

Towards a Better Future Making it Work

A Report on a Project to Support the Development of Services for People with Physical Impairments in Kent



**Centre for Independent Living Kent
and
The Simon Paul Foundation**



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SECTION ONE - THE PROJECT

The Project:

Kent County Council is transforming Adult Social Care. It is important that through this process of change individuals develop a better quality of life by receiving the right services at the right time in the right way. To this end, Kent County Council's commissioning team approached the Simon Paul Foundation and Centre for independent Living Kent to work in partnership to:

- Find out the views and experiences of physically disabled adults and their families and carers living in Kent, about what is working, what is not working and what needs to change in the design and delivery of services that best meet their needs, so that this can inform strategic planning for Kent's 'Transformation Programme'.
- Research examples of best practice within Kent and other local authorities so that we do not have to 're-invent the wheel' and can learn from these projects about how KCC can improve service delivery.

The information in this report, gathered through questionnaires, meeting and talking with physically disabled adults and their carers across the County, is to be used to assist the commissioning and provision of better services which support independent living for adults with physical disabilities. This will be developed through the Transformation Programme.

The aim of the **Transformation Programme (See Appendix VI)** is for people to be at the heart of Adult Social Care Services. KCC want to work together with their partners in the NHS and organisations in the care sector, in new ways. They have acknowledged that people with social care needs want greater choice and services that are more relevant to the individual. They want people to be receiving easy to access, good quality, integrated services that help to maximise their ability to live safely and independently in their community. By 2015, the aim is that Families and Social Care (Adults) will be in a position where it will be able to operate on a reduced budget.

KCC also state that "under no circumstances must we risk making decisions on unfounded information. We will not put users of social care or their carers at risk of being without the support that we have a statutory duty to provide"

The emphasis of this project is 'co-production', involving partnership work between KCC, independent disability-led organisations and physically disabled people and their carers, in order to contribute to the effective review and redesign of services.

The key service areas KCC wished us to consider were:-

- Provision of accessible information, advice and advocacy
- Support to access employment, education or social opportunities
- Equipment, adaptive technology, housing, and transport
- Enablement, rehabilitation and training
- Personalisation, Personal Assistant services,
- Respite/short breaks
- Transition planning and support

This report is the result of our discussions with adults who have physical impairments, their unpaid carers/family and the organisations and professionals who are currently offering support or providing services across Kent:

The Authors of this report:

The Council approached the '**Simon Paul Foundation**' and the '**Centre for Independent Living Kent**', who are both independent, user-led, disability charities working with and for disabled people to carry out this work.

The Simon Paul Foundation is an independent user-led charity working with and for physically disabled people, their families and others involved in their care to empower them to live fulfilled and independent lives. The Foundation supports individuals to take more control over their lives by ensuring that they have access to free specialist information and advice about anything related to living with a physical disability. They can help clients fight for their rights to benefits and services, provide emotional support and counselling, assist them with employing and training personal carers, and planning their own package of support. They also assist clients to obtain specialist equipment or adaptations in the home, find accessible holidays and generally gain support from a network of local services.

The Foundation has over 23 years of 'first hand' experience of working in the field of physical disability and is able to empathise with the needs and aspirations of physically disabled people, because the Foundation is led by, and employs, people who are themselves physically disabled. Sometimes they can respond more sensitively and effectively than large statutory organisations.

The beginnings of The Foundation's work go back to 1986, when its Founder and Chair, Simon Hawkridge, was in a car accident which left him totally paralysed from below the shoulders. It was his battle to secure funding to allow him to leave hospital and return to live independently in his specially adapted home that inspired him to set up the Simon Paul Foundation, in order to help others in similar difficulties. Since then Mr Hawkridge has been living in the community and working from home to support the development of the Simon Paul Foundation, in his role as Chair of the Trustee Board, during which time the Charity has continued to help a large number of local people who have a wide range of physical disabilities.

All of our services are available free of charge throughout North West Kent and the majority of our clients are spread out fairly evenly across the Swanley, Gravesend and Dartford areas. We are based in fully accessible accommodation just above Swanley Library, which is well situated, both in terms of proximity to other relevant services and the local community.

A key part of our service is to promote self help by introducing the concept of 'person-centred planning'. We offer clients help with the development of individually tailored 'person-centred' plans, enabling them to help themselves by choosing and controlling the type of supports they need, and to pay for this through available funding options including their own personal budget.

Our 'drop in' group provides the opportunity for sometimes isolated disabled people to meet together, and to learn from each other's experiences in an informal setting. Our workshops have widened participants' interests and knowledge base and increased their social networks, whilst they have been able to listen to guest speakers on a wide range of topics.

The Foundation has in the past taken a lead in setting up joint-funded care packages involving Social Services, Health Services and the Independent Living Fund, as well as encouraging and supporting disabled people to employ their own personal assistants and developing a 'person-centred' approach to support planning. The Foundation also played a key role in providing accessibility advice during the building of Bluewater Shopping Centre and Darent Valley Hospital.

The Simon Paul Foundation is working together with other organisations with similar goals and values.

Centre for Independent Living Kent (CiLK)

CiLK is an independent user led organisation, set up using the expertise of disabled people to provide tailored support to people with impairments to live full, enjoyable and independent lives. They support disabled people to live independently and campaign for an inclusive society which does not discriminate against disabled people. They believe that disabled people should have the same opportunities and quality of life that non-disabled people take for granted.

They want disabled people to be able to make their own choices, have control over their lives and be able to live independently in their chosen community. It does not mean doing everything yourself, but it does mean having the support and personal assistance to do so.

The current Directors are all disabled people providing support services through staff members and a small team of volunteers, all of whom have a disability or personal experience of it; five are also personal assistant employers.

CiLK, is a Company Limited by Guarantee and a Registered Charity, underpinned by the principles of the ‘social model of disability’, which means when they talk about ‘disabled’ people, they mean how society disables people with ‘disabling’ attitudes and barriers that excludes them whatever their impairment.

CiLK provides support and assistance to people with impairments across the county of Kent. The target audience was and still is, primarily those who have expressed an interest in living independently and want to manage, monitor and pay directly for their own ‘care’ requirements using Direct Payments (Personal Budget) or other monies to do so.

Since CiLK’s formation in 2002 they have assisted Kent Adult Social Services with a conference for disabled people ‘Shifting the Balance’ and provided training on the Social Model of disability. They worked with Kent Highway Services on training and access issues, contributed to KASS Active Lives 2007-2016 document, delivered an Advocacy project for disabled people and helped developed KASS Disability Related Expenditure Assessment (DREA) guidelines. In 2010 CiLK worked with KCC, MCCH, Eastern and Coastal Kent NHS and In Control, to hold the ‘Peer Support Planning’ workshop.

Through the success of a bid to The Big Lottery CiLK purchased a mobile unit in July 2006 and, until 2012, provided information and Direct Payment support to people all over Kent and Medway, taking the service to hard to reach individuals in rural communities as well as to popular locations. CiLK now uses various existing venues to offer this valuable service.

User involvement has led to greater empowerment of individuals and groups and increased participation in and contribution to society. Disabled People’s User Led Organisations can make services more effective, relevant and appropriate for users.

Methodology

Project Framework

The framework was designed so that as many people with physical impairments as possible would get involved and have an input, including those hard to reach individuals who are not connected to existing groups or services, as well as those who are actively involved with existing services and organisations.

The way we approached this was through the following methods:

- Questionnaires
- Visiting existing support groups
- Open forums
- Providers' forums
- Individual interviews

Questionnaires

A questionnaire was devised, with the approval of Kent County Council, for people with physical impairments and/or their unpaid carers/family members to have the opportunity to give us their views about Adult Social Care Services. The questionnaire was made available through the Kent County Council Website and the link circulated through all of our members, the existing groups we are in contact with and the larger organisations in Kent, to circulate to their members. It was also available in hard copy and large print and Kent County Council assured us it would be available in alternative formats if required.

Existing Groups

Visiting existing support groups of physically disabled people gave individuals who already knew each other and felt comfortable in each other's company the opportunity to discuss these issues in familiar surroundings. We visited 13 groups across the county (See appendix IV). These groups were briefed about the project and then a discussion was facilitated which was written up on a flip chart so that the group could see what was being recorded. Conversation was steered in the direction of identified key areas but also through topics that were important to group members.

Open Forums

Five Open Forums were held in the north, south, east, west and centre of the county which enabled individuals who were not connected to existing groups to get involved. These Forums were publicised through a wide range of disability related organisations and their networks (see Appendix III) who circulated details to all their members, contacts and connected organisations. Details were also circulated to all of the SPF clients and CiLK members. Similarly, we contacted Job Centre Plus to ask them to pass on details to those harder to reach individuals whom they come into contact with.

Providers' Forums

Three Providers' Forums gave the existing service providers, professionals and organisations that are currently supporting people with physical impairments the opportunity to share their views and experiences. These were also promoted through a wide range of community and voluntary sector organisations and their networks (see Appendix III) who circulated details to all their members, contacts and connected organisations as well as internally in Kent County Council.

Providers' Meeting

We also met with a group of Case Managers and Co-ordinators from the Dartford, Gravesend and Swanley Co-ordination Team.

Individual Interviews

Individuals were interviewed on their own. These meetings were similarly structured around the key themes and the questionnaire, but additionally allowed us to get much more detail and clarity about people's opinions and experiences.

The following report is a summary of what people told us and the suggestions they made.

'Consultations' and the 'Transformation' Programme

These two issues along with financial cutbacks, were constantly raised during our initial discussions with all the people we met as we introduced this project and we have therefore included some of the feedback at the beginning of this report as a background to the project.

Current concerns

People feel that there has been a lack of communication from Kent County Council about their 'Transformation Programme'. They would like clarification about the following: -

- What it all means and what it will mean for them.
- What the aims of the Transformation Programme are.
- What the timetable is for implementation.
- Where the Health Service and Primary Care Trusts fit into this.

Nearly all the groups and individuals that we met with wanted to know why there are so many consultations happening because many people had been involved with several consultations with different departments over the years, but they had seen little or no changes being made. Some of the things people said were:-

- “There have been too many consultations”
- “Why are they happening?”
- “What will happen next?”
- “When will we start seeing the results of the consultations?”
- “KCC might be listening but they are not acting!”
- “There has been a lot of TALK about 'Transformation' but no ACTION”
- “Don't KCC/NHS know the answers yet?”
- “What are the promises for change?”

Nevertheless, people were pleased that they were being consulted because they were beginning to have the impression that KCC assumed that services for people with physical impairments were adequate. However, they wanted to know what Kent County Council will do with the feedback and whether the Council will take on board what they are saying – including the services that they say are working well. They would like to get feedback from Kent County Council about this report and how that will happen.

They were concerned that KCC may not respond to this report and that consulting with disabled people may just be a 'box-ticking exercise'.

They wanted to point out that their opinions matter:-

- “I may have a brain injury but I have an opinion!”
- “People in authority need to come and meet us and listen to us!”

The majority of people we spoke to were also concerned about the confidentiality of the process and wanted assurances that their comments will be anonymous. Without this they would be afraid to speak up. We confirmed that no individual names would be added to our feedback.

Ideas for change

1. Improve communication between Kent County Council, other Service Providers and Physically Disabled People who use their services

- Reduce 'in-house' consultations, and instead let the people who will be affected carry them out!
- KCC need to look at 'in-house' services to see if money is being wasted, e.g. too much seems to be spent on information technology and various 'consultancy' exercises.
- KCC need to plan together with people after 'consultations' and develop services together. This could be achieved by introducing a 'Joint Partnership Board' model as in other services.

Knock On Effects of Funding Cuts

People are very worried about the potential 'knock on' effects of the increasing cuts to the services that they use and need. There is the concern that cutting support and not helping people at an early stage, when they ask for help, will lead to greater problems down the line, with people needing more costly 'critical' services, as their physical and mental health deteriorates through lack of support.

- The major issue is cutbacks.
- Government and Local Councils give with one hand, then take back with the other.
- All these cuts will impact on specialised services, the disabled individual and their family (unpaid) carers – who may end up in hospital or in nursing homes - especially when people are discharged too early from hospital with inadequate support or planning.

Ideas for change

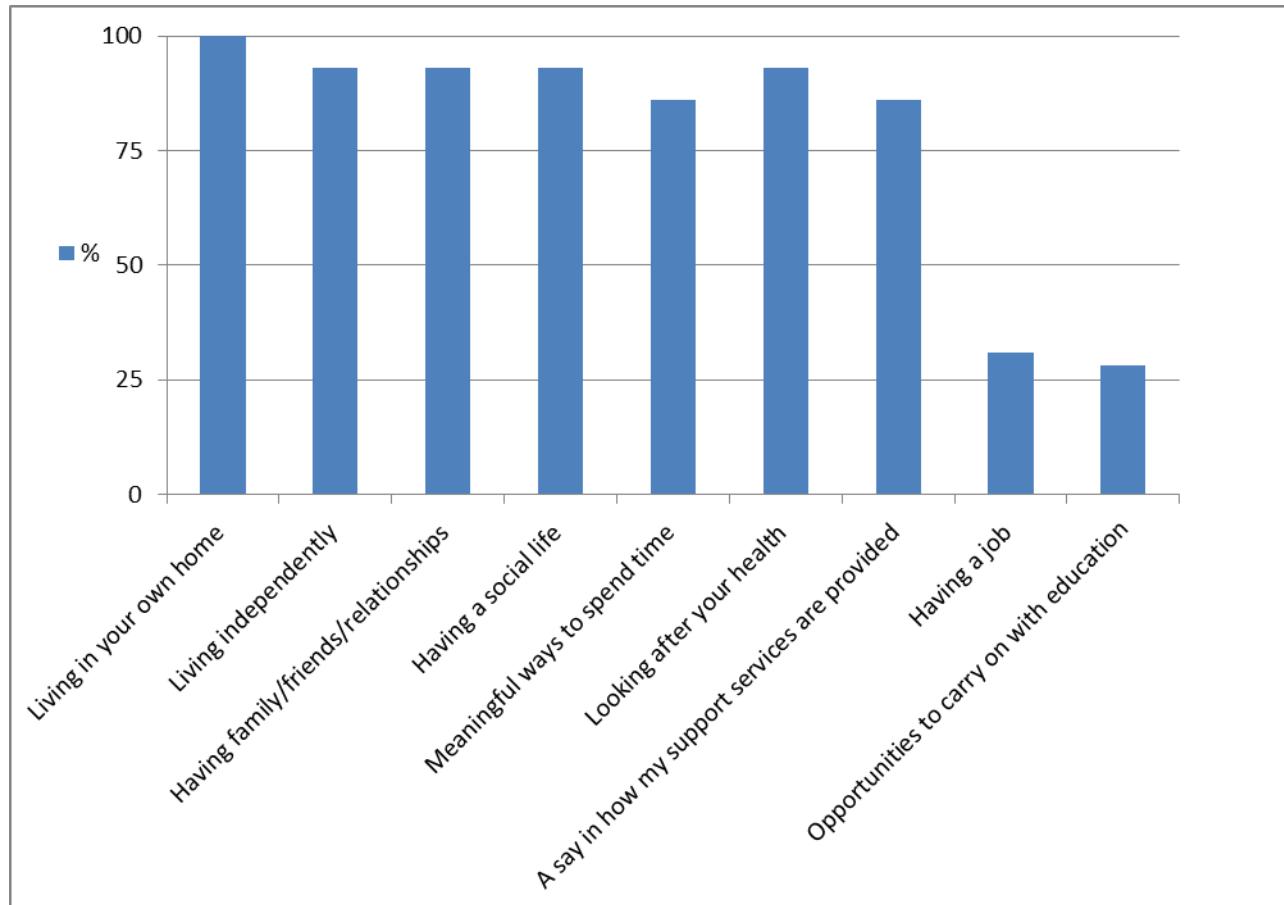
1. Kent County Council needs to work with other Service Providers and Physically Disabled People who use their services to design appropriate and relevant services

- More people in authority need to spend time with Support Groups and Resource Centres in order to understand their needs. Senior Managers should come down to meet everyone, promote changes and motivate staff.
- Physically Disabled People need to be able to speak directly to 'the top' and Service Managers and Disabled People need to talk to each other about how best to manage cuts. KCC needs to be honest and truthful with them about what will be cut and why. KCC needs to look around and see where money can be legitimately spent, rather than just cutting disability services and benefits. They need to evaluate the cost/impact if crucial services are cut and people end up in hospital or residential care homes.
- KCC needs to work with the NHS regarding funding services jointly.
- KCC needs to develop more 'preventative' services.
- Psychological and emotional support is needed now for physically disabled people and their families.

Independent Living – What Matters Most (Please refer to Section 5 and Appendix II)

We feel that it is important to set this report within a set of core values and common identified needs, as this should serve as the basis for future planning of services:

In the questionnaire we asked Disabled People what is most important for them to be able to have a good quality of life. The following graph shows the ‘very important’ and ‘important’ responses received. While the questionnaire represents only a small number of the total people we spoke to, the response did reflect the feelings of the majority.



The Disabled People's Movement has identified 12 ‘Pillars of Independent Living’ - the areas it believed to be the very cornerstones of independent living in our modern society.

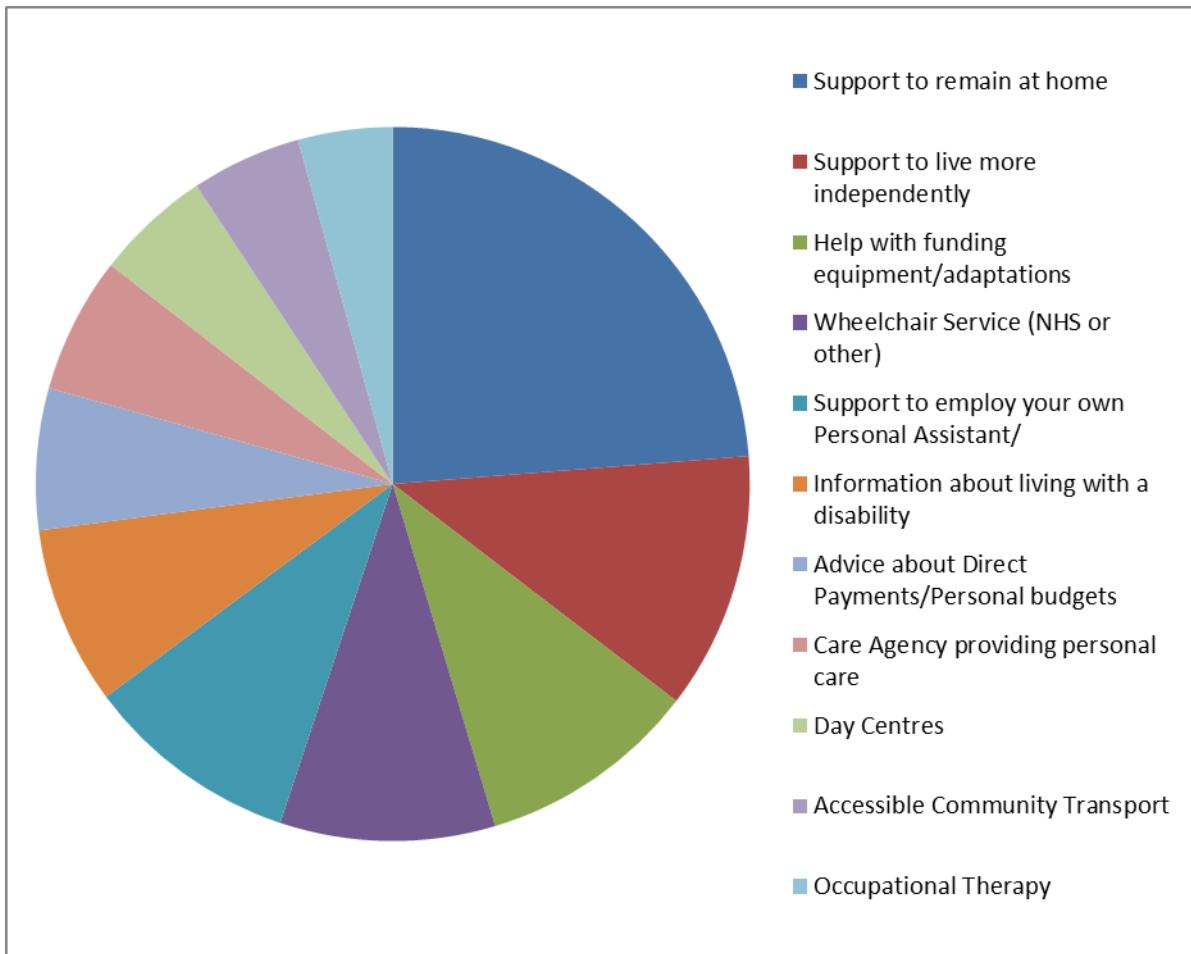
These basic needs were:

- Full Access to our Environment.
- A Fully Accessible Transport System.
- Technical Aids – Equipment.
- Accessible/Adapted Housing.
- Personal Assistance.
- Inclusive Education and Training.
- An Adequate Income.
- Equal Opportunities for Employment.
- Appropriate and Accessible Information.
- Advocacy (towards Self-advocacy).

- Counselling.
- Appropriate and Accessible Health Care Provision.

Judging by the responses and feedback we have received these are still relevant today, with the addition of family, friends, relationships, having a social life and having choice and control.

We also asked where they felt priority for funding needed to be, and their feedback also reflects the above 12 basic needs which are very much in line with what the majority of people were saying.



Therefore, we conclude that while the 12 basic needs are fundamental in allowing a person to live an independent life, we acknowledge that people feel that the following 10 priorities are pivotal:

- **Living in your own home.**
- **Support from family and friends.**
- **Paid support – employing your own personal assistant.**
- **Appropriate healthcare and counselling, if needed.**
- **An adequate income.**
- **Necessary equipment, technical aids and housing adaptations.**
- **Expert information, advice and advocacy.**
- **Accessible transport and an accessible community.**
- **Equal opportunities for education and leisure.**
- **Equal opportunities for employment.**

Transformation Programme

Our understanding of the Adult Social Care Transformation Programme – ‘Blueprint and Preparation Plan’ dated May 2012 and ‘Bold Steps’ dated December 2010, demonstrate that Kent County Council wants to:

- Focus on prevention and targeted interventions
- Ensure that services respond rapidly and are more effective
- Support carers and empower individuals to do more for themselves

They see this as an opportunity to transform Kent County Council and social care in Kent. They believe that this will empower more people to self-manage and will create a sustainable business.

About 750 stakeholders took part in the engagement activities for the Transformation Programme and six key themes were identified. These became KCC’s key principles:

- **Prevention, independence and well-being**
Enabling people to find solutions that meet their needs.
- **Support recovery, encouraging independence**
Support that maximises the opportunity to recover prior to any long term care decisions
- **Support at home and in the community**
Support and activities that encourage independence and prevent social isolation.
- **Place to live**
More options for people to live independently where they choose.
- **Every penny counts**
Providing value for money in everything we do.
- **Doing the right things well**
Ensuring the right processes are in place and applied consistently and effectively.

According to the ‘Facing the Challenge’ document, this year Kent County Council will need to cut its spending by £60 million. They think that with better procurement, increased prevention and improved partnership with the NHS – with joint commissioning on Health and Social Care services - will result in better outcomes for Kent residents at a lower cost, while also increasing the charges for services.

'Think Local Act Personal' – 'Making It Real' (www.thinklocalactpersonal.org.uk)

'Think Local Act Personal' (TLAP) is a national cross-sector leadership partnership focussing on maintaining the impetus towards personalised, community-based social care. The partnership brings together people using social care and family carers with central and local government, major provider bodies, third sector, voluntary and other key sector groups. It is complemented by the support of many additional organisations and initiatives and links strongly to regional and local groups concerned to support personalisation.

In April 2011, it committed over 30 national organisations to work together and to develop, as one of the key priorities, a set of 'markers':-

- Ensuring people have *real* control over the resources used to secure care and support.
- Demonstrating the difference being made to someone's life through open, transparent and independent processes.
- Actively engaging local communities and partners, including people who use services and carers in the co-design, development, commissioning, delivery and review of local support.
- Ensuring that leaders at every level of the organisation work towards a genuine shift in attitudes and culture, as well as systems.
- Seeking solutions that actively plan to avoid or overcome crisis and focus on people within their natural communities, rather than inside service and organisational boundaries.
- Enabling people to develop networks of support in their local communities and to increase community connections.
- Taking time to listen to a person's own voice, particularly those whose views are not easily heard.
- Fully consider and understand the needs of families and carers when planning support and care, including young carers.
- Ensuring that support is culturally sensitive and relevant to diverse communities across age, gender, religion, race, sexual orientation and disability.
- Taking into account a person's whole life, including physical, mental, emotional and spiritual needs.

These markers are being used to support all those working towards personalisation and can help organisations check their progress and decide what they need to do to keep moving forward to deliver real change and positive outcomes with people.

The result was 'Making It Real' a framework developed by the whole partnership, but very much led by members of the National Co-production Advisory Group, which is made up of people who use services and carers. 'Making It Real' highlights the issues most important to the quality of people's lives.

Councils and organisations should sign up to 'Making It Real' as a way of helping them to check and build on their progress with personalisation and also as a way of letting others know how they are doing – especially their local community and the people they serve.

We recommend that Kent County Council signs up to this!

SECTION TWO - Summary and Recommendations

INFORMATION AND ADVICE

The biggest issue coming from our discussions with disabled people and a key factor in all of the other areas of concern that were raised is the basic lack of useful information and advice, together with poor communication, which prevents people with physical impairments from being connected to key services, benefits advice and specialist supports that would enable them to live more independently. The people who we spoke to were very clear about what they want and how the current provision of information and advice, on both a national and local level, is falling short. The majority of people found that the official Government information was too difficult to understand, unclear and complicated. Information was primarily available on the Internet with no one to talk to clarify how this applies to their individual situation.

For those who acquire their condition and impairments there is a lack of information from Hospitals at the point of diagnosis about what happens next and about how the Adult Social Services procedures work. They need to know where to go or who to approach to get the information and advice that they need, as well as support to help them to navigate their new situation. They commented that the promotion of information is poor. They don't know who to ask or what to ask for and are left "not knowing what you don't know!"

People commented that the current provision of information was not readily available in the variety of accessible formats that are required. They are finding that there is too much emphasis on Information Technology and pointed out that there are still many people who do not have access to a computer or the knowledge to use the Internet. Of those who do use the Internet they remarked that the Kent County Council website was very hard to navigate. People felt that there was no central point for information where they knew that the information they would receive would be up-to-date and accurate. Almost everybody said that they need 'experts' to talk to 'face to face' - advisers who can explain the system to them in a way that works for them, so that they are able to ask for clarification if there are any elements that they do not understand.

There is also a problem of mistrust of Kent County Council and Social Services that needs to be addressed. People distrust the information that they are being given. There is a feeling that a number of Case Managers themselves do not know what is available or what people are entitled to, but of particular concern is a feeling that information is purposely being withheld, being difficult to access and being made overly complicated, in order to stop people from accessing services or benefits - as a cost saving exercise.

People complained that there are not enough independent organisations who can offer this type of information and advice or that those organisations that do exist do not have the resources to meet the demand for their services.

Recommendations

- People want clear, jargon free, relevant, accurate information in accessible formats and people to talk to who are independent experts and who can explain everything to them in a way that they can understand. For this to happen there needs to be a central point, an organisation that people feel confident will have all the latest up-to-date information. It would need to be fully staffed and have direct telephone lines.
- An information service needs to be supported by a dedicated website to signpost people and to act as a guide through Social Services but also all aspects of life lived with a disability, whatever that disability may be.

- Please see 'Best Practice' example in Section 5 for details of 'The Hub' - an information service in Surrey that is working well. This model would be a recommendation for KCC to replicate.

ADVOCACY

All of the groups and individuals noticed that Kent County Council has not formally commissioned an 'advocacy' service specifically for people with a physical impairment, and that this is a need which is likely to increase with the changes that are coming for disabled people both nationally and locally. Many people with physical impairments are telling us that they need and want someone to stand up for them and speak up for them. It is a misconception that people with physical impairments can always speak out for themselves.

Day Service groups are found to be a good source of advocacy as it allows for a group of people to stand together with and for each other, but there is a worry that the changes to these services will further break up these groups and therefore the peer advocacy support that they provide. Centre for Independent Living and the Simon Paul Foundation both offer advocacy support and encourage self-advocacy. However with limited funding, these services are under threat of closure.

Recommendations

- People are aware that there are good advocacy services in Kent, but these are generally available to people with a learning disability or a mental health condition. They do not understand why this provision is not extended to meet the needs of people with physical impairments. It would be difficult to simply widen the remit within the existing commissioned advocacy provision as the skill set and expertise required will differ from those required for learning disability and mental health. However, we would see this as an opportunity for partnership working so that Learning Disability organisations, Mental Health organisations and other Disability organisations could work together with a team of advocates across all these user groups taking note of the existing advocacy service models. This should be connected to a central Information Service.

PEER SUPPORT/DISABLED PEOPLE'S ORGANISATIONS/CHARITIES

Everyone whom we contacted told us that their main source of information, advice and support came from their peers – i.e. other people with physical impairments. People 'who have been there and done it', who understand the challenges and concerns and are the ones who can truly appreciate their situation. Disabled people's organisations and user-led organisations offer peer support, advocacy and share information. Disabled people and providers see that they are picking up the shortfall of the County Council's commissioned services. However, everyone is aware that they are also experiencing cuts at a time when the demand for their services is rising.

Recommendations

- These organisations are seen to be independent from Kent County Council and are trusted by the people who use them. Therefore, they are seen by many as the best place to go to get the information, advice, advocacy and support that they need. Often this is delivered by other disabled people who have the expert knowledge, either through first-hand experience or training, to give accurate and relevant advice in a way that the recipients understand and feel comfortable with.
- People would like financial security for the existing day services and support groups that

they attend so that their channels of peer support remain open. We stress that these are very important due to the lack of viable alternatives at this stage (See Day Centres).

- They would also like these user-led organisations to be giving training to the professionals who provide services, so that they can learn how to treat people who have physical impairments appropriately. In order to do this further investment is required into development partnership working between the independent organisations. This way they will be able to provide consistent, joined-up services to all the different user groups and be able to better tackle the many instances of complex and multiple care needs - for example, an individual who has a physical impairment and mental health issues.

ASSESSMENTS

People we spoke to told us that they have been overwhelmed by the number of 'assessments' and 'reassessments' that have been carried out on them, with the prospect of further assessments being imposed when the new benefits system of 'Personal Independence Payments' is introduced in April 2013. They feel that this will actually cost taxpayers more money.

They told us that assessments are far from 'holistic' or 'person-centred' as they rarely have control over a process which seems complex, bureaucratic, harsh and unfair and only addresses a limited number of basic support needs. Questions are often confusing or misleading, and at times seem to be trying to trip people up or catch them out. Additionally, Assessors appear to be poorly trained, lacking in up-to-date information and insensitive to the realities of living with a disability. Disabled people do not feel supported during and after this process, because assessments create stress, anxiety and fear, both in terms of having to constantly go over what they cannot do because of their disability and having Assessment Officers meticulously checking and rechecking their finances, including the disability benefits they depend upon. Sometimes they feel that this is an invasion of privacy and that they are being targeted by harsher assessment criteria. All this can have a major impact on their mental and physical health. To add to this, organisations that can provide support are experiencing cuts in their funding (e.g. Citizens Advice Bureau).

Locally they feel that hospital discharge and follow-up planning is also of a poor standard, if it happens at all. The impact of harsher assessments, together with an increase in KCC charges for Adult Care Services, has led to some disabled people being unable to afford enough care support hours or to continue to attend day services - which can result in increasing their health problems and isolation. To add to this, in a wider context, the new harsher government 'Work Capability' Assessments are also deemed as unfair and complex, whereby disabled people are regularly being wrongly assessed as being 'fit for work', as demonstrated by the number of successful appeals.

Recommendations

- Disabled people need clear, easy to understand, jargon-free information about the various needs assessment and financial assessment frameworks, and for this to be available in different accessible formats.
- The assessment process should be simplified and the number of assessments should be reduced so that there is less risk of duplication.
- Case Managers and Assessors need 'disability awareness' training and should themselves be well informed about the assessment process and the range of disabilities which this covers.
- KCC should make available clearer documentation about their eligibility rules for services especially Direct Payments and their Charging Policy.
- Appropriate support and advice should be available from independent disability-led

organisations to challenge unfair assessments.

SUPPORT PLANS

For some people 'person-centred' plans have been very helpful, but many people we spoke to do not have support plans which are meaningful, on-going and address the support they require to deal with the difficulties they face. Support from family members/unpaid carers is often taken for granted. Plans are generally not 'person-centred' where the agenda and structure should be led by the disabled person, but instead the process is led by Case Managers or other professionals, within a framework that is standardised not individualised, and essentially budget-led rather than needs-led. Identifying support needs around personal care often does not acknowledge that such tasks take time and cannot be rushed or ignored. Because supports are often not on-going or even proactive, this often results in crisis management over situations which might have been prevented by good quality person-centred planning. Please see Section 5 for a best practice example.

Recommendations

- The system of care planning and support planning should be reviewed so that it is genuinely 'person-centred', less bureaucratic, needs-led and not purely budget-led, and controlled by the disabled person - who is the expert rather than the 'professional'.
- The person-centred planning framework should be available in a range of different accessible formats, be easy to understand, and only require a minimal amount of paperwork.
- There is also need for KCC to promote and provide training in 'Person-Centred Planning' for both their staff, including Case Managers, as well as disabled people and their family/carers. This training could be delivered by independent user-led organisations including trainers who are themselves disabled and have experience of person-centred planning.
- Regular reviews should also be implemented to prevent an individual's situation deteriorating to crisis point.

CASE MANAGERS

People seem to have lost faith in Case Managers and the Case Management system. They feel that there is a lack of information and clarity about the role of Case Managers, whose numbers and availability seem to be decreasing. Liaison between Hospital Case Managers and Community Case Managers has been poor in some instances. There has been a lack of continuity due to the fact that few people have a named/allocated Case Manager. Added to this they are constantly being changed or relocated after major reorganisations of Case Management/Coordination and Assessment Teams. Sometimes people are not informed that their Case Manager has left or has closed their file. The service tends to offer short-term 'crisis' support, rather than preventative work, with some reviews not being carried out regularly.

They feel that a number of Case Managers are poorly informed about benefits and services relevant to disabled people, are not 'person-centred' in their approach and can even have a negative, patronising attitude towards them. People feel that it can be 'a lottery' over whether you get a 'good' or 'bad' Case Manager. A number of people are also very happy with the support they have received.

They do appreciate that recent departmental reorganisations have resulted in overworked Case Managers with ever increasing case-loads and longer waiting lists. Also due to the centralisation of the Co-ordination and Assessment Teams, many Case Managers are not based locally to where many of their disabled clients live.

Recommendations

- The role of Assessment, Co-ordination and Case Management Teams, including Hospital Case Managers as well as 'Care Navigators' needs further clarification to the public.
- Case Managers should be well informed with good training and support – they need to know what they are doing and what clients are entitled to. KCC should ensure that Case Managers have a holistic, person-centred approach to their work and positive attitude to disabled people.
- The recent reorganisation of Case Management Teams should be reviewed to ensure that the new teams have the capacity to meet the increasing demands on their services, to ensure that they do not become too overloaded and consequently cease to function effectively.
- People have told us that they need to have Case Managers more locally based, have more service continuity, better access to Case Managers, and consistency through dealing with the same person and be properly informed when there are changes or their file is 'closed'.

STATE BENEFITS

Throughout our conversations with individuals and groups they have expressed frustration and worry about major changes being made to the benefits system on a national level, particularly with the introduction of the 'Personal Independence Payment' and 'Universal Credit'. They feel that they are not being kept informed and updated about these changes and how it will affect them.

Since the changes to Employment Support Allowance and the Work Capability Assessment, Citizens Advice Bureau and other independent organisations are being stretched, with more people wanting help and support, so getting an appointment is getting harder. They imagine that this will get worse as demand increases and resources decrease.

They are also very aware of the negative public attitude and perception that people on benefits are all 'scroungers'. People feel that many genuine claimants are being punished as a consequence of convicting a few benefit cheats. They find this very unfair.

Recommendations

- We are aware that these are mainly national issues, but on a local level disabled people who are in genuine need want the information, advice and support to make sure that they receive all the benefits that they are entitled to - so that they have a reasonable quality of life and consequently avoid deprivation leading to ill health. If this does not happen they want the advocacy services and support to help them to appeal wrongful decisions.
- They would like the existing Benefits Advisers and Assessors to have better disability awareness training - preferably by disabled people. Again, this highlights the need for good Information, Advice and Advocacy Services.

DIRECT PAYMENTS

Many of the people we spoke to were not aware of the Direct Payments system and often those who were thought that it would be too complicated and difficult, so did not want them. However, the vast majority of current Direct Payment recipients, especially disabled people employing Personal Assistants, felt that Direct Payments gave them choice and control over their own lives. There seems to be a real lack of positive promotion of Direct Payments within Social Services and from talking to Service Providers. In some cases, there is a lack of understanding about how they work and the support that is available for Direct Payment recipients.

Recommendations

- People want clear rules and clarification about who is eligible for Direct Payments and how they can be used. At the moment this is often at the 'discretion of the Case Manager' which may be beneficial to some but not to others.
- When a Direct Payment is used for employing Personal Assistants, people need the support and information to do this, and to be told of the organisations who are there to provide this. Current recipients would like to have clarity over the rates agencies and services can charge an individual and the Direct Payment value needs to reflect this. It also needs to rise in line with the minimum wage.
- The individuals who employ their own Personal Assistants have raised the problems that they face when they need emergency back-up, for example if a Personal Assistant is unwell. They have suggested that they would benefit from the creation of a special Personal Assistant Agency. Some people remembered that KCC had set up such a service many years ago. They pointed out that this could also help with the recruitment process of employing their own support which would enable more people to use Direct Payments in this way, instead of relying on the more expensive Care Agency cover.

PERSONAL ASSISTANTS

Several of the people we spoke to are Personal Assistant employers, using their Direct Payments to employ their own Personal Assistants for all their support needs. On the whole they are very positive about this. They pointed out that initially they needed support to show them how to become an employer and how to deal with the responsibilities and training that this brings but once their PA support is in place they find that they achieve the level of choice and control that they want.

Knowledge, information and advice about how Direct Payments work and how they can be used is lacking and Case Managers are not positively promoting them, which makes people believe that they are too complicated and difficult. Support services are required to offer the training and information that people need to become an employer.

People pointed out that the financial amount of the Direct Payment has not been increasing in line with the minimum wage; therefore people are being forced to reduce the number of hours they can afford to pay for.

Some people who have Personal Assistant cover still need to rely on Care Agencies for emergency back-up, i.e. to cover Personal Assistant sick leave or holidays. This raises concerns over Care Agency charges, because Direct Payments are set at the lowest level but Care Agencies treat Direct Payment recipients as private clients and therefore charge a higher rate.

Recommendations

- Allocate more resources to prevent disabled people being placed into residential care, by providing more support for individuals to employ their own Personal Assistants and remain at home. It costs much more to place a disabled person in a nursing care home than for them to be properly supported to live independently at home, especially if they have a higher level of disability. KCC needs to get this right to prevent higher costs in the future.
- Address the high cost, discontinuity and inefficiency of funding Care Agency staff as opposed to supporting a disabled person to employ their own team of Personal Assistants. KCC needs to encourage greater uptake of Direct Payments and Personal Budgets in order to facilitate this. It works better for a disabled person to employ their own Personal Assistant because they manage the recruitment, develop the contract and determine the role of their Personal Assistant. As well as it costing less than Care Agency staff, it is less bureaucratic and maintains the principle of personalised supports.
- Create one or more Personal Assistant Agencies to meet the needs of emergency cover and to help with the recruitment process, as well as help with training and personnel issues.
- Disabled people would like better support services for Direct Payments and employing Personal Assistants. Supporting everything from recruitment, retaining staff, payroll and accounting. See Section 5 for best practice example.
- They would like a greater emphasis on Peer Support and to have the necessary services run by Personal Assistant employers.
- A review of the costing of Direct Payments is required and changes need to come into force so that Direct Payments are in line with the minimum wage.
- Case Managers need to have further training, incorporating training by Disabled People who are receiving Direct Payments and employ their own Personal Assistants.
- Case Managers and Disabled People need clear guidelines as to how Direct Payments work and how they can be used so there are less grey areas and fewer decisions left up to the discretion of the Case Manager.
- Clear guidelines need to be given to service providers such as Care Agencies, so that they are aware of what they can charge for their services.

PAID CARERS/CARE AGENCIES

Most of the people we spoke to have had experience of, or are receiving, support from paid ‘carers’. Problems have been raised about the Case Managers’ assessments of needs and the number of care hours required to meet these, with Kent County Council’s approved Care Agencies and their staff. Carers are expected to do far too many tasks in a limited time, which has been inaccurately estimated by Case Managers. On top of this, carers are expected to write records and Care Agencies are not allowing for staff travel time, so that carers are being forced to rush through their work with each client. Although basic tasks are being carried out, clients are complaining that this is at the expense of a real personal, caring service.

People believe that agencies do not employ enough carers in a bid to save money, which results in carers having an unmanageable workload. Their experience is that carers are unable to support people to do things for themselves as they do not have the time. It was also raised by the majority of people and Care Providers that there is a real problem with retaining staff. Carers are on very low wages and under a lot of stress, so staff turnover is high. This leads to a lack of continuity of care.

People tell us that while most staff have the correct practical training they frequently lack the sensitivity to treat disabled people with dignity and in the way different individuals would choose to be treated.

Many people also pointed out that while they require support with their personal care, they also require support with such things as housework, paperwork, shopping etc., but are being told by Case Managers that they must rely on family and friends to carry out these tasks. For some people this is unrealistic, if not impossible. Care Providers told us that the rate they are paid by Kent County Council is far less than the cost of providing the service. They are unable to retain staff and all new staff need training, which is an additional cost. Therefore, the service they provide has to be very basic and they are being forced to charge private clients a higher fee to make up for this.

Recommendations

- People want a more personalised standard of care where carers have the time to talk to the client, to support the client to do things for themselves and to encourage their independence. They also want a more 'holistic' approach to their care with consideration given to their needs beyond basic 'personal' care. Therefore, there is a requirement to review the assessment process, to take into account a realistic time-frame for carrying out support and ensuring that Care Agencies can afford to provide a high quality and 'caring' service.
- Our recommendations for how to approach this would be to encourage a greater uptake of the more cost effective Direct Payments so that the individual can have choice and control over the support that they receive. This will require further investment in Direct Payment support and support to employ Personal Assistants. It will also require further training of Case Managers about Direct Payments so that they can positively promote their uptake.

HEALTH AND REHABILITATION

People are confused about what is 'health' and what is 'social care' and which services come under which department. They feel that their needs come under their own heading of 'life' and this cannot be split neatly into 'social' care and 'health' care. Yet others think that combining them will be difficult.

In hospitals, at the point of diagnosis, people are not getting enough information. When they are discharged there is often a feeling that they are on their own, and that there is a lack of 'follow-up' in the community, particularly with services like physiotherapy. There were concerns about the lack of consistency and continuity and that there is no on-going system of care support. Many people did not see a Case Manager while they were in hospital.

People fear that rehabilitation, and enablement (including physiotherapy) are lacking, which they feel is short sighted. Good rehabilitation services could diminish the need for more complex (and costly) services including readmission into the healthcare system.

Experiences of GPs vary considerably but many people are reporting that their GP does not have the time and/or knowledge to 'signpost' disabled people or offer information or advice.

Recommendations

- People would like a structured 'pathway' through follow-up services after being discharged from hospital so that they can return to living independently. They would also like long term and ongoing support so that they can maintain their independence, and so avoid future decline and return to a situation where they need more complex (and costly) services.
- A good Information Service would mean that there would be less need for GPs to provide this, leading to less take up of the GPs' time. We understand that there is a scheme being piloted in some areas of Kent by the Health and Social Care Coordination Team, providing signposting and referral services from GP surgeries. (Also see 'Social Prescriptions' Page 52)

RESPITE SERVICES

People reported that there is a lack of information about 'respite' services and some confusion about what 'respite' can be provided. Respite can usually mean 'a break' for the disabled person in the way of a holiday or 'placement' in residential care. There are not enough accessible, affordable, supported holidays for physically disabled people and a lack of adequate funding, unless the disabled person is prepared to be placed in a staffed respite care facility with other disabled people. Only funding for an individual's paid carer is provided through Direct Payments (for just one week per year), but not the cost of the holiday itself, or for unpaid family/carers to accompany them. Family carers need a break too.

Recommendations

- There is a need to clarify the role and function of 'respite' services so that both the disabled person and their family carers can have regular 'breaks'. More funding for this should be made available. Respite serves as a preventative measure to ensure that unpaid family/carer support does not break down, so preventing the disabled person having to be placed into residential or alternative care.
- A wider range of services providing 'respite' or rather 'holiday breaks' should be made available, instead of placements in institutional residential care homes or hospitals. This can range from fully accessible holidays (with an option for families to be supported to go on holiday together with their disabled relative) to providing extra paid carer supports for the disabled person to remain at home whilst their relative has a holiday.

AIDS AND EQUIPMENT

There is a recurring complaint that there are unacceptable delays in processing applications for 'aids to daily living equipment' or grants for housing adaptations, especially wheelchairs, adapted bathrooms and kitchens. Smaller items such as 'grab' and 'bath rails' seem to be fitted quickly whilst 'splints' can be difficult to obtain. All major adaptations and equipment have to be processed through a large complex bureaucracy with too much 'red-tape', and people appreciate that it is not always the fault of individual Occupational Therapists or Housing staff. However people also felt that there was occasionally a lack of expertise, with bad advice being given on the range of alternatives and design issues.

There are long waiting lists and sometimes people can wait many months to get the right wheelchair and years for some housing adaptations to be installed. This forces some people to return home from hospital before equipment arrives or adaptations are installed and even have to borrow money to pay for these or other essential equipment such as a wheelchair!

There are clearly very limited funds available from local district councils and the NHS, whilst there is also a lack of accessible or adapted housing. Once again there appears to be a 'postcode lottery' in terms of who gets a better service, but clearly some districts do provide a better service and seeking help from disability organisations can be an advantage. The relocation of the NHS Wheelchair Service in particular has isolated it from the local community, whilst the service continues to deteriorate and is under-resourced.

People feel that they are not given enough choice and that proposed adaptions are not fully discussed or even agreed with them - for example, one person had an indoor lift installed but was not consulted about the implications this had on their kitchen or the necessary re-organising of doorways in their home. People recounted how they were often made to feel that only the professional 'knows best' and that the individual preference of the disabled person, and in some instances their family (who share the home), were ignored.

Recommendations

- There needs to be a review of the complex, bureaucratic, lengthy and costly process of applying for Disabled Facilities Grants as well as the provision of specialist equipment, **including wheelchairs**, in order to make it more efficient. Limited funding and resources need to be allocated where they are most needed, but priority should be to reduce waiting times to prevent disabled people having to struggle to manage an acquired disability, without adequate aids or adaptations to their home. This is clearly putting some disabled people (and their carers) at risk of injury and increased dependency.
- Initial assessments for types of aids and housing adaptations need to be more accurate so that Assessors get things right the first time – fitting the wrong adaptation means having to return and refit them, which is wasting money. KCC should also explore cheaper quotes from a wider range of contractors and review their 'approved' list regarding 'value for money'.
- Case Managers and Health Care Professionals should aim to fund high quality equipment and adaptations to facilitate independent living, as well as provide proper on-going support, follow-up and monitoring etc.
- The Council could save money by working with independent disability organisations such as REMAP, who design and provide individually tailored aids and adaptations for particularly complex problems.

DAY SERVICES

Historically there has been a difference of perception and philosophy about what makes a good day service between KCC and many disabled people who are using day centres. Whilst there continues to be a very limited range of alternative, accessible community facilities that can replace the need for traditional day centres, this will continue. People have experienced the closure of their day centre before equitable or better alternatives are established. Those alternative community facilities which are available - such as leisure centres – are not always fully accessible and do not provide on-site support to disabled people who need this in order to participate and enjoy these facilities. There is also a lack of meaningful daytime opportunities to interest young people.

People feel that KCC do not value the services and supports day centres are providing (with limited resources). Many disabled people we spoke to said that these are the only places where they can escape from isolation at home, give their family/carers a break, get support from each other, have social interaction, and enjoy some group activities. Staff at many day centres are nevertheless trying to do what they can to develop community opportunities for members to expand the range of options and opportunities to follow interests and leisure pursuits and even employment. This also raises the issue of choice, as many disabled people feel that the Council is not listening to what they are saying about their needs and wishes about how they prefer to spend their time during the day. It is ironic that some day centres are actually unable to take in individuals who have severe physical disabilities requiring a higher level of support because they do not have enough staff to provide 'one to one' support.

On the other hand, some people feel that the activities available in some day centres in Kent are very limited, as well as the facilities not being fully adapted for disabled people. This has forced some Kent residents to look outside the County for the quality of day services they require, in spite of transport not being included in their Direct Payment.

Harsh financial assessments for Direct Payments together with increased charges for accessing day services are reducing numbers and allowing services to run down towards possible closure. If disabled people lose their day service place, then they have little in the way of available meaningful daytime pursuits provided by accessible facilities and they will be stuck at home and isolated, with obvious consequences for their mental and physical well-being.

Recommendations

- KCC should acknowledge that the closure of traditional day centres should not go ahead before the proper planning and development of alternative fully accessible community facilities. Until this is complete, they should ensure that the current, often temporary, day service facilities are properly funded, fully accessible and provide a range of meaningful activities, for all levels of disability.
- KCC should work with local community facilities and private businesses to ensure that education, leisure and other facilities are upgraded to full accessibility standards, and that disabled people are properly supported by properly trained staff with affordable and accessible transport provision - perhaps by expanding the Direct Payments scheme.
- KCC should acknowledge the value of a number of existing day centres, where staff do their best to provide a reasonable range of activities, whilst members highly value the peer support, camaraderie and social networking these provide. Many members told us that this reduces their isolation as they often have 'nowhere else to go'.
- KCC Charging Policy should be more flexible, so that strict financial assessments do not exclude disabled people from being able to afford to attend day services, when the only alternative is to remain at home with little to occupy them.
- More people should be in receipt of Direct Payments to employ their own Personal Assistants so that they always have the necessary support to access whichever services they choose.

ACCESSIBILITY

In spite of the implementation of relevant sections of the Disability Discrimination Act 1995 and the Equality Act 2010 aimed at addressing issues such as accessibility to public buildings and community facilities, disabled people report that there is still a major shortfall in accessible buildings and facilities with the full range of ramps, dropped kerbs, lifts, wide doorways, automatic doors, large disabled toilets, comfortable well-located cinema seats and swimming baths with a warm hydro-pool etc.

Whilst many facilities are now more accessible (e,g 'Bluewater' shopping centre) there appears to be a lack of disability awareness by town planners and architects, demonstrated by the lack of understanding about the range of access needs of a variety of disabled people with very different mobility difficulties, as well as visual and hearing impairments. Disabled people feel that this is the consequence of planners' unwillingness to sufficiently use the expertise of disabled people themselves for advice about interior and exterior building design.

There is also lack of staff training in disability awareness at key public services and business premises and a limited number of up-to-date local guides providing publicity about what is easily accessible.

Recommendations

- KCC should continue to improve exterior and interior accessibility to public buildings and community facilities. They should increase their use of the expertise of disabled people, especially local 'Access Groups' to design and review access requirements.
- Town planners, architects and staff on duty in public buildings should have received a good standard of 'disability awareness' training.
- KCC should work together with disability organisations to create paid roles to 'police' disability discrimination in the community.
- Access guides to local facilities should be regularly published and updated.

TRANSPORT

Transport remains an issue for many people. Public transport, while improving, still has a long way to go. Some basic disability awareness training would be a good start, along with improvements to access at more railway stations and also fitting more raised kerbs where they are needed.

People want more flexible and easily available community transport which is not limited to hospital appointments or impractical times and just a few areas. People need travel costs incorporated into their Direct Payments and public transport networks need to consider day service locations in their routes.

Recommendations

- We understand that this is mainly a national issue but people feel that until transport and access to the community is improved it will remain a huge barrier preventing people with physical impairments from being fully integrated into society, particularly in the many rural parts of Kent.
- A step forward would be to ensure all transport companies, including Hospital Transport, are fully aware of their obligations to disabled passengers and ensure that all front line transport staff receive disability awareness training.
- Until the public transport network is improved there needs to be greater development and publicity about community transport services, making use of advice from the National Community Transport Association and the WRVS, who run many successful and cost efficient schemes.

EMPLOYMENT

Nationally, disabled people of working age are expected to be at work if they are deemed 'capable' by 'Atos Healthcare' Assessors. A job can boost a person's self-esteem and give them confidence, not to mention an income, so that they can begin to come off benefits. Although amongst the groups we met with, we were surprised by their negative assumption that because of their disability or condition they would never be able to work. However, people are unaware of the supports that are available in the workplace e.g. 'Access to Work' funding.

People told us that the government 'Work Programmes' were not successful for some people, often assuming that a disabled person would be looking at entry level, minimum wage jobs. Work

Programmes seem unprepared when it comes to people with a career history or higher levels of education. Some people said that they felt unsupported and that in the current recession they worry that there is very little prospect of finding work. They have the impression that there is not enough emphasis on encouraging employers to employ disabled people.

Recommendations

- Work programme providers such as 'Kent Supported Employment' and 'Scope,' need to be promoting the benefits and support that an organisation/business will receive to enable them to employ disabled people. They could encourage and help organisations to achieve the 'Investors in People' accreditation.
- It would also be good to see KCC lead by example and employ more people with physical impairments within the Council, particularly in roles that directly impact on disabled people.

TRANSITION (Child/Young People to Adult Services)

The majority of the people we met were older or had acquired their impairments later in life, but the few younger people we spoke to did say that as a child they were generally treated better by Social Services and that in their transition from childhood to adulthood, the assimilation into Adult Social Care Services has not been a smooth or easy process.

Many young people remain at home longer, partly through a lack of alternative supports and because there is an assumption that their parents will look after them longer. In fact they may prefer to move out of the parental home and to live independently, but they might need a lot of additional support from Adult Social Care Services. When they want to begin to live independently, the support is hard to get and often the disabled person is made to feel like 'a burden' for asking. There will soon be the added pressure of new housing benefit legislation concerning charges for having 'unoccupied' bedrooms in a family home, which does not take into account the need for a disabled young person to be able to return to their family for a short visit (and possibly an adapted room.)

There is also the need to consider the situation of a number of elderly parents who are struggling to continue to care for their disabled relative and are anxious about what the future may hold for their disabled son or daughter, when they are no longer able to care for them. They feel that planning for future supports should begin earlier, in order to prevent a crisis situation developing where for example, emergency residential care may be required.

Recommendations

- Whilst there will always be difficulties with making a smooth transition between different major services such as Children's Services, Adult and Elderly Care Services, early planning and co-ordination between the relevant Case Management Teams must be a key factor.
- 'Person-Centred Future Planning' needs to be a Case Management tool and/or be available from Independent Disability-Led Organisations who have the appropriately trained staff and trainers.
- Physically disabled young adults should be encouraged and supported to live independently from their parental home if they so desire, and this could prevent the need for this to happen later in life, as a result of a crisis situation.

PARALYMPICS

Since the end of the London Olympics and Paralympics in 2012, there has been much speculation about whether an enduring legacy will remain. Some people told us that the Paralympics has created unrealistic expectations of what every disabled person can achieve, because not every disabled person can have the range of support that Paralympic athletes had – i.e. financial help/specialist equipment/medical advice/regular physiotherapy/modern sports facilities/individual trainers etc.

Many people have not noticed significant changes in public attitudes towards disabled people since the Paralympics, in fact they feel that public attitudes are still much the same.

Recommendations

- KCC should maximise the use of new government funding ('Sports England' 2013) to invest in improved sport and leisure facilities for disabled people.
- They should build on the legacy of the Paralympics by implementing anti-discrimination legalisation more rigorously.
- KCC should learn from the example set by the Paralympics in all that they do, particularly in relation to Accessibility and Transport.

SECTION 3 - DETAILED FINDINGS

INFORMATION AND ADVICE

What is not working

The difficulty in getting hold of useful information and advice about available services as well as the lack of accurate, reliable, up-to-date, accessible information is the biggest theme coming out of all our discussions with disabled service users. Within the groups it was also predominantly the first thing people highlighted. Not knowing where to go for information or advice to start with, as well as not knowing who to ask to find out.

People need general information about living as a disabled person and what help is available to deal with the difficulties that having an impairment encompasses, as well as more specific advice ranging from accessing social care services, getting a case manager, applying for aids and equipment, as well as financial advice about direct payments and personal budgets.

The information received at the point of diagnosis varied greatly from hospital to hospital and differing conditions. Often the advice given was a 'condition specific' leaflet and very few people had contact with case managers within hospitals.

The general consensus about GPs and Health Care Professionals is that they are not equipped with up-to-date information or there is not enough time for information to be given.

The information given by the different District Councils seemed to vary, both in quality, availability and content. People felt that there was a lack of consistency, no central place to get information from, and no database resource that people could tap into to find out what they needed to know or who they needed to ask. They said that there was little or no publicity about where to go for information or advice, and a lack of signposting expertise.

Additionally, they raised the issue of accessible information, by which they do not just mean availability in all different formats but also clear, easy to understand, jargon free language.

The people we spoke to said that there is a lot of information on the internet, either from Kent County Council or through using 'search engines' to navigate the vast amount of information that is available. However they point out that there are still very many people who do not use computers. Almost everyone confirmed that they want to be able to talk to someone with the relevant knowledge and expertise. The groups we spoke to rely on informal support from their peers, from other group members, and people who have 'been there and done that'. While this kind of support is excellent and very valuable, there is sometimes a danger of misinformation when this is all that people have to go on.

Negativity

There is a lot of negativity and mistrust about information provided by Adult Social Services and Kent County Council, as well as central Government in general. People have spoken about how they believe that because information is not easily available, complicated and hard to understand, that this is being done intentionally in order to prevent the uptake of services and benefits and to save money. They have complained that Kent Contact and Assessment Service (KCAS) do not provide enough information about disability benefits and that there is a lack of independent advice (including legal advice) to help them to challenge unfair assessments and decisions about eligibility and entitlement to benefits and services. They also feel that it is a real 'post code lottery' as to what information they receive and the quality of information offered by Case Managers.

What is working well

All of the existing groups we visited said that their particular group works well and that they are given information that they need through these groups. However, the amount of negativity about what is lacking would suggest that while they do receive information and advice from these groups, they are not satisfied that this is adequate for all their needs.

Information, advice and support received from their peers within these groups and elsewhere is very highly valued. People like to get information from people who have experienced disability themselves. They expressed the view that other disabled people 'speak the same language' - they understand what the person needs from first-hand experience. The majority of people said that they would prefer to get information from disabled people - 'experts by experience'.

There are several user-led organisations and disabled people's organisations that work with the same ethos offering information and support, although these are not widely known.

Organisations that people have found to be useful included:-

- Disability Information Service in Kent, DISK
- Age Concern
- Shelter
- Citizens Advice Bureau
- MS Society/Scope/Stroke Association/Lymphoma Society
- D.I.A.L.
- Carers Network
- Sevenoaks Rehabilitation Service
- Medway Disability Information Unit

As well as the Simon Paul Foundation and Centre for Independent Living Kent.

However, concern has been raised about difficulties in getting appointments with a number of these organisations due to high demand and reductions in funding - especially when it comes to assistance with form filling.

The KCC Gateways

There was mixed feedback about the Gateways, ranging from people not being aware of their existence or what they are for, to finding them very useful. Their role is seen mainly as 'signposting', and it was felt by some people that it is good to have several different organisations in the same place. Whereas other people have said that they are difficult to get to, due to poor public transport, needing support to get there and distant location, as well as feeling that there was too much under one roof. Some people did not know how to find out who the right person to talk to was or when they were going to be available.

Ideas for change

1. Clear, easy to understand information

What people want is very clear from our findings - They want clear, jargon free, relevant information in accessible formats.

While many people use the internet and value some of the information they find on it, they also feel the need for human contact, to be able to talk to a person with the right expertise and experience. The majority of people would like to get this from other disabled people who have the first-hand experience and true understanding of the problems and challenges that they face.

The most vital information people require is:-

- Clear information about what disabled people are entitled to along with what services are available and signposting to these services.
- Information and signposting about benefits.
- Information about direct payments and clarification about what they can be used for.
- Information about major changes at a local and national level that will affect disabled people.
- Directory of the voluntary/charity sector organisations who are there to support disabled people.
- Information and clarity about who's who within KCC and what their roles are e.g. Case Managers.

A directory of services, support organisations and a 'who's who' of KCC Families and Social Care, together with other professionals that disabled people are likely to come into contact with, would help along with a 'pathway' manual to explain how it all works.

2. Disabled People's User-Led Organisations to provide information and advice

The lack of trust in Kent County Council, coupled with the preference for people to receive advice and information from other disabled people, demonstrates the need for disabled people's organisations to be at the centre of this aspect of service provision. Those who we met could envisage that such organisations would have multiple roles to help improve information-giving.

They would need to provide an independent website dedicated to providing information but it also needs to be available in alternative clear, jargon free and easy to understand formats. 'Face to face' and telephone advice and information provided by people who know what they are talking about is very important. People told us that getting the right and relevant information is the key! Comments included:

- Should Independent Disability-led Organisations provide this advice – yes!
- Newsletters have an important role.
- The best support/advice is from peer groups, disability support groups, and each other.
- Whilst there are a wide range of disabilities, there are a lot of supports/resources they have need of in common.

3. Better information on discharge from hospital and Case Manager on site

An information pack or manual should be given out at the time of diagnosis – for immediate information and to keep for later – because it can take time (even years) for the diagnosis to 'sink in' as a disability progresses. A folder with all necessary information with a 'step by step' guide to who does what e.g. like tree branches or pathways. Clear medical information too. A Patient Liaison Worker and/or Case Manager should be based in hospitals (we are told that this is working well in Hospice Teams).

What providers told us

Providers, on the whole, understand these issues, have an idea of what people actually want and need and they share their concerns. They agree that there needs to be much more clarity about the role of Case Managers and suggest that 'Care Navigators' need to be much more visible, to let individuals know what services are available, what supports and assistance they are entitled to and to be available to answer questions.

They feel that they need to have a better idea of what other organisations are providing, through more opportunities to network, having access to relevant service directories and through co-working (especially between Health and Social Care services). They would like there to be more information sharing.

They acknowledge that the disabled people they work with want control and easy access to information and resources.

ADVOCACY

Individual advocacy

The overriding opinion of all the groups and individuals was that there are no commissioned 'advocacy' services within Kent for people with a physical impairment. However, it is understood that this service does exist for Learning Disabilities and Mental Health services.

An advocacy service is required for this group, as many people with physical impairments are telling us that they need and want someone to stand up for them and speak up for them. It is a misconception that people with physical impairments can always speak out for themselves.

There is a feeling that more Case Managers should be fighting for the rights of their clients and backing them up. Instead this need is currently being met by support groups, charitable organisations and the third sector, but is not being funded. The Simon Paul Foundation provide advocacy through the support they give clients and Centre for Independent Living Kent has volunteer peer advocates who support people whenever possible. However both of these services are experiencing funding cuts and may not be able to continue offering advocacy in the future.

Group advocacy

The 'Active Lives Network' Day Service members feel that they used to have a strong voice and were supported by the Simon Paul Foundation, but now this is under threat. Having a strong voice has helped the Active Lives Network to survive but also provided a strong voice to campaign about local issues. Now with the break-up of the group into three smaller day services, they feel they have become 'lone voices' rather than 120 members standing together as before. Also the peer group campaigning members are ageing, and younger campaigners are not coming through. They fear that their very valuable day service is under threat and worry that the group will not be strong enough to preserve it.

Providers and professionals are in agreement that there is a need for advocacy and that for people with physical impairments there is very limited provision. They also pointed out that there is a lack of information about the few advocacy services that are provided by these charities and community sector organisations.

Ideas for Change

1. Commission and fund advocacy services for people with physical impairments

Involve disabled people in planning and running advocacy services. Independent organisations should provide advocacy - not Case Managers, who are limited by SSD systems, conflicts of interest and are already over worked. By commissioning and funding advocacy services and ensuring that current charities and community organisations have the funding to continue to offer advocacy for people with physical disabilities, will increase the number of advocates and improve the quality of information-givers and services.

Good practice examples

There are many examples of advocacy provision in Kent for other user groups. One service that has been highlighted to us is 'Invicta Advocacy Network'. Apparently this is working well and supporting many clients through advocacy initiatives.

PEER SUPPORT/DISABLED PEOPLE'S ORGANISATIONS/CHARITIES

Everyone who we engaged with told us that their main source of information, advice and support came from their peers – i.e. other people with physical impairments.

People 'who have been there and done it', (and who understand the challenges and concerns that they may have) are the ones who can truly appreciate their situation.

The peer support they have can range from informal friendships, local friendship groups, 'Facebook' pages, forums or websites to more formal peer support through (often user-led) disabled people's organisations.

Disabled People's Organisations and User-Led Organisations offer very valuable services for disabled people including peer support, advocacy and sharing information. They are picking up the shortfall of the County Council's commissioned services.

- Independent Charities/Voluntary Organisations are highly experienced – they know what they are doing and know what is needed!
- The many Support Groups (disability focused) are the best way to get the right information, advice and help, usually by meeting together informally!

The Providers we spoke to recognise that the Charity/Voluntary/Independent Sector has to make up for the gaps in Statutory services. They have told us that:-

- Cuts in services have left the Voluntary Sector to 'pick up the pieces' and meet the shortfall.
- Disabled People's User-Led Organisations, Charities, Voluntary and Independent Organisations are also being hit hard by funding cuts. Funding from Kent County Council is harder to secure and other funding streams are getting fewer and smaller with more organisations trying to compete for them.
- Voluntary Organisations also have had cuts in funding.
- People will not come to voluntary organisations if they know they have do not have enough resources.

Ideas for change

1. More involvement by Disabled People's User-Led Organisations in delivering services

- Support and develop Disabled People's Organisations and User Led Organisations to allow disabled people to provide advice, support and advocacy that is independent of KCC.
- Disabled People should be providing more training to staff working with physically disabled people as well as be 'policing' disability discrimination in the community and raising disability awareness.

2. Encourage Peer Support Groups

- Continued or additional funding is required for existing disability support groups and services. Services for disabled people should be run by disabled people – as in the North Kent Disabled Foundation Day Service, Dartford.

ASSESSMENT AND SUPPORT PLANNING

What is not working

Assessments

All the people we spoke to have been, and continue to go through, various assessment processes. They told us that there are too many 'assessments' and 're-assessments' which they feel are overly intrusive and the detail of information requested feels like an invasion of privacy. Filling in assessment forms is 'a nightmare' and can be overwhelming. Disabled people feel targeted by harsher assessments and that the information from the assessments is being used against them. Some people are just not good at writing or getting on the phone themselves and need a lot of support with this, but with Citizen's Advice Bureau and Legal Aid funding being cut it, leaves disabled people as 'easy targets'.

People cannot understand why so many new 'assessments' and 're-assessments' are really necessary and suggest that that this must be very costly! There is simply too much paperwork. People commented that 'so much form-filling must be a waste of money for the Government!'

The assessment process causes a lot of stress and anxiety which can have its own impact on an individual's health/disability. People are finding assessments stressful and frightening - as they have major funding implications for each individual. They say that financial assessment questions are confusing and misleading and that the questions and interview process are very complex. They suspect that questions seem to be designed to confuse and mislead people – to catch them out!

- One individual with a visual impairment completed an 'assessment' form which was apparently sent back because it was 'not in their own writing' - so the person sent it back in Braille!
- Another person was assessed three times after which they received nothing.

Their view is that there is no proper 'holistic' assessment. Assessments are not taking into account the full range of disabilities and related health issues people have and these do not always count on the assessment 'score' whilst the 'points system' is changing and becoming harsher.

"The Assessment process only focuses on what disabled people can't do and does not acknowledge how much people are doing for themselves by trying to live independently of services and how far a person has come to overcome their disability"

There is a lack of information from official sources about the assessment process and a lack of support over the impact of financial assessments. Different sections of the Department of Work & Pensions (DWP) don't seem to communicate with each other and people are dealing with a complex bureaucracy.

From people's experiences financial assessors are often not competent and make mistakes. Even Case Managers do not seem to be familiar with new 'financial assessment' forms. Direct Payments Assessors have also been unclear about eligibility criteria for Disability Related Expenditure' (DRE)

People feel they are being 'brushed aside' by people who 'just sit behind desks' or 'just sit around drinking tea!' They feel that Assessors don't know what is going on and are just 'ticking boxes'. They are unaware of the realities like the 'Food Bank' being set up in Folkestone (part of 'Churches Together Project'), as many people are losing benefits and even have no money for food.

[Assessment following period in hospital](#)

The quality of assessments has been found to be poor and there is a lack of consistency in developing and maintaining a care plan from Case Managers, with poor follow-up after a person is discharged from hospital. Sometimes long-term illness is not followed-up and monitored by the

Health Service, which causes problems if information is required during a new assessment, and a full 're-assessment' may be required for medical evidence. G.P.'s letters can also cost a lot of money.

It is assumed that if someone lives with a relative, they don't need much help, so they can be discharged and sent home without exploring the level of support that person's family member can give.

People felt that their own G. P.s did not have enough of a say or involvement in these assessments. Even though they often know their patient well, an unknown GP is usually allocated to carry out the assessment.

There are disagreements, disputes and confusion about 'Health' vs. 'Social Care' funding because there is not enough clarity about who pays for what.

Work Capability Assessments

There are many concerns about the Government 'Work Capability Assessments' being implemented by 'Atos'. There is a feeling that these assessments are wrongly assessing people as 'fit for work' by not appreciating the full impact of a condition. For example:

- They do not take into account the practical realities of living with M.S, when health can vary significantly from day to day and it is misleading to be categorised as 'fully fit for work'.
There is also no appreciation of the practical realities of managing M.S. in a work environment.
- Whilst 'Atos' recognise that someone is 'severely disabled' they can still categorise them as 'fit for work'! If the disabled person is managing to do some voluntary work this can count against them. There is a lack of clarity about what 'fit for work' actually means!
- Assessors and administrators contacted by telephone are often not experienced or knowledgeable about the range of different disabilities

Many people have appealed and many appeals have been upheld! There is also not much support available after an appeal has failed and not enough support from Social Services.

An appeal can take 3-6 months to go through, often requiring someone to chase it up. Appeal processes can be very stressful and is a lot for people to deal with without support.

People often say that:

- The person 'who shouts loudest' seems to get more support!

Charging Policy

The changes in eligibility rules has led to reductions in income for individuals who are still living with a disability - this can lead to person not having enough funding to attend the day service of their choice. For example, eligibility for attending Headway Day Centre (Ashford) used to be based on a medical referral not a financial assessment.

People asked why, after three years, are KCC beginning to charge for attending day services? Headway Day Centre staff were apparently not even informed that members were to be 'means tested' by KCC regarding charging. The Kent Charging Policy and the financial assessment appears to be unfair – one rule for one person – one rule for another.

An additional problem with the financial assessment for a Direct Payment is that when an individual is in receipt of Disability Living allowance which includes the 'care component' and they are receiving paid carer services from KCC, then KCC counts the 'care component' of the Disability Living allowance as income in the means test . This is all very difficult for people to understand and they do not feel that they are adequately supported as the assessments are not being explained to them properly.

Support Plans

Support Plans are not in place to monitor or support how Direct Payments should be spent. An assessment and support plan should acknowledge that tasks take time – especially when the person is disabled or has brain injury. The ‘care plan’ often does not identify what hours individuals actually need and people are not supported to think this through by the assessor.

Some people are getting no support from Case Managers. For example:

- One person had written their own support plan, gave it to their Case Manager – but the plan came back with many inaccuracies and there was no follow up.

KCC (Case Managers) have to agree the support plan – even if the 'self-assessment' was written by the disabled person themselves. Many people feel that Support Planning is not 'Person-Centred', often not accepting the agenda or framework of assessment wanted by the disabled person.

Assessments seem to revolve around the professional not the person - ‘professionals do not always know best!’

There appears to be conflict between Case Managers and the Financial Assessment Team with all decisions seeming to depend on the size of the budget in the Case Management Team. Services seem to revolve around 'crisis management' – rather than being 'proactive' - i.e. developing a good Support Plan/Person-Centred Plan to prevent the individual reaching crisis point. A Support Plan is not a ‘one-off’ and should be an on-going, active document.

The assessment process has often revealed that people need more support, but they feel that it is a constant battle to get the support they need! People 'give in' and try to sort out their own funds and supports, which they feel suits KCC as they are saving money. If the assessment process was easy to understand and use, then people would take up more benefits. People were suspicious that the complicated system and lack of information was another way for the Government to save money.

Personal/Individual Budgets

People we spoke to did not have or understand that they may be eligible for a personal or individual budget.

What is working well

- For some people Person-Centred Planning has been very helpful.
- The Citizens Advice Bureau has helped individuals as much as possible (but their funding has been cut as well as the Legal Aid Service).

Ideas for change

1. Improve availability of information about individual assessments and planning

- People need basic information about assessment and support planning in plain English. They could be given this on discharge from hospital as well as a completed care plan.
- KCC should provide a printed document about what the eligibility criteria are for Direct Payments and what can be purchased with a Direct Payment in order to clarify what is counted. The 'discretion' of Case Managers can go both ways and can be biased against or for a person. 'Discretion' over 'individual needs' should be a 'right' not a 'discretion'! This also should include the Disability Related Expenditure part of the financial assessment.
- People need help with challenging unfair assessments (e.g. 'Work Capability Assessments').

2. Provide more Training in Assessment, Person-Centred Planning and Disability Awareness

- Case Managers and Assessors need disability awareness training and should themselves be well informed about the assessment process and educated about the range of disabilities.
- There is also a need for KCC to promote and provide training in 'Person-Centred Planning'

for their staff. (See section 5) for differences between Person-Centred Plans and other plans).

- As a disabled person gets older and parents are no longer able to support them they should have a Person-Centred Plan which looks at what support may be needed in the future.

Good practice examples

- One participant runs a small business which provides Person-Centred Planning and Disability Awareness training which is called T.R.E.N.D. 'Training Resources Enable Never Disable'. They provide training to Case Managers/Social Workers and also go into schools. However, there is a lack of support/funding from KCC to continue this training.
- Good support provided from K.A.S.B.A.H. (Kent Association for Spina Bifida and Hydrocephalus) with Person-Centred Planning.
- See 'Best Practice' example, Section 5.

What Service Providers told us

What is not working

- KCC need to support a 'holistic' view of assessment instead of putting people in 'boxes'. KCC and services are just 'rearranging the furniture' and not dealing with the problems!
- There is a lack of training on the assessment framework and it is hard for professionals to keep up-to-date with changes in policies and services. It is difficult to retain staff, because of strain and stress, and we are losing well-skilled staff.
- There are problems with processing OT assessments, facilities grants etc. and this leads to longer waiting lists.
- The 'person-centred' approach is being limited by lack of time and thought about how to best meet community need. Focus on independence is difficult to achieve with the lack of flexibility in support packages.
- The 'F.A.C.E.' assessment pack is 'not fit for purpose' and the Care funding 'calculator' does not work.
- Sometimes parents/family members confuse things.
- People refuse help because services do not meet their needs, or help them the way they want to be helped. They need to remember that they have choice and control- instead they feel they have to be grateful and don't realise that they can complain etc.
- The assessment of needs is cutting hours of care and it is not always easy to prove the need. People are losing hours because they don't realise that if they don't use them they lose them - but people need different support/help at different times.

What Service Providers say Service Users want

Providers understand that service users need assessments to be more accessible and information about assessments needs to be easy to find.

They recognise that Case Managers' reviews should be 3 monthly and Person-Centred Planning should be part of their service routine and should include family members/carers. Early intervention is important and as people's needs change (and this can be gradual) so this requires regular reviews and on-going Person-Centred Planning.

People want ownership of their Person-Centred Plan and to have maximum independence, freedom of choice and control - rather than being restricted by budget limits. They want to have basic needs met and the right support when needed. Providers see that there is a need for creative solutions to problems and that providers need to be looking at the positives!

Provider's Ideas for Change

1. Improve Assessment framework

- Assessments need to centre on individuals, whilst freedom and potential for 'independent living' should be protected. There is a need to reduce duplication of many assessments.
- KCC needs to maintain 'Moderate' eligibility criteria so people can receive support services before their situation becomes 'critical'.

2. Improve Support Planning framework

- KCC need to take a preventative approach. They should deal with issues at an early stage so they don't need more complex services later down the line. They should invest in an appropriate level of support at the right time – if this is left too late the person deteriorates and then support costs more. They need to slow down, think and do things properly the first time, then maintain support, contact and continuity – instead of 'stopping and starting' an individual's care.

3. Improve information resources

- A proper 'Directory of Services' should be set up so everyone is aware of what's out there. Services need to work together, share good practice and take a 'holistic' approach.

CASE MANAGERS

What is not working

Information

As identified in the information summary there is a fundamental lack of understanding about what a Case Manager's role is and some recent confusion over how 'case manager' differs from 'care manager'. Some people didn't have one, others did, some have had one in the past but are no longer 'active', some just did not know who their Case Manager was or had tried and could not get one! When their Case Manager leaves or their case is closed, people are not always informed. Several people, whilst discussing Case Managers, felt that they would like one but didn't know how to go about getting referred.

Re-organisation

There was a strong feeling that funding cuts have had a detrimental effect on Case Management Services and reorganisation and restructuring has left people even more confused about what their role is, who they should contact and where they are located. There is a feeling that due to the cuts in numbers of Case Managers, their increasing case-loads are unmanageable, services are becoming too stretched to respond adequately and there is concern that 'cases' are 'closed' too quickly. There are a limited number of Case Managers available - so they can only do short term work and then have to 'close' the 'case'

Much like other services, it appears to be a lottery as to whether you get a 'good' or 'bad' Case Manager. The experiences people have vary from person to person with little consistency as to the service they receive. It is clear that they are overloaded and in some cases 'burning out'.

Case Managers change too often, resulting in a loss of the supportive relationship that has been established, so just as a disabled person gets to know their Case Manager, they have a new one. One

person had five different Case Managers over five years. It seems that resources are wasted by having to start all over again each time they have a new Case Manager and then fill in the same forms again. There is a lack of consistency and continuity.

Training and skills

Complaints are also around training issues. Many of the groups we spoke to have a lack of confidence that Case Managers are familiar with the assessments and forms that they are required to complete. Also some Case Managers have a negative attitude towards disabled people. Comments included the following:

- ‘Case Managers are not familiar with new ‘financial assessment’ forms and should be well informed about the assessment process’.
- ‘Case Managers need to know what they are doing’.
- ‘Case Managers should be encouraged not to be judgemental or patronising or ‘look down’ on disabled people. Some Case Managers are not very caring’.
- ‘There are not enough skilled Case Managers – the good ones leave or get promoted!’

Case Managers/Co-ordinators are being asked to resolve complex problems, instead of more qualified Senior Case Managers. People are not happy with some Case Managers who are not giving them the correct information and even suspect this might be deliberate. Some people are frightened to complain about their care when “you are at the mercy of carers” and “you can’t complain about your Case Manager to your Case Manager!”

People felt that formal organisations are not able to be sensitive to the needs of disabled people as well as disabled people themselves, who are “best by a mile”.

Reviews

Case Managers are expected to carry out reviews, rather than an independent person/organisation. Some people felt that these are not regular enough – i.e. six monthly or annual. It apparently took three years for a Case Manager to visit one individual - because as he lived alone, they assumed he did not need any support!

Hospital

Case Managers are not always available at hospitals – one person recounted how a Case Manager was not prepared to visit patients in hospital awaiting discharge, in order to liaise with community services and prepare a discharge plan - even when that person was referred to them by another professional.

Family Carers

Two parents/carers have not had much contact with any allocated Case Manager and were concerned about what will happen in future to support their daughter as they get older and when they are no longer there. On their own initiative they completed an assessment form and were awaiting a response from KCC.

What is working well

- Case Managers are helpful (once you have one), because they fight for things on behalf of their clients. They are very supportive (depends on the Case Manager) and can help with a support plan.
- One person had a ‘brilliant’ Case Manager.
- Members of Headway (Ashford) all have a Case Manager and Headway staff refer individuals and liaise with Case Managers.

- The Simon Paul Foundation liaise with the Case Management Team on behalf of clients when Case Managers change or are not available.

Ideas for change

1. Increase availability of Case Managers

- People felt that everyone should have access to a Case Manager, as there aren't enough of them.
- Case Managers should be encouraged to come out to day services in order to meet with disabled people and those who are supporting them. This would give all parties better insight into each other's roles and improve communication. They could be allocated/attached to day services such as the Headway Service or Active Lives Network.
- There is also a need to clarify the role of the Hospital Case Manager and improve liaison with Community Case Managers

2. Improve Training

- Case Managers should be well informed with good training and support – they need to know what they are doing, what people are entitled to and have disability awareness. They need training on how to develop Person-Centred Planning including 'future support' planning. They should receive training from Disabled People.

3. Better Communication

- KCC Families and Social Care Services should keep individuals informed of changes and restructuring, particularly when Case Managers/Coordinators are changed or leave.

4. Independent Reviews

- Reviews should be carried out by an independent organisation.

Case Managers

What Service Providers told us

What is not working

Re-organisation

The practice of absorbing other professionals (such as Occupational Therapists) instead of Social Workers into a Case Management role has two problems – the loss of needed specialists and de-skilling the Case Management role. Reduction in numbers has led to larger case-loads and longer waiting lists. There is now too much "red tape" and less time. The re-organisation has meant that KCC no longer have an office base in every town.

'Duty' Case Managers are usually available rather than 'allocated' Case Managers but people can feel intimidated by Case Managers whom they do not know.

There is a shortage of staff which is exacerbated during periods of staff recruitment or staff sick leave.

There needs to be more clarity on the role of Case Managers. Case managers feel that they have to prove what they are doing all the time.

Partnership working

There is a lack of action on 'Partnership Working' with other organisations, especially concerning information regarding benefits/direct payments/reviews – for example, Leonard Cheshire are not being invited to Care Reviews.

There has been a lack of communication with organisations such as the Leonard Cheshire Foundation about cuts being made to client's benefits. Case Managers are not informing organisations, which causes funding/fee problems, and it is not clear if their client is paying from a Direct Payment or KCC. The system for paying Direct Payments into a client's personal account can be confusing, and it can cause money management issues when payments are delayed and clients can fall into debt.

Provider's Ideas for Change

1. Increase Administration Resources

- They would like more administrative support to enable Case Managers, Coordinators and Support Workers to spend more time with the clients.

What Providers believe Service Users want

Service users want to be able to speak to one person and be given the correct contact name. They want to have the confidence in the person allocated to them that they know what services are available and what they are entitled to or eligible for.

They need continuity in terms of support and care with the same person to talk to.

A 'holistic', 'person-centred' approach is essential with a focus on the potential for disabled people to be independent and reduce their isolation.

THE BENEFITS SYSTEM

What is not working

New system

Throughout our conversations with individuals and groups they have expressed frustration and worry about major changes being made to the benefits system on a national level, following reviews of the current system. They are not being kept informed and updated about these changes and how it will affect them. At the same time they are concerned that Case Managers and other professionals do not seem to be fully informed and able to explain these clearly: Concerns people raised were:

- There is not enough information about major benefit changes coming into force - such as the 'Personal Independence Payment' (PIP) & 'Universal Credit'.
- This will require another set of assessments – which must be costing the taxpayer even more!
- Assessments are very stressful and the long process has its own impact on a person's health/disability.
- The many questions asked and the interview process are too complex
- Disability Living Allowance applications and review forms are focused on detailing all the things you cannot do - which is very dispiriting.

Reliance on Computer Technology

While much information about benefits is currently available online, a proportion of people do not have computer skills or easy access to a computer. They feel this is unfair because:

- New changes to the proposed benefits system will apparently only be computer-based.
- If all benefits' information is 'digital' it will be too complex and unfair to people who are not familiar with computer-based technology.
- People already become anxious and stressed when completing benefit forms and they will feel worse when confronted with computer-based form filling!

Lack of training

Whilst DWP Benefits Officers are overloaded with appeals, it is difficult to even get an appointment to get advice and assistance from the Citizen's Advice Bureau. There are concerns that Benefits Assessors and Advisers lack training in disability issues - including how to communicate with some disabled people.

Additionally, the average disabled person has a lack of knowledge about benefit entitlements, and often does not know how to go about finding out what is available. This can result in relying on other disabled people for informal advice, which can be problematic - as different people are entitled to different benefits and advice may not be always accurate. As a result, some individuals may have their hopes raised unnecessarily about benefits that they will in fact not be entitled to.

Volunteer Support Groups do not always have the qualifications or insurance to help people to fill in the necessary forms or to offer advice, The MS Society, South East Branch, run by volunteers say that this is a role that needs training qualifications and should be a full time paid role. Apparently the Citizen's Advice Bureau in Ashford is beginning to offer training to community groups and organisations so that they can help their members.

Lack of support:

The 'Jobcentre Plus' Service can offer very limited support. 'Jobcentre staff apparently direct you to their public phones for you to get your own information!' People need more comprehensive support as the worry and stress can impact on their mental health, leading to anxiety and depression.

It is ironic that if a person's benefits get stopped, as a result of an incorrect/inaccurate 'assessment' there are no safeguards available to get them through whilst the appeal process is ongoing - which is different if you are employed!

Culture of negativity

Disabled people feel vulnerable and threatened by a system that they feel is targeting genuinely disabled people to unfairly reduce their benefits. Support services to help disabled people to navigate their way through such a complex and confusing system are not being funded and they feel that the system seems to be 'weighted' against them.

Negativity, reinforced by the press and media, regularly portrays disabled people as 'scroungers'. Whilst disabled people achieved so much at the Paralympics, there has also been an unexpected public attitude of 'they can do it, so why can't you?' People may not realise that these athletes had the benefit of major funding, the best equipment and training, physiotherapy and medical support, which is not available to the vast majority of physically disabled people.

What Providers told us

The providers and professionals also noted that the detail about the new Personal Independence Payment (PIP), which will be replacing the Disability Living Allowance, needs confirmation and a lot more clarification for them - let alone the proposed recipients of this benefit. They agree that there is a lack of accessibility to information about benefits, along with a lack of support regarding

understanding what benefits and rights people have. They pointed out that clients are not always entitled to the services and benefits they expect.

There are very strong feelings about the way that Work Capability Assessments have a direct impact on reducing a disabled person's eligibility for Employment Support Allowance. Whilst this is a national issue, people need the support locally to help them with the appeal process as well as someone to accompany them to the assessments.

Ideas for change

1. Ensure easy access to up-to-date information, expert advice and personal support

- Disabled people need better support around benefit changes - they want people to be easily available to talk to on the phone as well as in person - face to face, rather than relying on a computer.
- Information should be freely available about major changes due to come into force such as the Personal Independence Payment (PIP) and Universal Credit. For example, people particularly want to know about the implications the loss of Disability Living Allowance will have on Motability.
- Independent Disability User-Led Organisations should be given funding to assist disabled people during the benefit application process and with general form filling.

2. Challenge negative perceptions

- Benefits Advisers and Assessors should have good quality Disability Awareness Training - preferably by disabled people.
- Disability Awareness Training should be extended to other public services in order to challenge the negative assumption that all disabled people are scroungers.
- The new benefits system should be implemented to ensure that disabled people who are in genuine need can access the benefits necessary for them to be able to have a better quality of life and consequently avoid deprivation leading to ill health.

DIRECT PAYMENTS

What is not working

It was striking, amongst the groups we met, how many people were not aware of the Direct Payments system. A lot of people did not receive them and those who had heard of them felt that they were too complicated and they were not interested in receiving direct payments anyway. Of the people who had previously received or are still using direct payments, the experiences were very mixed:

Lack of Publicity

Not everyone is offered direct payments when their social care needs are assessed, but for those who are, the main barrier preventing the uptake of direct payments seems to be the lack of information. While it does depend on the individual Case Manager, there does not seem to be any positive promotion of direct payments by Social Services about the choice and control that they can bring to an individual's life. Instead they are being described as complicated, hard work and a lot of responsibility for the individual. People are not being told about the support services that are available to help people to manage their direct payments.

Unclear eligibility rules

There is a lot of confusion and therefore a lack of clarity about how direct payments can be used and what this can pay for. Different Case Managers are saying different things and there seems to be an element of discretion and subjectivity about how they can be used, both within KCC but also

across other Counties. This is very confusing for the prospective user.

Money Management problems

Direct Payments also require people to manage their own money and to keep every receipt to account for what the direct payments have been used for. While some current users say that this is actually quite easy in practice, it is seen as a very daunting prospect for individuals new to the concept (as this is not the case for State Benefits). For some people, setting up a personal bank account for processing direct payments can be difficult, so they need support every step of the way from the offset.

Restrictions on what a Direct Payment can buy

However, there are some significant problems that direct payment recipients are experiencing. Cuts to Adult Social Care provision have led to support packages either being reduced or the threat that they will be. Disabled people have reported that they are being made to feel like they are not deserving of the hours of care that they receive because some Case Managers have apparently told them that other people need the help more urgently.

Some people have told us that they do not think that their assessments are accurate or their support plans are comprehensive enough and therefore payments do not cover their needs - for example, two days a week for daytime pursuits is not enough for some disabled people who feel that they want to be doing activities more than just twice a week. This means that they have to cram everything that they may want to do into the restricted time. They say that Case Managers are telling them that funding depends on 'individual needs', but in reality they have to fit in with what is available.

Incompatible rates of pay for staff

There has not been an increase in payment rates to match the increase in costs, both of services and of employing staff. For Personal Assistant employers this means that when the minimum wage increases, they are no longer able to afford the same amount of care and are having to cut staffing hours and therefore take risks with their own care. Having to reduce staffing hours is also putting pressure on staff retention, as Personal Assistants are being forced to look for extra hours elsewhere. For those people who still buy into 'agency care', there is some confusion as to the 'rate' direct payment recipients should pay. Social Services get a reduced rate, whilst private clients pay more. The direct payment amount is set at the KCC rate and yet agencies want to charge private client prices. This is resulting in some individuals having to either cover the shortfall or receive less care.

What Service Providers told us

What is not working

Rates of pay for Providers

There are similar problems for Service Providers. The cost of services to private individuals differs from the rates for Social Services clients. Some services are losing clients who are going elsewhere to have their needs met which reduces the funding providers have with which to function. When individuals move to direct payments, the money no longer goes straight to the service provider, and providers are complaining that they are not made aware when this happens. There have been instances when clients have not correctly understood or managed their money, through lack of support or information, and are later faced with invoices and debt, leaving the service provider having to chase this payment. Providers blame the lack of communication from KCC and lack of involvement in the 'support planning' meetings.

Lack of funding for transport

They see that cuts in benefits for service users, including cuts to transport to travel to services, make

it difficult for new users to come - for example, Leonard Cheshire Day Services are located in rural areas (Chipstead and Aylesford) and a taxi fare can be £40 per day, which is not factored into the support plan or direct payment.

Budget-led not needs-led

Providers and professionals are of the opinion that direct payments linked to individualised and personalised services are not really happening, because direct payments and personal budgets are not under the control of the individual disabled person. There is in fact a conflict, as people do not have real choices about what they can afford to purchase. Support Plans do not reflect this either as they are not 'person-centred'.

Lack of support

They see that the lack of advice and practical help are the main barriers stopping people from choosing the direct payment option - direct payment recipients need the right back-up to be able to organise and maintain their own supports i.e. Personal Assistants.

Case Managers raised the point that clients are not always entitled to services or benefits they expect, because their expectations have been raised by misinformation.

What is working well

How Direct Payments can be spent

The individuals who are currently in receipt of direct payments use them in a variety of ways to access their choice of services, such as day services/respite or to employ their own Personal Assistants.

This seems to be working well for individuals who employ their own Personal Assistants, because the individual can decide what support they want, in the way that they want it and can choose who to employ. This enables them to receive continuity in their support and an opportunity to have positive relationships with their Personal Assistants. With the right support and experience, individuals are managing the extra responsibility that comes with being an employer. Allowing individuals to select and buy into a variety of services means that there is much more choice, as they do not have to use standard local authority services if they can meet their assessed needs in a different, sometimes more creative way. For example, some people may use a direct payment to pay for gym membership. The 'Kent Card' system has made this even easier for direct payment recipients.

Some people feel that direct payments are better value for money and more cost effective.

Ideas for change

1. Increase uptake of Direct Payments

- More people need to be on direct payments, holding and controlling their personal budget (**but with the necessary support**). We could learn much from the 'person-centred' approach of Learning Disabilities Services nationally, as they have developed these principles for some time.

2. Promotion of Direct Payments

- Along with up-to-date information, better clarity and communication about what direct payments are and how they can be used, there is also a need for better promotion of direct payments through KCC Social Services and Case Managers to highlight the benefits and positive outcomes that direct payments can achieve.

3. Direct Payment support

- An Independent Disability-led/User led Organisation could provide a comprehensive Personal Assistant Employment and Recruitment Service by developing a Personal Assistant

'Pool' or Personal Assistant Agency. It could also offer support and information about using Care Agencies.

- Direct Payment Support Workers could be employed through Independent Organisations and/or work in partnership with KCC.

Best Practice example

In other Counties, including Surrey, there are successful Direct Payment Support Services being run by User-led Organisations with the backing of Surrey County Council. Please see 'Best Practice' example in Section 5.

PAID CARERS/CARE AGENCIES

What is not working

Funding for personal care and domestic tasks

The groups and individuals who we spoke to informed us that Care Agency staff can only carry out personal care and not general household tasks. However many disabled people need more than just personal care - they also require help with housework tasks, or paperwork and paying bills etc., but this is not factored into their support plans. Case Managers have informed some individuals that they must rely on family and friends for this kind of support. For many people this is unfair and puts too much pressure and strain on personal/family relationships. People are also being expected to be able to pay for this from their Disability Living allowance payment, but this does not provide adequate funding, as this money is being spent on living costs. Some examples people gave us were:

- One individual needed help with washing the kitchen floor – her ageing husband was expected to do this whilst he also deals with all her personal care. Her paid carer no longer comes and she has to rely on her husband for everything. If her husband is prepared to carry out all the personal care, why can't KCC provide domestic help?
- Another person depends on her son to carry out her personal care – is this appropriate?
- Another individual asked for a paid carer but was apparently refused, because he was living with his parents - he needed someone to help with going out of the house and accessing community facilities. Should he have to rely totally on his parents?
- Agencies can be restricted by the services that they offer - for some people it is difficult when agencies do not offer help with administering medicines.

Allocation of time

The time allocated for personal care tasks is often unrealistic for many disabled people and also their paid carers. Within unreasonably limited time the carer can also be expected to write reports about each visit. More often than not there is no allowance for travel time to their next appointment! It is felt that this is the fault of both the Care Provider Agencies and Social Services.

Key issues are:

- The lack of control over the times carers come and go is a problem for many people, as they can be kept waiting for unreasonable periods of time, if a carer is late.
- KCC/Care Agencies unrealistically limit the time allowed to carry out tasks – e.g. just half an hour to help a disabled individual to get up/shower/dress/have breakfast! etc.
- Carers organised by KCC end up rushing through personal care tasks – sometimes giving people only 10 minutes to get washed, dressed and ready! The carers are not necessarily to

blame.

- It is not clear whether this is due to the KCC contract or Agencies having to cut costs.

Lack of continuity of care

A general theme also includes the lack of continuity of staff through having different carers coming in (from one visit to the next) and then each having to be told (or having to read up on) what tasks they are required to carry out. The high turnover of staff raises concerns about continuity of training, and whether each new member of staff is adequately trained. There are mixed feelings about the carers who do not have English as their first language - some people are happy that they do a good job, whilst others find communication a problem especially if the disabled person has communication difficulties related to their disability.

Sometimes carers are regular and known to the person, but sometimes different people turn up who are not known to the person – it is naturally better to have regular/familiar carers. We were told that:

- Carers are poorly paid, have little time, no real career structure and agencies try to be 'money saving' for themselves which is not in the best interests of their clients or staff. This can result in a high staff turnover.
- Clients feel that it is no longer a 'caring' service - nor personal.

Care Agencies – staffing issues

There are negative feelings about Care Agencies and a view that they get paid a lot of money but do not offer a good quality service. Carers are seen to be paid very little to do very personal and difficult jobs. They are under a lot of pressure with a very big work-load, often being expected to see too many clients in a short space of time, with no consideration for report writing and travel time. This is seen as cost cutting by the agencies, and those who use their services believe that the Care Agencies should employ more staff so that each carer has a manageable case-load and so can spend an appropriate amount of time with each client. Carers do not have the time to enable people to regain some independence by supporting them to do things for themselves, but instead carers just tend to do things for them without the disabled person's input. This is not supporting people to feel like they have some control over how they wish things to be done in their own home.

While generally carers have a lot of basic training, they do not always receive training about how to interact with disabled people. Some people have said that carers can be patronising and do not know how to talk respectfully to disabled people.

What Service Providers told us

What is not working

- Providers are aware of the difficulties raised above, including the Care Agencies who attended our Forums. Retention of staff is a problem, due to staff being underpaid and under a lot of pressure.
- In our discussions with Care Agencies they explained that they are limited by the kind of care that they can provide within the time allocated to carry out assessed tasks, but they are also limited by what they are allowed to do. We were told that Social Services will only fund personal care and not general household tasks.
- The health of many clients deteriorates over time and yet needs assessments and support plans do not keep up with the extra time that is required, as tasks take longer - if anything, assessment of needs is cutting hours of care. There are cuts in hourly rates for staff and resources, but they need to keep up standards. This is causing a lack of continuity of care,

which has a 'knock on effect' for vulnerable people. They pointed out that this was the same for all organisations and that the voluntary sector is being pressured to 'pick up the pieces'.

- Another problem is that the KCC 'Care Service Calculator' means that they have to be recording and accounting for every minute of care provided in so much detail. If things do not go to plan (because as in life they often don't) they have to justify this to the Case Manager.
- Carers have to complete a lot of paperwork to prove what they have been doing, but no extra time is factored in to do this or for travel between clients.

Charging and rates

- In the past, KCC were charged a reduced amount by Care Agencies for 'block care'. KCC have continued to use this rate for direct payments. However, direct payment recipients are treated as private clients by the Care Agencies and are charged a higher rate for their care. This results in a shortfall between the direct payment and the agency charge. People are having make up the difference from their own funds, or if they are unable to do so, they are being forced to reduce the hours of care they receive.
- KCC Direct Payment rate does not include transport, which is a particular problem in rural areas, and times are being cut short so that they can fit clients in.
- Fees are not increasing to take on the additional responsibilities of specialists.
- KCC funded work is a lot more restrictive than private contracts.
- Care services have also highlighted that due to reorganisation within KCC and Social Services they are not sure which department is now paying for care. There is a real lack of communication between KCC and Service Providers.

What is working

- Some individuals have said that they are happy with the service that they get - although a good Care Agency seems to be 'a lottery'.
- Some people receiving Direct Payments use agency care as a 'back up' to their own paid carers - if one of their carers is away or unwell, then Care Agencies can step in with relative short notice. (However some will not provide a service for individuals who have 'complex care needs' due to 'health and safety' considerations or if tasks are defined as 'nursing').

Ideas for change

1. Promote employment of Personal Assistants by disabled individuals

- Allocate more resources to prevent disabled people being placed into residential care, by providing more support for individuals to employ their own Personal Assistants and remain at home. It costs much more to place a disabled person in a nursing care home than for them to be properly supported to live independently at home, especially if they have a higher level of disability. KCC needs to get this right to prevent higher costs in future.
- Address the high cost, discontinuity and inefficiency of funding Care Agency staff as opposed to supporting a disabled person to employ their own team of Personal Assistants. KCC needs to encourage greater uptake of Direct Payments and Personal Budgets in order to facilitate this. It works better for a disabled person to employ their own Personal Assistant because they manage the recruitment , develop the contract and determine the role of their Personal Assistant. As well as it costing less than Care Agency staff it is less bureaucratic and maintains the principle of personalised supports.
- Develop a Personal Assistant 'pool' or a separate 'PA agency' to make recruitment and

emergency cover easier.

2. Improve the service provided by Care Agencies

- Care Agencies need adequate funding and resources to be able to assist with a wider range of tasks such as giving medication and supporting people who have complex care needs. They need to be more creative, as disabled people need a range of supports in a range of different ways.
- Care Providers would like clearer 'work agreements' with each client about meeting their care needs.

HEALTH AND REHABILITATION

What is not working

Health v Social Care

People are confused about what is 'health' and what is 'social care' and which services come under each department. They feel that their needs come under their own heading of 'life' and this cannot be split neatly into social care and health! Physically Disabled People and Carers alike struggle to understand which department is paying for which service.

There is a feeling that these two departments need to work together to ensure that an individual has a smooth pathway through the system, but they are not sure how an integrated system would work. Key issues raised were: -

- What is 'health' and 'social care'?
- Integrated Health and Social care - how this will work?
- Lack of consistency/continuity between both services.
- Difficulties in transferring information between them e.g. Data Protection.

Some of the small groups were 'condition specific' - conditions that had been acquired such as Stroke, Multiple Sclerosis and Brain Injury. These groups often have recent experience of hospital care, especially at the point of diagnosis, discharge and then follow up, along with the support services that go along with this. They feel that there is less support these days from paid Carers, Physiotherapists, and Occupational Therapists as well as an overall reduction in support services. The groups said that there was a good service at the beginning, but that it falls away after a time, even though the disabled person is not 'better' and often the disability is permanent.

Hospital

Pretty much everyone agreed that at diagnosis there is little or no information given to people about the practicalities of living with long term illness or disability. The most information the majority received was a few leaflets about the condition by the relevant national organisations, such as the Stroke Association etc. There were mixed feelings about this. Some people felt that at this point the last thing that they wanted was information about physical disability and about things that may or may not be relevant in the future. However, with hind sight, they were in agreement that it would have been useful at this point to have had some information with details of who to contact or how to get help and support in the future – for example, how to get a Case Manager, so that they could just keep it somewhere safe to refer to, if or when they needed it.

Some people never had a visit from a Case Manager whilst in hospital, even when they requested it. Some people did not have a discharge plan/meeting or follow-up/liaison by a Hospital Case

Manager with community services and a Community Case Manager. There is a lack of clarity over roles of Hospital and Community Case Managers (e.g. Darent Hospital)

Comments have included:

- Having to wait six months for Physiotherapy/Speech Therapy after a stroke.
- Poor support after being discharged from hospital.
- No Physiotherapy/Occupational Therapy/Care Manager follow-up from Hospital.
- Being placed inappropriately in old person's home, rather than a 'rehabilitation unit'.
- Left in an 'institutional' setting for three months and poor follow-up arrangements to return home.

Continuity of 'on-going' services

People felt that there was a real need for a 'holistic' approach to services and they felt that there is a lack of a 'joined up' approach to service delivery. They felt that there was poor 'follow-up' in the community, with services like physiotherapy, once you have been discharged from hospital. There were concerns about the lack of consistency and continuity, so that there is no ongoing process of care. They also pointed out that once you lose access to a service, it is very hard to get it back. Key issues raised were: -

- No consistency on leaving hospital with support from Occupational Therapy or Physiotherapy in the community.
- If your health improves, services can just get cut off. It is best not to give up any services during 'good patches' or they will get lost for good as it is hard to get services re-instated without going backwards into the system.
- Splints – availability varies and is a 'postcode lottery'. London is apparently much better than Kent in providing these. In Kent no funding was offered - a patient needs support from Physiotherapy and training to use a splint, but this is often not recognised as necessary for a stroke patient - only for a patient with head injuries.
- Incontinence Pads. One lady explained that she has to keep ordering these on a regular basis otherwise she will lose the service. Ordering has to be in bulk, so she has far too many, but the NHS will not take back the excess! This seems like a waste of money.

Rehabilitation

The 'Sapphire Unit', at Gravesend Community Hospital aims to provide Rehabilitation and Respite Services, but some people feel that this is very 'institutionalised', with some past users of this service saying that it is not a 'rehabilitation' service and is not supporting independence - with its 'locked doors' policy, very restrictive rules and limited visiting times. They also informed us that there is a lack of Speech Therapy for stroke or other related speech problems, and a poor follow-up service - with a lack of community links and liaison with community support services.

Enablement

One participant recounted how they had poor 'advice' about getting in and out of the bath after returning home from hospital, as this was not demonstrated by the OT – simply 'monitored'. They did not feel that this was an adequate 'aftercare' service.

Physiotherapy

A lot of the people we engaged with felt that Physiotherapy provision was very poor, as many people have had bad experiences. They have found waiting lists to be very long, during which time their condition and ability decline and when they do get physiotherapy, it is only for a short time.

In order to maintain or preserve levels of ability with an on-going medical condition such as MS, Physiotherapy is required regularly for the long term. One person with MS told us that she had eventually received a course of Physiotherapy, but she was only seen once a month and each time had a different Physiotherapist - each one was from another country, on a very short term placement while they travelled in the UK. This meant that she spent the majority of the session explaining her condition and what was normal for her and no improvements could be recorded as they had not seen her before.

A number of people have had to fund their own physiotherapy, but this is very expensive and not something everyone can afford to do.

If people want to try to maintain or improve their own mobility or fitness, they are facing real problems accessing and using public facilities.

Some of the problems people have experienced are :-

- Physiotherapy is available at schools but not at adult day services.
- People are waiting for adult physiotherapy services both at home or at day services.
- Some Hydrotherapy services in Kent are no longer available. A Hydrotherapy pool is warmer and safer than public swimming baths, where there is often no staff support for disabled swimmers.
- There are 'special' sessions for disabled people at public swimming pools, but in some areas these are only available at 8 am or 4 pm - the worst times if you are a Disabled Person.
- At Swanley swimming baths, the lift often does not work and there is 'no guarantee' it will work! There is also a very steep ramp, so access is a real problem.
- Concession rules have changed at 'Cascades' swimming baths and bowling - during school holidays concessions for Disabled People temporarily stop!
- Public gyms, whilst labelled as 'accessible', have very little specialist equipment for people with reduced mobility/physical impairment.

District Nurses

District Nursing Services seem to be declining. Few people we spoke to had any contact with a District Nurse. One individual recounted a negative experience with the District Nurses being inflexible and not being prepared to work around times he was attending the day centre. Apparently they could not co-ordinate home visiting times with the timetable for Swanley Active Lives Network day service - and so the District Nurse was stopped. This client is no longer supported with taking his insulin injections - something he finds very difficult. He feels this is a role for District Nurses because his carers are not allowed or cannot do this. He would like someone to monitor and support him more, but the District Nurses apparently are not keen to monitor and make home visits regarding insulin injections in future.

General Practitioners

- There is a real mix of feelings about GPs. Some people have a really good relationship with their GP and the surgery but others do not. This seems to differ from GP to GP and surgery to surgery, rather than region - people feel that this is down to 'luck'.
- Although the general consensus is that GPs do not have the time to be giving a lot of information. While there are a lot of notice boards and leaflets in surgery waiting rooms, there can be too many, and it is difficult to find what you are looking for. There is also little confidence about the quality of the information or how up to date it is.
- Some doctors seem reluctant to make referrals and people feel that often the GP doesn't know what services are available or what their role is in connecting patients to them.

What Service Providers told us

- The Providers and Professionals are also concerned about the division of Health and Social Care. They told us that there is a lack of communication between Health and Social Services.
- They would like there to be more information-sharing and a data-exchange - perhaps even sharing budgets. Due to 'red tape' they cannot do this at the moment, which leads to costly and timely duplication of information, data and research.
- They would like to see a lot more 'Joint Working' - the NHS and KCC having more opportunities to work together. GPs need to work with Providers and Providers need to work closer with Health Agencies.

What is working well

- Speech and Language Therapy Service in Maidstone.
- Sevenoaks Rehabilitation Service has been very helpful after a person has a stroke.
- Some people had the benefit of a Case Manager being situated in the hospital who saw them before they were discharged and others saw Specialist Nurses, so they had a point of contact once they had gone home.
- Some people have a really good relationship with their GP and their surgery.
- Kent 'Enablement at Home' service runs for three weeks and then the client is re-assessed. This helps people to look after themselves at home and looks at aids and equipment that they might need. This requires GP, hospital, or self-referral through an assessment centre.

Ideas for change

1. Clear Information and Signposting

- There should be someone based at hospitals or on duty at GP clinics to make new referrals, to offer advice or to signpost people to the help and support they require.

2. Relevant Training

- Improved training for GP's and District Nurses regarding 'disability awareness', range of disabilities and available services.

3. Care Plans for Hospital Admissions and Discharge

- Develop a Hospital 'Passport' of information when someone is admitted - but for all different disabilities. This would explain what the disabled person needs/prefers (like a 'mini person-Centred Plan') e.g. medication, personal care etc. These "passports" need to be recognised by both Health and Social Care authorities.
- Discharge from hospital – people need to be properly prepared before leaving – learning basic skills on how to cope at home – e.g. preparing food.

4. Health and Social Care services working together

- Better collaboration within the community - Health and Social Care Professionals need to be in one place working together – the process of ongoing care and support needs to be interlinked and have continuity. More follow-up visits are needed to people returning home from hospital
- There needs to be less 'red tape' about giving medication, so that Carers can be trained and be able to administer this, and therefore reduce the workload of District Nurses.

5. Expand Community Facilities and Services

- There needs to be a proper Community Physiotherapy service that also regularly visits day services, as they have done in the past.
- Community Sports and Fitness facilities need to be accessible and offer better support, as well as be specially designed or adapted equipment for physically disabled people to use.

Good practice examples

Hospital ‘Passports’

A group of people who have Learning Disabilities in Kent have developed a hospital “passport” of information when someone is admitted to hospital so that staff are aware of their support needs and preferences.

Social ‘Prescriptions’

Social ‘Prescriptions’ have been piloted in Bromley. Social Prescribing is a way of connecting individuals with health needs to a local support network. This can be developed along with a person-centred ‘Health Action Plan’. Social Prescribing’ is claimed to have a range of positive outcomes for individuals, including enhanced self-esteem, confidence and motivation to take on challenges, and also develop social networks. Social ‘Prescribing’ could also be linked to the role of ‘Care Navigators’ based in GP surgeries, who can help the individuals to access the services and supports they need.

RESPITE SERVICES

What is not working

Availability

There is a lack of information about ‘Respite’, or more to the point, ‘Accessible/Supported’ Holidays for physically disabled people and/or their carers and availability is limited. Disabled individuals need more help with finding and funding accessible holidays. For example -

- There has been no proper 'Respite Service' for physically disabled people for nine years to replace 'Crispin House', in Margate.

People told us that they are only being allowed funding for one week’s ‘respite’ per year. Many disabled people need much more and parents/carers need a few more breaks, such as odd weekends away.

Individual or Carer?

There is also some confusion about whether 'respite' means a 'rest' or a 'holiday' and if this is for the disabled person or their carer. Currently funding for respite does not pay for a carer to have a break too, and only allows a break for the individual disabled person to go away. Staying at home for an unpaid family/carer is not necessarily a break – carers need a break from looking after the home too! Direct payments can pay for a paid carer to accompany the disabled person but this funding does not pay for the holiday itself – unless that means a placement in a staffed 'respite care' facility with other disabled people!

There is a lack of support for people who don’t normally have paid carers at home and a lack of information about how to get support when they need a holiday (respite) and require extra support from paid carers in order to go on holiday.

Some individuals do not have enough hours of paid carer support for them to be able to take these carers on holiday and even go together with the whole family, rather than just have to rely on the

family to support them (for whom this would then not be a real holiday).

If some people had enough Paid Carer/Personal Assistant support – it would be easier for the whole family to go on holiday.

If a person has a paid carer and no family, apparently they are not entitled to 'respite' either.

Many people on benefits give up as they cannot afford a holiday and/or pay for the extra support they would need.

What is working well

- Case Managers organise 'respite' at facilities at Gatwick or Herne Bay.
- 'Two Way Respite' – arranged by Case Manager at Kiln Court, Faversham is very good.
- Good support from 'Crossroads' Service (3 hours per day).

Ideas for change

1. Fund and identify more breaks/accessible holidays for disabled people and unpaid carers

- Disabled individuals should be given more opportunities to have a supported 'break', by having a genuine holiday with the necessary funding for carer support, as opposed to a 'respite placement' in an institutional setting.
- Alternatively additional paid carer support could be made available going into the disabled person's home to allow family members to have a break.
- Disabled individuals and their (unpaid) family member/carer should also be given an opportunity to have a supported holiday **together** (e.g. husband and wife/partner!). Disabled people should receive additional funding for carer hours to allow them to take paid carers with them on holiday and also be able to go away with the whole family, who could also get a break from carer responsibilities.

Good practice examples

- '**Care and support**', **Dover/Canterbury/Swale** - very good at assessing and supporting carers, a 'very valuable service'. They have been contracted to do 'carers' assessments' too. (unpaid carers)
- '**Volcare**' (**Voluntary Care**) - provides respite for carers – offer a good service, either going into the home or supporting people away on holiday for up to two weeks. Carers are volunteers (come from outside the area so not too local). Service is free to client.
- '**Alices Escapes**' provides short breaks for people suffering from cancer.
- '**Parkinson's Society**' provides service where volunteers come into the disabled person's home to allow family carer to have a break.

AIDS AND EQUIPMENT

Specialist Equipment, Aids and Housing Adaptations

What is not working

Discharge from hospital

Time

People have experienced a lot of difficulty with obtaining equipment or adaptations to their home after being discharged from hospital with an acquired disability or after a deterioration in their

health.

There are many delays in getting adaptations fitted such as a 'wet room', which for some people can take as little as three months (Swanley), or for others a number of years (apparently up to four in Thanet!). It obviously varies across District Councils, but waiting times are generally very long whilst the adaptation plans and grant applications are processed between Occupational Therapists and Housing Departments. Then they have to wait for fitting/building work to be carried out. Many people have to return home before their bathroom has been adapted.

Funding

Some people end up borrowing money to pay for adaptations to be done privately, as it becomes increasingly difficult for them to manage at home. Others have to rely on their family to help financially or provide personal care until the essential adaptations are fitted. They just cannot wait for the long and complex process of going through their local Council and end up paying for it themselves, even if they are entitled to a grant. Sometimes they have to pay part of the costs - £1,000 in one case. One person in Thanet ended up paying £6,000 to have 'wet room' installed privately, whilst another Thanet resident was on the waiting list for over two years to have their 'wet room' installed. Another resident in Sheerness had to buy their own hospital bed. However if they cannot afford to do it privately they may have to wait for years, and this can only delay the disabled person's rehabilitation as well as affect the health of their family carers.

A similar situation applies to smaller items of specialist equipment such as splints and boots (which are difficult to obtain through hospitals) or a bath board – which some people have again had to purchase for themselves. However grab rails and bath rails tend to be fitted relatively quickly.

Choice

Sometimes Occupational Therapists provide equipment that the person does not really want or need or it can be poorly designed and is therefore of little use.

Housing adaptations

Time

Major adaptations to housing are again taking a long time or just don't happen. There is a lack of suitable adapted housing available. People told us that in their experience the recommended quota of 'disabled friendly' accommodation in 'new builds' is not happening in practice with private firms, although Housing Associations are trying to follow this quota. It can take a minimum of two years in many Districts for adaptation work to be agreed, planned, and completed. Sometimes it is not possible to adapt a bathroom or kitchen and the disabled person has to manage or move home - where the accommodation can turn out to be unsuitable anyway.

Another person in Sheerness (renting from a private landlord) was told their home was 'not fit to live in' when they applied for adaptations. The bathroom installation was eventually fitted, but was still leaking. This individual has been 'on top' of the 'priority housing' list for some time but feels no closer to finding suitable housing.

Disabled Facility Grants

People are finding that Council 'Disabled Facilities Grants' are very difficult to get and there is often at least a two year waiting list. Sometimes people are simply informed that there is no funding available.

However, people feel that the contractors that KCC use have inflated prices (contractors have to be on a KCC 'approved list'), but individuals are finding that cheaper quotes are available through other builders.

Instead of making the necessary adaptations, people reported that the Council seem to try to

overcome these difficulties by putting the onus on the disabled person and only offer cheaper options or 'quick-fix' solutions – which involves the disabled person having to make compromises in order to get the work done cheaply – for example accepting a stair lift instead of a downstairs toilet.

People appreciate that it is not always the fault of Occupational Therapy/Housing staff as they are dealing with a large bureaucracy which is reluctant to agree anything but 'minor' adaptations. It is understood that the Disabled Facilities Grant for adaptations ranges from £5,000 - £25,000, which means that smaller 'mid-range' adaptations cannot be easily funded. There is a suspicion that KCC are concerned that too much demand will create major problems for them - for example, the 'Home Support Grant' is not given much publicity. People agree that in the past the Council was very helpful with adaptations but the service has deteriorated through lack of funds and people remarked that 'the contrast is now dramatic'. They said that:

- OT/Housing Officers don't come out for home visits very often (they suspect that this depends on the disability benefits a person has).
- Disabled people don't expect the Council to pay for everything, but do need their advice and support!

Choice

Disabled people said that they can feel 'pressured' during assessments by Occupational Therapists, when they do not take into account how the disabled person wishes their home to be redesigned to meet their disability needs. People feel that they are not given enough choice and that proposed adaptions are not always fully discussed or even agreed with them. For example, one person was fitted with an indoor lift but was not consulted about the implications this had on their kitchen or the necessary re-organising of doorways in their home. People recounted how they were made to feel that only the professional 'knows best' and that they ignored the individual preference of the disabled person.

- The professionals are 'playing it safe' by quoting 'health & safety' and making compromises that people don't want – these changes to their living environment are 'system-centred' not 'person- centred'.
- Disabled people want professionals to stop 'overprotecting' them by insisting they have adaptations they don't want e.g. 'through floor lift' instead of stair lift or downstairs facilities, widening door widths unnecessarily, or doing much more than is needed and unnecessarily restructuring the person's home. This is very costly but does not always need to be – the disabled person often knows better than anyone what they can manage and what compromises they can put up with.
- People feel that the 'professionals' need to listen to the disabled person and their family. Sometimes the bureaucracy is 'over-providing' aids and adaptations that people do not want or need. One family was told that if the recommendation from the Occupational Therapist was not accepted they would not get any grant, so the family gave up!

Poor Advice

The system for eligibility for funding for equipment and adaptations is not clear and people feel that there are too many rules about eligibility - e.g. needing to prove you will stay in your home for five years, if it is to be adapted. There is too much 'red tape' to just get a simple handrail – too many different people seem to deal with this and the bureaucracy slows things up.

There also is a view that some professionals carrying out assessments for housing adaptations actually do not have the skills and proper training and are giving bad advice. The concern is that Occupational Therapists are not always well-informed, are unclear and can even misinform people. There is a suspicion that this is to make sure there are not too many claims!

There is agreement that things need to be put right the first time, as fitting the wrong adaptation means having to return and refit it, which is again very costly.

[Post Code lottery](#)

The groups we spoke with believed that funding for Aids and Adaptations varies across Districts. In Thanet they felt that resources were limited as Thanet District Council has much less funds, whilst they thought Swale/ Herne Bay/Dover/Tenterden/Deal all vary but generally are short of funding. They think that things are very different (better) in other boroughs e.g. Bromley!

What is working well

- It helps if a Disability-Led Organisation makes the referral and follows it up.
- Good advice can really help in claiming a Disabled Facilities Grant.
- Some people in Canterbury are getting a good service from Occupational Therapy & Physiotherapy because the installation of aids and adaptations moves quickly with a proper initial assessment and ongoing support. Also good support from Case Manager regarding funding for this (but does depend on Case Manager). Occupational Therapist organised grab rails at a person's home within a reasonable time period.
- Two sets of crutches easily provided by Canterbury Hospital - one for upstairs and one for downstairs.
- In Folkestone money was available for minor adaptations with good support from KCAS e.g. grab rails fitted quickly.
- West Kent Housing organised handrails, stair rails and wet room efficiently.
- People from Thanet are quite happy with their adaptations and equipment services. Occupational Therapists are very active and have much direct contact with Swale Stroke Group. Disabled Facilities Grant takes about 18 months from beginning to end. Thanet do not have a waiting list.
- Sometimes the Council uses specialist organisations such as the Parkinson's Society to progress things.
- KCC can offer an 'interest free' loan.

Ideas for change

1. Review Disabled Facilities Grant process

- Case Managers and Health Care Professionals should aim to fund high quality equipment and adaptations to facilitate independent living, make sure that it is most appropriate to each individual's needs and provide proper on-going support/follow-up/monitoring etc.
- KCC should explore cheaper quotes from a wider range of contractors who are available and review their 'approved' list to ensure that they are getting the best 'value for money'.
- Initial assessments for types of aids and housing adaptations need to be more accurate – so that they get things right the first time – fitting the wrong adaptation means having to return and refit – which is wasting money.

2. Monitor Specialist Equipment provided

- KCC should monitor the equipment that is given to people who need it. If it is not needed anymore it should be returned and passed on to someone else, or sold as affordable second hand equipment.

3. Involve Independent Disabled People's and User-led Organisations

- Council's could save money by working with independent disability-led organisations to deliver equipment, aids and adaptation information. These are the people with the first-hand experience who can also provide alternative ideas from their own lived experience, such as the best place to buy equipment directly online etc.

Good practice examples

- People from Thanet are quite happy with their Adaptations and Equipment Services and apparently there is not a waiting list – they feel that their service would be a great example of 'Best Practice'.
- Occupational Therapists are very active and have much direct contact with Swale Stroke Group.
- 'REMAP' are very helpful – they design and provide individually tailored equipment, take on complex problems of equipment design – and come up with 'clever' solutions. They like challenges!
- West Kent Housing also has a good 'Handyman' service' - a 'Mr. Fix It' – a free service for disabled tenants on benefits - does little jobs – e.g. fitting smoke alarm, security etc.

What Service Providers told us

Providers were clearly aware of the above difficulties with the system for providing specialist equipment and the complex and lengthy process of applying for Disabled Facilities Grants. They would welcome improvements.

Wheelchair Service

What is not working

Time

In the experience of the wheelchair users we engaged with, it generally takes a long time to obtain a wheelchair, usually taking at least six months and then this can vary between Districts. More than one person recounted that it can take up to three years in some cases as there are long waiting lists. There can also be a long wait for repairs. For example:

- People in hospital can be left blocking beds as they wait for their wheelchair. The number of wheelchairs available has also been reduced – people used to get new one every five years but not now - they just get parts/accessories.
- People can also wait over a year for the Council to put in a 'dropped kerb' for wheelchair access and suspect that local Councils are cutting back on 'dropped kerbs'.

Location

They pointed out that all Wheelchair Services are now 'lumped' under Kent & Medway with the aim of improving efficiency, but people are not optimistic. They also do not understand why the NHS service moved away to Canterbury?

Funding

People said that they are having to make difficult choices between meeting all their equipment needs - for example, the mobility component of Disability Living Allowance can either be used to purchase a powered wheelchair or a 'Motability' car, not both. Some people also said that they are having to purchase wheelchairs out of their own funds even though they are entitled to assistance with funding – because it just takes too long and there is too much 'red tape', with constant assessments and re-assessments (which often prove to be inaccurate).

A resident in Sheerness had to buy their own powered wheelchair and even had to buy their own wheelchair tray, whilst another person bought their own power chair (and bags/holders for the back of it) at a cost of £2,000 because he did not know if he could get funding for this. Another person wanted a 'lighter' chair – so elderly parents could lift it. However, the Wheelchair Service did not agree, so the family had to buy the wheelchair themselves.

Wheelchair Assessment

People are not being properly assessed and it is not uncommon for the wrong type of chair to arrive.

A lot of form filling is required, especially if there is a need to change the original order after another assessment and the type needed is not the same. One individual was 'assessed' over the phone because an assessment visit would take at least 6 months to book.

It was pointed out that it is difficult to get a 'power chair' rather than 'manual' chair from KCC/NHS and that you have to have a 'special assessment'. There are strict criteria for getting a 'powered' wheelchair instead of a 'manual' wheelchair – the disabled person has to have an 'indoor chair' for six months before they can qualify for an 'outdoor' power chair, assuming that it takes all individuals that long to learn how to use it!

What is working well

- Wheelchair Service (NHS) in Canterbury is very good.
- 'Mobile Wheelchair Repair Service' in NW Kent (John).
- Wheelchair Service based in Maidstone, which makes home visits and comes out to Chipstead Lake Day Centre.

Ideas for change

1. Reduce Bureaucracy

- Assessments should be more accurate and the whole application process speeded up.

2. Better Training

- New Services need to know what they are doing - as a wheelchair is usually for life. Training should be provided by wheelchair users.

3. Review Policy

- People are finding the eligibility criteria for a wheelchairs and the voucher system unrealistic. At the moment people need support or confidence to challenge the rules, in order to get around unnecessarily strict rules of eligibility – e.g. house must be 'fully accessible'.

Housing Needs

What Service Providers told us

What is not working

Case Management Providers told us that there is:

- Lack of provision for supported living.
- Lack of housing provision, especially for young adults.

DAY SERVICES

What is not working

Differences in philosophy and perception of the concept of "Day Services"

Historically there has been a major difference in perception between Kent County Council and physically disabled users of day services – particularly day centres/resource centres. Kent feel that the traditional day centre model is 'institutional' and members should be encouraged to access ordinary community facilities. However disabled people do not feel there is enough evidence that a wide range of community facilities/activities are available to them or are even physically accessible! They therefore have no option but to continue to attend day centres. They also do not agree that these centres are institutional – in fact they value them for many things – especially the social networking and support they get from their fellow members and staff there. They also suspect that the reasons behind such closures are financial and whilst some day centres have been expensive to maintain, KCC have not put much of these savings from closures into creating and developing a reasonable range of accessible day service alternatives in the community. Staff at day centres are nevertheless trying to do what they can to develop community opportunities for members to expand the range of options and for them to be able to follow interests and leisure pursuits and even employment. It is ironic that some day centres are actually unable to take in individuals who have severe physical disabilities requiring a higher level of support because they do not have enough staff to provide 'one to one' support.

There is now real concern that the current day services which are still based around a traditional resource centre/day centre model, ranging from the 'Active Lives Network' in Swanley, Gravesend and Dartford, to the 'Well Resource Centre' in Dover and the 'Freedom Centre on the Isle of Sheppey, will close with nothing to replace them. Also Parkwood Day Centre in Maidstone is poorly funded and members do not have funding for attending enough days a week. There is a lack of information from KCC about what is happening and members are not convinced that KCC really want these services to continue.

Closure and Re-provision of Day Services

Most people using the Active Lives Network still mourn the loss of the Queen Elizabeth Foundation, Brent Resource Centre, in Dartford, which they feel was better than the current service. Even residents from Medway used to attend, as they preferred this to what was available locally. It was purpose built and had better facilities with everything together in one place. There were separate rooms and areas for a wide range of facilities:-

- Art Room
- Gymnasium
- Computer room
- Lounge area/games room
- Garden/greenhouses
- Proper changing/bathroom /toilet facilities
- Canteen with subsidised food

The Simon Paul Foundation was also based there providing information and advice and it was easy to get help and advice by 'popping in' to the Simon Paul Foundation office.

After the closure of the Queen Elizabeth Foundation Resource Centre in Dartford in 2007, where

the range of activities was based within one purpose-built building and members could attend for several days a week, the service was reduced to one day in Swanley, one in Gravesend and one in Dartford using three different buildings - two of which are not purpose-built. Members feel that these are being poorly funded.

Members were promised that they would be able to set up a new and better user-led day service with the help of an independent provider. Members were involved in developing the tender and interviewing prospective providers. Eventually the independent provider, 'Inspire,' was commissioned. With limited funding they have made a genuine effort to maintain a range of activities within the buildings provided, have purchased their own transport and begun to develop links to community facilities.

Some Kent residents have preferred to go to the Leonard Cheshire Day Centre at Chipstead Lake, where they can attend more than one day a week. Alternatively another group of ex-members set up their own charity, the North Kent Disabled Foundation, and rented a building in Dartford to set up their own day service based on the traditional model, because this is what a number of ex-members of the QEF wanted. They have also raised significant funds to purchase their own transport.

Increased Charges

After the Queen Elizabeth Foundation, Brent Resource Centre was closed with the promise of better day service opportunities, members were promised that their attendance at the new ALN day service was guaranteed and that the funding was 'ring-fenced' for their future placement. However KCC changed the criteria and 'moved the goal posts' as now everyone has to be financially assessed and be in receipt of a Direct Payment (unless they can afford to pay themselves) in order to attend the Active Lives Network and all new referrals require referral to a Case Manager for a financial assessment for a Direct Payment. All the day services we visited were concerned that the assessed contribution charges had become too high and some members are finding that the combination of a harsher financial assessment together with other benefit reductions means that they can no longer afford to go. The resulting reduction in numbers indicates that the service is being run down and the remaining members are worried that the Active Lives Network day service will be closed completely. To add to this there is not enough publicity about benefits of the ALN service, whilst other day service options are not being offered or publicised.

People told us they felt that Disabled People have to 'fit in' to what is provided, rather than have service designed around their needs.

Whilst service planners are rejecting the traditional day centre model as being 'institutional', many disabled people using day services feel strongly that this is a model they prefer, particularly as few alternatives are available, which are accessible and allow them to develop a wide range of interests whilst retaining their social network. They feel that what is left is being run down – as money is not invested in the buildings, staffing, developing new activities, or transport to get there (which Direct Payments do not cover), and there are signs of rising attendance charges on top of harsher financial assessments.

Members feel that KCC are cutting costs whilst not looking at what can actually replace traditional day services. If places like the Active Lives Network, Freedom Centre and the Well Resource Centre close, people will regress and become isolated – a vicious circle will develop as services are lost and people suffer. People feel that if they cannot afford to access meaningful daytime pursuits and social networks, they have nothing left.

Accessing alternative facilities in the community – leisure centres

Members told us that they were promised that alternative day service facilities such as leisure centres would be fully accessible and inclusive. However they told us that 'Cascades Leisure Centre' has unnecessary rules which exclude some disabled people - e.g. members cannot wear jeans as apparently this 'wears out' the equipment, or wear trainers. In fact, this is what a disabled

person needs or prefers to wear as a wheelchair user – for comfort and to avoid pressure sores/sore feet etc.

Cascades Gym also requires members to have a special medical certificate in order to demonstrate that members are 'fit to use the equipment' – apparently due to Health & Safety 'Liability' issues. GP's have apparently not been keen to issue a certificate to a disabled person. However, they have been prepared to issue a letter, but at a cost of £30.00. People on benefits can barely afford to pay this and why should they? People feel that there are lots of barriers and red tape preventing disabled people accessing Cascades Gym – many more would like to go!

Those who have attended have noted that staff at the Gym have not had the time to get to know individual disabled people well enough and need training (both general training and working directly with the individual) in how to best assist them.

The Hydrotherapy Pool at Darent Hospital is under-used and staff are not available on site to assist. Disabled people cannot just turn up – they need a formal referral to access hydrotherapy.

What providers told us

What is not working

- Charging policy and rates. In the past, KCC were charged a reduced amount for sending service users to day services provided by independent organisations on a block contract arrangement. Now that there is a move to Direct Payments, the amount that KCC will give to an individual to continue to attend the service remains the same. However, this was a reduced amount so the day services are having to charge individuals the full cost, which means that the Direct Payment that a person receives does not always cover the cost of attending the service. Providers can charge more to people with Direct Payments, and this results in some people not being able to afford to attend.
- KCC Direct Payment rate does not include transport and this is particularly a problem in rural areas.
- Cuts in benefits to service users – including cuts to transport to access day services such as Leonard Cheshire, Chipstead Lake and Aylesford. It is more difficult for new users to come to such rural areas - for example, a taxi fare can be £40 per day.
- Not enough community opportunities for young people – especially in current day service provision and not enough available through generic services – for example, lack of clubs for people of the same age group.

What is working well

What Day Service Users told us

- **Maidstone Leisure Centre and Parkwood Day Centre** provide a good service.
- The **Well Resource Centre, Dover** provides a good service - it is 'a place to make friends' - and 'feel safe' and members value the importance of peer support. It is open to people with any disability. Should be signposted as an example of good practice.
- The way the independent provider '**Inspire**' is running the '**Active Lives Network Day Service**' in N.W. Kent. 'Inspire' invested in this service - including buying two buses and employing staff. ALN members come and go as they please from bases e.g. Dartford Community Centre. Staff will support disabled people to go swimming and bowling. Bringing in 'Inspire' to run the ALN Day Service was the one time ALN members feel that

KCC really listened to them.

Some of the positive things people said about it:

- ❖ Being at the ALN 'is enough in itself - for company, support, socialising'.
- ❖ 'People don't have much else to do'.
- ❖ It is a 'Godsend' to 'be able to go somewhere'!

- The **Freedom Centre, Isle of Sheppy**, provides a good service. It offers a great deal to many people - a range of activities - Artwork, Social History class (members have written books), English, Computers, making Calendars (for fundraising). Members feel that the Freedom Centre is a 'unique centre'. Management are the only ones fighting for members and support from each other is so important.

Some of the positive things people said about it:

- ❖ 'We have 'the finest Tutors'.
- ❖ Staff are non-judgmental and 'treat us like human beings'.
- ❖ 'We are one happy family'.
- ❖ Provides a 'sense of belonging'.
- ❖ We can 'leave disability at the door'.
- ❖ 'It's about what you can do, not what you can't do'!
- ❖ Makes people feel 'enabled' not 'disabled'.
- ❖ It is like the 'Holy Grail' to people.

Members feel that the Freedom Centre is a 'unique centre' .Management are the only ones fighting for members and support from each other is so important.

- **Ashford 'Headway'** provides a good service. They have structured sessions in the mornings (e.g. literacy, numeracy) and informal sessions in the afternoons (e.g. games – as members are more tired.) They also go on outings. Members feel that they can relax and learn/re-learn skills again – rehabilitate. Members also support each other at Headway as a social group and feel that they could not manage without the help and support from 'Headway' day service.
- **Leonard Cheshire Day Centre, Chipstead Lake**, provides a good service. Members feel well supported by staff and come from a wide area in Kent :-
Swanley/Maidstone/Eccles/Gravesend/East Peckham/Sevenoaks/Larkfield/Tonbridge

Members do things they like/choose from a wide range of activities: -

- Cooking/pottery/ceramics/card-making/jewellery-making
- computers/needlework/music/gardening
- Sports: - 'crazy-golf'/'botcha'/football/archery/ten-pinbowling/curling/sailing/boxing!
- Cycling (at 'Cyclo-Park' Gravesend – new/modern venue)

All activities are free (apart from daily fee). Additional funding granted from Sport Relief!

Some of the positive things people said about it:

- ❖ "Best place to come". "We are like a family".

- **North Kent Disabled Foundation Day Service, Dartford** provide a good service. Currently cater for 38-70 age range. Must be ‘meaningful activities – so people want to come. Raised over £70,000 themselves to purchase their own accessible mini-bus with tail lift.
- **OT Service User Group, Broadstairs** provides a good service. ‘A great way to find out information and advice from Occupational Therapists and find out what is going on in the area’.

Ideas for change

1. Establish stronger links with Day Services

- More Senior KCC Managers need to go out and visit day centres to talk to people, explain what is happening regarding future planning and listen to what the members want.
- Case Managers should have better links with the day services so that people can understand who they are and what their role is. Visiting day services is an efficient way for Case Managers to pick up/follow up a number of referrals during one visit.

2. Maintain and Improve current Day Service provision or provide better alternatives

- Many members felt that the ‘Active Lives Network’ Day Services should revert to being provided in one large building, instead of splitting everyone up across Swanley, Gravesend and Dartford, so that they can participate more than once a week.
- Disabled People need to keep using/attending the Active Lives Network Service - otherwise this service will be lost. The ALN should be able to cater for all levels of disability – including ‘high level’ disability, which is not catered for as this often requires 1:1 support and there are not enough staff resources available. If people with ‘complex’ care needs had adequate Personal Assistant support through Direct Payments this might not be an issue.
- Provide ‘domiciliary/community’ physiotherapy at Day Centres so that many people can benefit. This could offset the lack of domiciliary Physiotherapy.

3. Improve accessible community facilities

- Public facilities’ staff require disability awareness training and changes are required to ensure facilities are fully accessible. Local sports facilities need specialist equipment so that anyone can use them.
- Staff at Cascades Gym do not know individual disabled people well enough and need training - both general disability awareness training and directly with each individual to learn about their support needs.

4. Improve public transport and access

- Until public transport and communities are made adequately accessible there will be a requirement for day centres. At the moment many of the day service attendees do not have real alternatives.

Good practice examples

- **Strood Leisure Centre, Medway**, offers specialist gym equipment and instruction by a staff member who is himself disabled.
- Some members attending **Ashford Headway Day Centre** have Care Agency staff coming in to provide individual support to them at mealtimes.
- **L.B.Bexley** day services are apparently able to cater for people with higher level support needs.

ACCESSIBILITY

What is not working

General

People that we talked to gave us many examples where buildings or facilities were inaccessible on the outside and/or the inside. There is a lack of disability awareness by town planners, architects and builders to accommodate the needs of disabled people and far too many buildings do not have reasonable wheelchair access or access for disabled people with other mobility difficulties. A lot of work still needs to be done to improve accessibility. The concern is that planners may just see disabled people as 'wheelchair users' rather than being blind, deaf or having a range of other disabilities.

There are not enough accessible facilities available in the community and people have to plan ahead and be well organised in terms of transport/access etc. This stops spontaneity when going out, as everything has to be carefully planned!

"If we complained about every issue we would do nothing else!"

Toilets & bathrooms

- Accessible Toilets are not always properly adapted to meet the needs of a full range of people with different disabilities and many do not have enough room for those individuals who require extra assistance from a carer.
- Doors can often be poorly designed for wheelchair users, with limited turning space. People commented that sometimes they 'Can't get in' - 'Can't get out'!
- Many accessible toilets are too low.
- Not everyone knows about the 'Radar Key' scheme or where to get a key from.
- Accessible toilets tend to be used by everyone, often have 'any old lock' and not always a 'Radar' key.
- Access to toilets in restaurants needs improving.
- 'Baby-changing' facilities should not just be located in accessible toilets.
- Accessible public facilities for washing/bathing (with hoist available etc.) are poorly advertised.

Leisure facilities

- The Hydrotherapy Pool at Medway Hospital was closed 5 years ago and all the original fund-raising efforts are now wasted – people told us that the facilities were very good with two Physiotherapists on duty. The service was closed and not replaced!
- Public swimming baths are too cold for many disabled people to use, as they often require a much warmer temperature than the average person and they usually do not have equipment such as as hoist or staff to assist. The swimming baths in Folkestone make disabled people go outside to get into the pool and also to get back (when wet!) to the changing rooms.

Cinemas & Theatres

- The location of seats in the theatre in Dover are not allocated with disabled people in mind. They are either at the back or end of a row, with a bar on the balcony which creates a restricted view. There is just one long row of seating for disabled people, which is typical of

many such venues.

- The 'Ashford Multi-Screen Cinema' has a screen which is far too high for people sitting in the 'wheelchair area' – customers have to look up all the time and then get a stiff/sore neck!
- Disabled Parking bays are often all taken and disabled people often give up without returning to use the facilities.

Shops

- Folkestone Shopping Centre - shops do not always make it clear that they have a portable ramp which is available on request.
- Too often shops have steps in shop entrances and many are still not ramped.
- In Sittingbourne ramps at supermarkets are not safe and are unstable. They are not suitable for some types of disability.
- A number of shops in Canterbury and Ashford have narrow aisles limiting wheelchair access.
- Lifts are available but not always obvious, and staff do not always want to bother to ask if a disabled person needs assistance. Lift doors and automatic shop doors can shut too quickly.
- There needs to be better advertising in shopping centres about accessibility!

Dropped Kerbs

- In Sittingbourne there are not enough 'dropped kerbs' in the town and in front of houses in residential areas.
- Alternatively there can be too many 'dropped kerbs' on some streets which creates very bumpy/narrow pavements with not enough room to get by in a wheelchair.
- Bricks are very bumpy for wheelchair users.
- In Ashford one individual's 'threshold' access at home took 18 months to sort out, then the council got it wrong - so they then needed to replace it!

'Folkestone Support Centre'

- It is ironic that this centre which sells mobility equipment has no lift, no raised kerb, an unsafe portable ramp, narrow doors and wheelchair-users have to go a long way round the back to get in!

Gritting pavements during winter

- Sevenoaks Council have not been gritting pavements around public buildings during snowy winter weather or around residential areas where disabled people live – apparently they are 'not allowed to' and the public are not allowed to do this either - as they could be sued if someone else slips and is injured!

What is working well

- Folkestone - Local 'Access Group' completed a 'wheelchair access survey' and published an access guide to Folkestone called 'Information is Key'.
- Canterbury town is generally accessible.
- Sittingbourne shopping centre is accessible.
- Darent Hospital in Dartford has a proper Hydrotherapy Pool.
- Dartford Access Scheme involves putting labels in shops which are accessible. Canterbury

University 'Access Group' levelled steps on campus and installed disability toilets recommended by 'Design/Library Group'.

- Ashford: - 'Open plan' design of town square has a 'European feel' - 'Shared Space' concept. This is more attractive, safer and good for wheelchairs - as no kerbs and one way streets.

Ideas for change

1. Review and upgrade access to public buildings and facilities

- All buildings and communities should be made 'Disability Discrimination Act compliant' under the new Equality Act 2010. This could be 'policed' by local Disabled People's Organisations, who could offer information and advice to public services and local businesses. Councils need to use the expertise of disabled people ('Access Groups' or D.P.U.L.O.s) to design and review access requirements and be able to advise people in authority who will listen.
- More disability awareness training should be provided for town planners, architects and builders as well as staff in public facilities – they need to understand what it's like to be in a wheelchair or blind (e.g. by being blindfolded during a training session).

2. Maintain an accessible environment

- Up-to-date information about what is accessible locally should be regularly available within all District Councils (e.g. Folkestone 'wheelchair access survey' - 'Information is Key')
- Councils need to grit pavements more efficiently during icy and snowy weather, as this is particularly a problem for wheelchair users and those who use walking aids.

3. Better Facilities for disabled swimmers

- Need to have more Hydrotherapy Pools (attached to public baths) which are extra warm - as most public baths are too cold for many disabled people. Appropriate equipment and 'hands on' support should also be made available.

TRANSPORT

What is not working

Public Transport

Amongst the groups of people we met, there were rumours that there are going to be further cuts in transport services and disabled people are already having many problems with transport within Kent, so there are a lot of concerns that they will feel even more isolated than they do now.

People are finding public transport poor, with little provision for accessibility. When travelling, people with physical impairments need to plan ahead. They are not able to be spontaneous, as the transport system is not reliable. Accessing the community can be very costly for people on benefits and even when they have travel passes, they are very restricted to the limited times that they can travel for free.

Buses

Bus travel is improving, but too slowly and bus drivers are not always helpful. They sometimes do not explain or demonstrate that the bus has a portable ramp and/or drive carefully when stopping next to a kerb, as they leave too much of a gap. Apparently there are strict rules that the driver cannot get out to help passengers and on-board cameras enforce this.

There is no modern clamping equipment or fitted seat belts on buses for wheelchair users. There is also the very frequent issue of pushchairs and children's buggies taking up the only wheelchair

space. A wheelchair should have priority, as a child can often be taken out of their pushchair and the chair folded out of the way, an option not available for disabled people. At present, disabled people are having to have this discussion (or argument) with the passengers, but it is felt that it should be the driver or the responsibility of the bus companies to adequately display this information.

Wheelchair users do not wish to have to cause a scene or be the focus of attention whenever they use a bus. There is also only space on buses for one wheelchair, making it very hard for wheelchair users to go out together. In some areas they are finding that electric wheelchairs and scooters are not allowed on the buses and in other places an individual requires a 'scooter bus pass'!

People already experiencing cuts to bus services were complaining of less buses and routes, while the fares continue to rise.

Bus passes are also a bone of contention. There are too many restrictions on bus passes, such as limited times and bus routes which qualify, so this just isolates and excludes disabled people. Some of the comments people made were:

- "Bus companies seem to think that disabled people do not get up and go out before 9.30.am!"
- "I am disabled 24 hours a day - not just from 9.30 am 'til 7 pm!"

At the moment not all buses are accessible. In Broadstairs the Occupational Therapy Service User Group said that they were promised 18 new accessible buses after the Olympics, but this has now been moved to March 2013.

Bus services vary from one area to another but other common complaints are:-

- Very infrequent services.
- Buses not sticking to their routes - so sometimes don't turn up.
- Lack of raised kerbs.
- Lack of Sunday and evening bus services.
- Lack of routes in rural areas.

Trains

Train journeys have to be planned with 24 to 48 hours' notice in advance of any journey with SE Trains, in order to book travel 'assistance' (which only provides help for a person to get on or off). If they travel daily, disabled travellers still need to give notice.

Not all stations are accessible, so a disabled passenger needs to check this before travelling or planning their journey. Deal Railway Station has no lift and it is a long way round to access the platforms by wheelchair. There is now a lift at Swanley Railway Station, but it is shut down after 8 pm. Railway station platforms are not all at the same level and gaps vary - so a wheelchair user or person with mobility impairments would struggle to access trains alone.

Taxis

There are a limited number of wheelchair-accessible taxis, and these always seem to be used and never free when people need one. There is a lack of information about accessible taxis for customers but also taxi firms offering this service. Taxi cabs which are accessible qualify for a reduction on their licence fee! Wheelchair users complain that they are not always strapped in securely. Taxis are a very expensive way for people to travel - especially when they are on benefits, but it is the only option for some people. For example:-

- One family has to use taxis to take their disabled daughter to hospital as public transport, community transport, and hospital transport are all inadequate.

Community Transport

The 'Community transport' service also has to be booked ahead - sometimes one or two weeks in advance for some schemes. It is very reliant on volunteers and there is always a need for more volunteer drivers. Usually these services are run by Voluntary Organisations who have limited funding, so administration for co-ordinating the service suffers and phone lines often have limited contact times.

'DIAL A RIDE' has been criticised as too inflexible, covering a limited area and has been described as 'useless!' People commented that 'they assume disabled people only want to travel before 6 pm!'

The Community Transport scheme 'Sun Bus' is also not ideal, as you have to order/book it and it is not much use for group travel.

Often these Community Transport services are forced to give priority to medical appointments due to the lack of resources.

Hospital Transport

When Hospital (Ambulance) Transport picks up the patient from their home and takes them to the hospital, in user's experience, a carer/partner cannot accompany them. The patient may feel anxious and distressed, so would really benefit from having someone with them. Apparently they cannot take electric wheelchairs.

There is a lack of clarity and understanding about entitlement to hospital transport, when the patient is in receipt of the Disability Living Allowance 'Mobility Component'. One individual had waited for hours for patient transport home, but was refused because they receive the DLA Mobility Allowance and were told that free transport is not provided for them like other patients, even though their illness impacted on their ability to use other transport options. This should not be the case and there needs to be more clarity on this with hospital transport services.

People complained about the lack of sufficient disabled parking bays at hospitals. One disabled individual was forced to park in an ordinary space when no disabled parking bays were available and got a ticket! This person felt that it should be a training issue for the parking attendants/traffic wardens.

People feel that there has been a big change in criteria for hospital transport services and that this is unacceptable. Patients are being told to drive to their hospital appointments, regardless of whether they are having treatment that affects their ability to drive.

The groups that we visited felt that they should not have to spend ages 'begging for this simple service'.

The general feeling about public and community transport is that 'it is easier to drive or be driven'!

Private – Motability

Many people with a physical impairment who receive the higher rate mobility component use this to get a Motability car. However, they feel that there is an assumption that because they have a car they are mobile and able to travel independently, but many people still have problems with getting in and out of their car and then also accessing buildings or the community, when they get out of the car. There is also an incorrect assumption that every disabled person will always have someone with them.

For a disabled person, having the use of a car is good - but there are still many problems that physically disabled drivers face. One person had to pay for his own disabled parking bay outside of his house, so that he could park close enough - but other disabled drivers would use it, as there were no other disabled parking bays nearby! The lack of accessible parking bays is a real problem in the community and the abuse of these bays is not sufficiently 'policed'.

Blue Badges

Most people with a physical impairment and mobility problems should be entitled to a Blue Badge, but these need to be easier to obtain and people need to be better informed about how to apply for them. Blue Badges expire after five years, but there are no reminders for renewal. The renewal process can take ten weeks, which is a long time to be without a badge, if you have not remembered soon enough. If an application for a Blue Badge is turned down, the appeal also takes too long and people do not know what they can do for transport in the meantime. All this will mean that the disabled person is unfairly left without transport!

Groups are concerned about how the changes from Disability Living Allowance to the Personal Independence Payment may affect their eligibility for Blue Badges and Motability cars.

Insufficient accessible transport provision in Kent is hampering access to the community for people with a physical impairment, and particularly for those who we spoke to, in accessing the following groups:-

Leonard Cheshire, Chipstead Day Service

Chipstead is in a very rural location with very poor public transport links and no raised kerbs closeby, preventing wheelchair users from accessing bus services. A 'Fast Track' bus service was promised but has not been set up.

A taxi fare can be as much as £40 per day and whilst KCC will pay for individuals to attend the service for up to three days per week, they are not prepared to pay for travel to and from the centre and it is not being factored into Direct Payments. Members have been fighting this for many years but with no success.

Active Lives Network

Since the Queen Elizabeth Foundation Day Centre (Brent Way, Dartford) closed, some members can no longer travel to the new venues at Swanley, Gravesend and Dartford, often because they do not live close enough to the relevant venue, or to the one they wish to attend.

Swale Stroke Group and Freedom Centre

Members have to rely on other members to take them to the Stoke Group. They have found public and community transport unhelpful. They believe that community services should be on a good bus route/train connection in order to be accessible.

Pedestrians

For people with physical impairments it can also be difficult being a pedestrian, whether using a wheelchair or other walking aids. The main concerns are:-

- Traffic lights/pedestrian crossings often do not allow enough time for a disabled person to cross the road safely.
- Too many 'push bikes' on paths or bicycle lanes, which is awkward for disabled people
- "Don't 'think bike' - 'think disabled people'!"
- Lack of 'dropped curbs' near community facilities such as leisure centres.

What is working well

General

While there are the problems we have listed, people are also having good experiences with travelling.

Buses

Having a bus pass is good, and it makes travelling by bus affordable. There are some accessible bus

routes that people think are working well, even if these are very limited.

Trains

Railway staff have been found to be very good, happy to help and efficient. Railway stations are gradually being improved - for example, the addition of a lift at Swanley Station, albeit only available until 8 pm.

Taxis

Taxis are mostly OK: 'When you get a good one stick with it'!

Community Transport

Community services (where they are running) are found to be very reliable, with friendly volunteer drivers. People are happy to pay the cheaper petrol mileage, but it is a shame that these schemes are not more flexible and they are very busy.

Hospital Transport

- Service for attending hospital appointments (Sittingbourne, Medway Memorial) is good - just phone up and transport is arranged.
- The HD1 exemption form is for help with hospital transport and includes help with car mileage.
- Voluntary Driver Service is very good for a reasonable charge.

Motability

People find 'Motability' to be very beneficial, as it takes the worry out of car ownership. Disabled People like the freedom that having a car gives them.

Dropped Kerb

West Kent Housing fitted 'dropped kerb' very quickly.

Ideas for change

1. Address issues of accessibility, availability and training

- All public transport should be available to disabled people at the same times as the rest of the public.
- Ensure that all public transport companies and staff have thorough disability awareness training carried out by disabled people, to highlight their responsibilities and to demonstrate how disabled people wish to be assisted.
- All railway stations should ensure that lifts work at all times.
- Bus passes should be valid at any time. Clear information needs to be displayed on buses and bus stops to show that wheelchairs have priority. More funding needed into bus services so that rural areas can be better served by bus routes.
- Increase the number of accessible taxis.
- More investment in Community Transport services so that priority does not have to be medical appointments and so that it can be open to all disabled people not just those over 60.

NB: The Daily Mirror (16 February 2013) reported that disabled bus and coach passengers must wait up to 5 years for proper help on journeys after the Government shelved plans for mandatory training for drivers. Awareness courses will be optional. EU law states that disabled people on long distance coach journeys are entitled to free assistance.

2. Blue Badge reminders and Parking

- KCC should send out reminders for renewals of Blue Badges - in line with national car road tax disc reminders.
- Parking meters should make it clear if parking is NOT free for Blue Badge holders. Training or rule changes needed for parking attendants/traffic wardens to allow people to park in ordinary parking bays, if all disabled parking spaces are taken.

EMPLOYMENT

Nationally, disabled people of working age are expected to be at work if they are deemed 'capable' by 'Atos Healthcare'. However the way that this is being forced upon genuinely disabled people, many of whom may never have worked before, leaves much to be desired and actually can put them off from seeking paid work. The current system does not adequately support individuals to find a job that matches their skills and aspirations.

A job can boost a person's self-esteem and give them confidence - not to mention an income, so that they can begin to come off benefits. There are 'return to work programmes' aimed at supporting people into employment and 'supported employment' services. It remains to be seen whether the new 'Universal Credit' system will actually help people out of the 'poverty trap' and allow them to come off benefits and into work, without being worse off.

What is not working

Quite a few of the people we spoke to were of working age, but hardly anyone was in paid employment, whether full-time or part-time, and many felt that they could not do any work.

Of those who have had the 'Work Capability' assessment and are now being expected to look for work, they reported the following:-

- 'Work Programmes' are not useful in finding suitable work..
- There is a lack of information about what employment support is available.
- There is, of course, a major lack of paid employment as it is hard for anyone to get employment in the current recession.
- Employers are still discriminating!

The Jobcentre seems to prioritise reducing benefit payments over finding people a job. Often the job information sent to job seekers is irrelevant. Job seekers have the feeling that 'Job-finders' are just 'ticking boxes' and fulfilling a basic function. They are not providing the expert advice or on-going support required by disabled people. People want to work but are not getting any help with finding a suitable job!

Individuals who we spoke to have had little support with finding alternative employment after redundancy and have found the 'Jobcentre' and 'Remploy' services to be ineffective - commenting that 'they have nothing to offer'.

Personal Savings and a lack of National Insurance contributions are preventing people from getting Employment Support Allowance. One couple told us about their disabled daughter who paid NI contributions for many years while working, but has now been unemployed for over two years and because she still has savings from the time she was working, she is not eligible. Her parents have written to their M.P. because they feel that they and their daughter were misinformed about her rights when she was made redundant.

The 'Work Programmes' are a long process with a lack of jobs available at the end.

Supported Employment

The Royal British Legions Industries (RBLI) was apparently commissioned to help with 'supported employment' but had proved to be of little use to one person we spoke to, who had used this service. They were not able to offer support to people who are well educated with a previous work history and who want help with finding a higher level job suited to their skills. They appear to be more used to dealing with people who have not worked.

The Shaw Trust now has this contract, but apparently they are not actually helping people find work, but are just giving advice.

Kent County Council has its own department for helping people to find and retain work – 'Kent Supported Employment'. However, there is a feeling that this department has had cuts, with staff having to work reduced hours - at a time when more and more people are going to be needing support.

Employers

People say that it does not feel like much is being done to encourage employers to employ people with physical impairments.

Many disabled people and employers do not know about the support that is available through '**Access to Work**', whilst the 'Access to Work' department seems to make the process and assessments complex and difficult.

What is working well

The Shaw Trust, Supported Employment Service, helped a couple of people with applying for jobs, writing C.V.'s etc. and can 'part-fund' employment for a disabled person for six months. Kent Supported Employment can also help with these things, but much more job-finding support is needed.

One person from our 'Open Forums' said that he has found work through information provided by his tutor at Canterbury University and now has a job with 'Spinhalb' Mobile Solutions, making applications for mobile phones. They are proving to be very positive and supportive employers.

Ideas for change

1. Encourage employers to employ disabled people

- There needs to be much more focus on businesses and potential employers to encourage them to employ people with physical impairments.
- There is a need for more work-based support so that disabled people can try out and use adapted equipment e.g. adapted keyboard. People are often not sure what they need until they start the job.
- When people are in work they need further support especially around ensuring the employer adheres to the Disability Discrimination/Equality Act 2010.

2. Provide realistic and relevant work programmes

- More help and support is needed for disabled people with a career history or as professionals who wish to further their career. Not all disabled people are 'entry level' job seekers!
- Help disabled people into work experience roles so that they can benefit from the experience of working and feel encouraged to seek paid work.
- There needs to be more information about computer-adapted software for disabled people, which is designed to meet the individual needs of **different** disabled people.

TRANSITION (Child/Young People to Adult Services)

What is not working

- The majority of the people we met were older or had acquired their impairments later in life, but the few younger people we spoke to did say that as a child they were generally treated better by Social Services.
- During childhood they were naturally supported by their parents and lived in the family home, but the problem is that Adult Social Care Services need to understand that once the disabled person becomes an adult they may no longer want to live with their parents and actually prefer to live independently! To do this they need much more support. When they want to start living independently, the support is hard to get and often the disabled person is made to feel like 'a burden' for asking.
- During transition from child to adulthood, the handover process from Case Manager to Case Manager has rarely been a smooth and easy process.
- In other cases where the young person has remained living with their parents through adulthood, there are more concerns about the strain on parent/carers with increasing age. Several such parents are very concerned about what will happen when they are no longer able to care for their grown-up child. They want support and plans to be put in place now, for the future, but are unable to find help with this.

Ideas for Change

1. Develop person-centred ‘transition planning’

- 'Person-Centred Future Planning' needs to be a Case Management tool and/or be available from Independent Disability Led Organisations, who have the appropriately trained staff and trainers.
- Forward planning is required for young adults who remain with their parents. Parents need to know what supports will be available for their disabled relative when they are no longer there.

PARALYMPICS

What is not working

Since the end of the London Olympics and Paralympics 2012, there has been much speculation about whether an enduring legacy will remain. Some people told us that the Paralympics has created unrealistic expectations of what every disabled person can achieve. For example:

- Not every disabled person can have the range of support that Paralympic Athletes had - i.e. financial help/specialist equipment/medical advice/regular physiotherapy/modern sports facilities/individual trainers etc.

Many people have not noticed significant changes in public attitudes towards disabled people since the Paralympics, in fact they feel that people's public attitudes are still much the same (e.g. talking over your head, patronising etc.) In fact, over recent months there has been a marked increase in reported verbal and physical abuse that disabled people are experiencing, often fuelled by distorted media coverage.

People don't feel that the Disability Discrimination/Equality Act 2010 is of any real use. They need information about how to use it to challenge discrimination and who to report things to.

What is working well

- However, other people we spoke to felt that the London Paralympics had made an impact

and has resulted in more awareness and more acceptance of disabled people.

- They feel that the Paralympics has had a positive influence in changing the perception of disability, amongst young people in particular.

Ideas for change

1. Challenge disability discrimination through active implementation of the Equality Act 2010

- District and County Councils should create paid roles to ‘police’ the community, to make sure that the community is accessible.
- Educate local businesses about the Disability Discrimination Act as well as how they should comply with it, in all areas of their business.

SECTION FOUR

Questionnaire Findings (See Appendix II for blank questionnaire)

Summary of initial analysis

Q.1 Completed by: 22 Adults 4 Family Carers 3 Both Total = 29

Q.2 Location:	Maidstone	= 8	Herne Bay	= 1
	Ashford	= 4	Hythe	= 1
	Folkstone	= 3	New Romney	= 1
	Swanley	= 3	Margate	= 1
	Gravesend	= 2	Canterbury	= 1
	Whitstable	= 2	Swanscombe	= 1
	Hartley	= 1		

Q.3 Services sought:

Mainly: -

Benefits Advice	7
Health Care Professional	7
Housing Adaptations	6
Information and Advice	6
Equipment	5
Direct Payments	4
Wheelchair Services	3
Employment	3
Emotional support	3
Independent Living	3
Access Information	3
Transport	3
Personal Assistant Recruitment	2
Disability Specific	2
Care Package	2
Social Services	2

Q.4 Help received from:

Voluntary Organisation/Charity	18
Other disabled people	15
Social Services	10
GP	9
Support Group	8
Hospital	7
Case Manager	6
KCC	5
Other:	5
<i>Internet/Housing/Other Carer</i>	
<i>OT/Simon Paul Foundation</i>	
None	4

Q.5 How easy to get help?	Neither Easy nor Difficult	10
	Very Difficult	8
	Difficult	5
	Easy	5
	Very Easy	1

Q.6 What would be the best way to find out information?

Expert disability adviser	12
Internet	10
Information in a range of formats (including 'helplines' NOT just computers)	5
At time of diagnosis	2
Social Services	2

Q.7 Which services used?

Wheelchair Service (NHS or other)	15
Support to live more independently	8
Support to remain at home	7
Case Manager	7
Information about living with a disability	6
Occupational Therapy	6
Support to employ your own Personal Assistant/Carer	6
Advice about Direct Payments/Personal budgets	5
District Nursing	5
Care Agency providing personal care	5
Day Centre	5
Physiotherapy	4
Support group	3
Help with benefits	3
Counselling Service	2
Accessible Holiday/Short break	2
Accessible Community Transport	2
Respite	1
Advocacy – someone to speak up for you	1
Help with planning your own support	1
Help with funding equipment/adaptations	1
Supported Employment service	1
Accessible Education service	1
Accessible Leisure service	1
Residential Service i.e. care home	0

Q.7 (a) How satisfied are you with the services you are using?

		VD	D	N	S	VS
Wheelchair Service (NHS or other)	15	2	1	3	4	5
Support to live more independently	8	1	0	2	1	4
Support to remain at home	7	0	0	1	2	4
Case Manager	7	0	1	0	1	5
Information about living with a disability	6	0	0	1	5	0
Occupational Therapy	6	1	0	0	3	2
Support to employ your own PA/Carer	6	1	0	1	2	2
Advice about DPs/PBs	5	0	1	2	2	0
District Nursing	5	0	0	1	1	3
Care Agency providing personal care	5	0	2	0	2	1
Day Centre	5	0	0	1	2	2
Physiotherapy	4	0	0	1	0	3

Q.8 Who is running the services used?

Voluntary organisation/Charity 12

*MS Support
SPF
CiLK
DIAL
Invicta
ILF
Disability rights
Leonard Cheshire*

National Health Service	11
Kent County Council	10
Employed by me	6
Private company	1
<i>Synapse</i>	

Q.9 What is most important?

	VI	I	N	UI	VUI
Living in your own home (adapted if necessary)	29	0	0	0	0
Living independently	24	3	1	0	0
Having family/friends/relationships	23	4	0	0	0
Having a social life	22	5	1	0	0
Meaningful ways to spend time	20	5	2	0	0
Looking after your health	21	6	0	0	0
A say in how my support services are provided	20	5	1	0	0
Having a job	6	3	8	2	6
Opportunities to carry on with education	4	4	10	2	5

Q.10 Three best ways to achieve these?

First way:

- **Self-Assessment/Holistic Assessment**
- **Less focus on assessments**
- **Maintain Funding/Benefits/Direct Payments/Personal Budget/ILF**
- **Unbiased/non-judgemental/accurate/face-to-face advice (not patronising or bullying)**
- **Having a say**
- **Single point of contact**
- **Better support – meaningful/ongoing**
- **Continue the work of independent disability led organisations**
- **The means to employ adequate Personal Assistant support**
- **Better respite for carers (breaks and family crises)**
- **Disability Awareness by employers/society**
- **Better awareness by employers to employ disabled people**
- **Accessible Education**
- **Accessible and affordable Transport**
- **Regular Physiotherapy**
- **Accessible Housing**

Second way:

- **Being at the centre of decisions**
- **Having physical/practical support**
- **Listen to me - not your rule book**
- **Be respected – not suspected – no cross questioning!**
- **Having access to independent/peer support**
- **Support from user-led organisations**
- **Disabled people's and user led organisations providing info. and advice locally**
- **Advice from people who know what is needed**
- **Support from trained staff/valued staff**
- **A named person to go to for help**
- **Independent support planning/brokerage**
- **More support to avoid relying on family constantly**
- **Continuity of Case Managers**
- **Assessments in person not by post**
- **System should not abandon people after initial input**
- **Meaningful ways to spend time e.g. having a social life**
- **Accessible buildings and accessible facilities so people can have a social life**
- **More job opportunities**
- **Target funding to where it's most needed**
- **Adequately resourced organisations**
- **Opportunities to try out different equipment**

Third way:

- Consultation needs to be taken seriously and acted on
- Ask people what they need instead of reorganising services with different priorities
- Disability Awareness training
- Assessment at point of diagnosis and promise of support as condition gets worse
- Living independently at home and better living conditions
- Doing things the way I want
- Being secure and safe in my own home
- Better appointment system – reducing phone bills
- Improve range of accessible adult education courses
- More accessible gyms and specialist equipment in ordinary gyms
- Support to have a social life and prevent isolation
- Having people in authority who understand and accept that disabled people can speak for themselves, know what they want and can live independently'

Q.11 Priorities for funding: (order of priority)

Top 10 Priorities

- 1 Support to remain at home
 - 2 Support to live more independently
 - 3 Help with funding equipment/adaptations
 - 4 Wheelchair Service (NHS or other)
 - 4 Support to employ own Personal Assistant/Carer
 - 5 Information about living with a disability
 - 6 Advice about Direct Payments/Personal budgets
 - 7 Care Agency providing personal care
 - 8 Day Centre
 - 9 Accessible Community Transport
 - 10 Occupational Therapy
-
- 11 Respite
 - 12 Physiotherapy
 - 13 Support group
 - 13 Case manager
 - 13 Advocacy – someone to speak up for you
 - 14 Supported Employment service
 - 15 District Nursing
 - 15 Help with benefits
 - 16 Help with planning your own support
 - 16 Accessible Holiday/Short break
 - 17 Residential Service i.e. care home
 - 17 Counselling Service
 - 18 Accessible Leisure Service
 - 19 Accessible Education service

Q.12 Ideas for Improvements?

Information & Advice

- Better advertising of existing services
- Better information about what services are available
- Clearer information about what help and support is available, what people are entitled to and how to access these
- Support from people with relevant expertise at time of diagnosis, then ongoing
- Honesty from appropriately trained provider staff, who can help you get what you need quickly and easily
- Advocacy for those who are most vulnerable and need someone to fight their corner

Peer support

- Find ways to support disabled people to help others
- More peer support through disabled people providing services for other disabled people
- Recognise value of Voluntary Organisations & Charities – give adequate sustained funding – also provides employment for disabled people and volunteering opportunities

Assessment & Direct Payments

- More information on Direct Payments – SSD staff should be better informed/trained
- More Direct Payment Support Workers
- Offer more Direct Payment funding to disabled people
- Plan what will happen after Independent Living Fund ends
- Continuity/consistency of eligibility for/availability of services – stop 'postcode lottery'
- Continuing Care Assessment should be based on 'need' not just ticking boxes or designed to avoid access to NHS funding
- Long term funding to ensure continuity
- Need to ensure continuity and not need a full 're-assessment' at every stage
- Proper Carer's Assessment

Paid Carers/Care Agencies

- Overhaul Domiciliary Care Service – Agencies need to take care of their Staff
- More monitoring of Domiciliary Care by Adult Services - re safety and hygiene in people's homes
- Review Care Plans – so there is time to complete tasks – not make up time
- Care Agencies are too keen to take on more work with inadequate staff
- Care agencies do not support 'Independent Living' - they cost too much with poor return - and should only be used as back-up in emergencies
- Disabled people should be encouraged/supported to employ their own Personal Assistants (and two for emergencies).
- Money saved could be put back into Direct Payments system

Case Management

- Continuity of Case Management support needed
- Case Managers should be 'social work-trained' – able and willing to 'advocate'
- Case Managers need more training about Independent Living

Disability Awareness Training

- Assessments should be client-led and based on individual need. Not budget-led, not carried out by people with inbuilt bias, or lack of understanding and compassion!
- Benefit help and advice should be given by a respectful person 'who does not treat me like a liar and cheat'.
- Carried out by a person who knows me and understands how painful/traumatic it can be to go over and over the history of my disability experiences

Accessibility

- Need suitable buildings for Day Services and good 'shake up' of facilities available, as these are often dire and depressing
- Maintain pavement repairs in Canterbury

Equipment

- Total review of Wheelchair Service needed
- Better and quicker access to Physio/OT/Wheelchair service
- Better funding for NHS staff and equipment

Employment

- Genuine 'Supported Employment' service – which ensures no loss of essential disability benefits and respects skills and talents of disabled people so they are not wasted!

Monitoring & Review

- Set up new 'quality monitoring' body -with independence to implement change - lead person with 'quality' background outside NHS. Requires culture change, to address high level of complaints/dissatisfaction with care delivery – address high level of complaints by using quality monitoring tool.
- Stricter surveillance of Care Agencies to ensure they provide personalised service based on client needs - without overcharging KCC and Clients!
- KCC should be more pro-active in helping disabled community rather than waiting to be told

Cost effectiveness

- Cut bureaucracy, money-wasting, duplication, lack of consistency in how funding is given – ridiculous system – needs common sense approach
- Quicker decision-making
- Better 'joined up working'
- Existing services need more funding allocated across them all

Q.13 Anything else?

- If KCC does not adequately fund Social Care, more disabled people will end up in hospital, costing more money. KCC are 'fire-fighting' instead of dealing with problems properly and preventing others developing
- Involve Carers and Service Users in working together to improve services
- More disabled people should be involved in Council Services as they understand the issues much better
- Case Managers need better understanding of Direct Payments system and be empowered to make quick decisions
- Carer's Assessment is 'a sham' – identified need is not acknowledged
- Some Case Managers are excellent – but some are more concerned with budgets,

- limiting person to basic care and not helping them to 'get out from these four walls'!**
- Need to be seen as 'legitimate case' – only then people help
- Doing things by the book causes unnecessary stress
- Once things are in place I can relax
- If they get it wrong, it all has to start again from the beginning!
- Wheelchair Service is rubbish!
- Lack of care from NHS Physiotherapy
- Need to urgently review why some disabled people are being refused hospital transport because they are in receipt of Disability Living Allowance (mobility).
- Make better paths for mobility scooters and better places to cross roads.
- Sceptical about 'consultations' – need to motivate people and give them hope
- Need to understand true meaning of 'independent living'
- Tried to approach MPs and KCC Cabinet Members but 'nobody listens'
- 'Too many chiefs, not enough indians'
- Our taxes are not going to those who need it. Cutbacks such as loss of Independent Living Fund means that some of the most vulnerable are suffering.
- 'I am ashamed to be a tax payer' 'why are the most vulnerable suffering?'
- 'Am desperate for someone to listen'.....gave contact number
- Thank you to case workers I have met
- Thank you to all those who have helped keep me mobile and at home
- Easy to criticise and forget to address the issue of overworked and demoralised staff
- A common sense approach is all that is needed

SECTION FIVE

Some Specific Examples of Good Practice

1. The Hub - Information Services

"The Hub, Redhill is a first-stop shop run by local disabled people catering specifically for the needs of disabled people and carers' The Hub is based at 41 Redhill High Street, in the heart of the community. It acts as a gateway to information, advice, advocacy and services. It helps more people to find the information they need to live more independently. The Hub also displays and sells a range of mobility aids and equipment."

The Hub was set up by Surrey Disabled People's Partnership in 2008, when Surrey County Council and SDPP came together with Action for Carers and the User-Led Organisation Project Board. They continued to develop and expand the model. They also had support from local councillors and the new Adult Social Care Director, Surrey County Council.

The aim of The Hub was to create an Information Service that would bring disabled people and their carers together in the community.

Traditionally Disabled People's Organisations are hidden away in an office somewhere, but they wanted The Hub to be high profile and easily accessible in a high street location. They needed to be independent from the council but also from day services. They aimed to create a service that people would want to go to and use, with their own branding.

The first Hub Information Service opened in Epsom in October 2010, but now there is a Hub in Redhill and Woking, with a Hub in Godalming opening in May 2013. More are set to open around the eleven districts in the county. Surrey County Council has committed to funding revenue and capital costs of a Hub in each of the boroughs until 2017.

The ULO Project Board worked to identify where best to set up 'Hubs' – considerations were accessibility and transport links, accessible toilet, minimum of three desks and a meeting room.

SDPP and The Hub spend a lot of time engaging with the communities where they are to establish a Hub. These engagement events with community groups were to attract volunteers and to find out what people want from an information service. This is partly because one of their main aims is to get local organisations to use it.

The Hub provides free and confidential information on many aspects of disability including Support, Equipment, Benefits, Transport, Leisure, Holidays, Education and lots more. Each of the Hubs offers continuity, the same standard of support, advice and customer service. The 'Walk-in' shop front provides a customer focus.

Disabled people are involved with the running of each Hub. Staff who are themselves disabled can often give the best advice. At each location there is a Volunteer Development Officer managing a team of disabled volunteers. The volunteering roles are treated just like a paid employment role, to give the volunteer real working experience. The volunteer is expected to treat the role as a 'job', with the same responsibilities such as time keeping, working hours, working attitudes and commitment whilst at the same time enjoying the same benefits such as training and development. It is hoped that people who volunteer at The Hub will gain confidence and experience and feel empowered. Many move into paid employment through developing skills and confidence. Surrey County Council's employment service for disabled people, 'Employability', uses the Hubs as a stepping stone for some of their clients.

The Hub at Redhill has between 20-30 volunteers doing shifts, either mornings or afternoons about three times a week. They are found through word of mouth, recommendations from other groups, The Jobcentre and Employability. The Volunteer Development Officer keeps records of each volunteer, the help and support they may need, and the training they have received etc. They also have regular 'one to one' sessions with the volunteer, as an employee would expect in a paid role.

As well as the permanent Hub locations they also offer a fortnightly face-to-face satellite service in Surrey Heath and hold information sessions at various day centres, surgeries and other venues in the area.

They organise regular ‘drop in’ sessions with different organisations/experts talking about different subjects. This includes a weekly session about welfare benefit advice and a monthly session with a solicitor about legal advice.

The Hub/Surrey Disabled People’s Partnership has the ‘Advice Quality Standard’, which is a quality standard that is awarded to organisations that give advice to members of the public on matters of a legal nature. It is awarded every two years and requires organisations to demonstrate that they are accessible, effectively managed, and employ staff with the skills and knowledge to meet the needs of their clients. Once achieved, the organisation details and certification will be advertised through the Advice Quality Standard (AQS) directory for a period of 2 years, after which point a further review of the service delivery will be required.

The Hubs have changed the way that people get information - they can now ‘drop-in’ and talk ‘face to face’ instead of getting information over the phone - a way that people prefer. In Redhill, they have over 200 people coming through their doors each month asking about all sorts of things. Often people come in with a specific query such as equipment, but through talking to that person volunteers are able to help them with many other issues at the same time.

They do not follow-up but refer on to local advocacy services. An Advocacy Service exists for physically disabled people and older people, as well as people with learning disabilities and mental health issues. They also 'signpost' people on to other services. If people return for more advice it does demonstrate that the Hub is providing a useful service.

At each location they record the numbers of people that they see and details of the kinds of enquiries they have, to justify to the council that the service is needed and good value of money.

In Surrey, the County Council has a good relationship with all three DPULOs:- Surrey Coalition of Disabled People, Surrey Independent Living Council and Surrey Disabled People’s Partnership. The three organisations work well together and people usually have membership of all three organisations. This means that there is a comprehensive range of services that The Hub can signpost people to. They are not just offering this information service to disabled people but also to carers, professionals, local organisations and any members of the public who may ask. Enquiries also come from businesses – e.g. employers asking for advice about accessibility.

The Hub is involved with the induction of new SCC staff, care managers etc. so that they can learn about The Hub as well as get some Disability Awareness training. They are also involved with several pilot projects including the ‘Trailblazer Project’ with Jobcentre Plus – giving people the opportunity to access all services through one portal, and Legal Advice in partnership with a local solicitor who specialise in Social Care. These pilot ‘drop-in’ sessions are going very well and they have been lucky in finding a solicitor who will do this for free. The solicitor tells people what they can do when they have a good case, however, the problem for people is taking it to the next step.

SDPP and The Hub have had to overcome many challenges and obstacles when working with the local authority.

- Getting the Local Authority to adopt the ‘Social Model of Disability’.
- Initially everything for the Local Authority was about ‘Risk’.
- They had to make sure that people really did have choice and control.
- Tender process – securing funding and getting the Local Authority and Health to understand that local organisations should bid for services.

- Surrey is now actually listening – not just ‘tokenism’.
- Encouraging people to help themselves.
- Biggest challenge is MONEY.

They stress that it is important to have a strong partnership with other organisations with shared values.

Clive Wood from The Hub and Surrey Disabled Peoples Partnership would be happy to meet with Kent County Council and perhaps with Surrey County Council to demonstrate the value of The Hub model.

NB: We have chosen this example as it combines a number of the suggested ‘ideas for change’ under one model.

2. Spectrum Centre for Independent Living - Recruiting Personal Assistants

Spectrum Centre for Independent Living, based in Southampton, has been providing support for Direct Payment recipients for many years. Working in partnership with The Independent Living Support Scheme (ILSS) the scheme aims to:

- Support Disabled People to recruit and employ their own staff.
- Enable Disabled People to live independently, by controlling their own personal assistance requirements.
- Enable Disabled People to take control of their own lives.
- Operates equal opportunities.

The scheme is a free resource service, funded by Southampton City Council, for all Disabled People living in Southampton who want to employ their own personal assistants to assist them to live independently.

It is an ‘introduction service’ between Disabled People, and personal assistants registered with the scheme, on the personal assistants register which is maintained by an Independent Living Support Worker.

Personal assistants can assist with things like housework, shopping, driving and personal support. The disabled person assesses their own needs, and these are matched with suitable personal assistants.

The scheme may be able to offer short term, or emergency backup staff at short notice.

Choice and Control

The individual interviews prospective personal assistants and chooses who to employ. SCIL offers access to advice, information and support on recruitment and employment procedures.

The individual can take advantage of the information and advice, even if they cannot find staff from their register. SCIL provides a home visiting service to assist with identifying individual needs.

Direct Payments and Self-Directed Support Advice Sheets

SCIL publish a number of advice sheets to provide Employers of Personal Assistants with information that they may find useful.

Advice

They offer advice and information sheets on all areas including: Employment Advice, Keeping Records, Tax and National Insurance, Guide to Employing a Personal Assistant, Working Time Regulations, Insurance, and information guides.

They also assist with and provide Record Keeping Form Templates including:

Direct Payments Expenditure Record
Personal Assistant Time Sheet
Personal Assistant Holiday Record
Personal Assistant Sickness Record

All support and information is provided by disabled people who are also employers of personal assistants.

SCIL has approximately 260 Personal Assistants on the register, 150 of which are currently active, and they are supporting over 300 Disabled People to live independently.

3. Person-Centred Planning - Not Just Another 'Assessment'!

With all the confusion about ‘assessments’, ‘care plans’, ‘support plans’ and ‘reviews’, having your own ‘person-centred plan’ is about getting a life and not just a service!

The Simon Paul Foundation has developed guidelines to ensure that the person is at the centre of planning their life. It is a process of continual listening and learning by everyone involved. The plan is focused on what is important to someone now, and for the future, and acting upon this with the help of a ‘circle of support’ of people who know them the best and care about them - including their family and friends.

Person-Centred Planning is not just about services as they are currently provided - it explores what is possible, not just what is locally available at the moment.

A person-centred plan helps the person to be clear about what they want services to do and how the support needs to be provided.

It means that the person is at the centre of planning their life.

Person-centred planning is about:	Person-centred planning is not:
<ul style="list-style-type: none">• Listening to and learning about what people want from their lives and how they want to plan	<ul style="list-style-type: none">• The same as ‘assessment’ and ‘care planning’ or ‘support planning’ etc.
<ul style="list-style-type: none">• Helping people to think about what they want now and in the future	<ul style="list-style-type: none">• The same as ‘reviews’
<ul style="list-style-type: none">• Family, friends, carers, professionals and services working together with the person to make this happen	<ul style="list-style-type: none">• Owned by statutory services• A way to create changes instantly – a quick fix!
<ul style="list-style-type: none">• A commitment to keep learning about the person and working on things	<ul style="list-style-type: none">• Just a new type of ‘assessment’• Just more forms to complete
<ul style="list-style-type: none">• For everyone who wants one	<ul style="list-style-type: none">• Only for people who are ‘eligible’

A person-centred plan could help the individual to pursue their aspirations by organising the appropriate support more effectively and exploring opportunities to get the most from the local community.

A Person-Centred Planning Worker, could help to develop the person-centred plan and put it into action.

The individual is always in control of the planning process - and in setting up a circle of support to help them.

Person-Centred Planning is rooted in the principles of rights, independence and choice.

Appendix I

Project Development – problems and challenges we encountered

During this project we encountered several problems that prevented us from reaching many of those people in Kent who have a physical impairment. Particular groups we were unable to contact were those who are not already accessing services, those who are hard to reach and younger people who are of working age. There are several reasons for this:

Reaching Disabled People across Kent

During our initial meetings with Kent County Council we talked about the feasibility of using their data-base to circulate information about this project to all the people who are recorded as having a physical impairment, and relevant service providers, but this was not possible either due to ‘data protection’ restrictions or because KCC do not have a central data-base with this information.

However, it was agreed that we could use the KCC website to announce and publicise the project and the dates for the Open Forums and Provider Forums. By the time this information was actually posted, these Forums were underway, so just a link to the Questionnaire with a brief summary was available on the website. The KCC website has also proved to be hard to navigate. We believe that this is in part responsible for the low number of Questionnaire responses. We gave all of our contacts a direct link to the Questionnaire and without this there would have been very little chance of them finding it.

We would have liked to have publicised the Open Forums and Questionnaire on Kent Radio and in the local press, to let people know what we were doing and why we were doing it, in the hope that those ‘harder to reach’ individuals would at least have the option to get involved. However, despite our best attempts we were informed by the KCC Communications Department that this was not available to us.

Lack of practical support in completing Questionnaires

Some people with a physical impairment need assistance with their paperwork and for filling out forms. They are unable to have provision for a carer to help them with this, as it is not recognised as a task funded through support packages. Therefore they would not have been able to complete a Questionnaire. Additionally, alternative formats were not made available through the KCC website, but we did issue a number of large-print/hard copies of the Questionnaire on request.

Scepticism

Many disabled people we spoke to were sceptical about “another consultation” and emphasised to us that they have been telling the Council what they need and what the problems are for a long time, but “nothing seems to change”. They expressed disillusionment, making comments such as “what’s different this time?” and “what’s the point?”

Even KCC staff were cautious about responding to us as they had apparently not been informed internally that this project was taking place. We were surprised by the lack of response from KCC Managers and staff to engage with this project.

Administrative support

At the beginning of this project, we had been informed that additional administrative support would be made available to us for this project, as the SPF and CiLK are both small charities with very limited resources. However, due to an on-going re-organisation within the KCC Commissioning Department, only a small amount of administrative resources were available to us.

Appendix II

Blank Questionnaire

Have your say on social care for adults with a physical disability

This questionnaire is your opportunity to tell us about your experience of social care services for adults with a physical disability. Give us your views on what is working, what isn't, what needs to change and offer your ideas about how things could work better in the future.

All feedback received will be carefully looked at and considered. Your answers are anonymous and will be treated with strict confidentiality.

Please continue on a separate sheet or reverse of paper if you require more space for your comments.

Q1. Are you?	An adult with a physical disability	
	A family member/carer of an adult with a physical disability	
	Both	

Q2. In which Kent postcode area do you live in?	
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Q3. What help/advice have you looked for in the past? <hr/> <hr/> <hr/>	
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Q4. Where did you find the help/advice you needed?	Kent County Council	
	Social Services	
	GP	
	Hospital	
	Case Manager	

	Voluntary Organisation/ Charity	
	Support group	
	Advocate	
	Other disabled people	
	Not getting any help at all	
	Other (Please specify)	

Q5. How easy was it to find the information you needed?	Very easy	
	Easy	
	Neither easy nor difficult	
	Difficult	
	Very difficult	

Q6. What would be the best way for you to find out this information?	
---	--

Q7. Which services are you currently using and how satisfied are you with these services?

		Very satisfied	Satisfied	Neither satisfied nor dissatisfied	Dissatisfied	Very Dissatisfied
Residential						

Service i.e. care home						
Support to remain at home						
Care Agency providing personal care						
Support to employ your own Personal Assistant/C arer						
Respite						
Accessible Holiday/Sh ort break						
Day Centre						
Accessible Community Transport						
Accessible Education service						
Accessible Leisure Service						
Supported Employmen t service						
Information about living with a disability						
Advice about Direct Payments/P						

Personal budgets						
Help with benefits						
Help with funding equipment/adaptations						
Case Manager						
Physiotherapy						
Occupational Therapy						
District Nursing						
Wheelchair Service (NHS or other)						
Advocacy – someone to speak up for you						
Support group/ peer support						
Counselling Service						
Help with planning your own support						
Support to live more independently						
Other (Please specify)						

Q8. Who is running the services you are using?	Kent County Council	
	National Health Service	
	Voluntary organisation/Charity	
	Private company	
	Employed by me	
	Other (please specify)	

Q9. Please rate how important to you are the following?

	Very important	Important	Neither important or unimportant	Unimportant	Very unimportant
Living in your own home (adapted if necessary)					
Having a job					
Opportunities to carry on with education					
Meaningful ways to spend time					
Having a social life					
Looking after your health					

Having family/friends/relationships					
Living independently					
Having a say in how your support services are provided					
Other (Please Specify)					

Q10. From the list you have rated as important in Q.9, please tell us what would be the best three ways to help you to achieve these?

First way	
Second way	

Third way	

Q11. Which services below do you think should have priority for funding? (Please choose up to six).		
	Residential Service i.e. care home	
	Support to remain at home	
	Care Agency providing personal care	
	Support to employ your own Personal Assistant/Carer	
	Respite	
	Accessible Holiday/Short break	
	Day Centre	
	Accessible Community Transport	
	Accessible Education service	
	Accessible Leisure Service	
	Supported Employment service	

	Information about living with a disability	
	Advice about Direct Payments/Personal budgets	
	Help with benefits	
	Help with funding equipment/adaptations	
	Case Manager	
	Physiotherapy	
	Occupational Therapy	
	District Nursing	
	Wheelchair Service (NHS or other)	
	Advocacy – someone to speak up for you	
	Support group/ peer support	
	Counselling Service	
	Help with planning your own support	
	Support to live more independently	
	Other (Please Specify)	

11a. Please prioritise the services you've selected above starting with the one you think should have the highest priority.

Priority 1	
Priority 2	
Priority 3	
Priority 4	
Priority 5	
Priority 6	

Q12. How could existing services be improved or are there any new ways you could be supported in the future? (please list your suggestions)

Q13. Anything else you would like to say?

Thank you for completing this questionnaire.

Please return completed questionnaires to the Simon Paul Foundation in the stamped addressed envelope provided at the following address:

**Simon Paul Foundation
Swanley Library & Info Centre
London Road
Swanley
Kent
BR8 7AE**

Appendix III

Disability Organisations/Support Groups we have contacted

Arrow Riding Centre (for people with varying disabilities)

Active Lives Network (day services)

Ability (West Kent Access Group)

Centre for Independent Living Kent, CiLK

D.I.A.L.

DISK (Disability Information Service, Folkstone)

Freedom Centre, Sheerness

Headway Day Centre, Ashford

INSPIRE

KASBAH (Kent association for Spina Bifida & Hydrocephalus)

Kent Supported Employment

Kent Association for the Disabled, Dover

Leonard Cheshire, Chipstead Lake Day Service

Multiple Sclerosis Society

North Kent Disabled Foundation

Parents Consortium

Parkinson's Association

Phab Club

RBLI Royal British Legion Industries

Service User Groups, Shepway/Ashford/Thanet

Simon Paul Foundation

Stroke Association

Tomorrows People (employment support)

Tonbridge & Malling Access Group

Thanet Disability Forum

Well Resource Centre, Dover

Wheelchair Users Group, Folkstone

These organisations and groups also distributed information about our project throughout their own networks

The following community and voluntary sector organisations distributed event information through their extensive mailing lists:

Advice Partnership East Kent, APEK

Case Kent

Voluntary Action Maidstone

We also contacted and met with:

SENDPO

Redhill 'Hub', Surrey

KCC's 'Local Account' Team

KCC Sensory Team

SILK (Dementia)

Professor Michael Oliver

Appendix IV

Groups and Forums

Groups we visited and where we facilitated meetings

18/10/12	Maidstone (Working Age) Stroke Association <i>(Pippins Bar, London Road, Maidstone)</i>	(12 attendees)
25/10/12	Canterbury M S Therapy Centre <i>(Merton Lane, Canterbury)</i>	(12 attendees)
29/10/12	Well Resource Centre <i>(Maison Dieu Gardens, Dover)</i>	(18 attendees)
31/10/12	Active Lives Network <i>(Temple Square Community Centre, Dartford)</i>	(35 attendees)
1/11/12	Freedom Centre <i>(St George's Avenue, Sheerness, Isle of Sheppey)</i>	(35 attendees)
5/11/12	Active Lives Network <i>(The Junction, St Mary's Road, Swanley)</i>	(12 attendees)
6/11/12	Active Lives Network <i>(Riverside Centre, Dickens Road, Gravesend)</i>	(35 attendees)
15/11/12	Ashford Headway <i>(Wotton Road, Ashford)</i>	(10 attendees)
20/11/12	Leonard Cheshire Disability <i>(Chipstead Lake Day Service, Chevening Road, Sevenoaks)</i>	(9 attendees)
27/11/12	Wheelchair Users Group Chronic Pain group <i>(St Andrews Methodist Church, Folkestone)</i>	(13 attendees)
11/12/12	West Kent Housing Access Group - 'Ability' <i>(The Junction, Swanley)</i>	(15 attendees)
11/12/12	Occupational Therapy Service User Group <i>(St Peter's House, Broadstairs)</i>	(11 attendees)
31/01/13	Swale Stroke Group <i>(CAB, Hope Street, Sheerness)</i>	(13 attendees)

(Total attendees = 230)

'Open' Forums:

26/11/12	Angel Centre, Tonbridge	(5 attendees)
29/11/12	Lenham Community Centre, Lenham, Maidstone	(2 attendees)
30/11/12	Swallows Centre, Wyverne Hall, Sittingbourne	(4 attendees)
12/12/12	Alexandra Suite, Swanley	(4 attendees)
13/12/12	Thanington Neighbourhood Resource Centre, Canterbury	(5 attendees)

(Total attendees = 20)

'Provider' Forums:

20/11/12	Ashford Business Point, Ashford (2 sessions)	(21 attendees (AM) (12 attendees (PM))
16/01/13	Sessions House, County Hall, Maidstone	(4 attendees)
<i>(Total Attendees = 37)</i>		

Group Meeting (Providers):

10/01/13	Dartford, Gravesend & Swanley Co-Ordination Team	(20 attendees)
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Additionally we carried out eight Individual Interviews.

Appendix V

Quotes from individual people we interviewed

Information and advice

“Having moved from Southampton I find that Kent is very lacking in providing information. In Southampton there was a place, an office complex that housed many organisations all involved with disability. It was always a good starting point, if the organisation or person you needed to talk to wasn’t housed in this building then someone there would definitely know where they were. In Kent there doesn’t seem to be that kind of central place to go. It is difficult to find the people or information you need to help you with all the different aspects of your life. There are a few organisations out there who try but they are underfunded, under-resourced and under-staffed.”

- S

“Too much reliance on sitting by a computer/using the internet I would rather get out and about to deal with people directly in order to get what I need!”

- J

Peer support

“If you are not living it you cannot really understand how hard it can be.”

- M

“Peer support is so important – if you are newly disabled and feeling overwhelmed and depressed you need to be able to talk to someone who knows how it feels and has been living with a disability for some years – nobody else can really understand.”

- H

Advocacy

“Is there advocacy? It never seems to materialise. It is imperative funding is made available for peer advocacy; we always hear talk of it but nothing ever happens. It is very important, but there has never been an advocacy service in Kent, other than CiLK, who I think have never been given the opportunity or funding to do this role properly. It needs to be given the same respect and value as it has within learning disabilities and mental health.”

- L

Centre for Independent Living/Disabled people’s organisations

“Most CILs are now suffering reductions of funding. Left with a system that still gives choice and control but only to people who are able to handle it. To newly disabled or unequipped people this is a minefield. National companies are doing very well out of disabled people. They should have set up CILs 30 years ago.”

- M

“Voluntary organisations/charities such as the Simon Paul Foundation don’t just provide employment that is sympathetic to the needs of disabled people - many of them have/did have a structured volunteer basis with training etc. which could lead onto employment, once people have regained confidence and developed skills. Therefore, funding for these organisations is a sound financial investment.”

- J

Assessments and Direct Payments

“Re-assessments happen relatively frequently. Always looking at how to cut hours but no cuts have been made yet. However, there has also not been an increase in the amount of money since he went on Direct Payments 3-4 years ago, so this has not increased in line with the minimum wage. Because of this he has to cut corners in order to pay staff. He feels strongly that you cannot replace human contact with technology. Human contact is important for people and avoids isolation and loneliness.

- L

“The Direct Payments System has been 'corrupted' by deficiencies and by lack of knowledge and understanding by Case Managers.

A lack of understanding about philosophy and principles behind Direct Payments
A lack of understanding about how this should be put into practice.”

- J

Case Managers

“She found her Case manager lovely, she did all that she could within the constraints, but the constraints are there. She no longer has a Case Manager, and hasn't for about 3 years now. Instead she is now under the Case Management Team.”

- D

Case Managers and Social Services

“Social Services need to adopt a less confrontational, terrifying process. If we didn't exist then they wouldn't exist. They intimidate people with reviews and assessments, people are ending up giving up their care package as they find it too intimidating.

They need to consider their own image with their customers – having this fear factor is not good for their image and is not fulfilling the objectives of what social services is there for. They need to be promoting the image that they are on our side. The majority give the impression that they are part of the big brother organisation.”

- P

“Social workers were about helping you to make sure you had the right tools and support to do what you needed to do in the best possible way, within your limitations. It feels like case managers are only about budgets and doing things as cheaply as possible now. Over time social workers have changed to care managers and now to case managers, the way the structure has altered seems to have taken the personal element and support away. Social workers were then your advocates so to speak. This is so important for many disabled people otherwise they will not receive the rightful services that will truly meet their needs.

The above seems to be due to budget constraints, we have lost the good that was happening in the past which would be much more cost effective in the long run. The unspoken message feels like there is an attitude; that disabled sick people need to get out there and do whatever they can do but we won't support you financially to do it.”

- L

“Social Services Manager said: “I can put you into care”! after I challenged their decision. Difficult trying to deal with other issues whilst being made to feel that you are “a waste of social service time and money.”

- J

“Stresses have a devastating effect on relationships – partner and family. Living with spinal cord

injury is difficult by itself. It can make a person feel - is it me? Made to feel guilty. Social services are "living off the backs of disabled people – are we here to provide employment "? I am happy to be part of providing that employment so long as it means we all work together rather than against each other. To use a cliché - if you look at the 'broader picture' with me in the middle and a spider graph of all the people connected to me I am extremely good value for money! I am always saying I must be one of the best recyclers of a pound coin there is!"

- J

Personal Assistants

"I do not want a carers getting involved with personal care i.e. bathing/showering, my boyfriend can help with these things, but I would like some help with other domestic things that I can no longer do or struggle with, to help prevent straining my relationship. A case manager told me that people have to rely on friends and family for things such as cleaning. I pointed out that my nearest family was an 85 year old deaf/blind grandmother; all other family are a long way away. To which he answered 'In that case you would have to go into residential care.'"

- S

"Managing Personal Assistants is all encompassing as all one's energy can be spent on this aspect! SSD need to understand that a Personal Assistant is not just a 'personal carer' – the role is 'enabling' and not just about being 'cared for' – the role is 'all-encompassing'.

We need to value having a P.A. and Direct Payments, by paying them a living wage with good working conditions including, holidays and sick pay (and pension options?).

Compare this to Care Agency!

It takes about one year to establish a P.A. into a team – training and 'settling in' a P.A.

A Personal Assistant cannot be trained before starting – they have 'to come in cold' and get to know the disabled person first!"

- J

"Employing your own PA works - Care agencies do not! Direct payments work if supported by a proper infrastructure."

- M

Aids and adaptations

"Trust people to know themselves, we are the experts on our conditions. Believe us when we say we need something, don't make us justify everything."

- D

Day Services

"Need coordinated plans on how to close things sensibly so that alternatives are viable and available. Taking a genuine solution to a problem and missing out the important part, just jumping to the end result!

Listen – set up the alternatives before closing the old. Offer different, integrated services for when things do close down."

- M

Training

"Attitudes - people don't consider disability; proper Disability Awareness training is not being given

to them by disabled people.”

- P

“More 'Disability Equality Training' to staff and **also to disabled people themselves** – delivered by disabled people, or people who have a real connection with disabled people or experience of what happens when a person becomes disabled. Currently there exists a very 'bad attitude' amongst service workers. Also if a disabled person is constantly treated as a second class citizen, they understandably can develop a bad attitude too!”

- J

General

“If, what is being said at the top by senior managers about truly enabling disabled people to maintain and gain independence, and the agenda is about choice and control for the individual, then why is this not reflected at the bottom in the front line services? It's a farce!

The structures that are in place at the bottom are not what is being reflected at the top, both because of a lack of finances and a lack of understanding of what the top are trying to achieve for the middle. It is just rhetoric - it shouldn't be, it should be about genuine support.”

- L

“Feels like, with all the cutbacks that are happening there is no room for choice or control, only room for danger.”

- L

“In all areas there never seems to be a middle road, it's 'Yes' or 'No'. They follow procedures, it's black or white; they aren't allowed to use common sense. For real choice and control there needs to be a grey area, you need to be flexible/fluid enough to think outside the box. Life is all shades of grey.”

- L

“It's one thing to have a physical impairment, but what social care now adds to that is another prison, another set of restrictions because of attitude, financial constraints and a rules and regulations that stop people being enabled to live as they would choose to.”

- L

“People are having to fight to have access, the problem is when you are having to fight for most aspects of your life you don't have the energy to fight for everything, people have to decide what are the most important things to fight for.”

- P

‘Having a say in your service provision’ would be nice but won't happen. Social Services won't pay for disabled people to attend meetings. Directors are on high salaries but expect volunteer disabled people to attend for nothing. This demonstrates that they don't feel there is value in disabled people's opinions.

Social services were going to have expert disabled people to come along and contribute, those with ability. How many disabled people work for KCC? Expert disabled people should be used. Why are KCC not employing disabled people, better to pay them to work than to be on benefits?”

- P

“Adult social Care Services, part of the problem is that the whole thing has turned out to be a fiasco.”

- M

