Wednesday 6th July 2016

Partnership Board Reps Report

Orange LIG
Supporting Carers and families
What’s working well

1. My Mum is invited to my meetings, and I like that
2. When I have respite at Hayling Island (Orchard Close) my Mum and Dad go on holiday somewhere too

What’s not working well

1. Sometimes meetings are cancelled or people don’t turn up. This is particularly bad Mum or Dad have taken time off work to attend.
2. When my relative rings Adult Services he has to leave messages and then no-one calls him back.
3. When my support worker does not turn up it causes problems for my parents because they need things to be organised.
What people said would make things better:

“Meetings should be in the evenings so that my Dad does not have to take time off work”

“Adult Services need to always let my family know if a meeting is going to be cancelled”

Eastleigh Self Advocacy Group (Eastleigh)

“I think it’s important to have close relationships with your family and carers”

“Very important to have good family relationships.”

“PCP and advocacy help keep me, my carers and family up to date with what’s out there”

“Its important have good support to help me keep my friendships and to help at meetings”

“I think it's important to see your friends and family.”
“Information for carers and families needs to always be in easy read”

“I'm happy living at home and I don't ever want to move out because I get on well with my mum.”

“I live with my dad he's my Carer and he's important to me”

“It would be good to have more easy to understand information on relationships. I had a bad experience once but I had good support to sort it out”

“It's hard to see each other (fiancée) but it's better than it was because our individual support workers help us to plan to see each other”

“It's hard to have time alone together as my fiancée lives in a shared house and he carers have to make sure everyone’s happy”

Romsey Self Advocacy Group (Romsey)

“My mum needs help to understand all about the different meetings as there’s lots of meetings”

“My parents always protect me but they don’t always have all the information about what’s going on”
“My carers are very good to me and my husband. They talk to my advocate so that we can all arrange things together. It is important that advocacy and my support speak to each other as it makes my life easier”

“My carers need more time to do everything”

“More information needed about what’s happening”

“Parents are very worried about all the cuts”

“My family are worried about Launchpad”

“Sometimes my carers feel left out of things they don’t always know what’s going on”

**Speaking Space (Romsey)**

“I need help from my support workers to see my friends and I also need them to organise how I meet my friends like sorting out the date and time.”

“Carers need a lot of support as they do lots of things and they are busy”

“Meetings should definitely be at a time that suits me and my carers”
“I enjoy meeting my friends in the community for activities like bowling but my carers need to know what other things are available”

“If I needed advice on relationships I would go my parents. I’d also ask the support worker who runs the relationship group at Speaking Space.”

“My parents need to have access to the right information to support me. It's needs to be clear and easy to read”

“My carers need to know what activities are out there for me”

“My parents get very tired sometimes looking after me”

“My mum and dad are getting on a bit they need help as well”

“I’m very happy living at home”

Yellow LIG
Romsey and Waterside Day Service (Hounsdown, Waterside and Totton)

“When I used to have reviews they were set at a time that suited me and my Carers”
“They always spoke to me first and then my Carers”

“My mum feels supported at meetings”

“My advocate helps me and my carers prepare for meetings”

“They give my mum lots of information and it's easy to understand”

“I live with my mum (as my dad died) mum is ok with the meetings because they explain things and use pictures”

“I live in supported living my carers are great!”

Jaden House (Totton)

“Staff give 1-1 chats and give hugs if you need it”

“When I was hospital the staff came to see me every day”

“Sometimes our Carers find it difficult to get information about us moving on because there is no suitable places for us to go”

“I don't need shared lives I need outreach and my own little flat”

“My social worker is s***t! She doesn’t make information clear and when I tell her she doesn't listen”
“I hate meetings”

“Meetings are boring”

“I hate it when social workers are late for meetings”

“Also me and my carers need help to find the right jobs and apprenticeship schemes. We need the information otherwise my staff have a hard job trying to find out about what’s out there”

“Some hospitals discriminate against our disabilities. When I went for an examination on my foot I was asked if I had disabilities. I asked what that had to do with my broken foot. Then I heard them both talking about me. I needed to have a shower chair available for when I was in hospital with my broken leg. This should be standard.”

Cornerways (Ringwood)
“My parents didn’t have any support at all”

“Parents need support with assessments”

“Clear information is important”

“I have to wait a long time for social worker to get back to me with information and it made me feel annoyed”

“Keep up lines of communication even when things are not going well”

“When I lived at home we did have support from social workers, my parents used to take control of the meetings and they didn’t always pass on the information and I never asked”

“Not a good experience of social workers as they leave all the time. Not good when I was younger my mum felt alone she didn’t have a good support network around her”

“Mum didn’t have a lot of support when I was younger

“My key worker fights my corner amazing”

Blue LIG

Supporting Carers and families
Farnborough Self Advocacy group

What’s working well

1. My brother knows where to go to get any information we need
2. The Doctors surgery have lots of information leaflets on things like, flu jabs, health checks
3. Staff at the hospital listen to my family when they take me

What’s not working well

1. My Doctors appointment is usually at a time to suit my Doctor, depending on how busy they are
2. Mum has to ring around to get information, or she asks me
What people said would make things better: -
“Information to complain should be more available”

Happy Club (Basingstoke)

What’s working well
1. “If my family have a problem they talk to my support provider”
2. “My advocate helped me and my family understand what Adult Services were saying”
What’s not working well

1. Most people said that their carers and families do not receive any support

2. “It took my parents ages on the phone to get support for me”

3. “My parents find it difficult to get hold of my social worker and she doesn’t return their calls”

4. “My mum and I look after each other we don’t get support”

5. No one knew what a carers assessment was or what support was available to their carers and family

What people said would make things better: -

• Adult services, Hampshire County Council and health need to talk to each other so we get the right information

• More people in Adult services to answer the phone
18 people in the group were asked about how their unpaid carers and families were supported and whether they felt that the promises made in the LD plan were being delivered. Some of the group had a little difficulty in talking about this as some were supported only by paid carers, some were very independent, and some didn’t have much information about how their families were supported.

What’s working well

1. We can ring up Social Services to get information.

2. We get information from Friday Network.
What’s not working well

1. The group are not sure if their families have had a carer’s assessment.

2. Carers often don’t know where to go for information. This makes getting the right support difficult.

   “My Mum had difficulty getting support at first”

3. Social workers don’t always talk to our families.

4. The only support from Health that family carers get is for their own needs – not their needs as a carer.

5. There is a risk of getting to a crisis point because carers are not getting the right support.

   “To get help, my Dad had to complain”

6. The T17 cuts are a worry for families.

What people said would make things better:-

- Information for carers should be more available and easy to access.

- Carers should be told about any change to support and told why the change is happening. Support providers and Social Services should be more open and clear about this.
“My Mum had a problem with paid carers not turning up. They should call in advance to let us know when there is a change or a problem”

- Planning ahead to prevent a crisis situation from happening.
- More information is needed about the T17 cuts and how it will affect support for us and our family carers.
Wednesday Network (Basingstoke)

What’s working well

1. My brother takes me to Doctors and Nurses appointments, it’s usually at a time that suits him

2. If I wanted to complain about not seeing my own Doctor, my brother would know who to complain to

3. Advocacy share lots of information with my family about services that might be of help. They bring information along to our group and share it with us

What’s not working well

1. My brother and sister didn’t know about my last care meeting, so they couldn’t go. They have now made another appointment for one.
Purple Lig (Winchester)

Hear Us and The Funky Lunch

My support workers don’t talk to Mum and Dad, my new support haven’t met my parents and they didn’t know my support hours were changing or why.

My Mum worries about me because I only get telephone support.

She helps me with my letters and cleans for me sometimes. She says she is worried what will happen to me because she is getting older and my Dad is already in ill health.

My Mum can’t be there for me all the time; I have support to sort things out.

It took my Dad a long time to get direct payments to pay my support.

He says it’s stressful. He’s going to have a holiday now.

My Mum and Dad get fed up with talking to lots of different people, and being passed around every time!

It can be hard to get the right information because different people tell you different things.

Mum likes my support, it is better now, not as many problems as before.

Sometimes my Mum should back off and let me do things for myself. I can do hard things; I am old enough to make my own decisions.

My Mum cares for me but we argue if she helps me in the flat, I get angry if she nags me too much.
I don’t want to talk about it, moving on. Mum and Dad don’t mind. My parents don’t understand why they all keep changing (support) staff and my support (hours). And he (Dad) still had to change my smoke alarm and fix the shower when it wasn’t working!

My Mum said she learnt a lot at my meeting (circle meeting). My nurse didn’t tell my Mum and Dad she was not seeing me anymore, I didn’t understand the letter. I think she was angry a bit because I think they should tell her really.

I should have two (review) meetings because Mum and Dad won’t go together. Mum wasn’t happy about it; I think she talked to someone on the phone.

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**Purple LIG**

**Saturday Drop In (Fareham) and SAY Group (Gosport)**

**Supporting Carers and Families**

“Yes we feel Adult services make meetings suit caring responsibilities. But please ask to speak to us as well if you call."

“Please make letters easy read about meetings – if you have spoken to my family about a meeting could a picture go on letter?”

“No jargon –Please!”
“Information about things in local area – please don’t give my family an email address or website they don’t know how to use it. (carers cant use work computers –not enough support hours to go to library to research)”

“Service users questioned if there carers know how to have their say about making local services better. New staff are not aware of the LD Plan.”

“Parents need info easily and quickly.”

“?? if my parents have ever been told/offered respite”

“Advocacy help so much by giving my son information at his self advocacy group that helps me know what's happening on a larger scale within hampshire.”

“Police – Please keep working with us and our family.”

“Person centred plans -10 people have them and families were at meetings, please help us involve our families more.”
“People do feel that their staff are respected and listened to.”

“Please make sure the right people we ask for are at our meetings I asked for my keyworker and got the manager who does not know me.”

“Management not expert support staff are so ask them”

“People think their family are not offered the right info –respite –we have to struggle before we get it.”

“Health –my mum is a Carer and I don’t know if her doctor has her registered as one and support her to have a health check like me.”

“My brother and I are carers and we feel we are responsible and not able to do things we want –more help for us as mum does not want the help but we do!!”

“Transport – next stop announcements are good some buses have them but don’t turn them on. Drivers still need to be helpful.”

Things people could do better to help

- More people to help my family
- More time with my carer would help my family
- When social worker sorts out an issue –check back all ok rather than closing and leaving.