

LifeStories:

Impact of infant institutionalization- a 60-year follow-up study



Patricia Lannen, PhD

Director

Marie Meierhofer Children's Institute,
Associated Institute of the University of Zurich

Historical institutional care practices in Switzerland



Population-based study in Zurich



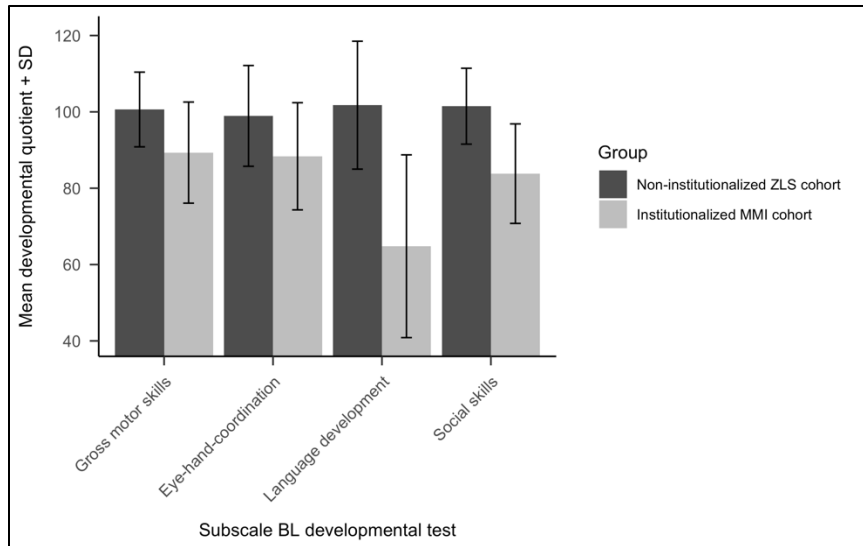
Marie Meierhofer, MD
1909-1998

- Health and development of all children below age three in all of the 12 infant care institutions in Zurich
- Comparison with the representative cohort of the **Zurich Longitudinal Studies (ZLS)**; University Children's hospital in Zurich)

T 1: 1958-1961 N= 431

T 2: 1971-1973 N= 143 (subsample)

Results: Early Childhood



Graph 1: Differential developmental outcomes between institutionalized and non-institutionalized children.

Between group:

- Development : $\beta = -.63$, $p < .001$.
- Language : $\beta = -.63$, $p < .001$
- Social skills: $\beta = -.61$, $p < .001$

Withing group:

- Higher birth weight:
 $\beta = .15$, $p < .05$
- Regular family contact
 $\beta = .20$, $p < .05$

Follow-up study adolescence

1971-1973, age 14, N=143

- Stereotypies
- Depression
- Speech and school problems
- Number of placement changes relevant for effect size

Meierhofer, Marie; Keller, Wilhelm (1974): Frustration im frühen Kindesalter. Bern, Hans Huber, 3. Aufl. (1. Aufl. 1966)

Meierhofer, M., & Hüttenmoser, M. (unveröffentlicht). Die spätere Entwicklung von Kindern, welche ihre erste Lebenszeit in Säuglings- und Kinderheimen verbracht hatten. Untersuchungsbericht zuhanden des Schweizerischen Nationalfonds für wissenschaftliche Forschung. Zürich: Archiv Marie Meierhofer Institut.

LifeStories Project

- What are the long-term health and development outcomes of early institutional placement under conditions of psychosocial deprivation across the life span?
- How do individuals placed in institutional care report on their subjective experience?



Social and Compulsory measures in Switzerland before 1981



Welfare and Coercion
National Research Programme

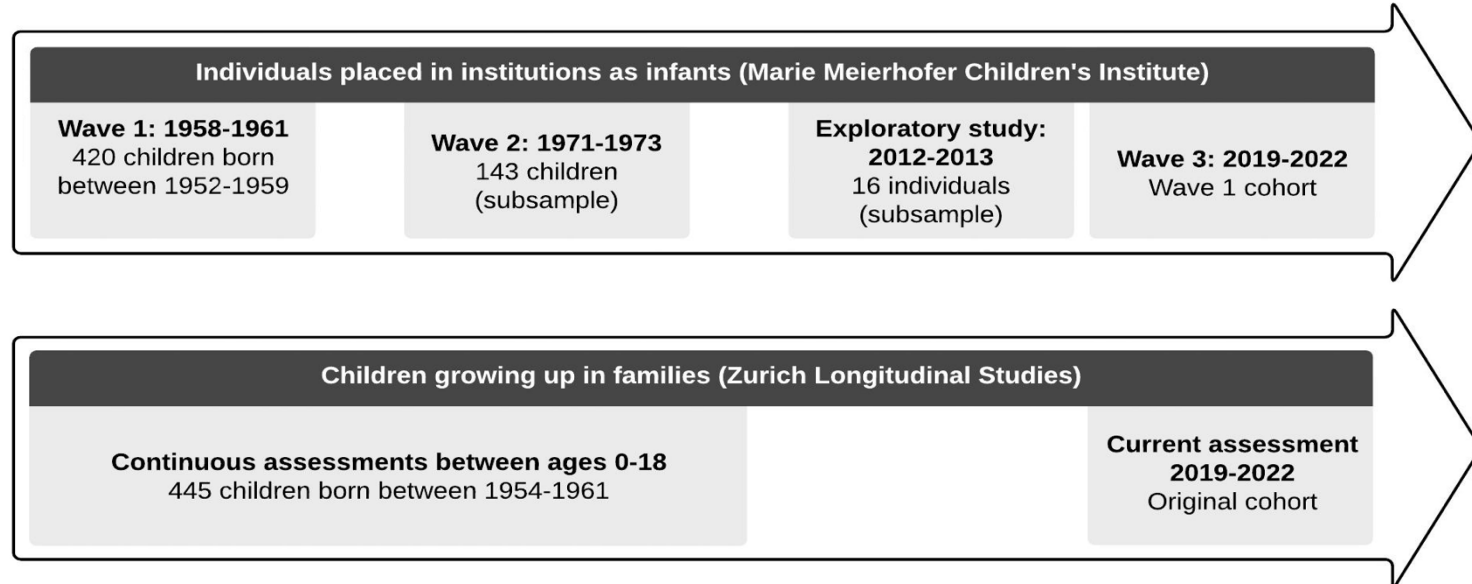
THE AGE OF INQUIRY
A global mapping of institutional abuse inquiries

HOME ABOUT BROWSE SEARCH CONTACT

This web resource maps inquiries into historical child abuse, which have proliferated since the 1990s. It focuses in particular on investigations into 'institutional child abuse', which encompasses a range of settings, typically outside the family but including arrangements such as foster care.

Wright, K., Swain, S., and Sköld, J. (2020). *The Age of Inquiry: A global mapping of institutional abuse inquiries*. Second edition. Melbourne: La Trobe University. DOI: <http://doi.org/10.4225/22/591e1e3a36139>

Study design



- Population-based study
- 60-year longitudinal study
- Representative comparison cohort
- Standardized development tests
Modern statistics
- Isolated effect of psychosocial deprivation

Development and Health of Adults Formerly Placed in Infant Care Institutions – Study Protocol of the LifeStories Project

Patricia Lannen^{1*}, Hannah Sand¹, Fabio Sticca¹, Ivan Ruiz Gallego¹, Clara Bombach¹, Heidi Simon¹, Flavia M. Wehrli¹ and Oskar G. Jenni¹

¹Marie Meierhofer Children's Institute, University of Zurich, Zurich, Switzerland; ²Child Development Center, University Children's Hospital Zurich, Zurich, Switzerland

OPEN ACCESS

Edited by: Laurence S. Liberman, Ludwig Maximilian University of Munich, Germany

Reviewed by: Mira Marzi, University of Zurich, Switzerland; Agnès Bino-Katig, Högskolan i Gäddede, Sweden

***Correspondence:** Patricia Lannen, lannen@mmi.ch

Specialty section: This article was submitted to Health, a section of the journal *Frontiers in Human Neuroscience*

Received: 20 September 2020
Accepted: 03 December 2020
Published: 23 January 2021

Citation: Lannen P, Sand H, Sticca F, Ruiz Gallego I, Bombach C, Simon H, Wehrli FM and Jenni OG (2021) Development and Health of Adults Formerly Placed in Infant Care Institutions – Study Protocol of the LifeStories Project. *Front. Hum. Neurosci.* 14:111891. doi: 10.3389/fnhum.2020.111891

A growing volume of research from global data demonstrates that institutional care under conditions of deprivation is profoundly damaging to children, particularly during the critical early years of development. However, how these individuals develop over a life course remains unclear. This study uses data from a survey on the health and development of 420 children mostly under the age of three, placed in 12 infant care institutions between 1958 and 1961 in Zurich, Switzerland. The children exhibited significant delays in cognitive, social, and motor development in the first years of life. Moreover, a follow-up of a subsample of 143 children about 10 years later revealed persistent difficulties, including depression, school related problems, and stereotypes. Between 2019 and 2021, these formerly institutionalized study participants were located through the Swiss population registry and invited to participate once again in the research project. Now in their early sixties, they are studied for their health, further development, and life-course trajectories. A mixed-methods approach using questionnaires, neuropsychological assessments, and narrative biographical interviews was implemented by a multidisciplinary team. Combining prospective and retrospective data with standardized quantitative and biographical qualitative data allows a rich reconstruction of life histories. The availability of a community sample from the same geographic location, the 1954-1961 cohort of the Zurich Longitudinal Studies, described in detail in a paper in this issue (Wehrli et al., 2020), enables comparison with an unaffected cohort. This article describes the study design and study participants in detail and discusses the potential and limitations of a comparison with a community sample. It outlines a set of challenges and solutions encountered in the process of a lifespan longitudinal study from early childhood into the cusp of old age with a potentially vulnerable sample and summarizes the lessons learned along the way.

Keywords: longitudinal study, lifespan development, institutional care, adverse childhood experiences, early childhood, child development, compulsory social measures, orphan care

Frontiers in Human Neuroscience | www.frontiersin.org
January 2021 | Volume 14 | Article 111891

Ethical concerns

- Institutional placement unknown to participant
- Institutional placement unknown to next-of kind
- Study participation as infant unknown
- Retraumatization through potentially distressing memories



[Check for updates](#)

OPEN ACCESS

CITATION:
Christos Pezirkianidis,
Platonon University,
Greece

REVIEWED BY:
Malteazt Krylben-Grank,
Medical University of Silesia in Katowice,
Poland
Stéphane Sallart,
Centre Neuchâtelois De Psychiatrie,
Switzerland

CORRESPONDENCE:
Patricia Lannen
lannen@mmi.ch

SPECIALTY SECTION:
This article was submitted to
Developmental Psychology,
a section of the journal
Frontiers in Psychology

RECEIVED: 20 August 2022
ACCEPTED: 04 October 2022
PUBLISHED: 28 November 2022

CITATION:
Lannen P, Bombach C, Sticca F,
Simon H and Jenni O (2022) The
LifeStories project: Empowering voices and
avoiding harm—Ethics protocol of a long-
term follow-up study of individuals placed
in infant care institutions in Switzerland.
Front Psychol 13:1022388.
doi: 10.3389/fpsyg.2022.1022388

COPYRIGHT:
© 2022 Lannen, Bombach, Sticca, Simon
and Jenni. This is an open-access article
distributed under the terms of the
Creative Commons Attribution License (CC BY). The
use, distribution or reproduction in other
forums is permitted, provided the original
author(s) and the copyright owner(s) are
credited and that the original publication in
this journal is cited, in accordance with
accepted academic practice. No use,
distribution or reproduction is permitted
which does not comply with these terms.

The LifeStories project: Empowering voices and avoiding harm—Ethics protocol of a long-term follow-up study of individuals placed in infant care institutions in Switzerland

Patricia Lannen^{1*}, Clara Bombach¹, Fabio Sticca¹, Heidi
Simon¹ and Oskar G. Jenni¹

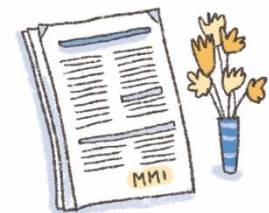
¹Marie Meierhofer Children's Institute, Associated Institute of the University of Zurich, Zurich, Switzerland, ²Child Development Center, University Children's Hospital Zurich, Zurich, Switzerland

Little empirical data exist to guide ethical decisions when conducting research with vulnerable populations. The current study assesses a protocol designed to mitigate risks in a population-based cohort of 246 individuals placed in care institutions as infants in a non-selective 60-year follow-up. In total, 116 (47%) individuals chose to participate, of whom 53 (55%) reported positive effects of participation such as the opportunity to fill some gaps in their life stories, to better deal with their past, and to understand previous family dynamics. Only three individuals (2.5%) explicitly reported negative short-term consequences such as feeling upset as a result of thinking about stressful times, but they nonetheless rated the usefulness of the study as high. For six participants (5%), psychological counseling sessions were initiated as a support measure. Our findings suggest that risk of harm can be managed with a rigorous ethics protocol when conducting research with a vulnerable cohort and therefore enable the voices of survivors to be heard. A step-wise approach in which increasing amounts of information were presented at each step, clearly operationalized passive decline, and direct and consistent contact with highly trained staff were considered key to mitigating distress.

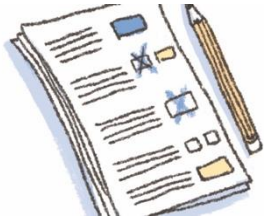
KEYWORDS:
ethics, vulnerable cohort, long-term follow-up, institutionalization, deprivation

Preparation, search and recruitment

- Preparation of study with survivors
- Search through population registry
- CH: 96% found
- Abroad: 38% found
- Total found: N= 349 (81%)
- N= 267 eligible for contact
- Participation 50% (N=132)



Data collection: mixed method



Questionnaire

- Physical and mental health
 - Well-being
 - Life events and transitions
 - SES and education
 - Resilience and sense of coherence
-



Neuropsychological assessment

- Cognitive and motor abilities
-



Narrative interviews

- Subjective life trajectory and biographical experiences

Results: Relevant themes 60 years later

Disclosure of placement

No memory about placement

Placement as taboo/family secret

Different life trajectories

Different ways of „making sense“ of the events

Impact on family system



Narrative interviews

Results: voices of survivors

Why did nobody help us then?

I have no roots

I have become strong and can now deal with anything

It is so painful to imagine that I was in that bed all by myself

I have experienced terrible things, but now I am ok

It feels like the loss of everything



Narrative Interviews

Cognitive functions 60 years later

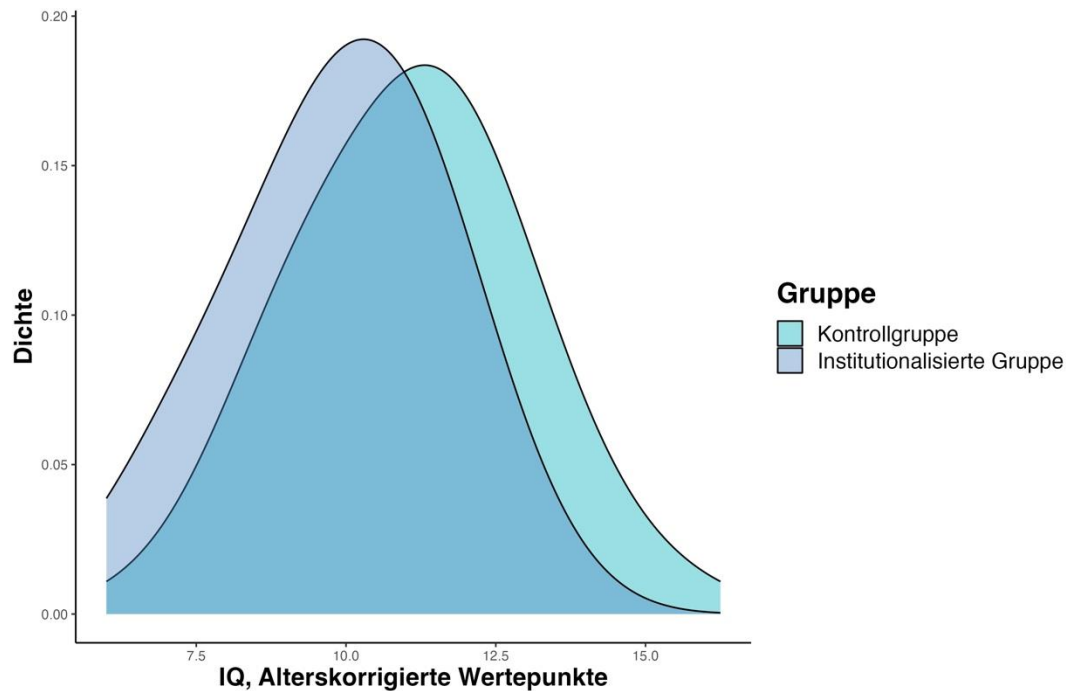


Figure 1: cognitive function, WAIS

Cognitive functions ($d = -0.67, p < .001$)

Child Abuse & Neglect 154 (2024) 106917

Contents lists available at ScienceDirect

Child Abuse & Neglect

Journal homepage: www.elsevier.com/locate/chiabuneg

Effects of early institutionalization involving psychosocial deprivation on cognitive functioning 60 years later: Findings of the LifeStories project

Hannah Sand^{a,b}, Fabio Sticca^{a,c}, Flavia M. Wehrle^{b,d}, Dominique A. Eichelberger^a, Heidi Simoni^{b,e}, Oskar G. Jenni^{b,d}, Patricia Lannen^{a,b,f}

^a Marie Meierhofer Children's Institute, Pfingstweidstrasse 16, 8005 Zurich, Switzerland
^b University of Zurich, Winterthurer 71, 8005 Zurich, Switzerland
^c University of Teacher Education in Special Needs, Schulhausmattenstrasse 298, 8057 Zurich, Switzerland
^d University of Teacher Education in Special Needs, Schulhausmattenstrasse 298, 8057 Zurich, Switzerland
^e Child Development Center, University Children's Hospital Zurich, Winterthurer 71, 8032 Zurich, Switzerland

ARTICLE INFO

Keywords: Early institutional care; Psychosocial deprivation; Neglect; Cognitive functioning; Lifespan; Dose-response effect.

ABSTRACT

Background: Institutionalization involving psychosocial deprivation affects child development negatively. However, there are few longitudinal studies, and no prospective study has yet examined the consequences of institutionalization in late adulthood.

Objective: Investigating effects of psychosocial deprivation on cognitive functioning 60 years later.

Participants and setting: A population-based survey of institutionalized infants and toddlers was conducted in Switzerland from 1958 to 1961 ($n = 387$; $M_{age} = 6.03$ years, $SD = 0.33$, 64 % female, 48 % Swiss nationality). In parallel, a comparison group of 399 family-raised children were assessed ($M_{age} = 0.85$ years, $SD = 0.50$, 46 % female, 100 % Swiss nationality). Six decades later, data on cognitive functioning were collected for 88 of the institutionalized group ($M_{age} = 62.63$ years, $SD = 1.32$), and 148 of the comparison group ($M_{age} = 65.06$, $SD = 1.32$).

Methods: Standardized tests were used: the Revised Letter Development Test in early childhood and a short form of the Wechsler Adult Intelligence Scale in late adulthood.

Results: Formerly institutionalized individuals scored lower on cognitive functioning ($d = -0.67, p < .001$), with the greatest difference in working memory ($d = -0.78, p < .001$). Longer duration of institutionalization increased the risk of lower cognitive functioning, indicating a dose-response effect. Institutionalization's impact on adult cognitive functioning was mediated by early childhood developmental status but not by later educational attainment.

Conclusion: This study confirms the early experience hypothesis, indicating that early life conditions have lasting effects on human development, even into late adulthood.

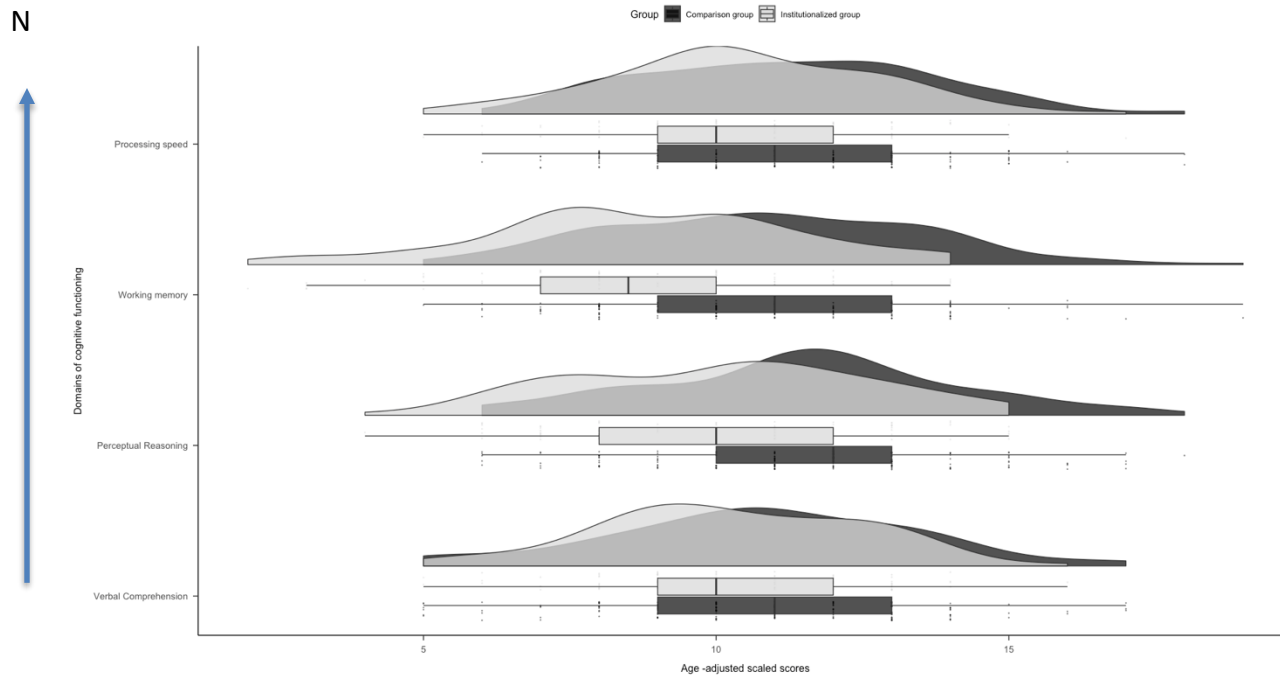
1. Introduction

Adverse childhood experiences (ACEs), such as abuse, neglect, and family violence (McLaughlin & Sheridan, 2016), are a major

^{*} Corresponding author at: Marie Meierhofer Children's Institute, Pfingstweidstrasse 16, 8005 Zurich, Switzerland.
 E-mail address: hannah.sand@kjp.uzh.ch (H. Sand), fabio.sticca@kjp.uzh.ch (F. Sticca), flavia.wehrle@kjp.uzh.ch (F.M. Wehrle), dominique.eichelberger@kjp.uzh.ch (D.A. Eichelberger), heidi.simoni@psychologie.uzh.ch (H. Simoni), oskar.jenni@kjp.uzh.ch (O.G. Jenni), patricia.lannen@kjp.uzh.ch (P. Lannen).

<https://doi.org/10.1016/j.chiabu.2024.106917>
 Received 3 November 2023; Received in revised form 10 June 2024; Accepted 20 June 2024
 Available online 1 July 2024
 0145-2134/© 2024 The Authors. Published by Elsevier Ltd. This is an open access article under the CC BY-NC license (<http://creativecommons.org/licenses/by-nc/4.0/>).

Cognitive functions 60 years later



Neuropsychologische Erhebung

Figure 2: cognitive function, WAIS

Working memory ($d = -0.78, p < .001$)

Health and development 60 years later

(preliminary)

Between group differences	
SES	B=0.43, p<.001
Physical health	B=0.21, p=0.03
Mental health	B=-0.09, p=0.01
Life satisfaction	B=0.3, p=0.01
Attachment security	B=0.47, p<.001
Emotion regulation	B=-1.09, p=0.027



Questionnaire



Neuropsychological assessment

Table 1: group differences 60-year follow-up

Data validity

Pre-existing group differences?

No differences in birth weight
Placed right after birth

Bias?

Non-selective for development during infancy and gender

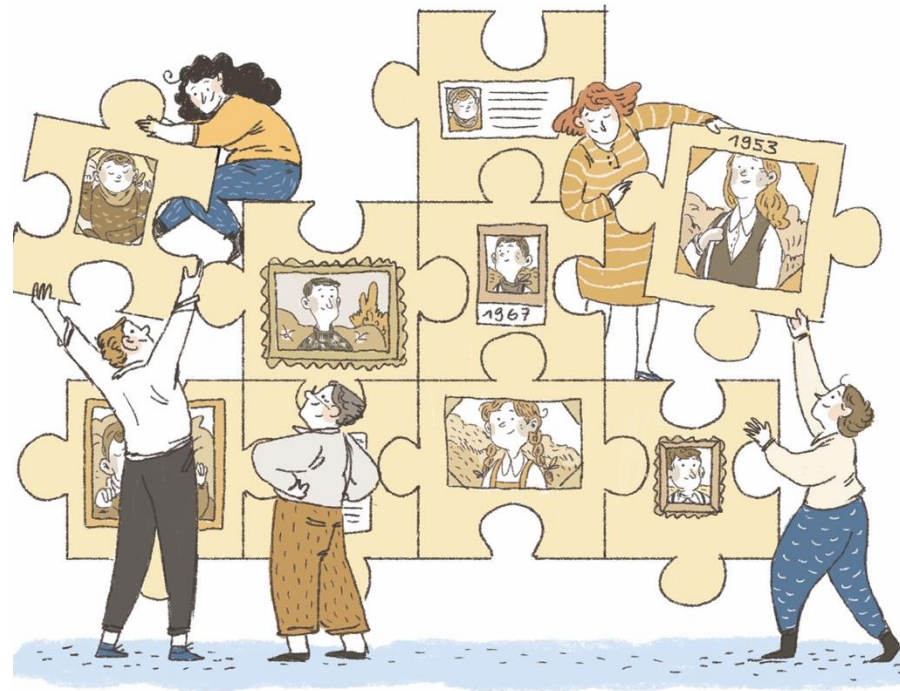
Dosage-effect?

Duration of placement
Family contact

Outlook



Implications



Social and compulsory measures and placements before 1981 in Switzerland



THE AGE OF INQUIRY
A global mapping of institutional abuse inquiries

HOME ABOUT BROWSE SEARCH CONTACT

Were you raised while in an institution?
Did the abuse happen in childhood?

ROYAL COMMISSION INTO CHILD SEXUAL ABUSE

Did the abuse happen in childhood?

This web resource maps inquiries into historical child abuse, which have proliferated since the 1990s. It focuses in particular on investigations into 'institutional child abuse', which encompasses a range of settings, typically outside the family but including arrangements such as foster care.

Wright, K., Swain, S., and Skold, J. (2020). *The Age of Inquiry: A global mapping of institutional abuse inquiries*. Second edition. Melbourne: La Trobe University. DOI: <http://doi.org/10.4225/22/591e1e3a36139>

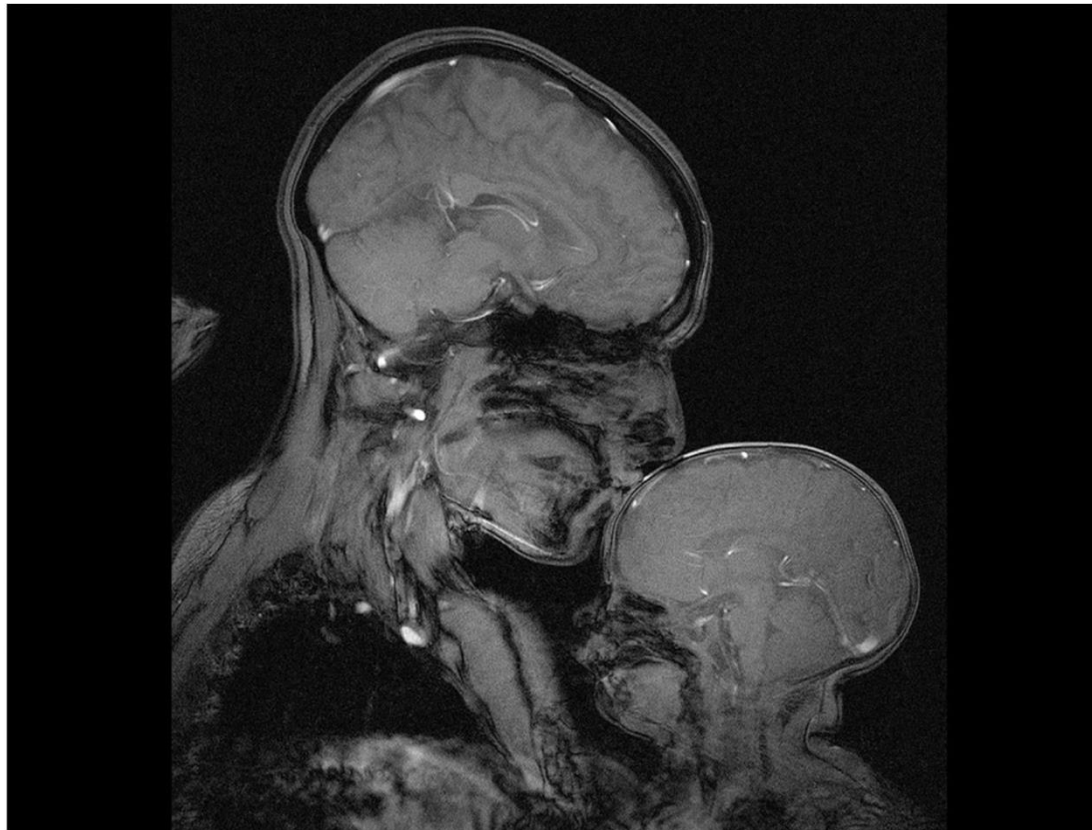


Fürsorge und Zwang
Nationales Forschungsprogramm

Institutionalization in a global context



The relevance of nurture and care



Scientists reconfigured a magnetic resonance scanner to capture a woman and her baby. Rebecca Saxe and Atsushi Takahashi / Department of Brain and Cognitive Sciences, MIT / Athinoula A. Martinos Imaging Center at the McGovern

«We are not the survival of the fittest,
we are the survival of the nurtured.»

Louis Cozolino

Thank you!



Patricia Lannen, PhD

lannen@mmi.ch

Marie Meierhofer Children's Institute, www.mmi.ch