



Ipsos-Eureka
Social Research Institute

Review of Transition of Young Adults Clinics

FINAL REPORT – ATTACHMENT 6: LITERATURE REVIEW

Prepared for: Department of Human Services

Ipsos-Eureka Ref: F5042

Date: 28 October 2008

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This introductory section provides an overview of the purpose of, and outcomes from, this literature review

INTRODUCTION

This literature review provides an overview of current research and activities regarding the transition of young adults with complex needs from paediatric to adult services. The review is not limited to work conducted in Australia, but examines the outputs and status of work undertaken worldwide.

This is not intended to be a document which reviews *all* available literature addressing the transition concept, rather it aims to inform a research project being conducted by the Ipsos-Eureka Institute of Social Research, on behalf of the Department of Human Services, Victoria. Specifically, its purpose is to assist the research team with the development of a set of detailed criteria for the evaluation of the Young Adults Transition Clinics which have been established in Victorian health services to date.

The literature examined in this paper includes publicly available information published in refereed academic journals, in periodicals, in documents published by government departments and professional organisations, as well as other information found on-line.

The Harvard referencing system has been adopted throughout this review. A full list of references is provided at Appendix A of this document.

This section outlines information in the literature which pertains to the definition of the transition concept

WHAT IS TRANSITION?

Defining transition

The most widely cited definition of 'transition' in the literature is that developed by Blum, Garell, Hodgman and Slap (1993), as outlined in their *Transition to Adult Health Care for Adolescents and Young Adults with Chronic Conditions Position Paper*, written on behalf of the Society for Adolescent Medicine in the United States. Blum et al. define "transition" as "the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-oriented health care systems". This definition has been cited in work published by researchers and clinicians worldwide, including that of Bennett, Towns & Steinbeck (2005), Cutler and Brodie (2005), Viner (1999) and Remorino and Taylor (2006), to name a few. A broader definition of transition is presented on the transitions website of the Royal Children's Hospital, Melbourne: as "the planned move of young people from paediatric health providers to adult providers/services" (Royal Children's Hospital, 2007).

While no other stand-alone definitions of "transition" were identified, authors have identified particular features of transition, including that transition is "complex" (Cutler & Brodie, 2005) and that it is a guided educational and therapeutic process, not simply an administrative event (Viner, 2001; Remorino & Taylor, 2006).

Blum, Hirsch, Kastner, Quint and Sandler (2002) identified the goal of transition, rather than defining it, in the Consensus Statement on Health Care Transitions for Young Adults with Special Care Health Needs prepared for the American Academy of Pediatrics, the American Academy of Family Physicians and the American College of Physicians – American Society of Internal Medicine:

The goal [of transition] is to maximise lifelong functioning and potential through the provision of high quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood.

In addition, Cutler and Brodie (2005) highlighted that the outcome of a successful transition is maximisation of the young person's quality of life, through high-quality, uninterrupted health care services, while Blum et al. (2002) reported that the ultimate goal of transition is to facilitate the development of successful self-management in young people with chronic conditions.

According Melbourne authors Kennedy, Sloman, Douglass and Sawyer (2007), the concept of transferring young people's clinical care from a paediatric to an adult health-care setting is not new, however to date transition has been managed on an *ad hoc* basis. The authors noted that transition has tended to be managed on a department-by-department basis, rather than being incorporated within any hospital or state-wide planning processes.

Why is transition important?

Researchers and clinicians have identified various reasons as to why the concept of transition is important. Firstly, transition is increasing in importance as more young people with complex disabilities and health needs are living well into adulthood, and as a result, need to transition from paediatric to adult health care services (Sloman, 2005; Viner, 2001). Sloman (2005) highlighted that a growing number of young people with developmental disabilities and/or other complex medical needs are surviving into young adulthood and beyond, partly as a result of significant advances in medical sciences and technologies (Sloman, 2005). This equates to an increasing trend in the demand for adult health services by young people with complex needs, where adult health services have not traditionally treated patients of this nature.

Second, effective transition is shown to improve patient health and life outcomes. For instance, studies of children with cystic fibrosis (Court, 1993, cited in Remorino & Taylor, 2006) and diabetes (Nasr, Campbell & Howatt, 1992; cited in Remorino & Taylor) have shown that effective transition programs improve health outcomes and the quality of life. Further, a well-timed transition from child-oriented to adult-oriented health care allows young people to optimise their ability to assume roles and functioning (Blum et al., 2002). A successful transition program will enhance a young person's autonomy, provide them with an increased sense of personal responsibility and facilitate self-reliance (Rosen, Blum, Britto, Sawyer & Siegel, 2003).

Transition has been described as "one of the greatest challenges facing paediatricians" (Remorino & Taylor, 2006). Retaining young adults with complex health care needs in paediatric services and not transitioning them into adult care comes with an array of problems. "Older adolescents deserve to be treated more as adults than as children. Keeping young adults in the paediatric system is working against this goal in many levels...." (Bennett et al., 2005).

The consequences of not undertaking transition, or not managing the transition properly, are argued to result in a range of negative outcomes for the patient. As noted by Kennedy, Sloman, Douglass & Sawyer (2007), failure to acknowledge and plan for transition to adult health care may result in

patients being “lost in transition”. In other words, without effective transition, as they grow into young adults, patients run the risk of not finding the most appropriate adult health care provider, or risk dropping out of the health care system altogether. This may result in a lack of continuity of care and reliance of crisis services, and as such, significant adverse health consequences (Fleming, Carter & Gellibrand, 2002; cited in Bennett et al., 2005; Kennedy et al., 2007). Remorino and Taylor (2006) emphasised the importance of understanding that adolescence is a time when young people are often at their most vulnerable (due to physical, emotional and psychosocial influences), and as such, there a greater risk that young people could drop out of the health system if not properly managed at this delicate time. In addition, it is critical that clinicians manage the transition process appropriately, as an abrupt transfer, particularly when precipitated by crises or an inability of the paediatric services to deal with adherence problems, may well be interpreted by young people as punishment and rejection by their previous carers (Viner, 2001), again, increasing the risk they will drop out of the health care system altogether.

This section provides an overview of information in the literature addressing ingredients for effective transition

WHAT MAKES FOR AN EFFECTIVE TRANSITION?

The previous section of this review highlighted the importance of effective transition for young adults with complex health needs. Much of the work that has been conducted with respect to transition of young adults to date has focused on identifying the requirements for an effective transition process. With that, there has been preparation of a wide range of documents, including best-practice guides, guiding principles and 'how-to transition' guides for health services, their patients and families alike, to help effective transition happen. However, as highlighted by Viner (2001), there has been no evaluation of the effectiveness of different approaches to transition. As reported above, Kennedy (2007) noted that to date, transition has tended to be managed on a department-by-department basis, rather than being incorporated within any hospital or state-wide planning processes. Thus, there is no formally recognised 'best practice' approach which has been consistently adopted.

With the aim to understand the requirements for essential transition, the following discussion highlights the key themes emerging upon an analysis of work completed by:

- Sloman (2005), Royal Children's Hospital, Melbourne;
- The Greater Metropolitan Clinical Taskforce, New South Wales (2006);
- The Department of Health and the Department of Education and Skills, United Kingdom (2006);
- Blum et al. (2002), American Academy of Pediatrics;
- Reiss, Gibson and Walker (2005), Institute for Child Health Policy, University of Florida;
- Rosen et al. (2003), Society for Adolescent Medicine; and
- Viner (2001), Middlesex Hospital, United Kingdom.

Recommendations developed by each of the abovementioned authors are provided at Appendix B to this paper.

The timing of transition must be appropriate

Essentially, all of researchers, clinicians and policy-makers who have examined the issue of transition of young adults have concurred that the timing when transition occurs is critical; particularly the time at which transition commences.

Viner (2001) emphasised that there is “no right time” for transition, and a flexible approach is important in terms of deciding when transition should commence. Most authors, however, agreed that transition should begin early, to allow sufficient time for planning and the move to adult-oriented health care. Authors also emphasised that all health care, whenever provided, should be developmentally appropriate.

For instance, Cutler and Brodie (2005) recommended that transition should begin when the young person is 13 years-old. Blum et al. (2002) suggested that a health care transition plan should be created by the time the young person is 14 years-old; while Sloman (2005) suggests that discussion regarding transition should be initiated in early/mid-adolescence.

The Department of Health, UK (2006) and the Greater Metropolitan Clinical Taskforce, NSW (2006) did not specify an age for transition commencement, although they each emphasised that timing for transition should be agreed to by clinicians, the young person and the young person’s family. Similarly, Rosen et al. (2003), while not recommending a particular age for transition commencement or completion, highlighted the importance that all services need to be appropriate for the young person’s chronological age, as well as their developmental attainment.

Viner (2001) considered that transition should not occur until the young person in question has completed the developmental tasks of adolescence, arguing that a transition target age of 18 years-old, or school-leaving age, is best. However, he did not refer to whether this was when the topic of transition should first be raised with the young person and/or their family, or whether this was when the formal “transfer” of the young person from being a paediatric health service patient to an adult health service patient. Avoiding the main “transfer” of a young person to an adult services during a particularly stressful time (for example, final high school exams) is also recognised (Sloman, 2005; Viner, 2001).

Transition should involve a period of preparation and education

The key reason why transition should commence early is so that the young person, their family and/or carer, as well as the practitioners, have sufficient time to prepare for the young person to leave paediatric care for adult care. This includes educating the young person and their family as to what transition is and what the process will involve, educating the young person about their health condition

and health care rights, and educating the young person and their family about the adult health care environment, and how it is different from paediatric health care services.

Viner (2001) suggested that “educational interventions should discuss adolescents’ understanding of the disease, rationale of the therapy, source of symptoms, recognising deterioration and taking appropriate responses, and how to seek help from health professionals and how to operate within the medical system”. He also suggested that leaflets about the transition program and details of the adult service should be provided in clinic settings from early adolescence; and that at this time, young people should be educated about the timing of key events in the transition process, as well as their health care rights. Similarly, the Department of Health, UK (2006) suggested establishing a preparation and education program for the young person and their parent, which would involve identification of the necessary skill set to enable the young person to function in the adult health service.

Sloman (2005) suggested preparing young people for a different system in a constructive and informative manner, and that the provision about ongoing care provision and who may be providing ongoing care, is essential.

MacReady (2002) acknowledged that limitations due to a young person’s cognitive ability may limit their ability to take in information with regard to their transition process. However to the extent that their cognitive abilities allow, she argued, “children with special health care needs should learn as much as possible about their condition and be able to impart at least some of the basic health related information, such as weight, height and Social Security Number. This will help to ensure that the patient becomes an independent adult with a productive future” (MacReady).

Young people and their families and/or carers should be involved in the transition process

Cutler and Brodie (2005) emphasised the need for transition care to be “patient-centred”. One way of achieving this is ensuring that young people and their families and/or their carers should be involved in the transition process throughout its lifespan.

Sloman (2005) highlighted that the involvement and inclusion of young people in the development of a plan for transition is vital to the success of the overall transition process. This is supported by the Greater Metropolitan Clinical Taskforce, NSW (2002), who in their Generic Guiding Principles for transition, suggested that transition planning should adopt a clinician and consumer-designed framework, advocating a team/partnership structure approach to continuity of care. Blum et al. (2002) and the Department of Health, UK (2006) made similar suggestions.

The transition process should be co-ordinated and continuous

Another common theme emerging regarding effective transition is that the transition process needs to be co-ordinated and continuous, with minimum disruption to health care provision. Viner (2001), Rosen et al. (2003), Reiss et al. (2005), the Department of Health, UK (2006), Blum et al. (2002) and Sloman (2005) have all suggested that there be a nominated individual responsible for coordinating the entire transition process for each young person undergoing transition. Specifically, Rosen et al. argued that transition is most successful when there is a designated professional, who, together with the patient and family, takes responsibility for the process. These authors also noted that having a nominated co-ordinator helps patients and families to facilitate and streamline the transition process, ensuring minimal disruption to health service provision. Westwood, Henley and Wilcox (1999, cited in Reiss et al., 2005) have also proposed that the use of “transition clinics” be adopted.

Authors have also identified the need for a “team approach” to transition, and highlight that the transition process involves a wide range of people and practitioners from different health and community services, over a long period of time. For instance, Sloman (2005) identified “a team approach is essential in order to provide a fully multi-disciplinary transfer document involving medical, nursing and allied health staff for the receiving hospital”. Sloman also recommended that clinicians include all relevant hospital departments in the transfer process (adopting the Hospital’s transfer summary record) and that clinical staff be encouraged to actively foster relationships with staff in the adult health services.

The transition process should meet the needs of a wide-range of young people

Rosen et al. (2003) argued that transition programs should be flexible enough to meet the needs of a wide range of young people, health conditions and circumstances. Each transition plan, the authors noted, should be individualised to meet the specific needs of the young people and their families.

Transition needs to incorporate the common concerns of all young people

In addition to being able to cater for each individual’s unique circumstances, researchers and practitioners have commonly reported the importance of understanding and recognising that adolescence is a significant life stage, and with it, comes a set of common concerns. Rosen et al. (2003) suggested that transitional health programs should be “prepared to address the common concerns of young people, including growth and development, sexuality, mood and other mental health disorders, substance abuse, and other health promoting and damaging behaviours”. This is highly congruent with the Principles of Transition offered by Sloman (2005) who noted that transition programs should be developed to “address common concerns of young people, including growth and development, sexuality, mood, etc.”. Similarly, Blum et al. (2002) stated that young people with chronic illnesses and conditions share the same health issues as their healthier peers. The authors

went on to state that to contribute to successful transition, health services therefore need to holistically address a range of concerns such as growth and development, mental health, sexuality, nutrition, exercise and health risking behaviours such as drug and alcohol use” (Blum et al., 2002).

Transition should be supported by effective communication channels and information flow

Accurate and relevant information flow between paediatric and adult health services, facilitated by effective communications channels, has emerged as another commonly reported factor contributing to successful transition. In exploring features of effective transition, Reiss et al. (2005) highlighted the importance of paediatric providers sharing medical histories with the adult-oriented provider. The Department of Health, UK (2006) noted information transfer as an important factor with regard to planning transition. Moreover, Blum et al. (2002) have stated that “close communication between paediatric and adult services will help bridge cultural and structural differences of the two health systems, resulting in smoother transition of young people to adult services”.

Transition should have appropriate managerial and administrative support

Viner (2001) highlighted that good practice in transition must include appropriate administrative support, both at an institutional and managerial level, and that this must be assured at both ends of the “transfer chain”. He argued that casual agreements between medical practitioners are “prone to failure” and that a formalised transfer checklist should be developed. This issue is further explored in the following section, which addresses barriers to successful transition.

This section reports an overview of the barriers to successful transition, as identified in the literature

BARRIERS TO SUCCESSFUL TRANSITION

As identified by Viner (2001), the idea of transition is not a new one; however, formal approaches to managing the transition process have only begun to emerge in the last decade; and even then, these have been undertaken in a largely *ad hoc* manner. Given that transition programs are only beginning to formally emerge, what is it that is holding back effective transition processes or preventing successful transition outcomes?

Difficulty 'letting go'

A common concern amongst authors when examining barriers to successful transition is the difficulties that young people and their families have with regard to "letting go" to their relationship with their paediatric health provider. The health provider may also have trouble letting go, after treating the patient in many instances for the whole of the patient's life. In a qualitative study examining the process of health care transitions experienced by American families, Reiss et al. (2005) identified a range of barriers to successful transition. One of these barriers was the reluctance of young adults and their families to leave familiar and trusted health care providers and settings; paediatric providers were perceived as more supportive and involved with the patient and their family (Reiss et al.). The Rhode Island Department of Health, USA (date not specified) also identified this as a barrier, coupled with "fear, anxiety or ambivalence about the transition to the adult health care system".

In a more extensive discussion of the issue, Viner (2001) highlighted "young adults are forced to lose respected and loved carers and are forced to trust new and unknown ones. Moving to adult services may also be seen as a step closer to disease complications or death, particularly with cystic fibrosis and diabetes". On the other hand, Viner considered the inability of paediatric professionals to let go

and trust the independence of the adolescent or the skills of the adult service as being “the greatest barrier to effective transition”.

Difficulty adjusting to adult health care

Difficulty adjusting to adult-oriented health care providers has also been widely identified as a barrier to successful transition. Reiss et al. (2005) found that a significant problem experienced by families during the transition process was that some adult-oriented health care providers had relatively less knowledge and training in the complex health needs of the relevant young adults. This made it difficult for young people and their families to develop trusting relationships with adult care providers. The authors reported that “this was magnified when the adult health provider was unfamiliar with the young adult’s condition and/or were unwilling to recognise the family’s or young adult’s ‘expertise’ and work with them as ‘equal partners’”. Further, the authors found that the differences in paediatric and adult-oriented health care also led young people and families to make negative assessments of adult-oriented providers’ medical knowledge (Reiss et al.).

In a similar discussion, Viner (2001) highlighted barriers to effective transition include that “adult physicians may have little interest in ‘paediatric’ diseases in adult life” and that “frantic clinics full of elderly sick patients are often alienating for young patients”. Often, the author reported, adult clinicians would give favour to elderly sick patients, as they perceived them as needing assistance more urgently than young patients, which resulted in young adults feeling isolated and a low-priority, something which they were not likely used to in paediatric care. In addition, Viner identified the risk that parents may feel left out as their ‘adult’ child transitions into an adult health service and takes on more responsibility for their own health care management: “Adult services rarely engage with families in the same way as paediatric clinics, and parents may sabotage transition if they feel excluded from all decision-making in the new setting”.

Lack of access to adult health services

The lack of availability of services within the adult sector for young adults with complex, multidisciplinary healthcare needs is also of concern (Lam, Fitzgerald & Sawyer, 2005). As identified in a study of American physicians, practitioners reported that a lack of time, a lack of reimbursement for their services and lack of psychiatric resources as their main obstacles to transitioning young people with chronic diseases (Johnson, 2007).

Time-related issues

The previous section of this paper highlighted the importance identified in the literature of getting transition timing right. Congruently, poor timing of transition is a barrier to its success. Reiss et al. (2005) identified timing as a barrier to successful transition, namely “using age as an indicator for readiness for transition, instead of developmental indicators”. In addition, Reiss et al. identified an

abrupt ending to paediatric care in the absence of a thoughtful and well planned transition to adult care, to be a barrier to effective transition.

Lack of awareness about what's available

A lack of awareness of available resources by both paediatricians and young people and their families is another frequently reported barrier to providing effective transition services. According to MacReady (2002), parents frequently cite their paediatrician's lack of knowledge about resources as a barrier to providing good adult care for their children. The Rhode Island Department of Health, USA (date not specified), in their Policy Brief addressing transition care, identified that paediatricians often do not know which adult primary care and speciality providers are qualified to provide the services that the youth needs, while on the other hand, they considered that there was a low level of awareness of the need for advanced planning for the transition to adult care amongst young people and their families. Reiss et al. (2005) identified a lack of communication between paediatric and adult health care providers as a barrier to the provision of effective transition care.

Other barriers to transition care not identified in the discussion above, but which warrant mentioning, include:

- The severity of the youth's disability and his or her level of maturity and understanding (Rhode Island Department of Health, date not specified); with Reiss et al. (2005) similarly reporting that problems associated with transition markedly increased for young adults with severely impaired cognitive ability.
- Lack of available infrastructure to support transition (Lam et al., 2005).
- Lack of adequate insurance coverage (in an American setting) (Rhode Island Department of Health; Reiss et al.).

This section reports an overview on transition activities which have been undertaken in countries other than Australia

APPROACHES TO TRANSITION: INTERNATIONAL

United Kingdom

The Department of Health and the Department of Education and Skills in the United Kingdom jointly released a paper in March 2006 (through the Child Health and Maternity Services Branch of the Department of Health) for providing best practice guidance for improving the transition of young people with long term conditions from children's to adults health services. The good practice guide aims to bring together current understanding and knowledge on the subject of transition between paediatric and adult services, relying wherever possible, on published evidence as well as opinion and expert knowledge from the USA, Canada and Australia, as well as the UK. A number of other initiatives are also being developed, subsequent to and in line with the development of the good practice guide; however, limited information about these is publicly available.

United States

While there does not appear to be any nationally coordinated policy or program with respect to transition established by the United States government, some individual States and health services have recognised the importance of transition and the need for formal approaches to transition planning. A selection of those for which information is publicly available are summarised below.

University of Washington PKU Clinic

The University of Washington PKU (Phenylketonuria) Clinic team provides resources to families of children with PKU and professionals who work with children with PKU. According to the Clinic's website, PKU is an inherited disorder, where a person with PKU has inherited the gene for PKU from

both his or her mother and father. Individuals with PKU are missing the enzyme for phenylalanine breakdown. Without following a strict diet that limits phenylalanine intake, phenylalanine builds up in the blood and can damage the brain. If phenylalanine levels in the blood stay too high for a long time, the damage to the developing brain is severe and irreversible (University of Washington PKU Clinic, 2002). The website notes that about one in every 15,000 infants born in the United States has PKU.

To assist adolescents with PKU prepare to transition out of paediatric care and learn to manage their condition independently, the PKU Clinic developed an “Adolescent Transition Curriculum” directed at adolescents of secondary school age. The Curriculum presents a range of information, educating adolescents about transition and the transition process, about PKU, information and skills they’ll need to know to manage their condition, and what to expect when they are in charge of their own medical care. The Clinic website provides a range of other tools and information sources for adolescents, young adults, their parents and health professionals.

The Curriculum is published on the Clinic’s website, at <http://depts.washington.edu/pku/transition.htm>

Rhode Island Department of Health

The Rhode Island Department of Health’s Office of Families Raising Children with Special Health Care Needs (the Office) and the Rhode Island Children’s Cabinet have identified health care transition of youth with disabilities and chronic health conditions to adult health care as a priority area. The Office has released a Policy Brief outlining its proposed implementation of a three-pronged approach to addressing transition, including a comprehensive state-wide needs assessment, family/youth outreach and education and health care provider training. To support this approach, similar to the PKU clinic, the Department’s transitions website provides a range of tools and information sources for young adults, their parents and health professionals to help facilitate successful transition. Information with regard to the degree to which the program has been implemented was not identified.

Georgetown University Centre for Child and Human Development

While it is unclear from the University’s website alone whether the Centre for Child and Human Development has established any formal transition program, it has prepared a checklist of things that young people with complex needs and their parents/families can do as they undergo transition to adult health care services, as well as advice for health practitioners.

This checklist is presented at Appendix C.

This section summarises transition activities which have occurred in Victoria and other states of Australia to date

APPROACHES TO TRANSITION: LOCAL

Victoria

The Review of Victorian Paediatric Services (the Review), completed by La Trobe University Health Management Group in 2002, identified the need for multidisciplinary teams of adult services to be developed and for overlap clinics to be established (Department of Human Services, 2002). The report identified transition as a major issue, largely due to inconsistencies in the transition experience for young adults. Overall, the situation was described as unsatisfactory, with many adults caught in a “limbo situation” (Department of Human Services).

In response to the Review’s recommendation, in 2004 the Department of Human Services commissioned the Transfer of Young Adults with Complex Needs Project. The project’s aim was to achieve the successful transition of 15-20 young adults with complex medical needs resulting from cerebral palsy and spina bifida from the RCH to St Vincent’s Health (for cerebral palsy) and Melbourne Health (for spina bifida). By its completion in June 2005, the project had achieved (Sloman, 2005):

- The establishment of clinics and piloting clinic models for the target patients at St Vincent’s Hospital and the Royal Melbourne Hospital (RMH), under the guidance of clinicians from the separately established Monash Medical Centre transition clinic.
- Actively overseeing patient transfer to adult health services for 11 young people.
- Ensuring needs and expectations of the young people, their families and the health team were met.

- Developing processes, protocols and relationships that would facilitate the routine transition of young adults from the RCH to the adult system, across Victoria.
- Informing the development of future Departmental policy regarding transition issues and service models for sub-acute services.

Roles of the transition clinics

In facilitating the transition of young adults with complex needs from paediatric to adult care settings, the Department (2007) noted that Victorian transition clinics should have in place:

- Referral processes and pathways that facilitate timely and appropriate transition from paediatric to adult care settings.
- Protocols and standard documentation to facilitate this process.
- Specialist assessment and management services for young adults with complex needs.
- A model of care encompassing client and family/carer consultation and engagement in the transition process.
- Processes and pathways for ensuring ongoing care and follow-up.
- Appropriate linkages with other disability and rehabilitation services, and mechanisms for referral to these services.
- Mechanisms to facilitate collaboration and knowledge-sharing about the complex health care needs of young adults across the continuum.

The current status of transition clinics in Victoria

Since the completion of the Transfer of Young Adults with Complex Needs Project, around 200 new clients have been seen by the transition clinics at St Vincent's and Royal Melbourne Health (RMH) (83 clients in 2006-06 and 117 in 2006-07) (Department of Human Services, 2007). Transition clinics exist at the following health services:

- Southern Health (at Monash Medical Centre), caring for young people with spina bifida, cerebral palsy and including urology and cardiology transition services.
- Melbourne Health (at Royal Melbourne Hospital), caring for those with spina bifida. Also provides cardiology, dermatology and immunology transition services.
- St Vincent's Health (at St Vincent's Hospital), caring for those with cerebral palsy. Also providing gastroenterology transition services through the Inflammatory Bowel Disease Clinic.

- Bendigo Health Care Group (Ann Caudle Campus), established in 2006 and caring for young people with spina bifida, cerebral palsy and other conditions.

It is understood that the Alfred Hospital provides immunology transition services, although no formal multiple needs clinic has been established there to date. A transition clinic at Barwon Health is also in its planning stages (Royal Children's Hospital, Melbourne, 2007).

New South Wales

The Greater Metropolitan Clinical Taskforce (GMCT) has developed a Framework of Transition Care for Young People with Chronic Childhood Illness. The purpose of the Framework document is to assist all stakeholders involved in the process of transition to manage this group of young people with chronic childhood illness through transition, to achieve successful health outcomes and enhanced quality of life for young people and their families. The document was developed as a generic tool which can be utilised by all relevant stakeholders.

In addition to outlining the series of Generic Guiding Principles for transition, as set out in Appendix B, the other key feature of the Framework is the presentation of an overarching Transition Plan for young people and their families and carers. The Transition Plan comprises 3 key phases: Preparation; Active Transition; and Integration. These are summarised below:

Phase 1: Preparation

- Formal identification of Paediatric Coordinating Team (PCT).
- Planning and preparation for active transition.
- Baseline Assessment of Readiness completed for and by young person, family/carers and staff.
- Identification, selection and inclusion of appropriate Adult Services.

Phase 2: Active transition

- Ongoing evaluation of assessment and readiness.
- Engagement of Combined Paediatric and Adult Transition Team (CTT) in partnership with young person and family/carers.
- Successful transfer to adult services.

Phase 3: Integration

- Completed transfer and integration into adult services.
- Quality outcomes evaluated.

- Assessment of readiness evaluated.

Western Australia

A Paediatric and Adolescent Chronic Diseases Transitional Care Working Party has been established under the Western Australia Child and Youth Health Network Advisory Group. The Working Party is currently beginning activities to develop a state-wide framework for transition in Western Australia, for patients transferring from paediatric to adult health care services, by identifying current major issues and challenges in transition, and identifying current best practices to address these. The Working Party's ultimate aim is "to ensure that the provision of care to patients in transition from paediatric to adult health services is planned, accessible, coordinated and continuous, as well as developmentally and psychologically appropriate, thus reducing the likelihood of adverse health outcomes, whilst meeting the expectations of the patient, their family and the transition team" (Western Australia Child and Youth Health Network Advisory Group, 2007).

CONCLUSION

The concept of transition of young adults from paediatric to adult care is increasingly being recognised as a critical component of the health care of young adults with complex needs. It is seen to result in positive health and life outcomes for the young adult and their families or carers. A range of programs addressing young adults' transition needs have been, or are in the process of being, established in health services in both Australia and overseas. Accompanying the establishment of transition services has been a large amount of work which has examined guiding principles or best practice for effective transition, as well as acknowledgment of the need to reduce identified barriers to successful transition. The overview of this work presented in this paper has been a highly useful source of information in informing the evaluation criteria for the Evaluation of the Young Adults Transition Clinics in Victoria.

APPENDIX A: REFERENCES

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APPENDIX B: PERSPECTIVES ON WHAT MAKES EFFECTIVE TRANSITION

Cutler and Brodie (2005)

In their article published in The Australian Health Consumer's 2004-5 issue, Cutler and Brodie highlighted some of the key issues they considered to be important to ensure successful transition:

- Transition should be patient-centred, flexible, responsive and coordinated. Successful transition should maximise quality of life through high-quality, uninterrupted health care.
- Discussions about transition should begin when a young person is about 13 years-old in order to allow enough time for planning. Important issues to consider include:
 - Selection of new health professionals.
 - How and when to say good-bye to the paediatric team, including how important medical information will be transferred.
 - Selection of the adult facilities.
 - Guardianship issues/role of the carer if the young person is dependent.
 - Money and equipment needs; billing, supply of medications and essential medical items and equipment.
 - Availability of outpatient facilities.
 - Young person's attainment and knowledge of their own needs.

Viner (2001): Middlesex Hospital, United Kingdom

Viner nominated the following key areas as prerequisites for successful transition in his article published in the Journal of the Royal Society of Medicine in 2001:

- A policy on timing of transfer – there is no 'right time' for transition and a flexible approach is important. Timing may be dependent on the developmental readiness and health status of the individual adolescent. Believes that transition should not occur until young people have largely completed the developmental tasks of adolescence; a transition target of 18 years, or school-leaving age, is best.
- A preparation period and education program, and identification of a necessary skill set to enable the young person to function in the adult clinic.

- Preparation must begin well before the anticipated transfer time.
 - Educational interventions should discuss adolescents' understanding of the disease, rationale of the therapy, source of symptoms, recognising deterioration and taking appropriate responses, and how to seek help from health professionals and how to operate within the medical system.
 - Young people should be helped to take responsibility for medications from as early an age as possible and should be seen by themselves in clinic visits from the age of 13 (with parents invited to join the session later).
 - A schedule of likely timings and events should be given to young people in early adolescence. Young people should be involved in developing detailed timings for their own transition.
 - Leaflets and material about the transition program and details of the adult service should be provided in clinic settings from early adolescence.
 - Young people should also be provided information about their healthcare rights and effective ways of dealing with medical staff situations, including casualty, waiting rooms etc.
- A coordinated transfer process – a coordinated process requires a coordinator. Highlights that Clinical Nurse Specialists, if available, are often best suited to run transition programs. About one year before the anticipated transfer date, adolescents should receive a detailed outline of the adult program and should undertake at least one visit to the adult clinic, preferably with parents and a trusted paediatric carer.
 - An interested and capable adult health service.
 - Administrative support – institutional and managerial – must be assured at both ends of the transfer chain. Casual agreements between doctors are prone to failure. A formalised transfer checklist should be developed.
 - Transition planning must involve primary care physicians, who may provide the only medical continuity for young people and their families during this time of continuity.

No formal evaluation of the effectiveness of different models of transition has been undertaken (and it is desperately needed).

Rosen, Blum, Britto, Sawyer and Siegel (2003): University of Michigan Medical School

The following points are the **Principles of Successful Transition** set out in the Position Paper Rosen et al.'s prepared for the Society of Adolescent Medicine in the United States:

- Services need to be appropriate for chronological age and developmental attainment.
- Transitional health programs should be prepared to address common concerns of young people, including growth and development, sexuality, mood and other mental health disorders, substance abuse, and other health promoting and damaging behaviours.
- A successful transition program enhances a young person's autonomy, an increasing sense of personal responsibility, and facilitating self-reliance.
- Transition programs should be flexible enough to meet the needs of a wide range of young people, health conditions and circumstances. Transfer of care needs to be individualised to meet the specific needs of the young people and their families.
- Health care transition is most successful when there is a designated professional, who, together with the patient and family, takes responsibility for the process. Each patient and family should have a coordinator and advocate who helps to facilitate and streamline their transition experience.

Reiss, Gibson and Walker (2005): Institute for Child Health Policy, University of Florida

These authors summarised information about effective transition in they observed in the literature:

- Begin transition early (no further details provided).
- Having paediatric providers share medical histories with the adult-oriented provider.
- Using nurses to oversee transition (Patterson & Lanier, 1999).
- Adopt the use of transition clinics (Westwood, Henley & Wilcox, 1999).
- Paediatric practitioners need to treat the ending of long-term clinical care in a thoughtful and planned manner.

Blum et al. (2002), American Academy of Pediatrics

The following **critical first steps to ensuring successful transition** to adult-oriented health care were prepared by Blum et al. for the Consensus Statement on Health Care Transitions for Young Adults with Special Health Care Needs, for the American Academy of Pediatrics, the American Academy of Family Physicians and the American College of Physicians – American Society of Internal Medicine:

1. Ensure that all young people with special health care needs have an identified health care professional who attends to the unique challenges of transition and assumes responsibility for current health care, care coordination and future health care planning. Executed in partnership with other health professionals, the young person and their families.
2. Identify the core knowledge and skills required for clinicians to provide developmentally appropriate health care transition services to young people and make them part of training and certification requirements.
3. Prepare and maintain an up-to-date medical summary that is portable and accessible.
4. Create a written health care transition plan by age 14, together with the young person and their family. This plan should include what services need to be provided, who will provide them, and how they will be financed. This plan should be reviewed and updated annually and whenever there is a transfer of care.
5. Apply the same guidelines for primary and preventative care for all adolescents and young adults, recognising that young people with special health care needs may require more resources and services than do other young people to optimise their health.
6. Ensure affordable, continuous health insurance coverage for young people with special health care needs throughout adolescence and adulthood.

Fourteen issues for consideration when planning transition services – Department of Health, UK

The 14 issues for consideration when planning transition services were set out in the Department of Health, UK's good practice guide Transition: Getting it Right for Young People:

1. Address professional and managerial issues. The biggest single obstacle to progress is in attitudes. Recognising that transition is a process, not an event, is the fundamental change of attitude that is required.
2. Recognise the differing perspectives of paediatricians, physicians and GPs. Handing patients over to another service is difficult for paediatric staff who become attached to their young patients over many years.
3. Establish dialogue between clinicians, management and commissioners and other agencies.
4. Appropriate environment.
5. Consultation with users – young people and their parents.
6. Agree a policy on timing for transfer.
7. Set up a preparation and education program for the young person and the parent: Identification of the necessary skill set to enable the young person to function in the adult clinic.
8. Plan a coordinated transfer process.
9. Identify interested and capable adult services.
10. Identify a co-ordinator. In cases where the young person has a number of different problems requiring input from different consulting teams, there needs to be a clear decision as to who will coordinate the young person's care and provide a holistic overview and integration of their various treatment and management needs.
11. Consider information transfer.
12. Monitoring and "fail-safe" mechanisms. There must be a fail-safe mechanism that ensures that the young person is regularly attending the adult clinic and has not defaulted or failed to attend or been lost to the system.
13. Ensure primary care involvement.
14. Negotiate administrative support. Institutional and management support need to be assured at both ends of the transfer chain.

Principles of Transition – Royal Children’s Hospital, Melbourne

The following Principles of Transition are set out in Sloman’s Report for the Transfer of Young Adults Complex Medical Needs Project (2005), as well as on the Hospital’s transitions website:

1. Initiate discussion regarding transition in early/mid adolescence as an integral part of the overall health care plan thus making it a normal part of caring for an adolescent with a chronic illness.
2. Transition is most successful where there is a **designated professional** who, together with the young person and family, takes responsibility for the process.
3. Young people and their family’s inclusion in the development of the **individual transition plan** is vital to the success of the process. Young people and/or their families are required to gain a significant number of new skills during the transition process. Their families and carers are often faced with a change in their role from that of primary carer to support provider.
4. Prepare them for a different system in a constructive and informative manner. Adult hospitals do run differently. Provision of specific information about ongoing care provision and by whom is essential. If services are not clearly obvious discussion with family about options available and differences in the adult system need to take place.
5. Encourage families and patients to be **assertive** and if necessary to be a strong advocate for their son/daughter.
6. Develop transition programs to address common concerns of young people including growth and development, sexuality, mood etc.
7. The process of transition to adult healthcare needs to occur within a developmental context
8. Carers need to recognize the importance of promoting the young persons’ increasing capacity for self care (commensurate with their ability)
9. A **team approach** is essential in order to provide a fully multi disciplinary transfer document involving medical, nursing and allied health staff for the receiving hospital.
10. Attention should be paid to ensuring collaboration with adult hospitals who will need to accept the responsibility of young adult patients. This requires on-going, regular communication between paediatric and adult health care services to enable clear processes to be developed for the successful transition of young people to adult services.

10 Golden Rules of Successful Transition – for practitioners – Royal Children’s Hospital, Melbourne

These 10 Golden Rules of Successful Transition are presented in the Hospital’s transitions website, on the page presenting information for practitioners:

1. Start discussions early. Communicate this to other departments involved in patients care.
2. Avoid transferring in Year 12 or during a stressful period i.e. avoid transfer during exacerbation of condition.
3. Identify a staff member to coordinate complex transfers e.g. clinical nurse co-ordinators. For these complex patients who see several different RCH departments, ONE department needs to communicate clearly their commitment to take on the responsibility for the coordination of a patients transfer.
4. Ensure patient has had the opportunity to spend time alone with their RCH team (i.e. without parents) before moving on to adult care and has successfully completed the health care skills checklist.
5. Include all other relevant RCH departments in the transfer process using the transfer summary record or similar document and provide the patient with a copy.
6. Clinical staff should actively foster relationships with adult colleagues, and create opportunities for consultation and education where required. Establish mechanisms for regular review of patients transferred/to be transferred.
7. Ensure patient has a clear understanding that they should continue to attend RCH until attendance at their first appointment at the adult hospital. This prevents a situation of 'in limbo' which can occur in poorly managed transfers. Reiterate to family that the patient should still attend the RCH until fully established with adult health care provider.
8. Encourage patient to feedback to paediatric site details of their transfer experience via the transition survey on the website.
9. Underlying principles of good transition are: Communication, Compassion and Common sense.
10. Seek help if you come across barriers to Transition. Transition Co-ordinator: 9345 4858 or www.rch.org.au/transition

Generic Guiding Principles for practitioners providing transition care - Greater Metropolitan Clinical Taskforce, NSW

These Generic Guiding Principles for practitioners providing transition care are set out in the Transition Care for Young People with Chronic Childhood Illnesses Framework document, prepared by the NSW Greater Metropolitan Clinical Taskforce (last updated April 2006):

- Transition is a planned process which is undertaken early and over time, by the paediatric health care worker/s, young person and family, with the objective of integrating into adult services by identifying and engaging adult services at an appropriate time. Planning and preparation continues in a collaborative team approach with stakeholders, in particular adult services, until transition is achieved.
- Transition planning should aim to provide health care that is uninterrupted, coordinated, developmentally appropriate and psychologically sound and it should meet the expectations of the young person and the transition team.
- Transition planning should aim to minimise health problems and enhance the quality of life.
- Planning and preparation should be managed to appropriate and agreed timeframes.
- Planned transition should facilitate access to adult health care providers and relevant support services thus ensuring optimal use of health services.
- Transition planning should utilise a clinician and consumer designed framework, which supports a team/partnership structure approach to continuity of care achieving better outcomes for chronically ill young people.
- Transition planning should develop and strengthen clinical networks, which improve access to the best possible care.
- Successful adolescent transitional services require the support of general practitioners, community resources and non-government organisations.

APPENDIX C: THINGS TO DO TO PREPARE FOR TRANSITION

National Center for Cultural Competence, Georgetown University (2001)

Downloaded from: <http://www11.georgetown.edu/research/gucchd/nccc/projects/cyshcn.html#what>
on 23 January 2008.

Things to Do to Prepare for Transition

What parents/families can do ...

As parents begin the process of transition their young adults from pediatric/adolescent care to adult health care, these considerations may be helpful in supporting your child through this process.

1. Find out the policies regarding the age and service policy limits for your child's pediatric/adolescent practice.
2. Find out your health care insurer's policy regarding the age limit of services under pediatric/adolescent care.
3. Begin discussing transition at 14-15 years of age with both your child and the health care provider. Foster the development of an independent relationship between your child and his/her health care practitioner. This provides a foundation for developing future relationships with adult health care providers.
4. Request that your pediatric/adolescent health care practitioner recommend an adult provider who is sensitive and knowledgeable of special health care needs and disabilities.
5. Find out how your insurer handles referrals and consultations for transition to adult health care.
6. Explore your state's legal requirements about the need for limited guardianship based on your child's unique needs.

What youth can do ...

There are a number of things you may consider as a young person preparing for or transitioning to adult health care.

1. Make a list of questions to ask your prospective health care practitioner such as:
 - Have you ever had a patient with special health care needs?
 - Are you willing to spend time with my pediatrician/adolescent health care provider to gain an understanding of my unique health issues?
 - Do office visits include a time for me to talk to you about my concerns?
 - Can I talk with you directly if I call you on the phone? Do you respond to patient e-mail inquiries?

2. Find out how your health insurance coverage works.
3. Keep a notebook or journal of current medications, specialists and other information that is relevant to your care.
4. Remember that your parents and family members are there to support you, and inform them when issues are too difficult for you to handle alone.

What health care practitioners can do.....

As a health care provider who is currently or is preparing to serve youth with special health care needs, consider the following suggestions to help make for a smooth transition process.

1. Use strategies that involve family for those youth who need and prefer this approach to health care. Many young people with special health needs or disabilities have received health care within the context of family. Mothers, fathers or siblings have often been a companion, supporter, advocate or facilitator in their care. They have a tremendous investment in the health and well being their family member with special health needs. Careful consideration should be given to how to involve families, in a meaningful manner, while simultaneously maintaining the highest level of independence and privacy for the youth.
2. Use culturally and linguistically competent practices. The concept of family, how family is defined and who comprises family is deeply rooted in culture. Perceptions of health, well being, illness and disability are also culturally based. Understanding the implications of these values and beliefs systems will enable practitioners to more effectively serve young adults and their families. Additionally, given how diverse the U.S. society is, health care providers also should consider the need for language access and linguistic competence in their practice.
3. Use a team approach to facilitate the transition process. The transition process is facilitated by collaborating with the youth, family members, referring pediatric/adolescent health practitioner and other specialists to gather helpful information. In addition to health care, individuals with special health needs or disabilities often require services and supports from an array of other systems such as social services, vocational rehabilitation and mental health. In some instances, physicians are required to authorize services. Your familiarity with these systems can be of benefit to the young adult and his/her family.
4. Access resources that may help with both transition and delivery of health care to young adults with special health needs. While there is no Federal mandate that insures transition to adult health care systems, there are resources that can help with this process. One example is the Healthy and Ready to Work demonstration grants funded by MCHB in many states. For more information, see <http://www.mchbhrtw.org/>



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