INFORMATION SHEET

STUDY TITLE  Child Disability and Families in Australia
RESEARCHER  Annemarie Ashton-Wyatt, PhD Candidate, School of Demography

What is the research about?

Very little demographic and social research has been done in Australia on families caring for a child with disability. This research will collect information from families in Australia. It will compare information on families who have a child or children with disability to families who have a child or children with no disability to see where there are similarities and where there are differences.

This research project uses population data analysis based on existing sources, such as the Census of Population and Housing and the Survey of Disability, Ageing and Carers. This part of the research aims to identify any patterns in geographic distribution, economic impact or family structure which may be associated with child disability.

Importantly, this research also seeks to better understand how the lived experience of child disability may affect families, particularly how parent relationships (with each other and with wider family members) may be changed. This aspect will be explored by interviewing parents of children with disability.

Why is this research useful?

Knowing more about how families with a child or children with disability are the same as or different to other families can inform the development of supports that better meet family needs and help to improve wellbeing for both children with disability and their families. Supports for families having a child with disability vary greatly throughout Australia. Regardless of service availability, the majority of care and support to children with disability is usually provided by immediate family members. The introduction of the NDIS aims to achieve greater access to supports for people with disabilities, but rollout of the scheme is limited at this stage.

Who has been selected?

The statistical information looks at the whole of Australia. Interviews with parents will take place at three locations across three states:

> Albury, New South Wales;
> Dandenong, Victoria; and
> Dianella area in Perth, Western Australia.

What will the interviews involve?

Interested participants living in the interview locations can register for a short telephone interview with the researcher. This will enable discussion of current wellbeing, collect some basic data on the family structure and recent events, and ascertain potential availability for a full interview which will take approximately one hour. Interview locations will likely be a library or community centre within each of the above locations.

To be eligible, participants must have a child with a diagnosed disability aged between 0 and 19 years. Families from one-parent and two-parent households are both encouraged to participate. At least one parent in each household must have a biological relationship to the child with disability. (Regrettfully the scope of this study cannot adequately address the often complex life events associated with foster and adoptive relationships as well as child disability, but this is hoped to be addressed through other work.)
Given that the research involves the disclosure of sensitive topics about family relationships, there is a risk that distress can be experienced by some participants as a result of discussing these issues. All participants will be supplied with a resource list of family or relationship counselling and support services to help reduce potential impact and encouraged to seek further professional help if required.

**How will my confidential information be protected?**

All information will be strictly confidential as far as allowed under the law. Your name and personal contact details will only be disclosed to the researcher’s supervisor via signed the consent forms as evidence of participation.

All interviews will be recorded on a digital voice recorder and the researcher may also make handwritten notes if required. Your name and names of family members discussed by you will be replaced by pseudonyms when audio recordings are transcribed. Recordings will then be erased.

Discussion of the research findings in the researcher’s thesis or any articles, presentations or other publications produced as a result of this work will not include any details which may be reasonably expected to enable identification of you or your family by a third party.

The researcher advises all participants that if they reveal information which reasonably indicates that the participant or a child in their family may be at risk of harm, the researcher is required to immediately suspend the interview and seek advice from her supervisor or other qualified personnel available at the Australian National University.

**Who is doing the research?**

Annemarie Ashton-Wyatt BCI (Hons) Grad Cert (Social Research) is a PhD Candidate at the Australian Demographic and Social Research Institute. She has extensive experience in social policy and advocacy working with families and people with disability. Annemarie can be contacted on (02) 6125 7035 or 0439 930 501 or via annemarie.ashton-wyatt@anu.edu.au

**Who is supervising the research?**

Dr Edith Gray BA (UC) Grad Dip (Population Health) MA (Demography) PhD (ANU) is supervising this research project. Dr Gray can be contacted via (02) 6125 4609 or edith.gray@anu.edu.au. Additional supervision is provided by Professor Bryan Rodgers BA (Hons) MA (Oxford) MSc (London) PhD (Bristol) and Associate Professor Bruce Smyth BA PhD is an advisor on this project.

**What is the School of Demography?**

The School of Demography (formerly the Australian Demographic Research Institute) is Australia’s leading research and training institution for demography and social research, recognized nationally and internationally for its work. It is located at the Australian National University in Canberra.

**What about ethics?**

This research project has been approved by the Human Ethics Research Committee at the Australian National University. The protocol number is 2011/662. If you would like more information please contact the Human Ethics Officer, Research Office via (02) 6125 7945 or human.ethics.officer@anu.edu.au for more information.

**What happens after the interview?**

The researcher will contact all participants by email to inform them when the thesis is available at ANU Library and also provide links to any articles or other publications resulting from this research project.