Coach, Care Coordinator, Navigator or Keyworker? Review of Emergent Terms in Childhood Disability

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Parents of children with developmental disabilities, such as cerebral palsy or autism spectrum disorder, are known to experience heightened levels of parental stress, greater psychosocial and physical health challenges, and undesirable changes to the family dynamics in face of their child’s disability (Raina et al., 2005). In addition, present health-care service models are not standardized nor are they nimble enough to address these issues in a rising number of children and families in need, where affected families are reported to experience long-wait periods, service gaps, and duplication in service delivery (Majnemer, Shevell, Rosenbaum, & Abrahamowicz, 2002). Health coaching is an educational and a transformational, content-structured, and pre-defined program that has recently emerged. It could be delivered by different and more accessible as well as more cost-effective means (e.g. distance/online manualized learning, group exchanges, and workshops). It could also possibly promote parental self-management and empowerment in the presence of their child’s chronic disability. Health coaching in childhood disability is increasingly being applied, studied, and advocated for as an evidence-based alternative to traditional methods and their limitations (Baldwin et al., 2013; Huffman, 2009; Missiuna et al., 2012; Ogourtsova, O’Donnell, & Majnemer, 2018). In view of this developing approach, different terms such as coach(ing), care/service coordinator, navigator, and keyworker are being utilized. At this point, it is essential to understand the nuances associated with these concurrently arising terms, as a preliminary step towards articulating operational definitions and their application in childhood disability research and practice.

To begin, according to the NHS The Evidence Center 2014 report on health coaching, “there is currently no one universally accepted definition of health coaching” (The Evidence Centre, 2014, p. 3); and “health coaching is an umbrella term used to describe many different interventions that coach or actively support people to self-care and a move away from a dependent model to one that is empowering and shared, based around a person’s own aspirations and goals” (The Evidence Centre, 2014, p. 2). In light of the lack of conceptual clarity, Olsen (2014) proposed an operational definition,
defining coaching as “a goal-oriented, client-centred partnership that is health-focused and occurs through a process of client-enlightenment and empowerment” (p. 24).

More specific to childhood disability, Rush and Shelden (2011), defined a coach as someone who supports parental learning through the development of collaborative partnership, by guiding the parent to achieve self-set goals via different learning strategies, and by elaborating on the parent’s existing competencies. Five elements are suggested to be essential to the coaching intervention in childhood disability and include: joint planning, observation of the new strategy, action (i.e. real-life opportunity to practice), reflection (i.e. self-assessment), and feedback (i.e. information on intervention, development, resources, and strategies) (Rush & Shelden, 2011). Foster, Dunn, and Lawston (2013) specify that the main difference between coaching and conventional therapy services is that coaches “do not tell the parent what to do”, instead they “help the parent problem-solve challenging activities related to their child” (p. 254). This also encompasses the occupation-based coaching, which is an intervention combining the principles of coaching with occupation-centered reasoning that focuses on “increasing positive child–caregiver interactions and child-learning opportunities in everyday routines and contexts” and “encourages parents to create their own strategies to match their unique circumstances” (Little, Pope, Wallisch, & Dunn, 2018, p.2).

In relation to that, we would like to emphasize that coaching, as opposed to usual therapy that clinicians provide when educating or training parents on certain skills, abilities or treatment strategies, can be differentiated by its structure and content features, where coaching consists of a pre-planned content (that is often manualized), specific dosage (i.e. program frequency and duration), and outcome measures that align with the initially set goals for the coach intervention. In addition, parental coaching in childhood disability could be delivered in different “teams”: (1) in the presence of the child (i.e. coaching while treating: team = coach + parent + child); or (2) in the absence of the child (team = coach + parent). The latter is potentially more accessible, feasible, and cost-effective as it could be delivered to groups of parents, remotely/online. In a parallel systematic review conducted by our team (Ogourtsova et al., 2018), we further identified that coaching can have a different “focus” and either: (1) be focused on the child (i.e. child-targeted approach), where parents are coached on delivering an intervention strategy to the child); (2) be focused on the parent (i.e. parent-targeted approach), where parents are coached on self/stress/mood-management techniques, advocacy skills, and coping strategies; or (3) combine these two methods (i.e. mixed approach). Finally, outcome measures can either be child (e.g. developmental motor skills, language skills) and/or parent-related (stress levels, self-efficacy). Refer to Figure 1 summarizing these coaching-related concepts.

Furthermore, as parents of children with developmental disabilities often face challenges in locating, initiating, and transitioning to and from suitable and needed health-care services for their child (Halfon, Berkowitz, & Klee, 1993), a service/care coordinator became essential to family-centered practices (Bruder et al., 2005), and bears different roles from the coaching model previously described. A service/care coordinator is defined as a professional with fundamental understanding of the health-care system logistics, who is “responsible for coordinating all services across agency lines and serving as the single point of contact in helping parents to obtain the services
and assistance they need, coordinating the performance of evaluations and assessments, facilitating and participating in the development, review, and evaluation of individualized family service plan, assisting families in identifying available service providers, coordinating and monitoring the delivery of available services, informing families of the availability of advocacy services, coordinating with medical and health providers, and facilitating the development of a transition” (Bruder et al., 2005, p. 178). Overall, the main concept of the service/care coordinator’s role is to offer families support, resources, and information that are tailored to their individual needs, and to coordinate care not only within the healthcare system, but also across systems, including the education system and social, financial, and recreational resource supports. Care coordinators thus often have an ongoing longitudinal relationship with the family in carrying out these responsibilities and may be part of the ongoing care team (McDonald et al., 2007). Moreover, in that same context of service coordination, the term navigator is often employed. Nevertheless, navigator’s roles and responsibilities differ from that of a service/care coordinator. Although navigators also must have a fundamental understanding of the health system, establish a patient’s eligibility for specific services based on defined criteria, collaborate with colleagues to determine what services a patient and their family need in the community, and seek to remove barriers by engaging across organizations; they may only have just one or intermittent contact with the family (Dohan & Schrag, 2005).

Further, the term keyworker was first introduced in the United Kingdom as a result of the statutory guidance of the 1989 Children’s Act. The role of the keyworker involves assisting parents in meetings and appointments related to their child, interpreting assessment results, offering tools and skills facilitating parental empowerment (Drennan, Wagner, & Rosenbaum, 2018), offering information and advice to parents, identifying
and addressing arising needs, accessing and coordinating services needed for the child and the family, providing emotional support and acting as an advocate (Sloper, Greco, Beecham, & Webb, 2006). From these various roles and responsibilities, it emerges that a keyworker thus acts as the main point of contact for the family; and his/her role, while including some of responsibilities of a service coordinator, is focused much more on empowering parents in facing different barriers related to their child’s disability.

To conclude, we propose that there are currently three main branches underscoring these terms and roles in childhood disability: (1) health coaching; (2) service/care coordinator and navigator; and (3) keyworker. We further encourage health-care professionals, researchers, and academics to make clear distinctions with respect to those terms that are so far used inconsistently and inter-changeably, while having quite different meanings, roles, and responsibilities.

**Disclosure statement**

No potential conflict of interests was reported by the authors.

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