

The Only way is UPP: Understand, Prepare and Prevent

Supporting individuals with a learning disability
and/or autism to lead healthy and active lives.



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Our Starting Point



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The Learning Disability and /or Autism Community do not have the same opportunities to develop their understanding of how to establish, maintain and benefit from a healthy lifestyle, resulting in poorer health outcomes.

Starting in childhood typically this group have limited experiences of wider society, resulting in reduced confidence and resilience which becomes a barrier to accessing health care, as well as having a direct negative impact on physical and mental health.

What Do we Know?



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Learning Disabilities

‘The health inequalities faced by people with learning disabilities in the UK start early in life, and often result from barriers they face in accessing timely, appropriate and effective health care (Emerson and Baines 2010)’

http://complexneeds.org.uk/modules/Module-4.1-Working-with-other-professionals/All/downloads/m13p020c/emerson_baines_health_inequalities.pdf

- Over 20 years less life
- Higher impact from Covid 19
- 3 to 4 times as likely to die from an avoidable medical cause of death.
- Lower levels of access to screening

<https://www.nice.org.uk/about/what-we-do/into-practice/measuring-the-use-of-nice-guidance/impact-of-our-guidance/nice-impact-people-with-a-learning-disability>

Autism

‘People with autism with or without an intellectual disability (ID) are at higher risk of multimorbidity in the physical and mental health domains.³ Around 30% of adults with autism have comorbid ID, physical, and mental health conditions.’

- Those with comorbid ID are more susceptible to physical health issues
- Those without ID are at higher risk of mental health problems, including higher than normal suicide rates

<https://bjgp.org/content/69/688/534>

Why Does This Happens?



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Low Levels of Activity

- One third of disabled children take part in less than 30 minutes of sport and physical activity per day.
- Disabled children's activity levels decrease significantly as they get older

<https://www.activityalliance.org.uk/how-we-help/research/5658-my-active-future-including-every-child>

- 'Systematic reviews indicate that people with IDs show significantly lower levels of physical activity than the general population and often lead sedentary lifestyles' <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7177820/>

Poorer Health Literacy

'Limited health literacy among adults with learning disabilities is explained by, "limited communication skills and reduced capacity to access and comprehend health information" (Baines 2010). The impact of communication difficulties on the development of health inequalities is highlighted in the Accessible Information Standard (2016) and in the, 'The Learning Disabilities Mortality Review Annual Report' (2017).' <https://www.rsph.org.uk/static/uploaded/f95556c0-9d3f-4d4c-b06f6e8ec5b77b9c.pdf>

'Responding to health needs often requires the knowledge of care givers and the understanding of individuals by health professionals'

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6388359/>

Social Determinants

'Pervasive socio-economic inequalities are experienced by this group of people with learning disabilities, who were less likely to be 'doing alright' financially or 'living comfortably', be employed for 16 hours or more per week, live in a high quality neighbourhood, feel safe outside in the dark, have two or more close friends or go out socially.' <https://ukhsa.blog.gov.uk/2016/10/04/health-inequalities-and-the-hidden-majority-of-adults-with-learning-disabilities/>

'Additionally, adults with autism experience a range of barriers to appropriate and timely health care and support. These include issues that are intrinsic to the nature of autism' <https://bjgp.org/content/69/688/534>

What is the Impact?

- **Poor health care costs money** – for example people with learning difficulties who are in pain associated with untreated disorders may develop challenging behaviour. People with poor mobility due to lifestyle issues such as obesity can require costly equipment, Addressing health care inequalities can make a significant contribution to the prevention agenda
- **It is a basic human right** to be able access health care and to be able to maintain good health



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- **People with learning disabilities and / or autism matter**

What Can we Do?



Understand, Prepare & Prevent: Provide opportunities for young people who have learning disabilities and / or autism to;

- Build their confidence to access environments outside the home reducing barriers to accessing health care
- Benefit from peer support to build confidence and resilience
- Increased their activity levels and establish healthy lifestyle choices early on in their lives
- Learn about health issues and to experience health interventions in a supportive and positive way
- Bring Parent Carers together to benefit from peer support and to share information that enables them to actively support young people with LDA to lead healthy live

PACC PFA Healthy Lives Programme



- Engaging & supporting Parent Carers
- Engaging young people
- Reassuring providers
- Providing the right support and facilities
- Creating a programme which worked for everyone
- Travelling to Ullapool !!



Enabling A Good Start in Life

- Female 18, no activities outside school, completed an activity each week on programme. Now joined a dance class and PACC Buddies. Performed nationally with dance team in December. Parents totally amazed
- Male 14- never done anything in holidays except with Mum Dad, Granny. Found it a life changer. Got up easily on activity days, tried new things, met school friends, made other friends. Family feel connected. Young man more confident. Joined two new activities.

What Can We Do?

Understand, Prepare, Prevent: Work with adults from the learning disability and/or autism community to improve their experiences of accessing health and social care services by ;

Understanding – Easy Access (not just physical)

- Reasonable Adjustments – Can I?
- Navigating the health systems – health is health!
- Understanding what Social Care can provide – knowing the system

Preparation - Training

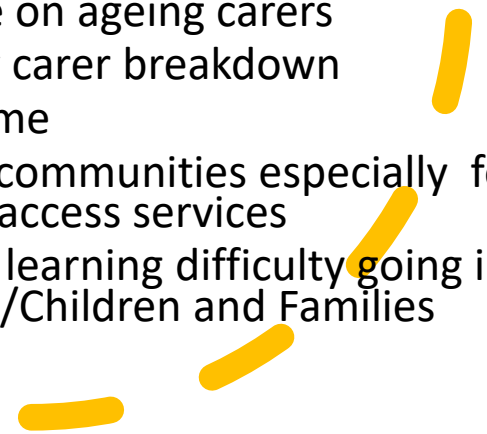
- For professionals - Mandatory Oliver McGowan training Tier 1 and Tier 2
- For people with a learning disability and/or autism on health (weight management, exercise, screening, annual health checks, menopause) and basic care (personal hygiene, relationships and sexuality, good parenting skills, end of life. Living with a long-term condition and ageing well)

Prevention – Moving On

- Planning for the future to reduce pressure on ageing carers
- Sufficient respite provision to avoid family carer breakdown
- Get where I live and my support right for me
- Provision of good housing and support in communities especially for those who live independently and do not access services
- Prevent children with parents who have a learning difficulty going into care or being part of the Public Law Order/Children and Families Support Service



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When 'UPP' works

My diabetes nurse from my doctors visits me every 14 days, she will keep coming until I get used to my machine. She helps me, treats me like an adult and with respect, she explains and shows me how to use my machine and she understands when I forget something. I was getting it wrong, without her support I wouldn't be able to use my machine, I would get ill and that would be bad for me, but it would cost you a lot more money. I felt very comfortable with her and was able to talk about something else that was too private to talk to my doctor about. It makes a big difference that she comes to my home, that she is patient with me and kind.



When 'UPP' is missing

I was going for an operation on my head, the surgeon said they didn't have any record of the problems with my breathing and didn't seem to know that I'd been into hospital by ambulance 3 times over 2 years with chest complaints. I told the surgeon all about what happened, and she was cross that my notes weren't up-to-date. The next day I had an appointment sent through for an X-ray for the next week. It's taken a long time, I have had a scan and 2 lots of X-rays and been taken into hospital again, but now I have an appointment with a doctor at the hospital at the end of January. I have my support going with me and that will make me feel better. Sometimes I think the doctors think I'm making it up, but I can't breathe, and I can't walk about like I used to.





Specialised Skills Training Needs

- There is a pressing need for Health and Social-care working in partnership to offer a programme of information and life skills training around online safety, sex and sexual health to support people in their modern adult life.
- Carers, paid staff and Shared Lives carers feedback this is an increasingly difficult area to sensitively support an individual with, who although has the right to an adult life does not always have the experience and life skills to navigate it.
- As well as having skilled support they trust around, people need the skills themselves to help prevent becoming vulnerable. **Person X case-study.**

Understand Prepare Prevent



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We hope you agree that the only way is UPP
Good health and active lives don't just happen,
people with Learning Disabilities and / or
Autism need to be given the same opportunities
as everyone else to develop healthy lives.

Thank You