

Pay More Attention

Myth-busting: research with children, young people and parents in hospital

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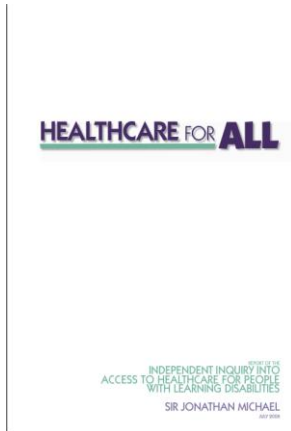
Professor Faith Gibson; Dr Charlotte Kenten; Assoc Professor Jo Wray; Dr Kate Oulton

Exec team: Oulton K, Wray J, Carr L, Whiting M, Hassiotis A, Jewitt C, Kerry S, Tuffrey-Wijne I, Kenten C, Russell J, Gibson F

Funded by National Institute of Health Research (NIHR)

Background: Pay More Attention study

A national mixed methods study to identify the barriers and facilitators to ensuring equal access to high quality hospital care and services for children and young people with and without learning disability and their families.



Learning Disabilities Mortality Review (LeDeR) Programme (2015-2018)



Improving the standard and quality of care for people with learning disabilities



The Learning Disabilities Mortality Review (LeDeR) Programme is commissioned by the Healthcare Quality Improvement Partnership (HQIP), on behalf of NHS England. Leaflet for professionals V1.3

Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) Executive summary

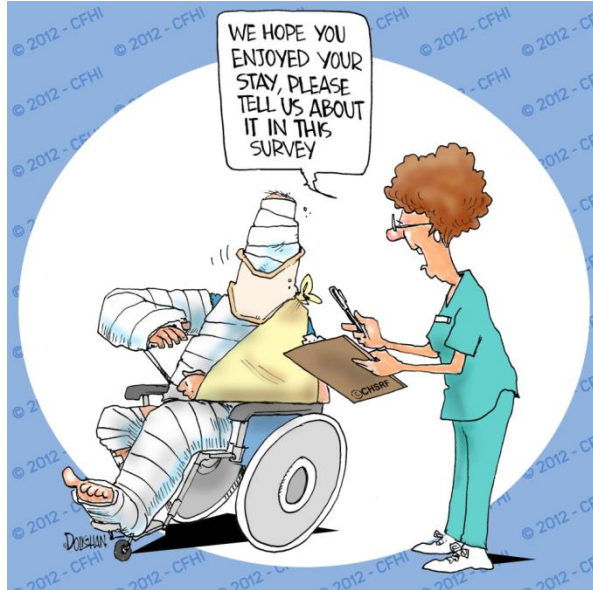


Pauline Hooley
Peter Skell
Peter Farrant
Marilyn Hooper
Anna Marshall
Leah Ryan

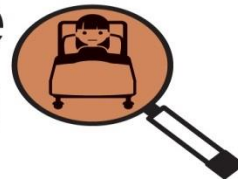
Pay More Attention



Conducting research with families in hospital



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Attention**

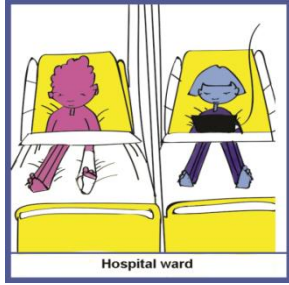


Phase 2 methods

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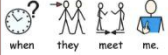




Hospital Room



Hospital ward



 Staff say hello to me	
 Staff when they meet me	
 Staff tell me who they are	
 Staff are friendly to me	

Parent safety review







Parent Safety Review Tool v 1.0/03/16 (RAS 17825)

Please think back over this hospital admission and reflect on your child's safety:

- What did you see that you thought was safe?
- What did you see that was unsafe?

We are interested in knowing anything you think is important including 'near misses' (incidents where something could have happened if you or another person hadn't prevented it) as well as times when something was done well.

Please fill in the boxes below, including the number of times this practice happened (if you know).

Medication	Comments	If you see something on safe, was this done well? (Y/N/NO)
		
		
		
		
		
		

The research team will not look at this document until after your child leaves hospital. For any immediate concerns, please speak to a member of your child's treating team.

Parents' diary

Pay More Attention Study, Great Ormond Street Hospital for Children


Parent's study ID:

Date of child's admission:

If lost, please return to:

For any queries please contact:
 Dr Charlotte Kenten (Pay More Attention Project Manager); 07901 075045
 Jess Russell (Pay More Attention Research Associate); 07561 431810

We usually have our phones with us from Monday to Friday, 8am to 5pm. If we are not able to answer the phone, please leave a message or send a text and one of us will get back to you as soon as we can.

 Great Ormond Street **NHS** Hospital for Children
 NHS Foundation Trust

Data collection in hospital: Parent myths



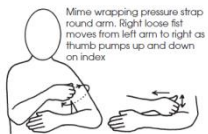
Data collection in hospital: Children and young people myths

It's up to
me if I want
to take
part.



Data collection in hospital: Children and young people with learning disabilities

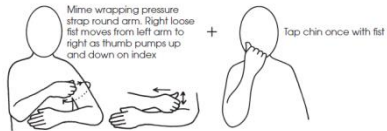
Procedures



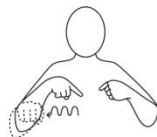
Blood Pressure Check























CT Scan



Blood Pressure Reading



ECG

 Staff	 say	 hello	 to	 me	
 when	 they	 meet	 me.		
 Staff	 tell	 me	 who	 they	 are.
 Staff	 are	 friendly	 to	 me.	

What worked well

- 1) Home visit
- 2) Short activities tailored to the needs of the child
- 3) Flexibility: timing, location, phrasing

What requires further development

- 1) Hospital tour
- 2) Flexibility around timing in the context of a national study
- 3) Parent diaries
- 4) CYP communication devices in hospital
- 5) Ascertaining information before approaching families

Conclusion

