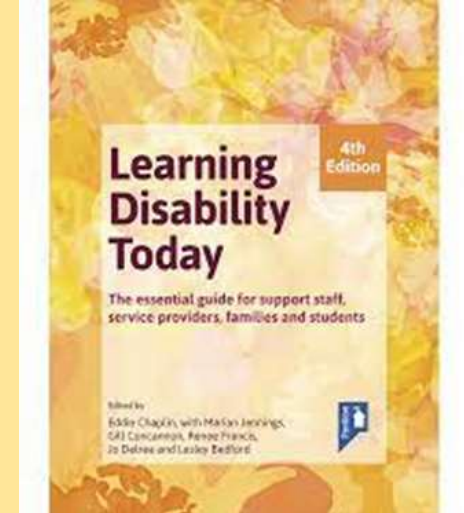


# Mental Health Support for People Learning Disabilities

Prof Eddie Chaplin

27<sup>th</sup> March 2024



A horizontal banner with a light blue background. On the left is the 'ldt learning disability today' logo. The main text in the center reads 'Mental health support for people with learning disabilities' in a purple font, with '27th March, 13.00 GMT' below it in a blue font. On the right, there is a pink circle containing the text 'Free webinar'. To the right of the circle are two black silhouettes of human heads facing each other, with colorful geometric shapes (cubes and spheres) floating between them, symbolizing thought or communication.



## What to expect







# Prevalence of Learning Disabilities

<https://ourworldindata.org/neurodevelopmental-disorders>

- Neurodevelopmental conditions, affect 15% of Europe
- The prevalence of learning disabilities ranges from 0.4 to 3%
- 115m people have a learning disability 56 % M and 44% F



# Mental Health (1)



- Mental health is a state of mental well-being that enables people to cope with the stresses of life, realize their abilities, learn well and work well, and contribute to their community.
- It is an integral component of health and well-being that underpins our individual and collective abilities to make decisions, build relationships and shape the world we live in.
- Mental health is a basic human right. And it is crucial to personal, community and socio-economic development.
- WHO <https://www.who.int/news-room/fact-sheets/detail/mental-health-strengthening-our-response>

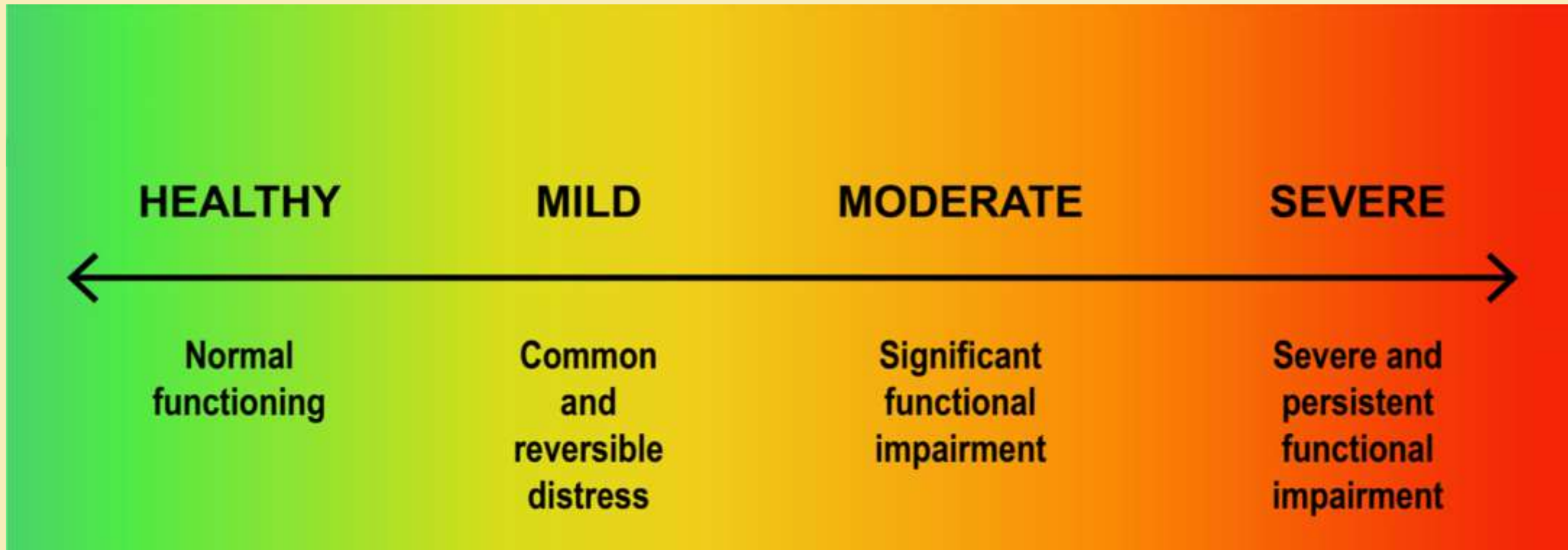


# Mental Health (2)



- Mental health like physical health needs are experienced differently by people
- MH can involve varying degrees of distress, from those needing some support to those with a mental illness
- Learning disabilities is not a mental illness

<https://opentextbc.ca/studentmentalhealth/>



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

<https://www.stevehardyldn.com/peter-and-friends-mental-health>





# Introduction

- People with learning disability experience mental ill health the same as others, although sometimes conditions or symptoms may present differently
- It used to be believed that learning disability protected individuals from mental illness, suicidal thoughts and behaviours.
- The reality is as in the general population, people with learning disability, can think about, attempt and die by suicide.

# Risk of common mental health problems in people with learning disabilities

- People with learning disabilities have higher rates of mental health problems, than those without learning disabilities
  - Schizophrenia estimated at three times greater than the general population (3% vs 1%)
  - Dementia is much higher amongst older adults with learning disabilities and is associated with an earlier onset in some groups such as People with Down's syndrome onset from 30-40 years
  - Reported prevalence rates for anxiety and depression is reported to be at least the same as the general population, but some estimate higher



# Harder to diagnose?

- Mental health problems can often be missed in people with learning disabilities
  - People may not realise the significance of events
  - Have trouble recalling information
  - Not understand what is happening or being asked of them
  - Symptoms can be lost amongst other behaviours being displayed
  - The person may be non-verbal and have difficulty expressing themselves
  - Many people put how the person is behaving and presenting down to their learning disability
  - Be complicated due to physical disorders (epilepsy, hypothyroidism)

# Good Practice in Assessment

Mental health problems in people with learning disabilities: prevention, assessment and management  
(NICE NG54)

When conducting mental health assessments, be aware:

- that an underlying physical health condition may be causing the problem
- sensory or cognitive impairment may mask an underlying mental health problem
- that mental health problems can present differently in people with more severe learning disabilities.



# Assessment, Communication

- Keep speech simple, jargon-free, one concept at a time.
- Beware acquiesce:
  - Are you happy? Yes
  - Are you sad? Yes
  - Are you Batman? Yes
- Beware suggestibility:
  - Are you happy or sad? Sad
  - Are you sad or happy? Happy

# Learning disability Assessment and Communication

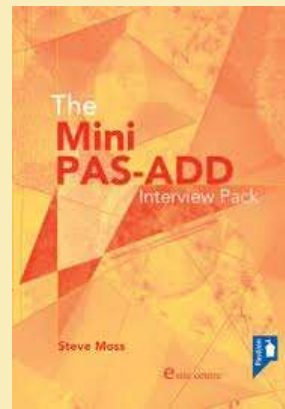
- Communicate with the person with learning disabilities first, not the carer – this is a frequent complaint from people with learning disabilities
- However, don't be shy to ask a carer for information or to help with communication
- Engage people in a way they understand

# Problems with psychiatric Diagnosis in people with learning disabilities

- There may be difficulty in understanding questions and answers
- Understanding of language or conditions such as anxiety and depression
- Atypical presentations e.g. sleep less or eat more, behavioral changes
- What we see can be out of character. or exaggerated

# Assessment Tools

- PAS-ADD
- Glasgow Depression Scale / Anxiety Scale
- PHQ-9



**PATIENT HEALTH QUESTIONNAIRE-9 (PHQ-9)**

How often have you had these problems during the last two weeks?

Problem	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself — or that you are a failure or let your family or friends down	0	1	2	3
7. Trouble concentrating, remembering things, or making decisions	0	1	2	3
8. Thinking about hurting yourself — or that you would be better off dead or hurting yourself in some way	0	1	2	3

Total score: \_\_\_\_\_

0 = Not at all, 1 = Several days, 2 = More than half the days, 3 = Nearly every day

0 = Not at all, 1 = Somewhat difficult, 2 = Very difficult, 3 = Extremely difficult

## Glasgow Depression Scale

(score of 13 or over indicates depression).

In the last week...	Prompts	no	some times	a lot
1.  Have you felt sad?	Have you felt upset, depressed, miserable, fed up, low?	0	1	2
2.  Have you been in a bad mood?	Have you felt bad tempered, wanted to shout at people?	0	1	2
3.  Have you enjoyed doing things?	Have you had fun?	2	1	0
4.  Have you enjoyed ...	Have you liked having ...	0	1	0

<https://patient.info/doctor/patient-health-questionnaire-phq-9>





# Depression

- Tiredness and loss of energy
- Sadness that doesn't go away
- Loss of self-confidence and self-esteem
- Difficulty concentrating
- Not being able to enjoy things that are usually pleasurable or interesting
- Feeling anxious all the time
- Avoiding other people, sometimes even your close friends
- Feelings of helplessness and hopelessness
- Sleeping problems - difficulties in getting off to sleep or waking up much earlier than usual
- Very strong feelings of guilt or worthlessness
- Finding it hard to function at work/college/school
- Loss of appetite
- Loss of sex drive and/or sexual problems
- Physical aches and pains
- Thinking about suicide and death
- Self-harm

# Anxiety

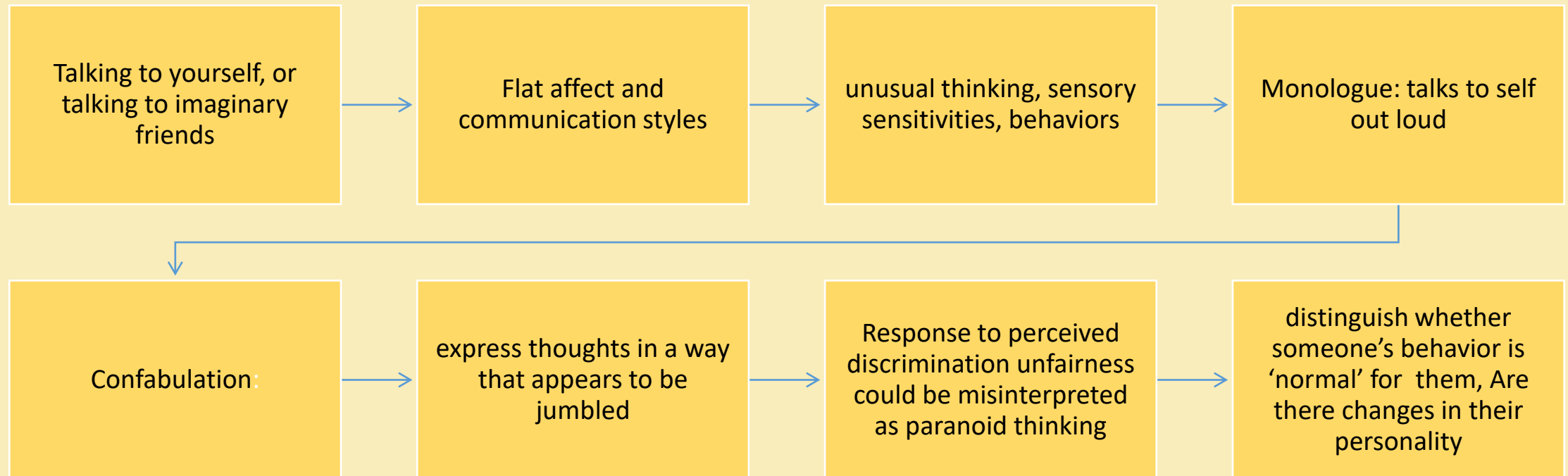
- Sometimes an event raises anxiety levels, but generally it's likely to be a number of things that increase anxiety levels. E,g financial worries, meeting new people or feeling unsafe travelling home late at night.
- Anxiety is a natural survival responses. It causes our mind and body to speed up to prepare us to respond to an emergency.
- These are some of the physical things that might happen:
  - Rapid and / or irregular heartbeat
  - Fast breathing
  - Weakened / tense muscles
  - Sweating
  - Churning stomach / loose bowels
  - Dizziness
  - Dry mouth
- Anxiety also has a psychological impact, which can include:
  - Trouble sleeping
  - Lack of concentration
  - Feeling irritable
  - Feeling depressed
  - Loss of self-confidence

# Psychosis

- Lose touch with reality
  - People can experience Hallucinations e.g. hear people talking when nobody is around or seeing things which are not really there
  - Develop false beliefs
  - Behaving in an odd manner
  - Difficulty in thinking clearly
  - Losing interest in daily activities
- Schizophrenia may develop during early adulthood
  - You may experience 'positive' and 'negative' symptoms of schizophrenia.
  - Positive symptoms are when you experience things in addition to reality. For example, you might see or hear or believe things that others don't.
  - Negative symptoms are when you lose the ability to do something, or it is affected. For example, losing motivation to do things or becoming withdrawn. They often last longer than positive symptoms



# Normal presentation or mental illness



# Suicide risk

- Evidence suggests higher rates of suicidal thoughts in people with learning disabilities
- Suicidal attempts can go unnoticed or are misconstrued e.g. believing that an act might be lethal which isn't

# Suicide risk and screening

- The suicide risk factors are in keeping with the general population
  - A diagnosis of clinical depression
  - history of self-harm
  - Unemployment
  - Loneliness
  - An increased need for support from others
  - Early onset mental illness
  - Being treatment resistive

# Signs

- Be careful to understand what is significant to the person
- Life events maybe different
- a change of staff
- A change in a role or job

## My Safety Plan



Getting through right now

Making your situation safer

Things to lift or calm your mood

Things to distract you

People to support you

List who you can talk to if you are distressed or thinking about self-harm or suicide

Emergency professional support

## My Safety Plan

If I feel I cannot stay safe from suicide...

I will talk to: \_\_\_\_\_

I will seek help from: \_\_\_\_\_

I will calm myself by: \_\_\_\_\_

I will go to my safe space: \_\_\_\_\_

My ideas for keeping safe: \_\_\_\_\_

## Reasons for Living

### Myself

I care enough about myself to live

I have the courage to face life

I want to experience all that life has to offer and there are many experiences I haven't had yet which I want to have

No matter how badly I feel I know that it will not last

I believe I can learn to adjust or cope with my problems

I am afraid of the unknown

### Family and Friends

It would hurt my family and friends too much and I would not want them to suffer

I would not want my family and friends to feel guilty afterwards

## Family and Friends (continued)

I have a responsibility and commitment to my family and friends

I love and enjoy my family and friends too much and could not leave them

My family and friends might believe I did not love them

### Understanding my choices

I believe killing myself would not really accomplish or solve anything

I do not want to die

I believe I have control over my life and destiny

I am afraid of the actual "act" of killing myself

### Hopes and beliefs

I have hope that things will improve and the future will be happier

I believe I can find other solutions to my problems

I believe I can find a purpose in life, a reason to live

I am curious about what will happen in the future

Life is all we have and is better than nothing

### Your own reasons

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Version 1.1 © 2016-2019 Granarorta Suicide Prevention

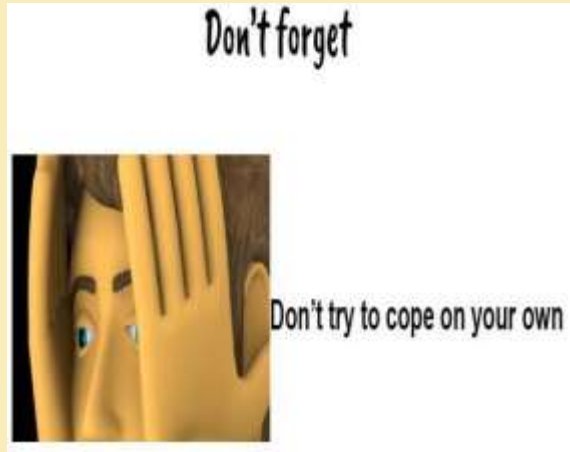


<https://www.mindworks-surrey.org/our-services/crisis-admission-avoidance/my-safety-plan>

<https://prevent-suicide.org.uk/stay-alive-resources/>

EST 1892

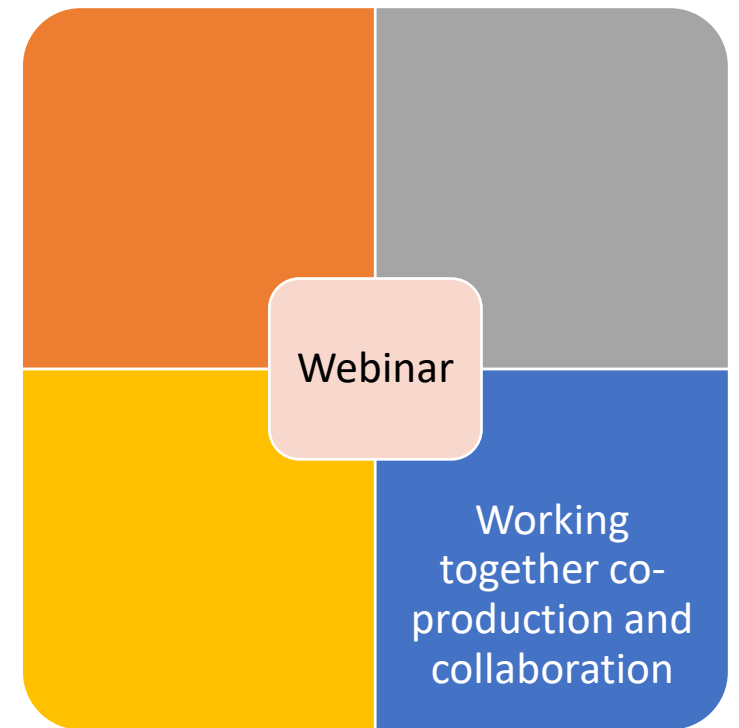
LSBU







## Aims



# Guided Self-help

for People with Intellectual Disabilities  
and Anxiety and Depression



Eddie Chaplin  
Jane McCarthy  
Steve Hardy  
Lisa Underwood

Debbie Spain  
Peter Cronin  
Liam Payton  
Jayne Henry

estia centre



Self-Assessment and Intervention: The SAINT

## Self-Assessment and **Int**ervention: The **SAINT**



Helping people help themselves.



This book was written to help people who are  
feeling upset.



This book can be used to record how you feel.



This book will help you recognise your feelings.



This book can also let others know when you  
are feeling upset.



In the book is a diary. You can write how you  
feel in the diary.



## Example 1

John felt upset so he looked at his SAINT book. Looking at the feelings list he saw number **6 – I feel down**.

Number 6 is about sadness.



John put the number 6 in his diary and thought: 'I must look at the ideas for coping in the SAINT book to see if I can help myself'.

The coping list gave John ideas that could help him.

He thought, 'I know, I will listen to music.' This was number **16 – listening to music or watching TV**.

John put number 16 in his diary.

John also wrote a note in his diary that this made him happy.

WEEKLY DIARY	
<b>Monday</b>  <b>6</b>  <b>16</b> I felt sad this morning and listening to music made me feel better	<b>Friday</b>
<b>Tuesday</b>	<b>Saturday</b>
<b>Wednesday</b>	<b>Sunday</b>
<b>Thursday</b>	<b>NOTES</b>

Feelings list		
	<b>4. I find it difficult to do things</b> <ul style="list-style-type: none"> <li>» I am losing interest in things.</li> <li>» I don't feel like going out.</li> <li>» I can't be bothered to change my clothes.</li> <li>» I have stopped activities and/or going out.</li> </ul>	If you had any of these thoughts, write number <b>4</b> on today's date in the diary.
	<b>5. I am having problems sleeping</b> <ul style="list-style-type: none"> <li>» I have trouble getting off to sleep.</li> <li>» I have trouble waking up.</li> <li>» I keep getting up during the night.</li> <li>» I feel tired all the time.</li> </ul>	If you had any of these thoughts, write number <b>5</b> on today's date in the diary.
	<b>6. I feel down</b> <ul style="list-style-type: none"> <li>» I feel sad.</li> <li>» I feel worried.</li> <li>» I feel tense.</li> <li>» I feel stressed.</li> </ul>	If you had any of these thoughts, write number <b>6</b> on today's date in the diary.

Coping list		
	<b>14. Go out</b> <ul style="list-style-type: none"> <li>» I will go out somewhere to make myself feel better.</li> <li>» I will go and see friends.</li> <li>» I will go and do something like the cinema or shopping.</li> </ul>	If you did any of the activities, write the number <b>14</b> on today's date in the diary.
	<b>15. Relaxation</b> <ul style="list-style-type: none"> <li>» I will do some relaxation exercises.</li> <li>» I will do deep breathing.</li> <li>» I will listen to a relaxation tape.</li> <li>» Use nice smells (aromatherapy, scented candles).</li> </ul>	If you did any of the activities, write the number <b>15</b> on today's date in the diary.
	<b>16. Listening to music or watching TV</b> <ul style="list-style-type: none"> <li>» I will go and listen to music.</li> <li>» I will play music or sing.</li> <li>» I will watch TV.</li> <li>» I will watch a DVD or video.</li> </ul>	If you did any of the activities, write the number <b>16</b> on today's date in the diary.

### Worksheet 6: Feelings

Angry



Anxious



Disgusted



Happy



### Worksheet 2: Linking thoughts, feelings and behaviours for depression

» An example for depression



» What you **think** – there is no point in going out

» How you **feel** – sad, depressed

» What you **do** – stay in bed

Reproduced and adapted with permission from Hassiotis et al (2013) A Manual of Cognitive Behaviour Therapy for People with Learning Disabilities and Common Mental Disorders. London: Camden & Islington NHS Foundation Trust and UCL.

Guided Self Help for People with Intellectual Disabilities and Anxiety and Depression  
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## what is depression?



- **depression** is when a person feels sad for long periods of time

## depression can make you feel



- bad about yourself
- lonely
- tired
- angry



- you may
  - not want to talk to anyone or go anywhere
  - find it hard to sleep
  - sleep too much
  - not feel like eating
  - feel like eating too much

## Worksheet 8: Certificate

**GSH**  
certificate

**Congratulations!**








you have finished your GSH.

Worker: \_\_\_\_\_
















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	What time did I go to bed?
	What did I do in bed?(Read, TV, sex)
	What time did I put the lights out?
	How many minutes before I fell asleep?
	What time did I wake up at?
<b>123</b>	Number of times I woke up?
	Number of hours I slept
	On waking up in the morning, how rested (10 most rested)

Example from the Feeling Down guide:

What can we do for you?	What is Anxiety?	What is Depression?
 You can talk with one of our workers who will ask you questions	 When you are worried and stressed you might feel anxious	 Depression affects a lot of people
 You can talk about how you think	 You might feel short of breath	 You might feel sad or tearful
 You can talk about how you feel	 You might have a sore tummy	 You might feel tired and find it hard to sleep
 We can support you if you are with unhelpful thoughts	 You might feel hot	 You might not be interested in the things you like
 We can offer you ways to feel better	 You might feel tingly	 You might find it hard to concentrate

Example of Easy Read Information from Feeling Down Guide

**How you feel when you are down, worried or depressed**

Each person is different. Some people say they feel physically unwell. Feelings (symptoms) they describe are:

 Dizziness	 Sweaty hands	 Feeling tense	 Not sleeping Being more tired than usual, so it's hard to get up in the morning
 Heart beating fast	 Mouth ulcers	 Wanting to bite your fingernails	 Feeling sick Butterflies in the stomach Diarrhoea or stomach pains

1. What is mental health? 17

**Things I Feel In My Body**

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

 Pain in my tummy <input type="checkbox"/>	 My breathing was difficult <input type="checkbox"/>
 Pain in my head <input type="checkbox"/>	 I was sick <input type="checkbox"/>
 Voices in my head <input type="checkbox"/>	 Not sleeping <input type="checkbox"/>
 My heart beating faster <input type="checkbox"/>	 My hands were sweaty <input type="checkbox"/>

3. What to do when you are worried about your mental health 52

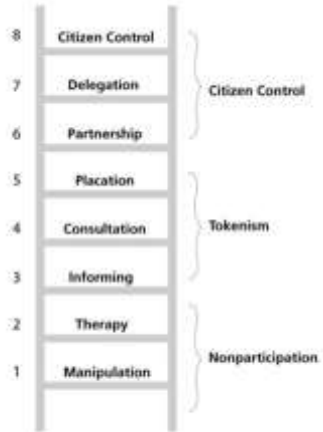




It's our mental health: involving people with learning disabilities in mental health services




The Tuesday Group



Arnstein's Ladder (1969)  
Degrees of Citizen Participation

PERSONAL VIEW



## What's good for mental health?

**Peter Croxle**  
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**Liam Peyton**  
Advisor, Estia Centre, London, UK

**Yolanda Zimock**  
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**Abstract**  
This paper describes the thoughts of three people with learning disabilities about mental health and what can help people stay mentally well.

**Key words**  
learning disabilities; intellectual disabilities; mental health; mental health promotion



<https://www.stevehardyldn.com/covid-19-book>



# 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 forced to go 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?
-

# Final Thoughts....

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- 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 pigeonhole 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

## 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

- If I want a relationship or become sexually active it's up me and none of your business
- If I'm a Sikh, a Muslim or Christian respect this
- I can make unwise decisions and mistake just like you I have the right to feel safe and protected
- I want 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



# Questions





# Thank You, Goodbye and Safe Journey

