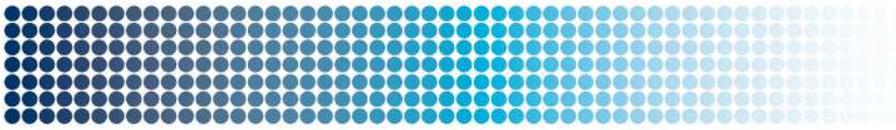# Motivating parents to be advocates: how parents can drive services forward for their children

Dr. Tim Moore

Plenary presentation at 5th Malaysian National
Early Childhood Intervention Conference
– *Passion Has No Parameters* –
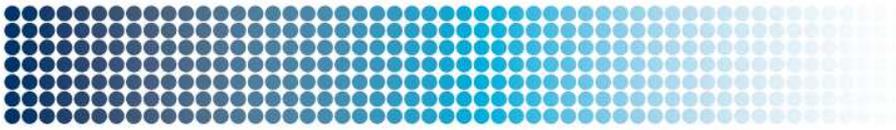
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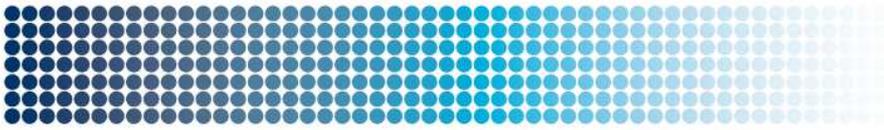Website: www.rch.org.au/ccch

ABSTRACT

Parental advocacy has been a powerful driving force in the development of early childhood intervention services in many countries. However, before addressing how to motivate parents to become advocates, there are two issues to be addressed. The first is whether parents can be reasonably expected to perform this role, given the demands upon them.

This paper begins by exploring the rationale for parental advocacy, as well as the risks involved. If we think it is reasonable and feasible for parents to act as advocates, the second issue to be addressed is what they should be advocating for. The answer to this question is not as obvious as it might seem, and needs to be understood in the context of evolving ideas about disabilities, developments in early childhood interventions services, and changes in the nature of the relationship between parents and professionals.

Three forms of parental advocacy are identified: parents can act as advocates for their child and family, as advocates for services, or as advocates for greater community understanding and acceptance of disability. With these forms of advocacy in mind, ways of helping parents decide what kind of advocacy role they might want to play, and how to support and motivate parents in these roles are described.

INTRODUCTION

Before addressing how to motivate parents to become advocates, there are two issues to be addressed. The first is whether parents can be reasonably expected to perform this role, given the demands upon them. If we think it is reasonable and feasible for parents to act as advocates, the second issue to be addressed is what they should be advocating for.

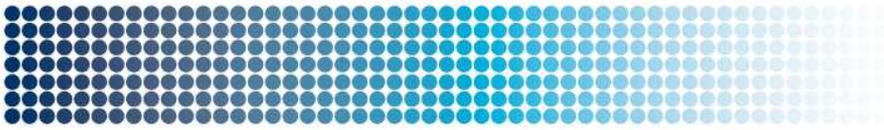## WHY SHOULD PARENTS BECOME ADVOCATES?

Is it reasonable to expect parents to become advocates? It could be argued that parents of young child with disabilities have enough challenges to face without also being expected to become advocates. Why should we ask them to do more?

There are several reasons why parents might benefit from developing advocacy skills.

Rationale for parental advocacy

- ***If parents are not assertive about their child and family needs, it is less likely that services will be provided and communities will be accommodating.*** Evidence to support this comes from a US study of parents of children with disabilities who considered advocacy to be a necessity (Wang et al., 2004). These parents viewed their advocacy activities as both a moral obligation and a means to improve services. While engaging in advocacy meant that parents had one more thing that they needed to add to an already busy schedule, they nevertheless felt it was essential for them to do. They perceived it as essential both for their child to access services and to ensure that services were improved so that their child could achieve appropriate outcomes.

- ***In the process of becoming advocates, parents develop new skills and competencies that make them better able to meet their child's needs.*** The same study by Wang et al. (2004) found that parents' advocacy efforts benefit families by helping them know their rights, know how to get resources and information, and know how to be assertive.

- ***In the process of advocating for their child, parents may overcome their own prejudices or fears of difference and disability.*** For a variety of reasons, people vary in their reactions to disabilities and differences in others. This is true of parents of children with disabilities, who initially may find themselves are battling with their own negative reactions and discomfort at the nature of their child's disabilities. This ambivalence is brilliantly documented by Andrew Solomon in *Far From the Tree* (2013).

  However, Solomon (2013) also describes how some families of children with disabilities and differences ultimately transcend the difficulties they face:

Some overcome external prejudice; others transcend their own apparent limitations. Parents may outgrow the bias they once had toward unfamiliar conditions; their children may transcend the idea that they are wholly defined by their singularities.

To illustrate this journey, Solomon quotes a mother's response to the question of whether she would cure her son's Down syndrome if she had a magic wand:

'If I could cure David, I would, for David. But I think that we've grown so much as a result of having to deal with this. We've had so much purpose. I'd never have believed twenty-three years ago when he was born that I could come to such a point, but I have. For David, I'd cure it in an instant; but for us, I wouldn't exchange these experiences for anything. They've made us who we are, and who we are is so much better than who we would have been otherwise.' (p. 217)

Other studies that have identified positive outcomes for families of children with developmental disabilities include Bayat (2007), Blacher and Baker (2007), Corman (2009), Dykens et al. (2005), and King et al. (2006).
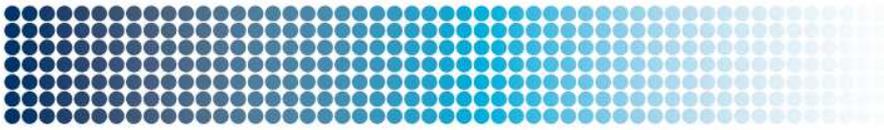
- ***Parental advocacy has been shown to be a powerful means of achieving change in attitudes and service provision***. Solomon (2013) describes the many factors that have led to changes in the ways that (Western) societies perceive and treat children and people with disabilities. In particular, he notes the importance of parental activism:

Change in both treatment and acceptance of people with Down's syndrome, however, continues to be driven by parents. By demanding that physicians treat their children's physical ailments as respectfully as they would those of non-disabled children, they have brought about an astonishing increase in life expectancy of people so diagnosed.

While these arguments for parental advocacy are powerful, we need to consider what risks might be involved in encouraging parents to become advocates.

What are the risks involved?

- ***There is a danger of adding to parental stress and anxiety.*** As Wang et al., 2004) have noted, advocacy can be a 'two-edged sword'. On the one hand, parents' advocacy efforts benefit families when they enhance their coping skills related to knowing their rights, knowing how to get resources and information, and knowing how to be assertive. On the other hand, advocacy can have a negative impact on families, harming their family's quality of life. It is especially challenging for families to engage in adversarial struggles and experience stress in advocating for services that they perceived should have been appropriately provided by professionals.

- ***Advocacy can distract parents from the task of understanding and adapting to their child's needs.*** Sometimes when children are diagnosed with a disability, parents become desperate to find the cure or the right treatment. In their quest, they often forget that their child is just a child and that the disability is only one aspect of the child. While there is nothing wrong in searching for ways to help children with disabilities learn and achieve more and live enriched lives, this search must be balanced with love and acceptance of individuals with disabilities for who they are and who they are to become (Falvey, 2005).

- ***Advocacy can be a way of avoiding the painful feelings associated with having a child with a disability.*** Some parents appear to launch themselves into advocacy work as a way of avoiding the pain of loss. (See Solomon, 2013).

With these thoughts in mind, we turn to the second issue that needs to be considered: what should parents advocate for?

WHAT SHOULD PARENTS ADVOCATE FOR?

The answer to this question might seem to be obvious: surely what parents should advocate for is more services for their children? But this is a case of being careful what you wish for – because it might just come true. It is important not to advocate for forms of service that you may have trouble changing later on, or that do not achieve the goals you have in mind for your child and family, or for children with disabilities in general.
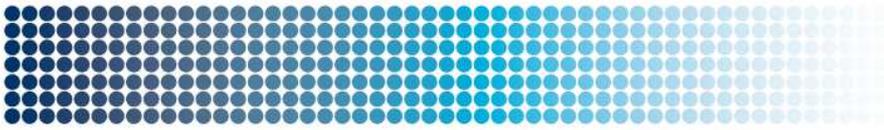
The issue of advocacy needs to be seen in the context of changes that are occurring in recognition of their rights of people with disabilities, in social perceptions of people with disabilities, and in services for people with disabilities.

Changing ideas about disability and disability services

Societal ideas about people with disabilities and how best to support them have changed in a number of ways over the past few decades.

- ***Recognition of the rights of people with disabilities*** (UNESCO, 2009; United Nations, 1989, 2006; World Health Organisation & UNICEF, 2012)

  The *Convention on the Rights of the Child* (United Nations, 1989) and the *Convention on the Rights of Persons with Disabilities* (United Nations, 2006) highlight how children with disabilities have the same rights as other children— for example to health care, nutrition, education, social inclusion and protection from violence, abuse and neglect. Ensuring access to appropriate support, such as early childhood intervention and education, can fulfil the rights of children with disabilities, promoting rich and fulfilling childhoods and preparing them for full and meaningful participation in adulthood (World Health Organisation & UNICEF, 2012). However, as UNESCO (2009) reports, throughout the world, children with disabilities experience stigma from birth and are more prone to exclusion, concealment, abandonment, institutionalization and abuse. Mortality rates among children with disabilities are 80% even in countries where under-
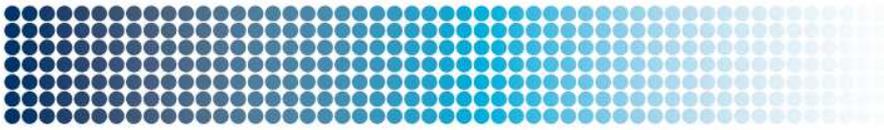
five mortality has declined below 20%. Strikingly, 98% of children with disabilities in developing countries do not attend school.

The Malaysian government has initiated some social policies initiatives aimed at support of persons with disabilities and their families. The Persons with Disabilities Act was passed in 2008. It was designed to reinforce the equality of persons with disabilities before the law. It specifically prohibits discrimination against a person simply on the grounds of disability in the areas of employment, education, housing, transportation, business activities, sports, recreational activities, access to public places, access to public facilities and services.

- ***Changing ideas about disability*** (Turnbull & Turnbull, 2002, 2003; World Health Organisation, 2001, 2002, 2007)

Over the past few decades, there has been paradigm shift in how disability is conceptualised (Turnbull & Turnbull, 2002, 2003; World Health Organisation, 2002, 2007). The old paradigm of disability holds that individuals with disabilities have deficits that need to be remedied in order for them to fit into the existing social environments and services. Thus, the onus is on people with disabilities to learn the skills and behaviours to fit in, rather than on society to adapt to accommodate to their needs (Turnbull & Turnbull, 2002).

The new paradigm of disability holds that a person has an impairment that becomes a disability as a result of the interaction between the individual and the natural, built, cultural, and social environments in which the person lives (Turnbull & Turnbull, 2002). Thus, a key point in the new paradigm is that people with disabilities do not need to wait until they develop a certain level of skill in order to participate inclusively in relationships and community settings, but rather they can do that from the outset as long as they have the appropriate level of supports which involves services, resources, and personal assistance to enhance the way that they develop, learn, and live (Turnbull & Turnbull, 2003). If we embed supports pervasively throughout all environments, people with disabilities and their families can live very different lives.

Old and new paradigms of disability: Evolutionary shifts in assumptions
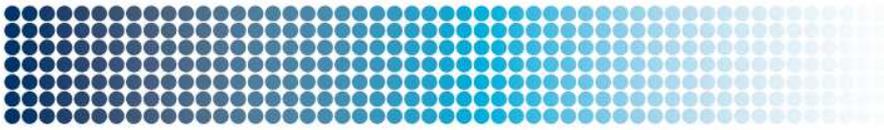(Turnbull & Turnbull, 2002)

Old paradigm	New paradigm
Disability is a deficit within a child resulting in functional impairments that invariably reduce their quality of life	A child has an impairment that does not become disabling if supports are available from partnerships across all environmental levels
The focus of services and funding is to provide segregated service programs that exclude children with disabilities from generic services and supports.	The focus of services and funding is on intensifying supports across all environmental levels so that children with disabilities and their families will experience inclusion and make meaningful contributions.
The focus is on "remediating" children's functional impairments so they will be less disabled and more able to "earn their way" into inclusion at all environmental levels	The focus is expanding partnerships to intensify supports across all environmental levels so that children with disabilities and their families can experience quality of life).

This new perspective is embodied in the World Health Organisation's model of disability, impairment and participation (World Health Organisation, 2001, 2002, 2007). The WHO's *International Classification of Functioning, Disability and Health: Children and Youth Version* (ICF-CY)(WHO, 2007) regards disability as neither purely biological nor social but instead the interaction between health conditions and environmental and personal factors. In this model, disability can occur at three levels:

- an impairment in body function or structure, such as a cataract which prevents the passage of light and sensing of form, shape, and size of visual stimuli;

- a limitation in activity, such as the inability to read or move around;

- a restriction in participation, such as exclusion from school.

Thus, an impairment only becomes disabling when the environment is not modified to allow the person to participate.

As well as changes in ideas about disabilities, there have been changes in ideas about early childhood intervention and the relationship between parents and professionals.

- *Changing ideas about early childhood intervention*

    Ideas and practices about how best to promote the development of young children with developmental disabilities have evolved steadily. The main change has been the move away from relying upon professionals to be the main agents of change in the child to recognising the paramount importance of the child's everyday environments and the role of parents and caregivers (Moore, 2012).

    This has led to changes in the relationship between early childhood intervention professionals and parents

- *Changing ideas about the relationship between parents and professionals* (Moore, 2012, 2014)
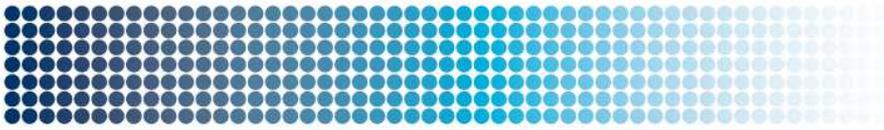
    We have learned that early childhood intervention is less effective when professionals act as the sole experts and make all the decisions about what to focus on and how to help the child. Parents make much better use of what professionals have to offer when they are engaged in a genuine partnership with them, and focus on the issues that are of greatest concern to them. Better outcomes are achieved when professional avoid trying to do things for families of children and disabilities and instead focus on doing things with them

    This shift in the nature of the relationship between parents and professionals is challenging for both parties, but is recognised as being necessary. As Amar (2008) has argued,

    > ' … to meet the needs of children with disability in Malaysia, we need to have a paradigm shift. Professionals and therapists need to change their perspective from service provision to training. There is a need to train the disabled and parents to look after their own rehabilitation (empowering them), to train CBR staff to run day to day service needs and to train (advise) government agencies and NGOs on the way forward in developing services. We require the will to relinquish "control" and distance ourselves from the "politics" of disability. We need instead to see children with disability and their family as partners and offer them care in a way which dignifies, best meets the needs of the person with disability, and takes into account his or her cultural and spiritual needs.

Conclusions regarding what parents should advocate for

- Parents should not advocate for services that will do things *to* them or *for* the child and family… but for services that will work *with* and *through* them to help them meet their child's needs

- Parents should not advocate for services that will seek to work directly with the child with little or no reference to parental needs or capabilities …but for services that seek to build on parental strengths and enhance their capacity to meet their children's needs

- Parents should not advocate for segregated disability services that, with the best of intentions, provide care and education separately from the other children … but for specialist services that are embedded in universal services and support the provision of inclusive services and social environments

We now turn to the question of forms of advocacy.

WHAT FORMS OF ADVOCACY ARE THERE?

Advocacy can take a number of different forms. The most basic (and important) form of advocacy is when parents act as advocates for their child and family. However, parents might also act as advocates for advocates for services, as advocates for greater community understanding and acceptance of disability, or as advocates for government policies.

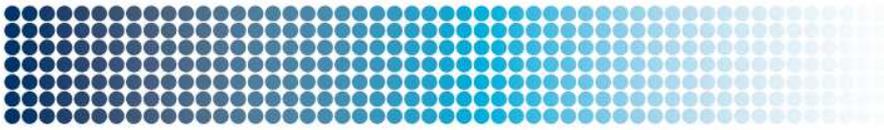- ***Parents as advocates for their child and family***

  Parent's prime responsibility is to their child and family, and they may need to become advocates on behalf of the child and family (including themselves) in order to get the support they need.

  Parents should expect and require from professionals that:

  – support is provided;
  – this takes the form of a genuine partnership;
  – the parent's main concerns be addressed;
  – the parents are helped to develop new confidence and skills in meeting their child's needs
  – the strategies chosen are consistent with their values and preferences; and
  – the needs of the whole family are considered

  One parent of two children with special needs (one with Asperger's syndrome and one with Attention Deficit Disorder), Jan Campito (2007) describes how when she first entered the world of special needs, she assumed the experts would tell her what was wrong, and how to help her children. Although she was an articulate, well-educated person, she became passive and trusting, only becoming active and assertive when she realised that no one was taking a lead role in getting appropriate help for her children. Since then, she has learnt to take an active role in advocating for her children, and helping meet their needs. From procuring evaluations, to understanding what the diagnoses mean, to selecting therapies and therapists, to following through on therapies at home and targeting needs to be addressed, to helping formulate IEPs, and to monitoring and intervening in their school settings, she has become a comprehensive advocate for her children with special needs.

  Another parent of a child with a disability, Amy Griffin (O'Hanlon & Griffin, 2004), describes advocacy at this level as changing the world one child, one family, one program at a time. Parents of children with disabilities can do this by providing parent-to-parent support to other families of newly diagnosed

children. Parents can also speak with other professionals and care providers about supporting families of children with special needs. Giving providers information about the joys and pains of raising a child with a disability helps them to become more sensitive when they work these families. Supporting parents as they work through the grieving process helps them approach community programs and ask, 'What do you need to help you accommodate my child with a disability?' We can change our communities by including families of children with disabilities in everyday activities.

- ***Parents as advocates for services***

  Apart from advocating for support for their own child and family, parents may also be part of efforts to advocate for the provision of services for all children with developmental disabilities in a particular district or region. These services can take the form of specialist professional early childhood intervention teams, as well as more general forms of family support (such as respite care). Parents may also advocate for access to mainstream services, such as early childhood programs or community facilities.

  Advocacy for services is not something a single parent would attempt on their own, but is best done in conjunction with other parents and/or professionals.

Early childhood intervention services in Malaysia

The First Early Intervention Centre in Malaysia was established in 1987. It was initiated by Malaysian Care, a non-governmental organization (NGO), with the help of Robert Deller, a child psychologist from Britain.
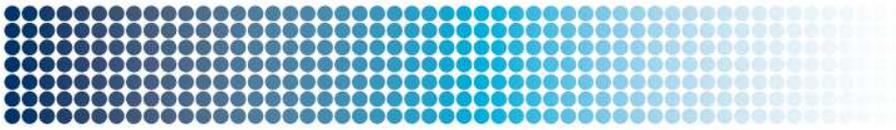
The Education Ministry's foray into early intervention services began in 2004 for children below six who have visual, hearing and learning impairments. The basic problems of running early intervention centres are lack of resources, trained staff and financial support from the Malaysian Government. The NGOs rely largely on donations and volunteers to keep the centres going. The long waiting list is not unusual as the number of special needs children continues to rise.

In 2003, primary education was made compulsory but the services for learning disabled students remain limited and fragmented.

According Amar (2008) services in many jurisdictions in Malaysia are fragmented, and provide little emotional support for parents. The result is low use of disability services and limited parental involvement in their child's program.

- ***Parents as advocates for greater community understanding and acceptance of disability***

  Although there have been efforts to enhance the status and support of persons with disabilities in Malaysia and their families, these measures have had limited impact on their daily lives (Clark et al., 2012). Promoting greater public understanding and acceptance of disability is an important role that parents of children with developmental disabilities can play.

There are a variety of ways in which parents can play a role in helping others gain a better understanding and acceptance of disability:

− They can talk to local services and business, and to community and faith groups, about the experience of raising a child with a disability, and how they can help

− They can also talk to professionals, helping them understand how parents of children with disabilities feel, and what forms of help are most acceptable

− Parents can also help people overcome their fears and prejudices about disabilities by finding straightforward ways of explaining their child's challenges and needs
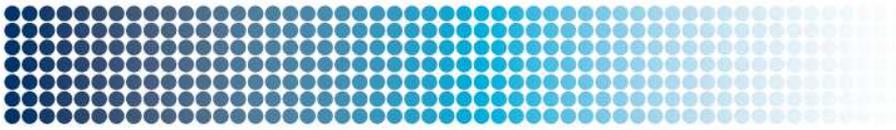
  Parents need to find ways of talking about their children's impairments and needs in ways that put other people at ease – managing other people's insensitivities to their child (Fullwood & Cronin, 1986).

- ***Parents as policy advocates***

This kind of advocacy seeks to change whole service systems through policies and funding. It is most likely to be effective when undertaken by a parent organisation representing the collective voice of many parents. It is also more likely to be effective if the parent organisation is partnering with representative professional organisations in making its case.

One US parent of a child with a disability, Liz O'Hanlon, describes this as a 'big-picture top-down approach to advocacy' (O'Hanlon & Griffin, 2004). The purpose of this brand of advocacy is to concentrate on systems change through systems infiltration. Parents and professionals form partnerships with system-level experts to provide a personal and professional point of view. This form of advocacy requires knowledge of parents' rights and rights of individuals with disabilities. This collaborative strategy helps professionals see policies and procedures from the parents' 'real-world' perspective.

Why is this type of advocacy so important? Big-picture advocacy can have a profound effect on policy development and implementation by providing system-level decision-makers with a family perspective. It can also benefit *many* people who have disabilities, rather than a single person or a small group of people.

Levels of advocacy

All these forms of advocacy can be carried out by individuals, groups or whole communities.

- ***Individual-level advocacy***

  Parents may act on their own, without support from or working with other parents. This is the most demanding form of advocacy, the one most likely to add to family stress.

- ***Group-level advocacy***

  Parents may support each other in their advocacy efforts – parent-to-parent support can be highly valuable for parents, especially when more experienced parents mentor those new to being advocates. The benefits of parent-to-parent support are well established, and guidelines for establishing informal or formal parent-to-parent programs have been developed (eg. Santelli, 2000).
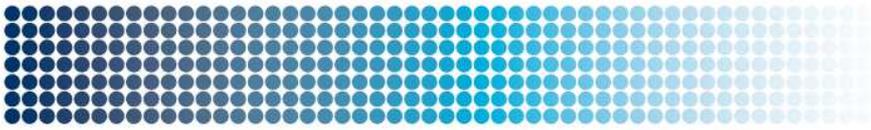
  Parent disability organisations can also play a valuable role in all forms of advocacy – advocating on behalf of individuals, services, community understanding and policy development. An example is the Association for Children with a Disability, a national support group in Australia (www.acd.org.au) – this is a not-for-profit information, support and advocacy organisation run by parents of children with a disability.

  According to Clark et al. (2012), some groups have formed to advocate for development of services for specific disabilities in Malaysia, but there is no evidence of the establishment of parent associations that allow for mutual support and joint action in advocating for their needs and the needs of their children.

- ***Community-level advocacy***

  A whole-of-community approach to advocacy seeks to engage a wide range of people in creating more inclusive services and communities.

  According to Clark and colleagues (2012), the model adopted in Malaysia for enhancing the quality of life for people with disabilities is the World Health Organisation's *community-based rehabilitation* (CBR) approach. This is a strategy for the rehabilitation, equalisation of opportunities and social inclusion of all people with disabilities in communities. The CBR approach can be implemented in communities where services for persons with a disability are extremely limited or entirely absent and promote the coordinated use of resources at a realistic and sustainable level. CBR rejects the institutional care model and supports the maintenance of persons with disabilities within their homes and communities. CBR is implemented through the combined efforts of people with disabilities themselves, their families, organisations and

communities, and the relevant governmental and non-governmental health, education, vocational, social and other services (Thomas, 2010).

The ultimate goal of the CBR approach is community-based inclusive development (CBID) (Asia-Pacific Development Centre on Disability, 2010; Thomas, 2010). The aim of this strategy is to ensure that persons with disabilities are fully included in all aspects of community life and have full access to all facilities and services. A twin track approach is often used: focusing on society to remove barriers that exclude persons with disabilities; and focusing on persons with disabilities to build their capacity and supporting them to promote their inclusion. This is a process which allows community members including persons with disabilities to express their needs and to decide their own future with a view to their empowerment, ownership and sustainability (Asia-Pacific Development Centre on Disability, 2010).

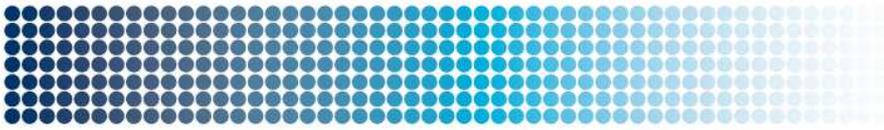## HOW CAN WE MOTIVATE AND SUPPORT PARENTS TO BE ADVOCATES?

Helping parents become effective advocates involves both direct and indirect approaches. Paradoxically, it is the indirect strategies that can be the most powerful.

Here are some suggestions drawn from the following resources: Association for Children with a Disability (2012), Campito (2007), Fullwood & Cronin (1986), Law et al. (2003a, 2003b), Wright & Jaffe (2014), and various National Centre for Learning Disabilities (www.ncld.org) publications.

- ***Build parent's confidence and competence by engaging them as partners in meeting their child and family needs.*** This is the single most powerful way of helping parents become effective advocates. To advocate for their children, parents need to learn to be able to meet professionals as equals, and they can learn how to do this through empowering relationships with professionals.

- ***Knowledge is power: give parents the information that will help them become effective decision-makers.*** This includes knowledge about developmental disabilities, ways of meeting the needs of children with such disabilities, as well as knowledge about services and the service system.

Professionals can also help parents develop the specific skills needed to become effective advocates:

- ***Be clear with parents that one of the explicit goals of your service is to build their capacity to become effective advocates for their child and family*** – but also make it clear that they will always be in control of how much of this role they take on and when

- ***Help parents understand the services and service systems they must work with*** - find out who is responsible for the decision and action they are seeking.

- ***Link parents with other parents, parent networks or support groups.***

- ***Help parents find ways of explaining their child's behaviours and difficulties in terms that will defuse other people's fears and prejudices.***
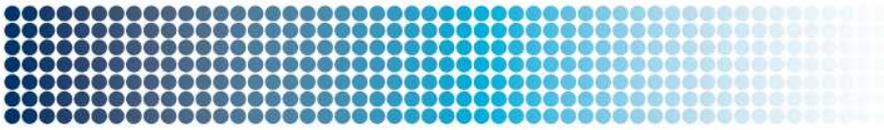
One particular strategy is to help parents prepare for meetings with professionals and services:

- ***Help parents understand what the meeting will involve*** - who will be there, what the aim is

- ***Help parents develop a clear idea about the outcome they are seeking*** – help them prioritise their concerns in case there isn't time to address them all at once.

- ***Help parents rehearse how they will explain their needs, and how to respond to issues that others might raise*** – while they need not always expect conflict, it helps to have a positive strategy prepared in case there is.

- ***Discuss (and model) the kinds of personal skills and behaviours that promote good outcomes*** - listening to other points of view, staying calm, focusing on getting a positive outcome for their child, and being prepared to negotiate and accept a compromise if an alternative solution is just as effective.

- ***Being organised helps*** – keeping accurate records about specific issues, and follow up verbal agreements in writing if needed.

CONCLUSIONS

- ***Should parents become advocates?*** Parents know their child and family best, and, so that others understand what they know, all parents need become advocates on behalf of the child and family (including themselves). However, we need to be careful to support parents in this role, to minimise the stress and maximise the chance of being successful. There will be some parents who are sufficiently well resources and organised who are able to undertake other forms of advocacy – at service levels, community levels, and even policy levels.

- ***What should parents advocate for?*** This is a case of being careful what you wish for. Not just any service will do. What parents should advocate for are services that will work with and through parents, that will build on parental strengths and enhance their capacity to meet their children's needs, and that support the provision of inclusive services and social environments.

- ***What form of advocacy should parents adopt?*** That's partly a matter of personal preference, and partly a matter of choice and circumstances. Whatever their choice, they will be changed in the process:

  > 'Whether … parents choose to work at the national level to change laws, the state level to change systems, the local level to change programs, or the individual level to change families and attitudes, each

parent's journey is personal and life-changing.' (O'Hanlon & Griffin, 2004, p. 27)

- ***How can parents be best supported in their advocacy efforts?*** The most effective way of helping parents become effective advocates is by engaging them in meaningful partnerships through which they can grow in confidence and capabilities.

RESOURCES

National Centre for Learning Disabilities. **How Parents Can Be Advocates for Their Children.** New York: National Centre for Learning Disabilities.
http://www.ncld.org/parents-child-disabilities/ld-rights/how-parents-can-be-advocates-for-their-children

National Centre for Learning Disabilities. **Advocating for Your Pre-School Child.** New York: National Centre for Learning Disabilities.
http://ncld.org/parents-child-disabilities/ld-rights/advocating-for-your-pre-school-child

National Centre for Learning Disabilities. **Essential Skills for Becoming Your Child's Advocate.** New York: National Centre for Learning Disabilities.
http://ncld.org/parents-child-disabilities/ld-rights/essential-skills-for-becoming-your-childs-advocate

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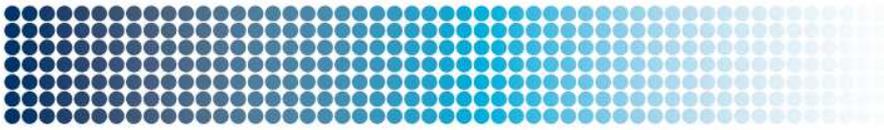http://apcdfoundation.org/?q=system/files/cbid.pdf

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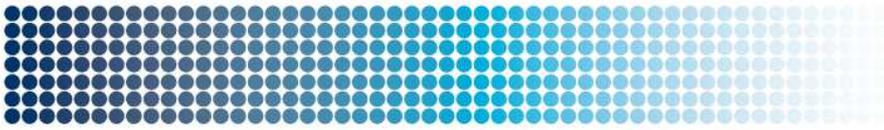
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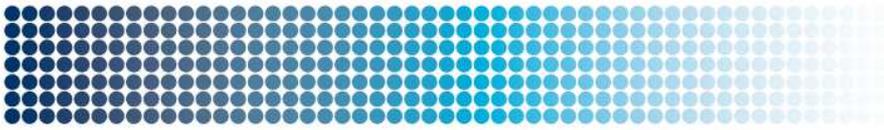
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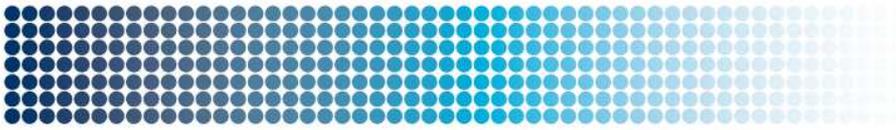http://www.who.int/classifications/icf/en/

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