Developing an Index of Care for Museum Use.

When human remains are displayed in a museum setting they bring home the humanity of our shared history in a way no other type of exhibit, however well curated, can achieve – and the more information available about the individuals represented by these remains, the more we are able to appreciate the differences and similarities between our ancestors and ourselves, and the result is a greater level of engagement with our past.

Disability and health-related caregiving are constants of human existence, and are immediately relatable. At some point almost everyone has needed care, has given care, or both. Where evidence in human remains suggests receipt of care to cope with disabling impacts of disease or injury, focusing on this deeply personal experience opens a pathway not only the person at the centre of the story, but also to the multiple, interconnected elements of the world this person inhabited. The past comes alive.

The goal of the '*User-Friendly Index of Care'* Project is to extend opportunities for learning about past disability and care to the widest possible audience. As experts in public education, museums have a very important role to play in achieving this. We have overwhelmingly written those with disability, and those who cared for them, out of our history; now it is time to recognise them.

THE PROJECT:

The **Index of Care** (www.indexofcare.org) is an instrument developed by and for bioarchaeologists researching past disability and health-related care provision. Case study-based, and triggered by evidence an individual lived with a pathology for which they likely required support, it contains four 'Steps' designed to help assess likely need for care; identify the sort of care required and provided; and interpret the implications of care for understanding the lifeways in which it occurred (see below). However, although the Index has been applied very effectively in archaeological research, it was created for specialists and can be complicated to navigate.

We believe a modified version of the Index might assist in developing interpretive materials when museum exhibitions contain human remains displaying evidence for pathology, and we provide an example of how this might work over the page. We are seeking museum staff willing to log into the Index and provide feedback on whether such a tool might be relevant for them. Specifically, we would like to find out from you:

- the extent to which human remains in museum displays are interpreted for the public - could a focus on disability and care enrich this?
- if '*yes',* could a tool such as the Index of Care be useful for this purpose?
- is the Index of Care usable as it currently exists, or does it need modifying to meet museum-purposes – and if so, what needs to change?
- would you be willing to become involved in developing and testing a version of the Index better suited to museum use?

The Four Steps of the Index of Care

Step 1:

Describe, diagnose, document

Describes individual's remains, mortuary treatment; records pathology; documents all aspects of lifeways. Provides context essential for analysis in Steps 2, 3 and 4.

Step 2:

Assess disability / need for care

(i) considers likely ***clinical*** features of pathology;
(ii) identifies likely ***functional*** impacts in terms of (a) *basic activities of daily living** and (b) *instrumental activities of daily living***; and
(iii) assesses whether care was likely required (if NO, study ends).

Step 3:

Construct model of care

Produces a model of likely caregiving in response to clinical and functional impacts [Step 2] within context [Step 1] constraints, addressing 'constants of care'***; indirect support; care duration; skills and resources required; etc.

Step 4:

Interpret implications of care

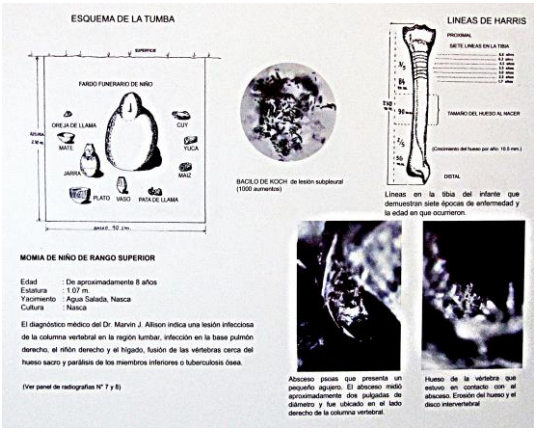
Unpacks implications of care model [Step 3] within context [Step 1] for insights into social relations, practice and organisation (generic decision pathway examines care choices made and possible motivations). Asks what lived disability and care suggests about the *person* at the centre of study.

* *'Basic activities of daily living'* are activities essential to survival. ** '*Instrumental activities of daily living'* are everyday work, social, and domestic activities. *** 'Constants of care' are practical elements of caregiving (e.g. provision of food, hygiene management) common across time and culture, often in response to problems in performing *basic activities of daily living*.

Applying the Index of Care

The column on the right summarises the results of a case study carried out in 2018 using the Index of Care. At this time, the remains of the Nasca Boy (a name coined by the case study authors in the absence of an identifier) were exhibited, in the company of several other mummy remains, in the Ica Museum, Nasca Region, Peru. Although respectfully presented, minimal information was provided about the child. The interpretive poster contained only a sketch of burial treatment; basic information on age, height, provenance, culture and diagnosis; and images of osteological and haematological evidence of disease.

The Nasca Boy: front view, and side view with grave goods in the background.



Official interpretive poster. *Images with kind permission of the Ica Museum.*

Comparing the Ica Museum poster's account of the Nasca Boy with that of the Index of Care, it's clear that a far richer story than a simple description of demographic status and disease is possible. We believe that an Index of Care, modified as necessary to meet specific museum requirements, could help facilitate enriched interpretation in such displays.

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Scan QR code to go to the Index of Care

The Nasca Boy[1]

STEP 1. DESCRIBE ~700AD; male; ~8yrs; Nasca, Peru. Well-preserved mummy. Diagnosis: histological / radiographic evidence for tuberculosis (TB); Pott's disease (TB of spine), onset ~2+yrs, progressing to paraplegia at ~6-7yrs; Miliary (blood borne) TB at 8yrs, death in days/weeks.

Mortuary: shaft tomb; textile-wrapped 'mummy bundle' sitting on adobe stool used in life for transport (unique arrangement); grave goods standard for child but for *atypical* set of panpipes. Lifeways: small farming settlement; likely kin-based; harsh climate, stressful political environment, declining population health. *Note: little known of children's status in Nasca culture.*

STEP 2. ASSESS NEED FOR CARE ***Clinical***: TB of spine: fever, weight loss, delayed growth, back / chest pain, respiratory/general immune system dysfunction; eventual immobility - impacting any/all organ systems. Miliary TB - blood-borne infection overwhelms all body systems.
Functional*:* delays in motor / social skills development, unable to participate in most 'normal' childhood activities (e.g. play, domestic tasks); paralysis results in problems with most / all '*Basic activities of daily living*'.
Care Needed? YES

Step 3. MODEL OF CARE ***Accommodation:*** likely included efforts to enable participation in social activities (critical for psychological wellbeing).
Direct support: all '*constants of* care' - continuing and intensive nursing, including regular monitoring of health status, hygiene (waste removal, bathing, protect integument), feeding (special diet?), maintain hydration and temperature regulation, massage and repositioning (encourage organ function, prevent potentially fatal pressure sores).

STEP 4. INTERPRET ***Community***: survival to 8yrs in harsh lifeways reflects commitment to care despite economic and emotional costs; primary carers likely immediate family, but enabled by group support. Unique mortuary inclusions: stool may reflect cosmology (needed for passage to, or use in, the afterlife?) or mark of identity; panpipes may have had shamanic significance or maybe reflect boy's love of music (?). Care in life and death indicate this child was highly valued, suggesting Nasca children *in general* may have been valued as individuals with distinct personalities and needs, filling existing knowledge gap. ***Individual***: persistence of caregiving, together with special burial treatment possibly reflecting personal interests, suggests a presence which rewarded love and expenditure of effort.

1 Tilley and Nystrom (2019) A 'cold case' of care: looking at old data from a new perspective in mummy research. *International Journal of Paleopathology* 25:72-81. Drawing by Geraldine Cave.