

## **Transparency in outcomes: a framework for adult social care.**

Parkinson's UK welcomes the opportunity to respond to this important consultation.

It is estimated that 120,000 people in the UK have Parkinson's. Parkinson's is a progressive, neurological disorder, with no known cure. Parkinson's affects people from all social and ethnic backgrounds and age groups.

Appropriate adult social care provision is crucial to enabling those affected to manage their symptoms, maintain quality of life and maximise their independence. As the condition progresses and there is a greater impact on daily living activities, this can result in an increased dependency for support and care, either informally or through private, voluntary or statutory care services.

### **Summary**

- There is very little evidence the proposals have been co-produced with service users, according to the putting people first agenda, instead the proposals appear driven by aspirations of government and councils to reduce performance management.
- The non mandatory nature of both the outcomes framework and suggested quality standards are not sufficient to equip local people with the levers to drive much needed quality improvements or reduce inequalities in social care.
- There is a clear risk that councils will be judge and jury over their performance with no independent analysis or benchmarking that would provide both local and national accountability.
- A major flaw is that councils will only report on those people "within" the system, this will fail to measure local authority policies on those who are no longer eligible for social care services.
- In conclusion, the outcomes framework should be a tool that provides accountability and comparability on how people's rights and entitlements to social care have been upheld. There should be a national overview of performance.
- Finally, there should be duties on council commissioners to report on outcomes and utilise quality standards in order to address inequalities and secure continuous improvements in care, providing parity with duties that will exist in public health and health commissioning.

**1. How should Quality Standards in social care balance guidance on service practice, cost effectiveness, what matters to people and outcome expectations?**

**2. How can we categorise Quality Standards in adult social care and what should be the topics for the first Quality Standards?**

**3. How can Quality Standards be developed to support service users as commissioners, and local people in their role to hold councils to account?**

We have taken these three questions together as there is an overall issue with Quality Standards in social care that hasn't been addressed in the consultation.

Quality Standards for social care must provide benefit to the public and justify the cost of their creation. We are concerned that there will be insufficient levers for this to happen if they are only "aspirational" and "non mandatory".

To succeed in social care, Quality Standards should add value amongst the other proposals within the consultation document of "excellence awards", "outcome measures" and "local accounts." This has not been made clear in the consultation.

In health they will be of use as they are a mechanism which the public (and the NHS commissioning board) can use to lever change (although we believe that the duty to use the Quality Standards in health should be strengthened). Current proposals are that:

- The Health Bill will ensure that health commissioners will be under a duty to "have regard" to Quality Standards by NICE;
- Premiums payable to GPs will link into commissioning outcomes that reflect Quality Standards; and
- The NHS commissioning board reports to the Secretary of State on outcomes delivered (which will also reflect upon Quality Standards)

There appears to be a clearer line of direction between the Department of Health, commissioner and provider for using Quality Standards in health than in social care. We are concerned that the Quality Standards for social care could become the poor relation to those in health.

We are also concerned that NICE, a body with no prior involvement in social care, writes the standards, as it lacks knowledge and experience on social care. There should be a requirement for NICE to engage fully with service users and carers as it develops these standards.

Social care is a complicated landscape of provision and commissioning. There are an estimated 30,000 adult social care providers and many more individual or small unregulated care providers which now deliver the majority of care. There are over 150 commissioners and increasingly many more "individual" commissioners armed with their own budgets.

The government is increasingly removing all national levers over council behaviour, for example with the abolition of Comprehensive Area Assessment and inspections by the Audit Commission and Care Quality Commission. Council behaviour is the main driver of social care quality in the system – it is councils that release the resources into the system that allow providers to operate, for individuals to purchase their care and they decide whose needs will be met.

The Department has more levers over the Care Quality Commission as a body that reports to the Secretary of State and benchmarks essential standards of provision, but its role in driving commissioning improvement has now gone. Unlike health and public health, where there will be a focus on improvements and addressing inequalities, there is no body taking an overview of social care and ensuring a fairer system develops.

Consequently evidence based practice has been and will continue to be much harder to disseminate, let alone implement as the Department has no levers. Testimony to this is the very many good practice guides and strategies that have not been utilised

to the full by commissioners, to the frustration of service users, carers and providers.<sup>1</sup> Aspirational, non mandatory Quality Standards will simply add to this pile.

Therefore, in answer to question 3, only by a **duty on councils to use Quality Standards for social care** will there be a satisfactory lever for the public to hold councils to account. A national body, which might most appropriately be the Healthwatch England in its reporting role, should also monitor the use of Quality Standards. The government should also consider what else can be done to improve the status of Quality Standards in social care that will provide parity with health and public health.

Question 2 asks for suggestions as to what sorts of topics would be suitable for Quality Standards in social care. In our view there is a need for integration with NHS Quality Standards so there are standards for conditions such as Parkinson's, which is a long-term neurological condition and where people do not necessarily differentiate between health and social care. The delivery of integrated care across the care pathway is a national policy goal but its implementation has been patchy.<sup>2</sup>

If there are to be stand alone Quality Standards for social care then commissioning should be one particular area of focus. With the deletion of Comprehensive Area Assessment and annual CQC inspections of adult social service departments, the Quality Standards should ensure there is a proper emphasis on commissioning practice as it is this which is the driver of quality.

Topics might also include Quality Standards for information and advocacy, aids and adaptations, daycare, support for carers and for people using self directed support as well as "traditional" regulated services such as homecare and residential care. There should also be a cross cutting standard for NHS continuing care, as this is an area which is the cause of much concern and disparity of approach in the treatment of people with Parkinson's.

#### **4. Do you agree with the proposal for a single data set for adult social care, supported by a single collection and publication portal?**

Yes it is vital that there is a single data set which is subject to collection and publication through the NHS Information Centre. However it is vital that the NHS Information Centre publishes the data in a user-friendly format. The "NACISIS" tool that it has developed is very unwieldy for those who are not statisticians. Summary data and tables that allow comparison between authorities will remain extremely important to the public.

We are concerned with references to national government not dictating the content of the data set, and that it will be for ADASS working with the NHS Information Centre to suggest what data should be shared between areas. We believe the principle should be that if the data is collected it should be shared as a matter of course, to allow for benchmarking and analysis of disparities. This is data which has been collected and funded through the public purse.

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<sup>1</sup> For example, the National Audit Office Interim report on the Dementia Strategy 2010 found that there were not robust levers to implement the strategy.

[http://www.nao.org.uk/publications/0910/improving\\_dementia\\_services.aspx](http://www.nao.org.uk/publications/0910/improving_dementia_services.aspx)

<sup>2</sup> Neurological Commissioning Support. Halfway through - are we halfway there? A mid term review of the National Service Framework for Long Term Neurological Conditions (2010). [www.ltc-community.org.uk/articles.asp?id=6093](http://www.ltc-community.org.uk/articles.asp?id=6093)

**5. Do you support the case for a set of consistent outcome-focused measures, which combine the best available data on social care outcomes?**

We believe that the outcome measures are a rational step on from the collection of data. However, as they are not priorities, targets and do not come with any expectation that councils will use them, we remain concerned that their use will vary across localities and so limit comparison. We believe that the outcomes should describe the entitlements that people have and should expect from social care.

In our view each council should be obliged to demonstrate the effectiveness of its social care services to service users and the wider public by using a set of consistent outcome measures. The localised approach to social care contrasts starkly with public health and the NHS outcomes frameworks which allow for national comparison and progress on health inequalities, with financial incentives for progress made.

**6. Do the four domains and outcome statements proposed adequately capture the breadth of outcomes which are relevant at the highest level to adult social care?**

The top level domains capture some, but not all of the most relevant "topline" issues for service users. A particular issue is that the outcomes framework and dataset does not attempt to measure the level of unmet need in the community and how local authority policies are impacting on those who may not be eligible for care. There are many "people with care and support needs" who find they cannot access council services due to increasingly restrictive eligibility criteria. The tools only measure those known to the council.

For people with Parkinson's and other long term conditions, continuity of care is absolutely vital. This includes timely access to services and good care co-ordination across health and social care boundaries. It also means being listened to and having an opportunity to shape services, and is not merely about being informed about your rights but also having your rights to care upheld.

Therefore we make the following suggestions for inclusion:

**Preventing deterioration, delaying dependency and supporting recovery** should therefore include as an outcome statement:

***People who have complex and long term conditions experience a co-ordinated and smooth progression of care through integrated assessments and local services that can meet a range of needs.***

It should also include reference to end of life care:

***People at the end of their lives receive care that respects their wishes and dignity.***

**Promoting personalisation and enhancing quality of life for people with care needs** should amend the final bullet:

***People engage socially and economically as much as they wish to avoid loneliness and isolation achieve independent living.***

**Ensuring a positive experience of care and support** should include:

***People's experiences and views contribute to shaping improvements in services and commissioners actively engage with communities and have an excellent knowledge of local needs.***

***Entitlements to social care and continuing healthcare are upheld.***

**Protecting from avoidable harm and caring in a safe environment** should include:

***Poor care is rapidly improved or stopped as people are empowered through well- managed and effective safeguarding and complaints systems.***

The four outcomes also omit to suggest any outcomes for commissioners. This is a major omission and there needs to be proper emphasis on commissioning practice. It is not enough (as in para 3.27) to state that publishing financial information alongside the outcomes is enough to allow for local analysis of efficient use of resources. People who use services need to know the outcomes that commissioners are expected to achieve with resources. This had been a focus of previous regulation (through CQC and CSCl) and must not disappear in the new regime.

<b>Suggested adult social care outcome domain</b>	<b>Suggested adult social care outcome statements</b>
There is a well functioning social care marketplace that provides choice and quality services.	<ul style="list-style-type: none"><li>• The social care workforce has the capacity, skills and commitment to deliver improved outcomes.</li><li>• Commissioning is based on knowledge of the needs of the local population.</li><li>• Services are developed that meet those needs, in partnership with the independent and voluntary sector.</li><li>• Resources are used efficiently and effectively and invested in partners (providers, people with personal budgets) to ensure quality.</li><li>• There is effective leadership and performance management based on clear priorities</li><li>• Opportunities to jointly commission and deliver integrated services with health and other partners are taken.</li></ul>

**7. Do you have any further views on how adult social care outcomes should align with other sectors to support integrated working? How might this be put into practice?**

For people with long-term conditions, such as Parkinson's, integrated working is vital. Integrated care has been demonstrated to contribute greatly to people's quality of life, and was a focus of the National Service Framework for Long Term Conditions. Joint outcome measures for people with long term conditions are therefore essential. It is important to get the architecture right to support integrated working, which includes:

- commissioning across the whole pathway
- pooled budgets and resources
- removal of artificial barriers, both organisational and cultural
- clear roles and responsibilities: and
- effective communication between organisations, particularly when someone "moves" across organisational boundaries.

**8. Do you support the proposal to replace annual assessments of councils conducted by the regulator with public-facing local accounts on quality and outcomes in adult social care?**

Social care is riven with inequalities and it is vital that levers exist to ensure a fairer system of social care across the country. This is a major concern for people with Parkinson's and has been highlighted in our members' survey and the recent All Party Parliamentary Group (APPG) for Parkinson's Disease Inquiry Report.<sup>3</sup> We are running a national campaign – Fair Care – to address the inequalities that people with Parkinson's face: [www.parkinsons.org.uk/faircare](http://www.parkinsons.org.uk/faircare).

Public Health England and the NHS Commissioning Board will have an overview of delivery for their respective sectors but there will be no public body with an overview of national performance of social care.

Independent national audit by the Care Quality Commission against national standards was one way of benchmarking performance and if it was continued it would put social care on an equal footing with public health and the NHS.

Local accounts will not be an independent report on what a council has achieved and these accounts will not provide a national picture of performance as there is no body that will draw all the accounts together. This may be what local government wants, but it is not driven by the requirements of service users who want a fairer system of care.

In our view, and depending on its independence, structure, and capacity the local Healthwatch could author the local account. This could then feed into the national Healthwatch to build a picture and feed into the Care Quality Commission's annual state of health and social care report.

**9. Do you have any local examples and evidence of the benefits of a local account-type approach?**

No.

**10. What is your view on the balance between requiring standard elements in reports, and allowing freedom to fit to local circumstances?**

There must be standard elements to allow for benchmarking and national comparisons of performance. Allowing councils to have total freedom on how they

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<sup>3</sup> All Party Parliamentary Group for Parkinson's Disease. Please mind the gap: Parkinson's disease services today (2009). [www.parkinsons.org.uk/about\\_us/policy\\_and\\_campaigns\\_1/parliaments\\_and\\_assemblies/appg/appg\\_report.aspx](http://www.parkinsons.org.uk/about_us/policy_and_campaigns_1/parliaments_and_assemblies/appg/appg_report.aspx)

report runs a high risk of selective reporting taking place. All local accounts should be hosted in one place, perhaps facilitated by national Healthwatch or CQC.

**11. The proposed accounts would only apply to council commissioners. What further actions, if any, might be considered to promote transparency amongst service providers?**

While there is clear evidence of a need to more robustly inspect providers (see our response to Question 15), we do not consider that the focus of the accounts needs to extend to service providers and should concentrate on commissioners who will not be performance managed either locally or nationally. Transparency mechanisms for service providers will include:

- the assessment against essential standards by CQC
- the monitoring by local councils through contract monitoring arrangements, and
- the role of Healthwatch locally which will have a role in assuring quality of services and dealing with complaints, and reporting upwards to national Healthwatch/CQC if there are concerns.

**12. Would you support an assurance role for the local HealthWatch in the production of accounts?**

Healthwatch could be the body that authored the accounts. This would depend on Healthwatch being an independent and well structured body that truly reflects the voice of service users. Safeguards need to be built into local Healthwatches to ensure they provide the necessary challenge to councils. In our view Healthwatch should be funded separately and independent of the council.

If these are to be self authored accounts, which are peer reviewed amongst councils, than at the very least there should be a duty for a council to obtain sign off by Healthwatch and to ensure that the account is widely consulted upon with people, and with service providers who deliver the majority of care.

**13. We would also be keen to receive views on whether user and carer-led assessments could support transparency and empower local people?**

Yes, and we would see this a role that the local Healthwatch should perform as it will enable it to get much better engaged with the community it serves. People will also feel much more able to express their views freely. But again this depends on Healthwatch being independent and fit for purpose, and these assessments will be meaningless if councils do not take them into account and act upon them.

**14. What role is there for 'payment by results' or other financial incentives on providers or commissioners at a national level to support the focus on quality and outcomes?**

We are sure that service providers would welcome the opportunity to apply for an "excellence" award but we wish to ensure that the award would go through a process of independent and thorough accreditation (and regular review). It will no doubt be useful to the public, including those who self fund and have personal budgets in seeking out those services which are striving for more than the "status quo" and therefore give these providers a competitive edge.

However the document goes on to say that "incentives for better commissioning are already built into our proposals" and refers to the Quality Standards and reporting on outcomes to demonstrate progress. Neither of these are mandatory and therefore cannot be described as incentives for better commissioning. As noted in our response to question 8, nor are there any outcomes listed that specifically report on commissioning.

The resources that commissioners make available to providers of social care are critical in delivering good quality services and a well rewarded workforce that provides continuity of care rather than a low paid, rapidly changing one. We are unclear how payment by results would work in practice in social care.

It infers payment only after costs have occurred and given the plethora of small businesses and charities in social care, even down to individual personal assistants, the ability to pay staff and pay for premises with the expectation of getting paid will be extremely challenging. And if social care users are to be the commissioners of the majority of care, the situation becomes even more complicated than in traditional block contracts of delivery.

It is also pertinent to note that even in the era of "star ratings" only 7% of local councils reported that they offered a differential to providers based on ratings.<sup>4</sup> This indicates there are not necessarily the resources within social care to offer rewards and incentives: indeed many providers observe that their only "reward" for quality is to retain their contract with the council as many rationalise the numbers of providers they deal with.

### **15. How should the Care Quality Commission ensure that future service inspections are risk-based and proportionate?**

We believe the role of inspection has gradually been scaled back to a situation where inspectors have reported their concerns in the press, service users find they are unable to rely on ratings as they increasingly age, and the public does not have the assurance it needs to make an informed choice. This has also led to duplication as local councils have stepped in, distrustful of provider self-assessment and long periods of time between inspections, and inspected services under the guise of contract monitoring.

We believe that the regulator's most important role is "on the ground" inspection, particularly through unannounced inspections of both council commissioners and of service providers. We note that the recent interim review of child protection services by Eileen Munro puts the emphasis on unannounced rather than announced inspections.

We have concerns about the independence and ability to challenge that local Healthwatches may have, given funding for them will not be ringfenced. It is essential that CQC has mechanisms to listen and act upon all concerns raised by individuals, service user groups and other interested parties, not just local Healthwatch.

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<sup>4</sup> Local Government Association and ADASS. Report on Adult Social Services Expenditure Survey 2008-9, para 3.15. [www.lga.gov.uk/lga/aio/1853692](http://www.lga.gov.uk/lga/aio/1853692).

**16. Does the regulatory model of registration, compliance and inspection provide sufficient safeguards for ensuring minimum quality standards across adult social care?**

We believe that the model does not provide sufficient safeguards, since the CQC's role only relates to regulated services. Adult social care is much more than residential care and homecare – it encompasses daycare, supported living, and extra care developments as well. Quality and safety also involves standards of conduct for personal assistants and other unregulated services, standards for training and pay of social care staff, and for commissioning of services. None of these have been addressed as a whole in the consultation.

**17. How best might independent monitoring of local council arrangements for managing services be secured?**

It is vitally important that the link between commissioning and quality of local services is made and we have made a number of suggestions for improvement. There is disappointment that CQC, from being a regulator that was to have an overview of both health and social care, is now a regulator only responsible for securing standards of provider delivery, although it will still have a role to investigate poorly performing councils if there are concerns. We believe locally Healthwatch – again depending on it being independent and fit for purpose - could have a vital role in triggering an independent review of the way a local council operates.

**18. Are these the most appropriate criteria for assessing measures? Should other areas be considered?**

Yes these seem to be appropriate criteria

**19. Throughout the outcome domains we would be grateful for your views on the particular measures proposed...**

We suggest that each domain needs much more amplification and supporting quality measures to ensure that they adequately reflect the picture of social care locally. It will also help identify if councils are using social care grants for their intended purpose, now that ringfencing has been removed. These include grants for social care reform, carers and for training the adult social care workforce.

1) Promoting personalisation should include quality measures on:

- Numbers of people assisted to live in the community rather than residential care
- Choice and range of local services commissioned by the council (for example numbers of homecare providers it contracts with)
- Choice and range of advocacy and independent living services available
- Average hourly direct payment rate comparative to average independent sector hourly rate (so measuring if people are being given real choice of use of regulated services)
- Proportion of disabled people who achieve social and economic wellbeing

2) Preventing deterioration, delaying dependency and supporting recovery should include quality measures on:

- Unmet need - testing at what level the authority provides fair access to care services and the numbers of contacts for assessments compared to the numbers of people who are eventually assessed and receive services.
- Proportion of carers offered a carers assessment
- Proportion of people with long term conditions receiving an integrated assessment and care plan
- Proportion of people at end of life who have their wishes and dignity respected (for example being enabled to die at home)
- Proportion of carers accessing respite breaks and proportion of carers who have been offered a health check

3) Ensuring a positive experience of care and support quality measures could also include:

- Data on appeals against social care and carers assessments or continuing care assessments
- Eligibility levels in operation
- Availability, accessibility and adequacy of information and advice for those who do not receive council funded care, as well as those who do.
- Engagement with communities, particularly hard to reach groups.
- Engagement with providers for example by measuring the training offered to the independent sector workforce by councils.

4) Protecting from avoidable harm and caring in a safe environment could also include:

- Management of complaints
- Provider enforcement data from the Care Quality Commission

**20. What are your views on the proposal to repeat the Carers' Survey every two years to provide a more regular comparable source of data on outcomes for this group?**

We support an annual survey of Carers to complement the annual Adult Social Care Survey. We do not believe this is too onerous for councils to collect given there is a reduction in other national reporting targets, for example the Comprehensive Areas Assessment. They will be undertaking the work for service users and it is important given the relationship between service users and carers there is a collection of data across the two. We also believe that with the ten year Carers Strategy remaining a national priority for government, there is national impetus for an annual survey.

**21. What are your views on designing common models for capturing outcome information at the local level, which would be adopted on a standard basis.**

We support a common approach and model to allow for comparison and benchmarking nationally.