Strategies for engaging with users

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NoviLunio

28 June 2017

What next…

Novilunio is a no profit organization and a community of professionals that operates in the medical, technological, educational and assistive fields.
Its members work in the 'aid assistive technology' and promote a specific line of thought and design procedure in the field of computer aids.

Novilunio's object is to formulate protocols to define guidelines that may make effective the use of computer aids by disabled and elderly people.

Novilunio does not sell products

NoviLunio

SEE THE PERSON
NOT THE DEMENTIA

Marie Skłodowska-Curie Actions
Work Programme

"... Ensure excellent and innovative research **training** as well as attractive **career and knowledge-exchange** opportunities through cross-border and cross-sector **mobility** of researchers to best prepare them to face current and future **societal challenges**."

REMIND

Novilunio & Remind

- **Community-based enablement programmes**
- For individuals with dementia and their families, we provide **skill development settings** that promote their personal resources and nurture **opportunities for enablement, growth, learning, and mutual support.**

- For communities at large, our educational programs focus on prevention, early diagnosis and intervention, as well as the development of communities that respect the fundamental human rights of people with dementia and the principles and articles of the UN Convention on the rights of people with disabilities

Novilunio and WPs

Objectives:

- Use of everyday technology and motivation (WP1)

- Investigate what motivates people living with dementia to found and join online communities

- End user involvement (WP1)

- User engagement strategies (WP2)

Methodology:

- Ethnographic methods, anthropological approach, participation-observation

- Online Focus groups

A pilot randomized controlled trial of a self-management group intervention for people with early-stage dementia.

Quinn C[1], Toms G[2], Jones C[3], Brand A[4], Edwards RT[3], Sanders F[5], Clare L[1].

RESULTS:
Thirteen people with dementia were randomized to the intervention and 11 to TAU. Two groups were run, the first consisting of six people with dementia and the second of seven people with dementia. There was a small positive effect on self-efficacy with the intervention group showing gains in self-efficacy compared to the TAU group at three months (d = 0.35), and this was maintained at six months (d = 0.23). **In terms of intervention acceptability, attrition was minimal, adherence was good, and satisfaction ratings were high. Feedback from participants was analyzed with content analysis. The findings suggest the positive aspects of the intervention were that it** fostered independence and reciprocity, promoted social support, offered information, and provided clinician support.

Social support group interventions in people with dementia and mild cognitive impairment: a systematic review of the literature

Leung P , Orrell M, Orgeta V.

Results
A total of 546 studies were identified of which two met the inclusion criteria. We were not able to pool data for further analyses, as the interventions tested in the studies meeting the inclusion criteria were too dissimilar in content.

The first trial (n = 136) **showed a benefit of early-stage memory loss social support groups for depression and quality of life in people with dementia**. The second trial (n = 33) showed that post-treatment self-reported self-esteem was higher in the group receiving a multicomponent intervention of social support compared with that in the no intervention control group.

Effects of Support Groups for Individuals with Early-Stage Dementia and Mild Cognitive Impairment: An Integrative Review

Ying-Ling Jao, Fayron Epps, Caroline McDermott

18 eligible research articles were retrieved.

Support groups showed positive impacts on:

- participant acceptance of cognitive impairment;

- performance and satisfaction of meaningful activity;

- Resilience and self-help;

- care partner coping self-efficacy, perceived support, and preparation and task effectiveness.

Findings also revealed that support groups were well accepted by participants and care partners. Few studies included ethnic diversity, limiting the generalizability of findings.

Mental Health Foundation

«The value of peer support on cognitive improvement amongst older people living with dementia»

«It highlights the groups as a promising approach for:
- *maintaining cognitive faculties,*
- *reducing social isolation,*
- *increasing social networks and improving overall wellbeing…. Participants also reported positive benefits of the groups on communication abilities, managing memory and managing their lives"*

Evaluation report

Peer support groups to facilitate self-help coping strategies for people with dementia in extra care housing

Prepared by Lauren Chakkalackal from the Mental Health Foundation, and Dr Jayasree Kalathil from Survivor Research

mental health foundation

Objectives & Methodology

Self-funded by Novilunio

Objectives:

- Investigate what motivates people living with dementia to found and join online communities

- Develop new support services in Italy based on these findings

Methodology:

- Ethnographic methods, anthropological approach, participation-observation

- Data collected from June 2014 to October 2016

Support and Advocacy: Of, by and for people with dementia

About

- 2,500 members with dementia in 38 countries

- Founded in 2014

- Mission: "… seek to represent, support, and educate others living with the disease, and the wider dementia community."

Onlines activities for their members

- **Communication**: web site, social media, booklets, newsletters, blog, media releases, video chats, emails…

- **Support**: support groups, Café Le Brain, webinars, videos, special social gatherings

www.dementiaallianceinternational.org

About

- Private facebook groups collecting in total about **3,000 members** from across the world

- Founder: **Harry Urban** in 2013

- Managed by people with dementia

- Members are PLWD and those caring for them

- 4 groups to **different types of dementia**

- **Spanish** + **informational** + **Social** groups

Look for «Harry Urban» or «Forget me not» groups on facebook

Commonalities & Peculiarities

Commonalities

- Post-diagnostic support: positive, safe & empowering

- Social inclusion, friendship, intimacy

- Finding new role and purpose

- Agency & contested expertise: "Expert by experience"

Peculiarities

- Global activism

- Mentorship

- Info exchange between PLWD and carers

Added value!

- **Peer-to-peer support:**
  beyond stereotypes, stigma & **prejudice**

- **Self-organized** of PLWD

- **Usability** and accessibility:
  <u>everyday technology</u>

- **Identities**, roles, purposes:
  quality of life, **empowerment**

- **Activists** in the making that fight
  stigma and discrimination

Total non-video participants: 4 ▾

Bruce Phillips

Unmute   Stop Video   Invite   Manage Participants   24   Share Screen   Chat   Record   End Meeting

Philosophy

perception – emotion – experience – movement – communication – autonomy

Novilunio community has closely observed reality and the disability phenomenon, and has tried to single out the fundamental moments in one's life.

This has shown that phenomena such as perception, emotion, experience, movement, communication and autonomy are fundamental to the human life.

Accordingly, we have outlined a "natural" path to develop our professional activities.
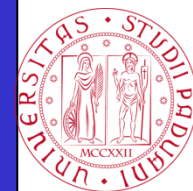
PERCEPTION

In order that a human being can perceive the reality surrounding him/her, he/she must be necessarily provided with perceptive organs.

Our senses – smell, hearing, sight, taste and touch – are human's instruments of sensorial perception.

Human can have other kinds of perception ….

perception
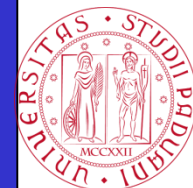emotion
experience
movement
communication
autonomy

EMOTION

What we perceive is codified and transferred to our nervous system.

Each kind of perception makes us generate some affective answer.

We all generate emotional reactions which at times are even imperceptible.

EXPERIENCE

Having generated some kind of feeling, we live through an emotional experience that enables us to establish a <u>connection</u> between what we perceive and every other thing.

Indeed, this emotional reaction enables us to remember things better and build stable relational processes.

perception
emotion
experience
movement
communication
autonomy

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MOVEMENT

Each kind of function effects a change from one state to another. The human locomotor system has underwent a long evolutionary process which has culminated in the present human motorial functions. Man is a bipedal being, has upper limbs free to move even during his walking, possesses an extraordinary forefinger-thumb pinch and an articulatory system for phonation…

perception
emotion
experience
movement
communication
autonomy
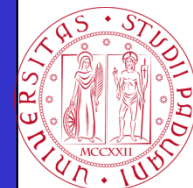
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COMMUNICATION

Communication enables man to perceive reality, interact with it and establish <u>relationships</u> with his fellow creatures and the environment surrounding him. Man is a social being, thus communication is the founding element in any society. Through his intellect, man can conceive and effect several forms of communication, from mime expressions to words, from writing to several forms of art.
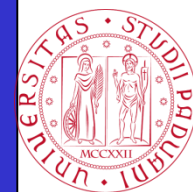
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AUTONOMY

The capability to move and communicate enable man to maintain his own <u>identity</u>.

Man wants to be autonomous and, as a general rule, find his own place in society.

It may seem a paradox, but the fact is that man needs to feel he is totally <u>independent</u> from his fellow creatures and, at the same time, perfectly <u>integrated</u> to society.

It is necessary that everything that may define a single person as unique and special may come out.

At the same time, man needs to experience the awareness that he is interdependent not only with his fellow creatures but also with the other beings.

perception
emotion
experience
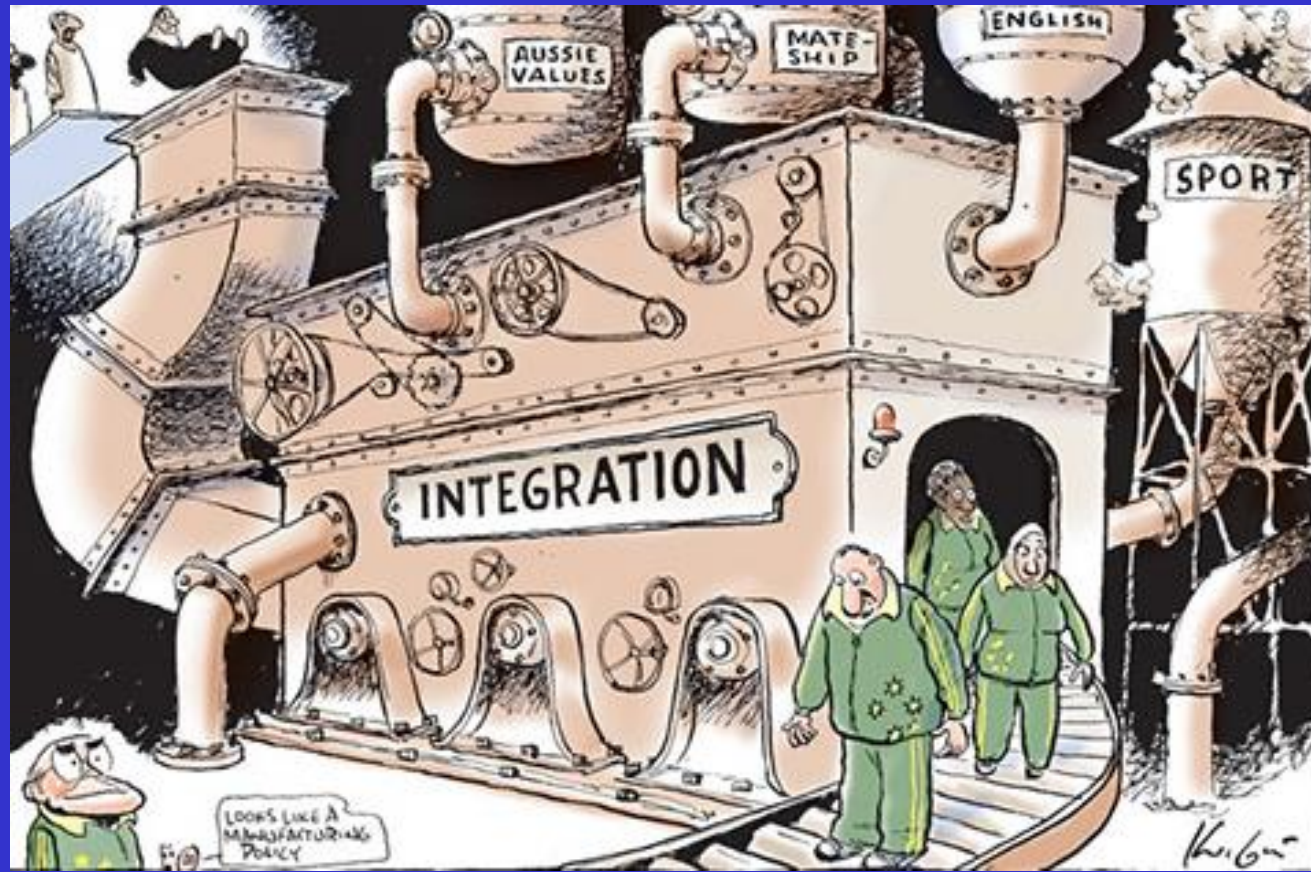movement
communication
autonomy

INTEGRATION

Our path leads us to a final result.
Man can produce civilization on condition that he is enabled to perceive, elaborate and live through experiences, and move, communicate and be autonomous.

perception
emotion
experience
movement
communication
autonomy

integration

movement

emotion

perception

communication

autonomy

experience

Novilunio

network
community

Definition of AT device

Any item, piece of equipment,
or product system
whether acquired commercially off the shelf,
modified or customized,
that is used to <u>increase</u>, <u>maintain</u>, or <u>improve</u>
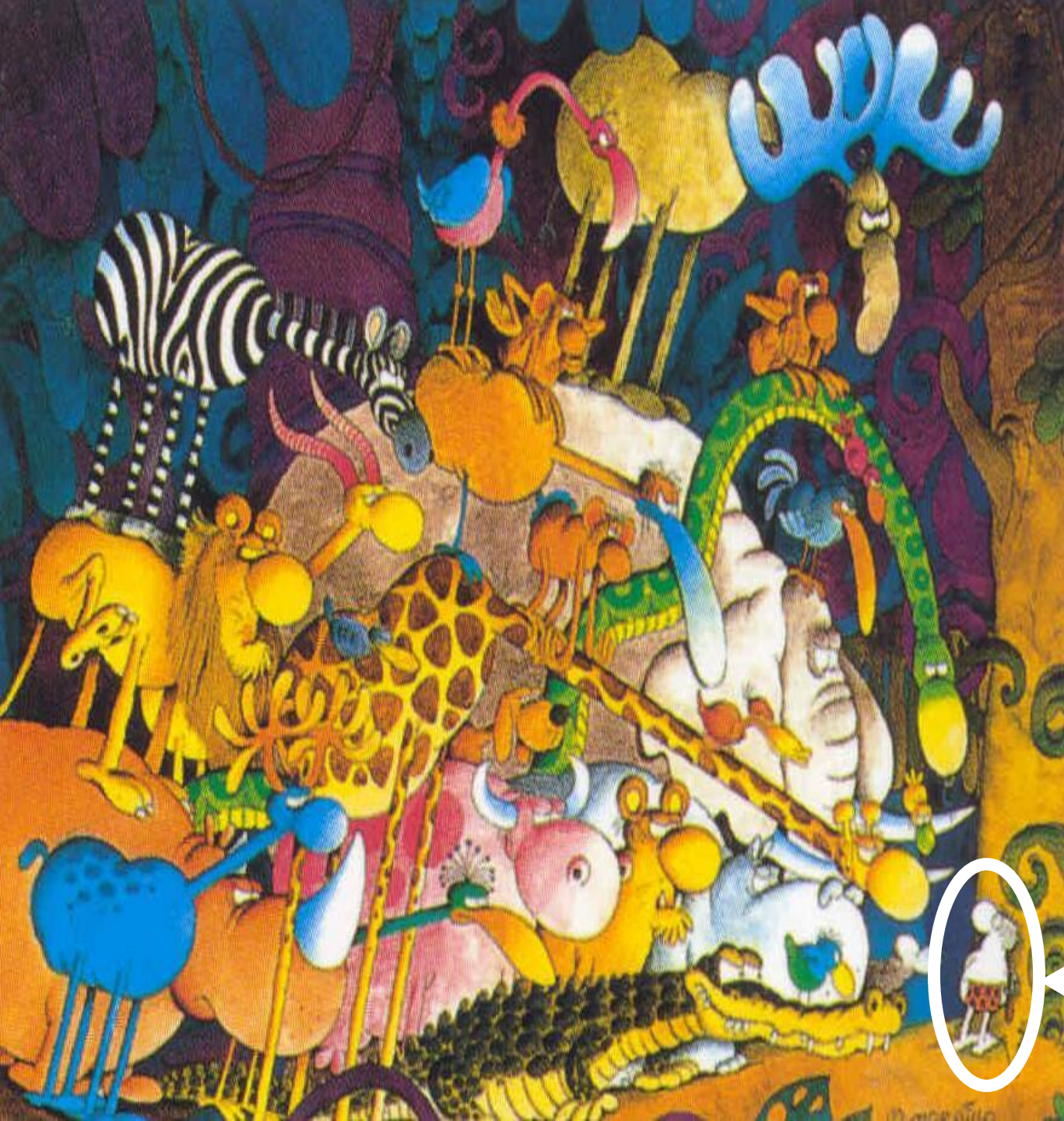functional capabilities of individuals with
disabilities

ASSESSMENT

A review of the patient's history as provided by parents, teachers, therapists and care givers

An individualized evaluation by a multidisciplinary team. This most often occurs at A.T. Labs.

USER

Matching person and technology

Matching Person and Technology
ASSESSMENT PROCESS

HOME :: March 9, 2016

Matching Person and Technology (MPT) Assessment Process

Continued advances in technologies have created a wide range of options in technology functions and features. As a result, consumers and providers often report feeling overwhelmed and confused when faced with decisions regarding device selection and use. In response to this, and in hopes of providing a more personal approach to matching individuals with the most appropriate technologies for their use, the Matching Person and Technology (MPT) assessment process was developed.

The MPT process contains a series of instruments (self-report checklists about consumer predispositions to and outcomes of technology use) which take into account

- the environments in which the person uses the technology,
- the individual's characteristics and preferences, and
- the technology's functions and features.

Characteristics within these three components can each contribute either a positive or a negative influence on technology use. If there are too many negative influences, the chance of the technology being successfully used is greatly reduced. In fact, the technology itself can appear perfect for a given need, but if the user does not possess the appropriate personal characteristics or does not receive needed support, that perfect technology may go unused or be used inappropriately.

The MPT process contains a series of instruments:

- For persons considering any kind of technology, but believe there may be a general reluctance to use technology, the *Survey of Technology Use (SOTU)* helps identify technologies an individual feels comfortable or successful in using so that a new technology can be built around existing comfort or success.

- Technology-specific forms are:

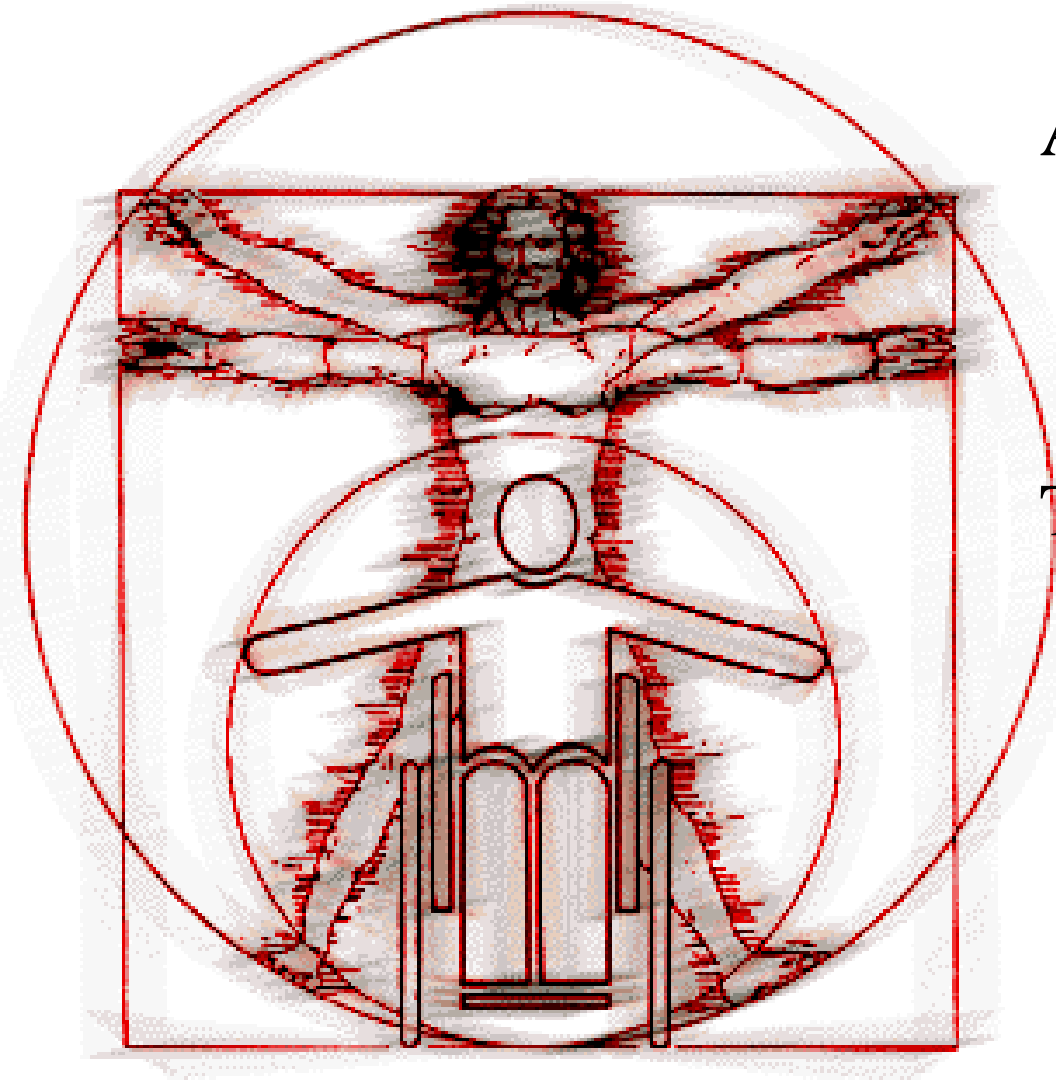http://www.matchingpersonandtechnology.com/

PLANNING

A written report with recommendations for assistive technology implementation.

The report provides specific product information in order to assist the school district, community center, agency or parent in implementing recommendations expeditiously.

DEVELOPMENT

The Computer Aid Lab supervises the development of the Life and Technology Project and training

Combine the Grace of Macintosh with the Power of UNIX

FOLLOW-UP

Keep in touch with the patient!

How the A.T. aid is going?

Update…

Thank you!

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Associazione NOVILUNIO Onlus

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