

Good morning/ afternoon everyone! I'm Thines Ganeshamoorthy and I'm a member of the Royal College of Paediatrics and Child Health Youth Advisory Panel. I am also a service user representative of the NICE GDG for the transition from children to adult services group. As someone who is 21 and having transitioned from all my children and adolescent services to adult services, I am delighted to be here to discuss my experiences of transition of services and how important good transition can be and the impact of a not so good transition.

Just to provide a bit of context to my medical condition, I have Osteogenesis Imperfecta Type 4 (Brittle Bones Disease). I was diagnosed of this rare genetic condition when I was 2 years old. I have had a variety of involvement from professionals in health and social care, ranging from physiotherapy and social services to lung specialists, rheumatologist, endocrinologist and neurologists. This has allowed me to see transition from a wide range of perspectives. I wish to share some of those with you today, in this I would like to touch on some main points, namely planning, transparency, communication and consistency.

Under paediatrics I felt endlessly supported and felt as though I was not alone. I had the support of a designated key worker (whom I picked) and through the use of multi agency planning pathway meetings; I was able to bring together all the individuals involved in my care in one room at least twice a year. This encouraged conversation and collaborations between the individuals involved in my care. This combined with the ability of my key worker to be my advocate and liaison between all these services allowed for easier communication and accountability, ensuring me a stress free path through my disability and health matters leaving me to concentrate on what was important to me, education and socialising. Allowing me to be who I was, a teenager!! However, when I moved to adult services things changed. The MDT style structure fell away and my key worker was no longer able to carry on in their role due to the different structures and criteria for qualifying for each service. This meant that on my 18th birthday, as well as dealing with A Level results and transitioning to university I was also burdened with having to take full and complete responsibility for my care and everything that it constituted. While I believe it is completely normal for someone to take control of their life and their condition, I believe this should be a gradual change not an immediate shift of responsibility. Their needs to be training and skills required in terms of self-advocacy, managing budgets and dealing with variety of different care professionals.

Another bug bear of Transition for me was an issue of consistency. Having had my care being managed at a variety of hospitals across the country I have had to be transitioned from their paediatrics to adult services and I have seen a glaring disparity in their regimes. In my local hospital I was promised joint appointments with my paediatricians and my adult consultant, tours of the adult wards and a lead in time prior to full handover so I had time to prepare myself for the new experience. However, this did not happen unfortunately. On my 18th birthday I got a letter setting up an appointment with my adult consultant who knew very little beyond what was in my notes and I was not given the type of transition that I would have liked. This left me feeling very uncomfortable and scared, which in my home local hospital should not be the case. I felt as though I

needed to pester my new consultant to give me answers to the questions I had and the appointments with my new consultant always seemed rushed and always seemed to be more for the formality of follow up rather than focussing on me and what was important to me. On the other hand, in my main hospital from which all my care was overseen at GOSH I was given a two year lead in period, several joint appointments with my paediatric consultant and my adult physician as well as tours of adult wards with time for me to discuss with ward staff about their protocols and for me to ask the questions that I wanted to ask. This is the type of inconsistency I would like to see change. All of these things aren't too hard to implement I believe, but it does so much to put the minds of young people like myself at rest.

Another area worth consideration is GPs. GPs as we have heard from Amy can provide some area for contention. In my experience, my GP does not want to see me due to my complex and chronic condition. They are afraid that anything they do may affect my other lines of treatment. This has led me to losing a pivotal stakeholder in my care and life, GPs are meant to be individuals who follow you throughout your life course and someone you can depend on even when other aspects of your life are going through transfer. However, this wasn't the case for me and I feel this is something that could change and needs to change. With GPs gaining greater responsibility of management of local care, I feel that GPs should get compulsory training in dealing with children and young people as well as treating individuals with complex and chronic conditions. This would not only increase the confidence of GPs to deal with young people such as myself but it would increase the confidence young people have in going to see their GPs and trust that they will be in good hands.

However, it is not all doom and gloom. As has been mentioned before there are many models of transition that has been working well such as the Ready, Steady, Go initiative in Southampton. It is our responsibility to ensure that we take these learning from across the country and try to implement these models nation wide rather than keeping them in pockets. To conclude, I would like to leave you all with my 5 C's which I believe would lead to better managed and easier transition: Collaboration, communication, clarity, continuity and consistency!

Thank you.