

Spina Bifida Adult Resource Team



Overview

- How the service is delivered
- Outcome data from a 12 month review
- Novel resources that have been developed
- Where to from here



'If I lived in a society where being in a wheelchair was no more remarkable than wearing glasses, and if the community was accepting and accessible, my disability would be an inconvenience and not much more than that. It is society which handicaps me, far more seriously and completely than the fact that I have Spina Bifida'.

1. SHUT OUT: The Experience of People with Disabilities and their Families in Australia; National Disability Strategy Consultation Report prepared by the National People with Disabilities and Carer Council 2009;
28http://www.fahcsia.gov.au/sa/disability/pubs/policy/community_consult/Pages/default.aspx (accessed 10 October 2012)



SBART service delivery

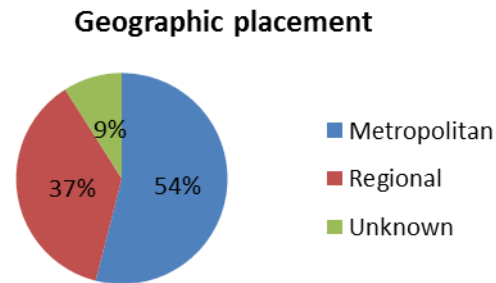
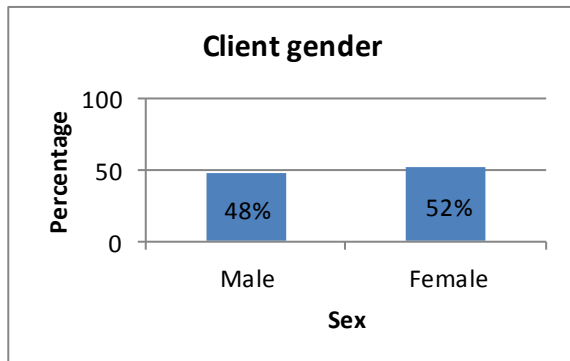
- Team
- What is the role of the service?
 - Facilitate transition from paediatric to adult services
 - Provide information and support to adults with spina bifida, their families and service providers to address health and lifestyle goals
 - Attend metropolitan and regional spina bifida clinics
 - Link clients to appropriate health/community services
 - Maintain regular contact with transition clients to ensure successful engagement with adult services
- Referral process



12 Month Review

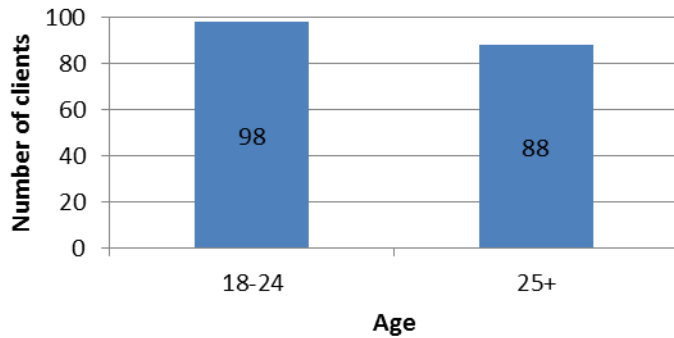
Aug 09-Aug 10

- At the time of the 12 month evaluation – 186 clients that had been connected or re-connected with adult services

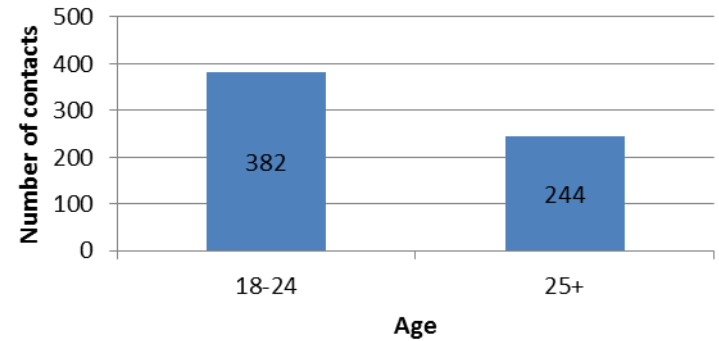


12 month review

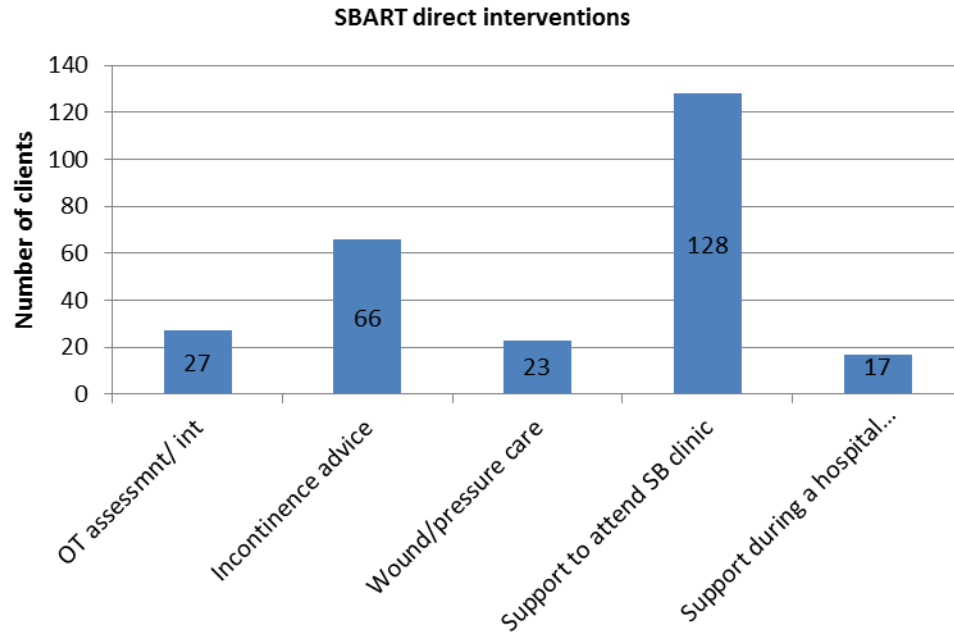
Clients by age group



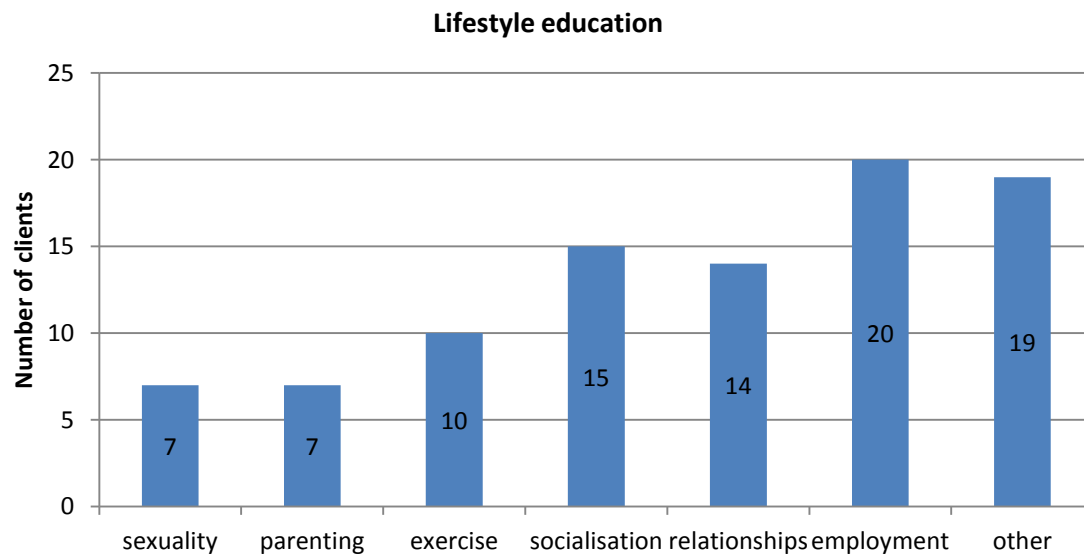
Number of client contacts by age group



12 month review

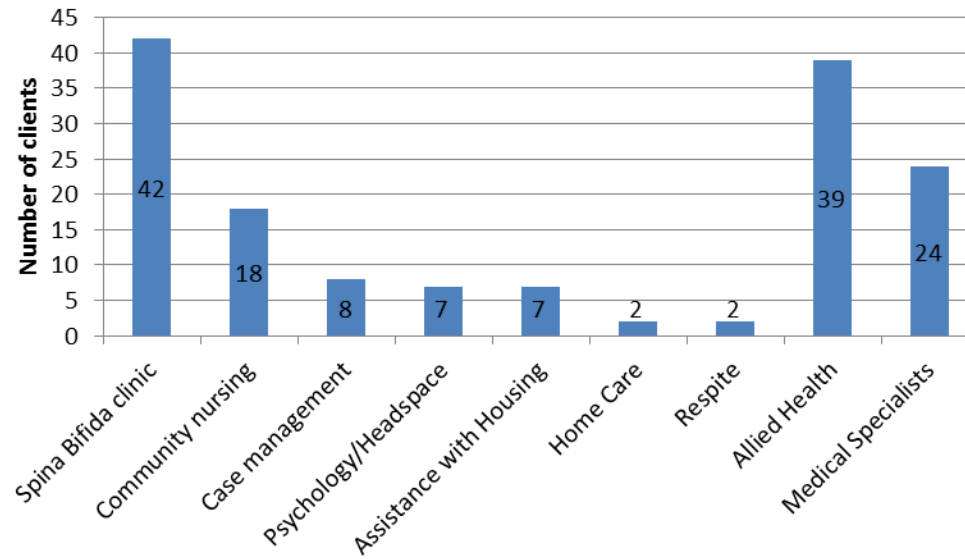


12 month review



12 month review

Referrals



12 month review - case study

Client

30 year old man with spina bifida and hydrocephalus.

Walks independently unaided, independent with self-care

Working part time in retail.

Living with his wife.

Some difficulties with planning and organising due to hydrocephalus but well supported

Journey

Developed an IT pressure sore

GP visit

General surgeon referral

Surgery booked for 2 weeks time

Surgery postponed for 6 weeks

Client presented to ED wound changed from 2cm to 10cm width

Surgery for wound debridement and closure, d/c 2 days post op

Re-presented at ED after 6 days with wound breakdown

Wound re-sutured d/c 2 days later

Represented at the surgeons rooms 1 week later and the wound had broken down'

Re-admitted for wound management and discharged to the care of the community nurses for dressings.

About 3 months after initial presentation the wound was not healed and a VAC dressing was commenced

Client experiencing severe hip pain

Osteomyelitis diagnosed and client admitted to hospital for treatment

Plastic surgery review in Sydney hospital, resulted in booking in for flap surgery. Client listed as non-urgent with a W/L of about 12 months

Client had surgery to debride and close the wound, almost 3 years after the initial presentation

12 month review - case study

SBART Involvement

Telephone support to client and support worker.

Liaison with local rehabilitation service

Nursing advice re: pressure management and wound dressing.

Support to regional OT on prescription of equipment.

Assistance to attend appointments in Sydney hospital for specialist services.

Support during hospital admission.

Assistance with provision of short term pressure care equipment.

Liaison with local nursing staff and rehabilitation service on discharge from hospital.

Outcome

After about 3 years the wound has healed

However, the client is now unemployed, his marriage has broken down and he is experiencing significant financial stress.

The client now uses a wheelchair as his main form of mobility.

SBART are continuing to work with the local case manager to support the client to work on his health and lifestyle goals

Challenges

- Large client numbers across a broad geographic area
- Referrals from adults in crisis who have been lost to regular follow up for many years
- Access to GP's and specialists – plastic surgeons, urologists
- Obtaining data from hospital databases
- Loyalty of young people and their families to paediatricians and children's hospitals and making adult hospitals and clinics more youth friendly
- Making time to evaluate progress and ensuring sustainability of the program



Resources - Facebook

- Research shows that social isolation is still very prevalent in people with spina bifida regardless of whether they use a wheelchair for mobility or ambulate independently. (Dicianno et al 2009)
- SBART has used facebook to provide connections with health providers and other people with spina bifida.



Resources

The screenshot shows a Facebook interface. At the top, the Facebook logo and search bar are visible. The user profile 'Jade OT' is shown in the top right. The left sidebar contains navigation options: FAVORITES (Welcome, News Feed, Messages, Events, Find Friends) and GROUPS (Northcott Spina Bifida ...). The main content area displays the group name 'Northcott Spina Bifida Adult Resource Team' with tabs for About, Events, Photos, and Files. A post by a user with a profile picture shows a colorful 'sbart' logo. Below the logo, the post text reads: 'Hi Everyone... I am very excited as this is my first post! Here goes: Part of having a healthy diet is also making you get enough water... but why? Here are some handy facts from the Dietitians Association of Australia website: The human body is made up of 50-75% water. Staying well-hydrated (especially in hot weather and when exercising) is crucial to making sure our bodies function at their best. There are many theories about the right amount to drink. Generally a rough guide of 1,500 - 2,000mL/day (or about 8 glasses) is advisable for adults. While all fluids can count towards your daily fluid intake, the Australian Guide to Healthy Eating recommends water as the best drink. It contains no kilojoules and is the best fluid for hydrating the body. (You can read the whole article here: http...'. Below the text is a link to 'Drinks | Dietitians Association of Australia' with the URL 'daa.asn.au'. The post has 87 members and a chat option. At the bottom, there are options to Like, Comment, Follow Post, Share, and View all 10 comments.



Resources



write a comment...

 **Jade OT**
Hey Guys,
I was thinking that we could have a different topic of discussion each week on facebook. That way i can post relevant sites and articles. we can talk about anything you guys think is relevant for the group. My inital thoughts were:
healthy eating
mental health
exercise
...
See More

Like · Comment · Unfollow Post · May 23 at 1:40pm

 7 people like this.

 I have lots to say about most of those topics,
good idea
May 23 at 1:44pm · Like

 Sounds great Jade, centerlink could maybe be a
good topic.
May 23 at 1:55pm via mobile · Like ·  3

 Great idea. Lord knows I've struggled with each and
every issue on the list to date.
May 23 at 2:01pm via mobile · Like

 What about public transport/accessibility issues? I
still can't seem to get a drama-free trip into the city despite the
amount of forethought and planning I put into it...
May 23 at 2:11pm via mobile · Like ·  3

 Think its great
May 23 at 3:08pm · Like

 what about the transition from manual wheelchair
to electric wheelchair.
May 23 at 4:07pm · Like ·  1

 I'll just comment where relevant for me if this idea
takes off
May 23 at 5:11pm · Like ·  1

 She's an ideas woman... Sounds like a great plan
to me. I too will contribute where it's relevant (and constructive) to
my situation
May 23 at 5:22pm · Like



- *“Myself, as well as the 90-odd other members of the Facebook group have found SBART to be an important part in bridging the gap left in consolidated support services and advice that we often face after leaving paediatric clinics.
..the confidential nature of this Facebook group gives adults with Spina Bifida as well as their families a safe, moderated forum to share experiences and concerns in a way that we had previously not been able to do. Jo, Jade and other staff within SBART have made our lives so much easier with this service - In some cases to such an extent that we wonder how we managed to cope without them”*



Resources – Hospital management guidelines

- Experience of the spina bifida collaborative that adults were falling through the gaps.
- Often first presentation to an adult service was in crisis.
- Therefore, best practice guidelines were developed in conjunction with the spina bifida collaborative.



Resources



Hospital Management Plan for young people and adults with Spina Bifida

DEFINITION:

Spina Bifida, which is derived from the Latin term meaning 'split spine' is a form of neural tube defect that occurs when there is incomplete development of the spinal cord, the bones forming the spinal column(vertebrae) and often the overlying skin

FUNCTIONAL DEFICITS:

Spina bifida frequently results in paralysis or paresis of the lower limbs, neurogenic bladder and bowel and some cognitive compromise. The disability issues include impaired walking, incontinence of bladder and bowel and learning issues particularly related to executive functioning. There is a range of disability from very mild to severe depending on the level of the lesion and the neurological complications.

SYMPTOMS

CONSIDERATIONS FOR TREATMENT

PERSISTENT HEADACHES Presents with: • Nausea and vomiting • Decreased level consciousness • Blurred Vision	PERSISTENT HEADACHES Presents with: • Fever • Cloudy Urine • Increase Incontinence	ABDOMINAL PAIN	SKIN BREAKDOWN	LOWER LIMB SWELLING	OTHER CONSIDERATIONS	DISCHARGE PLANNING
Shunt Dysfunction – needs a neurosurgical review	Urinary Tract Infection (UTI) NOTE: <i>Organisms in the urine are common in patients doing clean intermittent self catheterisations (CIC). No treatment is indicated unless there are systemic symptoms</i> IF PATIENT HAS A CLINICAL UTI WHY HAS THIS OCCURRED? • Routine – i.e. has run out of clean catheters as cannot afford to buy any • Poor SCIC Technique • Renal stones • Upper Tract Deterioration	Faecal Loading UTI, renal calculi Shunt Dysfunction Other including; oesophageal reflux, gall stones, appendicitis and bladder rupture (if bladder augmentation)	Pressure areas Lymphoedema Cellulitis Burns NOTE: <i>Most pressure areas are of a result of poor pressure care. Ensure that the adult is referred to an Occupational Therapist for follow up and review of their pressure care equipment</i>	Fracture Lymphoedema Cellulitis Deep Vein Thrombosis Other including; chilblains, eczema and poor circulation	When treating the acute medical problem other aspects of care need to be considered . DOES THE PATIENT NEED ASSISTANCE WITH MOBILITY? • walking frame / crutches / wheelchair • assistance with transfers • consider referring to rehabilitation team for further assessment DOES THE PATIENT NEED PRESSURE AREA CARE? • air mattress (ideal for when inpatients as help with protection against pressure areas on sacrum, legs and heels. • as an inpatient consider all chairs that client is sitting on. Wheelchair cushions can be used as pressure relief on other chairs DOES PATIENT NEED DVT PROPHYLAXIS? DOES PATIENT NEED ASSISTANCE WITH CONTINENCE CARE? • clean intermittent catheterisation • enema/bowel washout NOTE: <i>If an inpatient and is confined to hospital bed or has Intravenous drip and/</i>	When considering discharge planning ensure that: • Adults are assessed to determine how they will cope once discharged from hospital. Attention should be given to their mobility and personal/domestic care needs. • All adults should have their discharge summary sent to their { hospital management plan final specialist • The Spina Bifida Adult Resource team is contacted to provide support to the adult in the community and ensure they are followed up to prevent further hospital admissions



Where to from here

- Application for MSOAP funding
- Developing fact sheets
- Developing transition client telephone checklist
- Increase presentations on SBART and spina bifida to community services such as employment agencies



Thankyou

http://www.northcott.com.au/spina_bifida_group.php

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