

# Scrutiny Committee Report



24 June 2020

## Carers and Day Care Services – Covid-19

Report Sponsor

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<b>Council Plan reference</b>	
<b>Wards affected</b>	<b>All wards</b>

## Executive Summary

Day centres and/or opportunities offer a vital service to those affected by dementia, learning disability and frailty. Many help to support carers by providing respite from caring duties. All building-based day centres closed in March as part of the Government's lockdown to mitigate the risk from Covid 19. This action was necessary to prevent the spread of Coronavirus.

Closing day services has had significant impact on individuals and carers who have relied on this form of support; however the level of impact for many people is only now being understood.

MKC teams, alongside providers have been keeping in touch with vulnerable people who were accessing day services prior to the lockdown, however it is acknowledged that this contact in no way replaces the experiences, emotional and physical support provided in day centres.

## **What are we asking the Scrutiny Committee?**

1. To review the impact that Covid-19 has had on carers and day care services.
2. Consider the difficulties being experienced by services users.

### **Background**

Day centres and/or opportunities offer a vital service to those affected by dementia, learning disability and frailty. The council spends £3.4m (20/21) on day services across all adult client groups. Day services offer support to both vulnerable people and carers by providing respite from caring duties. All building-based day centres closed in early March as part of the Government's lockdown to mitigate the risk from Covid 19.

This will continue to have a significant impact on individuals and carers who have relied on this form of support.

It is widely accepted that older people are at increased risk of severe illness from Covid 19, and therefore need to be particularly stringent in following social distancing measures and staying at home. Given this, it is natural for older people, particularly those with pre-existing medical conditions, to feel concerned or affected by changes required to prevent infection from Covid 19.

One of the impacts of remaining at home without the opportunity to see family and friends is loneliness and social isolation that can be more commonly experienced in old age. The two concepts are discreet but related. Loneliness has been defined as "a subjective negative feeling associated with a perceived lack of a wider social network (social loneliness) or the absence of a specific desired social companion (emotional loneliness)" and social isolation as "the objective lack or paucity of contacts and interactions with family members, friends or the wider community".

People with a learning disability are also at a higher risk of death from Covid 19. They have comorbid mental health and underlying physical health needs which are substantially higher than the general population. About 21% of people are in contact with specialist health services. People with a learning disability die much earlier than people without a learning disability due to unequal access to healthcare, a lack of clinical curiosity and additional physical or mental health conditions. The average age for death for a person with a learning disability across England in 2018 was 59 years.

Although there is much less specific data, people with profound and multiple learning disabilities<sup>1</sup> are much more likely to experience the risk factors for susceptibility to Covid 19 than

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<sup>1</sup> Profound and multiple learning disability - is when a person has a severe learning disability and other disabilities that significantly affect their ability to communicate and be independent. Someone with PMLD may have severe difficulties seeing, hearing, speaking and moving.

other groups of people with learning disabilities. There are estimated to be 11,000 children and 19,000 adults living with profound and multiple learning disabilities in England. Additional risk is associated with the following factors:

- 21% of people with profound and multiple learning disabilities experience respiratory disease leading to frequent chest infections.
- 30% of people with profound and multiple learning disabilities experience dysphagia (swallowing difficulties), leading to a risk of aspirational pneumonia.
- Much higher rates of cardiovascular health problems and hypertension.

The number of people with learning disabilities dying a Covid 19 related death rapidly increased slightly earlier than the general population in the weeks ending 10th and 17th April 2020, after which the numbers have been rapidly declining. The nearest equivalent to the Office on National Statistics (ONS) data for people with learning disabilities is the LeDeR programme. <sup>2</sup>

In the general population, even at the (first) peak of the pandemic less than 40% of weekly deaths were attributed to Covid 19. For people with learning disabilities, approaching 70% of people's deaths were attributed to Covid 19 around the peak of the pandemic. The data shows that between 10 April and 15 May there were 134% more deaths over this time period than there was last year.

The pattern of deaths by age band is completely different to the general population. In the general population in England and Wales, 42% of people dying of Covid 19 were aged 85 years or more, another 32% were aged 75-84 years, and another 15% were aged 65-74 years. It is clear that people with learning disabilities are dying of Covid 19 at much younger ages than the general population (see Appendix 1)

## **Day Services in Milton Keynes**

### **a) Learning disabilities**

Milton Keynes Council currently commissions or provides the following services:

**Branch Out** – a relatively small horticultural-based day opportunity service based in Stony Stratford

**Camphill** – predominantly provided to people living within the Camphill community, although a small number (17) people are now accessing from the wider community.

**Macintyre** – provide a range of building-based and non-building based, bakery, café and intensive support services

**MK SNAP** – a predominantly building-based service focussed on developing skills for independence and employment;

**Phoenix Rising** – a craft, art and drama based service based in Stony Stratford

**Thrift Farm** – an open farm run by staff, volunteers and people with a learning disability.

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<sup>2</sup> The Learning Disabilities Mortality Review (LeDeR) Programme was set up as a result of one of the key recommendations of the Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD). It aims to make improvements in the quality of health and social care for people with learning disabilities, and to reduce premature deaths in this population.

**Tower Drive** – a building-based service provided by Milton Keynes Council for learning disabled people with complex behaviours and/or profound and multiple learning disabilities.

**What's the Drama?** – a small drama-based service.

**Whaddon Way** – a build-based service provided by Milton Keynes Council for people with profound and multiple learning disabilities. The people who attend Whaddon Way and Tower Drive have significant care and support needs and have profound and multiple learning disabilities (PMLD), complex health needs and/or behaviours of concern. Nearly 50% of the people who use the services are funded and case managed by NHS Continuing Health Care (CHC).

There are currently 278 people with learning disabilities accessing day opportunities; 144 people are living at home with family and a further 134 people live in supported living or residential care. Some service users access a number of these services across a five-day week, this is often due to family carers working and the cared-for person not being safe to remain at home alone.

### **People living at home with family/unpaid carers**

There are 54 (38%) people living with carers over the age of 60 years, of these 19 (13%) are being supported at home by carers over the age of 70 years; the oldest carer is 84 years old.

This brings some potential additional challenges in providing support to people with learning disabilities and their families. There are some learning disabled people who are either shielded themselves or living with shielded family members meaning they are unlikely to be able to access shared buildings at present. Where a family carer is older they appear to be anxious about accessing support due to the risk of contracting Covid 19.

All people living at home with family are being contacted by MKC social care teams on a regular basis. The regularity of contact is informed by a discussion between MKC learning disability services and the family carer. On average people are being contacted twice a month. The majority of contact is on the telephone. In addition most day service providers have also remained in contact with people who attend their services. It should be noted that feedback is predominantly via family carer rather than the direct voice of the service user.

The majority of people living at home with family carers do not receive a package of support at home e.g. for personal care. The two main reasons for this are that people do not need significant support with personal care or families may not want carers in their home. Support to families is focussed therefore, on providing a break from caring via day opportunities, short breaks and Shared Lives.

Whilst initially most family carers have not wanted additional support whilst isolating, the lack of day opportunities is starting to impact on people with learning disabilities and their families. The following information has been taken from the welfare calls to family carers and people with a learning disability. Concerns raised include:

Table 1: concerns by family carers via welfare calls.

Reason	Number of people	Potential mitigation
Boredom	11	Discuss possible ideas for activities, provide craft boxes or similar. Explore access to online activities.
Increase in behaviours of concern (challenging behaviour)	5	Explore reason with support from Positive Behaviour lead officer and offer additional support including 1:1 support at home or community.
Missing Friends	4	Explore opportunities to support to keep in contact via social media, video calling etc.
Frustration	3	See (boredom)
Signs of depression or new health concerns	3	Explore with family, support access to GP or specialist health staff within CTALD.

### People living in supported living or residential care

People living in residential care are provided with support over a 24-hour period. There are eight learning disabled people living in residential care attending day opportunities. The main purpose of attending and living in residential care is to maintain friendships or to access meaningful activities that may not be available where the person lives. The impact of not attending day services is likely to be experienced more by the learning disabled person than the residential care home. People are likely to miss both the stimulation and friendship that day opportunities provided. Residential care providers commission (pay for) day services on behalf of residents they support as MKC pays for 24-hour care and support in residential care.

There are 126 people with a learning disability in Milton Keynes living in supported living. Supported living is a service designed to help people with a wide range of support needs retain their independence by being supported in their own home. People in supported living have their own tenancy and are responsible for their own bills and cost of living. To afford these, the person may be entitled to a wide range of benefits and grants.

MKC commissions the support that the person needs to live in their own tenancy; this ranges from 1 hour per week to 24-hours day and night. Where a person is unable to attend a day opportunity the likely impact is loss of stimulation and friendship, however the additional impact is the need to arrange additional hours of support at home. MKC has commissioned additional support hours where these have been required in place of day services/opportunities. MKC social care staff are in regular contact with providers to check that they are able to continue to meet the needs of the people they support. Supported living providers have, to date, been able to meet the additional support hours required.

### Support that is currently provided

MKC social care staff are providing support to a small number of people with a learning disability who live at home with family. Support is risk assessed and provided in accordance with the Government's advice e.g. use of PPE. In addition to the support detailed in Table 2 below,

additional support is also provided by support workers in the Community Team for Adults with a Learning Disability (CTALD) and workers within the MK Supported Employment Service.

Table 2: Support provided to people who access Tower Drive and Whaddon Way Day Centres.

person	No. of Staff	days/ week	Pattern of Support	Hours / wk	Variations over 7 days	Support Provided
1	1 staff	4 days	Mon 7hrs, Tues 7hrs, Wed 1.5hrs Thur 2.5hrs	18hrs	same days	access community, home support provided for meal preparation and down time/ walk
2	1 staff	3 days	Mon 2hrs, Wed 2hrs Sat 3hrs	7hrs	same days	Walk
3	1 staff	2 days	Mon 2.5hrs, Thur 2.5hrs	5hrs	same days	supported to access the community. Walk
4	1 staff	3 days	Thu 3hrs, Fri 3hrs, Sat 3hrs	9hrs	same days	supported to access the community
5	1 staff	2 days	Tues 2hrs, Thur 2hrs	4hrs	different days each wk	supported to access the community.
6	2 staff	1 day	Wed 2hrs	2hrs	same days	supported to access the community. Walk
7	1 staff	3 days	Mon 3hrs, Wed 3hrs, Fri 3hrs	9hrs	same days	supported at home. Home feeding and activities
8	1 Staff	5 days	Mon 2hrs, Tues 2hrs, Wed 2hrs, Thur 3hrs, Fri 3hrs	12hrs	same days	supported to access the community. Walks
9	2 staff	1 day	to be confirmed	6hrs	Variation	out for drive/walk

Support provided by other day opportunity providers includes:

- Phoenix Rising – are delivering craft boxes to people at home and support via online activities
- Thrift Farm – are contacting all the people who usually attend giving news of the farm and checking on the welfare of the person.
- Macintyre – are providing 1:1 support via their Macintyre Support Plus service. They are also developing online resources e.g. music sessions, online bingo
- MK Snap – are contacting all the people who access their services.
- Camphill – are providing activities to each group of tenants that share a house. They are unable to support the 17 people who were accessing Camphill workshops from outside of the Camphill community.
- Branch Out – have been providing pots, soil and plants to people at home.

Changes in routines and care can be particularly stressful for people with learning disabilities and autistic people, and the measures that have been put in place during the outbreak will be bring additional challenges in how best to support and how best to communicate change to them. The health and social care CTALD has provided support for people who are finding the sudden change in their routine particularly challenging, for example, speech and language therapists have been helping to develop social stories to explain the reasons for the lockdown. Social stories are short descriptions of a particular situation, event or activity, which include specific information about what to expect in that situation and why.

Easy read explanations of the current guidance has been developed by the Government aimed at people with a learning disability.

In accordance with the Royal College of Nursing Physical Health Assessment and Monitoring for Covid 19 – A Guide for Nurses in Community Mental Health Settings (May 2020) and guidance from Central and North West London NHS Foundation Trust (CNWL), CTALD have assessed the risks of mental or physical health deterioration for all learning disabled people known to the team, 31 people are visited at least once a week and up to three times a week to monitor physical and mental health.

In addition to support from nurses, occupational therapy and speech and language therapy, clinical support is also provided by psychiatry and psychology within the CTALD.

### **MKC engagement with providers**

During week beginning 1<sup>st</sup> June meetings held with all LD day opportunity providers focussed on:

- What, if any support is currently being provided to their service users;
- What plans they have for opening their services including: risk assessments undertaken, methods of support; and
- Concerns that they may have.

Reponses were mixed:

- Most providers are supporting learning disabled people at a distance including providing craft boxes, telephone calls and online activities, some are supporting people on a 1:1 basis in the community or alone in a building.

- Most providers recognise that opening a building-based day service at present is both challenging and risky.
- One provider wants to open its service using social distancing, increased cleaning and ‘bubbles’ similar to schools for up to thirty people at any one time.
- All providers are keen to work with MKC to shape provision that supports learning disabled people in the safest way.
- Most providers are particularly concerned with the needs of learning disabled people living at home with family or unpaid carers rather than those living in staffed supported living or residential care.

An email was sent to all learning disability day services providers on Tuesday 9<sup>th</sup> June 2020 clarifying the MKC position on guaranteed payments ( see Appendix 2). The email indicated that we are not anticipating services to safely re-open on the same basis as they were prior to Covid 19. The email asked that where providers are currently providing support to some people and this has been discussed and agreed this MKC, we are keen that this arrangement continues.

We are working with all providers to determine if a safe model of service can be provided including using buildings whilst adhering to social distancing, infection protection and control, risk assessment and transport. The type of problems that we need to consider includes:

- How people can attend a building-based day service and maintain social distancing?
- How can people travel to a day centre?
- What risk assessments need to be in place?
- Who should be prioritised if there is limited capacity?
- Should those who are sharing their home with other learning disabled people attend day opportunities at present?
- Should people attend more than one day centre – many people attend a variety of day opportunities over a week.
- How can we support people who have underlying health needs who are living with shielded family carers?

These questions are relevant to all day opportunities whether they are provided by MKC or another provider.

#### **b. Older People**

There are three older person’s day services that were providing the following before the Covid 19 lockdown:

- Simpson Day Service – 210 sessions to 80 people
- Kitchener Centre– 35 sessions to 19 people
- Kilkenny House– 52 sessions to 30 people

All Services closed on 24<sup>th</sup> March but staff have been providing some support as follows:



**Table 3: Simpson – support provided to service users (week beg 1 June 2020)**

Home support	No. Visits/ wkly	No hours support	Telephone support	No. Calls	Meal support
20 people	56	76.75	21 people	22	2 people

**Table 4: Kitchener – support provided to service users (week beg 1 June 2020)**

Home support	No Visits /wkly	No hours support	Telephone support	No. Calls	Meal support
3 people	9	9.5	9 people	14	2 people

**Table 5: Kilkenny – support provided to service users (week beg 1 June 2020)**

Home support	No Visits/ wkly	No hours support	Telephone support	No. Calls	Meal support
3 people	5	5	6 people	17	5 people

Additional support is provided as follows:

**Care and response service** –up to 500 calls per week to older and disabled people

**Older People’s Social Work Team** – all 707 older and disabled people living in the community in receipt of a package of support have been contacted by the team. The frequency of calls has been agreed with the person.

Home care services have continued to operate as normal throughout the period of lockdown.

We are considering how we can support the unpaid carers of older people living at home, this is likely to include the support currently provided by MKC staff (detailed in tables 3,4 and 5 above) as well as additional support from home care or sitting-type services.

**c. Mental Health**

Rethink Milton Keynes - Rethink offers a community support service with a range of activities. The Rethink day service is commissioned by Milton Keynes Council and has 118 service users accessing four locations. Rethink have been providing telephone support to service users alongside support provided by the adult social care mental health team.

The Mix - provide drop in hubs in Central MK and Bletchley. The Mix offers opportunities to meet with services such as the Citizens Advice Bureau, join activities such as art, drama and computer games, meet friends and new people and be in a safe space.

Both these services are currently closed and support is provided by telephone, video-calling and home visits.

#### **d. Physical disability**

The majority of physically disabled people use a direct payment to arrange social activities. There are a small number of providers in Milton Keynes specifically focussed on supporting disabled people including Headway. Welfare calls have been made by adult social care and continue where these have been requested.

#### **Conclusion**

In light of the current circumstances, guidelines and alert levels, we are not anticipating that services will be able to safely re-open on the basis that they were prior to Covid 19. We need work with vulnerable people, carers and providers to develop models of support that are safe, reduce isolation and provide respite. Models will need to be flexible to meet need and to change in line with Government guidance. At present the priority is focussed on providing day opportunities to people living at home rather than people living in a care home or supported living provision. This is because the impact of the loss of day opportunity affects both people who use services and those people who provide care and support to them at home

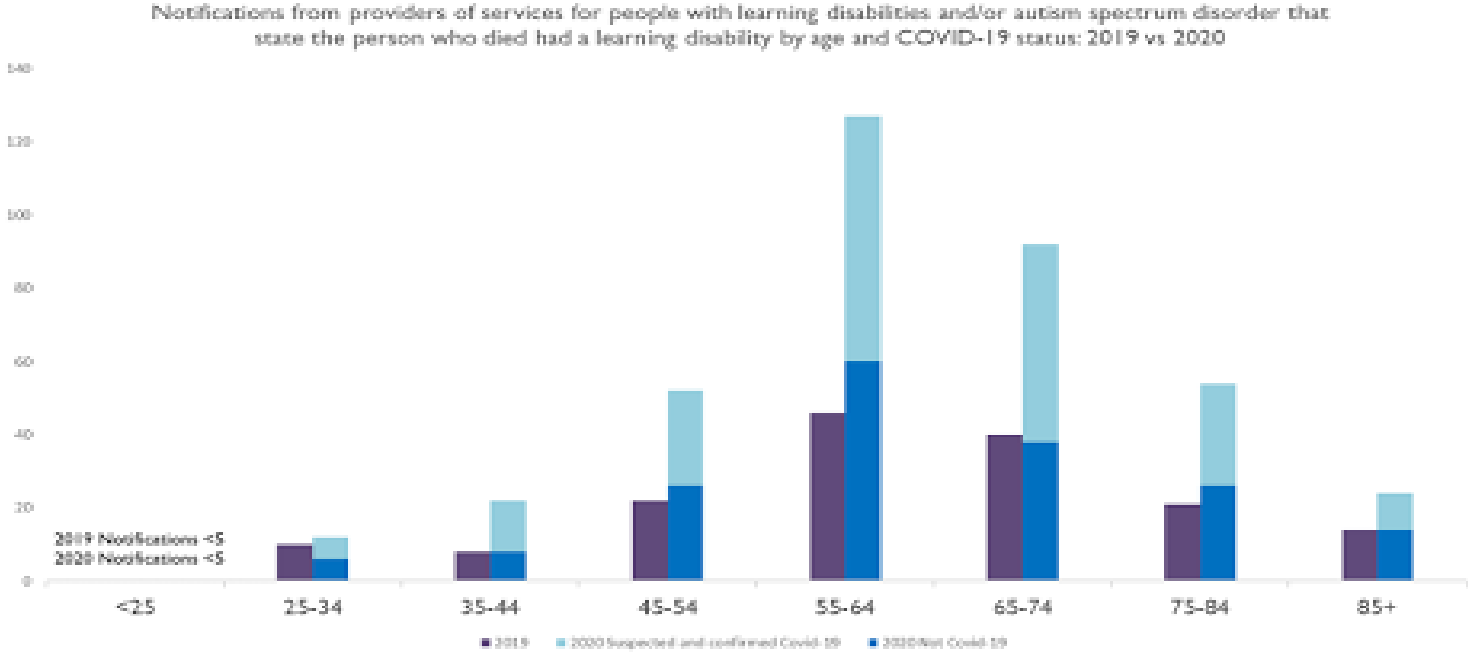
Ensuring that people know how to contact us cannot be underestimated. We have ensured that all people in receipt of care and support have been provided with details of how to make contact for support, or are being provided with regular telephone welfare calls.

#### **Next Steps**

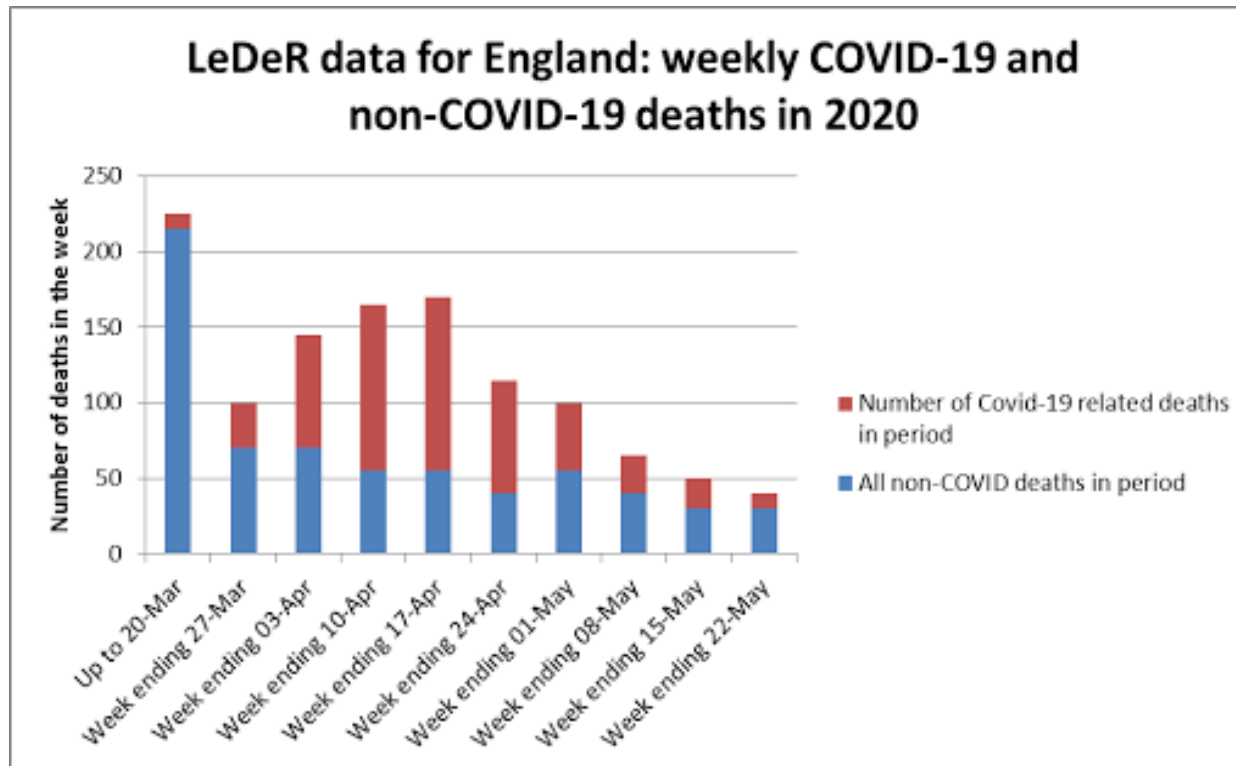
We will continue to:

- Make welfare telephone calls and visits as agreed with vulnerable people and/or their carers
- Provide support at home or in the community where required.
- Consider how buildings and transport resource can be used safely within government guidelines and with adherence to specific risk assessments.
- Work with MK Carers and local advocacy groups to engage with people to develop new models of support
- Follow national guidance
- Engage with other Local Authorities via the ADASS East Midlands Network in order to share and adopt best practice.

Appendix 1



Source: Care Quality Commission 2020



Source: Learning Disability Mortality Review (LeDeR) 2020

The Learning Disabilities Mortality Review (LeDeR) programme is funded by NHS England and commissioned by the Healthcare Quality Improvement Partnership (HQIP). It is the first national programme of its kind in the world.

Its overall aims are:

To support improvements in the quality of health and social care service delivery for people with learning disabilities.

To help reduce premature mortality and health inequalities for people with learning disabilities.

## Appendix 2

The following email was sent to all learning disability day service providers on Tuesday 9<sup>th</sup> June 2020.

*Dear .....*

*Thank you for meeting with Amanda, Michelle and myself last week. It was really helpful to understand better your position in relation to the current pandemic, and also your thoughts about the future model.*

*In light of the current circumstances, guidelines and alert levels, we are not anticipating that services will be able to safely re-open on the basis that they were prior to Covid 19. Indeed, it is difficult to know when this will happen. We do however, want to continue discussions about the model of service you provide, which I said during our recent meeting is important regardless of the pandemic. Where you are currently providing support to some people and you have discussed and agreed this with us, we are keen for this arrangement to continue.*

*Milton Keynes Council has committed to guaranteeing your payments from April through to the end of June. Given that it is not possible to safely provide buildings based day services for groups, and it remains very unclear when it will be safe to do so, we would advise you to now access financial aid through the government's job retention scheme and seek to furlough all available staff. We fully appreciate that there are other costs involved in relation to the work you do, and we are available to have further discussions about managing these costs.*

*If you have any further queries or points for discussion please contact us initially through the following email address:*