

Transitional Care for Rheumatology Patients in New Zealand

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A Practice Project Submitted to
Auckland University of Technology
In partial fulfilment of the requirements for the degree
of
Master of Health Practice (MHPrac)

2011

School of Health and Environmental Sciences

Table of Contents

TABLE OF CONTENTS.....	I
LIST OF TABLES	IV
LIST OF FIGURES.....	IV
ATTESTATION OF AUTHORSHIP.....	V
ACKNOWLEDGEMENTS.....	VI
ABSTRACT	VII
CHAPTER 1 BACKGROUND.....	1
PAEDIATRIC RHEUMATOLOGY IN NEW ZEALAND	1
<i>The National Rheumatology Team.....</i>	2
TRANSITION TO TRANSFER.....	3
EVIDENCE OF NEED FOR TRANSITIONAL CARE	4
<i>The Experience of Young People and Families</i>	4
<i>Morbidity of Rheumatological Conditions in Adolescence and Young Adulthood.....</i>	5
<i>Risk Factors in Adolescence</i>	5
<i>Psychosocial Development</i>	6
AIMS OF PROJECT	7
CHAPTER 2 PRACTICE PROJECT DESIGN	8
BACKGROUND.....	8
THE FRAMEWORK (METHODOLOGY)	8
PHASE 1 ASSESS (NEED FOR CHANGE IN PRACTICE) AND PHASE 2 LINK (PROBLEM, INTERVENTION & OUTCOMES)	9
<i>Consulting Stakeholders</i>	9
<i>Collecting Internal Data.....</i>	10
<i>Comparing External Data.....</i>	11
<i>Identifying the Problem</i>	11
<i>Linking the Problem, Interventions and Outcomes.....</i>	11
PHASE 3 SYNTHESISE (BEST EVIDENCE).....	12
PHASE 4 DESIGN (PRACTICE CHANGE)	12
PHASE 5 IMPLEMENT AND EVALUATE AND PHASE 6 INTEGRATE AND MAINTAIN	13
CHAPTER 3 FINDINGS.....	14
INCLUDING STAKEHOLDERS.....	14
<i>Key Stakeholder – The Patients.....</i>	15
Preparation for Adult Services	15
Flexibility.....	16
Positive Attitudes	16
Time to Practice.....	16
<i>Key Stakeholder – Parents</i>	16
<i>Key Stakeholders – The National Team.....</i>	17
<i>Key Stakeholders – Health Professionals</i>	17
Survey Development	18
Survey Administration.....	19
Results	19
Respondent Characteristics.....	19

Summary of Survey Results	22
<i>Key Stakeholders – Ministry of Health/National Board</i>	22
<i>Key Stakeholders – Service Manager and Nursing Leader</i>	22
COLLECTING INTERNAL DATA ABOUT CURRENT PRACTICE	23
<i>Historical Knowledge of the Service</i>	23
<i>Transfer Audit</i>	23
<i>Audit Process</i>	24
<i>Results</i>	24
COMPARING INTERNAL DATA WITH EXTERNAL DATA.....	26
<i>Diabetes Service Starship</i>	26
<i>Cystic Fibrosis</i>	27
<i>The Royal Children’s Hospital Melbourne (RCH)</i>	28
<i>Toronto SicksKids ‘Good2Go’, Canada (http://www.sickkids.ca/good2go/)</i>	28
<i>Janet McDonagh (DREAM TEAM) UK</i>	29
<i>Summary of External Data</i>	29
IDENTIFYING THE PROBLEM.....	30
<i>The Driving Forces</i>	31
Increased Independence/Autonomy of Young person.....	31
Improved Preparation and Planning	32
Support of Key Stakeholders (Service Manager and Ministry of Health)	33
Support/Advocacy of Clinical Stakeholders	34
Activity of External Sources.....	34
<i>The Barriers or Restraining Forces</i>	35
Staff Attitude	35
Family Resistance/Fear	36
Inadequate Resources/DHB Differences	36
Differences between Adult and Paediatric Services	36
Summary and Identification of the Problem	37
LINKING THE PROBLEM, INTERVENTION AND OUTCOME	37
<i>Outcome Measures</i>	38
<i>The Patient will be Prepared for the New Service Prior to Transfer</i>	38
The Patient will Establish Independent Health Behaviours.....	38
Patient has Disease Related Knowledge.....	39
<i>Adequate Exchange of Information will Occur</i>	39
Improvements in Health-Related Quality of Life	39
Satisfaction with Care	40
SUMMARY.....	40
CHAPTER 4 SYNTHESISE THE BEST EVIDENCE	41
SEARCH STRATEGIES	41
SOURCES OF EVIDENCE.....	42
People	43
Process	43
Place	43
Paper.....	43
<i>Policy</i>	43
<i>Transition Co-ordinator</i>	44
<i>Timing of Transfer</i>	45
<i>Readiness to Transfer</i>	46
<i>Individual and Flexible Transition</i>	46

<i>Collaboration</i>	47
Models of Transition	47
SUMMARY	48
CHAPTER 5 IMPLEMENTATION	49
PROPOSED PRACTICE CHANGE	49
DEVELOP A CLEAR PROCESS TO GUIDE TRANSITION	50
<i>Evolution of the Document</i>	50
CORE PRINCIPALS FOR TRANSITION	52
<i>Part One</i>	53
<i>Part Two</i>	53
<i>Part Three</i>	53
INDIVIDUALISED TRANSITION PLAN	54
<i>Co-ordination</i>	56
RESOURCES	56
<i>Resources for Young People</i>	56
<i>Resources for Rheumatology in New Zealand</i>	57
<i>Technology</i>	57
IMPLEMENTATION PLAN	58
<i>Phase 1- Approval of the RBP</i>	58
<i>Phase 2- Education about the RBP to Clinicians</i>	58
<i>Phase 3- Introduction of the Transition Plan to Patients/Parents</i>	59
EVALUATION	60
1. <i>Patient will be prepared for the new service prior to transfer</i>	60
2. <i>Patient will establish independent health behaviours</i>	60
3. <i>Patient will have disease related knowledge</i>	60
4. <i>Adequate exchange of information will occur</i>	61
5. <i>Patients and families will be satisfied with service</i>	61
CHAPTER 6 DISCUSSION	62
COMMENTS ON THE MODEL	62
CHALLENGES AHEAD	63
LOOKING TO THE FUTURE	64
<i>For Parents</i>	64
<i>For Clinicians</i>	64
<i>For Patients</i>	65
CONCLUSION	65
REFERENCES	67
APPENDIX 1: CLINICIAN SURVEY RESPONSE SUMMARY	76
APPENDIX 2: PAEDIATRIC SOCIETY OF NEW ZEALAND POSITION STATEMENT	87
APPENDIX 3: THE RECOMMENDED BEST PRACTICE	90

List of Tables

Table 1: Rating of Barriers to Setting up Formal Transition.....	21
Table 2: Individual Transition Plan	55

List of Figures

Figure 1: Rosswurm and Larrabee's (1999) Model for Evidence Based Practice	9
Figure 2: Multidisciplinary Involvement in Transition	20
Figure 3: Transfer Audit.....	24
Figure 4: Forcefield Analysis	31
Figure 5: The Four P's of Transitional Care (McDonagh, 2007, p. 480)	43
Figure 6: Key Elements from Initial Brainstorm	52

Attestation of Authorship

“I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.”

Signed:

Date:

Acknowledgements

I would like to acknowledge the following people for their substantial help and support during this project:

- Annette Dickinson for her support as supervisor and co-researcher for the focus group study.
- Starship Foundation for awarding the scholarship that enabled me to complete this project.
- The National Paediatric Rheumatology Service for their ongoing support and encouragement.
- Shoba Nayar for editing the final document

Abstract

It is generally agreed that health service transition is an essential component of high quality health care (Jackson & Pencharz, 2003). The implementation of a transitional care program ensures the safe and effective transition of young people with rheumatological conditions from paediatric to adult service.

The aim of this project was to develop and implement a recommended best practice to guide the transitional care program for the New Zealand Paediatric Rheumatology Service. Rosswurm and Larrabee's (1999) model for evidence based practice provided the framework for the development of the recommended best practice and the implementation and evaluation plan for the change in practice.

Rosswurm and Larrabee's (1999) model contains six phases: assessment, linking problems, interventions and outcomes, synthesising best evidence, designing practice change, implementing and evaluating, and integrating and maintaining. Given the time restraints for this project only phases 1-4 were completed. However, this report outlines the planning for phases 5-6 which will be completed by the National Rheumatology Service as part of the quality plan.

The assessment phase revealed that clinicians, patients and families were supportive of the development of a transitional care programme. They called for early preparation and planning and the need to have a flexible individual approach. Review of the transition programs in place around New Zealand and internationally provided models that could be adapted to suit the New Zealand rheumatology environment. However, the notion of a prescriptive and rigid plan for transition was considered inappropriate; instead a list of core principles were developed to guide the service and provide a basis for the recommended best practice.

To date there has been a lack of robust evaluation of transition programs. This report outlines clear plans and outcome measures for evaluation of the paediatric rheumatology transition program.

This report highlights the need for further research, particularly in relation to group education interventions, patient and family satisfaction, and the use of 'transition readiness' questionnaires as a means of measuring readiness for transfer. Other important areas for future research include investigating the long- term outcomes of a transition program on adult health attitudes and behaviours.

Chapter 1 Background

The care of children with chronic illness has changed markedly over the last 15 years. The numbers of young people with chronic conditions are growing (S. Sawyer, S. Drew, M. Yeo, & M. Britto, 2007). Due to improvements in survival and treatment regimes young people with chronic illness and/or disability are surviving into adulthood and this means that increasing numbers will make the move from paediatric to adult healthcare. It is this 'move' and the issues surrounding it that have gained increased attention within all speciality areas of paediatric healthcare.

In an attempt to smooth the upheaval for patients moving from paediatric to adult care, the development of multidisciplinary transition services have become popular and essential parts of policy development within paediatric hospitals (Russell. Viner, 1999). In New Zealand the need for such services is no different from the rest of the world. In 2009 the National Paediatric Rheumatology Service was established and one of the key service objectives was to set up a transition program or process for New Zealand rheumatology patients. Chapter one of this report will outline the pertinent background information and contextual issues that led to the development of this practice project, the aim of which is to develop and implement a Recommended Best Practice (RBP) to guide the transitional care program for the New Zealand Paediatric Rheumatology Service.

Paediatric Rheumatology in New Zealand

In 2008 the New Zealand Ministry of Health approved funding to develop a dedicated national paediatric rheumatology service. Prior to 2008, the service consisted of one adult rheumatologist, with an interest in paediatrics who was only able to commit 0.15 FTE to the paediatric rheumatology patients of New Zealand. The service was overloaded with patients who were receiving sub- optimal treatment or surveillance and there were many over age patients (over 18 years of age). As a member of the New Zealand Rheumatologic Association (NZRA) the rheumatologist raised concerns about the risks to patients, including the lack of ability to appropriately monitor patients on cytotoxic and biologic medicines, the lack of time to assist with

treatment plans of newly diagnosed patients and long waiting times for paediatric patients to be seen by a specialist. Three concerned members of the NZRA formulated a proposal to the Ministry of Health, outlined their concerns and proposed the development of a National Service. Finally, in 2009, the Ministry of Health approved funding and saw the appointment of a multi-disciplinary rheumatology team that would serve the children and families in New Zealand.

The National Rheumatology Team

The multi-disciplinary team was divided in two in order to meet the needs of the children and young people across New Zealand. One team, based in Auckland at Starship Children's Hospital, consists of a physiotherapist, occupational therapist, two part time consultant rheumatologists and the clinical nurse specialist. This half of the team cares for children from the North Island (excluding the Taranaki, Whanganui, Hutt and Wairarapa DHB's). The second half of the team, based in Hutt Valley, includes a consultant rheumatologist, clinical nurse specialist and physiotherapist. They are responsible for care in the South Island and the DHB's mentioned above.

The National Rheumatology Service provides care to the majority of children within New Zealand who have a rheumatologic condition. This encompasses a wide variety of inflammatory and non-inflammatory conditions of the musculoskeletal system as well as conditions of non-infectious multi-system inflammation. Some of these conditions are listed below:

- Juvenile Idiopathic Arthritis (JIA)
- Systemic Lupus Erythematosus (SLE)
- Juvenile Dermatomyositis (JDM)
- Vasculitis
- Hypermobility
- Connective tissue disease
- Scleroderma
- Chronic recurrent multifocal osteomyelitis (CRMO)

Within paediatric rheumatology, JIA comprises the largest patient group with over 1000 children and young people under the age of 20 years affected by arthritis in New Zealand at any one time. Over the last 20 years, the care of children and young people with JIA has changed immensely. In the past JIA was thought to "burn

out” when the child grew up and little consideration was given to the consequences of this condition in late adolescents and young adulthood. Many patients and caregivers were told that the condition would resolve itself by the teen-age years. However this is now known not to be the case. Studies in JIA report that a quarter of cases begin in adolescence and that at least one third will have active inflammation as adults requiring transfer to an adult rheumatology service (Oen, 2002; Shaw, Southwood, & McDonagh, 2004). The other conditions listed above, such as SLE, JDM and the vascular diseases, are also conditions that can require ongoing need for health services despite the patient growing into adulthood. SLE, in particular, if diagnosed at a young age (early onset) has been shown to be associated with more aggressive disease and worse outcomes (Tucker, 1998; Tucker et al., 2008). It is clear that many young people with rheumatology conditions will require eventual transfer to adult services; yet currently, there is no formal transitional care program to facilitate this process.

Transition to Transfer

One of the great challenges of working with young people who have chronic conditions is preventing them from getting lost in the transfer between paediatric and adult healthcare (J. E. McDonagh & Viner, 2006). The term *transition* is a hot topic in health circles and has come to the forefront of discussion in paediatric and adult services alike. Existing literature is persuasive on the need to improve transition services and it is generally agreed that health service transition is an essential component of high quality health care (Jackson & Pencharz, 2003).

Many clinicians within paediatric healthcare use the terms ‘transition’ and ‘transfer’ interchangeably. It is a common mistake to confuse transition with transfer and it is important to understand the distinction between the terms (Hersh, Pang, Curran, Milojevic, & von Scheven, 2009). The Society of Adolescent Medicine has defined transition as:

The purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult oriented health-care systems. (Blum et al., 1993)

This definition implies that a *process* is involved and requires years of education and preparation to address the medical , psychosocial and educational/vocational aspects of adolescent care (Janet E. McDonagh, 2007a). On the other hand, transfer is a *single event* during the much longer process of transition and is defined as the point at which a new provider assumes the medical care of a patient (J. E. McDonagh & Viner, 2006).

It is simplest to view transfer as one element of the transition process and to remember that the issues pertinent to transition must be continually addressed prior to, and after, the transfer of care occurs (Chira & Sandborg, 2004). This makes transition an issue for both paediatric and adult services. When these issues are neglected or overlooked, patients and families can feel ill prepared and abandoned at the time of transfer; one of many reasons why a transition process is needed (Chira & Sandborg, 2004).

Evidence of Need for Transitional Care

So why is a transition process needed? Once adolescents reach a certain age can they not just be transferred and left to an adult service to chase after them?

The answers to these questions are complex and will be addressed by looking at four different areas: 1) the experience of young people and families, 2) morbidity of rheumatological conditions in adolescence and young adulthood, 3) risk factors in adolescence, and 4) impact of psychosocial delays.

The Experience of Young People and Families

In one of the first early transition studies, Shaw, Southwood and McDonagh (2004) looked at user perspectives of transitional care for adolescents with JIA. They found that patients and families were frustrated and challenged by the lack of support and preparation for transfer to adult services in the absence of a transition care program. Young people and their families are often reported to be reluctant to leave the paediatric environment due to the length of time spent there, the trust that has been built up and fear of the unknown. Young people and their families are aware that transferring to adult services is an inevitable event and they clearly call for

preparation, planning and a proactive approach that can only be achieved through a transition process (Shaw et al., 2004).

Morbidity of Rheumatological Conditions in Adolescence and Young Adulthood

There is significant morbidity associated with rheumatological conditions including osteoporosis, increased anxiety and depression (Foster, Marshall, Myers, Dunkley, & Griffiths, 2003; PH. White, 2008). In a 2005 Canadian study, young people with JIA, when compared to those without JIA or with another chronic disease, reported greater negative effects on measures of mental health, higher incidence of other chronic illnesses and subsequent higher use of health services. Further, these young people were more likely to be limited in their activities and reported a negative impact on school and other home activities (Adam et al., 2005). Addressing the impact of rheumatological diseases on young people is important and an integral part of transition planning. It is also central in the planning of health and disease education, helping the young person with decision making and promoting self care (JE. McDonagh, Shaw, & Southwood, 2006).

Risk Factors in Adolescence

Considering risk factors in adolescence is always challenging for those working in paediatrics. The reality is risk behaviour, to a certain extent, is a normal part of growing up. Adolescence is the time when adult health promoting and self-management behaviours become established, and it is important that paediatric health services accept some responsibility for shaping and influencing young people's health attitude as they move on to adulthood.

There is a common belief (or denial) among paediatric health professionals that young people with chronic conditions display less risk behaviour than their healthy peers because they are more aware of their own health risks. This may not be the case. The truth is that sexual activity and substance use among young people with chronic conditions is found to be comparable with healthy peers (Aasland, Flato, & Vondivik, 1997; Wilkinson, 1981). It is important for the health care team to consider these facts when working with adolescents in rheumatology as many of the medications put the young person at higher risk for sexually transmitted disease due

to immune suppression and can have negative effects on the liver function (J. McDonagh & White, 2008).

Transition programs seek to address some of these important issues and offer the opportunity to discuss and assess youth for risk factors that may impact on the disease and transition to adulthood.

Psychosocial Development

Adolescence is a critical time of change and growth that may be disrupted by a chronic illness. In many ways, adolescence itself is filled with 'transitions'. There are many types of transition in this period, such as the movement from childhood to adolescence to young adulthood, the movement from home with family to independence or group living situations and finally the move from school to tertiary education or work. The presence of a chronic condition or rheumatological illness can be disruptive and potentially negatively impact the physical and other developmental tasks of this period. Rheumatological conditions and the medications associated with these diseases can result in slow growth and delays in puberty (P. White, 2008).

Delays in achieving psychosocial milestones, including vocational and sexual, have been reported in many chronic illnesses including JIA (J. E. McDonagh, 2007). Some authors have also identified increased unemployment among young adults with JIA; an important consideration during adolescent transition (Foster et al., 2003; Oen, 2002).

There is certainly evidence to support the benefits of a coordinated transitional care program including both improved disease control (Packham & Hall, 2002) and improved quality of life (PH. White, 2008).

Transition to adult healthcare should be seen as part of the developmental process for young people with chronic rheumatic disease so that the concept of eventual transfer to adult services can be normalised (Kennedy & Sawyer, 2008). Ultimately a transition program should help young people with childhood onset disease become independent in managing their chronic disease, while at the same time enabling them to complete the normal developmental tasks of adolescence.

Aims of Project

The transition from family oriented, developmentally focussed paediatric health services to more independently oriented adult service requires a collaborative process. In order to ensure that this process is smooth and that successful transition occurs for rheumatology patients in New Zealand a transition model for the service is imperative. Hence, the aim of this project is to develop and implement a RBP to guide the transitional care program for the New Zealand Paediatric Rheumatology Service.

Chapter 2 Practice Project Design

Background

This project grew out of a desire to improve transition services for young people. In 2009, when the National Rheumatology service was first established, several multidisciplinary team meetings occurred. These involved brainstorming, sharing ideas and plans for the service. One of the key discussions revolved around how the service cared for adolescents and young people, and who was most interested in working through the process of developing a transition program. At the time the service started there were a number of young people who were at an age when transfer was imminent.

The team agreed that it was important to identify one key member to undertake the task of designing the transition model for the team. This would involve writing a policy document that would reflect the core principles the team wished to uphold, as well as provide guidance for the unique situation of being a national service working across many DHBs. During one of the initial meetings I expressed a desire to be involved in developing the transition plan, as it was a particular interest of mine and the other members of the team had been delegated other tasks and projects. It was agreed at the first national team meeting that I would lead the development of the transition plan/process for the service.

The Framework (Methodology)

The planning of this project required a framework to guide development. Several models and frameworks have emerged over the years to help guide clinicians in their attempts to move research and theory into practice. For this project, Rosswurm and Larrabee's (1999) model for evidence based practice was chosen (refer to Figure 1, p. 9). This model was chosen as it provides a framework that guides nurses and other healthcare professionals through the process of developing and integrating an evidence based change (Rosswurm & Larrabee, 1999). The model is often described in relation to clinical based problems but also can be applied to the

development of guidelines, or in this case, a RBP. I used the six main headings to guide the project and in this chapter will discuss the methods used within each phase.

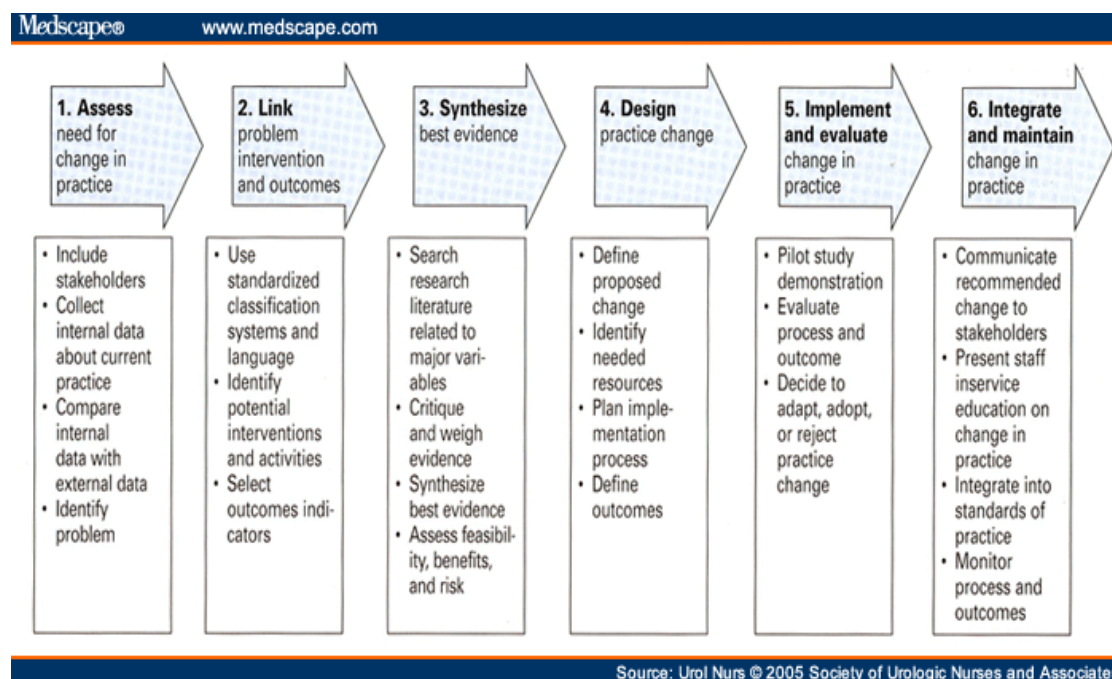


Figure 1: Rosswurm and Larrabee's (1999) Model for Evidence Based Practice

Phase 1 Assess (need for change in practice) and Phase 2 Link (problem, intervention & outcomes)

Rosswurm and Larrabee's (1999) original model showed two distinct phases of 'assessment' and 'link'; for the purpose of this report, these two steps have been combined into one phase. The results of the assessment/link phase will be considered as *findings* and will be reported in Chapter 3. Five major activities were undertaken in this phase including: consulting stakeholders; collecting internal data; comparing external data; identifying the problem; and linking the problem, interventions and outcomes.

Consulting Stakeholders

In the first assessment activity I determined who the key stakeholders were. Once identified, I used a variety of methods to gain information about their experience and

attitudes towards transition issues, as I recognised that their support and commitment would ultimately affect the success of my recommendations.

To ensure that I was meeting the needs of young people in the development of the RBP I wanted to include their point of view. I decided the best way to do this was to include the results of a qualitative study completed by Annette Dickinson and myself (Blamires & Dickinson, 2010). This study had already gained ethical approval and was conducted as part of service development examining the experience of young people with JIA who had been transferred from paediatric to adult services in Auckland. This was an important step in assessing the need for change, as it is well recognised that it is the young people who would be most affected by, and hopefully benefit from, the proposed practice change.

The next part of the plan was to undertake a National Survey of adult rheumatologists, pediatricians and nurses (via existing professional and service networks) using Survey Monkey. The hope here was to identify clinicians' perceptions of the transitional needs of adolescents within rheumatology service and the components they believed to be important in the development of a transition service. Once again this was all part of assessing the need for practice change.

Rosswurm and Larrabee (1999) recognised that in order to affect change within a healthcare organisation, it is important to secure commitment from management and the key stakeholders. This was done in the form of meetings and communication through emails and letters with the other key stakeholders identified.

Collecting Internal Data

The collection of internal data required me to look at the current situation within the service. One of the areas I wished to investigate was how successfully young people were transferring to the adult teams. It was therefore decided to conduct a transfer audit. A plan was made to audit and review the service database for the number of patients transferred between paediatric and adult rheumatology services during the period 2007-2009. The audit would include ascertaining how many young

people attended the first adult rheumatology appointment, how many continue to be followed up in the adult service, and how many were lost to follow up. The purpose of the audit was to provide me with an estimation of the rate of successful transfers prior to the implementation of a transition process.

Comparing External Data

This activity required that I look outside the rheumatology service to external transition programs and plans. Comparing internal data with external data (or benchmarking) can be done informally or through formal benchmarking programs. For the purpose of this project I chose an informal approach. I planned to gain information about health care transition models both in New Zealand and internationally.

Identifying the Problem

After consulting the stakeholders, comparing internal and external data, I determined that the proposed practice changes was the development of a RBP for adolescent transition in paediatric rheumatology. Before I continued I needed to determine the barriers and strengths that had been revealed in the first three actions of the assessment phase. Here I conducted a force field analysis and examined each force identified by the stakeholders to determine if there was a need to continue with the project and planned change.

Linking the Problem, Interventions and Outcomes

Within this phase I planned to link the problem with the desired outcomes and potential interventions in order to develop a specific goal for the project. In Rosswurm and Larabee's (1999) model they discussed the need to define the problem and the use of standard classifications for interventions and outcomes. They used the example of nursing diagnosis and classifications. These are ideal when working with a specific clinical problem but posed a particular challenge for this project. Thus, I chose to be guided by the main headings of the six phases without relying so heavily on the details in the sub-headings. The problem was determined based on the first part of the assessment activities and the intervention was determined to be the proposed practice change, with success of this intervention based on outcome measures described in Chapter 3.

Phase 3 Synthesise (best evidence)

The major activity of phase three is locating the best evidence relevant to the project goal (Larrabee, 2009). Activities in this phase involved identifying types of evidence, reviewing research concepts, planning and conducting a search of the literature.

The types of evidence I felt were most relevant to this project were clinical guidelines, systematic reviews, original research reports and expert committee reports. To critically appraise the research evidence I chose the Critical Skills Appraisal Programme ((CASP), 2006). The next step was to conduct the search itself. I planned to conduct a comprehensive literature review using primarily Medline and CINAHL databases. I also planned to search in evidence-based medicine reviews, Cochrane database of systematic reviews and to do general internet searches using the Google search engine.

After completing the appraisal of the evidence and weighing the internal validity and strength of the evidence, I synthesised the evidence. Chapter 4 will outline the key themes from the literature that are of particular relevance to the development of this project.

Phase 4 Design (practice change)

Within this phase I developed the document that would describe the details of the new practice. In this case the document took the form of a RBP guideline for the transition of young people from paediatric to adult services. A RBP is similar to a clinical guideline and is the accepted way of describing a process, procedure or practice within the Auckland DHB.

Within this phase of Rosswurm and Larrabee's (1999) model they discussed the importance of using a pilot. I knew that with the time constraints imposed by this project I would be unable to follow this plan. As described in the original proposal I intended to explore and define the proposed change, identify the needed resources and discuss how I planned to implement the change and then evaluate using the key outcome measures discussed from phase two (refer to Chapter 3).

Phase 5 Implement and Evaluate and Phase 6 Integrate and Maintain

As described in the practice project proposal the time frame of this project did not allow for the completion of phases five and six of Rosswurm and Larrabee's (1999) model. I will however, outline how the RBP will be implemented into practice through three key phases, which included approval of the RBP, education about the RBP to clinicians and introduction of the plan and RBP to patients and caregivers. An evaluation plan will be described in Chapter 5 outlining the key outcome measures.

Chapter 3 Findings

In phases one and two of Rosswurm and Larrabee's (1999) model they discussed the importance of assessing the problem and then linking the problem to interventions and outcomes. The model shows these as two separate phases; however, for the purpose of this project and chapter, I will join them together as there are many overlapping principles and themes. The assessment phase makes up the largest portion of this project and for that reason has been broken down into several parts. In this chapter I will report the results of the five major activities undertaken as part of the assessment phase, which are:

1. Including stakeholders
2. Collecting internal data about current practice
3. Comparing external data with internal data
4. Identifying the problem
5. Linking the problem, interventions and outcomes.

Including Stakeholders

There are a number of ways in which stakeholders were consulted throughout this project. In the section that follows, entitled "collecting internal data about current practice" that key stakeholders were also consulted to determine the details of current practice. In this first section the key stakeholders are identified and their involvement in the project is documented, including a stakeholder survey and a review of the pertinent results from a qualitative study undertaken within the service, which ascertained young people's experience of transfer from the Starship paediatric service to adult services (Blamires & Dickinson, 2010).

The first step in including stakeholders is to determine who the stakeholders are. In this case key stakeholders were determined to be:

- Adolescent rheumatology patients
- Parents

- Paediatric rheumatology team members
- Adult rheumatology teams around the country
- Paediatric teams from other DHBs
- Ministry of Health/National Board
- Medical services manager
- Nurse leader child health

Key Stakeholder – The Patients

As part of development of the National Paediatric Rheumatology Service a qualitative study was conducted in 2010 that explored the experience of a group of young people with JIA who had recently transferred to adult services. It is this study which has been used to provide the patient perspective for this project. Data was collected via a semi-structured focus group interview with 8 young people with JIA, who had recently transferred from paediatric to adult rheumatology service. Four key results of that study were able to provide the patient perspective for this current project.

- Preparation for adult services
- Recognition of a 'flexible' transfer time
- Positive attitude towards adult service
- Time to practice at being independent

Preparation for Adult Services

The young people explained that they were not prepared early enough in the transition process in relation to information about adult services, particularly in regard to who the key people were and what allied health services were available. They would have liked an earlier introduction to the new physical environment they were entering. Knowing about the differences and what to expect was felt to be helpful in making the transfer less stressful and intimidating.

Flexibility

The young people felt that their transfer was based on an understanding of their individual needs and that this was considered a key element of a transition process or program. Stability of disease was important and these young people were most comfortable with being able to transfer at a time that they felt their disease was under control. They appreciated the flexibility around timing and emphasised that transfer time should not be based around age.

Positive Attitudes

Paediatric services, and the need for the paediatric clinicians to portray confidence and assurance towards the adult service leading up to transfer, was also noted by the young people. It was clear from the study that perceived negativity toward adult services by paediatric clinicians inadvertently sent messages that created fear and distrust amongst the young people. The young people suggested that the development of a transition program would help them and their families understand that more *formal* or *different* does not necessarily mean worse.

Time to Practice

The young people felt that planning was important and they needed the opportunity to practice independently managing their condition. They wanted the opportunity to take this responsibility prior to moving to adult services; an important element to include when developing a transition service.

Key Stakeholder – Parents

During the duration of this current project, and as part of my role as nurse specialist, I informally talked to parents (often in the waiting area before an appointment) about their feelings of transferring to adult services. Some parents were ready for the change. Some felt that it would be easier once they were transferred, as they were already experiencing challenges when faced with an acute problem (unrelated to their rheumatologic condition) because their *child* was deemed too old for Starship. Some parents looked positively on the move to a different setting for the financial benefits it offered in that the new clinic was closer to home and provided free parking. Most reported a fear and concern about changing from a familiar to

unfamiliar service. Many reported that they did not have faith that the adult service would be able to provide the same level or quality of care. One mother was concerned about the lack of adult rheumatologists in the DHB in which they lived and was visibly distressed about *who* would look after her daughter. It was clear that there was a combination of feelings expressed by family in relation to transition. Parents worry about how different adult services are and how they do not engage families in the same way as paediatric clinics (Russell, Viner, 1999). Parents in the Starship service reported similar concerns to that reported in the literature; fear of the unknown, worry that their young person will not adequately look after his or her own health, and a strong sense of loss of trusted paediatric caregivers who must be traded for new and unknown caregivers in an adult service (Mietteunen, 2008).

Key Stakeholders – The National Team

From the initial set up of the National Rheumatology Service, transition has been on the agenda. It was decided early on that I would be the key co-ordinator to help develop this process for the team. Because of my particular interest and passion for youth health, the team members knew they had someone who would champion and lead the change.

The National Rheumatology Service fully supports the development of a transition plan and program. Verbal agreement by all members of the national team was given to proceed with development of a transition plan and it is written in as a core agenda item at all team meetings. All members see this as one of the key quality service objectives and consider their role in transition important for success. There has been clear commitment from the team in the form of providing feedback and engaging in discussions about how to move forward with the development of a transition plan; and there is agreement about the majority of key elements discussed to date.

Key Stakeholders – Health Professionals

I recognised early on in this project that the support and commitment from adult rheumatology was particularly important, as it is well noted in the literature that the

success of a transition program depends on active participation and interest of staff in the adult clinic (Chira & Sandborg, 2004; Kennedy & Sawyer, 2008; J. E. McDonagh & Viner, 2006; Russell. Viner, 1999). The first steps that I took were to find out who the various teams were and their location. As a starting point I arranged meetings with the nurse specialists from the various adult rheumatology teams, within the Auckland region. There was much enthusiasm by the nurses over the idea of a transition plan for the patients and they offered support in any way they could. More meetings and email correspondence occurred with adult rheumatology teams throughout the country. Teams within the Auckland region, Waikato and the Bay of Plenty have been most supportive and integral to service development plans. The nurse specialists from Auckland DHB, Waitemata DHB and Counties Manukau have all met with me on several occasions and will play a central role in the development of the transition plan.

The challenge of involving adult rheumatologists and seeking their views was deemed extremely important from the outset so it was decided that the best way to gain a better understanding of their attitudes towards transition was to use a survey. I also wanted to include general pediatricians because many pediatricians in New Zealand share care of tertiary patients who live in smaller regions of the country.

To elicit the views of this wide range of health professionals working with young people with rheumatologic conditions a national survey of adult rheumatology clinicians and general paediatricians was undertaken. The purpose of this survey was to:

1. Identify the attitudes of rheumatology practitioners and general paediatricians towards transition in New Zealand.
2. Obtain knowledge about what rheumatology practitioners and general paediatricians view as the key elements/people in successful transition.

Survey Development

The first step in survey development was to identify elements of health care transition and common themes or attitudes found in the literature. An online survey using Survey Monkey was created. Survey Monkey is a web-based tool that enables the user to create on-line surveys and export-collected data. The survey created

consisted of 26 multiple choice questions with the following headings: demographic data, multidisciplinary involvement in transition planning, and attitudes towards transfer, barriers, patient education and elements of transition (See Appendix 1 for Survey Response Summary).

Survey Administration

Contact was made with the New Zealand Rheumatologic Association and the New Zealand Allied Health Professionals in Rheumatology who agreed to send the survey link to all their members. Responses were also solicited from paediatricians, nurses and allied health professionals who share care of rheumatology patients around the country, including clinical directors of the various DHBs. In total, 120 people were emailed the link to the survey and given two weeks to respond. Data collection was completed between October 18th and November 5th 2010.

Results

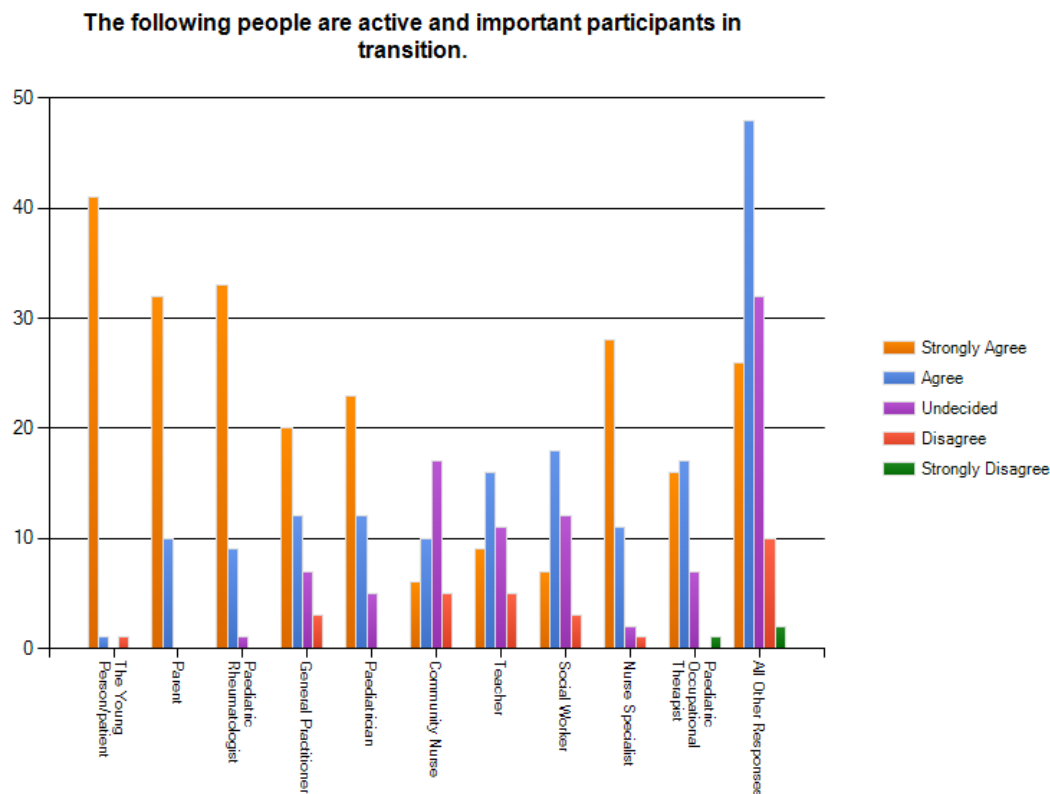
Responses were received from 38% (46 of 120) of the health professionals. I was unable to determine the responses by DHB due to an error in question 3 which neglected one DHB. I therefore eliminated this question from analysis. The survey was completed and all questions answered by the majority of respondents.

Respondent Characteristics

The largest groups represented in this survey were adult rheumatologists (28.3%), nurse specialists in rheumatology (19.6%) and physiotherapists (21.7%). There were largely more female respondents (71.7%) than males (28.3%). Only a small percentage had not treated patients over 18 years of age (19.6%), with a similarly small percentage (15.2%) having not treated patients under the age of 18. It was interesting to find that 35.6% of respondents answered that their service does have a formal transition program, despite the fact that I am unaware of such processes in place within rheumatology services in New Zealand. This could be a result of differing impressions about what constitutes a transition program and the fact that the survey did not provide a definition of transition. This is a limitation of the survey.

The survey asked respondents to answer questions about multidisciplinary involvement in planning transition. See table 1 for a summary of this data.

Figure 2: Multidisciplinary Involvement in Transition



The responses clearly show overwhelming support for a multi-disciplinary approach to transition planning.

The next section of the survey asked questions centred on attitudes towards transfer with the first three questions addressing the issue of ‘time of transfer’. Responses to this section showed that age was clearly an issue and was still very much the focus when the topic of transfer was raised. Two questions were asked about patients with ‘active disease’. The majority felt that the patient should *not* stay under paediatric care (70.8%) and 78.1% of participants felt that they should be transferred to an adult rheumatologist even with the presence of active disease. This is certainly surprising and sharply in contrast to what is often written about transfer being at a time of disease stability (Bell, 2007; Bowen, Henske, & Potter, 2010; S. M. Sawyer, Blair, & Bowes, 1997; Tuffrey & Pearce, 2003) and to the suggestion of the young people in Blamires and Dickinson’s (2010) study. The numbers of adult clinicians that completed the survey may have influenced these results. It is also interesting that when asked more directly about this in the question: ‘adolescent rheumatology

patients should be transferred when their disease is stable'; there was more support that this should occur with 7.3% strongly agreeing and 53.7% agreeing.

There was overwhelming support for addressing parental needs during transition with all respondents either strongly agreeing or agreeing.

Within this survey I also wanted to find out what the respondents felt were the biggest barriers to organising formal transition. Table 1 (p. 22) summarises the responses. The majority of respondents answered the series of questions on barriers and there was a wide spread of answers with the majority perceiving all of these items as barriers; the most significant barriers appearing to be funding and poor communication. This is similar to other studies that have asked health professionals about barriers to provision of transitional care (Shaw et al., 2004).

Table 1: Rating of Barriers to Setting up Formal Transition

Barriers	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
Limited clinic space	14.6 %	41.5%	14.6%	29.3%	0.0%
Funding	17.1%	43.9%	24.4%	14.6%	0.0%
Insufficient support for adult rheumatology team	9.8%	31.7%	22.0%	29.3%	7.3%
Lack of multi-disc service different DHBs	17.1%	34.1%	29.3%	17.1%	2.4%
Poor communication	34.1%	46.3%	12.2%	4.9%	2.4%

In the fourth section of the survey the questions focused on patient education and elements of transition. There was overwhelming support for education of young people about their condition, sexual health, medication and side effects and general health issues.

The final section addressed *elements* of transition. There was strong support for a dedicated transition co-ordinator (60%), the use of individualised transition plans (92.3%) and the notion of support for parents to assist their young person's independence (94.5%).

Summary of Survey Results

The survey results form a useful part of the assessment phase and several key points emerged that will be useful for the next steps in this project. Planning, multidisciplinary co-ordination and individual transition plans were deemed important aspects of transition. Timing of transfer remained a contentious issue. A number of barriers to providing transitional care were identified and education and preparation for adult care were seen as important. Transitional care, by the stakeholders surveyed was perceived as necessary.

Key Stakeholders – Ministry of Health/National Board

In 2009 when the National Paediatric Rheumatology Service was established a number of key service objectives were determined. One of these was to set up a transition program or plan for the young people in rheumatology service. This was a broad contractual requirement and the Ministry of Health did not stipulate any specifics about what a transition program needed to contain. Transition was clearly recognised as an important component of this new service and was given priority as one of the key roles of the clinical nurse specialist by the members of the team. This was essentially the catalyst for the commencement of this project and demonstrates the commitment of the Ministry of Health to the development of the transition program within rheumatology.

Key Stakeholders – Service Manager and Nursing Leader

Support for this project was clearly evident within the medical and nursing leadership of the hospital where the National Rheumatology Service is based and set as a performance objective by the service manager and nurse leader. Several meetings with both have occurred where plans and actions related to the development of this programme were discussed. The current nurse leader is extremely supportive of the transition plan in rheumatology and has given her endorsement for involving and seeking support from other clinical nurse specialists from other tertiary services at Starship Hospital. The hope is by working together elements of transition programs can become generic to all specialties.

Collecting Internal Data about Current Practice

Collection of internal data means looking at the current 'state of affairs' and examining current practice within the setting. In this case I needed to look within the paediatric rheumatology service and uncover as much information as possible about what was or was not happening for the young people within the service. Part of this collection of internal data was included in consultation with stakeholders but internal data was also collected by examining the current process for transition and transfer by speaking to the rheumatology consultant who had been the original member of the service. This helped to provide a historical perspective. I also wanted to know how successfully the young people were transferring to adult services so conducted a transfer audit.

Historical Knowledge of the Service

As previously mentioned the rheumatology service had been managed for a long time by one consultant who worked part time. Although this consultant has a special interest in paediatrics she was first and foremost an adult rheumatologist. When the national team was established, the process for transferring adolescents was very disorganised. Often young people were still in the paediatric service up to their 18th birthday at which time a transfer letter was sent and they found themselves suddenly in the adult clinic. The discussion about transfer to adult service usually occurred just prior to the actual transfer taking place; however despite this, the service still managed to have a fairly successful rate of transfer, as evidenced by the results of the transfer audit discussed in the following section.

Transfer Audit

To gain a better understanding of the current situation in rheumatology service a review of the current rates and success of transfer was undertaken. Although the service does not currently have a transition program they do have young people who grow up and require transfer to adult services.

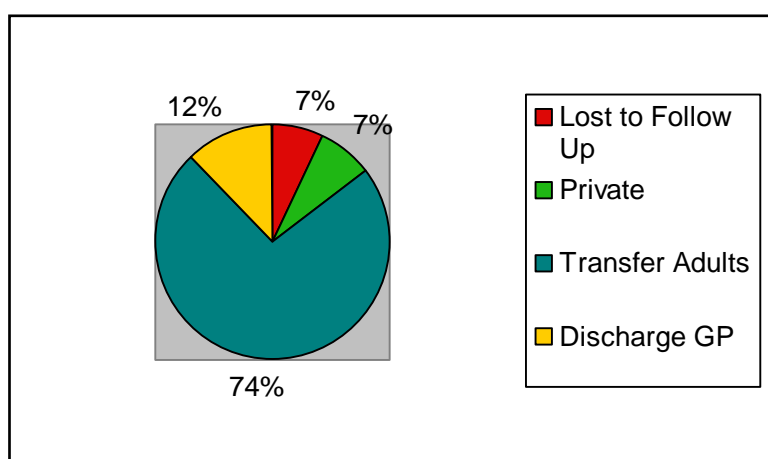
Audit Process

With the help of the Starship Hospital data analysts, the rheumatology database was reviewed. Rheumatology patients seen in Starship rheumatology clinic between the years January 2007 to September 2010 were identified. This information was presented on an excel spreadsheet which enabled the entries to be sorted by date of birth. I then systematically searched, using concerto (the Auckland DHB online patient clinical records), the list of patients with a minimum age of 16 years of age. I looked for appointments and referral letters. The intention of this process was to find how many referrals had been made by the paediatric service to adult services and consequently how many young people had made it to their first appointment in the adult rheumatology service. I was unable to determine ongoing attendance as some of these patients are seen in DHBs outside of the Auckland DHB.

Results

During the timeframe January 2007- September 2010, 41 young people reached the age in which paediatric care would come to an end (16-19years). At this point, the Starship clinical team decide whether it is appropriate for the young person to be returned to general practice for care or whether they are referred on to adult rheumatology service. Of these 41 young people, 11 were excluded from my analysis. These 11 patients were made up of 5 who were discharged from rheumatology back to their general practitioner, 3 patients who were lost to follow up, and 3 patients who chose to attend the private clinic of their paediatric rheumatologist who also had an adult clinic. The patients who attended this private clinic were excluded as these patients had already indicated that they would actively seek treatment by choosing the same rheumatologist and were therefore not transferring to another service provider. See Figure 3.

Figure 3: Transfer Audit



Following the exclusions, a total of 30 patients remained who were referred on to a public adult rheumatology service. This is the group of patients I was most interested in as I wanted to find out if the process that the rheumatology service currently used was successful in transferring patients to adult services.

These 30 young people represented a typical population of the rheumatology patients with the majority of the patients diagnosed with JIA. The patients had the following diagnostic categories:

- 7 ankylosing spondylitis/enthesitis related JIA
- 17 JIA
- 4 Systemic Lupus Erythematosus
- 2 Juvenile Dermatomyocitis

Successful transfer to adult care was the primary outcome variable, operationally defined as the patient having attended at least one appointment of any type following referral from rheumatology service. This is a similar definition to that used in two other studies which looked at rates of successful transfer (Hazel, Zhang, Duffy, & Campillo, 2010; G. Reid et al., 2004).

Although I was unable to determine ongoing care from this small audit, I could ascertain that the majority of patients within paediatric rheumatology were transferring successfully and attending initial appointments with adult rheumatology. This small audit showed that 29 out of 30 patients had attended their first appointment, which highlights that despite rheumatology not having a transition program, there is a high rate of successful transfer. This audit certainly had limitations and for the future it would be interesting to note ongoing attendance in adult services. Another interesting aspect for future research would be to determine the degree in which disease impacted on the patients lives prior to transfer, as this may have influenced their desire to attend. It is also important to note that the rheumatology service is small and has mostly good relationships with the adult rheumatology services.

Comparing Internal Data with External Data

Part of the process of assessing the need for change, according to Larrabee and Rosswrum (1999), is to compare internal data with external data. This comparison can also be thought of as 'benchmarking'. Benchmarking can be formal or informal and for this project the examination of external data was informal. I did approach each external program with a series of questions in mind so as to ensure fair comparisons could be made. I chose to look at two transition models from New Zealand, one from Australia, one from Canada and one from the United Kingdom (UK). In New Zealand there are some services that have implemented transition programs and there are certainly several reputable programs overseas. For the purpose of this project I felt it was important to consider the New Zealand context and looked at the Starship Cystic Fibrosis and Diabetes Transition models first. The two models were chosen as they are the only known formal transition programs within Starship Hospital. I also had opportunity to visit the Royal Children's of Melbourne Transition program, review the Hospital for Sick Children's 'Good2Go' Model and communicate via email with Janet McDonagh about her highly regarded transition rheumatology clinic in the UK, 'the DREAM team'.

I felt that this provided a good overview of local and international models. The main questions and areas I chose to address were as follows:

1. Use of a written transition policy
2. Overview of model
3. Tools/resources used and or developed
4. Outcome measures
5. Ongoing evaluation of program

Diabetes Service Starship

The Diabetes Service at Starship has the most established transition service in the Auckland region. It has been running since 2006 and I had the opportunity to see the clinic and spend the day with the transition co-ordinator. This service is fortunate to have a dedicated transition clinic and co-ordinator and has the patient numbers to justify this, caring for around 450 children and young people under the age of 18. They have based their model and resources on *Sweet: The Diabetes Transition*

Programme (Mater Children's Hospital, Brisbane, Australia)

(<http://www.sweet.org.au/>), the Royal Children's Hospital, Melbourne (<http://www.rch.org.au/transition>), and the British Columbia 'OnTrac' program (<http://www.bcchildrens.ca>). They have developed a number of checklists, resources and toolkits that are specific for diabetes patients and have very strict written guidelines around the time of transition and the way in which it happens for each young person. There are many positive aspects of this program including its resources, transition co-ordinator and multi-disciplinary approach but there are a couple of areas that require further consideration. This program has not been formally evaluated and I am unsure of how they determine success of their program as they have no clearly stated outcome measures. They also have extremely strict age specific guidelines and this does not necessarily allow for the flexibility that young people within the rheumatology service seem to request (Blamires & Dickinson, 2010). There is an assumption that chronological age alone indicates readiness for transfer which largely disregards the complexity of adolescent development (While et al., 2004).

Cystic Fibrosis

The transition model used by the Cystic Fibrosis team at Starship is based on the combination of two models: The Toronto SickKids 'Good2go' transition model (<http://www.sickkids.ca/good2go/>) and the Royal Brompton CF programme (<http://www.rbht.nhs.uk/healthprofessionals/clinical-departments/paediatrics/childrencf/service/transition-clinic/>). I had the opportunity to work within this team several years ago as a nurse specialist and was therefore able to participate directly in their program.

The team has a written document that supports its transition plan (although only a paper copy for the team to use), which involves transition checklists and a folder system that introduces parents to the concept at a very early stage, almost at the time of diagnosis. This philosophy of discussing transition from a very young age is supported in the literature as a key component to good transitional care (Department of Health Child Health and Maternity Services Branch, 2006; Kennedy & Sawyer, 2008; M. Paone, 1998; Russell. Viner, 1999; R. Viner, 2008).

One of the key strengths of this program is the established ties/relationship they have with adult services. The nurse specialist from paediatric and adult services meet regularly and both the adult consultant and the nurse specialist attend the paediatric clinic to meet the young person and his/her family. Although this program is well established they have not yet formalised their program with a written policy or plan. The current staff members that work within the service hold the knowledge of how the transition program operates. It would be beneficial to have formal documentation that would enable future staff to follow the standards. This program has also not been formally evaluated nor does it have outcome measures, although it does survey patients informally post transfer about their experience of transition.

The Royal Children's Hospital Melbourne (RCH)

I had the opportunity to spend time with the transition co-ordinator Sara Macnee just prior to the initiation of the transition program at RCH. The transition program at RCH begins early in adolescence and aims to complete the transition process at around 18-19 years of age. RCH provides extensive web based information for its young people, families and health professionals

(http://www.rch.org.au/transition/index.cfm?doc_id=8143). One of the strengths of the RCH transition program is its use of a generic transition co-ordinator and the fact that it has established overriding principles of transition that cross all tertiary services throughout the hospital. This ensures that everyone is working towards the same standards of transitional care. They have a number of tools and resources which are youth friendly and available on the internet. This program has a transition policy that is available on its website and clearly states that evaluation is a phase in its own right; however Sara informed me that this was still in process and the evaluation process has yet to occur (personal communication, April 2009).

Toronto SicksKids 'Good2Go', Canada (<http://www.sickkids.ca/good2go/>)

The Good2Go program aims to "prepare all youth with chronic healthcare conditions to leave SickKids by the age of 18, with the necessary skills and knowledge to advocate for themselves, maintain health-promoting behaviours and utilise adult health care services appropriately and successfully"

(<http://www.sickkids.ca/good2go/>).

They do this by having a nurse practitioner and psychologist who act as a resource team for the hospital. They have web-based information for patients and health professionals and a number of checklists and resources for staff to help implement the agreed transition standards within their own departments. This program recognises the importance of starting early and enabling the patient to move from a passive 'receiver' of health care to an active participant, manager and eventual supervisor of their own healthcare. They address issues other than health such as career planning and also discuss the phase of evaluation; however, I was unable to find evidence of evaluation or outcome measures.

Janet McDonagh (DREAM TEAM) UK

The Dream Team UK is based in Birmingham and has been active in the transition literature based on the enthusiasm of one of its team members. Dr Janet McDonagh is a clinical senior lecturer in paediatric and adolescent rheumatology at the University of Birmingham and Birmingham Children's Hospital NHS Foundation Trust from the UK. Janet is the lead consultant for the DREAM team (which stands for **D**edicated, **R**esourceful, **E**xpert, **A**dolescent **M**ultidisciplinary). This model is similar to the others mentioned so far. It has resources for health professionals, patients and families. It has an established policy and includes evaluation as part of its model. The program itself has also had early stage evaluation which can be found in a paper entitled *Growing up and moving on in rheumatology: development and preliminary evaluation of a transitional care programme for a multicentre cohort of adolescents with juvenile idiopathic arthritis* (JE. McDonagh et al., 2006).

Summary of External Data

It was useful to review the five models of transition and interesting to observe the similarities between each. The "disease specific" programs contained similar 'generic' elements when compared to each other and when compared to the more general hospital wide models. It is clear that there are number of components and/or key elements found in transition program and these will be discussed further under 'Linking the problem, intervention and outcome'. Most striking, in this external review, is the lack of formal evaluation, despite having evaluation as a step or part of their written transition processes. This illustrates the challenge of following through with all aspects of a plan or process when limited resources are a constant variable.

Identifying the Problem

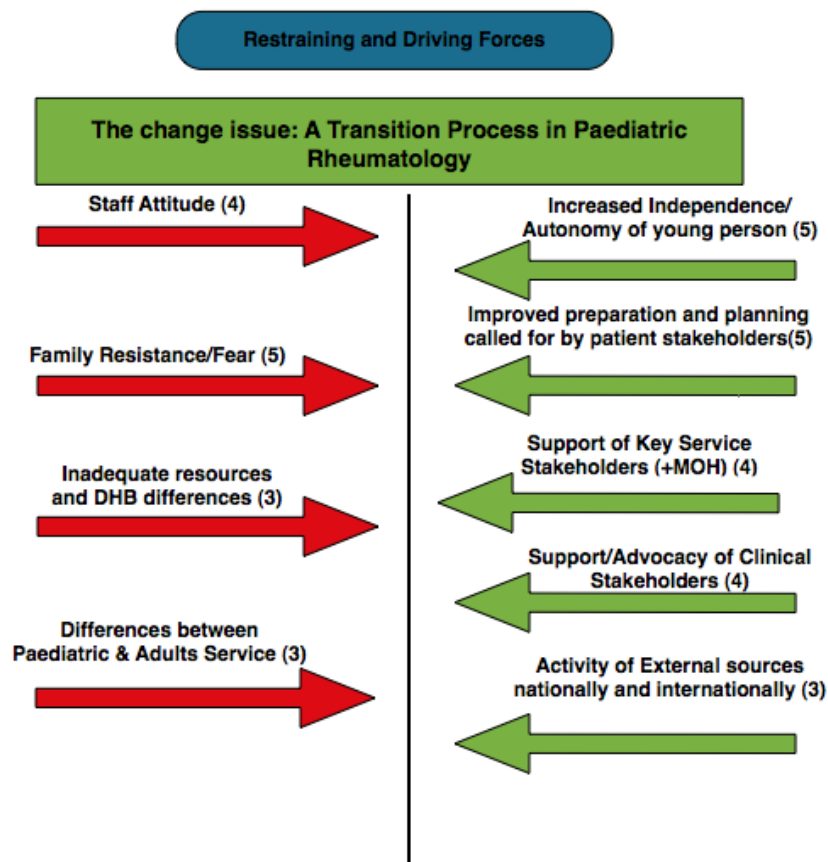
Identifying the problem, according to Rosswurm and Larrabee (1999) is the final part of the assessment phase. In the early stages of this phase I consulted stakeholders and compared internal and external data in order to substantiate current practice or find support for the need to change practice. The practice change identified in this project was the *Development of a Recommended Best Practice for Adolescent Transition in Paediatric Rheumatology*. Before moving to the next phase of the model, I wanted to clearly understand and identify the barriers and strengths uncovered thus far, in order to determine *if* and *how* I should proceed with the project. One of the most useful ways to do this is a force field analysis.

A force field analysis is a useful way of listing, discussing and evaluating the forces for and against the proposed change and allows you to closely examine the power of these “pros” and “cons” (Baulcomb, 2003). Once these influences are identified and along with the force they exert, strategies can be developed to reduce the impact of opposing forces and strengthen those that support the plan (Baulcomb, 2003). There are four steps to conducting a force field analysis:

1. Start with a well defined goal or change to be implemented
2. Identify the important stakeholders
3. Determine and document the “driving forces” and the “restraining forces”
4. Evaluate the forces in terms of strength and weakness

The key stakeholders were identified early in the assessment phase. Through the process of gathering internal data these stakeholders identified a number of restraining and driving forces. The forces identified by the stakeholders are found below summarised in Figure 4. Each force has been given a score indicating its strength, with 5 representing the strongest and 0 the weakest.

Figure 4: Forcefield Analysis



The driving and restraining forces revealed by the key stakeholders are echoed in the literatures on transition. Each of these will be examined, and the feedback from the key stakeholders discussed, in relationship to the literature.

The Driving Forces

Increased Independence/Autonomy of Young person

It is well recognised that adolescence is a time of stress and change and driven by a strong desire to become independent. The specific developmental issues such as identity development, autonomy, and coping with the altered parent-child relationship all mean that this is critical period to establish life long health related behaviours (Moons et al., 2009). The young people from the focus group described the feeling of growing independence in a positive light (Blamires & Dickinson, 2010). They enjoyed the fact that they were “growing up” and felt that the opportunity to practice making decisions and describe their health and medications was extremely

important. Anecdotally I would say that parent stakeholders were split on their feelings about their young person being seen independently. Many felt this was a great opportunity for their child to start to take ownership for their disease and develop communication skills; whereas others felt scared that their child would get the “information wrong” or not tell the whole story and that this would have a negative impact on the treatment plan. The literature would certainly suggest that a good transition process can offer the young person the opportunity to develop the skills they need to manage their condition. Transition, ideally, should help young people develop communication skills, assertiveness, advocacy and most importantly self-care skills that will enable them to take responsibility for their own health (Robertson, McDonagh, Southwood, & Shaw, 2006). The young stakeholders from the focus group expressed satisfaction at finally being treated as an adult (Blamires & Dickinson, 2010). This idea is supported in a paper by Miles, Edwards and Clapson (2004) who stated that for a young person with a chronic condition, transition can provide an improved sense of independence and control in the care-decision making process and a general satisfaction in being treated as an adult.

Improved Preparation and Planning

Three of the main key stakeholders, the patients, the parents and the clinicians, all support the notion of preparation and planning for the move from the paediatric to the adult health care setting. This was evident from the clinician survey, the focus group interview and from informal discussions with parents. Young people and their family members all call for preparation for adult services; they want to know the differences between paediatrics and adult services and where they will go and who they will see. Adult rheumatology services and nurse specialists in particular, also talked to me about the need for paediatrics to prepare young people better for the differences between paediatric and adult services. They talked about not wanting to be the “bad guys” when the young person was faced with processes and procedures that were different, for example a joint injection without entonox. At the same time I have had many discussions with these same stakeholders about recognising and understanding that preparation and planning is important for paediatrics services but that adult services also have a role to play.

Support of Key Stakeholders (Service Manager and Ministry of Health)

The National Rheumatology Service and the Ministry of Health objectives act as a significant driving factor for the initiation of a transition process in paediatric rheumatology. The service has been funded for three years by the Ministry of Health and one of the key service objectives is to establish a transition program/process for rheumatology patients. New Zealand does not seem to have reached the widespread, political and institutional support for transition that is present in other countries. The Ministry of Health does not appear to have made an official statement about transition; but clearly identifies transition as integral to the development of new services such as the rheumatology service.

Paediatric professional groups in New Zealand also recognise the importance of transition, as evidenced by discussion with key stakeholders in medicine and allied health, however there have been no official National Health Board policies put in place to support this enthusiasm. The Paediatric Society of New Zealand held their annual meeting in November 2010 and transition was clearly a hot topic with several presentations and much discussion stimulated. There was a real sense at this meeting that we need to look at this issue at a national level and several people turned to the points made in the 2004 Position Statement, *Meeting the care and support needs of young people with complex and chronic disability needs* (The Paediatric Society of New Zealand, 2005). Within this document several recommendations are made that surround the topic of transition and clearly show the support of the Paediatric Society for this important aspect of care (Appendix 2). Outlined in these key recommendations were:

The Paediatric Society of New Zealand (2005, p1) recommends to its members:

1. They encourage the establishment of developmentally appropriate systems to support the continuity of holistic care after age of 12 eg: develop adolescent services that focus on the transition to adult services
2. Support networking both nationally and internationally to deliver the best available services for young people with high health and disability support needs
3. Young people with complex and chronic health and disability needs require a transition plan clearly providing for continuity of care when they have reached the

age at which they would otherwise leave Paediatric care: the plan should clearly identify which option is chosen for ongoing holistic care

4. Discharge from paediatrics should not occur until the plan is agreed and operational.

Internationally there have been a number of consensus statements by organisations such as the American Academy of Pediatrics and the Society of Adolescent Medicine that advocate and provide guidelines to help in the development of transitional programs (American Academy of Pediatrics, 2002; David. Rosen, Blum, Britto, Sawyer, & Siegel, 2003). It is this high level of institutional and professional support for policy development that acts as a further push or driving force in favour of the planned change. I recognise and acknowledge that New Zealand's lack of support at this higher level not only acts as a driving force but also a barrier to individual services progressing plans for transition.

Support/Advocacy of Clinical Stakeholders

It is clear from the survey conducted with adult rheumatology teams and paediatricians that there is overwhelming support for establishing a transition process or program. This is evident from the information outlined as part of the assessment phase. It well known that staff attitude towards change is crucial to making any kind of practice change. This is no different when it comes to transition. In the literature it is clear that the success of a transition program is linked to the attitudes and enthusiasm of staff (Bennett, Towns, & Steinbeck, 2005).

Activity of External Sources

Clearly the global activity in health care would suggest that every paediatric centre should have a transition plan, transition co-ordinator and specialised transition clinic. While this is not entirely realistic it is important to recognise that the key stakeholders consulted in this project had varying degrees of the "perfect" transition program but all were making the effort to do *something* for their youth. It is important to note that the literature clearly advocates that health service transition is an essential component of high quality health care and that through the process of transition it is possible to improve this experience of change, for young people and their families (Jackson & Pencharz, 2003).

The Barriers or Restraining Forces

There were a number of restraining forces identified by the key stakeholders that are significant and deserve consideration. Although they exert considerable pressure on the proposed change, they are not uncommon barriers, as noted in the literature, and are not insurmountable. However, it is important to consider these and how they may be overcome in order to implement change.

Staff Attitude

In the early stages of this project I approached a number of key people within adult services from around the Auckland area. I sent an email asking to meet with various key people in order to talk about transition and to gauge opinions and attitude towards changing the process. Most DHBs were highly receptive and excited about the idea of improving transition for young people; however one response was, *“what is wrong with what we do currently? The paediatric Rheumatologist refers to our service. The patient goes on a waiting list. Eventually they are seen by us and they then stop seeing the paediatrician. What’s there to change?”* (personal communication, May 2009). I found myself faced with this attitude several times, with the adult service failing to see the need to change anything. In another email to me as I attempted to arrange a meeting to discuss transition, I was told *“Can you tell me what the problem is at present? We transition patients all the time from other paediatric services. It normally just involved a letter with any special details or a quick phone call to the SMO’s. I do not want to unnecessarily use up clinicians or other staffs time when it not absolutely needed.”* (personal communication, 15th June, 2009). It was clear that adult services can and do represent a huge obstacle to successful transition (Russell. Viner, 1999). This is in part largely due to the different philosophies of adult and paediatric health service, where one is family focused and the other is focused on the individual. It is often difficult to find an interested and capable adult service who will work together with paediatric services and there is a real sense in the literature that transition is in the minds of paediatricians but not so much in the minds of adult services (Kennedy & Sawyer, 2008; Robertson et al., 2006; R. Viner, 2008). In New Zealand this may be the case

in some areas as well, but certainly the majority of adult rheumatology teams have shown verbal support and positive attitude to the changes proposed thus far.

Family Resistance/Fear

The parent stakeholders, informally consulted, talked of a great deal of fear and uncertainty about transferring to adult services. They felt unsure and reluctant to “let go”; and one parent talked to me about feeling like they were being left out of their child’s life. One of the main differences between paediatric and adult-centered care is the role of the parents (J. McDonagh, 2007). Despite the numerous positive effects that a transition process may have on the adolescents, there is no denying the fact that parents require special attention in this process as well. Parents can feel threatened by the adult environment as they lose some control over their child’s health and treatment and there is real fear of the difference (Tuffrey & Pearce, 2003). Parents may also resist the change as they can feel that their expertise about their child’s illness is no longer of use (Russell, Reinbold, & Maltby, 1996).

Inadequate Resources/DHB Differences

The stakeholder survey conducted with the adult rheumatologists and paediatricians clearly identified a number of barriers to transition (Table 2. .p. 28), the majority and most significant being related to inadequate resources. The key stakeholders within Starship also identified the lack of available space to create “new” or different clinics, lack of institutional and team support and financial restraints as a barrier to organised transition processes. The other significant barrier was DHB differences. These differences provide a particular challenge when trying to envision a transition process. Every DHB varies with the adult rheumatology service available so it is therefore imperative that any transition plan must recognise and be flexible to suit these different environments.

Differences between Adult and Paediatric Services

The patient stakeholders talked about how they “did not feel special” in adult service and they were “just one of the many”. This idea that the young person does not fit into adult service is not uncommon. The differences between adult and paediatric service models are well documented and it was evident from my stakeholder

feedback that this expectation of *fitting in* to adults rather than adults *adapting to youth* is prevalent. This difficulty with age and the invisibility of adolescents is a challenge. Unfortunately adolescents fall into a no man's land in which they are too big for paediatrics and too young for adults. One could argue that this "too young for adults" stage stretches out into the early 20s and has an isolating effect on more than just those in their teens. It is okay for adult service to be different from paediatrics but it should stop to consider that adolescence is a unique time and as such requires an approach that considers how young people, particularly those with chronic illness, approach various developmental tasks. This will enable the development of a program of care that is appropriate and patient-oriented (Kennedy & Sawyer, 2008; Moons et al., 2009).

Summary and Identification of the Problem

It is clear from this process that there are a number of restraining and driving forces impacting the proposed change. The forces discussed here are strong in both directions working *against* the proposed plan and *for* the development of a transition process. They can all be addressed and managed within the practice implementation plan and through the process of linking the problem to key interventions and outcomes.

Linking the problem, intervention and outcome

Phase two of Rosswurm and Larrabee's (1999) model tells the project manager or team to define the problem using standard classifications for interventions and outcomes. The model compares this phase to the nursing process, linking nursing diagnosis with interventions and outcomes. This is a much easier task when looking at a specific clinical issue or problem but not so straightforward for this project and has been one of the downfalls of applying this model to my project. In an attempt to follow the model, despite its challenges, I will suggest that the problem is the: **lack of a formalised transition process for young people within paediatric rheumatology**. The intervention is the proposed practice change, **the development of a RBP for adolescent transition in paediatric rheumatology**. The success of this intervention will be based on outcome measures described by other transition

services nationally and internationally and from analysis of the assessment phase data as described in this chapter.

Outcome Measures

As the final part of this section I wanted to examine how established transition programs determined and measured success or failure. I wanted to know what the appropriate outcome measures were so that I would have a basis for evaluation. It proved to be quite difficult to find programs or papers that described how they had measured success. Papers often alluded to the importance of evaluation and standard setting; and established transition programs that I looked at discussed their plans to evaluate, yet I found very little evidence of this in action.

Through discussions with stakeholders and review of the literature I have determined the following outcomes that will measure success or failure of the RBP once implemented.

The Patient will be Prepared for the New Service Prior to Transfer

The idea of having early discussions about the adult service is well supported in the literature (Farrant & Watson, 2004; J. E. McDonagh & Viner, 2006; M. Paone, 1998). Preparation for the new service is clearly called for by adolescents and their families. A successful outcome here would be that all patients and their families get to know and meet the team from the adult rheumatology clinic they will be attending, prior to transfer time. It is highly important for patients to be able to see where they are going, get to visit the environment and meet the people who are going to look after them (Blamires & Dickinson, 2010).

The Patient will Establish Independent Health Behaviours

One of the aims of transition is to promote skills in communication, decision – making, assertiveness and self-advocacy (J.E. McDonagh et al., 2006). A transition program that provides young people with opportunity to gain these skills, such as being seen independently from parents, is key. We know that “in general, the adult healthcare system demands a higher level of personal responsibility and autonomy than the paediatric healthcare system” (D. S. Rosen, 2004). So it is reasonable to

suggest that one outcome measure should be an expectation that young patients can meet their own healthcare needs prior to transfer. This can be measured using transition readiness checklists and looking to programs that have developed other transition readiness tools.

Patient has Disease Related Knowledge

Patients need to become experts in their health history and must understand their disease and medications. Adolescents, in particular, need to know what impact their rheumatology medicines have on the many adolescent 'rites of passage' such as drinking alcohol and experimentation with drugs. Within this point, young people need to develop and have success at self-care. This can include things like self-medication and independent consultation. These items could also be measured using a survey format or readiness checklist and a successful transition program would have young people who have solid disease related knowledge.

Adequate Exchange of Information will Occur

Several papers talked about the importance of a carefully prepared summary that provides the outline for the adult healthcare team in the first year (Bennett et al., 2005; Crowley, Wolfe, Lock, & McKee, 2011; Janet E. McDonagh, 2007b). Young people with chronic illness have extensive medical histories and a successful transition program would include the development of an appropriate, comprehensive format for a patient summary. This helps the patient and the adult service that is receiving them and a successful transition program would ensure that this handover occurs some time prior to the transfer itself.

Improvements in Health-Related Quality of Life

The Childhood Health Assessment Questionnaire (CHAQ) is a tool used for evaluating functional capacity and independence in activities of daily living for patients with JIA and other rheumatologic disorders.

The questionnaire measures functional capacity and independence during the last week of daily life activities. It is made up of eight domains: dressing, arising, eating, walking, reach, grip, hygiene and activities. For each domain there is a 4 level difficulty scale that is scored from 0 to 3, corresponding to "without any difficulty" (0),

“with some difficulty” (1), “with much difficulty” (2), and “unable to do” (3). CHAQ also presents two visual analogue scales for pain evaluation and overall well-being evaluation (Ruperto et al., 2004). An overall improvement or at the least maintenance of CHAQ score would be a useful outcome measure for successful transition. There is some question as to whether an improvement may be mostly related to disease activity but certainly a transition program would hope to not see large increases in CHAQ scores.

Satisfaction with Care

It is important that the patients and families are satisfied with the process and one cannot deem a program a success without satisfaction. It would be important to ascertain their assessment/satisfaction of the physical environment, clinic procedures, information and support. This can be done through the collection of post-transition surveys/ questionnaires and through additional focus groups mid and post transition.

Summary

In this chapter I worked through phases one and two of Rosswurm and Larrabee's (1999) model for Change to Evidence Based Practice. I have assessed the need for change and linked the problem with an intervention and outcomes.

Chapter 4 Synthesise the Best Evidence

Throughout this project I have utilised the evidence to support the statements and information gathered and therefore do not intend for this chapter to be a further review of literature discussed in other chapters. However I would like to recognise that Rosswurm and Larrabee (1999) outlined this as a specific phase. Thus, in keeping with the framework I will discuss how I conducted the literature search for this project and briefly discuss a few key themes that support my implementation plan.

Search Strategies

I conducted a comprehensive literature review using primarily Medline and CINAHL databases. I also searched in evidence-based medicine reviews and Cochrane database of systematic reviews but was less successful with this approach.

Searches were limited to English language material published from 1997 onwards. I chose this early date, as there are a number of important older articles that discuss models of care.

Within these databases I used the following key words in various combinations: transition, chronic illness, and adolescent transfer, juvenile idiopathic arthritis, health care transition, transfer, and paediatric health care, and adult health care, young adult, transition from pediatric to adult, transitional care program, evaluation, experiences.

When I came across results from the first round of searches I used an author name search to find any additional studies. I also used the reference lists from the articles found of interest and this helped me identify more articles not found in the first search. In addition, I narrowed my search by combining (using the “and” command) with the terms JIA, diabetes, cystic fibrosis and congenital heart disease. I chose these chronic conditions to narrow the search to my question and enable me to look at conditions other than rheumatic diseases for comparison. I also knew from experience that these conditions, in many hospitals, have established transition programs.

Initially over 350 articles were found; however through limiting the search to the specific conditions listed I was able to narrow results and group according to chronic condition.

The following criteria were used to exclude studies from appraisal:

- Citations, which were letters to the editor, comments, editorials, abstract only, conference proceedings.
- Studies that focused on conditions other than those listed above were only included if they were evaluating a program or process already established

Sources of Evidence

This literature search was part of the larger search for this project and revealed a number of articles about transition. Like others, I found that the literature was mainly descriptive in nature with very few studies evaluating practice. Authors who have conducted systematic reviews since 2004 have noted this lack of robust evidence (Nakhla, Daneman, To, Paradis, & Guttman, 2009; David. Rosen et al., 2003; While et al., 2004) , however for this project it is still important to consider some of the key themes from the literature as it highlights the issues surrounding transition and addresses program development.

Planning is identified as a major factor in the success or failure of a transition process (Blum et al., 1993; S. M. Sawyer, S. Drew, M. S. Yeo, & M. T. Britto, 2007). Janet McDonagh and Russel Viner were some of the first clinicians to write about the issue of transition and share similar views about how to prepare young people and their families for transition. Viner (1999, 2008) described the basics of transition as simple and common to all diseases. He stated:

1. Prepare young people and their families well in advance for moving from paediatric to adult services and ensure they have the necessary skill set to survive and thrive there
2. Secondly prepare and nurture adult services to receive them
3. Thirdly, listen to young people's views. (Viner, 2008, p. 161)

Janet McDonagh added to this and described the four P's of Transitional Care (see Figure 4 below). McDonagh (2007b) emphasised that people are first and foremost the key to successful transition.

Figure 5: The Four P's of Transitional Care (McDonagh, 2007, p. 480)

<u>People</u>	<u>Process</u>
The Young Person	Written Transition Policy
Their parent's/caregivers	Transition Program
A Transition Co-ordinator	Evaluation and Audit
Interested Adult Services	
Primary Care	
Professional Training	
<u>Place</u>	<u>Paper</u>
Young Person Friendly Spaces	Informational Resources
	Administrative Support

Keeping in mind McDonagh's Four P's and Viner's basics I will now take a closer look at some of the key areas found in the transition literature.

Policy

The need to develop guidelines that facilitate the implementation and success of transition programs has been recognised by professional organisations. In 2002 a policy consensus statement by the American Academy of Pediatrics, the American Academy of Family Physicians and the American College of Physicians emphasised the need to have a written policy or guideline to support transitional care (American Academy of Pediatrics, 2002). This document placed transition in the minds of health professionals in America and is widely referred to in the transition literature. Two years later the Society of Adolescent Medicine published a position statement that also recognised the vital importance of organised transition programs supported by a written plan (Blum et al., 1993).

A transition policy is designed to provide information about transition plans, details of the agreements between paediatric and adult service, provides goals to work

towards and outlines when transition begins and also when transfer occurs. The literature surrounding the importance of written policy is mainly descriptive and is often disease specific with little empirical evidence that having a transition policy guarantees successful transition (Shaw et al., 2004). Despite this fact, some authors describe a written transition policy as one of the most important aspects of transition (Janet E. McDonagh, 2007b). McDonagh (2007b) discussed how a written plan ensures consensus; mutual understanding of the processes involved and provides a structure for evaluation and audit. I believe that it is in this final point that the strength of policy is most evident. The idea of a plan providing structure for evaluation is a key consideration in the development of any process that changes practice and supports the development of a RBP for the New Zealand Rheumatology Service.

Transition Co-ordinator

Along with preparation and planning, the literature clearly supports the idea of having one key worker or transition co-ordinator responsible for managing a young person's transition (Adam et al., 2005; American Academy of Pediatrics, 2002; Department of Health Child Health and Maternity Services Branch, 2006; Kennedy & Sawyer, 2008; J. E. McDonagh & Viner, 2006). The role is deemed important as it can help facilitate a seamless transition process, improve continuity of care, improve information sharing between services and ensure that structured transition takes place (Bennett et al., 2005; Russell. Viner, 1999; R. Viner, 2008; Yeo & Sawyer, 2005). A couple of papers that looked at programs with designated transition co-ordinators showed improvements in their identified outcome measures and the assumption is made that these improvements were partially related to the role the co-ordinator plays (Cadario et al., 2009; Holmes-Walker, Llewellyn, & Farrell, 2007). Shaw et al. (2004) published a qualitative study that sought to gain insight into the transitional needs of adolescents with JIA. This was a good qualitative study whose participants clearly indicated that key workers or key transition "contact persons" would help to alleviate confusion regarding transition. I could identify no studies that evaluated the co-ordinator role specifically, so it is unclear if variations to this role, such as identifying a patient key co-ordinator on a case by case basis, would be detrimental. For most health services in New Zealand, having one identified co-

ordinator would be challenging due to financial and resource limitations and undoubtedly a more creative approach to this aspect of transition would be necessary.

Timing of Transfer

So when does transition begin and when does transfer happen? This is an area that remains contentious. The literature would suggest that there are huge variances and differing opinions throughout the world. Some transition programs such as the OnTRAC program at British Columbia Children's Hospital suggests beginning early transition planning when the patient is 10-12 years of age (M. C. Paone, Wigle, & Saewyc, 2006). Most of the literature on transition would agree that starting early to prepare is key and most suggest a start age between 12-13 (Department of Health Child Health and Maternity Services Branch, 2006; J. E. McDonagh & Viner, 2006; M. Paone, 1998; Yeo & Sawyer, 2005). There is also a great deal of debate about the age of transfer itself. Some programs suggest that transfer occur at the same time that high school finishes, some suggest after school; whereas others are very rigid about the age of transfer as it relates to funding within the particular health system. A 2004 Canadian study found that there was an increased chance of successful transfer to adult care the later in age the *last* paediatric clinic occurred (G. J. Reid et al., 2004). This was a large study that looked at 360 patients all with the same chronic condition. It would be interesting to look at a study such as this in other conditions to see if this later age of transfer does make a difference. In a systematic review, Crowley, Wolfe, Lock, & McKee (2011) found that all 10 studies that met their criteria provided very little information on how age of transfer for individuals was decided. It would seem, once again, that there is a lack of strong evidence in this area.

Readiness to Transfer

There is certainly evidence from the literature that young people feel transfer time should be based on individual readiness and at a time of disease stability (Blamires & Dickinson, 2010; Brumfield & Lansbury, 2004; Department of Health Child Health and Maternity Services Branch, 2006; Shaw et al., 2004; R. Viner, 2008; Yeo & Sawyer, 2005). This important evidence comes from qualitative studies that have elicited the views of young people. Considering the experience and views of young people is an important consideration in the development of a transition program, there is no easy answer except to say that flexibility and developmental appropriateness is most important (J. E. McDonagh, 2007). In addition, the literature contains recommendations about the use of readiness checklists and questionnaires. There are a number of such tools that address readiness to transfer through looking at the young person's knowledge of their disease, its management and how much responsibility they take for looking after themselves. One paper described the development of a Transition Readiness Assessment Questionnaire (TRAQ) and the process of validating its use (Sawicki et al., 2011). The study suggested that the TRAQ is a useful and valid tool to assess transition readiness and it is clear that research should focus on use of this tool, or others like it, to assess transition readiness in adolescents.

Individual and Flexible Transition

A number of papers supported an individualised approach to transitional care that considers a number of factors including physical, psychological, intellectual and developmental readiness of the young person (Cooke, 2007; Department of Health Child Health and Maternity Services Branch, 2006; J. E. McDonagh & Viner, 2006; M. Paone, 1998; Shaw et al., 2004; R. Viner, 2008). Young people are heterogeneous and therefore it is impossible to have a transition solution that fits every person. It is very important that the transition process be "individualised to meet the specific needs of each adolescent, his or her family, the old and new providers and the system in which they find themselves" (Rosen, 1995, p. 14). The development of written transition plans are thought to help outline strategies for development of disease based knowledge and disease self-management skills (Bowen et al., 2010). More importantly, transition plans set clear goals for patients

and providers and allow for periodic assessment and of progress to determine readiness for transfer. There has been at least one study that showed that individualised transition plans and targeted patient education could improve Health Related Quality of Life Scores in young people with JIA (JE. McDonagh, Southwood, & Shaw, 2007). This study is of particular relevance to my project as it relates to both patient group and outcomes measured.

Collaboration

The success of a transition program requires good communication between patients, their families, the paediatric team and the adult team (American Academy of Pediatrics, 2002; Department of Health Child Health and Maternity Services Branch, 2006; Shaw et al., 2004). This acknowledges the importance of communication between services, but the reality in practice, is often difficult. It is recognised that there are differences in culture and practice between paediatrics and adults and it is essential that the two communicate well and find a way to meet halfway in order to facilitate transition for young patients (David Rosen, 1995; Sloman, 2005). In the systematic review by Crowley et al. (2005) they found that five out of the 6 successful programs involved either specific young adult clinics or joint paediatric/adult clinics. In the largest study the joint paediatric/adult clinics also produced positive clinical outcomes (Nakhla et al., 2009). This notion of at least meeting the adult service prior to transfer is also supported and echoed by qualitative studies where young people call for this directly (Blamires & Dickinson, 2010; Tuchman, Schwartz, Sawicki, & Britto, 2009).

Models of Transition

There does not appear to be a “best” model of transitional care and despite numerous articles being written about transition, three main models of transitional care are described: (1) disease focused, with the patient transferring from paediatric to adult specialist, (2) primary care model with the co-ordination of care being the job of the general practitioner and (3) generic adolescent with coordination by adolescent medicine specialists (S. M. Sawyer et al., 1997). In the most recent systematic review on transition by Crowley et al. (2011), the 10 studies that had shown statistically significant improvements in outcomes were all based on disease

specific models. Certainly this model is the most common and plausible for the majority of health care settings and is likely to be the reason for the results of their review. There are clearly advantages to each of these models but I could find no evidence that compared one to the other in terms of benefits to patients or improved outcomes. It may be in this case that decisions about what is the “best model” will have to consider the New Zealand context. In New Zealand, for young people with rheumatologic disease, the general practitioner cannot be a practical co-ordinator of rheumatology care. Most general practitioners are inexperienced in the complexities of rheumatological disease and would not have the time to co-ordinate this process. In the perfect world adolescent medicine specialists would be available for all youth with chronic disease; however once again the reality in New Zealand is that these resources are scarce. In actuality the disease specific model is the most likely transition model to fit.

Summary

The literature review on transition, revealed a large number of papers, however most of these tended to be descriptive in nature. The most recent systematic review of the evidence of effectiveness of transitional care programs suggests that we are still a long way from reaching the quantity and level of evidence to be confident in what constitutes the best transition program and its components (Crowley et al., 2011). This chapter is by no means an exhaustive review of the transition literature but contributes to the information gathered thus far and supports the implementation plan discussed in the following chapter.

Chapter 5 Implementation

Proposed Practice Change

In Chapters 3 and 4 I outlined how I conducted a comprehensive assessment and synthesis of best evidence in order to determine the practice change needed for the development of a transition program in paediatric rheumatology. For this project the practice change identified was the development of a RBP for transitional care in paediatric rheumatology. A RBP within the Auckland DHB is the accepted way of documenting processes and procedures and is similar in many respects to a clinical guideline. The development of an RBP supports Rosswurm and Larrabee's (1999) assertion that the first part of practice change is for "practitioners to describe the process variables or detailed sequence of care activities in the change in practice, usually in the form of a protocol, procedure or standard" (p 320).

In this chapter I will discuss here how I have developed the RBP, the key components and the process by which I gained approval from key stakeholders. Rosswurm and Larrabee (1999) described four key actions which need to occur during this step of the process:

1. Define the proposed change
2. Identify needed resources
3. Design the evaluation of the pilot
4. Design the implementation plan

For this project I do not plan to conduct the "pilot" as suggested by Rosswurm and Larrabee (1999). The time constraints for completing this report have not allowed me to complete the implementation phase; however, I will describe what has been done so far and what is planned. This will include defining the proposed change, identifying the needed resources and discussing how I plan to implement the change and evaluate using the key outcome measures discussed in Chapter 3. This chapter will be divided into four parts:

1. Developing a Clear Process to Guide Transition (Action 1)

2. Individualised Transition Planning (Action 1)
3. Resources (Action 2)
4. Implementation Plan and Evaluation (Actions 3-4)

Develop a Clear Process to Guide Transition

The first action in Step 4 of Rosswurm and Larrabee' (1999) model is to define the proposed change and this includes describing the details of the new practice. The format can take many forms (procedure, policy, care map) and the content should describe for whom the practice pertains to, the process of care, the timing and the expected documentation. Considering these points and the Auckland DHB guidelines for document development a RBP has been developed (Board, 2004).

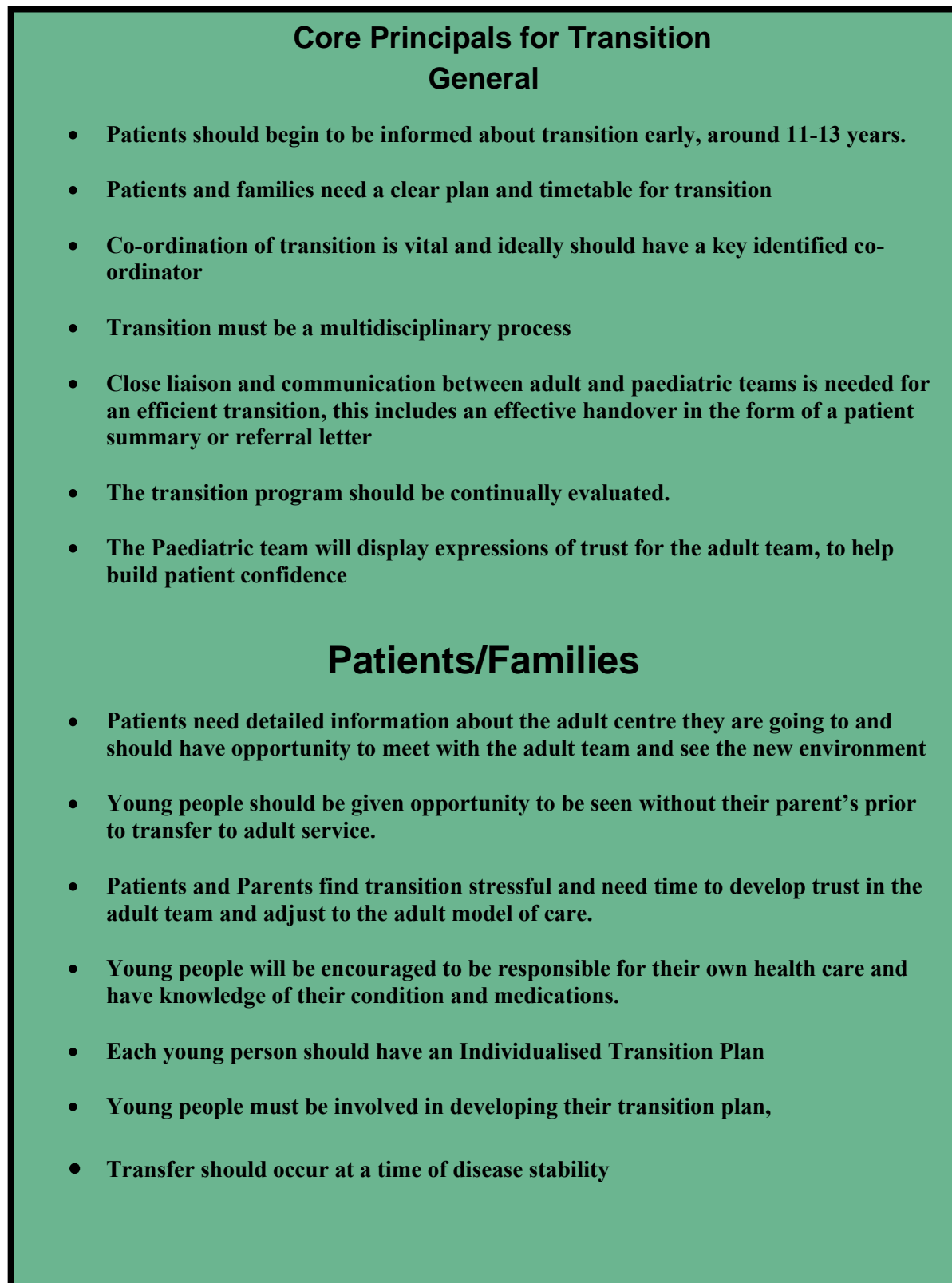
Evolution of the Document

The development of this RBP has been a lengthy process and the document itself has been in evolution since 2009. When I first began the job as nurse specialist for rheumatology there was pressure within the service to produce a document to guide transition, as this was one of the key objectives set out by the Ministry of Health. At that time, one of the consultants and I put together a draft document that was largely adapted from the Royal Children's Hospital Transition Program as this was where the consultant had previously worked and had gained permission to utilise it (http://www.rch.org.au/transition/index.cfm?doc_id=8143). I recognised that there were elements to this document that did not quite fit so rewrote the document borrowing large components from the Starship Diabetes Service, as this appeared to be the only tertiary service within Starship that has established a dedicated program. However, having had the opportunity to see the Diabetes Transition Clinic firsthand I recognised that it was not comparable to the situation within the rheumatology service. There were several reasons for this but the differences were mainly related to the large number of patients in diabetes service and the resources they had available, both in terms of physical space, dedicated co-ordinator and allotted clinic time. Further, through reading and research I was not comfortable with the rigidity of their time frames around transfer.

Information gained through the assessment phase, the literature review and through the experience of working within the rheumatology service, during the project, has meant that the document has gone through four to five different phases of development. It started out prescriptive with in-depth detail describing the phases of transition and what should happen in each. The finished RBP (Appendix 3) is much less a policy and more of a guide that contains core “overriding principles” that will help develop the link between paediatric and adult care for rheumatology patients and with hope provide a seamless transition and eventual transfer of care. The main reason for this change came through a realisation that there were too many variables between DHBs making it impossible to have one policy that would work throughout the country. Variables included the fact that some DHBs have an enthusiastic adult team while others do not even have an adult rheumatologist; some DHBs can provide joint consultation at the paediatric clinic whereas others would not; many adult services had nurse specialists keen to co-ordinate transition while others were lacking any multidisciplinary team. When I sat down to write the RBP, for what I hoped would be the final time, I thought it was important to “brainstorm” the most important and key points or “core principles” I wanted the RBP to uphold. This process was uncomplicated and involved writing down all of the key elements that stood out from the assessment phase. Figure 6 (p. 53) lists the results of this initial brainstorm.

I believed that if the RBP could contain these core principals then the rheumatology service would be able to provide transitional care consistent with the principles of best practice determined from the assessment phase.

Figure 6: Key Elements from Initial Brainstorm



With these core principles in mind, and following the Auckland DHB Document Development Guidelines, I divided the RBP into three parts (Appendix 3). The first part contains the objective, responsibility, frequency and associated documents. The second part contains definitions, outcomes and timelines/key phases. The third and final section of the RBP I call “components” and contains information about the key parts and resources available to support the process.

Part One

The Auckland DHB guidelines on document development are clear that in the first part of an RBP the objective must state the desired outcome and that there should be only one primary objective. They also require the developer to identify people responsible and under what circumstances the RBP would be put to use. This all fit nicely with the development of the RBP on transition.

Part Two

It was important that the RBP contain key definitions, including definitions of “transition” and “transfer”. White and Hackett (2009) described how to develop a transition policy and provided a template that encourages the provision of definitions within the first step. I also knew it was important to make sure that anyone who read the document understood that transition was a process not an event.

Within part two I wanted to provide a time line to help guide team members and patients through the process; and identify the key outcomes in order to provide a basis for evaluation. It is important to include a schedule of likely timings and events with an understanding that these timings will be flexible.

Part Three

Part three of the RBP contains detailed descriptions and examples of some of the components described in part two. Items such as readiness checklists and templates for the individual transition plans are found.

Individualised Transition Plan

Within a policy or RBP on transition, such as that described above, there is a need to be flexible. In order to fully describe the proposed change it is necessary to consider this flexible and individual approach as it is one of the most significant parts of the RBP.

It is clear from one of the earliest articles on transition that an individualised approach, meeting the specific needs of each adolescent and their family, is key to making transition work (Rosen, 1995). This 'individualisation' was also a theme that came out of the focus group interview conducted in the rheumatology service (Blamires & Dickinson, 2010). The young people in this study were very clear that they appreciated the fact that their individual needs were considered and they emphasised how 'individual' the experience of transfer was for each of them.

In a national survey by Shaw, Southwood and McDonagh (2002), it was found that 77% of rheumatology professionals considered individualised transition plans to be very important for young people and their parents. In the survey conducted as part of this project 92.3% of respondents supported individualised transition plans.

White and Hackett's (2009) article described nine components that should be included within an individual transition plan. Although these nine components are important I knew that if the process was cumbersome for the patient or the health professional that the plan would not be used. Rosswurm and Larrabee (1999) note that *simplicity* is important when introducing a new practice and suggest that decreasing complexity improves the likelihood of acceptance and therefore successful implementation (p. 320). Therefore, I came up with six core areas to be included in the individual transition plan (see Table 2).

Table 2: Individual Transition Plan

At each phase of the transition process there are new questions to help address these key areas.

Key Elements of the Individual Transition Plan	
Independent Health Care Knowledge	<ul style="list-style-type: none"> • Provide opportunity for young people to practice and develop communication with health providers without parental guidance • Encourage young people to learn how to describe their symptoms and to ask questions. • Empower young people to learn about their condition and treatment.
Psychosocial	<ul style="list-style-type: none"> • Assess risk behaviours, mood (HEADS) • Discuss risks of drugs, alcohol, smoking • Enable time to discuss future plans, including school, career • Acknowledge and help family cope with changing roles (provide parental support and opportunity to talk)
Health& Lifestyle	<ul style="list-style-type: none"> • Address the importance of nutrition, exercise, sleep • Assess pubertal development/growth • Discuss healthy eating habits
In addition to the three key areas above the plan should include:	
Discussion about the differences between Paediatric and Adult Rheumatology Service	<ul style="list-style-type: none"> • Provide information about the Adult service including physical location, names of the team members, • Discuss the practical differences including information about joint injections, prescriptions, timing of appointments • Provide opportunity to visit the adult clinic or meet the adult providers.
Creation of Medical Summary	<ul style="list-style-type: none"> • Prepare and maintain an up to date medical summary at the beginning of transition that is updated until time of transfer
Time Line	<ul style="list-style-type: none"> • In collaboration with the young person and their family discuss a timeline for the transition process.

Co-ordination

In order for this process to work, I recognised that one person within the health care team would have to take responsibility for completion of the individual transition plan with the patient and family and be responsible for keeping this updated. This person would become the identified co-ordinator of transition for the young person. In the literature the co-ordinator role in transition is seen as essential (Cadario et al., 2009; Department of Health Child Health and Maternity Services Branch, 2006; Holmes-Walker et al., 2007; S. Sawyer et al., 1998). Internationally many large hospitals, including the Royal Children's of Melbourne, The Hospital for Sick Children in Toronto, Great Ormond Street in London, Waikato Hospital in Hamilton, have designated transition co-ordinators. I recognised within the time frame of this project that the inability of the service to support one designated person due to lack of resources, means that this would not be a reality for rheumatology. The rheumatology service is, fortunately, interdisciplinary in its function and values every member as equal, important and capable. This interdisciplinary approach meant that when writing the section on developing a clear process for transition I was able to make assumptions that any member of the team could act as the key worker/co-ordinator, in much the same way that the team functions with regard to care and case management. The co-ordinator would be identified when the young person entered the early transition phase and would sit down with the young person and his/her family to begin documentation of the individual plan. This ideally would be kept as an electronic record, but for the time being will have to be kept as a paper record within the rheumatology service as current IT systems cannot support a new electronic transition record.. I will plan for these documents to be coded for eventual scanning into the computerised record.

Resources

Resources for Young People

Identifying needed resources is action two within step four of Rosswurm and Larrabee's (1999) model. They described the need to consider what resources will be required to enable the key players to perform the new practice. In this section they discussed patient/family education materials, fact sheets, and websites, and point out that the key is to first locate existing materials before moving on to developing new documents (Rosswurm & Larrabee, 1999).

I searched the internet for suitable resources and material and found a number of appropriate documents from The Royal Children's Hospital, The Hospital for Sick Children, The Dream Team UK, BC Children's Hospital and OnTracc and came up with a variety of information sheets, internet resources and websites. Where I have not already done so, permission will be sought to use these resources within the service. I plan to provide a list of useful websites within the RBP so they are available to health professionals, patients and families, at the beginning of transition. These information sheets and websites provide helpful information for young people in transition and I recognised that many could be used for our patient population. However there is still a need to develop New Zealand specific resources.

Resources for Rheumatology in New Zealand

Much of the literature, and most of the established transition programs, utilise and support the development of transition assessment tools/checklists (Birmingham Children's Hospital NHS Foundation Trust, 2005; Cooke, 2007; M. Paone, 1998; The Royal Children's Hospital, 2006; Toronto SickKids Hospital, 1999-2011; Yeo & Sawyer, 2005). For this project I wanted to develop a transition pack that contained a number of information pamphlets that could be either given out as paper copies or downloaded from the Starship website and, therefore, accessible nationwide. Due to time constraints I have been unable to complete all of the documents but I have enlisted the help of the graphic designers at the Auckland DHB and will be working on the development of these in the upcoming months.

Technology

Recognising the important role of technology in the way that young people gain knowledge and interact with each other, I feel that the next step would be to develop web based information specific to our service and patient needs; however due to time constraints this was not something I could complete for the current project. What I decided to do instead was source a list of useful websites for young people and describe what these contain so that they can at least have opportunity to utilise a medium they prefer and are accustomed. The other important consideration is the use of text messaging, as this is another medium of which youth are particularly fond. Text messaging is an area that should be explored further as it may provide a

means of communication and a method of reminding about appointments, as well as a way to provide support.

Implementation Plan

Phase 1- Approval of the RBP

The first part of the implementation phase has to do with giving opportunity for the key stakeholders to comment and contribute to the new RBP guideline. Feedback received will be considered and changes made to the document as deemed appropriate and acceptable. It is important that key stakeholders feel they have the opportunity to adapt and refine the innovation to fit the organisation and this is particularly important in the case of this RBP as it will be utilised throughout many different services and DHBs around the country. Rosswurm and Larrabee (1999) talked about giving opportunity for stakeholders to share their opinions and make suggestions about the new practice. The RBP will be sent out to selected adult rheumatology teams, paediatricians, the national rheumatology team members, selected nurse specialists from other specialty services, the medical service manager, Arthritis Parent Support Group in the community, and a randomly selected group of patients between 16-24 who are getting ready to transfer or who have already transferred.

The draft will be circulated for two weeks. Following the New Policy Development Guidelines, from the Auckland DHB, all feedback will be considered and written rationale will be provided for the amendments (or not) based on the feedback received (Board, 2004). The amended RBP will then be submitted to the document controller who will allocate a classification number and arrange signoff from appropriate people.

Phase 2- Education about the RBP to Clinicians

Success of a new practice requires that stakeholders have a clear understanding of the change and how it affects them, therefore it is imperative to have a strategy for education to introduce the change and the details that will help the team carry out the new practice (Larrabee, 2009).

The second phase of the implementation plan will include introduction of the document to the rheumatology team at the National Meeting in May 2011 through a formal presentation, outlining the key parts and documents and allowing opportunity for questions. At this meeting one of the key agenda items will be to discuss who will take the key transition co-coordinator role within each team and who will be responsible for managing the patient database and communicating with the appropriate adult team as patients reach the time of transfer.

The proposed plan to manage patients will be to utilise a spreadsheet that contains information tracking the age, information given and phase of transition of each patient. At this meeting I plan to seek feedback from the team on how to manage the individual transition plans. This may differ between the Starship half and the Hutt half of the national team but it is essential that these plans be easily editable and accessible at each patient visit. Once again the management of the plans and the patient list will need to be coordinated by one person.

Distribution of the RBP and associated documents to all key contacts within each DHB from around the country will occur following the National team meeting. There will be planned teaching sessions at outreach clinics to introduce the document, checklists and other transition resources to the adult rheumatology teams and allow time for feedback and questions from the adult teams.

Phase 3- Introduction of the Transition Plan to Patients/Parents

The RBP and plan for transition will be introduced to patients and families through informal discussion and an introductory letter that will accompany the transition checklist and other documents providing information about transition. Team members will need to commit to having discussions early so that the family and patient are aware of the change in practice.

This implementation phase will begin in July 2011, with the draft document sent out for comment. I plan to allow 3 weeks for comments to be returned. Once changes are made the final document will be implemented. The plan would be to have the RBP fully operational by September 2011.

Evaluation

The ultimate aim of this practice project and desired outcome of any practice change is improvements and positive outcomes for patients. Using the outcome measures described previously I plan to focus five areas for evaluation as described below.

1. Patient will be prepared for the new service prior to transfer

Prior to transfer every patient will have opportunity to meet at least one clinician from the service to which they will transition. Within the Auckland region they will also have the opportunity to visit the new clinic and learn about differences between services. This will be clearly documented in the individual transition plan and can be audited in the future to ensure continuing good practice. As part of this preparation the patient and family will be told about the differences regarding treatment. For example, available medicines, techniques for joint injections and method of changing appointments will be discussed and clearly documented prior to transfer.

2. Patient will establish independent health behaviours

Patients who have entered the transition phase will be given opportunity to be seen alone for a portion of the clinic time. They will be encouraged to answer questions about their health status, medications and to express an understanding of their disease and the treatment plan. The rheumatology service will plan to look closely at the available transition readiness questionnaires to deem if they are appropriate for our climate and plan to use these as a further method of evaluating if we are successfully meeting this outcome.

3. Patient will have disease related knowledge

Patients will be provided with age specific information about their disease and medications. The Royal Children's Hospital in Melbourne have agreed to provide their rheumatology teaching modules and once reviewed we will decide as a team how to use these. One possible scenarios is to have group education sessions, thus giving adolescents a chance to learn about their disease while at the same time enabling them to interact with other young people (in a blog format) with the same

condition. In the future I hope that a website could be developed that would provide easy access for young people to acquire information about their disease.

4. Adequate exchange of information will occur

Every patient will have a written transfer letter that follows the template included in the RBP. This template ensures that every clinician includes all pertinent information to the adult healthcare team. This letter will be sent well in advance of the actual planned transfer time to allow for waiting lists that vary between DHBs.

Communication between the paediatric co-ordinator and the key adult contact person will also occur well in advance through email or phone correspondence, thereby allowing exchange of psychosocial information that may not be available within the clinical summary.

5. Patients and families will be satisfied with service

The need to elicit the views and experiences of young people and the families as they move through the phases of transition will be important. I plan to develop a questionnaire that young people and their family answer at the beginning of the transition phase and again before transfer, in order to ascertain a positive effect in terms of readiness to transfer and confidence with self-management. I would also like to develop a postal survey that can be sent to patients 6-8 months post transfer in order to determine their satisfaction with the process. It is acknowledged that time and personal resources may limit the ability of ongoing evaluation.

This project is a tiny piece of the much larger puzzle of co-ordinating transitional care in rheumatology. Due to the time constraints associated with completing this report, as part of my academic study, the RBP has not yet been implemented. However, I continue to lead this project and have described how I plan to implement this RBP and subsequently evaluate it. Chapter 6 outlines the challenges that this project has posed, as well as commentary on Rosswurm and Larrabee's (1999) framework. This final chapter will summarise the project and discuss plans for the future.

Chapter 6 Discussion

This project has been challenging and stimulating, and has provided an opportunity to examine the literature on transition and models of transitional care as well as understand the climate for transition in New Zealand rheumatology service. When I originally agreed to take on the project of planning and writing the transition plan for the rheumatology service, I was concerned about how and where to begin. Through this project, the original RBP transformed from a prescriptive rigid document into a guideline with core principles; a positive change in that it better reflects the uniqueness of the New Zealand situation. Rosswurm and Larrabee's (1999) model provided a useful framework that helped to guide the process of moving research and theory into practice. Working through the phases described in the model, enabled me to manage the data analysis and assessment phase and provided order and structure to the project report.

The assessment phase illustrated the need to develop a transition process for paediatric rheumatology; the literature supported this and outlined key features to include. Overall there continues to be a clear need to appraise what constitutes a successful transition program and rigorous outcome measures need to be developed and continually evaluated.

Comments on the Model

Although Rosswurm and Larrabee's (1999) model was useful in many ways it also provided a number of challenges and I needed to adapt it to fit this project. The original model from 1999, on which the project plan was based, contains two distinct first phases. Phase one - assessment and phase two - linking the problem, interventions and outcomes. Working through the model I found that these two phases linked together into one phase which I entitled 'findings'. Towards the end of this project I discovered that one of the original authors June Larrabee had written a book that showed a change to the model combining these two phases into one. The revised model is entitled the *Model for Evidence-Based Practice Change* (Larrabee, 2009). After reading about this change (which was based on the authors

experience of mentoring nurses using the model in practice), I felt reassured about my decision to combine these first two phases.

I was also unable to meet the models expectations about the use of standard classification systems language, as this did not fit with the theme of the project. Instead I turned to the literature and the stakeholders to provide guidance around the setting of outcome measures.

Rosswurm and Larrabee's (1999) phase four focuses on designing a practice change. This practice change and subsequent implementation only occurs after a pilot test. For this project it was deemed unnecessary to design a pilot as the project itself was about the development of a guideline (the RBP). I think this model could be improved if it had an option, after the assessment and synthesis of the evidence phases, that allowed for a decision to go ahead with the change to practice or not. There is not always the ability or time to conduct a pilot.

The last challenge I would like to mention with Rosswurm and Larrabee's (1999) model has to do with its linear nature. Throughout this project I felt I was moving back and forth between the first three phases and in some situations developing parts of the RBP and its resources concurrently. The model describes its phases in a linear progression; yet I do not feel that this works for all projects as there are usually multiple processes occurring simultaneously. I feel it would be useful for the model to recognise that previous knowledge, experience and input from the literature throughout a project also influences the decision of whether or not to proceed with practice change.

Challenges Ahead

One of the biggest challenges ahead is maintaining momentum. I stated in the recommendations that ongoing evaluation is key, however the reality of time and financial restraints within services often provide barriers to making it happen.

The other key challenge will be to continue to engage and retain commitment from the adult rheumatology teams. As I have made abundantly clear throughout this

report, their participation is crucial for success. Hence, it is important that the co-ordinators within paediatrics continue to appraise adult rheumatology teams of transition plans, communicate early and effectively about patients and offer opportunity for them to feedback and comment about the process.

Looking to the Future...

For Parents

One area this project has not addressed well is parental needs during transition. There is a call for transitional care to be inclusive of parents and to enable them to become good advocates for their children, as well as support for the adjustment to changed relationships with young people (Janet E. McDonagh, 2007b; While et al., 2004). The RBP that has been written aims for this process, however it will be useful to seek feedback from parents in the future to see if their needs are being met, what their experiences are and what their perception of transitional care is when compared to their children's perceptions. It would be ideal to include parents in the development of future revisions.

For Clinicians

The need for staff training in relation to adolescents and young people's specific issues was not examined in this report. In New Zealand, as in other parts of the world, there is a lack of health professionals with special training in the needs of adolescents (JE. McDonagh et al., 2006; S. M. Sawyer et al., 1997). This training is needed across both the paediatric and adult settings as it is an area of great importance when working with young people. The notion of additional training for staff working with young people was highlighted in a 2004 New Zealand study (Farrant & Watson, 2004).

Throughout this project one of the key messages from the literature and from the review of internal and external data was the considerable lack of rigorous evaluated outcome measures in transition. One of the clear recommendations of this project is to ensure that before the transition RBP is put into action that the service commit to measuring its effect using the measures described on pages 71-72 of this report.

For Patients

All young people with chronic conditions in New Zealand should be given the necessary skills and tools to manage their own health as they move from the paediatric to adult setting. It is clear from the assessment phase of this project, and from the transition literature, that there are generic elements to transition that can be applied across all spectrums of disease. The population of New Zealand is small and therefore does not necessarily have the resources nor the need for transitional care programs individualised to each tertiary service. Following the completion of this project, the plan will be to decide if the rheumatology transition RBP can be utilised as a generic RBP for all Starship services. This will mean the sharing of adolescent-focused resources and help ensure all young people get some form of transitional care. The notion of pooling patients and resources across tertiary services has the potential to provide better research and evaluation opportunities. There are a number of possible areas and questions for further study that could be considered such as:

- Are certain youth more in need of transition services than others?
- Do the needs for transitional care differ depending on which disease or disability a young person has?
- What are the individual service factors that improve transition outcomes for patients?

It will also be important to consider the impact that transitional care has on long term outcomes for patients. Research in this area would contribute to the evidence of need for formal transition programs. If a link between decreased morbidity and subsequent cost to the health care system can be made then transition programs are more likely to attain financial and institutional support.

Conclusion

The move to adult care from paediatrics for young people with chronic rheumatologic disease is a major and sometimes stressful event. The need to provide a seamless and efficient transition to adult care includes preparation, planning and flexibility. It is essential for all health services to have a transition plan or policy as part of a quality service. The RBP, designed in this current project, aims to provide guidance for the

national rheumatology team in New Zealand to support people through this challenging time.

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Appendix 1: Clinician Survey Response Summary



Transitional Needs of Adolescents in Rheumatology
















1. Position/Job

		Response Percent	Response Count
Adult Rheumatologist		28.3%	13
Nurse Specialist in Rheumatology		19.6%	9
Registered Nurse		13.0%	6
General Practitioner		0.0%	0
Physiotherapist		21.7%	10
Occupational Therapist		6.5%	3
Paediatrician		8.7%	4
Social Worker		2.2%	1
		answered question	46
		skipped question	0



2. Sex

		Response Percent	Response Count
Male		28.3%	13
Female		71.7%	33
		answered question	46
		skipped question	0



3. Employed in:

		Response Percent	Response Count
Hawkes Bay DHB		0.0%	0
Taranaki DHB		0.0%	0
Wanganui DHB		5.4%	2
Mid Central DHB		2.7%	1
Wairapa DHB		0.0%	0
Mid Central DHB		5.4%	2
Hutt DHB		13.5%	5
West Coast DHB		2.7%	1
South Canterbury DHB		2.7%	1
Nelson Marlborough DHB		0.0%	0
Canterbury DHB		13.5%	5
Tairāwhiti DHB		8.1%	3
Auckland DHB		5.4%	2
Waitemata DHB		5.4%	2
Counties DHB		8.1%	3
Bay of Plenty DHB		8.1%	3
Waikato DHB		18.9%	7
	answered question		37
	skipped question		9



4. Did you treat or care for patients greater than 18 years of age during the last year?

		Response Percent	Response Count
Yes		80.4%	37
No		19.6%	9
		answered question	46
		skipped question	0

5. Did you treat or care for patients less than 18 years of age during the last year?

		Response Percent	Response Count
Yes		84.8%	39
No		15.2%	7
		answered question	46
		skipped question	0

6. Does your service have a formal transition program?

		Response Percent	Response Count
Yes		35.6%	16
No		64.4%	29
		answered question	45
		skipped question	1

7. The following people are active and important participants in transition.

	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree	Response Count
The Young Person/patient	95.3% (41)	2.3% (1)	0.0% (0)	2.3% (1)	0.0% (0)	43
Parent	76.2% (32)	23.8% (10)	0.0% (0)	0.0% (0)	0.0% (0)	42
Paediatric Rheumatologist	76.7% (33)	20.9% (9)	2.3% (1)	0.0% (0)	0.0% (0)	43
General Practitioner	47.6% (20)	28.6% (12)	16.7% (7)	7.1% (3)	0.0% (0)	42
Paediatrician	57.5% (23)	30.0% (12)	12.5% (5)	0.0% (0)	0.0% (0)	40
Community Nurse	15.8% (6)	26.3% (10)	44.7% (17)	13.2% (5)	0.0% (0)	38
Teacher	22.5% (9)	40.0% (16)	27.5% (11)	12.5% (5)	0.0% (0)	40
Social Worker	17.5% (7)	45.0% (18)	30.0% (12)	7.5% (3)	0.0% (0)	40
Nurse Specialist	66.7% (28)	26.2% (11)	4.8% (2)	2.4% (1)	0.0% (0)	42
Paediatric Occupational Therapist	39.0% (16)	41.5% (17)	17.1% (7)	0.0% (0)	2.4% (1)	41
Peers	16.2% (6)	40.5% (15)	29.7% (11)	10.8% (4)	2.7% (1)	37
Sibling	15.4% (6)	25.6% (10)	48.7% (19)	10.3% (4)	0.0% (0)	39
Paediatric Physiotherapist	33.3% (14)	54.8% (23)	4.8% (2)	4.8% (2)	2.4% (1)	42
Please list others who you believe to be important in transition planning?						13
answered question						43
skipped question						3

8. When patients with active disease reach adulthood they should stay under medical follow up with the paediatric team.

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Rating Average	Response Count
Answer	4.9% (2)	9.8% (4)	14.6% (6)	53.7% (22)	17.1% (7)	3.68	41
	answered question						41
	skipped question						5

9. When patient's with active disease reach adulthood they should be transferred to an adult rheumatologist.

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Rating Average	Response Count
Answer	29.3% (12)	48.8% (20)	9.8% (4)	12.2% (5)	0.0% (0)	2.05	41
	answered question						41
	skipped question						5

10. Adolescent rheumatology patients should be transferred when they reach a certain age.

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Rating Average	Response Count
Answer	5.0% (2)	35.0% (14)	30.0% (12)	30.0% (12)	0.0% (0)	2.85	40
	answered question						40
	skipped question						6

11. The transitional needs of parent's should be addressed.

	Strongly agree	Agree	Undecided	Disagree	Strongly Disagree	Rating Average	Response Count
Answer	51.2% (21)	48.8% (20)	0.0% (0)	0.0% (0)	0.0% (0)	1.49	41
	answered question						41
	skipped question						5

12. Adolescent rheumatology patients should be transferred when the family wants to

	Strongly agree	Agree	Neither agree , nor disagree	Disagree	Strongly Disagree	Rating Average	Response Count
Answer	7.3% (3)	19.5% (8)	46.3% (19)	26.8% (11)	0.0% (0)	2.93	41
	answered question						41
	skipped question						5

13. Adolescent rheumatology patients should be transferred when their disease is stable.

	Strongly agree	Agree	Undecided	Disagree	Strongly Disagree	Rating Average	Response Count
Answer	7.3% (3)	53.7% (22)	19.5% (8)	19.5% (8)	0.0% (0)	2.51	41
	answered question						41
	skipped question						5

14. Limited clinic space is a barrier to organising formal transition

	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree	Rating Average	Response Count
Answer	14.6% (6)	41.5% (17)	14.6% (6)	29.3% (12)	0.0% (0)	2.59	41
	answered question						41
	skipped question						5

15. A lack of funding is a barrier to organise formal transition

	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree	Rating Average	Response Count
Answer	17.1% (7)	43.9% (18)	24.4% (10)	14.6% (6)	0.0% (0)	2.37	41
	answered question						41
	skipped question						5

16. Insufficient support of the adult rheumatology team is a barrier to organise formal transition

	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree	Rating Average	Response Count
Answer	9.8% (4)	31.7% (13)	22.0% (9)	29.3% (12)	7.3% (3)	2.93	41
	answered question						41
	skipped question						5

17. The lack of available multidisciplinary team members at different District Health Board's is a barrier to formal transition

	Strongly agree	Agree	Undecided	Disagree	Strongly Disagree	Rating Average	Response Count
Answer	17.1% (7)	34.1% (14)	29.3% (12)	17.1% (7)	2.4% (1)	2.54	41
	answered question						41
	skipped question						5

18. Poor communication is a barrier to successful transition

	Strongly agree	Agree	Undecided	Disagree	Strongly Disagree	Rating Average	Response Count
Answer	34.1% (14)	46.3% (19)	12.2% (5)	4.9% (2)	2.4% (1)	1.95	41
	answered question						41
	skipped question						5

19. Young patient's should be educated about their condition.

	Strongly agree	Agree	Undecided	Disagree	Strongly Disagree	Rating Average	Response Count
Answer	95.0% (38)	5.0% (2)	0.0% (0)	0.0% (0)	0.0% (0)	1.05	40
	Comments:						9
	answered question						40
	skipped question						6

20. Young patients should be educated about general health issues.

	Strongly agree	Agree	Undecided	Disagree	Strongly Disagree	Rating Average	Response Count
Answer	75.0% (30)	25.0% (10)	0.0% (0)	0.0% (0)	0.0% (0)	1.25	40
	answered question						40
	skipped question						6

21. Patients should be informed about sexual health issues in the context of their disease.

	Strongly agree	Agree	Undecided	Disagree	Strongly Disagree	Rating Average	Response Count
Answer	55.0% (22)	42.5% (17)	2.5% (1)	0.0% (0)	0.0% (0)	1.48	40
	answered question						40
	skipped question						6

22. Patients should be informed about their medication and the side effects

	Strongly agree	Agree	Undecided	Disagree	Strongly Disagree	Rating Average	Response Count
Answer	90.0% (36)	10.0% (4)	0.0% (0)	0.0% (0)	0.0% (0)	1.10	40
	answered question						40
	skipped question						6

23. Patients should be offered a meeting with other adolescents with a rheumatology disorder.

	Strongly agree	Agree	Undecided	Disagree	Strongly Disagree	Rating Average	Response Count
Answer	27.5% (11)	60.0% (24)	12.5% (5)	0.0% (0)	0.0% (0)	1.85	40
	answered question						40
	skipped question						6

24. Patients should have a dedicated transition co-ordinator

	Strongly agree	Agree	Undecided	Disagree	Strongly Disagree	Rating Average	Response Count
Answer	32.5% (13)	27.5% (11)	37.5% (15)	2.5% (1)	0.0% (0)	2.10	40
	Comments:						7
	answered question						40
	skipped question						6

25. Patient's should have an individualised transition plan

	Strongly agree	Agree	Undecided	Disagree	Strongly Disagree	Rating Average	Response Count
Answer	33.3% (13)	59.0% (23)	7.7% (3)	0.0% (0)	0.0% (0)	1.74	39
	answered question						39
	skipped question						7

26. Parent's should be assisted on how to promote their young person's independence.

	Strongly agree	Agree	Undecided	Disagree	Strongly Disagree	Rating Average	Response Count
Answer	50.0% (20)	45.0% (18)	5.0% (2)	0.0% (0)	0.0% (0)	1.55	40
	answered question						40
	skipped question						6

Appendix 2: Paediatric Society of New Zealand

Position Statement



**THE PAEDIATRIC SOCIETY
OF NEW ZEALAND**

Secretariat:

Denise Tringham
P O Box 22 234
Wellington
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POSITION STATEMENT

**Meeting the Care and Support Needs of Young People with
Complex and Chronic Health and Disability Needs as they
Approach Adulthood**

STATEMENT ENDORSED BY:

- Office of the Commissioner for Children
- UNICEF New Zealand
- Council for Medical Colleges
- Royal New Zealand College of General Practitioners
- Cardiac Society
- Paediatric Dentistry, University of Otago
- Group Special Education
- Epilepsy New Zealand
- Heart Children New Zealand
- Cerebral Palsy Society
- Parent to Parent New Zealand
- New Zealand Organisation for Rare Disorders

March 2003
Nick Baker
Review: March 2005

Health of our children: wealth of our nation



**THE PAEDIATRIC SOCIETY
OF NEW ZEALAND**

Secretariat:

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POSITION STATEMENT

Meeting the Care and Support Needs of Young People with Complex and Chronic Health and Disability Needs as they Approach Adulthood

The Paediatric Society of New Zealand believes:

1. Special provisions need to be made for young people with complex and chronic health and disability needs, particularly with regard to their health care after the age of 12 years.
2. Young people with complex and chronic health and disability needs require a single local individual who has a role as a point of first contact and co-ordinator of a team of care.
3. Young people with complex and chronic health and disability needs require access to the best available national or international expert medical advice to direct their health care.
4. Young people with complex and chronic health and disability needs require access to habilitation and rehabilitation services appropriate to their age and developmental level

The Paediatric Society of New Zealand notes

1. That many young people with complex and chronic health and disability needs often have problems that are complex and/or rare and require input from a range of health providers and services
2. That many young people with complex and chronic health and disability needs have difficulty accessing coordinated care and expertise in rare disorders
3. That parents frequently report that apart from within General Practice it is hard to access inclusive holistic care within adult specialist medical services.
4. Many young people with complex and chronic health and disability needs have problems that are too complex or rare to be adequately managed by a General Practitioner alone.

March 2003
Nick Baker
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5. When transferred from paediatric care the process of access to specialist services by General Practitioner referral is procedurally complex and time consuming
6. Significant financial barriers frequently prevent young people with complex and chronic health and disability needs from adequately accessing General Practice and this often means transferring costs to individuals and families

The Paediatric Society of New Zealand recommends:

1. Development of systems for funding and implementation for a system of care that meets the needs of these children and young people.
2. That as systems of capitation or population based funding are developed care is taken to avoid any incentives that might discourage care for individuals with complex and chronic health and disability needs. Special recognition of the high cost of providing care for these people such as funding attached to the individual may be required.
3. Funding of care for young people with needs should support the best local solutions for continuity of holistic care. These might include:
 - Development of adolescent transition services
 - Initiatives within primary care
 - Funding for Paediatric Services to extend to young people up until their 18th birthday, (consistent with Paediatric Specialties Review (PSSR) and the United Nations Convention on the Rights of a Child (UNCROC)
 - Development of adult medicine and adult rehabilitation services with a special interest in young people with high health and disability needs
4. National networks need to be developed to support the complicated needs of young people with complex and chronic health and disability conditions which are frequently rare.

The Paediatric Society of New Zealand recommends to its members:

1. They encourage the establishment of developmentally appropriate systems to support the continuity of holistic care after age of 12 eg: develop adolescent services that focus on the transition to adult services
2. Support networking both nationally and internationally to deliver the best available services for young people with high health and disability support needs.
3. Young people with complex and chronic health and disability needs require a transition plan clearly providing for continuity of care when they have reached the age at which they would otherwise leave Paediatric care: the plan should clearly identify which option is chosen for ongoing holistic care
4. Discharge from paediatrics should not occur until the plan is agreed and operational.

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Appendix 3: The Recommended Best Practice

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Manual
NameSECTION NAME
(Section #)Auckland District
Health Board

Starship Rheumatology Transition Policy

Aim

This policy provides a framework in order to ensure the successful and seamless transition and transfer of young people from Starship Rheumatology to Adult services. This includes the timing of transition, the roles of clinical teams and the steps required in transition planning. A range of tools and resources are also provided.

Associated Documents

The table below indicates other documents associated with this policy.

Type	Document Title(s)
Hospital Policy	RCH Transition Document and Policy (01-00-039)_
Position Paper	Royal College of Nurses (2004). <i>Adolescent Transition Care. Guidance for Nursing Staff</i> . Court Rd, London pp1-21
Position Paper	Royal College of Paediatrics and Child Health (2003) The Intercollegiate Working Party on Adolescent Health, Bridging the gaps: healthcare for adolescents. www.rcph.ac.uk (accessed 4 May, 2009)
Article	McDonagh, J. E., & Viner, R. M. (2006). Lost in transition? Between paediatric and adult services. <i>BMJ</i> , 332(7539), 435-436.
Article	McDonagh, J. E., Southwood, T. R., & Shaw, K. L. (2007). The impact of a coordinated transitional care programme on adolescents with juvenile idiopathic arthritis. <i>Rheumatology (Oxford)</i> , 46, 161 - 168.
Article	McDonagh, J. E., Shaw, K. L., & Southwood, T. R. (2006). Growing up and moving on in rheumatology: development and preliminary evaluation of a transitional care programme for a multicentre cohort of adolescents with juvenile idiopathic arthritis. <i>J Child Health Care</i> , 10, 22 - 42.

Section: Section Name
File: THE RBPfinal.doc
Classification: XXXX/XXX/nnn

Issued by: Individuals Title
Authorised by: Individuals Title
Date Issued: Month YYYY

Page: 2 of 13

Topic Title

Auckland District
Health Board

SECTION NAME
(Section #)

Manual
Name

Starship Rheumatology Transition Policy

Article	Robertson, L. P., McDonagh, J. E., Southwood, T. R., Shaw, K. L., & on behalf of the British Society of Paediatric and Adolescent, R. (2006). Growing up and moving on. A multicentre UK audit of the transfer of adolescents with juvenile idiopathic arthritis from paediatric to adult centred care. <i>Ann Rheum Dis</i> , 65(1), 74-80.
Article	Scal, P., Horvath, K., & Garwick, A. (2009). Preparing for adulthood: health care transition counseling for youth with arthritis. <i>Arthritis Rheum</i> , 61, 52 - 57.
Article	Tucker, L. B., & Cabral, D. A. (2007). Transition of the Adolescent Patient with Rheumatic Disease: Issues to Consider. <i>Rheumatic Disease Clinics of North America</i> , 33(3), 661-672.
Article	Shaw, K. L., Southwood, T. R., & McDonagh, J. E. (2004). User perspectives of transitional care for adolescents with juvenile idiopathic arthritis. <i>Rheumatology (Oxford)</i> , 43(6), 770 - 778.

Section:	Section Name	Issued by:	Individuals Title
File:	THE RBPfinal.doc	Authorised by:	Individuals Title
Classification:	XXXX/XXX/nnn	Date Issued:	Month YYYY
Topic Title		Page:	3 of 13

Manual
Name

SECTION NAME
(Section #)

Auckland District
Health Board

Starship Rheumatology Transition Policy

Introduction

Most children with chronic conditions require ongoing healthcare into adulthood. Therefore successful transition from paediatric to adult care should be seen as an important goal and essential part of quality care for young people with chronic illness.

The concept of transition implies a "planned, purposeful movement of the adolescent or young adult with a chronic disease from a child (and family) centred to an adult orientated health care system"(Janet E. McDonagh & Viner, 2006).

The transition from a paediatric to an adult orientated service is not a sudden unanticipated transfer but an organised process of preparation and adaptation. The goal of which should be to "maximise lifelong functioning and potential through the provision of high quality developmentally appropriate health services, that continue uninterrupted as the individual moves from adolescence to adulthood" (American Academy of Pediatrics)

It is important to emphasize that transfer is not synonymous with transition: it is simply one of many events during the much longer process of transition (Shaw, K. L., Southwood, T. R., & McDonagh, J. E., 2004).

To ensure that successful transition occurs, each clinical team providing care for young people with a chronic condition should develop a transition model for their service. All young people should be supported with an individual transition plan.

Definitions

Transition

Transition is "the purposeful and planned movement of adolescents and young adults with chronic physical and medical conditions from child centred to adult oriented health care systems." (*Society for Adolescent Medicine, 1993*)

Transfer

Transfer is the handover of care to adult services. "Young people should not be transferred fully to adult services until they have the necessary skills to function in an adult service and have finished growth and puberty".
(*Royal College of Paediatrics and Child Health, 2003*)

Section:	Section Name	Issued by:	Individuals Title
File:	THE RBPfinal.doc	Authorised by:	Individuals Title
Classification:	XXXX/XXX/num	Date Issued:	Month YYYY
Page:	4 of 13	Topic Title	

Starship Rheumatology Transition Policy

Transitioning a Patient

Age of transition

Transition planning should be flexible in timing but should commence early in adolescence to allow the young person where possible, time to increase their capacity for self-care. Consideration should be given to education around their condition, promotion of self-management skills as well as assessment of their psychosocial needs.

Preparation for transition planning should therefore commence from age 11 years with education towards self-management followed by active transition planning from age 16 years.

Admissions Policy

In general, new patients will be accepted up until their 15th birthday. Patients previously treated at Starship may continue to be treated up to and including their 18th birthday for conditions for which they have previously been treated or related to their existing condition.

Section:	Section Name	Issued by:	Individuals Title
File:	THE RBPfinal.doc	Authorised by:	Individuals Title
Classification:	XXXX/XXX/hnn	Date Issued:	Month YYYY
Topic Title		Page:	5 of 13

Starship Rheumatology Transition Policy

Core Principals for Transition Planning

It is well recognised that there are challenges and barriers to successful transition of young people in New Zealand due to the differences between regions and District Health Boards. However the Rheumatology Team aims to be guided by the following core principals in order to ensure that the young person will have the skills to manage their care and will be followed up in the adult system:

General

- Patients should begin to be informed about transition early
- Planning is essential
- Each clinical team should identify a **transition co-ordinator**
- Transition must be a multidisciplinary process and there must be a co-operative working relationship between paediatric and adult services.
- A clear and concise patient summary/referral letter should be written to ensure an **effective handover**
- The transition program should be continually evaluated.
- Patients need detailed information about the adult centre they are going to and should have opportunity to meet with the adult team and see the new environment
- Young people should be given opportunity to be seen without their parent's prior to transfer to adult service.
- Young people will be encouraged to be responsible for their own health care and have knowledge of their condition and medications.
- Each young person should have an **Individualised Transition Plan (appendix 1)**
- Young people must be involved in developing their transition plan,
- Transfer should occur at a time of disease stability

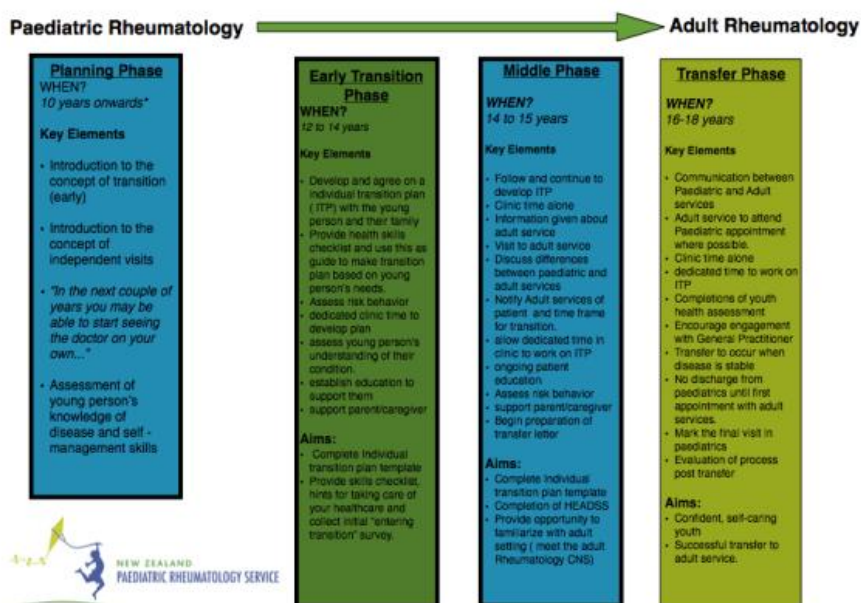
Section:	Section Name	Issued by:	Individuals Title
File:	THE RBPfinal.doc	Authorised by:	Individuals Title
Classification:	XXXX/XXX/nun	Date Issued:	Month YYYY
Page:	6 of 13	Topic Title	

Starship Rheumatology Transition Policy

The Phases of Transition Planning

Transition takes place over a period of years. It is a fluid process and therefore these phases should merely be used as a **guide for practice**. The individuality of patients and clinical settings will mean that variation is inevitable.

In this policy there are 4 phases of transition; the planning phase, early, middle and transfer phase. The flow chart below outlines these and provides the aims and key elements of each phase.



Section: Section Name
File: THE RBPfinal.doc
Classification: XXXX/XXX/nun

Issued by: Individuals Title
Authorised by: Individuals Title
Date Issued: Month YYYY

Topic Title

Page: 7 of 13

Starship Rheumatology Transition Policy

Planning Phase (10 years onwards)

This initial stage is from age 10-12 years. It is this stage that the young person and their family are *introduced* to the transition process and the young person is encouraged to participate in his/her own care.

- The concept of independent visits is introduced to prepare the young person and their family.
- Give the patient and the family a rough idea of likely timings but emphasize that this is flexible.
- Discuss the individual transition plan and explain that this will be developed within the next couple of years.

Early Transition Phase (12–14 years)

In this phase the young person and their family gain an understanding of the transition process and the youth practices skills, gathers information and sets goals to participate in his/her own care.

- If possible the team should consider providing adolescent specific clinics or attempt to group patients according to age.
- Introduce the concept of preparing to leave the paediatric setting by age of 16 years
- Team to decide on most appropriate team member to be transition co-coordinator
- Develop an individual transition plan considering the 6 areas in the template (see appendix)
- Provide opportunities for the young person to ask questions.
- The young person should complete a CHAQ (Childhood Health Assessment Questionnaire) at least once in each phase

Section:	Section Name	Issued by:	Individuals Title
File:	THE RBPfinal.doc	Authorised by:	Individuals Title
Classification:	XXXX/XXXX/nnn	Date Issued:	Month YYYY
Page:	8 of 8	Topic Title	

Starship Rheumatology Transition Policy

Middle Transition Phase (14-15 years)

The young person continues to develop self management skills and gathers information about their condition, medications and how this impacts on their day to day life.

- Follow and continue to develop Individual Transition Plan.
- Provide opportunity for the young person to be seen alone.
- Patient receives transition pack and has time with designated coordinator
- Coordinator notifies adult service about patient nearing time of transfer.
- Patient and family gain knowledge about adult service including introduction to adult team members and new environment
- Education about condition, medication and specific adolescent health and risk issues occurs.
- Completion of CHAQ
- Lead Clinician or coordinator should begin to prepare transfer letter.

Transfer Phase (16-18 years)

The young person has a good understanding of their health and is exhibiting self-care/management behaviors. The young person should be prepared to move towards adulthood and the adult setting.

- Assess the young person's ability to manage his or her own health care.
- Discuss future plans including career, sexual health and treatment plan.
- Transfer letter sent as soon to adult referral center

Section:	Section Name	Issued by:	Individuals Title
File:	THE RBPfinal.doc	Authorised by:	Individuals Title
Classification:	XXXX/XXXX/nnn	Date Issued:	Month YYYY
Topic Title		Page:	9 of 13

Manual
Name

SECTION NAME
(Section #)

Auckland District
Health Board

Starship Rheumatology Transition Policy

- Communicate directly with adult service to ensure all necessary information about patient is received
- Completion of CHAQ
- Ensure all allied health groups involved with patients care are aware of the transition and comprehensive referrals are made.
- The first appointment to see the adult team should be made prior to leaving Paediatric Services

At the time of transition to adult care

Transition is complete when the young person is actively engaged with adult services.. This is usually evident when correspondence is received from the adult service/team.

- Once this first appointment has occurred the young person may return for one last appointment with the understanding that care has been given to the adult service
- The paediatric team will ensure that the young person's final visit at Starship is a marked occasion and recognition is given to the young person by the team

Evaluation of the Transition Process

It is essential that the transition process is evaluated and success of transition planning is measured. It is also important to keep track of the number of patients and the phase of transition they are in. This can include:

Documenting the completed individual transition plans annually

Documenting the number of patients transitioned annually

Follow up satisfaction survey 6 months post transfer to adult services.

Section:	Section Name	Issued by:	Individuals Title
File:	THE RBPfinal.doc	Authorised by:	Individuals Title
Classification:	XXXX/XXX/nnn	Date Issued:	Month YYYY
Page:	10 of 13	Topic Title	

Starship Rheumatology Transition Policy

Appendix 1

Key Elements of the Individual Transition Plan	
Independent Health Care Knowledge	<ul style="list-style-type: none"> • Provide opportunity for young people to practice and develop communication with health providers without parental guidance • Discuss the differences between paediatric and adult setting (physical location/people and processes) • Encourage young people to learn how to describe their symptoms and to ask questions. • Empower young people to learn about their condition and treatment.
Psychosocial	<ul style="list-style-type: none"> • Assess risk behaviours, mood (HEADS) • Discuss risks of drugs, alcohol, smoking • Enable time to discuss future plans, including school, career • Acknowledge and help family cope with changing roles (provide parental support and opportunity to talk)
Health & Lifestyle	<ul style="list-style-type: none"> • Address the importance of nutrition, exercise, sleep • Assess pubertal development/growth • Discuss healthy eating habits
In addition to the three key areas above the plan should include:	
Discussion about the differences between Paediatric and Adult Rheumatology Service	<ul style="list-style-type: none"> • Provide information about the Adult service including physical location, names of the team members, • Discuss the practical differences including information about joint injections, prescriptions, timing of appointments • Provide opportunity to visit the adult clinic or meet the adult providers.
Creation of Medical Summary	<ul style="list-style-type: none"> • Prepare and maintain an up to date medical summary at the beginning of transition that is updated until time of transfer
Time Line	<ul style="list-style-type: none"> • In collaboration with the young person and their family discuss a timeline for the transition process.

At each phase of the transition process there are new questions to help address these key areas.

Section:	Section Name	Issued by:	Individuals Title
File:	THE RBPfinal.doc	Authorised by:	Individuals Title
Classification:	XXXX/XXX/hun	Date Issued:	Month YYYY
Topic Title		Page:	11 of 13

Manual
Name

SECTION NAME
(Section #)

Auckland District
Health Board

Starship Rheumatology Transition Policy

Appendix 2



You and your doctor

As you grow up it is important to increase your independence. This means developing the skills and confidence to talk to your doctor on your own. You will start by seeing the doctor on your own for part of the consultation. This helps you to understand and manage your condition and to increasingly take more responsibility for self care.

You and your parents or carers

You may notice that your parents are asking you to do more things. They may expect you to take on some additional duties in regards to your care, for example making appointments. It's all in the effort to prepare you for adulthood and even if it may not seem so, sometimes it's extremely difficult for parents to look at their children as adults and give them health care responsibilities. If you haven't already, try to accept this as a challenge or a natural progression of things.

Medications

Older adolescents have also learnt to be responsible for their own medications. Knowing the name of your medications, why you need them, and how much you need to take is a great start! Taking them without a reminder from a parent or guardian is the next step! Also very important is knowing how to get a prescription and how to get it filled.

Adolescence and your condition

It is important that you know about your condition and its effect on your growing, changing body. Perhaps there are some questions that you would like to have answered about this. It's important to understand what tests you need to have regularly, why and what the latest results were.

Preparation for transfer

- Become more independent around your health care needs. This includes making your own appointments, having sometime alone with your doctor, getting your prescriptions filled and maintaining any medical equipment you need.
- Use the [Health Care Skills Checklist](#) to see how you can prepare for Transfer
- Become more comfortable communicating with health care professionals, rather than relying on Mum or Dad to do all the talking



Section:	Section Name	Issued by:	Individuals Title
File:	THE RBPfinal.doc	Authorised by:	Individuals Title
Classification:	XXXX/XXXX/nnn	Date Issued:	Month YYYY
Page:	12 of 13	Topic Title	

Auckland District
Health Board

SECTION NAME
(Section #)


Manual
Name

Starship Rheumatology Transition Policy

Appendix 3

Health Skills Checklist

APPENDIX 3 FOR
ADULT
RHEUMATOLOGY
SERVICE



Key

1= I'm there (on to it!)
2= I'm getting there
3= Don't know
4= I'm thinking about it
5= No way!

These are some of the things that young people with chronic health conditions need to be aware of as they become an adult and move into the adult health system. Have a read and see where you fit...

	1	2	3	4	5	Comments
I can describe my health condition to others						
I understand the medical terms/words and procedures related to my condition						
I know when I need emergency help and how to get it.						
I speak up for myself and tell others what I need						
I take my own medications and know what they are for						
I know what tests I need to have, why and how often						
I keep a record of my health care visits and medications						
I know when I am getting sick and how to get help						
I know how to make my own appointments						
I am able to manage my own pain.						
I have a person who will help me with my health if my family cannot						
I am able to obtain sex education materials/birth control information as needed						
I know about how drugs/alcohol affect my illness						
I know what to expect in the adult service						
Questions to discuss with your Rheumatology Team before transfer						
Has the transfer been discussed between you and your doctor? Have you agreed on a date/plan?						
Will you have an opportunity to visit the new hospital/clinic and to meet with the health care team?						

Section:	Section Name	Issued by:	Individuals Title
File:	THE RBPfinal.doc	Authorised by:	Individuals Title
Classification:	XXXX/XXXX/hnn	Date Issued:	Month YYYY
Topic Title		Page:	13 of 13