

Dear West Sussex County Council

COVID & beyond – Locking out learning disabilities, locking in inequality

families & carers on why day support matters for people with learning disabilities and the people who care about them.

“how would YOU feel if you watched the world swinging back to normal but the key was not available to you...”

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Introduction

West Sussex County Council proudly states on the WSCC website:

“Our only purpose is to serve you; the people living and working in West Sussex. The County Council should make things easier and better for people living in the county.”

This report is from families and carers of people who have a learning disability/autism who are supported by the voluntary and community sector in West Sussex.

In November 2020 West Sussex County Council sent a letter to families and carers which clarified arrangements relating to the COVID pandemic. It also referred to longer term intentions regarding support for people with learning disabilities:--

“In the longer term, it is likely that the Council will not be making arrangements for attendance at a day service for those in 24 hour supported living and residential care other than in exceptional circumstances. This is to ensure that those with a lower level of support are prioritised.

The Council is also starting work to plan for how people are supported in the day and will want to get views from people who attend day services, family carers, day service staff, staff working on other settings and social workers. This will include consideration of the possibility of reducing activity that is focussed on buildings based day services.

While the Council has received some short term additional funding from the Government as a result of Covid 19, this will not cover the longer term changes that are likely to be in place. The Council needs to do all it can to manage the money available to support all the people with social care needs and it is therefore likely that some of the changes currently in place will stay in place longer term.”

The November 2020 Cabinet meeting papers included a proposal to cut lifelong services day services by £1,120,000 in 2021/22 and £1,120,000 in 2022/23, having already cut independent organisations' funding for day support by 20% in the middle of the Pandemic.

This month, more details were provided in an invitation to the Learning Disability Partnership Board meeting in March and consultation began with people who use day support.

In the meantime, we are seeing cuts are already underway, without consultation or discussions taking place.

The focus of this paper is to invite West Sussex County Council decision makers to engage in an open narrative with families and carers. Families and carers believe it is important for West Sussex County Council to understand the impact on our loved ones and those of us around them. We are giving you our initial thoughts on the

proposals and assumptions made by West Sussex County Council. Families and carers are asking for opportunities to meet with decision makers and to be part of meaningful decision making which will affect us and future generations.

We need to talk about COVID

Whilst the Covid pandemic has meant that many people with learning disabilities have at times been unable to physically attend their day support, it has emphasised the vital importance of being part of a supportive and understanding community, of contact with peers and of shared purpose and meaning. This shared experience is central to the wellbeing of not just people with learning disabilities but also their families.

“My mission in life is not merely to survive but to thrive, and to do so with some passion, some compassion, some humour, and some style”.

Maya Angelou

Being involved with ‘day services’ offers many things, personal therapeutic outcomes, physical exercise, achievement of goals and aims, enhanced mental health, the development of practical skills, pathways to employment, but perhaps most of all it enables people to experience contributing and belonging to an encouraging and vibrant community in which they feel enabled to “thrive”. These are the voices of families and carers whose loved ones have received support from the existing thriving, meaningful, progressive enterprise-focused services in West Sussex.

Families talk about surviving - we have coped remarkably well in comparative isolation but we are seeing the Pandemic taking its toll, and it is clear people’s physical and emotional wellbeing has been impacted. People have gained weight, lost mobility, become depressed, there is more challenging behaviour as people appear to be expressing their loneliness and frustration. Families have had to do more, often with less time, as their normal routes for support have been restricted.

Misconceptions and mole whacking

The love, care and support that families and carers provide is one of the most important foundations which help support people with learning disabilities to have good lives. However, many families depend on support from partners in care and families and carers are experiencing breaking point, concerned for their own and their family member’s wellbeing.

People with learning disabilities have poorer life chances than the general population. This is related to multiple disadvantages, and during COVID, research has evidenced they are up to 6 times more likely to die from the virus. Pre COVID research has shown again and again that people with a learning disability die two generations before the general population of preventable causes. The Government’s Social Care Taskforce has recommended restoring, maintaining and adapting support for individuals and families already assessed as having eligible needs. This means ensuring councils and CCGs pause care, health, or personal

budget reviews during the period of service disruption. We are concerned WSCC has already taken a number of decisions and we are seeing that meaningful consultation in the middle of the Pandemic is not possible. To base plans on the experience of the Pandemic is unwise and risks poor decisions being made.

What West Sussex County Council appear to be planning is to remove day support for many people. Our experiences suggest this will cause more isolation and increase disadvantage. Loneliness and inactivity is a killer – equivalent to smoking 15 cigarettes a day - people's needs won't go away because you have removed their support, they will present to the NHS, the criminal justice system and social care with increased, acute and more expensive needs.

We are alarmed at the prospects for our family members - what are people in supported living supposed to do all day? More financial resources will be needed to support people in their home, reducing opportunities.

The voluntary & community sectors use their resources to provide a wide range of opportunities in busy, thriving environments - many services are offered in the local community and these services encourage independence and integration. We have seen and support the impact of day support – we see our loved ones progressing, gaining skills and independence.

Day support and why it matters

This paper offers decision makers in West Sussex County Council an insight into day support which is provided across West Sussex in 2021 from the perspective of families and carers. We have mapped this to the assumptions and aspirations provided by West Sussex County Council to illustrate how things are working now and what is important to families.

West Sussex County Council says	We say	Statements
Most daytime support takes place in a day service building	This is not the case – support takes place in and around the community, there are many opportunities for people to engage in a wide range of activities, including leisure, sport, landscaping, art, drama. Aldingbourne, Apuldram & Ferring use social enterprise to bring thousands of visitors a year to their enterprises. They are vibrant, engaging and meaningful.	4, 6, 7, 8, 31, 36, 38, 45, 47
We need to look at how we can provide day opportunities for more people with less money.	Why have you prioritised day services for people with learning disabilities for cuts?	17, 36
People to be as independent as possible and part of their local community.	We see our family members gaining skills and developing independence with current arrangements. West Sussex' day services	4, 6, 7, 9, 13, 16, 21, 27, 32, 33,

	provide skilled & specialist support, people's health & wellbeing is improved. Our statements tell you the impact of removing support.	34, 35, 36, 37, 38, 39, 40, 41, 44, 45, 47
Get better at helping people to become as independent as possible.	Is this another way of saying we need to get better at spending less money on people with disabilities?	11, 17, 36
Support family carers.	Research in 2015 suggests unpaid carers save the UK economy about £132bn a year , ¹ the main carer's benefit is currently £67.25 a week if you care for someone for at least 35 hours a week. We depend on day services for our own quality of life and to be able to work. Plans to cut support & change the services provided will be detrimental to family carers.	2, 7, 13, 23, 25, 27, 31, 32, 34, 37, 39, 43, 47
We will try to keep things that are working well.	Please be honest about this, the proposals run counter to our experiences of what is working well.	2, 4, 7, 17, 36, 40, 41, 44, 45
More community based opportunities in different settings.	This may work for some people, we have concerns it will be counterproductive for many.	4, 36, 45
Providers working together to cover a local area.	We do not understand this statement.	
Prioritising people who live with their family, on their own and don't have much support	Supported living services do not have capacity to replace day services. It will cost more to support people in day services than to continue to support existing arrangements. People will be isolated and their health will deteriorate.	2, 4, 5, 7, 8, 16, 30, 34, 41, 42, 44, 45
People only going to 1 day service	This will work for some people but not for many. Can people with learning disabilities not have a choice and variety? This appears to be counter to the aspiration of people developing skills and increasing independence. How would this fit with progressive pathways?	7, 13, 18, 31, 32, 40
People attending up to a maximum of 3 days a week – any additional days by exception	What will happen for people on the other 4 days a week? The pandemic is highlighting the challenges we and our loved ones face.	5, 8, 13, 22, 23, 31, 32, 34, 44
Reducing transport costs with more people going to activities near where they live	West Sussex is a rural County. As with the general population bus services have been cut and public transport options have been reduced. People with learning disabilities may need some reasonable adjustments to enable them to live life.	31, 43

¹ [Unpaid carers save the UK £132 billion a year – the cost of a second NHS - Carers UK](#)

More opportunities to get independence, skills, peer support, volunteering or work experience and job skills	Existing support already provides a range of opportunities, on the basis of WSCC assessments, that meet the needs of our family member.	2, 7, 16, 31, 36, 43
There are some things in the new design that we can co produce together	What things can be co produced and what can't be? Who have you consulted with already? We need to meet with you.	19, 35, 36, 37
We will listen to what the impact of any changes are before deciding	The budget cuts are being voted on before this consultation has taken place. We need to meet with you.	1, 7, 13, 17, 36, 37
Independent advocacy will be available to support people with a learning disability	How can my family member access this? We need to meet with you.	

Life

The following pages are messages to officers, budget holders, politicians and the public. We are speaking up because we know that people with learning disabilities are too often overlooked and not heard. We have had lifetimes of trying to get good support for people we love. These are our stories, these are our pleas.

All the statements and case studies have been anonymised to respect the sensitive information people have shared.

We will start with a case study:-

'Mary' is a 38-year-old woman, who has been attending day services in Ferring since 2010. She has a diagnosis of a learning disability and borderline personality disorder. Mary has several instances of self-harm, suicidal thoughts, and problems with the law. Mary explains in her own words what attending day services means to her-

"I have a slight learning disability, it's hard to do things. Also, I have borderline personality disorder, my mood goes from high to low. I find it hard sometimes; people have to explain things a few times to me. I enjoy coming to Ferring and being with the animals. Sometimes it's like I'm a different person. I wake up and I haven't got anything to do. Sometimes I argue with someone and this makes me angry, sometimes I don't always listen.

I go to the top of a car park, it's like something in the brain tells me to... So, I go to the top of the car park. I then think this is no good for me and I need to phone someone to come and get me... So, I call the police. It's hard when people see me getting out of a police car at Ferring. I feel bad that someone else might do it. I love coming to Ferring, it's great here... It's brilliant. I feel safe at Ferring and I love all the staff. Sometimes when I have a bad day, I spend time with the goats or rabbits, and it makes me feel better. The staff always talk to me... They are kind and caring. They know all about me. They give me time out with the goats and I just spend 10 minutes and I pat them. I would be very upset if I couldn't come to

Ferring. For 10 years Ferring has been my life. If I didn't come to Ferring I'd be watching telly, getting bigger and bigger and getting into trouble. Before I came here, I lived in Hastings and I hung around with the wrong crowd. They knew I had a learning disability and would make me steal stuff. They took my money, took my phone and I thought they liked me. It's hard because no one else in my family has learning disabilities and I thought that making new friends was good. I would go down the pub and spend all my money, but they weren't my friends. One of them locked me in a room for three days and hit me. When mum came and saw me in Hastings, she didn't recognise me. My mum wanted to protect me, and she helped me move to Worthing. I've got my own place now and I come to Ferring and it's great... I'm learning! I'm learning how to do my washing, how to pay bills and stuff and my mum is proud of me. Ferring has really helped me with my confidence. I love helping in the café and serving tea and coffee to people. It's been amazing."



Families say:-

1. “ Looking at the recent one (letter) I am angry that they appear to have decided already.” (mother)

2. **Our daughter...** “ Our daughter B is in her early thirties and had been attending both Apuldrum and Aldingbourne for day services since leaving Fordwater Special School. Over the years WSCC Social Services have been attempting to both ensure B’s developmental and support needs are met, as well as to see that this is provided in the most cost effective way – for example by reducing 1:1 hours in favour of group sessions. B’s disabilities prevent her from accessing normal employment opportunities, so Day Services have provided her with a whole range of benefits that she would have otherwise missed out on – such as social interaction, developing friendships, shared experiences, skills development and learning life skills in a safe environment. We have found that both Apuldrum and Aldingbourne have worked with us to help tailor B’s activities to ensure continued development of a wide range of life skills. All of this within a cost effective model of mainly group activities. This resulted in 2019 to B moving into Supported Living with minimal 1:1 support (a level which we never thought would be achievable or sustainable) in the house, and accessing Day Services.

When lock-down started at the end of March 2020, it was clear to us as parents and to her support staff that the level of funding available for 1:1 hours was insufficient to continue to provide adequate support for B in Supported Living, as she was ‘locked in’ to her house with no access to Day Services and minimal attendance from carers. Therefore B moved home to live with us. We now provide her 1:1 support at no cost to the state, but do not have the professional skills to help her development, and one day we will not be able to do even this. During this time we

have to spend many hours a week caring for and undertaking activities with B – we are not sure how long we can continue to do this.

Whether living at home with us, or in her Supported Living home, reducing access to Day Services will have the effect of isolating B, who is not a ‘self starter’ and requires external input to stimulate activity and thinking. Surely in the long run this will lead to B being less resourceful, resilient and capable – all of which will place a greater financial burden on the state in the longer term. Let alone reducing her quality of life in the short term.

In summary, a reduction in Day Services could lead to a number of increased risks - increased cost in the long term, lower quality of life, loss of confidence and a more isolated and less capable individual. None of which anyone would

”
want. (parents)

3. **Our daughter...** *“just want to say thank you for making my daughter’s days easier, she is smiling and laughing again” (parent)*

4. **My son...** *“Well to start with L loves ACC and all the people he calls his friends...he is friends with everyone but no-one in particular, although has formed a stronger friendship with DE having worked with him and Ruby. But this is part of the uniqueness of ACC, in that it provides a large space for him to wander safely and independently and to join in when he wants to and to step back and watch when he doesn’t.*

If he is to just to go to and from certain activities it would take away that independence and freedom and would not suit his personality. It would mean more one to one and not the choice of people to interact with. More travelling, which interestingly enough is one of the reasons they had for not allowing ACC with the supported living house in Findon...the distance...travelling to and from...it is actually only a couple of minutes more time than the time it takes to get to ACC from here in Storrington!

ACC offers such a wide variety of activities and socialising, opportunities to go out into the community for sporting events and for different group works.

L has benefitted so much from all aspects of ACC life and there is still so much he can gain, he is learning all the time. His life would be very fragmented if he had to rely on several different activities at different sites and this would not be good for L as he does not like change and does not cope with transition well. The staff at ACC know L and his idiosyncrasies and he knows and trusts them. Different staff in different places would not be good for L.

He has been at ACC for 14 years in April and they are his extended family. He talks non stop about ACC and when can he go back. His stutter has got a lot worse in the eleven months he has been away from ACC. He lives for the day he can go back.

ACC has everything in one place and that suits L's personality and abilities. It would break his and my heart to take that away from him and would be a backward step in his development and independency skills.

L like most people with a severe learning disability have few choices they can make about what happens to them in life and I can guarantee that all the clients at ACC would choose to stay there and will suffer emotionally if they are forced to leave.”

5. **My brother...** “*The recent pandemic has highlighted to me in a very measurable way what day service activities usually provide for my brother because since March he has had no day service provision and the negative impact has been huge and really sad to witness.*

He has become quieter, more difficult, more reclusive, put on weight and become diabetic. His personal hygiene and his interest and ability to take care of himself has deteriorated. He seems to no longer have any interest in the day care centre which he has always loved. Instead of engaging in productive activities, he prefers to watch TV and he now leads an increasingly sedentary and solitary life. He doesn't show any interest in anything much at all. When he has had a brief period of targeted one to one time in November, we noticed a huge improvement in his mood and zest for life. But sadly it was very short lived as the member of staff who provided this was needed at the day centre where he is not yet allowed to return.

In addition to all this change, we lost our father in August to cancer and he has had to cope with this loss, which has affected him greatly, mostly by himself. The supported living staff do what they can but he has hours and hours each day on his own. Had he been at the day centre regularly, staff would have helped him long ago to find strategies to cope and would have kept him occupied and busy instead of allowing him to languish in his flat alone for so much of the time.

We are desperate as a family for him to return to day care services where the staff can take a genuine interest in him and provide the sort of individualised help that he so sorely needs right now. The thought that these services may be cut would mean a life of isolation for my brother and others like him, many of whom do not have people to speak up for them and their rights. He can't read, or write. He can't access social media without help, and so zoom calls or activities online which have helped so many of us recently, do not work for him.

I hope that the Council think really carefully about the balance of needing to save money versus the human rights and needs of the most vulnerable in our society who we all have a duty to take care of. ” (sister)

6. **My sister...** “ P’s partner died in January 2018, and she had endured a 12 year period of ill treatment. With my family’s support, P moved into her own flat in April 2018, and slowly began to smile again. I was advised to contact Number 73, and we first met lovely Debbie Allsop in June 2018. An absolute blessing! – P was able to apply for a disabled bus pass immediately, and with the bus stopping right outside No. 73, it gave her immediate independence too. Pre Covid, P joined in with everything she could. The Thursday night socials, and the Saturday club were just the tonic she needed. P’s self-esteem grew, along with her mental health, and her face literally lit up when she talked about No 73.

The cooking of lunches together, guidance on diet, the dentist visiting, fish and chip suppers, crazy golf, meeting in Hotham Park, Bingo, Bowling – everything that these social events bring together, must still be a priority for those supported, once Covid lets life get back to normality. Self-esteem, confidence, kindness, learning different skills, talking and laughing, make a huge difference to these people you support, especially those that live alone.

P also loves her Creative Arts session on a Thursday morning. Her confidence has risen, and she thrives on the praise she is given. P would be lost without these facilities.

I must thank Debbie, Claire and Helen for everything they have done to help P during lockdown. Thank you to Tracy Milward too who has kept in contact and sorted a volunteer job at the Charity Shop for P pre lockdown.

The social side of No. 73 is so important, and offers invaluable support, alongside boosting mental health and the well-being of its clients. ” (sister)

7. **Our sons....** “ This is not the most appropriate time to be looking at ‘what is working well with day services and what could be better’ – we understand that it is a difficult time for local councils and there is additional expense due to COVID but comparison is pointless when everyone is ‘firefighting’ at the moment. Parents/Carers, day service providers and clients have just had virtually a year of disruption, closure, change, additional pressure and stress. The day services we are involved with as parents of clients have worked tirelessly to provide as much service as possible and support everyone but it is simply not equitable to judge them or make serious decisions about the future of the provision when

- o We are still some way off knowing when and how services will be able to open up again

- *We have no idea what the new 'normal' is going to be*

There seems little point in making significant changes or decisions whilst so much uncertainty exists

- *As parents of clients who live outside the local area we feel West Sussex should be so grateful and so proud to be able to offer the services that Aldingbourne Trust provides; they should be looking to support and enhance the wonderful variety of opportunities it provides. Having looked at and experienced provision in other parts of the country this is second to none, whether it be staff or facilities, residential or day activities. They do not appear to appreciate how lucky they are and that most other councils in the country would give much to be able to offer similar to their clientele.*
- *As this is fundamentally all about saving money, it is hard to believe the council really has the best interests of the learning disabled, their carers and providers at the forefront of this exercise! We understand these are difficult times but cutting provision does nothing to support their claim of increasing independence for clients. Instead it will*
 - *reduce the benefit they receive, affect their health and well-being, their opportunity to develop skills, to socialise and to increase independence.*
 - *Impact parents/carers who rely on daytime services, who have to manage their own workloads, already put huge energy and time into those they care for and are often not far from breaking point themselves. They are hardly going to get 'more support and a break' if access to day services is reduced, it will pile more pressure on the home situation and may even result in clients having to go into full time care at additional expense for the authority.*

SO all this will do is shift the cost onto other services – mental health teams, social services, NHS, the benefit system – saving money in one area simply to push it to somewhere else is not seeing the 'big picture' – what is needed is joined up thinking across services appreciating that if peoples' needs are met this actually in itself reduces cost overall.

- *COVID19 – some day services opened up to some degree through the late summer and early autumn with a lot of additional protocols. Although very grateful for this it could by no means be considered normal provision in terms of interaction and experience.*
 - *Online services, outreach support and activity packs were developed because it was the only way to keep some form of connection and support for clients and offer at least some form of activity. However this was a 'stop-gap' and in no way should be seen as the new norm. Some benefits may be able to be built into provision going forwards but it cannot replace face-to-face in person activity.*

- *For many with learning disabilities, especially those on the autistic spectrum, coping with social interaction is a learned skill; some find it extremely difficult and live with a high level of fear and anxiety but benefit immensely from being in a supported, friendly environment where they can learn to interact face-to-face through consistent and regular attendance. If this is compromised there is no way they will increase their independence levels, social skills or well-being. They are at significant risk of being isolated if day opportunities are changed/reduced.*
- *Re 'Good quality of life'*
 - *Independence: the new buzz word and West Sussex are using it somewhat disingenuously! It is not necessary to have independence to experience a good quality of life – agreed that it is desirable for an individual to have as much independence as they are able to manage comfortably without undue risk so that their quality of life is enhanced, but full independence is highly unrealistic and making it a goal could put individuals under more stress and make them more vulnerable than need be.*
 - *Of course we want those we care for to achieve their potential but it doesn't depend on ability, they will do it by being supported appropriately to achieve it by having the right environment and activities to help with the development of their talents and skills.*
- *We understand that people with learning disabilities have strong views on what they want for their lives and wholeheartedly support this BUT having 2 sons with autism who do not fully understand the complexities of day-to-day life and the world at large we have to accept that sometimes their views are simply not realistic or practical. Yes their views should be sought and considered but to base changes/cuts on this would actually restrict their choices and not improve them in our view.*
- *More access to the community means more/higher levels of support, often 1:1 because there need to be more risk assessments taking their vulnerability and limitations into account, so it is not a cheaper option.*
- *Health & Well-being – keeping fit, being healthier won't happen if they spend extended periods of time at home/alone in their flats. Some find it difficult to go out for exercise unless it is built into their routine/schedule so to attend formal day provision is actually the best means of getting them out and improving their well-being!*
- *Better autism awareness is enhanced through day provision where there are dedicated and trained staff; the knowledge they have filters out into the community and increases awareness. With the best will in the world the community at large is not going to be better educated about autism and other disabilities if those who suffer from the conditions are isolated at home or display more challenging behaviour in public because their needs are not being met.*

- *Real work, real jobs, real wage – yes we can understand that but again we have to be realistic; holding down a job even if one can be found (and that is going to be more not less difficult post COVID) requires commitment and additional support and flexibility on the part of the employer. This is where provision such as The Aldingbourne Trust is so beneficial in providing ‘work’ opportunities through the many small businesses it runs through the Aldingbourne Country Centre, the Creative Art Studio, the Aldingbourne charity shop and the many volunteering enterprises such as Adopt a Station.*
- *Council plans:*
 - *Fewer people going to building based services – buildings have fixed costs regardless of the numbers using them – utilities, overheads and safety requirements. It would seem more sensible to maximise use of the facilities that are available. It is also much easier to have dedicated support and trained staff in a building provision with a higher ratio of clients to staff than in more open, community-based environments where 1:1 support is more likely as result of risk assessments. Clients also benefit from face-to-face social interaction and in building settings it can be supported and developed more successfully.*
 - *More community-based opportunities in different settings – isn’t this exactly what the Aldingbourne Trust does/promotes?? Centres of excellence at the Country Centre which is normally open to the public throughout the year and The Creative Arts Studio lead to increased awareness of learning disabilities in the community, opportunities for clients to mix positively with the local community in a safe and supported manner, work type businesses to learn real life skills and display their talents locally.*
 - *Limiting provision to 1 day service – such restrictions take no account of potential, skills development and run counter to the idea of increasing independence and the individual’s right to choose. How do provisions such as The Aldingbourne Trust who have more than one site come into this? – as far as we are concerned the Trust encompasses the whole range of provision and that is what the funding we have for our sons covers. The fact that ACC and CAS are on separate sites does not make each a different provision, it is one excellent provider offering its clients a wide range of supported opportunities.*
 - *Maximum 3 days – again one size doesn’t fit all. This may work well for some clients, for others it won’t. If the aim is to provide real life’ work experience where the individual may have the potential in the future to access employment then more is a better training and preparation for more independence later which is clearly the goal.*
 - *There should be opportunity for a progressive pathway – as an individual develops they may need to access different activities, have*

a different mix or more days – the more restricted and rule bound provision is the less flexibility and benefit there will be for users

We would be genuinely concerned if the proposals outlined by West Sussex Council were going to be detrimental to the provision of the Aldingbourne Trust. We would regard this as very short sighted of them. This is an excellent provider for the local community through the training, support and work opportunities it offers and as mentioned above is very rare commodity in this country! The Trust constitutes an amazingly diverse training ground for the individuals it supports which has been painstakingly built up over decades, and clearly meets all the criteria for learning independence skills and developing potential that West Sussex advocates. This has not come without cost or commitment – we have witnessed significant development and expansion over the past 5 years since our involvement with the Trust began and cannot commend highly enough the hard work and dedication of the management team and staff. To think that all this may be compromised by a ‘one size fits all’ approach from West Sussex simply to reduce their budget in the short term is beyond belief. ” (parents)

8. **My daughter...** “ *With reference to the proposed cuts to day services I can only speak on behalf of my daughter, A, but I hope that this may influence decisions made for other adults with learning disabilities who have no family or advocate.*

A attends the Aldingbourne Country Centre on four days per week and has done so for at least 20 years. It is her working life and vital to her mental health and wellbeing. She has a diagnosis of Learning Disability, Mixed affective disorder and bi-polar affective disorder. She has regular appointments with Dr. Arackal, Consultant Psychiatrist. I quote from his letter dated 7th January 21 “A’s current presentation seems to be similar to her previous episode. The lack of structure to her day due to the lockdown, inability to go to the Aldingbourne Centre does not seem to have helped her at all.”

During the spring lockdown A stayed with us, her parents, for four and a half months and again during the current lockdown until she can go back to Aldingbourne Country Centre. I am 71 and my husband is 85 and is currently being treated for cancer and heart disease. We sent A to Bognor to attend Aldingbourne when she left further education and we wanted her to be able to live as independently as possible.

I recognise the need for the Council to save money, but in my daughter’s case her care could be more expensive as without the day service she would need one to one care everyday and I know there would be more occasions when the Mental Health Team would be called.

In the notes sent by West Sussex they mention work, real jobs and participation in the local community. My daughter would like nothing less, but we have tried over many years and it just does not work. She has worked in Charity shops and cannot cope with difficult or intolerant customers. She had a supported job in a supermarket cafe, but any complaint or minor criticism and she became extremely distressed. As part of the Aldingbourne team she worked in the restaurant at Durban Road, but the customers were not the general public, they were social services staff. At the Country centre she feels valued and her confidence is helped every day. In this supported environment she works well to the best of her ability and takes on new challenges when offered. She considers it to be her "job". As for participation in the local community we have tried that as well. With a support worker she attended a belly dancing class, good exercise and she loved it, but she was asked to leave because the other customers threatened to leave as they found A's over enthusiasm disruptive.

Attending the Country Centre and with support accessing local amenities like the swimming pool with her support worker at weekends or her day off A stays well and happy. She enjoys the company of her peers and all the excellent support staff at ACC.

I urge the Council to consider these proposed cuts very carefully and ask the question. "Would it really save money in the long term?" Thank you for your attention. ” (mother)

9. **My son...** “ *I wanted to say that I think the day services are very important not only because they help individuals develop independence but also because they give individuals a sense of purpose and this raises their self esteem and helps them maintain a positive outlook and stable mental health. My son N who has autism and high levels of anxiety benefitted greatly from the day services at Aldingbourne. His attendance there and task of looking after the animals helped him feel useful and valued. He will miss working there if the day services are cut* ” (mother)

10. **Our family...** “ *To R & P the Aldingbourne Country Centre is their whole life and something they have really missed since the first lockdown. I have noticed a severe decline in their overall wellbeing since then without a structure to their daily routine and being with likeminded people and friends that understand and value them. I appreciate WSCC desire to encourage to adults with LA to be more independent thereby reducing the cost to the county but feel this is something that cannot be generalised and each person should be appraised on an individual case/ person and the consequences of not having the support.* ” (family)

11. **Our son...** “ *We are very happy with the services already provided at Aldingbourne. I believe that the council should be aware of how adversely changes can affect adults with ASD. I am a strong believer in, if it is working well, why change it. Are these changes in the client's best interest, or are they simply down to financial pressure?* ” (family)

12. **Our son...** “ *I am writing to explain how the restrictions on attending Day Services over the last 10 months has affected my son. I want you to comprehend how narrow his World has become, however I would also like to express how grateful we are to Milton Lodge, his residential home, for keeping him safe throughout this pandemic. My son is a young man of 33. He has greatly benefitted from accessing The Aldingbourne Country Centre and The Creative Art Studio for 15 years where they have helped him to develop towards his full potential. He enjoyed keeping fit at Felpham Leisure Centre by way of 'Swim and Gym' although support was needed to get him to and fro this activity. He was a happy, sociable man with Downs' Syndrome.*

If there is one thing that 'Lockdown' has highlighted to us all, it is the need to communicate, socialise and utilise our strengths to feel that our lives are enriched and worthwhile. Suddenly, denied our normal freedom, Mental Health and Wellbeing has become an issue for us all and not just a 'buzzword' in the media. Our lives have become grey, we have turned to online quizzing, jigsaws, phoning friends and reading copious amounts of books and magazines to help pass the time and fill the void. When loneliness looms like a big dark cloud we have taken ourselves off for a stroll around the streets or parks of our local area...yet, despite these opportunities afforded to us, the lack of freedom to participate in society has got us all down or near breaking point.

Now think what Lockdown has been like for someone who can't read. Those pleasant hours spent lost in a book are not a luxury shared by all! You want to speak to your family but you can't dial the number. You'd like to go for a walk but aren't capable of going alone. Your daily life, usually spent productively or creatively is reduced o hours of nothingness or tv, tv, tv!

Would you feel like screaming? Yes, so would I!

It is well documented that everyone's mental health has been affected by Lockdown and how sorry we have felt for ourselves, and others, experiencing anxiety. We commiserate wholeheartedly with those who's state of mind has suffered due to the deprivation of a full and meaningful existence... after all, being able to empathise makes us human. But now, thankfully, Lockdown for us 'normal' folk has a light at the

end of the tunnel; a key, by way of a vaccine, is turning and soon we will be able to partake in the wider World enjoying our favourite activities once more at work and play. We have experienced a life with 'cuts' and we did not like it! We will celebrate our newfound freedom with gusto '...Nothings gonna stop us now..!' as the song goes.

So how would YOU feel if you watched the World swinging back to normal but the key was not available to you, especially as others were able to heal their troubled minds? Desperate? Me too.

So don't forget how it feels right now to live a half-life and don't dare commit others to a life in the shadows FOREVER. Wasn't 10 months enough for most of us?

Leave the Day Services alone for the most vulnerable citizens in our community. Support don't detract!

Enough Shutdown

NO CUTDOWN! ” (family)

13. **Our son...** “K, is 22 years old and our only child. He was born prematurely (28 weeks). He suffered a major brain haemorrhage which resulted in his cerebral palsy. He has learning and physical difficulties and visual problems. He has also inherited a syndrome called Robinows Syndrome which I suffer from as well. This mainly causes dislocation of our joints. I have had a double hip replacement and surgery on my left foot and K has had a metal plates inserted in his hips and will need more surgery in the future.

K is very sociable and loves sport, especially F1. He also loves music, his favourite group is ABBA and being with his friends is very important to him. Being included and feeling part of a group is very important to K. Up until March of this year he had 4 days day care. He attended the Wrenford Centre on a Tuesday (now closed an absolute travesty yet another attack on adult social care in 2018) . The Point, run by Scope, on a Wednesday and Aldingbourne Country Centre on Thursday and Friday. Now, because of the cross infection rule, he only has two days at The Point.

Already the impact of his limited day care is starting to show. His routine has always been important to him and any change can lead to a deterioration in his behaviour. He has become very immature and is prone to tantrums which can result in violence towards me. I have found it very difficult to keep him entertained and stimulated. He really needs the company of his peers. It is very important for both of us that we have some time apart during the day. It cannot be right, or healthy, for a 22 year old young adult to spend so much time with his mother. If he were neuro typical it would be thought very strange for a young person to spend so

much time with their parents. He needs a young life and opportunities to explore new things and become more independent.

The impact on me is that I am becoming increasingly tired. These past 2 weeks have been particularly trying. I am recovering from an operation and should really be resting. K spent 4 weeks at Tozer House which enabled me to rest for that period but ideally I needed to rest for 6 weeks. It has occurred to me that the older I get this will become more of a problem. I can state quite categorically that without day care I could not care for him and have said as much to a key worker at The Chestnuts. We have seriously thought about residential.

I should point out that I attend to all of K's personal care. He is unable to wash and dress himself so he needs a lot of attention. It has to be pointed out that I receive Carers Allowance which is only £67.00 per week. If K were to go into a residential home it would cost far more. In fact The Mirror paper ran a campaign some years ago about how much money people like myself are actually saving the country. At the time of the campaign carers were saving the country 100 billion per year. Perhaps the money we need to run our service properly could be taken from the money unpaid carers save the country.

Central Government should be completely ashamed of themselves by reducing Local Government funding by 50% over the past 10 years. Local Authorities should be ashamed of themselves by setting budgets attacking the most vulnerable in our society time and time again. In West Sussex this will be the third round of cuts to adult social care in ten years. MPs of all colour, blue, red, yellow, stand up and talk about British values absolute nonsense they run a system for the rich and the

vulnerable like our people pay the price. ” (mother)

14. **My son...** “ Obviously I have concerns for my son one of which is that he is not getting out at all to interact with people. I appreciate all the zoom calls and Facebook meetings he has but it's not the same. ” (mother)

15. **My daughter...** “ When U first started at Lighthouse she attended the Wrenford Centre on a Saturday: Art in the morning, drama in the afternoon. The centre attracted many learning disabled who produced some fantastic work. There was however a cost of £10 each session. When the teacher left she was not replaced- thus the building (funded by W Sussex / tax payers ,stood empty on a weekend) I flagged this up to W Sussex suggesting they advertise for another teacher- even an enthusiastic art student who could enhance their C V . Sussex were not at all interested or supportive of this!
Given such lack of enthusiasm , I have no faith that the council will stimulate / support more opportunity for learning disabled adults. The majority of our children are easy to dismiss and ignore.

We need more Aldingbourne Centres . Spending less money to ' maintain opportunities and get a good quality of life' has proven impossible. Likewise to 'participate fully in life in their community' I would love to be proved wrong!!!
(mother)

16. **My daughter...** *“ You will see that West Sussex is attempting to reduce costs and possibly limit/ stop attendance at Aldingbourne for those in residential care.*

Unfortunately, because of Covid, an annual review is considerably overdue. If this was to take place it would once more confirm the need for U to attend Aldingbourne and highlight the enormous benefit that U obtains from attending. U considers Aldingbourne her place of work , she has been at a loss for the past year, going nowhere ,bar a short walk locally. She certainly has no interest in Zoom!

Over the years I have seen with despair the continual cuts and the effects they have on my daughter. Aldingbourne is the one positive. I also believe it is cost effective. While I commend West Sussex list of ' desired opportunities' for less money, the bottom line is that most people ,like U, need special help and integrating them into the community is fraught with difficulty (plus cost !) U would need support and there is little opportunity available locally. Also such excuses such as health and safety, insurance etc predominate. It is all very well to seek employment (let alone paid) My experience is that such opportunities are rare and often only available to the more able among our learning disabled. Post Covid I would think any such job will be scarce! .

U feels secure, confident and happy at Aldingbourne ,with a huge variety of activities and jobs. She can socialise and also gain new skills and independence. She has a purpose to her life.

In an ideal world, of course we would wish our children to mix and have the same opportunities as the more able. The reality is they are constantly failed and disappointed . I realise there is more demand than supply but it seems very cruel to deprive present clients of the benefits, friendships and opportunities

*” Aldingbourne provides and which is unavailable/ non existent elsewhere. **(mother)***

17. **Our son...** *“ I feel strongly about this and I will do anything I can to stop WSCC breaching the Human Rights of people with learning disabilities. This is essentially what they propose to do - Breach Article 14 of the Human Rights Act and the lesser known (and never adhered to in the UK from what I can see) Un Convention on the Rights of Persons with Disabilities 2008.*

Its appalling that WSCC are now using the pandemic and temporary switch to online support services for people with LD as some sort of evidence that physical

day services, consistent and specialist meaningful day time activity is no longer needed. It makes me sick that WSCC continue to dress up their funding cuts for people with LD by suggesting that it is better for them to be accessing mainstream services. This is right for some but not all and therefore a broad-brush approach to rationalising day services is not appropriate or lawful!

I would want to help WSCC understand that ACC is not a 'day centre'. It is a specialist day service, provided by specialist staff, in a specialist environment. The benefit of this type of service to a person with LD cannot be replicated with what they seem to be now proposing ie a zoom call and a support worker taking someone to Tesco to buy a meal deal once a week!!!! There are no local services in the community for people these days - so which ones WSCC are thinking that people with very complex needs are just going to 'fit into' is beyond me! This type of approach to day services for those who need and benefit from specialist services leads to isolation, discrimination and has a negative impact on physical and mental health. ” (mother)

18. **Our son...** “ *I do have some concerns about the provision of services as we ,hopefully, emerge from lockdown. Of course I entirely understand the Council's need to cut costs and I appreciate that it is very difficult for those of you involved in trying to give all the clients as much support as possible within the inevitable constraints.*

Obviously my main concern is for Q, but I am sure there are many others in a similar position.

I can see the merit of clients only accessing services 3 days a week but I am concerned that if they can only access one face to face service that people like Q will only have a very narrow experience.

Q has plenty of support and I have nothing but praise for the staff at X Road and all those who have provided craft etc for him and the others.

Zoom of course has been a lifeline for many but Q is unable to use it without a member of staff of being with him and he does not really relate very well to the audio visual experience. This narrows his experiences a lot.

In order for Q and others like him who are unable to use zoom etc I feel the opportunity to access more than one service is important for them to meet a wider group of people and to begin to .return to becoming part of the wider society and community even if it is only for 2 days a week in one place and one in another.

Q loved working on the farm and being part of the Country Centre community and he loved accessing the Art and Craft service. One without the other, although very much better than the status quo, would inhibit his return to any sort of normality.

I hope you understand where I am coming from. I have no option but to use Q as my example, and I know how hard you are working to plan how things will go forward, but I hope you will be able to work towards a wider experience for people

like Q even if it cannot be achieved in the short term. ” (parents)

19. **My son...** “ *There are a lot of assumptions there which are particularly wrong, especially since covid hit us and other reasons. It is wrong to assume there will be an alternative of community support, which always relies on volunteers. There is a national shortage of volunteers (in normal times - don't let West Sussex County Council use the fact there may temporarily be more volunteers as they will stop volunteering as they regain jobs post pandemic). Transport will also be under threat once more. Aldingbourne Country Centre was changed to meet some of the future needs and aspirations but still needs and deserves WSCC support to survive the next few years especially (I assume). Work experience/volunteering is just a pie in the sky thought at the moment for most clients I would have thought.*

Back to the old attitude of not to be seen or heard. ” (mother)

20. **My son...** “ *I just hope that F can remain at acc as this is his livelihood where he meets his friends and he's happy and likes his routine . My question is if he has to be placed elsewhere will this continue? As he wants to work what opportunities are there going to be for him?* ” (mother)

21. **My daughter...** “ *staff are fantastic, L gets tremendous amount from there and they are very specialist, but also provide a safe space for people will relax there. Lady called D who gets very anxious and thought she always made that noise, but when stayed for a session she calms down and gets on with her art work and that's to do with finding the space comfortable. Same with L, is facilitated by them but needs the staff to help her start, she wouldn't do it at home. That is really important in a day centre, the comfort and facilitating friendships which nearly all our young people struggle with, can seem fine with adults but facilitating being comfortable with others in their peer group and other people is a different matter. How fantastic and important that safe space is.* ” (mother)

22. **A carer's view...** “ *S lives in supported accommodation, and we are his support here and we would have to invest in having more staff to accommodate supporting him stimulated all day. Comes to you 3 times a week, thank god we have 1:1, zoom meetings etc. Have 6 people we support but constantly battling, staff furloughed so trying to entertain everyone and if S hasn't got you he'll be stuck at home doing nothing.* ” (carer)

23. **Our daughter...** “ *how thankful I am for all the teams support in keeping D going, initially with zoom and facetime live. Was initially difficult to*

access and anxious in accessing it, but as time has one on she has really blossomed. Lives at home with us 24 hours a day and has never left us and support has been brilliant. To take your service away from D or to decrease it would be heart breaking for her and extremely difficult for us to maintain D's support here. She's 29 this year so time moving on as we are so always looking at ways of trying to increase her interaction with other people. If you take away those choices and just 1 day, what do we do the rest of the week to make sure she is safe, she's not able to be left alone, not independent and totally dependent on us – ACC has been a lifeline for us over the years. Lovely diversity and the staff understanding of her needs is quite exceptional, Apuldram was her social day so it's heart breaking for them to take that away from her. ” (family)

24. **My son...** “ *The Pandemic has given us the most amazing evidence of what happens if you take away our services. All these people have been out of services for a long time and we've heard about the impact this has had on people's mental health.* ” (mother)

25. **My daughter...** “ *as far as people in residential not getting support, at moment someone like T is accessing zoom which is very difficult for her to do at all. Has only been able to do because I am doing it for her. At the moment I'm furloughed but if I wasn't at home or working at home they wouldn't be able to do that for her. If West Sussex didn't provide T would have no purpose and would stay in bed.* ” (mother)

26. **My daughter...** “ *I am interested in what West Sussex think these day services will be. Accessing services has been a godsend.* ” (mother)

27. **Our brother...** “ *K and I are W's carers and are both in full time employment. This last year has been rather tricky for all of us as we have not been furloughed or able to work from home. Therefore we could not support W in the same way as when he was attending ACC. During this time, W has been at home, mainly alone, with K coming home early when he can from his employment. Unfortunately, as I am a primary school teacher, our school has been open for the parents of key workers and vulnerable children, so I am not able to start work later or finish earlier.*

We really appreciated when W was invited back to ACC as this really helped with his mental well-being. For him, being stuck at home was to the detriment of his health. People who know W, know that he is a very sociable and lively character.

He refused to go on walks with us and became quite withdrawn. He has a shorter fuse and things that would normally be fine, tend to annoy him. This then has an impact on us at home and causes us anxieties that we are not doing the best by him and makes us unhappy that we cannot support him in the way he needs.

When W is at home he just sits watching telly, looking at magazines and sometimes does colouring - (which he's not really doing so much of now). Initially he started walking around the garden as part of his routine but even this has now fizzled out. W was unable to access online services as we were not at home to set them up for him at the actual time. Also, he finds learning new skills quite hard as he has a short attention span when learning something new and goes off on a tangent.

In addition to this we have to prepare his breakfast and lunch for him everyday and need to ring him when its lunch time as he would have no concept of time. So I ask, how would W cope if this was the new norm? Not very well. On the plus side of things, he is lucky that we all live together and he has family interaction when we are home from work and he has dinner around a table with us. My thoughts go out to all those other adults with learning disabilities who don't even have that.

Being at ACC provides W with a safe space and it also puts our minds at ease. We know that there are trained and educated support staff to look out for him when he is at ACC and he himself feels so much more secure as this has been his 'workplace' for the last 30 years . He absolutely loves going to 'work' everyday. It is clear to see that him calling ACC 'work' makes him feel like he has a purpose. Prior to lockdown, if ever we said that he wasn't to go to 'work' due to an appointment, he would be quite distressed and would keep saying that he 'needed' to go. So, I go on to say that what you provide for W is not just a 'day centre' to keep him occupied but a specialist service that makes him feel needed and gives him a purpose.

We thank you again for all that you do for W. It is very much appreciated. Without your services and hard work fighting for the cause, we would be at a great loss.
(brother & sister in law)

28. **My daughter...** *“ people like A look to be spending at least a year away from Apuldram and a “normal” routine. They have already coped with months of uncertainty with Covid restrictions and possibly more to come. The current staff team have been brilliant at minimising the impact but there have been distressing episodes which A has shared with the family. A cannot return to the centre, the H Road kiosk is no longer functioning and the nights are drawing in.*

*”
Poorer weather is inevitable. Her current Care Plan is now irrelevant. **(mother)***

29. **My sister...** “ *although A has access to a computer tablet she is unable to access online activities without support. I am sure that she is not alone in this amongst your clients.* ” **(sister)**

30. **My son...** “ *is in supported living, 24/7 sleep in house with 3 other males. They all attended day time services Mon to Fri during the working day. Additional staffing now required in lieu of day care attendance to keep them all safe while shielding at home. One staff member redeployed from day services to provide at home/community support, however, this restricts choice and movement. Are there going to be 2 staff at times at the house as they are all back. It's difficult if one doesn't want to go out, then no one can.* ” **(mother)**

31. **My daughter...** “ *To give you a little backgroundI am a retired school teacher, with experience of teaching music to Pre-school, Primary and secondary school children, teaching all subjects to Primary school children, teaching in MLD and SLD. My daughter S has Down syndrome and she is now 34 years old. At 16 she went to The Mount Camphill Community College in Wadhurst East Sussex. After leaving there she went to the Acorn Centre in Pulborough and then went to Chichester College to do Performing Arts and the Theatreinc. She gave up Theatreinc to concentrate on her art at CAS.*

I realise that all councils are reviewing day services and I understand that they were doing so before Covid, but now there is more urgency. However, it is crucial that WSCC do not cut things that are working well at present.

To move away from old school provision, where all people with LD went on a bus to a day service is only satisfactory if what is put in place is an improvement. More person centred services around people being in their communities is a laudable aim, but there need to be priorities like people being able to keep their friendships and people being less and not more isolated. It is critical that carers aren't left supporting their loved ones at home without help.

More choice and more control

This is possibly a commendable aim of some with LD. However, in my experience, many people with LD need to have person centred meetings, but they need goals and choices very carefully chosen and many are unable to organise themselves or have complex choices provided for them. I agree that more evening and weekend activities would be good and also in holiday time, when day services/college courses are not running. Obviously, it is desirable to have a mix of people and this is beneficial for both LD and the rest of the population. More independence is desirable, but true independence is only possible with sufficient support.

Be healthy

Keeping fit is very important for health and wellbeing. There is nowhere enough emphasis on weight control. We had many years battling to get S's weight down and this was only achieved by S returning home to stay. Neither Social Services or Aldingbourne Trust did sufficient to help her regain a healthy weight. S now has a determination to keep to a healthy weight and also keep fit and her support staff have been helpful in supporting her.

Work

It is an admirable aim that LD people have real jobs. With the present financial climate, this is not easily achievable. However, I do think that adults with LD can perform a useful role in all sorts of voluntary capacity and this can make them feel worthwhile.

Relationships

It is very often difficult for adults with LD to make and maintain friendships. They need help to facilitate their girlfriend/boyfriend relationships and it would be useful for them to have dating help.

Carers

Many family carers find it burdensome as well as rewarding to care for their adults with LD. They need to have support and respite, so that they can fulfil their own lives. Too many carers sink under the weight of their responsibilities.

Transport

Most transport issues require extra funding, whether having more training for bus drivers etc. or extra assistants to help adults with LD in accessing transport needs. Transport in the evening/dark and at weekends will be likely to remain an issue with cash strapped councils. More use of willing volunteers could assist, but only with sufficient vetting

Council Plans

*Some admirable aims but there is unlikely to be a possibility of improving independence with less cash. There needs to be proper investment in those services which are working well, whether building-based or community lead. **it's a ludicrous idea to just provide 1 day service for people.** People with LD are as varied as the general public, or maybe more so. They require a wide variety of services. Why shouldn't a person with LD do something to do with horticulture one day, a drama or dance session on another and a creative arts session on another? **The idea that there should be a maximum of 3 days per week of a day service is also nonsensical.** Their mental health is very likely to deteriorate, such that they will stop getting up in the morning and generally go into a decline if days are cut.*

Getting service users and carers view

I welcome this. it is essential that those who have an intimate knowledge of adults with LD are included in any decisions made.

With regard to my own daughter S, she has been given an excellent service by CAS at Number 73. She is a Down syndrome woman of 34 years, who has blossomed as a result of her achievement in Art at her day provision. She also has

autism and the safe and comfortable space at 73 has been superb..She has attended from 1-3 days at CAS. When she was at Chichester College doing Performing Arts and Theatrinc she attended less, but since leaving there, she chose to attend 3 days per week, as she was also volunteering at AgeUK at the Laburnum Centre. She would never have realised the talent that she had, if she had not been given the opportunity to have such excellent training and support at CAS. They have facilitated her in her art, given her a social group that she feels at ease with (this shouldn't be disregarded as it is equally as important) and her unique talent has developed.

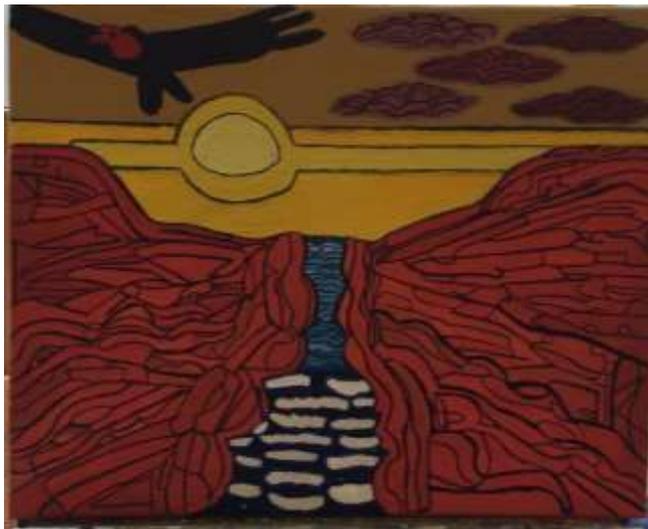
CAS involves itself in community project, eg painting a wall at Bognor Library, art using recycling materials, doing projects concentrating on different cultures and countries (African, Greek, Chinese, Australian), visiting places to inspire, eg. Marwell Zoo, Birdland, etc. They also have become involved in displaying work in the Novium Museum and Chichester Cathedral Flower Festival and numerous other good works. They have a close relationship with Pallant House Gallery and S has had her work displayed there as part of the OUsideln Project and became an ambassador for them. She has spoken about her art and had it displayed at The Pallant House Gallery and at the Aldingbourne Country Centre. She also won 3rd Prize in the Sussex Artists Award (an open competition for all artists).

S has also had her work displayed in Littlehampton, London, Manchester and New York by Heart and Sold- a platform for Down syndrome Artists.

S says that CAS gives her life purpose and it makes her happy. The art projects which they do give her ideas and she learns techniques and they help her with research.

Although S is able to do her art work well on her own, when she is motivated, she requires people, who understand her to keep her on task and also to help her with any problems she has, whether it's colour mixing, choice of multi media materials or research connected with her painting. Without her day provision S would go into a decline. She would go to bed very late- as late as 6 or 7 in the morning (as she has had a tendency to, since living in her own flat) get up at lunchtime and do nothing but play games on her phone or watch television.

I am including 3 photos of contrasting paintings to show you her unique ability
(mother)”





32. Our daughter... “

- 1) *Cutting back on the number of day centres D can attend:*
 - *Takes away D's human right to have a choice*
 - *Limits the variety and reduces opportunity available to D*
 - *Affects interaction with different peer groups/ friends, consequently losing contact with those friends from the centre that she is no longer attending resulting in alienation and isolation from social circles owing to D's inability to relate to people outside of place of common interest and also no longer being invited to social gatherings with those friends she has made through the centre she will no longer attending.*
 - *D will miss the interaction with people at the centre, which has helped with her confidence when out and about in the community.*
 - *D comes home from her centres happy and proud of things she has achieved from the day – this will be taken away from her.*
 - *D will need more allocated support hours as she cannot do anything without 1:1 support – not even leave her flat. But then is unlikely to get out of bed unless having support!*

- 2) *Cutting back on how many days D can attend her day centres:*

- *She is autistic and struggles with change and is likely to result in D having an anxiety overload, resulting in D not leaving her flat or doing anything and asking all the time where everyone at the centre is.*
- *Lack of understanding why she cannot attend resulting in her feeling that she has done something wrong.*
- *Insecurity as D struggles with changes happening without understanding and it makes her feel very scared and anxious about what next will go or change – past experiences resulting in D having a complete sensory overload and with her refusing to get up out of bed and leave her room*
- *Support risk as there will be no 1:1 for D during the daytime (out of core hours) other than daycentre. Therefore on those days she cannot attend her day centre, D will be in her flat all day alone and isolated, leading to depression and lack of ambition, no focus or purpose*
- *Health and safety hazards and issues arising out of D being left alone in her flat*
- *Bad for D's wellbeing – prone to withdraw and isolate – day centres helped D to interact and gain confidence in a safe and supportive environment – possible weight gain as no exercise*
- *No sense of purpose therefore no reason to get out of bed*
- *Would not drink and eat properly if left alone all day.*
- *Eyesight could deteriorate, as she would sit looking at phone and ipad all day (inches away from her face) in the hope of interacting with friends.*
- *Over stimulation from screens therefore resulting in not wanting to go to bed at night*
- *Would need extra financing for 1:1 to avoid issues above and that would be more expensive (cost of day centre = just over the cost of 2 hours 1:1 support)*

Carers

- *Will create a massive strain on us as parents, with both of us in our 60s*
- *Parents are also supporting aging parents and would find it challenging to provide more additional support for D.*
- *Would place additional pressure on my ability to both work and also to look after D. All three components of the WSCC interpretation of "quality of life" are essential for D's continued development and require a variety in both her daily routine and the support that is currently provided within her day centres. Any diminishment of this will result in these life objectives being incapable of realistic achievement.*

Furthermore, the less scope she has to attend her day centres, the more it is likely that she will become isolated within her accommodation rather than being able to participate fully in the life of her community. ” (parents)

33. **My son...** “*My son W has Down's Syndrome. He is 38. He lives at X Road Bognor Regis in supported Living with Aldingbourne Trust. He has not attended day Services since before lockdown in March 2020. Normally he attends*

ACC once a week and Ferring Country Centre 3 times a week. He needs routine in his life. He has been very much missing going to the WSCC Day Services.

His physical health and particularly his mental health has suffered a great deal without the WSCC Day Services, as well as the social contact. This has had an adverse effect on his language and communication skills. It is absolutely vital that the WSCC Day Services should continue without any cuts. Please do not allow the proposed cuts to occur! ” (father)

34. **Our daughter...** “ *From our perspective the Covid Pandemic and the loss of access to ACC and other daytime services has had a massive detrimental impact upon T’s mental health and physical wellbeing. She has become more anxious and her need for reassurance about day to day living and daily routines have increased from an already overwhelming level to one that is having an impact on our own mental health & wellbeing. Her level of dependency especially upon me has also increased and she has reverted to behaviour that she displayed when still in educational settings. This involves her need to have a favourite soft toy to be with her at all times when in the house and if we allowed it when going for daily exercise or trips out in the car with myself or her carer. She spends a lot of her day when not occupied talking to this toy and insists on including it in all our activities.*

She has developed an increased attachment to her carer and the lengthy periods spent at home because of the restrictions has exacerbated this. T is constantly sending messages via What’s App to her or myself seeking reassurance about daily routine and contact. She finds it difficult to understand the need for boundaries and when to give this a rest.

We like so many parents, guardians and carers are exhausted and the thought of getting back to some sort of “normal” routine with T accessing support away from the house at least 4-5 days each week filled us with some hope and energy to carry on.

T has benefitted from the brilliant Zoom meetings that your teams have facilitated, but as we would all acknowledge this cannot be a substitute for face to face contact that is so desperately needed once we come out of restricted access, when Covid cases have decreased and the vaccination programme is complete.

When reading the options outlined for discussion based on information supposedly submitted by individuals who were apparently consulted on what they would ideally like to have in place, we are stunned and quite frankly despairing disillusioned about the future for T and indeed for ourselves.

We care for T 24hrs a day at home with some current support from a PA to allow us to continue with our own work commitments.

If as is being suggested the access to Day Services are decreased this will not only impact upon T’s choices for daily inclusive and diverse activities, it will further impact upon her and our own already fragile physical & mental well-being. Surely by taking away the choice of how many days an adult may access a Day Service is

a discrimination against their Human Rights as cited in Article 14 of the 1998 Human Rights Act under discrimination.

As carers for T we support her to manage her budget for accessing support of her choice within the permitted organisations available. We are being told that her contributions are increasing but with this increase comes a decision to further remove choices which are currently working so well for her. So in effect WSCC are implementing increased charges for minimum and reduced support.

T has attended Aldingbourne for around 13 yrs since first accessing this when she was attending St Anthony's Special School and then Fordwater Special School. She has always enjoyed the diverse activities on offer at ACC and so enjoys the company of adults who she feels comfortable and unthreatened by. Since March 2020 T has seen the permanent loss of Hub Club which was run by Apuldrum and this leaves a gaping hole in activities she can access within her financial budget. If the proposed limit of 3 days is enforced upon her budget expenditure I would question how we are able to support T to access meaningful and enjoyable activities on the remaining 4 days each week as well as maintain our own paid employment and a semblance of some respite time for ourselves. Surely WSCC will see increased demand for financial support to fill these gaps as there will be no support available other than ours or a paid carer for increased hours and a breakdown in our ability to care for T at home in the future.

In the areas for discussions by WSCC decision makers it states that our children would like to access employment- when this question was posed to T she was quite adamant that she did not wish to be placed in this environment and stated that such environments made her feel very scared and unhappy.

The budget we hold for T includes an allowance for Respite and indeed this benefits T as she gets to spend quality time with others who have a bit more energy than we do after long periods of caring. The respite works well with activities in place such as ACC for a good portion of the week. If this was reduced then her care & support during respite periods would dissolve to meaningless days trying to find activities to fill them with no budget or choices to access anything.

It is difficult to summarise our feelings and thoughts on our situation and we have only touched the surface of how our life caring for T impacts on us and our worries for her future needs.

Please share this email and contents with personnel at WSCC. ” (parents)

35. **My son...** *“ I know R is desperate to get back there. I read through the wsccl info and I wonder who they spoke to and how they worded the questions, as it's quite easy to get the answers you want by how the questions are asked! I think it would be devastating for R if he was not able to return to ACC when safe to do so. He just doesn't get on with the Zoom activities etc. But really needs something to get his brain working again, planning things and the like. Having*

someone take him out for a few hours a week won't do that in the long term!"
 (mother)

36. **My daughter...** “ Dear Learning Disability Partnership Board
 I write with regards to your correspondence relating to Day Services dated March 2021. My daughter H is 31 years old and before the pandemic, she attended Ferring Country Centre two days a week and Aldingbourne Country Centre two days a week. H lives in a shared lives placement and visits us in our family home regularly.

H attended Ferring Country Centre for approximately 10 years and Aldingbourne for just under a year. H was thoroughly enjoying attending Aldingbourne and was really settling in. She chose Digital Media and Performing Arts sessions and was hoping to progress to working other areas of the centre such as the shop and looking after the animals in time.

When H was told that she could only return to one day centre after the first lockdown, she chose Aldingbourne and returned there twice a week until the most recent lockdown. The Aldingbourne programme was very different and H was only able to work outside on the farm for 4 hours in the morning but she continued to love her time there. At present Aldingbourne is closed and H is not able to attend, but she has decided that when the pandemic restrictions are lifted, she would like to attend Aldingbourne for 4 or 5 days a week.

For H, attending a day centre is everything. She calls it her ‘work’ and she wakes up every day with a sense of purpose because she has meaningful and enjoyable day time activities. The pandemic has shown us exactly what happens to H when her ‘work’ is taken away from her and it has been extremely distressing for us all to observe. H has literally mourned the loss of her day service and despite the amazing efforts of her shared lives carer P and family, nothing has been able to replace what H has lost. Her mental health has deteriorated and obsessive behaviours, challenging outbursts and low mood which had previously been well managed have returned.

H is a very special person, with very special needs. She needs specialist care in all environments and enjoys spending time with people like her. There is no other environment where H can receive the specialist support and activities on offer at a day centre like Aldingbourne and it is therefore an essential service.

The Board explains that they are considering new ideas to help people live ‘an independent life’. There seems to be some inference that attending a day centre prevents people from being independent. This is certainly not the case and I can assure you that attending a day centre provides people with learning disabilities with independence that they cannot achieve anywhere else in the community. It of course not the type of independence that non-disabled people expect for themselves, but for people with Learning Disabilities, this is their independence and it means everything.

It is important the Board understand that if they reduce or take away day services from people with learning disabilities, the stark reality is they will be condemning some of them to a life of nothing – no purpose, no choice, no independence, no social interaction, nothing. This social isolation will lead to poor mental health, poor

physical health and will place unimaginable strain on paid carers, families and other already overstretched health and social care services. People with learning disabilities are one of the most vulnerable groups of adults in our society so financial savings should be made in other areas of the council's budget before even a thought is given to day services having to face cuts.

The Board explains that because of Covid, Day Services have been forced to look at different ways to support people and seems to be suggesting that this proves that their plan to rationalise services is acceptable? Aldingbourne and other day centres have worked incredibly hard to provide an online offer during the pandemic; however, this has not and will never replace the face-to-face support and activities provided by day services. This is particularly the case for H who has a complex speech and language disorder and severe learning disability – online services just don't work for her. I urge The Board to understand the Pandemic has provided us with evidence as to what happens to people with Learning Disabilities when services are taken away. Speak to families, speak to clients, hear their stories. You will hear time and time again the devastating impact it has had on the individuals and their lives.

The Board says they want to give carers more support and provide them with a break. I know that for many families and carers, their relative attending a day centre is the only break they get. The reality is that previous local authority funding cuts to learning disability services has made 'respite care' a distant memory for many people and day services have become a lifeline which enables them to continue to carry out their caring role.

The board explains they plan to redesign day service models to provide more choice and control and have fewer people going to building based centres. They suggest people with learning disabilities should be accessing more community-based opportunities in different settings? I would like to ask 'where are these community based services you speak of?' 'Where are these different settings?' Even before COVID-19, the provision of local community activities for disabled and non-disabled people were scarce. Post COVID-19, they are going to be non-existent.

The Board is taking a very narrow view of day services. Day Centres like Ferring Country Centre and Aldingbourne Country Centre have worked tirelessly fund raising to ensure their centre amenities bring the public to them. Both these day centres offer activities such as petting farms, play areas, shops and restaurants that encourage the general public in and they are served by the people with learning disabilities who work there. Why are the board undervaluing day services in this way? Why are they suggesting that vulnerable adults need to access non-existent community based activities when the Day Centres have done everything possible to integrate the community into their service.

In conclusion, I would like to say I see through the Board's attempts to dress up the proposed funding cuts as opportunities to improve day services for people with learning disabilities. This is a social justice matter that must not be swept under the carpet along with the clients that use these services. It is clear that the proposed changes are purely finance led and this cannot be allowed. Reducing funding to day services will result in an unacceptable level of risk to the most vulnerable in our society and will have a devastating, wide ranging and long lasting impact people

with learning disabilities. ” (mother)

37. **My sister...** “ *It is completely disingenuous of the council to target these services at this time. There has been no attempt to understand the impact of the lockdown on service users. My sister received a call from a social worker on the second day of lockdown last March and there has been no contact since. She lives with my mother, who is now 80 and the enforced isolation of the last 11 months has been really hard for them both. The ACC staff who call each week (thank you for this ongoing contact) have probably noticed how very uncommunicative my sister has become.*

Attending ACC twice a week was a real lifeline for my sister and my mother. A structured time away from home provides a different focus. It cannot be replicated online and there is no genuine alternative provision in the community. WSCC appears to know without ever having asked that some service users have made alternative arrangements since ACC had to close. I can't imagine what they can be - given the fact that almost everything has shut. I suspect that many people are in the same situation as my sister - completely dependent upon elderly parents and having almost no external stimulation. I have done what I can to assist and we have managed to go for walks but my sister has become very insular and sometimes quite difficult. The effect on her mental health has been significant and the lack of a real day service if she cannot attend Aldingbourne in the future, will mean the position can only get worse.

I can't articulate my anger when I read the WSCC paper with its patronising and fake cheery tone. People with learning disabilities are so often at the bottom of the pile for help but seem always to be at the top of the list for cuts. How despicable to begin a consultation like this in the middle of a pandemic when the people affected have so little chance of responding effectively. I do wonder if the lack of proper consultation could be subject to a challenge. ” **(sister)**

38. **Our brother...** “ *Brother (parents deceased) of Male aged 60+ who has attended day services for over 30 years, lives independently own flat in Supported Living with early onset dementia. I have some thoughts on why Apuldram is so effective, and not really replaced by other services that perhaps are closer to 'organised leisure':*

- 1. Service users 'contributing to something' (weeding, baking, selling, etc.) - is really important for their self-worth and feeling genuinely part of something (having a job)*
- 2. The discipline of getting up and going to work' is really important, along with the need to behave responsibly while on site.*
- 3. The fact that Apuldram is outside, involves plants and animals and a wide variety of people interactions in a safe space - is really valuable.*

These are the reasons we feel X should be able to attend Apuldram as long as possible. It is important for his mental wellbeing, fitness and overall wellbeing.”
(siblings)

39. **Our son...** “ *When lockdown happened originally, there was a novelty aspect to it, and V enjoyed the unexpected 'holiday', time to indulge in DVDs and lounge on the sofa and catch up with Classic EastEnders. The ACC online meetings were very much appreciated to begin with, but after the jolly welcomes, and brief chats they soon were dismissed by V. The calls to make sure that V is ok, are great and he loves taking them, but they are an interruption, in a long day and not much more sadly.*

Parents A and B have tried to supplement his days with tandem cycle rides to the local shops with chocolate buttons as the reward, copious amount of cooking of cakes, recently drawing and a lot of TV and dvds. V's brothers have been having him to stay over, along with his Grandma, A & B have managed to get a series successful bubbles which comply with Govt. guidelines so V can get out of our house. These interruptions have been welcome, but ultimately, they are no substitute for structured days and weeks which are essential to V's general wellbeing which ACC and Apuldram provide.

For V, mentally planning for his week had been key to his world. V thrives on knowing exactly what is happening in his future, predictability, provides security whether that be when the TV times comes through the letter box, to what time we are cycling to the shop and making cake afterwards, it is crucial.

So, the anticipation of getting up at a specified time, preparing a bath, and meeting the bus give a basic structure to the day and structure a work and a rest day, and on paper you could recreate it, but it is having something to do next.....

The ride on the bus, grabbing the seat that you want, meeting your mates and the banter that goes with it provide structure.

I recall V arriving at Apuldram some time back, ignoring me to race (at V speed) to engage with staff, V announced that his brother was getting engaged, there was much distanced high fiving, a real chat and V returned later in the day with a custom made card for his brother who was the one getting engaged.

On the surface, that's what centres do and are supposed to do, but the staff do engage (both centres) at a 'mates' level and interact, with meaningful dialogue pitched at the client, sounds obvious but they are genuinely interested, offering a real opportunity to engage at client level, the staff are very special.

Most people engaging with V will ask how he is ,then run out of puff after a couple of sentences as they cannot either understand him clearly enough, or are not actually terribly interested in what he has to say.

The staff provide that communication thread, continuity and conversation, I had a chat with someone the other day who said that our children recognise and like to empathise with other people like them, much the same as 'ordinary' likeminded people do, at say a Bridge Club, or bowls.

V is very sensitive and has an empathy with people who are maybe not obviously successful or 'the best', this is apparent when watching Strictly where he knows the 'joke' or disabled dancer and chooses to support them, and aligns support accordingly, this is true with his little 'group'. He relaxes in their company, feels one of the gang, is at ease and is safe and content, and I rarely see this outside of the centre.

The centres are huge for V, but also for us, knowing that he is being challenged during the day, he comes home happy but tired, having done a shift, he has things to talk about. He is proud of his achievements in the kitchens, securing self-esteem and the feeling of belonging, proudly sporting his kitchen attire and matching hat. Physical exercise per se is not a realistic option for V at home where he has down time, but busying all day keeps him fit, without him being aware, yoga (not available now) is not a chore at work, and it helps to keep his weight under control and him fit and flexible, when he can do no more, he can rest without pressure to do more. This cannot even be lightly replicated online or at home.

These may all seem very small factors to someone not familiar with a learning difficulty, but together they combine to become hugely significant, to both V's mental and physical wellbeing.

Whilst we have been in lockdown, it has become apparent that it is easy for us to run out of ideas to keep V stimulated. Having recently been retired (parent A), I have been of some use, but parent B is in recovery from Breast cancer and the recent loss of her father, has made the recent months massively stressful for us, but also V. He has been in the thick of a deeply distressing period, he is sensitive and does understand what's going on, he has been very upset and we sense his anxiety, he does not get the respite that work at the centres provide and he is struggling.

I guess V is maybe a good cross section of some of these special people, as parents we do our best, but we aren't a total safety net, and as we get older we struggle to maintain a high level of input.

In summary, I cannot stress enough the importance of the centres to V's wellbeing, stimulating him mentally, but challenging him physically. We have noticed a change in him since lockdown and it's not for the better, we continue to struggle during this difficult period, as a family and individually. It is obvious that we, as V's parents can cope now, we could struggle a little longer with a protracted lockdown, but cracks are appearing, we can survive but the centres provide a safety net and a level of stimulation that we are unable to supply, and the help that we can offer will continue to decline in quality and quantity as we age, so what we have now is a minimum, we will need more help not less in the future.

The facilities that are on offer should/must not be diminished in any way, we are blessed with a supportive family, to help us, but I am sure that many people like V are less fortunate, they must be remembered too, it's not just about V, (but in our case it is!), he is loved and appreciated immensely, but maybe that is not enough for him now, let alone in the long term. ” (father)

40. **Our daughter...** “G, our daughter has been attending ACC for about 4 years prior to lockdown. She was so upset when we explained to her that she could not come and needed to stay home due to lockdown. She also attended Superstar arts 2 days a week and 3 at ACC. Her life like so many other people with learning difficulties was taken away from them, and nearly 12 months later she is still at home and really fed up with not being able to attend either ACC or Superstar Arts. Though we have been doing a lot of activities at home and both centres have been excellent in sending them home for her to do, it is not the same as having something to go out to do.. I think our young people have had it hard in the last 12 months and they need to get back to normal if ever it can be. I think that they should be allowed to attend both day services as many of the clients split their week between two centres. Lock down is not helpful to anyone and can cause mental issues. It is very frustrating to be kept away from friends and family and for G it has been far from helpful to be unable to visit her sister and family and to see other friends, as we are a very sociable crowd. On top to be stopped from her placements which she loves. These places that have been set up to help our young people and many of them are not able to work but this option gives them a real chance to show what they can do. G has really benefited from being at the day centres and has blossomed over the years. I would hate it if these services were to close.” (mother)

41. **The person we support...** “I am a lead senior in a support living setting where Y lives. Y attends the Aldingbourne Centre 3 times a week. Y loves attending the Centre and gets so much out of attending, it's the meeting of his friends being with likeminded people and learning new skills. For a year now Y has not been able to attend due to Covid. At first it was really hard for Y to understand why he could not attend this was a guy whom took great pride in getting his Aldingbourne T-shirt out the night before getting ready for his day then the making of the lunch box. Aldingbourne kept Y busy and he was learning new skills with skilled people. Now Y spends his days at home he doesn't go out he can't like most of us, and a year on its still hard for Y to understand fully why this is happening, Y is non-verbal so for him it's hard for him to tell us how he feels, we do know that he misses it so much. Y has contact from Aldingbourne giving him activities on zoom, although Y

does enjoy some of the activities Y finds it hard to be involved on zoom he would rather be there in person. What keeps Y going is us telling him it can only get better if we do what we are being asked of by the prime minister, but for now we need to do things this way to make us safe.

If Y wasn't able to attend the centre it would have a huge impact on his life, as he is a very sociable person and needs to be able to access this service to interact with his peers. As United Response staff, we do our best to keep Y stimulated in his day, however, he shares his home with other people who also require the same level of support and attention, so without Aldingbourne he is unable to achieve the same level of peer-to-peer interaction.

If Y wasn't able to go to the centre we would need to find some other replication for Y by doing something else with him, this might mean by approaching West Sussex and looking at his needs, which would in turn be an assessment, we would need to be able to support Y to be able to have some sort of structured day, I think it would have a detrimental effect on Y not being able to come to the centre. The Aldingbourne meets Ys's needs.

I cannot stress how much not being to attend the Aldingbourne Centre would affect Y it would be a great loss to him and so many other families whom get some much out of attending, it's their life. ” (carer)

42. **My son...** “ *Having just received a copy of the activities being offered in place of ACC by the supported living service I am looking at for T, I can only feel despair.*

They can only give him 9 hours one to one a week to go out from the house into the community and access an activity. What they have only as a maybe is working in a very small café in the outskirts of Worthing. I know from experience that there was a two year waiting list for working there, so can only assume it is at least that or may even be longer now. The rest of the time would be for leisure activities. So he would be in the house with three others for the vast majority of the week with one support worker. The people he would be sharing with have different needs, and ok would do some things together but really I think T would end up spending his time in his room on his PlayStation.

So my point is that ACC gives him a purpose in life, makes him feel like his siblings, he has a job. He is very proud of his job and talks about serving the customers and earning money. He can learn different skills and do other jobs at ACC and has done.

How West Sussex thinks it is in T's best interests to swap ACC for 9 hours a week....doing what? I just don't know. ” (mother)

43. **My son...** “ **Background**

- *S is a 23 year old young man, with a diagnosis of autism and associated learning disability. He also has a complex congenital heart condition.*
- *S attends Aldingbourne Country Centre 3 days per week.*
- *He lives at home and is supported by his family.*

Current Situation

- *Since May 2020 S has only been able to attend ACC sporadically and not at all in 2021 due to the Covid lockdown. Since spending an increased time at home, we have identified an increase in his autistic traits, such as repetitive behaviour and anxiety.*
- *S is one of the 25% of the West Sussex population who lives in a rural location. He has no access to public transport or any community facilities. When not at ACC he is entirely reliant on his parents to provide activities and support. Without ACC S has little social contact with anyone of his own age and feels very isolated.*
- *Since ACC has closed S receives a weekly telephone call from one of the support workers at ACC, which has been beneficial, however S enjoys the practical, physical aspect of his days at ACC so Zoom calls and online activities are of little interest to him.*

What S has gained from ACC

- *Attending ACC has given S a genuine sense of purpose and self-worth, he feels a valued member of the groups he works in.*
- *S's confidence has improved to carry out tasks and ask for help when needed*
- *S has been helped and encouraged to work alongside others*
- *S has felt secure in an environment with other similar adults (no threat of bullying or teasing)*
- *ACC has taught him both life skills and work-based skills*
- *ACC gives S the opportunity to learn practical, purposeful skills such as animal care, and farm skills.*

Impact of proposed cuts to Day Services

- *Without access to Day Services, S would be entirely reliant on his parents to give structure to his day,*
- *S would not have contact with other young people*
- *Without Day Services there is a real risk S would regress and become totally isolated and have no purpose or structure to his day.*
- *It would put an immense strain on his family as we would become permanent full-time carers.” (mother)*

44. ***The person we support...*** “*W was attending day services for 3 days a week with one-to-one support. Since the pandemic he has been unable to attend. During W's time at the centre, he would spend a large proportion of his day being very active.*

Where W has not been attending his placement, he has been spending large amounts of time in his flat. Due to his supporting hours remaining the same within his supported living setting, staff are unable to offer additional day support.

W has one walk a day and is spending the rest of his time in his flat. Although W is happy in his flat, he has limited space and is unable to undertake any form of home exercise routine to keep himself active. He also struggles with using the internet without staff support and doesn't like to engage in video calling. We are seeing an

increase of physical incidents towards staff and W has been involved in a higher number of accidents within his flat that he would normally. We believe this is due to W not being able to burn off the energy the way he would normally if attending his normal work routines.

W's mental health has also suffered. Due to the lack of interaction with people, W has become isolated and there is evidence this has impacted on his social skills. He often appears quiet around staff and seems to become angry or agitated much more quickly/out of the blue. W seems to be sleeping more often during the day due to lack of routine and interaction.

After the first 2 months of W not attending his day service it became apparent that he seemed to be feeling very low in mood. He was showing a lack of interest in things he would normally enjoy and seemed to be withdrawn. After an appointment with W's Psychiatrist, it was decided that W would benefit from an antidepressant drug. This is something that wouldn't need to be in place if W continued at the centre.

As well as the impact on W's Mental, Physical and emotional wellbeing it will also limit the amount of people that he will socialise with on a day-to-day basis. Due to the limited number of people he will see in a day, this will decrease the staffing ability to recognise any signs of concern in W, such as health changes, signs of abuse and neglect.

Due to W's support needs he is unable to access the community without a staff member present. When he is at the centre, with it being a controlled environment, he has the freedom to move around without fear of traffic, the general public and abuse. If he loses his placement, the support provided from supported living would be limited, not only in time, but ability to do such varied things. All this combined would have a great impact on his independence. It's very possible that it would result in W spending great portions of his day within his flat on his own.

The skills W learns within his supported living setting are very different from the skills he learns within day service. Supported living is very much based on day-to-day tasks of life. Within day service he has a wide range of skills sets to grasp, such as interaction with the public, horticulture, animal care, catering, customer service and more. These things added together bring a sense of purpose and meaning to W's life, without that he finds it extremely hard to remain focused and motivated.

In general, W doesn't like to socialise with the people he lives with. When he attends his day service he sees different people, such as, staff members, the public and others that attend. This is an opportunity for W to engage with different people and helps him build tolerance when it comes to interaction. He also learns basic social skills that would be forgotten if he was only interacting with supported living staff.

W has a good relationship with both of his parents, he keeps in touch with them via phone calls. W likes to visit, and stay over at his mum's house during some weekends and special occasions. Without W attending his centre W's mum has

found it harder to have W at her home. This is partly due to W's heightened need for support due to the lack of structure missing from his life.

There is a great concern around what W would do if he was to lose his day service altogether. There is evidence that this will have a long term impact on his mental, physical and emotional wellbeing. He will also become isolated from his peers, family and the community. There is a high chance that he would need to remain on medication to help him manage his anxiety for the long term. ” (carer)

45. **Our son...** “ *N likes his little flat in X Road. It has been something of a retreat, a sanctuary of his own. But these days the flat can sometimes seem more of a prison for N rather than a sanctuary. N has to cope for an extended period of time in this flat with no other activities in his life beyond watching TV and sometimes attempting to get factual information on his desk-top computer. He is neither able himself to access the online activities that Aldingbourne Country Centre provide during these Covid restricted times, nor is he capable of relating to or engaging in most of these anyway. On those days when staff are available to take him, he does go out for a walk, in much the same areas each time. In between, from his frequent brief phone calls to me, I get the impression N is often bored, and is already beginning to lose in interest even in his large collection of colourful books. With no structure to his week, N no longer seems to know which day of the week it is, or even care.*

This situation was understood to be temporary and N has adapted reasonably well to these extra restrictions to his life on the basis that he would be returning to his day services at Aldingbourne Country Centre once Covid restrictions were lifted. However this situation cannot be allowed to continue indefinitely simply because his residential needs are catered for in 24hour supported living.

N is in 24 hour supported living because his needs have been assessed as "substantial". He needs support with medication, with personal care, with keeping his flat hygienic and tidy, with managing money, with shopping, with having his meals cooked, and with general safety, as he can be a danger to himself. He also needs to be accompanied whenever he leaves the building as he is has an inadequate idea of road safety or of finding his way about and back again. N is supported in all these aspects of his life by cheerful, caring and often overworked staff at X Road. However the premises at X Road were not designed to cater for daytime activities for a large number of tenants every day, nor is it within the job description of these care staff to provide this type of service. N badly needs structure to his week, and a change of scenery three days a week has been an essential part of that until 2020.

N appreciates the contrast of the rural setting at Aldingbourne Country Centre. Here N is safe from traffic concerns and has relative freedom to explore the familiar extensive grounds of the centre. I understand N's favourite areas have been the Woodland Walk, the animal enclosures, the Digital Media centre, the cafes, the

quiet room where he can look at books, the recycling bins which he likes to keep an eye on. In addition, at his Day Services review in December 2019, it was noted that N had been swimming and the idea was proposed that N might be supported to do this on a regular basis, and also for N to try dog-walking from Mount Noddy Animal Centre. N is youthful and healthy and usually has a positive and bright outlook on life. He needs all these activities I've mentioned and the easy walks from one to another in fresh air and daylight. Variety and stimulation are important to maintain both his physical and mental wellbeing.

However, just as valuable as all these various activities is the presence of all the dedicated staff and volunteers at the Country Centre. They have provided a stable community for N for the last two decades, with what seems to me a pleasingly low turnover of staff. N feels secure knowing the staff well and other service users too. That the staff also know N very well is important because his mood and behaviour are unpredictable and occasionally distressingly challenging. Following an incident in 2013, N's WSCC funded hours were reduced from four to three days, so that he could have the 1to1 support which is essential to enable him to take advantage of all the benefits available to him at the Country Centre. This suits N very well as he is often uncomfortable in a group setting. He appreciates the company of his individual support staff and does not feel crowded. They know N very well indeed, are sensitive to his moods and are adept at steering N away from potential problems. I have always had the impression that staff enjoy working at the Country Centre and that those who support N even enjoy that too! I feel the atmosphere there is relaxed, friendly, accepting, supportive and, crucially, familiar to N.

Attendance at Aldingbourne Country Centre gives N the security of a regular routine and structure to his week, interaction with a different set of people, and most importantly, regular stimulation. It is essential that N returns long term to his day services here and for the same number of hours as previously.

N's history of challenging behaviour and unpredictable violent outbursts must not be overlooked. Support staff at X Road already report that N's mood has started to become more frequently aggressive. Recently staff have had to cope with several incidents and say they see N's frustration building up inside him, feelings which I imagine are difficult for him to understand or express verbally.

To prevent escalating trouble, it is vital that N starts to have more to his life than he has at present, and therefore vital that he returns to the Country Centre as soon as is safe and practical. To provide N with stability and security, this return to Aldingbourne Country Centre has to be long term.

Changes put in place at Aldingbourne Country Centre during N's absence have been necessary because of the pandemic. N finds change disturbing, but with sensitive support during his reintroduction to the Country Centre, I know he will acclimatise and soon be relieved to be back amongst those familiar faces he has missed for so long. The pattern of his week will then give structure to his life once more and will be good for him.

Experience shows that ignoring N's physical, mental and emotional needs for too

long inevitably leads to negative consequences. I would add that N's father shares my opinion of the value to N of his Day Services at Aldingbourne Country Centre.”

(parents)

46. **My son...** “ *I believe people with learning disabilities and their families have been excluded and forgotten in debates, planning and policy. They must not be collateral damage or the first in line for more cuts to services. At national and local levels there has been an emerging recognition of the importance of social care in keeping people safe and healthy. I am, therefore, dismayed at the decisions being made by West Sussex County Council to target significant cuts at people with learning disabilities. It is even more disappointing to discover that there has already been an arbitrary 20% cut and that this group are at the top of the County's list for further proposed cuts. I can only conclude that this group are misguidedly seen as an easy target and a quick win, without proper consideration being given to the wider, long term implications.*

The Learning Disability and Autism Advisory Group for the Government's Social Care Task Force has recently published their report on what needs to be done to support people through the pandemic. Their recommendations include the need to restore, maintain and adapt the support for individuals and families already assessed as having eligible needs. This means ensuring councils and CCGs pause care, health or personal budget reviews during the period of service disruption, unless requested to do so by the individual. The recommendations direct councils and CCGs to urgently identify and provide the level of resources needed to financially stabilize provider organisations who may be at risk of collapse. WSCC are clearly not following this guidance.

Knowing the disproportionate impact Covid-19 is having on the lives and deaths of people with learning disabilities the implementation of these recommendations and action to include and support people with learning disabilities are paramount and cannot wait.

I feel that it is also worth noting that, although a reduction in the delivery of Day Services, due to the constraints imposed by the regulations associated with control of the Covid 19 pandemic, seems to have been achieved without major incident, this is in no small part due to the alternative arrangements that have been put into place by the service providers. Notwithstanding this initiative by the service providers, the virtual/on line alternatives are only effective as a short term stop gap and a return to the previous regime is essential to the future well being of the learning disabilities community. This will not be achievable without adequate funding and you know as well as I do that, in the present financial climate, once funding has been withdrawn it will take years for there to be any chance of it being reinstated. I therefore urge that proper consideration be given to the long term

impact of any proposed cuts and that due regard is given to the moral responsibilities of WSCC to this vulnerable sector of the community” . (father)

47. **My daughter...** “*My 25 year old daughter has a learning disability (Down’s Syndrome). She has an EHCP and is currently still in full-time education, at Chichester College. During term time, her studies span 4 days a week and therefore she has not yet needed to regularly access any Day Services year-round. However even now, it is a real challenge to find enough suitable things to occupy her at weekends and particularly throughout the college holidays – which are much longer than school holidays. She has been fortunate to have attended ACC for a few days during previous summer holidays, when she worked at Durban House café, and in the client and the new ‘public’ café, and she loved it. She mixed with different people, made new friends, and thrived in a safe environment which supported her to shine and show what she can already do, to put her existing skills into practice and to have a go at new things. This encouraged her confidence and developed her self-esteem. She particularly loved the people interaction (with staff and others who attend the centre), had fun, and was happy and safe there. The routine and structure of the day at ACC suited her as, although on first impressions my daughter presents as quite able, she actually needs a considerable amount of support and supervision, to follow routines, stay on task, she needs guidance and help with equipment and reminders and prompting with time-keeping. Often these essential aspects of support are overlooked but with skilled specialist staff such as those at ACC who have experience of working with people with LD they understand. All this made a massive difference to me as her mum and carer because it can be exhausting having to explain the detail of what she needs again and again to people who don’t have that experience and knowledge.*

Even though my daughter has not started to properly access them, the thought of Day Services being reduced or closed is a real concern for parents like me. My daughter’s EHCP ends this year; what will she do once she has left college? Despite her attending specialist residential college previously and gaining valuable work skills there, she has tried and not succeeded in holding down a part-time job in the real world of work, even with the support of WorkAid. I am gradually coming round to the possibility that early aspirations of her finding ‘real’ work may actually be unrealistic – if so, what will she do with her time and how will she fill her days? I am concerned that without regular routine and structure to her normal week, such as is provided by current Day Services, she will become isolated, lose contact with her friends and will lack the skills and self-motivation to occupy herself purposefully and happily. The knock on effect will be mental health issues for her and very likely for us, her family, as at the moment we provide most of the daytime care she needs at weekends and in the holidays.

Many parents, including myself, would not be able to work if there is no suitable day service provision for their vulnerable adult child, which would have serious economic consequences for families like ours, also therefore adversely impacting siblings of the vulnerable person. Long term family and carer well-being is also vital – good specialist day service provision needs to be secure and reliable – we need to know it will be there long term - so that families can endeavour to live normal lives and have a break, while still maintaining the love and ongoing additional care they provide for their vulnerable adult child.

Finally I would like to add that I am not aware of any suitable community services at the moment which offer suitable alternatives to ACC/CAS. Indeed, I am very concerned to hear that the only one I'd heard of, Out There, is losing its funding.”
(mother)