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NATIONAL PERSONAL BUDGETS SURVEY 2013

Summary of main findings and next steps

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Ministerial foreword Norman Lamb, Minister for Care Services



Much progress has been made by most councils on increasing the numbers of people using personal budgets (PBs). Building on this, the Government has made it clear in the Care Bill that PBs will become a legal requirement for all eligible people. I am clear though, that simply increasing numbers does not guarantee choice and control for people, that currently some people and groups are benefiting more than others and that experience varies significantly

from place to place. Going forward we all need to focus ever more strongly on the outcomes and experiences of PB users and their carers. In order to do this, councils need to know – in real time and using low cost, manageable methods – what are the local results of their approaches to personal budgets delivery. Furthermore, they need to know this from the perspective of the local people and families using PBs and to use this knowledge to develop and improve local delivery.

For this reason I commend In Control and Lancaster University for the development of the Personal Budgets Outcomes Evaluation Tool (POET), Think Local Act Personal (TLAP) for commissioning the National Personal Budgets Survey using the tool and the 22 councils that have taken part in this year's survey. I would strongly encourage other councils to undertake and use similar local exercises to work with local user and carer organisations and build the intelligence needed to achieve local improvements. Such intelligence can be built into local business planning and used to powerfully inform Local Accounts as part of the use of the TLAP Making it Real markers of personalisation progress.

Turning to the headline findings of the survey a number of things stand out. It is very encouraging that in general we see people saying that outcomes are improving in most areas of life following receipt of a personal budget. I am very pleased to see that in the comments on impact on people's lives, survey respondents are very positive and that this extends to carers.

Further use of the data, alongside other intelligence, will be very helpful in exploring questions around how to ensure all groups benefit as much as possible, how to ensure all forms of personal budget offer maximum choice and control and how to best use innovations such as individual service funds. It is also very helpful that the growing survey numbers allow increasing clarity as to what seems to lead to the better outcomes – essentially following the key principles of self-directed support. These findings mirror those from the recent personal health budgets evaluation and I am pleased that a health version of POET is coming into use. This is especially important as we look to develop integrated health and social care PBs.

Of real concern in the current findings is that people often describe poor experiences of personal budgets process, unhelpful bureaucracy, delays, inflexibility and confusion about how people can spend their PBs and on what. These findings echo last year's survey and reflect similar concerns expressed in practitioner surveys and the findings of the recent Boyle report. Perhaps the starkest finding, however, is the level of variation from council to council. It appears that some councils are having much more success than others in delivering process leading to better outcomes and experiences. However, although this is a concern it also offers the opportunity to study more closely those councils making the most positive impact and share their approaches with others. I am pleased that TLAP, working with In Control, is committed to supporting councils to share this learning, including via the Towards Excellence in Adult Social Care programme.

The shift to self-direction in adult social care and other areas of public service is perhaps the biggest cultural challenge we have tackled, and we are still in the early stages, working in challenging times. The Government remains committed to supporting TLAP and councils, working with ADASS and the LGA to continue and build on the progress made to date.

About the 2013 Personal **Budgets Outcomes and Evaluation Tool Survey**

The Personal Budgets Outcomes and Evaluation Tool (POET) Survey surveys for personal budget holders and for carers of personal budget holders have been developed over several years as a way for people to report their experiences of personal budgets.

This is a summary of the POET survey run with 22 volunteer councils in England in 2012-13. It follows on from the first POET survey published in 2011. The full 2013 report, including detail of its methodology and findings, is published alongside this summary and is available from www.thinklocalactpersonal.org.uk.

In this shorter paper, we summarise the results, explore their possible implications and set out what TLAP plans to do next using the data from the surveys.

Who participated in the surveys?

In total, 2,022 personal budget holders completed the 2013 POET survey (with 20 councils having more than 50 respondents). As well as responding to the main survey questions, 488 of these personal budget holders also wrote comments about their experience of personal budgets. In total, 1,386 carers completed the POET survey (with 15 councils having more than 50 respondents), 490 of these carers also wrote comments about the impact of personal budgets on their own lives.

Personal budget holders and carers varied in how long they or the person supported had held a PB, whether they received social care support before their personal budget, how their PB was managed, what support people used in planning their PB and whether the views of PB holders and carers were reflected in the support plan.

The work was funded by Think Local Act Personal and delivered by Chris Hatton from the Centre for Disability Research at Lancaster University and John Waters from In Control.

Why is checking the results of personal budgets important?

Self-directed support and personal budgets remain at the heart of policy to reform adult social care. The Government is committed to their implementation, as are all the main political parties. The Care Bill states the intention to establish personal budgets in law for the first time and for all people eligible to receive their social care via a personal budget. Councils across England continue to increase numbers of PBs with figures from the NHS Information Centre showing that the numbers receiving personal budgets increased from 377,000 to 527,000 between 2010/11 and 2011/2. This means that it is ever more important to ensure that personal budgets are implemented well for all groups, that they really deliver choice, control and improved outcomes and that the experience of getting and using them is not over-burdensome or inflexible.

The intention of self-directed support is that individuals who need support and their families are told how much money their council will make available to them to meet their needs. The person needing support and those closest to them can then determine how best to use these resources and develop a support plan describing how the person's needs are going to be met. They can decide on a method of managing their budget from a range of choices - from direct payments to council managed and use the money flexibly to meet their needs and achieve their desired outcomes. This person-centred approach represents a fundamental cultural and systemic shift away from the approaches to allocating and directing resources that have characterised the social care system for many years.

However, despite the increasing numbers of people allocated a personal budget we remain in the relatively early stages of this shift and too often we hear that it is being delivered poorly with too much bureaucracy and not enough flexibility. It is a major system and cultural challenge for commissioners, providers and people using social care. Its implementation is taking place at a time of unprecedented financial challenge for councils. Serious concerns have developed that success in

achieving target numbers does not guarantee real transfer of power to people using social care or the extension of choice and control. Equally a range of experience and evidence suggests that currently some groups continue to be more likely to access and benefit from personal budgets than others. These serious challenges must be addressed if personalisation is to be truly successful and make a real difference for the many.

Personal budgets and self-directed support remain the subject of significant debate. Some people continue to suggest that personal budgets are the wrong way to pursue personalisation, or are not helpful for some groups. TLAP's position is that personal budgets alone cannot guarantee personalisation. This is why both within the markers of personalisation (Making it Real) and the main TLAP work-streams we focus on broader elements including co-production, market and provider development, information and advice. PBs are however, one important element and, given the clear and consensual policy position, it is vital that we focus attention on how to make them work well for all.

Experiences can vary from very poor to excellent. We need to know what leads to a better experience and outcomes and how these can be achieved. Varying views have been expressed about the 'active ingredients' of selfdirected support. Some have focused on the budget or how the money is held or managed. Others have emphasised aspects of the process such as the importance of planning, and some have stressed market development or supporting providers to meet new expectations.

To plan and make local improvements it is vital to examine the outcomes and experiences of people using personal budgets and use the learning to review and improve delivery. However, at the time of the last ADASS

personalisation survey, only small numbers of councils reported that they were doing this in real time with local people using personal budgets. Pressures on local capacity, including in performance teams, can make this difficult so it is essential to have robust but simple and low cost/capacity approaches. POET (Personal Budgets Outcomes and Evaluation Tool) is one such approach. As well as promoting local improvement, gathering this information from people and families can help us build a picture of what policy and development actions can promote positive change. For TLAP, the insights provided can help steer and support our work, which will help councils and others to achieve better results from self-directed support.

Reflecting this context, in 2011 the first National Personal Budget Survey was published by TLAP. It described the experience of 1,000 personal budget holders and 1,000 family carers as they took control of a PB. This second report is now being published in response to the need to continuously improve our understanding of the impact of personal budgets and the action councils and others can take to achieve the best results. The larger survey numbers (2,022 PB users and 1,386 carers) allow us to explore questions not possible in the 2011 report.

Using POET

The POET tool has been designed over a number of years by In Control and Lancaster University to capture people's lived experience of self-directed support in a consistent way. It

allows us to monitor what is really happening for people and to help answer some of the key questions. The POET survey tools gather views and experiences from personal budget holders and their family carers. It is designed to measure how well the council is managing to implement personal budgets and to what effect. Specific questions investigate people's experience of the personal budget process and the impact of the personal budget on their everyday life.

The tool aims to provide councils with a way of measuring and understanding their performance in real time, and as it is understood by local people who are looking to them for help. It is intended to complement other forms of evaluation by generating 'practice-based evidence'. This is produced by pooling information on routine practice across a range of localities to produce datasets big enough to address questions that could not be investigated using local information alone. Pooling together such information allows us to investigate questions such as: Are different types of personal budget associated with different experiences for personal budget holders? Do people with different needs for social care support have different experiences of personal budgets? Which factors are associated with more positive (and less positive) outcomes for personal budget holders?

Practice-based evidence is designed to complement other forms of research and intelligence required to generate the evidence crucial for guiding best practice. Compared to large-scale research projects, practice-based evidence projects are lower cost, have a relatively low impact on the people involved, are relatively quick to conduct and collect (and repeat), are

¹ Barkham, M and Mellor-Clark, J (2003). Bridging evidence-based practice and practice-based evidence: Developing a rigorous and relevant knowledge for the psychological therapies. Clinical Psychology & Psychotherapy, 10, 319-327.

closer to the reality of how services are routinely working (or not working) for people, and have feedback looped back to practice built into the process. Some of these advantages, however, are also limitations. For example practice-based evidence projects are dependent on the voluntary participation of interested services and people, making it more difficult to gain groups of participants that are nationally representative. In both the 2011 and 2013 National Personal Budgets Surveys, for example, direct payments users are over-represented compared to the national picture. In addition, because practicebased evidence projects are designed to be relatively easy to fit within routine practice, the range and depth of information collected is not as extensive as the information collected during large-scale research projects. Both large-scale research projects and practice-based evidence are therefore needed to provide the information to continuously improve practice.

Impact of personal budgets on people's lives

The POET survey now has enough people taking part to allow some important questions to be explored:

- What is the balance of good versus poor experiences of personal budgets?
- Do personal budgets work better for some groups of people than others?

- Is it important to know how much is in your budget and do more expensive personal budgets work better?
- Do particular types of personal budget work better than others?
- Do personal budgets run according to selfdirected support principles work better?
- What can councils do to increase the chances of them delivering 'good' personal budgets?

The 14 outcomes that were measured are:

- 1) Your physical health
- 2) Your mental wellbeing
- 3) Being in control of life
- 4) Being independent
- 5) Being in control of support
- 6) Getting support you need
- **7)** Being supported with dignity
- 8) Feeling safe
- 9) Choose where/who you live with
- **10)** Get/keep paid job (not measured for older people)
- 11) Volunteering and helping community
- **12)** Relations with family
- 13) Relations with friends
- **14)** Relations with paid supporters.

For detailed findings, please refer to the main report. Some of the headlines are:

1) What is the balance of good versus poor experiences of personal budgets?

Overall, less than 10 per cent of personal budget holders reported a negative impact on any of the 14 areas of their lives we asked about. Differences across groups of people and different types of personal budget are mostly therefore about the balance between making things better and making no difference.

- Overall, over 70 per cent of personal budget holders reported a positive impact on: being as independent as you want to be, getting the support you need and want, being supported with dignity
- Overall, over 60 per cent of personal budget holders reported a positive impact on: physical health, mental wellbeing, control over important things in life, control over your support

 Overall, over 50 per cent of personal budget holders reported a positive impact on: feeling safe in and outside your home, relationships with paid supporters.

There were other areas where personal budgets didn't seem to make a difference to most people. These were:

- Overall, over 50 per cent of personal budget holders reported that their budget made no difference in: choosing where to live/who to live with, relationships with family, relationships with friends
- Overall, over 80 per cent of personal budget holders reported that their budget made no difference in: getting and keeping a paid job (working-age adults), volunteering.

2) Do personal budgets work better for some groups of people than others?

The survey numbers allowed comparisons between: older people, working age adults with learning disabilities, working age adults with mental health issues, and working age disabled adults. Analysis showed that in eight of 14 areas there seems to be an equal impact across groups. These areas were: physical health, being as independent as you want to be, getting the support you need and want, being supported with dignity, feeling safe in and outside your home, choosing where to live/who

to live with, getting and keeping a paid job (working-age adults), relationships with family.

In some other areas of life there were differences. In some areas, PBs were less likely to make a difference for older people. These were: mental wellbeing, control over important things in life, control over your support, volunteering, relationships with friends, relationships with paid supporters.

3) Is it important to know how much is in your budget and do more expensive personal budgets work better?

Over 70 per cent of personal budget holders in the survey knew the amount of their budget with no differences across social care groups. People with council-managed personal budgets (61 per cent) were less likely than people with other types of budget (77-80 per cent) to know the amount of their budget. Of those who could estimate their budget amounts, people with physical disabilities had the highest value budgets (on average £200 per week), then people with learning disabilities (£170), then older people (£121), then people with mental health issues (£90).

Direct payments looked after by someone else were the highest value budgets (£171), followed by individual service funds (£146), then direct payments to the person (£138), then councilmanaged personal budgets (£120).

Knowing the amount of your personal budget was associated strongly with better outcomes for people with learning disabilities and physical disabilities though much less so for older people and people with mental health issues:

- Better outcomes in two out of 13 areas for older people
- Better outcomes in 11 out of 14 areas for people with learning disabilities
- Poorer outcomes in two out of 14 areas for people with mental health issues
- Better outcomes in 11 out of 14 areas for people with physical disabilities.

The estimated weekly amount of personal budget, however, was not associated with any outcome for any group. Analysis showed no linear relationship between costs and outcomes for any type of personal budget for any of the outcomes. Some people with low cost personal budgets report very positive outcomes, while others with higher cost personal budgets report less positive/more negative outcomes.

4) Do particular types of personal budgets work better than others?

Personal budgets of different types had varying impacts in different areas of life. All types had an equal impact on: physical health, choosing where to live/who to live with, getting and keeping a paid job (working-age adults) and volunteering. Council-managed personal budgets were less likely than other types of budget to have a positive impact (i.e.

more likely to make no difference) on: mental wellbeing, control over important things in life, being as independent as you want to be, control over your support, getting the support you need and want, being supported with dignity, feeling safe in and outside your home, relationships with family, friends and paid supporters.

5) Do personal budgets using self-directed support processes work better?

The survey asked whether personal budget holders got help to plan their budget and who from. The main findings were that over 80 per cent of people got help to plan their budget. Older people were less likely to get help, and people with council-managed budgets or direct payments looked after by someone else were most likely to get help to plan their budgets. Specific sources of help varied across social care groups and types of personal budget. Getting support to plan was associated with:

- Better outcomes in 13 out of 13 areas for older people
- Better outcomes in 12 out of 14 areas for people with learning disabilities
- Poorer outcomes in four out of 14 areas for people with mental health issues (this counter intuitive finding will require further exploration - it may, for example, link to who provides support to this group)

 Better outcomes in nine out of 14 areas for people with physical disabilities.

The survey asked whether personal budget holders felt their views were fully included in their support plan. Eighty per cent of personal budget holders felt their views were fully included with little difference across social care groups and types of personal budget. Having your views fully included in planning was very strongly linked to positive results.

- Better outcomes in 12 out of 13 areas for older people
- Better outcomes in 14 out of 14 areas for people with learning disabilities
- Better outcomes in 13 out of 14 areas for people with mental health issues
- Better outcomes in eight out of 14 areas for people with physical disabilities.

6) What can councils do to deliver a 'good' personal budgets process?

An important finding of the survey, consistent with the 2011 report, was that across most aspects of the personal budget process and most outcomes, there were big differences across the 20 councils with 50 or more respondents to the POET survey. We also asked personal budget holders how easy or difficult their council made it to go through nine aspects of the personal budget process and found big

differences across councils in these aspects of process. This offers the prospect of exploring what leads to better or worse results to help improve local delivery.

The analysis shows that councils generally find some aspects of the process more difficult than others and that they generally find it harder to achieve positive outcomes in some

areas than others. However, the best councils do well even in the more difficult aspects of the process. For all social care groups, councils making the personal budget process easier was robustly associated with better outcomes for personal budget holders. The same findings apply to carers.

These findings suggest that:

 Councils need to get aspects of the process close to the principles of self-directed support

- They need to personalise their processes as well as the support people get at the end of the planning process as different people have different preferences and needs and these should be reflected in the 'customer journey' for each person – for example, the type and level of assistance in planning support, the mechanism for managing the budget (DP, ISF, etc.)
- The process needs to be streamlined, timely and clear with only those limitations on flexibility that are really necessary.

To illustrate with an example based on the POET evaluation last year, one council carried out detailed work looking at the customer's pathway to identify the blockages, delays and areas for improvement.

The key areas highlighted were:

- The need for a leaner self-directed support process as a key priority area for improvement
- Changing the culture and 'Doing it Right'. Looking at policies and procedures, processes and systems, and training and staff skills mix
- Developing the market
- Improved access to information and availability of services
- Support planning delivering choice and control.

Actions that followed included:

A leaner self-directed support process

 The council introduced a single needs-based questionnaire and improved the Resource Allocation System (RAS) to focus on social care need rather than client groups. Confidence in the RAS led to improved management authorisations of budget.

- Improvements in delivery of prompt financial assessments lead to reducing the time taken to put personal budgets in place.
- A review of processes and forms took place leading to quicker and smoother recording of information within the case management system, reducing the number of stages and delivering a quicker and less complicated customer journey.
- The council co-produced a one-page handout that explained to people who use services and staff the self-directed support customer journey and helped to manage expectations.

Changing the culture and 'Doing it Right'

- A review of policies and procedures took place to embed self-directed support as the way the council delivers social care support.
- An assessment and care management review is underway to review working approaches, staffing and structures. This aims to have the right staff, in the right place, at the right time to underpin selfdirected support in the future.

Developing the market

Improvements to information within the council's Universal Services and commissioners working with providers to move from block to spot contract arrangements to ensure support and care is costed and purchased on an individual/ personalised basis. This will enable people to make positive choices about the support and outcomes they want to achieve and then to access activities or services that deliver them.

Support planning

A review of the support planning process took place with a support planning strategy delivered. The strategy provided a vision for the council that separates out the support planning stage from the professional process, to enable people to deliver support planning through a self-service approach, whilst ensuring those who need help to develop support plans continue to have access to information, advice and support.

Impact of personal budgets on carers' lives

Most carers of personal budget holders also reported positive experiences (though to a lesser extent than the PB users themselves):

- Most carers reported that their views were very much or mostly included in the personal budget holder's support plan (77 per cent).
- More than half of the carers reported that having a personal budget for the person they cared for made their life better in four of the nine areas of life we asked carers about: finances (52 per cent), having the support you need to continue caring and remain well (69 per cent), carers' quality of life (60 per cent), and carers'

physical and mental wellbeing (53 per cent).

- Fewer than 10 per cent of carers reported things getting worse as a result of having a personal budget in all but two of the nine areas of carers' lives we asked about: carers' physical and mental well-being (11 per cent), carers' social life (11 per cent).
- More than half of carers reported that having a personal budget for the person they care for made no difference to two of the nine areas we asked about: your relationships with other people who are important to you (51 per cent), being able to do paid work (69 per cent, although 41 per cent were over 65).
- In all but one of the eight areas of life we asked carers about – ability to do paid work, carers of older people were least likely to report improvements.

Comments written by carers reinforced and extended these conclusions. Carers were often highly positive about the impact of personal budgets on the lives of the personal budget holder, themselves as carers and other family members. However they were negative about all aspects of the personal budget process and, unsurprisingly, the stress and worry they associated with personal budgets for the person they were caring for.

Generally speaking carers in all the groups we looked at were more likely to report better outcomes if they felt their views were included in the supported person's support plan.

People's views about personal budgets

A total of 488 personal budget holders made written comments. The length of responses varied from a couple of words to several paragraphs, with most people providing just

a few sentences. Responses tended to illustrate more extreme experiences – either positive or negative. Where people took the time to write comments they were often very pleased or very displeased. This meant it was possible to identify responses as either 'broadly positive' or 'broadly negative'. Put simply, people's experience of the personal budget process was mixed, with over half (60 per cent) of the responses relating to process being broadly negative. Responses relating to impact on life were overwhelmingly (97 per cent) positive.

People's comments covered a wide range of concerns, but the majority could be categorised into three main themes. These themes were not mutually exclusive and some respondents wrote about all three. Some respondents wrote positively about some aspects and negatively about others. The three themes were:

1) Personal circumstances: including the nature and extent of disability and how this affected their life. Comments also reflected the importance of family relationships to respondents. People tended to indicate if they had answered the questionnaire on behalf of someone they cared for. Comments in this area were generally neutral.

- 2) Personal budget process: the experience of taking control of a personal budget. This included many of the different aspects of the personal budget process such as assessment, support planning, acquiring and directing support. People also wrote about their personal experience of the various staff they encountered, including those involved in assessment and charging as well as staff providing support directly. Finally people wrote about the complexity and timeliness of the process and the availability of information and advice. Comments in this area were generally either positive or negative. There were substantially more negative comments than positive.
- 3) Impact on life: the impact of having a personal budget on their life and that of those around them. People wrote about the importance of having personalised care and support, their concerns and hopes for the future, the impact personal budgets have had on their primary relationships. People also wrote about the importance of independent living, making key decisions, being in their own home and taking part in their local community. Comments in this area were generally either positive or negative and there were substantially more positive comments than negative.

How will Think Local Act Personal use the learning from this survey?

Think Local Act Personal (TLAP) is a partnership established to support the delivery of personalisation including through personal budgets. TLAP hosts the National Self-Directed Support (SDS) Forum, which brings together those with both a stake in and responsibility for SDS to plan and act to improve its delivery. The data from the National Personal Budgets Survey offers important support for this work. We suspect that some of the data presented in the detailed report will mostly be of interest to a limited group of people with direct responsibility for PB delivery or strongly concerned in influencing this. We have therefore produced this short summary of the findings.

It is good news that personal budgets are having a positive impact in most areas of people's lives covered by the survey and that while there are differences, this holds true across the participant groups. This suggests that the general policy direction remains the right one. However, there are differences of experience across groups, the experience of process remains difficult and frustrating for many and perhaps most notably, there are very clear differences in delivery from council to council. The survey confirms clearly that delivery according to the key principles of self-directed support is associated with the best results but these are clearly not always being followed.

These findings, alongside the frequent expressions of concern about aspects of local delivery from people and families using social care and practitioners, remind us that there is much to be done to deliver personal budgets well for all and everywhere. The 22 councils

who have used POET as part of this project are to be congratulated for their commitment to checking PB results and using the findings to develop improvement strategies. However, it appears that most councils are still not using POET or another approach to do this, and this begs guestions about how they know if their strategies are working.

The increased size of the data set will allow TLAP and others to inform important areas of our work. In particular the data can be analysed to explore in more detail what can lead to improved delivery and to focus on more detailed questions including what might work best for specific groups. In addition to looking directly at the experience of people using personal budgets, we will also be able to explore the experience of family carers to see what works best for them. In partnership with In Control and in support of the efforts of the Towards Excellence in Adult Social Care initiative, TLAP

plans to do a number of things in support of the local delivery of PBs. These include:

- Providing more focused briefings on key topics of interest to inform local improvement efforts and run workshops and webinars with partners to support delivery improvement.
- Advising central government on policy implications, including how the regulations and guidance for the Care Bill can be shaped to promote improved outcomes and experiences based on exploration of the key features of delivery likely to promote the best results.
- Advising local government on key aspects of improvement, for example on making changes to process to improve outcomes and delivery for specific groups. TLAP has current projects on streamlining process and increasing direct payments uptake and is working with DH, ADASS and others on how to improve personal budget delivery to older people. We will use the survey findings to inform and steer this work. For example we can look at which councils in the survey are delivering the best results and process and then explore and share their strategies with others. This can be used to support both general improvement but also explore what works best in specific areas of delivery and for particular groups.
- Support to local government will include sharing how some local councils are using POET findings with local people using services

- and families to plan and implement local improvement strategies.
- Identifying and sharing how personal budgets can best support family carers. This will be useful both for local councils in developing their local strategies but also for carers' organisations and others who provide information, advice and support to carers.
- The 2011 report, and now this 2013 version, highlight areas of life where on the surface personal budgets do not appear to be making much difference on their own. The larger data set for this report will allow us to explore this in more detail. For example we can consider what complementary activities may be needed to achieve outcome improvements. In addition, where some councils appear to have achieved improvement even in 'harder to impact' areas, we can explore what others can do to make similar progress.

Even more important than the insights the collective data provides is using it at a local level as part of improvement strategies for personal budgets. It can be used, alongside other data and intelligence to help understand what is working well and what needs to improve. In the appendix below, we share some outline examples of how councils and their local stakeholders have reviewed local delivery – some using POET – and planned or implemented improvements. TLAP will encourage and support localities to undertake this kind of activity.

