

## **The engaged family: Fostering family engagement within pediatric occupational therapy**

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Family engagement in occupational therapy (OT) can reduce caregiver burden, improve child skill, participation, or behavior, and increase parental empowerment and quality of life. Although OT practitioners (OTPs) and receiving families recognize the importance of family engagement, participation in the service delivery model remains limited.

A thorough literature review reveals three primary barriers to effective family engagement: (a) systemic factors, including insufficient administrative support, limited funding to provide training, current service delivery models and standards, (b) therapist factors, including high caseload demand, limited family engagement training, negative experiences or perceptions on the adopted service delivery model, and (c) family-related barriers including an invitation for involvement, time and energy, reported level of knowledge and confidence, and life context.

The Engaged Family program was developed to mitigate these barriers necessary to improve family engagement in OT services. This is a theory-driven, evidence-based, and web-based program for families of children receiving pediatric OT. The Engaged Family will directly serve the guardians and caregivers of children aged birth to 18, receiving OT services in any pediatric setting for any diagnosis.

The program aims to engage and empower families through prioritization of families' need for information, skill development, and connection to support the health and wellness of families and children. Sample topics include understanding their child's diagnosis, communicating with their child's healthcare team, and advocating for their child. The website also consists of The Family Academy: monthly online family workshops which provide education and support through virtual conferencing. The website and family workshop topics will be based on family-identified needs. The website will offer free content and resources and allow the option to purchase a three-month subscription service to receive more targeted information.

While educational websites currently exist, they may be challenging to navigate and discern the level of evidence supporting the information and resources. For this reason, The Engaged Family was developed using motivational, learning, and family-centered models. Evidence regarding the Hoover-Dempsey and Sandler model of parent involvement, Ryan and Deci's self-determination

theory, and Malcolm Knowles' adult learning theory informed the content and structure provided, as well as King's framework showing a continuum of family-oriented services.

The program evaluation includes constant connection with the participants to assess their needs and how they are met. Content is designed according to the participant families' prioritization of needs gathered from the Occupational Therapy Family Profile. Pre-post participation changes will be captured using the Efficacy to Connect subscales of the Parent Empowerment and Efficacy Measure (PEEM), participant surveys, and individual interviews. The Engaged Family program and the program evaluation findings will be disseminated among families of children receiving OT services and OTPs in the United States. The author hopes that The Engaged Family will foster family engagement in pediatric OT services by guiding families in the skills and confidence needed to improve participating family's and child's health and well-being.

### References:

- Martello, A. (2023). *The engaged family: fostering family engagement within pediatric occupational therapy* (Doctoral dissertation, Boston University).
- Mendoza, M. R. M. (2024). *Therahan: empowering Filipino parents, guardians, care partners, and grandparents of children with special needs in their homes through a hybrid telehealth training program* (Doctoral dissertation).



## 家庭的参与：促进儿童和青少年作业治疗中的家庭参与

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家庭参与在作业治疗（Occupational Therapy / OT）中可以减轻照顾者负担，改善儿童和青少年的技能、参与度或行为，并增强家长的赋能感和生活质量。尽管作业治疗师（OTs）和接受治疗的家庭都认识到家庭参与的重要性，但在服务模式中的实际参与仍然有限。

通过深入的文献回顾，发现有效家庭参与的三大主要障碍：（a）系统性因素，包括行政支持不足、培训经费有限、当前的服务模式和标准；（b）治疗师因素，包括高工作负荷、家庭参与培训不足、对所采用的服务模式存在负面体验或看法；（c）家庭相关障碍，包括参与邀请、时间和精力、知识和信心水平以及生活背景。

为解决这些障碍并提高家庭在作业治疗服务中的参与度，开发了“家庭参与”的项目。这是一个基于理论、循证并通过网络提供的项目，旨在服务于接受儿童和青少年作业治疗服务的儿童及其家庭。

“家庭参与”的项目直接为0至18岁、在任何儿少环境下接受作业治疗服务的儿童的监护人和照顾者提供服务。该项目旨在通过满足家庭的信息需求、技能发展和支持联系来促进家庭参与和赋能，支持家庭和儿童的健康和福祉。

项目示例主题包括了解孩子的诊断、与孩子的医疗团队沟通以及为孩子争取权益。网站还设有“家庭学院”：每月在线家庭工作坊，通过虚拟会议提供教育和支持。网站和家庭工作坊的主题将基于家庭的需求确定。网站提供免费内容和资源，并可选择购买三个月的订阅服务以获取更有针对性的信息。

虽然目前已有教育网站存在，但它们可能难以导航，并且难以辨别信息和资源的循证水平。基于此原因，“家庭参与”的项目采用了动机、学习和以家庭为中心的模式。Hoover-Dempsey 和 Sandler 的家长参与模型、Ryan 和 Deci 的自我决定理论以及 Malcolm Knowles 的成人学习理论为项目的内容和结构提供了依据，King 的家庭导向服务框架展示了家庭导向服务的连续性。

项目评估包括与参与者的持续联系，以评估他们的需求及其满足程度。内容设计根据从“作业治疗家庭档案”中收集的参与家庭的需求优先级进行。参与前后的变化将通过“家长赋能和效能测量”（PEEM）的“连接效能子量表”、参与者调查和个人访谈进行捕捉。“参与的家庭”项目及其评估结果将分发给美国接受作业治疗服务的儿童家庭和作业治疗师。作者希望“家庭参与”的项目能通过引导家庭掌握改善健康和福祉所需的技能和信心，促进儿少作业治疗服务中的家庭参与。

## 结论

尽管家庭参与过程中存在一些挑战，但作业治疗师在整合支持性教育和就业模式方面发挥着重要作用，这对于在自然发展环境中提升技能至关重要。通过这些努力，我们不仅能够改善个别儿童和青少年的康复结果，更能够在更广泛的社区中推广以家庭为中心的治疗模式，真正实现长期幸福感与生活质量的提升。

## 参考文献：

- Martello, A. (2023). *The engaged family: Fostering family engagement within pediatric occupational therapy* (Doctoral dissertation, Boston University).
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