A case study of enhanced clinical care enabled by Aboriginal health research: the Hearing, EAr health and Language Services (HEALS) project

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The gap between Aboriginal and non-Aboriginal Australian's health outcomes is well documented,[1-4] but there are relatively few examples of how service delivery can be enhanced, particularly in urban settings where most Aboriginal people live.[5] Aboriginal families experience greater barriers than other Australians when accessing health services for many reasons including: insufficient, often inconsistent funding for community health services; economic hardship; limited access to culturally appropriate health-care; discrimination; communication and language barriers; lack of transport; and other socio-economic barriers.[6-9] Disparity in middle-ear disease is a striking example. Aboriginal children endure a disproportionately high burden of middle-ear disease, with consequent hearing loss, speech and language impairment, and other complications such as chronic perforations and chronic suppurative otitis media.[10-12] For both Aboriginal and non-Aboriginal people living in New South Wales (NSW), waiting times for Ear, Nose, and Throat (ENT) surgery and speech-language pathology services routinely exceed six months and frequently exceed one-year.[13,14]

Abstract

Objective: To describe and evaluate Hearing EAr health and Language Services (HEALS), a New South Wales (NSW) health initiative implemented in 2013 and 2014 as a model for enhanced clinical services arising from Aboriginal health research.

Methods: A case-study involving a mixed-methods evaluation of the origins and outcomes of HEALS, a collaboration among five NSW Aboriginal Community Controlled Health Services (ACCHS), the Sydney Children's Hospitals Network, NSW Health, the Aboriginal Health and Medical Research Council, and local service providers. Service delivery data was collected fortnightly; semi-structured interviews were conducted with healthcare providers and caregivers of children who participated in HEALS.

Results: To circumvent health service barriers, HEALS used relationships established through the Study of Environment on Aboriginal Resilience and Child Health (SEARCH) to form a specialist healthcare network. HEALS employed dedicated staff and provided a Memorandum of Understanding (detailing mutual goals and responsibilities) for each ACCHS. Despite very tight timeframes, HEALS provided services for 653 Aboriginal children, including 5,822 speech-language pathology sessions and 219 Ear, Nose and Throat procedures. Four themes reflecting the perceived impact of HEALS were identified: valued clinical outcomes, raising community awareness, developing relationships/networks and augmented service delivery.

Conclusions: HEALS delivered rapid and effective specialist healthcare services through an existing research collaboration with five ACCHS, cooperation from local health service providers, and effective community engagement.

Implications for Public Health: HEALS serves as a framework for targeted, enhanced healthcare that benefits Aboriginal communities by encapsulating the 'no research without service' philosophy.

Key words: ear, nose and throat, speech-language pathology, service delivery, Indigenous

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Aboriginal Community Controlled Health Services (ACCHS) address many of the barriers Aboriginal families face when accessing healthcare by providing culturally appropriate services administered by Aboriginal staff for Aboriginal people.[15] In March 2013, and then again in 2014, NSW Health provided funding to the Sydney Children's Hospitals Network (SCHN) to provide ENT and speech-language pathology services for Aboriginal children identified through the Study of Environment on Aboriginal Resilience and Child Health (SEARCH)[16], using existing partnerships with five ACCHS. The result was the Hearing, EAr health & Language Services initiative (HEALS); a collaboration among Aboriginal communities, researchers and multiple health agencies.

We detail HEALS' capacity to circumvent traditional barriers to health service delivery for Aboriginal children and their families in six NSW urban centres. We report the processes for the rapid establishment of the HEALS' structure and governance, the volume of service delivery, and the perspectives of healthcare providers and children's caregivers towards HEALS' impact within the recipient Aboriginal communities.

Methods

Context

HEALS was implemented in conjunction with SEARCH, a community-initiated longitudinal cohort study investigating multiple health outcomes in urban Aboriginal children aged 0-17 years. SEARCH began collecting detailed audiology, ear-health, and speech and language data from Aboriginal children in collaboration with four ACCHS (Aboriginal Medical Service Western Sydney, Awabakal Newcastle Aboriginal Cooperative, Riverina Medical and Dental Aboriginal Corporation, and Tharawal Aboriginal Corporation) in 2009. Preliminary data provided evidence of a high burden of otitis media, hearing loss and speech and language impairment.[11]

In March 2013, responding to these identified needs, NSW Health indicated that $950,000 funding was available for audiology, ENT, and speech-language pathology services. As the funding was for the financial year there was a 17-week timeframe in which to identify suitable children and deliver the healthcare services. In 2014, the approach from NSW Health was repeated, albeit later, leaving a 13-week timeframe, with $800,000 available.

Service delivery data

Service delivery data (number of speech pathology sessions and ENT procedures) were based on weekly or fortnightly activity reports each ACCHS provided to the SCHN and the final report to NSW Health delivered in November 2013 and October 2014. We confirmed reports through communication with Project Officers based at each ACCHS, local service providers, The Sax Institute, and researchers and clinicians from the SCHN who oversaw the HEALS project. This activity was cross-checked with invoices received and with other sources of data such as the separate surgical list spreadsheets provided by the surgeons and public hospitals directly. Speech therapy intervention activity was also checked with speech pathologists directly when clarifications were needed.

Qualitative evaluation

Participants: Participants were recruited from four ACCHS: Awabakal Newcastle Aboriginal Cooperative, Riverina Medical and Dental Aboriginal Corporation, Tharawal Aboriginal Corporation, and Illawara Aboriginal Medical Service. Eligible participants included caregivers of children who received HEALS services, health service professionals, and senior ACCHS administrators involved in the delivery of HEALS services. Purposive sampling was used to ensure a diverse cross-section of participants.

Data collection: Face-to-face semi-structured interviews were conducted between February and December 2014. Interviews were conducted at the ACCHS by CY, SS, DK and PF; an Aboriginal researcher was present for all interviews. All interviewers had received training in qualitative research by AT (a social scientist), and had previously conducted interviews at the participating ACCHS. Because of this relationship, some ACCHS staff members knew the researchers. Participation was voluntary and all participants provided informed consent before the interviews took place. Participant recruitment ceased when saturation was reached. Interviews were audio-recorded and transcribed.

Data analysis: The transcripts were entered in HyperRESEARCH (version 3.5.2; Research-ware Inc.); a software program used to manage qualitative data. Using thematic analysis, three researchers (CY, SS, DK) independently coded the transcripts, inductively interpreted the data to identify emerging concepts and refined the themes relating to the outcomes of the HEALS intervention. The final version of the themes was agreed upon via discussion among the interviewers and AT. A summary of the preliminary findings was provided to participants should they wish to offer feedback; however, no feedback was received.

Results

Network establishment

HEALS was established and managed through SCHN (Westmead). The SCHN called on existing SEARCH relationships with five ACCHS (the original four SEARCH sites and a new relationship with the Illawarra Aboriginal Medical Service) who, in turn, successfully arranged partnerships with local health services and schools (Figure 1). A Memorandum of Understanding (MoU) was signed with each ACCHS in 2013, and again in 2014, detailing the mutual goals and responsibilities of the SCHN and the ACCHS throughout the duration of the HEALS project. In 2014, HEALS was able to expand further to provide speech-language pathology services at La Perouse Health Service.

Management

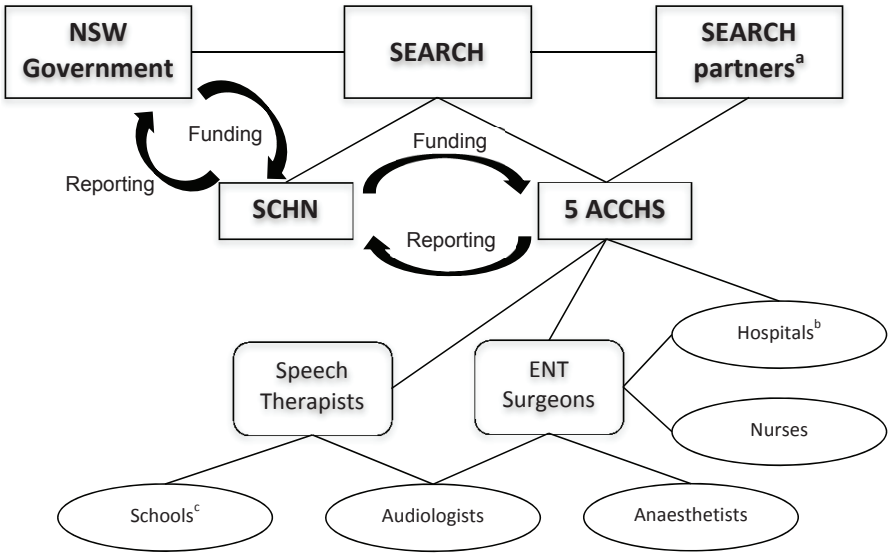
To ensure HEALS did not overburden the ACCHS sector's existing staff, part of the funding was used to employ a dedicated Project Officer at each ACCHS, all but one of whom were Aboriginal. In 2013, Project Officers worked 0.6 FTE during the time HEALS was operational at each ACCHS; in 2014, Project Officers worked 0.4 FTE. The Project Officer managed the participant list, amalgamating data from the SEARCH study with the ACCHS's own waiting lists and added eligible children during the course of the project as new needs arose. Children did not need to have been enrolled in SEARCH to benefit from HEALS and the ACCHS made the final decision about which children to prioritise for services. The only restriction on eligibility to access HEALS services was that the child needed to be younger than 18 years as the project was managed through the Sydney Children's Hospitals Network. The Project Officer also provided services that included: booking initial assessments; providing appointment reminders; following-up missed appointments; providing transportation for children and their families; data collection; and submitting weekly activity reports.

Children who could potentially benefit from HEALS underwent an initial pre-operative consultation or speech and language assessment if this had not already been done (e.g. children enrolled in SEARCH) and then, if needed, they were scheduled for surgery or speech-language pathology services (or both). Audiology services were provided at the discretion of the service providers and were funded as part of the ENT pre-operative service funding, not as a separate arm of HEALS activity. Children identified as having chronic suppurative otitis media, mastoiditis, cholesteatoma, or bilateral hearing impairment greater than 30db were prioritised for ENT assessment. Children identified as having severe speech and language impairment through previous diagnostic assessment (e.g. as part of SEARCH enrolment or routine ACCHS care) were prioritised for speech-language pathology services. NSW Health negotiated with the HEALS study team and the Sydney Children's Hospital Network to determine the total number of ENT surgical procedures and speech-language pathology services that would be expected given the available funds. For 2013, NSW Health set targets for HEALS to provide speech-language pathology services for 218 children, and ENT surgeries for 92 children.

Overall outcomes

In total, HEALS provided speech-language pathology services for 479 children and ENT surgeries for 191 children (17 children received both speech-language pathology services and ENT services). HEALS service outputs for 2013-14 are shown in Table 1. The number of services delivered varied by ACCHS due to the availability of local speech pathologists, and the catchment area of each ACCHS. Some services experienced delays due to difficulties enlisting the services of speech pathologists, however, the HEALS project team was able to find speech pathologists for those services that could not identify their own service providers. For ENT surgery, every ENT surgeon approached agreed to help. The ENT surgeons had their own lists scheduled for the rest of the year, however, as funding was available, they were willing to add additional lists, including on weekends, in order to meet the surgery targets. HEALS exceeded the targets set by NSW Health in both 2013 and 2014, despite a 16% decrease in funding in the second year.

Figure 1: The HEALS Network.



a: SEARCH (Study of Environment on Aboriginal Resilience and Child Health) partners include: The Sax Institute, Aboriginal Health and Medical Research Council, University of Sydney, Australian National University, Beyondblue, Charles Darwin University, University of Wollongong, University of Western Australia, The University of Newcastle
SCHN (Sydney Children's Hospitals Network)
ACCHS (Aboriginal Community Controlled Health Services)
b: Hospitals: Nepean Hospital, Calvary Hospital, Campbelltown Hospital, John Hunter Hospital
c: Schools: North St Mary's Public, Bidwill Primary, Tregear Public, Awabakal Preschool Glendale, Awabakal Childcare Centre Wickham, Awabakal Preschool Biraban, Ashmont Public, Tolland Public, Mt Austin Public, Bimbi Preschool, Kooringal Public, Ooranga Wandarrah Preschool, Rosemeadow Public, St John's Primary, Thomas Acres Public, Briar Road Public

Speech-language pathology services

Children receiving speech-language pathology services ranged in age from 18 months to 15 years (median 5 years 2 months, interquartile range 4 years 1 month, 6 years 8 months). Speech-language pathologists provided assessment and intervention for children with communication difficulties caused by congenital or developmental problems, illness, and emotional or physical trauma. These difficulties included unclear speech due to speech sound disorder, delayed expressive and/or receptive language such as vocabulary and sentence construction, reading, writing, voice problems and stuttering. The intervention provided by the speech-language pathologists was designed to suit each individual child and varied depending upon the type of communication difficulty, age of the child and caregiver priorities. For example, for children with unclear speech due to a speech sound disorder, intervention was focused on listening to, identifying and producing correct

Table 1: Overview of HEALS service delivery in 2013/14.

Aboriginal Community Controlled Health Service (ACCHS)	Location	Speech-language pathology services[a]				ENT Surgery	
		2013		2014		2013	2014
		No. of children	No. of sessions	No. of children	No. of sessions	No. of children	
Aboriginal Medical Service Western Sydney (AMSWS)	Mt Druitt	61	960	23	298	19	8
Riverina Medical and Dental Aboriginal Corporation (Rivmed)	Wagga Wagga	56	332	52	529	12	7
Tharawal Aboriginal Corporation	Campbelltown	64	831	56	607	22	18
Awabakal Newcastle Aboriginal Co-Operative	Newcastle	45	610	47	600	41	56
Illawarra Aboriginal Medical Service (IAMS)	Wollongong	45	275	54	322	N/A[b]	11
La Perouse Aboriginal Health Centre[c]	La Perouse	N/A	N/A	37	458	N/A	N/A
Total[d]		271	3,008	269	2,814	94	100

a: One speech therapy session was defined as ≤40 minute period of assessment or therapy
b: A late partnership with IAMS meant ENT services could not be offered at this ACCHS.
c: La Perouse joined in 2014 for speech-language pathology services only
d: 61 children received speech-language pathology services in both 2013 and 2014, three children received ENT surgeries in both 2013 and 2014

speech sounds in words, sentences and finally conversation. For children with delayed expressive language and reading difficulties, intervention was provided that increased their phonological awareness and their comprehension, production and ability to read different types of words, and sentences. Stuttering intervention aimed to reduce the number of dysfluent episodes produced during intervention and at home. The average number of speech-language pathology sessions per child was 11 (range 1–28). As therapy blocks could take many months and there was no prospect of completing therapy for all children in all services within the 2013-14 timeframes, the SCHN entered into an agreement with the ACCHS that enabled children who were likely to require further treatment to continue therapy beyond the end of financial year deadline. Speech-language pathology services were conducted at the ACCHS, in private consulting rooms, and at local primary and preschools, depending on the arrangements each ACCHS could put in place within the timeframe.

ENT Services

The SCHN and ACCHS jointly liaised with local audiologists, ENT surgeons, anaesthetists and hospitals to ensure appropriate pre-operative consultations, surgical procedures and post-operative assessments within the tight timeframes. Surgical dates were booked by the ACCHS at local public hospitals and one private hospital. Children's ages ranged from 13 months to 17 years 8 months (median 6 years 5 months, interquartile range 4 years 8 months, 9 years 9 months).

Table 2 shows the overall ENT surgical casemix for 2013/14. In 2013, HEALS eliminated the ENT surgical waiting list in every service other than two children whose operations were cancelled due to fasting non-adherence, and a few children from outlying centres affiliated with one of the ACCHS. Given this level of service delivery, the 2013 case mix provides a reasonable approximation of the ENT surgical need for Aboriginal children in NSW urban centres.

Qualitative evaluation: Healthcare provider and parent/caregiver perspectives

Of the 45 people invited to participate in the qualitative evaluation, 38 (84.4%) agreed. Participants consisted of 16 parents/caregivers and 22 health professionals. Overall, 30 of 38 were female; ages ranged from 21 to 69 years. We identified four themes that captured participants' perspectives of the outcomes of the HEALS program: valued clinical outcomes; raised awareness; developing relationships/networks; and augmented service delivery.

Valued clinical outcomes: HEALS alleviated health providers and caregivers' frustration caused by lengthy waiting times and allayed concerns surrounding the potential sequelae of prolonged speech-language impairment and ear disease. All participants believed that HEALS provided clinically beneficial services for children. Caregivers stated that HEALS effectively treated children's speech-language and ear disease problems, noting clearer and more confident speech, the absence of ear-disease symptoms, and other ancillary benefits (better sleep, quieter and improved behaviour, more reading, and increased social confidence/interaction) post-intervention.

Raising community awareness: Many participants felt that HEALS raised caregivers' awareness of: the symptoms of ear disease and speech and language problems, availability and access to specialist health services, and the efficacy and importance of treatment. *"I think now I'm aware of these things* (ear disease symptoms), *I can now go and ask. Before, I didn't know anything about it. I wouldn't have asked"* (Caregiver). As a result, these participants believed HEALS empowered the community, increasing caregivers' capacity to effectively identify ear disease or speech issues, and to access specialist services.

Developing relationships/networks: Partnerships, established and strengthened by HEALS, were valued for their potential to improve health service delivery through enhanced communication and collaboration. *"The partnership is so important. To have a partnership like that* (HEALS) *outdoes anything else"* (Senior ACCHS administrator). Many participants felt the cohesion between ACCHS, local health specialists, hospitals, schools and the broader community was a significant contribution to HEALS' success and were keen to be a part of similar programs. As a result of positive interactions with HEALS specialists, some caregivers felt they would be more comfortable seeking specialist treatment for their children. However, some health professionals noted that the short duration and stop-start nature of HEALS could damage community trust, limiting future involvement with similar health interventions.

Augmented service delivery: Health professionals thought that HEALS stimulated discussion and collaboration that facilitated the implementation of new services. For example, Riverina Medical and Dental Corporation and Tharawal Aboriginal Corporation continued to fund speech-language pathology services post-intervention, as both ACCHS recognised the benefit for their local children.

Table 2: Number and type of ENT surgical procedures in 2013/14.

Procedure	2013 (n=94)		2014 (n=100)	
	No.	%	No.	%
Adenoid/tonsil removal				
Adenotonsillectomy	40	(33.6)	36	(36.0)
Adenoidectomy	13	(10.9)	3	(3.0)
Tonsillectomy	6	(5.0)	15	(15.0)
Middle ear				
Unilateral ventilation tube	4	(3.4)	8	(8.0)
Bilateral ventilation tubes	29	(24.4)	20	(20.0)
Myringoplasty	9	(7.6)	8	(8.0)
Other ENT surgery	18[a]	(15.1)	10[b]	(10.0)
Total Procedures	119	(100)	100	(100)

Note: some children received multiple procedures.

a: Other ENT surgery in 2013 includes: nasendoscopy, turbinate cauterisation, ventilation tube removal, nasal stent removal, septum cauterisation, mastoidectomy and nasal mass biopsy.

b: Other ENT surgery in 2014 includes: implantation of cochlear prosthetic device, excision of thyroglossal cyst , excision of lesions of skin and other subcutaneous neck tissue, other excision of middle ear, microlaryngoscopy, ears cleaned under anaesthetic, reduction of inferior turbinates, cautery nasal septum, aural polypectomy, cautery and diathermy of septum/inferior turbinates.

Discussion

Ongoing disparities between Aboriginal and non-Aboriginal health outcomes demonstrate the need for policy that brings about tangible and sustained health benefits for the Aboriginal community. HEALS demonstrates that, with proper funding, efficient management, and a dedicated

and collaborative team, health services needed to help Close the Gap can be made more accessible to Aboriginal families, and that such enhanced clinical care can be piggybacked onto an existing research collaboration. The rapid delivery of services (5,822 speech pathology sessions and 219 ENT operations) for 653 Aboriginal children was achieved primarily due to existing partnerships with five ACCHS developed through the SEARCH research project. HEALS contributes a potential framework by which health interventions can be strategically targeted to community needs identified through research. The major threat to the success of the program is its sustainability, particularly due to lack of recurrent funding. Such a program could be rolled out to all ACCHS, and expanded to other chronic illnesses where there are blocks in routine service delivery.

In addition to receiving treatment, participants believed HEALS provided valued ancillary benefits with the potential to promote gains in Aboriginal healthcare access, and use. Health professionals noted that HEALS' success strengthened and augmented clinical networks, providing opportunities for new health services using partnerships established through the intervention. Participants believed the volume of HEALS services raised community awareness of ear and speech problems, as well as allowing a large number of Aboriginal families to access specialist treatment in a culturally appropriate and supportive environment. Consequently, HEALS was believed to encourage greater health service use, especially from Aboriginal families who were reluctant to attend non-ACCHS specialist services. HEALS also provided Aboriginal capacity building through the employment of an Aboriginal Project Officer at all but one ACCHS.

The strategic and efficient delivery of services was only possible through the willingness and capability of the participating ACCHS to manage local healthcare specialists, share culturally appropriate knowledge and provide personalised services facilitated by a dedicated Project Officer. HEALS showcases the ACCHS' abilities and supports previous literature highlighting the potential of these services as key players in the Close the Gap campaign.[15] The success of HEALS was also enhanced by the enthusiasm and goodwill of local ENT surgeons and speech pathologists who were cognisant of HEALS' goals and worked with the Project Officer to ensure children were accommodated swiftly.

Research among Aboriginal communities has not always been regarded favourably, often viewed as exploitative, culturally inappropriate, transient and predominantly led by non-Aboriginal people. More recently, within the research community there is recognition that the way in which Aboriginal and non-Aboriginal agencies collaborate is as important as the outcomes these partnerships are designed to produce.[17] HEALS was built on partnerships, founded by the SEARCH study that upholds the research guidelines advocated by the Aboriginal community, including the principles of close community consultation, capacity-building and the philosophy of "no research without service".[18-20] From research identifying Aboriginal children with otitis media, hearing loss and speech delay, the SEARCH network facilitated a rapid delivery of health services that became the HEALS program. HEALS provides an example of how strong relationships between researchers and the Aboriginal community that are built on mutual respect, trust, and common goals can be leveraged to enable the strategic delivery of health services for Aboriginal people.

The success of this framework offers an incentive for policy makers to provide recurrent funding to facilitate longer term planning through secure employment of managers, speech-language pathologists and pre-planning ENT surgical lists with the required audiology preparatory assessments. The ACCHS are a fundamental part of this framework, with services in every Australian state and territory and all large urban centres. ACCHS used local service providers and local schools to enable HEALS to rapidly provide services to children in need. This model could be replicated to address multiple Aboriginal health concerns on a national scale. Given the volume of children HEALS treated and the willingness of service providers, HEALS was only restricted by time and budget. These constraints resulted in a brief window of service, after which the HEALS Project Officer's employment was suspended, and, in most cases, so were the relationships between the ACCHS and local service providers.

While short-term health interventions have the capacity to provide long-term benefits; interventions that are unsustained or delivered in a stop-start fashion also have the potential to be perceived negatively when funding abruptly runs out.[21] From the perspective of the Aboriginal community this is a regular occurrence and can lead to frustration, mistrust and a reluctance to be involved in future interventions. An alternative strategy is to implement healthcare programs that demonstrate long-term vision by providing services that have a stable presence in the Aboriginal community with recurrent funding.[22] While this approach requires more commitment from federal and state level policy-makers, any serious strategy aimed at closing the gap should be mindful of the limited capacity short-term, small-scale health initiatives have in the face of such an important and challenging task, and how the perception of such initiatives may affect future involvement from the Aboriginal community.

The short lead-in time to completion time prevented the design and implementation of a clinical monitoring and evaluation plan in both 2013, and 2014. Hence, this evaluation is largely descriptive and a more detailed analysis of downstream outcomes for the children such as school attendance, school performance and developmental outcomes has not been possible. However, the importance of a quantitative evaluation should be stressed, and is planned for future iterations of HEALS. A further limitation is that we were not able to capture diagnostic level assessments of the speech sound and/or language delay the speech pathologists treated. Health professionals determined their management plan without interference from HEALS management, who focussed on service delivery. This enhanced efficiency, but limited our ability to document detailed speech-language pathology reports.

Given the socioeconomic and health disadvantages that the Aboriginal community face, programs providing easier access to specialist healthcare services are likely to be part of effective and achievable strategies to Close the Gap. Such programs are likely to benefit from collaborative relationships between Aboriginal and non-Aboriginal agencies based on mutual respect and common goals. HEALS included such a strategy, providing a framework for the delivery of specialist health services to a population with the greatest need but barriers to access. While this is a common paradigm in the Aboriginal health sector, the success of the HEALS intervention demonstrates that it need not be an enduring one.

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Supporting Information

Additional supporting information may be found in the online version of this article:

Supplementary Table 1: Illustrative quotations.