Whole Systems Approach to Obesity Programme – people with a learning disability in Surrey

Active Prospects

People leading aspiring lives

Narrative -

Introduction:

We acknowledge in this report that personal weight is complex and often is related to deeper trauma, emotional responses, and overall wellbeing. For the sake of this report, we will be using words such as obesity and trying to focus on our research.

In 2020 Active Prospects were successful in a bid for £20k to lead a pilot around Systems (i.e. the whole health social care, public and personal wellbeing space) approaches to obesity, funded by NHS and Public Health England, because of Covid death statistics. Data showed that people in the obese categories had been at much higher risk of death from Covid.

The idea was that by spending time looking at Systems and reasons why obesity rates were so high, at grassroots level, we would start to understand why many of the government strategies had previously not worked or made the required impact. Active Prospects then started its journey to map how this impacted on people with learning disabilities and support staff in Surrey. We did this by having monthly steering group meetings including key people who could influence, such as Commissioners from health and social care, stakeholders, providers, CTPLD, experts by experience and NHS England.

The first challenge was the scarcity of data relating to obesity levels for people with LD (Learning Disability) in Surrey, as it had never been looked at across the County in a strategic manner. This meant that there was no data with which to measure impact or to see what differences could be made. General public data however, showed that even though better than most counties in England, Surrey was still trending in obesity levels rising at quite alarming rates. This is consistent with NHS England predications, which state that by 2050 9 out of 10 people will be overweight or obese across England. In 2022 Liz Williams, Joint Strategic Commissioning Convener for Learning Disabilities and Autism, produced the required data specific to learning disabilities which raised startling concerns that far out measured the predictions from NHS England. The findings highlighted serious concerns including a higher risk to obesity in the following key areas:

- Living in supported living services or living alone
- Where you lived in Surrey with risks being much higher in the north west of the county.
- Being a female with a learning disability – 20-year age negative gap to the general population with an average death to 65 years
- 14–19-year-olds statistics showing high levels of people overweight and in obese categories.

Even though these statistics are Surrey-based it is reasonable to make assumptions that this would be a pattern in many other counties especially where levels of obesity were higher than Surrey.

The second challenge was getting consistent buy-in from key people and other providers. Most people had been previously working in an reactive way, not spending time mapping and researching the reasons that may contribute to the issue. . This was around the philosophy 'if it's not working then fix it' instead of spending time asking why obesity levels are rising despite many people having access to more information than ever around the risks. This also meant providers themselves, including Active Prospects, would need to accept our responsibility in this culture and address our own shortcomings.

The third challenge was once we had mapped all the reasons identified what systems would need to change, be understood, and have actions that make a real difference. List of top reasons:

- **Social Care**- is about caring which does not feel like a reason, but it summarises that for many people who work in health and social care they tend to put others before themselves. This often means they are role modelling to the people they serve that looking after our own health and wellbeing is not a priority. Social care is a low paid industry where many support staff are living in difficult circumstances, working long hours, complex shift patterns, with low levels of financial wellbeing. Often Social Care providers will have Wellbeing strategies, but these were not always role modelled and implemented as culture change.

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For example, many people reported they work through their break, or eat as they are working, even though they know they can and should take a break. Leaders in Care are often from care backgrounds and usually have the same ingrained value base.

- **The term 'caring'**- is also controversial in the aspect of wanting to protect, look after, keep safe, or comfort. Our findings showed that many staff enjoyed giving people they supported food as a form of comfort or reward, and a perception that people do not have much else in their lives. It was also widely used to support behaviour techniques or an acceptance if a person only ate 'beige foods' or had an extremely limited diet. Providers also admitted that they reinforced this with what was named as 'cake culture' where most celebrations, successes and daily events resulted in unhealthy food on a regular basis.
- **How it used to be-** many people talked about the good old days in care where staff and supported people would often eat together. There were chefs and catering staff and providers paid for staff meals. Where shift patterns were set, such as 12 hour shifts between 8am-8pm. Pay was historically higher and career options and training were well funded. It was recognised that some of this aligned to institutional living. However, it did highlight the diverse skills required now to be a support worker which were previously taken by professionals such as chefs.
- **Choice and control** – Many providers and staff were quite defensive around people's choice – including if they wished to eat unhealthily and be overweight. This led to many heated conversations around enabling a person to live with choice and control, motivational and directive practice, and where the lines of 'duty of care' started and ended. This is a particular factor attached to rising obesity in people in supported living or alone settings where people have capacity and means to make own meals. Many people with learning disabilities learnt digital skills through the pandemic with their support staff including the use of delivery services such as Deliveroo for easy home delivered takeaway meals, which often are unhealthy for regular eating.
- **Sensitive subject**- when we started this project many people stated that they did not like the term 'Systems Approaches to Obesity' and wanted to change it to healthy living or overall wellbeing. People have admitted that this has been a sensitive and difficult subject with many people on the steering group having to inwardly look at themselves, their own impact on people they support, and the impact of their organisation. There have been conversations in looking at this in a wellbeing overall way instead of the focus on weight. However, when working with people with learning disabilities where language often must be simple and to the point, should the term obesity be talked about more and not seen as a taboo tip-toe around subject, where terms like Wellbeing can be quite abstract.
- **Education –** it became apparent how little investment there was in staff training from the government around nutrition and hydration with many providers delivering the mandatory units on the Care Certificate or a 3-hour e-learning programme refreshed every 3 years**.** Providers did, however, have a range of tools such as recipe books, leaflets, and signposting. It was also clear that many support workers were influencing people we support with whatever diet or food plan they may be using themselves. For example, many people were being influenced by Slimming World, Weight Watchers, keto, or fasting techniques and there did not seem to be any universal agreement as to what advice should be given and used by all providers. This caused a lot of confusion as many diets and food plans contradict each other and did not provide a consistent approach. One key area of concern was around portion control as many people were not aware of what was a healthy portion in each food group. An example was 5 fruit and vegetable a day but what did this look like for example 1 apple but how many grapes? There is also a concern that on current care funding models this tends to only fund an average of 4-5 days a year for training staff in all required areas which is not enough to upskill a support worker to do their role. The government have committed to invest further in the workforce development programme but, this investment works out under £2 per staff working in health and social care per week.. Support staff require at the minimum at least 8-10 days per year training and reassessment if they are to meet the required outcomes for people's health and wellbeing.

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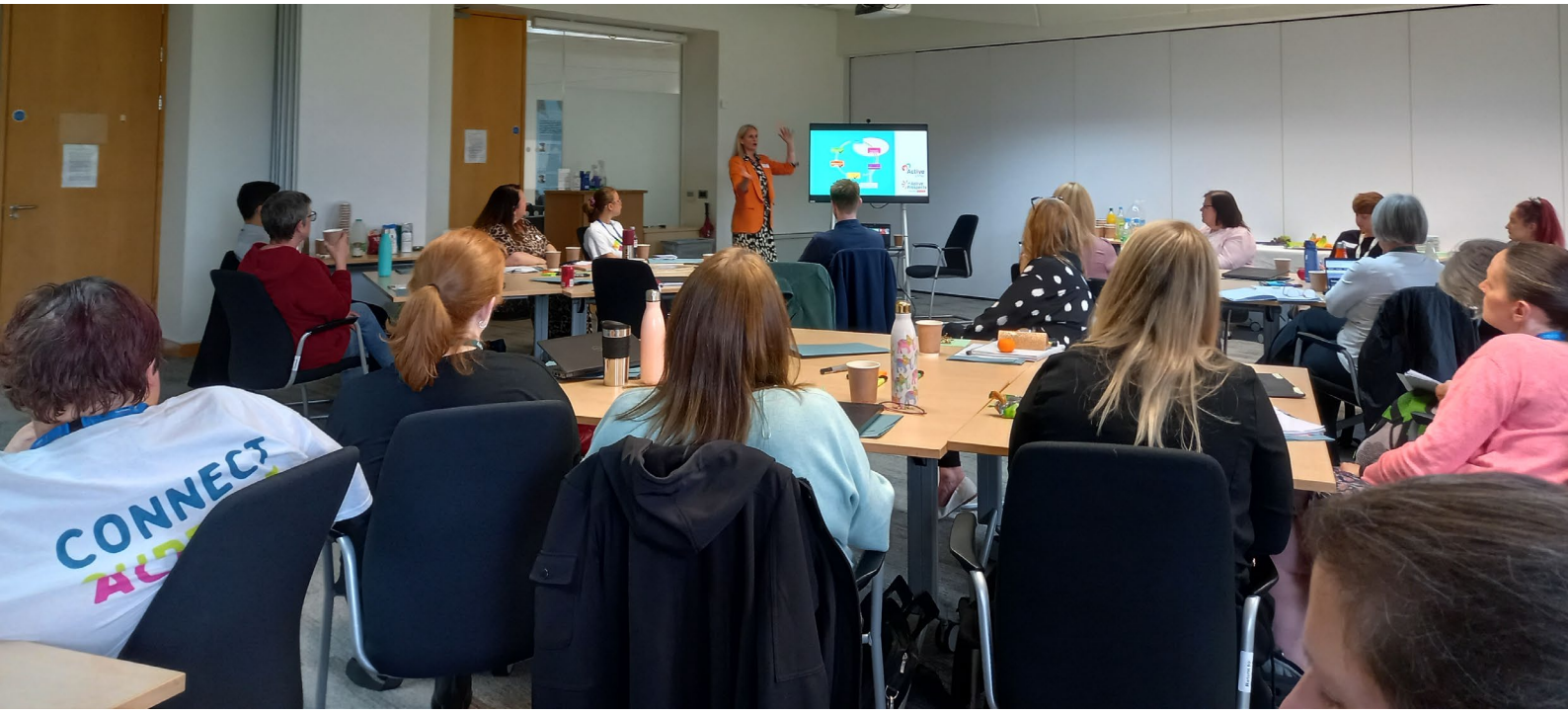
- **Accessibility-** this came out as a strong factor within Surrey in terms of accessing clubs, groups, and local facilities with much of it being linked to reduced funding in support models. For example, even though Surrey has a very accessible YMCA centre for disabilities, people's support funding might not cover the journey to get there, length of time to get ready, participate and get home. One key factor was around swimming, despite this always being a controversial subject in care and support for several years, encouraging staff to participate with swimming. We have noticed that increased numbers of support workers cannot swim.
- **Primary and secondary health care-** one major concern raised through the mapping and talking to our experts by experience, was around the known gaps in community health care. For example, there are gaps in people receiving annual health checks in all areas of Surrey, with some GPs not carrying them out at all. There were concerns that some were video linked and more of a checklist exercise than an opportunity to look at the whole person. For others they reported that whilst being weighed they were not told what they weighed or if there were any concerns. In some cases where people were identified as needing to lose weight, no further advice was given.
- **Specialist support.** There is a lack of accessible guidance around therapeutic behaviour and practice approaches for specific medical conditions and weight management such as Pradar Willis specifically for social care staff. This coincides with access to support for people to help deal with trauma and mental health where food has been a coping mechanism. The perception that the use of food is in some ways better than using alcohol or recreational drugs.



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What next?

Goals and impact

Principle 1. Awareness

To ensure commissioners, health settings and providers of learning disability services are aware of the concerns and are accountable to address and recognise these.

What does this look like in practice?

- All people who are involved in the care and support of people of learning disabilities are made aware of the key concerns especially highlighting the significant inequality gap between women's health and men's health to the general public, and the future concerns of 14-19 years old who are already at higher levels of obesity than previously thought.
- To continue the steering group sessions every two months with all influential parties within Surrey, and feedback into the Health and Wellbeing Surrey Committee. This is a long-term initiative and will need long term funding streams.
- All providers have a policy which outlines advice around weight management including Duty of Care guidance when a person lacks capacity, and motivational pro-active practice where they do have capacity. They need to address the culture of using food as a reward or to manage behaviours. They should give clear information around BMI (Body Mass Index), healthy weights, and waist measurement risks. It would be advisable to also include a range of healthy living topics within this policy to include support for smoking, alcohol, exercise, and emotional health. The policy should cover everyone within the organisation, recognising the impacts on staff as well.
- Support plans and risk assessments around hydration and nutrition also identify risks to managing weight, including appropriate weighing of people and when to call in professional support. If a person has sensory needs and their diet is limited what steps are being taken to support with this and recognise this could be a health risk.
- Providers sign up to the regular surveys to keep collecting data and review outcomes or impact.
- Guide to be produced for providers around practical tips and culture change to ensure risks to obesity are recognised and addressed.
- Experts by experience to be included in all areas of such projects through the Pro-Active Community, Surrey People's Group, and provider's own advocacy groups.

Principle 2. Education

Universal training which is recognised by all with clear standards.

- Work with Skills for Care, providers and CQC (Care Quality Commission) to establish an agreed criteria and curriculum for support staff to have the knowledge base and skills to support others with weight management.
- People we support education such as peer health and wellbeing champions and healthy conversation skills programmes that highlight the risks in accessible formats.
- Highlight the concerns around labelling of food products and try and work with some local food suppliers.
- Encouraging participation in 'Plant to Plate' projects such as grow your own on allotments or in socially prescribed green spaces if not in their own home settings.

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- Working with all support staff to develop awareness of healthy portion sizes so role modelling is possible with food preparation
- Hydration and Nutrition – expand on the current Care Certificate module to include a more detailed understanding of nutrition.
- Review training more frequently than 3 yearly. This should be reviewed or refreshed on an annual basis with appropriate training and staff back-fill budget to enable this, funded through Commissioning. Nutritional guidelines and recommendations change more often than 3 yearly.
- Food preparation workshops funded for staff and people we support to learn together.
- On-line training resources made available for anyone who would like to further their food preparation skills. This may include the EASI Cooking app, developed jointly by Active Prospects and JP Morgan Chase.

Principle 3. Regulation, commissioning, health and central government support

- At present there is no care regulatory oversight unless a service meets the criteria for the Care Quality Commission and people receive personal care for car providers of supported living.
- Providers need requirement to produce statistics annually to Surrey around health checks and feed into the data required.
- Commissioners of services accept that if providers are being paid to support a person with their health and wellbeing that this needs to be funded and commissioned by outcomes instead of hourly rates to support more personalisation and creativity with the person at the centre.
- Care costing models need to pay staff fairly (levels 3-4 minimum equivalent to NHS Agenda for Change) and funding for at least 8 days training a year, and adequate funding from Central Government to enable this.
- Central government investment per staff head in the training and development of social care staff delivering public service needs to more on par with the NHS.
- Annual health checks are fully accessible, inclusive, comprehensive and impactful – where people's health goals are fully discussed, and steps agreed that are followed through by all parties.
- Primary care to ensure accessible health services, with reasonable adjustments made. Dietary advice and support that is personalised and relevant to the individual, and people with learning disabilities.
- Annual health check reviews also review all medications - their efficacy, impact on weight and consideration of alternatives if on balance making a negative health impact.
- Access to qualitative accessible therapeutic support for people with a learning disability where conditions including abuse, poor mental health and trauma are self-managed through food.

Principle 4. Impact on people we support and our support staff

- Ensure people we support, and staff, are living lives within a healthy weight range wherever possible. Providers need to ensure there is data to evidence impact year by year.
- Outcomes measured by any recommended weight loss to demonstrate the Duty of Care necessary over realistic time scales for delivery.
- Evidence of improved eating patterns or choices in line with Government recommendations
- Inclusion and frequent review of weight management where applicable in support plans
- Options for staff to join any recommended weight loss support groups

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- Health improvements can be linked to weight loss e.g., improvements in Type 2 Diabetes, heart disease, joint pains. Sign up to the 10% challenge.
- Energy levels can be improved, when necessary, weight loss is correctly managed
- Exercise can be more manageable for anyone who has previously been limited by living above a healthy weight range
- Positive intentional weight loss can be linked to better mental health outcomes and mood
- Physical benefits from regular frequent exercise are proven to improve other medical conditions e.g., flexibility, joint pains, lung capacity and breathing related difficulties
- Feeling of self-worth can be improved from an increased ability to take part in physical activity and a sense of achievement if a set goal has been reached.
- Annual health checks are carried out in detail, face to face with clear plans of next steps including follow up.

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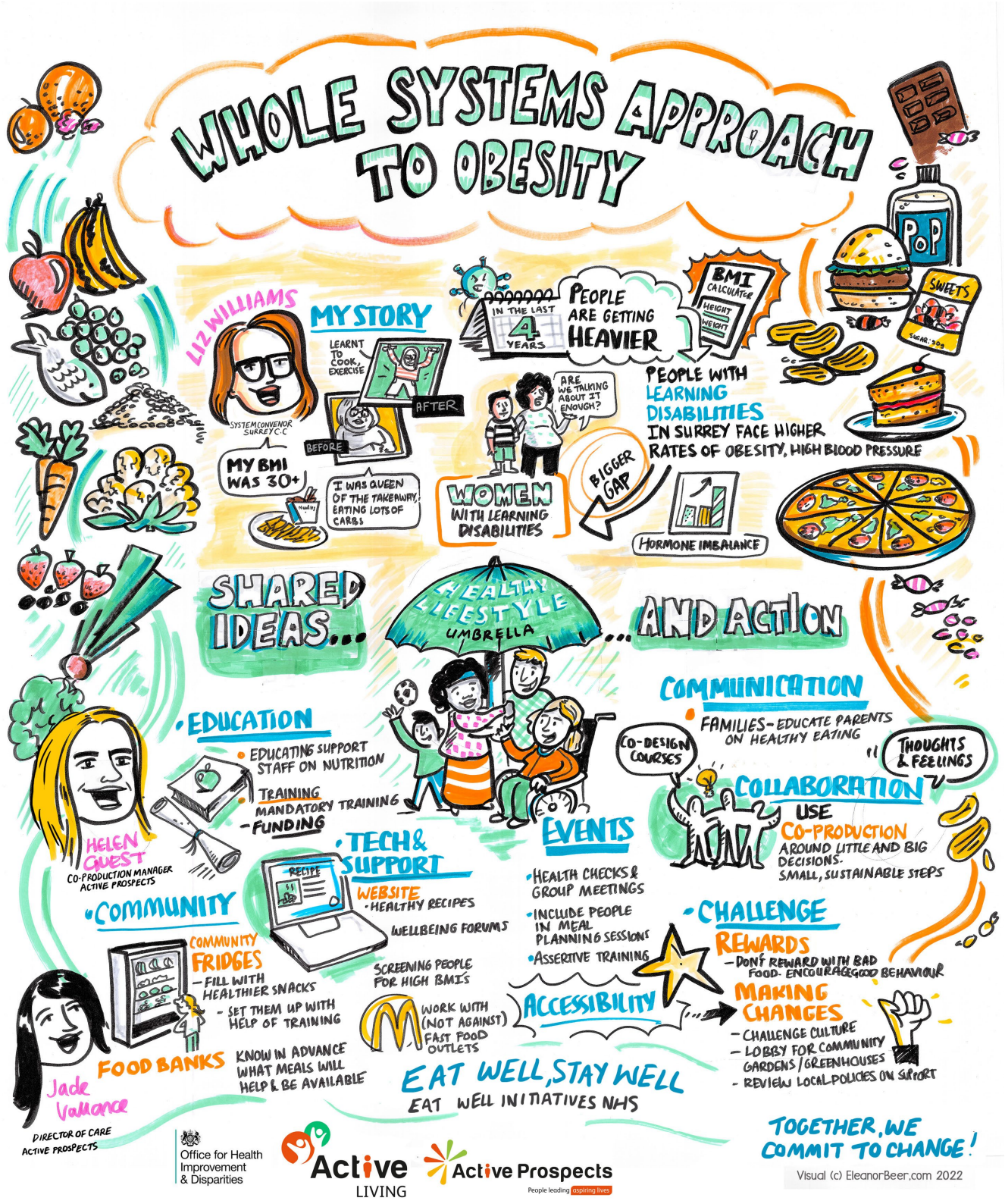

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