

Knowledge exchange and implementation to address the needs of Aboriginal and Torres Strait Islander families raising children with autism.

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The impact of autism

Autism is one of the most common developmental disorders affecting 1 in every 160 children

Impacts on communication, social interaction and behaviour

Early intervention is indicated for all children

Little is known about the impact of autism on Aboriginal children and communities, but there are additional barriers to accessing services for these families.

National roll out of autism support

In 2008 the Federal Government release the HCWA package \$180 million dollars for access to early intervention and information workshops for parents

PRC was program coordinator for the National Workshops program called “Early Days”

Aims of Early Days

1. Provide parents with information about autism (and links to local services) as soon as possible after diagnosis or whilst they are undergoing assessment
2. Provide **evidence based information** about autism and intervention approaches
3. Provide workshops that meet the needs of CALD and Indigenous families and those living in regional and remote areas

Parenting education for Aboriginal families

Few parenting education programs have been developed specifically for Aboriginal families (Wade, et al. 2012)

What doesn't work is adapting 'mainstream' programs for Aboriginal families without community involvement

(Mildon & Polimeni, 2012).

Co-production

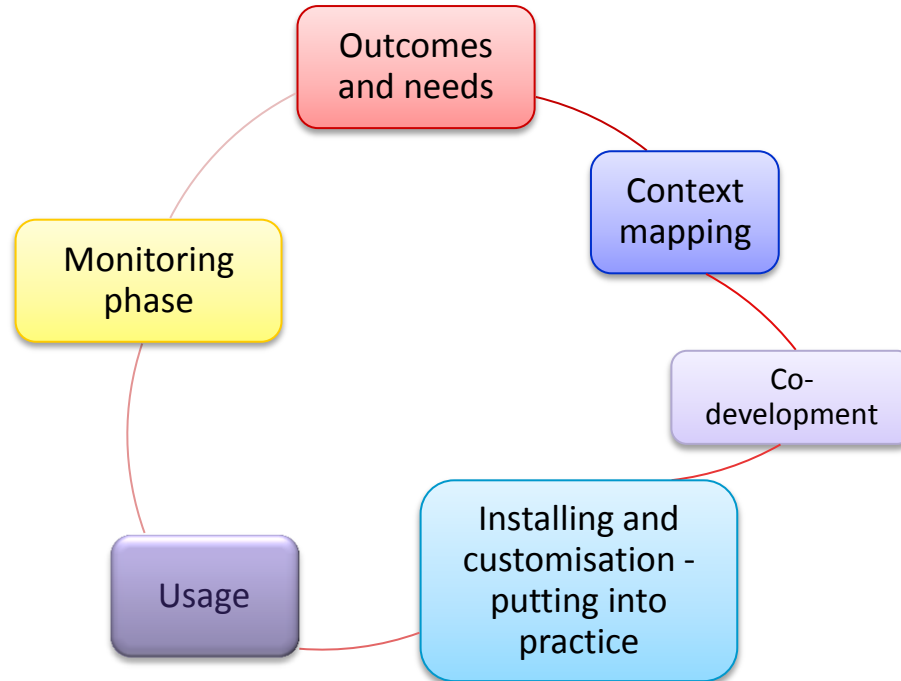
Joint production between those with research expertise and those with practice and context expertise.

“**Active** input by the people who use services, as well as – or instead of – those who have traditionally provided them”. (Mildon, et al., 2010).

Promising way to increase implementation and develop evidence informed approaches to service delivery that are implementable within the context they need to be used

Methods of co-production often not described in detail

Knowledge Exchange process at PRC



Co-production methodology

1. Nominate co-authors

Partnered with SNAICC before we developed anything

2. Clarify outcomes and needs

- Increase knowledge of autism and interventions that work
- Increase knowledge of local services
- Deliver workshops in culturally acceptable way

3. Initial planning

- What? *Culturally appropriate workshop*
- For Whom? *Extended family/community members
(decided by family). Not open workshops*
- By Whom? *Ideally by local Aboriginal workers*
- Where? *In local community, through Aboriginal
Community Controlled Organisations (ACCOs).*

We looked at workshop development *and* service delivery at the very beginning.

4. Evidence review

- What we know about autism
- What we know about working with Aboriginal communities
- What we know about Aboriginal families raising children with autism?

Consultations: Six Parents/carers

*Directors of four Multifunctional Aboriginal
Children's Services (MACS)*

5. Workshop development

PRC and SNAICC staff worked together to produce two workshops that had evidence based content delivered in a way consistent with:

- Learning styles
- Aboriginal child rearing practices
- Cultural context

One family workshop

One workforce development workshop

6. Service delivery development

We also co-produced a model for service delivery that would meet the needs of Aboriginal families

- Delivered through ACCO's – workforce development needed
- Co-facilitated by two (or more) people with content, cultural, and local service expertise
- All facilitators need cultural competency training
- Delivered at a time and community location of families choosing

7. Expert review

Three autism experts

Three cultural experts:

- Aboriginal parent (NSW);
- Aboriginal educator (trained child care worker from NT)
- Aboriginal staff member from SNAICC

8. Revision of workshop

E.g., 'Understanding Autism'

'Autism: No Blame, No Shame'

9. Publish

Careful attention given to branding, audio-visual materials, layout and design

Dissemination and Implementation

- Presentation delivered at SNAICC national conference
- Aboriginal workers identified in local communities with necessary skills to deliver who have families now
- Training/workforce development (8 workshops delivered to 109 workers)
- Co-facilitation (6 family workshops delivered to 36 participants)

Outcomes

Eight professional development workshops -109 workers

Acceptability and Satisfaction

- 94% workshop was helpful
- 97% workshop was easy to understand
- 92% workshop length, format & activities were appropriate
- 91% workshop content was relevant
- 93% workshop answered the questions I had about autism

Knowledge of autism also improved post workshop

Limitations

- Co-production takes time
- Co-production needs to be independent
- Staff continuity and relationships are important
- No best practice for co-production at present

(Needham, 2009)

Conclusions

- Co-production offers a promising method for improving the ‘implementability’ of programs and services for Aboriginal and Torres Strait Islander families
- Co-production can be used to develop the ‘what’ and the ‘how’ - increases acceptability and usability of a service
- The earlier it begins, the better
- Methodology of co-production needs to be more transparent



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