# 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).



## 家庭的參與:促進兒童和青少年作業治療中的家庭參與

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家庭參與在作業治療(Occupational Therapy / OT)中可以減輕照顧者負擔,改善兒童和青少年的技能、參與度或行為,並增強家長的賦能感和生活品質。儘管作業治療師(OTs)和接受治療的家庭都認識到家庭參與的重要性,但在服務模式中的實際參與仍然有限。

通過深入的文獻回顧,發現有效家庭參與的三大主要障礙: (a) 系統性因素,包括行政支援不足、培訓經費有限、當前的服務模式和標準; (b) 治療師因素,包括高工作負荷、家庭參與培訓不足、對所採用的服務模式存在負面體驗或看法; (c) 家庭相關障礙,包括參與邀請、時間和精力、知識和信心水準以及生活背景。

為解決這些障礙並提高家庭在作業治療服務中的參與度,開發了"家庭參與"的專案。這是一個基於理論、循證並通過網路提供的專案,旨在服務于接受兒童和青少年作業治療服務的兒童及其家庭。

"家庭參與"的專案直接為 0 至 18 歲、在任何兒少環境下接受作業治療服務的兒童的監護人和照顧者提供服務。該專案旨在通過滿足家庭的資訊需求、技能發展和支持聯繫來促進家庭參與和賦能,支持家庭和兒童的健康和福祉。

專案示例主題包括瞭解孩子的診斷、與孩子的醫療團隊溝通以及為孩子爭取權益。網站 還設有"家庭學院":每月線上家庭工作坊,通過虛擬會議提供教育和支持。網站和家庭工 作坊的主題將基於家庭的需求確定。網站提供免費內容和資源,並可選擇購買三個月的 訂閱服務以獲取更有針對性的資訊。

雖然目前已有教育網站存在,但它們可能難以導航,並且難以辨別資訊和資源的循證水準。基於此原因,"家庭參與"的項目採用了動機、學習和以家庭為中心的模型。Hoover-Dempsey和 Sandler 的家長參與模型、Ryan和 Deci 的自我決定理論以及 Malcolm Knowles 的成人學習理論為專案的內容和結構提供了依據,King 的家庭導向服務框架展示了家庭導向服務的連續性。

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項目評估包括與參與者的持續聯繫,以評估他們的需求及其滿足程度。內容設計根據從 "作業治療家庭檔案"中收集的參與家庭的需求優先順序進行。參與前後的變化將通過"家 長賦能和效能測量"(PEEM)的"連接效能子量表"、參與者調查和個人訪談進行捕捉。 "參與的家庭"項目及其評估結果將分發給美國接受作業治療服務的兒童家庭和作業治療 師。作者希望"家庭參與"的專案能通過引導家庭掌握改善健康和福祉所需的技能和信心,促進兒少作業治療服務中的家庭參與。

### 結論

儘管家庭參與過程中存在一些挑戰,但作業治療師在整合支援性教育和就業模式方面發揮著重要作用,這對於在自然發展環境中提升技能至關重要。通過這些努力,我們不僅能夠改善個別兒童和青少年的康復結果,更能夠在更廣泛的社區中推廣以家庭為中心的治療模式,真正實現長期幸福感與生活品質的提升。

## 參考文獻:

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