



Transition, It's More Than Just An Event: Supporting Young People With Type 1 Diabetes

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This paper discusses the importance of holistic person-centered care coordination services for young people with type 1 diabetes as they transition to adult health services. In response to the growing need for comprehensive, flexible, person-centered care for young people with chronic conditions, the new service *Trapeze: a supported leap into adult health* was established. Based in Sydney, Australia, Trapeze is a specialist adolescent chronic care service offering comprehensive care coordination services to young people with chronic conditions aged 14–25 years. Trapeze aims to support young people with type 1 diabetes by focusing on the individual needs of the young person and developing a mutually recognized relationship based on trust and respect, in order to facilitate a process whereby a young person feels safe enough to discuss some of the challenges they face in self-management, keeping their whole of life issues central to this process. The importance of holistic person-centered work is best exemplified through the stories of the young people enrolled in Trapeze. It is hoped that through the 'eyes' of the young people and by sharing their stories the approach to self-management and care coordination can be better understood.

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YOUNG PEOPLE WHO live with type 1 diabetes encounter a number of challenges when faced with the prospect of moving to the adult health system. Leaving the children's hospital, a place that they have come to know, trust and rely upon (Care Quality Commission, United Kingdom, 2014), can be for some a daunting experience, having to start again the process of relationship building and health care navigation. For others, the idea of leaving the children's hospital is filled with excitement and achievement. Generally, it is a mix of both.

These mixed emotions are fuelled by the numerous changes that take place during adolescence. Biological, emotional, psychological and social changes all add to the anxieties the transition process can create for some young people with type 1 diabetes. It is well established that much

of youth morbidity and mortality results from psychosocial issues such as drug use, unsafe sexual behaviors and mental health conditions such as depression, anxiety and eating disorders (Australian Institute of Health & Welfare [AIHW], 2008; Royal Australasian College of Physicians Position Statement: Routine Adolescent Psychosocial Health Assessment). In addition to these risk factors, the barriers to diabetes and self-management have been identified in research (Harwood, Bunn, Caton, & Simmons, 2013). It has been suggested that as health professionals we need to see through the 'eyes' of the young person with diabetes, as a means of reducing the high rates of youth mortality and improving their wellbeing (Simmons, 2001). The idea of seeing through the 'eyes' of the person is not new, for social workers have been working from a person-centered framework for decades, and relates to the fundamental practice and value of empathy. The person-centered model, while not a new approach, has yet to be mastered across different health sectors. Due to increasing demands on public health services, implementing

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effective person-centered practices can at times be difficult to achieve, but not impossible. Research into diabetes self-management and the health professional's role reinforces and supports a more holistic person-centered approach (Harwood et al., 2013), which endeavors to foster mutual trust and respect between the young person and the health professional.

Sawyer, Drew, Yeo, and Britto (2007) reported increasing evidence that young people with chronic conditions are doubly disadvantaged when they leave pediatric care because they engage in risky behaviors. For a specific condition such as diabetes there is increasing evidence of poorer outcomes for young people who may disengage from health services (Flemming, Carter, & Gillibrand, 2000). There is also evidence that providing appropriate transition services can impact positively on the young person's ability to manage their health and improve specific indicators such as HbA1C levels (Holmes-Walker, Llewellyn, & Farrell, 2007).

It is in response to this growing need for holistic person-centered care coordination of young people with chronic conditions that the new service *Trapeze: a supported leap into adult health* was established. Trapeze is a specialist adolescent chronic care service located in Sydney, Australia, offering comprehensive care coordination services to young people with chronic conditions aged 14–25 years. The service was established in 2012 as a multidisciplinary team and adopts a whole person integrated care approach, keeping the young person at the center of all health care planning. Supporting the young person to make the leap over to adult services, and ensuring the young person remains engaged with these services to prevent complications of their chronic condition, underpins the role of the Trapeze clinicians. The clinical management offered includes telephone and face-to-face support, a HEEADSSS (Home environment, Education and employment, Eating, peer-related Activities, Drugs, Sexuality, Suicide/depression, and Safety from injury and violence) assessment (Klein, Goldenring, & Padelman, 2014), health coaching, telehealth interviewing, and case planning services. The HEEADSSS assessment is a psychosocial interview for adolescents and is used to assess all aspects of a young person's life. In addition, Trapeze uses the innovative eHealth TickIT® platform to engage young people and assess their whole of life issues, as well as collecting baseline clinical data pertaining to transition readiness and wellbeing. Fundamental to this process is keeping the young person at the center of all care planning.

The Trapeze model of care can be implemented globally with local adaptation. In order to do this successfully there needs to be adequate support and commitment at all levels. This includes provision of requisite funding and support of all relevant stakeholders such as pediatric and adult providers in the primary, secondary and tertiary sectors. Investing in the process of transition and focusing on the age-specific needs of young people underpins this model of care. Optimal gains include future financial savings (Holmes-Walker et al., 2007) for both the individual and health care system, and importantly improved wellbeing and health outcomes for the

young person that may be sustained throughout adulthood (World Health Organization, 2014).

The need for comprehensive and flexible coordination is required as best practice in supporting adolescence during transition (Whitehouse, Brodie, & Towns, 2013). Trapeze aims to support young people with type 1 diabetes by focusing on their individual needs and developing a mutually recognized relationship based on trust and respect, so that the young person feels safe enough to discuss some of the challenges they face in self-management, keeping their whole of life issues central to this process. These whole of life issues are often the main concerns for young people as they transition, and no doubt impact on their self-management. Their experiences at school, university, or work; their relationships with their peers and family; their right to privacy and confidentiality; their desires to experiment with alcohol and drugs; and their mental wellbeing, are fundamental to how young people cope and self-manage their medical condition.

The work of Trapeze is best exemplified through the stories of the young people enrolled in the service. For the purposes of confidentiality their names and identity have been changed. It is hoped that through the 'eyes' of these young people and by sharing their stories the approach to self-management and care coordination can be better understood.

Jarod's Story

Jarod is a 16 year old young man with a history of type 1 diabetes diagnosed at 12 years old who was referred to Trapeze for transition support. He used an insulin pump which continuously administers subcutaneous insulin. His pediatric hospital file listed further chronic conditions of celiac disease and migraine. Dieting behavior, emotional issues, diabetes 'burnout' and poor glycemic control had been noted on his final outpatient clinic letter from the children's hospital. Biopsychosocial assessment incorporating the HEEADSSS framework in a face to face interview revealed that Jarod was one of two children of parents who both worked full time. The parental relationship was reported to be strained.

Jarod was approaching the end of his secondary schooling and achieving average academic performance, with good classroom behavior and no school absenteeism. He had strong friendships. Discussion about eating and exercise revealed concerning behaviors with bingeing, skipping meals and omitting use of his insulin pump. Jarod was in a peer group of friends who had also been diagnosed with eating disorders. There were no issues with drugs. He had recently broken up with his girlfriend. He denied depression, self-harm or suicidal ideation, although he reported symptoms of anxiety.

The nurse from Trapeze identified these behaviors using the HEEADSSS assessment tool and concluded that they may be symptomatic of an eating disorder and liaised with Jarod's General Practitioner and his different specialty teams, both in the children and adult hospitals, to coordinate

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