A service of ‘last resort’: the outcomes of a specialist paediatric continence service at Nurse Maude, Christchurch
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Bobbie Jones
Continence Advisor, Nurse Maude, Christchurch

Jackie Walker
Research Nurse, NZ Institute of Community Health Care

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Nurse Maude and the NZ Institute of Community Health Care

Nurse Maude, is a community based health service provider, located in Christchurch, New Zealand. The service was established more than 100 years ago as a district nursing service. In 2009, it has a staff of 218 nurses and 631 health care workers who offer extensive nursing and home care services throughout Canterbury. They receive about 1,200 referrals per month into their service from a variety of sources, including hospitals, medical specialists and general practitioners. These services are aimed at supporting people with either short term or long term health problems to stay in their homes during episodes of health care need. Nurse Maude also offers specialist nursing services, which include continence, stomal, diabetes, wound management, acute demand and palliative care. These services are provided either in the patient’s home, on-site or for hospital in-patients.

In mid 2007, the Nurse Maude Foundation seeded funding for the establishment of a research centre, the New Zealand Institute of Community Health Care (NZICH). The Institute was designed to provide advice and support for nurses interested in developing and completing clinical research with a focus on improving health outcomes for consumers of community health services. The Institute has a Director, Administrator and Research Nurse to provide research services for Nurse Maude staff. The centre has developed collaborative research partnerships with tertiary education providers and with external researchers. The Institute is also involved in consultancy work to support workforce and service development and professional development. These activities are designed to foster a centre of excellence for research and development projects that will lead to tangible improvements in community health care.
Foreword

Every parent has had to deal with a child who wets or soils themselves, after all this is just a normal part of growing up. Yet, when your child reaches four and beyond and still has difficulties in maintaining continence, the stress and strain can be overwhelming.

Bobbie Jones and Jackie Walker demonstrate that with the help of experts, who really do know what they are doing; children and their parents can be greatly assisted in both managing and improving a range of problems associated with continence.

The Ministry of Health is pleased to be able to assist in the dissemination of the positive results achieved by the Nurse Maude Continence Advisory Service and the New Zealand Institute of Community Health Care as, through ongoing research and development, it seeks to improve outcomes in this challenging area of practice.

Dr Mark Jones
Chief Nurse
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Introduction

Continence problems are common in children and can have significant effects on a child’s quality of life (Ellsworth, 2008). Children may develop a variety of continence issues, e.g. nocturnal enuresis (night time bed wetting), constipation or faecal incontinence, which are often challenging for health professionals in primary and secondary health services to treat effectively. In the USA, the prevalence rate for paediatric urinary incontinence is 10.5% and for constipation 22.6% (Loening-Baucke, 2007). Specialist continence knowledge is needed to: assess symptoms; develop management plans; monitor progress and provide ongoing education and support for the child and their parents.

Nurse Maude, is a community based health service provider, located in Christchurch, New Zealand. The service was established more than 100 years ago as a district nursing service. Its’ staff includes 218 nurses and 631 health support workers who offer extensive nursing and home care services throughout Canterbury. In mid 2007, the Nurse Maude Foundation seeded funding for the establishment of a research centre, the New Zealand Institute of Community Health Care. This centre was designed to provide advice and support for nurses interested in developing and completing clinical research with a focus on improving health outcomes for consumers of community health services.

This report will profile a specialist paediatric continence service provided by Nurse Maude in Christchurch. Through a case study approach, it will highlight the specialist skills and resources that the continence nurses bring to each child’s unique situation. Identifying details have been removed from the case study to ensure anonymity and consent obtained. The report will discuss how the service complements other continence/urology services, and the outcomes it achieves.

Context of the service

The Nurse Maude Continence Advisory service provides support, assessment, treatment, education, and prescribes continence products for anyone older than four years of age who has continence issues. These issues may involve difficulty getting to the toilet on time, making frequent visits to the toilet (day or night), having bowel or bladder leakage or other bowel problems (e.g. chronic constipation, nocturnal enuresis). The service also offers advice and information about catheter management, liaises with other health professionals and agencies, and provides information and education for the community and health professionals. Consultations are with a specialist continence advisor, who is a registered nurse or physiotherapist, who has completed further postgraduate training in the area of continence management. The service is located in the Specialty Nursing Clinic on the Nurse Maude site, in Merivale, Christchurch, with individual consulting rooms and easy parking for patients and their family/whanau.
Although Continence advisors provide education and training for other health professionals, their main role is to provide a clinical service. The paediatric continence service helps children and teenagers with a range of continence problems. In 2008, they received 128 new referrals to the service, 50 were females and 78 were males. The age at referral ranged from 4 years to 19 years, with most children between the age of 4 and 11 (See Figure 1). Two of the Continence Advisors, Bobbie Jones (a registered nurse with UK paediatric nursing experience) and Gill Prior (physiotherapist), work collaboratively to provide the service. Both advisors bring different strengths to the role from their professional backgrounds, and provide peer support to each other through a case review process. This article will highlight Bobbie’s role in the service and discuss the nursing model of care she uses to work with children with complex continence problems.

**Figure 1**
2008 - Age at referral to Nurse Maude Paediatric Continence Service

![Age at referral to Nurse Maude Paediatric Continence Service](chart)

**Accessing the service**

Referrals come from the parents themselves, from GP’s, Paediatric consultants, and other agencies working with children with disabilities (e.g. Lifelinks, Public Health Nurses, and the Champion Centre in Christchurch) (see Figure 2 next page). Once the written referral is received, it is triaged and prioritised for an initial assessment at the clinic. Most patients are seen within 6 – 10 weeks of referral, though urgent cases are usually seen within three weeks. This service is funded through a contract with the Canterbury District Health Board.
The initial assessment (see Figure 3 next page) is a crucial part of the process towards resolving continence problems and in-depth holistic assessments are needed to find potential contributing factors (Catto-Smith, 2005). Bobbie asks about the child’s history including birth (e.g. any prematurity, difficulty passing meconium), the process of toilet training, any pre-school health issues, and the child’s current health state. This enables her to build up a picture of what’s been happening, what health professionals have been seen, what interventions have been tried and what has worked/not worked. Building rapport with the child and their family is crucial to the assessment process, often there is a sense of embarrassment or despondency as to whether anything is going to improve the continence issue. Spending time finding out the child’s perception of the problem and what they hope can be done is essential to develop an individualised management plan. She often finds that a referral for the treatment of ‘simple bedwetting’ is not ‘simple’ at all. Many other contributing factors (e.g. chronic constipation) play a role in this common childhood problem (Continence Foundation of Australia, 2006).
Furthermore, as part of the comprehensive assessment, Bobbie is able to access clinic letters from the Paediatric service at the local hospital and gain additional information (e.g. past and present medications) from the child’s GP. Other sources of information include the child’s Plunket book, as well as diagnostic tests and X rays. She is able to undertake further assessments by using a bladder scanner and uroflowmetry. Uroflowmetry measures urine flow rates and the volume of urine passed, which is helpful for identifying obstructive problems. At the end of the first visit, Bobbie has a range of information to use in the development of a management plan, which is individually tailored to the child and their family/whanau. As a reflective practitioner, she uses reflection to consider all the possible management options before finalising the plan. Having easy access at Nurse Maude to research evidence, either through the internet or on-line literature databases, provides an evidence-based foundation to her practice.
Management plans

The initial assessment will determine the range and scope of the child’s written management plan. Often it will include collecting further information through the use of food/fluid or bladder/bowel diary to record specific problems. Neveus, et al., (2006) discuss how objective data collected in diaries are crucial to effective management. The Continence Advisors have a range of assessment tools (e.g. the Bristol Stool chart) that children, or their parents, can use to record the problem accurately (Lewis & Heaton, 1997). They also use a range of age-appropriate books to explain and educate about the normal workings of the bowel and bladder. There is a lot of misunderstanding about the normal physiology of the bladder and bowel, and books like ‘Beating Sneaky Poo’ (Heins & Ritchie, 1988) and ‘Tim’s problem’ (Reid, 2000) engage children in a fun way to help them understand what’s happening to them. As constipation is a common problem, (Wyeth & Chin, 2007), the advisors will recommend suitable laxatives for the child’s GP to prescribe.

Ongoing follow-up, education and support is a crucial aspect of this service to achieve good patient outcomes. After the initial assessment, children will be seen fortnightly, then four to six weekly, and then three monthly for ongoing monitoring and support. Bobbie liaises closely with the initial referrer and the child’s GP through a phone call, followed by a letter, to ensure her recommended management plan is discussed thoroughly and any questions answered. Cox, Morris, Borowitz & Sutphen (2002), suggest that building a better rapport with the child and their parents/family, helps them to disclose other psycho-social factors that contribute to continence problems. The flexibility to offer more frequent appointments to monitor progress effectively is certainly a strength of the service.

Case study

David (not his real name) was a four and a half year old, who was referred by his GP to the clinic for management of faecal incontinence, with alternating diarrhoea and constipation. He was to attend school in a few months time and his parents were really worried about how they would manage, as David soiled himself four to five times a day. David had been seen by the local Paediatric department, a Psychologist and a Dietician for about a year, without significant progress, despite a range of strategies tried. After receiving the referral, Bobbie rang the GP and the Paediatric Department to gather more information about the recent investigations taken (abdominal X ray, faecal specimens), the management plan and which laxatives David was currently taking. From this initial assessment, Bobbie recommended to the GP that David start taking a half sachet of Movicol twice a day to promote bowel regularity before he came for his first assessment.

The initial assessment revealed that David had started toilet training at about two and a half years, that he was continent of urine but had never been faecally continent. His parents had been completing fluid/food and bowel motion diaries over the past year, so were able to explain to Bobbie what David’s usual pattern was. Although this was helpful information, the parents were ‘sick of filling in diaries’ and were reluctant to provide further detailed information so Bobbie could analyse it. They really wanted ‘a quick fix’ as they were worried about the impending school start.
Bobbie discussed how important the diaries were for her to exactly understand what was happening between the interplay of fluid, food, activity and bowel motions. A compromise was reached where the parents agreed to document David’s incontinence – detailing what was only a smear on his underpants through to a large motion, and how frequently this was happening. Bobbie encouraged the parents to use the Bristol Stool chart (Lewis & Heaton, 1997) to document the bowel motions and this was a great asset to gather objective information.

Bobbie spent time exploring what the problem was like for both David and his parents, and David was able to say that he didn’t know when he wanted to pass a bowel motion. During the interview, David had been eating snacks continuously and he clearly demonstrated the gastrocolic reflex when he was incontinent of faeces during the assessment! This situation provided an excellent teaching opportunity to educate the parents about what factors trigger the need for defaecation. From her overall assessment, Bobbie developed a management plan, with a key strategy being a toileting regime at 15 – 20 minutes after food. However, this regime had to fit in with the family’s usual routines, e.g. to allow time for getting David toileted after breakfast before going to kindergarten.

At the next appointment, it appeared the Movicol was promoting bowel regularity and David’s motions were becoming more ‘normal’ in consistency. Bobbie noted that the toileting regime was starting to reduce the frequency of incontinence, but David was still passing some bowel motion in his underpants. Bobbie continued to see David and his parents monthly, but his mother was becoming very frustrated that David’s progress wasn’t happening fast enough and she expressed this openly. Dealing with this situation involved a change of focus, where only the father continued bringing David to appointments. To keep David’s mother involved, Bobbie re-wrote his management plan, giving detailed reasons for what was happening and why. She identified what the Continence Advisor’s role was, how the parent’s role was so crucial to ongoing success and this was provided to David’s mother. After a short time, David’s mother accompanied her son to appointments with Bobbie and their relationship became positive again.

**Value of nursing specialist service**

David attended the clinic with his parents during a period of nine months, but the investment of nursing time was only 16 nursing hours over this period. This time involved clinic visits, telephone calls and liaison with other professionals. That small investment of nursing time had ensured he was faecally continent for the first time in his life. One of the key components of his management plan was a close partnership with both kindergarten and school teachers, who facilitated the regular toileting regime. This case study highlights the importance of ongoing assessment, education and support over many months, to achieve success with continence issues that have been a problem for years. It also highlights a need for early referral to the Continence Service when progress is very slow.
Service outcomes

The successful results of any service are found in measured patient outcomes, both quantitatively and qualitatively. Many of the children/teenagers that the Continence Advisors see have complex continence issues and have often been treated by a range of health professionals for some time, before they are referred to the service. Because of the multi-dimensionality of their continence problems, successful results don’t happen quickly and behavioural change takes time. In 2008, 27% of children with continence problems were in the programme for up to a year, before they were discharged to be monitored by their GP (see Figure 4). In 2008, there were 265 children discharged from the clinic ranging in ages from 4 to 19 years (see Figure 4). This data indicates nearly half of the children are successfully treated and discharged within two years (46%) and by five years 71% of children have been discharged. Of the children who remained in the service for over five years (26%), all had complex continence problems related to intellectual and physical disabilities, with the need for long term, ongoing follow-up appointments.

Figure 4
2008 - Percentage discharged by length of time in service

Bobbie relates that “success in changing behaviours (e.g. increasing fluid intake or changing their diet to increase fibre) is more likely if you enter into a partnership with the child or teenager and their family/whanau, where the child/teenager feels involved and listened to”. For children with intellectual or physical disabilities, the Australian book ‘One step at a time’ (Continence Foundation of Victoria) provides a realistic framework for progress, and is a valuable resource frequently used by the advisors.
At times, her assessment indicates other specialist services are indicated and she is able to refer patients directly to Paediatric Consultants or Paediatric Surgeons for further assessment and treatment. The good working relationship she holds with local Paediatric specialists ensures that children are seen as early as possible.

One of the hallmarks of nurse-led services is the innovation that nurses develop through a nursing, rather than a medical, model of care. The use of technology (e.g. email and cell phones) is one way that nurses can engage with children and teenagers to contact, to motivate and educate more effectively. Bobbie has had success with using regular weekly texting to contact teenagers. She relates that this method “really gets responses from them, they’ll provide information to you readily, and you can challenge them to keep working on their goals”. They often send ‘cheeky’ messages back to her, and this contact maintains her relationship with them without needing a clinic visit. For teenagers, this method of contact fits in with their busy lifestyle by using a tool that is important to them.

There is a vast range of information and education on paediatric continence issues for health professionals working in primary care, but this information is not readily accessed in one systematic, organised resource. Bobbie is currently involved in a collaborative project to write the “NZ Continence Association Paediatric manual: continence needs in children” with Frances Ryan (Public Health Nurse, Christchurch) and Mary Anne Harris (Continence Advisor, Tauranga). The aim of this training manual is to provide current information for GP’s and Practice Nurses to help them provide generalist continence advice for children.

**Recommendations**

Nurse-led Paediatric Continence clinics provide services for children and their families using a nursing model of care delivery, so providing a point of difference from other health care services. The long term nature of continence management means that prompt entry to the service is dictated by workloads and resources available. For children receiving ongoing medical and allied health care, who are not making progress with their continence issue, then an early referral to this specialist service may achieve quicker outcomes. Early referrals may be facilitated more effectively if the profile of the service was further raised amongst services and health professionals who are involved in meeting children’s health needs.

**Conclusion**

Continence issues in children are often complex and linked to a variety of physical and psychosocial factors. The role of the Nurse Maude Continence Service is to comprehensively assess and develop management plans, using a partnership nursing model, to achieve best outcomes for the child and their family/whanau. For a relatively small investment of nursing hours, many children achieve successful outcomes that were not thought possible. The Advisors use their specialist continence knowledge and experience, coupled with flair and initiative to use new technologies, to provide ongoing support and education to patients. They work in collaboration with other specialist services, and with health professionals in primary care, to ensure the children are comprehensively assessed and given a range of ongoing treatments and support. The Nurse Maude Continence Service can offer longer term support, ongoing monitoring and education, all within a nursing model of care, for children with ‘simple’ or ‘complex’ continence issues. Although, at times, it appears to be a ‘service of last resort’ it works effectively to achieve patient’s goals in respect to continence problems.
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Contact Details

NZ Institute of Community Health Care
Director
PO Box 36126 Merivale
Christchurch
Phone: 03 375 4635

Nurse Maude
Director of Nursing
PO Box 36126 Merivale
Christchurch
Phone: 03 375 4200