



“Fulfilling and Rewarding Lives”: Evaluating Progress

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Fulfilling and Rewarding Lives: The Strategy for Adults with Autism – Evaluating Progress

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Contents

| | |
|--|-----------|
| Contents | 1 |
| Background | 2 |
| From targets to outcomes: a new approach to evaluating progress..... | 2 |
| Seven quality outcomes that will show progress | 4 |
| Three key ambitions to enable local communities assess how services are moving towards achieving outcomes | 4 |
| Using the outcomes and ambitions to hold services to account..... | 5 |
| Quality areas | 5 |
| 1. Adults with autism achieve better health outcomes..... | 5 |
| 2. Adults with autism are included and economically active..... | 7 |
| 3. Adults with autism are living in accommodation that meets their needs..... | 9 |
| 4. Adults with autism are benefiting from the personalisation agenda in health and social care, and can access personal budgets..... | 11 |
| 5. Adults with autism are no longer managed inappropriately in the criminal justice system ... | 12 |
| 6. Adults with autism, their families and carers are satisfied with local services | 13 |
| 7. Adults with autism are involved in service planning | 15 |
| Service Ambitions | 16 |
| 1. Local authorities and partners know how many adults with autism live in the area..... | 16 |
| 2. A clear and trusted diagnostic pathway is available locally | 17 |
| 3. Health and social care staff make reasonable adjustments to services to meet the needs of adults with autism..... | 18 |
| 10 Steps to Progress | 19 |
| 1. Appointing a local autism lead..... | 20 |
| 2. Including autism within key procedures..... | 21 |
| 3. Collecting and collating relevant data about adults with autism | 21 |
| 4. Developing an integrated commissioning plan | 21 |
| 5. Developing a plan to deliver appropriate levels of training to front-line staff | 22 |
| 6. Mapping local employment services that support adults with autism | 22 |
| 7. Mapping local voluntary services and social enterprises that support adults with autism | 23 |
| 8. Involving adults with autism, their families and carers in service design and planning..... | 23 |
| 9. Developing and implementing a staff survey about working with adults with autism..... | 23 |
| 10. Learning from and sharing best practice | 23 |

Background

From targets to outcomes: a new approach to evaluating progress

The first ever strategy for adults with autism in England, *Fulfilling and Rewarding Lives*, was published in March 2010 – as mandated by the Autism Act 2009. The strategy sets out a long-term vision and ambition to improve the lives of adults with autism. This Government is fully committed to the autism strategy and the vision it is founded upon:

‘All adults with autism are able to live fulfilling and rewarding lives within a society that accepts and understands them. They can get a diagnosis and access support if they need it, and they can depend on mainstream public services to treat them fairly as individuals, helping them make the most of their talents.’¹

However, the Government believes that the kind of long-term, cultural change embodied in this vision can only be achieved by putting ownership and responsibility for it in the hands of professionals on the front line. It requires an improved understanding of autism – in both public services and within wider society – and an increased ability to tailor services to meet the real needs of adults with autism at a local level. **It will not be achieved through centralised target-setting.** Rather, the Government is committed to a clear focus on and transparent approach to outcomes, and to working with our external partners to create the right quality frameworks and outcome indicators.

That’s why our approach to evaluating progress towards this vision is based on tangible quality outcomes – visible and measurable indications of whether the vision is being realised. This document identifies seven such quality outcomes, which are as applicable at a local level as a national one. These have been developed with a number of partner organisations including the Association of Directors of Social Care and the National Autistic Society. They reflect a wide agreement on key priorities as articulated through the national consultation which informed the development of the *Fulfilling and Rewarding Lives* strategy and on draft statutory guidance to secure the delivery of that strategy, as well as discussions with adults with autism, family carers and health and social care professionals.

These outcomes reflect the priorities and principles set out in the Government’s *A Vision for Adult Social Care*² and *Equity and Excellence*³, the vision for the future of the NHS. They also sit firmly alongside the wider outcomes proposed for the NHS, public health and social care set out in the Adult Social Care, Public Health and NHS national outcomes frameworks⁴ – in particular reducing health inequalities, promoting personalisation and enhancing quality of life for people with care and support needs, and ensuring a positive experience of care and support.

¹ DH (2010) ‘*Fulfilling and rewarding lives*’ *The strategy for adults with autism in England*

² DH (2010) *A Vision for Adult Social Care: Capable Communities and Active Citizens*

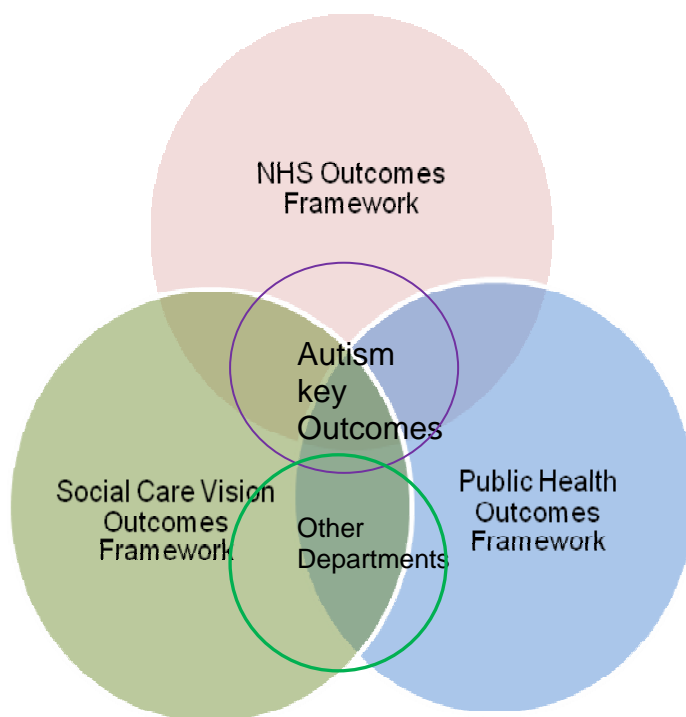
³ DH (2010) *Equity and Excellence: Liberating the NHS*

⁴ DH (2010) *Transparency in outcomes: a framework for adult social care*;

DH (2010) *Healthy Lives, Healthy People: transparency in outcomes, proposals for a public health outcomes framework*; DH (2010) *The NHS Outcomes Framework 2011/12*

Fulfilling and Rewarding Lives: Evaluating Progress

Diagram 1 below shows how the outcome frameworks align with each other and with the policies and initiatives of other Government departments.



These outcomes do not establish new national data sets or a central monitoring framework. But they do provide a consistent approach that will enable local evaluation of progress regardless of the delivery structures in place – so ensuring that changes to the NHS and social care provision do not inhibit the ability of local areas to innovate or to assess progress.

The document also suggests some methods for local monitoring of progress towards the desired outcomes – and encourages the publication of information to support transparency and accountability. Such information will be invaluable for organisations such as the Care Quality Commission, Monitor and the proposed NHS Commissioning Board, as well as for local benchmarking by councils and monitoring by citizens and consumer-led groups like HealthWatch England (subject to its approval in legislation).

Achieving these outcomes **will** make a difference to the lives of adults with autism, their families and carers. The Autism Programme Board will monitor what has been achieved by way of improving outcomes for people with autism, and analyse the causes where progress is slow. The way local areas choose to respond will be up to them – enabling them to identify the actions and interventions that will best meet the needs of adults with autism in their area.

Fulfilling and Rewarding Lives: Evaluating Progress

Seven quality outcomes that will show progress

1. Adults with autism achieve better health outcomes
2. Adults with autism are included and economically active
3. Adults with autism are living in accommodation that meets their needs
4. Adults with autism are benefiting from the personalisation agenda in health and social care, and can access personal budgets
5. Adults with autism are no longer managed inappropriately in the criminal justice system
6. Adults with autism, their families and carers are satisfied with local services
7. Adults with autism are involved in service planning.

These are all long-term outcomes: change will not happen overnight, and expectations need to be realistic. However, in each case these outcomes will have a concrete impact on the lives of adults with autism and their families and carers. What's more, working towards the achievement of the outcomes will, in itself, create service improvements.

An important issue for many people with autism, their families, and the groups which represent them is also to be assured that key processes are in place in all localities to identify and respond to the needs of adults with autism. Frequently expressed concerns are that many localities do not have good enough data on the numbers and needs of people with autism, nor are there appropriate systems in place to enable appropriate diagnosis and access to services. It is also important that services recognise and are sensitive to specific needs of adults with autism from black minority ethnic communities.

Adults with autism and their families have told us of their ambitions that both the strategy, and the statutory guidance for health and social care bodies to secure implementation of the strategy, will ensure that those systems and processes for assessment and accessibility are in place. For that reason, this framework also sets out those key ambitions and makes suggestions below on how to achieve transparency against these ambitions to enable adults with autism and their families and carers to seek the reassurance they need that real progress is being made.

Three key ambitions to enable local communities assess how services are moving towards achieving outcomes

1. Local authorities and partners know how many adults with autism live in the area
2. A clear and trusted diagnostic pathway is available locally
3. Health and social care staff make reasonable adjustments to services to meet the needs of adults with autism

Several of these outcomes and service ambitions can be measured using data that local areas already collect as part of the Joint Strategic Needs Assessment (JSNA) or to comply with other legislation or that they will want to collect to measure progress towards wider outcomes.

For each outcome and service ambition, a number of possible indicators for measuring change locally are suggested below. Local partners can use these to help them assess their own

Fulfilling and Rewarding Lives: Evaluating Progress

progress if they wish and to enable adults with autism, their families and carers and the wider community monitor the quality of local services. These are not directives: local areas may identify more suitable indicators or have equally effective existing tools and processes they can use.

Using the outcomes and ambitions to hold services to account

The outcomes and ambitions provide a consistent and tangible way to assess progress in each area. Over time, they will evolve into a jointly owned set of outcomes that all parties – local partners, adults with autism and their families and carers, central Government and others – can use to understand progress, and become a focal point for developing improved services.

Local areas are not required to measure their performance against these outcomes or publish results, but we hope that they will choose to do so as a means of assessing their own progress against the vision in the strategy and demonstrating that progress to local populations. Local authorities who self-assess against outcomes and ambitions will then be in a position to benchmark themselves against other local areas – providing a way for the public and services to compare progress in their area with others.

Data published locally can also be compiled nationally to monitor whether improvements to services are consistent, and whether some services are making more progress than others.

Quality areas

1. Adults with autism achieve better health outcomes

As *Fulfilling and Rewarding Lives* made clear health outcomes of adults with autism are worse than for the population at large⁵. Not only is the incidence of mental ill-health higher amongst adults with autism, but so are rates of premature morbidity. In everyday health care, adults with autism typically recover slower from ill-health or injury.

These outcomes are the result of a number of factors. Healthcare services have sometimes been hard for adults with autism to access: hypersensitivity to noise and light – something many adults with autism experience – can make healthcare settings unsettling, while others find it hard to book and keep appointments. During consultations, adults with autism may find it difficult to discuss symptoms and express views. The combined effect of these factors mean that many adults with autism have simply avoided visiting a GP or dentist and only access health care when they reach a crisis point. Other reported issues include difficulties keeping to a course of treatment – especially amongst those adults with autism who do not have a carer to support them.

The key steps to improve health outcomes, therefore, will focus on ensuring adults with autism are better able to access health care at an early stage. Services must be more accessible while staff need to make reasonable adjustments to their behaviour and communication so that they better address the needs of adults with autism.

⁵ *Fulfilling and Rewarding Lives*, paragraph 1.9

Fulfilling and Rewarding Lives: Evaluating Progress

Why does this matter?

Improving health outcomes is vital to achieving the overall vision for adults with autism and to reducing health inequalities (one of the core outcomes for public health). An improvement will in part reflect whether autism awareness training is working and health and social care staff are making reasonable adjustments to services.

But it is also something that will benefit health and social care provision locally: it will help reduce the need for intensive (and expensive) interventions at crisis point, instead helping adults with autism retain their independence through a more preventative approach.

How can local areas assess progress?

Under the proposed NHS and public health outcomes frameworks, NHS bodies will be increasingly expected to gather and publish information about health outcomes in the area. Those domains and indicators particularly relevant to this outcome include:

| | Domain |
|----------------------------------|---|
| Public Health outcomes framework | 2: Tackling the wider determinants of ill-health: Tackling factors which affect health and well-being |
| | 4: Prevention of ill-health: Reducing the number of people with ill-health |
| | 5: Healthy life expectancy and preventable mortality: Preventing people from dying prematurely |
| NHS outcomes framework | 1: Preventing people from dying prematurely Improvement area – Reducing premature death in people with serious mental illness <ul style="list-style-type: none"> • Under 75 mortality rate in people with serious mental illness |
| | 2: Enhancing quality of life for people with long-term conditions Improvement areas Ensuring people feel supported to manage their condition Improving functional ability in people with long-term conditions <ul style="list-style-type: none"> • Employment of people with long-term conditions Enhancing quality of life for people with mental illness <ul style="list-style-type: none"> • Employment of people with mental illness |
| | 5. Treating or caring for people in a safe environment and protecting them from avoidable harm – Overarching indicators: <ul style="list-style-type: none"> • Patient safety incident reporting • Severity of harm • Number of similar incidents These indicators are relevant to all NHS providers, including mental health services. |

Fulfilling and Rewarding Lives: Evaluating Progress

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|---|--|
| Adult Social Care outcomes framework ⁶ | 2: Delaying and reducing the need for care and support <i>Everybody has the opportunity to have the best health and well-being throughout their life, and can access support and information to help them manage their care needs.</i> <ul style="list-style-type: none">▪ Permanent admissions to residential and nursing care, per 1,000 population |
|---|--|

Data gathered to assess progress in general will provide a means of assessing the health and social care outcomes for adults with autism.

2. Adults with autism are included and economically active

Adults with autism are under-represented in the labour market. This has not only financial consequences on adults with autism and their families, but also means that adults with autism miss out on the inclusion and personal fulfilment that comes through work. What's more, it means that many adults with autism are dependent on benefits, and that UK employers are not benefiting from the skills and talents adults with autism can offer in the workplace.

Therefore, one of the overarching goals of the strategy is to enable more adults with autism to find – and keep – a job.

The recent Special Educational Needs & Disability Green Paper supports this goal, and proposes ways to remove barriers to this at both national and local level.

In March 2011, the Government published tools and materials under 'Valuing People Now', some of which will also help local partners to improve employment outcomes for adults with autism – particularly, new best practice guidelines for supported employment and a guide for Local Authority commissioners on supported employment⁷.

The Department for Work and Pension's commitment to improving the life chances of adults with autism is being reflected through active engagement with DfE in the preparation of the Green Paper for Special Educational Needs and Disabilities (SEND). Through this, the Department has highlighted the important contribution DWP will make towards supporting more flexible local services for people facing complex barriers with the introduction of the Universal Credit and through the Work Programme and Work Choice.

⁶ Adults with autism are not specifically identifiable in the measures in the Adult Social Care Outcomes Framework, although the outcomes themselves will be relevant and the total number is likely to include adults with autism. More work is needed to improve the information base for autism to expand the scope of such measures in future years.

⁷ See <http://www.valuingpeoplenow.dh.gov.uk/content/employment-resources-hub>

Fulfilling and Rewarding Lives: Evaluating Progress

Jobcentre Plus is working in partnership with external medical professionals, disability specific organisations, and service users to improve the customer service experience for people facing complex barriers through the Hidden Impairments National Group (HING).

Why does this matter?

If adults with autism are economically active, it may help to indicate whether:

- adults with autism are able to get the support they need, through Jobcentre Plus, local service providers and support networks and when in education, to develop their skills and prepare for employment (i.e. fair access to services, support and information)
- Jobcentre Plus and other key local service provider staff are making reasonable adjustments to their services to meet the needs of adults with autism
- adults with autism are succeeding in education – and whether that education is proving an effective route into employment
- employers are becoming more open to accepting adults with autism in the workplace
- sufficient support is available within the workplace, and reasonable adjustments are being made, to accommodate the needs of adults with autism.

How can local areas assess progress?

Relevant domains and indicators in wider outcomes frameworks include:

| | Domain |
|--------------------------------------|---|
| Public Health outcomes framework | 2: Tackling the wider determinants of ill-health: Tackling factors which affect health and well-being Proposed Indicator Proportion of people with mental illness and or disability in employment Employment of people with long-term conditions |
| NHS outcomes framework | 2: Enhancing quality of life for people with long term conditions Improvement areas Ensuring people feel supported to manage their condition Improving functional ability in people with long-term conditions <ul style="list-style-type: none"> • Employment of people with long-term conditions Enhancing quality of life for people with mental illness <ul style="list-style-type: none"> • Employment of people with mental illness |
| Adult Social Care outcomes framework | 1: Enhancing quality of life for people with care and support needs <i>People are able to find employment when they want, maintain a family and social life and contribute to community life, and avoid loneliness or isolation.</i> |

Fulfilling and Rewarding Lives: Evaluating Progress

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| | <ul style="list-style-type: none">▪ Proportion of adults with learning disabilities in paid employment▪ Proportion of adults in contact with secondary mental health services in paid employment▪ Proportion of working age adults in contact with social services in paid employment ('placeholder' – subject to development work). |
|--|--|

There are a number of different aspects of this outcome which local areas may want to assess.

- Reduced demand on care services – if more adults with autism are economically active, they will need less support from care services such as day care, social groups etc.
- Engagement of local employers – as part of examining local employment levels and patterns, authorities could survey whether local employers have recruited adults with autism and whether they have made reasonable adjustments within the workplace.
- Effectiveness of Jobcentre Plus services for adults with autism - Jobcentre Plus has an existing job outcomes framework, which records clearly when a Jobcentre Plus customer – across all its channels – moves into work. The framework also records what customer group the individual is from, providing a means of tracking how many adults with autism have successfully moved into work through Jobcentre Plus.
- Outcomes of education – colleges and universities typically record the destinations of leavers, and so may be able to provide an insight into whether adults with autism are translating their qualifications into employment.

3. Adults with autism are living in accommodation that meets their needs

Local authorities are required to take account of the needs of adults with autism when considering housing provision. However, at the moment, many adults with autism remain housed in unsuitable accommodation – reducing their ability to live independently – or have little choice about where they live. A large proportion live with their families, which is a particular problem for older adults with autism as it is unclear what will happen to them when their parents are no longer able to care for them.

Because autism is a spectrum condition, the accommodation needs of adults with autism differ enormously. Therefore the desired outcome here is simply that more adults with autism live in accommodation that meets their needs – whether that is residential care, supported accommodation, fully independent living, or local authority provision that takes account of any specific sensitivities or needs.

Why does this matter?

If more adults with autism are living in accommodation that meets their needs, it could help indicate whether:

- local authorities are fulfilling the equality duty by taking account of the needs of adults with autism in allocating housing
- housing provision locally meets the assessed needs of adults with autism

Fulfilling and Rewarding Lives: Evaluating Progress

- the needs assessment process, under the NHS and Community Care Act, is being implemented effectively.

How can local areas assess progress?

Relevant domains and indicators in wider outcomes frameworks include:

| | Domain |
|--------------------------------------|--|
| Public Health outcomes framework | 2: Tackling the wider determinants of ill-health: Tackling factors which affect health and well-being Proposed Indicator Proportion of people with mental illness and or disability in settled accommodation |
| NHS outcomes framework | 2: Enhancing quality of life for people with long term conditions Improvement area Ensuring people feel supported to manage their condition |
| Adult Social Care outcomes framework | 1: Enhancing quality of life for people with care and support needs <i>People are able to find employment when they want, maintain a family and social life and contribute to community life, and avoid loneliness or isolation.</i> <ul style="list-style-type: none"> ▪ Proportion of adults with learning disabilities who live in their own home or with their family ▪ Proportion of adults in contact with secondary mental health services living independently, with or without support |
| | 2: Delaying and reducing the need for care and support <i>When people develop care needs, the support they receive takes place in the most appropriate setting, and enables them to regain their independence.</i> <ul style="list-style-type: none"> ▪ Permanent admissions to residential and nursing care, per 1,000 population |
| | 3: Protecting from avoidable harm and caring in a safe environment – proportion of people with learning disabilities in settled accommodation |

A broad means of assessing progress would be to survey adults with autism to see whether they feel their accommodation meets their needs. A more specific approach would be to focus on the aspects of housing local authorities have more control over – for example, by examining

Fulfilling and Rewarding Lives: Evaluating Progress

whether they have been able to place adults with autism in accommodation that meets their needs as assessed under the NHS and Community Care Act 1990.

4. Adults with autism are benefiting from the personalisation agenda in health and social care, and can access personal budgets

Personalisation is integral to delivering improved care services for every individual – which is why it is at the heart of the Government’s vision for adult social care. The vision sets a challenge for councils to provide a personal budget, preferably as a direct payment, for everyone who is eligible by April 2013. It is also a core outcome for adult social care, and a key strand of *Equity and Excellence: Liberating the NHS*.

To achieve the goals set out in *Fulfilling and Rewarding Lives*, it is vital that personalisation is available to adults with autism, giving them more choice and control over the services they access.

Why does this matter?

If adults with autism are benefiting from personalisation, and are able to make choices about the services they receive, this will also indicate whether:

- the range of services available to support adults with autism in the local areas is increasing. Choice is only of value when there are suitable services and support available to choose from, so the introduction of personalisation is directly linked to the availability of relevant services.
- health and social care services are making reasonable adjustments to the personalisation process that enable adults with autism to understand and exercise choice.

How can local areas assess progress?

Relevant domains and indicators in wider outcomes frameworks include:

| | Domain |
|--------------------------------------|---|
| Public Health outcomes framework | 3: Health improvement: Helping people to live healthy lifestyles and make healthy choices |
| NHS outcomes framework | 2: Enhancing quality of life for people with long term conditions |
| Adult Social Care outcomes framework | 1: Enhancing quality of life for people with care and support needs <i>People manage their own support as much as they wish, so that are in control of what, how and when support is delivered to match their needs.</i> <ul style="list-style-type: none">• The proportion of those using social care who have control over their daily life.• Proportion of people using social care who receive self-directed support, and those receiving direct payments |

Fulfilling and Rewarding Lives: Evaluating Progress

The simplest way to assess this is by looking at the number of adults with autism receiving personal budgets year-on-year. Currently, very few are: this figure should increase over future years, in line with increases for other groups.

Because many adults with autism will need additional support to make choices about their care, it would also be valuable to measure the number of adults with autism who receive a personal budget **and** relevant support for their decision-making. Often such support will be commissioned through local HealthWatch or HealthWatch England.

5. Adults with autism are no longer managed inappropriately in the criminal justice system

Adults with autism can face particular difficulties if they come into contact with the criminal justice system. In some cases, this reflects an adult with autism reaching a crisis point. In some others, incidents occur or escalate largely or partially as a result of social and communication difficulties: had the situation been handled differently – and the individual's autism been recognised – the outcome may have been different.

What's more, once in the system, adults with autism may make their situation worse through their behaviour – for example, struggling to respond in interviews.

Increased awareness and understanding of autism – a fundamental goal of *Fulfilling and Rewarding Lives* – could help reduce the number of adults with autism in the criminal justice system. This would not only avoid inappropriate use of the criminal justice system – adding unnecessarily to the workload of CJS professionals – but also promise better outcomes for the individual, who in most cases will be better supported by community-based health and social care interventions.

Why does this matter?

More appropriate management of adults with autism outside the criminal justice system (when that is justified) and outside it would help indicate whether:

- police officers are becoming more aware of autism, and how it might affect an individual's behaviour – so they are able to deal with an incident involving an adult with autism appropriately and proportionately, in a way that takes account of the possible characteristics of autism
- health and social care services are meeting the needs of adults with autism, and taking a preventative approach which provides targeted support and early intervention so reducing the likelihood of the individual reaching a crisis point
- there is a change in the wider public awareness of autism – with 'autistic behaviour' no longer being viewed as requiring police intervention.

How can local areas assess progress?

The justice system gathers a wealth of information about crime and those who have committed it. If records also show when someone arrested or sentenced has autism, it will provide an insight into the numbers of adults within the criminal justice system that have autism.

Fulfilling and Rewarding Lives: Evaluating Progress

Relevant domains and indicators in wider NHS, public health and adult social care outcomes frameworks include:

| | Domain |
|----------------------------------|--|
| Public Health outcomes framework | 2: Tackling the wider determinants of ill-health: Tackling factors which affect health and well-being |
| NHS outcomes framework | 2: Enhancing quality of life for people with long-term conditions Improvement Area Ensuring people feel supported to manage their condition <ul style="list-style-type: none"> • Proportion of people feeling supported to manage their condition |
| | 2: Preventing deterioration, delaying dependency and supporting recovery |
| | 4: Protecting from avoidable harm and caring in a safe environment |

6. Adults with autism, their families and carers are satisfied with local services

Ensuring that adults with autism are satisfied with public services is an integral part of achieving the vision set out in *Fulfilling and Rewarding Lives*. Satisfaction levels with different aspects of services should also help influence future service planning and delivery – providing an insight into what works well and what doesn't.

Why does this outcome matter?

An increase in the satisfaction of adults with autism and their families and carers with local services indicates whether:

- the range of services available is meeting the needs of adults with autism
- staff delivering the services are responding to the needs of adults with autism
- services are making reasonable adjustments to the way they deliver their services to adults with autism.

How can local areas assess progress?

Relevant domains and indicators in wider health and social care outcomes frameworks include:

| | Domain |
|----------------------------------|---|
| Public Health outcomes framework | 3: Health improvement: Helping people to live healthy lifestyles and make healthy choices |
| NHS outcomes framework | 2: Enhancing quality of life for people with long-term conditions Improvement Area |

Fulfilling and Rewarding Lives: Evaluating Progress

| | |
|---|---|
| | <p>Ensuring that people feel supported to manage their condition</p> <ul style="list-style-type: none"> • Proportion of people feeling supported to manage their condition <p>Enhancing the quality of life for people with mental illness</p> <ul style="list-style-type: none"> • Employment of people with mental illness <hr/> <p>4: Ensuring that people have a positive experience of care</p> <p>Improvement Area</p> <p>Improving experience of healthcare for people with mental illness</p> <hr/> <p>5: Treating and caring for people in a safe environment and protect them from avoidable harm</p> <p>Overarching indicators:</p> <ul style="list-style-type: none"> • Patient safety incident reporting • Severity of harm • Number of similar incidents |
| <p>Adult Social Care outcomes framework</p> | <p>3: Ensuring a positive experience of care and support</p> <p><i>People who use social care and their carers are satisfied with their experience of care and support services.</i></p> <p><i>Carers feel that they are respected as equal partners throughout the care process.</i></p> <ul style="list-style-type: none"> ▪ Overall satisfaction of people who use services with their care and support ▪ Overall satisfaction of carers with social services ▪ The proportion of carers who say that they have been included or consulted in discussions about the person they care for ▪ The proportion of people who use services and carers who find it easy to find information about support |

The obvious way to assess progress is through satisfaction surveys – potentially both at the point of service delivery and on a periodic basis (quarterly, annually, etc). Though such surveys do not in themselves prove the ultimate **impact** of services, they offer valuable insights into the quality of the service provided and how these are perceived by the people who use them.

To gain a real insight into services, surveys should not focus simply on overall satisfaction (“Are you satisfied with the services you’re receiving?”) but also look at the **way** services are provided: satisfaction with staff knowledge, satisfaction with the information and advice

Fulfilling and Rewarding Lives: Evaluating Progress

available etc. This is particularly important given the nature of autism, which often means people respond literally to questions. Similarly, any such surveys should be available in accessible formats, and consideration should be given to ensuring that local autism representative groups are involved in periodic satisfaction surveys.

Bodies such as Local HealthWatch will be ideally equipped to conduct satisfaction surveys and compare results with other local areas.

7. Adults with autism are involved in service planning

Equity and Excellence: Liberating the NHS sets out a clear policy of involving patients in choices about their health and care: “no decision about me without me”. This reinforces the principle set out in the autism strategy that adults with autism (and families and carers) should be involved in decisions not only about their own care, but also about service design and planning in their local area.

This is not a quantifiable outcome – there here is no expected percentage of involvement. Instead, the desired outcome is that adults with autism, their families and carers and autism representative groups are given – and feel they have been given – opportunities to help shape the services that are delivered to adults with autism.

It is important to recognise that some adults with autism will require the support of an advocate to speak on their behalf and ensure their views are heard.

Why does this matter?

Greater involvement of adults with autism in service planning should help influence the services that are provided locally – both in terms of what types of services are available and how they are delivered.

How can local areas assess progress?

This can best be assessed through evidence that adults with autism, their families and carers and autism representative groups have been involved in service planning and design. This may be through formal mechanisms such as partnership boards or consultation events; it may be less formal, perhaps through visits from service planners to autism support groups. It could also form part of annual satisfaction surveys.

Relevant domains and indicators in wider health and social care outcomes frameworks include:

| | Domain |
|----------------------------------|---|
| Public Health outcomes framework | 3: Health improvement: Helping people to live healthy lifestyles and make healthy choices |
| NHS outcomes framework | 2: Enhancing quality of life for people with long-term conditions Improvement areas Ensuring people feel supported to manage their conditions <ul style="list-style-type: none">• Proportion of people feeling supported to manage their condition Enhancing quality of life for carers |

Fulfilling and Rewarding Lives: Evaluating Progress

| | |
|--------------------------------------|--|
| | <ul style="list-style-type: none"> Health related quality of life for carers (EQ-5D)⁸ |
| Adult Social Care outcomes framework | <p>1: Enhancing quality of life for people with care and support needs</p> <p><i>People manage their own support as much as they wish, so that they are in control of what, how and when support is delivered to match their needs.</i></p> <ul style="list-style-type: none"> The proportion of those using social care who have control over their daily life. Proportion of people using social care who receive self-directed support, and those receiving direct payments |
| | <p>3: Ensuring a positive experience of care and support</p> <p><i>Carers feel that they are respected as equal partners throughout the care process.</i></p> <ul style="list-style-type: none"> The proportion of carers who say that they have been included or consulted in discussions about the person they care for |

Service Ambitions

1. Local authorities and partners know how many adults with autism live in the area

This is a vital step in achieving the goals set out in *Fulfilling and Rewarding Lives*. A local authority can only make informed decisions about investing in services for adults with autism if it knows how many adults with autism it is supporting – and what kinds of support they need. As part of fulfilling the equality duty, and of completing the core data set for the JSNA, local partners are now expected to include information about numbers of adults with autism in the area. As the JSNA is the basis for local commissioning strategies, this will ensure the needs of adults with autism are considered in service planning: local areas will be expected to be accountable for the decisions they have made in commissioning and to show how they reflect the needs identified through JSNA.

This is very much a case of building on progress. The Care Quality Commission report *The State of Health Care and Adult Social Care in England 2009* found that 83% of local authorities surveyed consider the needs of adults with autism in JSNAs, commissioning strategies and plans.

⁸ EQ-5D is a trademark of the EuroQol Group. Further details can be found at www.euroqol.org

Fulfilling and Rewarding Lives: Evaluating Progress

However, it is widely agreed that autism is currently under-diagnosed and that the numbers of people with autism known to authorities is only a proportion of those who have autism. Local areas invest in services to meet recognised needs: if they are only recording a fraction of the total number of people with autism in the area, the level of investment will be smaller.

Why does this matter?

Knowing how many adults with autism live in the area is the foundation for service improvements. Achieving this ambition could also help indicate whether:

- recording and sharing of information across health and social care about adults already known to have autism is effective
- improved diagnosis – and the existence of a clear pathway in each area – is helping to increase the number of adults known to have autism in the local area
- information sharing between children and adult services has improved, and those diagnosed as children remain on local records
- local areas are working effectively with voluntary groups. Because some adults with autism may not want a diagnosis, or request care services, a further useful source of information could be local autism support groups, who may be able to provide an indication of how many adults with autism attend their meetings or access their services.

How can local areas assess progress?

The simplest method of assessing progress will be using annual figures about adults with autism used for the JSNA. Because autism is underdiagnosed, and the numbers of adults with autism known to the authorities is typically low, we would expect this figure to increase for a few years until it is broadly in line with national prevalence studies⁹, then level out.

2. A clear and trusted diagnostic pathway is available locally

Diagnosis of autism is a complex process, and in many areas there is currently no clear pathway for diagnosis. The strategy sets out an expectation that, following the publication of the NICE clinical guideline on Autistic Spectrum Disorders in Adults, each local area should develop a clear pathway to diagnosis. This should not only lead to an increase in the availability and accessibility of diagnostic services – i.e. that adults in every area can be referred for diagnosis – but also that diagnosis becomes more consistent and hence trusted.

This is a vital step: at present, a diagnosis of autism made in one area or by a certain professional is not necessarily accepted elsewhere. There is also evidence to suggest that some professionals are reluctant to refer adults for diagnosis as they are not confident in the process, and that some adults with (unconfirmed) autism are reluctant to be referred for diagnosis as they do not feel it would benefit them.

That is why the ambition here is not about whether more adults are diagnosed or referred, or satisfaction with the diagnosis. Instead, it focuses on whether **all** parties trust the diagnostic process: adults with autism, their families and carers and health and social care professionals.

⁹ A consortium led by the University of Leicester has been contracted by the NHS Information Centre to study rates of autism in a representative sample of adults in England. Findings are expected in late 2011.

Fulfilling and Rewarding Lives: Evaluating Progress

Why does this matter?

Having a clear and trusted diagnostic pathway available locally will mean that:

- it is easier to access diagnostic services
- diagnosis can be better integrated into assessment of needs – so adults diagnosed with autism are more likely to get the support they require
- local areas will have improved information about the numbers of adults with autism in their area, and their needs.

How can local areas assess progress?

The first step to take is the creation and documentation of the pathway locally. But to assess whether the pathway is clear and trusted is perhaps best assessed by surveying those who use it, i.e.:

- professionals (not only those who are referring/have referred for diagnosis)
- adults with autism, including those who have been diagnosed recently and those who were diagnosed previously (i.e. as children), and
- adults who were referred but not diagnosed.

In addition, surveys should include families and carers of adults with autism or referred for diagnosis, and autism representative groups. In the future, such surveys could be conducted by the local HealthWatch or Health and Wellbeing Board rather than the local authority, or a GP consortium, (subject to legislative proposals) to help ensure their independence.

3. Health and social care staff make reasonable adjustments to services to meet the needs of adults with autism

As *Fulfilling and Rewarding Lives* acknowledges, many staff working in frontline health and social care feel they do not have sufficient understanding of autism – and so are not confident in working with adults with autism. In particular, they do not know how to make reasonable adjustments to the way services are provided (which includes adjusting their own behaviour) to better meet the needs of adults with autism – an important aspect of ensuring a positive experience of care and support, and a contributory factor to treating and caring for adults with autism in a safe environment¹⁰.

This focuses on the impact of that training. It is not based on the numbers of staff who have received training, but instead on whether the training given has made a difference to the way services are delivered. This reflects the fact that once certain members of a team have received training, they can share their knowledge with their colleagues and make reasonable adjustments to the way the service is delivered that mean the training has an impact even before all staff are trained.

Why does this matter?

If staff are able to make reasonable adjustments to services to meet the needs of adults with autism, this will mean:

¹⁰ These are both part of the NHS and Adult Social Care outcomes frameworks.

Fulfilling and Rewarding Lives: Evaluating Progress

- mainstream services are more accessible for adults with autism – which in turn should mean they benefit more from those services (for example, if dental surgery staff make reasonable adjustments for adults with autism, this should mean that adults with autism are more likely to use those services, explain their problems, make choices about their treatment and respond positively to treatment)
- training is having a positive impact – staff have a good understanding of the needs of adults with autism and are aware of changes that have been made to services. At the same time, comparing services and the level of adjustments made may also help indicate whether certain groups or areas are better trained than others, and whether certain methods of training are more effective.

How can local areas assess progress?

The simplest way to measure this will be through surveys of both staff and adults with autism, and their families and carers and local autistic representative groups. Questions could look at different aspects of the service – for example, booking appointments, the physical environment in which the service is delivered, whether staff showed appropriate behaviour and understanding etc. Survey results can be compared year-on-year to see if there has been an overall improvement in the delivery of the services.

This also sits firmly alongside the key domains in the NHS and adult social care outcomes frameworks to ensure that people have a positive experience of care.

What happens next?

These outcomes and service ambitions are offered as a basis for local self-assessment and evaluation of progress towards the goals set out in *Fulfilling and Rewarding Lives*. There is no obligation on local areas to assess their performance against these but we believe there is a strong case to – as part of benchmarking progress and making decisions about investment, as well as providing the transparent information which will enable the public to hold them to account locally. In particular, bodies such as Local HealthWatch will expect to see such information, the NHS Commissioning Board will monitor the equality of service provision and the Care Quality Commission will assess quality of services.

To help local areas evaluate their own progress, Department of Health has developed a suggested template for self-assessment of progress, which can be found at the end of this document.

The Learning Disabilities Public Health Observatory (LD PHO) has been appointed by the Department of Health to collate and compile existing data on the prevalence of people with autism, what services they access, and the quality of those services. It will also create a generic template for estimating local area need for use when commissioning services for people with autism, and invite local areas to send information gathered using this template back to it. The LD PHO will then publish this information from each locality on a nationwide map or other tool to help compare progress nationwide. Further details of the work of the LD PHO can be found at: www.ihal.co.uk

Reviewing the outcomes and service ambitions

Our aim is to review these periodically to consider – with input from key external partners - whether they are still valuable indicators of progress. Because most involve long-term change,

Fulfilling and Rewarding Lives: Evaluating Progress

we do not anticipate them being altered a great deal, but it is important they reflect the progress that is being made towards the end goal. The goal is that these evolve into a jointly owned set of outcomes that all parties involved – local partners, adults with autism, their families and carers, central Government and other representative bodies – can use to understand progress, and become a focal point for developing improved services and delivering better outcomes for all adults with autism and their families and carers.

To that end, we would welcome any suggestions of alternative or additional outcomes that would help evaluate progress more effectively.

10 Steps to Progress

Achieving the outcomes and service ambitions set out above will take time: these are not short-term goals. To help local areas progress towards them, the following ten steps have been identified through analysis of existing approaches as valuable foundations for service improvement.

These steps are not focused on introducing brand new processes or requirements to support adults with autism: instead, they are practical things local areas can do to ensure that adults with autism are included fairly within existing processes and structures.

1. Appointing a local autism lead
2. Including autism within key procedures
3. Collecting and collating relevant data about adults with autism
4. Developing an integrated commissioning plan around services for adults with autism
5. Developing a plan to deliver appropriate levels of training to front-line staff
6. Mapping local employment services that support adults with autism
7. Mapping local voluntary services and groups that support adults with autism
8. Involving adults with autism, their families and carers in service design and planning
9. Developing and implementing a staff survey about working with adults with autism
10. Learning from and sharing best practice.

Some areas have already taken many of these steps, and so are in a strong position to achieve the outcomes faster. Their experiences and insight will be invaluable for those who have more ground to cover.

1. Appointing a local autism lead

DH guidance states that the Director of Adult Social Services (DASS) should ensure there is a joint commissioner/senior manager who has in his/her portfolio a clear commissioning responsibility for adults with autism.

Having a clearly identified autism 'lead' locally ensures autism is not overlooked. It means someone is there to champion the needs of adults with autism, to evaluate the benefits of potential services and to ensure that actions are followed through. It also provides a named contact within the local area for the public, for service providers and for others working in health and social care services. In particular, this will be invaluable as commissioning in health care becomes more distributed.

Fulfilling and Rewarding Lives: Evaluating Progress

Anyone appointed to this role should have a good understanding of autism.

2. Including autism within key procedures

In each local area, there are a number of key procedures, structures and strategies which shape the direction of public services. These include the JSNAs as well as strategies for transition, employment and housing, and various local planning boards. Forthcoming changes to the NHS and adult social care may introduce more such structures, such as local Health and Wellbeing Boards.

By specifically including autism within these procedures, structures and strategies local areas can make sure that the needs of adults with autism, as well as those of their families and carers, are considered. This also serves to drive up awareness of the needs of adults with autism more generally: once people are accustomed to considering them in core activities – and have a better understanding of what the needs might be locally – they will be more likely to translate this into their own work.

3. Collecting and collating relevant data about adults with autism

Service planning and improvement relies on accurate information. Already, local partners are expected to include information about the numbers of adults with autism in the area as part of completing the core data set for the JSNA. This is a vital starting point for decisions about services.

However, to drive service improvements local areas will also need to know how services are performing for adults with autism. Therefore, it will be important to collect data that helps monitor the effectiveness of core services, as set out in the ten outcomes above. In many cases, this will require collation of data that has already been collected to help monitor outcomes for adults with autism.

To help local areas gather relevant data, the Learning Disabilities Public Health Observatory (LD PHO) has been tasked with developing a generic template for estimating local area need for use when commissioning services for adults with autism.

4. Developing an integrated commissioning plan around services for adults with autism

Once local partners have a better understanding of the numbers and needs of adults with autism in their area, it becomes far easier to identify particular gaps in service provision or to spot ways services can be improved. These should then be addressed in commissioning strategies, with local partners expected to broaden the market of care services available locally to adults with autism, particularly through working with small social enterprises. Local areas will be held accountable for the way their commissioning decisions reflect the needs of the local population.

There is a strong business case to be made locally for improving services available for adults with autism, and in particular adopting a more preventative, supportive approach. Quite simply, providing the right support first time means that less money is wasted offering support and services that will not achieve the right outcomes.

For example, several areas have been able to reallocate resources from inappropriate placements of adults with autism in full-time psychiatric care, instead, they are able to provide

Fulfilling and Rewarding Lives: Evaluating Progress

day-to-day support that is more cost-effective and gives adults with autism greater independence. Other potential improvements include providing services that offer preventative support so fewer adults with autism reach crisis point (protecting them from avoidable harm), and improving information provision and signposting to autism support groups.

Evidence from the Getting a Life programme is that many young people with autism are not able to access further education in their local areas and some are placed in expensive out of area residential colleges. Where there is good person-centred transition planning and young people and their families discover what is possible in terms of support and life outcomes, they are opting for local services. Getting a Life areas have included colleges in their strategic planning so that they can learn about young people's aspirations and plan to develop a college curriculum which is much more focussed on life outcomes, particularly employment. This approach is leading to much better outcomes for young people and their families and a much more effective use of resources.

5. Developing a plan to deliver appropriate levels of training to front-line staff

Staff training has been identified as a priority in achieving the goals of the autism strategy. Front-line staff need to be – and want to be – more aware of autism and how it can affect people. That way, they can modify their attitudes and behaviour if necessary and make reasonable adjustments to services. They can also become more confident in suggesting referrals to diagnosis.

It would take very substantial time and resource to provide comprehensive autism training to all staff. Therefore, it is recommended that local areas develop training plans that identify priority groups for training, and make use of all available training methods to ensure the greatest impact from the available budget.

This essentially means taking a commonsense approach: GPs will typically need more training and information than administrative staff, etc. Those who provide care to adults with autism on a day-to-day basis should receive training before those who may only come into contact with adults with autism occasionally.

There is undoubtedly scope for local areas to develop cross-disciplinary training, to share resources between services and to identify local experts – such as autism representative groups or adults with autism themselves – to help deliver the training.

6. Mapping local employment services that support adults with autism

In almost every area, there are local employment services that have specific expertise in supporting adults with autism. To help maximise the opportunities to offer adults with autism relevant support to get a job, or develop their skills, local areas should have a full picture of the services available. Where there are no services, localities should consider commissioning to meet local need.

In many areas, it will be possible to use information already gathered around employment services for adults with learning disabilities as a starting point.

7. Mapping local voluntary services and social enterprises that support adults with autism

There is a very strong and well-established network of voluntary services, social enterprises and support groups for adults with autism across England and Wales. These range from informal friendship groups to specialist charities, some of whom provide valuable services such as employment or legal advice to adults with autism and even diagnosis.

These organisations can play a vital role in achieving the goals of *Fulfilling and Rewarding Lives*. They offer social interaction for adults with autism, and also a range of support for families and carers. It is therefore important for local areas to be aware of what services and groups exist locally and to understand their capabilities.

This will mean that public services can provide information on these voluntary groups to adults with autism and their families and carers, and also that they are able to commission services – where appropriate – from local voluntary organisations.

8. Involving adults with autism, their families and carers in service design and planning

The principle of involving adults with autism, their families and carers and autism representative groups in service design and planning is central to *Fulfilling and Rewarding Lives*. It is also in line with *Equity and Excellence: Liberating the NHS* which sets out the fundamental principle of shared decision-making that should underpin health and social care planning and delivery and individual packages of treatment or care: “no decision about me without me.”

While currently many local areas do this on an ad hoc basis, there is a strong case for adopting a more formal approach – introducing a plan or specific structures for engaging with adults with autism, families and representative groups on an ongoing basis. Local learning disability partnership boards can offer one model. Such a plan should include access to advocates, as some adults with autism will require an advocate to speak on their behalf.

9. Developing and implementing a staff survey about working with adults with autism

Front-line staff will have a very clear understanding of how well they are working with adults with autism: how confident they are in dealing with them, how much they feel they know about autism and what they would like to know to enable them to improve the service they provide. That is why some of the outcomes above focus on staff perceptions.

It will therefore be valuable for local areas to develop a staff survey about working with adults with autism. In many cases, this will be something that can be added into existing surveys or reviews, and need not be exhaustive. Any survey needs a baseline to help monitor progress, so an initial survey should be carried out as soon as practical and possible to understand current staff perceptions.

10. Learning from and sharing best practice

As with every area of public services, there are trailblazers who have made significant improvements to services for adults with autism and delivered impressive outcomes. It is

Fulfilling and Rewarding Lives: Evaluating Progress

therefore important that other local areas are able to learn from these organisations, and find out about their approach.

To this end, the Department of Health has already committed to support statutory guidance with best practice examples of services for adults with autism. These will be available online.

To access the self-assessment framework please see the accompanying document:

Fulfilling and rewarding lives: the strategy for adults with autism in England and statutory guidance - Essential Quality Outcomes for Local Self-assessment Framework.