



Caregivers of Children with Intellectual and Developmental Disabilities in Vietnam:

A literature review of experiences, needs, and support
programs

ECDAN Knowledge Fellows
program project

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Abbreviations

AAIDD	American Association on Intellectual and Developmental Disability
ABA	Applied Behavior Analysis
ADHD	attention deficit hyperactivity disorder
ASD	autism spectrum disorder
ATEC	Autism Treatment Evaluation Checklist
CBR	community-based rehabilitation
CCIHP	Center for Creative Initiatives in Health and Population
CGSQ	Caregiver Strain Questionnaire
CINAHL	Cumulative Index to Nursing and Allied Health Literature
CST	Caregiver Skills Training
ECD	early childhood development
ECDAN	Early Childhood Development Action Network
FMIP	Family Management Intervention Program
FMSF	Family Management Style Framework
FQoL	Family Quality of Life
IDD	intellectual and developmental disability
LMIC	low- and middle-income country
NGO	nongovernmental organization
Online PMI	Online Parent-Mediated Intervention
SRS-2	Social Responsive Scale, second edition
TIDieR	Template for Intervention Description and Replication
Vineland-3	Vineland Adaptive Behavior Scales, third edition



1. Introduction

Globally, most children with intellectual and developmental disabilities live in low- and middle-income countries (LMICs).¹⁻⁴ Children's disabilities interact with other child and family dynamics, conditions, and characteristics to influence family outcomes.⁵ It is known, for example, that families with children who have an intellectual and/or developmental disability are at higher risk of social marginalization and exclusion from education. Meanwhile, the literature pertaining to how to best support children and families living with intellectual and developmental disabilities generally lacks evidence from these resource-constrained settings.⁵ There has been limited but growing interest and efforts to better represent children and families from LMICs in the literature on intellectual and developmental disabilities. These initiatives have paid particular attention to structural, socioeconomic, and cultural differences and examined how these factors might limit the generalization of research evidence and lessons learned across various contexts.^{6,7} For example, there have been attempts to investigate caregivers' experiences and support needs,⁸ and caregiving beliefs and practices concerning children with intellectual disabilities,⁹ among others.

This project aims to further these efforts by examining the literature regarding caregivers' experiences and support needs in the rather under-investigated cultural context of Vietnam. In the last decade, as the number of children diagnosed with intellectual and developmental disabilities in Vietnam increased rapidly, the demand for intervention services appears to be also on the rise, along with an expansion of the workforce in disability-relevant fields.¹⁰ While the literature on intellectual and developmental disabilities in Vietnam remains significantly lacking, recently more attention has been paid to critically examining the current state of service provision and support for children with intellectual and developmental disabilities and their families. There are a small number of studies that focus on understanding the experiences and support needs of caregivers, who play the most critical roles in providing care and support for children. Some support programs and initiatives implemented by the government and civil society organizations have also been documented, providing further insights into their implementation process, effectiveness, value, and lessons learned. Systematic studies have been conducted regarding interventions, rehabilitation, and parent support programs for children with intellectual and developmental disabilities in low-resourced settings, such as in South Asia.¹¹⁻¹³ Therefore, a scoping review of caregivers' experiences, needs, and support programs is timely to capture the existing evidence and to identify research, implementation, and policy gaps in Vietnam.

To achieve this goal, this scoping review is guided by the following research questions:

- What is known about the experiences and support needs of caregivers of children with intellectual and developmental disabilities in Vietnam?
- What support programs, initiatives, and interventions to support caregivers have been implemented? What are the outcomes and lessons learned?



2. Definitions

According to the American Association on Intellectual and Developmental Disability (AAIDD), *intellectual disability* is characterized by significant limitations in intellectual and adaptive functioning as expressed in the conceptual, social, and practical domains with onset during the developmental stage.¹⁴ The definition of *developmental disability* is broader than intellectual disability and might include physical elements in addition to intellectual functioning impairments.¹⁵ A developmental disability is “likely to continue indefinitely; results in substantial functional limitations in three or more major life activity areas; and reflects the individual’s need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, and other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated” ([Developmental Disabilities Assistance and Bill of Rights Act Amendments of 2000, Sec. 102](#)). The diagnosis of a developmental disability might use a criterion that is categorical, i.e., a specific medical diagnosis such as autism spectrum disorders (ASDs), cerebral palsy, intellectual disability, spina bifida, etc., or functional, i.e., focusing on limitations in functioning in major areas of life activities.¹⁶ In this report, the term *intellectual and developmental disability* (IDD) is used to refer to the broader, combined field of intellectual disability and developmental disability.¹⁷

3. Methods

A search was conducted on the Cumulative Index to Nursing and Allied Health Literature (CINAHL) and Scopus (for English articles) and on CitationGate (for Vietnamese articles) using the keywords presented in Table 1. An informal search was also conducted using Google Scholar. Additional articles were identified by hand-searching the reference lists of selected studies and recommendations from the author’s colleagues. Due to time constraints, a systematic search of grey literature was not conducted. However, two reports from a quasi-experimental study on parent-mediated interventions were located and included in the report based on the author’s own experience in the field and knowledge of existing programs.

The researcher screened the titles and abstracts of all studies found and selected 22 publications in English and Vietnamese for further assessment of their relevance to the research questions. The review process used broad inclusion criteria and did not apply additional exclusion criteria or appraise the study, as is the case with scoping reviews.¹⁸ This is to include the largest possible amount of information and knowledge currently available.

Nineteen publications were included in the final review. The studies were published between 2006 and 2022, including 5 in Vietnamese¹⁹⁻²³ and 14 in English.²⁴⁻³⁷ Six of the latter studies²⁴⁻²⁹ came from the Family Needs Assessment Project—a collaborative research program between US experts and Vietnamese researchers (2003 to 2005) on intellectual disability/delay in the city of Hue. This set of studies provides valuable information about the situation regarding families of children with intellectual disability/delay in the period before the introduction of major legislative changes in disability support, such as the Law on Persons with Disability and the recognition of ASD as an eligible category. There are two reports from a quasi-



experimental study on parent-mediated interventions implemented by a local nonprofit organization, the Center for Creative Initiatives in Health and Population (CCIHP).

Table 1. Keywords used for scoping review.

	Keywords (English)	Keywords (Vietnamese)	Databases
Intellectual and Developmental Disabilities	Intellectual Disab* OR Intellectual Development Disorder* OR Cognitive Impairment* OR Cognitive Delay* OR Mental Retardation OR Developmental Disab* Autism OR Autism Spectrum Disorders OR Autistic Cerebral Palsy	“Khuyết tật trí tuệ” OR “chậm phát triển” OR “chậm phát triển trí tuệ” OR “thiếu năng trí tuệ” OR “chậm phát triển tâm thần” “Tự kỷ” OR “Rối loạn phổ tự kỷ” “Bại não”	CINAHL, Scopus, Google Scholar
Parents/ caregivers	Famil* OR Parent OR Mother* OR Father* OR caregiver* OR care giver	“Cha” OR “Bố” OR “Mẹ” OR “Cha mẹ” OR “người chăm sóc”	Citation Gate, Google Scholar

Abbreviations: CINAHL, Cumulative Index to Nursing and Allied Health Literature.

4. Results

4.1 Caregivers’ experiences

4.1.1 Stress and well-being

The impact of a child’s disability on parental stress is among the major themes reported in the selected study. Among studies from the Family Needs Assessment series, Shin and Nhan (2009) found that mothers of children with cognitive delays experienced an elevated level of parenting stress and lower level of perceived social support compared to mothers of children without the diagnosis.²⁶ The child’s cognitive delay was the primary predictor of parenting stress, while demographic and psychological factors such as parental health issues, economic status, educational level, and perceived social support compounded the stressful situation faced by mothers. Mothers also experienced more stress when the child with cognitive delay was a girl than a boy, whereas the reverse pattern was observed among mothers in the control group. This might suggest that having a girl with cognitive delays raises additional, uniquely concerning issues for mothers, such as pregnancy and menstruation.

Shin et al. (2006) reported differences between fathers’ and mothers’ experiences of stress.²⁴ The child’s level of functioning and behavioral challenges affected the mother’s stress level to a larger extent than the father’s. The mother’s stress level was directly related to the child’s characteristics (intellectual functioning and gender) and family factors (e.g., the



father's health condition), whereas financial situation and the extent of the social network directly affected the father's stress. This might reflect the traditional delineation of roles within a household, in which mothers are directly responsible for the development and well-being of the children, whereas fathers are more concerned with financial status and connection with the outer world and community. The presence of an intellectual disability in a child might have disrupted the parents' performances in these traditional roles (i.e., challenges in taking care of the children and a restricted social life for the family), resulting in parental stress. These issues warrant future research to capture the intersecting effect of gender on children's and their parents' lived experiences of intellectual disability.

Mai et al. (2020) found that among mothers of children with a diagnosis of "mental development delay," 80% reported stress scores above the clinical threshold level.²² Of the three subscales, the highest percentage (90%) reported an elevated stress level related to having to respond to the child's diverse needs, and 60% reported parental distress and parent-child dysfunctional interactions. It was significant that all three studies^{22,24,26} found that the child's diagnosis was the most prominent predictor of stress levels experienced by the mothers and that a higher severity of intellectual disability was associated with a higher level of stress.

Finally, Tong et al. (2021) studied the quality of life of 117 mothers of children with cerebral palsy attending a northern provincial hospital and found that more than half experienced moderate sleep disorders, and one-third experienced mild sleep disorders.²³ Mothers in the study also reported a high level of depression and tiredness. Level of education was found to be the most significant determinant of a mother's reported quality of life, such that a higher level of education was associated with a lower level of reported depression and tiredness. While the study examined various dimensions, such as sleep quality and depressive symptoms, it is unclear how it conceptualized quality of life and whether the tools have been adapted and validated to use for the Vietnamese population.

4.1.2 Stigma, discrimination, and social exclusion

Among the earliest studies on the topic was Ngo et al. (2012) regarding social exclusion and stigmas experienced by the parents.²⁹ The study found that culture-specific stigmas caused both children with intellectual disabilities and the family to be labeled and discredited and imposed restrictions on the family's social life. Social exclusion was negatively related to parents' educational level which, the authors argued, might be because parents with higher educational levels were less susceptible to self-stigmas related to "karma" beliefs. This finding emphasizes variations in perceptions and responses to disability at the interplay of cultural and demographic factors. Parents of children with autism in Vu et al. (2014) reported similar experiences of discrimination due to the belief in disability as a sin or punishment.³⁰ According to this study, societal attitude toward children with autism as "worthless" and "burdensome" resulted in parents experiencing feelings of hopelessness, disappointment, and anger, as parents reported facing judgment from health care providers regarding their children's "abnormality" such as "good for nothing" or "for decoration only."

Parents of children with intellectual disabilities expressed concerns about their children's employment and marriage prospects.^{19,29} The mistaken but prevalent association between autism and schizophrenia, even among health care providers, also caused fears and uncertainties among parents of children with autism regarding the children's future.³⁰ While these concerns might not be unique to Vietnamese parents, they are particularly antithetical



to the forceful Confucian values in the local culture which emphasizes one's self-attainment and cultivation, harmony, and the continuity of the family lineage through the practice of marriage and reproduction. Moreover, children with intellectual disabilities were overwhelmingly portrayed as burdens and described in terms of high dependency, e.g., unable to complete self-care tasks. Therefore, the presence of intellectual, communication, and behavioral challenges—and the assumed diminished capacity to achieve full adult status—marks intellectual disability, and by implication other developmental disabilities, as a devaluing condition and stigmatized identity.²⁹

4.1.3 Sources of support

Three studies were identified that examined the types and availability of support for parents of children with cognitive delays and/or intellectual disabilities.^{20,25,28} There was a significant lack of professional support and services as well as generally low utilization of these supports.^{20,25,28} A similar finding was revealed among parents of children with autism, who reported a lack of assistance in three key areas: professional support at the time of diagnosis, advice on intervention strategies, and follow-up or monitoring of intervention progress.³⁰ There was encouraging engagement and support, although still at a modest level, from other professionals, including therapists and social workers, as well as from parents' networks. Teachers were found to provide the highest level of social support and ranked first among the support coming from outside of the family circle (spouses and the maternal grandmother).^{20,25,28} However, teachers' support was mostly provided by kindergarten teachers, who had no prior training in special education. As many mothers from low-income households might not have access to private doctors or therapists for medical services, teachers appeared more accessible and were a valuable source of professional support, such as assistance in teaching and training. However, the availability of family, social, and professional support decreased for children with lower levels of intellectual functioning,²⁵ possibly due to the higher level of specialized care and support the children may require. This finding might highlight the need to improve the capacity of the disability-related workforce to be able to provide the appropriate services and supports to children who need them most.

Informal social networks were lower for mothers who had children with intellectual disabilities compared to mothers who did not, which indicated social isolation experienced by the former group.²⁸ Siblings provided more family-directed support, such as help with housework, than fathers—and daughters more than sons—possibly reflecting gender norms with regard to domestic and caretaking responsibilities within a household.²⁸ In addition, spouses (husbands) provided support mainly in the form of material (“earning money”) for the family, but not much emotional support. Support from the immediate family was primarily child-directed, such as feeding, playing with, and washing the child.

4.1.4 Family support needs

In the context of the significant lack of services and service providers, access to professional support, including intervention services directly provided to the children, was among the major needs reported by parents.¹⁹ In addition, Vietnamese parents of children with ASD have been observed to seek a variety of interventions, including educational, language, and behavior therapists as well as traditional medicines, modified diets, spiritual practices, and other supplementary and alternative methods, regardless of whether they have an established evidence base.^{21,30,37} There are two implications from this understanding. Firstly, increasing governmental oversight, safeguarding, and quality assurance of services and providers is

warranted to ensure that children and families have access to safe and quality services. Secondly, while the finding is not unexpected, it also needs to be considered in the broader cultural context. Seeking syncretic care underlines the prevalence and prominence of beliefs in karma and non-biomedical causation in Vietnam, which influences parents' reactions to their children's conditions.^{30,37} There is evidence from cross-cultural studies that suggests a similar pattern. For example, parents in the Congo Republic³⁸ and India³⁹ were described as drawing upon a combination of biomedical and supernatural explanations for their children's disability and using both western- and non-western-based approaches to coping. Future research in this direction would be helpful to inform culturally appropriate interventions and programs, for example by identifying the enabling and challenging factors in parents' use of and navigation through the service systems developed with a western, scientific evidence base.

Kester and Kaelin (2021) explored the needs of parents of children with intellectual and developmental disabilities in community-based settings.³² Caregivers expressed their wishes for gaining information, knowledge, and practical skills to support their children in activities of daily living, such as "washing, toileting, managing female hygiene, walking, or eating by him/herself." In addition to practical needs, such as financial support and support with daily life activities (e.g., taking care of the children or other household responsibilities), parents also mentioned the wish to access information through participating in parents' groups, to share experiences with other parents, and to attend training courses and workshops. This finding fits with existing evidence that suggests information, education, and training are fundamental areas of family support needs.⁴⁰

4.2 Support programs

This scoping review identified six studies that report the implementation and effectiveness of four support programs for caregivers of children with IDD in Vietnam. These programs are the Portage program,^{27,31} the Caregiver Skills Training (CST) program,^{33,34} the Online Parent-Mediated Interventions (Online PMI) program,³⁴ and the Family Management Intervention Program (FMIP).^{35,36} The Portage program was designed for children with intellectual disability, cerebral palsy, as well as children without a formal diagnosis but identified through the Vineland Adaptive Behavior Scales (Vineland-3) as having a developmental delay. Meanwhile, the other three programs target children with autism and their caregivers specifically. Notably, while the original CST program was designed to cover the widest range of IDD including autism, intellectual disability, speech-language delay, and attention deficit hyperactivity disorder (ADHD), in the Vietnamese trial, only children with autism were included in the study.

This section presents key themes from these studies and is structured based on the Template for Intervention Description and Replication (TIDieR) checklist,⁴¹ comprising 12 items for a comprehensive description of the intervention. Additional items, including measurement and outcomes, feasibility, acceptability, and lessons learned from each program are also reported when available.

4.2.1 Rationale, theory, or goal of the elements essential to the intervention

The four identified programs showed both similarities and differences in their theoretical foundations and goals. The Portage program, CST program, and Online PMI program used a family-based approach to train parents to deliver interventions for their children in



naturalistic, home-based settings. These programs were designed to involve nonspecialists in the delivery of care for children with IDD, situated in resource-constrained settings of suburban and rural areas of Vietnam, and could be considered among community-based rehabilitation (CBR) models. The programs provide knowledge and skills for parents to implement interventions that target key developmental areas, such as communications, social-emotional development, and behaviors. The FMIP fundamentally differs from the former three programs in its specific focus on improving family outcomes as a primary goal rather than the child’s outcomes, including improving quality of life and reducing the burden of care for caregivers. The key areas of support for parents were identified based on the Family Management Style Framework (FMSF), which are information, behavior and action, and perceived consequences.

4.2.2 Materials

All programs used ready-made curricula and manuals that were standardized to varying extents. Two curricula and materials were developed in English (Portage and CST) and translated into Vietnamese. These programs consisted of standardized curricula for facilitators and participants, including assessment materials and instruction manuals, and have been translated and field-tested in multiple languages and settings. Meanwhile, the FMIP and the Online PMI program were developed by the research/program team. The FMIP was adapted from the Building on the Family Strength program and was validated internally; however, detailed information on the adaptation and validation process was not reported. The Online PMI program was the only program that contained electronic materials in the form of recorded video lectures.

A summary of the key domains of interventions from the programs is presented in Table 2.

Table 2. Key domains of interventions.

Target domains	Portage	CST	Online PMI	FMIP
Communication/language/literacy	✓	✓	✓	
Social-emotional development	✓		✓	
Memory, problem-solving, reasoning	✓			
Motor	✓			
Sensory	✓			
Behavior management		✓	✓	
Playing and participation		✓	✓	
Child development; information about specific diagnosis (autism)			✓	✓
Caregivers’ emotions and coping skills		✓		✓



Target domains	Portage	CST	Online PMI	FMIP
Family relationships, family communication, and parenting				✓
Finding available resources, and transitioning into having a meaningful life				✓

4.2.3 Procedures (how, where, when)

All programs provided training for parents through a combination of group and individualized sessions, except for the Portage program, in which all sessions were conducted on an individual basis. In all programs, parents received coaching and supervision from the facilitators through home-based visits (Portage and CST), online meetings (Online PMI), or follow-up via phone (FMIP). Across the programs, in-person training sessions were delivered weekly and lasted between 1 and 2.5 hours/session. Individual coaching sessions of the CST and Online PMI programs lasted between 1 and 1.5 hours/session, whereas follow-ups conducted via telephone in the FMIP lasted 5 minutes on average. The total length of the interventions varied considerably across programs, with the longest duration having been from the two trials of the Portage program (12 and 6 months), followed by the CST and Online PMI programs (9 weeks), and finally, the FMIP (4 weeks). In addition to training for parents, as is standard with community-based rehabilitation models, the protocol for the Portage and CST programs involved training for facilitators, delivered by experts/specialists (master trainers), who would later deliver the training to parents. The first phase of the Portage program lasted three months, whereas no information was obtained regarding facilitator training for the CST program.

All sessions with parents took place at home (home visit), online (attending online training), or in a community-based setting (local hospitals or centers). This could be considered an advantage of all the programs, as it could mean saving travel time and costs for caregivers, which are often reported as major barriers to accessing services for families and children with IDD. In addition, the Online PMI program reported that nearly 80% of caregivers submitted between six and nine videos of their own practice at home with their children to receive feedback from the facilitators, suggesting the viability of this format of coaching and supervision. The COVID-19 pandemic has to a certain extent equipped the global health care workforce with the skills and infrastructure to deliver telehealth interventions. It is encouraging that there are existing efforts from Vietnam to use web-based and videoconferencing platforms to deliver support for families of children with intellectual and developmental disabilities. While more evidence is needed regarding its efficacy, the use of technology that allows for video conferencing, video modeling, and online coaching is a potential approach to explore in future programs, either as the primary platform or for supplementary support, such as providing refresher modules.³⁶ This would be an important area of focus for future research to contribute to the extant knowledge on the use of telehealth for delivery of rehabilitation services and support, particularly to rural and remote areas.

4.2.4 Providers

In the first trial of the Portage program, facilitators were teachers from special education schools who had relevant work experience—but no formal training—with children who had an



IDD. The more recent trial recruited college students with only a little knowledge or experience as facilitators in an attempt to determine the minimum level of knowledge and experience required for this task-shifting approach. For the CST program, there appeared a wider range of backgrounds and experiences of facilitators, who were recruited from local hospitals, training institutions, and special education centers. Information about the background of facilitators for the Online PMI program was not available. For the FMIP, the program developer directly delivered training to parents.

4.2.5 Implementation (planned versus actual)

While the Portage, CST, and FMIP interventions were adapted from an existing framework, only the Portage intervention addressed the issues of fidelity and quality assurance in their report. Families and facilitators in the first Portage program were required to report their weekly teaching objectives as a means for a supervisor to cross-check the planned teaching objectives and activities versus those that were actually implemented. In the second program, college students were assigned into pairs to support each other in the role of facilitator. However, even with the Portage programs, there were no formal procedures for assessing fidelity. It might be the case that the other programs also addressed these issues but did not include such information in published reports or it was in materials not located by this report. Considering that all programs involved training for caregivers and/or teachers who had little formal training, documentation of the training process and strategies should be given more attention in future program design.⁴² Overall, it remains imperative for future programs and studies to pay attention to the issues of fidelity to the adapted intervention and compliance with quality assurance standards, which will allow for critical evaluation of their value and effectiveness.

4.2.6 Measurements of effectiveness and study outcomes

For measuring child outcomes, the Portage, CST, and Online PMI programs used the Vineland Scales to measure pre- and post-intervention improvement in the child's functioning—in the domains of communication, socialization, motor skills, and daily living—obtained through parent interview. The CST and Online PMI programs used two other scales: (1) the Social Responsive Scale, second edition (SRS™-2), a supporting tool for autism diagnosis, and (2) the Autism Treatment Evaluation Checklist (ATEC), which covers the four domains of speech/language communication, sociability, sensory/cognitive awareness, and health/physical/behavior. For measuring caregiver outcomes, the Beach Center Family Quality of Life (FQoL) scale and the Caregiver Strain Questionnaire (CGSQ) were employed for the FMIP, a caregiver knowledge and skills test for the CST program, and patient health questionnaires for the Online PMI program. All instruments were translated into Vietnamese; however, the Vineland Scales was the only instrument that reported detailed information about the translation and validation process.⁴³ While appraisal of the studies' methodologies and intervention outcomes is beyond the scope of this report, the reviewed studies share limitations that reflect significant research gaps. The lack of tools for assessing child development and measuring intervention effectiveness in non-western, low-resource settings remains a challenge and a barrier to evaluating evidence-based approaches to early childhood interventions;⁵ the process for adapting standardized assessments and tools that were developed in high-resource settings requires careful consideration when applying them to low-resource settings.⁴² Where possible, the programs and interventions should document the process of translating and adapting these tools. Without consensus on diagnostic criteria, assessment, and tools to determine eligibility, children in the sample might be misclassified,



confounding the study outcomes¹¹ and making it difficult to identify specific strategies for different conditions/disabilities. Finally, follow-up data was only collected and analyzed for parents in the FMIP. Thus, future research might look to design longitudinal studies to better capture the sustainability and cost-effectiveness of interventions.

4.2.7 Acceptability and feasibility

Two of the four programs, CST and Online PMI, collected data on the acceptability and feasibility of implementation in addition to improving child and caregiver outcomes. Acceptance of both programs was evidenced in the high rate of uptake: more than half of the participants attended for the entirety of the nine-week CST program and two-thirds of the participants attended weekly sessions. The majority of the participants also reported the usefulness, accessibility (in terms of being easy to understand), and practicality of program contents. There remained some concerns about the overall structure of the program, such as the time spent on specific topics or between theory/practice components.

Fathers' engagement was also evaluated as part of the trial and findings were published in a separate report. Specifically, the program investigated motivating factors and barriers to fathers' participation in caregiving, playing, and other parenting activities at home, in order to identify suitable approaches to better engage men in intervention programs and the care of their children. Congruent with earlier findings about local traditional culture and gender norms that emphasized the man's role in the household as the financial pillar, these factors were found to have limited men from active involvement in caregiving and playing with their young children at home. The knowledge and understanding of a child's developmental challenges thus often marked the changes in the father's participation in caregiving and intervention. Other enabling factors for engagement included the father perceiving progress and improvement in the child as a result of his efforts to implement intervention and receiving psychological support from the family and community, such as connecting with other parents. This intervention offers important insights into gender-related issues in families' responses to children's disabilities—which are largely underexamined in the existent literature.

5. Discussion and Conclusion

Emerging themes from this report include a range of emotional, psychological, and financial challenges encountered by parents of children with intellectual and developmental disabilities; the need for support in accessing professional services, information, and education; and the nascent stage of professional support that was realistically accessible and/or used by the families. These enduring challenges interact and impact the children and families simultaneously; however, the small number of studies available for review suggests that too little effort has been put into documenting and examining how such complexities impact the effectiveness and success of existing interventions and support programs. Between 2006 and 2021, four programs/interventions that focused on supporting parents/caregivers were identified. All programs were at the pilot stage with a relatively small sample size and used theoretical frameworks and/or intervention packages developed in English and adapted into Vietnamese. Of the four programs, three focused on improving child outcomes, and only one focused on family goals including, such as improving parents' quality of life and reducing



caregiving burdens. Despite methodological limitations, these programs provide emerging evidence of the potential of parent-mediated interventions in improving child and family outcomes, especially in contexts with constrained professional resources and support. Using the TIDieR checklist to describe intervention components, this report identifies the following key areas for future research:

- **Rationale/theory:** the effectiveness and value of a family-based approach to train parents to deliver interventions for their children in naturalistic, home-based settings; a task-shifting and community-based approach.
- **Materials:** Documentation of the process of validation, translation, and adaptation.
- **Procedures:** The potential use of technological innovation (e.g., videoconferencing platforms, social media) to deliver training and support.
- **Providers:** Identification of the minimum level of experience/expertise required for caregivers/facilitators to effectively deliver training and interventions; the level and extent of supervision/coaching and follow-up required for quality assurance.
- **Implementation** (planned versus actual): Documentation of the training process and strategies.
- **Measurements of effectiveness and study outcomes:** Identification of tools for assessing child development and measuring intervention effectiveness and documentation of the process for translating and adapting these tools; longitudinal studies to better capture the sustainability and cost-effectiveness of interventions.
- **Documentation of the intervention's acceptability and feasibility.**

This report is inevitably not without shortcomings. Completed within a short amount of time, the depth and breadth of this literature review were limited. For example, the review might have missed a larger amount of scholarship on the topic, as only one database in Vietnamese, CitationGate, which has a very limited search function, was used. In addition, the inclusion of grey literature regarding programs and interventions implemented by nongovernmental organizations (NGOs) was dependent on the researcher's network and therefore neither systematic nor exhaustive. Along with a more systematic approach to searching data, quality appraisal of the selected articles would be a critical step in future attempts to conduct a review. Finally, the geographical coverage of the review was limited to mostly urban areas (i.e., the cities of Hanoi, Hue, and Nam Dinh); thus, the findings might not be reflective of the current status of services and support in other provinces with varying levels of resources, such as programs in more rural and remote areas, or those areas with different demographic characteristics, such as ethnic minority groups. This is likely both a practical issue and a research gap, as services and supports are both less likely available and less sufficiently documented. Such limitations constitute important topics for both implementation and research in order to yield more meaningful data.



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Appendix: Support programs and interventions for caregivers comparison chart

Note: Abbreviations in this appendix are defined at the bottom of the table.

	Portage program		FMIP	CST program	Online PMI program
Related articles	Shin et al. (2009)	Shin and Nhan (2009)	Mai and Chaimongkol (2022)	CCIHP (2021) ³⁴	CCIHP (2021) ³⁴
Program description	<p>Implemented in the natural home and community settings: activities, tasks, and routines based on daily living.</p> <p>Provide home-based services in rural communities to young children with disabilities in these target areas:</p> <ul style="list-style-type: none"> • Communication; language; literacy. • Social-emotional development. • Exploration; approaches to learning; memory, problem-solving, and reasoning. • Purposeful motor activity. • Sensory organization. <p>Aim:</p> <ul style="list-style-type: none"> • Facilitate parent-teacher interaction. • Disseminate knowledge and improve parenting skills. 		<p>Adapted from the Building on Family Strengths program, FMSF.</p> <p>Increase family quality of life and reduce the burden among family caregivers through three components based on the FMSF:</p> <ul style="list-style-type: none"> • Information: provide knowledge of autism. • Behavior management/action: apply a practical management approach. • Perceived consequences: raise family's awareness of having a child with autism. 	<p>Designed as a family-centered approach to be delivered by non-specialist care providers (nurses, community-based workers, or caregivers) as part of a network of health, education, and social services for children and their families.</p> <p>Disseminate knowledge and teach skills to foster their child's learning, social communication, and adaptive behaviors.</p>	<p>Based on ABA theory (12-17) and naturalistic developmental approaches.</p> <p>Support parents to learn skills for performing intervention activities with their children.</p>
Materials	<p>Ready-made curriculum, assessment materials, and instruction manuals.</p> <p>Curriculum covers five developmental areas: age-appropriate activities, interactions, tasks, routines, and explanations.</p>		<p>FMIP content developed by for the facilitator covering five aspects:</p> <ul style="list-style-type: none"> • Basic knowledge about autism; current interventions. • Management of emotional dimension. • Supporting family relationships, family communication, and parenting. 	<p>CST Training program manual, version 2.06 (translated into Vietnamese).</p>	<ul style="list-style-type: none"> • Recorded e-lectures (20 minutes each) on a Microsoft Office 365 Education platform. • Group e-meeting sessions. • E-coaching.

	Portage program		FMIP	CST program	Online PMI program
			<ul style="list-style-type: none"> Finding available resources and transitioning into having a meaningful life. <p>Booklet for participants (caregivers): schedules; content; key concepts; examples of strategies, action plan template, and evaluation form.</p>		
Procedures	<p>For facilitators:</p> <ul style="list-style-type: none"> Training (knowledge, developing objectives, task analysis) Supervisor-developed teaching objectives (modeling skills, home visits, monthly review sessions with teachers). <p>For parents:</p> <ul style="list-style-type: none"> Sessions delivered by facilitators (setting teaching goals, modeling, teaching) Coaching and feedback from facilitators and supervisors. 	<p>For facilitators:</p> <ul style="list-style-type: none"> Training (knowledge, developing objectives, task analysis) Supervision meeting; individual sessions <p>For parents:</p> <ul style="list-style-type: none"> Home-visit sessions (teachers work with children on the weekly goals and modeling for parents). 	<ul style="list-style-type: none"> Four weekly sessions delivered by the principal investigator. Weekly follow-up phone calls with each participant. 	<ul style="list-style-type: none"> Nine group training sessions. Three home visits (60 to 90 minutes/session). 	<ul style="list-style-type: none"> Twenty-one self-paced recorded lectures. Nine weekly group Zoom sessions (two hours each). Two one-hour individual Zoom sessions for each family.

	Portage program		FMIP	CST program	Online PMI program
Who	<ul style="list-style-type: none"> • Primary special education school teachers (more than four years' experience). • No formal training; ongoing training and supervision at special schools provided by foreign NGOs. • Parents 	<ul style="list-style-type: none"> • College students • Parents 	Principal Investigator as the trainer.	<ul style="list-style-type: none"> • Teachers as trainers. • Parents 	<ul style="list-style-type: none"> • Teachers as trainers. • Parents
How	In-person; home visit.	In-person; home visit.	In-person (workshop); telephone (follow-up).	In-person; home visit.	Online
Where	Home	Home	Hospital	Home	Home
When/How long	<ul style="list-style-type: none"> • Facilitator: three months of weekly training. • Parents: 1 hour/week over a period of 12 months. 	<ul style="list-style-type: none"> • Facilitator: three months of weekly training. • Parents: 1 hour/week over a period of 6 months. 	<ul style="list-style-type: none"> • Four 60-minute, in-person group sessions. • Weekly individual follow-up call. 	<ul style="list-style-type: none"> • Nine weekly group sessions (2.5 hours each). • Three home visits (60 to 90 minutes each). 	<ul style="list-style-type: none"> • Twenty-one self-paced recorded lectures. • Nine weekly group Zoom sessions (2 hours each). • Two individual Zoom sessions (1 hour each).
Implementation (planned)	Teachers and parents agreed upon weekly teaching objectives, daily homework, and observations of practice.	Facilitators visited the families in pairs to support and ensure that the implementation is carried out correctly.	No information	No information	No information

	Portage program		FMIP	CST program	Online PMI program
Measure of efficacy	Vineland-3		<ul style="list-style-type: none"> • Beach Center FQoL scale. • CGSQ 	Caregivers: <ul style="list-style-type: none"> • Caregiver knowledge and skills test. • Patient health questionnaires. Children: <ul style="list-style-type: none"> • SRS-2 • Vineland-3 • ATEC 	
Target disability	Down syndrome; intellectual disability; cerebral palsy.		Autism	Developmental delay, intellectual and developmental disabilities, speech disorder/delay, mild autism, ASD, ADHD, cerebral palsy, etc.	
Main outcomes	Significant improvement of the intervention group on personal care and motor skills.	Improvement of the intervention group in overall adaptive behavior, communication, and socialization.	Improved quality of life and reduced caregiver burden in the intervention group after the intervention.	<ul style="list-style-type: none"> • Increased caregiver knowledge in two intervention groups. • Improved total score of the adaptive behavior in intervention groups compared to the control group. 	

Abbreviations: ABA, Applied Behaviors Analysis; ADHD, attention deficit hyperactivity disorder; ASD, autism spectrum disorder; ATEC, Autism Treatment Evaluation Checklist; CCIHP, Center for Creative Initiatives in Health and Population; CGSQ, Caregiver Strain Questionnaire; CST, Caregiver Skills Training; FMIP, Family Management Intervention Program; FMSF, Family Management Style Framework; FQoL, Family Quality of Life; NGO, nongovernmental organization; Online PMI, Online Parent-Mediated Intervention; SRS-2, second edition of the Social Responsiveness Scale; Vineland-3, third edition of the Vineland Adaptive Behavior Scales.



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