

Peter and friends talk about mental health in people with learning disabilities and/or autism



Edited by Peter Cronin, Steve Hardy, Sandra Augustine, Lloyd Page, Christine Burke, David Mahon and Eddie Chaplin

Foreword by Nick Bouras



foundation for
people with
learning disabilities

EST 1892

LSBU

NHS

Oxleas

NHS Foundation Trust



Penge Publishers

Copyright © 2022 by Peter Cronin, Steve Hardy, Sandra Augustine, Lloyd Page, Christine Burke, David Mahon and Eddie Chaplin

All rights reserved.

Printed in the United Kingdom

Second Edition 2023 January

How to cite:

Cronin, P., Hardy, S., Augustine, S, Page' L., Burke, C., Mahon, D and Chaplin, E. (2022) Peter and friends talk about mental health in people with learning disabilities and/or autism, London: Penge Publishers.

Reference Type: Book

ISBN: To be advised

Author: Cronin, P., Hardy, S., Augustine, S, Page' L., Burke, C., Mahon, D and Chaplin, E.

Year: 2023

Title: Peter and friends talk about mental health in people with learning disabilities and/or autism

Place Published: London

Publisher: Penge Publishers.

Short Title: Peter and friends – mental health



EST 1892

LSBU

NHS

Oxleas

NHS Foundation Trust



Penge Publishers

Preface

Eddie Chaplin

On behalf of Peter and the rest of the editors, I would like to welcome you to this second volume of Peter and Friends which is all about mental health. We strongly believe 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.

Preparing this book we have seen that although many people were interested and said that they would read it, many found it difficult to know the best way to contribute. This was for several reasons which included stigma, they would be seen as weak, or people would treat them differently or it could bring up past negative experiences of ill health or when they had to go into a hospital. Our aim is that this book can help people understand mental health. By giving information and sharing experiences, we can increase awareness and show people strategies on how to look after their mental wellbeing just as we would look after ourselves physically.

Mental illness and poor mental health can happen to anyone but many people with learning disabilities are not only at an increased risk, but many people find it difficult to get support for mental health problems and for many it is only when they are in a crisis that services will step in.

In section one we have included personal experiences from people with learning disabilities on mental health. This includes positive messages and how people look after their mental health. Also included are case studies from people who work in mental health with people with learning disabilities. This section includes poems and other ways people express their thoughts and feelings. Section two is about the experiences of family, carers and those who support people with learning disabilities. In the third section we talk about mental illness and some of the common treatments, with insights into some of the services that are available for people with learning disabilities, this draws upon professional knowledge and people's experience. and offers insights into some of the services available. The fourth section is from two training organisations that aim to help people learn and recognise more about their mental health and ways to encourage mental wellbeing. This includes

people with learning disabilities who have trained to become peer mentors and trainers on mental health and wellbeing. The final section contains a selection of easyread information leaflets about mental health and common treatments.

This book has been put together like the first edition without a recognised publisher. So that the Peter and Friends series can be accessed by everyone we publish as a non-commercial collective under the name of Penge Publishers. Penge is an area in south London where the Editors get together for the majority of the Editorial boards and meetings and this is how we got the name. We apologise in advance for any stray typos or if anything gets lost in translation.

We hope that you find this book useful and welcome any ideas for any future books.



EST 1892

LSBU **NHS**
Oxleas
NHS Foundation Trust



Donators

Estia centre

Sponsors



Acknowledgements

We would like to thank contributors, interviewers and those who have supported people to tell their stories. A special thank you to Anna Donahue and her son Andrew for supporting the project from the start, giving up their valuable time, and organising and encouraging others to tell their story. Others who have our gratitude are those who have made donations to this second volume of Peter and Friends, their logos are on the previous page.

We are honoured to have Professor Nick Bouras write the foreword for this edition and for offering his valued insights. Nick is an inspiration for many of us who support the mental health of people with learning disabilities. He is a pioneer of specialist mental health services for people with learning disabilities, not only in the UK but also internationally.

For their advice, kindness, support and counsel, when and where it was needed, we'd like to give a special thanks to Sarah Offley, Marsh Stitchman, Joseph Fitton, Sharon Rodrigues and Paula Grant. We also offer thanks to Lisa Tan. Final thanks go to Lorraine

Regan from OXLEAS NHS Foundation Trust for supporting the project and Neil Basing at London South Bank University for organising the conference and launch. These two have given their unconditional support, time and energy from the first volume about COVID. and been instrumental in making things happen. The photos in this book are from contributors, <https://unsplash.com/> and <https://www.shutterstock.com/> Photosymbols are also showcased in some of the everyday easyread materials currently in use.



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 and 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. 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.

Lloyd Page

My name is Lloyd Page. I am 62 years old, I have a learning disability and I live in Bromley, Kent. I have worked at Mencap for over 30 years, a job which I love. I'm also a member of Lewisham Speaking Up as a self-advocate and I am a Green Light Champion for Learning Disability Services in Suffolk and Norfolk. I have published a lot over the years including Book Beyond Words and my own joke book. I am passionate about equality for people with learning disabilities.



Sandra Augustine



My name is Sandra. After helping with the Peter and friends COVID-19 book. I was invited to join and become part of the team of Editors. I am also getting more involved with my local community including Lewisham speaking up group and FPLD. My family come from Grenada and I am very proud of my Caribbean culture and telling others about it.

Christine-Koulla Burke



Christine is a Honorary Director of the Foundation for People with Learning Disabilities (FPLD), at London South Bank University. 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. 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, and also managed several European programmes with European partners and supported the work of the Valuing People with family leadership and managed the National Advisory Group for People with Learning Disabilities and Ethnicity.

David Mahon

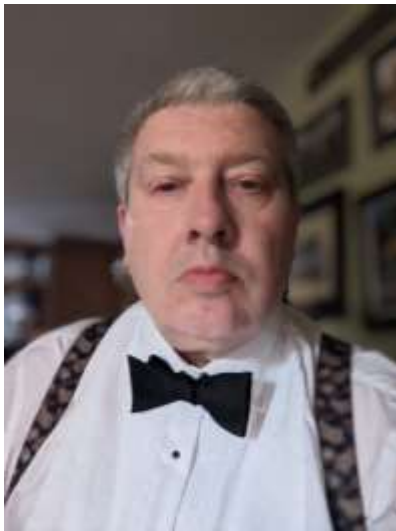
David Mahon is the Head of Programmes at The Foundation for People with Learning Disabilities. He has a background in managing projects and programmes covering a wide variety of different areas in addition to learning disabilities, including speech, language and communication needs, peer support, local



13

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 Head of the Scientific Committee for the European Association of Mental Health in Intellectual Disability. He is currently the Director of the Foundation for People with Learning Disabilities (FPLD), at London South Bank University.

FPLD works with people with learning disabilities to undertake applied research and social policy development. He was previously Editor of the Advances in mental health in intellectual disability and Advances in Autism Journals. His current research includes neurodevelopmental disorders in the Criminal Justice System and evaluating co-production projects.

Nick Bouras



Nick Bouras is Professor Emeritus of Psychiatry at the Institute of Psychiatry, King's College London. He was Consultant Psychiatrist, at South London and the Maudsley Foundation NHS Trust and was instrumental in the re-provision of services from three large institutions, Darenth Park, Grove Park and Bexley Hospital. He assisted actively in the development of community based multi-professional mental health services for people with learning disabilities and /or autism. He initiated the development of the Estia Centre that combined clinical services, training and research & development. His research is focused on health service-related topics including, assessment and clinical effectiveness of specialist mental health services, evaluation of multi-professional training methods, social and biological determinants of behaviour for people with learning disabilities and/or autism. He has held executive positions in several National and International organisations and has been Editor of several journals. He has published extensively in community psychiatry and mental health aspects of people with learning disabilities and/or autism. Several of his publications have translated into different languages.



Contents

Table of Contents

Preface	5
Eddie Chaplin	5
Donators.....	8
Sponsors.....	8
Acknowledgements	9
Editors Biographies	11
Peter Cronin.....	11
Steve Hardy.....	11
Lloyd Page.....	12
Sandra Augustine.....	12
Christine-Koulla Burke	13
David Mahon	13
Eddie Chaplin	14
Nick Bouras	15
Contents.....	16
Foreword	20
Nick Bouras	20
Peter’s introduction	23
Peter Cronin.....	23
Lloyd’s introduction	26
Lloyd Page.....	26
Section 1 – People’s experience	28
Andrew Donohoe Expert by experience, Plymouth, UK.....	29
Ruby Woods Expert by experience Plymouth.....	38
Vince’s story.....	43
Talking about mental health and why communication is important	51
By the ‘Can You Understand It?’ of Adult Learning Disability Service, Oxleas NHS Foundation Trust.....	51
Bill of Rights - for people with learning disabilities	56
	16



foundation for
people with
learning disabilities

EST 1892

LSBU **NHS**
Oxleas

NHS Foundation Trust



Penge Publishers

Inspired by the ‘Can you understand it?’ team, Bexley Mencap, Bexley Advocacy for All, Greenwich ResearchNet	56
Elizabeth’s story	57
I’m sorry	59
Poem by Elizabeth	59
Tracy’s Poem	61
Hayley’s Story in her own words	63
Haylish Version	63
Hayley’s Story traditional English	66
Our LGBT Get Together Zoom!	68
Our Mental Health!	69
By Dudley Voices for Choice, Lewisham Speaking Up, Bromley ResearchNet and Share Community	69
Mental health problems	71
By Dudley Voices for Choice, Lewisham Speaking Up, Bromley ResearchNet and Share Community	71
Final Thoughts.....	76
By Dudley Voices for Choice, Lewisham Speaking Up, Bromley ResearchNet, Share Community, Peter Cronin, Sandra August, Lloyd Page, Eddie Chaplin and Steve Hardy.....	76
Section 2 – Experiences from families, carers, supporters and allies.....	78
Written by families and groups of people with and who support people with learning disabilities ..	78
Everybody Dance: The many benefits of inclusion in dance	79
The DanceSyndrome Team.....	79
Anne Donohoe	96
Expert by experience, parent and professional Plymouth.....	96
Written by a grandmother Cornwall.....	139
Name withheld	139
Rebecca Scott About her brother Andrew Plymouth.....	142
Jackie Blank Access Theatre Cornwall.....	144
I support an inclusive theatre group in Launceston, Cornwall, called Access Theatre.	144
Kelly Clarke.....	148
Member of staff, Access Theatre, Launceston	148
SEND Teacher.....	157
Cape Town	157

Suicide Prevention - help for everyone.	161
Jon Bryant, Video Director and Producer	161
What is it like to see a psychologist?	170
Lucy - a carer and Dr Alison Clark, Specialist Counselling Psychologist, Greenwich Community Learning Disabilities Team Oxleas NHS Foundation Trust.....	170
Talking with James and his mother about their experiences of systemic family therapy.....	179
Information collected by Priyanga Jeyarajaguru, Assistant Psychologist and Simina Tantas, Undergraduate Psychology Student, Oxleas NHS Foundation Trust	179
Talking About Therapy.....	184
Rosamund Roach and Eolie Hampson, Bexley Psychology Team of Oxleas NHS Foundation Trust, Jane Menzies and members of Bexley Mencap.....	184
Identifying our feelings and emotions.....	189
Jill Davies, Clinical Lead Nurse for Mental Health in Learning Disability, Oxleas NHS Foundation Trust	189
Walking Group	203
Jeff Miles, Learning Disability Nurse and Lee Walker, Learning Disability Nurse at Oxleas NHS Foundation Trust With contributions from Kerry Taylor, Learning Disability Nurse and Emma Corrie, Specialist Support Worker, Oxleas NHS Foundation Trust.....	203
Section 3 - Towards mental wellbeing, mental illness and its treatments for people with learning disabilities.....	212
An introduction to mental illness in people with Learning Disability: information to support those close to the person.....	213
Christine Hutchinson, Lynnette Kennedy Jessica Lister and Rachel Mills	213
Improving access to health care for people with learning disabilities	263
Amanda Forester, Hannah Bloor, Jessica Lister and Lauren Barrett	263
What is occupation and why does it matter? The role of occupational therapists.....	281
Matthew Roberts, Rotational Band 5 Occupational Therapist, Cardiff and the Vales University Health Board	281
Positive behaviour support.....	292
Jessica Lister, Molly Harvey and Tom Wilson	292
How clinical psychologists work therapeutically in Oxleas NHS Foundation Trust	310
Sandra Baum, Paula Grant, Joel Parker and Bethan Ramsey	310
Oxleas NHS Foundation Trust Adult Learning Disabilities Psychological Therapies Team	310
.....	327
GPs and Community Paediatric services working with people who have a learning disability.....	328

Neil Douglas	328
Tom does not know how to ask for help and support due to attachment problems	346
Paula Sterkenburg & Marieke Weijburg-Melis, Psychotherapists, Bartiméus, the Netherlands	346
Learning to mentalize is something you do together!.....	355
About mentalizing-enhancing interventions in the care of people with intellectual disabilities	355
Florence van Schoonhoven and Mirjam Wouda (both healthcare psychologist and remedial educationalist) and Stichting Ons Tweede Thuis, the Netherlands.....	355
Medicines and your mental health.....	368
Bimpe Idowu, Senior Clinical Pharmacist and Paul Maycock, Chief Pharmacist, Pharmacy Team, Oxleas NHS Foundation Trust	368
Clozapine and learning disabilities - setting up a bespoke clinic	384
Sarah Westrip, Senior Mental Health in Learning disability Nurse and Denzel Mafukidze, Community Mental Health in Learning Disability Nurse, Oxleas NHS Foundation Trust	384
Section 4 - Training.....	396
Pass it on – Training and peer mentorship for people with learning disabilities	397
Dave Mahon, Pat Charlesworth, Pete Allum, Christine Koulla-Burke and Eddie Chaplin	397
Estia Centre - a specialist training in mental health support for people with a learning disability and autistic people	412
Ruwani Ampegama and Karina Marshall-Tate with quotes from people with lived experience and clinical colleagues	412
Section 5 – Easy read	432
About Mental health.....	433
Depression	438
Anxiety	440
Good mental health.....	443
Relaxation	444
Exercise	446
Healthy eating.....	449
Sleep	454
Information about medicines	456
Can You Understand it? Team Oxleas NHS Foundation Trust	456

Foreword

Nick Bouras

This publication is an important addition to our knowledge and understanding of mental health needs for people with learning disabilities and/or autism. Mental health problems for people with learning disabilities and/or autism remain difficult for service users, families and carers as well as professionals.

The mental health needs of people with learning disabilities and/or autism have been overlooked, in spite of some innovations in community care and support schemes. Service provision in some areas has lagged behind developments for local services, resulting in some people with learning disabilities and/or autism and mental health needs to have been placed in residential facilities a long way from their local communities and at times in unnecessary restrictive environments.

The lack of training on how to address their needs has contributed to the creation of a vacuum of knowledge for this population with adverse effects on their quality of life. The involvement of service users in all aspects of health and social care is of primary importance. People with learning disabilities and/or autism and mental health needs require to

20

be supported to have access to mainstream services and the use of psychological and other relevant therapies. The emerging research highlights the effectiveness of psychosocial interventions for people with learning disabilities and /or autism and mental health needs.

The all-embracing cover of this publication is presented in a well-structured simple and user-friendly format with contributions mostly from service users but also families, carers and professionals. Information includes signs of mental health problems as well as their remedy but most importantly first-hand experiences. It is promised to be a most useful tool that can be used to facilitate training and improve our understanding and practices in a most needed area for supporting people with learning disabilities and /or autism.

I am incredibly pleased to welcome this publication on “Peter and friends talk about mental health in people with learning disabilities and/or autism” offering a wide range of excellent contributions by colleagues with knowledge about mental health and related issues for people with learning disabilities and/or autism. It is my hope that this book will provide awareness to all concerned about the mental health needs of people with learning disabilities and/or autism and facilitate the necessary supports.

Nick Bouras

Professor Emeritus of Psychiatry

King's College London,

Institute of Psychiatry, Psychology and Neuroscience.



Peter's introduction

Peter Cronin

I am very pleased to be writing the introduction to our second book “Peter and Friends Talk About Mental Health’. During the time of covid I was very anxious but what kept me going was writing our stories for our first book about covid. It was a time that I really enjoyed and it took my mind off the lockdown.

I’m in a really good place at the moment. My girlfriends Sandra in a beautiful lady and is always supporting me. I have several jobs, one at the Co-Op twice a week and also with Lewisham Speaking Up, where I am “Representative for Employment’. I get loads of support from Marsh who work there and always includes me in conferences and meetings. My friends Eddie and Steve are great. I’ve known them for over 20 years. We always stand up for each other.

But things weren’t so easy years ago. I left a special school without any qualifications. I couldn’t read or write but I’m going to college to learn lots of new things. After school they told my mum that the only place I could go to was a day service. My mum who I love and

23

always stuck for me visited the centre. I can't remember exactly what she said but it was a 'no way' with some rude words. Sadly my mum passed away twenty years ago. I really miss her and I became depressed. So I went to see a counsellor, who really helped me. I also had panic attack so I saw a professional massage therapist and went to learn relaxation at classes. I still think of my mum and I thank her for what she did for me.

I got married over twenty years ago. I met my wife in a supported living house which we shared with four other people with learning disabilities. Supported living has its ups and downs. But my wife sadly passed away about 14 years ago. She was ill for a long time and I was prepared for it as I knew it was coming but it was still a shock. So I started to see the counsellor again and talking to her was very helpful. My support workers, friends at Lewisham Speaking Up and Eddie and Steve were so supportive.

Now days I live independently in my own flat with outreach support twice a week. My whole weeks is full of working, going to college, speaking up for other and going to clubs. But I still remember those

days when I felt so sad and depressed, so this is the reason we have written this book.

Peter Cronin, Expert by Experience

Lewisham Speaking Up and the Foundation for People with Learning Disabilities



Lloyd's introduction

Lloyd Page

In April 2020 I caught covid and was in Lewisham Hospital for a week. While recovering I got in contact with 'Peter and Friends' who were writing a book about stories of covid. I wrote a chapter for them and I was also interviewed at the book launch. I started fundraising for 'Peter and Friends' and promoting the book across the country. I am now a member of the team and I am so pleased.

The second book is about mental health. I've never had a mental health problem but some of my friends have. There is also a lot in the books about people with learning disabilities who are more likely to get a mental health problem. This is down to things like discrimination. This needs to stop. But also we need to offer support and services to those with mental health problems.

One area that I am really involved with is mental well-being. I always keep myself busy, be part of my community and helping others. This is really important. I hope you enjoy reading this book and learn something from the stories of others.

26

Thank you

Lloyd Page

Expert by Experience

Foundation for People with Learning Disabilities

MENCAP



Section 1 – People’s experience

This section shares some experiences of and discussions with people with learning disabilities about their mental health. We have made edits to spelling with the permission of authors, however in some cases some have developed their own written communication style which we have respected. So that the meaning is not lost we have added a more conventional version. However, we do urge you to read the original as it is essential for those supporting people with learning disabilities to get used to different communication styles to understand the person.



Andrew Donohoe Expert by experience, Plymouth, UK.



“I am very happy. I wake up happy in the morning. Eating breakfast keeps me happy and gives me lots of energy”.

“Doing personal care, keeping clean, keeps me happy.”

29



foundation for
people with
learning disabilities

EST 1892

LSBU

NHS

Oxleas

NHS Foundation Trust



Penge Publishers

“I generally just enjoy life really.”

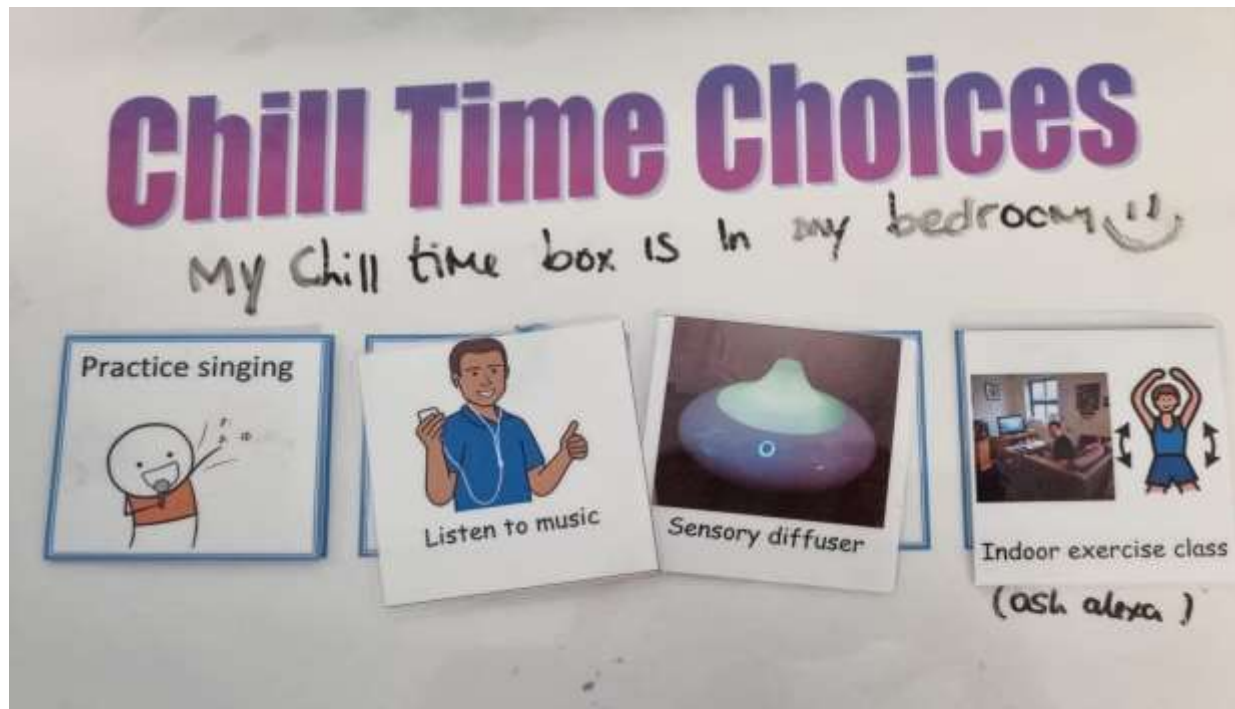
“Using my feelings chart makes it easier to tell PAs (Personal Assistants) how I am feeling. I can then talk about my feelings and why I might be feeling them. So, It has helped me to see more emotions and talk about them easier.”



Anxiety

When I feel anxious my brain feels tired and busy. I get anxious when things don't go as planned or I don't get my own way.

To help with anxiety and relax, I like a nice cup of decaf tea and some chill time between P.A. shifts.



Listening to music in my bedroom is good, or listening to recordings of friends reading stories on my phone. I also have a “Calm Box” with pictures of calming activities that I can choose to do. The visuals inside prompt me and remind me of nice activities I can choose from to bring me back to a good, happy and calm place. For example: using my diffuser and choosing an essential oil to use, playing Johannes Brahms, classical music, or “spa music” or having a herbal or fruit tea. A stretching session, yoga or meditation can help either with or without the diffuser or music. My PAs work

with me so that I learn techniques which hopefully I will then be able to do independently. Washing my dishes, tidying up and hoovering also help me to stay calm.

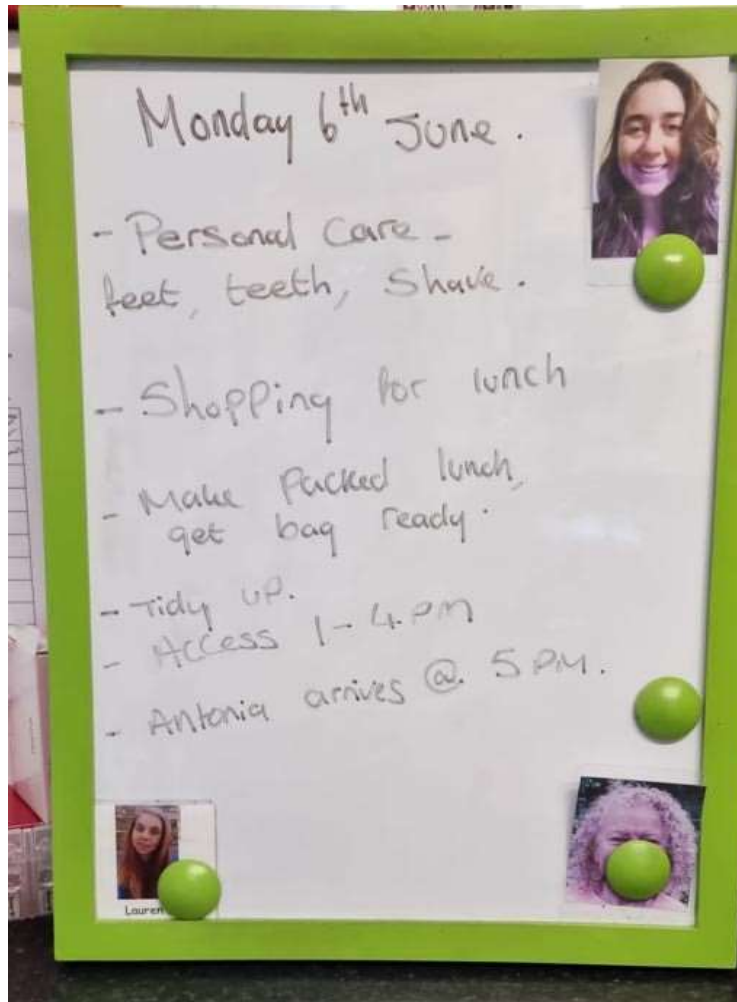
The box also contains some sensory or fidget objects which I can use e.g. chewing gum to chew, squishy objects to squeeze or some bright or reflective objects to manipulate.



Other things I do to help when I'm feeling anxious are:

- Speak to my mum
- Chat to a PA
- Use images to help me communicate and make decisions
- Have some TLC with the help of a PA at my flat e.g. having a fun facial, a hand massage or having a foot spa and foot massage
- Some professional TLC e.g. a facial or massage at a salon, or a haircut.
- I like looking through my TV magazine and choosing what programmes to watch.
- I write notes to my mum, sister and PAs about myself and what I would like. Sometimes these are difficult to read but I can often read them back to people.
- I check my rota and my whiteboard for what is happening and who I am with.

I like planning my daily routine on a whiteboard with my PAs so that I can see the structure of my day and feel calm and organised. I like to see the plans.



This includes pictures of the PA that is working with me. Having pictures makes it easier for me to understand and makes me feel secure. I like to tick things off as they are done so I can see where I am up to.

When there are changes with PAs and routine, I like to make a personalised visual rota to help me understand and be flexible with plans.

Things that I have learnt that keep me upbeat (happy and positive) are:

- Going to music, singing and drama groups
- Painting, especially my art classes
- Going to the gym
- Going for a walk
- A picnic
- Singing
- Dancing
- Moving Sounds (a group I go to where I play musical instruments)
- Seeing people like my sister, Rebecca and my mum
- Seeing my PAs

I also like occasional treats like a hot chocolate, a nice cake or biscuits, a few sweets or some chocolate.

Activities and social contact



During the pandemic I found it upsetting to not have my usual clubs and classes because I didn't get to see my friends. When online classes started these were great for making connections and getting creative. The online sessions made it easier to work closely with other classmates in watercolour classes, because the class tended to work together on projects.

I also looked at other online sessions such as discos, baking sessions, exercise classes like Joe Wickes etc.

I am very much enjoying being back in face-face activities again and re-connecting with friends again. I still prefer face to face sessions.

Eating and maintaining a healthy weight

It's easy to control my eating when I'm not hungry. When my PAs are around, I don't feel tempted to eat when I shouldn't. But sometimes when I'm by myself I turn into a 'big mouse' and I eat food from the fridge and from the kitchen. My PA's help me by taking food away that might tempt me and they bring it another time when we can enjoy it in healthy amounts. They have also printed out labels made on my computer which I can stick on food in my fridge which tells me if I can eat some of that food or not. (See photo of labels Don't Eat)

I like to make healthy food choices.

Healthy snack ideas include:

grapes, yoghurt, apples, watermelon, mini cucumbers, carrots, bananas, baby tomatoes, sugar snap peas, celery sticks, humous and nuts.

Andrew

Ruby Woods Expert by experience Plymouth



I'm Ruby, I am 25 years old and I'm diagnosed Autistic, with Dyslexia, Anxiety and OCD. I also struggle with Avoidant Restrictive Food Intake Disorder (ARFID), a very common eating disorder within the Autistic community. I was diagnosed Autistic as an adult as many of my traits were dismissed under my anxiety diagnosis when I was a child. I found this very difficult as I always knew there was so much

more going on. Autism and anxiety are separate but also interwoven so it can often be complex trying to figure out the two. I am on anti-anxiety medication to help me day to day but it can still become overwhelming. One of the things I personally have struggled the most with is the wider society not recognising me as

38

Autistic. I have had to mask¹ for so many years. As I also present in a different way to the general understanding of Autism I often feel isolated in my experience. This has left me feeling very lonely and confused about my place within the Autistic community and the Allistic² one.

I chose to research female presenting Autism and its representation in the arts for my master's degree. As a result I discovered that most Autistic females (Assigned Female At Birth) have high levels of anxiety due to the constant masking and this is not being recognised when they need support. I find it difficult to ask for support in an environment where people may question my struggles, which in turn makes my anxiety worse.

There have been many places that have offered support, the company I work for, being one of them. I work as a full-time theatre practitioner with Far Flung Dance Theatre who work with disabled and non-disabled members of the community. They have been so understanding with all of my access needs and have allowed me to be more confident in requesting them. I have also had support from the local hospital who have been able to put me onto the Autism services. This means I don't have to prove my diagnosis every time

I need support, it's already in place and I don't have to worry about the hospital which can be a very overwhelming place.

As previously said I also work mainly within the disabled community in the arts. For me it felt like I was surrounded by people I could finally be myself with and I love doing that work as a disabled artist myself. I have experienced their mental health alongside what we do. I spend a lot of my time building meditative exercises into rehearsals as many of the people I work with have high anxiety around performing, mainly from doing something wrong. I worry that this has come from society telling them their behaviour is wrong and the fear of doing that again. We are able to support in reminding everyone nothing can go wrong and offering constant reassurance if that is what people need.

There are certain things that I found to help my mental health. For me it was a small personal journey. I realised I was always speaking negatively about myself and even though it wasn't always easy, I started to try and only use kind words for myself. I also found that taking breaks was really beneficial. I know now that I need to be alone or take naps to recover from being social or masking and

that reduces my anxiety. I also found that leaving the house once daily helped. I really struggled over the pandemic with my OCD and got really afraid of leaving the house. These feelings then made it even harder when I did have to go out. So, I promised myself I would leave the house once a day even just for a walk and that has helped.

During the pandemic it was difficult as that was when my ARFID was at its worse. ARFID is an incredibly complex eating disorder around restricted eating. For me it means I cannot eat when I'm anxious or depressed as eating is already hard enough. I also cannot eat a lot of different food because the texture is too overwhelming. It means food is often linked around fear. I worry about going somewhere without safe foods, or having food choice because I know I won't eat. I lost a lot of weight because I didn't have the support with my eating disorder because it's often not recognised. It's not related to weight or body image or how I see myself. It is a full and genuine fear of food. I struggled a lot growing up as people just thought I was fussy and there is a lot of negativity around that, but I would sit crying for hours in front of a plate of food. Understanding where this came from has helped my mental

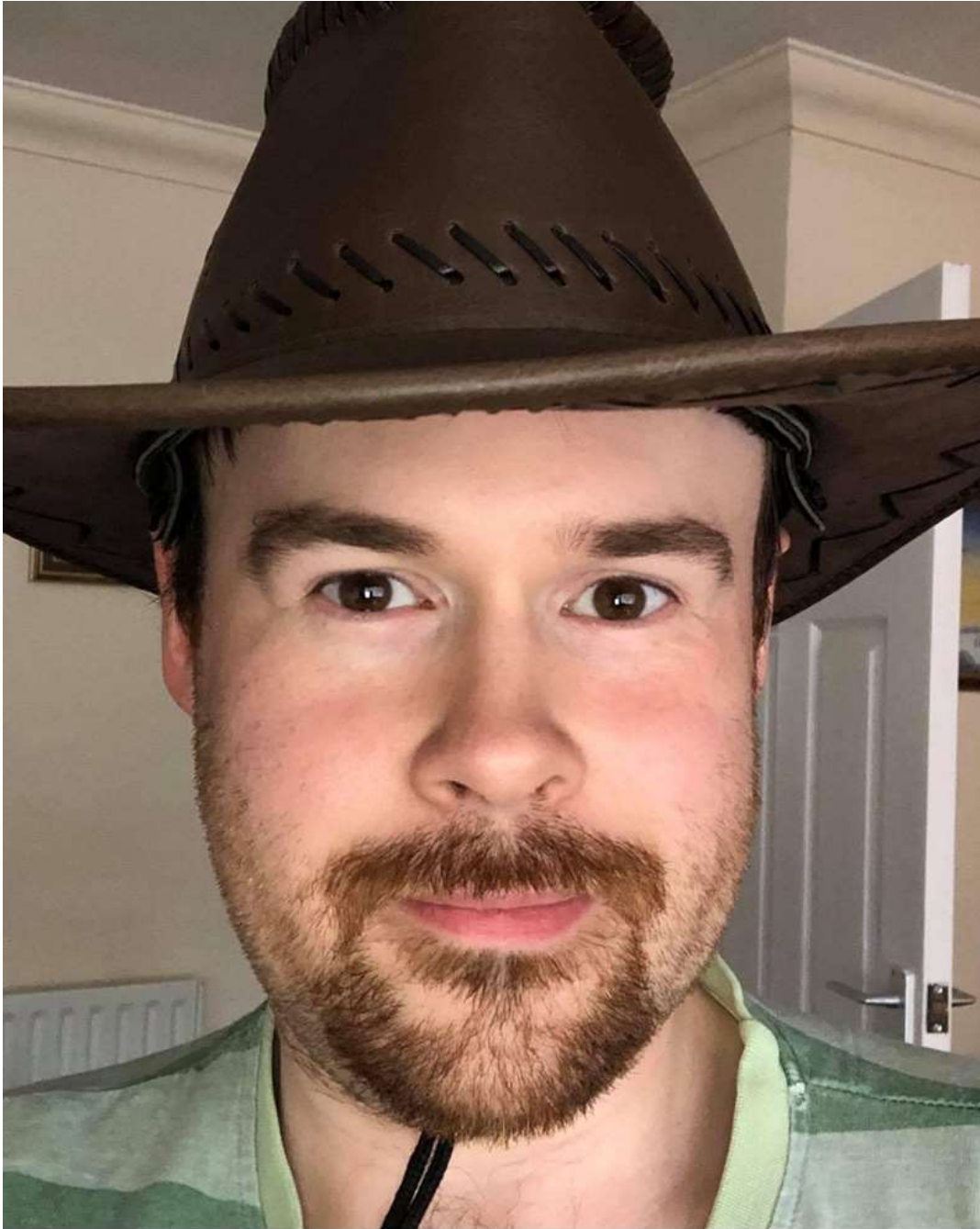
health a lot as I can understand but it's still a huge cause of anxiety. It affects something we do 3 times a day so it's always looming.

Mental health is something that is so huge in our society but is not always talked about within the context of disability. It's important to recognise the complexity of comorbidities and offer accessible information for everyone to understand. Then, hopefully, individuals, with any support they need, will be much more able to look after their own mental health.

Ruby



Vince's story



It's best to start from the beginning isn't it, because mental health is a really big thing. It affects people in so many different ways and you know it doesn't always affect the same two people in the same way. One of the main things that sets mine (mental health) off is anxiety. I do suffer from anxiety on a daily basis. The main way to control anxiety is by keeping your mind and body active, like go for walks and focus the mind on different things. Just getting fresh air that helps mental health. Try to avoid crowded places and that's especially since the pandemic. Another thing that really starts my anxiety and mental health off was when we went to an awards ceremony back in October. We were in a room with 500 other people and I didn't think I was going to last the night because that that is the biggest crowd. I didn't think I was going to last as it was noisy.

I do suffer from claustrophobia as well so if I'm in a room that is full, loud and is a real big obstacle to overcome. But people were there to support me. Sarah did well and helped me get through it. I think I did brilliantly because she was there. I think Aaron was really nice. I think the pint of lager helped.

Let's go back just a little bit cause you will know my story. This has been the bigger year. We need to come and think about what we're going to do and just having a the brief script of what you wanted to share. I'm not going to tell you what to say or what you're thinking about.

It was my first move from mums. It was probably the biggest move ever, to live my own life. Saying farewell to 22 years. It wasn't great at the outset and I laugh now to be honest. There are times where I felt like just running. I moved into supported living in 2009 and that was a real. I don't know if looking back over the years that I knew I had to make a change in my life.

Things were just going from bad to worse. My mum has a full time carer and it was affecting my mental health. It's just was getting to the stage where I just didn't really want to be here anymore. You want to be alive but I didn't really have anything worth living for. It was a very tough decision that night, but I knew I had to make a change. I got my social worker involved and she is a good social worker. She helps me but she couldn't make the decision for me. We went out for coffee and I needed a date then so I accepted this decision. I'm really glad I did it because it was like being born again.

It was a big scary move you know. I needed this now. Obviously moving out from the people you've known all your life and then into a house full of strangers. They don't know, you don't know these people. It's like when you've been asked out on a date. I didn't really know what to expect so you know it was a risk. I had to type letters to support workers and they were very supportive, very caring.

In my opinion learning to trust people is important. I had a friend for 20 years but it just turned bitter. Two very close friends who could be annoying but they really shattered my trust and I had to block contact because the trust was gone. There's no chance of friendship, it sounds that was a really tough decision. It didn't really affect my mental health because these people I went to school with, so I knew them for 20 years and when you think about it I'm 35 now so 20 plus years that's like 33% of my lifetime. That is a long time in that respect and I know these people that belong but when I actually lose contact with them it's a really painful decision but I knew I had to.

These things could really make my life complicated. So that was really tough. Tonight I'm going to think when you make these tough decisions that you think that it almost triggers your mental health or

in my opinion it doesn't help. I mean its exciting when you make a decision. But sometimes you know it can only make matters worse.

Can I ask you to explain something to me? When you say you suffer with mental health what does that mean to you? It's part of my everyday life. It's learning how to deal with it the best way you can. I mean you don't prevent everything. Trying to control stress levels, anxiety levels - you know you've got to be doing something right. It's interesting that when you move to supported living and you decided you wanted your own home, to be independent never counts. What's the best thing about living on your own well you know I can come and go when I want and you haven't got to inform anybody where you're going. But it might be a good idea to let somebody know, somebody that you trust.

If you're going away for a while, just for security reasons in case there's a fire in your home – then tell someone you trust. Whatever you know things go up and down like so it's just nice to have 'Peace of Mind'. Whenever you go out with your friends but you can't take them back to your family home. In anybody's position you can have somebody stop over for the night if you want to. It helps your mental health and having your own space rather than living in a shared

47

space. I feel like I've got a lot more privacy and space. Supported living was not a good move. Sometimes you see anti-social behaviour, having parties and as they do come down and couldn't get out of the building because of furniture left there.

God knows in my whole life this is very uncouth, an inconvenience remembering that they had to move out, were kicked out of their property. These things affect you, but it wasn't because of you, they were just rogue tenants. I think what I went through at that particular time I wouldn't want anybody with learning disabilities to go through this. It was absolutely horrendous, and I think my mental health probably was never worse. These things influence your mental health, is that right or just sometimes is it your own thoughts that control your mental health?

Obviously, you're aware of the situation and then you get your thoughts going around. At my age you know about the possible outcomes and sometimes when you consider the worst possible scenario that could happen. Lessons learnt never leads to another. I'm thinking about when we're in the pandemic, because I had no idea, and everything changed. I don't think that you'd expect in your lifetime. But there are somethings that really affected the way that

you were thinking. It wasn't that 'Oh yeah I used to get really extreme cleaners'. Also, like do I touch what come through my letterbox.

I don't think you were on your own at all, thinking that we had a lot of conversations, about the way that they were sharing information and sometimes that was so confusing that that would make us anxious.

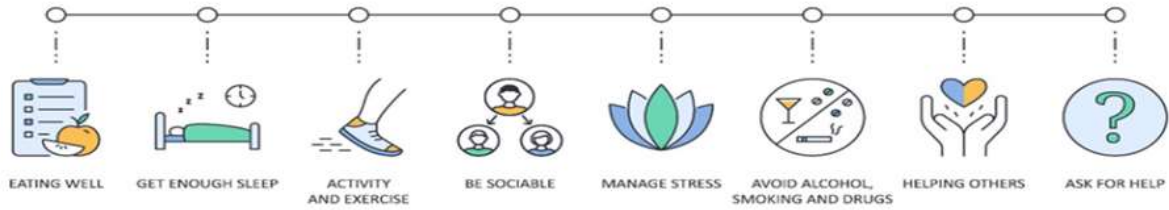
I think if you watch too much of the news it does have a big impact. I did make a brief appearance on the news that people with learning disabilities should be a priority to get vaccinated. We were far down the list as a priority. Thankfully we got prioritised, so it's just the point that the news could be really good for somethings.

It was really good that it highlighted there is a need for priorities but then in the other case they were counting numbers. It's like how many people lived in the world and putting perspective. It's trying to know what is right and what is wrong.

There is bad thing in the world that makes it a scary place

Good things are when it's great to share an afternoon with friends

MENTAL HEALTH



Talking about mental health and why communication is important

By the 'Can You Understand It?' of Adult Learning Disability Service, Oxleas NHS Foundation Trust

How do you communicate?

Talking and communicating are part of being a human being. Being able to communicate with other people to express ourselves and so we are heard is an important part of our mental wellbeing. To make sure we are heard some people may need support as there are many different ways that we can join in and make ourselves heard.

There are different ways of communicating:

- Talking
- Written
- Sign language
- Braille
- Gestures
- Lip reading

- Pictures
- Using objects

Using an objection to communicate, like pointing to the bath probably means 'I want a bath'

You need to check that the person you are communicating with understands you.

Talk at a pace that the person prefers. Not too fast, not too slow – what is right for the individual.

Be polite when communicating and listen back.

What is bad communication?

Bad communication is when:

- You can't take in information
- Not understanding the information
- Having information that is too long
- Use difficult words

All of these can affect a person's mental health.

Have you got any other bad examples?

Good communication is better – it helps the brain to process information better.

Quotes from:

James “To be able to understand someone. You may need to lip-read. If someone is partially deaf and you turn your back they can't hear you. They may have disability needs or need an interpreter and if they are from a different culture”

Michael “Communication can affect the mind. Takes time to process information. If they find it hard to understand - speak slowly, take your time. I find that breathing exercises help”

Sunny “It's very important that only one person speaks at a time. A person may use a picture board and point to things”

Chris “Using easy read information is really helpful. But they will need support the first time that they look at the information”

From our experience What is bad communication and what is good communication?

Michael “I haven’t come across bad communication myself. But if someone has been bad to you they can talk to the Samaritans and get help”

Sunny “The Housing Association – we couldn’t get help, pushed to one side, didn’t listen, not been given the chance to explain, didn’t listen or understand. Need to be educated and treat us with respect”

James “Wasn’t treated properly at college and I felt let down. I was able to tell his parents and they spoke to the college”

Chris Family support from family is helpful. My sister supports me when I go to see the doctor or going to the bank. I haven’t come across bad communication. Everyone needs support sometimes”

Sunny “When I go to the surgery they don’t get easy read information. I do have a black book (health profile), this is really helpful. Easy read care plans are important, especially with mental health”

Michael “I also have a black book which I take to the surgery and it has very detailed info like my height, weight and medication”

Sunny and Michael “Make sure that you have a hospital passport. They are good for physical and mental health”

Michael “I also have a communication passport. The passport has information about how I communicate and what the person needs to do to communicate with me. It has my photo on the front”

This is just a little bit about communication.

But please remember that good communication is the key to everything.

Being understood and understanding what is around you makes a great difference to mental health. We wrote a Bill of Rights with lots of other people, here it is next.

Bill of Rights - for people with learning disabilities

Inspired by the 'Can you understand it?' team, Bexley Mencap, Bexley Advocacy for All, Greenwich ResearchNet

This was inspired by the Can You Understand it Team at Oxleas. What follows is a Bill of Rights that tells people how they would like to be treated.

- Respect me and respect each other
- Speak slowly, clearly and politely
- Speak to me in a way I understand
- Please check I have understood what you are saying
- Speak to me first, then my carer
- Find out how I communicate
- Find out if I need a family member or advocate to speak for me
- Help me to make my own choices
- Ask me if I have a black book or hospital passport
- Make signs easy to understand in Oxleas and hospitals

Elizabeth's story

I've had mental health problems since 1994. I think that many people don't understand but I can rely on my family. My behaviour was described by others as being challenging. I don't think it was challenging, it was other people not understanding me or ignoring me. I was very anxious and used to get panic attacks. Also I used to hear voices and they said hurtful things. I saw a psychiatrist and I still do, they prescribed medication. It works most of the time except for when I'm really stressed and my mental health goes pear shaped. I've been to my local A & E quite a few times. I still have some problems with other people but I am concentrating on the good things in my life. I go to a community centre in South East London. I do English and Maths and computer but I really enjoy the art class. I have joined an art network. I have completed lots of art work that I'm really proud of, you can see a couple pieces in this book. I have done lots of pictures of dogs and cats made a butterfly out of wool and a wool cat in a frame. I have also done a rabbit spending five weeks on it before bringing it home to finish. A hobby of mine is building Lego, I've done Christmas, armed cars, fish tanks and Disney among many others. Writing poetry calms me

down and helps me express myself. I keep myself busy and this really helps my mental health.



I'm sorry

Poem by Elizabeth

You are somewhere, I'm nowhere

Two places that never meet, yet our silence is loud enough for the
whole world to hear

I know I was hard to love, I know in the end it was too hard
I expect nothing else, it's time to leave once your good place runs
out of time

You entered with promises, left with anger
I'm sorry you were the same and I'm sorry I was to blame

I was your world

I miss you

Relief has passed and here we are or there you are

Alone not caring for someone who is badly or good in person

Show my love in day and night on my phone if anyone needs
friends or to talk in person



Tracy's Poem

I'm a disabled woman,

My name is Tracy.

But I'm much more than that;

I'm really kind and funny.

When I meet other people,

Autism is all they see.

They look at anxiety, I shout:

Look at the real me!

I'm a wise person;

Disabled people are all unique.

So please do not make assumptions,

And listen to us speak.

To have goals and opportunities:



foundation for
people with
learning disabilities

EST 1892

LSBU

NHS

Oxleas

NHS Foundation Trust



Penge Publishers

They do their bit.
Our lives should be much better-
I'm determined to change it.



Hayley's Story in her own words

The following story is an example of how people may want to express themselves differently. Hayley who wrote the story has developed a language which she calls Haylish. Below is the original story. For those who have difficulty understanding the words, Hayley has kindly agreed for us to also provide a translated version.

Haylish Version

Hi my name is Hayley ll naw share my story wiv you

ryse

I ryse to tel you my storey

Abowte the suferen and it's glorey so torn i kant say gode bye

To the feres and tormented lyes

I will sone fele the hert agene

Of klenshed fists vat give me payne

My skars will slowley diserpere

I still have to carry on liven in fere

63

I beleved if it wode never end
The luven reminders vat he did send
I Karey his werds wiv me every day
It hornts me still it never goes away
The torture wunse hert me alot
The Payne is still ver I never forgot
My kryes and skremes I do still hear
At tymes I still see him so klere
I wayted so longe for vat day to kum
Sumwun to Find and help me to run
Wye he did it hapern is so unklere
I was torn skared and liven in fere
My heart is Vers for vem to tayke
I'm weak and my bones will brake
I do as I'm towlde ill kepe moven on
I'm so lonely everyday is to longe
I Won't sufer in silense no more



I wil stand and kepe rysen more
standen wiv my hede held hye
I don't fele the nede to hyde and kry
Never will my fredem drift away
Vem abusers shode be in fere today
Ill ryse to protekte you all day frowe
To love and cherish etsh uvers too
I am a servyver and verey strong
We nede uvers to say vat we belong
Bad finges hapern and isent fare
Vers pepel to talk to and to kare



Hi, my name is Hayley and I want to share my story with you

I will tell you my storey
About the suffering and so torn I can't say goodbye
To the fear and tormenting lies
I will soon feel the heart again
Of clenched fists that give me pain
My scars will slowly disappear
I still have to carry on living in fear
I believed it wood never end
The love reminders that he did send
I carry his words with me everyday
It haunts me still it never goes away
The torture wounds and hurts me a lot
The pain is still real I never forgot
My cry's and screams I do still hear
At times I still see him so clear
I wanted so long for that day to come
Someone to find and help me to run
Why did it happen is so unclear

I was torn, scared and lived in fere
My heart is yours for you to take
I'm weak and my bones will brake
I do as I'm told, I will keep moving on
I'm so lonely everyday, it is too long
I won't suffer in silence no more
I will stand and keep trying more
Standing with my head my head high
I don't feel the need to hide and cry
Never will my freedom drift away
The abusers should be in fear today
I'll rise to protect you all day from now
To love and cherish others too
I am a survivor and very strong
We need other to say we belong
Bad things happen and it is unfair
People to talk to and to care



Our LGBT Get Together Zoom!

We ask questions and learn more about LGBT stands for



To shout out and to be free
Knowing its ok to be who you feel to be
It's been a long time for this group to arrive
We want to carry this on and for it to thrive
We saw this moment and we took its hands, for us to be heard
and to make a stand

We do exist, we are all people like you
We are supportive, friendly and funny too
Speakers, games and learning new things
Excitement about what each meeting brings
No judgements are made for us to hear
A safe place to talk freely without any fear

68

Our Mental Health!

By Dudley Voices for Choice, Lewisham Speaking Up, Bromley ResearchNet and Share Community

Mental health means different things to different people

Mental health is your mental health and is unique to you

Mental health is how you are feeling at this moment – your emotions

As human beings with all feel lots of emotions, like

- Happy
- Anxious
- Worried
- Sad
- Angry
- Frightened
- Overjoyed
- Excited

Everyone has different feelings and emotions throughout the day

So you may be happy when you see a friend

But you may be sad or angry if you just miss a bus to see your friend

Our emotions change all day long.

Some people call this 'it's being human'

Somebody famous called mental health 'a rollercoaster'

A rollercoaster has ups, downs, it make you excited, anxious, happy and frightened.

Between all of these emotions you have a feeling of what you call 'normal'

A time when they are no ups and down

All of these emotions are normal and we call these 'our mental health'



Mental health problems

By Dudley Voices for Choice, Lewisham Speaking Up, Bromley ResearchNet and Share Community

Firstly we want to say:

Having a learning disability is NOT a mental health problem!

Being autistic is NOT having a mental health problem!

Autistic people and those with learning disabilities can develop mental health problems – just you can!

But we can also get better just like you can!

Our lives change every day

Different things happen to us every day

Somethings you can control – like deciding on what you are having for dinner

Somethings we can't control – like the weather

And sometimes we can't control our emotions

Sometimes things happen that affect our mental health

If your pet dog passed away, it would be a normal emotion to feel sad

How long would you feel sad?

But what if this sadness lasted for weeks and stopped you from going to work?

You then lost your job and had to wait for benefits

Your mood and emotions would probably be:

Stressed, anxious, worried, desperate

You may feel that there is 'not a light at the end of the tunnel'

When these things happen we call it a 'mental health problem' or 'mental illness'

But people aren't born with mental problems

Mental health problems don't last forever

People can and do feel better

What to do if you don't feel well

If you feel different or don't feel normal – what should you do?

First thing is to talk to a family member, a friend or someone who supports you

Tell them:

- what feelings you are having
- has anything happened recently
- has anything upset you?
- are you being bullied?

- Anything else that you can think of, even something that doesn't feel important

But what if you don't realise you are feeling different, you aren't your normal self?

Your family, friends or those who support might think that you are different

They will ask you the questions instead

It would be great if you and your family sort out the problem

But the problem continues you should go to your GP

Again tell the GP everything

Go to the GP with someone you trust

The GP may just recommend that you need some time to relax and do something nice

But the GP may also ask you to:

- Join a gym (for free until you feel better)
- A self help guide to mental health (family or friends can support you with this)
- See a counsellor or therapist
- Take a short period of medication
- Or if it's a serious mental health problem they may ask you to see a specialist

But remember we all have mental health problems at one time in our life

Having a mental health problem is a 'normal' part of life

People get better from mental health problems. So if someone tells you that they have a mental health problem, please remember:

- They need help
- Treat the person with respect
- Listen to the person
- And remember it could be you!

Final Thoughts....

By Dudley Voices for Choice, Lewisham Speaking Up, Bromley ResearchNet, Share Community, Peter Cronin, Sandra August, Lloyd Page, Eddie Chaplin and Steve Hardy

I want to live my life like you

But all of this research says I will die 23 years before you

During my life I will probably be abused and assaulted

I will probably be forced to live somewhere I don't like

I will probably be on the minimum wage or on benefits

If I'm in supported living how many staff will I get in one year

But I will try on living my life in your world

Don't I breathe the same air as you?

Do I need food and water like you?

Do I deserve your respect and to be treated with dignity?

I thought I had the same rights as you? Isn't this called 'levelling it up?'

Can I speak my mind and be heard?

Aren't I allowed to have our own opinion, even if I don't talk poshly?

I want the right to vote, can anyone help me register
I would like a good education and not to be left away at home
Don't put me in a pigeon hole and value me as to my status
A supermarket worker is as important as a member of parliament
I deserve the same opportunities as you
I have the right to good healthcare
I have the right to treatment by doctors that know about the
needs of people with learning disabilities
Don't I have the right to my own home
I don't need to be locked away for years when I haven't committed
a crime or have a mental illness
If I want a relationship or become sexually active it's up to me and
none of your business
If I'm a Sikh, a Muslim or Christian respect this
I can make unwise decisions and mistakes just like you
I have the right to feel safe and protected
I want to live my life without any restrictions
I may want to get married and have children
I should have the same life expectancy as you

I have the right to good mental health support

Section 2 – Experiences from families, carers, supporters and allies

Written by families and groups of people with and who support people with learning disabilities

This section is about promoting positive mental health and talks about what we can do and what people are doing to help.



Everybody Dance: The many benefits of inclusion in dance

The DanceSyndrome Team

Jen Blackwell is a dancer and a musician. As well as being the Founder of DanceSyndrome, where she is a Director, performance artist and Dance Leader, Jen is also lead flautist for Special Virtuosi in Manchester and the Vice Chair of music group Xylosound, based in Huddersfield.



79

Jen also happens to have Down's syndrome. Her learning disability has never stopped her from having hopes, dreams, and passions but she has faced many barriers in realising them because of it.

Jen was born in 1981 and her parents have fought tirelessly since then for her right to follow her own path and live an independent life. She has a dedicated and carefully chosen support team who have enabled her to “dream, believe, achieve”, as she puts it.

Jen went to mainstream school and whilst there she realised how much she loved to dance and decided that she wanted to become a community dance leader. After leaving school in 1999, Jen found herself in the frustrating position of not being able to fulfil her ambition because there was no suitable dance training for a person with a learning disability. After 10 years of unsuccessfully searching for training that was inclusive, and appropriate for her needs it became clear that many other people with learning disabilities were in the same situation - excluded from mainstream dance. Something needed to change, so Jen and her parents took matters into their own hands. They formed DanceSyndrome in 2009 and it was registered as a charity in 2013.

DanceSyndrome is an inclusive dance charity that aims to provide opportunities for people with learning disabilities to become visible leaders. The charity has the unique ethos that every activity should be disability led. People with learning disabilities work collaboratively to design and deliver sessions alongside professional Dance Artists. As choreographers, performers and workshop leaders, dancers are empowered to explore dance practice in a fully inclusive way, working collaboratively with other people of different levels of ability and experience. In 2022, DanceSyndrome is a successful local charity based in Lancashire, with a three-year business strategy which aims to take the organisation to the next level as a North-West leader in inclusive dance practice, with a clear plan to develop progression pathways from early years to adulthood and a robust social replication model.

DanceSyndrome's research with their own participants in 2019 shows how vital dance is to positive wellbeing.

100% of participants reported feeling happier since joining.

100% felt better about the future.



EST 1892

LSBU

NHS

Oxleas

NHS Foundation Trust



100% felt a sense of belonging.

85% said their confidence and self-esteem had increased.

100% said they had gained teamwork skills.

94% said that they had gained new skills to use at home, work, or college.

76% report being more involved in their community than before joining DanceSyndrome.

86% were inspired by the fact that people with learning disabilities were visible leaders of the sessions.

These incredible statistics from community dance workshops clearly demonstrate the power of dance to improve health and wellbeing and self-esteem, and they align with Jen's own personal lived experience. Talking about how her love of dance grew, Jen said "I was always dancing as a child. Dancing helps me to focus my energy. When I'm dancing, I'm in another world and everything else just disappears. It's an amazing feeling. Dancing has so many

benefits for your health and wellbeing, everyone should try it! Dance is brilliant because you can just put music on and start dancing anywhere! Then you have to believe in yourself, because everyone can achieve if you believe you can. 'Dream, believe, achieve' is my favourite motto!"

Jen said "I am very proud of what DanceSyndrome has achieved. I started this charity to help other people like me who couldn't access opportunities in dance because they had a learning disability. I always feel so proud when I see my friends living a life in dance because I know that my charity has helped them to follow their dreams. Without DanceSyndrome people might still be lonely and feeling lost, like I did before I started the charity."

People with learning disabilities aren't the only people to benefit from this inclusive environment that Jen has created. DanceSyndrome's professional Dance Artists all feel that their lives have been enriched by their involvement in such an inclusive dance space.

Donna Wheeldon is Jen's supporting Dance Artist and Lead Carer. Having worked with Jen for over a decade, both as a dancer and

carer, she really sees the impact that inclusion can have on the lives of everybody involved with Jen.

"I trained at Merseyside Dance and Drama Centre straight from leaving high school. Taking a 3-year professional dancer and teaching training course. I left college with a Distinction as a Professional Dancer and qualified as an ISTD and RAD dance teacher in all genres.

"From there I performed around the world on cruise ships and in many production shows. Moving up the ladder from Dancer to Choreographer to Show Director. Once deciding to settle down I moved back to the UK and opened my dance school.

"One day in 2011, while practising a routine in my dance studio, a very quiet, shy but poised looking young lady walked through the door with her mum. Little did I know back then, this beautiful lady would change my life forever... That beautiful lady was Jen. She had joined my dance school to take private ballet lessons.

"Every private lesson I took with Jen turned out to be a lesson for myself. Though Jen really didn't pick up the exact technique I would

be working on, she just blew my mind with her beautiful stunning grace and passion from within. This was very rare to see, I wanted to see more.



When DanceSyndrome first asked me to take a couple of workshops with Jen in Blackpool, I jumped at the chance. Jen showed me the ropes. How she wanted to take the session and what routines she'd like to teach.

"Our first session was magical. Never before had I seen such joy, love, and passion from a group of people. It was a pure pleasure. Every session from then on was exactly the same: fun and loving. This was so new to me, but every day I learnt from Jen. Not only through dance but also from the disability inclusion side.

Every day can be different; everyone has their ups and downs. Being part of Jen and DanceSyndrome has shown me how to achieve the very best, not just through technique but from the passion from within.

"11 years down the line, how life has changed! I'm now Jen's lead carer (though I'd rather call it best buddy), as well as being a Dance Artist for DanceSyndrome. I've been privileged to perform at some amazing venues, including the Edinburgh Fringe Festival twice, we opened the show at the National Learning Disability and Autism Awards, and we've been invited to Buckingham Palace and the House of Lords through Jen's work. All of this is with the most amazing bunch of dancers, whom I now call my dancing family. Nothing in the dance world compares to this."

This inclusive way that DanceSyndrome works has been pioneered by Sophie Tickle, DanceSyndrome's Artistic Director. Sophie has

played a fundamental role in developing the co-leadership model and overseeing DanceSyndrome's two key training programmes. 'Dance By Example' leadership training is an accredited course, up to Level 2, which DanceSyndrome offers to people with learning disabilities to teach them the skills needed to co-lead inclusive dance workshops in the community. It is DanceSyndrome's flagship programme and is the basis for the co-delivery of all the workshops that the charity delivers. It empowers people with learning disabilities to be able to achieve the qualification from which they gain many transferable skills that help them at home, in work and in other parts of society.

Sophie also developed an 'Inclusion Approaches' one day training course for professional Dance Artists to gain insight into how an inclusive dance company can work with people with disabilities and to strengthen their own inclusive practise. This doesn't just apply to a dance setting, though, and DanceSyndrome are increasingly delivering this course in other business settings to emphasise the benefits of inclusion in all parts of the workforce.

Both courses aim to generate awareness of the barriers that people with additional needs may face and create an increased knowledge

and understanding of how people with additional needs may feel in settings that are not inclusive. Participants can learn simple ways to offer adaptations, how to use language in an inclusive way and how to give every dancer a voice so that every person in every session has the best possible experience. The hope is that by continuing to teach these principles, one day in the future there will not be "inclusive dance", just that all 'dance' will include all people. Sophie's own experiences in the performing arts were the reason that she came to develop these training courses. Dancing and performing have been a part of Sophie's life since the age of three. Growing up she completed all her vocational dance and drama exams and went on to study Drama at Exeter University where she graduated with a first-class honours degree. An applied arts module during her course really confirmed the power the arts have in engaging, stimulating, and motivating participants in a truly unique way. During this module Sophie ran workshops in primary schools, a sixth-form college, a young offenders secure unit and a pupil referral unit. Whilst working in these very different environments Sophie was struck by the way that the arts activities engaged participants, built confidence, stimulated their focus and creativity whilst developing transferable skills without them even realising it.

Seeing this confirmed in her mind the power the arts have, and she became committed to use performance and arts activity to motivate, excite and stimulate thought.

Sophie reflects, “When I finished my degree I felt I wanted to use the arts in a different way because I had experienced, first hand, their power to transform people’s lives. It shocked me that people didn’t work inclusively because to me it was very natural, and I’d always lived my life inclusively without thinking about it. So inclusive community dance practice was one of the areas that I really wanted to work in as it offers people more opportunities to develop.”

“You can’t expect to come out of university and walk into a paid job without experience, so I volunteered at DanceSyndrome. It was the best thing I could have done. Working with the existing Dance Artists, I had to learn on the job by listening to the dancers, learning from the dancers, and responding to the dancers needs and wishes. As we grew and received support from funders I was offered a paid position as Lead Artist in 2013.”

Sophie recalls how daunting it was to mould together a dance company comprising such great diversity. “We decided to take a step back on our journey and give ourselves time to bond as a company and to look at all these amazing, wonderful people who all had interests, skills and wishes and see how we could bring them all together as a community to engender a sense of team.”

“DanceSyndrome is unique because it’s truly disability led. It has grown and been born out of the ideas of people with disabilities who wanted to create a future for themselves. There wasn’t the opportunity for Jen to make a career for herself in dance at that time and there weren’t any opportunities that met her individual needs.”

“Our training recognises that every workshop is different” says Sophie. “There’s no such thing as one size fits all. It’s completely inspired by the dancers with their disabilities and their abilities, passions, and interests. It could be high energy, fitness-based or a more creative, contemporary style, or something in between.”

Keen to spread the word about inclusive practice further, the Inclusive Approaches training is now delivered to different audiences. DanceSyndrome can deliver two-hour workshops in schools, universities and businesses, and the content focuses on

how inclusion is important in all areas of life. It identifies considerations and adaptations to make all practices truly inclusive.

Sophie recognises that the rate of personal development and its magnitude differ from dancer to dancer and, as she puts it, “Every small step is as important as a major stride whether this is empowering someone who previously watched from the sidelines but didn’t have the confidence to join in or, well, our dancers performing at the Edinburgh Fringe!”

So, what advice would she give to a Dance Artist who may be thinking about becoming involved in co-delivered, inclusive dance?

“As a freelance artist it can sometimes feel very lonely and so I would say really think about the potential of co-delivery. Having someone to bounce ideas off, inspiring each other, taking different roles within sessions, being able to deal with a difficult situation whilst your co-leader keeps the rest of the group engaged, and reviewing the session together are just some of the many advantages of co-delivery.”

“The biggest reward for me is seeing people grow. The changes I’ve witnessed in each dancer are huge. They are confident individuals. They’ve got their own voices. They’ve got their own opinions and they’re not afraid to express them. The scale of the transformation can’t really be put into words.”

In 2019, DanceSyndrome investigated the concept of "co-creation" on a more in-depth level. Co-leadership of regular dance workshops and training was now established, but the team wanted to extend this to performance work too with the co-creation of choreography. Arts Council England were keen to explore this in more detail and provided funding so that three DanceSyndrome Dance Artists could collaborate with three disabled choreographers and explore what happened when they collaborated in this way.

One partnership that has come out of this approach was the "Dancing Daves" as they are affectionately known.

Dance Leader David Corr, who has Down's syndrome, said "You need to respect each other and encourage your partner's ideas. You should treat your partner as you would like to be treated. I

enjoy it all but seeing dancers perform your choreography is amazing!"



Professional Dance Artist David Darcy said "At first I found navigating the relationship between me and my partner difficult, because I felt like he saw me as the teacher as we've worked in this way in the past. We had to find a new and different way to approach how we worked together. It's really important to understand everybody's individual needs. When sharing your ideas you need to make sure you give time to allow your partner to understand why you're approaching things the way that you are and give past experiences. You need to allow time and space for development and it's really crucial that you get feedback on what is working for each of you. There were so many highlights, but for me the main highlight is always the end product.

When you see your partner's face light up, he had a moment when he went "Wow", and seeing people realise they have potential that they didn't know that they had is something I really treasure."

The findings from the project were fascinating and on analysing the reflections from the professional Dance Artists it became clear that at times they had all compromised on the development of their own artistic concepts or had allowed their co-creator to pursue their own ideas as the priority so that they were not seen to be overpowering the other person's voice. This artistic compromise is

not always easy, and it is testament to the truly inclusive nature of the DanceSyndrome Dance Artists that their priority was to allow people with learning disabilities to have their voices and opinions heard. The reflections also showed that the Dance Artists all felt that because of those compromises that they had made, the finished performance pieces were something better, more unique, and different which could not have been achieved without co-creation.

This whole process shows how important inclusion is to both those with learning disabilities and those without. DanceSyndrome's motto is that "Everybody can dance and there is beauty and significance in all movement", but inclusive dance is so much more than that. In an inclusive dance environment, **everybody**, regardless of age, gender, race, ability, or disability, sees benefits to their health and wellbeing, their sense of community and their day-to-day life skills. **Everybody** feels happier, more optimistic and has a sense of belonging. **Everybody** feels more creative, more fulfilled and wants to contribute. But most importantly, **everybody** should have the opportunity to join dance sessions that are accessible and inclusive so that they are able to reap these many rewards.

Anne Donohoe

Expert by experience, parent and professional Plymouth



96



foundation for
people with
learning disabilities

EST 1892

LSBU

NHS

Oxleas

NHS Foundation Trust



Penge Publishers

Currently the importance of “mental health” is a much talked about topic, but “***What is mental health?***”¹

Mental health is complex, we talk a lot about good mental health these days, but what actually constitutes “good mental health”?

It seems we often talk about its absence rather than defining, agreeing and acknowledging what good mental health is. After all, what is healthy or acceptable to one person is unhealthy or unacceptable to another. Who defines and sets the bar for what good mental health is? It appears to be highly subjective and defined by a combination of factors such as family, society, culture, religion etc. Different families can have very diverse opinions. When one man’s terrorist is another man’s freedom fighter is it any wonder that as society becomes more polarised so has the frequency with which one side accuses the other of madness?

Every day we see heated discussions on line which lead people to exclaim “Are you mad?”

Of course, no one wants to be called mad.

These very negative views of mental health are rooted in a past, where there simply wasn't the care, understanding or medical help available to help those in need. I can still remember visiting a relative in a secure mental institution as a child with my parents, accompanied by a matron with a huge bunch of keys, which jangled as she unlocked every door in front of us and locked them again behind us. It was like a visit to the worst kind of Dickensian institution where all the patients were "mad". The sights, sounds and violence were terrifying to experience. My cousin was about 30 years old and had had some kind of mental health issue or breakdown. Today, with proper care and support, she would probably be living in society and her mental health challenges might not have even been noticeable.

Sadly, today there is still a "belief that disclosing one's mental health problems may be viewed with mistrust and could result in discrimination."

"The Psychologist", October 2021, pg. 35, 'One for sorrow ... seven for a secret', Lived Experience, Vanessa Moore.

People are still scared about the implications of having poor mental health. Recently a Plymouth teenager, Jessica Mowbray, was awarded £2,500 from Derriford Hospital where she worked after her line manager revealed to colleagues that she was off work due to mental health struggles. (Plymouth Live News, Amber Edwards, 14/09/2022 15:36)

This “Peter and Friends” publication centres around mental health and “difference and disability”. Unfortunately, today, all too often, those with “differences and “disabilities” still face an uphill struggle, trying to maintain and retain good mental health when they have to deal with the extra day to day challenges of life often with very little support. In addition, if they do develop poor mental health, this adds to their feelings of difference and “disability” and once their mental health declines this can lead to a downward spiral not only affecting their mental health but their physical health and their whole wellbeing. In addition, this then affects parents and carers and also how others view them, sadly, often negatively.

Everyone's experience is different.

To help illustrate these different experiences, I have gathered several special insights kindly written for me by a variety of people, in the area of autism, learning difficulties and mental health. Some are from "Experts by Experience" like my son Andrew Donohoe, who has Fragile X Syndrome, and comments from Ruby Woods, a young lady with autism, dyslexia, anxiety and OCD. Then there are the views of family, Andrew's sister, Rebecca Scott, and myself, Anne Donohoe, as Andrew's mum. I am also someone who has had to advocate for Andrew in a professional sense for the last 32 years, since he was born. I have fought for the best possible life for him.

There is also an anonymous submission from someone I know, a grandmother who writes about her granddaughter with DiGeorge Syndrome and the awful effects a difficult family break up has had on her granddaughter's mental health and that of the whole family.

Jackie Blank and Kelly Clarke write from their experience working within the areas of mental health, autism and learning difficulties. They are involved with, help run and support a drama group called “Access Theatre” which Andrew is a member of.

Finally, I have some comments from Cape Town by a teacher called Clara Machado on how her students on a Vocational Programme have coped in the last couple of years. Please find these stories and read them as these stories are part of Andrew’s journey and mine.

What I have written illustrates our journey, Andrew’s, his sister’s and mine. Towards the end of my chapter, I describe where that journey finally led us. It’s a simple idea we’ve dubbed “Andrew’s World” and we’ve already begun developing the core layout of what hopefully will become a “Wikipedia of care” that collates experiences across every county and health authority in the UK . All the authorities vary in their provision of care and support for those with differences and “disabilities” but hopefully together and through this county by county approach a true picture will emerge where we can all campaign for uniform national standards.

Below, I begin my discussion with some of our “lived experience” as a family to illustrate how life changing and stressful it can be even just getting a diagnosis for your child. Then there is the potentially life long road of care ahead. I therefore focus, not only on the mental health of those with autism or learning difficulties, but also how this affects the care-givers and the family’s mental health. It is well recognised that caring for a “special” child or adult is extremely stressful and can cause anxiety, depression or other mental health issues. Unfortunately, there still isn’t enough support either practical, financial, emotional or professional. Sadly, there have been far too many cases of carers taking their own lives in desperation. Sometimes also taking the lives of those they care for at the same time because the carer does not know how their loved one will be cared for after their death and this fills them with horror.

Anne’s story and discussion about mental health, autism and learning difficulties.

I spent hundreds of hours getting Andrew’s diagnosis. When voicing concerns about how much my young son slept I was told by the health visitor that I should stop complaining as most mothers

were desperate for their children to sleep. I was concerned that sleeping so much meant that there was something wrong intellectually. Explaining how little food my son kept down and how much he vomited had no effect and at this stage I was labelled a neurotic mother until one day I scooped the vomit up and put the container on my GP's desk. "Oh! This much!" was the astonished reply. After this, it took another 2 years of battling for help, before finally a consultant paediatrician who had worked at Great Ormond Street Hospital, a hospital I hold in high esteem, examined my son for 3 hours and then agreed with me. She said that there was something wrong with Andrew but she did not know what. She continued

"You are either the type of mother who wants to know or the type who doesn't think it necessary."

Not being believed about my son's medical and mental problems had been extremely detrimental to my well-being and mental health. It had also impacted on my husband and our relationship and to the wider family including Andrew's sister. At one stage Andrew used to sleep in a cot in his sister's room and sometimes

she would get out of bed and run along the corridor shouting “Mummy, daddy, Andrew has been sick”. She was 3 years old.

Also, as an educationalist, and someone interested in health, medicine and nutrition, of course I wanted to know what was wrong with Andrew to work out how to help him. I wanted to make sure that he got the best start and chance in life. As a Special Educational Needs and Disability (SEND) professional I firmly believe in targeted early intervention.

Giving every child the best possible start in life “will generate the greatest societal and mental health benefits.” (Pg. 8 Executive Summary, Social Determinants of Mental Health, World Health Organisation, WHO, 2014).

At this stage I asked to be referred to a consultant at another hospital in another city. I had researched their specialism and after more than 2 and a half years of fighting Andrew was finally diagnosed with Fragile X Syndrome and my “neurotic” label could be removed. My mental health had suffered since Andrew was born. Gradually now it started to improve. From my own experiences, and those of others I have supported professionally

through the years, I know first-hand how much caring for a child with a difference can negatively impact on mental health.

I think, the earlier, and easier, a diagnosis of learning difficulty or autism is made, the better the outcome should be for the child and that of the parents and caregivers, including their mental health.

My next task was to research Fragile X Syndrome in order to make sure that Andrew got the best medical help and therapeutic interventions that he needed. Sometimes there wasn't the knowledge or research to show the way so we had to be creative and "invent" strategies, routines and protocols. As an educationalist I designed his home and school education programme in conjunction with the schools I negotiated with. This was to try and ensure the best physical and mental health for Andrew and to ensure he learnt as much as he could. Thankfully, he is still developing and learning, but as he gets older his needs, including his mental health needs, change.

All this has also had a huge impact on my own life and mental health as it has had on Rebecca, Andrew's dad Steve, and my mum, Theresa, Andrew's grandma. It has been proven that parents, in particular, in families who have a child with a disability generally have poorer health as a result and can die prematurely. Unfortunately, Andrew's dad died when he was 60 years old. I know Andrew's diagnosis and helping to look after Andrew had a profound effect on Steve's health and life. Mentally Steve never recovered from the shock and the diagnosis. It effected Steve's physical health as well as his emotional and mental health. No matter how wonderful Andrew is, Steve wished every day that things were different. Neither Steve, nor I, were ever the same people after Andrew's birth.

The experience of parenting Andrew has been very hard and I have had to force myself to do lots of things that I didn't want to do and which didn't come easily. Caring for Andrew has taken its toll on family life and Steve's life and mine, in particular, but it has not all been negative. It has had positive benefits, in that as a family we have witnessed someone who was given very little chance of speaking and walking, or having a good quality of life, leading a life

that is valuable and enjoyable. We and others have learnt so much from Andrew and he lights up many peoples' lives. Another positive is that I have done some things that I would never have done e.g. writing this piece, doing an M.Ed. in Special and Inclusive Education, speaking at conferences, helping many other individuals and families as a result of my experiences. etc.

Andrew is now a young man of 32 years. Areas where I think there is a lack of information, help and resources which effect mental health for people like Andrew are listed below:

- Speech, language and communication – continuing to work on understanding and appropriate conversation as an adult
- Relationships
- Sex
- Gender
- Mental health
- Bereavement
- Eating challenges and disorders
- Small group work e.g. to practise social conversation or communication at work etc.



- Preparation for some kind of work or voluntary work and support “into work”
- Or just appropriate special interest or social groups where there is support

These are areas that Andrew needs professional input yet speaking to Andrew’s psychiatrist, there seems very little, sometimes nothing, locally in Plymouth to help. Personally, I have sought help for Andrew with appropriate social and friendship groups to enable him to have positive relationships and to help avoid feelings of isolation which could in turn lead to poor mental health. Appropriate groups are very difficult to find. Nationally there must be some very good services for people with autism and also some excellent services for people who have mental health issues, but I think it will be difficult to find specific services geared to those who have autism or learning difficulties **and** mental health problems. Locally I do not know of specific services for people with autism who also need help with their mental health.

In addition, after Steve’s death, I asked various GPs at our practice and Andrew’s consultant psychiatrist, the specialist behaviour

team, Learning Disabilities Team and various therapists, for specific help for Andrew regarding bereavement and the loss of his father. Andrew had sadly, and unexpectedly, found his dad dead at home at a time when his dad was quite well and his death was totally unexpected. At the time professionals said it might not be the right time for support. It might be too soon. Five years on there has been nothing, apart from one very inappropriate session about 2 years after his dad died, which did more harm than good. Beforehand I was very specific about what might cause Andrew stress and be counter-productive. This was totally ignored. I have been very concerned for Andrew's mental health. We have managed the situation by ourselves, as a family and support team with very little guidance. The professionals say we have done a remarkable job. That's great! But I would have liked professional support and guidance for myself, our family, Andrew's team of Personal Assistants (PAs) and Andrew himself.

Jeremiah's Journey, a bereavement support programme exists for those up to 18 years old in Plymouth but the adult services in this area seem non-existent.

<http://jeremiah'sjourney.org.uk>

One area where Andrew has had challenges is eating. Issues with food have wide implications for people with autism and learning difficulties. Eating disorders have the highest mortality rate of any mental illness and food issues can cause significant mental health problems in anyone, but for those with autism or learning difficulties it is even more complex. Eating disorders in autistic people are poorly understood but they tend to be more severe and longer lasting. In 2022, generally, the incidence of eating disorders is rising.

Elsewhere in this publication, Ruby Woods describes her struggles with Avoidant and Restrictive Food Intake Disorder (ARFID). I helped a friend's teenager who has Asperger's Syndrome who has been dangerously underweight and controls her own intake of food. She refuses to eat most foods and has a very restrictive diet. She also lies about what she has eaten, throws food away secretly and refuses to take medication prescribed by her psychiatrist to help her depression, which would hopefully help with her food issues. She pretends to take the drugs, then hides them in her cheek and spits them out at the first opportunity.

“The fact that autistic people are vulnerable to chronic eating disorders, alongside other mental illnesses, may be one reason why they die one to three decades earlier, on average, than non-autistic people.”

Research at Bournemouth University suggests that the link between autism and eating disorders may be due to an inability to identify emotions.

<http://theconversation.com/amp/link-between-autism-and-eating-disorders-may-be-due-to-an-inability-to-identify-emotions-new-research-143022>

I did not want eating to become a mental health problem for Andrew and have monitored Andrew’s eating since he was a baby when he used to vomit most of his food every day due to a medical problem. Despite Andrew’s sensory issues I always tried to provide Andrew, and his sister, with a balanced and healthy diet and tried to educate them both about food and food choices. I did not want Andrew to have a limited diet and only eat a small selection of foodstuffs due to sensory issues or autism so always encouraged Andrew to eat a wide variety of foods with different colours,

111

textures, smells and tastes. He now eats most things apart from mushrooms and prawns – probably the slimy texture puts Andrew off. I also didn't want Andrew to restrict his eating so that he developed anorexia type symptoms, nor did I want him to binge eat and have uncontrollable urges to over eat or have Prader Willi type symptoms. For Andrew, the difficulty is managing the quantity, and frequency of food. Andrew can become noticeably anxious or excited at the prospect of certain foods and drinks. This may be linked to interoception (a lesser known sense), anxiety, difficulty recognising his emotions or his inability to modulate his impulse control and self-regulate himself. Andrew eats especially when he is alone in his flat. His weight crept up to over 17 and a half stone despite lots of exercise and ensuring all meals and snacks were healthy.

<https://www.peacepathway.org/blog/interoception-the-hidden-sense>

Initially we tried to enable Andrew to learn to regulate his food intake himself independently but with support. After time it became clear that this was not working and Andrew's weight kept increasing. Unfortunately, despite our best efforts and trying a

variety of strategies, we have had to restrict whatever food we leave in Andrew's flat. He rarely has a cake or a packet of biscuits at home as he would just start eating them and finish the lot. I don't know if he has any awareness of hunger or being full. He has overeaten to the extent that he has made himself ill with stomach pain, vomiting or diarrhoea. I don't know if he really understands enough about over-eating, putting on weight and trying to limit his own intake. At his flat, he always has access to fresh fruit and vegetables, a couple of low-fat yoghurts and sometimes some humous. We do not leave a loaf of bread, lots of cheese or ready to eat snack foods as Andrew would just eat the lot in between his PAs arriving and leaving during the day or at night before he went to bed. This can be quite serious as Andrew has tried to eat frozen food straight from the freezer. This has included taking bites from raw chicken breasts. He has also taken a bite out of a block of butter or cheese in the fridge. Andrew has always enjoyed cooking and as he has got older he has got more creative in the food he binges on, even mixing salad leaves with any sauces and condiments he has e.g. chilli sauce, curry powder, soy sauce, mayonnaise etc. After a huge effort over more than 3 years Andrew's weight is now 14 and a half stone and if possible, he is going to lose a little more. A strategy we developed recently was

asking Andrew to choose a snack every day which he is told he can eat at night when he is by himself as long as he doesn't start making himself other "concoctions". This hopefully motivates him and gives him a sense of independence, self-control and self-esteem. After much work I think Andrew has more of an insight into his own eating but it still takes a lot of effort and vigilance for those concerned in his care and is difficult to manage.

For Andrew, I know being overweight affects how he feels and his mental health. Unfortunately, there still isn't enough research on eating disorders, autism, learning difficulties, how this might affect mental health and what strategies to use. There are no national guidelines for treating eating disorders in autistic people. Look at the "Eating Disorders" section of the website below:

<http://www.autism.org.uk>

There is a significant number of people with anorexia who are also autistic, some say 20% (National Autistic Society), others say 35% (PEACE project, Kings College, London) and these two conditions have symptoms in common and the two conditions may even be linked. There is also evidence that anorexia is harder to treat in

individuals who have autism and treatment needs to be adapted to a more skills-based approach including dietetics and occupational therapy input.

<https://www.thelondoncentre.co.uk/autism-spectrum-disorder>

PEACE is a new Pathway for Eating disorders and Autism developed from Clinical Experience at the South London and Maudsley Hospital in conjunction with Kings College London. This research suggests that around 35% of people experiencing an eating disorder may also have an autism spectrum condition. See:

<http://www.peacepathway.org/>

Recent research linked to PEACE has resulted in this book being published in 2021, “Supporting Autistic People with Eating Disorders. A guide to adapting treatment and supporting recovery.” Edited by Kate Tchanturia, a professor at the Institute of Psychiatry, Psychology and Neuroscience.

Here are a couple of links to lived experience accounts of people with anorexia and autism.

Atypical anorexia: Facing an eating disorder, Autistically. 6.8.20

<http://www.reframingautism.com.au/atypical-anorexia-facing-an-eating-disorder-autistically/>

Autism& Anorexia, 5 Things you need to know about the interplay

<https://www.youtube.com/watch?v=Zsp3b8GOBFs&authuser=0>

As regards research linking eating disorders with learning difficulties, again there is not enough research but the incidence of eating disorders in this population is again higher than in a neurotypical sample.

“The main finding was that 27% of cases showed indices of an eating disorder. Among the eating disorders, binge-eating was the most prevalent. Incidence of anorexia nervosa was higher than that of the general population.”

“Prevalence of Eating Disorders in Adults with Mental Retardation Living in the Community”, 2004.

[https://doi.org/10.1352/0895-8017\(2004\)109%3C501:POEDIA%3E2.0.CO;2](https://doi.org/10.1352/0895-8017(2004)109%3C501:POEDIA%3E2.0.CO;2)

Weight surveys indicate that 2–35% of adults with intellectual disabilities are obese and 5–43% are significantly underweight, but the contribution of diagnosable eating disorders to these figures is unknown.

Eating disorders in adults with intellectual disability, 2008.

<https://onlinelibrary.wiley.com/doi/abs/10.1111/j.1365-2788.2000.00308.x>

One proposal is that neuropsychological deficits in various cognitive domains pre-exist and underlie the aetiology of eating disorders.

<https://link.springer.com/article/10.1023/B:NERV.0000028081.40907.de>

Eating and over-eating is a very sensory experience. Chewing helps calm him. I am sure this, and also anxiety, contribute to Andrew's difficulties with managing food. One positive outcome of the pandemic was that it did provide an opportunity to update Andrew's sensory profile using video calls with the help of his

Occupational Therapist, his sister, carers, myself and of course Andrew. Ensuring that Andrew has sufficient but not too much sensory stimulation helps to lower anxiety, keep him calm and therefore have mental health benefits. Oral stimulation was an area we looked carefully at when doing Andrew's sensory profile. To help him keep calm Andrew likes to chew gum. He also likes to carry small mints with him. Andrew's sensory profile and strategies to manage it were then disseminated to his care team in a video meeting. I am sure that managing Andrew's sensory needs and anxiety have really helped him.

Talking about anxiety or asking what makes Andrew feel anxious in turn creates anxiety for Andrew. He doesn't like the thought of being sad or anxious. He doesn't like to think of himself as "down". He always wants to feel and be happy and to be seen to be so. This means talking about mental health with him is tricky. It is an area that was difficult to talk about during the pandemic and it is something we are still working on.

Things that help Andrew are, being on time, not rushing and having a daily timetable to create calm and structure. Knowing what he will be doing and with whom helps him.

During the pandemic I also started to write a blog called “Corona Virus Support Blog”.

<http://annedonohoe.com>

In Andrew’s flat there have always been a variety of resources to use to keep low moods and anxiety at bay. Before the pandemic I bought lots of new resources, so that he could replicate some of his activities that he was no longer able to do due to lockdown, in some way in his flat. e.g. items to make an ice cream parlour, an Italian restaurant, a nightclub in his hallway with cocktails which he could invite his friends to on Zoom etc. You can see Andrew featured in many of these activities on my “Corona Virus Support Blog” which is on my website: e.g.

<https://annedonohoe.co.uk/new-corona-virus-support/f/andrew%E2%80%99s-glastonbury-june-2020>

My blog was a way of recording what Andrew was doing during the pandemic and to hopefully entertain or give ideas to others, but it was also a way of encouraging Andrew to do things which were home based rather than going to the various timetabled activities across the week which he normally attends. Andrew needed something to replace all of the activity that he was used to in his week which disappeared overnight when Covid-19 arrived. My blog and Andrew's contribution were a way of protecting Andrew's mental health. Keeping Andrew active really helps reduce his anxiety. If he isn't at the gym or swimming, Andrew also enjoys yoga, dancing, stretching exercises and meditation as a way to feel calm and promote happy hormones.

The blogs were not only a way of motivating and interesting him but also gave him a sense of purpose. This helped him focus and stabilise his mental health through a very difficult period.

I don't think that vulnerable people like Andrew and others with autism or learning difficulties, or those being cared for at home, were given enough help and advice during the pandemic. Neither were their families or carers. I am sure that their mental health, and

that of those who care for them, suffered as a result as the rise in mental health issues in the general population since the pandemic has been recognised.

<https://www.mind.org.uk/coronavirus-we-are-here-for-you/coronavirus-research/>

My blog was also a place for information and articles aimed to help others during the pandemic. It became obvious that what people needed was accurate and up to date information. It was while writing these blogs and researching information for them that I realised how difficult some information was to find. Finding relevant information quickly and easily helps to alleviate stress and anxiety. I tried getting local and national information from a variety of sources and looked at many local websites and national ones including .gov sites for help. Some sites were very difficult to use, some had incorrect, or out of date information or no relevant information at all. It was extremely time consuming. It still isn't easy to find what you want, particularly what is available locally. There is no standardisation between local government websites. Each Council website operates differently and the .gov site is not easy to

navigate to find the information that you need even if it is there. As a parent put it to me

“You almost need to know what it is that you are looking for and how to access it before you can find it.”

Some websites just send you around in loops. Sometimes the information is inaccurate, out of date or just wrong. It is very time consuming, frustrating and not a good use of anyone’s time let alone a sleep deprived parent.

In particular I think the pandemic highlighted how people with autism and learning difficulties are often forgotten. Help, support and information for these individuals wasn’t necessarily available before or during the pandemic or now. This all impacts on everyone’s mental health.

So, as the world started to return to some kind of “new normal” I stopped writing on the blog and thought how can I start making this

information more accessible so that other people and perhaps even organisations could be spared the time I had wasted.

It would be great if there was a one-stop shop which is easy to use to cut down on the time, energy and stress people face just trying to find out about services and help available in their area. If there was one place where all of the information that people like us might need could be found, then under health, there would by now be a mental health section with a wealth of shared experience that we could all draw down on. Also it would illustrate how different health authorities had risen to the challenge and thus it might better arm people to expect and request more from their particular council or health authority.

Imagine if your journey began with a simple screen like this and the more you delved deeper the more answers you got that were specific to your particular needs:



A lot of the historic information regarding my journey would already be in Andrews World (under the AUTISM and FRAGILE X sections), as would the latest twists and turns of his story so far.

Even during the lifetime of my writing this piece the goal posts have already changed and new services are now available my area.

On 7.4.2022 the Devon Mental Health Alliance (DMHA), a partnership of [six member organisations](#), was launched. Their remit is to improve access to mental health services, create stronger pathways and brand-new services, and identify new opportunities to support people across all of Devon's communities. The evolving collaborative body will work closely with the Devon Partnership NHS Trust and Livewell Southwest as lead statutory partners. Livewell has a presence in Plymouth so hopefully as a result services locally will improve.

The DMHA collectively support around 30,000 people across Devon every year with complex life situations and multiple disadvantages. The Alliance will serve as the 'backbone' to the mental health system within Devon, with lived experience at its core, making all services more accessible to the people who need them.

<http://www.mentalhealthdevon.co.uk/>

<https://www.mentalhealthdevon.co.uk/news/2021-12-17/what-is-the-devon-mental-health-alliance>

The DMHA currently have a rolling programme advertising for suitable staff to provide these 1:1 or small group interventions to support those with complex needs. Suitable training has been identified as an issue and a priority.

In addition, a new anonymous online mental health support service has been launched across Devon, Plymouth and Torbay. It is called Qwell (www.qwell.io). It is delivered by mental health provider Kooth. The aim is to ensure that every adult living in Devon has access to a choice of support to managing their own emotional health and wellbeing by providing all adults over 18 with free anonymous, confidential, digital mental health support 24/7. You do not need a referral from a health professional. Qwell offers access to therapeutic services, a peer support community and a live text chat via which appointments can be made. Children and young adults already have professional support from Kooth. (pg. 20, Plymouth Chronicle, September 2022)

126

Due to the national focus on mental health post the Covid pandemic of the last 2 years hopefully mental health services will improve nationally and locally, including support for those with extra challenges. For example, on 9.6.22 there was a meeting briefing of the Greater Manchester Youth Combined Authority entitled

“How can schools better support neurodivergent young people? A summary of neurodivergent young peoples’ views from across Greater Manchester”.

This paper looked at well-being, friendships, understanding yourself, peer acceptance, staff understanding and use of restraint and exclusion. It said that neurodivergent people are often misunderstood and have very difficult experiences, especially in schools, and that this has a very detrimental effect on them and their mental health. There is a selection of quotations from the young people and their families. The report has many implications regarding the mental health of these young people and poses several important Key Questions.

<https://drive.google.com/file/d/1DMbqNV3M8xEFxiCbpSHPEd1PRA5Hdfc-/view>

The report explores having meaningful friendships. A huge number of neurodivergent young people say they feel alone, and there are two key reasons why:

1. Not having access to social opportunities where they can meet others who understand them (e.g. a meetup for young people with ADHD only.)
2. Not having access to social opportunities based around their interests

Often young people say:

There is a lack of provision available to help them connect with like-minded young people. Whilst there are sometimes social opportunities available based on their interests, the events are often not very inclusive, making them inaccessible for neurodivergent young people. (See my blog dated 14.6.22 “How can schools better support neurodivergent young people?” <http://annedonohoe.com>)

One telling finding is that neurodivergent young people say that the main reason they struggle in school is because grades are prioritised over wellbeing.

Below is a link to a group for autistic young people. In this unique community, autistic young people (and neurodivergent adult volunteers) collaborate and connect on a daily basis, creating a shared space in which the young people can be themselves and thrive. They believe the community that they have created helps to support mental health. See comments from their blog.

<http://spectrumgaming.net>

“When I was in year 4, I couldn’t tell anyone I was autistic, as I learned that people thought autistic people were brainless and were bad for society” - anonymous Spectrum Gaming member

“Through school I learned that who I am is not ok. I still haven’t recovered from this as an adult” - anonymous Spectrum Gaming member

Neurodivergent students would like greater staff understanding in schools.

“they promised things and I trusted them but it never happens (multiple times) they didn't listen to me or what I have to say or what I would like to do. They thought I looked OK on the outside but on the inside, I was having a mental breakdown” - anonymous Spectrum Gaming member

"My junior school said I was definitely not autistic and I was fine in school once I had been dragging in crying. I wasn't fine at all, I was breaking inside all the time. I got diagnosed autistic aged 13 by then I had suffered a lot of unnecessary trauma and developed extreme anxiety, I struggle to go to school at all." - anonymous Spectrum Gaming member

Being exposed to these experiences early in life is very likely to affect someone's view of themselves and their mental health for the rest of their lives.

As highlighted in my first paragraph, mental health is obviously complex. New mental health conditions are periodically recognised and added to in diagnostic manuals like the DSM-5 in the USA or

the ICD-10 in the UK. Currently, there are 33 types of mental health problems on the information and support page of the MIND website. These are even more complex to deal with when the person has other needs like a learning difference or autism. People with “autism are more likely to experience mental health problems than the general population.” (www.mind.org.uk/about-us/)

Two reports and a Panorama documentary highlighted how vulnerable people, such as those with autism, learning difficulties and mental health problems have had truly awful experiences and have not had the support and care they needed.

<https://www.childrenscommissioner.gov.uk/2019/05/20/many-vulnerable-children-with-learning-disabilities-are-stuck-in-mental-health-hospitals-for-too-long-in-poor-conditions/>

<https://www.cqc.org.uk/news/releases/cqc-calls-action-fix-closed-system-leads-people-learning-disability-or-autism-being>

<https://www.bbc.co.uk/programmes/m00059qb>

I believe that there is much more research regarding mental health and neurotypical people than for those who have mental health issues and learning differences or autism. Before we can effectively help people, we need data and research.

When I asked in schools recently whether they kept a separate record in their Special Educational Needs and Disabilities (SEND) database showing those with Autism or Learning Difficulties who **also have** mental health issues, the answer was always “No”.

Services and personnel need information and training not only to treat people effectively but also to enable them to feel confident and knowledgeable about treating them.

“I have experienced services that treat mental health and autism as completely separate issues and both services seem fearful of people with the other condition.”

<https://www.mind.org.uk/about-us/our-policy-work/equality-and-human-rights/autism-and-mental-health/>

There is now a link on the “Mind” website to new research and a free good practice guide for professionals: “How to adapt mental health talking therapies for autistic children and adults”, Published on 12 August 2021

<https://www.autism.org.uk/what-we-do/news/adapt-mental-health-talking-therapies>

There are so many suggestions currently on how various things may improve your mental health. Hopefully many are suitable or adaptable for people with autism or learning difficulties. I will give an example from one area which has been widely promoted, that is, being “outside and in touch with nature”. There is a very exciting and innovative project called “Myplace” delivered by the Wildlife Trust for Lancashire, Manchester and North Merseyside in partnership with the Lancashire and South Cumbria NHS Foundation Trust. It is a green wellbeing project to which you can self-refer. Ecotherapy has been shown to be beneficial for good mental health. Projects like these are hopefully inclusive and suitable for people with learning difficulties and autism.

Music has also been shown to have a positive impact on mental health and wellbeing. Andrew has been a member of various choirs, one for over 15 years. Andrew really enjoys music and singing and it makes him happy. Recently, as a family we became involved in a project called “Green Spaces, Dark Skies. A Journey into the Landscape”. This project combined music, movement and the outdoors. Andrew, Rebecca and I sang as part of a choir to record a soundtrack for a film recorded at Meldon Dam on Dartmoor. We were also participants in the film as “Luminators” carrying lanterns which changed in response to the soundtrack. It was a very positive and uplifting experience for us.

<https://www.youtube.com/watch?v=FH7pwG-vSMk>

The overview to the World Health Organisation (WHO) report “World mental health report: transforming mental health for all” (16.6.2022) says

“All over the world, mental health needs are high but responses are insufficient and inadequate.” This report . . . “is designed to inspire and inform better mental health for everyone everywhere. Drawing on the latest evidence available, showcasing examples of good

134

practice from around the world, and voicing people’s lived experience, it highlights why and where change is most needed and how it can best be achieved. It calls on all stakeholders to work together to deepen the value and commitment given to mental health, reshape the environments that influence mental health, and strengthen the systems that care for mental health.”

The WHO has examples of risks and protective factors that determine mental health. See page 21 of this report <https://www.who.int/publications/i/item/9789240049338>

There is a correlation between low income and mental disorders (WHO) but also a correlation between “low educational attainment, material disadvantage and unemployment” which many people with learning differences and autism experience. (Fryers T, Melzer D, Jenkins R, Brugha T. “The distribution of the common mental disorders: Social inequalities in Europe”. Journal of Public Mental Health. 2005; 1(14) page numbers: 1-12.). Social isolation is also a factor in poor mental health outcomes and also a feature of “difference and disability”. (WHO)

“Social inequalities are associated with increased risk of many common mental disorders.”

(Pg. 8, Executive Summary, Social Determinants of Mental Health, World Health Organisation, 2014)

I would suggest that anyone who has a learning difficulty or Autism is already likely to be disadvantaged and “socially unequal” despite attempts to remove various kinds of discrimination in everyday life over recent years. For example, the number of people with differences, disabilities and autism who are employed world-wide is not anywhere near representative of their number in society. On 16.5.22 there were estimated to be approximately 3.32 billion people employed worldwide. An estimated 1 billion people, around 15% of the world’s population, live with disabilities. An estimated 386 million of the world’s working-age people have some kind of disability says the International Labour Organization (ILO). Unemployment among people with disabilities is as high as 80% in some countries. Employers often assume that persons with disabilities are unable to work. (ILO).

<http://www.un.org/development/desa/disabilities/resources/factsheet-on-persons-with-disabilities.html>

People with autism or learning difficulties are therefore unlikely to have access to being able to earn money for themselves. This is not good for their self-esteem, and therefore their mental health, but it also means that this section of the population is potentially poorer, and relying on the state or friends and family for money. Historically, as well as a way of earning money, working has also been a way of indicating “your place” in society and helps to define you. It gives you a sense of belonging, an identity, a sense of self-worth and independence. It is also a way of giving something back to society, particularly if this is voluntary work. Whichever it is, work can also motivate people, helps them be in a routine, can provide social interaction and possible social activities outside of work etc. So, all of these unemployed people with “differences” who are denied the opportunity to do paid or voluntary work, are further disadvantaged, and although already likely to be prone to mental health issues, this is likely to be exacerbated as a result.

To reduce the risk of mental disorders, action needs to be taken across the whole of society. It needs to be proportionate and at local, community, national and international levels.

There also needs to be specific research and targeted services for those with autism and learning difficulties **and** mental health issues, as well as appropriate training for staff

As the WHO says

“The evidence is convincing that policy making at all levels of governance and across sectors can make a positive difference to mental health outcomes. Empowerment of individuals and communities is at the heart of action on the social determinants. Our intention is that this paper will stimulate further research and urgent action in all countries, worldwide.”

Anne Donohoe.

If you are interested in potentially becoming a local contributor to Andrews world please don't hesitate to contact me. Thank you.

Name withheld

“My Granddaughter”

I have written about my granddaughter who has Di George syndrome. She was shielding throughout the whole of lockdown as well as going through a really rough time with her parents divorcing. She was finding it really hard to express her feelings. She has many medical appointments throughout the year. And of course shielding made this really difficult. She did not want to go into a hospital environment during the pandemic. She has definitely struggled with her mental health.

I have talked to her about taking part in this publication but she does not feel comfortable to do so and to share her feelings personally although she has given me permission to describe her situation.

At this time, she's had to talk to many professionals as has finally made the decision to live with her mother. Now her father has made

it extremely difficult for her to see her brother. Her brother is living with her father. The courts are so behind and they're only doing telephone and zoom court hearings, which is so impersonal. There is so little support. The waiting and time this has taken so far is terrible. The whole thing has been a total nightmare for everyone concerned.



I myself feel my family have been let down by the system that is meant to support them from lack of resources. And the enormous cost for anything to do with legal proceedings. All of this has had a significant impact on my granddaughter's mental health but also negatively affected the mental health of other family members and caregivers.

I hope you will understand this is all very raw for me still. It was only when I started to think about writing something for you I realised how deeply this has affected us all. I am not sure that I am in the right place to write at the moment but wanted to say something to show how people with "differences" find it so extremely difficult when caught up in these kinds of family situations.

The support and resources are sadly lacking or non-existent. The timescales are far too long. All of this was further exacerbated by the pandemic. Sadly, there must be many other people with autism or learning difficulties who are still struggling through situations like this.

(name withheld)

Andrew finds it difficult to talk about his feelings, especially about what is making him feel a certain way. This sometimes makes it difficult to help him, as we don't know what the barriers are that we need to remove in order to help him to feel better. Sometimes his language seems to convey that he understands more than he does too. He can get frustrated if asked too many questions about how he's feeling and why. We also have to be very careful around language that we use, and the frequency of certain terms. For example, Andrew has heard the word anxious and uses the word, sometimes appropriately and sometimes inappropriately. I am not 100% convinced he really understands what it means. Andrew can also apply negative connotations to words which some other people would not see as negative, and can be sensitive about the use of these words. For example, people sometimes ask him if he's OK, or why he's quiet, and he has come to associate quietness, especially, to times of low mood, because generally, when Andrew is in a good mood, he is bubbly and loud and full of life. This means that if someone is being 'quiet' Andrew now associates this with negative emotions. I am trying hard to reframe the language I use

and to make sure that Andrew knows it's OK to be quiet sometimes etc.



I think Andrew generally enjoys life. He likes to make people happy, and he is a happy person most of the time. He loves dancing and singing and he has a great sense of humour.

Rebecca Donohoe

Jackie Blank Access Theatre Cornwall

I support an inclusive theatre group in Launceston, Cornwall, called Access Theatre.



I have many years' experience in personally and professionally supporting individuals and family members with learning disabilities and associated challenges. Mental Health concerns are always on the agenda but with very little understanding of the effects this has on peoples' lives. In the general population, this subject is being pushed by so many to make it part of the everyday norm to be discussed and acted upon and rightly so, but for marginalised groups there is this underlying sense of 'it's just part of life' or 'you just have to get on with it'.

Individuals who have autism or learning difficulties I have worked alongside communicate about loneliness, lack of opportunities to meet with friends and sometimes family. How through the pandemic, these feelings were exacerbated, because there were fewer opportunities and access to technology was extremely limited. If technology was available many needed support to access it and therefore could not have private conversations with friends, and special people in their lives. This isolation created a fear of the unknown for them and their friends and families. Now life is moving on these feelings of isolation and fear have not gone away as services have not returned to the same level as in earlier days for many and they are still cut off from friends causing real distress.

Parents and Carers often talk of the relentless fight to get access to services for their loved ones and how this creates tensions in their lives having to split themselves in several ways every day just to survive. They feel isolated as it is hard to find people to talk to. Parents and carers groups are great but reinforce the fight, don't necessarily give space for you to "be you" and enjoy your life outside of caring. The pandemic brought about the enormous stress of having to have individuals at home for 24 hours a day for an unknown time period, with little or no support from services and the fear of what would happen if they were taken ill. Just the day to day life of shopping etc was so stressful and for parents, carers with no technology expertise to do online shopping etc it was a real struggle. Life became even more isolated and frightening, people living on nerves, especially when your family member had no comprehension of what was going on and their lives had suddenly been turned upside down. Trying to support this was extraordinarily difficult. They talk of being abandoned, feeling that no one cared for them or their loved one/s. Some even talked of how it might be better to end it all, for all concerned.

Professionals were also left floundering, with little support and no guidance about how they could support individuals and families. Services shut their doors and many remain shut. This was seen as a real kick by many. Many tried to offer technological alternatives but this was not a great success. When it was possible, the technology was working and there was 1-1 support, often people were too frightened to take this up and try this option. The impact of not being able to provide services was huge on staff as they knew how important they were to their clients. A difficult time for staff as well.

My insight into all of this has been enhanced by being part of a theatre company that tried to maintain links with all its members throughout the past couple of years using whatever means were available. Conversations I now hear that sessions have restarted, have enhanced my understanding and made me realise even more, how services need to be available to all in our society not just for those who have a high profile or who can shout the loudest.

Jackie Blank

Clara Machado

Kelly Clarke

Member of staff, Access Theatre, Launceston



Also input from Anne Donohoe

Mother of Andrew, a participant and supporter of Access Theatre

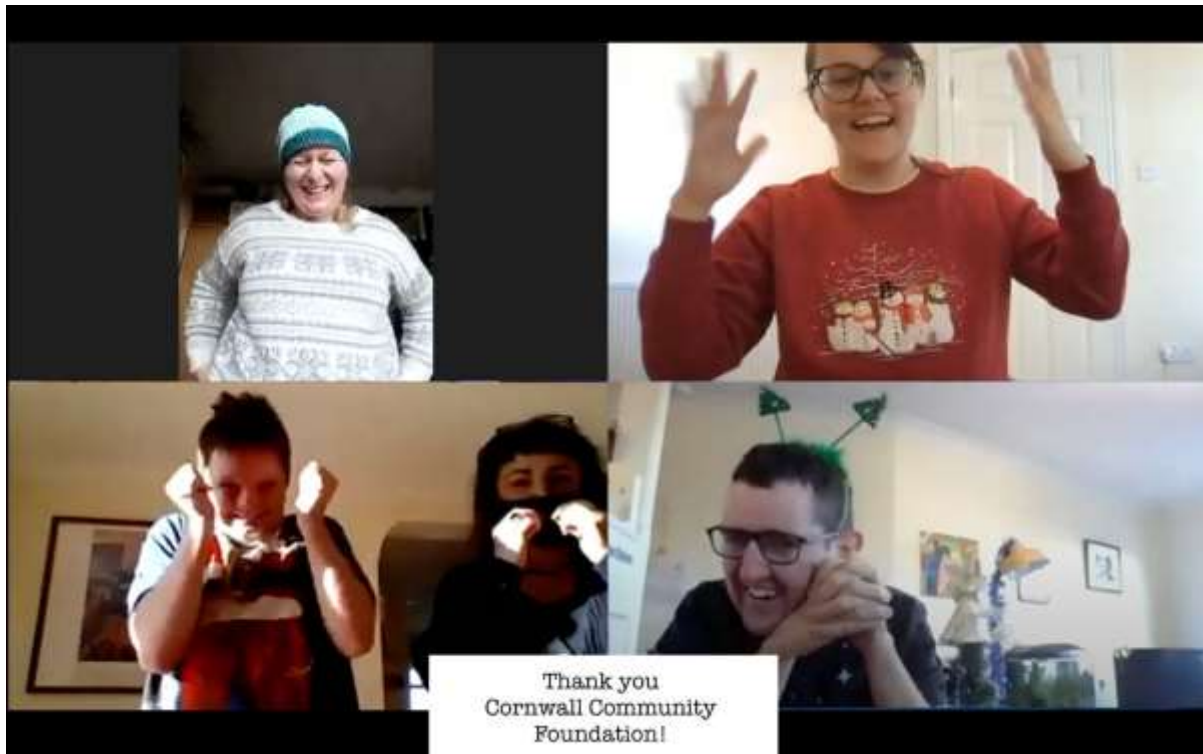
I am involved with an inclusive drama group, called “Access Theatre”. All the members have various challenges including Autism, Learning Difficulties and Down Syndrome. The group meets once a week for 3 hours from 1.00-4.00 pm. Some people arrive early before the group starts and socialise informally and often eat their packed lunch together. There is also a break for a drink and a snack during the session when members can socialise again. There is a very good atmosphere among members who are very supportive of each other. The leaders of the group are excellent at supporting the clients in all kinds of ways but, importantly, informally each week, they support their emotional needs. At the beginning of each session everyone shares with each other how their week has been and if anything important has happened to them. In this way happy things like birthdays and sad things like the death of a loved one can be shared. In addition all of the members of this group co-operatively join in exploring, deciding on and planning what the next performance will be. Due to the pandemic all of this stopped abruptly.

Apart from all of the concerns regarding Covid-19 and the huge anxiety this caused, the resultant suspension of “Access Theatre”, also affected the clients greatly. It was a major change to their routine and their week and the sudden nature of the change was likely to increase anxiety. For some group members, it was the main event of their week, and the total of their social life. Research shows that the lack of social contact is detrimental and associated to an increase in mental health problems like anxiety and depression, low self-esteem and increased stress.

<https://www.mind.org.uk/information-support/tips-for-everyday-living/loneliness/about-loneliness/>

Members of the group expressed how lonely and isolated they felt.

The pandemic was a time of great change for us all. “Access Theatre” did not initially have the resources to move online. Some clients did not have the technology, connectivity or skills. It took many months before “Access Theatre” was able to move online. Cornwall Council helped by providing some funding for an extra enabler to help make online sessions work.



When Zoom sessions began not everyone wanted to join the sessions or were unable to do so. For some it was the very first time that they had interacted face to face online. Certainly interacting online as a group was new to them all. It was a very different experience for the clients. They had not only to get used to seeing their friends in 2 dimensions on a screen but also get used to when to speak, when to be on mute, where to look etc. There were also the usual technical teething problems and the session was much shorter. Nevertheless those who joined these

151

activities welcomed the meetings and the return of the social contact. They seemed happy with the prospect of the sessions, enjoyed them and seem to benefit from them.

Many of the “Access Theatre” clients are vulnerable or live with vulnerable people so it was a long time before face to face sessions were considered again. All the members of the group were consulted about whether to return to face to face sessions. Clients and staff were very nervous, but all the members said that they had missed these sessions and that the online meetings were just not as good. Nevertheless, some group members were so anxious that they did not want to come back and still haven’t returned. Others could not return due to extreme vulnerability issues themselves or with those they live with. Eventually after much preparation, and once it was deemed “safe”, the first “in-person” sessions began again but in a different format. There was no informal socialising or sharing lunches. The whole group had to ensure as far as possible that they were Covid free, wear masks, sanitise their hands, and only use certain toilets. There was no socialising before sessions and no break in the middle of the session as access to making tea and coffee in the kitchen was banned. The group were only allowed

to meet in the large hall which was very well ventilated with open windows and the front door to the Council building was always left open. Chairs for the group members to sit on were arranged in a very large circle with very generous socially distanced spaces between them and there was minimal movement during the sessions. Sessions were only 2 hours long, not three.

All the members had to get used to very different protocols. You could see that they were anxious and not relaxed. Many did not look happy at all. Some had got so used to the online sessions that they were very stressed about meeting in person again. For so long, throughout the pandemic, they had been told not to meet people and to socially isolate. This general overall lack of social contact had made isolation “the norm”. Particularly for those on the autistic continuum, it would be another change of routine from a very protective low arousal environment to a more challenging situation with sensory input, personal contact and all of the demands that these bring. And, although the group would be returning to a familiar environment and see familiar faces again the characteristics of the sessions would be different. So it wasn’t as if

they were returning to the sessions as they had been before, something they knew. All of this created stress and anxiety.

Almost a year after re-starting the face to face sessions the protocols are gradually relaxing and the sessions are reverting to almost to pre-pandemic levels. Some of the health and safety protocols remain in place, however, but there is more movement during sessions, less strict social distancing (although hugging, shaking hands and other very close contact is still restricted) and singing is allowed. Gradually the group got used to each other again and everyone is now much more relaxed. It is great seeing everyone smiling and laughing once more. The stress, tension and anxiety have now vanished. The joy of having this group together again is fantastic. The new sessions have been a success and everyone prefers them to the online sessions. Not only that but “Access Drama in my view has helped build peoples’ confidence in being in group scenarios and how social distancing and mask wearing has reduced. The group asked for a social event and having a performance gave them all something to be excited about.”



On 14/07/2022 this culminated in the groups' first performance in nearly 3 years. It was called "Cruising in Cornwall". A comic drama about passengers on a cruise ship and what happens when the onboard entertainment fails and the passengers have to step in and provide the entertainment themselves for those on board.

It is my strong belief that meeting as a group online, sharing what has happened to them each week, then coming together to co-operatively in person once more to make drama has helped these individuals' mental health.

Kelly and Anne.



SEND Teacher

Cape Town



How the pandemic affected the mental wellbeing of students with autism or learning difficulties that I taught in Cape Town, South Africa.



All lockdown restrictions have currently been lifted in South Africa, but the wearing of masks indoors is still mandatory and the numbers of guests/spectators at events is still limited.

Lockdown was a very difficult time. The children and young adults I work with sometimes have trouble fully expressing themselves, but each one of them was able to talk to the level of loneliness and boredom they felt while living in hard lockdown in particular. Although none of them have a diagnosis of depression, it was a keyword that came up a lot. Whether or not many of them have a deeper understanding of what depression means they were all able to relate to feelings of loneliness, frustration, hopelessness and boredom.

None of these learners have siblings and found that being isolated from their friends and classmates was particularly difficult. Only being able to spend time at home with one or two parents took its toll emotionally. Each family had a different approach of how to manage their children's wellbeing during lockdown and this ranged from ensuring there were specific activities to do each day, to allowing as much screen time as possible. Some parents

commented that they noticed a very clear difference in their child's mental health and spoke about the fact that they noticed their child was depressed. In one instance, the child in question referred to not feeling lonely or bored at all because they were keeping themselves busy by playing online games and watching series and box sets. In fact, they spoke more about the fact that their father was stressed and upset about not being able to work, but that they felt safe inside because outside was where the virus was.

All of the children and young adults I work with live in free-standing houses with gardens and pets. Despite this, all of them mentioned that they missed taking their dogs for walks and being able to go to a park. Some of them began to talk to their neighbours over the wall, but still felt lonely because they missed their friends and it wasn't the same talking to adults.

When we began doing online school there was an initial feeling of excitement to talk to classmates and people they knew, but they all found it particularly tiring to try and listen to lessons and other people speaking online and to try and do their work. In fact, they all found this more stressful than the isolation of hard lockdown.

Currently, the learners I work with are all talking about how they are fed-up with needing to wear masks and sanitise everywhere they go. They have spoken about wanting to get back to normal and how some of them are confused because the rules are often different wherever you go and this makes them feel unsafe - only once the virus is gone will it then be safe to stop wearing masks?

Written by **Clara Machado**, March 2022

From the point of view of several learners between the ages of 13 and 19. Vocational Programme for special needs high school learners in Cape Town, South Africa



Suicide Prevention - help for everyone.

Jon Bryant, Video Director and Producer

Warning from Jon

Suicide and suicide prevention is not something we talk about very much so if you are feeling very low right now then maybe this isn't the right time for you to read this article.

If you do feel very low, then please find someone as soon as you can that you trust and tell them how you are feeling so they can support you. If you can't find the right words to tell someone then you could always show them this article to start a conversation.

My story

On a personal note, like a lot of young men I went through some tough times around that age, later in life I shared my story with the Samaritans for their website in the hopes that it might help someone else who was very sad see that you can get through tough times like I have. The main point is that talking to someone can help you turn a corner, not harm yourself and see that things can and do get better even if it doesn't feel like it at the time.

161

After my rocky times in my early 20's I have spent most of my life behind a camera of some sort, I'm also a bit dyslexic and still struggle to spell even simple 5 letter words with confidence, school was really hard for me because I found spelling so difficult which made writing extra hard too.

I started making videos about 40 years ago for really big companies, so I have a lot of experience in every aspect of making videos. About 10 years ago I started to use what I had learned about making videos to try and help people and in particular those with a learning disability. I like the feeling of knowing I have made a difference.

My first project for people with learning disabilities was a project for Origin Housing Association. Tenants with a learning disability could not be expected to read and understand the 40 page "tenancy agreement" everyone had to sign because it was all written in legal speak and long words. The written version was far too complicated. After all, how can you stick to the rules if you don't understand them? It turned out even tenants who did not have a

learning disability found this version of their tenancy agreement much easier to understand 😊

So, I set about making my version of an “easy read video” and converted the horrid and confusing 40-page legal tenancy agreement into a “see and hear” version for supported living tenants. I put this on a DVD with easy-to-follow chapters. I tried to make it interesting to watch so when we got to the bit about not keeping pets and not putting up a satellite dish unless you had special permission, I had some fun. I think people understand and remember fun things far better than a list of words and rules.

All the way through the project I worked closely with a group of the supported living tenants sharing ideas and making sure I really was making the tenancy agreement easier to understand for them. I went on to make do the same thing for Dimensions who provide supported living accommodation all over the country.

Suicide Prevention Project

After working on these projects, I was asked by a suicide prevention charity if I could make something for people with learning disabilities to help them if they were feeling life was just becoming too much and they wanted those feelings to go away forever. When I looked there was nothing I could find to help people with learning disabilities who were feeling very, very sad.

Suicide means ending your life because you feel so sad you don't want to be alive anymore and there can be many reasons for feeling that way. So, I needed to understand some of the reasons or "triggers" for people having these feelings. I also needed to learn what the experts thought was the best way to help, then I had to find a "see and hear" way to convert the suicide prevention courses I attended into something everyone could understand in my version of an easy read video.

Because it's such a difficult thing to talk about for everyone not just people with a learning disability I wanted to make something that could help people start talking, so if a family member, support

worker or carer was worried about the person they looked after they could watch it together and start talking about the feelings.

If there is one message out of all this it is please find someone you trust to talk to if you are feeling so sad if you have thought about hurting yourself or just want the pain to stop. Talking works, once you have shared your feelings there are things you can do to help yourself feel not so sad.

I contacted people on social media explaining what I wanted to make. I needed to talk to people who had been affected by someone close to them ending their life. This was without a doubt the toughest research I have ever had to do; the stories were so sad.

Several parents contacted me and shared their experience of losing someone very close to them. I also spoke to my group of people that had learning disabilities who lived in the community often with very little support except local charities. I was deeply shocked at how many of them had lost friends who were so sad

they had ended their lives. This made me want to do the best job I could.

I thought about using actors to help but I thought it might be too real and scary. In the end I felt the best way was to mix photographs with a “character” I created. The character was made to look a bit like a cartoon. I made it make the person blink, look around, smile, look sad and even shy too, this meant trying out lots of ideas as I had never done this kind of thing before.

I tried to make the video work for everyone. If you had poor sight just listening would tell the story. If you had a hearing problem, you could watch it without needing the sound on. I even researched style of text words on screen. A font that was easy to read is “Architect Small Block” which had come out top in a research study when tested with people with a learning disability. I have a learning difficulty and I certainly find it “easy on the eye” and it feels friendly and unthreatening unlike letters reminding you to pay a bill or a newspaper headline.

I decided it would be easier to use my voice on the video, that way if I wanted to change something I could just record myself again. I think if I was doing this project again, I would use different people voices for different parts of the country, so their accent (way of speaking) was familiar.

The first scene in the video looks like this. I hung the duvet over my guitar to make it look like a person, then covered the guitar up with my very sad looking person.

The main idea behind the project was to make something that could be used to start a conversation, if you have a learning disability, we understand it can be hard to find the right words or understand powerful feelings that make you feel very sad.

A common part of all suicide prevention training is to help people understand what is making them feel so sad. It might be the loss of a parent, loneliness, its different for everyone. The thing is sometimes people are too shy to talk about how low they feel so the video just lets you know it normal and OK to feel like this.

There are lots of organisations who offer text or chat as a way to talk it's all about what works for you. It's a very sensible idea to find out who you would contact if you ever felt so sad and maybe put those numbers on your fridge door so you can always find them. These are all the things it was important that the video explained.

Once you understand the things that make you feel sad you can then stay away from things that bring up these feelings. If seeing or doing something brings back these feelings people often call them "triggers".

A really important message in the video is about the good things you could do to make yourself feel better. So, we asked people to think about those things in life that made them happy, it can be the little things like your favourite food or maybe pictures of a day away you enjoyed, sport, your favourite cuddly bear, nature, whatever makes you happy. The you can make a list of these things to remind yourself that sad feelings don't last forever no matter how bad it feels at the time.

When we feel really sad we forget the good things in our lives, so finding ways to bring back happier memories can be very helpful.

If you want to watch the video, you can see it here <https://youtu.be/FNaWcmIEM9c>

Having finished this project if I ever see anyone who is really sad I will always go to them and ask in a kind voice “are you OK? would you like to talk? And tell them my name. You never know you just might be the person that said the right thing at the right time for a very sad person to start talking and get some help.



What is it like to see a psychologist?

Lucy - a carer and Dr Alison Clark, Specialist Counselling Psychologist, Greenwich Community Learning Disabilities Team Oxleas NHS Foundation Trust

The names Lucy, Keera are not the real names of the people involved. This is to protect their identity.

Background

My name is Lucy. I am 62 years old. I have a daughter called Keera. Keera is 37 years old. She has moderate learning disabilities and autism.

Life has sometimes been very difficult for us, and some really bad things have happened. These bad things happened when I was a little girl and then again when Keera was a little girl. They were things that made us feel very unsafe and frightened.

My psychologist is called Alison. Alison says that when really bad things happen it is called trauma. Trauma can make people very anxious. It can make you worry about everything. It can make you

170

feel unsafe all the time, even when the bad things are not happening anymore.

I used to feel very anxious all the time. Keera used to feel anxious too. Sometimes her behaviour showed this. She would shout and sometimes she would lay on the floor and kick and bang her head.

How was it at first?

When I was first referred to psychology, I did not know what to think. I did not know what to expect. It was all a little bit strange first of all because Alison was a new person that I had to get used to. I did not know if the therapy was for me or for Keera. I did not know what to say to Alison at first. At first, I thought therapy might only be for mad people! Now I know that helping me also helps Keera.

It has really helped me to be able to talk about what happened to me in the past and talk about Keera and the problems she has. Her behaviour has got a lot better. There are still some problems and I feel it is still early days, but we are a lot better than we were.

Anxiety was a big problem in my life. Alison explained that when bad things happen to someone a lot, they start looking out for bad

things. They start expecting bad things to happen. What she said was true. That is what it was like for me. Alison said that it is like there is an alarm in our brains. When lots of bad things happen, the alarm becomes too sensitive and goes off at the slightest hint of something bad. This is what makes us feel anxious. Lots of bad things had happened to Keera and me. I did not feel calm. I felt very anxious a lot of the time.

Sometimes it has been difficult for me to trust professionals. I have been to meetings with them, and I thought they did not think I was very good at being a Mum to Keera. At first, I thought it might be the same with Alison. I thought Alison might judge me. After the first session I was so worried, I rang her boss. Alison talked to me about it the next time we met, and it was all okay. You see it was quite confusing at first, I did not know what to expect. I was not quite sure what was happening because of so many things that happened in the past. I thought Alison was going to be like them again.

How was the therapy?

My therapy started just before Covid, so we did not have many sessions where we were in the room together. Most of the time we just talked on the telephone. Covid was a really hectic time and Keera could not go to the Day Centre. This meant that she was at home with me when Alison rang, and I could not talk about difficult things because I did not want Keera to hear. I was protecting her so sometimes it felt a bit awkward. At this time, I was able to talk to Alison about the everyday things that were difficult for Keera and me. It helped to have somebody ringing me every week and checking that we were alright. Keera sometimes used to talk to Alison but not for very long and she did not like it if Alison asked her questions, so Alison just used to listen to her. It was not an easy time, but we managed to get through it.

When Keera went back to the Day Centre, I was able to talk more to Alison. I enjoy the therapy but some things I was talking about were very upsetting, like the past and all that but I got through it.

Some of the things I had never talked to anyone about before, not even my Mum or my sister. I always thought no one would believe me or that they would think I had done something bad. When I

talked to Alison, I was happy because someone believed what I was saying. At first, I did not want to say anything about what had happened. I had never talked about it, and I had tried to forget about it, but I couldn't. In the end I just had to say something about it all. It was good to have someone listen to me and believe what I was saying. It explained why I was like I had been in the past. Why I was so anxious and felt so unsafe. I wanted other people, especially the professionals to know why I was so anxious in the past.

I really look forward to the therapy sessions. It took me a long time to tell Alison about the things that had happened because I had not spoken about them before, and I needed to trust her and get to know her quite well before I could tell her about them. I do feel really comfortable in the sessions talking to Alison though and I could tell her anything.

I can talk to Alison about upsetting things and I am not scared to tell her if I disagree with her about something. One of the difficult things that we talk about is Keera having respite care. This is something that really worries me because Keera had respite care

once before and she was treated really badly so I am frightened that it will happen again. I am also worried about what will happen to Keera if I am sick and not able to look after her. It is a difficult thing to talk about because it is really worrying but I can use my therapy with Alison to talk about it and to think about all the different things relating to it. I do not like talking about it but I also know it is something I have to think about and so I think about it in my therapy sessions.

Thinking about the therapy and what has changed

I have not finished my therapy yet. I have been working with Alison for a long time but sometimes I feel like we have just started and there is a lot more that I want to tell her about. I think it will take time, but I know we might have to finish at some time.

I think I have changed quite a lot since I started therapy. I feel much calmer and less anxious. Alison says that I speak more slowly and that I pause to listen. I think that I can think more clearly too. I was bottling all this up for years. I used to drink quite a lot in the past. When I was younger, I used to drink to block out all the bad things that have happened. I was trying to block it out all the time. The

175

funny thing is, now that I can talk about it to Alison, I don't need to block it out anymore. I couldn't talk to my family because I didn't know what they would think of me. Most of all, I did not want to upset my mum. If my dad had found out what had happened, he would have gone berserk. I was a bit scared of what would happen if I told anyone. I was scared of upsetting them and scared of what they would think of me.

When we used to have professionals' meetings, I used to get very anxious about the meetings before they happened. It was scary going to a meeting room and sometimes there were people there who I did not want to talk in front of and then all my words got mucked up. We had the last professionals' meeting at my house and Alison was there. It felt much better, and I was able to say what I was worried about and what I wanted. I have worked with some of those professionals for a long time and they said that they noticed how different I was.

What will you remember most?

What I will remember most about the sessions is being able to talk about all the horrible things that have happened to Keera and to

me. I have also been able to talk about family and about how worried I was that professionals were not on my side. I have been able to say some important things about who I do and do not want to look after Keera and to be involved in her care.

I feel more listened to now, especially by professionals. Alison has listened to me in therapy, and I think other people listen to me more as well.

The sessions last for about an hour and that is quite long enough. At the end of the sessions if I have been talking about some difficult things, I sometimes feel a bit strange afterwards and get upset. It is okay though because I can think about it all and it helps me to know that there will be another session next week.

Would you change anything about therapy?

I find it very hard to talk about respite care for Keera. I would like to not talk about that. Alison says I don't have to talk about it but there is part of me that wants to talk about it and sort it out. It is tough to talk about it.

What do you like about therapy?

I had some therapy before, but I couldn't talk to them. I can talk to Alison. I really like the way Alison listens. She has very good listening skills. She listened and she didn't get upset or judge me.

What would you say to someone who was thinking about therapy? Would you recommend it?

I would say "Go to therapy! If you need help you should go". I told my mum once she should think about going to therapy. I would tell people it is very helpful. "If people didn't have psychologists they'd be in a right bad way. If they are stressed or upset or their son or daughter got out of hand, they need to talk to a psychologist to help them through. I think so anyway".



Talking with James and his mother about their experiences of systemic family therapy

Information collected by Priyanga Jeyarajaguru, Assistant Psychologist and Simina Tantas, Undergraduate Psychology Student, Oxleas NHS Foundation Trust

In this chapter we share the experiences of James and his mother, who met with an Oxleas community learning disabilities psychology service for systemic family therapy. This means that the psychology team helped James and his mother to work together to overcome their problems. James and his mother met with a team of three psychologists. One psychologist spoke with James and his mother, whilst the other two psychologists listened. After they listened, the two psychologists talked about what they heard in front of James and his mother. They also shared some ideas with James and his mother about how to overcome their problems.

James and his mother had nine family sessions with the psychology team. The following is a summary of what James and his mother said about meeting with the team.

Talking with James

Mum and dad have always supported me and made me feel loved. So, when my dad passed away during the COVID pandemic, I felt like I was in a dark tunnel and could not reach for the light. I was finding it hard to cope. I also felt like I could not speak to my mum about my feelings. This meant I would always be out late at night and not tell her. My mum told me that I should seek help about my dad's death, so I could speak to someone about my feelings. I had bereavement counselling via the telephone. It did not help me because it did not get to the bottom of my problems. Because of this, I was referred to psychology in the community learning disabilities team.

As I was in a dark tunnel, I thought it would be a good idea to have therapy with the psychology team. I imagined therapy would mean talking about my problems to a psychologist, which I thought would be helpful. Surprisingly, I was not nervous about meeting the team because I was thinking about getting to the bottom of my feelings. In the past, I was told that I could not do things and was treated differently because I have learning disabilities. But the psychology team made me feel comfortable from the very first session. I slowly

opened up and would always look forward to meeting with the team. I felt respected and heard by them. I chose what issues to bring to the session. The team gave me enough time to speak. Mum came with me into the room for all my therapy sessions. Mum and I liked this because we were able to talk about our thoughts and feelings together and listen to one another.

I built a good relationship with the psychology team. So, when it came to an end, I was very sad. I miss having my weekly therapy sessions and speaking with them. However, I am happy that I can see the light and I am now out of the tunnel.

Since the sessions, my relationship with my mum is better. We tell each other everything, including what we are thinking and feeling. We also do some activities together such as going on holiday breaks. I understand why my mum was worried about me, so I make sure to tell her when I am going out and what I am doing. I am now back at work, and I enjoy seeing my friends.

I will always remember the lovely psychology team. They gave me hope that I can get out of the tunnel. I would not change anything about the therapy sessions because they helped me feel better. I would also tell other people to have therapy with the psychology team if they needed help.

Talking to James' mother

I was very worried about my son. After my husband died, I was feeling very sad. I was also scared of how James was dealing with his dad's death. I understood that he was scared of losing me.

I was very happy knowing that my son will soon start therapy with the psychology team. I was hoping that they would help him feel better and less anxious. I wanted James to know that just because his dad died, it would not mean that he will lose me as well. I was present at every therapy session. I looked forward to meeting with the team and talking about our problems. I felt very comfortable with them. James did not speak much at first. He did not want the team to know about his problems because he wanted them to like him. But in time, he opened up. In the past, James was often treated badly by people because he has learning disabilities. I do

not like people speaking for him and putting words in his mouth. James can speak for himself, but he needs time to understand what has been said to him. I was very happy that the psychology team was patient. The team was lovely, and they let James and I speak freely about our feelings and ideas. My favourite part of the therapy was that they took their time to understand everything that had happened and how this changed our lives. I liked listening to what James had to say, as it was the first time, I was hearing it. The team made sure that he knew they would help him get out of the tunnel. I was very happy hearing that.

I think therapy helped James and I a lot. I can see he is now less anxious. Having therapy together helped us become closer. I started feeling happier and more relaxed because we had a chance to talk to one another about our feelings. Honestly, I would not change anything about the therapy sessions. The team was lovely and patient. They helped us a lot. I would recommend therapy to anyone who is struggling to deal with their feelings. I was so happy with the service that I even recommended therapy to one of my neighbours.

Talking About Therapy

Rosamund Roach and Eolie Hampson, Bexley Psychology Team of Oxleas NHS Foundation Trust, Jane Menzies and members of Bexley Mencap

Four people with learning disabilities talked together about their experiences of getting psychology help from Bexley community team for people with learning disabilities (CLDT) which is part of Oxleas NHS Trust. Bexley Mencap members John, Mike, Jasmine and Amy (not their real names) came with their support worker, Jane Menzies to talk with Rosamund Roach and Eolie Hampson, clinical psychologists from the Bexley CLDT about coming for therapy. We asked them lots of questions and here are their answers.

“How did people feel about coming for therapy?”

“I felt a bit anxious”

The group talked about mixed feelings about coming for therapy. Mike had thought it was “*a good idea*”, but John had heard about someone who had said therapy wasn’t good, so he was a “*bit unsure about therapy*”. Jane had encouraged everyone to come as she thought it could help with their problems.

Everyone shared that they had felt anxious before coming. It was new. They did not know what it would be like. They wondered “*what would happen next*”. One person worried about being judged.

“What made it easier for people to come to therapy?”

“Having somebody you trust come with you”

Everyone in the group had someone come with them to their first sessions with the psychologist. The group said it was important that this was someone who was “*trusted*”, either a parent, a partner or support worker.

The group also talked about the psychologist helping them to come. One important thing we heard was that the psychologist had “*listened*” and everyone had liked their psychologist.

“What happened in therapy?”

Everyone agreed that it had been good to talk. Mike said that “*getting [feelings] out*” was really important. John told us about “*working things out*”.

We heard from Jasmine, Mike and Amy that the psychologists had found practical ways to help with problems. They talked about practicing new things in the sessions. Useful things included wearing headphones, mindfulness and “*calming walking*”. John said for him it was about thinking differently; “*changing his thoughts, behaviour and ways and ‘being more positive’*”.

Pictures and drawings were used in therapy. Amy was shown that treatment was like going up a ladder “*one step and two step then three step and four step*” and feeling “*better*” and “*happier*” with each step. Jasmine said she had special picture of a roundabout to remind what to do when she got anxious.

Jasmine also told us that she has a diary so she could write down “*all the brave things*” she has done. This helped her to keep going.

Jasmine also told us that her friends had made a video talking about what she achieved and her courage. She watched this in her last session, with her parents and Jane from Mencap. Jasmine said it was “*amazing*” that everyone had noticed her “*hard work*”.

“What was it like having therapy?”

The group talked therapy taking time. The psychologist didn't give up *“she kept telling you that they would find something [...] she kept listening to you”*. We heard that people tried lots of things to find the right thing. It was not always easy, but everyone was pleased they gone.

“What changed after therapy?”

“Life is continuing to get better and better now”

Everyone in the group talked about therapy helping them. Jasmine was able to do something she would have been too anxious to do before, *‘I went to Luton [...] by train’*, Amy told us she had been able to go with her mum for the first time in years. For Mike it was about feeling happy and better. John said therapy had helped him to *‘be more positive’ “changing my thoughts and thoughts and my ways’*.

Amy told us that things were so much better now, and she doesn't need to use to use all the psychology ideas anymore, *“[I] don't need headphones anymore”* and can speak to others instead. Jasmine

told us she still has anxiety but was more “*used to it now*”. She described that when anxiety nearly stops her from doing things, she says to herself “*I wanna do it*” and goes ahead and does it. After she has finished it’s like “*phew, I’ve done it now*”.

The group all shared that other people had noticed the difference in them. Jane, who has known all the group members, said how much she thought they all got from coming to psychology.

“What would the group say to someone thinking about going for therapy?”

- Therapy is good for helping people with their problems
- Take someone you trust to your first session
- Keep going.... your ‘problems won’t go away in one go
- ‘Have a book’ to write down your progress

Thank you to Amy, Jasmine, John, Mike and Jane Menzies from Bexley Mencap for talking with us and Chloe Hayes, student psychologist for help in writing this article.

Identifying our feelings and emotions

Jill Davies, Clinical Lead Nurse for Mental Health in Learning Disability, Oxleas NHS Foundation Trust

This chapter gives the reader practical ideas on how to support people with learning disabilities to learn how to identify a range of feelings linked to physiological effects on the body.

It is well known that people with learning disabilities have a greater risk of developing mental health disorders compared with the general population. Prevalence rates vary from 20.1% to 40.9% (Taylor et al, 2004, Cooper. et al, 2007).

There can be delays in diagnosing such issues because people some with learning disabilities find it difficult to communicate their distress so can be reliant on family and support workers to identify and refer on for help. One way to improve this is to educate people with learning disabilities on how to recognise their feelings themselves. By being able to recognise those unhelpful feelings,

people will have a sense of ownership of them and utilise strategies to address them.

Background

Nurses from the Bromley Mental Health in Learning Disability Team (MHiLD Team) have developed a range of tools to support people known to the service in understanding and responding to feelings, in particular, anxiety and anger. The Bromley MHiLD team are part of the Bromley Community Learning Disability Team (CLDT) and assesses and treats adults with significant learning disabilities who have psychiatric disorders and/or challenging behaviour.

The ideas discussed in this article were developed for 'The Good Mood' group, whose aim was to inform and educate people with learning disabilities about anxiety and low mood in a supportive environment. The nurses run these groups with other members of the multi-disciplinary team, such a psychology and with a co-facilitator with a learning disability who has already attended the course.

'The Good Mood' group is based on learning from the following pieces of work. These are: -

'Mental Health Promotion for people with Learning disabilities. By Hardy, Woodward, Halls and Creet, 2009.

Feeling Down: Looking after my mental health. Foundation for People with Learning Disabilities, 2015.

FRIENDS for Life. Paula Barret. This programme teaches children and young people techniques to cope with anxiety. It promotes well-being and social and emotional skills by using a cognitive behavioural therapy framework, often in school-based groups.

FRIENDS for Life Adapted Version Foundation for People with Learning Disabilities, 2015

This is an adapted version aimed at children and young people with learning disabilities.

In 2015, Special FRIENDS, was published for children and young people with autistic spectrum disorders (ASD) and attendant learning difficulties (age 9-13 years).

Due to Covid 19 restrictions, the 'Good Mood' group was unable to meet in person from 2020 to 2022, therefore the exercises were implemented on an individual basis. This article will give the reader ideas on how to apply some of these ideas and exercises in a family or supported living setting.

Practical ways to support identifying emotions

We used four basic emotions as the core of the course, see Figure 1.

They were Happy; Sad, Anxious; Angry.



Figure 1. The four key emotions.

Recognising emotions in others

We used magazine cuttings and accessed images from the internet of a range of emotions. Other sources of materials include online communication databases such as Photosymbols or Widget. The important thing is to make sure the person you are working with can understand the context of the image. Some people prefer real live photos rather than symbols such as Widget.

Emotional situations

Once the person/people understand each image of the emotion, the next step is to assess their understanding in the context of other situations. Showing short video clips from popular TV programmes (EastEnders is usually a winner!) and asking what the character on the programme is feeling. If you don't have access to video clips, finding photos of the key emotions from the internet, magazines or newspapers can be as helpful.

The 'Mental Health Promotion for people with Learning disabilities' pack by Hardy, et al (2009) provides lots of scenarios and examples to garner a conversation around recognising feelings.

Family members and support workers will have lots of their own examples to use if there is no access to the pack.

There is also useful information in section one of the 'Feeling down' pack by Foundation for People with Learning Disabilities (2015). This section is called 'What is mental health' and has images and examples of when people feel down, worried or depressed. This pack is free to download and has lots of useful information that can be used in a group or on an individual basis.

Identifying our own emotions

The next stage of this work is to apply the previous learning to ourselves. Using the photos, video clips or handouts from the above-mentioned packs, ask the person if they have experienced that emotion (focus on happy; sad; angry; anxious). If yes, ask them what happened to make them feel like that.

After this ask them when this happens, does anything change in their body? For example, do they cry if sad; have tense muscles if angry, smile if happy; or sweat or heart beats faster if worried.

De-stress toolkits



Figure 4. De-stress objects

We all have different ways of coping with stress, and what works brilliantly for one person will not help another. During our work with people with

learning disabilities, the nurses share a toolkit with a variety of objects that people can explore and help identify what works best for them. The kit we use in Bromley (Figure 4.) includes:

Laminated photos of dogs, public transport, a desert island and other relaxing scenes. It's best to have a range of scenes and can help a conversation around what picture would help the person

relax. Pictures can be used with prompts such as ‘what can you see’; ‘what is happening’, ‘how does it make you feel?’

Spinners and squeeze objects. Some people find these very relaxing and small items can be kept discretely on the person so can be used in public. One young person takes hers to college with her to help her feel calm in the transport to and from there.

Hand cream/perfume. Having a smell or the action of applying hand cream can offer distraction from a stressful situation or provide a relaxing situation such as preparing for bed.

Pens/pencils/paper. Having an opportunity to draw or scribble is another way to refocus unhelpful thoughts.

Photo of music/TV. Obviously, we cannot keep these in a relation toolbox but can provide visual prompts to help people think if these are ways to aid relaxation.

Relaxation exercises

At the end of each identifying feelings session, it is helpful to practice some relaxation exercises together. Relaxation exercises only work if people practice them regularly (think about learning to cycle or drive a car), and this needs to be brought into daily life for it to be sustained. People with learning disabilities learn more slowly over a longer period of time, so making time to spend just a few minutes each day to use these methods will help. They could be using the above methods and combining it with some traditional relaxation techniques, such as:

Deep breathing

Progressive muscle relaxation – in which you ask the person to tense up and then relax certain parts of the body (usually starting at the feet, moving to legs, stomach, hands, shoulders and face).

Mindful moments – for example, play some relaxing music, or take a small piece of chocolate and describe it and eat slowly with clear instructions.

We hope this short article gives readers some practical ideas on how to approach this subject with people with learning disabilities. Remember, there is no right and wrong, the key is use ideas and materials that resonate with the people you live or work with.

References

Barrett P. (2012). My Fun FRIENDS Book. 3rd Edition. Barrett P. (2012). Fun FRIENDS: A facilitator's guide to building resilience in 4–7-year-old children through play. 3rd Edition. Barrett P. (2012). FRIENDS for Life: Activity Book for Children. 6th Edition. Barrett P. (2012). FRIENDS for Life; Group Leaders' Manual for Children. 6th Edition

Barrett P. (developed in association with Smith C and slack G.) (2015). Special FRIENDS: Group Leaders' Manual. 1st Edition.

Cooper, S.A., Smiley, E., Morrison, J., Williamson, A., and Allan, L. (2007), "Mental ill-health in adults with intellectual disabilities: Prevalence and associated factors" in British Journal of Psychiatry Vol. 190, pp. 27–35. Available online at: <http://www.ncbi.nlm.nih.gov/PubMed/17197653> (accessed 26/02/14)

Davies and Rositter (2016). FRIENDS for Life – building resilience and emotional well-being (second edition). London: Foundation for People with Learning Disabilities.
<file:///C:/Users/DAVIESJ/AppData/Local/Temp/MicrosoftEdgeDownloads/ea4b1077-2ef6-4cf8-b8dc-e575a6db6337/FRIENDS%20for%20Life%20guide%20September%202016.pdf>

Feeling Down: Looking after my mental health (2015) Foundation for People with Learning disabilities.

Hardy, S., Woodard, P., Halls, S., and Creet, B. (2009) 'Mental Health Promotion for people with Learning Disabilities'. Pavilion.

Taylor, J.L., Hatton, C., Dixon, L., and Douglas, C. (2004), "Screening for psychiatric symptoms: PAS–ADD Checklist norms for adults with intellectual disabilities" in Journal of Intellectual Disability Research Vol. 48, pp. 37–41. Available online at: <http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2788.2004.00585.x/abstract?deniedAccessCustomisedMessage=&userIsAuthenticated=false> (accessed 26/02/14).



Walking Group

Jeff Miles, Learning Disability Nurse and Lee Walker, Learning Disability Nurse at Oxleas NHS Foundation Trust With contributions from Kerry Taylor, Learning Disability Nurse and Emma Corrie, Specialist Support Worker, Oxleas NHS Foundation Trust

Introduction

The idea for setting up walking group came from research that Jeff and lee had undertaken highlighting the positive outcomes that a group like this could provide. Research has shown that people with learning disabilities face social isolation and segregation and are not engaged in activities for much of their time. This can lead to a negative impact on their physical and mental health.

A walking group was identified as an effective way to enabling people to have an activity to promote social inclusion and integration into their local community. They would also gain some choice and control over their activity. It had the added benefit of promoting regular physical exercise. It was hoped that this would lead to improvements in the groups physical and mental health.

How we went about setting up the Group

When planning the group, we had to consider various important factors when setting up the group considering service user preference, time and day, staff availability and venues.

Time and day

After consulting with the potential members, the group was set at a time when the group members were able to use their bus passes and avoided times when public transport would be busy. The day was set for when most service users did not have routine appointments.

The walk chosen was for around 20- 30 minutes and was agreed that we would go at the pace of the slowest member of the group. This was followed by the group having a coffee at a café

Venue

When choosing a venue in which to hold the group, we considered having different venues each week on a rota basis, we felt that whilst this would offer variety and differing environments having

different venues could cause potential risks as the service users would have to learn new routes each week to get to the walking group, which could have caused undue stress and anxieties. Some of proposed venues were not all on flat terrain with a variety of surfaces which we thought could potentially excludes some service users.

The venue chosen was a centrally located park and was easily accessed by public transport. A risk assessment of the park was carried out including potential hazards such as stairs, wildlife and dogs. A route was devised which avoided any potential hazards and did not involve crossing any roads. A café was identified that was suitable and agreed to accommodate the group.

Information

An easy read invite letter was produced which was provided to service users. A previous pilot study showed that sometimes people needed more information and reminders, so this is done either by telephone or face to face with group members or their care staff.

From the start of the group, we decided that all members of the group would have a say in it, so everyone decided the length of the walk, which café to go to and for how long. The group was initially planned for 12 weeks but the group members enjoyed it so much that they decided to keep the group running through the winter.

What We found

Service users' feedback that they enjoyed having a chance to talk and meet with others and some new friendships were made. Carers were included in the group and appreciated having a chance to meet with other service users and had an opportunity to meet healthcare professionals in an informal setting. The nurses that ran the group felt that they got to spend quality time in a relaxed non pressured environment with service users. One nurse commented that this was her favourite part of the week.

Over the course of the walking group different students joined in with sessions all of whom expressed that it had been a positive experience as they got a chance to meet and interact with group members.

On reflection several other benefits were gained from the group. We noticed that some of the service users mental and physical health improved, social skills were practised, health promotion messages came up and were discussed with the whole group over coffee. All group members were given pedometers. These were effective in sparking conversations about daily exercise, some group members used these daily to help them to increase their levels of exercise. On some of the walks group members were encouraged to stop and do a short, guided relaxation exercises which some group members felt they benefited from. Other discussions included COVID vaccinations, Flu vaccinations, healthy eating, conversations about medications, food storage and fluid intake.

Initially the group started with around five members, the group were asked about new members joining which they agreed to so at the time of writing the group has a regular attendance of ten group members plus carers and parents.

As the group grew some members wanted to walk faster and for longer. The venue chosen allowed us to split the group at certain

points where a slightly longer or shorter route could be taken where everyone was able to choose which route they would rather take. We found that many of the group members enjoyed the café visit with this lasting for an hour or longer.

One aspect of the group which was difficult to quantify but was an integral part of the success of the group was that everyone had a chance to experience fun and laughter.

We used 2 cafés over the course of the group and due to the frequency, that we attended these the group became “regulars”. The café staff would accommodate for the group and built up good social interactions with group members. One of the café’s was able to provide a special Christmas lunch for the group where they opened the café especially for group members and provided a lot of festive celebrations including a visit from Father Christmas, and carol singing following the lunch.

Service User Lead Agreeing Route

Café The United Nations, Recognises the right of all disabled people to participate equally in the community and requires States to enable disabled people to be fully included and participate in the, (European Coalition for Community Living, 2009).

One group member shared that she struggled with mental health problems and the group has really helped her to develop her confidence and to feel less anxious when socialising as she gets to practise, and these skills can take time to develop. She said that it is her favourite day of the week and that she always looks forward to Mondays. When asked other group members all said that it was a good chance to meet people and to “have a chat and to laugh”.

Reflections

One key issue was that the group just “seemed to work” and it was difficult to understand why this was the case. After a lot of thought there appeared to be subtle but important factors.

Group identity everyone in the group was referred to as a group member and was included in decisions about the group. Group members had flexibility as to how far they walked, whether they joined in with café visit and for how long.

The nursing staff engaged all members of the group using open questions. Initially service users would direct all their conversations with nursing staff however nursing staff would involve other service users in the conversations and gradually interactions between service users evolved and friendships were formed.

An example of how the group bonded was one service user wore a novelty pair of socks on one week and proudly showed them to the group. This became an interesting talking point as each week as several members the group would wear novelty socks which was a topic for fun and conversation.

Initially the nursing staff were able to remember conversations with service users from the week before and discuss these as service

users gradually got involved, they were able to show compassion and empathy for other group members.

An example of this being that one of the group members cat had died other group members were able to offer support and empathy. This sparked conversations around bereavement and managing loss which all group members joined in with.



Section 3 - Towards mental wellbeing, mental illness and its treatments for people with learning disabilities

This section is from people you treat and offer support for people with learning disabilities and includes case studies from people who work in mental health with people with learning disabilities



An introduction to mental illness in people with Learning Disability: information to support those close to the person

Christine Hutchinson, Lynnette Kennedy Jessica Lister and Rachel Mills

Introduction

This chapter has been written by four Consultant Learning Disability Nurses; members of the UK Learning Disability Consultant Nurse Network. It will provide information aimed at family carers, support workers and student professionals.

The chapter provides an overview of the main mental illnesses and how these might present differently in someone with a learning disability; there is a section on how to seek help and support if you are concerned that someone may be becoming mentally unwell. This includes some of the barriers that may be experienced, in particular diagnostic overshadowing. This is where someone attributes the person's presentation to having a learning disability rather than another cause.

The final sections of the chapter consider the issues when someone is admitted to a mental health hospital, what the assessment process is, what assessment and treatment you should expect the person to receive, advocacy and how this can help even if there are family members and others involved with the person. We also provide some information on the legislation of Mental Health Act and Mental Capacity Act.

A list of further reading is at the end of the chapter for those who want to delve deeper.

Mental Illnesses and how this may present in people with learning disability.

People with a learning disability may be at an increased risk of experiencing mental ill health as they are more likely to experience negative life events such as deprivation, poverty, abuse and other traumatic events such as loss of relationships and stable home; all which can increase risk factors.

Many people with a learning disability may find it difficult to tell others what they are experiencing or how they are feeling and so it is really important that those supporting them observe for behaviours which might help to give more information.

Every person's experience of mental illness will be individual to them. Changes in behaviour may be very subtle and difficult to notice, especially to people who do not know them well, or they may be quite obvious. With mental illnesses in people with a learning disability there can be quite an overlap of signs and symptoms and it may take a specialist health professional to work through which mental illness is affecting the person. Keeping a note of your observations, when behaviours occur, what happened and how long it lasted as well as information about events occurring around the same time will help build up a picture of the change you are seeing and inform subsequent assessments.

Anxiety and Depression

Anxiety and depression are often interlinked, and the assessment and treatments are very similar. As such we have grouped these two mental illnesses together.

Anxiety is having feelings of worry, unease, nervousness or fear. Having feelings like these can be completely normal and can be part of everyday life and experiences (such as having a job interview, or going to new places with new people) and can even help people in certain situations such as having more motivation, staying alert etc.

But sometimes it can be distressing, and people can find it hard to manage or control these feelings. When this happens, people can often experience changes in their daily lives and may be unable to do the things that they usually do or want to do because of these feelings. Anxiety disorders have been reported as one of the most common forms of psychological distress for people with a learning disability and for many people with a learning disability it can be quite difficult to express feelings of anxiety

Symptoms: Anxiety can have an impact and affect both how you feel emotionally and physically. It can cause you to be/have:

- Panicked

- Irritable
- Worried or restless
- Difficulty concentrating
- Feel like you're not involved in what's going on around you
- Dizzy or light-headed
- Short of breath or like you can't breathe
- Feeling sick
- Feel like your heart is fluttering, beating too fast or strong
- Increased Sweating
- Going to the toilet often
- Having sleep problems

Lots of people have feelings of anxiety and some people can hide it quite well. In people with a learning disability, it may affect how they behave such as not wanting to go to certain places or see certain people; avoiding situations or activities; the person may become more withdrawn, or their behaviour may become more challenging or agitated.

Depression

Depression is a term which is used to describe a depressed mood and/or loss of pleasure in most activities. It should be abnormal for the person and last for more than two weeks. Its severity is determined by both the number and severity of symptoms and the impact it has on the person's everyday functioning- what is normal for them. People may often experience feelings of hopelessness and in some cases, people may have suicidal thoughts, meaning getting help and support is essential.

Symptoms: There are lots of different symptoms of depression, with people being affected in lots of different ways. Some of the common symptoms people might feel are:

- Upset, sad or tearful
- Hopeless or helpless
- Numb or empty
- Guilty, worthless, irritable or restless
- Unable to enjoy or do activities that you usually do

- Lacking self-confidence or lacking in self-esteem
- Worried or anxious
- Wanting to hurt yourself or suicidal

Some of these feelings might lead people to behave differently such as:

- Avoiding people such as family and friends and avoiding doing activities that are normally enjoyed
- Wanting to spend lots of time alone
- Not wanting to go to work, daytime activities or school
- Not being able to think clearly and not able to make decisions
- Not being able to concentrate properly

Depression isn't always just about what people feel. Some people can also experience physical changes. These can include:

- Being tired or having a lack of energy
- Sleep problems changes in appetite or weight
- Having problems with sex or having a lack of sex drive

- Unexplained physical health problems such as aches and pain

For people with learning disability, particularly those who are unable to understand or communicate how they are feeling, there may be more levels of self-isolation, withdrawing from daily routines and activities they usually find motivating. Equally there may be an increase in behaviours that challenge, agitation, self-injury and anxiety. You may note the person being more dependent on their family or carers than usual or notice what may seem like a loss of skills both in terms of self-help and independence as well as social skills.

Communication difficulties can mean more reliance on observation of changes in functioning including sleep, and eating to identify symptoms of depression. The person may not use emotional language to describe how they are feeling

Cause: How someone has learned to cope with things and what's happened in the past forms how we deal with things in the future.

Sometimes, people can find a trigger or identify a reason that they are experiencing anxiety or depression. This might be a life event significant to the person, but not necessarily significant to those around them. Changes in circumstances such as bereavement, loss of a relationship, loss of occupation, change in family circumstances or the birth of a child. It can also include matters such as changes in routine, sudden changes or lots of changes in a short space of time, crowded places, and environments that might be overstimulating (too bright or noisy). But sometimes, there are no obvious triggers, with some people becoming anxious or depressed for no reason that they can think of or nothing that is obvious to their family or carers.

If people have a family member who has anxiety or depression, they are more likely to develop anxiety or depression themselves.

Assessment: There are self-assessment tools available on the internet that people can complete which will help them to understand if they might need help or support. The onset and interpretation of symptoms can be more complex in people with a learning disability and may require more in-depth assessment and

observation by a health professional to help to understand the presentation. Health professionals have a range of assessments that can identify anxiety and depression. This can range from taking an assessment of the person's history, using specific questionnaires such as the Generalised Anxiety Disorder 7 questionnaire (GAD-7); Personal Health Questionnaire 9 (PHQ-9) for depression to using specialist learning disability tools such as the Glasgow Depression Scale for Learning Disability (GDS-LD) and Glasgow Anxiety Scale for Learning Disability (GAS-LD).

Treatments: Often some of the most important parts of treatment are about the day-to-day support people have available to them. Try to maintain normal routines/structure to the day, maintaining or regaining a level of occupation is very important to recovery. Where possible provide a means of communication to help the person express how they are feeling provide reassurance to the person and a calm environment around them. This may include the use of social stories, emotions cards, and communicating through play/role modelling.

Some people need more targeted help, and all our evidence states that talking therapies provide the best long-term recovery. Cognitive Behaviour Therapy (CBT) is the main talking therapy that helps with anxiety and with depression, this can help people to think about what makes them feel as they do, how their feelings change the way they behave and thereby agree on actions that can make a positive change in both feelings and behaviours.

For some people medication is needed, this may be because their learning disability is such that they wouldn't be able to engage with talking therapies, even if these were adjusted to meet their specific communication needs or because the anxiety or depression is so severe that the other more useful treatments might not get a chance to work. Medications can be prescribed by many health professionals, your GP, mental health or learning disability nurse or a psychiatrist.

Psychosis and Schizophrenia

The term psychosis encompasses many symptoms associated with significant alternations to a person's perception, thoughts, mood, and behaviour. Psychosis is when someone loses touch

with reality and may experience the world very differently from others through experiencing hallucinations or delusions.

Psychosis can be a one off experience referred to as having a “psychotic episode”, for example linked to acute infection, or it can be a longer-term condition or psychotic disorder, the most common of which is schizophrenia. People can recover from psychosis, but it can be a very distressing experience and may cause severe changes in behaviour, schizophrenia however is often a long-term psychotic disorder.

Symptoms: Symptoms are described as positive or negative. Positive symptoms include thought disturbance, where speech, thoughts and behaviour are disorganised, this can affect a person’s cognition and may cause difficulties with concentration, memory, processing, sequencing of tasks and their ability to understand information and make decisions. Positive symptoms also include hallucinations and delusions.

Hallucinations are an experience of something, which has not occurred. These experiences may be either pleasant or unpleasant and can be, regular or infrequent, short lived or long lasting. Symptoms of hallucinations include:

- Hearing voices or sounds
- Seeing things which are not there
- Tasting things, you haven't eaten,
- Feeling as though someone has touched you when not there,
- Smelling things, others cannot.

Delusions are having fixed beliefs, which are not shared by others but feel very real. These beliefs can be distressing and may involve paranoid thoughts such as that strangers or family may want to harm them or that they have been poisoned by the government. Delusions of grandeur are beliefs of being powerful or of significant importance such as being a God or member of the royal family.

Negative symptoms of psychosis include loss of motivation, social withdrawal, reduced communication or very flat mood.

Behaviours to observe include:

- Being guarded, worried or frightened of others.
- Appearing to respond to something which is not there,
- Being more anxious, emotional or agitated than usual
- Withdrawing from their usual activities, interests or friendships
- Stop looking after themselves; not eating properly or stop taking prescribed medications.
- Stop attending to their hygiene or house chores.
- Wanting to spend more time alone
- Changes to their appetite or sleep pattern
- Needing more help with tasks than usual
- Being annoyed, upset or irritated
- Being confused or forgetful including being mixed up about everyday tasks.

Cause: Psychosis has a number of causes. For brief psychotic episodes these are often caused by acute infection or altered states after illness or an operation such as delirium.

A number of life experiences may be potential triggers for psychosis, both brief and longer term or for causing a relapse.

These include:

- Stress, anxiety and being very tired.
- Childbirth and menopause.
- Homelessness, divorce, grief, racism, separation.
- Being the victim of abuse
- Experiencing traumatic events such as the loss of your home or friendships
- Taking or withdrawing from alcohol or illegal drugs such as cannabis.
- Some health conditions including a brain tumour or brain injury, and neurological conditions such as dementia or Parkinson's,

Research also shows that genetics can increase the risk of experiencing psychosis, particularly schizophrenia and that men from black, Asian and minority ethnic backgrounds are more likely to experience psychosis.

Assessment: If a person is experiencing symptoms of psychosis, it is very important that they see their GP as soon as possible. The GP will be able to assess for any physical health causes for their symptoms and provide appropriate treatment for any identified physical health needs. The GP can refer the person for assessment to specialist mental health or learning disability services where a specialist mental health assessment is needed.

The specialist health professional will undertake a holistic assessment of the person's needs, this should include

- A review of physical health checks the GP completed, previous medical history including significant physical health conditions in relatives and any further physical health screening needed
- The person's accommodation and support arrangements including any life events past and present
- Details of the symptoms and past psychiatric history including experiences of mental ill-health in relatives

They will want to rule out other potential causes for psychotic symptoms such as physical illness, post-traumatic stress disorder, severe anxiety and depression. They will also want to screen for other related mental illnesses such as bipolar and schizoaffective disorder (see later).

Treatment: The person's support arrangements are important to recovery, having stability in accommodation and support, no significant stressors and people who can provide reassurance during distressing symptoms all help with recovery. Family and support teams are often offered support in how to manage the times when the person's symptoms present.

Good proactive plans for managing physical health are important, particularly where the psychotic episode has been linked to this.

Talking therapies can help manage some symptoms and how the person perceives these. Many people can learn to live with hallucinatory activity through the use of CBT and proactive and

reactive strategies, The Hearing Voices Network may be helpful here.

Medication is likely to feature for most people, for short periods or as required where the psychosis is transient or for those whose experience is severe and enduring. Medication is available in various forms, how the symptoms are impacting and the level of risk to the person or others will inform whether medication will be either oral or injection.

Where a person's symptoms are putting them or others at significant risk, or they are rapidly worsening, they may need to be supported by the accident and emergency (A&E) department. Here a duty psychiatrist will be able to assess and advise or police may need to be called where they have the powers to take the person to a place of safety.

If the person refuses to get help, their parent, nearest relative or carers can request that the local authority arrange for a mental

health assessment to be completed and a hospital admission arranged (see later).

It is important once the person is successfully treated to prevent relapse by recognising the early signs of illness, taking medication as prescribed and talking to others about the condition. Getting help quickly helps to speed up recovery and can stop people from getting very poorly.

Antipsychotic Medication Monitoring: Antipsychotic medication can work very well in the treatment of psychosis and psychotic disorders, but as with all medications they can have side effects and with this group of drugs the side effects can be quite serious. There are some monitoring requirements that are standard for everyone with some of these needing to be more frequent depending on the person's medical history and side effect profile. The health professional prescribing the antipsychotic medication should have a clear, monitoring plan for the person that they have also shared with family and care staff. The Monitoring usually includes:

- Weight, BMI and waist circumference

- Blood pressure and pulse
- Blood tests
- ECG

The Glasgow Antipsychotic Side-Effect Scale (GASS) and The Liverpool University Neuroleptic Side Effect Rating Scale (LUNERS) are commonly used to monitor for side effects.

Mood Disorders including bipolar disorder and Schizoaffective Disorder

Mood disorders are where a person's general emotional state or mood is distorted or inconsistent with their circumstances and interferes with their ability to function. They may be depressed as described above or have periods of mania (described below). There are many types of mood disorders, and these can often be linked with many other mental disorders.

Bipolar disorder is identified by cycling between two mood states: depressive lows and manic highs. If the person experiences four

232

or more episodes of mania and depression in one year. It may be referred to as rapid cycling which affects more women than men.

Schizoaffective disorder is a combination of schizophrenia symptoms and mood disorder symptoms.

Symptoms: The depressive symptoms are no different to those described above for depression. Mania is where there is a period of abnormally elevated, extreme changes in your mood or emotions, energy level or activity level. This highly energized level of physical and mental activity and behaviour is a change from the person's usual presentation and can last in some cases for many hours or days. Manic symptoms include:

- Having an abnormally high level of activity or energy.
- Feeling extremely happy or excited — even euphoric.
- Not sleeping or only getting a few hours of sleep but still feeling rested.
- Having inflated self-esteem, thinking you're invincible.

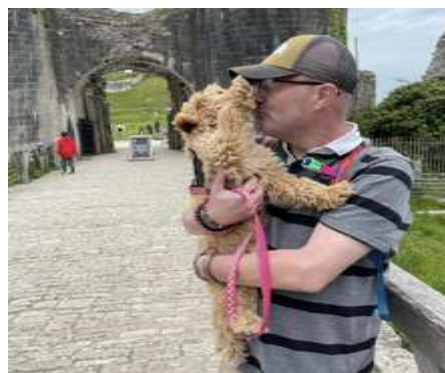
- Being more talkative than usual. Talking so much and so fast that others can't interrupt.
- Having racing thoughts — having lots of thoughts on lots of topics at the same time (called a “flight of ideas”).
- Being easily distracted by unimportant or unrelated things.
- Being obsessed with and completely absorbed in an activity.
- Displaying purposeless movements, such as pacing around or fidgeting when sitting.
- Showing impulsive behaviour that can lead to poor choices, such as buying sprees, being overly friendly or reckless sex

In people with learning disability changes in mood states, including mania may be seen through increased behaviour that presents a challenge, levels of agitation and insistence on a specific order to routines or activities.

Cause: Stress and trauma are recognised triggers for mood disorders, some research suggests there is a genetic link for some mood disorders.

Assessment: Mood disorders in people with a learning disability may be misdiagnosed initially as sometimes one mood state may be more prominent or obvious than another. Specialist mental health or learning disability services must be involved in assessing for mood disorders, a full holistic assessment as described in the section on psychosis would equally apply here.

Treatments: A person's support network is important as with all mental illnesses/disorders. Keeping active and making time to do things that the person enjoys is an important part of any keep well plan. Direct treatment of mood disorders usually includes a combination of medication and talking therapies tailored to the individual's needs. Whilst there are specific mood stabilising medications, some people are treated with antipsychotics and/or antidepressants depending on the presenting symptoms.



Personality Disorder A person with a personality disorder thinks, feels, behaves or relates to others very differently from the average person. There are several different types of personality disorders that include a pattern of inappropriate behaviour that is deeply ingrained and causes long term difficulties in personal relationships and/or daily functioning. People who have symptoms of different types of personality disorders may be diagnosed as having

Mixed Personality Disorder. Often this pattern of behaviour can be traced back to adolescence.

Borderline personality disorder is one of the most common types and is linked to disturbed ways of thinking, impulsive behaviour and problems controlling emotions. People may have intense but unstable relationships and worry about people abandoning them.

Antisocial personality disorder is linked with a person who gets easily frustrated and has difficulty controlling their anger. They may blame other people for problems in their life, and be aggressive and violent, upsetting others with their behaviour.

People who have a personality disorder may also have other mental health problems

Symptoms: People with personality disorders have difficulties in

- Getting on with friends and family
- Making or keeping close relationships
- Listening to other people
- Learning from one experience and applying that learning to another experience
- Controlling how they feel and their behaviour
- Keeping out of trouble
- Managing their emotions leading to risky behaviours towards themselves and others

Cause: It is not exactly clear what causes personality disorders, but it is thought to be a combination of factors including the environment people grow up in, difficult and traumatic early life experiences and genetics.

Assessment: There are additional challenges when diagnosing people with learning disability with personality disorder due to delays in personal development, difficulties with communication, lack of research that can provide reliable assessment tools and overlap of behaviours that may be displayed by someone with a learning disability but can be seen as a symptom of personality disorder. As such assessment of someone with a learning disability should only be completed by specialist health services.

The assessment should include behavioural observations and obtain information from a variety of different sources and should focus on the presentation and how this affects the person and how they are living their day to day lives (functioning). Generally, there is a higher age threshold for diagnosing personality disorder in those over 21 years and a diagnosis should not be made if someone has a severe or profound learning disability.

Treatment: The support network around someone is important to them feeling safe, secure and have trusting relationships where perceived injustices and emotional responses to situations can be worked through. Talking therapies can be helpful including CBT

and Dialectical Behaviour Therapy (DBT) a type of CBT that which focusses on those who experience intense emotions.

There is no medication to treat personality disorders but people may be prescribed medication to treat specific symptoms linked to other mental illnesses.

Eating Disorder and Avoidant restrictive food intake disorder (ARFID)

People with eating disorders use disordered eating behaviour as a way to cope with difficult situations or feelings. This behaviour can include limiting the amount of food eaten, eating very large quantities of food at once, getting rid of food eaten through unhealthy means (e.g., making themselves sick, misusing laxatives, fasting, or excessive exercise), or a combination of these behaviours.

There are different types of eating disorders and we have listed those most commonly seen in people with learning disability who have an eating disorder:

Anorexia Nervosa is where a person will severely limit the type and amount of food they eat and may do lots of exercise, make themselves sick, or misuse laxatives to get rid of the food eaten. Some people with anorexia may experience cycles of bingeing (eating large amounts of food at once) and then purging

Bulimia Nervosa is where people are caught in a cycle of bingeing and then trying to compensate for that overeating by purging

Binge Eating Disorder is where people binge eats, but do not follow this with purging, far from being enjoyable, binges are very distressing, often involving a much larger amount of food than someone would want to eat. People may find it difficult to stop during a binge even if they want to.

Avoidant restrictive food intake disorder (ARFID) is a condition characterised by the person avoiding certain foods or types of food, having restricted intake in terms of the overall amount eaten or both.

Pica is a feeding disorder in which someone eats non-food substances that have no nutritional value, such as paper, soap, paint, chalk, or ice. For a diagnosis of pica, the behaviour must be present for at least one month, not part of cultural practice, and developmentally inappropriate

There are specific conditions such as Prader-Willi Syndrome where compulsive eating and binge eating are linked to the genetic disorder rather than considered to be an eating disorder in its own right.

Where to get help if you are concerned about someone's mental health

People with learning disability who have mental health needs may receive support from a range of services. Where the person can access support from mainstream mental health services with or without reasonable adjustments, they should be supported to do so.

Health services available to support those with mental illness include:

- GP
- Emergency Departments and their Liaison Psychiatry Service in emergencies.
- Generic mental health services such as Community Mental Health Team (CMHT) or Child and Adolescent Mental Health Services (CAMHS)
- Specialist Community Learning Disability Teams (CLDT)

Under the Equality Act there are additional duties for services where someone has a 'protected characteristic' which includes learning disability and includes mental illness amongst other characteristics. A reasonable adjustment is one of these duties and requires a change to how services are offered to accommodate needs arising from the person's learning disability or mental illness. Where the person needs reasonable adjustments to access health services, the service will plan their intervention according to the individual's needs. This could include wheelchair access, easy

read information or making changes to appointment times, duration or locations.

Primary Care: Your GP: The person's GP offers the first point of contact for health services and many people will be supported by their GP. However, the GP also offers a gateway to other services and can make the required referrals to specialist health services listed below.

It is advised that people with learning disability aged 14 and over are known to their GP by a code being added to their GP file and have a learning disability specific annual health check. This is because we know that it can be more difficult to know when someone has health needs and annual health checks identify unmet health needs. Early detection is important to help prevent avoidable ill-health.

In addition to checking physical health, the GP contract requires them to check "*the presence of behaviour disturbance*" which can help to identify possible mental health needs and ensure the

person gets the right support. We know that our physical health can affect our mental health and vice versa.

Some talking therapies are available through primary care, Improving Access to Psychological Therapies (IAPT) service.

Secondary Care this is the next level of care and includes community and hospital care usually structured around specialist needs.

Emergency and Crisis Support: All areas have mental health crisis helplines. It is important if you are concerned about someone's mental health and you believe it to be a crisis, that these services are contacted. They can guide you to the right service for the person and help you decide if the crisis warrants emergency service response, such as police or attendance at Emergency Department.

These services are in addition to charities that also provide crisis support such as the Samaritans and to signposting services such

as the Hub of Hope, an app for smartphones that provides information on the nearest mental health crisis support to your location.

Community Mental Health Services: Many people will be supported by generic mental health services such as early intervention teams, community mental health teams (CMHT), crisis and home treatment teams (CRHTT/HTT), Child and Adolescent Mental Health Services (CAMHS) and other such specialist mental health services. They may provide short or longer-term care. They may support with medication, arrange regular visits and make sure the person is getting the right health and social care support. These services usually consist of a range of specialist mental health professionals, including, mental health nurses, social workers, occupational therapists, psychologists and psychiatrists.

Community Learning Disability Teams (CLDT): Where a person with learning disabilities needs cannot be met by mainstream mental health services, even with reasonable adjustments, there are local CLDTs. CLDTs support people who need specialist support, assessment or treatment with their physical or mental

health needs from learning disability nurses and health professionals specialising in learning disability. Some CLDTs have age limitations while others are all age.

CLDTs include several professionals, their make-up can vary from area to area but usually comprise community learning disability nurses, occupational therapists, speech and language therapists, physiotherapists, psychologists and psychiatrists. Some areas also have other specialist health workers such as art, music or drama therapists.

Diagnostic overshadowing

Diagnostic overshadowing is when a professional/person makes the presumption that an individual's presentation or behaviour is because of their learning disability, autism or mental health condition rather than thinking about what else could be causing the issues such as a physical health complication.

This means that for some people, a physical illness may go undiagnosed or untreated. A simple example of this could be if

someone is banging their head with their hand or against something, people may presume that this is self-injurious behaviour that is challenging rather than considering if the person has an ear infection, dental pain or headache that is causing pain or distress. This can become more serious when people have serious underlying health complications, such as cancer, that are not considered or screened for.

Research has demonstrated that people with a learning disability die on average 20 years earlier than the general public. It is important to prevent diagnostic overshadowing by improving care, reducing health inequalities and preventing premature deaths.

Similarly, this can mean that distressing mental illnesses can go undiagnosed or untreated. It is known that the sooner treatment for mental illness starts, the better the chances of that mental illness being successfully treated.

When an admission to a mental health hospital is needed

It is always better, wherever possible, for a person to receive the assessment and treatment they need at home. People generally cope better and recover quicker when they are in familiar surroundings with people they know. As such admission to a mental health hospital is something that health services will try and avoid.

However, some people do need to be admitted to a mental health hospital, this may be because their symptoms present risks that cannot be managed at home or the specific assessment and treatments, they need are only available in hospital.

Admissions to mental health hospitals can take some time to plan and arrange, this can mean that interim support is needed at home or where the person is. There are specialist teams that support people who are in a mental health crisis, sometimes called crisis intervention teams, home treatment teams, rapid intervention teams or intensive support teams. The staff working in these teams will have regular and lengthy contact with the person and their support network, to continue assessments and start treatments

whilst the person is awaiting in an inpatient bed, they may deliver some direct support, teach people about different approaches, and provide emotional support to those offering round the clock care and support to the person.

The difference between the number of people needing a mental health bed and the number of beds available in mental health hospitals means that assessments have to be made to ensure that admission is clinically necessary and appropriate. A Mental Health Act Assessment will need to be arranged, this assessment involves two doctors who are approved under section 12(2) of the Mental Health Act and a professional, usually a social worker, but maybe a nurse or occupational therapist who is an Approved Mental Health Professional (AMHP). These three people will each assess and discuss with each other whether a recommendation for admission under the Mental Health Act needs to be made.

Mental Health Act Assessments: Each of the UK countries has a Mental Health Act^[1] that they follow when it is thought that someone needs to be admitted to a mental health hospital. The Mental Health Act Assessment may have several outcomes,

- The person should not be admitted and should instead receive specific assessment and treatment at home, in this case the AMHP will signpost which services should be referred to and, in some circumstances, will facilitate the involvement of those services.
- The person should be admitted and has the capacity to make the decision to be accommodated in hospital for care and support. This is called an *informal admission*. The person is free to leave the hospital at any time if they are informal, they do not have access to the protections of the Mental Health Act such as mental health tribunals and advocates, but equally they are not subject to the restrictions of the Mental Health Act.
- The person should be admitted under a Mental Health Act section for assessment (section 2), this would be used where people are not sure what is causing the person's mental distress and where assessment by specialists in hospital will help with that, it lasts for no more than 28 days. Whilst on this section some treatments may be started, this can help to the diagnosis of those assessing.

- The person should be admitted under a Mental Health Act section for treatment (section 3), this would be where the person's mental illness is known and the person needs to start or restart treatment or needs a change of treatment, it lasts for up to 12 weeks in the first instance but can be extended.

It is important that people who know the person well speak with the three professionals doing the Mental Health Act Assessment, the more information they have about the person the better their assessment will be. Things like how the person usually communicates, engages in activities, and interacts with others and what kinds of things may have caused distress, significant events such as losing someone close to them, changing accommodation, being physically unwell and so on. Try and collect information together and if you have recordings then summaries of these are useful, including the number of times something might have happened.

If a decision is made to admit the person to a mental health hospital, a search for a bed will start to take place, sometimes a bed can be found near where people live, and sometimes it may be

a distance away. If the person is admitted to a bed some distance away, keep asking the question of when they can transfer to somewhere near to home or be discharged. There is a lot of information that tells us the further someone is from their home and family, the longer it takes for them to become well and therefore the longer they end up staying in hospital.

Sometimes people who commit a crime and end up in court might be sent to hospital for assessment and/or treatment. There are different numbered sections for people who are sent to hospital by the courts or transfer to hospital from prison.

All legislation relating to human rights must be incorporated into how services are offered to people, particularly those who are admitted to mental health hospitals.

Mental Capacity Act Legislation

Most UK countries have laws relating to the care and treatment of those who lack the mental capacity to make decisions for themselves.

In England and Wales, the Mental Capacity Act 2005 (MCA) applies to people aged 16 and over and sets out principles to promote decision making by the person wherever possible as well as provision for how to determine a lack of capacity and make decisions for that person.

What happens when people are admitted to hospital:

National Institute for Health and Care Excellence (NICE) 2016 recommended that it is good practice that all people with learning disability and/or a serious mental illness should have a key worker who:

- coordinates all aspects of care, including safeguarding concerns and risk management
- helps services communicate with the person and their family members, carers, or care workers (as appropriate) clearly and promptly, in a format and language suited to the person's needs and preferences
- Monitors the implementation of the care plan and its outcomes.

The key worker may be part of the community mental health services or community learning disability services. When a person is admitted into hospital the key worker should share the following information with the inpatient clinical team:

- Communication plan/passport and or Speech and Language assessment
- Health action plan (HAP)
- Hospital passport
- Previous psychiatric reports (if applicable)
- Mental health care plan/recovery plan/relapse prevention/crisis contingency plan

Once admitted to hospital the person will be seen by several different clinicians, these clinicians will have experience in working with people with mental illness and may also involve those who specialist in learning disability in completing their holistic assessments of physical and mental health needs as well as daily support needs. This information will be used to create a holistic person-centred care and treatment plan.

The inpatient staff, with support from the community key worker, will ensure that the care and treatment plan set out expected outcomes and the roles and responsibilities of everyone involved in delivering it, and that:

- the person can easily access all interventions and services in the plan
- it is communicated to everyone involved, including the person and their family members, carers, or care workers (as appropriate)
- There is an agreement on when the plan will be reviewed.

Health Commissioners: Health commissioners in each of the UK countries have a responsibility for funding the care and treatment that someone needs, this includes ensuring that the care and treatment offered are of good quality and achieve the health outcomes expected.

Care and Treatment Reviews (CTR): In England, these reviews are completed for anyone with a learning disability in a specialist mental health hospital. The CTR has four key lines of enquiry, is

the person safe, are they getting good care and treatment, what are the plans for the future and can the person's care and treatment be given in the community instead, those reviews for children and young people (CETR) also include consideration of education provision as a component.

The CTR is chaired by the responsible health commissioner and supported by two independent experts, one with lived experience and one with clinical experience. They can take place in the community before someone is admitted to hospital but must take place four weeks after admission if one in the community was not done.

If the person's stay in hospital lasts more than six months, then the CTR/CETR will be repeated.

In addition to CTR/CETRs the responsible health commissioner will undertake review visits every 6-8 weeks and someone who has responsibility for discharge planning should also be having regular contact.

Discharge Planning: This should commence immediately before or on the first day of admission to ensure there are no barriers once the person has completed the assessment and treatments that can only be offered in hospital. Each of the UK countries has different approaches to discharge planning and mental health after-care.

Mental Health Act (England and Wales) section 117: This section of the mental health act sets out that for people who have been on a Mental Health Act treatment section and who need any care after leaving hospital that is

(a) Meeting a need arising from or related to the person's mental disorder; and

(b) Reducing the risk of a deterioration of the person's mental condition (and, accordingly, reducing the risk of the person requiring admission to a hospital again for treatment for mental disorder)

Should receive that after-care free of charge, no matter their personal situation.

It is a joint responsibility of social services and health services to assess what after-care needs the person has; to arrange those after-care services and to review the aftercare arrangements at least annually. Social and Health services usually have a joint policy agreed on how this joint duty will be implemented.

Advocacy

People have a right to be involved in discussions and to make decisions about their care. People may self-advocate or may need help from a professional advocate who can help the person to speak up and be heard (instructed advocacy) or speak in their stead having ascertained the person's likely preferences and/or wishes (non-instructed advocacy). They help to ensure a person's rights are upheld and their needs are being met. The advocate's role is to represent the person's wishes and interests. This may be through helping the person to speak or by speaking on their behalf.

The four UK countries each have different statutory advocacy provision and different arrangements for the provision of non-statutory advocacy.

In England and Wales the statutory right to advocacy is outlined in:

- The Care Act 2014
- The Mental Capacity Act 2005
- The Mental Health Act 1983

The roles of this statute are explained below. Statutory advocacy can be delivered in an instructed or non-instructed manner, services must take into account the availability of a person's statutory advocate when arranging meetings, share information as appropriate to support them in their role and support the advocate to develop a good relationship with the person.

Care Act Advocacy: Under the Care Act, people who have substantial difficulty in understanding social care processes will be helped to understand their rights under the Care Act and to be fully involved in a local authority assessment, care review, care and support planning or safeguarding process.

Independent Mental Health Advocacy (IMHA): Access to an IMHA is a statutory right for people detained under most sections of the Mental Health Act, subject to Guardianship, on a community treatment order or a conditional discharge.

Independent Mental Capacity Advocate (IMCA): IMCAs are a legal safeguard for people who lack the capacity to make specific important decisions: including making decisions about where they are accommodated (in hospital for 28 days or more; in the community for 8 weeks or more) and about serious medical treatment options. IMCAs must be instructed to represent people where there is no one independent of services, such as a family member or friend, who can represent the person.

Summary

- People with learning disability can and do experience mental illness and other mental disorders

- Diagnosing mental illness/disorder in people with learning disability can in many cases be a complex process requiring people with specialist health knowledge
- Diagnostic overshadowing and other issues can prevent people from receiving a timely and accurate diagnosis and cause barriers to accessing and receiving services
- The legislation is different in each of the four UK countries, so it's important to know the relevant legislation for where the person with learning disability lives or is accommodated
- People with learning disability can be supported to live long meaningful and quality lives if their physical and mental health needs are recognised and treated early, proactive health checks are an important part of the service offered to people with learning disability.

Useful links on mental illness

MIND 0208 519 212 www.mind.org.uk

Rethink Mental Illness 0300 5000 927 www.rethink.org

<https://www.hearing-voices.org/hearing-voices-groups/find-a-group/>

Mencap 0808 808 1111 <https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/health/mental-health>

[1] The following information give reference to the terms used in the Mental Health Act for England and Wales



Improving access to health care for people with learning disabilities

Amanda Forester, Hannah Bloor, Jessica Lister and Lauren Barrett

This chapter has been written by four experts in supporting people with a learning disability to access healthcare. Amanda is an Expert by Experience Advisor who has a learning disability, Hannah is a Learning Disability Health Facilitation Nurse and Jessica is a Consultant Nurse in Learning Disabilities – all three working at North Staffordshire Combined Healthcare NHS Trust. Lauren is an Acute Liaison Nurse.

Background to learning disability healthcare.

In 2001 the government released a white paper called Valuing People, which set a number of actions to reduce the health inequalities experienced by people with a learning disability and prevent avoidable, premature death. It brought the introduction of strategic health facilitators to support primary care identify people with a learning disability, set targets for the provision of annual

health checks and health action plans, and identified the need for Acute Liaison Nurses to support access to acute services.

Six years later, in 2007, Mencap published their report “Death by Indifference” which told the stories of 6 individuals with a learning disability who had died avoidably due to healthcare services not understanding or responding to their needs. Following that report, many more families told the stories of their loved ones who had also died avoidably.

These deaths highlighted the extent to which the NHS struggled to meet the needs of people with a learning disability; which had avoidable and catastrophic consequences. It highlighted the need for the Acute Liaison Nurse role to support hospitals set up flagging systems, hospital communication passports and deliver learning disability awareness training to staff.

21 years after Valuing People White Paper was published, health inequality remains a significant concern for people with learning

disabilities, who remain at risk of much shorter life expectancy than the wider population and often experience poorer health outcomes.

Learning from the Lives and Deaths of People with Learning Disabilities (LEDER):

LeDeR is a national programme set up to review all deaths of people with a learning disability over the age of four, with the aim to identify why people are dying and if any of these deaths are avoidable. Each year LeDeR writes an annual report of their findings. It identifies common themes and highlights the prevalence of disease amongst the learning disability population.

These reports have said that there are still more people with a learning disability dying in hospital than expected. Many of the recommendations that come out of the LeDeR reviews are around training for general staff, recognising signs of ill health and ensuring learning disability is not considered to be a co-morbidity. These are all things that Annual health, checks, health action plans, health facilitation nurse and acute liaison nurses help with.

In 2022 LeDer revealed that while deaths due to pneumonia are falling, diseases of the circulatory system, diseases of the respiratory system, cancers and diseases of the nervous system remain the top causes of mortality for people with learning disabilities. Covid-19 remains the leading cause of death for people with learning disabilities.

What is an annual health check?

People with learning disabilities can sometimes find it hard to know when they are unwell or may struggle to tell someone about it. Often people rely upon others to ensure their health needs are met.

It is therefore recommended that all people with a learning disability aged 14 years and over have a health check every year. This gives people time to talk about anything that is worrying them, means they can get used to going to visit the doctor and gives the opportunity to identify early warning signs of illness that might otherwise be missed.

GP practices should offer an annual health check each year for all those on their learning disability register. It is really important

therefore that the GP knows who their patients with a learning disability are.

At the end of the health check, the health professional will develop an easy read Health Action Plan which will detail health goals for the person and who is responsible for achieving these.

Personal Experiences

To raise awareness of the importance of Annual Health Checks and Health Action Plans, Expert by Experience staff employed by North Staffordshire Combined Healthcare NHS Trust have created a video. This video has many different versions to reach out to the groups of persons less likely to attend for their health checks.

Follow this link to view the video:

https://www.youtube.com/watch?v=da_FnRZvo5s

There are also lots of other useful resources available online such as Mencap's #DontMissout campaign.



Do you have a learning disability? Tell your doctor.

They can offer you extra support – making things easier at your appointments.

You could also get a free Annual Health Check.

To find out more, speak to your doctor or visit www.mencap.org.uk/dontmissout

#DontMissout



What to expect

A healthcare professional such as a nurse or a doctor, at the person's GP practice, complete the Annual Health Checks. This will review the person's physical and mental health, including:

- Health promotion advice (talking about staying well and things that can improve health)
- A chronic illness and system enquiry (such as asthma, constipation, swallowing etc.)
- A physical examination (i.e. weight, blood pressure, height, pulse, blood saturation, urine sample test)

268

- Epilepsy review (if appropriate)
- Behaviour and mental health review
- A specific syndrome check (if appropriate)
- Medication Review
- Carer and family needs
- Support with transition (from child to adult services)

Amanda who starred in North Staffordshire Combined Health Care Trust video has also shared her experience of attending for her annual health check:

Hi my name is Amanda and I have a Learning Disability, I go to the doctors to have my annual health check every year. The doctors or the nurses who work at the surgery talk to me and ask me how my health is. They weigh me and do my blood pressure and they also do my height. The doctor then asks me if I am up to date with the dentist and eye tests, but I haven't been the dentist for ages I need to go the dentist to have my teeth checked, I will have to make appointment.

The receptionists are friendly and this makes me feel calmer about going, the waiting room is nice and sometimes I can listen to music.

The health action plan helps to keep me healthy and gives me advice about improving my health.



Health Action Plans

Health action plans, otherwise known as HAP's, were promoted by the government's 'Valuing People' white paper as a useful tool to help ensure people's health needs are recognised and that they receive the support required to help keep them healthy.

The image shows two examples of Health Action Plan (HAP) forms. The left form is titled "MY HEALTH ACTION PLAN" and includes sections for "HEALTH ISSUE", "HEALTH ACTION", and "PERSON RESPONSIBLE". The right form is a "HEALTHY BALANCE CHART" with categories like "Diet and Nutrition", "Teeth, mouth and swallowing", "Toilet", "Eye and ears", "Feet", and "Mobility".

An example of a HAP is given below; however, they can look different from one area to another. What is important is that they are part of an individual's person-centred planning map out the key action points agreed upon as part of the persons' annual health

check, and any other helpful information such as what are their goals, health outcomes and how these will be achieved.

It is good practice for the person to have a copy of their HAP in a format they can understand.

Acute Liaison Nurse.

The Role:

Currently, the Acute Liaison Nurse service varies from area to area. Some hospitals have 1 nurse, some have a small team and others don't yet benefit from a ALN service. Some hospitals may also have a person with a learning disability working within the team to provide expertise by experience.



Despite this variance in ALN provision, all Acute Liaison roles have a number of common responsibilities and all share the aim of enabling acute settings to undertake system wide changes, required to reduce health inequalities and prevent avoidable deaths.

This is achieved through providing training to hospital staff, implementing a flagging system and supporting them to make reasonable adjustments required (see MH Chapter for more details on reasonable adjustments). This may be on individual case bases or may apply to departments processes and pathways. The focus is always to improve the hospital experience and health outcomes for people with a learning disability.

Acute Liaison Services will often engage with Mencap's campaigns including 'Treat me well' to aim towards a learning disability friendly environment and equity of care when people are accessing acute services.

To find out what support is available in your area, contact your hospitals patient experience team or look on their website

Case Study's:

We thought it would be useful to share some ammonimised case studies to give examples of how ALN can support people who need to go to hospital.

Aiden

During an admission for problems with his legs Aiden began refusing food and drinks for a long time. Physical causes were ruled out. The ALN supported the ward to connect with Aiden's community Psychiatrist so they could explore possible mental health causes for his decline and refusal to eat. The psychiatrist prescribed some medication but Aiden did not understand what this was for and also refused to take this. The team were becoming very worried about Aiden's physical and mental health.

The Acute Liaison Service supported the ward staff to complete a mental capacity assessment which determined that Aiden lacked capacity to understand what the treatment was for, or that his health was declining by not complying with medication and by refusing to eat or drink. A Best interest discussion was therefore held to consider the best way to support Aiden and to help him recover.

The best interest decision made was for Aiden to have a Nasal Gastric, or NG tube placed. This is a feeding tube that goes down your nose into your stomach. This worked for a few days but Aiden became frustrated with it and kept pulling it out. The Acute Liaison Nurse organised another best interests meeting to review Aiden's situation and consider alternative ways to best meet his needs. Hospital staff were unsure if Aiden's cognition and behaviour would ever improve and the ALN played a vital role in advocating that Aiden would improve if mental health medication was given regularly and he was getting adequate nutrition and hydration; another solution was needed. It was decided that Aiden would be more likely to tolerate a PEG- a tube that goes directly into the stomach for feeding as this can be less irritating than an NG tube and offers a more permanent solution. Following the PEG being fitted, Aiden quickly became less withdrawn and started gaining back some of the weight that had been lost. Aiden was soon discharged home to continue his treatment and rehabilitation with his mobility in an environment he knew and was comfortable in. He is now back to his baseline and living a very good quality of life.

Sophia

Sophia had been experiencing post-menopausal bleeding and was anxious about going to the hospital for investigations. The Acute Liaison Nurse spoke with Sophia and her family to find out her preferences and what reasonable adjustments would help Sophia to have the scan she needed. The ALN then worked with the ultrasound department to plan for Sophia's appointment and ensure they would make the adjustments required to support Sophia having her scan and attended on the day to offer support and guidance. The ultrasound department did a fantastic job of ensuring Sophia didn't have to wait too long, introduced themselves and communicated in a way she could understand. They even played her favourite music to help her relax.

Khalil

Khalil needed to have an MRI scan. Khalil had autism and could get very anxious in strange environments or when out of his routine. This could lead him to behave in a way that could put him or others at risk. It was therefore agreed that it would be in Khalil's best interest for the MRI to be completed under general anaesthetic. The Acute Liaison Nurse reviewed the case and

identified that Khalil also suffered from anxiety and related behaviours for other types of health appointments. This meant that some needed investigations had not occurred. The ALN worked with the GP and the hospital clinicians to arrange for the other outstanding investigations to also be completed at the same time and therefore avoiding the need for multiple anaesthetics and trips to the hospital and enabling Khalil to have the health investigations he required but struggled to access. The investigations went ahead under GA and Khalil was supported so that he did not have a bad experience. The investigations did identify that Khalil had some concerning health conditions for which he then started the required treatment. He is now recovering well. Without these interventions, Khalil may have died prematurely.

Amanda's Top Tips

Finally, we wanted to share Amanda's Top tips for making reasonable adjustments (things services can do to make a better experience) and enabling people to access health services:

- LD alert flags on systems – to let people know I need more help

- Double appointment slots – so I have longer to talk about my problems and understand you
- Early or late appointments – so I am not waiting as long
- Quiet room when waiting – so I don't feel as nervous
- Confirmation of appointment in easy read – so I don't miss my appointment
- Easy read letters or phone calls – So I understand my health needs
- Not using medical jargon/confusing words- I don't always understand confusing words
- Ask me what the problem is and what I want.
- Listen to my carers- they know me best and they know what I am like when I am well.
- Don't assume the cause of my health problem is my learning disability- I have always had my learning disability, but I have not always had these symptoms.
- If I am in hospital- look after my family/ carers so that they can help me.

For more information visit:

For easy read books and resources <https://www.easyhealth.org.uk/>

NHS Annual Health Checks

<https://www.nhs.uk/conditions/learning-disabilities/annual-health-checks/>

Annual Health Check (Easy Read)

<https://www.mencap.org.uk/advice-and-support/health/dont-miss-out/dont-miss-out-annual-health-checks>

Health Action Plans (Easy

Read):<https://www.mencap.org.uk/sites/default/files/2016-06/What%20is%20a%20health%20action%20plan%3F.pdf>

For further information on these topics we recommend the following key reports

2004: Treat me right!, Mencap

2007: Death by indifference, Mencap

2008: Healthcare for all: report of the independent inquiry into access to healthcare for people with learning disabilities, Department of Health

2008: Six Lives, Parliamentary and Health Service Ombudsman

2009: Valuing People Now, Department of Health

2010: Six Lives Progress Report, Department of Health

2012 Death by indifference: 74 deaths and counting, Mencap.

2014- CIPOLD- The Confidential Inquiry into the Premature Deaths of People with Learning Disabilities

2021/22- LeDer Report: <https://www.kcl.ac.uk/research/leder>

What is occupation and why does it matter? The role of occupational therapists

Matthew Roberts, Rotational Band 5 Occupational Therapist, Cardiff and the Vales University Health Board

This book follows on from a previous publication tracking the experience of the covid-19 pandemic for people with learning disabilities and/or ASD (Autism Spectrum Disorder) published in 2020. They ranged from defiant and optimistic to raw and emotive, and mental health emerged as a central theme in several stories. The long-term legacy of the covid-19 pandemic is likely to be significant pressure on mental health services, many of which were already struggling. Despite improvements in recent years the area of dual diagnosis – mental health and Learning Disabilities/ASD continues to be characterised by misunderstanding and paternalistic (we know better than you) attitudes. Lockdowns stopped us from doing the things that matter the most to us. The things that make us who we are. Our Occupations. Without those things people can feel anxious or like they have lost control over their own lives. This is known as Occupational Deprivation, and for many individuals with Mental Health diagnoses and Learning

281

Disabilities and/or Autism this is the norm. They may be deprived by their environment, society, or their altered patterns of thought/behaviour. Treatment of mental health problems often involves psychological “talking therapies” which rely on a high level of verbal communication and insight into your behaviour. With people with learning disabilities and/or ASD we need to find more accessible ways of communicating about our feelings and how these feelings impact our day-to-day life. Occupational Therapists can be helpful in this process.

Occupational Therapists will often be told they have a strange job. It's a difficult role to explain because it is goal-oriented and can mean different things to different people. In mental health and learning disabilities services you might see an Occupational Therapist in someone's house, doing an activity they enjoy in the community, or a hospital setting. The key goal of occupational therapy with people with learning disabilities and/or ASD is to support individuals to live happily with a balanced lifestyle and routine, provide advice and support on how to manage independently with everyday tasks, and enable them to engage in meaningful occupations (activities/tasks) in their community and at

home. Occupational Therapy works alongside and is an alternative to pharmacological (medicine) treatment. They work as part of a multi-disciplinary team in many settings and are increasingly expected to work generically in mental health services (nurses and therapists having similar or overlapping roles). Occupational Therapists need to get to know the personalities and behaviours of the people with learning disabilities they are working with and incorporate them into planning and goal setting. People with learning disabilities and/or ASD often don't have the same opportunities as others within society, and one of the goals of the profession is to think creatively and problem solve to enable full participation in an engaging Occupation-filled life.

This simplest definition of an Occupation is something a person needs, wants or has to do to stay happy and healthy. This might be a self-care activity, a leisure activity or something relating to productivity (professional/voluntary/educational).

Recent evidence shows that the rate of mental health problems for people with learning disabilities is double that of the general population (NICE 2016). This can be caused by negative life

events, fewer support mechanisms, and other people's attitudes. These can lead to patterns of behaviour that may appear destructive or challenging, however, all behaviour is communication, and it is part of the role of the Occupational Therapist to approach such individuals with understanding. Rather than analysing the root causes of behaviour in early life occupational therapists seek to address them indirectly through engagement in person-centred occupation. The origins of the profession were in mental health settings, supporting individuals who had experienced the trauma of war to recover their identity and restructure their lives through purposeful activity. It is a profession that believes firmly in positive risk taking, believing that individuals need to be given the opportunity to re-learn patterns of behaviour and make mistakes in order to improve (RCOT 2017). Within hospital settings the focus of Occupational Therapists is often getting people back into the community in a safe manner. This may lead to the profession being seen as "activity coordinators" so we need to be clear in our justification and communication of our value in such settings. It's not just about keeping patients entertained, it's about using valued occupations as a vehicle to improve holistic health and wellbeing.

When supporting someone with a learning disability and a mental health diagnosis it is important to understand their diagnosis but not let it define the individual. Occupational therapists focus on understanding and modifying behaviour rather than treatment of defined conditions. The separation of these two might be particularly significant for people on the Autism Spectrum who may experience extreme distress at change or unpredictable events, which may be misinterpreted as an acute mental health episode. Individuals with ASD are likely to require a different approach taking into account their level of support and communication needs/preferences.

Occupational Therapists assess, plan, undertake interventions and critically evaluate their impact on individuals, groups and communities. A treatment episode in the community may look like this:

John is a 53-year-old man with downs syndrome and suspected dementia. He has been referred to the community learning disability occupational therapy team because he appears to be distressed and staff at his supported living accommodation are

unable to help him calm down. He is withdrawing into his room increasingly often and starting to have occasional bowel accidents.

Assessment

The Occupational therapist went on a visit to John's home and met his care team. Through discussion it became evident that some of the behaviour was being caused by interaction with another housemate. A collaborative discussion was had about how daily routines within the house could be altered in order to minimise the disturbance of either resident's routines and occupations. John's personal care routine was discussed, and he tends to have accidents first thing in the morning as he is reluctant to come out of his room. The occupational therapist undertakes an objective assessment of a functional task – making a cup of coffee.

Planning

Discussions were had regarding John's preferred occupations and staff were advised on how best to interact with him and his new style of communication – to consider what John needed now rather than how he had always previously behaved. The Occupational

therapist also reviewed his environment which had been stripped back because he was being destructive and damaging things e.g., ripping paper and discussed how this may be reinforcing the behaviour by depriving him of his right to occupation. Staff were encouraged to explore the sensory feedback John was getting from this destructive behaviour and consider ways calming proprioceptive (heavy muscle work) activities could be used to substitute these behaviours.

Intervention

The Occupational Therapist returned on 3 further occasions to model and educate regarding the plan and promote engagement between John and the staff. A monitoring sheet was introduced to track how often such behaviours were occurring to monitor for patterns. Staff trialled a new strategy of requesting to go to the toilet using photo cards. John was offered ear defenders to trial in communal areas when his housemate's behaviour appeared to make him uncomfortable.

Evaluation

After the treatment episode the Occupational Therapist contacted the house to review how things had been going. The assessment of the functional task was repeated 2 months later to monitor for change in John's functional abilities. John's family were also informed of changes and actively contributed to the development of a new occupation focused plan.

Occupational therapists believe that small changes can make a huge difference. You don't realise how important the little things are until you can't do them, something we all learned during the pandemic. Health is no longer considered just the absence of disease, and mental health is recognised now more than ever as debilitating. Yet despite the work of advocates and charities few understand the correlation between learning disability and increased likelihood of mental health problems. A lack of understanding of this relationship can lead to professional responsibilities being neglected and can lead to over-medication and tragic incidents like Oliver McGowan – a young autistic boy with epilepsy who died after being prescribed anti-psychotic medication. Despite the presence of occupational therapists in

hospital settings, the profession's priority is to support people in their own environment and context in the community. Within secure settings part of the profession's responsibility is grading the patient's reintroduction into the community. For example, if someone's goal is to go to KFC you might start by going for a walk in the hospital garden, then round the hospital site, then to the local shop, then order a delivery and go out to collect it from the driver etc. The aim is to change things slowly and give the individual more independence and responsibility each time in a controlled manner. It is important for Occupational Therapists to lead by example in these settings, and work to alter cultures that typically avoid risk-taking in any form.

Occupational therapists help people learn how to find their place within a society which may often seem scary and daunting. The profession believes strongly in therapeutic group work and the sharing of experience and skills while engaging in occupations. In a group environment, individuals in hospital or in the community can share their love for an activity like music, football, art or dance. Programmes like Recovery Through Activity which were designed for mental health services have been adapted for use with a

learning disability population. Occupational therapists pride themselves in being specialist generalists, something that is particularly handy in a setting as diverse as this.

Mental health episodes might be ongoing or short term for individuals with learning disabilities. Supporting people to re-engage with their community and find professional opportunities may be a key part of the Occupational therapist's role in this context. This may include collaborative discussions with managers, the provision of reasonable adjustments and flexible working, voluntary work as a way of developing experience, and an assessment of the work environment to ensure it is suitable for the individual's needs.

Occupational therapists, along with other professions, advocate for people with learning disabilities and autism to be included in society and given opportunities for paid work, however, there is a long way to go with only 5.1% of adults with a learning disability in England currently in paid work (NHS Digital 2021 – Mencap website). Occupational therapists would benefit from collaborating with charitable organisations like Mencap to improve this record. Other

opportunities for future of occupational therapy in this context may include the design of more accessible work/social spaces for businesses, the adaptation of play areas to meet accessibility requirements in parks/colleges, the provision of transition support for people in hospital or those about to leave education, or the adaptation of respite services to relieve pressure off families and prevent the need for some acute admissions. As one of the fastest growing healthcare professions I am hopeful that the work occupational therapists can do to support those with learning disabilities and/or ASD has only just begun.



Positive behaviour support

Jessica Lister, Molly Harvey and Tom Wilson

This chapter has been written by three Positive Behavioural Support (PBS) experts all working at North Staffordshire Combined NHS Trust. Tom is an Expert by Experience Advisor who has a learning disability and supports the PBS project; delivering training, supervision and introducing a standardised PBS plan template across the county. Molly is a Learning Disability Nurse and Jessica is a Consultant Nurse in Learning Disabilities; both of whom have extensive experience in supporting people and their support circles with behaviours of concern.

What is Positive Behaviour Support?

PBS is recognised as best practice in supporting people with learning disabilities who may display behaviours of concern.

PBS aims to develop an understanding of the person and their behaviour. It uses the knowledge of the person from those who know them best, the person's thoughts and wishes and evidenced

292

based behavioural assessments to analyse the function of the person's behaviour. Using this information, a person centred PBS plan is agreed on which seeks to adapt the person's support to increase the quality of their life and give consistent person centred support. This approach results in a reduction in the frequency and intensity of the behaviours of concern occurring. The PBS plan is then monitored and reviewed so that it can be tweaked where needed to best meet the person's needs.

What are behaviours of concern?

Behaviours of concern, previously known as challenging behaviour, can present in many ways. The NHS defines behaviour as "challenging" if it puts an individual or those around them at risk, or leads to a poorer quality of life.

Examples of behaviours of concern include:

- Biting, scratching, hitting, spitting, screaming
- Self-injurious behaviour, head banging, cutting, acting dangerously

- Inappropriate sexualised behaviour
- Damaging property, throwing things, breaking things,
- Smearing, soiling

Why do we use PBS?

People with a learning disability are more likely to show behaviours of concern, which can lead them to experience social isolation, high levels of restrictions and even overuse of medication.

Often behaviours of concern are a result of the person having difficulty expressing what they are feeling, want or need, or can be a sign that something is wrong such as the person is in pain or discomfort, have an unmet need or are in distress. These, often complex and risky behaviours can cause their support network great difficulty in “reading these behaviours” and interpreting what they are telling us.

Positive Behavioural support is an evidenced based intervention and person centred model of care, which supports individuals to

live a fulfilled life and reduces the likelihood of potentially abusive and restrictive practices from occurring.

What are the 6 key principles of PBS?

The PBS Academy explains the 6 P's of Positive Behavioural Support as;

- Person-centred: ensuring the individual is always at the centre.
- Partnership: working closely with the individual and their supporters.
- Planned: creating a clear PBS plan to ensure shared understanding and accountability.
- Positive: focusing on being preventative, not just reactive.
- Purposeful: using a Functional Assessment to know the reason for behaviours.
- Process driven: following a process of identifying, assessing, planning, implementing, monitoring and evaluating data.

Challenging the stigma

Supporting a person that is displaying behaviours of concern can be challenging and may cause the person's support network confusion, frustration and even emotional distress. Sadly, this can lead to changes in their preferred staff or activities; further adding to the distress, they are experiencing.

At these times, it is important to take time to consider 'what is this behaviour trying to tell us? "What is the function of the behaviour? What is the impact of the behaviour upon the person?

It is helpful to avoid using negative connotations about the behaviour as this can influence people's perception about the person and takes away from the need to consider the behaviour as a complex communication system.

It is helpful to focus on details that describe what you see instead. For example, phrases such as 'they were kicking off' or 'they are on one again' or "they were attention seeking" are inappropriate and should be swapped for 'the individual was shouting and

swearing for x minutes’ or ‘the individual banged the door x times’, “the person was repeatedly seeking engagement”. This helps to ensure that we view the behaviour as a part of the person’s behaviour at that time. It also helps to give practitioners a good understanding of what the concerning behaviour actually is.

What does the PBS Pathway look like?

The positive behavioural support pathway is a theory-based intervention set into 4 stages. How this is utilised may vary from area to area depending on the services available, but the evidence is applicable universally.

Stage one- functional analysis

The initial stage uses assessments to identify and analyse the form (what it looks or sounds like ie ripping clothes), the function of the behaviour of concern and what factors “maintain” the behaviours to keep occurring.

The function is separated into four key areas;

- sensory stimulation,
- escape
- access to engagement
- access to tangibles (anything that we can feel/ touch).

Data will be collated from speaking to families, schools, colleges, day provisions or anywhere else, the individual accesses care, support or recreation. These people may also be asked to keep records of the behaviours when they occur. These records may be incident forms or something called “ABC charts”.

ABC charts are a key tool to help identify the factors contributing to behaviours of concern. They identify:

- *Antecedent* (trigger): What happened immediately before a behaviour occurs?
- *Behaviour*: What does the behaviour look like?
- *Consequence (response)*: What happens after the behaviour has occurred?

CLIENT NAME:	STAFF NAME:	DATE/TIME:
A – Antecedents / Triggers	B – Behaviours	C - consequences
<p>Who else was present?</p> <p>What was the client doing during the preceding 5 mins?</p> <p>What were others doing during the preceding 5 mins?</p> <p>Describe any interactions involving client during preceding 5 mins?</p> <p>Did anything immediately trigger the behaviour?</p>	<p>What did the client do? (descriptive terms)</p> <p>How long did it last?</p> <p>How severe would you rate the episode on 0 – 10 scale? (0=mild; 10=very severe)</p>	<p>How did you respond?</p> <p>How did others respond?</p> <p>How did the incident resolve itself?</p> <p>What was gained/avoided/delayed by the client?</p>

Different services will have different templates for ABC charts. Table 1 gives an example of what this may look like.

Table 1. ABC Chart example

To support the behavioural assessment, the PBS practitioner may also complete direct or indirect observations. The observations aim to identify key themes or patterns in behaviour. Where behaviours of concern are not observed, it aims to identify factors of support, which may be able to be replicated in other aspects of the person's care and support.

Depending upon the person's needs, other professionals such as Speech and Language therapists, Psychologists and Occupational therapists may complete assessments such as communication/comprehension assessments, skills assessments and sensory reports. These assessments help to determine the function of the behaviours of concern and identify the individual's skills and interests to support meaningful engagement as a proactive strategy.

Whilst the PBS pathway is being followed, it is recommended that the person has a physical health screen to ensure that any possible physical causes for the behaviour (such as pain) are addressed. The Chapter Keep Healthy and preventing Ill health gives more

information on the importance of this for people with learning disabilities.

Once all this information is gathered, a “Formulation discussion” is held to review the evidence and validate the hypothesis of the behaviour.

Stage 2 Planning interventions:


Once the PBS team have completed their analysis, they will use the understanding of the person's behaviour, their care environment and available support and resources, their aspirations and things they enjoy, to make recommendations on how to improve the person's quality of life and reduce their behaviours of concern.

Stage 3 Positive Behaviour Support Plan:

PBS plans can look different from area to area or even each individual may create their own. Some areas, such as Staffordshire

have a standardised template to support consistency in approach and ease of use for staff/ family (see picture).

They should all, however, work with the individual to increase their choice and independence and use the information gathered so far



Positive Behaviour Support Plan

[For support in completing this please refer to the PBS Plan guidance document]

Date of initial plan:	Last review of plan:	Next review date:

This plan was created & agreed by:		
Name	Role	Contact Details

PART A: BACKGROUND

<p>1. Who / Contact Details</p> <div style="text-align: center; margin-top: 20px; font-size: small;">INSERT PHOTO</div>	<p>Name:</p> <p>NHS Number:</p> <p>Date of Birth:</p> <p>Address:</p> <p>Telephone:</p>
--	--

to support the persons support circle to truly understand the behaviour of concerns function and create a plan which identifies strategies to increase the person's quality of life and to prevent, identify and support during behaviours of concern.

These strategies are grouped into three categories; primary strategies, secondary strategies and reactive strategies:

Primary strategies: these are things that reduce the likelihood of the behaviour occurring; for example, managing situations that you know will trigger a behaviour (eg boredom or anxiety), changing environments (such as managing sensory stimuli), and providing opportunities for a new experience and acquiring new skills.

Secondary strategies: are plans for what to do if the primary strategies do not work and behaviour starts to escalate. These might include using calming approaches, changing the environment, and diverting the individual's attention to an activity they enjoy.

PBS Plan Grab Sheet

Name:		
Primary Strategies (What to do to prevent the behaviour happening)	Secondary Strategies (What to do when the individual is showing warning signs)	Reactive Strategies (What to do when the individual in crisis)
<p>How does the individual present at their baseline (on a normal day to day):</p> <p>What do to keep the individual happy and settled</p> <p>Communication/Interaction:</p> <p>Structure and Routine:</p> <p>Sensory Needs:</p> <p>Environment Needs:</p> <p>Activities and other Strategies</p> <p>What new skills to focus on</p>	<p>Warning signs:</p> <p>How to support the individual when they are displaying early warning signs:</p> <p>Communication/Interaction:</p> <p>Environmental Management:</p> <p>Distraction/Redirection:</p> <p>What strategies can the individual utilise when they are displaying early warning signs?</p> <p>PRN Medication [if required]</p>	<p>When the individual is in crisis they may:</p> <p>How to support the individual when they are in crisis:</p> <p>Environmental management:</p> <p>Distraction/Redirection:</p> <p>What strategies can the individual use when they are in crisis?</p> <p>PRN Medication [if required]</p>
Post Incident Support	<p>How to support the individual</p> <p>How to support others</p>	



place to be used as a response to an incident of behaviours of concern. They aim to take control of a situation and minimise the risk to the individual and others.

The next picture on the previous page shows the PBS plan summary or Grab Sheet created by North Staffordshire Combined Healthcare Trust, which is used as a standardised template across Staffordshire. Other areas will have their own version.

Stage 4: Review and update

The PBS plan will be regularly reviewed and revised to make sure that it reflects the person changing needs, interests, health and risks. It will evolve and grow with the person as their skills and needs change over time. It is recommended that Positive Behavioural support plans are reviewed monthly, however, this may need to be more frequent if an increase in the behaviour of concern has been noted or if an individual's skills and goals have developed.

Tom's Top Tips.

Tom has co designed and co presented PBS training to a large number of services within Staffordshire. He gives the following PBS top tips!

- Before supporting someone, read their care and support plans so that you know the signs that they are becoming distressed and can help them before it gets worse.
- Support the person to help write their plan
- Help the person to make choices about their life.
- Have a Can do Attitude. Be ambitions!
- Focus on preventative strategies, rather than reactive ones.
- Help the person to lead the life they want and be included in society.
- Help the person to be more independent and to reduce any restrictions they live with.
- Build positive relationships and support contact with friends and family
- Communicate in a way people can understand
- Consider environmental influences to the person
- Make reasonable adjustments where needed.
- Listen to their behaviour. All behaviour has meaning!

306

- Have fun and enjoy life!

We thought it would be helpful to give an ammonimised example of how PBS plans are used:

Oliver was referred to a PBS service due to an increase in behaviours of concern. Oliver was living in a residential service and was supported by three support staff. Staff often had to give Oliver PRN medication to manage these behaviours. These behaviours had led to a significant reduction in meaningful engagement with others or participation in activities he enjoyed.

The PBS practitioner completed the behavioural analysis; collecting information from carers and family, getting to know the person and completing observations. This identified key themes and functions of behaviour and concluded that the person's behaviours of concern were often exhibited at the end of an activity and when the environment is busy.

Additionally, a sensory assessment, communication and comprehension assessment, health assessment and skills assessment were completed. The assessments helped to identify any unmet or current needs and Oliver's abilities, which may be contributing to or maintaining.

A PBS plan was produced to identify how to support Oliver when the behaviours are not displayed and outlined the preventative strategies which support Mr X to maintain a good quality of life. The plan specified Oliver's goals, values and preferred support.

Interventions were recommended which included recommendations of adjusting communication and introducing a visual timetable to support Oliver prepare for the ending of activities and offer a motivating activity at the end of each task. The intervention also gave recommendations for the duration of time Oliver's spent in busy communal areas as this was a known trigger for distress. This time then became more frequent but shorter in duration to prevent him from becoming isolated, reduced Oliver's levels of distress and increased his engagement with others.

The PBS plan was reviewed regularly to ensure it remain appropriately and effective. Based upon the intervention both the intensity and frequency of the behaviours of concern decreased significantly and there had been a significant improvement in Oliver's quality of life and his relationships with others in the household.

Useful links

[For family carers - Challenging Behaviour Foundation](#)

[The PBS Academy UK | Home | PBS Academy Website | Positive Behavioural Support \(PBS\) Competence Framework](#)

[An Introduction to PBS - YouTube](#)

[Challenging behaviour - Advice and Support | Mencap](#)

[A Brother & Sister's Journey Through Opioid Addiction | PBS Short Docs - YouTube](#)

<https://www.challengingbehaviour.org.uk/> Challenging Behaviour Foundation

How clinical psychologists work therapeutically in Oxleas NHS Foundation Trust

Sandra Baum, Paula Grant, Joel Parker and Bethan Ramsey

Oxleas NHS Foundation Trust Adult Learning Disabilities Psychological Therapies Team

Introduction

We are clinical psychologists, and we are also systemic practitioners. This means that we are also trained in systemic therapy (sometimes called family therapy). This training helps us to work with families and staff who support people with learning disabilities in a way that makes them feel included and listened to by working alongside them. We work for the National Health Service (NHS) in the UK. We work for Oxleas NHS Trust which covers three South London boroughs, Bromley, Bexley and Greenwich. We all work in community learning disabilities teams. This means that we work with lots of different professionals such as speech and language therapists, occupational therapists, physiotherapists, art therapists, nurses and doctors.

In this chapter we will tell you about what is important to us in our work; what we do in our work; who we talk to and how we prepare to work with people with learning disabilities and their networks. We will tell you how we include people with learning disabilities in conversations and how we work with people who cannot talk. We will tell you about how we ask for feedback so we can find out how we are doing. We mention some challenges in our work. We end the chapter by telling you how we finish working with people so that they feel looked after.

What is important to us: our values

There are many values or ideas that are important to us when we work with people with learning disabilities and their networks. We have learnt many of these ideas through our systemic training. We try to remember these whenever we meet with people with learning disabilities and their networks.

Some of these ideas include:

- We don't blame people.
- We plan our work together with people with learning disabilities.

- We try to bring together people with learning disabilities and those that support them.
- We try to make sure that everyone's voices are heard and that everyone feels respected.
- We take time to understand all the different things that are important to people with learning disabilities and those around them.
- We try to treat everyone with fairness and kindness.
- We believe that everyone has to learn and make changes to improve the lives of people with learning disabilities. This includes us, families and care staff, not just the person with learning disabilities themselves.

What our work looks like and who we talk to

We work with people for lots of different reasons. Some of the reasons people are referred to psychology are:

- They have had a scary or upsetting thing happen to them (a trauma).
- They are feeling sad, angry or worried.

- There are difficulties in important relationships.
- An important person in their life has died.
- There has been a big change in their life.
- Other people are worried about things that they are doing (challenging behaviour).

Setting things up

We have lots of different ways of working with people when they are referred to psychology. We often start by talking to the person who made the referral. We ask:

- Who is asking for this?
- What do they want us to do?
- Who do they think we should work with?

We try to find out about the important people and places in the person's life.

- Who is in their family?
- Who else works with them?
- Who supports them?

- Who do they support?
- Do they go to school, college, a day service or work?

We then make a plan about how to start the work.

Different ways we work

Our systemic training has taught us how to work with people with learning disabilities and the people who are important to them. We do this in lots of different ways:

- Sometimes we also invite other members of their family. This is called family therapy or family sessions.
- Sometimes we bring lots of people together: the person with learning disabilities, their family, their support workers, other important people. This is called a network meeting.
- Sometimes we work with the staff team working with the person with learning disabilities. This is called a staff consultation.
- When we meet with a family, a network or a staff team, we try to have more than one psychologist present. This helps us to listen to all the different voices and ideas. It also helps us to think of new ideas.

- We can also meet with people on their own. We might ask people questions about who is important in their lives. This helps us to learn more about how everyone can work together to help the person with learning disabilities. This is called psychology sessions, one-to-one therapy or individual therapy.
- We meet with people in different places such as a therapy room, at their home, at their college or at their day service.
- We sometimes work with people for a short time. Other times, we work with people for a long time. The work could be just one meeting, a few meetings or it could last for over a year. We ask people to find out how long they think they need to see a psychologist for.

How we prepare to work with people

We take time to prepare the sessions before we meet people. We say, “Hello” to the person with learning disabilities and their family and/or support staff when they come and meet with us before we sit down in a therapy room. We ask the person with learning disabilities where they would like to sit and who they would like to

sit next to. We ask other people where they would like to sit in the therapy room so that everyone can see each other.

We begin by saying who we are. We ask everyone what they would like to talk about and say that it is 'OK' if there are things that people do not want to talk about. We think carefully about what we can do to help people feel comfortable so that they are able to speak with us. In psychology sessions, we sometimes talk about difficult or upsetting things. When people get to know psychologists, they may feel safer to talk about difficult things.

At the first meeting

When we first meet someone, we want to get to know them. We want to find out about the person. We also ask about the problem that is causing trouble in their life.

These are some of the questions we ask:

- What do you like doing?
- Who are the important people in your life?
- How do you spend your week?

- What do you think is the problem?
- When did you first notice the problem?
- When is the problem around?
- When is the problem not around?
- How do you want things to be different in your life?
- What have you already tried to make things better?
- What else might help to make things better?
- Who else helps you with this problem?

Working together

There are lots of different things that we do in psychology meetings. Some of these are:

- Understanding problems: how they started; what effect they are having on the person's life and relationships.
- Talking about what is going well in a person's life.
- Talking about important people and relationships.
- Making changes: trying out new ideas; doing things differently.

- Learning new skills.

When we work with more than one person, we try to hear everyone's ideas. We do this by making sure that everyone has a chance to talk. We find it helpful to hear lots of different ideas. It doesn't matter if everyone doesn't agree.

How we include people with learning disabilities in our meetings

- We use pens and large sheets of paper to write down and to draw what people want to talk about. We listen to what people say, we try and use simple language to check that we have heard correctly what people are trying to say. We ask, "Is this what you said? Can you tell me more so I can be sure that I have understood you?"
- We use thumbs up and smileys to check if the person with learning disabilities is OK to talk about something.
- Sometimes we ask people to draw what the problem looks like. We ask, "Can you give the problem a name?" "What colour is the problem?" "Are there times when the problem is

smaller?” These questions help us to see people as separate from problems.

- Many people with learning disabilities watch British TV such as BBC1’s *EastEnders* or ITV’s *Coronation Street*. Sometimes we talk about TV characters and their relationships. This can help people to talk about what is happening in their lives.
- Sometimes people find it easier to draw pictures rather than talk to a psychologist. We then ask questions about the drawings.

How we work with people who cannot talk

We try to include people with learning disabilities even if they cannot follow what is being talked about because they cannot speak or understand the spoken word. We ask someone else who is important in the person’s life to “step into the shoes of the other” by asking them if it is OK to speak twice, once for themselves and once for the person without a speaking voice. We say that we know that it is hard to do this and that it is not about “getting it right” but that it is helpful for us to think about what life is like for them so that we can hopefully have more understanding.



Reflecting teams

Sometimes, we work with a reflecting team. The reflecting team is usually made up of one, two or three people from the psychology team. The reflecting team listens to what everyone says in the session. At some point, the psychologist will ask the reflecting team to share some of their thoughts and ideas. The people in the session listen to this and then say what they thought of it.

How we ask for feedback: how are we all doing?

As we carry on working together, we try to listen carefully to people.

We ask:

- Are we talking about the right things?
- How are you finding the sessions?
- Is the work we are doing making a difference to your life?

Sometimes we show people pictures of faces with different emotions. We ask people to point to how they are feeling at the beginning of the meeting. We do this again at the end of the meeting. We might ask, “How did our meetings change you from

feeling angry to feeling relaxed?” This helps us learn what is making a difference.

At the end of each session, we ask people what their experience was like. We sometimes ask them to rate on a scale:

- How much they felt heard, understood and respected?
- Have we talked about what they wanted to?
- Is our way of working a good fit for them?
- Was there something missing in the session they would like to talk about next time?

If people are not finding something helpful, we will talk about this together. We will think about what we can do differently so that the sessions work better for them.

Most of the time people tell us the meetings are helpful. Some things people have told us include:

“I have been able to tell you about things that I was not able to share before”.

“I feel lighter after I talk with you.”

“You always see the good in our family. This gives us hope.”

“I feel valued when I talk to you.”

“My problems are easier to manage now. Things don’t get out of hand.”

“I have found my voice. Now I can speak up.”

Challenges of our work

We really like working with people with learning disabilities. However, sometimes the work can have challenges. These include:

- People can tell us about very difficult things that have happened to them. This can feel very emotional for them. We help people to think about how they can talk to us in a way that they do not feel overwhelmed at these times.
- Sometimes, people might feel ashamed or embarrassed to talk about something. They might not feel safe enough with us to start with. We take things slowly and show care to people to try and build trust.
- Sometimes people may not understand our questions. They might find it hard to answer them. We will try to ask them in a simple way. We might give different possible answers so they

322

can choose an option. We might use drawings to help explain things.

- Sometimes people have lots of different worries and problems. It can be hard to know what to talk about first. We try and understand the different worries and ask, “Where shall we start?”. We ask how they would like their life to be different and think about how we can take small steps in this direction.
- Sometimes people in a family or staff team want to talk about different things. We try extra hard to listen to the person with learning disabilities. However, it is important to listen to everyone in our sessions. We find that this usually helps them to get on better.
- There are lots of people who want to talk with us. There are only a few psychologists who work with people with learning disabilities in each community team. Because of this, sometimes we cannot see people as often as we would like to.
- Sometimes people with learning disabilities do not have a lot of other people in their lives who they can talk to. This can make finishing therapy difficult for them as they worry that they will be lonely.

We do things to look after our own mental health. We might go for a walk at the end of the day, listen to some relaxing music or do a hobby when we have finished work.

How we finish working with people

Ending our sessions with people can be difficult. They can feel very close to us, and we grow to care deeply about them too. Sometimes the problems they have spoken about to us are completely better. Sometimes they have “learnt how to live” with the problem even if it is still around. The person with learning disabilities might tell us they are ready to end, or we may suggest that we start planning this. We do not end the work suddenly. We agree on a certain number of sessions before we finish. We might have a visual way for people to see that the sessions are coming to an end e.g., crossing off the petals on a flower until there are none left.

We take time to think about the person’s thoughts and feelings about ending. We ask questions about:

- What have they achieved that they are they pleased about?

- Are there any difficult feelings like sadness and worry about ending?
- How can they hold on to the progress they have made?
- Who else can they talk to?
- Who will support them to keep moving forwards in their life?

We usually write an easy read letter with pictures and simple language about what we have spoken about together. People can read the letter whenever they want to remember us or the things we have talked about. Some people treasure these letters and keep them for many years.

We ask the person how they would like their last session to be. Would they like a certificate to show what they have achieved? Would they like other people to join, to witness their achievement and share their thoughts about the work with them? Would they like to share food and drink together?

Often the last meeting can be a mixture of sadness about ending but also joy about what everyone has learnt together and hope for

the future. We let people know that they can get in touch to update us on how they are doing. We tell them that they can see a psychologist again in the future if they need our support again.

Summary

In this chapter, we have written about some of the work we do as psychologists when we do therapy with people with learning disabilities and their networks in Oxleas NHS Trust. There are other things we do as well such as assessing people to find out what they are good at and what people struggle with and what help they need. We would have to write another chapter to tell you about our other work! Not all psychologists work in the same way as it depends on where you work, who you work with and what extra training you have had. We hope that if you see a psychologist, this chapter will have helped you to get some idea about what to expect.



326

Books to read about the way we work (not in easy read)

Baum, S. & Lynggaard, H. (Eds.), (2006). *Intellectual Disabilities: A Systemic Approach*. London: Karnac Books.

Jones, V. & Haydon-Laurelut, M. (Eds.), (2019). *Working with People with Learning Disabilities: Systemic Approaches*. London: Red Globe Press /Macmillian International2021/22: LeDeR Report: <https://www.kcl.ac.uk/research/leder>



Introduction

My name is Neil Douglas and I worked as an NHS GP in Tower Hamlets, East London until 2015 and subsequently as a Community Paediatrician for Barts Health until 2021.

In this chapter I will cover how GPs and Community Paediatric services focus on working with people who have a learning disability especially if they have problems with mental health.

How GPs work

Traditionally GPs work with a defined population of patients who are registered with them. In the NHS they are the first port of call for physical and mental health problems but also act as gatekeepers for secondary care services with access to specialist care. GPs work within multidisciplinary teams which include nurses and nurse practitioners who are responsible for screening and chronic disease management and will often have advanced skills in assessment, diagnosis, and treatment.

The Covid 19 pandemic has changed the landscape of GP work completely with many practices adopting triage systems whereby patients are offered appointments or advice via the most appropriate means based on their clinical need. This has resulted in more telephone and online contact and has reduced face-to-face consultations significantly.

To care for mental health some GPs will have in-house psychology support, offering services such as short-term CBT (cognitive behavioural therapy) for patients with mild to moderate anxiety or depression. It is important for GPs to maintain a strong relationship with local Community Learning Disability teams who can offer more specialised advice and help for people with a Learning Disability (LD).

Navigating the system

The use of different modes for consultation may be confusing and difficult to navigate both for people with LD and their carers. For people where English is not a first language the assistance of translators or advocates is essential. Difficulties may arise when a family member offers to translate on a patient's behalf. This may compromise confidentiality and there may be a significant conflict

of interest however well-meaning that family member is. This can be true when there is an issue around mental health which may also be complicated by stigma. However, many services may rely on carers or relatives to perform this role which, although expedient, is not always desirable.

There have been recent developments in IT to facilitate the patient journey in terms of booking and cancelling appointments and access to information. It is important that these innovations are easy to use and accessible for people with LD.

Medication

GPs are responsible for prescribing and monitoring most medication. Patients on long-term repeat medication should have their medication monitored by their GP or specialist at regular intervals and this may involve blood tests.

GPs have an important role to play in STOMP (stopping over medication of people with a learning disability, autism or both [NHS England » Stopping over medication of people with a learning](#)

[disability, autism or both \(STOMP\)](#)). Psychotropic medications, which affect how the brain works, are prescribed for conditions such as depression, anxiety, sleep problems and psychosis. They are often given to people with learning disabilities, particularly when their behaviour is seen as challenging, and this is sometimes not the most helpful approach. Side effects from medication may outweigh the benefits.

Local pharmacists are helpful when medication is prescribed, and it is very important before commencing medication to know what side-effects may be expected and what to look out for in terms of response e.g., some drugs may cause nausea which affects appetite or drowsiness which may affect the ability to perform and enjoy normal daily activities. Rare but serious side effects like severe allergic reactions, movement disorders or blood disorders may be more difficult to spot in people with LD especially if there are communication difficulties, so it is important not only that the patient is aware but also that carers are informed of potential difficulties.

A new online medication pathway resource for family carers has also been developed to assist with these issues. [About this resource - Medication Pathway \(challengingbehaviour.org.uk\)](http://challengingbehaviour.org.uk)

Annual check-ups

Since 2006 GPs have been incentivised to provide better care for people with LD by the introduction of yearly LD check-ups. Initially this scheme was for adults with LD but has been extended to teenagers from the age of 14. The check-ups recognise that people with LD often have undiagnosed problems due to difficulties in accessing services, communication difficulties and so-called diagnostic overshadowing i.e. medical problems presenting with atypical symptoms or behavioural changes (see case study 1). The mode and delivery of these check-ups can vary quite considerably in quality and delivery within and between different geographical locations.

Identification of other factors that may affect mental health such as dependent alcohol or illicit drug use are also important, and many localities will have specialist services for these problems.

The annual check-up results in a Health Action Plan which is shared with the patient and includes advice on health promotion and screening as well as specific interventions around mental and physical health needs.

Many people with LD have sensory problems such as hearing loss, poor eyesight or specific sensory sensitivities that can make access to care difficult and it is important that practitioners are aware of these difficulties so that they can be mitigated as far as possible during a consultation. Liaison with carers is essential for this to happen.

It is also known that people with Learning Disabilities with syndromes such as Down's have specific associated morbidities such as hypothyroidism, congenital heart defects, and dementia and it is important that GPs recognise this and can detect problems early (case study 1).

It is also recognised that people with LD have higher rates of mental health problems including psychosis, depression, and anxiety. The presentation of these problems may be atypical and require specialist assessment.

Mental Capacity

One issue of particular importance to GP is that of mental capacity. Mental capacity is the ability of a patient to make informed decisions about their own health and should always be assumed unless there is evidence to the contrary. A GP will have to decide if the patient can understand the information that is given to them, if they are able to retain this understanding and weigh up the pros and cons of any action that is advised. Mental capacity will vary depending on the condition/treatment at issue. A practitioner also must weigh considerations for patient wellbeing and safety as well as the safety of other people. Community LD teams are often helpful in addressing these issues.

Challenges

GPs are trained to offer holistic care to their patients, and this will mean breaking down barriers of traditional medical thinking and organisation which separates physical and mental health into mutually exclusive areas. It can be a problem to both patients and GPs when specialist services including mental health operate within artificially boundaried silos with respect to this. One can understand this because services are often overwhelmed by the demand for available resources, but this does not help the patient whose needs should be central to the delivery of care.

Community Paediatrics

Community Paediatrics is delivered by specialist teams including doctors, occupational therapists, speech therapists, physiotherapists in liaison with CAMHS (Child and Adolescent mental health services), social services, educational psychologists, and schools.

Learning disability may present at birth with specific syndromes or may become apparent later through delays in development such

as difficulties with achieving milestones such as walking and talking. These are often complicated by sensory difficulties (vision, hearing, different perception, and experience of stimuli) and behavioural symptoms.

Diagnostic assessments are required to determine the cause of a child's difficulties, identify where specific therapeutic interventions are helpful and to recognise and build on a child's strengths. Because the brain is dynamic and developing quickly it is important to apply therapeutic interventions early to maximise their effect and have a positive impact on future achievement.

There is an important distinction to be made here about diagnostic labels. Not all children with developmental delay will go on to develop learning disability. Global developmental delay is a non-specific diagnosis that implies delay in two or more modalities of development but unless coupled with a more specific diagnosis does not always give clues about long term outlook in terms of educational outcome or functional ability in adult life.

Mental Health

In children mental health problems such as depression or anxiety may present with behavioural changes or symptoms such as sleep disturbance in younger children. Older children with difficulties may present with self-harming behaviours or eating disorders.

Separating physical from mental health is not particularly helpful particularly in people with LD as an approach to help may include interventions in both modalities and recognising the overlap of the two to overall optimal health outcomes. The same difficulties with diagnostic overshadowing exist in children as much as in adults. Sensory difficulties with eyesight or hearing are especially important to detect at a young age.

Treatment must take account of the developmental stage of the child and in particular the way the child or young person communicates.

Autism

It is worth making specific mention of autism (ASD). Not all people with autism will have a learning disability – it is a spectrum both in terms of communication difficulties but also in terms of co-morbidity. It is known that ASD is associated with mental health co-morbidities such as ADHD (case study 2) and psychosis. Difficulties exist for this group of patients with long waits in many areas for diagnostic assessment. This is important as delays in diagnostic assessment delays definitive diagnosis and therefore access to services that may be helpful e.g. specialist educational provision to EHCPs (Education Health and Care plans) which may not be provided without a diagnostic label.

In my experience a query diagnosis of autism was the most common reason for a child to be referred to our service. Parents were often left in limbo and without timely diagnosis were left with anxiety and practical difficulties about how best to help their children. All the evidence points to better outcomes for the child and families if early diagnosis and help is given.

Attention Deficit Hyperactivity disorder (ADHD)

Some community paediatric services will have specialist diagnostic assessments to diagnose ADHD and others will rely on assessments provided by CAMHS. The condition often presents in young children with restlessness, difficulties with concentration and challenging impulsive behaviours. It can be difficult to diagnose in children with developmental delays as there may be considerable overlap in symptoms due to learning difficulties or behaviour associated with the developmental stage of the child.

Advice and support including educational support is important for parents and medication may have a beneficial effect although there are common side effects which require monitoring and dose adjustment.

Children who are looked after

Special mention should also be made of the role of community paediatric services with looked after children i.e. children who are placed in the care of a local authority. Children with learning difficulties are disproportionately represented in this group and

removal of these children into care away from their families although necessary is also traumatic. These children have a compulsory medical assessment by law in their first 4 weeks in care and this includes a comprehensive assessment of physical, developmental, and mental health. It is particularly important that foster carers are given as much information about the children as possible with support from social services and education services to minimise the impact of removal from birth families. The management of behavioural and mental health difficulties often requires specialist intervention recognising the trauma that these children have experienced. This trauma often exacerbates pre-existing learning difficulties and if not addressed leads to mental health problems in adulthood which may include depression, anxiety, low self-esteem, and substance abuse.

Social contexts

In both Community Paediatrics and General Practice, the primary focus is on assessment and treatment of medical conditions. However, our patients live in the real world of family and community. In deprived communities inequalities result in an increase in adverse outcomes including increased morbidity and

decreased life expectancy. It is therefore important that people have access to all help that is available within local communities – the statutory help provided by local authorities and education but also access to adequate housing and financial benefits to which they are entitled. Often the provision of these benefits is dependent on supportive medical information and advice. Nobody should underestimate the benefits to health and well being to both patients and families of the provision of often seemingly minor items such as parking permits, small specific home adaptations to make living space safer or the application of Education Health and Care plans, PIP payments or respite provision.

Facilitating the move to adult services

Community paediatric services often have an important role in co-ordinating care for their young patients especially when they are transitioning to adult services. GPs often take on this co-ordinating role in adulthood.

Mental health services for adults are often more fragmented and hence more difficult to navigate and again the local community

team for people with learning disabilities has an important part to play in facilitating and delivering care.

8 top tips for consultations

In this section I will conclude with some top tips for consulting with GPs and Community Paediatricians which may also be applied generally to other health professionals.

1. Don't be afraid to be upfront about telling professionals how you feel and what you need. They may not be able to provide everything you want but it helps for them to know.
2. Make sure you are on the practice's Learning Disability Register. Don't assume they know you have a learning disability if you are seeing someone who doesn't know you. Although this should be flagged on your medical records many practices now employ short -term locums who will not be familiar with your background.
3. Keep a file of your own records including reports and copies of hospital letters. GPs should have access to all this information, but other specialists won't, and it is sometimes important to have this to hand especially if you have a complicated medical history.

4. If you have a list of problems you would like to discuss make sure the things that are most important to you are at the top of the list.
5. You have rights about your access to services and how services accommodate your needs. Make sure you know about them and use them. Think about what the best and easiest mode of consultation for you would be – phone, online, or face-to face. The provider of services must take reasonable measures to help you access care.
6. Ask for explanations or to repeat things you don't understand about your treatment or plans to help you.
7. Make sure GPs and hospital services have up to date contact details for you and your carers.
8. Summary care records (SCR) are an electronic record of important information about you created from GP medical records. If there are things about you that are helpful for people to know such as sensitivity to noise or having someone you know around in an emergency make sure that this is added to your summary care plan.

Resources: www.rethink.org

Case study 1

JG is a 56-year-old man with Down's syndrome who lives in supported housing. At the annual check-up, his carers told me that he had become increasingly anxious about going out, so much so that he was now housebound and socially withdrawn. Observation of him at home indicated that he was having difficulty moving around his familiar living space and clinical examination showed dense bilateral cataracts. He was anxious because he couldn't see properly but being non-verbal, he was unable to communicate this. Referral was made for specialist ophthalmic assessment and surgery was recommended. The local LD team were very supportive in assessing his ability to consent to treatment and facilitating his hospital visits. They coordinated a Best Interests meeting. Surgery went ahead with a successful outcome, and he was able to resume normal activities including trips outside when his vision was restored.



Case study 2

SB is a 7-year-old with a diagnosis of autism. He can communicate verbally and attends mainstream school and has an Education Health and Care Plan. The school are worried because he is restless and has problems concentrating on his work despite the help of a teaching assistant. He often runs out of the classroom and on two occasions almost made it out of the school gates to the main road raising concerns about his safety. His parents confirm that they have similar difficulties when they are at home and must keep doors and windows locked. The possibility of Attention Deficit Hyperactivity Disorder (ADHD) was raised and he was referred to local CAMHS for assessment. The diagnosis was confirmed and he was commenced on medication which significantly helped his behaviour and improved his interactions in school and at home.



345



foundation for
people with
learning disabilities

EST 1892

LSBU **NHS**
Oxleas

NHS Foundation Trust



Penge Publishers

Tom does not know how to ask for help and support due to attachment problems

Paula Sterkenburg & Marieke Weijburg-Melis, Psychotherapists, Bartiméus, the Netherlands

We are both psychotherapists at Bartiméus in Doorn, the Netherlands. Bartiméus is a care organisation for persons with a visual or visual-and-intellectual disability. The department of psychotherapy was founded about 35 years ago.

At this department, a therapy was developed for persons with attachment problems. These problems can form if a person in childhood did not have a caring parent(s), but instead experienced (emotional) neglect and sometimes abuse. Also, frequent or long-lasting separations from a parent can contribute to attachment issues. When the caregiver is not able to care for the child, the child has no one to turn to when in he/she is in trouble. The consequence is that they have no place to turn to when they have problems. As these persons will usually experience a lot of stress, they also show a lot of problem behaviour. For these persons we have developed

a special therapy called the 'Integrative Therapy for Attachment and Behaviour' (ITAB).

About Tom

We describe the treatment given to Tom (this is not his real name).

Tom is 49 years of age. He has a moderate intellectual and a visual disability. Tom was placed in a group home when he was 8 years of age. His parents could not provide the care he needed. They did not provide the emotional care and support a child needs. As long as all can remember Tom always had problem behaviour. Tom would scream and showed a lot of aggressive behaviour towards others (grabbing others, hitting and biting). The team tried to teach him new behaviour, but the problem behaviour did not change. The caregivers were very scared and tried to avoid contact with him.

Treatment

The attachment therapy (Integrative Therapy for Attachment and Behaviour) focuses on building an attachment relationship between persons with attachment problems and the psychotherapist.

The treatment consists out of three phases:

- 1) Building up the attachment relationship.
- 2) Learning new behaviour.
- 3) Transferring the relationship to the daily caregivers.

Generally, because of the development of an attachment relationship during treatment, most of the person's problem behaviour gradually fades away. This is because the attachment relationship acts as a buffer for stress.

In a research study by (Sterkenburg, 2008), one of the authors, we found a significant reduction in problem behaviour and significant lower levels of stress.

The attachment therapy for Tom

During the first session, the daily caregiver and Tom together came to the therapy session. However, from the second session on, the caregiver did not come into the session and only saw Tom off at the therapy room and picked him up again at the end of the sessions.

First phase

The sessions took place within the therapy structure. The first step was welcoming Tom to the session by making talking to him and drinking hot chocolate together. Then, Tom shared his experiences of the past few days, including what went well for him and things that had bothered him. The therapist was very sensitive and aware: she let Tom determine the pace of storytelling and play. Next, on Tom's request, play material was introduced. At first, Tom loved the puppet theatre dolls. Later, his interest expanded to playing with musical instruments and building with Duplo blocks. The therapist gave Tom the space to come up with the rules for play and later the therapist would add to the rules of play. Entire structures were made, which eventually resulted in a fortress with knights and soldiers.

From the start, Tom enjoyed the therapy. Later on in the therapy sequence, he found it hard to wait for the next session. Tom had learned to trust the therapist. His growing enthusiasm to see his therapist, was obvious in the beginning when the therapist left the room, Tom would stop playing. Later on once trust had been established he continued playing by himself, knowing that the

therapist would return to him. Another good sign was that his play shifted from being inward and self-centred to focusing on the therapist and the environment.

Second phase

Over time, Tom's stress reduced, and his problem behaviour reduced. However, in his group-home stress did still build up. Tom came up with an idea and found a way for his caregivers to help him when he got stressed. When in a stressful situation, Tom would raise his finger. Stress for Tom was, likely to happen when he felt annoyed or was startled by things in his environment. When his caregivers saw the raised finger, they would immediately go to Tom and prompt him to a private room to help him calm down by talking with him. Rooms that were used for this purpose were his bedroom and the dining room when vacant. This instant help in emotion regulation aided him to better cope with all types of situations. As a consequence, he showed more positive behaviour and his previous problem behaviours occurred less often.

Third phase

Slowly, the frequency of the treatment sessions was reduced. Tom himself suggested that he could start with a job on the days that he no longer received therapy. This was a very big step for him! Having a job, making candles, went very well as he had no problem behaviour and showed that he enjoyed his work.

Also in this phase, the caregivers working in Tom's group home and workplace received training in how to meet Tom's needs. The focus of the training relied on being sensitive and caring; how to observe and recognize when Tom is under stress; and how to react in a caring and secure way to help Tom regulate his stress.

Rounding off the treatment

During the end assessment, Tom mentioned that he really felt that he could rely on his caregivers when he experienced stress. His problem behaviour completely disappeared. He has learned to cope with his stress and now trusts others during moments of stress. He more often asked for help. He felt that they were there for him.

Conclusion

At this point in time, Tom is still doing very well. He now approaches his caregivers when he experiences stress, and he can cope with stress much better. Tom enjoys going to his work. He also finds joy in music and loves to go cycling with his caregivers.

Not only for Tom but also for many other clients the attachment therapy truly worked out very well. We wrote about other people experiencing this therapy with its positive results in a book called 'Attachment therapy: Practical examples of the Integrative Therapy for Attachment and Behaviour in persons with a visual-and-intellectual or intellectual disability'. This book can be downloaded free of charge (see below).

We strongly hope that all people with an intellectual and/or visual disability, who have persistent problem behaviour, have difficulty dealing with stress and are diagnosed with attachment disorder, can be helped with Integrative Therapy for Attachment and Behaviour.

If you want to read more about the attachment therapy, please read:

Sterkenburg, P. S. (2008). *Intervening in Stress, Attachment and Challenging Behaviour: Effects in Children with Multiple Disabilities*. Bartiméus Reeks, Zeist. ISBN: 9789071534577.
<https://www.bartimeus.nl/book-intervening-stress-attachment-and-challenging-behaviour-bartiméus-series>

Sterkenburg, P. & Andries, V. (red). (2021). *Attachment therapy: Practical examples of the Integrative Therapy for Attachment and Behaviour in persons with a visual-and-intellectual or intellectual disability*. Bartiméus Reeks, Zeist. ISBN/EAN: 9789491838224 <https://www.bartimeus.nl/book-attachment-therapy>

Sterkenburg, P.S., Zaal, S. & Dekkers-Verbon, P. (2021). Development of emotion regulation and the role of the attachment relationship. In De Bruijn, J., Van den Broek, A., Vonk, J., Twint, B. (ed.) (2021). *Emotional Development and Intellectual Disability: A guide to understanding emotional development and its implications*. West Sussex, Pavilion Publishing and Media Ltd. Chapter 6. pp.117-134. ISBN 978-1-914010-58-3

About the authors

Paula Sterkenburg is professor at the Department of Clinical Child and Family Studies of the Faculty of Behavioural and Movement Sciences, in the Netherlands. She is a licensed psychologist/therapist and works at Bartiméus in Doorn. She coordinates the Academic Lab 'Social relationships and attachment: persons with visual and/or intellectual disability' of Bartiméus, the Vrije Universiteit Amsterdam and Ons Tweede Thuis.

Marieke Weijburg-Melis is a healthcare psychologist. She works at Bartiméus, at the Department of Psychotherapy in Doorn, the Netherlands. She also teaches courses in signalling attachment problems and the possibilities of treatment. Also, Marieke supervises other therapists.

Learning to mentalize is something you do together!

About mentalizing-enhancing interventions in the care of people with intellectual disabilities

Florence van Schoonhoven and Mirjam Wouda (both healthcare psychologist and remedial educationalist) and Stichting Ons Tweede Thuis, the Netherlands

Susan

Susan (not her real name) is 45 years old and has what is called a borderline learning disability. This group of people experience many of the same things as people with a mild learning disability but they may be slightly more able in some areas of life. She lives in an apartment complex, where caregivers are present day and night. She gets both planned and unplanned assistance.

Like everyone else, Susan can get stressed. But Susan feels stressed much more often and more easily than others. Also, she immediately feels when other people are stressed, even if it's just a bit.

This hypersensitivity to stress was caused by unpleasant events in her past. Also, the contact with other people in her past felt unsafe

or hostile. Some people asked more of Susan than she could handle. She also didn't learn how to deal with stress very well.

For years, it has been difficult to see what Susan needs. Even people close to her sometimes didn't know. Contact with caregivers made Susan stressed. The stress made her react fiercely and she pushed others away. She was comfortable with only a few caregivers.

When a caregiver was in a hurry or had a lot on their mind, Susan sensed this. She felt that the caregiver was unreliable. This made her tense up. It felt like they were not there for her. As a result, she broke off contact.

Some caregivers felt that it was difficult to help Susan. This is because Susan wanted to be in control and tell the caregivers what to do. If the caregivers didn't do this, Susan would show them the door.

Caregivers did not know why Susan behaved this way and how they should respond. Caregivers said things like:

"Susan gets mad because she doesn't get her way. But, she's not in charge here."

Caregivers then (more and more) told Susan what to do. They did this to show they were in charge and not Susan. This made Susan feel very insecure and misunderstood. She shut out the caregivers even more.

Some caregivers felt insecure or annoyed. They felt like they always did the wrong thing. As a result, caregivers were stressed themselves when talking to Susan. Susan could feel this tension, which made her feel even more unsafe. It is better to search for underlying reasons for behaviour. Susan did not want to be in charge of things. She wanted to be heard. She felt unsafe. Susan wanted to make things more predictable. Predictable situations feel safer. That was the reason she told the caregiver what to do.

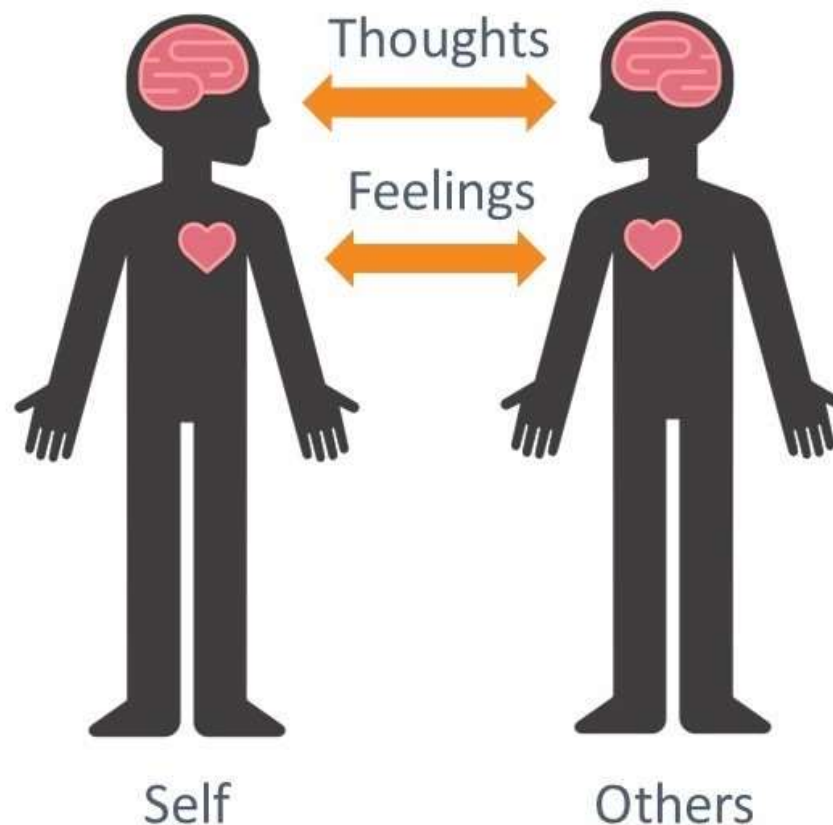
Susan and her caregivers kept reacting to each other. The situation moved downwards. This negative circle of communication needed to be changed. To make this change, learning to mentalize seemed to be a good way. Susan participated in a modified form of MBT.

Some of the caregivers completed MBS-training. MBT and MBS are both about mentalizing.

What is Mentalizing?

Mentalizing: we all do it, and so do you! But what is it?

Simply put: it is about understanding the other and yourself.



That sounds simple, but it's quite complicated. With mentalizing, you try to understand where your own feelings come from. Also,

you think about how your feelings affect other people. As well as how other people influence your own feelings and thoughts. So, learning to mentalize is something you do together! It's about how we affect each other.

Mentalizing is being curious about yourself and others. For example, when you are stressed, what does this do with another person? Or: when you feel insecure, do you act different from when you feel confident? What does this do with the conversation you are having?

You never know for sure what the other person thinks or feels. When mentalizing, you try to see yourself as the other person does. For example: when you yawn during a conversation, the other person could think you are bored. But maybe you are just tired. If you say so, the other person might not be offended. Mentalizing is also trying to see past the other person's behaviour: what could the other person feel, think or want? It all starts with knowing and understanding your own feelings and thoughts.

When people consciously mentalize, there are fewer misunderstandings. It is easier to deal with difficult situations and

problems. Also, asking for help is easier. This means experiencing less stress. In general, contact with other people is more pleasant. It helps to understand what is going on between the other person and you!

What is MBT

MBT is an abbreviation of Mentalization Based Treatment. In short: with MBT, you learn to reflect on your own feelings and emotions. You also learn how to explore what others might think and feel. And finally, you learn how thoughts and feelings affect behaviour.

Susan gives an example:

“I was going to visit a friend for Easter. But I thought, she probably wants to go hang out with her boyfriend. So, I cancelled. But maybe I filled in what she wanted too soon. Actually, I don't know if I don't ask her... But that's scary!”

During Susan's treatment, they spoke about assumptions. An assumption is something you believe is true, without you having proof. Believing things to be true without having proof, can influence your behaviour. In this case: Susan cancelled the visit, because she assumed that her friend wanted to spend Easter with

someone else rather than her. If we don't check assumptions with the other person, we might feel bad about it. This could cause unnecessary stress.

In Susan's case, one of the caregivers she felt comfortable with, was present at the conversations between Susan and the MBT therapist. The therapist helped her to slow down the process, by asking questions about her thoughts, feelings and needs. In this meeting, Susan explained how caregivers could help her. Situations that stressed Susan out, were analysed. They used the MBT-method 'stop and rewind'. Susan could then explain what happened to her when she feels stressed. Like refusing contact. She could also explain what she needed.

A stress thermometer was made. On this thermometer you can read how Susan feels and acts when she is relaxed. And also:

- 1) how Susan feels and acts when stress increases
- 2) how she can stay relaxed
- 3) what she can do to feel better
- 4) how caregivers can best react in the different stress levels.

This stress-thermometer made the support for Susan more predictable.

What is MBS

Some of Susan's caregivers followed the MBS training. MBS is the abbreviation of Mentalizing Based Support. This means that the caregivers learn to mentalize better themselves. By doing so, they can help Susan to mentalize also.

For example, they learned about attachment and disturbed attachment. Attachment determines how well a person is able to trust others. They also learned that it is important to explore why someone reacts in a certain way. Susan's caregivers learned to be curious about where Susan's behaviour was coming from. It is important to make contact without any assumptions.

In the contact with Susan, it was important not to think 'she'll probably refuse my support anyway'. With an 'empty head', it's easier to make a real connection.

Susan's caregivers are now also aware of their own behaviour. If they rush to Susan or feel stressed, Susan immediately picks up on it. That makes her feel nervous and irritable. Susan tells us what triggers her in a bad way, in contact with other people:

“New people, because I don’t know them. And I don’t know if I can rely on them. And when people are too busy, I can’t think. People being direct, or putting too much pressure on anything, makes me very nervous. I’ll just walk away. It doesn’t work. They need to slow down, help me make decisions and not decide things for me. And I can take more, from someone I know well.”

It is good to be aware of your own feelings, thoughts, behaviour and wishes. Because you then can examine the feelings and thoughts of the other person. And also: explore how your feelings and thoughts and their feelings and thoughts influence each other. By doing that, you help the other person do the same.

It also helps Susan a lot, that caregivers explain what they do and why.

For example, they say things like: *“Sorry, I’m asking three questions at once, that’s not helpful. What I wanted to know is...”*. Or: *“Sorry, I’m out of breath because I took the stairs, that makes me a bit flushed!”*

Explaining makes Susan feel heard and more secure. The caregiver explains about themselves and others. They name what they see and clarify things. As a result, Susan feels heard and seen. She experiences less stress. Because her stress drops, there is more room for her to think. Because of that, she is also able to mentalize better herself.

How are Susan and her caregivers doing now?

We asked Susan what changed the most:

“Caregivers ask what I want or need more often. They used to push through, which made me very tense. They also might look at my facial expression a bit more. You can see quite clearly when I’m tense or confused or so. The other thing that helped very well, was the stress-thermometer. We still use it, and it helps me a lot! I recognize my own stress sooner. And caregivers and I talk about my level of stress and what I need in the same way.”

“Also, it’s easier for me to say when I don’t want contact or feel stressed. I get regular visits, but if there is a caregiver I don’t know well, they ask what I want. Before, they would push on. The way it’s going now, is much better!”

364

Caregivers say they understand Susan's behaviour better. They better realise how their own mood influences Susan. They slow down their pace and explain more. They ask her instead of telling her. Of course, sometimes it doesn't go as planned. But there is enough trust to recover contact between them.

Susan and her caregivers are proud of what they achieved together!

Possibilities of mentalizing for people with intellectual disability

There is growing attention to the importance of mentalizing. Specifically in the care of people with intellectual disabilities. We think this is a very good thing! Practical books on this theme have been published. Also, the Academic Lab 'Social relationships and attachment: persons with visual and/or intellectual disability'¹ offers training on mentalizing. Mentalizing Based Support promotes mentalization in relationships. It is important that caregivers are aware of the emotions, within the other and themselves. And that their own behaviour influences the relationship they have with the client.

About the authors

Susan lives in a care facility for people with an Intellectual Disability called Ons Tweede Thuis, in the Netherlands. She lives in a studio apartment and can rely on assistance 24/7. She lives with her pets. Florence van Schoonhoven is a healthcare psychologist and remedial educationalist at Ons Tweede Thuis (healthcare provider for people with disabilities in the Netherlands).

Mirjam Wouda is a healthcare psychologist, remedial educationalist 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.

Literature overview

Bateman, A., & Fonagy, P. (2012). Handbook of mentalizing in mental health practice. Arlington: American Psychiatric Publishing.

Dekker-van der Sande, F., & Sterkenburg, P. (2016). Mentalization can be learned: Guidelines for all parents and caregivers supporting persons with a visual impairment and/or intellectual disability and also suffering from a problematic attachment,

psychiatric disorders and/or behavioural problems. Bartiméus Series. <https://www.bartimeus.nl/alle-publicaties/book-mentalization-can-be-learned>

Derks, S., Willemen, A. M., Wouda, M., Meekel, M., & Sterkenburg, P. S. (2021). The co-creation design process of 'You & I': a serious game to support mentalizing and stress-regulating abilities in adults with mild to borderline intellectual disabilities. *Behaviour & Information Technology*, 1-13.

Sterkenburg, P. S., Meddeler-Polman, B., & Schrijver, J. (2022). Attachment in practice: Workbook for everyone involved in the education and care of children and adults with a visual-and-intellectual or intellectual disability. Bartiméus, Zeist. <https://www.bartimeus.nl/alle-publicaties/book-attachement-in-practice>

Website: [Academische Werkplaats Sociale Relaties en Gehechtheid - Bartimeus](#)

Medicines and your mental health

Bimpe Idowu, Senior Clinical Pharmacist and Paul Maycock, Chief Pharmacist, Pharmacy Team, Oxleas NHS Foundation Trust

What is this chapter about?

This chapter explains how each main group of mental health medicines work. You can make some notes in a notebook as you read through.

If you would like to discuss your medicines or find out more about an individual medicine, ask your doctor, pharmacist or key-worker during your next appointment. You could take your notes along.



What else is in this chapter?

There is a “List of Useful Websites” at the end of this chapter. We have chosen these websites as they provide information and support for your mental health. You may find other websites useful about mental illness in general. Make sure you are reading from trusted websites.



Inside our heads...

Before we find out how medicines work, we need to understand how the brain works.

The brain is made up of millions of tiny threads called “nerve fibres”. These nerve fibres are bundled together to form different sections of the brain. Each section has a different job, e.g., one section controls our movement and another our speech. Messages are sent from one part of the brain to the other via chemicals known as ‘neurotransmitters’ (neuro = nerve; transmitters = messengers)

Therefore, neurotransmitters are chemicals that carry messages between nerves. For this reason, they are also called “chemical messengers”. The brain talks to itself and the rest of the body using chemical messengers, of which there are many different types.



The main chemical messengers involved in keeping our **thoughts**, **beliefs** and **mood** healthy are:

- ❖ Dopamine
- ❖ Noradrenaline
- ❖ Serotonin

The medicines described in this chapter increase or decrease the levels of these chemical messengers in our brains. This strengthens or weakens the messages passed in the brain

If you want to know more about the way medicines work, ask your doctor or pharmacist.

Antipsychotics

How do antipsychotics work?

Antipsychotics work by blocking (reducing) **dopamine** in the part of our brain that controls our thoughts. They help reduce psychotic symptoms such as

- ❖ **hallucinations** (seeing or hearing things that are not there),
- ❖ **delusions** (unusual thoughts or ideas, and beliefs about things that are not real) and
- ❖ **thought disorder** (difficulty thinking clearly).

371

Psychotic symptoms are also a part of many illnesses like schizophrenia, mania and depression. They may also be brought on by taking street drugs such as cannabis, trauma, stress, some physical health conditions such as brain tumour and as a side effect of some medicines

Other uses of antipsychotics

- ❖ Some antipsychotics are used as mood stabilisers (see below)
- ❖ Antipsychotics are sometimes used to help with depression that is difficult to treat.
- ❖ Low doses of antipsychotics are sometimes used to treat anxiety.

How long do you need to take them for?

Antipsychotics usually take about 2 weeks to start working properly and then you need to take them until you are completely better. If your doctor says you have schizophrenia, or you have repeated episodes of psychotic symptoms, taking antipsychotics all the time can help prevent you from becoming unwell again (having a relapse).

What about the side effects?

Different medicines have different side effects and how one person reacts is not necessarily how another person will. Some side effects are worse when you first start a new medicine or have the dose of your medicine increased, e.g. sleepiness, dry mouth, etc. They usually wear off slowly after you have taken the medicine for a few weeks. Ask your pharmacist if you would like more information about side effects. Your side effects will be checked regularly and at least once a year using a scale called 'GASS' (Glasgow Antipsychotic Side Effects Scale).

If you take antipsychotics all the time, it is important to find the lowest dose of that medicine that keeps you well with as few side effects as possible. You and your doctor or pharmacist should do this together. If one medicine does not suit you, your doctor or pharmacist can talk to you about other medicines that might suit you better.

Physical health checks

People with severe mental illness are at greater risk of cardiovascular disease and diabetes than the general population.

A physical health check should be carried out at least once a year to detect any developing physical health problems.

For advice about the effects of your medicines on weight gain, fertility, sexual function, childbearing issues, and with alcohol, street drugs, caffeine, smoking please ask your doctor, pharmacist, key worker or refer to any of the websites listed at the end of this chapter.

Why should I take antipsychotics?

Antipsychotics can keep you well.

Sometimes, your doctor may prescribe an antipsychotic for a short period to help manage an episode of psychosis.

If your doctor says you have schizophrenia, you will need to take medicines for a long time (years). If you can't put up with the side effects of your medicine or just feel that you don't want to take it anymore, discuss this with your doctor, key worker or pharmacist. We know that most people with schizophrenia who come into hospital, have become unwell because they have stopped taking their medicine.

If you have another illness (not schizophrenia) you might not need to take antipsychotics for as long. Ask your doctor.

Don't just stop taking your medicine. Speak to your doctor, keyworker or pharmacist first.

There are two main groups of antipsychotics. The first group are known as **typical' Antipsychotics and includes** older medicines such as Chlorpromazine. These may cause side effects that affect a person's movement. They may also cause dry mouth, blurred vision, dizziness when standing and constipation.

The second group known as **Atypical Antipsychotics** includes clozapine, risperidone and olanzapine. These cause fewer movement side effects than the older medicines. But may cause other side effects such as weight gain. They may also make you dizzy, sleepy or constipated.

Clozapine:

Clozapine is one of the newer antipsychotics which is especially helpful when other antipsychotics have not worked well. You must have regular blood tests to continue taking clozapine. Ask your

pharmacist for more information about clozapine.

Antidepressants

There are 4 main groups of antidepressants:

- ❖ Tricyclic and tricyclic related (TCAs)
- ❖ Selective serotonin reuptake inhibitors (SSRIs)
- ❖ Serotonin and noradrenaline reuptake inhibitors (SNRIs)
- ❖ Monoamine oxidase inhibitors (MAOIs)
- ❖ Others

Please check any of the websites listed at the end of this chapter for the group that your medicines belong to.

No one antidepressant is any better at treating the symptoms of depression than another. However, each person will have a different response to any one medicine than another. What works for you may not work for someone else and vice versa.

You should start to feel some small improvement after a few days. Most people find that it takes 1-2 weeks for them to start feeling the

benefits from their antidepressant. It usually takes 4 to 6 weeks to have its full effect.

How do they work?

They block reuptake mechanisms on both noradrenaline and serotonin nerve fibres so you will have increased levels in the brain, and this helps to lift your mood.

What about the side effects?

Side effects of antidepressants vary depending on which one you are taking. Speak with your pharmacist if you need more information.

What are Discontinuation Symptoms?

Antidepressant medicines should not be stopped suddenly as this can cause 'discontinuation symptoms'. These feel like a mild version of flu and happen a day or two after stopping the medicine. The symptoms will clear up by themselves in a few days but can be avoided completely by reducing the dose of the antidepressant slowly over a few weeks. Plan this with your doctor.

Changing from one antidepressant to another

If one antidepressant is not working for you, your doctor will probably want you to try a different one. Most antidepressants cannot be taken together so you will need to stop the first one slowly and then start the new one. Talk to your doctor and key worker if you are finding it difficult to cope.

How long should I take antidepressants for?

·After you have fully recovered from depression, in general **you need to continue taking the antidepressant for at least another 6 months to prevent you from becoming unwell again.** For people who have had two or more episodes of severe depression, it may be better to take the antidepressant for much longer, at least another 2 years after getting better. Discuss with your doctor how long you should take your antidepressants for.

Here are some examples of common symptoms you may have if you are getting depressed:

- ❖ feeling low and tearful
- ❖ not eating
- ❖ not sleeping well, waking early in the morning
- ❖ feeling anxious

- ❖ becoming preoccupied with sad things
- ❖ feeling guilty about things that are not your fault
- ❖ finding it difficult to concentrate
- ❖ having thoughts of killing yourself

Mood Stabilisers

What are Mood Stabilisers?

Mood stabilisers are used to treat **bipolar affective disorder**, sometimes known as **manic-depression**. People with Bipolar affective disorder experience episodes of depression – feeling very **low** and lethargic, mania – feeling very **high** and overactive and times of having a normal mood. This can go on for several weeks or longer. Some people just have ‘highs’ and some just ‘lows’. When taken regularly, mood stabilisers can reduce both how badly and how often you get mood swings.

The medicines most commonly used as mood stabilisers are **lithium, anticonvulsants and antipsychotics**

How long do you take them for?

The mood stabiliser that works best for you needs to be taken long-



term. If you are high, you may also need to take additional medicines, e.g. antipsychotics to control the symptoms. If you are low, you may also need to take an antidepressant. Once you are well, the aim is to keep you well on just a mood stabiliser.

Lithium

If you are prescribed lithium, you should be given a **purple lithium patient pack** which has all the information you need to know about taking lithium, lithium monitoring and possible side effects. Ask your pharmacist for another copy if you need one.

Before you start you will have some blood tests to check your kidneys, thyroid and parathyroid gland are in good working order. You will have a blood test a week after starting to see what level of lithium is in your blood. Depending on the result, you may have your lithium dose (how many tablets you take) increased or decreased. You will have another blood test a week later to check the level is now right. If it is, **you will need a blood test every three to six months** to check the level stays the same. You will also need blood tests to check kidney, thyroid and parathyroid gland function at least every 6 months.

- If the level is too low, the lithium will not work properly

Some other medicines, including some that you can buy, can affect your lithium level so **always check with a pharmacist or doctor** before you buy other medicines or if new medicines are prescribed for you.

What are the side effects?

You may have some side effects when you first start taking lithium. Most are quite mild and usually wear off after a week or two. The most common side effects of lithium are tremor of the hands, stomach upset and passing a lot of urine or feeling very thirsty.

What can make lithium level get too high?

- Dehydration (can be caused by sweating in a hot climate, sickness and diarrhoea, having had too much alcohol)
- Big changes to the level of salt in your diet.

Speak to your doctor, you may need to have your lithium level checked.

If you have any questions or worries about your lithium treatment, talk to your doctor, pharmacist or keyworker.

Anticonvulsants

Some anticonvulsants (antiepileptics) are also used to help stabilise the mood. Examples are valproate, lamotrigine and carbamazepine. For more information about this group of medicines, speak with your doctor, keyworker, pharmacist or check any of the websites listed at the end of this chapter.

Antipsychotics

Antipsychotics are sometimes helpful when treating episodes of mania or to treat bipolar disorder in the long term. Please see the section on antipsychotics above for more information about antipsychotics.

Why should I take mood stabilisers?

Mood stabilisers can help you stay well in three ways:

- **Length of relapse** If you do have a relapse, mood stabilisers can reduce the length of time you are ill for.
- **Severity of relapse** If you have been taking a mood stabiliser, your relapse will be less severe than if you had not.
- **Frequency of relapses** You will be well for longer in between relapses and be ill less often.



People who have a bipolar illness often have the same symptoms at the start of each relapse. If you realise you are becoming unwell and tell your doctor early enough, they will be able to alter your medicines to prevent a full relapse. For example, if you are going high, your doctor is likely to prescribe an antipsychotic. It is not always easy to notice these symptoms if you become unwell very quickly. This is where your family and friends can help. If they know what to look out for, they can tell your doctor when they realise you are becoming unwell. Write up a list of the symptoms you get when you are becoming unwell with the help of your key worker.

Finally.....

Do not share your medicines with friends or family members.

Do not stop taking your medicines without discussing with your doctor as you may become very unwell.

Some medicines are affected by other medicines so always let your doctor, including your GP, know which medicines you are taking.

Useful websites

www.nhs.uk NHS Choices

www.rcpsych.ac.uk Royal College of Psychiatrists

www.rethink.org Rethink mental illness

www.mind.org.uk MIND

Clozapine and learning disabilities - setting up a bespoke clinic

Sarah Westrip, Senior Mental Health in Learning disability Nurse and Denzel Mafukidze, Community Mental Health in Learning Disability Nurse, Oxleas NHS Foundation Trust

This chapter will focus on how the community learning disability team set up a bespoke service for people with learning disabilities who are on clozapine treatment to help manage their mental health. At the time of setting up the clinic, the community learning disability team had 5 service users who were on established clozapine treatment.

Clozapine is an antipsychotic drug that is prescribed when other antipsychotics have not been effective in treating psychosis and can only be prescribed when 2 other antipsychotics have failed to be effective in treating their psychosis (NICE, 2014). Clozapine can cause neutropenia which is a condition where the number of neutrophils in the bloodstream are decreased, leading to a reaction in the body's ability to fight off bacterial infections. This can be life threatening which is why all service users on clozapine must be registered with a central database and undergo regular mandatory blood tests throughout their treatment.

Our outpatient pharmacy team have a specialist clozapine service to help support and manage these results in a timely manner and to also offer specialist advice when required.

In addition to the neutropenia risk, there are other side effects which are required to be closely monitored including severe constipation. This can also cause fatalities if signs and symptoms are not well managed and taken seriously as it can lead to severe bowel obstruction (Every-Palmer S *et al*, 2016). The other side effects include weight gain, tachycardia, postural hypotension, dysphagia, Gastrointestinal side effect, and anticholinergic side effects just to name a few. The list is very long and for this reason there is a need to ensure that the side effect management of this group of people is a priority to ensure their health needs are adequately met.

Problems prior to setting up the clinic

The service users used to go to a phlebotomy centre and then the bloods were sent via courier to a central database. There were occasions where blood results were not received in time and sometimes the bloods were lost in transit. This can affect medication as clozapine cannot be dispensed until the blood results have been read to ensure neutropenia risk is within the normal limits.

Service users and their families/support teams would also have to call and book a blood test every month which was not always the same time which caused problems with timely blood results. Our team also then had to carry out physical health checks at individual's homes as we did not have a base where the bloods were being taken. This also caused problems as there was only 1 professional screening monthly and did not allow much more collaborative working.

What did we need?

As a team we identified that we needed to ensure that we could better manage the risks and prevent potential fatalities from people with learning disabilities taking clozapine by making reasonable adjustments to ensure the right amount of time, easy read information and support is available to them and their families and carers (LeDeR, 2018).

We were able to secure a clinical area within our workplace to run a monthly clinic. This allowed us to allocate a 30-minute timeslot for our service users to go through everything in a timely manner to help ensure information was understood. The clinics are run with 2 healthcare professionals to ensure all information and tests can be conducted appropriately. We also needed to

386

build a rapport with the phlebotomy team to help them understand why we require reasonable adjustments for our service user group and explain how we can best support them with this. We were able to secure a meeting with the phlebotomy manager and lead phlebotomist and agreed on a monthly date for service user attendance, service users would be fast-tracked and have support from our team to have the bloods taken if required, we provided a folder with relevant information for each service user including blood stickers, database identity numbers, dates of all blood tests and our contact details. We also provided the team with a training pack about learning disabilities and clozapine management to support their team with adequate knowledge.

Once this working relationship was established, we were then able to develop the clozapine clinic protocol.

Every month, we agreed that all service -users who came to the clinic would be supported to have their routine blood tests at the stage of their treatment, and close physical health monitoring using an assessment chart for side effects which we adapted in an easy read version. They would also have their blood pressure, pulse, temperature, weight, waist measurement, active discussion around constipation and dysphagia and



advice/refer on accordingly. We also organise additional blood screening and cardio-investigations as appropriate in line with national guidance (NICE, 2014).

Health promotion is paramount to our monthly clinics, and we have ensured that easy read information has been made available with regards to physical health and clozapine management. We even adapted the main Antipsychotic side effect checklist known as the Glasgow Antipsychotic side effect scale (Waddell and Taylor 2007) to our own easy read version where we also adapted the questions to ensure dysphagia symptoms were also screened during every assessment. To ensure this self-rating tool was adapted to meet the needs of our service-user group to the best of our abilities, we had support from our specialist support worker in Mental health and learning disabilities who attends and has supported the development of the clinic and from our patient Communication and information lead from the Trust to develop it. We then sent it to a service - user group called the 'Can you understand it' team, who are a group of service users with learning disabilities who look at developed easy read material to give appropriate feedback to ensure the material is user friendly. Thankfully they approved our version, and it has been used all over the trust ever since, not just for people with learning disabilities. It is on our Trust website

388



foundation for
people with
learning disabilities

EST 1892

LSBU

NHS

Oxleas

NHS Foundation Trust



Penge Publishers

and sent to specific clinicians who express they require support in this field.

This allows us to routinely monitor side effects of medication in a format the service users understand and ensures that service users medications are reviewed regularly and are at the right dose which is in line with the Stopping over medicating of people with an intellectual disability (STOMP) agenda which was devised from Transforming care (NHS England, 2016).

Quality Improvement

Once the clinic was set up and had been running for over a year, we completed a quality improvement project. The project aimed to reduce incidences of constipation by 50% in our client group who use clozapine medication by March 2020, to improve our practice and service user health outcomes.

We discovered from our previous data that over eighty per cent of the people we were monitoring suffered from constipation likely because of taking clozapine. We identified this data using our adapted version of the Glasgow Antipsychotic Side-effects Scale (Waddell and Taylor 2007). When we identified this issue, we set out to significantly reduce the rate of constipation. During project planning and review of the literature we identified 3 main issues, lack of staff and client awareness, staff and carers had

limited guidance on how to manage constipation and lack of tools to assist with accurate monitoring of bowel habits.

To address these issues, we developed a training pack for staff and clients detailing constipation management and detection. We also developed easy read information leaflet for clients and carers including signs and symptoms of constipation. In addition, we provided carers with the Bristol stool chart (Lewis and Heaton, 1997) widely recognised chart used to monitor constipation. This tool was reviewed monthly in the clinic to review client progress and accurately detect constipation. Furthermore, we implemented client specific constipation guidelines for as required and regular medication. These guidelines were also sent off to the GP with recommendations for first line treatment and as required medication.

The End User Experience

To gain an understanding of how well our clinic was going, we decided to measure the success of our newly established clozapine clinic. We collected information about the clozapine clinic. We collected this information to find out what our service users, carers and families thought about the service and how it can be improved. We asked the following questions:



- 1. Were you happy with your monthly clozapine clinic appointments?*
- 2. Was the information given to you about the clozapine clinic easy to understand?*
- 3. Are you able to take your medication and go for your blood test?*
- 4. Do you know about the side effects of clozapine medication?*
- 5. Do you have help to fill in your black book/personal health profile after your clozapine clinic?*
- 6. Did you have enough time to discuss your health needs at your clozapine appointment?*

Most people answered yes to all the questions. The feedback was very positive from service users, carers and families. Mostly, they felt it was good to have physical health and side effects of clozapine medication monitored every month, and time to discuss any concerns they might have.

One of the carer's told us, 'This helps me to support my daughter and it makes me feel at ease'. Another family member told us 'A structured routine clinic is important for effective management of side effects and regular monitoring'. An individual with a



learning disability who uses the service told us, 'I like coming to the clinic to talk about my health with people who know me.'

We set up the clozapine clinic with the key purpose of providing quality, structured and personalised service that provides robust clinical monitoring, a focus on education, intervention and enhancing clinical outcomes for people with learning disabilities who take clozapine and those who support them. Research tells us that the clozapine medication is not used often due to various potentially life-threatening side effects and the lack of confidence from prescribers regarding its monitoring once prescribed (Joober and Boksa 2010, Kar *et al*, 2016).

Kar *et al*, (2016) highlight the need for a structured approach to monitoring clozapine and establishing a routine clinic as a primary solution to increasing confidence in its management. We found this to be true in our clozapine clinic. The clinic continues to thrive and most importantly the client's we serve are benefiting from regular and thorough monitoring of their treatment therefore improving their clinical outcomes.

What's next for the clinic?

We strive to continue to achieve high levels of service-user satisfaction through maintaining high standards of care,

392



foundation for
people with
learning disabilities

EST 1892

LSBU

NHS

Oxleas

NHS Foundation Trust



Penge Publishers

reflecting on current practice and looking at where improvements can be made. We shall continue to develop the clinic further and implement the changes we have made specifically from our constipation Quality Improvement project and ensuring our continuing professional development opportunities around constipation and other areas, particularly side effects related to clozapine remain up to date and current.

Dysphagia is another area which is very important in ensuring accurate assessment and intervention for those who take clozapine. We have been in liaison with our professional lead in Speech and language therapy around this subject area and have sourced ideas on how to further assess. This will be developed further over time.

Service-user involvement has been key to the success of this clinic so ensuring that we gain regular feedback and are responsive to ideas for change from the people who attend the clinic is paramount.

Lastly, we will ensure that learning and findings from our clinic are shared amongst the wider multi-disciplinary team to gain further feedback and to allow for a holistic approach to the service-users we support in order to deliver the best possible care.

References

Every-Palmer S, Nowitz M, Stanley J, Grant E, Mark H, Dunn H, et al. *clozapine-tested patients have marked gastrointestinal hypomotility, the probable basis of life-threatening gastrointestinal complications: a cross sectional study*. EBio Medicine, 2016.

Joober, R., & Boksa, P. (2010). Clozapine: a distinct, poorly understood and under-used molecule. *Journal of psychiatry & neuroscience : JPN*, 35(3), 147–149.

Kar, N., Barreto, S., & Chandavarkar, R. (2016). Clozapine Monitoring in Clinical Practice: Beyond the Mandatory Requirement. *Clinical psychopharmacology and neuroscience : the official scientific journal of the Korean College of Neuropsychopharmacology*, 14(4), 323–329.

<https://doi.org/10.9758/cpn.2016.14.4.323>

Learning Disability Mortality Review (LeDeR) Programme (2018) *Annual Report 2018*. University of Bristol.

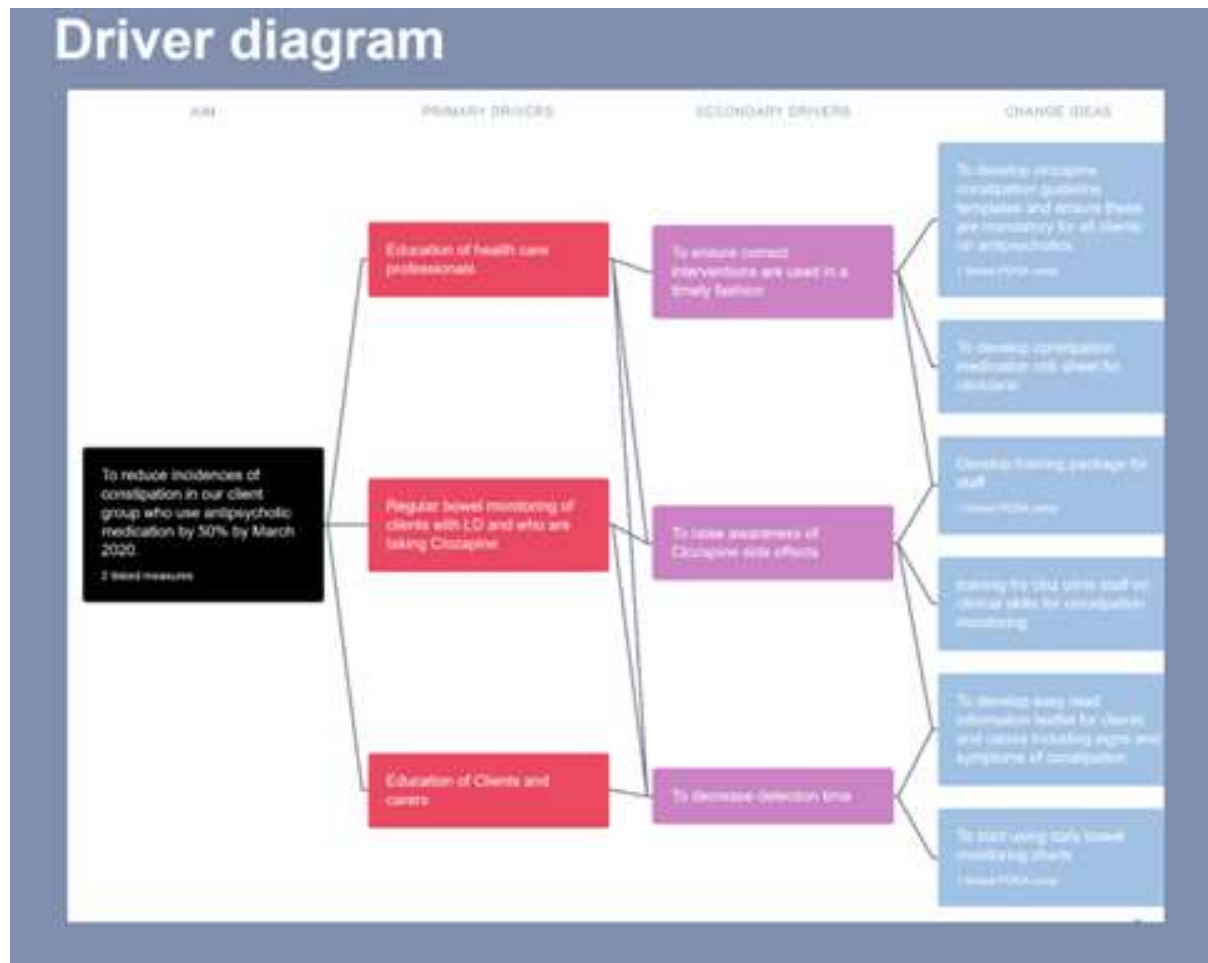
Lewis, SJ, Heaton KW (1997) *Stool form scale as a useful guide to intestinal transit time*. Scandinavian Journal of Gastroenterology 32: 920-4.

NICE (2014) *Psychosis and Schizophrenia in adults: prevention and management (NICE guideline)*. National Institute for Health and Care Excellence.



NHS England (2016) *Stopping overmedicating of people with intellectual disability, autism or both*. 2016.

Waddell L and Taylor M (2008): *Glasgow Antipsychotic side effect scale GASS*. *J Psychopharmacological* 2008 22 238.



Section 4 - Training

This section talks about some of the Services and treatments available within local services specifically for people with learning disabilities.



Pass it on – Training and peer mentorship for people with learning disabilities

Dave Mahon, Pat Charlesworth, Pete Allum, Christine Koulla-Burke and Eddie Chaplin

In 2018 the Foundation for People with Learning Disabilities received funding from the Big Lottery Fund to develop and deliver the Pass-it-on Project. The aim of the Pass-it-on Project was to provide the opportunity for people with learning disabilities to learn all about mental health and provide them with the skills to manage peer support groups and share what they have learnt – to Pass-it-on! It was intended to show that mental health peer support could be successfully delivered by people with learning disabilities and that this peer support would lead to positive outcomes for those that attended peer support groups.

The project focused on the positive ways we can stay happy and healthy. People learnt all about what mental health is, how we can all do things to support our mental health (the 5 Ways to Wellbeing), how we can support others, and how we can make positive plans for our mental health. There is also a Pass-it-on workbook to help support learning.



The project built on the Foundation's previous project about mental health 'Feeling Down'. This coproduced project



culminated in a guide for people with learning disabilities about mental health. It was developed with people with learning disabilities and the content was based on what people with

398

learning disabilities said they wanted. It featured sections about what mental health is, how to keep yourself well, what to do when you are feeling worried about your mental health, planning a visit to your GP and a GP information pack. The Guide is available at the Foundation's website www.learningdisabilities.org.uk.

We knew from research that people with learning disabilities are more likely to develop poor mental health than the rest of the population. People with learning disabilities can be particularly vulnerable to mental ill health for several reasons. This includes issues with poor physical health, socioeconomic factors such as poverty and a lack of meaningful opportunities (for example employment opportunities), a lack of support and the attitudes of some in the general population that can lead to stigma and discrimination.

Traditional mental health interventions for people with learning disabilities do not utilise the skills and experiences of people with learning disabilities themselves. Peer support groups in mental health are increasingly being recognised as a really good way to help people better understand how they are feeling, to help them feel less isolated and for sharing thoughts and ideas about how to manage their mental health. We wanted to show that peer



support in mental health for people with learning disabilities could be an effective way of supporting their mental health.

So how did the project work? The project followed a cascade model highlighted below.

Pass-it-on Teachers	Train the trainer People with learning disabilities are trained to lead Pass-it-on training sessions.
▼	
Pass-it-on Peer Supporters	Peer supporter training Pass-it-on Teacher supported to deliver six face-to-face mental health training sessions to people with learning disabilities and their supporters/workers. Those that complete the course become Pass-it-on Peer Supporters.
▼	
Pass-it-on Peer Support Group Members	Peer Support Groups Pass-it-online Peer Supporters and their supporter/worker co-deliver five workshop sessions to a peer support group in their local area.



Before the pandemic arrived Pass-it-on was delivered face-to-face. However, with lockdowns and social distancing, this was



no longer possible. Therefore, we adapted Pass-it-on so that it could be delivered online.

Delivery online presented its own challenges but advocacy and support organisations across the country worked hard in the early months of the pandemic to ensure that people with learning disabilities developed the skills to access video apps to help them stay connected to the people around them.

We found that the project had very positive outcomes for people who engaged with it. A common theme was that peer support groups provided a good outlet for people to talk about their thoughts and feelings. One peer supporter noted, 'People have felt isolated, connecting and talking has really helped'. A peer group member stated that, 'It's been hard so it's good to be able to talk about how you feel. Head like a cement mixer. Good to let it out, like air coming out of a balloon. Easy to bottle it up, that's not good'. Another peer group member commented, 'It helped me to talk about stuff. I'm glad I talked about how I felt. I was quite anxious, very anxious'.

The workshop materials also pose questions, such as ‘what is mental health’, and ‘What helps you when you are feeling down’. ‘People understood the course content and engaged in lots of conversations and discussions which was really good. The questions got people talking about mental health and what they think, which was great. Everyone had a lot to say about things and got involved. The conversations just grew and grew.

The project also had a practical effect on the behaviours of those that took part. The 5 Ways to Wellbeing encouraged people to talk about the kinds of things they could do, sharing thoughts and ideas. It helped some to try new things or rekindle old interests. One peer group member talked about how these discussions had encouraged her to take more exercise and to try cooking healthier meals. Another peer group member talked about how what he had learnt helped him to support a friend who was going through a bad time.

A peer supporter told us that the learning and responsibility of running a peer support group had had a significant impact on her mental wellbeing, encouraging her to revisit cognitive behavioural therapy and noting that she had been more able to support her own mental health without support from her local



mental health team. She talked about how leading the sessions had made her feel good about herself and that she had been doing more meditation. She told us that, 'Since training and since delivering sessions, I have been managing my mental health much better'.

All of the people we spoke to were supportive of peer-led mental health support by people with learning disabilities for people with learning disabilities. Peer supporters noted that their life experiences were valuable because they could relate to peer group members and visa-versa. They also spoke about the value of peer supporters as role models and leaders, how the responsibility of leading sessions had helped to build confidence. They felt that as role models it would encourage people to do more.

Peer group members echoed these sentiments, 'They can share experience and say how they got through. They know what it's like so it's better. It's important that we can speak for ourselves. S (peer supporter) knows what it's like, she's the same as us, it's about us. She knows what bothers us so it's better. Another peer group member put it simply, 'If it's about learning disability then it should be run by someone with a learning disability.

Our initial findings are really positive. They suggest that peer support in mental health for people with learning disabilities works and that it has lots of positive benefits for all involved. Although the funded part of the project is now over we are continuing to make it available and collect data and information to help strengthen these conclusions.

During the project we were able to train 33 people with learning disabilities and their supporters to become Pass-it-on Teachers or Pass-it-on Peer Mentors. They in turn were able to pass on what they had learnt to around 150 people through peer support groups in their local area. Peer support groups took place across the country with sessions taking place in London, Sussex, Dorset, North-East, Oxfordshire, Gloucestershire, Cheshire, Yorkshire and Kent.

Peer support across a range of areas is becoming more and more common for people with learning disabilities and we feel this should be encouraged. 'Nothing about us without us!'



Pass-it-on >>>

Pass-it-online

ACTIVITY BOOK



YOUR NAME _____



EST 1892

LSBU



Oxleas

NHS Foundation Trust



Pass-it-online

Session 1:

What is mental health?



407



EST 1892

LSBU



Oxleas

NHS Foundation Trust



>> My Staying Healthy Plan

The 'My Staying Healthy Plan' can help you think about how to look after your mental health.

In it you can write down all the things that make you feel good and happy. The example below shows you how to fill the plan out.




The plan can remind you to keep doing these things and help to stop you from feeling low or down in the future.

In the first box think about what you will do.

In the second box think about when you will do it.

In the third box think about who you could get to help you.

My Staying Healthy Plan - Example

 What will you do?	 When will you do it?	 Who will help?
<ol style="list-style-type: none">1. Relax by going to relaxation class2. Go out with friends for coffee3. Talk to my sister as it makes me feel less anxious when I talk to her4. Tidy my room. Open the window in the morning to let some fresh air in. Put an air freshener in the room. This will help me sleep better5. Go to the GP this week to talk about how I am feeling and about not sleeping.	<ol style="list-style-type: none">1. Once a week2. Once a week3. Every evening4. Once a week5. This week	<ol style="list-style-type: none">1. Jane will help me2. My friends3. My sister4. My support worker5. My sister

Mindful seeing



- It's very easy to go about our busy lives without really noticing the world around us.
- It can be relaxing to take a moment to look at the things around us.
- Becoming more aware of the present moment can help improve our mental health.



Instructions

1. Next time you go for a walk find one thing to really look at.
2. It could be a flower, a building, a picture. Anything.
3. Stop for a few seconds.
4. Look at the shape of the object. Look at its outline.
5. Notice the light and the shadow. Is it rough or smooth? Look at all the different colours.
6. Now notice how your attention has been captured by this one part of the world around you.
7. Now look around. Look at all the other things around you. You could even try it at home!

25

Slide 7: What does mental health mean to you? (15 mins)



How to do it

- Ask the group:
 - 'When you hear the words 'mental health', what does it make you think of?'
 - 'What does it mean to you?'

[Let the group talk about what 'mental health' means to them. Do they see it as a bad thing?]

Remember our mental health is about all of the different ways that we think and feel. Sometimes our mental health is good and we feel positive, other times we may feel a little down so our mental health is not so good, and sometimes we are somewhere in between.

You may want to ask the group some questions like these:

- Is mental health a bad thing?
- Do you think we can do things to help ourselves to stay happy and healthy? What kinds of things could we do?
- Do you feel uncomfortable talking about your mental health? (Talking about how we feel with other people can help us make sense of our thoughts and feelings)]

8

What are the 5 ways to wellbeing?



Stay connected



Be active



Be aware



Give to others



Keep learning

Pass-it-online

How could we help someone if they were feeling down, worried or depressed?



Pass-it-online



Estia Centre - a specialist training in mental health support for people with a learning disability and autistic people

Ruwani Ampegama and Karina Marshall-Tate with quotes from people with lived experience and clinical colleagues

In this chapter we introduce you to the Estia centre and give detailed insights into its vision, missions and value-based activities.

Introduction to the Estia Centre

The Estia Centre is an integral part of the Behavioural and Developmental Psychiatry Clinical Academic Group (CAG) at the South London and Maudsley NHS Foundation Trust (SLaM), part of King's Health Partners AHSC and sits within the Health Services and Populations Research Department at the Institute of Psychiatry, Psychology and Neuroscience at King's College London.

The Estia Centre functions as a training, research and development resource for staff who support adults with a learning disability and additional mental health needs and as part of the National Autism Unit for those staff that support autistic

412



foundation for
people with
learning disabilities

EST 1892

LSBU

NHS

Oxleas

NHS Foundation Trust



Penge Publishers

people. The Centre is widely acknowledged as one of the market leaders in mental health and learning disability training and research.

We understand the value of the life stories of people with lived experience to influence and develop the health and social care workforce. We aim to deliver high quality and consistent learning and development through a process of training delivery, quality monitoring, and evaluation, and through the provision of ongoing support and supervision to our clinician colleagues and experts through experience. Everything we do is grounded in the latest legislation, policy and evidence-based research.

Estia centre is a Skills for care Endorsed training provider and is a C&G Quality Assured centre.

Estia centre is focused on partnership working in all its activities as seen below in the vision, mission and values.

Vision statement

Learning together to create healthier lives for people with learning disabilities and autism.

413

Mission statement

We work in partnership to inspire a committed, passionate and competent workforce through quality driven, evidenced-based learning and research.

Values

1. **Working together** - We are better and stronger when we recognise our differences and work in partnership.
2. **Promoting good practice** – We lead by example to inspire and empower.
3. **Inclusive** – Through coproduction we support everyone to contribute and achieve their full potential.
4. **Evidence-based** – We aim for continuous improvement through quality assured practice, research and evaluation

Historical context

Following the introduction and implementation of the Community Care Act 1990 many of the long stay institutions where people with learning disability lived were closed. A New model of community living was introduced, supporting people with a learning disability to live in their own homes in their local

community – to live ‘An ordinary life’. At the time a group of mental health professionals who worked in South East London community learning disability services noticed that there was a gap in awareness and understanding about the mental health and behavioural needs of some adults with a learning disability. To address these gaps in knowledge and equip residential staff with the skills needed to support people well, these multi-professionals proposed a strategy to develop a specialist service to design and deliver training based on emerging research and clinical practice in the field. In 1999, the Estia centre was set up as an adjunct to the Mental health in Learning Disability Team (MHiLD) to bring together a programme of research informed training and service evaluation.

The Estia Centre led the way nationally and internationally in researching and evaluating new service models and psychiatric treatments for adults with a learning disability and supporting evidence-based practice across MHiLD. In 2020, the Estia centre expanded its activities to include autism in collaboration with the National Autism Unit at South London and Maudsley NHS Foundation Trust. The Estia centre continues to thrive as a specialist learning and development centre about learning disability and autism. It currently employs clinical and teaching



staff and academics as well as a permanent substantive post employing a person with a learning disability and lived experience of using mental health services as a learning disability training facilitator.

Why provide specialist mental health training in autism and learning disability

Specialist mental health training in autism and learning disability is essential. It provides clinical and support staff with the required knowledge, skills and values-base to enable the most effective assessments, treatments and interventions to support people with a learning disability, autism or both experiencing mental illness.

We know that people with a learning disability and autistic people can experience higher rates of mental illness and mental health difficulties than the wider population. We also know that accessing mental health services can be challenging for many. These challenges have multiple origins, but many are based on poor systems and assumptions and stereotypes and the values base of health professionals. Co-produced training for health professionals has a limited but growing evidence base with early indicators suggesting that it has the potential to improve health

416



foundation for
people with
learning disabilities

EST 1892

LSBU

NHS

Oxleas

NHS Foundation Trust



Penge Publishers

professionals' knowledge, values and confidence to work with people with a learning disability and autistic people. However, we also know that many organisations struggle to meet mandatory training targets and that staff can quickly become fatigued by constant training demands. Indeed, across our own roles and jobs, we have probably all felt at times like training takes up an inordinate amount of our working time – endless mandatory training when we've got 'actual work to do' - telling us things that we already know or that we quite possibly don't need to know. There are even some experts who say that training does not work! So, with this in mind how do we ensure that the training that we develop and deliver will achieve what it sets out to and that it will make a difference?

The purpose of training – a personal reflection

I remember being struck by a piece of information from a lecture whilst doing my nurse training – it went something like 'in our professional life we will only ever know about 50% of what we need to know. Now figure that to pass your exams you only need to get 50% which would mean that if you passed at 50% then in reality you would only know 25% of what you are supposed to know'. I was perplexed by this statement - my petulant 19-year-old-self thinking '*Well what on earth are we were all doing in this*



lecture theatre then?’ - and it has stuck with me ever since. It is this that brings me full circle – training and education clearly do make a difference and we retain information, knowledge and skills throughout our lives – even the useless bits (which I can assure you at some point in our long lives will turn out not to be - see how I’ve remembered this and now I’m using it). Whilst it has little bearing on my daily life as a Registered Nurse, it tells me about the value of knowledge and training and how creating intrigue and thinking long-term is key to success. Therefore, when I am developing and delivering training, I must think: how will it relate to and improve the trainees' daily working lives? What will inspire them? How will it improve the lives of people with a learning disability and crucially, if the trainees are only going to remember 25% of what I say then what is the take home message that I want them to remember in 5, 10, 20 years' time?

So, while our professional lives are filled with training and it can feel burdensome, it is there for a reason. That reason sadly is usually because of a failing in healthcare that has led to an adverse event or an avoidable death that we want to prevent from happening again. We are all too familiar with the list of reasons why training about the mental health needs of people with a learning disability and autistic people is required and we



won't repeat them here. But the reasons are multiple and nuanced and can be broadly grouped into the following:

- Indifference
- Discrimination
- Systemic barriers
- Lack of knowledge and skills
- Failure to share information
- Failure to adhere to the law (Human Rights Act, Equality Act, Mental Health Act, Mental Capacity Act)
- Failure to listen to families and paid carers
- Higher levels of co-occurring physical and mental illnesses across the lifespan

This last point is significant because delivering training that can help health staff to recognise unmet health needs and prevent diagnostic overshadowing (where an illness is not diagnosed because clinicians assume the presentation is due to the disability) will ultimately lead to quicker diagnosis, better treatment outcomes and better experiences of health services for people with a learning disability and autistic people.



The research tells us that there are higher levels of mental illness amongst this population and that those living with mental illness are more likely to die prematurely from medically avoidable causes. This doesn't have to be the case. But how do we promote training uptake to our mandatory training trained out colleagues? Targeted training that is co-produced can change clinicians' knowledge, skills and values-base for the better. Working with experts by experience through co-production demonstrates that we live by our values –that we practice what we preach – and smashes preconceived ideas and stereotypes out of the ballpark. The power of hearing stories directly from those affected means that what we are saying is more likely to be retained and acted upon in the future. This is the message that we want our trainees to remember in 5, 10, and 20 years' time.

How do we deliver that message?

We at the Estia Centre are constantly exploring ways of delivering training to staff that will have the highest impact on their practice; ultimately resulting in better services and experiences for people with a learning disability and autistic people. We will now describe some of those training initiatives.



1. Learning Disability simulation training

Clinical simulation training is increasingly being used as an education tool across healthcare services and Universities. Simulation enables students and clinicians to be exposed to clinical situations in a real-life manner but within the safety of the classroom. It allows for experiential learning and a safe environment to test out new clinical skills without risk to patients. Skilled facilitators use a combination of teaching and reflective practice to aid trainees' development of knowledge and skills. Involving people with a learning disability as simulated patients and co-producing content based upon real life experiences and research about health inequalities has been paramount in the Estia Centre's collaboration with Maudsley Learning and the Baked Bean Theatre Company to develop and deliver learning disability simulation training. Simulation training with actors with a learning disability has been developed and delivered to clinicians across health services from GPs and pharmacists to psychiatrists and registered nurses across all fields of practice. Evaluative work has shown that trainees' confidence, knowledge and skills increased after the training however long-term follow-up to establish behaviour change has not been possible. The actors also valued their role as paid colleagues who were able to influence and the change the practice of health staff – totally

‘turning the tables’ as one actor put it - in terms of power dynamic. We have now expanded this to providing Simulation training on autism with autistic actors from Access All Area.

2. Bespoke learning disability and autism training

In addition to the prospectus training, Estia centre partners with organisations such as the National Autism Society and other local and national organisations, designing and delivering bespoke training to local, national and international organisations.

Some examples of these include learning disability related topics, to local nursing homes, specialist day facilities, day resource centre, residential homes, simulation training local universities and national provider organisations.

Autism related topics Kent & Medway NHS Services, NEFLET, Croydon university Hospital

Quote from an autistic facilitator on partnership working

“Then in 2017 I met RA who is exceptional and who is always keen on listening, when she doesn’t know. This is SO refreshing and can only come from a person who is confident in her own skin, and not overcome with hubris like many unfortunately still

422



foundation for
people with
learning disabilities

EST 1892

LSBU

NHS

Oxleas

NHS Foundation Trust



Penge Publishers

are. RA has treated me like a fellow human being, a colleague, someone with value. Our relationship is respectful, free of anxiety, and based on mutual trust. Working in co delivering training is paramount for the success of service improvement for autistic people, but not just in co-production. If the autistic person, or person with lived experience is paired with someone who uses their “power” to make unilateral decisions, it is just going to be a pointless exercise. Think of it like a magnificent recipe in theory. If you use substandard ingredients, you will not obtain the best dish, will you? So it then becomes a vicious circle.”

3. National training and projects

Health Education England funded Autism Pilot- Co-produced Train the Trainer for adult inpatient mental health services. Estia centre in collaboration with the National Autism Society and Maudsley Learning successfully co-designed and co-delivered a 4-day Train the Trainer programme.



Quotes from participants that attended the pilot training include:

“Experts by experience - gaining insight into experiences from autistic people themselves is really important and helpful.”

“I enjoyed having a lot of time to reflect, discuss and share experiences, this really facilitated a deeper appreciation and learning for me”.

“Opened my eyes to new areas of practice and made me think about what we are currently doing on the ward and how we can improve”

“I thought it was good there were different trainers from different backgrounds, e.g., NAS, experts by experience, to give different perspectives.”

National Learning Disability Death Review (LeDeR) – Coproduction team member: This funded nationally represented group of people with learning disability and autistic people meet online once a month to discuss deep dives (these are specialist illnesses or topics that have been highlighted in the report e.g., diabetes) and to engage with other people in finding ways of

424

improving the health of Learning disability and autistic people. This group is led by Kingston University and includes Foundation for People with Learning Disabilities (FPLD) and Pathways Associates. This group has just produced an excellent easy read version of the 2021 LeDeR report including a video version for wider access to the important points raised in the main report. This has been rated excellent by NHS England.

Quotes from group members include:

“I am so shocked at the number of deaths recorded for people with learning disability and other people from COVID, it made me cry”

“I am happy to be part of this group and we can do things that will make a difference to people with learning disabilities dying too young”

“It is good to meet with everyone once a month to talk about how we can make things better for people”

“It was nice that we all got support to take part in the video”



SE regional LeDeR service evaluation funded by Health Education England Kent, Surrey, Sussex intellectual disabilities programme and carried out in partnership with Maudsley Learning explored how LeDeR reports are shared, and objects set for practice improvements in relation to the report findings within SE regional Integrated Care teams.

4. Yearly prospectus training

The Estia centre has a yearly rolling prospectus of training. This is the training that is delivered to local care providers to support the treatments, interventions and behaviour programmes being implemented through the clinical MHiLD teams. This relationship between specialist education providers, clinicians and paid carers stems from the origins of the Estia Centre. The rolling prospectus training is divided into 3 modules. Each module contains learning disability related topics which are created through demand and the translation of novel research evidence into daily practice.

Module 1 workshops are aimed at staff that are new or have limited experience working with people with a learning disability.

Module 2 workshops are aimed at staff with substantial experiences working with Learning disability

Module 3 workshops are aimed at staff working in supervisory or managerial roles

All workshops are co-designed and co-delivered by subject matter expert clinicians and with input from people with a learning disability.

The training is tailored to different learning styles combining practical and experiential learning opportunities with more traditional teacher led material. The voices of people with a learning disability and autistic people are included in different ways for example, there are films of people sharing their lived experiences, individuals coming and delivering training with clinicians, individuals giving permission to use their stories as case scenarios in training.

International links/activities

Presenting at the European Association of Mental Health and Learning Disability international congress

427



foundation for
people with
learning disabilities

EST 1892

LSBU

NHS

Oxleas

NHS Foundation Trust



Penge Publishers

2017 runner up prize for Poster presentation of learning disability simulation training.

2021 presenting the reasonable adjusted employment project employing a person with learning disability at a co-produced symposium.

MB our training facilitator with lived experience said, ***“I really enjoyed talking at the Berlin conference, it made me feel good, many people who listened also asked me questions about how I got the job and how, I managed in the lockdown and working from home.”***

5. Publications

In 2020, Estia centre in collaboration with London South Bank University revised and published through Pavilion a training pack on Introduction to health and Mental Wellbeing for staff Supporting Adults with Intellectual Disabilities.

‘Reasonably adjusted?’ employment project

This project, funded by the Health Education England Kent, Surrey, Sussex intellectual disabilities programme, enabled the Estia Centre to provide a targeted co-produced training programme for colleagues in Adult Mental Health Services

(AMHS). Over a period of 12 months, we were able to make reasonable adjustments to HR processes to enable the employment of an expert by experience to join the team to co-produce and co-deliver training about learning disability across our AMHS services.

We developed training materials and tested their effectiveness with 8 cohorts (average 20 participants per cohort). The evidence shows that they found the training to be helpful, that it increased participants' skills, confidence and motivation to provide good care and treatment for their patients with a learning disability. We also produced an accompanying good practice guide called 'Reasonably Adjusted?' that colleagues could refer to when thinking about the types of reasonable adjustments that they need to make at various key points across a patient's journey in AMHS. The value of this work has been recognised within our organisation which has now enabled Estia centre to create a permanent post for an expert by experience with a learning disability. Our expert by experience has this to say about the project and her work:

“I was very nervous coming to the interview as there were four people interviewing me. But I recognised some of them and they all made me feel relaxed.”

“I am very happy with my job, but it was hard when lockdown made us stay at home. When I got the iPad, it was much better and easier for me to learn how to use it to work from home and do training online.”

“In my job I can do many things like training, joining groups, interviewing staff and many other things, I am happier now to speak to large groups of people because I have done it many times.”

We at Estia centre are all very excited about not just supporting our current expert by experience training facilitator’s development but looking to how we can build upon this success. We would like to create more employment opportunities for people with a learning disability and autistic people and support our colleagues in adult mental health to develop their knowledge and skills in this area thereby reducing health inequalities on multiple levels.

Learning disabilities autism education and training needs to be developed that can address the knowledge, skills and attitudes that healthcare professionals require to provide effective care and treatment to learning disability. A blended approach that includes the co-design and co-delivery by people with a Learning disability is likely to be the most effective particularly as contact people with a learning disability is known to promote positive attitudes amongst healthcare professionals.

So, if you are going to remember only 25% of what we have said in this chapter, which 25% should it be? What do we want you to remember in 5, 10, or 20 years' time? With the right support people with a learning disability and autistic people can and do achieve great things. That we are not asking for everyone to be a specialist, simply that we all take the time to understand a person's learning disability or autism, that we value their contributions and that we make reasonable adjustments to ensure equitable health outcomes and experiences. Involvement and co-production enable us to achieve all these things and if we can get that right then everyone else will benefit!



Section 5 – Easy read

This section includes resources and information leaflets in easyread about looking after our mental health.



About Mental health



Sometimes things can happen that make us sad

These things can include

- falling out with friends
- being bullied or abused
- losing someone special



Sometimes it is because things we are used to change - like

- moving home
- a friend moving away
- losing a job



When we are sad

- We might feel down or stressed
- We might feel nervous or worried.
- Most people feel like this for a little while.
- Most people get back to normal quickly.
- When this happens it is called a mental health problem



Eat



Mental health problems can make us do things differently

These are some of the things that might happen.

- The person might eat more or less
- The person might sleep more or have trouble getting to sleep
- The person might not enjoy activities anymore.
- The person might feel anxious and worry a lot
- The person might not talk to their friends or family
- The person might spend more time alone
- The person might feel tired all the time
- The person might have strange thoughts in their head



There are different types of mental health problems. Two of the most common are

- Anxiety
- Depression



You should see your GP if you have been feeling sad or worried for a while

The GP will try to help and may offer

A professional to talk to or offer medication



if you need more help. They might send you to see a mental health professional like a

- psychiatrist
- psychologist
- counsellor
- nurse
- social worker

People with mental health problems can get better



What happens in the assessment?

The professional will find out what is wrong by asking you questions about how things have been and find out more about you

Before having the assessment you should think about what you are going to ask



Some of the things you can tell the professional are:

- how you are feeling
- any problems you are having and when they started
- if anything bad has happened
- any changes in your life
- how you have been sleeping and eating
- if you have been missing your normal activities
- any medications you take



Talking to other people

The professional might need to get more information.

They might talk to other professionals that you have seen.

They might look at records or reports about you.

They might want to talk to your family or carers



Remember

It might feel like the professional is being noseey



But they need to know a lot about you so they can give you the right support

Don't forget you can ask the professional questions as well



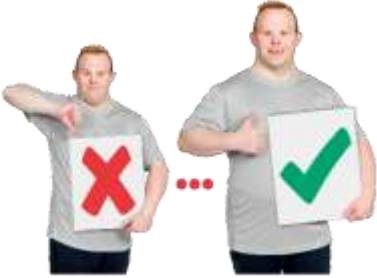

If you feel anxious about the assessment you could take someone along with you

Depression

	<p>Everybody gets sad or down sometimes</p> <p>People might feel sad for lots of different reasons, like</p> <ul style="list-style-type: none">• falling out with friends• losing someone special• being bullied
	<p>Most people feel better after a little while</p> <p>Some people might feel sad for a longer</p> <p>When this happens, it is called depression</p> <p>Depression is a type of mental health problem</p>
	<p>People who have depression don't feel the same as usual. They feel different</p> <ul style="list-style-type: none">• They might feel sad• They might lose weight• They might not want to do activities they enjoy

	<ul style="list-style-type: none"> • They might feel tired all the time and have trouble sleeping
	<p>People with depression can get help</p> <p>If you have been feeling sad or down for a while, you should tell someone</p> <p>You should make an appointment with your GP.</p>
	<p>The GP is there to help.</p> <ul style="list-style-type: none"> • They might send you to a counsellor or mental health professional • They may also give you medication <p>A counsellor will talk to you about your problems.</p> <p>They will help you cope with your problems.</p> <p>If depression lasts a long time the GP might ask you to see a psychiatrist.</p>

Anxiety

	<p>Anxiety is when you feel nervous or worried</p> <p>Everybody gets anxious or worried sometimes</p>
	<p>You might feel anxious when:</p> <ul style="list-style-type: none">• you meet new people• you go for a job interview• if you get lost• if you are late for something• if you are in a crowded area
	<p>Feeling anxious is normal</p> <p>Feeling anxious usually goes away quickly</p> <p>When you stop feeling anxious you feel normal again</p>
	<p>But for some people anxiety can be a problem and feel very scary</p> <p>Some people get anxious a lot</p>

	<p>Some people might not know why they are feeling anxious. Anxiety can stop people from doing what they normally do, like their activities.</p> <p>When this happens it is a mental health problem</p>
	<p>People feel differently when they are anxious</p> <p>Some of the things you might experience are</p> <ul style="list-style-type: none"> • feeling dizzy • sweat a lot • breathing faster • heart beating faster • feeling sick • needing to use the toilet more than normal • getting headaches
	<p>People with anxiety can get help</p> <p>If you have been feeling anxious for a while, you should tell someone</p> <p>You should make an appointment with your GP</p>







The GP is there to help.

- They might send you to a counsellor or mental health professional
- They may also give you medication




A counsellor will talk to you about your problems





They will help you cope with your problems

Good mental health

	<p>Having good mental health is important</p> <p>Having good mental health helps you get on with your life</p>
 	<p>There are lots of things you can do that are good for your mental health</p> <p>These things can help you stay well</p> <p>exercise</p> <ul style="list-style-type: none">• talking to someone about how you feel• keeping busy in the daytime• eating healthy food• doing things you enjoy• having a social life• getting enough sleep and rest• relaxation
	<p>You could include some of these activities in your weekly timetable</p> <p>If you do these things it might stop you from becoming ill</p> <p>Everyone worries sometimes</p> <p>If you are worried you should tell someone you trust about it</p>

Relaxation

	<p>Everyone gets stressed and worried sometimes. It is part of life</p> <p>There are things you can do to help yourself when you feel stressed or worried</p> <p>Finding something that relaxes you is good for stress and worries.</p>
 	<p>Relaxation is good for your mental health</p> <p>Relaxation is different for everyone. Some things people do to relax:</p> <ul style="list-style-type: none">» going for a walk» having a bath» reading a book <p>Think about what you can do to relax</p>

	<p>Try a relaxation exercise</p> <p>Sit down or lie down in a relaxing position</p>
 	<p>Make sure the room is relaxing. There are no bright lights</p> <ul style="list-style-type: none"> • It is quiet • It is not too cold • It is not too hot • Make sure you will not be disturbed • Play some relaxing music • Take deep slow breaths <p>Think about something that makes you happy</p>
	<p>Spend some time each day relaxing. You could ask someone to help you make a relaxation plan</p> <p>You can write down your plan and follow it each day</p> <p>You can use your relaxation plan when you feel stressed or worried</p>

Exercise



Exercise is good for your mental health
Exercise can make you feel happy
Exercise can help keep you fit
Exercise can give you more energy
Exercise can to concentrate better



Exercise helps you sleep better
Exercise can help you lose weight



At first make small changes

There are some small changes you can do that can help like

- going on short journeys walk instead of taking the bus
- walking up the stairs instead of taking the lift



You should try to do exercise at least 3 times a week

There are lots of different types of exercise

- going for a walk
- swimming
- going to the gym
- jogging
- cycling
- keep fit classes



Find an exercise that you enjoy and make time to do it
You could exercise with a friend

If you have not exercised before you could visit your GP for advice



Planning exercise

Ask someone to help you plan your exercise

Make sure it is something you like doing



Think about the exercise you want to do

Put the exercise in your weekly timetable







Things you need to think about and put in your exercise plan


- Where can you do the exercise
- Do you need any equipment for the exercise
- What help do you need to do the exercise
- Do you have to pay for the exercise

Healthy eating

	<p>Eating a healthy diet helps us stay well</p> <p>Eating a healthy diet is good for your mental health</p> <p>Having a healthy diet is about eating the right foods</p> <p>Having a healthy diet is about drinking the right drinks</p>
	<p>Some foods are good for you. Fruit is good for you like apples, oranges, pears, plums and bananas</p> <p>Vegetables are good for you</p> <p>You should try to eat fruit and vegetables every day</p>

	<p>Other foods that are good for you are</p> <ul style="list-style-type: none"> • brown rice • brown pasta • wholemeal bread • grilled or baked fish • salads
	<p>Some food is bad for you if you eat it all the time.</p> <p>You should only eat these foods every now and again</p>
	<p>Too much fat is bad for you. Foods with lots of fat in are fish and chips</p> <ul style="list-style-type: none"> • or crisps • butter • cheese • eggs <p>You should only eat these foods every now and again</p>

	<p>Too much sugar is bad for you. Food and drink with lots of sugar in are</p> <ul style="list-style-type: none"> • sweets • chocolate • fizzy drinks • cakes • biscuits <p>You should only eat food with lots of sugar every now and again</p>
	<p>Drinking lots of water is good for you. Drinks that you should only have now and again are</p> <ul style="list-style-type: none"> • tea and coffee • fruit juices
	<p>People can drink alcohol to relax and to socialise with friends</p> <p>But drinking too much alcohol is bad for you</p> <p>Drinks that have alcohol in include</p> <ul style="list-style-type: none"> • Beer • lager and cider

	<ul style="list-style-type: none"> • wine • spirits like vodka-whisky-gin-rum <p>Drinking too much alcohol is bad for your mental health</p> <p>You should only drink alcohol a few times a week</p> <p>You should not drink more than a couple of alcoholic drinks in one go</p>
	<p>Mealtimes and portions Eating at regular times helps with healthy eating</p> <p>You should have:</p> <ul style="list-style-type: none"> • breakfast • lunch • dinner <p>You could have a snack in the morning and the afternoon</p> <p>Try and pick a healthy snack like a piece of fruit</p>



Think about the size of the meal you are eating

You could write a weekly meal plan. See if someone can help you write the plan

Your meal plan should include lots of healthy foods and only a few of the other foods



If you need help with your diet there are lots of places where you can get information

You could ask:

- a practice nurse at your GP surgery
- Ask to see a dietician

If you are overweight and would like help, you can see your GP

The GP can give you advice and support

Sleep



Sleeping for 8 hours every night is good.



Time

Things that help you have a good night's sleep are

- going to bed at the same time every night
- getting up at the same time every morning
- doing some exercise in the daytime
- having clean bed linen
- make your bedroom nice and comfortable
- make your bedroom not too hot or too cold
- doing something relaxing in the evening, like having a bath
- having your dinner early in the evening, before 8 pm
- having a milky drink before bed
- if you are worried about something tell someone before you go to bed
-





Things that you should not do:
don't sleep in the daytime.
some drinks can keep you awake
at night. You shouldn't drink these
in the evening. Some of these
drinks are:


- tea
- coffee
- cola
- energy drinks.
- try to avoid drinking alcohol.

If you are regularly having trouble
getting to sleep, see your GP

Information about medicines

Can You Understand it? Team Oxleas NHS Foundation Trust

	<p>People with mental health problems need help to get better.</p> <p>Some people will be given medicines to help them get better. Medicines can only be given by a doctor. Sometimes a nurse will be allowed to write a prescription</p>
	<p>The doctor will tell you:</p> <ul style="list-style-type: none">• what the medicine is called• what the medicine is for• when you should take the medicine• how long you should take the medicine• if the medicine can make you feel unwell. We call this a side effect.• what may happen if you do not take the medicine <p>After telling you about the medicine the doctor will ask you if you want to take it. This is called getting your consent.</p>

	<p>It is important to keep taking your medicine until your doctor tells you to stop.</p>
 	<p>About your medicine</p> <p>Your medicine has different names. You can ask your doctor or chemist about these names.</p> <p>Your medicine can be a:</p> <ul style="list-style-type: none"> • tablet • capsule • liquid • injection <p>Your medicine can also be in different colours and sizes.</p> <p>If you are worried about your medicine, please speak to your doctor.</p>
	<p>Important information to remember</p> <ul style="list-style-type: none"> • Check how much medicine you should be taking • Take your medicine at the time it says • If you start to feel unwell when you take your medicine tell your doctor straight away.



Getting your medicine from the chemist

- It is important to check you have the right medicine when you get it from the chemist.




Ask if they have any easy read information about the medicine

- Ask if they have information in pictures.
- The chemist is there to help you with your medicine
- Your medicine may be in a blister pack if you find it difficult to take your medicine.
- The blister pack will tell you when you need to take your medicine

It is important that you know about the medicines you are taking.

It is about your mental health and keeping well!!




My Mental Health Care Plan

Name:		DoB: dd/mm/yy		RiO number:	
			Date of care plan		
			Updated		
<div style="border: 1px solid black; padding: 5px; width: fit-content; margin: 0 auto;"> Photo of staff </div>			<i>I am seeing</i> <i>from the Bromley Mental Health Team</i>		
			<i>I need help with :</i> <ul style="list-style-type: none"> • • • 		

Reviewed by the Can you understand it? team

Nov 2017

My Plan

	<p style="text-align: right;"><i>My medicines</i></p> <ul style="list-style-type: none"> • .. • .. • ..
	<p><i>Things I can do to get better</i></p> <ul style="list-style-type: none"> • .. • .. • ..
<div style="border: 1px solid black; width: 100px; height: 100px; margin: 0 auto; display: flex; align-items: center; justify-content: center;"> <div style="border: 1px solid black; width: 60px; height: 40px; display: flex; align-items: center; justify-content: center;"> <p style="font-size: 8px;">Photo of staff</p> </div> </div>	<p><i>Who I can talk to if I need more help</i></p> <ul style="list-style-type: none"> • .. • .. • .. <p style="text-align: center;">  <i>Phone number</i> </p> <p>.....</p>

Please tick the box

I am happy with my careplan

Yes No

I understand my careplan

Yes No

I agree to share this with people involved in my care

Yes No

Name

Date: / /

Checking side effects from antidepressant medicines

Please give us the following information

Name:		Age
Male <input type="checkbox"/>	Female <input type="checkbox"/>	Date

Please write down the medicines you take and how much each day






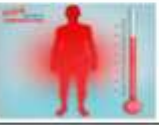



.....









.....

.....




We want to find out if the medicines you take are making you unwell. We call this side effects.

	over the past 2 weeks	Never (0)	once a week (1)	a few times (2)	every day (3)	tick <input checked="" type="checkbox"/> if it upsets you
	I feel more sleepy					
	I have had headaches					



	over the past 2 weeks	never (0)	once a week (1)	a few times (2)	every day (3)	tick  if it upsets you
	I have felt dizzy when I stood up					
	I have felt my heart beat faster					
	I feel lost not able to think clearly					
	My hands or arms have been shaky					
	I feel hotter than normal					
	I am yawning more often					
	I have put on weight					
	I am sweating more than normal					

	My vision feels blurry					
	My mouth feels very dry					
	I find it difficult to have a wee					
	I have felt sick. I have vomited					
	I find it difficult to have a poo					
	I am eating more					
	I am eating less					
	I am having trouble sleeping					

	I feel like the room is spinning					
---	----------------------------------	--	--	--	--	--

	over the past 2 weeks	Never (0)	once a week (1)	a few times (2)	every day (3)	tick  if it upsets you
Type 7  <small>Shitmy, my world goes... Bleeding liquid</small>	I have diarrhoea					
	I have had problems enjoying sex					

Have you felt well over the last two weeks since you started your medicine?


Have you felt unwell since you started your medicine? If so these maybe side effects . Tell us how you have been feeling


.....

.....


.....


Have you seen your doctor about feeling unwell from side effects of your medicine?



Have you stopped taking your medicine due to side effects or feeling unwell ?








 

Reviewed by the Can you understand it? team August 2021


Checking side effects from antipsychotic medicines



Please give us the following information

 Name		 Age	
 Male <input type="checkbox"/>	 Female <input type="checkbox"/>	 Date	

Please write down the medicines you take and how much each day









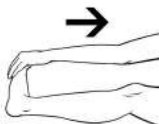



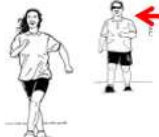

.....








.....

.....






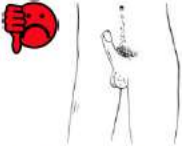
We want to find out if the medicines you take are making you unwell. We call this side effects.





	over the past week	Never (0)	once a week (1)	a few times (2)	every day (3)	tick <input checked="" type="checkbox"/> if it upsets you
	I feel more sleepy during the day					
	I feel spaced out					
	I have problems swallowing					

	over the past week	never (0)	once a week (1)	a few times (2)	every day (3)	tick  if it upsets you
	I have felt dizzy when I stood up					
	I have felt my heart beat faster					
	My muscles sometimes have a twitch or feel tight					
	My hands or arms have been shaky					
	I have problems sitting still					
	I sometimes dribble					
	My walking has been slower					
	My face or body has a twitch					

	over the past week	Never (0)	once a week (1)	a few times (2)	every day (3)	tick ✓ if it upsets you
	My vision feels blurry					
	My mouth feels very dry					
	I find it difficult to have a wee					
	I have felt sick. I have vomited					
	I find it difficult to have a poo					
	I have been going for a wee more often					
	I have wet the bed					



	over the past week	Never (0)	once a week (1)	a few times (2)	every day (3)	tick  if it upsets you
	I have felt more thirsty					
	My nipples feel sore and swollen					
	I have noticed fluid coming from my nipples					
	I have had problems enjoying sex					
	Men only I have had problems getting an erection					
Scale 0-16: absent/mild side effects		17-32: moderate side effects				
33-48: severe side effects						
SCORE						
BP Pulse Sats						
Weight Waist Temp						

	Tick  'yes' or 'no' for the last 3 months	yes	no	Tick  if it upsets you
	Women only: I have noticed a change in my periods			
	Men and women: I have been putting on weight			

Reviewed by the Can you understand it? team






Images from Change Picture Bank

Updated Oct 2021




Checking side effects from Clozapine medicine



Please give us the following information

 Name:		 Age
 Male <input type="checkbox"/>	 Female <input type="checkbox"/>	 Date

How many drinks do you have each day?

 cups of coffee
 cups of tea
 fizzy or energy drinks



Do you smoke?




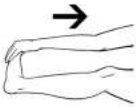



Yes No If 'yes' how many cigarettes a day








Are you smoking more or less in the last month (please tick ✓)





I am smoking **more** cigarettes each day
 I am smoking **less** cigarettes each day

We want to find out if Clozapine is making you unwell. We call this side effects.

	over the past week	never (0)	once a week (1)	a few times (2)	every day (3)
 I feel more sleepy during the day					
 I feel spaced out					

	over the past week	Never (0)	once a week (1)	a few times (2)	every day (3)
	I have felt dizzy when I stood up				
	I have felt faint or light headed				
	I have felt my heart beat faster				
	My muscles sometimes have a twitch or feel tight				
	I sometimes dribble				
	My vision feels blurry				
	My mouth feels very dry				

	over the past week	Never (0)	once a week (1)	a few times (2)	every day (3)
	I have problems swallowing				
	I have felt sick. I have vomited				
	I have had heartburn				
	I find it difficult to have a poo				
	I have been going for a wee more often				
	I have wet the bed				
	I have felt more thirsty				

	over the past week	Never (0)	once a week (1)	a few times (2)	every day (3)
	I have felt more hungry				
	I have put on weight				
	I have felt out of breath				
	I have had chest pain				
<p>GASS scale 0 - 16: absent/mild side - effects 17 - 32: moderate side - effects 33 - 48: severe side - effects</p> <p>GASS score </p>					

Tell us about any other side effects you have had over the last week

.....

Physical health monitoring

BP **Pulse** **Temp**.....

Weight **Waist** **Sats**

Actions:

.....



foundation for
people with
learning disabilities

EST 1892

LSBU



Oxleas

NHS Foundation Trust

