

Postural care and the confidential inquiry into premature death of people with learning disabilities

Presenter: Sarah Clayton

Summary

We will outline the findings of CIPOLD.

Recommendation 9 states “CCGs must ensure they are commissioning sufficient and sufficiently expert, preventative services for people with learning disabilities regarding their high risk of respiratory illness. This would include expert, proactive postural care support”

But what does this mean in reality?

Aims and Objectives

This workshop will provide an opportunity to explore the following elements:

- What is ‘expert, proactive postural care support’ – who does it, what does it include, and are you providing it?
- What is co-production – how does co-production differ from traditional service delivery?
- How do we focus on objective outcomes – what are the service centred outcomes we are used to working to, and how can we balance these with person centred outcomes?

Background

We have considered Postural Care and Protection of Body Shape within a Positive Deviance model as described in “The Power of Positive Deviance” R. Pascale, J. Sternin, M. Sternin.

“Positive Deviance is based on the observation that in every community there are certain individuals or groups whose uncommon behaviours and strategies enable them to find better solutions to problems than their peers, while having access to the same resources and facing similar or worse challenges”

There is a lack of accountability for service delivery in this area which has led to the development of a culture of impunity in which basic, person-centred outcomes are not being recorded, collated or shared. The Living University is an international online platform where information and, most importantly, results can be shared freely. By highlighting the phenomenal success in some parts of the UK and overseas we may focus attention on areas that are achieving the best results as well as disseminating materials and strategies that have led to this success. Our aim is to improve outcomes for people and their families, to raise awareness of the preventative and restorative potential of Postural Care and to foster accountability for service delivery. The Living University also serves to provide access to information for individuals and their families in order to raise expectations of what may be possible using Postural Care.

One success story shared will be that of Wakefield. The dramatic reduction of numbers of children with hip dislocation (a common, often painful, debilitating secondary complication associated with reduced mobility for many children and young people) has been co-produced through partnership, working with individuals and their families, alongside changes in behaviour by a diverse range of

practitioners, including the local orthopaedic surgeon, therapists, teachers, teaching assistants and short break staff. Wakefield also changed their equipment provision systems and processes, all of which has taken almost 10 years to achieve.

The result is astonishing: A total of 274 children and young people aged between 0 and 18 who access the physiotherapy service in Wakefield led by Suzanne Carter. Of these 122 have a Gross Motor Function Classification Scale (GMFCS) of 1, 106 have a GMFCS of 2 or 3, and 46 have a GMFCS of 4 or 5. Not a single child or young person accessing this service has a dislocated hip and, in the past 12 months, only 4 have undergone preventative soft tissue surgery. This success not only impacts on the lives of individuals and their families, but it is also cost effective.

Discussion

Discussion will focus on the findings of the original Inquiry and progress since publication.

This workshop has been accepted for the CIPOLD Conference in March 2014 following which further information will be available.

References

Heslop et al: "Confidential Inquiry into the Premature Death of People with Learning Disabilities: Final Report." Norah Fry Research Centre, March 2013

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