

Autism Partnership Board

The Carers Centre on behalf of families
who support people who have autism

carers of people who have autism meeting (City and County carers) 20th July

Jackie Robinson from De Montfort university came to talk with us again about the work she is doing with people who have Asperger syndrome.

The work they are doing looking at:

- Me understanding me
- Me understanding others
- Others understanding me

Using this way of thinking it helps people to understand why we sometimes have difficulty understanding each other.

County Carers learning Disability Partnership Board sub group 1st September 2017

- We started to prepare for the Partnership Board meeting on 2nd November which was going to be about family Carers.
- We heard about some training that is going to be done with staff to help them to understand family carers needs and issues better.
- Family carers raised the concern that since the Care Act they are getting less support.

Carers Assessment meeting 14th September 2017 (City Carers Meeting)

- Most of the carers at the meeting had completed a carers assessment.
- The carers said they had asked for an assessment.
- They were not sure that one would have been offered if they had not asked for one.
- They said that they had not received a care plan for themselves as part of the assessment.
- They did feel that by completing an individual carers assessment that their caring situation was better understood.

carers of people who have autism meeting September 21st (City and County Carers)

- At the meeting we talked about Personal Independent Payment (PIP)
- We looked at the paperwork the National Autistic society had written about PIP.
- The website is: <http://www.autism.org.uk/30701>
- If you want to know how to claim PIP you should go to the Government webpage at: <https://www.gov.uk/pip>

Carers Meeting 25th September 2017 (City Carers)

- There was a family carers meeting with Steven Forbes Strategic Director of Adult Social Care.
- After listening to Mr Forbes we realised that unless things alter at a National Level there are going to be some serious problems for Councils to deal with.
- The problems will make things difficult for a lot of people.

Carers of people who have a learning disability meeting 27th September (City Carers)

- A potential safeguarding issue was discussed.
- The case showed that social care staff are under a lot of pressure.
- Our concerns are that no short cuts are taken when a reported concern is received by social services.
- We do not want a tragic situation to happen. It reminded us that we all need to think about keeping people safe.

Carers learning disability meeting 27th September (continued)

- We also talked about healthy eating. This is something that is important for everyone which is why this information has been included in the presentation.

These are some useful webpages to help with eating healthily:

- Healthy eating:

<http://www.nhs.uk/Livewell/Goodfood/Pages/Healthyeating.aspx>

- The eat well guide:

<http://www.nhs.uk/Livewell/Goodfood/Pages/the-eatwell-guide.aspx>

- Fruit and vegetable portions:

<http://www.nhs.uk/Livewell/5ADAY/Pages/Portionsizes.aspx>

More useful NHS webpages about healthy eating

- Eating meat and staying healthy:

<http://www.nhs.uk/Livewell/Goodfood/Pages/meat.aspx>

- Food and diet:

<http://www.nhs.uk/Livewell/Goodfood/Pages/Goodfoodhome.aspx>

- The checking you weight is healthy guide:

<http://www.nhs.uk/Tools/Pages/Healthyweightcalculator.aspx>

- The calorie checker:

<http://www.nhs.uk/Tools/Pages/Calorie-checker.aspx>

Meeting Friday 13th October for carers mental well-being group (City Carers)

In the group we looked at different aspects of caring and mental well-being

We identified were that there are a number of family carers who are caring for someone who does not have a mental well-being identified need but that the carers themselves have.

Needs of a carer who has mental-wellbeing needs of their own

This can create a number of problems for this group of family carers including:

- Pidgeon-holing by some professionals: i.e. People not taking a holistic approach to the caring situation and professionals still tending to concentrate on the person identified as requiring a needs assessment. N.B. This is whether it is the person the carer is caring for, or the carer as a mental well-being service user (not as a carer of someone else).
- Carers not having enough time to deal with their own needs and often having to hide them from those around them
- Carers feeling that their anxiety is used as a way of saying they are over dramatising issues rather than looking at the situation as triggering the anxiety and helping with that.

Carer issues raised in the mental well-being group:

- To have professionals recognise that long-term caring can impact on the mental well-being of a family carer.

There are a number of ways this can happen:

- Carer may ensure that the person they care for eats the right food on time but the carer often skips meals or eats convenience meals. This can have long-term consequences along with mental well-being issues it can contribute to damage of their organs. (Cirrhosis and kidney issues as well as heart issues) .

Carer issues mental-wellbeing group continued

- Carers will often rely on medication to help them carry on. This again can add to long-term health problems for family carers as they are not necessarily getting the right treatment.
- Carers not being recognised as carers by the community because the person they care-for's health issues stems from alcohol related issues. The fact that the person may have underlying mental well-being needs seems to be ignored. Blame culture issues. This can make it difficult for carers to feel accepted by others.

Needs of a carer who has mental-wellbeing needs of their own

- Having cultural issues understood.

The carer having to hide their mental well-being needs and pretend to be doing part-time work to hide the fact that they are caring but unable to work due to their mental well-being needs.

This can create difficulties in terms of having to be away from the person they care for, for longer than they wish.

Having to find places to go away from near where they live to pretend they are out working,

If they are at home people questioning them about why they are not at work, or placing increased demands on them.

Leicestershire Learning Disability Partnership Board Meeting 2nd November

- This Partnership Board meeting was dedicated to family carers.
- There was a presentation about the Carers Strategy
- There was a presentation and discussion about issues around being a family carer.

County Carers learning Disability Partnership Board sub-group meeting 6th November 2107

- At this meeting the group discussed how to use a webinar and had a demonstration to help them. The idea is to try and support other carers who are unable to make the meetings join in.

Carers of people who have autism meeting 16th November (City and County carers)

- We looked at the Autism Act 2009 and what the strategies cover.

<http://www.legislation.gov.uk/ukpga/2009/15/contents>

- The latest Autism Strategy

<https://www.gov.uk/government/publications/think-autism-an-update-to-the-government-adult-autism-strategy>

- The latest Autism Statutory Guidance

<https://www.gov.uk/government/publications/adult-autism-strategy-statutory-guidance>

Carers Self help group

We have had a lot of self-help group meetings between July and today.

Family carers have been able to use the group to:

- Look at carer assessments
- Look at how to obtain help with getting aids and adaptations
- Look at difficulties with the benefit agencies
- Look at issues around getting a diagnosis referral
- Issues around the mental well-being of the person they care for and their own

Future events we will be covering for carers

- 22 November at the carer centre there will be a presentation by health about trips and falls and how to avoid them which may include some exercises that you can do even if you are not very mobile. 10:30 to 12:30 (carers centre)
- 24th November the next meeting of the carers and mental well-being group at the carers centre 10:30 to 12:30 (carers centre)
- 4th December: County carers of people who have a learning disability group will be covering PIP 10:00-12:30 at County Hall
- 4th December: The Carers Christmas dinner at MORE

Future events we will be covering for carers

- 28th November Carers Rights information session 1:30 at the Carers Centre
- 11th December Crafty Carers 10:00 at the carers centre
- 11th January City Learning Disability Carer Group 10:30- 12:30 at the Carer Centre
- 17th January City Carers Mental Well-being Group 10:30-12:30 at the Carers Centre
- 18th January City, County and Rutland: Carers Autism Group 10-12:30 at the Carers Centre
- 5th February County Family Carers of People with a learning disability meeting 10:00-12:30 County Hall

Useful information we have found to help people

- <http://w3.cerebra.org.uk/help-and-information/guides-for-parents/problem-solving-toolkit/>

This helps to look at how to access public services. It was written for parents of disabled children services but is full of a lot of ideas that can be useful for adults as well.

Finally

Thank you for listening to our presentation.

Any questions?