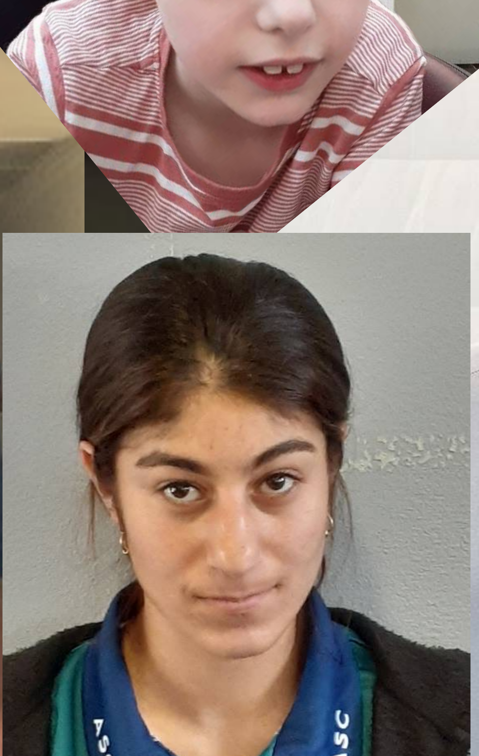
Health
Hunter New England
Local Health District

Respect, Deciding *with* People with an Intellectual Disability

Specialised Intellectual Disability Health Team
(SIDHT) HNECC LHD

SANTA,
THINK



FILA

ABORIGINAL LANGUAGES IN NSW & ACT

Githabul
Ngarabal
GOLD COAST
Warwick
Tweed Heads
Wadigali
Karenggapa
Muruwari
Bundjalung
Gunu
Lightning Ridge
Barranbinya
Moree
Tenterfield
Lismore
Malyangaba
Bandjigali
Bourke
Walgett
Kamilaroi
Inverell
Yamba
Grafton
Barundji
White Cliffs
Narrabri
Gumbainggir
Wandjiwalgu
Wailwan
Nganyaywana
Coffs Harbour
Coonamble
Nambucca Heads
Wiljali
Armidale
Broken Hill
Wongaibon
Coonabarabran
Tamworth
Dainggatti
Kempsey
Gilgandra
Biripi
Port Macquarie
Menindee
Geawegal
Dubbo
Scone
Taree
Barindji
Ivanhoe
Muswellbrook
Forster-Tuncurry
Danggali
Maitland
Wonnarua
Worimi
Barkindji
Wiradjuri
NEWCASTLE
Yitha Yitha
Darkinung
Orange
Meru
Kureinji
Bathurst
Hawkesbury
CENTRAL COAST
Awabakal
Berri
Mildura
Madi Madi
West Wyalong
Katoomba
SYDNEY
Latje Latje
Hay
Dharug
Eora
Nari Nari
Gundungurra
WOLLONGONG
Dadi Dadi
Wadi Wadi
Goulburn
Bowral
Wagga Wagga
Tharawal
Wemba Wemba
Ngunawal
Deniliquin
CANBERRA
Baraba Baraba
Echuca
Cummeragunja
Albury
Wodonga
Ulladulla
Ngarigo
Yorta Yorta
Shepparton
Wangaratta
Yuin
Cooma
Ngurraiillam
Jaitmatang
Bega
Waveroo
Eden
Bidwell

Reconciliation NSW

SIDHT for HNE & CC LHDs

Hunter New England:

Trish Stedman CNC/Team Leader

Karissa Freestone Social Worker

Renee Selway Admin Officer

Kate Thomson Bowe Paediatrician

Ria Leonard Psychiatrist

Sachi Fernando Rehab Physician

Central Coast:

Angelina Lee Intellectual Disability Care Coordinator

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Person, first

Miss S

15 year old who loves:

- Making jewellery
- Photography
- Playing with her puppies
- Card games likes UNO

Social History

- Lived with foster mum since age 3
- Full parental responsibility shared with Department Communities & Justice (DCJ)
- No contact with natural mother
- 3 siblings
- Maternal Aunt and grandmother

Background

- Moderate intellectual disability
- Genetic changes
- A new diagnosis (May 2021)
- Speech and language disorder
- Overweight 107kg (healthy weight range 45kg-61kg)
- Increased risk of developing type 2 diabetes
- Other health related issues linked to increased weight

Unmet Health Needs – referred by Paediatrician

- Increasing weight
  - Poor diet
  - Refusing recommended medication
  - Limited physical activity/movement

- Foster mum also overweight
- Foster mum disempowered

Barriers

- Behaviour and relationship patterns
- Previous experience with medication trial
- Disengagement with Dietitian/ Physiotherapist

Foster mum said to Paediatrician:

"you just don't understand the lifestyle, the whole picture"

SIDHT Consultation

- Involved Miss S, Foster mum, support coordinator
- All SIDHT members involved

Key points

- Hearing her voice
- Communication style
- Likes and interests
- Good day
- What they are hoping to get out of the consult?

Capacity to make decisions is NOT

Did you wake up on your 18th birthday, better able to make complex decisions, than the day before?

Capacity to decide is LIKE

Do you ask someone you trust their thoughts when you are making a big decision?

SIDHT Consultation

Let me know that the responsibility to explain things clearly is on you the provider

Chunk and Check the information you provide

Use plain language (Keep It Simple for Safety-KISS)

Find out how I like to learn

Explain any misunderstandings until understanding is achieved.

Check your client's current understanding

Ask your client to explain back in their own words

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We’ll come back to Miss S, the recommendations and outcome shortly.

So, why does there need to be a specialised health team for people with an intellectual disability?

Service needs

Health conditions in People with ID [PwID] are frequently under-recognised, misdiagnosed and mismanaged, due to:

- Diagnostic overshadowing
- Factors related to the person’s ID which complicate assessment, such as verbal communication and cognition challenges
- Unavailability or lack of appropriate assessment tools;
- Lack of training and confidence of health professionals in treating PwID
- Discrimination in healthcare systems
- Lack of coherent service models
- Lack of specific inclusion of PwID in the formulation of health policy
- Poor coordination between services and treating agencies

Dying too young

- Age at death for PwID substantially (20-36 years) lower than general population
- Twice as likely to die from potentially avoidable causes
- Most common underlying causes of death:
  - Choking
  - Respiratory – aspiration pneumonia
  - Heart disease
  - Cancers – lack of screening
  - Nervous system deaths – related to epilepsy

Premature death

A significant proportion of 'premature' deaths were in people who experienced multiple physical health problems in addition to their disability diagnosis:

An average of 4 comorbid health conditions per person

Health Needs

High % with comorbidities in ID population

- 11% diabetes, epilepsy, gastrointestinal and respiratory conditions, swallowing and feeding disorders (impacting on dental and nutritional health), obesity, vision or hearing problems
- 40% comorbid mental illness
    - higher rates of schizophrenia, affective disorders, anxiety disorders and dementia
    - present to EDs twice as often
    - admissions are twice as often and twice as long

People with Intellectual Disability in NSW 2014-15

Local Health District	Frequency	% LHD population
Sydney	5,996	0.96
South Western Sydney	14,253	1.52
South Eastern Sydney	5,916	0.66
Illawarra Shoalhaven	2,403	0.60
Western Sydney	10,547	1.14
Nepean Blue Mountains	4,748	1.30
Northern Sydney	6,729	0.74
Central Coast	3,146	0.94
Hunter New England	15,198	1.67
Northern NSW	3,705	1.25
Mid North Coast	3,378	1.58
Southern NSW	1,497	0.74
Murrumbidgee	3,530	1.46
Western NSW	5,445	1.95
Far West	714	2.31
Albury Wodonga	519	1.00
Total	**82,724**	**1.15**

Eligibility

To be eligible for this clinical service a child, adolescent or adult with intellectual disability will have:

- complex health conditions, and
- a current unresolved health problem, and health care needs that cannot be met by usual care.

Will receive:

- MDT health assessment and care plan with recommendations
- Referrals to other services

NOTE: The team does not provide routine reviews and will refer to health and other services as needed. The team can provide advice, information and resources to GPs and the other clinicians who will provide ongoing health care to the client.

Capacity Building

- The team will undertake a program of activity to build the skills, knowledge and experience of mainstream health clinicians in the long term.
- The activity will be with GPs, general practice teams and NSW Health staff.
- This includes activity with clinicians who have patients who are not or will not be clients of the SIDHT

SIDHT Consultations

Person-centred

- Who is the patient
- What do they like and want
- How can we communicate with you

Involving stakeholders

- GP or paediatrician
- Psychologist or BP
- COS
- SP and OT

Understanding expectations

Person Centred Practice

"Person Centred Practice puts the person at the centre of EVERYTHING we do."

→ The person is placed at the centre of the service and treated as a person first.

→ It recognises that every client is a unique and complex person.

→ The focus is on the person and what they can do, NOT their condition or diagnosis.

→ Supports focus on achieving the person's aspirations, acknowledges their strengths and is tailored to meet their needs and unique circumstances.

Primary Differences

SIDHT- Person Centred	Service/ System Centred
Talking with the person	Talking about the person
Planning with the person	Planning for the person
Focus on strengths, abilities	Focus on diagnosis , deficits
Finding solutions that could work for anyone, preferably community based	Creating supports based on what works for that diagnosis.
Things are done that way because it works for the person	Things are done that way because it works for the staff or the service
Family and Community members are seen as TRUE Partners	Family and community seen as peripheral

SW Intervention Miss S

1) Financial:

- Assistance to apply for carers Allowance
- Assistance to apply for DSP for Miss S
- -Assistance to apply for TFN

2) Community Access:

- Assistance to COS to lodge S100 review NDIS for funding increase for therapy and DSW support.
- Completion of application for Companion Card

SIDHT Recommendations for Miss S

- Endocrinology referral
- Medication
- Dietary changes
- Join peer group
- Sleep schedule
- Primary care screening

- Activity/movement
- NDIS plan review including:

Support worker hours ↑ for social engagement

Allied Health↑

COS hours ↑

Outcomes & Feedback

- Medication compliance
- Increase social activities – groups, 1:1 and with mum
- Change of diet
- Weight loss

Reflections

- Person first
- Communication
- Empower people

Deciding *with* people with intellectual disability

- Respects their rights
- Places the person at the centre of their health care and wellbeing
- Every person and each decision is different
  - May need varying supports for decision-making
  - Communication supports
- May
  - Teach them to SPEAK OUT
  - Reduce vulnerability

- It ALWAYS take time

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Thank you

Specialised Intellectual Disability Health Team

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