

# Promoting the Healthy Young Children with D Disabilities, and The

## The Evolution of Theory

The provision of specialist support services to young children with developmental disabilities and delays, and their families, is a relatively recent development, with a history of only 25 to 30 years. These services, which have come to be known as early intervention services, have evolved rapidly over this time, both in the growth of services available as well as in their philosophical orientation. In Australia, this evolution has been a 'bootstrapping'

exercise, generated by the early intervention field itself rather than driven by government initiatives and policies. Although much has been achieved, there is still much to be understood about the nature, form and funding of early intervention services.

As early intervention services have evolved so have definitions and aims, so that even relatively recent statements now need some modifying. As currently conceptualised, early intervention refers to a range of specialist and generic support services provided to young children who are either at risk or who have developmental disabilities and delays, and to their families.

At the child level, support services are designed to maximise the child's developmental and functional adaptation to their family and community environments. At the family level, the aim is to provide families with the support, knowledge and skills they need to meet the needs of the child and other family members.

Early intervention services are thus targeted at a subset of young children. The age range is from birth to school entry, making early intervention the first link in the chain of services for children with disabilities and their families. Early intervention services are also of proven value for young children who are vulnerable or at risk. These children include those who for biological reasons (such as low birth weight) or environmental reasons have an increased risk of having developmental problems.

From the outset, it is important to see the children and families who are supported by early intervention services in the wider context. All families with young children need support from their immediate family and friends, from their local community and from society as a whole to carry out the job of rearing children effectively. For some families,



This article outlines the scope of early intervention services to young children with developmental disabilities, and their families. Discussion centres on how these support services have evolved and how they achieve change. Research findings regarding the effectiveness of services and outcomes for families are presented, and critical factors involved in successful family intervention are identified.

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this job is made more difficult by various factors – such as unemployment, homelessness, marriage breakdown, physical or mental ill health, geographical isolation, or having a child with a disability. These families need additional forms of support which, in the case of families of young children with developmental problems, takes the form of specialist early intervention services. These families are thus a subset of families with additional stresses who are in turn a subset of all families with young children. The effectiveness of the additional support provided to families of young children with developmental disabilities is thus significantly linked with and dependent upon the nature and quality of the general support society provides for all families of young children and the additional supports available for families with additional stresses.

### Changes in Philosophy and Practice

In its short history, early intervention philosophy and practice has evolved rapidly. Four ways in which these have changed are worth noting.

### *From a treatment to a promotion orientation*

Early intervention has followed the natural evolutionary path, evident in other areas of human services, from an initial focus on treatment, succeeded by an emphasis on remediation, and culminating in an increasing emphasis on promotion (Dunst et al. 1990; Simeonsson 1994). In early intervention, this has resulted in a general emphasis on empowerment and efforts to acknowledge and build on the existing strengths both of children (Zeitlin and Williamson 1994) and of families (Singer and Powers 1993).

### *From professionally-directed to family-centred practice*

As in many other forms of human service, early intervention has seen a shift away from a service delivery model in which the professionals controlled the process of diagnosis and treatment to one which seeks to base service on needs and priorities identified by parents, building upon existing family competencies and mobilising local resources (Dunst et al. 1988; Duwa et al. 1993). This

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family-centred approach is based on a partnership between parents and professionals, with the parents making the final decision about priorities and intervention strategies, and represents a profound shift in the manner in which early intervention services are delivered.

### **From a child-focused to a family-focused approach**

The initial form in which early intervention was conceived was child-focused: services primarily took the form of specialist interventionists worked directly with the child. Research indicated that this approach did not produce lasting change and experience

employment, housing, transport and health.

### **From simple linear causal models to complex transactional models**

This progressive broadening of early intervention goals went hand in hand with a reconceptualisation of how early intervention achieved its effects. The first early intervention programs were based on an underlying assumption that direct child-focused therapeutic and educational programs were all that was needed to create long-lasting changes in children. The failure of such programs to achieve permanent change soon led to the development of theories (Sameroff and Chandler 1975) and practices (Bromwich 1978)

suggested the parents' needs for support and information were being neglected. Programs were developed to address these gaps, becoming more parent-focused. Subsequently, the needs of the family as a whole came to be considered as well. This included recognition of the needs of other family members, such as siblings and grandparents, as well as consideration of the overall circumstances of the family, including

based on a transactional model of change and development, in which development was seen as the result of a dynamic reciprocal interaction between the child's biological and intrapersonal characteristics on the one hand, and family and community factors on the other. More recently, there has been a further elaboration of a developmental contextual model (Lerner 1991 1995) which takes account of the changing nature of the child's environment.

The shift from an exclusive child-focused mode of service delivery to one that also includes services directed at parents and the family as a whole represents the adoption of an ecological systems perspective that has had profound ramifications for early intervention, broadening the aims and the range of services.

First, the aims have been broadened so that the child is no longer the sole goal – supporting the parents and the family are now regarded as important goals as well, not only because of the consequent benefits for the child but as legitimate goals in their own right. (Thus, even if early intervention services for a severely disabled physically dependent child resulted in only very limited developmental and functional gains for the child, there may have been many significant positive changes achieved in family functioning).

Second, the range of services has also been broadened. Besides the structured

**Figure 1** Forms of intervention with families of children with developmental disabilities

Level	Focus	Forms of Service	Outcomes
<b>Child</b>	Child's disability Other intrapersonal factors (eg. temperament)	Medical intervention Direct therapy services to the child Structured teaching programs	Maximise child's cognitive functioning Maximise child's adaptive and social functioning.
<b>Parents</b>	Reactions to child's disability Knowledge and skills in managing child's disability	Individual counselling Marital counselling Parent education programs Parent-to-parent contact Parent support and discussion groups	Increased parental capacity to care for and educate child Meet parents' personal needs Prevent breakdowns in marital relationships
<b>Family</b>	Siblings' attitudes to disabled child Attitudes of extended family members	Group programs for siblings, grandparents Respite and special home help Holiday camps Financial and welfare assistance	Increased family capacity to care for and educate child Reduction in level of family stress
<b>Community</b>	Community attitudes to child with disability Ability of local generic services to cater for child with disability	Integration of child into local community settings In-service programs for generic early childhood staff Ongoing specialist support for support for child in local community settings	Child able to attend local community services Child has regular contact with non-disabled peers Community develops greater understanding and tolerance for children with disabilities
<b>Society</b>	Societal attitudes to disability Adaptability of generic services	Advocacy Public education Government policy and funding	Children with disabilities able to live at home Cost saving to society Increase in human dignity

educational and therapy services offered directly to children, there are a range of other programs for parents (including counselling support, parent-to-parent programs, education programs) and families (including programs for siblings and grandparents, respite care, financial counselling and support). In addition, early intervention services are provided to the community (in the form of support and training to generic early childhood services) and to the wider society (advocacy, public education).

Third, the adoption of an ecological approach has highlighted the key role of family supports and of the importance of helping parents mobilising local supports in normative ways in preference to becoming dependent upon professional services (Dunst 1995a; Dunst et al. in press; Trivette et al. in press).

Figure 1 (from Moore 1993) illustrates how these different forms of service relate to specific outcomes at each level.

As others have noted, (Hornby 1994; McGurk 1996), this systems approach corresponds to the ecological system model originally proposed by Bronfenbrenner (1979, 1986).

What this model illustrates is that early intervention is not a single form of service but a range of services provided to children, families and communities according to their individual and collective needs at the time. Thus, no family receives the same combination of services as another family, and what a particular family needs at one point in time may vary from what they need later on.

The other feature of the model that should be understood is that the effect of this systems approach to service delivery is more than the sum of its parts: intervening at different levels simultaneously has a multiplicative rather

than a summative effect. This is illustrated in Figure 2 (from Moore 1993) which shows how interventions at a particular level have strong first-order effects but also have 'trickle-down' second-, third- and fourth-order effects of diminishing magnitude on other levels in the system. Thus, improvements in child functioning (for example, becoming toilet trained or learning to sign) will ease the strain on the parents who might then be more relaxed in other settings (for example, at work). Similarly, if the parents gain a better understanding of their child's disability, their increased confidence will enable them to help the child more effectively and also help other family and community members do the same.

Looked at from an ecological perspective, early intervention is limited in what it can achieve by a number of external factors beyond the control of parents and direct service providers. As Zigler (1990) has noted: 'Thanks to the ecological model, we are now aware that the child's development is not only influenced by the family system, but by other systems far removed from the family's control. The child is thus influenced by the family, which in turn is influenced by the nature and effectiveness of our major social systems, such as the world of work, the school, the media, and available health services. Thus, any complete evaluation of an early intervention program would assess whether the entire ecology of the child has become more conducive for human development.'

Thus, early intervention is limited in what it can achieve by broader economic and social factors beyond its control.

Zigler (1990) again: 'The ecological model has clear implications that we not oversell what we can realistically accomplish with current early intervention programs. In many

instances these programs simply cannot change enough of the ecology or the larger environment to make a real difference in the lives of families. The problems of many families will not be solved by early intervention efforts, but only by changes in the basic features of the infrastructure of our society. No amount of counselling, early childhood curricula, or home visits will take the place of jobs that provide decent incomes, affordable housing, appropriate health care, optimal family configurations, or integrated neighbourhoods where children encounter positive role models.'

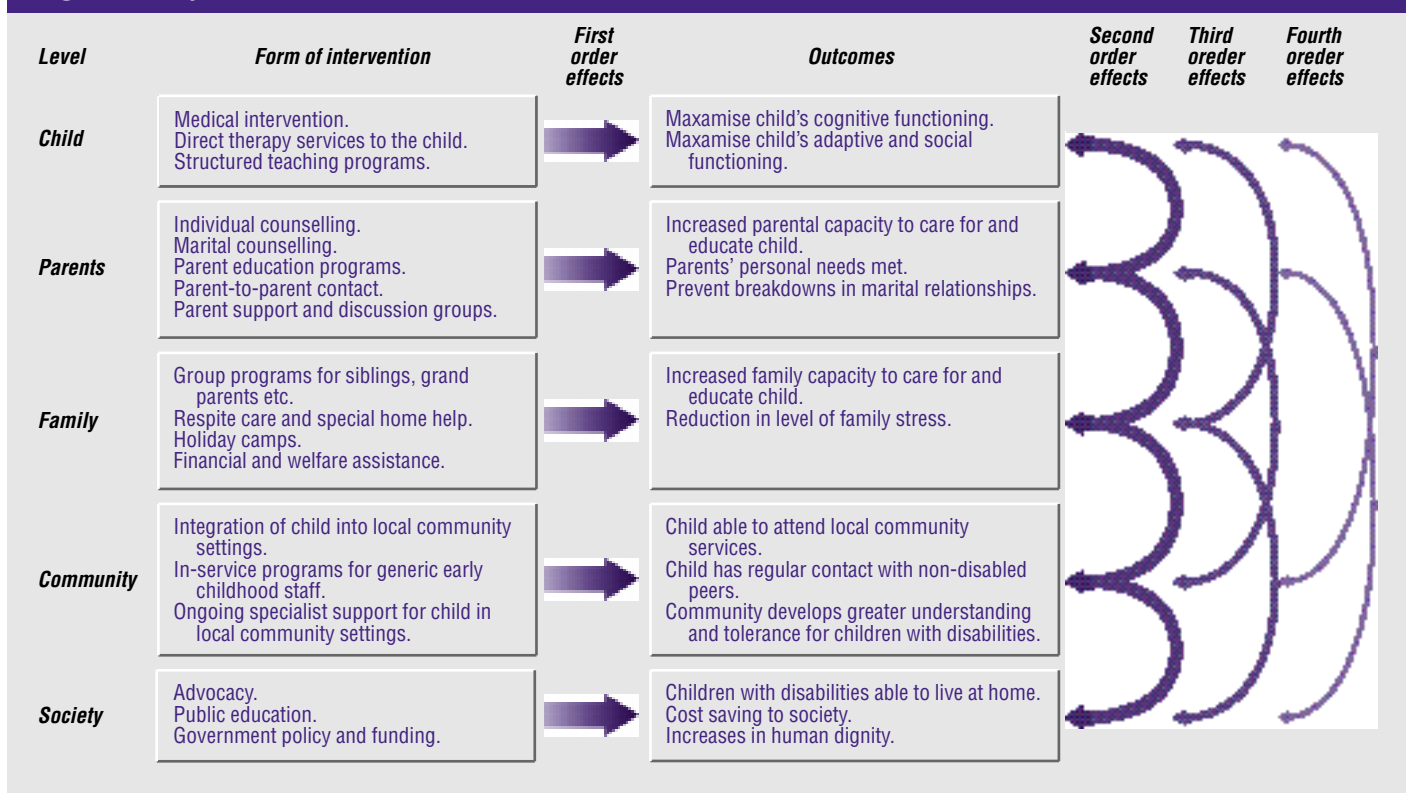
### Efficacy of Early Intervention

All of this background is necessary for an understanding of how early intervention approaches the issue of healthy functioning in families and what the current research issues facing the field are. Because of changes in philosophy and practice, the research questions facing the field 10 to 20 years ago have changed and a new wave of research is now being undertaken in the light of the reconceptualisation of early intervention's goals and methods.

The first wave of research was based on a simple causal model and asked a simple question: Is early intervention effective? That is, does specialist child-focused intervention have significant long-lasting beneficial effects on children's functioning (often narrowly defined as cognitive functioning as measured by norm-referenced ability tests)?

The early research indicated that the answer to that question was No, and the subsequent reconceptualisation of early intervention was partly the result of the search for a service delivery model that *would* produce long-lasting results. It took a good 20 years of experiment and research before it

**Figure 2** Impact of different forms of intervention



was clear what kinds of programs did have significant long-lasting effects on children's functioning. For environmentally at-risk children at least, such effects were only produced by early intervention programs with the following characteristics: intervention began early in the child's life; the program was sustained rather than intermittent or for a limited time only; the program was reasonably intensive; the program was structured and developmentally purposeful; and the parents were involved and efforts to modify the home environment were made (Guralnick and Bennett 1987; Lazar and Darlington 1982; Ramey and Ramey 1992; Zigler and Muenchow 1992).

However, there were important caveats. First, these effects were more marked for at-risk children (for example, those from socially disadvantaged backgrounds) than for children with disabilities. Many of the latter still benefit significantly but the extent to which the interventions are responsible for the changes has been difficult to establish (Dunst, Snyder and Mankinen 1987).

Second, the effectiveness of programs for children with developmental disabilities varies according to the severity of the disability: not surprisingly, the more severe a child's disability, the slower their developmental progress (Dunst, Snyder and Mankinen 1987; Shonkoff et al. 1992).

Third, although the overall picture was clear, the details were not. It had still not been established exactly how early we needed to start, what form of parental involvement was best, what adaptations (if any) were needed for children with different disabilities. In short, we knew that early intervention worked, but not how.

Fourth, in the meantime, the 'goalposts' have been shifted: the reconceptualisation of early intervention described above had resulted in an expansion of both the outcomes sought and the range of services involved, as well as a modification of the manner in which services are delivered. (Thus, most of the studies of early intervention with children with disabilities only measured a narrow range of child outcomes, with no attempt being made to look at effects on parents and families.)

All this has generated a new set of research questions necessitating a second wave of efficacy research (Guralnick 1991; Guralnick, in press).

## Results of Second Generation Efficacy Research

Recent research into early intervention has focused on the efficacy of the family-centred approach, the influence of social support on parents and families, and the nature of effective helping.

Evidence is emerging that different types of programs can be empirically differentiated and have different influences on those receiving the services, with family-centred programs having the most positive impact on the functioning of parents and families. For example, in a study of the effectiveness of the family-focused intervention model (Bailey et al. 1986), Caro and Derevensky (1991)

found that this approach resulted in higher levels of parental satisfaction, accelerated rates of progress by children with moderate to severe disabilities, and acquisition of functional skills by families.

In a major review of the evidence relating to the impact of social support on the behaviour and development of young children with disabilities and delays, and their families, Dunst et al. (in press) conclude that the evidence demonstrates that 'social support has direct, mediational, and moderating influences on the behaviour and development of children with disabilities and their families'.

The exact nature of these influences is beginning to be understood. According to Dunst et al. (in press): 'In general, social support provided by informal personal network members had the greatest positive effect on behaviour functioning, and the more components and dimensions of social support relationships that were considered, the greater the percentage of variance accounted for in the outcomes by social support. Furthermore, the effects of informal social support were found to be greatest on the behaviour of the recipient of the support,



and exerted less powerful but nonetheless significant influences on the behaviour and development of other family members. Additionally, it was found that deliberate attempts to provide support was most effective when it was done in response to an indicated need for particular kinds of information or resources.'

The authors point out that what this accumulating evidence indicates is that social support functions as a form of early intervention, albeit only one of the many factors influencing personal and family functioning. They also note that, although the evidence for the effectiveness of formal support systems (that is, those provided by professionals) is not strong, there is other evidence to suggest that such support is found to be helpful by parents when delivered in a genuinely empowering way. This implies that there needs to be a shift in the ways that professionals interact with parents if the support they offer is to have positive consequences.

The importance of helping practices has become increasingly apparent. Dunst et al. (1988) have noted that 'it is not simply a matter of whether or not family needs are met, but the manner in which needs are met that is likely to be both enabling and empowering'.

Evidence to support this contention is accumulating. Studies by Dunst and his colleagues (Dunst 1995b; Dunst et al. 1996; Dunst et al. 1995; Trivette, Dunst and Hamby,

in press-b) and others have shown that an empowerment model of helping is associated with greater parental wellbeing compared with an expertise-based approach. Different program models and philosophies are reliably associated with actual help-giving practices, so that the more family-centred the program is, the more empowering the helping practices of the staff are. Different program philosophies and different helping practices are in turn associated with greater parental sense of control, so that the more family-centred the programs are and the more empowering the helping practices, the stronger the parent's sense of personal control.

These findings (summarised in Dunst 1995b) are very robust: positive outcomes for children and parents are reliably associated most strongly with certain helping practices and philosophies, regardless of the characteristics of the children or the parents/families. Programs guided by empowerment and family-centred models were consistently the ones in which parents reported the most effective help-giving practices.

Other research is beginning to delineate the exact qualities that make helping practices truly effective. There is evidence that good 'clinical' skills (such as active listening and empathy) on the helper's part may be a necessary but not sufficient condition for promoting a sense of personal control in parents (Trivette, Dunst and Hamby, in press (a), in press (b)).

What is also needed is participatory involvement, defined by Dunst and Trivette (in press) as helping practices that 'provide help receivers with opportunities to discuss intervention options and the benefits and limitations of different choices, provision of information for making such choices, collaboration and shared decision making between help receivers and helpers, active involvement of help receivers in carrying out decided upon options, and otherwise involve help receivers actively and meaningfully in the helping relationship'. The authors propose that effective helping involves three key elements: the technical competence and knowledge of the helper, the personal characteristics (such as the ability to listen) and attitudes of the helper, and the use of participatory involvement practices.

## Research Questions

Despite these encouraging results, it is clear that there are still many questions to be answered regarding the best way to support young children with developmental problems, and their families. There are at least three types of research needed: pure, applied and evaluative. Below are a few of the questions to be addressed to indicate the scope of each type of research.

*Pure research.* What is the exact nature of the impact that different forms of disability have on children's development? How does that impact vary according to the age of occurrence? What are the causes of different types of developmental problems? What impact

does having a child with a disability or a developmental problem have on families of different compositions, qualities and cultures?

*Applied research.* What forms of service delivery are most effective for families of different compositions, qualities and cultures? What forms of service delivery are most effective for children of different disabilities and different ages? What are the cost-benefits of different forms of service delivery?

*Evaluative research – at the state or regional level.* How many children are in need of service and where are they located? Are they all receiving some service? How efficient is the system for identifying children and giving them access to the services they need?

*Evaluative research – at the service delivery level.* Are services delivering the supports that families need? Are service providers supporting families in the manner that is most conducive to helping children and families?

This just an indication of the kinds of research questions still to be addressed. Expanding and gaining general agreement on this research agenda is an important task yet to be undertaken.

### Strategies for Future Research

There are several problems in planning and conducting research to address all these questions. First, there can be major problems finding matched groups in which all the potentially relevant variables are controlled. This is partly because there are often very small numbers of children with particular disabilities. Second, there are ethical constraints on conducting trials using control groups – parents and service providers alike find it hard to accept that, as part of an experimental trial, children should be deprived of a service thought to be of benefit to them. Third, there are relatively few researchers working in the field and they are scattered across a wide range of institutions. Fourth, neither the State nor Federal governments have yet to recognise early intervention as a significant priority and provide the research funding needed to address the many questions to be addressed.

In the light of these difficulties, the following strategies are proposed.

- *Seek the collaboration of universities, hospitals and early intervention settings across Australia in addressing the research agenda.* One of the best strategies for addressing the many research questions in early intervention is to establish links between researchers and institutions across Australia in order to agree on an overall research agenda (of the kind sketched above) and a systematic shared approach to tackling this agenda.
- *Conduct collaborative research between service providers and university departments.* Marfo (1996) has advocated this approach as particularly valuable for conducting evaluation studies, either at the individual agency level or the overall system level.

- *Conduct conjoint studies with institutions (such as the Australian Institute of Family Studies) which are involved in research into families in general or other subsets of families.* We need to know much more about how families of young children with disabilities both differ from and are similar to families whose young children have no developmental problems. By routinely including families of children with disabilities as subsamples of studies of families in general, we can illuminate the situation of both lots of families.
- *Develop more sophisticated models of how early intervention achieves its effects.* Both research and practice need good models – those that exist include Bronfenbrenner's ecological systems theory (Bronfenbrenner 1979, 1986), Sameroff's transactional model of development (Sameroff and Chandler 1975; Sameroff and Fiese 1990), Dunst's social support model (Dunst et al. 1990), and the multilevel intervention model described earlier (Moore 1993). (Another interesting recent model is that proposed by Brown and Pollitt (1996), to



explain the impact of malnutrition on children's cognitive development). None of these successfully capture the full picture of the complex interactions between children with disabilities and their environments in ways which enable us to plot their development and understand the causal links involved, and further work in developing a model that does reflect all these complexities is needed.

- *Focus research on the factors associated with resilience in families and children.* We have only recently begun to explore the personal qualities and external circumstances that enable some children and families to cope well with the challenges posed by disability (Werner 1990). Garbarino (1982, 1990) has suggested a framework that incorporates factors that impede children's development (socio-cultural risk factors) as well as those that enhance development (which he calls opportunity factors). Dunst and Trivette (in press) present preliminary evidence that child development outcomes are depressed as the numbers of risk factors increases and are improved the more opportunity factors there are.
- *Conduct multi-site studies.* One of the ways of overcoming the problem of small group numbers is to conduct multi-site studies in which the same intervention program is delivered to groups of children/families in different sites. Even though the numbers in each group may be

small, if it can be demonstrated that a particular intervention is effective in a number of different sites, then our confidence in the findings is all the greater. (This is, in effect, a form of simultaneous replication.) One of the strengths of the Infant Health and Development Program (Ramey et al. 1992), perhaps the largest and most expensive efficacy study ever conducted in early intervention, was the fact that the program being tested was delivered in eight different sites across the United States and proved effective in all of them.

- *Conduct research using several methods of enquiry rather than relying on one.* This approach has been advocated by Robson (1993) as a way of overcoming the problems of interpretation involved in the use of a single method of enquiry. One can have more confidence in a set of results if they are confirmed by several different methods of data collection.
- *Conduct longitudinal research making use of improved research methodology.* Much of the efficacy research done to date has been methodologically flawed. Common problems include the use of non-representative samples; the use of univariate designs (in which a single outcome variable is studied); the assessment of development in only one behavioural domain using few dependent variables; the use of cross-sectional rather than longitudinal designs; making comparisons between programs with different aims; and failing to document the exact nature of the program delivered in such a way that it can be replicated. More rigorous research designs are needed, including longitudinal studies focusing on intraindividual change and the differences between individuals rather than changes in a group of children on a single attribute (such as IQ). As Dunst and Trivette (1994) have pointed out, there are now many methods (such as hierarchical linear modelling) for estimating change in individuals which can be used in such studies.

### Conclusion

From this overview of the evolution and present state of the early intervention field, it can be seen that there have been considerable changes in the way that services have been conceptualised and delivered. These changes have involved a significant broadening of the aims of early intervention and a heightened awareness of the critical importance of the way in which services are delivered. Early intervention services are no longer exclusively focused on the child's disability but are much more concerned with the child in the context of the family and community and with helping the family meet the needs of all family members, including the child with the disability.

Thus, early intervention is now more generally concerned with promoting the healthy functioning of young children with developmental disabilities and delays and their families. Seen in this light, we can expect to find many commonalities between the early

intervention field and other health- and family-related fields, which opens up the possibility of some useful exchange of ideas and practices.

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