**Learning disability DES**

I am seeking feedback about the DES, following a request by Ben Dyson, chair of the VPN health team at the Department of Health. I have already had comments from the South West, North West and East Midlands Health networks, and have summarised the responses so far below. I have also included a section at the end on issues that were raised, that are not specific to the DES, but which could be important issues for more general good practice guidance.

Comments needed by 26th January

**Who should be included in the DES**

There was widespread support for including all people with learning disabilities on the QOF register.

Reasons given:

* People with learning disabilities are often on no one’s radar, so getting to know their GP practice may be a powerful support and mechanism to uncover many health (and social) needs.
* Many areas are reviewing access to social services and amending eligibility criteria upwards, so even fewer people could be eligible for a health check in future.

There some strong support for including young people from 15 years onwards.

Reasons given:

* Improved transition – with GPs being ‘keyed’ into the process.

However there were also some concerns:

* Children at special schools are likely to have an annual medical with the paediatrician which would mean duplication.
* There is a need to work on including primary care in the transition process first. We need to think about some joint working with paediatricians, education and social care so we transfer some of the knowledge and trust into primary care. As more children with long-term disabilities survive into adulthood, there is a growing question about which professionals will support their health as well as other needs. We need a proper handle on the challenges of transition and some specific resources to support the process before extending the age range.

**Coding and data capture**

There was widespread concern regarding coding issues. Although the DES includes a list of codes, it would be better if there was a more restricted list of codes to identify learning disabilities. It was also suggested the following codes could be added:

* LD health check declined
* Offered health check
* Completed health check

Extracting data from GP systems could be added to the DES including an electronically recorded follow-up, in order to improve health inequalities monitoring, needs monitoring, health promotion and practice profiles. However, this is made difficult by the different computer systems GPs use.

Would it be possible to add a CQUIN to the DES with the aim of getting GP practices to report outcomes? For example, in one area two learning disability nurses check the content of the health check, the HAP and follow up actions from information forwarded from the practice.

Could a requirement for data sharing with the local hospital be added in – or a question ‘are you happy for me to inform your local hospital…’

**Payment**

There was broad agreement that the payment process should be made easier. The split in payment has deterred some practices.

There is a need to build in that all returns of numbers must be given before the end of March each year. Many areas don’t do this so the true picture is not reflected in the annual returns.

There was a concern that monitoring and payment validation was lacking. Some areas have offered the DES and a LES or even a QES (bundle of services), with evidence of GPs being paid for health checks that are poor or non-existent (where payment has been given ‘on trust’).

**Training**

There was concern that the DES was not properly supported by the training outlined.

Reasons given:

* No rolling programme – there needs to be refreshers
* Awareness training is insufficient for carrying out a good health check. The process of a health check has the potential to cause real distress, and requires reasonable adjustments to be built in. Sometimes doing the full health check is not appropriate, and we should be careful about what clinicians are doing with vulnerable people driven by pro forma. These complexities are not addressed in the training.

**Practices not signed up to the DES**

There was a lot of support to formalising a mechanism in the DES by which other GP practices could offer health checks to patients registered with GPs not signed up to the DES. A couple of people also suggested that the PCT (CCG) should publish a list of participating practices so that people could choose who to register with.

However, another practice doing the health check was thought to be a poor second by some, who felt that more work should go into finding out why practices didn’t sign up.

**Health Action Plans (HAPs)**

Some respondents thought the DES should include the requirement for a HAP to be produced following the health check, although others felt that a ‘health check plan’ was the key. One person suggested that a brief medical history and current medical conditions summary could be produced for the person to use in their health passport/HAP.

**Quality**

In order to improve consistency, there should be some sort of quality measure built into the DES, although concerns were raised that this may reduce the ability to tailor the health check to an individual’s needs. There was a lot of support for a PROM to be built into the DES, and that the requirement for reasonable adjustments should be made more explicit.

**An annual health check?**

There was a suggestion that a review of clinical need should be carried out to determine whether an annual or bi-annual check is required.

**Other issues not specific to the DES but relating to the wider health check process**

Pre-health checks

In one area specialist health staff (CTLD matrons) were going to visit a few patients with moderate or more severe learning disabilities to ascertain any concerns, barriers to be examined (eg sensory impairment such that would make some physical contact cause distress) any communication tools that could be useful for the patient, carer or clinician, and what reasonable adjustments might be needed and achievable. The matrons would then provide person-specific guidance to the Practice on how to make the health check most appropriate to the person. We may not be able to do the full Cardiff check but if we do the best we can for that person without causing distress then we have at least laid the basis of follow-up contact. This way of working could be powerful training for the primary care team.

Interface with tertiary services

Many people with moderate or more severe learning disabilities attend tertiary care centres and see a Doctor. From the patient and family point of view, such a trip once or usually twice a year, feels like “seen Dr, job done”. The tertiary team do not have the remit of carrying out a broader health check but it would be great for the patient if their fuller health check could take place while in the tertiary setting.

Children

The issue of coding for children with a learning disability was raised. Disabled children rarely get a specific learning disability code, and it can be difficult to identify the degree of learning disabilities a child has. It would be helpful to have national input on this issue.

Carer support

Concerns were raised regarding the variable support people with learning disabilities get from their carers when accessing the GP. Although some support workers are excellent, some deny any personal knowledge of the patient or demonstrate utter lack of responsibility or engagement. There is a major concern that GP practice learning disability lists are supposed to match those known to social services but the latter is not actively furthering their clients’ health care, and GPs can struggle to understand any individual’s care package and how it affects health action planning.

One solution is to adjust social care contracts so that provider organisations are directly responsible for helping their clients be at ease with the health check, attend with them, and commit to support actions in the health plan. Clearly the DES cannot be used to put leverage on social care, however this does have implications for the broader success of the DES and for GP and Council joint commissioning.

Please send comments to sue.turner@ndti.org.uk