Developmentally Appropriate Healthcare (DAH)

Workshop Facilitator Notes
A practical guide to facilitate focus group sessions.

Purpose

This toolkit is designed to share the learning from the Transition Research Programme with young people, to help them understand the research and to see if their experience of transition is similar to what the research tells us.

Notes for facilitators

The activities below should be facilitated by skilled and knowledgeable staff who know the young people well, and are confident in supporting young people to discuss and process their experiences. Further guidance and information is available in Appendix 1.

For different groups of young people, different images and language may be more appropriate. The facilitators should select the most appropriate images/language for the young people who will be involved in the activities. The questions/statements can be reworded if needed, as long as the core meaning remains intact.

About the TRP

Purpose: The Transition Research Programme (TRP) is a 5-year programme of research examining how health services can contribute most effectively to the successful transition of young people with complex health needs from childhood to adulthood.

Aims: The overall aim of the programme is to provide NHS commissioners and trusts with evidence about what might help young people with long-term health problems as they transfer from child to adult services. This will help them to allocate resources and structure services accordingly. Within this larger aim, the Programme has three objectives. These are to:

1) To work with young people with complex health needs to determine what successful transition means to them and what is important in their transitional care
2) To identify the features of transitional care that are effective and efficient
3) To determine how transitional care should be organised, provided and commissioned

Young people's involvement: The Programme has a young person's working group called UP. As the TRP is about improving young people's experiences of transition we think it's vital that young people have a say in *how* our Programme is run. This is where UP come in! They offer us help and advice and also complete various tasks for the Programme. Their help has been invaluable to the Programme.

After the activities

We are keen to hear how many young people are engaged in activities relating to the research and whether their views agree with the findings. We would be grateful if you could keep track of the following from the session you facilitate and report it to us via the survey in <u>Appendix 2</u>:

- Number of young people who were involved in the session?
- Did all of the young people agree on which statements they felt were true or false? If not, in what ways did they disagree?
- Did the young people identify similar influencing factors from the Transition's Got Talent activity?

The research

At the beginning of the study the researchers were aiming to determine the barriers and facilitators to the implementation of Developmentally Appropriate Healthcare (DAH) for young people.

What is Developmentally Appropriate Healthcare (DAH)?

- It is person-centred/individual
- Considers physical/mental/emotional capacities
- We need to understand more about this
  o When is it done well?/When is it done badly?
- DAH can help children and young people understand more about their health and how to manage conditions

With the initial scope of the research in mind, the researchers began by talking to and interviewing managers and clinicians and other health care professionals in order to try and find out more about what DAH was and how it was being implemented.

During the initial stages of this process they soon realised that the situation was not clear cut, there were differences in opinion about what DAH was, in many cases there was no set definition or recognition of DAH and it was not at the same stage in the process of implementation across all of the research sites.

Also, during the course of the research we realised that a factor implemented in a specific way could be a barrier in one context but a facilitator in another.

As a result of this we have shifted focus and in what follows we have arranged our findings around a list of the key factors that influence the implementation of DAH:

1. **Everyone has a different idea about DAH**
   There is a lack of a clearly defined and embedded concept. If there is no clearly defined concept and set of associated practices then this makes it difficult for people to associate the work they do with DAH and understand it: *'when you use that word I don't know what it means' (Interview)*.

   There is a need to find a way for health professionals to agree on a unified idea about DAH.

2. **Find a way to make sure all health professionals use it properly.**
   A clearly defined policy or strategy enables people to develop familiarity with the idea and develop an understanding of the associated practices that staff are required to do to put it into effect. But for implementation to be successful people need to agree with it and put it into practice: *'just because there is a policy does not mean to say that people are going to look at it or stick to it' (Field note)*.

   Find a way to make sure all health professionals use it properly

3. **Find the evidence to show it works.**
   The role of research can contribute to the base of knowledge that is needed to identify and provide DAH services for young people, as well as raise the profile of the issue. Notably, two of the participant organisations have a history of research on transitional care, which serves as an important foundation: *'the research I was doing got a bit of momentum. It kind of just became more visible … informing, certainly, the XXXX services within our trust (Interview).'*

4. **Get spokespeople to talk about it.**
   Get leaders / key people / champions / health professionals / charities / government / children and young people, etc. who are invested in pushing DAH forward are an important part of the implementation process. The emphasis here is on more than one person because: *'it doesn't work if you just have one enthusiast in one clinic. Of course it helps in that particular clinic, but it doesn't take the Trust forward' (Interview).*

   However, in terms of sustainability of these services, particularly in a Trust without a specific agenda to push DAH forward, champions may be vital for the continued existence of these services: *'champions are a good thing to have because not everybody champions the adolescent cause' (Interview).*

This is also true for other Trust-wide initiatives in Trusts without a specific agenda to push DAH forward: *'we do different stuff. But it's, I suppose, it relies on me doing it. (…) if I dropped dead tomorrow, everyone would carry on doing what they're doing without, you know...'* (Interview).

5. **Make it a priority - Children and young people matter!**
   Small numbers of young people and competing demands. Young people are often perceived to be *'very rarely unwell'*, and there are larger populations that the hospital needs to provide for such as the elderly*: 'I don't look after any children or young adults. The median age of my patients is about 70'* (Email correspondence). As such, for some, innovations around young people's health are not always seen as a priority.

6. **Ask the children and young people to help design services.**
   This can be through feedback, participation, planning, etc. Young person's involvement in creating change. Involving young people in the design of the service can serve to inform and legitimise the work that is being undertaken: *'developmentally appropriate young people's healthcare isn't just about the delivery of healthcare, it's about the involvement of young people in designing the delivery, in checking the delivery and in informing what you need to do when things aren't right'* (Interview).

7. **Better training for health professionals to work with children and young people.**
   Training around Adolescent Healthcare or DAH. Training can help to raise awareness and understanding of DAH (and adolescent development) and lead to a better understanding of the requirements of DAH in practice. Although, not a substitute for practical experience, it serves as a good way of creating a network or body of people who are engaged in adolescence and DAH: *'a good group of people across the Trust that we can actually send these youngsters to who've got more awareness of the issues that they could have'* (Interview).

8. **Culture change – change the idea that health professionals 'don't have enough time'.**
   Also, there are too many health practitioners involved with one child or young person. Continuity and change in the structure of the organisation, at the level of staffing: *'the turnover's too fast, of staff…. We'll never follow a young person through. … Nurses have been swapped over to cover different areas. Somebody's just left, so the young person, young, uh, the nurse has left to move into her role, there's a new one moved in. She's been off sick. There's maternity leave. It's not about people. The consultant's changed. So, you, it's not about a key worker, it just doesn't work … it's about consistency of approach, not a person'* (Interview). This can create practical issues, where

continuity of care in terms of specific personal is a problem, whereas continuity in terms of procedures enables innovations and good practice to be sustained.

9. **Different approaches to DAH.**
Some people suggested that a particular approach for dealing with young people was needed: impacting upon communication skills (communicating with young people and their family, information giving, teaching self-management skills), consultation dynamics (giving young people time on their own, incorporating the family, managing times and spaces) and assessment criteria (covering psychosocial and vocational aspects as much as biological/physical aspects): 'We need to be a bit less formal with them … a bit more of an informal type approach, and bit more person-centred rather than a rigid clinic system where you're in and out, see the doctor, and that's it' (Interview).

Others think that DAH does not impact on their clinical approach or, indeed, that DAH is not about the clinical approach but environmental issues: 'So as I say you're not mixing two year olds with 14 year olds, so I think it's really the physical environment. I personally don't think that your approach to the patient is any different (…) clinically, whether they are 2, 12, 22; it makes no difference, you treat -- you're there to treat their medical condition. But I think the environment in which they receive that treatment is probably more important' (Interview)

10. **Finding time.**
Time is an important (but perhaps disputed) factor in the provision of DAH. Paediatric patients often get considerably more time in their appointments than their adult counterparts (the exception may be the young adult clinics). Yet in some cases this seems to be less frequently acknowledged than some of the other factors: 'X says that would be difficult for Adult clinicians due to the time that they get for their clinic appointments. Y and Z suggest that clinicians could make time if they wanted to, and that actually it is more about the anxieties that clinicians feel when talking to YP' (Field note).

11. **Physical spaces – Children and young people have nowhere to meet.**
There is often no fixed space for adolescents, and any space that is allocated for adolescents is often subsumed within the spaces for children or adults. In such situations, clinicians need to work to find alternative solutions, drawing on a range of resources within their scope of influence. Children and young people have nowhere to meet.

12. **Teamwork.**
Teamwork is an important feature of being able to provide DAH. Part of this is consistency and joined up working both within and across specialties and

organisations – however much of the evidence to emerge from our findings suggests that this does not always happen.

Health professionals should support each other to enable there is not a repeat of advice and services for the children and young person.

13. **Cultural differences and distinction.**
The difference between paediatrics and adults are a factor: 'Paediatrics is quite different to adult medicine, most adult physicians have become, what I'd call, ologists in that they've specialised in a very specific area […] Whereas paediatricians are general physicians and they look after everybody' and 'the adult teams don't necessarily, their way of working doesn't necessarily fit with how the children's ward works. Um, the, um, communication between, you know, we all think we speak the same language but reality is we just don't' (Interview).

What this might mean for young people

DAH is about the experience a young person may have when attending a clinical or medical appointment. It attempts to identify a set of principles and a way of working that can improve a young person's experience.

Activity 1: Factors that influence… True or False

Facilitator to use the key factors outlined from 1-13 and to ask young people to suggest if they agree of disagree that the factor would influence their experience of seeing a medical professional (GP, consultant, nurse).

(For smaller groups this can be done as one group with people raising their hands for each statement).

Young people may identify with any or all of the research statements. During the activities and the discussion, the young person may well begin to identify with different statements. This may reflect a change in knowledge or understanding of their experiences of transition. It is valuable for the facilitators and the young people to discuss and reflect on any changes. It is also helpful for young people to articulate if they do not identify with any of the statements.

Activity 2: Transition's got Talent

https://research.ncl.ac.uk/transition/youngpeoplepage/theyoungpeoplesworkinggroup-up/

Using the film clip, Transition's Got Talent developed by UP young people's group, facilitators should play each scenario in the clip giving the young people in the room an opportunity to be the 'judging panel'.

After each short scenario, pause the film and ask the young people:

- Is this a good example of working with young people?

- How would this make you feel?

- Complete the sentence, 'This situation would be better for young people if…'

Record the sentences on flip chart to share back at the end of the session.

The following are some additional questions that can be used as prompt if required:

- All children and young people are the same
- Respect – do you feel children and young people are always respected
    - What do you think this means?
- Does it help if health people try to 'relate'
- How would health people gain your trust?
- Stereotypes – how can this hurt children and young people?

At the end of all of the scenarios read back the statements that the young people completed as part of this activity.

Facilitate a short discussion on:

- Are they similar to the influencing factors that the research suggests?
- Are there any differences?
- Which do they think are the most important?

Appendix 1: Guidance and Further Information

The activities in this toolkit should be facilitated by skilled and knowledgeable staff who know the young people well, and are confident in supporting young people to discuss and process their experiences. This includes providing emotional support to deal with difficult experiences or reactions. The young people should be comfortable in discussing their experiences and feelings in the setting.

Appendix 2: Please share young people's feedback on the research and activities with us via our online survey:
https://www.surveymonkey.co.uk/r/TransitionResearchProgrammeDAH

- Number of young people who were involved in the session?
- Did all of the young people agree on which statements they felt were true or false? If not, in what ways did they disagree?
- Did the young people identify similar influencing factors from the Transition's Got Talent activity?

Acknowledgements

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