Self-determination and Resilience: 2 empowerment approaches for youth with disabilities and their parent carers

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Why bring these two concepts together?

- Both have been applied to individuals with disabilities

- Self-determination is important to individuals with disabilities because:
  - It emerged as a result of related social movements such as self-advocacy, self-determination, disability rights, and independent living movement (Ward,1996)

  - It is a "way of life" for all people and an opportunity to experience better quality of living (Ward, 1988)

  - It is a critical outcome of the transition services for students with disabilities (Halloran, 1993)

Resilience is important because:

- Some children and young people do better than others having had very similar experiences – there is hope for everybody

- Promotes the possibility of positive chain reactions
  "Therapeutic actions need to focus on steps that may be taken in order to reduce negative chain reactions…Protection may also lie in fostering positive chain reactions, and these, too, need attention in therapeutic planning'. (Rutter, 1990: 137)

- Offers idea of mechanisms and processes helps us think about what we **can** do in the midst of what might feel overwhelmingly difficult

- Wherever you start is good enough – little things can have big consequences

- 'Ordinary magic' that anyone can do (Masten 2001)

- Provides the possibility to fight structural issues **and** change the way individuals deal with things

Bringing different perspectives together

- Mariola's journey to self-determination
  - Developing theory of self-determination from the youth perspective

- Kim's journey to resilience
  - Applying theory to practice with parent carers of disabled children and young people

- Commonalities in our journeys
  - Meaningful relationships
  - Emotional resiliency

HOW you deliver services as important as what you deliver

- Good communication skills
- Demonstrate respect for parent expertise
- Ability to step back
- Ability to step outside your discipline
- Diplomacy
- Family focus
- Empathy
- Rapport
- Negotiation skills

- Listening skills
- Ability to work with team
- Knowledge of other agencies
- Knowing what's available
- Say when you don't know
- Time management
- Ability to plan
- Good organiser
- Understand disability issues

(Greco 2005)

Frustration with Research

- Both constructs:
    - have numerous definitions/models
    - been described through long lists of concepts (i.e. skills, attitudes, abilities, etc.)
    - are surrounded by conflicting statements

- *Self-determination:* it is not clear whether self-determination is a process or an outcome; if it is simply a set of attitudes, skills and abilities, or whether it represents a more complex construct that includes the environmental context

- *Resilience:* the risk factors and their consequences are widely known and routinely used in describing both research and programs…The sad truth is that far more is invested in research to understand the consequences of risk factors for young children and parents than in designing, testing, and taking to scale interventions that might change the all too predictable negative trajectories' (Knitzer & Cohen 2007, p.358).

There is a need for a broader range of ideas and contexts when looking at self-determination and resilience

Selected definitions of Self-determination

- Process driven by the intrinsic motivation of each of us to be the primary determiner of our thoughts, feelings, and behavior (Abery, 1994)

- Acting as the primary causal agent in one's life and making choices and decisions regarding one's quality of life free from undue external influence or interference (Wehmeyer, 1996)

- Combination of skills, knowledge, and beliefs that enable a person to engage in goal-directed, self-regulated, autonomous behavior. An understanding of one's strengths and limitations, together with a belief of oneself as capable and effective are essential to self-determination. When acting on the basis of these skills and attitudes, individuals have greater ability to take control of their lives and assume the role of successful adults in our society (Field, Martin, Miller, Ward, and Wehmeyer, 1998a)

Definitions of resilience:

- The indication of a process which characterizes a complex social system at a moment in time. (Fonagy, Steele et al. 1994: 233)

- Resilience does not constitute an individual trait or characteristic… resilience involves a range of processes that bring together quite diverse mechanisms…' (Rutter 1999: 135)

- Resilience is an emergent property of a hierarchically organized set of protective systems that cumulatively buffer the effects of adversity and can therefore rarely, if ever, be regarded as an intrinsic property of individuals. (Roisman, Padrón et al. 2002: 1216)

- Adequate provision of health resources necessary to achieve good outcomes in spite of serious threats to adaptation or development. (Ungar 2005b: 429)

19 characteristics of self-determination

- Awareness of personal preferences, interests, strengths, and limitations;
- Ability to differentiate wants and needs;
- Ability to make choices based on preferences, interests, wants, and needs;
- Ability to consider multiple options and to anticipate consequences for decisions;
- Ability to initiate and take action when needed;
- Ability to evaluate decisions based on the outcomes of previous decisions and to revise future decisions accordingly;
- Ability to set and work toward goals;
- Problem-solving skills;
- A striving for independence while recognizing interdependence with others;
- Self-advocacy skills;
- Ability to self-regulate behavior;
- Self-evaluation skills;
- Independent performance and adjustment skills;
- Persistence;
- Ability to use communication skills such as negotiation, compromise, and persuasion to reach goals;
- Ability to assume responsibility for actions and decisions;
- Self-confidence;
- Pride; and
- Creativity (Field et al., 1998)

Some aspects of resilience are obvious

- Good education, love and sense of belonging, decent standard of living, great parenting, intelligence, good looks, opportunities to contribute …

BUT WHAT IF LIFE HASN'T DEALT YOU SUCH A GOOD HAND?

- Tipping points, processes and mechanisms …

Resilient Therapy – one way of working with children with families

- Strategically harnesses selected therapeutic principles and techniques

- Designed to work in contexts of constellated disadvantage

- Rooted in a scholarly framework that takes its inspiration from resilience theories and research

- Explicitly integrates routine child mental health practice and personal experiences with these theories & research

- Can be used across contexts and by different practitioners

RESILIENT THERAPY MAGIC BOX SUMMARY

POTIONS:	BASICS	BELONGING	LEARNING	COPING	CORE SELF
REMEDIES	Good enough housing	Find somewhere for the child to belong	Make school life work as well as possible	Understanding boundaries and keeping within them	Instil a sense of hope
	Enough money to live	Help child understand his/her place in the world	Engage mentors for children	Being brave	Teach the child to understand other people's feelings
	Being safe	Tap into good influences	Map out career or life plan	Solving problems	Help the child to know her/himself
	Access and transport	Keep relationships going	Help the child to organise her/himself	Putting on rose-tinted glasses	Help the child take responsibility for her/himself
	Healthy diet	The more healthy relationships the better	Highlight achievements	Fostering their interests	Foster their talents
	Exercise and fresh air	Take what you can from any relationship where there is some hope	Develop life skills	Calming down and self-soothing	There are tried and tested treatments for specific problems, use them
	Play and leisure opportunities	Get together people the child can count on		Remember tomorrow is another day	
		Responsibilities and obligations		Lean on others when necessary	
		Focus on good times and places			
		Make sense of where child has come from			
		Predict a good experience of someone or something new			
		Make friends and mix with other children			

NOBLE TRUTHS:

ACCEPTING	*CONSERVING*	*COMMITMENT*	*ENLISTING*

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Support work proving to have some potential

- Clubs, hobbies, summer camps
- Belonging to something good - families, peer groups
- Mentors who stick with kids over time
- Continuity of practitioner
- Constructing a life story that makes sense
- Reframing experiences
- Getting kids to 'do good' for others, volunteering etc.
- Being paid
- Holistic interventions that don't just tackle 'the issues' or 'one issue'

Conceptualizations of Self-determination

- **Psychological constructs (PC)**
  - 35 psychological constructs were identified
  - PC promoting independence, autonomy, locus of control, agency of *self,* accompanied by abilities, knowledge and beliefs were the most referenced in the literature
- **Skills** (S)
  - 25 skills were identified
  - advocacy, goals, choice making, decision, making, problem solving, taking action and responsibility, self-regulation, evaluation and learning were the most popular
  - The least popular skills were interpersonal skills that enable individuals to carry on effective relationships with others (i.e. ability to communicate, collaborate, or negotiate)
- **Ecological phenomenon** (complex reciprocal interactions of individuals and their environments)
  - Shifts some of the responsibility for nurturing self-determination to the environments;
  - School environment got the most attention

Barriers to Self-determination

Intrapersonal Barriers

- Psychological barriers:
  - low self-confidence (lack)
  - low self-definition
  - low self-awareness (lack)
  - maladaptive perceptions
  - negative attitudes
  - external locus of control
  - beliefs of helplessness
  - dependence
  - emotional difficulties (e.g., depression)
- Skills barriers:
  - lack of skills
  - inflexible pattern of problem-solving
 - little self-direction

Environmental Barriers

- conflicts with family
- stress
- values
- overprotectivness
- lack of responsibilities
- limited experiences (e.g., choice, control, self regulation, goal-setting, and problem-solving.
- no/few opportunities to practice skills associated with self-determination (e.g., choice)
- lack of family involvement
- controlling & over structured environments (create dependency)
- negative school climate
- segregated settings
- inconsistent/fragmented or lack of supports
- negative attitudes
- disability stigma & stereotypes
- paternalistic approach
- limited knowledge base about the language and culture of disability

Conceptualizations of Self-determination

- **Process-oriented construct** (relationships that exist among self-determination components)
  - relationships between psychological constructs and skills were recognized most frequently by researchers (for example, person who is confident makes better choices)
- **Developmental phenomenon** (progression from birth to maturity that manifests itself through developmental stages and milestones across the lifespan (Field et al., 1997; Malian & Nevin, 2002; Sands & Doll, 1996)
  - self-determination changes and looks differently over a person's life span of childhood, adolescence and adulthood (Malian & Nevin, 2002);
  - current research focuses mostly on adolescence;
 - opportunities to learn and practice self-determination begin in childhood.
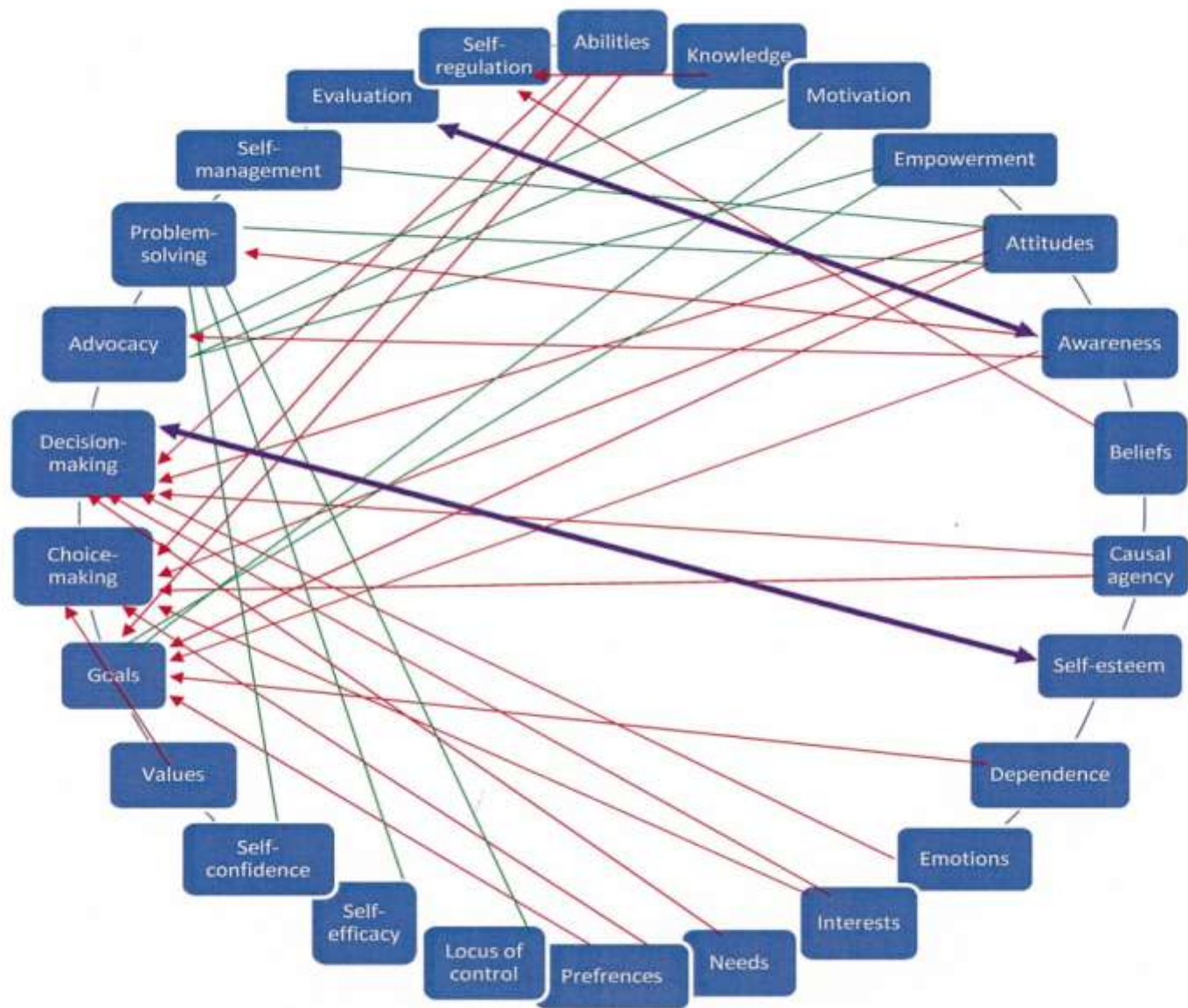
How we manage our frustration with research

- Advocate for more complete and comprehensive conceptual frameworks that are grounded in theories from other disciplines to broaden our understanding of the construct and provide a richer context

- Promote learning loops between policy, research and practice that informs development of solid theoretical foundation

- Translate theoretical framework to an aligned, consistent, and understandable practice

- Elevate the lived experience – nothing for us without us

New framework of self-determination
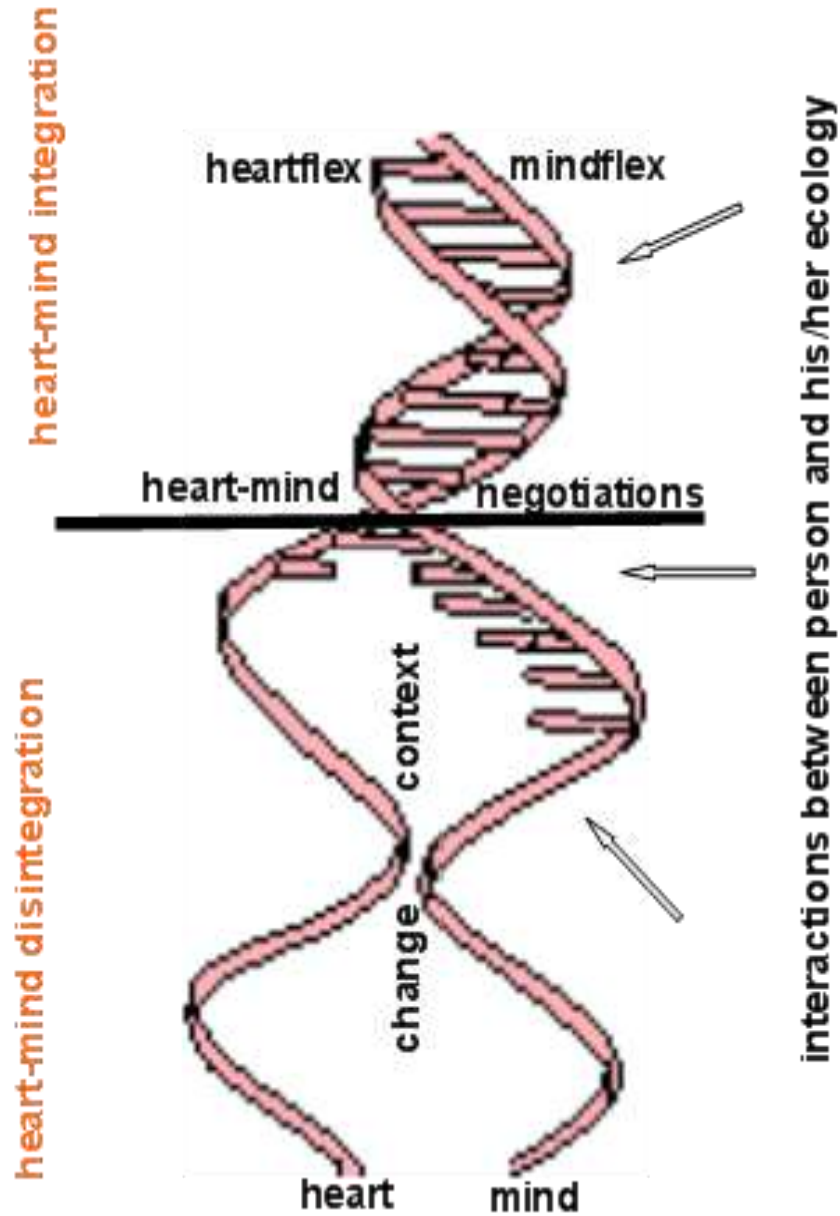
New framework of self-determination
(Rosser, 2010)

- **Mindlflex:** process of adjusting our mental models (mindsets) to accommodate new experiences; flexibility to alter and adjust our goals, decisions, values, etc.

- **Heartflex:** process of regaining emotional balance (coherence) by managing emotions from the heart level

- **Heart-Mind Negotiations:** communication process between heart and mind to establish the coherence between heart and brain (Childre & Martin, 1999)

- **Heart-mind disintegration/integration:** transformation process influenced by *change* and *ecology* contexts to integrate new experiences and learnings

- **Interactions between person and his/her ecology:** process of bi-directional influences between person and his/her environments (Bronfenbrenner , 1977, 1979)

- **Change context:** continues adaptation process to changing situations, conditions , circumstances, etc.

What similarities to you see between the two concepts?

- Is self-determination part of resilience?
- Is resilience part of self-determination?

Example of resilient work with parent carers

- Deliberately addresses tension between personal agency and social structure to promote resilience and self determination agenda

- Insiders Guide Parent Support Course for parents of disabled teens (6 session course)

- Aims to assist parent carers to build capacity to positively manage the challenges of raising disabled teens and promote self determination.

- Partnership model, co-delivery by parents and practitioners together

Insiders' Guide Parent Support Course

1   The Journey So Far

How we got here, adapting expectations, what's helped, what other parents say helps with transition to adulthood & adult services

2   Travelling On

Managing stress, noticing our own resilience qualities, ideas for building resilience further

3   Getting the Best out of Others

Seeing different perspectives, building communication and negotiation skills, keeping it positive

4   Getting out and about Friendships & Fun

Why socialising matters, being your child's social secretary, mapping belonging webs for your child and yourself

5   Navigating your way around Puberty

Skills for talking about teen issues, puberty and what it means for your child, coping strategies

6   Looking Ahead

Mapping the group journey, consolidating resilient moves for the next steps

Working with resilience in mind

- The problems professionals face are neither predictable nor simple. They are **unique and complex**. Arising from environments characterised by **turbulence and uncertainty,** complex problems are typically value-laden, open-ended, multi-dimensional, ambiguous, and unstable. They resist being tamed, bounded or managed by classical problem-solving approaches. As a result, the art of being a professional is becoming the art of managing complexity. (Klein 2004)