

# National Review of Transitional Care



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May 2007



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# Foreword from Diabetes Australia

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Diabetes Australia recognises the need for greater awareness of and support for young adults with type 1 diabetes as they transition from a paediatric to adult care setting.

Not only is it seen as a period of possible change in care setting, it is also a time of other significant milestones and challenges for many young people. Consequently, it is important to ensure that young adults have access to services which are responsive to their specific needs while maintaining best possible standards of care.

Diabetes Australia believes *The National Review of Transitional Care* is a positive step forward in identifying and clarifying the issues facing both young adults with type 1 diabetes and their healthcare professionals.

Diabetes Australia looks forward to exploring the recommendations in further detail and, in partnership with other key stakeholders, initiating appropriate responses and programs. We encourage all key service providers to identify how they might do the same.

We thank Eli Lilly Australia for their financial support of this review.



Brian Conway  
Executive Director, Diabetes Australia

# Executive Summary

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There are around 40,000 young people under the age of 30 with diabetes in Australia. Most are facing a lifelong regimen of insulin replacement and monitoring of blood glucose as a result of having type 1 diabetes. Of these individuals, adolescents face increased insulin resistance due to physiological changes and are at high risk of developing complications, highlighting the importance of regular care reviews to monitor and control the condition.

The transition period has been documented by many as a challenging time for both young adults and their healthcare professionals. In many cases the move from a familiar and supportive paediatric care setting, to an adult setting which has a focus on type 2 diabetes and self management, results in cases of poor clinic attendance and individuals 'falling through the gaps'. Occurring at a time which generally coincides with many other challenges related to early adulthood, the transition period raises many issues which, while recognised by many, have received little attention when compared to the many other aspects of diabetes management generally.

The first ever national forum to consider the issues related to the transition period for young adults with diabetes was held on 22 August 2006. Convened by Eli Lilly and supported by Diabetes Australia and the Juvenile Diabetes Research Foundation, the forum brought together health professionals and young adults with diabetes from around Australia and identified priority areas for further investigation, of which mental health, transitional planning and peer support programs were top priorities.

The *National Review of Transitional Care* was commissioned to explore current initiatives and resources available in the three priority areas. As part of the review, communications agency Cube conducted 13 one-on-one in depth interviews to explore specific knowledge and involvement in each of the three areas. The review process also included distribution of a survey to members of the Australia Diabetes Educators Association.

## Transitional Planning

The review uncovered that while the transition period is unanimously regarded as a priority, planning and programmes to facilitate the transition process are generally ad-hoc. The lack of resources and the numerous diabetes services operating exclusively from one another in the private and public setting were cited as examples for the challenges in formalising the process.

Several successful transition programs were uncovered and detailed in the review, with education and a co-ordinated / integrated process between paediatric and adult settings cited in successful programs. Among the recommendations and opportunities suggested by review participants were to develop formal guidelines or a standard of care for adults with type 1 diabetes, for transitional planning to start at diagnosis and for further investigation into the potential of the National Diabetes Services Scheme (NDSS) to help improve support available to young adults during the transition phase. A 'transition information kit' template was also suggested which would provide all clinics with a guide of what and when to be providing information to adolescents and/or young adults and their families.

## Mental Health

The NDSS "Young Adult Needs Assessment" research conducted in 2006 uncovered that almost a quarter of 16 – 23 year olds with diabetes self-reported experiencing some form of depression. This was partnered with one hundred percent of review participants believing that there was not nearly enough mental health support for young adults with type 1. The review uncovered that there is very limited access to mental health services, most of which were limited to people with severe mental health issues. Several online resources were noted as valuable tools, however the main issues identified were the lack of mental health care

professionals available and the lack of understanding or recognition of mental health issues. Among the recommendations and opportunities suggested were to incorporate mental health as part of a regular diabetes clinic which would help to educate and normalise mental health. The importance of mental health signposting for diabetes healthcare professionals and education for young adults were also seen as key to help identify and prevent potential issues.

### Peer Support

Peer support programs were identified as a priority from the forum and the review uncovered a number of existing peer support initiatives, however the majority of review participants believe that structured or formalised peer support is resource intensive and only of benefit to a small number of people. Online resources such as websites, chat rooms and email buddy programs were noted as far more effective and relevant to this specific group of people. It was also recommended that other technologies such as podcasts, webcasts and SMS be explored for this age group.

It is suggested that recommendations and opportunities identified in this review are explored by all stakeholders to ensure a consistent and unified approach nationally and the delivery of the best possible standard of care.

# Introduction

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Type 1 diabetes is the one of the most common chronic diseases of childhood, affecting 10,000 Australian children and adolescents each year, with its incidence rising 2-4% per year<sup>1</sup>.

For individuals with type 1 diabetes, it is a lifelong regimen of insulin replacement and glucose level monitoring to control the condition which creates a burden for individuals and families of those with type 1 diabetes<sup>1</sup>.

Children and adolescents with type 1 diabetes are also liable to acute, subacute and chronic complications of diabetes and at a greater risk of developing cardiovascular disease<sup>1</sup>. It is therefore vital that individuals have regular reviews of diabetes control and of the risk factors for the development of microvascular and macrovascular complications of diabetes as part of the long-term management of type 1 diabetes<sup>1</sup>.

Adolescence is a time when major physiological changes occur leading to increased insulin resistance<sup>1</sup> which makes glycaemic control more difficult. Insulin dosages are typically higher during adolescence and most teenagers need to switch to a multiple injection regimen<sup>1</sup>. Coupled with the physical, environmental, emotional and psychological challenges facing all adolescents, individuals with type 1 diabetes often struggle to cope with the demands of diabetes care. It is important that adolescents and young adults maintain and develop self-esteem and independence at a time when diabetes care itself is at its most challenging<sup>1</sup>.

The transition process from paediatric to adult services is often difficult and has been documented by many as an area of need for those with type 1 diabetes<sup>1,2,3,4,5</sup>. There are higher rates of non-attendance at clinic appointments during the transition phase<sup>1,2,3,4,5</sup> which can lead to poor management of the condition and increased risk of complications.

The first ever national forum to consider the issues related to the transition period for young adults with type 1 diabetes was held on 22 August 2006 at the Gold Coast Convention Centre, Queensland. Supported by Diabetes Australia (DA) and the Juvenile Diabetes Research Foundation (JDRF) and convened by Eli Lilly, the forum brought together health professionals, peak representative bodies and most importantly, young adults with type 1 diabetes from around Australia.

As a result of the forum, a number of priority areas for young adults with type 1 diabetes during the transition period were identified - the top three being transitional planning, mental health services and peer support.

To establish an understanding of the initiatives and services currently available in these three areas, the *National Review of Transitional Care* was commissioned by Diabetes Australia, supported by JDRF with sponsorship from Eli Lilly. Communications agency Cube PR Pty. Ltd. was tasked with conducting the national review to identify the gaps in current services and any opportunities for future activities or developments in each of the three areas.

As part of the review, Cube conducted 13 one-on-one in depth interviews with a variety of individuals including young adults with type 1 diabetes, endocrinologists, diabetes nurse educators, counsellors and representatives from DA and the JDRF. The interview explored with each participant their specific knowledge and involvement in each of the three areas. A pro-forma survey was also distributed via the Australia Diabetes Educators Association to its members and this data has also been incorporated into the report. The information from the interviews and surveys was then analysed and compiled by Cube to create the *National Review of Transitional Care*. The opportunities and recommendations presented in this review will be considered by DA, JDRF, Lilly and other key stakeholders for further activity and development.

The review has involved detailed research and in-depth discussions with healthcare professionals and young adults with type 1 diabetes from across Australia. It is however not an exhaustive review and there may be areas or initiatives that have not been uncovered as part of the review

No quotes in this review have been attributed to any individual.

# Transitional Planning

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## Introduction

Transition in the context of diabetes care refers to the process of an individual moving from a child or adolescent health setting to an adult health service. It has been previously defined as a 'purposeful, planned movement'<sup>1</sup> however, this review has uncovered that the majority of transition processes are ad-hoc and unplanned.

Adolescence, regardless of whether a chronic condition is involved, is already a time of significant physical, psychological and environmental change. Young adults living with type 1 diabetes are not only facing these changes but they also have to come to terms with managing a chronic, life-long condition.

In most cases they are also facing the upheaval of moving from a very familiar and supportive healthcare setting, to an adult one where they are handed full responsibility of managing their condition. Many also describe the situation of being 'lumped' into the same category as type 2 patients.

The National Health and Medical Research Council (NHMRC) guidelines state that the formal transition phase:

*'...should occur at a time of relative stability in the adolescent's health and may be coordinated with other life transitions. A useful age at which transition should take place is the end of high school or when the adolescent leaves school to join the workforce.'*<sup>1</sup>

However it goes on to state that other factors including the adolescent's wishes and their emotional and physical maturity should also be taken into account. The guidelines state that the transitional process should involve a preparation phase from the age of 12 years, a formally arranged transition phase from the ages of 16-18 and an evaluation phase from the ages of 18-19.

As identified by all review participants, an unsuccessful transition process can cause a number of complications for young adults with type 1 diabetes, most notably for the young adult to 'slip through the gaps' and fall out of the healthcare system. This may mean the individual is not accessing regular specialist diabetes care, may not be successfully managing their diabetes and subsequently putting themselves at high risk of health complications.

## Current initiatives and resources

The review explored the current examples of transitional planning and the resources available to young adults with type 1 diabetes and healthcare professionals to assist them in the transition process.

What was uncovered was that whilst the transitional process is unanimously regarded as a priority, planning and programmes to facilitate the transition process are generally ad-hoc. 80 percent of individuals interviewed said there were no formal transition plans built into the services with which they were involved with. There were several reasons for the lack of a formalised plan, the main being a lack of resources to devote to it. It was also raised that with so many different diabetes services in both the private and public setting operating exclusively from one another, it is very difficult to manage transition.

### - REAL TRANSITION PROJECT

In 2003/2004 the twelve month 'Real Transition' project was conducted by consumer group Reality Check young adults with diabetes Inc. in partnership with the Royal Melbourne Hospital and funded by the Australian Government Department of Health and Ageing.

The objectives of this project which stemmed from improving attendance at the transition clinic, were to:

- Develop an effective and replicable plan for the transitional phase
- Develop young people's information seeking skills to enable more effective self management
- Engage young people in the improvement of their health services.

The project involved consultation with over 100 young people who visited the Royal Melbourne Hospital's fortnightly Young Adult/Transition Diabetes Clinic over a nine month period. As a result of research and consultation with patients in the clinic and the contribution of a representative steering group, 16 activities were identified, trialled and evaluated at the clinic including:

- SMS reminders for clinic appointments
- The production of a welcome sheet to explain how to change appointments and what to expect at the clinic
- Setting up a library
- The availability of food and drinks at the clinics
- The production of various fact sheets
- Joint pre-transition information session

A key driver and finding of the project was that patients may attend their first appointment upon transition from children's services but frequently drop out of the system in their first year of adult services. Resources to follow up patients not attending adult clinics are limited.

Unfortunately, mainly due to funding and the restraints of the acute hospital system, only a selection of the 16 activities deemed as necessary to improve attendance were continued beyond the life of the project.

This review however, has identified several health care services both in metropolitan and rural settings, which have a more structured formal transition plan and process. It is worth noting that in more than one case these corresponded with a close geographical location of the paediatric and adult services; however this is not always a factor in successful transition. Below is a selection of examples:

### - THE ROYAL CHILDREN'S HOSPITAL AND ROYAL MELBOURNE HOSPITAL, MELBOURNE, VICTORIA

The Royal Children's Hospital and Royal Melbourne Hospital (RMH) have a very well structured transitional programme. Approximately one year before transition, The Royal Children's Hospital run an open day and invite several adult centres from Melbourne, including RMH to speak to young adults on the services they offer.

For young adults that do choose to move on to RMH, an endocrinologist from The Royal Children's hospital whenever possible will attend the RMH clinic so there is a familiar face on hand.

The Royal Melbourne Hospital also runs a late afternoon/ early evening transition clinic, staffed by both paediatric and adult clinicians. The timeslot allows the young adults the flexibility of coming to the clinic after work, school or university commitments.

## Transitional Planning

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### - NORTHERN RIVERS AREA HEALTH SERVICE (NRAHS), BALLINA/ BYRON, NSW

In a similar style to this review, the NRAHS undertook a detailed review of current literature and existing models of transitional care as part of their development of a transitional program for the area. The NRAHS encompasses the rural areas of Ballina, Byron, Lismore and Grafton which has a very transient young adult population, requiring a flexible transition programme.

As part of the review project a number of tools to aid transition were developed by the service and successfully implemented in the diabetes centres in the area.

The centres now develop detailed care plans for individuals before transition, provide comprehensive information pamphlets on the phase, as well as run a one-day adolescent workshop for individuals to take part in before transition. They also issue a self knowledge questionnaire for the individuals to assess what understanding they do have and help identify any further support or information needed.

As the area encompasses a very transient population, the service also links individuals with appropriate facilities in the area they are moving to. They also seek permission to follow up with the individual to ensure they are feeling supported in their new healthcare setting and identify any issues.

### - QUEENSLAND DIABETES CENTRE, MATER HEALTH SERVICES, BRISBANE

An adolescent transition clinic has been operating at the Queensland Diabetes Centre at the Mater since 1997. The centre uses a "best practice" model of care with co-located clinics and shared personnel. This means that when children are approaching the end of primary school, staff in the paediatric clinic start to discuss with the children moving on to the adolescent clinic. Their first appointment is usually some time in their first year of high school and is located in the same diabetes centre with some of the staff remaining the same. The staff mix in the adolescent team is half paediatric and half adult, so that the young people gradually get exposed to the experience of adult care. This also facilitates a melding of healthcare approaches.

For the next five to eight years at the adolescent clinic, issues of transition are addressed including re-education, independence, alcohol and existing adult care options.

Transition from the adolescent service to adult care occurs any time from the end of high school to approximately twenty years of age when the young adult feels ready and life is stable. Again the young adult can choose to stay within the diabetes centre and move on to the young adult clinic where there continues to be some familiar staff and structure. A photo board in the waiting area is one example of introducing patients to the other care providers. The option of all care being available from the one centre provides familiarity and consistency which is valued by the patients.

Mater Health Services has also received Queensland Health funding via the Clinical Practice Improvement Centre for a two year project to develop and implement a transitional model and resources for the state.

### - DIABETES TRANSITION SUPPORT PROGRAM, WESTMEAD HOSPITAL, SYDNEY

The Diabetes Transition Support Program at Westmead Hospital was established in 2001 to prevent poor clinic attendance and reduce hospital admissions of young adults with type 1 diabetes as they moved from paediatric services to the adult health system.

The majority of patients supported are managed through a Young Adult Clinic located in the Diabetes Centre at Westmead Hospital, which is staffed by adult clinicians and allied health

professionals. The premise of the Young Adult Clinic was, and remains, to provide an appropriate service for young adults aged 15-25 years, to engage them in establishing and maintaining adult self care management behaviours, while supporting them through the complex social and developmental stage of young adulthood. Two hundred and eighty young people are currently supported by the service.

The service provides:

- A dedicated diabetes educator/transition coordinator who works exclusively with young adults and adolescents with diabetes and is the first point of contact for all interaction with the service;
- A resource DVD developed for young people newly referred to adult services introducing them to the clinic, how to get there, staff, contact details and the differences between paediatric and adult health systems;
- Shared care and prior introduction for some patients at Children's Hospital Westmead;
- Clinic hours from 2pm – 7pm to allow flexibility around work / study commitments. The clinic is held in the diabetes centre, separate from adult clinic areas with a relaxed environment to allow for peer interaction and opportunistic diabetes education. Afternoon tea is provided at the clinic;
- Appointment reminders by SMS, email or phone call and re-booking of missed appointments
- Psychologist and dietetic services as well as complication screening as part of routine appointments;
- After hours emergency phone support to prevent hospital admissions
- Strong links with Children's Hospital Westmead and also with local GPs, who are a main source of referral for those with uncontrolled diabetes who may have "slipped through the net of transition";
- Peer supported newsletter and education evenings

Since commencement of the service there has been a one third reduction in admissions with diabetic ketoacidosis, sustained over the last three years. Significant improvements in diabetes control have been achieved with a reduction in HbA1c of 0.5% from that at initial referral. If young adults are appropriately supported in adult services clinic attendance can be maintained, diabetes control improved and hospital admissions reduced.

- GREATER METROPOLITAN CLINICAL TASKFORCE (GMCT) – TRANSITION CARE FOR YOUNG PEOPLE WITH CHRONIC CHILDHOOD ILLNESSES / DISABILITIES, SYDNEY, NSW

The taskforce was set up in 2002 by the NSW Department of Health to look at transition programmes for young people (12-24) with a chronic illness. Although the taskforce does look at all chronic illnesses, diabetes is a priority group.

The taskforce does not set up specific programmes, rather they help develop resources, education programmes and support groups to help facilitate the transition process. They also help provide introductions and a familiar face at the adult services when the individuals move across.

The taskforce also manages a database of children with chronic illnesses to help track their progress through the transition process. The database also keeps record of referrals so that they can monitor where an individual has moved on to and/or if they have followed up on their appointments (permission is sought from the young adults before they are added to the database). The database is very much in its early days but it is hoped it will be a successful tool to aid the transitional phase.

## - GYST – A LIFE GUIDE FOR YOUNG PEOPLE WITH DIABETES ON THE MOVE

In 2003 a DVD resource “GYST- a life guide for young people with diabetes on the move”, was commissioned by Diabetes Australia with funding through the National Diabetes Services Scheme (NDSS) an initiative of the Australian Government. “GYST” is an acronym for ‘get your stuff together’.

The content of the DVD covers all of the transition issues including finding a new medical team, moving out of home, getting a license, getting a job, tertiary education and travel. The DVD was produced after consultation with young adults with type 1 diabetes who have had to contend with these transitional issues. The DVD follows the progress of Kyle (a young man with type 1 diabetes) as he negotiates this period in his life. There is also factual content from housing, employment, licensing and medical experts. The DVD is currently being reviewed by the Department of Health and Ageing and it is intended that the DVD will be distributed to NDSS Registrants aged 16-23 over and to key health professionals and diabetes clinics.

## Forthcoming initiatives

- There are plans in 2007 for the development of a more integrated transitional programme between Adelaide Women & Children’s Hospital and Royal Adelaide Hospital, however at the time of the review this was still in the initial planning stages.
- In early 2007, the GMCT will run a pilot transitional programme in the Illawarra region of NSW. This will include employing a project manager for six months to look at the number of young people with a chronic illness using healthcare services and identify the issues and gaps they face as they move through transition.
- Several participants referred to an educational online resource being developed as part of the Novo Nordisk Dawn Project. This project will be piloted in 2007 in partnership with The Adelaide Women and Children’s Hospital and the University of Wollongong.

The online resource would involve the young adult logging on to talk to a Diabetes Educator. The educator would direct the individual to online resources so they can learn more about type 1 diabetes - the intention is the individual would then come back to the educator and be able to ‘chat’ and ask further questions. There is also the potential to build in supervised peer mentorship, as well as parent and teacher support programmes and facilities for rural areas.

## Issues identified

### - PRIVATE VS PUBLIC SETTING

One of the issues highlighted by several participants in the review was that a large percentage of children and adolescents are cared for in the private setting. This makes it difficult to facilitate a formalised transitional process between private and public services. As one participant put it:

*“We have no idea what education or resources they have had before their move, so it makes it difficult to facilitate planning.”*

### - THE ADULT SETTING

The lack of services in the adult setting was also considered problematic. Several review participants believed paediatric settings in general were “excellent”, “incredibly well managed” and “offered a very thorough and supportive environment for both parents and young people”. In contrast, the consensus was there are huge gaps in the adult setting and a lack of specialist services for type 1. Many review participants referred to the adult setting’s focus on

“acute centric” care and that people with type 1 diabetes are “lumped together with type 2 patients”. This means that young adults with type 1 are then exposed first hand to severe complications of diabetes like amputees and blindness, which for a group who are already feeling vulnerable and confused about their condition, is not considered the right environment.

It was also stated by several review participants that there is a general lack of understanding in the adult healthcare setting and the general public of the differences between type 1 and 2 diabetes – especially with the media focus on the rise in type 2 diabetes amongst obese children. This lack of understanding leads to frustration and disillusion for the young adult and can result in the person leaving the system and the complications around this. To pre-empt this situation, it was proposed that young adults are educated further on the differences and the focus of the adult setting, so that when the young adult does move into the adult setting they are prepared and know what to expect.

One review participant believes:

*“The acute centric approach in our treatment of chronic condition actually burns families out and causes young people to drop out of the system.”*

Several review participants believed that hospitals need to start treating type 1 diabetes as a chronic condition and treat proactively and holistically rather than waiting for complications to occur.

#### - THE ROLE OF PARENTS

The parent's role in transition was also discussed in great depth and identified as a major issue that needs to be addressed. However, it is agreed that there needs to be a balance in terms of the parent's involvement in the transitional phase.

Different examples mentioned by review participants demonstrated there is no definitive answer to the extent of a parent's involvement in a successful transition. There were several cases of parents who took a step back early to let young adults take over managing their diabetes, yet this still resulted in complications and the young adult poorly managing their diabetes. On the contrary, there were examples of parents controlling their child's diabetes right up until the age of 18, which led to young adults who were completely unable to manage themselves and ensuing physical and psychological complications.

It is generally recognised that every situation is different, however parents do need to be educated alongside the young adult so that they can learn to gradually hand over to their children and enable their children to successfully take control of managing their diabetes. There also needs to be recognition of the significant impact the transitional phase has on the parent and the need for support groups and information specifically for the parents.

#### - NO INTEGRATION BETWEEN THE STATES AND TERRITORIES

Several participants mentioned their frustration at how there is a constant ‘re-inventing of the wheel’. Examples were given of ‘fantastic resources’ that had been developed in other states, by schools, diabetes centres or DA and their frustration when people tried to produce their own version rather than simply stream-lining and creating something at a national level.

#### - TRANSITIONAL PLANNING AS A SYMPTOM OF A GREATER PROBLEM

Several participants also believe that issues with transitional planning are a symptom of a larger problem and that successful transition is secondary to the issue of mental health. There are so many external factors that can affect how smooth the transition process will be eg. home life, school, university etc., so although we can assist the planning process, we need to be mindful of other influences happening outside of the healthcare setting.

## Recommendations

### - DEVELOP FORMAL GUIDELINES OR A STANDARD OF CARE FOR ADULTS WITH TYPE 1 DIABETES

There are NHMRC guidelines on Type 1 diabetes in children and adolescents; however there is currently nothing in existence for adults, highlighted by several participants as an area of need. This could also include more detail on the transition phase and link closely to the guidelines for children and adolescents.

### - TRANSITIONAL PLANNING NEEDS TO START AT DIAGNOSIS

Children and adolescents need to be educated from day one on what to expect in the coming years to prepare them and to help facilitate a smoother process.

### - VERTICALLY INTEGRATING ADOLESCENT AND ADULT SERVICES

Particularly in rural areas, or in health care settings where there are no linked paediatric and adult services, vertically integrate the two into one service. This could involve allocating certain days to a particular age group and have the appropriate specialists in attendance. This can also play a role in encouraging relationships and offering a peer support environment for young adults.

### - EVENING CLINICS FOR ADOLESCENTS / YOUNG ADULTS

Offering evening clinics which are structured around school, university and work commitments and staffed by both paediatric and adult clinicians. This however is a resource intensive process and involves a commitment from staff.

### - DEVELOPMENT OF INFORMATION AND SUPPORT VIA THE NDSS

Registration with the National Diabetes Services Scheme (NDSS) generally occurs for most people with type 1 diabetes shortly after diagnosis due to the fact that they can access subsidised blood testing strips and free needles and syringes.

The NDSS currently has over 800,000 members including approximately 30,000 young adults with type 1 – (equivalent to 95– 99 percent of young Australian adults with type 1). Information can be sent to NDSS Registrants which is considered of true value to help manage their diabetes.

Although there are limits on what information can be sent and how often, this is potentially an area that could be explored further to help follow individuals as they move through the system and ensure they are accessing appropriate care.

### - ENSURING TRANSITIONAL PLANNING CONSIDERS THE YOUNGER ADULTS

It is recommended that any transitional planning be mindful of the younger adults i.e. 16-18, as well as younger teenagers and ensure that their voices are heard. Several review participants mentioned that some of the consumer attendees of the 2006 Youth Forum were older young adults, i.e. 20-22 who because of their state in life would naturally be more confident and willing to voice their opinions. Review participants believe it is important we also consider the younger end of the spectrum, their circumstances and needs, which can be very different to that of someone in their early 20s and ensure that we seek their input into any developments.

### Opportunities for development

#### - A TRANSITION INFORMATION KIT TEMPLATE

Develop a template of a transition information kit that could be provided to all diabetes clinics. This could be downloaded from any DA website and incorporate a checklist and timeline of information that should be provided to young adults and their parents. The information kit could also contain PDFs of pamphlets, other materials to include in the kit, template letters and useful contact details. The individual clinics could then personalise the kits and provide local contacts and adult clinics for young adults, as well as include any other information they think necessary.

#### - INVESTIGATE THE NDSS REGISTER

Explore the possibility of using the NDSS register as a tool in assisting transitional planning. This could involve using data such as the individuals' date of birth to track their age and thereby when they are approaching the age of transition, sending information to the individual – whether this be via email or post, or to their health service. Privacy considerations would however need to be taken into account and may require revision of existing information disclosure practices and permissions in consultation with the individual. Information could be sent at various stages of the transitional phase not only as reminders but also to ensure they feel supported and know where to access the services and information they need.

#### - TRANSITIONAL PLANNING BEST PRACTICE 'COMPETITION'

At a national level, DA could run a 'competition' or search to find diabetes clinics or health services operating the most successful transitional planning or programmes that could be used as a benchmark for a 'national' standard. This would not only encourage services to evaluate their current transitional planning and bring attention to the area but it would also give services who have developed successful programmes or tools the recognition and the chance to share their ideas with others.

# Mental Health

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## Introduction

Mental health is now more recognised as an important issue in healthcare. However there is still a great deal of stigma attached to the area and the terminology used in addition to a misunderstanding of the issues and concerns it encompasses<sup>6</sup>.

Adolescents and young adults are still building their confidence and self-esteem, so adding to this coming to terms with a chronic life-long condition, only makes the time more emotionally challenging<sup>1</sup>.

The preliminary results from the 2006 'National Diabetes Services Scheme (NDSS) Young Adult Needs Assessment' (unpublished) uncovered that almost a quarter of 16-23 year olds indicated they experienced depression as a long-term condition. This sentiment was further confirmed at the 2006 Youth Forum where the area of mental health was uncovered as a key priority of the attendees.

## Current initiatives and resources

One hundred percent of people interviewed as part of this review believed there was not nearly enough mental health support for young adults with type 1. They all agreed that mental health in general is definitely much more of a focus than it was ten years ago, however it is believed there is still a long way to go before it receives the understanding and recognition it deserves and as such the resource required to deliver the appropriate services. It was suggested that although health professionals now recognise the issue of mental health, it is still seen as the bottom priority for young adults with type 1 diabetes.

### - HOSPITALS AND CLINICS

Of the 15 diabetes clinics who provided information on the services they offer, eight (53 percent) did have some access to psychiatry or psychology services. The remaining seven services had no mental health support or resource available at all.

Of the eight services with access to mental health services however, six (75 percent) were only available for people with severe mental health issues and/or close to being admitted to hospital. The services were also generally part of the hospital psychiatric ward and so there were issues of wait-listing and clinicians having limited knowledge of diabetes and the issues individuals faced.

Only one of the 15 clinics investigated as part of this review had any general counselling or psychology services on offer for young adults with type 1. The services were purely of a reactive nature only.

### - ONLINE RESOURCES

Outside of the hospitals and clinics, there are several very useful online services - 'Diabetes Counselling' and 'Reality Check'. Both of these resources were identified by 100 percent of review participants as very important, which they regularly referred young adults to. Several participants also referred to 'Diabetes Kids and Teens' and 'The Injectors'.

#### - [www.diabetescounselling.com.au](http://www.diabetescounselling.com.au)

This is a national online counselling service for all ages and types of diabetes, which has been operating for six years. For the past three years it has been funded by Diabetes Australia, as part of the NDSS program.

The services on offer include email counselling, email buddy programs, chat rooms, links to other resource and a story page for individuals to share their story. It is a mainly an online service however, there are also limited telephone counselling and phone sessions. The site has over 600 forum members and almost 400 involved in the email buddy program. The website receives an average of 12,000 visits every three months.

- [www.realitycheck.org.au](http://www.realitycheck.org.au)

Reality Check, part of the Type 1 Diabetes Network, aims to create opportunities for young adults with type 1 to share their knowledge and experiences of living with diabetes.

The Network offers various specific resources such as online communities ([www.realitycheck.org.au](http://www.realitycheck.org.au)), education seminars and printed resources. The Reality Check website has 1,000 active members, 2,600 on a newsletter mailing list and receives an average of 800-900 visits every day.

### Forthcoming initiatives

- In 2007 as part of their transition programme, Royal Adelaide Hospital is looking to employ a counsellor to see every new young adult that comes into the adult service. The counsellor will be a member of the standard healthcare team. The details have yet to be finalised but the aim of the service is to help normalise and de-stigmatise mental health for young adults and that seeing a counsellor is part of a normal appointment. It is also to ensure the young adult has a familiar face to go to if they need to talk to someone or have any issues and ultimately to ensure they feel supported.
- The 2006-2011 NDSS Funding Agreement between the Australian Government and Diabetes Australia has recognised psychosocial aspects of diabetes as a key focus area. Work will commence in 2007 to identify opportunities for the NDSS to support through Strategic Development Grants and National Projects.

### Issues identified

#### - LACK OF DIABETES MENTAL HEALTH CARE SPECIALISTS

The major issue identified was that there are almost no psychiatrists, psychologists or services. As such the specialists available are only able to focus on critical issues, which means no general counselling is accessible on a day-to-day basis. As one review participant explained;

*"We wait for the condition to have reached crisis level before we treat them, rather than focusing on identifying problems early and stopping them from progressing."*

#### - CRITICAL AGE

Clinicians interviewed as part of the review believe that if mental health isn't addressed at this critical age, it will inevitably lead to chronic complications down the track.

*"It is such a critical time when you are handing over responsibilities to the young adult. They are already feeling uneasy and apprehensive so this is the key time they need to feel supported."*

### - A LACK OF UNDERSTANDING OF WHAT MENTAL HEALTH IS

Mental health covers such a range of issues and concerns and healthcare professionals may not necessarily have the time to either recognise the signs or have the time to get into discussions around mental health.

The terminology is also problematic and there is still a great deal of stigma attached to the area. As a result young adults are either unable to recognise when they do need help or reluctant to seek assistance because of the connotations in the area of mental health. It was suggested by several review participants that mental health needs to be normalised as much as possible and mental health literacy amongst the group be created.

### - DIABETES TRADITIONAL MODEL OF CARE

Diabetes exists in a traditional medical model of care – we recognise the disease, we treat the symptoms. Mental health does not really fit well into the acute model of care so we need to change the continuum of care needs to be changed.

### - RECOGNISING MENTAL HEALTH IS A VERY REAL ISSUE FOR YOUNG ADULTS WITH TYPE 1

Healthcare professionals need to recognise and understand that when putting a child on a strict regime from such an early age, it is only natural that a high number of individuals are going to look at escape outlets and test the boundaries – whether that by using alcohol, drugs or with risk taking behaviour or suffer from depression. It is important for healthcare professionals to educate adolescents and young adults about mental health and ensure they have the resources and support available to help manage any potential issues and minimise self harm.

### - FLEXIBLE AND SPECIFIC SERVICES FOR YOUNG ADULTS WITH TYPE 1

Mental health services need to be structured around the young adult, their lifestyle and their interests and needs. Some services like chat rooms are not fully utilised because they are run at times not suited to a young adult. It is important that we offer flexible services and engage young adults in the development of these services so that they are truly focussed on their needs.

## Recommendations

### - MAKE MENTAL HEALTH PART OF THE STANDARD CARE MODEL

It was suggested by 95 percent of review participants that mental health should be part of the normal healthcare visit. Young adults should see a counsellor or psychologist at the same time they see their endocrinologist or diabetes nurse educator - it should not just be a response to a crisis.

### - PROVIDE MENTAL HEALTH SIGNPOSTING FOR ALL DIABETES HEALTHCARE PROFESSIONALS

Offer simple training for all diabetes health professionals on how to recognise and address potential mental health issues so that these can be identified early and managed effectively to prevent future complications.

### - EDUCATE PEOPLE ABOUT MENTAL HEALTH

Educate young adults and their parents on the area of mental health and help to normalise the area to remove the stigma. This also encourages young adults to feel more confident in seeking support.

### - EXPAND AVAILABLE RESOURCES

Diabetes Counselling online is a highly regarded and valuable resource and it has been suggested by several review participants to develop the resource further so that more people can access the service. It has also been suggested that more type 1 specific resources are added to this service.

## Opportunities for development

### - MENTAL HEALTH SIGNPOSTING FOR ALL DIABETES HEALTH PROFESSIONALS

There is an opportunity to provide diabetes health professionals with training or a resource on signposting mental health issues. This would be aimed at giving all health professionals a better understanding of what the area of mental health encompasses and more particularly, highlighting the mental health issues facing people with type 1 diabetes.

The training would focus on ensuring healthcare professionals better understand and recognise the issues facing individuals with type 1 diabetes and the role they can play in providing best quality of care to limit any further psychological stress. It would also need to ensure all healthcare professionals are confident in identifying clinically significant mental health issues and when referral to a mental health professional is necessary or appropriate.

### - MENTAL HEALTH EDUCATION FOR YOUNG ADULTS WITH TYPE 1

The preliminary results of the *NDSS Young Adults with Diabetes Needs Analysis* and many years of literature have already highlighted that depression is a very real issue for young adults with type 1 diabetes. There is therefore an opportunity to educate young adults on the area, create a better understanding of what mental health is and the impact it can have on managing diabetes.

This education should be incorporated before and during transition and could be done in various ways. The area of mental health could be incorporated into a knowledge questionnaire to ascertain what understanding each individual does have. On transition open days where adult health services are present, a counsellor or social worker is also in attendance to talk simply about mental health and where to go for support.

# Peer Support

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## Introduction

In the process of conducting this review, it was uncovered that the majority of participants believe formal peer support is a difficult and resource intensive process which only benefits a small group of people. Whilst many do see it has benefits if run well, they identified that it requires a huge investment of time and support from both the organisers and the participants.

## Current initiatives and resources

Several formalised peer support programmes were identified by review participants across the country. These include:

- 'Dynamic Intent' – Queensland
- 'Insight' – West Australia
- Teenagers Group at Melbourne Royal Children's Hospital
- 'Life is Sweet' – South Australia
- Reality Check – Sydney, Melbourne, Adelaide, Townsville
- The Injectors - Melbourne

Online resources such as Reality Check and The Injectors websites, Diabetes Australia NSW's website Diabetes Kids and Teens and Hypostasis, were all identified as peer support resources.

Many of the paediatric diabetes clinics and hospitals across the country operate individual peer support meetings, adult information evenings and activities such as nights out, camps or BBQs. Several clinicians also plan certain clinic days around a specific age group, to encourage individuals to form friendships and see familiar faces each visit.

Juvenile Diabetes Research Foundation also run the Youth Ambassador Program, which is focussed on advocacy and raising awareness of type 1 diabetes in the media and community. The objectives of the program are to support JDRF's mission of raising awareness, supporting research and raising funds for type 1 diabetes. At first sight the program did seem to have potential as a peer support offering, however as many of the ambassadors are in remote regional areas and the objectives of the programme are focussed on raising awareness of type 1, there is not the infrastructure or the opportunity to move into peer support.

## Issues identified

- BELIEF THAT STRUCTURED PEER SUPPORT IS ONLY FOR A SMALL GROUP OF PEOPLE AND RESOURCE INTENSIVE

The majority of people interviewed as part of the review, including both patients and healthcare professionals, believe that formal peer support programs and activities only benefit a small group of people and as such is a resource intensive program for few benefits.

- DIFFERENT NEEDS AND DESIRES FROM PEER SUPPORT ACTIVITIES

Different people respond to different options – there is no 'one size fits all' for peer support. Some people may prefer online peer support and chat rooms, others may prefer face-to-face meetings, camps or social events. Several people interviewed as part of the review believed that informal peer support through online resources or more informal meetings and events is more successful than any formalised peer support system with set dates, times and venues.

### - AGE AND STAGE IN LIFE OF PARTICIPANTS

As previously mentioned, peer support is not only resource intensive for the organisers, but also takes commitment and support from the participants to make it work. Many people interviewed believe that because of the many environmental changes surrounding young adults, organised peer support is difficult to facilitate over a long term.

Young adults at this age may be moving away for work or university, travelling or starting careers which restrict the amount of free time they have for structured peer support. The needs and wants of these young adults will also inevitably change as they get older. They will also grow out of young adult peer support groups, so considerable resource needs to be devoted to attracting new participants and keeping the peer support running. This is further evidence that online based activities may be the best means of enabling this age group to access support and information when required.

### Recommendations

Although peer support was identified as a priority from the 2006 Youth Forum, the majority of review participants believed that formal peer support programs such as mentoring and facilitated meetings and activities were not always effective and resource intensive activities, therefore recommendations and opportunities in this area are limited.

### - EXPLORE FURTHER ONLINE PEER SUPPORT PROGRAMS

Many review participants noted that peer support activity needs to be tailored around current trends and technology to ensure it is accessible and of interest to young adults. Resources like pod casts, webcasts, on-demand media, mobile phone technology as well as current resources like chat rooms and email need to be explored as further avenues for peer support programmes. Although all review participants believe face-to-face peer support does work for a small number of young adults, online communities and other media which are less formal and more importantly, accessible when convenient to the individual, are much more appropriate and of interest for this age group.

### - DIABETES AUSTRALIA STATE AND TERRITORY BRANCHES

It was suggested by several review participants that the individual Diabetes Australia state and territory branches are in the best position to set up peer support activities – both face-to-face and online resources. Peer support at a national level (barring online resources) is difficult to manage so it was suggested state and territory based activities would be more effective.

Several Diabetes Australia state/territory branches are already operating very effective and active peer support programmes, working closely with health services and other organisations, so it was suggested these should be benchmarked and used in other states and territories.

### Opportunities for development

#### - EXPLORE FURTHER TECHNOLOGY OR ONLINE RESOURCES FOR CURRENT PEER SUPPORT

Discuss need to expand online support from just 'chat room' or forums to more structured resources, utilising the technologies already available e.g. SMS, podcasts, live streaming etc. There is an opportunity to add services to existing peer support programmes.

# Conclusion

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The objectives of the *National Review of Transitional Care* were to explore the existing initiatives in the three identified priorities of transitional planning, mental health and peer support and to uncover any opportunities for development in these three areas. It was clear from the responses of all participants, both healthcare professionals and young adults with type 1 diabetes, that the areas of transitional planning and mental health are key concerns.

As detailed in this review, the transitional process has previously been explored in great depth by several health services and organisations. Several services have implemented successful tools or programmes and it was suggested by review participants that these be made available at a national level. There were also several issues highlighted including the numerous public and private diabetes clinics operating independently and the lack of resources available, particularly in the adult setting, however several opportunities were also identified. It is recommended that the NDSS database be explored further as a tool to better support young people during the transition period and link them to services and information through regular correspondence. It was also suggested a national 'template transition information kit' should be developed and made available to all services as the standard model of care.

Mental health is clearly a major issue affecting young adults with type 1 diabetes and as this review has uncovered, it is a very under resourced area. There are almost no services offering general counselling for young adults and any available psychology or psychiatry services are limited and primarily for crisis situations only. There are also very few mental health individuals trained specifically in the area of diabetes. Although many of the issues identified revolve around resource and funding, there are several opportunities for development that were suggested. It was recommended that existing services like Diabetes Counselling be expanded and more specific type 1 diabetes services be added to this resource. The creation of a mental health education programme for young adults with type 1 diabetes was also suggested to help increase literacy amongst the group and normalise the area of mental health so that issues are identified before they progress.

The area of peer support, although identified as a key priority of the 2006 Youth Forum, did not seem to be as an important an issue for review participants. The majority of participants believe that formalised peer support programmes only benefit a small group of people and involve a large investment of time and support. It was however suggested that avenues such as online and mobile technologies be explored further for peer support programmes, in addition to more DA state and territory offerings.

The issues and challenges identified in conducting this review and the subsequent opportunities and recommendations highlighted have provided an opportunity to begin to make in-roads in delivering a better standard of care for young adults with type 1 diabetes. These recommendations should be explored by a group representing all stakeholders to ensure a consistent and unified approach nationally.

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# Appendix

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## Telephone questionnaire for interviews For healthcare professionals/ organisations or a service

**Name:**  
**Position:**  
**Organisation:**

I am working on behalf of Diabetes Australia, with support from the Juvenile Diabetes Research Foundation and Lilly to conduct a review of the current initiatives and resources for young adults with type 1 diabetes. We are particularly interested in the transitional care process – that is, the move from child or adolescent services to adult services and the initiatives and support available.

The Youth Forum held in August on the Gold Coast, identified as priorities the areas of Mental Health, Peer Support and Transitional Planning. In moving forward we are trying to gauge what is currently being done in each of these areas. The age group we are focussing on is young adults 16-23.

### In relation to Mental Health Services

Specifically for your organisation...

- What mental health services does your organisation offer? Are any of these services specifically for young adults with Type 1 diabetes?
- What role do you believe mental health services should play in the transition of young diabetes care?
- Is mental health support built into your transitional planning?
- Does your organisation offer mental health support specifically for young adults with type 1 diabetes and/or transitional care?
- If so, what type of services do you offer eg. Counsellor(s), online services - chat room, email support, group sessions, support materials?
- Are these services well used by young adults? What do you think works well and why?
- Are there any mental health resources that you offer that are not fully utilised? Why do you think that is?

Outside of your organisation...

- Do you believe mental health rates high enough in the area of transitional care?
- Do you know what else is available in terms of mental health support?
- What do you think is done well?
- What else do you think needs to be done? eg. What gaps are there? Are there any services that could be utilised better?
- Generally do you believe young adults know where to go to for mental health support?

### Peer Support

Specifically for your organisation...

- Do you offer any peer support / buddy programs for the young adults with type 1 diabetes, particularly through the transitional phase?
- If so, can you give me a bit of information on how they are set up, how long they last for and how they work?
- Do you offer any training for peer support?

- Do you offer any meetings/support groups for young adults transitioning (*NB. This may have been touched upon in mental health discussions?*)
- What do the meetings cover and how often do these occur? Who facilitates these?
- What do you think makes these successful?
- Do you have any further plans in the area of peer support?

Outside of your organisation...

- Do you know any other peer support programs that work well? Why do you think they are successful?
- What else do you think would work well or what do you think young adults with type 1 diabetes would benefit from?

### **Transitional Planning**

- How does your organisation get involved in planning the transition process? What role do you play?
- Can you give me some detail about what services you offer in the area of transitional planning?
- What resources are available in terms of transitional planning?
- The parents' role was identified as a priority area at the Youth Forum– what services do you offer to parents of transitioning young adults?
- What else do you think parents could benefit from?
- Do you offer any resource/ or an education program to young adults to prepare them for the transition phase. If so, can you give me some detail on how this works?
- Outside of your organisation, what other resources/services are available to educate young adults and build their knowledge/skills during their teenage years?
- Are you familiar with any health services that manage transitional planning well? Can you give me a bit of detail on these?
- Why do you think they are successful? What works well?
- How do you think the transition between children's to adult hospitals could be better managed?
- What systems/processes do you think would assist the process?
- If a young adult does 'slip through the gaps' during the transitional phase, how do you manage this?
- Further to this, do you know of any organisations or systems that help monitor teenagers/young adults as they move to the adult system?
- In your opinion, what is not working in the area of transitional planning?
- In rural areas in particular, how do you think we could better manage transitional planning?

Have you any other comments you would like to share?

**Telephone questionnaire for interviews**  
For young adults with Type 1 diabetes

**Name:**

**Age:**

**Stage of transition:**

I am working on behalf of Diabetes Australia and the Juvenile Diabetes Research Foundation to conduct a review of the current initiatives and resources in the area of type 1 diabetes transitional care.

The Youth Forum held in August on the Gold Coast identified as priorities the areas of Mental Health, Peer Support and Transitional Planning. In moving forward we are trying to gauge identified as priorities for moving forward.

**In relation to Mental Health Services**

- Do you know what mental health services are available to you? eg. counselling, support groups, resources
- Do you think there is adequate emotional and psychological health support available? Is it easy to access/utilise?
- Were you given information about what services were available? Who provided this information?
- What do you think is missing or under-resourced? What do you think people like yourself need or could benefit from in the areas of emotional and psychological support?
- Were you educated about the emotional and psychological factors as part of your transition phase? Do you think enough emphasis was placed on it?

**Peer Support**

- Were you ever involved in peer support or buddy programs? If so can you give me a bit of information about how this worked/works?
- (If no to above) Do you know of any peer support programs that exist?
- Would you ever take part in a peer support program? What do you think would be the benefit of such a program?
- At what stages of the transition phase in particular do you think it would be most important to have peer support in place?
- How do you think peer support would work best– eg. group sessions/ phone calls/ email/ regular meetings?
- What else do you think would work well or you think young adults would benefit from?

**Transitional Planning**

Questions will be tailored depending on stage of transition.

- How have you found the transition from adolescent to adult services? Can you go into detail with me about how you moved from one service to the other?
- Did you feel like you knew what to expect when you moved to the adult setting?
- What were the biggest challenges of moving to the adult services?
- What resources were available to you? Eg. education, support, counselling etc.
- Were your parents involved in the process?
- How were they involved? Could their involvement have been handled better?
- What could have been done better to make the transition process easier?
- Do you feel supported now? Are you keeping appointments with your health team?
- Have you any other comments on transitional planning you would like to share?

# Survey of Services for Young Adults with Type 1 Diabetes

The following survey has been commissioned by Diabetes Australia and is supported by JDRF and Eli Lilly to establish an understanding of the initiatives and resources currently available for young adults with type 1 diabetes and to identify the priorities for future programs. To ensure information about your service is captured, please complete this form and forward to **Susannah at Cube via susannah@cubepr.com.au or fax 02 9377 1199 by 22 December 2006**. Data collated will be de-identified and published in a report and made freely available to diabetes service providers.

Organisation Name: \_\_\_\_\_

Name of Person completing this form: \_\_\_\_\_ Position: \_\_\_\_\_

Street Address: \_\_\_\_\_

Town/Suburb: \_\_\_\_\_ State: \_\_\_\_\_ Postcode: \_\_\_\_\_

Telephone: \_\_\_\_\_ Fax: \_\_\_\_\_ Email: \_\_\_\_\_

## 1. Type of Service (tick as many boxes as relevant)

Aboriginal Medical Service	<input type="checkbox"/>	Community Health Diabetes Service	<input type="checkbox"/>	Diabetes Specialist Centre	<input type="checkbox"/>
Diabetes Educator Services	<input type="checkbox"/>	Diabetes Support Group	<input type="checkbox"/>	Dietitian-Nutritionist Services	<input type="checkbox"/>
Division of General Practice	<input type="checkbox"/>	Exercise & Physical Activity	<input type="checkbox"/>	Hospital Diabetes Service	<input type="checkbox"/>
Medical Centre/General Practice with special interest in Diabetes	<input type="checkbox"/>	NDSS Sub-Agent	<input type="checkbox"/>	Not-for Profit Health Organisation	<input type="checkbox"/>
Optometry Services & Eye care	<input type="checkbox"/>	Podiatry Services & Foot care	<input type="checkbox"/>	Other	<input type="checkbox"/>

## 2. Specialists Available (tick as many boxes as relevant)

Adolescent Diabetes Services	<input type="checkbox"/>	Exercise Physiologist	<input type="checkbox"/>	Podiatrist	<input type="checkbox"/>
Diabetes Educator	<input type="checkbox"/>	Indigenous Health Worker	<input type="checkbox"/>	Psychologist	<input type="checkbox"/>
Diabetes Educator – Credentialed	<input type="checkbox"/>	Interpreter Service for NESB	<input type="checkbox"/>	Social Worker	<input type="checkbox"/>
Diabetes Resource Nurse	<input type="checkbox"/>	Ophthalmologist	<input type="checkbox"/>	Other	<input type="checkbox"/>
Diabetes Endocrinologist	<input type="checkbox"/>	Optometrist	<input type="checkbox"/>		
Dietitian-Nutritionist	<input type="checkbox"/>	Physiotherapist	<input type="checkbox"/>		

## 3. Programs and Activities conducted to support young adults with type 1 diabetes

In the following three areas, please describe any programs, activities or resources your organisation currently undertakes or commits to **specifically for young adults (16-23) with type 1 diabetes** leading up to and during the transition period (from child/adolescent services to adult services).

**Mental Health** (eg. counsellors, support services & programs etc): \_\_\_\_\_

**Peer Support Programs:** \_\_\_\_\_

**Transitional Planning** (i.e. involving healthcare team, young adults/parents to manage the move between child/adolescent and adult services) \_\_\_\_\_

Please feel free to go onto a separate page or provide copies of any materials you have generated in these areas.

**Please return to Susannah Wilson via susannah@cubepr.com.au/ or fax 02 9377 1199 by Friday 22 December 2006. Thank you for your assistance.**

Your right to privacy is respected. The collation of personal information provided in this form will be used solely for the purposes of Cube in collating the survey results. Only de-identified data will be provided to Diabetes Australia, JDRF and Eli Lilly. The survey results will be published in a report using de-identified data only and will be freely available to interested services.



