



MOTIVATING PARENTS TO BE ADVOCATES: HOW PARENTS CAN DRIVE SERVICES FORWARD FOR THEIR CHILDREN

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OUTLINE



- Why should parents become advocates?
- What should parents advocate for?
- What does advocacy look like?
- How can we motivate and support parents to become effective advocates?
- Conclusions

WHY SHOULD PARENTS BECOME ADVOCATES?



WHY SHOULD PARENTS BECOME ADVOCATES?



- 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
- *In the process of becoming advocates, parents develop new skills and competencies that make them better able to meet their child's needs*
- In the process of advocating for their child, parents may overcome their own prejudices or fears of difference and disability
- *Parental advocacy has been shown to be a powerful means of achieving change in attitudes and service provision*

WHAT ARE THE RISKS INVOLVED?



- There is a danger of adding to parental stress and anxiety - advocacy can be a 'double-edged sword':
 - *On the one hand, parents' advocacy efforts benefit families when they enhance their coping skills helping them know their rights, know how to get resources and information, and know how to be assertive*
 - *On the other hand, advocacy can have a negative impact on families, especially when it involves arguments and struggles*
- *Advocacy can distract parents from the task of understanding and adapting to their child's needs*
- *Advocacy can be a way of avoiding the painful feelings associated with having a child with a disability*

WHAT SHOULD PARENTS ADVOCATE FOR?



WHAT SHOULD PARENTS ADVOCATE FOR?



- It is not just an issue of advocating for *more* services: we need to be careful *what* services we ask for
- 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.

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CHANGING IDEAS ABOUT DISABILITIES AND DISABILITY SERVICES



Recognition of the rights of people with disabilities

- 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
- In Malaysia, the *Disabled Persons Act* (2007) 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.

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CHANGING IDEAS ABOUT DISABILITIES



World Health Organisation (2001). *International Classification of Functioning, Disability and Health*. Geneva, Switzerland: WHO.



World Health Organisation (2007). *International Classification of Functioning, Disability and Health - Children and Youth Version (ICF-CY)*. Geneva, Switzerland: WHO

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CHANGING IDEAS ABOUT DISABILITIES (cont)



The *International Classification of Functioning, Disability and Health: Children and Youth Version* (ICF-CY) regards **disability** as neither purely biological nor social but instead the interaction between health conditions and environmental and personal factors.

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.

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CHANGING IDEAS ABOUT DISABILITIES (cont)

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

Turnbull & Turnbull, 2002

CHANGING IDEAS ABOUT DISABILITIES AND DISABILITY SERVICES (cont)



Changing ideas about early childhood intervention

- Ideas and practices about how best to promote the development of young children with developmental disabilities continue to evolve and change
- The main change is 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
- New strategies have been developed to help parents and caregivers provide young children with developmental disabilities with experiences and opportunities that help them participate meaningfully in everyday activities
- This has led to changes in the relationship between early childhood intervention professionals and parents

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CHANGING IDEAS ABOUT DISABILITIES AND DISABILITY SERVICES (cont)



Changing ideas about the relationship between parents and professionals

- 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 professionals 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

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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....

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: WHAT SHOULD PARENTS ADVOCATE FOR?



- NOT for services that will do things *to or for* the child and family...
BUT for services that will work *with* and *through* them to help them meet their child's needs
- NOT 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
- NOT 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

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WHAT DOES ADVOCACY LOOK LIKE?



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FORMS AND AGENTS OF ADVOCACY



Forms of advocacy

- Parents as advocates for their child and family
- Parents as advocates for services
- Parents as advocates for greater community understanding and acceptance of disability
- Parents as advocates for government policies

Agents of advocacy

- Individuals
- Groups
- Communities

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FORMS OF ADVOCACY



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.

What might parents need to expect and require from professionals?

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

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FORMS OF ADVOCACY (cont)



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
- This kind of advocacy would usually be done in conjunction with other parents and/or professionals

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FORMS OF ADVOCACY (cont)



Parents as advocates for greater community understanding and acceptance of disability

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

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FORMS OF ADVOCACY (cont)



Parents as policy advocates

- This kind of advocacy seeks to change whole service systems through policies and funding
- This kind of advocacy 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
- This form of advocacy can have a profound effect on policy development and implementation by providing system-level decision-makers with a family perspective.

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AGENTS 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

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LEVELS OF ADVOCACY (cont)



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 an not-for-profit information, support and advocacy organisation run by parents of children with a disability

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LEVELS OF ADVOCACY (cont)



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
- 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
- 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

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Asia-Pacific Development Centre on Disability (2010). **Community-based Inclusive Development: Principles and Practice.** Bangkok, Thailand: Asia-Pacific Development Center on Disability.

The goal of CBR is **community-based inclusive development**

The aim 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.

The 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.

It 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.



HOW CAN WE MOTIVATE AND SUPPORT PARENTS TO BECOME ADVOCATES?

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STATEGIES FOR MOTIVATING AND SUPPORTING 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:

- **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.

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STATEGIES FOR MOTIVATING AND SUPPORTING PARENTS TO BE ADVOCATES (cont)



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**
- **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**

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STATEGIES FOR MOTIVATING AND SUPPORTING PARENTS TO BE ADVOCATES (cont)



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

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STATEGIES FOR MOTIVATING AND SUPPORTING PARENTS TO BE ADVOCATES (cont)



- **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.

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CONCLUSIONS

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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)
- Some parents may also be 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's needed 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

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CONCLUSIONS (cont)

What form of advocacy should parents adopt?

- This is partly a matter of personal preference, and partly a matter of resources and circumstances
- Whatever their choice, parents are likely to 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)

How can parents best be 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

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