Evidence summary for collaborative, parent/carer-led, occupational therapy home programmes for children and young people

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About this resource

This evidence summary is aimed at occupational therapists and is accompanied by infographics for children, young people and families. The evidence presented below is from peer-reviewed studies that have been included in systematic reviews (Milton and Roe 2017, Novak and Honan 2019, Wuang et al 2013). Additional studies have been included to answer particular questions about implementing home programmes (Kirkpatrick et al 2016, Milton et al 2020, Novak et al 2007).

*What is the **purpose** of this resource?*

Occupational therapy home programmes increase the amount of therapy a child receives, either between treatment sessions or during a break from therapy provided directly by occupational therapists. Home programmes support occupation-centred goal attainment and embed therapy into everyday family life activities (Novak et al 2009).

Parents describe home programmes as being '…a form of guidance and advice, which become a way of life.' and use 'the guidance and support they gain from home programmes to build confidence about how to help their child' (Novak 2011, p209).

This method of service delivery has been used with children aged from 18 months to 15 years to optimise performance and progress in a range of occupations including: play (e.g. riding a scooter, catching a ball), self-care (e.g. feeding, bathing, dressing) and productivity (e.g. handwriting, cutting with scissors).

*Definitions of **key terms***

- **Occupational therapy home programmes**: 'therapeutic activities that the child performs with parental assistance in the home environment with the goal of achieving desired health outcomes' (Novak and Berry 2014, p384).

- **Collaborative:** a partnership between parent/carer, child and therapist 'built by establishing rapport, listening, sharing and learning; fostering parental experience; and empowering parental decision-making' (Novak 2011, p198–199).

- **Parent/carer-led:** goals set with parent/carer and child, with parents/carers supported to perform therapeutic activities and deliver the programme with their child (Kirkpatrick et al 2016, Novak and Berry 2014, Wuang et al 2013).

- **Evidence:** Peer-reviewed studies included in systematic reviews (Milton and Roe 2017, Novak and Honan 2019, Wuang et al 2013), randomised controlled trial (Kirkpatrick et al 2016) and articles identified to answer specific questions (Milton et al 2020, Novak et al 2007).

*What **populations** has this intervention been shown to be effective with?*

Home programmes have been shown to be effective for children with cerebral palsy and children with intellectual disability (Novak and Honan 2019).

*What is the known **effectiveness** of this method of service delivery?*
Novak and Honan (2019) identified that home programmes are an effective intervention when the contents of the programme are based on best-practice evidence. Intervention provided by parents has been found to be as effective as that delivered by therapists (Baker et al 2012). Strong evidence supports the use of occupational therapy home programmes to improve functional goal attainment in areas such as self-care and fine motor activity for children with cerebral palsy and/or intellectual disabilities (Milton and Roe 2017, Novak et al. 2009, Novak and Honan 2019, Wuang et al. 2013).

Home programmes have been shown to be **effective** when they include these **5 steps** (Novak and Berry 2014)

1. Establish collaborative partnership with parent/carer and child.
2. Facilitate child and family to set goals to work on at home.
3. Choose evidence-based interventions* which match goals and can be woven into everyday family life.
4. Provide regular support and coaching to family to identify improvements and adjust as needed.
5. Evaluate outcomes together.

*See Novak and Honan (2019),Table 1 and Figure 3, for details of effective evidence-based interventions.

To ensure optimum results, programme design must be occupation-centred and founded upon a combination of family-centred care, best-evidenced interventions, methods and measurements, and occupational therapy professional theories, ethics and reasoning (Milton et al 2020).

*What **equipment** is required?*

- Exercise logbooks (regular notebooks can be used) as a reminder to practise and to capture the activities and time spent doing the programme.
- Physical or electronic resource file of suggested activities to facilitate discussion with family.
- Tools to deliver information in a way that meets parents' preferred learning style, e.g. paper or electronic.
- Tools to record activities in an instructional format, e.g. text, photos, video etc.
- Tools to assist with outcome measure analysis – paper or electronic – including text, photos or video.

Other specific types of equipment will be determined by the goals. For example, toys, games, feeding and school productivity items are commonly used to support goal attainment. Splints may also be necessary depending on the client group and method(s) being used (Milton and Roe 2017).

*What processes **support the success** of this method of service delivery?*
Home programmes are most likely to achieve positive outcomes when therapists:

- Design the programme with the family, based on the family and child's goals.
- Develop the programme in the home environment to support a family-centred approach and deepen the therapist's understanding of the child/family's routines, interests, culture and values.
- Provide a small number of activities working towards 3–5 goals that parents/carers feel confident and capable to carry out safely and therapeutically.
- Coach and model ways to grade activities so they are at just the right level of challenge.
- Encourage emotional and physical support from other family members.
- Ensure the family have sufficient time to implement the interventions used in the home programme; under-dosed programmes are unlikely to be effective.
- Ensure access to, or provide, equipment for activities including logbooks, toys and other resources.

- Provide prognostic information and guidance about what progress to expect for the child and family.
- Ensure a co-ordinated team approach rather than multiple programmes.
- Follow up and provide regular feedback on progress to the child and family.
- Evaluate outcomes after the home programme and share with the child/family and all relevant stakeholders.

(Milton and Roe 2017, Novak et al 2009, Novak and Berry 2014, Wallen et al 2011).

*What **qualifications, skills and training** are required?*

Occupational therapists are qualified to design and deliver home programmes as part of their training, but further development may be beneficial, such as:

- Keeping abreast of the latest evidence-based interventions to use in home programmes.
- Developing skills in implementing family-centred care and coaching (Coyne 2015).
- Experience in grading and modelling to ensure activities are at just the right challenge level (Milton and Roe 2017).
- Knowledge of, and skills in, using appropriate client-centred outcome measures e.g. Canadian Occupational Performance Measure, Goal Attainment Scaling.
- Mentorship from experienced colleagues to develop skills (Milton et al 2020).
- Courses for specific evidence-based interventions.

*What is the **time commitment for the service provider**?*

The number and duration of sessions will vary according to individual need and service provider. Every home programme package should, however, include an initial session to set goals and design the programme, and a final session to measure outcomes. Timings may be as follows:

1. Initial home visit to set goals and design programme in the home environment (about 1.5 hours in total).
2. After the first visit, clinician to develop a logbook and home programme document with list of suggested therapeutic activities, including illustrations or photographs, and an agreed timetable.
3. Follow-up visits to check progress, support and coach the family to monitor improvements, and make changes when necessary (45 minutes per visit).
4. Final follow-up visit to evaluate outcomes (45 minutes).

(Novak et al 2007)

*What is the **time commitment for the family and child**?*

The number and duration of sessions will vary according to individual need and the programme as negotiated with the family, but should include the following elements:

1. First session together with the clinician (about 1.5 hours).
2. Implementing the programme several times per week (see dose below).
3. Keeping a logbook to record activities and duration (approximately 2 minutes per session).
4. Progress checks with the clinician (45 minutes).
5. Evaluating outcomes together with the clinician (45 minutes).

*What is the **dose** (quantity of time; frequency and duration) required for effectiveness?*

The dose varies depending on the population and the approach being used; however, as a rule of thumb, based on the evidence, home programmes should be implemented every other day for about 15 minutes over 2–6 months. Where programmes are targeting upper limb use using constraint-induced movement therapy or bimanual training, longer sessions over a longer period of time will be required; see Hoare et al 2019 and Novak et al 2020 for further details.

Home programmes targeting goal-based tasks done by the child with cerebral palsy, led by the parent/carer and supported by the occupational therapists in the home environment, are effective with 16–17 minute sessions, 18 times per month for 8 weeks (Novak et al 2009).

Home programmes comprising repeated practice of home-based activities tailored to interests and abilities of the child 15 minutes, 5 times a week for 3 months are effective for children with uni-lateral cerebral palsy (Kirkpatrick et al 2016). Low-intensity upper limb activities incorporated into play for as little as 1 hour per week, resulted in a small but sustained benefit (Kirkpatrick et al 2016).

Children with intellectual disabilities make progress using home programmes with 15-minute sessions, 15 times per month for 20 weeks (Wuang et al 2013).

Cautions / Contraindications

- Occupational therapy home programmes are a tool to *increase the dose of therapy and improve desired health outcomes*. Occupational therapists need to be clear in their communication with families that unless a sufficient dosage is achieved, home programmes are *unlikely to be effective* and not worth doing.

- Occupational therapy home programmes are not for every family, only for those that choose to have one.

- There is the potential for families to feel overwhelmed or burdened by the time commitment and effort required to carry out a programme with their child.

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