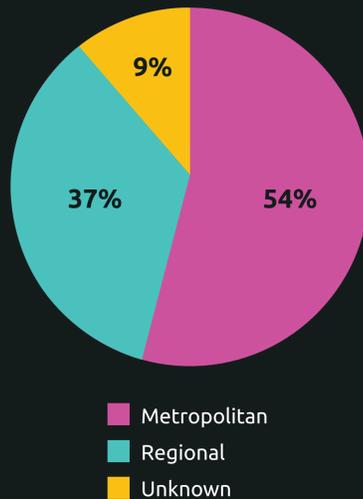


# Spina Bifida Outreach Clinics

## Case For Change

- 40% of Spina Bifida Adult Resource Team (SBART) customers live in Regional NSW
- Many Regional based SBART customers were receiving no specialist care or care by paediatric outreach services
- Spina Bifida (SB) is a complex congenital condition that requires lifelong, coordinated health management
- Due to medical advancements, people with SB are living longer. This is resulting in an increased demand for care in adult health services
- Metropolitan areas offer clinics with: Rehabilitation Specialist, Clinical Nurse Consultant and Senior Occupational Therapist from SBART – no equivalent in regional areas

Geographic placement of SBART clients



## Approach

In order to provide an equitable service in both Regional and Metropolitan areas, SBART coordinated:

- Specialist multidisciplinary Spina Bifida Outreach Clinics for customers
- Workshops to upskill local clinicians in Regional areas

In 2012 SBART, with the support of the Sydney Royal Prince Alfred Hospital (RPA), successfully submitted a funding application to the Rural Health Outreach Fund to provide:

- A Rehabilitation Specialist
- SBART Team support
- Administrative support

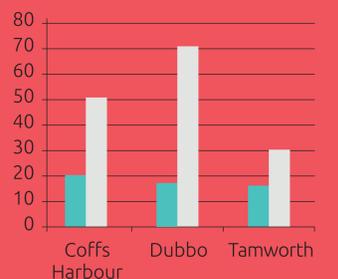
In 2015 clinics commenced biannually in Dubbo, Coffs Harbour and Tamworth.

## How Did We Measure Success?



### 1 Service delivery during 2015

- 46 SB customers attended the outreach clinic
- 152 post clinic service
- Over 90% attendance rate at outpatient clinics sessions provided



Attendance at Regional clients and follow up service provision



### 2 Client Journey and satisfaction – a case study

Kelly\* is a 33 year old with Spina Bifida and hydrocephalus. She lives independently in Dubbo and is self sufficient in daily living activities, but requires support with complex decision making situations and problem solving. Kelly's care is complicated by her Chait button for bowel washouts, bladder augmentation and VP shunt. Kelly had been attending paediatric outreach clinics until 2012 due to a lack of available adult services. Kelly attended Sydney RPA's Spina Bifida clinic in 2014, but this was not an ongoing feasible option for her or her family.

In 2015, Kelly was able to attend the SB Outreach clinic in Dubbo. The clinic identified a number of critical health issues and intervened with direct support and referrals. As a result, Kelly avoided major renal complications through improved links to urology and renal specialists. She was also linked with appropriate adult specialists including neurosurgeon specialists for shunt complications and allied health specialists for assessments and ongoing support. Additionally, Kelly received education for pressure relieving techniques, self-catheterisation and sex education, all to empower her to realise her potential.

Kelly's mother was full of praise for the clinic. "It's so great, you get relevant support and have a chance to talk to people about things that you haven't even thought about. Kelly loves it too because she feels more comfortable attending the clinics in her own town rather than travelling to a strange place like Sydney – and that makes it so much easier for me to manage, while she receives appropriate support."

\*Name change for privacy reasons



### 3 Upskilling

To ensure there is continued support for adult Spina Bifida customers living in Regional areas during times between clinics, the SBART team upskill via:

#### Education for customers, their families and carers

- Provision of best care practices for Spina Bifida: catheterisation, pressure management, sexual functioning and health management
- Sharing of resources i.e. factsheets and hospital management plans
- Education about National Disability Insurance Scheme

#### Education provided to Local Services

- Attendance at clinic by rehabilitation registrars and students
- Meeting with local rehabilitation consultants
- Networking meetings with local allied health professionals
- Education session for nurses allied health and support workers

## KEY LEARNINGS

1 Importance of coordinated and multidisciplinary care for Regional adults with Spina Bifida that involves local teams supported by a specialist service.

2 Strengthening links through face-to-face clinics facilitates capacity building in local services and empowers individuals to manage their condition

#### Authors

Jade Johnston Team Leader SBART Northcott; Sydney NSW 2077; Rebecca Hudson, Occupational Therapist, Northcott; Sydney 2077 ; Joanne Brady Clinical Nurse Consultant SBART Northcott, Sydney 2077, Indu Nair, Snr Staff Specialist/ Head of Department, Rehabilitation Medicine, Royal Prince Alfred Hospital, Sydney, NSW 2050; Carolyn West, Visiting Medical Officer, Spina Bifida Clinic, Sydney, NSW, 2050; Lynne Brodie Agency for Clinical Innovation, Chatswood, 2067

1800 818 286

northcott@northcott.com.au

northcott.com.au