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**Services doing the best they can: service experiences of young adults with type 1 diabetes mellitus in rural Australia**

Running title: Experiences of rural young adults with diabetes

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## **Abstract**

**Aims and Objectives:** To describe the healthcare experiences of young adults with type 1 diabetes who access diabetes services in rural areas of New South Wales, Australia.

**Background:** The incidence of Type 1 diabetes in childhood and adolescence is increasing world-wide; internationally difficulties are encountered in supporting young people during their transition from children to adulthood. Consumers' experiences and views will be essential to inform service redesign.

**Design:** This was a qualitative exploratory study.

**Methods:** Semi-structured telephone interviews were conducted with 26 people aged 18-28 years living rurally, recruited through staff in four regional healthcare centres in 2008.

**Results:** Two key themes were evident: lack of access (comprised of transfer to adult services, access to health professionals, access to up to date information), and age appropriate provision. The impact of place of residence and personal motivation crossed all themes. Participants contrasted unfavourably the seamless care and support received from paediatric outreach services with the shortages in specialist and general practice-based care and information, and practical problems of service fragmentation and lack of coordination experienced

as adults. They identified a range of issues including need for ongoing education, age appropriate services, and support networks related to developing their ability to self manage. They valued personal service; online and electronic support was seldom volunteered as an alternative.

**Conclusion:** This was a first view of rural young people's experiences with adult diabetes services. Reported experiences were in line with previous reports from other settings in that they did not perceive services in this rural area of Australia as meeting their needs; suggestions for service redesign differed.

**Relevance to clinical practice:** New models of age-appropriate service provision are required, to meet their needs for personal as well as other forms of support, whilst acknowledging the very real resource limitations of these locations.

**Key words**

Diabetes, consumers, qualitative study, adolescents, transitional care, health services research

## Introduction

Type 1 diabetes represents a global health challenge, with prevalence in those under 14 years increasing worldwide (Green 2008). Australia has one of the highest rates in children with the incidence in those aged under 15 increasing from 19.1 per 100,000 in 2000 to 23.9 per 100,000 in 2008 (AIHW 2010). Good glycaemic control can be achieved to avoid adverse outcomes (DCCT 1993) - but often this is not the case (Bryden *et al.* 2003; NHS Information Centre 2011).

In rural Australia, most children and adolescents with type 1 diabetes have access to well resourced paediatric outreach programs from tertiary metropolitan hospitals, and local support from community health services and resident paediatricians. This level of support ends at around age 18 when they are transferred to adult services for ongoing care. In common with other countries (NHS Information Centre 2011) there are substantial variations in services available in different geographical areas, but service shortfalls are reported in most regions (NRTC 2007) and adult services are very differently configured and resourced, with a focus on self-management and adherence to management regimens to minimise risks of long term complications (Vinsentin *et al.* 2006). Service users are expected to be knowledgeable and mature enough to manage their own diabetes and to interact with a mix of health providers including specialists, primary care physicians (PCPs, or General Practitioners), community health, pathology and hospitals. Shortage of adult services for type 1 diabetes has been identified (NRTC 2007), with reduced support and 'visibility' particularly

for young adults (Lundin *et al.* 2008). Infrequent planned use of adult services by young adults has been reported, often associated with poor diabetic control and increased use of acute services for crisis management (Fleming *et al.* 2002; Kipps *et al.* 2002; Lam *et al.* 2005; Perry *et al.* 2010; Hatherly *et al.* 2011). In response, structured transition programs have been developed in metropolitan areas, which recognise the multifaceted needs of emerging adults (Weissberg-Benchell *et al.* 2007; Holmes-Walker *et al.* 2007). However, little information is available about services or the experiences of service users in regional and rural areas. This study aimed to explore the experiences of young adults with type 1 diabetes (T1DM) accessing adult diabetes services in four rural locations within New South Wales (NSW), Australia.

## **Methods**

### **Setting and participants:**

Hunter New England Health (HNEH) provides publicly funded hospital and ambulatory care to 840,000 people in a geographic area the size of England across northern NSW. In 2008 it served one metropolitan, fourteen designated regional centres (with specialist diabetes services), and many small rural and remote communities. In rural areas most adult diabetes care is provided by PCPs and generalist hospital and community staff, with limited access to other professionals (NDSS 2006; HNEH 2008).

Young adults with T1DM living in HNEH, aged 18 to 28 years and at least 12 months post discharge from paediatric diabetes services were recruited through a convenience sample of four regional community health centres (Table 1). Initial invitations were posted from Diabetes Nurse Educators (DNEs) to all eligible young adults identified on local records and registers. A second invitation, with an 'opt out' letter, was posted to those who had not responded after two weeks. DNEs then provided researchers with the last known phone contact details for eligible participants who had not responded to postal invitations. The researcher telephoned and, where participants had not received an information and consent form, these were posted and a follow-up phone call made. Where no response was received either to postal or telephone invitation, information was sent to the last known address of the parents. Posters were distributed to 54 pharmacies in 25 towns and to a regional university; project information was published in two local newspapers (Figure 1).

### **Data collection**

A semi structured telephone interview schedule was developed by the research team and piloted with the young service user team member. Telephone interviews were chosen as participants were 2-7 hours travel time distant from the research base. The schedule comprised a combination of validated scales to explore aspects of participants' life experience in relation to their diabetes (not reported here), and a series of open questions and probes exploring their experiences and perspectives of adult diabetes services, and what they

perceived an 'ideal' service might comprise. Participants were asked to estimate their satisfaction with the services they received during their last year with paediatric services, and the most recent year with adult services on a scale of 0-100. Interviews lasted 35 - 60 minutes and were conducted by one researcher (JD) in 2008. Participants consented to audio taping of interviews, using a speakerphone, Olympus digital recorder and external microphone. Recruitment continued until data saturation.

### **Data analysis**

Qualitative data from the open questions in the interviews were transcribed verbatim and analysed by one researcher (JD). Framework Analysis was chosen, as this is suitable for analysis of data collected from specifically-focused rather than inductive research questions (Ritchie & Spencer 2002). It entails a systematic process of sifting, charting and sorting material according to key issues and themes, using a 5-stage approach. These include rereading transcripts for familiarisation with data; setting up a thematic framework addressing the original research questions; indexing data according to that framework; rearranging the data into a series of thematic charts, and mapping and interpreting the data to address the key objectives of the qualitative analysis.

Rigor was ensured by member checking of transcripts by 58% and circulation of summary findings to 100% of participants. An audit trail was maintained during data collection and analysis. An initial sample of transcripts was coded

independently by a second researcher (LP), and emerging themes discussed and agreed. Subsequent analyses were jointly reviewed and agreed.

### **Ethical issues**

The study was approved by health services and university Research Ethics Committees.

## **Results**

### **Participants**

Twenty six young adults were interviewed (Table 2). Since accessing adult services nine participants had a planned diabetes service contact once per year or less, ten had a maximum of two contacts per year and seven contacted diabetes services quarterly. Since transferring to adult services 13 had experienced at least one unplanned admission to hospital and 11 had accessed a hospital Emergency Department, for diabetes-related causes.

Participants were significantly less satisfied with adult than paediatric services, with mean (SD) ratings of 63.9 (27.8) compared to 85.2 (13.9) ( $F=545.523$ ,  $p<0.001$ ). Their experiences were expressed through two main themes ('lack of access' and 'age-appropriate services'), with the impacts of place of residence and personal motivation cutting across them.

### **Lack of access**

### *Leaving paediatric services*

Participants had positive memories of outreach paediatric clinics, describing them as thorough, friendly, professional, substantial, supportive and reassuring. There was a strong focus on family and self, on education and access to information, and there was a feeling that these clinics met participants' needs.

*'In children's... once every four months you'd get all the specialists come up from [city] hospital, which was really good. And you'd go along and they'd do your HbA1c and they would talk to you about it and you know, you felt like they were ... at the top of the field kind of thing. But once you turn eighteen ... all that kind of stuff, it's like it just stops'. (male, 27 years)*

Most participants reported having been told they were no longer eligible to attend paediatric services when they turned 18 years of age, or earlier.

*'I didn't really have a choice from moving on because as soon as I turned eighteen, like they said they couldn't see me anymore' (male, 20 years)*

Loss of eligibility and access to paediatric services occurred abruptly for these participants, who did not report any sense of preparation for this event. Neither did they report being connected with local adult services in any meaningful way in advance of this. In some cases, they could not recall receiving any information about local adult diabetes services. Only three participants spoke of seeking referrals and advice about what to do next.

*'They just sort of cut you off' (female, 27 years)*

Transfer often coincided with moving to a new location, for work or study. Those transferring to major cities had the benefit of access to more comprehensive services. Others relied on finding a suitable PCP to provide or coordinate their care, and refer them to a specialist endocrinologist. This often entailed travel to other locations.

*'I went to the, like the local GP and he suggested that, I think there's a service in [town] that I can go to and seek assistance, like an educator. But I haven't been there yet'* (female, 21 years)

Engagement with adult publicly-funded diabetes services was often hampered by difficulties in finding basic information, such as location, opening hours, and services offered. Participants attended adult services less regularly than they had attended paediatric services, and often contact was made when things were not going well, rather than on a regular basis. In one centre participants had the option of being on a diabetes register with an annual recall system, run by the local Division of General Practice. Those who were part of this system were enthusiastic. Participants in other locations thought regular reminders would be useful.

#### *Access to health professionals*

Adult service contacts were not like these young people's experiences of contacts with paediatric services. They reported appointments as harder to get,

often with a lengthy waiting period; consultations were shorter, and at inflexible times, making access problematic, particularly for those in the workforce on fixed hours. Appointments were perceived as less personal.

*'It seems a lot more like a general doctor's visit now days, which makes it, you know it's harder to get in to see them'* (female, 27 years)

Access difficulties related to lack of services, inflexible or difficult access and cost, as paediatric services were covered by government scheduled fees. The majority of comments on workforce shortage related to specialist clinicians, particularly endocrinologists. Lack of specialists both compromised access and restricted choice. Access to an endocrinologist depended on where participants lived, or their willingness or capacity to travel. Several participants spoke of accessing visiting specialists, but had not done so. The majority of participants did not travel to major cities regularly, if at all, and relied on local services.

Participants were much more reliant on their PCP, but access to PCPs was also problematic in many towns, particularly at short notice, and there was regular staff turnover in some locations.

While appointment times were limited, individual clinicians would often go out of their way to accommodate the needs of young adults. Where local health practitioners were supportive and knowledgeable, this was appreciated.

*'...basically if my GP didn't communicate to me that these are the people and this is how you go about it, then ... I wouldn't have a clue what to do really'* (male, 25 years)

*'I think having the educator there ... someone who can help you with it because doctors aren't always available for that kind of thing and you know at eighteen you're not always ready to just start playing with it all by yourself'* (female, 22 years)

#### *Accessing up to date clinical information*

Specialists were seen as the most credible source of up to date clinical information about diabetes, and a number of participants with limited access to specialists felt they were missing out, even though they acknowledged other sources of information. Accessing health professionals via the telephone or internet was mentioned infrequently. Those who did mention ringing community health for information had found staff helpful, but saw this as inferior to personal contact. Some felt that although this was a lesser option, it was good enough. Others did not see this as an option, and would ring only if the matter was urgent to them. Not all participants had access to the internet at home (14 of 20 who were asked had access), and only two reported using the internet as a resource for information, education or support.

Three participants had insulin pumps; three others mentioned them, but didn't know how to obtain one. One young person was actively seeking to get a pump, but had no idea who would provide support in starting and using it.

*'I'd like to have more specialists so that in the country you can get more of the newer things that come out. ... it would be good to be able to go to a specialist and talk about the options that are, like insulin pumps and all that kind of stuff, but it's just really not an option here'* (male, 27 years)

### **Age-appropriate services**

Participants reported feeling out of place with local diabetes services that primarily served older people with type 2 diabetes, and were consequently focused around their needs. They felt the lack of input appropriate to their life style and life stage.

*'Someone who can understand the fact that at twenty one you're not going to live the lifestyle of a seventy year old and be completely regimented, and is willing to kind of give and take'* (female, 22 years).

Participants reported feeling valued in paediatric clinics. They also reported feeling they were not necessarily ready to take on the responsibility of self-management at the point where this was required by their transfer to adult services. They regretted their loss of connection with their established health care providers. It was important to participants to have access to health care professionals they felt comfortable and connected to, and once their eligibility to paediatric services was withdrawn they felt it was often a matter of luck as to whether this occurred.

*'The biggest problem that I found was that physicians generally dealt with people with type 2 diabetes so their understanding of type 1 diabetes was very limited ... I had people wanting me to live a life I couldn't or wouldn't do' (female, 22 years).*

At the extreme, participants could experience this mismatch between their needs and the way services were managed as emotionally confronting.

*'I personally don't find [adult diabetes clinics] that useful ... it's really horrible to sit there and watch all the complications they have and what they're going through. For me, who's only twenty six, like that's quite a big jump in age difference. There was no one my age there. It was all elderly people and it was always late. .... there doesn't seem to be anything catering for my age group. '* (female, 26 years)

Participants past their teenage years were aware of the life-stage issues they had encountered in their teens, and recognised that, whilst the services may not have met their needs, they also might not have been responsive patients.

*'Teenage horror years... I was awful. I'll admit it' (female, 23 years)*

With age and greater maturity, some found local services which they reported being comfortable with. However, the commoner perception was that adult service delivery was not well matched to the needs of their age group.

*Fragmentation and lack of coordination*

Participants commented on the lack of structure of the adult compared with paediatric services. Withdrawal of regular, readily accessible endocrinologist consultations, the subsequent need for multiple referrals to get routine care, and the increased reliance on primary care were sources of regret. Rather than regular appointments being provided, they were expected to be proactive in seeking care; only a minority of participants did this for routine care. Even when they did, participants reported that not all PCPs provided comprehensive or coordinated clinical care.

In place of a regular 'one stop shop' paediatric clinic, participants found themselves interacting separately with a mix of public health and private services. They were thrust into the role of 'project manager' of their healthcare, with no prior training for the role and variable family and professional support. One centre offered adult diabetes clinics attended by DNEs, a dietitian, a general physician and an ophthalmologist, but these were very poorly attended by these young adults with type 1 diabetes because of restrictive clinic dates and times, long waits and absence of other young adults. The majority attending these clinics were older people with type 2 diabetes mellitus. Attendance could entail long travel times, appointment times that were reported as inflexible and difficult to accommodate within lifestyles. Clinics often over-ran entailing long waits to see staff.

*'I'm good with my diabetes but I don't like sitting in a room for four hours waiting for a doctor, going in and seeing him for five minutes and then leaving. There's not really any point turning up' (female, 23 yrs).*

Nonetheless, participants appreciated the limited support that was available.

*'They do the best they can do with what they've got and how they've got to do it'*

(male, 24 years).

### **Suggestions for service redesign**

Asked how services could be configured to meet their needs, participants thought primarily in terms of how adult services could be more like those they had experienced and valued as children. A number of key issues were identified.

#### *Education:*

Participants had ongoing education and support needs as young adults. They recognised that their needs had changed as they assumed responsibility for their diabetes care. However, they felt their opportunities for education and support had reduced at the time when they needed them most. Whilst paediatric clinics had a strong emphasis on education, participants felt they had not necessarily been as receptive, or learnt as much, as they later found they needed to know. Then, at this later stage, education was not so easy to access.

*'There doesn't sort of seem to be a lot of help ... for the people who are my age, which is probably, in my eyes, which is where you need to be starting to really educate 'cause it's now that I'm really listening, (laughs) 'cause as a teenager they tell you lots of things that if you're in that state of mind where you don't take*

*it on board. Whereas now, I take a lot more on board so it's (laughs) probably more helpful now'* (female, 26 years)

*'I know when you're a bit younger you don't really listen, but as you get older they [can] probably give you a better understanding about what is better to eat and what's not so good to eat'* (male, 24 years)

### *Social and peer support*

These young people were geographically dispersed. They had difficulty finding social support networks, and often did not know other young people with type 1 diabetes. They felt isolated, acutely aware of their difference with an experience they could not share.

*'Diabetic educators and doctors and that, they would say 'I know how you're feeling' - and they've got no idea. They haven't got diabetes. Somebody who knows actually how I'm feeling would help a lot'* (female, 27 years).

They identified a lack of peer support or any specific social support networks bar any family members with type 1 diabetes.

*'A group would be useful. ... It's just the main thing of having someone that knows what I am going through to talk to'* (female, 27 years).

One participant had experienced an 'adult' Diabetes Australia camp, as well as children's camps, and had found these beneficial.

*‘Just getting together with other people my own age that have diabetes, and seeing how they deal with it and having a gathering where you can get information and still have a good time. ... partners as well ... so that they could also learn more about managing it’ (female, 22 years).*

## **Discussion**

This was a relatively small sample of young rural adults with type 1 diabetes, and it is difficult to gauge how typical their experience was, although the key themes reported were consistent across the group. Comparing relevant statistics of registrants on the National Diabetes Services Scheme (NDSS) (Diabetes Australia 2008), invitations to participate in the research were estimated to have been sent to around 60% of young people with type 1 diabetes living in the areas and meeting eligibility criteria. Shortfalls between the numbers of young people able to be accessed through healthcare professionals and NDSS estimates may have been due to out-dated contact details (only one third were still resident where their details were registered: Table 2), young people accessing care outside the area or living locally but not accessing care. These are likely to have contributed to the low response rate of 23%. It is notable how few responded to postal invitations with most recruited through mobile phone contacts (Figure 1). This reinforces that this age group are not easy to access, with young adults in rural communities, particularly, likely to move for work and tertiary study. Other limitations for the work include the possibility of biased sampling and social desirability-driven responses. First contact came from local healthcare

professionals, and this may have deterred response from a group ultimately dependent on healthcare services, particularly if their experience was negative. However, the research team were mindful of the possible disadvantages of chosen methods, were at pains to stress their independence from local services, to standardise questions but use individual prompts, not to steer interviews but maximise response. Participants' responses contained both negative and positive perspectives of services and did not present an obvious bias toward either extreme.

The notions of access and equity are synonymous with public health care systems but are not easy to apply, particularly in rural areas where resources are spread across sparsely populated areas and where it is often difficult to recruit and retain qualified health care professionals (Pong & Russell 2003; Asthana & Halliday 2004). Consequently many rural communities experience less choice, and lower levels of service than their urban counterparts and users incur significant costs when travelling long distances to access health facilities. Findings are consistent with data from Canada (Pong & Russell 2003), the USA (Dussault & Franceschini 2006; Mulvaney *et al* 2011), the UK (Asthana & Halliday 2004) and two Australia-wide studies (NRTC 2007; Dept of Health and Ageing 2008). Using qualitative, in depth techniques we identified further issues, including need for greater psychosocial support, the importance of strong support networks, and a desire to be better informed as important issues for young adults with type 1 diabetes.

Holmes-Walker et al (2007) demonstrated that if young adults with type 1 diabetes can transition to a young person's service with additional support, flexible appointments and appointment reminders, clinic attendance is maintained, diabetes control is improved and hospital admission rates with diabetic keto-acidosis are reduced. In Canada, a transition service focused on guiding rural young people with type 1 diabetes from paediatric to adult services has been developed, based on a systematic process of referral, tracking and monitoring to encourage appropriate service usage (Van Walleggem *et al.* 2006). It also incorporates educational and peer support programs, and has demonstrated enhanced continued engagement of young people with health care services. Geographical and population similarities between Canada and Australia, and the needs identified in this study, indicate that a similar system might be effective in Australia.

Whilst transition programs have been developed in metropolitan NSW over the last five years (Holmes-Walker *et al.* 2007; Steinbeck *et al.* 2007), there was no sense of preparation for transition in the findings from these rural areas. None of these rural young adults reported preparation for the move to adult services or gave any indication that they had a good understanding of the adult services available to them. Paediatric outreach services may not see this preparation as part of their brief or may not be aware of local adult services. Whilst participants spoke highly of individual practitioners, services overall appeared to fall short of what participants felt they needed. Most of these young adults accessed adult

services less regularly than they had paediatric services. The lack of cohesion of adult services presented challenges, particularly for those in employment with rigid working conditions, as has also been reported from non-rural studies (Lundin *et al.* 2008; Scott *et al.* 2005).

Online resources have been suggested, such as email buddy programs, podcasts and webcasts (Scott *et al.* 2005), but participants in our study were more interested in local support programs delivered in person or possibly via the internet; there was limited motivation for proactive service usage. Allen and Gregory (2009) reframed transition to ask how best to meet the needs of young people with diabetes at this stage of the life course: when asked what type of diabetes service they would like, these young adults talked in terms of current service models and did not nominate any different approaches. Service limitations were recognised, but no alternatives suggested. As in the study of Scott *et al.* (2005) they wanted their time to be treated as valuable, reflecting their active lives, and endocrinologists and dietitians topped the list of health care professions for whom they sought but missed access, reflecting those providers generally least available in rural areas.

## **CONCLUSION and RELEVANCE TO CLINICAL PRACTICE**

This study gave a voice to young adults managing type 1 diabetes in rural areas of NSW, Australia. These young people form a small group amongst a much larger population of older people with type 2 diabetes. Our findings highlight the continuing lack of resources for services for them, to support effective transition

from paediatric care and establishment of effective adult self-management which has been shown to reduce complications (DCCT 1993). Beyond inequity of services, the message of this study is the need to find new approaches to match service development to local needs and preferences. Contrary to some reports (NRTC 2007) and assumptions, members of the 'Facebook' generation may value personal healthcare delivery and may not volunteer online or electronic service delivery as preferred options. The ongoing challenge is how to reconcile inadequate rural resources and the need to provide age-appropriate, flexible, coordinated and responsive specialist and peer support.

Declaration of Competing Interests: Nothing to declare

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#### *Author contributions:*

LP designed and managed the project, co-analysed the data, drafted and revised the manuscript.

JL designed the proposal, supervised the project, and revised the manuscript.

KS designed the proposal, supervised the project, and revised the manuscript..

JD recruited participants, conducted the interviews, co-analysed the data, drafted and reviewed the manuscript.

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**Table 1.** Community health and specialist services\* available at the four main recruitment centres in 2008

Location 1	Locations 2 and 3	Location 4
<p>Weekly general adult diabetes clinic with a specialist physician, 3 diabetes nurse educators (DNEs)/nurse consultant, a dietitian and an ophthalmologist. Individual appointments with DNEs and dietitians available. Resident physicians in town.</p>	<p>Joint services provided by 2 DNEs and a dietitian, based on individual appointments. No specialist input, no resident or visiting endocrinologists. Resident general physicians in town, but none with a special interest in diabetes.</p>	<p>Diabetes clinics cater for all ages including children, serviced by a nurse and two community dietitians, but often lack experienced staff. Patients are generally managed by a PCP/ GP. The local Division of General Practice runs a voluntary database and recall system. No resident or visiting adult physicians.</p>

\*Note: Most staff <1.0 fte

**Table 2.** Demographic details of participants

Sex, female: male n (%)	14 (53.8): 12 (46.2%)
Age, mean (SD) years	24.2 (2.4)
Duration with Type 1 diabetes, mean (SD; range) years	13.3 (5.3; 3-25.25)
Location of origin, n (location 1, 2 and 3, 4)	11, 13, 2
Still reside in same area, n (%)	9 (34.6)
In employment/ student/ unemployed	20 /2 /4

**Figure 1.** Recruitment process and response rates

