

Appendix D: Expert Witness testimony

Expert witness on Transitions from mental health inpatient care for children and young people

Section A: NCCSC to complete	
Name:	Laurie Oliva
Job title:	Youth Engagement Manager
Address:	YoungMinds, Suite 11 Baden Place, Crosby Row London SE1 1YW
Guidance title:	Transition between inpatient mental health settings and community or care home settings
Committee:	Guideline Committee 5, 16 th June, 2015
Subject of expert testimony:	Children and Young people – Review Question 8 <i>‘What is the effectiveness or impact of specific interventions to support children and young people during transition between inpatient mental health settings and community or care home settings?’</i>
Evidence gaps or uncertainties:	<ul style="list-style-type: none"> - The effectiveness of specific interventions for children and young people (including cost effectiveness) on admission and/or discharge from hospital - Reintegration into the school system for children and young people (which is UK specific) after discharge from hospital - Self-directed and peer support for children and young people (and carers/ families) during transitions - Components of care packages for children and young people which support them during transition. - Lack of evidence reporting views and experiences of children and young people.
<p>For each of our review questions we search for, assess and present evidence relating to views and experiences as well as evidence about the impact of specific interventions within the review area.</p> <p>Gaps in evidence that have been identified include the following:</p> <ul style="list-style-type: none"> - The effectiveness of specific interventions for children and young people (including cost effectiveness) on admission and/or discharge from hospital, aside from one UK service evaluation (Kyriakopoulos M et al., 2015). - Reintegration into the school system for children and young people (which 	

is UK specific) after discharge from hospital

- Self-directed and peer support for children and young people (and carers/families) during transitions. We found one study which addressed a peer-support service but this was for adults and based in New Zealand (Geraghty, 2011).
- Components of care packages for children and young people which support children and young people during transition.
- Very little evidence reporting views and experiences of children and young people; we only found one English study (Hepper, 2005) and one study from Northern Ireland (Scott, 2001). In addition, we found a third study, but numbers of children consulted was not reported and research method employed were poor (Kyriakopoulos et al (2015)).

Section B: Expert to complete

Summary testimony:

[Please use the space below to summarise your testimony in 250–1000 words – continue over page if necessary]

YoungMinds has been commissioned by NHS England to engage with young people who are using inpatient CAMHS now or who have in these services in the past and their families to find out:

- How involved young people and their families are in planning their own care and helping make decisions about inpatient CAMHS services;
- If young people and their families would like to be more involved in these decisions, including engaging directly with NHS England and if so, how they would like this engagement to look;
- What has been positive and negative about their experiences of using inpatient CAMHS and how they think these services could be improved.

To date, YoungMinds has interviewed 24 young people who are currently staying in CAMHS inpatient units and engaged through a participatory workshop with 21 parents of young people who are currently or have in the last year used inpatient CAMHS.

Information relevant to these guidelines is summarised below:

Admissions

Key themes arising in how parents & young people reported experiencing the admissions process to inpatient CAMHS:

- Inadequate community support which would have prevented admission;
- Insufficient information was available to them before admission about the service they/ their child would be admitted to;
- Lack of participation of both parents and young person in the decision about admission and within care planning once admitted- including lack of involvement in setting outcomes for the hospital stay;
- Poor communication from staff at inpatient CAMHS with parents- lack

of information and dismissive tone;

- Issues exacerbated when young person placed further away from home.

Discharge

Key themes arising in how parents & young people reported experiencing the transitions process from inpatient CAMHS to the community:

- The transition was overall experienced as poor for all families- varying between two extremes of being inadequately planned and rushed or unnecessarily delayed;
- Some families found the process rushed and parents reported young people being discharged with insufficient planning & support set up in the community;
- Other families found the discharge unnecessarily delayed by the prioritisation of process over the needs of the individual young person, for example delaying discharge because a place could not be found in a step-down service, even when young person and parents didn't believe or understand why such a process was needed;
- Community CAMHS (and other services including education and social services) not adequately engaging with the discharge process so when the child made the transition home no support was in place;
- Inadequate support and planning for home leave including no provision if child experienced crisis; no guidance on coping strategies for parents and often poor logistical planning (e.g. young person waiting hours for scheduled leave because medication not dispensed).

Key improvements that parents & young people wanted to see during transitions to and from inpatient CAMHS are:

- Greater participation in making decisions about when to admit/discharge a child;
- More information about the service the child is being admitted to prior to admission and greater participation in setting outcomes for hospital stay and care planning;
- Improved integration between inpatient and community CAMHS and other key services such as education and social services;
- A more child-centred approach which puts the needs of the individual child (and family) above process;
- Some parents and young people strongly felt that improved and increased community support would have prevented a hospital stay being necessary.

References (if applicable): N/A

Expert witness on Transitions from mental health inpatient care for people with Dementia

Section A: NCCSC to complete	
Name:	Dr Amanda Thompsell
Job title:	Consultant in Old Age Psychiatry
Address:	South London and Maudsley NHS Trust
Guidance title:	Transition between inpatient mental health settings and community or care home settings
Committee:	Guideline Committee 7, Tuesday 29 th September, 2015
Subject of expert testimony:	People living with dementia, Review Question 7: <i>What is the effectiveness or impact of specific interventions to support people living with dementia during transition between inpatient mental health settings and community or care home settings?</i>
Evidence gaps or uncertainties:	<p>We sought studies which met the following criteria:</p> <ul style="list-style-type: none"> (a) Population is people living with dementia. In health settings, population may be subject to the provisions of the Mental Health Act, Deprivation of Liberty restrictions or the Mental Capacity Act. (b) Population are in transition (admission to or discharge from) between a mental health unit and their usual place of residence in the community (own home, care home, etc). (Transitions in and out of general medical inpatient settings are out of scope, covered in another guideline.) (c) Interventions must concern support of people with dementia and their carers through transitions (ie not focus on the inpatient experience unless linked to transitions). <p>We found no evidence on effectiveness or cost effectiveness of interventions designed to improve transitions between inpatient mental health settings and community or care home settings, for people living with dementia.</p> <p>We found no research identifying and evaluating variation and opportunities for improvement in approaches to reducing re-admission and time</p>

	<p>spent in inpatient mental health settings for people living with dementia.</p> <p>We found no evidence on the impact of out of area placements (placement in specialist services or in services with available beds) on admissions into, and discharge from, inpatient mental health settings for people living with dementia.</p> <p>We also found no evidence that people living with dementia had access to inpatient support with other mental health problems (where dementia may be masking other treatable mental health issues).</p> <p>Liaison and support between practitioners in inpatient mental health and in care home settings are of particular interest for this topic.</p>
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Section B: Expert to complete

Summary testimony:	[Please use the space below to summarise your testimony in 250–1000 words – continue over page if necessary]
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Background

I am currently a consultant old age psychiatrist working in a specialist care (long-stay) Unit at the South London Maudsley NHS FT and as such am responsible for supervising transfers of patients with dementia and in some cases severe enduring mental health issues into care home and community settings. I also worked for many years with a team providing support to Care Homes in South London. As such I have seen transitions from both sides and the following guidelines represent my views of best practice based on more than 15 years' experience.

Evidence

The two key issues to ensure a safe and effective transfer are communication and planning. We have found when assessing new patients for admission to our unit that we were not consistent in our assessments and issues were missed. For that reason we produced an assessment checklist to ensure that the assessor gathered all the relevant information. We also produced a discharge checklist again to try and reduce the risks on transfers. We also produced a transfer communication flow chart for care home residence to hospital and back to care home.

Particular issues to consider include:

- (i) Communication with the person with dementia and any lay carers:** They should be involved in the planning as much as possible. It is important to allow enough time to this transition planning. The way that

the person is treated by staff can have an impact on their overall experience and often people particularly with dementia need more time to feel supported and heard. Ideally they should visit the new care setting themselves and perhaps take a meal there. If that is not possible then showing photos or videos should be seen as a minimum. It is also very useful if they can meet some of the staff carers so that they will have a familiar face.

(ii) Communication with staff at the new home to allow evaluation:

The new home should evaluate properly and realistically its ability to care for the person or it risks accepting somebody whose needs they cannot meet. Often the staff in the acute setting have little idea what the new setting can provide. In particular the new home should receive a good understanding of the person's physical needs including any skin-care or continence issues and any mobility, eye-sight, hearing or swallowing difficulties. So often the physical needs are paid less attention to than the mental health needs when coming from a mental health unit.

(iii) Communication to plan care going forward: A checklist should be used to ensure that the new carers receive in writing all the information they need. This should include up-to-date details of:

- the information mentioned in the previous paragraph
- the nursing care plan
- current or past psychiatric problems such as depression which may be likely to re-occur at the time of loss to ensure that staff are aware of the signs of relapse. This should include what the signs of the person deteriorating are both mentally and physically and most importantly what to do if there are signs of deterioration.
- where the person is a moving out of area or between services (particularly if they have other long standing mental health issues) then clarifying (before the transfer happens) who is going to follow up the person, and what services are going to be responsible for the follow up, is essential to avoid distressing delays.
- any follow up appointments
- any DNAR or future health care wishes expressed /discussed
- clarification of money arrangements and if they are currently under a deprivation of Liberty authorisation.
- copy of the Decision support tool (DST).

(iv) Planning the move: To help have a smooth transition, drawing up an individual timetable is helpful and arranging a discharge meeting where everyone (ward and care home staff) can attend prior to the move is also critical. We have gone to the care home to do this when they cannot spare the time to visit the ward. This is a time to share information and ensure that special equipment, chairs, sticks and frames are in place and go with the person with dementia. Too often transfers are so rushed that this meeting is omitted.

When it comes to the day of transfer we check the person being transferred is fit for transfer and abort if they are not. We also consider the

time that the person is transferred e.g. when there is less traffic so that the journey will take less time. We find it is helpful if the person who goes with the patient knows them well and it is best if their relatives go to. For those with complex needs the staff who has gone on the transfer does a shift with the care home staff to help them understand the persons' needs.

(v) Post-move actions for the transferring unit: It is good practice for the transferring unit to phone up after 48 hours to check all is well and to do a follow up visit after a week to make sure that everything is settled. We find it is helpful for the review to be undertaken by ward staff rather than by community teams as the ward staff are better placed to notice any changes. We also keep contact with the family to make sure that they feel supported and that the transfer has gone well.

(vi) Post-move actions for the receiving home: To be able to meet the emotional and psychological and mental health needs of their new resident it is important to quickly develop a knowledge of that person. The use of a life history explaining the person's interest and past experience is very helpful and can reassure the resident and their relatives that you are keen to get to know them and help the transfer in to the new environment. Some have found that if the relatives or the carer can prepare a scrap book with pictures of familiar faces and people that are important to the new resident with their names written underneath it is helpful when staff engage in conversation with the new resident. As part of the interaction with the resident and the resident's family, staff should look to find out details such as:

- the person's previous coping skills (this can again help staff think of strategies to reduce any potential difficulties);
- the person's food preferences, preferred routines, spiritual and cultural needs etc.

References (if applicable):

Both are rather old papers and are about relocations but the principles are still relevant to transfers.

Relocation of the Elderly Medical care research and review 53..3, 291 to 333 Castle N 2001.

Guidance by the department of health on the transfer of frail older NHS patients to other long care settings health service circular hsc1998/048