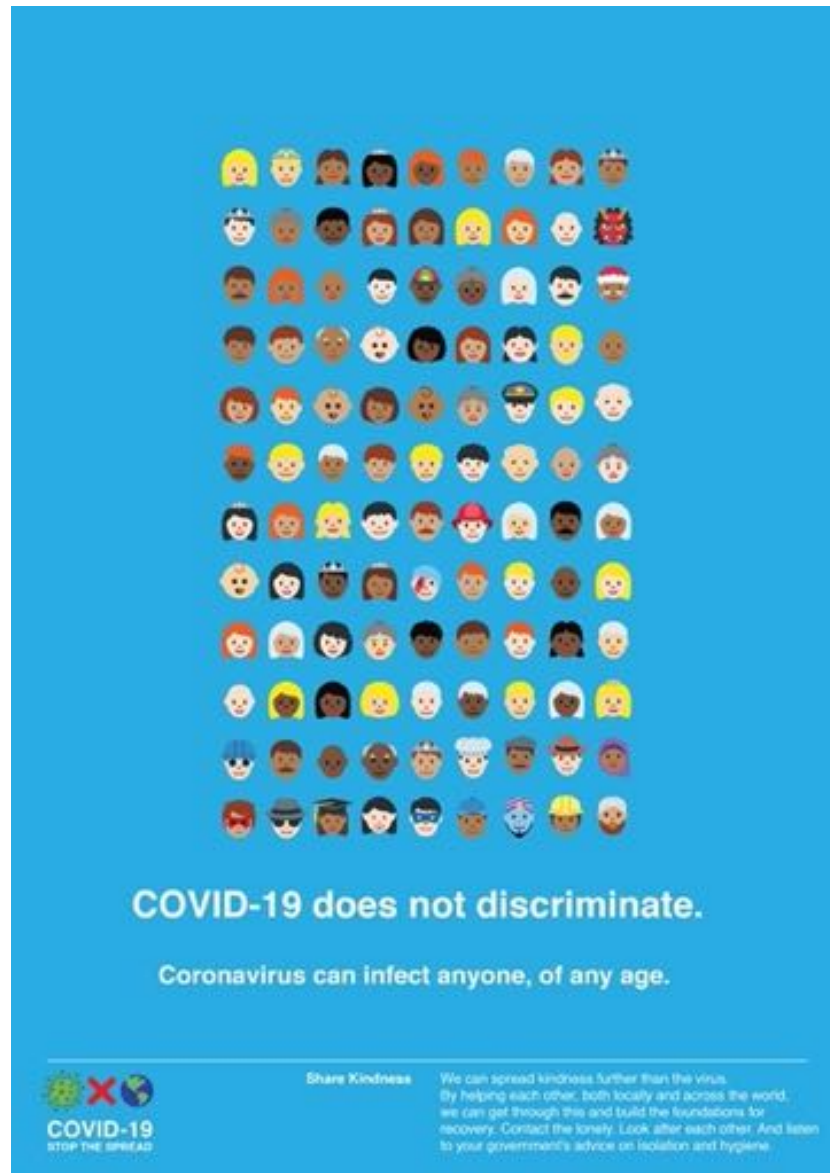


# PETER & FRIENDS TALK ABOUT COVID-19 AND HAVING A LEARNING DISABILITY AND/OR AUTISM



Peter Cronin, Steve Hardy, Matthew Roberts, Christine Koulla-Burke,  
David Mahon and Eddie Chaplin

PETER & FRIENDS TALK ABOUT COVID-19 AND  
HAVING A LEARNING DISABILITY AND/OR AUTISM

EST 1892 **LSBU**



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**NHS Foundation Trust**



**foundation for  
people with  
learning disabilities**

## Table of Contents

<b>Preface.....</b>	<b>10</b>
<b>Acknowledgements .....</b>	<b>11</b>
<b><i>Editors Biographies.....</i></b>	<b>12</b>
Peter Cronin .....	12
Steve Hardy .....	12
Matthew Roberts .....	13
Christine-Koulla Burke.....	13
David Mahon.....	14
Eddie Chaplin .....	15
<b><i>Dedications.....</i></b>	<b>16</b>
Remembering John Clarke.....	16
Remembering our friend .....	17
<b><i>Foreword by Professor Ruth Norway and Paula McGowan.....</i></b>	<b>18</b>
<b>Wales .....</b>	<b>18</b>
Professor Ruth Northway.....	18
<b>United Kingdom and Australia – .....</b>	<b>21</b>
Paula McGowan .....	21
<b><i>Chapter One – All about COVID and why we wrote the book .....</i></b>	<b>28</b>
Peter Cronin, Eddie Chaplin, Matthew Roberts, Steve Hardy, Bexley Mencap, Lewisham Speaking Up and Shared Communities .....	28
<b>The reason why we produced this book .....</b>	<b>28</b>
Peter Cronin .....	28
An Introduction to COVID-19 – .....	30
Eddie Chaplin .....	30
<b>COVID changes day by day 2020 .....</b>	<b>34</b>
Matthew Roberts .....	34
<b>Staying healthy at home.....</b>	<b>41</b>

Steve Hardy Matthew Roberts and Eddie Chaplin .....	41
<b>Chapter Two – Insights and experiences from people with learning disabilities.....</b>	<b>63</b>
<b>Austria .....</b>	<b>63</b>
Corona-virus and people with learning difficulties.....	63
Oswald Föllner .....	63
<b>“Would have done two months of radical lockdown” .....</b>	<b>65</b>
Sebastian Gruber .....	65
Translated from German by Susannah Leopold .....	65
Julius Szebeni.....	67
Report by Günther Leitner .....	69
Josef Hochmeister .....	71
Report by Kopera Kunst.....	72
Report by Maria Schwarr .....	76
Me, my boyfriend and that horrible coronavirus By Hanna Gugler Translated from German by Susannah Leopold .....	79
Vienna, July 15th, 2020. An interview with Lisa Rötzer .....	82
<b>Canada.....</b>	<b>84</b>
Victor Pereira - self-advocate .....	84
<b>England .....</b>	<b>86</b>
Peter Cronin’s story .....	86
Sandra’s story.....	87
Cath’s Lockdown Story.....	89
Daren’s Story .....	92
Chris Bromley Research Net member .....	99
David Bromley Research Net member .....	100
John (Pseudonym used at the request of the artist) Bromley Research Net member	101
Ted (Pseudonym used at the request of the artist) Bromley Research Net member..	103
BS Bromley Research Net member .....	104



Richard, Greenwich Research Net member .....	106
Ronald, Greenwich Research Net member .....	108
Kevin, Greenwich Research Net member .....	110
Laura, Greenwich Research Net member .....	113
Emma, Greenwich Research Net member .....	115
Richard, Greenwich Research Net member .....	116
Val's Story .....	118
Lord Timothy's Lockdown Story .....	122
Mark Bates (self-advocate in Campaign 4 Change) .....	127
Alex Starley (self-advocate in Campaign 4 Change) .....	129
Andrew Frith (self-advocate in Campaign 4 Change) .....	130
Fiifi Tetteh (self-advocate in Campaign 4 Change) .....	131
Mary Woodall (self-advocate in Campaign 4 Change) .....	132
David Ross (self-advocate in Campaign 4 Change) .....	134
Magie's Story .....	136
Andrew Donohoe My Covid-19 Story .....	142
Dinesh's story in Lewisham .....	149
Greg' Story .....	149
Lloyd – FPLD .....	152
Mikey – FPLD and involvement matters Eastbourne .....	154
Patricia – FPLD .....	158
Richard and Charlotte– FPLD .....	162
Scott and Amanda– FPLD .....	167
Sonia– FPLD .....	170
Alex's Story .....	174
Nathan Coronavirus Pandemic – COVID 19 .....	176
<b>Ghana .....</b>	<b>178</b>

The impact of Coronavirus on Gifty.....	178
Johannes's Story.....	183
<b>Netherlands.....</b>	<b>185</b>
'Also when Corona is over, I want to keep walking in the evening' Yvonne Schillemans & Mirjam Wouda .....	185
"Try to make something of it, there are always things you still can do" Mark Meekel and Suzanne Derks.....	192
Corona stress and Corona gains Saskia van der Weck & Paula Sterkenburg .....	196
'It's important to make the best out of every situation' Leroy van der Kust & Evelien van Wingerden .....	203
The self-advocates of 's Heeren Loo Mid Netherlands: Stories by Benjamin, Frank, Sam and Maaïke van Rest from the Netherlands. Coping with the COVID-19 crisis .....	206
<b>Scotland .....</b>	<b>215</b>
Alisha Black.....	215
Susan's story .....	218
<b>Spain.....</b>	<b>223</b>
Fernando's story or the sweeter side of life .....	223
<b>South Africa .....</b>	<b>229</b>
Michyle's story .....	229
<b>Wales .....</b>	<b>232</b>
Pete's Story.....	232
Shane's Story .....	234
Janice's Story. Advocacy Matters Wales – Cardiff .....	235
Adam - My Positive Pandemic Story.....	237
Rhyanydd Orford (self-advocate in Campaign 4 Change).....	241
Alex Roberts (self-advocate in Campaign 4 Change) .....	242
<b>Chapter Three - Stories from parents and carers.....</b>	<b>244</b>
<b>England .....</b>	<b>244</b>
Anne Donohoe, Andrew Donohoe's Mum's Story.....	244

Notes about my brother, Andrew Donohoe and lockdown, by his sister, Rebecca .....	258
Kaye and CJ's Story .....	259
Saba and Raana's Story .....	260
Keeping connected during coronavirus .....	260
<b>Wales .....</b>	<b>263</b>
Dawn and Jack's Story .....	263
<b><i>CHAPTER Four Individuals, teams and organisations supporting people with learning disabilities through the virus .....</i></b>	<b><i>268</i></b>
<b>England .....</b>	<b>268</b>
Azeez Interview .....	268
Jim Blair Interview .....	273
Jeanette Gallivan.....	281
Jenny's Story - SPICE – Life in Lockdown.....	285
Pippa Richardson interviews apprentices with learning disabilities and autism during COVID-19 about their experiences.....	286
Ben McCay My life during lockdown .....	295
My Name is Ben McCay, I am Co-Chair of the trustees at My Life My Choice.....	295
Nicola Payne's Story - Life changes overnight.....	299
Reflective correspondence during COVID 19.....	302
Daniel and Karmelle .....	302
Mark Topp's Story (Care Leader) .....	312
Lindsay's Story Year of the Nurse and Midwife.....	319
Lockdown and me! Interview with Personal Assistant Anne Donohoe.....	327
Lockdown and me! Interview with Personal Assistant Antonia Eastwood .....	329
Lockdown and me! Interview with Personal Assistant Jodie Saunders.....	331
Lockdown and me! Interview with Personal Assistant Kerry Rochford.....	333
Lockdown and me! Interview with Personal Assistant Lauren Brinsom .....	335
Lockdown and me! Interview with Personal Assistant and sister Rebecca Scott .....	338

<b>Ireland.....</b>	<b>339</b>
In Limbo: The impact of the pandemic on people with an intellectual disability .....	339
Dr Evan Yacoub .....	339
<b>Malaysia.....</b>	<b>344</b>
Prof. Dr Toh Teck Hock, Sibul, Malaysia.....	344
<b>Netherlands.....</b>	<b>354</b>
Supporting people with ID during the COVID-19 crisis: Stories by Christiaan, Bernadette, Sander, and Edithe Rot.....	354
<b>Scotland .....</b>	<b>363</b>
Linda Craig.....	363
<b>South Africa .....</b>	<b>371</b>
Dr Zuzana Matousova-Done .....	371
Teaching, working and learning in Cape Town during COVID-19 - Clara Machado ...	384
<b>Spain.....</b>	<b>389</b>
Almudena Martorell, Learning Disabilities and COVID in Spain.....	389
.....	<b>393</b>
<b>Wales .....</b>	<b>393</b>
Paula Hope's Story - Reflections on connections .....	393
Hannah's and Susan's Story - Wellbeing and working together.....	400
Engaging people with a Learning Disability upon an Acute Admissions Unit during COVID-19 outbreak: Hannah's story.....	402
Susan's Story Supporting people with a Learning Disability living at home in their community during COVID-19 outbreak.....	407
<b><i>Chapter Five - Mental health, technology and the 5 Ways to Wellbeing – Coping with the pandemic.....</i></b>	<b>413</b>
David Mahon and Christine-Koulla Burke The Foundation for People with Learning Disabilities. ....	413

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## Preface

This book has been put together over a six-month period, without a publisher. So, we apologise in advance for any stray typo or if anything gets lost in translation.

As you will see in the book, we thought it important to write this book as many of us feel that people with learning disabilities have been largely forgotten during this pandemic. This book will hopefully help people's voices to be heard and not only the specific difficulties people have experienced but the remarkable resilience they and their carers have shown.

In writing their story many people have been assisted by family, friends and carers in different ways. This is why the style changes, to try and catch the person and their preferred style of communication.

In the book are stories from people in a variety of different situations, including workplaces, family homes, in supported living, people in hospital including patients or staff in general hospitals, Assessment and Treatment Units and Medium Secure Units.

It is our strong belief that everyone has the right to speak up and be heard wherever they are, and this should be respected. Everybody has a voice, and everybody matters whoever they are, and it is our duty to assist them to be heard.

## Acknowledgements

As well as thanking all of the contributors, interviewers and those who have supported people to tell their story. We would like to say a special thank you to Sir Norman Lamb and Hayley Newman for supporting the project and giving up their valuable time to agree to speak at the launch.

We would also like to thank Professor Ruth Northway and Paula McGowan for their foreword and offering their valued insights. Ruth is a continued advocate for Learning Disability Nursing and Paula has been instrumental in bringing Oliver's Mandatory Training for all health and social care on learning disabilities and autism.

For their advice and counsel, we'd like to say a special thank you to Mr Azeez, Kaye Jone, Elaine Hurault and Sharon Rodrigues for their kindness, offering guidance and support when it was needed.

Jon Bryant has been an absolute star with producing the maps you will find throughout this book. We would like to thank Sunny Sokhal and Cardiff University Vox of their amazing performances at the launch.

Finally, a thank you to Lorraine Regan from Oxleas NHS Foundation Trust for supporting the project and Neil Basing at London South Bank University for organising the virtual conference and launch and to Jon Bryant for producing the maps for each country.

The photos in this book are from the Editors, contributors and <https://unsplash.com/>.

## Editors Biographies

### Peter Cronin



Peter is a self-advocate and representative for employment at Lewisham Speaking Up. He is widely recognised as one of the leading self-advocates and is widely published in books and chapters. Peter speaks all over the UK about the mental health of people with learning disabilities and has been a champion for people with learning disabilities for decades.

He hopes to see the day when people with learning disabilities are treated as equals.

### Steve Hardy



Steve registered as a nurse for people with learning disabilities in 1994. Since then he has worked in various settings including supported living, in-patient services, education in the NHS and as a lecturer at the Institute of Psychiatry. He is currently a Practice Development Nurse at Oxleas NHS Foundation Trust and the Associate Editor of Advances in

Autism. In his own time, he is an Independent Consultant Nurse specialising in supporting people with learning disabilities to have a platform to be heard, through writing for journals and blogs, and speaking at conferences to campaign for a better life.



### **Matthew Roberts**



Matthew has been involved in supporting individuals with learning disabilities and autism, directly and indirectly, for more than five years. He has worked in support worker, research assistant, teaching assistant, fundraising, and occupational therapy assistant roles across a variety of settings and is passionate about enabling independence and forming connections with people with communication difficulties. He has worked within the charity sector, education and NHS services, and is currently studying a Postgraduate Diploma in Occupational Therapy at Cardiff University.

### **Christine-Koulla Burke**



Christine is Director of the Foundation for People with Learning Disabilities (FPLD), at London South Bank University. FPLD works with people with a learning disability to undertake applied research and social policy development. She previously worked for: the Mental Health Foundation as the Equalities Lead on prevention and combating inequalities, She is Deputy Chief Executive of Circles Network and as a senior manager in various organisations for over 40 years. She has developed and managed many social change programmes and research in both health and social care, nationally and internationally. promoting co-production and the involvement of self-advocates and families in all programmes. She has worked internationally on deinstitutionalisation. As well as managed several European programmes with European partners and supported the

work of the Valuing People with family leadership and managing the National Advisory Group for People with Learning Disabilities and Ethnicity. Has published many articles, guides and training publications. She holds a BA Hons in Psychology, MSc in Child Psychology, and a Diploma in Psychotherapy.

### David Mahon



David Mahon is the Head of Programmes at The Foundation for People with Learning Disabilities. He is currently leading on the Foundation's Pass-it-on Project a project all about mental health for people with learning disabilities.

David has a background in managing project and programmes covering a wide variety of different areas in addition to learning disabilities, including speech, language and communication needs, peer support, local authority provision and electoral reform. David is an experienced trainer and has developed a variety of different training programmes. David has also acted as an electoral monitor in the former Soviet Republic of Georgia for the Organisation for Economic Co-operation and Development.



## Eddie Chaplin

Eddie is Professor of Mental Health in Neurodevelopmental Disorders at London South Bank University and Secretary for the European Association of Mental Health in Intellectual Disability. Eddie has extensive clinical experience in both local and national mental health services for people with learning disability



and autism He is the Editor for the Advances in Autism Journal, and his current research involves neurodevelopmental disorders in the Criminal Justice System and evaluating co-produced peer-mentoring projects.





## Dedications

### Remembering John Clarke

We as a Learning Disability team were very fortunate to have known John. He was one of the founder members of the Can you understand it? team which is part of the Oxleas Learning Disability Editorial Team which has been running for over ten years. John also sat on the Service User Interview Panel and in his words 'always got the right person for the job'.

He had so many lovely qualities but what stood out was his determination to speak for people with learning disabilities. He was a 'Quality Checker' and visited many GP (Doctors) surgeries to check if they made reasonable adjustments for people with learning disabilities. He also was an assistant MP for the Greenwich People's Parliament.



As Joel Parker (Psychologist for Greenwich Learning Disability Team) summed up John perfectly 'He was also a wonderful storyteller, had a wonderful sense of humour and was a prolific creator of "crazy art"- remarkable geometric drawings- each one unique and offering fresh perspectives, just as he did in each conversation that we shared.

It really feels like one of the very great lights in our learning disabilities community has gone out.'

RIP John Clarke who passed away during COVID.

### Remembering our friend

To our special friend Robin, we will always think of you.

Thank you, Robin, for all did for speaking up for Research Group.



## Foreword by Professor Ruth Norway and Paula McGowan



### Wales

### Professor Ruth Northway

2020 has been a roller coaster year for most of us. Things have changed in ways we probably never thought were possible, and high levels of uncertainty remain. In this context much has been written and many debates have been held. However, some voices have perhaps been more difficult to hear in these discussions and these include those of people with learning disabilities, their families and others that support them. The editors of this volume are thus to be commended for seeking to change this situation and for creating a platform through which their stories can be shared more widely.



Reading through these accounts has been a privilege and the experience has certainly led me to reflect on what I feel are the key messages. At one level there is a sense of commonality in that those things that have affected all of us (such as restrictions on our movements and concerns regarding our health) have likewise affected people with learning

disabilities. This is true not only in the UK but (as these accounts show) also across continents.

However, it is also evident that many of the changes brought about by COVID 19 have had a different and often more significant impact on people with learning disabilities. For example, whilst many of us have struggled with official policies and guidance that change regularly and often appear contradictory, dealing with the amount, complexity and changing nature of such information has been very challenging for people with learning disabilities. This has been particularly the case where information has not been provided in accessible formats. Similarly whilst policies such as banning visitors to accompany patients admitted to hospital were implemented to try and reduce the risk of infection this did not take account of the risks that would be involved for those who require a supporter to interpret and communicate their needs to healthcare staff. Many of us have felt the loss of face-to-face contact with family and friends but for some people with learning disabilities and their families this has been particularly traumatic. Experiences such as these and the possible impact on people's health and well-being are likely to have a continuing impact for some time to come.

Nonetheless it would be a mistake to conclude that the experiences have been totally negative. What struck me in a number of the accounts is the positivity and resilience that individuals have often shown in the face of adversity. There is great sense of the need to support and help each other. There are also some great examples of creativity from people with learning disabilities, their families and supporters as they try to find new ways of doing things.

At the present we do not know what the immediate future holds, but it seems likely that COVID 19 will influence our lives for some time to come. In going forward, therefore, it is important that we learn lessons from these accounts and use this learning to support people with learning disabilities in living their best possible lives. It is also important that we continue to listen, learn and act.

Thank you to everyone who took the time to write their account and to share it with us. Thank you also to the editorial team for bringing this project together in such a short time. I hope that other readers enjoy reading it and learn as much as I did.

Ruth Northway

Professor of Learning Disability Nursing

University of South Wales



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## United Kingdom and Australia –

**Paula McGowan**

Written at the beginning of June 2020



During the Corona Virus pandemic, everyone was given the gift of time. This was a gift that my husband Tom and I didn't want, because it was empty space. By that, I mean that we couldn't run away from the truth and reality of Oliver's death. We no longer had the luxury of long working hours to distract our minds, from the horrors of what had happened to Oliver and our deep, deep loss.

What helped- Distraction? Trying to focus on positive things. Looking after my mental health was incredibly important. I did this by concentrating

on Oliver's legacy, the Oliver's Mandatory Training for Health and Social Care staff, which I talk about below.

COVID-19 has been somewhat different in Australia compared to the UK. The actual numbers of people who have been infected with the virus and those who have died has been significantly lower compared to the UK and the rest of Europe. However, like the UK, the Australian government has issued strict instructions which generally, people have adhered to.

We also have and abide by Social Distancing rules and we certainly saw shortages of essential supplies in the supermarkets. Like the UK, we also had queues to enter shops and supermarkets. Cinemas, theatres, restaurants and coffee shops were closed. Many small businesses couldn't cope with the loss of revenue and have sadly closed permanently.

I am aware that COVID 19 has affected the mental health of many people. I believe that we should be mindful in that one person's isolation, or experience of COVID-19 can be very different for other people. For example, I am very fortunate to have a beach nearby, where my husband and I are able to go for walks. The beach for us is an essential part of our daily routine and this helps us cope with our grief and the current ongoing investigations into Oliver's death.

COVID-19 can be a very different experience for many people. Some people are fortunate in having large gardens even swimming pools and tennis courts. These experiences cannot be compared to a person who may live in a flat or apartment, who do not have access to a garden or are not able to visit a local park or woodland. Government restrictions placed on people in the UK meant they were allowed to leave their homes for just one hour per day for exercise.

I am painfully aware that many learning-disabled people may be experiencing lockdown and COVID 19 without help and support to understand what is happening, not having regular access to their families. Crucial community support has been reduced and even lost in many cases. Many people with a learning disability are isolated and lonely having to fend for themselves. They are not able to access many services that were available to them before the pandemic and this will potentially have an adverse effect on their mental health. Shockingly, I am told that they are not able to access any mental health support at this time.

My father recently contracted COVID-19 whilst in a nursing home. He is a very frail elderly man in the later stages of Parkinson's disease. He has many comorbidities alongside this. He has no mobility and suffers from many chest infections including pneumonia. Despite this, he was treated very well at his local hospital. He was given appropriate antibiotics and has survived where many people have not been so fortunate. My father has consented to a DNR (Do not resuscitate) being placed in his medical care charts. This was agreed after meaningful discussions with him and we took place. This has not been the case for everyone.

COVID 19, has uncovered blanket DNRs placed on many people who live in care homes, this includes healthy learning disabled and or autistic people. I find this not only shocking but also shameful that any doctor could do this. Worse still, those affected had not been consulted about this. For me, this is absolute discrimination and screams of survival of the fittest. What type of society allows this to happen to its most vulnerable people?

However, this is not new. The Learning Disability Mortality Review reported before the pandemic, that people who have Down's syndrome

had also been placed illegally onto DNRs without their or their family's knowledge or consent. There was no reason for this other than they had an Intellectual Disability. Shocking, isn't it.

For far too long, many people who have a learning disability have had poor and unequal access to quality health care. They have suffered from bias, discrimination alongside diagnostic overshadowing. Things must change and I dearly hope that the Oliver McGowan Mandatory Training will be the start of this.

I remember meeting Steve and Peter last year in Birmingham, where they were both giving a powerful presentation about the Human Rights of learning-disabled people. It was apparent to all that they both have a real passion and drive to address social inequality and injustice that many learning-disabled people face every day.

Until Oliver's avoidable death, I had no idea that people who have a learning disability and or autism face such discrimination. I was utterly ignorant. I was appalled to discover, that this discrimination starts at the beginning of life, where the foetus of a disabled child can be terminated right up to the point of birth, whereas a termination in what is seen as a non-disabled foetus cannot happen after 24 weeks gestation. How can a civilised society allow such prejudice?

I would like to tell you about my Advocacy.

When Oliver died, we, as a family, were devastated as were his friends and teachers. We couldn't believe what happened to Oliver. We knew it was abuse to administer a type of medication that Oliver simply did not need. We thought we were alone. We thought that Oliver was the only one until I went on social media and discovered that there was research showing that he was one of 1,200 people in England who have learning

disabilities and who die each year because they are not getting the right health care.

I simply could not stand by and allow this to continue. I started a parliamentary petition asking for all doctors, nurses, health care practitioners and social workers to receive mandatory standardised training in autism and intellectual disability. It was clear from Oliver's inquest that the medics had no understanding of autism and intellectual disability. We believe that this cost Oliver his life.

We also strongly believe that it is wrong that clinicians do not receive training that allows them to effectively treat vulnerable patients such as Oliver. We started Oliver's campaign, which has a website (<https://www.olivermcgowan.org/>) with updates, information and resources. Oliver's campaign is about inclusion, equality and acceptance. It's about breaking down barriers that discriminate against and isolate those who are more vulnerable than us. Oliver's death has highlighted this discrimination that exists in England for people who have autism and learning disabilities.

When Oliver was being treated by doctors and in hospital, I believed that the doctors and clinicians were trained in autism and intellectual disability and that they knew more than me. However, it became clear from the inquest into his death that there was no mandatory training for health professionals in relation to this issue.

On 22 October 2018, I took my petition to the UK parliament demanding that training on intellectual disability and autism be mandatory for all health and social care professionals. This petition ultimately led to the UK government making a commitment in 2019 to introduce the Oliver McGowan Mandatory Training in Learning Disability and Autism for all

health and social care staff. This commitment was outlined by the UK government in their consultation response that was titled 'Right to be heard' This commitment was also in response to the recommendations made in the second annual Learning Disabilities Mortality Review.

The Oliver McGowan Mandatory Training in Learning Disability and Autism is now being trialled in England and will then be evaluated before being rolled out nationally. I hope that we will also manage to get the UK Health and Social Care Act 2008 (Regulated Activities) Regulations 2014 amended to require all NHS and social care providers who carry out regulated activities to ensure that their staff have achieved the learning outcomes relevant to their role. Current plans are that these changes would come into force in April 2021.

For further information regarding Oliver McGowan Mandatory Training is here:

<https://www.hee.nhs.uk/our-work/learning-disability/oliver-mcgowan-mandatory-training-learning-disability-autism>

I very much look forward to reading this wonderful book. I am always inspired to read about the strength, determination and resilience that learning-disabled people have.







## Chapter One – All about COVID and why we wrote the book

**Peter Cronin, Eddie Chaplin, Matthew Roberts, Steve Hardy, Bexley Mencap, Lewisham Speaking Up and Shared Communities**

### **The reason why we produced this book**

**Peter Cronin**

I started to become really worried back in March when COVID was all over the news. I had a cough, and we weren't allowed to see the GP (Doctor) face to face so I had an appointment on the telephone. He said I should take my temperature and then get back to him if it's high. I don't have a thermometer and even if I did, I can't read. I called Steve up and he asked me to touch my forehead and it didn't feel hot. He also asked if I can't taste





anything, I could taste so then I knew I didn't have COVID.



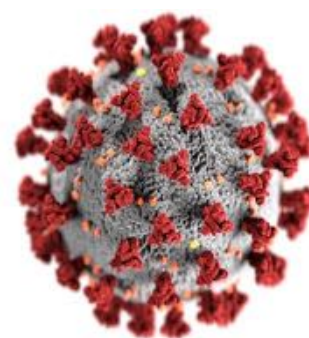
The government and the NHS all provided easy read information, but I can't read, and I live by myself. I normally have two mornings of outreach support, but this stopped due to the virus. I felt unprepared, I didn't know what was going on and I was having sleepless nights.

So, I spoke to Christine, Eddie, Matthew, David and Steve. I told them we need to tell people my story and stories from other people with learning disabilities. We are treated like second class citizens and I wanted to tell the world how people with learning disabilities are treated. So, this book was born, and we are so happy to have stories from all over the world.

Finally, I'd like to recommend an easy read guide on COVID-19 which has been written by MENCAP

<https://www.mencap.org.uk/sites/default/files/2020-07/Information%20about%20COVID-19%20AH%20.pdf>

## An Introduction to COVID-19 – Eddie Chaplin



This book has been designed to help people with learning disabilities and/or autism to share their stories and experiences during the coronavirus pandemic. from both those who have caught the virus and those trying to protect themselves and stay safe.

Many people with a learning disability and their carers feel that they have largely been forgotten during the coronavirus pandemic and left to fend for themselves. Public Health England (PHE) estimates that 3,400 people with a learning disability die each year. Information from NHS England and NHS Improvement (NHSEI) shows that between the 16 March and 10 May 2020, 1,029 people with a learning disability died in England, with 45%, (467), linked to coronavirus.

Initially PHE said information on the deaths of people with learning disabilities from COVID-19, will not be published until 2021. Since this we have had published a report by them in November 2020.

Deaths of people identified as having learning disabilities with COVID-19 in England in the spring of 2020

Which can be downloaded at

[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/933612/COVID-19\\_learning\\_disabilities\\_mortality\\_report.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/933612/COVID-19_learning_disabilities_mortality_report.pdf)

With the easy read version at

[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/933613/COVID-19\\_learning\\_disabilities\\_mortality\\_report\\_easy\\_read.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/933613/COVID-19_learning_disabilities_mortality_report_easy_read.pdf)

Some of the main findings include, 623 deaths of people with learning disabilities were reported to LeDeR, given the likelihood of under notification, it is estimated the true figures is 956, deaths. This is respectively 2.3 - 3.6 times the rate in the general population.

COVID-19 in the learning disability population is spread more evenly across age ranges with higher rates across all adult age groups when compared to the general population with the largest number of deaths between the ages of 55 to 64 years old. In young people with learning disabilities the risk was further increased.

For learning disabled males, the death rate was higher compared to females with learning disabilities by between 1.4 -1.6 times depending on the source used.

The proportions of COVID-19 deaths in people with learning disabilities that were of a person from an Asian or Asian British group, or a Black or Black British group were greater than the proportions in deaths from other causes in 2020.

However, it is still the case that people with learning disabilities are more at risk than most groups. Added to this many will be:

- unable to understand government advice to stay safe and to protect themselves
- confused as Carers are unsure what advice to give
- having issues seeking help with symptoms

- affected by the rationing of NHS services which have been postponed because of coronavirus
- at increased risk of existing poor physical health, e.g. respiratory disorders, heart disease and obesity
- living in communal settings where self-isolation is difficult and with no control who comes in and out of where they live.

To help stop the spread of the disease there are things we should think about when supporting people with learning disabilities.

- Finding accessible information on local and national guidance on reducing the risk of infection <http://radiant.nhs.uk/coronavirus-COVID-19.html>
- Give support to get into a routine of regular handwashing
- Try to encourage people not to touch their face unnecessarily and to wear a face covering
- Maintain social distancing, keep two meters apart. If you invite friends who do not normally live with you make sure they maintain social distancing
- Clean everything after use when new people are in the house, also encourage others such as family or carers not living with you, to respect your space and social distance
- Loneliness can be more of a problem use phones and computers to keep in touch with friends, family and services. EasyRead does not help if it's not sent to people. and not everyone can access online information.

Remember guidance changes so keep everyone up to date.

Coronavirus is explained below in figure 1 taken from the WHO.

Overview	Prevention	Symptoms	Getting help
<p>Coronavirus disease (COVID-19) is an infectious disease.</p> <p>Most people infected with the COVID-19 virus will experience mild to moderate respiratory illness and recover without requiring special treatment. Older people and those with underlying medical problems like cardiovascular disease, diabetes, chronic respiratory disease, and cancer are more likely to develop serious illness.</p> <p>The COVID-19 virus spreads primarily through droplets of saliva or discharge from the nose when an infected person coughs or sneezes, so it's important that you also practice respiratory etiquette (for example, by coughing into a flexed elbow).</p>	<p>To prevent infection of COVID-19, do the following:</p> <ul style="list-style-type: none"> <li>• Wash your hands regularly with soap and water or clean them with alcohol-based hand rub.</li> <li>• Maintain at least 2 metres distance between you and people coughing or sneezing.</li> <li>• Avoid touching your face.</li> <li>• Cover your mouth and nose when coughing or sneezing.</li> <li>• Stay home if you feel unwell.</li> <li>• Refrain from smoking and other activities that weaken the lungs.</li> <li>• Practice physical distancing by avoiding unnecessary travel and staying away from large groups of people</li> </ul>	<p>COVID-19 affects different people in different ways.</p> <p>Most common symptoms:</p> <ul style="list-style-type: none"> <li>• fever.</li> <li>• dry cough.</li> <li>• tiredness.</li> <li>• Less common symptoms:</li> <li>• aches and pains.</li> <li>• sore throat.</li> <li>• diarrhoea.</li> <li>• conjunctivitis.</li> <li>• headache.</li> <li>• loss of taste or smell.</li> <li>• a rash on the skin, or discolouration of fingers or toes.</li> <li>• Serious symptoms:</li> <li>• difficulty breathing or shortness of breath.</li> <li>• chest pain or pressure.</li> <li>• loss of speech or movement.</li> <li>• Seek immediate medical attention if you have serious symptoms.</li> </ul>	<p>People with mild symptoms who are otherwise healthy should manage their symptoms at home.</p> <p>On average it takes 5–6 days from when someone is infected with the virus for symptoms to show, however it can take up to 14 days.</p> <p>If it's not an emergency, contact NHS 111 online. If you have no internet access, you should call NHS 111. For any emergency conditions, if you need to call an ambulance, dial 999 and inform the call handler or operator.</p>

Figure 1. About Coronavirus adapted from WHO to include UK advice

## COVID changes day by day 2020

Matthew Roberts

The global COVID-19 pandemic has posed a huge number of challenges to vulnerable populations across the world. Much recognition has been given to the elderly, who from an early stage have been protected by policies such as shielding, and there has been belated recognition for the disproportionate impact on Black, Asian, and minority ethnic (BAME) communities in the UK and elsewhere. However, people with learning disabilities and autism should also be considered in this category and the following chapter explains how the regular changes in government guidance and restrictions on freedoms affected this underrepresented demographic. Due to the complex and unique nature of each nation's experience of the pandemic, this chapter will primarily focus on the United Kingdom (UK) but will conclude by reflecting on the variety of international experiences on tackling similar socio-economic challenges. Hindsight can easily obscure the complexity of a situation, so the following section will attempt to chart the chronology of the government's response in an impartial manner using the UK government's official policy tracker.

The tracker begins the 10<sup>th</sup> of January 2020 where the first guidance was published for health workers and clinicians on control measures and management strategies in response to COVID-19. This was accompanied by Public Health Advice for Travellers to Wuhan, which included simple precautions such as minimising contact with birds and animals and practising good hand hygiene. On the 2<sup>nd</sup> of February, a COVID-19 public information campaign began, followed by a new NHS surveillance system to detect cases on February 26<sup>th</sup>. On the 28<sup>th</sup>, test sites were rolled out including 'drive-through' testing and further public information campaigns



followed on March 4<sup>th</sup> particularly focusing on handwashing for 20 seconds. On the 12<sup>th</sup> of March, the government moved from the 'contain' to the 'delay' phase of its COVID-19 response – those with symptoms were told to stay home for 7 days but weren't required to be tested. Ten days later shielding measures were first introduced to protect 1.5 million people identified as higher risk and or extremely vulnerable. On the following day, further social distancing measures were brought into effect, which stopped social gatherings and closed certain businesses. On the 17<sup>th</sup> of April, the government announced that current social distancing measures must remain in place for at least a further three weeks and outlined the 5 tests for adjusting lockdown. The five tests include evidence that the NHS can cope across the UK, a sustained fall in daily death rates, evidence the rate of infection is decreasing, confidence that supplies of testing and Personal Protective Equipment (PPE) can meet demand and no risk of a second peak. Looking at these five tests now in the context of a potential second peak it leads one to question, were these in fact met before the lockdown was eased?

The pattern of public education campaigns followed by shielding and restrictions on large gatherings has been followed relatively consistently across many different countries. The main differences have been in the speed at which these were enacted and their severity in terms of preventing groups of people meeting in public and private. Many have criticised the piecemeal nature of the UK government's transition into lockdown and praised the response of nations like New Zealand who took more definitive initial steps that could subsequently be eased more quickly with a lower rate of infection. To put these dates into context major gatherings were still taking place well into March in the UK, with the last premier league football match for example occurring on the March 9<sup>th</sup>.

Some of the stories in this book illustrate how the gradual and constantly shifting nature of these changes were a source of stress and anxiety to many individuals with Learning Disabilities. From March until June 26<sup>th</sup> there were 92 daily COVID-19 briefings and two national addresses by the prime minister each of which communicated complex information in a way that was very difficult for individuals with communication difficulties to comprehend. However, the gradual relaxation (and potential local or national reintroduction) of the new rules imposed by the COVID-19 pandemic have arguably caused even greater confusion and concern within this demographic.

On the 11<sup>th</sup> of May, the UK government released 'Our Plan to Rebuild: The UK Government's COVID-19 recovery strategy' and published guidance for employers on how to get their businesses and workplaces up and running safely. Later the same day the Prime Minister revised his message to 'Stay Alert Control the Virus Save Lives', a message that was heavily criticised in the media for its ambiguity. Despite the government's attempts at clarity and transparency in the gradual relaxation of lockdown measures it was openly mocked with comedians such as Matt Lucas parodying the video saying "So we are saying: don't go to work, go to work, don't take public transport, go to work, don't go to work, stay indoors, if you can work from home go to work, go outside, don't go outside, and then we will, or won't, something or other." While this is obviously an exaggerated portrayal of the prime minister's address it illustrates the confusion it may have been met with by individuals with learning disabilities, whose relatively clear initial lockdown messages were now thrown into disarray with complex and often subjective terms such as 'stay alert', 'flatten the curve' and 'R number'. On the other hand, mapping and charting of the specific localities worst affected were then

introduced, alongside COVID Alert levels were introduced for the first time using a traffic light system bringing a level of clarity and simplicity to the message.

On the 18<sup>th</sup> of May the loss of, or change in, a person's sense of smell or taste was added as a symptom of COVID-19, the beginning of a gradual process of realising that the symptoms of COVID-19 aren't limited to a dry cough and fever. The impact of this change was dramatic. People with learning disabilities and autism were now being told that not only had all the rules about this new scary disease changed but even its symptoms were adapting and shifting. A 14-day self-isolation rule for those entering the UK from a foreign country was introduced on May the 22<sup>nd</sup>, another area which has since been revised and amended frequently. Portugal for example was banned in May, opened to tourism in July before closing again in August. While

this may have not directly affected people with learning disabilities or autism from travelling to these destinations the fluctuations in messaging and communication are likely to have been met with confusion,



and potentially anxiety. As different countries aimed to tackle their varying rates of infection international arrivals were often scapegoated to a greater or lesser extent. As well as the rate of infection, politics, economics and

physical geography seemed increasingly significant in the list of countries deemed 'safe' and enforcing a quarantine on international arrivals became increasingly reciprocal and petty.

A subsequent easing of lockdown was undertaken on the 1<sup>st</sup> of June which included allowing those 'shielding' to visit others outdoors, groups of up to six from different households to meet outdoors and primary schools to open to Nursery, Reception, Year 1 and Year 6 students. On the 13<sup>th</sup> of June, single households were allowed to join with one other household and form a 'support bubble', another



concept which was not explained in an easily accessible manner for individuals with communication difficulties. On the 15<sup>th</sup> of June, the government reversed its policy on face masks by making them mandatory on public transport, with limited exceptions including some individuals within the learning disability community. Individuals exempt from these rules were given no clear means of identifying themselves, which may have contributed to public disapproval for them seemingly disobeying the new regulations. Shops selling non-essential goods opened later the same day, a move that undoubtedly boosted morale and increased the freedom of movement for those with learning disabilities who had

experienced relative isolation the preceding months. Those returning to shops found tape on the floor and new 'one-way systems' to minimise exposure to other shoppers. These were new, confusing and unfamiliar and at first strictly adhered to. However, over the subsequent months these began to be more flexible and the job of shop, bar and restaurant employees to enforce strict social distancing measures became more and more impossible. The government's two metre ruling on social distancing was amended to 'One metre plus' on the 24<sup>th</sup> of June. From the 3<sup>rd</sup> to the 31<sup>st</sup> of August the "Eat Out to Help Out" scheme was introduced, aiming to kickstart the suffering hospitality industry. And just as it seemed that we were getting back towards a 'new normal' local lockdowns were introduced, bringing in different often contradictory rules for specific localities. These were often announced on national news with several days warning, but in some cases, they were announced with almost immediate effect causing a much more dramatic disruption. For example, Matt Hancock the UK Health Secretary announced on Twitter at 9:17 pm on the 30<sup>th</sup> of July that Greater Manchester, Blackburn, Burnley, Hyndburn, Pendle, Rossendale, Bradford, Calderdale and Kirklees would join Leicester in Local Lockdown from Midnight. This is particularly noteworthy given the public uproar at the speed at which Lockdown rules were introduced in parts of India on the 24<sup>th</sup> of March, leaving thousands of seasonal workers trapped in unfamiliar urban areas.

The challenges of communicating a truly national message and coordinating a unified response to a pandemic such as COVID-19 are undoubtedly monumental. However, these examples illustrate that almost every hard and fast rule the government set about the virus was subsequently altered, corrected or reversed. This is undoubtedly partially a result of a lack of understanding about the virus and the impossible

balancing act between COVID-patient's needs, those of the 'non-essential' health services which had been suspended, and the economic impact which could potentially be more widespread and enduring. The aim of this chapter is not to criticise or judge, but merely to encourage the reader to attempt to interpret these cleverly worded, well-meaning, calculated series of changes from the perspective of someone with a limited grasp of the written word or the English language. This publication aims to identify some lessons we have learned from the pandemic, and one of these must be the need for a targeted, reactive government response that reflects the diversity of the populations it is addressing. The use of complex, politicised rhetoric only makes the life-threatening, anxiety-provoking issue of COVID-19 more incomprehensible.





## Staying healthy at home

Steve Hardy Matthew Roberts and Eddie Chaplin

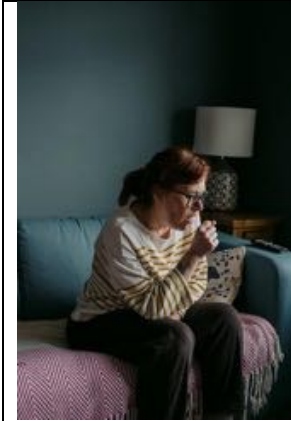



All over the world people have been on lockdown at different times. The reason is COVID-19. It's a new virus that started in China towards the end of 2019. Anyone can catch COVID-19, as it's spread by coming into contact with someone who has it or by touching something that COVID-19 is on. It does not discriminate but some people are more vulnerable, including people with learning disabilities.



A 'second wave' of COVID-19 is happening again across Europe. We saw this as an opportunity to remind us all of all 'how you can stay healthy at home'.



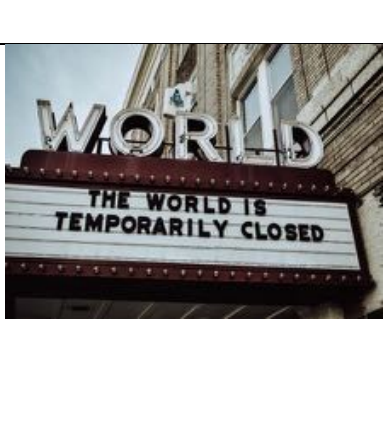


Firstly, let's start with some easy ways to avoid catching COVID-19:

		<p>Wash your hands regularly for 20 seconds</p>
		<p>Use a tissue to cover your mouth and nose when coughing</p>
		<p>If you don't have a tissue use your elbow</p>
		<p>Avoid touching your face</p>

	<p>Wear a mask when outside of your home</p>
	<p>Stay away between 1 to 2 metres from people outside your home</p>







Many places have started to gradually reopen across the world, but there are some types of places not yet open to the public in the UK:

		<p>Some places are still closed</p>
		<p>Theatres and cinemas</p>
		<p>Music Venues</p>
		<p>Many sports venues such as football clubs</p>



Many countries have introduced a rule that only a limited number of people can use and be in certain places. These include:


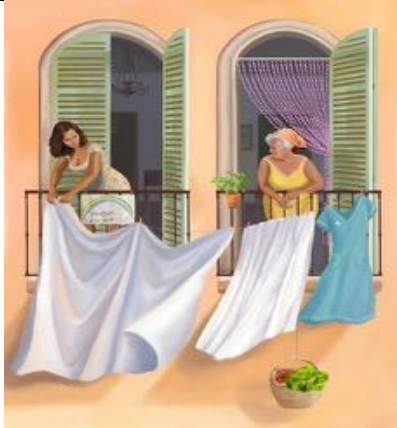
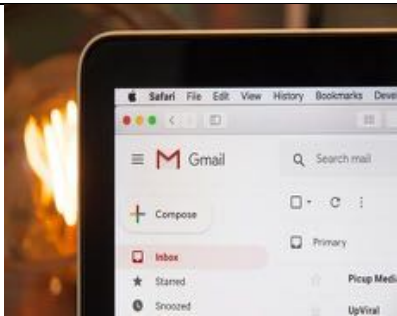
		<p>Restaurants</p>
		<p>Pubs and bars</p>
		<p>Shops and supermarkets</p>
		<p>Public transport</p>

Five important ways to stay mentally and physically well if we enter another lockdown:

1. Staying in touch with family and friends

There are several easy ways to keep in touch with those you care about. Try to contact at least one person every day. Here are some ways you can stay connected:

	Make regular telephone or mobile calls
	Skype, WhatsApp, Facetime or zoom
	Virtual games or quizzes
	Social media like Facebook or Twitter

	<p>Look for online groups where people have similar interests as you</p>
	<p>Talk to your neighbours over the fence</p>
	<p>Walking</p>

Remember to stay safe on the internet

<https://www.changepeople.org/Change/media/Change-Media-Library/Blog%20Media/Keeping-Safe-Online-Easy-Read-Guide-Small-File-Size.pdf>

<https://www.learningdisabilities.org.uk/learning-disabilities/publications/staying-safe-social-media-and-online>





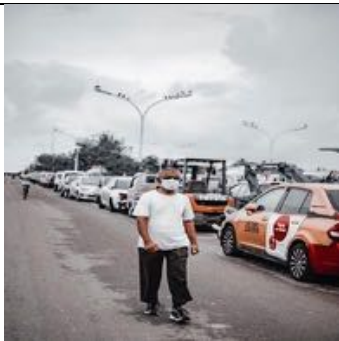
## 2. Regular exercise

First, during the lockdown, some people have started to exercise for the first-time using YouTube or online groups. Lockdown can be stressful for everyone, so take it easy and remember to enjoy the exercise. Doing regular exercise is good for your physical health but it is also great for your mental health. Doing exercise produces chemicals in your body that helps keep you happy.

Make exercise a part of your daily routine. There are plenty of recognised exercise experts on YouTube, which are free to watch. Whatever exercise you choose, take it slow, make small changes and make sure you have fun!



3. During lockdown in the UK we were allowed to go out to exercise once a day. Here are some suggestions:

	Jogging
	Following an exercise video on YouTube
	Walking

4. Don't watch too much news and try to avoid using the internet for news




Now it's important to keep informed – especially as COVID-19 rules can change daily. We recommend that you choose one source of where you get the news about COVID-19. Choose either a TV or radio news show. Almost anywhere in the world BBC or CNN are available.





It may seem strange to ask you not to watch the internet for news. You can watch the internet if the news is from an official site like Sky, NBS

or BBC. But stories on the internet can be fake and not true. They are often used to scare people and it can be difficult to tell what is true and what is fake. Just remember to keep to one news programme that is widely recognised and trusted.

## 5. Try to find opportunities to be positive





During COVID-19 and especially lockdown it can be difficult to stay positive. But some things can help you stay positive:

	Listen to music that makes you feel happy
	Do something that you feel excited or passionate about. COVID-19 or lockdown may limit what you can choose but think hard about it.
	Learn a new skill – there are many free webinars online that can teach you different skills. Or watch some of the daily TV shows that teach you new skills such as restoring furniture or get ideas for your garden from the TV.



	<p>When you keep in touch with people daily say thank you to them and tell them that you value your friendship.</p>
	<p>Keep on smiling as you won't be on lockdown forever.</p>
	<p>Challenge 'negative' thinking – turn it around like 'is there another way of approaching this'.</p>
	<p>Have faith in yourself, try positive thinking every day. "I can do this", "I've been here before and I got through this", "I've got great friends"</p>

## 6. Structuring and planning your day

Research suggests that people who have daily structure and routine are:

		Stay healthy in mind and body
		More productive
		Achieving your big and small goal
		Better sleep



	<p>Remaining calm</p>
	<p>Knowing your expectations</p>





## My Feelings Chart

Feeling – please tick how you felt								What was happening when you started feeling this way?		What helped?
Confused	Angry	Worried	Sad	Anxious	Depressed					
Monday										
Tuesday										
Wednesday										
Thursday										
Friday										
Saturday										
Sunday										

Key to a structure is planning! Here are some tips that may help:

	<p>Plan your next day the night before</p>
	<p>Start with an 'anchor' event events e.g. breakfast, lunch, dinner</p>
	<p>Choose one goal that you want to achieve</p>
	<p>Make sure you add some 'must do's' e.g. cleaning</p>



	<p>Choose a time to catch up with family or friends</p>
	<p>Make some time for some exercise</p>
	<p>Choose some time for something you enjoy</p>
	<p>But remember that these aren't set in stone – you can change somethings if you want</p>


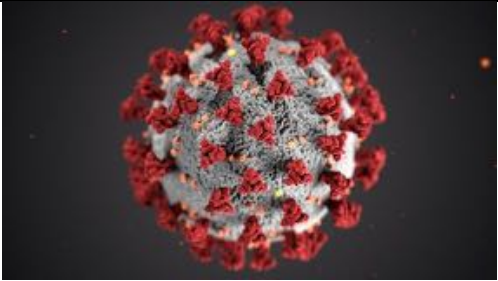




### **What lessons have we learnt from COVID-19**

These points were written by Bexley Mencap, Lewisham Speaking up and Share Community with support from Matthew Roberts and Steve Hardy



- Everyone needs information about COVID-19, how to stay safe and what rules we should follow. But ‘one size doesn’t fit all’. We need a range of how the information is delivered:

	<p>Easy read</p>
	<p>Pictures</p>
	<p>Audio</p>
	<p>Videos on the internet or TV. For example, YouTube or NETFLIX</p>

This information must come out at the same time as everyone receive it.

- There are so many forums, taskforces, meetings and committees which are run by local private or charity organisations, local authorities or councils, health bodies like the NHS or governments.

We want assurance that every one of these bodies has representation from people with learning disabilities. Not just a token but a platform to have your voice heard. Especially with COVID-19 how many organisations included people with learning disabilities



and provided papers which are accessible to the individual. It's time for real change no more rhetoric.

- There are regular simulations held by small or local organisations and others held by the government. This is where they act out, typically a catastrophe like a flood, fire or terrorist attack. There are between 1 – 2 % of the population that have learning disabilities. So you would expect 2 actors with learning disabilities in every 100 actors. There are plenty of professional learning disability theatre companies. These professional actors should be included and one of these professions can act the role of a person with severe or profound learning disabilities.
- Much more support is needed for people with learning disabilities especially those who live by themselves. Daily contact during a lockdown does so much good for your mental health. Also, how do

councils plan to support these people who do not have access to a computer, tablet or smartphone and cannot read?

- Everyone agreed that people with learning disabilities should receive the right information, at the right time and in a form that is accessible to the individual. We heard the term 'second class citizens' so many times during these conversations.
- There should be a range of activities for people to do during the lockdown, as isolation is very difficult for anyone.
- Councils should provide a list of contact numbers if you need any help 24 hours a day. Also, as soon as people were allowed back on public transport and in shops, people with learning disabilities with have underlying conditions<sup>5</sup> should have been provided with 'exempt' cards from wearing masks. It is so unfair that people with learning disabilities have been bullied and even attacked when an exempt card on a lanyard would maybe prevent this.
- There has been an ongoing daily amount of difficult to understand and sometimes it contradicts what was said the day before. A good example of this is the term 'social bubble' - what does this mean?
- At the beginning of COVID-19, NHS staff were given priority in supermarkets, then they included older people. Does anyone know if people with learning disabilities included?
- Are councils paying back the money taken from direct payments for day services? When day services have been shut since March and only a small handful are now open.
- Has anything been done to teach people with learning disabilities what social distancing is and what does one or two meters mean?
- Everyone agreed that lives would have been saved if we went into lockdown earlier.

What are the groups looking forward to!



A cure or vaccine for COVID-19



We want to go back to face to face meetings, not zoom



Meeting up with friends and family



	<p>Not having to wear a mask anymore</p>
	<p>Going back to RADA college</p>
	<p>I would like to go to the cinema</p>
	<p>Day centre reopening</p>



	<p>Going back to normal</p>
	<p>Being treated like a real person, not a second class citizen</p>
	<p>Being happy!</p>



Training and employment support for  
disabled people



## Chapter Two – Insights and experiences from people with learning disabilities

### Austria

### Corona-virus and people with learning difficulties

### Oswald Föllerer



I was at my girlfriend's home when COVID-19 started. Therefore, I was not alone. Unfortunately, I could not see my grown-up son. He was home alone.

I have not seen anyone else. My family and I were healthy.

I have worked a lot with Skype, Zoom and WhatsApp. So, I could keep in touch and work from home. In the beginning, it was very difficult. I did not have a computer. I had to wait until I got a computer for my work at the Self-advocacy Center in Vienna.

I was then able to work from home. I have answered my emails. I spoke to the support persons on the phone. There was only partial information in Easy-To-Read Language. This is a problem for people with learning difficulties. If this is the case, they cannot understand everything. I turned to politics. I suggested that every household gets a folder. All the important information should be in the folder written in Easy-To-Read Language.

Difficult language was sometimes used on public transport. They announced: "We thank you for your cooperation." That is not Easy-To-

Read Language. They should have said: "Thank you for participating." There were exit restrictions for all people in Austria. It was especially hard for people with disabilities, who live in residential facilities. They were not allowed to go outside. They were no longer allowed to go shopping. They could not see their family and friends. No one was allowed to visit them.

The exit restrictions were difficult for me. Since I am an active person who likes to be outside and meet other people. I tried to take many walks. I could not play darts with my friends. I painted a lot instead.

I was very shocked when COVID-19 started. I did not want to accept the situation at the beginning. I am glad that I can go outside now and meet people. I can also take part in the darts championship. The rules are not so strict anymore.



## **“Would have done two months of radical lockdown”**

**Sebastian Gruber**

**Translated from German by Susannah Leopold**

I was at work every day during lockdown in Austria because I work in customer service at an insurance company – Allianz – and answer the phone. I have to be there for the customers to be able to answer their requests. In our department, we also have people in a risk group and a couple of mothers – one who is a single parent. So, I had to come in every day and there were no restrictions on going out. I found the time exhausting because I wasn't allowed to work from home. We don't have many people to take customer calls.

The normal telephone service hours are from 7 a.m. to 6 p.m. but this was shortened to 8 a.m. to 4 p.m. during corona so my working times changed. All other customer service centres and offices had shorter opening hours, and, for a while, the customer service centre could only open when it kept to a lot of rules. But during the four weeks of lockdown, we did get a free lunch from the company.

In the company, the number of employees was reduced by 20% so in our department there were only five instead of 30 employees. We had to sit diagonally across from each other so that we could keep three metres apart.

I always kept myself well informed about corona so that I knew what to do and what not to do. After work, I could sometimes see my friends and my family as well. But I couldn't see my grandparents because they are 87 and 81 years old and therefore in a risk group. When I wanted to

pop by for a quick visit, I had to wear a mask. I didn't feel lonelier because I could do hobbies like running and cycling, I just couldn't play football with friends. As a whole, my life didn't change because of lockdown but I did miss my grandparents.

At the moment we have a small second wave because people are not sensible, and a few don't wear their mask in the underground or on the train or in Aldi. A couple had very interesting ideas and held a tissue in front of their mouth or even just their hand. That is sad. Without that, we might have the whole thing behind us already. If it had been necessary and could have prevented the second wave, I would have done two months of radical lockdown.

### Things I Feel In My Body

If you have felt these things, put a tick in the box



Pain in my tummy

☐

My breathing was difficult

☐

Pain in my head

☐

I was sick

☐

Voices in my head

☐

Not sleeping

☐

My heart beating faster

☐

My hands were sweaty

☐

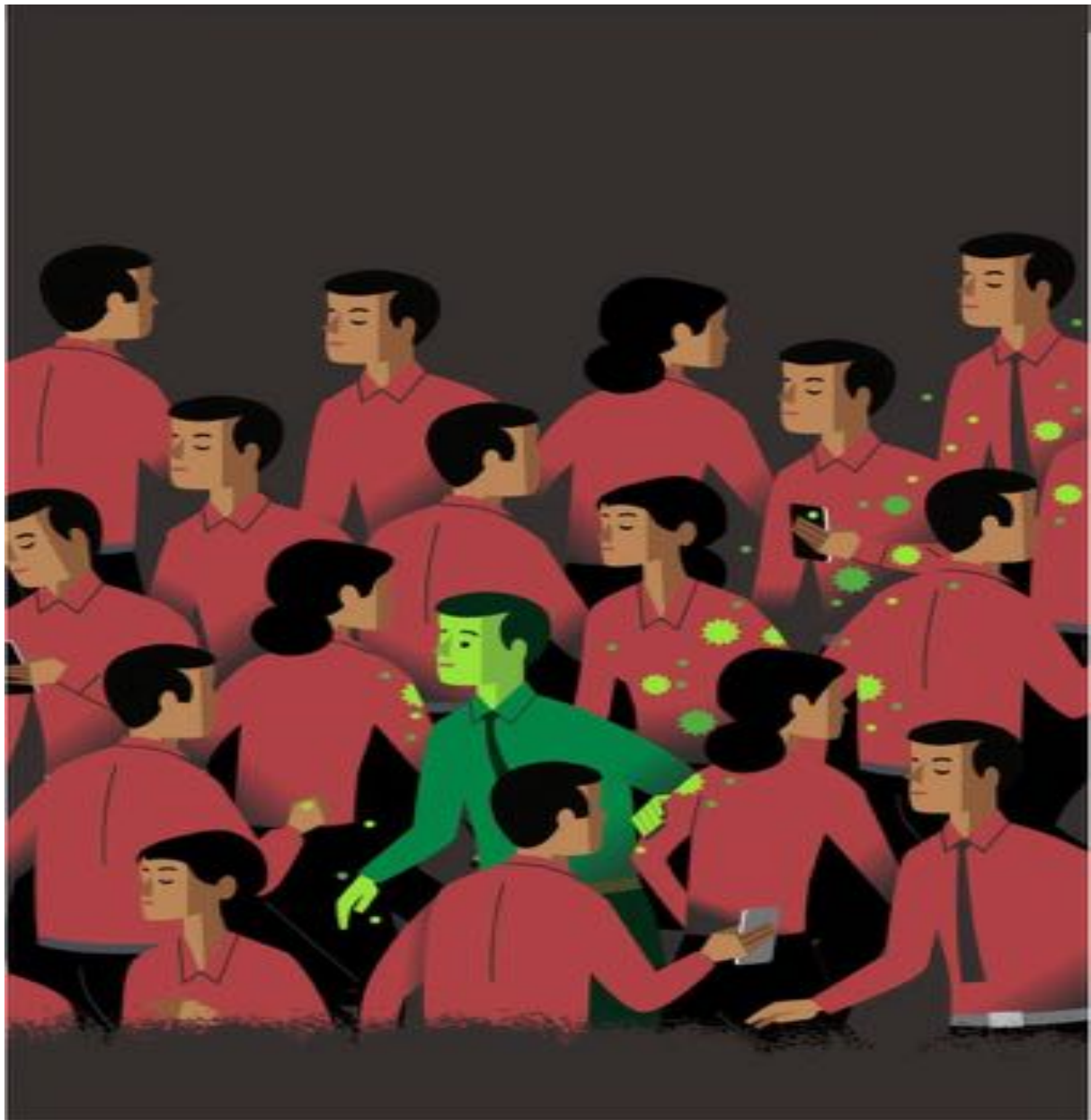
## Julius Szebeni

Speaking of my health I was fine, but it was a difficult time. I went shopping but you couldn't meet your friends. That was stupid from my point of view. At the beginning of the Corona crisis I went for a walk, but then my brother phoned me and asked where I was and told me to come back home. My mother reproached me for why I went for a walk because she is in the risk group. I didn't leave my flat for two months because my mother was afraid that I would infect her. I only went shopping and then back home. I also phoned my friends. I asked how they were doing and what they were doing. It turned out that it was not different for them as for me. They also couldn't do much. They weren't allowed to meet their family or celebrate a birthday. It was just as difficult for them to endure and cope with it as it was for me. Most have either played Play Station 4 or watched TV and DVD movies. I did that too. I also played games on my phone. After a while, my friends and I could not hear the word Corona. It was everywhere in the newspaper, on television and in advertising. It was a difficult time for everyone. It wasn't easy. Especially if you are not used to it. Many are not used to being isolated for so long. It's hard for everyone. I wasn't allowed to celebrate my mother's birthday with her or my brother's. We were able to celebrate my birthday on May 12th together. This wasn't possible before. Every now and then I did my laundry or cleaned my flat. I slept long.

I was looking forward that I could come back to work on May 18th. I am happy that I can meet friends again and that since May 15th you can meet again in the coffee house to have a coffee. I was very happy that I could celebrate my birthday with my brother and mother. I wish that there would



be normal soccer matches again, that you could go to the soccer stadium in Hütteldorf to watch matches. I would be happy if the cinemas open again so that I can go to the cinema with friends again. I would like to be able to go to the cinema with my brother again. I am looking forward to my courses at the adult education centre. If it is true, they will start in autumn, if not next year 2021. I've heard that the Danube Island Festival will take place in autumn. I would be very happy if this came true.



I



## Report by Günther Leitner

I was fine during the Corona period.

My family and I were healthy.

I strictly followed the government's rules.

That was important to me.

I had fewer social contacts.

I have only seen people with whom I live in a household.

Therefore, I could not see my girlfriend.

That is what we agreed on.

I spent a lot of time with my daughter.

My daughter was not allowed to go to school.

She got her school chores over the phone.

We took many walks together.

And played together.

I was just as independent in the Corona period as I was otherwise.

I did all the shopping by myself.

I helped in our family business.

We have a restaurant.

No guests were allowed to come to us.

However, we delivered food.

We did our work for the self-advocacy centre from home.

We worked a lot with the cell phone.

We also had team meetings with zoom.

There was a lot of information about Corona.

On TV, the newspaper and the radio.

However, there was less information in Easy-to-read Language.

This would have been important,

so that everyone can understand the situation.

I am glad the rules are not so strict anymore.

However, people no longer keep a safe distance.

This can be very dangerous.



## Josef Hochmeister

I've been doing very well. But it was also a difficult time. I often went for a walk. I went where few people were. I cleaned my flat. Sometimes I did my laundry. I slept long. I got up late. I also cooked. I also went shopping with my assistant. But my assistant from the partially assisted living worked fewer hours. That's why she didn't have that much time.

I was happy when my support person called me that we would start to work again on May 18th. I am happy that you can meet friends again. I was happy that coffeehouses opened again on May 15th. I was happy when I could visit my dad in Lower Austria again. I am happy when the coffee house from partially assisted living opens again. We usually meet there every Wednesday. Unfortunately, it is not open at the moment. I'm looking forward to play bowling and go walking again. I'm looking forward to the cooking class which I would have done. Unfortunately it couldn't take place. I would be happy if I could start my job as a co-course instructor in autumn.



## Report by Kopera Kunst

I was a little scared during this difficult time.

It was a new situation.

Suddenly everything stopped.

All our lives stopped.

My mother and I were at home alone.

I went shopping by myself.

In supermarkets, some products were no longer available.

For example: toasted bread.

In the beginning, I did not know why.

People were making panic purchases.

We were asked to remain calm.

And the situation calmed down at some point.

When it all started,

it was a little scary.

In the beginning, there was no information in Easy-to-Read Language.

That worried me.

I was afraid for my mother.

She is a bit older.

I was afraid,

that she could get infected.

There should have been immediate information in Easy-to-Read Language.

Our family was very careful.

We followed the rules.

We stayed healthy.

There was a lack of masks at the beginning.

There was not enough information about how you can get a mask.

Masks were issued in supermarkets.

But not always for free.

An important rule is: keep a safe distance.

It is not always easy to keep a safe distance.

For example, when the supermarket is crowded.

The cash registers are very close together.

It is nearly impossible to keep a safe distance.

Everyone did his or her best.

But you always felt like you were doing something wrong.

Our Politicians had to work very hard.

They did not know how to deal with this difficult situation.

They were a little bit overwhelmed at the beginning.

It is confusing for people with learning difficulties,  
that the media is using two different names for the virus.

Some people call it “Corona Virus”.

Some people call it “COVID-19”.

There should be consensus about the name of the virus.

However, I have good friends.

They helped me understand.

Even though it was a difficult time,  
many new things have emerged that did not exist before.

For example, we had exchange meetings via video conference.

Through these meetings, the Self-Advocacy Centre Vienna was able to reach many people throughout Austria.

People were able to stay connected, even though they had to stay at home.

However, not everybody has access to the internet.



Or knows how to use it.

Therefore, many people with disabilities were isolated at home.

But spending time at home has some advantages.

I was able to rest and relax.

I watched a lot of Netflix.

This extra time at home,  
allowed me to start painting again.

I was inspired by this difficult time.

I painted masks.

So they didn't look so scary and boring.

Everyone was thrilled.



## Report by Maria Schwarr

I was actually very well during the corona-crisis.

I have not had any problems.

I did not get sick.

I was not afraid either.

The corona virus is particularly dangerous for people from the risk group.

Older people.

Or people who have diseases.

For example, asthma or lung diseases.

The exit restrictions were very unfamiliar in the beginning.

However, you have to live with it.

So that you do not get infected.

I stayed in my apartment.

Sometimes I went for a walk.

I live with my sister.

My sister went to the supermarket for us.

She also sewed protective masks for ourselves.

I have drawn a lot.

And read a lot.

I also practiced music.

I play harmonica.

I also watched television.

I talked to friends on the phone.

However, I have not met anyone.

All sheltered workshops in Austria were closed.

I was unable to go to work for 3 months.

From March to June 2020.

I still got the pocket money.

I have been working again since July.

I am happy,

that I can work again.

Furthermore, I could not go to the self-advocacy-centre

for people with learning difficulties.

I work in the management-team.

During the exit restrictions, I spoke to my support persons on the phone.

And we all had conference calls together.

And later also video conferences.

There is the possibility of a second wave.

But I am not afraid.

Many people are no longer careful.

They keep too little distance.

It is important,

that you keep your distance and wash your hands.

So that you do not get infected.



## **Me, my boyfriend and that horrible coronavirus By Hanna Gugler**

### **Translated from German by Susannah Leopold**

I have a boyfriend. His name is. Matthias and he is so sweet

and so romantic, and sometimes he's such a clown, and then he just says pear to me: pear, pear, pear! And that annoys me sometimes, but teasing is a sign of love, and he really teases me.

I didn't see my boyfriend for 22 weeks, that was a really long time for us, because love is what it is, and we can't change that; because I belong to my boyfriend and he belongs to me. We're a happy couple and we belong together always and we do lots of shared things together. But not now, we couldn't see each other because of bloody coronavirus, and that's awful because we belong together.

We didn't see each other for such a long time because it is important to be careful because of coronavirus. His family said that they want to be careful and mine as well, and when we see each other we want to kiss, but we can't because when you kiss you can get coronavirus, and that was why we couldn't see each other.

All because of the virus

My boyfriend missed me every day and I missed my boyfriend so much too. It was such a long time that I couldn't cuddle up with my boyfriend and couldn't kiss him either.

I was in Stephanshart and my boyfriend was in Allhartsberg, that's not near me at all. I wanted to see my boyfriend again and I was always so lonely and so alone when he didn't have time for me, and then I was so sad that he didn't write back.

I always write about my love because love always writes the truth.

I only saw my boyfriend on video on Skype and Whatsapp. So, I can always see if my boyfriend is doing okay, and I was so glad to be able to see my boyfriend again, I never want to leave him alone, and I always write about my love because love always writes the truth. We wrote to each other and said that we always love each other, or when we'd be able to see each other again, and I was so happy, I always cried because I was so happy. A big fat tear always came rolling down. All this because of bloody coronavirus.

Our first kiss was in Schüsselhub

I am so happy that I have my boyfriend to cuddle. Soon, in Autumn, on 23rd November, we'll have been together for seven years, because I met him and we fell in love. Our first kiss was seven years ago, in Schüsselhub, that's where we lived then, and that was where I got my first kiss from my boyfriend, and we've been together ever since.

He dances like a dancer and he is very good at kissing, and he's my kissing machine because he tastes as good as fruit salad and pasta salad, and I want to eat him up. He's so good at massages, and he's my massage studio, and he can massage my feet too because I love my foot massage. My boyfriend can climb much better than me, and I like him, just as he is. And he also has problems with maths and I do too. Sometimes he can be so stubborn too, I don't like that very much, that my boyfriend can be so stubborn.

He also says that I'm so sweet and that I'm as beautiful as a red rose, and I like that a lot, and he is always beautiful too, gorgeous like a prince.



Usually we see each other a lot, but now we can't see each other and can't do anything together. I can talk to my boyfriend about everything, about what's deep in his heart, and he can write to me whenever he wants. Sometimes he even writes that he wants to marry me, and I said I do and he said I do too, because he is so in love with me. I want to start my own family with my boyfriend, really, and that's why I've fallen so in love with my boyfriend, and he's so much in love with me too. He'll forever be my one and only in the world and everything he does is good.

That's what we need after this time with the bloody virus

On 14th June I saw him again, and I was so excited and made myself quite sexy for him, I put on different clothes, and I was so glad that I saw my darling again. I could see him because now there isn't as much coronavirus anymore, and we wanted to see each other so much. He came to see me and we kissed and talked for two hours, about how he is and what he is doing. When the bloody virus is gone, we'll see each other a lot more often, because I need more love and more kisses and more cuddles, really.

I really really hope that this coronavirus comes to an end soon, and it's been so annoying for so long already, and I want to be able to see my boyfriend like normal again and do things, and I really want to finally celebrate my birthday, I really miss that, really, with a BBQ and vodka as well. Yep, that's what we need after this time with the bloody virus.

The German original of this text was published in the Austrian daily paper Der Standard.

## **Vienna, July 15th, 2020. An interview with Lisa Rötzer**

- Have you been able to see friends and family?

**During the first two weeks I was in my residential community with my friends. The last few weeks I was only with my parents.**

- Have you had COVID-19?

**No, I did not have COVID-19 and I was not ill.**

- If you haven't had COVID-19, have you been given enough information?

**I had a lot of information from the internet, radio, family, friends, and the newspaper**

- Have you been given a mask or gloves to protect yourself from COVID-19?

**I had many masks, one from Aida (Oida mask! [note: Aida is a local bakery]), one self-made by a neighbour, one from my sister, a very normal one and two were presents.**

- How have coped with 'lockdown'?

**It was very hard at the beginning in the two weeks in the residential community. Then it was very pleasant at home with my parents. We were outdoors in the fresh air a lot.**

- What have you been doing during COVID-19?

**I made a lot of cushions and relaxed and tidied up a lot.**

- Have you done any activities or hobbies?

**Yes, hobbies like walking and listening to music and sleeping.**

- Who helped you with the activities?

**I was supported by carers and my parents and friends.**

- How have you been feeling since COVID-19?

**I feel good, somehow relieved.**



## Canada

### Victor Pereira - self-advocate



Basically, what life is like during COVID. It's really put my life into perspective. It makes me appreciate how much I've been taking things for granted. And it's really put in perspective on how lucky I am that I got such good parents and such good coworkers.

It's like, I'd be going to Dramaway for most of the year, I have really been thankful that a place like Dramaway exists. The facilitators are so nice, and they make you feel like COVID doesn't exist because they distract your brain with all the fun activities they have planned. The students there are really inviting and really there to talk to you about their day. It's just an amazing organization.

I was just like, it's hard being stuck in the house all day and I really am lucky - what if people with other developmental disabilities don't have that. I'm fortunate enough that I have Zoom meetings and WebEx meetings. And I can do tons of stuff at home but sometimes I get bored like I want to exercise, I want to jump around but I can't because I have other people living in my house, my mother and father, and sometimes I just want to go to the YMCA but nope it's closed because of COVID. I just wanted to go to drama, but no, it's closed. I just want to go to Dance Rock, Dance Rock is a place where people with special needs go to dance, but no, COVID.

It really puts everything in perspective, like, okay, this is happening. This is what I'm going to tell my grandchildren about, like, this is how COVID was. It was a really difficult time. You guys have no idea what we went through.

And it's just you have to be thankful for what you have. And you have to be thankful for the people you surround yourself with it. If you surround yourself with toxic people, you're going to have nobody. If you surround yourself with helpful people, COVID is going to be easier. And that's why I always surround myself with nice kind people like my wonderful boss, Irfan, and my wonderful colleague, Erica. The team is still growing.

It's just amazing how we can survive COVID, through the Internet. Honestly, I don't know what I would be like if I didn't have good Internet and a really good job and good functions like this Saturday, I'm going to have basketball practice. And its exercise and I get to talk to my basketball friends on Saturday, even though we don't play basketball, we could still exercise. We still can work around things and that's what matters.

I always try to see the positive rather than the negative, it's just my way of thinking and that's how you should be, you know what I'm saying.

## England

### Peter Cronin's story



People with learning disabilities should have equal rights, fairness and treated like human beings. People should care about the feelings of others and have the same opportunities as others. There should no racism, no prejudice, treated equally as everyone has the same blood and the government needs to do more for people with learning disabilities and COVID-19.

Some people find 'lockdown' really difficult as do I. Once I realised that I didn't have COVID I was so bored. Normally I like to keep myself busy. I clean at PLUS (supported living service) twice a week in the early mornings, work in a cake shop once a week and work in the Co-Op for one day. I also go to college where I do art, English and computer lessons. I also go to the Gateway Club and visit my local church once a week. Then suddenly everything stopped.

I'm the representative for Employment with Lewisham Speaking Up. They carried on with their meetings but did this via the computer. I don't have a computer so I couldn't even meet up with my friends. Luckily my girlfriend Sandra lives in the flat next to mine. So at least we kept each other company. We went for daily walks to the park, played games and watched TV.

when we started this book, I met with Steve once a week and I also went with Sandra and Steve to Eddie's House. We discussed the content, advertising the book and planning presentations. It was great to have a purpose, and something will come out of it in the end. I am so proud to be involved in this book and thank everyone who has contributed to it.



## Sandra's story

I was born in Grenada and lived there when I was a child. COVID really reminded me of the sad time when my auntie died of pneumonia in Grenada. I have heard that COVID is like pneumonia. This made me feel so scared. Luckily Peter was there to keep me safe. I had a falling out with my sister. We normally see each other every Saturday. But as I'm deaf I find telephone calls really difficult. We misunderstood each other but now we are seeing each other face to face I get on much better with my sister. I hope that COVID ends soon and we can go back to our normal lives.



# KEEP EACH OTHER SAFE

WASH  
YOUR  
HANDS



PROTECT  
EACH OTHER  
BY STAYING  
APART



STAY SAFE  
STAY AT HOME



## **Cath's Lockdown Story**

***Monday 23rd March 2020***

***Part 1***

When we first started in lockdown, I didn't fully understand what it was all about and why.

People who have died with this COVID-19 my heart goes out to their families who have lost their lives through this horrible virus.

During lockdown I have found it really hard not seeing my boyfriend but staying at home is the best way of keeping myself and my family and friends safe away from this virus and stopping people not getting the coronavirus hoping that this lockdown will ease soon.



***June 1ST, 2020 My lockdown Story Part 2***

During lockdown I have been occupying myself keeping myself busy and that I have been doing some arts and crafts making cards and other things too.

I have been learning and doing some research on dementia ready for me to do my training work as I am a ward befriender for the NHS at Pinderfields Hospital and I love what I do, I work with patients with dementia and Alzheimer's I volunteer at the intermediate care unit at Wakefield Queen Elizabeth house.

I feel great in myself as I am trying to lose weight and it's working; I take our family dog for walks.

I do some volunteer work for Fiona Sharp she is the strategic Health Faciliatory and I am the co-chair of the health subgroup the Patient Experience Group for people who have learning disabilities to have their say on their health.

### ***My lockdown Family, Friends, Boyfriend Part 3***

My family means so much to me and I wouldn't know what I would do without them they are my world, as long as they are safe and that's all I want I love my family.

Once this lockdown is over the first person, I would like to see is my boyfriend (John) I can't wait to see him again doing things together spending some quality time together and I am going to give him a big hug too I have missed him.

But all I want is that people who mean so much to me to keep safe and I will see you all soon.



My friends mean so much to me too everyone needs friends around them and when it's over I would like to see mine too I love to spend some quality time with my friends they are important to me.

But my family will always come first always and my boyfriend too I love them so much.

#### *June 9TH, 2020 Cath's New change Part 4*

During lockdown in part 4 I have had a new change, a new hair colour in which I feel great in myself I am losing weight and I feel a lot happier too in myself I look really well.



Putting together a lockdown story has made me feel great in myself and it has given me the opportunity that writing this lockdown story and I would like to share this story with all of you too.

Hope you will enjoy reading this Cath's lockdown story thank you very much and appreciated.

*Thank  
you*

## Daren's Story

Those who know me, know I write to make sense of the world, or more specifically my little world. As I write we are in the middle of a pandemic. Lives are turned upside down everywhere, literally. People are coping with how they need to with current social distancing and lockdown restrictions.

Here in my world I am lucky enough to be able to keep working and helping people through my work. That is potentially what is keeping me from spiralling into a complete ball of despair. If this trauma I currently feel has a long-term effect, now is not the time to open that can of worms. Hopefully by putting pen to paper I am dealing with some of that trauma as always has been the case with my life experiences.

My son is nineteen, twenty in two months. I daren't even think that far ahead to be honest. He is the most amazing human being on this planet. Of course, I am biased. I am his mum. He is my world. I love him with every breath in my body, as a mum should.

He is pre-verbal. That's a positive way of saying he doesn't speak vocally other than some short noises which those who know him understand. That and mumumumum - That one and only word reserved for me. It's been a





roller-coaster together and now is not the time to go into all that, but he lives in a residential home with three other young people. He has learning disabilities, physical disabilities, autism and complex health needs. His understanding is “here and now” There is no “then” or “there” This takes away the ability to use video calling to communicate whilst we cannot see each other. Part of this is my own fault. In the past I had used photos and videos to show him who was going to turn up at the house (and that was last minute otherwise he would be distressed because they hadn’t turned up “now”) so the concept of using video to communicate in one way is out of the question along with the telephone.

So here we are. Thirty-five days (at the time of writing) since I saw and communicated with my son. The last day we were together being, ironically, Mother’s Day. We had a lovely afternoon together. Naturally there was a lot of anxiety around as people spoke of coronavirus and what it would mean in life. The day after the government implemented the restrictions. At first, I was in denial and didn’t envisage that I wouldn’t still see my boy. As that first day passed it dawned on me, this was going to be the case.

I get it. It is for his safety. He has chronic lung disease and uses oxygen so even more so important he is shielded as much as possible. It physically hurts though. The longest we have been apart being when he first moved into his new home was nine days. That allowed him to settle. Seems cruel but cold turkey was the only way for this to happen. Again, another story not for now.

Most days I just get through. Not good days, not bad days. Just days and I figure it’s ok for days to just be days. It’s ok to be numb. But there are

moments in those days when I allow myself to think too much. What is he doing? What is he thinking? Does he think I have abandoned him?

It feels like a bereavement, but I don't feel easy using that term as so many people are going through the real concept of what that means due to the virus. At the same time, my friends' circle and I have always had the mutual understanding no matter how heavy the load is or not, that load matters, as it's important to the person carrying it. On a similar thread I have friends who right now are at home with the people they care for. Life as a carer is tough. Tough beyond what many non-carers could imagine. The moments of respite do uphold. The moments where carers can do wonderful nothing. Those are the moments carers crave. Not because they don't love the person they are caring for, don't be daft. But because those moments are the moments that allow them to recharge and be the person they are looking after needs them to be. In addition to the added anxieties of what's and ifs right now, so many of my friends are not getting the respite they need. Sleep deprivation is huge. Life is unexplainably difficult, yet they have to continue for those they care for. For some it means an escalation of violence and meltdowns. I have been there. I know what this means. So, yes, I do feel guilty a bit for feeling as I do as their pain and anxiety is so great. However, as stated it's not right to compare plates as each one matters.

My bereavement is a different loss. It's not permanent, or at least I hope events don't make it that way. That's a whole new anxiety. I daren't think of if my son becomes poorly what that means. My bereavement is selfish but unselfish. Selfish as I am allowing myself a pity party, openly thinking about my own pain in not seeing my son but unselfish as I am doing it to protect him.

The biggest pain I feel is when I think of how my son feels. What does he understand? Does he think I have abandoned him? I am told he asks for me ...says mumumumumum but his support workers distract him. How does he feel about that even? Does that make him feel his request is not valid? Does he blame them? Does he have a concept of blame? Does he think I don't love him?

He is supposed to be shielded but they have had to take him on short walks with his housemates as part of the routine. Not sure how I feel about this. I know he needs it but to think he is exposed whilst out, that is a balance they get right I have to trust. Trust is the word. I have to trust his caregivers that the decisions they are making day to day are the right ones. I have to trust their own hygiene measures to keep him safe when they change shifts and come from the outside world. That's a big stumbling block in my mind. I have been out for one walk in the last few weeks, I want to be sure I am safe to see him when I am allowed, yet carers change shifts. I know that has to happen. Though it doesn't dissolve my jealousy that so many get to see him. I have to add they are doing a fantastic job and continuity in staff I believe is there.

Each day I get a short email about how he is and what he has done that day. Those emails keep me going along with pictures posted online for me to see. I live for updates in these ways right now. The emails vary depending on who sends them I can tell which are clinical copy and pastes from/for their daily record keeping and which are wrote specifically for the purpose of letting me know how he is and what he has been doing. I worry. I worry if he's OK. I know they would call if he got sick or there was an emergency situation, but my mind goes into overdrive.

Some days I spend ages looking at pictures of my son, either recent or older ones. I watch videos over and over again. They make me happy, but they make me sad and yearn for him.

I never envisaged anything other than death would keep us apart for more than a few days. Simply when we can't be in the same room, we cannot communicate. It hurts. The umbilical cord was never meant to be stretched this far. It's not right, yet it is right as it is for his safety, but what is it doing to his mental health? I pin my hopes on his here and now persona being his saving grace. I just need to find mine also.

This leaves me to say one more very important thing thank you to his support. I know and trust they are all doing everything they can for him to keep him active, distracted and most importantly safe when they have their own anxieties for their own families.

And to my son... one day at a time. Miss you. Love you xxx

Further to my last post, this is a happy post to say that exactly 35 days later (so exactly 70 days apart in total) my son and I were reunited. I won't go onto the whys and wherefores on here as the important thing is, our hearts were healed.

I didn't know it was going to happen until the night before, and safe to say I was like a child on Christmas eve. I did not sleep at all well. I had arranged to arrive at his house at ten am so I could use the allocated entrance and get PPE'd up! The morning dragged until I got in my car and drove towards his house. Whilst sitting in a small queue of traffic I felt the emotion begin to bubble up, but I got it in check. I had dreamt of this

moment for ten weeks. I expected not to be able to control emotion, but as always, I needed to focus on the needs of my son. To go in there a crying bubbling mess would be a sensory overload for him. I had no idea how he would react anyway. I decided I needed to act as if I had only seen him yesterday.

That was the stance I took. I was in the room. His support went to fetch him. I couldn't help but call out his name. I needed him to hear my voice. I heard the familiar shuffle noise he makes when he's walking. Those steps getting closer. The moment was here.

I was wearing a mask and I had to lift it momentarily so he could see my full face. I could see him visibly taking it all in and processing. Then he smiled. That beautiful smile. That smile, that is the curve that always straightens my world.

My heart healed in that moment.

We were able to spend a couple of hours together and I am so proud of how he coped with me wearing a mask and PPE etc. We adapted our old familiar games.

**We had fun.**

**We were mum and son.**

**Reunited.**

**Together**

**Perfect.**

Lorena Hauton





## Chris Bromley Research Net member

1. Which piece of art did you choose?

**This is a picture of Chris' cats, Genie and Batman.**

**'They stopped feeling lonely'**

**'They kept me laughing my head off'**

**'I spoke to them, and they watched TV with me'**

**'When I went out for my walk they were always waiting for me at the door, when I go into the wood and come back to my flat they were waiting for me this made me feel happy.'**



## David Bromley Research Net member

'That house is my home. In the picture is a television which is in my home.

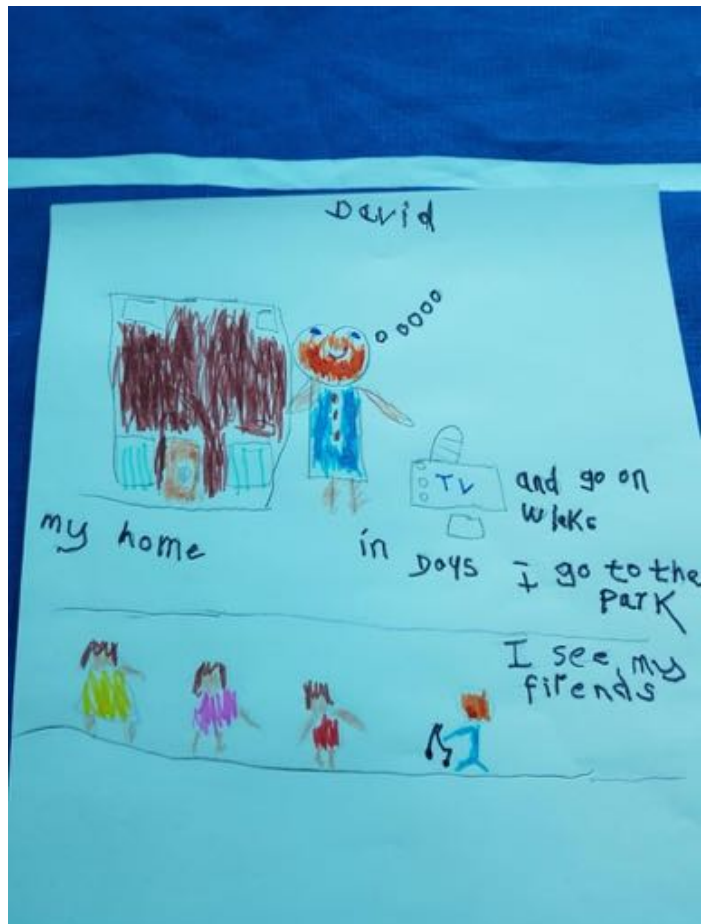
There is a sky box and me standing there. The dots are my thoughts.

Then there are my friends and seeing them in the park. Then I am going to see them with my walker.'

'My thoughts were thinking about not being able to see my friends. It was a bit depressing not being able to see my

friends. Then all of a sudden you were able to see friends. One of my friend's I wasn't able to see, it was brilliant when I was able to see her, I call her my granddaughter. I like talking to her'

'Lockdown affected a lot of people; people couldn't socialise with each other. Socialising is very important. Seeing people is nice and helping people. Some of the people on the picture don't have other friends and are on their own quite a lot. Some of my friends call me a lot. I help them, it helps their confidence and your confidence. It lifts you up a bit when you know you are helping people. That's what I like, helping people to get out of themselves.



**John (Pseudonym used at the request of the artist) Bromley Research Net member**

John chose to share a picture of a motorbike



Why did you choose this piece?

**“I just like motorbikes. We are fixing up one at the moment [...] It’s for a friend, we will give it to a friend. I drew this [picture] a couple of days ago. My Dad did the outlines and I did the rest. It makes it easier for me. I’m ok at drawing but sometimes I get wandering hands”**

What was it like doing the piece?

**I like the colours and it turned out well, it was nice to do it with my Dad. You have to be careful that the felts don't run into other colours. I was careful and put a bit of paper on the work to make sure the colours didn't run.**

What do you see that you are proud of?

**All of it! [...] I like the road being black the most. The road reminds me of the roads I go on with my dad [...] It helped going outside. It's nice to get the fresh air.**

Thinking about your picture, what do you think that this says about what is important to you?

**Just to be safe. Be safe and watch out for motorbikes on the road. The walks are important, you have to cross and be careful and make sure you're safe.**

What do you think the person who helped you thought about the painting?  
What skills did they notice you use?

**"My Dad liked all the different colours, so did my neighbour."**

**Ted (Pseudonym used at the request of the artist) Bromley Research Net member**

“I drew a wine glass first, then I painted the bottle of vinegar. The wine box where the glass goes I think the wine box is a boot too.

“The vinegar reminds me of putting on the chips. The boots reminds me to put them on my feet when I go walking

I drew this first as it came to my mind. I never drew something like that before. I am not an expert at drawing but I thought ‘Have a go at it’. I feel proud of it”





## **BS Bromley Research Net member**

Why did you choose to send these pictures?

**“I like sitting in the garden, spending time with my family. We do summer kebabs and kids come around to play in the garden. Mum likes cleaning the garden and putting flowers. I help cut the grass, and keep the garden clean.”**



What was it like doing this piece of art?

**“I took the picture with my phone [...] My niece and nephew they showed me how to take pictures. They wanted to help me. I think they’d be happy, they’d say I took some smart pictures. I’d like to take more pictures of my hobbies.”**

What do you see that you are proud of?

**“I am proud of the flowers. They are nice. I love the trees too. You can pick the fruits and eat them. We’ve got pear, apple, figs, and cherry trees, grapes and strawberries too [...] They are very old trees.”**



Who else could you tell about those pictures?

**“The group might like it; I miss them all and the staff too.”**





**Richard, Greenwich Research Net member**

1 What have you valued about being at home more?

*Prompts/additional questions: What is the best thing about being at home?*

**Not much, it's been difficult**

2 What have you learnt from being at home more?

*Prompts/additional questions: If you have learnt any new skills, what are they?*

**I Hoover more, have more time to do that, it stops me getting bored and is a bit of exercise**

3 What has been difficult about being at home more often?

**Having the news talking about the same thing, it's boring. It's also boring being at home more.**

*Prompts/additional questions: If you have felt worried, what has helped you to feel calm?*

**Taking time to relax, watching tv. Not watching the news as much, instead watching quiz programs. I like testing if can get the questions right.**

4 You said that ..... helps you to feel better, why is this important to you?

**I feel better by hoping we can go back to Research Net. This would be important to me, so I can continue to learn and catch up on the work we have all missed.**

5 What advice would you give to someone who is finding things difficult at the moment?

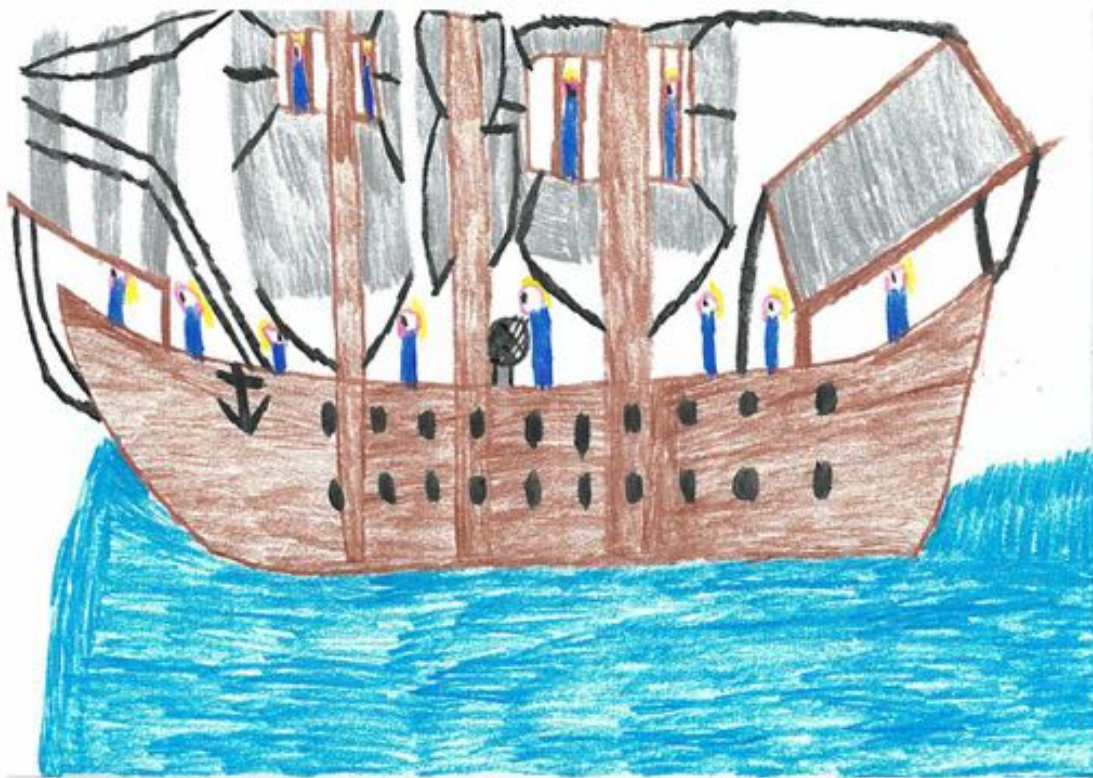
**Persevere, even if it's not easy. Hang in there, look forward to the group being able to start again in the future, you have something to look forward to, Research Net is on the horizon.**

*Prompts/additional questions: What is helped you? What could help someone else? Why is it important to take care of yourself?*

**To stay healthy, stay fit and well. Try and be strong and know you have something to look forward to.**



Ronald, Greenwich Research Net member



Which piece of art did you choose?

**A pirate ship**

Why did you choose this piece?

**Because it was the longest to draw, and my favourite to draw. Dad let me borrow a boat statue, this gave me ideas, like drawing it as a pirate ship.**

I see that you used (pencil, pen, paint), what made you choose this?

You have used (colour), why did you choose this colour

**I used colouring pencils, hard to start with, had to keep sharpening then, they were running out.**

Show interest in the elements... Continue with curious questions about shape, size, form...

**The colour that the ship statue was, brown with black ropes. I put the figures in, to make it more interesting and the sea, this wasn't on the statue**

How long did it take to draw?

**A very long time**

What's good about drawing?

**I think it's amazing the way I drew it; it was one of the hardest ones I have ever drawn, and it took an extremely long time to draw.**





**Kevin, Greenwich Research Net member**

What have you valued about being at home more?

*Prompts/additional questions: What is the best thing about being at home?*

**Keeping safe from virus**

**Colouring in, drawing, writing, watching DVDs, music, radio.**

What have you learnt from being at home more?

*Prompts/additional questions: If you have learnt any new skills, what are they?*

**Clapping for NHS, and Community Learning Disability Team- who are superheroes. I find the clapping strange, but good. It's noisy and makes me feel a bit anxious but it's nice to see people doing it.**

**Doing things, I wouldn't normally do before, art and colouring in.**

What have you learnt from being at home more?

*Prompts/additional questions: What skills did you use? What steps did you take?*

**Doing more art, like drawing pictures of the coronavirus, like people in hospital. Using my imagination to draw these.**

**I learnt to draw with family, they suggested that I do this during this time.**

**I saw other people do it first and then had a go. I use colour, felt tips or colouring pencils.**

What has been difficult about being at home more often?

**Not being able to go out**

**Seeing people sitting out on the grass, not following rules.**

*Prompts/additional questions:*

*If you have felt worried, what has helped you to feel calm?*

**Classical music**

How have you coped with the difficult things?

What makes you feel happy?

**Colouring in, drawing, writing, watching DVDs, music, radio**

You said that ..... helps you to feel better, why is this important to you?

**Classical music, it's not too loud, can just sit and listen to it in my chair with legs up. It makes me feel happy inside.**

What might you be able to do in the future, that you weren't able to do before?

**More time to draw**

What advice would you give to someone who is finding things difficult at the moment?

**Just relax, at home or in the garden.**

**Don't think about the virus too much, do other things.**

*What is helped you? What could help someone else? Why is it important to take care of yourself?*

**Important to take care of yourself, because I don't want to get the virus and die from it, sometimes worry about that happening. So I listen to the radio, takes my mind off it, or I do some drawing or writing.**





Laura, Greenwich Research Net member



Which piece of art did you choose?

**Pain by numbers, it's my favourite. It was the first one I did, proud of it.**

Why did you choose this piece?

**I like the colours.**

**Used an iPad**

How long did ti take to draw?

**2 days. Skills: just need to enjoy it, feel calm and relaxed doing it.**

When you look at this picture, what do you see that you like? Was it easy or difficult? What skills did you use?

**Enjoy doing this, on iPad enjoy. Have to concentrate, tiny details, have to zoom in and zoom out**

Did anyone help you?

**I did this on my own.**

What's good about drawing?

**Loads of it.**



**Emma, Greenwich Research Net member**

What have you chosen?

**Photo Son's Birthday cake. I chose because I thought it would be nice to show the cake.**

Why is this important to you?

**Cos it was a big birthday.**

Favourite part?

**I like the bucket, with the beer, and the way it's made. The ice is made from Foxes mints.**

What did it taste like?

**Mint gave it more of a taste, Red velvet cake**



**Richard, Greenwich Research Net member**

Why have you chosen the picture of Disney plus?

**I have been watching it for the majority of lockdown. I have been watching animated movies.**

Favourites?

**Aladdin, Hercules, Pinocchio, The Hunchback of Notre Dame and Sleeping Beauty.**

What do you like about Disney plus?

**Large selection of TV shows that watched as a kid, in the 90s and action movies. It's for nostalgia**

How do you feel?

**Feel good, I am watching favourite shows and movies**

Why was it important during lockdown?

**A wide variety of stuff to watch, and something new to watch. I watch it for entertainment, it's been important for me during lockdown, because I am not watching the news.**



Anything else about Disney plus?

**It's a good streaming service, it's good value for money.**

What difference did it make to your day?

**It doesn't get boring, there is a variety of stuff on there.**



## Val's Story

My name is Val, Valerie Sharville. I am 62 years old. I live in my own bungalow in Eastbourne, on a residential site. I have carers 4 times a day. My bungalow has ceiling hoists, I use an electric wheelchair and buttons for my doors, possums for helping me to use the telephone and TV and I have my meals delivered. My carers help me with personal care, eating and drinking and other things. My family are very important to me they live in Kent, sometimes it seems like a very long way away.

I listened to the news about COVID but didn't really know about it. I knew I didn't like the sound of it. What I didn't like was that I was not allowed to go to the day centre. I was really worried about not being allowed to see my family. This really scared me, I didn't like it not being able to see people and being on my own, I was lonely. I thought it would be ok though as everyone said it was just for a few weeks.

My family brought me an iPad. I have never used one before. This was so I could use facetime. My niece brought it down the weekend before lockdown – she wore a mask and gloves – that was when I then felt really worried. It was horrible, she couldn't stay long, we stayed outside. She showed me how to use the iPad and she made it as accessible for me to use as possible.

I felt very lucky, as having the iPad meant I could call my family and see them, we had group chats and I felt a little less lonely. I would ask, "How long will this go on for? I don't like it?". Nobody had any answers. I was really missing my mum as well. She had to shield as she is 90. She was very lonely as well. We would talk on the phone – she was becoming more confused.

My carers had to start to wear masks and gloves. My cleaner who came in weekly, the lady who did my feet and my hairdresser all had to stop coming to see me. My meals were left in the doorway and the man wore a mask when he did this. I couldn't see anyone, and it made me feel horrible.

Then after three weeks, I started to get a sore throat this was for a few days. I ached and had a headache. The doctor prescribed some linctus. I felt horrible. We wondered if it was the heating as I was cold sometimes and the carers were putting this on. I had a little cough for a little while, but I have thickener in my drinks and have certain ways in which I have to eat my food. We wondered if this was why? I had been shielding, only had visits from carers and they had now been wearing masks and gloves for weeks. It was just a little tickly cough and didn't seem always. The carers said I should put my hand over my mouth – but I find that difficult. I kept crying because I felt weird and did not know why. I thought it was because I was so fed up.

Then I woke up and my carers helped me the same as always with my shower, breakfast and hoisted me into my comfy chair (I didn't feel like using my wheelchair). They said I was not right at all. They called the ambulance. The ambulance arrived and the





carers face-timed my niece. I was scared, I did not want to go to hospital. We agreed I should go.

When I was there it was very scary, first of all they thought I had a urine infection and could go home. Then I was really ill. My niece said they called her and asked her some questions and the doctor, said I was very, very ill. They thought I had COVID. I didn't know any of this. I can't remember much. I was in hospital for eight days. When I was in there, I just know I was sad and



couldn't understand why family were not visiting me. The hospital staff sometimes couldn't understand what I was saying. I didn't like it. They all had masks, aprons and glasses. I couldn't understand them and was very sad. I just wanted to come home. I was scared for my family, as they hadn't visited me in hospital, and I didn't know why. I did notice that other people did not have visitors.

When I came home, my niece and sister were waiting for me. My niece stayed with me and then my sisters stayed to help look after me with my carers visiting for a few weeks. My carers were wearing gloves, aprons, masks and things over their faces for **ages. They still wear masks, aprons and gloves. Me** on Holiday.

When I arrived home from hospital. I was so pleased to come home, but I was very weak, tearful and tired all the time. I couldn't eat much for weeks

and weeks and still had a little cough. I have had to see the speech and language therapist again as how I eat, and drink has changed again. I keep getting more infections. I am very tired still and it is 12 weeks later. I have to go to bed in the afternoon most days. I can now see my family at weekends – we do socially distance though.

I still don't know how I caught it.

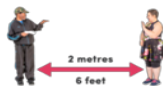
We have had a few hours out and about – I went on the Eastbourne Eye. I also had a holiday to look forward to in a lodge in Hampshire which my sisters and nieces took me on. This is what kept me going as I really look forward to this.

I really miss the day service and still don't know when I will see my friends again. I still think it will be a long time. I will be glad when it is all over.

I am happy to wear a mask when out and about.



## Lord Timothy's Lockdown Story



### Lord Timothy's Lockdown story

**How have you been in lockdown?**

It's been boring.

At first I didn't go out at all. United Response did my main shopping for me.

-I watched the tele.

-I used my phone to video chat until it packed up.

My cat lucky kept me company.

I spoke to people on the phone.

I chatted to my neighbour in the garden and she helped me with some shopping too.



**Have you been able to see friends and family?**

-I have been chatting to my neighbours.



-I have been talking to friends from Manchester, Yorkshire and other places ,on the phone,.



-Paul and Charlotte from the Learning disability team have called me.



My brother calls me twice a day.



Charlotte from the learning disability team completed a mini hospital passport with me in case I needed to go to hospital.



Now I can see my friends a bit more its better.



## Have you had Covid 19 ?



-I haven't had it.



-I had an ear infection.

-I had tablets from the Doctor.



-It worked ok I called the doctor and he called me back.

It has been ok to get to talk to a Dr during COVID.



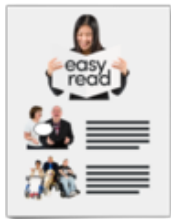
-The local ,hospital are still writing to me in small print.



-I have asked so many times for easy read letters about my appointments. Now I have had some help to write to them to ask for easy read letters. I hope that works.



**If you haven't had Covid-19 ,have you been given enough information?**



My friends at the Norwich group have been sending me some easy read information.



**Have you been given a mask or gloves ? Are you wearing a face covering on public transport?**



-I have got 2 washable masks and some disposable ones.



-I have got some hand gel and some gloves.



Is there anything else you would like to tell me about your experiences during lockdown?



It has been boring being cooped up inside all the time.



I shall be glad when everything is back to normal.



When people wear masks it is difficult to hear what people are saying.



Some people are not sticking to the rules now we can go out again.



They get too close to me and it makes me angry and worried.



Story made with photo symbols after a phone interview on 18<sup>th</sup> June and 16<sup>th</sup> July 2020.



## Mark Bates (self-advocate in Campaign 4 Change)



It's been alright, but since the lockdown I haven't seen my mum. So it's been quite hard as well. But other than that I have just been keeping myself busy doing stuff in the house, trying to do some work online, shopping, and pretty much keeping up with work and friends and boxing on Zoom. Good thing is that everything is starting to reopen, so I managed to do some boxing out with

friends, which is quite good. Everything is looking up at the moment.



**Christopher Holloway** (self-advocate in Campaign 4 Change)



I found it a bit hard, because it is an unusual routine and I had a different timetable. I look forward to lockdown ending when I will see my mum.



## Alex Starley (self-advocate in Campaign 4 Change)

My experience during the lockdown is that the staff were wonderful, they



helped me cope with it a lot. On the other side, I'm not happy because I can't go to church, because all the churches are closed and I can't worship in a proper way that I'm used to. The churches are open now, but a limited number of people are allowed in and we're still in lockdown.

That's my experience of lockdown.





## Andrew Frith (self-advocate in Campaign 4 Change)



It's been strange, because with the type of people that I live with we are obviously following what we have to follow, but it was hard to understand it, especially when our staff use masks – I know why and they know why, but when trying to explain the things that are happening, we've got to do this, we've got to do that, I found it strange.

Because when I first came here ('cause I used to be at another home around the corner) I used to decide what to do and when to go out, but now I only leave for hospital appointments because I have to. It's been quite strange, but the staff help you get used to it and if you're not sure they help you out.



**Fiifi Tetteh (self-advocate in  
Campaign 4 Change)**

In lockdown I've been keeping myself busy and doing stuff - I've been making my own T-shirts and building a shed and my own minibar. I just want it to go back to normal.



## Mary Woodall (self-advocate in Campaign 4 Change)

COVID has been a really difficult time for me, it's felt like a stolen period of time, time I should've been with my friends, family and loved ones. It's also been a boring period of time, not being able to do much outside and there's only so much you can do indoors.



At the start of COVID, we had lots of restrictions and less free movement, just to go out for essential items of food or medicine and exercise once a day. With my family living a stone's throw away, I was lucky enough to see my dad and dog once a day for a dog walk.

Until a month or two ago, I went to different places to walk my dog.

One of the highlights in COVID was clapping for the NHS every Thursday at 8 pm.

At the beginning of COVID 19, our supported living service had a tenants' meeting and our Manager explained what COVID is and told us all about it. Since then she was giving us regular updates. Unfortunately, anyone can get COVID and not be showing any symptoms at all.

Like most other people have experienced, shopping during COVID 19 has been very hard because you don't know who has COVID but luckily enough I did it online which is a great advantage and life skill to take in life.



During the coming months, we've had fewer restrictions and more free movement, even though everything's not how it was before or back to normal. I've been able to go to my family home for night, I also had an amazing 28th birthday BBQ at my family home with my family.

And I am lucky enough to go on holiday to Dorset with my family and cousins.

I was also lucky enough to produce a film with Elmi, about the disability lanyard. To let other disabled people with learning disabilities and hidden disabilities know how it's used, what it's used for. The film was a great success and it will be posted on the C4C Facebook page, YouTube and Achieve together website.

I think we can only hope that the COVID 19 will get back to normal or a new normal, with even less restrictions and complete free movement and let's hope that the COVID 19 will die down. Thank you to the NHS for helping people during this time and helping other people to stay healthy.



## David Ross (self-advocate in Campaign 4 Change)



COVID-19 had affected me really badly because I was not able to go out with my parents for a cup of tea and a Bap. My parents were not able to visit me at either and I really missed them. I was not able to go swimming or the cinema, both of which I very much enjoy. I also miss going out to see my friends.

I missed Eurovision because it had to be cancelled and it was very hard on all of us. The Tokyo 2020 Summer Olympics had to be cancelled also and I was looking forward to watching it. Drama classes were cancelled and that was really terrible because I always enjoy going to drama as I was making lots of friends and learning new skills.

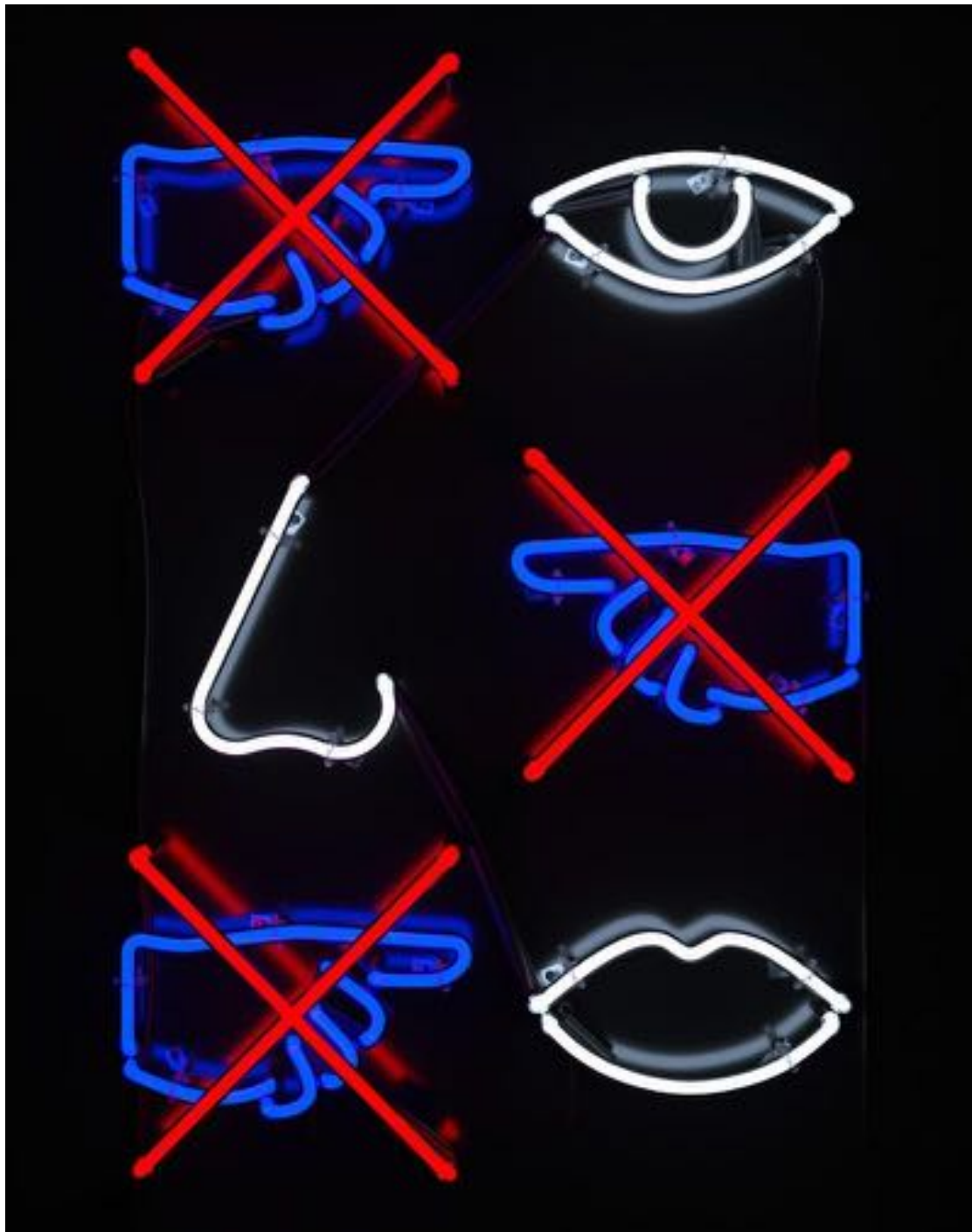
Britain's Got Talent, another of my favourite, was cancelled which really upset me because I love it. The Voice UK and Kids got talent too was cancelled.

We were not able to get our hair cut for a long time, although the staff did try to make my hair look as tidy as possible.

Finally, late June I got to see my parents. I was very happy and they were happy to see that I had lost some weight. That is all down to the staff and myself. They were supporting me out nearly every day for exercise and we did very long walks, as that is one of the things I love doing even when there's no lockdown.

Another happy occasion for me was on my birthday when the staff supported me to prepare a picnic lunch with my family. The staff were all great, they prepared chicken, pizzas, sandwiches, water etc. all you would

need to make a great picnic and supported me to meet my parents where we went to the park for lunch and afterwards they had bought a carrot cake which we had with coffee. It was a splendid day because I turned 27 years old.



## Magie's Story

This is my journey through COVID and Lockdown

My name is Maggie. I have a learning disability and can sometimes experience mental illness.

I live independently in a flat. I have three hours of support per week from a support worker.

I have two paid jobs, one working as a travel buddy supporting someone to access the day centre and the other working as an expert by experience training facilitator at Estia centre.

I also volunteer at the Lambeth Assembly and work with a team that design and send out easy read meeting minutes and other documents.

I also go to do arts and craft and flower arrangements.

In March when the lockdown was introduced, I was sad. I was told that I have to stop going to both my jobs.



I knew it wasn't safe to go out and meet friends which I liked and enjoyed.

I was also worried about getting ill with the virus.

I was very lucky to have many people to support me through this time.

My colleagues at the Estia centre introduced me to Zoom which was difficult for me to understand at the beginning but with lots of support, reassurance and trying many times I learnt to use it well.

This meant that I could work from home and join in meetings with the BEDE centre as well as the Assembly.

I couldn't do the Travel Buddy job as the centre had to close for a while, but I still joined the staff with training and keeping in touch on zoom.

Before the lockdown my favourite thing in my Estia job was the Mindapples group that we run on a Monday. This is for people with learning disabilities to come and socialise, learn and share things together.

I really enjoyed this and with the lockdown as we couldn't run these sessions, I was sad and missed my friends from the group.

But soon we had some idea to do this session on Zoom as a virtual group. We had some students from King's College who volunteered to help in doing this. So, we started the Mindapples zoom group on Monday afternoons. This was good as some new people who couldn't come to the sessions before could now join in

Last year we did a learning disability Pride march during learning disability awareness week. We were planning to do another event this year, but we couldn't because of the lockdown.



We then decided to do a special session of the Mindapples group and invited a special guest to come along, we got an invite to talk about the group at the Lambeth Assembly meeting and learning disability nurses and champion group meeting that week.

We wrote a blog about the Mindapples group which was published on King's Health Partners newsletter, website and NHS England Twitter, Instagram and website too. This



was exciting, my 'claim to fame'! <https://www.kingshealthpartners.org/latest/2913-keeping-patients-connected-during-lockdown>.

Although I couldn't be physically at work, I found myself doing many work things that kept me busy. I managed to go out and exercise as well as meet with friends following safety guidelines.

Although there were many good things there was also some sad news which upset me a lot. People I knew died during the lockdown and we couldn't go to the funerals or be with other people who also knew the same people. It took me a long time to come to terms with these losses and even now I can feel sad when I remember the people who died. It was good to be able to talk to people about my feelings and remember the people and why I liked and loved them.

I always go to visit and stay with my sister during Easter but this year I couldn't, and this upset me as I was looking forward to it and haven't seen



them since Christmas. We just had to keep in touch with each other on the phone.

One time I was feeling ill and I thought I had the virus. My support worker helped me to contact the GP who arranged for a taxi to get me to a special clinic. I was assessed there, and they put me in an ambulance and sent me to Guys and St Thomas Hospital, Accident & Emergency department, as they said I may be having the virus but also, I was dehydrated. I was scared but my work colleague and the nurse kept in touch with me. Luckily, they tested me and found that I did not have the virus. I was relieved to go home and rest.

My birthday was in May and I knew that I couldn't meet with anyone to celebrate. I felt sad but then my art teacher invited me to go for a picnic at the War Memorial park. I was glad to do this. We wore masks and maintained social distance when we met. It was a nice sunny day and I really enjoyed being with her on my birthday.

On the Monday after my birthday, they also arranged a virtual birthday party at the Mindapples session. This was good fun, and everyone sang happy birthday to me and we made a virtual cake on the Zoom.

In April I had to reapply for my job as the training facilitator as before I was on a fixed contract. My support worker helped me to fill the application form and post it. As I have learnt how to use Zoom, I was interviewed on it and they gave me the job. I was proud of myself as I did the Zoom interview without support and managed to answer the questions from all four people who interviewed me.

Lockdown has taught me many things. I know that with the right support I and other people with learning disabilities can learn many things including coping with difficult situations and times.

It was also helpful to have instructions that we need to follow in lockdown in easy read documents.

During the lockdown I have co-produced a training/information resource to help professions that work in mental health hospitals to understand and support people with learning disabilities better.

I learnt how important it is to have many friends and people that I can contact and keep in touch in difficult times like this. I even kept in touch with my friend who was stuck in Ghana during this time.

I am now learning to use Microsoft TEAMS which is another way you can work and meet people virtually. I want my story to help other people like myself to know and feel confident about doing and learning things.

I hope this will help professionals, staff and other people to know and be encouraged to be patient, offer support and resources that help people with learning disabilities to overcome difficulties and achieve things and be successful in their lives as any other person.





## Andrew Donohoe My Covid-19 Story



Life before lockdown was fine. Pretty good. My life was happy, organized. My life before lockdown was a lot busier with lots of classes, where I would meet different friends. There were not so many restrictions like having to keep our distance, wear masks or wash our hands a lot.

Before lockdown I used to do a lot of activities such as: choir, Funky Lama Drama, Access Drama Group, swimming lessons, Art classes (watercolours and acrylics), Routeways Youth Group, karaoke at a pub etc. Before lockdown my life was very busy with lots going on.

When I heard about “lockdown” I felt pretty embarrassed about lockdown – everything was not opening again. Like cafes and restaurants were shut. Museums and cinemas were shut.







Lockdown was a very sad time. My timetable had to change. I preferred my timetable before lockdown.

Seeing my PAs was good.

I think we went in to lock down because of coronavirus. We had to go into lockdown and we had to stay at home because of the virus. Because we didn't have anywhere else to go. We had to because we had to keep our distance.

It was strange at the time.

The news said stay at home because the coronavirus wouldn't go away. My life changed after the UK went into lockdown. I had to stay at home as much as possible so that I could stay safe and avoid the virus. My staff changed. I could only have some of my PAs working with me. I had one person to cover all day from 8.30am to 10.30pm instead of 2 or 3 people a day. This was really good. I was grateful that they stood in and protected me from infection.



We had to keep our distance, two metres, and do social distancing. We had to change high fives to high elbows.

I couldn't go on transport or use taxis. I couldn't do my regular routine.

Everything had to close. Schools were closed. The pubs were shut. The gyms were shut. Restaurants were closed. Swimming pools were not open.

My activities closed down. My groups and clubs had to shut down too.

I felt really happy about staying at home for a while because I didn't have to go anywhere and it was quite relaxing really. After some time I felt rubbish and bored of not going out anywhere.



Being in lockdown made me feel sad at times because it lasted a long time and I couldn't see my friends, but we could see people on Zoom and



go to Andrew's Hallway Prysm which made me feel happy. I did Prysm nightclub in my flat and made cocktails.

To keep myself entertained during lockdown I listened to music especially classical music. I did some running as well. I went for long walks, did lots of cooking, nice food, and did Joe Wicks workouts. I did lots of housework and baking buns and cakes.

I also made travel shows in the flat with my favourite flamingo Tracy. We went to Florida in America, Singapore and Australia.

So, what did I learn about myself? I felt really chirpy and happy because I get to see all of my PAs. I need to just be happy and be flexible. Seeing my family makes me happy.

I missed lots of different things in lockdown. I was pretty disappointed because I was no longer in that community environment. I missed my friends and still miss my friends. During full lockdown I haven't gone to my clubs. Everything's had to close down.



I've missed going swimming at the Life Centre and Moving Sounds (a music group). I missed going to the theatre, choir, TR2 for Funky Llama Drama, Access Drama Group and also Animate Drama and Beckly. I missed going to iGrow on a Tuesday once a month – this is a meet up group. The churches haven't been open.

I missed going on buses and catching the bus home by myself.

I missed some of my PAs who have been on lock down as well.

The hardest thing about lockdown was not going to Beckly (playcentre/youth club), and my theatre groups, Access, Animate and TR2. Also not going to pubs.

I was asked what helped me get through lockdown. Staying at home and being safe but being active. Dunno really. I think everything. Keeping your distance, washing my hands, using hand sanitizer and wearing facemasks. Yes, I felt safe. Mum did a good job of organizing everything and carers did a good job too. I am very grateful to them.

Exercise helped me through lockdown too and doing lots of running and Prysm. Seeing friends online and having PAs around.

My family and PAs did things that really helped me. Seeing people in the evenings is great. (But I could only see my carers). I have been learning how to do running – a new thing for me. I have been doing lots of running. Doing Zumba (on YouTube) has been fun. Doing 'Glastonbury Festivals' at my flat. 'Prysm nightclub' at my flat. YouTube and Zoom have been fantastic. Doing Funky Llama (Theatre Company) socials online has been brilliant. I did some basketball with a PA (Personal Assistant). I rode a bike on the Plymbridge Trail. I did Yoga with Adrienne and Joe Wicks on my

laptop. I worked with my occupational therapist on Zoom to make a Calm Box. I like the big calm ball.

I also had big activity boxes my mum made for me before lockdown. I liked choosing activities from these. I made things. I painted stones, tried knitting, did some watercolours. Later, my art classes were online. I made cakes and designed a pizza, I did “MasterChef” and made a café in my flat. These were great.

I learned some new skills during lockdown like using Zoom and running. I’ve learnt a new skill in doing my travel show about Australia!

My PAs asked me what has changed since lockdown happened? We have to wear masks in Lidl and Morrisons. Everything is changing – lockdown is being lifted a bit but the gyms haven’t been reopened yet. We still can’t go to church and some of the places I enjoyed going to still aren’t open. I also still can’t go on the buses and have to wear a mask all the time.

Some of my activities went online. My watercolours class was on Google Classrooms. I watched my art teacher on my laptop. Using Zoom has helped. I liked seeing different people. Beckly, Funky Lama and Moving Sounds used Zoom.

I used Zoom every Friday night. I had a nightclub called Prysm in my flat with my PA and invited my friends. Prysm helped. It was fun. I liked seeing different people. I used to go to the Prysm nightclub in Plymouth on Friday nights before lockdown.

I didn’t want to see people in London. (Because of the amount of virus there).

The theatres are still not open, which makes me sad because I enjoy going to see shows.

So, anything else I want to tell you about lockdown? I find it easy to understand and I feel like I know what's going on.

I've enjoyed coming out of lockdown. You still keep your distance and you wear a mask. I feel good about wearing a mask.

If lockdown continues I will use Zoom. I hope activities will be online. It is better having them online than not at all.

### **Andrew Donohoe**

A collection of my thoughts about Covid-19 and "lockdown" taken from interviews in July and August 2020 with 4 personal assistants, my mum and my sister.



## Dinesh's story in Lewisham

I used to work at the National Theatre before lockdown, it looks as though I won't get to work there anytime soon. I'm a student at RADA and I'm studying technical theatre and stage management. I haven't been back to college since March, but we are going back in September. I'm really looking forward to going back to college in the West End. I enjoy drama school, technology, drawing and rigging.

I wasn't able to leave my home for three weeks and I found this very difficult, especially keeping to a routine. I'm enjoying seeing my friends and we have got used to social distancing. One thing I didn't understand was 'social bubble', the government should use easy language. We got so many mixed messages from the government and the news; it was very confusing. I find wearing masks and glasses unpleasant, but I know it's for my own and other safety.

I'm going on public transport to get to college. I will be taking the train to Charing Cross and then walk to RADA. We will have our temperature taken at the entrance and then repeated later in the day. I've really enjoyed going to Lewisham Speaking Up and catching up with my friends on Zoom. One thing I've missed is going to the gym in Lewisham but it's opening again soon.

I'm really positive about the future – like finishing my course at RADA and then finding a job as a crew member in the theatre.

I hope everyone will not catch COVID.

## Greg' Story

I found it really difficult to isolate myself. It's really important as I felt really suicidal and I don't want other people to feel like this. My mood was really

flat, I felt suicidal and I wanted to end my life because I wasn't allowed out at all. I recognise it now – I was depressed. All the news and this really upset you, so I stopped watching it.

I've had counselling and this really helped me. Talking the problems through and discussing how I'm feeling. The counsellor suggested that I should think about what you can do and think of all the positives in your life. Listened to music helped me through the bad times.

I cheered myself up by buying a Xbox. I'm really into sports games. I watch cricket as much as possible and I go to Lords and the Oval. Cricket season has started and I'm watching it on TV but it's not the same as being there live. Some of my friends play cricket at a high level. I also like snooker and going to the hall for a game and playing darts in the pub. I haven't done my favourite things in months. Southampton FC is my favourite team.

I work for Seeability. I love my job and I love helping other people. I'm an associate and I help people with sight problems and help and tell them to think about ability, not disability. Part of my role is challenging MP's and trying to get them to change their attitudes.

I've adapted to technology because I'm using every day. You will often find me on Twitter or Facebook and I often use Zoom. I've been out to my mums, my family and this really helped me.

I recommend to everyone to keep making progress, don't bottle things up, keep talking to people, communication is the key. If it happened again – don't be scared and try not to worry.



The country hasn't learnt from the COVID and a second wave is very much likely. MPs come in on your TV and look like pains in the backside. Everybody's life matters.

Patience is the key because you can tell someone how you are feeling. Think positive – everyone is the same boat.

We are all affected by COVID.



The next stories are from friends of the Foundation for People with Learning disabilities interviewed by David Mahon and Christine Burke

## Lloyd – FPLD

Lloyd lives at home with his mother. He has been working for the same charity for the last 27 years. His brother helps support both Lloyd and his mother, who has dementia.

In April Lloyd contracted Coronavirus and was admitted to hospital.

‘I had been feeling really, really ill and I had a cough. It was my brother



that detected that something was wrong, and he took me to Lewisham Hospital. I was in there for a week and was kept on oxygen while I was there. My mum was really worried about me.’

‘I was really scared. I thought I was going to die because of all the stories I’d heard but I survived! I was allowed visitors, which really helped me.’

‘When I first became aware of Coronavirus, I realised that it was serious. People with learning disabilities were not supposed to go out and had to isolate themselves. Being stuck at home I was really fidgety at first, but I got more used to it.’

‘I kept myself busy during lockdown. I watched TV and did other things. I missed work but I’m going back in September. I’ve been there for 27 years!’

‘I was glad when we came out of lockdown. I thought I can’t deal with this much longer.’

Lloyd has advice for people that find themselves feeling ill like he did, ‘Keep calm and call NHS 111 if you are worried. Look out for the symptoms, I had a cough. I was lucky because we caught it early but if you are worried then you should call an ambulance. People need to know what the symptoms are so they can get support early.’

‘My message is that we need to spend more money on research so we can beat the virus and get it done. People with learning disabilities should remember to follow the rules and stay home when they have to.’

‘My message to me is, I am still here, and we will survive!’



## Mikey – FPLD and involvement matters Eastbourne

Mikey lives in Sussex in supported accommodation. He is a member of the rock band Delta 7 and regularly DJs in his local area.

Mikey didn't really take it seriously at first, he thought it was a wind up. However, within a couple of weeks, he had realised how serious it was and recognised the danger it posed. 'It's scary. You can't see it; you don't know where it is. It's taken a lot of lives.'

'Lockdown has been frustrating and annoying. You

can't do what you used to do, and we have no idea how long it will last! I feel like a prisoner.'

'It's hard to explain how I have felt as lockdown has gone on. I feel really anxious some days but then on other days I just get on with things. Having people to talk to has really helped. Having Zoom and Teams meetings online has been a great way of staying connected and has helped me to get through it. Technology and the internet have been great.'



‘I’ve not been able to go anywhere exciting but I’m lucky as my house has a garden, so I have spent a lot of time out there socially distanced from the other people in my house.’

‘I’ve been able to do bits around my music; I’ve done some lyrics and I’ve been part of a few Gig Buddy’s socials, but it’s been hard not to be doing gigs and not to be doing my DJ-ing. I’ve really missed DJ-ing as it is really fun and is a great way to meet new people.’ I was also meant to have a DJ interview for a hospital radio slot but that couldn’t happen.’

‘I’ve missed having a routine. I tend to play it by ear each day, which is more difficult. I’ve really missed the other band members and the gigs although we have been able to do some rehearsals on Zoom. It’s not the same as meeting in person though.’

‘Not being able to go swimming has been really hard. I really enjoy a regular swim. I used to go with my gig buddy, so I’ve really missed that. Not going means I’m not getting the same amount of exercise I used to get.’

‘I’ve also missed volunteering. I volunteer at the Hippodrome Theatre in Eastbourne and I’m just hoping it survives.’

‘I’ve used a lot of technology during lockdown. I have used Microsoft Teams and Zoom for the first time. I’ve also been using WhatsApp, Facebook and Tik Tok and I use Facetime on my iPad to talk to my nan. I was worried about my nan. She struggles a bit with technology but she’s getting better.’

‘I’ve not had too many problems with technology. Mostly I find it easy to use and I’d be confident to set up meetings online.’



We asked Mikey about what he expected when we leave lockdown and he was both scared and worried. 'It's a strange world we live in now. I can't see things getting back to normal anytime soon. I've been into town and even though it was pretty quiet it still made me feel quite anxious. It felt really different. I think it will take a while before I properly start getting out. To do that I need the right help and support.'

We asked Mikey what he was looking forward to in the future and he was cautious about getting back out there, "I'll take small steps, I don't want to rush back out.' However, there were lots of things he was looking forward to doing. 'I can't wait to go swimming and get back into my voluntary work. I'm also looking forward to gigging and making music and having a good laugh!'

There are some positives to come out of the crisis. Miley spoke about the mutual support provided by himself and his friend Ruth. He also spoke about how the people he lives with have all bonded together. 'We've had our ups and downs, but it has made out friendships stronger'.

Mikey's message from the crisis is to take every day as it comes. Help and support the people around you where you can.







## Patricia – FPLD

Patricia is the Chair of the Foundation for People with Learning Disabilities (FPLD). A lifelong advocate for the rights of people with learning disabilities, Pat is a regular speaker and trainer. As Chair of FPLD Pat ensures that the work of FPLD reflects the needs of people with learning disabilities.



Pat did not realise the seriousness of COVID19 early on, 'In the beginning, I thought it wasn't all going to blow over quite quickly. Since then I've realised that it is very serious and things may not get back to normal until the new year or beyond, if it ever gets back to the normal we are used to!'

Pat has been very concerned about how little support people with learning disabilities and autism have received during lockdown and is angry about do not resuscitate policy for these groups. 'Things should have been in place for people with learning disabilities and autism. We will hear a lot more about how they have been treated and why they had 'do not resuscitate' on their records. I want to find out how many people with learning disabilities died. If it wasn't people with learning disabilities, they would all be prosecuted. They concentrated on hospitals, hardly at all about people in care homes and people with learning disabilities were right at the bottom, they didn't think about us at all.'

'A lack of personal protective equipment (PPE) meant that people with learning disabilities who needed support were left to cope by themselves. Support staff couldn't help because they couldn't be safe.'

'The lockdown was very worrying. I'm over 70 and have long term health conditions so I'm very vulnerable. I was worried about how it would affect my mental health. I was very ill in a psychiatric hospital once and I did not want to get to that again.'

'I got to the point where I felt nothing, empty. I don't want that again. Luckily, I had my friend Christine (from FPLD) to help me. We supported each other. We checked on each other a lot and having that support means I don't go back to that place again.'

'FPLD's Pass-it-on project, which is all about mental health, also helped me. I was involved from the start and I have learnt a lot of ways that I can keep myself happy and healthy. At FPLD we have also done a tea and chat Zoom meeting every Tuesday where we get together. It's been good to talk and check how everyone is and we get to laugh and have fun.'

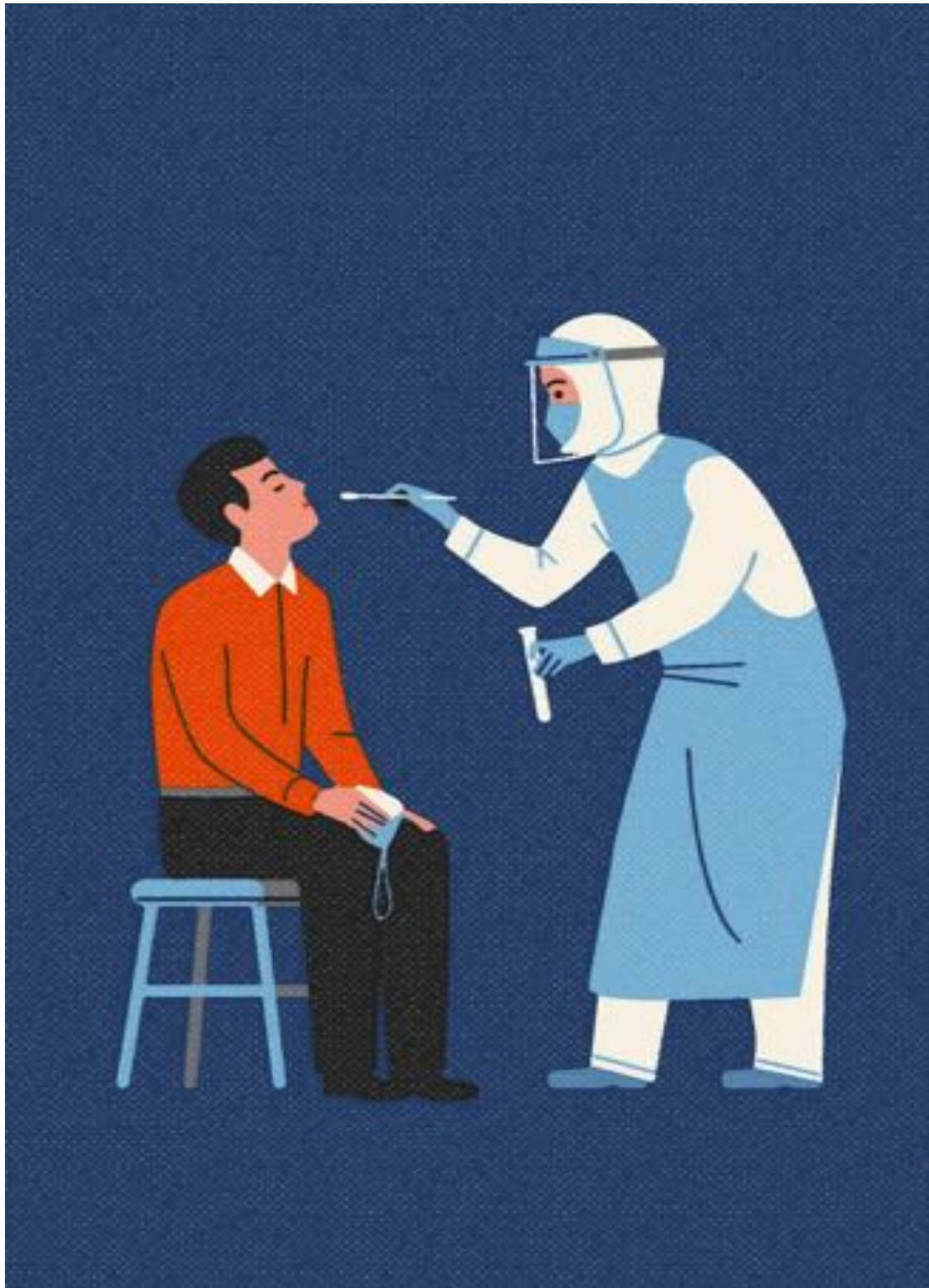
I've kept connected with lots of people, like my three cousins and this has brought us closer together.

Pat also has a friend that lives nearby, 'My Friend Peter was also a great help and we supported one another. Peter also lives on his own. We thought carefully about whether we could see each other but as we both live on our own and have had very little contact with others, we thought it would be safe. We go food shopping together and we have supported each other.'

'My connections helped me keep going and helped me to stay positive throughout. I also kept very busy, phoning friends, watching TV, cleaned out things I hadn't done for a while. I left the house twice a week, making sure I was physically distancing and wearing a mask on the bus. I learnt to use Zoom and Teams for video meetings which meant that I could see my friends and keep doing work for FPLD. Downloading the right apps for my computer was difficult but my computer teacher helped me a lot.'

Pat believes that we need to learn from the lockdown. 'We need to look after our mental health. This is really important. We need to make sure that people with nobody in their lives have someone to talk to. Living on your own could make you feel very isolated if you don't get any support. People need emergency plans to make sure they can continue to have good lives and be safe.'

'It's more than care, it's love.'





## Richard and Charlotte– FPLD

Richard is a member of the Foundation for People with Learning Disabilities Advisory Group. Richard works for Mencap and has led a number of campaigns for people with learning disabilities including projects around relationships and sexual health. Richard and Charlotte entered lockdown expecting their first child (which they have already named Alfie) and is due to be born later this year.

Both Richard and Charlotte both found lockdown difficult when it was introduced.

Charlotte is expecting a baby and Richard was furloughed.

Charlotte felt that the rules confused everyone. We weren't sure what we could do and what we couldn't





do. Being pregnant I wasn't sure what the rules were for me. Do I have to be even more careful? There was no information for us. What is the R-Rate? Why use this?' Richard agreed, 'It was all jargon. People with learning disabilities need information too. It's confusing and then they contradict themselves and do what they told you not to do. It's all double Dutch.'

Richard and Charlotte found lockdown difficult to deal with at first. 'I couldn't work which made me feel upset. It was like having a prison sentence. It felt like I couldn't breathe', said Richard. Charlotte agreed, 'I'm stuck in a hostel room, I felt like a prisoner.'

Neither Richard nor Charlotte realised how long a lockdown might last. 'At first I thought, 'ok it gives me time to prepare for the baby', but after three weeks and no sign of the lockdown ending, I started to feel really anxious'. Richard agrees, 'It was horrible, but I thought it would be for a month or something. Everyone started breaking the rules and the people in government didn't take their own advice and caught it. They should have set a good example, but they didn't.'

Charlotte's pregnancy also created problems the couple had to deal with. Richard was not able to join Charlotte for scans at the hospital. 'It's important being a parent and I wanted to support Charlotte all the way through. I had to wait outside the hospital, and I was worried about Charlotte having to go in on her own. It really started to build up in my head, I started getting panicky.' Charlotte started to feel very anxious, 'The baby's father should be there. It was hard for me knowing Richard was stuck outside the hospital worrying about me.'

Charlotte also has fits and on one occasion that had to call for an ambulance. 'They wouldn't let Richard come in the ambulance, but we

needed each other so in the end they let him come. I needed him with me.'

Sadly, Charlotte's grandfather also passed during lockdown and they were not able to go to the funeral or support Charlotte's grandmother through it. 'We felt helpless', said Richard.

As lockdown went on Richard and Charlotte relied on each other and got even closer. 'We're superglued together!' said Charlotte. They have been watching TV and films together, playing games. 'Netflix has been good, and I can stay in touch with people on Facebook. I also download games for my phone' says Richard 'But I found out EastEnders is off until September! Oh, my days!' They are also part of the catch-up group that meets once a week on Zoom hosted by Foundation for People with Learning Disabilities. 'The catch-up helps to take the pressure off, we're able to relax and talk with the rest of the group', says Richard. 'We've got to know the group; we were made to feel welcome. It's been really good to talk about how you are feeling and what you have been doing', says Charlotte.

Charlotte says that 'we've gotten better at filling our time, but it can be quite stressful to find things to do every day when you're stuck at home. Time goes really slowly when you have nothing to do!'

Charlotte says, 'I've really missed family, romantic dinners with Richard and a big Mc5lds meal!' Richard has also missed a McDonalds but has also missed, 'Comicon, friends, work. I think I would have gone mad without Charlotte!'

Richard and Charlotte have made use of technology to stay in touch with people, but Richard initially found different apps like Zoom and Microsoft Teams difficult. Charlotte helped him to get used to them. However, it has

not been perfect, Charlotte said, 'I've not seen my nan in person for a long time. We talk on the phone but she's not good with technology like Zoom or Facebook. It would have been nice to see her face to help her when we lost granddad.' Richards dad is the same, 'Dad is old fashioned, he can't use technology. I'll admit though, when I first heard of Zoom, I was, 'what's that?', I was like an old granddad when I first tried to use it. Easy when you know how but you need help at first'.

Both couldn't wait for lockdown to ease, 'I want to see my dad and go shopping.' Charlotte was nervous about leaving the house but said, 'I'm nervous to leave the house but I'm also sharing a kitchen at the hostel which is difficult. It's not socially distanced so it feels almost as bad to be in as out.' Richard noted that the empty streets outside make it, 'look like there has been a Zombie attack! It makes you nervous to go out!'

Despite their nervousness, they both wanted lockdown to end, Charlotte said, 'I think it will feel really emotional when we can get out', while Richard said, 'Freedom! Release from prison!' Richard wants to get back to work but worries about how he will be able to travel there, 'what if COVID doesn't go away.' Charlotte is also concerned about where they get the money for masks to keep themselves and other people safe.

There are exciting things on the horizon for Richard and Charlotte the biggest of which will be the birth of their baby (Alfie). 'I'm really looking forward to having Alfie, making a family and making a home. I need Richard close to me when I go into labour!'

They both think that more could be done in the future if this happens again. They both agree that information needs to be simpler. Richard has always been a very vocal advocate for clear information for people with learning disabilities, he thinks, 'information should be clear and accessible

so that people with learning disabilities can find out what is going on when they need to, not days later when it may be too late.’ He also has a suggestion for briefings, ‘there should be a disability spokesperson at all briefings to explain what is going on.’ They both feel that more support should be available to help people cope, that there should be more advice about what you can do to stay busy.

A big positive to come out of a bad situation is that, ‘During lockdown we have supported each other, and we were there for each other. Our relationship has only gotten stronger!’



## Scott and Amanda– FPLD

Scott and Amanda live on the Isle of Wight and have a five-year-old daughter. Scott works for a national charity.

The pandemic has had a big impact on Scott and Amanda, Scott says, 'The Corona Virus has caused a lot of deaths. It is a new strain of flu, there is no cure, and everybody is vulnerable. It could kill a lot of people. I have already lost a few people at work and one of our neighbours has also died.'

'We are very aware of how devastating this can be for people's lives. It can turn them upside down. It is horrible.

Scott and Amanda felt pressure and distress even before lockdown happened, as Scott says, 'For us it first started when people started to panic buy. We still did our normal shop and we could not work out what was going on. All the panic buying was a nightmare, we started worrying about how we would buy the food we need. I was worried about how I would feed my family. We have a little girl and we needed to know that we could feed her.'

'When lockdown happened, there was nothing we could do but we worked with the support worker and they helped us to try and work it all out. It was very confusing and worrying. It took weeks to get an online slot with the supermarket. In the end I had to walk 40 minutes to the local Tesco and 40 minutes back to get essential food for my family. I was really scared that I could not feed my family.'

‘I found myself in a corner in the house crying because it was all too much. I did not know how I could protect my family.’

‘We registered with all the supermarkets to get an online delivery slot, but it took us weeks and weeks.’

Amanda feels that more should be done if this happens again, ‘If people do online shopping, they should make sure vulnerable people get slots. Maybe the GP could send a list to supermarkets and they could give you a slot.’

‘The system was not there to help people with learning disabilities or to stop panic buying. People with learning disabilities could not understand and then on top of that we had lockdown rules. They weren’t explained and there was no support to get the information we needed.’

Scott continues, ‘The rules were difficult for us, saying you could only go out for essentials and only go out to exercise once a day. We are an active family; we like being out a lot and walking.’

Amanda adds, ‘That was hard for us. How do you tell a 5-year-old little girl that we can’t go out today?’

She continues, ‘They need to do something to help people cope with children. Some days I get low because my daughter does not listen to me. But if she is happy. I am happy and if Scott is happy, I am happy. When he is struggling to cope then it brings me down. Our daughter picks up on this. When a child is not happy what can you do. We need more advice on this. Getting her to do things could be difficult. Exercise with Joe Wicks was wonderful, and we all did this with him, but she did not like this every time and would not do it, so we had to find other things to do with her. I think that if you did exercise with your child and put it on YouTube then



they could see another child doing it and they would be happier to do it as well. More and more families would get involved and it would be more fun!’

Amanda was also mostly responsible for home schooling, ‘We were getting a lot of work from the school and it was tough because our daughter has additional needs so there was no way she could sit down and concentrate all that time. Also, if I found it difficult to understand then so would she, as I couldn’t explain it properly. When she could go back to school a little bit that helped a little bit but on days, she was at home it could be difficult. Scott would be working from home which was really tough with a five-year old.’

Amanda has found it particularly difficult at times, ‘We found out I have borderline autism and ADHD which has made things worse and at one point I just felt like walking out. It had gotten too much for me.’

Scott says, ‘It was tough, but we get on with it don’t we. We’ve managed really well.’ Amanda replies, ‘We don’t argue as much as we used to. It’s brought us closer together. Despite all the worries and stresses, it has made us closer as a family.’



## Sonia– FPLD

Sonia lives in Sussex and is a very active member of the wider community and of her local learning disabilities community. For a number of years Sonia has been running a friendship group that meets each week in a pub in Hastings. It has proven to be an incredibly popular initiative which brings people together, creating friendships and reducing feelings of loneliness.



Sonia is also a multi medal winning athlete at the Special Olympics including a number of gold medals.

Before the COVID crisis struck Sonia didn't think it would be serious, 'I just thought it was like flu and that not many people would die. When I saw the number of people dying going up and up, I realised it was really serious. It made me feel frightened for myself, for the people I live with, for my friends and for my mom and dad. I was in the shielding group so it

didn't feel like there was anything I could do. I've worried about my sister as she is vulnerable.'

'What really worried me was that I had a family friend who may have had it, but I was not able to get a test. The Manager where I live tried to get tests for clients and staff, but she was told that supported accommodation was right at the bottom of the list. It was really worrying knowing that you might have it but couldn't get a test'.

'Over the first three months boredom was the major thing. It made me feel quite stressed. I'm pretty active, I get out a lot. After three months of lockdown there's nothing left to watch on TV.'

'Doctor and therapist appointment were also stressful. I didn't know how I would do them. Over the phone is not great, I want to see the doctor in person. Telling them how I feel has been difficult. I really prefer face-to-face meetings. They should definitely keep face-to-face meetings when this is all over.'

'I've been supported at the flat by staff and now I can go back to the Parchment Day Centre. The support from both has been really good. Staff have come and met me at a distance and that really helped. Power Advocacy have also been really helpful. They've helped me with all my calls. The weekly catch-up with the Foundation for People with Learning Disabilities and meetings with the Involvement Matters Team (The Involvement Matters Team, IMT, is run by East Sussex County Council and Sonia sits on this group) have really helped. They have helped to keep me connected and it breaks up the day.'

During lockdown I've really missed the local meetups I do in the pub for people with learning disabilities. I don't know when it will be safe to do that again as there are a lot of us! I also missed face-to-face meetings with IMT and travelling up to London for meetings with the Foundation for People with Learning Disabilities. Not being able to go to Parchment Day Centre has been difficult too. I've missed loads of things, football, swimming, day trips, doing Makaton, gardening. It's taken a big part of my life away.'

'When I first left the house, I was pretty nervous, but staff helped. I went to the local garage and went for a walk. It was made a bit stressful as not everyone you walk past was keeping to the two-metre rule.'

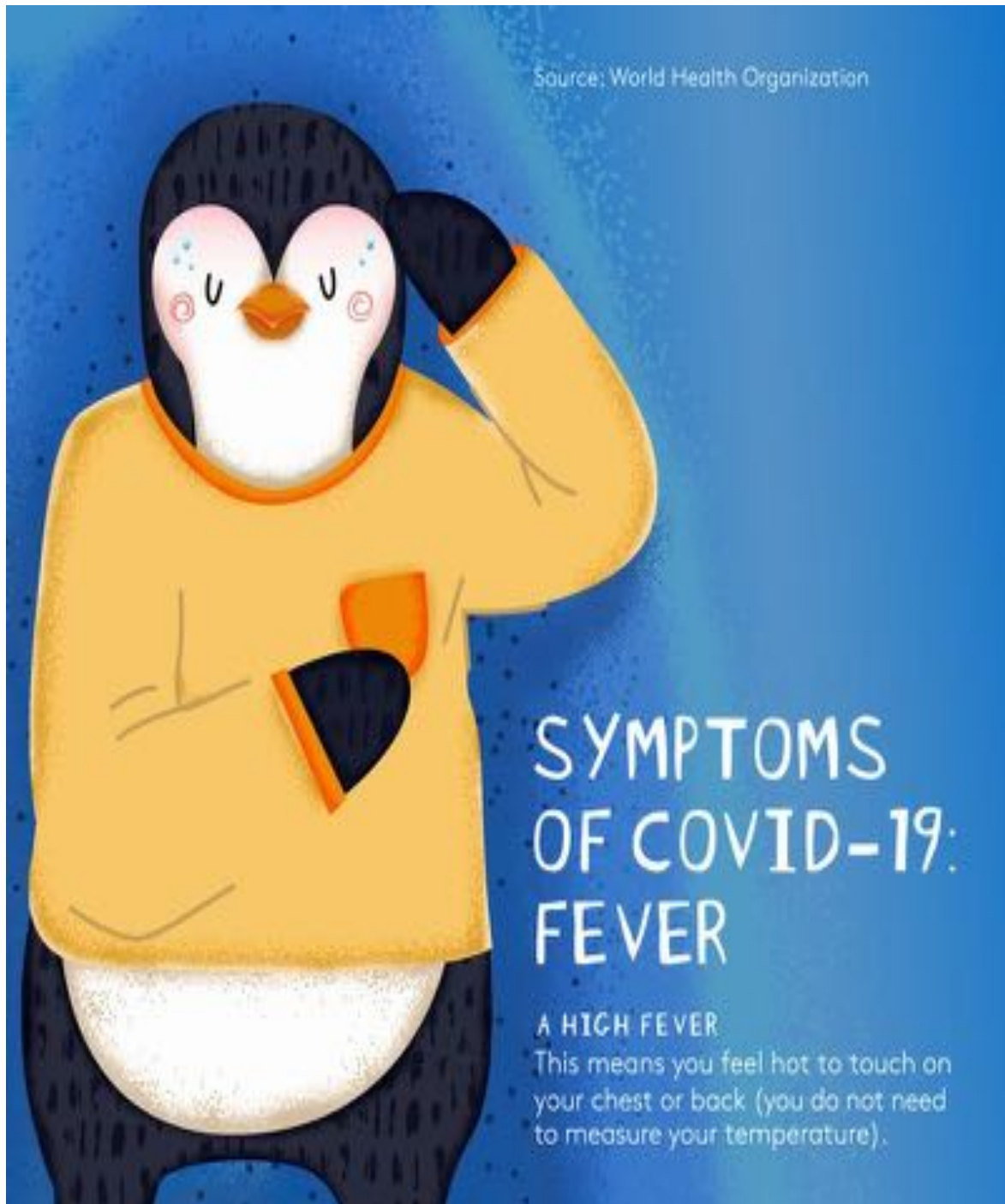
'I'm very nervous about coming out of lockdown. The death toll is too high. You don't know who might have it. Everyone needs to be super careful in the house. I'm going to wear a mask too to stay a bit safer.'

'I've been staying connected to people through Zoom and Microsoft Teams. I found them difficult at first and had to rely on staff to help me. I can do it all myself now. I've used a lot of technology to stay occupied. I've got a Smart TV, but I also use iPlayer and YouTube.

'If something like this happens again the government needs to make sure that people in supported accommodation can get tested. Without testing it made us all feel really anxious.'

'Overall I think I've become more resilient during the crisis. It was really worrying when we went into lockdown, but I learnt to cope.'

‘My message for people in the future that find themselves in the same situation is to not let yourself get low. There are lots of things you can do and try. It will just make things worse if you worry too much.’



## Alex's Story

### COVID-19 and me

- ⇒ My name is Alex.
- ⇒ I am 20.
- ⇒ I have spent the time during COVID at home with my mum, dad, brother and sister.
- ⇒ It was my birthday in May. I had a really nice cake.



I do not know anything about COVID as I have a severe learning disability, autism and expressive and receptive language disorders. That means that I cannot understand complicated words or things.

I was at College before COVID. When I came home, I was shielded. I do not know what that means. I was sent long letters about it that I cannot read.



I have spent a lot of my time at home looking at cartoons, doing puzzles, colouring, and cooking. I am very good at helping with cooking. I like chopping vegetables and making cakes.



I really like walking with mum and dad in Epping Forest. I find it very relaxing.

I find sleeping difficult and my mum bought me a weighted blanket which has helped me. I yawn a lot if I do not get enough sleep. I have a weighted vest and an exercise ball. These help me to not be so hyper because of my sensory needs.

I saw some people from my college online. They had a meeting about me. I did not understand the meeting. That is why my mum and dad have become Care and Welfare Deputies for me, appointed by the Court of Protection.

Mum and dad work and they and my brother and sister have been caring for me at home. It would be nice to know what will happen in the future, but we do not know yet.

## Nathan Coronavirus Pandemic – COVID 19

Hello all readers. I am Nathan. I am writing about the DREADFUL occurrence of the coronavirus pandemic. Now, this is a tough time, because for me it is still going on. I am in your past and my present.

It all started gradually, we heard it in the news from time to time, then it became gossip at school, then the teachers were acting strangely, then everything went KABLAMO! And my life was turned upside down.

For me, the main kablammo was straying from the normal timetable, and because I am autistic, this made it a HUGE JUMBLE. I found it really hard when schools shut down for the first time. Now, I bet you are thinking, 'Aww, why can't I go to school?' Well it is because it is HORRIBLE. It is like you get set never-ending homework EVERY DAY. And then everything else went KABLAMO! Starting with the house. We have just started with building works. This means a WHOLE HALF of the house is unable to reach now. This meant we had to take everything out of that half and move it elsewhere. That meant because I used to work there with my mum, I got moved, which confused me to where I am going. Then we got delivered lots of stuff, most of it wasn't even ours! Then we discovered our ENTIRE INTERNET CONNECTION WIRE was UNDER a PILE OF RUBBLE. I was really sad, as I rely on Minecraft and Zoom to keep connected to the outside world. We also discovered that there was a wasp nest in the roof, about the size of a large football. And now, my sister has become attached to her bed (she became a teenager) I have no company but birds.

Sometimes I just sit outside and talk to myself, imagining the birds are having a conversation with me. They aren't. My tortoise is a bit confuddled why everyone is always around, because my dad used to go to work all through the day, and whilst we were at school, my mum was teaching in the end room.

Since lockdown, my room has become messier, I think. It is probably because I spend a lot of time there as my bed is there and my bed is soft and nice to sit on. The whole family is getting to know the local wildlife because as it is spring, we have lots of baby birds, and we are around a lot more because we are at home. I hope COVID-19 ends soon.



## Ghana

### The impact of Coronavirus on Gifty



My name is Gifty Quansah. I am from Adabraka in Accra.

#### **What do I understand about Coronavirus?**

Because of the coronavirus. It is a sickness. It started in China – it is in different countries. Because of it when you greet people you use your elbow rather than your hand. The person has to wear a facemask. It will help you avoid the sickness.

I don't know. I don't know where it is. People are afraid of the coronavirus. Afraid of the sickness. I am not afraid.

#### **But My friends are not living here any more.**

"They are in the house. I miss them – Maame Yaa (Jacob, Prince, Dorcas and the other Gifty) because we don't have class now. I like talking to her. We also worked together. Early in the morning, she would wash and I would sweep."

#### **My life so far under lockdown.**

"I wake up early in the morning to sweep. If (When) I finish, I will bath. Then I have breakfast. Auntie Rebecca cooks it – we have porridge and bread. We sometimes bake the bread ourselves. If the man who is deaf comes, they will call me to clean the bowls ( prepare the tins) so we can make the bread.



“We don’t spend time outdoors in the compound. We don’t have classes. Those who usually go to school are staying home. We stay in the dormitories. All of us have gone inside to rest, to watch TV.

*Do you see anything of the boys? (The boy's block is separate from the girl's block)*



We can meet in the summerhouse to talk, do exercise.

After breakfast. I wash the bowls. Not for the school children – they do their own now they are not going to school – but for these people ( the other people with disabilities)

After that, I help in the kitchen. I put charcoal inside the fire. I take a big pot and put it inside the fire. I take fresh water. When the fire is going hard and the water is hot and bubbling, if you want to cook rice, you then put

the rice in the water. You can have rice cooked in different ways. I like fried rice best. It has oil and vegetables and my favourite vegetables are cabbage and carrot)

**Since the virus, I have been helping more in the kitchen. I enjoy it.**

**What things are different because of the virus?**

We use soap and running water.

If you go out, you have to wear a mask to cover your nose and mouth.

**I stay in. I don't go out.**

(other people go out to the shops)

We have our own church services. (*this is a continuation of what happened before Covid but Gifty is taking a greater role in organising and leading prayers etc.*)

We do church on Wednesday and Friday and Sunday. I help get things ready.



Early in the morning we wake up early to do everything. We sweep the church hall. We move the chairs. After the service, I clean away the chairs.

The first thing – you pray. If the prayer is finished, you do worship. If the worship is finished you do praise and worship. This includes dancing and will always include singing. You then sit for testimony – all of us give testimony – including songs, prayers.



Then there is another song. A quiet song to remind us that God has done everything for us. You then call on the Pastor to preach the Word of God. The pastors we have here live here- like Pastor Mike. They don't have a church outside. On other days they look after the boys. (*they are the carers*)

I like watching Good News on TV. I watch TV in the kitchen when we have finished our work there. If people hear good news they don't have to be afraid. I am not afraid.





## Johannes's Story

My name is Johannes I am 18 years old.

The reason I couldn't come outside is because of the coronavirus. Unless the coronavirus settles down, I won't be able to come out.



**What is**

### **Coronavirus?**

Coronavirus is a thing – a sickness that is not a good sickness. It's a sickness that keeps worrying everybody. It worries everybody. Yes it worries everybody. It's not good for you if you continue with that sickness. That sickness will continue doing its work.

### **How can I protect myself against it?**

You have to clean the place, to always clean the place – and keep it neat -every day you have to clean the place. If you do it, you will make it leave.



The hardest thing about the coronavirus for me is it has made me not to go out. It's made me be inside always. Made me not to come out. Inside always. I can't come out to get fresh air.



## Netherlands



### **‘Also when Corona is over, I want to keep walking in the evening’ Yvonne Schillemans & Mirjam Wouda**

Yvonne Schillemans (46) is an expert by experienced and co-researcher at Ons Tweede Thuis, a care facility for people with an Intellectual Disability in The Netherlands. Yvonne has a mild intellectual disability. She independently lives assisted in her own apartment in a residential tower. There are meetings places for communal coffee drinks, dinners and to undertake activities. Yvonne can ask for the assistance of the caretakers when needed.

Yvonne heard of the COVID-19 virus via the TV. She also got informed by her caretakers’. At first, I was still hoping that the virus would not come this way, unfortunately, that did happen’. Coincidentally Yvonne was already at home because of the flue, she just was about to go back to work on March 16<sup>th</sup> when she heard this was not possible because of the virus. ‘That was quite tough. If you work, a break for a week in between is nice, but it was very unclear when I would be able to start to work again, and by now it is taking a long time. I think I have been at home for 18 weeks now.’

Meanwhile, daytime activities are possible again in little steps and measures have been eased, but Yvonne is not able to start yet.

‘It goes one step at a time. I do understand that. First the residents from the living group get to go back to their daytime activities, because they

were on top of each other 24 hours a day. Then conflicts easily arise. Our turn will follow later, as we can easily retreat every now and then into our own apartment.’ However, not everybody understands this according to Yvonne. ‘Why are they aloud and I am not, I sometimes hear. But different rules apply to everyone.’

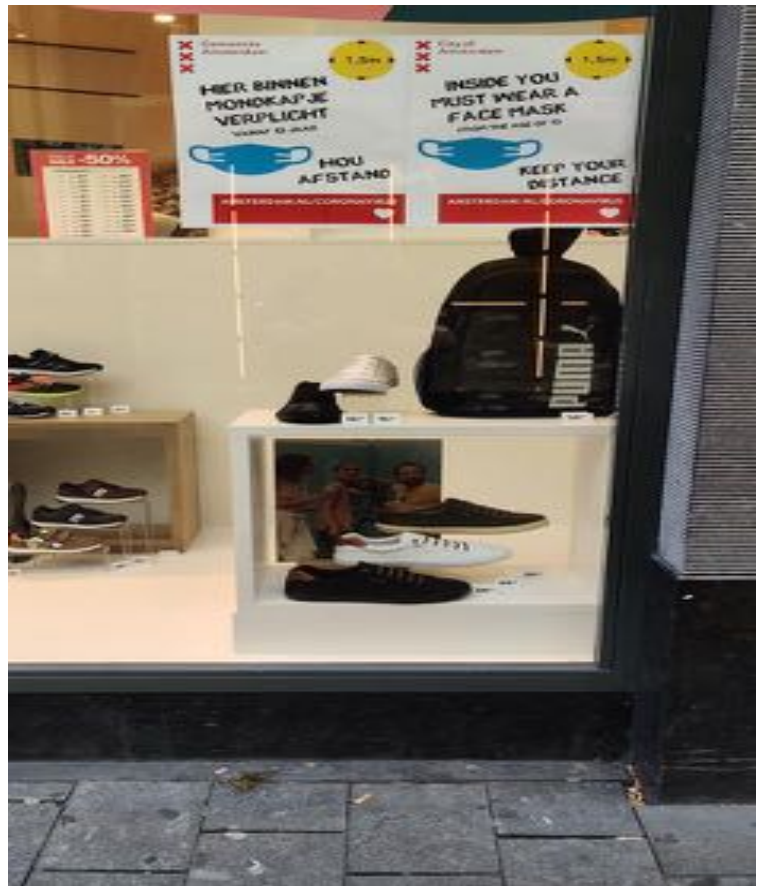
Apart from work stopping abruptly in March, Yvonne had to also immediately stay inside of her apartment for a few days, all by herself. ‘A caretaker got tested on COVID-19. Fortunately, there appeared to be no COVID-19, but it scared me.’ After those four days, Yvonne was allowed to go outside again, however a lot was changed because of the lock-down measures. ‘I usually do groceries every day. I do not do this on a weekly basis, because I often don’t know a few days in advance what I want to eat. Besides, I enjoy doing groceries. In the first period, Yvonne was only allowed to do groceries once or twice per week. This she found tough, also because communal grocery shopping was no longer possible. ‘Fortunately, I can take care of myself quite reasonably, however other residents need guidance whilst doing groceries, and this was not possible anymore. The residents of the living group weren’t allowed to go to the shopping centre for weeks. So, in that sense I was lucky’.

Despite this, the period that Yvonne had to stay inside a lot because of the measures, has brought her something positive too. ‘Thankfully, I am not a person who gets bored quickly. I gained a new hobby in the Corona time. I started doing diamond-painting. I have to make sure however that



my cat doesn't take off with the little stones, but it's a lot of fun to do. Without Corona, I probably wouldn't have had any time for that'

Also, Yvonne has consciously stuck to a good daily routine. She got out of her bed on time and did not lay in. 'No, I didn't want that, imagine that I'll be able to go back to work in a few weeks, then the step of waking up early will be too big'.



Yvonne finds the situation quite hard though. 'I can think of what to do and decide quite a bit by myself, however I do have the feeling I get restricted in my freedom'.

Now that working is no longer possible, activities are organised in the communal area for whoever wishes to join. Also, residents are helped with thinking about what they could do themselves.

'You can do something for yourself in the communal area or go for a walk alone. And sometimes we help the group from the first floor with labor-related work ".

Residents are not obliged to participate in these activities. Yvonne goes eSeey now and then, even if it's just for a coffee. "This way the caretakers see me for a moment. Because I always say that things are going well. But sometimes it's actually not the case and then the caretakers will notice it in my voice'.

Yvonne says that things went less well for her in April. She missed her job. Also, her parents' wedding day was in April. They passed away. 'It is difficult that I can no longer rely on them during a period as this one. I also would have liked to go to their grave. I always do that in April. But now I couldn't go there by public transport. Together with my caretaker, I figured out how to get there by bicycle. Fortunately, she saw that I wasn't doing very well'.

Fortunately, Yvonne has found other ways to keep in touch with her family and friends. 'My brother also lives with Ons Tweede Thuis. Of course, I also could no longer see him. He just had a new mobile with WhatsApp. I called his caretakers to see if we could video call, because permission was required for this. My brother doesn't understand the Corona measures and was grumpy, also with me. I try to get him in a more positive mood via video calling. This doesn't always work. Then I call his caretakers and they go to see him'.

Yvonne now also video calls her friend who lives in the eastern part of the Netherlands, even if it's just briefly. 'I also have a lot of contact with her children. Then they say; "We miss Soepkip", because that's what they call

me, and then my friend texts me to see if I can video call them'. That is very nice!

For Yvonne it took some getting used to having to think very carefully about receiving visitors. 'A good friend of mine came by spontaneously". I was downstairs and I hadn't seen him for a long time. That's why we gave each other a hug, but that's not allowed. My caretakers immediately called the manager and then I wasn't allowed to enter the common area for a few days. I did actually understand that. Because of the way they handled it, without any consultation, I felt treated like a small child at that moment. I then ran away angry. You shouldn't do something like that to me'.

A few days later I did however call the caretaker and we cleared the air. I told her that I would like to have been approached in a different manner, fortunately, she did understand this. If I am not sure whether something is allowed or not, I will consult with her. I also am always open and honest, because I don't want to infect others unconsciously'.

Yvonne notices that these kinds of situations are complicated for caretakers. 'When they receive an email about the new measures they say; 'Oh no, not about the Corona event again!'

There is a lot of uncertainty for clients, but this is also the case for caretakers, Yvonne notes. 'Caretakers are told the rules from higher up. It isn't always easy for them to make the rules clear to the clients. Sometimes they receive a lot of resistance, there is a lot of misunderstanding. That's tough for them'.

In terms of support, little has changed for Yvonne. During the week she has various moments under supervision. These moments have remained the same, although Yvonne does notice that the caretakers generally have less time because the residents in the groups need more attention.

Now that the measures have been relaxed in May, Yvonne would like to receive visitors again. 'By now, a good friend of mine has paid me a visit. We (residents) are not allowed to pay visits ourselves yet, if all goes well, this will be possible again in July. I have already planned an appointment'. Yvonne finds it exciting to carefully keep thinking about keeping a 1.5 meters distance and she is also curious how this later will take place at work.

The positive side of this period, according to Yvonne, is that she now started walking a lot more than before. 'Even when Corona is over, I want to continue walking through the neighbourhood for 15 minutes in the evening, I now go to places I have never been before'.

Yvonne is also proud of how her facility is doing. 'We haven't had any conflicts yet. My brother tells me that there has started to be more quarrelling between residents at his facility. So I think we're doing quite well and decent here'.

Yvonne is also proud that she has been able to keep it up for so long. 'I continue to enjoy myself. Of course, sometimes I feel a bit trapped and then I would like to work again, but I have also learned to have a lot of patience'.

## About the authors

Yvonne Schillemans is an expert by experienced and co-researcher at Ons Tweede Thuis, a care facility for people with an Intellectual Disability in The Netherlands. She also works at the community centre 'Westend' in Amstelveen. She is assisted in her own apartment where she lives alone in Amstelveen.

Mirjam Wouda is a healthcare psychologist and scientist practitioner at Ons Tweede Thuis (healthcare provider for people with disabilities in the Netherlands) and a clinical lecturer at the Vrije Universiteit Amsterdam, the Netherlands.

August 30<sup>th</sup>, 2020

Amsterdam,

The Netherlands



## **"Try to make something of it, there are always things you still can do" Mark Meekel and Suzanne Derks**

Mark Meekel (43) is an expert by experience at Ons Tweede Thuis, a care facility for people with intellectual disabilities in the Netherlands. Mark has a mild intellectual disability; he lives on his own and receives individual supervision at flexible times during the week (ambulatory supervision). He talks about his experiences during the period in which the COVID-19 virus in the Netherlands brought public life to a standstill.

"I heard about the COVID-19 virus and the measures via the television," Mark said during the interview. He also followed the news via his phone. After a while, he received an email from Ons Tweede Thuis and a short message in the letterbox that all flexible guidance and other appointments were cancelled until further notice. That was the biggest thing that changed for him: "I had to hold back a bit in receiving visitors."

All general activities organized by Ons Tweede Thuis were also stopped. "Suddenly, it became a small world". In particular, he found it strange that practically all public life came to a standstill, but also that people started hoarding so much food and supplies at the beginning. "Why?" He wonders. Because he lives on his own, he was still allowed to go outside, but he preferred not to do so. "I found it difficult to stick to the measures. Suddenly you have to pay attention to everything, and everyone was still passing each other without keeping distance. This got better when measures got enforced. The fact that people don't take the measures into account makes it difficult and also stressful in the beginning ". Because of his health and if he had an important appointment, for example a hospital visit, he preferred to avoid public places.



In the period during which people in the Netherlands had to stay indoors as much as possible, he did different things such as tidying the house, sitting outside enjoying the weather, reading books, working in the garden, reading old holiday reports and simply walking around outside. He mentions that he mainly spread out the activities and did not start doing everything in a rushed manner. He now had time for things he otherwise would not have gotten around to. Maintaining contact with other people, such as friends and family, mainly occurred via calling by phone, later video calling also took place. "I called people a little sooner or was called by people sooner." Even though he usually didn't see people that much, he now didn't see anyone for weeks and that was very unusual. Also, staff in the common areas of his housing facility had lessened. "That is very strange, sometimes you just don't know what is going on."



The measures against the spread of COVID-19 have been loosened as of mid-May. About 3 weeks after the measures started, he received a message from his supervisor who wanted to make an appointment again to speak via (video) calling. Sometimes this was just an appointment of half an hour per week or every other week. But this was better than nothing. In the meantime, he has also spoke to his parents face-to-face and he would like to go out for dinner with them soon again. He also wants to have an ice cream with a friend of his in the near future. "By now I am starting to feel the need of having some more contact with others and I am starting to see people again."

He has doubts whether he will see other people like the other experts by experience at Ons Tweede Thuis, who normally meet on Mondays, soon again. They have now started video calling in groups and he thinks this will stay this way for a while.

Positive about the period in which he mainly remained at home, he finds is that the house is now nicely tidy, and the garden has been maintained. He also is proud of the fact that he has not gotten bored yet during this period. "While it did get harder to keep from getting bored, that's something that hasn't happened." He also likes that he can now move freely again and has to think less. "Because I can be away from home again, I can pick up on things around the house again without having to think about spreading activities to avoid boredom. I don't have to let it rest any longer ". What he feels less positive about from this period is that his holiday, which was planned for the end of May, has been cancelled. "Normally it's on my mind for weeks and I can really look forward to it."

Mark especially learned to appreciate his freedom a little more. He would also like to say to others: "Just see what happens. It

won't always be easy, but it is the way it is. Try to make something of it and do the things you can still do ".

### About the authors

Mark Meekel is co-researcher (an expert by experience) at Ons Tweede Thuis, a care facility for people with intellectual disabilities in the Netherlands. Moreover, Mark is co-researcher at the Vrije Universiteit Amsterdam: with his valuable knowledge, he helps various studies at the university aimed at people with intellectual disabilities to fit even better to this target group.

Suzanne Derks is PhD student at the Vrije Universiteit Amsterdam, the Netherlands. Her project focuses on the Serious game 'You & I', a game aimed at improving mentalizing and stress regulating abilities in people with mild to borderline intellectual disabilities.

August 30<sup>th</sup>, 2020

Amsterdam, The Netherlands



## **Corona stress and Corona gains Saskia van der Weck & Paula Sterkenburg**

Saskia (52 years old) is the mother of a son who turned 19 during the corona period. She was officially not allowed to visit him during his birthday. He has Down syndrome; a severe intellectual disability and he also has some autistic features. It is complicated to communicate with him as he cannot speak with words, yet, he understands many words. He needs help and support with all everyday matters. He can eat and drink by himself, but not serve food or pour drinks. He needs support with all daily practical matters. For three years, he lived in a sheltered home which can house 14 people with disabilities. It is a home owned by, and once set up by family members of people with disabilities, but it is now affiliated with a larger healthcare institution. The house is situated in a normal residential area. It is a large villa with a large garden.

The restrictions in visiting arrangements as a result of the COVID-19 epidemic started in March 2020. There were strict visiting arrangements for people with intellectual disabilities and everyone had to stay at home as much as possible. At that moment the mother Saskia could no longer visit her son. Saskia mentions: "I would normally (pre COVID) visit my son every week or every two weeks and then we would spend time together, I would read to him or we would go for a walk in the neighbourhood or in the garden. None of that was possible anymore after COVID-lockdown started. However, we were able to make video calls. Video calling makes it nice that we can see each other, and we already had experience with that, because we have family abroad. "We have used video calling more often so he knows that. Fortunately, we were able to make video calls. "

It was initially important and good that there were restrictions, because there was so much uncertainty about COVID-19. However, it is very complicated and difficult when someone has an intellectual disability. Parents of children and adults with a disability were allowed to let their child come home, but then, once they had been home, their child was no longer allowed to go back to the group-home. Saskia says: "That was not an option for me, because I could not take care of him myself for a long period of time without knowing when it would end. So that was not an option. .... I then really informed myself about corona: what that virus did. Further diving into the problem is actually what I always do when there is something wrong with my child. For example, I have asked for information from the corona research division at the University of Nijmegen, and I have searched the internet for information, for example on the site of the *Vereniging Gehandicaptenzorg Nederland*. And I made sure that I ran as little risk as possible myself. So I stayed indoors as much as possible and had little contact with other people, as if I was in quarantine".

Saskia started working in the garden doing jobs around her house during this time, like many others in the Netherlands. Like most people, she went for a walk and avoided social contacts. [the city, the supermarket] as much as possible. She also did her shopping online. She has kept in touch with others by calling or video calling friends and family.

Her son's day-to-day carers sometimes sent photos of him. Saskia also sent him parcels containing 'corona pyjamas', which she had sewn for him, a T-shirt with an "I love you" text on it and "Big kiss from Mama". She also sent cards to him. She says: "I sent him parcels with little jokes in





them that I know he likes". Unfortunately, Saskia did not receive a video from the staff showing when he opens a package or how he reacts to a note. She mentions: "I don't even know if he received it. I did ask if they had received it, they confirmed that. But later I didn't ask anymore".

With respect to the team of carers: Before the corona time, the team was not up to strength and there were many temporary staff. And an advantage of the corona time for her son was that the day care was closed, and because of that people from the day care came to work in the home where her son lived and now have continued to do so. Saskia describes this as a "corona gain".

It was a very challenging time for parents of children with intellectual disabilities. It turned out that one of the staff members had tested positive for corona. Her son also got some symptoms. A corona test turned out to be negative, which reassured her enormously. Saskia says: "Until then I was very tense, because, normally, if there is something wrong with my child, I go to him and feel his cheeks and then I would know what is wrong with him, and now I couldn't. That was very difficult."

The measures described in a letter from the management to parents came across as very far reaching for Saskia. Standard instructions had been described: 1) keep your distance, 2) visit him "through the window", 3) in case of contact, a staff member would come along, and this person would then hold him back if he would get too close. Saskia says: "The first time I saw him I wore a face mask and he thought that was so strange. Then it took a long time before he dared to look at me. For our first bike ride I bought plastic face protectors... we went cycling and had a break to eat strawberries. And then he didn't look at me for fifteen minutes". Saskia indicates that this was a very challenging time.

Still, Saskia indicates that there were also "corona gains". She started doing more WITH her son instead of FOR her son. She also indicates that she thinks that the staff have gotten to know her son better and that they can now pick up his communication signals better.

Regarding the measures for the future, it will be very important to realize in future that parents who are themselves in 'quarantine' are actually less of a risk to people with intellectual disabilities than staff on rotating duties. Organizations could at such a time ask parents to fill the gap and to accompany them, add parents to the team, following the same restrictions and allow them to be in the house with their child. This is very important. Saskia describes: "A mother of a roommate of my son "kidnapped" her child to see her child. That almost makes me cry, it is bad that you have to "kidnap" your child.

This was also a time of reflection: Saskia indicated that it was necessary to discuss what should happen if her son became ill. As a parent you will then be faced with very difficult situations: Saskia mentions: "Am I going to take care of him at home again? I realize that he is a child who, when the ICUs are full, choices will be made in the ICU. I really know that they would give preference to that healthy young man. That is a confronting realization. That your child is a kind of a "second-class citizen". While it doesn't feel that way to me. This has been confronting. And also to some extent I do understand that. I understand that you are not admitting my child and you are giving that young man a chance".

Looking back, many parents of a child with an intellectual disability will approach things differently next time. Saskia mentions: "I might have started looking for opportunities to have contact earlier. We have all been

surprised by the situation and let it take its course for quite a while”. She also indicates that it is important that parents can keep in touch with their child at all times and it is also important staff continue to communicate with parents about how the person with a disability is doing. If video calling is not possible, there are alternatives: write a letter and send photos. It is important for both parents and children and adults with intellectual disabilities to see and speak to each other during moments of stress and tension, such as during such a major pandemic.

### **About the authors**

Saskia van der Weck is a developmental psychologist working at Ago Natura, an outdoor youth care organization and mother of her son with a severe intellectual disability and his younger sister.

Paula Sterkenburg is professor at the Vrije Universiteit Amsterdam and clinical psychologist at Bartiméus an organisation providing care and services to persons with a visual-and-intellectual disability. She coordinates the Academic Workplace ‘Social relationships and attachment: persons with visual or visual-and-intellectual disability’

August 30<sup>th</sup>, 2020, Amsterdam



## **‘It’s important to make the best out of every situation’ Leroy van der Kust & Evelien van Wingerden**

Leroy, (29 years old) is an expert by experience at a large care organisation in The Netherlands. He has a mild intellectual disability. In his residential home he has his own apartment, but there is always someone nearby to help him when he is in need.

Leroy heard about the Coronavirus via TV. He also got information from his caretakers who came to talk about it with him. ‘That hit home, to hear that the virus came close and that all kinds of measures were necessary to stop it. I had not expected that to happen’.

The measures changed a number of things for Leroy. First of all, he was no longer able to go to work. ‘Everything closed. For example, the regular appointments with my mentor were stopped, and the restaurant that belongs to my residential building had to be closed. Also, Leroy’s parents weren’t allowed to visit him any longer. However, after a while they put up a visitor tent near the residence, which was a special tent where residents and visitors could meet.

‘It took some time getting used to, I had to switch gears. In the beginning I found that difficult, but I got used to it after a while. I could accept the situation as it was.’

During this period, Leroy’s days looked a bit different from the usual where he would go to work. ‘My supervisors from work came by our homes. This allowed me to do some of my work from home. And we still went to the shops, for example.’ Leroy also kept in touch with his family and friends during this time, via (video)calling. ‘It was unusual that this was the only possibility now, but I had done it before, so it was not completely new to me.’

Leroy experienced being home as quite boring, as he was not able to go out. He is happy that he can go back to work again now.

‘Now that measures have been eased, most things have gone back to normal, or are almost back to normal for me.’ However, Leroy explains that there are small things that are different, even now the measures are loosened. For example, the sport continues but in smaller groups. Also, the groups at Leroy’s work are smaller. ‘We cannot all be at work at the same time. Our workplaces are arranged differently. I notice that, but I can accept this new situation.’

Despite this, the period that Leroy had to stay inside a lot because of the measures has brought him something positive too. ‘I have tried to learn other languages. I like to be able to speak a few words of German and French. This is useful for holidays, but also for international conferences for my work as a co-researcher. I’m going to try to keep it up.’

Leroy would like to say to others that it’s important in a period as this, to know how to contact people who can help you or who you can talk to.’ That was nice for me to know, even if it was not often necessary.’ Leroy also says that it’s important to make the best out of every situation and even view something negative in a positive way.

### **About the authors**

Leroy van der Kust is an expert by experience at ‘Ons Tweede Thuis’ a care organization for persons with an intellectual disability. He is also a co-researcher within the research projects of ‘Social Relationships and ICT’ at the Vrije Universiteit Amsterdam.



Dr. Evelien van Wingerden is a researcher at the Academic Workplace 'Social relationships and attachment: persons with visual or visual-and-intellectual disability' Bartiméus – Vrije Universiteit Amsterdam, the Netherlands.

August 30<sup>th</sup>, 2020

Amsterdam, The Netherlands



## The self-advocates of 's Heeren Loo Mid Netherlands: Stories by Benjamin, Frank, Sam and Maaïke van Rest from the Netherlands. Coping with the COVID-19 crisis

From the Academic Collaborative Center 's Heeren Loo – Vrije Universiteit Amsterdam

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*One at a time, our five faces appear on screen as we enter our video call. The self-advocates Benjamin van Ark, Frank Brakke, Sam France and coach Hessel Rienstra are ready, and start making jokes among themselves, it's a good vibe. Several of them are very happy to be back at the office - at a safe distance from one another. 'Listen, if I knock on the walls, you will hear it at Benjamin's, do you hear it?' The self-advocates of 's Heeren Loo Mid Netherlands are ready to share their corona-stories with you.*

*Written by  
Maaïke van Rest, senior researcher*

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### What are our job activities like?

'We do very little at the moment!' But within seconds it turns out not to be little at all. 'We always provided trainings to people, and actually during the crisis as well, but then through videos.' The self-advocates get excited and start giving many examples: 'We make videos to teach people of our society about life with intellectual disabilities.' Recently the self-advocates created a video about having an addiction, for example, so students could learn what it is and how someone with a disability can cope with it. Before corona, the self-advocates also conducted interviews on the streets to test people's knowledge about intellectual disabilities. They created informative videos about sexual diversity and they occasionally worked as live training actors, 'So that professionals can practice their acquired support skills on us.' The self-advocates are sometimes invited as speakers for health care organisations or at intellectual disabilities

conferences, for example to do the grand opening. And they provide digital lectures for students at various Universities and Colleges throughout the Netherlands. Their job is very diverse. ‘During the corona crisis, we also shot some videos of us telling jokes to entertain people and make them laugh!’ Finally, they proudly tell about the instruction video they created about how to use video calls during the corona crisis. ‘This video was even shared online by our Deputy Prime Minister Hugo de Jonge!’ The self-advocates are having a lot of societal impact.

### What is our goal?

‘We want to let our society get more acquainted with people with intellectual disabilities or autism.’ The self-advocates try to do this by providing information about their lives, about what it is like for them to get a job, to live independently or at a residential facility, or they provide information about addiction problems. They think it is very important to be able to participate in all themes and conversations about care, to which previously, people with ID were never invited. Such as in policy and in education. ‘We’d like to be involved in everything that has an impact on people with ID in any form. The client council within our organisation also does this in a formal sense, they have a say in various subjects. And we would like to stay informal. We try to be “Dennis the Menace” to keep them on top of things.’ Coach Hessel just wants to be sure: ‘You’ll shout out when I’m telling nonsense, right?’ Followed by the immediate response: ‘Yeah well, you always talk nonsense!’. The self-advocate colleagues are feeling comfortable making jokes toward and about each other. ‘Self-mockery is very important around here.’

## Could you still meet with people during the crisis?

My name is **Benjamin van Ark**, I am 28,  
I live independently and I like video gaming  
'Luckily, we were able to make video calls so I could see my colleagues.  
And my father calls me every week to ask about my days. He's not that technically brilliant, so video calling wouldn't work; it is already a blessing that he knows about WhatsApp! We have a chat and then he passes the phone on to my mother. With Pentecost and Father's Day we were able to talk face to face again. For safety reasons we used the 1½ meters in between, but we could see each other and we were able to speak. Usually we have a cup of coffee together and that didn't work out for a very long time, but I'm glad we were still able to talk. Right in front of my house there is a nice little park. Actually visiting the park is another cup of tea, but I do have the opportunity.' On screen we hear someone laughing and then Sam shouting out loud: 'Hahaha, Benjamin and sunlight... Benjamin doesn't actually come out, because he likes his man cave too much.' Benjamin happily responds: 'Yep, I am not an outdoor person, but, during Easter I did have an Easter brunch with my family in that park. Keeping the 1½ meters distance of course. As I have a tape-measure, I could keep perfect distance!'

## What were the new rules because of COVID-19?

'Because I live independently, I thought I would be able to do a little more than others. Like, to go outdoors keeping the right distance and safety. Some rules of 's Heeren Loo did not apply to me in my opinion, because I live alone. So in case I would get ill I could quarantine myself. I had some discussions about it to get more freedom, for example for my father's

birthday, as I really wanted to go. I talked to my parents and my mother was not happy about how I was not allowed to do things because of the rules, she was really angry. Then she called the manager and arranged permission for me to do some things and get my freedom. She works as a day care professional, so she knows a lot about which safety rules to follow. Many rules of 's Heeren Loo only applied to people living in a residential home. But they do not apply to me, because I could not infect other people in a group. After my mother had called, the next day I was allowed to go to my parents: the manager made that decision for me. So I could visit my parents from a safe distance while wearing a mask!'

### **My hobbies during the corona crisis**

'Of course I'd love to have enough shows to watch and games to play, I like gaming! I trained for this being a gamer; staying indoors all day. But there were times that I woke up and watched 90 episodes of a show in one weekend! I only took a break to eat breakfast, lunch and dinner. At first the lockdown just felt a bit like a long extended weekend. It really made a difference that I still had some work to do, otherwise I sometimes couldn't remember what day it was. That is why I went shopping on specific days; luckily, I don't need any help doing that. And I am so happy to be able to work again. It was nice doing all that gaming and watching shows, but my job is also very nice! I hope to see my two other colleagues in real life again soon.'

'We also realised that social distancing is sometimes quite good for some people with autism: people no longer have to shake hands or give three kisses (in the Netherlands we give three...). That's great. Although this

rule was not democratically elected, but the law says nothing about such crises!’

### **What have you been through due to COVID-19?**

My name is **Frank Brakke**, I am 41, I live at a residential facility and I like to computer and to play the keyboard.

‘Do you know how I feel about corona? It sucks. There were all these different rules around here. It was almost like they invented the rules just the way it suited them. It was very confusing, sometimes we were seen as a group at my facility, but then sometimes we were perceived as individuals and the rules changed. I also know of people who got COVID-19. There were eight quite close to me. Six of them were from my group; four residents and two support workers. And some other people at our facility whom I know as well. Very sadly, one has passed away, that just happened... When the crisis had been going on for a while, we were reluctantly happy because it felt like it had skipped us, but then it happened anyway. And it did not feel like ‘s Heeren Loo helped us as much, so I had to call the regional committee about how things were arranged around here. The rules changed very often. And when there were some rules, these were very unclear to us. For example, when four of our residents fell ill they were immediately picked up. Suddenly three of them came back, but the next day they were ill again. It seemed like there had been a mistake: They were not better at all! Then, the next day they told us how it was not a mistake, but it turned out that they had regained COVID-19 for the second time. The information they gave us was incorrect and it was all so contradictory. To us it felt like they don't even treat animals this way. It is simply not human. Luckily, the support workers all agreed with me. I even saw some support workers cry about how it all



went down. About how we were treated and how they were treated themselves. To get some answers they called the Community Health Services who explained that people can contain the virus within their body for up to 80 days. So it could indeed happen that it took a long time for our residents and that after a few weeks they could still be tested “positive”, but that they’re no longer contagious. That information helped, but it was a very sad and anxious time for us.’

### **My activities during the corona crisis**

‘At first I was not allowed to leave our residential site. Just once, it was five weeks ago, because I had to go to the hospital. And next week I can come back to work! We need one more permission. Unfortunately for me my house and job are in different regions. If I had worked and lived in the same region, it would have been possible to come back much earlier. It is actually quite close to one another straight as the crow flies. But our organisation is divided into a number of regions across the country, and the rules differ. And especially since we had people with COVID-19 in my residential facility, it was far from clear whether I could leave for another region to go to work. It always takes several days to approve something, because sometimes some manager doesn't work on Friday for example. In the meantime at home, I did nothing much. At one point I could help at the supermarket on our residential site. I brought groceries to the several homes on site wearing a mask and gloves. I was allowed to do that for three weeks and I really needed it! I was getting nuts about just sitting at home, so being able to work was really great! Just to feel the freedom. Once I got back home, I felt very angry and I threw some chairs around. Nobody was able to calm me down, well, the support workers succeeded after a while. The manager wouldn't come, because he couldn't do

anything. But when I calmed down, I just stayed in my room a lot and messed around a bit. Gaming a bit and playing a little keyboard. It had been a while ago and I had rediscovered my keyboard. It does help sometimes and then it doesn't at other times. Luckily, I was able to talk to my colleagues from time to time. Every Monday we had our team meetings through video calling and then we could chat about how we were doing. And the intern support worker and I have had a lot of contact. Our chats became less and less work-related and more and more social! Or I could call my sister. That was nice, sometimes we were in contact almost daily.'

### **What type of support or help did you receive during the corona crisis?**

My name is **Sam France**, I am 28, I live independently, and I like fashion, clothing shopping and my girlfriend

'Actually the same as usual, I got outpatient care once or twice a week. Usually one at work and one comes home. But that was no longer allowed at work, they dropped it. Everything had to be digital, so we talked on FaceTime or on Google Teams. That made it quite difficult for me, because she could not really see my facial expressions or my feelings. I found that hard, because I wanted to discuss a feeling, but could not really show it. It also feels a bit like, we are in this together and we have to deal with it! It is now all being decided for me, I actually have no control over it whatsoever. But thousands of other people have that with me. It is actually kind of like against our National Law: the Mental Health Act on Restriction, everything is now imposed on us by the Dutch government. We still have to ask our Prime Minister Mark Rutte to file a report!'

## How did you experience the lockdown?

‘After two months I really went nuts. At first you might think, “Oh nice, a little vacation.” But soon you’ll start thinking: “No, I want to have an education, I want to go to school, I want to do my internship and I want to go to work and see my colleagues!”. It just eats you up. How is this going to work out in the end? I have often wondered about that. And sometimes I really couldn’t remember what day it was. I asked my coach Hessel if I could come to work, but various managers were unclear about it, because I had to travel by public transport. That was difficult, those conflicting messages. And I could see my colleagues going to work, because they did not need public transport. I was annoyed by all the rules that were imposed on us. But I also felt happy because of some rules, like people may no longer come too close to you and there are not too many people in one room. It provides less sensory information and I like that. Because I can get frustrated or angry by people who come so close to you. Then I’d think: “Take a step away from me!” Also, I actually did quite a lot during the lockdown. We were not allowed to physically visit each other, but luckily I was able to keep in touch using my iPad. We recorded ourselves telling jokes and I made a video for a postcard campaign by 's Heeren Loo. I never thought people would send so many cards! More than 30,000 cards! I also like that my video has been viewed so many times and people realise that it is really necessary to send someone a postcard during corona-times. I was able to contribute to that. At home, I also acted as my mother's informal caregiver, because she is not physically healthy anymore. Corona prevented her from doing the things she was doing before, because her fear of corona kicked in. She no longer dared to go shopping. Then I started taking care of her, started cleaning, and just

checking in on how she was doing. It's weird to think that I am her son, but now I am also her informal caregiver. It gave me mixed feelings. Because you don't want her to worry, but I do understand her feelings, because it is kind of scary. Sometimes you have to cover your own feelings and then tell her something else to help. I couldn't have imagined of how intense it would be, but I am proud to be there for my mom. Luckily, now she can go outside a bit more. I will still take care of her and of course always at a safe distance.'

### **What have you been through because of COVID-19?**

'I do know of someone who got COVID-19; it is my former support worker. They had to give him oxygen at first, but it got even worse, so they gave him medication to let him sleep. And he was on other medication too, it was very intense. I have a very good relationship with him and I was quite worried because you know people can die from it. Luckily, I kept in mind, "He's a young guy." I was stressed for three weeks! He is now slowly recovering. To let him know that I think of him, I contacted his wife, sent him a text and a postcard. I find it important to do that for him.'



## Scotland

### Alisha Black



My name is Alisha Black and I am 27 years old. I live in Glasgow.

I had a bad start just before lockdown. My grandad died one week before lockdown. It was even more upsetting as the very first day Nicola Sturgeon locked us down was my Grandad's funeral, but no friends or family that lived far away could even attend. It was hard.

Lockdown has made it very hard for me as I didn't get to see my Gran after the funeral. I was also really upset and sad that I didn't get to see my little brother who also has autism and other problems. I could only drop stuff off to him that was also upsetting that I could not give him a hug. It was also his birthday during lockdown it was a very strange birthday as I had to stand outside to give him presents and to sing him Happy birthday with his cake. He was happy that he got presents and a balloon and cake. I also didn't get to see my dad as he has a health issue. I was sad and feeling down as I didn't get to see them.

I was very lucky that I didn't catch COVID-19 and none of my family did.

I was really worried about COVID-19 and didn't have enough information about COVID-19. I got that stressed and worried I called my disability nurse to help me with more information. She sent me some information on COVID and some leaflets but unfortunately, they didn't make sense to me. It was hard to understand. It would be helpful if it was better understanding for people with learning disabilities and autism.

I didn't cope really well the first two months of lockdown I was staying in bed longer and I didn't have my normal routine of going to work. Then the

woman across the road found out I worked as a support worker and she asked me to help with her daughter who has Cerebral Palsy, epilepsy and other health issues. I was really happy she asked as I had something to wake up to each day. So, from then on, I was coping a bit better, but don't get me wrong I still had off days. Who doesn't?

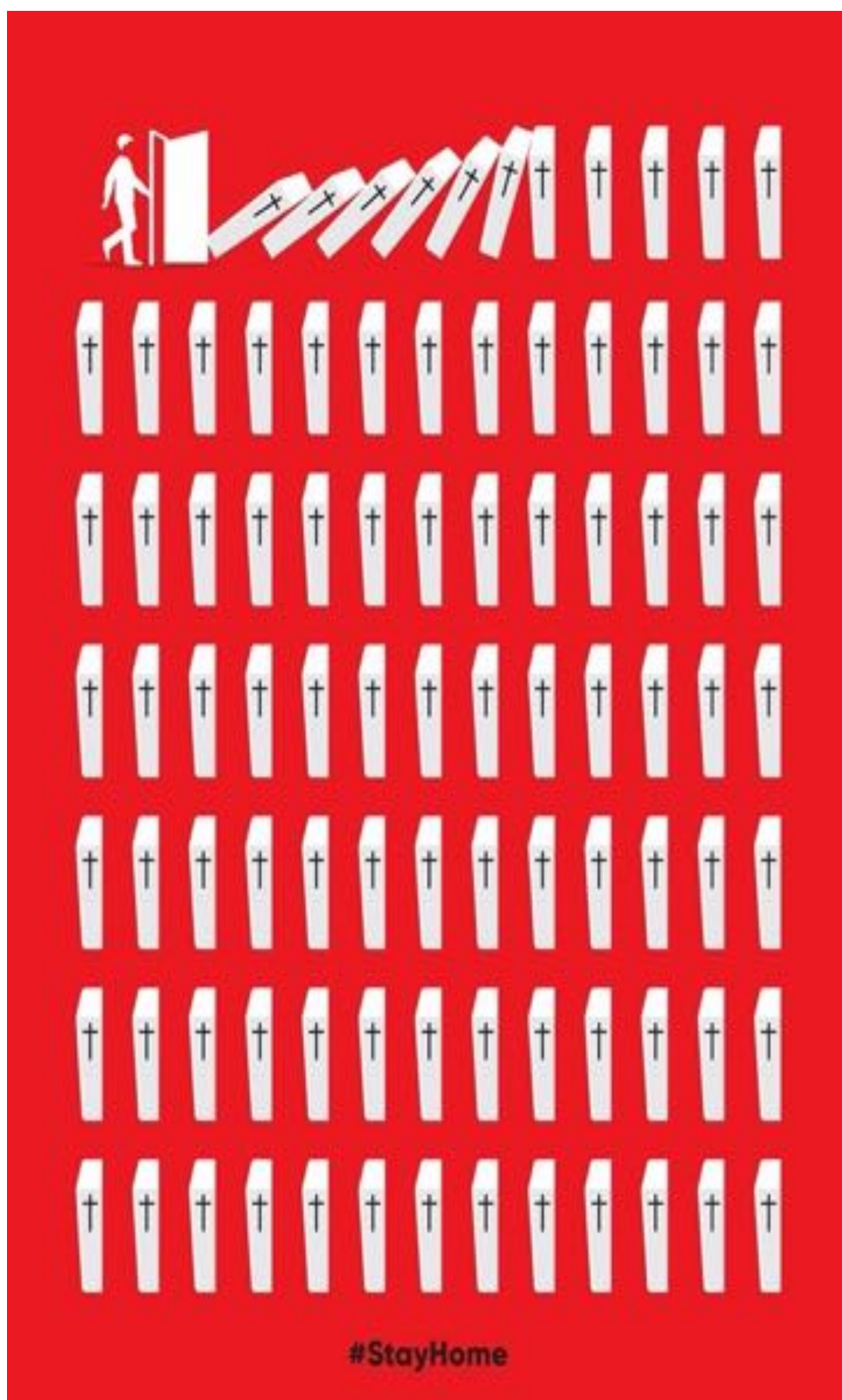
My mum and disability nurse helped me during lockdown by giving strategies to do like going in the garden or shopping. That little girl has helped me a lot during lockdown by supporting her. Thanks to her mum and Dad.

At the beginning of lockdown, I didn't do many activities but when I started helping with the little girl, I did a lot of activities. We went on long walks and on the bikes. I also was on trampoline and swings. I also went swimming at Hogganfield Park it was fun – I even lost a happy stone.

I have been feeling lost and unsettled that I didn't have my normal routine. Sometimes I have been depressed, upset and sad.







## Susan's story

I've been at home, just with my husband and my two boys. My daughter is starting college soon, she doesn't live at home. During COVID-19, I didn't see family. None at all. Other than May 4th, I went to my mums to hand her a birthday cake and all that. We just social distanced, I felt as if I couldn't not go down. She stays on her own. I was able to keep in touch with my mum and my daughter on video call and on WhatsApp. It was all new to me! I knew you could get on video call and Messenger, but WhatsApp is all new to me. I think it's a really good way of keeping in contact, to see somebody on the video.

My husband thought he did have COVID-19. An ambulance came out and he was tested on the back of the ambulance. And they said no, he absolutely didn't have it. He was taken to the health centre by ambulance transport. His GP didn't believe the ambulance testing, they said they wanted to test themselves. So they sent him by ambulance transport to a different health centre and he got tested. Oh, he said it was absolutely dreadful over there. The way the security guard was treating everyone, he was shouting at people to hurry up and get their face mask on. It wouldn't have been good for anybody who didn't know what they were doing, like someone with severe special needs who can't take the feeling of facemasks. If that had been my older son, he would have been so upset.

The likes of the GP were in a bit of a panic about all this. Well, I was worried too. I had heard stories of people going into the testing centres to get tested and if they had it, they never went right home. They get sent right to hospital. And I heard some people never saw members of their families after that. When he was negative, I was so glad.

I think we have coped a lot better than some families have coped. There is a lot of families been arguing, and abuse and that. It made me feel really lucky that I wasn't with my ex. If I had been with him, we would have been very much arguing.

One thing I enjoyed was I enjoyed seeing the kids out in the back garden on their bikes. I enjoyed being closer to them. I didn't do quite as much as what other people, like my cousin, did with her kids. She baked with them and did loads of other stuff like maths with them. I did some sensory stuff with them, like playing with playdough and getting them to make their beds up and throw their dirty washing down the stairs. My youngest was funny, he just picked up his trousers and his pants and socks and threw them over the bannister. It near enough hit me on the head! I also did reading and counting cubes with them both.

It was a lot of the other stuff, with them in the garden. My son had a big trike he got from school, and on his birthday in May we got him a football. And he never put it down after that. Every day, we had him outside. I loved watching him having so much fun kicking the ball about.

And something else I thoroughly enjoyed. One of my friends put a quiz on Facebook. We could see her but she couldn't see us. That was great, anyone who did something like that. It got all of us able to communicate and ask how each other was. She had prizes for the winners of the quiz. I could text her and say, 'I'm waving to you!' and then she would wave back to me. I was rubbish at the quiz, it was just about the fact that we could still keep in touch.

And I did a Zoom group with my advocacy group. I thoroughly enjoyed that since it's been set up. They gave me a tablet to use for my Zoom group. That's kept me going, very much so. When they send the Zoom

link to the tablet, my husband sets it up for me, and leaves me to it! They did different things each week, like picture bingo, and I won two prizes.

Well, because of the clinics closing down I couldn't attend my clinics again - for my psoriasis or do my light treatment to take the spots all away. That was closed before I got to the end of that treatment. And then the other clinic closed down as well, and the pain clinic for my slipped disc and nerve damage as well. If I wanted to phone up and talk to them if I felt like something wasn't working... I felt disappointed as if that was me stuck. That didn't stop me from going out for a walk every day. There is a path at the back of the houses outside the back, and it's not near any roads and that's where my youngest plays with his friends up and down the path. Sometimes I would walk it from one end to the other end. A wee walk to get my legs working.

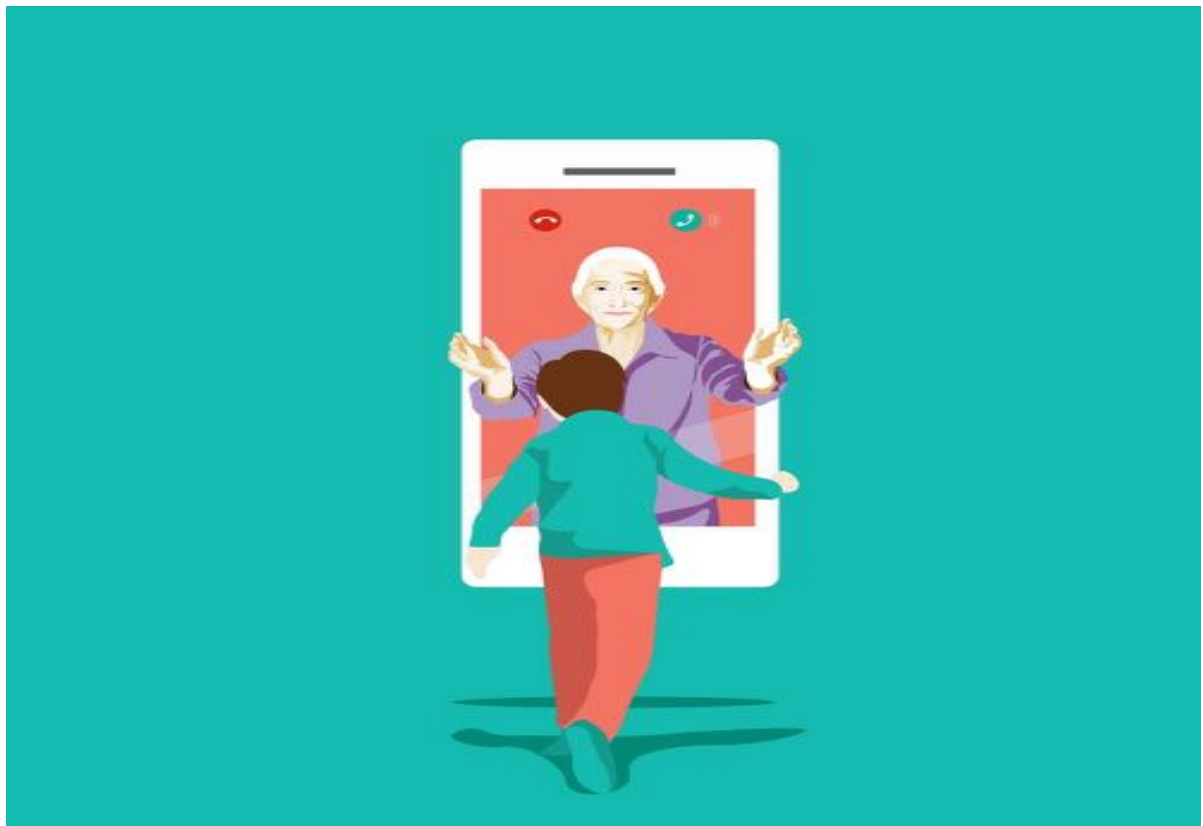
And I would go down to the shop, but I will say shopping wasn't a good experience at all. Normally I love food shopping. Going food shopping is something that relaxes me. Like if I'm feeling stressed out, I end up buying five blocks of cheese. But during lockdown I didn't enjoy going food shopping at all. It was horrible. I was so concentrated... when someone was walking towards me, I quickly walked in the other direction up the aisle. My husband wasn't like that when he was down at the shop, so I thought maybe it was just me panicking. But then I talked to my neighbour, and she was worse than me! She said everything she buys; she washes it all down in the sink. And I said to her, before all this started, I would take the second thing back on the shelf, but since all this, I've been going all the way to the back of the shelf. I felt a lot more relaxed since everyone started wearing masks in the shops.

I would say, for people with special needs, it's just the way it is for everyone else. People who don't have disabilities, I've spoken to them and there's a lot of them that's all been panicking. One of my friends who went to a mainstream secondary school, she ended up back in the mental hospital. It can affect anyone.

Since the rules have changed, we have not actually been out the way lots of other people have been out. Because I'm still worried as still going about in high schools and everything. And there's a school just down the road from us that has had a number of cases of it, and it's close. And then there' are so many cases in pubs with people drinking and then talking. We haven't done anything like that so far. One of my husband's friends wanted me to go out this Friday to play snooker. And again, I'm worried about that. I have talked to him about that. All the cases. People say oh I won't do that, but they get a drink in them and then anything happens. We have been to cafes for lunch, which is absolutely brilliant. There's a cafe nearby my two sons' schools, it's great how it's set up. They have the tracing sheet all set up. It's been great being able to go there.

With my kids going back to school and my daughter about to go back to college, my husband and I have been worried about them. Especially my daughter at her age group starting college. I felt sorry for the primary 1s, like my youngest son. He missed out on his graduation from nursery to school. And my daughter missed her leaving prom from school too. So, basically, I felt sorry that they missed out on lots like that. I felt sorry for them and I just thought that it must be so hard for the primary 1s to understand the social distance thing. They've been taught to mix with other kids before that. I know it's a must, but it's a shame for them all. They can't run about with all their friends, just some of them.

I'm just taking it day by day, because I don't know if we will be brought into a new lockdown with all this happening. Or every school and every pub getting shut down. And all the churches are back as well, but there's only a certain number and we've not gone. But I've been watching the church online, which in actual fact I've found really good in all that. It's on all week. Before the virus happened, on Sundays I would be so sore in the morning and I would be late getting to church, while my family was down there in plenty of time. I could only get there 20 minutes before it finished. But with it online on Facebook, I've been going on and watching the church service. I hope they actually continue that, it's a good thing for people who can't manage it down to the church. So I would hope that that continues, that they continue that for anyone who can't manage down!





## Spain



### Fernando's story or the sweeter side of life

Fernando is not from this planet. He's not even part of this galaxy. He belongs in another dimension. Fernando must be some kind of an angel or extraterrestrial creature because he's dedicated his whole life to the pursuit of saving others'. He saves lives without breaking a sweat or losing his smile.

Without going any further, in 2011 he prevented a man from taking his own life in the underground. The same underground where no-one, except Fernando, would consider leaving their soul on.

"That morning in May, he tells me, proudly, a guy jumped to the tracks", expecting, undoubtedly, that the machine would fulfil, punctual, its fatal destiny. That hopeless man was waiting for his minutes to expire when Fer took a glimpse of him and without any second thoughts he rushed to warn the security guards in the station, who held him up from the tracks, back to safety.

To Fernando, who followed the same way every day from home to the Foundation and back again home, that unknown man had become part of a familiar scenery and, to some extent, he had started worrying about him. He would check out that man's condition on a daily basis, and just his presence in that station platform -even though he might find him yelling or moving his arms up and down without making any sense- was something that reassured him.

Every day that Fernando waited for the train, he would observe the wandering of that poor old devil soaked in liquor and misery, and so his imagination would fly away trying to sort out the details of his doomed

story: he wondered what might have happened to him and how he could help him in some sort.

That morning in May, while he observed from some distance one of those heated rants against invisible (and surely abiding) adversaries, Fernando witnessed something else. That man had decided to add an unexpected twist of fate to his continuous story, an epic conclusion up to the standards of his situation.

All of a sudden, he jumped to the tracks and walked into the tunnel". Obviously, he couldn't expect that instead of a sure death he would find the compassion of another man, just in time to ruin all his plans. That's how, in the suburban garden of rush and heavy faces, a wisp of humanity bloomed, at least for some hours.

From 9,30 to 5 PM, Fernando is an employee in the Candy Workshop at A LA PAR Foundation. In the evening -or whenever his duty calls for him- he becomes... a superhero? A guardian angel? No, Fernando doesn't think he belongs in any of those categories. He sees himself "like a normal person, just like any other guy" although he's spent his whole life hearing that he's "intellectually disabled".

During the months of the lockdown, he turned into a full-time anonymous hero. He couldn't leave home or do any work or even take the underground... and his parents needed him more than ever. So, Fernando Cavero, 43 years old, became the main support for his household and his small family for the most difficult weeks of the pandemic. "We are three brothers, he says. I'm the youngest of all three and the only one who still lives at home, with my father".

His father, still recovering from a recent stroke, went through some critical months. "Lockdown made it impossible for him to go to the Care Center to continue his rehab therapy. That was a hard blow", Fernando admits. That's how, just overnight, father and son found themselves as lonely as

ever, in the middle of the hurricane and with the newscasts announcing every day, everywhere, the breakout of the Apocalypse.

Luckily enough, Fer has steel nerves and a reckless sense of determination. For him, life has always been an obstacle course and this thing, coronavirus, was not going to make a difference for him. He washes his hands, he wears his gloves and his mask and there he goes to the streets, ready to track down his new routine. He does the shopping, rushes to the chemist's, takes out the rubbish... He goes from here to there -focused, self-absorbed, diligent, with his mask up to his eye-brows-fulfilling all his duties without any concessions to euphoria or self-pity. To the contrary, he embraces all this as part of his new everyday life. After all, he needs some hustle now that he can't go to work, he tells himself. All throughout Spain's State of Alarm, Fernando delivers methodically and pulls through all the daily duties and fills the longest hours with large doses of his innate talent: his contagious "good vibes". Usually, it's his workmates at the candy workshop who benefit the most from this outstanding personality. A healing explosion of positive energy that leads systematically to an outbreak of jokes and puns that have earned him everyone's sympathy and the category of non-official showman at the Candy Workshop in the Foundation.

"- A man goes to the chemist's and says "My headaches so bad, do you have anything?"

"No, I feel quite fine, thanks"

Now he knows it's time for him to dedicate his father the best part of his repertoire: "Come on, dad, cheer up! We can't fall apart now in any way, shape or form. We've got to hold on. Daddy! Do you know the story of the

girl who asked her mother: “Mom, can we have a dog for Christmas?” and her mother said “No, we’ll have turkey, as we do every year”

You’ve got to give Fer all the credit in the world for his emotional coaching while the world seemed to collapse outside closed windows: empty streets, masked neighbours, suspicious cops around every corner, shop assistants with sour faces (or should we say just “eyes”?)... Even Fernando hesitates for some seconds when he remembers everything that he had to go through, it’s obvious that there’s no way he would like to put up with all that again.

I let my mind fly too and I briefly surrender to melancholy. How hard it was in those first days to discover the sound of one’s own steps, the unknown flow of one’s own breath through the mask! We suddenly found out that no-one had taught us how to bridle our most primitive impulses, how to stay alert in our safe and comfortable cities. I remember the exact weight of that mortal fear that, like a distant echo of our species, pinched you every time you went outdoors, those suddenly threatening outdoors, just paved with uncertainty and an oppressive silence...

- “I googled how to start a fire, but I didn’t get any matches”

- Fernando! Enough now!...

It was April. It seemed that we were starting to feel “at ease” with the crisis (or so the TV said!) COVID was still hitting hard but we were finally starting to bend the damn curve. However, the ICUs in the whole country were struggling to find a free bed, doctors were still short of equipment and we had 1000 casualties each day. 1000 deaths per day! How cold can figures look from a distance!

The girl who helps with the household chores turns the phone to Fernando: "It's your mother's nursing home".

"Mom had been sick for a long time. He suffered from Parkinson's and Alzheimer's -Fer tells me-. The nursing home where she lived was struck badly by the coronavirus. She left us on April, 25th". I can't help but get emotional at this point of the story, but before I can pity him, Fernando gets back to one piece: It was terrible, but you don't know how lucky we were. We could hold a funeral for her -only six people could go and were distanced from each other- but at least we could do it and give her our good-byes. I feel privileged for that". Fernando and the bright side of life. Sometimes, however, even he feels weak. By May, the weight of so many daily emotions starts to pay its toll. Fernando misses his normal life, his dull and peaceful day after day he enjoyed so much without even knowing and that now seems so far away. He misses above all his friends from the Foundation: "recalling so many funny moments with them relieved me during the lockdown, it was a way of pulling some air in my lungs before fighting back again". Very few people fight like Fernando does, although what he really embraces with a passion -and you should know by now- is telling jokes. "I will have to tell them with a mask on. I see quite a few people not wearing them in the streets and that's utterly irresponsible".

Having lunch with his workmates, sharing anecdotes while they finish off some cakes they've been ordered, talking about nothing in the break time, gossiping in the ear when new visitors come to the workshop... he misses all those simple things but, above all, Fernando misses their smiles when he tells them a good joke. "He still tells them, even on video calls!", admits a workmate... "Yeah, but it's not exactly the same", says Fer with a whine.

A diverse group of people, including men and women of various ethnicities, are shown from the chest up. They are all wearing face masks that feature the national flag of a different country. The flags visible include the United States, United Kingdom, Canada, Turkey, Italy, South Africa, Norway, Australia, Israel, France, India, Brazil, Sweden, Germany, Iran, South Korea, China, Switzerland, Spain, Russia, and the United Arab Emirates. The background is a plain, light gray.





## South Africa

### Michyle's story



Dear World

I want a car, a home, a wife and kids.

Maybe someday, my own business.

This dream never seemed like a reality, but now for the first time, it could be.

I recently got a permanent job as a groundskeeper at a local hospital.

I'm so proud!

At this hospital, they treat people who, like me, have intellectual and developmental disabilities. I have fetal alcohol spectrum disorder and so I never thought I would be able to get such a good job; help support my mom and be able to save money up. People with intellectual and developmental disabilities don't usually get jobs like this.

I want to buy a car for my mom and I, she had to sell hers a few years back when our roof broke. I'm hoping to find an old Toyota Corolla from the '80s, my favourite car from my favourite car brand.



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about the numbers of people dying from COVID 19, it made me feel really depressed.

I feel like it's holding me back.

I don't know how far it will spread.

When will lockdown end? It's really scary because I've seen videos of people being hurt by the army who are here in lockdown.

There are more gangsters in our neighbourhood, they're always standing on the street corners.

I worry about my mother. It's sometimes hard to eat, I feel really nervous. I don't know what I will do without her. She also worries about me, that I'll forget to do the things I need to stop the virus. She reminds me to wash my hands, my clothes, my mask when I get home, even though our work sent me and my colleagues for training.

We're very close, my mom and me. She adopted me when I was three years old after my biological mother passed on. She's looked after me so well for all my life.

Things are bad now in the time of COVID. But her and I, we keep hoping. I have my job, my plans for the future. I take it day by day.

Sincerely,

I want a Future

P.S My Toyota Corolla should be white.

## Wales



## Pete's Story

### **Pete is a member of Advocacy Matters Wales**

Pete is feeling positive about the virus and lockdown. He knows the restrictions will be lifted soon!

He is looking forward to when the Voices Group can get together again and carry on with the work that we do.

He has been doing different things to keep busy.

He spent most of the lockdown with his brother in Devon. He is back in Cardiff now.

He has been sorting out his CD collection.

Pete enjoys watching documentaries about sports and railways.

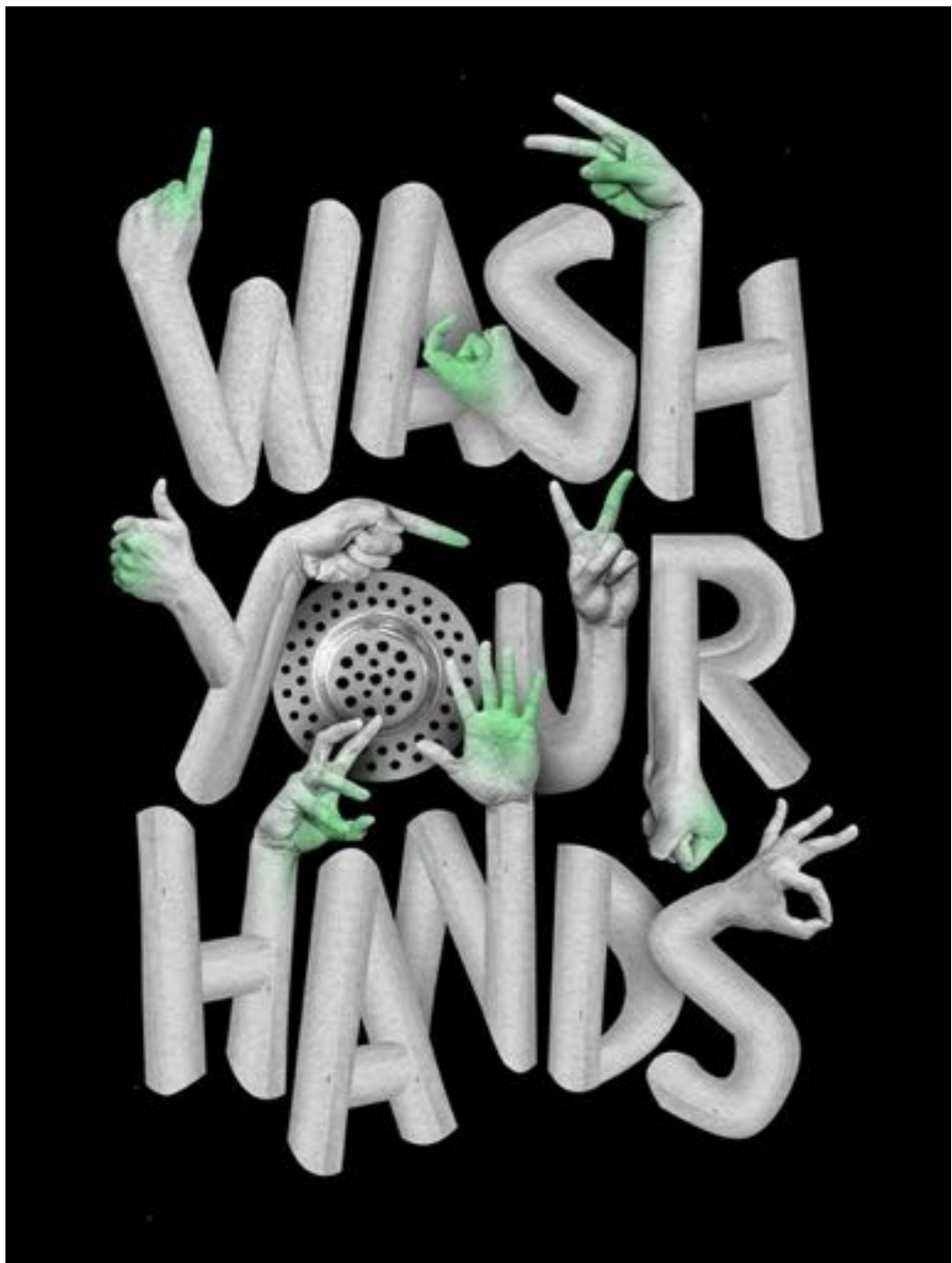
He has managed his shopping by getting his food delivered.

Pete went to town for the first time in ages. He thought the social distancing was being handled very well.

Pete has kept in touch with his friends and family by phone.

The message Pete would like to send out to the world is:

**"Thank you to my care worker for all he's done and to the NHS staff and all the people who have kept us safe!"**



## Shane's Story

Shane is finding Lockdown difficult. He has never known anything like it before. Sometimes it gets on top of him. He battles through and talks to people about how he feels.

He is glad to see things starting to open. He is still being sensible and is careful not to take any chances.

Shane helps at the allotment. He does things like watering the strawberries. It gives him a break from thinking about social distancing.

He is careful not to eat too much junk food. He walks around his local area to keep his weight down.

He plays on Play Station 3.

He plays snooker.

He is writing a list of new games he wants to buy.

The message Shane would like to send to the whole world is:

**"Even though things are easing up, don't take any chances! I hope to see the Voices Group soon!"**



## Janice's Story. Advocacy Matters Wales – Cardiff

Janice is being careful to follow the new rules.

The gym that she just started going to closed due to the lockdown.

She has been enjoying watching quiz shows and doing puzzles on her iPad. Janice loves her soap operas and police dramas.

She also has college work to keep her busy!



Janice and her brother live close to one another, so she buys food for him when she goes shopping. She leaves the shopping on his doorstep then stands back, so they don't have to stand close together.

Janice only goes shopping when she has quite a lot of things to buy.

She is also keeping in touch with her friends and family by phone or face time. Janice thinks the lockdown is strange, but she is happy and just getting on with things.

The message Janice would like to send everyone is:

- Stay positive
- Find things to do, like watching your favourite TV shows
- Keep in touch with friends and family on the phone or talk to your neighbours

Janice had a test for COVID-19. She posted it back one day and then it came back the next day – it was negative.

Janice lives in a keyring type block of flats. They used to have a warden but now they have telehealth – Janice prefers the warden.

She really misses the advocacy matters meetings and looks forward to them starting again.

Janice recently had her annual health check and the GP receptionist was rude to her so reported her to the GP manager. She wants to have the flu jab and a COVID-19 vaccine when it's available. Because she has problems with her immune system she needs as much protection available. Some of her friends keep telling her not to have the vaccine. She doesn't mind them telling her once but then they should stop. It's her decision and it will help keep her safe.

Janice told her that on the Welsh news they have someone using sign language. She asked us if they do that in England – we embarrassingly said no.

She is really looking forward to seeing her friends face to face, going to the bingo and she doesn't mind wearing a mask! It was great for us to meet Janice – who always looks on the bright side of life.

## Adam - My Positive Pandemic Story

Although this story is written as though I'm talking, it has actually been written by my nurse, who knows me well, along with my help and my consent.

Firstly, let me introduce myself; my name is Adam, I am 27 years old and I love computer games, Dr Who, Star Wars and animals, I think I like animals the most and have even volunteered with the RSPCA in the past.

I have a diagnosis of Autistic Spectrum Disorder (ASD), a learning disability, diabetes and have generalised anxiety.

I have been cared for and supported as an inpatient at Ty Lafant, an assessment and treatment unit for adults with learning disabilities and/or mental health problems based in Aneurin Bevan University Health Board for approximately 6 months.

I have been working alongside the staff to find a suitable placement within the community that meets my needs and it is important that it is one that I like.

I wanted to share my story with you as it has been a difficult time for everyone during this pandemic, however in many instances individuals with learning disabilities have been affected the most. This pandemic brings many things with it including, illness, anxiety, isolation, changes in routine, anger and many other upsetting and confusing factors.

I have had first-hand experience of the coronavirus (COVID-19), its worries and affects and I'm happy to share my positive experience.

On the 28<sup>th</sup> of March 2020, I began to feel poorly, and the nurses noticed a change in my presentation as well as cold-like symptoms, which included a persistent cough.

The nurses recorded my physical observations which seemed normal, but they were still concerned about me and contacted the doctor who advised everyone to wear Personal Protective Equipment (PPE) when working with me, I was offered some too.

I had to be isolated from the other in-patients just in case, which meant staying away from the communal areas of the ward. I didn't like this at first and didn't understand why everyone had to wear PPE or why I couldn't see the other patients or visit my family.

I love going for walks, accessing the community to go shopping and seeing my pet dogs at my mother's house; all this had to stop.

The staff were very supportive, they helped me understand why these changes needed to be made, the importance of following the rules set out by the local health board and the government, and they made social scripts for me using easy read information and lots of pictures, which I like. I didn't really like being isolated, but I understood that it was for my safety and the safety of others. The staff at Ty Lafant helped me stay busy and set up an activity room for me to use with some of my items from home.

Later that morning I agreed to let the nurses swab my throat and send the swabs off to the laboratory to test for the virus; the staff kept reassuring me and explained what was going to happen at each step of the procedure, this helped me stay calm.

Over the following few days my symptoms got progressively worse, my temperature was high, and I felt generally unwell. I was supported to access the accident and emergency department to rule out any other health concerns, but everything was okay.

Back at the ward, my swab came back as positive, meaning that I had the coronavirus. The staff and my family were worried about me because I was classed as high risk due to my diabetes and other comorbid conditions.

I had to stay safe and remain isolated for 7 days, the staff supporting me all wore gloves, masks, visors and aprons. I had my meals and medication brought to me, my blood pressure and other physical observations were carried out every 4 hours (even through the night which I didn't like at first!) and I saw the same staff member for the entire shift to minimise any potential cross-infection to others.

At the end of the seven days, I got to access communal areas again and spent a lot of time in the garden with staff enjoying the sunshine and playing games with them. It was really nice to be able to watch television with others and eat my meals with the other patients again.

As my symptoms reduced my physical observations only needed to be recorded once per shift and staff only needed to wear the amber PPE (mask, visor, gloves and an apron) when within two meters of me or when in clinical environments and wore green PPE (mask) the rest of the time, this made me feel happier and less anxious.

Today is the 22<sup>nd</sup> of April 2020, it's almost 3 ½ weeks since my COVID-19 symptoms first appeared and I'm all better and feel fine.

I still miss being able to do the things I'd normally like to do, such as going to the shops and visiting my family, but the staff have helped me shop online and the ward was lucky enough to be donated an electronic tablet so that I can video call my family if I want to.

The moral of my story is that you can be categorised as vulnerable, have other comorbidities or diagnoses that put you at higher risk than others, but with the right support and by following the guidance you can get better.

My name is Adam, I have a learning disability, ASD and other comorbidities, today I found out that a new placement has been found for me; oh! And I beat the coronavirus.





## Rhyanydd Orford (self-advocate in Campaign 4 Change)

Throughout COVID there were lots of unusual circumstances. There've been times where there really has been lots of confusion, lots of information gathering and watching life changing as we knew it before, but luckily for myself, I've had lots of supportive people around, also I had the privilege of living with people I



consider very good friends, and we kind of carried through, whether that's doing gardening, making Tik Tok videos, craft projects, changing the rooms around – you know, keeping the momentum going. And also trying to pick each other up when there were times when we didn't know which direction we were going, because obviously overnight things just kind of stopped. And it's a very big change, but it's promising to see things starting to lift slowly again. There was also a great unity as well when we clapped for the NHS every Thursday at 8 PM to show our appreciation.



Very great to hear the whole community and further. It's been up and down, but everybody pulled together really well.

## Alex Roberts (self-advocate in Campaign 4 Change)



The pandemic has been quite hard. It's been really hard not to see family and friends like I used to. I had to self-isolate for 2 weeks at the beginning of the pandemic. I have been having regular updates from my care manager and recently we have been able to do our own shopping again. I found it quite hard to do my shopping online only and do online banking.

But this has highlighted how we should take advantage of life, because you never know what's around the corner. This will change life as we know it, it will never be the same again. It might be eventually, but it won't be the same until next year, because obviously when you go shopping you have to keep a distance of 2 meters. I went to Tesco and found it quite hard to do my regular shopping. We used to have people going in and out of the aisles in any direction, but it's not like that anymore – it's a one-way system, which I found quite frustrating because I'm not used to it. But the main outcome is, I've started self-defence classes online. I can't wait until this lockdown is over, because I miss seeing people, I miss seeing my mum, I miss seeing my step-dad, my auntie and others. It's been very hard. But the guidelines have been put in place not just for their safety, but for our safety as well, so that COVID doesn't spread. I work for the Conservatives as well, been having regular meetings with them on daily basis, watching the news, seeing when we will be released, following the social care plans they put in place – it's just hard work and, to be honest, I actually broke down mentally because I can't see my mother. And I love

seeing my mother. But the main point I want to say is thank you to the NHS who have been there for people who suffered from COVID-19, and supporting them and making sure that they got the “all clear”. Because COVID isn’t nice.

So I want to say thank you to everyone in the NHS. Thank you very much.



## Chapter Three - Stories from parents and carers

### England



### **Anne Donohoe, Andrew Donohoe's Mum's Story**

I am the mother of a 30-year-old young man called Andrew. His story is in Chapter 1.

I organise his individual support package and his care team. I am also a professional in the world of education and Special Educational Needs and Disabilities (SEND). My mum is nearly 93 years old, lives seven hours drive away, and has Alzheimer's/ Dementia. I organise her care team too. In ordinary times this is challenging. Since January 2020, with COVID-19, the challenge has been intense, for me, and my family.

I say from January as I have lived and worked in Asia and have friends and professional connections there. When the first announcements of a new virus were reaching the UK, I had two Malaysian friends staying with me who arrived at the very end of December. One of my friends is a businessman who had recently visited China. Soon after they left me about 4.1.2020 I became very unwell with flu-like symptoms and a chest infection. After initial unsuccessful treatment by my GP, he ordered Tamiflu and told me to stay at home for 10 days and rest. I recovered but have since wondered whether that was COVID-19.

As I was recovering news of the new virus was gathering pace. I was getting information from Hong Kong and my friends in Malaysia and Singapore. In addition, a very good British friend who is very intelligent



and has a scientific mind, was telling me that this was going to be bad. He knows Andrew. He said I had to prepare now so by the end of January I was beginning to make plans.



Andrew lives in his own flat in a building which has about 7 other residents with challenges who need support. There is a communal lounge and a shared entrance, lift and corridors. There are always staff on site. As I made my plans for Andrew and his team, I consulted the manager of the care team providing support for the other residents in the building. I wanted to dovetail my plans with theirs and be aware of anything they were putting in place so that I could inform his carers and teach Andrew what to do. There were no plans or protocols yet from their organisation. At the beginning of the pandemic, I quickly realised that

there was very little information or support for those with differences and “disabilities”. I decided I would have to do the research myself.

Andrew has Fragile X, a “learning difficulty” with links to Autism, Attention Deficit Disorder, sensory issues and potentially challenging behaviour. To maintain Andrew’s emotional and behavioural stability he has a timetable across the week with Personal Assistants (PAs) to enable him to access activities. This is funded by Direct Payments. It is a very busy and finely tuned programme. Local Social Care representatives have said it is the best programme they have seen. This had taken years to build and put into place. I began to realise that all of this was in jeopardy and everything was going to have to change. The bedrock of Andrew’s existence, his routine and the activities that he loves, were all going to disappear. I began to get very nervous about how he would react and also how much he would understand.

How do you teach a 30-year-old man about a life-threatening pandemic when they can’t add  $2 + 3$ ?

No matter where I looked there was no advice about what to do particularly for people like myself who look after people in their own homes. Below is a copy of an email I sent my son’s social worker after weeks of unanswered emails and phone calls.

24.03.2020

I have been preparing for the current situation for eight weeks or more now. I have been using extra hours to deal with all of the changes that have to be made to keep his care team and Andrew safe.



As I have been unable to speak to you, I am informing you that I will be processing some of these extra hours in the next pay run. Due to a lack of contact, I have no choice but to go ahead with this.

I know these are exceptional circumstances but have tried ringing you on many occasions, your phone mail is often full and as you know I have sent you previous emails which I have not had replies to.

I didn't get a reply.

After more fruitless emails and phone calls, I sent another email with a list of questions that I needed answers to. These ranged from asking where I could get PPE from for Andrew's care team, if there was a bank of emergency carers in case Andrew's team all became infected, to what arrangements Social Care would make if I died and his sister died (the only relatives that Andrew has that could be responsible for his welfare). I said.

"I need specific advice from yourself or a manager in Adult Social Care about how to deal with the Coronavirus as things progress and get worse."

I asked for answers by 4 pm that day.

I got a response. Several of my questions didn't have an answer at all. Below is a selection of typical answers I did receive:

- I can't answer that
- At the moment, all I can advise is that this would be looked into should the need arise.
- I am not able to confirm this as we have not been given this information by the City Council.

- I will need to source advice on this
- This would be explored when the need arises.

It became obvious that there was nothing.

I also realised that I would not be alone. That there would be people in my city who would be in the same position as me, organising a person's care at home for someone funded by Direct Payments with no support, advice or guidelines. Furthermore, it wasn't just a local problem, it was also a national one. At least I also had a professional background in SEND. I have worked with organisations, families, individuals and in the community. My experiences as a mother of a child with learning difficulties have always informed my professional practice and vice versa. I decided to start a coronavirus blog on my website to share information with others. I also decided to publish what my son was doing during lockdown to hopefully give others ideas but also to motivate my son so that he could see the posts and feel that what he was doing was valuable and worthy of sharing. It also gave Andrew another focus and interest to help replace everything around him that was closing down.

<https://annedonohoe.co.uk/new-corona-virus-support>

Then reading "Andrew's Story" please refer to the appropriate posts on my blog to illustrate what he is saying. Andrew was involved in the making of each post that he features in and has learned new skills in the process e.g., being involved in choosing images from a mobile phone app to illustrate films he has made with his Personal Assistants (PAs), being involved in the whole process of making short films from discussing ideas and deciding content to the final editing. He has given his permission for all of these posts to be shared.

Nevertheless, I was very nervous as lockdown approached because Andrew needs to be busy. His behavioural and mental stability can depend on routine, predictability, activity and social contact. He has a timetable of activities over seven days and a rota of staff to support him. He gets anxious about changes in routine. This structure that he has, is built around him and is his safety net. Andrew is a social animal and loves mixing with people and doing things with others. He needs positive feedback even if this is not overt, just sensed. These professionals and others involved in his activities, that he has grown to know and feel confident, comfortable and happy with, help to keep him positive and “up-beat” and to feel safe, secure and cared for. They motivate, help and guide him and contribute to enable him to build his own sense of worth. They acknowledge him as a person, with a personality, feelings and rights. They also notice if he isn’t quite himself and communicate this to his team.

Andrew is a member of a community choir, three drama groups, a music group, a social meet up group and attends two adult art classes, acrylics and watercolours. He goes to the gym three times a week and swimming twice a week. He also loves going out to restaurants, cafés, pubs, the cinema, the theatre, live music gigs and dancing.

Andrew volunteered two mornings a week at a local café for nearly 14 years before they closed down. People visited the café because they knew he was there. He would always greet the customers enthusiastically and would remember the regulars. There was a sense of community, care and sharing.

Andrew loves his activities. There was no way to predict how he would react when they ceased. I feared he might have a complete meltdown and

become very challenging to deal with. This spurred me into action. Below are some key things I did:

In case my mum's carers or my mum got COVID-19 our emergency plan was that my daughter would stay in Plymouth with her brother and take over the organisation of his care. I would have to travel up to Newcastle upon Tyne to be with my mother.

I carefully explained to Andrew about the virus, trying not to over complicate it or frighten him. See the PDF at:

<https://annedonohoe.co.uk/new-corona-virus-support/f/preparation-with-an-individual-to-help-their-understanding>

I contacted his specialist speech and language therapist and we worked on ideas for a personalised social story with visuals. I also sourced other visual information, some of which I had been sent from Asia, other resources from key websites eg:

MENCAP, especially their free Easy read resources.

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

The Fragile X Society,

<https://www.fragilex.org.uk/>

National Autistic Society,

<https://www.autism.org.uk/>

Foundation for People with Learning Disabilities,

<https://www.learningdisabilities.org.uk/learning-disabilities/>

**Gradually some information emerged, but not from the local authority, nor from Government. That was a huge black hole still. It still is.**

I scaled down his care team to three PAs, my daughter and myself to create consistency and to cut down the number of people Andrew was in contact with. We all only saw the people we lived with. I live alone.

I instigated safety protocols at Andrew's flat including keeping his PAs personal possessions and outdoor clothes in a cupboard away from Andrew's belongings, increasing cleaning routines at Andrew's flat, wiping door handles and window handles every day with antibacterial wipes, soaking his sponges and cleaning cloths in Milton and water overnight and washing his clothes after they had been used. I published my protocols on my blog in case they could help others.

<https://annedonohoe.co.uk/new-corona-virus-support/f/preparation-and-guidance-for-parents-and-care-personnel>

Here is some video of Andrew cleaning his handles.

<https://annedonohoe.co.uk/new-corona-virus-support/f/when-i'm-cleaning-handles-reinforcing-clean-and-tidy-means-safe>

Andrew was taught how to wash his hands as advised and how to use hand gel. He carried some with him in his bag. We explained the use of masks to him.

Andrew loves music and singing and so one of his PAs, Lauren, made up a song for them to sing together, "Mr Flexible Is My Name"

<https://annedonohoe.co.uk/new-corona-virus-support/f/song---mr-flexible-is-my-name>

Before lockdown I bought about six large plastic crates with lids. I made activity boxes to help.

<https://annedonohoe.co.uk/new-corona-virus-support/f/preparing-a-whole-range-of-activities-for-isolation-or-lockdown>

I also used this opportunity to contact Andrew's multi-disciplinary Community Learning Disability Team. His psychiatrist did a review of his medications with me which is ongoing to help Andrew not to get too anxious. We did a comprehensive review of Andrew's behaviour with a specialist Positive Behaviour Support Advisor, a Speech and Language Therapist and a Sensory Occupational Therapist (OT). He now has an updated behaviour plan, new visual symbols and a revised sensory assessment (which we did via Zoom with Andrew, the OT, PAs and myself). The sensory assessment resulted in three "Calm Boxes" to help Andrew fill his time. One for Andrew's flat, one for my house and one for his sister's house. All of this was to try and ensure that Andrew remained stable during the pandemic.

Preparing Andrew and his team for the pandemic was a huge task and exhausting and frightening as I felt very much by myself and responsible for the whole team's welfare without any specific body or organisation to turn to, that was giving appropriate, specific advice for myself and others like me. I am very pleased to say that we all stayed well. Andrew coped remarkably and his team did an extraordinary job of caring for him and also making sure he had as much fun as possible. They also supported



me. I must mention Andrew's sister, Rebecca here, who was an exceptional support to Andrew and myself.

Andrew did not have a meltdown at all but got fed up towards the end of lockdown. He also got confused when he saw things starting to open up again about what was available and what was not. For instance, when it was announced that the pubs were to reopen, he said excitedly

"The coronavirus is over!"

Sadly, it is not, and Andrew hasn't been allowed on public transport or in taxis since before the beginning of lockdown. He has now been to pubs if they have outdoor seating, and restaurants and cafes, but rarely inside. He wears masks appropriately with a little help. Sadly, none of his activities have re-started yet face-to-face although some are now online. He is getting used to this and enjoys them. At least he can see some of his friends again. So, Andrew learnt new skills during COVID-19 and uses Zoom and Google Classrooms now with support. We also bought his grandma a Portal and kept in touch with her via video links to that. Another new skill is going running. We had to keep his exercise up as he has a tendency to put on weight easily. But, the whole area of how to manage activities, like drama, for people like Andrew still needs work. There hasn't been enough support and guidance generally about how to restart any activities for people with "special or individual needs". Special Schools have said they haven't been given enough guidance either.

Rather than write in detail here about all the things Andrew did during lockdown and how he coped, please discover them for yourself by looking at my coronavirus blog.

<https://annedonohoe.co.uk/new-corona-virus-support>

You will find many posts here about Andrew during COVID-19 with text, photos and video ranging from “Travel Shows” of different countries made by Andrew with a PA, walks and picnics, an exercise circuit drawn with chalk in the car park, Glastonbury in his flat and a nightclub called Prysm he created on Zoom for an hour every Friday for himself, family and friends throughout lockdown. Andrew celebrated his 30<sup>th</sup> birthday during the height of the virus and we had to cancel his party and have a Zoom party instead. It was actually very good and as it was online it allowed many people to attend who wouldn’t have been able to come, friends from Australia, Spain, Cyprus and the Philippines for instance. There is also a series of blogs called “A Day in the Life of Andrew”. One for every day of the week, which shows what he did each day on a typical day in lockdown. On 10.07.2020 I wrote a post called “Creative Arts Roundtable with Tracy Brabin MP and Luke Pollard MP”. I was involved in a Zoom meeting about the Arts and funding generally. Also, specifically about the Theatre Royal Plymouth which was cutting staff drastically as a result of the virus. The Theatre Royal organises so many classes and activities for people like Andrew. I only hope that there is a way that funding can be found so that these essential services for those with autism, learning differences and other challenges can restart.

On my coronavirus blog, there are also some posts about other young people with challenges that I know, Sam, Ryan, Becky and Emily.

My thanks to them for sharing their stories.

### **Conclusion:**

While writing this an overriding thought became prominent as a parent but also as a carer and a professional. That is, that the situation for people

with autism, learning differences and “disabilities” is just not good enough.

<https://annedonohoe.co.uk/new-corona-virus-support/f/“people-with-learning-disabilities-have-been-forgotten”>

Things may have become much worse in the pandemic, but I would argue it has just highlighted how care, services and facilities for my son Andrew, and so many others like him across the UK, are hanging by a thread. These depend on volunteers, goodwill, and committed professionals who generally are underpaid and overworked for what they do. Funding is hardly ever secure and consistent but perilous, insufficient, delayed and last minute. This makes planning ahead extremely difficult, which despite everyone’s best efforts can affect the quality of the service provided. Sometimes organisations have to try to keep activities and groups going without funding until the result of a bid is known.

Carers are undervalued, underpaid but also don’t have a career structure. They often get the bare minimum of training yet have to organise, check and administer medication and supervise the total wellbeing of individuals. This can involve monitoring their weight, diet, health and general wellbeing, behaviour, sensory needs, language and communication, social interaction, safety and mental health. To do this well you need certain personal qualities and common sense but also good training and an effective support system or a good team behind you.

Andrew’s team of carers is supervised and trained by me although I get everyone to share insights about Andrew and his needs and we learn from each other as well as from Andrew. We communicate all the time in a variety of ways, communication book, a What’s App group, phone calls, email and where possible face-to-face. We used to have face-to-face

meetings but now do this on a joint video call. Andrew and I advertise for, interview and employ the staff ourselves. We choose very carefully. We have been lucky that for over the last 10 years we have had wonderful people who have really added to Andrew's life. They all say that working with Andrew and as part of his team has been an amazing experience personally and professionally.

Since January 2019 I have been fighting for a rise in the rates my local council pays to Andrew's carers through Direct Payments. The skills they have and develop and the dedication I expect from them are worth much more than the National Minimum Wage of £8.72 per hour. Carers' pay rates are not consistent across the country. Other local authorities, like my mother's, pay more than this as standard. This is not fair. So, I continued this fight for better pay for Andrew's staff throughout the pandemic. Finally, on 03.09.2020 I had written confirmation that a rise for Andrew's carers was considered at a "High Cost Panel" on 26.06.2020 and a rise in the hourly rate was granted. I felt very emotional. I didn't know whether to laugh or cry. This had taken me 1 year 8 months.

I have worked professionally with individuals, families and in the community, in mainstream and special schools, with doctors, psychiatrists, psychologists and therapists. Nothing has changed my view. Andrew is lucky. A whole section of people in our country are being ignored and neglected by the Government and all the way through society. There is still so much ignorance about their needs. These people don't often have the voice or the platform to represent themselves or their position. Let us hope this publication helps to change that. People with autism, learning differences and other challenges are currently at risk in all sorts of ways. Their quality of life is often shameful. COVID-19 has highlighted this. How can we sit by and allow this to continue?

If the pandemic has taught us anything, it is that this has to change.

**Anne Donohoe MEd., PGCE, MBPsS, mum, carer and professional.**



## Notes about my brother, Andrew Donohoe and lockdown, by his sister, Rebecca



I think Andrew coped surprisingly well with lockdown. I expected him to be a lot more stressed, but he settled into his new routine very quickly and even wore masks without any fuss. This was because he had lots of new activities to do with his PAs and he has a great relationship with them.

He did start to get a bit fed up as the months went on which is understandable. He's very sociable and missed his friends and activities.

There wasn't much outside support at all. At the beginning, the rules were fairly clear and it was easy for Andrew to follow these. However, after the rules started changing frequently it got more and more confusing for Andrew. When the pubs were opened Andrew said to me 'that's it, lockdown is finished.' He got a little upset and cross when he realised that not everything was safe and open and there were still lots of restrictions in place.

It would have been helpful to have an online portal or a telephone hotline to ask for help with queries about procedures in lockdown. I am sure there are some people in similar situations who also desperately needed respite care, which wasn't available to them.



## Kaye and CJ's Story

CJ is a 52-year-old man who has no hearing or speech, has a learning disability and is on the autistic spectrum. Overall CJ has coped & responded to the COVID-19 crisis very well in respect of the sudden withdrawal of most of his crucial routines that matter to him and his sense of wellbeing with minimal anxiety. The most significant of these routines being eating out for breakfast/ brunch two x weekly. CJ has always preferred his own company and spending time alone on his iPad, so for CJ the lack of day services and remaining at home for significant periods of time without visitors did not cause him any real concern. When we went into lockdown I asked CJ if I could write on his treasured wall diary, and I put a cross through each day he would either not be eating out or going into day services and although obviously perplexed he accepted the changes to his world quite well. I have attempted to ensure CJ still has his weekend breakfast at home but this has caused some issues because I have also been mindful that CJ is not getting any exercise at all, so my attempts to direct him to a more healthy option has always been received with joy and has prompted several aggressive incidents. As CJ's long term one to one carer COVID-19 has forced me into question & debate, what CJ wants.



## Saba and Raana's Story

### Keeping connected during coronavirus

“See you soon”. This message, sent to me by my sister Raana at the start of lockdown in March, was heartbreaking to read. COVID-19 meant, of course, that I would not be seeing my sister anytime soon (she lives in supported living two hours away from me).

Because Raana finds communication tricky, we rely on face-to-face contact to keep in touch – she does not use the phone for voice or video calls, and she prefers to send short sporadic messages. So, from the moment the UK entered lockdown, I knew that if I was to have any meaningful contact with her (beyond communicating through her support staff), I'd have to think creatively.

Which is literally what I did. Raana loves drawing and making so – via some amazing contacts on social media - I spent a few days collecting pictures of bright, uplifting handmade arts and crafts to message her. I ended up with around 50 crowdsourced crafts and art including abstracts, flowers, faces, figures and animals, all made by learning disabled people and their families. I put the homemade treasures into a colourful online gallery which I was able to share with Raana.

Sharing messages with my sister about the gallery and sending her video recordings describing the pieces of art meant that I could keep in touch in a more engaging, visually appealing way.

But it has still been unbelievably tough.

As Raana's regular routine has vanished under lockdown, my family and I have been trying to manage my sister's anxiety from a distance.

And when we do see her, it's bittersweet; our outdoor visits are "facilitated" by staff (who are, by the way, excellent) to ensure social distancing. The general feeling of uncertainty and that learning disabled people were being, yet again, overlooked was reinforced by the government's failure to issue any specific COVID-19 guidance for supported living until August.

Families too have been under enormous strain. A recent social media poll by the charity Sibs (of which I am a trustee) reflects the impact on families: of 117 adults with disabled brothers or sisters, 91 per cent said coronavirus makes their situation as a sibling more challenging.

I have also been worried about the impact of social isolation and change of routine on my sister. There is a risk that the progress Raana has made towards independence will be undermined. More widely, learning disabled people, their families and campaigners have had a hard-won fight for greater rights and visibility – and now, thanks to coronavirus, it is under threat. It is shameful that death rates among learning disabled and autistic people have doubled during coronavirus, and the challenges in getting hold of personal protective equipment and tests are well documented.

Against this challenging backdrop, I try to focus on the good stuff; the fact that I can now meet my sister face-to-face (albeit outdoors for the time being) and the fact that the change of routine has meant she has tried out some new activities that she enjoys (like gardening). Living under the shadow of COVID-19 has also reinforced the incredible role that Raana's support staff play in our lives; we would have been lost without their energy, enthusiasm and positivity.

Being aware of what's working and what's possible, helps me keep some kind of balance through this testing time. I also like to remember my

sister's words on the art gallery I shared with her, created thanks to some creative, keen people and families (most of whom I've never met). I asked her what she thought of the gallery and she sent a characteristically short but accurate message in reply: "that good". And then "very kind".

\* [Saba Salman](#) is a journalist and author of [Made Possible: Stories of success by people with learning disabilities](#)



## Wales



## Dawn and Jack's Story

There was a growing sense of nervous anticipation in the hospital where our learning-disabled, autistic son (age 17 years) was a patient. In the hospital restaurant, coronavirus was the main news item on the large wall-mounted television, and everybody was being told to wash their hands. However, all we could focus on was Jack. It had taken three weeks to get Jack the help he needed and by the time he was blue lighted to the hospital his appendix was so badly perforated he had abdominal sepsis. His small bowel had an obstruction and had attached itself to his appendix. We knew that we had come close to losing our son and all our energies were concentrated on getting him the care he needed to ensure that he made a full recovery.

When Jack returned to his secure residential placement, he had lost so much weight that he was 7 stones, 1lb. Being so underweight meant that he was extremely vulnerable to the coronavirus and infection. We would love to have taken him home, but he was too ill to travel the 105 miles back to Pembrokeshire. Furthermore, we had fought hard to ensure that good care was in place to support Jack's recovery. We would not have been able to have accessed the same support should we have taken Jack out of the residential.

Since Jack had been admitted to the hospital, we had been living in a nearby travel lodge. We had just returned to our home in

Pembrokeshire to wash dirty laundry when we got a call from the residential to say that everything was about to go into lockdown. We were told that since Jack was so unwell, we could come back to the residential for one last visit before the lockdown came into effect. Upon arrival, our temperatures were checked, and we were asked to wash our hands before entering Jack's flat. Perhaps Jack sensed something was wrong because he proceeded to have a full meltdown. After he had calmed, it was soon time to leave. We had no choice but to leave Jack standing in the corridor, clutching his stomach in pain, eyes wide with fear.

Jack struggled being separated from his family and we missed him dreadfully. Jack had only been at the residential a few months when it went into lockdown. He was there because his special school could no longer support him and because no other local alternative provision could be found. Due to his learning disability and autism, he found it very difficult to understand what was happening. Jack had a calendar with future 'Mum and Dad' visits marked on it and suddenly these visits weren't happening. We worked very hard with Jack's staff creating social stories to help Jack understand what the coronavirus was and what it meant in terms of visits. We wanted to help create a new sense of routine for Jack so replaced the 'visits' in the calendar with 'Skype' dates. A common perception is that autistic people prefer online interactions because they can often reduce the emotional and social load experienced in face-to-face interactions. However, Jack has struggled with Skype, often preferring to engage with the camera off or with his face partially hidden.

As the weeks passed, Jack became increasingly distressed at being separated from his family. His language, which has always been echolalic



and repetitive, began to reflect his growing anxiety. He began to repeatedly ask, 'What's around the corner?' And 'Are these scary times we're living in?' We sent Jack 'Mum's' jumper to cuddle and smell, and with the support of his keyworker created a 'family' photo wall for him to enjoy. We also bought Jack a go-kart in the belief that it would be fun and that the exercise would be beneficial for his physical and mental wellbeing. This proved to be a good purchase - Jack has loved spending time on his go-kart.

Weeks turned into months and the missing continued. While on the one hand, it was good that Jack's residential was doing everything that it could to prevent the virus from entering the facility, it came at the cost of the human rights of the individual. Everything felt increasingly institutional, with restrictions on freedoms, visits and an increase in restrictive practices – in Jack's case, supine (floor) holds. Jack's therapy, for example, was suspended, meaning that all work to help him begin to access the community was called off. It was as if Jack was a prisoner. Separation from Jack also meant a loss of control. Before the coronavirus, we could check on Jack at his flat to ensure that his personal needs were being met and that he was happy and safe. During the lockdown, we found ourselves constantly telephoning and emailing to check on whether this or that was okay.

When a standard email from the Marketing and Communications team informed families that they were now able to visit their sons/daughters, but only if they took them off-site, we were determined to challenge the decision on the basis that Jack could not access the community and therefore was being discriminated against. With the support of several learning disability charities across Wales, Pembrokeshire County Council and a Labour Member of the Senedd we managed to bring

about a change to the Albert Heaney guidance relating to care home services, which meant that families could visit their loved ones on site, albeit outdoors in the grounds. This guidance was published in June. A continuing disappointment, however, has been the blanket nature of this guidance which has failed to take into account people's very different needs. For instance, the guidance recommends that visits last around 30 minutes. For someone like Jack, this would be too distressing. Jack needs lots of time to be able to relax and engage. Furthermore, Jack lives 105 miles away-quite a long way to go for a 30-minute visit. Fortunately, Jack's residential has had the foresight to recognise this and has permitted all families hourly visits. Not all residentials may have taken this decision.

At the beginning of August Jack came home for the weekend. The entire visit was risk assessed and meticulously planned. Jack's first words upon entering the house were, 'No more scary times'. At first, we were unsure of each other but soon found ourselves again. Jack told us how much he missed and loved us, and we responded in kind. On one occasion Jack became very distressed, which I believe was a reaction to all the trauma that he had experienced as a result of his illness and then having to go into lockdown. We had fun. We watched Disney films and had an Unbirthday Tea Party in celebration of Jack's favourite Disney film, Alice in Wonderland. We danced and hugged. Then Jack had to go back, and we were pulled apart again. A dislocated family.

Autumn will soon be upon us and we have no idea what this will mean for Jack and our visits. With no change to the care home guidance, how will we continue to meet up outdoors in bad weather? Furthermore, some

residents have struggled with outdoor visits, meaning that they are missing out on quality time spent with their families.

So, what now?

We fear a second wave. We fear being separated at Christmas.

What Jack's story should teach us is that not everyone with a learning disability coped well during the lockdown. Many people with a learning disability have struggled during the coronavirus pandemic. Like Jack, they have struggled to cope with significant changes and loss of routine. Many have had support removed, have been unable to attend the places where they met up with friends or took part in meaningful activities. Bored, anxious, and lonely they became the forgotten.

As we move forwards, we must learn from this and ensure that the support that people with learning disabilities and their families need is there - not just today but for the rest of their lives.

Dawn Cavanagh (Jack's mother, autistic parent).

August 17<sup>th</sup> 2020

## CHAPTER Four Individuals, teams and organisations supporting people with learning disabilities through the virus

### England



### Azeez Interview

Azeez works as a Modern Matron at Atlas House in South East London. Atlas House is a 13-bed inpatient assessment and treatment unit for individuals with learning disabilities, mental health diagnosis and challenging behaviour. We discussed some of the challenges and opportunities for learning and development that the COVID-



19 pandemic has produced for the management, staff and service users.

Azeez was asked what had changed at Atlas House since the start of lockdown and initially discussed the staff absences of up to 14 days as both a logistical and managerial challenge. He explained how a phased return policy was quickly adopted in which staff were encouraged to return to four-hour day shifts initially rather than the usual 14-hour shift. This would then be extended to five-hour shifts on their second and third day back before reintroducing them to their typical pattern of working if they

felt ready. As well as those who fell directly ill the management team had to be responsive to staff shielding or on carer leave, and he explained how managers would check in with these colleagues regularly to ensure they continued to feel part of the team. Azeez said that during staff meetings this new policy had been discussed at length and staff reported that it helped them to regain energy and feel supported. Further protocols were required to ensure that Atlas House was able to keep its staff and service users safe in line with social distancing protocols: changing clothing before and after their shift, provision of additional PPE and alcohol gel, relaxing security procedures to enable leaving the ward through the back door and reducing the capacity of the multidisciplinary team (MDT). office and staffroom. As well as these protocols which were actively in place throughout the pandemic other plans were put in place which as of yet have not been needed – for example, the use of the self-contained “flat 5” between the communal ward areas as a potential flat for a service user showing symptoms. In terms of access to the community for service users, Azeez described how site walks and staff going to shops on behalf of service users had become the only plausible option. He said that this was initially managed on a daily basis, but since the changes in policy for people with autism and learning disabilities they had extended this to several walks a day. Throughout lockdown the ward had been closed to families and external professionals but at the time of the interview, these restrictions were beginning to ease. However, the protocol still dictated no more than one family to visit a day for up to 90 minutes, families were encouraged to bring their own PPE but would be provided with some if they were unable to do so. Finally, we discussed the new responsibility of the shift coordinator to check the temperature of each staff member once a day and service user twice a day.

Next Azeez was asked about the response of staff and service users to these changes which he believed had been very positive in general. For the service user's information regarding the restrictions was presented in an accessible format which staff went through with patients. Due to the communication difficulties of some service users, Azeez reported that it had been difficult to assess the full extent of their comprehension of these changes, however, he argued there hadn't been any issues to date. There had been no complaints about reduced community access and service users were reportedly happy to wear masks when driving in the ward car when prompted. Azeez believed the two iPads that the ward had been provided by Oxleas NHS Foundation Trust had played a part in this, by enabling service users to have continued contact to their loved ones and alleviate some of their worries. In terms of Atlas House staff, Azeez reported positive feedback in team meetings and claimed the phased return policy was welcomed by staff who saw it as supportive and considerate. Due to the lower than usual number of service users currently residing at the unit, there were sufficient staff to accommodate these changes and resources were provided on the Oxleas internal intranet site for those who had experienced the virus. He finally commended senior staff for leading by example and modelling good practice throughout this trying time.

We then discussed the impact that the pandemic has had on service user engagement and interaction. Azeez reported that initially, things were very stressful as constantly changing government guidelines made group work and most 1:1 work impossible. He was concerned initially that Atlas House's residents were bored but admired the creativity of the staff team in finding ways to engage and interact with them. Wii games, table tennis, table football, the garden and the outdoor gym have been valuable outlets



for the service users. Some therapy staff continued to attend in person to facilitate these activities, while others including art and music therapy staff sent suggestions remotely to be carried out in person on the ward.

The interview took place at the point where restrictions were beginning to be relaxed and when asked what was likely to change at Atlas House Azeez's first response was allowing visitors. He acknowledged the impact that being separated from family and friends for between three and four months had on some service users and was very pleased to be able to reunite service users with their loved ones. His next priority was a gradual reintroduction of the regular ward timetable including specialist individual and group sessions and community outings. Providing the best treatment possible would ensure that discharges could run smoothly and Azeez welcomed the return of this structure. As well as families coming in, he discussed the return of external professionals who often come to Atlas House for Care Programme Approach (CPA) and Care & Treatment Review (CTR) meetings, which have taken place remotely throughout lockdown. Azeez discussed this as one of the major changes he anticipated in the aftermath of the pandemic, as for some service users or their families who lived a long way away geographically these meetings were the first that they were able to directly engage with. Depending on the timeline for the easing of restrictions Azeez anticipated meetings to continue in this manner for some time, and potentially to be used permanently in some instances to ensure the voices of family members can be heard.

When asked what he was proudest of during the pandemic Azeez responded with the resilience, commitment and dedication of the staff

team and the ongoing support they have given to Atlas House' service users. He claimed that this period has led to a greater acknowledgement of the commitment of junior staff by their managerial counterparts and believed that it had brought the staff team together as people shared experiences and empathised with one another. He was also very pleased to report that no physical intervention or restraint had been necessary to date throughout these changes. He was also very pleased to have had the opportunity to celebrate learning disability week in the garden of the local TOPS Day Service. All of Atlas House's service users attended this event, where they spent several hours eating, drinking and socialising with compliance with Social Distancing and wearing of PPE equipment.



## Jim Blair Interview

Jim Blair works for NHS England / Improvement as an Independent Clinical Reviewer undertaking Care and Treatment Reviews with and for people with learning disabilities in community and assessment and treatment services, also practices as an Independent Consultant Nurse in Learning Disabilities assisting services to enhance and evolve the care they provide across primary, acute



and community health and care settings. Jim is also Associate Professor (Hon) of learning disabilities and the Learning Disability Advisor at the States of Guernsey's Health and Social Care Board. He has worked as a Consultant Nurse Learning Disabilities at St. George's Hospital and Great Ormond Street Hospital and as a Specialist Clinical Advisor for the CQC. When asked how he has personally been during the COVID-19 pandemic Jim described a strange new world where London has become a ghost town and we rely on screens rather than having genuine face to face interactions. He described the shift of a large amount of his work to online platforms including attending Care and Treatment Reviews over Zoom or Microsoft Teams. He described this as a very positive experience on the whole as you can really see an individual in the context of their setting. It

is great that these reviews could take place, but they are not as good as on-site visits.

Next we discussed his work as a learning disability nurse and how he has been supporting other members of the profession throughout the pandemic. Jim had been heavily involved in the promotion of 'books beyond words' easy read materials throughout the pandemic, which he was highly complimentary of. He also discussed trying to ensure suffering is minimised for both staff and service users by asking difficult questions, for example, what is going on with PPE and how can we care plan to ensure inpatients retain contact with families and friends through technology.

Jim mentioned both positives and negatives in terms of the government's response to COVID-19 for people with learning disabilities. In the early days of lockdown there was a level playing field in terms of people's experiences, although many people with learning disabilities have experienced isolation as many of their friends are paid staff. On the positive side he discussed how undertaking care and treatment reviews virtually have been very positive for some service users who find face to face interaction in a meeting difficult or anxiety provoking. They were able to send pre-recorded video messages in order to get their voices heard at meetings where in past they may have been intimidated by a large group of well-meaning but unfamiliar professionals. Jim described the need to be dexterous with our planning moving forward and ensure that the needs of the specific individual are considered. The major criticism of the government's handling of the crisis has been in terms of communication and muddled information. Jim also criticised the reliance on the written word to communicate these messages to people with communication and comprehension difficulties when images can say more and be easier to

understand. Although pictures are often labelled 'patronising' Jim made the point that we don't feel patronised when we see images on safety cards for aeroplanes and transport networks including the London Underground or the motorway. He praised the work of books beyond words whose materials have emerged quickly and can be used to explore fears and questions during lockdown but criticised the fact that these hadn't been the product of central government policy but the work of charity organisations.

We then talked about the impact of COVID-19 on the Learning Disabilities Mortality Review (LeDer) programme which Jim agreed was very important. He argued that there should be more specific training for those undertaking these investigations, and that it should be a specific role or a designated professional's responsibility rather than an add on or afterthought. He urged those involved to drill down into the details as this was the only way of making effective systemic change and believed that there should be additional COVID-specific investigation into the higher rates of death of people with learning disabilities.

Jim Celebrated Learning Disability week by showcasing and shining a light on people's talent. People need to tune into the individual's frequency and see them as a person rather than just in terms of their challenges or issues. Examples of this kind of practice during the pandemic include City Lit's class for life and the use of books beyond words for people with varying levels of communication and comprehension. He counted himself lucky to have been able to celebrate directly with people with learning disabilities, some of whom he considers close personal friends. Friendship is key and he described how these friendships have been formative learning experiences both for himself and for those with Learning Disabilities he supports.

When asked about the way that restrictions on freedom of movement and assembly were communicated Jim replied that they had been poor at a national level. He believed messaging hadn't been as consistent or tight as it should have been but commended the work of the learning disability community to build an accessible network of information. COVID passports were created to help people understand what was going on and what it all meant, but Jim repeatedly emphasised that these should have been coming from the centre not the third sector. He acknowledged that this unprecedented situation was a huge challenge for the government but argued they could have made messaging clearer as the impersonal and confusing daily briefings were watched by those with learning disabilities with increasing anxiety and distress by a service user he knows personally. This individual would watch the news constantly and become more anxious as he was unable to understand it. Jim said that he was able to eventually manage some of the anxieties, with support from his carers, by watching the news just once a day.

When asked about potential changes in societal attitudes towards people with learning disabilities as a result of the pandemic, Jim argued this can only be concluded retrospectively. He claimed we need to learn from the data collected in terms of mortality and other factors but recognised that the fact that learning disability week took place during the pandemic may have helped awareness. He spoke of the changes he has observed within the world of learning disabilities in his career and argued that things appeared to be moving forward, although time will tell if these produce systemic change or are short-lived.



Jim argued the government's response to support BAME individuals and people with learning disabilities had been poor. Although the government faced an unprecedented situation, they found it difficult to tune into specific demographic differences, for example that BAME individuals are more vulnerable to respiratory, cardiac and diabetic conditions. Similarly, people with Learning Disabilities experience disproportionately high rates of respiratory difficulties, which was not recognised in the governmental response. We then discussed other issues which have disproportionately affected those with learning disabilities, which included the fact that many support worker staff with close personal relationships to service users were put on the furlough scheme. Jim acknowledged the difficulties faced by organisations who were struggling to stay afloat but argued that the focus should have been adjusted more quickly. He commended the changes that were made to regulations on daily exercise but argued that they weren't quick enough which would have made things difficult for individuals with sensory processing difficulties.

Jim was then asked if he thought the voices of people with learning disabilities being heard at a government level, within national organisations like NHS England and Mencap, or within Local Authorities or Local NHS trusts. His answer to each was "no". He argued that local advocacy groups and care providers had potentially allowed these individuals voices to be heard but preferred to phrase it differently. Jim argued that we need to get away from coproduction as an idea as this inherently implies two separate entities are involved in all organisational efforts. He argued a fusion approach was the future, saying he would always give talks and presentations alongside an individual with learning disabilities or one of their family members. That way you have them there to hold you to account for what you say and make sure that you are

representing them accurately and fairly. Jim asked why there wasn't a greater representation of people with learning disabilities at all levels of society: MP's, Local Councillors, co-national directors, governors on NHS Trusts, porters, in post rooms, clinic areas or in kitchens. He argued visibility of people with learning disabilities empowers them as a group within society, and that "getting people involved in work that has real value helps to shape a new culture in which inclusion is taken as a given". His goal was societal transformation, and he told a story about an event he presented at with an individual with Learning Disabilities named Lloyd to illustrate this point. Lloyd asked Jim to tell his story on his behalf, but Jim encouraged him to speak up for himself and get his voice heard. After being empowered to do so Lloyd overcame his initial hesitation to be very confident and grew and learned from the experience. Lloyd was used to having other people speaking for him, but Jim enabled him to retake control over this aspect of his life. Jim discussed the campaign nothing about me without me but argued it seemed just to be rhetoric at present.

Jim shared some positive stories from the past few months, including the transition of a project he is involved in called 'class for life' from a physical to a virtual platform. He described difficulties in the first few sessions as people were getting used to the technology but argued that some have really enjoyed the new platform, particularly for those for whom travel is an issue. He argued that things that we have learned from the pandemic will enhance people's lives, suggesting for example that perhaps some elements of annual health checks could take place remotely with the support of a familiar carer to reduce stress and anxiety. They may be able to attend for a shorter or more specific period of time, while the triage process may also be enhanced by newly developed technologies. While practitioners will need to continue to be creative in this respect, many

technological solutions now exist. Jim anticipates that this may lead to a shift of thinking from what someone can't do to what they can with assessments of their ability rather than their deficiency.

Discussing the international response to COVID-19 specifically in relation to people with learning disabilities, Jim anticipated that there would be significant regional variation. Although increased levels of social isolation are likely to be a common experience, he anticipates that the speed and nature of governmental response to have varied. He recognised that finances and resources available will vary but stressed that it is not just a case of finance but how well staff are supported. He hopes that some of the positive technological experiences will have occurred internationally, but also recognised the different perceptions of disability in different societies and how this may have impacted on people with learning disability's experience.

Finally, Jim was asked what his proudest achievement was in his decades advocating for people with learning disabilities on a national and international stage. He responded that his ultimate ambition is to ensure that people with learning disabilities have their rights and are more engaged and involved in decisions about their lives. However, his proudest achievement was having friends with learning disabilities, and he stressed that these aren't one-way relationships where they learn from him, but transactional ones where they learn from each other. He has enjoyed writing and publishing with people with Learning Disabilities and helping them to feel positive about an interaction. His key message was to tune in to what the person is really saying. To the naked eye, salt looks like sugar so you really have to get the individual personally, avoid jumping to conclusions and the blinding force of diagnostic

overshadowing. He hopes that this is something he has achieved this to some degree within his professional career and is incredibly proud of it.

Jim's passion for people with learning disabilities shone through during the interview, he spoke passionately as an advocate, a friend and an ally. The interview was still clearly on his mind in the subsequent days as he reached out to me by text to offer to share his personal experiences of being diagnosed with COVID and discussing the care sector. He asked me to add that he would like to see parity between the care sector and the NHS going forward, as this was evidently not effectively managed as illustrated by shortcomings in PPE and COVID-testing. He also stated that there must be an urgent review into the increased mortality rates for people with Learning Disability during the pandemic, which he emphasised must result in action and not rhetoric.



## Jeanette Gallivan

Jeanette is Commissioning and Inclusion Officer at East Sussex County Council. She supports the Involvement Matters Team (IMT). IMT is the reference group for people with learning disabilities in East Sussex. provide guidance and advice on learning disability.

‘This has all been a whirlwind. We’ve never experienced anything like this before. It impacts on everyone no matter who you are. It doesn’t matter who you are, no-one is immune. People have had to come together to support one another which has created community cohesion. None of us knew how to be, or what comes next.’



‘Over time I’ve gotten used to how things are now and there is a degree of comfort, safe in this new bubble. It’s been a testing time at home with everyone here (husband and children). We have had to navigate new relationships and boundaries.’

‘At the start of the year, I don’t think I appreciated the impact that COVID19 would have. I didn’t realise it would go on for months. Before lockdown I

started to realise the urgency and fetched my son from University two days beforehand.’ As the weeks went by and the death toll grew, I really understood how serious this all was.’

‘Early in lockdown I found myself constantly thinking and overthinking, ruminating on what may happen. I also found other people, for example in the supermarket, made me feel stressy.’

‘It took me some time to get the balance right between working at home and the other parts of my life. I was working quite a lot. I think I’m getting the balance right now. I’ve been even busier during lockdown and I’ve had to adapt to not being able to meet people face-to-face. IMT meet more now, once a week, online, however, meeting online doesn’t work for everyone in the group. Some don’t want to meet online while others have found it difficult to access the technology. IMT also has a text group now and I make regular phone calls to group members. This enables me to help and support group members where I can.’

‘I have found that I have spent a lot of time creating easy-read materials to help people with learning disabilities in the local area understand what is going on. However, things change very quickly so I’ve had to stay on top of all of that.’

‘I missed the connections with other people, and it felt like groundhog day for a while. As things have started to ease, I’ve become excited by the new freedoms but also anxious about leaving my bubble. I’ve missed going shopping with my daughter and I’ve missed being at work.’



‘I’ve learnt a lot during lockdown. I think I would have gotten into a routine earlier on and made sure that I created clearer boundaries between work and home life. I’ve also learnt that working from home full-time is not for me. I miss the contact with others and the informal



chats with colleagues. A real positive to come of all of this though is that I do more regular exercise, which I do with my daughter. Overall, I coped better than expected, I found some structure. I think though that if I had known it would go on for months and months I might have panicked!’

‘I think what has been clear is that people with learning disabilities were not necessarily finding out or at least processing information at the same time as everyone else did. Information should be more accessible so that people with learning disabilities can understand what is going on when they need to.’

# SYMPTOMS OF COVID-19: SHORTNESS OF BREATH

## A SHORTNESS OF BREATH

This means you are finding  
it difficult to get air into  
your lungs.



Source: World Health Organization

## **Jenny's Story - SPICE – Life in Lockdown.**

Written by Jenny Neville from conversations with Daniel Docherty, Delwyn Lord, John Cullen & Stevan MacDonald.

SPICE is a group of people with lived experience employed by Future Directions CIC as 'Experts by Experience'. Since Lockdown the group have been staying in touch by having weekly zoom meetings. I asked the group how they have found lockdown; they all agreed that it has been hard. Daniel said that he's found it "depressing and repetitive – I'm doing the same thing every day". He went on to say that it's not helped his mental health and he's missed seeing his friends and doing things that he enjoys. John also said that it's been hard, and he's missed not being able to see his family and friends. He recently became an uncle and although his sister has sent him some photos of the baby, he's missed not being able to see her. Stevan and Delwyn also agreed that not being able to see friends has been the hardest thing about lockdown. Everyone said that they missed each other and can't wait to get back together and start working again. Daniel, Delwyn and John have all had birthdays during lockdown and Stevan's 50<sup>th</sup> birthday is coming up in September. He's hoping to have a party to celebrate. Initially he wanted to go to the pub but is now hoping to have a party and barbeque in his garden instead. Daniel said that he's used to being busy and he's missed working with SPICE and Pathways Associates, and the day centre that he used to go to has been closed so he's missed going there. Delwyn, John and Stevan also said that they miss working with SPICE and going to Salford University. Everyone said that they haven't been going out much. Delwyn has been "going to the park and the shops but that's about it". He said that he's not been spending any money so is saving up for

when he can go out again. Abby, another member of SPICE, made a jar that she puts 10p in every day until the virus goes away and she can spend it. We all agree this is a good idea. John said that he's been going out with his mask on, he's been on the bus and tram and has been out shopping and walking. He said that he sits on his own and keeps to himself. Stevan has been out in the car with his staff and has been going out for walks. Everyone said that they have enjoyed keeping in touch with each other through zoom. We have had weekly meetings and done quizzes, sang songs, and chatted with one another. Daniel doesn't use zoom and he feels that he's missing out, but he keeps in touch with people through Facebook and Messenger. He said that "I love Facebook during lockdown because I can keep in touch with my friends and other people I know. I think Facebook has been a lifeline to me." He has made up some groups on Facebook about things he enjoys such as Harry Potter and Transport and has invited his friends so he can chat to them. This has been a good thing. Everyone is now looking forward to getting back to normal, although people are worried about when this will happen. John said that he is a bit anxious about the future and can't wait to get "back to normal". They said they wanted to do something together when lockdown is over. Everyone agreed that a party or a meal out would be a good idea.



## Pippa Richardson interviews apprentices with learning disabilities and autism during COVID-19 about their experiences



The apprentices are all from Dynamic Training UK, which specialises in working with individuals aged 16 - 24 with an EHCP (Education Health and Care Plan) and is written in their own words. This is written in the words of the learners with learning disability and/or autism.

### **Introducing you to the Apprentices who gave their time:**

**Mr A** - Inclusive Apprentice – Business and Administrator Level 2 Framework. Mr A carried on working throughout, based from home. He does not have a job coach but is supported by a support worker and his employer. Mr A continued to work on apprenticeship supported by his Skills and Development Coach and his employer.

**Mr B** - Inclusive Apprentice – Business and Administrator Level 3 Apprenticeship Standard. Mr B carried on working throughout, based from home. He does not have a job coach, however Mr B continued to work on apprenticeship supported by his Skills and Development Coach and his employer. Mr B completed his apprenticeship standard at the end of July 2020. He has successfully passed his apprenticeship standard with a Distinction.

**Mr C** - Inclusive Apprentice – Adult Care Worker L2 Apprenticeship Standard. Mr C carried on working throughout in his workplace. His job coach was furloughed, however Mr C continued to work on apprenticeship supported by his Skills and Development Coach.

**Miss D** - Inclusive Apprentice – Level 2 Diploma Early Years Practitioner Framework. Miss D was furloughed. Her job coach was also furloughed, however Miss D continued to work at home on apprenticeship supported by her Skills and Development Coach.

**Miss E** - Inclusive Apprentice – Level 2 Certificate for Children and Young People's Workforce Framework. Miss E was furloughed. Her job coach was also furloughed, however Miss E continued to work at home on apprenticeship supported by her Skills and Development Coach.

### **Coronavirus is also known as COVID-19. What do you know about Coronavirus/COVID-19?**

**Mr A** - I know that it is a virus of sorts spread through physical contact, attacks immune systems. Attacks respiratory systems. It has claimed the lives of many. Keep your distance, don't touch anyone, isolation, wash your hands, soap.

**Mr B** - Coronavirus spreads through the air and can contaminate people, if people have a weaker body, like elderly, can kill people. I don't know too much about how it works, I only know how to avoid it. Until recently, was not engaged in seeing others actively as it could pass COVID onto others, also using facemasks, and always hand sanitiser and washing hands, and wiping you get as it may have COVID.

### **What about public transport? what do you wear?**

A mask. You have to wear a mask if you go into a supermarket or shop.

**Mr C** - Disease, can get it from touching from other people and if not 2 metres away you get it and you can die from it, it spread from people to someone else. Have a bath every time I can, I go out. Wash my hands more than 30 seconds and more than a couple of times every day and wash hands when you touch food. Clean worktop and something.



**Miss D** - It's like a bug but this one is more difficult to have a cure and it is all in the air and it's not a very nice virus. Wash hands with soap and water if you are out and no hand soap use hand sanitiser and wear a mask. On buses, trains and in cabs wear a mask.

**Mr E** - Coronavirus – people in hospitals, people are dying, illness, loads of people are dying, some are recovering, you have to isolate yourself for 14 days, self-isolation, you can't mix with your family members. You can't do your daily things, you have to cover your face on a bus, sitting two metres away from people. When you wear a face mask you feel alienated.

NHS people are doing a lot, they can't do so much if people do not stay and home

### **How has Coronavirus/COVID-19 made you feel?**

**Mr A** -- It hasn't made me feel different, but I don't want to go out, Have you been out? - yes been out.

**Mr B** – It's made me feel a bit more concerned as I have to be careful, so I don't bring COVID into my own home. Also, the high incidence of death in other countries.

**Mr C** - A bit nervous, anyone from care homes is likely to get COVID-19 more.

**Mr D** - So many mixed emotions, agitated stuck indoors all the time, a bit upset and you can't go out all the time, and can get a bit angry with family as you are stuck with them every day in the house. Feeling a bit claustrophobic as stuck in my bedroom and at times nowhere else to go. I sometimes can manage this and distract myself. When I am not managing, me and my brother have arguments with each other.

He has autism as he gets angry and frustrated, he plays with his Xbox and mates. I am playing games on my Xbox and catching up with course work

and talking to other family on video calls and phone calls. It has been a really bad year with the coronavirus

**Miss E** - Made me feel upset for other people, sad for others that they can't

**Mr B** - do, if you have got, sitting at home, can't see your family, makes me upset for others, you can't do your normal things, sitting, you can't go to work, you have to sit in one room, it can depress a person, you know. From my perspective, it makes me sad. If they have it they can't talk to people and that is more sad. This can affect their mental health. We can go out with a mask but what about those people who are affected by it, they have to sit isolated and not see their family as they don't want to put their family at risk.

### **How do you deal with feeling sad?**

I try not to think about it, try to occupy myself maybe distract myself other activities and keep myself busy.

### **How has Coronavirus/COVID-19 changed your daily work life?**

**Mr A** -It has made it so that work colleagues stay in their homes to avoid the COVID-19 pandemic.

Travelled to work in a taxi, do you miss going into the office? Yes, I miss going into the office. Do you know when you will be able to go back to the office?

My manager – explained the numbers of staff going to the office, only one person in a lift at a time. The council are keeping number low to people who can't work from home. Where employees can work at home, they will. My manager suggested meeting in a team get together to meet up at a safe distance. Mr A's team has a daily 09.30 team meeting, colleagues- 'it has been really nice'.

**Mr B** - has restricted my daily work life as I was going to the office to work, my tasks are all to be done at the office, so I am not doing any of the

work that I was doing which was: setting up rooms for training and scanning documents. Now based at home at not working as all the documents I would scan were confidential that I cannot do at home. They are keeping me on as an apprentice during this time, (so I am not furloughed but working through apprenticeship work and being paid as an apprentice.

**Mr C** - I have to wear a mask every time I go into work and then and wash my hands more times through the day.

They do not move me so still working with residents. Lots of fun.

**Mr D** - Not getting up early has been very difficult, keep sleeping through the morning so I am trying to get up early to get my routine back.

**Mr E** - Basically, now due to this COVID-19, trying to keep occupied, when will I start and when will I go back to work?... instead of thinking about it, I go for a walk. I cannot put people at risk.

### **Do you have contact with the manager?**

The children centres – they can't call the family in, due to everyone mixing and children mixing, the children centres are still closed. The manager calls me once per month.

### **How has Coronavirus/COVID-19 changed your apprenticeship?**

**Mr A** - It has changed my apprenticeship quite a lot, as I can't physically go into work and have to work from home.

**Mr B** - cannot go to the office, to complete tasks that I can only do at work, being at home has allowed me to focus more on the apprenticeship tasks that I have been given, and all meetings I have are through Zoom and Microsoft teams and before coronavirus, my Skills and Development Coach would come into the office (meet face 2 face).

**Mr C** - It takes longer to complete coursework because my job coach can't come inside my care home. My Skills and Development Coach and I, we do the course work on Zoom.

**Mr - D** I am at home learning. When I am at work, I learn more, as new things happen at home to learn from. I used to meet my Skills and Development Coach face to face and a big change is that we meet on Zoom. Do you like Zoom? I like the sessions but would be easier in person as things can go wrong on the computer!

**Miss E** - Before, I used to meet my Skills and Development Coach in the library and now the change for me is we meet on Zoom. I am learning new skills and my tutor does different activities using Zoom, a different way but fun for doing my activities opens your eyes to different things, there is lots of technology and apps out there. I am enjoying it actually; it is really different, and I am having lots of fun. My Skills and Development Coach is lots of fun, gives me insight into my coursework.

### **What support have you received from your Skills and Development Coach? Mr A**

**Mr A** - I have received a lot of good support and they have helped me a lot during this epidemic.

My Skills and Development Coach support and the service where I work, they have given me advice and helping to stay on task.

If my Skills and Development Coach sends work, emailed work, set work ERR workbook.

### **How did your Skills and Development Coach support you with this?**

**Mr A** - ERR – employment rights and responsibilities, she told me what I had to do, explaining some of the words meant, power points and handouts, also for maths using BT bitesize. If I needed help, I could

email My Skills and Development Coach.

I am fine with Zoom, email or calls.

**Mr B** - My Skills and Development Coach has given me support by me emailing her the work that I have been doing, we have sessions as we did before but have them on Zoom or Microsoft teams.

**Mr C** - We do Zoom meetings every three weeks.

**Miss D** - My Skills and Development Coach has helped me if I have got confused, she will explain in a different way for me to understand it. We go through the work and look at which bits that I need to work on more. My Mum uses Zoom, so I also learnt from my Mum, sometimes I help my Mum with Zoom.

**Miss E** - Lots, supported me so much with coursework and apprenticeship, thankfully, you know, I don't know where I would be without my Skills and Development Coach, she is really good.

Different activities, explains very well, and then demonstrates stuff. Explains the task very well so I understand it.

### **Did you meet your tutor/my Skills and Development Coach face to face before Coronavirus/COVID-19?**

**Miss A** - I met my Skills and Development Coach face to face before the whole COVID-19 epidemic.

Now it is using Microsoft teams (MST) – it was weird at first now becoming more normal.

### **How did you tutor/my Skills and Development Coach support you to use Zoom/Teams?**

**Miss A** - Yes, all helped me using MST, as I did not use it all and I had quite a lot of trouble with it,

How do you find it now? s, I can use MST really well.

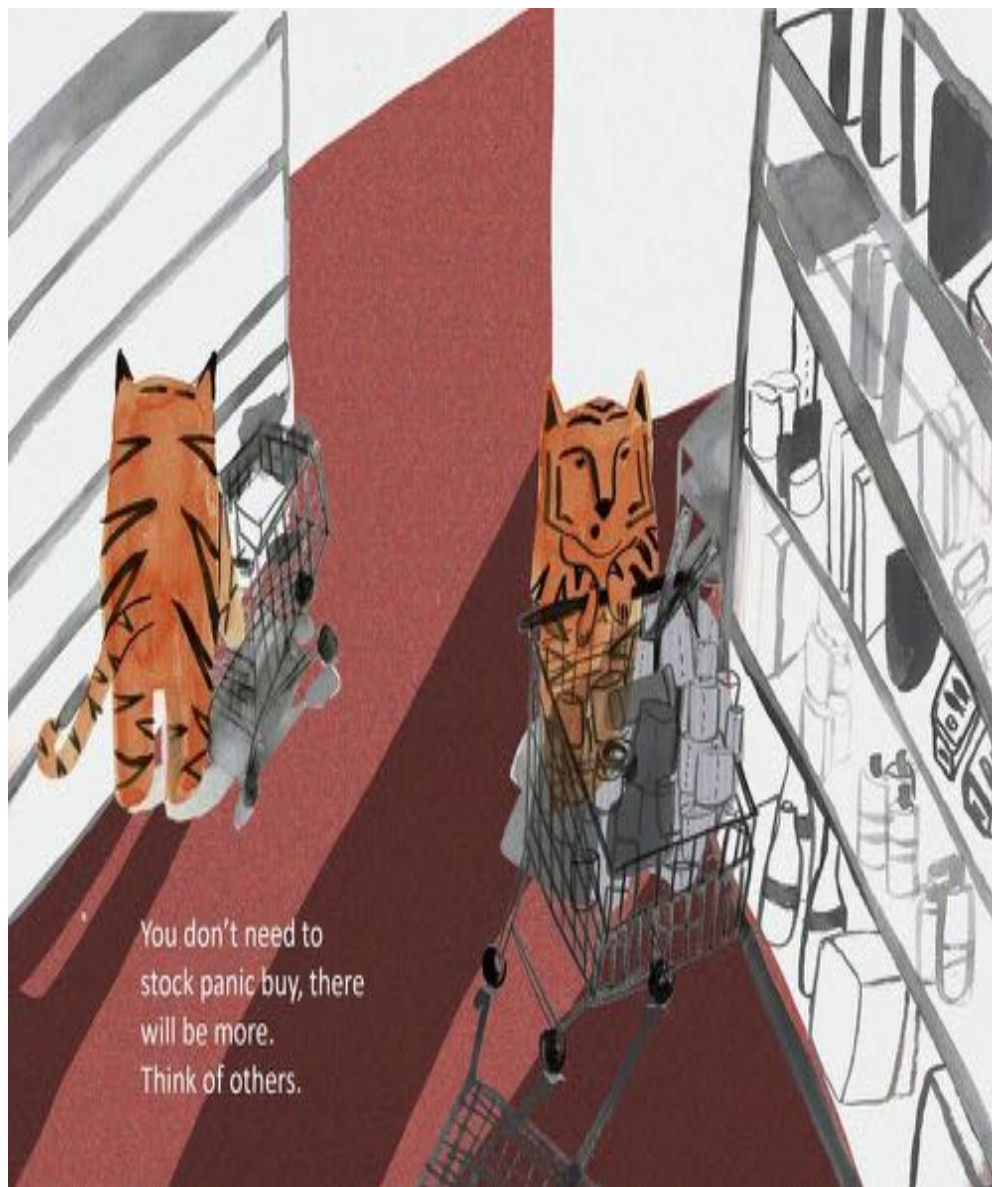
**Miss C** - Zoom

**Did you meet your tutor/my Skills and Development Coach face to face before Coronavirus/COVID-19?**

**Miss D** Yes and on Zoom (for follow ups)

**Did you meet your tutor/my Skills and Development Coach face to face before Coronavirus/COVID-19?**

**Miss E** - Yes, previous my Skills and Development Coach, but CH on Zoom. We had 'phone calls and now I am OK on Zoom, I struggle with the camera, but worked through it.





## **Ben McCay My life during lockdown**

### **My Name is Ben McCay, I am Co-Chair of the trustees at My Life My Choice.**

In response to government coronavirus advice, the Jobs and money team which I am part of decided all current My Life My Choice activities/projects/services will be suspended for the time being. Which made me feel depressed as I did not know when I was going to see anyone again. We decided that My Life My Choice will offer a telephone, social media, and mail out service to all 600+ members in order to provide Coronavirus information and support. My Life My Choice have constantly sent myself and the members updates in easy read otherwise I with the rest of the members, would not understand what was happening with coronavirus along with activities to do at home. So I would not feel so lonely at the begin of the lockdown I start to ring up my life my choice members to see how they were coping with the lockdown which I enjoy doing it was nice to be able to speak to someone as it would be the only person I spoke to some days. One of my friends is a DJ and he set up a group on Facebook so that could play music to his friends I enjoyed listening to music and chatting to everybody. Other things I have been doing to keep myself busy are playing games on my Wii and watching DVDs and TV.

In May my auntie died of coronavirus and my best friend was ill with coronavirus for six weeks before he recovered and it left me upset, depressed and frightened so I decided I would buy my own facemasks which I did online and delivered to my house which I now wear when I go and do my food shopping once a week. My sister has been very kind and caring since lockdown started, she rings me once a week, has sent me

food shopping and DVDs by online delivery and she helps me and my niece playing online games together.

At beginning of May, the Jobs and Money team wanted to start meeting again, we now meet online once a week. In the middle of May and beginning of June I was in the local Newspaper I wanted to help shine the spotlight on deaths of people with learning disabilities due to coronavirus and I was keen to put out a call for prioritisation for vaccines and I mentioned all this on the local Radio station in June as well.

When the government announced that someone living on their own can form a social bubble with another family. My sister phoned me to ask if I would like to form a bubble with her family, which I have agreed to. I have been twice to see my sister and her family. With my sister driving down to pick me up and taking me back. I have really appreciated it was lovely being in close contact with my family again it gave me a break from me been on my own so much.

In June we had our first trustee meeting online which I chaired It was a great success this was then followed up by first champions group meeting online which I am part off they do all charities campaign, the main topic at the moment is of course coronavirus/COVID19. My local my life my choice self-Advocacy group start in June online. It was nice to see members I have not seen since before lockdown started.

Since lockdown started, I have been doing more online shopping have been buying batteries for my Wii, toothbrush heads for my electric toothbrush. New clothes and trainers I needed along with ink and paper to print off the agenda and meeting notes to help me chair my monthly trustee's meeting it has been easier than flicking between screens.

In July I had my first visit to the town centre since lockdown started. I needed a haircut, so my destination was the local barbers I use. Which reopened the first weekend in July. I do not feel safe yet to use public transport. I decided I would take a slow walk into the town centre and avoid all the busy main roads so I would meet less people and so I could socially distance with safety. When I got to the barbers, I put on my face mask and washed my hands with the hand gel provided I then sat in the barber's chair and had a disposable gown put around me then barber cut my hair. When the barber had finished, I got up out of the chair and went to the till where I paid for my haircut. I was then asked to write down my name and contact phone number so the barbers to contact me if someone had coronavirus when I was in the barbers that day and I would need to self-isolate for fourteens days. I then left the barbers washing my hands with my own hand gel after I left and took a slow walk back home the way, I came.



Before



After!

In July, I was interview by BBC South Today at my house. I said how lonely I was feeling. The only contact I have with people is online or people ringing me up on my mobile phone. The members keep on asking me when are we are going back to the office but the government advice is still to work from home if you can. I mention how conflicting government

information is for people with learning disabilities. How everything has been left up to self-advocacy groups to help people with learning disabilities understanding what is happening during the crisis and stop them feeling so lonely. This I month I have decided to join online as many of my life my choice groups self-advocacy groups as I can. I am looking forward to seeing members I know well and members I have not met before.

I will not feel one hundred per cent safe to do all the things I did before coronavirus until I have had the Vaccine.



## Nicola Payne's Story - Life changes overnight

If you don't listen to the news or have headlines alerting every 5 minutes on your mobile phone, life can feel calm and safe and you can just get on with your everyday tasks and routines.

This is the way many people supported at MacIntyre live their lives, feeling safe and knowing that life as we know it is not a bad place and we just get on.

Like many, I was just bobbing along when, like a big dark rain cloud, coronavirus came into our lives. Not really understanding the severity of what was to come, tuning into the daily news updates hearing more and more and starting to fully understand the enormity of the impact this virus was going to have on the world and of course, the people supported at MacIntyre and our staff teams.

Support at MacIntyre has been amazing and so consistent: we all pulled together and didn't want to leave anyone behind. There was a plan in place - which sometimes changed daily - but never once did I feel or witness our senior teams panic. This was reassuring and made me believe that we could get through this; it makes such a difference working in a team in times like this.

My role at MacIntyre is office based so at the beginning of COVID-19 I did feel a bit useless, not being hands on, wanting to pull up my sleeves and do whatever I could. I had to think of how I could still feel like I was helping in these strange times. So, I made contact with some teams and offered to be on the end of my phone if anyone supported needed a person to talk to. Well, it didn't take long before I received a call from a lady who sounded extremely anxious. Alice\* introduced herself and said, "I hope

you don't mind me calling?" so I quickly reassured Alice that she could call whenever she needed.

Life had changed overnight for Alice\*: she usually led an active, jam-packed life made up from college days, visiting family, eating out and visiting her local beach. Like many, all our lives changed overnight, and part of my job now was to make sure Alice had a place to share her feelings.

We spent many hours talking about COVID-19; the government; the daily news briefings at 5 pm; how we planned to digest the new changes that we were having to adhere to; how they impacted on Alice's life; what we could do to keep well and calm - and of course patient - as life as we knew it had changed, and we didn't know when it was going to go back to "normal" and if it ever would!

The daily calls from Alice would vary. I would pick up the phone to hear laughter, sadness, frustration, confusion and fear. We would never say that these feelings were wrong, or that you should not be feeling this way: the expression "we're only human" was used a lot. Time spent reflecting helped: planning for when life could go back to the way we once knew and making a visual jar of future dreams really helped take Alice's mind off the everyday news.

A few months passed and calls became less frequent and I knew that the easing of restrictions would be having a positive impact on Alice.

One Friday afternoon, and I was slowly working my way towards the weekend, Alice's name flashed up on my phone. I hadn't heard from Alice for a few weeks: when I answered Alice was so excited to tell me that she



had been swimming in the sea (a past-time she loves) and had plans to see her Grandfather and lunch at her favourite café. Life as Alice once knew it was slowly returning to normal. Alice understood that this could change again, but for now was going to embrace what she loved safely. Alice knows that COVID-19 is still in our world and knows that I am just a phone call away when she needs advice or just a listening ear.

I know from our conversations that Alice is a strong lady; she loves her routine but has learned that she can be flexible, patient and that she can see light at the end of the tunnel.

Coronavirus has taught me so much and changes that I will keep with me forever. I have been lucky to meet a lovely person in this pandemic who taught me so much too.



\* name changed

## Reflective correspondence during COVID 19

Daniel and Karmelle

### Introduction

What follows is a reflective correspondence between myself and Karmelle Maslen – Pre-Registration MSc Learning Disability Nursing student. At the time of the lockdown, Karmelle and I were engaged in a module on assessment and care planning with people with learning disabilities. This module comes halfway into the first year of the Pre-Registration MSc programme and is the opportunity for the students to identify and articulate the unique contribution that Registered Learning Disability Nurses can make to the lives of people with learning disabilities, their families, and professionals that might support them.

Compared with the other fields of nursing – Adult, Mental Health, Child and Learning Disabilities- our field is small; however, comparisons are not a useful indicator of value. Each year we welcome cohorts of people from all backgrounds that have been touched by the lives of individuals with learning disabilities, and we wave goodbye to a group for caring clinicians and erudite activists, who are enthusiastic to explore how they may change the world through creating inclusive communities with people with learning disabilities. Kingston University is not unique in that regard, there are five universities around London doing the same, and many more across the UK and Ireland, all passionate about ensuring that the nurses that graduate from their organisations enable people with learning disabilities live healthy safe and fulfilled lives.

*Written in April 2020*

This past six weeks we have seen remarkable changes to our lives, that has brought a disease causing death and destruction, disrupting all our

lives to minimise the impact on those we believed would be most vulnerable, the old, those with multimorbidity, and of particular concern – people with learning disabilities and their families.

**Daniel:** On Sunday 1<sup>st</sup> March, I stood on a central London street, in amongst a crowd of 16000 others waiting for the start of a half marathon. The banter that usually bounces relating to the weather, trainers, tips for injuries and the like, focussed this time on only one subject the virus and the consequences for our shared pastime. Several asked why was the event taking place in the face of such risk, as a nurse, I reflected for a moment of the significance of being there for me, my family and the thousands of other people whose lives were about to change.

**Karmelle:** I have greatly enjoyed University and the learning which we have received. All the lectures and workshops have been stimulating and I feel very lucky to be attending the number one University for Nursing in London. Having worked with people with learning disabilities as Placements Officer over the last ten years I chose Kingston University as I wished to expand my knowledge in life and grow further. I knew deep down that my role would be to care, to help and enable people to have a quality of life better.

The nursing cohort I joined is very friendly and warm, I didn't feel that anybody was excluded at all. Student life was enjoyable and there was plenty of lively discussion in the classroom, sharing of learning, ideas and many practical skills.

**Daniel:** As the news chugged along about the storm from the east blowing towards us, day to day activity to educate the next generation of nursing felt ever more prescient, while the traditional practices of classroom discussions and debate appeared less and less viable. Having used video

conferencing software to a greater or lesser success for some years, adapting classroom sessions to make the best use of this software appeared to be a practical way forward. It also became a necessity as guest lecturer contacted me to advise that - as a parent carer of a daughter with Down's syndrome who had experience of acute respiratory illness, that she would not be visiting the University and could we make use of video conference to ensure the students were not disadvantaged by her absence.

In discussions with the cohort, that one significant reason for their selecting this mode of study related to the interactions and intellectual stimulation of learning with others. As such it was planned for the module schedule to remain the same but move into the Video Conferencing software acknowledging that family life and further disruptions may also impact on their ability to attend, as such the sessions would be recorded for viewing at a later point.

**Karmelle:** Now, due to the impact of Coronavirus and the Pandemic, the library is closed, and we cannot attend University, however we are still having our class lectures in our own homes, using a Zoom. For all of us, this software was rather strange at first and we felt rather out of our comfort zones and uncomfortable. Some people could not connect however we are now all managing to connect, and we are quickly getting used to it.

The experience for me is not as relaxed as a classroom setting would be. There are times when everybody wants to contribute and share ideas and everybody speaks up at once, yet only one person can be heard on Zoom at a time. I imagine that this probably causes some issues for the lecturer who must manage these contributions.

**Daniel:** Teaching offers a significant amount of freedom to create, guide and facilitate learning, and while I had what I had assumed to be transferable skills from other online social media activity, I had not been prepared for the challenges of transferring classroom materials to an online environment and the issues this might create for lecturers and learners alike. Adam's (2011 see figure 1) model for learning a new skill, as we – students and lecturers developed our awareness of our incompetence at making the use of this learning environment

Figure 1 Adaptation of Adam's (2011) four stages of learning a new skill including Howell's (1982) fifth stage, applied to the transition from classroom based activity to online teaching on an MSc module.



It perhaps should have been expected that the social norms in this new environment might be best negotiated with new ground rules. In the virtual world, this might be about maintaining mute, until asked to contribute directly, to use a symbol to show the speaker that they wish to contribute.

Rewa & Hunter (2020) makes the observation that the medium of – laptops, tablets, phones – for this online teaching are multitasking tools and as such we need to be mindful to focus on the subject matter of the classroom time, will mean switching off alerts, notifications and interfering software applications.

**Karmelle:** One advantage of using Video Conferencing, is that the students who are quieter or shyer in a classroom setting may find it easier to share on Zoom when speaking within the comfort of their own homes. I have noticed that some students who were quieter in the classroom, speak more in the virtual environment.

**Daniel:** Teaching and learning from one home to another, in some cases bedrooms can blur the professional and personal roles that can create role dissonances and conflict, particularly when we had guest lecturers such as people with learning disabilities and family carers.

**Karmelle:** The main thing that is missing for me is camaraderie and relationships that cannot be built in the same way online as face to face. As a group of five students, I felt that ourselves and our tutors have bonded as a group, however this now feels more remote. We still get on well, however sometimes connection is lost and sometimes students cannot appear on video screen. The camera is switched off which makes it harder to connect properly as they are just a voice.

**Daniel:** One tool that some VC software's offer are breakout rooms, this has enabled smaller groups to work entirely separate from each other, in a way that would be difficult to replicate in a classroom. While this doesn't resolve the perceived distance of other students, a shared task that can be attended to somewhat independently provides a focus on the activity,



and the learners develop a more heightened awareness of their own and colleagues' attributes and areas for development.

**Karmelle:** Another issue may be delivery of my formative assessment, this was an online presentation of my assessment of a case scenario, a young man called Carlos who had Fragile X syndrome, who's recent unstable epilepsy was posing a risk to his ability to manage independently. I presented my plan to utilise the Moulster and Griffiths Learning Disability Nursing model (2019) to help me identify the strategy for supporting Carlos. Presenting this via screen share them and speak as the slides are delivered on video and it will be very different to a normal presentation. However, all the knowledge can still be shared this way as it can in a demonstration.

**Daniel:** Nursing is a profession that is predicated on good communication, and that this move to online assessment has tested students and academics alike to further adapt these skills. What has been clear from Community Learning Disability Nursing practice is that infection risks have been reduced through using this video conferencing software's, as such it is entirely appropriate to have students develop these skills while in a teaching and learning setting. In 2021 we have plans for the formative assessment to a face to face community assessment with actors from Baked Bean Company, depending on the conditions at that point, it's entirely possible this could be taken into an online environment.

*Postscript dated 5<sup>th</sup> August 2020*

**Daniel:** As lockdown has eased, it is positive to reflect that Karmelle and her colleagues all successfully completed their assessments for this module. Teaching and learning have continued in the online world with new and exciting technologies being tested, enabling academics to have

more autonomy over the learning environment. Plans for the new academic year remain in flux, however shorter chunks of online delivery are planned with more scaffolded independent activity, reserving synchronous – sessions where all students and lecturers are working together at the same time- teaching opportunities for discussion and debate on understanding and learning.

**Karmelle:** A unique set of circumstances seem to arise when lecturers are teaching a smaller cohort such as a cohort of Learning Disability Nurses. While students have greater time and opportunity for bespoke support from the lecturers, this can also bring its own pressures to be engaged, to respond and to be right or at least not be wrong! As such students can be quieter and the conversation must be led a great deal by the lecturer, who needs to encourage students to contribute and speak up, this in turn puts pressure on the lecturers. In addition, I wonder whether students are more reluctant to attend lectures in which face to face interaction and communication are required. In the wake of the pandemic, passive learning seems to be preferred by students and appears to be a more successful form of delivery.

**Daniel:** It is clear that some future generations of Learning Disability Nurses will likely have reduced opportunities to wrestle with the concepts in a traditional way in classrooms in the presence of others, however there are examples from online education organisations that show that the challenge of preparing nurses for the future health and care environment is not insurmountable.

**Karmelle:** To summarise, I believe the pandemic could have affected the learning experience of student nurses in a number of adverse ways, but with resilience, we have begun to organically adapt to the changing

circumstances and do things differently. We still have the vital sense of bonding and camaraderie that is essential to working with families and other professionals as we are still meeting and corresponding via WhatsApp. Our cohort has had regular meetings with our tutor weekly and when the library re-opens a group of myself and other student nurses from a variety of fields will be meeting in the University again. One vital issue to consider is that of an inequality which has arisen due to the socio-demographics of students. Some may have issues such as childcare or low incomes due to the pandemic and these issues may impact upon their university performance, giving rise to a potential ethical dilemma, of whether marks should be mitigated or not due to the impact of the pandemic

**Daniel:** In the life of a Registered Learning Disability Nurse the subject of inequalities plays a significant role based on -amongst other things -the high proportion of premature deaths (Helsop et al, 2013), and continued reduced life expectancy (LeDeR Team, 2019) of the people with whom we work. The pandemic - along with other contemporary issues- have offered ample opportunity to reflect on the structural inequalities in our systems, just one of these being the digital poverty (Holmes & Burgess, 2020) that some students might find themselves in and how we can attend to this in a way that mitigates this disadvantage.

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# Novel Coronavirus COVID-19

FOR HEALTHCARE FACILITY STAFF

## *Coping with stress*



**It is normal to feel sad, stressed, or overwhelmed during a crisis**



**Talk to people you trust or a counsellor**



**Maintain a healthy lifestyle: proper diet, sleep, exercise and social contacts with friends and family**

**Don't use alcohol, smoking or other drugs to deal with your emotions**



**If you have concerns, talk with your supervisor, and if you start feeling unwell tell your doctor immediately**



## Mark Topp's Story (Care Leader)

As I look back over the last few months it is hard to imagine some of the struggles I have faced to ensure the safety and wellbeing of the residents I support. As I start to write this, memories are flashing back, and I know it is going to sound like something from a fiction film.

My earliest memory is my phone pinging with messages in a WhatsApp group talking about the virus news in China. If I am honest, I hadn't read or seen anything, but I thought I better check it out. I spent the next two days reading articles from Australia and China and talking to other friends working in care about what they are thinking. I remember reading one article about a mass spread in a care home in Spain and it made me decide what would become the norm for over a hundred days! We went into lockdown.

I remember phoning family and friends of my residents, cancelling appointments and home visits and having to explain and reassure them this was for the best, but at the same time not really knowing if it was, whether I needed to in fact go into lockdown and to be completely honest not really having a clue what I was doing. Life as we all knew it in the care home stopped! My residents were supported to go out, two, three and sometimes more per day and suddenly they couldn't go out the front door.

I spent the rest of that week juggling and collating the information on the news, social media and fellow social care managers to pass onto my staff team and to create easy read posters and guides for my residents so I could explain what was happening to them, keep them updated and



reassured. Our lovely front door area turned from pot plants and flowers to a foot dip and an army regime to ensure we were disinfected as we entered and left the home.

The next couple of weeks I spent battling various elements. First the food shortages started, our regular weekly slot with a local supermarket was cancelled by them and we were left like everyone else in the country trying to get hold of food supplies. There was no support from the local authority, and we had no priorities in the queues for weeks to begin with. I remember perfecting a route over a few weeks from work to my house to maximise food supplies. I would leave work, go to the local coop, drive to the next town to their Co-op and then onto Tesco, drive down the road to Sainsbury's and then down the motorway home stopping at my local Tesco, Sainsbury's and the village Co-op. I would then do this route back to work the next day. At the very worst I had to use the village page on Facebook to beg for supplies of food and milk. I was going multiple times a day due to the limit on items you could purchase to get enough but as much as I was getting in, it was just being used and going... trying to feed thirteen people on empty shelves and items limited to two or three per shop is bloody hard work! I am incredibly grateful to the village for their support getting us through that hard time, and in particular to one supermarket guy who donated us enough milk for a month. I won't name him, but if he ever reads this please know I am so thankful and grateful!

As the food situation got under control with my new perfected route, staff and my director doing food shops, I was growing aware the whole time of the lack of PPE and this was highlighted even more when I had a service user begin to display symptoms and having to self-isolate them in their room. Encouraging someone who never usually stays in their room not come out is incredibly hard, although it was easy in comparison to what

was to come with the lack of support from local authorities, public health and the local Clinical Commissioning Group (CCG). I reported the symptoms and my concerns about how we didn't have enough PPE to last us for the period he would self-isolate, but no one called me back and no replied to emails. To be honest I was angry at how someone could be just left and how no one was supporting the staff to be safe. The next few days I spent time buying overalls, masks and goggles from anywhere I could get hold of them whilst chasing for support which never came! Looking after someone who you don't know if they have the virus or not, with concerns of if you will have PPE to see you through is terrifying and I spent time reassuring staff it would be okay and putting on a front whilst secretly being so worried about taking an invisible virus back home to my wife and children. I had told the staff after we had seen many media reports of lack of PPE that if it came to it, I would support the residents with no PPE. My wife and I decided it would be best for her and the children to move out of the family home due to the risk of me bringing anything home. My life changed at that point... I remember packing their bags, tears rolling down my face explaining to my children who were far too young on reflection about how daddy would be going away to help people stay safe from the virus and having no answers to their questions. How long would they be gone from me? Who would help me stay safe if I got the virus? Would I see them for their birthday? Would I be back for Easter? I just grabbed and hugged them tight and told them to make sure they looked after each other, kept mummy safe and were good for their granny and papa! I told them to go get on their shoes as I gave my wife a long goodbye cuddle and then helped them to pack the car and stood and waved goodbye whilst inside my heart broke into a million pieces. For the rest of the

pandemic and as I write this for over 100 days, I have only had contact with them via video calls and writing and posting letters.

My resident isolated for 14 days, in that time no reply to any emails and no phone calls back to support but on reflection this opened my eyes to what would happen if the virus actually entered and I knew as a home we were alone in the fight and I bulk ordered masks, gloves, aprons, gowns as and when I could. What had been a stressful 14 days became a COVID lesson in disguise and touch wood from then to now, I have had enough PPE to last!

The next few weeks I spent time out of the office doing my normal day job to spending it on the floor. As a staff team we made a pact we would make the days fun and lively and we spent the days singing, dancing, gardening, colouring in, doing arts and crafts, having water fights, playing hide and seek and one fond memory I hold was spending Easter in the care home, hiding over 100 Easter Eggs for the staff and residents to search for. On reflection I cherish those memories as some of the best I have had whilst working in social care and whilst the world on the outside had stopped, life on the inside was joyous and a delight.

I wish I could end my COVID story on this high, but sadly a daily briefing left what would become one of the biggest moments of my COVID story. I was sat in the garden, sun shining listening to the daily briefing and it was dedicated to social care and testing was announced. Finally, I remember thinking, daily testing for residents and staff was long overdue. I had seen various news reports and spoken to a number of managers who had lost residents to the virus and it was scary to think of the impact on those families not being able to say goodbye, those residents living in those services and the mental health of both the residents and the staff. I

logged onto the testing portal the day it was opened but was met with an error message, I didn't really take in what it was saying and just phoned the helpline which wouldn't connect. I tried again but the number wouldn't work. I left it for the day thinking it was the first day and perhaps it was overloaded with people registering so left it and tried again the next day. I got the same error message, this time I took more notice of what it said. It was telling me that tests were only for those over 65 years old and those with dementia. What happened next, I cannot fully recall. I remember being so angry that the test wasn't for everyone.

The more I thought about it and the more I spoke to people, the more annoyed I found myself. Who had made the decision not to test people with a learning disability and/or autism, who decides who should have a test and who shouldn't and why should some care staff working in parts of the sector be tested and in other parts not? I logged into change.org and created a petition. I used the next couple of weeks to speak to any news outlets, radio presenters and used social media to promote the petition, speaking to anyone who would listen and help me in getting the word out there. Throughout my campaign, it was never about the test itself, but it was about the human rights of those I supported and many others in care services. I felt strongly that many people living with a learning disability did not choose to be in the care system, so why should they be penalised and denied a test, why should someone with a disability not be tested when someone else living in another care home could be and I continued to promote the campaign.

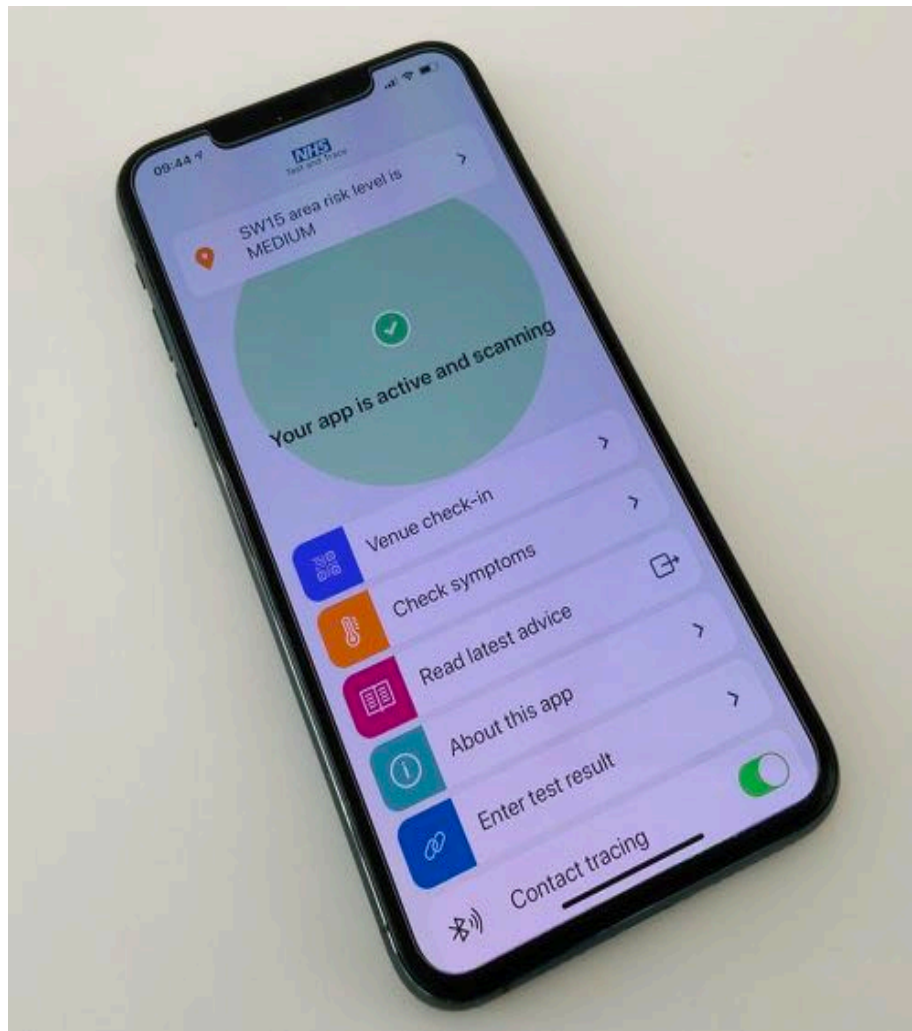
I was approached by carehome.co.uk to feature in an article about the campaign, talk about the discrimination for those not eligible for testing

and it went viral being shared nearly 14,000 times in a few day and the article became the main focus of many reports and started the much needed conversation about testing and my petition quickly amassed over 400,000 signatures. The next few days flew by, with so many tweets being reshared and seeing people talking about testing and backing the campaign was amazing! The government announced testing for those living with a learning disability a few weeks later which was amazing news.

The petition is still live as those living with a learning disability and/or autism still cannot get re-testing and knowing that every person that reads a tweet or a Facebook post or sees the petition is one more person we educate about how in 2020 there was still so much injustice to those living with a disability and highlights how much further we as a society need to work to tackle this injustice.

For now, I am currently continuing to keep the atmosphere within the care home positive. We go out every day for a walk around the village and lucky that we have so many different animals to spot on our journey, including horses, goats, geese, alpacas and chickens. We are planning next week to open the home to visitors in the garden and to return to some kind of normality in August. The journey of COVID has been long and tiring and has bought emotions of sadness, laughter, fun and anxiety. I do not feel we are anywhere out of the woods at the moment, but I hope once we get on the home straight, we look back, reflect on what went wrong, look forward and reform social care.

For me, I will continue to fight for those living with a learning disability and/or autism to be accepted by society and ensure they are given equal chances and opportunities.





## **Lindsay's Story Year of the Nurse and Midwife**

In January it looked like it was all happening elsewhere, there were conflicting messages and I was watching what was happening in Wuhan and then Italy and hoped if it came here and the government would act and do something to prevent it being the same.

In February It started getting closer to home, notices were being put up in the gym I go to and at work. There was a lot of guidance about washing our hands (whilst singing "Happy Birthday" twice), fit testing of masks started, it was starting to feel more real. I wondered about my role, would I be able to see people, we talked about it a lot, we were waiting for government advice. We work with very vulnerable people and were keeping up to date.

It really hit in mid-March, I had a patient on my caseload who was admitted to A&E, no cough or temperature, he was lying on his bed with abdominal pain, not eating and drinking, the carers spoke to his GP and I, we decided to call an ambulance. I thought they would do some tests and he would be sent back home; this was on a Thursday and I came back to work on Monday to find he was in Intensive Care Unit (ICU) and on a ventilator.

He had Down's syndrome, he was in his early 60s – he was admitted before the criteria were decided about ventilation and a frailty scales came into use, but he tragically passed away two weeks after being admitted. I feel that he was given every fighting chance and treated in the same way as anyone else. However, it was a very sobering and tragic event.

We started making provisions for working from home, there was talk of some of us being redeployed to support inpatient services. I work in the

community and along with my community colleagues, was put on standby to support cover sickness in the learning disability inpatient wards, although we did not need to be redeployed in the end.

I started to do banks shifts to cover sickness on acute mental health and dementia inpatient wards. Unfortunately, some patients on these wards were lost to COVID-19 as well as staff being off sick. It was a very emotional time.

Usually we are based within offices at a hospital, and we have a clinic area there as well, where patients are usually brought in to be seen face to face by clinicians. I regularly visit patients in their own home and to monitor their progress and support them in their usual environments. Of course, when lockdown happened it was no longer safe to bring people into the clinic or to visit them at home unless there was clinical urgency.

We needed to keep the number of staff working in the office down to maintain social distancing, so there was a lot more working from home. We started trying to find innovative ways to stay in touch with patients. Not all the patients have the technology and some needed help setting up or needed carers to help them.

Usually we would also see patients face to face in the clinic at the hospital, however, this had to stop. We were doing appointments over the phone and video calling. We were also sending out resources via post, which ranged from information about the virus in easy read format to help people with learning disabilities understand lockdown. Some also required advice on how to cope with all the changes, and how to keep themselves stimulated and occupied at home.

Reactions to lockdown amongst the people we support were varied. Some people coped exceptionally well and some even embraced the extra time

they spent at home and pursuing their interests at home. Unfortunately, some people struggled and were not sure why they could not see their family or friends and their structured activities and routines were suddenly gone. We needed to look at new ways to support people to keep in contact and find structure and routine at home. This included sending out activity packs or getting in touch with their friends via Zoom who live in other homes.

As professionals we kept in touch via video call, which helped provide reassurance, ensuring that their wellbeing was maintained but also gave others an opportunity to talk to someone else outside their home.

Within our team we considered which of the people we work with were most vulnerable, either due to risk factors for catching COVID-19 or how they may cope with lockdown. We implemented a traffic light system (green, amber & red), this was to help our colleagues know who to contact and how often, should one of us go off sick or be redeployed to another service. This helped my colleagues when I needed time off after my own Mum passed away from the virus in April.

There is a lady on my caseload who survived COVID-19. When they are in hospital, I would usually visit my patients face to face, of course during the pandemic this was not possible. This happened at the height of the pandemic, and I found myself liaising via telephone a lot with the hospital. I remember telling staff at the hospital what her usual presentation is (independently mobile, friendly, alert) and making sure that she was not being judged purely on how she appears when unwell. I found myself raising concerns such as around appropriate use of Do not attempt cardiopulmonary resuscitation (DNACPR), in this case “learning disability” was put on the paperwork and it was changed because learning disability

is not a clinical reason for DNACPR and decision should be based on her clinical presentation. A frailty scale was starting to be used to make decisions about ceiling of care, and there were questions raised about its use in people with learning disabilities on a national level, which I also raised concerns about and made sure that those using the scale were aware of her usual presentation.

Fortunately, she did survive, despite the fact she had been close to palliative care and her recovery took a long time. When she was due to leave the acute hospital, there were questions raised about whether she was a candidate for rehabilitation, and I along with other professionals from my team including physiotherapists argued that she should be given the chance. She went to a rehabilitation ward before returning home. It took over 3 months, but she is looking much more like her old self again and has made an amazing recovery.

I can understand that difficult decisions had to be made, especially at the height of this pandemic. The battles faced by those with learning disabilities and those supporting them were confounded by COVID-19 and it's important we do not lose sight of the inequalities often faced.

As lockdown is easing, I've noticed that things have been getting busier for my team. The effects of lockdown have started to take their toll, months down the line. People who had been discharged in the last couple of years have started to be re-referred due to the stresses of lockdown and anxieties around the virus.

There was a bit of a quiet time, especially at the height of the pandemic when the acute hospitals were busy, I was calling people asking if there is anything we can do. I think as well, there was a feeling that people didn't want to bother the NHS at that time, but it is getting busier now.

Outside of my usual role I found myself working on a dementia ward (bank shifts) where a significant number of patients had been diagnosed with COVID-19. I found myself putting people on oxygen, which I had not done for a while, barrier nursing people who are confused and distressed in their own rooms, liaising with duty doctors and calling ambulances when patients needed to go to an acute setting. Being a Learning Disability nurse, I felt that my skills were transferable to dementia care and I was able to understand and interpret what people needed.

I think I've learnt how technology can be used going forward. It has made me think about how technology can be used to support the people we work with and keep in touch with the multi-disciplinary team. If there is a 2<sup>nd</sup> wave, at least we now have the technology set up and ready and will not be as much of a rush to be technologically prepared.

Even as things go back to normal, I would like to continue using technology as this can lengthen the time I spend with patients, even virtually, and their care and allow me to spend less time in my car and driving between lots of home visits. It has made me rethink how time is used and think of innovative ways to work.

I think the current government should have learned that we should lockdown in time in the event of a second wave, even if this is done by local regions rather than nationally. We should PPE stocked at ready to reduce risk to both professionals and patients.

As we have learned more about COVID-19 I have found it very important to keep up to date with the latest scientific evidence around the virus and treatment. This allows me to rethink about who is most at risk or vulnerable, for example having learned that even mild obesity can put

somebody at risk, I can keep this in mind when talking to patients about their lifestyle.

Specialising in mental health and learning disability, I have also read up about the long-term psychiatric effects of COVID-19, including psychosis and mood disorder as this may affect the people I work within a future wave of the virus.

People can present with atypical symptoms like the man who passed away with abdominal pain, people aren't necessarily going to be coughing to begin with. We are all learning but it is relating it to my own practice.

It depends on the person and why they want to get into nursing, don't do it just for a stable career. If you are genuinely interested in a career, you can work well as a team, reflect, then go for it. I've had difficult days, I've cried and doubted my ability, but I never regretted it. You have got to be willing to learn and take on responsibilities.

I know of people who have considered leaving, some have found working during these times quite traumatic. With learning disability nursing you have to be able to stick up for people and rely on relatives and carers, you've got to be willing to listen and stand up yourself.



## Lockdown and me. My Covid-19 Story, Andrew Donohoe. An explanation of how Andrew told his story through a series of interviews.

Andrew Donohoe is my son. He is 30 years old. He has Fragile X syndrome. This is a genetic condition, which can cause a range of issues with language, emotions, attention, behaviour and social interaction. Fragile X is the most common inherited cause of learning disability.

Andrew was interviewed by 4 personal assistants, his sister and myself about covid-19. I thought he might give different views to each person and I wanted to record these. I then collated his 6 responses and wrote them as a story before reading this to Andrew. He said it was how he felt.

I have included the original interviews which reflect his level of communication more accurately. People with Fragile X can be quite repetitive, have tangential speech, topic hop or obsess on a particular area, and find sequencing and the concept of time challenging. In the final story I removed some of the repetition and changed the sequence of the comments, but not the sense of what he said.



A lot of what Andrew refers to and many of the activities and experiences he had during covid-19 are published on my Coronavirus Blog on my website. Please have a look.

<https://annedonohoe.co.uk/new-corona-virus-support>

There are lots of photos and videos of what Andrew did and this will help to explain the things he talks about in the text below and give a real flavour of his covid-19 story.

I would like to thank Andrew's Personal Assistants (PA's) Jodie, Antonia, Lauren and Kerry for their help and support during the pandemic and for interviewing Andrew for this book. I would also like to thank Andrew and his sister, Rebecca.

Anne Donohoe

**Making cocktails for  
Andrew's Zoom Prysm**



## **Lockdown and me! Interview with Personal Assistant Anne Donohoe**

### **What was life like before lockdown?**



Lockdown was a very sad time. My timetable had to change. I preferred my timetable before lockdown.

### **What happened when we went into lockdown?**

My staff changed. I had one person cover all day from 8.30 am to 10.30 pm instead of 2 or 3 people a day. This was really good. I was grateful that they

stood in and protected me from infection.

### **Why did we go into lockdown?**

We had to stay at home because of the virus. My gym and swimming pools were not open. My activities closed down.

### **What did you miss during lockdown?**

I was pretty disappointed because I was no longer in that community environment. I missed my friends and still miss my friends.

### **What has happened since being in full lockdown?**

I haven't gone to my clubs. I have started running. I have been doing lots of running. I did some basketball with a PA (Personal Assistant). I rode a bike on the Plymbridge Trail. I did Yoga with Adrienne and Joe Wicks on my laptop. I worked with my occupational therapist on Zoom to make a Calm Box. I like the big calm ball.

I also had big activity boxes my mum made for me before lockdown. I liked choosing activities from these. I made things. I painted stones, tried knitting, did some watercolours, my art classes were online. I made cakes and designed a pizza, I did MasterChef and made a café in my flat. These were great.

### **What has helped you get through lockdown?**

Staying at home but being active. Keeping your distance, washing my hands, using hand sanitizer and wearing facemasks.

Yes, I felt safe. Mum did a good job of organizing everything and carers did a good job too. I am very grateful to them.

### **What has changed since lockdown happened?**

Some of my activities went online.

My watercolours class was on Google Classrooms. I watched my art teacher on my laptop.

Using Zoom has helped. I liked seeing different people. Becky, Funky Lama and Moving Sounds used Zoom.

I used Zoom every Friday night. I had a nightclub called Prysm in my flat with my PA and invited my friends. Prysm helped. It was fun. I liked seeing different people. I used to go to the Prysm nightclub in Plymouth on Friday nights before lockdown.

If lockdown continues, I will use Zoom. I hope activities will be online. It is better having them online than not at all.

## Lockdown and me! Interview with Personal Assistant Antonia Eastwood

### What was life like before lockdown?

Before lockdown I used to do a lot of activities such as:

Choir

Funky Llama Drama

Access drama group

Swimming lessons

Art classes – watercolours and acrylics

Routeways youth group

Karaoke at the pub.

Before lockdown my life was very busy with lots going on.

### What happened when we went into lockdown?

Everything had to close. Schools were closed. I had to stay at home. I felt really happy about staying at home for a while because I didn't have to go anywhere, and it was quite relaxing really. After some time, I felt rubbish and bored of not going out anywhere.



### **Why did we go into lockdown?**

We had to because we had to keep our distance – we are doing high elbows instead of high fives!

### **What did you do to keep yourself entertained during lockdown?**

I listened to music, especially classical music. I did some running as well. I also made travel shows in the flat with my favourite flamingo Tracy. We went to Florida in America, Singapore and Australia. I did lots of housework and baking buns and cakes.

### **What did you miss during lockdown?**

I missed going to Tr2 for funky llama drama and also animate drama. I missed going to igrow on a Tuesday once a month – this is a meet up group.

### **What has happened since being in full lockdown?**

Everything is changing – lockdown is being lifted a bit but the gyms haven't been reopened yet. I find it easy to understand and I feel like I know what's going on.

### **What has helped you get through lockdown?**

Seeing friends online and having PAs around.

### **What has changed since lockdown happened?**

Now I use zoom to talk to Becky, Moving Sounds, Funky Llama.



## **Lockdown and me! Interview with Personal Assistant Jodie Saunders**

### **How did you feel when you heard about ‘lockdown?’**

I felt pretty embarrassed about lockdown – everything was not opening again. Like cafes and restaurants were shut. Museums and cinemas were shut. Seeing my PAs was good.

### **How did your life change when the UK went into lockdown?**

Staying at home.

Not going on transport/taxis.

Not doing my regular routine.

### **Did you learn anything new about yourself?**

I felt really chirpy and happy because I get to see all of my PAs. I need to just be happy and be flexible. Seeing my family makes me happy.

### **What was the hardest thing about lockdown?**

Not going to Beckly (Playcentre/youth club).

I miss Animate (Theatre Group) & TR2 (Theatre Group).

Not going to pubs.



**What have your PAs or family done that's really helped you in lockdown?**

Seeing people in the evenings is great.

Running – a new thing.

Doing Zumba (on youtube) has been fun.

Doing 'Glastonbury Festivals'/'Prysm nightclub' (youtube/Zoom) has been fantastic.

Doing Funky Llama (Theatre Company) socials has been brilliant.

**What new skill have you learnt in lockdown?**

I've learnt a new skill in doing my travel show about Australia!

**Anything else you want to tell me about your lockdown story?**

I've enjoyed coming out of lockdown.

You keep your distance and you wear a mask. I feel good about wearing a mask.



## Lockdown and me! Interview with Personal Assistant Kerry Rochford



### **What was life like before lockdown?**

My life before lockdown was a lot busier with lots of classes, where I would meet different friends. There were not so many restrictions like having to keep our distance, wear masks or wash our hands a lot.

### **What happened when we went into lockdown?**

We had to stay at home as much as possible so that we could stay safe and avoid the virus. We had to change high fives to elbows. I could only have some of my PAs working with me. Being in lockdown made me feel sad at times because it lasted a long time and I couldn't see my friends,

but we could see people on Zoom and go to Andrews Halway's Prysm which made me feel happy.

**Why did we go into lockdown?**

The news said to stay at home because the coronavirus wouldn't go away.

**What did you do to keep yourself entertained during lockdown?**

Prysm nightclub and cocktails, running and long walks, lots of cooking nice food, and Joe Wix workouts.

**What did you miss during lockdown?**

I missed going to Access, Animate and Beckly and catching the bus home by myself.

**What has happened since being in full lockdown?**

We still can't go to church and some of the places I enjoyed going to still aren't open. I also can't go on the buses and have to wear a mask all the time.

**What has helped you get through lockdown?**

Exercise helped me through lockdown

**What has changed since lockdown happened?**

The theatres are still not open, which makes me sad because I enjoy going to see shows.

## **Lockdown and me! Interview with Personal Assistant Lauren Brinsom**

**What was life like before lockdown?**

Pretty good. My life was happy, organized.

**What happened when we went into lockdown?**

Pubs, restaurants and gyms closed.

My groups and clubs had to shut down too.

**Why did we go into lockdown?**

It was strange at the time.

I think we went in to lock down because of coronavirus.

**What did you miss during lockdown?**

I've missed going swimming at the life centre, moving sounds.

Missed some of my PA's who have been on lockdown as well.

**What has happened since being in full lockdown?**

The churches haven't been opened.

We have to wear masks in Lidl and Morrison's.

**What has helped you get through lockdown?**





I think everything, keeping my distance.

Being safe and staying at home.

**What has changed since lockdown happened?**

Nothing has changed.





Supporting Andrew during this pandemic has been a joy. It has been easier than expected, Andrew understood and coped better than imagined.

I'm grateful I could keep working as it helped me get through the lockdown.

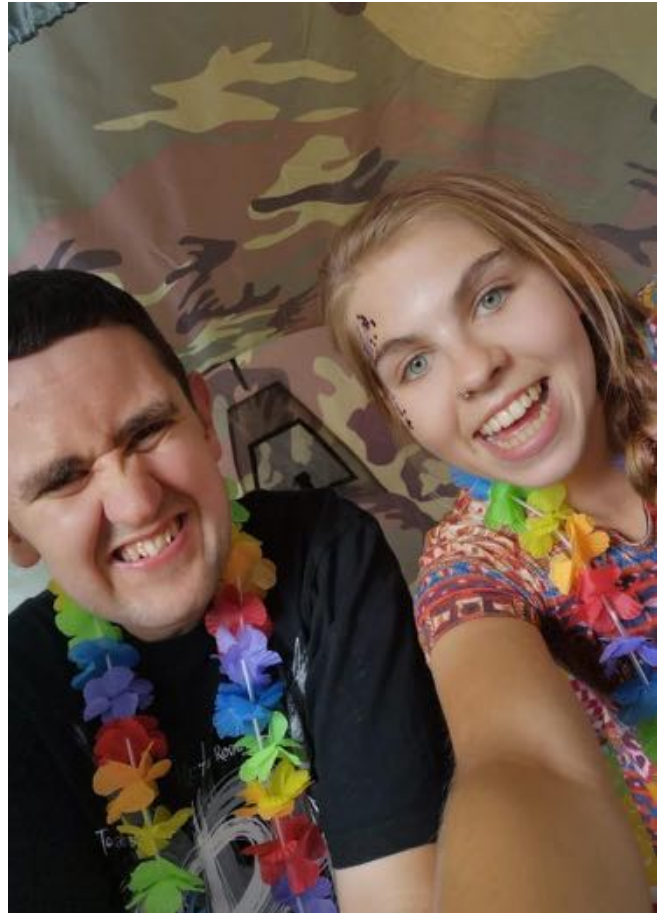
It was fun being flexible and thinking on my feet of different things to engage Andrew to keep him happy and active.

As I'm fairly new to the team I found that this time in lock down

has given me the chance to get to know Andrew better and his behaviours, also find my feet and gain confidence.

Before lockdown things were very structured and the routine rarely got altered, it has been a great opportunity to make new routines and make being flexible fun.

Sometimes there has had to be a lot of explanation and reassurance that things will be ok but never has it been a problem.



## **Lockdown and me! Interview with Personal Assistant and sister Rebecca Scott**



**What was life like before lockdown?**

It was fine.

**What happened when we went into lockdown?**

We had to keep our distance, 2 meters, social distancing. The pubs were shut. The gyms were shut.

**Why did we go into lockdown?**

Because we didn't have anywhere else to go.

**What did you miss during lockdown?**

Lots of different things. Going to the theatre, choir, the buses.

**What has happened since being in full lockdown?**

Everything's had to close down.

**What has helped you get through lockdown?**

Dunno really. Doing lots of running. Prysm.

**What has changed since lockdown happened?**

I didn't want to see people in London.

## Ireland

### **In Limbo: The impact of the pandemic on people with an intellectual disability** **Dr Evan Yacoub**



It is important to start by saying that a number of people with Intellectual Disability I have spoken to during the pandemic have coped reasonably well. For some it has been an opportunity to spend more time with family, for some it has been a break from attending a day centre daily. However a number have struggled and this number appears to me to be increasing as time goes on. Every issue I describe below has arisen in my daily clinical practice. None are hypothetical or anticipated challenges. There are a number of areas of potential concern such as reduced safeguarding oversight visits and the potential impact of pandemic-related news and use of PPE which I will not be discussing. They may well be having a significant impact on such a vulnerable population, but this piece focuses on areas I have observed in my clinical practice.

I felt a sense at the beginning that some of my patients engaged well with the government's message to unite by staying apart in order to contain the virus. As time has gone on however, the realisation that the staying apart is going on and on has been difficult. I want to describe a number of scenarios to help me describe the impact.

One young man, who longs to stay home with family when in independent living, moved in with them as lockdown was approaching. As time has gone on he has found it difficult to spend all his time with family and now remembers why his move into independent living was so important. He is torn between moving back to his apartment, which will mean that visiting his elderly mother with underlying conditions has a risk which is difficult to

quantify, and the potential loneliness of living alone with no visits or visitors. As the government's roadmap is revealed, his ability to resume social activities from his apartment in the complex world of social distancing is frightening to navigate. Add to this the need to be supported by multiple staff, the risk of being an asymptomatic carrier and usually socialising with a group which contains a number of people with underlying conditions and the perfect storm for anxiety is complete.

One young man had been struggling at home, and him and his family were informed that a brief respite placement was being arranged. Essentially, a supported holiday, this would have enabled the young man who spends the vast majority of his time with his parents rather than peers to get a break and a holiday which he has never had. It would have given his parents the opportunity to recharge, reflect, and welcome him back in a context of rejuvenated enthusiasm. Unfortunately, the pandemic has led to the cancellation of this placement, with no date in place for when it might happen.

One gentleman who was very happy where he was living, was at risk from the virus. He is in his 70s and has medical issues. He was also sharing a room and lived in a house with numerous others in addition to numerous staff which reflected the level of support need in the residence. To protect him, he was transferred to a single room in a residence nearby to a place where he knows no one. He is healthy, and has more freedom, but looks lost with no prospect of returning to the place he loved.

These people and many others are in limbo. I have realised whilst considering their plight that it has been helpful for me to be in the position part-time to influence and contribute to a number of guidance documents

in relation to the pandemic. What this gave me is an awareness that what people with a learning disability are experiencing is simultaneously being experienced by other vulnerable groups such as those with chronic mental health issues and the elderly. As the roadmap is gradually revealed, many questions remain unanswered given how little we still know about the virus.

A number of key challenges continue to exist.

For those in residential settings, seeing family members is problematic. The bans on visits, or visits only taking place whilst keeping 2 metres apart made perfect sense to start with. Given that the definition of close contacts includes the duration of 15 minutes or more, will the possibility of some brief physical contact during visits for those who have gone months and months without hugging a loved one become a reality soon?

In my view we have an opportunity to review day programme provision. Where there is clear evidence that people would benefit from a group activity, will we soon be witnessing day centre activities in a large well ventilated room with everyone 2 metres apart up and down the country?

Preparedness by services for a surge in cases can be problematic in terms of service provision. Closing services in case they are required as an isolation facility again made perfect sense at the beginning. As time has gone on there is an obvious question arising; will public mental health become a bigger issue than public physical health soon?

Remote working and telemedicine have been in some instances a helpful way of efficiently delivering services, assessments and interventions. The infrastructure for doing this in rural services remains elusive in some

settings. As time has gone on however, a number of complex scenarios have highlighted that there is no substitute to meeting people face to face in some situations to truly engage them, understand their situation or find out what is really going on in their lives. Preparing our offices and buildings, and more importantly the public, for a return to regular face to face appointments is an enormous challenge.

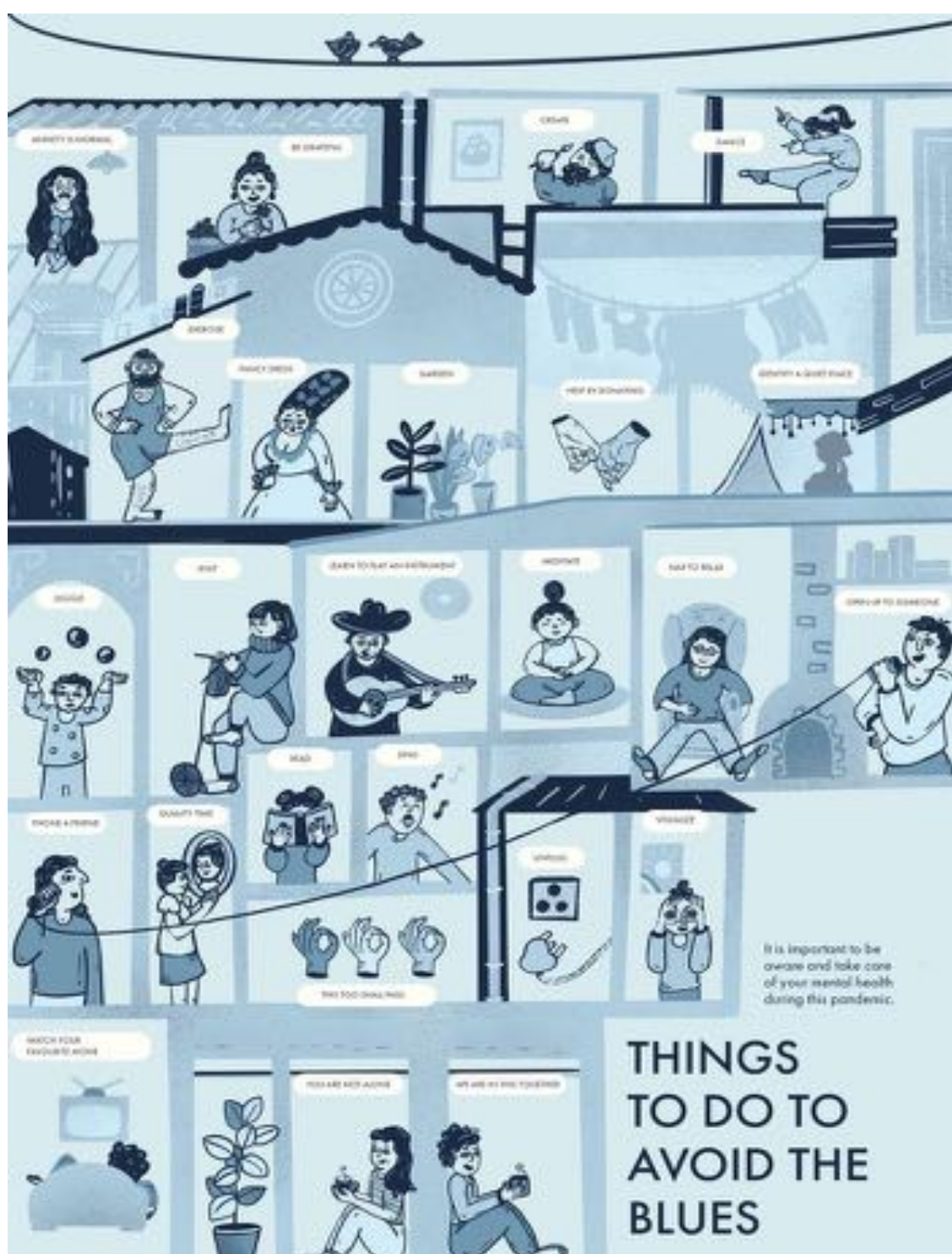
What people with intellectual disabilities require moving forward contains elements some of which are under our control and some are not. They need clear guidance which can be implemented about what is safe and what is not. However given how new the virus is the preciseness of information on proximity, duration of contact, face masks (and their potential impact on social connections), journeys and vulnerability to infection is open to challenge, misinterpretation and new findings. As providers of services to vulnerable groups it is our job to keep ourselves updated and communicate findings in a simple, clear and effective way.

Dr Evan Yacoub

Consultant Psychiatrist and National MHID Clinical Development Lead

Former chair of the faculty of learning disability, College of Psychiatrists of Ireland and former acting National Clinical Advisor & Group Lead for Mental Health, HSE, Ireland





## Malaysia



## Prof. Dr Toh Teck Hock, Sibü, Malaysia

My friend and colleague Dr Toh, works with many individuals with learning difficulties and their families, carers and professionals in Malaysia. Professor Dr Teck-Hock Toh is Consultant Paediatrician at Sibü Hospital and Adjunct Professor, Faculty of Medicine, SEGi University, Sibü, Sarawak, Malaysia. He sent me the following contribution. Please see the brochures he has included which are distributed in Malaysia via email, mobile phones and as hard copies. The term “Intellectual Disability” is widely used in Malaysia rather than “Learning Difficulty” or other terms used in the UK.

*Thank you, Dr Toh,*

We developed these brochures and translated them into many languages (e.g. Chinese, Malay, Iban, Tamil, Kadazan). Hopefully, people with Intellectual Disabilities (intellectual disabilities) can understand the situation and COVID-19 better (and also parents with special needs).

Lives for people with disabilities and parents has been challenging. Not only to have to face COVID-19, and the many restrictions which have also been put on them, but also because people with Special Needs (SN) are deemed as having a higher risk of catching the infection. Or they may not be able to



comply with the many standard operating procedures that have been imposed in many places for safety such as social distancing, wearing of masks and hand hygiene. For example, the community-based rehabilitation centres are not being opened yet for children to access their early intervention program because of these concerns. Yet, on the other hand, many places with a much higher risk of transmission, such as cinemas, and karaoke venues, are allowed to open.

During the movement control order (MCO) period, many therapy sessions were postponed as they are deemed to be non-essential services or moved online. These changes to the child and family's routines and expectations have put enormous stress on the children and

their families. As a result, many children not only did not progress but have developed many complications and issues.

Nevertheless, the MCO has provided many parents with an opportunity to work directly with their children (for many this was the first time they worked with their children in this way). These opportunities allow them to understand their children better and to be able to see the needs of their children and the change necessary for their children to progress. Those who chose to make the change to adapt to the new norms could have seen their children making progress.

It is important that while we are fighting the war against the dreadful virus, not to forget that children with SN require special attention, and their needs during the pandemic become higher.

Dr Toh Teck Hock





## Safe Practices for Young Children Returning to Classes



Children can catch COVID-19 infection; and, transmission between children and adults does occur.<sup>1</sup> However, it is important for young children to return to classes (playschool, kindergarten, therapy, etc.). We recommend the following when classes start.



If unwell, stay at home, do not go anywhere except for seeing the doctor.



Greet by waving or saying "hi" instead of hugging or shaking hands.



Wear a mask and/or a face shield (prepare at least two masks, for changing if wet or after eating/drinking).<sup>2,3</sup>



Do activities without body contact, e.g. board games, colouring, singing, reading, etc.



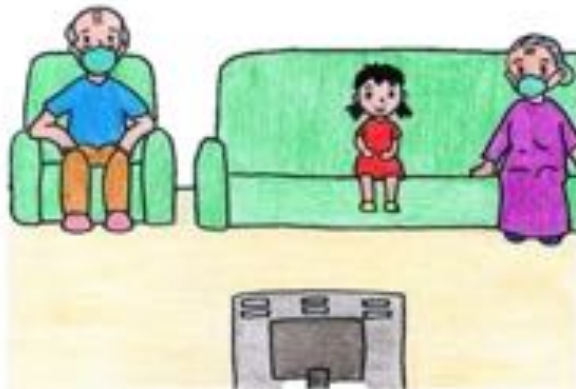
**Stay Safe, Keep Healthy!**



**Wash hands with soap and water correctly, and frequently.<sup>4</sup>**



**Take a bath first after reaching home.**



**Elderlies and people with chronic illnesses to wear masks and keep physical distancing at home.<sup>2,3</sup>**

**References:**

1. Castagnoli R, Votie M, Licari A, et al. Severe acute respiratory syndrome coronavirus 2 infection in children and adolescents - a systematic review. *JAMA Pediatr.* 2020 Apr 22. doi:10.1001/jamapediatrics.2020.1467.
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Text by Prof. Dr Toh Teck Hock & Mr Toh Aw Zien (Association for Children with Special Needs Sibü)

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Graphic Design by Ms Ting Sing Hymn (Fu Yuan Kindergarten, Sibü)

16 June 2020





# Social Distancing

## What does it mean?

- ☐ Stay away from places with many people
- ☐ Keep a distance of one meter<sup>1</sup> (about one-and-a-half adult's arm-length) from each other
- ☐ We can help fight the infection



Wash hands frequently with soap and water, or hand sanitiser



Queuing and keep at least one meter<sup>1</sup> away from people



Crowded place

# Red Light - Avoid / Don't Do



- Places with many people moving around



Market / shopping mall



Cinema



Wedding dinner



Party

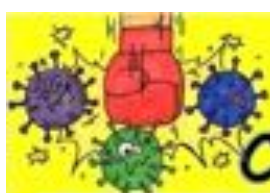


Tuition

- Visitors coming to your house and workplace
- Taking public transportation if it's not needed  
(e.g. balik kampung, go shopping mall, visit friends)







## Yellow Light - Can Do, But Be Careful



If allowed by authority / government:



Travel by public transport  
(bus, train), if really needed



Play sports in the open air  
with family or a few friends



Buy things you need in grocery/ supermarkets, or pick up  
medicines (keep at least one meter<sup>1</sup> away from people)



At least one meter<sup>1</sup> apart in  
an open-air restaurant  
(better to take away food)





## Green Light - Safe to Do



Play in the home garden



Home cooking and eat at home



Read a book or listen to music in private



Cycle, or walk and jog in open park or stadium  
(if allowed by authority / government)



Pack takeaway food







- ☐ Do things online (e.g. video / phone calls, e-payment, e-learning).
- ☐ Wash hands frequently with soap and water, or hand sanitiser, for 20 seconds.



**Disclaimer:** This graphic brochure is designed for easy read by people with learning difficulties, children, and those who might not read well. Readers should refer to formal sources (e.g. World Health Organisation) for a more detailed description of the topic on "social distancing".

<sup>1</sup> World Health Organisation. Advice for public [Internet]. Cited 20 March 2020; Available from <https://www.who.int/emergencies/diseases/novel-coronavirus-2019/advice-for-public>.

Text by Prof. Dr Toh Teck Hock & Ng Lai Thin  
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Graphic Design by Ms Ting Sing Hymn (Fu Yuan Kindergarten, SibU)  
22 March 2020

## Netherlands

### Supporting people with ID during the COVID-19 crisis: Stories by Christiaan, Bernadette, Sander, and Edithe Rot



From the Academic Collaborative Center 's Heeren Loo – Vrije  
Universiteit Amsterdam - The support workers of 's Heeren Loo Mid  
Netherlands

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*During the press conference on March 15<sup>th</sup>, our Prime Minister Mark Rutte announced the government's national control measures. A so-called “intelligent lockdown” started. Care organisations for people with intellectual disability across the Netherlands stopped their daily activities and visits. On June 24<sup>th</sup>, the relaxation of visiting regulations started on a national level: “no, unless” became “yes, unless”. From July 1<sup>st</sup> onwards, the people regained more freedom. Also at 's Heeren Loo. From that moment on, people with intellectual disability regained space to move around, just like everyone else. On August 18<sup>th</sup>, a new warning message and slight adaptations to the regulations were announced by our Prime Minister.*

*Written by Edithe Rot,  
behavioural and scientist practitioner*

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When the support workers were asked if they would like to share their experiences in supporting people with a mild intellectual disability (mild ID) during corona time, they did not need much time to consider. Three support workers from 's Heeren Loo Mid Netherlands tell their story enthusiastically, motivated to do the best for the people with mild ID they support, even in difficult times.

Organisation 's Heeren Loo provides care and support at various locations throughout the country to people with intellectual disabilities, young and old, including about 1,200 people with mild intellectual disabilities. ‘As a support worker you ask yourself every day: How can I support people with



ID on their way to fully participate in society? This question seems now more important than ever in these corona times where new rules apply for social contact.'

### How do you look back on the crisis so far?

I am **Christiaan Hilhorst**, I'm 46 years old. I became a support worker because I want to bring people forward in life in a way that suits them best. My group consists of six boys/men from 20 to 35 years old. They all have a mild intellectual disability and autism. There are three other groups housed in our building. During this time of corona, we have started to work more closely together.

'I still remember it vividly. After our Prime Minister's press conference in March, in which he announced total lockdown, the world suddenly changed. We suddenly had to be careful with each other not to infect each other. No more visitors were allowed. After the press conference had ended, one of my boys walked up to me and said, "Tonight three of my friends want to come over here." Really, he had never asked me that before. Under any other circumstances, I would have welcomed them right away, but I mean, the press conference had just ended less than half an hour ago!'

'The emphasis in supporting our boys was on taking others into account. That is exactly what many people with mild ID and also autism find so difficult. Suddenly no one was allowed to leave the house, no visits from friends, not allowed to see parents. Even more, it is also an invisible enemy. How do you explain that? As a support worker, you felt compelled to be very strict, to say 'no' more than usual. You almost felt like a police officer. But you do not want to be like that at all. You could not allow

anything, however much you wanted it. I found it very annoying to have to say "no" all the time. Luckily, they did accept it, because I have built up a good relationship with them.'

### Three stages gradually improving our freedom

'It started with the total lockdown. We were very much in this together, feeling that life like this was not so nice. However, it was clear. Our boys with mild ID knew what was and was not allowed. We hoped and expected it to only take a short while. Then the next phase with relaxation of the lockdown started and it created a difference between people living in a residential home and people living elsewhere. Our boys were allowed to do much less, because they belonged to a group including people from the category 'vulnerable'. Then our boys heard on TV that things were allowed to the population, but that did not apply to them. I really found this phase the most difficult one, because the rules were so unclear and different for everyone. That was difficult to explain.

In the last phase, which we are in now [July], we have more freedom of movement again as long as you stick to the rules, such as keeping 1½ meters distance. Now our boys can visit parents again and they can go back to work. It is starting to go back to normal again. In our work, we can focus more on supporting them in normal life, but with corona rules such as keeping an appropriate distance and washing hands a lot. That is doable. You can sit down with an individual to discuss what is important to him in life. First, the organisation determined top-down how to behave and there was no room for individual input.'

## Have you felt vulnerable to become infected?

‘Yes. I was at work when I heard that a colleague was infected. I immediately called my wife to see what we would do. Am I going into quarantine; am I going to lock myself up in a room? My wife was at home, her temporary work had completely been cancelled. My children were at home because the schools were closed. We decided to continue acting as normal as possible, but by taking into account the people around us extra carefully, also our parents. That was difficult, but luckily we did not get infected. Keeping life as normal as possible was the best way for us.’

## How did you experience the lockdown?

I am **Bernadette van Zoelen**, 33 years old. I work in a training home where young people learn to live and function as independently as possible. We have eight young people in the house, the youngest is 16 years old and the oldest is 20. They all have a mild intellectual disability and additional problems such as attachment disorder.

‘I thought it was very intense, but I did get a lot of positive things out of it. It also gave the youths a certain peace of mind. The social pressure is always high, especially for these young people with mild ID. They want to be part of everything but are actually not able to handle it well. Their social contacts disappeared and with that the social pressure, because they just stayed here, inside. We had actually expected when the lockdown started: one week and then all hell breaks loose, so to speak. However, that did not happen. I thought it was very special that they feel very safe here with us. And that they did very well because we could offer so much closeness. It shows again how much guidance these young people need. That got even more apparent to us. I did find the working hours supporting them

very intensive. Not because there were conflicts, surprisingly not, but because these young people are constantly around you. You are the safe haven to them. We spent all day with them, because they could not go out now. In the evening I was really exhausted.'

### **What activities did you do with the youths you support?**

'We quickly created a day program for them: homework moments for school and educational tasks, such as jigsaw and word search puzzles for those who could not attend daytime activities or work. In addition, we played sports with them, we involved them in cooking dinner, and we played many games. We also worked in the garden together. At one point, we all started crafting postcards for a retirement home. I thought that was very beautiful and special. We sat at the table all afternoon crafting. We got more in touch with them.'

### **What did you find difficult?**

'When the relaxation of the lockdown was announced by the government. Then it got complicated. Our youths thought that this also applied to them, but it did not, because within 's Heeren Loo the relaxation did not go that quickly. We have of course explained all the regulations and the risks, but we noticed that these young people also need their network. Some went out anyway or ran away from home. Of one girl who ran away, we suspected she had contacts with a loverboy. We were really worried then. After returning home, they had to be quarantined for 2 weeks for safety, but of course, they did not understand it that way. You can try to explain it, but it felt like punishment to them. You feel very much like a tyrant. I found those 2 weeks of quarantine very intense for these young people.'

You are all the time considering about what you can do for them. I saw that some became depressed going from one quarantine after another. You realise it is their inability which results into having to quarantine them. I thought it was very unjust. When the government released more relaxation of the regulations, but 's Heeren Loo still did not agree, we sent a critical email: This is no longer reasonable!'

### **What did you think when the lockdown came in the news?**

I am **Sander van Norden**, I turned 26 during the lockdown. I work in a home with young people between 18 and 23 years old with a mild intellectual disability and additional problems such as ADHD. I have been doing this job since I was 18. I have thought thoroughly about what I want to say.

'I worked a late shift with a colleague. I think that was on a Sunday night. As support workers, a lockdown is something that is a shock for us personally, and certainly for the young people with mild ID. I have experienced that the calmer I was, the calmer the youths became around me. You have to explain everything very clearly. Then they feel like we take care of them. It was sometimes difficult to get back to work and show all that calmness and clarity, while sometimes you yourself also found things difficult about what happened in your private life and all. I personally found it very difficult that I was not allowed to let these young people leave our site. And that they were not allowed to go to the supermarket. I understood that it was to protect them, but it was very against my nature to lock people up, so to speak.'

## **And when the government announced more freedom?**

‘It was difficult that during the press conferences on TV, our youths heard the Prime Minister say that people were allowed more and more, while we had to tell them that because they live with us in a residential facility, they were not given more freedom. That is very difficult to sell. Within the organisation, the relaxation of the regulations lagged behind the rest of the Netherlands. It took more than two months before our youths were allowed more. That is a very long time. The worst thing I felt was that they were not allowed to go to the supermarket, so they did not have their own free choice to buy tobacco or a snack. We as support workers were also not allowed to leave the residential facility during our shift. So, before or after our shifts, we bought tobacco for them. Actually, you do not want that at all, because you know that smoking is bad. So that goes against your own principles.’

## **How was it to keep at 1 ½ meters distance?**

‘I found that very difficult. I really felt that the youths sometimes needed small physical contact. One time, I did pat one of them on the shoulders and said I thought he was doing very well and that I was proud of him for how he complied with all the corona regulations. If they are only allowed to do so little and you compliment them on how they are doing, they can get back to it for a while.’

## **Do you notice differences now more is allowed?**

Now that they are allowed to do more [July], other problems arise. Because the youths were not allowed to leave the site during the



lockdown, they also did not come into contact with the "temptations" in society. We have young people living here who, while they were used to smoking weed a lot, could not buy any weed. As a result, some felt much better after a while and were more approachable. Now that they can get their weed again, they fall back into a negative spiral. So when I look back on it now, I have experienced the pros and cons of the corona crisis. During the lockdown, you had to guide them how to deal with life within the rules and regulations of the lockdown and now I have to teach them how to deal with the big world again. The first period of the lockdown was well organised and clear, both for the youths and for us support workers. However, I personally experienced the regulations as very unpleasant. You do not want to lock up anyone. It is inhumane that you are not allowed to see your family for 8 or 10 weeks. I do this job because I want to give people opportunities and their freedom. I had to do the opposite. What I liked was that parents sent us supportive messages that we were there day after day for their children.'

### **What if there will be another lockdown?**

I've thought about that personally. Quite often actually. But I do not see that happening that quickly now [July]. I do think that it will be very difficult for the young people with mild ID. I think it will be worse than the first time. Here we go again. I think the youths will rebel more against it. That they will not take it again. Some of them at least. However, I think again we will gradually get back into a lockdown. If there are several infections' again,



## Scotland



## Linda Craig

My name is Linda and I work as an Occupational Therapist for people with learning disabilities. I work as part of a community team in Scotland – our area covers towns, villages and rural locations so I normally spend a lot of time driving around from place to place. My job involves looking at how people spend their time and what activities (occupations) they engage in, what they are good at and what they need help with, supporting people to learn new skills or build on the ones they already have. I also look at any issues around processing sensory information and suggest strategies and activities to help with that. I help people to be more independent where possible and make sure they have a routine that includes a range of activities that they enjoy and benefit from (including a balance of self-care, productive and leisure activities). I also try to make sure the environment (at home, work, college or day services) meets their needs – this might be before someone starts attending a service or moves to a new place to live, or it might be making changes somewhere they already attend or live. I help people to keep safe at home and/or out in the community – thinking about what things people can do on their own and what things they need someone to help them with (this sometimes involves providing specialist pieces of equipment).

When the lockdown first started in March, we were told to take our laptops and work from home and that we shouldn't go to see our service users unless it was really urgent to avoid spreading the virus from place to place. The NHS trust I work for were great at getting things in place to keep staff

and service users as safe as possible, as quickly as possible. After I started working from home it was really busy as we had to try and move from paper notes to electronic systems pretty much instantly – this is something that would normally take months of planning and would be rolled out in stages. We had to learn to use new systems and get used to new ways of working and communicating. We started to rely on phone calls, emails and video appointments to communicate with service users, families, caregivers and service providers. It was difficult to learn new skills quickly as well as keep in contact and support people. In the beginning everything was so unsure – we didn't know if we would stay in our own jobs or if we would need to go and help out somewhere else like hospital wards or other community services. All of the day centres and community projects had to close down pretty much overnight and suddenly everyone was at home and no one was able to go out of their houses. This was a really scary time, and everyone had to work hard to support each other the best we could.

There have been lots of really difficult things about this pandemic – the deaths, illness, the impact on people's physical and mental health, the disruption to people's lives and businesses, lots of people arguing about what is right and wrong when it comes to dealing with COVID-19. For people with learning disabilities and Autism, this can be even harder to understand, I think as a whole nation and wider world we are all struggling to understand and are worrying about how long this virus will be with us and when, if ever, our lives will go back to normal. I want to focus on and share with you some of the things that I think have been important lessons for me and that I hope will help make me a better friend, ally and professional to people with learning disabilities and Autism. I hope that maybe other people in the wider community will also reflect on their own

experiences during this ongoing pandemic and understand more about what it's like for many people who have learning disabilities and other issues that affect their communication, mental health, physical health and understanding of the world around them.

### ***Communication***

Normally if you asked me if I feel confident in communicating with others, I would say yes, I do. During the pandemic, I have had to use lots of different types of communication and it has given me a tiny bit of first-hand experience of communicating in a way that isn't your preferred method (in my case my preferred method would be face to face). I've always been aware that this can be really uncomfortable and difficult but haven't really experienced it myself. This has made me reflect in a new way on what it must be like for people whose communication style doesn't always match up with what society expects or what is considered 'normal' – it's frustrating and it can make you feel anxious or worried, dealing with that day in day out must be exhausting. Having worked with people with a variety of communication styles and methods I was aware of the importance of doing everything you can to support someone's communication - whether that's pictures, signs, gestures, objects, ways of talking, etc. but what I hadn't experienced first-hand was what it was like to be forced to communicate in a way that you don't feel comfortable with. My experience is only a very tiny glimpse into what this is like and doesn't compare to having to deal with that every day, but I think it's helped me understand a bit better and reminded me to keep making communication a priority.

### ***Learning new skills***

Learning new skills is hard work. As an Occupational Therapist I am often working with people to develop their existing skills and be a little bit more

independent, or maybe explore new skills and interests. Lockdown forced me to turn my attention on myself and explore some new skills so that I could fill my time at home. I think it's been a while since I tried to learn anything completely new and although it can be rewarding it can also be frustrating. My new skill was trying to grow vegetables. I enjoyed the process, but my end products were a bit of a disaster. Gardening is something that for years I have supported various people to access and engage in but it's not an easy thing to master so well done to all you super gardeners out there – I have a whole new respect for your dedication and skills. I'm very much looking forward to getting back to spending more time face to face with my service users so I can learn from them. I enjoyed digging up and clearing the overgrown veg patch more than I have looked after the plants so maybe I actually like digging not gardening. This experience has reminded me that learning new things takes practice, encouragement and perseverance and that it's ok to enjoy some bits of the activity and not others. Even if your end product wasn't what you expected the process is still worthwhile, plus you can always try again.

### ***Being at home and isolation***

Early on, when we were all under lockdown in the UK, we were only allowed out once a day for an hour – understandably most people were unhappy about this. This experience made me think about the people who are housebound and don't go out at all or who completely rely on others to take them out. To be able to leave your house and get into the daylight and fresh air is such a basic need but still there are so many elderly and disabled people who don't get out at all or who get out very rarely. The focus on providing support is so much around what people need to survive – shelter, food, water, personal care and so little about what they want or what would improve or enrich their lives. I hope as a society we don't



forget what it was like to not be able to do the things we want to and that that helps us to have a bit more empathy for those have a disability, or are elderly, or have a mental health issue, or are incarcerated, or live in poverty and as a result are always restricted in what they are able to do. For those of us who have a safe, comfortable home to isolate in and the technology to communicate with others we are really, really lucky and I hope we don't go back to taking these things for granted. One thing that has been nice to see is that people in my local area have been offering to help out with shopping, picking things up, transport, donating technology/devices and lots of other things so I really hope this continues. I think we all need to look at how we personally can include other people, whether that's visiting a friend or relative, calling someone up to say hello, offering a lift, asking a neighbour if they need anything from the shops, volunteering or if you provide a community group/activity/service can you do it in an accessible space so more people can attend? Small changes and gestures can make all the difference.

### ***Filling your time is hard and routine is important***

I wouldn't be a very good Occupational Therapist if I didn't believe that routine is important. During lockdown, like most other people my normal routine has been disrupted. Luckily for me I have been able to carry on working so I have had the structure of work (although that has mainly been from home) but the things that would normally fill my time outside work were really reduced and (to a lesser extent) still are. I've had to make an effort to keep a routine and to keep a balance of activities – I definitely noticed that when I let this slip it would negatively affect my mood. Sometimes a 'lazy day' watching TV and not doing much can be nice and relaxing but if you do that every day you might start to feel more tired and fed up and feel less like doing anything. The things I found that help me

are: getting up and having a shower everyday even if I'm not leaving the house; putting on nicer clothes and doing my hair some days; cooking a meal I haven't made before or haven't made for a while; doing something active like a walk, gardening, or a jog; tidying up and cleaning my house so it's a nice place to be in; watching a film or TV series that I enjoy; listening to podcasts; listening to my favourite music and listening to some new music; looking after my house plants (I used to be terrible at caring for them but have gotten much better and now have quite a few that are still alive – so far); getting up and going to bed at roughly the same time every day – this is quite a hard one to stick to but it really does help your sleep; sometimes avoiding listening to or watching the news (on TV, radio or social media) – it's ok to take a break from this when it feels overwhelming; playing board and card games – sometimes I play board games online; doing things I've been putting off around the house like painting, sorting through my clothes, tidying out drawers that are full of junk – these aren't really 'fun' but you get a good sense of achievement afterwards; reading books; taking care of my dog – this has been a huge help to me as it's meant that I have to go out for a walk every day with the dog even if I don't feel like it – I don't know if without her I would have done that every single day but I think it's been a really big help. Having a pet has been lovely during this pandemic because they are good company, our dog makes me laugh with the funny things she does and I think caring for a pet is really rewarding. Basically I've tried to keep busy as much as I can and make sure that every day involves some activities that are self-care, productive and leisure/relaxing to make sure that I keep my mental health good as well as following all the recommendations around avoiding COVID-19 to stay physically healthy too.

Thank you for reading my COVID-19 story, I look forward to reading and learning from other peoples too.

Some pictures of my before and after of the overgrown veg patch I cleared and some seedlings and house plants I have been growing and caring for.



This is our dog Ruby helping me work from home and out on our daily walks.



## South Africa



### Dr Zuzana Matousova-Done

Through my eyes and heart

I live in Cape Town, South Africa. An amazing part of the world surrounded by popular beaches and the stunning mountain walks that are a short drive or walk away. I trained as a Learning Disability Nurse in the UK, but my qualification is not recognized here as Intellectual disability falls under the umbrella of Mental health. Although changes may come in the future as South Africa has gazetted its own White paper on the Rights of Persons with Disabilities in March 2016 and many professionals working in this field recognize that a completely different set of skills are required to meet this client group's needs and desires and support them in the integration into the society and their communities. I have worked in various settings, including NPOs concentrating on life skills development and long-term accommodation, as a volunteer with families and individuals from low- or middle-income households (therefore travelling into townships and poor areas were not always the safest) and an adaptive surfing development and coaching program. Life pre-COVID seemed to be improving every day and despite all the challenges, people working in the field of intellectual disabilities seemed content and looking forward to more exciting opportunities.

The excitement started to wane when we all begun to watch the media with regards to the COVID-19 pandemic stats and with the lockdown at the end of March. Masks become a mandatory accessory when going outside and the selling of alcohol and cigarettes became prohibited adding additional stress and anxiety to people's already fragile state of mind. It was hard to explain to people with intellectual disabilities that they can no longer have a cigarette or a beer/glass of wine or that it had to be rapidly reduced (not everyone could stock up due to financial constraints). Adapting to this new and rapid change increased incidences in challenging behaviours and violence, especially at the beginning.

South Africa did not seem to be prepared for the impact of the lockdown, which was necessary as the numbers of cases and death were increasing. With no support, confined to their own homes with family members that were almost "strangers", many people with intellectual disabilities found it difficult to cope. The same was happening to their family members with parents stressing out about their loss of income and a lack of social security; many families with people with intellectual disabilities were going hungry. People with intellectual disabilities that live in a home have also had difficulties to adjust to changes that were happening with not only the staff rosters, food menu and infection control precautions, but also with cultural and religious belief systems (no more going out or religious gatherings).

My mobile started to ring nonstop even from people that I have never met before, but who were in the same position as the parents and people I have been involved with. The phone calls had the same underlying content: uncertainty, anger, worries, anxieties, desperation, needing support and even financial help to buy basic food and toiletries. Sometimes it was a question of "life and death" (when food was not



consumed for days as there was none or no resources to purchase it with). Even though I got involved in making masks, sourcing food vouchers, making sandwiches or food kitchens it was not enough. As a trained professional I found myself emotionally and physically drained. I felt overwhelmed and helpless. I had to not only look out for the people with intellectual disabilities and their families but also to look after my own family who, like everyone else, was confused and anxious. I have been living in Cape Town for some time, so I got used to the need for food and resources, but not on such a massive scale. Every family and person with intellectual disabilities I knew was requiring support in basic physiological needs as per Maslow Hierarchy of needs. Further, with no financial resources, there were other potential threats including loss of shelter, security and safety.

So, I reached out to other professionals and colleagues. I learnt a long ago that debriefing, reflective practice and journaling keeps me focused and my mental and physical wellbeing in check. A practice that, I found, is not that common in SA. I have learnt that many of my colleagues too lost income and were unsure of the future. But we all adapted. New skills and techniques were developed and customised: some provided support online or telephonically, some received special permission to support people with intellectual disabilities and their families in the community (which was quite difficult to obtain at the time) and some concentrated on supporting the frontline professionals. We all learnt together and shared a mixture of emotions.

Even though “the new normal” is different and somewhat scary, many of the people with intellectual disabilities and their families seem to have

overcome their initial fear and are trying to rebuild their lives. It is heart-warming to receive voice messages and notes from my client group, which is a lot more positive than a few months ago. I am so grateful for the experience that I have gained, as reading about crisis in third world countries and actually experiencing it is totally different.

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From my reflections in conversation with photojournalist, Chris de Beer-Procter

In April I was asked a number of questions regarding my involvement with people with intellectual disabilities and their families during the lockdown.

PWIDD - People with Intellectual and developmental disabilities

## **What are your worries about PWIDD and the virus?**

### **Medically and socially/personally/emotionally**

My worries at the time included:

- 1) Most of the people with intellectual disabilities that I have been working with have a compromised immune system, co-morbidities, health issues and diseases (incl. diabetes, hypertension, asthma, allergies, gastrointestinal issues (GI)), mental health issues and are on medication with some experiencing the side effects.
- 2) Majority of them are from low- and middle- income households. Therefore, their vulnerability increases and my worries further include

- environment (for example noisy environment as everyone is at home and for those with sensory issues, this is hard to cope with as there may not be anywhere to escape to)
- sanitation (for example not being able to afford cleaning products, toiletries, hand sanitizers or even toilet paper)
- a lack of accessible drinking water in some instances
- lack of food and nutrition (themselves or their loved ones losing out on earnings and not having any income)
- lack of exercise (which some of them need in order to keep their energy levels under control or their bodies free from stiffness and pain)
- not being able to go out on the sun (again in some instances) – a lack of vitamin D has an impact on maintaining a healthy immune system.

3) A lack of understanding of what is happening right now and unpredictability, which can lead to health and social care issues. In the care homes and facilities, the residents are being educated by the staff. However, in the home situation it can be a different scenario. There are many informative materials designed for people with intellectual disabilities, but they may not be accessible to them due to a lack of support or their socioeconomic status as most of the materials are online and they need internet access, which many of them may not have. If the material is accessible, it may take a long time and many different learning materials/approaches for people with intellectual disabilities to reach some kind of understanding of the situation. Currently, in their home environment, they may be relying on the media or their own observations of the situation at home and around them, possibly getting more anxious, confused and scared. Further, imagine if you have difficulty in hearing or

vision or cannot communicate verbally and are surrounded by people who may not necessarily understand your needs (some of the care homes have been closed and have sent the residents home; schools and other facilities are closed too). This then contributes further to an increase in your anxiety and a decrease in tolerance levels. This may result in an increase in violent and emotional outbursts, which impacts on the family and environment and may further result in resentment and negativity.

4) Some people with intellectual disabilities are in lockdown with family members with whom they may not get along well. There is an increase in challenging behaviour and outbursts and many family members may not necessarily know how to deal with it. There is a lack of professional support as it is; now with the lockdown there is very little support to guide everyone through building healthy and positive relationships.

On one side there is an opportunity to get to know each other and to strengthen relationships but on the other side, all of us have own routines and some of us are better at adapting and tolerating than others.

5) People that have been out all day, are now at home. Those that had busy schedules have none or very little stimulation.

6) People with intellectual disabilities love to attend religious institutions. Now those are closed.

On top of this all they may be missing their friends, their work colleagues as not many have access to social media or other means of communication. They are missing out on life skills development, Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs) and some of them may even regress. There is more to come when the

lockdown restrictions ease over the period of time, for example, understanding social distancing (if you are used to shaking hands or a hug when seeing someone and now you can't and it does not make sense) or wearing masks (when going for a walk or to the shops. You see everyone in masks. You cannot suddenly work out what they are saying as their face is covered; the non-verbal cues and facial expressions are no longer there. Or if you are hard of hearing or deaf and rely on lip reading, suddenly you are excluded from socializing and conversations. Other factors bearing in mind when wearing masks include sensory issues, not touching the mask or your face, it may be uncomfortable, hard to breathe, constantly washing or disinfecting hands if you touch it, the way how you put the mask on and off). By the time the person learns all these socially acceptable new rules, the mask wearing for instance, may be removed.

Some adapt better than others, some don't at all. All depends on the support network and a level of understanding and coping mechanisms.

**Can you shed some light on the context of people with intellectual disabilities and this virus? Any word yet on how it's affecting the community?**

Unfortunately, I have not been able to support people with intellectual disabilities and their families in person, therefore I am relying on the social networks and platforms and other means of communication, which is interpersonal and unpredictable (network issues for instance) causing sometimes more anxiety and distress. I have been receiving a lot of distressed calls, trying to support individuals with intellectual disabilities, families or the community as much as I can. If I know them, I can guide

them through already implemented strategies and interventions, which may be forgotten about and support them in applying them to the new scenarios (quite often old behaviours may occur when in distress) in order to adapt and cope better. But it is challenging when new behaviours occur and there is a need for finding causes, cues and triggers first. You are relying on families and people with intellectual disabilities accounts and feedback, and more often than not, the feedback may not be as accurate, reflective or descriptive as you need it to be in order to guide them all through it and develop some sort of strategies. I found myself in situations where I was asked for my opinion or support of people with intellectual disabilities whom I do not know at all. Those scenarios are the most challenging ethically and personally for me. I can refer the people with intellectual disabilities, families or professionals to resources or walk them through in order to identify or at least make them aware of the causes, cues and triggers, but it is challenging to design a plan or an intervention without any assessments and face to face contact. This then adds to the anxieties, distress, desperation and may end up in behaviours that the person would not normally display. You are aware that they have a huge need, you want to help but currently can't, so it does not leave you in a good space. As a professional you learn to reflect, to debrief to cope with these emotions but at the end of the day, you just make another referral or alert the appropriate agencies. And there have been professionals and support agencies on the same boat as you.

Times are tough for everyone and we are all being challenged in order to find more effective and innovative ways to support people with intellectual disabilities and their families as much as you can. I check on the people with intellectual disabilities and their families known to me as often as I



can. The frequency depends on the feedback I am receiving. It further helps that I have a good relationship with the families and know them well. I know which families would have never asked for support or help and would be silent and try to deal with things on their own. I would love to say to all the people with intellectual disabilities and their families, carers and loved ones that right now, support is important, and they are not alone. Be kind to yourself and be honest if someone asks you how you are. Even if they cannot help you, getting things off your chest, get the emotions out, goes a long way. It may help you to cope, to increase your tolerance levels or to brighten your day at very least.

### **How equipped do you think medical workers are to deal with the particularities of people with intellectual disabilities?**

The medical staff has its hands full right now and I admire them. Not an easy scenario.

But to answer your question: it depends on the hospital, level of training, level of experience of the staff working with people with intellectual disabilities, their personality and tolerance level on the day as well as on the level of understanding, communication abilities, capabilities and disability of the person with intellectual disabilities.

In my experience, the medical staff needs further training in caring for people with intellectual disabilities that have sensory issues, communication issues, profound and multiple intellectual disabilities, or present with behaviours that challenge at very least. Usually, a carer or a family member is able to aid the medical staff on the needs of the person with intellectual disabilities. I would suggest for the families and care homes to develop a hospital passport reflecting the basic information

about the person. One page with key issues including basic information about the person, health and social care needs, favourites, communication, ADLs (basic activities of daily living). This will support both sides to gain a better understanding of each other quickly under the current, very stressful and anxiety provoking, situation. The families or the caregivers cannot visit therefore cannot provide that link between the two parties. If the wards are busy and there is a skeletal staff, it may be difficult to establish a rapport, and those working with people with ID know that this takes time. So, the hospital passport, I found, has its place and it was effective in the past when we were sending residents to hospitals for procedures. We had great feedback.

**What advice do you have for families/carers of people with intellectual disabilities during this time?**

To hang in there and not to be afraid to reach out and ask for advice or help. Even if it is just to chat to someone. It is particularly important to keep on top of things, maintain good mental health and to regulate tolerance levels. Making sure that you have some sort of support at hand. Everyone is doing what they can with minimal or no resources and they do have my admiration. Because it is not easy, and the information and restrictions are being changed almost on an hourly basis. It is so easy to change your mind and outlook on things depending on how you feel in that particular moment, what you read and where you are. So, do not be harsh on yourself if (or when) you lose perspective and the emotions pour out. Be kind to yourself and keep reminding to yourself that you are doing the best you can under the circumstances. It is like navigating a large

ship through a hectic, unpredictable storm with the view of saving everyone on board.

**What do you think the public needs to know about people with intellectual disabilities, especially now?**

The public is aware that this group of people and their families and caregivers are particularly vulnerable right now. Reaching out, being non-judgmental, supportive and understanding is what is required right now. Shopping, securing food, understanding rules and the law, applying for aid or financial assistance may be particularly challenging at this stage especially if many NPOs or professionals were not able to assist personally.

Equally, the same applies to the future. Some people with intellectual disabilities may have difficulties to re-integrate back into the communities and may need to be re-taught many basic aspects of daily living. So, patients and understanding have been (and will be) playing a massive role.

**Anything else you think is important?**

Whatever approach is chosen it must be holistic and person centred, reflecting views and learning curves from across the board (including people with intellectual disabilities, families, carers, therapists, medical staff, schools, care homes, workplaces etc.) before further strategies are developed.

Because of the current state of affairs and economic crises, many care homes, schools, work environments and other facilities catering for people with intellectual disabilities will require more support than usual especially with integration. This applies to families with people with intellectual disabilities and people with intellectual disabilities who live in the communities too. As there are a lot of financial losses across the board due to the lockdown leading to a loss of income in many instances the required professional care may not be financially possible for many people with intellectual disabilities.

Many families have lost their earnings and may be looking to the state for support where in the past they would have been able to pay for private care or therapy or facility. In my current experience, there are not enough state provided professionals and non-professionals as well as non-profit organisations (NPOs) and facilities as it is. The services are already overwhelmed and many families, individuals with intellectual disabilities and sectors are left without proper support or with heaps of paperwork and instructions they do not know what to do with. The state sectors and services are providing placements and community services for students studying towards a professional degree in health and social care who work directly with the people with intellectual disabilities, families, schools and facilities. Those students leave at the end of their placement and there is a genuine hope that someone else will pick up the case and/or continue with the current plan. The continuity and effectiveness, however, depends on the funding as well as availability.

There are many foreign professionals that are trained in the fields of intellectual disabilities abroad or have years of experiences working with this group of people. It is a long process to get registered with any professional body in SA and quite often, the professionals' qualifications

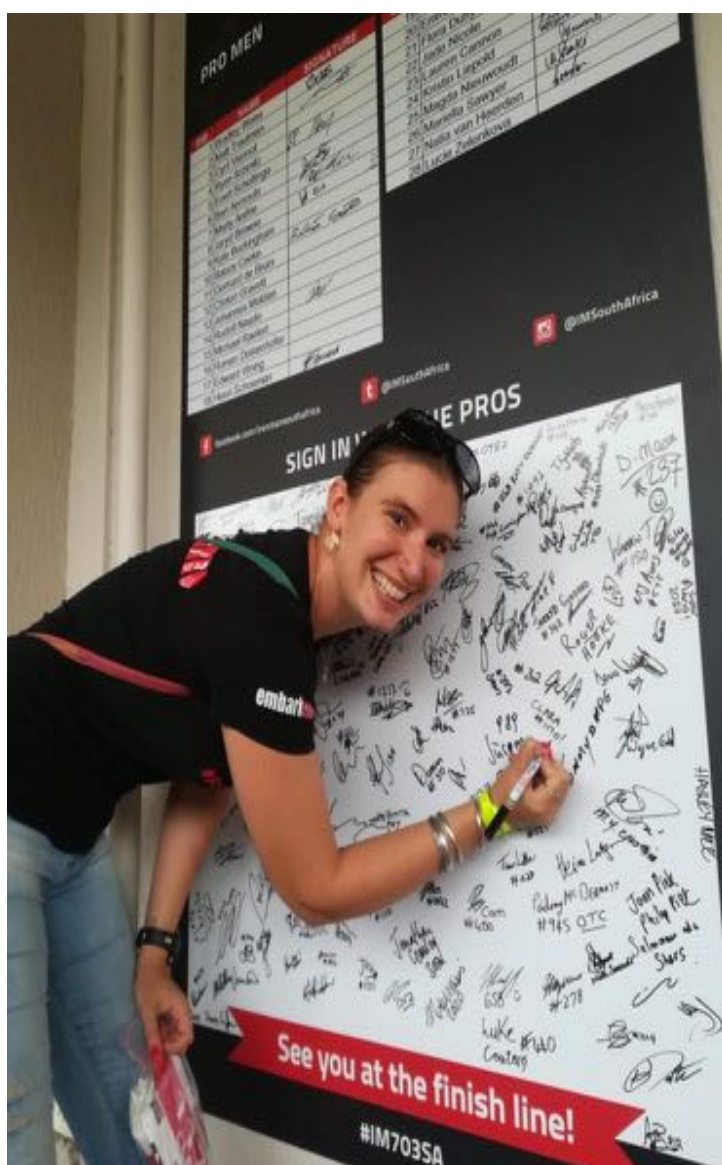
may not be recognized by the registration body or meet the registering criteria as intellectual disabilities falls under mental health; it is not a separate field. Those professionals then work in different fields as they may not have finances and support for redoing the qualification in South Africa altogether therefore their expertise is lost. Creating a platform for those professionals where their expertise can be utilized whilst being supervised and/or working under certain criteria towards the registration may ensure continuity of care and/or affordable and accessible services for people with intellectual disabilities and their families.



## Teaching, working and learning in Cape Town during COVID-19 - Clara Machado

I am an outsourced remedial teacher at a middle school in Cape Town, South Africa. Before lockdown hit, I was working with children in a one-on-one capacity between the ages of 12 and 16 with a range of needs and abilities. Many of them were on the Autism spectrum, some had specific reading disorders; there were children who needed support with executive functioning along with comprehension and thinking skills as well as overall academic support.

Once lockdown was put into place and our school decided to go with an online learning programme there was the challenge of being able to continue my work with the children on a virtual platform. Most of the children I worked with, including all of the children on the spectrum, decided not to continue with virtual Learning Support. The main reason being that they struggled to engage online and found it very difficult to work with a person over a





screen rather than face-to-face. The other reason was due to finances as many of their families experienced

severe financial losses and could no longer afford Learning Support.

After the first month of lockdown, when it became apparent that this was not going to be a short-term problem and the school decided to continue with the (slightly reduced) curriculum as per normal, more of the children I had worked with wanted to pick up Learning Support again. It was a challenge to figure out how to best help the children and not be with them physically. Thankfully we all found our feet and I found that doing Learning Support online was not an impossibility.

Since our school reopened in July most of the children are back (coming on alternate days so as to avoid overcrowding) and my caseload is now busier than it was before lockdown. I am able to continue working on a one-on-one basis and am also continuing with online lessons for the children who have opted not to return to school. Many of the children I am currently working with fell behind in the curriculum during lockdown because of the overall struggles of engaging online, finding it difficult to manage themselves and their work independently, the distractions of home and the general stress and anxiety that has shadowed us all during this time. My sessions in July were mostly spent ensuring that children were caught up on their work, reteaching and revising curriculum content. Since August, now that restrictions have eased even more and there is more of a consistent school routine, I have been able to return to focusing on developing comprehension and thinking skills with the children.

I also work at a children's home as a homework tutor. The children's home provides residential group care for children (many of whom have specific learning disorders) who aren't able to live with their biological families. The children's home has close links to the school community, with many of the

children attending the school system. My role is to provide homework supervision and tutoring for the children in middle and high school.

Some of the children at the home would usually be able to spend their weekends with their families, however due to the lockdown regulations being so strict in South Africa the children were not allowed to visit their families or have their families come to the home and visit them. These regulations only eased towards the end of August, which meant that these particular children were not able to see their families in person for almost six months. This took its toll emotionally on the children who were also feeling increasingly claustrophobic and experiencing cabin fever to varying degrees. For the first two months of lockdown people were not allowed to leave their homes, so the children were all cooped up together and it was very frustrating for all of them.

Once school reopened two of the children did not want to go back. They were worried about getting sick and stressed about the whole rigmarole around having to change clothes and shower as soon as they got home each day. Added to the fact that this was in the middle of the coldest and wettest winter in many years, they lost all motivation to go back to school. Despite being able to see their friends and interact with teachers in person (something they both struggled with online) their anxiety was such that the thought of going back to school was very overwhelming.

As the months have progressed more children are returning to school, but many of them (the children I work with at the school as well as those at the children's home) are struggling to transition between online and at-school learning. As the children are still required to come to school on alternate days it is proving to be quite stressful and difficult for them to bridge the gap between independent online learning and being at school. My personal belief is that the focus on academics should have been lessened during this time. I found it challenging and frustrating that the

children, and teachers, were still being asked to perform at a “normal” academic level when our world is in such turmoil. I am proud of the school for endeavouring to maintain a level of schooling and academics with which to keep the children engaged, but the emotional cost of this continues to take its toll. My priority during this time has been to make sure the children I work with can make it to the end of the year with a sense of identity, have their mental health intact and build on their resilience and thinking skills to be able to manage the obstacles life will put in their paths.

Clara Machado

Remedial Teacher

### **How I met Clara**

I have known Clara Machado since she was about 11 years old when I moved to Cape Town. Her family lived next door to ours. Our families and our kids spent a lot of time together. Through this, she saw my son (Andrew) and his challenges and what support he had and how I taught him. She was great at playing with him and helping him. From early on I knew she could deal with him and his needs extremely well. Clara also learnt about my work across Cape Town in Special Educational Needs, with doctors, psychologists, therapists, schools, organisations and parents. Clara’s mum worked in schools too as a librarian and in some support roles. Clara developed a great interest in helping children and learning and decided to become a teacher. She is a natural teacher.

She quickly became involved in Special Educational Needs and Autism. I know how highly thought of she is and how exceptional she is in working with children and families and what a worthwhile contribution she makes.

She has had various roles in Cape Town, including working as an educational therapist within a programme for autistic children. She has also worked in schools in London, UK.

Thank you so much for your Interesting and valuable contribution, Clara.

Anne Donohoe Cape Town, South Africa



## Spain

### Almudena Martorell, Learning Disabilities and COVID in Spain



I am Almudena Martorell, president of the A LA PAR Foundation. I want first to introduce our organisation, where we work with people with learning disabilities for their rights and participation, designing supports where they find barriers. We provide these supports through different services: education (200 hundred school students), sheltered employment (we count with more than 150 employees with learning disabilities); ordinary employment (around 200 people with learning disabilities are hired in the Spanish workforce through our service yearly); mental health and challenging behaviour services,



access to justice and victim support, independent living, sports (with two Paralympic sportsmen!)... And willing to keep on growing to serve the rights of people with learning disabilities, because we believe that their full participation makes better societies for all.

As you might know, Spain is one of the countries which has been most shaken by the Coronavirus pandemic. And, like the rest of the world, we are really worried and have suffered a lot. Probably one of the worst moments was the beginning of the lockdown, not knowing what was going to happen, how contagious this was... We were also very worried about the survival of our organisation. Many of our activities were forced to close, and therefore many of our sheltered employment businesses. But also some others could continue, because they were considered “essential”: basically our service of parcel delivery in the neighbourhood and our contract with the Spanish Postal Service for the cleaning



and disinfection of their boxes.



As many of our workers (we are 500 workers in the A LA PAR Foundation) had to go to temporary unemployment (our Foundation completing the salaries) because of the forced shutdown of our activities, we had to take a thoughtful decision: though the parcel delivery and box cleaning services had always been undertaken by workers with learning disabilities, maybe this time those had to be the workers who had to be protected, and therefore should stay at home, and put the workers without disabilities to develop these tasks, though they were not their usual commitments, their commitments had been shutdown.

### **What do you think had to be done?**

I don't know which is the correct answer, but I would like to share with you our decision, and I would also love to share your thoughts and opinions if you would like to send them over to me.

We decided that we could not take any decision based on someone's condition. This meant that we couldn't decide saying "as this worker has a disability...". If someone was at risk, or their families, or had to take care of someone who had to stay at home (kids, elderly...), those could be motives to decide who should not work during the lockdown. But those could be present either having or not having a disability. We also decided that as an organisation we had no authority to eliminate someone's right to being useful and having the privilege to boar with others during such tough moments. Moreover, it was a very important moment to shine and break prejudices about the value of people with learning disabilities. It reminded me of women in World War II, and the images we all still remember of their value.

So, all the 150 employees with learning disabilities worked every day during the shutdown, except those which expressed medical risks for them or people they lived with, as happened to the rest of the workers. None of them got infected, which they could have as everyone, and in that case, it wouldn't have been fair to judge the decision on a posterior fact. They demonstrated their courage, their value and their responsibility –it was impressive how they respected the sanitary measures-. Thanks to all and congratulations to always standing up to your dreams.



## Wales

### Paula Hope's Story - Reflections on connections



I was one of those lucky people who had a holiday at the start of the year before COVID 19 had hit the UK and while we still knew little about the way our lives would change in the way that they have. I went to Tenerife and while I was there an outbreak of COVID happened in one of the nearby resorts, there was no impact on me and my holiday until it was time to travel home and I started to see people in



the airport wearing masks and gloves. Once I returned to work it was clear that we had COVID 19 preparations in place and we were aware of what the impact of this could and would be for people in our services. It was a very worrying time and I started to see a change in my own

behaviour and my mental health. I started to become very anxious about when I might be able to travel home to Middlesbrough to see my family and friends, I was scared that I might not see some of them ever again and I was worried watching the news, listening to the radio and seeing the messages on social media about what was going on in the world and how people were behaving. Shopping became anxiety provoking and frustrating and as my world started to become smaller, with so many future events being cancelled (holidays, conferences, award ceremonies, networking events, trips to the cinema and theatre) I started to feel despondent, hopeless and scared.

I was conscious that in the decisions being made people with learning disabilities could have quickly been forgotten about and excluded. It started with the original messaging, 'don't worry, it only affects the old and the vulnerable' and as we know a society is judged on how it takes care of people in those groups. Next, it was the poor quality information about what the public were expected to do to keep safe, with key figures openly describing how they were going around shaking hands and suggesting that the virus was just like flu, which kills thousands in the UK every year (still more likely to kill the old and vulnerable). The memes were flying around, poking fun at the guidance: stay home, unless you have to go out, then go out! Once the restrictions came people immediately ascended to the hills and took picnics with them, flouting the guidance and increasing the risk to themselves and others. The Public Health guidance said stay home if you think you have COVID19 but also that you could go for a walk once a day.

I thought about the people with learning disabilities and their families who may be confused, worried, scared and frustrated with the information and confusion going on around us. I wanted to reach out and reassure, simplifying information and connecting people. After a particularly sleepless night, I got out of bed at 3 am and did two things. I drafted a letter of thanks and support to the nurses in our service who were dealing with unprecedented levels of change, challenge and communication and I set up a COVID 19 Facebook group for sharing information on meeting the needs of people with learning disabilities/intellectual disabilities during COVID 19.

‘Hi all, I’m sure we are all getting lots of information and sharing in various ways. I thought setting up a group like this could become a resource bank and let us share things in one place that we can easily access. We might also be able to support each other through what undoubtedly will become even more challenging times. Please share ideas, share information and share the page’.

I wrote this message and shared with all of my friends and colleagues who have an interest or career in supporting people with learning disabilities. My former colleague, Steph Carr who is a speech and language therapist was keen to support the group to make sure that information would meet good communication standards and so the two of us became co-administrators. We have 1,200 members in the group, people with learning disabilities, their families and staff, student nurses, teachers and a wide variety of interested people contribute to the discussion, sharing information and requesting support to meet the needs of people with learning disabilities.

While administering the group I have seen people put various posts in that have been about giving and receiving information. Sometimes people share very useful resources that they have designed with an individual in mind, e.g. somebodies' brother who needed support to understand places were closed, these resources can then be adapted and further personalised. Other times people have made requests, they need to help somebody understand something and want to know if there is a resource available e.g. why we need to wear masks in shops. However, not everybody who wants to join the group has understood the purpose of the group, there are some people who want to sell services such as psychotherapy or remote classes. There have been some materials shared that do not meet the objective of the group and it can be challenging to think about what might be motivating somebody to want to be part of the group. We have set questions to ensure that people understand that this is about the support we can give to people with learning/intellectual disability but there is a broad range of people who will say they have a disability and want support to understand benefit entitlements, claims forms, their diagnosis even. Facebook is an international platform, this means that there are people looking to join from all over the world and potential cultural, communication and political barriers can exist. We have had some requests from journalists who want to connect with members as well as researchers and storytellers which has given people with learning disabilities a platform to share their experience and be heard. There is a great sense of responsibility to ensure that the group does what it set out to do and does not lead to exploitation or increase potential stress or anxiety for people. Overall it has been a positive experience and members of the group are supportive and respectful of each other.



In the world of learning disability, we have long given the message: 'if we get it right for people with learning disabilities, we get it right for everyone' and this has certainly been highlighted with the need for clear and easy communication which has supported people to make decisions about their health and contact with others during the pandemic. Where the messaging has been loose, unclear or open to individual interpretation this has been very challenging for everybody. Working together, listening to the fears and anxieties of the population and supporting clear communication, that is timely and responsive is so important to make sure that nobody gets left behind. Working through COVID 19 has challenged all of us to do things differently and to ensure that the people we support are at the front of our thinking, never has the need for us to work in partnership with people with learning disabilities and their family and supporters been greater. Ensuring that policy makers and public health information is written and shared in a way that people can understand, process, retain and repeat has been so important.

We know that people with learning disabilities often experience health inequalities in a fully functioning health system, there were many concerns raised about how people with learning disabilities would get fair and equal treatment during COVID:19. There was some misinformation and some poor dissemination of information that didn't always fit with the human rights based models that we employ in supporting people with learning disabilities. At the beginning of March we saw the issue of the rapid NICE guidelines inclusion of a frailty score, there was lots of information being shared on social media about the concerns regarding the use of the frailty tool for people with learning disabilities, subsequently NICE issued a statement to be clear that the frailty tool recommended within was not suitable for assessing people with learning disabilities and although they

have not recommended an additional/alternative tool they have been clear that an individual assessment would be needed where the Clinical Frailty Score is not indicated. There were many families and people with learning disabilities who were concerned that they may have been disregarded or deemed unsuitable for treatment if this was not taken on board.

In my role, as a nurse consultant I have been able to highlight key issues at a level where action can be taken and guidance can be influenced. This has meant that I can support our teams and the people in our services to respond confidently, share good practice, highlight areas that have the potential for ethical or moral challenge and keep people safe. I have seen colleagues stepping into new ways of working, finding themselves bombarded with information and needing to adapt the way that they meet with and support people with learning disabilities all while dealing with their own anxieties, challenges and caring responsibilities. A new language has replaced our everyday conversation: lockdown, social distancing, PPE, COVID 19, Coronavirus. These words are everywhere and with them comes the potential to exclude those people who do not have the capacity to engage in the conversation.

It has been awe inspiring to see the way we have been able to use technology to run our services and keep process in place so that people with learning disabilities continue to have their needs met and understood, but we must not forget about the importance of human connections and ways of being. In some ways, I have felt more connected than ever to my colleagues across Wales and the rest of the UK, we have worked together to problem solve, share information and raise issues that have evolved out of generic advice and guidance that has needed to be carefully interpreted and targeted for people with learning disabilities and their

families. We know that people with learning disabilities often experience high levels of loneliness and social isolation, there is fear for some about how they will be able to access the community supports that they want and need and as services have needed to reshape and reposition ways of working this means, going forward there is an even greater need to be inclusive, reach out and connect, keeping in touch and finding ways to build lighter moments into our days is very important, particularly as a COVID way of living is going to be with us for some time.



## Hannah's and Susan's Story - Wellbeing and working together

During the COVID 19 pandemic there have been necessary changes to the way that all learning disability services have been able to work with people with learning disabilities and their families. Many of the professionals working in multi-disciplinary teams have needed to make individual decisions with families and people with learning disabilities about meeting their support needs at this time, reducing face to face contact and utilising technology where possible to maintain support, advice and reassurances. One of the most overwhelming responses to the pandemic many of us observed was the generosity of members of the public and businesses and an outpouring of gifts, food, drink and items to ease people's stay in hospital.

In this article Hannah Samuel (Staff nurse, Acute admissions unit) and Susan Owen (Community learning disability nurse) reflect on how they worked together, having never met before to share ideas, developing wellbeing resources and providing support to people with learning disabilities and their families in and out of hospital to lift spirits, provide person centred active support and engage through art, sensory materials and creative approaches through challenging times. There will also be reflections from people using our services on how they felt about the development of the packs.

By connecting with each other through social media these learning disability nurses have shared good practice, ideas for innovation and gathered feedback from people with learning disabilities and their families. They have developed resources which have facilitated activity, and this has provided additional support to people with learning disabilities at a time that has been very anxiety provoking and potentially

could have seen a deterioration in mental health and wellbeing as well as an increase in challenging behaviour.



## Engaging people with a Learning Disability upon an Acute Admissions Unit during COVID-19 outbreak: Hannah's story

'COVID-19' or 'coronavirus; the words that make our ears prick up and the hairs on our arms stand on end, the scary, unknown virus that has taken over and turned everyone's world upside down.

As a nurse working on an acute admissions unit, Hannah describes seeing a myriad of changes for individuals using our services. The introduction of the lockdown and social isolation; causing the once comforting and inviting environment to be flipped into a clinical and socially isolating environment. Structural and change in the delivery of care has been necessary due to the guidelines provided by Government, local guidance and application of policies. Staff who usually offered a kind smile and a reassuring hand are now governed to cover their smiles with PPE or remain two meters away, avoiding any unnecessary contact. The individuals we support were very confused and distressed by this, leading to anxieties rising rapidly and unfortunately some individual's journey to recovery have taken large steps backwards.

Since the initial lockdown was implemented by UK Government, people in inpatient settings have found this increasingly stressful and emotionally straining due to not being able to see their extended networks, including family, carers and friends. Although many individuals throughout the country are experiencing increased anxiety and depression living in a state of social isolation with the added worry of contracting COVID-19; the people admitted to the unit before and during this pandemic also have the added stressors of unfamiliar faces and environment, experiencing a personal crisis and the inability to seek comfort from those that know them



best during a time of personal uncertainty. Other individuals have experienced heightened anxiety due to not completing usual routines, especially those who experience daily outdoor activities/vehicle trips as part of their therapeutic input. Within the unit we have observed an increase in some people's anxiety also leading to an increase in agitation and behaviours presented.

To support people, we have ensured that we keep those who have the capacity to understand the situation updated with easy read information on COVID-19. This has explained how to maintain safety through following the Government guidelines, along with daily updates we have received internally, helping us make sense of how to apply this to practice. We have held structured and as necessary ward meetings to discuss with patients the information on COVID-19 and discussed any of the service users concerns. As always, a person centred, and individualised approach has been necessary to ensure that people are given support to understand the information in a way that has meaning for them. For some people understanding that there is a virus has helped, while others have needed to know that places are closed.

Following three weeks of lockdown to the ward, the wonderful news of reasonable adjustments and changes to restrictions for individuals with Learning Disabilities and Autism was gratefully received. This allowed individuals within our service to access vehicle rides and exercise within open spaces, for some this was wonderful. For other individuals the initial three-week lockdown and fear of contracting COVID-19 had exacerbated anxieties so much that they had regressed in their treatment and became withdrawn and non-engaging, fearful of interacting with staff. We needed to find alternative activities for these individuals.

Within the acute admissions unit, people were used to being supported in a variety of ways to access the community and the resources we had to engage in meaningful activities were usually purchased by individuals in line with their own interests and wants and wishes. We did not have a resource of activities and materials that we could maintain peoples' interest in to support ongoing engagement with. As a team, we discussed this issue in numerous handovers and attempted to devise a plan to improve on ward activities and occupation during such strict lockdown regulations. It was agreed that we reach out to our local communities for help. We had seen such an outpouring of generosity with responses to the NHS, particularly for those who were unable to have visitors and members of the public had provided toiletries, nightwear and activities to the wider acute services. An Amazon Wish list was devised in collaboration with the individuals we were supporting to ensure that we would be requesting activities and items that would be important and comforting to them. The list modestly included gardening activities, board games, jigsaws, music, DVD's, sensory items, snacks and toiletries.

Once the list was created, we shared with a few colleagues who were very generous, however we could not rely on solely these colleagues to help fund the list. Hannah took to social media to share the story of the ward and how the lockdown had affected the individuals using our service. The Wish list exploded and within 72 hours we had received notification of purchase for everything we had requested. The individuals we supported continued to offer ideas for activities they would enjoy or what they thought would be helpful for others. The wish list continued to be shared through social media networks.

Through social media we then received a very kind message from a local business owner who requested to share our story and list with other small

businesses and friends and also offered to deliver some of her products to the ward for service users and staff to enjoy. We gratefully took her up on her offer and a few days later received some beautiful cakes along with a few more generous donations from our wish list.

The daily Amazon deliveries became a highlight of people's day, staff included, all were eager to see inside the cardboard boxes and try out any new activities. Slowly but surely, we began to see service users engaging again and having fun; forgetting about what was going on in the world for maybe even just ten minutes was a huge relief for some. Sensory items particularly have been a wonderful asset to help individuals relax and distract from the anxieties they were experiencing.

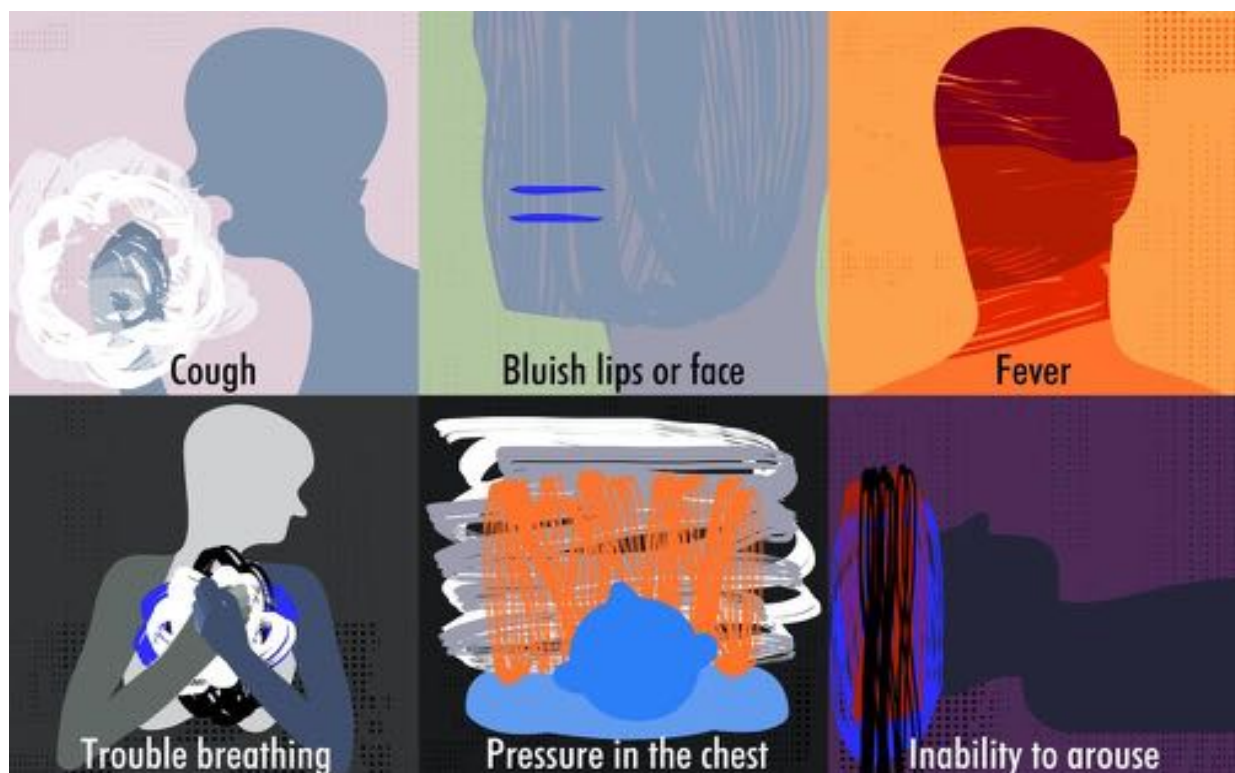
Through creating and sharing this wish list, not only have we gained a lot of very nice items and activities but also a new community presence within our local area. The community now understand what the service provides and are eager to support us. Each Thursday a local Thai take away chose to deliver fresh food to the ward, providing a much-needed morale boost to the ward environment. The power of social media! Large, multi-national companies have also made generous donations to the ward. and service user's mood and wellbeing have improved immensely through the introduction of these donations as well as the wish list.

To help with the huge issue of loss of contact with family, friends and carers we put forward an application to the health board for an iPad for the ward that patients could utilise to face time people important to them. To be able to see their loved ones or support staff face-to-face has such a positive impact on the service user's mood and overall presentation, especially some of the people we support who have a diagnosis of Autism. These individuals in particular have responded better to the face-

to-face conversations rather than previous attempts at phone calls. This use of technology has also received positive feedback from families, friends and carers as they feel at ease to see their relative looking well.

The whole experience of lockdown upon an acute admissions unit has been a rollercoaster of emotions for both service users and staff, however through the support of our local community and friends on social media we have turned a scary and unpredictable time for our service users into a fun, exciting and warm environment where they are able to experience a positive recovery process with the added bonus of a slice of cake!

Hannah is a staff nurse



## **Susan's Story Supporting people with a Learning Disability living at home in their community during COVID-19 outbreak**

From the very beginning of the COVID 19 pandemic and response to the Government restrictions put in place to manage the spread, we as health professionals have had to adapt to a very different way of caring for and supporting people with learning disabilities in the community. I work as a community learning disability nurse supporting adults with learning disabilities in various settings across the Vale of Glamorgan along with my health colleagues which include nurses, speech and language therapists, physiotherapists, occupational therapists and communication development officer. The Department of Health and Social Care, within their COVID 19 guidance for carers 2020, clinically defines people with learning disabilities, who often have higher overall levels of chronic disease and a higher risk of respiratory disease than the general population, as 'extremely vulnerable'. With some of our own health staff self-isolating or shielding and very early on we saw offices closing as we were directed to work from home our practices needed to quickly adjust so that we could continue to support people with learning disabilities who live alone, live with elderly parents, and live in supported living accommodation or residential care in an effective and caring way. We needed to be proactive in our approach to identify those who are more vulnerable and those whose regular care needed to withdraw to keep people safe from the virus and keep people informed on the government restrictions in a format that they could understand. Working from home left us all feeling a little isolated but through a variety of communication platforms, we as a health team held regular virtual meetings to identify those who were most vulnerable, work out a system that allowed us to check in with them and share out easy read information

about COVID 19 and what that meant for them. Along with our social service colleagues we kept in touch with care providers for adults with learning disabilities within the Vale to share relevant information to keep people safe and well.

As the lockdown restrictions continued and we recognised that many of the people we support were shielding for their own health reasons or those of their family. We as a community health team recognised the potential impact of this on their mental health and the negative impact a lack of structure and routine can have for the people we support. The National Development Team for Inclusion (NDTi), 2017, presented key findings when exploring the impact and effectiveness of meaningful activity for people with mental health which included people experiencing positive outcomes from participating in meaningful activity. Within their research, they concluded that meaningful activity can offer a person a sense of purpose, structure or routine to a person's day and achievement of skills or a feeling of being useful. Meaningful activity can improve a person's wellbeing by offering them creative challenge or self-expression and in turn can improve confidence, aspiration and self-esteem.

As health professionals, we were also aware that changes in routines and care can be particularly stressful for people with learning disabilities and the measures that put in place during the outbreak presented additional challenges in how best to support and how best to communicate change to the people we support. With little structure, usual day occupational services have been withdrawn, people becoming socially isolated as a community team we worked together to look at home based activities, easy read online resources, developing activity timetables for people with profound and multiple learning disabilities,



paper based activity resources and shared these with people with learning disabilities, their families and carers. It was important that accessible information was provided to support people with learning disabilities so that they could better understand COVID 19 and the measures introduced to manage the virus. We needed to consider solutions to support those who may have been anxious about the COVID 19 situation and those whose behaviours that challenge, particularly as we had limited contact to offer our support.

The physiotherapists and Occupational Therapists worked alongside their Cardiff Community Support Team colleagues to develop online videos which included mindfulness, exercises, activities with professional advice from physiotherapists and occupational therapists. Within the Vale we continued to look at resourceful ways to support people with learning disabilities to keep physically and mentally well during the COVID 19 lockdown. It was then through browsing through social media I came across Hannah's wish list for one of our AAU's through a mutual friend sharing her post. Many of the people we support in the community continued to be supported at home and we were aware of the increased anxiety and stress that they and their families were experiencing. Not everyone was confident using online resources and I wanted to adopt this very practical idea and develop it in a community environment to benefit everyone. Hannah and I were soon put in touch and Hannah's enthusiasm and support was instrumental in developing the very successful Rainbow Packs that benefited in more ways than we could have hoped.

I initially approached my health colleagues and management with the idea to make up bags with practical, useful and fun items that people could use at home to stay physically and mentally occupied. –I was met with a positive response and with support from Hannah I developed an Amazon wish list which was posted on social media. The items were carefully selected considering people's needs, their physical abilities, sensory needs, mental health needs, likes and dislikes and our health colleagues worked together and using their professional knowledge advised on suitable items to go into the bags. We adopted the rainbow image which is widely used as a hopeful emblem during the COVID 19 pandemic to design our 'Rainbow packs'. The responses from social media were very positive with kind messages of support and our post was shared widely. It did not take long to take off and parcels were delivered on a daily basis. Gifts were donated by friends, colleagues before being shared in different community groups and donations were coming from the wider community in Vale of Glamorgan, the Rhondda, Bridgend and Cardiff. Within my own local village, we saw a fantastic community spirited event held by Reality Fitness, which set up physical challenges, the proceeds raised were shared between our Rainbow Packs and another worthy local cause making face masks for key workers. We were overwhelmed by the generosity of our community to support people with learning disabilities during what can only be described as a difficult time for us all.

Individual bags were made up with the donated items with each person's individual needs considered including sensory needs, what they enjoy doing and what activities can help them feel calm. The organisation of the deliveries was well coordinated and followed all social distancing rules. As the deliveries went out and feedback from the people we

support, and their families were full of praise. One family expressed their gratitude through our social worker and said to pass on their message that 'the wonderful 'Rainbow Pack' arrived yesterday, what a fantastic idea. It was carefully put together and the contents seem absolutely spot-on and tailor made for her. Please thank all those involved for the great care they have taken in pulling this pack together for her and putting this pack together and taking the time to deliver it. It is hugely appreciated'. Other feedback included 'That's exactly the kind of things we could do with' and 'The pack couldn't have arrived on a better day' as they have been 'finding things difficult'. The bags did not just offer well thought out items but also an opportunity for people to see health professionals and have a doorstep chat or catch up. It was a good opportunity to remind people that the health team were still here to offer our support and in some cases during the deliveries my colleagues reported back that some families really needed a chat. Within the rainbow packs, we included a certificate for staying at home and protecting the NHS and for some people the easy read activity timetable for people with profound and multiple disabilities. As word got out our social service colleagues identified more people that would benefit from the rainbow packs and we managed to deliver sixty bags to people with learning disabilities who live alone, live with their partner or their families throughout the Vale of Glamorgan.

From the beginning of the COVID 19 pandemic and the government restrictions placed on us all, we have been required to adapt our practices to best meet the needs of the people we support. People with learning disabilities have higher rates of health problems associated with their diagnosis making them extremely vulnerable and requiring them to shield. Those who were may become isolated from their

community. A lack of social interaction, social support or meaningful activity can cause depression and increased anxiety for people with learning disabilities, (Austin et al., 2018; Bond et al., 2019). Within the Vale of Glamorgan, we have witnessed increased anxieties and stress on people with learning disabilities and their families or carers and this has guided our decision making and planning when supporting people with learning disabilities in the community. As a health team we worked together developing easy read information about COVID 19, developing timetable activities, checking in with people, sending out online links and developing the rainbow packs has offered people with learning disabilities ongoing support for their well-being and has allowed us as health professionals to continue to support them effectively. The work completed in the Vale Community Support team including the rainbow packs not only benefited the recipient's well-being but the whole process encouraged joint working and lifted morale within the team. Adapting our practices was a rewarding experience and we hope that it has in some way helped to minimise the impact of the lockdown and reduce stresses and develop positive relationships with families during these unprecedented times.

Susan is a community nurse.

## Chapter Five - Mental health, technology and the 5 Ways to Wellbeing – Coping with the pandemic

### **David Mahon and Christine-Koulla Burke The Foundation for People with Learning Disabilities.**

The Foundation for People with Learning Disabilities (part of London South Bank University) is an organisation that works with people with learning disabilities, their families, carers, local authorities and service providers. Working with people with learning disabilities we undertake projects and research with a simple aim: to make things better for people with learning disabilities.

Our *Pass-it-on* Project is a project to help people with learning disabilities to learn more about mental health and the practical things we can all do to stay happy and healthy. The project was developed with people with learning disabilities and delivers peer-led workshops to peer groups.

Previously, our guide, *Feeling Down: Looking after my mental health*, again developed with people with learning disabilities, helps people with learning disabilities to understand how to look after their mental health, teaches people how to use a staying healthy plan and gives information to help people with learning disabilities when they visit their doctor.

<https://www.learningdisabilities.org.uk/learning-disabilities/publications/feeling-down-looking-after-my-mental-health>

We all have mental health, sometimes it is good, sometimes not so good and sometimes it is somewhere in between. Our mental health is about how we feel and that depends on what we are experiencing in the world

around us. The things we experience affect our emotions in both good and bad ways.

Dealing with uncertainty can make it much more difficult to maintain good mental health and 2020 threw us one uncertainty after another. COVID-19 spread across the globe, we were thrown into lockdown and limitations were put on what we could and could not do. Suddenly we were asking ourselves: What is COVID? How dangerous is it? How can I protect myself? When will I be able to see my friends and family again? How long will lockdown last? When will we have a vaccine?

Isolated from friends and family these uncertainties made it more difficult to maintain good mental health. In any ordinary year a significant number of people are affected by a mental health need. In the general population around 25% of us will develop a mental health issue. However, for people with learning disabilities this figure is much higher, at least 40%. This is during an ordinary year and 2020 was a far from ordinary year.

There are lots of reasons why people with learning disabilities are more affected by mental health issues. They face many more barriers in life than the rest of the population and have access to far fewer opportunities. People with learning disabilities are more likely to experience poverty, abuse, stigma and other negative life events. They can also experience less support from services that are sometimes not properly adapted to support the needs of people with learning disabilities.

When lockdown began, we had real concerns about how people with learning disabilities would stay connected, particularly those that lived alone or already felt isolated. Good connections are a vital part of how we stay happy and healthy. Our connections to other human beings help us



to feel we belong, give us an opportunity to talk about our feelings and can make sure that we feel loved and valued.

‘I don’t like being in lockdown, why do I need to stay home alone all the time. I want to go out and go to London.’

‘I felt quite scared. I sat in a corner and cried as I did not know how to protect my family.’

At the Foundation we started a weekly group with the people we work with and our friends at the Involvement Matters Team at East Sussex County Council. Once a week we met via Zoom to talk about how we were feeling and to share a joke and a laugh. The group have told us that this was a really important part of their week, being able to connect with others and relieve the pressures and stresses of lockdown.

However, meeting on Zoom was not perfect and it took a lot of effort to get some members of the group online. Without the support to download, or use video calling apps, or without the technology or the broadband it took time to get everyone connected.

We’ve spoken to a lot of people about how they used technology to stay connected and for some it has been a great new way to connect with others but for some people it has left them more isolated and thus more likely to develop a mental health need.

Learning disability organisations providing services and activities adapted very quickly to lockdown. Now that services and activities could not be provided face-to-face they worked hard to get activities online and over time sourced phones and laptops to help fill the technology gap for the people they work with. Learning disability advocates have been starting and running groups to keep people connected. As a result, countless new

relationships have been formed and people have been able to keep in touch with one another. It has really been an admirable effort across the country.

From our research we know that technology has been really important to many people with learning disabilities during lockdown. In addition to new ways of communicating, people have used phones and computers in lots of new ways to help them stay fit, to keep the mind active, and to stay entertained. The people we spoke to told us that they had tried online shopping for the first time, were listening to music, accessing film and TV and using online exercise programmes to stay fit. They have also used their phones and laptops to be creative and to learn. They told us that they had been writing stories, taking photos, drawing and designing, and improving their IT skills. All of these activities can help us maintain good mental health. They have filled a gap for people during lockdown and hopefully they will supplement people's lives in the future.

'I have learnt how to use Zoom, Skype and lots of websites for my shopping.'

'I have had training to use Zoom as I have not used it before. I have also had help to use a site where you can make cards to send to people.'

It's terrific that so many people are now using more technology to stay connected, stay active and stay entertained but it's not perfect. We all want to return to a degree of normality where we can see our friends and family as and when we want to. It feels like technology has helped fill the gap to some degree but it's not the same. During lockdown though it has been a lifeline for many.

Video calling apps have become really important for many people but not everyone has been able to use them (or has wanted to use them!). Many people have found it hard to download video calling apps and not everyone has the support to do it. We know from experience how difficult it can be to help someone download Zoom when you are trying to support them remotely. There are other issues: Some people do not have the hardware - laptops or tablets or smartphones; some do not have access to the internet, often due to cost; others can access apps like Zoom on their phones but cannot afford the extra data required to use these regularly.

‘I don’t have access to the internet and so I can’t join the groups that I used to go to when face-to-face, as they have all moved online now and I can’t go. I can’t always keep in touch with people as I run out of credit’.

At a time when our use of technology can help support our mental health, we find some people with learning disabilities are being left behind. This could become more problematic in the future. The temptation for many services will be to use technology more and more. We understand this. Budgets are stretched and video calling is a tempting way to make the money go further. However, it is not the right option for everyone. There are still lots of people who will want face-to-face meetings with, for example, their GP or mental health services or will simply not have the means or the technical skills to attend via video calls. Services need to bear this in mind.

As we become ever more reliant on technology, we need to make sure that people are not left behind. There is now so much online that can supplement what we already do. It has provided many of us with support when we have needed it, whether seeing someone’s face through video

calling, providing us with entertainment or providing access to fitness programmes or creative outlets. We need to think about how we can provide more people with learning disabilities with these options. We need to think about how they can access them, how we can ensure they have the right technology and the support to use it, and how issues around simply being able to get online can be navigated. Lockdown has been a difficult time for all of us. We have all had to cope with the effects on our mental health. For some, the use of technology has alleviated these stresses and worries but for others we worry that without this support during lockdown their mental health will have suffered.

‘I am enjoying doing meetings from home and seeing all my friends.’

‘It is really hard to keep in touch when I only have a basic phone and no contract, as I run out of credit a lot. I would like support to access the internet and technology.’

Many of us have used technology to support our mental health during the pandemic but like our physical health we need to keep working at it. You won’t get rid of a beer belly sitting on the couch and maintaining good mental health takes work too. While technology can help us there are still lots of things we can do to prevent mental health needs arising.

At the Foundation, we put prevention at the heart of everything we do and our work on mental health is no different. Our *Pass-it-on* project and our guide *Feeling Down: Looking after my mental health*, both focus on helping people to understand what mental health is and the actions we can all take to stay happy and healthy. At this time, and when things return

# Pass-it-online

## Session 2:

# The 5 ways to wellbeing



to normal (whatever that may look like) it is more important than ever that we take positive steps to maintain good mental health.

In our *Pass-it-on* workshop sessions, we focus a great deal on what people can do to stay happy and healthy, looking at how making plans can help us and exploring how the 5 Ways to Wellbeing can help improve your mental health and wellbeing. The 5 Ways to Wellbeing are five steps that can help you to feel more positive and help you to deal more effectively with what life throws at you.

The 5 Ways to Wellbeing are: Connect with others; Be active; Be aware (pay attention to the present moment, sometimes called mindfulness); Keep learning; and, Give to others.

### ***Connect with others***

Strong relationships with the people closest to us can allow us to share our feelings. Relationships can help us to feel like we belong and make us feel more confident about ourselves.

Connecting with others during the pandemic has become more difficult than normal but there are still ways in which we can see the people we love and even make new connections and friendships!

You could do lots of things to stay connected, you could: arrange a time each week to call someone close to you; you could arrange a call on a video app so that you could see someone face-to-face; you could meet someone for a socially distanced walk; you could create a friends or family group on WhatsApp; you could join an activity online with a learning disability provider and see old friends and meet some new friends.

When restrictions loosen connecting with others will get easier. We will be able to visit our friends and family in person; we will be able to meet people more easily for a coffee or a pint in the pub and we will be able to make long-term plans again.

### **Be active**

Healthy body – Healthy mind’ is a well-worn cliché but its true! Doing regular exercise has been proven to be good for our mental health. This doesn’t mean that we need to spend hours and hours at the gym, we just need to find something that suits us. It could be a run around the park or it could be some seated exercises. Whatever works for you.



Our options have been more limited during the pandemic and particularly during the lockdown. Gyms, pools and leisure centres were all closed, and we were allowed only one hour of outdoor exercise per day. With more time on our hands' many people found new ways to be active. A lot of us walked more than we had before, and many others found exercise programmes online.

However, it can sometimes be difficult to find the motivation to do exercise when we are feeling low. We need to remind ourselves that we can do simple things to stay active. You could do some housework. Yes, housework! Housework is a physical activity that gets the heart beating and the blood pumping. You could find an exercise programme on a website like YouTube. You can do this for free and there are lots of different programmes that suit all kinds of people – from energetic workout sessions, Zumba and dance classes to more gentle workouts and sessions designed specifically for people with mobility issues. There are lots of different options.

## **Be aware**

Becoming more aware of the present moment can help improve our mental health. We are often so caught up in what has already happened or what might happen in the future that we forget to stop and take a moment for ourselves.

Becoming more aware of the present moment is sometimes called 'mindfulness'. It is about becoming more aware of the sights, smells, sounds and tastes that you experience. It is about reconnecting with our bodies and the different sensations we experience. Becoming more aware of the present moment can help us to enjoy life more and better understand ourselves.

There are lots of things we can do to become more aware. You could find a time each day to do some breathing exercises, to breathe deeply and become more aware of your surroundings. You could play some music and put all of your energy into listening to it. You could take a break each day from social media – perhaps you could turn off all your social media for 30 minutes a day. You could try yoga or meditation.

Something else you could do is called ‘mindful seeing’. As we go about our busy lives, we can stop noticing the world around us. It can be relaxing to take a moment to look at the things around us.

- Next time you go out for a walk find one thing to really look at.
- A flower, a building, a leaf. It could be anything.
- Stop for a few seconds.
- Look at the shape of the object. Look at its outline.
- Notice the light and the shadow. Look at all the different colours. Is it rough or smooth?
- Now notice how your attention has been captured by this one part of the world around you.
- Now look around. Look at all the other things around you.
- You could also try to this at home. Sometimes we are so used to somewhere that we don’t notice what is right in front of us.

### *Keep learning*

Learning can help us feel better about ourselves and can help us to feel more satisfied with life. It can help us to feel more confident and give us more purpose.

Learning doesn't have to be about picking up a textbook, there are lots of ways that we can learn new things. You could learn how to cook a new meal. Dig out an old cookbook or go online and find a recipe on a cookery website. You could go to a museum or art gallery (many of which you can now access online from the comfort of your own home). You could listen to a podcast series. You could learn how to draw or paint, or how to crochet or knit. With your new skills you could make gifts for friends and family.

There are lots of courses available online, you could learn some new skills or take your current skills to the next level. There are also lots of interesting websites. For example, [explore.org](https://www.explore.org) features live and recorded camera feeds of animals in the wild. It can be surprisingly relaxing to watch footage of elephants feeding or puppies playing (this also fits with 'Be aware'!). You could learn all about a place you have always wanted to go to and then use google maps to visit. Why not learn all about ancient Egypt and then visit the Pyramids.

### ***Give to others***

Being kind and giving to others can help us to feel more positive. It can also make other people feel happier. Giving time to others can also help make our relationships stronger. During the pandemic it may seem that giving to others would be hard to do but there are lots of things, both large and small, we can still do.

Staying in touch with people right now can have such a positive impact on our friends and family. A regular call to someone on their own could be a lifeline to them, letting them know that you care about them.



You could send a friend a letter or an email to let them know you're thinking of them and to tell them how you are. Why not draw or paint a picture, take a photo on your phone and send it to someone.

Paying somebody a compliment is a really easy way of giving to others (as long as you mean it!). Simply telling someone that we think their new shoes suit them can give them a lift. Reminding someone of how much we value them as a friend can give them a huge lift!

Wearing a mask when you are out and about is just about one of the best ways that you can give to others right now. While wearing a mask can help you to stay safe from COVID-19 it is most effective at ensuring that we do not pass COVID-19 on to others. Wearing a mask shows that you care about the people around you and the people in your community. This is an expression that we can all make, that we want everyone to be safe and healthy.

### ***Making plans***

We know that the 5 Ways to Wellbeing can make us feel happier and healthier but it can be difficult to stick to things, especially when we are

feeling a little low. Making a plan or an activity planner can be a good way to remind us to keep doing those things that make us happy.

Pass-it-online

Session 3:

# My Staying Healthy Plan



## My Staying Healthy Plan

Use the ideas in this part to think about how you can stay healthy.



For example, you could use a weekly activity planner to help remind you to do each of the 5 Ways to Wellbeing. At the end of the week, perhaps on a Sunday you could plan what you are going to do for the next week. You might decide that on Monday you will **connect with others** by calling your mom and dad in the morning, **be active** by taking a walk in the afternoon and **keep learning** in the evening by listening to a podcast. On Tuesday you could **give to others** in the morning by checking in on a friend to see how they are, and in the afternoon, you could **be aware** by taking some time for yourself to listen to some music. Fill in your planner for the rest of the week with lots of activities to keep you happy and healthy. Tailor your planner to activities that you enjoy and check it each morning to see what you have coming up.



We don't know how long we may have to live with limitations on our freedoms so it is important for our mental health that we utilise whatever support we can find. Technology has been incredibly helpful for many people during the pandemic but there are lots of other things we can all do to stay happy and healthy. The 5 Ways to Wellbeing are a great start and something to build on but we need to remember that we can all support each other in small ways. Remember, a simple phone call can make a world of difference. It reminds us we are not alone, and that people care about us.



# COVID-19

## COVID-19 AND YOUNG PEOPLE PROTECT YOUR MENTAL HEALTH



The COVID-19 situation is a **stressful time for everyone**, including young people. Chat with or videocall friends and family to stay connected.



Limit how much social media and news you consume. **Avoid rumors and misinformation** by getting news from trusted sources.



Exercise or meditate at home. **Reach out to a trusted adult or professional** if you need help.



#COVID19 #ITHRIVE



World Health  
Organization  
Western Pacific Region

BE AWARE.  
PREPARE. ACT.  
[www.who.int/coronavirus](http://www.who.int/coronavirus)

