EPTRI®
European Paediatric Translational Research Infrastructure

How Culture, Ethnicity, and Religious Observation Shape User Acceptance of and Accessibility to Pediatric Medical Technologies

Prof. Patrice L. (Tamar) Weiss
ALYN Hospital | University of Haifa

ALYN PARC
The Helmsley Pediatric & Adolescent Rehabilitation Research Center

EPTRI Webinar– 8/4/2025

אוניברסיטת חיפה
UNIVERSITY OF HAIFA
جامعة حيفا

Cultural, ethnic, and religious factors significantly influence the acceptance and accessibility of pediatric medical technologies

Cultural Impact: Factors like religion, geographical region, family structure, and education shape health beliefs and practices. Families often rely on cultural and spiritual values for health solutions.

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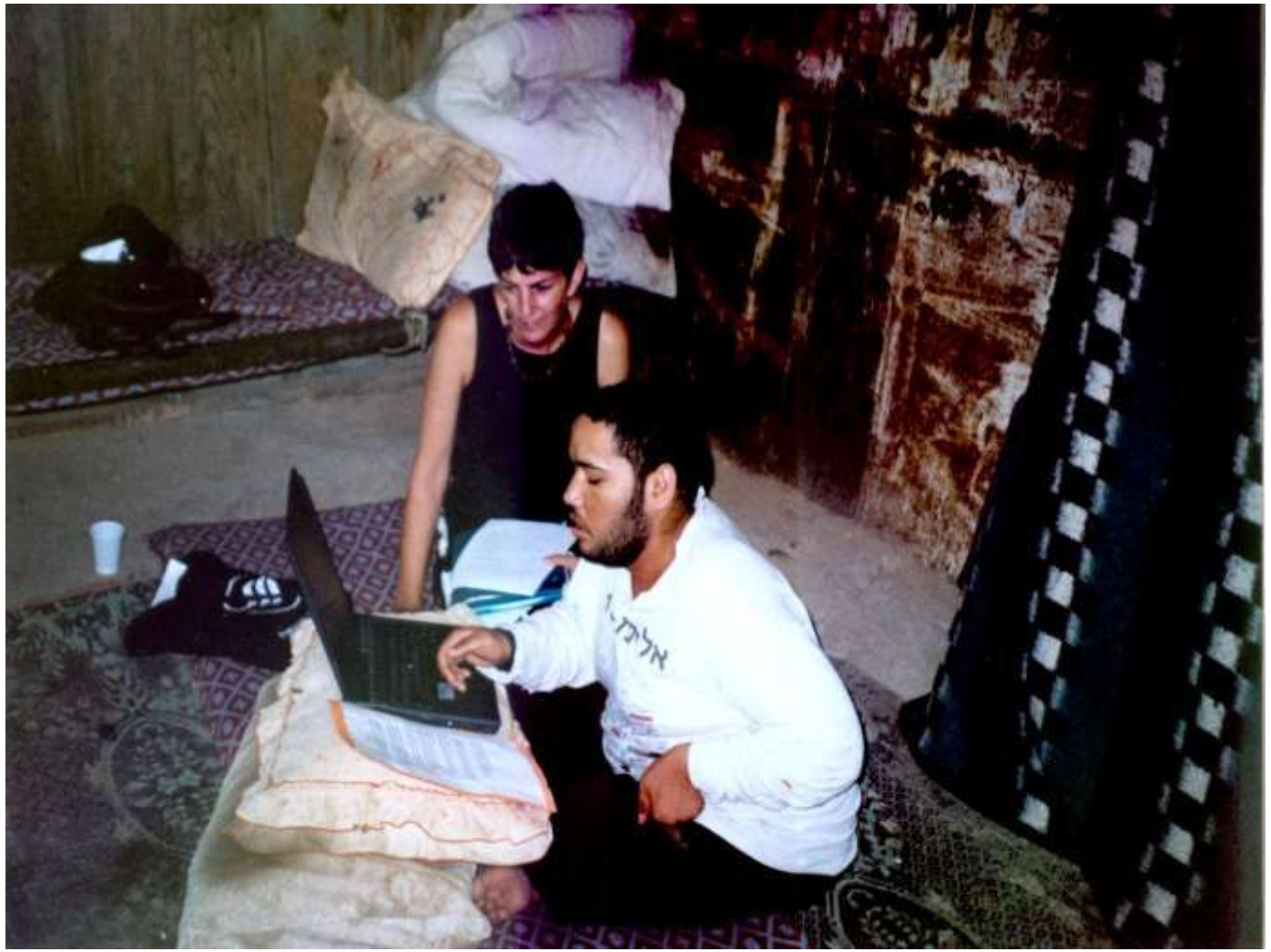
Religion: Religious beliefs affect nutrition, medical care, and health practices. For example, dietary restrictions and rituals vary across religions like Buddhism, Islam, and Judaism.

Geographical Region: Cultural differences influence perceptions of health, illness, and pain. Practices like using talismans or avoiding eye contact are common in some regions.

Yildiz S, Toruner EK, Altay N. Effects of different cultures on child health. J Nurs Res Pract. 2018;2(2): 06-10.

Participatory design approaches and culturally tailored frameworks can be effective in creating inclusive, context-sensitive solutions



However, notable gaps remain in addressing both systematic and unintentional biases related to religious, ethnic and cultural diversity

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ALYN HOSPITAL
Pediatric & Adolescent Rehabilitation Center
Jerusalem, Israel

Global facility for active & intensive rehabilitation of children and adolescents facing a diverse array of physical challenges (TBI, ABI, SCI, neuromuscular & genetic conditions, bone and joint diseases, severe burns, oncology).

ALYN provides specialized rehabilitation for children and adolescents from across Israel, regardless of background, religion, or nationality

3-Prong Approach

Prong 1: Helmsley Pediatric & Adolescent Rehabilitation Research Center (PARC)

Remote & hybrid tele-rehabilitation

Personalization of simulated rehabilitation tasks

Novel Patient Reported Outcome Measures

Authoring tools, dynamic monitoring

Pediatric Orthopedic Rehabilitation
Dr. Sharon Eylon

Technology for Rehabilitation & Independent Performance
Dr. Naomi Gefen

Pediatric Neurological Rehabilitation
Dr. Keren Politi

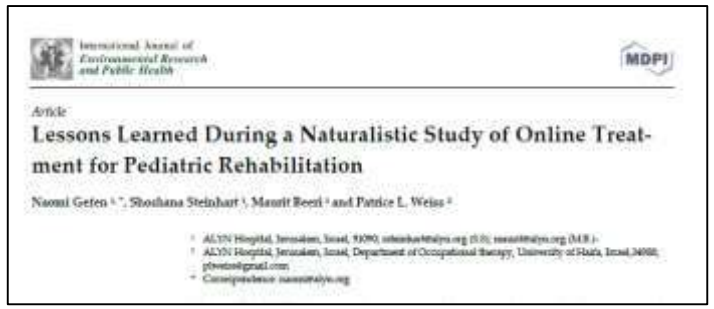
Motion analysis to improve therapy effectiveness

Laboratory for Pediatric Motion Analysis & Biofeedback Rehabilitation
Dr. Simon-Henri Schless

Pediatric Neuropsychology & Rehabilitative Psychology
Dr. Neta Yitzhak

Applied Pediatric Rehabilitation Research Foci
Prof. Tamar Weiss

EEG monitoring to track response to treatment


International Journal of Environmental Research and Public Health

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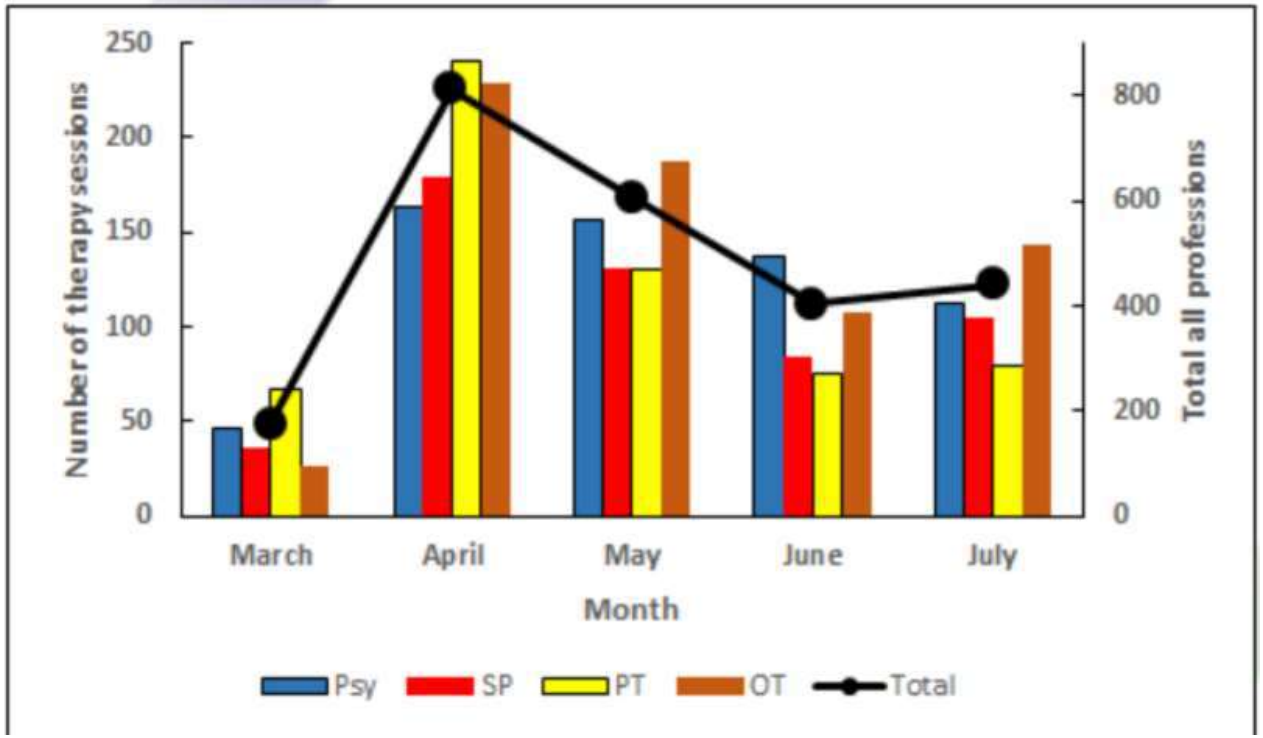
Article

Lessons Learned During a Naturalistic Study of Online Treatment for Pediatric Rehabilitation

Naomi Gefen [1,*], Shoshana Steinhart [1], Maurit Beeri [2] and Patrice L. Weiss [2]

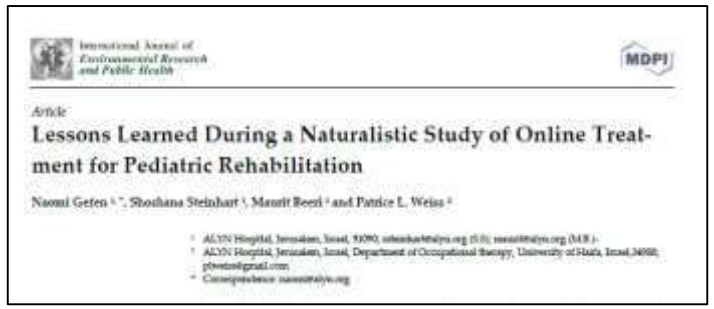
Constraints related to use of tele-rehabilitation



144 children participated
61 therapists
2500 therapy sessions March-July 2020
2 Focus Groups

What is attractive about online, at-home therapy?

- Convenience (but need to respect boundaries)
- Develop good habits for “home-work” between therapy session



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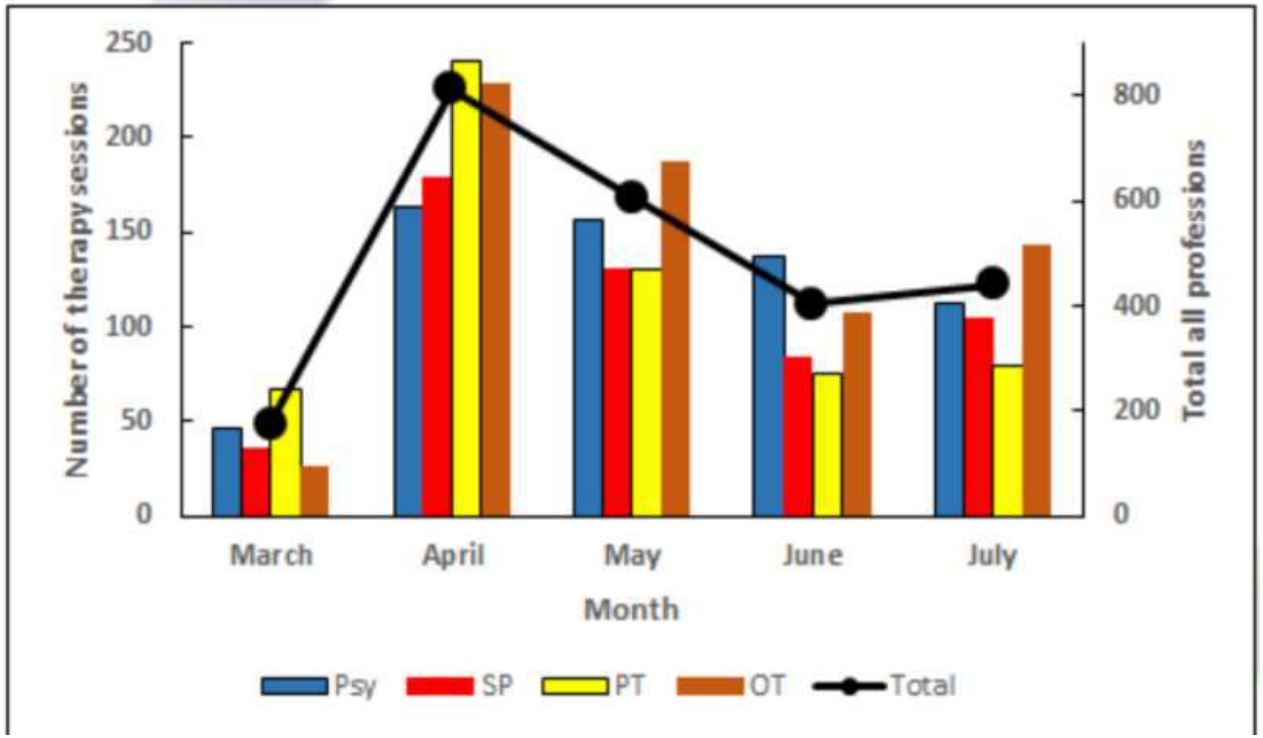

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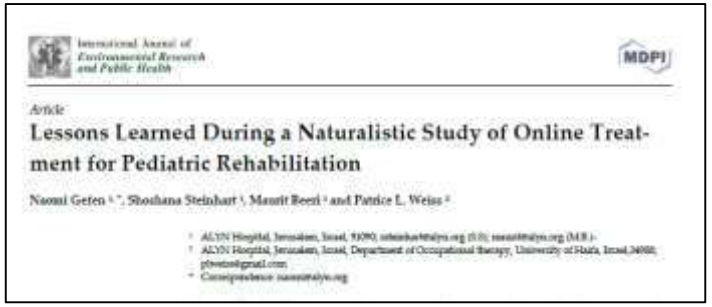
- Adopt only appropriate therapeutic objectives
- Continue to explore developing technologies that will provide greater data on users



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[2] ALYN Hospital, Jerusalem, Israel; Department of Occupational Therapy, University of Haifa, Israel,34988, pbweiss@gmail.com
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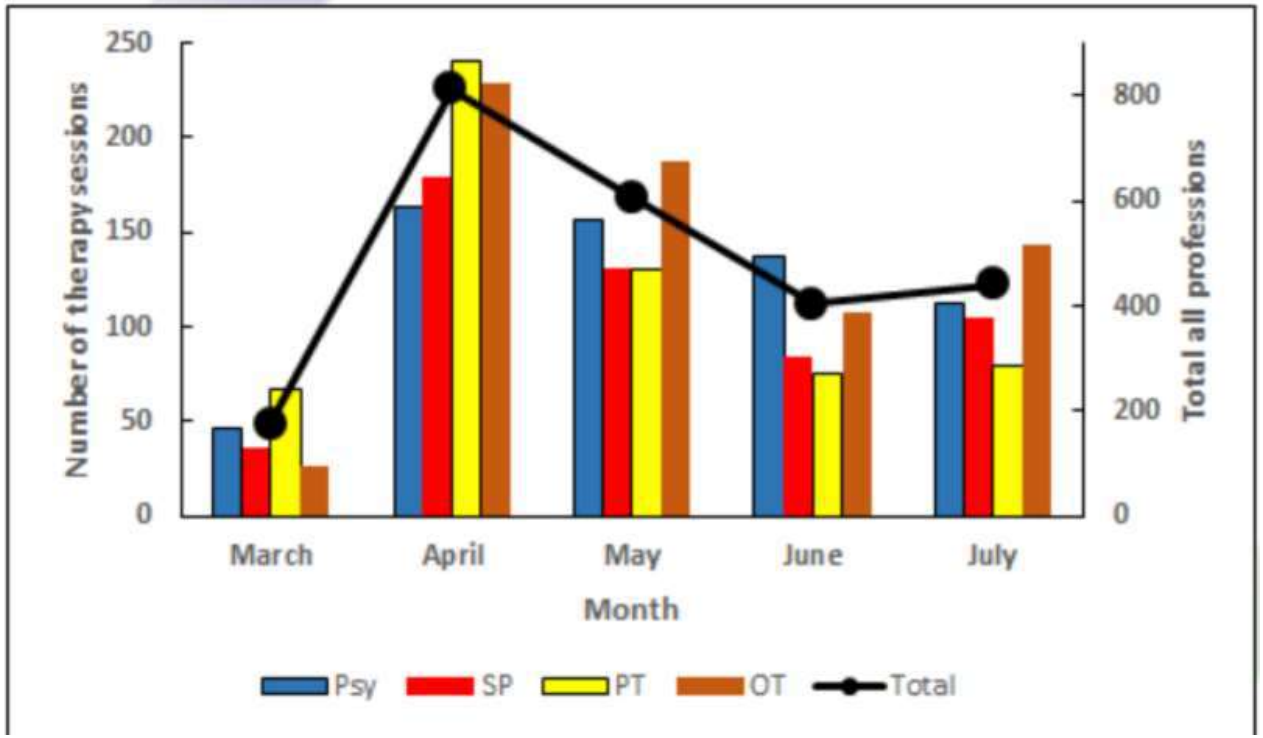

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- **Be aware of culturally-sensitive issues (modesty) such as refusal of female adults (e.g. mothers) in ultra-religious Jewish and Arabic sectors be videotaped.**

LIMBQ-Kids Patient-Reported Outcome Measure (PROM) for Children with Lower Limb Length Discrepancies

Chhina et al. Journal of Patient-Reported Outcomes (2021) 5:30
https://doi.org/10.1186/s41687-021-00299-w

Journal of Patient-Reported Outcomes

RESEARCH Open Access

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children MDPI

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>100 Instructions and Questions related to:

-Appearance
-Physical health
-Psychological health
-School
-Social health

Forward & Backward Translation + Cognitive Debriefing

A Guide for Translation and Cultural Adaptation of the Q-Portfolio Questionnaires

Cognitive Debriefing Interview Guide
1. Ask each participant the following questions about the instructions: a) What are the instructions asking you to do? If the patient does not understand the instructions, describe what the instructions are asking them to do and then ask the following: b) How can the translation of the instructions be improved so that you can understand them correctly?
2. Ask each participant the following questions about each questionnaire item: a) What is the item asking you? If the participant does not understand what the item is asking, describe the item's meaning to the participant and then ask the following: b) What was difficult to understand about the item? c) Is there a specific word that was difficult for you to understand? If yes, what is the word? d) How can the translation of the item be improved so that you can understand the item's meaning correctly?
3. Ask each participant the following questions about the response options: a) What do the different response options mean? b) Describe the difference between the response options. If the patient does not understand the differences between the meanings of the response options, describe the differences and then ask the following: c) What was difficult to understand about the response options? d) Is there a specific word that was difficult for you to understand? If yes, what is the word? e) How can the translation of the response options be improved so that you can understand the meaning of the response options correctly?

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Identified unique needs for Hebrew PROM:

- need to have gender specific versions of PROM
- Need to have versions with and without vowel markings

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Prong 2: ALYNnovation Center

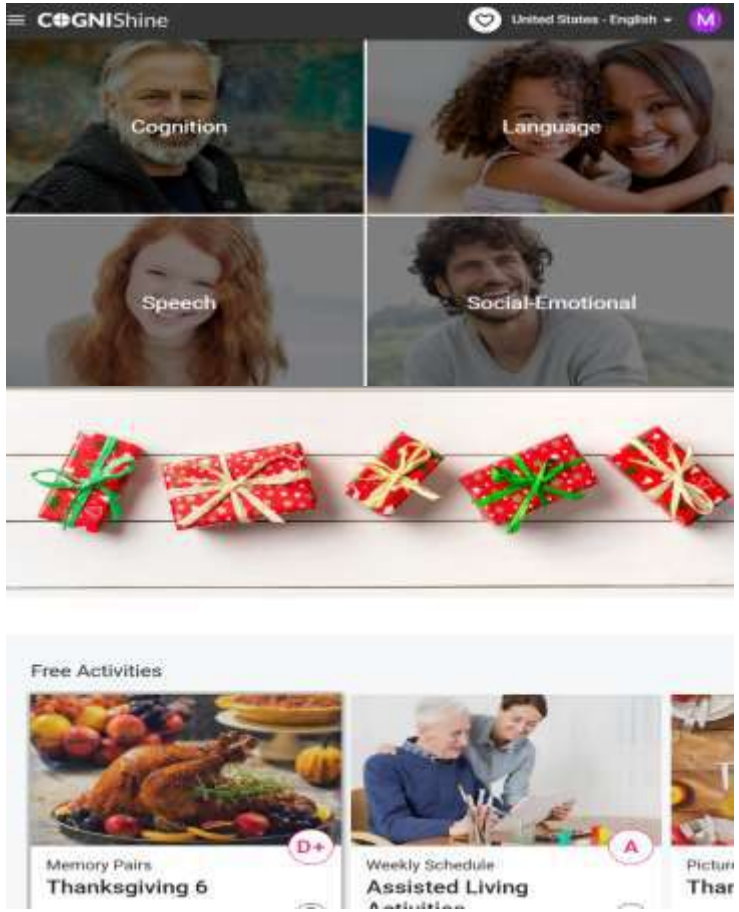
16
Startups

18
Products

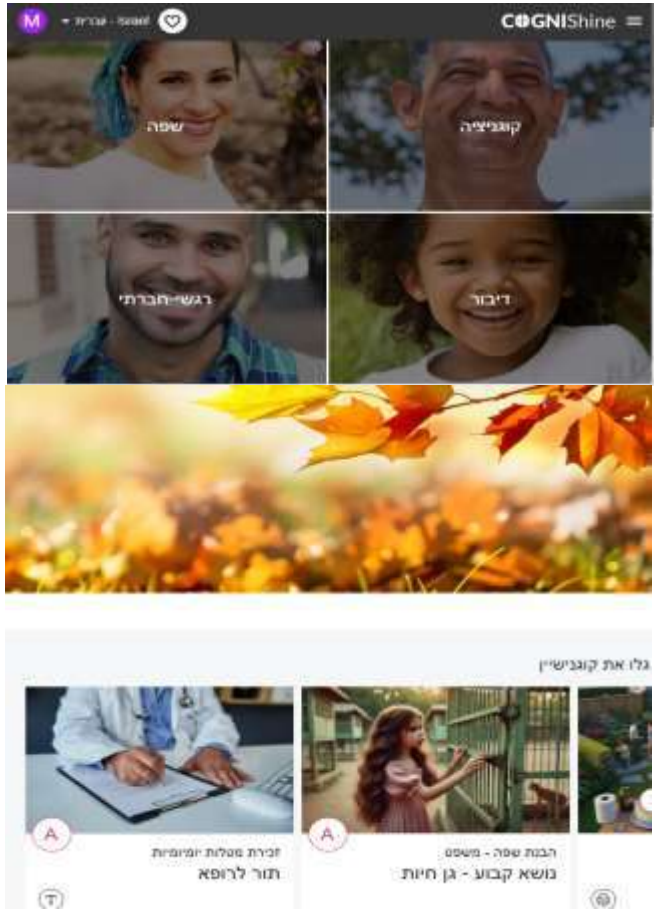
ALYN HOSPITAL

COGNIShine

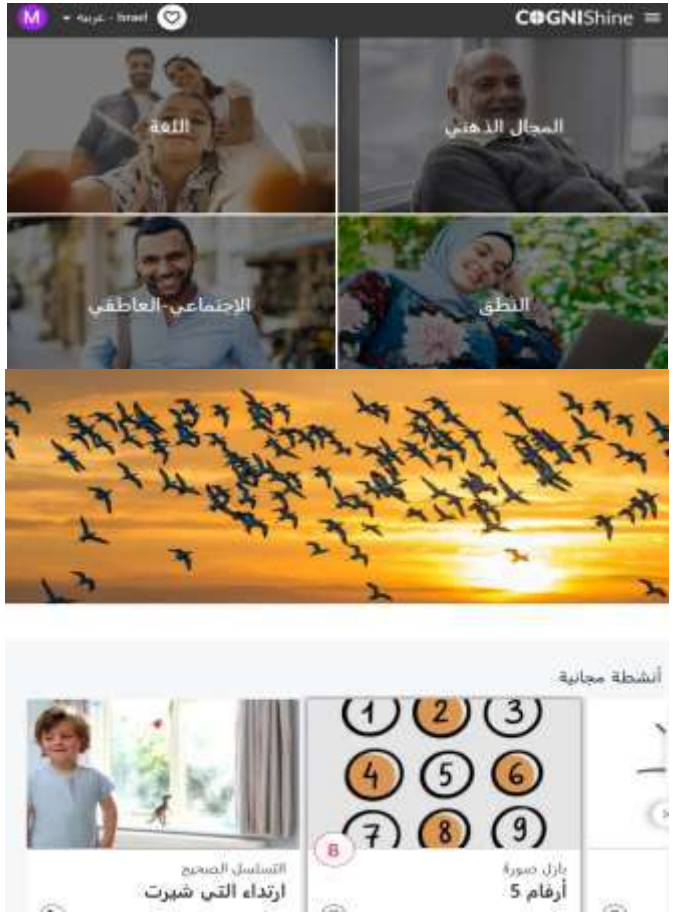
Accessible, Multi-lingual, Multi-culture online platform to provide cognitive and language rehabilitation



English



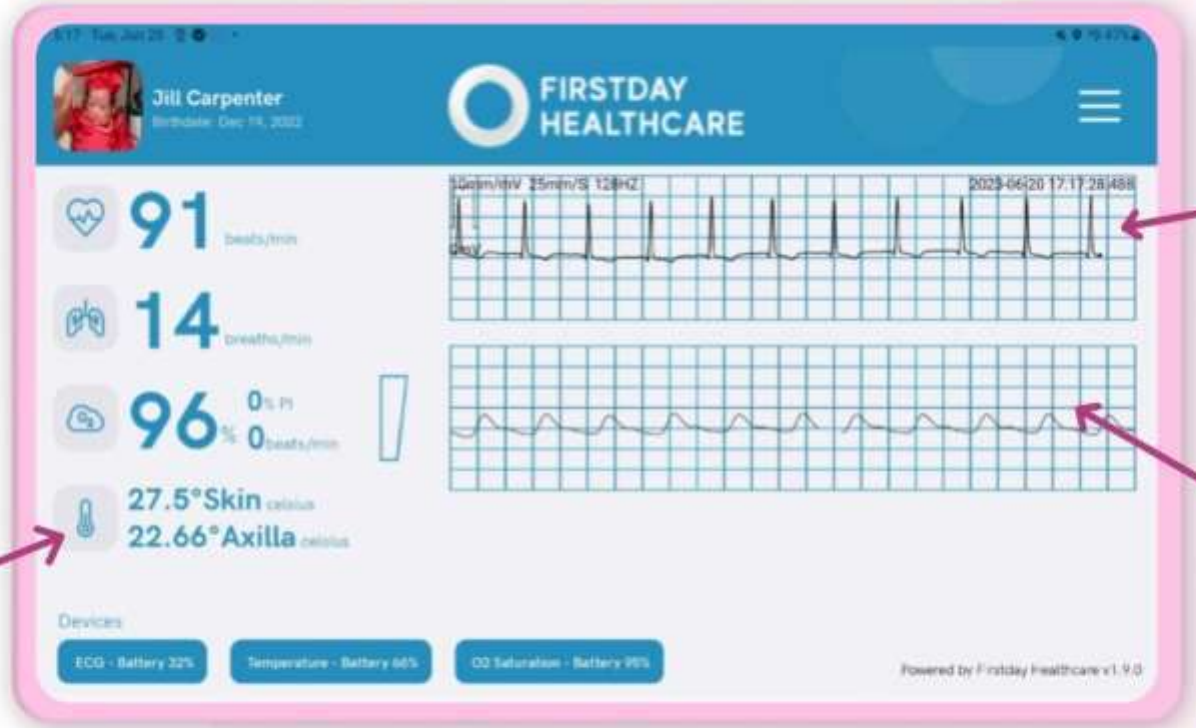
Hebrew



Arabic

Firstday Healthcare provides continuous monitoring and 24/7 access to reduce parental anxiety by transmitting alerts of key physiological biomarkers

Infant's vital signs are collected from medical grade wireless sensors by Bluetooth to the Firstday Healthcare Gateway tablet



Parent Smartphone App

Avoid smartphones –
need alternative alert systems

Realtime Vital Signs

Graph vital sign trends and share results with others. SMS alerts sent to families and care team based on predetermined set values.

Medical Record

Upon login to our app, parents are able to find their infant's entire NICU medical record, which is constantly updated by our team. Parents can then download and share parts, or the entire record, with the click of a button.

Infants Providers / Appointments

All contact information of infant's doctors with upcoming appointment dates with SMS reminders to improve compliance.

HIPAA Compliant text and video

Have a question or concern at 2AM? Our 24/7 neonatal providers are available to provide assistance and loop in the infant's Pediatrician as well as the hospital Neonatologist.

Avoid smartphones –
need alternative alert systems

WHEELCHAIRS OF HOPE

Durable, low-cost wheelchair, for developing countries

ALYN HOSPITAL

Unique Challenges in some parts of world: Wheelchairs of Hope

- UNICEF and WHO report that **7 million children in developing countries need wheelchairs (W/C) but lack access**:
  - ~90% cannot attend school or interact with peers

- Major barriers of most option:
  - adult-sized wheelchairs unsuited for terrain
  - mechanical challenges
  - high costs for poor families

Unique Challenges in some parts of world: Wheelchairs of Hope

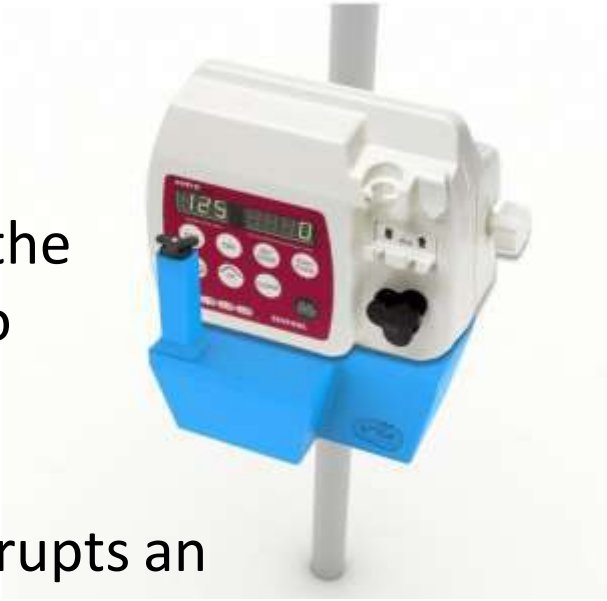
- Wheelchairs of Hope developed a durable, **low-cost (< $120), low-maintenance, easy-to-navigate wheelchair** for developing countries
  - Comes in 3 bright colors, is lightweight & ships globally with simple assembly instructions.
  - **Used by >10,000 children in 27+ countries**

- Currently collaborating with ALYN Hospital to develop a **2nd-generation W/C with improved head support and recline** to help children with more complex conditions

https://www.youtube.com/watch?v=wBuZSUHNpnw

Prong 3: PELE – Customized low- and hi-tech solutions to accommodate diverse needs

https://youtu.be/l89KBfcwxQY



- Feeding devices such as the Kangaroo automatically beep when the feeding session is over. Typically, a switch needs to be released to stop the beeping.
- This is considered to desecrate Sabbath observance since it interrupts an electoral circuit. PELE created a solution to prevent Sabbath-observing families who would otherwise have to wait until the end of Shabbat to stop the beeping.
- Adaptation allows the beep to be detected; after a predetermined time, an automatic mechanism is activated that presses the machine's off button.

There continue to be many additional sensitive issues related to pediatric care:
that technology does not yet solve

- **Use of technologies that facilitate independence and/or communication but cannot be used by Sabbath observers**

Additional sensitive issues related to pediatric care:

Need for creative technology solut

- Incontinence intervention when caregiver of same sex is not available
- Hydrotherapy in mixed therapeutic pools when modesty is of concern
- Not all cultures have similar views of importance of a child's independent functioning: e.g., eating and dressing on their own

Using technology in a way that respects cultural, ethnic and language diversity

- Recognize, learn about & respect **diverse user needs and attitudes**
- Engage with communities during **design and testing phases to created culturally responsive innovation**
- Aim to bridge gap between **technology and tradition by fostering collaboration among clinicians, researchers, and families**
- Adopt only **equitable, ethical, and effective rehabilitation solutions**

Thank You!