MCH Autism Professional Development Program

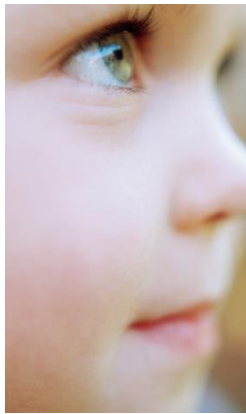**Dr Josephine Barbaro, BBSc (Hons), PhD**
Senior Research Fellow

Victorian Maternal and Child Health Conference
26th October, 2018

Program Background

- In 2017 - Andrews Labor Government announced a package of $1.1 million to deliver training to Maternal and Child Health (MCH) nurses in the early identification of Autism Spectrum Disorder (ASD) in children

- Key program initiatives were:

  - Increase the early identification of ASD in young children

  - Build MCH nurse skills to identify ASD and provide appropriate referrals and supports for families

  - Better support children and families earlier in managing ASD to optimise long-term educational and social outcomes

The Social Attention and Communication Study (SACS)

Community-based Identification of Autism in Infancy and Toddlerhood

Dr Josephine Barbaro[1,2], Ms Lael Ridgway[3], Professor Cheryl Dissanayake[1,2]

and the SACS team

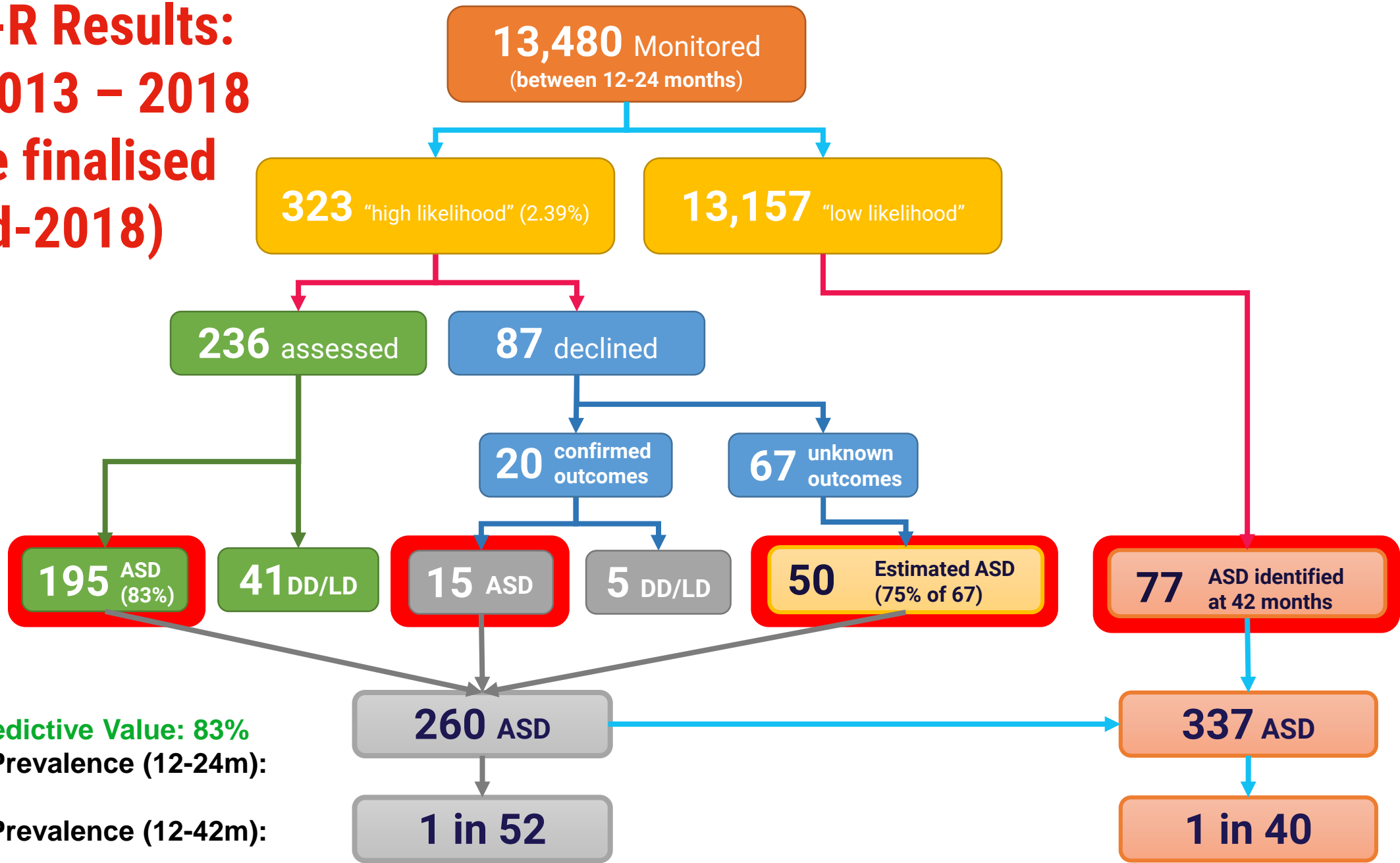[1]OTARC, School of Psychology and Public Health, La Trobe University

[2]Autism CRC

[3]School of Nursing and Midwifery, La Trobe University

AutismCRC

LA TROBE UNIVERSITY

SACS (2006-08) and SACS-Revised (2013-18)

- Over 400 Maternal and Child Health (MCH) Nurses trained in Victoria on early social-communication milestones

  - Half-day workshop; videos comparing children with and without autism

- Developmental surveillance conducted at 12, 18, 24 month routine consultations

- ~ 36,000 children monitored

- Children at "high likelihood" of autism referred to SACS team for thorough developmental assessments

- Followed-up every 6 months until 24 months

- Diagnostic decisions made at 18/24 months and confirmed at 48 months using gold standard diagnostic instrument and cognitive assessments

**SACS-R Results:
June 2013 – 2018
(to be finalised
end-2018)**

13,480 Monitored
(between 12-24 months)

323 "high likelihood" (2.39%)

13,157 "low likelihood"

236 assessed

87 declined

20 confirmed outcomes

67 unknown outcomes

195 ASD (83%)

41 DD/LD

15 ASD

5 DD/LD

50 Estimated ASD (75% of 67)

77 ASD identified at 42 months

260 ASD

337 ASD

Positive Predictive Value: 83%
Estimated Prevalence (12-24m):
1.93%
Estimated Prevalence (12-42m):
2.50%

1 in 52

1 in 40

Long-term outcomes of early detection in the SACS cohort

- **Autism Symptoms Decreased**

  - Follow-up: 24 m → 48 m (86% ASD diagnostic stability; 14% no longer met ADOS criteria by school age; Barbaro & Dissanayake, 2016)

  - Follow-up: 24 m → 7 − 9 y (73% ASD diagnostic stability; 27% no longer met ADOS criteria by school age; Clarke, Dissanayake & Barbaro, 2017)

- **Cognitive Improvements**

  - Percentage of children with Intellectual Disability decreased from 64% at 24-m to 8% at 7−9 years; Clarke, Dissanayake & Barbaro, 2017)
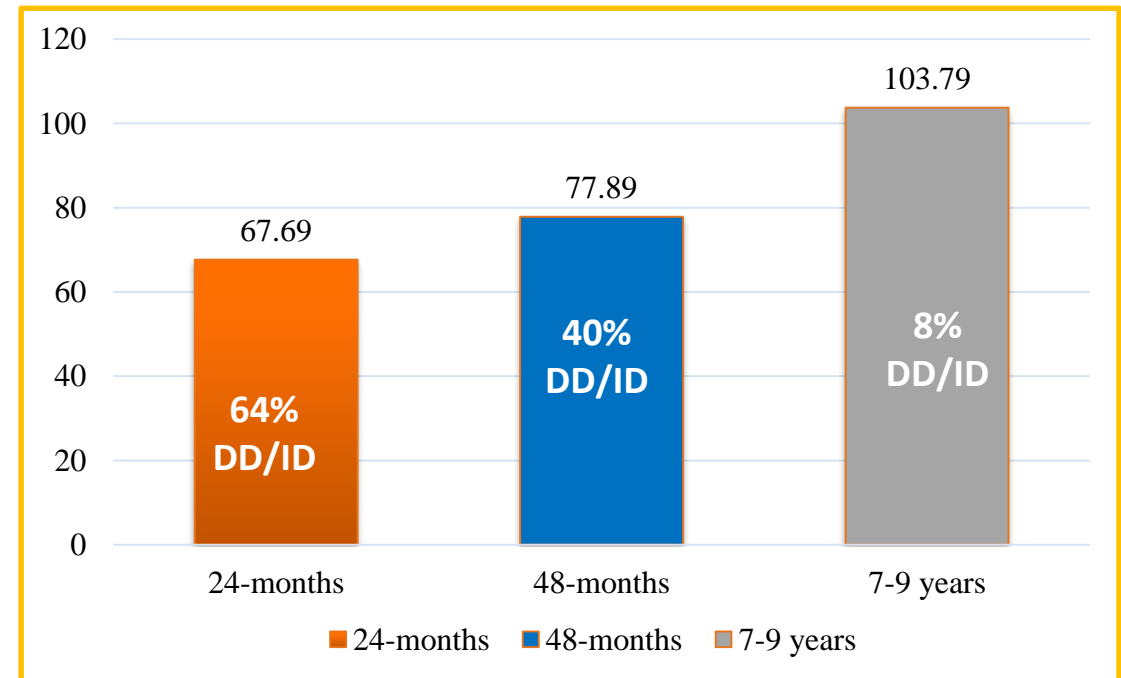
Comparison between children diagnosed early (24 months) and later (3-5 years)

Cognition:

- 8% of children diagnosed early have an ID in comparison to 24% of children diagnosed later

School Placement:

- 77% of children diagnosed early attend mainstream school compared to 58% of children diagnosed later

Ongoing support:

- 60% of children diagnosed early are receiving ongoing support compared to 90% of children diagnosed later

Children in the SACS cohort:

- Were diagnosed significantly earlier than controls (**18 months earlier**)

- Began early intervention at a significantly younger age (**12 months earlier**)

- Received significantly more early intervention than children in the control group (*M* = **11 months**)

SACS Roll out

- Australia (VIC, TAS, NSW, QLD, SA)

- Bangladesh

- Nepal

- China

- Japan

- New Zealand

- Poland

- Singapore

- South Korea

- Spain

MCH Autism Professional Development Program

Objectives

- Develop comprehensive understanding of current learning needs of MCH nurses in early identification of autism and social-communication skills through Training Needs Analysis

- Cultivate knowledge around lived experience of parents interacting with MCH service

- Develop a Professional Development Package tailored to needs of entire MCH Workforce (Universal, Enhanced, ACCO, MCH line, MCH students, Early Parenting Centre staff)

- Enable MCH to grow in confidence and skills in monitoring early social communication skills, discussing concerns with parents, and establishing effective and collaborative referral pathways

- Evaluate the training program, and present recommendations/findings to inform future professional development and implementation

Core Team

Dr. Josephine Barbaro

Senior Research Fellow
OTARC, La Trobe University
Provisional Psychologist, Monash University

Developer of the SACS tool that will be implemented as part of the project and co-founder and lead clinician in Australia's First Early Assessment Clinic for Autism.

Professor Cheryl Dissanayake

Director of OTARC
La Trobe University

Founding Director of Australia's first research centre dedicated to autism and Co-applicant for the project. Professor Dissanayake brings expertise in early identification and early intervention of ASD, biological markers of ASD

Lael Ridgeway

Coordinator, Child Family and Community Nursing
La Trobe University

MCH nurse and educator at LTU, has worked with the SACS team since its inception in 2006 and continues to advise, develop, and refine project plans associated with the SACS project. She also sits on the MCH Expert Reference Group for the Department of Education and training (DET).

Supporting Team Members

Radhika Nair
Project Manager
OTARC, La Trobe University

Radhika has experience in working on various SACS projects and is currently involved in the translation project of ASDetect.

Dr. Melissa Gilbert
Research Officer
OTARC, La Trobe University

Melissa have been involved in research on women's health, occupational therapy, disability, and family law. Currently she is working on SACS research.

Erin Beattie
Research Assistant
OTARC, La Trobe University

Erin has been working on various SACS projects including the ASDetect Evaluation study. She is also pursuing a career as a psychologist.

Dr. Nancy Sadka
Research Officer
OTARC, La Trobe University

Dr. Sadka has been extensively involved in advocacy, research, and clinical work with autistic children and adults.
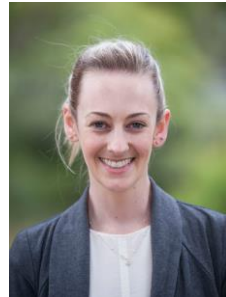
Dr. Rachel Jellett
Research Fellow
OTARC, La Trobe University

Rachel is practicing psychologist in this area. Rachel has experience in teaching postgraduate courses in professional counselling skills and is an active researcher in the field of Autism.

Alex Haschek
Research Officer
OTARC, La Trobe University

Alex has been involved in research for approximately 4 years in a variety of disciplines and roles including public health, education and most recently autism and adults.

Advisory Group

An Advisory group has been formed to seek expert guidance and support in areas of strategic importance

The group is supported by 12 experts, including:
- Academics
- Autistic individuals & advocates
- Parents/carers of children with autism
- MCH, MAV, & DET representatives
- Community & Allied Health professionals
- Educational advisors
- Industry service providers (AMAZE, Raising Children Network)

These advisors are experts in the areas of autism, parenting, infant and child development, MCH nursing, early intervention, advocacy, and service delivery.

Program Scope

Training Needs Analysis (TNA)

01

Identify needs to develop Autism PDP to provide necessary knowledge, information and tools to assess young children (11-30 months) for autism

Professional Development Package (PDP)

02

Development of evidence-based SACS training package, mapping of referral pathways, and parent resources

Training Delivery

03

Face-to-face and online SACS training covering rural/regional and metro regions
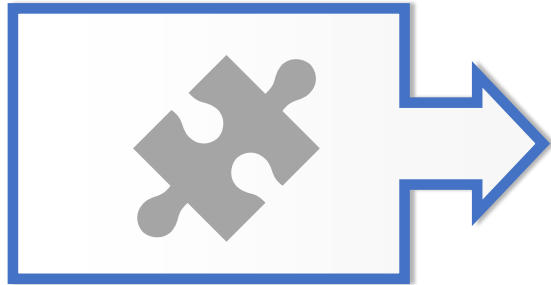
Evaluation

04

Post-training evaluation survey to determine effectiveness of training and project objectives

Program Activities

Training Needs Analysis (TNA)

Surveys
- To identify needs and develop PDP
- De-identified survey sent to entire MCH Workforce
- Survey will take around 15–20 mins to complete

Referral Pathways Session with MCH Coordinators
- Group workshop to discuss local referral and intervention pathways
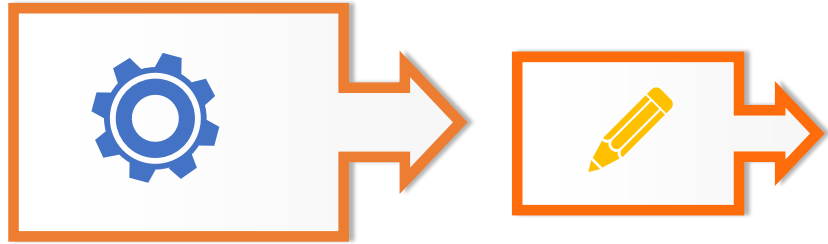- 90 min session at Nov 2018 MCH coordinators meeting

Focus Groups with Parents (SACS and Non-SACS)
- To develop information to support families of children identified at "high likelihood" for autism
- A total of four sessions with parents from metro and rural/regional areas

Program Activities

Professional Development Package (PDP)

Training Delivery

Re-Design and Develop
- Evidence-based SACS training to monitor early social-communication milestones during children's routine checks, to determine "high likelihood" of autism in children aged 11-30-months, based on the SACS "key" items
- Raising concerns with parents
- Local referral pathways and supports/interventions
- Resources for families
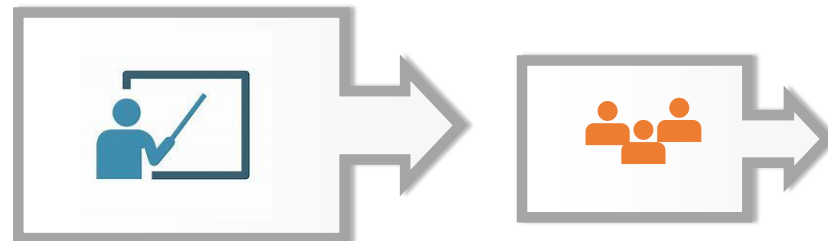
Blended Training approach
- Pre-online reading (Mid-March 2019). To be completed before face-to-face trainings commence
- Face-to-Face training sessions (April–Early June 2019)
  - 25 half-day workshops (10 rural and 15 metro); max 50 participants to facilitate participant engagement
- Online Modules available for those unavailable to attend training (e.g. on holidays etc.)
  - Refresher content available for MCH workforce to access as needed until the end of the program lifecycle
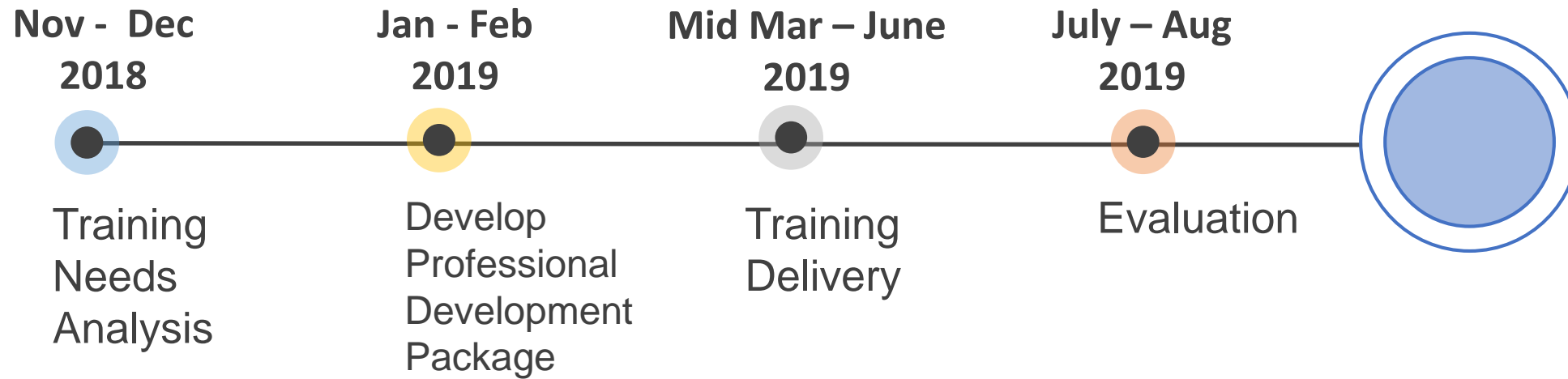
Program Activities

Evaluation

Evaluation Methodology
- Mixed-methods approach taken to evaluate the effectiveness of the PDP
- Online survey for MCH workforce complete post training
- Online survey also sent to parents/caregivers who attend MCH services to evaluate the training package from their perspective
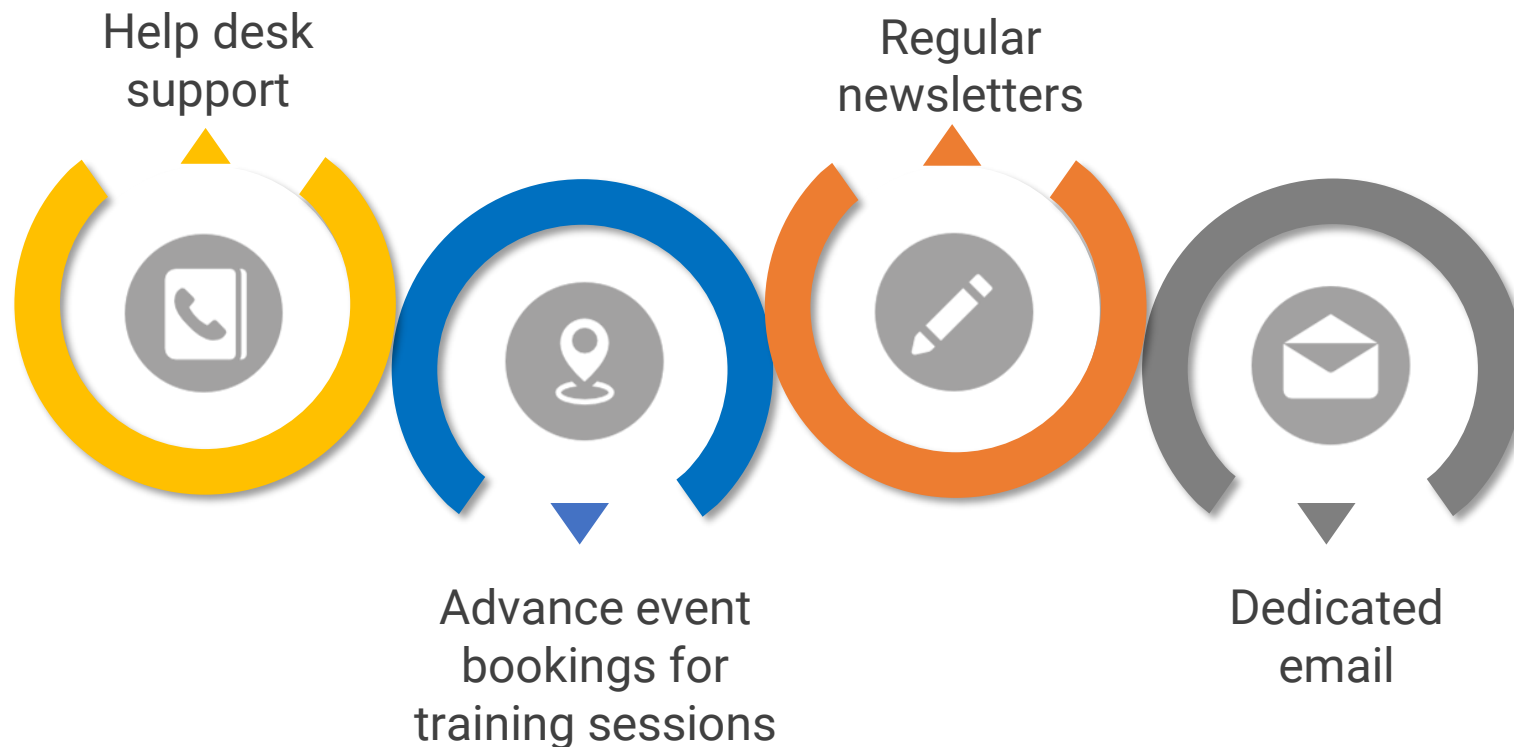
High Level Timelines

Nov - Dec 2018

Jan - Feb 2019

Mid Mar – June 2019

July – Aug 2019

Training Needs Analysis

Develop Professional Development Package

Training Delivery

Evaluation

- Key dates will be shared with all of you as part of our regular communication

Program Communication

- Regular communication to inform all MCH nurses on the upcoming activities
- Various communication channels will be set-up to encourage two-way communication
  - Help desk support set-up during the training delivery stages
  - Dedicated email sacs.vic@latrobe.edu.au for timely response to all queries
  - Invites will be sent in advance for booking into preferred training session date

Help desk
support

Regular
newsletters

Advance event
bookings for
training sessions

Dedicated
email

Questions and Comments?

Thank you

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