SUNNAAS REHABILITATION HOSPITAL

Making sure rehabilitation research makes a difference for real life problems
- Examples from recent brain injury studies.

Marianne Løvstad

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Professor, Dept. of Psychology, University of Oslo

The main aim in all rehabilitation is to help reestablish a sense of purpose and meaning in peoples lives

”Disordered mind, wounded soul: The emerging role of psychotherapy in rehabilitation after brain injury” - Prigatano 1991

What is brain injury rehabilitation about?

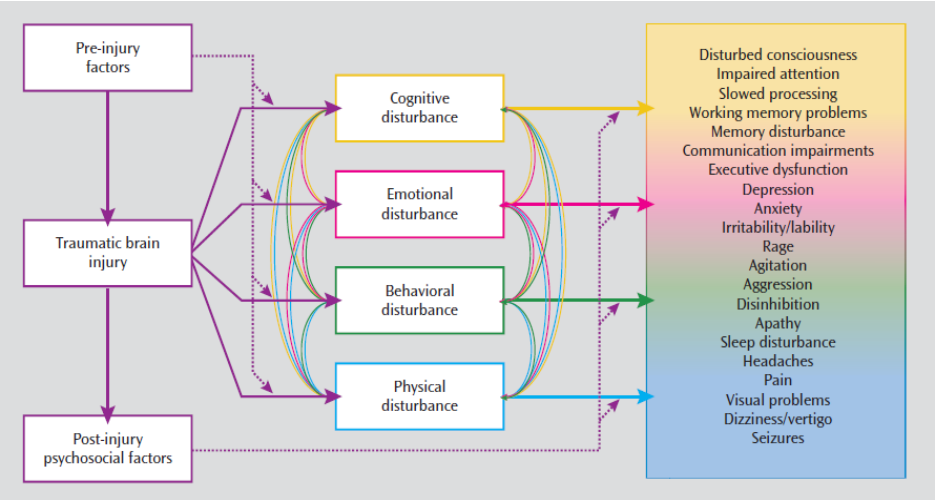
... a process whereby people with brain injury work **together** with professional staff and others to **remediate** or **alleviate** cognitive deficits arising from a neurological insult.

- focus is on **improving aspects of everyday life** and
- needs to involve **personally meaningful themes**, **activities, settings and interactions**

Wilson, 2008; Ylvisaker & Feeney, 2000

Necessary starting point

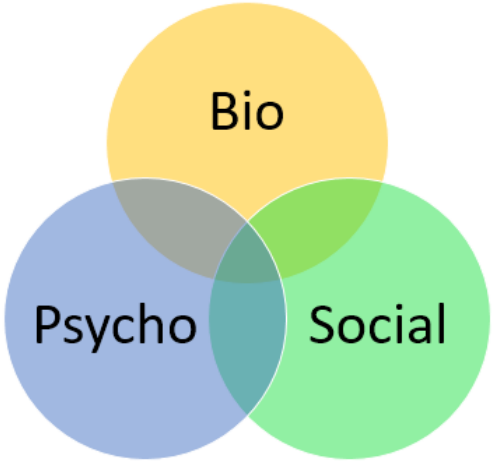
- Brain injuries cause extremely **heterogenous** outcomes
- Brain injuries interact in complex ways with **pre- and comorbid factors**
- Despite functional stabilization, the **impact of brain injuries varies** throughout the life-time

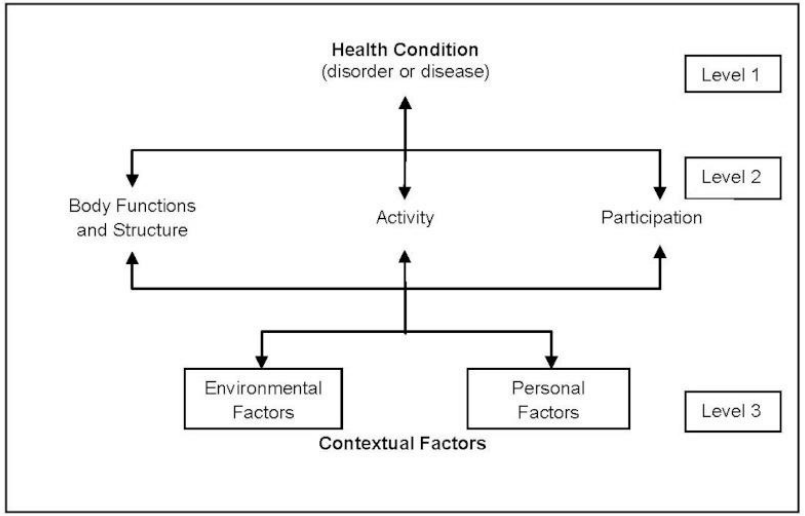


Adapted from Silver & Arciniegas (2008). Brain Injury Medicine. Eds. Zasler, Katz, Zafonte, 963–994.

- Brain injuries are not a one-time acute event, but a **life-long and dynamic condition**
- **Unmet needs** are common in the chronic phase
- Interventions need to be **patient-centered** and adress **everyday life** and **participation**

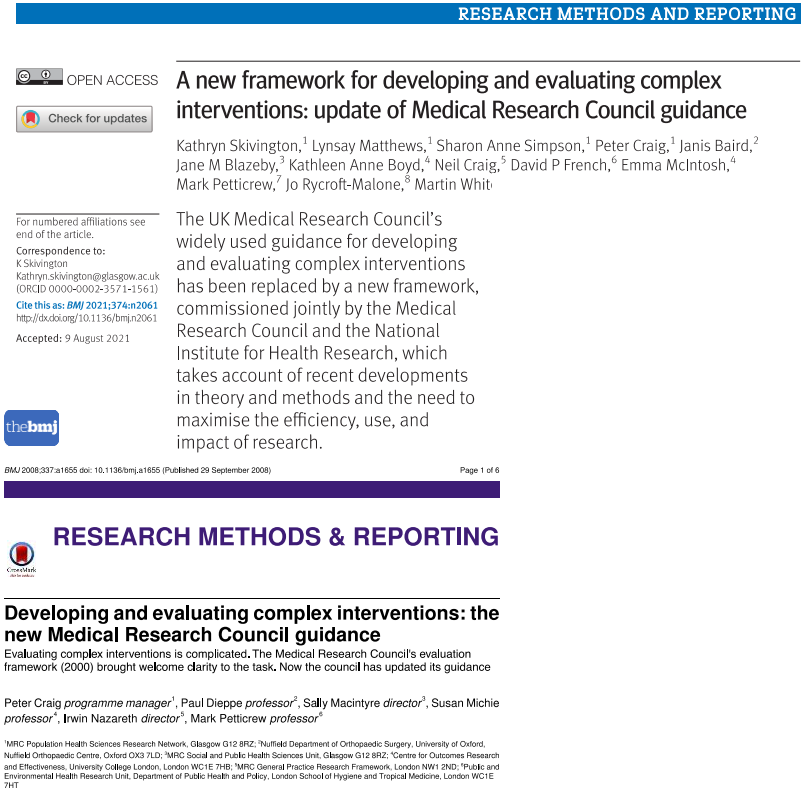
Biopsychosocial perspective: International Classification of Functioning, Disability and Health (ICF) (WHO)





- a person's level of functioning is the result of a dynamic interaction between her or his health conditions, environmental and personal factors.
- The ICF is a biopsychosocial model which integrates social and medical approaches to disability.

Complex and heterogenous conditions call for complex and heterogenous interventions



RESEARCH METHODS AND REPORTING

OPEN ACCESS

Check for updates

A new framework for developing and evaluating complex interventions: update of Medical Research Council guidance

Kathryn Skivington,[1] Lynsay Matthews,[1] Sharon Anne Simpson,[1] Peter Craig,[1] Janis Baird,[2] Jane M Blazeby,[3] Kathleen Anne Boyd,[4] Neil Craig,[5] David P French,[6] Emma McIntosh,[4] Mark Petticrew,[7] Jo Rycroft-Malone,[8] Martin Whit

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Cite this as: *BMJ* 2021;374:n2061
http://dx.doi.org/10.1136/bmj.n2061

Accepted: 9 August 2021

The UK Medical Research Council's widely used guidance for developing and evaluating complex interventions has been replaced by a new framework, commissioned jointly by the Medical Research Council and the National Institute for Health Research, which takes account of recent developments in theory and methods and the need to maximise the efficiency, use, and impact of research.

BMJ 2008;337:a1655 doi: 10.1136/bmj.a1655 (Published 29 September 2008)

RESEARCH METHODS & REPORTING

Developing and evaluating complex interventions: the new Medical Research Council guidance

Evaluating complex interventions is complicated. The Medical Research Council's evaluation framework (2000) brought welcome clarity to the task. Now the council has updated its guidance

Peter Craig *programme manager*[1], Paul Dieppe *professor*[2], Sally Macintyre *director*[3], Susan Michie *professor*[4], Irwin Nazareth *director*[5], Mark Petticrew *professor*[6]

[1]MRC Population Health Sciences Research Network, Glasgow G12 8RZ; [2]Nuffield Department of Orthopaedic Surgery, University of Oxford, Nuffield Orthopaedic Centre, Oxford OX3 7LD; [3]MRC Social and Public Health Sciences Unit, Glasgow G12 8RZ; [4]Centre for Outcomes Research and Effectiveness, University College London, London WC1E 7HB; [5]MRC General Practice Research Framework, London NW1 2ND; [6]Public and Environmental Health Research Unit, Department of Public Health and Policy, London School of Hygiene and Tropical Medicine, London WC1E 7HT

- Treatment effects are the sum of all program ingredients and the synergies between them
- Many active ingredients, difficult (impossible?) to disentagle isolated elements
- Takes into account the context of service delivery
- If implemented, what happens to the context?
- What real world effects could the intervention have?

Examples from two goal-oriented studies:

Borgen *et al. Trials* (2020) 21:294
https://doi.org/10.1186/s13063-020-4195-5

Trials

STUDY PROTOCOL Open Access

Traumatic brain injury—needs and treatment options in the chronic phase: Study protocol for a randomized controlled community-based intervention

Ida Maria H. Borgen[1,2*], Marianne Løvstad[2,3], Nada Andelic[1,4], Solveig Hauger[2,3], Solrun Sigurdardottir[3], Helene L. Søberg[1,5], Unni Sveen[1,5], Marit V. Forslund[1], Ingerid Kleffelgård[1], Marte Ørud Lindstad[6], Laraine Winter[7,8] and Cecilie Røe[1,9]

Rohrer-Baumgartner *et al. Trials* (2022) 23:169
https://doi.org/10.1186/s13063-022-06048-8

Trials

STUDY PROTOCOL Open Access

Rehabilitation for children with chronic acquired brain injury in the Child in Context Intervention (CICI) study: study protocol for a randomized controlled trial

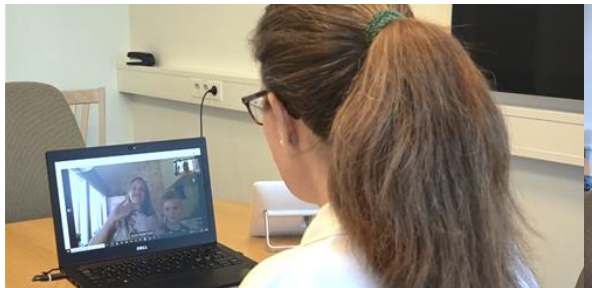
Nina Rohrer-Baumgartner[1*], Ingvil Laberg Holthe[1,2], Edel Jannecke Svendsen[1,3,4], Cecilie Røe[4,5,6], Jens Egeland[2,7], Ida M. H. Borgen[2,5], Solveig L. Hauger[1,2], Marit V. Forslund[5], Cathrine Brunborg[8], Hege Prag Øra[1], Hilde Margrete Dahl[9], Line Kildal Bragstad[4,6,10], Eli Marie Killi[11], Maria Sandhaug[11], Ingerid Kleffelgård[5], Anine Pernille Strand-Saugnes[11], Ingeborg Dahl-Hilstad[12], Jennie Ponsford[13,14], Laraine Winter[15,16], Shari Wade[17,18] and Marianne Løvstad[1,2]

THE CHILD IN CONTEXT INTERVENTION
THE CICI STUDY

Funded by The Research Council of Norway

Common for the studies

1. Ask for **Target outcome areas:**
   - name and rate severity of main problem areas /challenges in daily life caused by the injury
2. Establish **SMART-goals** and **goal attainment scaling**
3. Use **evidence-based strategies** to reach goals
4. Predominantly **tele-health** interventions
5. In the **chronic phase**

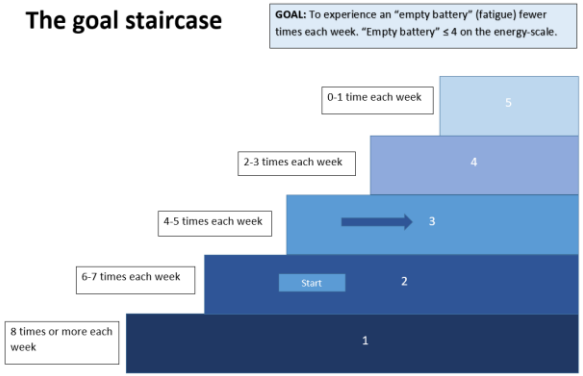


SMART goals and Goal Attainment Scaling (GAS)

Goal Attainment Scaling:

- **+2 =** *A lot better than expected*
- **+1 =** *A little better than expected*
- **0 =** *Expected level of achievement*
- **-1 =** *A little less than the expected level* } **Baseline level**
- **-2 =** *A lot less than the expected level*

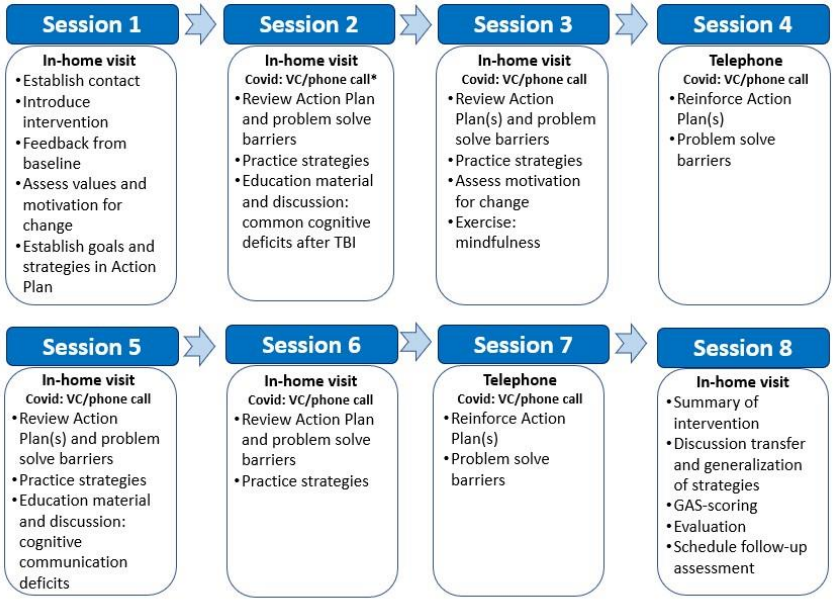
The goal staircase



Bovend'Eerdt et al., 2009; Kiresuk & Sherman, 1968; Malec, 1999; Turner-Stokes, 2009

Evidence-based strategies to reach goals

Traumatic brain injury; needs and treatment options in the chronic phase. A randomized controlled community-based intervention.

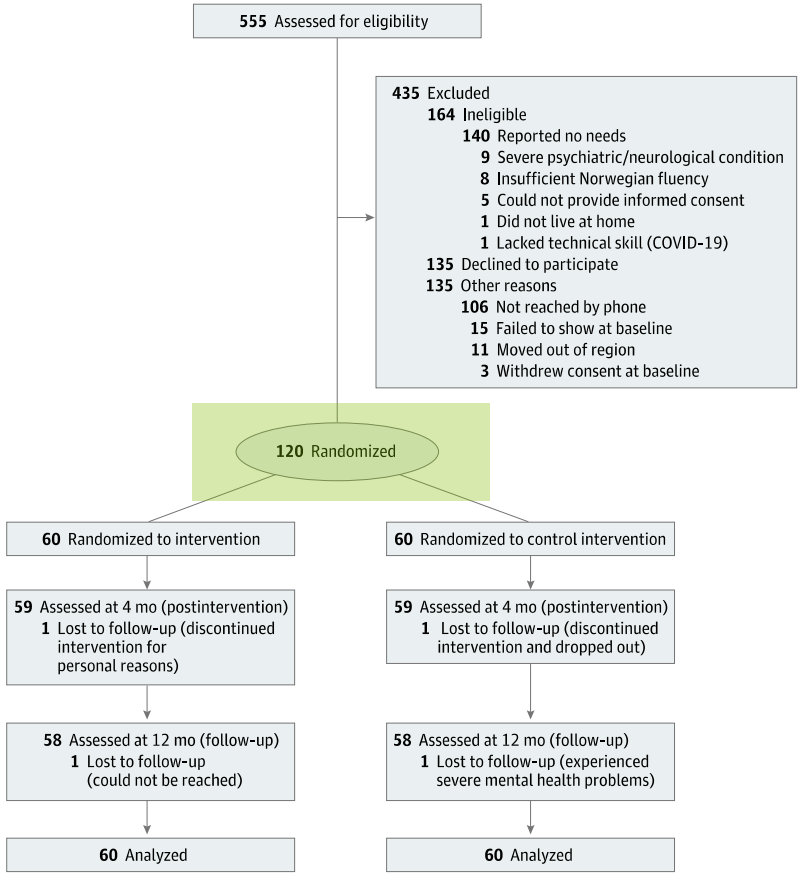


*Delivery format was adjusted due to the Covid-19 pandemic, i.e., videoconference (VC) and phone calls replaced some home visits to reduce risk of infection.

Main approach:

- Identify main problem area(s)
- Establishing SMART goals and Goal attainment scaling (GAS)
- Establishing Action Plan that include goal, GAS and strategies
- Train strategies and problem solve barriers
- Family members invited and encouraged to participate

Figure 1. Study Flowchart



All participants ($N = 120$)	Mean (SD)/*n* (%)/ median (range)
Age, y	45.15 (14.44)
Number of men	85 (71%)
Education level	
≤10 y	10 (8%)
11-13 y	69 (58%)
14-16 y	24 (20%)
≥17 y	17 (14%)
TBI severity by GCS score[a,b]	9.3 (4.3)
Mild complicated	41 (36%)
Moderate	18 (16%)
Severe	54 (48%)
Time since injury,[c] y	4 (2-24)
Cause of injury[d]	
Transport-related accident	50 (43%)
Fall	39 (34%)
Violent incident	9 (8%)
Other (sports- or leisure-related)[e]	18 (15%)
Work status	
Full-time employment	30 (25%)
Part-time employment[f]	29 (24%)
100% disability pension	55 (46%)
Retired	6 (5%)

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Results – problem areas and goal attainment

J Head Trauma Rehabil

OPEN

Patient-Reported Problem Areas in Chronic Traumatic Brain Injury

Ida M. H. Borgen, Cand. Psychol.; Ingerid Kleffelgård, PhD; Solveig L. Hauger, PhD; Marit V. Forslund, MD, PhD; Helene L. Søberg, PhD; Nada Andelic, MD, PhD; Unni Sveen, PhD; Laraine Winter, PhD; Marianne Løvstad, PhD; Cecilie Røe, MD, PhD

Target Outcome categories by domain	Patient, n (%)	Family member, n (%)
Cognitive difficulties	**92 (77%)**	**47 (60%)**
Memory	44 (37%)	18 (23%)
Executive functions	35 (29%)	31 (40%)
Attention	26 (22%)	9 (12%)
Processing speed	7 (6%)	2 (3%)
Language	6 (5%)	3 (4%)
Visuospatial	2 (2%)	1 (1%)
Somatic difficulties	**97 (81%)**	**56 (72%)**
Fatigue	61 (51%)	38 (49%)
Dizziness/balance	20 (17%)	9 (12%)
Sleep	19 (16%)	7 (9%)
Sensory functions	18 (15%)	9 (12%)
Pain	17 (14%)	11 (14%)
Motor functions	11 (9%)	6 (8%)
Natural functions	2 (2%)	1 (1%)
Emotional difficulties	**46 (38%)**	**38 (49%)**
Anxiety	14 (12%)	6 (8%)
Irritability	13 (11%)	17 (22%)
Emotion perception and regulation	9 (8%)	8 (10%)
Depressive thoughts and feelings	9 (8%)	7 (9%)
Identity, acceptance, and sense of self	5 (4%)	6 (8%)
Coping with stress	3 (3%)	2 (3%)
Social function and participation	**29 (24%)**	**31 (40%)**
Social participation	13 (11%)	16 (21%)
Self-sufficiency	6 (5%)	1 (1%)
Social communication	4 (3%)	10 (13%)
Lack of meaningful activities	4 (3%)	0 (0%)
Behavioral dysregulation	3 (3%)	9 (12%)

Journal of *Clinical Medicine*

MDPI

Article

Goal Attainment in an Individually Tailored and Home-Based Intervention in the Chronic Phase after Traumatic Brain Injury

Ida M. H. Borgen [1,2,*], Solveig L. Hauger [2,3], Marit V. Forslund [1], Ingerid Kleffelgård [1], Cathrine Brunborg [4], Nada Andelic [1,5], Unni Sveen [1,6], Helene Søberg [1,7], Solrun Sigurdardottir [8], Cecilie Røe [1,9] and Marianne Løvstad [2,3]

SMART goal by domain	n
Cognitive difficulties	**38**
Memory	20
Executive functions	10
Attention	7
Language	1
Somatic difficulties	**53**
Fatigue	22
Sleep	12
Motor functions	8
Dizziness/balance	7
Pain	4
Emotional difficulties	**35**
Anxiety	10
Irritability	10
Depressive thoughts and feelings	8
Emotion perception and regulation	3
Coping with stress	3
Identity, acceptance, and sense of self	1
Social function and participation	**25**
Social communication	9
Lack of meaningful activities	7
Social participation	4
Self-sufficiency	4
Behavioral dysregulation	1
Total goals	151

- 93% (!) positive goal attainment
- All participants improved on at least one goal
- Median GAS change: +2

Results RCT

JAMA Network Open

Original Investigation | Physical Medicine and Rehabilitation

Effect of an Individually Tailored and Home-Based Intervention in the Chronic Phase of Traumatic Brain Injury
A Randomized Clinical Trial

Ida M. H. Borgen, PhD; Marianne Løvstad, PhD; Solveig L. Hauger, PhD; Marit V. Forslund, PhD; Ingerid Kleffelgård, PhD; Nada Andelic, PhD; Unni Sveen, PhD; Helene L. Søberg, PhD; Solrun Sigurdardottir, PhD; Laraine Winter, PhD; Marte Ørud Lindstad, MSc; Cathrine Brunborg, MSc; Cecilie Røe, PhD

- Primary outcomes:
  - Participation →
  - Brain injury related QoL →
- Secondary outcomes:
  - Brain injury symptoms ↓
  - Anxiety symptoms ↓
  - Generic QoL ↑

The Child in Context Intervention

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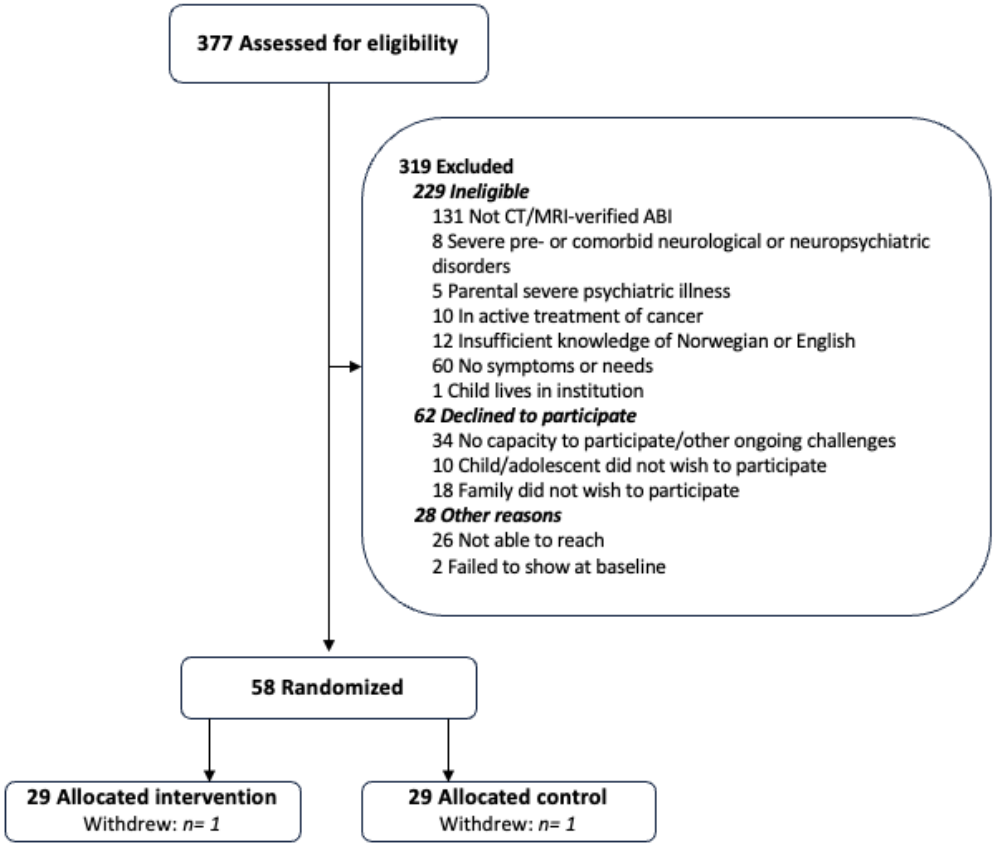
- Individualized, manualized, goal-oriented rehabilitation for children (6-16) with ABI in the chronic stage
- Involves children, families and schools

Recruitment	Baseline assessment	Intervention / control group	Assessment after 6 months	Assessment after 9 months
	One face to face meeting with baseline assessment, before randomization	• 7 online family sessions • 4 school meetings • 1 one-day parent seminar • SMART goal approach • Psychoeducational booklet: Control group: • Treatment as usual	Main outcomes: • Parent reported brain injury symptoms • Parenting Self-efficacy	

THE CHILD IN CONTEXT INTERVENTION
THE CICI STUDY

CICI: preliminary results



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Journal of Clinical Medicine

MDPI

Article

Feasibility and Acceptability of a Complex Telerehabilitation Intervention for Pediatric Acquired Brain Injury: The Child in Context Intervention (CICI)

Ingvil Laberg Holthe [1,2,*], Nina Rohrer-Baumgartner [1], Edel J. Svendsen [1,3,4], Solveig Lægreid Hauger [1,2], Marit Vindal Forslund [5], Ida M. H. Borgen [2,5], Hege Prag Øra [1], Ingerid Kleffelgård [5], Anine Pernille Strand-Saugnes [6], Jens Egeland [2,7], Cecilie Røe [4,5,8], Shari L. Wade [9,10] and Marianne Løvstad [1,2]

Svendsen et al. BMC Health Services Research (2023) 23:603
https://doi.org/10.1186/s12913-023-09589-z

BMC Health Services Research

RESEARCH ARTICLE Open Access

Children's, parents', and teachers' experiences of the feasibility of a telerehabilitation intervention for children with acquired brain injury in the chronic phase – a qualitative study of acceptability and participation in the Child In Context Intervention (CICI)

Edel Jannecke Svendsen[1,2,3], Eli Marie Klift[4], Nina Rohrer-Baumgartner[1], Ingvil Laberg Holthe[1,2], Maria Sandhaug[4], Ida M. H. Borgen[1,5], Shari L. Wade[6,7], Solveig Laegreid Hauger[1,2],

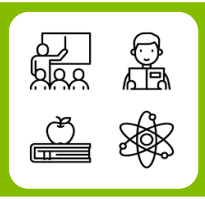
- SMART-goal domains and goal attainment in an individualized, goal-oriented intervention for children with acquired brain injury and their families. ¶

  Ingvil Laberg Holthe[1,2], Nina Rohrer-Baumgartner[1], Edel Svendssen[1,3], Cecilie Røe[4,5], Ida M. H. Borgen[1,5], Solveig L. Hauger[1,2], Jennie L. Ponsford[6,7], Jens Egeland[2,8], Shari L. Wade[10,11], Marianne Løvstad[1,2] ¶

- Children and families in need of rehabilitation in the chronic stage of acquired brain injury: clinical characteristics and main challenges in daily life ¶

  Nina Rohrer-Baumgartner[1], Ingvil Laberg Holthe[1,2], Edel Jannecke Svendsen[1,3], Hilde M. Dahl[4], Ida M. H., Borgen[1,4], Solveig L. Hauger[1,2], Malin S. Thulesius[1], Shari L. Wade[5,6], Cecilie Røe[4,7,8], Marianne Løvstad[1,2] ¶

CICI: problem areas according to the ICF



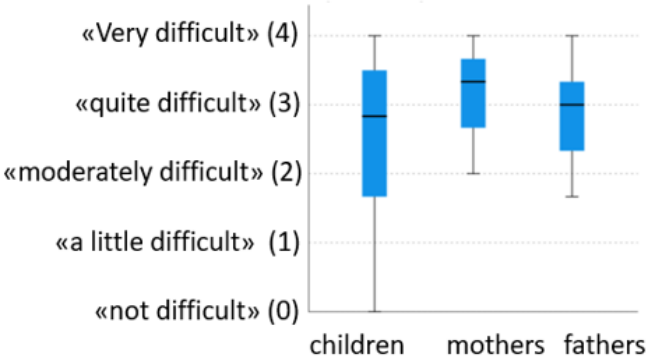
School

Fatigue

Emotional functions

CHILDREN: most frequent pABI-related challenges in daily life by ICF codes				
Rank	*ICF code*	*Description*	*ICF category*	*% of children*
1	D820	School education	Activity and Participation	70,7%
2	B130	Energy and drive functions	Body Functions	53.4%
3	B152	Emotional functions	Body Functions	44.8%

PARENTS: most frequent pABI-challenges in daily life by ICF codes				
Rank	*ICF code*	*Description*	*ICF category*	*% of parents**
1	B152	Emotional functions	Body functions	71%
2	B130	Energy and drive functions	Body Functions	61%
3	D820	School education	Activity and Participation	48%



CICI: Goals and goal attainment

90 goals, mean of 3 per family (range 1-5)

- 76 (84%): children's challenges in everyday life
- 14: parent issues (e.g. handling the child's symptoms, parents emotional functioning, siblings, family´s social functioning

Executing tasks independently in everyday life

N = 31

Emotional symptoms

N = 27

Fatigue and sleep

N = 19

Support functions and services

N = 17

Cognition

N = 11

Social interaction

N = 10

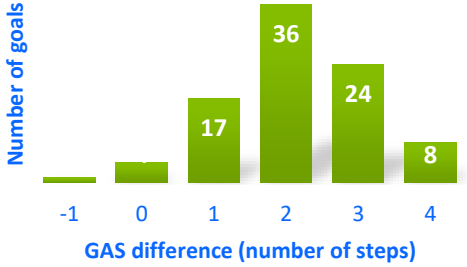
School

• N = 8

Physical functioning

• N = 7

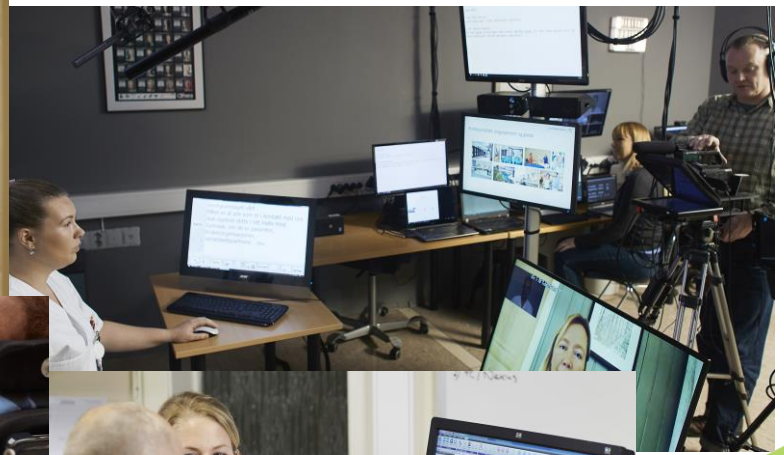
- 94% positive goal attainment
- Median GAS change: 2



Conclusions; rehabilitation research should:

- Embrace **complexity** and acknowledge the **dynamic** nature of injury impact
- Be **person-centered** and **individualized**
- Adress **everyday life** challenges
- Involve patient **context**
- Be specific and **goal driven**
- Be based on **evidence based recommendations**
- Adress **chronic** symptoms in the **community** setting

A thorough clinical, theoretical and empirical understanding has to be the basis of program development and is a prerequisite for successsfull implementation of rehabilitation technologies.



Thank you

- huge tribute to all exceptional institutions, co-auhtors, PhD students, post docs and collaborators in Norway, Australia & USA

- grateful for very close collaboration with Profs. Andelic & Røe and their research group at Oslo University Hospital

Funded by The Research Council of Norway