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# Introduction

## People First Dorset COVID-19 update

We welcome this opportunity to share how we have been able to support people with learning disabilities experiencing complex social issues and inequalities, who have been adversely affected by the impact of COVID-19, where they have needed it most.

We have been able to use our established position of trust within this community and support beneficiaries in multiple ways, where their needs were less well served by mainstream provision, and essentially keep people safe and well throughout the pandemic.

The main areas of need we have addressed have been isolation and loneliness, accessible information, mental health and physical wellbeing and opportunities to speak up.





# What do we usually do?

1

Enable people to make and sustain friendships in their community, create opportunities to speak up and develop action groups so that issues affecting the lives of people with learning disabilities can be addressed at the earliest opportunity.

2

Empower people with learning disabilities to take the lead in addressing their concerns successfully; to develop stronger self-advocacy skills; have a better understanding of their rights; and build peer networks so they may (more confidently, effectively and independently) address the inequalities they experience on a daily basis.

3

Enable people with learning disabilities to develop stronger, more productive relationships with key decision makers (i.e. statutory services, housing, health bodies), who will realise the benefits that working together can produce significant improvements for all.

4

Develop an increased awareness and empathy from the community for people with learning disabilities, who will in turn find the community a more inclusive and fairer environment to live in and engage with.



# 5

Develop a better understanding of how to create cost effective and sustainable solutions for people with learning disabilities, so we can better address the inequalities they experience.



# What actually happened?

## (what we did)

### 1. A global pandemic struck

COVID-19 changed everything, for everyone.

### 2. We listened

Initially, and throughout year, we have actively listened and talked with members, to find out what their needs were at any given time.

We have responded dynamically, innovatively and swiftly (sometimes even creatively) with support as needs changed.

The biggest positive is that the funding has enabled us to support members in the different ways they have needed. Thanks to this, almost all are coping well, despite the very difficult situations many find themselves in.

### 3. Face to face groups ceased

Immediately we rang all members to check in. How were they coping? We listened. What did they need? We listened some more.

Our members were scared, confused, many struggling with disruption to routines. They missed friends and didn't understand Government guidance.

We have responded with phone calls (some daily), online group calls, sending out vital government updates in an Easy Read format (via social media, mail, email) so that our members have a point of reference to help them understand how the world has changed so dramatically.

We have supported individuals digitally to connect and use zoom. Phone calls have continued to all beneficiaries periodically too, at times where crisis may be more likely. For example, prior to Christmas we ensured beneficiaries were okay in

the build up to and during the festive time; again when the latest lockdown and vaccines were announced. The team continue to check in to see how beneficiaries are coping and if support needs have changed.

**“Our daughter is only coping thanks to the support that you have given her throughout the last year. Having the events online to look forward to, as well as the calls, has been a lifeline for her. She really enjoys seeing her friends online, and the team also supported us through a very difficult personal situation.”**

Parent of People First Dorset  
Beneficiary



#### 4. We introduced Connect

In May 2020, we developed an eye catching and accessible booklet (initially fortnightly, now monthly) which reaches over 1500 individuals. **Connect** enables members to:

- Understand key messages from the government, health and local council bodies without becoming confused or scared. We liaise with the council and health bodies to ensure local updates are included.
- Have a point of contact and connection with their community via the publication.
- Do activities which interest them while in lockdown. The newsletter features a friendship section where individuals can connect with friends on a 'message board' and share news/stories; a speaking up section which highlights members key concerns; a fun activity section with puzzles, word searches, spot the difference etc; and a wellbeing section with simple gentle exercises, recipes, mindfulness activities and more.

In addition **Connect** has:

- Helped us and health/council bodies understand key concerns and worries for people with learning disabilities in Dorset and Somerset, as well as learn how people are being resilient. This has

informed us in how best to respond to their needs as the pandemic continues, and adjust our services to support individual needs.

- Supported carers, some of whom we know struggle to share key messages, by providing engaging activities for the people they support.

In some publications we have asked for feedback, enclosing self-addressed postcards which can be easily returned. We also now include our timetable of online activities, and details on how to book.

#### 5. Introduced a comprehensive programme of online activities

From March until September, in addition to regular phone calls, we held c.90 zoom calls with small groups of members. In October, six monthly Speaking Up groups were re-introduced online, along with eight monthly friendship groups (quizzes, games etc), eight exercise classes (dance, yoga etc) plus wellbeing workshops.

Members have also connected with other self-advocacy groups nationally, notably regular online zoom catch ups with Sunderland People First.

**“Thanks to the support from all you, it’s helped me to manage. I don’t know what I would have done without your support, all the calls, the Connect and knowing you were there for me”**

People First Dorset Beneficiary

#### 6. Responded at times of additional need

More support was needed in the build up to Christmas, when guidelines changed and when vaccines began to be rolled out. We have supported members to understand why these actions were being introduced and information around them. In the latest lockdown, where members have experienced increased feelings of isolation and loneliness, we have responded with more phone calls to those requiring additional support, and increasing the number of zoom sessions.

We will keep listening to the needs of members as guidance changes in the coming months and adapt our support as required.



# The difference our support has made

## Feedback and notable outcomes

### 1. Case studies – Emily and Nesta

To demonstrate the importance of the work People First Dorset do, we have put together some case studies with our members. In Q&A format, they detail first hand the impact of COVID-19 and the steps we took to support individual members throughout the pandemic. These case studies can be found in the appendices of this document (p.22-25).

### 2. Connect

Members are actively involved in contributing to this publication. For example, Paul was feeling low, missing discos, and contacted us to say he was upset they could not start up again. He loves music and likes to DJ. We offered him a monthly slot in Connect where he shares his top ten songs each month, i.e. December featured Christmas songs.



Issue No: 4 July 2020

People First DORSET

Connecting people with learning disabilities in Dorset



Issue No: 8 November 2020

People First DORSET

Connecting people with learning disabilities in Dorset

# Connect Feedback

"I love Connect and have done all the activities already"

People First Dorset  
Beneficiary

"I am supporting a lady who is struggling with mental health problems. I took her a copy and it really cheered her up today"

Community Nurse  
Dorset Healthcare

"I would just like to say what a great newsletter this is. I don't know anyone at People First Dorset, and have no involvement with you, but would like to pass on my thanks to all involved. I thoroughly enjoyed it"

Support Worker  
Dorset Blind Association

"Check out the lovely People First Dorset and their Connect magazine. Fabulous Dorset charity doing some brilliant work with some lovely lovely people"

CEO Dorset Council

"Connect is simply marvellous. I love receiving it and it is so packed full of information and uplifting things. I even send it to a friend in Hertfordshire when I have finished with it, as she has a learning disability and enjoys it too"

People First Dorset Beneficiary

"Connect has given me ideas of things to do. Like relaxation, puzzles and the recipes. Connect reminds me that even though I can't see members in person, to see all the photos, it makes me feel people are still there, even though I can't actually see them"

People First Dorset Beneficiary

### 3. Maintaining friendships; avoiding social isolation

We have enabled individuals to maintain friendships, avoid social isolation and even develop new friendships around the country.

We have also provided activities for people to look forward to – both our own and via collaboraton. With People First Forum, we helped host their 'Big Night In' online nightclubbing event.

Many of our members are deepening their friendships with the regular zoom calls, getting to know each other in different ways and supporting each other in ways they didn't know they were able to do.

**"The phone calls are a lifeline. Each Monday and Thursday I wake up and think oh good, I'm getting a call today and it brightens my day. Having someone to talk to, who understands, has really helped me"**

People First Dorset Beneficiary

**"The zoom calls are brilliant and as I have had to stay at home, it's been so good to see my friends like that"**

People First Dorset  
Beneficiary

**"It felt good to be able to support another friend on a zoom call who was having a bad day, and how nice it was that I and others in the group could offer our friend support and encouragement while she was feeling low"**

People First Dorset Beneficiary

**"I don't know what we would have done without the support that our daughter has received from People First Dorset. She loves seeing her friends and being able to take part in the activities, as well as listen and talk about what's on their minds. It's helped us too as parents knowing that gives her support and brings her happiness"**

Parent of People First Dorset Beneficiary



## 4. Beneficiaries taking the lead and Speaking Up

Beneficiaries remain at the core of our work, and have very much led our response to the pandemic, speaking up about concerns and in turn enabling us to support in ways which work best for them.

Through frequent and ongoing conversations via phone calls and zoom sessions, beneficiaries have fundamentally shaped delivery. Calls inform the team how individuals are coping and of any immediate concerns, enabling us respond to changing needs and develop our response accordingly – in turn supporting them with activities which meet needs.

Exercise to music sessions and physical activity sessions were introduced in response to the demand from individuals for more fun based activities featuring exercise. These are also proving beneficial for the mental well-being of individuals, who say it takes them away from worries of everyday life, giving them something enjoyable and fun to look forward to.

Continued conversations mean we are responsive to further changing needs, such as when new guidelines are announced, and are able to support individuals as necessary.

Beneficiaries take the lead in choosing themes for Speaking Up groups, such as mental health, wellbeing, health checks.

Flexibility during the sessions has been key as individuals may need different support by the time the group is held. For example, in January, when ‘a good day’ theme was chosen (supporting Dorset Council in their consultation to improve services for people with a learning disability) beneficiaries were anxious about vaccines, so it was necessary to focus on supporting individuals to share these concerns before moving on to the consultation.

Beneficiaries say they feel listened to and that activities are meeting their needs. They say they feel an important part in steering delivery, particularly noted at Speaking Up groups, where beneficiaries are best able to voice concerns and explore solutions.

## 5. Collaboration and networking

Collaboration with local organisations, i.e. the Local Authority and CCG, has enabled us to share outcomes, ideas and improve services. More productive relationships with all have ensued – online makes joint working faster and often easier. We can connect quickly, with no need to meet in person, and take action as necessary.

We have linked, through Learning Disability England (LDE), with many other self-advocacy organisations around the country to find out how they are managing and sharing best practice. Regular zoom calls hosted by LDE has enabled this to happen.



## 6. Improved understanding of rights

Members have indicated they have a better understanding of their rights (i.e. rights to vaccine, rights for the right care and support) through building peer support groups and developing their self-advocacy skills online.

Members are telling us what they need and how they need it, confidently engaging with staff. It is thought the smaller groups have enabled members to develop their skills more effectively.

# What else did we do?



## 1. High number of deaths for people with learning disabilities from COVID

It is key to note, and there has been much publicity in the press, the announcement by Public Health England last November highlighting that people with learning disabilities were six times more likely to die in the first wave of the pandemic than other people, and up to 30 times more likely to die if they were younger. People with profound and multiple learning disabilities and people with Down's Syndrome were

prioritised for early vaccination. Following much campaigning by many local and national organisations (e.g. LDE, Mencap) and high profile individuals (e.g. Jo Whiley) all people with a learning disability have now been prioritised. This understandably caused considerable anxiety for many of our members.

We have been reassuring members about the vaccines, notably to understand the information around having a vaccine (do they need one, easing fears of if it will hurt, how they work etc) and reminding members of the need to still stay safe and follow guidelines.

We have also sent out Easy Read documents on vaccine information by post and via other links such as the WhatsApp groups which beneficiaries use.

We also made a video with a member who received the vaccine and her experience of it, to share with others who are anxious.

This can be viewed here: [bit.ly/3k5zdB0](https://bit.ly/3k5zdB0)

## 2. Experiences of individuals with mental health conditions and a learning disability

Another unexpected outcome is that we have a small number of beneficiaries who also experience mental health conditions,





such as anxiety. The feedback from them is that although it has not been easy, they have said it is not as bad as they thought because 'everyone is in the same boat as us'. In 'normal times' they feel more isolated as no-one can see their anxiety, and feel left behind. Now that much of the general population are experiencing a degree of anxiety, they feel that they are less alone. Their biggest anxiety is what happens when we 'get back to normal' and they worry that they will be left behind again.

### 3. Safeguarding alerts

The team spent considerable time dealing with a couple of serious safeguarding alerts, not picked up by statutory services. Both are resolved.

### 4. Bereavement

We are exploring developing a new bereavement project in light of some members losing close family. This would be a peer to peer support group, facilitated by trained professionals.

### 5. Environment

We secured funding to develop a project which supports members to better understand climate change and the environment. We are conscious that

mitigating climate change is important and UN have reported people with disabilities are being left off this agenda. We are working with Dorset County Museum to deliver this.

### 6. Influencing

We began working with The Social Change Agency, putting together a small working party (including two members of our Management Committee and two trustees) to better understand our ability to influence, and develop an influencing strategy.

### 7. Business Plan

We updated our business plan last year in the light of COVID and are currently developing a new three year business plan, working closely with trustees, staff and our Management Committee.

### 8. Policies

We updated all of our policies, which were also reviewed by an external evaluator.

### 9. Trustee Appraisals

We developed and introduced a trustee appraisal system. Trustees received their first appraisals last year.

### 10. Marketing Materials

We further solidified our brand and are developing additional marketing materials, including a new brochure (aimed at grant providers and funders) and a fundraising flier to be distributed to the local community to raise awareness and further funds.







## **11. Developing long term sustainability of self-advocacy organisations**

People First Dorset are part of a small working group leading a national conversation to explore the future of self advocacy organisations, along with Learning Disability England and the Open University.

## **12. Working more effectively**

As an organisation, working online can bring greater and quicker results for individuals, i.e. less travel means we can have more meetings and conversations online, using our time more effectively.

## **13. Meeting CEO Dorset Council**

Members had a one-to-one with Matt Prosser, the CEO of Dorset Council, a regular annual catch up, which took place online.

## **14. Interview panel for Local Authority**

The SMT were part of interview panels for senior director and commissioning roles in Adult Social Care at Dorset Council.

## **15. Working with our Local Authority**

We're taking a key role in the local authority consultation of social care services and their review of the learning disability services across Dorset.





## 16. Supporting individuals to live independently

We continue to support four members to move out of the family home into independent living. The moving date is now expected in April.

## 17. Working with research projects nationally

We are also continuing to work with other partners such as University College London on the STORM project, where we are a member of the Steering Group and Working Party. STORM seeks to understand and improve the experiences of people with a learning disability to manage and resist stigma.



## 18. Easy Read

We are continuing to develop our Easy Read services, notably working with the local authority and House of Lords. We are currently marketing these services more widely.

## 19. Management Committee and Trustees

Both the Management Committee and Trustees have met monthly online throughout the pandemic, ensuring they are informed of how the team are responding and members are managing.



## 20. Database

The Senior Management Team have continued to work on creating the new database (now complete), to allow us to better record and monitor outcomes. We have also appointed an external evaluator and designed a measurement tool to monitor these outcomes. It is hoped that if groups resume later in the year, this can be used. We will monitor the situation closely and if we need to change activities and run groups remotely again, we will amend the recording tool appropriately.

# What have we learnt?

1

Support for individuals has been vital

2

With the right support members have been resilient. Lives have not got worse, so there has been little demand for additional statutory services.

3

Members have learnt to speak up in different ways, e.g. digitally and via the written word

4

That being flexible, energetic and creative has been key, in order to adapt services quickly in line with changing needs of individuals and situations

5

That everyone is different and there is not a one size fits all. That support needs to be tailored to each individual

6

That people with profound and multiple learning disabilities (PMLD) are very hard to connect with in a pandemic, unless we can reach them through their supporters

7

Building toolkit of self care which members can use is key

8

That working remotely has enabled great networking and collaboration = better outcomes



# 9

That there have been clearly many inequalities for people with learning disabilities during the pandemic (inappropriate do not resuscitate orders being put on people, much higher number of deaths etc) and that there is still much work to do to ensure equal rights for people with learning disabilities

# 10

That, still the most important thing for almost all members is being able to maintain friendships

# 11

That things can change quickly for people so regular communication is key

# 12

That it is very hard for people with learning disabilities to understand key messages, such as government updates on how to stay safe, and that much reinforcement and easy read ways of demonstrating such messages are vital

# 13

That people will need a lot of support getting back to 'normal'

# 14

We still love what we do (but we knew that anyway!)

# What next?

## Getting back to “normal”

It is clear that the long term impact of the pandemic has affected beneficiaries, and a further concern is how they will manage post pandemic. For some who have experienced stress and trauma, the support needed will be quite significant.

We are also increasingly aware from conversations with beneficiaries of the additional staff time and support they are

likely to require once they are able to safely transition back to face-to-face meetings. We anticipate running more intensive, smaller and additional meetings/events as we support members to manage the ‘new normal’ and to re-build their confidence.

It is also clear that beneficiaries have had very different experiences of the pandemic. Some are already ‘out and about’, keen to ‘get back to normal’, so support to ensure they still stay safe and take precautions is key. Others have barely left the home and are very anxious about doing so. Support for them to continue to manage the long term lockdown and re-integration is key.

## Continued support

Support for beneficiaries, whatever their anxieties are at any given time, will be essential for a long time to come. Also important will be opportunities to listen and share experiences so that beneficiaries learn and develop skills to support each other, where possible. There is already one example of a member who took round a magazine to a friend who was shielding. Both benefited

from the experience enormously. The one who received the magazine felt ‘thought about’ and cared for - the person gifting it, felt really good to be able to support a friend in need. Empowering members to develop peer support networks will be a key focus moving forward.

Even when groups are able to resume, it may take a long time for some to return, and we need to be in a position to support people during this transition.

## Long-term funding

With regards to long term funding to support beneficiaries, the staff team have been putting together marketing materials on the charity to help the public and funders better understand what we do, and why support is, and will be, critical. This will be launched as part of a fundraising campaign later in the year.

Developing a strong supporter base may take some time to build, so we will still be reliant on grant funding for a little longer. We also cannot rely on volunteers to support projects where skilled staff are still very much required.



Without funding the organisation would not have been able to respond to the needs of adults with learning disabilities across Dorset in a way which has, and continues, to meet their needs. We know that they would otherwise have struggled so much more, possibly resulting in more beneficiaries reaching crisis points and the need for much greater intervention by ourselves and professionals.

## Impact

Funding from a variety of different sources has made a hugely positive and significant impact on our members lives. We are incredibly grateful to all our funders over the last year who have enabled us to support beneficiaries in the ways they need it most.

Our conversations with beneficiaries and their carers tells us that the reason that they have coped, as well as they have, is largely down to the continued activities, calls and support from People First Dorset.



# Appendices



# Our Management Committee







# Covid-19 Case Study:

## Emily's Story



### Introduction

Emily is 30 years old and lives with her mum in Dorset. Social isolation and loneliness are already extremely prevalent for people with learning disabilities. During the pandemic we have adapted our projects to support our members.

We wanted to know how COVID affected our members. This is Emily's story (in her own words).

### How did you feel at the start of the pandemic and lockdown?

At the very start of it all I was a little worried about the virus not just for my family but for all the residents in the care home I work in.

Once I heard we were only allowed out once a day for exercise I wasn't too worried because I was still going out to work. I did worry that other times I would be bored and had to think of things to fill time.



# Let's empower people with learning disabilities, together.

## What helped most?

I am very grateful for the support I get from People First Dorset. I get lots of zoom calls, phone calls, the Connect newsletter, jigsaw puzzles and books.

## Was it helpful, and why?

All these things have helped me stay in touch, to pass time with friends and at home in the evenings and weekends. If I was worried about anything I have had someone I could talk to. I always knew there was someone I could talk to apart from my mum.

It always cheered me up on the zoom calls to my friends and with Laura. We laughed so much she even called us the gigglers group.

At first I was confused about what the government was saying. I was grateful for Connect and its easy read updates.

To find out more about the work of People First Dorset please visit our website:  
[www.peoplefirstdorset.org.uk](http://www.peoplefirstdorset.org.uk)

## Anything else that has supported you?

I also had a difficult personal problem during lockdown and was able to talk it through with Laura on the phone, who gave advice and knew who else could help me.

## The last word, from Emily's Mum:

People First Dorset and particularly the Friendship Club have always provided a safe and happy social life for Emily so I was concerned that she would be really missing her friends during lockdown. However, Laura really pulled all the stops out and a good deal of support was provided, Emily especially enjoyed and looked forward to the regular Zoom meetings. It was great to hear her and others laughing.

With regard to the personal issue Emily mentioned, Laura also helped me through this difficult time, ensuring it was managed in a professional way and resolved as quickly as possible.







# Covid-19 Case Study:

## Nesta's Story



### Background

Nesta lives alone in Dorset and her friendships consist of people met at the Friendship Club. The impact of lockdown due to COVID-19 on her personally was immense.

Social isolation and loneliness are extremely prevalent for people with a learning disability. That's why we worked with our members to create a community based Friendship Club, enabling people like Nesta to develop and maintain peer group friendships. This is Nesta's story, in her own words.

### How she felt at start of lockdown

I was really worried and didn't know what to think or how I would manage. It was all so unexpected.

### What happened next

I got a call from People First Dorset, who asked how I was. It was really nice of them to think about me. I felt they cared about me and I didn't feel so alone.

I told them about my worries and they offered to call me if I wanted to, which I did!



# Let's empower people with learning disabilities, together.

## What happened throughout lockdown

Since March, I have had calls from People First Dorset staff at least twice weekly. We have a good chat for an hour, and talk about all sorts of things. Each Monday and Thursday I wake up and think, 'Oh good, its them calling today'.

They have helped me to cope during a very difficult time. Some days when I felt low, it was really good to talk things through.

They also helped me with things to do, because I don't really like TV, use computers or smart phones. I said I'd try a colour by numbers book, which they sent me with some colouring pencils, and although I like doing it, it's a lot harder than you would think!

When their new booklet, Connect, came out, I was very pleased. First, it was very helpful as it helped me understand what the government were telling us to do. I didn't know some of these things before, so that was good.

It also gave me ideas of things to do like relaxation, puzzles and the recipes. Connect reminded me that even though I can't see my friends (other members of the Friendship Club) to see all the photos in it, makes me feel people are still there, even though I couldn't actually see them in person.

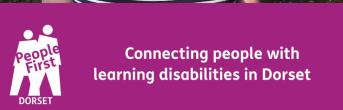
I was also so pleased when one month they printed something I had shared with one of their team. It was something my mother told me and was '**yesterday was history, tomorrow is a mystery, and today is a gift, which is why it's call the present**'. Mum would have been so proud of me, to know that this was published in Connect.

## The impact of reaching out

Now in February, I still have calls twice a week. It's different people now but their Manager, who called me throughout lockdown, still also calls me to have a chat. **I don't know what I would have done without them.**

To find out more about the work of People First Dorset please visit our website:

[www.peoplefirstdorset.org.uk](http://www.peoplefirstdorset.org.uk)

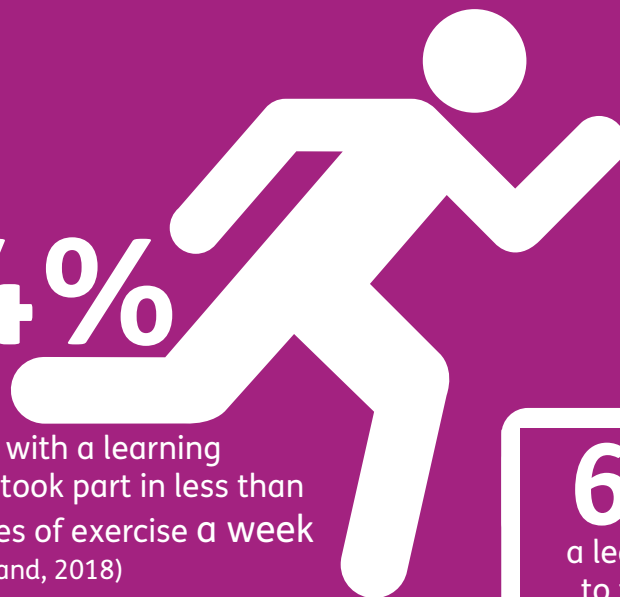




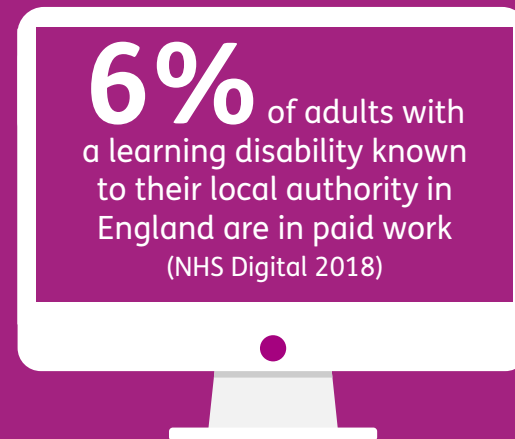
**1.5 million  
people have  
a learning  
disability in  
the UK**

**44%**

of people with a learning disability took part in less than 30 minutes of exercise a week (Sport England, 2018)



**6%** of adults with a learning disability known to their local authority in England are in paid work (NHS Digital 2018)



**1hr**



1 in 3 young people with a learning disability spend less than 1 hour outside their home on a typical Saturday (Mencap, 2019)

Studies suggest the rate of mental health problems in people with a learning disability is double that of the general population

(Cooper, 2007; Emerson & Hatton, 2007; NICE, 2016)

**6x**

The COVID death rate for people with a learning disability is reported as much as 6 times the general population (Public Health England 2020)



# Thank You

With all of the support we have received we have been able to deliver:

120

Zoom  
Sessions  
since November

39

Online Fitness  
Groups  
December - February

43

Speaking Up  
Group Hours  
November - February

30

Friendship Club  
Quiz Nights  
since November

13,500

Connect magazines distributed

1,052

Telephone calls made through the  
pandemic

## Funders





## What we did March 2020 - March 2021

AKA: A summary of what we were supposed to do, *but could not do*, so this is what we did that we were allowed to do, and which we did working from home *as we were not allowed to leave home except for those of us who could not work from home.*

To find out more, visit our website:

**[www.peoplefirstdorset.org.uk](http://www.peoplefirstdorset.org.uk)**

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