## Evidence tables for review question: D.2b What are the best methods to deliver and coordinate rehabilitation services and social services for children and young people with complex rehabilitation needs after traumatic injury when they transfer from inpatient to outpatient rehabilitation services?

**Table 15: Quantitative evidence tables**

| Study details | Participants | Interventions | Outcomes and Results | Comments |
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| **Full citation**<br>Braga, L. W., Da Paz, A. C., Ylvisaker, M., Direct clinician-delivered versus indirect family-supported rehabilitation of children with traumatic brain injury: a randomized controlled trial, Brain Injury, 19, 819-831, 2005<br><br>**Ref Id**<br>1206832<br><br>**Country/ies where the study was carried out**<br>Brazil<br><br>**Study type**<br>RCT<br><br>**Aim of the study**<br>This study aimed to compare the effectiveness of primarily parent- | **Sample size**<br>N=87 (randomised)<br>• Family-supported rehabilitation=44<br>• Clinician-delivered rehabilitation=43<br><br>N=72 (analysed)<br>• Family-supported rehabilitation=38<br>• Clinician-delivered rehabilitation=34<br><br>**Characteristics**<br>Age in months [Mean (SD)]:<br>• Family-supported rehabilitation = 97.66 (29.61)<br>• Clinician-delivered rehabilitation = 96.95 (30.30)<br><br>Gender (M/F):<br>• Family-supported rehabilitation (n) = 20/18 | **Interventions**<br>• *Both groups:* 12 months of intensive, individualised rehabilitation programmes.<br>• *Intervention group: Family-supported rehabilitation.* The intervention began with a 2-week assessment period, with scheduled hospital visits each morning. These visits consisted of multi-disciplinary assessments that identified areas needed for targeted rehabilitation (e.g. communication, activities of daily living). At least 1 parent attended each of these assessments, as well as daily support group meetings and training sessions. Information sessions included parental education on TBI, taught by trained members of the rehabilitation team. The support group and information sessions took place daily. Support meetings used a group therapy approach, encouraging parents to explore their feelings and concerns about their child's injury and rehabilitation, as well as share stories and coping | **Results**<br><br>*Changes in ADL (measured using SARAH scale of motor development) [mean (SD)]*<br><br>Higher=better.<br><br>At baseline:<br>• Family-supported rehabilitation: 2.5 (1.3)<br>• Clinician-delivered rehabilitation: 2.4 (1.3)<br>• No significant difference between groups<br><br>At 12 months (post-intervention)<br>• Family-supported rehabilitation: 3.1 (0.8)<br>• Clinician-delivered rehabilitation: 2.6 (1.1)<br>• Significantly higher (better) in the intervention group (p=0.018, Chi-squared test using proportions in each SARAH scale rating group) | **Limitations**<br>**Quality assessment: Risk of bias assessed using revised Cochrane risk of bias tool (RoB 2)**<br><u>Domain 1: Risk of bias arising from the randomization process</u><br>1.1 Was the allocation sequence random? Y - Computer-generated random number table.<br>1.2 Was the allocation sequence concealed until participants were enrolled and assigned to interventions? NI.<br>1.3 Did baseline differences between intervention groups suggest a problem with the randomization process? N - None of the baseline characteristics were significantly different.<br>*Risk-of-bias judgement:* Some concerns.<br><u>Domain 2: Risk of bias due to deviations from the intended interventions (effect of assignment to intervention)</u><br>2.1. Were participants aware of their assigned intervention during the trial? Y - Not possible to blind due to the nature of intervention. |

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| delivered rehabilitation exercises with specialist supervision to physician-delivered rehabilitation exercises with no family involvement. Secondary aims were to determine possible parental characteristics that might affect their ability to deliver the home rehabilitation exercises, and if children which most severe injuries responded better to the intervention.<br><br>**Study dates**<br>Not reported.<br><br>**Source of funding**<br>Not reported. | • Clinician-delivered rehabilitation (n) = 19/15<br><br>Time since injury* [Mean (SD)]:<br>• Family-supported rehabilitation = 15.66 (7.18)<br>• Clinician-delivered rehabilitation = 13.41 (6.71)<br>* Unit of time not specified in study but likely to be weeks.<br><br>Injury cause: not reported but inclusion criteria stated traumatic brain injury<br><br>Severity of TBI (severe/moderate):<br>• Family-supported rehabilitation (n) = 23/15<br>• Clinician-delivered rehabilitation (n) = 18/16<br><br>Glasgow Coma Scale score [Mean (SD)]:<br>• Family-supported rehabilitation = 6.66 (3.30) | mechanisms with peers. Clinicians also performed home visits during this time, using these to inform a child's rehabilitation and increase integration of the programme into family routine. Each child had 2 case managers (ensuring at least 1 was available at all times) from rehabilitation specialities, relevant to a child's needs and goals, assigned to teach exercises to family members. Case managers also supported families, making home visits and school visits if needed. They organised referrals to other healthcare disciplines, and co-ordinated care. The assessment period informed the rehabilitation programme, rehabilitation goals and support programme. The rehabilitation programme was designed around simple activities that could be done at home using common household items. Tasks from different specialties were combined as appropriate, decreasing the number of different tasks children and parents had to carry out while targeting the same areas. To educate parents on the rehabilitation exercises, rehabilitation centre staff created a collection of over 200 illustrations designed to guide | | 2.2. Were carers and people delivering the interventions aware of participants' assigned intervention during the trial? Y - Not possible to blind due to the nature of intervention.<br>2.3. If Y/PY/NI to 2.1 or 2.2: Were there deviations from the intended intervention that arose because of the experimental context? PY - Children in the intervention group could have received more intensive rehabilitation (more frequent or longer sessions than protocol) at home than children attending clinic for their sessions.<br>2.4 If Y/PY to 2.3: Were these deviations likely to have affected the outcome? Y.<br>2.5. If Y/PY/NI to 2.4: Were these deviations from intended intervention balanced between groups? N.<br>2.6 Was an appropriate analysis used to estimate the effect of assignment to intervention? Y - Intent to treat.<br>2.7 If No/PN/NI to 2.6: Was there potential for a substantial impact (on the result) of the failure to analyse participants in the group to which they were randomized? NA.<br>*Risk-of-bias judgement:* High risk.<br><u>Domain 3: Missing outcome data</u> |

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| | • Clinician-delivered rehabilitation = 7.50 (3.80)<br><br>*Unit of time not specified in study but likely to be weeks.<br><br>**Inclusion criteria**<br>Participants had to:<br>• Be aged between 5-12 years old<br>• Admitted to participating paediatric Rehabilitation centre<br>• Diagnosed with moderate TBI (defined as Glasgow Coma Scale score 9-12 or >12 if accompanied by diffuse brain swelling/skull fracture/intracranial mass lesion) or severe TBI (defined as Glasgow Coma Scale ≤8)<br>• Injury still in chronic stages (defined as sustained between 6-30 months before study commencement) | parents through the tasks, as well as help them modify everyday home routines to achieve rehabilitation objectives. It was decided to use illustrations rather than verbal instructions as many parents were illiterate or had difficulty with reading. For each child's rehabilitation programme, an individualised manual was created that included roughly 14 of these illustrations. Folders were updated regularly to include new tasks, in response to a child's progress and feedback. Parents began by watching professionals performed the rehabilitation exercises on their child but gradually assumed responsibility throughout the initial 2-week assessment period. This progression was based on parental competence and confidence in their skills, under the supervision of healthcare professionals. 2 families did not feel confident at the end of these 2 weeks, so received training for another week. After the assessment, parents took over the rehabilitation at home, attending bi-weekly (assuming 2 times a month but not stated) appointments at the paediatric rehabilitation centre. During | | 3.1 Were data for this outcome available for all, or nearly all, participants randomized? N - 15/87 (17%) participants lost to follow-up (6 (13.6%) in intervention group, 9 (20.9%) in control group).<br>3.2 If No/PN/NI to 3.1: Is there evidence that the result was not biased by missing outcome data? N.<br>3.3 If No/PN to 3.2: Could missingness in the outcome depend on its true value? Y - Possible that participants with worse SARAH scores were unlikely to continue with treatment.<br>3.4 If Y/PY/NI to 3.3: Is it likely that missingness in the outcome depended on its true value? PN - Although there is a difference in drop out rates between the 2 arms, the article reports that this is mainly due to the practical challenge of transporting children to and from the clinic.<br>*Risk-of-bias judgement:* Some concerns.<br><u>Domain 4: Risk of bias in measurement of the outcome</u><br>4.1 Was the method of measuring the outcome inappropriate? N.<br>4.2 Could measurement or ascertainment of the outcome have differed between |

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| | • Chronic cognitive and/or physical impairment<br>• Family consent for participation, as all children were enrolled with either/both parents<br><br>**Exclusion criteria**<br>• Co-morbidities include:<br>○ Presence of significant vision or hearing loss<br>○ Severe psychiatric disorder<br>○ Frequent drug-resistant seizures<br>• Child in a unresponsive state<br>• Child not attending school<br>• Family did not give consent for participation | these visits, progress was evaluated, new goals were set, and any problems were discussed. Rehabilitation programmes were adjusted, and changes were made to manuals, with parents being fully trained in any new activities.<br>• *Control group: Clinician-delivered rehabilitation.* 5 x 2 hour conventional rehabilitation sessions per week, given directly by rehabilitation healthcare professionals. Children attended an average of 91% sessions throughout the study period. Clinicians followed conventional rehabilitation procedures (dependent on their rehabilitation field), and treated children without parental presence. Clinicians were free to request consultations from other rehabilitation specialities and communicated with a child's school as needed (for information and instructions) but did not make any concerted effort to co-ordinate rehabilitation services. No home or school visits were carried out. Parents received no training about their child's rehabilitation but did attend information and support group sessions (as described in the | | intervention groups? PN - Use of validated instrument (SARAH scale), following similar procedures and at similar time points.<br>4.3 If No/PN/NI to 4.1 and 4.2: Were outcome assessors aware of the intervention received by study participants? N - Assessors were blinded.<br>4.4 If Y/PY/NI to 4.3: Could assessment of the outcome have been influenced by knowledge of intervention received? NA.<br>4.5 If Y/PY/NI to 4.4: Is it likely that assessment of the outcome was influenced by knowledge of intervention received? NA.<br>*Risk-of-bias judgement:* Low risk.<br><u>Domain 5: Risk of bias in selection of the reported result</u><br>5.1 Were the data that produced this result analysed in accordance with a pre-specified analysis plan that was finalized before unblinded outcome data were available for analysis? NI.<br>Is the numerical result being assessed likely to have been selected, on the basis of the results, from...<br>5.2. ... multiple outcome measurements (e.g. scales, definitions, time points) within the outcome domain? PN.<br>5.3 ... multiple analyses of the data? PN. |

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| | | intervention group) during the initial 2-week assessment period in order to help their coping of their child's trauma. | | *Risk-of-bias judgement:* Some concerns.<br>Overall risk of bias<br>*Risk-of-bias judgement:* High risk.<br><br>**Other information**<br>None. |

*ADL: Activities of daily living; F: Female; M: Male; N: Number [or No if answering a risk of bias checklist question); NA: Not applicable; NI: No information; PN: Probably not; PY: Probably yes; SD: Standard deviation; TBI: Traumatic brain injury; Y: Yes*

**Table 16: Qualitative evidence tables**

| Study details | Methods and participants | Results | Risk of bias assessment using the CASP qualitative checklist |
|---|---|---|---|
| **Full citation**<br>Rashid, M., Caine, V., Newton, A. S., Goez, H. R., Healthcare professionals' perspective on the delivery of care to children with Acquired Brain Injury (ABI) and communication with their parents, Journal of Pediatric Rehabilitation Medicine, 11, 125-131, 2018<br><br>**Ref Id**<br>1183107<br><br>**Country/ies where the study was carried out**<br>Canada | **Recruitment strategy**<br>Invitations were sent by an intermediary to the entire multi-disciplinary team in brain injury clinic. Convenience sampling used to recruit healthcare professionals involved in long-term rehabilitation of children (and families) with ABI.<br><br>*Inclusion criteria*<br>Not reported.<br><br>*Exclusion criteria*<br>Not reported.<br><br>**Setting**<br>Brain injury clinic of large urban rehabilitation centre.<br><br>**Participant characteristics**<br>N = 15 healthcare professionals | **Findings (including author's interpretation)**<br><br>• Author's theme: Reframing healthcare professional's roles and perceptions<br>○ Example quote: "for our complex cases with so many people involved there is the illusion that somebody will have their eyes on the child when discharged" (p. 128, Rashid 2018)<br><br>• Author's theme: Practice rewards<br>○ Example quote: "When families become so strong and find the time to volunteer and give back to the community by assisting others, it is inspiring and rewarding and means that the system did well." (p. 128, Rashid 2018) | **1. Was there a clear statement of the aims of the research? (Yes/Can't tell/No)**<br>Yes - To explore healthcare professional's experiences and views regarding the needs of families' rehabilitation needs for children with ABI.<br><br>**2. Is a qualitative methodology appropriate? (Yes/Can't tell/No)**<br>Yes - Appropriate to explore healthcare professional's experiences and views.<br><br>**3. Was the research design appropriate to address the aims of the research? (Yes/Can't tell/No)**<br>Yes - Appropriate to explore healthcare professional's experiences and views.<br><br>**4. Was the recruitment strategy appropriate to the aims of the research? (Yes/Can't tell/No)** |

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|---|---|---|---|
| **Study type**<br>General qualitative inquiry<br><br>**Study dates**<br>Not reported. | *(No further details reported.)*<br><br>**Data collection and analysis**<br>Semi-structured interview questions during 60-90-minute focus groups which took place in hospital. Interview scripts were designed to start initial conversations, with spontaneous conversation following as focus groups progressed. Thematic analysis conducted in 5 stages. | • Author's theme: Finding ways forward<br>○ Example quote: No quotes presented for this theme. | Can't tell - Wide variety of professionals included in focus groups but convenience sampling introduces some bias. Additionally, large urban rehabilitation centre may serve different ABI population than rural areas.<br><br>**5. Was the data collected in a way that addressed the research issue? (Yes/Can't tell/No)**<br>Yes - Focus groups with semi-structured interview questions used and justified clearly. No mention of data saturation, but not necessary for aims of research.<br><br>**6. Has the relationship between researcher and participants been adequately considered? (Yes/Can't tell/No)**<br>Can't tell - No discussion surrounding relationship between researcher and participants. Important due to using focus group setting and semi-structured interviews.<br><br>**7. Have ethical issues been taken into consideration? (Yes/Can't tell/No)**<br>Yes - Informed consent received and ethical approval granted from Health Research Ethics Board (University of Alberta) and Alberta Health Services.<br><br>**8. Was the data analysis sufficiently rigorous? (Yes/Can't tell/No)**<br>Can't tell - Discussion surrounding analytical rigour i.e. credibility and transferability. However, description of analysis does not |

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| | | | include mention of multiple or independent researchers. Minimal raw data presented.<br><br>**9. Is there a clear statement of findings? (Yes/Can't tell/No)**<br>Yes - Discussion of evidence for and against findings, with reference back to original research question.<br><br>**10. How valuable is the research?**<br>Moderate value for current question – Good sections on how best to co-ordinate care using both healthcare and non-healthcare resources.<br><br>**Overall methodological limitations (No or minor/Minor/Moderate/Serious)**<br>Moderate concerns.<br><br>**Source of funding**<br>This study received funding from Alberta Centre for Child, Family and Community Research.<br><br>**Other information**<br>None |

*ABI: Acquired brain injury; N: Number*