

Families and Disability. Building an Inclusive Framework: A Cultural Challenge

*Alessia Cinotti*¹

Abstract

An inclusive perspective certainly requires revisiting the intersection between families, disability, and environment. However, this alone will not bring about a more inclusive approach to families unless inclusivity is also embraced in the broader culture. Cultural barriers continue to pose the greatest challenge to building a framework of inclusion that supports parents.

Keywords: families, disability, cultural challenges, inclusion, human rights.

Abstract

La prospettiva inclusiva richiede certamente di rivisitare l'intersezione tra famiglie, disabilità e contesti, che però non potrà incidere su un nuovo approccio alla famiglia, senza un'equivalente valorizzazione del piano culturale che, ancora oggi, rappresenta la sfida più importante per costruire un *framework* inclusivo per il supporto alla genitorialità.

Parole chiave: famiglie, disabilità, sfide culturali, inclusione, diritti umani.

Introduction

The *intersection* between families, disability, and environment has traditionally received scant attention within academic research, national policies, and international conventions. More recent debates have yielded a broad consensus regarding the key role of the family in the dynamic interaction between persons with disability and their environment (WHO, 2001) and the consequent urgent need to provide families with educational support (Caldin, 2022). Parents require support if they are to play a generative and reflexive role and actively participate in deci-

¹ Associate Professor in Didactics and Special Pedagogy at the Department of Human Sciences for Education “Riccardo Massa” – University of Milan-Bicocca.

sion-making processes (UN, 2006). This implies the need to develop a more co-operative and supportive partnership between families, teachers, early education and care practitioners, healthcare professionals and academic researchers. All these actors may need support and encouragement as they learn to work as equal partners (Pavone, 2015).

Nevertheless, families continue to be perceived as a “weak link” (that is to say, as “helpless”, “in need of assistance and protection”, “sick”, “unfortunate”). Indeed, once certain social representations have been produced and deployed, they are never definitively set aside. Persistent social representations can continue to condition cultures, practices, and policies at both the micro and macro levels (Booth, Ainscow, 2002; Kalubi, Bouchard, 1998; Lepri, 2011; Ramel, 2014).

Yet, the traditional representations of the family are not in keeping with a human rights approach. They do not promote the emancipation of families or foster self-determination in relation to their life prospects (Cottini, 2021, Martínez-Tur *et al.*, 2018). An inclusive perspective certainly requires revisiting the role of families, yet this will not bring about a new approach to the “family” and “disability” unless inclusivity is also embraced at the broader cultural level. The latter step remains the principal challenge we face in building a framework of inclusion.

1. *Family and disability: A question of human rights*

Since the drafting of the Convention on the Rights of Persons with Disabilities (CRPD) in 2006, disability can no longer be approached as a healthcare issue demanding an exclusively healthcare-based response. The CRPD has established respect for human rights as the founding principle underpinning the rights of persons with disabilities. As stated in the Convention itself, “despite various instruments and undertakings, persons with disabilities continue to face barriers in their participation as equal members of society and violations of their human rights in all parts of the world” (Preamble). Such barriers and violations can also be experienced by the parents of persons with disabilities, who often encounter isolation, discrimination and/or find that their *set of possibilities* is more limited than that of families whose children do not have disabilities (Sen, 2002). Yet, inclusion and participation are essential to human dignity and to the enjoyment and exercise of human rights for both persons with disabilities and their families. The core issue is that everybody, including parents, with no exceptions, must be given equal opportunities and be truly included in

society. This is not a matter of claiming “special rights” for families, but of asserting the need to protect and promote their basic rights, which are sometimes viewed as less urgent than the rights of family members with disabilities, or alternatively are overlooked or taken for granted.

Culturally and politically speaking, disability should no longer be viewed as the “problem” of an individual and/or family, that is to say, as a “personal/family tragedy”. Rather, it is a *biopsychosocial* issue (WHO, 2001) that first invokes collective responsibility and then individual responsibility. Indeed, in its International Classification of Functioning, Disability and Health (ICF), the WHO emphasizes the importance of social contexts, where individuals and their environment interact. Arguably, contexts can also be of *hindrance* in the everyday lives of the families of people with disabilities, who encounter *barriers* that can limit their own participation and/or functioning, to borrow a key term from the ICF.

The context – as the ICF (2001) clarifies – can hinder the performance of a person (or a group of people) by either presenting barriers (e.g., architectural barriers) or by not offering facilitators (e.g., the failure to provide appropriate aids). Hence the need to raise awareness (and this is a cultural challenge) and re-organize contexts to make them accessible to all (families with children with and without disabilities). *Differences* should be read as challenging us to promote change by seeking to overcome (or limit) the barriers posed by contexts. Such barriers are often unintentional and may take the form of structural, organizational, relational or cultural obstacles.

In relation to cultural obstacles, Lepri (2020) argued that situations of disability (which also include parents) need to be freed from two social representations that have dominated throughout history and remain strong today: the *bio-medical* social representation, which reduces the person with disabilities to “someone who is ill/a patient to be treated”, and the *welfarist* social representation that equates having disabilities to being an “eternal child”. Thus, even today, we continue to imagine these people as continuing to require the levels of attention and protection that are typical of childhood throughout their entire lives, forcing them into a condition of subordination and dependence. This poses an insurmountable obstacle to the possibility of growth, autonomy, self-determination, and the construction of an adult identity (*Ibidem*). We still find it exceedingly difficult to imagine and design educational projects for persons with disabilities – especially intellectual and/or complex disabilities – that foster their social participation, autonomy, exploration of the world, and taking on of social roles.

As mentioned in the *Introduction*, the dominant social representations of persons with disabilities have – indirectly – influenced the social representations of teachers, educators, healthcare practitioners, etc. concerning the families of these individuals. More specifically, they appear to have fostered a social representation of such families that is distorted and incomplete, and far removed from a “realistic” image of “flesh-and-blood parents”.

2. *Cultural challenges to inclusion: Questions, and future prospects*

The inclusion of families of children with disabilities demands an acceleration of the current cultural shift towards approaching parenthood from a perspective of *human rights, citizenship, and self-determination*. Only in this way we could transcend the notion of a “personal/ family tragedy”, which – still today, as mentioned earlier – pervades the broader community and, sometimes, even schools and educational services. Thus, new methods of support must draw more deeply on *pedagogical knowledge* and revolve around changing and enhancing the context by activating a support network that encompasses families, services, practitioners, and the community (Caldin, Giaconi, 2021).

Existing cultural approaches to supporting parents must be revisited; we must move beyond the current, mainly transmissive methods, which envisage a trajectory that is mapped out and directed by experts and is standard for all families. Indeed, the support offered to the parents of children with disabilities continues to be informed by the biomedical model. It tends to be “delivered from on high” by experts, from a predominantly clinical/specialized perspective that sees the parents’ role as mainly passive.

The alternative would be a participatory model of shared intervention and educational action with a focus on generating new opportunities in everyday lives of children with disabilities. However, the current pattern is paradoxical: the main interlocutors of practitioners should be the parents (and/together with the person with disabilities). The interaction between these figures (parents, practitioners, persons with disabilities) should represent the *key coordinate* for educational work with parents (Bouchard, Kalubi, 2003; Kalubi, Angrand, 2020).

The goal should be to move progressively away from a perspective that sees practitioners as “experts” and to develop a cultural perspective that views the expert as co-facilitating possible trajectories with families.

Responsibility for such jointly developed trajectories should be shared and participatory. Viewing support in this way means interpreting parents as *causal agents*, with the aim of making families increasingly autonomous (including from the point of view of having the possibility to choose) and “at the helm” of their plans for their own lives and for their family lives. In this sense, it is important to foster the ability – of the parents, in this case – to intervene actively and transformatively in their everyday life contexts, so that they can perceive themselves as “effective” in managing events (and not as delegating their role to others).

Let us therefore outline different cultural approaches to supporting families in the area of disability. This exercise will demonstrate that the meaning attributed to the term *support* is by no means univocal (in the culture) and that this is reflected in the different kinds of possible intervention (in practice). Dondi (2018, 2022), for example, proposed four leading “models” that practitioners may draw on:

1) the *professional-centred model*: practitioners are the experts when it comes to identifying the needs of children and their families. There is an underlying expectation that the family should trust and rely upon the practitioner, who has all the answers;

2) the *partnership with the family* model: practitioners see the family as “executive”, or capable of effective intervention, yet defining the needs of children and families and what constitutes suitable intervention continues to be the “prerogative” of the professionals;

3) the *working model with a focus on the family*: practitioners see the family as “consumers” who, with the right help, can choose between the different options identified and presented by professionals;

4) the *family-centred model*: professionals see the family as an equal partner; interventions are tailored, flexible, and designed to cater for the needs of individual children and their families, and to strengthen and support family functioning; the family is the ultimate decision-maker.

These four approaches represent *culturally different* ways in which practitioners can relate to parents. Albeit with different nuances, the first two models are both characterized by a logic of separation; the parent is seen as “passive” and “reliant”, and/or as a “good” performer who, however, follows a “route” that has already been defined and presented by others (namely, the practitioner in the role of expert).

In the second two approaches, the support offered is more family-centred – and in the last approach particularly, attention is paid to the needs of all family members and, not just to the needs of the child or

young person with disabilities. Thus, support progressively becomes a *complex, global and situated* trajectory, within which the family is called to play a responsive role.

This is not a merely a “technical” matter and/or related to practitioners’ “professional competences”, but also – and above all – a cultural mindset. It requires de-constructing the concept of “support” that historically took root in the collective imagination of practitioners and the wider community, with a view to building a new concept that is more in keeping with the construct of self-determination. This challenge does not only involve practitioners. It also concerns the stereotypes, expectations, and cultural models of parents, as well as the meanings that they themselves attribute to support (What do they expect? How do they imagine it?).

In other words, a “family-centred” approach also requires parents to behave differently towards the services they encounter (from the nursery to the day centre, and so on). Specifically, this will involve not behaving like passive recipients who are “waiting” for a “solution/pathway” to be mapped out for them, but rather as co-actors and co-protagonists along a trajectory that is always in the making (Coyne, 2015). Support services will need to foster parents’ ability to cope with “problems” and “complex situations” by *intentionally* and *reflexively* mobilizing and/or seeking out personal/family/contextual resources.

All this will require them to engage with the real everyday lives of families, where learning is not based on a merely theoretical knowledge, but on the acquisition of both parental and reflexive competence. Indeed, the fact that support pathways for families are experiential makes them reflexive by nature. This is in keeping with the complexity of education in our contemporary era and with the educational challenges that contemporary parents encounter in their everyday lives.

Today, reinforcing parental competence is a key aspect of enhancing support for families who are dealing with disability in their lives. Thus, competence-based support may offer a new cultural framework, in which the family is seen as driving inclusive processes at the *intersection* of families, disability, and environment.

Conclusions. The cultural challenges involved in attaining inclusion

This discussion about supporting the families of children with disabilities reflects the complexity that currently characterizes support services for all families (with or without children with disabilities).

Hence, we need to set up a network of services (including schools of all levels) that draws on the conceptual framework of the inclusive approach. These services would analyse the educational and social needs of families, promote inclusion by creating opportunities for group activities and encounters, and encourage the participation of families in their everyday life contexts. Ideally, they would cater for the diverse needs of all families, in recognition of the fact that all contemporary families face similar, distinctive educational challenges (Milani, 2018; Riera, Silva, 2016). Inclusive services would embrace the epistemological paradigm of difference (which can comprehend an infinity of characteristics).

This would entail seeing “difference” as a resource for designing and implementing educational projects that stimulate learning/transformational processes and participation. As it is defined here, support for families is also in line with the family education perspective; it speaks to Enzo Catarsi’s – still highly relevant – call for a fostering and non-reparative perspective «that values the family’s existing resources and helps parents to give their best and to independently construct a parenting style that relies on reflexive reasoning» (2006, p. 17; my translation).

Hence, a key goal is to enhance parents’ reflexive competence, and to enable mothers and fathers to learn from their everyday lives, via a recursive cycle comprising *experience*, *reflection*, and *knowledge* (Catarsi, 2002). This will require more visiting and parental support projects in one of the settings where it is most difficult to intervene: the home. Such projects must not be exclusively focused on healthcare during the post-partum period or breastfeeding, although this is very important area, but rather must also target families’ educational and social needs.

From a nurturing perspective, it is important to initiate educational work with families at an early stage and to apply a multimodal approach to overseeing children’s educational and social development, especially during their crucial first thousand days of life. This will represent a key step towards forging a relationship between services for families and everyday life settings. Working on educational and social dimensions directly in the home, especially while the child is still very young, will require overturning traditional intervention strategies. For example, home visit programmes might include events held in the evening or on weekends, to offer a flexible response to the needs of families at times when both parents can realistically be present (while avoiding sensitive times such as baby feeding times, bedtime, etc.). Parents’ pedagogical knowledge may be built up via home visiting projects with an educational figure such as a socio-pedagogical practitioner. A key aspect will be

helping parents to develop the planning dimension of their parenting, a cornerstone of education that involves anticipating the future and what it is possible to achieve by means of *intentional* educational action.

At the same time, the infant-toddler centre will also play a fundamental role. This is – potentially – one of the most inclusive settings that families can encounter at the beginning of their parenting journey. It is a setting that offers education to children (with and without disabilities) and also to their parents, via the provision of everyday, diffused forms of support, including – where necessary – by directing families towards specialized services for specific needs (Cinotti, 2016). The other great strength of the infant-toddler centre is its mandate to intervene at a very early stage in the child's life. Infant-toddler centre staff encounter parents and children (with and without disabilities) while the latter are still very young and offer early childhood education programmes (UNESCO, 1994) that are aimed at enhancing parenting skills as well as providing crucial educational opportunities to the children themselves.

This early encounter between the infant-toddler centre and families evokes the concept of «educational prevention» (Catarsi, 2000, *passim*; my translation), defined as reaching out to (and bringing together) parents in their everyday life contexts and identifying – as early as possible – the areas in which they require minor support. In this case, support can mean helping parents to draw on their existing and/or latent (or not known yet) resources, whether at the individual, family, or collective level. Thus, the infant-toddler centre offers a socio-cultural and relational framework for implementing processes of growth and transformation with the families that “pass through” and “live in” this educational setting.

A key question that applies to the provision of support to parents – which has been raised by Cottini (2021, 2017), albeit not directly in relation to parenting – is that of not confusing inclusion with hospitality. More specifically:

if we limit ourselves to opening the doors, but we are not willing to also make changes to the setting to allow everyone to actively participate, we are effectively hosting people in an environment, but with the conviction that it is not truly theirs, given that they do not have all the characteristics required to fully take part in it (Cottini, 2021, p. 15; my translation).

If we assume that standard settings (such as the infant-toddler centre) must offer true inclusion (and not mere hospitality), we need to recognize that inclusive processes can only be successful if they permeate set-

tings in all their breadth and complexity, transforming them into facilitating environments that guarantee equal opportunities and equal access and participation rights (Caldin, Cinotti, 2020).

Once again it is clear that the crucial factor is the culture that surrounds the provision of support to families and, in this regard, special education offers us a key lesson. The extensive expertise (Caldin, 2019) that comes from forty years of school integration and inclusion will not benefit contemporary inclusive processes if we forget that what “works” for a person with disabilities often becomes a resource for everybody. (A classic example of this is wheelchair ramp that also benefits a pregnant woman, an elderly person, a young man whose leg is in a cast, a young woman with a heavy suitcase to carry, etc.). If we transfer this perspective to the domain of support for (all) families, we realize that practices routinely implemented with/for the families of children with disabilities can/should be routinely implemented with all families.

Our experience with disability allows us to “zoom in” on educational issues/challenges that also affect families whose children do not have disabilities (Cinotti, 2016). Thus, «the techniques, care, choices, and tools that have already been tested, including in separated settings» (Canevaro, 1999, p. 29; my translation) – as, for example, in ad hoc settings for families with disabilities – may be introduced into all settings (e.g., infant-toddler centres, schools, socio-educational services, etc.).

After all, one of the tasks of special education is to implement special intervention, that is to say, uncommon intervention, which however is waiting to become common, to be repeated, and universally shared (Montuschi, 1997). This transition – from the special to the ordinary – is a fascinating *cultural challenge*. A challenge that is framed to us by the inclusive approach as a path to follow, not by ourselves, but together with families.

References

- Booth T., Ainscow M. (2002): *Index for Inclusion. Developing Learning and Participation in Schools*. Bristol: CSIE.
- Bouchard J.M., Kalubi J.C. (2003): Les Difficultés de Communication Entre Intervenants et Parents d'Enfants Vivant Avec des Incapacités. *Éducation et Francophonie*, vol. 31, n. 1, pp. 108-129.
- Canevaro A. (2006): *Le Logiche del Confine e del Sentiero. Una Pedagogia dell'Inclusione (per Tutti, Disabili Inclusi)*. Trento: Erickson.
- Canevaro A. (1999): *Pedagogia Speciale. La Riduzione dell'Handicap*. Milano: Bruno Mondadori.

- Caldin R. (2019): Voce «Inclusione». In L. d'Alonzo (a cura di): *Dizionario di Pedagogia Speciale*. Brescia: Morcelliana, pp. 259-264.
- Caldin R. (2022): *L'Arte dell'Educare e dell'Includere. Riconoscimenti, Attese, Responsabilità*. In Id. (a cura di): *Pedagogia Speciale e Didattica Speciale. Le Origini, lo Stato dell'Arte, gli Scenari Futuri*. Vol. 2. Trento: Erickson, pp. 21-88.
- Caldin R., Cinotti A. (2020): Voce: «Inclusione». *Enciclopedia Italiana di Scienze, Lettere ed Arti. Decima Appendice*. Roma: Treccani.
- Caldin R., Giaconi C. (a cura di) (2021): *Disabilità e Cicli di Vita. Le Famiglie tra Seduttivi Immaginari e Plausibili Realtà*. Milano: FrancoAngeli.
- Catarsi E. (2000): *Comunità Locale e Prevenzione Formativa. I Ciaf della Toscana*. Firenze: Giunti.
- Catarsi E. (2002): Il Ruolo dell'Animatore di Educazione Familiare. *Studium Educationis*, vol. 1, n. 1, pp. 31-39.
- Catarsi E. (2006): Educazione Familiare e Pedagogia della Famiglia. Quali Prospettive? *RIEF-Rivista Italiana di Educazione Familiare*, vol. 1, n. 1, pp. 11-22.
- Cinotti A. (2016): *Padri e Figli con Disabilità. Incontri Generativi, Nuove Alleanze Educative*. Napoli: Liguori.
- Cottini L. (2017): *Didattica Speciale e Inclusione Scolastica*. Roma: Carocci.
- Cottini L. (2021): *Didattica Speciale per l'Educatore Socio-Pedagogico*. Roma: Carocci.
- Coyne I. (2015): Families and Health-Care Professionals' Perspectives and Expectations of Family-Centred Care. Hidden Expectations and Unclear Roles. *Health Expectations*, vol. 18, n. 5, pp. 796-808.
- Dondi A. (2018): Siblings. *Crescere Fratelli e Sorelle di Bambini con Disabilità*. Cinisello Balsamo: San Paolo.
- Dondi A. (2022): *I Gruppi di siblings Adulti. Una Proposta di Metodo per Sostenere Fratelli e Sorelle di Persone con Disabilità*. Cinisello Balsamo: San Paolo.
- Kalubi J.C., Angrand R. (2020). Représentations du Pouvoir Communicationnel des Parents: Synthèse sur deux Décennies d'Analyse Réflexive en Partenariat. *Phronesis*, vol. 9, n. 3-4, pp. 11-24.
- Kalubi J.C., Bouchard L.M. (1998): Les Relations Entre Professionnels et Parents d'Une Personne Vivant Avec une Déficience Intellectuelle. Situations d'Aise ou de Malaise. *Revue Francophone de la Déficience Intellectuelle*, vol. 9, numero spécial Colloque Recherche-Défi, pp. 41-45.
- Lepri C (2011): *Viaggiatori Inattesi. Appunti Sull'Integrazione Sociale delle Persone Disabili*. Milano: FrancoAngeli.
- Lepri C. (2020): *Diventare Grandi. La Condizione Adulta delle Persone con Disabilità Intellettiva*. Trento: Erickson.
- Martínez-Tur V., Estreder Y., Moliner C., Gracia E., Pătraş L., Zornoza A. (2018): Dialogue Between Workers and Family Members is Related to Their Attitudes Towards Self-Determination of Individuals with Intellectual Disability. *Journal of Intellectual & Developmental Disability*, vol. 43, n. 3, pp. 370-379.

- Milani P. (2018): *Educazione e Famiglie. Ricerche e Nuove Pratiche per la Genitorialità*. Roma: Carocci.
- Montuschi F. (1997): *Fare ed Essere. Il Prezzo della Gratuità nell'Educazione*. Assisi: Cittadella Editrice.
- Pavone M. (2015): *Scuola e Bisogni Educativi Speciali*. Milano: Mondadori.
- Ramel S. (2014): Elèves en Situation de Handicap ou Ayant des Besoins éducatifs Particuliers. Quelles Représentations chez de Futurs Enseignants? *Revue Suisse de Pédagogie Spécialisée*, n. 3, pp. 20-26.
- Riera M.A., Silva C. (a cura di) (2016): *Il Sostegno alla Genitorialità. Uno Studio fra Italia e Spagna*. Milano: FrancoAngeli.
- Sen A. (2002): *Rationality and Freedom*. Cambridge: Belknap Press-Harvard University Press.
- UN (2006): *The Convention on the Rights of Persons with Disabilities* (<https://social.desa.un.org/issues/disability/crpd/convention-on-the-rights-of-persons-with-disabilities-crpd>; last access: 14.03.23).
- UN (2015): *Transforming our World: The 2030 Agenda for Sustainable Development* (<https://sdgs.un.org/2030agenda>; last access: 16.03.23).
- UNESCO (1994): *The Salamanca Statement and Framework for Action on Special Needs Education*. Paris: UNESCO.
- WHO (2001): *International Classification of Functioning, Disability and Health (ICF)*. Geneva: WHO.

