

# The Lililwan Project: developing a culture—and language-appropriate FASD diagnostic checklist for history-taking in an Australian Aboriginal community

Harry Yungabun<sup>1</sup>

<sup>1</sup>Nindilingarri Cultural Health Services, WA

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Harry Yungabun is a senior member of the Walmajarri language group who acts as an Aboriginal community navigator on *The Lililwan Project*, and is Chairman of the Marra Worra Worra Aboriginal Corporation. He is highly respected among all Fitzroy Valley language groups and is adept in tracking and catching bush tucker.

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## Background

The Lililwan\* Project, the first active case-ascertainment study of FASD prevalence in Australia, is being conducted in the remote Fitzroy Valley of the Kimberley region of Western Australia. Fitzroy Valley has a population of 4,500 mainly Aboriginal people living in 45 discrete communities representing five distinct language groups: Bunuba, Walmajarri, Wangkatjungka, Nyikina and Goonyandi. The most commonly spoken language is Kriol (Aboriginal English). To gather accurate demographic, cultural, social and biomedical data for Stage 1 of this project, we aimed to develop a comprehensive checklist and use it to take a medical history and to document this process.

## Methods

A medical history checklist designed to obtain information by interview from parents and carers of 7 and 8 year old children was developed. It includes items that allow documentation of known clinical features consistent with diagnosis of FASD and permit application of both the University of Washington FASD 4-Digit diagnostic code and the American Institute of Medicine Diagnostic criteria with regard to risk levels for alcohol consumption, growth parameters, birth defects and developmental problems consistent with FASD. Items from the Australian Longitudinal Study of Indigenous Children (2008) that pertain to early life trauma were also included. This checklist was initially developed by a team of Developmental and General Paediatricians, then modified by a senior Aboriginal leader, the CEO of the Nindilingarri Cultural Health Services, to ensure that the questions were culturally appropriate. The checklist was refined by two local Aboriginal community members ('Community Navigators') with input from an Aboriginal representative from the Kimberley Interpreting Service to inform the content and specific language used and enhance understanding of the questions. The checklist was administered by a member of the research team with access to an Aboriginal Community Navigator to ensure accurate interpretation of answers. A two-part study was performed to assess inter- and intra-rater reliability (results will be presented separately). Ethics approval was obtained for this project. Prior to the interview parents/carers were given information about the project in a language of their choice and invited to participate and if they agreed written consent was obtained.

## Results

The history checklist includes 114 questions seeking information about child and parent demographics, language, place of residence and living conditions, Data on prenatal exposures (including alcohol), neonatal history, early childhood trauma (relevant to these remote Aboriginal communities) and health and educational outcomes are collected. It incorporates culturally-appropriate language (e.g. 'grog'= alcohol; 'growing up'= child rearing). Of 113 parents/carers approached to date, 108 have consented to participate and all have found the questionnaire acceptable and understandable. The checklist takes approximately 50 minutes to complete.

## Conclusion

In order to gather accurate historical data in diverse Australian Aboriginal communities, there is a need to collaborate with community to refine the language used and to facilitate understanding and ensure the

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\* Lililwan is a Kriol word meaning 'all of the little ones'

content is culturally-appropriate. The Lililwan Project values and respects Aboriginal language, culture and tradition and takes these into account at all stages of study design and implementation.

### Learning objectives

1. To increase awareness of cultural and language diversity in Australian Aboriginal communities.
2. To introduce a FASD diagnostic checklist for use in FASD prevalence studies in Aboriginal communities and the process of its' development.