

Carers Reference Group
Friday 31st May 2019
Carers Leeds, The Headrow, Leeds

Present at the meeting		Guest Speakers
Elaine Wilkes, Mental Health / Learning Disability Carers Leader based at Carers Leeds Louise Mills, Adult Social Care Patricia Hardwick, Family Carer Yvonne Ugarte, Family Carer Shirley Evison, Family Carer Kausar Iqbal, Family Carer Lynn Bailey, Family Carer and Facilitator Madeleine Fahy, Through The Maze Jackie Hartley, Family Carer Maire Sykes, Family Carer Ann Seaton, Family Carer Maureen Lumb, Family Carer Suzanne Jackson Bailey, Family Carer		Kevin Brighton, Hate Crime Co-ordinator, West Yorkshire Police John O'Dwyer, NIHR Doctoral Research Fellow, Leeds Institute of Health Sciences University of Leeds
		Apologies
		Ian Brooke-Mawson, Strategic Commissioning Manager (Carers) Becky Mitchell, Family Carer Liz Davis, Family Carer
1.	Welcome and introductions	
	Lynn opened the meeting and asked everyone to introduce themselves. The apologies were recorded as above.	
2.	Safe Mark Scheme – presentation by Kevin Brighton	
	The Safe Mark Badge scheme has been given a small amount of funding to be trialled in Leeds and Calderdale. The scheme is designed to assist vulnerable/disabled individuals when out in the community. The idea is that if an individual chooses to wear the badge, staff will recognize the badge and give the individual more time and support without them having to explain their personal circumstances. (Reasonable adjustments). This would be particularly useful for front line staff working in transport, the police and the retail sector etc. Real life examples of where problems have incurred include; • A young man with brain injury had reported that when on nights out, bar staff, taxi drivers and doormen assume that because he had slurred speech, he is drunk and refuse to serve him • A young lady had to explain to a public transport drivers and a supermarket cashier that she was terminally ill after they had challenged her for how she used their services The scheme is also designed to protect people: there are over 3000 cctv cameras in Leeds, monitored 24/7. If one of the cctv camera operators spots a person wearing the Safe Mark Badge and believes they are in difficulty, it will help when they get assistance to them.	

	If the scheme is successful, it will be rolled out further and linked to the existing Safe Places Scheme. Police cadets are going to start auditing the Safe Places and identify which places need more training. There is already joint working with other schemes such as Street Angels and Angels of Freedom. The Police are also training staff, such as social workers, about Hate Crime. A lot of people are unaware that targeting vulnerable adults is classed as a hate crime and gives the police/courts extra powers to deal with the perpetrator. After the presentation there was a lot of discussion about the Safe Mark Scheme. Here are some of the key points raised • if people with learning disabilities wore the badge, it could make them even more vulnerable to criminals. Some people don't realize that they are already at risk. • some people with learning disabilities like to wear their existing disabled badges and this is a concern to their families • not everyone wants to wear a badge or be labelled – the badge is designed to just show that the person needs extra care but it won't disclose their disability • Members shared ideas of alternative types of badges – if the trial is successful and gets more funding, there may be an option to offer alternatives. • The scheme is designed for all vulnerable adults and may work for some but not all. The group thanked Kevin for coming to talk about the scheme. Kevin thanked the carers for their feedback and ideas and agreed to provide an update later.	
3.	Quality of Life Measure Tool (HRQoL) – John O'Dwyer	
	John provided an update on the study which is exploring the way health related quality of life is measured for adults with a learning disability. They want a questionnaire that people with learning disabilities can complete themselves. The hope is that this will be a more reliable measure for use in decisions relating to the services and support adults with learning disability receive. John has worked with Leeds Partnership NHS Foundation Trust to develop easy read papers and has also met with the Learning Disability Peoples Parliament. The study is now in phase 2 and requires further participation from people with learning disabilities and family carers. John asked for volunteers to take part in an interview about the easy read questionnaire and to attend a focus group. Carers shared their experiences of using easy read literature and volunteered to take part in the study. After the meeting, John sent further details about the study and an application form in case anyone else would like to volunteer. (Sent with the minutes).	
4.	Carers update – Elaine Wilkes	
	Elaine circulated copies of the Carers Leeds newsletter and provided an update. Comfort Call – Carers not yet registered with the service were advised to do so, however there is a waiting list for home visits from the service. Focus group meetings have been planned for May/June to help shape the future of the service. Action: Elaine agreed to find out what would happen in the event that a carer's emergency situation	EW

	remained the same after receiving their allowance of free emergency cover. This item will be added to the next meeting agenda. Carers Wellbeing – On a previous occasion carers were invited to attend a meeting about wellbeing hosted by Carers Leeds. This is currently being reviewed. The new Live Well Leeds consortium has appointed a part-time worker to support family carers around mental wellbeing and signpost them to the appropriate services. The new worker can complete an assessment which will be accepted by all the organisations within the consortium. This will save the carer from having to repeat their story. Carers can also chose not to disclose some of the information. Day trips unsuitable hours – A carer had previously raised an issue regarding the unsuitable times carers’ trips are organised. Elaine agreed to feedback this back to Carers Leeds.	
5.	Ribby Hall feedback	
	Carers praised this year’s training, especially the personalised information they received. One of the items was around access to banking, which the Carers Leeds Partnership are also looking into – the Carers partnership minutes are available here. Papers from the course will be sent out with these minutes. Carers agreed to think about what would be useful if the course is available next year.	
6.	Minutes of the meeting held 15th February 2019	
	The minutes were agreed as an accurate record	
7.	Any other business and dates of the next meetings	
	Dental services – consultation on the future of the community dental service and consent/best interest decisions to treatment on behalf of a person with a learning disability. There was a query around whether carers had received a response to these issues raised previously. Response: the issue around consent had been explained at the extra meeting held 9th February 2018. Please click here for the minutes. With regards to the community dental services, this issue had been raised at a Board meeting some time ago but there was no one present at the time to speak on behalf of the dental service. It may be possible to invite a guest speaker to cover this. Action: this item will be referred to the Health Task Group and /or guest speakers invited to a future meeting. Possible future agenda items / guest speakers • Personal care – there was a query around support workers not providing the necessary levels of care. • Vitamin D levels – there was a query around the contents of the annual health check Dates of next meetings • Friday 6th September 2019 • Friday 22nd November 2019	

First draft