Tackling
Health Inequalities

DISCUSSION
PAPER

VODG

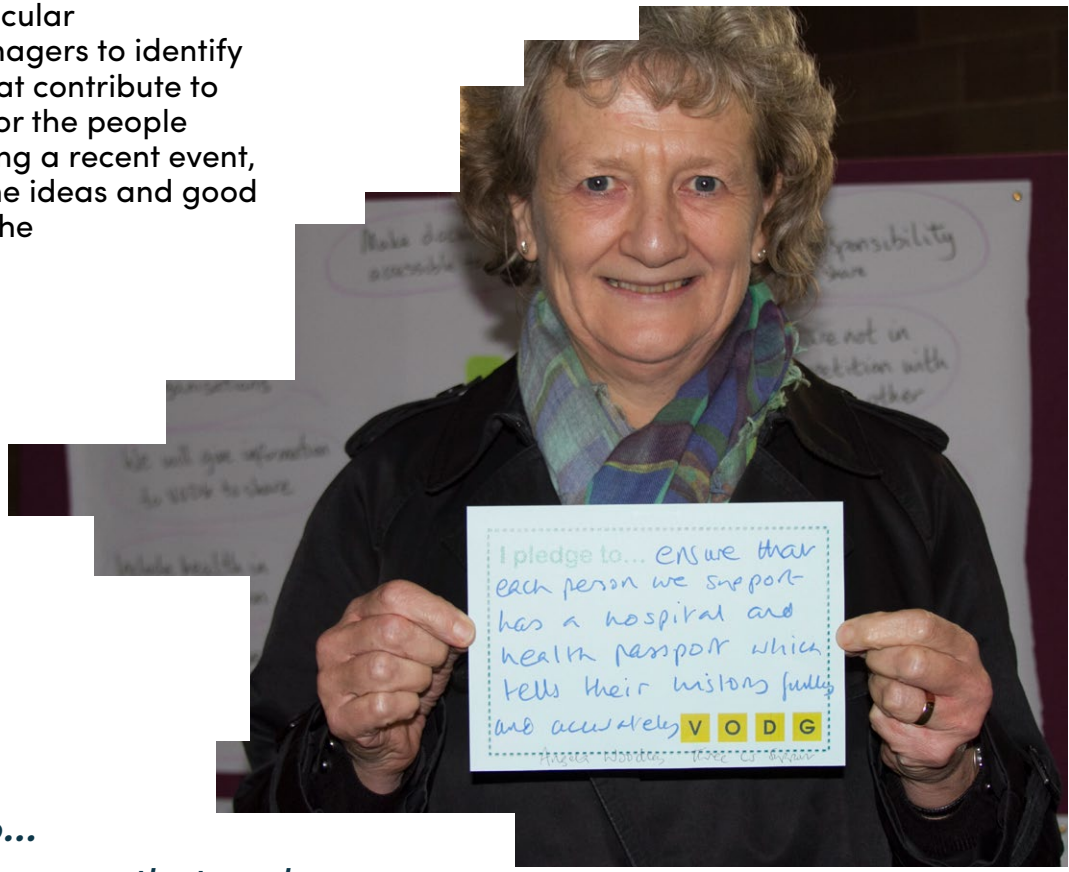
INTRODUCTION

Social care and support providers are uniquely placed to work alongside disabled people and their families and to understand their health needs in the context of their life circumstances. Therefore, enabling people to get the very best from health services and promoting healthy lifestyle choices are fundamental aspects of good support.

Tackling health inequalities is a key priority for VODG (Voluntary Organisations Disability Group), in particular encouraging service managers to identify and deliver on actions that contribute to better health outcomes for the people being supported. Following a recent event, this paper summarises the ideas and good practice discussed, and the decisions made.

I pledge to...

... seek out myths and focus on the real cause!



I pledge to...

... ensure that each person we support has a hospital and health passport which tells their history fully and accurately ...

THE NATIONAL PICTURE

There are over 11 million people with a limiting long-term illness, impairment or disability in the UK[1]. Disabled people seek more health care than people without a disability and have more unmet health needs. They are likely to experience greater vulnerability to developing additional health conditions and higher rates of premature death. For instance, men with a learning disability die 13 years sooner and women with a learning disability die 20 years sooner than people without learning disabilities[2].

> “Disabled people have better access to health provision where services work together. Where services don’t work together they are not joined up and decisions are made without the person.”

Self-advocate delegate at health inequalities event

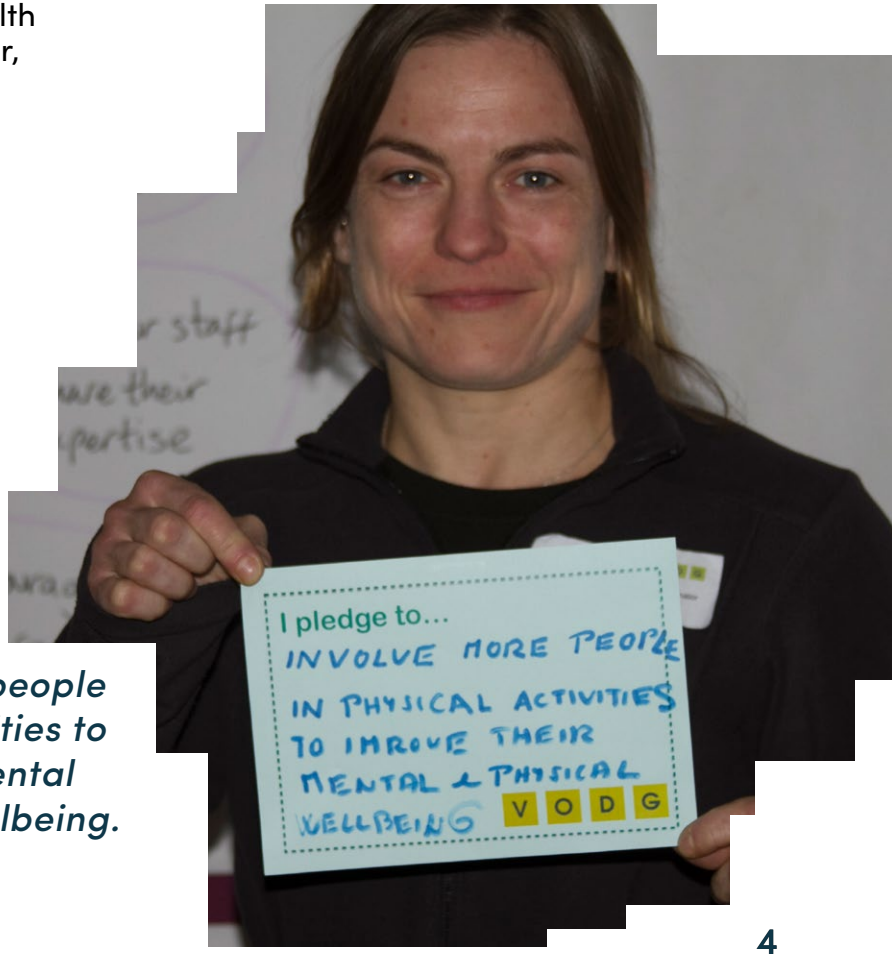
[1] Office for Disability Issues and Department for Work and Pensions (2014) *Disability prevalence estimates 2011/12* Accessed: www.gov.uk/government/uploads/system/uploads/attachment_data/file/321594/disability-prevalence.pdf

[2] University of Bristol (2013) *Confidential inquiry into premature deaths of people with learning disabilities* Accessed: www.bristol.ac.uk/cipold/reports

THE NATIONAL PICTURE

Some studies indicate that disabled people are more likely to engage in health risk behaviours, such as smoking, poor diet and physical inactivity[3]. For example, less than 10% of adults with learning disabilities in supported accommodation eat a balanced diet and care staff generally have a poor knowledge about public health recommendations on dietary intake. Meanwhile, over 80% of adults with learning disabilities engage inphysical activity below official minimum recommended levels[4]. However, health promotion activities rarely target people with disabilities. For example, women with disabilities receive less screening for breast and cervical cancer than women without disabilities. Adolescents and adults with disabilities are more likely to be excluded from sex education programmes.

The people supported by VODG members have a wide range of disabilities, yet have a shared experience of poorer health outcomes than the general population. As a group of social care and support providers, VODG is creating the conditions to enable members to work together to enable people to make informed health and lifestyle choices and live healthier, more active and more fulfilled lives.



I pledge to...

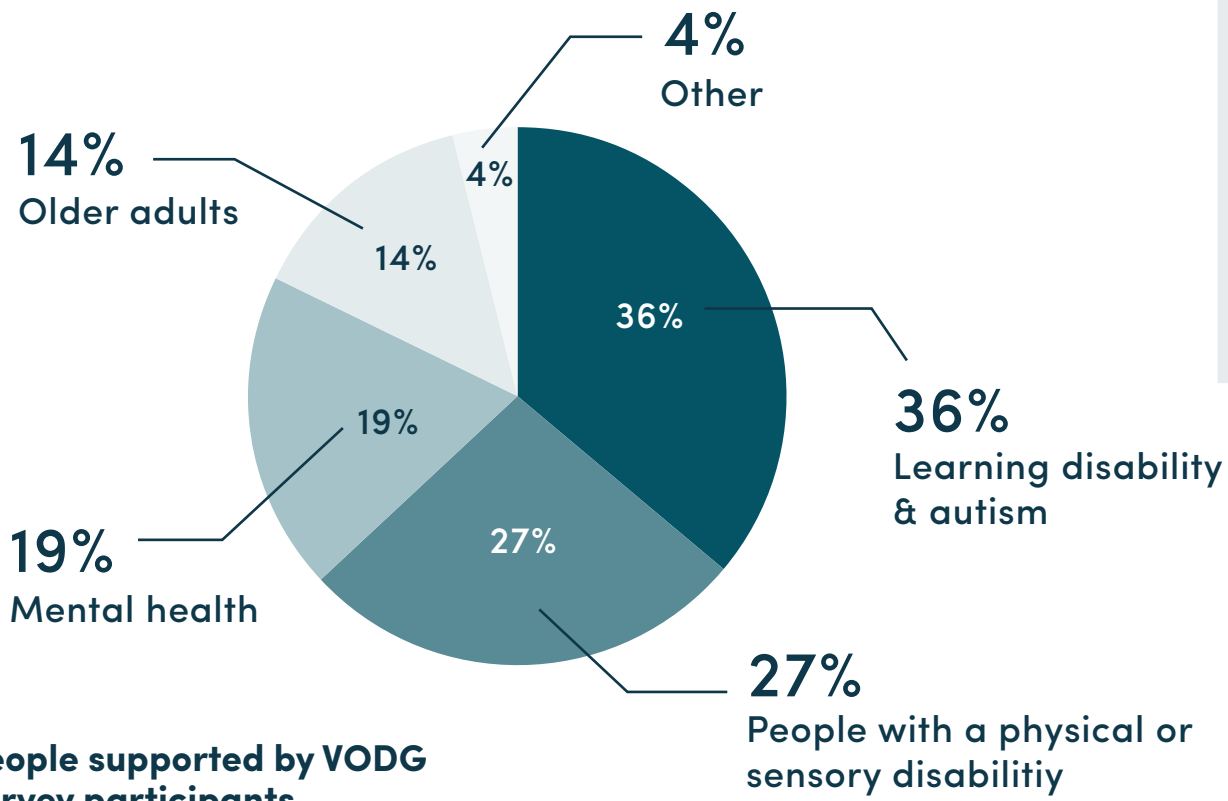
... involve more people in physical activities to improve their mental and physical wellbeing.

[3] World Health Organisation (2011) *World report on disability* Accessed: www.who.int/disabilities/world_report/2011/report/en

[4] Improving Health and Lives: Learning Disabilities Observatory (2013) *The health equalities framework* Accessed: www.ndti.org.uk/uploads/files/The_Health_Equality_Framework.pdf

THE CHALLENGES FOR CARE AND SUPPORT PROVIDERS

VODG has carried out a survey of providers about their experience of supporting disabled people to access health services. 26 organisations, supporting people with a wide range of needs, took part in this survey.



People supported by VODG survey participants

Aspects of support with health care which providers said were working well in some geographical areas were:

- Health Action Plans
- Relationships with community learning disability teams
- Use of a hospital book or passport
- The anticipatory care calendar
- Enhanced GP services

However, providers described good practice as localised, rather than consistent across the whole country.

THE CHALLENGES FOR CARE AND SUPPORT PROVIDERS

Providers were asked to list both their top three **successes** and **challenges** in relation to ensuring good health for the people they support. These were:

Top three **successes**

1. Improved monitoring of health and setting/achieving health goals. This included collecting good health data, increases in participation in screening programs and monitoring of health conditions.
2. Training for staff or the people they support on a variety of health issues, including increasing staff confidence to raise important issues with health professionals.
3. Initiatives to promote healthy lifestyles, including diet, exercise and reducing harmful behaviours such as smoking.

Top three **challenges**

1. Staff and the people they support having a low awareness about the importance of living a healthy lifestyle, including eating a healthy diet and taking exercise.
2. A lack of understanding by NHS staff, especially hospital staff and some GP's, of the difficulties accessing health services faced by people with learning disabilities.
3. Poor access to mainstream NHS community services.

> "Letters about screening are not accessible and do not explain what people are being invited to."
>
> Delegate at health inequalities event

> "There needs to be a clear understanding by everyone about the rights of vulnerable people to reasonable adjustments in A&E."
>
> Delegate at health inequalities event

WHAT WORKS? - REASONABLE ADJUSTMENTS

At our tackling health inequalities event delegates presented and discussed case studies and identified behaviours, attitudes and practices which have contributed to positive health outcomes for people using care and support services.

What works: reasonable adjustments

The NHS is required to make it as easy for disabled people to access health services as it is for people who do not have a disability. Reasonable adjustments are the context and person-specific changes which help make this possible. The importance of getting these right, and the role care providers play in this, were key themes in the case studies.

For example, adjustments to how NHS staff communicate with people are crucial to ensuring that deaf people receive the health care they need. Otherwise, deaf people can find themselves bypassed, excluded from conversations about their health, and their right to privacy ignored.

Other examples focussed on how workers' understanding of the individual can be used to help that person cope with an unfamiliar or stressful situation.

CASE STUDY: ACTION ON HEARING LOSS

Alan, who is deaf and has additional needs, required radiotherapy treatment. No interpreters were booked for the month of treatment due to cost and because the procedure was the same every day. However, the nurses needed to know from Alan how he was feeling on a daily basis.

In order to meet Alan's communication needs, Action on Hearing Loss staff created a well-being log covering all the questions the nurses would ask. They prompted Alan to complete the form every day before treatment. The nurses then used this to work out if Alan's treatment needed to be adjusted. It also helped his support provider to monitor the side effects of treatment.

The well-being log allowed clear and accurate communication between Alan, the radiotherapy nurses and care and support staff and enabled him to complete his treatment successfully.

KEY LEARNING POINT:

There are steps we can take to increase a person's autonomy and privacy in their involvement with health services.

Information on communicating well with people, with hearing loss, including training on deaf awareness and British Sign Language can be found at: www.actiononhearingloss.org.uk

WHAT WORKS? - REASONABLE ADJUSTMENTS

CASE STUDY: DIMENSIONS

Martin, who has a learning disability, had a seizure and needed to go to A&E. He had never had a seizure before.

Reasonable adjustment 1:
The paramedics wanted to take Martin to hospital in the ambulance. However, Martin gets very distressed around medical staff. As he was in his car at the time of the seizure, the paramedics agreed that he should stay in his own car and be escorted to hospital by the ambulance, complete with blue lights and siren.

Reasonable adjustment 2:
Once at the hospital the support worker ran into A&E and explained that Martin becomes distressed around medical staff. In order to help him stay calm, the staff who were to attend to Martin put on their outside coats so they just looked like everyone else.

Reasonable adjustment 3:
Martin was given medication and it was vital that clinicians observed his response to treatment. However, he insisted on leaving the hospital as soon as he could. Consequently, the service manager and the liaison nurse agreed that, as Martin loves car journeys, after he had taken his medication all three of them would go out in the car and the nurse would carry out the observations in the car.

KEY LEARNING POINT:

We can use our knowledge of people to help make their experience of health services more comfortable.

> “While the consultant has the clinical knowledge, we have the knowledge of the person.”
>
> Delegate at health inequalities event

WHAT WORKS? EQUIPPING STAFF

A high priority for social care providers is the need to equip their staff with the skills and knowledge to advocate for the people they support regarding their health, and to have confidence to engage in equal conversations with clinicians and other NHS staff. Providers described a range of initiatives to address this area of concern and there was consensus that there was more to be done.

> "It takes one brave person to make a difference."
>
> Delegate at health inequalities event

Behaviours and attitudes that help us to tackle health inequalities

- Viewing health as an essential element of the support worker role.
- Empowering staff teams to advocate for the people they support.
- Giving staff permission to have time to talk, reflect and discuss.
- Feeding back learning from events to staff teams.
- Following up on our commitments in the learning disability health charter.

Practices that have worked well

- Increasing staff confidence to engage with health professionals through providing a great induction, follow-on staff training and the use of coaching and mentoring.
- Consistently giving the message that staff are able to advocate and challenge on behalf of the people we support.
- Upskilling staff, so that they have the necessary skills and knowledge to support people in relation to their health.
- Ensuring staff have the evidence of how a person has been feeling to present to medical professionals.
- Involving teams in developing tools to support people well.

WHAT WORKS? DELIVERING GOOD SUPPORT

Collaborative relationships, high quality communication and record keeping and a willingness to engage in important conversations with disabled people and their families are areas of good practice that have resulted in better health outcomes.

> "If there is something wrong, do something about it."
>
> Delegate at health inequalities event

Behaviours and attitudes that help us to tackle health inequalities

- Helping the people we support understand that they are experts about their own health and wellbeing.
- Being brave, confident and challenging.
- Building trust with hospital staff.
- Asking the right questions; preparing by thinking about what you need to know from health professionals in order to support the person well.
- Thinking: 'What would I expect for someone I love?'

Practices that have worked well

- Having open, honest conversations with the people we support, their family members and staff.
- Developing accessible information that is specific to the person.
- Good communication and joint working between health and social care teams.
- Use of communication and hospital passports.
- Good planning and monitoring systems for health.
- Hertfordshire has introduced My Purple Folder; this contains all the person's health information and is taken to every appointment.
- Ensuring that we keep relevant historical information about people's health.
- Taking responsibility for coordinating best interests meetings.

CASE STUDY: TURNING POINT

Emma has a learning disability and complex health needs including Jubert's syndrome, which has resulted in kidney failure. This means that she required peritoneal dialysis (PD) on a daily basis and throughout the night, which significantly restricted her activities and quality of life.

Unfortunately, after eight years, her PD treatment began to lose its effectiveness and she started to experience life-threatening bouts of peritonitis. During one of these episodes, the hospital called a meeting to determine whether Emma should receive alternative treatment; it was anticipated that without treatment she would die within two weeks.

DIALYSIS

There are two types of kidney dialysis:

PERITONEAL DIALYSIS: where dialysis fluid is pumped into the abdomen to draw out waste products from the blood passing through vessels lining the inside of the abdomen.

HAEMODIALYSIS: where blood is diverted to an artificial kidney machine where it is filtered and then returned to the body.

CASE STUDY: TURNING POINT

Emma's support team presented a quality of life document, which showed how she spent her time, her plans, aspirations and hopes for the future. The document described the life Emma wanted. A transplant was ruled out by the consultant which meant that the only viable option was haemodialysis. However, the clinical team were concerned about the risk of infection should Emma touch an exposed line. The support team advised that they could provide minimal restraint, if necessary, when the dialysis lines were exposed. They argued successfully that this was the least restrictive option, as there was a real risk of death if the treatment was not pursued. The support team was given three days to undertake the required training and then Emma would begin to receive haemodialysis three times per week.

The change to haemodialysis has had a huge positive effect on Emma's quality of life. She is now able to go out for the day; she has joined a drama group which she loves and has been to discos. The change which has excited her most is that she has been able to go on holiday to Kefalonia. This was risk assessed by the consultant who specified that three fully trained support staff would be needed to accompany her. Her staff then contacted a hospital in Kefalonia who agreed to enable Emma to access dialysis whilst on holiday. Once the availability of dialysis was confirmed, the hospital renal team dealt with the final arrangements for treatment.

It has even been suggested that Emma may now be a potential candidate for a transplant. Without the staff team advocating so strongly on Emma's behalf, her outcomes and quality of life would have been very different.

KEY LEARNING POINT:

Persistence and skilled advocacy, based on an in-depth knowledge of the individual and their wishes, can change a person's life.

WHAT WORKS? SHARING GOOD PRACTICE

Learning from each other is key to improving how we tackle health inequalities. Delegates offered these top tips for sharing good practice, both within their organisations and more widely within the sector.

Top tips for sharing **good practice within organisations**

- Share good news stories via emails, newsletters, team briefs and social media.
- Empower staff to share their learning.
- Use case studies in team meetings.
- Use cross-organisational working to disseminate good practice.
- Use reflective practice in support and supervision sessions.
- Hold a stock of information and toolkits as internal resources that can be used as needed.

Top tips for sharing **good practice externally**

- Join an external task force or steering group.
- Post good practice on the organisation's website or in social media.
- Present at conferences.
- Be willing to share our learning when things go wrong.
- Take opportunities to work collaboratively with other providers, including through VODG.
- Offer placements to student nurses.
- Develop a magazine for families or other external audiences.

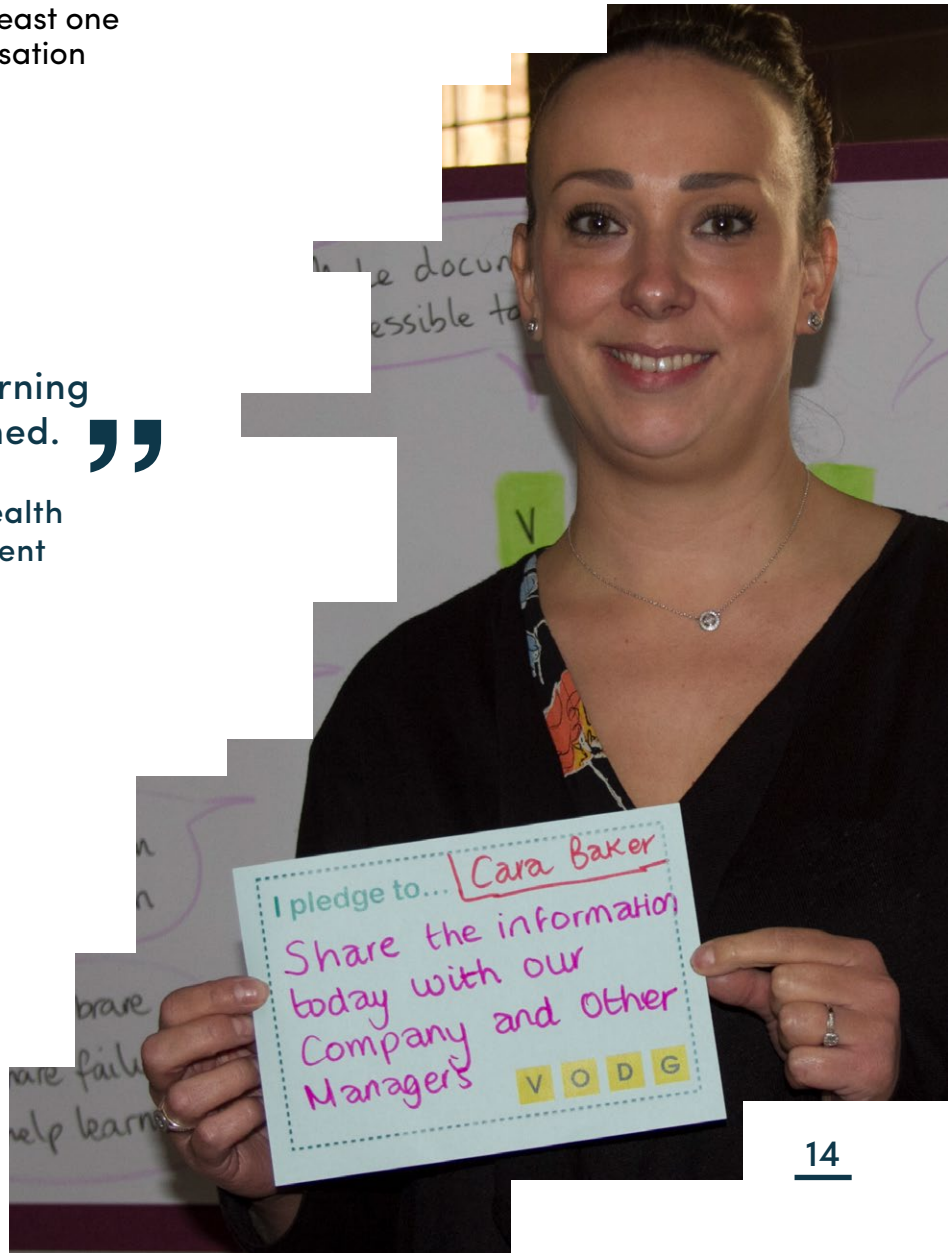
A COMMITMENT TO ACTION

Delegates made individual pledges to take specific actions to tackle health inequalities. There was a strong mutual commitment to continuing to share learning, tools and good practice. In order to support this, VODG will seek funding to produce an e-bulletin on tackling health inequalities. Each bulletin will have a different health or lifestyle theme. A list of topics will be agreed with members who will also be asked to contribute tools, case studies and learning materials.

VODG will host a further health inequalities event in 2018, with a least one free place per subscribing organisation to VODG.

> "We need learning to be sustained."
>
> Delegate at health inequalities event

> "How do we stop working in silos?"
>
> Delegate at health inequalities event



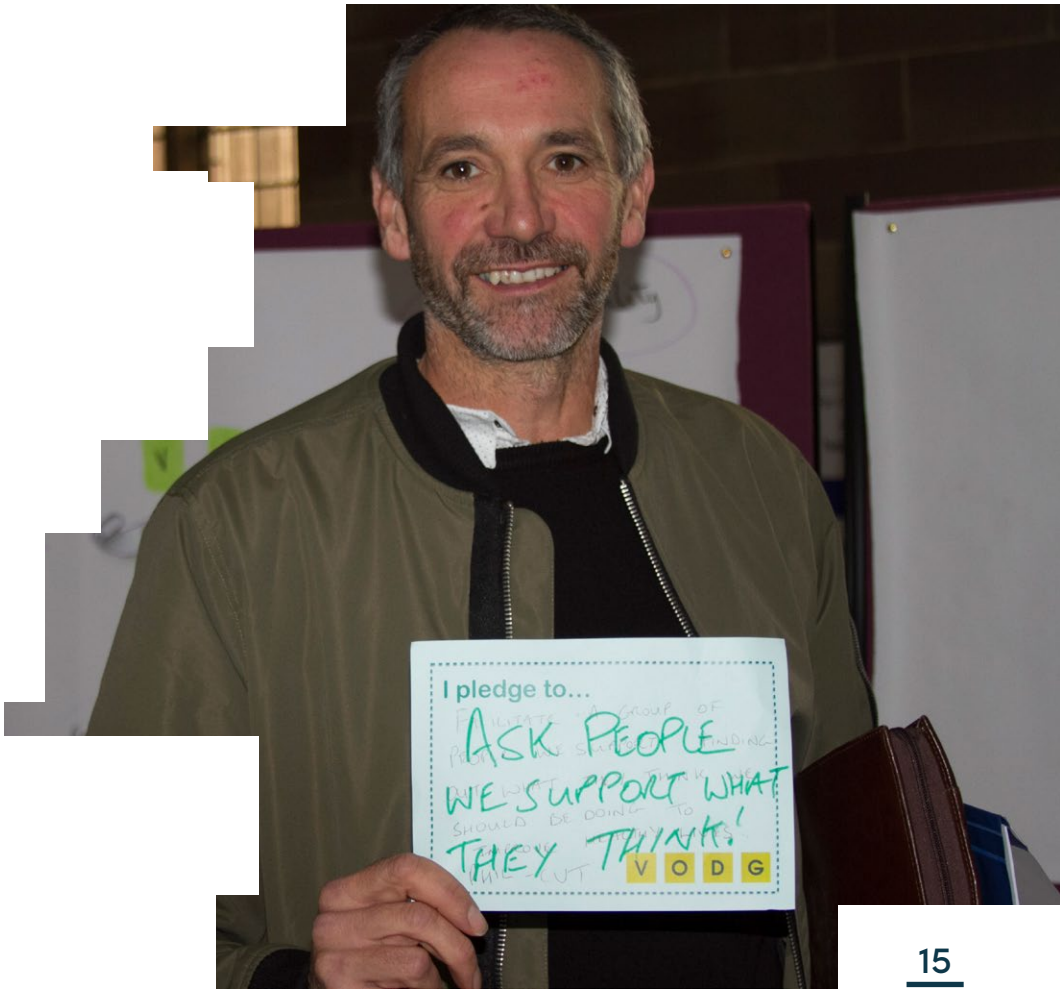
REMEMBER THE BIG PICTURE

Improving how we support people with their health needs is just one factor in delivering better health outcomes. Health inequalities result from the complex interaction of the social and economic inequalities experienced by disabled people. Good healthcare can contribute to an estimated third of the improvement in people's life expectancy. The remaining two-thirds has been attributed to activities aimed at:

- Changing lifestyle behaviours, such as diet and exercise.
- Tackling the social and economic injustices, such as unemployment and poverty, that lead to health inequalities.

Therefore, VODG will continue to contribute to the wider health inequalities agenda through championing the rights of disabled people in all our campaigning and practice development activity.

> "There is no competition between us when working on health inequalities."
>
> Delegate at health inequalities event



RESOURCES

- VODG has recently re-launched the learning disability health charter to include tackling over-medication. The revised charter can be found at: www.vodg.org.uk/campaigns/learning-disability-providers-challenged-to-tackle-health-inequalities
- The Tizard Centre offers a free massive open on-line course (MOOC) in autism. Further information is available at: www.kent.ac.uk/tizard/news/?view=1444
- SeeAbility provides easy-read information about eye care at: www.seeability.org/looking-after-your-eyes
- Information on communicating well with people, with hearing loss, including training on deaf awareness and British Sign Language can be found at: www.actiononhearingloss.org.uk
- Information about the Anticipatory Care Calendar can be found at: www.innovationagencynwc.nhs.uk/our-work/PatientSafety/anticipatory-care-calendar
- Information about My Purple Folder can be found at: www.hertfordshire.gov.uk/services/adult-social-services/disability/learning-disabilities/my-health/my-purple-folder.aspx

ACKNOWLEDGEMENTS

With thanks to the following member organisations who have contributed to VODG's tackling health inequalities steering group:

Action on Hearing Loss

Active Prospects

Dimensions

FitzRoy

Imagine, Act and Succeed

MacIntyre

Partnership Support Group

SeeAbility

Turning Point

United Response

Responsibility for any errors or omissions remain the responsibility of VODG.

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