



**Healthwatch St Helens
Personalisation Conference -
*My Life, My Choice?***

**Langtree Park
20th November, 2014**

Healthwatch St Helens held a conference on 20th November, 2014 at Langtree Park. The title of the conference was, '***Personalisation - My Life, My Choice?***

Members of the Management Committee had envisaged holding such a conference for more than a year and the aim of the day was to have open and honest conversations with people who use and work within health and social care services.

Steering Group

The steering group was made up of 3 of the Healthwatch St Helens Management Committee; Elaine Cotterill, Jane Dearden and Alan Griffiths, supported by Emma Rodriguez Dos Santos and Jayne Parkinson from the support team.

137 people attended, ranging from members of the public who use personal budgets, people working in the voluntary sector and representatives from the local authority.

BBC News Northwest' Dave Guest chaired the Conference and facilitated a question and answer session with a panel of people who gave presentations on the day

Presentations

All presentations and video footage can be found at [Healthwatch St Helens YouTube Channel](#)

- **Julie Stansfield (In Control)**
With more than 23 years' experience in health and social care sectors, Julie began her career in rehabilitation services, which led to her becoming a manager of older people's services at the age of 21. Julie is rooted in her passion for inclusion and enabling people to have the support they need to lead an ordinary life. In 2003 she was the co-founder of the national charity, "In Control Partnerships", which instigated self-directed support and the Personalisation Agenda in health and social care policy and practice, enabling people and their families to be more in control of their health and social care provision.
- **Anne-Marie Mason (NHS England)**
Anne-Marie has worked in the field of health and social care for over 10 years, in the statutory, voluntary and private sectors. She established the first dedicated Personal Health Budget Support Service for individuals and families in Cheshire, working alongside the Primary Care Trusts to implement and deliver personal health budgets.
- In 2013, Anne-Marie established Health Your Way to support individuals to access personal health budgets and assisting health and social care professionals to navigate the world of personalisation. In addition, Anne-Marie wears a number of 'hats', as the North West Regional Lead for Personal Health Budgets on behalf of NHS England, she is an Associate with the national charity 'In Control' and is a regional mentor within the NHS England Voluntary and Community 'Gearing Up for Personal Health Budgets' programme.
- **Gavin Croft & Karen Saville-Croft**
Gavin and Karen are a couple who live life to the full with the support of a personal health budget. They have experience of working within the social care sector in a variety of roles. Their passion, enthusiasm and determination to live an ordinary life their way has been shared both nationally and internationally, within Westminster to audiences that include people with disabilities, carers, health and social care professionals, Ministers, third sector organisations and the private sector.

In their presentation, they shared their factual experience and their own journey to enable people to understand the culture changes needed and how to take that first step.

- **Sam's story**

Cath is known to many for her role as the Lead Engagement Officer for the Borough Forum in St Helens but spoke in her capacity as mum to 11-year-old Sam, who has autism.

Cath gave a 'story so far' account of her experiences, highlighting good practice such as a clear ASD pathway that led to a same day diagnosis with a consultant paediatrician and the quick allocation of a family support worker. She went on to talk about the challenges of living with a child who has complex difficulties, her hopes and expectations for the future of personalised budgets and what this could mean for the quality of life for whole families.

- **Alan Griffiths**

A member of the Healthwatch St Helens management committee, Alan is the parent carer for 31-year-old Christopher, a young man with a learning disability and various long term conditions.

Among others, Alan is involved with Mencap in both Liverpool and St Helens, The Hurst and Mill Green Special Schools and The New Gateway Club, a social club for adults with severe learning disabilities and he has been a member of the St Helens Learning Disability (Valuing People) Partnership Board since it started.

Alan shared his and his wife's experiences of the journey through their son's diagnosis, the various professionals who made a difference along the way, to obtaining the right support to enable Christopher to live as full a life as possible.

Alan felt the journey would have been much easier if there had been more integration between health and local authority services and his family found the experience of transitioning from children's to adults services very difficult.

- **Rachel Cleal (Adult Social Care & Health)**

Rachel is the Assistant Director for Adult Care Management in St Helens Council. She has worked in St Helens since July 2014 and in Health and Social Care for 27 years.

Rachel started her career in the voluntary sector working with people with learning disabilities. She has had various roles over the years including, volunteer, social worker, personalisation programme lead, and managing integrated health and social care community teams.

Rachel is committed to working with people to ensure that they can live the life they choose in their local community.

- **Sarah Bullock (St Helens CCG)**

Sarah is a Senior Commissioning Manager in the Integrated Commissioning team, which commissions Adult Services, support across St Helens Council and St Helens Clinical Commissioning Group.

Sarah has worked in St Helens for around 6 years and is the lead officer in relation to personalisation across health and social care. She led the launch of the St Helens "My Life, My Choice" campaign in 2009 and remains committed to improving and developing personalised health and social care services for local people.

Sarah has been working on the implementation of Personal Health Budgets within St Helens. Other areas that Sarah works on include Dementia, End of Life Care, Falls and Mental Health.

Other local people's stories

Staff from the Healthwatch support team read out stories that local parents who weren't able to attend the Conference had written.

- One local mother shared her experiences of trying to get enough support to enable her to be an effective carer for her 16-year-old son who has autism, epilepsy and various other health issues. She highlighted the struggle she has faced for most of her son's life in the hope that her story might help to improve the situation for other local families.
- A father spoke highly of the occupational therapy and physiotherapy services that his 10-year-old daughter has benefited from. He implored services not to give up on disabled children and gave examples of how children can exceed expectations as long as they are given the support they need.
- A local mum with a son who is age 6 who has Down's Syndrome. He attends mainstream school as his mum who works with children, didn't want him to be treated any differently. She felt this would provide him with the best start in life as he already faces barriers due to his disability, however being taught like a mainstream child he would follow the same curriculum. She wanted him to be taught systems like the 3 'R's and this would not have happened in a special needs school. She felt her son would not have had this opportunity without the help from St Helens Council who have provided funding for a 1:1 teaching assistant within his school, which is outside the St Helens area. He can now write his name, recall and write the alphabet as well as counting from 1 - 10. He still has some difficulties, though, such as getting dressed and he struggles to communicate. Daily tasks can be almost impossible some days but he is so caring and loving with everyone he meets. I am so proud to see what he has accomplished and I am looking forward to tackling his future challenges. I know this will be very hard as he gets older. I hope that I have made the right decisions for my son and we live every day as a new day.

Question & Answer session (chaired by Dave Guest):

To start things off, Dave summarized the 'take home messages':

- People need to be 'at the centre' with support that is relevant for them
- Service users and families need to make the implementation happen, do not wait for the authorities to put it in place for you, make yourself aware of what can be done!
- There are few cannot do's, mostly it's about making sure the support is right for the person
- 'Transition' - either from children's to adults' or from adults to older people's services or between health or social care responsibility is a noted and a **major difficulty** for the service user/patient

Q. Can there be a trouble-shooter for if/when mistakes are made?

(One of the conference attendees had received a demand for finances which turned out to be a mistake)

A. This was not answered on the day.

Q. Who's going to catch people when they fall through the net because they cost too much and so they are passed between services?

A. There was a discussion but no conclusive answer. Some people felt this was a role that Healthwatch and other advocacy organizations became involved in, albeit this was not their main role. The family or the carer ends up being 'the safety net'.

Q. Is there a possibility of groups of people who have individual needs but want a mutually supporting living arrangements?

A. Things are happening locally on this, a group of families that have recently met with Sarah Bullock are considering options and some decisions are to be made February 2015.

Q. Alternative therapist costs - will they ever be included in things that are eligible for personal budgets?

A. Yes eventually why not?

Q. Can you choose a service instead of the block booked provider?

A. This is precisely why people should have a choice via Direct Payment, Personal Health Budgets etc. There is no reason why cannot have a service that has been assessed as needed and then if appropriate the local authority or CCG 'tops up' for additional services if appropriate e.g. autism-specific speech and language therapists. Several people in the audience said this was

NOT happening in practice in St. Helens and that people were being advised by their care managers that commissioners would not 'top up'.

Q. Can we think more about ensuring support enables people to live/cope with each other rather than enable them to live apart (respite).

A. No answer required, there was no disagreement with this as a principle.

Q. What about getting the additional money for what you want?

A. If you can prove the improved outcomes from the better service and you can argue that the provider of choice is what you need.

Market Place stalls (please contact Healthwatch for more information)

- Amputation, Inspiration, Motivation (AIM)
- Bridgewater Oral Health Promotion
- Carers Centre
- Coalition of Disabled People
- Crossroads Care
- Deafness Resource Centre
- Health Improvement Team - Children & Young People
- Health Improvement Team - Public Health
- Health Your Way
- Healthwatch Independent Advice & Advocacy
- Home Instead
- Making Space
- Motor Neurone Disease Association
- West Lancs Peer Support
- St Helens Clinical Commissioning Group
- Together for Wellbeing

Closing comments

Elaine Cotterill, Healthwatch St. Helens committee member summed up how important it was that the conference had got people together and talking about the issues and thanked everyone for attending.

“We, as the community of St Helens have historically had clusters of people either working in Health and Social Care, living with a disability or supporting a loved one to have as good a life as possible. We also have lots of groups doing some really good and positive work, but we have never, as far as we

are aware, actually managed to get as many of those good people together in one room and actually start a conversation.

Plenty of chatting goes on within those groups about the personalisation process and how it's working or not, depending on who's opinion you are listening to! However, until a conversation is started that includes everyone, we just keep going round in circles, often with the person needing support getting lost in translation!!

Today was about, as I am sure you now know, bringing everyone together. To share experiences good and bad, to listen, learn and together, we can start to shape our vision for the future. It has, I think you will agree, been a broad cross section of experiences and if some of it was difficult to hear for whatever reason, then please, imagine trying to walk a mile in our shoes. This is real life and all we are trying to do is to make it as good as possible for our loved ones. If you can make a difference in any capacity as a healthcare professional or otherwise then please try to do so and keep this conversation flowing.

Everyone in the borough who needs additional support, should have all the options explained in a way that they understand and makes sense to them. Only then, can they make the choice that's right for them or their loved one. Never ever forget that Personalisation is about the individual and what is right for THEM, it's a bespoke, tailored support package that works for one person. No one else's support plan will ever be the same. It is non-prescriptive, it is unique. What works for you won't necessarily work for anyone else.

We are lucky in St Helens to have an authority that tries to be forward thinking. We need to work together and support them to help make that happen in practice. It's all well and good saying the words, but if they are not put into practice effectively, then they are simply empty words and false promises.

It's not all about money, many support plans if actioned properly without a traditional local authority tick box, will in fact be far more cost effective than the older model of support. However, it is about what works best for the individual. If it's working don't fix it, if it's broken or breaking down, let's get it right. Services should fit the person not us fitting into services.

Hopefully, today will have given you, either personally or professionally, something to think about and we aim to keep this conversation going until everyone is included in the decision making and we are getting it as right as we possibly can.

Healthwatch St. Helens will be sharing the information gathered from today, with everyone who has a vested interest in shaping that vision. We will make sure your comments, praise or concerns are taken seriously and we will feed that back to you.

I hope today has been a good one for you. I hope that now we have had that first conversation we have perhaps broken down some barriers between 'them' and 'us' and it's no longer 'them' and 'us' but 'we'.

Together we can make change happen.

Please - one last thing, we don't want anyone to leave with any unanswered questions or comments? Your feedback is vital if we are to get this right. We have opened up the market place and we along with many of the speakers and panel will be here for as long as you need us.

Please mingle, and keep the conversation going. I'll leave you with our vision for the future..."

For more information (and paper copies of this report)

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Appendix 1 - Personalisation Event Feedback

The delegates were given a feedback form asking for their comments and these were the top ten issues that arose:

Anything you liked about the event?

- Karen and Gavin's presentation
- Good topics/venue
- Question and answer session
- All presentations/personal stories
- Lots of good quality information given
- Meeting people/networking
- Understanding personal care budgets
- Enjoyed everything about the day
- Good quality speakers - especially Dave Guest
- Well organised and run to time

Anything you disliked or that could have been improved?

- No video of Karen and Gavin available
- Two speakers went on too long
- Stories very negative, although true, will not inspire anyone
- Lots of information - sometimes difficult to take it all in
- No mention of mental health on the 'market place' handout
- Too long sitting and the tables were too close together
- Not a wide variety of food
- Temperature in the room was either too hot or too cold
- Not enough microphones
- Nothing - the whole day was excellent

Any other comments?

- Very information day - engaging and well organised
- Good turnout with a good mix of people
- I would definitely attend other relevant events
- Hope this is the first of many

Continued...

- Today was excellent, but needs to be followed up in perhaps six months, so we can find out how these systems are actually working, and examples again of people who are now benefitting with the new style of provision
- More promotion, education and training is needed for everyone
- Need this event, or some of the speakers, for health/social professionals
- A very important conference, giving the true stories, information and future plans
- Really impressed with Healthwatch
- Congratulations on a 'fab' event re. Personalisation