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NORTH WALES SOCIAL CARE AND WELL-BEING
SERVICES IMPROVEMENT COLLABORATIVE

Carers' strategy: mapping carers journeys report

June 2018

Introduction

As part of the discussions on the North Wales Regional Partnership's Carers Work stream, it became apparent that in order to understand better what carers' experiences of current services are, that it would be useful to map their journeys.

The purpose of mapping carers' journeys was to:

- Establish to what extent the carers' experiences are different to the process
- Identify who in the process can support carers
- Understand what needs to change and improve

Method

In order to complete this work, we worked with our local authority and health partners to look at carers' cases. This work focused on carer journeys through statutory services including how well services worked with the third sector to provide what matters to carers.

The time available meant that only a small number of cases could be looked at.

Conwy: 3 cases – carers of older people

Denbighshire: 1 case – carer of individual with learning disability

Wrexham: 1 case – carer of an older person

BCUHB – 1 case – mental health rehabilitation patient, Llanfairfechan

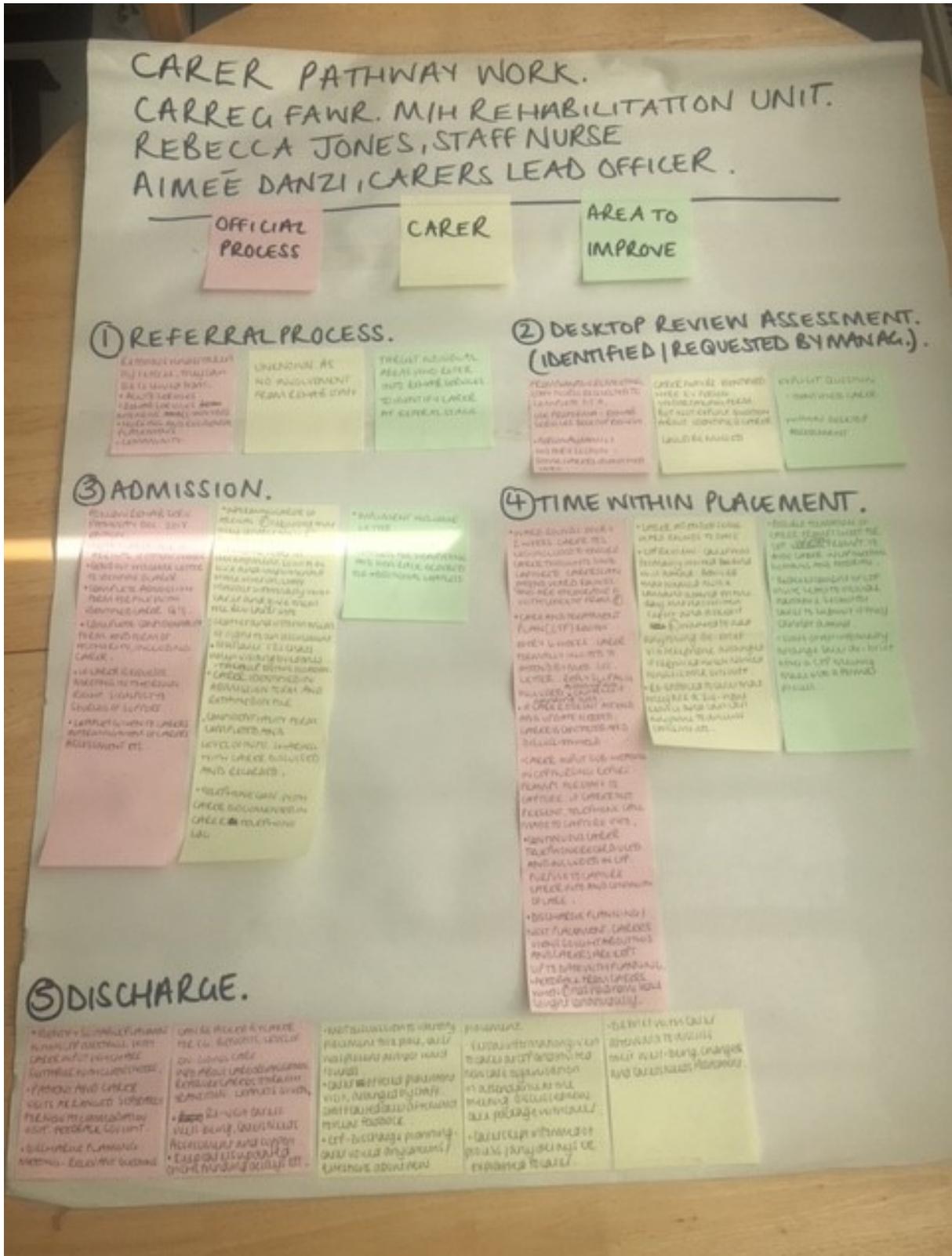
In Gwynedd, we looked at the support service for mental health service user in one area of the county and understood its impact on a small number of cases.

The journey mapping task had two aspects to it:

- 1) Mapping the process
- 2) Mapping how the individual goes through the process (the carer's journey)

Working with relevant professionals in local authorities and health, we understood from their experiences and from case files and notes how things are for carers. As

discussions took place, the process and carer's involvement was documented on paper, leading to a discussion on how things could be improved. An example is included below.



It is important to emphasise that the case examples taken were not representative of the whole carer population across the region. They were however, drawn from

different service areas across North Wales and provided an opportunity to learn from individuals' experiences.

What the journey mapping tells us

The work demonstrates individual carers' journeys and has been useful to add to the qualitative evidence partners have already drawn together in the carers' stories and case studies.

From this work we have been able to understand better how things are for carers and learn what's working well, what could work better, and what needs to change. All of this has been considered alongside other things that we have learnt from carers.

Although the journey mapping work looked at a small number of carers' cases across the region, it reflected the following:

About the carer:

- That many carers refuse a carers assessment. This may be partly because many carers consider themselves a parent, husband, wife, partner, son, daughter, brother, sister, friend or neighbour, rather than as a carer.
- That carers tend to wait until they reach crisis point until they contact social services
- That carers are grateful for the support that they do receive and do not tend to ask for more
- That carers are ready to provide their feedback and opinion on the sufficiency of the service that they receive when invited to do so
- That person centred reviews focusing on what's going well, and what's not going well are beneficial to the carer
- That there are examples of carers making self-referrals to the Single Point of Access Service (SPOA)
- That carer involvement may at times lead to carer overwhelm
- That carers need emotional support

About local authority and health services:

- There are examples of SPOA services and GPs working well in identifying carers and having 'what matters' conversations with them
- That there is good practice in terms of carer engagement within BCUHB, e.g. treating the carer as an equal partner, welcoming the carer, providing information, documenting family circumstances, inviting the carer to talk, involving the carer in discharge planning, carer viewing of the person cared for's accommodation, involving the carer in the person cared for's treatment planning

- That it is important in some cases to meet the carer outside of the home environment and to ask their preferred method of communication
- That Direct Payments work well to offer flexibility to carers and in avoiding over prescribing of carer breaks (i.e. a set number of hours delivered by a contracted provider)
- That getting the right support for the person with learning disabilities can be crucial to the well-being of the carer. In one case the person cared for was eligible for an integrated care and support plan. Once that was in place the carers' well-being outcomes were able to be met with some support from the third sector and by signposting to other support in the local community.
- That advocacy is important to make sure the wishes and needs of the carer and the person being cared for are fully considered
- That there are examples of 'sitting' services providing additional services for the person cared for, e.g. taking them on outings, making the most of the time with the person cared for
- That there is a gap in carer break 'sitting' services for mental health service users
- The term 'sitting service' may be misleading; whilst a sitting service is not the same as replacement care, it does however refer to a service that regularly offers more than sitting with the person cared for
- That group support in mental health services cannot work in areas where the population is more dispersed and depends on one to one support services
- That carers are referred for expert information and assistance to the third sector organisations

About our workforce:

- That good quality services are provided by carer aware professionals who are committed to their work and to thinking creatively to tailor the service around the person cared for and carer
- That committed and dedicated professionals can add value to services and think outside 'process pathways' in order to create a pathway that suits the individual carer and person cared for
- That there are several points along the person cared for's journey where practitioners need to consider the carer, offer a carers assessment and check how the carer is coping or whether anything has changed. We saw good examples of this.
- That auditable formal carer pathways supported by the guiding principle of placing the carer at the centre of the service may facilitate culture change
- Although professionals can work to ensure that the carer pathway is a smooth one within their service, the carer may not have had a positive experience

prior to their encounter with that service, or after their encounter with that service

- That good communication between the professional who is supporting the carer and professionals who are supporting the person cared for is crucial
- That supporting the carer to become more confident, promote their independence, maintain their identity and maintain and build resilience is important
- That social services link with third sector support services and other services (e.g. OPUS) where it's been identified that that is useful but that professionals need to be reminded and updated of third sector support that is available

To what extent are the carers' experiences different to the process?

Whilst there are clear processes within health and social services to establish what matters to carers and to support them, the work undertaken suggests that the most important aspect is to be carer aware, to be guided by the needs of the carer and to work together with the carer and person cared for, placing them at the centre of the service.

Who in the process can support carers?

Different areas of service may be providing good quality services for carers, however, it is important that the experience of the carer is consistent throughout their journey. This may mean looking at the consistency of the carer's experience within one organisation as well as along a journey where the carer will be coming into contact with different organisations.

What do we need to do to change and improve?

- Further work needs to take place to understand the reasons why individuals with caring responsibilities refuse carer assessments
- Look at the possibilities of Direct Payment to enable flexibility in carer break services for carers
- Work in partnership to ensure that the carer journey is a smooth and seamless one from their first encounter with services that might be able to support them
- Ensure that carers are supported in their involvement with services, e.g. through briefings and de-briefings, and staff prompts where appropriate
- Consider whether carer champions within organisations would be helpful
- Consider the possibility of extending the principles of Triangle of Care (which have been piloted in BCUHB mental health services) to other service areas
- Ensuring that professionals are aware of third sector and other support services available to carers
- Consider how well the processes work when people move from one local authority to another.