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Healthcare professionals talking:

Are services for young adults with type 1 diabetes fit for purpose?

RUNNING TITLE

Services for young adults with type 1 diabetes

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ABSTRACT

INTRODUCTION

The challenges of becoming a mature adult may distract young adults with type 1 diabetes from disease self-management, increasing risks for premature morbidity and mortality. Despite the importance of young adults with type 1 diabetes engaging with preventative diabetes-related healthcare services, few studies report healthcare professionals' experiences and perceptions of the support that is available, including during the period of transition. This study sought to determine these factors across diverse contexts in one health jurisdiction.

METHODS

This qualitative study was undertaken in New South Wales, Australia. Recruitment was based on a snowball sampling technique, which began with members of an established diabetes service group. Data were collected by individual semi-structured interviews with 16 healthcare professionals, most of whom were Registered Nurses (75%), working at differing levels of expertise and responsibility across metropolitan and regional/rural areas. Data were analysed using thematic analyses.

RESULTS

Participants overwhelmingly recognised the time and care needed to support young adults with type 1 diabetes to prepare them for adult self-management and to work with adult diabetes services, and the importance of youth-friendly services. They reported shortfalls and inequitous distribution in services for these young adults. Two themes, addressing the present and future

possibilities, expressed their perceptions of services for this population: *working with what is available* and *mapping a route to better services*.

CONCLUSION

Findings identify opportunities for development in the planning and provision of specialist multi-disciplinary healthcare support for this population. New ideas are needed for policy and practice innovation and for the infrastructure to facilitate this, to ensure that young adults with type 1 diabetes have access to consistent and coordinated diabetes healthcare services, particularly in non-metropolitan settings.

INTRODUCTION

Type 1 diabetes incidence is increasing world-wide, especially in children and young people aged under 15 years [1]. Detectable chronic complications of childhood-onset type 1 diabetes become evident after only around 12 years disease duration [2], and increasing rates of type 1 diabetes in this young population mean potentially greater numbers developing and progressing complications at earlier ages. The vascular complications that are the outcome of sub-optimal self-management are common amongst young adults with type 1 diabetes [3]. Taken together, these observations indicate increasing numbers of people at risk of premature morbidity and mortality [4].

An important contributor to this situation is the deterioration in glycaemic control that is commonly seen as children move into adolescence and young adulthood [3, 5]. The challenges inherent in this life transition into mature adulthood distract many young adults with type 1 diabetes and limit their ability to effectively self-manage their diabetes. Many become involved in intimate relationships, others focus on career choices; most move away from their parental home, and daily routines often become less structured. Health risk-taking behaviours are common [6, 7]. Perhaps unsurprisingly, young adults with type 1 diabetes have high rates of acute diabetes-related healthcare contacts [5, 8] and uncontrolled blood glucose in the form of hypoglycaemia is the major immediate cause of hospitalisation [9]. Such contacts, mostly through Emergency Department presentations, accrue much larger financial costs to healthcare providers and the community compared to preventive care [10, 11]. Young adults with type 1

diabetes have been shown to self-manage their diabetes better when in regular contact with diabetes healthcare services for disease management and early complication detection, treatment initiation, monitoring and secondary prevention [12]. This is particularly the case during the vulnerable period of transition from paediatric to adult-based diabetes healthcare services. However, it is at this point that many lose contact with services [4, 13-16].

Adolescent and young adult transition from paediatric to adult diabetes healthcare services should occur in a purposeful, structured and collaborative manner [4, 6, 17, 18]. However, as few diabetes services world-wide have evaluated their transition outcomes and even fewer have done so in a rigorous and systematic fashion [6, 12, 14, 19-24], there is little known about how services function in routine practice; inadequacies of transition care models increase the risk of diabetes care disengagement. Surprisingly, few studies report healthcare professionals' experiences and perceptions of the support that is available, including during the period of transition. This study aimed to determine these factors from participants based across diverse contexts in one health jurisdiction of New South Wales (NSW), Australia.

METHODS

Design and Data Collection

This descriptive qualitative study took place within and in partnership with Hunter New England Local Health District (HNELHD), a public health service provider for approximately 875,000 residents across 130,000 km² of NSW, including metropolitan, regional, and rural areas.

During the study period, publicly funded diabetes healthcare services were delivered by HNELHD staff in settings including acute, base and community hospitals, community health centres, outpatient clinics and specialists' rooms. Specialist routine diabetes services for children and adolescents with type 1 diabetes were delivered in the metropolitan centre and at outreach clinics across the region. Routine preventive services for adults with type 1 diabetes were provided through the metropolitan ambulatory care centre and by specialists in a number of regional sites in base hospital ambulatory care, in community and aboriginal health and diabetes centres and in specialists' rooms, in some cases on a 'fly-in fly-out' basis. Outside of the metropolitan centre most adult diabetes services concurrently supported both type 1 and type 2 diabetes patients, with the latter predominating. A dedicated young adult service for type 1 diabetes was available in the metropolitan centre. Separately, a network of general practices provided general practitioner, nursing and allied health services across the region.

Data were collected by individual semi-structured interviews undertaken by an experienced Registered Nurse researcher during October to November 2016. Topics in the interview schedule (Appendix 1) were developed during discussions by research team members, reviewed and piloted with clinicians from another health district. Topics were provided to consenting participants ahead of the interviews. Participants were asked to briefly describe their professional background, workplace setting and geographical location.

Sample

Participants were eligible for the study if they were healthcare professionals (medical, nursing or allied health staff) with current or recent responsibility for providing care for people with type 1 diabetes within HNELHD. Recruitment was based on a snowball sampling technique, as there was no local list of diabetes healthcare professionals. Sampling began with members of an established HNELHD- wide diabetes service group, who were asked to identify eligible healthcare professionals they were aware of, regardless of whether they themselves decided to participate. Recruitment ceased when broad representation was achieved across geographical locations and no further eligible individuals could be identified or recruited. Potential participants were emailed information and consent forms; those returning completed consent forms were telephoned to arrange suitable interview dates. Of 43 persons listed as potential interviewees, access and availability issues posed problems with only three declining to interview.

Procedure

Interviews were conducted face to face in a convenient room at participants' workplaces. Each interview commenced with an introduction and explanation of confidentiality principles. All interviews were audio recorded, and brief field notes collected, during and afterwards; personal preconceptions and biases were addressed through maintenance of a reflective journal. Ethical approval was obtained from HNELHD and University of Newcastle Human Research Ethics Committees.

Data Analyses

Audiotaped interview data and field notes were transcribed verbatim into Microsoft Office Word 2016, deidentified and imported into NVivo 11 software. Data were analysed using Gibbs's [25] framework, which entailed transcription and familiarisation, code building, theme development, and data consolidation and interpretation. Transcripts were read by members of the author group (MH, SJ and LP), the first and second authors' initiated coding and theme organisation, which was developed and discussed with the third author to reach consensus. Multiple investigators for the analysis allowed development of complementary and divergent understandings, and provided a context in which beliefs, values, perspectives, and assumptions could be revealed and contested. Credibility, transferability and confirmability of research findings was established through use of triangulation, thick description and an audit trail, respectively [26].

RESULTS

Interviews were conducted with 16 healthcare professionals. Most were female (n = 12, 75%) and Registered Nurses (n = 12, 75%), working at differing levels of expertise and responsibility. Nine participants (56%) worked predominantly in metropolitan and seven (44%) in regional/rural areas. Interviews lasted a mean (SD) 37.2 (12.3) minutes.

Participants overwhelmingly recognised the time and care needed to support young adults with type 1 diabetes to prepare them for adult life, for independent diabetes self-management and to be effective users of adult diabetes healthcare services. They reported shortfalls and inequitous distribution of services for these young adults. Two themes, addressing the present and future possibilities, expressed their perceptions of services for this population: *working with what is available* and *mapping a route to better services*.

Theme 1: Working with what is available

This theme encompassed a thread of inequity. Participants perceived inequity and inequality in the healthcare professional support available to young adults with type 1 diabetes from a number of perspectives. Firstly, geographical inequity was reported. Participants in regional/rural geographic locations expressed concern that young adults received different types and degrees of support dependent upon whether they were able to attend metropolitan services or were restricted to what was available in their local settings. All young adults with type 1 diabetes were eligible to access the metropolitan publicly-funded services, with a general practice referral, irrespective of where they lived. The service sought to operate as a unitary service area-wide. As one healthcare professional stated:

“They [service provider] are quite unique in the way that they have structured and organised themselves and try and deliver a comprehensive service across metropolitan, regional and rural areas. I think that’s incredibly commendable” (HCP: 1).

However, the barrier was often whether or not the young person was resourced and able to journey to appropriate specialist services, which could be as much as eight or more hours travel each way.

A second source of inequity derived from the differing ways that paediatric services operated. Some paediatric services, with no local young adult services, operated flexible discharge ages, continuing to support young adults through paediatric services into their twenties. Other paediatric services, however, discharged their patients at age eighteen or when they left high school, or earlier if the young person adopted 'adult' lifestyle characteristics such as long-term relationships or becoming pregnant. Outreach of specialist services from the metropolitan paediatric hospital meant that services available through their paediatric services region-wide comprised greater type 1 diabetes specialism and a wider multi-disciplinary mix than most adult diabetes services.

A further inequity in service access resulted in differences in access to and use of diabetes-related technologies such as continuous subcutaneous insulin infusion (insulin pump; CSII) therapy and continuous glucose monitoring (CGM). Both technologies require support from specialist staff to initiate and to use them to optimise glucose control. Initiation of insulin pump therapy requires a relatively brief period of intensive input and education to individualise insulin delivery algorithms and ensure the young people are able to manage the technology effectively. However, access to long-term specialist support is also required. Such expertise was scarce in non-metropolitan adult diabetes services. Some participants, employed in environments

where they perceived inequity to have been sustained over many years with little change, almost conceded that this was only to be expected as part of non-metropolitan living.

Specialised diabetes healthcare support was provided by members of healthcare professional teams from metropolitan areas to some regional/rural settings, either in person or using telehealth. As a communication technology, telehealth was viewed by participants both positively and negatively. Participants in regional settings were thankful for any specialist input, and telehealth enabled this where there was otherwise none; however, this form of support was only sporadically available, and many saw it as inadequate or only workable as an adjuvant rather than sole communication medium. A major difficulty raised both with outreach teams and telehealth consultations, predominantly by participants working in regional/rural settings, was that if problems were encountered between outreach visits/telehealth contacts, young adults had to manage with whatever generalist care was available locally. Unless young adults were willing and able to travel to metropolitan or regional centres, access to publicly-funded specialist diabetes healthcare could be difficult or unavailable. In regional and, particularly, rural areas there was also limited access to private diabetes practitioners, with endocrinologists particularly scarce. In such circumstances there was considerable reliance upon general practitioner (family) physicians (GPs).

Regardless of setting, participants expressed the importance of young adults with type 1 diabetes having support mechanisms outside of the specialised diabetes healthcare team. GPs were considered by participants to be especially important, particularly for day to day general

healthcare and encouraging the patient's independence of family members. This might include, for example, taking responsibility for their medication by requesting prescriptions and the booking of consultation follow-up appointments. However, participants did not view GPs as specialists in the care of young adults with type 1 diabetes, especially in relation to use of CSII.

Highlighting the inadequacy of this model of care, one regional interviewee stated:

".... the majority of their [General Practitioner] caseload is older people with diabetes where it's so much about complications management. Their lifestyle advice that they're used to giving is not lifestyle advice that suits a teen or young adult lifestyle." (HCP:1)

Family members were perceived as instrumental in ensuring patients' attendance at diabetes-preventative care appointments and were pivotal in providing the support needed to assist/encourage development of diabetes-related self-care skills and achieve positive health outcomes. However, this support was not always available, especially in situations of family breakdown. Participants, particularly in metropolitan settings, also perceived that the involvement of families could, at times, be detrimental to young-adults with type 1 diabetes, inhibiting the development of essential diabetes-related self-care skills. When the time came to transition patients from paediatric to adult-based diabetes healthcare services, the parents were sometimes reported as unready for this, and occasionally described as 'floundering' when their 'child' moved on or away from the family home.

Theme 2: Mapping a route to better services

The second theme addressed both the potential and their vision for diabetes services. Opportunities to optimise services were frequently flagged by identifying what should change in current provision.

The metropolitan centre had a dedicated adolescent and young adult type 1 diabetes service with access to a range of healthcare professionals. It was largely well-regarded by participants. In some respects, this service operated as a 'one-stop shop' where young adults could have all their diabetes care needs catered for in one visit. Despite the sometimes stark comparison between this model and what was available to young adults with type 1 diabetes locally, participants in regional/rural settings regarded this service model positively. They recognised that this model benefitted those who could attend by its youth-focus, and, for young adults able to travel, reduced the time required and made it easier for local clinicians and administrative staff to organise multi-disciplinary appointments for them.

They reported a number of key components of this service, including its location, which favoured ease of access and parking, which were identified as important to promote attendance. The appointment of a transition coordinator was widely regarded as an important contributor to the success of the service. This position was viewed as an important link, bridging the gap between adult and paediatric diabetes healthcare services. Participants highlighted a desire for improved collaboration and communication between paediatric and some adult-based diabetes healthcare services when considering transition preparation and processes, including the sharing of medical records, especially for other specialist or off-site services such as mental health. A

transition coordination position could not eradicate but could improve cross-service transition problems.

Only in the main metropolitan setting was a transition process described as a regular part of practice. Referrals to the transition coordinator were increasing and becoming increasingly common, although the process for this was described as unclear, with confusion amongst some healthcare professionals. In regional and most rural areas, transition was viewed as problematic and was largely perceived as a 'transfer' rather than 'transition' process. Young adults with type 1 diabetes would commonly leave paediatric and access adult diabetes services in consecutive appointments, with little or no preparation for the change. Many of such adult diabetes service appointments were described as neither age-appropriate nor geographically close to young adults' place of residence; many were delivered by healthcare professionals described as not youth-friendly. Regional and rural participants expressed disapproval of this and saw these features as essential for effective care.

Another opportunity for improvement concerned clinic scheduling. Clinics were frequently scheduled on days and times perceived by staff as unsuitable for patients; participants expressed frustration, believing this contributed to young adults becoming lost to diabetes-related healthcare. A general perception that clinics were under-utilised meant they were deliberately overbooked to maximise use of available time but this could result in crowded waiting rooms and long wait times, and be counter-productive.

All participants wanted to provide holistic care and were concerned not to focus solely on glycaemic control. In regional and rural areas, diabetes services were reported as predominantly generic and consequently tended to cater predominantly to the majority target population of older adults with type 2 diabetes, and to focus on glycaemic control to prevent development of complications. This was not seen as an appropriate or effective approach for young adults.

Even in metropolitan settings most services were not age-specific, and even where such services were available, other patients, including those of older age or with other forms of diabetes, such as cystic fibrosis-related diabetes, were often allocated appointments, to expedite referrals or make use of the multi-disciplinary support available through these clinics. Where young people were engaged and happy with their diabetes service some participants were reluctant to refer patients on or to discharge them from youth-friendly paediatric or young adult services. As a result, clinics designed to support children, adolescents or young adults were managing ever-wider age groups of patients. Whilst this maintained specialist support for some, this practice was regarded as unsuitable considering the differences in levels of maturity. It also eroded the age-specific specialist diabetes healthcare available to young adults with type 1 diabetes. Many participants wanted young people with type 1 diabetes to have tighter age-targeted healthcare. They felt this would facilitate development of diabetes-related self-care skills, helping young people meet the particular barriers and challenges of their age, such as driving, using Medicare (the Australian public health system), schoolies (an Australian tradition

of high-school graduates holidaying following their final exams), university and employment, alcohol and illicit drug use. Smaller, more similar-aged clinics were seen as more beneficial.

“I think if you really want to target young people with type 1 diabetes, you don’t say that an 18-year-old is the same as a 30-year-old. I think they need separate group sessions where you can target the different age ranges or different developmental stages”

(HCP:6)

Further, over-crowded clinic lists could delay the first appointment for new clinic referrals. Participants recognised that the first appointment in adult or young adult services should occur in good time post discharge from paediatric services. However, this initial appointment provided to young adults with type 1 diabetes, particularly in metropolitan settings, was frequently delayed. Some participants expressed concern that new clinic referrals were often not triaged as priorities, with patients commonly experiencing lengthy delays to first appointment, despite reports that clinics had substantial ‘fail to attend’ rates:

“We’re having issues at the moment of getting the kids in. So, for one of the kids, the adults (clinic) got the referral in January. It was triaged four days later, and the kid did not get his first appointment till October.” (HCP:4)

A final characteristic discussed as essential to the success of services was staff stability. Medical staff, particularly, were viewed as rotating too frequently, which was seen as detrimental to the development of trusting and enduring relationships. Senior nursing roles, by comparison,

were often long-held with many having relationships with patients extending over many years or even decades, and to several generations of families.

Participants recognised the importance of making use of opportunities to change and improve the diabetes-related healthcare on offer to young adults with type 1 diabetes.

Participants believed that increased financial costs from improved healthcare support for young adults at this pivotal life stage of life would be recouped through reduction in diabetes-related hospital presentations and admissions. Regardless of setting, care provided was often thought of as predominantly crisis management.

“... in all honesty, it feels a bit like we just move from crisis to crisis with people and we’re not given the time to prepare people properly. I mean, I think we do well and I think we do good education, but I just think we’re lacking the time to put into preparation and prevention.” (HCP:9)

Participants wanted to make this a priority, for funding and staffing to improve the multi-disciplinary support available from team members such as endocrinologists and social workers. They felt that having healthcare professional support solely dedicated to CSII would meet the specialist technology support needs that were a particular deficit. They also wanted diabetes educators employed to run a telephone advice line outside of office hours. Highlighting commitment to patient care, some participants reported going above and beyond their work requirements by giving out their personal phone numbers to patients and immediate families, although their criteria to do this were unclear.

“We used to be on call and the powers that be, as in the hospital hierarchy, cut all that. They said it was cost saving, and that didn’t sit well with me because when I look back through my notes and saw how many that would ring during the night or of an evening because they weren’t sure how much [insulin] to give. They now have to ring the helpline which just says take them straight to hospital. So, they are paying now for at least a hospital bed for several hours if not overnight, instead of paying one of us a small amount just to be on call” (HCP: 2)

Despite their service development suggestions, participants acknowledged that some adolescents and young adults with type 1 diabetes, such as those with mental health, social and/or legal problems, were very hard to engage or simply chose not to access adult-based diabetes healthcare services. Participants saw no option but to accept this.

DISCUSSION

Our research provides important insights into healthcare professional experiences and perceptions of diabetes-related services available to young adults with type 1 diabetes across a large Australian geographical area. It surfaces contemporary practice issues and lays out a platform for service innovation and research of relevance to many public health service providers worldwide.

Young adults were perceived by participants to have inequitable access to specialist type 1 diabetes healthcare, with concerns raised that young adults could get different types and quality

of adult-based support dependent upon whether they were able to attend metropolitan services, or were restricted to what was available in their local settings. This inequity is reflected elsewhere [13, 27, 28]. Many diabetes services were described as not age-appropriate, ineffective at development of diabetes-related self-care skills, or delivered by healthcare professionals who were described as not youth-friendly. However, the metropolitan centre, which operated a well-regarded dedicated adolescent and young adult type 1 diabetes service with access to a wide range of healthcare professionals, was clearly an example of what can be achieved. The benefits of having a transition coordinator and a model of care where young adults have all their diabetes care needs catered for in one visit has been widely documented [29, 30].

International recognition of the specific and unique needs of the adolescent and young adult age group is increasing [31]. The transition period from paediatric to adult-based healthcare systems has been flagged as in need of particular attention [4, 31, 32]. Lack of attention to this age group undermines the work of paediatric services and findings add to the growing body of evidence describing shortfalls in healthcare professional support for this population [13, 27, 28, 33]. Participants highlighted the need to prioritise funding and staffing for the care of young adults to ensure their access to this support. They voiced the need for healthcare appropriate to this age group. This study extends current understanding by identifying opportunities for change at many levels of the health care system to facilitate improved access for young adults to ongoing healthcare professional support for type 1 diabetes disease management, complication detection, treatment initiation, monitoring and secondary prevention.

Participants also voiced the need for diabetes healthcare professionals solely dedicated to CSII. This is consistent with the expressed desire of many other healthcare professionals, for improved and perhaps dedicated services for CSII users; encouraging growth of a structured team approach, enabling more consistent patient follow-up and perhaps better patient outcomes from use of this common diabetes-related technology [34]. Differing types and degrees of support, dependent upon whether young adults were able to travel or were restricted to what was available locally, resulted in differences in access to and use of diabetes-related technologies. With the majority (70%) of CSII users in Australia situated in major cities [35], the availability and range of appropriate CSII expertise was perceived to exert a pervasive effect, including determination of whether CSII use was initiated or even raised as an option with a patient [27]. Collectively this indicated scope to improve the access and support available for young adults with type 1 diabetes around use of diabetes-related technologies. Given that CSII have been reported to deliver benefits for users [36], health economic data could demonstrate not only the cost-benefit of such services but also the costs of failing to support adolescents and young adults in use of diabetes-related technologies.

Other opportunities included employing diabetes educators to work via telephone on-call outside of office hours. Access to diabetes healthcare professionals outside of hours could support patients using all forms of insulin delivery, providing timely assistance and determining the requirement for (and potentially preventing if unnecessary) hospital presentations. With after-hours mobile phone support for young adults with type 1 diabetes associated with reduced

progression of ketosis to diabetic ketoacidosis [37], such services could be cost-neutral. Across Australia, after hours CSII and CGM support is routinely available from pump manufacturers, although concerns have been raised by diabetes educators at calls being diverted to agents in other countries and the sometimes “textbook” advice provided [34]. Non-type 1 diabetes specific after-hours telephone health support services are also routinely available [38, 39], but are not necessarily able to provide appropriate support.

There is a need to better understand how e-technologies can be utilised in diabetes-related healthcare. Integration of healthcare records across services on a system-wide mandatory rather than voluntary basis would facilitate communication [27]. Consideration could be given to increasing capacity and willingness to use communication technologies, particularly video-conferencing. Video-conferencing can include personal communication software such as Skype™ [34, 40] which can be utilised at relatively low cost. The Royal Australian College of General Practitioners has advised there is no clear evidence to suggest that Skype™ is unsuitable for clinical use [41]. Increased capacity to use video-conferencing could facilitate more responsive and targeted care, and support professional development and peer support amongst diabetes healthcare professionals. Young people with type 1 diabetes are reported to have re-engaged with specialist diabetes healthcare through use of this technology [42]. However, video-conferencing does rely upon having adequate internet network coverage, reported in some non-metropolitan areas as erratic [34].

Criteria for access to subsidised diabetes-related supplies as part of the National Diabetes Services Scheme could be reviewed. Currently, registration requires initial healthcare professional input, but there are no in-built inducements or facilitators to promote regular engagement of young adults with type 1 diabetes with diabetes health-care teams. Young adults can obtain subsidised diabetes-related supplies without contact with a diabetes healthcare team. Perhaps engagement with diabetes healthcare services could be promoted if equipment subsidies were conditional on this. Financial incentives for healthcare professionals could also be considered, although their influence on outcomes have not been demonstrated [43-45].

There are some limitations with our findings. Firstly, the use of snowball sampling may have generated sampling bias, and recruitment methods employed depended on self-selection. Findings also derived from healthcare professionals employed by a single public healthcare provider, at a single point in time. However, our sample comprised a large proportion of healthcare providers covering a very large geographical area.

In summary, young adults with type 1 diabetes are a high-risk group. Findings add to the growing body of evidence world-wide indicating deficiencies in services for this age group, and shortfalls in the planning and provision of specialist multi-disciplinary healthcare professional support for this population. There is a need for policy and practice innovation, and the infrastructure to facilitate this, to ensure that young adults with type 1 diabetes have access to

consistent and coordinated diabetes healthcare services, particularly in non-metropolitan settings. Wider capacity to use technology, particularly in the form of videoconferencing, and review of resource allocation may be necessary. Unless change is made, many young adults with type 1 diabetes will continue to develop, progress and require healthcare for complications that are the avoidable outcomes of sub-optimal disease self-management.

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CONFLICTS OF INTEREST

None.

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APPENDIX

Appendix 1: Interview schedule

Can you tell me what services are provided locally for adolescents and young people with type 1 diabetes?

What do you think about the way they work? Do they work well? Do young people attend?

Are there any/ many people who choose not to attend? What support is available to them?

Are there any specific things that happen to help prepare these young people for adult life with diabetes? Can you tell me about this?

What do you think about the way they work? Do they work well? Do young people make use of them?

What would you like to see happen next for diabetes services for young people? If there was an opportunity, what do you think it would take to make things work better?