

Evaluation of the Demonstration Support Network Program

Evaluation Plan

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1 Introduction

The Social Policy Research Centre (SPRC) has been commissioned by the NSW Department of Ageing, Disability and Home Care (DADHC) to evaluate the Demonstration Support Networks Program.

The Support Networks Program is designed to provide support networks for children and young people with a disability, their parents and siblings. DADHC has funded seven demonstration projects to develop, test and implement flexible and innovative practices that address the needs of children and young people with a disability and their families. These demonstration projects will be established over a three year period (2008-11) across metropolitan, regional and rural settings of NSW and will consist of the following:

- Two support networks with a focus on autism spectrum disorders: one for children and young people (between 8 - 18 years of age) with an autism spectrum disorder (peers); and one for parents of children and young people (up to 18 years of age) with an autism spectrum disorder.
- One support network that addresses the needs of peers and siblings (between 8 - 18 years of age) and parents of children and young people with a disability in a rural area.
- One support network for children and young people aged between 8 and 18 years who have a sibling with a disability.
- One support network for children and young people with a disability, aged between 8 and 18 years.
- One support network for children and young people with a disability, and/or siblings of children and young people with a disability, from culturally and linguistically diverse (CALD) backgrounds.
- One support network for Aboriginal families, children and young people with a disability.

There are several anticipated benefits of the Program, and the evaluation will ascertain the extent to which these benefits are achieved, and the implications for improving policy and practice. A review of international and national practice in this area found support networks benefit children and young people with a disability and their families in specific ways. Peer support networks enable young people with a disability to reduce social isolation and to develop the social skills required to establish and maintain friendships. Parents benefit from speaking with other parents in similar situations and have found other parents speak with a kind of authenticity and authority that is not available from others. Siblings need to be supported to share their feelings and experiences with others who have a brother or sister with a disability.

The purpose of the evaluation is to:

- determine how effectively the Demonstration Support Network Program is delivering the intended outcomes
- identify the key features of effective support networks and the extent to which each of these features contributes to the effectiveness of the network in relation to the specified target groups for this Program;

- identify how the outcomes for families, peers and siblings can be sustained and those features that will enable the support networks to have the capacity to operate beyond the life of the demonstration; and
- identify improvements to the current demonstration support network model which would inform future service system development.

The evaluation will be conducted between September 2009 and December 2010. Data will be collected from project clients, staff, managers and other stakeholders (for example, services with whom the projects collaborate). Sources of data are:

- Administrative/project data: project activities and documentation including performance measures. Deidentified data will be provided to the evaluators from the projects and DADHC.
- Key stakeholder consultation: face-to-face, in person and focus group consultation with key stakeholders
- Interviews, focus groups and surveys: children and young people, their siblings, parents and other family members; project staff and managers; and community and agency stakeholders.

In person interviews and/or focus groups will be conducted with project staff and managers at the project sites. In person interviews and/or focus groups will be conducted with project clients at the project sites or mutually convenient public locations such as a restaurant or park.

Project staff and other service providers will be invited to participate in an interview via letter. Project clients (children and young people, their parents, siblings and peers) will be approached at arm's length via flyers on notice boards or other locations in the project sites. We will also project staff to refer families to the study by providing families with contact details for the researchers.

Draft discussion guides for focus groups and interviews will be refined during piloting. Topics to be discussed will include effective and ineffective program elements; perceived changes and benefits (e.g. better family relationships, improved self-esteem); and recommendations for change. Project managers will, in addition, be asked about recruiting and maintaining clients, and program sustainability.

During this phase of the research we will consult with project staff and the Evaluation Working Group to assess the quality and availability of deidentified administrative data that can be used in the evaluation. If necessary, survey instruments will be developed to collect outcomes data from project client. It is not possible to develop these survey instruments before analysis of existing data sources.

2 Methodology

This section describes the proposed methodology of the outcomes and process components of the evaluation. The focus of the evaluation is the Demonstration Support Network Program. Therefore, data collected from each of the seven projects will be used to identify key features of effective networks and possible improvements to the model for different target groups, population groups and geographic areas.

Data will be collected from stakeholders for each of the seven projects. Qualitative and quantitative data instruments will be developed, in consultation with DADHC, to collect *outcomes* and *process* data. Outputs, from project and other administrative data sources (e.g. number and type of participants; activities conducted) will be analysed to present a comprehensive account of the program as part of the evaluation.

Data sources

Identification of data sources and instruments will be finalised in Phase 1 of the research but will include at least the following.

- Administrative/project data: project activities and documentation including performance measures
- Key stakeholder consultation: face-to-face, in person and focus group consultation with key stakeholders.
- Interviews, focus groups and surveys: children and young people, their siblings, parents and other family members; project staff and managers; and community and agency stakeholders.

We will seek the assistance of the project manager and the Evaluation Working Group in identifying and recruiting participants. SPRC is experienced in a range of recruitment methods, and in ensuring that data is collected under conditions of safety and respect.

Data collection and instruments

We will use qualitative and quantitative instruments in both the process and outcomes components of the evaluation. This will allow comparisons to be made between different projects; and will also ensure that the views and priorities of the program participants are central to the evaluation.

Due to time and resource constraints, a pre-test/post-test design is impracticable. Therefore, we will pay particular attention to the collection of retrospective data, in order to ensure that stakeholders can describe changes over time as a result of their participation in the program. We will also investigate, in consultation with the Evaluation Working Group, options for collecting data from comparison groups of children with disability and their families who are not participants in the Demonstration Support Network Program: for example, clients of program providers in other areas, or families on program waiting lists.

Outcomes data may include:

- Children and young people: increased confidence and social interactions; improvements in family relationships

- Family members: increased confidence and improved social interactions; improved access to informal and formal support; improvements in family relationships
- Project staff: observed changes to children and young people's confidence and social interactions; observed changes to family relationships and interactions; improvements in service co-ordination and service delivery.
- Community and agency stakeholders: observed changes to children and young people's confidence and social interactions; observed changes to family relationships and interactions; increased social and economic participation by children and young people, their siblings and parents.

Process data may include:

- Children and young people, family members: features and characteristics of the group that are most helpful; recommendations for change.
- Project staff: barriers and facilitators to effective delivery of the network program; critical success factors; lessons learnt and recommendations for change.
- Project managers: barriers and facilitators to effective planning and management of the network program; critical success factors; lessons learnt and recommendations for change.

Data will be collected via face-to-face interviews and self-complete surveys. Qualitative measures will be collected from each of the seven projects and analysed individually, to capture project-specific information, and comparatively, to capture information across the Program as a whole.

Data collection instruments will include at least the following:

- Project-specific survey instruments (online and/or mail)
- In-person semi-structured interview schedules

Draft interview schedules were submitted for ethics approval in September 2009. Survey instruments will be designed after data scoping from each of the projects.

Other instruments, which may be developed as appropriate, include:

- Focus group topic guides
- Standardised survey instruments
- Interviewer-administered surveys

We will work in consultation with the Evaluation Working Group to develop draft instruments, which will be piloted and refined in Phase 2 of the research. Instruments will be designed to capture the specific activities and outcomes of individual projects and the Program as a whole.

Fieldwork will be completed in two phases. Fieldwork for the first five projects will take place between January and June 2010. Fieldwork for the final two projects will take place between July and August 2010. A presents a summary of the projects and data collection.

Table 2.1: Preliminary evaluation questions and sources

	Evaluation component	Possible data sources
1. To what extent has the <i>Demonstration Support Network Program</i> been effective in achieving the intended Program outcomes for children and young people with a disability, their parent and siblings, and specifically, for Aboriginal and CALD communities and for children and young people with autism and their families?	Outcome	Project/administrative data Project staff and manager interviews Children and young people interviews Family survey Project staff and manager interviews External stakeholder interviews
To what extent is the planning and delivery of support funded under the Program in line with the Program principles and the goals of the three types of networks (parent, peer, and sibling)?	Process	Project/administrative data Project staff and manager interviews
To what extent have the intended outcomes for children and young people with a disability, their parents and siblings been achieved? What, if any, were the unintended outcomes?	Outcome	Family survey Project staff and manager interviews External stakeholder interviews
What factors helped and hindered in the achievement of the outcomes?	Process	Children and young people interviews Family interviews Project staff and manager interviews
How many children and young people with a disability, their parents and siblings participated in the support networks and what is the range and average length of time for each group to be engaged?	Process	Project/administrative data
2. To what extent is the planning and delivery of support funded under the Program in line with the Program principles and the goals of the three types of networks (parent, peer, and sibling)?	Process	Project/administrative data Project staff and manager interviews
How effective were the processes used by network projects to raise awareness of the role and benefits of the networks for families?	Outcome, Process	Family interviews Family survey Project staff and manager interviews External stakeholder interviews
What factors contribute to the effective participation in support network projects of families, particularly Aboriginal families and families from a culturally and linguistically diverse background and children and young people with autism and their families?	Process	Family interviews Project staff and manager interviews External stakeholder interviews
What barriers, if any, prevent the participation of these families?	Process	Family interviews Project staff and manager interviews External stakeholder interviews

	Evaluation component	Possible data sources
How might these barriers be addressed?	Process	Family interviews Project staff and manager interviews External stakeholder interviews
How effectively do the networks meet the needs of families in metropolitan, rural and regional areas?	Outcome	Family interviews Project staff and manager interviews External stakeholder interviews
3. What factors will enable the outcomes for children and young people with a disability, their families and siblings to be sustained and the support networks to be maintained beyond the life of the demonstration program?	Outcome, Process	Family interviews Project staff and manager interviews External stakeholder interviews
How have the demonstration projects contributed to the capacity of children and young people with a disability, their family and siblings to establish and maintain informal supports?	Outcome	Children and young people interviews Family survey Project staff and manager interviews
What measures have been put in place to promote the sustainability of the program's focus and outcomes?	Process	Project staff and manager interviews External stakeholder interviews
What is the nature of co-ordination and inter-sectoral collaboration across the range of services and supports established through the projects?	Process	Project staff and manager interviews External stakeholder interviews
How will this contribute to the sustainability of the projects beyond the life of the demonstration program?	Process	Project staff and manager interviews External stakeholder interviews
What are the strategies that will increase the sustainability of outcomes for the three target groups?	Process	Project staff and manager interviews External stakeholder interviews
4. What improvements could be made to the current demonstration support network model and what else could be provided which would achieve similar outcomes?	Process	Family interviews Project staff and manager interviews External stakeholder interviews
What has been learned about the characteristics of effective networks?	Process	Family interviews Project staff and manager interviews External stakeholder interviews
To what extent does each of these characteristics contribute to the effectiveness of the networks for each target group?	Process	Family interviews Project staff and manager interviews External stakeholder interviews
What do the participants indicate about their experiences that will inform	Process	Children and young people interviews

	Evaluation component	Possible data sources
improvements to the models of operation?		Family interviews External stakeholder interviews
How can the program be improved to better meet the needs of each of the three target groups (parents, peers and siblings)?	Process	Children and young people interviews Family interviews Project staff and manager interviews External stakeholder interviews
How can the program be improved to better meet the needs of Aboriginal families, families from a cultural and linguistically diverse background and families of children with autism?	Process	Children and young people interviews Family interviews Project staff and manager interviews External stakeholder interviews
Are there alternative ways to achieve the same outcomes?	Process	Project staff and manager interviews External stakeholder interviews

3 Management

The evaluation will be led by Professor Ilan Katz, who will be assisted by kylie valentine in research design and project management. Brooke Dinning will be responsible for identification of data sources and instruments and co-ordination of data collection, analysis and reporting. Karen Fisher and Rosemary Kayess will provide expert advice. Marianne Rajkovic and Karla Heese will be responsible for data collection. Brooke, Marianne, Karla and Dr Pooja Sawrikar will analyse the data and write interim and draft reports, under the supervision of Ilan and kylie.

Table 3.1 details the research tasks for each member of the research team.

Table 3.1: Personnel and research tasks

Research task	Principal accountability	Other staff
Client liaison, research design, quality assurance	Ilan Katz	kylie valentine
Document review, evaluation plan, evaluation performance measures	kylie valentine	Brooke Dinning, Marianne Rajkovic, Karla Heese
Expert advice: disability, evaluation methods, instruments	Karen Fisher, Rosemary Kayess	
Ethics	kylie valentine	Brooke Dinning, Marianne Rajkovic
Key stakeholder consultation	Brooke Dinning	Marianne Rajkovic, Karla Heese, kylie valentine
Communication strategy (project stakeholders)	Brooke Dinning	Marianne Rajkovic, Karla Heese
Data sources and instruments, piloting	Brooke Dinning	Marianne Rajkovic, Karla Heese
Data collection	Marianne Rajkovic, Karla Heese	
Data analysis	kylie valentine	Marianne Rajkovic, Karla Heese, Pooja Sawrikar, Ilan Katz
Reporting	kylie valentine	Ilan Katz, Karen Fisher, Brooke Dinning, Pooja Sawrikar, Marianne Rajkovic, Karla Heese, Karen Fisher

Ethics

The primary committee for ethics approval is the UNSW Human Research Ethics Committee (HREC). Approval will be sought from other HRECS where necessary. As gaining ethics approval to involve children and young people, and their families, is likely to be a complex process, we will undertake a two-stage ethics process, to ensure that consultation with key stakeholders can commence in Phase 1 of the research.

Ensuring child protection and participation are central ethical issues in research with young people and children. Researchers working with young people have particular ethical responsibilities. These include duties to provide protection; processes to support informed consent; privacy; confidentiality; mechanisms that address power imbalances; and researcher commitment to reflexivity (Skattebol, 2008). The researchers will support children and young people who are participants of the networks to participate in the evaluation, in accordance with these responsibilities.

The UNSW has a Code of Research Practice by which the SPRC abides. UNSW is committed to the highest standard of integrity in research. All human research activities are governed by the principles outlined in the National Statement on Ethical Conduct in Research Involving Humans (National Health and Medical Research Council et al., 2007). The University's Code of Conduct for the Responsible Practice of Research sets out the obligations on all University researchers, staff and students to be aware of the ethical framework governing research at the University and to comply with institutional and regulatory requirements.

Interviews with children and young people with disability

We will conduct interviews and possibly focus groups with children and young people, their siblings, peers and parents. The target population for three of the projects include children and young people with a disability, including Autism Spectrum Disorder. It is therefore possible that children or young people with autism may volunteer to participate in interviews or focus groups. Autism is a developmental disability that sometimes involves intellectual impairment. Other projects are not focused on specific disabilities, and it is possible that children or young people with intellectual disabilities may volunteer to participate in interviews or focus groups.

All interviews with children and young people will be conducted with a parent or adult support person in attendance. The choice of focus groups or interviews will be made by the participants. Focus group discussions may be preferred as the projects themselves focus on peer support and group activities. Children and young people with disability will be interviewed only if they have the capacity to read and sign consent forms, and are supported by an adult or peer to participate. We will consult with parents and project staff prior to interview/focus group to determine if participation in the evaluation is likely to cause distress, and ensure there are additional opportunities to opt out of the discussion or terminate the interview if so.

Timelines and deliverables

The research will be conducted in four phases, as shown in Table 3.2.

Table 3.2: Project timelines

	2009			2010					
	Jul-Aug	Sep-Oct	Nov-Dec	Jan-Feb	Mar-Apr	May-Jun	Jul-Aug	Sep-Oct	Nov-Dec
Phase 1: Finalise research design									
Document review									
Evaluation performance measures , communication strategy									
Ethics approval from UNSW HREC and other HRECS as necessary									
Key stakeholder consultation									
Draft and final evaluation methodology and project plan, inc. draft outline of the interim and final reports									
Project status report									
Phase 2: Data sources and instruments									
Identify data sources.									
Develop evaluation tools									
Draft and final instruments and measures (project manager approval)									
Pilot and refine instruments									
Project status report									
Phase 3: data collection and analysis									
Data collection and analysis: 2008 networks.									
Report: draft data analysis (first round)									
Data collection and analysis: 2009 networks.									
Report: draft data analysis (second round)									
Report: draft analysis (both rounds)									
Project status report									
Phase 4 reporting									
Draft final report									
Final report									

Table 3.3 summarises the project deliverables

Table 3.3: Deliverables

	Description	Submission date
Phase 1: Finalise research design		
Draft evaluation framework	10-15 page report, including methodology, timelines, deliverables, draft outline of interim and final report.	15 September , 2009
Evaluation performance measures	Draft and final measures	30 September , 2009
Final evaluation framework	10-15 page report, including methodology, timelines, deliverables, draft outline of interim and final report	15 October, 2009
Project status report	5 page report and meeting with working group	30 September, 2009
Phase 2: Data sources and instruments		
Draft instruments and measures	Interview schedules, surveys, flyers and project information, information and consent forms. Submitted to project manager for review/approval, in line with institutional ethics requirements	15 December, 2009
Project status report	5 page report	15 December, 2009
Report on pilot to Evaluation Working Group	3-5 page report	31 March, 2010
Project status report	5 page report and meeting with working group	31 March, 2010
Phase 3: data collection and analysis		
First round: interim report	Interim report on evaluation of 2008 (Parent Support: Autism Spectrum Australia; Peer Support: Autism Spectrum Australia; Comprehensive Support Network - Rural: Northcott Disability Services; Peer Support: Youth Connections; Siblings Support: The Junction Works)	11 June, 2010
Project status report.	5 page report	25 June, 2010
Second round interim report	Interim report on evaluation of 2009 networks (Comprehensive Support Network - Aboriginal families: Uniting Care Burnside; Sibling Support Network: CALD)	10 September, 2010
Draft findings and analysis	Draft report on the analysis of findings across the seven projects developed.	24 September, 2010
Project status report.	3-5 page report	24 September, 2010
Phase 4 reporting		
Draft final report	Draft final report, including executive summary, analysis and key findings	November 12, 2010
Final report	Final report, incorporating changes in response to feedback from the working group	December 17, 2010

4 Communication strategy

Communication with DADHC

kylie valentine will be primary contact person at SPRC for DADHC. She will attend meetings with the Evaluation Working Group, with at least one other researcher on the project.

Communication with project managers

Project staff will be contacted by letter in the first instance. Project managers and staff will be informed about the evaluation and invited to participate in the research. Letters will be sent to the 2008 projects in October 2009 and to the 2009 projects in February 2010. This letter will be followed up by phone call to identify sources of administrative and project data that will be available to the evaluators, and any internal evaluation or monitoring activities. Letters will be presented to DADHC for review prior to being sent to the projects.

Communication with evaluation participants

Interview and focus group participants will be given detailed information about the evaluation at time of data collection. Participants will be sent a thank-you note with contact details for more information shortly after data collection. Throughout the course of the evaluation Marianne Rajkovic will be the primary contact person at SPRC for project staff and clients. A short (1 page) plain language report and/or the final report will be sent to all interested participants.

Communication with project staff and clients

Information about the evaluation will be made available in postcard and A4 poster form for each of the project sites, and appended to any survey instruments. This material will be presented to DADHC for review prior to being sent to the projects.

5 Reporting

The project will deliver status reports throughout the research design and data collection phases, two interim reports and a draft final and final report.

Short (approximately 5 pages) status reports will be presented to the Evaluation Working Group, for internal use, on four occasions.

Status reports

30 September, 2009

31 March, 2010

25 June, 2010

24 September, 2010

Two interim reports on the analysis of findings for all seven projects will be presented to the Evaluation Working Group, for internal use. The report on the first five projects will be delivered by 11 June, 2010. The report on the final two projects will be delivered by September 10, 2010.

Interim report 1: First round of data collection: Draft outline

1. Description of projects
2. Method and sample
3. Key themes and challenges

Interim report 2: Second round of data collection: Draft outline

1. Description of projects
2. Method and sample
3. Key themes and challenges

Draft and final report: Draft outline

1. Introduction
2. Summary of findings in relation to the evaluation questions
3. Background
4. Summary of the projects
5. Method and sample
6. Findings
 - Implementation: barriers and facilitators to planning, implementation and management
 - CALD families
 - Aboriginal families
 - Outcomes: parent, peer, sibling, young people with disability

- Critical success factors
- Sustainability

7. Summary, recommendations and conclusion

	Description	Submission date
Phase 1: Finalise research design		
Draft evaluation framework	10-15 page report, including methodology, timelines, deliverables, draft outline of interim and final report.	15 September , 2009
Evaluation performance measures	Draft and final measures	30 September , 2009
Final evaluation framework	10-15 page report, including methodology, timelines, deliverables, draft outline of interim and final report	15 October, 2009
Project status report	5 page report and meeting with working group	30 September, 2009
Phase 2: Data sources and instruments		
Draft instruments and measures	Interview schedules, surveys, flyers and project information, information and consent forms. Submitted to project manager for review/approval, in line with institutional ethics requirements	15 December, 2009
Project status report	5 page report	15 December, 2009
Report on pilot to Evaluation Working Group	3-5 page report	31 March, 2010
Project status report	5 page report and meeting with working group	31 March, 2010
Phase 3: data collection and analysis		
First round: interim report	Interim report on evaluation of 2008 (Parent Support: Autism Spectrum Australia; Peer Support: Autism Spectrum Australia; Comprehensive Support Network - Rural: Northcott Disability Services; Peer Support: Youth Connections; Siblings Support: The Junction Works)	11 June, 2010
Project status report.	5 page report	25 June, 2010
Second round interim report	Interim report on evaluation of 2009 networks (Comprehensive Support Network - Aboriginal families: Uniting Care Burnside; Sibling Support Network: CALD)	10 September, 2010
Draft findings and analysis	Draft report on the analysis of findings across the seven projects developed.	24 September, 2010
Project status report.	3-5 page report	24 September, 2010
Phase 4 reporting		
Draft final report	Draft final report, including executive summary, analysis and key findings	November 12, 2010
Final report	Final report, incorporating changes in response to feedback from the working group	December 17, 2010

6 Evaluation performance measures

Phase 1: Finalise research design
Key documents and relevant issues integrated into the agreed evaluation methodology and project plan
Key stakeholder views incorporated into evaluation plan and methodology
Structure of interim and final reports will provide clear and concise understandings of the findings and recommendation and address the evaluation questions, as reflected in the evaluation plan
Evaluation plan and methodology reflects Project objectives and program logic
Evaluation plan and methodology is clear, concise and fit for purpose
Phase 2: Data sources and instruments
Key data sources identified and described
Draft and final instruments presented for approval in a timely and sufficiently consultative manner
Evaluation instruments and material are accessible and appropriate
Instruments piloted and refined to collect data to answer the evaluation questions
Phase 3: data collection and analysis
Data collection and analysis conducted as agreed for the five network projects established in June 2008 and the two networks established in 2009
Interim report provides sufficient detail to be able to determine that the evaluation is proceeding efficiently and will achieve the required objectives
Phase 4 reporting
Draft Final Report addresses the key evaluation questions and the overall project objectives
Final Report reflects the outcomes of discussion and recommendations from the Evaluation Working Group

References

National Health and Medical Research Council, Australian Research Council and Australian Vice-Chancellors Committee (2007), *National Statement on Ethical Conduct in Human Research*, Commonwealth of Australia, Canberra.

Skattebol, J. (2008), *Making a difference: Methodology discussion paper*, Social Policy Research Centre, Sydney.

Appendix A: Summary of projects and data collection

Target Group	Program	Location	Outputs	Start Date	Data collection
Parents of children or young people with an Autism Spectrum Disorder, with a focus on CALD Communities	Parent Support: Autism Spectrum Australia (ASPECT)	Forestville - Sydney	60 families annually	1 April 2008	Jan-Jun 2010
Children or young people (8 – 18 years) with an Autism Spectrum Disorder	Peer Support: Autism Spectrum Australia (ASPECT)	Forestville - Sydney	110 peers annually	1 April 2008	Jan-Jun 2010
3. Peers, siblings and parents of children and young people with a disability, including an autism spectrum disorder and with an Aboriginal focus	Comprehensive Support Network - Rural: Northcott Disability Services	Parramatta (Head office)	40 families annually	1 April 2008	Jan-Jun 2010
Children and young people 8 – 18 years with a disability	Peer Support: Youth Connections	Gosford NSW	240 young people annually	1 April 2008	Jan-Jun 2010
Siblings or children and young people with a disability from CALD backgrounds	Sibling Support Network: CALD MDAA	Sydney Metro North and Metro South area – based Parramatta City LGA	30 young people annually	April 2009	Jul-Aug 2010
Young people aged between 8 and 18 years who have a sibling with a disability, those from ATSI and CALD communities, and who have minimal support networks in place.	Siblings Support: The Junction Works	South West Sydney	12-25 clients annually	1 April 2008	Jan-Jun 2010
Aboriginal families, children and young people 8 – 18 years.	Comprehensive Support Network - Aboriginal families: Uniting Church in Australia Property Trust (NSW)	Dubbo		1 Jan 2009	Jul-Aug 2010