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Title	Longitudinal study of children who leave care
Author(s)	Devaney, Carmel
Publication Date	2013
Publication Information	Devaney, C (2013) Longitudinal study of children who leave care. Department of Children and Youth Affairs, .
Publisher	Department of Children and Youth Affairs
Link to publisher's version	http://www.childandfamilyresearch.ie/sites/www.childandfamilyresearch.ie/files/longitudinal_study_of_children_who_leave_care.pdf
Item record	http://hdl.handle.net/10379/4582

Downloaded 2019-05-24T21:24:33Z

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APPENDIX 4

LONGITUDINAL STUDY OF CHILDREN WHO LEAVE CARE

SCOPING STUDY UNDERTAKEN
AS PART OF THE IMPLEMENTATION OF THE
NATIONAL STRATEGY FOR RESEARCH AND
DATA ON CHILDREN'S LIVES, 2011-2016

This literature review was commissioned by
HSE Children and Family Services
and carried out by **Dr. Carmel Devaney**,
UNESCO Child and Family Research Centre,
National University of Ireland, Galway

APRIL 2013

DEPARTMENT OF CHILDREN AND YOUTH AFFAIRS

INTRODUCTION

This brief discussion paper considers the research design for longitudinal studies generally and a specific 10-year follow-up study on children who leave care in Ireland. This initial discussion paper is developed in advance of discussion on the detail of this specific study with the commissioners and therefore does not refer to the detailed expectations for the study. Rather, the paper considers general issues in designing a longitudinal study. The first section reviews the research literature on longitudinal studies, while the second section proposes a tentative design for this specific study based on the information available at this point.

RESEARCH LITERATURE ON LONGITUDINAL STUDIES

Longitudinal studies involve repeated measures of the same people over time, with extended series of data collections (Robson, 2011). Such studies can measure prevalence of particular factors at several points in time and can provide information on causation, prognosis, stability and change (Rutter, 1995). They allow for factors to be examined for stability and continuity, and can identify developments over time (Sanson *et al*, 2002).

There are two types of longitudinal study: a *prospective* longitudinal study, which follows samples into the future, and a *retrospective* longitudinal study, which covers data relating to the past. In retrospective designs, the research collects data at a point in time about the situation at some earlier point in time as well as the current situation (Robson, 2011).

There are advantages to prospective studies. They avoid problems with recall bias that occur in retrospective studies and there is less need to rely on administrative records. Prospective studies are useful for exploring developmental sequences that place children at risk and highlight the factors that protect children from risk and create resilience. The investigation of outcomes suggesting resilience as well as poorer outcomes can be undertaken in detail in prospective studies (Hunter *et al*, 2002).

A prospective study allows researchers to measure a number of characteristics relating to the child and control for this using statistical analysis. This type of study allows for collection of a number of interrelated factors in a child's life (e.g. school, community, family, work). Qualitative data can also be collected from a number of perspectives concurrently (Taplin, 2005); this can include the young person, the relevant staff members and family as appropriate.

Research design

In designing a longitudinal study, there are a number of specific considerations that require decisions at the outset of the design process. These are briefly outlined below.

Sampling

The sample size in any study depends on many factors, including the number and types of research questions, the study period, funding and resources, and retention rate (Taplin, 2005; Robson, 2011). Most of the major longitudinal studies on children in out-of-home care have recruited their samples from children entering care within a specified timeframe. Including every child in a particular timeframe can help avoid potential sampling errors.

Other methods of sampling can also be employed (Robson, 2011). These include:

- simple random sampling, which involves selection at random from the full population list;
- systematic sampling, which involves taking every *n*th name from the population list;
- stratified random sampling, where the population is divided into a number of groups or strata where members of the group share a particular characteristic; or
- a cluster sample, where the population is divided into a number of units or clusters, each of which contains individuals having a range of characteristics. The clusters are then chosen on a random basis.

A low or biased pattern of recruitment into a study can affect the generalisability of the responses obtained in a longitudinal study. Response bias is also an issue to consider in the sampling process since a sampling bias may occur as a result of the methods used to recruit the sample. As Soloff *et al* (2003) note, it is possible that the characteristics of the children lost from the sample will be different from those in the final sample. The children who are more mobile and harder to access will cause a bias in the final sample and result in the findings being less generalisable.

Consent from children and young people in care

A major difficulty in conducting research with children in care is involving them as research participants and obtaining consent. Consent issues for children considered to be 'vulnerable' are particularly sensitive (Robson, 2011). Berrick *et al* (2000) described the problems they had obtaining permission to interview children in care: consent was required from a number of different individuals and agencies. The legal status of children in care can involve parents, social workers and judges. Access to children in care may be tightly controlled or there may be ambiguity as to who is in a position to provide this consent. However, as Robson (2011) suggests, excluding a particular group of people from research because they are deemed 'vulnerable' is questionable and the onus is on the researchers to find ways to obtain consent.

Response rates

Along with an appropriate sampling method and consent, the issues of response rates and retention also need consideration. The National Survey on Child and Adolescent Well-being (2003) of children in out-of-home care in the USA reported a response rate of 56%. Of the 1,291 children in this foster care sample, 727 completed the interviews; of the final sample, 23% were deemed ineligible, 14% were unavailable after repeated attempts, 9% refused to participate and 3% were unavailable or uncontactable for some other reason. The Longitudinal Studies of Child Abuse and Neglect (LONGSCAN), which focused on the effectiveness of different service delivery characteristics on children in out-of-home care, reported a response rate of around 60%; this study calculated that a sample size of 8,500 children would be needed in order to obtain a study sample of 5,000 (Hunter *et al*, 2002).

Retention

The issue of retention among participants in a longitudinal study has additional factors over other types of research study. In order to draw conclusions from the data collected, it is necessary to minimise attrition. In a longitudinal study, the potential for attrition is greater since the longer the duration of the study, the more likely selective attrition will occur. Farrington (2000) showed that the more elusive and uncooperative subjects tended to be involved in more anti-social and criminal behaviour. More mobile respondents are more difficult to follow-up (Taplin, 2005). Guterman (2004) also points out that the issue of attrition is even more concerning when the number in the sample being studied is relatively low.

However, careful planning can help improve retention. Loeber and Farrington (2004) suggest planning for continued contact by collecting detailed information on the children's contacts and requesting permission to search records that will help locate participants at a later stage.

The frequency of follow-up data collection can affect retention. As Loeber and Farrington (2004) advise, it is important not to make the data collection so frequent that participants become resistant and drop out. The benefits of staying in the study must outweigh the perceived costs of participation. The provision of financial or material incentives is regularly used as a strategy to improve retention in studies with vulnerable populations (Kotch, 2000). Although not a study on children in care, Soloff *et al* (2003), authors of the Longitudinal Study on Australian Children (LSAC), usefully describe their most successful retention strategies. These include: tracking questions in the study instruments; maintaining and frequently updating the database of participants' contact details; communicating regularly with participants by sending 'Season's Greetings' cards, change of address cards for notification of moves, regular newsletters and mail-back surveys; and encouraging identification with the study through marketing, media exposure, freephone numbers and websites.

Data collection - Timing

Timing needs to be considered at all stages of a study - at recruitment, during follow-up interviews and long after the individuals have exited care. Recruiting children and young people early in their time in care allows examination of the factors that affect outcomes during their placement and possible return home, whereas if a participant is recruited later the focus may be on their aftercare experiences (Taplin, 2005). There are differences in the time of recruitment in the larger longitudinal studies completed, with children being recruited 5 months after they entered care (Hunter *et al*, 2002) or only 2 weeks after entering foster care (Delfabbro *et al*, 2002). Fixed interval follow-up collection allows the research to express rates of change over equivalent periods of time and study the onset of new behaviours. This works best when the interval is not too long because of the problem of inaccurate recall of events (Taplin, 2005). One rationale for determining the frequency of the follow-up collection is the speed at which the developmental changes are expected to occur. In LONGSCAN, data collection points corresponded with critical points in the children's development, at age 4, 6, 8, 12, 14, 16 and in young adulthood (Hunter *et al*, 2002). Annual telephone interviews were conducted in the intervening years. In the original NSCAW design, the follow-up interviews were planned for every 6 months; however, this had to be revised due to the workload involved and the follow-up interviews were conducted at 18 and 36 months only.

Once young people have left care, they can be more difficult to locate. But once located, they can provide valuable insight into their experiences after leaving care. Longer timescales in the study allow for a greater number of follow-up collections to be completed.

Data collection - Methods

The major prospective studies have collected data using a number of methods. The most common is face-to-face interview, but this is often complemented by data from administrative records, self-completion questionnaires and assessment tools (Taplin, 2005).

An advantage of the interview in a prospective study is that large amounts of qualitative data can be collected concurrently. The NSCAW researchers interviewed the young person, the former caregivers and the social workers involved. The research also placed more emphasis on the young person's self-reporting as they got older and moved on in their life. Researchers also placed increasing emphasis on cultural, community and peer risk and protective factors relative to family or primary caregiver (Taplin, 2005).

Data collection - Type of information

The questions asked and the ways in which they are asked depend on the information required and the age of the participants. Measures used and questions asked must be sensitive to the lives of young people and their time in care. In designing LONGSCAN, the cultural and developmental appropriateness of the questions asked was determined by conducting a pilot test and qualitative interviews, which assessed the acceptability, sensitivity, comprehensibility and comprehensiveness of the measures (Hunter *et al*, 2002). The goal was to develop interview protocols that were culturally and developmentally appropriate, but not so specific that they would not apply to the full sample of young people. Berrick *et al* (2000) suggest the use of advisory committees that consist of a number of parties relevant to care and care placements, including young people, to support the research process and to ensure that the information required is collected in a sensitive manner.

Data analysis

Prospective studies generate a large amount of data at different points in time and from multiple respondents. This poses a number of challenges at the data analysis stage (Robson, 2011). The NSCAW advise that these challenges are identified at the design stage: identifying the major research questions that will be addressed, the data elements that will be used to answer the questions and the types of analysis that will be employed to answer the questions. Each wave of data collection in a longitudinal study also involves ensuring all sources of data have no identifying information, are collated, entered, edited, checked and then analysed - all of which takes a substantial amount of time (Loeber and Farrington, 2004).

Summary

Prospective longitudinal studies provide rich sources of information, but require detailed consideration at the design stage to ensure all of the complex design issues are addressed at an early stage. This paper has noted many of the issues that require consideration in all longitudinal studies. However, each study has its own specific issues depending on the context and the tentative design for the proposed study below illustrates some of these points.

PROPOSED LONGITUDINAL STUDY ON CHILDREN WHO LEAVE CARE (10-YEAR FOLLOW-UP)

Research design

As with any research project, clarity is necessary at the beginning to ensure the research successfully answers the required questions. The initial research design needs to consider:

1. the background to and rationale for the study;
2. the overall aims and objectives of the study;
3. the sample group (purpose and types of care included, the number of young people in care*/leaving care, the number of young people included in the study, other key stakeholders);
4. appropriate research methods to answer the research question (qualitative or quantitative methods);
5. the timing and frequency of data collection;
6. the type of analysis appropriate to the methods and research question;
7. the output in terms of report types (numbers and timing) and a plan for dissemination of the findings;
8. the overall governance of the research study;
9. the use and membership of an advisory committee (including young people who have been/are in care).

This follow-up study on young people leaving care would involve a prospective study over a period of 10 years, with an agreed overall research question. The study would focus on gathering the following information:

- young people's experiences pre-care and while in care (on a broad basis, including extended family contact, school and community networks, etc);
- the positive aspects/challenging aspects of the care process;
- opportunity for participation, involvement in decision-making, etc;
- the delivery and management of the care service by the HSE and partner agencies;
- communication, contacts and relationship between children/young people and care staff (residential, social work and others);
- the overall outcomes for young people (aligned to the 7 National Service Outcomes for Children in Ireland - OMC, 2007) in the short, medium and long terms;
- the experience of leaving care and on the availability/accessibility of aftercare supports and services;
- family contact while in care/family re-unification on leaving care.

A clear set of aims and objectives based on the overall research question needs to be teased out with the commissioners of this study and the research team.

* In April 2009, there were 5,589 children in Ireland in the care of the State, with 376 of these children in residential care. HSE figures from 2008 show that 90% of children in care are placed in a family setting or in a foster home. Two-thirds of these are placed with general foster carers (families unknown to the children previously) and one-third are placed in the care of a relative or neighbour with whom they have had a previous relationship (OMCYA, 2009, p. 10).

Sampling

A full sample of the population group in care/leaving care at a particular point in time would be included, or at least a random sample of this population group. To determine the period required, the research team would need to determine the numbers of young people who leave care over a year-long period and consider this sample size. This could include both planned and unplanned moves from the placement. Including every child in a particular timeframe will support the generalisability of the responses obtained in the study and avoid potential sampling errors. Based on the response rates of between 56%-60% in other prospective studies reviewed (see above), this study would need to aim for a full sample of the leaving care population in order to ensure adequate numbers for the study.

Including a large sample group in the study will also help protect against a reduction in participants due to issues of consent, response rates, retention and attrition. Consent will be required as the children leave the care system and are eligible for inclusion in the study. Informed consent will be necessary, with all participants fully informed about all aspects of the study and their part in it. Different processes will be required for young people under or over the age of 18. For those under 18, the consent of parents/guardians will be required, in addition to the consent of the young person themselves. The legal status of individual participants will determine this process and will warrant consideration by the research team in terms of the timing of gaining consent and the resources required for this.

In a longitudinal study, the potential for attrition is greater since the longer the duration of a study, the more likely selective attrition will occur. Attrition may be reduced by regularly updating the contact details of the participants, keeping in regular contact with participants and collecting data at regular intervals. A 'thank you' for their participation may also be offered to reward participants for their involvement.

Methodology

A mixed-methods approach is recommended for this study. Qualitative methods will be best suited to gain insight into the lived experiences of the participants and are 'orientated towards exploration, discovery and inductive logic' (Patton, 2002, p. 55). Quantitative methods emphasize quantification in the data collection and in this study will provide information on, among other things, the profile of participants and the number, length and type of care placements.

One-to-one interviews are the most appropriate method to ensure the level and depth of data is collected to provide a complete picture of the young people's time in care and their views on this. Interviews will also be best suited to gaining insight into the views of the other key stakeholders in the care/aftercare experience (e.g. staff members and extended family).

Self-administered questionnaires and data from administrative records will complement the qualitative data collected and allow for a profile of participants to be compiled, with detailed information on their care placements.

The frequency of data collection needs to achieve a balance between adequate contact with participants to maximise retention and not being so frequent as to cause resentment or frustration. Fixed interval follow-up collection allows the research to consider change over equivalent periods of time and study new behaviours or developments.

Follow-up contact with care leavers on a bi-annual basis will maintain contact and avoid inaccurate recall of events due to time lapse (Taplin, 2005). The long length of this study (over a period of 10 years) will allow for valuable insight into the experience of those who leave care.

Data analysis

The types of analysis employed will need to answer the overall questions. The qualitative data will be analysed inductively and thematically and supported with the use of the computer package NVivo. Qualitative analysis is particularly inductive in the initial stages when the researcher is concerned with identifying possible categories, patterns and themes (Patton, 2002). NVivo is used as a tool to manage and organise the analysis. The statistical software package Predictive Analytics Software (PASW), Version 18 (formerly known as SPSS) will be used to run statistical analyses on quantitative data.

Dissemination of findings

Given the length of this study, there will be a number of time points for dissemination of the data. Regular publication of data will support the research study itself and encourage participation from stakeholders. There will be a broad audience interested in the findings of the study and therefore a number of different channels will be necessary to convey the findings to all interested parties. Reports, summary reports, pamphlets, presentations and media briefings will be produced at regular intervals, as agreed. Particular sensitivity will be practised with regard to the care leavers in the publication of these findings. The possibility of their involvement in the dissemination of the research findings will be considered and the necessary support structures will be put in place as appropriate.

Governance

An advisory committee is necessary to oversee this study, with representation from the commissioners, other key stakeholders and young people in care/having left care. The advice and expertise of other researchers who have been involved in long-term prospective longitudinal studies is also necessary to support the study. Terms of reference for this group will be agreed at the outset of the study.

Estimated costing

Resource	Per annum (€)	Over 10 years(€)
Principal Investigator	30,000	300,000
Post Doctoral researchers (x2)	180,000 <i>(inclusive of all associated costs)</i>	1,800,000
Travel costs	20,000	200,000
Materials	50,000	500,000
Project administration	25,000	250,000
Researchers (x5) for intensive fieldwork rounds	40,000	400,000
Data inputting	20,000	200,000
Dissemination	10,000	100,000
Expert consultation	15,000	150,000
	390,000	3,900,000
Overheads @ 20%	78,000	780,000
VAT @ 23%	107,640	1,076,400
TOTAL	575,640	5,756,400

Summary

This section has outlined an initial design proposal for a longitudinal study on children who leave care. The text is intended for use as a basis for further detailed discussion with the commissioners of the research in order to explore the research required in full and to develop a research plan subsequently based on this information.

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