PERSONAL PLANNING FOR DISABLED PEOPLE

Calderdale Disability Advice Resource Team (DART)

Evaluation of a two year project funded by
Calderdale Clinical Commissioning Group

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Executive Summary

It was just what we wanted and needed to know but no-one had ever told us about.

Key Findings:

- Users reported significant changes in reduced stress levels, improved mental and physical health, and in general feelings of improved well-being e.g increased feelings of happiness, improved confidence and motivation.
- Over two-thirds of respondents (72%) reported improvements in their physical and/or mental health.
- Financial gains for clients calculated on an annual basis amounted to £638, 466.
- 90% of respondents reported an improvement in their quality of life.

Project summary

The two-year project was funded by Calderdale Clinical Commissioning Group in September 2013 and commenced in April 2014. It was based on two previous pilots carried out by DART both of which showed positive outcomes. The project aimed to assist both those patients who are given a new diagnosis which may impact upon their future, and those newly disabled people, e.g . those who have become so through accidents/injuries. many of whom often face immediate major financial upheavals on matters such as mortgages; pensions; benefits ; access to suitable housing etc., thus creating a need for accurate and comprehensive advice to enable them to plan for their 'changed future'

The personal planning process aims to assist disabled people to control and coordinate the help they need. A Personal Plan identified the short, medium and long terms needs that that service users had, and what advice and information they would require to meet them and from which agency in the area they could access such services.

Between April 2014 and May 2016, when the project ended, it assisted 510 people of which 102 were directly referred by NHS and adult social services staff. Service users were assisted with 4.548 separate issues. Just over a half of which related to welfare benefits.

The service was delivered either at DART's offices or in a third of cases by home visit and clients were evenly distributed across all council wards.

Evaluation

Monitoring forms were completed by 282 service users and the end of project evaluation was based on a sample of 50 users, who were asked to self-evaluate their feelings on a range of overall health and well-being issues prior to commencing the personal planning process and again once the plan had been agreed.

Whilst the project did not reach its overall target of 700 users it exceeded the outcome targets for improved quality of life, peace of mind, access to transport, leisure and social facilities as well as access to health and support services. The project just missed the target for reported improved confidence.

One easily identifiable reason for not reaching the overall targets was that many cases were more complex than had been anticipated. This is illustrated by the fact that the number of issues per client was 13 compared with 8 in the previous pilots.

- Users frequently mentioned in their feedback that they had not been able to obtain this help from elsewhere;
- The home visiting by DART was appreciated by clients who stated that they might otherwise not have sought or obtained advice;
- A feasible business case could be built to show that interventions such as the Life Planning project can produce identifiable savings to the NHS and other care services;
- DART as an organisation is linked to a wide range of networks and partnerships all of which have the potential to benefit from the experience of this project and the enhanced capability it has brought to DART;
- In its work on Life Plans DART has established and refined a specialist service with proven benefits that deserves support as without it no alternative could be found elsewhere in the region.

1. The Project

1.1. The project began in April 2014 and ended on 31st May 2016. DART had been developing the life planning concept since 2008 with a small pilot project funded by a charitable trust. The evaluation of the original pilot concluded that: *The benefits in financial terms alone are significant. DART's figures show that additional benefits of £121,000 over a year were obtained for the 26 clients participating in the pilot…..In addition there are other less tangible benefits such as improved coordination between services and, very importantly, clients' peace of mind, well-being and quality of life.*[1]

1.2. In 2012, support was obtained from Calderdale Clinical Commissioning Group (CCG) for a more extensive pilot over six months and targeted at 40 potential users. The funding context was the Calderdale Needs Assessment (or Joint Strategic Needs Assessment, JSNA) by which NHS Calderdale and Calderdale MBC work together to understand the future health, care and well-being needs of their community. DART's pilot sought to address the JSNA priority of 'meeting the needs of those with long-term conditions'.

1.3. A particular emphasis for the project was to target newly disabled people who often face major financial upheavals and may need to address a wide range of issues including:

- Employment
- Financial support
- Home and housing options
- Health and support
- Education and training
- Rights
- Transport
- Everyday life and access
- The needs of carers

1.4. The key lessons from this pilot were:

- Newly disabled people face a range of new challenges but the most pressing is often financial. In this pilot the average increase in income per person/family as result of the Life Plan process was £4261 p.a.
- More than half the issues dealt with were non-financial. The Life Plan project provided person-centred as opposed to problem-centred advice. With an average of 8.6 issues per client, Life Plans demonstrate the range of issues that can be dealt with by a single intervention.

- Clients have welcomed the provision of a written Life Plan as it provides them with a checklist of actions that they can control.
- The Pilots demonstrated that the Life Plan process can contribute to improvements in service users health and well-being.
- DART's experience and acknowledged understanding of disability is a significant factor for clients.
- The time input per case is not disproportionally higher than casework completed by other advice services.
- Life Plans are not to be considered as a one off. as disability is not a temporary problem. This inherent difference in DART's client base deserves much greater recognition from funders.

1.5. The evaluation report[2] concluded that: *with the experience of these pilots DART now has in place the mechanisms, processes and skills to make this a mainstream service. What it now needs is investment from funders to enable the establishment of a permanent service bridging advice, health and the range of ancillary services for people with disabilities.*

1.6. Based on the experience gathered from the two pilots, DART submitted a further bid in 2013 for a full service targeted at *the non-medical needs of newly disabled people which, we believe, will in many cases directly assist medical responses through improved well-being and emotional and mental health.*

1.7. The project aimed to assist both those patients who are given a new diagnosis which may impact upon their future, and those newly disabled people, e.g . those who have become so through accidents/injuries. many of whom often face immediate major financial upheavals on matters such as mortgages; pensions; benefits ; access to suitable housing etc., thus creating a need for accurate and comprehensive advice to enable them to plan for their 'changed future'.

1.8. Funding was agreed in September 2013 with the aims to:

- Enhance the capacity of DART to improve their client's and carer's quality of life through the personal planning service (Life Plan);
- Enhance capability of DART to generate a viable 3rd sector market from which Calderdale CCG can commission high quality and safer services in the future.

2. What is personal planning?

2.1. Meeting the needs that may arise from disability could involve an array of services. The personal planning process aims to assist disabled people to control and coordinate the help they need. A Personal Plan will identify the short, medium and long terms needs that they may have, and what advice and information they will require to meet them and from which agency in the area they can access services.

2.2. DART is particularly keen to work with those people who 'become disabled'. The onset of disability can be due to deterioration in physical and mental health, accidents, children born with a disability and disabilities/deterioration in physical / mental health relating to substance misuse e.g. Hepatitis C, HIV etc. Where disability is a relatively sudden event, such as injury, the trauma of dealing with this as well as the many life changes it can brings may be overwhelming. (DART had specific target groups within this service which were those people who fit into the CCG Strategic priorities e.g. Respiratory; Cardio-vascular; Endocrine; and Musculoskeletal)

2.3. How does a personal plan work? DART receives referrals from a wide range of statutory and voluntary sector organisations working with people who live in Calderdale. The referral is initially more usually for advice on a single issue e.g. benefits or adaptations. DART aimed to develop this network of relationships to seek referrals of disabled people and particularly newly disabled people and/or their carers in order to develop a longer-term advice plan aimed at assisting the disabled person to control and coordinate the help they need. The Personal Plan consists of three stages:

2.3.1. A personal interview(s) at the client's home or at DART's office which would discuss the client's needs and aspirations over the next three to five years or whichever period is most appropriate.

2.3.2. A written report summarising the options open to the client and recommending an action plan. Immediate needs are dealt with and likely future needs identified and included in the plan. With the consent of the user, a copy of the action plan could be made available to other appropriate agencies for information and as a tool to contribute to any required future action.

2.3.3. Regular reviews and updating of the plan as each stage is achieved.

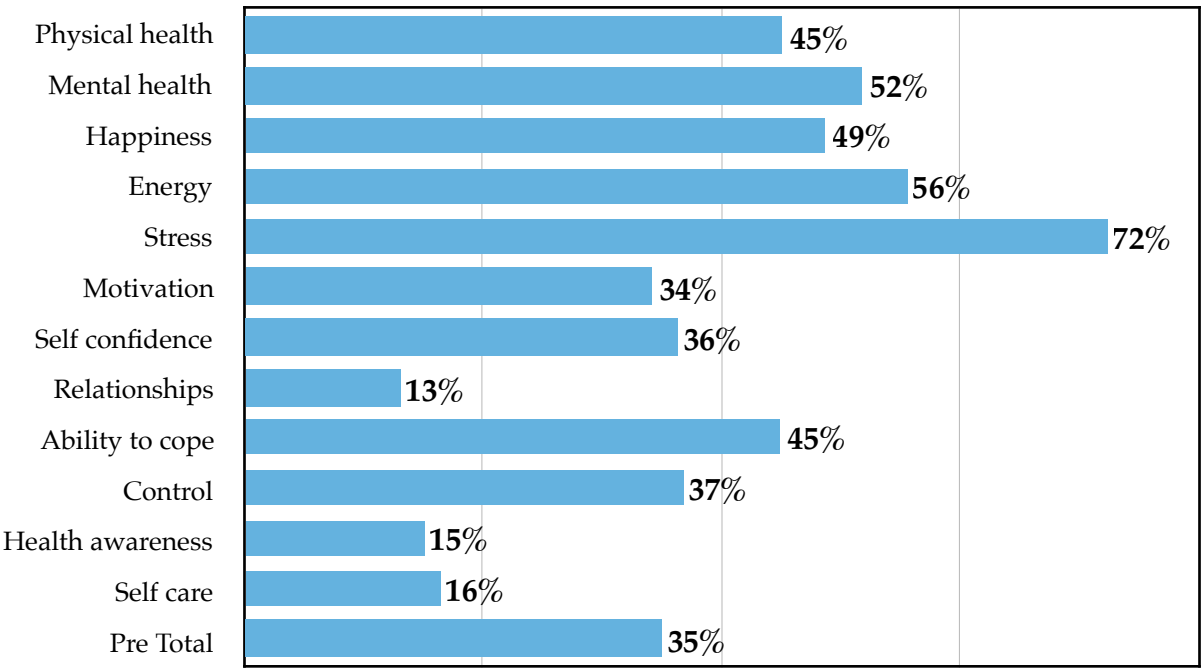
3. Outcomes Summary

N.B. The following data is based on a sample of 50 cases, (10%) of the total project beneficiaries.

3.1. Wellbeing:

Users were asked to self-evaluate their feelings on a range of overall health and well-being issues on a scale of one (worst) to five (best) prior to commencing the personal planning process and again once the plan had been agreed. The following chart shows the increase in average scores across the sample.

FIGURE 1: % INCREASE OF AVERAGE SCORE PRE AND POST ADVICE.

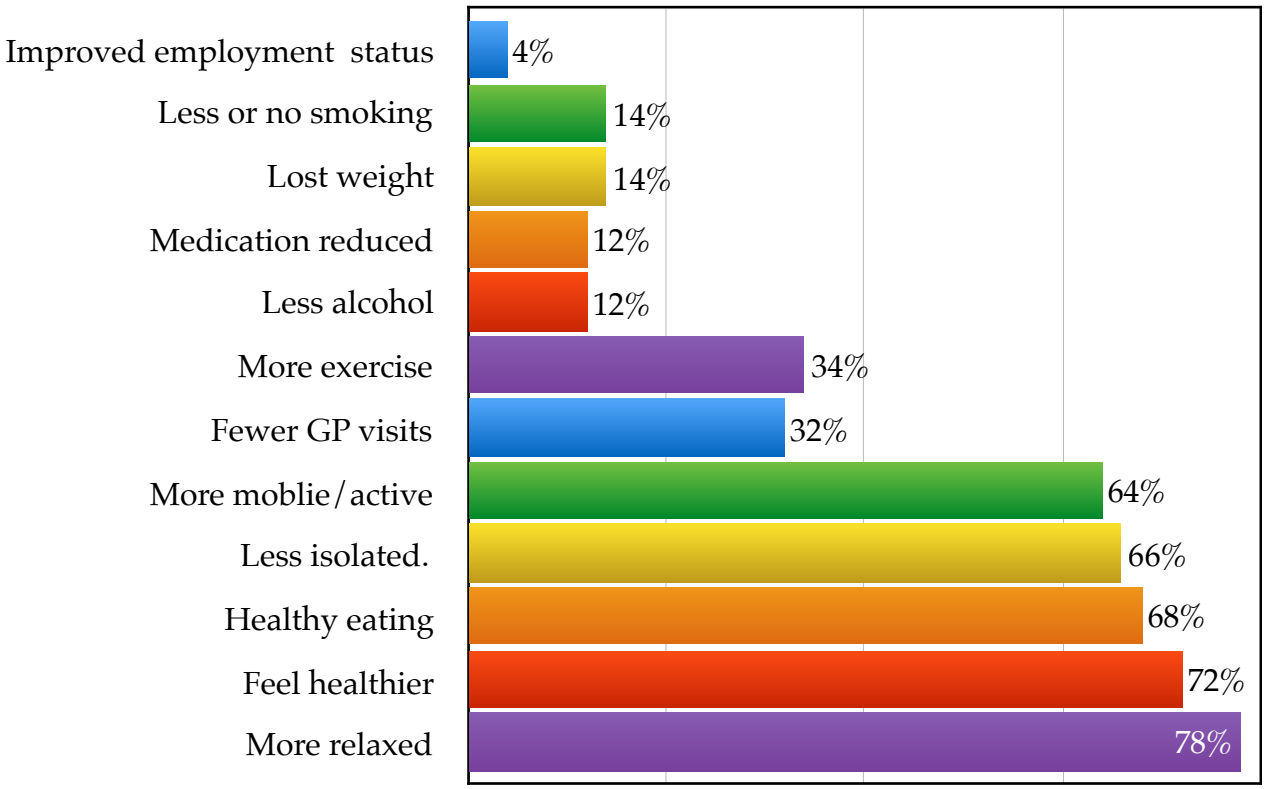


The most significant changes are that users reported reduced stress levels, improved mental and physical health, and in general feelings of improved well-being e.g increased feelings of happiness, improved confidence and motivation. Perhaps as a result of this most users reported a significant increase in energy levels

3.2. Health and healthy living:

Following advice from DART users were asked to self-assess the impacts that this advice had on their health and their daily health activity.

FIGURE 2: HEALTH OUTCOMES



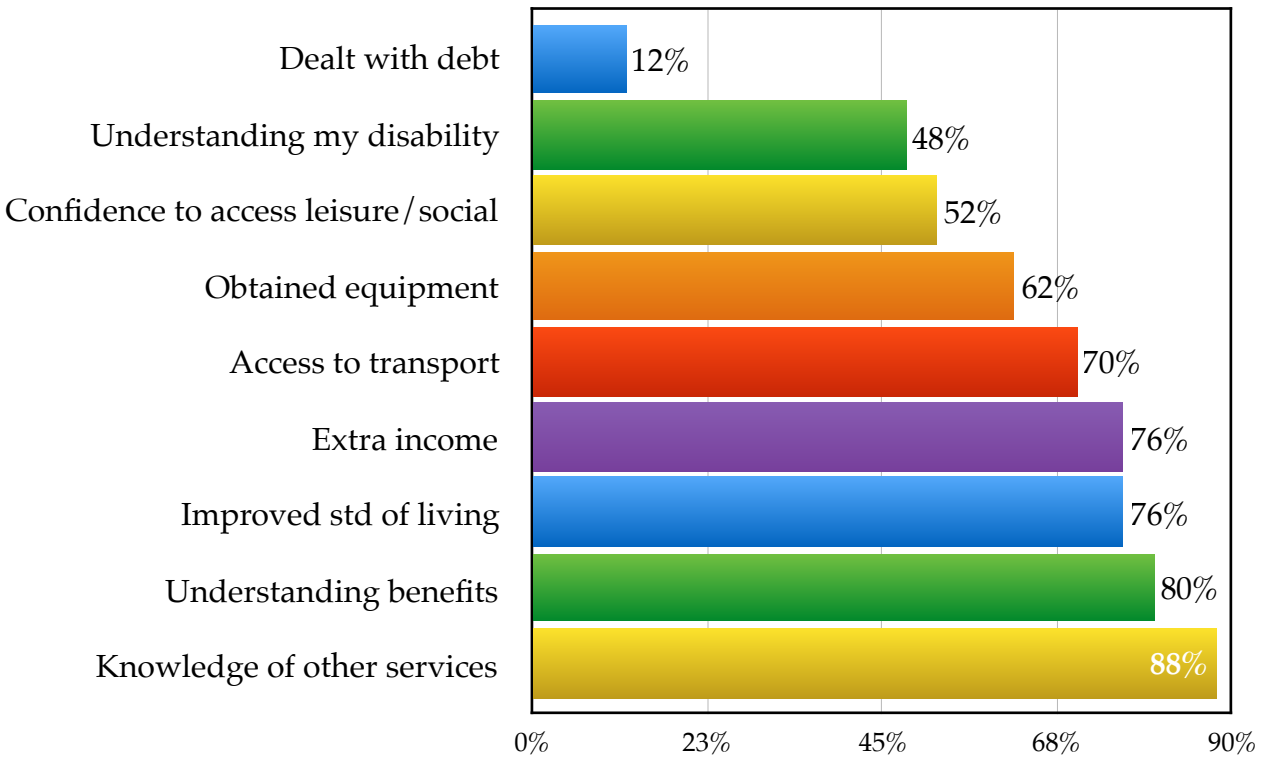
The well-being outcomes clearly link to improved health outcomes such as healthier eating, increased activity and reductions in smoking and alcohol use. Once those who do not smoke are discounted (30) the reduction in smoking is more significant as 7 of the 20 (35%) who admitted to smoking had said they had ceased or reduced tobacco intake.

Also worth noting is the reported reduction in GP visits, and medication, both specific targets of the CCG funding. Over two-thirds of beneficiaries (72%) believed that their physical and/or mental health had improved as a result of the advice from DART. Principally the reported improvements were in mental health because, as many commented, their physical health could not improve.

3.3. Other outcomes

As well as the health and well-being outcomes users were asked what other impacts the advice had made. These included tangible benefits such as increased income well as other benefits such as greater access to social and leisure activities and increased knowledge of other services.

FIGURE 3: OTHER IMPACTS OF ADVICE



Principal impacts were additional income and a consequent increase in their standard of living as well as improved access to services and social activities.

Finally, beneficiaries were asked if they were motivated to continue to improve their health, 90% said they intended to do so.

4. Project outputs

4.1. The project ran from April 2014 to May 2016. Over this period 510 people were direct users of the service. Project outputs are as follows:

- Total issues raised were 4,548 of which just over a half related to welfare benefits;
- around a third of contacts were through a home visit;
- 102 direct referrals were received mainly from NHS services (36) and Adult Social Care (21);
- Almost all clients were persons with a disability or expected long term medical condition and the remainder (18) were persons with a caring responsibility;
- Financial gains for clients calculated on an annual basis totalled £638, 466.

4.2. Monitoring forms were completed by 282 users and showed that :

- Clients were evenly distributed across all council wards the highest being Illingworth/ Mixenden (13%) and the lowest Luddendenfoot (2.5%);
- The main age groups were 50-64 (30.5%) and 65-79 (28%)
- Less than a half (48.5%) of respondents were married or cohabiting, 22.5% were single people and 28.5% were widowed, divorced or separated.

5. Meeting the targets

In its original funding bid DART had set a target of reaching 1050 people who would directly benefit from the service. This was based on an average reach of 350 people per year over three years but the project was subsequently revised to a two year project meaning the total target reach was reduced to 700. Therefore it was also reasonable to scale down other targets to take account of the shortened project term. These were:

- 333 people will report an improved quality of life - originally 500;
- 333 people will report improved peace of mind - ditto;
- 333 people will report improved confidence in living with their disability - ditto;
- 200 people will report improved access to transport, social and leisure facilities - originally 300;
- 200 people will report improved access to health advice and support - ditto;
- We estimate 30 current services would benefit from improved referrals (in and out) and more comprehensive information about an individuals needs.

5.1. Project beneficiaries:

The planned start date of December 2013 for the project was postponed, as the experienced staff that were initially in place to deliver the service, were working to complete another project. The Life-Pan project therefore started in April 2014, becoming fully operational in September 2014 , this was due to the proposed lead-in period which was needed to set up the project and establish the data base, as included in the project plan. There were some minor recruitment problems in year one, which meant that the service ran at a reduced capacity for part of this first year. The added loss of a key experienced member of staff through sudden bereavement created additional challenges.

In addition the project did not receive the expected number of referrals from GP practices and other NHS services, an issue that was apparently found across a number of CCG funded projects despite Sector Support attempts to increase voluntary sector access to Practice Managers and resulting in fewer than expected cases in year one. The Project sought to make up this shortfall in year two.

DART has recorded 345 users of the service of which 48% were couples which would mean around 510 people have benefited. Whilst this is below the original target, DART gave possible reasons for this in its mid-term report to Calderdale CCG that "*the Life Planning Project has proven to be more time consuming than anticipated, as it has been impacted by ongoing Welfare reform changes, in addition, some presenting clients have had more complex issues than we anticipated resulting in multiple contacts over longer periods of time.*"

5.2. Client issues

Total issues identified were 4,548, an average of over 13 per household. Half of these related to welfare benefits and the overwhelming majority (80%) concerned new applications for benefits that had been unclaimed in the past.

The number of issues per client was significantly higher than that found in a previous pilot[3], which identified around 8 issues per client, and therefore lends support to DART's mid-project assessment comment, in that they were encountering more complex cases in within the delivery of this project.

5.3. Quality of life

Quality of Life is commonly measured across five dimensions: physical health and well-being, material well-being, social well-being, emotional well-being, and development and activity.

The self-evaluation process that DART used to measure the impact of its service covers all of these. Taken as whole the results show a significant improvement in all areas. Only five out 50 users did not report an improvement with the remaining 90% reporting significant improvement. If the figure of 510 beneficiaries is accepted then the target of 333 people reporting an improved quality of life has been exceeded i.e. 90% of 510 =459.

The results across the five dimensions are:

- physical well-being: self-evaluated scoring improved by 46% post advice
- material well-being: 76% obtained additional income and said this had improved their standard of living
- social well-being: 66% reported that they felt less isolated and clients reported improved self-confidence (36%), motivation (34%) and an improvement in their relationships with others (13%);
- emotional well-being: significant improvements in happiness (49%), mental health (52%) and reductions in stress (72%)
- Development and activity: 64% said that they were more mobile/active, 52% reported increased confidence to access social and leisure activities and 70% reported improved access to transport.

Current estimates are that £678,000 in extra benefits on an annualised basis have been obtained for the client group.

This figure is likely to increase quite significantly as all claims submitted during the life of the project are still to be finalised. This averages over £1900 pa. for each household or £36 per week.

Client comments:

> *The help has made our lives a little easier*
>
> *Increased income - jointly me and my wife are £290 pw better off*
>
> *I am less stressed on a daily basis and have a better relationship with family members . I also feel I have more time to look after myself now.*
>
> *His increase in benefits has allowed him to take part in more social activities. He is less agitated/anxious and relationships within the family have improved.*

5.4. Peace of mind

The improvements in mental health and wellbeing have all contributed to improved peace of mind with 78% of clients reported feeling more relaxed which translates to almost 397 people using our figure of 510 beneficiaries. This is above the target of 333.

Client comments:

> *I can't explain how much help this service was to both me and my wife. Our peace of mind was something we didn't expect to get.*
>
> *The peace of mind is priceless.*

5.5. Confidence

Several indicators point to increased confidence both in living with their disability and in accessing external support swell as social and leisure activities. Almost a half (48%) said they now had a better understanding of their disability and 52% reported increased confidence to access services and social activities.

These results are below the target 333 people reporting increased confidence as this translates to around 250 people.

Client comments:

> *Having advice helped me to accept that I need to take more responsibility for myself and not let others make decisions for me.*
>
> *More confident, less stressed.*

5.6.Access to transport, social and leisure facilities

This is well above the target of 200 people as 70% of clients reported improved knowledge about access to transport which is also reflected in the 52% who said they now had more confidence to access social and leisure activities.

Client comments:

> *I am now able to buy a mobility scooter due to increased income*
>
> *It has helped me to get out more*
>
> *Getting out more now I know about the access bus.*

5.7. Access to health advice and support

Also above the target of 200 people was the improved knowledge that 88% of respondents said they now had of other services that could help.

Client comments:

> *There are agencies to get help that I had never heard of.*
>
> *The most valuable thing is knowing there is help out there when I need it.*
>
> *The advice given made me accept some things I can't change but some I can. I am very happy to have found out that there is help out there and that I can access it if I choose to.*

5.8. CCG Objectives

In the funding agreement with DART , the CCG set an objective for DART to create a comprehensive evidence base to demonstrate the impact of the service on:

- Clients and carers
- health and social care system

The impact on clients and carers has been largely evidenced in earlier section of this report but what about the impact on the health and social care system?

Feedback from users shows that the service has contributed to reductions in GP usage and medication with 32% reporting fewer GP visits and 12% saying that they had reduced their medication.

Other reported impacts that should benefit health systems include:

- reduction or cessation of smoking - 14%
- increases in exercise - 34%
- healthy eating - 68%
- weight loss 0 14%.

Client comments:

> *I have become more aware of the impact of smoking and have cut down*
>
> *I have lost a stone and now walk daily 10,000 steps. I was very sedate as in pain but I am now all for my health*
>
> *I eat better and worry less*
>
> *I joined a slimming class for free via my GP. I didn't know about this.*
>
> *Reduced smoking - I am seeing a stop smoking nurse.*

6. Evaluation

DART has been developing its life planning service since 2008 with two pilots in 2008 and 2013 and this extended project funded by Calderdale CCG. Each evaluation has proven positive showing strong outcomes and supportive feedback from users.

Following the initial pilot in 2008 DART hoped that the life planning process could be put on a firm footing as a mainstream service but since then funding for services such as this has become more insecure and harder to obtain. Yet the concept of life planning has proven itself time and again. At its core is the advice and help on benefits. Since 2008 life planning has secured almost £900,000 in additional annual benefit income for 404 clients, an average of over £2200 each.

However, life planning is much more than this. By targeting clients with new medical conditions and/or those with long-term debilitating health conditions it assists clients with elements of forward life planning, helps them to work towards their recovery and to regain their independence. In many cases this will involve planning for a different future than may have been previously envisaged by the client and their family.

By offering each client a holistic service approach which in addition to a welfare benefits assessment includes active assistance to claim any entitlement, also seeks to empower clients to explore and improve their access to appropriate services including: housing; education; employment; health and other relevant services. (See Appendix 1 for case examples)

The examples illustrate the complexities of much of the advice and of the systems and procedures that many people, not just those with disabilities, find daunting and often overwhelming which can add to stress and a lack of confidence.

Combining a range of issues within the life planning assessment enables them to be dealt with in a single process avoiding the need for clients to identify and contact several agencies for separate but linked problems.

6.1. Health benefits of advice

Over the last two decades more evidence has emerged of the health benefits of advice and its potential to reduce demands on NHS services. The key finding of a report in 2015 from the Advice Services Alliance[4] was that *the effects of welfare advice on patient health are significant and include: lower stress and anxiety, better sleeping patterns, more effective use of medication, smoking cessation, and improved diet and physical activity.* The evidence from this project fully supports that finding.

In 2012, Citizens Advice published "An overview of possible links between advice and health" funded by the Department of Health summarising the considerable body of evidence of the health benefits of advice. Overall we have identified over 40 studies since 1993 examining the health impacts of advice.

Although providing strong evidence that good advice makes a significant contribution to improved health outcomes the majority of studies are concerned with welfare benefits advice. We have not identified any current studies that examine the impacts of such comprehensive advice as that offered by DART in its life planning service.

If DART is ploughing a unique furrow then the evidence it is accruing from its life planning process offers a pointer to the added value of holistic advice and support which may be particularly applicable to people with disabilities who by virtue of the disability may encounter more problems than a non-disabled person.

6.2. A necessary service?

Users frequently mention in their feedback that they had not been able to obtain this help from elsewhere, e.g:

> *DART provide a service that is very difficult to access in Calderdale. I found it hard finding the right support. My application for PIP was successful thanks to the advisor at DART.*

> *It was just what we wanted and needed to know but no-one had ever told us about.*

The argument for specialist disability advice services has been lost in recent years. Many such services have closed because of funding cuts or been merged into generalist services. Yet the original case for a specialist service was that it better understood disability issues, was more empathetic , and could tailor its service for disabled people. For example the home visiting by DART was appreciated by clients who might otherwise not have sought or obtained advice.

> *I liked that it was face to face and in my home. I get anxious away from home and find it difficult to get out.*

> *I liked that she was able to come and visit me in my own home. This made it a much more comfortable meeting.*

Clients also made frequent mention of the manner in which the advice was given e.g. patient, simple language, understanding.

> *She was patient and helpful. I think she was aware that I was flagging and did her best to let me have some information in small chunks.*

A feature of specialist disability advice services is that compared to other advice providers they can be more expensive. Giving people the time they need and offering a home visiting service may add to the cost but for some people this may be the only way that the advice they need can be given. The evidence from this project would support this.

Clearly many of the clients surveyed have not been able either to access or been provided with the advice they need despite being in contact with various NHS and other statutory services. While their health needs may be being addressed the range of problems that they had and that the life planning project identified had either not been picked up or had not been addressed by other services. Yet as shown by the health and wellbeing outcomes from this project the non-health issues may well have had health impacts.

6.3. Building the business case

Much of the research mentioned above has its origins in attempting to develop a business case for advice. In straightened times funders are placing greater emphasis on value for money from investment in services and consequently the advice sector has sought to show that investment in advice is cost effective mainly through savings it can make to other areas of social provision.

Largely this has concentrated on management of debt or prevention of homelessness but little has been done in assessing the health expenditure savings gained through advice. For example savings might accrue through fewer GP visits arising from less stress and anxiety, and reductions in medication. The outcomes from this project show a third of respondents reporting a reduction in GP visits, and 6% reporting reducing medication, and clear evidence of reduced stress and other health benefits.

Among the key messages contained in a report from the Kings Fund in 2012[5] were:

- Many people with long-term physical health conditions also have mental health problems. These can lead to significantly poorer health outcomes and reduced quality of life.
- Costs to the health care system are also significant – by interacting with and exacerbating physical illness, co-morbid mental health problems raise total health care costs by at least 45 per cent for each person with a long-term condition and co-morbid mental health problem.
- This suggests that between 12 per cent and 18 per cent of all NHS expenditure on long-term conditions is linked to poor mental health and wellbeing – between £8 billion and £13 billion in England each year. The more conservative of these figures equates to around £1 in every £8 spent on long-term conditions.

The report concluded that that *the prevailing approach to dealing with long-term conditions – shifting towards self-management and reducing demands on formal care–is at risk of failing unless we recognise that many of the people affected have co-morbid emotional or mental health problems that can reduce their ability and motivation to self-manage.*

On average each GP visit costs the NHS £45 and average prescription costs are £41.35. Add to this the long-term benefits of improved wellbeing, both emotional and financial, and the cost benefits become manifest.

A feasible business case could therefore be built to show that interventions such as the Life Planning project can produce identifiable savings to the NHS and other care services.

6.4. Building DART's capability

The second aim of the CCG funding was to *Enhance capability of DART to generate a viable 3rd sector market from which Calderdale CCG can commission high quality and safer services in the future.*

DART's work has long been carried out in partnership with other services. It is currently working with Calderdale Carers Project and has recently completed a partnership project called Making Advice Work.

This was developed in spring 2013 by four lead partners: Calderdale Citizens Advice, WomenCentre, Age UK and DART . The partners sought to maximise the reach and impact of advice services across Calderdale, by pooling their resources and venues and supporting the wider voluntary service community to connect customers with advice, either directly or indirectly.

A report on the project[6] noted that p*artners have gained a far deeper understanding of the Calderdale advice environment – enabling them in turn to work more strategically and to draw on complementary skills and resources across the district, where these exist, rather than building from scratch.*

The joint working developed through the project continues with, for example, DART working with other organisations through the Welfare Reform Partnership and the BACHS Group, which is developing a new model for the future of Cancer Support services. It is also working with NHS Services on the Life Plan Service (Respiratory nurses) despite capacity issues and problems in engaging GP services to network making it quite difficult to develop relationships.

DART is therefore linked to a range of networks and partnerships all of which benefit from the experience of this project and the enhanced capability it has brought to DART. In addition, DART has obtained the Advice Quality Standard (AQS) giving clients confidence in the 'Quality assured' service and is also working towards the achievement of the CCG 'Quality for Health' quality mark.

Consequently the CCG and any other funder can therefore be assured of high quality and safer services from DART and through its partnerships with other services the transmission of the skills and experience it has developed.

7. Looking to the future

This project is the third life planning project albeit the most comprehensive. Each of the pilots and this project have produced strong outcomes showing significant financial and emotional well-being outcomes. DART's experience in developing its life planning process supports the findings of many studies over recent decades that such interventions carry major benefits not only to the individual user but also to the health and social care services that they use.

Over the next decade, disabled and chronically ill people face a major impacts from the Government's welfare reforms. These are listed in Appendix 2. The charity Revitalise surveyed disabled people in 2015 and found that 8 out of 10 (83%) disabled people and their carers are concerned about what the future holds, with nearly half (43%) saying they were either very worried or had never been so worried about what is in store for them. Only 5% said they were unconcerned about the future.

Recently released research from the charity Turn2Us[7] found that almost three-quarters (73%) of low income households claiming means-tested benefits are worried about future changes to the welfare system. This figure was highest amongst those unable to work due to disability or long-term illness, with a huge 90% concerned about welfare reform.

In addition cuts to local authority social care budgets add to the fears of many disabled people about the amount and quality of help they can expect in the future, a future when they may be facing deteriorating health as a result of their condition.

It is to be hoped that DART can maintain its Life Plan service with renewed funding and ideally it can obtain long term funding to establish it as a mainstream service. The Making Advice Work noted that a *key learning point is that specialist advice should be just that – it is neither appropriate nor responsible to seek to engage generalist workers in giving specialist advice.*

In its work on Life Plans DART has established and refined a specialist service with proven benefits that deserves support as without it no alternative could be found elsewhere.

> *DART is such a valuable service. We have struggled for years. I was actually in tears after the first visit as I couldn't believe someone could do so much in such a short time.*

Appendix 1: Example Life Plans

NB identifying information removed to protect anonymity

Example 1

Date of first contact 25/08/2015:

RD is a male aged 58 years. He lives alone and owns his own home.

He did work in a sales role for a company in Leeds but had a stroke 6 months previous to the contact date. The stroke caused some reduction in mobility and memory problems. RD believes he is not receiving any income.

26/08/2015

An Adviser visited RD at home.

RD was currently receiving Personal Independence Payment (PIP), daily living component at the enhanced rate of £82.30 p.w. and mobility component at the enhanced rate of £57.45 p.w. and ESA (CB) of £73.10 p.w. He was waiting to be assessed for a group and was advised he to contact his adviser when the medical assessment form arrived. He was in receipt of any Council Tax Reduction (CTR) but an appointment was arranged with Calderdale council's benefits visiting team to see if he would be entitled to any further reduction.

RD was still employed by the company he worked for in Leeds as a sales representative but his Statutory Sick Pay (SSP) had come to an end in July. The advisor spoke to his employer by phone and they advised that they were looking into finding an alternative role for RD but that it would be very unlikely that he would be able to return to his role as a sales representative as he was no longer able to drive. They were waiting for further information regarding RD's condition before they were able to make set plans.

RD stated that he struggled with the stairs and the adviser recommended he speak to Accessible Homes at Calderdale Council regarding adaptions to his home.

RD stated that he was supported by the memory nurses and the Stroke Association. The adviser recommended that he contact Gateway To Care to find out if any further support is available. RD eats a healthy diet, does not smoke and does not drink.

RD stated that he would like to work in some capacity in the future and would be happy to be trained in another area but did not have a specific need for training. The adviser told RD that should he be allocated to the work related activity group of ESA, he would be required to partake in work related activities so training would be available.

RD stated that he had had a company car but was no longer able to drive due to the effects of the stroke so now used public transport. The adviser gave RD information leaflets about travel concessions.

RD stated that he was basically happy with the social contact he had. He had a kitten, his son visited when home from university, he regularly saw his sister and went to the gym when possible.

This completed the advice session and RD was sent a copy of all of the above information and advised to contact his Adviser for help with any related issues as they arose.

15/09/2015

The adviser contacted RD to chase if he had received the medical assessment form for ESA. RD stated that this had not been received. The adviser spoke to ESA and they confirmed that the form had not yet been sent. RD was informed of this and asked to contact the adviser when this arrived.

24/11/2015

RD's therapist contacted the adviser as RD was again under the impression that he was not receiving any income again. The adviser assured the therapist that RD was in receipt of benefits and called RD to re-advise him of his income.

RD told the adviser that he had had a letter from ESA requesting another fit note. The adviser told RD that he needed to contact his doctor for a fit note and send this to ESA.

The adviser asked RD if he had received the ESA medical assessment form and he stated that he had not. The adviser called ESA to chase the medical assessment form and was informed that this had been completed and returned and that RD would soon be contacted for a face to face assessment. The adviser also enquired about income based ESA for RD as he was on contribution based only but eligible for income based, which would then allow him to receive the enhanced disability and severe disability premiums. ESA advised that RD needed to send his P45, bank statement and letter from DWP regarding his award of PIP. The adviser called RD to advise him of this and sent a letter.

07/12/2015

A message was left for the adviser from Age UK. RD had been in touch with them and stated that he was not receiving any income. The adviser called Ray to advise what he was in receipt of. RD stated that there was not enough money left in his account to pay the mortgage and he didn't know why. The adviser arranged a home visit with RD for 10/12/2015 to look at his finances.

10/12/2015

The Adviser visited RD at home. The adviser went through RD's financial paperwork with him. There was a letter stating the he owed money for a community alarm and there had been no change in the amount of CRT. The adviser contacted Calderdale Council, the arrears for the community alarm had been paid and another home visit regarding CTR was arranged.

The adviser called ESA, RD has not yet been assessed for a group and this could take some time but once the decision has been made, the payment will be backdated to March 2015. The adviser was informed that they had been advised incorrectly on 24/11/2015 regarding applying for the income based part of ESA and that a form (ESA3) would need to be completed. The adviser requested that the ESA3 be sent to the office address.

RD's bank statements were showing only the mobility component of PIP being paid. It had been confirmed that RD was in receipt of the enhanced rate of both mobility and daily living by the DWP over the phone and in an award letter. The adviser called PIP and they acknowledge that both had been awarded and that they would need to refer the case to their payments section to be investigated and that someone would call RD. The adviser asked that they be the contact due to RD's memory problems.

The Adviser called RD's mortgage provided and explained the situation with RD's benefits and that this was why payment had been missed but that it make take some time to rectify. The mortgage provider where also made aware of RD's memory problems.

The adviser told RD that they would be in touch to arrange a further home visit once the ESA3 had arrived.

15/12/2015

A message was left for the adviser by DWP stating that RD's daily living component of PIP was not in payment as he was in a care home. The adviser contacted the DWP to tell them that this was incorrect. They stated that they had information that RD was in a care home from the beginning of March 2015. The adviser said they would look into this and get back to them.

The adviser spoke to RD but he did not recall being in a care home. The adviser contacted social services and they informed the adviser that RD had been in an intermediate care bed, which is in a care home, on leaving hospital after his stroke. However, RD was discharged on 13/03/2015.

The adviser called DWP to inform them of the date RD was discharged. They stated that this would be passed to a case manager and that this could take a few weeks to process.

16/12/2015

The adviser called RD to explain the situation with PIP daily living.

21/12/2015

The adviser visited RD at home to complete the ESA3.

11/01/2016

The adviser received a call from RD stating that his mortgage provider were chasing payment. The adviser recommended that if RD was able to make a payment of some form it would be best to do so and to reiterate the issue he was having with his benefits. The adviser told RD that they would chase the PIP daily living payment the week after.

19/01/2016

The adviser called DWP regarding PIP and was told that RD's case has been passed to a case manager on 07/01/2016. The adviser asked when this was likely to be looked at and was told that there was no set timescale but that if RD had not had a daily living payment by his next payment (15/02/2015) to contact them again. The adviser called RD to advise him of this.

15/02/2015

Call from RD to advise that the daily living component of PIP has not been paid. He stated that that he is still unable to pay his mortgage as there is not enough money going into his bank account and he is now at risk of losing his home. The adviser asked that he drop his bank statement off at the office.

16/02/2015

RD dropped his bank statement off at the office.

The adviser called DWP regarding PIP daily living. They stated that a form had been sent to the nursing home to be completed to confirm what date RD left. They stated that the form was sent on 20/01/2015.

The adviser called social services to find out which care home RD had stayed in.

The adviser called the care home to enquire if the form had been received. They stated that they had not had the form but that there were several buildings and if post is not addressed properly it can get lost. The adviser was given the name of the physiotherapist for a second form to be addressed to.

The adviser called DWP and informed them that the form had not been received and asked that they second form to be completed. The adviser gave the name of the physiotherapist and full address of the care home for the form to be sent to.

The adviser called Step Change Debt Charity, as RD had already been in contact with them and asked that they contact RD to give him some advice about his mortgage. I was told that they could not call RD on my request as I did not have authorisation on RD's account. The adviser explained that they did not want any information, they wanted someone to contact RD as due to his memory problems. The adviser was again told that they could not do this.

The adviser called RD to advise him of the situation with PIP and that he need to contact Step Change about your mortgage as they would not allow the adviser to request that they call him.

The adviser advised RD that he had an overdraft on his bank account, which would be enough to make a mortgage payment and that it may be best to do this if he is at risk of losing his home.

Example 2

This life plan is a record of what you discussed with your adviser, and details any further advice needs you may have in the future. It also sets out a number of planned actions by whom and when. Please keep this Life Plan safe as you may need to refer to it again in the future.

Name xxxxx
Date of birth xxxxxx
National Insurance number xxxxxxxx
Health problems/Disability: Hit by a car on 16/9/14 resulting in multiple fractures to right leg, head injury and nerve damage to two fingers on right hand
Date of referral: 18th November 2014

Date of interview: **5th December 2014**

This is a summary of what you told us:
You were involved in a road traffic accident on xxxxx when you were hit by a car; you were taken to the Huddersfield Royal Infirmary then transferred to the Leeds General Infirmary for 2 operations then back to HRI. You sustained a severe leg injury which has a frame with 25 pins in. You have been told it will be 12 months or more before the injury will heal and the Consultant is not certain it will be right even then.
Prior to the accident you had been working at the xxxxxxxx as a Health Care Cleaner for the last seven years. You said you were receiving Sick Pay from work. You wanted to know what would happen when your Sick pay ran out and if you could claim any other benefits. You were also spending quite a lot on prescriptions.
You have great difficulties getting about at the moment as you cannot bend your right leg much and rely on support to get anywhere. You can get into a car or ambulance with support but not onto public Transport.

1. Financial Advice/Benefit Issues: You were not sure how much you were being paid at the moment as the sick pay is paid into your bank and you cannot access your account and you only get a bank statement every 3 months.

Advice/action: I said it was likely you would be receiving SSP and that you would need to claim ESA before it ran out which would be mid-March 2015. You can claim ESA 3 months before then but would need 1) a form SSP1 from your employer giving the SSP end date 2) a current sick note and 3) a fit note. You will try to sort these. Someone had downloaded an ESA form for you so I completed it in readiness of you obtaining the supporting documents.

We discussed PIP which replaced DLA and I explained that the DWP liked people to make the initial claim over the telephone. You said you had no credit on your mobile and could

not access a landline. I said I would make enquiries re a clerical claim. I would let you know the outcome of my enquiries by telephone.

You were not sure about your level of savings not being able to access your bank account.

2. Employment issues: You are still employed by a cleaning company based at xxxxxxx

Advice/action: You enquired about going back to work in some kind of admin role but you would need transport. We discussed Access to Work assistance but you didn't think your employer would be able to find you an alternative role. You will need to see what happens with your leg in the long-term because if you cannot return to your normal role you may need to retrain.

3. Home and Housing Options: You are living with a friend to whom you pay a contribution to the rent and other bills on a non-commercial voluntary arrangement and currently spend most of your time in your own room due to your poor mobility. Various friends and neighbours have supplied you with equipment to help you.

Advice/action: You could ask for an assessment from an OT to see if there was anything else they could provide to make your life easier.

4. Health and Support: Hospital Transport Survey.
You mentioned that prescriptions were costing you a lot of money; you had enquired about exemption on health grounds but had been told that you needed to have permanent disability preventing you from leaving home without the help of another person to qualify.

Advice/action: We completed the above survey particularly as you had experienced some difficulties with it in recent times.
Re Prescription charges, would need to check the rules, my understanding was it is a 'continuing' rather than permanent disability. Alternatively you could look at a pre-payment certificate as a way of saving money or we could complete a Form HC1 to see if you qualify for help on low income grounds.

5. Education and Training:

Advice/action: You may need to think about retraining if you are unable to return to your normal occupation.

6. Rights: You mentioned that you had recently been in touch with a Solicitor to make a claim for compensation for the RTA and that this would be done on a no win no fee basis.

Advice/action: You will chase this up with the Solicitor, but I advised that this type of case did take a long time.

7. Transport: You are unable to use public transport at present.

Advice/action: I will sort out some information on the Community Transport Service

8. Everyday Life and Access: You said you were bored at home and would ideally like to go somewhere to lessen the boredom of being confined to your bedroom all week. Transport is an issue and you would need good access to wherever you went due to the need to use a wheelchair.

Advice/action: You said that someone from Neighbourhood Schemes service had been to visit you to look at ways they could get you involved back in the community, they said they would send you some information

9.The needs of carers: N/A

Advice/action:

I confirm that the advice/information I have provided in this life plan is correct based on the information provided by the client and/or his/her representative
Adviser xxxx
Date 10/12/14
Date this Life Plan was posted to the client: 10/12/14

Further actions/advice

Date
Input
Advice/Action
December 2014 - ESA form- We will send the claim once the documentation you need is received

PIP form -I have requested a Part 1 form to be sent out
This was done on 5/12/14 once it is received I will complete it with you. You will meet the backwards qualifying criteria from 16/12/14

Prescription Charges -Temporary conditions do not qualify you for the health exemption, we could look at making a claim on low income grounds but I will need to have full details of your income

Social/Leisure - You are waiting for the Neighbourhood scheme to get back in touch with you to arrange something to make you less socially isolated.

19th December: Home Visit

Input
Advice /Action

ESA
You have obtained the SSP1 from your employer who had not completed the date that SSP runs out. I telephoned your employer who sated that you would have received 11 weeks SSP on 22nd December so I will calculate the 28th Week from there. I also asked your Employer to send you wage slips as you cannot access them on line. You had also obtained another sick note but this runs out on 10/2/15 so you will need to obtain another one before then. You are going to the bank later today to find out your Bank balance and once you have this you will phone so that I can add this to the ESA form prior to posting it to the Job Centre Plus Office at Crossfield House.

Prescription charges
We discussed completing an HC1 (low income grounds claim) but if your Income is £200 as you think than it would be unlikely you would qualify for help.

PIP
I wrote to request a clerical Part 1 form on 5th December due to the problems of phoning them. The 3 month backwards qualifying period was up on 16/12/14 as your accident was on 16/9/14. I said we could wait a while longer for it to arrive. I advised that once the second part of the claim had gone in it could take 26 weeks for it to be processed.

Alternative work with current employer

You said you had discussed with your employer whether you could do something sitting down but they could not come up with any suggestions.

16th January 2015: Home Visit
Input
Advice/Action taken
Re ESA
Completed the application form, enclosed with SSP1 and the Doctors fit note, said I would post it to JCP at Crossfield House in Halifax **(Form Posted 19/1/15)**

Re PIP, you had managed to phone the enquiry line to register your claim and had now received the second part of the claim form for completion

We discussed your health problems and I completed the PIP form, applying for both the Daily Living and Mobility components. I advised you of what would happen next and that you may need to undergo an assessment. You mentioned that you would have difficulty attending a centre for the assessment due to not being able to use transport very well and certainly not if you did not have any help. I put this on the form. **I photocopied and posted the application form on my return to the office.**

xxxxx to get back in touch once you hear anything about the ESA or PIP applications.

21st January telephone call from Client
Re ESA, CLIENT said she received a telephone call from the DWP stating they had been in touch with her Employer who said ESA was due to end on 20th Feb. This is not six months from when she last worked (15/9/14/)
Also said they would be sending her another form as she had claimed too early. She got the number from her phone could I ring them back?
From my calculation of 26 weeks SSP would end on or around Monday 16th March. Client confirmed she had had no previous sick period prior to the accident which occurred on Tuesday 16th Sept 2014 on her way to work. I said we should wait and see what form they sent and deal with it from there.

I don't understand why they are sending another form if they are saying ESA becomes payable from 21/2/14
I explained I could not ring them back because they would not give any information to me if the client wasn't with me (data protection) Will wait to see what form they send out.
Client kept saying they were sending a PIP form

I said I thought she was becoming confused with SSP and PIP. PIP was a totally different benefit and had nothing to do with her work or the date SSP ran out. I will explain this again when I go see her when the 'form' arrives.

27th January Home Visit
ESA - The DWP had sent another form out this was not much different to the downloaded one we sent previously. Client said her employer had told her SSP runs out on 4th March
Completed the form, posted with the SSP1 and the Fit note. They had not returned the wages slips so assume they will link when this second claim arrives.

PIP- Client had received a letter stating her claim had been forwarded to ATOS who may or may not need to see her. This could take 26 weeks or more
Noted. It was now just a question of waiting for the decision.
Prescription Exemption on health grounds
Client said her hospital consultant had now signed the exemption certificate so her prescriptions were now free.

Personal Injury compensation - Client said her Solicitor had been in touch to say there may be a problem with her claim as the police had not provided the relevant information at the time of her accident.

9/2/14 Telephone call from client
Client said she had received a PIP assessment appointment for Tuesday 24th February at 9am in Pudsey. She can't travel by public transport or in a taxi. She said she had phoned ATOS who told her to get a Doctors letter stating why she couldn't travel and send it to the DWP. When she asked which DWP office she was told she would be put through to the DWP but she ran out of credit before they answered.
Said I would call to collect the details at a visit on Wednesday 11th at 10am

11/2/15 Home visit
Discussed the ATOS request
Wrote down the details
12/2/15 Phoned ATOS they said the letter should go to the office dealing with her PIP claim. Phoned client gave her the address.

Client said she had now received notification that her ESA would be paid at £72.40 per week from 4th March. Advised her that she would eventually receive an ESA 50 to assess her capability for any work and after this she would go into the Work related activity group or Support group
12/2/15 later… Client phoned to say she had received the ESA50 due back by 13th March
Said I would arrange to visit her nearer the deadline date and phone her back in due course.
18/12/15 Phoned client to check on the address dealing with her ESA so I could send sick note
Sunderland Benefit Centre, Wolverhampton- posted with covering letter.

3/3/15 Home visit
Re ESA completion, form due back on 13/3/15
Discussed her health again, client said her Consultant had said her leg was now worse than before the operation. Discussed the descriptors for ESA. Completed the form, to photocopy prior to posting
Client mentioned a Working Tax Credit overpayment from 2007/08 She said she only had Tax Credit for one year and her application form was completed by someone at the Local Tax Office
Suggested she wrote and told them this and she should ask for a detailed explanation of how they had arrived at the decision she had been overpaid.

Client asked about holiday pay. She said she had 20+ days entitlement from last year that she had not taken due to her accident and had been told if she didn't take them she would lose them. How could she be on holiday if she was off sick?
She would need to check her contract of employment. Some holiday entitlement was accrued on the basis of being at work and some contracts did not permit a carry-over of holidays into another year. She could take pay in lieu of the holidays which would be more than her ESA and as this is contribution based, would not affect her entitlement.
4/3/15 Re ESA 50
Form photocopied and posted.

11/5/15 Telephone call from client
Client said that she was finally going to receive a visit from ATOS on 14/5/15 to assess her PIP claim. She will be supported by someone from an organisation called Disability Support Calderdale (Advocacy) who asked if she had a copy of her application to refer to before/during the ATOS visit.
Said I had made a copy of her claim and would drop it in to her.

13/5/15- took copy of PIP claim to xxxx's flat.

11/6/15 Telephone call from client
Client has her PIP decision she was awarded Enhanced Daily Living (18 Points) and Standard Mobility (10 Points) It is a 3 year award.
She now wants to explore the possibility of getting a Carer as she is not getting much help.
She said that she could claim CA so that she could pay an Agency to look after her.
She then went on to talk about Carers Credit (Reading further info section from PIP award letter)

The decision on the Mobility seems harsh, will discuss with client.

I explained that Carers Allowance could not be used in this way. To discuss further.
Advised this was not applicable to her
Arranged to visit her on 12/6/15 at 10.30 am.

12/6/15 Home Visit
Client had in fact been awarded the standard rate of **Daily Living** (8 points)
10 points for **mobility** as the HCP had indicated she could manage more than 20 metres but no more than 50 metres.

This was applicable to her circumstances

Discussed the criteria it was agreed I would request a Mandatory reconsideration on her behalf.
Re Council Tax. Client's landlord had received a **Council Tax Reduction** notice they were both worried that he owed the Council money
Checked the letter, he did not owe any money but they were now aware Client lived at that address and had checked the non-dependent rule.

Blue Badge, Client said she was going to Customer First today by Taxi to apply

Further queries around the information contained in the PIP award letter re **IS;PC;JSA; UC;**

Access to Work and **Tax Credits**
Advised that none of these were applicable to her at present. Briefly explained what each one was for.

12/6/15 Typed up a Mandatory Reconsideration submission for Client, posted with covering letter to Payment 3, Mail Handling Site A

3/7/15 Client called into the office
Re ESA Client wanted to send her latest sick note to JCP wasn't sure where it was to go
Copied sick note, gave copy to Client posted through internal post

Re PIP Mandatory reconsideration
Confirmed to Client that the request was submitted on 12/6/1/5 she had not received a response as yet.

3/9/15 Office appointment

Re: Income related ESA. Client said she wanted to claim this instead of Contribution based ESA as there were passports to health benefits/other through receiving Income related.
I said as far as I understood it if someone qualified for Contribution based benefits they had to claim them. Client was adamant she had spoken to JCP who said this would be ok and had sent her a form. Completed the form which Client said she would take to JCP to put through their internal mail
Re: Dental penalty charge. Client said she had now paid the cost of the dental charge and had spoken to someone at Debt recovery who said if she wrote again they would consider waiving the penalty
Hand wrote the letter for xxxxx- posted

Re PIP Mandatory reconsideration- Client told me she had received a decision which was not to upgrade the award.
Client did not wish to pursue the matter any further.

Appendix 2: Planned welfare reform changes

From April 2016

- The amount by which a tax credit claimant's income can increase in-year compared to their previous year's income before their award is adjusted (the income rise disregard) will be reduced to £2,500.
- New legislation will allow the Secretary of State to review the household benefit cap each year. Once passed the intention is to impose a cap reduction to £20,000 (£13,400 single rate) and £23,000 in London (£15,410 single rate) from April 2016.

From September 2016

- Reduction in support available as part of Disabled Students Allowance.

From April 2017

- Bereavement support payment replaces current bereavement benefit system.
- New ESA claimants who are placed in the Work-Related Activity Group will receive the same rate of benefit as those claiming Jobseeker's Allowance, alongside additional support to help them take steps back to work.
- Those aged 18 to 21 who are on Universal Credit (UC) will have to apply for an apprenticeship or traineeship, gain work-based skills, or go on a work placement 6 months after the start of their claim. Apart from certain exceptions (those considered vulnerable) they will not be allowed to claim Housing Benefit/UC housing costs element.

From April 2018

- New Support for Mortgage Interest (SMI) will be paid as a loan, to be repaid upon sale of your house, or when you return to work.

From May 2018

- Expected date for completion of personal independence payment assessments for working age claimants moving from DLA. From April 2020
- Cap on social care costs in England will be £72,000.

From October 2020

- State pension age for both men and women increases to 66. From November 2021

From April 2026

- The Government will start to raise the State Pension age to 67 in stages from this date.

From April 2028

- State pension age will be 67.

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