

The Association for Successful Parenting

KEYNOTE ADDRESS
David McConnell, University of Alberta

2010



**Enhancing the lives of families headed
by parents with intellectual disabilities**

The Association for Successful Parenting
Conference, Denver, Colorado

www.fdsa.ca

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Earlier in my career I would attend conferences and there would be maybe one or two papers on parents and parenting with learning difficulties - and there would be even less people in the audience. If you were lucky the other speaker would stay for your paper. Times have changed. At many of those



same conferences it is not unusual for there to be 20 or more papers on the topic -- and often standing room only. Next month in Rome, the European chapter of IASSID is holding a conference, and there will again be something like 20 papers on parents and parenting with learning difficulties. And of course here we have a conference dedicated to the topic.

Times have changed. Earlier in my career, practitioners would often express to me their sense of isolation... Now, there are a number of connection points (opportunities for self advocates, practitioners and researchers to share their ideas, to share their experiences and to have them normalised). TASP is one of those connection points. Another is the Australian Healthy Start network – with multi-disciplinary and cross-sector hubs in communities across the country. And at the international level there is now a dedicated group of researchers and practitioners comprising the IASSID SIRG on Parents and Parenting. The SIRG is responsible for the latest book on the topic, titled “Parents with intellectual disabilities: past, present and futures”, which includes contributions from 8 or 9 different countries.

I want to take this opportunity to encourage you all to join this international network – so that researchers and practitioners all around the world can learn about the exciting things you are doing – and similarly, so you can learn about the exciting things that are happening elsewhere –in Sweden, the Netherlands, England, Australia and elsewhere. At the back of the room you will find a flyer with instructions on how to become a member.

Times have changed. I get the feeling that we are on the verge of ‘critical mass.’ There is nothing more powerful than an idea whose time has –and maybe the time has come for the idea of genuinely supporting parents with learning difficulties and their children. There are a number of reasons for my optimism. One is the creation of those networks or connection points I have just mentioned – TASP, HealthyStart, IASSID SIRG.

Another reason is the now burgeoning literature on parents and parenting with learning difficulties. Research in the field goes back for over a century – but most of the research has been published in the last 10 to 15 years. Summaries of virtually every article published can be found on the Healthy Start website (www.healthystart.net.au).



Another reason is the recent and landmark UN Convention on the rights of persons with disabilities. The convention affirms the right of persons with disabilities, including persons with learning difficulties to “marry and found a family”... And under Article 23, states parties are obliged to take “effective action” to eliminate

discrimination, and to render “appropriate assistance” to parents with disabilities in the performance of their child-rearing responsibilities.

And yet another reason for my optimism is the establishment of the Healthy Start initiative in Australia. Healthy Start is the first government funded national strategy to build systems capacity to support parents with learning difficulties and their children. It sets a precedent. My hope is that other nations may follow suit.

Taken together – I cannot help but feel, as one American evangelist put it; **“It is Friday, but Sunday is coming”**.

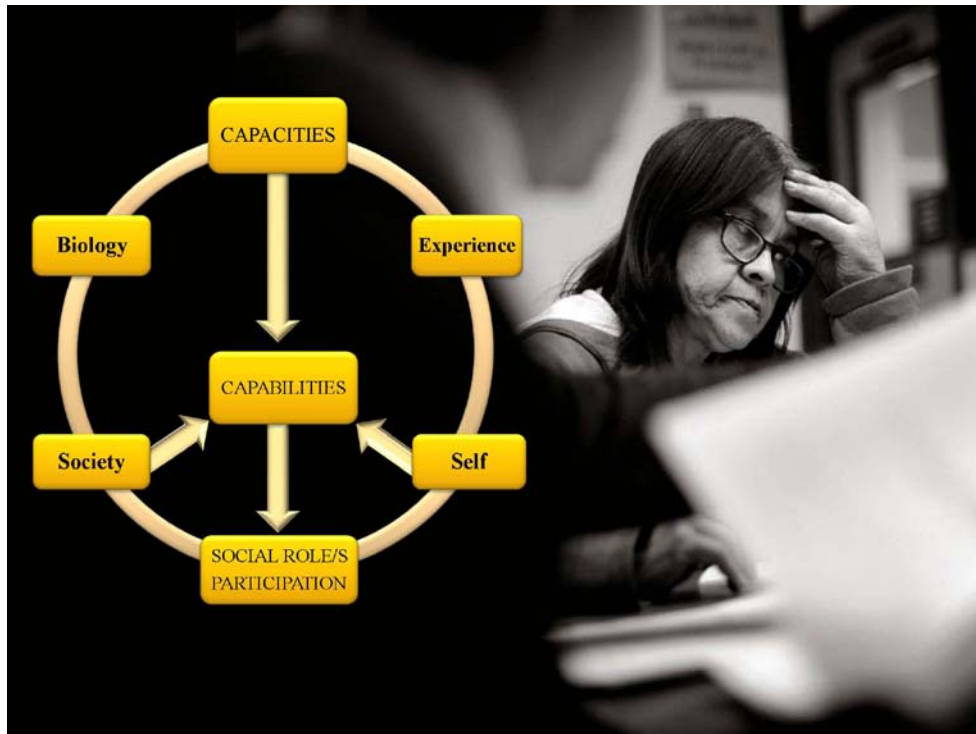
Today I want to talk about ideas. Ideas are powerful. Ideas are the engine that drives the way we think and live. Ideas have the power to transform our interactions with, and subsequently the lives of parents with learning difficulties and their children. And ideas are hard to change: our minds are very good at filtering out information that is inconsistent with our existing ideas and beliefs. Unfortunately this means that if we expect parents with learning difficulties to fail (and all too often we do), our minds look for any evidence to confirm our expectations and often look past any evidence to the contrary.

I thought hard about this presentation. I was tempted to take this opportunity to tell you about some exciting new programs and resources that we have been developed for parents with learning difficulties, programs like “the Supported Learning Program”. The SLP is a group based program designed to strengthen the social relationships of mothers with learning difficulties, promote their participation in community life, and in turn, improve their wellbeing and the wellbeing of their children. In an Australian trial this program showed tremendous promise... by the end of the program many of the moms were empowered, they reported lower levels of stress anxiety and depression, and many had joined interest groups, started volunteering, and enrolled in courses and so on.

And I would also like to tell you about a new resource called “Healthy Start for me and my baby” – which is designed to promote the participation of pregnant women with learning difficulties in their pregnancy care. Our recent Australian birth cohort study found that women with LD are more likely than their peers to experience pregnancy difficulties – including preeclampsia, stress and depression. And their children are more likely to be born preterm, have low birth weights, and to be admitted to neonatal intensive care. Improving the health of pregnant women with learning difficulties and improving the intra-uterine environment for their developing children is essential to enhancing parent-child wellbeing. Addressing this must be a priority for us going into the future.

But I am not going to talk anymore about these new and exciting programs today. I am convinced that the positive change we want to see in the world—positive change in the lives of persons and parents with learning difficulties and their children—begins with ideas. My aim then is to encourage all of us to go away and think deeply about the ideas that drive our practice, and the ideas that impact the lives of parents with learning difficulties and their children. Most importantly, I hope we will go away thinking about the relationship between the two! That is, how certain ideas impact families headed by parents with learning difficulties by way of, (or through) us!

Before I move on - I want to acknowledge here that the photos that you will see come from a Denver Post multi-media project on poverty here in Colorado. Although the families shown are not families headed by parents with learning difficulties – at least not that I am aware of – poverty is a fact of life for many of the families we work with – and an issue that has been neglected...*I don't know if you have seen our report on child maltreatment investigations in Canada... We found that parents with learning difficulties who were investigated for child maltreatment (10%) are more socioeconomically disadvantaged than other parents who are investigated for child maltreatment – and most of those other parents were dealing with poverty on some level!*



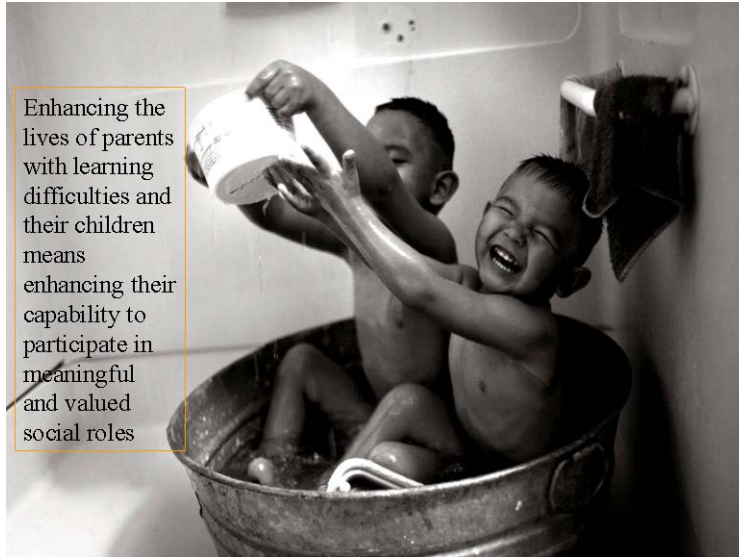
Dialectical model of human development and social integration

1. Dialectical model of human development and social integration

The ideas I would like to discuss today are depicted in this model. This model is my attempt to bring together micro and macro perspectives – that is to integrate biological-psychological perspectives (which focus on the individual) and social-cultural perspectives (concerned with the influence of society and culture) on human development and social integration. I think we need both if we are to advance the rights and enhance the lives of families headed by parents with learning difficulties *and their children*.

I also want to note here that it was not my intention to create a peace symbol – it just turned out that way. I will define terms in just a moment – but first let me summarise a few of the central ideas.

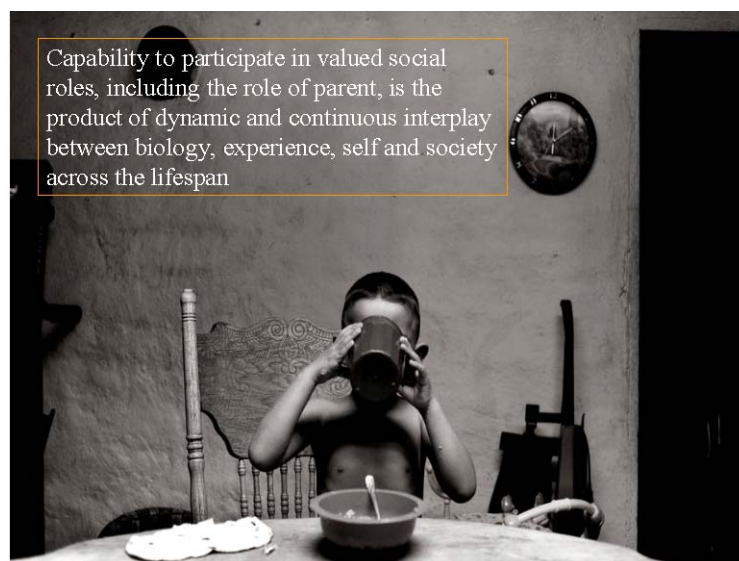
The first idea is that enhancing the lives of parents with learning difficulties and their children means enhancing their CAPABILITY to participate in meaningful and valued SOCIAL ROLES and relationships.



Enhancing the lives of parents with learning difficulties and their children means enhancing their capability to participate in meaningful and valued social roles

Participation in social roles connects us to society – and research shows that being connected to others is vital to our health and wellbeing. For example, participating in meaningful and valued social roles promotes sense of identity and belonging, as well as purpose and self-worth.

The second idea is that capability to participate in valued social roles (including but not limited to the role of parent) is the product of dynamic and continuous inter-play between biology, experience, self and society across the lifespan (and even across multiple generations).

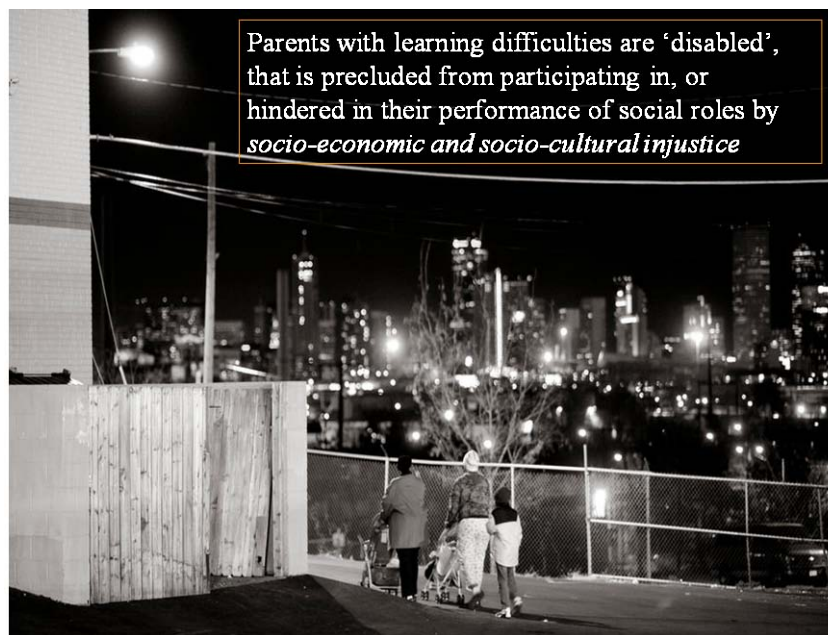


Capability to participate in valued social roles, including the role of parent, is the product of dynamic and continuous interplay between biology, experience, self and society across the lifespan

The subtext here is that the determinants of human capabilities are many and complex: we can focus too much on parental learning difficulties per se.

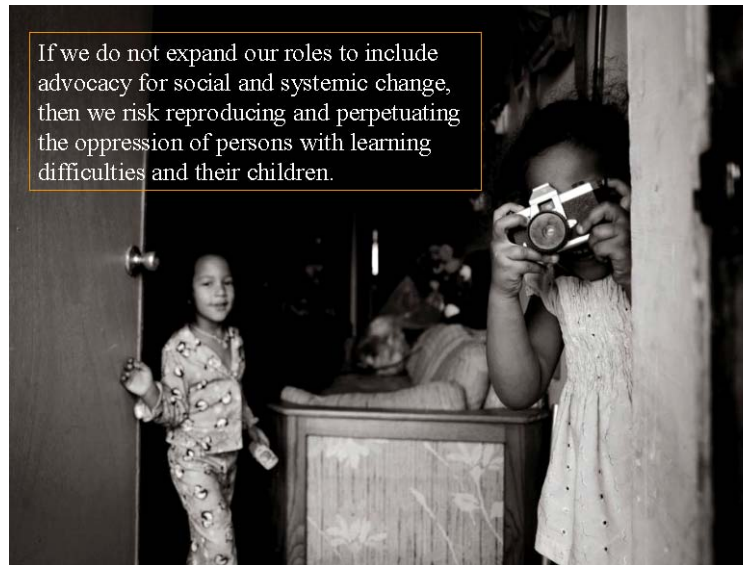
The third idea is that parents with learning difficulties are ‘disabled’, that is precluded from participating in, or hindered in the performance of valued social roles (including but not limited to the parenting role) by socio-economic and socio-cultural forms of injustice (put simply, by poverty and prejudice).

The solution involves ‘redistribution’ – or more specifically strategies to ensure that families headed by parents with learning difficulties are not denied an adequate material standard of living, including strategies that will promote access for parents with learning difficulties to meaningful, income generating employment.



And the solution involves ‘recognition’ – that is recognition that parents with learning difficulties are just the same, only different. Specifically, recognition of the ways in which parents with learning difficulties are in many respects just like other parents (e.g. for example, all parents need support!), and at the same time, we have to recognise that parents with learning difficulties have some unique support and learning needs, and in turn, we need to take the necessary steps to ensure that human services are accessible and able to accommodate these ‘differences’.

The fourth idea is more provocative – that is, if we do not expand our roles to include advocacy for social and systemic change, then we may reproduce and perpetuate the oppression of persons with learning difficulties – and their children. Coming back now to the model – let me define some of these terms.



What are 'roles'? You can find many definitions of 'role' in the literature. The one I like best is perhaps the simplest: ROLES ARE CONCEPTS THAT CAN BE PLAYED, like mother, child, doctor, fireman, social worker, friend, sister, son, volunteer, student, neighbour, athlete, rock-star, and 'client'.

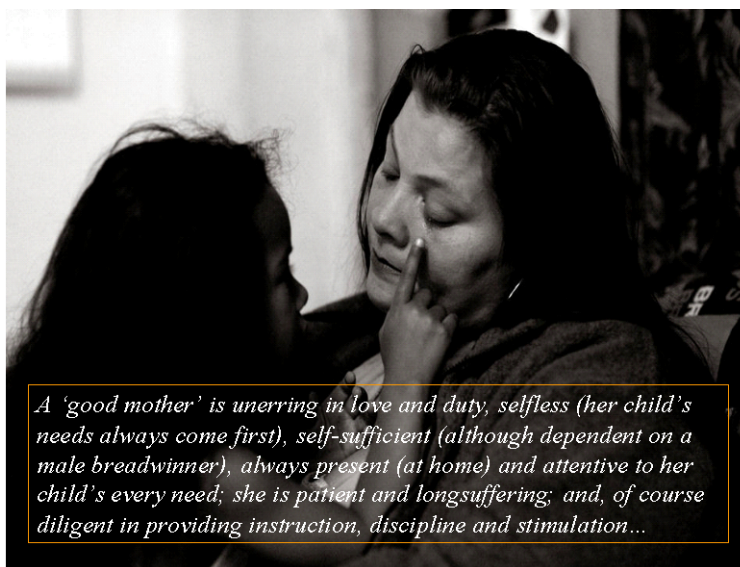


What makes a role 'social'? Roles are social for a number of reasons.

1. One is that roles link individuals to society. To put this a little differently, ROLES IDENTIFY WAYS THAT PEOPLE BELONG TO EACH OTHER.
2. Another reason why roles are social is that they come with scripts – or generalised expectations (that is expectations shared by members of any given society and culture) about how a role should be played. *There is, for example, a social script for the role of mother. This script defines the role of mother by specifying certain expectations of how a mother should behave. The key point here is that roles are not simply what people do, but ideas about ways of acting that guide role performance and enable us to interpret others' actions as constituting role performances.*
3. A third reason why roles are social is that they are not necessarily chosen by us: *we may be cast in certain roles.*

Historically, persons with learning difficulties have been cast in devalued social roles, including the role of 'fool', 'holy innocent', 'the eternal child', and of course the role of client. The script for these social roles requires persons with learning difficulties to be subordinate, passive and dependent, to defer to the judgement and authority of others, and to comply with their 'direction'.

If we juxtapose what we expect of persons with learning difficulties with what

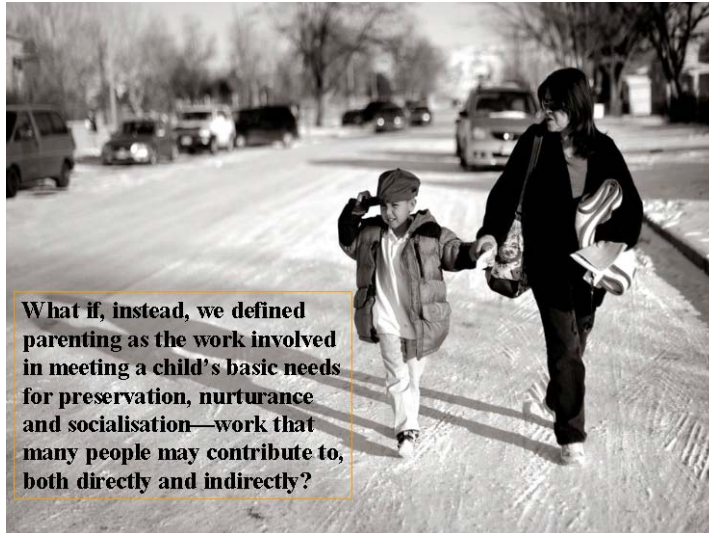


we expect of mothers or parents in our society, then it is easy to understand why so many persons with learning difficulties run into opposition when they become parents. Consider what we expect of mothers – or at least what was expected of mothers until quite recently –

A 'good mother' is unerring in love and duty; selfless (her child's needs always come first), and self-sufficient (although dependent on a male breadwinner); always present (at home) and attentive to her child's every need; she is patient and long suffering; and, of course diligent in providing instruction, discipline and stimulation.

The social expectations and norms for mothers and mothering are changing – the 1950's vision does not quite have the same power over us... Since the early seventies the participation of women and mothers in the workforce has grown exponentially. One reason is that many women have rejected the expectation that they should forego careers, and should be wholly and solely invested in child-rearing. [Similarly, an increasing number of men are rejecting the idea that their role in caring for their children is secondary or optional]. Another reason is that many women have no real option: many families depend on two incomes. The dual income family is now more common than the traditional female carer-male breadwinner family. As a result many families are 'outsourcing' child care: some employ nannies, others use day homes or formal daycare facilities. The point is that in modern families, there are potentially many involved in raising the children.

An observation I would like to make here is that despite the fact that the script for the role of mother and parent is being re-written – mothers and parents with learning difficulties are still being evaluated in terms of how well they perform the role of mother or parent as this was scripted in the 1950's. I have heard *child protection agencies, time and time again argue that because a mother was receiving X number of hours of assistance per day or per week, that others were really raising her children.* And I have seen courts, *time and time again apply a standard which says that parents must be able to 'stand alone'.* There is a double standard here: It is OK for dual income families to rely on outside support, but it is not OK for parents with learning difficulties.



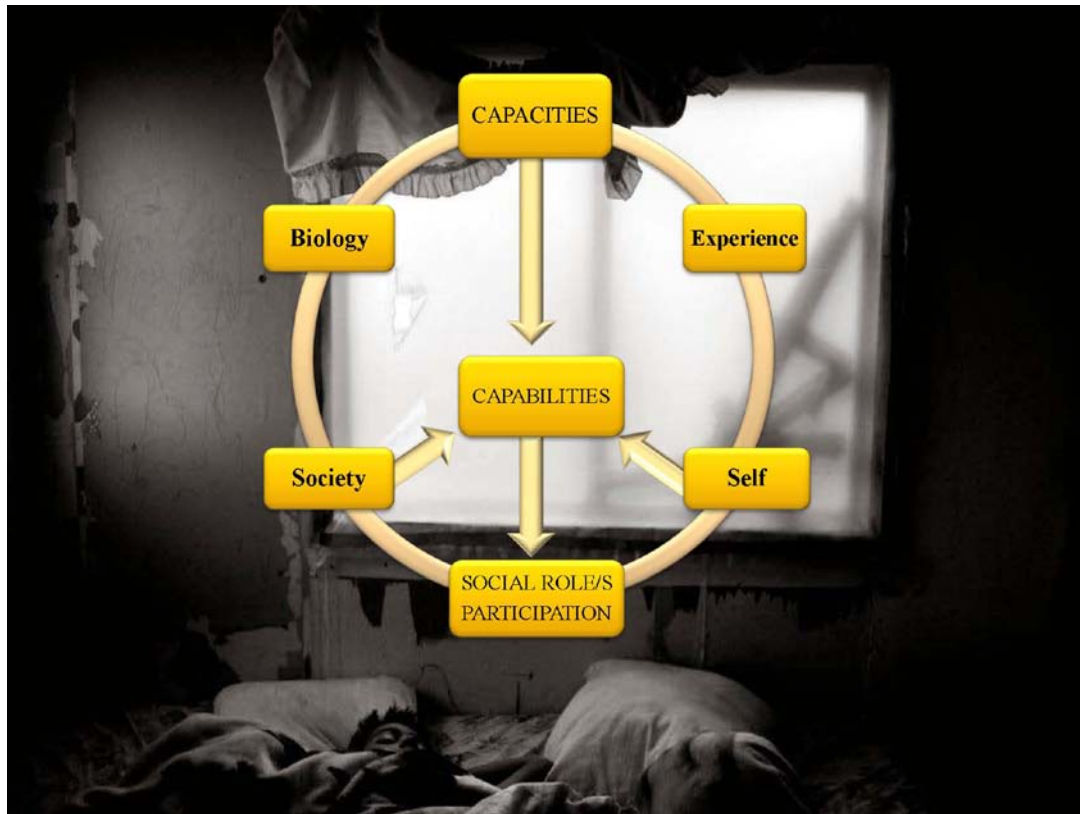
What if, instead, we defined parenting as the work involved in meeting a child's basic needs for preservation, nurturance and socialisation—work that many people may contribute to, both directly and indirectly?

The 1950's script is oppressive for all women. And empirically daft. No parent stands alone. We need to stop thinking of parenting in such restrictive terms – that is in terms of what parents do in raising their children. What if, instead, we started by thinking about what children need? What if we

defined parenting as the work involved in meeting a child's basic needs for preservation, nurturance and socialisation – *work that many people may contribute to*, both directly and indirectly, ... {not just mum, but dad too, not just mom and dad, but siblings and grandparents too, not just family members, but family friends and neighbours too; not just family, friends and neighbours, but coaches, teachers, and child care providers too; and not just family, friends, neighbours, coaches, teachers, child care providers, but 'town planners' too... As the adage goes - "*It takes a village...*".

Going back to the model – we can see that capability to participate in social roles – depends in part on social expectations -- or the social 'idea' of how that role should be performed. The implication is that if our idea of parenting changes, then how we assess capability to participate in the parenting role must change too. If we accept the idea that parenting is a social rather than a solo activity then our assessments of parenting capability would look at how a child's needs are being met within their broad social network and community. We would have to take into consideration the shared responsibility and contributions of the many to meeting the child's needs. If we accept the idea that parenting is a social rather than a social activity, then we may think a little more broadly and creatively about how we ensure that children's needs are met. Parent education is important, of course. But other – direct to the child – supports may be beneficial too – like quality childcare, Big Brother/Big Sister or Aunties and Uncles, or participation in Scouts or other youth group activities.

BIOLOGY, EXPERIENCE, SELF AND SOCIETY

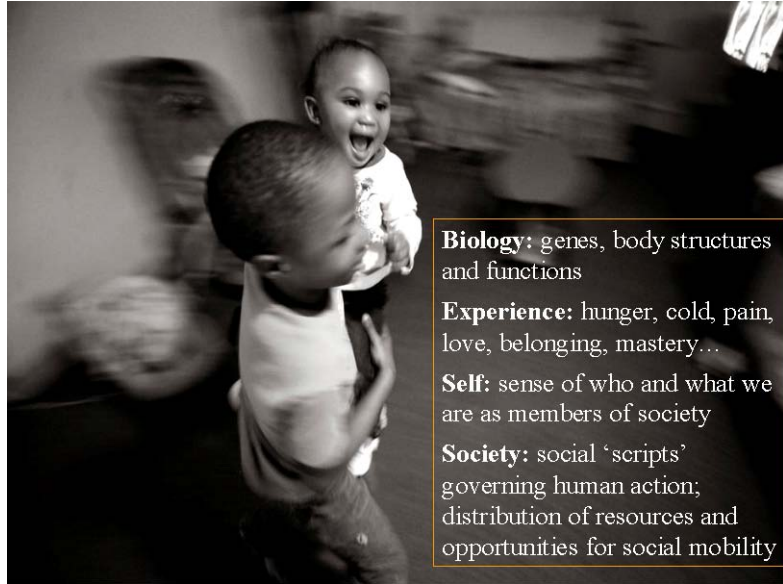


Around the outside of the circle you can see the concepts of biology, experience, self and society. *They are connected in this way because they are inextricably linked... They are 'causally linked'... but I would go so far as to say that they are aspects of one indivisible whole (i.e. they mutually constitute each other), which is different from merely saying that they are causally linked.*

BIOLOGY here refers to our genetic makeup, our body structures and functions (including cognitive, neuromuscular, sensory, cardiovascular, digestive, etc).

EXPERIENCE, well I am sure there are lots of ways to think about and classify human experience. We could for example draw a distinction between experiences of our own bodies and the material world that we inhabit (so experiences of hunger, cold, sleep deprivation, pain and so on) and experiences of our selves as actors in the social world in which we live (which might include experiences of love and belonging, mastery and failure, and so on).

SOCIETY has cultural and material dimensions. It includes (but is not limited to) (1) ideas about people (*what kind of people there are*), ideas about what roles are suitable for different kinds of people (for example, what roles are suitable for women), and social scripts/expectations for the performance of social roles...

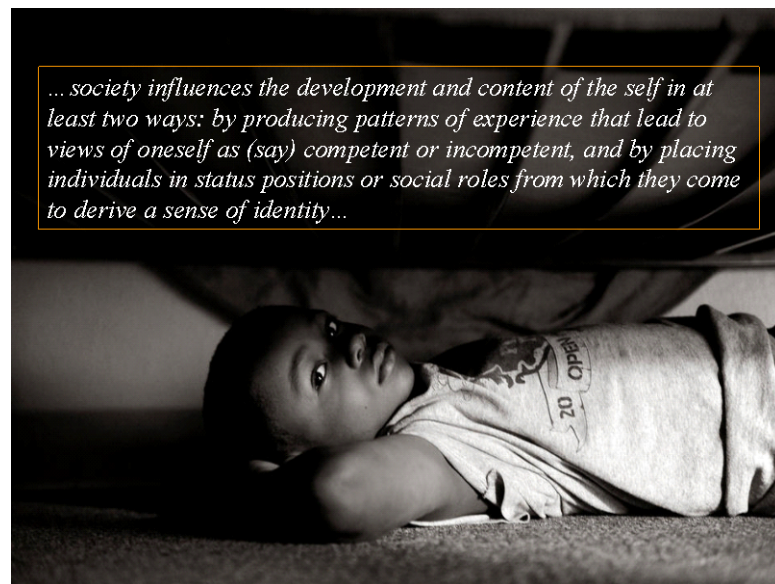


Biology: genes, body structures and functions
Experience: hunger, cold, pain, love, belonging, mastery...
Self: sense of who and what we are as members of society
Society: social 'scripts' governing human action; distribution of resources and opportunities for social mobility

And bound up with this cultural dimension is (2) the way in which material resources and opportunities are organised and distributed, including income, housing, green spaces, playgrounds, education, health care, employment, supports and services and so on.

Finally, the **SELF** includes our beliefs, values and goals: It is the entity a person envisions when he/she thinks about who they are. It is the SENSE OF WHO AND WHAT WE ARE AS MEMBERS OF SOCIETY.

Internalisation of social roles



... society influences the development and content of the self in at least two ways: by producing patterns of experience that lead to views of oneself as (say) competent or incompetent, and by placing individuals in status positions or social roles from which they come to derive a sense of identity...

An important point here is that *society influences the development and content of the self in at least two ways: by producing patterns of experience that lead to views of the self as (say) competent or incompetent, and by placing individuals in status positions or social roles from which they come to derive a sense of identity...*

When persons with learning difficulties are cast in devalued social roles (such as 'welfare client') and internalise those roles (a phenomena we call 'clientification'), then this will be expressed in the way they see them 'selves' – it will pervade their sense of who they are as a member of society.

Participation in meaningful and valued social roles, on the other hand, creates the space, opportunity and occasion to reflect on and re-imagine one's self in different ways. When persons with learning difficulties internalise new roles, and the sense of value and positive behaviours that go with them, they may be empowered and transformed. Parenting itself is one valued social role that can transform the self-concepts or identities of persons with learning difficulties.

One mother with learning difficulties comes to mind: When I first met the family, there were 4 generations living together: great grandma, Grandma Shirley, Joy (mom with learning difficulties) and Andrew who was just a baby at the time. Andrew is now a young man. When I first met this family, Grandma Shirley took a greeting card off a bookshelf – There was a picture of a rose on the cover. She said to me, when Joy became a mother it was like watching a rose open.

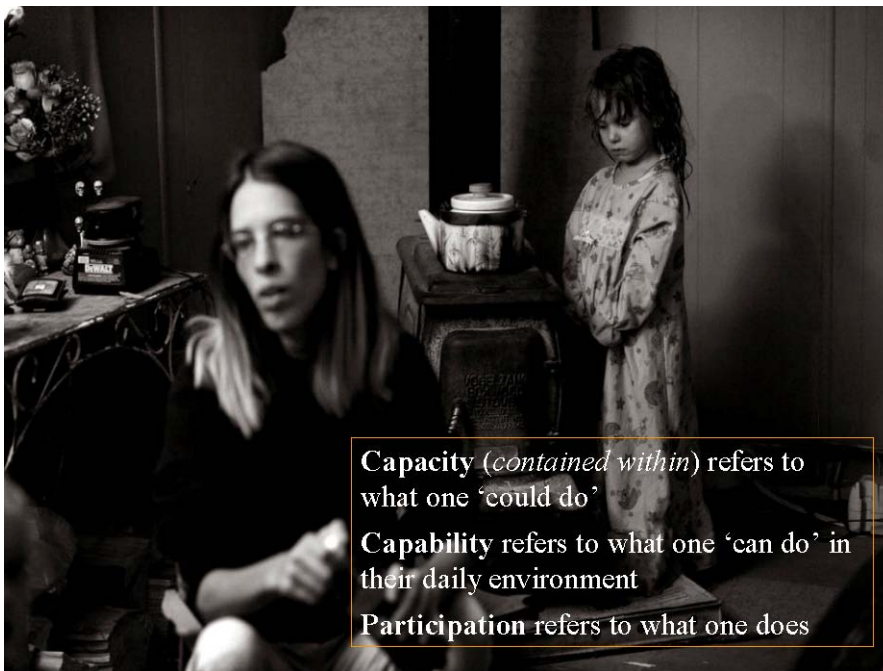
Participation in other valued social roles, including student, volunteer, worker, artist and so on ... also has the potential to strengthen social relationships and empower parents with learning difficulties. **HAVING MULTIPLE SOCIAL IDENTITIES IS POTENTIALLY A SOURCE OF RESILIENCE.** This is part of the reasoning that underlies the Supported Learning Program.

CAPACITY, CAPABILITY & PERFORMANCE

What do I mean by capability? **Capability** here refers to what one ‘can do’ in their daily environment. It is to be distinguished from the notion of **capacity**, which refers to what one ‘could do’ (one’s potential if you like), and from **participation**, which refers to what one actually does. In the model, biology and experience come together in human capacities. Capacities feed into capabilities – but cannot alone explain capabilities. Society and self also feed into capabilities.

2. Explaining human variation

I want to turn now and focus on the question of how we understand variation in human capacities and capabilities.



Historically, we have questioned and wondered whether it is nature or nurture? (*Is it biology or experience, genes or environment?*); We have questioned and wondered whether it is ‘agency or structure’? (*Is the individual responsible or is*

society to blame?). Most scientists now think that we have been asking the wrong questions. Research has revealed a number of problems with singling out either nature or nurture, self or society as explanations for human variation.

One problem is that no single factor can adequately explain the tremendous variation we see with respect to human capacities and capabilities. With respect to nature (biology) for instance, whatever measure of individual differences we use, two individuals with the same characteristics can have quite different outcomes (**Multifinality**), and two individuals with different characteristics can have the same outcomes (**Equifinality**). *We see this with parents with learning difficulties. Two parents with similar IQs can show very different parenting capacities. And two parents, one with an IQ much lower than the other, can display very similar parenting capacities. It is the same story when it comes to nurture (or experience).* Whatever measure of experience or environment we employ, we find that two individuals with the same experiences can have quite different outcomes, and two individuals with different experiences can have the same outcome.

Another problem is that research is showing that biology, experience, self and society are more interdependent than we ever could have imagined. For example, we have known for a long time that our genes and the environment interact in complex ways: For instance, variations in our genetic makeup determine how experience is translated into capacities (& health conditions). But research in the new fields of epigenetics and epigenomics is revealing that **we do not merely inherit our parent's DNA sequence, we also inherit their history – their experiences and the experiences of our ancestors!** Experience can mark our genes or genome in a such way that it changes how our genes work (which genes are turned off and on) – and these 'marks' may be passed on from one generation to the next!

The key point is that in order for us to understand human development and human variation, we have to take into consideration the continuous and dynamic interplay between biology, experience, self and society. Human development and the development of human capabilities is complex!

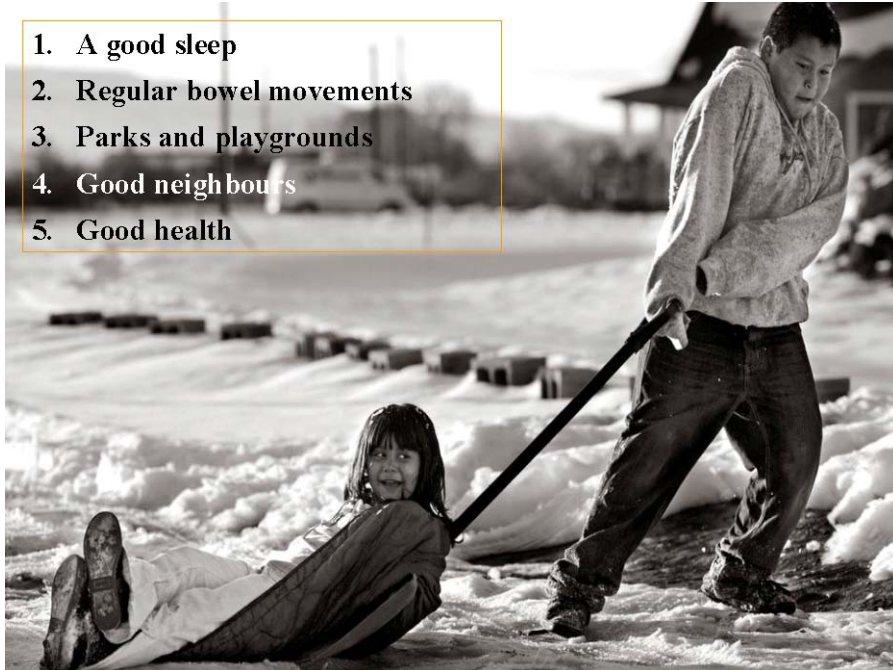
Diagnostic overshadowing

Now, how have we approached the problem of causality with respect to parents and parenting with learning difficulties? How do we make sense of or explain their capabilities (or lack thereof)? I think often we get stuck on biology- and specifically cognitive functioning. The 'idea' of learning difficulties or intellectual disability is so powerful that we can fall into the trap of interpreting everything through that lens. A fancy name for this is 'diagnostic overshadowing'. Because of diagnostic overshadowing we can overlook many influences on parenting capability and child outcomes – even seemingly obvious ones.

And when parenting deficiencies are attributed to parental learning difficulties, we may have little hope or expectation of improving the family's situation. In other words, because we cannot remedy learning difficulties, the assumption may be that we cannot remedy any perceived parenting deficiencies either. In Australia and England we found that this kind of thinking went a long way towards explaining the disproportionately large number of children of parents with learning difficulties who are placed out-of-home.

Professional assessments often focus on cognitive functioning and parent capacities including *parenting knowledge or skills – or parenting performance in clinical, artificial settings*. *But to avoid the mistake of false attribution – to avoid diagnostic overshadowing*, assessments must take into account experience, self concept and societal context... Research in our field has identified a number of 'biological' and 'experience' factors that may influence the capability of persons with learning difficulties to participate in the parenting role. These include but are not limited to parental mental health, the parent's own upbringing – including exposure to abuse, the experience of financial hardship, and social support. Here I just want to highlight a few factors that may get overlooked.

1. A good sleep
2. Regular bowel movements
3. Parks and playgrounds
4. Good neighbours
5. Good health



1. A good night's sleep. I remember my wife saying to me: "you know if I get enough sleep I can cope with just about anything, but if I don't get enough sleep I struggle to cope with just about anything". *How often do we ask the parents we work with about the adequacy of their sleep? How often do we think about offering supports to enable the parents we work with to get a good night's sleep?*
2. Regular bowel movements! My wife and I have three children (photo) – our first born, Lachlan, is delightfully eccentric. Some years back, we were concerned about his apparent Jekyll and Hyde behaviour. In Hyde mode, Lachlan was irritable and aggressive – sometimes hitting or even biting other children. Together we analysed his behaviour and came up with a host of hypotheses (most of which revolved around the question of what we as parents must be doing wrong!) - Anyway - the answer came in the form of a bowel movement. We observed that after a bowel movement Lachlan was an angel. Beforehand, not so much!

3. Parks and playgrounds: My children go stir-crazy if they are kept indoors for too long. The local park and playground is a space we can go together, a space where we can meet other parents and children, a place we can play together. My wife and I learn all sorts of important things from the parents we meet in the park – things like when the soccer season starts, what is good to see at a local festival and so on. And it is through those informal exchanges that our experiences as parents are validated and normalised, and through which parenting ideas are shared. My point here really is that if, for whatever reason, opportunities for such informal social interactions are lacking, then parents miss out on a primary source of learning and support – incidental though it may be.

4. Good neighbours. In Australia, England and Canada my colleagues and I have examined child protection investigations and court cases involving parents with learning difficulties. One intriguing finding was that risk of sexual abuse was a more common concern in England compared with Australia. This appears to be related to where parents with LD live: In Australia, public housing tends to be more disbursed. In England, parents with LD tended to be concentrated in what Tim Booth calls ‘sink estates’. These are communities where vulnerable people and people with problems tend to be lumped together. And when people with problems are lumped together problems can be multiplied. In such communities it appears that parents with LD and their children are more likely to be targeted by and/or exposed to potential offenders. The point here is that one of the difficulties that was frequently attributed to parental learning difficulties – that is, vulnerability of children to sexual abuse - all but disappears when public housing is disbursed/distributed.

5. Good health. Some years back, I got to know this mother who lived in a country town in Australia. This mother had two daughters. Both were in care at the time with court proceedings pending. The child protection authority was seeking permanent out-of-home placement. When this mother opened the door to her home I was almost bowled over by the smell of urine. And I was struck by how unwell this mother looked. Over the course of my interview with her, I learned that she had been incontinent since the birth of her last child – she had to wash her sheets everyday. And I learned that she had diabetes – for which she had received no treatment at all. Afterwards, I interviewed this mother’s caseworker, and I asked if this mom had received any support to resolve her health issues. Turns out that no one had really thought about it or thought about the potential link between her health and her parenting. *Her problems were just assumed to be caused by her learning difficulties.* In the coming months, this mother received treatment for her diabetes and her incontinence was resolved. When I went back to see this mother she was like a different person. And the child protection authority was planning to restore her daughters back home – which is where they wanted to be.

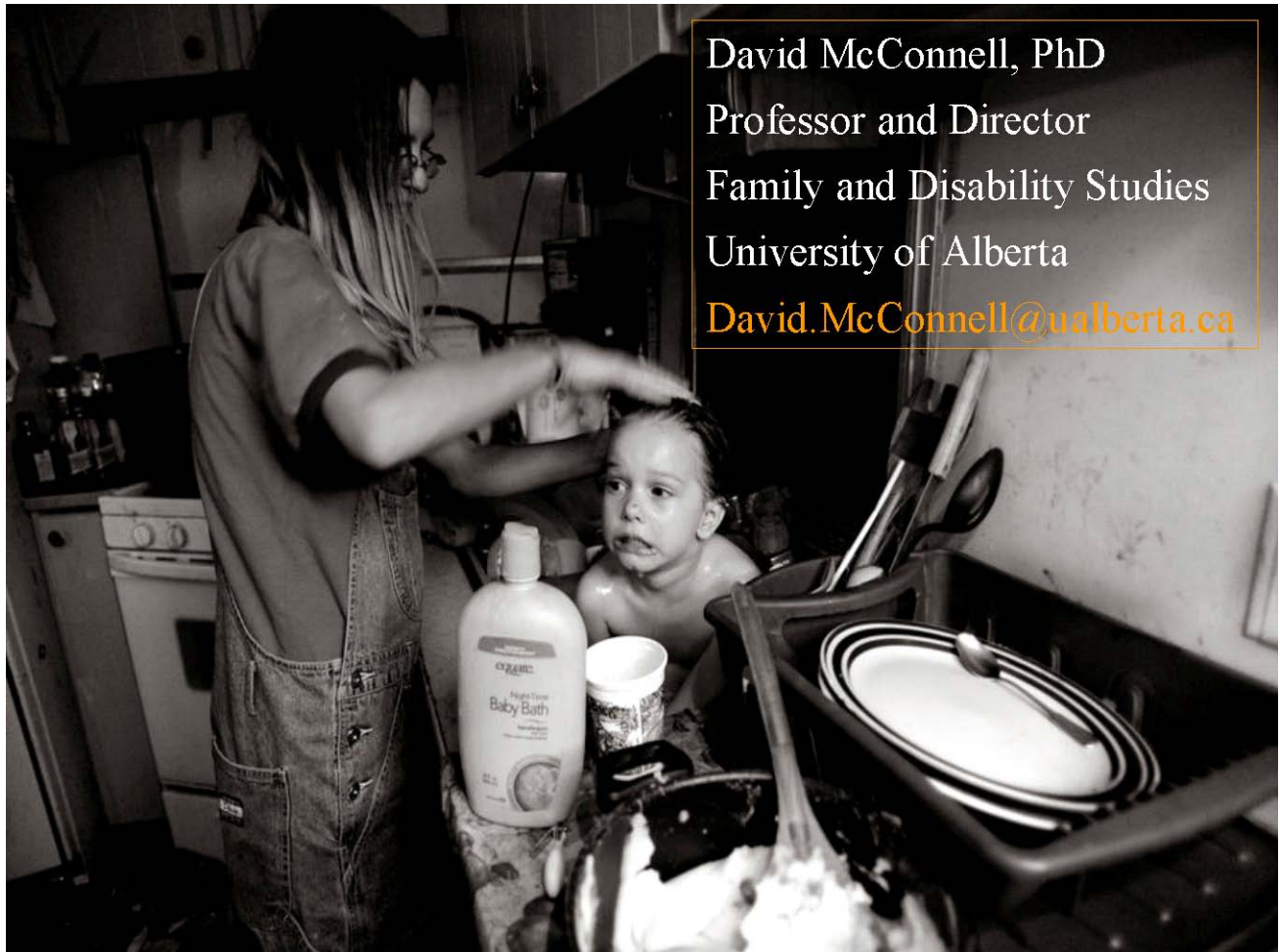
In Conclusion...

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