

Social support and families of children with disabilities: Towards positive family functioning

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ABSTRACT

The aim of this paper is to explore the social networks inventory as a tool for interventionists. The bio-ecological and developmental niche models form the theoretical framework within which examples from the field of disability attempt to highlight patterns that exist within the different levels of family's social networks and their implications for rehabilitation planning and goals. A discussion of social networks and current literature regarding the impact of support on parents of children with disabilities is presented. The nature and the composition of members in the family's and child's networks are discussed together with the lack of overlap and the implications of enmeshed social networks between the child's communication partners and that of the family's in order to highlight implications of these patterns for family well-being. Implications for positive family functioning and the role of the interventionist in this process are proposed.

Key words: communication partners, disability, family functioning, intervention, social networks and support

Introduction

Social support can be viewed as a function of social networks, therefore facilitating an understanding of social networks is pivotal to promoting positive family functioning. An understanding of the theoretical models underpinning family systems and support provides insight into the reciprocal nature of influence which exists between individuals and the systems in which they function, and how this promotes the well-being of the family^{1,2}. The bio-ecological model^{1,3} and the developmental niche model⁴ are presented here as the theoretical framework on which the positive functioning of families can be viewed.

Bronfenbrenner's **bio-ecological model**¹ describes the influences of the surrounding environment of an individual and how this environment comes to influence his or her development. The environment and the individual's specific characteristics appear to work in tandem to influence personal development. The family and the parent-child dyad are seen as systems where interaction occurs, as two or more individuals cooperate in mutual understanding of each other. The family and dyad exist in a broader context: support is provided in and between other systems in the environment which influences the family and the dyadic systems. In the bio-ecological model^{1,3} different systems of influences occur at distinct levels. These systems are the micro-system (the child and close caregivers are found at this level), the meso-system (which denotes communication and relations between micro-systems, eg, meetings between interventionists and parents), the exo-system (which denotes settings that affect the child more indirectly, ie, the child is not an active agent in these systems, for example, the parents' workplace) and the macro-system (which can be found furthest away from the child and denotes societal and cultural beliefs and values that shape and influence the lower order systems, for example, child-rearing patterns and attitudes to disability). In a similar fashion support may be accessed at each network level, ie, professional team members collaborating with a particular family to provide assistive technology for a child with disabilities would be located at the meso-system level. The further the system is from the family, the more indirect its influence on the family's coping.

Super and Harkness⁴ focus their **developmental niche model** more specifically on the impact that the surrounding environment and various systems have on the development of children. Within this model, the

culture as a whole must be taken into account and consists of the direct context of the child. This context is composed of *settings*, *caretaker psychology* and *customs*. These three sub-systems surround the child and influence development directly through the concrete environments of everyday life (*settings*), the general practices of caretakers (*customs*) and the values, ideas and belief systems of the caretakers (*caretaker psychology*). By attending to activity settings of families in relation to social and cultural practices, sustainable interventions can be designed. Families organise and shape their members' activity, function and development through daily routines. In creating and maintaining routines, families respond to sometimes conflicting circumstances. This process has been called family accommodation⁵. Therefore both theories view the environment and individual as two constructs which work together in interaction to facilitate development. Whilst Super and Harkness⁴ place more emphasis on the role that culture and customs and beliefs play in influencing development, both theories highlight the systems of influence that surround the child and family and state that they are influential in determining the quality of life and development of individuals. As a result, mapping the social networks of families requesting intervention services provides relevant information essential for assisting them to utilise the support structures available in their contexts optimally.

The impact of social networks on family's functioning

The concept of social networks provides a framework that can be used both to explain and map the social support of the individuals operating within them. To understand the role of social networks, it is important to highlight some general characteristics of the social networks of families with individuals with a disability.

Burchinal, Follmer and Bryant⁶ describe three components of social networks:

- ❑ *network size* refers to the number of individuals within it or how extensive the network is;
- ❑ the *network composition* refers to the categories of individuals within it eg, spouse, children, grandparents, interventionists;
- ❑ the *network density* refers to the quality of interactions among the individuals in the network. They conclude that although size and the



component parts of the network contribute towards the nature of the network's influence on the family, it is the composition and density that produce the most impact on the adjustment process in daily life⁷. Therefore, families which have more categories of individuals within the network and share quality interactions with them are more likely to experience its full positive impact⁸.

However, persons with disabilities often have restricted social networks^{9, 10}. In addition to the size (smaller denser networks), the composition is also different, eg, there are many more paid interventionists who serve as important sources of support as compared to families of typically developing children. Thus the presence of a disability and the impact this has on social networks cannot be overlooked in the intervention process.

The impact of supportive networks on families within an early intervention framework has been much researched in the literature with regard to its impact on adaptive parenting and accommodation. These benefits include, but are not limited to: positively influencing the coping strategies of parents; utilising more nurturing parenting styles; fostering more stimulating home environments; being more responsive to their infants¹¹⁻¹⁶.

Trute and Hauch⁷ studied thirty-six families who had adjusted well to the birth of a child with developmental disabilities. They found that these successful families had small networks that were abundant in support provision. These families had high levels of cohesion and unusually high spousal boundary density; ie, both parents maintained mutual contacts and shared relationships with others. Furthermore, Hashima and Amato¹⁷ found that it is less likely to locate parents with a hard, harsh parenting style in families with supportive social networks. Research conducted by Nitz, Ketterlinus and Brandt¹⁸ on teenage mothers, has shown that they are less punitive and more responsive to their children if they have access to supportive social networks. In addition to the impact on parenting styles, mothers with higher levels of support experienced higher levels of emotional and physical well-being compared to mothers with lower levels of support¹⁹.

The value of supportive social networks is therefore evident in that it has a positive impact on parenting styles, which makes them more tuned in towards the child's needs, hence supporting better family harmony which in turn promotes optimal child development. Social networks, therefore, play a significant supportive role in the lives of families.

Social Networks: Exploring Patterns of Support

Blackstone and Hunt-Berg²⁰ developed a tool called the Social Networks Inventory (SNI) to describe the informal and formal social networks of the communication partners of persons with communication disabilities.

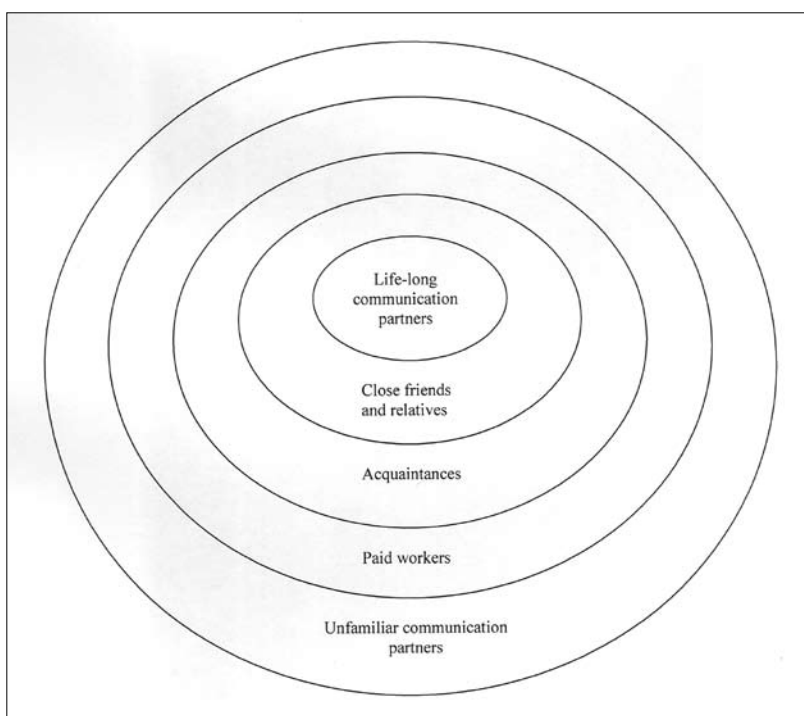


Figure 1: Social Networks Communication Inventory

The procedure involves interviewing at least two communication partners who are close to the person with a disability, in order to map the social networks with particular reference to the communication partners.

Communication partners are documented in a diagram of five concentric circles: the first circle includes the person's life-long communication partners, the second circle includes close friends/relatives, the third circle includes acquaintances, the fourth circle includes paid workers and the fifth circle usually includes unfamiliar partners. Additionally, within these circles, the primary communication partner, the most skilled communication partner, the most frequent communication partner, the favourite communication partner, the communication partner most willing to learn and the communication partner most willing to teach others about the person with a disability are chosen. The person's modes of expression and communicative strategies are also discussed in the structured interview. Thus, the Social Networks Inventory can not only be used to study the composition, density and size of networks, but also the quality and characteristic features of the communication of both the individuals and their communicative partners and the support provided in and across the circles⁹.

As a third step, the Social Networks Inventory can be used with families that include a person with disabilities to compare how the social networks of the person with a disability are described with how the social networks of the family as a whole are described. As a result of this visual mapping of the relationships between the individual's communication partners and the family's communication partners, implications for intervention with the individual with special needs can be drawn. This information can then be used to plan interventions, for example aimed at increasing participation with a wider variety of communication partners in the social network of persons with a disability's or identifying strategies that may assist the person when interacting with the regular communication partners of the family.

The Social Networks Inventory is therefore an accessible way to understand a person's context of social support and array of communication partners. In this manner, the composition, function and quality of social networks are highlighted. Identification of communication partners in the life of the person with a disability and comparing such to that of the family could facilitate intervention planning.

Application of Social Networks: A Communication Inventory

Three primary issues relating to the nature of social networks will be discussed, drawing from research in the field of disability utilizing the inventory. Firstly, the nature and composition of members in the family's and child's networks will be evaluated. Secondly, issues relating to density of social networks ie, the lack of overlap between the child's communication partners and that of the family's as well as the implications of enmeshed social networks between child and family networks will be sketched.

Nature and composition of partners in each circle

As part of an ongoing longitudinal study in Sweden²¹, the Social Networks Inventory is used to describe and compare the circles of communication partners of the family and the child for eight families with children who have multiple disabilities. As described above, a member of the family is asked to describe the circles of the family and of the child. All the children function on a pre-symbolic level and use facial expressions, vocalisations and gestures as communicative expressions. The parents describe their children as having different degrees of problem behaviour, and/or severe medical problems and intellectual impairment. All the children have moderate to severe hearing and visual impairments.

Preliminary results show that the children and families have many interventionists in circle four, between 20-65 ($M = 40$), and that the children have few communication partners in the other circles. The results also show that the children's and families' circle two (close friends/relatives) and three (acquaintances) include different communication partners. The discrepancies vary slightly for each family,

but tendencies amongst the families do emerge. Firstly the children's personal assistants, staff at day-care centres and other children with disabilities are seen as close friends (circle two) of the children but not of the families. Secondly, aunts and uncles, half-siblings and family friends are seen as relatives/close friends (circle two) of the families but not of the children. For some of the children, relatives such as uncles and aunts and sometimes grandparents, are found in the children's fifth circle, which denotes unfamiliar partners. Over time, it appears as if the poor overlap remains between the families' and the children's social network.

The parents and the personal assistants were considered to be the primary and the most skilled communication partners. Over a period of time, the personal assistants and staff at day-care centres move closer in the children's social networks but not in the families'. Furthermore, by using the inventory longitudinally, the children's continued communication dependency on these interventionists and parents becomes evident.

From the inventory, parents' perception of their child's relationships with other children as communication partners also becomes clear. Most children are perceived to have few children in their social networks. A few children have some other children in their second and third circles, but most of the children do not show any interest in other children and have no friendships with other children. The children that do exist in the social networks are siblings, friends of siblings and cousins. Over time, it would appear as if children with disabilities have little contact with children without disabilities.

Thunstrom²² also evaluated Social Networks in a sample of 22 Swedish families with children who had moderate disabilities. Data from this research project indicate that the social networks of children who are deaf or hard of hearing who used symbolic and/or sign language are smaller in size compared to those of other children functioning on a pre-symbolic level. The size of the social networks of these children was generally small and also decreased as age increased. The mothers, who were often employed as the children's personal assistants, were described as being the most important and primary communication partners of the children. The children most often communicated with adults and seldom had important communication partners of the same age, except for their siblings.

Joseph²³ reported that within a sample of 45 mothers of children attending signing schools for the deaf in South Africa the vast majority of mothers had inadequate signing skills, which impacted on their ability to communicate effectively with their children. It has been observed that for the majority of deaf children the communication methods used at school do not commonly match those used in the home where speech dominates²⁴⁻²⁶. The primary communication partners, in such a situation, tend to be the interventionists and learners in the educational context and other members of the signing community. Unless parents of these children engage with this community of sign language users they can become isolated from their children. This fact results in a very different scenario from the one sketched in the previous example, in which parents often formed the primary or most skilled communication partner. It is even plausible that for some families, immediate family members may be positioned in circle five, ie, unfamiliar partners.

The child in residential school facilities presents with even more visible differences within network composition. In examining the social network circles, circle one: primary caregiver (changes from mother to house mother), circle two: close family (changes from siblings and relatives to peers); circle three: acquaintances (many in the school system); fourth circle: paid workers (many interventionists, employees of the school); unfamiliar partners (many people who engage with the school generally, and family members). Thus, it is evident that the circles for the family and child do not overlap and are not expected to merge as the child grows older. These differences must be acknowledged and addressed in intervention planning. Lack of overlap has implications for information transfer between two networks where the child is expected to function within both networks, with serious implications for support and intervention. Therefore drawing family members into the child's existing social network seems crucial, in order to prevent alienation of child and/or close family members.

The above examples clearly indicate fundamental differences, not only with respect to the children with disabilities, but also regarding the roles of other family members. The composition of the children with disability's communication partners is different from what would be expected in terms of typical children and who they communicate

with. In addition, the role of family members, paid interventionists and peers has been altered from what is expected in families with typically developing children.

Implications for positive family functioning

The acknowledgement of the importance of social inclusion for the individual with disabilities within the community networks is well supported in the literature²⁷⁻²⁹. However, in the context of family-centred intervention it is important to approach the family as a whole and not just the person with a disability. The bio-ecological theory by Bronfenbrenner³⁰ states that the child can be surrounded by many important persons, not only the parents, as the child may be active in many micro-systems. Individuals and families have specific interactional patterns and routines that need to be taken into account in intervention. The shift from a child-centred approach towards family-centred intervention reinforces the experience in intervention practice of the need to move control from the realm of interventionists to that of the family in identifying relevant resources for family support³¹⁻³³.

Thus, irrespective of whether the family is engaging in formal (from interventionists) or informal support (from persons in the individual's or family's family or friendship circle), it is obvious that in order to benefit optimally from social support, the family in focus must believe that their social networks have the ability to fulfil a need that they have identified^{13,34}. However, it is very seldom that families identify the need for social support and possess the skills to verbalise such needs and mobilise their social networks for assistance³⁵.

If one considers that social support can be divided into different components or dimensions - *functional*: type and quality of help; *relational*: the quantity and different types of relationships; *structural*: frequency, duration and physical proximity of support; *constitutional*: the actual need and type of support given; and *support satisfaction*¹³, the enormity of the task of accessing support from a network becomes evident. Thus interventionists need to be in a position to assist families to mobilise their own sources of support. This implies that they are able to highlight together with the family, the current status of their social networks, verbalise what type of support would be beneficial, by whom it should ideally be provided, and the expected duration of this support.

Social Networks Inventory is a tool which assists interventionists and families in reaching that goal. Thus interventionists may need to assist families to do any of the following:

1. Strengthen the overlap between child and family communication partners, ie, the ties between the educational setup and the home context should be strengthened so that families and children do not become isolated.
2. Diffuse the overlap between child and family's communication partners dependent on where the family is and the goals they identify for themselves and their child, ie, respite care, participation in community activities, etc.
3. Seek to broaden and establish new sources of support to address existing needs that cannot be met by current social support resources available to the family.
4. Redefine and manage social support resources at strategic phases in the family's life cycle as it is obvious that the degree of overlap is not static over time.

As interventionists, it is important to endeavour to assist families to develop dense and cohesive networks, as the nature of a person's social networks will influence the kind of opportunities and experiences that the person will encounter²⁰, which ultimately influences the success of family adaptation. By utilising such an inventory together with similar techniques such as eco-mapping it is possible to identify supports which are present within the networks but that are not currently being optimally utilised. Interventionists use such a tool in exploring support resource options with the family, which will then address not only the needs of the child with a disability, but also other family members.

Conclusion

This article has attempted to highlight some of the factors impacting on the nature of support within networks available to families of children with disabilities. Furthermore, by utilising an approach such as the Social Networks Inventory, families and interventionists are able to obtain detailed information regarding the current resources which are being



accessed by the individual and the family. The use of such a tool in intervention highlights not only the needs of the child with a disability, but also other family members. However, this tool is not without limitations and much research is still needed in order to better explain, from a variety of perspectives, the value of setting out social networks as the building blocks on which sustainable intervention efforts are based. What is clear, however, is that the challenge in family-centred intervention remains how to involve all important communication partners in intervention efforts and thus ensure the utilisation of all the possible sources of support available to the family. The Social Networks Inventory is one such tool which can be used to facilitate this process.

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