

Community success stories

Making FASD History

FASD diagnosis, prevention and interventions – evaluating and scaling up successful models in remote Australian communities



WARAJANGA MARNTI WARRARNJA
TOGETHER WE WALK ON COUNTRY



Funded by the NHMRC, WA Health, and BHP; led by the Marulu Unit and Hedland FASD Networks



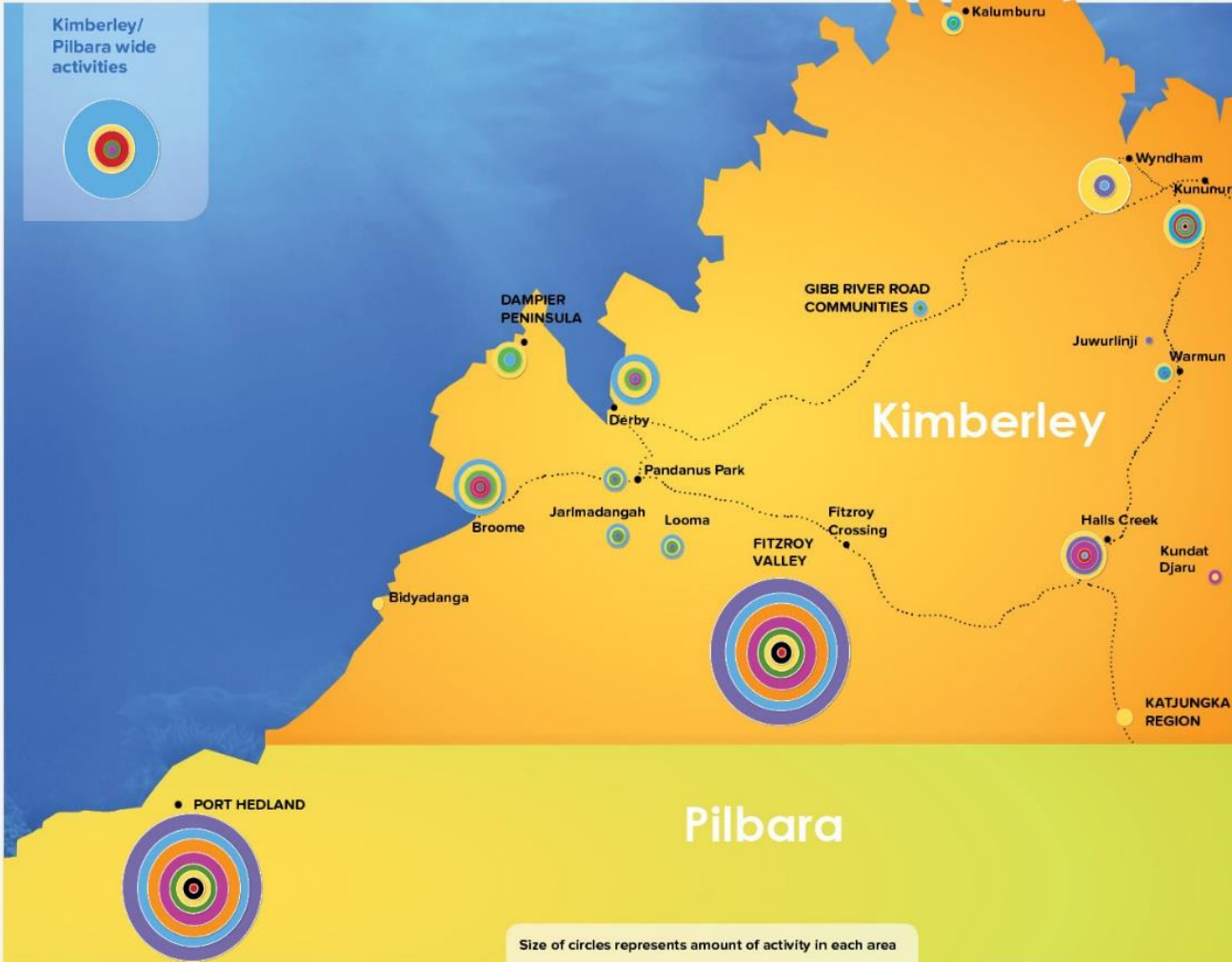


Adapted from Canadian FASD Prevention Researcher Nancy Poole's Four Part Model



Kimberley and Pilbara Regions

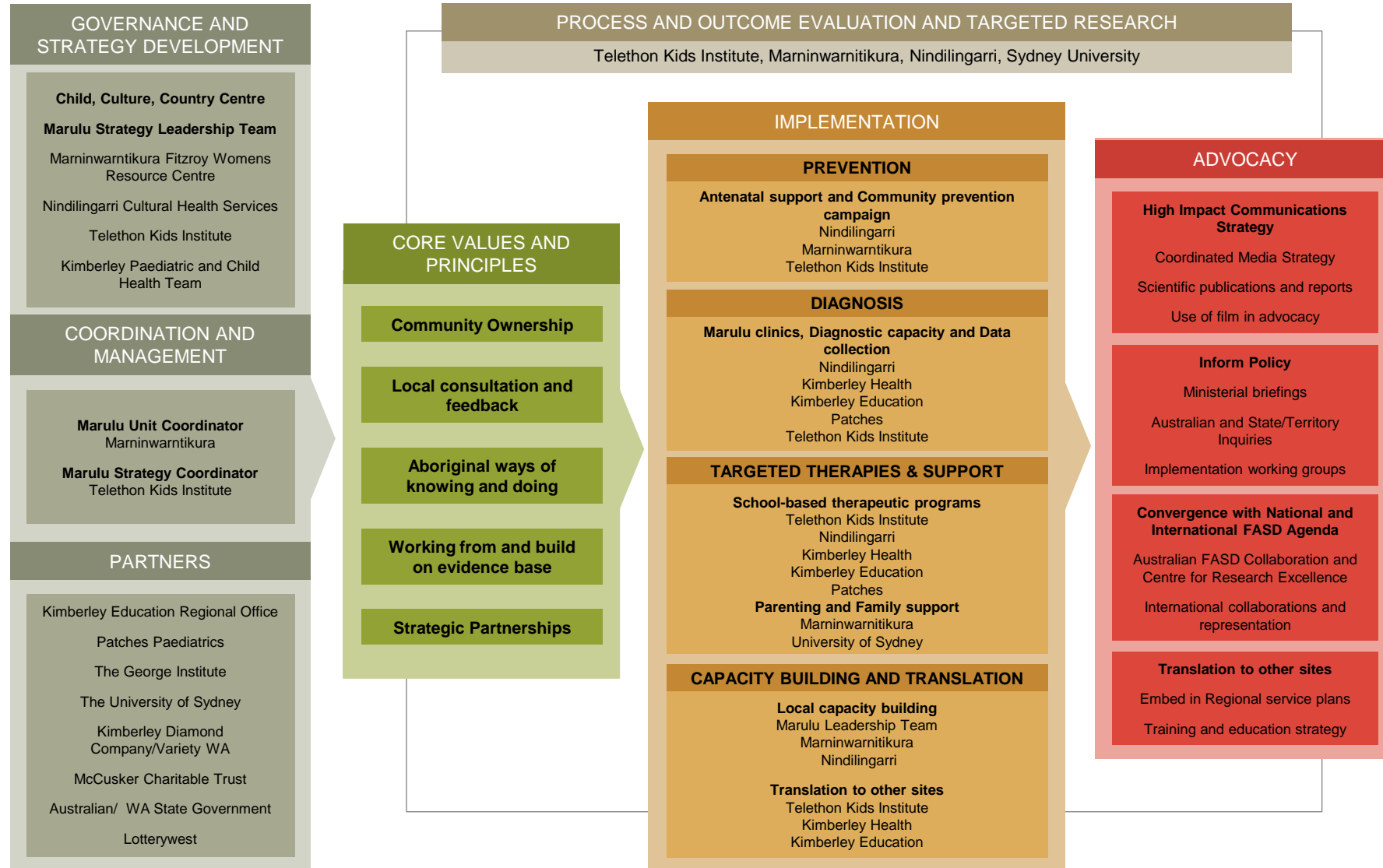
Prevention Level Activities



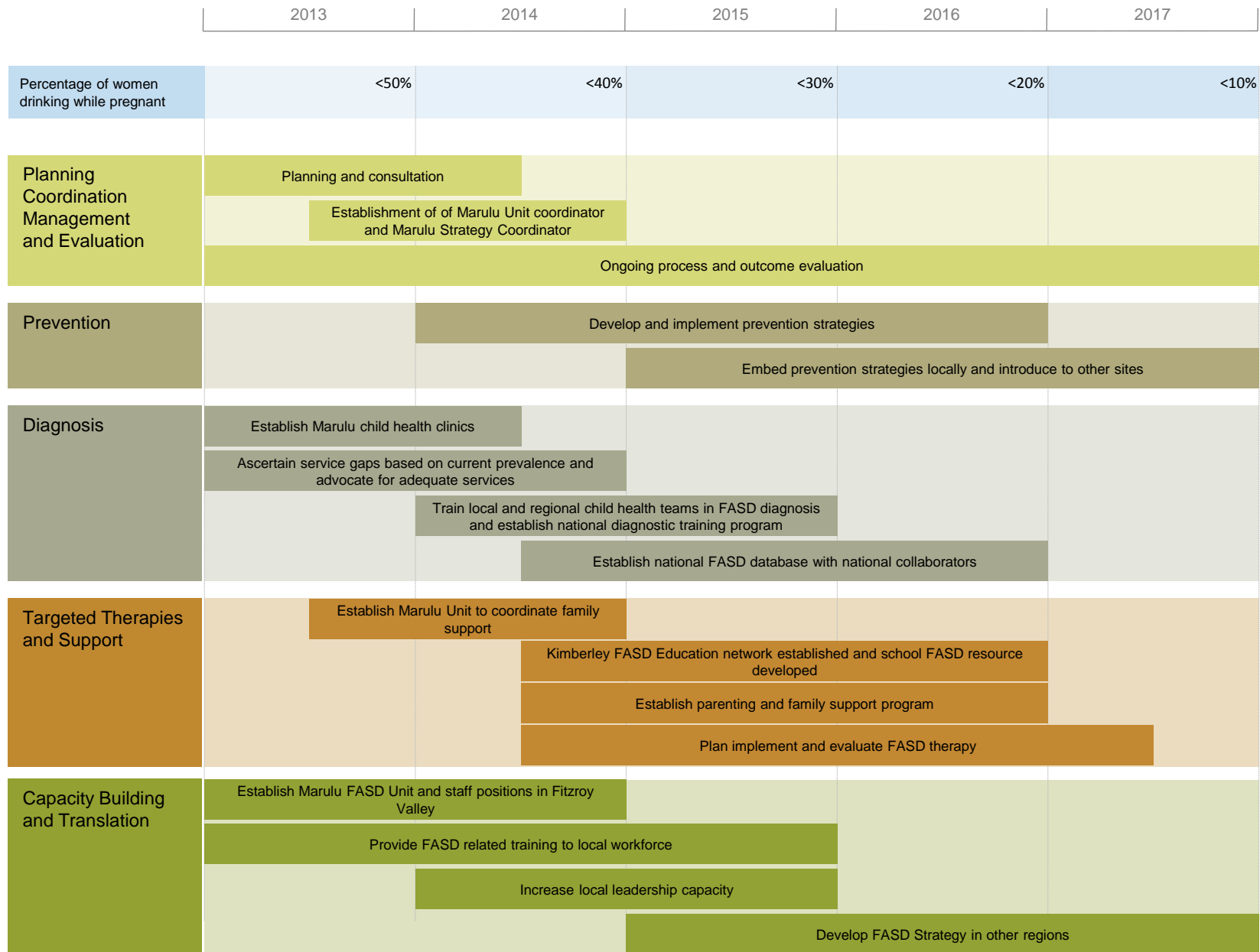
PREVENTION LEVEL ACTIVITIES

<p>Level 1 - Broad awareness and health promotion</p>	<ul style="list-style-type: none"> Community awareness through mass media Community event Community support groups Health education resources Integrated Education Girl's Empowerment Groups Pre-conception care Reducing unplanned pregnancy-contraception and family planning Guidelines Health practitioner training-raising awareness of FASD
<p>Level 2 - Women of childbearing age and networks</p>	<ul style="list-style-type: none"> Antenatal screening Brief intervention Motivational interviewing Health practitioner training- alcohol use during pregnancy
<p>Level 3 - Targeted support for pregnant women with alcohol/social issues</p>	<ul style="list-style-type: none"> Access to antenatal Care* Alcohol counselling Support for women with alcohol problems Support for women with social problems Rehabilitation services Harm minimisation Access to specialised care Specialised maternity care Supporting women affected by domestic violence
<p>Level 4 - Postnatal support</p>	<ul style="list-style-type: none"> Parenting support Postnatal care Access to postnatal alcohol counselling
<p>Supportive alcohol policy</p>	<ul style="list-style-type: none"> Total alcohol bans - supply reduction Localised alcohol restrictions Alcohol restrictions- supply reduction Broad alcohol management strategy
<p>FASD Diagnosis and Therapy#</p>	<ul style="list-style-type: none"> Diagnostic services Therapeutic services Health practitioner services
<p>Alcohol Use in Pregnancy and FASD Related Research</p>	<ul style="list-style-type: none"> Quality improvement and evaluation Epidemiology Intervention studies
<p>FASD strategy coordination*</p>	<ul style="list-style-type: none"> FASD Strategy Coordinator in local community organisation Engagement of stakeholders in FASD prevention activities

MARULU FASD STRATEGY - MAKING FASD HISTORY



FITZROY CROSSING MARULU FASD STRATEGY 2013 - 2017



PILBARA FASD STRATEGY 2015 - 2019

	FY 2015	FY 2016	FY 2017	FY 2018	FY 2019	
Percentage of women drinking while pregnant	?	Less 10%	Less 10%	Less 10%	Less 10%	
Planning Coordination Management and Evaluation	Community consultation and planning, Environmental scan					
	Established Hedland FASD Network					
	Ongoing FASD Network meetings, process and outcome evaluation					
Prevention	AUDIT-C	KAP	AUDIT-C	KAP	KAP	
	Formative research to plan Prevention intervention					
		TV Ads	Targeted prevention	TV Ads	messages	TV Ads
	Intensive ANC and PNC for high risk mums					
Diagnosis	Training in Assessment and PATCHES FASD Clinics					
	PATCHES clinics in schools					
	Support development of local FASD Model of Care			Evaluate local Model of Care		
Targeted Therapies and Support	Ascertain gaps and needs and candidate programs					
	Develop and implement therapeutic parenting support program for CPFS					
	ALERT Program					
Capacity Building, Policy and Translation	Support Hedland FASD Network					
	Provide FASD related training to local workforce					
	Support local leadership capacity, advocacy and liquor restrictions					
	Community researchers					



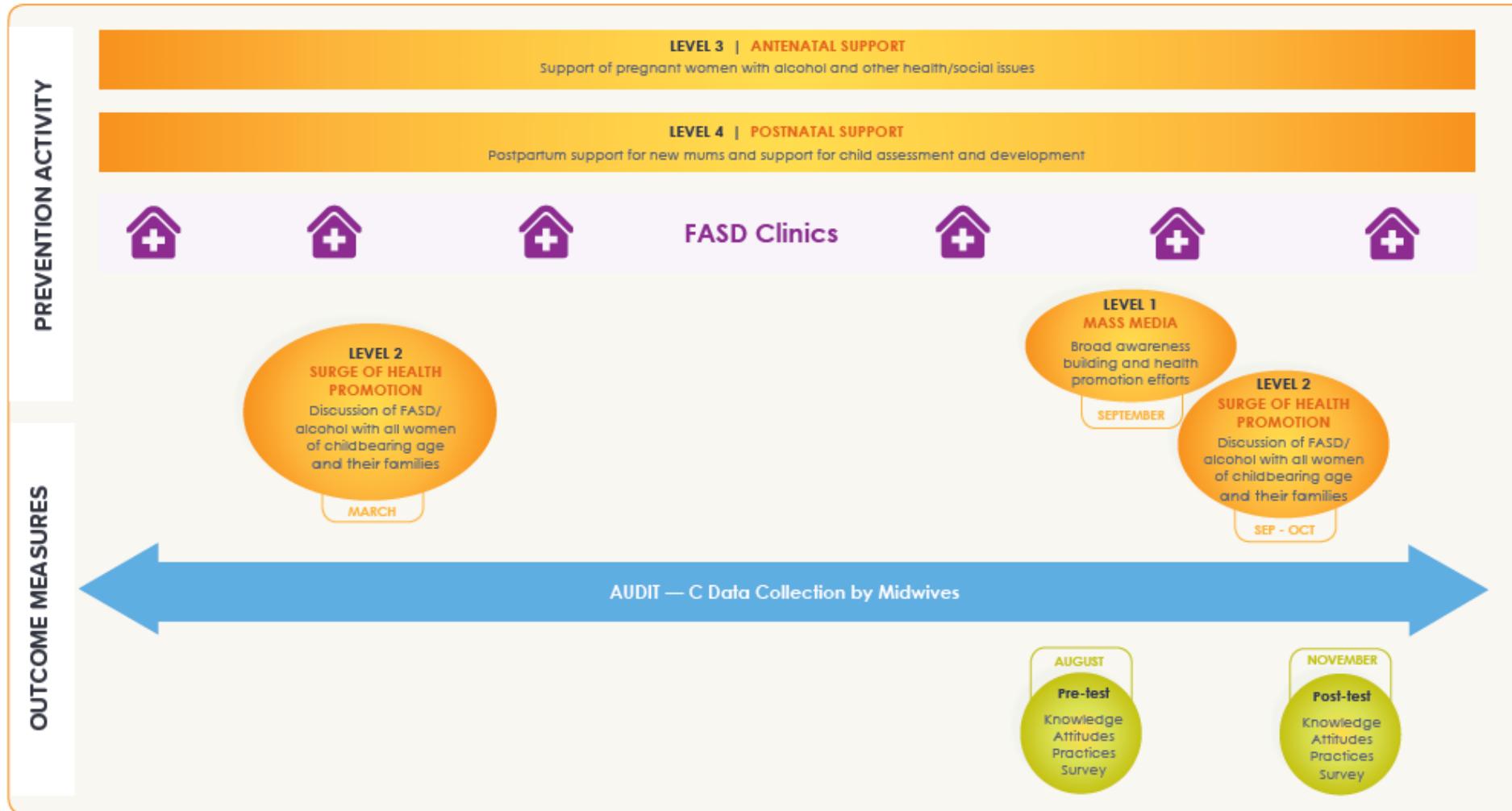


Annual FASD Prevention Strategy Activities

TARGETS

↓ Percentage of women drinking while pregnant

↑ Community Knowledge, Attitudes and Practices of alcohol use in pregnancy





FASD Prevention Strategy

Research Goal

- To develop, implement and evaluate The FASD Prevention Strategy to increase the proportion of women abstaining from alcohol while pregnant.





Methodology

- Participatory action research
- Support local organisations to develop and implement The Prevention Strategy
- Evaluate impact on rates of pregnant women abstaining from alcohol during pregnancy
- Document The Prevention Strategy





Meet the Kimberley Project Team





Meet the Pilbara Project Team



Level 1 & 2 Activities: Fitzroy



Television Ad



"Alcohol Think Again" poster



Marulu T-shirt



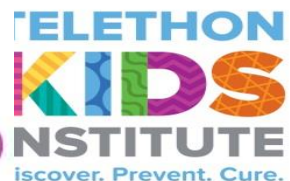
Brochure/Pamphlet/Flyer



FASD Awareness Day/Walk



Social Media (Facebook, etc)





Level 1 & 2 Activities: Pilbara

Broad awareness building and health promotion efforts

Where to get help

If you or someone you know needs help with drinking, please call, email or drop in to see someone at any of the following services:

Bloodwood Tree Association
 P | (08) 9138 3000
 W | www.bloodwoodtree.org.au
 A | 19 Hamilton Rd, South Hedland

Pilbara Aboriginal Drug and Alcohol Program (PADAP)
 P | (08) 9174 1240
 W | www.health.wa.gov.au/services/detail.cfm?obj_id=353
 A | Hedland Health Campus, Colebatch Way South Hedland

Wirraka Maya Health Services
 P | (08) 9172 0444
 W | www.wirrakama.com
 A | 17 Hamilton Road South Hedland

Yaandana Family Services - James River Rehabilitation Centre
 P | (08) 9172 4490
 W | www.yaandana.org.au
 A | 51 Hampton Street, Rosburne

About us

The Telethon Kids Institute is working with Wirraka Maya Health Services and BHP Billiton to help make FASD History in the Pilbara. Our team is working with the community to find ways to:

- 1 Stop kids being born with FASD
- 2 Diagnose kids who might have FASD
- 3 Support kids and families affected by FASD

No Gurry (grog) for Healthy Babies: Alcohol and Pregnancy

Having alcohol at any time in your pregnancy can hurt your baby

If you'd like to know more about the project:
 Email: david.tucker@telethonkids.org.au
 Call: Dave Tucker | 0422 440 724
 Roz Walker | 0427 011 023

Making FASD History in the Pilbara

TELETHON KIDS INSTITUTE
 BHP BILLITON
 HEALTH SERVICES
 PILBARA REGION

In partnership with the Hedland FASD Network and acknowledging the contribution and guidance of the Hedland FASD Community Reference Group

No Gurry (grog) for Healthy Babies

Having alcohol any time in your pregnancy can hurt your baby

What is FASD?

FETAL ALCOHOL SPECTRUM DISORDER (FASD) is caused by drinking alcohol during pregnancy. It can affect the development of a baby's brain and body in different ways. Drinking alcohol during pregnancy can make kids:

- 1 Be born small and grow slow
- 2 Have a short temper
- 3 Have trouble at school
- 4 Not remember things
- 5 Have trouble hearing and speaking

These troubles are sometimes called FASD.

If you would like to know more about the project or get involved:
 Email: david.tucker@telethonkids.org.au
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Making FASD History in the Pilbara

The Telethon Kids Institute is working with Wirraka Maya Health Services and BHP Billiton to help make FASD History in the Pilbara:

- Stop kids being born with FASD
- Diagnose kids who might have FASD
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TELETHON KIDS INSTITUTE
BHP BILLITON
HEALTH SERVICES PILBARA REGION

In partnership with the Hedland FASD Network and acknowledging the contribution and guidance of the Hedland FASD Community Reference Group

What is FASD?

FETAL ALCOHOL SPECTRUM DISORDER

Drinking during pregnancy can make some kids:

- 1 Be born small and grow slow
- 2 Have trouble at school
- 3 Not remember things
- 4 Have trouble hearing and speaking
- 5 Have a short temper

These troubles are sometimes called FASD.

FASD stays with kids their whole life

but together we can:

- 1 Help kids with FASD
- 2 Help families support kids with FASD
- 3 Work with schools and services to support families and kids with FASD
- 4 Stop kids getting FASD

Help **mothers and dads** not to drink during pregnancy

How can you help make FASD History?

It's up to us all to make sure our babies are healthy

FASD is everyone's business and it can affect kids from all backgrounds

To keep your family strong and stop FASD:

Avoid grog if you're trying to get pregnant or think that you might be pregnant

Support your friends and family not to drink if they are pregnant

Boozies - support your women by not drinking around them while they're pregnant

Don't feel alone - if you or someone you know needs help reach out.



Level 3 & 4 Workforce Capacity Building

- Training of antenatal and primary care workforce – AUDIT-C; Brief Intervention & Motivational Interviewing; Health Pathways (PHN's).
- Training in cost effective FASD Diagnosis and Therapy/Support approaches.
- Developing sustainable funding pathways with inbuilt drivers of efficiency and accountability – MBS, NDIS, Agency-funded (Child Protection and Justice).



Community Engagement & Capacity Building

- Aboriginal Health Services as Lead Partners.
- The direct involvement of Aboriginal people and their families.
- Increase the capacity of families and communities to support children with FASD.
- Recruit, train and employ community members as researchers.



Results

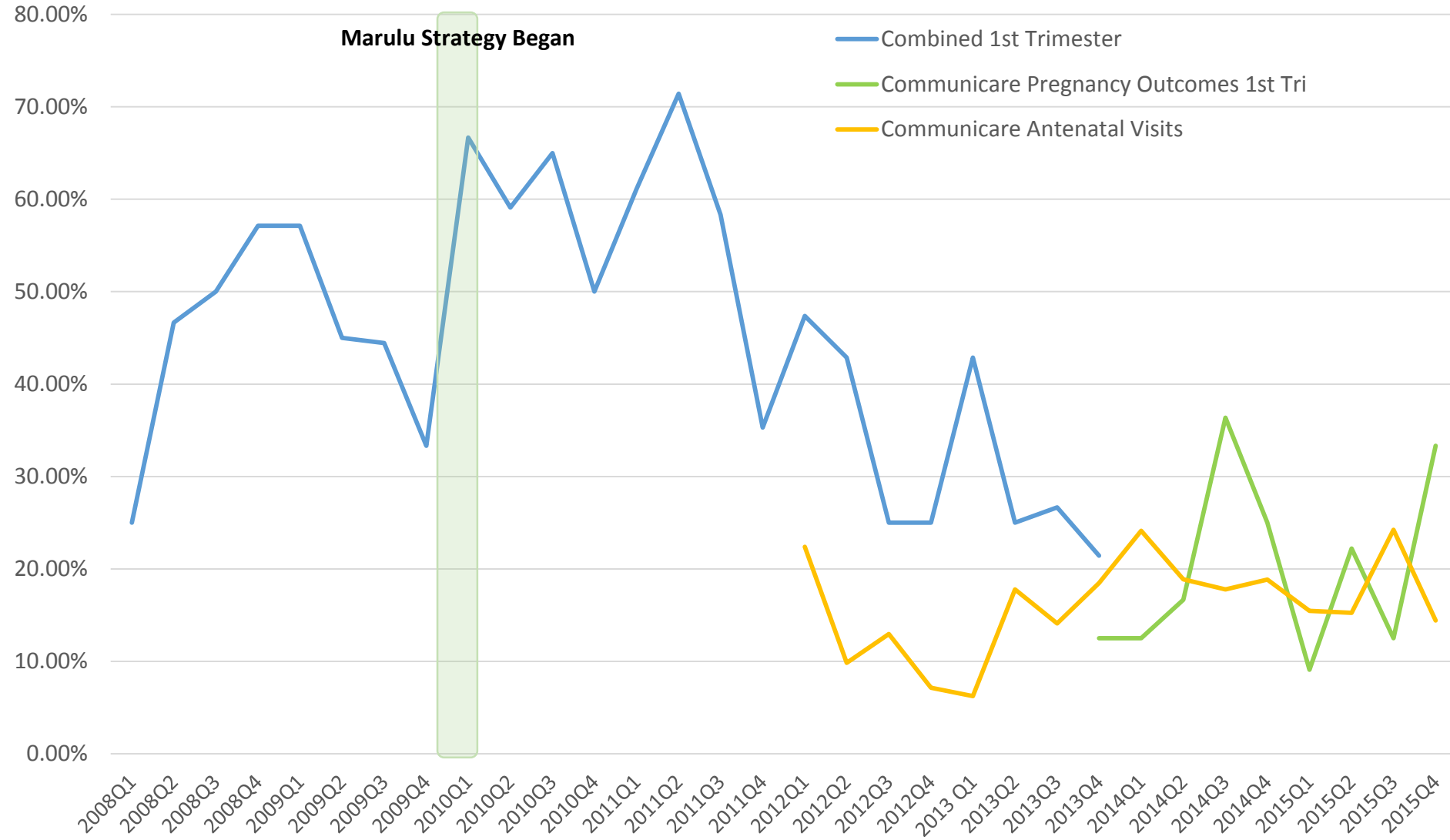


Alcohol Consumption During Pregnancy

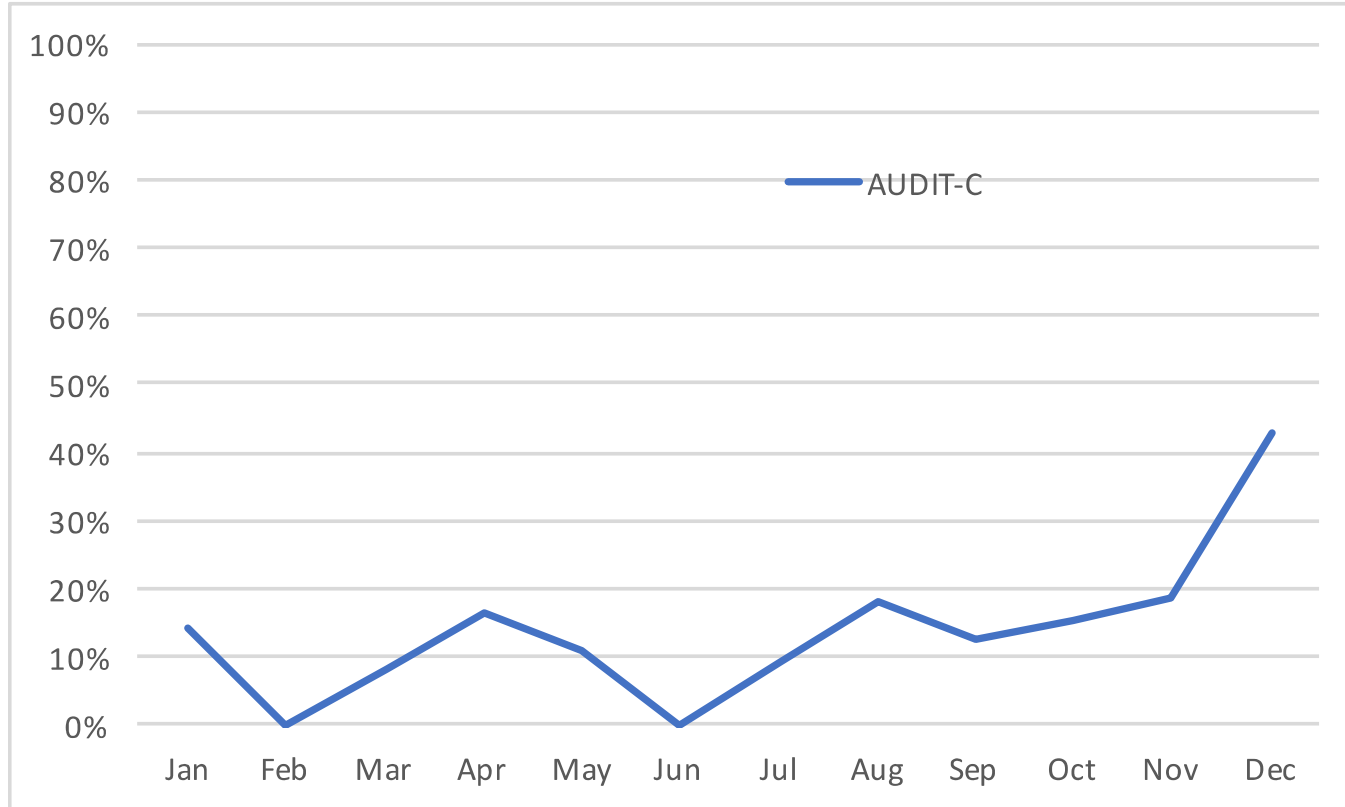
- Self-reported alcohol consumption.
- Recorded by experienced midwives in Fitzroy.
- ~900 pregnancies in the Fitzroy Valley between 2008 – 2017.



Proportion of Women Consuming Alcohol in the 1st Trimester, Fitzroy Valley



AUDIT-C Any Consumption After Knowledge Pregnancy 2016





KAP Survey

- 60 questions in 11 categories.
- Quantitative and qualitative.
- ~35 minutes to complete.
- Designed to be culturally appropriate and conducted with local community researchers.
- Data from first 1100 surveys presented here.



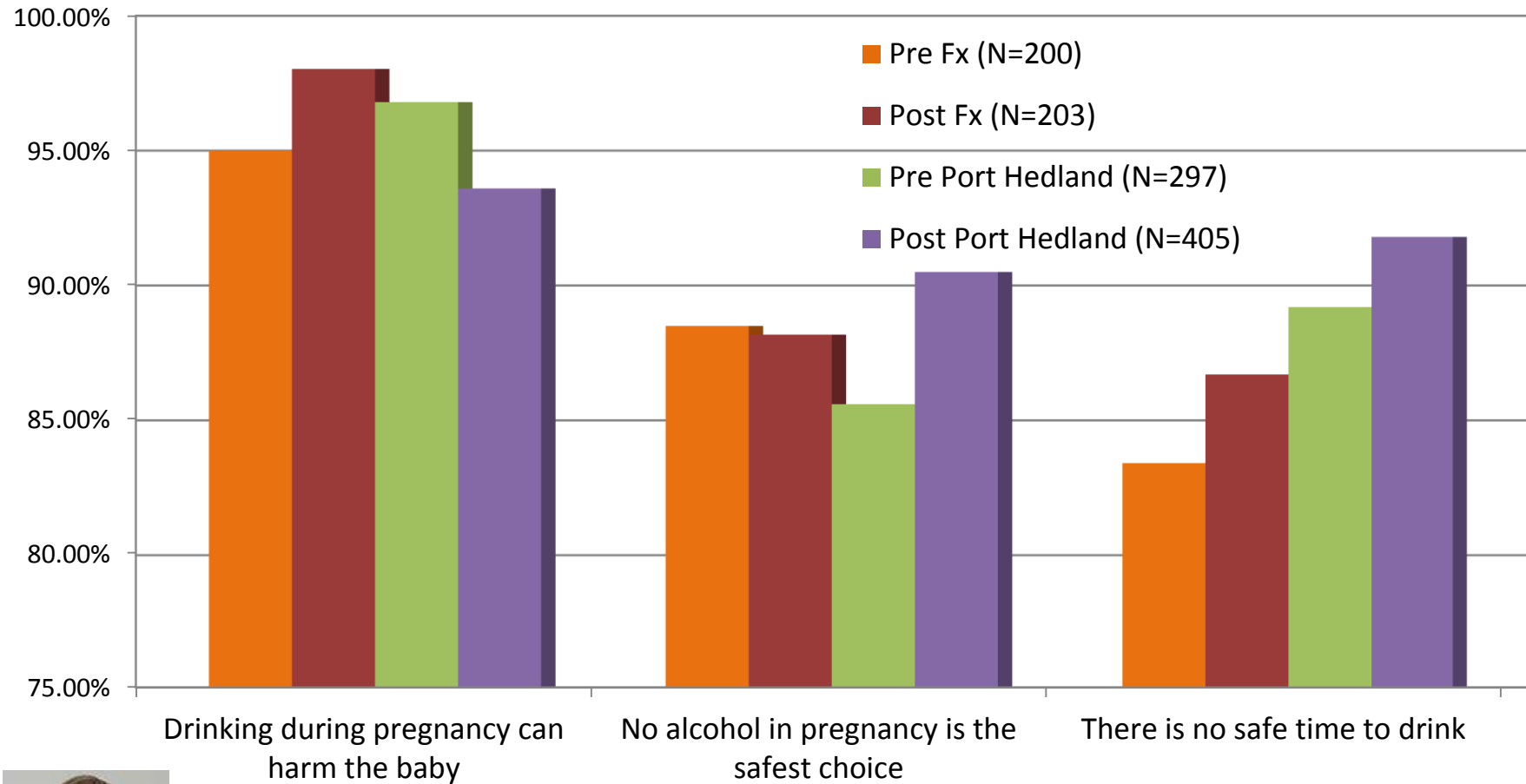


Data Collection



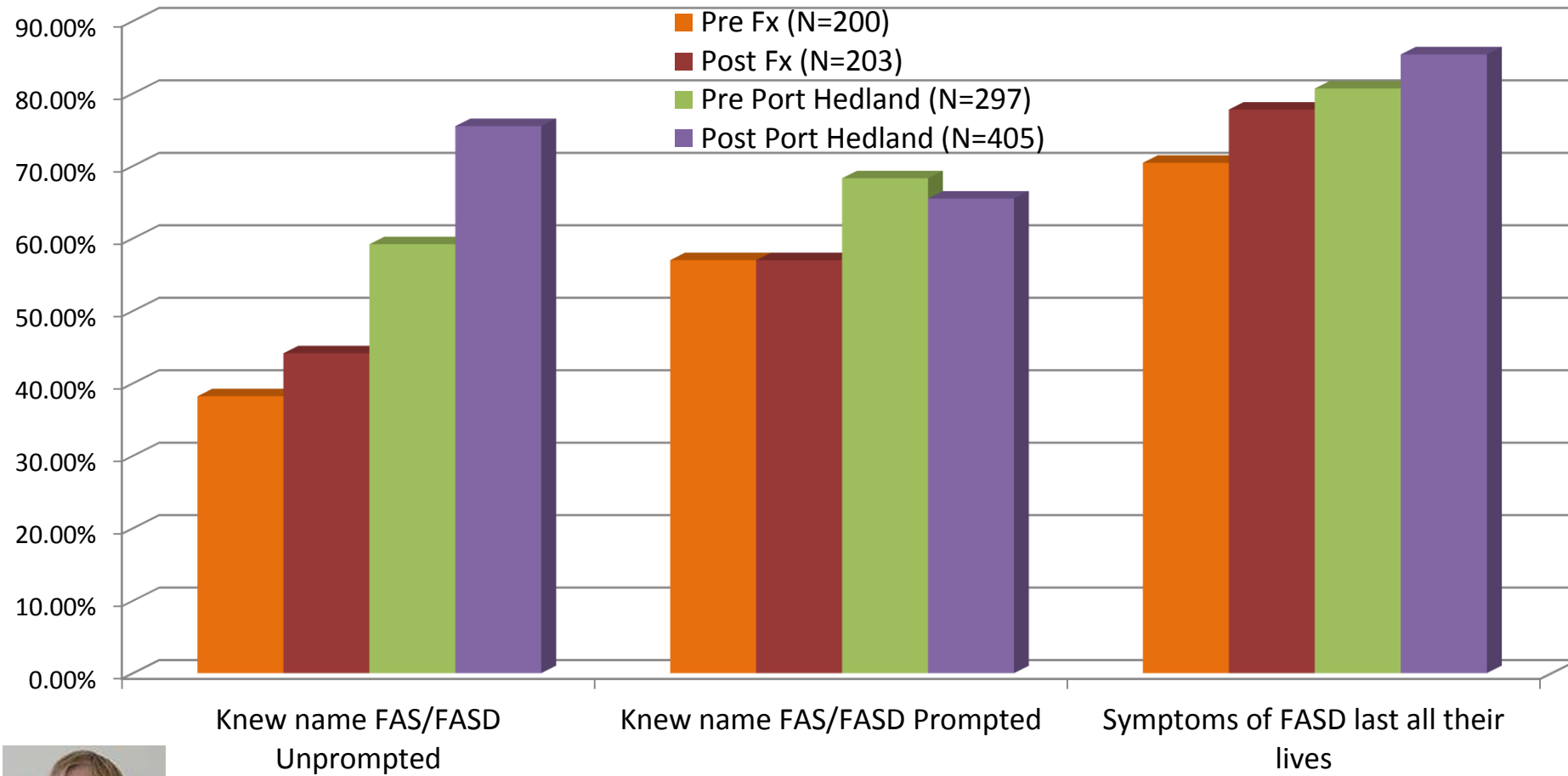


Drinking in Pregnancy Knowledge





FASD Knowledge





FASD Prevention Summary

- Alcohol consumption during pregnancy in the Fitzroy Valley in the 1st Trimester of pregnancy has dropped from 65% to <20%.
- Knowledge of the dangers of drinking during pregnancy was high in both areas.
- There are some gaps in the knowledge of the finer details about FASD, and acting to prevent FASD.
- Communities can overcome the problem of FASD.





FASD Diagnostic Services and Models of Care National Project

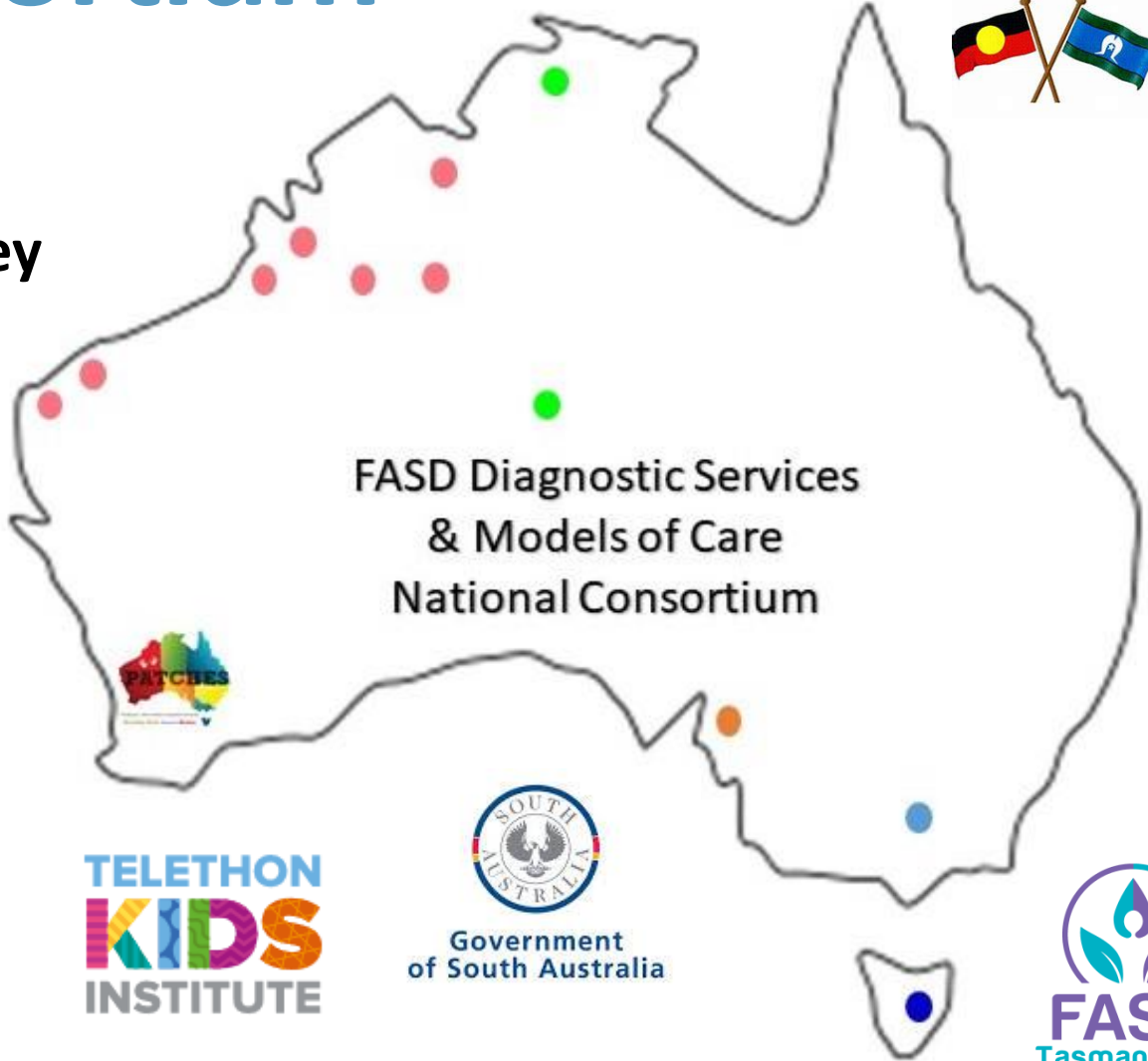
National Consortium



FASD National Program:

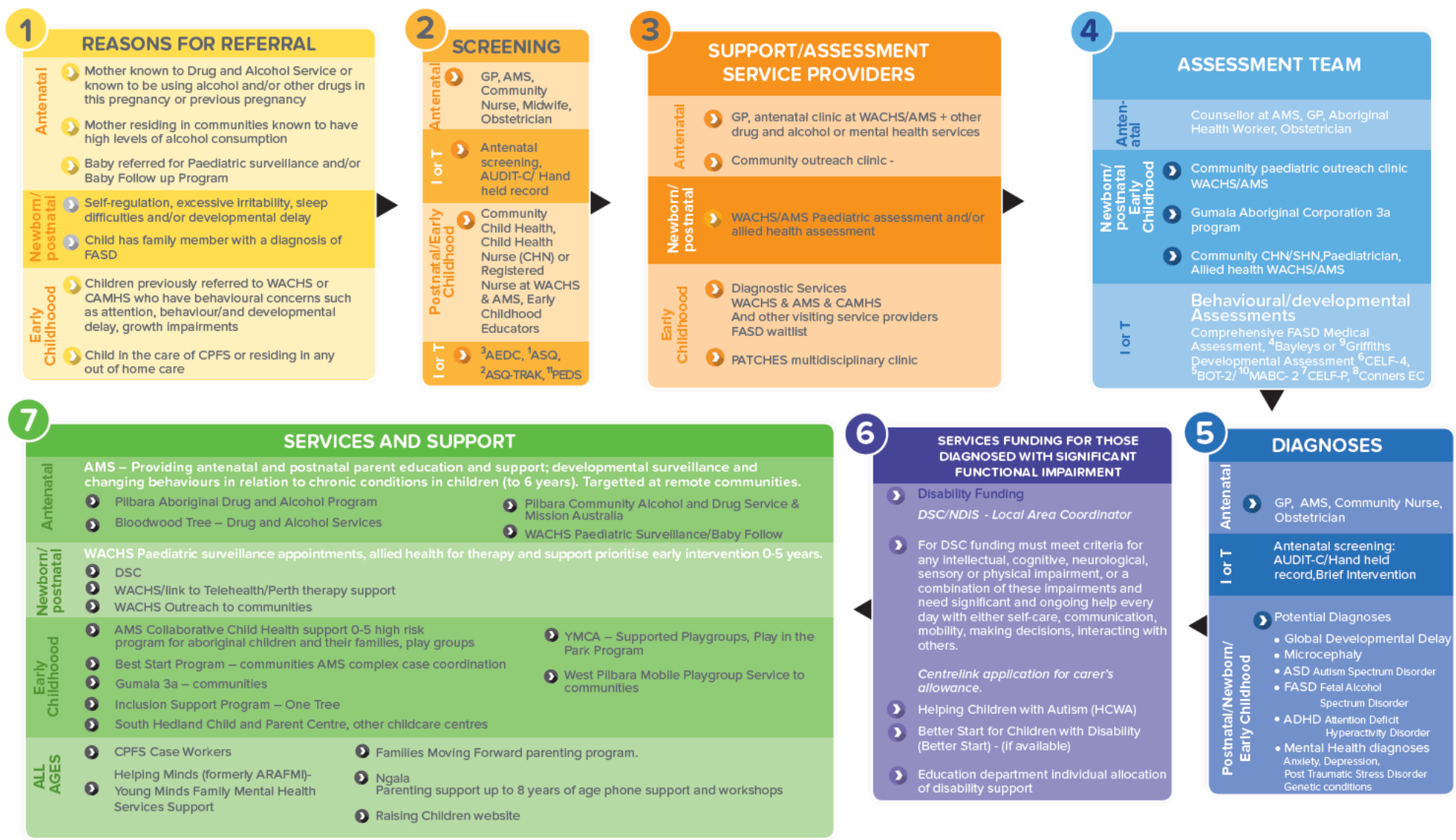
- WA: Metro, Pilbara, Kimberley
- NT: Darwin, Alice Springs
- SA: Adelaide, Ceduna, Yalata
- VIC: Shepparton
- TAS: Hobart, Launceston

Funded by the FASD Diagnostic Services and Models of Care Grant Opportunity Grant



Program Objectives:

1. Map and integrate existing service capacity and processes.
2. Develop and implement sustainable regional FASD models of care.
3. Models of care will be based upon existing models established in the WA Pilbara.

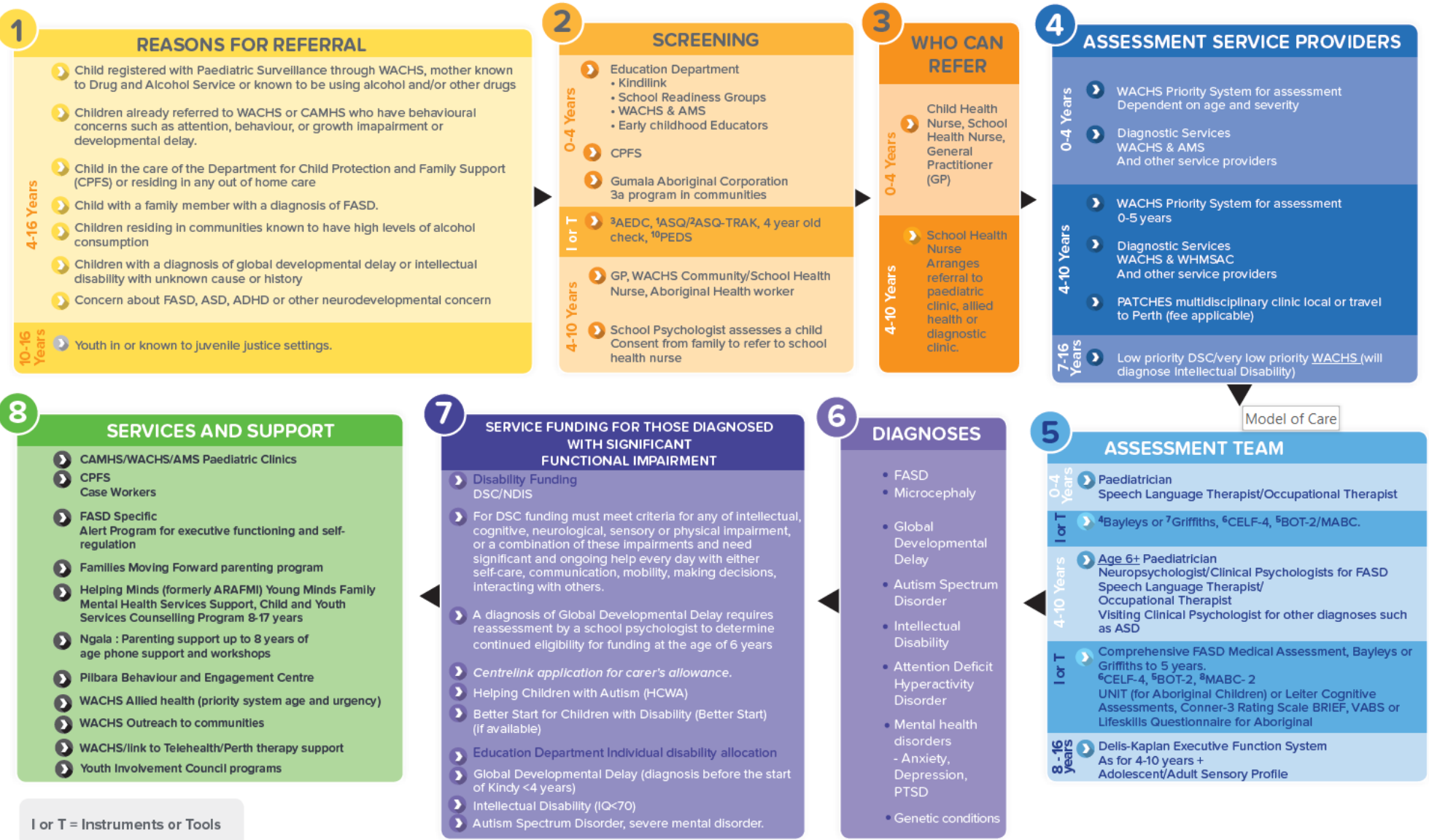


I or T = Instruments or Tools

Assessments: ¹Agnes and Stages Questionnaire (ASQ), ²Agnes and Stages Questionnaire for Aboriginal Children (ASQ-TRAK), ³Australian Early Development Consensus (AEDC), ⁴Bayleys Scales of Infant and Toddler Development, ⁵Bruninks-Oseretsky Test of Motor Proficiency-2, ⁶Comprehensive Evaluation of Language Fundamentals 4 - English Screener (CELF-4), ⁷Comprehensive Evaluation of Language Fundamentals Preschool (CELF-P), ⁸Conners Early Childhood, ⁹Griffiths Mental Development Scales, ¹⁰Movement Assessment Battery for Children-2, National Disability Insurance Scheme (NDIS), ¹¹Parents Evaluation of Developmental Status (PEDS), ¹²Wide-range Assessment of Memory & Learning (2nd edition)

Organisations: Aboriginal Medical Service (AMS), Child and Adolescent Mental Health Service (CAMHS), Department for Child Protection & Family Support (CPFS), Disability Services Commission (DSC)

Note: No specific screening tools are available for FASD.

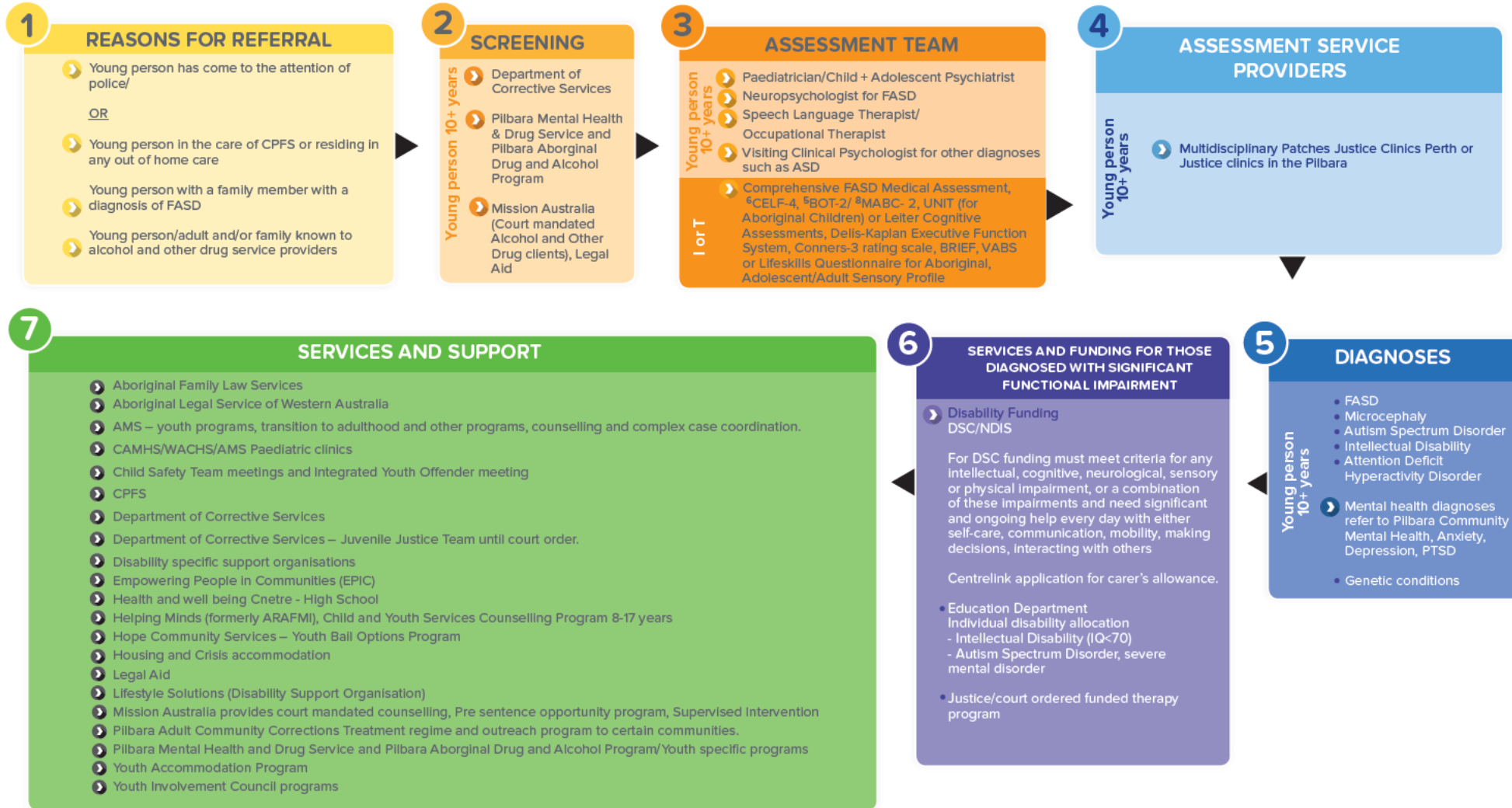


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Organisations: Aboriginal Medical Service (AMS), Disability Services Commission (DSC), Western Australian Country Health Service (WACHS)

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Program Objectives:

4. Expand FASD diagnostic services.
5. Deliver financially sustainable FASD clinics, therapy, and support, for children and adults at high risk for FASD.
6. Establish a Graduate Certificate in FASD assessment and diagnosis, consistent with a national standard for FASD diagnosis.



PATCHES Diagnostic Service activity (Q4 2017)

PATCHES WA & NT FASD Diagnostic Clinic Assessments Sept – Dec 2017

WA Metropolitan Clinics	32 assessments
WA Justice Clients	22 assessments
<u>WA&NT Outreach Clinics</u>	<u>24 assessments</u>
Total	78 assessments

PATCHES Diagnostic Service activity Justice system (May 2016 - May 2018)

PATCHES Justice system Assessments Sept – Dec 2017

Justice (Youth 63, Adult 17)	80 assessments
<u>Medicolegal (Youth 38, Adult 13)</u>	<u>51 assessments</u>
Total	131 assessments
*FASD Assessments for NT Royal Commission	16 assessments

PATCHES Therapy Service activity (April 2018)

PATCHES Kimberley and Pilbara Therapy Service delivery April 2018

Kimberley – Broome, Derby (5 therapists)	244 hours of therapy
Pilbara – Hedland, Karratha (4 therapists)	204 hours of therapy
<u>Perth-based Telehealth (2 therapists)</u>	<u>10 hours of therapy</u>
Total for April	458 hours of therapy



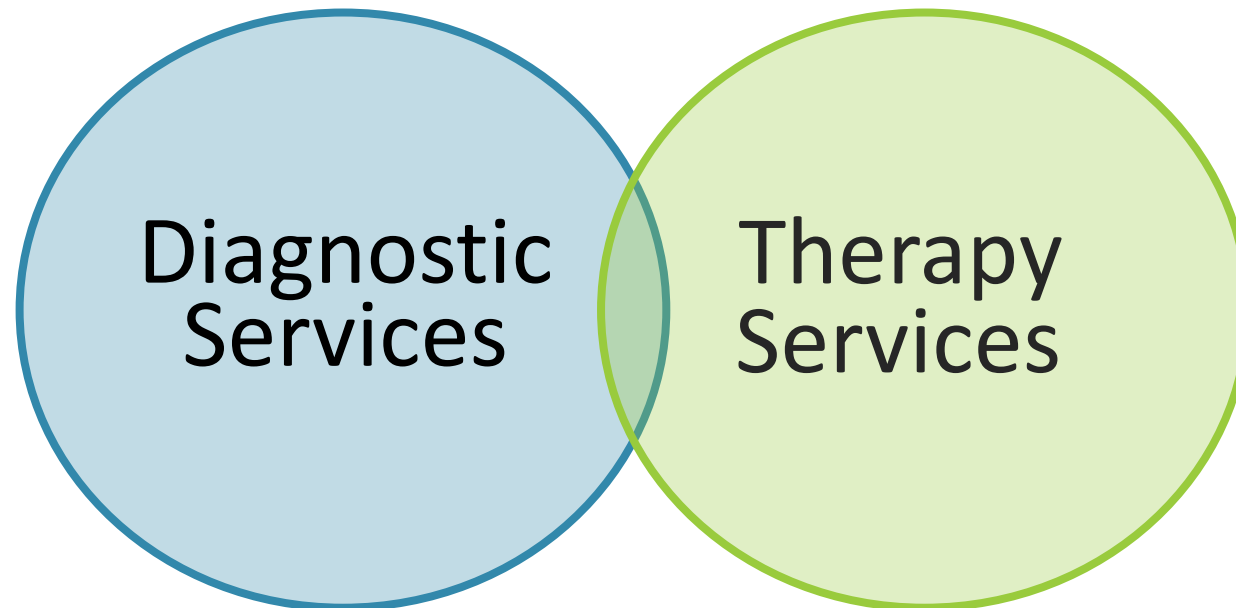
Therapy & Support approaches for FASD

Diagnosis and Therapy interconnect

Behavioural Therapy • Clinical Neuropsychology • Clinical Psychology

Clinical Social Work • Developmental Paediatrics • Exercise Physiology

Generalist Psychology • Occupational Therapy • Physiotherapy • Speech Pathology





The Alert Program®

How does your engine run?

Developed by Occupational Therapists Mary Sue
Williams and Sherry Shellenberger of Therapy Works, Inc.

“Our bodies are just like a car engine, they can run on high, low or in a just right state”

(Williams & Shellenberger, 1996)



“How’s **your engine** running?” ©



PROGRAM OUTLINE



STAGE: 1. Learning the engine words

Step 1: Introduction to the Alert Program®

- * Adults and child gain an understanding the Alert Program® principles and start to learn the engine words.
- * Adults and child begin to identify sensory strategies that are already being used as well as sensory sensitivities that child may have.
- * Adults and child identify goals for the Alert Program® including times of the day where engines are high or low.

Step 2: Learning the engine words

- * Adults and child learn: what does low engine, high engine, and just right engine look and feel like?

2. Changing engine speeds

Step 3: Experimentation

Try out different sensory-motor strategies for changing low and high engines, and for keeping engines just right.



3. Regulating engine speeds

Step 4: Getting specific

Goals: Identify and apply specific strategies that change the child's engine. Parents help the child practice strategies between sessions.

Step 5: Practicing sensory-motor regulation

Goals: The child starts to identify his/her own engine speed and to implement sensory-motor strategies to change their engine. Families and carers help the child practice strategies between sessions.



Positive Behaviour Program - for Families; Schools; and Tough Nuts

Developed by **Dr Carmela Pestell**, Clinical Psychologist, Clinical Neuropsychologist and **David Szczecinski**, Clinical Social Worker, **Ms Janelle Clifton**, Occupational Therapist, **Dr James Fitzpatrick**, Paediatrician, and **Ms Maureen Carter** CEO, Nindilingarri Cultural Health Services

Program Objectives

1. Develop a basic understanding of Autism/ FASD/ Attachment/ Early-Life Trauma and how this affects children and adolescents.
2. Recognise how we all respond to physical, mental and emotional distress.
3. Be mindful of creating and maintaining a secure attachment space.
4. Demonstrate an understanding of modelling, relationship building and limit/boundary setting.





**Together, and only together, we can
Make FASD History**















Thank you



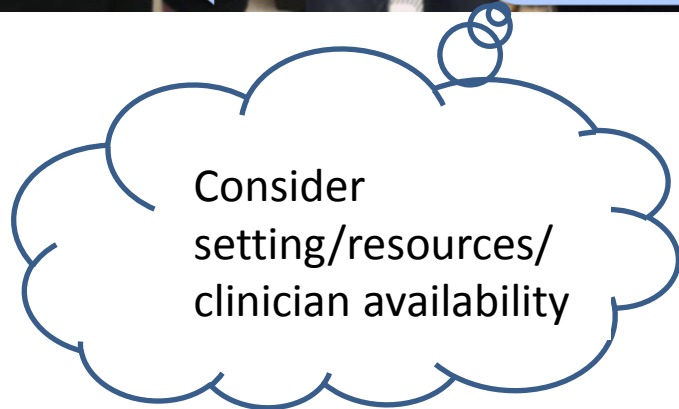
Anatomy of a Multi-disciplinary FASD Diagnostic Clinic

Diagnostic Assessment Models

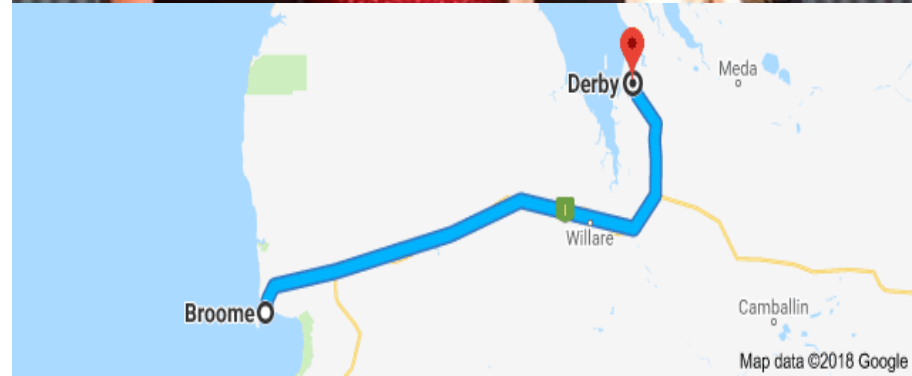


Full inter-disciplinary team

vs. more streamlined approach



Consider setting/resources/clinician availability





Paediatric Child Health & Education Services
Healthy Kids Learn Better

Multidisciplinary Team Clinic

Youth Justice Services - Cnr Walcott and Lord St – Mount Lawley

Team

Coordinator – Tiffany Kempton
Paediatrician – Dr James Fitzpatrick
Neuropsychologist – Candy Cheung
Speech Pathologist – Di Raby

Clients

Client 1 – [Redacted]
Client 2 – [Redacted]
Client 3 – [Redacted]

Time	Candy Cheung	James Fitzpatrick	Di Raby
8:30-9:00	Case Conference		
9:00-10:00		[Redacted]	[Redacted]
10:00 – 11:00	[Redacted]	[Redacted]	[Redacted]
11:00 - 12:00			
12:00 – 1.00	[Redacted]	Phone Panel Meeting - [Redacted]	[Redacted]
1.00-2.00		[Redacted]	
2.00-3.00	Case Conference / Report Writing/Lunch		

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