Metanoia in Early Intervention: Transformation to a Family-Centered Approach

Metanoia en Atención Temprana: Transformación a un Enfoque Centrado en la Familia

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How did it happen? How did early intervention for very young children with disabilities become so divorced from the family, so clinical, and so removed from science? In this article, I argue for a family-centered approach to early intervention, based on the literature. I describe some specific practices for implementing this approach as well as some instruments to measure the fidelity with which the practices are used. Finally, I discuss how the field is being transformed by a partnership between opportunity (the Routines-Based Model) and a changing mindset (metanoia).

Keywords: Early intervention, Family-centered practices, Routines-based model, Routines-based interview, Natural environments, Family consultation.

¿Cómo ha ocurrido? ¿Cómo fue la atención temprana para niños muy pequeños con discapacidad llegar a ser tan divorciada de la familia, tan clínico y tan eliminado de la ciencia? En este artículo, sostengo adoptar un enfoque centrado en la familia para la atención temprana, con base en la literatura. Describo algunas prácticas específicas para la aplicación de este enfoque, así como algunos instrumentos para medir la fidelidad con la que se utilizan las prácticas. Finalmente, discuto cómo el campo se está transformando por una asociación entre la oportunidad (basado en las rutinas de modelo) y una mentalidad cambiante (metanoia).

Descriptores: Atención temprana, Prácticas centradas en la familia, Modelo basado en rutinas, Entrevista basada en rutinas, Entornos naturales, Asesoramiento familiar.
Introduction

A family-centered approach to early intervention means four activities should happen:

- Professionals should interact with families in a friendly, supportive, and respectful way;
- Professionals should provide families with opportunities to make meaningful decisions about the early intervention they receive;
- Professionals should meet families’ needs beyond the development and learning of the child (McWilliam, 2010a); and
- Professionals should take advantage of the learning opportunities families provide their children (Dunst, Raab, Trivette, & Swanson, 2010).

The evolution of early intervention was influenced by fields of rehabilitation, psychology, medicine, and education, leading to a notion that a child between birth and 6 years of age could spend an hour a week with one or more professionals (each) and this would make a difference to the child’s development and learning. This direct, hands-on method violates what we know about how children learn. Young children learn through repeated interactions with people and objects, distributed over time—throughout the day and week. They don’t learn in lessons or sessions, the way older children do (Gopnik, Meltzoff, & Kuhl, 1999).

Parents or other caregivers who spend time with young children teach them more than people realize. In fact, young 4-year-old girls were observed to engage in richer conversations with their mothers than with their teachers (Tizard & Hughes, 2008). With children in early intervention, positive benefits accrued to the children when their families used everyday activities as sources of children’s learning opportunities but they did not when professionals embedded their interventions in everyday activities (Dunst, Bruder, Trivette, & Hamby, 2006). This finding is an important warning about the popularly conceptualized “embedded instruction” (VanDerHeyden, Snyder, Smith, Sevin, & Longwell, 2005). Children with difficult temperaments are especially susceptible to the effects of both parenting and child care quality (Pluess & Belsky, 2010). In fact, early maternal sensitivity, especially before the child was 36 months old, predicted positive social problem solving and fewer aggressive responses in kindergartners and first graders (Raikes & Thompson, 2008). Therefore, the environments families create, including the way they talk to, read to, play with, and teach their children are powerfully influential on the child’s development and learning.

Families benefit from their own informal-support network, such as friends, family, and neighbors, and from formal support from early intervention professionals (Steel, Poppe, Vandevelde, Van Hove, & Claes, 2011). Being nice to families seems to be natural to early interventionists (McWilliam et al., 1995), and indeed this is necessary. But it is insufficient. In the U.S. early intervention law ("Individuals With Disabilities Education Act," 2004), services such as family training and counseling are supposed to be provided (Turnbull et al., 2007). Services, however, are not the issue (Trivette, Dunst, & Deal, 1997): Professionals working with the family should assess, facilitate, and provide support to families. Therefore, the rationale for taking a family-centered approach to early intervention is because of how children learn, the fact that families are already
using naturally occurring learning opportunities, and support to families results in positive outcomes.

1. Literature review

The leading expert in family-centered practices has been Carl Dunst, who defined them as follows:

*Family-centered practices treat families with dignity and respect; provide family members with information needed to make informed decisions and choices; actively involve families in obtaining resources and supports; and practitioner responsiveness and flexibility to family requests and desires.* (Dunst, 2011)

Dunst’s concepts of family centeredness have evolved from social-support theory (Langford, Bowsher, Maloney, & Lillis, 1997); from a pragmatic notion that supporting families is the way to capitalize on families’ natural assets, such as the learning opportunities they create in their regular routines (Dunst et al., 2010); and from helpgiving theory in human services (Dunst, Boyd, Trivette, & Hamby, 2002). In both contrast and concert, Ann Turnbull has approached the same idea, family centeredness, in terms of family systems theory (Broderick, 1993); family quality of life as an outcome (Poston et al., 2003), and the notion that being nice to families isn’t enough (Turnbull et al., 2007). In family systems theory, what affects one member of the family affects all members, at some level. Importantly in early intervention, it is a reason to ensure the primary caregiver of the child has the supports he or she needs to carry out parenting tasks in a positive, cheerful, and developmentally enhancing manner. If family quality of life is a goal of early intervention, as some experts have proposed (Park et al., 2003), we need a measure of it.

Turnbull has developed the Family Quality of Life (FQoL) Scale, which captures six individual-person factors (receipt of support, emotional well-being, health, physical environment, productivity, and social wellbeing) and four family factors (family daily life, family interaction, economic wellbeing, and parental role) (Zuna, Selig, Summers, & Turnbull, 2009). This work matches the considerable scholarship on family quality of life by Verdugo (Verdugo, Navas, Gómez, & Schalock, 2012) and Giné (Balcells-Balcells, Giné, Guàrdia-Olmos, & Summers, 2011), in Spain. In contrast, I have developed a scale specifically for early intervention, called similarly the Scale of Family Quality of Life (FaQoL), with only four factors: Access to Information and Services, Family Relationships, Child Functioning, and Overall Life Satisfaction (García Grau & McWilliam, 2014). Turnbull, with many colleagues, has argued that family quality of life would be enhanced by greater use of the supports supposed to be provided by the state directly to families, such as family training and counseling ("Individuals With Disabilities Education Act," 2004).

My contribution to the understanding of family centeredness has revolved around three key practices (McWilliam, 2010a). First, developing an ecomap to understand the family

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1 This definition conveys the message but suffers from the way the language is used. For example, practices do not treat families in any manner; it is the user of practices who does. Nor do practices provide anything or actively involve anyone. The last clause doesn’t fit the sentence structure, because there’s no verb. Edited, this definition should say, “Professionals employing family-centered practices treat families with dignity and respect; provide family members with information needed to make informed decisions and choices; actively involve families in obtaining resource and supports, and are responsive and flexible in addressing family requests and desires.”
ecology has focused professionals and families on the importance of the family’s informal support network (McWilliam, 2010c). Second, conducting a Routines-Based Interview has proven to be a valuable support to families in identifying specific goals for themselves and their children (Boavida, Akers, McWilliam, & Jung, 2015). Third, using family consultation has given professionals a structure for helping families reflect on their children’s interests and abilities in the face of the demands of daily routines (McWilliam, 2010d). The next section discusses these and other practices constituting a family-centered early intervention model.

2. Practices

A family-centered approach means that all early intervention activities are performed with the common goal of strengthening families. One cannot simply be nice to families and assume that’s all it takes. Nor can one do one activity, such as asking families what goals they want for their child, and assume that that makes the program family centered. A holistic approach means everything is aimed at the outcome, but an approach cannot be simply a mindset (Fitzgerald, Ryan, & Fitzgerald, 2015). The mindset has to be articulated in the form of practices, so we can observe and measure the implementation of family centeredness. This behavioral perspective—that we should go beyond reading professionals’ minds—allows for the reciprocal nature of mindset or attitude and practice or behavior, as shown in Figure 1. Whereas one might argue that we have to change mindsets to get people to do the right thing, my model is based on the cynical notion that that is an inefficient and potentially risky order. Rather, we should teach people to carry out family-centered practices, and their minds will follow.

Consequently, the Routines-Based Model of early intervention has seven core practices that constitute a package. This package is individualized for the family, which is the purpose of the needs assessment and intervention planning phase. The phase consists of understanding the family ecology, determining functional needs for everyday competence and family life, and setting functional and family goals. The next phase is the provision of support, also known as “service.” This entails organizing who will provide the support, how the support will be provided, and to whom. A simplified version of the Routines-Based Model (RBM) is shown in Figure (McWilliam, 2010c).
To understand the family’s ecology, an ecomap is constructed with the family (Jung, 2010). They tell us who lives with the child, their informal supports, their formal supports, and their intermediate supports. We draw a diagram indicating the amount of support, in three levels of thickness of lines, provided by each support. We also show how a member of the network might be a source of stress. Ecomaps are particularly important for showing informal supports, yet early intervention is almost always focused on formal supports—what services can we throw at a need (Trivette et al., 1997; Turnbull et al., 2007). The size of the informal network does not necessarily indicate more support. For example, in a study of families and informal support networks in Portugal, most families with children received little support, but those that did received it mostly from parents (children’s grandparents), especially the mother’s (Wall, Aboim, Cunha, & Vasconcelos, 2001). In the RBJM (McWilliam, 2010c), when a need arises, the first thing we look at is the ecomap, to see if an informal or intermediate support can meet the need. We call this whipping out the ecomap.

Second, we develop an RBI to (a) establish a relationship with the family, (b) to obtain a rich and thick description of child and family functioning, and (c) to end up with a list of functional and family goals chosen by the family (McWilliam, Casey, & Sims, 2009). Even though the basic structure of the RBI involves asking families about children’s engagement, independence, and social relationships in everyday routines, it also produces family needs. Typically, the RBI results in 10-12 goals, most of which are child goals, with the rest being either child-related family goals or family-level goals (e.g., related to basic family needs or to needs that enrich parents’ lives, such as time for themselves, more education, or job-related desires).

At the end of the RBI, families choose goals that professionals subsequently write, in this model, as either participation-based child goals or family goals. An example of the former might be Eric will participate in play time, dinner preparation time, and bedtime by reaching for objects he can see or hear. We will know he can do this when he stretches out his
arms to make an object sound or move, 5 times at play time, dinner preparation time, or bedtime on three consecutive days. The family wanted Eric to be able to play with objects; this came up when they discussed play time, dinner preparation time, and bedtime—three of their routines—and his problem was that he wasn’t reaching for things. They also decided the criterion (a) for attainment would be 5 times in the routine, (b) for generalization would be only one of these routines in one day, and (c) for maintenance it would be three consecutive days. An example of a family goal might be Brittany will have one hour for herself a week, with no child care responsibilities, for six consecutive weeks. Again, she decided on this goal and on the criteria.

The fourth practice is the use of a primary service provider (PSP), which is one consistent professional working with the family on all child and family needs, contrasted with the multidisciplinary approach, in which separate professionals work more or less at the same frequency as each other, focusing only on their area of expertise (McWilliam, 2010b; Shelden & Rush, 2010, 2013). One study of 777 Spanish families showed that working with more than one professional, regularly, resulted in lower family quality of life (Garcia Grau & McWilliam, 2014). In this approach, the family has the opportunity to strike a strong relationship with a professional, who supports the whole child and family. When that PSP needs help, he or she can obtain it through various contact methods with other team members, including the joint home visit. Organizing services to provide the family with a PSP explicitly acknowledges the importance of the relationship between the family and one professional.

Services take place in the locations where the child would be if the child didn’t have a disability (Woods, Wilcox, Friedman, & Murch, 2011). These places are considered natural environments or least restrictive environments. American law mandates these environments should be used whenever possible, to ensure children with disabilities and their families are not shunted into metaphorical special-education trailers. The inclusion principle, in the RBM, extends to giving families as “normal” a life as possible, in the belief that we should not abnormalize family life any more than necessary by the way we provide services (Bailey & McWilliam, 1990; Nirje, 1995). The use of natural and inclusive environments is central but not mandatory for implementation of the Routines-Based Model. I am working with a number of countries where the first step is to have clinicians adopt a family-centered approach, even if they don’t leave their clinics. When clinicians were told to work in natural environments, we saw that a simple location change does not, in and of itself, fix the issue of how supports should be provided. Many clinicians simply shifted their clinical, medical-model practices to the living-room floor. The rationale for providing services in natural environments is both conceptual and moral. The conceptual idea is that services should be as convenient for families and relevant as possible. A clinic-based approach dumped on the living room floor is convenient but not necessarily relevant, if the clinician is working on skills that don’t matter in the child’s actual life and the parent is merely an observer, if that. The moral idea is that we should not put people with disabilities in disability-only environments, away from the mainstream of society. Educators tend to understand this idea, because of a history of educational inclusion, but it’s less of a compelling moral stance for medical-allied health professionals, such as pediatricians, occupational therapists, physical therapists, and speech-language pathologists. Even psychologists, with their history of clinic-based therapies. These disciplines have a history of seeing people in specialized settings. House calls are largely a thing of the past. It is therefore
not immoral in the medical model to expect “patients” to come to the office, clinic, or hospital. In fact, these institutions take on an impressive importance. I call them the **churches** of early intervention: rehabilitation centers, programs for children with autism, hospitals, clinics. They are often beautiful, well decked out, sometimes architecturally interesting\(^2\), and hard for professionals to leave, to go on home or community visits. Worshipping in these churches is probably antithetical, however, to the principle of working in natural environments, which should include a particular way of working with families.

How professionals interact with families is more complicated than one might think. Most professionals are nice to families, treating them with respect and kindness, which is easy to do, until a conflict arises. But being nice to families is not our main reason for being there. It is to ensure families have the knowledge and skills to parent their child towards maximal functioning by the child and maximal quality of life for the family, which are related (García Grau & McWilliam, 2014). As my earlier comments indicate, not all professionals have embraced this role; they have assumed their role was to intervene directly with the child. But, for professionals who did understand the importance of building the capacity of families, how to do this was hardly considered.

Traditionally, it seemed like an easy task: Professionals would meet the families, decide what problems needed to be addressed, make recommendations for interventions for the family to carry out, and evaluate how the parent had performed and what progress the child had made. This pedagogical approach, where adult education was carried out as though parents were children, essentially used expert consultation (Graham, 1998). In the RBM, however, family consultation is the label applied to a collaborative-consultation approach. In collaborative consultation, the consultant (e.g., home visitor) and consultee (e.g., parent) together decide what the problem is, together decide what the intervention should be, and together decide whether the intervention was successful, both in the parent’s carrying out the intervention and in the child’s progress. Consultation is not bad, despite some writings in the field (Rush & Shelden, 2011); bad consultation is bad. Good consultation, which means in our field collaborative consultation, is good. I have used the term family consultation to emphasize the particular consultee and because the consultation focuses on the child’s performance in routines and on the family’s needs. Family consultation is similar to coaching as described by Rush and Shelden (2011); some technical differences exist but essentially they both involve an andragogical approach (Knowles, 1978), a focus on child functioning in the context of routines, and an understanding that all the intervention occurs between professionals’ visits. An essential feature of family consultation is asking many questions before offering a suggestion, so the suggestion is more likely to be on target and the family is more likely to feel like a meaningful contributor, thereby empowering the family (i.e., building their competence and confidence). This empowerment helps the family’s self-efficacy, making them more self-reliant as time

\(^2\) Some examples are Fundación Teletón Paraguay Asunción, with its captivating architecture by Gabinete de Arquitectura and its use of recycled materials throughout; the Associação do Porto de Paralisia Cerebral rehabilitation center on Alameda de Cartes, with its bee hive motif on the ceiling, its prominent although inconvenient main-ball ramp, and its surfeit of square footage; l’Alquería, the Catholic University of Valencia’s early intervention center, which includes a glassed in Roman wall on the children’s courtyard play space; and Siskin Children’s Institute, in Chattanooga, Tennessee, with its towering glass entrance, religious-artifacts museum, and Reggio Emilia-inspired classrooms. At Siskin, it should be said, the early intervention team does not even have offices in the building; they work from their homes, in communities.
goes on (Koren, DeChillo, & Friesen, 1992; Lloyd & Dallos, 2008; Trivette, Dunst, Hamby, & LaPointe, 1996).

Not only families, but children’s teachers receive collaborative consultation. When early intervention professionals show up at a child’s classroom, the teachers’ reactions can range from exasperation to apathy to joy. Exasperated teachers might have found the therapist (a term I’ll use for convenience but that includes special-education teachers) superior acting or disruptive. Apathetic teachers might have found them irrelevant or incomprehensible. Joyous teachers might have found them amiable, considerate, relevant, and comprehensible. In the RBM, we train visitors to the classroom in rules of consultation, in collaborative consultation, and in a method of integrating therapy called *individualized within routines*. In this last method, a speech therapist, for example, might go to a classroom, officially to “work with” Domingo, who has significant communication delays. Domingo is playing by himself—his engagement level quite unsophisticated, in that he is moving toy farm animals around in quite a repetitive way. The speech therapist assesses the situation and talks to the teacher. It’s free play time, and Domingo chose those toys to play with. Other children are around, but none interacting with him. The speech therapist and the teacher talk for about a minute about the strategy they agreed upon the previous week: To get another child to join the adult and Domingo in play, with the adult then backing away, to promote peer interactions. The teacher said she had been unable to back away, because, as soon as she did, the other child also stopped interacting with Domingo. The professionals wondered if the strategy had been the right one after all. The speech therapist said she’d give it a try to see if she could figure out an adjustment that might work. While the teacher talked to some children nearby, the speech therapist joined Domingo in the play in which he was engaged. This was also of course the teacher’s routine (i.e., play time), a very important point. Domingo let the speech therapist play with him. She then called over another child who came happily enough. She had the children divide the animals. Domingo was the shepherd and the other child the pig farmer. Instead of simply backing away and leaving the children to develop a play situation, she established a scenario for them. She asked Domingo where he wanted to put the sheep. He pointed to the barn. She asked the other child where he wanted to put the pigs. He said the corral. The speech therapist said that was a lot of work for the shepherd to do by himself and for the pig farmer to do by himself. She asked Domingo who could help him move all the sheep. Domingo pointed to the other child. The speech therapist asked the other child if that was all right. The child said yes and said, “Then Domingo help me move pigs.” The speech therapist said that was a good idea and summarized the plan: “You will help Domingo move the sheep to the barn, and, Domingo, you will help him move the pigs to the corral. OK, guys.” With that, she backed away enough to make it clear she was no longer in the play context but close enough for her to observe. This succeeded, and the speech therapist made sure the teacher could see and she briefly reviewed what she’d done. This is *individualized within routines*: join the child in whatever the child is engaged in and weave intervention into that engagement, making sure to communicate with the teacher.
3. Program Evaluation

To determine whether the practices are being implemented correctly and are having the desired effects, the RBM involves helping programs evaluate their work. Determining whether professionals are doing what they set out to do and the quality of those practices is formative evaluation. Determining effects is summative evaluation. The following figure shows a simple but common evaluation plan for programs implementing the model.

![Evaluation Plan](image)

Figure 3. Plan of implementation of the model
Note: Elaborated by the author.

**Checklists** are the backbone of the RBM. They specify what is to be done, they provide a reminder for professionals, they are a platform for training, and they provide implementation fidelity data. We have checklists for all the major practices (e.g., constructing ecomaps, implementing RBDs, making support-based home visits). Each checklist has actions the professional should take, making sure to convey the important evidence-based skills involved in the practice but still leaving room for individualization for the particular child, family, or classroom. The professional reads the checklist to understand what is expected. A common saying of mine is You can’t expect people to do something if you don’t tell them to do it. The checklist tells them how to do it (Boavida et al., 2015; Casey & McWilliam, 2011; Gawande, 2010). Some checklists in life are read-do, such as recipes (Gawande, 2010). Others are do-read, such as packing lists. Many serve both functions: We read them to know what to do and then again to ensure we did everything. Our checklists are similarly used to guide behavior and to review behavior, including self-checks. For example, after a home visit, an early interventionist can go through the Support-Based Home Visit Checklist to see whether she remembered to do all the steps. When training people to implement practices, we know we need to observe them and give them feedback, because this is essentially the only scientifically proven training method. Twenty years ago and more, Reid and associates conducted some of the finest research on performance-checklist-based training. In one study, for example, 10 supervisors were trained in how to observe and give feedback (Parsons & Reid, 1995). The training modeled what they were to do with direct-service staff members: It involved on-the-job observation and targeted feedback. Following training, all supervisors met criterion for providing feedback. Checklists have their roots in
behaviorism. An example of this foundation is in a study of performance feedback on the safety of client lifting and transfer, where the task analysis of lifting and transfer procedures was converted into a checklist (Alavosius & Sulzer-Azaroff, 1986). Staff were observed, and checklists were scored. Weekly, observers provided written feedback, which was consistently followed by improvements in safe performance.

More recently, checklists were used to compare in-service training alone and in-service training with feedback, on data collection accuracy for direct-care staff working with individuals with intellectual disabilities (Jerome, Kaplan, & Sturmey, 2014). All three staff improved their data collection accuracy from instruction to in-service and from in-service to in-service plus feedback. In a Swiss study of postgraduate training on communication skills teaching, the number and type of communication skills identified did not differ between the intervention and control groups (Perron et al., 2014). The investigators concluded that a problem with their feedback was that blank sheets instead of checklists were provided for the supervisors to give feedback. In a study of a direct-observation checklist in a pediatric emergency department setting, specific history and physical-examination checklists for a range of common conditions were developed (FitzGerald et al., 2012). Interns and faculty observers reported that the checklist-based observation facilitated clear and useful feedback and revealed gaps that would not have otherwise been identified.

RBM checklist items receive three scores: observed, partially observed, and not observed. An item can also be scored as not applicable. The passing criterion is usually 85% of the applicable and observed steps correct. Sometimes a maintenance criterion is added, such as 85% correct on two consecutive observations. These data tell us about the extent of implementation fidelity, an important component of formative evaluation.

Checklist data are labor intensive, because someone has to be available to watch individual people performing tasks. A more efficient but less reliable evaluation method is a self-report rating scale. In the RBM, we use the Families in Natural Environments Scale of Service Evaluation (FINESSE II) (McWilliam, 2011a). Nineteen practices are described, with the scale ranging from bad ways of carrying them out (1) to good ways of carrying them out (7). Professionals rate what they typically do on the 7-point scale and what they consider ideal on the same scale. The discrepancy between their typical-practice score and their ideal-practice score is why we call this a discrepancy tool. The FINESSE II covers many dimensions of providing early intervention, from how to describe the program (services versus supports), through intervention planning (professional decisions versus family decisions), to service delivery (professionals working directly with the child versus professionals consulting with caregivers). We are currently studying a family-completed version, called the Family FINESSE, with which families rate what they typically experience with what they would ideally experience. This tool might provide a more accurate portrayal of typical practice than does the professional self-report. These tools cover many different activities in early intervention and are completed by professionals or families, so data can be gathered from more people than checklists allow for. We recommend the FINESSE be administered to monitor the quality of service delivery, to plan professional development, and to judge the effectiveness of professional development.

If the model is being implemented as described, we should see children and families make progress on their goals. First, goals will be more functional, more meaningful than
before implementation. Second, the criteria for measuring goal attainment will be more meaningful. Third, the quality of the goal attainment data will be more authentic, if less precise. To standardize goal attainment as best one can, considering they are created for a host of ability levels, ages, disabilities, skills, and contexts, we use goal attainment scaling (GAS). We follow the convention of placing the actual goal with its criteria at the midpoint on a 5-point scale (Kiresuk, Smith, & Cardillo, 2014; Maloney, Mirrett, Brooks, & Johannes, 1978). This midpoint has a score of 0. If the child attains his goal as determined on the plan, with its attendant generalization and maintenance criteria, the team assigns the goal a 0. Criteria are also established for -1 (less than aimed for but still some improvement) and -2 (barely moved from the baseline rate). They are also established for +1 (better than expected) and +2 (even better than that). Because goals in the RBM have well-defined quantitative criteria, it is easy to decrease and increase the numbers to fill in the other four levels (i.e., -2, -1, +1, +2). Every time a goal is discussed with a caregiver, the early interventionist rates the progress, usually with a discussion with the caregiver. Not every goal is discussed at every visit, because in the model we have 10–12 goals, so the GAS ratings are intermittent. When a rating of 0 is attained, meaning the goal is met, the family has the choice of continuing to work on the goal or terminating it and, potentially, replacing it. If the family wants to continue working on it, with the same type of criteria, the goal remains in place, and the team is now working towards a +1 or a +2.

We always take goal completion data with a grain of salt, because lower expectations can be met more easily than can high expectations. Nevertheless, the goals are the backbone of a plan, so, if we’re going to take them seriously enough to make them functional and family centered, we should take them seriously enough to monitor their attainment. GAS makes it possible to have a standardized way to monitor all the different kinds of goals possible.

Families should be able to report the supports they receive, so we can hear directly from the consumer and not have to rely on professionals’ self-reports. The Family FINESSE, mentioned earlier, assesses what families received, but the proximal outcome is whether families were actually helped by what they experienced. The ideal instrument for families to rate this might not exist, but the Family Outcome Scale-Revised (Bailey, Hebbeler, & Bruder, 2006) is promising. The scale has two parts: family outcomes and helpfulness indicators. The five family outcomes are understanding your child, knowing your rights, helping child develop and learn, having support systems, and accessing (sic) the community. The items pertaining to these outcomes are asked in terms of the extent to which the items occur (from not at all to completely). In contrast, the three helpfulness indicators are knowing your rights, communicating child’s needs, and helping child develop and learn, and these are asked in terms of the extent to which early intervention was helpful (from not at all helpful to extremely helpful). These questions are therefore attribution questions, in that families are attributing their outcomes (knowing your rights, etc.) to “early intervention.” How families might identify early intervention is unclear. For example, do they count the private therapist who is not participating on the legally established intervention plan? If both the mother’s aunt and an early intervention professional coached the mother, how does the mother make the attribution of early intervention as a helpful source? Despite potential problems of the helpfulness items, the proximal outcomes of understanding your child,
knowing your rights, helping child develop and learn, having support systems, and gaining access to the community are promising ones to assess.

If goals are met and families have immediate benefits from early intervention, in the long run we expect children to function well and families to have a good quality of life. The first of these distal outcomes we measure with the Measure of Engagement, Independence, and Social Relationships (MEISR) (McWilliam & Younggren, in press) and the Classroom MEISR ( ClaMEISR) (McWilliam, 2014a). These instruments are rated by parents and teachers, respectively. Each item is a functional skill typically needed for a child to participate in home routines (MEISR) and classroom routines (ClaMEISR). The percentage of skills the child can perform in each routine can be sorted by engagement, independence, and social relationships; by developmental domains; or by U.S. Department of Education global outcomes. The MEISR has also been crosswalked with state early-childhood standards and the International Classification of Functioning (Boavida, in press). Some programs will also want to use norm-referenced developmental tests, which have their place. The MEISR / ClaMEISR is useful because of its clear relevance to functioning in everyday routines. The proportional change index (Kratochwill, 2013; Wolery, 1983) or other change indices can also be used with the tool, to estimate the difference early intervention made.

Family quality of life (FQoL) can be conceptualized in a number of ways. Examination of the factors in different measurement systems is one way to arrive at a definition of this construct. FQoL was derived from the quality of life studies (Shalock, 1990). Family quality of life took the construct from the individual to the individual’s parents or other family members (Brown & Brown, 2014; Poston et al., 2003). We have developed and tested a scale, the Family Quality of Life Scale (FAQoL) (McWilliam, 2011b), finding it has four factors for American families: Access to Information and Services, Child Functioning, Overall Life Satisfaction, and Family Relationships (Garcia Grau & McWilliam, 2014). We found that a three-factor solution worked better for Spanish families, so it might be worthwhile examining the structure of the instrument for different groups. Of the four factors used in the U.S., the two affected by early intervention were Access to Information and Services and Child Functioning. The other two are presumably stable enough that early intervention doesn’t materially affect them.

A comprehensive program evaluation, therefore, can be done with six types of measures: ratings of typical practice, checklists, goal attainment scaling, family ratings of their immediate outcomes, family ratings of their distal outcomes, and child functioning.

4. Transformation of the Field

The field is transforming itself slowly but surely. Three important changes are a shift away from the medical model, acknowledgment of adult learning theory, and a reinvigorated focus on functioning.

The field has long recognized that the medical model was not appropriate for early intervention (Hanft, 1988; McWilliam, 2014b; McWilliam, Young, & Harville, 1996). The medical model is characterized by specialists providing hands-on intervention to children, relegating families to an observer role, seeing the child in a clinical setting, ignoring the context of the child’s everyday life, and believing—and therefore teaching parents—that the child’s improvements were the result of weekly sessions with the
specialist. The field is repudiating this model as atheoretical, short-sighted, and ineffective (McWilliam, 2014b). First, educators have been at the forefront of understanding that intervention happens between visits (McWilliam, 2012). Some leaders in the anti-clinical movement, however, have come from occupational therapy (Campbell & Sawyer, 2007; Pérez, 2012), physical therapy (Shelden & Rush, 2013), and speech-language pathology (Rush & Shelden, 2011). Second, practitioners are now recognizing that working with families isn’t simply about getting them involved in our business, but rather our getting involved in their business—their routines, their priorities, and, to the extent they want, their lives (Dunst, Bruder, & Espe-Sherwindt, 2014). Third, they are moving out of clinics, hospitals, and centers into homes, communities, and preschools (Woods et al., 2011). Fourth, they are working with caregivers to help children learn skills they need in their everyday routines (Hwang, Chao, & Liu, 2013). Fifth, they are accepting that children learn throughout the day, not just in professional-led sessions (Dunst et al., 2010). These five revolutions in thinking and practice are rendering the clinical approach obsolete.

Adult learning theory is important because early intervention is a field about working with adults—with parents and other adult family members, teachers, and other professionals. Malcolm Knowles (Knowles, 1978) explained that adult learning theory had five assumptions, which can be traced to shifts occurring in early intervention. The first assumption was about self-concept—that learners should have minimum instruction and maximum autonomy. In the RBM, the family makes the important, the meaningful decisions. The second assumption was about the adult learner experience—that learners have had time to grow experiences in life and have acquired a wide knowledge base. Therefore, enlightened early interventionists have a wide range of instructional design models and theories to appeal to the varied experience levels and backgrounds of natural caregivers. The third assumption is about readiness to learn—that adult learners move toward learning opportunities that promise a social reward or a reward in society. In the RBM, we try to keep families’ lives as normalized as possible, so they can run those lives successfully, as they and society define “successfully.” The fourth assumption is about orientation to learning—that learners have to know the reason and the timing of what they are learning. Twenty-first century early intervention focuses on how the topics we address with families will meet families’ self-identified needs. The fifth assumption is about motivation to learn—that learners question the validity of learning opportunities if they don’t see a real need for acquiring new knowledge or skills. Therefore, in the RBM, we often need to point out the fallacy of current practices. Knowles had four principles of andragogy that he postulated could be used to address these five assumptions. (Knowles, Holton III, & Swanson, 2014). The first principle was that adults must be involved in the design and development of their learning experience. In the RBM, we follow families’ preferences for how home visits are divided among talk, practice, child issues, family issues, one routine versus another, informal-support relationships, formal-support relationships, and so on. The second principle was that experience should be at the core of all learning tasks and activities. Hence, modern early interventionists use collaborative or family consultation, asking many questions before making suggestions (McWilliam, 2011c). The third principle was that real-life applications and benefits must be linked to the learning material. In the RBM, the focus is so much on child functioning in routines that families are certain the interventions are applicable. The fourth principle was that adult learners should have
the opportunity to absorb information rather than simply memorize it. In today's early intervention, families are not drilled with information in a manner indicating we expect them to memorize strategies. Instead, the strategies are co-created with the early interventionist and the family. These nine lessons from andragogy, five assumptions and four principles, have helped the RbM be family centered and effective with children.

The third swing in the field is from nonfunctional skills to functioning in routines. Again, it's slow: a big ship cannot make an immediate 180-degree turn; it takes a wide berth and time. Hence, when I develop implementation plans with programs, states, or countries, they are usually for 4–5 years, and we have been developing these plans around the world for the past six years. Early intervention has long been criticized for being oriented towards children's deficits (Michnowicz, McConnell, Peterson, & Odom, 1995). This orientation is not surprising, considering the field exists for children deemed to have a disability, which, by some definitions, means they are “deficient” in some developmental domains. In contemporary early intervention, however, professionals are, I hope, increasingly focusing on what a child needs in order to participate meaningfully in his or her environments. A boost to this focus is the International Classification of Functioning for Children and Youth (Björck-Akesson et al., 2010; Stucki et al., 2002; World Health Organization, 2007), which considers both (a) functioning and disability and (b) contextual factors. The former are composed of (i) body functions and structures (e.g., physiology) and activities and participation (e.g., executing tasks in the current environments). The latter are composed of environmental factors (e.g., the physical, social, and attitudinal world) and personal factors (e.g., attributes of the person). People with impairments are coded along these four components, which is vastly preferable to the medical-model system of giving a person with a disability codes only for their impairments, as is done with the International Classification of Disease (World Health Organization, 2016). In some countries where the RbM is strong, such as Portugal and Taiwan, so is the ICFCY (Chen et al., 2013; Threats, 2010).

In Greek mythology, the god of opportunity, Kairos, passes by and leaves Metanoia in his wake. Metanoia is not the apologetic, sad woman oppressed by her regret that she seems. The concept of metanoia embodies a change of mind, which, in partnership with Kairos (opportunity), can become “a personal learning process, a pedagogical tool, and a rhetorical device” (Myers, 2011) (p. 1). This article has made the case that the RbM provides the Kairos. Now it’s up to the field to make the basic and permanent change William James called metanoia (Clarkson, 1989).

References


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