



# Sefton Carers' Strategy 2014-2019

## Consultation Report

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# Summary Report

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## Sefton Carers Strategy 2010-2013 – where we are starting from ...

The current Carers' Strategy 2010-2013 was developed in collaboration with a number of partners across the Borough. The Strategy focussed on achieving 13 strategic objectives, and over the past three years agencies across Sefton have improved information for carers, provided carers with emotional support and helped improve their overall health.

As part of the process of writing the strategy the Sefton Carers Centre consulted with carers to find out what worked well for them and what challenges they faced in their caring role. Carers wanted a system that was on their side rather than one that frustrated them at every turn, including much more support to help them manage the twin demands of work and caring responsibilities. They wanted far more personalised support and greater scope to control and customise services, including in healthcare where identifying needs and ensuring prompt access to services can be so critical. Above all the need – repeated many times throughout the consultation – for better support for respite and short breaks.

## Sefton Carers Strategy 2014 – 2019 – where we are going ...

This report provides a summary of the findings from the consultation and engagement process undertaken on the Sefton Carers Strategy 2014-19. The consultation and engagement process took place over a twelve week period from November 2013 until February 2014, and included a wide range of methods including world cafe events, mini workshops, meetings, and a web based on-line and paper survey. In total, in excess of 600 people engaged with the process. Regardless of whether people are old, young, disabled, living in the north or south of the Borough, there were some common themes that repeatedly emerged during the consultation and engagement process:

- Carers want to be involved in discussions with health professionals and other providers about the person they care for. A concern here is that “confidentiality issues” are deemed as being more important than making sure that the carer knows what the cared for person’s needs and requirements are. This is particularly the case for young carers where health professionals are reluctant to discuss issues with them.
- Carers need to know that there is appropriate support available for the person they care for during times of emergencies, particularly when the carer themselves is unwell or unable to carry out their caring duties.
- The different services for carers and the people they care for should be joined up and closer to where people live.

- Carers need to be able to access information so that they know what is available, where to go for help and advice with regard to things such as benefits, medical advice, etc.
- Young carers would like more support at school/college and understanding of the issues they face.
- Parents with disabled children are finding it difficult to get a diagnosis which means that they cannot access support services or benefits.
- Activities for carers are often held at times which are not convenient and in locations which are not always easy to get to i.e. from 1.00 – 3.00 p.m. which prevents parents of disabled children from participating as they have to collect children from school, or be at home for them when they are dropped off.

## Key findings from the on-line survey (Adults)

The survey was completed by 505 people. These results relate to those people who replied and identified themselves as carers:-

- Of those who identified as carers **74% are women** and **26% are men**.
- The biggest age group (**43%**) for people who are carers is **40-59**, closely followed by those aged **60-75 (34%)**. **17%** of carers are aged **74+** and **6%** in the age group **25-39**.
- The majority of carers in Sefton are **retired (48%)** or **unable to work because of caring commitments (24%)**. Some carers do **work full time (10%)** or **part time (11%)**. The remainder are **unemployed (5%)** or **full/part time students (1%)**.
- With regard to the length of time that people have been caring for, the majority have been doing so for **2-5 years (35%)** closely followed by **6-10 years (24%)**, **11-20 years (21%)** and **21+ years (17%)**. **3%** identified themselves as **new carers** who have been caring for less than 1 year
- **Adults with a disability or limiting long term illness** are identified as the main group that people care for (**64%**), closely followed by **Frail Elderly People (23%)**. The percentage of carers who look after a **child with a disability or limiting long term illness is 12%**.
- Carers were asked to rate the quality of the services that are available to them with **42% finding that services were good**, **25% average**, **excellent 22%** and **poor 10%**.

- When asked if carers found time to look after themselves, including getting enough sleep, eating well, visiting the doctors/dentists, and their own wellbeing needs, **44% replied that they were finding time to look after themselves, 49% said that they didn't always find the time and they sometimes neglected themselves, and 7% said that they were not eating or sleeping well and neglecting themselves.**
- Carers were asked to rank four options as being very important, quite important, not very important, and completely unimportant:-
  - **being involved in all stages in the planning of care for the person cared for throughout life changes, and ensuring that carers have a voice;**
  - **the different people and services who support carers should talk to each other,**
  - **Information on services, where to go for help, etc., is clear, timely, accessible,**
  - **Young carers are supported as much as possible in order that they can live fulfilling lives and progress with their education, career and life aspirations.**

The results indicate that carers ranked all the options equally as **very important**.

- Similarly, when asked to identify their top three priorities to help them in their caring roles, **access to targeted information and advice** came out **first**, **care close to home** came **second**, and **access to activities in local communities** came **third**.

## Key findings from the on-line survey (Young People)

The survey was completed by 6 young carers. These are the key findings:-

- All of the 6 young people who responded were **boys**.
- The majority of young carers (**80%**) care for **another young person** with the remainder (**20%**) caring for an **adult with a disability or long term illness**.
- The biggest age group who care for somebody else is **10-13 (50%)**, with the rest coming from the under **10 group (25%)** and the **18-21 group (50%)**
- With regard to the length of time that young people have been caring for, the majority have been doing so for **6-10 years (50%)** with the rest spread evenly over the remaining options (**25% each**) of **less than one year, 2-5 years and 11-20 years**.

- When asked if young carers found time to look after themselves, including getting enough sleep, eating well, having good attendance at school, doing their homework and going out with friends, **50% replied that they were finding time to do this and 50% said that they didn't always find the time and they sometimes didn't sleep much or eat well, or have time to do homework or meet friends.**
- The young carers were asked to rank four options as being very important, quite important, not very important, and not at all important (**Being involved and having a say when plans and changes are being made about the person I care for, the different people and services who support carers should talk to each other, so that they all know what's going on, and things don't get repeated, Information on services, such as where I can go for help, is clear, easy to find and read, up to date and available and Giving me enough support to do well in education, getting and keeping a job and doing well in my future**) . The results indicate that carers ranked all the options equally as **very important.**
- Similarly, when asked to identify their top three priorities to help them in their caring roles, **being given better information and advice** came out **first**, with care close to your home for the person you care for, access to activities in your local community for yourself and the person you care for and Someone for you to talk to, who will listen to you coming joint second.
- Young carers rated the quality of the services that are available to them as **average (60%)** and **excellent (40%)**

## Key findings from World Café Events

The following are the key findings from the two world café events that were held in December 2013. The events were run as small focus group style consultation in a relaxed informal atmosphere.

- Carers need to be supported to look after themselves as well as the person they care for, including carers assessments
- Carers need to be involved in the care planning process for the person they care for. This includes health care professionals including them in discussions about treatment and care pathways, and not using confidentiality to exclude carers.
- Carers need to know that support is in place in case of emergencies where they cannot undertake their caring role. It is important that this is appropriate and doesn't mean the cared for being admitted to hospital.
- Carers need access to information that is up to date, gives them details on where to go for help and advice and is accessible.

## Key findings from Young Carers

A separate event was held for young carers, organised and facilitated by young carers themselves, supported by the Sefton Young Advisers. A separate questionnaire was also prepared for young carers.

These are the key findings:-

- Young carers often feel excluded from discussions about the person they care for, particularly with medical professionals who use terms that young people don't understand, don't explain about prescriptions, and can be patronising.
- Young people would like more support and understanding at school/college, so that their teachers are aware of their caring role and understand the problems that this can bring for young carers and their homework, attendance records, etc.
- Young carers need access to information to tell them where to go for help and advice, what is available and how to get it and this needs to be in an easily accessible format.
- Young carers worry about what will happen to the person they care for if they want to go to college or pursue a career that may take them away from home. They want to have the same opportunities as their friends.

## Key findings from specific groups:

Organisation	Key Findings
Sefton Partnership for Older Citizens - Maghull	<p>The group felt that the following were considered to be the <b>most important</b>:-</p> <ul style="list-style-type: none"> <li>• Access to health and wellbeing services</li> <li>• Carers having a voice</li> <li>• Support for all life stages</li> <li>• Information, advice and advocacy</li> </ul> <p>Some people found it difficult to choose as they were not carers themselves and felt that their view may be different to somebody who has a caring responsibility</p>



Organisation	Key Findings
Sefton Partnership for Older Citizens - Bootle	<p>The following were considered to be the <b>most important</b> by the group:-</p> <ul style="list-style-type: none"> <li>• Access to Health and Wellbeing</li> <li>• Support for children and young people who are carers</li> <li>• Carers having a voice</li> <li>• Carers involved in plans</li> </ul> <p>Access to health and wellbeing was deemed important because carers need to be looking after themselves, so they can continue to care.</p> <p>Some members of the forum felt that hospitals and doctors do not engage with people well after they reach a certain age – especially those with chronic illnesses.</p> <p>Support for children and young people who are carers is important. It is also important to identify the hidden young carers.</p>
Mental Health Forum	<p>They group looked at the key themes from the strategy and ranked them in order of importance. Their top options were :</p> <ul style="list-style-type: none"> <li>• identifying and including carers</li> <li>• carers have a voice</li> <li>• carers involved in care plans,</li> <li>• support for all life stages</li> </ul> <p>Those attending liked the format of the engagement and They liked the fact that mental health was mentioned in the consultation questionnaire.</p>



Organisation	Key Findings
Parents and Carers Together – Southport Group	<p>Six parents, who are carers of children with disabilities, attended meeting. They ranked the most important key themes in the Strategy as:-</p> <ul style="list-style-type: none"> <li>• Identifying and including carers</li> <li>• Carers involved in care plans</li> <li>• Carers having a voice</li> <li>• Support for all life stages and Peer and Community Support</li> </ul> <p><u>Other comments</u></p> <ul style="list-style-type: none"> <li>• Courses offered by the Carers Centre are at times and venues that parents can't do. Can these be looked at, particularly having them in Southport.</li> <li>• There are no specialist play schemes in the North of the borough that parents can access and many activities are for older children, however, some of the children are 13 (so are old enough) but have a mental age of 8 so can't attend</li> <li>• There is a gap in ADHD services / activities in the north the majority are in the Bootle area.</li> <li>• GP's don't understand the needs of carers only concentrate on child's problems and not the problems faced by parents.</li> </ul>
Parents and Carers Together – South Sefton Group	<p>Nine parents attended the meeting. The parents were carers of children with disabilities or additional needs. They ranked the most important key themes in the Strategy as:</p> <ul style="list-style-type: none"> <li>• Carers having a voice</li> <li>• Support for children and young people who are carers</li> <li>• Access to health and wellbeing services</li> <li>• Support for all life stages</li> </ul> <p><u>Other Comments</u></p> <ul style="list-style-type: none"> <li>• Lack of support for parents with children of additional needs – no access to support except the group at the Children's Centre.</li> <li>• Siblings of young carers also need support, i.e. mental health support and counselling.</li> </ul>

Organisation	Key Findings
	<ul style="list-style-type: none"> <li>• Information needs to be in simple language – not using long medical terms and words that we don't understand.</li> <li>• Many activities in the holidays are not suitable for children with additional needs. Children with additional needs who haven't been diagnosed cannot attend the specialist holiday activities.</li> <li>• It takes a long time for the child to be diagnosed.</li> <li>• Carers are not getting a plan or being re-assessed – getting offered support but the support is not meeting the needs.</li> </ul>
Sefton Carers Action Group	<ul style="list-style-type: none"> <li>• Need for policies to support needs when participating in work/education/training.</li> <li>• Lead on “ integration “ to ensure that CCGs and other NHS bodies are taking practical and supportive action to improve well being of Carers</li> <li>• Demonstrate effective range of services to prevent/delay development of needs before “crisis” point is reached.</li> <li>• More assessments will be needed to meet influx of self funders even if they are delegated and to “ensure “ full range of rights can be addressed which will be more than access to small grants of up to say £200</li> <li>• The Council must demonstrate how they intend Carers to access the FULL range of preventative services rather than just saying these exist.</li> </ul>

## Perceived gaps in the Sefton Carers Strategy

- Parent Carers – No Carer Assessment in the new Care Bill
- Learning Disability
- Mental Health
- What happens when carers die
- What happens when someone becomes a Carer suddenly
- What happens in a crisis
- Transitions between being a young carer and becoming an adult carer
- Multiple complex disability (including learning disability)

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## Background

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### Carers' Strategy 2010-2013

The current Carers' Strategy 2010-2013 was developed in collaboration with a number of partners across the Borough. The Strategy focussed on achieving 13 strategic objectives, and over the past three years agencies across Sefton have improved information for carers, provided carers with emotional support and helped improve their overall health.

### Sefton Carers' Strategy 2014-2019

The refreshed Sefton Carers' Strategy 2014-2019 has been developed in partnership with carers and providers. A workshop was held in October 2013 at which key themes for consultation were established together with a set of draft strategic objectives which led to the development of the Sefton Carers' Strategy. Discussion also took place with regard to what carers would like to see in the Strategy and the best ways to consult with carers.

The five strategic objectives identified for the strategy are:-

- Carers Involvement
- Joined up & in partnership
- Information
- Whole Life Approach
- Young Carers

These relate to the National Strategic Objectives in the National Framework for Carers.

## The Consultation and Engagement Process

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This report brings together the feedback from the communities of Sefton and lays out the key points and recommendations that have emerged through our conversation with the public and stakeholders over the recent months.

Sefton Council, Sefton Clinical Commissioning Groups (CCG's), Sefton Council for Voluntary Services, and Sefton Carers Centre have worked together, to ensure that as many people as possible and those particular groups most affected have had the opportunity to comment and to have an input into the way Sefton Carers Strategy.

A small working group was established which included representatives from Sefton Council Business Intelligence and Performance Team, Sefton Carers' Centre, PSS (Sefton Young Carers), young people from Sefton Young Carers and Sefton Young Advisers, and Sefton Council for Voluntary Services in order to develop a consultation and engagement plan.

This report brings together the feedback from the communities of Sefton and lays out the key points and recommendations that have emerged through our conversation with the public and stakeholders over the recent months.

## **What are the aims of the engagement process?**

The aim of the consultation and engagement process is to engage carers, the public, key stakeholders, Elected Members and the diverse communities of Sefton so that they can have a say on what their priorities for the Sefton Carers' Strategy are.

The outcome of the process is the development of a final version of the Carers Strategy for Sefton 2014 – 2019 which will inform the future planning, commissioning and delivery of services for carers in Sefton.

## **Engaging Sefton's communities; what we did and why**

The process of planning for the Carers Strategy started with data analysis: we looked at the data, information, service mapping and previous consultations and drew up a list of priorities based on what we know about life in Sefton for Carers. The aim of the community engagement process was to firstly establish whether the Carers in Sefton felt that their needs were addressed by the emerging priority areas and if they felt that they were not met then what had we missed, what were the gaps?

A workshop was held in October 2013 with key stakeholders and the carers themselves at which key themes for consultation were established together with a set of draft strategic objectives. Discussion also took place with regard to what carers would like to see in the Strategy and the best ways to consult with carers. This led to the development of the draft Sefton Carers' Strategy.

In order to find out what the community's response to the draft Sefton Carers Strategy we used the following methods:-

- 2 World Cafe Events
- Youth Event
- Table discussions / workshops
- Questionnaire – both hard copy and on-line
- Information on the website

## How did we engage?

### World Café Events

The World Café approach involves small discussion groups discussing specific topics in an informal “café” style setting. Each World Cafe session was delivered in a relaxed, friendly atmosphere and people were invited to drop in and share their comments and thoughts over a cuppa! A “lead” on each table guided discussions and made notes on the points agreed, although participants were encouraged to add their own comments on the paper tablecloths provided.

Three “World Café” sessions were held:-

- Crosby Civic Hall, 2<sup>nd</sup> December 2013
- Family Life Centre, Southport, 3<sup>rd</sup> December 2013

### Young Carers Event

A separate event was held for Young Carers and their families on 30<sup>th</sup> November at the Dove Centre in Formby, as it was felt that young people would feel more comfortable discussing issues with their peers rather than being included in a more adult session. The event was organised by PSS together with some of the young carers themselves, assisted by Sefton Young Advisers.

A group of young carers attended the World Café event at Southport on 4<sup>th</sup> December in order to feedback the comments from the Young Carers event.

### Table Discussions/Workshops

The Table Discussions/Workshops enabled engagement with stakeholders as part of their existing meetings where, following a presentation, they worked in small groups to discuss the issues further and provide direct feedback.

### Website and On-line Questionnaire

The Website and On-line Questionnaire enabled the questionnaire to be completed on line if people had internet access. The information they might need to inform their comments was also available on-line. This made use of our eConsult technology which processed the responses and provided us with a report of the results.

### Paper Questionnaire

A paper version of the questionnaire was provided for those people who do not have access to the internet. This was distributed via the Sefton Carers’ Centre using their database to ensure as wide a distribution as possible.

## Comments from other groups

Comments were received from groups who have an interest in the Carers Strategy but who are not necessarily carers themselves..

## What did the consultation tell us?

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### The World Café Events – 2<sup>nd</sup>/3<sup>rd</sup> December 2104

Due to the relatively low numbers booked onto the event it was decided to hold a small focus group style consultation although the World Cafe theme was still adopted i.e. a relaxed informal atmosphere. However 22 people attended the two events, including a number of young carers.

Discussion took place on the four overarching themes which have been identified from both the National and Sefton Objectives:-

- Supporting Carers to Remain Healthy and Well
- Enjoy a Life Outside of the Caring Role
- Planning of Care through Key Transitions
- Information

Two questions per themes were discussed and the following is the outcome of the discussions that took place. These also include the comments from the young carers who attended the World Café events:-

#### Theme One - Supporting Carers to remain Healthy & Well

##### 1. *What does remaining healthy and well mean to you as a Carer or Care Provider?*

- Having a good diet or exercise plan
- 'Me Time' is important but difficult to find 'me time' if you are a carer
- Short courses on healthy eating and the food benefits.
- Short training courses for Carers to enable them to deliver basic courses peers i.e. basic counselling skills, alternative therapies, stress management etc...
- Exploring different methods of treatment not only for the cared for but for the Carers i.e. alternative therapies/ holistic Therapy – but these are often limited in the number of sessions that carers can access.



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- Being able to undertake social activities away from the Caring role and not having to worry about the responsibilities/commitments whilst participating in such activities i.e. Crown Green bowling. It was felt that such activities help with not only the physical wellbeing but also the mental wellbeing of the Carer.
- Caring for the Carer is of the utmost importance. The need to remain physically and mentally well is a top priority. “No-point having a carer if the carer is not healthy and well”.
- Carers often put their needs to the bottom of the list or they do not see their needs as important.
- Practical advice
- Courses such as the “Looking After Me Course”

#### Feedback from young carers

- Having the time to go out
- Being able to eat healthy food and feed/cook the person being cared for healthy food – vouchers for healthy food, for underprivileged families
- Emotional health – always worried about the person being cared for whilst at school
- Being able to talk to friends – “teachers too busy to listen to my worries”
- Training for teachers on how to support young carers to be more understanding and considerate and to have a greater understanding of personal circumstances
- More access to mentors – having a nominated person to talk to

#### 2. *What support would you require or would help you remain healthy and well?*

- Knowing where to access various social groups/alternative therapies - signposting
- Someone to help with identifying the needs of the Carer as Carers often do not recognise or feel they can ask for support.
- Having the reassurance that the person they Care for is looked after well in their absence.
- Short ‘Healthy Eating’ course to provide information on various food groups and the benefits these food groups have on energy levels etc...

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- Timing/access to alternative treatments and assessing what people need based on the individuals need not the cost.
- Providing short courses to which deal with how to stay fit and well and these being local and accessible for carers i.e. at various times in the day to cater for Carers who work.
- If funding not available to run certain activities/courses possibly have facility for Carers to pay part of costs?
- Stress management courses
- Counselling services
- Reassurance that the person being cared for is safe and looked after whilst the carer has 'me time'.

#### Feedback from young carers

- Opportunity for holistic therapies
- Pampering! – would help self esteem
- Lifestyle passes for swimming etc
- Greater access to healthy/budget food classes
- Support with transport and equipment
- going out for tea as a family

### **Theme Two - Enjoying a Life Outside of the Caring Role**

1. *What is important to you to enable you to enjoy a life outside of the caring role?*
  - Knowing the person(s) who you care for are looked after appropriately whilst you are doing other things.
  - Having places where the cared for can go to that are specifically designed to cater for their needs.
  - Duration/ length of time the cared for are away (respite) would be better if they could be taken to and from place of respite as the effort of transporting the person can be problematic and cause stress to the Carer.
  - Having a variety of places/things to do for the Carer/Cared for.

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- Financial/job support needs – flexible working is a good idea but carers can't always afford to take the drop in wages that comes with this

#### Feedback from young carers

- Having somewhere to go – respite groups and activities
- Leisure activities – time with friends or to talk to youth workers “Just having a chance to go out”
- Having the same opportunities as my friends do
- School trips abroad can be a problem and more financial help for school trips – “I feel that I am missing out, not learning or socialising”
- Important the person being cared for is looked after whilst out – to help young carers not feel guilty
- Being able to ring home from school and special cards to leave early
- Schools looking at detentions – recognising that maybe keeping people in at break times and lunch times is more appropriate than after school as young carers have to go home to care
- Young carers need a break between caring and homework – no time to socialise – schools need to remember this

#### 2. *What do you need to achieve this?*

- Quality respite care
- Good information i.e. signposting of activities
- Early identification of needs for both Cared for and the Carer – possibly via the local GP
- Need “escape time”
- Support from friends
- Option of longer-term alternative therapy support – carers may be able to contribute financially

## Theme Three - Planning of Care through Key Transitions

### 1. *In what way would you like to be involved in the planning of care for the person you care for?*

- From the beginning – Carers thoughts and feelings being taken into account. Recognising that the Carer is a key partner in the design of care given/needed.
- When multi-agency CAF meeting take place important for the Carer to be privy to all information i.e. when caring for an adult who also has a child and the carer has limited information with regards to the child due to patient confidentiality.
- Closer working/information links with Health, Local Authorities and Schools
- Being more aware of PCP (Person Centred Plans)
- Clear Communications with Carer and professionals during various key transitions in Carers/Cared for life i.e., changing job, marriage, divorce and most of all when the Cared for dies.
- It was felt not enough practical/emotional support was available for the Carer when they no longer have a caring role. Planning for when the Carer can no longer provide care i.e. if they die or become ill themselves.
- When emergencies happen (such as the carer becoming ill or being in hospital at short notice) the needs of the person being cared for are not always met in the most appropriate way i.e. instead of being supported to go home, they are kept in hospital which is not appropriate.

#### Feedback from young carers

- Appropriate methods for communication
- Need to know situation, for example medication doses
- An accessible FAQ sheet
- Involve carers at doctor's appointments. Need more respect and communication off doctors.
- The different doctors/consultants roles are not clear – e.g. oncology, orthopaedic, psychiatric
- Being respected by my parents, supporter, Dr etc. "I am the carer but I am often overlooked"

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- Being kept informed of all aspects of the care plan for my parent

2. *What key things would help you become/stay involved in the planning of care?*

- Ongoing clear lines of communication, being kept up to date with changes to care packages
- More rights to access certain information when caring for more than one person (especially grandparents caring for grandchildren)
- Wider family/friends circle being aware of care given by the carer
- Knowing the Cared for would be looked after appropriately if anything happened to the Carer.
- Double appointment slots with local GP or medical professional to discuss care needs as sometimes not enough time allocated to discuss sensitive issues.
- Confidentiality is sometimes an issue – when medical staff refuse to speak to the carer about treatment plans, medicines, etc., for the cared for person. This needs to be addressed
- Carers assessments not a routine thing – the carers assessments should include prevention to help carers remain healthy and well
- Funding to train volunteers and carers to provide alternative therapies

Feedback from young carers

- Prescriptions explained more
- “Doctors actually identifying and recognising me as a carer and giving me respect”
- “Doctors speaking to you, not down to you”

## Theme Four - Information

### 1. *What type of information do you feel would support you in your caring role?*

- What is out there and support for Carer on receiving this information at an early stage?
- Newsletters as a lot of older Carers are not Computer literate
- Information on short courses/alternative therapies
- Volunteering
- Information on peer support groups
- Information of holiday lets especially designed for Carers etc...
- Days out for Cared for and Care to do together

#### Feedback from young carers

- More clear information about illnesses
- Understanding carer and cared for rights
- Understanding complaints procedure
- Using the Sefton Directory
- More carer addressed letter
- On-line information doesn't feel safe enough for sensitive subjects

### 2. *What is the best way for you to access information?*

- Local Papers
- Newsletters
- Carers Centre
- Consultation events like this one
- Information given in plain English

## Additional comments

The general feeling from both events was that it had been a worthwhile process for participants. Lots of information was exchanged between Carers and Professionals. Also some valuable links between new and old Carers were forged. The format of the events was well received by participants (i.e. relaxed World Cafe style) as it was felt that this allowed conversation between participants to flow naturally. The format also enabled carers, the people who are cared for and providers to have a dialogue and this also led to carers making contact with service providers.

**Information** was highlighted as being an important part of all of the above themes and questions. Carers need to have information so that they know what is available, where to go for help and advice with regard to things such as benefits, medical advice, etc. It was also felt that with regard to information from the medical profession about the person being cared for, this was a big problem as “confidentiality issues” were deemed as being more important than making sure that the carer knows what the cared for person’s needs and requirements are. It was felt that the Sefton Directory will go a long way to helping with information as this means a lot of information will be in one place.

## Sefton Young Carers Event

**Consultation event, 30th November 2013, 10.00 a.m. – 1.00 p.m., the Dove Centre, Formby**

An event for young carers in Sefton was held on Saturday 30<sup>th</sup> November at the Dove Centre in Formby. The session was planned by PSS with input from young carers and the Sefton Young Advisers.

The aim of the event was to gain feedback from the young carers group and a fun session was devised to gain information about their experiences and feelings of being a young carer. A group of 12 young people aged 7-14 yrs attended. The young people played a game of bingo and if their number came out, it was their turn to answer a question around being a young carer. The following information has been collated from their answers:-

- The young people in the group expressed how they felt the young carers group provides them with an opportunity to have a voice, time away from home life, have fun, meet new people in similar situations and experience new activities. The sessions that take place are planned by the young carers themselves which empowers them and gives them ownership of the group. This was voiced in their answers to the question, “we decide on things to do...the staff try to make it happen.”



- The group were asked if staff at the young carers group are helpful to which they answered, “yes by listening, cos not many people do; they give advice and options for me to chose the best way forward.” The group reported they feel comfortable, safe and relaxed when with PSS young carers staff.
- When the young people were asked about activities there were numerous favourite times they could recall. These included a residential break away, sailing, first aid course, lazer quest, a pamper day, games and forest school. All the sessions run boost young peoples’ self confidence, social skills while challenging them physically and mentally. One young person said “...helps me feel better about myself.”
- When young people were asked questions about school they had mixed feelings. A lot (9/12) felt they benefited from young carers staff having one to one’s with them and also advocating on their behalf to teachers about certain situations. (These included bullying issues which the young people felt did not get addressed correctly). The majority of the group felt they did not enjoy own clothes days as this just made them stand out and become targets for bullying. Other young people in the group had an identified teacher or mentor who is fully aware of situation and approachable if a problem occurs at home or school.
- Overall, the young carers group fed back that the sessions provide an outlet for them to sound off, have a break form home, meet new people in similar situations, be listened to and valued.
- One young person shared “I need to be part of young carers because before I had no one to speak to about my worries about my mum, nobody understood and nobody to help me make sense of what was wrong with my mum...I now know more about her condition and that everything will be ok.”

### **Discussion Points**

#### **Access to Services**

- I am happy to help and don’t mind sharing my time. It would be useful to have more accessible places to go this would make me happy.
- Happy to care to but need time to myself
- My dad can’t drop me off at school as it is too busy for him to get out of the car and he is not allowed to pull in to the grounds.
- Parent evening disabled spaces are not allocated to people with disabilities and my dad has missed out on attending parents evening due to not being able to park close to the school.
- I would like time to spend with my friends.

### Respect from Professionals

- Don't like being taken out of class to support my brother
- Professions talk to my dad then he talks to me I'm not included.
- There is a lack of understanding within schools. I get bullied but the teachers don't understand
- I want people to listen and give me time.
- Teachers will make threats about keeping me behind at the end of the day
- Professionals who understand what a young carers is, as often people just miss us.
- I don't fully understand my brother's condition but nobody talks to me.

### Schools, Work and Caring

- Support for young carers within schools is helpful
- It's important to have time to let of steam and our break times have now been made shorter
- Hate own clothes day
- It would be useful if I could opt to learn about something I am interested in.
- I get in to trouble at school but I am told off and not given the opportunity to explain.
- I am often sleepy at school
- I have a poor diet
- If I am late I get detention but can't stay as I have to get home for my mum.
- It would be good if half a day a week at school could be spent doing something of choice.
- Our school go swimming once a week this is great because I can't do this with my parents.
- I worry about the person I care for during the day

## Young People's Questionnaires

A separate questionnaire, based on the adult questionnaire, was developed for young people. 6 young people completed the form and the results are as follows:-

<b>Question 1 – Who do you care for</b>	<b>No of responses</b>	<b>%</b>
A child with a disability or long term illness	4	80
An adult with a disability or long term illness	1	20
A frail, elderly person	0	0

<b>Question 2 – How old are you</b>	<b>No of responses</b>	<b>%</b>
Under 10	1	25
10-13	2	50
14-16	0	0
16-18	0	0
18-21	1	25




<b>Question 3 – How long have you been caring for somebody else:-</b>	<b>No of responses</b>	<b>%</b>
Less than one year	1	20
2-5 years	1	20
6-10 years	2	40
11-20 years	1	20




<b>Question 4 – We would like to know how YOU manage and if you are able to look after yourself too. This includes things like getting enough sleep or eating well, having good attendance in school/work, doing homework, going out with friends or just generally looking after yourself.</b>	<b>No of responses</b>	<b>%</b>
I am sleeping and eating well and am able to find time to do homework, go to school/work, see my friends and look after myself	2	50
I am sleeping much or eating well and I don't always have time to do homework, go to school/work or see my friends. I don't look after myself very well.	2	50
I am not sleeping and eating at all. I can never find time to do homework. I often miss school/work. I don't get to see my friends and I don't look after myself.	0	0

<b>Question 5 - How important are each of the following to you</b>	<b><u>Very Important</u></b>	<b><u>Quite Important</u></b>	<b><u>Not very important</u></b>	<b><u>Not at all important</u></b>
	<b>Replies</b>	<b>Replies</b>	<b>Replies</b>	<b>Replies</b>
Being involved and having a say when plans and changes are being made about the person I care for.	4	1	0	1
The different people and services who support carers should talk to each other, so that they all know what's going on, and things don't get repeated	5	1	0	0
Information on services, such as where I can go for help, is clear, easy to find and read, up to date and available	4	2	0	0
Giving me enough support to do well in education, getting and keeping a job and doing well in my future	3	2	0	0

<b>Question 6 – How would you describe the quality of the services currently available to you as a carer?</b>	<b>No of responses</b>	<b>%</b>
Excellent	2	40
Good	0	0
Average	3	60
Poor	0	0

<b>As there is less money and people available to all the organisations who provide services for carers , if you could only choose three things from this list to help you in your caring role, what would they be? (Please tick three only)</b>	<b>No of responses</b>	<b>Ranking</b>
Being given better information and advice	3	1
Care close to your home for the person you care for	2	2
Access to activities in your local community for yourself and the person you care for	2	2
Advice and support about money/benefits and how to plan	0	0
Support to stay in school, college, training or work	1	3
Someone for you to talk to, who will listen to you	2	2

What is the first part of your Post Code		L30	1	25%
		L31	1	25%
		L36	1	25%
		PR8	1	25%
Are you:		A boy	6	100%
		A girl	0	0
How old are you?		Under 10	1	17%
		10-13	2	33%
		14-16	0	0
		16-18	0	0
		18-21	3	50%

What are you doing during the day		<table border="0"> <tr> <td>At primary or high school</td> <td>3</td> <td>50%</td> </tr> <tr> <td>A part time student at 6<sup>th</sup> form college/FE/University</td> <td>0</td> <td>0</td> </tr> <tr> <td>A full time student at 6<sup>th</sup> form college/FE/University</td> <td>1</td> <td>16%</td> </tr> <tr> <td>In full or part time work</td> <td>1</td> <td>16%</td> </tr> <tr> <td>Unable to work because of caring duties</td> <td>0</td> <td>0</td> </tr> <tr> <td>Not in school/college/work</td> <td>1</td> <td>16%</td> </tr> </table>	At primary or high school	3	50%	A part time student at 6 <sup>th</sup> form college/FE/University	0	0	A full time student at 6 <sup>th</sup> form college/FE/University	1	16%	In full or part time work	1	16%	Unable to work because of caring duties	0	0	Not in school/college/work	1	16%
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Disability – Do you have?		<table border="0"> <tr> <td>Physical Disability</td> <td>0</td> </tr> <tr> <td>Problems seeing/blindness</td> <td>0</td> </tr> <tr> <td>Learning difficulty</td> <td>1</td> </tr> <tr> <td>Problems hearing/deafness</td> <td>0</td> </tr> <tr> <td>Mental health problems</td> <td>0</td> </tr> <tr> <td>Another illness that affects what you do every day</td> <td>0</td> </tr> </table>	Physical Disability	0	Problems seeing/blindness	0	Learning difficulty	1	Problems hearing/deafness	0	Mental health problems	0	Another illness that affects what you do every day	0						
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Another illness that affects what you do every day	0																			
Ethnicity		<table border="0"> <tr> <td>White British</td> <td>3</td> </tr> <tr> <td>White English</td> <td>1</td> </tr> </table>	White British	3	White English	1														
White British	3																			
White English	1																			

## Table Discussions/Workshops

The Table Discussions/Workshops enabled engagement with stakeholders as part of their existing meetings where, following a short presentation, they worked in small groups to discuss the issues further and provide direct feedback.

Following the World Café events, a number of gaps with regard to specific groups were identified, including parent carers with younger children and older carers.

The following groups were involved and provided valuable feedback:-

### Sefton Parents and Carers Together – Southport Group

Friday 7<sup>th</sup> February 2014, Parenting 2000, Mornington Road, Southport

Six parents, who are carers of children with disabilities, attended meeting. They were asked to work in pairs and to look at the key themes from the strategy and to rank them in order of importance from 1 (being the most important) to 10 (being the least important).

Following analysis the following were considered to be the **most important**:-

- Identifying and including carers
- Carers involved in care plans
- Carers having a voice
- Support for all life stages and Peer and Community Support

The selection that was the **least popular** was access to work and training.

### **General Feedback/Comments**

Some of those attending said that they found it hard to choose between the options as they considered that they were all equally important.

### **Discussion Points**

- Parents can't attend work or training as the children use specialist transport from school to home and get dropped off at 3.30 pm. If parents are late back the children become very distressed due to their disabilities. There are no after school clubs so it isn't possible to have children dropped off any later.
- The Carers centre ring constantly to offer PC courses from 1-3 pm at the Carers Centre in Crosby. However parents live at the north end of Southport and must get a bus and train, so there is no way they can get back for 3.30 pm for school drop off. Could the course be earlier? Parents suggested 11-1 pm or nearer to Southport?
- Parents would be very interested in courses that would help them care such as speech therapy, etc.
- The public transport from Crossens and Maghull is very poor and limits what parents can do.
- There are no specialist play schemes in the North of the borough that parents can access. In the February half term brochure, the closest session that parents can access is one football session in Formby.
- Parents are offered 2 hours respite per week at the Crosby Lakeside Centre, but choose not to access this as it takes over 1.5 hours to get there and back, and as the session runs from 6-8pm, children wouldn't get to bed until 10pm. This is not actually respite as parents haven't got time to go home and have to stay with the children.
- Many activities are for older children, however, some of the children are 13 (so are old enough) but have a mental age of 8 so can't attend. Also many activities offered do not meet the need of the children, i.e. may be aged 7 but needs nappies and specialist activities however these are not offered.
- Direct payments for some families have stopped as they no longer meet the criteria that the disability team have set; this is causing some issues for people.



- There is a gap in ADHD services / activities in the north the majority are in the Bootle area.
- Could there be a credit card sized card with details of key numbers on it that can be kept in a purse for when access to the internet isn't available or when you are away from home.
- Professionals change appointments without telling parents. Parents turn up and have a wasted journey. Change time of appointments to times which aren't convenient or not suitable.
- GP's don't understand the needs of carers only concentrate on child's problems and not the problems faced by parents.
- Professionals make judgements about parent/carers – they don't ask what we do know and what we are capable of doing.
- When diagnosis is made the information from GP's is not good – need to know where to go and who to go to for help.
- GP's just dispense drugs for depression instead of offering talking cures.
- Need signposting to support groups who offer help and Peer support is very important.
- A buddying scheme would be good.
- Support so that parents can attend meetings is needed especially where other children are involved.
- Information needs to be in simple language – not using long medical terms and words that we don't understand.
- The needs of parent/carers aren't being identified.
- Professionals don't accept the word of parents/carers that there are problems and what possible solutions might be.
- Respite for carer and the cared for – even if it is just for one night – or even a few hours.
- Isolation is a big problem.
- Aiming High is good but again all in the South of the Borough and the children need to be old enough to attend.

### **Sefton Parents and Carers together - South Sefton Group**

G:\Policy\CSU\Public Engagement and Consultation\carersstrategy

Author: June McGill

Version 0.3 – 08.05.14

13th February 2014, Netherton Children's Centre, Magdalene Square, Netherton

Nine parents attended the meeting. The parents were carers of children with disabilities or additional needs.

They were asked to work in pairs and to look at the key themes from the strategy and to rank them in order of importance from 1 (being the most important) to 10 (being the least important).

Following analysis the following were considered to be the most important:-

1. Carers having a voice
2. Support for children and young people who are carers
3. Access to health and wellbeing services
4. Support for all life stages

The selection that was the least popular was access to work and training.

### **General Feedback/Comments**

Some of those attending said that they found it hard to choose between the options as they considered that they were all equally important.

### **Discussion Points**

- Lack of support for parents with children of additional needs – no access to support except the group at the Children's Centre.
- Important that support is available for children and young people who are carers as they need to have a life as well as being a carer
- Important that the school has knowledge of who are carer's and that as well as caring for an adult, they may also be carers of children with additional needs.
- Schools make CAF appointments that are not convenient or parents are not given much notice – there is a lack of communication between partners and with carers
- Schools and other organisations need to know what is available so they can signpost people
- Siblings of young carers also need support, i.e. mental health support and counselling.
- Support for carers with children with additional needs should be on-going.
- Access to work and training is very important for people with mental health problems and disabilities.

- Information needs to be in simple language – not using long medical terms and words that we don't understand.
- Time –out for carers – especially during school holidays for children with additional needs.
- Parents would be very interested in complementary therapies to help them relax.
- Many activities in the holidays are not suitable for children with additional needs. Children with additional needs who haven't been diagnosed cannot attend the specialist holiday activities.
- Direct payments for some families have stopped as they no longer meet the criteria that the disability team have set; this is causing some issues for people.
- It takes a long time for the child to be diagnosed.
- Carers are not getting a plan or being re-assessed – getting offered support but the support is not meeting the needs.

## Older People's Forums

### Maghull Older People's Forum - Tuesday 28th January 2014

The meeting was held in St. Andrew's Church Hall, Maghull, starting at 1.30 p.m.

Approximately 40 older people attended the forum meeting. They were asked to work in pairs and to look at the key themes from the strategy and to rank them in order of importance from 1 (being the most important) to 10 (being the least important).

Following analysis the following were considered to be the **most important**:-

1. Access to health and wellbeing services
2. Carers having a voice
3. Support for all life stages
4. Information, advice and advocacy

The selection that was the least popular was access to work and training.

### General Feedback/Comments

Some of those attending said that they found it hard to choose between the options as they considered that they were all equally important.

Some also found it difficult to choose as they were not carers themselves and felt that their view may be different to somebody who has a caring role.

### **Bootle Older People's Forum - Tuesday 11th February 2014**

The meeting was held at Linacre Mission, Bootle, as part of the scheduled Older People's Forum, between 1.30 – 2.15pm.

Thirteen people attended the Forum. They were asked to work individually and to look at the key themes from the strategy and to rank them in order of importance from 1 (being the most important) to 10 (being the least important).

Following analysis the following were considered to be the most important:-

1. Access to Health and Wellbeing
2. Support for children and young people who are carers
3. Carers having a voice
4. Carers involved in plans

The selection that was the least popular was access to work and training

### **General Feedback/Comments**

Some of those attending said that they found it hard to choose between the options as they considered that they were all equally important.

### **Discussion Points**

- Access to health and wellbeing was deemed important because carers need to be looking after themselves, so they can continue to care.
- Some members of the forum felt that hospitals and doctors do not engage with people well after they reach a certain age – especially those with chronic illnesses.
- Information, advice and advocacy was felt to be essential as it can be a comfort knowing what is available and can provide lots of support. Friends were also important in providing support when needed.
- There needs to more promotion and awareness of what services are available for everybody and for those who need help. Healthwatch should promote itself more.
- Support for children and young people who are carers is important. It is also important to identify the hidden young carers.

- Services need to be more joined up.
- Carers should be involved in plans at all life stages.

## Sefton Mental Health Service Users Forum

17<sup>th</sup> January 2014, Feelgood Factory, Netherton

A Meeting was held at the Feelgood Factory in Netherton from 11.00 am till 1.00pm. 5 service users attended. Other agency staff were also present (3) who had experience of either being a carer or knew of someone close who had been a carer also contributed.

They group looked at the key themes from the strategy and ranked them in order of importance from 1 (being the most important) to 10 (being the least important).

Following analysis the following were considered to be the most **important** :-

- identifying and including carers
- carers have a voice
- carers involved in care plans,
- support for all life stages

The least important, which was agreed across the three groups was 'access to work and training'.

### Discussion Points

- Those attending liked the format of the engagement (pictorial with key bullet points from the strategy) and then asked to scale from 1 to 10 (with 1 being most important and 10 being the least).
- They liked the fact that mental health was mentioned in the consultation questionnaire.
- They felt that scaling the themes/bullets was very personal to individual experience in terms of what was important.
- They were appreciative of us coming out to see them.

## Comments from Other Groups

### Sefton Carers Action Group

The group feel that there must be definitive proof that the 4 priority areas are being met and not box ticking just to meet targets.

## The Care Bill

Whilst this is Work in Progress we can still say that:-

- There will be a “ duty “ to respond to eligible needs (NOT the current “power”)
- Councils will be required to make available more breaks and Carer personal budgets.
- Self funders will now be included meaning more bureaucracy/ less money to disburse.
- Will those financially disadvantaged suffer due to Self Funders flexing their financial muscles?
- The need to robustly enforce the Equality Act so inequalities are non-existent.
- Clause 4 is a Statutory Duty regarding information services.
- Need for policies to support needs when participating in work/education/training.
- Lead on “ integration “ to ensure that CCGs and other NHS bodies are taking practical and supportive action to improve well being of Carers
- Demonstrate effective range of services to prevent/delay development of needs before “crisis” point is reached.
- More assessments will be needed to meet influx of self funders even if they are delegated and to “ensure “ full range of rights can be addressed which will be more than access to small grants of up to say £200.

### The Carers Strategy:

- The Council must demonstrate how they intend Carers to access the FULL range of preventative services rather than just saying these exist.
- As yet the strategy is just a skeleton on which a lot of flesh needs to be added and as always “the proof of the pudding....”

## The Questionnaire

The questionnaire was available on-line (via e-Consult) and as a hard copy. It was available for people to complete over a 12 week period from November 2013 to February 2014. The questionnaire was also distributed by the Carers Centre to people on their database. A copy is attached at Annex 2.

Accompanying the questionnaire was a draft strategy which provided people with a summary of what we have found. The questionnaire provided people with the opportunity to tell us what they thought about this and to tell us if they thought we had missed anything.

A total of 505 people completed the questionnaire. 474 people have fully completed the questionnaire and 31 people have partially completed the questionnaire (i.e. they have not answered one or more questions in the consultation; this may include monitoring questions).

It is important to note that these results are not representative of the Sefton population. The results of the questionnaire will support the feedback from the other engagement methods used.

<b>Question 1 – Are you:-</b>	<b>No of responses</b>	<b>%</b>
A Carer	435	95
A member of the public	7	1.5
A Council Officer	1	0.25
A Clinical Commissioning Group Board Member, Lay Member of Officer	0	0
Other Health Professional	1	0.25
A voluntary, community and faith organisation	2	0.50
An organisation that is commissioned to provide services to carers	4	1.00
Other	7	1.50

The following identified themselves as voluntary, community and faith organisations or an organisation that is commissioned to provide services to carers



- Carers Training Service (part of Sefton Carers Centre)
- Sefton Carers Centre
- Slater & Gordon Lawyers
- Parent of a young adult person living in supported tenancy
- Formby Carers Support Group
- Sefton Mental Health Users Forum
- The Stroke Association
- Norwood Surgery
- GP Practice, Southport
- Sefton New Directions Ltd.
- People First Merseyside

<b>Question 2 – If you are a carer, are you:-</b>	<b>No of responses</b>	<b>%</b>
A carer of a child with a disability or limiting long term illness	55	12
A carer of an adult with a disability or limiting long term illness	286	64
A carer of a frail, elderly person	105	23
Transitional Carer i.e. parent of a young person who is moving from Children's services to Adult services	1	0.50
A young carer (up to age 16) looking after an older person	1	0.50
A young carer (up to age 16) looking after a young person	0	0
A young carer (16-21) looking after an older person	0	0
A young carer (16-21) looking after a young person	0	0

<b>Question 3 – How long have you been caring for somebody else:-</b>	<b>No of responses</b>	<b>%</b>
Less than one year	15	3
2-5 years	156	35
6-10 years	109	24
11-20 years	97	22
21+ years	72	16

<b>Question 4 – Thinking about how much time you have to look after yourself – in terms of getting enough sleep or eating well, having time to attend doctor’s, dentist or other medical appointment, or looking after your own general wellbeing – which statement best describes your present situation</b>	<b>No of responses</b>	<b>%</b>
I am sleeping and eating well and am able to find time to attend to my own health and wellbeing needs	201	45
I am not sleeping and eating as well as I should and I am not always able to find time to attend to my own health and wellbeing needs and I sometimes neglect myself	219	48
I am not sleeping and eating at all well and I can never find time to attend to my own health and wellbeing needs and I am neglecting myself	31	7

<b>Question 5 - How important are each of the following to you</b>	<b><u>Very Important</u></b>	<b><u>Quite Important</u></b>	<b><u>Not very important</u></b>	<b><u>Completely unimportant</u></b>
	<b>Replies</b>	<b>Replies</b>	<b>Replies</b>	<b>Replies</b>
Being involved in all stages in the planning of care for the person cared for throughout life changes, and ensuring that carers have a voice	404	47	9	2
The different people and services who support carers should talk to each other, so that they all know what’s going on, and things don’t get repeated	380	65	5	2
Information on services, where to go for help, etc., is clear, timely, accessible, and kept up to date and in the correct format	402	45	2	3
Young carers are supported as much as possible in order that they can live fulfilling lives and progress with their education, career and life aspirations	379	34	4	5

## Question 6 - Is there anything missing from this list that you consider important to you?

115 people completed this question. These are their comments:-

- More assistance to legal/benefit matters for the disabled, adapting home.
- Feel that I'm wasting my time filling this in
- Social workers and doctors listening to us (concerns) and treating us with care as we are the people nearest to the user.
- Have a rating system for Sefton carers to rate and make comments on e.g. daycare, respite and being a patient in hospital. People with dementia are vulnerable and can be taken advantage of in many ways. A respite provision Sefton uses, serves sausage rolls and beans or fishcake, chips and peas (fish not allowed) for evening meal. My mother was very stressed by this and her ability meant that she was aware of being given substandard food that somebody without dementia would not be offered.
- Evening carers meetings for carers who have to work during the day time.
- Should be a freephone number for emergency help, i.e. if carer has an accident
- The help is not easy to find. I cared for two years without knowing from anyone whom I could ask for advice and support. It was pure chance I found out about the Carers Centre and if I had not mentioned it at Shoreline Church I would have still been on my own.
- Benefits advice for carer and person cared for. Someone to listen to carer.
- I try as much as possible to make sure Tommy gets all the help and care he needs, from the right people
- Chances to meet and get together with others in a similar position
- Recognition that carers are the first line of prevention and can be part of the solution to Council/NHS budgetary problems. However, if not properly supported carer breakdown will increasingly occur and they too will become service users rather than service providers.
- My involvement would be linked to aspects I can support. Cohesive, joined up services that communicate effectively to better support the family

- That people supporting carers know that carers don't necessarily reveal all that they are going through, out of a sense of duty, responsibility, love, guilt, emotional involvement and that there is often a level of personal neglect that goes unnoticed by the outside world.
- It is very very important that the carer has someone to turn to in a crisis situation at any time
- Support for carers should be equally available to carers who work
- Being able to share information with Doctors and specialists without the cared for being involved with.
- Support in Education - reduce need for school head to phone with details of 'incidents' occurring. Statement of special educational needs annual review. Official report required from Aiming High to explain why short breaks at High School, science clubs etc. are not made available, to give social inclusion. Sefton Departments do not co-operate at all. Education, Sefton Holiday events, Aiming High to meet needs for short breaks in Southport by allocating support staff to support children in need. This situation began at age 3, nursery and remains unresolved now age 11- secondary.
- Caring for someone takes all your energy and time in their company and when you leave them to go home you still are doing, thinking and worrying about them. Leaves little time to rest or sort problems. Not all services are aware of carers pressures i.e., Doctor's reception staff.
- Carers Contact Magazine
- I am not a young carer but think it is appalling that youngsters have to be carers. More education about specific conditions: this is beginning with dementia awareness (hooray!!), but other conditions need understanding for the carer to handle the situation as well as possible
- Being able to access help quickly
- I realise the one thing you haven't got is money - but this is a problem for me too! Carers Allowance is something towards my own living expenses but not nearly enough and I have to 'raid my pension pot'. I am lucky that I have something to raid - I am sure there must be others who have not. The irony of course is that I was planning to pay for my care if and when I need it when I am elderly
- Places to go for a chat and catch up and cup of tea

- GP's are aware who carers are and are aware of the impact being a carer can have on their patient's health
- No time for recreational activities, e.g. a computer class or to see a film. I feel that older carers need opportunity to take advantage of courses - form example - which are on offer but can't be accessed because of the needs of the person we are caring for
- I think an online question and answer about the person you care for would be helpful as with mental health issues it is so difficult to voice to psychiatrist and behavioural etc in front of the person who will deny etc or a visit from nurse
- At the present time there is nothing missing, but I am on medication for angina and irregular heartbeat. I think information on services is good for every carer to know. I try not to let my condition stop me looking after my wife.
- The biggest problem at present is getting a wheelchair bound person to and from hospital appointments
- GP's should contact carers on a regular basis to make sure they are o.k. and get health checks regularly. Everything is for patient not carer
- Adequate financial and respite support for carers
- Time for going to Doctors, Dentist, Hospital, Chiropodist, Asthma Clinic
- Services especially for the carers wellbeing, i.e. to get up and running befrienders who can call at the house for a coffee and a chat - (most carers are confined to the house as cared for can't be left and sometimes won't accept strangers in their home)
- We currently have Warren Care who provide personal care for my 91 year old mum. They have difficulty in providing continuity of care and have needed my presence to ensure that they are aware of mum's medication and changes to her treatment plan. My mum is elderly and responds to someone whom she is familiar with. It has been evident that mum has had different carers on a daily basis. The Council need to address the support services they use.
- Reviews of circumstances. Not being dismissed just because you are old!
- My circumstances are unusual as my daughter lives in supported housing a short distance from myself. I feel I have been left on my own since I came to live near my daughter. As to the delicate nature of my daughter's illness and the tragedy surrounding it, all the talking in the world will not do anything for me or my daughter.
- Services, professionals etc, to not just consider care opinions but listen and act upon them. To consider individual situations and not presume all carers feel or

have the same experiences. to have social workers who act as advocates and not gate keepers

- Community education : i.e. shops, restaurants, hairdressers being proactive in easing visits by supplying chairs and taking the time to listen and be aware that patience is essential to carer and the cared for
- It's all very well being involved as long as carers/carers are listened to, and involved in final decisions
- How are carers expected to attend courses or workshops when they cannot leave the person they are caring for?
- More direct communication from Social Services
- I do not have access to any support or other carers with similar
- Sometimes I feel like walking away from it as I do get very upset and I feel so down
- I would like nurses, doctors or anyone else who visits the person I am looking after, to ask me 'about the answers the patient is giving' as there not always the right answers. Also to ask 'how I am' - they seem to ignore me
- I believe that services are "going through the motions" , "talk the talk" not "walk the walk"
- Respite care for long term carers i.e. the one being cared for to be offered "a holiday", to give the carer some respite. The views of carers to be respected, they should not be patronised by those providing services.
- More care from doctor and nurse in the clinic having to wait 4 weeks to see a nurse 1 week to see a doctor or having to get to the Drs at 8am to queue outside at 8am for appointment at 10am
- You only find out about these things like Sefton Carers Centres by word of mouth. It should be advertised more i.e. GP's surgery, Hospital's, Hospital Clinical Area's, South Neighbourhood Centre (Park Road)
- Communication between all services involved i.e. GP / NHS i/e/ hospitals etc/social services etc and that the person cared for and the carer are equally treated as a "package" as their health & wellbeing impact on each other e.g. age, health needs, social needs and most importantly are they able to deal with all forms, regulations and paper work through the system.
- The absence of home visits for my 41 year old, housebound, son. Other than 3 monthly psychiatrist appointments to reduce stress and great tiredness to myself (mother and carer)

- As services get less and they will do under this Tory government the young carers must come first
- Procedures and timescales should be detailed and available so that the carer can plan and understand and the future timescales and expectations
- There is someone to listen and give emotional support
- Having a Social Worker who keeps in touch on a regular basis.
- Keeping track of how a care situation is going. A simple phone call may do just to check. At least once a year twice is better
- Respite
- I think it is very important that provisions are made/sorted for when the parents / carers are no longer able to care for the child / children. I am very concerned about this.
- There are no services currently available to me that I am aware of
- Just to make sure that as person who has cared for my niece now in supported housing that all these wonderful services keep on for people who will need them in the future. Because without them Rebecca would not be the woman she had developed into today. Thank you.
- Free legal information. One main reference person for the carer.
- Young cared for need a safe environment to meet without carer present that you know they will be well looked after, lots of suitable respite has been closed and Direct Payments taken over, but a safe warm place to meet others is now rarely available, they need to be away from home environment and encouraged to mix with others
- It is vital that carers have mental health professional support out of hours.
- Carers need access to emergency help, advice and support in the dementia field at out of hours crisis events. For example a carer may need practical support during the night and or at week-ends.
- Where possible, allowing for age, infirmity, illness, frailty, the cared for person should be involved in planning stages and ongoing changes to the support being received.
- I am housebound now due to 3 separate illnesses 1) Mylintus 2) Astoma 3) Neck and lower back problems/Arthritis in spine knees and hands. I used to be the main carer for our son, but my husband had both legs amputated and is in a wheel chair so now there are three of us in one house and we are all being cared



for by our daughter who is working, keeping a house and she has a 3 year old girl. There aren't any questions about our situation and I know we aren't they only ones in this situation?

- Carer can be compromised by person being cared for is it a friendship or a cross to bear?
- People/persons are always treated as individuals and their wishes/ways are met as much as possible.
- I was retired on health grounds
- Vital independent help available and advice. I received cash help for keeping fit.
- For services to communicate better between each other and to keep to their word when considering service users themselves/and for them not to be so overworked through cuts so not able to provide adequate care never mind 'good' standards of care.
- I think £57 is nowhere near enough to live on as a carer. 24/7 call and nothing to live on causes much more stress and worry.
- Services should be central around the client, choice of carers times etc.
- More support for carers of adolescents with learning and mental health issues.
- I am a service user/carer rep for MerseyCare NHS Trust. We need to care for the Carers and the rest of the time I consider that the cuts to community services has had a massive impact on carers and service users alike.
- That all services are equally accessible to everyone in the borough regardless of where they live taking into account the nature of being a carer.
- Clear info about any free benefits that would help our limited budget.
- Yes, not being treated as an outsider "Data Protection" is a much used and erroneous excuse.
- I was originally my wife's carer, I now have physical difficulties and restricted in the help I can give.
- Being given time to attend to my own needs without the worry that the person I care for is in need.
- Clear info about any free benefits that would help our limited budget
- Other family members should be encouraged to help carers like myself instead of walking away



- As a carer it would be helpful if I could get help with bus fares or a bus pass.
- Re question on whether I am sleeping well, although I have ticked the first box there was nowhere for additional comments as, with regard to sleeping, I regularly get up during the night to help my mother when she needs to use the commode. This is to prevent falls.
- I feel that when I need to speak to someone or query something it seems to take a long time to actually speak to the correct person and it sometimes can take weeks before a visit can be arranged.
- No support No Services
- When contacting social services it is important that the person/persons you contact are helpful and understanding as this is important if you have problems.
- I feel alone and sad at times
- Access to benefit information - where to go etc. What a 'carer' can be entitled to claim (depending upon circumstances) - 'new carers' don't always know what's available.
- Elderly carers (65+) should be supported as much as possible so that their lives do not become intolerable and they do not suffer ill-health as a result of the stress of caring. Ditto for carers who also work. Respite care should be readily available and not curtailed
- Support should be given to all carers regardless of income - we've all paid our taxes and should not be turned down for help "because you've got too much money" (my social workers' quote). How can I possibly devote time to searching out the best care when I am looking after my husband 24/7.
- The ability to provide honest feedback to Sefton Council on the Care Services provided (by non Council providers) and see improvements or cancellations or contracts/sanctions where standards are failing or require improvement
- There are a lot of carers who don't realise they need support or know how to get support (like my self). Come up with other ways to reach vulnerable carers, isolated carers
- Carers are sometimes kept in the dark over what benefits they are entitled to - their careers also. This information should be given. Carers should not have to struggle to find out what is available.
- For services to be more local and accessible. Carers duties may not allow them to travel too far. If these services were closer, I would be able to use them.
- That we are always aware of services / funding etc that is available to us. We may not know about these.

- Being provided with information on services that are available through local GP's, etc., Funding for alternative treatments, accessing herbal medicine, vitamins. Doctors do not inform patients what alternatives there are to just being given prescription drugs. Doctors do not monitor side effects ?!!!
- As a carer there is no contact from Sefton regarding entitlement originally entitlement is 4 weeks P.A. no notification if still same. Should carers assume nothing has changed?
- Carers really need support as the whole of their life is the person they care for and their needs are ignored.
- None I can think of
- I care for 2 people, son 21years+ and father 6-10years
- Equipment stores and OT people should keep records of which appliances are best for each disabled person in order to replace appliances efficiently
- Older carers need support as well.
- Information provided regarding "allowances" that the carer is entitled to claim
- That the elderly may lose access to a doctor who knows their history each time they visit a surgery. If changes are seen in their health early, so much more can be done for them to lead an active life. Staying in their own homes and not filling hospitals, etc.
- I now work part time to look after my mum. Services need to be flexible enough to accommodate people like me if they are to be accessible.
- Services to support adults with learning disabilities find employment
- The provision of a regular free or low-cost break for carers without financial assessment in recognition of the 24hour job they do. This needs to be in the home of the 'cared-for' person as it is not always possible or preferable to access day care.
- Someone to give you an overview of the illness and the implications for the person and the carer.
- The person the carer is caring for , is included (if able ) in the decision making process
- Carers should be made aware of the different advocacy services available and what they can offer men and women with learning disabilities.
- Financial help and information

- Carers representation in key decision around the care of their person.
- All agencies need to co-operate e.g. One Vision Housing, OTs, GPs etc and this has not been our experience
- The provision of Day Care and Respite services for older people.

<b>Question 7 – How would you describe the quality of the services currently available to you as a carer?</b>	<b>No of responses</b>	<b>%</b>
Excellent	97	22
Good	194	43
Average	111	25
Poor	45	10

### **Additional Comments**

- Don't know. Not attended any carer meetings for some years now as last time what was on offer didn't meet our needs.
- Don't know as I am unable to attend anything arranged. Seems good and wish I could take part
- I don't ask for help
- All services are currently self-funded, I need more help to ascertain whether my 96 year old father could qualify for some state disability allowance.
- Don't use the carers centre. They don't provide what I need to help with my elderly mother e.g. practical help
- The information I receive from Sefton Carers' Centre is useful. I do not use any other services
- My contact with my son is peripheral making this question irrelevant
- At the moment I don't need any services
- I look after my mum on my own. I was a carer for 21 years. Left to look after mum.
- Myself has two children with additional needs I myself have bipolar and had purpal psychosis when daughter was born. My husband had to go to work no help for him to be at home when I was ill my sister who had three children had to look after us all. Life is hard him working. sometimes family life falls apart they don't take this into consideration

- Feel that because no diagnosis there is not much support for carer or children

<b>Bearing in mind that less resources are available to provide services in all sectors, what would be your priorities in helping you to continue in your caring role? (please tick top three)</b>	<b>No of responses</b>	<b>Ranking</b>
Access to targeted information and advice	269	1
Care close to your home for the person you care for	260	2
Access to activities in local communities for yourself and the person you care for	204	3
Financial advice and support on personal planning and budgeting	143	5
Training and support to continue to undertake you caring role.	128	6
Access to emotional support, counselling and social networks	190	4

### Anything else?

- Hightown seems disadvantaged for the person I care for due to travel and transport costs - have to get her to Formby or Crosby myself or by taxi. One "fitness" session is organised in Crosby for me.
- Evening and weekend availability of staff at Carers Centre would be lovely
- If and when you need to see someone you can see them soon
- Help for me. I am supporting my husband 24/7. What would happen if I were ill. We are struggling now financially and emotionally
- Tommy would like to go swimming in a controlled harness if you could help with this
- respite care
- Statement of special educational needs annual review. To include official Aiming High short breaks report for access to peer groups at Southport High Schools to provide inclusion at after school science clubs etc.... Child unable to meet any social development milestones, leading to continued 'incidents' in education.
- When she has these temper tantrums she will pick any thing up and throw it. She will pick tables and chairs up and throws them around the kitchen, she does it out of the blue so you do not know when she is going to do it. She hurts herself all the time.


- Access to help in emergencies
- Access to respite care
- Someone at my local GP surgery to regularly discuss my health needs as I have a long term chronic illness too.
- The day centre in Marion Square became too expensive. Age Concern should provide the same day centres in Sefton as they do in Liverpool which are affordable to a person on a pension. I appreciate that the council doesn't have the funding. I have cared for an aunt and uncle and now my stepmother. I have seen the excellent work the NHS does and the council providing care services. A great need that needs to be addressed is that an elderly person can be very lonely. Because of the lack of funding to the council charities and the local churches could work together with the council providing affordable transport and day centres as age concern does in Liverpool
- I feel sometimes it would be nice for me to have someone call to house to discuss any problems for example like health officer does for new mums
- some hope of a day centre in Southport
- Mears turning up on time i.e. not up to 2 hours late
- telephone befriending service
- When the carers association have trips and they never pick up in Maghull. With no transport it is impossible to get to Waterloo for 9.00 am
- It would be good if we had a bigger place or bungalow
- More support for my son
- Blue badge for car for my daughter who has Downs Syndrome and for my mother who is elderly and also has heart problems, diabetes and severe macular degeneration
- A free phone number like 'etc' help lines - just to talk our down times
- home visits from GP, clinic nurses hospital clinic nurses, to avoid unnecessary travel under stress for household frail elderly persons
- Respite
- We have carers in 10 hours of a night which is a great help can get bit of sleep
- A greater respect by qualified staff in the community for the role of carers and the willingness to listen so the best advice is given in all situations. Sometimes NHS

staff are too focused on following a format and they don't consider the patient's nursing needs i.e. to avoid hospital admissions versus staying at home (admission can cause trauma)

- Could do with (when weather not too cold) for person to take husband out more. Delta have taken him out on only a few occasions since we moved to this downstairs flat1 from the one above Flat 3 on 14th June 2013. He now has a wheelchair and being on ground floor is a godsend. He is just over 18 stone and not many persons can manage to push him in his chair from Delta Care. I am 76 years of age and I can't push him at all.
- Respite is very important
- Less resources does not add up. We have resources to increase foreign aid by 10% funds for asylum seekers increase by 15% so why are less resources being provided to care for disabled?
- Crisis management help, help when things go wrong or there is trouble
- As a pensioner looking after a 30 year old I cope because of the services I receive at the moment. Any cut will have direct effect on my health and my daughters.
- care close or as close as possible is important
- The physical attendance of a support worker and the carer on appeal days are the first priority because I am unable to be with mum all day
- Emergency Care Cover if usual paid carer/s not available - existing system limited should be financially supported / improved.
- To receive as much information as possible regarding medication
- Faster access to services as in some cases it may be too late and less closures to stop the overload on other services. Often people are forgotten and standards of care drop.
- I think all the things on this list should be going on all of them are of vital importance.
- Information should be local and not the other end of the borough. Access to activities is very important. Southport office should cover Ainsdale! Domiciliary Services. Many of the activities put on cannot be attended by a carer of a severely disabled person. It requires too much time away from that person.
- Day care for people with any form of Mental Health need is essential. No one can be expected to endure 24 hour supervision without respite.

- I do not have any social help
- Ensuring that Adult Day Centres stay open. These are essential for disabled Adults to have some social outlet and to provide some respite for their carers.
- Day Centre for elderly but frail old people but mentally able, with stimulating activities
- I was extremely disappointed to have my mother's respite reduced from 28 days to 17. This is the only opportunity for my husband and I to have a break where we can do just as we want at a time that suits us.
- I do have family input for emotional support and practical help
- The odd home visit would benefit both of us
- Each carer will have different priorities depending on their circumstances and family support
- Respite
- Equal treatment for all carers
- I have ticked 4 because I feel they are all very important. If I didn't care for both of my parents it would cost the government a lot more money and they wouldn't be as happy as they are now. They still live in their home. I am their main carer with support from family members
- The waiting list for financial advice is long and local CAB offices use expensive phone lines that have automated messages that are not helpful as they invariably signpost you to websites. Not everyone can afford access to the internet and the local libraries are closing down thus marginalising poorer people further.
- Having access to information in relation to what is available through local GP's. I found herbal medicine and vitamin therapy for my son.
- To continue having respite break. I am concerned if respite breaks/support are stopped or reduced I would find it very difficult to continue in my role of carer
- More time for carers who have a young family too!!
- More help in emergency situations





Equalities Monitoring

Post Code		Completed by 339 people	<b>L9</b>	1	<b>L10</b>	7
			<b>L13</b>	2	<b>L20</b>	33
			<b>L21</b>	25	<b>L22</b>	24




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 Author: June McGill  
 Version 0.3 – 08.05.14

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		<p><b>L23</b> 39    <b>L30</b> 22</p> <p><b>L31</b> 39    <b>L37</b> 38</p> <p><b>L38</b> 4    <b>L39</b> 4</p> <p><b>PR8</b> 58    <b>PR9</b> 38</p> <p><b>PR</b> 2    <b>DE4</b> 1</p>
Gender 	Completed by 402 people	<p>Male 104 (26%)</p> <p>Female 298 (74%)</p>
Disability 	<p>Indicated a disability completed by 178 people</p> <p>Consider themselves disabled completed by 314 people</p>	<p>43 (17%) Have a physical impairment</p> <p>24 (10%) Have a visual impairment</p> <p>12 (5%) Have a learning difficulty</p> <p>45 (19%) Have hearing impairment</p> <p>29 (12%) Have mental health / mental distress</p> <p>87 (37%) Have a long term illness</p> <p>102 (32%) consider themselves to have a disability</p>
Ethnicity 	Completed by 434 people	<p>300 (69%) White British</p> <p>114 (26%) White English</p> <p>1 (0.25%) White Polish</p> <p>3 (0.75%) Welsh,</p> <p>5 (1.50%) Irish</p> <p>2 (0.50%) Scottish</p> <p>3 (0.75%) Other White</p> <p>1 (0.25%) Black Caribbean</p> <p>3 (0.75%) Asian &amp; White</p> <p>1 (0.25%) Other Asian Background</p>
Religion 	Have a religion	318 (77%) Have a



	completed by 409		Religion
	Indicated a religion completed by 293	280 (95%)	are Christian
		9 (3%)	are Buddhist
		1 (0.5%)	is Hindu
		1 (0.5%)	is Jewish
		2 (1%)	are Sikh
Sexual Orientation 	Completed by 358 people	346 (97%)	Heterosexual
		7 (2%)	Gay
		1 (0.25%)	Lesbian
		3 (0.75%)	Bisexual
Gender  	Completed by 400 people	396 (99%)	Live in the gender assigned at birth

# Contributors

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## List of Contributors to the Sefton Carers Strategy (No particular order)

This list contains the people and organisations that offered sustained and invaluable support to the process. We would like to thank everyone who was part of the process and it would be impossible to list and thank everyone as it was a huge piece of work. In particular we would like to thank:

- Southport Parents and Children together group
- South Sefton Parents and Children Together group
- Sefton Carers Centre
- Sefton Carers Action Group
- Sefton Mental Health Service Users Forum
- Rachel Jones, Sefton CVS
- Sarah xxxxx, Sefton PSS Young Carers
- Abbie – Sefton Young Carer
- Jenny Southern, Sefton Young Advisers
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**Finally we would like to acknowledge and thank all the people of Sefton who contributed to this report.**