

Help is just a click away

Social Network Sites and Support
for Parents of Children with Special Needs

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Series in Sociology



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Short Introduction

Support for parents of children with special needs plays a critical role in the wellbeing of the children and the family (Winton, Sloop, & Rodriguez, 1999; Al-Kandari, 2014; Yau & Li-Tsang, 1999; Scharer, 2005). While working in an organisation for parents of children with special as both teacher and volunteer back in Taiwan, the author had opportunities to talk with some of the parents. In doing so, the author realised SNSs are often mentioned as tools for collecting information or communicating with other parents. **Within recent years, SNSs have also been suggested as important tools that help provide better support for parents without restrictions of location and time** (Nieuwboer, Fukkink, & Hermanns, 2013; Scharer, 2005). Also, the author realised that not only parents were using the SNSs as tools, but the organisation was also using it as one of the main platforms for supporting parents in a variety of different ways.

The main purpose and focus of this book will be on helping the reader to understand the role that virtual communities play in providing support for parents of children with special needs. Through the author's first-person narrative, this book will help the readers understand how Social network sites and virtual communities empower parents to gain control of knowledge and their relationships with professionals. It indicates how information and support related to parenthood and parenting skills was easily accessed through virtual communities. Parents were found to join together to share their experiences of parenting, comfort one another, and advocate for their needs through the virtual communities. This book also raises the issue which the parents occasionally excluded members of the community to ensure that all members shared similar parenting values.

This book introduces the case study of three virtual communities for parents of children with special needs based in Taiwan. All three virtual communities were established by parents; two are managed by parents, and one is managed by a professional. The cases will be introduced to the reader with the rich and detailed qualitative data, including web-based observations data of the parent-parent and parent-professional online interactions, and the in-depth semi-structured interviews of 14 parents, 7 professionals, and 6 administrators.

The structure of the book will also be guided by the five themes of the conceptual framework: developing parenting skills, online medical resource, educational provision, welfare resource and finally leisure.

Foreword

Parental involvement, parental support: some questions

Alan Dyson

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This book is about how the parents of children with special educational needs and disabilities support each other. Specifically, it is about the emergence of ‘virtual communities’ in which parents seek and offer support through the medium of the internet, and about the ways in which the use of this medium impacts on their relationships with professionals. Dr Lu’s study innovative study is focused in Taiwan and explores the workings of such virtual communities there. However, the growth of parental support groups and networks, and the transformation of the possibilities for support through virtual communities are international phenomena. In this short chapter, therefore, I wish to set Dr Lu’s work in its wider context, and to raise some questions that are important in relation to parental support wherever and however it is delivered.

The wider context

In education systems across the world, parents wish to see their children do well and will engage with schools if this seems likely to help their children. For most of them, such engagement is a relatively straightforward business. They may receive routine reports on their child’s progress, or take part in major decisions about which school the child will attend or what direction her/his studies will take. Perhaps they will work more closely with the school to resolve the minor problems that arise in all children’s school careers, and perhaps some will support the school in more tangible ways – helping to raise funds, for instance, or doing voluntary work in the school.

The situation for parents of children with special educational needs and disabilities, however, can be very different. In many places major advances have been made to improve the capacity of school systems to respond to student diversity, yet it remains the case that children with special needs are likely to need something different from the more-or-less ‘standard’ provision that is

offered to their peers. Their parents may have to engage with medical professionals to understand the implications of their children's difficulties. They may then have to engage with teachers and other education professionals over what kind of provision is available and will be most appropriate for their child. This may well not simply be about choosing the best local school, but about deciding whether any local school is able to provide for the child and whether the child should be educated alongside their peers or in some form of special schooling, or even in a residential school. In some cases, a clear range of options may be available, but in others there may be little choice, or indeed, no appropriate provision. Parents may find themselves struggling with schools and the school system to have their child's difficulties properly assessed and to have provision properly resourced. Even where provision is good, parents may need to work closely with teachers – and, frequently, with medical and other professionals – to overcome the multiple difficulties that their children face. They may find that transition points in the system require particular efforts on their part. The high quality provision developed laboriously in one school may disappear when the child has to move on, not least when s/he to leave the school system and move into what is often the less supportive world of post-compulsory education and the labour market.

This level of engagement imposes demands of the parents of children with special educational needs and disabilities significantly beyond those placed on most other parents. Not surprisingly, therefore, parents have sought and/or have been offered various forms of 'support' – a useful but problematic term, as we shall see – to help them navigate the complexities of the school system. Such support has, in the past, typically been offered by the school system itself and has been somewhat paternalistic in nature. Teachers and other education professionals have tended to act as the experts in the situation, telling parents what their child 'needs' and how those needs can best be met. In the absence of information to the contrary and with few alternative forms of support, parents have had little option other than to accept the decisions made by professionals on their behalf.

Gradually, however, this situation has begun to change. First, many education systems have come to see more authentic forms of parental involvement, both as a resource schools can draw on in enhancing the quality of their provision and as a right to which all parents are entitled. Parents of children with special needs and disabilities, in particular, have begun to be seen as 'experts' on their own children's needs and potentials, and as a necessary counterbalance to professional interests in decision-making. In the English education system, for instance, where my own work is located, the need to view 'parents as partners' was recognized over four decades ago (Department for Education and Science, 1978), and since then there has been a steady stream of guidance

and regulation giving parents a key role in decisions about where their children will be educated, what type of provision will be made by their schools, and how their studies will progress (see Department for Education & Department for Health, 2015 for a recent example).

Second – and partly in response to this first development – there has been a rapid growth in and around many education systems of parental support groups and networks. These come in all shapes and sizes, from informal networks of parents in particular places, to national advocacy groups focusing on one or other type of disability, to activist groups campaigning for particular types of provision (inclusive provision being the obvious example) or for better resourcing or for higher-quality provision.

Although these groups and networks are extremely diverse, they do share one common feature: they all offer what we might call ‘horizontal’ support to parents. In other words, they seek to offer support to parents other than through the hierarchical, professionally-dominated structures of the education system. In some cases, the support available is entirely peer-to-peer as parents create their own informal networks to share experiences and help each other through the complexities of school systems. It is clear in that parents of equal status offer informal support to one other. In other cases, support comes from organizations that are more professionalized, with their own employees, experienced managers and external experts. Even here, however, the support that parents receive comes crucially from people who share their interests and concerns rather than from professionals within the education system who are (necessarily) paid to serve the system’s interests. It is this shift of focus which makes the term ‘support’ – useful though it is as a form of shorthand – somewhat problematic. It implies a degree of dependency between supported and supporter which is inappropriate when people with a common interest work together, and it fails to capture the range of activities in which these groups might engage. Helping parents cope with the emotional impact of having a disabled child, for instance, is quite different from working with parents locally to fight for the best provision for their child, and this is different again from campaigning nationally for system-level change

Recently, these two major changes have been accompanied by a third, and it is this that is the focus of Dr Lu’s book. The expansion of the internet in general, and of social media in particular, has shifted the power dynamics of ‘support’ even further. Now large numbers of parents have access to sources of information about disability and about educational provision that were previously difficult to find. They become less dependent on the ‘expert’ views of professionals within the education system when they can – in principle at least – read on the internet the latest research on their child’s difficulties, find out what kind of provision is made in other localities and systems, and learn

how other parents have secured high-quality provision for their children. Moreover, face-to-face support groups and networks have now been supplemented by what Dr Lu calls 'virtual communities'. Using social media, parents can now engage with each other far easier and on a much more widespread basis than has been the case in the past. They can – again, in principle at least – talk instantly to parents in other parts of the country and other parts of the world, put out requests for information, contact their own chosen experts directly and, if the need arises, rapidly organize coordinated action.

Some questions

On the face of it, these developments are entirely positive. It is difficult to argue against the close involvement of parents in their children's education, or against the need for parents to be as well-supported and as well-informed as possible. Likewise, although it is certainly the case that education professionals have a key role in providing this information and support, it is difficult to argue that independent sources of information are not also important or that the most effective forms of parental support are often provided by other parents. If 'virtual communities' serve to facilitate these ends, therefore, their recent appearance on the special needs scene has to be seen as a beneficial development.

However, Dr Lu's study suggests that things may not always be as straightforward as they seem. The growing focus on parents as partners and advocates, together with the accompanying growth in support groups and networks, raises important issues about who provides support, who accesses it, and to what ends. In particular, there are specific questions that arise when support is offered through virtual communities. Dr Lu explores some of these questions explicitly, and others will no doubt occur to readers as they read her rich account of what these virtual communities look like in practice. My own list, however, is this:

- First, there is the question of *inclusion and exclusion*. Not all parents have easy access to the internet and social media. Even where they do, not all feel equally comfortable using these resources. Moreover, virtual communities may have practices which effectively exclude certain parents. Perhaps they have rules which bar some parents, or perhaps they recruit members in ways which fail to reach all parents, or perhaps they operate in such a way that some parents feel they cannot participate fully.
- Linked to this is the question of *power and control*. Who runs these virtual communities? Who decides which parents can

participate, what information gets circulated, what kinds of activities the group will pursue, or what kinds of stances it will take? Are these people representative of all parents, or are they a self-selecting elite? And on what basis do they decide what is in the best interests of parents and of their children?

- This, in turn, is linked to the question of *purposes and practices*. What do virtual communities see as the focus of their activities? Are they there to offer personal support to parents, or to help parents navigate complex special education systems, to campaign for system-level change, or – more likely – to offer some mixture of these? Whatever they see as their purpose(s), how fit are their structures, knowledge and methods for achieving them?
- There is the further question of the *validity of information*. Both virtual communities and the wider internet offer parents potentially rich sources of information. However, they can also offer parents *misinformation*, not to mention a good deal of ‘noise’ in the form of irrelevant information. How, then, is information selected and validated? Do individual parents have to do this for themselves – and if so, do they have the resources for such a challenging task? Or does someone do this on behalf of parents – and if so how well equipped are they for this task, and who has given them the authority to undertake it?
- Finally, there is the little-discussed question of *individual versus collective needs*. Parents are rightly concerned with the interests of their own children. The networks and groups they join may help them advocate for those interests and may well also advocate themselves for a particular group of parents and children – those with a particular disability, for instance. However, education systems operate on the basis of meeting collective needs in a context of more-or-less limited resources. Conflict between individual and collective needs is not inevitable – but neither is it uncommon. Even in the most generously resourced systems, a victory for one child or group of children may have to be bought at the expense of others. How, then, do parental support groups and networks, whether in the form of virtual communities or not, deal with this situation? How far do they – or should they – take into account the collective interest? And how do they engage with the education professionals who have to work on

behalf of a wider collective, and who frequently come into conflict with parental groups for precisely this reason?

These are major questions about a support landscape that is changing. Yet studies of support groups in action – and, particularly of ‘virtual communities’ – are not as common as one might hope. In this respect, Dr Lu’s innovative study has done a real favour to all those who run such communities, or who participate in them, or who work with them.

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