn't dehydrate. We tell him every hour to urinate in the toilet or else he wets himself. We sit him down on the toilet after his evening meal for him to have a bowel movement or else he soils himself. We choose his clothes and help him dress. He wakes many mornings and repeatedly hits us because he doesn't want to get up and brush his teeth. He screams and hits us during meals because he becomes annoyed. When school transport is late, he hits and kicks us because he is annoyed at having to wait.

Gregor requires three adults to accompany him when in the community because of his capacity for aggression. When confused, anxious, or overwhelmed, he strips off his clothes, bites, hits, kicks, pulls hair, screams, and/or runs away. Since stimuli in the community cannot be controlled, Gregor cannot be screened from the things that might trigger his behaviours and so it follows that since there are only one to two adults (his parents) with him, the three of us have become quite isolated. He goes to school; he comes home.

3. Available Childcare

We have no childcare, per se. We used to have someone from Epilepsy Scotland come to take Gregor out for several hours once a week but that was ceased long ago because Gregor was getting bigger and his behaviours were harder to control/deal with. He was placed in danger on one occasion in particular when he stripped in the street while it was snowing. The worker could not manage the situation, a passerby intervened and provided support, and they walked Gregor home, half-naked through the snow. He was home and sick with fever for four days. Epilepsy Scotland changed the staff and increased the ratio to 2:1. Still, they could not manage Gregor's behaviours – hitting and running away and so on. The agency then changed the service to in-home care only. Gregor no longer left the home and Roger and I would have to leave the home if we wanted respite. Even with this arrangement, one of the agency workers would not come back to the home after Gregor broke his bed in half during her three-hour shift.

¹ Not child's real name

We've placed ads and searched for childcare but Gregor's needs are such that we get no response or people have come briefly but not returned. We can't take Gregor anywhere, really. Not reliably and often not safely. He does have interests: movies, swimming, bowling, riding on trains and buses and in cars and on planes. But he can't enjoy them because he can't get to them. He doesn't understand that these things have to stop at some point. He doesn't understand waiting. Earlier this year, we took him on a trip. Because of his violent outbursts on the streets and in restaurants, we hid most of the time in the hotel room. On the plane ride home, the crew expressed concerns that he might not be able to fly. The reason they worried was because we taxied for so long that Gregor became enraged and attacked me. He unrestrainedly hit and bit me and pulled my hair, screaming the whole time. It was a prolonged attack that he repeated once more. I share this to illuminate the difficulties we have in helping him to access what he enjoys. When CAMHS worked for several months with us, they too experienced these violent behaviours. Week after week they attempted to help me get Gregor to walk downstairs to the market for a banana. But they, professionals, were out of their depth and eventually the service stopped, having improved none of Gregor's capacity for accessing the community.

Section 4 Playscheme usage

We use playscheme. Gregor has received six weeks for the past several years. There are often issues with transport but otherwise it has consistently been wonderful for Gregor. He has a wonderful time because he gets to play in a safe environment and experience something other than school and home, which is rare for him. He doesn't have friends. He doesn't have anyone but me and his dad and his teachers. His life is extraordinarily narrow despite his active nature and lively disposition. To put it simply, when Gregor is home for days and days on end, he begins to abuse me out of sheer frustration. Any other kid would have pals they'd go see or simply possess the ability to go out on their own for a walk even. But not Gregor. And since my husband has to work – someone needs to – Gregor and I am stuck home alone together for many hours. Gregor's needs are such that I cannot, every day, be his personal caregiver *and* his playmate; I cannot take him out anywhere on my own. He has needed playscheme and benefitted from it greatly.

5. Impact of reduction in number of playscheme weeks to 4.

We have no alternatives to playscheme. Without it, Gregor will be home and further isolated. I don't work outside of the home because of Gregor's needs. What little I do outside the home ceases altogether when Gregor doesn't have school or playscheme. We call it 'lockdown'. So we see having fewer weeks available as an increase to 'lockdown' in our home. As I've indicated above, Gregor's behaviours increase during these times and, frankly, my mental health sometimes suffers as well.

We are a resilient family but I cry a lot, especially when Gregor is home for long stretches of time because he has nowhere else to go. My husband and I have a gulf in our relationship where Gregor resides which is to say that we do not have much time for each other. Gregor takes up so much emotional space and his physical needs are such that when he has nowhere to go, we really do all suffer. And the support of our partner, which we need most, we sacrifice because we cannot leave our flat together. One of us stays with Gregor while the other steps outside. While we feel alone and isolated, Gregor too must feel alone and isolated; my heart breaks for him even when he's hitting and kicking and so, exhausted and sad for him, I feel that much more alone and isolated, and so on and so on. We become hopeless. I think Gregor becomes hopeless. He has crying spells at night. That is the impact, that is life with no place for our son to go.

This case study was written by Gregor's mum.

Case Study 2: Jemima

1. Family Details

Jemima² will be 13 years old in early 2018. She has Autism with Global Development Delay and has significant Secure Attachment issues. I am a single carer with 3 grown up adult children, two who live in England. My grown-up children visit Jemima and I when they can. Caring for Jemima is a full-time commitment. It would not be possible to hold down a job and care for her. The sleep deprivation alone is a huge factor.

2. Description of Child at St Crispin's Special School

Jemima is non-verbal with a loud range of vocalisations. Her sleeping pattern is erratic and her behaviours challenging. She has some understanding of verbal communication particularly with people she knows and within environmental settings familiar to her where she recognises routines and where she feels understood and able to make requests. She responds to simple everyday verbal phrases used with picture symbols and pointing. Caring for Jemima is demanding, particularly when she hasn't slept: when Jemima hasn't slept, neither have I.

3. Available Childcare

I am a foster carer and I receive some respite. Since Jemima was a small child her complex needs were such that a multidisciplinary team decided she required a 50/50 care package, one week with one carer(s) and the following week with a different carer(s) however for over a year Local Authority have not been able to provide this level of care placing considerable pressures on my family, friends and I.

4. Playscheme usage

Since 2012 when I became Jemima's foster carer we have applied for 6 weeks of playscheme. Most years Jemima has received 4-6 weeks. We have had occasions when Jemima's playscheme place has been withdrawn at short notice to free up a place for another child. In summer 2016 she did not receive any summer playscheme and this seriously threatened the stability of her placement.

During school holidays, particularly the long summer holidays, without day care provision to make it possible to have a break from the loud vocalisations and lack of sleep it becomes exhausting. As a foster carer, alternatives to playscheme do not exist. Family and friends are able to offer childcare to let me get out of an evening, but would not have the capacity to look after her during the day due to the complexities of Jemima's behaviours.

5. Impact of reduction in number of playscheme weeks to 4.

Playscheme is essential to the wellbeing and stability of Jemima and her foster care family. She needs the structure and outlet it provides, without this her sleeping patterns become even more erratic. Trying to provide 24-hour care and appropriate mental, emotional and physical stimulation for Jemima without sleep is an impossible task. Having transport to the playscheme is equally important as driving without sleep is a risk factor. To avoid family/foster care breakdown Jemima requires a minimum of 6 weeks playscheme.

6. Other

Children like Jemima with complex needs requiring constant supervision unable to occupy them selves without supervision and who have limited social opportunities and limited alternative social environments to go to, require opportunities to develop and grow out-with their home/ family environments. **We rely on playscheme as there are limited alternatives. Playscheme is a life saver**

² Not child's real name.

and can avoid children being placed permanently in a residential unit and the costs that goes with that type of provision.

When children are young it may be possible to use mainstream facilities such as soft play and trampoline centres, as it's possible to scoop small children up and redirect negative behaviours, however, as teenagers this is not the case. Undoubtedly it requires a lot of resource in terms of energy and skill to enable children who are significantly disadvantaged by their complex needs to access essential opportunities to access activities and social interaction

During school holidays it's an impossible challenge to do this 24 hours, day after day. As parents and carers we become burnt out in our attempt to do the impossible. In term time we somehow rise to the challenge, however, during school holidays our ability to cope is diminishes as 24 hour care depletes our capacity. Under this pressure parents and carers can struggle to provide their children and young people with the activities **essential** to the social learning much needed for their child's overall mental and emotional stability & development. Parents/ carers and their families health and wellbeing is significantly affected by limited resources to support them in providing this **essential** social integration and equal opportunities. Playscheme provides our children who are significantly disadvantaged by their complex needs to access essential opportunities to access activities and social interaction with their peers. This vital resource provides our vulnerable children with the structure they require in order to cope with school holidays and avoid family crises.

This case study was written by Jemima's foster carer.

Case Study 3: John

1: Family Details

John³ is 13 years old and attends St Crispin's Special School. He lives with his family; Mum, Dad, older brother (aged 14), younger sister (aged 9) and dog, Teddy. His older brother also has an additional need (language processing disorder).

2: Description of Child at St Crispin's Special School

John has a diagnosis of Autism, ADHD with PICA tendencies. He is a lovely friendly boy but has very complex needs. His communication difficulties, no speech and severe learning disability often make the world a scary place. John functions much better with routine and structure. John also requires a very high level of supervision to keep him safe because of his PICA he drinks and eats lots of non-edible substances some of which can be toxic. His behaviour has become more challenging since becoming a teenager. He is prone to self-harm particularly when stressed or unhappy.

3: Available Childcare

John's Dad is often away with work and I am the main carer for the whole family. I also work part time as a merchandiser in retail. This not only provides a valuable income for our family of 5 but also helps me to cope with the stress of caring for a severely disabled child and two other children on my own.

4: Playscheme usage

The playscheme is a fundamental necessity for our family during the holidays for many reasons. It is not possible to find any other safe, suitable and appropriate childcare for John during the holiday because of the high level of supervision 2 to 1 care he requires. My family live in London and both sets of parents are in their 70's and not physically able to keep up with John. He needs to be cared for in a group setting. It is not feasible for one carer to entertain and keep him safe in a home setting for any length of time. John also thrives on the routine of the playscheme as the activities are well suited to his needs and the staff are well aware of John's challenging behaviour and support each other as well as him. He loves to be active and because of his ADHD this physical activity helps with his wellbeing. He also really enjoys being around other children even though he doesn't interact with them.

John has attended the Lothian Autistic Society playscheme every holiday when eligible since he was in P1. We have always applied for the maximum allocation as soon as forms came out and have been successful. It is testament to his needs and enjoyment of attending such a playscheme whilst school is not running that he comes home although unable to express through words how his day has been, but a huge smile on his face.

5: Impact of reduction in number of playscheme weeks to 4

I will not be able to cope on my own in the summer holiday without our 4 week allocation. For the reasons above, (i.e. no other suitable childcare options) John's behaviour and health will significantly

³ Not child's real name.

deteriorate without the daily playscheme structure. I am concerned that his levels of self-harm will increase if he had much more time on his hands and stuck in the house. It is his only opportunity to access suitable play activities that other children take for granted and his two siblings rely on this time to be able to access some of the things they enjoy e.g. having friends over, going out to eat, cinema and bowling, all of which their brother finds too difficult to cope with. This has been exacerbated during the teenage years when his behaviour has meant that it is at present too much of a challenge for us to go on a family holiday as we have done in the past.

Lastly, I am not able to take 4 weeks off work. Whilst my employer understands my situation, a retail position will not allow me to take this significantly extra amount of time off during a busy period.

6: Other

I have already written a very detailed letter about our circumstances to Kerry Miller expressing my grave concern that such a reduction in playscheme allocation for such a disabled child would have a very detrimental effect to not only his mental and physical health but mine too.

This case study was written by John's mum.

Case Study 4: Victor

1. Family Details

There are 6 of us: dad, myself and three siblings aged 18, 14 and 4 years. Victor⁴ has a severe learning disability, severe autism and Epilepsy. His 18 year old brother has recently been diagnosed with High Functioning Autism. I generally work 5 days per week but am only contracted to work for 3 days per week to meet demands of care needs. Grandparents live in the area but due to age and health problems are no longer able to provide a regular level of support.

2. Description of Child at St Crispins

Victor suffered severe oxygen deprivation at birth and we always knew that he would have difficulties. He has a severe learning difficulty, severe autism and has recently started having seizures and so has now been diagnosed with Epilepsy. He is nonverbal. He has no sense of danger and needs constant 1 to 1 supervision in all areas of care. He would happily stick his hand in boiling water, eat anything, run over the road or throw things around the house. His behaviour can be challenging, he can hit and lash out when he is upset or confused.

He does not play with toys, he does not join in games and needs 1 to 1 help to participate in any activities. He needs 1 to 1 support in all levels of personal care. When he is out in public he will scream, bite himself, throw things around, lie down on the ground and can be very disruptive.

3. Available Childcare

Victor needs 1 to 1 care and is not able to access any other type of holiday cover. Previously I have used Grandparents to help but as they are getting older, Victor is getting bigger and they can no longer cope with his behaviour. Their health is poor and I have no idea how I will manage from now on.

Victor now has epilepsy and I am told this makes it even more difficult to access playscheme as they require more cover to help deal with these children. I can't afford 1 to 1 support for Victor during the holidays. The youngest sibling is currently at private nursery which makes it possible for him to have some respite during the holidays but once he attends school this will no longer be available. There will be mainstream services he can attend but there are no other options for Victor other than playscheme.

Victor has complex needs and requires experienced support and safety provided in a group setting. Even if he were to have 1 to 1 personal assistant it would not provide the same level of safety for both carer and Victor. He is unpredictable and due to Epilepsy 1 to 1 trips out of the home could prove impossible. Playscheme allows Victor to access activities that are not met by any other service.

Victor previously attended Royal Blind School, Holiday Club but it quickly became apparent that this was not a suitable option and he only attended a few sessions. They were unable to cope with his needs. This was a few years ago when he was less challenging than he is now due to age and size.

It is near impossible to find a solution that fits all the children in the family and any activity requires the family to be split.

⁴ Not child's real name

As a working mother, playscheme is the only option of child care that Victor can access.

4. Playscheme usage

Victor has used the full capacity of playscheme every year. I have always applied for this immediately as it is essential that the full allocation is accessed due to the needs in the family. It has been invaluable in allowing me to work and allowing the other children enjoy a small part of their holidays too. It is hard being a sibling of a disabled child and they have made far too many sacrifices as it is. My family could barely cope with 6 weeks let alone 4. In an ideal world we need more, I would recommend 8, 9 even 10 weeks.

Playscheme allows Victor to access activities that are not possible in the house due to Victor hitting, kicking and pulling his youngest sibling's hair. We cannot do "normal" family activities and playscheme allows the children to do normal things like going to a café. Victor gets so much out of playscheme and the fact that he has carers who know and understand his needs are invaluable to him and the whole family. He needs the order of something to do every day. He likes routine. He loves being social and he loves mixing with his peers at playscheme.

Victor now has epilepsy which means he requires even more supervision in the home which means the other children's needs are neglected even more. The only con going forward for playscheme is the lack of transport but I would happily sacrifice that for more weeks.

5. Impact of reduction in number of playscheme weeks to 4.

Victor gets so much out of playscheme and losing weeks means losing routine, stability and any sense of security. This in turn leads to challenging behaviour and even more disruption in the family. Victor becomes bored and disruptive. There is no other group childcare Victor can access. 1 to 1 is expensive and not as safe as playscheme. Personal Assistant are hard to find and need time to build up a relationship, they may not be able to cover hours required and if they are unwell then you are left stranded.

A severely disabled child puts a huge pressure on the family especially the other children who have suffered terribly over the years. Family life is hectic and school holidays are an absolute nightmare to say the least. It is very difficult for the other children. His eldest sibling went off the rails age 15 (the same time Victor didn't sleep for 2 weeks) as he couldn't cope with all the chaos that Victor brings in the house. He couldn't stand all the screaming and spitting out of food. He wouldn't bring his friends home and just stayed out all the time and he dropped out of school. He got into trouble and was eventually referred to CAMHS. He has since been diagnosed with high functioning autism and has been struggling for years to deal with the family life. This emphasises the point about why our children need more support and more respite and more playscheme. Families are in crisis.

My daughter also struggles to cope and is desperate for some attention as the majority of my time and dad's time is spent caring for Victor's needs.

My youngest son probably suffers the most. Victor becomes very annoyed at him, perhaps he doesn't like the noise and energy that he brings. He is full of fun but Victor is taking away his childhood by constantly hitting him, pushing him, pulling his hair and kicking him. He is a distressed 4 year old and this has been noticed at nursery. If he was living in any other family where he was being subjected to this level of abuse there would be some sort of intervention. Although social work are involved, playscheme is an essential part of respite for the family.

The children need time to lead a normal life. This is only possible when Victor is under other supervision. I cannot take Victor into restaurants, cafes, the cinema etc . He cannot cope with that. He finds it too stressful, but the other children just want to do small, everyday, things. Just time to be themselves, instead of being the siblings of a disabled child.

The whole family can't even sit at the table to enjoy a meal as it becomes disruptive. Victor will spit food out and throw cups and plates around. Sleeping is disturbed and caring for Victor means the whole family are often emotionally and physically exhausted.

I have a supportive employer, however, I also work in a small team and there are expectations required from me. Relying on transport means making excuses for being late and caring needs, hospital appointments all need to be requested. I arrive at work already fractious from dealing with challenging behaviour in the morning. I have discussed on many occasion the options of time off in holidays but been refused. I can only take maximum of 2 weeks in the summer holidays and 1 week at Easter. 4 weeks of playscheme makes it impossible and is causing even more stress in the family. I honestly do not know what to do. Juggling work and disabled child is hard enough. I can't progress at work as I can't work full time hours due to care needs and the family have made so many sacrifices already. I need to work to support the family and I do not have any care for next year.

For my family playscheme is not an option it is a necessity, children need to have a chance to have a childhood. The family is already socially isolated and a reduction in playscheme will only increase this.

This case study was written by Victor's mum

Case Study 5: Julia

1: Family Details

Julia⁵, age 11, is an only child in a two adult household. Dad works full time and Mum works part time (2 days a week). No extended family help at all. Mum is carer for an elderly parent and another elderly relative (both of whom have ongoing serious mental and physical health issues). Other grandparents have been in long term hospital stays. Extended family all live in some distance from Edinburgh. Mum has health issues which cause fatigue and spells of illness, and cause severe back and neck pain. Needs support from dad to do physical activities with the child, who is boisterous, strong and lively.

2: Description of Child at St Crispin' s Special School

Julia has a diagnosis of autism and complex learning disability. Also has hypermobile joints and motor skill delays. Has severe and multiple allergies that require an EpiPen to be carried at all times. Needs help in all aspects of self-care – dressing, toileting, (smears faeces if she gets chance) tooth-brushing and eating. Has little concentration and cannot occupy herself at all for any length of time beyond pressing buttons on musical toys or repetitively bouncing or spinning a ball. Does not watch TV or play games. She does not have “playdates” with other children. Sometimes can sign “yes” but is non-verbal and relies on handing over photo cards to request food. Throws food around and empties drawers, turns on taps, eats non-food items. Will use physical strength to get what she wants i.e. force way into kitchen and empty fridge (she is tall and strong). Has severe sleep disorder and is up for hours every night. Can become frustrated and punch self and the wall, and poke herself in eyes. Has little sense of danger and can suddenly run off into road (has to wear backpack with reins) or grab and eat allergens/ non-food items when outside. Sometimes takes food from people in cafes and will take food and toys from babies – for example we have to hold on to her if we see someone with a balloon. Will use physical strength to get what she wants i.e. force way into kitchen and empty fridge (is tall and strong). Has severe sleep disorder and is up for hours every night. Can get very upset and stressed at change of routine.

3: Available Childcare

We have a PA who comes for approximately 30 hours a month (6 sessions at weekends or evenings). Unfortunately, as she works at school, she usually goes away in school holidays, and if not away works at playscheme (as do most of the PAs), so we have little to no childcare in holidays. We have not yet found a private playscheme who would take our daughter. We have no support whatsoever from family or friends, and indeed are carers for several family members.

4: Playscheme usage

We use playscheme and for last few years have used 6 weeks. We found 6 weeks to work well for us (7 would have been helpful but we manage with 6). It has worked very well for us as a family. We would use 4 weeks in summer and dad could take 2 weeks holiday so he could help out with childcare, and we would use one week in October and one in Easter and just manage the other holidays as well as we could. Julia loves playscheme. Is sociable and loves meeting and being with other people and children. Really enjoys all the activities and sensory play. Runs eagerly to bus every morning and has

⁵ Not child's real name.

big grin when she returns. She enjoys the structure and continued routine. Julia gets to be more physically active and social than she would be at home with Mum and she sleeps better.

5: Impact of reduction in number of playscheme weeks to 4.

We struggled to find a PA in first place, and she is not generally available during holidays. We are not aware of anyone who could help us in holidays, nor of any alternative provision we could use, even if we could pay. We would not be able to afford to pay a PA to cover all or even many of the hours that playscheme covers, or to afford a mainstream playscheme with 1:1 support, even if we could find one. If we used our self-directed support payments to fund more childcare in holidays we would miss out on respite the rest of the year, respite which is vital to maintaining our relationship (the only time we have alone together at all!) and sanity levels, and to ensuring that we are able to be the best parents we can be to our daughter!

Even with 6 weeks provision, Dad is still going over his allotted 4 weeks of holidays from work, as he needs to help out most days, and with even less, his job could be at risk. He has a high pressure job and is already suffering from stress and pressure from having to juggle the needs of the family and extended family (we are generally providing support and care to 3 people EVERY DAY). Without his income the family's quality of life would suffer and they would be pushed into poverty and struggle to pay mortgage and costs of living. Mum's health issues would worsen with caring for a child with high needs all day then caring for elderly relatives at night, and her ability to care well for Julia would reduce. Mum could also lose her job due to illness if she is forced to take on even more caring (she has suffered frequent illnesses in the past year already and suffers from chronic pain at work requiring medication), and this loss of income would also affect the family's quality of life and Mum's sense of independence. She would be close to physical and mental breakdown with even more full time care of 3 people with high needs, and has already been unwell and suffering from stress.

Our daughter is very hard to entertain compared to a typically developing child. She cannot access mainstream sporting or art activities like other children. She doesn't really enjoy usual family activities such as cinema, and always wants to leave before end and kicks off. We can only go to 2 or 3 places to eat and needs 2 people to supervise her. If she goes to museum or somewhere like aquarium she runs around it not looking at anything then wants chocolate in cafe then goes home. In playparks she will jump off high play equipment and run in front of swings. If taken to soft play will sit or lie at bottom of slide and be in danger. Used to enjoy swimming but hasn't been keen for a while. Sometimes undresses in public. Goes to beach and throws sand around for 10 minutes then goes back to car. Mum is unable to engage in physical activities with Julia out of house alone (i.e. playpark, soft play and swimming) due to back pain and health issues, and cannot drive. Therefore, if playscheme was cut Julia would have to spend 2 weeks more a year mainly in house with mum, being bored, and causing mischief, with only short trips out. We have no garden and she is unable to go outside routinely to use up energy.

Julia is so happy at playscheme that she has cried when she has heard us discussing it not being on as much, so we have to discuss it out of her earshot. She enjoys seeing other children and her friends from school and especially thrives on the continuation of routine from school and going somewhere every day. She would be bored, lonely and stressed without this routine and miss it very much indeed.

This case study was written by Julia's mum

Case Study 6: David

Our youngest son, David⁶, attends St. Crispins. He is 8 years old and has 2 brothers, Tom (age 20) and Simon (age 15) as well as a sister Tamara (age 17). Both myself and David's father are currently without employment, although we are both taking a Spanish class at a local community centre. David's dad has recently completed a Higher English course, with a view to completing a teacher training course. Tom is attending Edinburgh College, Simon and Tamara are both still at school, attending Firrhill and Woodlands respectively. Neither of us have any family in Edinburgh; the nearest being my father, who lives in North Berwick, or my husband's sister, who lives in Aberdeen.

All our children are on the autistic spectrum. As you may imagine, this makes for a very stressful life. Although we are both unemployed at the moment, we still have a very busy household, with meetings and appointments with health care professionals involved with the children, to school meetings, to just trying to keep the children occupied and happy. David also has very erratic sleep patterns, which results in neither of us getting enough sleep at times. This can, occasionally, make us grumpy and irritable towards each other and the children.

Tom has a diagnosis of Asperger's, Simon has been diagnosed with high functioning autism, Tamara has autism with GDD and David has a diagnosis of autism, GDD and sensory processing disorder. David is non-verbal and communicates via a combination of peccs, object signifiers and taking your hand and pushing it towards what he wants. David requires a lot of attention, he is able to occupy himself for very short periods only. He does not have the ability to carry out "self-care tasks." He can undress himself to an extent; he can remove his trousers, shoes and socks. He is still in nappies and rarely shows any awareness of having soiled himself. David has no sense of danger and cannot be left unattended in the kitchen or, be left in the bath unsupervised. We cannot leave any windows open in an empty room, or David may try to climb out of them. He has done this before, he climbed out of his, first floor, bedroom window onto the ledge. He has no road sense, and needs to have his hand held when near a road.

David shows some very challenging behaviour, ranging from tantrums (where he will scream, jump up and down and bang his hands on tables or walls), to pinching and scratching himself and anyone within reach. He will also head butt people when frustrated or angry, as well as walls, doors and door frames, we refer to these episodes as "meltdowns" or "kick-offs." David also hits and scratches himself. Despite his age, David is physically very strong and it is not unknown for him to push us out of his way. As Tamara is "noise sensitive", David's meltdowns can act as a trigger for her and she will also become upset, leading to a kick-off from her. Tamara's meltdowns are even worse than David's. Being an adult, she is also physically strong and is able to push us away. She also has been known to punch, kick, bite, scratch and throw things at us. She has even, on occasion, tried to attack David, who she blames for just about everything! However, neither of them are as bad when they are at school

⁶ Not the childrens' real names

or playscheme. Home is their “safe place” and they tend to act out more here than they do elsewhere. This is another reason for the rising stress levels during the school holidays.

David, although non-verbal, does make a low moaning sound, which is another trigger for Tamara. This is just one of many triggers for her. Tamara is also very demanding of attention from me and often resents the time I spend with David. She will also often tell Jim that “David’s been bad” when he isn’t even home from school yet. Tamara cannot bear to be on the same floor of the house as David, let alone in the same room. This means our time is spent primarily looking after David and Tamara. This, of course, has the knock-on effect of us spending very little time with Tom and Simon, who are often left to their own devices.

David has a befriender who takes him every second Saturday from 10am until 6pm. Apart from that, we have no other access to childcare. There used to be a special needs children’s club at Pentland Community Centre every Friday afternoon, but that was suspended for the summer holidays and, currently, there is not the funding to start it up again. That club was the only club or group for special needs children in the South of Edinburgh. Tamara used to get respite at Seaview, but that is no longer available now she has turned 17. Although we have some friends in the area, none of them are comfortable looking after David and Tamara for an evening, to give us a chance to go out for a meal or to the cinema. We also have no family in Edinburgh, who could help us, there is only myself and my husband.

Both David, and to a lesser extent, Tamara, need structure. Neither cope well without it. It is fair to say that the school holidays fill us with dread. This is not exaggeration or hyperbole. We know that we will not be able to find any activity that all the children will enjoy. David loves swing parks. Tamara likes them to a certain extent, but becomes bored easily and Tom and Simon do not enjoy them at all, especially as we spend all our time making sure David and Tamara are safe. Tom, Tamara and Simon enjoy going to the cinema, whereas David will not sit and watch a film for that long. Also, Tom and Simon will not watch the same films as Tamara.

When we do go to a swing park, David can often show some challenging behaviour. He likes certain pieces of equipment and will often have a kick-off when he is told he has to come off. He also does not understand the concept of waiting. If there is another child on the piece of equipment he wants to go on, he will have a meltdown because he has to wait and can’t get on. This has the knock-on effect of Tamara going into a bad mood and having a meltdown of her own and Tom and Simon feeling uncomfortable and not wanting to go out as a family. This is particularly common during school holidays, as the parks are busier and louder.

We have used playscheme for many years. Tamara and Simon attend the St. Crispins playscheme, while David goes to the Oaklands one. We have usually applied for, and usually receive, an allocation of 6 weeks. This gives us the opportunity to spend some decent, quality time with Tom and Simon, as well as each other. We actually think we need more weeks of playscheme, not less. Tamara and David both enjoy going to playscheme. They get to try some new things, while still having some structure.

Playscheme also has more “resources” than we have and could devote the time and attention to David (and Tamara) that we cannot. If there is a “con” to playscheme, it is that there can sometimes be a lack of communication, but that is an occasional, mild irritation.

To lose 33% of our playscheme allocation would have a dramatic impact on our family. We barely cope as it is, at times. If we were to lose 33% of a service that we actually need more of, we would struggle as a family. We would not be able to afford any kind of alternative care or respite. Tamara may be able to cope with the loss of 2 weeks playscheme, as she is not as severely affected as David, but David absolutely would not! The time we spend with Tom and Simon would be reduced (and it’s little enough as it is) We would effectively be housebound, as we would not be able to find anywhere we could go as a family that would be of interest to all our children and our relationship with each other would suffer as well, as the stress levels in the house rise due to a combination of tiredness, anxiety, waiting for the next meltdown to name but a few.

This case study was written by David’s parents

Case Study 7: Polly

1: Family Details

Polly⁷ is an only child who attends St Crispin's Special School. She is 8 years old. Her parents both work but as a consequence of the severity of Polly's needs, they work fewer hours than they would like to. Her father works a compressed week so that he can have a day off a week. Her mother has had to reconfigure her career and now works part time; 3 days a week. Due to Polly's needs, her Mum has had to change the type of work she does and now earns at half what she did before Polly was born.

The family have no relatives in the UK although relatives do visit to provide some help, this is very occasional. In addition, Polly's father was diagnosed with a long term degenerative condition a few years ago. This condition currently affects him with fatigue and paralysis or numbness and tingling in his face and limbs. It is exacerbated by stress and lack of rest.

2 Description of Child at St Crispin's Special School

Polly has a diagnosis of autism and suspected significant learning disability. She has almost no communication apart from facial expression and reaching for objects she wants. She is working on using pictures to communicate but makes slow progress and her ability to use pictures limited and variable. Polly cannot carry out any self-care tasks. This means we have to dress her and undress her, wash her, dry her, brush her teeth, comb her hair and change her nappies. Her understanding of the purpose of these tasks is limited and her co-operation varies. As she gets bigger and stronger, carrying out personal care is getting more difficult. Polly's reach is longer and she will pull our hair or hit us round the head as we try to perform these tasks. She also bites to try to prevent us from doing things she does not want.

Polly is only just beginning to learn to play. This means she still plays like a very young baby. She likes to explore different textures in messy play, or to knock things over. Given that she is now 8 years old it's really challenging to arrange these kinds of activities at home – it's very messy, things get broken and damaged. It's difficult to occupy Polly at home apart from allowing her to watch TV which she likes to do but even then, she needs to be closely supervised – she will get up and bash the screen. She requires frequent programme changes or will get frustrated.

Polly has very few ways of controlling her environment, she can get very frustrated. Polly often has meltdowns in which she will try to hurt herself or others. She will bite and hit, she head bangs and she screams. This can be very upsetting. Polly also has sensory processing difficulties and finds it difficult to be in confined busy noisy places.

3 Available Childcare

We currently employ a PA for Polly for after school Monday-Wednesday. She takes Polly out to a local park and then feeds her dinner at 5pm. On Thursdays we have a space at the schools after school club – Polly loves this and comes home happy but that means on Thursdays I have to work from home so I can drive across town to pick her up. On the weekends Polly attends the kidsown weekend club for one day other weekend. She's matched into a group of similar children and that gives us some time off. On other weekends we use a nanny agency to book childcare. This has to be booked in minimum

⁷ Not child's real name.

3 hour slots but is needed as we are unable to look after Polly ourselves for a full day. We book to take her out in the afternoons which generally works quite well. We have a pool of agency staff that we are familiar with and we spend time training them. We have come to an arrangement with the agency where we pay more than the usual rate in order to attract staff willing to look after Polly. Thus, childcare is generally 1 to 1 and expensive.

We are unable to use any more informal shared care arrangements – such as sharing care by having friends over and then reciprocally sending Polly to stay with a friend after school or on the weekend. We also cannot make use of any of the clubs and activities provided by Edinburgh Leisure or other providers as she would need to be accompanied by 1 to 1 support and the activities are pitched at a level she cannot join. Family come to visit us and will help look after Polly but it's very occasional – about once or twice a year.

While we currently have access to some childcare, it's very expensive as we have to pay for someone to be 1 to 1 with Polly. Some of that cost we can recoup using self-directed support but a sizeable sum we pay for ourselves. Paying for 1 to 1 nannies helps give us a break but it does not provide Polly with time to play with other children. We know she loves to do this as she hugely enjoys afterschool club and playscheme. As Polly gets older and bigger the opportunity to pay for 1 to 1 childcare will reduce as she will become heavier to push in a buggy or wheelchair and her size will make her difficult behaviours more risky and hard to manage. We are very worried about how we will cope with this.

4: Playscheme usage

Ever since Polly became eligible for playscheme we have applied for the full 6 week maximum allocation because we don't know how we would manage without it. Indeed, in the last year and a half I stay home on the days the booking forms are expected so I can fill in the form and hand deliver it immediately to guarantee we get the weeks we need. Playscheme is an absolutely critical part of how I manage to stay employed and how we manage to look after Polly at all. Those weeks of the year when no playscheme is available are very difficult. We book a lot childcare to help us manage and try to organise help from extended family but it's always very difficult and, when we can, we book additional days off work when school reopens in order to stay home to recover.

The year before Polly became eligible for playscheme we had to arrange childcare for the whole summer as nursery was closed. It was a huge undertaking and we spent the whole year planning and saving for this. It cost us about £375 for each week and we needed about 4 weeks. I had to spend a lot of time hiring, interviewing and training staff. Even back then when Polly was just 5 I had to split the week between 2 people as it's not possible for 1 person to look after her all day for several days running; it's too relentless. Both of us had to arrange to work from home so that there was always someone on hand to help out with lunch and transitions.

5: Impact of reduction in number of playscheme weeks to 4.

The playscheme that was available until summer 2017 was almost miraculous. There were some problems and difficulties but the providers did a lot of preparation and knew really well how to look after Polly. Polly would come home almost every day with a big smile and every indication of having had a good time.

Without playscheme it's difficult to see how I would be able to stay in work. I already use the reduction to part time working to make up for the additional leave I need to recover from the 6 weeks we care for Polly at home without school or playscheme. Losing my job and the prospect of satisfying work of any sort will be profoundly depressing. Having to give up my career has been really difficult for me and I would worry about the impact on my mental health of losing more of my professional identity.

We also worry about the isolating effect of losing playscheme on Polly's social life. She has very few chances to be with other children outside education. She has no friends that could come over, no cousins or other children that visit, her ability to play and communicate is so limited that it's very difficult for her to interact with other children at play parks even though she tries. She is not able to access the usual places that other children go to have fun because they are too loud and too busy.

6: Other

Our ability to find agency childcare will become even more restricted within the next few years as Polly gets older and bigger. Her behaviour will make it extremely difficult to find carers for her so we feel our access to childcare will get more difficult even as we will need increasing amounts of it. We are also concerned about the extreme vulnerability of having our non-verbal daughter cared for by agency staff individually. Despite checking PVG status of any staff we hire it would be far preferable for more of her care to be provided within the context of clubs or activities with multiple supervised staff, to make sure she is safe and make sure she is not neglected or abused by her carers. Having to hire even more of such care through agencies and personal assistants is profoundly worrying.

Polly loves going out and exploring the world but doing so is hard work and can be risky due to her challenging behaviours and lack of danger awareness. We try hard to keep her world interesting but the fact is we can't provide her with as much stimulation as playscheme. With fewer weeks of playscheme available, Polly will be bored at home as we have to get on with household tasks and she can't really play. This leads to frustration and an increase in challenging and self-injurious behaviour. It will be horrible to see our child unhappy and hurting herself as a result of the reduction in playscheme.

This case study was written by Polly's mum

Case Study 8: Harry

1. Family Details

Harry⁸ is an only child, he is 6 years old. He has a diagnosis of autism and severe learning disability. He lives at home with his mother and father, both parents work full time. One set of grandparents live 30 miles away. They are getting less able to care for Harry, but can do a short time like maybe a half day of care in the home only, no outside trips etc. The other grandparent are 80 miles away and unable to do more than 1 or 2 hours child care, again within home. No family in Edinburgh/Lothian area. Some friends for emergencies but they all have their own children.

2. Description of Child at St Crispins

Harry needs help with all aspects of personal care. Changing his nappy can sometimes be a two person job. Harry is non verbal with a developmental age of 10 months. He is hyperactive and has no sense of danger. Harry is very loud and a poor sleeper. We need to be out of the home all weekend as it's unfair on our neighbours, one of which has just had a stroke. Harry is unable to travel on public transport due to meltdowns and constant grabbing of people. Harry does not use PECS or signs etc.

3. Available Childcare

Harry attends one session of after school club. We had a babysitter who we could call upon for help maybe once per month but she is now pregnant and due to Harry's outbursts it's not possible for her to care for him alone. We have been waiting since January for a section 23 assessment and presently have no social worker.

We have tried to access some of the special needs drop in events but these are not suitable for children as impaired as my son. We have had to leave these drop ins as they were unsafe. There was either no secure doors, food out on display (my son has Pica and will eat anything), no appropriate toys (my son cannot play with age appropriate toys, he needs baby/toddler toys). Not enough support workers (I could not even get time to go to the toilet myself), no appropriate changing facilities for my son (he requires a change no bench suitable for an adult, not a baby changing table).

Other events aimed at disabled children, such as the autism-friendly soft play session at tumbles are at times when my son should be eating and getting ready for bed. He needs routine and going out at dinner time is not suitable. These soft play areas also usually have access to food and as they are not segregated. This means I can't go as my son is obsessed with food and will steal from peoples' plates, rather than play in soft-play.

⁸ Not child's real name.

We are only really able to take him to the park (where we have to make sure he doesn't eat from the ground or rubbish bins), even then as he has no balance skills we have to find a toddler swing, but usually he is too tall for these and his feet drag along on the ground.

Playscheme is an invaluable service for my son to even be able to play. Taking a severely disabled child into regular settings is difficult and incredibly upsetting, both for him, as he can't access them properly, and for us as parents, as he we watch our son be excluded from something that other children take to granted. It is absolutely heart-breaking to see my son try to play with other children and then their parents pick them up and move away from my child who is screaming and stimming. Being with other children like himself is the only place I see my son get to be himself.

4. Playscheme Usage

Harry had enjoyed his full allocation of playscheme this year. The reduction will make it difficult for us as a family as we all need the continuity and routine for Harry. We find it hard to access regular soft play sessions due to Harry's inability to play safely with other children. We don't get invites to people's homes. We sometimes visit The Yard but find the sand and water play is dangerous as Harry just eats the sand. Often other families there are eating picnics and Harry will have a meltdown if he can't take someone's food.

5. Impact of Reduction in Playscheme

There are no other facilities for my child to attend a holiday club in school holidays. He is not able enough to attend a mainstream setting even with 121 care. 121 childcare at home is both expensive and not suitable. My son needs to be out, he needs to be active, he needs to see other children. A regular childminder could not cope with my son in the home all day. It's difficult to leave the house with a child who won't walk and needs specific changing facilities. My family are getting older and no longer able to care for Harry for more than a couple of hours. Our family live quite far away and we are quite isolated.

In being home with an adult all day my son misses out on being with other children. Bear in mind my son can't go outside to play after school with other children. School is the only setting he has that chance. If playscheme provision is removed I think my son's happiness will be severely impacted. He loves the social aspect of it and I see how happy he is each day when he comes home. We have no idea how to keep him happy if he loses out on playscheme hours. As a family it's very hard to spend all day moving around from parks to home to parks, trying to stay out of the house and spare our neighbours the endless shouting and screaming. Myself and my husband have virtually no time to ourselves and this can cause tension at times. Ideally, we would have continued with the same amount of playscheme provision as this gave us a mix of routine for Harry and also enough time together as a family.

As a working family, using all of your holidays to look after your child is normally to be expected, however, I honestly find it incredibly difficult to look after Harry all day long on my own, with my husband taking different weeks off work so that we can cover all school holidays. Harry is exhausting physically and emotionally. As we have no respite, I suppose we look upon the odd free afternoon when Harry is at playscheme and I'm off work, as respite. I think the reduction will see us seeking more

help from the disability social work team. I've found it strange that only a small increase in cost for the playscheme has been requested. As a working family we would have been prepared to consider a significant increase in cost for a continuation of a great service. It's almost impossible to find any qualified, trustworthy organisations to work with my child. We don't have the choice of private companies or individuals that neurotypical children have.

I think with cuts to provision I would eventually have to give up Work. I don't think this would help my son as I'm sure I'd be very unhappy, probably have to give up my Home, lose the income required to look after a disabled child(which is estimated at 3x the norm). It all looks a bit bleak without playscheme. My child is hard work. He is relentless and it's severely affecting my own mental health, my husbands mental health and also our marriage. We are constantly tired, irritable and not our best as parents. The thought that you will look after your child until the day you die is one of the most difficult things I face each day. Trying to be a working parent is even more difficult. When my child is at school, I work. When I'm not working, I'm home with my child. It's a constant battle to keep him safe and happy. My neighbours have complained to my landlord about the noise. I don't know if I'll get another six-month lease and live in constant fear of being made homeless. I currently have no section 23 provision and have been waiting almost a year to get this done. I don't see any light at the end of this tunnel and when things like playscheme get cut it's like a blow that hurts so much you feel an actual pain, worrying about when the point where you snap will come. Will I lose my job? Will I become mentally unwell? Will I say or do something I regret? The stresses are multiple and endless.

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