

Service User and Carer Recognition Event

Wednesday 29 May 2013



A Summary of Service User and Carer Feedback

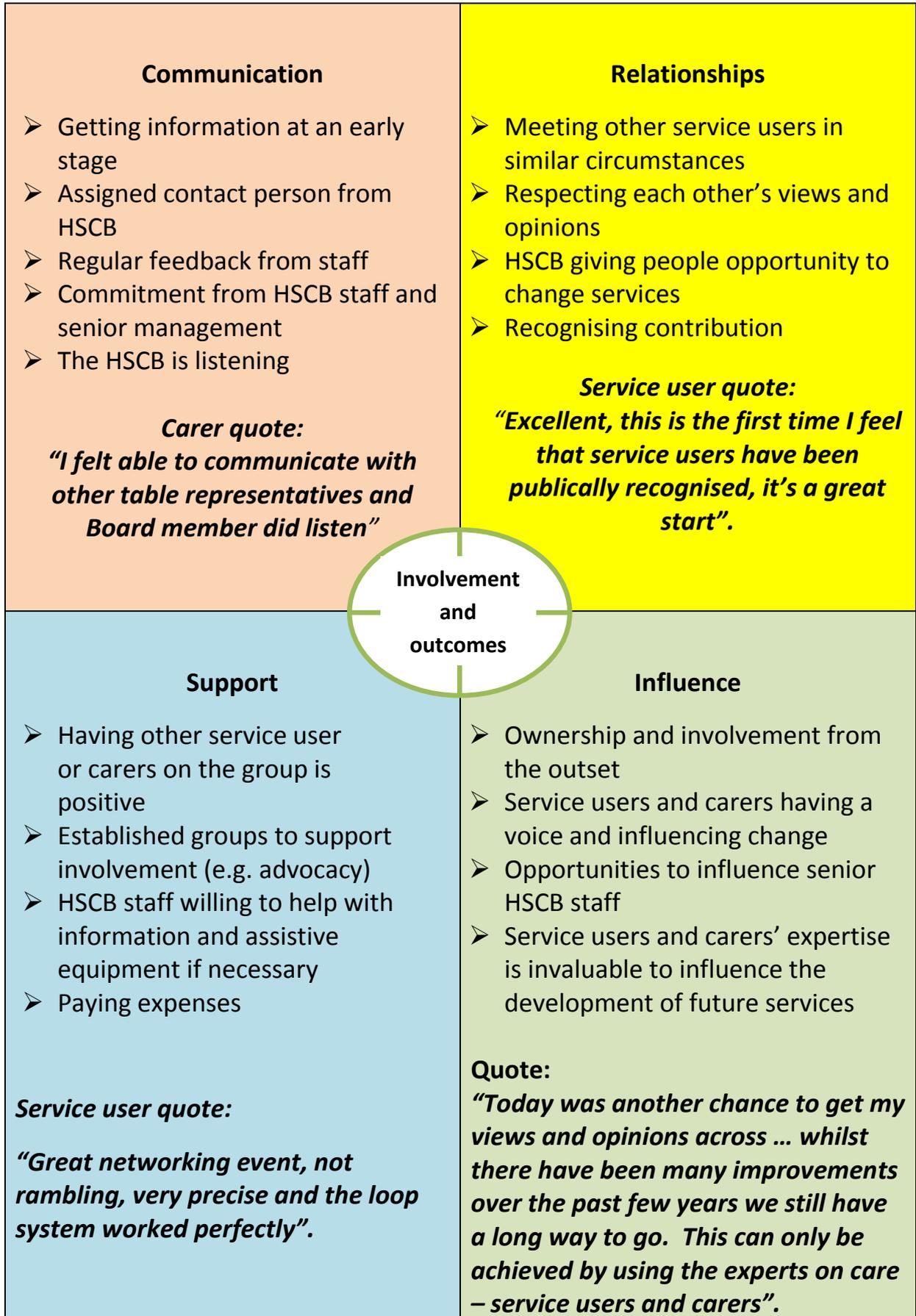
Introduction

Wishing to acknowledge and recognise the ongoing involvement of service users and carers the Health and Social Care Board (HSCB) held a celebration and recognition event on Wednesday 29 May in the Dunadry Hotel, Antrim. The event was attended by 90 service users, carers, and Health and Social Care staff. In addition to celebrating the involvement of service users and carers those in attendance were given the opportunity to inform the HSCB of what was working well and what was not working and to put forward suggestions for future improvements in relation to service user and carer involvement in the work of the HSCB.

This paper provides summary feedback from the event. It is presented in the format of 'what worked', and 'what didn't work' and is collated under the following four themes; Communication, Relationships, Support and Influence. This is in the belief that work on these themes would ultimately result in more effective involvement and better outcomes for service users and carers. The paper also highlights a number of ways in which the HSCB could further improve its involvement with service users and carers.

In addition to the feedback requested, a number of issues relevant to other agencies were raised. The HSCB will undertake to draw these to the attention of the relevant agencies.

What worked?



What didn't work?

<p style="text-align: center;">Communication</p> <ul style="list-style-type: none"> ➤ Lack of up to date information ➤ Don't understand the language used and the use of acronyms ➤ Professionals working in silos and no joined up approach ➤ Not being listened to ➤ No feedback <p>Service user quote:</p> <p><i>"Use more basic, down to earth language so that service users can get more involved in discussions and not feel isolated and intimidated by the use of abbreviations and jargon".</i></p>	<p style="text-align: center;">Relationships</p> <ul style="list-style-type: none"> ➤ Feeling isolated ➤ Contribution not acknowledged ➤ Poor staff attitudes ➤ Lack of trust, honesty and respect ➤ Constant use of the same service user and carer representatives <p>Quote:</p> <p><i>"I felt my involvement was tokenistic I ended up upset, isolated and intimidated and withdrew from the process".</i></p>
<p style="text-align: center;">Support</p> <ul style="list-style-type: none"> ➤ No training and lack of support for service users or carers ➤ Not having early notice of issues to be discussed at meetings ➤ Reimbursement of expenses complex and off putting ➤ Time pressures and working to organisational deadlines ➤ Limited support for people with complex needs. <p>Quote:</p> <p><i>"Felt we were not adequately supported to be involved, without support involvement can be an intimidating process".</i></p>	<p style="text-align: center;">Influence</p> <ul style="list-style-type: none"> ➤ Little or no opportunity for engagement in specific areas of the HSCB work ➤ Service users or carers not involved at all levels of decision making ➤ Not having a clear understanding of role and purpose of involvement ➤ Little or no opportunities for involvement in decision making at local level ➤ Not being involved from the start ➤ Lack of structure, with no beginning, ending or outcomes. <p>Quote:</p> <p><i>"They listened but didn't always hear what we were saying; it felt like we were banging our heads off a brick wall".</i></p>

One thing service users and carers would change about working with the Health and Social Care Board

- Provide timely information
- Good involvement is based on establishing good relationships
- Training for service users and carers
- Listen to us
- Involve service users and carers in all aspects of health and social care
- Communicate in a “jargon free” language
- Induction training for new service users and carers
- Agreed venue, times and format for meeting with service users and carers
- Prompt processing of reimbursement without duplication
- Involve service user and carers in training for professionals
- Greater transparency
- Practical support to facilitate participation
- Assurance that service users and carers are honestly part of the debate and decision making process
- Use of a range of appropriate involvement methods that are age appropriate
- Interactive web site
- The HSCB needs to have a range of ways of involving service users not solely using existing service user groups or representative organisations
- Provide regular feedback including outcomes
- Don't always use the same service users or carers
- Use other service users or carers for support as involvement can be an intimidating process
- Ensure involvement at a local and regional level.



The Health and Social Care Boards key areas to improve its involvement with service users and carers

The Health and Social Care Board has considered the feedback collated from the service user and carers recognition event on 29 May 2013 and has given an undertaking to improve on the areas that service users and carers felt “**worked**” and address some of those area that “**didn’t work**”. In taking forward this work the HSCB has identified that the following priorities will be actioned and monitored.



- Every service user and carer group which works with the Health and Social Care Board should be supported by a HSCB representative with specific responsibility to inform, discuss and address areas of concern from service user and carer representatives prior to and following each meeting of that group.

Action by: To be implemented by October 2013 monitored by the Personal and Public Involvement Lead.

- The Health and Social Care Board, Public Health Agency, Business Services Organisation, will review the service user and carer reimbursement policy taking on Board comments provided and will re issue a simplified policy.

Action by: October 2013 monitored by the Personal and Public Involvement Lead.

- Health and Social Care Board staff will be issued with a directive instructing them not to use abbreviations or acronyms without an explanation in all publically available documents in compliance with the Accessible Information Formats Policy.

Action by: January 2014 issued by Chief Executive.

- Where service user or carer representation is being sought the Health and Social Care Board recommends proportionate representation from service users and carers and where appropriate a minimum of two service users or carers per group.

Action by: September 2013 monitored by each Directorate.

- The HSCB will promote uptake of PPI training opportunities among its staff and work in collaboration with the Public Health Agency to develop a range of training materials with and for service users, carers and staff.

Action by: December 2013 monitored by the Health and Social Care Board and Public Health Agency.

- The Health and Social Care Board and Public Health Agency will host an annual event to facilitate service user and carers who work with the HSCB PHA to come together and share experiences and learning.

Action: December 2013 monitored by the Health and Social Care Board and Public Health Agency Personal and Public Involvement Implementation Group.

Next steps

This paper identifies key areas that the HSCB in conjunction with the Public Health Agency will undertake to improve its involvement with service users and carers. These will be taken forward by the HSCB personal and public involvement core group which is chaired by Fionnuala McAndrew, Director of Social Care and Children.



Fionnuala McAndrew
Director of Social Care and Children

August 2013