

Lightening the evaluation footprint in a sensitive area: identification and management of intrusiveness in the area of sexual abuse research

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Abstract

This paper introduces the concept of ~~a programme and~~ an evaluation “footprint” ~~and a modelling tool for representing the “footprint”~~. Both were developed in 2007, in the context of ~~planning and implementing an evaluation of a pilot programme to improve parenting practices of parents of sexually abused children.~~

The term “footprint” is ~~used as a metaphorical analogy with the word as it is used in ecology.~~ The “footprint” of a service is defined ~~here~~ as everything the consumer receives, is required to initiate, fill in and comply with in order to obtain and receive the service. In the case of this pilot, the service includes requests to take part in evaluation research, so the consumer’s experience of the programme and the evaluation are not able to be separated.

~~The authors believe that in order to protect service users adequately, it is necessary for evaluation to consider the combined impact of all aspects of a Programme on the recipients.~~

~~The relevant dimensions for this programme and evaluation, making up the total impact, were:~~

- ~~• ACC’s [the funder’s] generic administrative requirements,~~
- ~~• ACC’s requirements specific to this Programme,~~
- ~~• The delivery processes of the parenting sessions and~~
- ~~• Evaluation research requirements.~~

~~The “footprint” metaphor was chosen to describe this cumulative impact perspective. In research or programme administration, it is clearly possible to achieve a certain goal without finding out about, or being accountable for the range of impacts accrued in reaching the goal.~~

~~During 2006 ACC began a research-based pilot programme to provide support for the parents of sexually abused children through the provision of parenting support sessions focused on parental stress management and parenting practices.~~

In line with all New Zealand Government initiatives, continued funding for the ~~parenting~~ pilot required ~~s~~ demonstrated effectiveness. ~~At least five sets of ethics guidelines aimed at protecting users of the service applied to this Pilot and its evaluation. However, the evaluator’s role gave them the responsibility for making decisions about the degree of intrusiveness which would be considered acceptable for the effectivenesseffectiveness of the research.~~

~~Parents of children who have been sexually abused are a particularly difficult population to recruit into services because of the nature of sexual abuse and its effects on families.~~

The evaluators were faced with the need to balance the power of potential research into effectiveness, with intrusiveness into the lives of service users. ~~As will be demonstrated in the body of the paper, t~~The evaluators had a unique perspective since they “see” ~~all a programme and administrative #~~aspects of the Pilot ~~service~~ from beginning to conclusion, unlike the researchers or service providers ~~who tended to be familiar only with their component.~~

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~~-At least five sets of ethics guidelines aimed at protecting users of the service applied to this Pilot and its evaluation. However, the evaluator's role gave them the responsibility for making decisions about an acceptable degree of intrusiveness.~~

~~Aside from programme effectiveness, other drivers for the evaluation were t~~The need for current and future consumers of the service to be assured that the programme and the evaluation were safe for them to be involved with and would not be unreasonably intrusive into a potentially sensitive area ~~were the two drivers for the evaluation.~~ Development of the concept of the "footprint", and a method for describing a "footprint" to analyse the degree of intrusiveness of a research proposal were key components in reaching the chosen balance between the ~~three~~ drivers.

The paper briefly discusses the application of ethical frameworks in the design of a research based pilot and its evaluation and notes the lack of processes for consultation with user groups in this situation.

The "footprint" analysis does not replace consumer consultation. However in the absence of consumer consultation options, it allows the evaluators to consider the programme and its evaluation from the point of view of possible unintended impacts on the population the programme is intended to benefit.

Background

The 2006/2007 New Zealand (NZ) Government Budget allocated additional money to the Accident Compensation Corporation (ACC) to fund a pilot programme that provides parenting support for families of children with sensitive claims.

The ACC is a no fault accident insurance scheme. It includes provision for claims for mental injury as a result of sexual abuse. These are referred to as "sensitive claims", and are case managed by a specialised and administratively separated unit within ACC.

The initiative ~~aims to provide~~s parenting support sessions to the non-offending parents or caregivers responsible for a child with a sensitive claim. The parenting support sessions ~~aim to~~ provide coping strategies to care givers, who in turn can better understand the child, and better manage his or her behaviour. The pilot assumes that providing a more supportive environment will assist the child who has been sexually abused in rehabilitation and recovery.

~~The pilot was supported by Government on the basis that it would extend ACC's ability to provide parenting support to claimant's families, within strict guidelines, in order to facilitate rehabilitation outcomes for children with sensitive claims.~~

~~Existing Previous~~ parenting support provisions for children ~~did~~ not permit counsellors to have paid sessions with the parents or caregivers of a child claimant, unless the child was present for the majority of the session. The pilot recognised the rehabilitative significance of that issues of parenting and parental attitudes to the child, and/or the abuse could be important to discuss but detrimental for a child to hear.

The evaluators recognised from the start that evaluation of this service would have particular challenges. It was anticipated that

- parents of children who have been sexually abused would be a difficult population to recruit into services because of the nature of sexual abuse and its effects on families
- parenting assistance might be less acceptable to parents than counselling services for their children.
- recruitment of parents into the evaluation would be harder again than recruitment into the service because the evaluation offered no direct benefit to the parent.

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The parenting support service is provided by counsellors who are registered with ACC to provide contracted sexual abuse counselling, and who have recent experience in counselling sexually abused children for ACC.

~~As a condition of registration with ACC, ACC counsellors already~~ work under various professional Codes of Ethics, and receive clinical supervision. Both ethical guidelines and clinical supervision provide guidance to counsellors about circumstances requiring them to refer a client to a different service, such as Mental Health in the case of suicide risk, or notification to the Department of Children, Young People and their Families (CYF) in the case of imminent risk to a child. ~~Therefore, no additional provisions for clinical risk management were required for the Pilot.~~

The paper describes the stepwise process of developing the ethical and practical framework of the evaluation of the Parenting Support Pilot. ~~As planning developed,~~ The issue of research power compared with intrusiveness ~~was present from the beginning, but~~ assumed progressively more significance ~~as planning developed.~~

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The Parenting Support Programme

The programme includes:

- One assessment session and 5 sessions of parenting support, parallel to and/or parts of sessions or whole sessions jointly with the child as decided by counsellor and parent
- ~~Recipients of parenting support are non-offending parents or care-givers*~~
- The focus of the parenting support is on:
 - Training in coping skills
 - child management
 - ~~education about abuse, and~~
 - ~~communication with the child about abuse related issues.~~
- ~~There is a specific requirement to include goals in more than one setting e.g. home, school and wider family gatherings in order to apply and practice parenting strategies discussed in parenting support.~~
- The parenting support is not personal counselling or therapy for the parent/s /caregivers. Parents are likely to describe personal or relationship needs, including sexual abuse history. Information about appropriate service options is provided by the counsellor and referrals if appropriate.

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* Defined as parent or parents or caregivers with care of the claimant against whom the claimant has made no allegations of sexual abuse.

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Programme and Evaluation Design Challenges – aiming for a light footprint

The objectives of the evaluation were is-to:

- Indicate from the counsellor and recipient viewpoint whether the initiative has been effective in delivering its stated outcomes
- Provide feedback on the efficiency of the process/design of the initiative
- Provide feedback to ACC about whether this pilot initiative should continue into the future
- Provide information from the providers and recipients about any obstacles to the effectiveness of the initiative

Ethical Challenges

-Is everyone OK?

1. The Planning Stage

During the early conceptual thinking around the design of the pilot it quickly became apparent that there were a number of ethical issues that would require resolution for the pilot to move forward. Initial guidance was sought from the ACC Ethics Committee at an early stage was sought and the issues were discussed with the Committee over a period of months. Each subsequent Continuing discussion allowed the continuing refinement of issues and their resolution of issues. The issues identified at an early stage of programme development, and their initial resolution are outlined in the following table

Figure 1: Ethical Challenges Visible at the Programme and Evaluation Planning Stage

Issue	Evaluator Action	ACC Ethics Committee Role	Actions by Others
1. Does ACC Ethics approval process apply to services to parents, who are not claimants?	Consult ACC Ethics Committee re jurisdiction	Jurisdiction confirmed	
2. Funding provision required a randomised control group design. Literature review and advocacy groups suggested parenting support would be effective.	Recommended change to within subject control design	Supported view that a randomised control group design was not appropriate due to the possibility of harm due to if service being withheld.	Pilot Programme manager obtained approval from funder for change to research design
3. Pre and Post treatment Data on parenting were required for; entitlement, clinical goal setting and effectiveness evaluation. ACC requires a needs assessment to establish entitlement to all services; the targeted programme will require clinical assessment, and the	A "before and after treatment" assessment of parenting issues and parental confidence was developed to provide data for the three purposes from one contact <u>between counsellor and parent</u>	All programme and research documents and procedures reviewed	

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evaluation will require impact data- What is the least intrusive way to satisfy all these requirements?			
4.Lack of access for families to culturally appropriate counsellors registered with ACC	Include questions on cultural appropriateness of the service in all interviews with parents	Discussed issue but accepted the reality of the situation that there was are not sufficient culturally appropriate counsellors who met criteria in all geographic areas.	
5.Contacting parents for the evaluation would require their informed consent	Submit Information and Consent process to ACC Ethics committee for approval Offer multiple opportunities for parents to “opt out” of the evaluation.	Provided guidance as to appropriate process and wording. Approved final process and documents	
6.Counsellors require the opportunity to make an informed choice to contract into the pilot, on the basis that participation requires compliance with programme design and participation in evaluation	Information regarding evaluation requirements and programme parameters provided to counsellors prior to contracting	ACC Ethics Committee provided guidance as to key issues that needed to be placed in front of counsellors.	
7. Assessment information collected for parenting support potentially available to the child in future years	Request legal clarification of future information access rights	Provided guidance in the area of future information access rights and discussed process.	Pilot Programme manager obtained legal opinion and incorporated this in Information for Parents.
8. Evaluation research would require suitably skilled people to interact with parents of sexually abused children	Appropriate skills of researchers specified in the evaluation criteria for the RFP		
9. Time scale of evaluation would require confidential programme document storage at the programme operation site	File management procedure agreed with operational staff	Ensured that programme managers had put an appropriate document storage system in place that ensured confidentiality of information.	

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Placing aAll these issues ~~were provided informally and discussed with, before~~ the ACC Ethics Committee for information and guidance as appropriate, prior to a formal application for approval. This ensured that the Committee input could be incorporated into the programme and evaluation design before final submission.

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Dealing with Ethical Challenges as the Programme and Evaluation Evolved
2. The RFP Stage

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While the programme is supported by ACC as part of its “business as usual” the evaluation ~~[apart from the Formative Evaluation] is being has been contracted to externally managed by the University of Auckland, a University research team.~~ ACC has a formal procurement process that required the development of a Request for Proposal (RFP) and the formal assessment of the resulting Proposals. This process revealed new ethical issues, that had not been identified in the programme design stage. These are summarised in the following table.

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Figure 2: Ethical Challenges Visible at the RFP Stage

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Issue	Evaluator Action
1. Some research proposals added paper and computer tests for parents to planned evaluation measures which would increase the power of the research but would have added to the level of intrusion for these consumers	Examination of research “footprint” of each proposal
2. Some research proposals included sending psychometric tests to parents at home concerning their own and child behaviour	<p>An assessment of each proposal was made for possible risk to family members from papers arriving or being filled in at home</p> <p>Guidance to researchers that no “sensitive” material should be sent <u>to the parent’s home</u> on paper or <u>requests made that parents fill in computer based assessment tools, filled in at home</u></p> <p>An assessment of each proposal was made for possible risk to family members from papers arriving or being filled in at home</p>
3. Some researchers showed no indication of understanding the sensitivity of parents in any interview situation regarding sexual abuse	Selection process removed these proposals

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The concept of the research “footprint” emerged from this process of reviewing the potential research proposals. ~~What emerged was what the evaluators described as the “research footprint”.~~ Given the sensitive nature of this research, and the potential that parents could be harmed just through their participation, it was felt that the research needed to be as un-intrusive as possible. The evaluators assessed each proposal from the point of view of understanding the amount and nature of the parent involvement. Some proposals were eliminated due to the magnitude of possible respondent burden and others because they did not show understanding of the ethical sensitivities. Two examples of this “footprint” analysis follow:

Figure 3. A Comparison of Two Research Footprints
Illustrated: Programme and Evaluation sequence from the point of view of what is asked of parents

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Intrusiveness	Programme Sequence	ACC Requirements	Programme Requirement	Example 1 - Research	Example 2 - Research

Level		ment		Requirement	Requirement
Low	Step 1	Lodge claim lodgement form (ACC 45)			
Moderate	Step 2	Initial indication of interest by parent (ACC 2476 Response and Consent Form)			
Highest (content & length)	Step 3	ACC 2475- Parenting Needs Assessment Form (ACC 2475)	Sets goals for programme	Qualitative Data on needs and treatment goals	Qualitative Data on needs and treatment goals
High (content)	Step 4 During session One			Briefing by counsellor about 2 self report questionnaires	
High (content and at home)	Step 5			Fill in 2 questionnaires	
High (taped)	Step 6 after session one			Taped Phone interview	
High (content)	Step 7		Sessions 2,3,4		
High (content)	Step 8	Parent review of progress including (ACC 2477 Achievement Summary)	Session 5	Qualitative Data on goal progress	Qualitative Data on goal progress
High (taped)	Step 9			Taped Phone interview	
High (content and at home)	Step 10 12 months from start of sessions			Fill in 2 questionnaires at home	
High (content)	Step 11 36 months from start of			Brief phone survey re impact of programme	30 min Phone interview

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	programme				
High (content)	Step 12			Receive feedback on research results	Receive feedback on research results

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3. The Formative Evaluation Stage

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The ACC evaluation team undertook a formative evaluation of the programme during its first six months of operation. ~~During this process t~~The sensitivities of parents became very clear. Just the act of providing feedback to the evaluators concerning the operation of the programme brought intense emotion, with some parents in tears within the first few minutes. This was difficult for the evaluators as the risk of possible harm to the parents had to be balanced against the need to ensure that the programme was meeting the needs of those who were participating.

Decisions around recruitment of parents into the programme were also sensitive. If parents were recruited too early in the process there was a risk that the child's claim could be declined and the offer of parental support would be withdrawn. If recruitment was left until after the claim had been accepted (which can take several months) then there is a risk that valuable time for parenting support could be lost, leading to a possible risk in the rehabilitation of the child. ~~This issue emerged in the formative evaluation and required careful consideration by the evaluators of the "least harm" option.~~

Figure 43: Ethical Challenges Visible at the Formative Evaluation Stage

Issue	Evaluator Action
1. Evaluation contact with parents showed high emotional sensitivity	Offered interview termination Alerted process and impact evaluators of degree of sensitivity of parents
2. The Sensitive Claims Unit has secure storage for information, as a matter of course. The need for storage of sensitive personal information by the in-house ACC Evaluation staff, during the formative evaluation, had not been foreseen	Personal information kept locked away Personal information shredded at the conclusion of the formative evaluation
3. The timing of particular process elements, such as recruitment could lead to harm for both the parent or the child	Recommended programme elements that would harm participants the least.

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The evaluators realised that at times people are going to face risk of harm no matter what the programme designers and evaluators do to minimise the harm. In the case of this evaluation parents relived to some extent the traumatic experience of the child's abuse just through being interviewed by the researchers. This was on top of the experience they had just had ~~offer~~ the counselling sessions and the memories these had brought to the surface.

Resolving the Ethical Challenges- How useful were the various Frameworks?

There are a number of ethical frameworks that have an application with this programme and its evaluation. These are:

1. The ACC Ethical Guidelines
2. ACC Code of Claimants Rights

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3. The Australasian Evaluation Society – Guidelines for the Ethical Conduct of Evaluations
4. The New Zealand Association of Counsellors – Code of Ethics
5. Code of Ethics for Psychologists Working in Aotearoa/New Zealand, 2002
6. The New Zealand Ministry of Health – Regional Ethics Committee
7. The University of Auckland Ethics Committee

~~Issues are described in these guidelines at an overview level. When considering specific practical solutions to ethical questions it was found that the various ethical guidelines were not particularly helpful, as the perspective of the service consumer is not strongly present in some of the ethical frameworks.~~

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For example – the AES Guidelines for the Ethical Conduct of Evaluations calls for evaluators to look for potential risks or harms:

“The decision to undertake an evaluation or specific procedures within an evaluation should be carefully considered in the light of potential risks or harms to the clients, target groups or staff of the programme. As far as possible, these issues should be anticipated and discussed during the initial negotiation of the evaluation.”

~~But~~ that is the only time that consideration of the risk of harm to consumers is mentioned. The evaluators in this study wondered to what extent AES had involved the non professional community in the construction of its ethical guidelines.

However the New Zealand Association of Counsellors Code of Ethics ~~is~~ more explicit in ~~their~~ its consideration of harm to consumers. The Code calls for Counsellors to act with care and respect for individual and cultural differences and to avoid doing harm in their professional work. The Code specifically calls for Counsellors to take all reasonable steps to protect clients from harm, to take account of their own cultural identity and biases and to work towards bi-cultural competence. The Code also covers areas such as informed consent and respectful language.

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Discussion- The Experience to Date –

▲ Stakes are always high ~~for family members~~ in sexual abuse services–. This applies to family members, agencies and service providers. Secrets are revealed, information is shared in new ways, and relationships change.

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~~The potential therapeutic benefits for abused children, of P~~parents having new understandings of the effects of sexual abuse on their children, and how to support their children best, may lead to benefits for abused children. ~~This is are~~ the territory of the Parenting Support Programme.

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The extreme sensitivity of delivering support to these parents, given the complexity of the situations they were facing, was shown at each stage of the evaluation. planning. For example, the formative evaluation data of the first small group of parent assessment information showed that 2 of the 10 parents in this group were parents of a child or young person who had sexually abused a sibling. One parent interviewed in the formative evaluation ~~Some parents in this first group had walked in-witnessed on her~~ their child's abuse while it was occurring. Because this formative evaluation was early in the programme, and the programme recruited parents of children with new claims, the parent's discovery of the abuse was typically less than six months before taking part in the evaluation interview.

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This meant that the formative evaluation took place at a time when the sexual abuse events were fresh in parents memories, so feelings were raw ~~One parent interviewed in the formative evaluation had this experience. She had completed the programme, but the initial event that she witnessed was less than six months earlier.~~

Media controversy and disagreement between professional groups are also common for sexual abuse services. These conflicts can be distressing and confusing for service users, and give the field a reputation of being risky for professionals.

There is an ongoing issue for ACC in recruiting and retaining enough accredited counsellors to provide sexual abuse counselling.

The evaluation of the Pparenting Support Pilot has required the evaluators to take into account the approach and ethical perspectives of each of the professional/ discipline groups involved in funding, administering, delivering and researching the Pilot. The mix of experience and training of the evaluators contributed positively to this aspect of the evaluation.

As has been described earlier, each group has its own ethical framework which guides its members as to how to protect service users and themselves as they carry out their particular tasks. Each group is in some way accountable within its own framework for the way in which its tasks are carried out.

~~The evaluators came to believe that in order to protect service users adequately, it was necessary to consider the combined impact of all aspects of the Programme [ACC's generic administrative requirements, ACC requirements specific to this Programme, the delivery of parenting sessions and research requirements].~~

~~The evaluators chose the "footprint" metaphor to describe this cumulative impact perspective. In research or programme administration, as in the international food trade, it is clearly possible to achieve a certain goal without finding out about, or being accountable for the range of environmental impacts accrued in reaching the goal.~~

The process and outcome evaluation of the Parenting Support Pilot is about to begin. Within the original evaluation aims, the evaluators have modified the initial evaluation plan at each stage as issues emerged or changed in relative prominence. The breadth of perspectives included in the evaluation has facilitated this process. Being close to the programme

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administrators, and linked to service providers has placed the evaluators in a good position to identify and consider the ethical issues as they emerged.

The evaluators intend to continue to develop and refine the “footprint” as a tool for analysis of programmes and evaluation research, in other projects within ACC’s evaluation programme.

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References

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The New Zealand Association of Counsellors – Code of Ethics

Code of Ethics for Psychologists Working in Aotearoa/New Zealand, 2002

All the ethics frameworks

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