A focus on Transitions: Child to Adult Services

Royal College of Psychiatrists Wales Webinar (June 2022)

This webinar was both organised and chaired by Dr Amani Hassan in June 2022. It featured four main speakers: Simon Jones, Dr Jaya Balakrishna, Dr Surekha Tuohy and Dr Dave Williams and focused on transitions from child to adult services.

This report has been written by Dr Darchana Patel, an RCPsych Wales Policy Attachment, in her capacity as a trainee in psychiatry.

Speakers

1. Simon Jones
Head of Policy and Campaigns, MIND Cymru
Conducting research on transitions and 0-25 services
Mind report 'Sort the Switch' The experiences of young people moving from Specialist Child and Adolescent Mental Health Services to Adult Mental Health Services in Wales (May 2022)

2. Dr Jaya Balakrishna
Consultant Adult Forensic Psychiatrist, Ministry of Defence
On the 0-25 steering group in RCPsych representing the Adult Faculty and on the Child and Adolescent Faculty
RCPsych Wales position statement on transitions 'Delivering better outcomes for children and young adults – new service models and better transitions across mental health' (November 2022)

3. Dr Surekha Tuohy
Consultant Community Paediatrician and Paediatric Neurodisability Consultant with a special interest in epilepsy, Swansea Bay
Runs paediatric epilepsy courses for British Paediatric Neurology Association and manages transitions frequently in her daily work

4. Dr Dave Williams
Consultant Child Intellectual Disability Psychiatrist, Aneurin Bevan
Independent Welsh Government Advisor for Child and Adolescent Mental Health, Chief Medical Officer for Welsh Government and Chair of Children in Wales

Mind Cymru "Sort the Switch"

(From Simon Jones' talk)

In May 2022 MIND Cymru published "Sort the Switch" a document reviewing the experiences of young people in Wales moving from Specialist Child and Adolescent Mental Health Services (CAMHS) to Adult Mental Health Services, (AMHS) covering transitions from 2017 to 2021. Young people voluntarily signed up and ultimately 8 young people contributed their views through semi-structured interviews in November 2021. Despite the small sample sizes, these young people were from various geographically locations across Wales, however the ethnicity diversity of the Welsh population was not captured within this sample. Transcripts of the interviews were thematically analyses to identify common themes that most impacted these young people's experience of transition across mental health services.

Many mental health professionals are unlikely to be surprised by the key 'pain points' identified by the study, as they echo concerns raised by young people and their families across many health boards. The young people in the study felt they did not receive clear and/or adequate information about the transition, i.e., what the process entailed, who would be involved or that an advocate is available if needed. Those that did not transition and were discharged from specialist mental health services felt signposting to other support services was poor.

Though care and treatment plans are regularly used in mental health, either formally or informally, these young people felt the use and follow through of these plans during transition was inconsistent and they did not feel they were sufficiently involved in the formulation of the plan. These young people were often left feeling unsure if they would be accepted by adult mental health services, with delays in accessing the support even once they has been accepted. Those in 'limbo' had no interim support, feeling abandoned and cut-off from CAMHS, however some CAMHS professionals did 'step-up' and provide support in this interim period. The gap in support often results in the young person's mental state deteriorating, even in those who were previously doing well within CAMHS.

Improved communication between professionals and different services was a common theme throughout, as communication was often not clear nor consistent. In keeping with the views of many professionals, these young people also felt that transitioning across mental health services should occur at a later stage in their lives. Around the age of 17/18 they experience many other life changes that have an impact on their mental health, and so moving to a new mental health service at the same time often de-stabilises their mental health difficulties further. University students are a worrying example of this, as they often move away from home and have poor experiences of transition to local

mental health support services, either University-based or primary/secondary care-based.

One of the most impactful findings, and one of most concern, was young people being made to feel they had to provide proof of ongoing illness requiring further support from the adult mental health services. This caused significant worry and distress to the young people during the transition process in case their assessment with the adult mental health service was on one of their "good" days. Though it is not the intention of the clinician or service to make young people feel this way, it indicates that the way the transition process is currently being implemented is having an adverse impact on young people.

As part of the "Sort the Switch" report, MIND Cymru and the young people have co-designed an outline of the 'ideal' pathway. The report acknowledges that 'design challenges' continue to exist along the pathway that require further local and regional consideration, alongside young people, to find effective and implementable solutions. The co-produced overall recommendations by the report include improving the information given to young people about the transition process and better co-development of the care and treatment plans. In addition to this they recommend changes to the acceptance criteria for CAMHS and AMHS, the decision-making process around the move between these services and the support offered when there is a gap between the two services.

The overarching recommendation requests that both Welsh Government and local health boards improve their monitoring standards so they can demonstrate that all aspects and principles of the care transition guidance are being fully implemented across Wales.

0-25 RCPsych Wales Steering Group

(From Dr Jaya Balakrishna's talk)

RCPsych Wales has been working on transitions broadly for a few years now, and in February 2022 this work was taken on by the newly formed 0-25 steering group. The groups' aim is to identify and address the key principles and challenges to providing mental health services for 0-25year olds. Providing safe, effective and efficient transitions is one area of their work and they recently released an interim position statement regarding this. NHS Scotland is working towards improving 0-25 services, whilst NHS England has well established steering group which has been a useful reference point for NHS Wales' group.

Transitions exist in all areas of children and young people's lives, not just mental health. All of them faces several transitions during the educational journey and

those requiring support from social services faces transitions during the support too. In addition to this, there are many developmentally changes that occur across the first 25 years of a person's life that are gradual transitions over days, weeks, months and years. Many of these individuals will also experiences changes in their home lives with some of these being perceived as positive transitions and some negative transitions i.e., parental separation, death of relatives, home moves, birth of new siblings. The goal for mental health is to provide transitions that are gradual and a positive experience.

One area of transitions that requires significant work is around student mental health for those moving onto further education and university. Their GP or mental health team may be either at home or near their university, or neither or both, creating a complex web of transitions and support services that may not interact with each other effectively. Undergraduates affiliated with the military has access to mental health services from defence in addition to local services. Morrison guidance means that military has co-responsibility for the individual for a 6-month period after discharge from the service. This is an example of one aspect of good transition care that has been adopted by some NHS services across the UK.

Many believe that children and young people experience different mental health difficulties and disorders to adults, however this is a myth. Another common myth is that if children had a better upbringing or social experience then these difficulties would not arise. Though both contribute to adverse mental health, they are not singularly causative as mental health difficulties are multifactorial in aetiology. These myths are present amongst some professionals and clinicians working within adult and child mental services, both in the public and private sector, and so highlighting and addressing these are an important step in increasing collaboration between services and thus an improvement in transitions.

What services should look like for 0-25year olds is a complex challenge with various possible solutions. Should child and adolescent mental health services (CAMHS) raise their upper age limit, and if so to what age? Or should adult mental health services (AMHS) lower their age limit to 16 in line with other medical specialities? Should there a hybrid model to reduce transitions or a separate 16-25 mental health service to remove the transition at age 18? Alternatively, should mental health services be more flexible and not age-restricted or reconfigured based on clinical conditions? All of these come with their own set of different challenges as well as improvements. The recently published position statement by the steering group reviews some of these options. Changes to transition care need to be patient-centred and lead to an improvement in service provisions, but they also need to be realistically implementable.

Current transition guidance and practice
(From Dr Surekha Tuohy's talk)

"Transition not a single event but a gradual purposeful and goal orientated process". "It is the process of empowerment to equip young person with skills and knowledge necessary to manage their own health care". Therefore, engaging young people in the process through discussions around their needs and starting the transition process earlier is likely to result in a better transition. It is well documented that long-term health conditions, both physical and mental, impacts many aspects of an individual, e.g., identity, mood, sense of normality, capacity of social participation, feeling stigmatised or misunderstood. As a result, transition processes need to allow time for these dynamic factors to be considered and reviewed regularly during the process.

Various guidelines and guidance around transitions currently exist within the UK, based on data and information from different sources. The CQC England document "From the pond to the sea" was based on views from 180 young people aged 14-25 with complex needs and/or their parents. Things that worked well with these young people's transition of care was being given good information with good communication and consistent care. However, there were several things lacking in the transition process, i.e., no transition plan, no lead professional, lack of experience, poor planning and preparation and needs of the parent/carer not being considered. Current transition guidance from England and NICE guideline from 2016 recommend there should be a documented transition plan and an allocated accountable transition worker.

Other recommendations include support in the 6 months before and after transition, involvement of the GP and addressing all aspects of the individual's life not just their physical and mental health, e.g., housing, education, employment. The Welsh guidance on transition would like services to achieve a safe and effective transition with a focus on the young person ensuring high quality and person-centred integrated care is provided. To deliver this it advises the implementation of the NICE guideline and the use of a rights-based approach as outlined in the Social Services and Wellbeing Act 2014. Providing assurances to young people and their families is an integral part of the Welsh guidance.

Within current healthcare models around the UK, there are some are best practice examples of transition care. One example is the Ready, Steady, Go approach used in Southampton Children's Hospital where they used a questionnaire based model to inform the young person's transition needs at various stages during the process. Another is the HEADDS programme in

Birmingham Children's Hospital where they use a psychosocial interview tool to capture information on various aspects of the young person's life. Northumbria Healthcare Foundation Trust carried out a NIHA observational study to inform their guidance "Making healthcare work for young people" so that they could deliver "developmentally appropriate healthcare" which included transitions.

Dr Tuohy regularly manages transitions a part of her paediatric epilepsy clinic in Swansea. They have clinics specifically allocated to teenagers where they are encouraged to discuss the healthcare needs, including transitions plans, first alone then with the presence of their parent or carer. To ensure a safe and effective transition is achieved between professionals, the service has joint paediatric and adult neurologist transition clinic where the young person's diagnosis and previous investigations are reviewed, and a management plan is formulated with agreed follow-up from the appropriate team. In complex cases this may require more than one appointment.

Dr Tuohy runs a similar professionals' transition clinic with the adult intellectual disability team in Swansea, and often these include various other professionals involved in the young person's life, e.g., teachers, social worker, child health clinician, challenging behaviour and disability team. To reduce distress to the young person during the transition process, this clinic is held in the Paediatric Unit to ensure changes to their care and service provisions occur gradually.

A transition experience can have a lasting impact on the young person and their family, so it is important to get it right for them and the service. Research (Clover at al 2018) shows that three features are strongly associated with improved outcomes: appropriate parent involvement, promotion of health self-efficacy and meeting the adult team before transfer.

Managing crisis in transitions and improving service provisions
(From Dr Dave Williams' talk)

"Beyond the Call" was an audit completed in Wales exploring 999 calls and presentations to emergency services, and it showed that of those relating to mental health 20% of these were in 16-25year olds. This age can be challenging for many, but particularly those who have experienced other difficulties either in the past or the present such as domestic violence, substance misuse, precarious accommodation, not being in education, having been/being in the social care system. Many systems around the young person stop or change around age 16 (social care, education, legal system) and so they no longer have an anchor that is grounding and supporting them consistently. In addition to this, the average 16-19year old is at a very different developmental stage compared to their younger

average 12-16year old, adding another challenge to their daily lives. The “Beyond the Call” audit showed that under 15s mostly called as they couldn’t cope with relationships, bullying or school, whilst 16-25year olds called due to difficulties with self-harm, substance misuse, gender identity and housing.

Where 16-25 services exist, the focus tends to be around crisis management and though this is helpful in short-term it doesn’t reduce recurrent crisis presentation during these transition years. Refocussing on crisis prevention through the provision of good mental health assessments around self-harm and suicide ideation, better housing support and coherent, well communicated multiagency plans would most likely be more beneficial for those in this age group. Some possible solutions to managing crises in the transition age group would be more joint work between CAMHS and AMHS, designated 16-25 beds rather than CAMHS beds and Crisis Houses to de-escalate the Crisis without admission to hospital.

For improvement in service provision and transition care to occur there has be a cultural change. Solutions to many problems already exist somewhere in Wales, but due to the lack of sharing of experiences and pathways local services spend vast amounts of time formulating solutions. Within health boards, services waste time trying to figure out who is responsible for the problem and thus who should have to work out the solution and provide the service to address the problem, i.e., healthcare, social care, third party. However, ultimately mental health is multifactorial affecting multiple aspects of an individual’s life and thus it is everyone’s problem to some extent. This extends to the ongoing overfocus on the age boundaries of services.

To improve transition care for young people, services need to start by using existing provisions more effectively. Once this has been achieved, gaps in provisions need to be addressed through new functional services. These new services may use existing pathways/ideas and adapt them to fit locally or regionally. Gaps in services are likely to change over time as new solutions take time to implement during which time the problem is likely to have changed too. Therefore, to ensure the longevity of new services, they should be flexible to adapt to changes in response to ongoing reviews that are based on regular data collection from the service. 16-25 services co-designed and co-produced with 16-25years old and their families are likely to more effective than those produced by professionals in isolation.

As with all change, barriers exist that make change difficult to instigate or implement. Many services across the UK are overstretched with resources being limited and staff being busy, allowing little physical and mental capacity for change to be considered. For change to occur under these circumstances it has

be accepted that there will be a deterioration in performance and provision whilst change is being implemented, however the change will ultimately result in improvements. Change requires clear, present leadership beyond 9-5 as most mental health crises occur out of normal working hours and so service provision during these hours will require changes. Change requires money and tight service budgets often hinder change, which is one of the barriers to the provision of 16-25 services. Whether 16-25 services are standalone, part of CAMHS or part of AMHS, both money and staff would need to be reallocated to provide the service.