



## Acknowledgement of Country

### **Artwork**

*Ngurang Dali Mana Burudi — a place to get better*

The map was created by our Aboriginal Health staff telling the story of a cultural pathway for our community to gain better access to healthcare.

Artwork by Aboriginal artist Lee Hampton utilising our story.



# Patient Centred Care- Planning for Admission 'What Does It Really Take'

**STrIDeS (Specialist Team for Intellectual Disability Sydney)**  
**Maria Heaton CNC**

# Outline

- Describe the community journey for a person with complex support needs and unmet health issues.
- Describe the pre hospital planning.
- Discuss reasonable adjustments and practices that enabled mainstream services to identify and respond to his particular needs.
- Lessons learned.

# Mr T:

- 39 year old man with Severe Intellectual Disability.
- Unmet medical issues: Self harm, dental, continence issues, constipation, rectal prolapse since 2009
- Family Hx: Living with ageing mother (CALD background) in DOH accommodation. Father in RACF with dementia. Mother assists with personal cares difficulty cutting hair/ toenails

# Mr T: Unmet Medical Need

- Longstanding haemorrhoids and rectal prolapse since 2009
- Not attended follow up appointments with GP or Specialist.
- He becomes very agitated in medical settings
- Mother unable to consistently support him.

# Mr T: Communication

- Responds to simple instructions.
- Relies on routine and structure
- Uses variety communicative strategies: single words, facial expression, body language (gesture, pointing and leading a carer)
- Rarely communicates pain or discomfort verbally.

# Mr T: Complex Behaviours

- Easily anxious and distressed.
- Vocalising by growling, repeating words, yelling
- Physical aggression to others - Punching people near him
- Absconding in the community including taking off his clothes
- Sexualised behaviours in the community
- Walks out in front of cars
- Self Injurious behaviour

# Mr T: Trauma History

## Trauma background:

- Reported to have had negative childhood experiences with father
- Negative experiences with hospital and clinicians: required IM sedation and physical restraint to take bloods
- Negative experiences with police: handcuffing and capsicum spray when found after absconding from carers



# Mr T: Strengths and Supports

- Community Program - centre based
- All supports are 2:1 ratio
- Collaboration between services and therapists
- Committed to providing support and working to improve the situation
- Trusted relationship with mother

# Vulnerabilities contributing to unmet health

- Severe Intellectual Disability
- Very limited informal supports
- Behaviours that challenge health services to meet his needs
- CALD background
- Trauma background
- Low socioeconomic background

# STrIDeS Involvement

## First Appointment: at the Day program

- Main issues - rectal pain, constipation, haemorrhoids, rectal prolapse
- Difficulty engaging with health care services
- Multiple presentation to hospital
- Carer stress
- Challenging behaviour limiting service provision
- Meds: infrequent use of Laxettes. Had tried Coloxyl, Lactulose, Movicol

# Management Plan from first appointment

1. Manage constipation/haemorrhoids/rectal prolapse
  - Bowel chart, fluid/ fruit/ diet, aperients
2. Re-engage with colorectal service
3. Increased services to support mother
4. Re-engage with GP: telephone discussion
5. Work towards being able to do physical examination
6. Behaviour chart

**Information, Information and more information!**

# Mr T : Data collection chart

MEDICATION LOG for XXXXXX																	
Name of medication	Dose	Frequency	Monday		Tuesday		Wednesday		Thursday		Friday		Saturday		Sunday		Comments
			AM	PM	AM	PM	AM	PM	AM	PM	AM	PM	AM	PM			
Coloxyl	2 Tabs	Daily															
Lactulose	15 mls	Twice Daily (8 hours apart)															
Fibre	1 tsp	Daily															

	Bowels	Self-harm	Sleep	Comments
Monday				
Tuesday				

# Second appointment 3 weeks later

- Improvement in bowels with regular aperients
- Improvement in diet
- Improvement in behaviour
- Staff receiving training in behaviour support

## Plan:

- To re-engage with GP, titrate aperients
- Referral to Psychiatry for Assessment

# Third clinic- 4 months later

## Joint clinic with psychiatry:

- Refusing to take the aperients
- Increase in self injurious behaviour and aggression
- No mental illness

## Plan:

- Home visit for carer support
- Further aperient recommendations
- Awaiting colorectal appointment
- Ongoing behaviour Support

# Fourth Clinic 3 months later: Case conference

- Support workers and behaviour support practitioner present
- Behaviour: Improved
- Aperients: Intermittent adherence
- Diet: improved and now drinking more fluids including water
- Colorectal clinic appointment: PRN **anxiolytic** prescribed



# Fifth Clinic: one month later

- Refusing to take aperients
- Support for carer
- Colo-rectal clinic: will require admission and surgery

**How can we make the admission least traumatic for everyone?**

# Hospital Support Plan: Community Case conference

**Case Conference** - STrIDeS Clinicians, NDIS support staff, Behaviour Support Practitioner, Support Coordinator and Key worker

1. Education to support staff regarding what an admission would involve
2. Exploring what might work and what might be possible
3. Role of support staff offer during hospitalisation and post discharge
4. Development of a risk assessment plan for hospital

# Hospital Risk Assessment

<b>Intervention</b>	<b>Likely behaviour</b>	<b>Strategies that are known to encourage compliance</b>	<b>Reasonable adjustments needed</b>	<b>Comments</b>
Observations (Temperature, pulse, respirations, BP)				
Medication (pain management tablets/patches/injections)				
Toileting				
Feeding (including bowel prep fluid)				
Nil by mouth (fasting)				
Dressing wounds				
Medical assessment/reviews				
Showers				
Bed linen change				
Walks				

# Hospital Support Plan: Hospital Case Conference

## **Case conference with Hospital to discuss needs, reasonable adjustments and Hospital Risk Assessment**

STriDeS Clinicians, NUM, SW and Support Coordinator

1. What can the ward offer
2. What can STriDeS do to support
3. What can support staff do to support
4. What adjustments are reasonably able to be implemented

# Hospital Executive Support for Reasonable Adjustments

## Hospital Executive Support letter

- Entering the hospital via a quiet entrance
- Admission prior to procedure in pre-identified ward
- Permission for NDIS support workers to be present (24hr/day)
- Accommodation in a single room

# Hospital Admission

- Went better than anticipated: Colonoscopy, Altemeier's procedure, levatorplasty
- 4 days (3 nights). Nil incidents on ward
- Support staff present 24hours
- PRN anxiolytic
- Able to be discharged home: Did not need to go to respite

# Quote - Nursing Unit Manager

*“It was a pleasure to meet Mr T, the team and I believe his admission went very smoothly. I think the combined team effort made all the difference. For example, having the support of the Executive Unit and security team allowed us to smoothly admit him via a private entrance of the hospital and straight to the ward. Of course, the support of the carers on the ward was also fantastic – it was wonderful to see the rapport they had with him.”*

# Quote - Behaviour Support Practitioner

*“I dropped in to see Mr T at the hospital on Friday last week. I was extremely pleased with the success of Mr T’s admission and surgery. I must admit that I was not confident that he would manage to get through it. I want to acknowledge Mr T for showing us his capabilities. A (Support Coordinator) and the RNC team have been persistent and flexible. It’s hard to imagine success without their contributions. The collaboration, transparency, flexibility and communication between the STRIDES team, hospital staff, RNC has been outstanding.*

*I want to thank everyone for applying a truly person-centred approach towards Mr T.”*



# Quote - Support Coordinator

*“It was teams working in collaboration and truly understanding Mr T’s support needs as well as his physical health conditions. Everyone from the medical team, GP admin staff to the security team made a full commitment to making Mr T feel as safe and supported as possible.*

*Another important factor was the trust that Mrs A (mother) built up with the teams; when I first met Mrs A and Mr T 18 months ago she was extremely reluctant for Mr T to take any medication and surgery was out of the question as she was very afraid of the outcome.*

*Staff reported that Mr T was reluctant to leave hospital on Sunday – a true testament to how safe and supported he felt through the process. ”*

# Lessons learned

- Working in Partnership: Family, Support workers, Support Coordinator, Behaviour Support Practitioner, GP, Inpatient team and STRiDeS
- Slow process
- Resource Intensive
- Need a champion in the community and the hospital
- Perseverance
- Long term focus: working hard now for future benefits

# Thank You

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