

# 发展迟缓幼儿“参与”的概念与干预

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【关键词】 参与; ICF-CY; 早期干预

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根据世界卫生组织于2007年所颁布的《国际健康功能与身心障碍分类系统-儿童及青少年版》(International Classification of Functioning, Disability and Health-Children and Youth Version, ICF-CY), 增加“活动与参与”, 被视为发展迟缓儿童早期干预的重要目标<sup>[1-2]</sup>。此外, 联合国身心障碍权利公约(The Convention on the Rights of Persons with Disabilities, UNCRPD)<sup>[3]</sup>及联合国的儿童权利公约(United Nations Convention on the Rights of the Child, UNCRC)<sup>[4]</sup>均说明了所有儿童应享有机会均等、平等对待、不歧视及回归主流的权利, 并与其他儿童平等地参与日常生活活动<sup>[5]</sup>。依据 UNCRPD, “参与”是指儿童在其家庭、学校及社区生活中被视为主动的参与者, 同时儿童也有权利被尊重。这个“参与”概念充分反映了个体应有完全被社会接纳的权利<sup>[6]</sup>。联合国公约同时也影响发展迟缓学前教育政策<sup>[7]</sup>。然而, 有关发展迟缓儿童“参与”的促进策略, 实为新的课题与挑战。因此, 以下将简介儿童参与的定义、发展迟缓幼儿参与的重要性、及以参与为基础的干预趋势。

## 1 幼儿参与的定义

依据 ICF-CY, “活动”被定义为个体所执行的一项任务或是行动, 而“参与”被定义为“融入生活情境”。然而, “活动”与“参与”在儿童实际生活中难以区分。“活动与参与”内含两个构念, 分别为“表现”与“能力”。“表现”为在一般或生活情境下所做的; “能力”为标准情境下能做的。依此定义, “参与”仅可能在“表现”的定义下被测量。然而, “参与”的意涵却远大于单纯的“表现”, “参与”所涵盖的广泛面经许多学者尝试归纳<sup>[7-13]</sup>。首先, “活动”被定义为组成生活的小单位,

其包含了简单的功能性活动或是有目的地去进行一连串简短的功能性活动或与个人较相关的活动; “参与”则反应出从事于整个活动并达成一个较大目标与社会性较相关的<sup>[1-2]</sup>。CF-CY/ICF 试图也在其手册附录3中阐述“活动”与“参与”的区别<sup>[1-2]</sup>, 并详列了4种不同的选择进行活动及参与编码<sup>[1-2, 14]</sup>。由 ICF-CY/ICF 所提供的4种方案显示“活动”端到“参与”端之间的趋势为: 由个人到社会、由标准情境到生活情境、由小单位概念到大面向, 同时其中也涵盖交集的位码, 所以由活动到参与的概念无法完全切割<sup>[15]</sup>。“在生活情境下的能力”用来补充“能力”与“表现”间的衔接落差, 也就是“在日常生活中能做的”<sup>[11]</sup>, 或照顾者预期儿童能在日常生活中可达到的能力<sup>[16]</sup>。“在生活情境下的能力”并非只是个人内在的能力, 而是和环境所提供的机会和自由选择有关<sup>[17-18]</sup>。“活动”及“参与”在概念上有重叠的部分, 见表1。在“参与”端, 有社会学及发展心理学观点<sup>[7, 10]</sup>。社会学观点强调儿童参与是资源存有性、可近性与可负担性, 以及与一般儿童相同的机会及经验<sup>[7]</sup>。发展心理学观点强调参与是儿童对于活动投入程度的主观经验, 如儿童自觉的喜好、自主性、动机及自我效能等<sup>[19-20]</sup>、儿童精神上主观的融入或投入的强度, 而非仅止于参与的频率<sup>[7, 10]</sup>。此外, 参与的意义须包含“个人可以自主控制其生活”, 主观的投入程度与儿童所处的情境是否能被儿童本身或周围的人所接纳或周围环境是否能针对儿童的需求调整密切相关<sup>[7, 10]</sup>。“成功的参与”是对参与活动觉得有趣, 感到成功, 可以独立执行, 以及可以和其他人一起参与活动<sup>[21]</sup>。然而, ICF/ICF-CY 手册中, 参与的操作型定义并未涵盖“精神投入程度”或“主观融入经验”等概念。

综合以上, 有关“参与”表现的各层面, 包括儿童在活动中需要协助的程度、活动种类的广度及多样性、活动的频率、与谁一起从事哪些活动等; 而心理学角度层面所测量的内容包括参与活动的愉悦、投入、偏好及动机强烈程度、照顾者或儿童对于活动儿童活动参与的满意度、自觉活动的重要性等等<sup>[22-23]</sup>。

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表 1 参与之面向与“国际健康功能与身心障碍分类系统-儿童及青少年版年” (ICF-CY) 各成分及构面的对应关系<sup>[15]</sup>

| ICF-CY 架构        |               |                                                                                                                                                                   | 活动参与的面向   |               |     |      |
|------------------|---------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------|---------------|-----|------|
| 第一部分<br>功能及失能    |               | 第二部分<br>情境因素                                                                                                                                                      |           | 较多限制          | ↔   | 较少限制 |
| 活动               | 参与            | <div>环境因素</div> <div>↑</div> <div>资源存有性/可近性/可负担性</div> <div>↑</div> <div>↓</div> <div>↓</div> <div>↓</div> <div>↓</div> <div>↓</div> <div>↓</div> <div>个人因素</div> | 标准情境下的能力  | 能力较弱          | 独立性 | 能力较佳 |
|                  |               |                                                                                                                                                                   | 在自然情境下的能力 |               |     |      |
| 表现               | 较多协助          |                                                                                                                                                                   | 协助程度      | 较少协助          |     |      |
|                  | 活动种类较少        |                                                                                                                                                                   | 活动多样性     | 活动种类较多        |     |      |
|                  | 频率较少          |                                                                                                                                                                   | 频率        | 频率较多          |     |      |
| 心理学/融入生活的主观经验及感受 | 投入程度较低/投入时间较少 |                                                                                                                                                                   | 投入性       | 投入程度较高/投入时间较多 |     |      |
|                  | 愉悦程度较低        |                                                                                                                                                                   | 愉悦程度      | 愉悦程度较高        |     |      |
|                  | 动机较低          |                                                                                                                                                                   | 动机        | 动机较高          |     |      |
|                  |               |                                                                                                                                                                   | 较不满意      | 满意度           | 较满意 |      |

2 发展迟缓幼儿以“参与”为基础的干预趋势

儿童在日常生活的“参与”有关其心智、生理、健康行为<sup>[24-26]</sup>、人际关系及重要的技巧或能力的发展。学龄前发展迟缓儿童透过与生活环境互动及各种生活活动的参与,学习到如何与他人互动、相处并处理日常生活事务的技能<sup>[24-25]</sup>。然而有特殊需求的孩童在“参与”层面上往往有较多的限制<sup>[28-34]</sup>。受到人权的概念兴起及障碍相关研究结果的影响,“参与”已被认为是儿童接受疗育、复健及安置计划的最终目标<sup>[22,35-40]</sup>。

目前台湾地区教育部门也配合幼托整合,订定“幼儿园教保活动课程大纲”,主要在于提供幼儿适宜年纪的经验,以幼儿生活为基础,以统整方式实施。此课纲强调增进“知觉辨识”、“表达沟通”、“自主管理”、“想象创造”、“关怀合作”及“推理赏析”等六大能力,而非从前“分科教学”的知识灌输。依据美国幼儿教育部提出 3 个早期干预原则<sup>[41]</sup>,包括:①尊重所有儿童及家庭;②高质量、完整且整合的以家庭为中心的服务及支持;③儿童在家庭及社区中主动参与的权利。由此可知,台湾及美国发展迟缓幼儿的融合早疗或融合教育的趋势是提供儿童充分参与及融合的机会以利儿童主动探索、自主独立及与人沟通。因此,“参与”不但是发展迟缓儿童复健目标设立的核心,也是目前融合教育及教保政令的核心。有关学龄前发展迟缓儿童的“参与”测量请参考黄霏雯等<sup>[15]</sup>的文献。

依据前述提及的美国幼儿教育部 3 个早期干预原则<sup>[41]</sup>,Campbell<sup>[42]</sup>最早提出以参与为基础的早期干预,

其主要的目的是在于促进儿童参与社区与家庭的活动与作息。之后,许多学者纷纷提出以参与为基础的早期干预原则,并提出具体做法<sup>[35,43-45]</sup>,以及所可能遭遇的困境<sup>[46-47]</sup>。Palisano 等<sup>[45]</sup>所提出的原则包括:目标导向;以家庭为中心;专业与家庭协力;以儿童及家庭优势为基础;生态观点;自我决定。依据此原则,从以往强调治疗儿童及其家庭的缺损的观点,转而诱发儿童及其家庭成功地达成在特定的情境中所想做的及所能做的<sup>[45]</sup>,同时也强调儿童在自然环境(包括家庭、学校及社区)的融合及参与日常生活作息。通常儿童在特定的地方或生活情境养成生活习惯或执行与同伴相仿的作息活动,也因而对于该地方或情境有归属感。我们所想训练儿童的活动若能成为儿童们或其家庭生活作息的一部份,不但能在日常生活中不断的练习强化儿童的技能,更能使儿童在执行活动时有所归属感,也就是“参与”在生活情境中的重要性<sup>[43]</sup>。因此,以参与为基础的早期干预强调儿童与生活情境的动态关系,其介入方法涵盖调整儿童的物理性及社会性环境,或在自然情境中练习,让儿童有机会在现实的时间限制及情境需求下成功地执行活动。同时,包含以较宽广的角度来看儿童是否能在自然情境中完成有动机想做且需要做的活动,以使儿童成功地参与生活<sup>[45]</sup>。详细分析以发展迟缓幼儿的参与为基础的干预原则及具体作法,可由儿童的参与与生活情境<sup>[48-49]</sup>、家庭的参与疗育<sup>[50]</sup>、以及专业人员参与式的提供干预服务三方面着手<sup>[51]</sup>。延伸此以参与为基础的干预原则所发展出的干预方案,还包括“以作息为基础的干预”<sup>[48]</sup>、“以活动为基础的干预”<sup>[52]</sup>、“学习机

会”等<sup>[53-54]</sup>。

针对神经动作障碍的儿童,荷兰及加拿大也所提出相关的方案及实证研究,包括特殊幼儿的调适及照护-以家庭为中心方案及情境干预<sup>[55-57]</sup>。虽然这方案可能因为不同的干预族群而有不同的重点及成分,但都强调:家庭成员是儿童重要的教导者,专业的角色在于同时引导家庭成员及儿童;利用日常活动及作息作为儿童的学习情境。

近代的文献显示,对于发展迟缓儿童而言,传统神经发展取向及以改善身体功能及构造或以发展领域为主的干预缺乏疗效实证支持或是疗效结果呈现分歧<sup>[58-60]</sup>。而新的干预趋势则是引导家长协助儿童克服、减少或适应环境的障碍,并让儿童有充分的机会利用自发性的动作活动及能力来探索环境及与环境(人或物)互动以达功能性目标<sup>[60]</sup>。这些实证结果同时呈现了功能性成效及传统发展领域的成效<sup>[55-56,61-63]</sup>。功能取向成效强调儿童在家中、课堂及社区中的技能的发展,希望促使儿童(及其家庭)在目前或甚至于未来的环境中成功,是一种个别化且强调优势的方式。传统发展领域取向的目标是根据一般儿童所设计,其目的在于找出儿童技能发展落后的区块,这种以儿童的弱点为依据取向,会促使我们辨识或矫正儿童所残缺的部份。研究显示,采取以参与为基础的方案相对于传统干预在传统发展领域的成效并无显著差异<sup>[55,61-62]</sup>;然而,在功能性成效,包括儿童玩兴<sup>[63]</sup>、自发性动作<sup>[56,63]</sup>、生活自理的独立性 & 社会关系则显现不同参与面向的疗效证据<sup>[62]</sup>。虽然,神经动作发展障碍儿童接受以参与为基础的干预并未显示较传统干预具较佳的动作能力进步,研究却发现动作能力的进步与治疗师引导家长所花时间呈正相关( $r=0.92$ ),与专业诱发或延续婴儿自发性动作行为所花的时间呈正相关( $r=0.92$ ),且与传统的被动感觉刺激治疗所花的时间呈负相关( $r=-0.97$ )<sup>[61]</sup>。因此,就功能性成效而言,以参与为基础或功能性取向的早期干预,仍是较佳选择。

### 3 结论

促进学龄前发展迟缓儿童在日常生活的“参与”是当前早期疗育重要趋势。根据儿童以参与为基础的干预理念,参与是干预的方法,也是干预的目标。在传统干预模式下,家庭藉由专业服务往往处于被动接受服务的角色。以参与为基础的早期干预强调以家庭为中心,专业与家庭采合作式团队模式,专业藉由引导让家长主动性与专业共同讨论并设定符合生活情境需求的目标,疗育的主要方法在于提供以及协助儿童与其家长参与的机会与策略。

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