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Evidence Based Practice Review

PEER REVIEWED

Activities, Participation, Accessibility and Safety in the Home Environment for Children and Young People with Physical Disabilities: A Systematic Review

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Abstract

Background: In Australia, nearly two percent of children and young people under 15 years with a disability have physical restrictions. Many will require occupational therapy at some stage in their lives to facilitate independence in activities of daily living, participation, home accessibility and home safety.

Objective: This systematic review aims to identify effective occupational therapy for children and young people with physical disability in the home.

Search Methods: Eligible quantitative research studies published between 2005 and 2020 were identified in the Cochrane Data Base of Systematic Reviews, Cochrane Central Register of Controlled Trials, Home Modification Information Clearinghouse, PubMed, OTseeker, Google Scholar, and major occupational therapy journals.

Data Collection and Analysis: The first review author screened titles and abstracts of all potential studies identified for inclusion in the review. Full text reports were retrieved, and the second review author independently screened these and identified studies for inclusion.

Results: Overall, 29 quantitative studies fitting the inclusion criteria were examined in this systematic review.

Authors Conclusions: While the quality of the studies in this area of physical disability is varied in breadth and scope, there is generally moderate to high quality evidence for the effectiveness of occupational therapy interventions in the areas of self-care and functional mobility; and low to moderate for participation in domestic living/household tasks; and low for home modification. There is no evidence for safety in the home for children and young people with a physical disability.

Keywords

Children; young people; home; physical disabilities; occupational therapy; activity; participation; home safety.

Contribution of Authors

This is the first edition of Evidence-Based Practice Review: Activities, Participation, Accessibility and Safety in the Home Environment for Children and Young People with Physical Disabilities: A Systematic Review, for the Home Modification Information Clearinghouse, UNSW Sydney.

Bess Fowler PhD OT, devised the project, developing the main conceptual ideas, research design, undertaking the literature review, writing and editing the manuscript with input from the secondary reviewer.

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Theresa Kirwan MPH OT contributed to the overall research design, literature review, editing and providing a current occupational therapy community practice perspective.

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Glossary

Activity	The execution of a task or action by an individual [1]
Activities of Daily Living	Activities oriented towards taking care of your own body, including: bathing/showering; toileting and toilet hygiene; dressing; eating and swallowing; feeding; functional mobility; personal device care - personal; personal hygiene and grooming; sexual activity. [2]
Adaptive Seating	Provision of support at the level of trunk and pelvis for children and young people needing physical assistance in most transfers. [3]
Assistive Technology	Any device, system or design, that allows an individual to perform a task that they would otherwise be unable to do, or increase the ease and safety with which a task can be performed. [4]
CareToy	A tele-rehabilitative tool, useful in providing intensive, individualised, home-based, family-centred early intervention in infants.[5]
Child Focussed Therapy	Primarily focused on changing factors within the child at the domain of body function and structure, with the assumption that these changes will improve their abilities in the domains of activity and participation.[6]
Context Focussed Therapy	A dynamic systems approach to development and family-centered services to facilitate the development of alternative treatment approaches that focusses on the child and family within their environment. [6]
Clinical Reasoning	In occupational therapy, it is the process used by practitioners to plan, direct, perform and reflect on client care. [7]
Constraint-Induced Movement Therapy	The practice of restricting the functional hand while training the affected hand.[8]
Disability	Mild limitation - no need for help and no difficulty, but uses aids or has limitations. Moderate limitation - no need for help but has difficulty. Severe limitation - needs help sometimes or has difficulty with a core activity Profound limitation - greatest need for help, that is, always needs help with at least one core activity. [9]

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Domestic Life	Includes household tasks - preparing meals; doing house work; caring for household objects; and assisting others.[1]
Effectiveness	Is a measure of the extent to which a specific intervention, procedure, regimen or service does what it is intended to do for a specified population.[10]
Evidence Based Practice	A clinical decision making framework that encourages clinicians to integrate information from high quality quantitative and qualitative research with the clinician's clinical expertise and the client's background, preferences and values when making decisions.[11]
Experimental Study	In which conditions are under the direct control of the investigator, and in which a population is selected for a planned trial of a regimen whose effects are measured by comparing the outcome in the experimental group with the outcome of another regimen in a control group. A randomised controlled trial is the most common example.[10]
Functional Mobility	Moving from one position or place to another (during performance of everyday activities), such as 'in-bed mobility', 'wheelchair mobility', and 'transfers'.[2]
Home Safety	The awareness and education of risks and potential dangers in and around a home which may cause bodily harm, injury, or even death to those residing in and around the physical structure of a home.[12]
Knowledge Translation	The synthesis, dissemination, exchange and ethically-sound application of knowledge to improve health, health service delivery and the healthcare system.[13]
Home Modification	Changes made to the home environment to help people to be more independent and safer in their own home and reduce any risk of injury to their carers and care workers. [14]
H HABITAT	Home-based hand-arm bimanual intensive therapy.[8]
Intervention	A health intervention is an act performed for, with or on behalf of a person or population whose purpose is to assess, improve, maintain, promote or modify health, functioning or health conditions.[15]
Injury	Physical or physiological bodily harm resulting from interaction of the body with energy - mechanical, thermal, electrical, chemical or radiant, or due to extreme pressure. [16]

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Oxford Levels of Evidence	Level 1: Systematic reviews of randomised controlled trials. Level 2: Randomised or observational studies with dramatic effect. Level 3: Non-randomised controlled trials cohort/follow-up studies. Level 4: Case series, case controlled studies or historical controlled.[17]
Observational Study	A non-experimental study that does not involve any intervention. [10]
Occupational Therapy	A client-centered health profession concerned with promoting health and well-being through occupation. [18]
Occupational Performance	The ability to perceive, desire, recall, plan and carry out roles, routines, tasks and sub-tasks for the purpose of self-maintenance, productivity, leisure and rest in response to demands of the internal and/or external environment.[19]
Participation	Involvement in a life situation.[1]
Physical Home Environment	Physical layout or amount of space and furniture in the home.[20]
Risk Factors	Health risk factors are attributes, characteristics or exposures that increase the likelihood of a person developing a disease or health disorder - such as disability status.[21]
Routines-based early intervention	Providing the children with learning opportunities in naturally occurring contexts (i.e., daily routines) and systematically uses collaboration and coaching to set functional goals and implement service plans with the family.[22]
Self-care	The set of activities that comprise daily living, such as bed mobility, transfers, ambulation, dressing, grooming, bathing, eating and toileting. [23]
Unintentional Injuries	Injury for which there was no evidence of predetermined intent. [51]

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1. Background

1.1. Why conduct a systematic review?

The quantitative literature on self-care, functional mobility, home modification, domestic life, and home safety for children and young people 0-18 years with a physical disability, is variable in quality and completeness. The apparent gaps in the evidence, in an important area of practice for occupational therapists and their clients, prompted the preparation of this systematic review of the quantitative literature, to provide the basis for knowledge translation, evidence-based practice and future research.

The principle model used in this systematic review is the World Health Organisation (WHO), International Classification of Functioning, Disability and Health (ICF) Child and Youth [1] which emphasises the effectiveness of the 'fit' between the person, health status, development and the home environment.

The target population for this review is children and young people with predominantly physical disabilities, including: neurological conditions, such as cerebral palsy (or those at risk of this condition), spinal cord injuries, acquired brain injury, and developmental delays, often associated with prematurity or low birth weight; other physical impairment; juvenile arthritis; and genetic conditions. The focus of this review is on those individuals with moderate and severe physical disabilities. [9]

1.2. Rights of children and young people with disabilities

As background to this review, it must be emphasised that children and young people with disabilites have the right to live in accessible domestic home environments. This concept is enshrined in United Nations Convention on the Rights of Persons with Disabilities Article 9. [25, 26, 27]

1.2.1. Universal Design

From the perspective of the rights of children and young people with disabilities, universal design is an important concept. Buildings and other environments should be constructed to suit all members of the community and not just the able-bodied. The concept of universal design was developed in America and promoted usability, accessibility and aesthetics.[28] Another innovative approach to architecture in everyday life [29] places disability at the beginning not the end of the design process and consquently aims to eliminate the disparity between ability and disability.

In relation to the application of universal design characteristics to those with cerebral palsy, some of the concepts include the effective use of space, including flexiblity and simplicity in addition to integrated safety features that require minimal effort to use. [30]

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In their literature review and synthesis, Watchorn et al [31] also use the WHO ICF[1] model and emphasise the concepts of the person-environment relationship to accessibility, usability and universal design.

1.3. Prevalence of disabling health conditions in children and young people in Australia

To ensure a contextual overview, occupational therapists are advised to become familiar with the burden of major health disorders in children and young people with disabilities, including the extent of disability in the population, the need for assistance, and the socio-economic factors associated with housing and injury. In Australia, one of the most useful sources of population and housing information in relation to home environment and modifications is derived from the Australian Bureau of Statistics (ABS) particularly the most recent Census of Population and Housing in 2016.

Overall, the ABS 'Census of Population and Housing' data presents a valuable source of information on 'persons' and 'dwellings' which is uniquely related to the 'person-home- environment-fit' concept and equates appropriately to the WHO ICF C&Y [1] model.The Census provides important aggregated demographic information including, age, gender, level of disability, family status, geographic location (including regional and remote), language spoken, incomes, home ownership status and number of occupants, which have important influences on therapy. These data sources provide high level evidence in Australian populations, on the number and proportion of children and young people (0 to 18/19 years) with disabling conditions ranging from mild, moderate to severe.[32]

1.3.1. Data from the 2016 Census of Population and Housing

The total Australian population in 2016 was 23,401,892 million, of which 50.7% were female and 49.3% male, living in 9,901,496 private dwellings. *The number of children and young people 0-4 years was* 1,464,779; 5-9 years was 1,502,646; 10-14 years was 1,397,183; and 15-19* years was 1,421,595, totaling 5,786,203.[33]

*Note this represents 5-year age groups and consequently includes 19 year-olds

1.3.2. Children and young people with disabilities

In 2018 in Australia 7.7% of children and young people under 15 years living in a household had a disability and 1.8% had a physical restriction. * Girls (0-4 years 1.5%; 5-14 years 3.7%) are least likely to experience a severe or profound functional limitation than boys (0-4 years 3.3%; 5-14 years 7.5%). 9

*Note this includes some individuals classified into more than one disability group. Data not reported for those aged 15-18 years

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1.3.3. Disability and assistance with activities of daily living

Approximately two-thirds of children with a disability (not only physical) need assistance in activities of daily living, including assistance with communication (39%), mobility (32%) self-care (28%) and health care (25%). In addition, around half of all children with a disability need help with thinking, making decisions, managing emotions, making friends, keeping relationships and/or interacting with other people. 34

1.3.4. Aids and equipment

The use of aids and equipment is a common compensatory therapy for people living at home with a disability, as these devices improve functional independence. In Australia in 2018 there were 4.4 million people living with a disability, around 2.3 million, (including children and young people) or a little over half, used aids and equipment.

1.3.5. Housing, dwellings, tenure

In addition to population data, the Census provides pertinent information on housing (dwellings) - a key focus of the 'person-home-environment-fit' WHO, ICF [1]in independent functioning, home modification and safety for children and young people with disabilities living at home.

Housing tenure is also important, as private renting may present difficulties in allowing housing modifications to accommodate the needs of the child or young person with a disability.[35] In relation to secure housing, private tenants are in a weaker position than owners, as they must seek the approval before home modifications can be undertaken.[36].

An Australian report on 'Housing insecurity and precarious living' identified six factors relevant to all renters, namely: lack of privacy, belonging, physical comfort, housing mobility, instability and a perceived unsafe environment. [37]

1.3.6. Models considered

In this systematic review, the primary model is functioning and the 'person-environment-home-fit' framework, outlined in the WHO ICF C&Y. [1]

Other important frameworks related to occupational therapy and this topic, are the 'Occupational Performance Model (Australia)',[38] 'Model of Human Occupation',[39], 'Client and Family Centred Care',[40] and home safety - the 'WHO Safe Communities' [41] framework for the prevention of injury in whole populations.

The WHO ICF C&Y [1] increasingly used in disability research and practice as it focusses on function, a fundamental concept in occupational therapy. In relation to occupational therapy for school aged children with cerebral palsy, based on the WHO

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ICF components a survey [42] found that while occupational therapists understood 'activities and participation', including activities of daily living and mobility.

The following diagram describes the four relevant WHO ICF C&Y [1] components 'Interaction', 'Environment', 'Developing Child' and 'Activity' and 'Participation'.

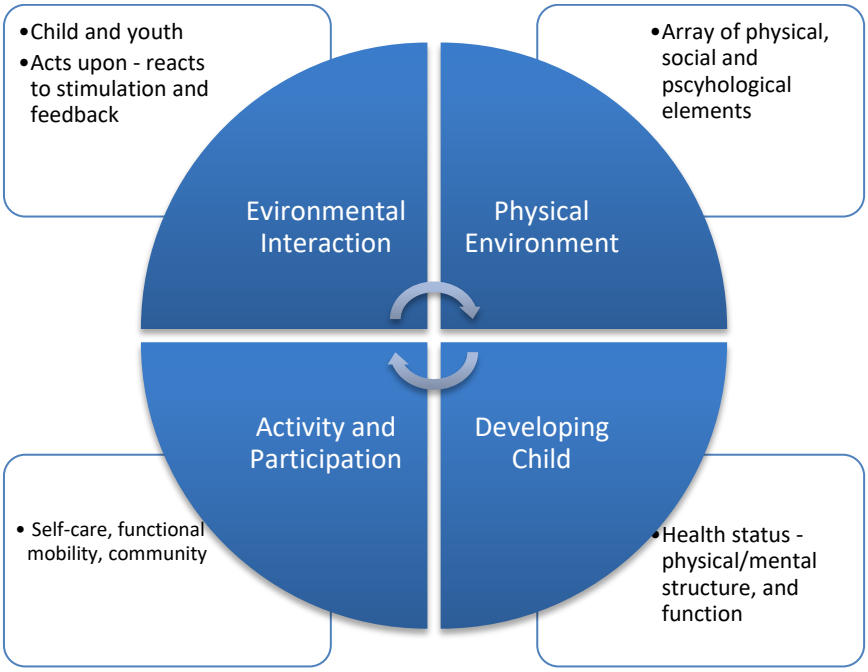

Figure 1: World Health Organisation International Classification Child & Youth (ICF pp 43-44 [15])

This classification system includes activities - self-care and functional mobility; and participation - domestic life for the child and young person at home.

In relation to *self-care* the WHO ICF specific tasks are: Washing oneself (d510); Caring for body parts (d520); Toileting (d530); Dressing (d540); Eating (d550); Drinking (d560); and, Looking after one's health (d570). [1]

A more recent development in foundation research [43],[44] is the 'Self-Care Activities Dataset' (SCALDI) centered on ICF-CY, which will be useful for research.

For *functional mobility* the tasks are: Walking and moving (d450-d469), Changing and maintaining body position (d410-d429); Transferring oneself (d420); Carrying, moving and handling objects (d430-d449); Fine hand use (d440); and Hand and arm use (d445). [1] (p 43-44) **

**Note: Adapted from ICF-C&Y p. 18 ICF CY and specific health disorders and conditions

In relation to the developing child or young person, an individual's abilities to perform activities of daily living increases markedly between the ages of 3 to 6 years, and

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continues to improve between 6-15 years, after which performance stabilises until 50 years of age, when it begins to decline. These findings are from a descriptive study [45] (Level 2) of 4,398 typically developing people between 3 and 93 years, using existing data from Assessment of Motor and Process Skills.[46]

As pre-school children develop, the focus changes from parents or caregivers, to child-initiated activities in occupational performance skills and independence in activities, such as toileting and bathing in the home environment [47] (Level 3).

One very useful source of information in relation to the typically developing child or young person, is the 'The Longitudinal Study of Australian Children' (LSAC) or 'Growing up in Australia'.[48, 49] (Level 1). This study is a joint initiative of the Australian Institute of Family Studies and the Australian Bureau of Statistics and the Department of Social Services. This high quality, national cohort study of ten thousand children and young people between the ages of 0-15 years, (the latest reporting age), commenced in 2004 and is on-going. The study provides useful points of comparison and potential goal setting in occupational performance for children and young people, their families and occupational therapists.

In relation to the developmental trajectories of mobility and self-care capabilities in young children with cerebral palsy, a longitudinal study [50] (Level 3) of children aged 1-4 years with cerebral palsy, found that there was a considerable variation between individual children which equated with the actual Gross Motor Function Classification System [51] levels in occupational performance in self-care and mobility.

In relation to domestic life the WHO ICF specific tasks are: Household tasks (d630-d649); Preparing meals (d630); Doing house work (d640); Caring for household objects (d650); and Assisting others (d660). [1] p 43-44.

In 2018, of the 4.2 million Australians (all ages) living at home with a disability, 12.2% had modified their homes: 8.1% had installed hand grab rails, 5.8% had modified their bathroom, toilet or laundry, and 2.6% had installed ramps. [35]

In the qualitative literature, a relationship was found between impediments in occupational performance in self-care and the need for home modifications and this was the main reason for people applying for grants for home modification.[52] Also, occupational performance and safety are enhanced by home modifications.[53] An Australian author [54] identified six dimensions important to home modification practice, including person, occupational, physical, temporal and social dimensions; and found that builder workmanship and client involvement in decision-making were important aspects in the home modification process.

Seven major barriers have been identified a person or family contemplating home modifications. These included no perceived need, possible stigma or insufficient social support, potential cost, concerns about aesthetic appeal, tenure in the home and lack

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of knowledge about the home modification process. [55] Finally, parents of 11 children with movement disabilities reported their major considerations for home modifications were the child's independence/self-esteem, time constraints, home safety, acknowledgment of the role of parents' roles, information needs, and aesthetic aspects of the alterations.[56]

The 'injury' component is not featured as a separate area in Figure 1, but it is a combination of all factors: the physical home environment, activities, participation, the developing child or young person and carers. Occupational therapists would benefit from awareness of the burden of injury and effective safety interventions in the home, particularly for children and young people with disabilities.

An age-standardised child injury hospitalisation rate of 1,489 per 100,000 in Australia is reported in a large study (n=686,409) [57] and provides a high-quality profile of injury in children and young people in Australia. This data linkage study (Level 1) includes the entire Australian population of children and young people aged from 0 -16 years, covering admissions over a 10-year period 2002-2012. The cases, defined as injury-related hospitalisations, are consequently 'hard' outcome measures. Regrettably the rate of injury in Australia has not decreased over a ten-year period.[57]

In addition, unintentional injury is the leading cause of death and long-term disability in children as shown in systematic review of a recent cohort study (Level 3).[58] A systematic review found that Indigenous children suffer a significantly higher burden of morbidity and mortality from unintentional injuries compared to non-Indigenous children [59] (Level 1).

More children and young people with disabilities suffer unintentional injuries than their typically developing counterparts. A systematic review and meta-analysis[60] (Level 1), using a sample of 83,286 children and young people, compared children 0-4 years and 5-9 years, and found that those with physical disabilities experienced double the risk of unintentional injury, than their typically developing counterparts.[60] These findings are supported in a systematic review [61] (Level 1) showing that children with a recognised disability status had a greater risk of more than twice (2.39) for unintentional injury. In addition, the likelihood of injury for children with disabilities compared to the typically developing, using medically attended injuries as the primary outcome measure shown in a case-control study [62] (Level 4), was 4.46, that is more than four and a half times higher risk. Also in an administrative data study children and young people 0-17 years, with a single disability, (3.8%) had a statistically significantly higher prevalence of injury than children without a disability (2.5%) [63] (Level 3).

While it is recognised that children with disabilities have a higher rate of injury than the typically developing [62] and there is minimal research with this group into toy injuries, specifically from ride on cars [64] (Level 1). This situation is particularly concerning, as ride-on-toys account for 35% of all injuries and 42.5% of hospital admissions in people

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less than 18 years old, treated in US Emergency Departments in the whole population. This peaks at the age of 2 years with 80% occurring at home.[65]

Injury patterns are related to gender, age and developmental stage of the child or young person. For the total Australian population, more boys than girls are injured, with males accounting for a little less than two thirds of the injury related hospitalization of those between 0-16 years [57] (Level 1). These patterns also change with age and the emphasis of safety intervention must adapt to the child's developmental age [57] (Level 1).

The type of injury varies with the developmental stage of the child or young person. When typically developing young children are first learning to stand up, walk and later run, they are subject to 'developmental falls' that do not usually require hospitalisation. For the child with a physical disability, however, a similar fall may result in a more severe injury that may require hospitalisation.[47]

Home is the most common specified place of an incident causing injury (24.5%) for children and young people aged 0-16 years [57] (Level 1). This information has implications for delivering occupational therapy, particularly hazard reduction, such as support rails in the bathroom. Age-related falls were the most common mechanism of injury, with fractures being the most common type of injury [57] (Level 1).

The location the home where the injury occurred included: Outdoor area 16%; Bedroom 9%; Indoor living area 6%; Kitchen 5%; Bathroom 4%; Garage 1%; Driveway to home 1%; Laundry 0.2%; Home unspecified place 57%.[66]

For typically developing children and young people there is moderate to high level evidence that supports a number interventions in home safety and the prevention of unintentional injury. Kendrick et at [67] (Level 1) found that parent education and home safety equipment is an effective method in reducing unintentional injuries in the home in typically developing children. These interventions should have implications for home safety programs for children and young people with physical disabilities.

1.4. Australian Standards

Australian Standards© provide useful information in relation to the physical home environment, occupational performance in self-care, functional mobility, aids, equipment, and assistive technology. In particular, Australian Standard® AS 1428.3 - 1992 - 'Part 3: Requirements for children and adolescents with physical disabilities - design for access and mobility' is informative.[68] This standard covers those aged 3 to 18 years with physical disabilities from a number of diagnostic groups and consquently is relevant to this systematic review.

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1.5. Current Australian Context

1.5.1. National Disability Insurance Scheme

The Australian National Disability Insurance Scheme Act (2013) is the legislative framework designed to operationalise the National Disability Insurance Agency (NDIA) and the National Disability Insurance Scheme (NDIS). The NDIS affords independence, social and economic supports for Australians with disabilities up to the age of 65 years. [69]

The NDIS is a major, national, comprehensive and positive development in the delivery of services for people with disabilities and their families in Australia. The change from block funding to providers, to direct delivery to the individual, through financial grants that are goal directed, planned, mangaged and controlled by the person, is significant. The NDIS is based on an insurance actuarial model,[69] and is now operational in all states of Australia. [70] The principal philosophy of the NDIS is consistent with occupational therapy models of pratices, such as occupational performance [38, 71 ,72] independent functioning,[1] and family-client-centred care.[73]

While the NDIS is of great benefit to individuals with disabilities and their families some limitations however, are apparent in the implementation of this scheme. In 2019, the Australian Government undertook a review of the NDIS and the findings include the need for more flexibility for children in a family-centred approach. [70] There is a need, however, for occupational therapists and other health professionals to assist parents and families to navigate the NDIS systems to receive the optimal services available.[74]

The role of occupational therapy in the NDIS is recognised and many occupational therapy interventions are delivered through this scheme, in particularly consultative services,[75] assistive technology,[76] and home modifications. [77]

1.5.2. Higher density housing

Another relatively recent development is that a quarter of all Australian dwellings are now higher density housing such as apartments and townhouses than previously. From the age of 4-5 years and onwards, nine out of ten children in the LSAC study children were living in a separate (detached) housing. One in five children in the study were living in a home rented by their parents; and around three out of five were living in a home that their parents had purchased and were paying off with a mortgage.[49]

1.6. Importance of the Review

The quantitative research literature on self-care, functional mobility, domestic life, home modification and home safety for children and young people 0-18 years with a physical disability living at home in the community varies in quality and completeness. This

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apparent deficit in the literature, in an important area of practice for occupational therapists and their clients, prompted this critical systematic review of the literature.

2. Objective

To systematically review and appraise the 'person-home-environment-fit' literature from interventional and observational studies, within the scope of occupational therapy practice, aimed at developing and describing the levels of activity and participation, physical home environment accessibility, and home safety for children and young people with a disability at home in the community.

3. Methods

3.1. Protocol

A protocol, based on the Preferred Reporting Items for Systematic Reviews and Meta Analyses (PRISMA) protocol, was submitted and accepted by the Home Modification Information Clearing House in February 2020.

Appendix II: Protocol for Systematic Review

3.1.1. Inclusion criteria

This systematic review includes published quantitative studies on improving and describing the levels of activities of daily living in self-care and functional mobility, participation in household tasks, home accessibility and safety using the following criteria:

The participants are children and young people 0-18 years with long term (six months and over), predominantly physical health conditions including neurological disorders, developmental delay, congenital/genetic disorders, spinal cord or brain injuries, juvenile arthritis, and amputation, receiving occupational therapy in the home. The disorders included are based on the NDIS, in List A [78] and List B.[79]

The current study types included are experimental interventional studies including systematic reviews and meta-analyses, randomised controlled trials, and observational, descriptive cross-sectional surveys, cohort/follow-up studies, case-controlled studies, historically controlled studies or case series; English language with full-text reports and published between January 2005 and June 2020; in-home care interventions provided by occupational therapists or within the recognised sphere of occupational therapy practice; interventions by parents and carers in co-operation with occupational therapists; and home modifications.

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3.1.2. Exclusion criteria

Studies relating to children and young people with Downs syndrome, mental health issues, intellectual disability, autism, developmental co-ordination disorder; intended injury; hospice, end-of-life or palliative care services delivered in the home; carers; quality of life, exercise programs with no activity component; pain, and psycho-social home environments.

Electronic searches of 5 databases were undertaken from January to March 2020, including the: Cochrane Data Base of Systematic Reviews; Cochrane Central Register of Controlled Trials; Home Modification Information Clearing House, PubMed; and OTseeker. In addition, five major occupational therapy journals as well as the Australian Bureau of Statistics and Google Scholar were examined. The first author hand searched reference lists of articles to find other studies, and relevant researchers were contacted to clarify details of studies.

The first review author (BF) screened the titles and abstracts of all potential studies identified for inclusion in the review. Full text reports were retrieved and the second review author (TK) independently screened the studies and identified those for inclusion, and recorded the reasons for exclusion of ineligible studies. Any disagreements were resolved by discussion between the two review authors.

The Oxford Centre for Evidence-Based Medicine (OCEBM) [17] was used in this review. The OCEBM method has previously been employed in paediatric occupational therapy research [80] and has the advantage of including research that has useful evidence even though it is not of the highest quantitative level of systematic reviews or randomised controlled trials as used in the Cochrane Collaboration.

Quantitative evidence

Level 1:	Systematic reviews of randomised controlled trails
Level 2:	Randomised or observational study with dramatic effect
Level 3:	Non-randomised controlled trails cohort/follow-up studies
Level 4:	Case series, case-controlled studies, or historically controlled studies

Table 1. Oxford Centre for Evidence-Based Medicine.

Note: In the Oxford Centre for Evidence-Based Medicine the ‘Level may be graded down on the basis of study quality, imprecision, indirectness (study PICO does not match the question), because of inconsistency between studies, or because the absolute effect size is very small; Level may be upgraded if there is a large or very large effect size.’

Throughout this systematic review the terms Levels 1-4 will be used but only referenced here.[17]

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On occasions, individual randomised controlled trials reported in systematic reviews are separately appraised, if these have a particular relevance to the inclusion criteria and practice.

The Preferred Reporting of Systematic Reviews and Meta-Analyses (PRISMA) statement is used as a guide to the framework of this systematic review. [110]

Grading of Recommendations, Assessment, Development and Evaluations

In addition to the OCEBM the Grading of Recommendations, Assessment, Development and Evaluations (GRADE) working group grades of evidence are also use to appraise the quality and strength of the recommendation of the quantitative studies.[81]

Quality	Confidence level
Very low	The true effect is probably markedly different from the estimated effect
Low	The true effect might be markedly different from the estimated effect
Moderate	The authors believe that the true effect is probably close to the estimated effect
High	The authors have a lot of confidence that the true effect is similar to the estimated effect

Table 2. Grading of Recommendations, Assessment, Development and Evaluations

3.2. Research Questions

1. What is the effectiveness of occupational therapy in self-care, functional mobility, domestic life, home modifications and home safety for the home environment, in children and young people 0-18 years with long-term physical disabilities? (Interventional studies)
2. What are the effects of risk factors such as physical disability status and physical home environment in relation to the context of the 'Person-Environment-(home)-fit' on occupational performance or functional independence? (Observational/risk factor studies)

The 'Population', 'Intervention', 'Comparison', and 'Outcomes' (PICO) [82] model was used to devise the evidence-based practice research questions.

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Problem	Intervention	Outcome	Comparison	Target population
Difficulty with: Self-care; Functional mobility; Domestic life; Home accessibility; Home safety.	Occupational therapy, or similar interventions, undertaken at home; Activities; Participation; Home modification; Home safety.	Standardised, paediatric and youth rehabilitation outcome measures; Morbidity injury rates: Specifically, designed instruments.	Usual care; Wait list; Alternative interventions; No occupational therapy; Own control.	Female and male children and young people, 0-18 years of age; Predominantly physical disabilities.

Table 3. Summary of Problem, Intervention/interaction, Outcome, Comparison, Target Population

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3.2.1. Search Terms

Problem	Intervention	Outcome	Comparison	Target population
difficulty with: activities of daily living OR participation OR access OR Safety	occupational therapy OR remedial OR compensatory OR contextual OR self-care OR mobility OR functional mobility OR assistive technology OR powered mobility OR domestic life OR household tasks OR home modification OR housing adaptation OR home safety OR home Injury prevention	goal attainment OR occupational performance OR independence OR unintended injury OR	usual care OR waitlist OR no occupational therapy OR own control OR no control	Children OR young people AND physical disability AND home AND neurological conditions OR developmental delay OR Genetic

Table 4. Search Terms, Problem, Intervention/interaction, Outcome, Comparison, Target Population

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3.2.2. Summary Measures

The outcome measures used in the included studies in this review were standard paediatric and adolescent indicators for occupational therapy and rehabilitation, such as goal setting, occupational performance, person and environment 'fit', and morbidity and mortality rates for unintentional injury.

3.3. Question Refinement Strategy

The WHO International Classification of Functioning (ICF) [15,1] framework is well known, and often applied by occupational therapists. The unique relationship between this model's components and the need to describe and use the '*person-home-environment-fit'* framework[1]

and the inclusion of the growth and development component influenced the choice of this model.

As it covers a variety of study designs such as cross sectional surveys, case control studies and case series, as well as systematic review and randomised controlled trials, the Oxford Centre for Evidence-Based Medicine (OCEBM) [17] was used to assess the quality of the research. Using the OCEBM increased the scope of the work, however, included studies that were not directly interventions. The observational studies contribute important evidence on risk factors, particularly disability status, home environment and normative data, that provide occupational therapists with comparative perspectives on functional performance within members of the target group.[83]

While considered, this systematic review did not cover qualitative studies, as analysing this research type was not within the expertise of the main author. The systematic review did however, include qualitative findings in the background and other sections.

Another issue was the possible inclusion of socially disadvantaged children and young people in addition to those with a physical disability. This inclusion was rejected as being outside the health scope of the systematic review, even though high quality findings on home modifications were available from New Zealand.[84]

Similarly, a comprehensive systematic review from the Home Modification Information Clearinghouse,[14] was not included as it did not specifically meet the target age requirements.

The MeSH term 'home' was critical in this systematic review. Studies were selected if the word 'home' was used in the title, abstract, or text of the published study. On occasions, other synonyms such as 'housing' ,'household', 'and 'community' (not school, leisure or transport) were accepted. A number of studies were obviously intended to be applied at home, however, were not tested in that environment so were excluded. [85] Some studies specifically compared established occupational therapy interventions usually undertaken in a hospital or clinic with a similar intervention being delivered at home, so were included.[86] In research studies that included both home

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school, leisure or transport components, only the 'home' component findings were reported.[87]

In addition, the term 'participation' was sometimes used to describe 'activities' such as self-care,[83, 88 ,89] under the WHO ICF. [1]

Also, the adjective 'functional' is appended to the WHO ICF [1] term 'mobility' as this exemplifies occupational performance attributes. Also participation in 'domestic life'[1] applies mostly to older children and young people as they develop and are expected to undertake more household tasks.

The preliminary search of the literature identified some additional divergence in the use of terminology.[14] For example, 'home modification' (not a MeSH term) [53] is used in Australia, while in North America the term 'housing adaptation' is the favoured MeSH term. [90] Consequently, the final search included both terms.

In relation to injury in the home, only apparent 'unintended' injuries were included, as the field of 'intended' injury is large and complex and is not in the scope of this systematic review. Initial searches found minimal literature of injury prevention for children and young people with disability however, there is a reasonable quantity of high-quality literature for typically developing children and young people. This information could have been included but was considered outside the scope of this systematic review. In particular, children and youth with physical disabilities have specific needs (such as wheelchair egress), and a much higher risk (over twice) [61] of unintentional injury in the home, than the typically developing child or young person.

The inclusion of remedial, compensatory [91] and contextual [92] studies presented some difficulty, as more remedial occupational therapy is now provided in the home particularly in relation to the NDIS and not just physical home modifications. While the interventions were mainly provided by occupational therapists, some other related professions also undertook relevant research, for example, 'Ride on Cars'. The phrase 'within the scope of occupational therapy' was used to account for this situation. In addition, particularly for younger children, parents or carers often act as providers of therapy delivered in the home.

Detailed reporting and critical appraisal of occupational therapy assessment and outcome measures used in the home are not included in this systematic review due to the depth and complexity of the material available.

3.4. Search Strategy

The 'Medical Subject Headings' (MeSH) 93 and 'All Fields' were used in a variety of combinations in this systematic review.

Appendix III: Example - PubMed Search: Home Safety Disabled

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HMinfo Library search

- Home Modifications for Children: An Annotated Bibliography
- Considerations for using anthropometrics to modifications for children
- Caring for the carer: Home design and modification for carers of young people
- Landscape Modification: An alternative to residential access ramps and lifts
- Systematic Review: Evidence on Home Modifications

Standard Electronic Database search

The search was undertaken in early 2020 and repeated prior to submission.

Five databases were searched including English language studies published between January 2005 and July 2020, including the:

- Cochrane Data Base of Systematic Reviews: https://www.cochranelibrary.com/
- Cochrane Central Register of Controlled Trials: https://www.cochranelibrary.com/central/about-central
- Home Modification Information Clearing House: https://www.homemods.info/
- PubMed: https://pubmed.ncbi.nlm.nih.gov/
- OTseeker: http://www.otseeker.com/

Online (World Wide Web) Search

- Australian Bureau of Statistics: https://www.abs.gov.au/
- Australian Institute of Health and Welfare: *www.aihw.gov.au*
- Australian Occupational Therapy Association Research Resources
- Electronic ‘hand’ searching of reference lists and database.
- Google scholar: https://scholar.google.com/scholar
- Mendeley - Reference Management Software & Researcher www.mendeley.com
- ProQuest https://www.proquest.com/

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Other Literature

- Kidsafe: Child Accident Prevention Foundation of Australia: https://kidsafe.com.au/
- https://www.cerebralpalsyguidance.com/cerebral-palsy/living/home-modifications/
- Centers for Disease Control: Child Safety and Injury Prevention https://www.cdc.gov/safechild/index.html
- Australian Injury Prevention Network: https://aipn.com.au/injury-resources/injury-topics/child-injury/
- The Melbourne Children's Hospital: https://www.rch.org.au/kidsinfo/fact_sheets/Safety_Around_the_home/
- Huang H, Galloway J. Modified ride-on toy cars for early power mobility: A technical report. [94]
- http://deakinhomeresearchhub.com/why-home/

Legislative and Regulatory Documents

- United Nations Convent on the Rights of Persons with Disabilities Article 9. [26]
- The National Disability Insurance Scheme Act (2013), which provides parameters for the establishment, guidelines, and implementation of the National Disability Insurance Scheme (NDIS).[69]
- Disability Discrimination Act 1991.[95]
- NDIS List A: https://www.ndis.gov.au/about-us/operational-guidelines/access-ndis-operational-guideline/list-conditions-which-are-likely-meet-disability-requirements-section-24-ndis-act. [78]
- NDIS List B: https://www.ndis.gov.au/about-us/operational-guidelines/access-ndis-operational-guideline/list-b-permanent-conditions-which-functional-capacity-are-variable-and-further-assessment-functional-capacity-generally-required. [79]
- https://www.ndis.gov.au/participants/home-equipment-and-supports/home-modifications-explained
- Australian Institute of Health and Welfare 2020

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4. Outcomes of Search

The review process, with the number or relevant studies and other documentation, is outlined in Figure 2.

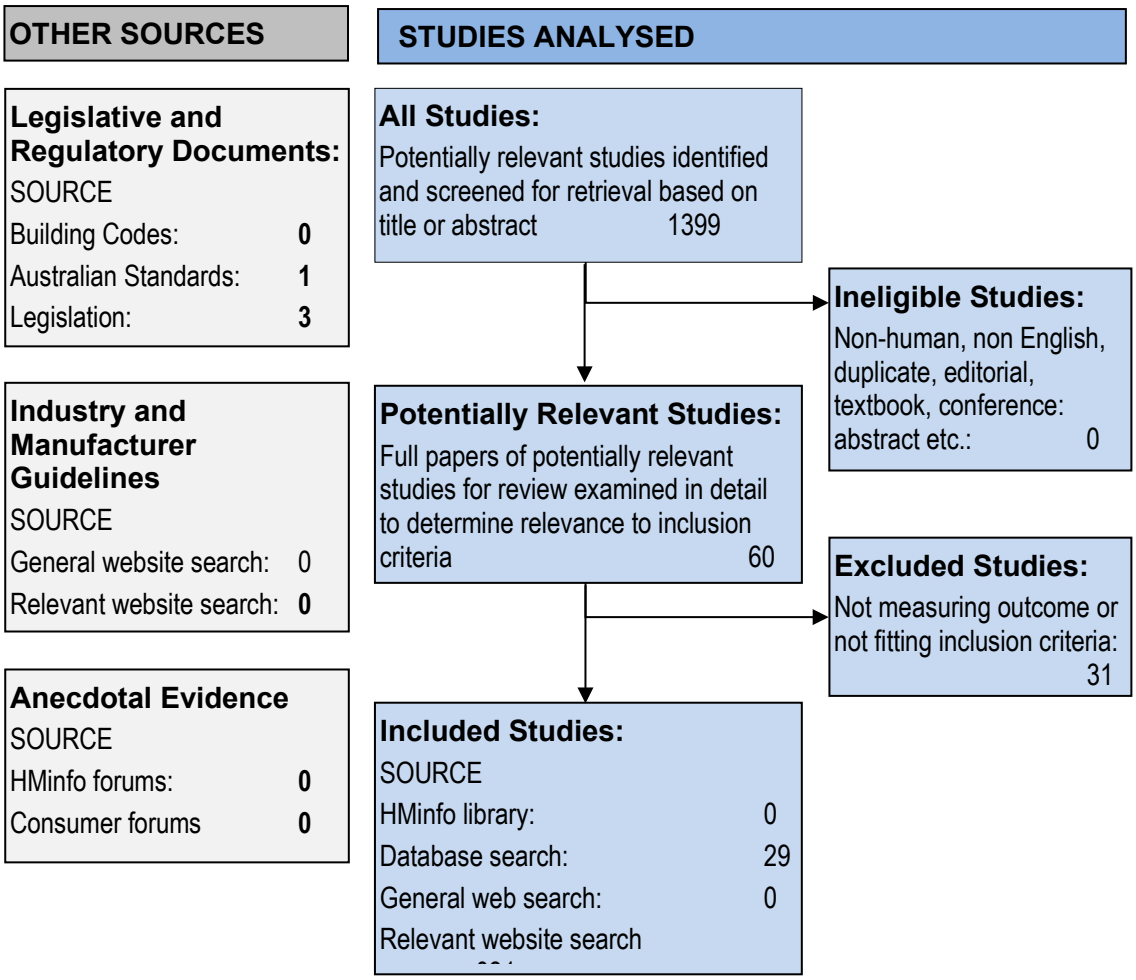

Figure 2. Flowchart of studies

4.1. Studies Analysed and Outcomes

Summary of results - Check 'Glossary' for definitions.

Total n=29

Fitting the inclusion criteria for:

- Self care

In relation to the specified target groups in the home setting, for '**self-care**' [96], there is ***high*** quality evidence that improved upper limb function including self care requires more than 30-40 hours of practice and individual goal achievement required more than

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14-25 hours face-to-face OT and home practice. There is ***high*** quality evidence that context-focussed home occupational therapy, is as effective in self-care and mobility as child-focused therapy[6] that occupational therapy home programs improve self-care. [97]

There is ***moderate*** evidence that Mother (or carer) Handling Training – self-care, feeding, dressing, lifting, carrying, bathing, toileting, sleep – improves gross motor, but not fine motor function.[98] There is ***moderate*** evidence that modified Constraint Induced Movement (mCIM) Therapy is effective in improving motor function (as is Bimanual Therapy').[8] There is ***moderate*** evidence that CIM therapy improves functional performance in self-care. [99] There is ***moderate*** evidence that Routines-Based Early Intervention is effective in improving self-care.[100]

There is ***low*** to ***moderate*** evidence showing that H HABITAT improves dexterity and the attainment of functional goals, but not bimanual performance.[101] There is ***low*** evidence that functional abilities and task performance indirectly impact on home participation [83]; that adaptive seating systems may improve activity and participation [3]; and that assistive technology is effective with activity, participation and contextual factors.[91] There is ***low*** evidence that adaptive seating enables engagement with self-care [102]; and that OT home programs improve participation in self-care. [103]

- Functional mobility

In relation to the specified target groups in the home setting for **'functional mobility'** there is ***high*** quality evidence that CIM therapy performed at home has a positive effect on the involved upper-limb ability and occupational performance.[86]

There is ***moderate*** evidence that CareToy improves motor skills.[104]

There is ***low*** *to* ***moderate*** evidence that modified ride-on cars are effective in developing early mobility skills.[105,106]

There is ***very low*** evidence that mCIM therapy provides greater improvement in upper limb function at home in the natural context.[107]

- Domestic living

In relation to the specified target groups in the home setting for '**domestic living',** there is ***low to moderate*** evidence that disability prevents active participation in daily self-care and family-care tasks at home.[108, 109] There is ***low*** evidence that Pathways and Resources for Engagement and Participation is effective in improving and maintaining adolescent participation [110]; and that physical limitations may affect the frequency of a child's participation in activity outside of school.[111] There is ***low*** evidence that those with physical disabilities did the same household tasks as children without a disability, but needed more assistance. [112]

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- Home modification

In relation to the specified target groups in the home setting for '**home modification'** there is ***low*** to ***moderate*** evidence of difficulty getting into and around the home and accessing bathrooms [113]; that needed environmental features are unavailable to many children who require enlarged rooms, adapted toilets, modified kitchen and hoists at home, and grants for home modifications. [114]

There is ***low*** evidence that environmental barriers and supports explained 50% to 64% of variation in participation in home-based activities [115]; that children were least restricted moving about in and around their own homes [116]; and that environmental access of European children, across all impairment levels, showed variations between regions.[117] There is ***low*** evidence that children perceived the physical accessibility of their home to be relatively good, while outside the home the environment was perceived as less accessible [118]; and that fifty percent of parents report home modifications had a moderate to very large effect on the child's function.[119]

- Home safety

In relation to the specific target group of children and young people with physical disabilities there is ***no*** quantitative evidence fitting the inclusion criteria for '**home safety**'.

Summary of the outcomes in a tabular format are provided below.

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Activities: Self-care

First author, year	Study design Level *	Setting #	Total number	Age/Gender	Diagnostic category or disorder	OT or within scope	Regime	GRADE	Effectiveness
Jackman, 2020 [96]	Level 1 Systematic Review	Home	25 (Motor functioning) 20 (Goal setting)	$\bar{x}$ age 18 years	Children and young people with cerebral palsy	Motor functioning Goal setting and achievement	Remedial Contextual Self-care: Upper limb function: 30-40 hours Goal achievement: 14-25 hours	High Randomised Controlled Trials High quality measures	OT – upper limb function required more than 30–40 hours. OT – goal achievement required more than 14–25 hours face to face and home.
Angsupaisal, 2015[3]	Level 1 Systematic Review	Home	9 studies	<19 years	Children and young people with cerebral palsy (Severe- non-ambulatory)	Adaptive seating systems (AdSSs)	Remedial Contextual Undertake daily activities (self-care) enhance participation.	Low Poor methodological quality of studies	AdSSs – may improve activity and participation
Henderson, 2008[91]	Level 1 Systematic Review	Home Environ-ment Contextual Family centered care	54 studies	<19 years	Children with cerebral palsy Myelomeningocele, Feeding difficulties One or more functional impairments	Assistive technology (AT) Independent feeding Living skills Mobility Modifying the environment	Remedial Compensatory Contextual Feeding Living skills Mobility Environmental modifications	Low Most studies out of date range	AT – effective with activity, participation & contextual factors
Ghorbanpour, 2019 [120]	Level 2 Randomised Controlled Trial	Home	40 I=20 C=20	.5 to 6 years ($\bar{x}$ age 3.7 years) Girls 12 Boys 28	Children with cerebral palsy Moderate to severe motor difficulties	Mothering handling training (MHT) Self-care, Feeding, Dressing, Lifting, Carrying Bathing Toilet	Remedial Motor function 4 hour session	Low Pilot Underpowered	MHT – effective in improving gross motor, but not fine motor function. (p <0.001)

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Chamudot, 2018[8]	Level 2 Randomised Controlled Trial	Home	33 I=17 mCIMT C=16 BIM	11.1 months ($\bar{x}$ age) Girls 14 Boys 19	Children with cerebral palsy (Hemiplegia)	Constraint-induced movement therapy (mCIMT) Bimanual therapy (BMT)	Remedial Contextual Play at home – daily 1-hr play sessions for 8 wk.	Moderate Single blind	mCIMT – effective, significantly large and equal improvement in hand and gross motor function ($p < .001$) mCIMT and BIM are equally effective
Ferre, 2017 [121]	Level 2 Randomised Controlled Trial	Home	24 1=12 C=12	4.9 years – 10 years 1 month 14 girls 10 boys	Children with cerebral palsy (Unilateral)	Hand-arm bimanual intensive therapy (H-HABITAT) Dressing, undressing, cutting with scissors, eating	Remedial Contextual Functional goals 2 hours per day, 5 days per week, for 9 weeks	Low Small numbers	H-HABIT improved dexterity and occupational performance in functional goals, but not bimanual performance. ($p<0.001$)
Johari, 2016[98]	Level 2 Randomised Controlled Trial	Home	40 I=20 C=20	5-12 years Girls 8 Boys 32	Children with cerebral palsy	Mother Handling Training (MHT) Self-care, Feeding Dressing, Lifting, Carrying Bathing, Toilet	Remedial Contextual 5 hour training and then implemented for 3 months in home months with OT supervision	Moderate Sample size power 80%	MHT- motor skill in the intervention group was higher than that of the control group After 3 months ($p = 0.001$).
Hwang, 2013[100]	Level 2 Randomised Controlled Trial	Home	31 families I=15 C=16	5-30 months ($\bar{x}$ age 17.4 months) Girls 11 Boys 20	Children at risk of developmental delay	Routines-based early interventions (RBEI) Self-care Goal setting	Remedial Contextual 6-month RBEI vs. traditional home visiting (THV)	Moderate Single-blind	RBEI was more effective than THV. Both showed equal improvement in developmental domains.
Law, 2011 [6]	Level 2 Randomised Controlled Trial	Home	128 1=57 C=71	1 to 5.5 years ($\bar{x}$ age 3.5 years) Girls 49 Boys 79	Children with cerebral palsy	Focus on Function (FOF) Functional Goal directed tasks	Contextual Remedial 6-9 months 18-24 sessions	High Well designed	FOF - effective contextual approach in home equally effective as child-centred in functional activity – self-care and mobility

Lin, 2011[99]	Level 2 Randomised Controlled Trial	Home	21 I=10 C=11	4 to 9.1 years Girls 9 Boys 12	Children with cerebral palsy, congenital hemiplegia or quadriplegia Reduced function in the affected upper limb	Constraint Induced Movement Therapy (CIMT) Reaching, grasping, manipulating, self-care and mobility activities	Remedial Contextual Individualised 3.5–4 h a day, twice a week for 4weeks.	Moderate Small numbers, but adequate power.	CIMT – effective in improving unilateral grasping skills and unilateral/ bilateral functional performance at 6 months.
Novak, 2009 [97]	Level 2 Randomised Controlled Trial	Home	36 I=12 (8 weeks) I=12 (4 weeks) C=12	7.7 years ($\bar{x}$ age) Girls 11 Boys 25	Children with cerebral palsy	Occupational Therapy in the Home (OTIH)	Remedial Contextual Functioning 8 weeks 17.5 times per month for an average of 16.5 minutes per session	High	OTHP – produced statistically significant differences in function and parent satisfaction. (p " .01)

Activities: Functional Mobility

First author, year	Study design Level *	Setting #	Total number	Age/ Gender	Diagnostic category or disorder	OT or within scope	Regime	GRADE##	Effectiveness
Durand, 2018[86]	Level 1 Systematic review	Home	30 Studies 15 at home 15 in group	1.5 -16 years	Children and young people with cerebral palsy, stroke' traumatic brain injury (Unilateral hemiparesis)	Constraint induced movement therapy (CIMT)	Remedial Contextual 2 to 7 sessions per week, for 2 to 15 weeks.	High All Randomised Controlled Trials	CIMT – positive effect on the involved upper-limb ability and occupational performance in home and group
James, 2019[106]	Level 2 Scoping review	Home	14 studies	≤6 years	Mobility limitation	Powered mobility Modified ride-on cars (MROC)	Compensatory Remedial	Low Case studies plus 1 case controlled	MROC – effective in developing early mobility skill
Sgandurra, 2017[104]	Level 2	Home	41	3-9 months (Corrected age)	Children with developmental disorders	CareToy Early intervention.	Remedial Contextual	Moderate	CareToy – effective home-based, individualised early intervention in motor

	Randomised Controlled Trial		I=19 C=21	Girls 8 Boys 11	*Pre-term* infants at risk neuro developmental disorders without severe medical complications	Tele-rehabilitation Intensive Customised Family-centered Home based	Activity based intervention 8 weeks 4 weeks 30–45 minutes for 4 weeks	No goal setting	development at least in preterm infants significantly higher (p=0.050)
Participation: Domestic life – None									
Home Modification – None									
Home Safety – None									

OT= Occupational Therapy (or within the scope of OT), I= intervention group; C= control group; *Oxford Centre for Evidence-Based Medicine Levels;

may have other settings but includes home; RCT=Randomised Controlled Trials; $\bar{x}$ = Arithmetic mean.

Table 5. Self-care, functional mobility, domestic life, home modification and home safety for children and young people with predominantly physical disabilities (Interventional)

Activities: Self-care

Frist author, year	Study design Level *	Setting #	Total number	Age/gender	Diagnostic category or disorder	OT or within scope	Interaction -risk factors	GRADE	Outcomes
Albrecht, 2017[83]	Level 3 Cross sectional survey and secondary analysis	Home	395 care givers report	1 month to 5 years 11 months Girls 173 Boys 222	Children with developmental delay (or at risk)	Occupational therapy (OT) Daily activities	Contextual	Low/moderate	OT- functional abilities and task performance indirectly affects performance at home.
Rigby 2009[102]	Level 4 Case series – comparative	Home	30 children and parents	4.5 years $\bar{x}$ age	Children with cerebral palsy	Adaptive seating Self-care	Contextual	Low	Parents reported that their young children with CP were more able to engage in self-care and play activities when using specific adaptive seating devices in their home
Novak, 2007 [103]	Level 4 Case series – time series	Home	20	2-8 years ($\bar{x}$ age 3.8 years) Girls 4 Boys 16	Children with cerebral palsy – hemiplegia	Goals for independence in self-care and use of the affected arm	Contextual	Low	OT – preliminary suggestions possible effectiveness

Activities: Functional Mobility

Frist author, year	Study design Level *	Setting #	Total number	Age/ Gender	Diagnostic category or disorder	OT or within scope	Interaction – risk factors	GRADE	Outcomes
Pritchard-Wiart, 2019 [107]	Level 4 Case series Mixed methods	Home	4 Children 5 Parents 2 Therapists	13- 58 months Girls 0 Boys 4	Children with cerebral palsy, arthrogryposis, hypotonia	Modified ride on toy cars (MROC) Young movers Powered mobility	Compensatory Functional mobility and independence 1.3 to 2.9 days per week, 12-63 min in duration	Very low Limited numbers No controls	MROC are feasible for early exposure to power mobility not requiring extensive seating modifications

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Huang, 2018[122]	Level 4 Case series pre-post test	Home and Hospital	29	1-3 years Girls 17 Boys 12	Children with motor disabilities	Modified Ride on cars (MROC) Mobility and social skills training	Remedial Contextual 2 hours for 9 weeks - hospital 9-week home program (mean: 200 min/week)	Moderate Controls	MROC - both groups improved but not maintained. Hospital group showed most improvement
Participation: Domestic life									
Frist author, year	**Study design Level ***	**Setting #**	**Total number**	**Age/ Gender**	**Diagnostic category or disorder**	**OT or within scope**	**Interaction -risk factors**	**GRADE#**	**Outcomes**
Anaby, 2018[110]	Level 3 Cohort/ study Interrupted time series	Home	28	12 -18 years Girls 14 Boys 14	Children and young people with moderate physical disabilities	Pathways and Resources for Engagement and Participation (PREP)	Contextual Risk factors - physical disability and physical home environment	Low	PREP environment-based interventions are effective in improving and maintaining adolescent participation
Dunn, 2013[112]	Level 3 Cohort study matched	Home	46 PD=23 TD=23	6-10 years 11-14 years Girls 18 Boys 28	Children and young people with physical disability (Able to use upper limbs)	Household tasks Self-Care (13 items) and Family Care (21 Items)	Contextual Tasks at home Risk factors - physical disability and physical home environment	Low No controls	Children with PD did same household tasks but needed more assistance Younger children performed significantly fewer tasks than the older children
Alghamdi, 2017[108]	Level 3 Cross sectional survey	Home	694	1.5-12 years ($\bar{x}$ age 6 years) Girls 311 Boys 283	Children with cerebral palsy, Monoplegia Hemiplegia Diplegia Triplegia Quadriplegia Gross motor delay	Frequency and enjoyment of children's participation in family activities	Contextual Risk factors - physical disability and physical home environment	Moderate/low Large numbers From good cohort study	Children with higher gross motor, manual, and communication functions had higher frequency and enjoyment of participation, compared to children with lower functions.

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								Convenience Sample	
Amaral, 2014 [109]	Level 3 Cross sectional survey	Home	75	9.3 years ($\bar{x}$ age) Girls 36 Boys 39	Children with cerebral palsy (and Down Syndrome)	Participation in family-care tasks	Contextual Risk factors - physical disability	Low Low numbers Not true population cross sectional survey	Actively engaged in daily self-care and family-care tasks; participation at home ***not*** prevented by disabilities
Galvin, 2010[116]	Level 3 Survey	Home	20	5.3-15.3 years 11 years ($\bar{x}$ age)	Children and young people with acquired brain injury, stoke, traumatic brain injury	Participation Household tasks Family tasks Self- care Mobility around home	Contextual Risk factors - physical disability and physical home environment	Low Small numbers Not true cross-sectional design	Children were least restricted moving about in and around their own homes
Engel-Yeger, 2009[111]	Level 3 Cross sectional survey	Home	52	12-16 years 13.4 years ($\bar{x}$ age) Girls 33 Boys 19	Cerebral palsy Diplegia Quadriplegia Athetoid	Participation outside school	Contextual Risk factors - physical disability and physical home environment	Low Comparative study	Physical limitations may affect the frequency of a child's participation in activity outside of school
Home Modification									
Frist author, year	**Study design Level ***	**Setting #**	**Total number**	**Age/ Gender**	**Diagnostic category or disorder**	**Intervention OT or within scope/ health benefits**	**Interaction – risk factors**	**GRADE**	**Outcomes**
Stephens 2017 [113]	Level 3 Cross sectional survey	Home	428	10-14 years Girls 184 Boys 244	Children with physical disabilities using at least one mobility device	Home modification and accessibility Accessibility of essential everyday spaces at home such as	Compensatory Contextual	Moderate/low Large numbers	Difficulty getting into home 62%; Getting around home 91%; Accessing bathrooms 88%

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						washrooms (bathrooms) and toilets	Risk factors - physical disability and physical home environment	Large magnitude of effect	
Espín-Tello 2017 [114]	Level 3 Cohort/ study	Home	594	8-12 years ($\bar{x}$ age 10.4 years) 13-17 years ($\bar{x}$ age 15.1 years) Girls 249 Boys 345	Children and young people with cerebral palsy	SPARCLE 1 & 2 Access Functional independence	Compensatory Contextual Risk factors - physical disability and physical home environment	Moderate/low Large Numbers Randomly selected	Environmental features are unavailable to many children. Need enlarged rooms, adapted toilet, modified kitchen and hoists at home, grants for home modifications
Anaby, 2014 [115]	Level 3 Cross sectional survey Comparative	Home	576 groups	5 to 17 years	Children and young people with and without disabilities	Modifiable environ-mental factors. Environment barriers and supports	Compensatory Contextual	Moderate Large numbers Comparative	Environmental barriers and supports explained 50% to 64% of variation
Colver, 2010[117]	Level 3 Cohort study	Home	818	8 to 12 years	Children and young people with cerebral palsy	SPARCLE Access	Contextual Risk factors - physical disability and physical home environment	Moderate to low Large numbers No controls	The access of European children, across all impairment showed variations between good and poor
Prellwitz, 2006[118]	Level 3 Cross sectional survey	Home	82	7-15 years 11.5 years ($\bar{x}$ age) Girls 39 Boys 43	Children with spina bifida, muscular diseases, cerebral palsy	Restricted mobility	Contextual Risk factors - physical disability and physical home environment	Low No controls	Considered home physical environment relatively good while outside the home the environment was less accessible

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Østensjø, 2005[119]	Level 3 Cross sectional survey	Home	95	4.8 years ($\bar{x}$ age) Girls 40 Boys 55	Children with cerebral palsy	Environmental modification Assistive devices	Compensatory Mobility (50%) 25% on self-care skills (25%) Risk factors - physical disability and physical home environment	Very low No controls Not proper cross sectional survey	Fifty percent of parents reporting home modifications had a moderate to very large effect on the child's function
Home Safety – None									

OT= Occupational Therapy; *Oxford Centre for Evidence-Based Medicine Levels; PD = Physical disabilities # Setting, may have other settings but includes home;

TD = Typically developing; $\bar{x}$ = Arithmetic mean.

Table 6. Self-care, functional mobility, domestic life, home modification and home safety for children and young people with physical disabilities (Observational)

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Caution: In relation to adverse effects, occupational therapists need to be aware of the potential for some children not to tolerate CIM therapy [123] and the safety implications of ride on cars.[65]

4.2. Completeness and Quality of Evidence

The evidence for self-care, functional mobility and domestic life was moderate, however 'home modification' was low and 'home safety' was not available for the target groups.

Four systematic reviews [96, 3, 86, 91] which fitted the inclusion criteria were included. A recent systematic review on occupational therapy dosage for interventions in both clinic and home provides high level evidence.[96] It is recognised, however, that the quality of systematic reviews is dependent of the robustness of the studies reviewed, for example, a scoping review [106] that included 13 case studies was excluded.

Generally, for self-care and functional mobility, the evidence was moderate with eighty percent being observational studies. The literature included one non-randomised controlled trial,[124] three cohort studies and five cross sectional surveys.[108,116, 111]

Relative to home modification the studies are all observational, specifically cross sectional surveys or cohort studies (Level 3).

For home safety there was no studies directly related to injuries such a falls in those children and young people with cerebral palsy and none within the date range undertaken by OT. No studies were identified for musculoskeletal injuries resulting, for example, from falls for the major diagnostic categories of children and young people with cerebral palsy.

4.3. Limitations

The limitations of this systematic review are the inclusion of lesser quality research designs, such as case series, which have a higher risk of bias, and not exclusively randomised controlled trials as found in the gold standard of the Cochrane Collaboration. In addition, this review did not include qualitative studies; however, these were often covered in the background text.

5. Conclusions

This systematic review provides comprehensive information on the quality, scope and applicability of interventions in the home for children and young people with predominantly physical disabilities. This facilitates improving the effectiveness of home-based programs by knowledge translation. [125]

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5.1. Implications for research

While there is moderate quality research into self-care, functional mobility and to a lesser extent participation in domestic life, there is a pressing need for more high level studies, particularly randomised controlled trials, systematic reviews and meta-analyses, into occupational therapy for home modification and home safety.

While occupational therapists are especially aware of the importance of home safety, for children and young people, little research has been undertaken in this area. Occupational therapists have the background in rehabilitation, disability, task analysis, ergonomics, safety, child development, as well as family- and child-centred care, to undertake high level research into home safety and injury prevention.

5.2. Implication for practice

Occupational therapy in the home for children and young people is well established in Australia, particularly through the NDIS. Currently, the COVID 19 pandemic in 2020/1 presents challenges for service delivery.

To ensure the provision of effective occupational therapy in the home for clients and their families, occupational therapists need to be aware of the best interventions for the relevant age and disability groups. The refrain needs to be 'the research says' and this includes engagement with parents, children and young people, referral sources and funders.

An evidence-based practice commentary, in relation to children with cerebral palsy, concluded that 'home programs' are effective if the occupational therapy is based on effective interventions, and the parents are respected, supported and coached in the goal oriented service delivery at home. [126]

When applying interventions particularly those devised and researched in a clinical or rehabilitation setting, it is important to ensure the fidelity of the intervention both in terms of theoretical framework and skills.[127] Occupational therapists need to undertake the appropriate professional development and seek mentorship when appropriate, to ensure the faithful application of specific specialised interventions.

In relation to adverse effects, occupational therapists need to be aware of the potential that some children not to tolerate Constraint-Induced Movement Therapy [123] and the use of ride on cars for all children and young people. [65]

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As this study did not involve humans, no ethical approval was required.

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