



## **‘What good looks like’**

### **Building the Right Support Delivery Board Advisory group report**

**June 2023**

# **What Good Looks Like report**

This report was developed and written by the Building the Right Support Advisory Group.

Members of the advisory group include people with lived experience and family carers supported by the Health and Wellbeing Alliance.

The Local Government Association and the Association of Directors of Adult Social Services are Partners in Care and Health (PCH), supporting councils to improve the way they deliver adult social care and public health services. PCH has supported the advisory group to produce this independent report.

It was commissioned by the Building the Right Support Delivery Board.

## Foreword

Decades continue to pass in which autistic people and people with learning disabilities are knowingly marginalised, excluded, and have their human rights violated. Every so often the quilt of oppressive silence is lifted with a scandal and people see our subjugation for what it is – blatant human rights violations.

Like many others, my experience involved state sanctioned warehousing and routine restraint – chemical, physical, mechanical, and environmental. At its worst I was locked in a room and fed on the floor with only a mattress for company, while the eyes of those charged with caring for me looked on through a window like I was some rabid animal. Others have not been so lucky as me and have died the most degrading, painful, and horrific deaths. After media expose of our treatment, the abuse is decried for a short time, a report is commissioned in which people with lived experience are involved in a tokenistic way and then we are forgotten again. There will be no apology and the practices continue, hidden in plain sight. We deserve better.

A focus on ‘what good looks like’ in the community is a positive step forwards, however each time I have sat down to do the work I have felt tsunamis of frustration, anger, and resentment. Transforming Care failed me as it has failed so many others. The recommendations of previous reports have not been fully implemented, and there are concerns that the actions required for change in this report will not be enacted either. Tired staff are frantically trying to do what works in the context of a broken system that is creating harm to people. Therefore, to learn from these failures and value the solutions suggested by those affected, there must be wholehearted system changes.

We all know that autistic people and people with learning disabilities should live in their own homes, on an ordinary street, and in ordinary communities. It is obvious that we should avoid warehousing people in institutions, whose environments knowingly aggravate the autistic disposition and cause trauma. However here we are, in 2022, with autistic people and people with learning disabilities carted off to *hospital* because there are not the right services to meet our very ordinary and predictable support needs. This has been called a national scandal but really it smacks of far worse than that.

In our consultation with people with lived experience we spoke to no-one who had experienced anything that was consistently **good**. In the darkness of the system, people experienced only pinpricks of light. In all these instances professionals acted *despite the system*. This co-produced report has therefore sought to highlight these examples of good practice and draw out key principles that can be applied more widely. It also includes a list of necessary actions, to help Integrated Care Systems, and others know what they need to do to create better support in the community and prevent the over-reliance on highly restrictive and often abusive institutional models of care. There is nothing new in them. They have all been highlighted before. I suppose that is one strength of this report.

Ultimately, I have had to see this work as a means to 'say it how it is.' In doing so I hope it contributes in some small way to shifting power and changing cultures. As Norman Lamb said 10 years ago in the Foreword to *Transforming Care: A national response to Winterbourne View Hospital* (DHSC, 2012), 'It is about promoting a culture and a way of working that actively challenges poor practice and promotes compassionate care across the system'. It seems like Norman's vision is a long way off, simple as it is. We must once again wait to see what changes - if anything. Like the reports that have preceded this one, change will only happen if the principles and necessary actions are implemented effectively, and solutions are co-produced. In the meantime, I hope those currently being failed are as safe as they can be and that the sense of urgency and desperation people with lived experience feel is acted upon now.

Alexis Quinn, Co-Chair of the advisory group

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## Executive Summary

This co-produced report was commissioned from the Building the Right Support (BTRS) Advisory Group, as part of the wider action plan developed by the Building the Right Support Delivery Board. The advisory group is made up of people with lived experience, including family carers. The work was sponsored and supported by Partners in Care and Health, run by the Local Government Association (LGA) and the Association of Directors of Adult Social Services (ADASS).

The group spoke to people face to face and used online surveys to identify what people thought 'good' would look like. They also undertook a review of relevant published reports and searched and reviewed available evidence to gather evidence- also looking at previous reports and their recommendations.

Using the information gathered, the advisory group set out to find examples of 'good' community supports, to learn about them, and what it took to overcome some of the barriers to getting them in place.

This report includes seven key principles that 'good' community supports show in their day-to-day work. These are that 'good' community supports are...

1. Ethical: work to uphold human rights and operate within the law.
2. Creative: Finding solutions and thinking outside of the box to get there.
3. Personalised: Focused on the whole person, and what matters to them.
4. Agile: Work quickly to deliver what is needed.
5. Focused on valuing people: Seeing the assets people have, including those supported, parents, carers, and staff.
6. Pragmatic: Do all it takes to make things work.
7. Well led: They lead by example and influence wider system leadership.

In addition, the group consciously noted the concerns raised by people during their consultation. Many of the things people thought were not good, were echoed by others, and addressing the bad experiences, and their causes needs be tackled. Therefore, the advisory group looked at things as they are now, reflected on the good examples and considered what change is needed across systems to make sure that 'good' is experienced by more people.

They identified the actions needed to ensure that 'good' happens everywhere. These actions are particularly relevant for developing integrated care systems (ICS), but that also span wider community agencies. These are listed under ten key headings.

- Rights and Legislation
- Commissioning
- Homes
- Children and Young people
- A focus on the whole person
- Relationships
- Help when people need it.
- Funding

- Justice
- Employment

It is important to note that the actions are outlined in more detail in the report in section nine, and that they have formed part of the wider Building the Right Support action plan. It is hoped that they will also positively influence plans within some organisations that sit outside of health and social care.

## 1. Introduction

The Building the Right Support (BTRS) Delivery Board asked the advisory group to write this report. It includes an evidence base, principles, and examples of good practice about 'what good looks like' in terms of community services across England for autistic children and adults and children and adults who have a learning disability. In sharing this information, we aim to consolidate understanding of the necessary conditions and 'must haves' when it comes to achieving good outcomes in a sustainable way.

The BTRS Service model<sup>1</sup> identified a vision:

"Children, young people and adults with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition have the right to the same opportunities as anyone else to live satisfying and valued lives and, to be treated with the same dignity and respect. They should have a home within their community, be able to develop and maintain relationships and get the support they need to live a healthy, safe and fulfilling life."

The advisory group is aware that no-one area can fully demonstrate the delivery of this vision today, however through our work we are aware of initiatives that demonstrate some aspects of this vision, for example, those that are upholding human rights, demonstrating a capability approach, achieving better outcomes, and those that 'see the person first' exist. However, rather than these being widespread they are often 'uncommon practice.'

The advisory group have high ambitions about how things could be, this means acknowledging that a radical change is required, not only in health and social care but across the wider community.

This report will share the known barriers to making good happen and provide information and ideas about how to overcome them. A list of requirements for delivering 'good' within the community is included in at the end of this report.

This report demonstrates what can be possible when we create the right cultures and work together.

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<sup>1</sup> ADASS, LGA, NHSE (2015) Building the Right Support. Service Model for Commissioners of Health and Social Care Services. (Online) <https://www.england.nhs.uk/wp-content/uploads/2015/10/service-model-291015.pdf>

## **2. How this report was created**

The advisory group wrote this report after investigating what 'good' looks like. It used the following activities to do this:

- A review of relevant published reports and their recommendations
- An initial scoping consultation, that also gathered the insights and views of individuals.
- Searching for and reviewing relevant literature, and evidence gathering from previous reports.
- Information gathering on those services or supports that people told us were good.
- A second consultation to make sure that the information in the draft report was useful and relevant.

### **Ethical considerations during consultations**

The advisory group were keen to ensure that stress for individuals was minimised during the gathering of insights and views from individuals. For example, at the beginning of the sessions facilitators made it clear that people could leave at any time. In all the meetings there were others present who knew the people providing feedback, and there were regular checks from facilitators asking how people were finding the session.

Prior to the group feedback from people with lived experience, people were briefed about the What Good Looks Like project. It was made clear that people had a choice about whether to join in with sharing their views, and that people should only share what they feel comfortable sharing.

All individuals had a known advocate, support or family member with them during the discussion. The focus of the conversations was aimed at reflecting on 'what good looks like.' If people recalled negative experiences, these were reframed looking at what could be better, and the actions that could be taken to improve the experience of people and families.

### **2.1 Review of previous relevant published reports.**

The advisory group are aware of over 20 previous reports which had made recommendations about the improvements needed in community supports and services. Therefore, a review was conducted, so that previous learning could be gathered. (Appendix 1)

We found that although many of the recommendations in the reports influenced national guidance or policy, there was often a lack of evidence that they directly influenced practical change on the ground. Some influence from these reports is pending particularly in relation to recommendations related to the Mental Health Act review, and some changes are hindered by lack of wider reform, including delays in social care reform.



Other work has been undertaken to identify those factors that make a positive difference to individuals. ‘Helping people thrive’<sup>2</sup> identifies those things that make a real difference to people, including organisations and individuals who ‘go the extra mile’ in making sure that the right help is there for people when they need it. It is clear that having this everywhere requires commitment and good national and local planning to make it work.

We are also aware of very recent reports, including the Care Quality Commission report ‘Out of sight – who cares?’ (2022).<sup>3</sup> The findings in this report highlight the urgent need for good support in the community:

**“...overall, we found that people got better care in the community than in hospital. Services generally had a good understanding of people’s needs and tailored their care and environment accordingly to meet the needs of the individuals.”**

## 2.2 Search and review of relevant evidence

In order to expand understanding of the current context, a review of available information and evidence gathering was undertaken to see what wider published research was telling us about the issues raised in the consultation.

The majority of the evidence presented came from published systematic reviews and draws from a wide range of published studies, where these were available. All of these were published in peer reviewed journals, but a small number of studies are independent evaluations or studies undertaken by expert organisations.

The table below presents the evidence gathered from a wide range of published research. It is presented using a series of questions and then the summarised findings seek to answer those questions.

Question	Findings
Does co-production secure better outcomes for individuals and reduce costs?	Yes: There is evidence from a range of different sources. The Named Social Work pilots also found cost reductions and a good return on investment.
Do the perceptions and views of health and social care staff influence how they support individuals?	<p>Yes</p> <p>The absence of training about and experience of working with individuals with a learning disability and autistic people resulted in</p> <ul style="list-style-type: none"> <li>• professionals being more fearful of the individual.</li> <li>• less likely to co-produce care planning or treatment information with the individual and</li> <li>• were more risk averse</li> </ul>

<sup>2</sup> <https://www.learningdisabilityengland.org.uk/wp-content/uploads/2020/06/Helping-People-Thrive-0000002.pdf>

<sup>3</sup> <https://www.cqc.org.uk/publications/themed-work/rssreview>

Can the barriers to self-directed support be overcome?	Unclear. Evidence in this area is unclear with the last evaluation of the Scottish government's work to implement self-directed support being undertaken in 2017. Broadly it can be said that work to systematically understand actual, rather than perceived barriers, and the actions required needs more work, recognising the vast range of individuals who could use self-directed support.
Are universal mental health services putting in place adaptations to meet the mental health needs of autistic people and people with a learning disability?	No. Evidence found, <ul style="list-style-type: none"> <li>• a high use of emergency departments to access mental health and physical health services,</li> <li>• poor knowledge and skills amongst psychiatrists and</li> <li>• a large-scale meta-synthesis found mental health services do not adequately support autistic adults and can even cause additional harm.</li> </ul>
Do strengths based social work practice deliver better outcomes?	Unclear. National Institute for Health and Care Research literature review did not find clear evidence that strengths-based practice delivered better outcomes BUT the evidence review conflated evaluation of social work practice with an evaluation of community asset building activity. Other smaller reviews have found evidence of practice.
Is Positive Behaviour Support (PBS) an effective intervention?	Yes. It is effective but only when done properly. One randomised control test found no evidence of impact but compliance with PBS methodology was poor. Other studies have found good rates of effectiveness.
Is the right to develop and experience intimate relationships recognised in how services are provided to people with a learning disability and autistic people?	No. The research shows that for people with a learning disability that the perceptions and views of support workers, professionals and family carers can act as barriers to people with a learning disability establishing and maintaining intimate relationships. These barriers were further amplified for LGBTQ+ individuals. For autistic people it was found that research in this area is very undeveloped with previous research either completely overlooking it or focussing on sexual offences. More recent research designed with autistic people has identified priorities for future research.
Are social care and NHS services aware of the needs of specific race, culture and faith groups in the way services are provided to people with a learning disability and autistic people?	No. Research indicates that whilst issues of double discrimination have been highlighted for many years that action to reduce discrimination and secure equity of service/outcomes has not progressed

<p>Is inpatient provision for young autistic people meeting its obligation to support young people who are starting to, or have, identified as Lesbian, Gay, Bisexual, Transgender Queer+? (LGBTQ+)</p>	<p>No.          Limited research findings but insight gathered on NHS mental health LGBTQ+ specific provision showed that there is a lack of insight/understanding about the need to provide specific and adapted services.          Insights from autistic young people who identify as LGBTQ+ indicate that discriminatory, inappropriate and insensitive language is used.</p>
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These findings from the review of existing information identified that good practice is not always systematically implemented. This negatively impacts upon those things that people told us were important to them in order to live a good, ordinary life.

There are also wider inequalities, including gender that affect specific groups. For example, more than 22 percent of autistic women are hospitalised for a psychiatric condition by age 25, a fraction five times higher than for women without autism and nearly twice that of autistic men.<sup>4</sup>

We also found from the review of previous reports, that recommendations have not always been fully implemented. This also related to information provided in the later focus groups, when people shared with us that there appeared to be a lack of accountability, not only in relation to compliance with report recommendations, national guidance, research findings on best practice, but also in relation to legislation; in particular, legislation relating to human rights and equality.

Through feedback from individuals, examples of good practice were identified, but this raised a question about ‘Why some areas have ‘good’ examples of services or support responses, whilst others do not?’

One aspect that this report considers is the importance and impact of culture in creating solutions that work. Strategies, laws and guidance may be written, but it is whether (and how) these are implemented that determines whether this positively impacts on people and their lives.

It is important to understand the relevance of culture in those places and organisations where ‘good’ happens. In this report, it is vital to not just note what was good, but how it came about, the motivations for change, and what barriers had been overcome to make ‘good’ happen. From this a number of key principles for good practice were identified.

The health and social care landscape in which we operate is changing. There is a potential danger that whilst change means to bring about benefits, sometimes unintended outcomes happen as a result of change. The potential changes in the Mental Health Act may lead to increased numbers of people in other parts of the wider system, such as

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<sup>4</sup> <https://www.spectrumnews.org/news/psychiatric-conditions-hospitalize-almost-one-in-four-autistic-women-by-age-25/>

prisons. This has been termed 'The Penrose Hypothesis'<sup>5</sup> and we should be prepared to have a broader view and a coordinated response to anything that could create problems.

It is this learning that is valuable to share with others, in the hope that can be used to support positive change elsewhere.

## 2.3 Feedback from the initial consultation

### What do we mean by 'good'?

An initial consultation with autistic people, people who have a learning disability and their carers, in online groups helped us understand what people thought was 'good' in their lives. Fifty-four people attended these groups in total. People participated from self-advocacy groups, including a group of young people and their parents. Invites went to groups and members decided whether they would take part in the discussions.

An online survey was used to find out more from an additional 547 people. This provided the group with the views and opinions from individuals about what mattered to them, and also examples of what they thought good looks like. (Appendix 3)

It is important to state that the consultation enabled the advisory group to understand the views and insights of a significant number of respondents but acknowledge the limitation that this feedback cannot be fully reflective of the experiences of **all people** with a learning disability and autistic people and therefore be generalised.

During the groups and in the survey a large number of people reported negative experiences of support, which they shared. During this process individuals were supported by group facilitators and some also had support from carers and/or parents. Ahead of the discussion, guidance was also given to people to share only what they felt comfortable sharing, and that they could leave the session at any time. Facilitators also sought to use an appreciative inquiry approach asking, 'What could have been better?' This enabled people to say what could have made a difference, and this helped to identify the kinds of support, or gaps, to investigate further. Much of this information was used to help create the necessary actions to make good change happen.

In the groups four main questions were asked

- What does good look like to you?
- What support do you need to have this good life?
- What are the barriers to getting the life you want?
- Are there any great services or support you'd like to tell us about?

Feedback from people said that 'good' includes having:

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<sup>5</sup> <https://www.cambridge.org/core/journals/the-british-journal-of-psychiatry/article/penrose-hypothesis-in-the-second-half-of-the-20th-century-investigating-the-relationship-between-psychiatric-bed-numbers-and-the-prison-population-in-england-between-1960-and-20182019/B2DBE9F9D0E92A96B9AFC340FA7A3713>

- Choice, control and autonomy – people spoke about having sufficient money to explore, choose and buy in their support.
- Getting the right support at the right time – the financial freedom to get what you need, when you need it. At the centre of this is being able to buy support from people who see caring as a career and who are well trained.
- Being valued and treated with dignity and respect – mutuality, feeling supported in decision making.
- Young people’s experience reflected a lot about the need for belonging and acceptance. They explained that segregated settings are sometimes chosen because of feeling unwelcome in some mainstream schools or society, some young people reported that they are regularly bullied in their everyday life. Many of these issues related to wider societal culture and the need to have their human rights fully supported, this has also been confirmed by recent research<sup>6</sup>

Fundamentally the feedback was that ‘good’ reflected the need for...

***“The same stuff as every other human”***

This included appropriate housing, a choice of education (mainstream, proper inclusion, special schools, courses) and having loving relationships and purpose.

The advisory group reflected on the initial feedback and identified that it aligned to the Keys to Citizenship<sup>7</sup>.



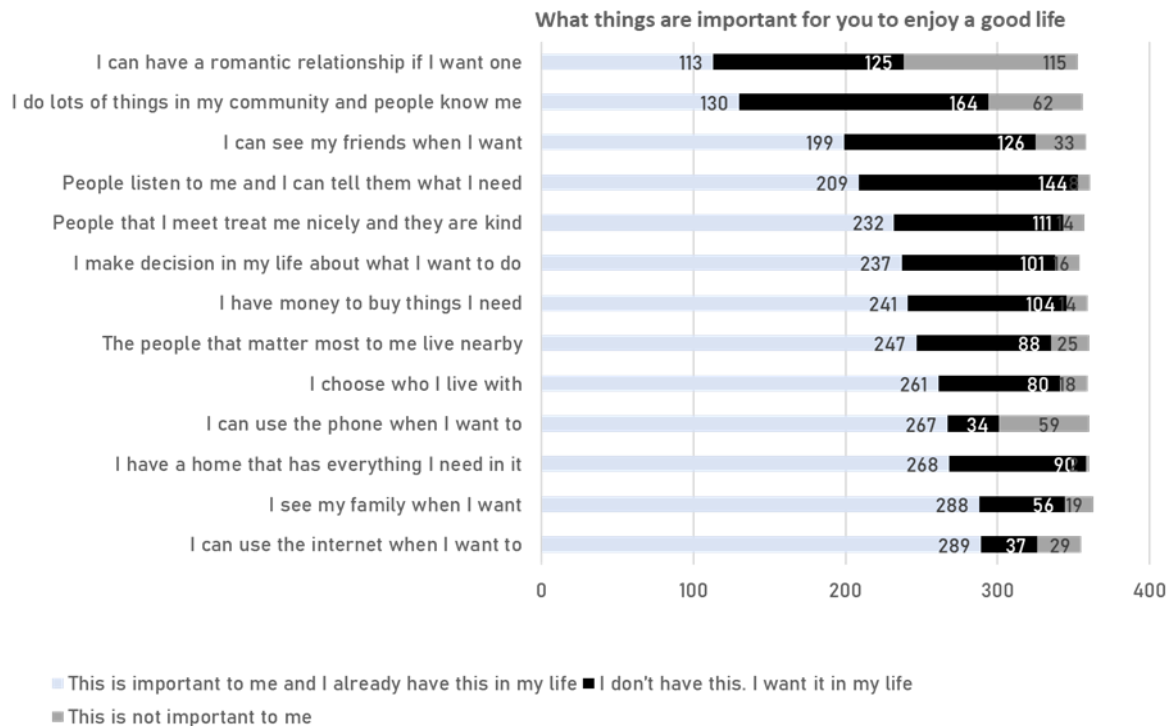
**2.4 Findings from the survey**

A key point from the survey is that ‘good’ relies on the right responses and support across our wider community. It spans aspects of life that are beyond health and social care.

<sup>6</sup> <https://www.scope.org.uk/campaigns/disability-perception-gap/>

<sup>7</sup> <https://citizen-network.org/library/keys-to-citizenship2.html>

Housing, education, work, responding to hate crime - including bullying, and the need for better access generally were all cited.



The bar chart shows the things that people felt were important to have a good life. Survey responses indicate that there are four areas where the most people did not have it but wanted it in their lives.

- Activities and visibility in local communities.
- Control: people being listened to about what is needed and making sure action followed.
- Romantic relationships – which scored higher for “I do not have this and want it” in the second tranche of survey responses.
- Seeing my family, use of the internet, a home with everything I need, and I choose who I live with score highly for ‘important to me and I already have this in my life.’

A further question asked: ‘What support do you need to live a good life?’ These were the answers:

- **Advocacy, co-production, and better communication skills from support workers:**
  - This included being listened to, having control over how services are provided and the right expertise/skills in services (both the survey and text responses).
  - Increased access to social workers (adults and children’s) was a strong theme in the text responses alongside requests for increases to care package provision.
- **Improving understanding of neurodiversity in schools and Special Educational Needs and Disability services:**

- This was highlighted in the text responses indicating further support was needed to help young people access education in schools with appropriate skills and experience of supporting children with neurodevelopmental conditions.
- **Health equity and more awareness of diagnostic overshadowing:**
  - Support from health services and specialists emerges a consistent theme for all the questions asked. Whilst not receiving the most mentions, it was consistently referred to.

This was useful feedback as it helped the advisory group to focus on the right supports and services, which could demonstrate good practice.

## 2.5 Gathering information about ‘good’ services and support

It was these aspects of good practice shared by respondents that helped identify those supports or services that could be explored further. Direct suggestions from respondents about specific examples in these areas were considered for further investigation.

Selected initiatives were identified using feedback from the group participants. Key leads for those organisations were then interviewed by an advisory group member using a list of questions (Appendix 4)

Answers to questions described:

- What the support or service is, where it takes place and who it helps?
- The environment in which the good practice takes place?
- How was the support or service set up?
- The challenges that have been overcome.
- Who helped and what their values, beliefs and motivations were?
- How better solutions were achieved?
- How much it cost to set up and run the initiative?
- What the future holds?

## 2.6 The second consultation

Once a draft report was completed, the advisory group went back to the same first face to face groups to discuss the report. The purpose of this was to check back with groups that the report accurately reflected the early scoping sessions with them, and also to see what their perceptions were, related to the principles and actions.

There was a strong consensus that the principles and necessary actions were suitable and appropriate with no disagreement about the content.

Most attendees expressed the things that needed to change. It was a sharp reminder of why getting community support right is critical. One mother told us:

**“My daughter has been in 19 hospitals in the last 14 years.”**

A list of comments was collected following the second consultation sessions and reviewed against the document. Whilst most comments reinforced the actions and principles already outlined this report some adjustments were made to reflect additional comments or proposed ideas for positive change.

### 3. System barriers to getting the right support to the right people at the right time

Our initial review identified a number of barriers experienced by people within our communities. These barriers included:

- That practice across the board has not fully changed to reflect the recommendations, guidance and strategies published since the response to Winterbourne View in 2012.<sup>8</sup>
- Long-term change has often been hampered by short-term planning with service redesign and financial planning constrained in short time scales. In some instances, there was a culture of seeing commitments as a one-off time limited activity.
- No co-production can lead to the wrong support offered at the wrong time. The risks individuals present are often poorly understood, and strategies too often focus on staff ratios or restrictions rather than working with individuals to mitigate risks.
- People are often expected to fit within ‘funding categories’, and their holistic needs get lost whilst organisations debate the category an individual should be fitted into and, therefore, who pays. This also causes delays.
- There was a view that there is too much focus on gatekeeping and eligibility criteria, with the result that both time and money are wasted on deciding whether someone can have a service, rather than providing the right support at the right time. One parent remarked: **“How bad do things have to get before I have the right criteria for a service?”**
- Often the low levels of co-production (at all levels) presented a significant barrier to development because working with individuals and families helps leaders to know what needs to be put in planned for and put in place.
- The language used across services creates a barrier because it directly influences how we think about people and their aspirations. Language is important to address as it impacts on conceptualisation and beliefs.
- A system wide lack of accountability that allows for a wide range of unlawful practice to go unrecognised and unchecked in some places. This related to a

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<sup>8</sup> <https://www.gov.uk/government/publications/winterbourne-view-hospital-department-of-health-review-and-response>



number of areas, but particularly the requirement for local authorities to make sure that people who live in their areas receive services that prevent their care needs from becoming more serious or delay the impact of their needs. (Care Act 2014)

## **4. Overcoming barriers – developing key principles**

After the semi-structured interviews with providers, an analysis of how those community initiatives had overcome barriers and delivered 'good' support or services took place. The findings were summarised into seven key principles of practice that the examples demonstrated.

The seven key principles were identified by looking at two factors. Firstly, the accepted barriers that exist in trying to deliver 'good' services and supports and secondly, the activities or qualities needed to overcome these.

## **5. Seven key principles of good practice**

Below are the seven key principles of good practice identified for good support to thrive. Brief examples have been provided that demonstrate these principles in action. Further links have been added that provide a full case study and website links.

**All these providers are community based and were selected because of how they demonstrated one of the key principles identified. It is important to note that these examples were selected at a moment in time and how they operate may change in the future.**

### **5.1 Ethical**

Barriers can be overcome by using rights-based approaches to working with individuals and protect their human rights. This is reflected in people's values and in how they support people.

Too often, human rights are not upheld, and people can experience overly restrictive practice. This has been a widely reported and a long-standing problem, with devastating outcomes for some autistic people and people with a learning disability and leading to overly long stays in hospital, abuse and in some cases death.

Without working ethically and in line with legislation, the situation is unlikely to change. Some of the people we spoke to felt that the perceptions of seeing hospital as a safer place for people to be failed to acknowledge some potential risks to the person, including the trauma of being in a strange environment away from family. Conversely there was a view that positive risk taking related to living life as part of a community, was not widely supported using human rights-based approaches. This is a long-standing issue:

**“Some families report that services are extremely risk-averse, to the extent that they injure the person’s quality of life rather than manage the risks involved. ...As well as prejudice and discrimination, expectations of what is possible to achieve are very low.”<sup>9</sup>**

Jim Mansell (2010. Raising our Sights)

Failure to support rights and enable positive risks to be taken in the community means that there is a risk of continuing in the same way, creating harm that is costly in terms of individual distress and a potential misuse of our public resources.

As part of this approach, some people told us that voices need to be heard. Advocacy support has in some areas been diminished as demands on funding increase. By making sure that the voice of people is heard, listened to and acted upon, leaders will know how to develop proactive plans that deliver “good” the first time, and can help to avoid wasting time and resources in the longer term.

Therefore, system leaders, and particularly those with Senior Responsible Officer roles in emerging Integrated Care Systems, need to value this “independent voice” and actively nurture it in order that they know what needs to change at place based and neighbourhood levels.

Once people are living in the community, we need to avoid the potential for harm created through exclusion. The view of the advisory group and of the people we spoke with is that this approach needs to make sure that our wider communities are welcoming of all, and that together we co-produce the right reasonable adjustments so that the Equality Act 2010 is upheld by enacting the public sector Equality Duty.

The Act has three aims:

- Removing or minimising disadvantages suffered by people due to their protected characteristics.
- Taking steps to meet the needs of people from protected groups where these are different from the needs of other people.
- Encouraging people from protected groups to participate in public life or in other activities where their participation is disproportionately low.

There is growing evidence that disabled people are not having their rights upheld, and many public services still are inaccessible.<sup>10</sup>

Therefore, the necessary action to deliver ‘What good looks like’ everywhere is **to uphold the human rights of the individual, and work within the law and statutory guidance.** Everyone has rights embedded in statute, and not meeting these is unlawful and can waste time and resources.

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<sup>9</sup> <https://kar.kent.ac.uk/24356/>

<sup>10</sup> <https://www.lgo.org.uk/information-centre/news/2022/may/equal-access-for-all-should-be-at-the-heart-of-services-ombudsman-says>

In order to consciously work in a human rights-based way, organisations need to build this way of working into their processes, including their policies. Staff should be trained and supported to understand how their actions uphold human rights.

The way that we work to support individuals and families, needs to be inclusive and evidence based. This means using really good co-production in developing those policies and processes that influence working cultures, as well as at an individual level. People need to know how to do this as a natural part of their role, because they believe in the values and beliefs that underpin this.

Another aspect of the ethical principle is that people keep each other to task and call each other to account. This means that leaders allow for assertive challenge to take place within organisations, and they create safe spaces and processes for this to happen.

Arguably, good inclusive community approaches consider those general initiatives that might happen across a specific city or neighbourhood and develop them to make sure that discrimination and exclusion does not happen.

**‘From a human rights perspective, inclusion requires addressing discriminatory structures that have led to exclusion, deprivation of resources and lack of opportunity.’**

United Nations, Office for Human Rights

Examples of initiatives that support the ethical principle were selected because they demonstrated aspects of this approach in different ways.

**The Halton Intensive Support team** are using a human rights-based approach to risk management and believe that a fundamental paradigm-shift is needed in the way care is planned, delivered, and monitored- and that for the right kind of support to be ‘built’ and for restrictive practices to reduce, care needs to be underpinned by the legislative backbone the Human Rights Act 1998 provides.

They use the previously devised ‘Keeping me Safe and Well Risk Assessment’ (KMSAW; Lee et al., 2008) and the framework of the Human Rights-Joint Risk Assessment and Management Plan (HR-JRAMP; Greenhill et al., 2008) to support people. This human rights-based approach pulls together a range of theories and models to best meet people’s needs and works more broadly than a behavioural model on its own. The approach uses tools that have been co-produced by people with learning disabilities that are accessible.

The result of using this approach is that people being admitted to hospitals has significantly decreased following the implementation of a human rights-based approach to intensive support.

- Read the British Institute of Human Rights publication called [The Difference it Makes Putting Human Rights at the Heart of Health and Social Care](#).

**Sheffield Voices** values its “independent voice” and campaigns to uphold the rights of disabled people by educating and training individuals and services, it ensures that the voices of people with a learning disability and autistic people or both are heard in local, regional, and national policy making.

It helps people by:

- Encouraging commissioners and managers to listen and act to their concerns
- Bringing people together to support each other and find solutions to problems they may have encountered
- Building on individual strengths and skills to deliver activities and projects

By using their collective voice, Sheffield Voices have been influential in changing approaches in a range of organisations including Sheffield Health and Social Care NHS Trust, housing, transport, and primary care. This supports a shared view that people having the right to equal high-quality services, and that this is recognised by organisations.

- Access [the case study about Sheffield Voices](#).
- Access the Sheffield Voices [About Us](#) web page.
- Access the Sheffield Voices video [Speaking Out on Issues of Abuse at Firshill, Sheffield](#).
- Access the [Learning Disability England Barriers to Self-Advocacy](#) paper.

**The Autism and Learning Disability Digital Inclusion Network (ALaDDIN)** is part of the 100% Digital Leeds programme which promotes inclusive digital support to help people with jobs, health, and social participation. – 100% Digital Leeds is core funded by Leeds City Council with additional short-term funding tied to specific projects including from Leeds CCG (ICS) and one-off central government funding streams.

The programme is rooted in the city’s long-standing work to reduce poverty and economic inequality, and to secure healthy and fulfilling lives for all its citizens.

ALaDDIN explicitly recognises that people with a learning disability, autistic people or both can be excluded from the digital world and was established in response to Covid-19 with a focus on addressing the digital divide experienced by this group.

This programme has a focus on outcomes: in itself, increased digital inclusion is not the driver for change, but it is being used as an enabler to include more people in the workplace, secure better health for more and to increase social participation.

- Read the [full case study about ALaDDIN](#)
- Access [the Digital Inclusion video from ALaDDIN - Forum Central](#)
- Find [a description of the network](#)
- Read [an evaluation of the digital inclusion work by Leep1](#)

## 5.2. Creative



Barriers are overcome when people are confident at finding solutions that work for individuals by listening to their aspirations. They work with families as true partners and listen and act. They are adept at working with partners inside and outside of local government and the NHS to help people achieve their aspirations. Funding and other resources are used creatively and are not constrained by bureaucracy.

Building the Right Support is based on tailoring the right support at the right time, with people in their own homes. Yet we are aware of times when people are still expected to 'fit' into things that are already there. We even heard examples of places still developing provision that does not allow for full choice and control to be available. This often leads to problems as unsuitability of support and/or accommodation which then contributes to a breakdown.

What each person needs is unique and both planning for this and getting this in place can be challenging. It is likely that organisations have not had to fund or support unusual or unique requests in the past. Really listening what matters to the person and responding to it demands that we are flexible in the ways we find and use resources, and indeed how we work within the existing 'rules.'

People told us that getting timely support (and preventing escalation of needs) is hampered by the barriers in place for people to meet eligibility criteria for a particular service. The 'rules' of who gets to use a service are often enshrined in eligibility criteria. This had for some people created a crisis that could have been avoided if support had been offered earlier. Indeed, it is ironic that the eligibility criteria is put in place to protect resources in one place can end up with a much higher spend in another part of the system, along with unacceptable levels of distress and trauma for people and their families.

Part of working creatively means that we have to shift from old ways of doing things to new creative ways of working. Working creatively demonstrates the need to move away from heavy professionalisation and specialisation to much more collaborative, transparent ways of working sometimes described as a DIY 'maker culture,' that reflects the shift in power, and indeed supports New Power<sup>11</sup> values. Some of this maker culture is reflected in the way that good organisations use community assets and seek funding from a wide range of sources to complete the mission to which they are committed.

In terms of the creative use of resources, organisations may be fearful about how taxpayers view them if they use funding in creative ways to meet needs.<sup>12</sup> Part of the challenge is to focus on prevention and outcomes for the person, rather than outdated notions of what constitutes 'treatment.' Furthermore, the costs of this 'treatment' including the costs of inpatient care, may be far in excess of the less costly, creative solutions that could have been used earlier to avoid crisis.

The aim is to involve people in designing the solutions that work for them and to provide the individual funding to deliver the unique things that will make a difference.

Organisations who demonstrated 'good', take their time to listen to what people's communication (including behaviour) is telling them, and they build relationships with people so that communication through behaviour is consistently understood, and creatively responded to.

They also adopt a learning approach realising that people change over time and what might have been a good solution five years ago may not work today.

Creative use of resources and being able to work flexibly within guidance and legislative frameworks is crucial to delivering good support built around the person, according to their preferences. They also adopt a view that everything is possible and that by using 'strengths-based' approaches this is a realistic expectation.

Organisations that can provide very bespoke provision are a developing feature across England and elsewhere in the UK. This activity needs full support to create responsive providers that offer flexible, bespoke and creative support for people in their own communities. Staff are matched to work with the person, and they are sourced from those

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<sup>11</sup> <https://hbr.org/2014/12/understanding-new-power>

<sup>12</sup> <https://www.theguardian.com/society/2015/sep/01/nhs-scheme-provides-holidays-satnav-and-pedalo>

communities where people choose to live, maximising all their local knowledge to help people be part of local life if they choose to.

**"Where, after all, do human rights begin? In small places, close to home – so close and small that they cannot be seen on any maps of the world. Yet they are the world."**

**Eleanor Roosevelt**

This means having supportive commissioning that recognises that getting to really know a person takes time. This is no 'one size fits all' but understands exactly what the person needs, including recognising previous trauma, triggers and the things to avoid, as much as the things to try out and explore.

**Imagineer** was founded on inclusive principles and was set up to work with any person contacting the organisation with the intention of developing of community of self-direction. with the intention of not recreating the silos of the health and social care system. Imagineer helps the person be in the driving seat of their own lives and to identify the resources available to them starting from a place of community.

Through the years of experience gathered through the community developed around self-direction inadequate understanding or misunderstanding of the regulatory framework for assessing care needs, direct payments and personal budgets has been identified and challenged Imagineer seeks to work through this by holding onto two beliefs:

Everything is possible - the prime meaning here is to think beyond what is available via service structures to think about what is possible from a place of community and a wider perspective on resources.

Asset based viewpoint: how do we make and create new resources with individuals rather than fitting them into what just happens to be available – and avoiding the square peg round hole scenario?

The conversation starts with 'what does a good life look like' followed by 'how can we make that possible?' Rather than this is your level of budget and how do you wish to use it? People are good with their money and make it work for them,

**"Some people may have big ideas of what they want to achieve – but they do not expect their personal budget to pay for them."**

- Read [the full case study about Imagineer](#)
- Visit the [Imagineer website](#).
- Read [Monica's story](#).

## 5.3 Personalised



A barrier shared with us by people in our consultation was that rather than be seen as whole people, many people are instead ‘fragmented’ by their various diagnoses or the specific services that they need to use. “Good” support demonstrated true person centredness and aimed to understand the whole person. These supports use the tools that are human rights based or person centred to help build plans with people using conversations (not standardised assessments) based on asking ‘What matters to you?’ rather than ‘What is the matter with you?’<sup>13</sup>

Personalised care has been a part of health and social care policy for decades, and yet many autistic people and people with a learning disability told us that they still experience an approach that sees their ‘condition’ first and not them as a whole person. This results in autistic people, or people with a learning disability telling their story over and over again, with services never really seeing their holistic needs or even their personal strengths.

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<sup>13</sup> <https://www.england.nhs.uk/south/our-work/integrated-personalised-care/embedding-integrated-personalised-care/>



Personalised care is a key principle of health and social care policy and yet it remains a challenge to make sure that autistic people and people with a learning disability have full access to shared decision making, social prescribing, personalised care and support plans, personal budgets (Including the 'right to have' a personal health budget as part of S117 aftercare)<sup>14</sup> and supported self-management.

We know that evidence shows that people will have better experiences and improved health and wellbeing if they can actively shape their care and support.

Having support or services that do not meet a person's unique need and expects them to 'fit' into a standard service creates barriers of access and reduces the usefulness of what is on offer. Additionally, it often does not comply with the Equality Act 2010. When these are critical services, like psychological support, this can have a serious negative impact on the wellbeing of the person and those around them.

Not having access to work has an impact too - having money to do the things that people want to do in life means that paid employment is important, yet in 2021 in the UK, disabled people with severe or specific learning difficulties, autism and mental illness had some of the lowest employment rates compared to the wider population.

Good organisations really 'get' the person and take time to find out what works for them. They adapt their approach according to what individual people need and in doing so help to address the inequalities faced by individuals to make sure the 'same stuff as everybody else' can be accessed by all.

**Respect for All** is run by a registered charity offering counselling and therapy for children, young people and adults across Greater Manchester. Their approach is different because therapy is changed to fit the needs of the person. It recognises that people with a learning disability and autistic people do not fit into the standard Improving Access to Psychological Therapies (IAPT) and the early support offer that is offered to the wider population.

**“We believe counselling is for everyone and everyone is different. The smallest of changes can make a huge difference to someone's life. Our work is guided by the needs of our clients.”**

Therapists work closely with people to develop their approach which is adapted and changed to the person's needs. These changes might mean offering individual therapy sessions for people who find group therapy difficult to cope with or agreeing a pace and type of help that fits the person and ensures that sensory and processing needs are appropriately met.

The service provides a strengths-based approach to working with individuals experiencing anxiety, depression, 'stress of fitting into society,' loneliness, social isolation, and trauma. It also works with families to develop strategies for supporting family members. The result of this way of working is that people feel listened to, and individuals feel able to take further steps after they have attended.

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<sup>14</sup> <https://www.england.nhs.uk/wp-content/uploads/2014/09/guidance-on-the-legal-rights-to-personal-health-budgets.pdf>

“Finally, someone understands and sees me.”

- Read the [full case study about Respect for All](#)
- Visit the [Respect for All](#) website

**PLUSS Plymouth Autistic Employment Project** is commissioned by the Department for Work and Pensions, Job Centre and run by the Community Flexible Fund and the Council. People are referred by the job centre and the project welcomes those who have either been identified as neurodiverse by job coaches, those who identify as neurodiverse, those with an autism diagnosis and it does **not exclude people waiting for a diagnosis**. The service is for individuals who want to have a job but have struggled with obtaining or retaining employment in the past.

Time is taken to listen to people, including what their preferred method of communication is and, to ensure that the individual does not have to repeat their story, the information held by different agencies is collated in one place. They find out a bit more about what they want to do next, and a bespoke approach is developed for everyone. This could include work experience, help with writing a resume or job application, or work placements in specific roles. It focusses on first working with the individual to reduce social isolation or some wellbeing activity, if that is what is agreed. They also work with prospective employers including making sure that reasonable adjustments are in place and ensure that the interview environment reflects the person’s sensory needs.

The service also provides advice and support to employers to ensure that they can do the right things to support individuals in the workplace.

The scheme also benefits from not having to stick with the prescribed guidelines or routes into employment associated with other Job Centre Plus programmes such as the Health and Work programme.

- Read [the full case study on the Plymouth Autistic Employment Project](#)
- To read a local press article about the [Neurodiversity Employers Network](#)

## 5.4 Agile



Energy, flexibility and drive are needed to overcome barriers to people living great lives as part of their communities. It requires people who are confident working with individuals to find solutions that work for them, and people who understand the legislative requirements, financial frameworks, and national guidance they need to work within. They make systems work for individuals and understand that prompt action is needed to make good change happen.

People told us that often good things happen, but that they have had to fight for it, sometimes over years. They also talked about long delays, waiting for things to change. This was especially true of people waiting to get out of hospital.

Timely responses and solution focussed energetic support are critical features of a 'good' community response. For many long stays in hospital and frequent delays are not only frustrating, but they are also harmful. What 'good' looks like in the community assumes getting into the community in the first place if you have been in inpatient care.

Flexible support is needed to meet the wide range of human needs of people when they are living in the community. This can be sensitively supported by a variety of provision, but

the community and voluntary sector can often move quickly to spot a need and use collective community assets to create the unique types of support that people value.

People told us that having friends and romantic relationships are a key part of living a good life, yet research suggests that 1 in 3 young people with a learning disability spend less than 1 hour outside their home on a typical Saturday (Mencap, 2019).

In a survey by Sense, over half of disabled people reported feeling lonely, rising to over three quarters (77%) for those aged 18-34 (Sense 2017).<sup>15</sup>

For most people having a good life is rooted in doing the things they love, and having other people share the joy of common interests.

**Safe Soulmates** is a friendship organisation for adults who have additional needs including autistic adults and adults with a learning disability. It runs social events and can support individuals to form romantic relationships if there is a mutual connection. They also use a robust co-production approach that it is driven by the individuals who are members. The Steering Group is chaired by an individual with lived experience and events are developed to meet what members want.

Safe Soulmates carried out consultation in 2017/2018 and established that there is huge need for a not-for-profit dating and friendship organisation. They recognise that people want different types of friendships and romantic relationships, and the format of the events/sessions they initiate means that individuals can choose the types of relationships they want to build. It has worked with professionals to help shift their understanding of the importance of relationships for people with additional needs and ensure that professional skills and competences are developed.

It also provides a way into sexual health services that have been adapted to the needs of autistic people, people with a learning disability or both, with Diverse\* a sexual health charity in Cambridge and an umbrella organisation Supported Loving run by Dr Claire Bates. (Link below\*)

- Read the [full case study for Safe Soulmates](#)
- To visit the [Safe Soulmates website](#)
- For more information about [Supported Loving](#) \*
- For more information about [Diverse](#)
- For information about wider [LGBTQ+ social groups](#)

**Gig Buddies** is for adults with a learning disability and volunteers that want to go to cultural events. It helps people with a learning disability to access (and be visible accessing) mainstream culture events. This can range from a music festival to the theatre to a local band playing a gig at a pub.

It is described as an 'anti-service' because it is a framework for people to do what they want with people who wish to also do those things. It works because of the simplicity of

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<sup>15</sup> [https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/friendships-research-and-statistics#:~:text=Research%20suggests%20that%201%20in,%2D34%20\(Sense%202017\).](https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/friendships-research-and-statistics#:~:text=Research%20suggests%20that%201%20in,%2D34%20(Sense%202017).)

the idea. Gig Buddies matches DBS checked volunteers and people with a learning disability. It is about friendships and challenging the idea that people with a learning disability should only do things that only put on for people with a learning disability and only have friends that have a learning disability.

It is led by people with a learning disability, and they can sack their volunteer if it turns out that their interests are not the same. Someone was once sacked for not dancing enough! Fundamentally it helps individuals with a learning disability find out what tribe they want to be a part of and join it!

More franchises are happening, and Gig Buddies is growing, even in Australia. This way of working will continue and grow, after Covid real events are now on the horizon again.... So back to Glastonbury!

- Read the [full case study about Gig Buddies](#)
- Visit the [Gig Buddies website](#)
- Read [the evaluation of the initial model](#)
- Watch [a short documentary about Gig Buddies](#)

Many of the people we spoke to in the scoping consultation talked about the need for relationships, and to be supported by this. For people identifying as Lesbian, Gay, Bisexual, Transgender or Queer+ (LGBTQ+), negative attitudes, including denial of sexuality and/or gender identity can feel like 'just another wall' to be faced with. In turn this creates stressors that can contribute to worsening wellbeing, including mental distress. Life can feel isolating, when your 'whole self' is not recognised.

In part some of this recognition for support can be addressed through personalisation and educating the mainstream and LGBTQ+ community. What is clear is that people can bring their different skills to the table to make life better, and we can learn together. For families, supportive approaches that recognise the need for information and how to best support their adult children identifying as LGBTQ+ is also helpful.

**United Pride Friends** is a group service for members of the LGBTQ+ community with autism and learning difficulties. The primary purpose of their group is giving members a safe place to meet new people and make friends.

United Pride Friends provides a wide and diverse range of services for their group members. Here is a summary.

- Befriending service
- Online webinars
- Group talking sessions.
- Facebook & social media platforms
- Safe space meet ups
- Activities & events
- Support services
- Information on other organisations
- Educational information
- Workshops

All the services are provided in a confidential and safe setting.

Looking to the future it is recognised that more is needed. This is an area that is not always understood or supported nationally and would benefit from creating a stronger evidence base. This means that more funding for research is required.

- Read the full case study about [United Pride Friends](#)
- To visit the United [Pride Friends website](#)

### **mASCot**

Parents and Carers told us about the need for support and information to navigate the complexities of 'serviceland.' For parents of children and adults this included interfaces with education, health and care.

**mASCot** is a flexible and agile membership group for the parents of autistic children in Brighton and Hove. It is open to all parents with children and young people with or awaiting an autism diagnosis. It provides mutual support and help to over 1100 members, including some face-to-face groups and training support for parents including coffee mornings, occupational therapy training/support on sensory regulation and hiking groups. For parents it created a sense of being part of a defined community of people who understood their world and would not judge them. The group operates through an online community via Facebook.

It's focus remains on mainstream education and reducing the social isolation experienced by many children in schools; and supporting families that are experiencing problems working with health/ education using the unique advice and knowledge from other parents. This peer-to-peer support between parents is not formalised but it is more organic where parents align with and support each other.

There has been a steady shift in the relationship between the local authority SEND part of the business and health with mASCot. Over the years there has been a growing willingness to involve mASCot and give them a place at the table in conversations about services, policy changes and how things are working on the ground.

- Read the [full case study about mASCot](#)
- To visit the [mASCot website](#).
- To read the [evaluation of the initial model](#)

## 5.4 Focus on valuing people



A key way to overcome barriers in providing good support is by making sure people are listened to, and decisions are based on accurate information. Organisations and people who want to make good change happen welcome challenge. Valuing people includes those who work in the organisations at all levels, they are confident in making decisions because they have had good training and are supported by their managers to be open and honest. They embrace wider co-production, people's unique skills interests are valued and used to improve lives.

Providing the right support for many people relies on having stable, motivated staff teams that are valued. A key aspect of having 'good' support is recruiting and retaining those people who have the right values and approach to support others. This means that their everyday interactions are driven by their intrinsic values and beliefs and supported by their high levels of knowledge and skills.

The role is complex, and staff need to be paid well to attract and keep them in work, (There is competition for their labour in other sectors). Commissioners need to recognise the unique nature of the role and a different approach is needed in relation to funding the

right support, away from standardised commissioning frameworks that do not always reflect the level of skill required.

Providing good support in the community is essential and recognising the unique skills and talents of everyone is key to making things work together. Michael's story demonstrates how working together made a huge difference to his life.

**Family Led Support** is funded through Oxfordshire County Council via direct payments, this bespoke, family-run provision is for a young man who was neglected, restrained, over medicated, and abused as an inpatient in various assessment and treatment units (ATU's). They operate in Oxfordshire to support the young man, Michael, with his very complex needs, both in terms of his learning difficulty and with regards to his mental/emotional health and wellbeing.

His past horrific experiences of abuse in inpatient services ultimately served as the motivation to set up a completely bespoke provision, built around him and based on the building blocks of his home, family, and familiarity with his local community.

Michael's experiences of clinical institutions are very much still felt today and the care now in place was established to empower him to make choices about his home and life. He attends as many of his chosen activities as he safely can, and his staff manage to strike a conscientious and considered balance between keeping him and themselves safe whilst not becoming completely risk averse. His home and life are run and directed by him, where that is achievable. It is a home first and foremost, not a "service." The support provided is genuinely person centred.

The staff team constantly reflect and reevaluate their approach to ensure they are not making choices on behalf of him, and they are working to empower him with more independence and control of his own life. They see him as a human who is struggling, and they approach him on a human level; 'paid carers' is a crude term, wholly unfit for the types of interactions and quality of rapport that he has with his team - they're life enablers.

### Compassion and respect

Time is devoted to just being with Michael and chatting with him in a low-demand manner. This is an affirming and normal experience for all of us, and evident here. Michael is listened to with respect and compassion.

On days where he is struggling and trips to busy environments are likely to be too overwhelming for him, staff don't just check in for observations, they sit with him, eat with him, play games and dance with him; they talk with him about how he's feeling, not because they have a clipboard and pen and need data to complete a report, but because he's upset, and they want to be there for him.

The family enlisted a training provider who had worked with Michael in the past to develop a bespoke training package that aimed to give the best possible insight into who Michael was as a person; his likes, dislikes, communication style, sense of humour, and relationships were all explored using videos, photos, stories from people that know him. Underpinned with theoretical data, the training enabled his staff to recognise him almost



as if they already knew him, not as a client whose triggers they had to be aware of, but as a person whose struggles they felt for.

### Values

The staff team's values are in line with the highest aspirations many provider organisations have, but in practice often fail to meet.

### Stable and knowledgeable staff team

As a result of this approach there has been a notable lack of staff turnover. Staff love working here and genuinely like and admire Michael. They have developed the ability to 'tune in' and read his subtle cues so that they are able to adjust any given situation to manage his anxiety.

### Reflective practice

The team demonstrates extremely high levels of openness, honesty, insight and is open to reflecting on what does or does not work. The way the team works is a consequence of recruiting individuals with the right values and the ongoing work to support staff learning and development. This includes encouraging reflective practice and creative thinking. This reflective practice has been supported greatly using videos so the team can look back at their interactions with Michael and learn from them.

### Ongoing training and expertise

The team are kept up to date with national guidance and best practice. They have studied, researched, and been supported to learn about Trauma Informed Care, Autism, Active Support, Intensive Interaction, and Mindfulness. Fundamentally, they are willing and open to learning and development and put it into practice.

### Looking to the future

Michael's family and staff have shown incredible dedication and resilience in their fight to get the right support for him, throughout, and despite, a prolonged period of great uncertainty and a massive effort to establish resources, he is now looking at moving into a place of his own, close to family in a place that he knows well.

- Read the full case study about [Michael's Family Led Support team](#)
- Read a report looking at [What does good look like](#) by the University of Kent

A focus on valuing people was a critical principle in demonstrating good community-based support. These organisations really looked at the strengths and skills of the people that they are involved with, including the people they support, families and staff. There is a mindful and conscious focus on working with communities and individuals using all their assets.

**Lives Through Friends** practice as support brokers, community workers and campaigners in order to 'keep grounded.' They have the explicit aim of assisting people who need social care support to 'self-direct' and have a recognition that the current system

obstructs innovation as it is overly process driven, focused on risk assessments and legal frameworks.

They support people with ‘complex reputations,’ and multiple diagnoses and their support providers for twelve months to help the individual live back in the community. This is done by helping with community networks, speech and language therapists and occupational therapy expertise, psychology, and behaviour support colleagues at Studio 3 e.g., low arousal, understanding of trauma. Working with the system and get professionals to think differently about solutions that are meaningful to the person, they encourage innovative thinking, seeking simple and cost-effective solutions. Their approach is based on relationships, knowing the person, living with the person, sticking with it when things get difficult.

The work of Lives Through Friends involves rebuilding, or building from scratch, those networks and supports that enable providers to work with communities in a creative and asset-based way. Having a supportive attitude to workforce is crucial, getting staff on board and retaining them with good training and pay. “Workers need to know they are valued and that they know the people they support better than professionals.” Lives through Friends ‘recruit’ providers and only work with passionate leaders. Most organisations are usually off the commissioning framework so they can negotiate good rates of pay for staff.

- Read [the full case study about Live Through Friends](#)
- Visit [the Lives Through Friends website](#)
- View [the Silent Minority film](#)
- View a video from [Studio 3 on behavioural approaches](#)

**BetterTogether** offers a service in East London/Essex covering the London Boroughs of Newham, Havering, and Thurrock. They support adults (from the age of 16) and work with people who have any disability. Bettertogether is registered with CQC to provide personal care. They are a member of Shared Lives plus which is an umbrella organisation, which sets best practice guidance and offers support for all Shared Lives schemes nationally.

The support is highly personalised, and people are matched with a Shared Lives carer who provides the care and support needed by sharing their home, family, and community life. Taking the time to understand each person and match them to a shared lives carer is crucial. The underpinning values are that they are strength based and value each person who uses the service but also valuing their Shared Lives Carers. Everyone has unique skills and something to offer.

They work proactively with specific communities when a specific match was needed. For example, working with the local Sikh community through the local temple. It is true place-based working and Shared Lives carers are a wonderfully diverse group of people bringing a range of life-experiences to their work.

- Read [the case study of BetterTogether](#)
- Visit the [Shared Lives Plus website](#)
- Read about the BetterTogether on the [Shared Lives Plus website](#)
- Read the evaluation of the [Shared Lives Mental Health Project](#)

- View [the CQC inspection report on Newham Shared Lives](#)

## 5.6 Pragmatic



In order to make 'good' happen, it is recognised that there needs to be a significant commitment to make things work. This means that partners work together to quickly put in place what an individual needs to keep safe and well in their own home. They will question the value of an admission or continued stay in hospital and always bring practical community alternatives to these discussions.

Solution focused; flexible approaches are required to keep people in their community. This means being good at practical problem solving and not putting issues in the 'too difficult box' never to be addressed. It sometimes means 'going the extra mile.'

Tackling issues head on, including crisis scenarios, are crucial to ensuring that people can live and stay in the community. It is also rare that one person or organisation can do this all on their own, partnership working is needed to make sure that hospital admissions can be avoided, whilst still using the opportunity of crisis to find new solutions.

This approach is evident for people of all ages, including children and young people. By offering support in educational settings with good working between parents and schools, sensible co-produced responses can help to avoid exclusion and enable children to thrive.

**The Rapid Intervention Team (RIT) and React Teams** work together to provide a county wide specialist health and social care service for people with a learning disability who are at risk of being arrested and/or being admitted to a mental health hospital. It is part of Somerset's Transforming Care programme response.

The Somerset Foundation NHS Trust's RIT is part of the Learning Disabilities Specialist Health Service and was established to minimise the risk of inappropriate hospital admissions and out of county hospital and community placements. RIT provide mental health, behavioural and low-level forensic community support, and provide a key working role for people with a learning disability who are detained under the mental health act.

Likewise, the React Team, provided through Realise, was commissioned by Somerset Council especially for this innovative service. It consists of social care staff who are very experienced and have a strong background in working with mental health difficulties and behaviour that challenges.

Both team's work in collaboration to provide community-based assessment and treatment, and direct care and support when required, to enable people to remain in their own homes whenever possible. They are very flexible, and as such are always prepared to be called out at short notice when agreed via Somerset's 'Blue Light' process which is led by Somerset's Clinical Commissioning Group.

For people that do require an admission to hospital, the team's will provide in-reach and discharge planning support.

In addition, the teams may also support people within a registered bungalow in Taunton, which can serve as an alternative to hospital when it's safe and appropriate to do so.

[Read the full RIT and REACT team case study](#)

## **Autism in schools**

The Autism in schools project initially commenced in North Cumbria and North East in 2018, following on from the success of the project in NCNE it was rolled out nationally across all seven regions of England. The project is co-produced and based on what was learned from, understanding the needs of autistic young people and listening to the voice of autistic young people and their families. The model describes three key elements to help implement practical ways schools could improve the experience for young people with autism.

- building relationships and networks of support for school staff, health and social care professionals, parent/carers and autistic children and young people,
- developing learning opportunities for schools and Parent Carer Forums,
- understand and promote the voice of autistic children and young people

The Autism in schools project's primary focus is autistic young people however it is acknowledged that the work would meet the needs of a range of neurodiverse young people and those with additional needs. The project also aims to support parents and carers working closely with the parent carer forum to support the development of relationships and networks of supports, this has been achieved by supporting Parent

Carer Forums to develop mini forums strengthening networks for parents, providing support and improving communication between parents and schools.

Autistic children and young people make up 75 per cent of admissions into mental health hospitals. Many children and young people had been excluded or out of school prior to admission. Parents reported missed opportunities, schools being unable to effectively support autistic children and young people and systems not being joined up, compounded by a lack of support networks for parents and families.

- Read the [full case study about the Autism in Schools project](#)
- To read the [Phase 1 evaluation report](#)
- To read the [Phase 2 evaluation report](#)

Organisations working pragmatically together can have an impact on the wider system, helping to support early skilled help, particularly in schools. In this example autistic children receive better support through the combined forces of two parent led organisations.

**Brighton & Hove Parent Carers Council (PaCC)** was established in 2008, and **Amaze**, established in 1997. Amaze is the host organisation for PaCC and operates across East Sussex and Brighton and Hove. The two organisations work in close partnership for parents and carers of children and young people (0-25 years) with a disability/special educational need (It is not diagnosis dependent). Amaze and PaCC are pan-disability and many families seeking support have children with neurodevelopmental conditions including autism and learning disabilities.

PaCC takes forward work to ensure that the parent carers voice is heard in policy making and service development. This includes identifying emerging trends from parent carers, collaborating with providers to highlight gaps and quality concerns, and co-ordinating input into service design conversations. Its steering group is made up of parents, and they bring a range of expertise so that the broad experiences of parent carers ensure that clinical and education services are working appropriately for children and young people.

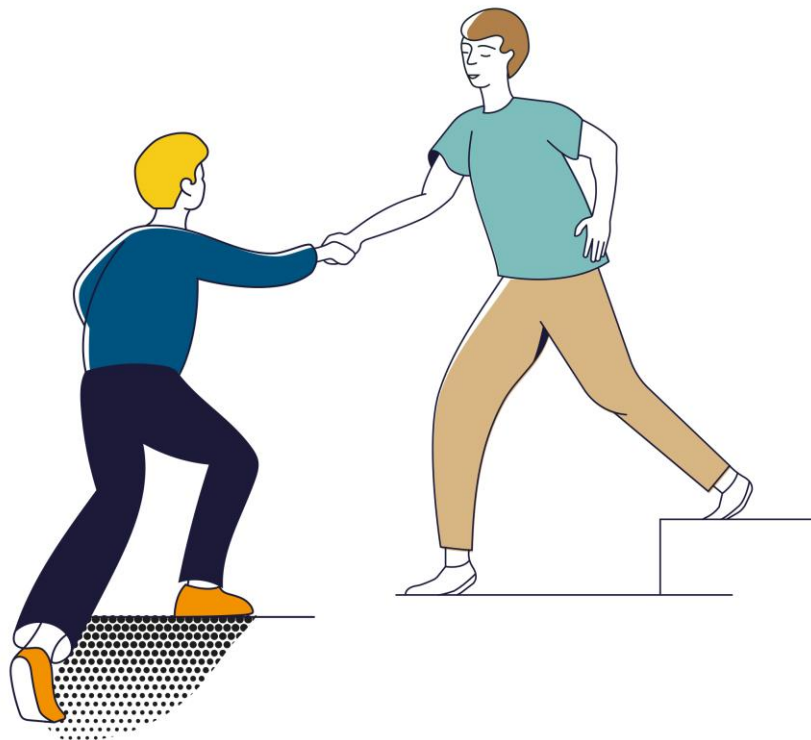
Amaze is also parent led, deeply practical and focused on ensuring each family is given the right support, at the right time. It recognised that advice and support to parents needs to be professional and accurate whilst responding to new trends/concerns emerging from parent's experiences where advice/guidance needs are evolving. Examples of the services provided by Amaze include a SEND advice service, disability benefits advice and support, a well-developed parent peer-to-peer support network, groups for young people aged 14-25 and a well-established dad's group.

Together they have been working with the mental health providers to reshape early support services and Single Point of Access, they are also highlighting the needs, adaptations and provision required from CAMHs services to better support neurodiverse young people. Examples of their work include ensuring that co-production is embedded in the working culture of the local statutory organisations including participation in recruitment of senior roles, sitting on strategic boards, and regular meetings with senior

managers, co-ordinating engagement in service developments for example the Children and Young People's Single Point of Access for Mental Health Services.

- Read the [full case study of the Brighton and Hove PaCC and Amaze](#)
- Visit the [Amaze website](#)
- Read about [the impact of Amaze](#)
- Read about [Parent and Carers Council Brighton](#)

## 5.7 Well led



Leaders who model best practice and take positive risks are effective in helping overcome barriers. They trust their teams and will sometimes work creatively around constraining 'rules' to push forward. Where local policy is constraining good ways of working, they will seek to influence system change using the tools and levers at their disposal.

Strong leaders create a learning, rather than a blame culture within their organisation. They make sure that all staff such as finance, human resources, and legal support, have

the same aim- to meet the needs aspirations of people they seek to serve. Everyone knows what their job is to make it happen.

Strong leadership not only impacts within single organisations, but the positive benefits can be felt across wider systems, helping to push forward the things that people need to experience good ordinary lives in the community. They are good at speaking 'truth to power.'

They also know that the good change they make happen will carry on even if they leave because they have the right people in place to keep good values and beliefs alive in practice.

Some of the challenges within the Building the Right Support programme of work, relate to complex societal needs that involve a large number of organisations, funded from different government budgets, and who may have differing priorities. However, in order to make things work well for people on the ground, those organisations need to come together and understand what they need to do to help people, have a life in the community that feels supported and safe. Instead of seeing this as "just too difficult" strong leadership across systems develop clear plans for change.

Leadership can be shown by both individuals and organisations, and the key features of effective leadership are that it is principled, courageous, innovative, transparent, humble, confident, and approachable.

**In Control** started in 2003, and now operates across England. It was set up originally by the Department of Health in England, and Mencap. It originated because funding was being identified to sit alongside person centred care but there used to be no choice and control for people about how money could be used better. Self-directed support sought to embrace self-determination and to help people avoid perverse incentives within the system including the crisis driven criteria, that often operates across many systems.

In Control has a broad scope and is very inclusive, but it does have three key areas of focus in that it exists to offer help to anyone who needs support of all age groups, aims to support to help people live an ordinary life and will not support any action that results in institutional living and to advance the education of the public- and seeks to ensure that people are included and that their human rights are upheld.

Across the wider system In Control aims to provide a platform of people, there to help. Sometimes it has meant they need to stay balanced 'on the fence' to maintain key alliances and relationships which includes local councils and hospitals. They seek to challenge in a way that supports to organisations and builds networks.

They recognise that any future change has to be done together, building on human connections, and understanding and have been deliberately active in shaping public policy and have sought to politically influence where this is needed. They speak with conviction to policy makers and know that stories make a difference.

**"It helps to take issues requiring resolution from number 10 Any Street, to number 10 Downing Street."**



- Read [the full case study of In Control](#)
- Read about the [Be Human work on In Control](#)
- Read about [Partners in Policymaking](#)
- To read about the [evaluation relating to Individual Budgets](#)

Greater Manchester is the first city-region to develop a **Health and Justice Strategy**. It is fully inclusive of people with a learning disability and autistic people. It was the first time that health, social care, and criminal justice services came together to look at the issues in an integrated wider strategy.

The strategy utilised research and coproduction to make sure that it was evidence based and focused on the issues important to people. The aim of this strategy is to improve the health of people who are already in the criminal justice system, or who are at risk of entering it either as a victim or offender. The aim is that this will reduce the risk of some people becoming a victim and prevent others from getting involved in crime.

There are four groups of people that particularly emerged from the development and engagement processes, and one of these is people with a learning disability, autistic people, or those with a communication disorder. This work programme includes vulnerable young people who require that their needs are comprehensively assessed in a timely way. They also identified a need for better support for young people with additional vulnerabilities such as learning disability, autism, school exclusion, or childhood trauma, to help to break the cycle of becoming a victim or offender.

Senior leadership was critical to getting the strategy agreed and supported, this included the Chief Operating Officer for the Health and Social Care Partnership and the Deputy Mayor for policing, crime criminal justice and fire. A major lesson was identified in that it was the senior people involved that really ‘got it.’ In the main this was because all individuals had either a personal connection with, or a deep understanding of, the needs of people with learning disabilities, and/or autistic people.

**“As well as being able to influence hearts and minds, delivering and developing a successful strategy requires having leaders who also have “teeth” In effect the position and influence to make change happen.”**

- Read the [case study about Greater Manchester Health and Justice Strategy](#)
- Read about [KeyRing involvement with the criminal justice system in Greater Manchester](#)
- Read [the LGA report on people with a learning disability and autistic people in the criminal justice system](#)

## 6. A note on language: Think before you speak

What ‘good’ looks like and how we communicate it is important. The words we use to describe people can impact on how we think about people and can influence the thinking of others with whom we communicate.

Most people like to think of themselves as good, caring, empathic people. Many people have watched documentaries, listened to news stories, and decry the abuse autistic people and people with learning disabilities have suffered in some institutions. But what is it that creates the conditions in which such abuse takes place?

A possible explanation lies in the concept of ableism. Ableist language is one of the most subtle but common forms of ableism. Because language communicates and perpetuates attitudes and beliefs, it can affect how we support and care for people.

We see many examples where language used suggests that the difference inherent in autistic people and people with learning disabilities are a product or expression of deficit, disorder, or deficiency. Below in the table adapted from Bottema-Beutel et al.2021<sup>16</sup> are some examples of ableist language followed by the alternative language that could be used.

<b>Ableist language</b>	<b>Alternative</b>
Special interests	Areas of expertise, focus, passionate interest
Special needs	A description of special needs
“When you get better you can....”	“When we have gotten the right support is in place....”
Challenging behaviour/disruptive behaviour/problem behaviour	Meltdown (when uncontrollable behaviour), stimming (when relevant), specific description of the behaviour (e.g., self-injurious or aggressive behaviour)
High/low functioning, high/low severity or support needs	Describe specific strengths and needs, and acknowledgment that the level of support needs likely varies across domains (e.g., requires substantial support to participate in unstructured recreation activities, but minimal support to complete academic work)
Suffering from autism	Impact and/or effect
Autism symptoms	Autistic characteristic
Treatment	Support services or strategies
“Why can’t you just...?”	“What can I do to support you...?”

The language choices we make when talking about neurodiverse people can either maintain or challenge ableism. We can demonstrate ‘good’ ourselves by the language we choose to use.

<sup>16</sup> Kristen Bottema-Beutel, Steven K. Kapp, Jessica Nina Lester, Noah J. Sasson, and Brittany N. Hand. Autism in Adulthood. Mar 2021.18-29.<http://doi.org/10.1089/aut.2020.0014>

Often the use of this language is the product of unconscious processes happening, is not intentional and can seem harmless. For example, micro-aggressions in the form of invalidations, dismissing someone's feelings and/or insults describe the brief, everyday exchanges that send denigrating messages<sup>17</sup>.

These might include telling a person whose only diagnosis is autism that they can leave the inpatient unit when they have 'sorted out their autism,' they can go on Section 17 leave, and when they 'start behaving themselves'. Another example is using the word 'idiot' to describe someone's behaviour. Using person first language (person with autism) rather than identity first language (autistic person) is also experienced as a microaggression for many autistic people.

Clinicians are often completely unaware of the presence of microaggressions occurring all around them and that they may even be committing them themselves (Williams, 2020)<sup>18</sup>. The effects of ableist micro aggressive cultures on neurodiverse people might include, but are not limited to, increased power differentials (people feeling that they are powerless, and others have power over them), feeling blamed for neurodiverse characteristics (that are an intrinsic part of the person), decreased mental well-being (which exacerbates distress), marginalisation, victimization, and bullying.

Recognising that the language we use impacts how people are treated is the first step towards rights-respecting care and support. Think about the language you use to understand, describe, and interact with yourself and others.

Being neurodiverse does not make you immune to using ableist language, nor does having peoples' best interests at heart. Actively scrutinising, challenging and educating can and will make a difference.

Darlington Learning Impairment Network wrote a series of open letters<sup>19</sup> about language used and how it impacts. Words like 'cohort' to describe groups of people or talking about "beds" rather than people, were picked out as examples of dehumanising language.

The network set a challenge to professionals which included

- Not to use "LD" when describing disabled people
- Challenge anyone you hear using it.
- Talk to and agree with disabled people the words to use to describe them.

**"We think that words like these are about being in Service Land. These words are not used to describe how non-disabled people live their lives. We think that by using words like these people are trapped in Service Land people are even called Service Users!"<sup>20</sup>**

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<sup>17</sup> Smith L. #Ableism. Center for Disability Rights. n.d. <http://cdrnys.org/blog/uncategorized/ableism>

<sup>18</sup> Williams, M. (2020). Managing microaggressions: addressing everyday racism in therapeutic spaces. ABCT: Oxford University Press.

<sup>19</sup> <http://www.dldlive.org.uk/media/1350/open-letter-1.pdf>

<sup>20</sup> <http://www.dldlive.org.uk/media/1352/open-letter-3.pdf>

If we are sincere and committed about making 'good' happen everywhere, with people living ordinary lives as part of their community and not in Service Land our language needs to change to reflect this.

- To read [Bryony Shannon's blog about missing words](#)
- To watch the [Citizen Network webinars on the power of language](#)
- Darlington Learning Impairment Network wrote [a series of open letters about use of language](#)

## 7. Co-production- a golden thread

Throughout the examples in this "What Good Looks Like" report, an essential feature of good is that organisations work closely with people with lived experience and others to co-produce. Co-production is based on working with other as part of a reciprocal and equal partnership. It often gets confused with other approaches.

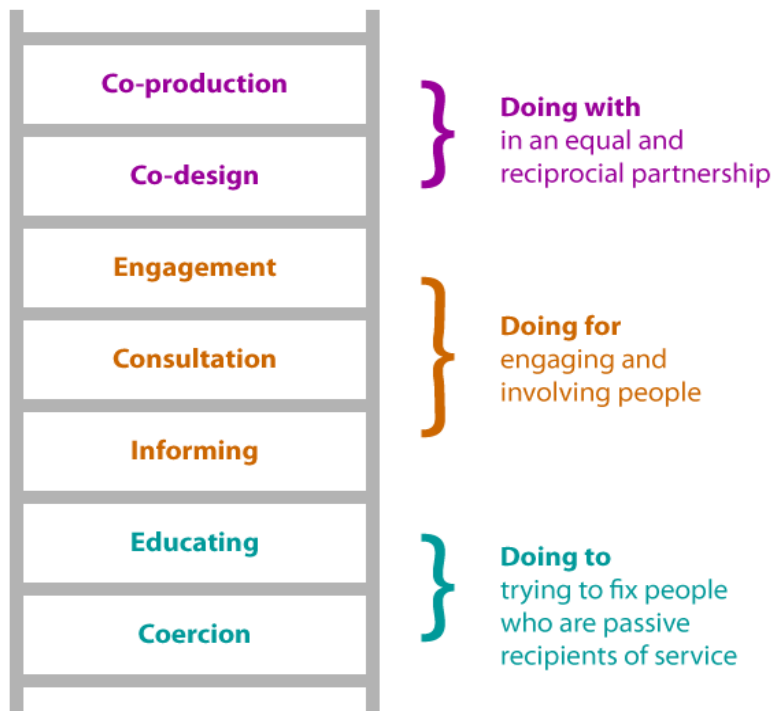
**"Unfortunately, with the increasing use and profile of the word "co-production", there is also increasing misuse. To understand what co-production is, it is important to understand what it is not."** <sup>21</sup>

**Think Local Act Personal**

The ladder of co-production is a useful way of making these important distinctions.

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<sup>21</sup> <https://www.thinklocalactpersonal.org.uk/co-production-in-commissioning-tool/co-production/in-more-detail/what-makes-co-production-different/>



As the examples in this report show, co-production leads to:

- Improved experiences and outcomes for people
- Improved trust
- Positive relationships
- Practical and creative solutions that work - first time!
- Better use of resources
- Shared learning
- Improved confidence in services
- Improved community capacity and assets
- Show where there may be less demand for some services.

The Care Act 2014 has this description...

**'Co-production is when you as an individual influence the support and services you receive, or when groups of people get together to influence the way that services are designed, commissioned and delivered'.**

There is a wide range of information available to help people and organisations with co-production. There is a great opportunity currently to make sure that people are involved in the developing Integrated Care Systems.

- Read ['What is Co-Production: A guide' by Think Local Act Personal](#)
- Read [Social Care Institute for Excellence \(SCIE\) a guide on the principles of co-production](#)
- Access [NHSE Co-production resources](#)

- Read [How will we know integration of health and care services is working?](#) A Kings Fund blog

## 8. The importance of culture in making ‘good’ happen

It is clear that many recommendations have been made in many reports in an attempt to ensure ‘what good looks like’ happens everywhere.

Making good change happen takes many different kinds of approaches. It is hoped that people would automatically do the things that have been outlined in the ‘necessary actions’ part of this report. A lot of the requirements are about being human – listening, believing and acting on what people say, because it aligns to our beliefs and values as people.

Often responding as human beings in a system that is sometimes institutionalised, and dehumanising can be challenging for everyone. Rules, and processes that remove our ability to see the person, financial incentives that create barriers, and overly restrictive controls on resources stifle creativity and create unintended consequences that can mean harm or death to some people.

For some, the change needed may feel threatening to them. Moving budgets from organisations to people may feel like a loss of control or power. Some companies running inpatient services may fear a loss of profits. In the wider system developing frameworks that truly support personalised care and support may require more effort than the ‘one size fits all’ approach that we have seen historically.

The aim of creating a ‘good’ culture is that people will do the right things automatically because “that’s the way we do things around here.” (Deal & Kennedy, 1982)<sup>22</sup>.

Culture can be hard to pinpoint, but it influences what people do and how they act. ‘Good’ cultures are based on having the right values and beliefs and using our roles to do what is right by the people we seek to serve. Culture can feel like a hard idea to understand, it may feel a little bit vague. However, it can be described in more concrete ways, and understanding the components of culture can provide us with an understanding of the levers we can use to create the conditions to make good change happen.

Leadership is particularly important and Senior Responsible Offices within developing Integrated Care Systems will need to understand what aspects of culture they can influence to enable ‘good’ to happen for autistic people and people with a learning disability. One aspect of supporting national leadership relates to the suggestion that a new role could be developed, that of National Commissioner for autistic people and people with a learning disability. The idea is that this could work in a similar way to the National Commissioner for Children role.

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<sup>22</sup> Deal, T., & Kennedy, A. (1982). *Organization Cultures: The rites and rituals of organization life*. Reading: Addison Wesley

Cultural change is needed at grass roots level too. The Care Quality Commission have addressed this issue related to direct provision in their report 'Right Support, Right Care, Right Culture.'<sup>23</sup> Learning Disability England are also calling for change as part of their 'Good Lives' campaign.<sup>24</sup>

This model (below) maps some of the necessary actions and other levers for change against a cultural web model. It has some suggestions about how to influence culture to support 'good' happening.

## Using the cultural web model Adapted from Johnson and Scholes-1992

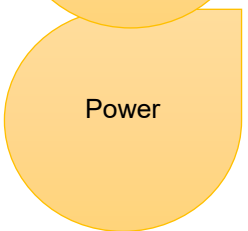
This daisy or flower shaped model considers the key areas across organisations that can shift culture- here we are applying it more broadly across our system. In the adapted model, the centre of the flower is our area of focus-what good looks like. The petals described below are the things we can do to shift culture.



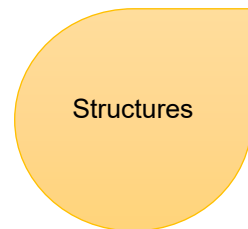
**Stories:** Use powerful personal stories and case studies for learning. This also includes the use of persuasive evidence for real change. It enables us to put our shared humanity to good use.



**Symbols/Language:** The words we use forms the way we and others think. Train people about language. Make it easier to challenge "othering" words that keep people in "Serviceland."



**Power:** Increase the choice and control people have about decisions that affect them. This includes the use of resources at all levels-nationally, regionally, place based, and by the individual. Create greater flexibility so resources can be used creatively.



**Structures:** Understand where informal and formal hierarchies exist. Aim to build real, human relationships and trust across systems, including with people and families. Develop collaborative structures based on mutual respect for local strategic decision making.

<sup>23</sup> <https://www.cqc.org.uk/sites/default/files/20200929-900582-Right-support-right-care-right-culture-FINAL.pdf>

<sup>24</sup> <https://www.learningdisabilityengland.org.uk/our-work/current-work/good-lives-2020-2/>



Controls

**Controls:** Identify and address Incentives and disincentives. Make sure that the financial rewards are for doing the right things. Consider who has responsibility and accountability? Where are consequences of actions owned and felt? How are you measuring success? Consider eligibility criteria for services, are they too restrictive, creating risks elsewhere in the system and for the people you seek to serve?



Rituals  
and  
Routines

**Rituals and routines:** Reflect on the way we do things around here- what are the written/ unwritten rules and permissions? Be explicit about the beliefs and values you want to drive 'good' - include them in recruiting, inducting, and training staff.



## 9. Necessary actions for change

It is acknowledged by professionals, families, individuals that the current system is not fit for purpose.

**“Collectively we must decide - do we continue to prop up this failing system and allow some individuals to continue to come to harm or indeed die in it or do we all make a sincere decision with government, and make a commitment and say, “it must change, starting now!”**

By reflecting and learning from the feedback from people and families, the relevant information and evidence gathered in this report, and the investigations undertaken as part of the ‘What good looks like’ workstream, a number of requirements for change have been identified. Many of these necessary actions have been highlighted by numerous previous reports related to service failings, harm and some deaths.

### **An important note on the actions identified in this report.**

It should be made clear that many of the actions listed below, and referenced throughout the report, are not legal requirements although some are. However, all members of the advisory group believe that these **must** be enacted so that positive change happens. It is their hope that national and local systems will make the positive changes outlined in this report to improve the lives of citizens and their families.

## 9.1 Rights and legislation

Where we are now	Necessary actions	What good looks like
<ul style="list-style-type: none"> <li>• Some people are not having their rights upheld, this leads to abuse, trauma and in some cases death. Part of the problem is a lack of essential training on human rights for inpatient staff, staff working in the community, CAMHS staff, advocates, adults, young people and families.</li> </ul>	<ul style="list-style-type: none"> <li>• Organisations should act on the legislation that is already in place, otherwise they are acting illegally. Law relating to the Human Rights Act 1998, The Care Act 2014, Equalities Act 2010, are particularly relevant.</li> <li>• Staff working in systems need co-produced training based on legislation, this should use real life case studies because they are relevant in everyday decision making.</li> <li>• Relevant legislation also needs to be actively promoted across organisations in their policies, and quality checks.</li> <li>• People using services should be told what their rights are.</li> </ul>	<ul style="list-style-type: none"> <li>• People working across the system understand the law and make rights respecting decisions in their every-day practice.</li> <li>• They understand legal frameworks, foundation laws, and which policies, directives or decisions are not rights respecting.</li> <li>• As a result, challenge takes place when rights are not upheld.</li> <li>• This leads to legislation being properly embedded in practice, and in turn, this supports people's wellbeing.</li> </ul>

<ul style="list-style-type: none"> <li>• There is a general lack of accountability within the system. Actions and recommendations from key reports are not always fulfilled.</li> </ul>	<ul style="list-style-type: none"> <li>• Areas should ensure that advocacy and legal support are easily accessible for people. This will include a need to provide better information related to, and funding for advocacy and legal support.</li> <li>• The fully independent Senior Intervenor role would be valuable in local areas, it could be funded as a permanent post in each region of England.</li> <li>• In addition, a continuance of the funded national Keyworker roles is critical to supporting action related advocacy with individuals. Individuals and families know how to contact them. The post is reviewed and potentially broadened.</li> </ul>	<ul style="list-style-type: none"> <li>• Because of compliance with the Care Act 2014 local services that people need are in place and wellbeing is considered and promoted.</li> <li>• Prevention of escalating needs is supported, and sufficient services are in place. This means that people are less likely to end up in hospital.</li> <li>• Access to community support is easy for people to use and is reasonably adjusted.</li> <li>• Organisations are more accountable for their actions; challenge is welcomed leading to improve practice to deliver what matters to people.</li> </ul>
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## 9.2 Commissioning

Where we are now	Necessary actions	What good looks like
<ul style="list-style-type: none"> <li>Some commissioners are still placing and keeping individuals in unsafe placements due to a lack of local suitable support.</li> </ul>	<ul style="list-style-type: none"> <li>Commissioners should use co-production to design what is needed in local areas in an equal and reciprocal partnership. (Effective Partnership Boards need to be part of this approach).</li> <li>Commissioners should have good knowledge of their local area and use their wider commissioning responsibilities to actively support BTRS - including making sure that specific health and social care provision is in place in line with the Care Act 2014 and that it meets the model of care described in CQC's statutory guidance Right support, right care, right culture.<sup>25</sup></li> </ul>	<ul style="list-style-type: none"> <li>The local offer of support includes lots of choice for people, it includes a number of small organisations that can offer bespoke support that is tailored to people in their own homes. Accommodation is part of this planning too.</li> </ul>
<ul style="list-style-type: none"> <li>Many wider community services are still not reasonable adjusted, this means that people with unique needs can't use them. Therefore, people experience inequalities that impact on their health and wellbeing.</li> </ul>	<ul style="list-style-type: none"> <li>All commissioners (not just those involved in specialist services) should look at how they ensure that autistic people and people with a learning disability have equal access to all community services with reasonable adjustments in place, as service providers are legally obliged to do.</li> </ul>	<ul style="list-style-type: none"> <li>Inequalities are reduced because wider services have the right reasonable adjustments in place. This improves the quality of life that people experience. This will include health screening services, primary care, psychological therapies, justice systems and employment support.</li> </ul>

<sup>25</sup> <https://www.cqc.org.uk/guidance-providers/autistic-people-learning-disability/right-support-right-care-right-culture>

<ul style="list-style-type: none"> <li>• The useful relationships between commissioners and the people they serve in the community is an important foundation of good commissioning. There are missed opportunities when people do not work together to improve things, and this can lead to poorly informed commissioning decisions.</li> </ul>	<ul style="list-style-type: none"> <li>• Seeing families as allies is critical, and commissioners should ensure that the person, and what matters to them, is central-starting with personal aspirations.</li> <li>• Commissioners need to acknowledge that individuals and families can drive the way that care is planned, recognising that those who know the person well, are the biggest asset in realising effective support from an early age.</li> </ul>	<ul style="list-style-type: none"> <li>• Commissioners listen to people and respect the skills and knowledge of families and individuals and include them fully in planning and decision-making processes at the highest levels and from the very start. This means that solutions are found together using everyone’s knowledge and skills. This results in good relationships between people and their commissioner, this means that partnerships are created to support progress</li> </ul>
<ul style="list-style-type: none"> <li>• Some commissioners may not have the necessary skills and/or support within their own organisations to do what is needed to help people. Given the responsibility and potential impact on the public of this role, concern has been raised that the commissioning role is not regulated.</li> </ul>	<ul style="list-style-type: none"> <li>• Commissioning could be made a regulated role.</li> <li>• Commissioners should be both supported and accountable for their actions. They should have a high degree of understanding of Learning Disability and Autism.</li> <li>• Commissioners should be supported to access training and use information from organisations like Skills for Care.</li> <li>• Statutory organisations in which commissioners work need to recognise that delivering the required bespoke approaches will mean doing things differently. For example, enabling the creative use of funding or changing contracting processes to deliver what is needed for the person</li> </ul>	<ul style="list-style-type: none"> <li>• Commissioners are supported by their organisations, and well trained , both in the needs of the people they serve and in the technical skills and knowledge required to be a good commissioner. This ensures they are confident decision makers and can champion the needs of people in the wider system.</li> </ul>

### 9.3 Homes

Where we are now	Necessary actions	What Good looks like
<ul style="list-style-type: none"> <li>The process for securing bespoke homes for people is complicated. Many commissioners are not aware of what is needed to make it happen.</li> </ul>	<ul style="list-style-type: none"> <li>Commissioners should have access to skilled housing support to prevent delays and blockages.</li> </ul>	<ul style="list-style-type: none"> <li>People get homes that reflect their needs and preferences on time. There are no hold-ups in people moving on because accommodation is in place. This is great for people because it means that they are not failed.</li> </ul>
<ul style="list-style-type: none"> <li>There is a crisis now in getting the right accommodation for people- Urgent action is needed. Many areas have no firm, detailed plans about how to develop a wide range of options of personalised accommodation that reflects the needs and aspirations of people, including a choice about who they live with. Many people are living with people they don't know which can be really stressful. Some people naturally want to live with a partner/spouse but housing options are limited to enable this.</li> </ul>	<ul style="list-style-type: none"> <li>Integrated Care Systems need to ensure that planning for homes is in their plans.</li> <li>Councils and registered social landlords should work together with families to make good housing plans that allow for bespoke homes to be available now and in the future.</li> <li>Part of this plan could look at developing cooperative housing that includes mixed tenure options, family based solutions, and those that include homes with partners/spouses.</li> </ul>	<ul style="list-style-type: none"> <li>There is an end to delays related to getting a home because early planning has taken place, and everyone knows that they have a duty to support citizens.</li> <li>Because the choice of homes is wider and more flexible there is a shift to support more "natural" relationships, based on love and choice. These relationships are likely to be lifelong.</li> </ul>

<ul style="list-style-type: none"> <li>• There is no BTRS associated funding plan in place for housing in many areas in the longer term- this can lead to confusion, disagreement and delays. This means people stay longer than is needed in hospital or inappropriate accommodation which can be harmful to them.</li> </ul>	<ul style="list-style-type: none"> <li>• All national and local agencies need to work together to make it easier to fund housing for people who have specific needs so that their wellbeing is protected.</li> <li>• Government mandated directives related to housing should require the funding of subsidised, ethical and value-led specialist supported housing and a range of other housing options in the community.</li> <li>• Local authorities should work with developers using Section106 and environmental levies to provide funding for specialist accommodation. Local planning department staff need to be aware of the BTRS programme and why it is important.</li> </ul>	<ul style="list-style-type: none"> <li>• There are funding plans in place, which use a wide range of funding streams- and this means that people get the right home in time and in line with their support plan, and this support their wellbeing. This is a huge relief for people, families, and the support provider. It makes moving into a new home the exciting and positive experience it should be.</li> </ul>
<ul style="list-style-type: none"> <li>• Many people, families and people working in the current system find accessing funding for housing, often it is a complicated process that is hard to understand and access.</li> </ul>	<ul style="list-style-type: none"> <li>• Funding for housing including the NHSE capital grants and Homes England funding for development of specialist accommodation needs to be timely, clear and easy to access.</li> <li>• Grant funding needs to be flexible. NHSE and councils need to continue looking at capital resources that they can sell to release funding for the programme.</li> </ul>	<ul style="list-style-type: none"> <li>• Funding is more accessible and easier to apply for. This means that there are less delays in accessing funding and it is used effectively, because it is part of a planned approach.</li> </ul>

<ul style="list-style-type: none"> <li>• People and families are not always involved in how capital grants are used when the funding has been allocated. If they are involved this can sometimes feel tokenistic, or a ‘tick box exercise’ because plans have already been developed without them.</li> </ul>	<ul style="list-style-type: none"> <li>• When grants have been allocated, thinking needs to be more creative involving people and families and in decisions, right from the start about their proposed home. Having a real choice of property needs to be enacted .</li> <li>• Some consideration of having personalised budgets to buy a home (backed by legal charge arrangements) to source the right housing may be useful. Parent-carers also need to be engaged about adaptations in existing properties, so their knowledge is used well in making the right decisions.</li> </ul>	<ul style="list-style-type: none"> <li>• People and families are aware in advance about when funding is to be made available.</li> <li>• Integrated Care Systems are clear about how co-production fits in with the early application for and use of funding. Because of this, really creative solutions are found locally, and people get what they need. This offers value for money too.</li> <li>• Funding for adaptations offers better value as the knowledge of parent- carers and people themselves will have been used to make good purchasing decisions.</li> </ul>
<ul style="list-style-type: none"> <li>• Some housing providers still don’t understand what Building the Right Support is all about, and still develop institutional, inappropriate kinds of housing. This can lead to problems with registration or people simply don’t use them because they don’t meet a people’s needs. It can lead to a waste of public money and delays.</li> </ul>	<ul style="list-style-type: none"> <li>• Create a national, well led consortium of values based, ethical housing providers and investors. (from private investors through to statutory grant makers.) This will finance new properties that meet people’s needs.</li> </ul>	<ul style="list-style-type: none"> <li>• Funding is sourced by organisations that really understand what people need. They are agile and proactive about finding out what people need and deliver funding to support the provision of homes, in line with locally produced plans. This means that there is the right ordinary housing available for people in their area when they need it.</li> </ul>



<ul style="list-style-type: none"> <li>• Even if people are in rented accommodation with a tenancy, they may still at some point in the future be asked to leave their home or even be evicted. Any property owner can choose to sell their property. This can have an absolutely devastating impact on people and lives are turned upside down. In some cases, this can create a crisis which means that people could end up in hospital. Home ownership means people cannot be evicted because they own all or part of their home.</li> </ul>	<ul style="list-style-type: none"> <li>• Shared ownership is an option for some people and schemes such as the Home Ownership for people with Long term Disabilities (HOLD) scheme should be expanded . It is possible to make it financially viable if statutory funds can be used to top up the rental element. Capital grant funding, (or family funding where possible) can be used to secure a deposit using a legal charge arrangement</li> </ul>	<ul style="list-style-type: none"> <li>• Some people can (if they want to and are able to) own all or part of their home. This helps them and their families feel really safe and confident about the future. With shared ownership, maintenance of their home is undertaken by the housing association which is helpful. This means that their home is well kept, and everyone's investment is protected.</li> </ul>
<ul style="list-style-type: none"> <li>• Families do not always get the right information or support to navigate the whole housing system. Information is complex and legal support scarce. Key staff like Social Workers are not housing experts either. Families, individuals and advocates need good legal advice so they can make informed decisions, challenge unfair decisions and have their rights upheld in relation to housing.</li> </ul>	<ul style="list-style-type: none"> <li>• More information should be made available to families. A national specialist advice service with the ability to help people plan ahead is also needed.</li> <li>• Planning with pensions for future housing provision should be made possible for families who are able to do this and perhaps help others too. A new product endorsed by the Government could be explored.</li> </ul>	<ul style="list-style-type: none"> <li>• There is greater accountability in the system which helps protect people's rights. People and families have the best information to help them plan into the future, making well informed decisions. This helps people use their own and local resources better. People have greater peace of mind; decisions have been taken using the best information</li> </ul>

<ul style="list-style-type: none"> <li>• Some people end up in hospital because they don't have a place to stay. Either because they have been asked to leave or because they live with other people which impacts on them. This creates a crisis that would be better supported if local accommodation was available to use</li> </ul>	<ul style="list-style-type: none"> <li>• Crisis planning needs to include specialist, local, short term housing options. A study of what can be provided for short breaks, and more supported crisis accommodation would be useful to undertake on a national level. 'Sanctuaries and havens of safety and peace' are needed in each area, the planning of these should involve people and families.</li> <li>• A virtual accessible panel of hands-on troubleshooting expertise (where there is a crisis) should be used to make sure that support and accommodation, in the short term, is well planned and are urgently put in place.</li> </ul>	<ul style="list-style-type: none"> <li>• People using short term support are much less likely to end up in hospital far away. They stay local where their natural relationships are supportive and where people know them. Trauma is minimised and the longer-term effects of the crisis are reduced. Learning about what happened and what needs to change stays local, and the new information is used to help plan a better future.</li> <li>• Crisis is minimised as local accommodation is available and avoids people leaving their local area.</li> </ul>
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## 9.4 Children and Young People

Where we are now	Necessary actions	What good looks like
<ul style="list-style-type: none"> <li>Education, Health and Care Plans are not always reflecting what matters to children and young people. Some aspirations are not fully supported.</li> </ul>	<ul style="list-style-type: none"> <li>Ensure good planning that is truly person centred is part of Education Health and Care Plans.</li> <li>Children and young people set their own goals and aspirations in their plans. A "what matters to you?" conversation is mandated as the basis for all planning rather than using a "tick box" approach.</li> <li>Staff involved in planning are trained and understand the needs of autistic children and children with a learning disability.</li> </ul>	<ul style="list-style-type: none"> <li>Everyone supporting with the person knows what their goals are and uses their skills to help the person meet them. Families and young people know what help is available and they get what is important to them without waiting.</li> </ul>
<ul style="list-style-type: none"> <li>People and families don't always feel listened to or believed, even when they are raising serious concerns. Sometimes services are slow to act and/or communication is poor. Sometimes families feel blamed.</li> <li>Lack of early help can create problems later in life or creates crisis. It can have a long-term impact on the opportunity to develop.</li> </ul>	<ul style="list-style-type: none"> <li>Listen to parents and children, respect their knowledge and skills and provide early support that is right for them rather than precipitate crises through not listening and acting.</li> <li>Additionally, staff should be trained about and aware of the risks of institutionalising parent-carer blame<sup>26</sup>.</li> <li>Others such as Pastoral Managers in schools should have good working relationships with commissioners to provide feedback about what is working and what isn't.</li> </ul>	<ul style="list-style-type: none"> <li>People working with families listen and ensure rapid and continuing communication.</li> <li>They believe what people tell them and seek urgent help when it is needed, and this helps situations from deteriorating, avoiding harm.</li> <li>Relationships with parent-carers is good and creates effective partnership working around the child.</li> </ul>

<sup>26</sup> <https://www.lukeclements.co.uk/institutionalising-parent-carer-blame/>

## 9.5 A focus on the whole person

Where we are now	Necessary actions	What Good looks like
<ul style="list-style-type: none"> <li>• People told us that sometimes the way they are seen by services, often as a diagnosis rather than a whole person, is damaging. This is also exaggerated by the 'fragmentation' of services which might just be focussing on one particular need a person has, rather than the whole human being in front of them.</li> </ul>	<ul style="list-style-type: none"> <li>• Training of staff is needed to make sure that the issue of 'fragmentation' is understood. It is also part of value-based approach. Co-ordination of support is needed so that truly personalised support happens across the board. If people need help, anyone collaborating with the person needs to find out and understand what matters to them, so that they can see how their offer of help fits with the person.</li> </ul>	<ul style="list-style-type: none"> <li>• Anyone seeking to support a person understands the whole person and what matters to them. Support is properly coordinated and because of this people experience support that fits their life. Time is saved because there is better coordination, actions aimed at helping the person have good outcomes.</li> </ul>
<ul style="list-style-type: none"> <li>• The way that people are viewed by society has a direct impact on the way that help, or support is offered. Language used has a role in shaping the way that this happens. A lot of language used is dehumanising or "others" autistic people and people who have a learning disability. Its use often places the person in a permanent 'Serviceland' rather than someone living a real life like anyone else. Terms like Service User deny a person's whole humanity for example.</li> </ul>	<ul style="list-style-type: none"> <li>• Greater awareness is required across the community, so people know what language is harmful. Training of staff by people with lived experience to bring about change is critical. Suggestions for alternative language is helpful and this should be promoted in practice.</li> <li>• Local and national media organisations also have a duty to positively promote the use of better language.</li> </ul>	<ul style="list-style-type: none"> <li>• Language used is positive and fully reflects our shared humanity. This leads to a change in the way ideas about people are communicated, in turn this means that people are treated more inclusively and are seen as whole a whole human being in their real-life context</li> </ul>

<ul style="list-style-type: none"> <li>• People are sometimes overly constrained and are not allowed to grow personally because they are denied the possibility of taking positive risks. Risk aversion is sometimes used as a rationale for keeping people in hospital that can make people miserable and cause trauma. This is a human rights issue.</li> </ul>	<ul style="list-style-type: none"> <li>• Ensure that positive risk taking is supported in the community and shared with the individual keeping them in the driving seat whenever possible and /or those who know and understand them very well. Best interest decision making (Mental Capacity Act) must be used when people are deemed to lack capacity about specific decisions. Some people with capacity will make unwise decisions like the rest of us.</li> </ul>	<ul style="list-style-type: none"> <li>•</li> </ul>
<ul style="list-style-type: none"> <li>• Autistic people and people with a learning disability are often denied their sexuality and/or their gender identity. This is likely to cause real distress to people and does not fully support their human rights.</li> </ul>	<ul style="list-style-type: none"> <li>• Education of people, families, schools, support agencies and the wider public is needed to make sure that people are able to be their full self.</li> <li>• Support organisations should make sure that staff are 'matched' with individuals and can function as positive supports.</li> <li>• Further research is needed in this area to support a better evidence base for the strategic planning of local resources.</li> </ul>	<ul style="list-style-type: none"> <li>• People feel comfortable being who they are, as a whole person, knowing they are fully part of the community. Stressors related to unrecognised sexuality and/or gender identity are removed, and people have better wellbeing as a result.</li> <li>• People and organisations act within Human Rights legislation.</li> </ul>

## 9.6 Relationships

Where we are now?	Necessary actions	What Good looks like
<p>Many of the people we spoke to told us that they wanted more relationships in their lives. This may include friendships or romantic relationships. (Love is one of the Keys to Citizenship)</p> <p>Meeting people and developing natural relationships often happens through social contact at school, work places or going to leisure facilities like pubs, clubs, restaurants or gigs. Some people also use online dating or organised ways to meet others.</p>	<p>Autistic people and people with learning disabilities need to know and understand their rights. They also need to learn that they can challenge when providers or carers are saying that they are not allowed to do something that they have a legal right to have (Articles 8 and 12), including relationships.</p>	<p>People are a normal part of the social life of the community. People have more friends, and some people have long term partners and get married if they wish. Because people have natural relationships that last -they have less loneliness and less loss in their lives. This is better for their health and wellbeing.</p>
<p>Opportunities to stay out late are often limited by services, particularly when they receive paid support that ends at a given time every evening. This limits opportunities for love and friendships.</p>	<p>If people are getting support, it needs to be flexible enough to support people getting out to create and sustain relationships. There are good examples about how people can be supported to access more places to have fun and meet people.</p>	<p>People become less reliant on paid support, (but where paid support is in place, staff fully respect a person's right to have relationships of all kinds). Support is flexible and supports people to stay out late.</p>
<p>Having people, we love in our lives is a fundamental right. Some of those relationships may be intimate and sexual yet this is often not supported by services when people have paid support in place.</p>	<p>People providing support need to find out what people want in their lives, including support or information related to accessing sexual health and/or family planning services.</p>	<p>People have the opportunity to have safe, sexual relationships like other people. People are supported and well informed to make their own decisions.</p>

<p>For autistic parents, or parents who have a learning disability, pregnancy and childbirth can sometimes be unsupported or in some cases traumatic- particularly when assumptions are made about abilities to look after a child are made and attempts to take away children are the first action rather than the last.</p>	<p>Primary care, maternity services and health visitors should have training and access to information that supports the human rights of people, particularly of mothers. A wide range of advice and information is available to help. "Better Births" stipulates that all mothers should have a personalised care and support plan. This is a great opportunity to bring in specialist advice and advocacy to plan the right support with mothers (and partners) after having a 'what matters to you?' conversation. Staff should be aware of the mental capacity act, and also where to source advocates or support if required.</p>	<p>Pregnancy and childbirth feels supported and mothers feel that all is being done to help them nurture and care for their baby. There are opportunities for conversations to take place regularly with professionals and others to make sure that this remains a positive experience.</p>
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## 9.7 Help when people need it.

Where we are now	Necessary Actions	What good looks like
<p>Eligibility criteria for services is often excluding which means that often support is not accessible when people need it. This means that needs escalate. This can have longer term negative effects for children and young people in particular, whose development and wellbeing is affected. Over time it could be argued that this creates an additional financial cost to local services.</p>	<p>Eligibility criteria needs to be reviewed and allow for greater access that supports wellbeing and is preventative in nature. The review of criteria should be undertaken with local groups of people and families to discuss which services in particular need focusing on.</p>	<p>People challenge plans and priorities across health care and the wider range of council services and identify practices that have an unintended consequence of escalating needs.</p>
<p>People can experience crises because early help isn't available locally, (or eligibility criteria means things need to get worse before help is offered) This often causes harm. People who move area can be impacted if eligibility criteria is different to the place that they have moved from.</p>	<p>Services need to offer early help to prevent deterioration, this includes removing overly restrictive criteria for services. This also means that commissioners need the knowledge to find out what people would find most useful in their area, and put it in place, and/or work with the community and voluntary sector to develop better preventative responses, including peer support. Greater consistency between areas is needed about who can and can't use services.</p>	<p>People can get the help they need earlier because services don't have eligibility criteria that excludes people. This helps people achieve their goals in life because they get the help they need when they need it. People can move area and expect similar levels of support in the services they need.</p>



## 9.8 Funding

Where we are now	Necessary actions	What Good looks like
<ul style="list-style-type: none"> <li>• Although there have been previous recommendations about what kind of bespoke support works for people this hasn't happened everywhere, and money is still being spent on institutional kinds of support including hospitals.</li> </ul>	<p>Resources need to be put into truly building support around the person in their community keeping their aspirations central and supporting the right to a good life, like everyone else.</p>	<ul style="list-style-type: none"> <li>• People live the life that they want in the community as full citizens. Funding is spent on bespoke support or things that people say matter to them and provides early help. Capital funding is available to help people get ordinary homes, and to support improved accessibility of buildings, transport and facilities in the local community</li> </ul>
<ul style="list-style-type: none"> <li>• A lot of good initiatives start and stop because funding is temporary or because there is a change in national or local government that decides to stop funding things that are working. This is devastating for people who find them useful</li> </ul>	<ul style="list-style-type: none"> <li>• Local and central government should develop long term plans and investments that are fully supported. Good change needs an opportunity to be embedded and supported.</li> </ul>	<ul style="list-style-type: none"> <li>• We have long term plans related to investment and service development that are co-produced with people -They have cross party support so if politicians change, plans do not.</li> </ul>

<ul style="list-style-type: none"> <li>• Personalised funding is really valued by people but if you are a child growing into an adult, or someone whose needs are changing this can create a horrible and worrying change in funding as there are new application processes and often too much “red tape” to contend with. For some people it can mean losing support they have found critical with dreadful consequences.</li> </ul>	<ul style="list-style-type: none"> <li>• Establish an integrated ‘without boundaries,’ all age, health, education and social care budget in each place, that individuals with a learning disability or autistic people have access to and can spend on the things that will keep them well and active in their local community.</li> <li>• People have a “what matters to you?” conversation first-before anyone even thinks about money. What people need must be explored and sourced-from universal services, community-based support and finally specific targeted support that may need personal funding.</li> <li>• If a person has a personal budget it must move with them, be flexible, and able to be used creatively to meet the outcomes that they have identified.</li> </ul>	<ul style="list-style-type: none"> <li>• People use universal and community services if that helps them, some people have their own budgets, they know how much they have and use it to meet their goals. They can use it really creatively on things that really make a positive difference to them.</li> <li>• Families are less worried about their child preparing for adulthood because they know that funding will continue without disruption. This makes teenage years much easier to manage, and helps with exciting, confident and positive planning for the future, in turn this helps people thrive.</li> </ul>
<ul style="list-style-type: none"> <li>• When people have their own budget sometimes, they might need support with brokerage. (In fact, many of the advice and support services have been affected by austerity measures along with other low level preventative community services.)</li> </ul>	<ul style="list-style-type: none"> <li>• Having the right advice and support about using funding is needed .Brokerage should be better supported in local areas, so it maximises choice and control and ensures good use of public funds that support great outcomes for people.</li> </ul>	<ul style="list-style-type: none"> <li>• People and families are really well informed about what services are out there and make confident choices about how they use their personal budget. Good services get more work and poor ones cease to exist. -New kinds of support that are needed begin to be developed and this extends choice</li> </ul>
<ul style="list-style-type: none"> <li>• Some services rated as ‘inadequate’ are used in some areas, due to the lack of alternatives. They are often expensive, and people realise that these are potentially harmful, and offer poor value for money.</li> </ul>	<ul style="list-style-type: none"> <li>• De-commission inadequate services and transfer the released monies into a locally managed fund so that the people using these services can co-produce (with commissioners) a plan about what support needs to be in place locally</li> </ul>	<ul style="list-style-type: none"> <li>• People are safer and engage in local commissioning and planning decisions. Trauma is reduced and in turn this reduces the need for longer term trauma related support over time.</li> </ul>

<ul style="list-style-type: none"> <li>• Because Education, Health and Social care have separate budgets still in many places, this can cause arguments and delays about who offers the proactive funding that prevents deterioration and crisis. It means that taxpayers fund expensive hospital care rather than the helpful local things that must be offered much earlier on to people.</li> </ul>	<ul style="list-style-type: none"> <li>• Integrated Care Systems should develop pooled budget arrangements, -this can help to address the financial disincentives. They must consistently provide needs-led services rather than services that are reliant on a specific diagnosis to access (Diagnoses can take many years to secure.) ICSs should consider how Education, Health and Care Planning top-up funding (or DSG high needs block funding) can be integrated into a personalised all age health, education, and social care budget</li> </ul>	<ul style="list-style-type: none"> <li>• National guidance says that funding disputes must never cause delays, and this is regularly enacted in practice because budgets are pooled the overall money 'in the public purse' is spent on the right things. As a result, trauma is reduced, and less time is spent arguing about who funds what. This means that there are better outcomes for people and better value for money is realised.</li> </ul>
<ul style="list-style-type: none"> <li>• People told us there is an overall lack of specific support and services for autistic people of all ages who do not have a learning disability. This is creating crisis that can lead to hospital admissions and means that organisations are not compliant with the Care Act 2014</li> </ul>	<ul style="list-style-type: none"> <li>• Investment must be put in planned and put in place to support autistic children and adults who do not have a learning disability. Plans must be coproduced.</li> </ul>	<ul style="list-style-type: none"> <li>• There is an equal offer of support to autistic people who do not have a learning disability. This means that they get the help they need to live their life as part of their local community.</li> </ul>
<ul style="list-style-type: none"> <li>• People often need things that statutory services struggle to fund because of lack of flexibility or permission about what money can be spent on - as long as these are legal and support outcomes. This can impact on the way that personal budgets are used.</li> </ul>	<ul style="list-style-type: none"> <li>• Integrated Care Systems need to support the use of well-funded personal budgets that can be used creatively by people, this should also include one off capital budgets.</li> </ul>	<ul style="list-style-type: none"> <li>• People are allowed to identify spending that has positive outcomes for them. People are given the flexibility to use funds creatively.</li> </ul>

## 9.9 Justice

Where we are now	Necessary actions	What Good looks like
<ul style="list-style-type: none"> <li>Some adults and young people told us they are regularly bullied, or experience hate crime in the community, and/or on transport and in schools/workplaces. -The impact of this is that they sometimes choose to be in more segregated environments, just to feel safer.</li> </ul>	<ul style="list-style-type: none"> <li>Integrated Care Systems need to work together to create welcoming communities as part of place-based working.</li> <li>Council leaders responsible for commissioning transport, employment and education services must make sure that hate crime is not tolerated on public transport or in schools or workplaces, and that staff are trained in knowing how to listen to people and respond.</li> <li>In schools all children and young people are taught about inclusion at an early age and their part in it.</li> </ul>	<ul style="list-style-type: none"> <li>People are part of their local community and feel safe within it.</li> <li>If there are any issues, they know how to raise concerns and know that they will be listened to, and crimes acted upon in a prompt way. Adults have an understanding of how they can include everyone in their communities.</li> </ul>
<ul style="list-style-type: none"> <li>Some adults and young people told us they are regularly bullied, or experience hate crime in the community, and/or on transport and in schools/workplaces. The impact of this is that they sometimes choose to be in more segregated environments, just to feel safer (Continued)</li> </ul>	<ul style="list-style-type: none"> <li>Police should take steps to support the recording of hate crime and prosecute offenders. Numbers of reported hate crimes, and actions taken must be relayed back to partnership groups and Integrated Care Boards. Resources for police are needed to ensure they can act to support this. The use of “safe places” in the community may need a review, or further support.</li> </ul>	<ul style="list-style-type: none"> <li>Prosecutions are made when crime has been committed and this acts as a deterrent.</li> <li>In the community people know where safe places are, they are properly supported by the police and members of the community including retailers and leisure facilities.</li> </ul>

<ul style="list-style-type: none"> <li>• In the light of proposals to exclude some people with a learning disability from the non-forensic powers of the Mental Health Act: research evidence suggests that this could have the unintended consequence of pushing people with intellectual disability, and potentially autistic people, into the criminal justice system, including prison. (Also called the Penrose Hypothesis<sup>27</sup>)</li> </ul>	<ul style="list-style-type: none"> <li>• Integrated Care Systems need to work together to develop effective pathways across their systems that identify opportunities for prevention and intervention where people are at risk of becoming detained in the criminal justice system. This will mean collaborating with people, families, advocates, education, health (particularly liaison and diversion teams), social care, housing, welfare benefits, police, legal services, probation and the community voluntary sector.</li> </ul>	<ul style="list-style-type: none"> <li>• There is an agreed multi agency pathway that people understand and that is fully supported by key groups and individuals. Interventions are undertaken to divert people away from criminal justice routes to more wellbeing related personalised support in the community. As a result, there is no rise in people with a learning disability or autistic people ending up in prison.</li> </ul>
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<sup>27</sup> [The Penrose hypothesis in the second half of the 20th century: investigating the relationship between psychiatric bed numbers and the prison population in England between 1960 and 2018–2019 | The British Journal of Psychiatry | Cambridge Core](#)

## 9.10 Employment

Where we are now	Necessary actions	What Good looks like
<ul style="list-style-type: none"> <li>• People told us that having money to do the things that they wanted in life is important. Yet, many people are excluded from paid work.</li> </ul>	<ul style="list-style-type: none"> <li>• Employers in local areas need to make their process of employment more flexible by tailoring recruitment and post-employment-processes around people and their needs. Examples include adjusted interview processes, job carving, job coaching, and buddy systems at work.</li> <li>• Staff working in job centres, must be aware of the need for reasonable adjustments to support people.</li> <li>• Access to work funding must be made available to help people</li> </ul>	<ul style="list-style-type: none"> <li>• More people who have a learning disability and autistic people have paid work. They also are supported to pursue careers and development once in work.</li> </ul>
<ul style="list-style-type: none"> <li>• Aspirations related to paid work are low for autistic people and people who have a learning disability. The unique, strengths, skills and abilities of individuals are not recognised, and access to employment is difficult because of the lack of reasonable adjustments in application processes and post-employment support.</li> </ul>	<ul style="list-style-type: none"> <li>• Councils have a role in supporting more inclusive economies in their local area and they should consider the needs of all potential employees. (Some areas have specific groups that work together to employ neurodivergent people for example).</li> <li>• Member organisations in the Integrated Care System can lead by example and actively employ autistic people and people who have a learning disability in paid work.</li> </ul>	<ul style="list-style-type: none"> <li>• Employers benefit from having a diverse workforce with unique skills and abilities.</li> <li>• Local areas have a coordinated response to supporting paid work.</li> <li>• Some people may be some traders or have small businesses where they have specific skills that lend themselves to this way of working.</li> </ul>

<ul style="list-style-type: none"> <li>• Access to computers or lack of digital skills can function as a barrier for some people wanting to work.</li> </ul>	<ul style="list-style-type: none"> <li>• Enabling programmes of work such as improving people’s access to digital or online ways of working also need to be developed inclusively so that people can learn about and apply for job opportunities.</li> </ul>	<ul style="list-style-type: none"> <li>• People find out about job opportunities, or training and education that will help them get paid work. Support is easy to find to help with using online job applications, or in accessing IT kit to make this possible.</li> </ul>
<ul style="list-style-type: none"> <li>• Some people are worried about trying employment and coming off benefits, because getting back on is problematic.</li> </ul>	<ul style="list-style-type: none"> <li>• People need to be supported around their benefits and understanding how they can maintain a living income, either in work or out of it. This means having help to make the right claims and speedy responses to them.</li> </ul>	<ul style="list-style-type: none"> <li>• People feel confident about trying a range of jobs or employment.</li> </ul>

# 10. Appendices

## Appendix 1- Review of relevant published reports

Summary.

**At the commencement of this programme of work, a review of relevant published reports was undertaken to identify what previous reports had been published and to review progress against recommendations.**

**The structure of the review covered.**

- **People, their rights and a good life**

This covered 17 reports starting with key reports including.

Winterbourne View - Time for change, through to Transforming Care, Building the Right Support. It also contained CQC content such as “Out of Sight, who cares?” It covered the Governments response to the Human Rights of people detained in hospital during the Covid 19 pandemic.

**Key findings**

Progress has been patchy: - some recommendations have been subsumed in the MHA white paper or statutory guidance. CQC have established changes in inspection regimes. Some legislation such as the “Right to have” a Personal Health Budget (if eligible for S117 aftercare) is not systematically implemented. However, there has been a stronger focus on workforce and training.

A striking observation is that from Winterbourne view to Building the Right Support, many of the problems needing to be addressed in the system remain, 11 years on.

- **Commissioning for wellbeing**

This covered 11 reports, including reviews by the National Audit Office into care services for people with learning disabilities and challenging behaviour. The “No voice unheard, no rights ignored” consultation also listed some key recommendations, many have been reiterated in this report. This section also included additional training and guidance for commissioners which has been established. Funding remains a focus in many reports, and we have seen the introduction of some additional funding, but this is mainly focussed on discharge.

**Key findings**

The Care Act 2014 identified a need for a focus on wellbeing and on areas having the right local supports in place (Sufficiency) However public funding remains stretched and this is not evidently in place in many areas- use of pooled budgets is also inconsistent. Another feature of commissioning is the recent restructures in the newly created Integrated Care Systems and developing provider collaboratives. It remains to be seen how these will impact on the delivery of the right supports at a local level.

- **Community assessment and support when people want or need help**

Fourteen reports were reviewed in line with this area of focus. Key documents included many listed earlier, but also ‘The Bradley Report’ and ‘Beyond the High Fence’ consider what happens when people may get in trouble and end up detained as part of the justice system. This was also highlighted in ‘The Autism act- 10 years on.’

**Key findings**

The need for crisis response (both local support and available accommodation) is listed in several early reports. The advisory group found that lack of crisis



accommodation is still a concern (this also was highlighted for children and families needing crisis support).

## **Appendix 2 - Searching and reviewing the evidence**

Following the scoping consultation response and advisory group discussions, an evidence gathering exercise was undertaken to find answers to several key questions. These are listed below with very brief answers.

### **Question: Does co-production secure better outcomes for individuals and reduce costs?**

Answer: Yes- There is evidence from a range of different sources. The Named Social Work pilots also found cost reductions and a good return on investment.

### **Question: Do the perceptions and views of health and social care staff influence how they support individuals?**

Answer: Yes- The absence of training about and experience of working with individuals with a learning disability and autistic people resulted in professionals being more fearful of the individual, less likely to co-produce care planning or treatment information with the individual and were more risk adverse.

### **Question: Can the barriers to self-directed support be overcome?**

Answer: -Evidence in this area is unclear with the last evaluation of the Scottish government's work to implement self-directed support being undertaken in 2017. Broadly it can be said that work to systematically understand actual, rather than perceived barriers, and the actions required needs more work – recognising the vast range of individuals who could use self-directed support.

### **Question: Are universal mental health services putting in place adaptations to meet the mental health needs of autistic people and people with a learning disability?**

Answer: No. Evidence found a high use of emergency departments to access mental health and physical health services, poor knowledge and skills amongst psychiatrists and a large-scale meta-synthesis found mental health services do not adequately support autistic adults and can even cause additional harm.

### **Question: Does strengths based social work practice deliver better outcomes?**

Answer: NIHR literature review did not find clear evidence that strengths-based practice delivered better outcomes BUT the evidence review conflated evaluation of social work practice with an evaluation of community asset building activity. Other smaller reviews have found evidence of practice.

### **Question: How effective is Positive Behaviour Support (PBS) as an intervention?**

Answer: One randomised control test found no evidence of impact but compliance with PBS methodology was very poor. Other studies have found good rates of effectiveness. - So, it must be done properly.

### **Rapid review- “Double Discrimination”**

**Question: Is the right to develop and experience intimate relationships recognised in how services are provided to people with a learning disability and autistic people?**

Answer: Many people felt this was really important to have, but many felt constrained by professional caregivers, and they felt a lack of support and control. There was a view that interventions were sometimes unhelpful and intrusive and were related to perceptions of risk. Gaps around education on sexuality and relationships, particularly for autistic young people was identified.

**Question: Are social care and NHS services aware of the needs of specific race, culture and faith groups in the way services are provided to people with a learning disability and autistic people?**

Answer: Many people living in Black, Asian and minority groups had trouble getting a diagnosis, and even then, accessing services. Communication and trust are key issues. Black people with learning disabilities are less likely to be offered psychotherapy, more likely to be offered drugs, and more likely to be treated by coercion in inpatient settings, even after socioeconomic and diagnostic differences are considered.

**Question: Is inpatient provision for young autistic people meeting its obligation to support young people who are starting to, or have, identified as LGBTQ+?**

Answer: There was a lack of confidence, knowledge and skills expressed by care givers about how best to support young people who are starting to, or have, identified as LGBTQ+. For individuals, negative experiences included being asked personal, invasive questions unnecessarily, being misgendered, speaking to their parent without them present, and doctors using outdated terminology.

## Appendix 3- Online survey questions

### “What good looks like” – Our first survey



The government wants to improve the lives of people with a learning disability and autistic people.

This work is called, “Building the Right support.”

### **We need your help.**



We want to find out what people in our community think good support looks like.

We must ask autistic people and people with a learning disability about this. We are also asking family carers.

You can help us by doing this survey.



When we have listened to what people have said we will write a report.

The report will share what we have learned. We will share how good services and support were made so that other areas can learn how to do it.



If you would like, you can ask a friend, relative or an advocate to help you with the questions.

It is your views that we are interested in. Those helping you should support you to tell us your views.

## Confidentiality



Your answers are confidential. This means that we don't know your name or your answers.

Doing this survey will not affect the services and support you receive.

## Some questions

1. Please tell us if you have been a patient in a psychiatric hospital?

This is a hospital that should help you feel mentally well and happier.

Yes	No

2. Who is answering these questions?

(You can tick more than one box)

Who I am	Please tick
I am a person with a learning disability	
I am an autistic person	
I am a family carer	
I am a paid person or an advocate	

**3a. What things are important for you to enjoy a good life?**

Below is a list of things that might be important to you.

Tick if you **have** these things in your life already.

Tick if you don't have the thing but you **want** it.

You can also tick the box if this is **not important** to you.

THINGS IN LIFE	THIS IS IMPORTANT TO ME AND I ALREADY HAVE THIS IN MY LIFE	I DON'T HAVE THIS. I WANT IT IN MY LIFE	THIS IS NOT IMPORTANT TO ME
I see my family when I want.			
I can see my friends when I want.			
The people that matter most to me live nearby			
I can have a romantic relationship if I want one			
I can use the phone when I want to			
I can use the internet when I want to			
I choose who I live with			
I have a home that has everything I need in it.			
I have money to buy things I need.			
People listen to me, and I can tell them what I need			
I do lots of things in my community and people know me.			
People that I meet treat me nicely and they are kind.			
I make decision in my life about what I want to do			
I do lots of different activities that I like every week.			

I eat healthy food and take exercise.			
I like the people that support me, and I have all the help I need.			
I can go to the places I want to easily. For example, I can take a bus or a taxi when I need to.			
I have a job.			
I can learn new things if I want to. For example, going to college, doing a course or hobby.			
I am involved in plans about me (e.g., Care and Treatment Reviews, Person Centred Plan, Positive Behaviour Support plan)			

**2b What else do you need to have in your life?  
Please tell us in the box below**

**3. What support do you need to have a good life?  
Please tick the box**

<b>TYPE OF SUPPORT</b>	<b>TICK THIS BOX IF YOU NEED THIS TO HAVE A GOOD LIFE</b>
I need people to advocate (Speak up) for me.	
I need to be able to contact a lawyer to help me.	

<b>I need support from people that understand me and know how to help me.</b>	
<b>I need people to ask what is important to me. then I need them to do what is important.</b>	
<b>I need people to help me in my own home.</b>	
<b>I need help making appointments and getting to appointments.</b>	
<b>I need support to talk to health professionals. For example, I need help understanding and writing down what the doctor tells me.</b>	
<b>I need access to specialists. For example, a Speech and language therapist or a counsellor.</b>	
<b>Getting urgent help when I need it.</b>	
<b>I need people to help me get a job. This means helping me apply and helping me in the interview.</b>	
<b>I need people to help me learn new things.</b>	
<b>Help to find housing.</b>	
<b>I need help managing my money and getting benefits.</b>	
<b>I need people in the community to understand my needs and treat me respectfully.</b>	

**4. What stops you from achieving the good life you want to have?**

**Please tell us in the box below**

**5. Are there any great services or support that you could tell us about?**

**Please tell us in the box below**



Thank you for helping us by completing this questionnaire.

We will be collecting all the information from everyone and will include this in our final report.

If you, or your friend or relative, have questions you would like to ask about the survey please contact.



## Appendix 4: Gathering Information Sheet

### “What Good Looks Like” Gathering Information Sheet

Name of the proposed “Good” project/service	
Which area of focus for the report does this cover?	
The name of the person/people you are interviewing.	
Name of the interviewer	
Date of the interview	
The name of the organisation that runs or supports this project/service	
Who funds the project/service?	
Where does the project/service operate? (Town or County)	
A description of the project/service <ul style="list-style-type: none"><li>• Who is it for?</li><li>• What age range of people does it help?</li><li>• What needs does it meet- or who does it help?</li><li>• How does it help people?</li></ul>	
Who is allowed to use it? (Are there any eligibility criteria?)	
Is this project/service related to housing or accommodation? (Y/N)	
What was the motivation to set this up?  How did the project or service come about?	

<p>A brief history.</p>	
<p>Why do you think it has worked as well as it has and what made the difference?</p> <p>Key people? Beliefs and values? Support? Processes? Thinking? Actions?</p>	
<p>Were there any barriers to overcome in developing this project/support?</p> <p>How did you get round the barriers?</p> <p>Please describe them.</p>	
<p>What makes it good?</p> <ul style="list-style-type: none"> <li>• How does it help people achieve their goals, hopes and dreams?</li> <li>• Is it a project/service of good quality?</li> <li>• How does it support someone's human rights?</li> <li>• Is it particularly creative or innovative?</li> <li>• Does it offer added value to people who don't directly use it, or does it help the community? (Social value)</li> <li>• Is it good value for money?</li> <li>• Anything else</li> </ul>	
<p>Is it possible to speak to people who have used this service?</p> <p>Are there any quotes you have about this service from people who have used it, that you can use and have permission to share?</p>	

<p>Are there any inspection or quality reports from CQC, Ofsted or Quality Checkers? What do they say about the service? (Please add any online links or references if you are able to)</p>	
<p>Do you know how much it costs?  How is this funded? (Voluntary or commissioned, self-funded)</p>	
<p>Are there any information links about this service online that you can add?</p>	
<p>Has anyone done any research or evaluation about this service? -Can you add any links or references?</p>	
<p>What does the future look like for this service- are there any risks to it in the foreseeable future, and why?</p>	

## Appendix 5 - Human rights

### The rights protected by our Human Rights Act:



Right to life  
(Article 2)



Right not to be tortured or treated in an inhuman or degrading way  
(Article 3)



Right to be free from slavery or forced labour  
(Article 4)



Right to liberty  
(Article 5)



Right to a fair trial  
(Article 6)



Right not to be punished for something which wasn't against the law when you did it  
(Article 7)



Right to respect for private and family life, home and correspondence  
(Article 8)



Right to freedom of thought, conscience and religion  
(Article 9)



Right to freedom of expression  
(Article 10)



Right to freedom of assembly and association  
(Article 11)



Right to marry and found a family  
(Article 12)



Right not to be discriminated against in relation to any of the human rights listed here  
(Article 14)



Right to peaceful enjoyment of possessions  
(Article 1, Protocol 1)



Right to education  
(Article 2, Protocol 1)



Right to free elections  
(Article 3, Protocol 1)



Abolition of the death penalty  
(Article 1, Protocol 13)

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